

Six Lessons for COVID-19 Rehabilitation From HIV Rehabilitation

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Novel coronavirus disease 2019 (COVID-19) is a pandemic comparable to human-immunodeficiency virus (HIV) in many ways. It is an infection with no known vaccine or cure, no licensed treatments early in the pandemic ¹, presents with diverse functional problems that are amplified by other health conditions and aging ^{2,3}, and disproportionately affects key and vulnerable populations ^{1,4}. COVID-19 is increasing the burden of disease and disability and will continue to do so ⁵. Rehabilitation has played and will continue to play a vital role in case management ⁶. Although the long-term consequences of COVID-19 remain largely unknown, evidence from the HIV experience could inform the evolving practice of COVID-19 rehabilitation.

Rehabilitation is a fundamental health service within universal health coverage and enables greater participation in education, employment, and community life, with far-reaching health, social and economic benefits ⁷. The field of HIV, disability, and rehabilitation has taken ground-breaking strides to advance practice, education, and research ⁸. We outline 6 key lessons from HIV rehabilitation for consideration to inform COVID-19 rehabilitation.

Lesson 1

Anticipate disability during and after acute management of COVID-19, and recognize its potentially episodic nature.

The episodic disability framework (EDF) highlights how people living with HIV can experience multidimensional and episodic disability, characterized by unpredictable periods of wellness, illness, and loss of functioning ⁹. The EDF describes disability experienced by people living with HIV, has cross-cultural applicability ¹⁰, and is relevant to other chronic health conditions ³. COVID-19 is a respiratory viral disease with multi-organ involvement, resulting in potentially temporary and episodic health challenges such as impaired lung function, physical deconditioning, cognitive impairments, impaired swallow and communication, and mental health disorders ². The multidimensional sequelae of COVID-19 may present a heterogenous cluster of unpredictable, prolonged, and relapsing symptoms ¹¹⁻¹³ requiring interprofessional rehabilitation ¹⁴. Attending to the multidimensional, episodic, and unpredictable nature of disability defined within the EDF can be used to better understand the dimensions of COVID-19-related disability that people experience and the

contextual factors that might exacerbate or alleviate dimensions of disability and can help inform areas in which to focus interventions or service provision efforts to address disability over time.

Lesson 2

Understand that the disability dimension “uncertainty or worry about the future” may play a role in COVID-19–related disability.

Uncertainty refers to the extent an individual worries about potential episodes of illness they might experience, the severity and potential outcomes of an illness, and the impact of worrying about future health on life decisions such as employment and personal relationships¹⁵. Uncertainty, defined within the EDF and measured with the HIV Disability Questionnaire (HDQ)¹⁶, is the most present and severe disability dimension experienced by samples of people living with HIV in Canada, Ireland, the United States, and the United Kingdom¹⁷. Uncertainty is at the center of disability experiences directly influencing symptoms, daily activities, and social participation¹⁵ and can also contribute to stigma¹⁸. Comparable to HIV, COVID-19 may be accompanied by fear, isolation, stigma, unknown long-term consequences and uncertainty, affecting experiences of employment, community participation, and quality of life^{19,20}. It will be important for clinicians and communities to consider uncertainty and its impact on mental health, function, and social inclusion for people affected by COVID-19. Acknowledging uncertainty in the context of COVID-19 may improve capacity for self-management and improve outcomes²¹.

Lesson 3

Develop disability- and rehabilitation-focused responses to COVID-19, as in the 2016 “Political Declaration of HIV and AIDS [acquired immune deficiency syndrome]: On the Fast Track to Accelerating the Fight Against HIV and to Ending the AIDS Epidemic by 2030.”

²²

Perceived focus on the biomedical, pharmacological, and impairment-oriented approaches to HIV posed challenges to individuals who face widespread barriers in accessing health services²³. The global response to COVID-19 would benefit from a disability and

rehabilitation lens, to reduce disparities and preserve the worldwide commitment to universal health coverage, inclusive of rehabilitation.

Lesson 4

Prepare for the long-term impact of COVID-19 on key and vulnerable populations to help prevent inequality, stigma, and unintended social consequences, making every effort to leave no one behind ^{4,22}.

Lesson 5

Build on existing research networks in HIV rehabilitation to provide foundations for developing the field of COVID-19 rehabilitation.

The Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC) ⁸ is a research network comprised of community, academic, and clinical stakeholders to promote knowledge transfer and exchange, establish and strengthen multi-stakeholder partnerships, and establish coordinated responses for identifying and addressing priorities in an emerging field. CIHRRC has bridged partnerships among professions dealing with HIV and other health conditions to inform clinical practice and research ²⁴. Establishing international research networks in COVID-19 rehabilitation could help translate knowledge from initial epicenters to mitigate impacts in emergent regions and help foster community partnerships that may cultivate mechanisms to raise the profile of, and evidence for, COVID-19 rehabilitation.


Lesson 6

Include and focus on people living with and affected by the infection in all responses to the pandemic.

The Greater Involvement of People Living with HIV (GIPA) is a guiding principle that calls for the active and meaningful participation of people living with and affected by HIV in the inception, development, implementation, monitoring, and evaluation of policies and programs ²⁵. GIPA is a rights-based approach that acknowledges the universal rights of people living with HIV to self-determination and participation in decisions that affect their lives. In the Global North, the EDF and HDQ were derived in collaboration with, and from the experiences of, people living with HIV ^{9,16}. In the Global South, community and academic

partnerships push for integration of rehabilitation into HIV care ²⁶. Similarly, the experiences of people with disabilities are utilized to advocate for accessible HIV prevention, treatment, and care ²⁶. It will be equally fundamental to include and meaningfully engage people diagnosed with, affected by, and recovering from COVID-19 to enhance the quality and effectiveness of the COVID-19 response, including rehabilitation.


Research, practice, education, and policy stakeholders must ensure that optimal function and quality of life is included across all responses to COVID-19, as has been a goal for responding to HIV. Evidence suggests that rehabilitation is fundamental in the context of communicable viral disease presenting with systemic health challenges ^{2,27}. Lessons from HIV rehabilitation could expedite a community-engaged rehabilitation response to COVID-19, the identification or development of disability measurement tools reflecting experiences of people with COVID-19, and the sharing of information about appropriate service planning and delivery.

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