Chapter 10

Employment as a Social Determinant of Health: An Urban Partnership's Experience with HIV Intervention Development and Implementation Using Community-Based Participatory Research (CBPR)

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In the USA, more than 1.1 million persons are living with HIV/AIDS. Annually, 74 % of new HIV infections occur among men and 63 % of new HIV infections occur among MSM. The rate of new HIV infection among MSM is 44 times that of other men and 40 times that of women. Although MSM represent 2–10 % of the US male population 13 years of age or older (depending on the study and how MSM behavior is defined and measured), they account for 48 % of persons with HIV/AIDS overall, and 64 % of men with HIV/AIDS [1–3]. Compared with the rate of HIV infection among white MSM, the rate is approximately three times higher among Latino/Hispanic MSM and is more than seven times higher among African-American/black MSM. Moreover, since 2001, across all racial/ethnic groups, the only transmission group with significant increases in HIV diagnoses is MSM. Of men with new HIV infections, MSM represent more than 80 % of white men, more than 70 % of Latino/Hispanic men, and more than 60 % of African-American/black men [4, 5].

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The Health and Well-Being of Persons with HIV

The introduction of antiretroviral therapy, which limits the ability of the HIV to replicate itself, has led to profound declines in AIDS-related mortality [6–8]. As persons with HIV live longer, serious non-AIDS-defining illnesses have replaced opportunistic infections as the leading causes of death. These illnesses include cardiovascular disease, diabetes, anxiety, depression, and bipolar disorder [9, 10].

Furthermore, as HIV infection progresses, persons with HIV may experience impairment in three key domains: physical, mental, and neurologic health [11]. Physical health, for example, may be increasingly affected as HIV disease progresses, and persons with HIV can become fatigued, be unable to independently perform activities of daily living (e.g., hygiene, ambulation, meal preparation, and eating), and be less active. The long-term use of antiretroviral therapy also has been linked to body changes that include fat gain concentrated in the abdominal area, peripheral fat loss, and development of metabolic abnormalities (e.g., glucose intolerance, hypercholesterolemia, and hypertriglyceridemia). These bodily changes may induce psychologic distress, increase the risk of cardiovascular disease and diabetes, and impair physical activity [12–15].

Furthermore, CD4+ lymphocyte counts of less than 50 cells/mm^3 of blood are associated with significant functional impairments and increased morbidity and mortality; a normal CD4+ count ranges from 500 to 1,500 cells/mm^3 [16, 17]. Although HIV infection affects the immune system function at any CD4+ count, the risk of opportunistic infections and noninfectious complications of HIV increase as the CD4+ count declines. Current treatment guidelines recommend the initiation of antiretroviral therapy for all persons with HIV, regardless of CD4+, to decrease the risk of disease progression and to reduce the risk of HIV transmission. Disease-specific preventive measures such as prophylaxis of pneumocystis pneumonia when the CD4+ count is less than 200 cells/mm^3 or pneumococcal vaccinations are also indicated to decrease the risk of HIV-associated complications [15, 16].

Among some persons with HIV, mental health can be affected by the strain of living with HIV (e.g., family and/or partner rejection and stigma) and the onset of comorbidities, including mental health disorders and/or substance use or abuse, and may lead to disability and functional impairment. Depression, anxiety, psychologic distress, and posttraumatic stress may also increase as HIV disease progresses. These conditions can reduce the quality of life and increase mortality. Depression has been consistently associated with poor treatment adherence and increased HIV risk behaviors (e.g., substance use and abuse and inconsistent condom use) [18–24]. Posttraumatic stress disorder has been reported in 16–54 % of persons with HIV; this comorbidity is associated with both substance abuse disorder and major depressive disorder and has been correlated with a compromised immune system, lower CD4+ count, poor treatment adherence, and increased HIV risk behaviors [25–30].

Neurologic dysfunction may occur among some persons with HIV as a result of HIV infection and/or opportunistic infections. These impairments may range from mild asymptomatic cognitive impairment to severe dementia, presenting as sensory impairments, and neuropathy. As HIV progresses, persons with HIV may experience decreased mental capacity (e.g., forgetting to eat or take medications), visual impairments, and loss of cranial nerve function (e.g., ability to taste, chew, and swallow). The impact of HIV on neurologic health includes impairment of cognitive abilities to plan tasks, learn and process new information, retrieve information, and manage medication. Neurologic impairment also may include deficits in executive functioning and attention [31, 32].

