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Coming Together in the Fight Against HIV: MOMS’ Principles of Effective Community Partnerships

Susan Davies, Angela Williams, Trudi Horton, Cynthia Rodgers, and Katharine E. Stewart

Introduction
HIV is the fourth leading cause of death for women ages 25 to 44, an estimated 70% of whom are mothers (National Center for Health Statistics, 2005). While the science related to HIV continues to make tremendous gains, HIV continues to spread, especially among those most vulnerable, as a result of insufficient resources to expand education, increase awareness, and provide testing and counseling services (Plowden, Fletcher, & Miller, 2005). Stigma has a particularly strong impact on mothers living with HIV, and while this population could benefit immensely from social support, too often they experience rejection and exclusion from their social networks (Ciambrone, 2002). Issues related to stigma and disclosure also prevent many individuals from participating in HIV prevention and treatment programs. Other obstacles include limited public support and overwhelmed service providers due to insufficient resources. In order to make strides in primary and secondary HIV prevention, novel approaches must be developed that earn the trust of at-risk community members and reinforce HIV service providers in their efforts. Such strategies will benefit from the integration of multiple diverse perspectives that generate more creativity and collective expertise. To be conducted effectively, they will also require more shared resources and cross-cutting collaborations.

This article describes a thriving campus-community partnership comprised of the University of Alabama at Birmingham’s (UAB) Department of Health Behavior and seven key community-based organizations and healthcare clinics dedicated to serving individuals who are living with HIV. We share five partnership principles we employed to guide the project’s development, implementation and evaluation. Some of these principles will be familiar to most readers, while others — or the way that we applied them in our community — are quite unique. All of them collectively generated enthusiastic collaboration among partners. Included in the discussion is: 1) how our fundamental goal (to support, empower, and validate our priority population) guided MOMS education and outreach efforts and helped synergize HIV efforts among our partners; 2) how we used several innovative and entertaining strategies to inculcate our community partners with MOMS’ primary messages and aims; and 3) how MOMS used key opportunities to provide reciprocal support to our partners and cultural sensitivity to the community at large.

What is “MOMS”?
Making Our Mothers Stronger
The MOMS (Making Our Mothers Stronger) Project is a randomized, controlled behavioral trial for mothers living with HIV. Women who are over 18 years of age, HIV+, and a primary caregiver of a child between four and twelve years of age are eligible to participate.
The NICHD-funded 5-year project aims to reduce parenting- and health-related stressors and improve social support networks among HIV+ mothers, and ultimately improve the functioning of families affected by HIV. Many HIV+ women experience the challenges of being both a caregiver for their children and a patient themselves. Unlike most secondary prevention trials that aim to reduce HIV transmission and reinfection via sexual risk reduction strategies, MOMS aims to enhance quality of life issues by focusing on the specific needs of mothers and children affected by the HIV epidemic. While the MOMS Project is designed for women across the sociodemographic spectrum, our population closely reflects that of the larger population of persons living with HIV in the U.S: predominantly those of color and of low socioeconomic status. As such, our intervention aims to meet the stress reduction needs of mothers living with HIV and the stresses of stigma, multiple responsibilities, very limited resources and, potentially, discrimination. Through six weekly two-hour sessions, participants come together for small group sessions that focus on reducing stress, increasing coping skills and fostering supportive networks. While the educational and problem solving activities are an important part of the intervention, the peer-based support system provides an equally vital component: a sense of community for this previously isolated population.

Why MOMS Needed Partners

While it can be said that all projects are more effective and relevant with the active involvement of the affected population, MOMS had unique barriers to participation that made partnership and community buy-in essential. The sensitive nature of the topic and the need to ensure confidentiality of patients’ HIV status presented a hurdle to recruitment efforts: clinicians and service providers were unable to put us in direct contact with our priority population. Thus, we had to rely solely on them, our community partners, for referrals of potential participants meeting MOMS inclusion criteria. The following is a discussion of the principles and strategies we used to conduct a needed community-based program that could be adapted for use in other settings and populations to strengthen partner alliances and interactions.

