

Utilizing the community-based research approach to examine mental health and support services issues related to HIV-associated neurocognitive disorder

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Abstract

Human immunodeficiency virus (HIV)-associated neurocognitive disorder is an emergent public health problem known to HIV researchers and scientists, but unfortunately, is a concern that still needs to be better recognized by people living with HIV and HIV service providers. Research studies have reported that between 30 to 50% of people living with HIV who have access to combination antiretroviral therapy are and will be affected by this disorder. This raises the need to find more appropriate research approaches for examining issues that will significantly impact people living with HIV experiencing or at risk of developing neurocognitive impairments.

People living with HIV who are symptomatic of HIV-associated neurocognitive disorder are more likely to have mental health issues, progression to dementia, difficulties in performing activities of daily living, lower medication adherence, access barriers to adequate health and social services, and poorer quality of life. Because of its key principles and tenets, community-based research is a viable alternative to traditional research approaches for examining mental health and support services issues related to HIV-associated neurocognitive disorder. As an alternative approach, it would be able to examine issues relevant to people infected and affected by HIV in considerable depth and detail while taking into account their greater and more meaningful involvement.

Community-based research would be able to ensure people living with HIV and HIV service providers opportunities for equal participation, productive partnerships, ownership of new knowledge, shared responsibilities, and empowerment in HIV research processes dedicated to help them address issues related to HIV-associated neurocognitive disorder.

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Introduction

Central nervous system involvement in human immunodeficiency virus (HIV) infection is a major public health concern in resource-poor settings but also poses as a significant public health problem in industrialized countries with access to combination antiretroviral therapy (cART) [1]. Research studies have reported that between 30 to 50% of people living with HIV (PLWH) with access to cART are affected by HIV-associated neurocognitive disorder (HAND) [1-3]. This would mean that out of the estimated 36.7 million PLWH worldwide in 2015 [4], conceivably as much as 18.4 million individuals were affected by HAND.

HAND is an all-inclusive designation given to the spectrum of conditions that cause cognitive, motor, and/or behavioral impairment in HIV infection [2]. PLWH can experience mild to moderate impairment related to concentration, learning, communication, problem solving, and decision making in their lifetime even if they take cART as prescribed [5, 6]. Research studies have shown that even in its mild forms, HAND is associated with higher rates of virological failure, mental health problems, progression to dementia, difficulties in performing instrumental activities of daily living, challenges in obtaining employment, lower medication adherence, access barriers to health and social services, and poorer overall quality of life [1, 3, 5].

As PLWH begin to recognize their inherent risk for developing HAND, or start to experience manifestations attributable to it, they could understandably develop anxiety and mental health issues such as (1) increased frustration with their self-reported reduced mental acuity or inefficiency in work, homemaking, and social interactions, (2) persistent feelings of guilt or shame about their increased dependence on others for help with problem solving or decision making, and (3) significant mood changes resulting from impaired cognitive functioning that interferes with day-to-day activities, which hospital-based and community health providers in HIV services would have to address in their provider roles. Unfortunately, providers in HIV services may not routinely receive the necessary training to address neurocognitive impairments and resultant mental health issues. Providers could find these impairments and related issues difficult to differentiate from clinical problems such as major depression, anxiety disorders, problematic substance use, medication side effects, and the effects of accelerated aging [2, 7]; problems that could also lead to neurocognitive decline not related to HAND.

Although there has been an abundant number of clinical and quantitative research studies conducted to examine the pathogenesis [1, 8], nomenclature [6], diagnostic and screening criteria [3, 5], and treatment [1, 3, 5, 8] of HAND, there has been little qualitative research studies undertaken to investigate the perspectives and lived experience of PLWH and neurocognitive impairment [9, 10], and hardly any research studies to examine the mental health and support services issues related to HAND. Mental health issues related to HAND may include mental illness or other

psychological sequelae resulting from HAND, pre-existing or concomitant mental health issues that could be conflated or confused with HAND, and mental health issues resulting from other medical conditions or social circumstances (i.e., homelessness, isolation) PLWH experience that could aggravate the effects of HAND. Support services issues related to HAND may include lack of HIV service provider competence and preparedness to address HAND, limited resources in the HIV sector to manage HAND, and access barriers that PLWH may encounter to avail appropriate support services related to HAND. It would therefore be an important endeavor to examine and promote viable alternatives to traditional research approaches that could generate new in-depth and detailed relevant knowledge on how to address critical mental health and support services issues related to HAND, which in turn could help HIV service providers support PLWH experiencing neurocognitive impairment in their future work.