The term "executive functioning" describes a set of cognitive abilities that are necessary for goal-directed behavior. Executive functioning includes the ability to initiate and stop actions, to monitor and change behavior as needed, and to plan future behavior when faced with novel tasks and situations [33]. Executive function deficits are associated with psychiatric disorders that include depression, anxiety, obsessive-compulsive disorder, attention-deficit disorder, and hyperactivity disorder. Higher levels of executive functioning are significantly correlated with effective coping styles when confronting challenges (e.g., adapting to changing demands and/or environments). Persons with HIV who confront distress by using problem-solving and behavior modification techniques (e.g., problem-focused coping) have been found to have significantly better health and a higher quality of life than those who cope by denial. When persons with HIV face stressful life events, their coping responses have been identified as significant moderators to attenuate the disruptive effect of stressors and to improve self-management [34–36]. Self-management has the potential to positively affect the physical, mental, and neurologic health of persons with HIV.

Self-management Interventions

Among persons with chronic health conditions, self-management has been defined as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic health condition. Efficacious self-management interventions positively affect the cognitive, behavioral, and emotional responses that a person needs to maintain a satisfactory quality of life and increase his or her ability to effectively monitor the chronic condition to maintain optimal health. In a review of 145 peer-reviewed published interventions designed to improve self-management of chronic health conditions, eight common components were identified that align with the three domains of health (physical, mental, and neurologic) affected by HIV (Table 10.1; [37]).

Self-management has been used to improve health outcomes across a variety of chronic conditions, including depression, asthma, arthritis, and diabetes [37, 38], but few studies have applied self-management concepts to management of HIV, including adherence to antiretroviral therapy. This lack of research is particularly unfortunate because HIV-related mortality is contingent largely on the ability of persons with HIV to adhere to treatment regimens [16, 39, 40]. However, among the limited available HIV-related studies harnessing components of self-management, interventions have improved adherence to treatment regimens and increased CD4+ counts, assisting the human body to fight disease, through lowering anxiety and increasing self-esteem, coping skills, and treatment adherence [6, 16, 36, 41–46].

Table 10.1 Components of self-management

Information (e.g., diagnosis, prognosis, and treatment)
Medication management (e.g., strategies to increase adherence, and identifying and reducing barriers to adherence)
Symptom management (e.g., cognition, fatigue, pain, physiology, and relaxation)
Management of psychologic consequences (e.g., anger, depression management, anxiety management, and stress)
Lifestyle (e.g., exercise, nutrition, leisure, and activities of daily living)
Social support (e.g., family, friends, peers, and significant others/partners)
Communication (e.g., with health- care providers)
Other strategies (e.g., executive functioning, goal setting, planning, decision-making, problem solving, and coping)

HIV and the Effects of Employment on Health

The effect of unemployment on health and psychologic well-being has been well documented in the literature [47–50]. Unemployment has been identified as an independent predictor of depression, mortality, and psychiatric symptomology [51–56]. Several longitudinal studies have presented the correlation between unemployment and poor health [50, 57, 58], mental illness [54, 59], increased maladaptive health behaviors [60], lower executive functioning [61], and increased mortality [62, 63].

Among persons with HIV, employment is associated with better mental health and quality of life, suggesting a therapeutic benefit [64]. In a large-scale study of 2,863 persons with HIV, researchers found that those who were employed reported better mental health (e.g., lower anxiety, lower depression, and increased social functioning) and higher physical functioning and were less likely to have difficulties with activities of daily living than those who were not employed [65]. In a similar study, among 702 men with HIV, those who were employed better handled life difficulties, had lower psychologic stress, and better managed their health than those who were unemployed [66]. Moreover, persons with HIV without stable employment, relative to those with stable employment, are at significantly increased risk for psychologic distress, suicidal ideation, psychiatric symptoms, and anxiety and are more than twice as likely to be hospitalized or die [67–71]. Unfortunately, despite the potential health advantages of employment (or perhaps more precisely, “work,”) for persons with HIV, the unemployment rate for this population ranges from 45 to 62 % [59, 72].

HIV and the Effects of Social Support on Health

The psychosocial impact of HIV infection may render persons with HIV susceptible to social isolation and result in a lack of social support. Social support has been defined several ways and measurement remains challenging; however, in general, social support includes emotional, tangible, informational, and companionship support [73–75]. In general, higher mortality has been reported among men who have few close friends or relatives, less frequent contact with people, and reduced participation in social activities [76–79]. Social support may buffer the impact of a variety of stressful life experiences, including those related to illness and unemployment. Among persons with HIV, those with social support have demonstrated less anxiety and depression and had fewer somatic complaints than those without adequate support. Furthermore, social support is important in adjustment to diagnosis and prognosis, and has correlated with slower decline in CD4+ counts, better adherence to treatment, and reduced HIV risk behavior. Moreover, the role of the health-care provider as both informational and emotional support for persons with HIV has been documented in the literature; providers have been identified as being helpful, providing reassurance, validating worth, and preparing for a potential AIDS prognosis [6, 7, 70, 80–86].

