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AIDS Care

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title~content=t713403300>

Community-based research in AIDS-service organizations: what helps and what doesn't?

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Online Publication Date: 01 January 2009

To cite this Article Flicker, Sarah, Wilson, Michael, Travers, Robb, Bereket, Tarik, McKay, Colleen, van der Meulen, Anna, Guta, Adrian, Cleverly, Shelley and Rourke, Sean B. (2009) 'Community-based research in AIDS-service organizations: what helps and what doesn't?', *AIDS Care*, 21:1, 94 — 102

To link to this Article: DOI: 10.1080/09540120802032650

URL: <http://dx.doi.org/10.1080/09540120802032650>

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Community-based research in AIDS-service organizations: what helps and what doesn't?

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(Received 20 October 2007; final version received 05 March 2008)

Background. Community-based research (CBR) approaches have become commonplace in many North American HIV communities. In many large urban centers, AIDS-service organizations (ASOs) have become active research hubs, advocating for research dollars in community settings. While ASOs have historically integrated local knowledge into their prevention, care and advocacy initiatives, many are now initiating or collaborating in research which addresses emerging issues encountered in practice with clients.

Objectives. To investigate barriers and facilitating factors for ASO engagement in CBR.

Methods. We conducted a survey ($n=39$) and one-on-one semi-structured telephone interviews ($n=25$) with executive directors and CBR coordinators from ASOs in Ontario, Canada. The survey queried four major areas of interest (organizational demographics, ASO CBR activities, potential barriers and facilitators for CBR engagement, and what roles stakeholders play in CBR initiatives). The interviews focused on exploring these issues in greater depth as well as understanding barriers and facilitating factors to people living with HIV/AIDS engaging in CBR.

Results. ASOs in Ontario are moderately supportive of CBR in their organizations. However, our survey and one-on-one interviews indicate that funding and organizational resources are both important barriers and facilitators to ASO involvement in CBR projects. Attaining access to research ethics boards and concerns that CBR results will not be acted upon also emerged as barriers to CBR, particularly once funds and organizational resources have been attained. Initiatives designed to enhance the skills of research team members emerged as another important facilitator.

Conclusion. Increasing emphasis from program funders on more rigorous evaluation and accountability, coupled with pull from increasingly empowered communities demanding much more active roles in setting research agendas, means that CBR is likely here to stay. Attending to barriers and facilitators will help with enhanced ASO engagement in CBR.

Keywords: HIV/AIDS; community-based research; mixed methods; case study

Background

In the search for accountability, quality and the development of new approaches to [HIV] prevention and intervention, funders, researchers, community based organizations, and service providers are finally coming to realize that research partnerships are both inevitable and desirable. (Schensul, 1999, p. 281)

Community-based research (CBR) approaches have become commonplace in many North American HIV communities. This shift has resulted from demands within affected communities, and increased commitment from professional organizations, federal research funders, and health researchers throughout the 1990s (Schensul, 1999). In many large urban

centers (e.g. Toronto, Vancouver, New York City, San Francisco), AIDS-serving organizations (ASOs) have become active research hubs, advocating for research dollars in community settings. While ASOs have historically integrated local knowledge into their prevention, care and advocacy initiatives, many are now initiating research which addresses emerging issues encountered in daily practice with clients.

In Canada, the epidemic has largely been fueled through pathways of inequity. Stigmatized groups (e.g. men who have sex with men, injection drug users, low-income people of color – especially those hailing from HIV endemic countries – and Aboriginal peoples) shoulder a disproportionate burden of disease (Public Health Agency of Canada, 2006). In this

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context, organizations like the Ontario HIV Treatment Network and the Ontario AIDS Network help to broker community–university partnerships in Canada’s most populace province toward supporting community efforts to address the epidemic.

According to Paez-Victor (2002), CBR strives to involve community members in all stages of the research process: from “input” (communities initiate research ideas and projects), to “process” (communities remain intimately engaged throughout data collection, analysis and interpretation phases) to “outcome” (communities play significant roles in mobilizing knowledge in support of social change). The HIV CBR literature continues to demonstrate the benefits of including affected communities in research, particularly in the production of community-relevant research and policy outcomes (Carolo & Travers, 2005; Flicker, 2006; Mosavel, Simon, van Stade, & Buchbinder, 2005; Travers, Leaver, & McClelland, 2002; Trussler & Marchand, 2007). Recent contributions provide best-practice models for conducting HIV CBR (Harris, 2006), examining power and process dynamics within HIV CBR (Chung & Lounsbury, 2006), and situating CBR within larger HIV policy discussions (Travers et al., 2007).

