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At the Intersection of HIV/AIDS and Cancer: A Qualitative Needs Assessment of Community-Based HIV/AIDS Service Organizations

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Abstract

Due to advances in treatment, persons living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) are living longer, but with aging, immune deficits, and lifestyle factors, they are at increased risk for cancer. This challenges community-based AIDS service organizations (ASOs) to address the growing cancer needs of persons living with HIV/AIDS (PLWHA). Community-based participatory research was applied to engage ASOs in exploring their capacities and needs for integrating cancer-focused programming into their services. Focus groups were conducted with a community advisory board (CAB) representing 10 community-based organizations serving PLWHA. Three 90-minute, serial focus groups were conducted with a mean number of seven participants. Topics explored CAB members' organizational capacities and needs in cancer prevention, detection, treatment, and survivorship. Transcript analyses identified six themes: (a) agencies have limited experience with cancer-focused programs, which were not framed as cancer specific; (b) agencies need resources and collaborative partnerships to effectively incorporate cancer services; (c) staff and clients must be educated about the relevance of cancer to HIV/AIDS; (d) agencies want to know about linkages between HIV/AIDS and cancer; (e) cancer care providers should be culturally competent; and (f) agencies see opportunities to improve their services through research participation but are wary. Agency capacities were strong in relationships with clients and cultural competency, a holistic view of PLWHA health, expertise in prevention activities, and eagerness to be on the cutting edge of knowledge. Cancer education and prevention were of greatest interest and considered most

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feasible, suggesting that future projects develop accordingly. These findings suggest a high level of receptivity to expanding or initiating cancer-focused activities but with a clear need for education and awareness building. Qualitative findings will inform a large quantitative survey to validate identified themes, which will be applied in developing interventions to assist ASOs in adopting or expanding cancer-focused activities.

Keywords

cancer prevention and screening; community-based participatory research; focus groups; health disparities; HIV/AIDS; qualitative methods

Persons living with human immunodeficiency virus (HIV) infection or acquired immunodeficiency syndrome (AIDS) have improved life expectancy since the introduction of highly active antiretroviral treatments for long-term management of the disease (Palella et al., 2006). Indeed, by 2015, the proportion of persons living with HIV/AIDS (PLWHA) ages 50 years and older is expected to reach 50% (Detels et al., 1998; Effros et al., 2008), an increase that is due both to improved treatments and newly diagnosed infections in persons aged 50 years and older (Administration on Aging, 2010). A number of countervailing factors and comorbid conditions that are uniquely concentrated among PLWHA, n particular cancer risk factors and cancer, threaten these hard-won gains in life expectancy (Lewden et al., 2008). Among these factors is, first, with an aging PLWHA population comes increased risks for a number of cancers, such as those of the breast and prostate (American Cancer Society, 2010). Second, immune deficiencies caused by HIV infection increase risks for cancer, both the AIDS-defining (Centers for Disease Control and Prevention, 1992) and non-AIDS-defining cancers (Shiels et al., 2011). Third, human papillomavirus (HPV) infection, which increases risk for anal, cervical, and tonsillar cancers, and hepatitis B and C infections, which increase risk for liver cancer (National Cancer Institute, 2011), are prevalent among PLWHA. Fourth, smoking tobacco, which is markedly elevated among PLWHA (Burkhalter, Springer, Chhabra, Ostroff, & Rapkin, 2005; Nahvi & Cooperman, 2009), causes many cancers, including lung, head and neck, and bladder cancers (American Cancer Society, 2010). These factors contribute to the elevated incidence of cancer among PLWHA (Engels et al., 2008) and the growing proportion of malignancies within HIV/AIDS that are not AIDS related (Bonnet et al., 2009).

Some 25% of all AIDS deaths are due to non-HIV-related causes, and non-AIDS-defining malignancies contribute substantially to this mortality (Sackoff, Hanna, Pfeiffer, & Torian, 2006). Deaths due to AIDS-defining malignancies have remained stable, while the proportion of lethal non-AIDS-defining malignancies has been growing (Bonnet et al., 2009). Thus, not only are cancer prevention, early detection, and improving access to medical care important means to help preserve quality and quantity of life for the HIV-infected, but taking these actions can help reduce health disparities seen in both cancer and HIV disease (American Cancer Society, 2010; Centers for Disease Control and Prevention, 2004; Dray-Spira, Gueguen, & Lert, 2008).