The *National HIV/AIDS Strategy*

The effect of employment on the health of persons with HIV has been recognized and addressed by the White House through policy development. In the *National HIV/AIDS Strategy*, for example, the Social Security Administration is designated as the lead agency responsible to assist persons with HIV to access income supports, including job skills and employment. (For a review of domestic US HIV activities for federal departments, see the *Overview of Domestic HIV/AIDS Activities Across Federal Departments* at http://aids.gov/federal-resources/national-hiv-aids-strategy/overview-fed-domestic-hiv-aids-activities.pdf). The *Social Security Administration Operational Plan for Implementing the National HIV/AIDS Strategy* involves three areas: (1) conducting outreach to at-risk communities to educate members of these communities about the assistance of SSA programs; (2) updating policy to ensure more accurate disability determinations and expediting the time for eligible claimants to gain access to health care; and (3) assisting persons currently on disability to return to work through the Ticket-to-Work and Self-Sufficiency Program, Work Incentives Planning and Assistance, and Protection and Advocacy for the Beneficiaries of Social Security initiatives [87]. Ongoing and authentic engagement of and participation by persons with HIV is certainly a strategy that should be utilized, and best processes developed, identified, and implemented within the framework of the *National HIV/AIDS Strategy*.

In 2010, the Institute of Medicine of the National Academies provided recommendations to update the Social Security Administration Listing of Impairment regarding HIV [88]. Recommendations include (1) persons with HIV with CD4+ counts of <50 cells/mm^3 should be allowed disability and be regularly evaluated, (2) specific types of severe or fatal conditions should be considered as permanent disability among persons with HIV, and (3) persons with HIV with severe HIV-associated conditions that limit functioning also should be allowed disability and be regularly evaluated. The recommendations acknowledge that not all persons with HIV are able to enter employment or re-employment.

Our Community-Based Participatory Research (CBPR) Partnership

Our CBPR partnership was initiated in 2002. The clinical director of Whitman Walker Health (WWH) in Washington, DC, and an academic researcher from The George Washington University (GW) began a dialogue to develop a partnership to explore the needs and priorities of persons with HIV. The idea was that if the needs and priorities were authentically explored and thus better understood, action or intervention would be possible, and these possible actions or interventions would be the most promising to positively affect the health and well-being of persons with HIV. We chose CBPR as an approach to our research to ensure community engagement and full participation in all aspects of the research. Although what is described as CBPR in some of the more recent literature tends to lack key values and principles underlying CBPR, our emerging partnership tried, and continues to strive, to adhere to the ways in which CBPR has been conceptualized and practiced by leading community-academic partnerships in the field; our emerging partnership was founded on and integrated accepted values and principles of CBPR that are widely available and published [89–95].

Members of our ongoing partnership were, and in fact remain, committed to establishing structures for full and equal participation by community members, organization representatives, and academic researchers to improve community health and well-being through individual, group, and community action, and through policy and social change. We also emphasize multidirectional and co-learning, reciprocal transfer of expertise, and sharing of decision-making power. To ensure greater cultural congruence and social relevance of our research, members of our partnership, including African-American/black gay men with HIV, have been directly involved throughout the research processes, including the development of research questions, design and conduct of studies, data analysis and interpretation of results, and dissemination of findings.

A hallmark of CBPR is that a community "outsider" (such as a researcher from a university) can work best in partnership with community members [90–93, 96]. However, such authentic partnership takes time and its development must be systematic. Thus, members of our emerging partnership (i.e., community members, organization representatives, and academic researchers) committed the time and effort to develop the partnership. Partnership members from WWH had a profound understanding of service delivery and the facilitation of interventions and programs designed for persons with HIV. They had valuable experiences trying to meet community needs and a sense of what works and what does not work during service delivery and the implementation of programs.

It is important to note that academic researchers always bring with them the reputation of their academic institutions, favorable or not, as perceived by the community and organizational partners. In our studies, the academic researcher brought the reputation of GW, the reputation of the Graduate School of Education and Human Development (GSEHD), and the reputation of GSHED graduate counseling students completing internship placements at WWH. Furthermore, when community members questioned the academic researcher's interest in working with them, he found it useful to share relevant experiences, which included working as an HIV public health educator, facilitating support groups for persons with HIV, providing HIV testing and counseling services, and managing national AIDS clinical drug trials. These clear links to the concerns relevant to community members increased the academic researcher's credibility. Representatives from WWH also highlighted their overlapping interests and shared their perspectives with persons with HIV to reinforce growing trust and initiate acceptance of the academic researcher as a partner. To further develop trust, the academic researcher volunteered as a facilitator for WWH group counseling sessions; this service allowed community members and organization representatives from WWH to interact with the academic researcher in a setting not influenced by a research agenda.

