TITLE: HiVitality Retreats: an effective peer-led intervention for empowering adults living with HIV

AUTHORS: King, H.; Witney, T.

AFFILIATIONS:

King: School of Health Wellbeing and Social Care, The Open University, UK

Witney: Institute of Epidemiology & Health, University College London, UK

Introduction/objective(s)

Efforts to end HIV/AIDS are frustrated by persistent structural inequalities and stigma which inhibit access and adherence to treatment. Whilst effective psychosocial support can help PLHIV mitigate the effects of internalised stigma, access to mental/social support is variable across nations. There are knowledge gaps and no well-established interventions targeting internalised stigma.

Global experts recommend person-centred, context-specific, evidence-based and community-led approaches to empowering PLHIV. This paper reports on one such approach for ameliorating internalised stigma. The UK peer-led charity HiVitality has been running residential retreats for PLHIV since 1992. Retreats allow members to explore positive lifestyle changes, build support networks, and reflect on the challenges of living with HIV in a safe, confidential environment. The impacts have been described as life changing. HiVitality has a small operating budget (<£30k per annum) and is run entirely by volunteers who are all PLHIV.

Throughout 2021-2022 HiVitality collaborated with the Open University to enhance the therapeutic value of retreats, evaluate effects, improve understanding of internalised HIV stigma, and understand the operational context for this small peer-led charity approach. Together we undertook research and coproduced a refreshed retreat programme based on principles of person-centred therapy. This paper describes the coproduced design method, the intervention, psychosocial outcomes, and delivery/implementation issues.

Methods

The project obtained ethical approval from The Open University Human Research Ethics Committee HREC reference number 4315. A key principle was for PLHIV to design, implement, monitor and evaluate the intervention from its inception. A flexible, phased approach was employed consisting of:

- Literature review (internalised HIV stigma, interventions, person-centred group working)
- Analysis of HiVitality feedback data and scoping work to understand processes/challenges
- Cyclic codeveloped programme design/implementation/review process
- Data collection via audio-recorded/transcribed and thematically coded group sessions (x2) and semi-structured interviews (x10), and two post-retreat online surveys (generating scale and open-ended data).

Results/Emerging findings
This coproduced intervention was delivered across four 2.5-day residential retreats (>120 participants). The evolving programme consisted of A) an introductory session B) six semi-structured 60-minute discussion sessions C) one music therapy-inspired session, and D) a closing/debrief session. In total 36 group sessions were delivered.

Research findings were generated on the social context for members’ participation, the core features of retreats providing benefits, the healing processes described by members and the impacts experienced. Features such as peer-leadership, exclusivity (for PLHIV), openness, group structure, flexible format, group dynamics, reflection and bonding processes were found to be key to benefits obtained. Challenges to implementation exist around capacity and resourcing.

Discussion/conclusion/implications

This peer-led approach has been received favourably by participants and initial findings indicate it has beneficial psychosocial effects that over time may ameliorate internalised stigma. Whilst further work is required to evaluate long-term effects of the programme, early stage findings support the premise that person-centred, community-led approaches can be transformational for PLHIV.