Although cancer, notably Kaposi sarcoma as an AIDS-related cancer, has been salient since the beginning of the AIDS epidemic (Centers for Disease Control and Prevention, 1981), the growing intersection of HIV/AIDS with a broad swath of cancer types poses new challenges to a number of audiences, including community-based organizations serving PLWHA, academic researchers, policy makers, and health care providers. HIV/AIDS service organizations (ASOs) span the provision of mental health and substance abuse care; case management and psychosocial services; HIV testing, education, and training; and housing, legal, and other financial support. Many ASOs also are involved in research (International Council of AIDS Service Organizations, 2009). In the United States, there is a national population of PLWHA estimated at 1.1 million (Liao et al., 2011), and at least 600 community-based ASOs (personal communication, CDC National Prevention IN, May 26, 2011). In New York City, there are about 30 ASOs and a population of PLWHA estimated at 109,000 (New York City Department of Health and Mental Hygiene, 2010). High rates of nonengagement in HIV medical care and the overrepresentation of racial and ethnic minorities and persons with low-income status within HIV/AIDS (American Cancer Society, 2010; Centers for Disease Control and Prevention, 2004; Dray-Spira et al., 2008; Fleming et al., 2002) are conditions that increase the likelihood that cancers will be diagnosed at a later and more advanced stage of disease. Because ASOs are often in the forefront in promoting early detection of HIV infection (International Council of AIDS Service Organizations, 2009), the successful implementation of cancer prevention and early detection activities may depend on strong linkage to ASOs' current core activities and capacities, such as in HIV/AIDS prevention and detection.

Community-based ASOs provide an untapped potential for addressing the cancer-related needs of PLWHA because of their close relationships with the communities they serve; however, their readiness to do so is largely unknown. To date, no published studies have been found that examine ASO capacities, interests, needs, and readiness to undertake this endeavor; thus, the purpose of this study was to remedy this gap in knowledge. Any interventions to assist ASOs in developing cancer programming would require their collaboration; thus, the project discussed herein used community-based participatory research (CBPR) as the model to guide exploration of ASO capacities and needs across the cancer care continuum as it intersects with HIV/AIDS care (Israel, Schulz, Parker, & Becker, 1998). Researchers in the City College of New York–Memorial Sloan-Kettering Partnership for Cancer Research, Training, and Community Outreach invited Gay Men's Health Crisis (GMHC) to join the research team as the community investigative, co-equal partner in the newly formed HIV/AIDS and Cancer Community Research Collaboration, henceforth called the "Collaboration." As the oldest community-based organization (CBO) in the fight against AIDS, serving more than 11,000 clients annually, GMHC was well poised to bring community voices into the development and works of the Collaboration. GMHC staff was responsible for convening a Community Advisory Board (CAB) comprising representatives of 10 CBOs with programming activities relevant to the intersection of HIV/AIDS and cancer, and GMHC staff members have been full partners in the grant application and budgeting process, the development of the research design, and the analyses of data.

The resulting HIV/AIDS and Cancer Community Research Collaboration operated in a multidisciplinary mode co-led by a troika comprising community-based health specialists and researchers at GMHC, a physician researcher at a minority-serving university, and a behavioral scientist at a cancer center, and seeking input by a community outreach program, senior investigators in a research committee, and a CAB. In alignment with broad principles of CBPR that have been articulated by Israel and colleagues (Israel, Eng, Schulz, & Parker, 2005), the project aimed to strengthen the Collaboration and develop its focus by gathering data iteratively through focus groups and reciprocal feedback with community stakeholders. Funding for the study was shared equitably among the three leaders, and CAB members were compensated for their time and effort. In the recruitment of CAB members, GMHC received confirmation that the topic of cancer within IV/AIDS was relevant and newly emerging as a distinct concern within these agencies. The CAB members were viewed as essential participants in the creation of knowledge gained from the efforts of the Collaboration.

Given the lack of data on how ASOs were responding to cancer concerns, the purpose of this qualitative study was to identify capacities, facilitators, and barriers to the uptake of cancer-focused programming by ASOs. As the Collaboration is a research partnership, it was important to probe for experiences with and attitudes about forming research partnerships. These qualitative data were intended to aid in developing a quantitative, community-based survey of cancer-focused programming capacities and needs that was targeted to a large regional sample of community-based ASOs. The ultimate aim of the ongoing Collaboration is to develop educational and cancer prevention and control interventions that build the capacities of ASOs to deliver evidence-based cancer programming to their PLWHA clients or those at risk for HIV infection.

