A model of care for the rehabilitation of people living with HIV in a semi-rural South African setting

Author:
Verusia Chetty

Emerging Public Health Practitioner Award

Since the introduction of antiretroviral therapy in South Africa, people living with HIV have a longer life-span. However, this is associated with an increase in disabilities related to the virus, co-morbidities and side effects of medication. Rehabilitation professionals have seen a surge in the need to address the disabling effects of HIV through service delivery in resource-rich settings. However, in resource-poor settings, such as in South Africa, there is a recent understanding of the demands that these new health-related needs of millions of people on antiretroviral treatment place on rehabilitation. Moreover, the paradigm shift from a biomedical model towards a biopsychosocial model of care for people living with HIV experiencing disabilities compels rehabilitation professionals to address both physical and social barriers to rehabilitation in their recourse to care.

The prospect of new needs for rehabilitation raises the question of the model of care that can feasibly address these dynamic changes and integrate patient-centred, evidenced-based rehabilitation practice into the response to HIV in South Africa. An Integrated Learning in Action approach underpinned this project, and included several sub-studies in a semi-rural healthcare setting in the province of KwaZulu-Natal, South Africa. The stages of this approach, in logical progression, involved the multidisciplinary healthcare team at the site, affiliated non-governmental organisation representatives, service users and experts in the field.

Three phases led to the development of a model of rehabilitative care. The first phase entailed a review of international rehabilitation models; phase two involved an enquiry into the perspectives of key stakeholders. The final phase focused on reaching a consensus with experts on the framework guiding the model of care. The aim of the chapter is to present the developed model of care and gauge its relevance in relation to policies that have an impact on rehabilitation practice in South Africa.
Introduction

With more than 6.4 million people living with HIV, South Africa is the epicentre of the global HIV pandemic. The introduction of antiretroviral therapy (ART) in the mid-2000s saw the transition of the infection from a terminal to a chronic disease. People began to live longer but started to experience disabilities related not only to the virus but also to its co-morbidities and ART. HIV-related disability is now an issue of concern for health services in South Africa where disability related to HIV will have a profound impact on an already fragile healthcare system and its overburdened rehabilitation services.

Grafted upon this, healthcare scientists and clinicians have begun to see the integrity in shifting the focus of disabilities from a medical model to a biopsychosocial model, giving society a degree of responsibility in constructing an enabled environment for people with disabilities, including those living with HIV. A multi-professional and multisectoral response is needed to initiate a change in recognising disability as a biopsychosocial phenomenon that confronts the structural and environmental barriers faced by people with disabilities. Rehabilitation frameworks have also needed to undergo a dynamic shift in discourse from a professionally centred prescriptive practice to one that is client-centred and empowered. The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) has lent itself to the current paradigm shift from a unilateral perspective into a multi-dimensional framework that promotes an understanding of disability in a more nuanced manner. The ICF proposes that disability should not only be seen to affect an individual’s body and function, but also their social and environmental contexts. The interactions between health conditions, intrinsic contextual features of the individual, and extrinsic contextual features of the social and physical environment, make this framework well disposed to address the novel challenges facing disability care in resource-limited settings, and has offered potential for positive impact in HIV- and disability-focused research.

In recent years, an emerging body of literature produced by rehabilitation professionals in South Africa has highlighted the impact of HIV-related disability on HIV care. Challenges around accessing rehabilitative care for people living with HIV who experience disability is of major concern and researchers concur on the need to develop a more comprehensive and feasible model of care for healthcare settings where HIV is endemic. A recent preliminary study investigated how such a model of care could serve a public healthcare setting that typifies the South African context. This study highlighted processes in the development of working models in resource-rich contexts and led to a consequential question of how to frame these already successful models of rehabilitative care into a South African setting. The study underpinned the development of a model of care for the rehabilitation of people living with HIV in a semi-rural setting using a Learning in Action approach developed by the Athena Institute in Amsterdam. A combined use of qualitative and quantitative methods enabled the collection and comparison of a large diversity of perspectives in phased activities structured along the lines of the transdisciplinary research approach. In practice, the process is cyclical and dialogical; for example, the output of one stakeholder group forms the input for another group, so that information receives extensive deliberation and rigorous redefinition to the point of being widely understood and acknowledged as relevant for practical use. Each sub-study of the project was integrated in the Interactive Learning in Action approach and focused on different levels of integration into the model of rehabilitative care to address the disabling effects of HIV in a specific setting in a hyper-endemic country. The prospect of implementing this as a pilot model to reshape the lack of empirical evidence based on rehabilitation strategy requires the review of policies guiding the rehabilitation discourse in South Africa.

