Integrative Strategies to Address Complex HIV and Mental Health Syndemic Challenges in Racialized Communities: Insights from the CHAMP Project

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ABSTRACT

Marginalized communities bear a disproportionate burden of syndemic challenges related to HIV, mental illness and addiction. Stigma is a major barrier to effective responses. CHAMP, an innovative community-based intervention that integrated psychological intervention and collective empowerment strategies to reduce stigma, was found to be effective for such a population.

Key words: stigma reduction, integrative intervention, synergistic response, community engagement

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RÉSUMÉ

Les communautés marginalisées sont touchées de façon disproportionnée par des défis syndémiques liés au VIH, à la santé mentale et aux dépendances. Or, dans ces communautés, la stigmatisation constitue un obstacle majeur à la mise en place de moyens efficaces permettant de relever ces défis. Dans cet article, nous présentons un projet novateur, CHAMP, réalisé en Ontario. Ce projet, axé sur la communauté et qui s'appuyait sur des interventions psychologiques et sur des stratégies d'autonomisation collective afin de réduire la stigmatisation, a montré qu'il s'agissait d'un outil efficace auprès des populations marginalisées.

Mots clés : réduction de la stigmatisation, approche intégrée, effet de synergie, participation communautaire.

Research evidence indicates that synergistic epidemics, or syndemics (Singer, Bulled, Ostrach, & Mendenhall, 2017), are not merely concurrent mental disorders or physical diseases. Rather, they are health conditions that must be understood in biological, psychological, and sociocultural contexts. Synergistic epidemics of HIV, mental illness, and addiction (i.e., concurrent diagnoses of depression, PTSD, addiction, and HIV) are inequitably distributed across different populations. The prevalence of mental illness or substance use is higher among people living with HIV than the general public. Racialized immigrants and refugees, men who have sex with men, sexual minority youth, women living in poverty, transgendered people, and people with substance use bear disproportionate burdens of concurrent health and social challenges, with racialized and marginalized groups in Canada and the US having disproportionately high rates of HIV and mental illness. Across all groups, social stigma has been identified as the major barrier to effective syndemic responses (Singer et al., 2007). Stigma related to HIV, mental illness, or addiction is enmeshed with other social stigmas fuelled by homophobia, sexism, racism, and other forms of prejudice and discrimination. Stigma deters vulnerable and affected individuals from seeking information or services that are critical to early diagnosis, timely treatment, care adherence, and optimal health. Therefore, effective syndemic response must include stigma reduction.

INNOVATIVE PRACTICE AND OUTCOMES

Community Champions HIV/AIDS Advocates Mobilization Project (CHAMP), funded by the Canadian Institutes of Health Research (CIHR) and sponsored by the Committee for Accessible AIDS Treatment, was a community-based intervention project that aimed to reduce HIV and other related stigma (e.g., sexual stigma, mental illness stigma) and promote social justice and equity. The authors were the principle investigators of the project and have no conflicts of interest. CHAMP was informed by existing evidence on stigma and the results of two local studies (Chen, Li, Fung, & Wong, 2015; Li, Wong, Cain, & Fung, 2016) that identified stigma reduction as a priority in addressing syndemics among immigrants and refugees living with HIV in Toronto, Canada. CHAMP was the first stigma reduction intervention study in Canada that engaged both people living with HIV (PLHIV) and without HIV (non-PLHIV), and stakeholders across diverse sectors (health, media, faith, and social justice) in the African, Caribbean, Asian, and Latino communities. CHAMP was innovative in multiple ways:

1. **Meaningful engagement of affected communities:** A key barrier in implementing and sustaining evidence-informed practice in health programs/services is the lack of meaningful engagement of stakeholders, including community members who are living with, or affected by, the health issues (Landeweer, Molewijk, Hem, & Pedersen, 2017). The community was engaged throughout the entire project, from design to recruitment, implementation, and dissemination of results. The project team began by organizing three community knowledge translation and exchange (KTE) forums and engaged over 80 participants that included immigrants and refugees living with HIV, service providers, community leaders, policy makers, and decision makers. The aim of these forums was to: (i) share the results and recommendations of two local studies on access to mental health services and engagement of community leaders to address stigma; (ii) present current evidence on stigma reduction strategies and potential interventions; and (iii) engage forum participants to select a stigma reduction intervention deemed most relevant and appropriate for the affected communities.
2. **Community-campus multi-stakeholder partnership:** The project team, from the outset, was deliberate in forging a multi-professional partnership that included clinicians, service providers, community members with lived experiences, and researchers from the disciplines of psychiatry, nursing, community health, sociology and anthropology. Guided by the principle of Greater Involvement of People Living with HIV/AIDS (GIPA), the project team also recruited and mentored research associates who were racialized people living with HIV. A project advisory committee, consisting of 12 members, guided the project and seven organizational partners were actively involved throughout. This type of partnership enabled us to innovate in terms of intervention design and evaluation methodology.
3. **Integrative intervention design:** CHAMP was innovative and effective because its integrative design was grounded in the lived experiences of PLHIV. At the initial KTE forums, we presented five stigma-reduction strategies identified through a literature review, including peer-to-peer support, empowerment education, social marketing campaigns, cognitive behavioural therapy (CBT), and acceptance and commitment therapy (ACT). The PLHIV participants chose two strategies based on their lived experience and everyday struggles— acceptance and commitment therapy to help them deal with their psychological suffering and empowerment education to give them the skills to challenge stigma and discrimination. This led to our design of an integrative intervention that addresses both internalized and social stigma and utilizes both individual psychological and collective empowerment strategies.

