

## Chapter 2

# HIV Prevention in a Rural Community: Project GRACE—A Multigenerational Approach to Community Engagement

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Advances in HIV prevention have great potential to reduce the incidence of HIV in USA, but to date, have had a limited impact on the epidemic in the communities most affected by the disease. Effectively preventing HIV within rural, racial/ethnic minority, and other underserved communities requires looking beyond strategies

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that target individual-level risk determinants and considering strategies that target high-risk populations, address structural determinants of HIV risk, and harness social and sexual networks and interpersonal relationships [1, 2]. When considering what works best for a particular community, group, network, or other social unit, it is also important to examine key demographics and other characteristics of group members, as well as the contexts in which they live and work. These considerations represent potential areas for developing and tailoring interventions [3].

In this chapter, we explore the use of a community-based participatory research (CBPR) approach to develop, implement, and evaluate an intervention to prevent HIV in a rural community, highlighting the efforts of the Project GRACE (Growing, Reaching, Advocating for Change and Empowerment) Consortium, a community–academic partnership based in eastern North Carolina. The Project GRACE Consortium draws on the strengths of community, academic, and public partners with the goal of developing a multilevel, multigenerational, culturally specific, feasible, and sustainable prevention intervention to address the disproportionately high rates of HIV among African-American/black communities in two eastern North Carolina counties. This multigenerational approach to HIV prevention acknowledges that many social behaviors are learned by observing others [4] and builds on the strengths of multigenerational relationships and the existing interconnectedness among generations [5].

We begin this chapter by exploring the impact of HIV on the southeastern states and rural communities in North Carolina, particularly in African-American/black communities. We then highlight the unique process used to engage community members in the formation of the Project GRACE Consortium, the subsequent multigenerational intervention known as Teach One Reach One (TORO) that was born out of this Consortium, the lessons learned throughout the process, and recommendations for future research. Lastly, we describe research needs and priorities in terms of prevention and community engagement among African-American/black populations in the southeastern USA, particularly in rural communities.

## **The Impact of HIV on the Southeastern USA and Rural Communities**

The disparate spread of HIV and other sexually transmitted infections (STIs) within African-American/black communities is a crucial problem in the USA. The US Centers for Disease Control and Prevention (CDC) estimates that 1.2 million persons are currently with HIV in the USA. The most severe burden of HIV continues to be in the African-American/black community, compared with all other races and ethnicities. African-Americans/black represented approximately 12–14% of the US population in 2010, but in the same year accounted for an estimated 44% of all new cases of HIV infection. In 2010, the estimated rate of new HIV infections among African-American/black men was six and a half times higher than that for white men, and more than two and a half times higher as that for Hispanic/Latino men and African-American/black

women. In the same year, the estimated rate of new HIV infections among African-American/black women was 15 times that for white women and more than three times that for Hispanic/Latina women [6, 7].

Although often not well recognized outside the region, the HIV epidemic is especially profound in the southeastern USA. The South has the highest rate of new AIDS cases and the highest number of adults and youth living with and dying from AIDS. Although the South accounts for only 37% of the US population, it accounts for more than half of the persons with HIV and 50% of all new HIV infections in the USA. During the past several years, the number of persons with HIV in the South has exceeded those in all other regions of the country. In 2010, eight of the ten states in the country with the highest rates of HIV infection were in the South: Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas. Moreover, African-Americans/blacks in the South are disproportionately affected. Whereas African-Americans/blacks make up 20% of the overall population in the South [8], more than half (56%) of persons with HIV in the South are African-American/black [7, 9].

A large proportion of the southern population lives in rural areas, and most HIV/AIDS cases in the South are concentrated in these areas, with 65% of all AIDS cases in the South being among rural populations [10]. Although some factors associated with HIV transmission, such as inconsistent condom use [11], limited partner selection options [12], poverty [12, 13], and poor access to care [13], can be similar in both rural and urban settings; other factors may be more common in rural settings, such as having an untested sex partner [11], believing that the untested partner is HIV negative [11], lack of HIV-prevention outreach [13], and higher rates of HIV stigma [13]. Additionally, limited recreational opportunities have been shown to be a contributor to HIV transmission in rural settings [14].