Method

Participants

Study methods and procedure were reviewed by the institutional review boards at both Memorial Sloan-Kettering Cancer Center (MSKCC) and the City College of New York and deemed to be exempt from full review. The study’s primary community partner, GMHC, accepted these institutional review board decisions. A CAB was formed to explore mutual interests and needs at the intersection of HIV/AIDS and cancer for CBOs serving persons living with or at risk for HIV/AIDS. The CAB comprised 10 representatives from New York City metropolitan area CBOs. The CAB and the HIV/AIDS and Cancer Community Research Collaboration were established in 2009 to be an ongoing, long-term partnership. All grant applications, funding, and academic products related to the Collaboration’s work were intended to support the participation of community partners and build their capacities in this area. Criteria used to identify potential CAB member agencies and their representatives were the following: (a) diversity in mission and services offered to PLWHA; (b) diversity in subpopulations served; (c) geographic diversity, that is, all New York City boroughs were considered; (d) individual representatives and alternates should have extensive knowledge about the services and structure of their agencies; and (e) agree to attend quarterly meetings. Of 14 organizations contacted, 10 (71%) agreed to serve on the CAB (see Table 1). Those declining did so mainly due to lack of time to commit to additional activities beyond ones in which they were already engaged.

While all the organizations serving on the CAB are community based, and none are free-standing medical care or health clinics, all work directly with PLWHA in some capacity. With the exception of one research-focused agency, each organization provides a number of services to its clients. Their diverse missions and foci regarding HIV/AIDS services include HIV+ women; the incarcerated and formerly incarcerated; the lesbian, gay, bisexual, and transgender population; and AIDS-related education and research. Of the 10 CAB members, only 3 indicated that they currently provide cancer-focused programming, and among those who did, they cited cancer education workshops, medical care, nutrition education, education about HPV, and cancer screening and treatment referrals.

Procedure

Focus group methodology was chosen because it has a rich and productive history within CBPR research (Farquhar, Parker, Schulz, & Israel, 2006) and is appropriate for assessing perspectives, capacities, and needs in an emerging and understudied topic. Furthermore, the CAB was conceived as the representative of the community unit of identity (CBOs providing services to PLWHA or persons at risk for HIV infection), with shared identities and interests, enabling the Collaboration research team to engage the community directly in the topic of cancer concerns for PLWHA. Although the method of conducting serial focus groups with the same participants is not novel (Sormanti, Pereira, El-Bassel, Witte, & Gilbert, 2001), our approach of doing so with a CAB was, and it had the benefits of efficient use of CAB time and study resources while strengthening members’ cancer knowledge and capacities to disseminate this knowledge within their agencies and communities. The research team intended for CAB members to develop increased knowledge and sensitivity to the issue of cancer concerns for PLWHA over time in order to better inform the Collaboration of their ideas on how to integrate these concerns into their current agency structure and programming.

In preparation for the first focus group, group discussion guidelines were developed with the ultimate aim of planning and goal setting for the Collaboration (Krueger & Casey, 2009). The leadership team convened to generate areas of focus and items related to assessing ASO needs across the cancer care continuum. Five areas emerged as foci: (a) current or past cancer-related programming activities (experiences), (b) fit of cancer-related programming with organizations’ missions and current activities (barriers and facilitators), c) capacities to expand or integrate cancer-focused activities (capacities), (d) interest in specific types of cancer programming (interest/readiness), and (e) perceptions about potential cancer research relationships (research receptivity), given the commonly held community mistrust of academic researchers (Kone et al., 2000). The qualitative methods specialist (ES) steered the process of guideline development, which was informed by the primary aim of ultimately assessing the needs and capacities of ASOs in a quantitative, tri-state survey. The research team was attuned to the broad dissemination and implementation issues for ASOs through input from GMHC collaborators. CBPR principles influenced the guideline development in that we assessed not only needs or deficits but also capacities and strengths. Through an iterative process of research team feedback and refinements, consensus was achieved, and the final guidelines and probes were developed. The guidelines were adapted for each of the three cancer continuum topics and groups.

