

Literature Review Summary & Overview

The Impact of Community-Based HIV Prevention Interventions in Canada, Commonwealth Nations and the US

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March 2009

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Introduction & Background

More than 20 years after its emergence, HIV/AIDS continues to be a serious public health threat in Canada and throughout the world. It is estimated that 58,000 Canadians were living with HIV infection at the end of 2005. This represents a 16 percent increase over the 2002 estimate of 50,000. With the increase and in some cases a marked resurgence of HIV incidence rates among certain segments of the Canadian population, the epidemiological evidence suggests permanent vulnerability.

Since the HIV/AIDS epidemic began, community-based organizations (CBOs) have brought the lived experiences of persons living with HIV/AIDS (PWHAs) 'to the table', calling attention to the prevention needs of some of the most marginalized people in Canadian Society. In response to emerging and urgent needs, CBOs have provided prevention efforts that have been flexible, timely, innovative and creative.

Impetus for the Literature Review

For over 20 years, the AIDS Community Action Program (ACAP) of the Public Health Agency of Canada (PHAC) has supported community-based organizations in delivering HIV prevention interventions based on the principles of health promotion and community development. Through the commissioning of the document, *Literature Review: The Impact of Community-Based HIV Prevention Interventions in Canada, Commonwealth Nations & the US*, PHAC hopes to come to an understanding of the extent to which community-based prevention programs and approaches, both in Canada and internationally, have been rigorously tested and found to be scientifically credible within the context of preventing the further transmission of HIV.

The impetus for the literature review included a recognition of the limitations of a bio-medical approach to HIV prevention. The role that CBOs have played and continue to play in HIV

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prevention has been absent in much of the discussion regarding bio-medical approaches (e.g. microbicides, vaccines, increased access to HAART). Additionally, in order to effectively curtail the HIV epidemic in Canada, the *Federal Initiative to Address HIV/AIDS in Canada* calls for the use of evidence to inform programs and policies, as well as a strong community-based and non-governmental response to the epidemic. Researching the role of CBOs in delivering effective prevention initiatives and disseminating those findings reflects a growing recognition within the HIV prevention community that, in order to be effective, prevention planning must be an evidence-based process, informed by the epidemiology and the ongoing evaluation of existing programming. The federal government's recognition of the importance of 'knowledge transfer and exchange' and of community involvement is underscored within the *Public Health Agency of Canada Strategic Plan: 2007-2012*.

Purpose of the Literature Review

The **Problem Statement** that provided the framework for the review is as follows:

What is the relationship between community-based HIV primary- and secondary-prevention best practices on HIV/AIDS incidence rates and/or changes in risk behaviours and/or testing/sero-status determination?

The **Intended Outcome** of the review is as follows:

The identification and assessment of the impact of community-based HIV best-practice primary- and secondary-prevention initiatives on HIV/AIDS incidence rates and/or changes in risk behaviours (including HIV-related knowledge and self-efficacy), and/or testing/sero-status determination, in Canada, Australia, New Zealand, the UK and the US.

Methodology

The authors of the literature review undertook a systematic review of English-language, peer-reviewed articles published between 2000 and 2008 pertaining to community-based HIV prevention interventions in Canada, Australia, New Zealand, the UK and the US. While the focus of the literature review was on studies conducted specifically within community-based settings, a selection of randomized control trials was also included, provided they met the following criteria: a) clear demonstration of community-level research involvement, and/or b) integration of 'diffusion of innovation' theories and practices within the research.

