The Role of Physiotherapy in the Lives of People Living with HIV

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Overview of Presentation

• About Realize

• What is HIV?
  • Prevalence
  • Co-morbidities
  • Episodic Disability

• What can physiotherapists do?

• Tips for working with people living with HIV
Realize
Realize

• *Realize* was founded as the Canadian Working Group on HIV and Rehabilitation in 1998 by people living with HIV, AIDS service organization representatives, government, program and policy-makers, researchers, and rehabilitation and other health care providers.

• In order to promote a comprehensive approach to rehabilitation in the context of HIV, *Realize* is multi-sectoral, and multi-disciplinary in its membership and activities.
Realize members come from across Canada and include people living with HIV, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, and the employment sector.
Realize

• Four main strategic directions that encompass four key areas of research, education, policy and practice:
  • Access to Rehabilitation,
  • Labour Force Participation and Income Support,
  • HIV and Aging, and
  • Mental Health
Human Immunodeficiency Virus (HIV)

An overview
Human Immunodeficiency Virus (HIV)

• Sexually-transmitted and blood borne infection
• Impacts the immune system
  • CD4 cells (T-cells) are attacked decreasing their numbers
  • Increases risk of infections
• CD4 count and viral load measurements provide information on the progression of the virus (CATIE, 2017a)
HIV

• First diagnosed in Canada in 1982 (CATIE, 2017b)

• Lived experience of PLWHIV has changed tremendously since the early stages of the epidemic
  • Consistent use of combined antiretroviral therapy (cART) can halt the replication of the HIV virus and vastly slow disease progression
  • Recent studies show that the life expectancy of many men living with HIV who have full access to treatment may approach that of their HIV-negative peers
  • Same doesn’t appear to be true for women, people of colour or those who use drugs and live with HIV due to decreased access to resources for health (Public Health Agency of Canada, 2015)
Prevalence of HIV in Canada

- 63,000 people living with HIV in Canada at the end of 2016 (PHAC, 2018)

Percentage of Men and Women living with HIV of Total Prevalence of HIV in Canada

- Women (23%)
- Men (77%)
Prevalence of HIV in Canada: Exposure Categories

- The Public Health Agency of Canada (PHAC) uses ‘exposure categories’ to describe sub-populations based on how they likely became infected (PHAC, 2018)

![Pie chart showing the distribution of exposure categories for total HIV prevalence in Canada. Men who have sex with men (52.5%), Men who have sex with men - Injection drug use (3.0%), Injection Drug Use (11.3%), Heterosexual categories (33.2%), Other (0.2%).]
Indigenous Communities

- Indigenous communities are disproportionately impacted by HIV
- Differential impact of the social determinants of health, including income, education, and housing
- Persistent racism and the consequences of residential schooling and colonialism have impacts across generations which, along with the determinants of health, can lead to increased vulnerability to infection among Indigenous persons

(PHAC, 2014a, 2018)
UNAIDS 90-90-90 Targets

- UNAIDS developed the 90-90-90 treatment cascade as a strategy to end HIV/AIDS by 2020 (UNAIDS, 2014)

90% of all living with HIV will know their HIV status
90% of all living with HIV will receive antiretroviral therapy
90% of all receiving antiretroviral therapy will have viral suppression
HIV as a Chronic Health Condition

• HIV is now considered a complex health condition (PHAC, 2015)
• First cohort of older persons living with HIV who were diagnosed in the early stage of the epidemic are now aging
• Accelerated vs Accentuated aging?
• Effects of long term infection, co-morbid chronic health conditions, aging, and/or HIV-related complications
HIV and Aging

• Over 25 000 people living with HIV are over the age of 50 (UNAIDS, 2013)
  • ¼ of all new HIV infections are in people aged 50 or older (Bourgeois et al., 2017)
Co-Morbidities

Several health conditions are known to be more prevalent among PLWHIV as compared to those who are not living with HIV such as:

- Mental health issues;
- Pain;
- Frailty;
- Lung disease;
- Asthma;
- Diabetes;
- Stroke;
- Osteopenia/osteoporosis;
- Peripheral neuropathy;
- Cancers (anal, liver, cervical, and Hodgkin’s Lymphoma)

(Benevides et al, 2017; Escota et al, 2016; Kendall, 2014; Pinzone et al, 2012; Thaczuk, 2011)
Frailty

• “Clinically recognizable state of older adults with increased vulnerability, resulting from age-associated declines in physiologic reserve and function across multiple organ systems, such that the ability to cope with everyday or acute stressors is compromised” (Chen, Mao, & Leng; 2014)
  • PLWHIV on treatment have a higher rate of frailty than the general population (Deeks, Lewin, & Havlir; 2013)
  • Frailty also is more likely to occur at a younger age in PLWHIV (Desquilbet et al., 2007)

