

PROSPER! An Intervention for HIV+ African American women

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PROSPER! Staff

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Main Findings

- DEBI projects should be adapted and enhanced to make them more responsive to the needs of African American women.
- Using a women-centered and women-focused approach builds empowerment and facilitates behavior change.
- Women who complete the PROSPER! intervention report increases in risk reduction behaviors.

The Women's Collective (TWC) is implementing PROSPER!--an innovative intervention designed to provide prevention case management (PCM) in conjunction with group level interventions (GLI) to help African American women living with HIV/AIDS prevent or delay adverse health outcomes. PROSPER! targets both newly diagnosed HIV+ African American women ages 18 and up and those who have been out of a system of care. The goal of the project is to enhance the quality of life of African American women living with HIV/AIDS in the District of Columbia by providing multi-tiered, integrated health care options and support services. The project was funded through the GENERATIONS: Strengthening Women and Families Affected by HIV/AIDS initiative with support from Johnson & Johnson and the National AIDS Fund in collaboration with the Washington AIDS Partnership.

Background

The District of Columbia's population is largely made up of people of color: African Americans account for 57% of the population, Hispanics 9% and Whites 30%. Black women make up 60% of the female population. In 2004, almost 78% of all new AIDS cases in the District were among African Americans. For women in the District in 2004, the AIDS incidence rate increased to 113.3 per 100,000, compared with the national rate for women of 9.5 per 100,000. There are currently 3,342 women living with AIDS in the District, of whom 90% are African American.

The work of TWC began in 1993 and grew out of the life experience of our founder/executive director, Patricia Nalls, a woman living with HIV/AIDS. She used her personal experiences to create TWC, a community-based organization run by and for women living with and at risk for HIV/AIDS in the Washington, DC area. TWC provides a broad range of services through its HIV Care Management and HIV Prevention pro-

grams, which include: family-centered case management services; early intervention services; peer outreach; comprehensive risk counseling services; counseling, testing and referral services; prevention with positives; peer-based support groups; and emergency assistance, among others.

Why this project?

PROSPER! addresses complex issues such as sexual abuse, self-perception, domestic violence and economic status. We also take into consideration various health concerns that affect Black women in greater proportion than other women, such as high blood pressure, heart disease, diabetes and other illnesses unrelated to HIV/AIDS. We utilize a variety of approaches to ensure PROSPER! is woman-focused, family-centered and peer-based. TWC provides services for women through a comprehensive family-centered program that promotes the participation and empowerment of women, reducing risk based on their self-defined needs.

African American women living with HIV/AIDS have unique psychosocial, cultural, legal and financial issues. The Centers for Disease Control and Prevention (CDC) has created the Diffusion of Effective Behavioral Interventions (DEBI) project to bring science-based HIV prevention interventions to service providers. We wanted to use the scientifically proven DEBI project Healthy Relationships (HR) for HIV+ women, but knew that the intervention needed to be adapted to address the needs of African American women. We adapted the HR intervention and is in the process of evaluating the effectiveness of our adaptation, PROSPER!. TWC also recognized the importance of providing PCM that would further support women in their risk reduction and behavior change efforts during the program.

Intervention

PROSPER! utilizes the DEBI intervention Healthy Relationships as its core intervention. Healthy Relationships is a five-session, small-group intervention for men and women living with HIV/AIDS. It is based on Social Cognitive Theory and focuses on developing skills and building self-efficacy and positive expectations about new behaviors through modeling behaviors and practicing new skills. TWC added five group sessions specifically designed to meet the prevention needs of African American women that focus on: gender and ethnic pride, self healing, empowerment, treatment adherence, mother-to-child transmission, biological markers, family coping and co-infections. These sessions support women





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as a whole and are intended to improve their overall physical and mental health.

TWC provides Metro/bus tokens to attend all interventions, offers snacks/meals for all office visits, and provides incentives and child care on-site during GLI activities. We offer counseling, testing and referral services (CTRS) for partner(s) and family members. PROSPER! is provided within the context of all TWC services--meaning that participants have access to mental health therapy, peer counseling, support groups, skills building groups and complementary therapies, among our many other services.