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Of the 20 studies described in the literature review, 18 were US-based studies (Coyle et al., 2006, DiClemente et al., 2004, Dowling et al., 2007, French et al., 2000, Gasiorowicz et al., 2005, Grinstead et al., 2001, Kalichman et al., 2001, Kellerman et al., 2006, Latkin et al., 2003, Lauby et al., 2000, Masson et al., 2007, Mosenia et al., 2004, Nanin et al., 2004, Rhodes, 2004, Wendell, et al., 2003, Williams et al., 2006, Ross et al., 2006, Sikkema et al., 2000,), one was UK-based (Harding et al., 2004) and one was Canadian-based (Leaver et al., 2004). The *Federal Initiative to Address HIV/AIDS in Canada* identifies eight 'vulnerable populations', including men who have sex with men (MSM), women, youth, incarcerated populations, intravenous drug using populations (IDU), Aboriginal/First Nations populations and people from countries where HIV is endemic. Looking to these articulated groups, no peer-reviewed, experimental and/or quasi-experimental research was identified among Aboriginal/First Nations populations, among rural populations, or among people who have emigrated from countries where HIV is endemic. Similarly, while a few studies were found that highlight work being done with youth populations within CBOs (Coyle et al., 2006; DiClemente et al., 2004) and one process evaluation of a 'youth-driven' project was garnered (Hampton et al., 2005), there were no applicable studies regarding prevention programming being conducted by youth-driven CBOs and/or projects in and of themselves.

Research Challenges

Within the review, a number of research challenges were identified and discussed, including the inherent difficulty of conducting behavioural and/or bio-medical intervention trials with HIV incidence as the outcome. It is difficult to determine how many infections have been averted by any particular prevention program, delivered by a CBO or otherwise, as the causal chain between delivery of a program and changes in HIV incidence is lengthy and may be affected by a number of external factors. Virtually no research has been conducted that conclusively demonstrates the impact of HIV prevention efforts on final disease outcome, be it incidence rates, or related variables such as deaths due to AIDS. Furthermore, the durability of intervention efforts is not well known. Challenges with recruitment, retention, attrition and adherence in prevention trials have impacted the quality and availability of HIV prevention research. Finally, HIV prevention science relies on subjective self-reports that may relate to activities that are personal and in some cases illicit rather than on biological markers such as incidence rates, and a lack of consensus exists about the validity of these markers.

Ethical considerations also impact research in this field, including issues regarding 'informed consent' and establishing appropriate control conditions in randomized trials of prevention interventions (e.g. the obligation to provide condom counseling to all participants in prevention trials). Any research into prevention that targets PWHAs requires sensitivity to the potential for

such research to be politically divisive and stigmatizing. A look at secondary or ‘positive’ prevention, for example, must be examined within the context of the increased criminalization of HIV non-disclosure within Canada.

Within community-based environments, there are additional challenges to the research. Outcome-based evaluation, and the ‘gold standard’ of randomized control trials, require interventions with high program integrity and clearly defined outcome measures, as well the use of control or comparison groups, the ability to track clients over time, large numbers of study participants to achieve the required statistical power necessary to conclude effectiveness, and the human and financial resources to implement and maintain the evaluation activities (e.g. staffing, study participant incentives, ‘wraparound’ services such as childcare and food, etc.). Because of these challenges, many CBOs rely on process evaluations to determine an intervention’s success. Without identifying behavioural outcomes or equivalent comparison groups, process evaluations provide continuing challenges to researchers in determining the effectiveness of a CBO-level HIV prevention initiative, and analysis is often compromised by unclear details of sample and methodology suggesting unreliable conclusions.

Finally, little empirical research has been conducted to study how evidence-based interventions diffuse from research into practice (from clinical trial to “real life” community settings), and even less research has been done in this respect with regard to HIV/AIDS interventions. While systematic reviews and meta-analyses are useful in outlining which interventions work and describing the magnitude of their effect within a research context, they often fail to effectively examine how and why an intervention works, or, perhaps more importantly, why an intervention does not work. Similarly, little research has been conducted about how to effectively move community-level interventions into practice (versus one-on-one counseling and small group risk-reduction interventions which are unlikely to reach the large groups of people who are ‘at risk’).