As trust was established, a network of persons with HIV became more involved in our partnership. Today, our partnership consists of members from local HIV communities in Washington, DC, and members from WWH, a nonprofit community health center serving the metropolitan area with expertise in lesbian, gay, bisexual, and transgender (LGBT) health care and HIV health care; the GW GSEHD, with leadership in educational training and research that is committed to assisting culturally diverse communities, including local HIV communities; and the Wake Forest School of Medicine (WFSM), with leadership in CBPR and commitment to identifying and responding to the needs of the community most affected by HIV through rigorous research methodologies while adhering to CBPR core values and principles.

During the ongoing partnership meetings, persons with HIV, organization representatives, and academic researchers continued to share experiences pertaining to the challenges and priorities of persons with HIV and HIV-service providers and brainstormed ideas and next steps, including the development of meaningful interventions to promote the health and well-being of persons with HIV. As is well described in the CBPR literature, building and nurturing trust and maintaining transparent communication were paramount during this process.

After about a year of partnership development and trust building, members of our established CBPR partnership chose to explore the effect of employment on the health of persons with HIV, based on several factors, including medical advances have increased longevity for persons with HIV, and an increasing number of persons with HIV are seeking employment or re-employment. Members of our partnership wanted to blend our knowledge and perspectives based on the experiences of persons with HIV and the lessons learned in the provision of services to them with what is theoretically understood about self-management and scientifically known about the effects of employment on health and well-being for this population. The process that members of our partnership engaged in included two key questions:

- "What do we want to know about employment among persons with HIV?" and
- "Why do we want to know it?"

These types of questions are frequently used in CBPR studies to ensure that the research focuses on moving to action (i.e., some type of intervention or promotion of positive change to improve health) rather than research for research's sake [96–99]. This movement to action reflects another hallmark of CBPR: research should lead to some tangible form of action to improve the health and well-being of communities. In fact, most often CBPR should improve the health and well-being of the immediate community; participants in research should benefit from research [89–94, 96, 100–102].

During the past decade, members of our partnership conducted four participatory research studies based on the priorities of persons with HIV. The studies were funded and further supported by leveraging intramural and extramural resources. For each study, community members, organization representatives, and academic researchers developed the research protocol using a participatory and iterative approach. To facilitate each study and increase validity, members of our partnership also created, reviewed, revised, and approved study designs and data collection protocols. Furthermore, participants were recruited by community members and organization representatives. Much effort was also placed in analyzing and interpreting data through participatory approaches. For example, together community members, organization representatives, and academic researchers conducted content analysis to finalize preliminary findings. We also identified organizations (e.g., US Social Security Administration, SSA, the American Medical Association, the US Department of Education Rehabilitation Services Administration, and AIDS service organizations) to target for the dissemination of study findings. We used a strategic approach and leveraged networks to reach leaders and members of these organizations. Furthermore, dissemination of study findings included presentations and workshops at conferences and meetings sponsored by local, regional, and national societies and associations, including the National Council on Rehabilitation Education, the National Rehabilitation Association, the National Rehabilitation Counseling Association, and the American Public Health Association, and international societies and associations such as the International AIDS Society and the British Psychological Society. We published papers in peer-reviewed journals such as *AIDS Education and Prevention* and *Journal of Rehabilitation*. The participation of persons with HIV, organization representatives, and academic researchers ensured that the processes and products of our research were authentic, meaningful, and insightful and that the dissemination of findings was broad in order to have an impact on both research and practice.

Our CBPR Partnership’s Research History

The four studies our CBPR partnership conducted included an initial study based on our priority to understand the effect of employment on the health and well-being of persons with HIV, two studies that built on the findings of the first study and took us closer to action and intervention, and a fourth study to pilot an intervention.

Employment Beliefs Study

Members of our partnership developed, piloted, and distributed the Employment Interest Survey to persons with HIV receiving services at WWH. The survey was completed by 324 persons with HIV, 204 (63.0%) of whom were unemployed. Regardless of employment status, 287 (88.6%) of the participants reported they wanted help gaining employment or re-employment. Participants identified employment as having positive benefits that they valued, including increased self-esteem, autonomy, social interaction, and quality of life. They also identified groups of persons influencing their decision to become employed (e.g., family, friends, and primary health-care provider) and impediments to employment (e.g., level of job-seeking skills, level of job training, medical instability of HIV prognosis, loss of public assistance, lack of transportation to and from a workplace, and lack of jobs perceived to provide flexible work schedules to accommodate adherence with prescribed medical treatment).

Employment Perspectives Study

In this study, members of our partnership attempted to gain further understanding of the perceived impact of employment among persons with HIV by conducting six focus groups with a total of 54 participants who self-identified as African–American/black and unemployed. Participants reported valuing employment; identified advantages (e.g., increasing one's ability to become self-sufficient, increasing self-esteem, and increasing social interaction) and disadvantages (e.g., exacerbating stress and work environments that stigmatize their HIV status and are not HIV sensitive) associated with employment; identified individuals influencing their decision to become employed (e.g., family and healthcare providers); and delineated facilitators (e.g., job-seeking and job-training skills and job accommodations) and impediments to employment (e.g., HIV discrimination in the workplace, loss of SSA benefits and other public assistance, and side effects of medications) [85].