This chapter will highlight the steps taken to produce the model of care and discuss all related phases, from the review of international models of rehabilitative care, to enquiry into stakeholders’ perspectives and expert feedback on the model framework. This will be followed by discussion and a graphic representation of the existing rehabilitation framework and the newly developed model of care, summing to a review of current legislation guiding rehabilitation and its discourse in South Africa, and the relevance of the developed model.

Phase 1: A review of international models of rehabilitative care

The need for a rehabilitation model to address the disparities of public health care for people living with HIV in South Africa

Rehabilitation frameworks in South Africa differ from the public to the private sector. There is a disparity with regard to resources available to individuals accessing public health services compared to individuals who can afford private care. The public health sector lacks the infrastructure and funding to manage the healthcare demands of the large number of people dependent on its services and is confounded by poor governance and shortages of healthcare workers. Initially the premise was to review models guiding rehabilitation and to appraise current rehabilitation frameworks offered within the public health sector. The review was conducted as an imperative theoretical guide to the development process of a model of rehabilitative care.

The definition of a model of care is ambiguous but consensus lies in it being defined as “a multifaceted concept, broadly defining the way in which health care is delivered including the values and principles; the roles and structures; and the care management and referral processes. Where possible, the elements should be based on best-practice evidence and defined standards, and provide structure for the delivery of health services and a framework for subsequent evaluation of care.” Internationally, it has been recognised that shortfalls in the delivery of care, such as poor infrastructure, led to the development of novel models by healthcare professionals and policy-makers as a strategic response to these demands. Evaluation of working models of care guiding rehabilitation in Australia steered the development of the framework for a model of care in the study context. The process development of these Australian models propitiously suited the current state of play in the current South African rehabilitation front. For instance, the Department of Health in Western Australia describes the process of developing a model of care in five major phases: Phase 1: Understanding the health policy context; Phase 2: Defining and understanding the current state of play; Phase 3: Translating evidence-based research and expert opinion into best practice; Phase 4: Consulting broadly
with stakeholders and incorporating feedback, as appropriate to produce a finalised model of care and Phase 5: Endorsement of the model of care by advisory group and health networks.\textsuperscript{18} Initial steps towards the development of such a model in South Africa have commenced. For example, preliminary work has been explored as reflected in Phase 1 (Understanding the health policy context in South Africa). Evidence has been provided revealing that current health policy does not as yet include the disabling effects of HIV and its rehabilitative redress in HIV care in South Africa.\textsuperscript{19,20}

In Phase 2 (Defining and understanding the current state of play), researchers in HIV and rehabilitation clearly describe the current state of rehabilitation in the context of HIV in South Africa. They have highlighted the increasing disablement experienced by people living with HIV and its association with the roll-out of ART in the mid-2000s, conceding that as the number of people living with HIV increases in South Africa, the need to address their disabilities becomes an imperative for health care and healthcare professionals.\textsuperscript{2,3,9,10} However, strategies for streamlining intervention in health structures remain a challenge.\textsuperscript{6,12}

In Phase 3 (Translating evidence-based research and expert opinion into best practice), researchers in South Africa have been conducting fruitful investigation into HIV and disability;\textsuperscript{3,9,10} however, much can be drawn from global contexts on best practices and rehabilitation guidelines. Canada, for example, is among the leading countries addressing rehabilitation of people living with HIV, and for over 15 years has mobilised a working group of stakeholders to form the Canadian Working Group on HIV and Rehabilitation (CWGHR).\textsuperscript{21} CWGHR has established original educational material informing the rehabilitation of people living with HIV in Canada, some of which has been adapted with contextual variance in sub-Saharan Africa to apprise and aid rehabilitation practice.\textsuperscript{22} The module proposes to bridge the existing knowledge gap of rehabilitation at a local level in low- to middle-income contexts. Implementing these adapted guidelines aims to offer a feasible approach of providing holistic and multidisciplinary services for people living with HIV in these settings.

Phases 4 and 5 (Consulting broadly with stakeholders and incorporating feedback, as appropriate to produce a finalised model of care, and Endorsement of the model of care by advisory group and health networks) are now being initiated in South Africa.\textsuperscript{6} At a pilot context-specific stage, this project also boasts engagement with experts and key stakeholder reflection in its development of an evidence-based and feasible approach to a model of rehabilitative care. The model proposed communication, both formal and informal, in repetitive meetings to share information and solicit feedback regarding the sustainability and the running of the model. Additionally, evaluation is often achieved by involving key stakeholders to give feedback on the progress and impact of the model.\textsuperscript{16,23}

From the international review, strategies that have been identified as crucial for a meaningful process and development of a working model in rehabilitation were incorporated into a synthesised framework and are reflected in Figure 1. The synthesis of frameworks is explicit in addressing the rehabilitation needs identified as essential in a South African context. In this synthesis, the trajectory of care for people living with HIV is linked with the care setting and underpinned by principles and critical enablers. The framework emphasises that the process of model development needs to include objectives as an imperative for a rehabilitation model.\textsuperscript{9} In developing the model to guide rehabilitation, the key processes that have already been tested in resource-rich contexts such as Australia needed to be further tailored to meet the needs of a resource-poor context. The framework (Figure 1) provides clarity on the elements that should be considered in the development of such a model. The

\begin{figure}
\centering
\includegraphics[width=\textwidth]{synthesis_of_models_of_care_in_rehabilitation.png}
\caption{Synthesis of Models of Care in Rehabilitation}
\end{figure}
next phase involved engagement with key stakeholders to gain their perspectives on the rehabilitation framework that contemporarily guided practice at the study setting.