Results & Discussion

Twenty studies meeting the search requirements were identified and discussed, including HIV prevention interventions pertaining to outreach, workshops/trainings, peer education, prevention/awareness campaigns and secondary prevention. While challenges to the research methodologies, including sample size, participant attrition, generalizability and lack of control or comparison group, affect the irrefutability of a number of the studies reviewed, the collective findings demonstrate that community-delivered HIV prevention interventions can and are successful in altering risky behaviours, increasing testing rates and/or reducing the transmission of HIV.

Outreach

For the purposes of the literature review, 'outreach' was defined as an activity that typically involves trained professionals visiting geographic regions where a target group is known to frequent in an attempt to disseminate information, to provide condoms and/or harm reduction supplies, and/or to refer individuals to related services. Five studies (Kellerman et al., 2006; Dowling et al., 2007; French, 2000; Wendell, et al., 2003; Rhodes, 2004) provided evidence of the efficacy of community-level outreach as an HIV prevention intervention.

Education & Training

'Education and training' was defined as an activity that is typically delivered via workshops and/or training sessions, as well as through the development and distribution of HIV/AIDS education and awareness materials and resources. Six studies (Leaver et al., 2004; Lauby et al., 2000; Harding, 2004; DiClemente, 2004; Grinstead et al., 2001; Williams et al., 2006) provided evidence of the efficacy of community-led workshops and trainings as HIV prevention interventions.

More specifically, 'peer education' typically involves the use of members of a community to affect positive/pro-active behavior, knowledge and attitude change among other members of the same community. Four out of five studies (Latkin, 2003; Sikkema, 2000; Ross, 2006; Mosena et al., 2004) in the literature review presented strong findings that HIV/AIDS peer education initiatives can produce substantial beneficial effects with regard to risk reduction and behavior change, while one study (Coyle, 2006) produced limited findings.

Prevention & Awareness Campaigns

A focus on large scale, broad-reaching media campaigns (often utilizing multi-media messaging sources for wide audiences) that speak to the role of community within the campaign development, implementation, uptake and/or evaluation, produced one single research study (Nanin, 2006). This study highlighted the important role of community within the development, implementation and uptake of prevention and awareness campaigns.

Harm Reduction

'Harm reduction' for the purposes of the literature review included syringe exchange programs (SEPs) operated specifically by and within CBOs (versus by health care professionals such as doctors, nurses and/or researchers within larger, institutional and clinic-based settings), and yielded

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one study (Masson et al., 2007). The findings from this study suggested that CBOs may not be the most optimal environment for syringe exchange services; rather, SEPs that are integrated into public hospital or clinical settings may serve as a valuable strategy to engage hard-to-reach IDU populations in behavioural interventions designed to reduce HIV risk transmission behaviours and to increase access to, or engagement in, the use of secondary and tertiary preventative medical care.

Secondary Prevention

With regards to secondary or 'positive' prevention (i.e. prevention among people living with HIV/AIDS), two studies (Kalichman et al., 2001; Gasiorowicz et al., 2005) demonstrated the potential and unique role and impact that CBOs can play in working with their clients/members to prevent further transmission of HIV.

Parallel & Collateral Benefits

A number of studies within the review identified significant outcomes and 'added benefits', with regards to findings of specific projects. Some of these parallel and collateral benefits included: individual self-efficacy, self-esteem and empowerment, individual economic enhancement, partnership development and CBO capacity building, and creation of strong and supportive communities.

The Economic Case for Prevention

Extensive research has been conducted in the United States (US) around the economic case for HIV prevention, with cost-savings or cost-effectiveness identified as a national goal as well as a key consideration for the Centers for Disease Control (CDC) in funding allocations, which explicitly instructs HIV prevention community planners to consider the cost-effectiveness of different interventions when ranking them for possible implementation. This research demonstrates that prevention efforts in the US are held to high standards regarding both their efficacy/effectiveness and return on investment.

