An Empowerment Intervention for Women Living with HIV and Its Adaptation for Women with a Diagnosis of Breast Cancer

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Because of improved therapeutic strategies, both human immunodeficiency virus (HIV) infection and breast cancer can be considered life-threatening illnesses that eventually become a chronic condition. Both diagnoses carry a psychological impact, stigma, body alterations, intense medical evaluations, and therapies. Both conditions are prevalent among minorities, especially women of Hispanic heritage. This article describes an empowerment intervention originally designed for women living with HIV and adapted for women with a diagnosis of breast cancer. We will describe the conceptual framework for the intervention and the rationale for the chosen groups. The Women's Empowerment Intervention Model consists of a series of six full-day workshops in which multiple biopsychosocial dimensions are explored within the group, and diverse experiential activities are carried out related to the day's topics. The workshops were modified to deal with the specific issues that women confront when diagnosed with breast cancer. This model was chosen precisely because it deals with specific aspects of healing and living with a chronic illness. We propose that HIV should be viewed as a chronic condition and compared to other conditions that affect women's lives in similar ways. (*Ethn Dis*. 2005;15 [suppl 5]:S5-128–S5-132)

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Introduction

Women are one of the fastest growing risk groups with HIV/AIDS in the United States and constitute approximately half of the AIDS cases in the world. According to the latest statistics of the Joint United Nations Program on HIV/AIDS (UNAIDS), 39.4 million adults in the world are living with HIV/AIDS. Among those, 44.6% of them are women, and most are of reproductive age. A total of 2.2 million children under 15 years of age are living with HIV/AIDS, and half of those are girls. Heterosexual transmission is the most common risk factor for HIV infection among women in the United States and the world.[1] HIV transforms a woman's life by increasing the burden of care on her immediate and extended family, as well as on herself. AIDS mortality has been dramatically reduced in countries where antiretroviral therapy is available. One of the success stories of the availability of antiretrovirals is the dramatic reduction in mother-to-child transmission (MTCT) that guides current recommendations,[2] and has been accomplished in industrialized and developing countries.[3] With improved treatment availability in many countries, the issue of adherence becomes more relevant each day. Concerns about lack of adherence and its determinants among minority populations are serious and merit scientific study to gain knowledge of these issues, especially among women.

Empowerment and Adherence in Women Living with HIV

Our current project is examining the role of personal empowerment from a woman's perspective and its effect on adherence to highly active antiretroviral therapy (HAART) and clinic visits. We are also evaluating the role and effect of the empowerment intervention on the biological outcomes of adherence, ie, on viral suppression and disease progression (or lack thereof). The issues that surround HIV care, adherence, and viral load for women are unique and require more assertiveness from consumers.

Breast Cancer Seen as a Life Threatening Condition that Becomes Chronic

According to the American Cancer Society, an estimated 211,240 new cases of breast cancer will be diagnosed in the United States in 2005. An estimated 81% of women with breast cancer survive the condition. Between 1990 and 2000, the number of women who died of breast cancer dropped 2% each year. Slightly more than two million women living in the United States have been diagnosed with and treated for breast cancer. Survival rates are classified by the stage at which the breast cancer diagnosis was made. The average survival rates for each stages are as follows: stage I, 92%; stage II, 71%; stage III, 39%; and stage IV, 11%.[4] To the extent that breast cancer treatment improves quality of life and survival, the condition could be considered a chronic illness, and interventions must be designed with this in mind.

Breast Cancer Interventions

The landmark prospective study done by Spiegel et al[5] found an

association between a psychosocial intervention and survival in 86 women with metastatic breast cancer. The one-year intervention consisted of weekly support group therapy with self-hypnosis for pain. At the 10-year follow up, three of the patients were alive. Survival from time of randomization and onset of intervention was a mean 36.6 months in the intervention group compared with 18.9 months in the control group, a significant difference. Many variables were assessed, and the only variable to affect survival time significantly was the psychosocial intervention. This was the first time that a behavioral intervention was proven to prolong survival in women with breast cancer. Greer et al studied 69 women with breast cancer and found significant differences between short-term (five years) and long-term (10 years) survivors; the former were described as hopeless, helpless and stoic, as compared to the latter that coped with their disease by denial or had a ''fighting spirit.''[6] Again, coping styles and emotional factors (hopelessness, helplessness) were related to long-term survival. Ippoliti et al studied psychological behavior and immune function in a convenience sample of 38 women with stages I and II breast cancer and a matched control group.[7] The women with breast cancer showed diminished immune function, impaired interpersonal communication, unsatisfactory sexual activity, and increased depressive symptoms at a significant level ($P<.01$). The study by Spiegel supports the development of specific interventions targeting the psychological variables associated with improved quality of life and survival.[8] If human behavior can be changed, survival changes can be improved. A randomized study comparing standard care ($n=15$), weekly support group sessions ($n=16$), and imagery ($n=16$) was carried out by Richardson et al.[9] For all women, interferon gamma increased, quality of life improved, and natural-killer cell activity remained unchanged. Compared with standard care, both interventions improved coping skills (seeking support) and perceived social support and tended to enhance meaning of life. When comparing imagery with support, imagery participants tended to have less stress, increased vigor, and improved functional and social quality of life.