**Phase 2: Engaging with key stakeholders on a Rehabilitation Model as key to comprehensive care in the era of ART**

A focus group discussion was conducted with 30 participants comprising people living with HIV and experiencing disabilities, the multidisciplinary healthcare team at the healthcare site, and site-affiliated non-governmental organisation representatives. An interpretive phenomenological approach using Van Manen’s pedagogy was used to understand stakeholders’ perspectives on barriers and enablers of access to rehabilitation within the health structure. Table 1 reflects the themes and categories emerging from the discussion. Similar to previous work in this setting, stakeholders identified a lack of accessibility to centrally situated health care as a fundamental barrier to rehabilitation. Furthermore, funding contributed to the vicious cycle between poverty, disability and rehabilitation. People living with HIV experiencing disabilities in this study were faced with financial constraints limiting them in attending the hospital-based rehabilitation sessions. Furthermore, they reported being unable to return to work to obtain an income to supplement the cost of these visits. The healthcare workers in the same setting conceded that finance was also limiting them in implementing policies at a local level and obstructing access to rehabilitation.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental Constrains</td>
<td>Centralisation of services</td>
</tr>
<tr>
<td></td>
<td>Commute obstruct</td>
</tr>
<tr>
<td>Fiscal Challenges</td>
<td>Funding feud</td>
</tr>
<tr>
<td>Institutional Limitations</td>
<td>Staffing vs workload dilemma</td>
</tr>
<tr>
<td></td>
<td>Poor collaboration of multidisciplinary team</td>
</tr>
<tr>
<td>Participants’ Recommendations</td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Proposed model of care</td>
</tr>
</tbody>
</table>

Source: Chetty and Hanass-Hancock, 2015

Poor multidisciplinary collaboration and lack of identification of disabilities followed by referral to appropriate services was a confounding challenge that was echoed by stakeholders. The lack of professional healthcare staff was believed to contribute to this poor collaboration; this is a great concern within the public healthcare domain as healthcare professionals migrate to well-resourced countries such as Australia, Canada and the United Kingdom, leaving South Africa under greater financial and workforce strain. The shortage of rehabilitation staff in the region is even more daunting, especially in resource-poor settings, because of the large population in need of the services. Community-based rehabilitation (CBR) can compensate for staff shortages in resource-poor settings. Community members, families of people living with HIV and people living with HIV themselves can be capacitated through task-shifting and training to provide some form of rehabilitation within communities and homes. The empowerment and skill development of people living with HIV, community health workers and caregivers could also be harnessed to address issues of accessibility. CBR has however not been sufficiently assessed with regard to its effectiveness within a South African rehabilitation healthcare setting, and the implementation and understanding of CBR is still debatable as healthcare professionals seem to have disparate understandings of its design.

In a second step, we used the information gleaned from the participants to inform a framework that supports the development of an appropriate model of care. The four strategic categories, i.e. objectives, principles, enablers and care settings as outlined in Figure 1 were used as a lens through which to discuss the findings. The improvement of access to care; reducing inequality in health status; providing safe, high-quality health care; promoting a patient-centred continuum of care, and optimising health services were viewed by stakeholders as fundamental objectives. Leadership and a multidisciplinary team approach were common principles to be included in the framework for rehabilitation; however, evidence-based practice as a guiding principle lacked attention by stakeholders at the site. Education and training for rehabilitation healthcare teams at all points of care was believed to be a critical enabler, and task-shifting to empower lay personnel such as community health workers was believed to be a key imperative by stakeholders. The home, clinics, hospital and outreach facilities were viewed as essential settings in which to provide appropriate, timeous rehabilitation within the care delivery system.