Utilizing an economic threshold evaluation analysis, US researchers have recently called for an investment of \$1.321 billion in prevention, noting that this expenditure would be cost-saving to the United States as a society if it could avert only 22,094 of the expected 160,000 new HIV infections over the next four years. They argue that analysis of the costs of unmet needs should determine

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the total health care budget to provide necessary, evidence-based prevention services to all those in need (Holtgrave, 2007). Numerous evaluations of specific interventions to determine whether the economic benefits resulting from changes in risk behaviour (or other variables) equal or outweigh the costs of designing and implementing the intervention have also been conducted.

Two meta-analyses document evidence of the cost-effectiveness of interventions, particularly small-group, community-level and outreach-based activities with moderate- to high-risk populations (McKay, 2000; Pinkerton et al., 2002). Overall, many types of HIV prevention interventions have been subjected to cost-effectiveness analyses and found to be either cost-saving or cost-effective relative to other interventions in public health and medicine (Holtgrave & Curran, 2006).

Several peer-reviewed studies noted in the literature review also argue that prevention programs prevent HIV infections. One study compares the 'observed' HIV incidence curve with an incidence curve that would have occurred had HIV prevention programs not been in place. Using conservative assumptions this analysis estimates that from 1988 to 2000, the HIV programs fielded in the US (funded by the CDC) averted between 204,000 and 1,585,000 HIV infections (Holtgrave, 2002). Another study by the same author examines the decline in AIDS deaths from 1995 to 2002 and explores if this was due to prevention, treatment advances (HAART) or some combination thereof. The author concludes that the drop in AIDS deaths may have been due in large part to early prevention efforts, while the subsequent advent of HAART precipitated a more rapid decline that would have otherwise been the case (Holtgrave, 2005).

Applying the economic evaluation technique of threshold analysis to a Canadian context, in 2003, it was estimated that the direct lifetime medical care and treatment costs were \$150,000 to \$160,000 per person. Indirect social costs relating to a loss of productivity and premature death were estimated to be as high as \$600,000 per person (Martin Spigelman Research Associates, 2003). Using these 2003 figures, the current committed investment of \$84.4 million need only prevent 563 new infections per year in order to avoid the equivalent amount in long-term costs associated with medical care (\$150,000 at 563 new infections). Taking into account the combined figure for medical costs and loss of productivity, only 141 new infections need be averted each year (\$600,000 at 141). Averting a total of 563 infections and 141 infections respectively, would represent averting only 17 percent and 4 percent of the new infections estimated or 2005.

Research Recommendations

Based on the identified challenges of garnering ‘evidence’ on the impact of CBOs on HIV prevention, and the lack of sufficient research in the area, the following recommendations arose from the literature review. These recommendations were suggested as a means to fill in the ‘gaps’ in the existing research while meaningfully and effectively involving community in the research process:

- 1. Resources need to be devoted to documenting and researching interventions developed at the grass-roots level by organizations intimately involved with the communities they serve.** PHAC and other public health bodies should explore how they can foster knowledge transfer and exchange (KTE) between HIV prevention researchers and CBOs that are the major providers of HIV prevention programming. Community involvement is a key aspect of any successful integrated approach. CBOs in Canada have created many of their interventions ‘organically’, from their own front-line experiences and unique local circumstances. These interventions are often developed intuitively, in response to tremendous need and an epidemic growing in numbers and complexity. Although many of these interventions may have never been formally evaluated, they may hold great potential, especially if they serve high-risk populations (Eke et al., 2006; Lyles et al., 2006).
- 2. Resources need to be allocated towards building the capacity of CBOs to research their locally-developed interventions, ultimately advancing to a randomized controlled trial in the event that early monitoring and evaluation detect positive outcomes.** This would work to further the goal of KTE through existing mechanisms such as the Canadian Institutes of Health Research (CIHR), and in particular, the CIHR Community-Based Research (CBR) Program. The concept of knowledge exchange (as opposed to transfer) recognizes the value that CBOs bring to the process and the mutual benefits associated with translating research into practice, and is important to the work of CBO staff, consumers/clients/members including persons living with HIV, researchers and public health personnel. In the face of the ever-changing epidemic and vulnerable populations, it is critical that community-based efforts be studied to better inform both HIV prevention research and practice (Eke et al., 2006).