The three CAB meetings at which focus groups were held occurred over a 4-month period in 2009–2010, and all CAB members were invited to attend the three focus groups. Attendance across the three focus groups was on average seven members. All participating members provided their consent for the focus groups to be audio-recorded. The method of conducting focus groups during the CAB meetings was chosen because doing so acknowledged the constraints that resource-lean CBOs have in allowing staff to participate in projects that may compete with their direct organizational responsibilities. Furthermore, this approach was both novel and CBPR-grounded in that it immediately engaged CAB members in the knowledge generation process and demonstrated that the Collaboration's research team valued their active involvement. We appreciated that any individual representative would likely be unable to attend every CAB meeting and focus group; hence, our methodology combined a pragmatic approach of accepting that different CAB agencies would participate as they were able, with the same applying to individual representatives of the agencies. The meetings were held at GMHC, and all CAB focus group participants were offered a $150 honorarium per meeting and light refreshments. Each of the three focus groups was preceded by an educational presentation at the meeting in which the Collaboration's research team provided hour-long overviews of cancer prevention, screening, and treatment/survivorship, respectively, and facilitated discussion of each topic. The two aims of these presentations were to provide the CAB members with enough information about the cancer continuum topic to enable their full participation in the focus group and to build their cancer knowledge capacities. After the meeting's presentation there was a short break, the focus group was conducted for 1.5 hours and was audio-recorded, and recordings were transcribed for analysis. Focus groups were moderated by persons experienced in qualitative methods (ES) and community research (NC, JG). Focus group guidelines (Table 2) aimed to glean information about the organizational fit of cancer-related services, types of cancer-related services already provided, types of cancer-related services that organizations would be interested in providing, and the ASOs' research experiences and interest in participating in cancer-related research. At each CAB meeting after the first, a summary of the prior focus group's thematic analyses with supporting quotes was presented. This method reinforced the value of CAB engagement, provided another opportunity for members to comment on the topic and analyses as well as to consolidate received education about the topic, and helped arrive at a consensus about their agencies' mutual needs.

Table 1 presents characteristics of CAB member participants in the focus groups. Attendance at each topical group was, respectively, 7, 8, and 6 members. Of the 13 individuals participating (primary and alternate organizational representatives), 38.5% attended only one, 46.2% attended two, and 15.4% attended all three focus groups. The mean age of participants was about 43 years, over half were female, and most were ethnic or racial minorities and had a graduate degree or professional training. Participants had been with their organization on average for 5.5 years. While nearly half of the participants had experience with cancer prevention activities, only one had experience with cancer screening or cancer treatment. None had experience in cancer research.

Qualitative Analysis

An inductive, targeted text analysis was used to analyze focus group transcripts. This method entailed identifying recurring thematic patterns within the data rather than approaching analyses with predetermined themes in mind. Because the team lacked specific data about the facilitators and barriers to implementing cancer-focused activities within ASOs—a novel area of inquiry—this approach was appropriate. The analytic process involved reviewing and interpreting the focus group transcripts to identify overarching concepts and patterns that emerged directly from the data (Boyatzis, 1998; Patton, 2002). The analysis team was guided by a qualitative methods specialist (ES), who developed an analysis template in which analysts were asked to identify themes related to planned topics explored in the focus groups as well as other themes that emerged and were of interest to the analysts. The analytic team also comprised the study leaders (JB, EL, SC); GMHC's HIV Prevention Researcher (JG), Community Educator (MK), and Coordinator of Community Based Research (NC); and the research assistant (GC). Each analyst first read a given focus group transcript and entered descriptive findings (synthesis of narrative content) and interpretive findings (analyst's perception of underlying meaning, if any), supported by verbatim quotations, into a template for that transcript. After this process, the research team met to synthesize their independent reviews and reach agreement on salient findings, creating a summary findings document for each focus group. A final analytic step was to synthesize findings across the three focus groups, whereby each team member independently reviewed every team members' observations and the consensus observations for each focus group, and recorded a cross-group synthesis in a fourth data analysis template. In a form of analyst triangulation, the team first considered whether the independent analysts had reached similar conclusions during their review and synthesis of the focus group findings (Patton, 1999). Furthermore, the extent to which the salient themes recurred across the three focus groups was assessed (Guba, 1978). Analysts reached similar conclusions in their cross-groups analyses, and most themes manifested in each focus group. Finally, the research assistant generated a comprehensive document of analysts' summaries across the three focus groups.

