

ECHO

Employment Change and Health Outcomes Study
– Final Report
December 2016



ONTARIO
HIV TREATMENT
NETWORK

Background

- As people with HIV live longer, they want to be able to work, support themselves and contribute to society.
- Studies show that employment is associated with better mental and physical health outcomes among people living with HIV.
- However, unemployment is a persistent problem among people living with HIV:
 - Despite progress in treatment, people with HIV continue to live with an episodic illness that can limit their ability to participate consistently in the workforce.
 - People with HIV can face discrimination in the workplace, as well as a lack of HIV-friendly workplace policies, such as flexible work hours, time for medical appointments, and opportunities to work part-time.
 - People with HIV who are on disability may worry about the loss of benefits and drug coverage if they return to work.
- According to studies in the U.S., Canada and France, 45 – 65% of people living with HIV are unemployed or on some form of disability.
- There is an urgent need to improve employment among people living with HIV.



ECHO was the first Canadian study to collect information on employment and work conditions among people living with HIV.



We wanted to understand employment rates, mental and physical health outcomes, and barriers to employment among people living with HIV.

Methodology

ECHO used a mixed-methods approach combining qualitative and quantitative methodologies.

In the quantitative portion of the study, we followed 540 people living with HIV over the course of two years. Data were collected through interviewer-administered questionnaires at baseline, 12 months, and 24 months. Interviews with people living with HIV were conducted at two HIV clinics and 13 AIDS service organizations in Ontario.

The two-year observation period provided enough time for participants to change employment status and to experience employment-related changes in health.

We collected data not just on employment status but on the psychological and social structure of participants' work situation (e.g., decision-making authority, coworker support, supervisor support, job insecurity and physical demands).

We also collected data on depressive symptoms, employment-related discrimination, and workplace re-entry concerns.

In the qualitative portion of the study, we spoke with 30 people living with HIV – both employed and unemployed. We asked about the rewards and challenges of work, as well as people's decisions to stay with or return to taxable employment.

Community-based research

Collaboration with AIDS service organizations

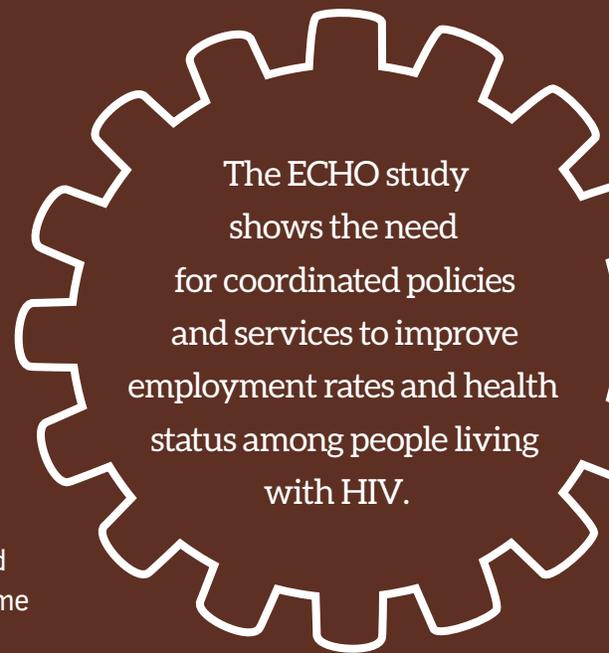
ECHO was grounded in the principles of community-based research. Researchers worked collaboratively with AIDS service organizations during all stages of the project, including identifying the research questions, developing the protocol, designing the questionnaire, and advising and assisting with participant recruitment, data collection and analysis and dissemination activities.

Involvement of peer research associates

The investigative team hired and trained peer research associates throughout Ontario. Peer researchers were involved in participant recruitment and data collection efforts. At any one time, there were up to ten peer researchers working on the study. All peers were offered support around returning to work. Many of the peers went on to full-time employment, further education, or other projects.