In 2009, African-American/black adults and adolescents represented 50% of HIV diagnoses and 49% of reported AIDS diagnoses in rural areas [6, 7]. Researchers and practitioners have identified contextual factors within rural communities that play significant roles in the disparate infection rates among minorities. These community-level challenges include economic hardship, racial/ethnic discrimination, and gender imbalance. However, other factors also contribute to racial disparities in HIV infection and are unique to rural communities, including limited access to health care, lack of perceived and real patient confidentiality in local health care settings, inadequate HIV-prevention outreach, HIV stigma, and community resistance to prevention efforts.

To date, HIV-prevention efforts designed for rural communities have largely targeted persons with HIV. These interventions have primarily focused on linking persons with HIV to care. Some interventions and programs focus on connecting people with HIV with skilled providers [15–18]. Other interventions and programs include medical care providers who provide brief, tailored HIV- and STI-prevention messages during the patient's regular care, educate patients about safer sex practices, screen patients for HIV- and STI-transmission risk behaviors, facilitate reductions in high-risk behaviors, and offer additional prevention services. Few interventions have been implemented in rural communities that focus specifically on the

**Table 2.1** Demographic characteristics of counties of interest with high prevalence of HIV in 2006

County	Total population	African-Americans/ black		Whites		Persons with HIV	
		Total percentage	Percentage living in poverty	Total percentage	Percentage living in poverty	Percentage African-Americans/blacks	Percentage white
Edgecombe <sup>a</sup>	55,606	58	27	40	9	86	11
Nash <sup>a</sup>	87,420	34	23	62	7	82	11
Halifax	57,370	53	34	43	11	85	14
Northampton	22,086	59	29	39	9	89	8
Wilson	73,814	39	30	40	9	90	8

<sup>a</sup> Partnership communities

prevention of HIV- and STI-transmission risk behaviors among those not infected with HIV. To our knowledge, the Hope Project [19], targeting rural men who have sex with men (MSM), the Students Together Against Negative Decisions (STAND) intervention [20], targeting rural youth, and the HoMBReS intervention [18], for immigrant Latino men who are members of rural recreational soccer teams, are the only three behavioral interventions that have been developed specifically within and for rural communities.

## HIV in North Carolina

In North Carolina, the highest numbers of reported HIV/AIDS cases are found in urban/metropolitan counties; however, the counties with the highest incidence of HIV are rural [21]. Furthermore, some of the highest rates of HIV in the state and the most significant HIV and STI disparities are found in the community in which our partnership works, including both Nash and Edgecombe counties. These two counties are located in northeastern North Carolina and are bounded by Halifax, Northampton, and Wilson counties. In Edgecombe and Nash counties, HIV and poverty rates are all disproportionately higher among the African-American/black population than among other racial/ethnic populations (Table 2.1).

In Nash county, 82% of people with HIV/AIDS in 2006 were African-American/black, although only 34% of the county's population was African-American/black; the corresponding percentages for Edgecombe county were 86 and 58% [15, 21]. Furthermore, 23 and 27% of African-Americans/blacks live in poverty in Nash and Edgecombe counties, respectively, compared with 7 and 9% of whites. The bordering counties of Halifax, Northampton, and Wilson are similar to Edgecombe and Nash counties in terms of demographic features and high rates of poverty and HIV [21, 22].

Nationally, the greatest HIV burden among all racial/ethnic groups is found among African-American/black youth, accounting for 55% of reported HIV infections among those ages 13–24-years old. Between 2002 and 2006, 23% of new HIV/AIDS cases in Edgecombe county and 21% in Nash county were reported to occur

in African-Americans/blacks 20–29-years old, whereas the rate of new cases was minimal among whites in the same age-group. Given the latency period from HIV infection to the development of AIDS, most persons with AIDS who are in their 20s likely acquired the infection in their teenage years [15, 23–25].