Five Principles of Partnership that Contributed to MOMS’ Success

Principle #1: Demonstrate that you value your partners’ expertise and input.
We seized opportunities to interact and collaborate with seven core HIV organizations as our community partners: three HIV/AIDS community agencies (Birmingham AIDS Outreach, AIDS in Minorities, AIDS Alabama); three healthcare clinics (1917 Clinic at UAB, Family Clinic at Children’s Hospital, St. George’s Clinic at Cooper Green Hospital); and the statewide HIV coalition (HIV Prevention Network). We demonstrated how much we valued each by involving them from the start and seeking their expertise in key program aspects. Since its inception, MOMS sought and garnered the support and endorsement of our partner agencies. Having worked with many of these partners before on HIV-related projects, we integrated their experiences and perspectives into the MOMS Project proposal. Upon receipt
of funding, we looked to them for input on all aspects of the project, from program promotion and participant enrollment to intervention content and evaluation strategies. We created a Community Leadership Advisory Board, composed of three partner staff members and three community health advocates. This Board provided ongoing guidance to the MOMS investigative team throughout the project period. From the front lines of patient care and case management, these individuals were an invaluable asset, making suggestions that often turned out to be crucial (e.g., for confidentiality reasons, do not invite children to project informational meetings and do not put “HIV” on any recruitment flyers). Their input ensured that our intervention was responsive to the social and cultural characteristics of the participants, enabling us to more effectively engage mothers living with HIV into care. These project advisors reviewed all MOMS session materials, and even participated in mock intervention sessions, providing a friendly audience as well as invaluable feedback as our health educators were getting up to speed on intervention delivery.

Principle #2: Connect with partners by uniting around a central theme. For us, that meant coming together in the fight against HIV. While working ardently on meeting the needs of HIV+ persons in our community, the MOMS Project raised provider awareness with regard to the unique needs of mothers living with HIV. As mothers with HIV are living longer, this underserved population needs support at various levels for coping with the multiple challenges their circumstances can bring. Increasing commitment to the fight is the recognition that living with HIV can negatively impact the mother’s children (via manifestations of maternal depression resulting from social isolation, multiple role strain and concern over children's future well-being). As in many other communities, our HIV-focused clinics and community based organizations are largely overextended and understaffed. MOMS enables providers to increase the diversity of their service offerings by offering a needed program not currently available anywhere else. Further, the MOMS Project brought together a large, diverse group of service providers that prior to that had minimal interaction and even less collaboration together. Prior to the MOMS Project, few collaborative efforts existed in the community to address the rising incidence of HIV and its inherent problems. MOMS provided a needed bridge for learning about other partner activities, sharing resources and information, and reinvigorating individuals and groups working in the area of HIV/AIDS.

Principle #3: Create novel opportunities for positive partner interactions. Recognizing that healthcare and community-based staff members have multiple concurrent obligations, we looked for innovative, time-efficient ways to strengthen the project’s alliance with these important partners. As we prepared to launch our recruitment efforts, we tried to come up with something a little different to make the MOMS Project stand out in our partners’ minds. Our partners are still talking about this very “outside the box” event.