Each participant enrolled in PROSPER! receives a total of seven individual PCM sessions and ten GLI sessions.

Prevention Case Management (PCM)

Initially, TWC conceived of PCM consisting of a series five sessions for each woman. However, after review of PCM records and outcomes and considering the intensive needs of women, the program is now working with women to complete seven sessions of PCM. The rationale for this change is our strong desire to ensure women are getting substantive support for their risk reduction and prevention efforts, in addition to reinforcing information learned in PCM sessions over time. Issues that are brought up at the group level can be addressed more fully in PCM sessions to further support women and enhance their efforts.

Referrals are an important aspect of the program. There are three types of referrals that PROSPER! utilizes in PCM in order to ensure women are getting additional support: referrals to group sessions, STD screening and mental health therapies.

Group Level Intervention (GLI)

Sessions 1-5 are from Healthy Relationships. Sessions 6-10 are TWC's added sessions.

- Session 1 Stress Factors and Communicating Effectively
- Session 2 Triggers and Barriers
- Session 3 Disclosure to Partners
- Session 4 Safer Sex/Risk Reduction
- Session 5 Condom Skills/Problem Solving
- Session 6 Gender and Ethnic Pride

- Session 7 Co-Infections
- Session 8 Adherence
- Session 9 OB/GYN issues, Mother-to-Child Transmission
- Session 10 Empowerment

The groups are structured so that ten sessions are held for five consecutive weeks with two sessions each week. The weekly groups are held at Cada-Vez, a local restaurant located next door to TWC. The restaurant is totally reserved by TWC at the time of the groups for complete privacy and to ensure the confidentiality of women. Women receive personalized service weekly by the same server in an atmosphere that is plush and full of beautiful floral arrangements. Women are greeted by soft music when they walk in the restaurant. Tables are adorned with chocolates and rose petals to add to the ambiance. Women report feeling special weekly as they receive support from their sisters on how to have healthy relationships and take care of themselves.

Two physicians present to the group. One presents on mother-to-child transmission and OB/GYN issues. The other covers co-infections, re-infection and adherence to medical regimens including medical appointments. These sessions are co-facilitated by Patricia Nalls, founder and executive director of TWC. We also create questions for women to ask their physicians when they attended the doctor. We use this session to teach women how to advocate for themselves and demand good healthcare. The participants ask questions of physicians and other health care professionals they would not ask in the physician's office before they were empowered to do so.

At the end of each GLI session every woman receives a beautifully wrapped gift which camouflages the contents, which includes condoms, dental dams and lubricants. It also includes products from stores such as Victoria's Secret, Bath and Body Works, and items such as decorative plates, CDs, journals, inspirational books and other products that they look forward to receiving weekly.

At the end of the ten sessions, participants receive a cash incentive for the completion of the group series and their individual PCM sessions. TWC found that distributing this incentive upon completion of the program was an extra bonus for the women and assisted with retention of women through the life of the program. It is important to note that many of the women reported that the incentive was not their primary reason for participating.

Empowerment

PROSPER! has been very successful in empowering women who complete the program. There is clearly little that can compare to the empowerment the women receive when they are among their peers receiving support. The feelings of isolation and hopelessness are shattered as they learn

of their sisters' struggles and victories over the very thing they thought was impossible to overcome. They share in each others pain, fear, grief, and joy. They create a bond of sisterhood that has lasted far beyond the 10 weeks. See the Case Study to the right.

As an example, the first group at TWC to complete the curriculum decided they did not want to stop meeting. They chose a leader among themselves to organize and coordinate their bi-weekly activities which included going to movies and museums, and holding support groups meetings called "Prospering." The Prospering group meets bi-weekly to support women's efforts towards maintaining healthier lifestyles. All groups are co-facilitated by a peer, which greatly supports women in their commitment to behavior change. Women have maintained the bond of sisterhood created in their PROSPER! group and have supported each other in obtaining GEDs, with relationship issues, and by accompanying each other to court and doctors visits.