• The Frailty Phenotype Model indicates that weakness, weight loss, exhaustion, low activity, and slowed performance can lead to falls, disability, dependency, and death as the health outcomes of frailty (Chen, Mao, & Leng; 2014)
Pain

• May be rheumatologic, neuropathic, musculoskeletal or secondary to low body weight

• Similar in prevalence and intensity to patients with cancer (McGuire, 2003)

• There is an observed prevalence of pain related to people who present with the frailty phenotype
  • As the frailty phenotype may be reversible there are implications related to pain (Petit et al., 2018)
Mental health issues and/or substance use

• Depression is the most common mental health issue for PLWHIV (Nanni, Caruso, Mitchell, Meggiolaro & Grassi, 2014)
  • Approximately 30% of PLWHIV experience some form of depression (Choi et al., 2016; Rusch et al., 2004)

• Substance use is more common among people living with HIV than in the general population (Skalski, Sikkema, Heckman & Meade, 2013)
  • Reduced cART adherence is associated with recent use of alcohol, cocaine, stimulants and heroin, though it appears not to be impacted by cannabis use (Rosen et al., 2012; Slawson et al., 2014)
Mental health issues and/or substance use

- PLWHIV experience many different social factors such as isolation, lack of familial and social support, discrimination related to gender, sexuality, and of having a sexually transmitting infection, violence, feelings of hopelessness, and drug use.
- Stigma, even so many years after the first cases of HIV were seen, is still a factor in the lives of PLWHIV.
- These factors can be implicated in the high rates of depression for PLWHIV.

(Nanni, Caruso, Mitchell, Meggiolaro & Grassi, 2014)
Episodic Disability

- Episodic disability is defined as any symptoms and impairments, difficulties carrying out day-to-day activities, uncertainty and worrying about the future, and challenges to social inclusion that may be experienced on a fluctuating basis, both daily, and over the continuum of living with HIV.

(O'Brien, Davis, Strike, Young & Bayoumi, 2009)
Episodic Disability and HIV

• The concept of episodic disability has emerged based on the health related challenges that adults living with HIV experience.

• Participants felt the term disability itself suggested permanency in contrast to their experiences living with the fluctuating periods of health, but it was recognized the importance of the term disability which often was required in order to access crucial social services and supports.

(O'Brien, Bayoumi, Strike, Young & Davis, 2008)
Episodic Disability Framework

Dimensions of episodic disability

- Symptoms / impairments
  - Adverse effects of HIV or meds (fatigue, diarrhea, nausea, pain, etc.)
- Difficulties with day-to-day activities
  - Stress, anxiety and depression
  - Fear, decreased self esteem, shame or embarrassment, loneliness
- Challenges to social inclusion
  - Parental roles
  - Work and school
  - Personal relationships
- Uncertainty
  - Other social roles and activities

Dimensions of episodic disability. Four dimensions of episodic disability and their sub-components that may be experienced by adults living with HIV.

HIV and Physiotherapy
HIV and Disability

• >30% of PLWHIV in Ontario report having at least 1 other health condition
  • Diabetes, congestive heart failure, etc (Kendall et al., 2014)

• 72% of PLWHIV in Canada are living ≥2 health conditions along with HIV (O’Brien, Ibanez-Carrasco, Carriere, & the HIV Health and Rehabilitation Survey Team, 2016)

• Most PLWHIV had experienced at least one
  • Impairment (>90%),
  • Activity limitation (80.4%), and/or
  • Participation restriction (93.2%) (Rusch et al., 2004)
HIV and Rehabilitation

- Canadian national survey of PT, OT, SLPs
  - 61% never knowingly worked with PLWHIV
  - 27% would not like to work with PLWHIV; 46% were unsure about working with this population
  - 91% believe that they need specialized training to work with PLWHIV
  - 50% agreed or strongly agreed that many rehabilitation professionals are uncomfortable working with PLWHIV

(Worthington et al, 2008)
HIV and Physiotherapy

• Physiotherapists already know how to work with PLWHIV
  • Managing disablement caused by the primary illness,
  • Any comorbid conditions

• We understand chronic health conditions and their impact on multiple body structures

• We have experience working with impairments, activity limitations and participation restrictions

(Canadian Physiotherapy Association, 2012)
Where and How Does Physical Therapy Fit? Integrating Physical Therapy into Interprofessional HIV care
Heather deBoer, Matt Andrews, Alana Petrie, Stephanie Cudd & Ellie Leung
Advisors: Kelly O’Brien and Soo Chan Carusone

• **Purpose**: To investigate the role of physical therapy in HIV care from the perspectives of people living with HIV and health care professionals with expertise in HIV care.

