

Long-Term Survivors Support Group

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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.

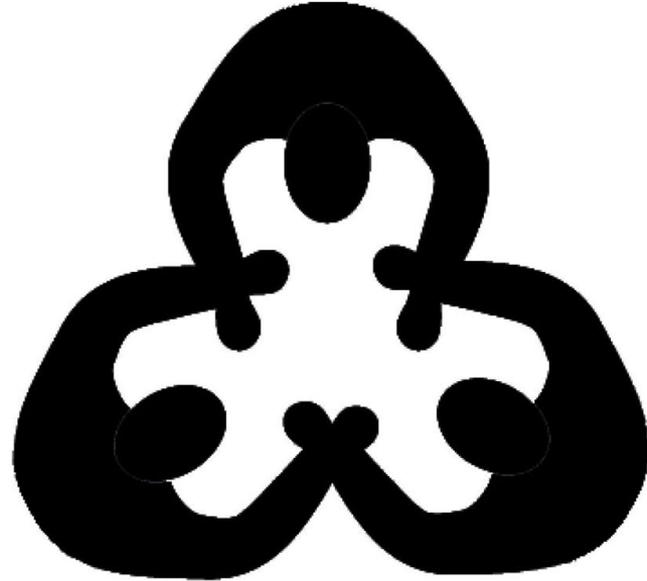


HIV Day Center

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.



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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

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