There are many terms in the literature which have been used to describe collaborative research processes (e.g. Community-based participatory research, participatory action research) (see Savan & Sider, 2003; Wallerstein & Duran, 2003 for an overview). For our study, we used the term “CBR” because it is the most widely accepted in the Canadian research landscape.¹

Despite the numerous benefits of CBR, several key barriers have been identified. A recent comprehensive review of CBR literature recognized three key (often intersecting) areas: (1) poor community incentives and capacity to be partners in CBR projects; (2) poor academic incentives and capacity for researchers to act as partners in CBR projects; and (3) inadequate and insensitive funding mechanisms (Viswanathan et al., 2004). While the Canadian HIV sector has made significant advances through supportive CBR funders (e.g. the Canadian Institutes for Health Research and Ontario HIV Treatment Network), unique barriers such as those that prevent individuals living with HIV from taking leadership roles in research (Travers et al., 2007) and institutional and structural barriers that prevent ASOs from engaging in CBR prevail (Guenter et al., 2005).

Several facilitating factors have also been described, including: the need for adequate human and financial resources, building trust between stakeholders, and promoting change within existing systems (Ansey & Gaventa, 1997; Cottrell, Lord, Martin, & Prentice, 1996; Savan, 2004). Within this

complex framework of CBR barriers and facilitators, a recent national Canadian survey found high satisfaction rates among community-based organizations with respect to their involvement in CBR processes (Flicker, Savan, Kolenda, & Mildner, 2007a).

While assessments to date provide excellent insights for broad strategies, they may not adequately address the complexities of any one sector (e.g. HIV/AIDS, housing, immigration, etc.). Therefore, given the unique characteristics and increasingly complexity of the community-based HIV sector in Ontario, Canada, we undertook a provincial case study to investigate whether special barriers and facilitators exist for ASO engagement in CBR.

Methods

We used a mixed methods design that consisted of surveys and one-on-one semi-structured telephone interviews with executive directors (EDs) and CBR coordinators from ASOs in Ontario. In *AIDS Care*, we have published results from this dataset that focused on the Greater Involvement of People Living with AIDS (GIPA) principle in Ontario’s HIV CBR sector and therefore, we provide an abbreviated outline of our methods here (Travers et al., 2007).

We adapted a survey tool developed by Flicker et al. (2007a) in their investigation of the status of CBR on health and social issues in Canada. The survey was designed to allow ASO EDs or program managers to share experiences and thoughts about CBR. It covered four major areas of interest: (1) organizational demographics (e.g. size of agency, clients served); (2) the range of CBR activities ASOs are involved in; (3) factors which either facilitated or posed challenges for ASOs to conduct CBR; and (4) information about the roles various stakeholders play in CBR initiatives.

EDs of ASOs funded by the AIDS Bureau of the Ontario Ministry of Health and Long Term Care ($n = 51$) were invited to complete an online survey and or delegate the survey to a senior program manager if they felt it was appropriate. Thirty-nine of those invited completed the survey, yielding a 75% response rate. Survey responses were analyzed in SPSS v15.0 for descriptive frequencies and differences between groups on key variables. The analysis presented here focuses on specific barriers and facilitators to ASO CBR involvement.

Survey findings were further explored through one-on-one, semi-structured interviews with EDs, program managers and CBR coordinators of ASOs. ASOs were purposively sampled to reflect the diversity of organizations serving Ontario’s HIV sector (e.g. geographical, client base, size, etc.). Eighteen

EDs and program managers and seven CBR coordinators were invited to participate, all agreed.

We asked participants about the general experiences of their ASOs with CBR, barriers to the engagement of ASOs and people living with HIV/AIDS (PHAs) as partners in CBR, and factors which facilitate greater community engagement. Detailed notes and transcriptions were taken, entered into N-Vivo 7 and thematically analyzed.

