5TH INTERNATIONAL FORUM ON HIV AND REHABILITATION RESEARCH

UNIVERSITY OF MANCHESTER SUMMARY OF EVIDENCE PRESENTED

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KEYNOTE

Acknowledging the multidimensional and multidisciplinary trajectory of rehabilitation and HIV

The Canadian Working Group on HIV and Rehabilitation (CWGHR) was set up 25 years ago as an interdisciplinary group to transfer knowledge about the practice of rehabilitation and lived experience to wider audiences. The International Classification of Functioning, Disability and Health (ICF) model was applied to people living with HIV to change the way we think about rehabilitation in a person-centred approach. Funding was obtained, guided by the lack of evidence and the need to establish a burden of illness. The phrase "episodic disability" was coined, and by 2006, a model was developed by experienced clinicians, which was presented at AIDS 2006. In 2007, a scoping review and focus groups led to methodological advances in episodic health and disability sources the life course. Collaboration, inclusivity, and holistic knowledge mobilization/translation were celebrated, and people living with HIV were included as co-researchers. KTE/KMb included mentorship programs, multimedia publications, and research priorities were developed for rehabilitation for those living with HIV.

RESEARCH EVIDENCE SESSION #1 – ROLE OF MENTAL HEALTH REHABILITATION INTERVENTIONS IN HIV AND AGEING

Dana Rosenfeld, *University of Westminster*: Ageing with HIV: Psychosocial challenges and Implications

The speaker discussed the challenges of aging with HIV, which is a personal and complex experience. Older people living with HIV have a harsher experience due to the intersection of psychosocial and health factors. Before 1996, social networks of older people living with HIV were hit the hardest. Long-term care for them is a complex and important issue, which is worsened by NHS funding issues. There is a need for dedicated funding for HIV and health issues associated with older people living with HIV. The age at which a person was diagnosed with HIV is an important factor. Self-advocacy is vital, and healthcare professionals should look out for older people living with HIV.

Anna Hughes, *George House Trust*: Holistic support for an aging cohort

The community participant discussed the challenges faced by older people living with HIV, particularly women and black Africans, who often experience social isolation. Most often, persons living with HIV prefer face-to-face support over virtual support, especially those who lack social networks. It's important to have a trusted person to talk to and address psychosocial needs. Prioritizing basic communication needs over technological advancements is crucial for this demographic. Support groups should include people with different backgrounds to share experiences and normalize living with HIV while aging with HIV.

Kelly Birtwell and Graeme Donald, *University of Manchester*: Delivering Mindfulness-Based Interventions for People Living with HIV

Mindfulness is about being present in the moment, and it can be helpful for people with a range of physical and mental health conditions. People living with HIV are more likely to struggle with mental health and depression. The Positively Mindful study evaluated an 8-week mindfulness course for people living with HIV. It found the course was acceptable to people, and they reported a range of benefits, including seeing their life anew. Two people felt worse after some of the mindfulness practices, and it is important to be aware of the challenges and negative effects from mindfulness as well as the benefits. Trauma-sensitive and person-centred approaches to mindfulness can help to reduce and manage some of these risks.

Jaime Vera, *The Silver Clinic, Brighton and Sussex University Hospital NHS Foundation Trust* : Implementation of frailty screening in people living with HIV: lessons from the Silver Clinic

Aging with HIV requires healthcare professionals to provide personalized care coordination and use geriatricians to address the unique physical health needs of people living with HIV who are older than 50 [1][3]. A multi-morbidity care plan must take into account all their needs[1]. Healthcare professionals must be trained on, and aware of, frailty [1]. The physical health needs of people living with HIV who are older than 50 need to be recognized as unique compared to the rest of the elderly and aging population [1]. However, the current NHS funding may not allow for frailty screening and person-centered care for a large population of people living with HIV who are older than 50 [1]. Frailty screening should not become another tick-box exercise as is common in NHS [1].

References: [1] The Evidence Base for an Ideal Care Pathway for Frail … [2] Frailty and frailty screening: A qualitative study to elicit … [3] Geriatric patients living with HIV treatment & care

Francisco Ibanez-Carrasco, *University of Toronto:* Access to service for people living with HIV experiencing neurocognitive difficulties: the HEADS Up 2 Study.

The HEADS UP 2 study looked at how people living with HIV access services for neurocognitive difficulties. It found that many people don't know how or when to access these services. There are also few services in Canada that focus on neurocognitive difficulties experienced by people living with HIV. Clinicians and community providers don't know enough about these difficulties. People can use technology and clever ways to improve their health literacy. Social factors such as stigma may also impact access to services. A map of an individual's social network and a tech-check can help improve access to services and quality of life.