The final CHAMP model consisted of two training programs: (i) Acceptance and Commitment Therapy (ACT) that promoted psychological flexibility through mindfulness exercises and experiential activities underpinned by six core processes: defusion, acceptance, present moment, self-as-context, values, and committed action; and (ii) Social Justice Capacity Building (SJCB) that engaged participants in collaborative learning to promote a critical understanding of social justice and tapped into their lived experiences and community strengths to develop collective strategies to address stigma. Each of the training programs consisted of four half-day sessions. Participants were randomized to receive SJCB with and without ACT. In addition, two structured reconnection sessions, one at three months and another at nine months, were

organized to bring participants together to share how they had applied their learning in everyday life to address stigma and social inequities.

Innovative Evaluation Methods

We used mixed methods to evaluate the effectiveness of ACT and SJCB. Participants took part in focus groups before, and nine months after, the CHAMP training. They also completed surveys with validated scales on internalized and enacted AIDS stigma, ACT-specific measures, and social action readiness before, immediately after, and nine months after the training (Li, Fung, Maticka-Tyndale, & Wong, 2017).[1] In addition, we drew on health promotion evaluation methods and invited the participants to complete monthly activity logs over nine months to capture any stigma reduction and social justice advocacy activities that they had undertaken since they completed the CHAMP training. The monthly activity logs proved to be extremely useful in demonstrating the impact of the intervention since the validated scales only captured attitude change and intention to act, but the activity logs captured participants' actual behavioural change and concrete actions.

Evidence of the Effectiveness of CHAMP

We used a purposive sampling strategy to reach diverse communities. A total of 66 participants, including 35 PLHIV and 31 non-PLHIV, were recruited and randomly assigned to two intervention arms: SJCB only and SJCB + ACT. Project participants self-identified as African/Caribbean (45%); Asian (37%); Hispanics (18%); born outside of Canada (80%); female (53%); male (45%); transgender (2%); and LGBTQ (23%). We received ethics approvals from three universities and one health organization. Informed consent was obtained from all participants prior to data collection and intervention. Results from quantitative surveys indicated that SJCB and ACT were effective in reducing internalized stigma among PLHIV and enacted stigma among non-PLHIV community leaders. Participants had significant increase in terms of action consistency with their values, and readiness to speak out against stigma and advocate for social justice. Qualitative data from the focus groups indicated that ACT worked at the intrapersonal and interpersonal levels to reduce stigma and promote compassion, and SJCB worked at the interpersonal and collective levels to promote collaboration, development of collective goals, and committed group action.

Participants' monthly activity logs were powerful in illustrating the impact of CHAMP. Each of the submitted descriptive entries of the participants' actions was categorized in terms of their level of impact: at the personal, interpersonal (family, friends, co-workers), community (organizational), and societal levels. At nine-month post-intervention, a total of 62 participants remained with CHAMP and had carried out 1,090 logged activities (Li et al., 2015). Actions relating to six key areas emerged: championing against social injustice, promoting physical, mental, and social support of PLHIV, supporting education and awareness of HIV, challenging stigma and discrimination, building community networks, and promoting empowerment and resilience. Specific examples of champion activities included self-care and seeking help to address depression; personal disclosures of HIV status to family/friends/faith leaders/teachers; a group project to create an anti-stigma video; a community film event organized by a faith leader to address homophobia; and

a program organized by faith leaders who worked with correctional services to address the mental health and HIV needs of people in prison.

IMPLICATIONS, LIMITATIONS, AND FUTURE DIRECTIONS

CHAMP demonstrated that complex syndemic challenges may require innovative solutions that integrate knowledge and insights from different disciplines, and meaningfully engage affected communities. The use of both psychological and collective empowerment strategies in CHAMP has proven to be effective, not only in shifting attitudes, but also translating into documented championship actions to reduce stigma related to HIV, addiction, racism, homophobia, and mental health challenges. The study was limited because it was conducted in one particular urban Canadian setting, which may not exactly apply to other geographical or social contexts. Another limitation concerns the lack of a control group. Because of its effectiveness, the CHAMP intervention design has since been adapted and used in the Strength In Unity project, funded by the Movember Foundation, to reduce stigma of mental illness among Asian men and communities in Calgary, Toronto, and Vancouver, engaging a bigger sample size and a control group. Given the positive results, the CHAMP interventions have also been adapted for use with the Acceptance and Commitment to Empowerment (ACE) program, a 10-session peer-driven program for people living with HIV, addiction, and mental health challenges. Most recently, the CHAMP team has successfully worked with a coalition of five community agencies to secure five-year program funding to scale up CHAMP in the community setting to address syndemic challenges faced by racialized and immigrant communities in Toronto. The results of these projects will further contribute to knowledge on effective mental health and HIV syndemic responses in the community.

ENDNOTE

1 Scales used in CHAMP pre- and post- surveys included the AIDS-Related Stigma Scale (A-RSS); Internalized AIDS-Related Stigma Scale (IA-RSS); Acceptance and Action Questionnaire version II (AAQ-II); Freiburg Mindfulness Inventory (FMI); Values Living Questionnaire (VLQ); and Community Champion Readiness Scale.

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