Results

In order to support individuals living with HIV, 51 ASOs are active across the province of Ontario. A large number of them are clustered in the Greater Toronto Area (GTA). As most people living with HIV concentrate in urban areas, all participating ASOs ($n = 39$) reported an urban mandate. However, approximately half of the sample ($n = 17$; 44%) reported serving both an urban and a rural clientele. For further details on the organizational characteristics of the survey respondents see Travers et al. (2007).

Respondents were asked to consider how important 24 factors are in facilitating CBR using a 5-point Likert scale (where 1 = not an important facilitator

and 5 = very important facilitator). Figure 1 outlines the top 15 identified facilitators based on mean scores, which we have condensed into 13 facilitators due to the fact that the top three facilitators (increased funding, funding for long-term initiatives and additional access to start-up funds) were all related to increased funding. The three factors related to increased funding were combined by taking the average of each of their individual means. Other highly rated facilitators (e.g. documentation of CBR “best practices”, model partnership contracts, support and participation from community members, opportunities for academics to participate in skill development with respect to community concerns and providing an annotated list of CBR funding sources) are focused on broader project development and implementation stages of CBR. We found no significant statistical differences (based on *t*-tests) on any facilitating factors between organizations that served exclusively urban centers and those that also worked in rural settings.

Respondents were also asked to rate the importance of 13 potential barriers to CBR using a 5-point Likert scale (where 1 = not an important barrier and 5 = very important barrier). Figure 2 outlines these 13

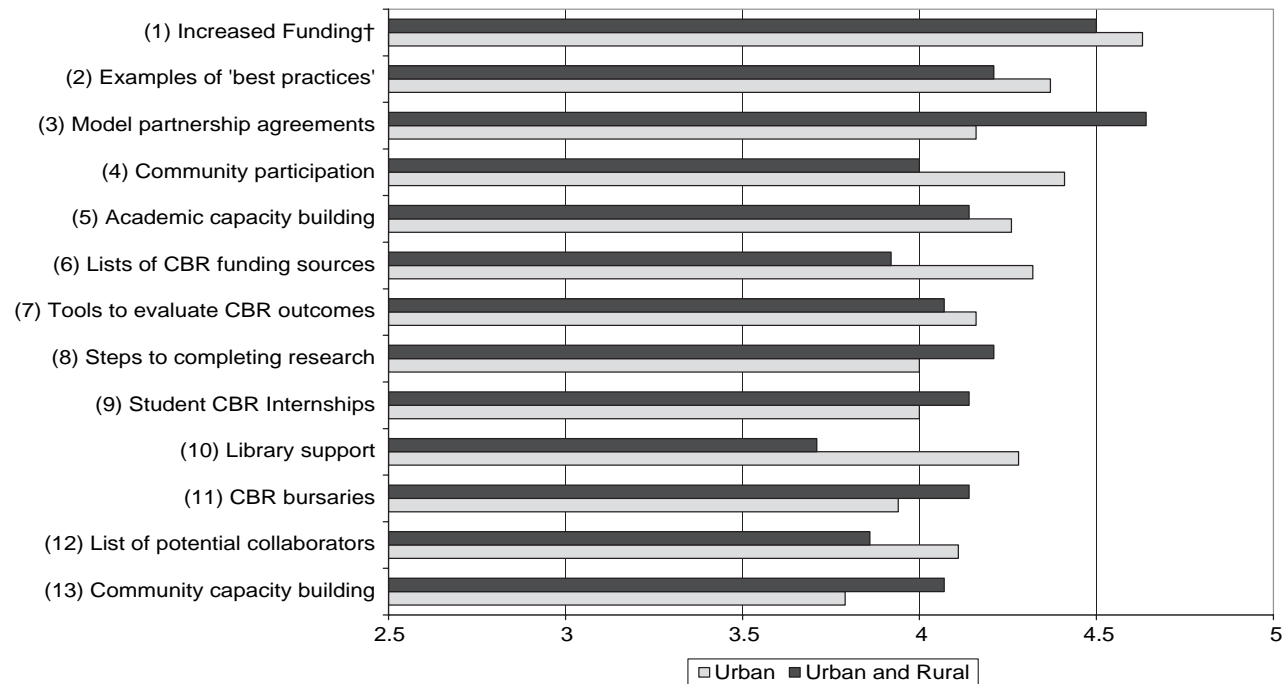


Figure 1. Top CBR facilitators for urban and urban/rural ASOs*.