3. **The integration of community input and involvement into the development of HIV prevention research is required from beginning to end.** Key stakeholders need to be engaged in a participatory process with involvement at all levels of research: evaluation planning, implementation, dissemination and diffusion. This is necessary to ensure that prevention interventions that are researched, developed and disseminated are relevant to CBOs as well as feasible for them to implement (Eke, et al., 2006; Gilliam et al., 2002).
4. **Specific strategies to support vulnerable populations in the development of their own prevention research need to be augmented.** While there have been a number of recent successes in this area (e.g. the BC HIV/AIDS Community-Based Research Capacity-Building Program, the Cedar Project (Spittal et al., 2007)), this recommendation remains especially salient for Aboriginal/First Nations populations, rural populations, populations from countries where HIV is endemic, youth and PWHAs. These strategies must define, integrate and respond to culturally-specific ways of gathering and sharing information (Beatty et al., 2004; Duran & Walters, 2004; Gordon et al., 2005), and comprehensive plans for capacity-sharing and collaboration between researchers need to be well-thought out and implemented from the outset (Majumdar et al., 2004).
5. **The need for HIV/AIDS research must to be balanced against the need for responsiveness.** The epidemic is rapidly changing and growing increasingly complex. Prevention interventions need to be responsive to changes in the epidemic in order to be relevant and effective. The effects of restricting the flexibility and responsiveness of scientific research are exemplified by the work done by the US CDC, which while laudable, has distinct limitations. Only 9 percent of the intervention evaluation reports housed in the CDC database target MSM (Collins et al., 2007), the population most affected by HIV/AIDS in the US and with the highest incidence rates. Accordingly, some of the highest-risk populations most in need of effective prevention tools (MSM of colour, substance-using MSM) are not the focus of the intervention packages or training available through the REP Project or the DEBI Project (Lyles et al., 2006).
6. **CBOs in Canada need to be sufficiently supported in adopting and adapting existing evidence-based HIV prevention interventions and moving them onto the ‘front lines’.** This entails a capacity building process that goes beyond the mere dissemination of information (Gandelman, et al., 2006; Peterson & Randall, 2006). Those prevention

interventions need to be sufficiently robust in that they not only meet the 'efficacy' (scientific) criteria, but also meet the 'effective' criteria – able to produce positive outcomes under varied, complex, unpredictable and sometimes resource-poor conditions (Collins, et al., 2006).

7. **Adequate resources are required to assess the long-term effectiveness of community-based HIV prevention interventions.** Few studies use follow-up periods of six months or more after the intervention, making a determination regarding the long-term impact challenging (Mize, et al., 2002). Additionally, a commitment to behaviour change is often a multi-stage, multi-year process, including periods of 'relapse' (Prochaska & DiClemente, 1992). One- and two-year funding terms for many community-based projects makes it virtually impossible to assess whether or not an intervention is successful. Resources are needed to allow CBOs the time to implement their initiatives, engage their communities and evaluate their results.
8. **HIV prevention science must be comprehensive and multidisciplinary, incorporating a range of biomedical, behavioural and social science interventions.** This reflects the reality that HIV/AIDS is a complex biological, behavioural and social phenomenon (Auerbach & Coates, 2000).
9. **A 'combination' or 'both ends' approach to HIV/AIDS prevention research is required.** 'Best practices' and 'most effective' interventions must be applied in combination, and must be linked to other efforts to address the macro-social conditions that contribute to disparate vulnerability to HIV (Auerbach & Coates, 2000), or, in other words, the social determinants of health. A balance between 'culturally-supported interventions' and 'evidence-based', efficacious interventions is also recommended, especially with respect to Aboriginal/First Nations populations in Canada (Duran & Walters, 2004).
10. **Further research is required on integrated care models for HIV primary and secondary prevention.** HIV prevention needs to become increasingly imbedded in the context of other services such as housing, drug and alcohol treatment, mental health, employment, and counseling for issues related to 'coming out', etc. (Kelly & Kalichman, 2002). This is especially true given that HIV is an epidemic that impacts the most vulnerable or marginalized in Canadian society.