Windows to Work

Members of our partnership decided that sufficient knowledge had been gained through the first two studies and that it was appropriate to initiate a project that had potential to improve the health and well-being of persons with HIV. The partnership chose to use photovoice, a method of inquiry closely aligned with CBPR, to further the understanding of the impact of employment for persons with HIV.

Photovoice is a qualitative research methodology founded on the principles of critical theory, constructivism, and documentary photography. Basically, critical theory focuses on exploring and intervening upon the social and economic inequalities and promotes system change, and constructivism defines learning through the individual's interactive process of developing and constructing meaning through experiences [41, 86, 103, 104]. The photovoice process involves a series of procedures that include the following [103]:

1. Identification of community topic of interest
2. Participant recruitment

3. Photovoice training
4. Camera distribution and instruction
5. Identification of photo assignments
6. Discussion of photo assignments
7. Data analysis
8. Identification of influential advocates (those who would be allies for change if their consciousness was raised)
9. Presentation of photovoice findings
10. Creation of plans of action for change

Through photovoice, participants photograph issues of concern and participate in group discussions about the photographs taken through empowerment-based facilitated dialogue. The process helps participants from the community to reflect on community needs, priorities, and strengths; engage in critical dialogue; share knowledge; and move toward collective action. The photovoice process typically includes a community forum for participants to share their experiences through their photographs and words. Representatives from community-based organizations and others who are identified by photovoice participants as potential partners (influential advocates) who might support participants after having their consciousness raised are invited to the forum to learn from photovoice participants. By design, influential advocates have some existing power and resources (e.g., job-based or political influence and skills) and may partner with photovoice participants to develop action plans based on needs, priorities, and spheres of influence [41, 86, 103].

Explicit within photovoice is group interaction through which participants are encouraged to discuss their photographs; respond to one another; ask questions; comment on one another's perspectives; and exchange anecdotes, experiences, and ideas. This methodology can identify pertinent variables and nuances that outside researchers may not otherwise be able to foresee and/or identify [86, 103]. Photovoice is well suited as a method within CBPR because it is highly participatory, is a research methodology, and explicitly moves toward action, which, again, is a hallmark of CBPR [86, 103, 105].

A total of 11 men with HIV with a history of full-time work but who were currently unemployed participated in the study. Nine of the participants self-identified as African-American/black and eight self-identified as gay. Participants identified 19 issues important to them when considering employment and grouped these issues into five categories: (1) advantages of employment (e.g., enabling financial responsibility, enabling one to provide for self and others, increasing social skills, and increasing self-esteem); (2) disadvantages of employment (e.g., assimilating into workplaces that are unfriendly to persons with HIV, not being able to adhere to prescribed medical treatment, and losing eligibility for some HIV-related services); (3) referents influencing their employment decisions (e.g., family and health-care providers); (4) facilitators of employment (e.g., motivation, job training, job-seeking skills, work clothing, and transportation to and from the workplace); and (5) impediments to employment (e.g., inability to adhere to prescribed medical treatment, lack of workplace accommodations, loss of Medicare coverage, and lack of HIV education in the workplace). Using their data and interpretations of findings, participants developed an action plan to become employed, which they titled the "Employment Decision-making Model for Persons with HIV/AIDS" (Fig. 10.1). As immediate results of participating in the Windows to Work study, four participants applied for SSA benefits and five explored the viability of the SSA Ticket-to-Work and Self-Sufficiency Program to become employed [106].

The Helping Overcome Problems Effectively (HOPE) Intervention

The process for developing the HOPE intervention was iterative and took several months. For the first few months, members of our partnership held a series of face-to-face meetings to build common understandings. Community representatives presented priorities and perspectives of persons with HIV; organization representatives presented issues affecting persons with HIV receiving services; and academic researchers presented relevant scientific literature and theory. Together, we reviewed the literature; shared the experiences that only community insiders (those living with and most closely affected by HIV) would know; discussed how approaches would be translated into actual intervention components and implementation practice (including activities); and reviewed efficacious interventions for persons with HIV based in health behavior, theory, and self-management. Because theory is intended to explain the processes involved in behavior change, understanding and integrating theory with perspectives on black gay men's experiences were crucial to making informed decisions about the intervention. We established a reciprocal co-learner relationship among community members, organization representatives, and academic researchers to share decision-making responsibilities and support the empowerment of the HIV community's ownership of the entire intervention development and research process.

Members of our partnership also conducted interviews with persons with HIV who were not part of the partnership to further identify strengths, assets, and challenges and to refine and validate partnership ideas for intervention. Partnership members analyzed the interview data. We identified African-American/black gay men with HIV as our priority group, and the results confirmed that employment was a priority among this community. This priority included the impact of employment as a social determinant of health.