Staff

The program is spearheaded by the PROSPER! program coordinator who is responsible for implementation, monitoring and assessment of the program. The coordinator conducts PCM sessions, documents program progress, maintains program infrastructure and coordinates and monitors program implementation and evaluation. The GLI sessions are co-facilitated by the clinical supervisor and the PROSPER! program associate. The program associate, supervised by the coordinator, coordinates PCM and GLI sessions, facilitates GLI sessions, documents women's participation, collects data, conducts data entry and conducts other programmatic activities. She ensures quality program delivery. The founder/executive director, accountant and development director work behind the scenes to ensure appropriate accountability with program implementation, monitoring, accounting, and record keeping.

Evaluation

Prevention Case Management

Each PROSPER! participant is required to complete a pre- and post-risk assessment form to measure their risk and knowledge about HIV/AIDS upon entering the PCM program and at the end of the program. During PCM sessions, PROSPER! staff use a number of forms to track and document the participants' progress, but the risk assessment is the main tool used expressly for PCM evaluation purposes. The program coordinator reads the pre-risk assessment questions and women responded orally.

TWC staff decided to revise the risk assessment that evaluates the knowledge, attitudes, behaviors, and beliefs of the participants before they begin PCM sessions and after they complete the sessions. We found the length of the risk assessment to be excessive and we are now working to reduce the number of questions without losing the information needed to document outcomes. The PROSPER! staff developed their own session tracking log system for tracking each referral given during PCM.

Group Level Intervention

Group sessions are evaluated using pre- and post-test measures. The HR training has its own evaluation tools that assess participants' knowledge and behaviors at the start of the Session 1 and at the completion of Session 5. The TWC five week curriculum also uses evaluations at the beginning of Session 6 and at the end of Session 10.

During the previous two GLIs, pre- and post-evaluations were done before and after each TWC curriculum component. For example: a pre-test was done before the Session 6: Gender/Ethnic Pride, and a post-test was done immediately after the session. TWC staff decided to eliminate evaluations for each session and instead conduct one pre-test before the five sessions begin and conduct a post-test after all five of the sessions are over. This step will help reduce the burden of paperwork for both the staff and participants and generate better evaluation results.

Selected Key Findings

As of February 2006, we have completed the PROSPER! intervention with two different groups of women. We have:

- Enrolled 46 women in PCM and conducted 300 individual PCM sessions;
- Enrolled 31 women in GLI and completed 2 series with 10 group sessions each; and

Demographics

The majority of women (98%) who have participated to date are African American; the remaining 2% are Latinas. The majority of the women (56%) are in their mid-40's. Approximately 78% of the women receive public health insurance. The women report an average income of \$579.00/month. More than 90% make under \$15,000/year and 18% report no income. Sixty-one percent of the women report having a middle school or high school education. Of the remaining women, there are 15% who report either having some college education, or receiving an associates degree. More than 50% are not married and 50% have a contact person listed who is a family member, which indicates disclosure in the family. The majority are heterosexuals.

Case Study: Ms C

Ms. C is single with no dependents in her late 30's. She described herself as someone who enjoyed life, traveled to different islands, worked for the government and owned her own home.

Ms. C was diagnosed with AIDS in 2003. At the time of this diagnosis she was diagnosed with cryptococcosis infection, PCP pneumonia, pancreatitis, encephalitis, and multiple medication reactions.

When she first walked through our doors that day in May she was very weak. She could hardly see; she walked with the aid of a walker. She lived at home with her parents because she was too weak to take care of herself. Her mother brought her to TWC where she was referred to Mental Health Services and to PROSPER!.

Ms. C reports that the first PROSPER! group changed her life. She never thought she would be one of "those women" who she now saw as saving her life. As she sat in the room and listened to the stories of triumph and victory from the other women, she felt like she "got a piece of her life back." She felt hope for the first time. The women rallied around her with unconditional love and support. They exchanged numbers and really loved her and empathized with her new diagnosis.