**Phase 3: Attaining expert consensus on the Rehabilitation Framework guiding a Model of Care for People Living with HIV in a South African setting**

In this phase of the study, 12 experts in HIV and rehabilitation in South Africa were selected using maximum variation sampling and engaged in a modified Delphi survey based on findings from the preliminary literature review and an exploratory enquiry into stakeholder perspectives. The experts included doctors, nurses, physiotherapists, occupational therapists, a speech-language therapist, a speech and hearing therapist, an audiologist, a sexual health educator, a social worker, and a psychologist. To be included in the study, they had to be employed in a South African setting with two or more publications in the field of HIV and rehabilitation/disability pedagogy was used to understand stakeholders’ perspectives on barriers and enablers of access to rehabilitation within the health structure. Table 1 reflects the themes and categories emerging from the discussion. Similar to previous work in this setting, stakeholders identified a lack of accessibility to centrally situated health care as a fundamental barrier to rehabilitation. Furthermore, funding contributed to the vicious cycle between poverty, disability and rehabilitation. People living with HIV experiencing disabilities in this study were faced with financial constraints limiting them in attending the hospital-based rehabilitation sessions. Furthermore, they reported being unable to return to work to obtain an income to supplement the cost of these visits. The healthcare workers in the same setting conceded that finance was also limiting them in implementing policies at a local level and obstructing access to rehabilitation. Poor multidisciplinary collaboration and lack of identification of disabilities followed by referral to appropriate services was a confounding challenge that was echoed by stakeholders. The lack of professional healthcare staff was believed to contribute to this poor collaboration; this is a great concern within the public healthcare domain as healthcare professionals migrate to well-resourced countries such as Australia, Canada and the United Kingdom, leaving South Africa under greater financial and workforce strain. The shortage of rehabilitation staff in the region is even more daunting, especially in resource-poor settings, because of the large population in need of the services. Community-based rehabilitation (CBR) can compensate for staff shortages in resource-poor settings. Community members, families of people living with HIV and people living with HIV themselves can be capacitated through task-shifting and training to provide some form of rehabilitation within communities and homes. The empowerment and skill development of people living with HIV, community health workers and caregivers could also be harnessed to address issues of accessibility. CBR has however not been sufficiently assessed with regard to its effectiveness within a South African rehabilitation healthcare setting, and the implementation and understanding of CBR is still debatable as healthcare professionals seem to have disparate understandings of its design.

In a second step, we used the information gleaned from the participants to inform a framework that supports the development of an appropriate model of care. The four strategic categories, i.e. objectives, principles, enablers and care settings as outlined in Figure 1 were used as a lens through which to discuss the findings. The improvement of access to care; reducing inequality in health status; providing safe, high-quality health care; promoting a patient-centred continuum of care, and optimising health services were viewed by stakeholders as fundamental objectives. Leadership and a multidisciplinary team approach were common principles to be included in the framework for rehabilitation; however, evidence-based practice as a guiding principle lacked attention by stakeholders at the site. Education and training for rehabilitation healthcare teams at all points of care was believed to be a critical enabler, and task-shifting to empower lay personnel such as community health workers was believed to be a key imperative by stakeholders. The home, clinics, hospital and outreach facilities were viewed as essential settings in which to provide appropriate, timeous rehabilitation within the care delivery system.

**Phase 3: Attaining expert consensus on the Rehabilitation Framework guiding a Model of Care for People Living with HIV in a South African setting**

In this phase of the study, 12 experts in HIV and rehabilitation in South Africa were selected using maximum variation sampling and engaged in a modified Delphi survey based on findings from the preliminary literature review and an exploratory enquiry into stakeholder perspectives. The experts included doctors, nurses, physiotherapists, occupational therapists, a speech-language therapist, a speech and hearing therapist, an audiologist, a sexual health educator, a social worker, and a psychologist. To be included in the study, they had to be employed in a South African setting with two or more publications in the field of HIV and rehabilitation/disability pedagogy was used to understand stakeholders’ perspectives on barriers and enablers of access to rehabilitation within the health structure. Table 1 reflects the themes and categories emerging from the discussion. Similar to previous work in this setting, stakeholders identified a lack of accessibility to centrally situated health care as a fundamental barrier to rehabilitation. Furthermore, funding contributed to the vicious cycle between poverty, disability and rehabilitation. People living with HIV experiencing disabilities in this study were faced with financial constraints limiting them in attending the hospital-based rehabilitation sessions. Furthermore, they reported being unable to return to work to obtain an income to supplement the cost of these visits. The healthcare workers in the same setting conceded that finance was also limiting them in implementing policies at a local level and obstructing access to rehabilitation. Poor multidisciplinary collaboration and lack of identification of disabilities followed by referral to appropriate services was a confounding challenge that was echoed by stakeholders. The lack of professional healthcare staff was believed to contribute to this poor collaboration; this is a great concern within the public healthcare domain as healthcare professionals migrate to well-resourced countries such as Australia, Canada and the United Kingdom, leaving South Africa under greater financial and workforce strain. The shortage of rehabilitation staff in the region is even more daunting, especially in resource-poor settings, because of the large population in need of the services. Community-based rehabilitation (CBR) can compensate for staff shortages in resource-poor settings. Community members, families of people living with HIV and people living with HIV themselves can be capacitated through task-shifting and training to provide some form of rehabilitation within communities and homes. The empowerment and skill development of people living with HIV, community health workers and caregivers could also be harnessed to address issues of accessibility. CBR has however not been sufficiently assessed with regard to its effectiveness within a South African rehabilitation healthcare setting, and the implementation and understanding of CBR is still debatable as healthcare professionals seem to have disparate understandings of its design.

