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Time, Dual Roles, and Departments of Public Health: Lessons Learned in CBPR by an AIDS Service Organization

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Abstract

Community-based participatory research (CBPR) is an important approach to inform the development and implementation of HIV/AIDS prevention and treatment strategies. However, there is a paucity of literature describing CBPR from the perspective of community-based organizations (CBOs), specifically AIDS service organizations (ASO). Focusing on the perspective of the executive director (ED) from the partnering ASO, we describe in this paper lessons learned during *Project Counseling Others About Contacts and Exposures with HIV (COACH)*, a CBPR, qualitative study intended to examine perspectives and experiences of professionals and clients regarding partner notification (PN) for HIV. Specifically, we describe

opportunities and challenges associated with the time investment, balancing a dual role of service provider and researcher, and partnering with the department of public health. This description of the perspective of the ED from the ASO and the associated lessons learned may inform the actions of other CBOs, including ASOs, considering partnering with academic institutions for CBPR.

Keywords

Community-based participatory research, HIV, community health services, capacity building, contact tracing, community-institutional relations

CBPR, an important approach for addressing health inequities among marginalized and stigmatized populations,¹⁻³ provides an opportunity to improve strategies for HIV/AIDS prevention and treatment among men who have sex with men (MSM). CBPR is a collaborative research approach among communities affected by the issue being studied, researchers, and representatives of organizations empowered to turn research results into policy change. The research is designed in the context of an equitable partnership of academics and community members so that questions relevant to the community are addressed and research is conducted to directly inform policy and social change.^{1,4-7} Given these principles, CBPR represents a key manner in which to develop culturally aware, contextually appropriate,

and action-oriented approaches to improve health of vulnerable populations, including MSM.^{6,8-10}

Community-based ASOs have participated in CBPR to inform^{11,12} and promote HIV/AIDS prevention^{13,14} with different populations,¹⁵⁻¹⁹ including the development of a chat-room-based HIV prevention intervention for gay men¹¹ and a program involving outreach, service delivery and research with commercial sex workers.¹⁵ As a community-based ASO in New Haven, Connecticut, a medium-size metropolitan area with four research universities, AIDS Project New Haven (APNH) is routinely approached by academics to participate in research projects. APNH provides comprehensive services to HIV-infected individuals, including medical case management, financial assistance, mental health and substance abuse

treatment, meal delivery, nutrition counseling, and support groups. The agency offers HIV testing and provides outreach and prevention services. APNH serves more than 400 clients annually, with a staff of 16 and an annual budget of \$1.2 million. APNH has partnered with universities to recruit for surveys, evaluate programs, and conduct outreach testing more than 12 times in the past five years. Not until the current collaboration, *Project Counseling Others About Contacts and Exposures with HIV (Project COACH)*, had APNH participated in research that incorporated the principles of CBPR. Because there are limited existing data on the perspectives of ASOs serving as a community research partner,²⁰ especially from the lens of a team including members newly introduced to CBPR, we present lessons learned from our community-academic-health department research partnership to inform future CBPR collaborations, particularly those including ASOs.

WHY DID WE START OUR CBPR PROJECT?

Partner notification (PN), or contact tracing, is an effective public health tool²¹ for increasing the rate of diagnosis of undetected HIV. PN is the process of confidentially informing the partners of a person diagnosed with a sexually transmitted infection of a potential exposure to an infectious disease.²² PN occurs most effectively when it is a collaboration among public health officials, known as disease intervention specialists (DIS),^{23,24} and those who link clients to medical care, including medical case managers (MCM).²¹ The implementation of routine PN for HIV among MSM has been challenging.^{25,26} Based on literature among a clinic-based MSM population, barriers to PN include (1) a lack of knowledge about PN, (2) fear of partners' reaction, rejection, stigma associated with HIV,²⁷ and (3) challenges in identifying and reaching partners.²⁷

We started our CBPR project to assess the perspectives of PN of MSM engaged in community-based services. As we built our research team with those potentially affected by our research and those who might be able to make policy change, we also decided to address the perspectives of PN among DIS and MCM.

HOW DID WE START OUR CBPR PROJECT?

Our CBPR project, *Project COACH*, emerged out of our shared interest to improve the implementation of PN in Connecticut. Recognizing our common interests, a member

of Yale's Center for Interdisciplinary Research on AIDS, introduced us, the three main partners: the Executive Director (ED) of APNH (community), the Sexually Transmitted Disease/Tuberculosis Program Director for the Connecticut State Department of Public Health (DPH), and a health services research fellow (academic). We expanded our team to include the Director of Client Services from APNH, a DIS supervisor from DPH, and an academic researcher with expertise in qualitative methods and CBPR.²⁸

At APNH, we chose to work on this project for three reasons: (1) We recognized that PN was an important strategy for improving the timeliness of diagnosis for those unaware of their HIV status, (2) involvement in the project could inform client services, and (3) PN had recently been identified as a priority by the Centers for Disease Control and Prevention,²¹ impacting our performance measures and funding. At DPH, we chose to work on this project because we had concerns that our program was not being implemented as effectively as possible. As researchers, we chose to work on this project because we had learned of its potential effectiveness at reaching high-risk individuals when accessed, but understood that it was underutilized.

