Evidence-Based Management of an Individual Living with HIV

Kelly K. O'Brien, Stephanie A. Nixon

This paper uses a case study to highlight evidence on disability and rehabilitation in the context of HIV in order to inform future practice and research.

A CLINICAL CASE

Bella is a 54-year-old woman living with HIV who presents in an outpatient clinic with fatigue, weakness, and overall deconditioning 3 weeks post-discharge after a 1-week hospital admission for pneumonia. She is currently taking highly active antiretroviral therapy (HAART), her CD4 count is 550 cells/mm³, and her viral load is undetectable. Bella has peripheral neuropathy in both feet, which results in pain and difficulty in standing for long periods. She was also recently diagnosed with osteoarthritis of both knees. Bella has been on HAART for 5 years and has lipodystrophy, a common adverse effect of this therapy characterized by a change in body composition with increased visceral fat and reduced subcutaneous fat. Bella is a single mother of three, currently on leave from her job as a real-estate agent. Upon assessment, Bella states that despite feeling better since her hospital admission, she experiences daily fluctuations in her health, finding it difficult to get out of bed or perform household chores on certain days. She also recognizes that she is “getting older” and experiences increasing fatigue. Bella finds it difficult to manage the uncertainty related to the “ups and downs” of her illness; she worries about providing for her family and managing her health if another episode of illness arises. Bella’s goals are to return to work and to develop strategies to prevent future episodes of illness.

CLINICAL QUESTIONS

1. What types of disability might Bella be experiencing?
2. What types of rehabilitation interventions can address these challenges?

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Evidence from the Literature: Disability

Adults living with HIV have defined disability as any impairments, difficulties in carrying out day-to-day activities, challenges to social inclusion, or feelings of uncertainty that may be experienced daily or over the course of living with HIV.^{1,2} In 2004, a survey of people living with HIV in British Columbia documented an overwhelming prevalence of impairments (80%), activity limitations (81%), and participation restrictions (93%).³ Most prevalent impairments were pain, diarrhoea, reduced libido, weakness, poor concentration, headache, and fatigue. Most prevalent activity limitations related to vigorous and moderate activities, sexual activities, and household chores. Most prevalent social participation restrictions related to sexual, student/employee, and financial roles. Respondents to this survey were primarily white (89%) sexual-minority males (77%) aged 30 through 49 (64%).³

Solomon and Wilkins examined barriers to participating in society from the perspective of 23 women living with HIV (mean age: 41 years) in rural and urban areas of Canada.⁴ Themes linked to decreased participation included living in poverty, enduring depression and isolation, fearing disclosure and stigma, tolerating symptoms, experiencing barriers to work, and lacking supportive networks. Themes linked with enhanced participation of women included the meaning of children, balancing life with HIV, accessing supportive networks, and possessing a strong self-identity. Authors highlighted the interaction among personal, environmental, and health-related factors and the need for support specifically for women living with HIV.

Further complicating the experience of living with HIV is the episodic nature of disability, characterized by unpredictable periods of wellness and illness.¹

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Uncertainty is a key dimension of disability, including worrying about one's future living with HIV and about the unpredictability of the timing, severity, and potential consequences of the next episode.

Ageing with HIV: An Emerging Issue

As individuals with HIV live longer, they may experience accelerated and premature effects of ageing, resulting in a range of concurrent health conditions that further complicate their disablement. Concurrent health conditions associated with HIV include osteoporosis, cardiovascular disease, osteonecrosis, neurocognitive impairments, liver disease, and higher rates of cancers. These conditions are often experienced in combination⁵ and may be compounded by long-term antiretroviral use.^{6–9} A survey of approximately 900 older adults with HIV in New York found that 91% of respondents experienced at least one concurrent health condition, while 77% experienced two or more.⁵ Oursler et al. demonstrated that men over age 50 taking HAART had decreased exercise capacity, functional performance, physical activity, and grip strength.¹⁰ Older women in particular are at greater risk of developing lipodystrophy,¹¹ which is associated with several risk factors for cardiovascular disease, including diabetes, insulin resistance, hypertension, elevated total cholesterol, and elevated triglycerides.^{12,13} Lipodystrophy may also be associated with poor body image (due to redistribution of body fat) and with reduced quality of life.^{14,15} Uncertainty is further exacerbated by ageing, as older adults may be unsure whether their disablement is due to HIV, concurrent health conditions, adverse effects of long-standing medication, the ageing process, or a combination of these factors.¹

The types of disability experienced by Bella include impairments (pain, fatigue, weakness), difficulties with day-to-day activities (standing for long periods, performing household chores), challenges to social inclusion (inability to work), and uncertainty about her future because of the unpredictable and episodic nature of HIV. Bella faces the added complexity of disablement related to ageing and concurrent health conditions such as lipodystrophy and osteoarthritis.