RESEARCH EVIDENCE SESSION #2 – ROLE OF MENTAL HEALTH REHABILITATION INTERVENTIONS IN HIV AND AGEING

Natalie St. Clair-Sullivan, *Brighton and Sussex Medical School:* Exploring frailty and frailty screening for older people living with HIV

Frailty refers to the physical and mental decline that can come with aging, which can lead to a loss of independence and have a domino effect on one's wellbeing. The terms "frailty" and "vulnerability" are often used interchangeably. While there is a difference between age-related frailty and health-related frailty, mental fragility can also contribute to overall frailty. People want to focus on living well, not just aging well. Psychosocial elements of frailty should be prioritized when discussing it with patients. The experience of aging and living with HIV is complex, as losses in one's personal life can compound on one another. Frailty impacts mental health, which is distinct from "normal frailty." The need for studies on healthcare providers' knowledge and skills in caring for aging people with HIV is highlighted. Discussions about frailty should be approached with care as they impact psychosocial experience and mental health. Screening tools need to be person-centered, as generic tools do not reflect the complex experience of aging with HIV. Healthcare systems present barriers to access, with too many layers for people to navigate to reach the right service or professional.

Liam Townsend, *St. Vincent's Hospital, Dublin, Ireland:* Investigating and modifying frailty in People Living with HIV

Frailty has a negative impact on the clinical status of people living with HIV (PLWH) and increases the risk of adverse outcomes, including hospitalization, institutionalization, disability, and premature death. Pre-frailty is a condition that predisposes and usually precedes the frailty state, and is characterized by losses in physical, psychological, or social domains [2]. "*Inflammageing*," the age-related increase in pro-inflammatory markers in blood and tissues, is a strong risk factor for multiple diseases and is highly prevalent in elderly individuals, including people living with HIV. Personalized care coordination and geriatricians are necessary to address the unique physical health needs of aging people living with HIV, and interventions should focus on physical movement rather than pharmacological treatment. It is important to use a person-centered care approach that focuses on holistic abilities over blood results/biomarkers. The high medicalization associated with other comorbidities makes HIV harder to treat in older people, and primary care is not currently that useful in HIV treatment.

Andrew Eaton, *University of Regina*: Examining adapting cognitive remediation group therapy as an online or hybrid intervention for people aging with HIV and cognitive concerns

People living with HIV face a lot of stress due to poverty, chronic illness, and stigma, which can worsen their condition. Cognitive concerns are common among middle-aged persons living with HIV. Mindfulness-based stress reduction (MBSR) is a promising intervention that can help reduce stress and emotional distress in HIV-positive populations. However, there is still not enough evidence to determine its effectiveness in improving disease progression. Modern treatment of HIV can protect from further cognitive damage, but it cannot repair pre-existing damage.

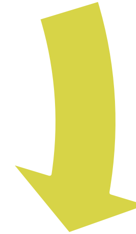
Kelly O’Brien, *University of Toronto*: Lessons Learned Piloting an Online Tele-Coaching Community-Based Exercise Intervention Study with Adults Living with HIV

Research suggests that exercise programs can have positive outcomes for people living with HIV, including improvements in physical performance, adiposity, cardiometabolic outcomes, overall health, and wellbeing. However, there are environmental, personal, and social barriers to exercising in conventional exercise environments such as gyms. Online exercise is a viable option, especially in light of the COVID-19 pandemic and future environmental crisis. Building online communities for exercise is challenging, and there is evidence of attrition from online programs due to a desire for "real, in-person" connection. Despite this, there is good representation of women and transgender persons in online exercise programs, which helps reduce barriers to participation.

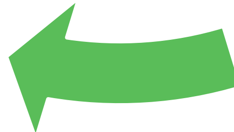
PANEL

Technologies should be used to pave the way for in-person interventions rather than replacing them. Any tech-aided or based intervention requires a significant amount of time, effort, and tech-literacy to implement

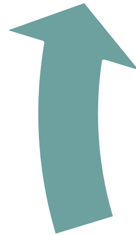
Technologies must be considered as channels for communication rather than the end goal.



Researchers are developing interdisciplinary software that gamifies physiotherapy exercises for older adults.