*The facilitators are listed in order of importance based on the overall mean ratings from the survey respondents. All questions were asked on a 5-point scale: 1 = not an important facilitator and 5 = very important facilitator. The facilitators listed in this figure were tested for significance (using *t*-tests) based on the urban and urban/rural dichotomy with none resulting in significant differences at the $\alpha = 0.05$ level. †Increased funding is a composite score for the top three facilitators that were all related to funding. The specific categories and their overall means were: additional funding (mean = 4.61), funding for long-term initiatives (mean = 4.53) and greater access to start-up funds (mean = 4.48).

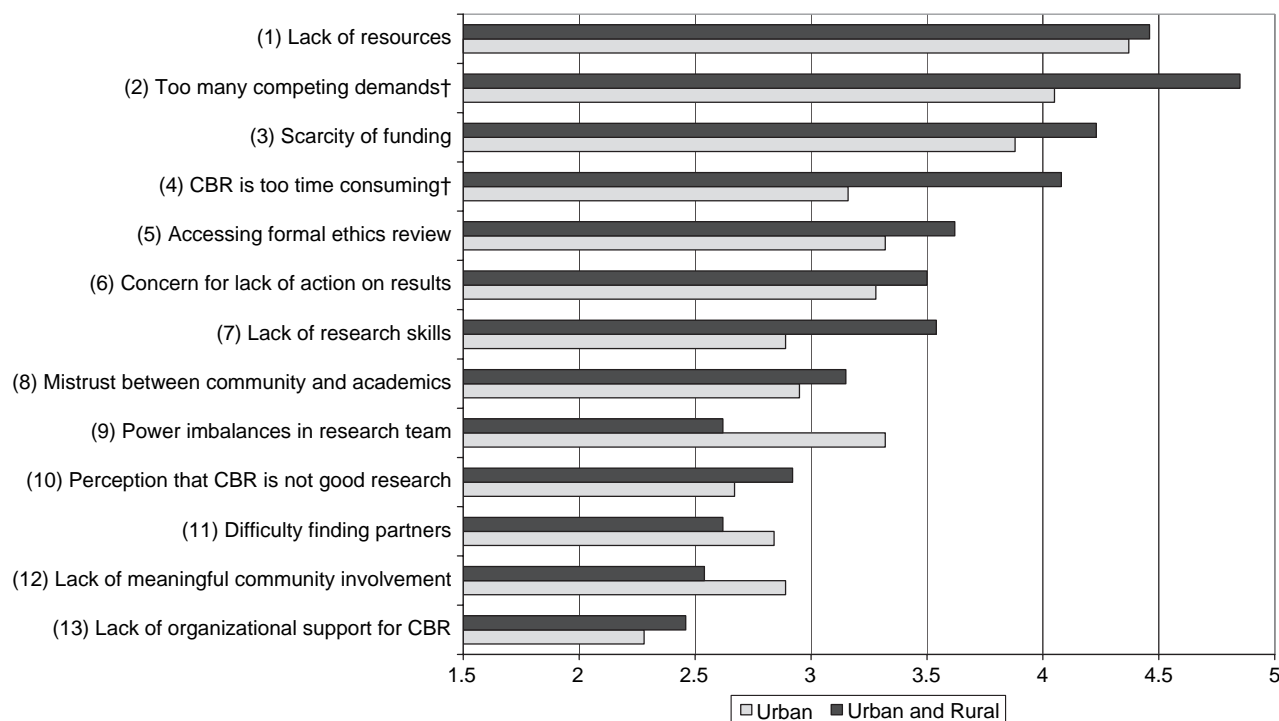


Figure 2. Top CBR barriers for urban and urban/rural ASOs*.

*The barriers are listed in order of importance based on the overall mean ratings from the survey respondents. All questions were asked on a 5-point scale: 1 = not an important barrier and 5 = very important barrier. †All barriers listed in this figure were tested for significance (using *t*-tests) based on the urban and urban/rural dichotomy. ‘Too many competing demands’ ($p = 0.006$) and ‘CBR is too time consuming’ ($p = 0.023$) were found to be significantly different based on the urban–urban/rural dichotomy.

barriers to CBR, based on mean scores. As can be seen in Figure 2, four out of the six top barriers to CBR are related to organizational resources. These included funding concerns (e.g. scarcity of funding resources dedicated to CBR projects) and related organizational resources (e.g. space, computers and staff), competing organizational responsibilities, and lack of time. The other two – difficulty accessing formal ethics review and concern that results will not be disseminated or acted upon – are distinct in that they represent additional barriers that need to be overcome once the financial and resource-based challenges are addressed (this may explain why they are rated as less significant). Based on statistical comparisons (*t*-tests), we found that respondents from organizations that serve both urban and rural areas rated the “competing demands” and “time scarcity” barriers significantly higher than respondents from organizations that serve only urban areas.