We then decided to begin an iterative process to develop a theory-based, group-level intervention to address employment among persons with HIV. Our partnership agreed to base the intervention in social cognitive theory [107], HOPE theory [108], and self-management [37], and locally collected interview data that included the experiences of African-American/black gay men with HIV. To ensure greater cultural, contextual, and educational congruence, partnership members, including African-American/black gay men with HIV, were directly involved throughout development of the intervention and in designing its implementation and evaluation.

Seven unemployed African-American/black gay men with HIV participated in the study. The intervention comprised a 2-hour orientation session, a baseline assessment, seven weekly 3-hour interactive group sessions, and a 3-month postint-

Fig. 10.1 Employment decision-making model for persons with HIV/AIDS

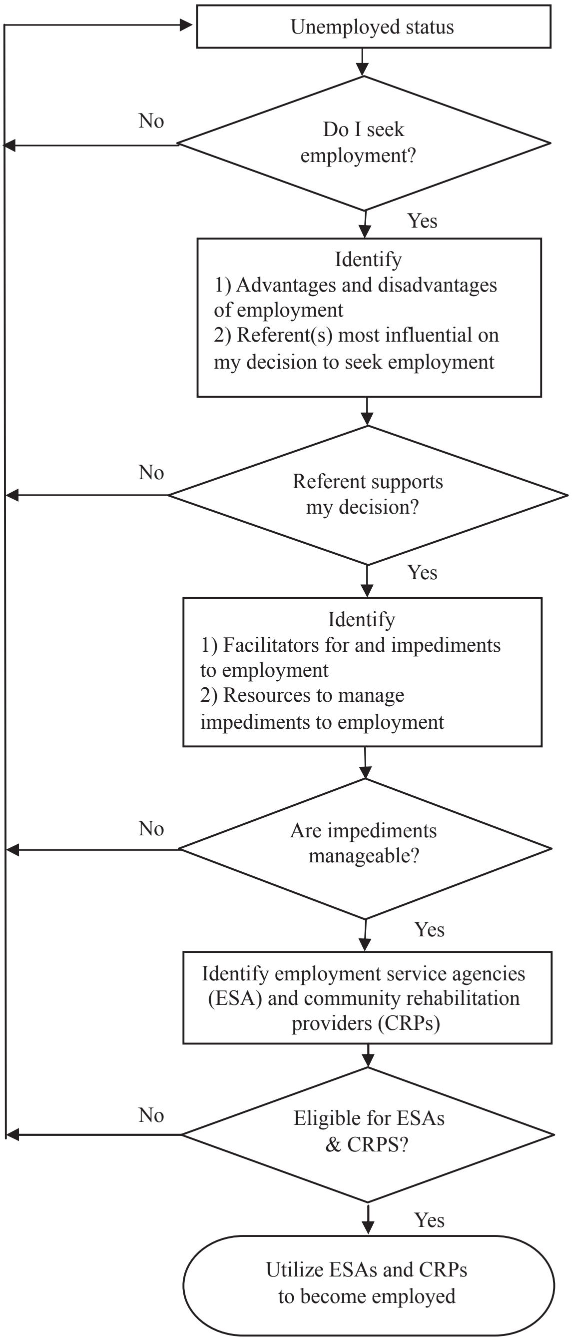

Table 10.2 SPARTAN model

*S*chedule your visit with your health-care provider
*P*lan your questions; log your symptoms on paper and take this with you
*A*sk your questions and present your symptom log to your health-care provider
*R*epeat the health-care provider's responses to each question and use a "check-out" phrase of "Is that right?" or "Did I hear you correctly?"
*T*ake notes and write the health-care provider's response to each question
*A*pply the information to create goals and action plans
*N*avigate through the health-care system with the new information to make informed decisions and better manage your health

ervention assessment with a structured interview. The weekly 3-hour intervention sessions were content specific (e.g., understanding HIV, working with medications, working with health-care providers, HIV tests and treatment, lifestyle management, and employment). Each session included modeling, vicarious learning, and verbal persuasion; exploring physiologic cues; modeling pathway thoughts and agency thoughts (from HOPE theory); and components of self-management. Each session concluded with participant feedback. Participants shared narrative accounts; identified life experiences in which they had successfully created and achieved goals by overcoming barriers; explored potential barriers to goals; and identified supports and resources to overcome barriers and achieve goals.

Members of our partnership also wrote, submitted, and were awarded a pilot grant to implement and evaluate the newly developed intervention. Evaluation of the intervention indicated that among a variety of study findings, participants reported significantly decreased anxiety, depression, and fatigue and increased self-efficacy, treatment adherence, self-esteem, physical activity, and job-seeking skills. Participants also created the SPARTAN model (explained in Table 10.2) to facilitate and enhance communication between persons with HIV and their health-care providers (Table 10.2). Participants reported that the use of the model improved communication with health-care providers and helped them better manage their health care and medical treatment. The results suggest that the HOPE intervention may be promising to enhance health outcomes of persons with HIV.