Results

The results of the overarching themes across all three focus groups are presented. Theme 1 relates to the agencies' experiences in implementing cancer-related programming and how any activities are framed and promoted. Theme 2 describes resources and support that agencies need to develop and implement cancer-focused programs. Theme 3 represents the need for cancer-related programming to be considered relevant to PLWHA by agency leadership. Theme 4 describes agencies' interest in exploring the linkage between PLWHA and cancer. Theme 5 indicates the importance of being culturally sensitive to the unique needs of PLWHA when offering them cancer services. The sixth theme describes agencies' perceptions of opportunities and challenges in collaborating with research organizations. Themes are presented with a brief explication and supporting quotes from diverse group participants (65% from racial, ethnic, or sexual minorities and 45% from women, with only three participants contributing more than one quote, two quotes being the maximum per individual).

> *Theme 1:* Most agencies had limited experience implementing cancer-focused programs, and when they had, the programs were not framed as cancer specific.

Most CAB members' agencies provided few, if any, cancer-specific activities. One notable exception was an organization dedicated specifically to lesbian, gay, bisexual, and transgender cancer concerns. Programs that did address cancer were framed from a holistic or wellness perspective, such as embodied in health fairs. Cancer-focused activities at these agencies tended to be episodic, such as sponsoring a one-time smoking cessation group or an annual mobile mammography event. Regarding cancer screening activities, one group member reported:

> We don't have the capacity for that, but we have … health fairs … where we hope to have that kind of screening there. We do have … people come in and do presentations on cancer.

No agency reported referring clients to clinical trials targeting AIDS malignancies, as they were unaware of trials specifically targeting cancers within HIV/AIDS, but many had referred clients to AIDS treatment trials.

> *Theme 2:* Agencies need resources and collaborative partnerships to effectively incorporate cancer services.

Participants stated that they must have adequate resources to successfully develop and implement cancer-related services. Funding opportunities from city and state health departments targeting cancer service implementation arguably play the most significant role, but other important resources are (a) solid data on the link between HIV/AIDS and cancer, particularly within a CBO's own client base; (b) collaborative partnerships with cancer-focused organizations; (c) culturally competent physicians to whom they can refer patients; and (d) interpreters for immigrant populations.

Participants believed that referrals to community resources will allow CBOs to provide access to services, alleviating the impact of their resource limits by sharing the onus of PLWHA cancer needs. Participants expressed great interest in involving city and state health departments, who add credibility to the agency and its services, and medical providers, who can ensure that their clients receive competent care. Two participants stated:

> Organizations are recognizing that they can't do everything on their own. They just don't have the capacity to [provide] information, education, resources, so they have the partnerships.
>
> The issue [care of an aging HIV+ population] has gotten very complex and collaborating … has got to be the name of the game. It's the only way to do it economically … [and] effectively.
>
> *Theme 3:* Staff and clients must be educated about the relevance of cancer to HIV/AIDS.

Participants reported that agency staff, clients, and the organizations' leaderships must be educated and convinced of the need to expand their focus to include cancer concerns. The possibility of cancer-related services conflicting with or being outside of the missions of these organizations was raised as a potential barrier to buy-in at the leadership and staff levels. One participant noted that executive leadership must be persuaded to incorporate cancer services within agency programming, and another grappled with integrating cancer into her agency:

> I think … incorporating it educationally … not only clients but staff as well. … Adding it to some of the support groups … having staff from up to down understand it, how it interacts with HIV … this being another comorbidity.

Additionally, several participants stated that cancer could be seen as “one more thing” added to a full list of competing priorities. One participant explained:

> It has to be very clear that this isn’t “just one more thing,” this [cancer] is an emerging trend that’s going to make a dramatic impact on the lives of the people you work with.

Participants identified strategies to mitigate this perception: (a) clients must be able to use cancer services while still having their basic needs met, for example, housing and food and (b) agency staff and leadership need data on the link between cancer and HIV/AIDS to convince them of the necessity and timeliness of the issues of cancer risk and care. For example, one participant noted a recent change in her agency’s mission statement to include chronic illnesses, thus providing flexibility to expand the scope of activities to include cancer.