WHAT IS OUR CBPR PROJECT?

Project COACH aimed to bolster DPH's PN program by gaining a comprehensive understanding of current assets and challenges to PN for HIV among MSM living in Connecticut. We used a CBPR approach to our qualitative project.²⁹ We sought to characterize perspectives and experiences of PN with health department involvement using a focus group³⁰ of MCM ($n = 14$), and in-depth, in-person interviews³¹ of MSM seeking community-based services ($n = 24$), and all of the Connecticut DIS ($n = 7$). Our multidisciplinary research team was diverse in profession, age, gender, race, sexual orientation, and HIV status. Consistent with CBPR principles, the core team met twice a month during the design phase of the project and each member informed all stages of the research process, including the research aims, study design, analysis, and plans for dissemination.^{32,33} To build research capacity, all study team members were invited to participate in research skills training (i.e., in-depth interview training; *Atlas.ti* workshop) and financially supported through the health service research fellowship to attend national scientific meetings. Consistent

with the use of a memorandum of understanding, we discussed, documented, and shared the documentation with each other of our roles and responsibilities.³³

To maximize our work's relevance and the potential translation of our findings into action, throughout the two years of the project, we presented to and incorporated feedback from several academic and community entities, including experts in infectious disease, public health, and HIV/AIDS community advocates; the community advisory board organized by a local research university;^{34,35} and statewide, multidisciplinary teams involved in planning and implementing HIV/AIDS services and research.

Given the diversity of the MSM population in terms of personal and relationship characteristics,³⁶⁻³⁸ we recruited from multiple settings to collect a range of experiences, including APNH ($n = 9$); a nonprofit serving the Lesbian, Gay, Bisexual and Transgender community ($n = 5$); a substance abuse treatment center ($n = 2$); and through peer referral ($n = 8$), the process by which one participant recruits their peers to participate.

The focus group was led by the ED of APNH and co-facilitated by the research fellow. To optimize the validity of the data collection by matching characteristics of the study participants and research team members,³⁹⁻⁴¹ the ED of APNH, who identified as a member of the community, interviewed the MSM and the research fellow interviewed the DIS. The focus group and interviews were conducted between September 2011 and March 2012.

We conducted recruitment and data collection until we achieved thematic saturation.²⁹ Our interviews and focus groups were semistructured discussions, which we audio-taped, professionally transcribed, and reviewed for accuracy. Our three-person multidisciplinary data analysis team consisted of the leaders of the focus group and interviews as well as the CBPR expert. We used the constant comparative method, based on a code structure that was developed using grounded theory.²⁹ The project was approved by the Human Investigations Committees at Yale University and DPH. All participants provided verbal informed consent and the study was compliant with the Health Insurance Portability and Accountability Act.

All members of the study team have been involved in informing the dissemination of *Project COACH*, which has

included providing recommendations for improving the implementation of the PN program to statewide multidisciplinary teams involved in planning and implementing HIV/AIDS services, the development of an information sheet for providers,⁴² a training on cultural diversity for DIS, a webinar on Partner Services,⁴³ and manuscript preparation.

METHODS

Throughout the two years of the project, the research fellow sent minutes from each meeting to document discussions, plans, and agreed upon changes. After the project was largely completed, we had a team meeting, informed by these meeting minutes, to discuss the ways in which the ED of APNH perceived the project was helpful and a hindrance to the mission of APNH. The ED wrote the initial draft of the paper, which was then expanded upon by the research fellow. The manuscript was then edited with input from the other team members. Below we present three tensions—of challenges and opportunities described by the ASO's ED.

LESSONS LEARNED

Time Investment is Challenging, Yet Translated Into Capacity Building

Consistent with other community-academic research projects, the greatest perceived challenge by myself, the ED from APNH, was the time invested in the project.^{5,10,33} As an organization with a mission to deliver client services, I found it difficult at times to justify the time spent on the research project both to other staff and to the board of directors. *Project COACH* was sometimes perceived as a distraction, and once even a barrier from completing my defined roles and responsibilities. Whereas the director of client services determined early on in the project that he had to limit his involvement to the development, implementation, and dissemination of the project because of his other responsibilities, and he was not involved in data collection and analysis, I was intimately involved at all stages. I spent approximately 20 hours per month for eight months dedicated to the project, with a range of activities (Table 1). This time was compensated at a rate of \$21 per hour, consistent with university policies for consultants. This ultimately accounted for approximately one fifth of the total budget for the project. Although this time

typically occurred during regular work day hours, at times it required work during evening hours.