With respect to the barriers and facilitators identified in the survey, four of the facilitators and six of the barriers consistently emerged as important themes in the qualitative data (see Tables 1 and 2). The interviews revealed that issues surrounding funding are complex. Agencies were frustrated about

how rare it was for community-based organizations to get compensated for their investment and contribution to partnered research endeavors. As such, the issue was not simply about increasing funding but also reallocating and reconfiguring budgeting practices so that ASOs could (1) be the direct recipients of research grants and/or (2) increase their internal capacities to conduct research and maintain active research programs. Several urban ASOs in our study housed full-time research coordinators to accommodate growing research mandates. These positions are often cobbled together from a variety of sources, and core funding for such positions is scarce. In contrast, few ASOs that serve both rural and urban areas had the internal resources to support a full-time dedicated research staff. Ironically, since the ASOs that serve both rural and urban areas are often the only group in a large geographical region to serve PHAs, they are called upon with increasing regularity to partner in research. As such, it was not simply about increasing resources available for CBR funding but also about diversifying the types of funding accessible to accommodate start-up funding, staff-release time, staff and research assistant training and development, capacity building, and action planning.

Table 1. Major facilitators for CBR emerging from qualitative interviews.

Facilitators	Interview quotes
Increased funding	<p>We're not getting funded to do the research, we're not getting the big ... dollars ... There's a political piece as well right that would need to be addressed in terms of CBR being effective and working properly ... you know who gets funded, what gets funded, why does it get funded ...</p> <p>I think something that could be a help is ... contributing some funding to organizations for participation you know to help support the hours like volunteer projects and then you know that would allow for people to actually devote some time, dedicated time away from programs that we're actually funded to do, to participate fully.</p> <p>I think to be able for us to really realize the goal of capacity building ... I mean ... it has to be a longer term where you allow this kind of capacity building to take place ...</p> <p>I think we need to really think of is what to do with these RAs and to really build the capacities not by project but there needs to be more kind of a long term planning for these people and the process in terms of capacity building.</p> <p>Ideally I would like to have a position dedicated to research development ... if a research institute could house somebody here, provide you know the infrastructure, that's the ideal.</p> <p>The resources that have enabled us to do it are organizations ... who understand the need and actually took a chance and gave you know a non-academic institution start up money.</p>
Model partnership contracts, CBR job descriptions and sample proposals	<p>I think models could be given to organizations ... explaining what community-based research is, what they have to do and then get training on how to do it. I think they would do it ... most organizations are interested.</p> <p>[Y]ou can possibly have this tool kit alongside with your you know funding approval and saying oh here are some resources I can use to train your research assistants, a manual or here's something that you know if you want to do a training workshop for your research assistant, you can take some resources from this manual.</p>
Support and participation from community members	<p>[W]e needed more community involvement in terms of uhm PHAs in the studies somehow ... we needed to develop mechanisms for giving people a stake in the study.</p> <p>[I]f researchers are interested in partnering with organizations that it's something that starts from the beginning of the you know the idea of the project so that it doesn't feel like an add-on at the end, just like "oh I'll include some community people to make it look like we're actually community based."</p>
Skills enhancing opportunities for academic partners to learn more about community concerns	<p>I think it would be absolutely fabulous if internships were available for students even for very very large universities downtown to come up and get our internship and partnership and facilitate the research at a community based organization up North. [N]ot just workshops for people who don't have sort of traditional research skills but workshops for people who do have skills in these ther areas such as capacity building and working with community organizations.</p>

Issues around resource development were closely linked to other human and physical resources, namely time constraints. Several respondents talked about how there were not enough hours in the day to complete regular tasks that were part of their job descriptions (e.g. service delivery). Research was often understood to be important but not quite as pressing as meeting the demanding needs of a population that is so dependent on services.