In a second step, we used the information gleaned from the participants to inform a framework that supports the development of an appropriate model of care. The four strategic categories, i.e. objectives, principles, enablers and care settings as outlined in Figure 1 were used as a lens through which to discuss the findings. The improvement of access to care; reducing inequality in health status; providing safe, high-quality health care; promoting a patient-centred continuum of care, and optimising health services were viewed by stakeholders as fundamental objectives. Leadership and a multidisciplinary team approach were common principles to be included in the framework for rehabilitation; however, evidence-based practice as a guiding principle lacked attention by stakeholders at the site. Education and training for rehabilitation healthcare teams at all points of care was believed to be a critical enabler, and task-shifting to empower lay personnel such as community health workers was believed to be a key imperative by stakeholders. The home, clinics, hospital and outreach facilities were viewed as essential settings in which to provide appropriate, timeous rehabilitation within the care delivery system.
Consensus was determined by an *a priori* threshold of 70% of agreement and interquartile range ≤ 1 on criteria to be included as essential or useful in the model of care framework. This was composed of two sections. Section 1 asked experts about criteria to be included in a theoretical framework for a model of care for the rehabilitation of people living with HIV. Four sub-categories were highlighted, i.e. objectives, principles, enablers and settings. A four-point ordinal scale was used. The scale included: (i) Essential: criterion must definitely be included in the framework, (ii) Useful: criterion can be included in the framework, (iii) Unnecessary: criterion must definitely be excluded from the framework and (iv) Unsure: unsure about this criterion. Section 2 reflected the current rehabilitation pathway at the study setting in a biographical sketch describing the various sites attached to the central hospital, e.g. clinics, community outreach centre, and also reflected the healthcare staff employed at each setting. The experts were asked to suggest viable pathways, referrals and interlinkages between available settings using their experience and clinical expertise.

Following the first round of the questionnaire, experts agreed that improving access to care; high-quality, appropriate and safe care; a multidisciplinary team approach; optimal communication between all stakeholders; evidence-based practice, education and training for healthcare workers, and home-based rehabilitation were essential for the model of care. Table 2 reflects the interquartile ranges and frequency distributions of the highly conceded criteria.

Following the second round, experts conceded that task-shifting to lay personnel and the training of all healthcare workers on the use of universal screening tools for disability were fundamental for optimal care. Furthermore, people living with HIV should be referred to the community outreach centre for follow-up management and rehabilitation.

The inquiry with the Delphi technique suggested that an alternative model of care in rehabilitation should factor in context-specific themes that can lead to the improvement of service delivery at all points of care. The expert panel agreed that access to high-quality, appropriate treatment is essential for people living with HIV; however, in an earlier enquiry of patients’ perspectives of care, access was a major barrier to continued rehabilitation. Expert panellists concurred with previous studies that the collaboration of the multidisciplinary team is essential for the fluidity of a rehabilitation framework. However, collaboration is based on optimal communication and understanding of individuals’ roles in the multidisciplinary team and hierarchy teams, and role overlap leads to a breakdown in communication.

Experts agreed that a key enabler for service delivery of a model of care including rehabilitation in a South African setting is education and training at all points of care for healthcare workers. Furthermore, evidence-based practice has been referred to as the “cornerstone for management” of people living with HIV by expert panellists. Workshop-based training and continuous professional development are strategies that can be harnessed to address this need. Researchers in the field of education and training for managing HIV in the field of rehabilitation in South Africa believe that the strategy of mainstreaming HIV management into the undergraduate curriculum is vital for South African health care and tertiary education.

The expert panellists concurred that home-based rehabilitation (HBR) was essential in facilitating an alternative model of care in a semi-rural context. HBR involves training of lay personnel or community health workers to meet the rehabilitation needs of people living with HIV in their own home. Theoretically, HBR would address barriers to rehabilitation such as physical access and lack of transport. Task-shifting at the study setting was achieved by training of community health workers who are employed at the community outreach centre at the study setting was seen as an imperative to improve service delivery. Task-shifting models have seen success in resource-poor contexts where lay personnel were appropriately trained to meet