The successes of our CBPR research studies are attributed to the incorporation of the nine well-recognized principles of CBPR [90, 91, 93, 96, 105, 109]. Within our partnership, for example, we worked with the local HIV community as a unit of identity. Our partnership recognized and built on the strengths, assets, and skills that existed within this community. To address social inequities and share power, we engaged in and facilitated a collaborative and equitable partnership throughout the entire research process. African-American/black gay men with HIV were not merely reduced to intervention targets or recipients of intervention, they were actively involved and engaged in the research process and participated throughout. African-American/black gay men with HIV (as well as other persons with HIV), organization representatives, and academic researchers were involved in study conceptualization, study design and conduct, data analysis and interpretation, and dissemination of findings. All partners shared decision-making power and resources.

We also balanced research and action for the mutual benefit of all partners. As a partnership, we fostered multidirectional and co-learning among members to build capacity. We created transparent processes that embraced clear and open communication. When identifying priorities, we embraced the roles, norms, and processes evolving from the input and agreement of all partners. Building on each partner's strengths and assets, we developed, administered, analyzed, and interpreted study findings, while offering continual feedback among our partnership members. From the CBPR studies conducted, we distributed the findings and knowledge gained to all partners. All partners were involved in the dissemination of findings to community members, research and clinical audiences, and policy makers.

Our four CBPR studies have resulted in a long-term sustainability that has lasted for more than a decade, extending beyond a single research study or funding period, to further explore and intervene on the needs and priorities of persons with HIV in Washington, DC. We also contend that the ongoing work, commitment, and input from all partners have increased the authenticity of the study methods, the trustworthiness of findings, and the development of the most promising interventions possible to meet the needs and priorities while using approaches preferred by communities. Our partnership demonstrates that CBPR is a long-term process, sequentially building on these processes over time.

Community Engagement Lessons Learned

CBPR relies on community engagement and participation to identify community needs and priorities, promote the most accurate understanding of health phenomena, and ensure the development and implementation of meaningful actions or interventions that have the highest potential to improve community health and well-being. Furthermore, CBPR studies are more likely to occur in a culturally, contextually, and educationally congruent manner. Our partnership was able to blend various perspectives and experiences to yield more informed knowledge while building capacity of persons with HIV, organization representatives, and academic researchers. We have learned several lessons to better facilitate our own future CBPR studies and provide insight to other CBPR partnerships.

Time Invested is Substantial

Authentic CBPR partnerships require a substantial investment of time. It takes time to develop trust and build rapport, and over time, the strengths, values, and knowledge of all partners can be better identified, appreciated, and mutually harnessed.

Researchers Must Acknowledge Reflexivity and be Reflective

Often conflated, in this case, reflexivity is a position and reflectivity is a process; reflexivity is the recognition of a researcher being integral and part of what is being observed and integral to what is being studied; the researcher cannot be removed from the research. Reflectivity is the process of reflecting upon one's position as part of the research and one's assumptions and attitudes that influence not only what is known and how it is interpreted but what is occurring. Reflexivity recognizes that researchers affect what is being researched while reflectivity is understanding this impact, interpreting phenomenon in light of this fact. Thus, throughout our CBPR process, the academic researcher, in particular, had to be introspective to be conscious of reflexivity and willing to learn about the nature and essence of local HIV communities. The academic researcher also had to be keenly aware of possible bias toward identifying research questions that aligned with his areas of research that may not align with the priorities of persons with HIV or WWH staff. He had to ensure that his way of conducting research and generating knowledge and understanding did not overshadow other ways that may be more authentic to the community. Academic researchers must acknowledge, and work in a manner that recognizes and appreciates the importance that CBPR assigns to approaches to true community engagement as well as community priorities and community ways of "doing things" and interpreting what is learned.

Power May Not be Balanced

Imbalances of power commonly occur among community members, organization representatives, and academic researchers. When conducting partnership meetings, members did not contribute equally; some members were more vocal than others and tended to lead the decision-making process. We had to establish structures for participation to ensure that those voices that were less "loud" (i.e., less assertive) were heard. We also found it necessary to address groupthink during discussions and decision making [110]. Groupthink occurred when the desire to maintain good relationships became more important that reaching good decisions. During groupthink, input from outside resources may be ignored and decisions may be made without critical analysis. For us, groupthink occurred when there was no real or perceived immutable research timeline and when partners did not apply critical thinking skills.