> *Theme 4:* Agencies are interested in education about linkages between HIV/AIDS and cancer.

Nearly all participants were receptive to expanding their educational programs to incorporate cancer and highlight its intersection with HIV/AIDS, particularly from the perspective of cancer prevention. Very few members wished to engage in activities further along the cancer care continuum, such as cancer treatment or survivorship. Participants were most interested in programming with which they had experience and capacities for implementing, such as workshops, social marketing, and peer-to-peer interventions. Among the topics deemed essential was aging of the HIV/AIDS population with a focus on medical comorbidities and psychosocial concerns associated with aging. Additionally, the topics of stigma associated with both cancer and HIV/AIDS and fear of cancer as yet another life-threatening illness for PLWHA were considered important to address. Participants considered how to weave cancer messages into an HIV/AIDS focus and proposed reinforcing the same lessons learned in HIV/AIDS—that timely cancer screening can improve treatment efficacy and survival. For example, one participant stated:

> I’m still getting that it’s going to be very important to have people see how [cancer and HIV/AIDS] relate. … Can we have workshops around that? Can we have conferences around that. … We gotta bring the awareness, gotta get people on board.

Additionally, ASOs were increasingly challenged to serve an aging client population, resulting in the added responsibility to address aging-related comorbidities such as cancer.

By focusing on the nexus of aging, participants identified a salient and comprehensible linkage between cancer and HIV/AIDS. One participant stated:

> How do you sell this, how do you tell a client that they need to be screened [for cancer]? We weren't talking about this 5 years ago, and it's the onus of responsibility on the agency … to communicate that older adults with HIV face a panoply of issues that they never saw before.

> *Theme 5:* Cancer care providers should be culturally competent and understand the needs of PLWHA.

Many participants stated that being able to provide and refer to organizations equipped to offer culturally competent care is imperative for their clients, who include racial/ethnic and sexual minorities, immigrants, drug users, and those with limited English proficiency. Participants took pride in their agencies' knowledge and capacities to deal with the needs and resource deficits of underserved PLWHA, but they were concerned about how these needs would be managed within cancer care. For example, one participant stated:

> For [sexual minority] people, there are many reasons that they avoid screening … perceived discrimination or previous negative experiences, so unless you promise a difference there, no one's gonna go [to the cancer care provider].

Another participant explained that lack of health care insurance may prove a barrier for undocumented immigrants to receive cancer services.

> I just want to add the … undocumented [immigrant] population … even if we were able to promote cancer screening and get them into … culturally competent settings for cancer screening, does that mean … that they're going to get all the care that they need when they have no primary medical insurance?

> *Theme 6:* Agencies see opportunities to improve their services by participating in research but are wary about the loss of autonomy and irrelevant research findings.

Participants were receptive to participation in research about cancer within HIV/AIDS. They were hopeful that doing so would provide them with data that could inform service development and help them obtain funding. They expressed the need for tangible help from researchers, including grant writing assistance and access to student research assistants. Several participants mentioned positive experiences in research partnerships, noting that their collaborations led to funding for which they otherwise would have been ineligible and data useful for making service program decisions. They cited three factors that would discourage their collaboration with researchers. One is a perception that their agency would be "used" simply to gain access to their clients without real benefits to the agency. A second concern, especially for small organizations, is the potential loss of autonomy when a "research Goliath" wants to partner with them. The third concern is that the findings emerging from research collaborations would not be useful to them in better serving their clients. Participants stated that if they were involved from the inception of a research project it would be more likely to ensure findings are useful to them.

> The beginning of the relationship, you think you're gonna get so much information, and then the information that comes out is not what you asked for, and it's very

> frustrating, and then the staff get very frustrated because they were expecting different outcomes, and now it's just a report to NIH that had nothing to do with what was supposed to happen with our clients.

In summary, these six themes highlighted that organizations have had limited experience implementing cancer-focused programs and need partnerships and culturally competent cancer providers to help them grow this area. To spur the uptake of cancer programming there must be proactive education campaigns targeting agency leadership, staff, and clients about the linkages between cancer and HIV/AIDS. Research partnerships with cancer researchers are seen as having potential benefit to help them improve and implement cancer-focused services, but they are wary of researchers' motivation and the usefulness of research findings. We now discuss the implications of these findings.