## **Project GRACE—Growing, Reaching and Advocating for Change and Empowerment**

The CDC defines community engagement as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” [26]. The Project GRACE Consortium was formed in 2005 in response to the concerns of community members about the profound impact of HIV in two neighboring counties: Edgecombe and Nash. Preexisting ties between the community stakeholders in these counties and the academic partners facilitated the development of this partnership. In prior formative work, HIV disparities had been identified as one of the top three major health concerns by both lay community members and representatives of community-based organizations. During the months leading up to the official formation of the Project GRACE Consortium, several stakeholders and community leaders from Nash and Edgecombe counties expressed a desire to begin addressing the HIV epidemic in their counties. In recognition of this health crisis, the decision was made to create a community–academic partnership with the explicit mission of addressing HIV disparities in these two counties [16].

There are many approaches to community engagement. To establish the Project GRACE Consortium, we used the 4-stage approach to partnership development articulated by Florin [15, 27, 28]. These four stages are (1) initial mobilization, (2) establishment of the organizational structure, (3) building capacity for action, and (4) developing an action plan. These initial stages lay the groundwork for action by engaging community partners, broadening the base of community support, identifying the strengths and capacity of community representatives, delineating roles for all partners, ensuring shared decision-making, developing organizational infrastructure, building capacity to support subsequent action steps, and planning for subsequent action and intervention development, implementation, and evaluation [16].

### ***Initial Mobilization***

Communities can be variably defined. In line with the CDC definition of community engagement, we define “community” as a group of people with existing relationships who share a common interest, live in the same geographic area, or share a similar ethnic/cultural background [15]. For the Project GRACE Consortium, we

defined our community as individuals residing in or invested in the health of the African-American/black population in Nash and Edgecombe counties. As we developed the Consortium, we identified and invited a broad range of key stakeholders to participate in an initial planning meeting to ensure that a range of community perspectives were represented. There were 15 attendees at the initial meeting, including individual community members and representatives of local community-based education, health, social service organizations, as well as faith-based organizations. These attendees were encouraged to “spread the word” in the community about the formation of this community–academic partnership and to solicit participation from other organizations, agencies, and community activists [15].

Over time, the partnership grew and members worked collaboratively to solicit federal funding for the effort. In our grant writing efforts, we applied the principles of CBPR to ensure full engagement and participation of all members of the partnership. We developed teams composed of community members and academic investigators, who each provided insight into study design, feasibility, and evaluation plans. These efforts resulted in funding through a grant from the National Center on Minority Health and Health Disparities to UNC-Chapel Hill. After obtaining funding, we used subcontracts to community-based organizations to ensure that financial resources were divided equitably between community and academic partners.

Broad and appropriate representation in the Project GRACE Consortium has been essential to ensuring the acceptability and relevance of the intervention in the community. For example, although some of the organizations in our partnership have a health focus, others have missions that are not explicitly health related. Establishing broad representation requires effort, but our initial partners also recognized that maintaining such broad representation would be more challenging because membership and leadership at organizations tend to change fairly often. To gain and maintain broad representation, a community outreach specialist was hired from the community to work with the university-based project coordinator and representatives of the various subcontracting organizations to develop a matrix of community service providers, local leaders, and influential persons within both counties. The community outreach specialist contacted additional potential Project GRACE Consortium members to describe the project and invite them to attend one of the quarterly Consortium meetings. We created an e-mail Listserv that is still in use and can be accessed by all Project GRACE Consortium members to share information about upcoming community events and professional development activities. We also provide updates about Project GRACE-related activities through a regular newsletter. Consortium members drew on their knowledge of the community and on their professional and social networks to extend invitations to stakeholders that represented a broad range of community perspectives, experiences, and insights [15].

### ***Establishing Organizational Structure***

Although the Project GRACE Consortium engages a broad set of community partners, we recognized that we needed a core set of individuals who would be responsible for rigorous planning, oversight, and coordination of the long-term vision of

the project. We decided to use the governing structure of a highly active Steering Committee that meets monthly. The Steering Committee consists of representatives from all contracting and subcontracting partner organizations and community leaders in each county [15]. The Project GRACE Consortium and Steering Committee provide a system of “checks and balances” on one another’s decisions and activities. In addition, six subcommittees were created to tackle logistical aspects of Project GRACE activities. These six subcommittees are (1) Communications and Publications, (2) Research and Design, (3) Nominating, (4) Bylaws, (5) Events Planning, and (6) Fiscal and Budget. Each subcommittee is chaired by a community stakeholder and may be co-chaired by an academic partner. Subcommittee members represent our broader membership and are expected to report back to the Steering Committee [16]. This organizational structure, while complex, ensures a high degree of community engagement and participation at every level. This structure also builds sustainability, trust, and transparency.

