

Long-Term Survivors Support Group

Daniel Howell, MSW

Long Term Survivors Program Coordinator, HIV Day
Center, Ecumenical Ministries of Oregon

Ph.D. Student, Portland State University

Daniel Howell, MSW

Worked as the Long-Term Survivors Program Coordinator at the HIV Day Center from 2020 -2021.

I currently work at the Day Center as a Mental Health Support Specialist

I am also a Ph.D. Student in the School of Social Work studying care work and care ethics in social movements.

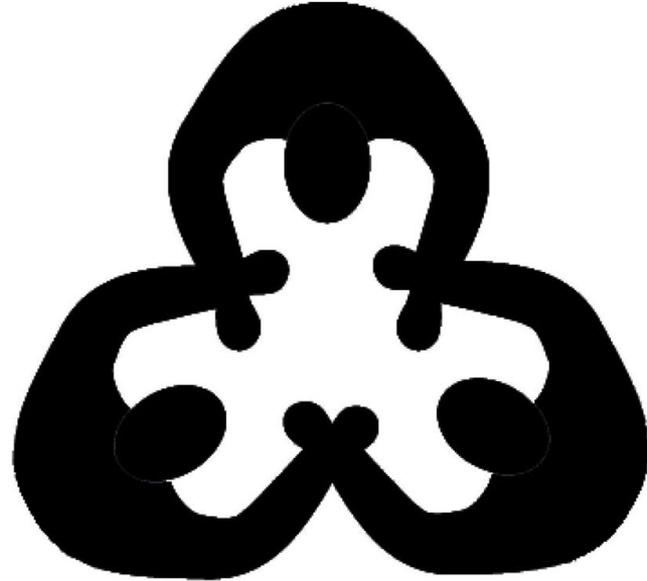


HIV Day Center

HIV Services

Ecumenical Ministries of Oregon's HIV Services programs provide a community that strives to address basic needs of individuals living with HIV/AIDS with respect, compassion and safety.

The HIV Day Center is open 5 days a week, providing meals, showers, survival supplies, and staff support.



COMMUNITY • RESPECT • SERVICE

A program of Ecumenical Ministries of Oregon



@EMO HIV Services



@emo.hiv.pdx



(503) 460-3822

Learning objectives

At the conclusion of this activity, the learner will be able to:

Improve psychosocial outcomes in Long-Term Survivors by addressing mental health concerns unique to the population through targeted interventions. Specifically, the program targeted aspects of grief and loss, complex trauma, and social isolation through self-help/ mutual aid strategies, peer support, and connection to mental health professionals.

Improve physical wellness outcomes (e.g. medication fatigue, long-term side effects of medication use, effects of aging, social determinants of health) through targeted interventions such as small-group discussions with medical providers, peer support, and food-as-medicine approach.

Increase social support through fostering peer connection. This objective was achieved primarily through focus on social activities, in-group mutual aid, and resource connection.

Overview

- Defining “long-term survivor” and presenting current research
- Pilot program review
 - Curriculum development
 - Overview of Topics
 - Recruitment and results
- Client testimonials
- Limitations and challenges
- Next steps

Who are Long - Term Survivors of HIV?

- Long-term survivors (LTS) are aging. More than half the people living with HIV (PWH) in the US are over 50 (CDC, 2018)
 - 50-54 years (33%); 55-59 years (29%); 60-64 (19%); 65+ (18%)
- Long-term survivors are predominantly male (77%; CDC, 2019)
 - The classification is likely inaccurate, as the CDC has not included transgender women in their data collection until recently.
- Long-term survivors are multiply marginalized.
 - 39% of LTS are Black, despite comprising only 12.4% of the U.S. population (Brennan-Ing, 2021)
 - Trans/ gender-diverse survivors are disproportionately affected, including barriers to medical access and rates of infection (Dragon et al, 2017)
 - Rates of poverty are higher among trans/ gender-diverse and cisgender female survivors compared to cisgender male survivors.

Who are Long - Term Survivors of HIV?

Three classifications of long-term survivors emerge from research:

- Diagnosed pre-ART
 - These are considered the long~~est~~ term survivors, and comprise the smallest subgroup
- Diagnosed post-ART
 - Diagnosed after 1996, lived with diagnosis for ten years or more
- Diagnosed from birth
 - Generally speaking, this cohort is younger than the others

What does research say about the needs of LTS?