Discussion

To our knowledge, this is the first study to apply CBPR methods and report on community-based HIV/AIDS service organizations' readiness to integrate cancer care perspectives and activities into their current programming. Within HIV/AIDS, the use of CBPR methods in community– academic partnerships has gained ground, although their use in designing interventions is less common (Corbie-Smith et al., 2011). To assure that the ASO community's perspectives guided the Collaboration's efforts from its inception, a large and well-connected ASO (GMHC) was co-equal partner of the leadership troika—sharing equitably in the funding resources and actively guiding the project. This unique leadership structure established a legitimate convening capacity that has borne fruitful results, with CAB membership stable over the first 2 years (80% retention). This critical decision to go beyond the traditional arrangement of an entirely academic research team convening a community advisory board meant that early on there was a built-in community consultation. This structure yielded confirmation of the growing interest among ASOs in the issue of cancer and aging for their clients, but also ASOs' limited cancer programming experience and resources. Early input of the community perspective led to an emphasis on assessing ASOs' needs (deficits) in order to eventually develop interventions to address those needs, but the qualitative approach explored capacities (strengths) and interests as well—data that are necessary to inform future efforts at dissemination and implementation of evidence-based cancer knowledge in those settings.

Analyses of focus group data held with representatives of organizations serving PLWHA or those at risk for HIV infection revealed a high level of receptivity to learning about the impact of cancer on PLWHA and a readiness to both link cancer concerns to the aging of the PLWHA population and collaborate with cancer experts to boost their capacities to meet the educational needs of staff and clients. The organizational strengths identified in the focus groups included an orientation toward viewing PLWHA health in a holistic way that would enable the incorporation of cancer concerns. Participants were quick to apply lessons learned in HIV/AIDS to cancer, such as a strong focus on primary and secondary prevention. They were eager to learn and be on the cutting edge of knowledge and services to PLWHA, as represented by the aging and cancer nexus, and to consider research and educational collaborations that helped them improve services. Indeed, some CAB members had reported spontaneously that they had taken information presented to them during Collaboration meetings back to their home agencies and presented it to colleagues, a sign of motivation for communicating new information relevant to their care of PLWHA. They expressed confidence in their knowledge and expertise accrued from long-term relationships with PLWHA and wanted this expertise and cultural competence present in the provision of cancer care for their clients in other settings. These organizational capacities bode well for the Collaboration’s planned efforts to engage ASOs in the dissemination and implementation of evidence-based cancer education and activities.

A number of specific themes emerged indicating the overall novelty of “thinking cancer” for AIDS-focused agencies. As the focus group topics moved further along the cancer care continuum, the level of knowledge and interest in providing services related to that topic declined. CAB members had the most experience and comfort in activities such as promotion of smoking cessation or cancer screening among their clients. Within cancer, prevention and education are often starting points in early CBPR work (Davis et al., 2011). Aligned with calls for a new paradigm to address the broader health concerns of an aging HIV+ population (Justice, 2010), CAB members expressed the need to address cancer risk and comorbid cancer. They cautioned, however, that much intra-organizational education about the intersection of the two diseases had to be done in order to pave the way for implementing cancer-focused programs for their clients. As the participants noted, a growing awareness of the aging of the PLWHA population provides opportunities to expand ASO services to meet emerging needs. The collaborative process that CAB members desired fits well with CBPR goals and methods (Israel et al., 1998) and reinforces the value of this approach in working with a community of HIV/AIDS service agencies. Implications of these findings for ASOs include the usefulness of linking cancer to aging in the HIV-infected population, which may provide an intuitive rationale for introducing a focus on cancer for PLWHA—both for staff and their clients. Within ASOs, staff will need education about cancer risks and concerns for PLWHA, resources will be needed to build in-house capacities to undertake cancer-focused programming, and in some cases agency mission statements will require modification to incorporate cancer concerns. Collaborations with culturally competent cancer providers and experts in the cancer care continuum can alleviate the burden of these tasks for ASOs.