Discussion

Over the last two decades, there has been a burgeoning interest in community-based research (CBR) as an approach to improve prevention and intervention outcomes within diverse cultures and contexts, shining a spotlight particularly on the potential of action-oriented and community-partnered efforts to conduct health and health disparities research [11, 12]. Numerous variations of the term CBR exist across the globe – action research, participatory research, community-based participatory research, and participatory action research – all of which share a set of core principles, characteristics, and tenets, despite their differences in goals and change theories [11]. This set of core principles, characteristics, and tenets emphasizes the value of research that is (1) participatory and action-oriented, (2) engaging academic researchers and community stakeholders in a joint process in which both contribute equally or equitably, (3) primarily applied and focused on frontline issues that are relevant and important to the community, (4) a co-learning process, (5) utilized to transform and inform the community and create social action or change, (6) emancipatory and empowering, where participants can increase control over their lives and their democratic participation in their communities, (7) conscious and mindful of sources of power and addressing power relations, and (8) adherent to scientifically accepted research standards and ethical guidelines [11-14].

The historical roots of CBR within the Northern tradition date back as early as the 1940s when Kurt Lewin challenged the gap between theory and practice, and sought to solve practical problems through a research cycle involving planning, action, and then investigating the outcomes of the action [11]. Lewin rejected the positivist belief that researchers study an objective world separate from the meanings understood by participants as they act in their world. Later in the 1970s, a second tradition of CBR arising from Africa, Asia, and Latin America, known collectively as the Southern tradition, emerged, receiving its impetus pre-

dominantly from the structural crises of underdevelopment, liberation theology, Marxist critiques of social scientists, and the search for new approaches by educators and community leaders in populations most vulnerable to globalization [11]. Separately or combined, both Northern and Southern traditions of the CBR approach sought to understand and address issues within core concepts of participation, collaboration, knowledge, trust, power, and praxis that enables all participant stakeholders to reflect on their own practice in the continuum of CBR [11-15].

Interestingly, CBR has been increasingly recognized among healthcare professionals as an approach to collaborative research and critical reflection on community health practice [16]. In more recent decades, the contribution of CBR investigators could no longer be undervalued. Many community-engaged and collaborative studies stand as worthy examples of the promotion of the set of core principles, characteristic, and tenets of the CBR approach; some of which will be cited and described later in this discussion.

The notion of utilizing CBR to improve public health [11, 13], and in particular, examine critical issues related to HIV/AIDS [14, 15-17], is not a novel idea. Because of community calls over the years for genuine collaboration in HIV research processes, and the complexity of HIV/AIDS as a prominent global health problem, CBR has become a promising alternative option to traditional research approaches for examining complicated social and health service issues related to HIV/AIDS. Since the mid-1990s, proponents of CBR have used it as an approach to conduct studies on HIV/AIDS social and health service research [17]. Peer-reviewed research articles have proposed frameworks for conducting CBR on HIV/AIDS issues [14]; reported on challenges, barriers and facilitators to utilizing CBR to study HIV/AIDS [15, 18]; and provided evidence to support the use of CBR as a laudable approach for public health and HIV research [14]. In their article discussing CBR as a new and not-so-new approach to HIV/AIDS prevention, care, and treatment, Rhodes, Malow, and Jolly cited several research studies that successfully utilized CBR to establish academic-community partnerships to explore epidemiologic data, conduct community focus groups to examine various stakeholder perspectives, and hold iterative discussions with community leaders and organizational representatives to help determine community priorities [17]. Similarly, in a systematic literature review of studies published from 2005 to 2014 that employed CBR to examine social and health service issues related to HIV/AIDS, Coughlin noted 44 examples of studies that proved CBR as an effective and flexible approach for addressing HIV prevention and intervention issues in diverse population subgroups [19]. The studies summarized in his review followed more recent trends in the epidemic such as increasing HIV rates of African Americans who live in rural areas of the southern United States, increasing rates among African Americans and Hispanics in different urban and rural areas of the United States, increasing disparities among young adults who are African American (particularly among men who have sex with men), and increasing rates among women.