- **Mental Health support**
 - Re: survivors guilt, complex grief
- **Social support (Barroso et al., 1997)**
 - Re: isolation
- **Physical wellness**
 - Aging (Brennan-Ing, 2020)
 - Medical education, resource sharing, material support (Brennan-Ing, 2020)

Curriculum Design

- Focused on addressing needs among the three domains identified in research: social supports, mental health, and physical wellness.
- Curriculum development was informed through a mixture of research, community partnerships, and client voice.
- Some guiding questions throughout the curriculum development process:
 - Is this what the community is asking for?
 - What work is already happening? How can we support each other?
 - How does this curriculum address the intersectional needs of the community?
- Final design resulted in a 12-week curriculum following peer support group models
- We also included material support into the program budget, linking clients to necessary care items

Overview of Topics

Week 1: Introductions, group norms, and orientations

Week 2: Strengths of long-term survivorship

Week 3: What is your story?

Week 4: Mental health: Navigating survivors' guilt

Week 5: Cooking and nutrition: Food as medicine

Week 6: Aging with HIV

Week 7: Advanced medical planning

Week 8: Medical advocacy and medication management

Week 9: Dating and relationships

Week 10: Community connection: Tips and tricks for navigating HIV services

Week 11: Open discussion

Week 12: Closing and evaluation

Recruitment

- Recruitment conducted primarily word-of-mouth via HIV services network and peer-to-peer.
- Requirements for participation included long-term survivor status (10+ years living with HIV), and to qualify for services at the Day Center (300% below Federal Poverty Level)
- 16 clients total attended over two cohorts
 - Attendance was incentivized by the guarantee of a gift card at the end of 12 weeks for those who attended more than 50% of meetings

Outcomes

- Pre/post tests were administered to measure success of the program
 - World Health Organization's 26-item Quality of Life Scale (Brief)
 - Clients demonstrate increases in understanding of services, social connection, and mental health support at the end of the sessions.
 - Clients who attended more meetings demonstrated greater increases.
 - Clients maintained high levels of medication adherence and access to medical services throughout the group.
- Qualitative outcomes were also recorded as part of the post-survey to contextualize quantitative outcomes.

Client testimonials

“I really enjoyed hands-on activities. The cooking and nutrition class was fun and beneficial. I am cooking for the first time in ages.”

“HIV/AIDS tells us we are alone as long-term survivors. This group reminds me that is not true.”

“I am learning to figure out what I want in life and to have goals again.”

“HIV, death, loss, and homelessness is not my entire story. I am a resilient survivor.”

Limitations & Challenges

- COVID! Of course!
- Recruitment/ Retention of Spanish-speaking clients
- Representation of female/ woman-identified clients
- Transportation

Next Steps

- Maintaining relationships through periodic reunion events
- Participants identified a desire for mentorship of newly-diagnosed individuals
- Maintaining partnerships with other organizations within the HIV services network



References

- Barroso, J., Buchanan, D., Tomlinson, P., & van Servellen, G. (1997). Social support and long-term survivors of AIDS. *Western Journal of Nursing Research*, *20*(5), 554–582. <https://doi.org/10.1177/019394599701900502>
- Brennan-Ing, M. (2020). Emerging issues in HIV and aging. Sage. <https://www.sageusa.org/wp-content/uploads/2020/07/emerging-issues-in-hiv-and-aging-may-2020.pdf>
- Centers for Disease Control and Prevention . (2019). HIV surveillance report, 2018 (Preliminary). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>
- Centers for Disease Control and Prevention . (2018). Diagnoses of HIV infection among adults aged 50 years and older in the United States and dependent areas, 2011–2016. HIV Surveillance Supplemental Report, 23(5). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>
- Dragon, C. N., Guerino, P., Ewald, E., Laffan, A. M. (2017, Dec). Transgender Medicare beneficiaries and chronic conditions: Exploring fee-for-service claims data. *LGBT Health*, 4(6), 404–411. <https://doi.org/10.1089/lgbt.2016.0208>
- The Well Project . (2018). Who are HIV long-term survivors? The Well Project. <https://www.thewellproject.org/hiv-information/long-term-survivors-hiv>

Disclosures

Daniel Howell, MSW, has no relevant financial interests with ineligible companies (commercial interests) to disclose.

This continuing education activity is managed and accredited by AffinityCE in cooperation with Health Resources and Services Administration. Disclosure will be made when a product is discussed for an unapproved use.

AffinityCE staff, Health Resources and Services Administration staff, as well as planners and reviewers, have no relevant financial interests with ineligible companies (commercial interests) to disclose.

Commercial support was not received for this activity.

How to Claim CE Credit

If you would like to receive continuing education credit for this activity, please visit:

<https://ryanwhite.cds.pesgce.com>

Thank you!