### ***Building Capacity for Action***

The activities that occurred during the initial mobilization and establishment of organizational structure were necessary to ensure the development of strong and trusting relationships among Project GRACE Consortium members (including the Steering Committee). Efforts to build trust and capacity were also facilitated by structured and ongoing trust-building activities.

For example, all Consortium members—both community and academic partners—participated in a 4-day workshop called “Changing Racism and Other ‘Isms’: A Personal Approach to Multiculturalism.” This workshop was conducted by consultants from VISIONS, Inc., an African-American/black, locally owned company based in Rocky Mount, North Carolina, that provides training and support to community-development projects. The workshop highlights, confronts, and challenges oppression of all types at the institutional, cultural, interpersonal, and personal levels.

We chose the “Isms” workshop for two reasons. First, it would help build the capacity of partnership members to recognize and address the various forms of oppression external to our Project GRACE Consortium that could represent a potential influence on the spread of HIV within the community. Second, it would allow us to see how different forms of oppression might operate with and between partnership members, thereby threatening the success of our efforts. This 4-day workshop is required of new project staff and members of the Project GRACE Consortium, to ensure that all involved have a shared vision and similar orientation to our partnership and work.

In addition to the 4-day “Isms” workshop by VISIONS, Inc., Project GRACE Consortium members also participated in an annual retreat to evaluate the CBPR process within the Consortium. Prior to each retreat, consultants from VISIONS, Inc. met with Consortium members to evaluate the extent and ways in which CBPR principles have been adhered to through the use of semi-structured interviews. This periodic process evaluation focuses on (1) community partners’ knowledge of the

project; (2) identified facilitators, barriers, and recommendations; (3) “Isms” and cultural differences; and (4) empowerment. During the retreat, the results of the evaluation are presented and used as a basis for strategic planning. It is at this annual retreat that changes in Consortium activities, procedures, and policies are discussed.

### *Planning for Action*

In preparing to identify HIV-prevention efforts relevant to those living in Nash and Edgecombe counties, members of the Project GRACE Consortium conducted a needs and assets assessment. This assessment was conducted to identify community needs, resources, goals, and objectives to guide the choice of strategies and plans for intervention implementation and evaluation. This process underscores our mission to be facilitators of social change and community empowerment; we do not use a deficits approach to community health promotion and disease prevention.

The assessment consisted of focus groups and key informant interviews. During the spring and summer of 2006, we conducted a total of 11 focus groups with three main populations: community youth 16–24-years old, adults 25–45-years old, and formerly incarcerated adults (any age). These populations were selected because they represent the groups for which the rates of HIV are highest (e.g., youth and formerly incarcerated individuals) and those living with and caring for these individuals. We also conducted 37 key informant interviews in the fall and winter of 2006. The methods have been fully described elsewhere [29, 30]. Briefly, for both the focus groups and the interviews, we recruited through local community-based organizations and the use of flyers, print and radio advertising, and snowball sampling. In keeping with our desire to involve community members throughout the research process, we hired and trained interviewers and note-takers from the local community. These staff were trained by a professional, African-American/black-owned, qualitative research firm to conduct the focus groups and interviews.

In keeping with our CBPR principles, the research design and data interpretation and analysis processes were conducted collaboratively by both community and academic partners who were members of the Research and Design Subcommittee. Subcommittee members developed the guides for the moderators of the focus groups and interviews. After the data were collected, members of the Research and Design Subcommittee were divided into teams to review the data and develop the qualitative data-coding strategy. Here again, teams were always composed of both community and academic representatives, to ensure validity of the findings. To corroborate the validity of the findings, the data were presented at a quarterly Project GRACE Consortium meeting to a broader audience of community members and stakeholders.