“As mothers with HIV are living longer, this underserved population needs support at various levels for coping with the multiple challenges their circumstances can bring.
the MOMS Project début to community participants, and provide a motivating activity to help increase retention of key MOMS messages, (e.g., eligibility criteria, intervention aims, participation requirements). Partner staff members were asked to perform a talent that illustrated the messages of the MOMS Project. Talent included impersonations (e.g., Diana Ross and the Supremes with “Ain’t No Mountain High Enough to Keep Me from MOMS”), humorous skits from well-known commercials, musical performances and poignant poetry that embodied MOMS themes. Having the event on April 1st (April Fool’s Day) from 5 to 7 pm with great food and beverages (provided by corporate sponsorship) added to our ability to pull off an entertaining, inimitable evening. Each partner’s CEO/Director served as a judge for the partner talent show. For the closing act, the MOMS team led attendees up to the stage to join in the finale chorus of “We Are the World.” This event generated tremendous enthusiasm and a huge turnout. It was the first event to capture the participation and support of all the core HIV clinics/organizations. As Medical Director of UAB’s 1917 Clinic (and Director of the UAB Center for AIDS Research) Dr. Michael Saag stated, “I think this is the first time when all of us have been in the same room at the same time, and, it’s about time!” Following the event, videotaped copies were presented to each POP along with movie treats at a prearranged special showing at each partner site. The MOMS team has used this video at subsequent recruitment and outreach activities. We attribute this event’s enormous success to our ability to use and build on the positive relationships previously established with our partners. Without this dynamic, we imagine it would have been much more difficult to convince these individuals to risk looking foolish in front of so many others. After first ensuring personal commitment to participate from each agency director, we engaged staff at each agency to help us identify an individual willing to serve as their agency’s “MOMS and POPS” coordinator. This person was charged with the task of generating collective support and enthusiasm, scouting for potential talent acts, and obtaining personal commitment from fellow staff. The MOMS team provided them with everything they needed, from ideas to props to pep talks, while also helping to foster a little competitive spirit among the agencies.

The encore second annual event, “MOMS and POPS II” (again held on April 1st) called on partners’ strategies, not singing skills, to highlight MOMS themes. Knowing that we could never replicate the famous inaugural MOMS and POPS, and appreciating our community partners’ time and schedule constraints, we sought to retain the entertaining, team-building qualities of MOMS and POPS while minimizing our partners’ preparation time. Partner teams competed in variations of two popular games: MOMSpardy (modified version of Jeopardy) and MOMSboo (modified version of Taboo). This event proved to be fun, entertaining and undemanding for attendees. Stormy weather coupled with the event being held on a Friday night (to keep it on April Fool’s Day) hindered attendance. We surmise that another crucial element was different from the previous year that may have reduced turnout: by merely having to show up at the event to participate in game show activities (rather than having to prepare an act and perform in front of your peers), we may have inadvertently reduced commitment and appeal for the event. After all, how often do opportunities come along for overextended service providers to join coworkers in planning a performance using skills rarely conducive to the work environment?
Principle #4: Find or create opportunities to reciprocate support for your partners in their efforts.

Community workers can be potent change agents, yet their multiple roles and responsibilities often undercut their efforts. In addition to the physical toll, significant emotional investment is inherent in their jobs. Such dedication and overload can severely affect health and well-being. MOMS has always placed high priority on supporting our community partners’ efforts in various arenas. In showing appreciation and reverence for our partners, we offered both emotional and instrumental support, by providing stress reduction talks and wellness workshops at partner staff meetings and retreats, as well as tangible aid and resources via health fairs, health care summits, meetings and other initiatives. While participating in a partner’s series of health fairs at housing projects, the MOMS team recognized that many attendees were more interested in giveaways than health related information. A new opportunity presented itself: MOMS started offering free hand massages, a win-win activity that allowed us to relieve the stress of attendees, provide them with a “free gift,” and also give our team members time to talk to the attendees about the MOMS Project during the massage. This personal connection with so many of our community members elucidated to us one of the MOMS Project’s fundamental tenets: “People don’t care what you know until they know that you care”. Perhaps the biggest indicator of a healthy partnership is when one faces a crisis situation and knows they can ask for and count on support and assistance from their partners. When budget cuts threatened to reduce AIDS funding and services, our three potentially affected community agency partners called on us, and we argued before the City Council on their behalf urging local officials to maintain current funding levels for these vital community service organizations.

Perhaps the biggest indicator of a healthy partnership is when one faces a crisis situation and knows they can ask for and count on support and assistance from their partners.