The strengths of this study include its grounding in CBPR principles: building on strengths and resources in the community of ASOs; facilitation of a collaborative, equitable partnership in the full research endeavor; and fostering co-learning and capacity-building among all partners (Israel et al., 2005). The focus group participants were highly engaged and diverse in gender, race/ethnicity, and geographic location within New York City. Despite these strengths, the members of the focus groups were drawn from one source, the Collaboration’s CAB, which comprised 10 ASOs among the 14 invited to join; thus, members may not represent the population of ASOs and their staff. Furthermore, study findings may not reflect overall ASO perspectives in New York City or State, or the country. This study was a formative step toward the development of a quantitative survey to assess similar topics among a larger group of ASOs in New York, New Jersey, and Connecticut. That survey will provide confirmatory data needed to launch future projects to address cancer care needs. Furthermore, due to CAB members’ interest in cancer prevention and tobacco use, the Collaboration is undertaking a pilot trial focusing on enhancing smoking cessation motivation and improving access to evidence-based public health cessation resources.

The Collaboration research team has planned a tobacco assessment and intervention workshop for CAB agency staff to build their capacities in this area and will recruit from this trained cohort the interventionists for the control condition of the pilot trial for tobacco-dependent PLWHA. It is hoped that this will further anchor the Collaboration’s activities within the community of ASOs and build internal capacity for the tobacco use intervention (Mohr et al., 2009). In this way, the conduct of the Collaboration exemplifies the cyclical process of developing local knowledge and partnerships that promote co-learning and capacity building and demonstrates a long-term commitment to identify and explore challenges and opportunities and to take community-level action to improve the well-being of PLWHA.

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Table 1

Characteristics of Focus Group Participants and Their Agencies

Characteristics	**Frequency**	**Percentage**
Individual focus group participant information (*n* = 13)		
Male	8	61.5
Female	5	38.5
Race/ethnicity[a]		
White	5	41.7
Black/African American	6	50.0
Hispanic	4	30.8
Other	1	8.3
Education		
High school graduate	1	7.7
College degree	1	7.7
Graduate degree or professional training	11	84.6
Cancer experience		
Prevention	6	46.2
Screening	1	7.7
Treatment	1	7.7
Research	0	0
Other	6	46.2
Age (mean years, *SD*)	42.8	11.1
Employment at organization[a] (mean years, *SD*)	5.5	4.9
Community advisory board organizational information (*n* = 10)		
Experience in cancer-related activities		
Provides cancer-related services	4	40
Involved in cancer-related research	3	30
Clients served (% endorsing client categories)		
Gay men, lesbians, and bisexuals	9	90
Transgender persons	8	80
Substance users	8	80
Homeless persons	8	80
Older adults	7	70
Adolescents	6	60
People with mental health concerns	6	60
Migrants/refugees	5	50
Incarcerated persons	3	30
Special needs populations	2	20
Children	1	10

Note. The sample size for each of the three focus groups was *n* = 7, 8, and 6 participants.

[a] One respondent’s data are missing.

Table 2

Focus Group Topics and Questions

Questions about the nature of organizations' past or present cancer-related activities

- Describe current cancer-related activities
- If offered, how are those activities framed or promoted?

Sample Question (Focus Group 1, Cancer Prevention): Is the activity or program thought of and promoted as "cancer prevention"? If not, please explain in what conceptual model such programs are framed.

Fit of cancer-related activities at these organizations

- What would make integration successful or unsuccessful
- Potential barriers and challenges
- Considerations in serving minorities or underserved PLWHA clients
- Community partnerships and resources

Sample Question (Focus Group 2, Cancer Detection): What considerations would have to be given in promoting cancer screening to ethnic and racial minorities/underserved PLWHA clients?

Types of cancer-related activities these organizations would consider expanding or initiating

- Activities they would consider
- Reasons for their consideration
- Resources needed to expand or add services
- Education and training

Sample Question (Focus Group 3, Cancer Treatment/Survivorship): What additional resources (financial, training, etc.) would your organization need to provide or expand cancer treatment or survivorship services?

Interest of these organizations in participating in research concerning cancer

- Experiences in the conduct of research
- Interest in participating in research
- Capacity for research participation

Sample Question (Focus Group 3, Cancer Treatment/Survivorship): What capacity (knowledge, experience, skills, or resources) does your organization have for conducting research or program evaluation in the area of cancer treatment or survivorship-related activities?

Ending/conclusion of the focus group

- Discussion of any topics that were not previously covered
- Identification of important, "take away" messages

Sample Question (Focus Group 1, Cancer Prevention): What issues that we have discussed do you think are most important for us to take away from this focus group?

Note. PLWHA = persons living with HIV/AIDS.