From the focus groups and interviews conducted during our needs and assets assessment, a clear and consistent message emerged; simply, HIV-prevention efforts within our local community needed to focus on youth. Participants reported that the individual and social factors at the heart of the local epidemic (e.g., norms regarding sexual initiation and condom use, gender-based power differentials in relationships,

and HIV stigma and its impact on HIV testing and health service utilization) were often learned across generations and therefore preventable or were amenable to change during adolescence. Participants also identified the need to place change in the context of the family and community. In order to reduce the rates of HIV and STIs, members of the Project GRACE Consortium decided that a family-based multigenerational intervention involving youth and their parents or primary caregivers (hereafter referred to as “caregivers”) was needed and should be our priority.

The comprehensive approach to partnership development used by members of the Project GRACE Consortium provided a “collective confidence” that the future interventions we developed would be based on a thorough understanding of the needs of the target population and would build on existing community capacity to ensure sustainability [16]. In the sections that follow, we detail the process by which we integrated our CBPR approach with intervention mapping to develop our intervention [16, 31].

## **The Teach One, Reach One Intervention: A Multigenerational Approach**

After collecting the formative data, we conducted intervention mapping to develop the intervention structure and content. Intervention mapping is a structured process for developing an intervention that is carried out in a series of steps that move from review of relevant literature and data to, ultimately, evaluation of the resulting intervention program [16, 31]. Step 1 involves conducting a needs and assets assessment. The structure and results of our needs and assets assessment were described earlier. Step 2 involves developing intervention goals, and in Step 3, the intervention methods are specified. Lastly, in Step 4, the program components are developed.

### ***Preparation for Intervention Mapping: Co-learning on Applying Health Behavior Theory***

After the formative data were collected, we proceeded with the next steps of intervention mapping with the Steering Committee and lay members of the community. This process consisted of intensive all-day workshops, group conference calls, and in-person meetings involving all partners in each step of the process, during May 2007 through January 2008. Our emphasis on capacity building and co-learning process included ensuring that all partners understood intervention mapping methods and had a working knowledge of health behavior theory. Thus, we conducted a half-day primer for partners that introduced several health behavior theories that could inform our work in effective intervention development. We used written condensed summaries of multiple major theories [16, 32], supplemented with abbreviated didactic sessions and small-group discussion. This format offered

an opportunity for collective discussion about the importance of theoretically driven interventions and the relevance of constructs from different theoretical theories and models. It also allowed opportunities to discuss, answer clarifying questions about, and refine our process [16].

### ***Intervention Mapping Workshop***

Following the primer session to explore health behavior theory, we held an intensive 2-day workshop that initiated Step 2 of the intervention mapping process. The workshop was facilitated by a project staff with previous training and real-world experience using intervention mapping methods and by Steering Committee members who reviewed the formative research findings and facilitated the small-group sessions. During the first half of the first day of the workshop, we reviewed intervention mapping methods and recapped the findings from the formative research. During the second half of the first day, we organized a working group session wherein small groups consisting of both community and academic partners compiled lists of intervention goals to address the high rates of HIV in the local community. On the second day, we developed and refined the initial set of desired behavioral outcomes as well as drafted associated performance objectives required to achieve those outcomes, using a group consensus process [16].

### ***Post-workshop Intervention Mapping Activities***

Small groups of community and academic partners worked on other remaining tasks from Step 2 over the next 4 months. The remaining tasks included (a) refining performance objectives, (b) identifying determinants contributing to health behaviors, and (c) creating intervention matrices. Community and academic partners worked to further refine the proximal behavioral and performance objectives as they defined the behavioral determinants through an iterative process. All intervention matrices were reviewed as they were developed and presented to the larger group of collaborators until consensus on completeness was reached. To uphold the CBPR principles of co-learning and dissemination, early products from our collaborative work were periodically presented to the larger community at Project GRACE Consortium meetings. These presentations provided community members and leaders an opportunity to remain up-to-date on activities and structure to provide feedback [16].

### ***Select Theory-based Methods and Strategies***

Step 3 in the intervention mapping process focuses on matching the intervention methods to the performance objectives identified during Step 2. This task is accomplished by answering the key question: “*How* can we influence people to meet the



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