### Table 2: Frequency distribution and (Interquartile Range) IQR of first questionnaire

<table>
<thead>
<tr>
<th>CONCEPT</th>
<th>ESSENTIAL Frequency (Interquartile Range)</th>
<th>USEFUL Frequency (Interquartile Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>OBJECTIVES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving access to care</td>
<td>100% (constant)</td>
<td></td>
</tr>
<tr>
<td>High-quality, appropriate, safe care</td>
<td>91.7% (0.00)</td>
<td>8.3% (0.00)</td>
</tr>
<tr>
<td>Multidisciplinary team approach</td>
<td>83.3% (0.00)</td>
<td>16.7% (0.00)</td>
</tr>
<tr>
<td><strong>PRINCIPLES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimal communication between all stakeholders (people living with HIV, the multidisciplinary healthcare team and community outreach partners)</td>
<td>91.7% (0.00)</td>
<td>8.3% (0.00)</td>
</tr>
<tr>
<td>Evidence-based practice</td>
<td>83.3% (1.00)</td>
<td>16.7% (1.00)</td>
</tr>
<tr>
<td><strong>ENABLERS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education and training at all points of care (Healthcare workers)</td>
<td>83.3% (0.00)</td>
<td>16.7% (0.00)</td>
</tr>
<tr>
<td><strong>SETTINGS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home (Domiciliary-based care setting)</td>
<td>91.7% (0.00)</td>
<td>8.3% (0.00)</td>
</tr>
</tbody>
</table>

Source: Chetty and Hanass-Hancock, 2015.

---

*SAHR* 2014/15
the needs of people with disability in communities. Task-shifting is an effective strategy for addressing shortages of healthcare staff who are essential for effective rehabilitation. It is also important that policy-makers carefully define the roles, skill set and practice domains of lay personnel and ensure appropriate remuneration in order to retain staff and maximise service delivery. One of the questions arising from this investigation is related to how policy supports this need for disability-related healthcare worker training and task-shifting. Further research in this area is urgently needed in order to prepare for the millions of people already living with HIV on ART in the region. CBR coupled with task-shifting is believed to be a winning combination to address the decentralisation of services and improve access to care which is also in keeping with expert consensus within this phase of the study.

Phase 4: Presenting the new Model of Care for Rehabilitation of People Living with HIV in a South African semi-rural setting

In the current study setting, people living with HIV who require rehabilitation can only access services at the centrally situated hospital, as there are no rehabilitation services provided at radial clinics. However, the community outreach centre, which is a site-affiliated non-governmental organisation, sends community health workers into the community and into patients’ homes to offer basic care and psychosocial support. Figure 2 is a diagram of the current framework guiding rehabilitation.

The model of care depicted in Figure 3 is the proposed model of care for the rehabilitation of people living with HIV at a semi-rural context. It places emphasis on the ‘home’ as a care setting. Rehabilitation should be offered within the home utilising a task-shifting strategy for the community health workers who should be capacitated through appropriate training and supervision by the multidisciplinary team to manage people living with disabilities in their homes. The community outreach team is regarded as a mandatory overarching structure to offer continuous care through collaboration and consultation with people living with HIV experiencing disabilities in their own environment.

The fundamental principles underpinning the model as seen in the building blocks in Figure 3 are essential to improved delivery and seamless care. Some principles seemed to achieve greater consensus among experts and stakeholders in the study, i.e. improving access to care, and offering high-quality and appropriate care. Healthy lifestyle practices, a multidisciplinary team approach, optimal communication between all stakeholders, evidence-based practice, and education and training for all healthcare workers were also agreed as being essential principles. Furthermore, task-shifting to lay personnel by the rehabilitation team, referral of patients to the community outreach team for follow-up, and training of all healthcare workers in the use of universal disability screening tools were essential building blocks, as depicted in Figure 3. Other keys to a successful model of rehabilitative care involved enabling patient-centred care that maximises functional independence and promotes health under good leadership to govern the process of implementation. These principles and proposed delivery systems should be reviewed under the current rehabilitation discourse guiding practice in South Africa.

The model of rehabilitative care lensed through a policy review

A review of policies impacting rehabilitation in South Africa was essential to establish the relevance of the model of care developed in this project for current practice. To achieve this, a systematic chronological review of policies implemented in the post-apartheid...
era that were identified by the author as influencing the rehabilitation of people living with HIV was conducted. The synthesised framework in Figure 1 was used as a tool to systematically review the policies chronologically. The four pillars within the synthesised framework for rehabilitation, i.e. objectives, principles, enablers and settings, formed the review filter. The relevant matching criteria that were identified in the policies are reflected in Table 3 under the synthesised framework.