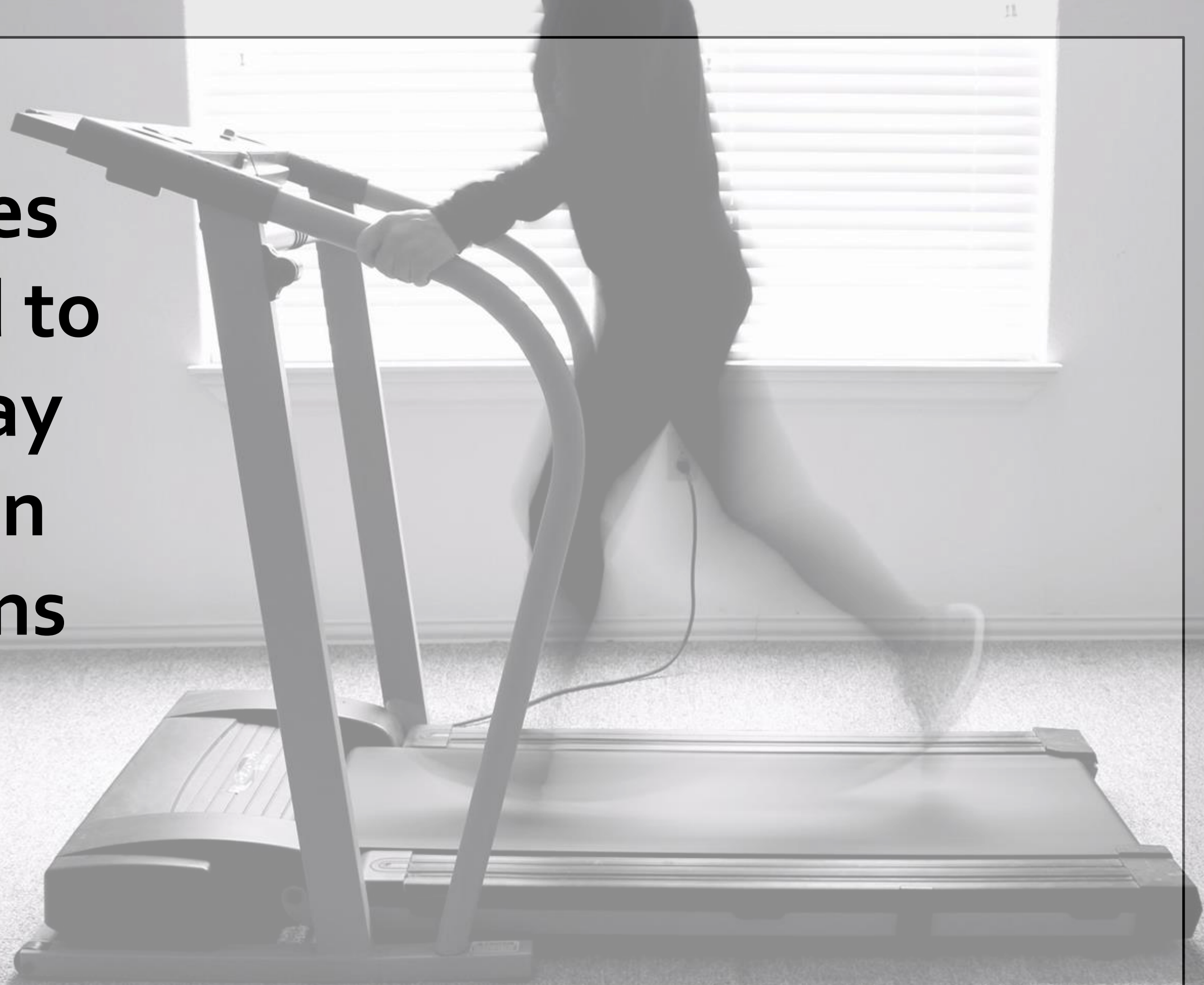
Old technologies still work, for example, a "telephone buddy services" for people living with HIV is a simple tech intervention where somebody calls somebody elese for up to 60 minutes for up to 12 weeks.



Technologies are channels for communication but do not substitute the efforts of communicating with one another.

Well established technologies like telephones still greatly aid our social, psychological, and physical rehabilitation efforts

Technologies can be used to pave the way for in-person interventions rather than replacing them.



Additional info.

- A review of 75 controlled trials found that mobile technology-based health interventions, such as text messaging, can improve disease management and health behaviors, but high-quality, adequately powered trials of optimized interventions are needed to evaluate effects on objective outcomes.

