

Uncertainty and Living Strategy Use among Adults Living with HIV during the COVID-19 Pandemic

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Purpose, Participants and Data Collection

Purpose: To describe disability (including uncertainty), impact of COVID and self-care living strategies used during the COVID-19 pandemic.

Methods: Cross-sectional web-based survey (June-Aug 2020)

Participants: Adults living with HIV who participated in a previous community-based exercise (CBE) study in Toronto, Canada, supplemented by word-of-mouth.

Data Collection

- HIV Disability Questionnaire (HDQ) (presence, severity and episodic nature across 6 health dimensions)
- Living Strategies (51 strategies derived from Episodic Disability Framework: frequency of strategy use; change since pandemic)
- Demographic and COVID-19 questionnaire.



Analysis: HDQ domain scores (median; interquartile ranges (IQR)); Living strategies: descriptive (% of participants engaged in living strategies) and change in strategy use (increase/decrease/no change). Demographic & COVID variables: descriptive.

Results: Participant Characteristics

No participants reported testing positive for COVID-19

114 CBE study participants emailed

51 (45%) completed the questionnaires + 12 participated via word of mouth

Total: 63 participants

Characteristics	Number (%)
Median Age (IQR)	57 years (49, 65)
Male	53 (84%)
Female	10 (16%)
Live alone	39 (62%)
Personal gross yearly income <\$30,000 CAD	33 (52%)
Employment status	
Working for pay	18 (29%)
Retired	12 (19%)
On Disability	18 (29%)
Most Common Concurrent Conditions	
Chronic pain (e.g. arthritis)	21 (33%)
Mental Health (e.g. depression, anxiety)	24 (38%)
Trouble sleeping (e.g. insomnia)	22 (35%)
Undetectable viral load (<50 copies/mL)	61 (97%)
Overall Health - Very good or Good	42 (67%)
Health status compared to previous year:	
Better now than one year ago	19 (30%)
About the same as one year ago	25 (40%)
Worse now than one year ago	19 (30%)

COVID – Health Care Services / Supports	Number (%)
HIV Care	
Receiving care from HIV doctor during COVID	61 (97%)
Remote (telephone / online) connect with doctor	45 (71%)
Difficulties accessing healthcare	25 (40%)
Access to HIV medication impacted by pandemic	10 (16%)
Decreased health care services use during COVID	23 (37%)
Services or supports accessed during pandemic	In-person/remote
Friends	18 (29%) / 24 (38%)
Family Doctor	16 (25%) / 24 (38%)
HIV Doctor	9 (14%) / 26 (41%)
Family	8 (12%) / 24 (38%)
COVID – Experiences and Lifestyle Changes	Number (%)
Working during COVID-19	16 (25%)
Not working prior to pandemic	29 (46%)
Reduced wages or work hours	22 (33%)
COVID-19 Experiences	
Fear of getting COVID-19	47 (75%)
Fear of giving COVID-19 to someone else	35 (56%)
Worrying about friends, family, partner, etc.	54 (86%)
Frustration of boredom	50 (79%)
More anxiety	47 (75%)
More depression	34 (54%)
Changes to sleep pattern	37 (59%)
Getting support from friends, family, partners, etc.	33 (52%)
Lifestyle changes due to COVID pandemic	
Practicing social distancing	60 (95%)
Isolating / quarantining from others	44 (70%)
Avoiding going to gym or exercise class	54 (86%)
Following media coverage on COVID	55 (87%)
Changing travel plans	44 (70%)
Stocking up on food and supplies	36 (57%)
Exercising less (frequency or intensity)	46 (73%)

Results: Disability & Living Strategies

Disability

Highest Median HDQ Severity & Presence Scores: Uncertainty and Mental-Emotional health challenges

HDQ Domain (n=63)	Presence Median (IQR)	Severity Median (IQR)	Episodic Median (IQR)
Physical Symptoms	50 (25, 65)	16 (9, 25)	10 (0, 30)
Cognitive Symptoms	66 (0, 100)	17 (0, 33)	0 (0, 33)
Mental-Emotional Health Symptoms	73 (46, 91)	25 (14, 41)	9 (0, 36)
Uncertainty or Worry about the Future	64 (54, 86)	30 (16, 43)	0 (0, 14)
Difficulties with Day-to-Day Activities	22 (0, 56)	11 (0, 25)	0 (0, 11)
Challenges to Social Inclusion	58 (25, 83)	23 (14, 48)	0 (0, 0)

Bold and highlight: highest domain scores; Range 0-100.

Change in Frequency of Living Strategies Use:

Of the strategies reportedly changed during the pandemic by the majority of participants, the most common related to social interaction.

Living Strategies

Frequency of Use: Majority of participants reported sustained use of positive living strategies during pandemic.

Living Strategy Select strategies (out of 51 total) chosen from key components of the Episodic Disability Framework	Few times a week or Everyday n (%)	Most Common Change during pandemic n (%)	No Change n (%)
Lifestyle - I exercise	33 (52%)	29 (46%) Decreased	20 (32%)
Maintain Focus - I focus on maintaining my health	52 (82%)	19 (30%) Increased	36 (57%)
Life Balance - I try to stick to daily structure or routine	36 (57%)	23 (37%) Increased	29 (46%)
Plan / Anticipate Future - I plan for and anticipate changes in my health	25 (40%)	12 (19%) Increased	45 (71%)
Outlook - I have a positive outlook on life; use hope and optimism	45 (71%)	12 (19%) Decreased	41 (65%)
Blocking Out of Mind - I drink alcohol as an escape to forget the COVID pandemic	7 (11%)	12 (19%) Increased	48 (76%)
Social – I spend time with friends, partner, family, etc	20 (32%)	18 (29%) Decreased	25 (40%)
Social – I spend time interacting with others on the internet	17 (27%)	30 (48%) Increased	24 (38%)
Social – I isolate myself from others	27 (43%)	21 (33%) Increased	30 (48%)

Most Common Change: If decreased: Blue; If increased: Green

No Change - Bold: majority of participants (>50%) did not change in strategy use

Summary & Conclusions

Summary

- Uncertainty followed by mental-emotional health challenges were the most severe dimensions of disability experienced by participants.
- Most participants remained engaged in care; accessed services and supports remotely.
- Majority reported 'more anxiety', 'more depression' or 'frustration of boredom'
 - potentially reflected in HDQ scores of mental-emotional health and uncertainty.
- Majority reported sustained use of positive living strategies during pandemic.

Considerations for Interpretation

- Timing of cross-sectional questionnaire administration (after wave 1; prior to wave 2)
 - unable to compare to pre-pandemic HDQ scores
- No large impact on employment; majority in sample not working prior to pandemic
- Impact of pandemic physical activity - majority of participants from CBE study

Conclusions

- Role of uncertainty is important to consider in the context of the pandemic.
- Understanding the use of self-management or living strategies can help provide an understanding of how to tailor delivery of health and support services during the COVID-19 pandemic.

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