Figure 3: Model of Care: Synthesised Framework
<table>
<thead>
<tr>
<th>Policy</th>
<th>Date of inception</th>
<th>Key underpinnings for rehabilitation</th>
<th>Implications on project rehabilitation framework</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The Constitution of the Republic of South Africa</strong></td>
<td>1996</td>
<td>Everyone has the right to have access to health care services. Discrimination on the basis of disability is prohibited.</td>
<td>Improving access to care. Influence policy development.</td>
</tr>
<tr>
<td><strong>National Strategic Plan for STIs HIV and TB (NSP)</strong></td>
<td>2012-2016</td>
<td>The new NSP includes persons with disabilities as a vulnerable group and lists a number of services in relation to access, prevention, treatment care and support. This new plan is also dedicated to the management of PLHIV and mentions the prevention of disability in the title of objective 3. The plan does not include rehabilitation strategies such as physical, vocational and social approaches.</td>
<td>Access is a key implication for prevention interventions for people with disabilities in objective 3 of the plan. However the plan falls short in addressing any other key concerns for rehabilitation strategies.</td>
</tr>
</tbody>
</table>

Table 3: Policies relevant to rehabilitation in the context of HIV
Following this review, it was evident that South African legislation is enabling in its redress and changes the disability and rehabilitation discourse from that of a practitioner-administered service for physically impaired individuals to that of a rights-based approach and in addressing not only individual impairment, but also societal and attitudinal barriers. The historical political climate in South Africa initiated policy reform resulting in the Constitution of the Republic of South Africa in 1996, and the Integrated National Disability Strategy (INDS) in 1997. The year 2000 saw the development of two reform policies that had a direct impact on rehabilitation discourse, namely the National Rehabilitation Policy (NRP) and The Primary Health Care Package (PHC) for South Africa. In 2007, South Africa became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Finally, the National Strategic Plan (NSP) on HIV, STIs and TB for 2012–2016 formed part of the review as an attempt to position the model within the country’s health-rehabilitation framework.

The Constitution states that “everyone has the right to have access to health care services.” Inadequate access to care was a major barrier to rehabilitation health services in this project and this contravenes the fundamental right of people living in South Africa to such access. Solutions to this contravention were discussed by stakeholders and proposed remedies included improving the rehabilitation pathways and referral structure within the model. Decentralising services through the task-shifting approach and focusing on HBR to access rehabilitation services was believed to be fundamental for this purpose. Indeed, this is not a negotiable privilege; according to law it is a right. Despite the issue of access being such a critical imperative in South African legislation, discussions with community health workers in a previous study at the same facility highlighted that even though universal design and appropriate information in the form of Braille may be expensive improvements to make in this healthcare setting, they are essential to address access to care.

The rights of people with disabilities, specifically those living with HIV as in this rehabilitation project, are further promoted and protected by the Integrated National Disability Strategy (INDS), a White Paper issued by the Office on the Status of Disabled People in the Presidency. The INDS, developed in partnership with people with disabilities and disabled people’s organisations, defines rehabilitation as “facilitating the participation of people with disabilities as active members of society.” Key policy areas included rehabilitation, barrier-free access, and community development, acknowledging the neglect of rehabilitation in legislation. The White Paper has developed policy objectives, strategies and mechanisms for each of these areas. However, there remains a lack of evidence related to the translation of this policy into practice and its feasibility. Further research that synthesises efforts on the ground and establishing how far they meet the policy objectives is required.

In 2000, The National Rehabilitation Policy and PHC package for South Africa were developed, advocating the need for integrated rehabilitation services to be provided at the primary level of care. The premise is to transform service delivery through creative strategic implementation of CBR frameworks and clearly defined objectives and standards of rehabilitative care. Focus was placed on the ‘Therapy Assistant’ who was mandated to manage people with disabilities in the community under the supervision of qualified therapists. The role of the therapy assistant was unfulfilled in the existing framework guiding rehabilitation at the health facility. Again, in this project, task-shifting was regarded as a solution by all stakeholders to equip the community health workers who are employed at the outreach centres to fulfil the role of the therapy assistant and to practice under the supervision of the multidisciplinary team. This is an approach that seems feasible not merely to improve access to services but also to address the lack of personnel offering such services. Both policies offer extensive comprehensive strategies to improve the healthcare system in South Africa. However, no evaluation of implementation in practice has been evidenced.

In 2007, South Africa ratified and signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its optional protocol. The UNCRPD sets out legal obligations for States to entertain and support the realisation of the rights and dignity of people living with disabilities. A paper evaluating South African policy on disability highlights the various articles of the Convention that pertain to rehabilitation, i.e. Articles 9, 19, 20, 25 and 26. Article 9 speaks to accessibility, compelling States to provide appropriate infrastructure, transportation and health care. Access to information is also seen as an imperative. As discussed in alignment with South Africa’s Constitution, access is a right and not a privilege, yet over a decade later, it is still a point that is not comprehensively addressed in practice. This emphasises the need to change the face of service delivery and for the purposes of this project, the delivery of rehabilitation within its specific context. Articles 19, 20, 25 and 26 respectively address the rights of people with disabilities to live independently and be included in the community; personal mobility; health and habitation; and rehabilitation. These, among other articles, address disability as socially constructed and are cognisant of the interactions between health conditions, intrinsic contextual features of the individual, and extrinsic contextual features of their social and physical environment.