Fundamental to the practice of reciprocity is healthy, ongoing communication. MOMS kept support channels open and mutual enthusiasm heightened through steady communication with partners. These efforts took various forms: we met monthly with partner representatives at HIV Prevention Network meetings, hosted several Network meetings, attended “Lunch and Learn” events and weekly Pre-Clinic meetings, presented project information at staff meetings, attended fundraising events hosted by partner organizations, communicated with partners about potential funding opportunities, and sought partner input and referrals on issues affecting MOMS participants that were outside the scope of our services (e.g., housing, shelter, clothing, furniture, food, Christmas boxes, children’s camp opportunities, etc.) We also provided ongoing support and encouragement via special occasion cards, candy baskets, homemade cakes and other small but appreciated acts of kindness.

Principle #5: Join forces with partners to create education and advocacy activities that raise awareness in the larger community.

In efforts to reduce HIV-related stigma and increase awareness of HIV’s enormous impact on women, MOMS spearheaded a community event, “Faith, Facts, and Fashion” for World AIDS Day 2004. The focus was centered on Women and Girls and based on the United Nations theme, Have You Heard Me Today? The theme highlights how gender inequality...
fuels the world AIDS epidemic. As World AIDS Day is an effort to extend life, the county’s HIV Prevention Network planning committee — led by Angela Williams (MOMS Health Educator, Community Health Advisor and coauthor of this paper) — diverted from the gloom and doom message that is frequently bundled with AIDS awareness efforts to craft an event that celebrated the lives of women and girls. The primary challenge in planning this event was determining how to effectively engage the faith-based community. Ms. Williams used her expertise as a Community Health Advisor and active participation in faith-based organizations to develop a format that would appeal to a diverse group of participants. “Faith, Facts and Fashion” celebrated World AIDS Day with a fashion show showcasing the beauty and solidarity of Women Leading Change in faith-based organizations and the community. One hundred women, representing diverse community members, change agents, college faculty, staff, and students and consumers, used the stage to provide facts about HIV.

Women in RED (faith leaders and/or their wives) brought high fashion to the runway, modeling red apparel representing the HIV/AIDS Red Ribbon. The women in BLACK (clinicians, researchers, consumers, community advocates) donned black apparel and communicated an HIV/AIDS-related fact to the audience (e.g., FACT: In the U.S., 58% of new HIV/AIDS cases among 13-19 years are girls; FACT: Women are more likely to become infected with HIV during intercourse then men. Male-to-female transmission is estimated to be eight times more likely than female-to-male). One of the key factors in the success of this event was the process of multiple agencies with somewhat diverse missions and target populations truly joining forces to host an event that was situated IN the community and designed to appeal to a wide variety of individuals FROM the community. Each organization or agency contributed at least one resource to the successful completion of planning and implementing this event (e.g., one agency took the lead in acquiring sponsors for the food and beverages; one agency took the lead in acquiring resources to cover the costs of printing programs). This event highlighted the significant impact that can be made on individuals in the community (who may not typically receive education and information from an individual agency) when multiple agencies work together proactively to develop an event designed to reach individuals from a variety of religious backgrounds, neighborhoods, professions, and affiliations.

Conclusion: Working Hand in Hand with our Community
Each MOMS event and activity strengthened the relational dynamics with our POPS. In addition, each partner gained a clearer understanding of how together we can offer a full circle of services to mothers who are living with HIV. The MOMS Project demonstrates the synergistic effects of working together, including increased connections of patients to services, improved social and professional networks, enhanced communication practices and strengthened collective problem solving. Most important, in an area so plagued with overload-related staff burnout, MOMS generated renewed commitments among HIV clinicians and service providers to continue the fight against HIV.
HIV is a tremendous public health problem and a significant threat to our communities. Reducing HIV disparity among women of color and/or economic disadvantage is dependent on much more than designing appropriate interventions; it will require concerted collective efforts among numerous community entities to ensure that those most in need (who are therefore also most reluctant to risk participating) are connected to services and feel safe in accessing them. Healthcare practitioners and community-based staff play a key role in the success of large-scale HIV intervention studies. Using creativity, commitment and reciprocity, MOMS gained the support and collaboration of seven HIV community service providers to develop and implement a unique, culturally appropriate community-based program. The MOMS model illustrates how strengthening campus-community partner relationships can lead to the successful development and implementation of a highly-tailored program for a hard to reach, underserved population.

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