

Support Group Forums as a Creative Intervention to Maintain Optimal Health

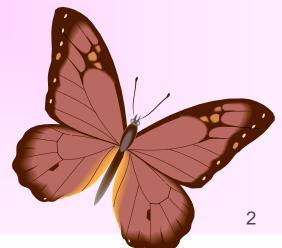
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Finding the Right Resource to Help Manage the Disease is Important!

- The Women's Supportive Services program (WSS) is a program of the Community Healthcare Network (CHN) which empowers women and their families to remain emotionally, physically and spiritually strong. In partnership with the AIDS Institute, the WSS program has served as a beacon of hope for HIV positive women for the past 20 years, many of whom are undocumented immigrants.
- WSS is one piece of an integrated service delivery model which is holistic, integrated, and comprehensive. The staff in this program partner with HIV experts at CHN, as well as other medical providers to offer medical, treatment adherence, dental, nutrition, podiatry and mental health services.
- Throughout the service delivery process, women are offered a broad range of support options, some of which includes the following:
 - Crisis Support/Long Term Counseling
 - Advocacy: to obtain health insurance, financial benefits, legal services, etc.
 - Escort Services
 - Support Group Services
 - Assistance with Medical Care Coordination
 - Emergency Financial Assistance
 - Psycho-Educational Workshops
 - HIV/AIDS Education
 - Transportation Assistance
 - Consumer Advisory Boards



HIV/AIDS Infection Rates Amongst Women in NYC: A Snapshot

- The impact of the HIV epidemic on women has increased dramatically, both in the United States and in New York City.
- According to the most recent Center for Disease Control (CDC) statistics, women currently account for 20% of new HIV infections (and 24% of those living with HIV).
- New York City has one of the highest HIV infection rates in the country and is home to a large number of HIV positive immigrants



HIV/AIDS Infection Rates Amongst Women in NYC: A Snapshot (Cont.)

- As of 12/31/11, studies have shown that there are 32,398 women living with HIV/AIDS in NYC.
 - 58.3% are African American
 - 32.5% are Hispanic
 - 7.6% are Caucasian
 - 1.6% Other
- HIV and AIDS affects Black and Latina women at much higher rates than other population groups. More than half of all women in the United States living with HIV/AIDS are African American. Eighty-two percent of women with AIDS are Black or Latina.
- According to current research, most of these women were infected through unprotected sex with men, often times with their primary partners.

Positive Coping: HIV is an Everyday Commitment

- Seeking appropriate care is very important, yet very difficult for some women, often times because of the following:
 - Fear of rejection from family, friends, and the community in general.
 - Women are considered to be the "gatekeepers" of the family, and often times tend to put the wellbeing of other people before their own health and wellbeing.
- Appropriate care includes access to the following:
 - Medical care
 - ➤ HIV medication
 - > Nutrition
 - ➤ Mental health

HIV Disease is Not Only a Medical Issue, it 's a Psychosocial One as Well

- *HIV/AIDS* affects the whole person: physically, emotionally and spiritually. Living with an HIV diagnosis can be very difficult, and for some people, the emotional aspects of HIV are as difficult as the physical aspects.
- *HIV/AIDS* is a chronic illness that forces women and their families to cope with an uncertain progression of the disease, medication regimens, the grief related to the loss of health, etc.

HIV Disease is Not Only a Medical Issue, it's a Psychosocial One as Well (Cont.)

- Unlike other chronic illnesses, HIV/AIDS is much more complicated because of the misperceptions that people have related to the mode of transmission (sexual activity and intravenous drug use)
- For women with HIV, issues of isolation, trust, and empowerment continues to be central. As a result, they can experience numerous emotional issues.

Women with HIV/AIDS Often Deal with Numerous Emotional Issues

- *Fear* and *shame* can prevent women from confiding in others and gaining much needed emotional support.
- Loss HIV has been called the disease of many losses. For example:
 - Loss of stable health
 - Loss of financial freedom
 - Loss of relationships (partner, spouse, family, friends, etc.)
 - Loss of weight/ appetite
 - Loss of physical attractiveness
 - Loss of social roles
 - Loss of future goals, etc.

Women with HIV/AIDS Often Deal with Numerous Emotional Issues (Cont.)