Article 4 promotes research and appropriate technology to underpin service delivery, which includes rehabilitation as well as appropriate staff training. Despite the identification of these pertinent articles and the integral position of rehabilitation discourse within them, there is still poor translation of these components into practice, particularly in South Africa’s response to HIV and AIDS.

The goals and strategic objectives of South Africa’s National Strategic Plan (NSP) for STIs HIV and TB for 2012–2016 are guided by evidence from various reports and include the needs of the disability sector. From 2007 to 2009, the disability sector highlighted the need to develop accessible and disability-inclusive HIV and AIDS programmes, calling for mobilisation of resources for disability and prioritising persons with disabilities in the HIV and AIDS response. The NSP describes persons with disabilities as a vulnerable group and lists a number of requisite services in relation to the national approach of access, prevention, treatment, care and support. This plan is also dedicated to the management of people living with HIV and mentions the prevention of disability in the title of objective 3. Although initial efforts are underway to integrate issues related to disability and HIV, the plan does not include any traditional rehabilitation strategies such as physical, vocational and social approaches. However, in order to prevent and mitigate the disabling effects of HIV, rehabilitation has to be recognised as a crucial component of HIV management.
The policies informing the discourse of rehabilitation in South Africa advocate the importance of collaboration with people with disabilities as active participants in transforming practice and promoting these individual’s rights. The development process of the model for rehabilitative care in this project included engagement with people living with HIV and people with disabilities as active voices that speak as key stakeholders and experts throughout all phases of the project. This partnership added perspectives that are often relegated, and allowed the author to reflect on the integrity of the paradigm shift to inclusivity and collaboration with the key populace. The project undertaken provides a model that is pertinent to current South African legislation and builds on key aspects such as accessibility, rights, participation of people with disabilities, and their empowerment. It promises fluidity of care for people living with HIV through improving access through a rights-based approach and empowering of communities through recourse to a rehabilitative framework.

Conclusion

In this chapter the author has identified that people living with HIV in South Africa and globally are increasingly experiencing disabilities and require health systems to offer comprehensive delivery of rehabilitative care. In her foreword to the NRP in 2000, the then Minister of Health in South Africa acknowledged the challenge in transforming the extensive document into action and implementation. Today, a similar challenge prevails. South Africa offers enabling legislation to support the discourse for rehabilitation. However, there is a lack of empirical evidence translating policy into practice and vice versa. The implementation of the model developed in this project serves to address this translation gap in its proposed form. The model aimed at providing redress in a semi-rural setting is informed by a multi-staged research process using empirical evidence to improve its outcomes. Various stakeholders and experts agreed that HBR and task-shifting from rehabilitation professionals to lay personnel is crucial for improving accessibility to rehabilitation services via collaboration with a supportive multi-professional supervisory team in a resource-poor setting. These strategies, coupled with ongoing education and training, implementation of disability screening tools and strengthened referral systems, are further enablers of rehabilitation frameworks guiding public health care. The cost and feasibility of implementing such a model has not been addressed by stakeholders, although the financial constraints on rehabilitation were described as a barrier to care at all levels.

Recommendations

The piloting of the model presented in this chapter should go hand in hand with a cost and feasibility evaluation arm to ensure the effectiveness of such a framework within a South African setting. In 2008, Kautzky and Tollman concluded in their perspective on primary health care in South Africa, that in order to preserve the primary health care services which are critical to decentralise and strengthen the already burdened health systems, new models of care offering novel designs are warranted. This is a promising nudge for the implementation of the model of rehabilitative care presented in this chapter. Its implementation will require support from the governing authority in health care and funding structures which will be vital to enable the piloting of the proposed model. This chapter placed the development of the model of rehabilitative care within a semi-rural, resource-poor context. Should this prove to be feasible and cost-effective, it could serve as a pilot model to inform the development of future health and rehabilitative models of care at a national level.

Acknowledgements

This study is supported by the Medical Research Council of South Africa in terms of the National Health Scholars Programme from funds provided for this purpose by the National Department of Health. Jill Hanass-Hancock, Hellen Myezwa, Saul Cobbing, Pragashnie Naidoo are thanked for their supervision, mentorship and critical appraisal of the project.
References


53 South African Medical Research Council. National Health Scholars Programme, PhD Scholarships: An initiative by the National Health Research Committee [NHRC]. 2015. [Internet]. [cited 2 October 2015]. URL: http://www.mrc.ac.za/researchdevelopment/PhDsScholarshipcall.htm