In addition to monetary issues, participants also suggested that concrete accessible toolkits and templates would assist ASOs in engaging in CBR and

help to ensure that they were not constantly "re-inventing the wheel". Creative suggestions were also offered for creating training opportunities for academics and graduate students to learn more about community settings. Leveraging graduate student support was cited as a win-win strategy for both providing tangible "real-world" experience to trainees as well as getting extra hands on deck to complete research tasks.

Another common theme that came up was research fatigue amongst the HIV community. Several respondents talked about how much research

Table 2. Major barriers for CBR emerging from qualitative interviews.

Barriers	Interview quotes
Lack of resources (e.g. space, computers, time and staff)	Each time the possibility of a CBR project comes up, it is always about time . . . They're hired to do the job descriptions that they're hired for. So fitting CBR on top of what we do day to day and week to week is always a challenge. [D]ue to our human resources, due to our funding limits and everything, we can't. Only when we do have those things we can go forward. It would be wonderful to have somebody who can write proposals and we get the proposals funded and then we have the committee and we do something. But we don't have that. I mean we have a lot of ideas, we want to do these things but we just can't so we stick with the basics of what our organization has to do.
Too many competing demands to make time for CBR	You end up doing two or three jobs in small organizations and often only getting funded by one source. [Y]ou put kind of things on hold because you just don't have the time to sit down and write a proposal right because you're busy with something else. I think we need to do more systemic work but it's hard when you serve a very high need population and you're under-resourced.
Scarcity of funding resources designated to CBR projects	What you want to achieve in CBR is take your time to really build up the research capacity of your community and also to build an equitable partnership between community and academics right and those processes take time and money and you need human resources to go through that process and to me I just find the current funding scheme for CBR to be . . . I think it's actually working against what you're trying to achieve in CBR. So that's something I would identify as challenging. Even though the enabling portion of it was very successful, we have not been successful in actually implementing that enabling grant right. So there are some challenges there.
CBR projects take too much time to complete	. . . the minute you start going out and trying to develop a program to find out, answer questions, it takes a tremendous amount of manpower, it takes tremendous amount of time. The team is huge and people from different areas are coming together, people from CBOs, ASOs, housing, housing service providers, academics. They're all coming together in this team and it's been a long time to develop a study design and it took much longer than we had anticipated or planned for it. So that was one of the challenges.
Difficulty accessing formal ethics review	[T]he ethics review process has always been very challenging for the Aboriginal community because ethics certificates are only issued by universities and hospitals in Canada right. So when we write a proposal, it's always being reviewed generally by non Aboriginal people. [W]e could have interviewed more if we would have had more time. Our time constraints were crunched because it took so long to get the . . . ethical review.
Concern that results will not be disseminated or acted upon	There are people who may feel that well you know here we go again, I may have to participate in another project that I've participated in before and didn't really see any results. [O]nce the project is over, then there's nobody there to do the follow up and that goes so much also for knowledge transfer . . . we do our research project and then the information is out there but there's no way to determine how it's being used.

gets done in the community without appropriate follow-through and action.

Finally, ethical review was cited as a salient barrier. Simply accessing appropriate ethics review is impossible without an academic partner. Many respondents also complained about how long it took

to navigate the process and described significant delays (particularly in projects that had to go through multiple review boards because co-investigators were housed at different institutions). Finally, others talked about how the ethical review process did not accommodate community-based ethical paradigms

(this was particularly salient for those ASOs that worked with Aboriginal communities).

Discussion

Principal findings

ASOs in Ontario are moderately supportive of CBR in their organizations with approximately 80% having been involved in at least one CBR project in the last five years. However, our data indicates that funding and organizational resources currently pose important barriers to ASO involvement in CBR. Given that funding and resources are the most highly rated barriers to CBR, it is not surprising that increased funding was overwhelmingly cited as the most important facilitator for participating in and conducting CBR. Additional important barriers – attaining ethics review and concerns that CBR results will not be acted upon – appear to be issues that arise after funds and organizational resources have been attained. With respect to factors other than funding and organizational resources, we found that important facilitators for CBR mostly involved initiatives to enhance the skills of the research team.