The hours spent dedicated to *Project COACH* ultimately translated into several benefits for me, personally, and the ASO as a whole. First, by being actively involved in all stages of the research process, there were opportunities for training and implementation of research skills. For example, from a training session, I obtained a basic understanding of semistructured, in-depth interviews. Further, by conducting the interviews and reviewing the transcripts with qualitative research experts who considered my capacity building a key aspect of the project, my skills were further developed. When I attended a three-day academic research conference, I increased my knowledge of research, CBPR, and its potential impact.⁴⁴ That these skills and insights would directly inform future work became evident when I led discussions at APNH about using qualitative methods to perform a quality assessment of a separate long-standing APNH program.

Second, through involvement in participant recruitment, data collection, and subsequent participant confirmation, I extended my professional network to other organizations with a complementary client-focused mission, including to the sites

from which we recruited and interviewed participants. Before *Project COACH* there had only been minimal exchanges between these organizations. In addition, my relationships with DPH were also strengthened and continuously reinforced through the project, increasing the ability of APNH to link with DPH on behalf of clients. These relationships may serve as the foundation for future research partnerships, while informing and improving the provision of client services.

Third, the collaboration highlighted and led to further training for the MCM, many of whom were employees at APNH. Specifically, the research identified, among MCM, a varied comfort with discussing sexual risk behaviors and disclosure practices, as well as strategies for promoting PN. In response, the DIS supervisor on our research team conducted a two-hour training with the MCM on Partner Services, where they role-played discussions about sexual risk behaviors, HIV status disclosure and the program with clients.

Finally, the knowledge, networking, and experience gained through *Project COACH* contributed to successful grant applications to implement prevention programming, resulting in an opportunity for APNH to further develop its promotion and utilization of PN.

Table 1. *Project COACH*: Executive Director's Hours

Hours	Timeline	Activities
~2–4 hours/month	December 2010 – July 2012	Team meetings: Relationship building; refining research question and designing project; reviewing transcripts and discussing emerging themes; planning dissemination.
~1 hour each	July 2011, Fall 2012	Trainings: In-depth interview training (1 session); <i>Atlas.ti</i> training (3 sessions).
~2 hours total	September 2011	Data collection: Facilitated focus group with medical case managers.
~1 hour each (plus 1 hour travel on 3 occasions)	September 2011 – March 2012	Data collection: Conducted in-depth in person interviews ($n = 24$) in New Haven, Hartford, and Bridgeport.
3 days	November 2011	Conference attendee: Poster co-presenter at Robert Wood Johnson Foundation Clinical Scholars Program Annual National Meeting.
~1.5 hours each	April 2011	Participant confirmation: Conducted by community partner with MSM (at APNH and HGLHC) and MCM.
~1.5 hours each	June – September 2012	Dissemination: RWJF CSP Steering Committee; -Connecticut HIV/AIDS Identification and Referral Task Force; Connecticut HIV Planning Consortium.
~1 hour	August 2012	Teaching: RWJF CSP Case Study presentation.
~6 hours	August – September 2012	Manuscript preparation.

Although the project could have been completed within a shorter period of time, this may have limited the opportunities for capacity building and likely would have impaired the quality of the project.

Balancing a Dual Role: Researcher and ED

Consistent with the experience of community-engaged researchers,⁴⁵ balancing the dual role of researcher and ED was challenging. Through the conduct and analysis of the focus group with the MCM and interviews with MSM, I gained a deeper understanding of my staff and clients. For instance, I gained a greater understanding of some of the complex issues clients face, such as substance use, housing, return from incarceration, and complex interpersonal relationships. I learned of client frustrations in dealing with staff, especially related to follow-through and clear communication. I used this information to inform programmatic decisions and client service quality improvement, such as the frequency of MCM meetings as a step toward fostering stronger relationships, interstaff support, improved staff supervision, and client service evaluation. Similarly, with a deeper understanding of client needs, I worked to empower clients and decrease in clients' "victim" stigma by creating a client feedback mechanism, and a consumer committee to provide ongoing feedback and suggestions.

On the other hand, some of the knowledge that I learned as a researcher was challenging to navigate. Based on an interview with a client, I learned about suboptimal performance of one of the MCM, ultimately leading to further investigation and disciplinary action. Similarly, I met an HIV-infected man who was not engaged in services at APNH, but was a potential client, who reported initiating legal action against his previous providers. We spent time at our research team meetings discussing the ethical, moral, and best possible approaches to these challenges because I was concerned about providing services to him.