Key academic and community partnerships

ECHO featured several community and academic partnerships including collaborations with the OHTN, St. Michael's Hospital, Sunnybrook Hospital, Regent Park Community Health Centre, the AIDS Committee of Toronto, and the Toronto People with AIDS Foundation. These partnerships strengthened our study design, implementation, data collection and interpretation and KTE efforts, and most importantly provided capacity-building opportunities for community members living with HIV.



“I love to work. I don’t know how come I went so long without working, you know. I can’t imagine not working now. I can’t imagine my life just staying home.”



“It gives you a sense of purpose. It gives you a sense of accomplishment. It certainly pays your bills and that’s a good reward.”



“For me I have a better quality of life. I can own and pay for my home, and [have] a better financial situation.”



“That feeling of participation in something bigger than what my little tiny cubicle job is makes [work] a very good place to go, almost an exciting place to go.”



Key findings

Employment is good for health

Employment improves physical and mental health among people living with HIV. Besides providing regular income, employment imposes a time structure on the day, compels regular contact with non-family members, connects people to larger goals and encourages regular activity. ECHO found significantly lower levels of depressive symptoms among people living with HIV who were employed in high-quality jobs. Physical health was also better among those in secure (as opposed to insecure) employment.

“You can’t predict when you’re going to feel okay and when you’re not going to feel okay. So being able to call in sick, having provisions where the employer can hire a replacement but you don’t lose your job.”

Employment supports needed

HIV can make it difficult to maintain employment. Among ECHO participants, 52% were not in the labour force. Only 24% of non-employed participants were actively looking for work. The majority of non-employed participants were on disability, suggesting they may not feel healthy enough to work in some capacity. Non-employed participants on disability were concerned about losing their health benefits and income if they did take a job.

“I would lose my disability. I would lose my prescriptions. I would lose my dental. I would lose my comfort zone. I might not be safe at the new job.”

Employment discrimination is a reality

Forty-two percent of participants reported experiencing employment-related discrimination, mostly on the basis of their HIV status, sexual orientation and/or ethnicity. Participants also reported being concerned about not having enough education or the right skills to secure the sort of job they’d like to have.

Employment quality matters

Employment is associated with lower depressive symptoms in people living with HIV, but this relationship seems restricted to jobs with better employment conditions. We found that bad jobs may be as bad or worse for mental health as no job at all.

The mental health of participants who were unemployed was often comparable to or even better than the mental health of participants working in poor quality jobs. Returning to work or gaining employment may not necessarily result in mental health gains if employment quality is not taken into account.

“Everybody’s challenge is drug coverage. A lot of places don’t provide it at all or if they do, they don’t provide it right away.... If I couldn’t count on a drug plan I think that I would have very limited options.”

The Employment Change and Health Outcomes Study (ECHO) was a community-based research project grounded in partnerships with community-based agencies, including AIDS service organizations:

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Access AIDS Network
AIDS Committee of Cambridge, Kitchener, Waterloo & Area
AIDS Committee of Guelph and Wellington County
AIDS Committee of Ottawa
AIDS Committee of Simcoe County
AIDS Committee of Thunder Bay
AIDS Committee of Toronto
AIDS Committee of Windsor
AIDS Niagara
Black Coalition for AIDS Prevention
Bruce House
HIV/AIDS Regional Services
Ontario HIV/AIDS Strategy
Ontario HIV Treatment Network
Regent Park Community Centre
Regional HIV/AIDS Connection
St. Michael's Hospital
Sunnybrook Hospital
The AIDS Network
Toronto People with AIDS Foundation

The investigative team would like to thank all community-based agencies and peer researchers who made this study possible.

More information about employment in the context of HIV can be found on the OHTN's website:

www.ohntn.on.ca/research-portals/social-drivers/employment.

We dedicate this report to three peer researchers whose involvement meant a great deal to us, and who died in the years following the project's completion:

Marisol Desbiens
Michael Hamilton
Devica B. Hintzen

Funders