- Many women with HIV/AIDS often experience depression which can reveal itself via:
 - Sleep disturbances
 - > Appetite change s
 - Withdrawal from all activities
 - ➤ Failure to find pleasure in favorite activities
 - ▶ Fatigue
 - Difficulty concentrating, etc.
- If depression is unresolved or untreated, it can lead to self destructive behaviors such as substance abuse, attempted suicide, etc.
- Several studies confirm that the significance of depression and low self-esteem can directly affect the clients' compliance with medical services.

Living Beyond HIV: Social Support Theory

- Psychosocial interventions such as support groups have proven to play an important role in enhancing the quality of life for patients suffering from medical illnesses. In a support group, participants are able to **share their personal life journey**, their thoughts, feelings and experiences.
- A notable study concluded that positive social support **promotes psychological adjustment** in medical conditions with chronic high stress related to HIV stigma.

Living Beyond HIV: Social Support Theory (Cont.)

- Social Support Theory indicates that social support can serve to protect individuals from the negative effects of stressors, such as stigma and discrimination.
- Social supports serve to **protect** individuals against the negative effects of stressors by helping them to interpret stressful situations less negatively.

Living Beyond HIV: Common Functions of Social Support

Emotional Support- The provision of empathy, affection, trust, intimacy, encouragement or caring. Emotional support lets the individual know that they are valued.

- **Tangible Support** The provision of financial assistance, material goods, or services.
- **Informational Support** The provision of advice, guidance, suggestions or useful information to someone.

<u>Companionship Support</u>- The type of support that gives someone a sense of social belonging. The value of this type of support can be seen in the relationship between companions who engage in shared social activities.

Living Beyond HIV: The Value of Support Group Services

- Support groups can help **break the cycle** of emotional despair that can lead to isolation, depression and other behaviors that can often times cause health to decline. Groups have the potential to impact on an individual's positive adjustment to the illness and ultimately the course of the disease.
 - > Provides a forum for others who have HIV to share their similar experiences, reduces the anxiety of facing the illness alone and normalizes the disease-related feelings and experiences.
 - > Provides a major source of inspiration by hearing first-hand how other participants have learned to cope in similar situations.

Living Beyond HIV: The Value of Support Group Services

Several studies show that HIV positive individuals who participate in support group forums often:

- Obtain invaluable information about "hard-to-find" resources, new HIV treatments, proper nutrition, and different approaches to medical care
- *Improve their relationship with the medical provider*
- *Have better treatment adherence outcomes*
- Decrease high-risk behaviors for re-exposure to HIV
- Increase knowledge regarding their rights about living with HIV/AIDS
- Are better prepared to address the issues of disclosure with family members or significant others

Living Beyond HIV: The Value of Support Group Services (Cont.)

- Increase their social network develop relationships with others who they can rely upon to provide emotional support during difficult times. This is especially important for immigrant women.
- ✤ Utilize healthier, less avoidant, coping strategies
- * Experience less emotional distress, higher self-esteem, and less loneliness
- Increase problem solving skill development
- Improve personal development (increase assertiveness, conflict management skills, etc.)
- ✤ Gain an increased sense of empowerment and control over their lives
- ✤ Gain confidence to develop new goals for their lives

Barriers to Participation in a Support Group

- *Recent studies indicate some of the following barriers which impact support group participation:*
 - Concerns about privacy
 - ➢ Fear of speaking in a group
 - Transportation issues
 - ➤ Stigma and discrimination
- In response to some of these barriers, the WSS program does the following:
 - Conducts weekly telephone tag activities to provide reminders about the support group forums and to address identified barriers.
 - Provides transportation assistance and escort services, as needed to ensure maximum participation.

4 Stages in the Process of Change for HIV + Women



Stage 1: The Burdened Self

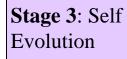


Characterized by emerging concerns faced by women after receiving an HIV positive diagnosis Moving beyond feeling overwhelmed by burden and begin developing and employing strategies to improve quality of life

Stage 2: Turning

Point





Accept consequences of past actions and understand that there are consequences associated with positive and negative behavior. Note - CM and supportive services are most effective in this stage.



Stage 4: New Possibilities

Women accept that there are conditions associated with continued progressbeing willing to establish supportive relations, disclose status, and serve as a role model.