Breast Cancer Interventions for Hispanic Women: Current Gaps

Most studies in breast cancer interventions have been carried out in White women. The few programs that have focused on Hispanic women are related to epidemiologic characteristics, knowledge and attitudes about breast cancer, breast cancer screening behavior, and access to services. Hubbel et al reported that Latinas more often preferred not to know if they had breast cancer, were afraid to tell their husbands if they had breast cancer as it would affect their relationship, and believed that compared with women of other ethnic groups they were very likely to get breast cancer.[10,11] They were three times as likely as White women to believe that they needed a mammogram only when they had a breast lump. One of the possible explanations for the higher breast cancer mortality among Hispanic women might be a late presentation for diagnosis. This finding might be related to personal fear of the screening procedures, reduced access to screening services, or both. The same cultural reasons for not accessing screening services might affect adherence to breast cancer treatments and might hinder active personal involvement in their own disease process and healing. Our intervention is one of the few specific empowerment programs designed and implemented among Hispanic (in this case Puerto Rican) women.

METHODS: THE WOMEN'S EMPOWERMENT MODEL

We define empowerment as a process of awareness throughout which women recognize their capacity to achieve individual and social changes. This process involves a mental and spiritual awareness that enables them to gain greater control of the physical, psychological, and social dimensions of the healing process. Our model incorporates the basic principles of the Biopsychosocial Model developed by George L. Engel.[12] The Biopsychosocial Model proposes to engage the patient's participation in further clinical and laboratory studies and to elicit the patient's cooperation in activities aimed to alleviate distress and/or correct underlying derangements that may be contributing to distress or disability. The Women's Empowerment Model[13] is also based on Freire's empowerment pedagogy,[14] Bandura's self-efficacy theory,[15] and Branden's principles of awareness process.[16] Freire's empowerment pedagogy suggests that the educational process involves an open dialogue between educators and participants that is an interactive rather than a didactic exchange of information. To Freire, the purpose of education should be human liberation, which means that people are subjects of their own learning.[17] The learning process is in both directions, and from this interaction both the educator and the participant develop skills for behavioral change. Bandura states that to achieve self-directed change, people need to be given not only reasons to alter their behavior but also the means, resources, and social support to do so. Success requires not only skills but also a strong self-belief in one's efficacy to exercise personal control. Self-efficacy refers to a person's assessment of his or her ability to perform certain actions. Perceived self-efficacy influences the probability that a person will engage in a particular behavior, the amount of effort he or she will devote to this behavior, and the length of time he or she will continue to perform this behavior.[18] An individual will change his or her beliefs about his or her own self-efficacy when they have achieved mastery of a task by effectively performing it. An

increased sense of self-efficacy leads to behavioral change, which in turn results in improved outcomes.[19] Branden defined the awareness process as the art of "living consciously." "Living consciously is a state of being mentally active, rather than passive. It is the ability to look at the world through fresh eyes. Living consciously is seeking to be aware of everything that bears on our interest, actions, values, purposes, and goals. It is the willingness to confront facts, pleasant or unpleasant. It is the desire to discover our mistakes and correct them."[16]

Our model incorporates a third aspect: awareness, which is the awareness or increased consciousness that the meaning and purpose of one's on life, which facilitates the permanency of the changes. This aspect also integrates the intervention into a biopsychosocial model for health care. Since the intervention relates to life changes that affect the participant's health, it has to be consonant with the clinical approach. Our concept of health is based in the assumption that a healthy human being has a balanced mind-body-spirit connection. Illness is interpreted as an imbalance in the relationship of mind-body-spirit that is expressed or first noticed in the body. In order to facilitate bodily healing, the mind and spirit also need to be attended to. Studies on the effect of different mood states on immune function, susceptibility to illness, and death support the need to incorporate all three aspects into our model. This characteristic makes it unique, in addition to the fact that it was developed for women and is therefore gender-specific.

WOMEN'S EMPOWERMENT INTERVENTION WORKSHOPS (BRIEF DESCRIPTION)

The Women's Empowerment Intervention Model consists of a series of six full-day workshops in which multiple biopsychosocial dimensions are explored within the group, and diverse experiential activities are carried out related to the day's topics. The need for a safe space and confidentiality is assured during the process. All participants agree to keep personal information disclosed during the sessions confidential.

The women are paid for their participation in the workshops, and childcare is not provided on site. Children are not allowed during the sessions so that women are forced to focus on themselves. The intervention aims to facilitate self-care and provide a space for women to consider themselves as human beings, not just as mothers. All sessions begin with a meditation/visualization experience and end with a bonding exercise. We will describe the workshops in detail first as they apply to women living with HIV followed by the modifications and adaptations for women with a diagnosis of breast cancer.