These experiences reinforced for me how important it was that I was not directly involved in routine client services to minimize biases, but also highlighted some of the unexpected challenges in CBPR. It was essential for me to use our research meetings as a forum through which I could regularly debrief about my experiences.

Partnering With the DPH

My apprehension about partnering with the state DPH for *Project COACH* may have been consistent with the majority of community members who do not trust in health departments,⁴⁶ but it was not professionally ideal. Relatively new to Connecticut, I had had limited experience with the individuals at DPH previously. My perception was that DPH moved slowly and had significant bureaucratic limitations, as well as some staff with limited expertise in working with culturally diverse populations. I understood, however, that having their involvement in the project was a critical step toward promoting change in practice.

Through the project, I had the opportunity to develop a professional and personal relationship with some of the staff, including the research team members. Although my beliefs about staffing limitations and cumbersome bureaucracy were reinforced, I learned about the strong dedication of DPH staff to their roles and commitment to their communities. I also gained a new perspective of how thoroughly staff is trained for their roles, as well as their extensive experience. Consistent with other communities, I learned that one of the challenges in partnering between CBOs and DPH was that at DPH, the DIS have been in their positions for over 10 years, whereas there was frequent turnover within the CBOs.⁴⁷ I have now ensured that new staff are introduced to DPH staff and appropriately trained.

This newly developed partnership between APNH and DPH has grown into new collaborations, with direct impact on our clients. For example, the DIS on our team joined one of the support group sessions held at APNH to educate HIV-infected male patients about Partner Services.

CONCLUSIONS

With the experience of several previous non-CBPR community-academic research projects, the value of CBPR to APNH became evident through *Project COACH*. These conclusions are drawn from the perspective of the team involved in *Project COACH*. Given the growing support for conducting CBPR, specifically for HIV/AIDS research,⁴⁸ and in general, and the necessary time investment for successful CBPR for all parties involved,²⁸ APNH has adopted principles

for deciding whether to participate in a CBPR project, which we share below. In essence, the principles are centered on optimizing adherence to the principles of CBPR⁶ (Table 2). First, be clear about the expectations around time investment and what is feasible within the needs of the organization; allow this to inform the roles and responsibilities assumed for the project. Second, choose academic partners who are committed to investing their time in fostering an equitable research partnership while being flexible about the needs of the community partner, ensuring the academic researcher's commitment to adhering to CBPR principles. Third, from the beginning consider how the project will lead to capacity building for the individuals and the organization, specifically considering areas for desired improvement. Fourth, decide on a forum through which to process unexpected experiences and challenges. Fifth, collaborations with academic and non-academic partners, including health departments, can create important opportunities for conducting research with direct impact on program implementation; consider including these "third" partners whenever appropriate and feasible. Finally, identify how the collaboration may translate into unique opportunities for engaging the clients served by the organization and directly empower them in the process.

Careful consideration of CBPR principles⁶ throughout a project may ensure both the highest quality process and

outcome, including experience of the community partner.¹⁰ Indeed, CBPR is an essential approach for informing and developing interventions to decrease the burden of HIV/AIDS in our communities. Although the tensions inherent in the lessons learned (time vs. capacity building; balancing dual roles and transcending mistrust of a governmental organization for the benefit of clients) have been described previously, this description from the perspective of an ASO's ED is unique in the literature and may serve to engender a greater comfort with CBPR among ASOs. Future research should build on previous work^{20,44,49} and focus on how to increase the participation of ASOs in research and how to optimize their role as well as how adherence to the principles of CBPR affects outcomes of capacity building and client outcomes.

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The contents of this work are solely the responsibility of

Table 2. Lessons Learned and Recommendations

Lessons Learned	Recommendations
Time Investment vs. Capacity Building	<p>Discuss project with the board and staff early on.</p> <p>Negotiate reimbursement for team members.</p> <p>Define project roles and responsibilities of each staff members upfront.</p> <p>Determine role of organization at each stage of research process (e.g. defining the research question, designing methods, data collection and analysis, dissemination).</p> <p>Identify and make available opportunities for development of research skills and networking.</p> <p>Choose academic partners who are dedicated to capacity building of community partners and flexible around time commitments.</p>
Researcher vs. Executive Director	<p>Create opportunities to interface with clients and staff in new ways.</p> <p>Minimize conflicts of interest and biases when designing approaches to data collection.</p> <p>Decide upon a forum for processing unexpected events.</p>
Partnering With Governmental Agencies	<p>Be open to partnerships given potential benefits for program implementation.</p> <p>Identify collaborative opportunities for solutions-based program improvement.</p>

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