- The program recruits culturally competent staff who are passionate and committed to the team-work approach.
 > "You can't fake it 'til you make it."
- Foster a warm, inviting and confidential **meeting space**. This includes a strategic seating plan, nutritional refreshments, decorative tableware, holiday decorations, etc.
- The staff work hard to ensure retention and participation in support groups by:
 - > Utilizing the talent and skills of all team members.
 - ➤ Using the "positive relationships" that staff build with the participants

- Offer the participants **24 hour access** to staff to address crisis situations.
- Build upon the participant's **individual strengths** and encourage them to be an active part of the healing process for themselves and others.
- Provide client **incentives** based on collaborations with other organizations who are able to provide non-restrictive funds for gift cards and other basic essentials.
- Offer supportive counseling services after support group sessions based on individual client needs.
- Offer educational workshops to the participants on the same day that the support groups are held.

- Some women prefer to leave the neighborhood for **confidentiality** reasons. Therefore, we offer support group services to women who reside in the New York City area.
- **Partner with healthcare providers** to obtain referrals and also to encourage regular participation.
- The program is located in a health center which offers a "one-stop shopping service model":
 - comprehensive medical services
 - social work services
 - nutritional services
 - treatment adherence services
 - health education services
 - *podiatry services*
 - dental services, etc.

- The program acknowledges the importance of birthdays, major holidays and various cultural celebrations. For people with chronic illnesses, these celebrations are important.
- Conduct continuous **fundraising** activities to solicit meaningful donations to offer socialization activities and to provide some basic necessities.
- Use creative and **innovative approaches** to educate the participants about various daily-life issues. For example, domestic violence, safe sex, family life, relationships, etc.

- Continuously stress the importance of self care.
- Offer consumer **advisory board** meeting forums to ensure that participants have a voice in the service delivery model.
- Offer two different types of weekly support group forums: women's only and co-ed.

Positive Outcomes From WSS Support Group Participation

- Women who regularly attend our support group forums are more likely to:
 - attend required primary and specialty care appointments
 - have an increased understanding and self awareness about the role that they play in achieving positive health outcomes
 - have improved doctor/ patient relationships
 - practice healthy coping mechanisms when feeling depressed
 - have an increased sense of self esteem and self worth



Testimonials

- "I feel like a part of this place and I look forward to coming here."
- "It's not easy to survive in NYC, but I get support from this program. WSS is my family."
- "People here meet you where you are at and they work with you."
- "I don't like to be alone, because it makes me sad. Since I started to come to support group, I feel much better. I love the girls, they are like family to me."
- "I can truly say that I am very grateful for this program. WSS has helped me whenever I am in need of support ranging from emotional to financial...Thank God for WSS."
- "The program is very satisfying. The staff are very resourceful and have helped me obtain many services that I otherwise would have never been able to obtain on my own."



Testimonials (Cont.)

"The socialization is great. I can be open and I'm free to let it all out."

"I feel that I get good information and I like being with women who have the same experience."

"I get to laugh and have fun in group. I'm always looking forwarding to what we do next in the group ... I feel supported and wonderful. It gives me strength to help and share with others."

"Initially I came to the program for medical care, and I thought that I could handle the disease alone. But I found out that I needed the support. I have felt great ever since."

"Group helps me realize that I don't have to do it alone. I know that when I don't show up, I'm missed by the other women."

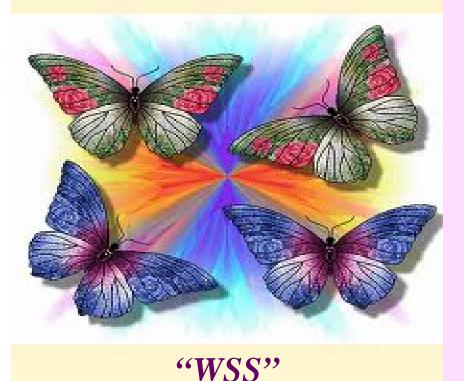
"I feel like I am meeting with my family. I can discuss what's bothering me. It helps get me going."

"I enjoy coming for healing. I was weak before, and I didn't know who to turn to... I love it!"



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Women's Supportive Services Program



Life lessons from a Butterfly!

Let go of the past... Trust the future... Embrace change... Come out of the cocoon... Unfurl your wings... Dare to get off the ground... Ride the breezes... Savor the flowers... Put on your brightest colors... Let your beauty show...

Author Unknown

"If Nothing Ever Changed, There Would Be No Butterflies"



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THANK YOU!!