- When used, the evidence-based app - called Keep-On-Keep-Up- will help reduce the thousands of injuries – which are often serious and sometimes fatal - in the over 65's caused by falls. Find it here: https://kokuhealth.com/

- Telephone buddy services involve calling a person living with HIV for up to 60 minutes for up to 12 weeks, but it is not a replacement for in-person interactions. See: https://ght.org.uk/telephone-buddy-volunteer

- The TEx Study, which involves an app to track weight, BMI, exercise, and monthly group work, requires a lot of time, effort, and tech-literacy to implement but it shows hope for future community based exercise. See https://hivinmotion.ca/tele-coaching-community-based-exercise-study/

- The HEADS UP 2 Study found that although there is poor access to cognitive rehabilitation services in Canada, gadgets such as timers, scheduled robocalls for medical appointments and other technology can help persons living with HIV, especially those ageing and with cognitive difficulties. See https://bit.ly/3ZYVV1W

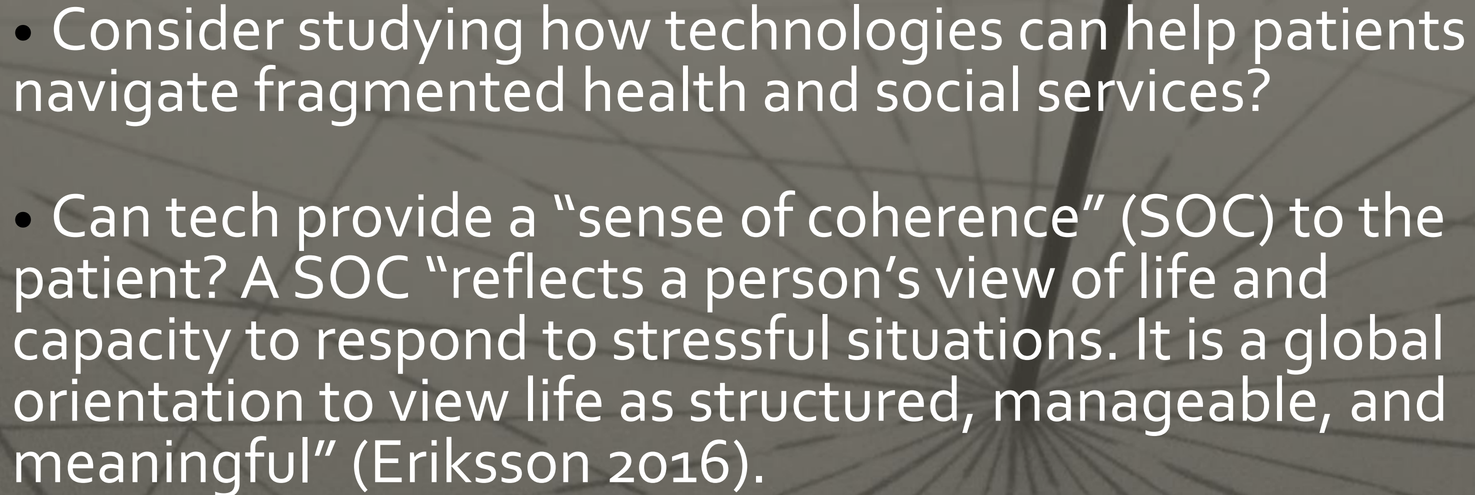
KEY IDEAS OF THE 5TH HIV AND REHABILITATION FORUM

Use old and emerging technologies as paths to physical rehabilitation

Use of old and emerging technologies as paths to rehabilitative connections as personal as the connections we develop in person (e.g., phoning a buddy at specific times each week).

Train clinicians and researchers to better understand ageing and associated conditions such as frailty, vulnerability, ageism, etc.

Communicate clearly and to wide audiences/stakeholders the meaning of key technical terms in the area of physical rehabilitation and aging such as frailty, vulnerability, susceptibility and social vulnerability, death and dying. The concept, and the very mention, of ***ageing*** triggers different conceptualizations for different people. Ask yourself, “How do diverse people ageing with HIV speak about and express vulnerability and other terms?”



- Consider studying how technologies can help patients navigate fragmented health and social services?

- Can tech provide a “sense of coherence” (SOC) to the patient? A SOC “reflects a person’s view of life and capacity to respond to stressful situations. It is a global orientation to view life as structured, manageable, and meaningful” (Eriksson 2016).

- Include dying, death, and assisted death in the conversations about rehabilitation which seems to solely focus on living longer (not the same as living well)

We need research that focuses on the lifecourse of persons living with HIV (regardless of the time of diagnosis) and that makes distinctions between phenotypic and non-phenotypic forms of frailty. Phenotypic ageing defines frailty as the presence of five components: weakness, slowness, exhaustion, low physical activity, and unintentional weight loss.

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