Workshop 1 (Mind-Body-Spirit and Health)

Workshop 1 begins with loving-kindness visualization in which the person reviews her life from the present to childhood. A group discussion of the diverse experiences and the their meaning follows this segment. This point is when feelings of anger are expressed about the means of acquiring HIV (usually from a sexual partner). A discussion on mind-body-spirit issues with specifics on managing emotions and the effect of emotions on health and the immune system ensues. A theater exercise is carried out during the afternoon[20] in which the participants are divided into smaller groups and an experience of disclosure is shared. Each group presents a play in which a disclosure scene is portrayed, and each participant plays one of the characters in the story. A group discussion follows the plays, and the workshop ends with a bonding activity.

Breast cancer patients go through the same meditation and life-theater exercises as HIV patients. Like the HIV patients they focus on the emotional effect of their diagnosis and on disclosure issues.

Workshop 2 (Healing Through Forgiveness)

Workshop 2 begins with a different meditation/visualization exercise in which the colors of the rainbow represent different emotions and states of awareness. This exercise provides participants with an opportunity to bring unresolved issues about their illness to the surface. The initial visualization exercise enables participants to concentrate on the group discussion that follows. During this workshop, we address the importance of adherence to HIV treatments, and different strategies are shared. The relationship between thoughts and health is explored, as well as the healing power of forgiveness. Forgiveness is described as a process (not an event) that is personal and internal. Among the most common issues that participants identify as needing forgiveness are acquiring HIV from a partner and childhood experiences and feelings of abandonment.

During the breast cancer workshops, we discuss the impact of life experiences and stressors and deal with forgiveness as a healing strategy. Misconceptions about breast cancer treatment are also discussed.

Workshop 3 (HIV and Breast Cancer 101 and Advanced)

This workshop is completely dedicated to HIV, the immune system, the symptoms and signs, the laboratory measurements, and the medical interventions available. No question is considered "dumb," and any topic can be addressed, from transmission to viral dynamics, resistance, pregnancy, and misperceptions about treatments. Side effects and alternatives for overcoming them are also discussed. By this time,

participants feel comfortable within the group, and HIV issues can be discussed freely. Adherence is approached as a survival skill. All sessions begin with a meditation/visualization exercise and end with a bonding/sharing exercise.

At the breast cancer workshops, we present current information about breast cancer epidemiology, risk factors, diagnostic strategies, definition by staging, survival, treatment options, chemotherapy, tumor markers, and follow-up. For those on long-term medications, adherence issues, self love, and survival skills are discussed.

Workshop 4 (As Life Goes On ...)

During this workshop self image, self esteem, beauty, and body changes as a consequence of therapy are dealt with. For women, the concepts and perceptions of beauty are important. Not only is disease progression related to physical changes (weight loss, skin changes, etc), but also the newer, more potent HAART therapies have side effects such as fat redistribution and skin thinning. The concepts of self-love, self-care, and finding our true personal beauty are dealt with during this workshop. A makeup artist provides technical expertise in an entertaining, fun, and instructional way. During the afternoon, sexuality is explored, and specific demonstrations on safer sexual practices with actual products are carried out. Female and male condoms, lubricants, dental dams, and other sexual paraphernalia are demonstrated by a volunteer from a community-based organization with expertise in safer sexual practices. The participants also carry out a life theater in which alternative strategies and arguments for sexual negotiation are presented.

For the breast cancer participants, the discussions are focused on self-image, self-love, sexuality, sexual practices after the diagnosis, prosthesis, reconstructive surgery, and related issues.

Workshop 5 (Ready for Changes)

A visualization/meditation exercise that focuses on our readiness for change is carried out. The focus of this session is on lifestyles and health, as well as complementary therapies. It includes a discussion and demonstration about nutrition as it relates to HIV and/or its medications. An exercise session that includes relaxation, stretching, low-impact aerobic exercises, and upper and lower body strengthening exercises is carried out. A qualified exercise trainer is in charge of this session. The benefits of exercise on the immune system, emotions, and self-esteem are discussed. In the afternoon, complementary therapies are introduced such as reiki (hand healing), acupuncture, yoga, and others.

The breast cancer workshops concentrate on specific changes for healthier lifestyles including nutrition, exercise, and relaxation. The exercise session includes specific instructions on how to approach the swelling secondary to axillary lymph node dissection. In addition, strengthening exercises are conducted according to the participant's age and health status. Cancer prevention through improved nutrition is discussed as well as the relationship of several relaxation techniques to stress levels, immune function, and survival.

Workshop 6 (Self-Help Groups)

The last workshop is used to discuss the concept of self-help. The difference between support and self-help groups is also explained, and participants are encouraged to continue their connection through self-help groups within their communities.

DISCUSSION

As women encounter either life-threatening illnesses or chronic health conditions, they need to develop specific skills and make life changes to improve not only survival but also quality of life. Although interventions have been developed for women facing either HIV or breast cancer, most of the published literature has focused on White or African-American women. We are addressing health disparities by developing interventions for Puerto Rican women living with HIV and with a diagnosis of breast cancer.

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