• Focus Groups (People Living with HIV) and Interviews (Health Care Professionals) from February to May, 2017
  • People Living with HIV: adults 18 years of age or older living with HIV (n=13)
  • Health Care Professionals from Canada and the United Kingdom who self-identified as having expertise in HIV care (n=12)
I do things now that I could not do before, so it [PT] makes you feel self-confident and builds up your self-esteem and makes you feel like you’re part of the rest rather than an outcast. (Person living with HIV)
Kobler Rehabilitation Class

- Improvements observed:
  - Physical function - decreased pain, increased mobility and strength
  - Quality of life
- Goal Attainment Scaling goals met
Casey House

• Toronto-based HIV-specific hospital
• Clientele present with complex social concerns and multiple comorbidities
• I was seconded to Casey House to spearhead the development of the Physiotherapy Department in their new Day Health Program
• A successful program with a waitlist
  • Offering 1-1 appointments and group based programs
Practicum Placements

• Have been facilitating PT and OT placements at community-based HIV organizations
• Allows students to learn about the role of rehabilitation in the lives of people living with HIV and introduces the HIV community to what rehabilitation can offer

“In preparation for this placement, I wrote a paper on OT and HIV/AIDS for a class on chronic conditions. This was extremely helpful for me in preparation, but not until I actually spent time with members at ACCM did I truly understand the needs, experiences and areas for OT intervention”

~ OT student
Working with People Living with HIV
Stigma

• Even though the HIV epidemic is more than 30 years old, health care provider stigma is still present in various settings
  • Creates a barrier to accessing care for PLWHIV (Wagner, McShane, Hart & Margolese, 2016)

• PLWHIV often face intersecting forms of stigma and discrimination when attempting to access health services based on:
  • Real or perceived HIV status,
  • Gender and/or sexual identity
  • Race/ethnicity
  • Engagement in sex work
  • Homelessness/poverty
  • Mental illness
  • Drug use
  • History of incarceration (Mill et al., 2018)
Helpful Approaches

• Mirror your client’s preferred language
• Don’t ask how they acquired HIV
• Don’t assume that HIV is their most important concern
• Listen and learn
  • The client is usually an expert in terms of managing their own health
  • Try to understand why the client may be frustrated or angry
• Don’t overuse personal protective equipment or avoid touch if it is a normal part of providing care
• Be informed of local services and support for people living and aging with HIV
• Maintain confidentiality
• Refer to the client as a person living with HIV (avoid AIDS)
Using Inclusive, Non-Stigmatizing Language

• Keep in mind too that not all clients are heterosexual or cis-gender
  • Ask about your client’s “partner” rather than assuming they have a husband or a wife
  • Ask about “relationship status” rather than assuming your client is married or in a monogamous relationship
  • Ask the client what their chosen name/pronouns are (She/he/they, her/him/them, hers/his/theirs…)
• Gently challenge oppressive comments
• Don’t assume that clients will disclose their true sexual or gender identity upon admission
Helpful Resources

- International Classification of Functioning, Disability, and Health
  - Towards a Common Language for Functioning, Disability and Health: ICF

- Older adults, sexual orientation and gender identity

- Stigma and some strategies to combat individual, environmental and policy related stigma:
  - Achieving a Stigma-Free Health Facility and HIV Services by Carr, Kidd, Fitzgeraled & Nyblade

- Role-emerging placements
    - Specific to OT students but does provide some context for other health professions
Helpful Resources

• **Realize Resources**

  • [E-Module for Evidence-Informed HIV Rehabilitation](#) (2015)
    • A comprehensive resource for rehabilitation professionals responding to the increasing role for rehabilitation in the context of HIV and concurrent conditions.

  • **On-line Course** – Rehabilitation in the Context of HIV: A Self-Directed On-line Interprofessional HIV Course to Increase the Capacity of Rehabilitation Professionals:
    • Developed and maintained by **Realize** in collaboration with the Canadian Physiotherapy Association (CPA), the Canadian Association of Occupational Therapists (CAOT), and the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA).

• **Episodic Disabilities Network**

  • Sponsored by **Realize**, the Episodic Disabilities Network brings together organizations working on issues affecting people with episodic disabilities and serves as a pan-Canadian forum for issues relating to episodic disabilities.
References


References