Conclusions

Of the 20 articles reviewed, all but two (Coyle et al., 2006; Masson et al., 2007) present evidence that community-based HIV prevention initiatives can affect increased rates of testing and healthy behaviour changes among high-risk populations. These results alone, however, do not do not adequately articulate the distinct role that CBOs play in delivering HIV prevention interventions. Much of the literature described the cost-effective/cost-savings, meaningful and very 'real' benefits of CBOs within the interventions examined and upon the communities they serve. CBOs offer a unique advantage in the areas of responsiveness, flexibility, trust and creativity, resulting in behaviour change that is characterized by individual and collective self-efficacy, self-esteem, empowerment and the creation and augmentation of strong and supportive local communities.

Researchers in the field acknowledge that without the prevention activities of community-based organizations, the HIV/AIDS epidemic could well be greater (Ramirez-Valles, 2002). For example, grassroots activism and the work of CBOs is credited with the equivalent of 'a public health milestone of global importance' in Australia, namely a significant decline in HIV incidence that occurred in the mid-1980s and continued for 20 years (Plummer & Irwin, 2006). Utilizing robust back-projection data, researchers examining the evolution of the epidemic noted that the greatest decline in HIV incidence preceded any significant government or research initiatives. The study indicates that in Australia, the non-government sector/CBOs had the capacity to bring about dramatic reductions in incidence in the absence of extensive research and formal national and regional strategies (e.g. through peer outreach programs for MSM, sex workers, etc.). The researchers, therefore, call for an increased recognition of the importance of proactive 'grassroots' behaviour changes in HIV prevention (Plummer & Irwin, 2006). The value of community-level action in Australia has been recognized by other researchers, along with that country's historic commitment on all levels to harm reduction initiatives, most notably needle exchange and needle provision (Lenton, 2005).

In Canada, community involvement has played a key role in the fight against HIV/AIDS since the beginning of the epidemic, propelling change on both an individual and societal level. Volunteers and activists, many of them persons living with HIV, led the first grassroots care, education and prevention activities and created CBOs to assist some of the most affected populations.

Grassroots organizations continue in many cases to be the primary providers of HIV-related prevention services as well as non-medical care.

CBOs have the advantage of being able to be flexible, timely, inventive and innovative in response to emerging need, including taking on provocative issues and bringing the lived experiences of PWHA's 'to the table'. CBOs make vital contributions to the discourse surrounding politically sensitive issues or interventions in all areas of the prevention, care, treatment and support continuum (e.g. global and domestic access to essential HIV medications, the development of a nationally coordinated HIV/AIDS strategy, needle exchange/supervised injection sites) and call attention to the prevention needs of some of the most marginalized people in Canadian society. CBOs are often staffed by community members, peers, and PWHA's, lending a sense of credibility and understanding of the communities that they serve. CBOs can and do play a vital role in changing HIV risk behaviours, increasing HIV testing rates and reducing HIV transmission.

To obtain a full copy of *Literature Review: The Impact of Community-Based HIV Prevention Interventions in Canada, Commonwealth Nations and the US*, by Jennifer Evin Jones and Sheena Sargeant (2009), please contact **Moffatt Clarke, Program Consultant, The Public Health Agency of Canada, BC/Yukon Regional Office** at Moffatt.Clarke@phac-aspc.gc.ca.

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