While there were no significant differences between ASOs that serve only urban settings as compared to those that serve both urban and rural settings in terms of facilitators toward CBR, there were some in terms of barriers. ASOs that serve both urban and rural areas rated the barriers of “too many competing demands to make time for CBR” and “CBR projects take too much time to complete” significantly higher as compared to ASOs that serve only an urban area.

Study meaning

This study has shown that there are a number of significant barriers that hinder CBR amongst Ontario ASOs and there are clear facilitators that can be put in place.

It is not a surprise that funding issues were seen as being the most significant factors affecting CBR activity amongst ASOs, as the scarcity of funding to support CBR projects is well documented in the literature (Cottrell et al., 1996; Green & Mercer, 2001; Minkler, Glover Blackwell, Thompson, & Tamir, 2003; Plumb, Price, & Kavanaugh-Lynch, 2004; Sclove, Scammel, & Holland, 1998), and these findings also parallel data across other sectors in Canada (Flicker, Savan, McGrath, Kolenda, & Mildenerger, 2007b; Flicker et al., 2007a and b). Traditional funders rarely have the funds set aside to foster the lengthy period of start-up funding required necessary for seeding long-term partnerships. In addition,

funders are rarely able to accommodate both research and program/action budgets.

It should be noted however, that ASOs in Ontario enjoy access to dedicated HIV CBR funding opportunities (in addition to a variety of other funders that support HIV CBR). Both national (the Canadian Institutes for Health Research) and provincial (the Ontario HIV Treatment Network) funds have been specifically designated for supporting CBR. In addition, both agencies also offer seed grants and workshops/dissemination funding, so it was therefore somewhat surprising that this issue came up so often. The frustration with resource restrictions may be emblematic of the not-for-profit sector as a whole being increasingly squeezed while the epidemic is becoming increasingly complex (Cain & Todd, 2002).

A potential explanation for the significant differences that we found between urban and urban/rural organizations on two barriers to CBR (too many competing demands and CBR projects being too time consuming) could be that organizations that serve rural areas have greater demands placed upon their service delivery due to the more expansive area they have to cover. In addition, it is likely that there are simply less academic partners to draw from in areas that are not located close to one of Ontario’s major urban centers, which are increasingly where much of the CBR activity takes place.

Strengths and weaknesses

The primary strength of our study is that it builds upon extensive literature about barriers and facilitators for conducting CBR by offering insights into an entire community-based HIV/AIDS sector. As a result, this study offers a unique contribution to the literature by providing both quantitative and qualitative evidence about important CBR barriers and facilitators facing ASOs. An important limitation of our study is that it draws only on the perspectives of EDs, program managers and CBR coordinators of ASOs and does not include participants from organizations that fund or support ASOs in their CBR activities. Therefore, we are not able to provide a reliable strategy for how to facilitate CBR at this time as we need to better understand the constraints of these stakeholders first. Another important limitation is our small sample size, which requires that our results and statistical comparisons be interpreted with caution. Lastly, we have used an unstandardized survey tool. However, this tool was developed in a previous study through extensive input and feedback from experts in the field to help ensure strong content validity (Flicker et al., 2007a).

Implications

Increasing emphasis from funders on more rigorous evaluation and accountability, coupled with pull from increasingly empowered communities demanding more active roles in setting research agendas (rather than simply being research subjects) means that CBR is likely here to stay. Our findings suggest that all parties involved would be wise to consider the social, political, and economic constraints and opportunities for CBR partnerships. If CBR is here to stay, sustainable funding streams from government and non-government organizations are necessary that recognize the unique nature of ASOs as research producing organizations. Specifically, ASOs often do not have the “in-house” resources for research initiatives that may be commonplace to researchers based in academic facilities or research-based foundations. Therefore, CBR funding streams may need to provide additional or different types of resources (e.g. assistance with obtaining ethics approval or with dissemination activities after a project is completed) to ASOs for them to be better poised to consistently execute high-quality CBR projects.

Future research

Future research initiatives should focus on evaluating CBR-specific funding streams by consulting with both ASOs and funding organizations. This will provide insight into whether these funding streams are meeting the complex needs of ASOs that are interested in conducting CBR and may discover ways in which they can be modified. In addition, there is a need to investigate how to alleviate the burden of other barriers to CBR such as facilitating easier access for ASOs to ethical review boards. Lastly, national or international comparisons would be welcome.

Note

1. In the USA, similar research is often referred to as CBPR.

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