Furthermore, in some partnerships, when a power differential among members exists because of differences (e.g., language, socioeconomic status, position, title, and level of education), true participation may be reduced to those powerful members who control the communication. Within CBPR, there will always be power differentials; one example is that academic partners often have terminal degrees (e.g., PhDs). Thus, these power differentials are likely to affect group cohesion because those with less power or perceived less power may refrain from authentic engagement and participation and/or those with similar statuses may interact with one another and form alliances, consciously or unconsciously excluding others. Members of our partnership agreed that while the desire to maintain good relationships was important, our "getting along" must not override the importance of reaching good decisions; in fact, we chose to embrace conflict as a form of quality improvement for the good of our research.

Broad Perspectives Should be Included in Review of Study Materials

Members of our partnership agreed that we would work together in teams to develop all study-related materials (e.g., grant applications, protocols, instruments, guides, manuals, and consent forms). Each team required representation from each of the categories of partnership members representing the HIV community, WWH, and GW. After development, all materials would be further validated by members from the broader partnership. At times, members of our partnership also consulted with others in the community (i.e., those who were not members of our partnership) to review materials that we thought needed further insight and/or validation; we recognize that members of our partnership may not always have all the expertise and insights needed as we develop, refine, enhance, and/or adapt materials. We contend that our approach of including diverse voices and perspectives enhanced the quality and content of materials, making them more meaningful and theoretically stronger and improving their scientific soundness. Clearly, materials developed in this manner are more culturally, contextually, and educationally congruent.

Engaging Organization Representatives is Valuable

We found that it was key to engage organization representatives (e.g., case managers and health-care providers) who interact directly with persons with HIV at the site where we recruited study participants. Our partnership met with case managers multiple times prior to each study for their guidance. These case managers did not want to join the partnership but wanted to help, and members of our partnership knew how important they would be to study success. They provided insights on how to more effectively recruit persons with HIV, including which incentives would be effective and where/when (e.g., location, day of week, and time of day) implementation of the intervention should be scheduled to ensure maximum recruitment, participation, and retention of participants.

Next Steps

Based on lessons learned from the pilot test, our partnership is refining the HOPE intervention, and we plan to more rigorously test the intervention among gay men with HIV. We are committed to continuing to involve community members, organization representatives, and academic researchers in all phases of our research to enhance its quality and validity. Currently, members of our partnership are preparing a randomized controlled trial (RCT) to compare mental health and employment outcomes among 50 gay men with HIV, including those in underrepresented ethnic/racial minority populations. Often it is assumed that communities do not want RCTs to be used; however, it has been shown that over time, as communities gain trust and understand how evidence can be used to improve community health and well-being, RCTs are not always out of the question [96].

Community Needs and Priorities Related to Employment

The four research studies conducted by our partnership have identified that persons with HIV have an interest in employment and a strong desire to become employed, and a priority for members of our partnership continues to be the effect of employment on the health and well-being of persons with HIV. More longitudinal studies that explore the effect of employment on the health of this population are clearly warranted.

Across our studies, members of our partnership identified four areas of need for persons with HIV to secure employment. These needs included: (1) education and training about job-seeking skills (e.g., identifying job vacancies, completing applications, creating a resume, and developing interviewing skills) to be competitive in the job market and workplace; (2) treatment adherence interventions; (3) instruction on how to request accommodations while employed, as a person meeting the criteria for disability under the Americans with Disabilities Act (ADA), to ensure that they feel comfortable and are able to adhere to prescribed medical treatment (e.g., requesting leave); and (4) information on the potential loss of public assistance (e.g., Supplemental Security Income, SSI, Social Security Disability Insurance, SSDI, and Temporary Assistance for Needy Families, TANF) while employed.

Concluding Thoughts on CBPR and the Health of Those with HIV

Although our partnership sets a priority on the effect of employment on health and well-being, we recognize that health status may impede employment. Members of our partnership are committed to further research to inform policy at the local and community and national levels to assist those who are able to be employable to have access to available resources and training. As we pursue this, we continue building partnerships to improve health outcomes among persons with HIV and disseminating our research findings to inform policy. We recognize the power of authentic (as opposed to token) engagement and participation of persons with HIV, organization representatives, and academic researchers throughout all phases of the research; working together and blending perspectives, ideas, insights, and experiences will better impact the lives of persons with HIV in our communities and beyond. We contend that our research questions have been more relevant to community needs and priorities and more insightful to action that promotes the health and well-being of persons with HIV. We also contend that CBPR has led to a more developed understanding of health phenomena within this highly vulnerable population and about a social determinant of health (i.e., employment in this population) that has been neglected to date. In fact, just as CBPR has evolved as an approach to reduce health disparities among vulnerable populations, employment is beginning to be recognized as a social determinant of health. Using CBPR as an underlying approach to research has profound potential to improve the lives of persons with HIV. Our partnership is an example of CBPR as a successful approach to community engagement and participation, and we are committed to our continued use of CBPR.

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