For the purposes of conducting research on mental health and support services issues related to HAND, there are compelling reasons why CBR would be a viable approach to utilize. First, CBR in public health is a collaborative approach to research that strives to equitably involve community members, organizational representatives, and researchers in all aspects of the research process [13]. It acknowledges the value of the diverse knowledge, skills, and expertise of all kinds of participants involved in the CBR collaboration. So in research exploring issues related to HAND, CBR would give equal importance to the education and training of research scholars, the perspectives and work experiences of providers in HIV services, and the perspectives and lived experiences of PLWH and neurocognitive impairment. As an alternative paradigm that ensures community participation in research, CBR would be able to help establish structures or take down barriers for the full and equal participation of researchers, service providers, and PLWH [17]. The involvement of PLWH would no longer be limited to participating in surveys, focus groups, and one-on-one interviews. CBR would promote participation of PLWH from the start to the end of the research process in a variety of ways [11, 13, 17]. Specifically, whether as volunteers, service providers, or employees in management/administrative positions in AIDS service organizations, PLWH are able to take on more active and meaningfully involved roles in CBR studies. For example, in a 2016 to 2017 study conducted in Central and Southwestern Ontario, Canada, examining the awareness and knowledge of community-based service providers on HAND, PLWH were able to fully and actively participate in the study, not only as participant recruiters and interview participants, but also as core members of the research project team (along with academic researchers) who were heavily involved in the decision making processes impacting the conduct of the study, or as Community Advisory Board members (along with leaders and service providers of HIV/AIDS agencies) who were able to provide guidance, monitoring, input, and feedback, from the creation of the study's research questions up to the dissemination of the study's findings through a Knowledge Mobilization plan that was co-created with PLWH [20, 21].

In this regard, CBR would also be able to support the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, which aims to realize the rights and responsibilities of PLWH, including their right to self-determination and participation in decision making processes that affect their lives [15]. CBR has become a recognized tool for addressing issues of power and exclusion within academic-community relationships by inviting the community's equitable involvement as research partners [22]. Within the context of HIV/AIDS research, this includes a commitment to the GIPA principle at all stages of the research process. Specific ways of adopting the GIPA principle within CBR are through the provision of employment, training and continuing education, and capacity building opportunities for PLWH as peer research assistants (PRAs). In their study examining the experiences of PRAs in HIV/AIDS research

on homelessness among PLWH, Greene and her colleagues drew data from two in-depth focus groups with seven PRAs that helped determine ways to interrogate power differences between PLWH and academic researchers in CBR, as well as promote self-determination for PLWH [22].

Second, CBR facilitates productive partnerships in all phases of the research process [13, 17]. In addition to ensuring stakeholder participation, CBR establishes the role of each stakeholder as a valued partner in the collaboration, as opposed to merely being a participant. This increases the possibility of overcoming distrust of research on the part of community members and potentially bridges cultural/contextual gaps that exist between partners [13]. Through the establishment of Community Advisory Boards, principles of collaboration, terms of reference, and memoranda of agreement, proponents of CBR have historically provided opportunities for academic researchers and community partners to come to an understanding that promotes egalitarianism in research partnerships. CBR would be able to build on the strengths and resources of all partners, as well as bolster their personal, research, and program development capacities [11, 13]. With CBR, providers and PLWH would be able to help academic researchers identify community needs and refine research questions related to HAND, resultant mental health issues, and associated HIV services, as well as offer significant contributions to the design of research methods and analysis of findings; while academic researchers would be able to install safeguards to ensure reliability, validity, rigor, and trustworthiness of the research process, resulting in a mutually beneficial partnership for all stakeholders.

Third, CBR disseminates knowledge gained from research to all partners involved and makes certain that all products of the research are shared [13, 17]. This acknowledges that all partners involved can use knowledge gained from the research to direct resources and influence policies for everyone's benefit. With the sharing of knowledge in CBR, a multidirectional exchange of information and co-learning would take place among PLWH and neurocognitive impairment, providers in HIV services, and academic researchers [17], which in turn would enhance the relevance, usefulness, and use of the research findings and analysis [13]. From their participation in the research process, PLWH could learn reliable information about HAND, strategies for addressing day-to-day neurocognitive challenges and promoting their mental health, and better ways to access what they need from community services. Similarly, providers could also gain from the shared products of research the knowledge they need to improve HIV services, and successfully support clients with neurocognitive impairment and resultant mental health issues. Academic researchers could disseminate the lessons they learned from their partners and the research conducted through various forms of knowledge translation and exchange platforms and products in order to reach a diverse and wider audience of stakeholders.

It is important to note that these gains and rewards from the increased participation and meaningful involve-

ment of PLWH in CBR studies dedicated to address mental health and support services issues related to HIV/AIDS are much more likely to be reaped in research endeavors that uphold a specific culture of collaboration and mutual trust between academic and community partners, which was described earlier in the discussion of CBR's set of core principles, characteristics, and tenets. A culture wherein scholarly researchers, service providers, PLWH, and other relevant stakeholders from the community have a genuine spirit of collaboration and built trust that all partners believe that no single individual or agency has all the requisite expertise, resources, and relationships to address the wide range of social, political, and economic factors that combine within the larger sphere that determines health [11-16].