At each new appointment the staff could see a visible change in Ms.C. Week after week we saw the benefits of the support and education she was now receiving. The first time she came in without her walker, she walked slowly and held on to the walls for support. She now walks on her own and has gained weight, confidence and lots of education regarding HIV. She is considering dating and would love to resume living on her own.

While all of the participants in the program are HIV+, they are at risk for transmission and co-infections. Two-thirds of the participants did not know a lot about HIV/AIDS upon entry to the program, and two-thirds of those who responded did not know how to prevent co-infections from substance use.

Data are still in the analysis stage by the independent evaluator, Mosaica, the Center for Nonprofit Development and Pluralism in Washington, DC. Mosaica and TWC will be issuing comprehensive qualitative data on the PROSPER! program in year two.

Lessons Learned

The main lesson learned from PROSPER! is the importance of knowing your population and being amenable to change once the implementation process starts.

If It Doesn't Work, Fix It

PROSPER! has learned to assess challenges and make changes when needed to improve our program. Examples include:

Number of PCM sessions: Initially women were enrolled in five PCM sessions. However, it proved difficult to address myriad issues and ensure behavior change with five sessions. Women are now enrolled in seven PCM sessions that make the PCM experience more substantive.

Reorganizing GLI Sessions: For the first two PROSPER! groups, GLI sessions occurred once a week over a ten-week period. However it was difficult to retain participants. With group three, we scheduled the GLI sessions twice a week over five weeks. Women now have more enthusiasm and retention is high.

Challenges in scheduling appointments and reaching women: It was a challenge getting some women to attend PCM appointments. The barriers included, but were not limited to: bad weather, changes of address, changes of phone number, disconnected phone numbers; not returning or answering calls. For clients who are without telephone service, we mail weekly, handwritten notes to inform them of the need to contact the office.

Capturing GLI information: It was often challenging for facilitators to capture all of the insightful issues discussed on paper and still stay engaged in the group process. Initially, one person facilitated and another person recorded notes in the first series. We now use a tape recorder so both facilitators can be active in the group process while capturing more complete details of the sessions.

Low literacy rates: After assessing evaluation tools, we discovered that many questions assumed to be simple, were difficult for the women to understand and interpret. We revised forms for

lower literacy levels and staff now read evaluation forms out loud for GLI and PCM sessions.

Strengths of the PROSPER! Program

- **Programming for women by women-** TWC prides itself on being sensitive to the needs of women and plans programs based on what women have said they will benefit from or need. Women living with HIV/AIDS are involved in the planning and execution of the program.
- **Nurturing staff-** Women in the program are always met by compassionate women on staff who support them at all levels of the program.
- **Women-friendly incentives-** TWC purchases items that are nurturing and make women feel special, such as bath and body products, inspirational books and CDs. The incentives were also wrapped in beautifully colored gift wrap.
- **Non-judgmental environment-** TWC's curriculum is women-friendly and not judgmental when dealing with disclosure. A holistic curriculum should include material that is also empowering and gender-focused.
- **Personalized follow up-** When someone is out sick or absent from the group she gets a friendly call along with a personalized hand written note on colored paper with expressions of compassionate concern.
- **Expert presenters in the field-** Deliver important and timely information and help women increase their comfort around doctors and other professionals.
- **Private dining in quaint setting-** Providing nutritious meals is important as women are on limited budgets that don't often enable healthy eating habits. In addition, a restaurant setting makes the women feel special and nurtured.
- **Transportation and childcare-** Women reported that they often do not attend programs due to lack of transportation or child care. Both are provided to women to ensure participation.
- **Experienced facilitators-** Groups are co-facilitated by experienced staff that possess knowledge of group dynamics, women's issues and HIV/AIDS. Staff also can identify potential crises that may arise from group discussions that may trigger trauma and provide the appropriate referrals to in-house mental health therapies program and other crisis interventions as needed.
- **Ready resources and referrals-** PROSPER! benefits from having all of TWC's resources available to women when they needed them.

For more information on TWC and PROSPER! please contact:

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