EVIDENCE FROM THE LITERATURE: INTERVENTIONS

Exercise

Rehabilitation may address or prevent disablement experienced by adults living with HIV. However, evidence on rehabilitation interventions in the HIV literature is limited, with the exception of exercise. Two systematic reviews explored the effects of aerobic and progressive resistive exercise among adults living with HIV.^{16,17} Collectively, these reviews included 16 randomized controlled trials; 17 meta-analyses were performed

in the resistive exercise review, and 13 meta-analyses were performed in the aerobic exercise review. Results indicated that performing continuous or interval aerobic exercise, or a combination of continuous aerobic and progressive resistive exercise, for at least 20 minutes three times per week for at least 5 weeks is safe and may be beneficial for adults living with HIV who are medically stable.^{16,17} Exercise is associated with improvements in selected outcomes of cardiovascular fitness (maximum oxygen consumption), weight and body composition (arm and thigh girth), and quality of life (depression-dejection symptoms).^{16,17} The majority of results from individual studies demonstrated improvements in strength and psychological outcomes.¹⁷ Meta-analyses did not demonstrate any differences in immunological or virological outcomes (i.e., CD4 count or viral load) between exercisers and non-exercisers, which supports the evidence on the safety of exercise for this population.

Types of aerobic interventions for adults living with HIV studied in the literature include stationary bike, walking, jogging, running, rowing, stair-stepping, stationary cycle ergometer, and cross-country and ski machines. Exercise intensity for aerobic exercise in the literature ranges from 50% to 85% VO₂max or from 55% to 85% heart-rate maximum, three times per week for 5 to 24 weeks.¹⁶ Types of resistive exercise studied include concentric and eccentric muscle training, isotonic resistance exercises, and weight training for the upper and lower body, often in accordance with the American College of Sports Medicine guidelines.¹⁸ Most exercise interventions include warm-up and cool-down periods with stretching components. Intensity of exercise is gradually progressed, and exercise may or may not be supervised.

Mutumura et al. explored the effect of aerobic exercise training on people living with HIV in Rwanda who were taking HAART and had lipodystrophy.¹⁹ Participants randomized to 6 months of exercise training demonstrated improvements in metabolic outcomes, cardiorespiratory fitness, body composition, and quality of life relative to non-exercisers.²⁰ This is the first study to demonstrate the impact of exercise in a developing country. In contrast to the majority of earlier studies in the aerobic and resistive systematic reviews,^{16,17} 60% of participants in this study were women.

Management of Neuropathy

The most common form of HIV-related neuropathy is distal symmetrical polyneuropathy, characterized by numbness, tingling, and pain bilaterally in the feet and, occasionally, hands. Neuropathy can lead to difficulty sleeping, weakness, difficulty ambulating, and reduced quality of life.²¹ Little evidence exists on HIV-associated neuropathy rehabilitation interventions. Desensitization techniques (e.g., ice massage, dry-towel massage) have

shown little effect.²² A systematic review, not specific to HIV and comprising three studies, indicated that resistive exercises may moderately improve muscle strength among people with peripheral neuropathy.²³ Compensatory strategies such as adaptive footwear have been used to increase support and cushioning to relieve pain. Hot baths were highly rated as an effective self-management strategy by people living with HIV; other strategies self-reported to ease discomfort included staying off one's feet, rubbing feet with cream, taking analgesics, walking, taking vitamin B, massage, acupuncture, and reflexology.²⁴

Returning to Work

The decision to return to work after an episode of illness is complex, often requiring careful consideration of uncertainties related to health status, financial safety net, workplace environment, and job demands.^{25,26} Vocational rehabilitation has been positively associated with successful reintegration into the labour force.²⁷ The Canadian Working Group on HIV and Rehabilitation (CWGHR), a national, multi-sectoral organization, has partnered with other illness groups to promote vocational rehabilitation and flexible policies to enhance work opportunities and income support for people living with HIV and other episodic illnesses.²⁸

Bella may benefit from a combination of the above rehabilitation interventions, including a comprehensive aerobic and progressive resistive exercise program to improve her strength, activity tolerance, and body composition and to enhance her ability to carry out her daily and work-related activities; adaptive footwear to relieve neuropathic pain; and enrolment in a vocational rehabilitation program customized to her goal of returning to work. Interventions will require specific tailoring in accordance with Bella's age, her lifestyle, and her concurrent osteoarthritis and neuropathy.

CURRENT OPINION AND FUTURE DIRECTIONS

Exercise as a rehabilitation intervention in HIV has received much attention, but research findings should be interpreted cautiously. Variability in exercise interventions, participant characteristics, and outcome measures makes it difficult to determine the appropriate frequency, intensity, time, and type of exercise to maximize benefits. Studies have also been characterized by small sample sizes and large withdrawal rates. Because study participants cannot be blinded to exercise, studies may have overestimated the benefits of exercise. The long-term effects of exercise also remain unclear. Finally, most participants were men under the age of 50, which limits our ability to generalize benefits to women or older adults living with HIV.

Avenues for future research are abundant. A national

scoping study by the CWGHR identified six research priorities in HIV and rehabilitation:

- (1) disability and episodic disability, (2) concurrent health conditions aging with HIV, (3) HIV and the brain, (4) labour force and income support, (5) access to and effectiveness of rehabilitation, and (6) development and evaluation of outcome measurement tools.^{29(p.448)}

These priorities highlight the need for research to explore interventions beyond exercise for preventing or reducing disability and enhancing quality of life for people living with HIV. Increased research involving women and individuals ageing with HIV is also needed.

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