Lastly, CBR encourages all partners to think critically about the sharing of power, ownership, and responsibilities involved in research collaboration [13, 15, 17]. CBR promotes the sharing of power in a collaborative relationship [13, 17]. With traditional research approaches, providers and PLWH would have little input on who would be the best study participants to recruit, which research methods would be most appropriate to use, and how to interpret particular research findings that they are intimately familiar with as persons with work or lived experience pertinent to the findings. With CBR, providers and PLWH would not only have a voice to express their perspectives, but also have the power to influence and make decisions in the research process. CBR also establishes shared ownership of the knowledge produced during and after the research is conducted [17]. It acknowledges that all participants in the research collaboration are equal partners in the endeavor to obtain answers to the research questions they identified and posed together. Just as importantly, CBR designates a shared responsibility for the generation of valuable knowledge from the pursuit of a specific research agenda, such as examining and addressing mental health and support services issues related to HAND [13]. This would mean that it would no longer be just the researchers' responsibility to ensure that the research process and products of research are reliable, valid, rigorous, and trustworthy. Providers and PLWH would also have the same responsibility as equal partners to make certain their perspectives, and work or lived experiences, are represented and used in the most just, productive, and accurate manner.

Like any other approach to examining and addressing significant public health issues, including mental health and support services issues related to HAND, CBR is unfortunately not free of barriers, hiccups, and setbacks, and is in fact, often encumbered with challenges to successful implementation. In his article that examined two HIV/AIDS CBR studies that were conducted in Alberta, Canada, Harris noted that one challenge common to both studies they explored was the lack of experience and knowledge of many community members living with HIV/AIDS in the conduct of stakeholder-engaged research (e.g., data collection techniques) [14]. Although some PLWH from the community were interested in taking on more active roles in the research

studies, they were also reluctant to take on responsibilities in the research process that they felt they were not equipped to manage. In their article investigating gaps between theory and practice, Travers and his colleagues also noted similar challenges to involving PLWH in HIV/AIDS CBR with regard to lack of capacity – many PLWH believed they were ill equipped to take on roles in CBR studies because of lack of training, resources, and expertise [15]. Other challenges to successfully engaging PLWH in CBR studies have been subsequently described in academic literature: (1) HIV-related stigma and discrimination, (2) health-related concerns resulting from or in addition to those due to HIV/AIDS, (3) the professionalization of AIDS service organizations and credentialism creating unwelcoming environments to PLWH in HIV/AIDS CBR, (4) other issues taking priority (e.g., income, shelter, food, and medical care), and (5) the mistrust of academic researchers based on the experiences of PLWH in prior research studies [15, 18].

Fortunately, it has been documented that these challenges to the successful engagement and meaningful involvement of PLWH in HIV/AIDS CBR studies can be decreased or overcome by community rallying and the social support networks that have developed in many communities of PLWH. Through the development of community connections and organizational groups that foster volunteer work, leadership and board involvement in community agencies and HIV/AIDS local and national committees, and fund-raising programs, PLWH have become increasingly encouraged to productively contribute to CBR studies they believe would have an impact on their needs, wellbeing, and daily lives [14, 22]. Other facilitating factors that have been documented to help overcome challenges to raising the confidence and interest of PLWH in participating in HIV/AIDS CBR studies examining and addressing mental health and support services issues include: (1) academic partners who recognize and value the lived experiences of PLWH as expertise, (2) training and mentoring opportunities, (3) financial remuneration, (4) trust building, and (5) the flexible accommodation of the circumstances and needs of PLWH. Although there are challenges to conducting rigorous and highly engaged CBR, there seems to be real advantages and rewards to the implementation of the approach. Challenges can be decreased or overcome by careful considerations to the details of the CBR project during the early stages of project conceptualization and creation of research proposal [14, 15].

Conclusions

Based on the discussed principles and rationale for the use of CBR, it stands as an important approach for researchers to seriously consider, particularly for conducting research on mental health and support services issues related to HAND. People living HAND experiencing mental health issues and issues accessing competent support services understandably have good reasons to refrain from engaging in research studies, no matter how well-meaning the studies purport to be.

Because of the principles, tenets, and practices it espouses, there is a greater likelihood that CBR will be able to increase the engagement, participation, and meaningful involvement of people living with HAND experiencing mental health and support services issues in studies committed to addressing their circumstances and needs. As an approach, not only would CBR improve the quality of the research process by engaging local knowledge and expertise based on the perspectives, and work or lived experiences of the people it is meant to help, but it would also improve the quality of life of providers and PLWH by furnishing them considerable opportunities for equal participation, productive partnerships, the generation and ownership of new knowledge, significant responsibilities, and empowerment in HIV/AIDS research processes.

Conflict of interest

The authors declare no conflict of interest with respect to the research, authorship, and/or publication of this article.

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