



## SYMPOSIUM: SUPPORT GROUPS FOR WOMEN WITH BREAST CANCER: TRADITIONAL AND ALTERNATIVE EXPRESSIVE APPROACHES

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### Introduction

Dance therapists and other arts therapists have traditionally been trained in mental health settings. However, funds for mental health are drying up, and the whole field of mental health is becoming influenced by managed care and economic concerns. The field of physical health and illness is a growing new area of work in which arts therapists can be extremely beneficial. It has been repeatedly shown that between 50 and 75% of the presenting symptoms brought to primary physicians are either amplified or caused by psychological factors (Wickramasera, 1998). Dance therapists, working holistically with mind, body and spirit, are uniquely positioned to work with illnesses that become manifest in body, mind and spirit.

The last 5 years have seen an enormous surge of interest in integrated healthcare, especially since the Eisenberg study revealed that 1 out of 3 Americans were using alternative and complementary medicine. Since that time, not only has this figure increased, but alternative and complementary medicine is proving to be cost-effective and to increase customer satisfaction. Insurance companies are increasingly covering alternative medicine, and hospitals are competing to start complementary medicine centers.

Support groups are springing up in outpatient clinics, and recent research shows that these groups can

improve coping, mood, and even length of life (Spiegel, Bloom, Kraemer, & Gottheil, 1989). Yet, these support groups remain primarily verbal. Newer research is just beginning to show the effects of alternative and complementary support groups, such as yoga and qigong, on the healing process (Sancier, 1996).

Breast cancer is an assault on a woman's body and on her entire being. Because it represents mental, physical, emotional and spiritual issues, it can be especially amenable to the treatment effects of dance/movement therapy. This article covers the results of a symposium presented at the American Psychological Association in San Francisco, 1998. The symposium consisted of representatives from four related support groups, two of which used expressive art forms. The groups all used an existentially based support group format, but two specifically integrated dance/movement therapy, art and story-telling into this format. Phenomenological and empirical data will be used to demonstrate the effects of these existential-humanistic approaches.

Dr. Classen discusses the first approach, supportive-expressive group psychotherapy. Because it is from this therapeutic framework that the remaining three approaches are derived, the aim of this section is simply to describe the treatment model. This model, developed at the Psychosocial Treatment Laboratory

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at Stanford University School of Medicine, is described in terms of the therapeutic process and goals, the role of the therapist and the basic existential issues raised. Supportive-expressive group therapy is existentially based and aims to help patients live their lives more fully in the face of a life-threatening illness. Participants are helped to express their deepest concerns and feelings, many of which are existential in nature. Supportive interactions are nurtured both within and outside the group and active coping strategies are encouraged. The focus of the therapy includes mourning the losses that cancer brings, adjusting to a changed self and body image, coping with the effects of the illness on relationships, working through fears of dying and death and creating meaning from the experience.

In the second approach, Dr. Serlin transforms the therapeutic model by incorporating movement and arts. Thus, her existentially-based expressive-supportive group format also uses movement, relaxation, arts and imagery to work with issues of fear, body image, mood, and spirituality. This group is not just verbal, but is multimodal. Although recent research documents the effects of psychosocial support groups on women with breast cancer, very few studies have yet examined the effects of physical exercise and imagery in a holistic integrative model on the psycho-social-spiritual effects of women with breast cancer. This study therefore evaluated the effects of movement on healing in women with breast cancer. This research at California Pacific Medical Center's Institute of Health and Healing in San Francisco uses a quantitative and a phenomenological qualitative approach to assess outcome, and pilots a new body image scale which is based on phenomenological data.

Dr. Frances describes the third approach which presents the use of healing stories to work with the effects of living with breast cancer. The healing stories group at California Pacific Medical Center's Institute of Health and Healing uses image and story to help patients explore their illness as a "chapter" in their life stories. By becoming aware of the cyclical nature and the common elements of stories shared with others, patients experience release, a renewed sense of perspective and hope.

Finally, Dr. Angell describes adapting supportive expressive group therapy into a journal program for patients in rural settings. The Sierra-Stanford Partnership project investigates how to apply this supportive/expressive model to a rural setting to help these women receive immediate and continuing educational

and emotional support. An innovative, community-based, interactive workbook-journal approach was developed, which includes facts on breast cancer, references for local community resources, supportive narratives of the personal experiences of women with breast cancer who live in rural communities, and journal space for women to include their own thoughts and questions. The psychosocial effect of this workbook is assessed across two samples of women: those who are newly diagnosed with primary breast cancer, and those who are about to finish their medical treatment for primary breast cancer.

#### Supportive-Expressive Group Therapy for Cancer Patients

Cancer is a chronic, life-altering, potentially catastrophic and oftentimes life-shortening illness. It can elicit strong emotional reactions, such as fear, grief, rage, depression, anxiety, shame and even thoughts of suicide. The confusion and sense of powerlessness along with the inevitable changes within the newly diagnosed patient are frequently also difficult for the patients' family and friends. The consequent reactions of family and friends can often have the effect of intensifying the patient's experience of existential aloneness and disequilibrium.

Social support has been shown to greatly help patients cope with these stressful life events (Raphael, 1977; Rodin, 1980; Rodin & Voshart, 1986; Turner, 1981). Support groups and other psychosocial interventions enhance the quality of life of the cancer patient (Fawzy, Fawzy, Arndt, & Daniel, 1995; Krupnick, Rowland, Goldberg, & Daniel, 1993; Trijsburg, van Knippenberg, & Rijpma, 1992) and may even influence the course of the disease and prolong lives (Fawzy, Fawzy, & Hyun, 1993; Linn, Linn, & Harris, 1982; Spiegel et al., 1989). The literature suggests that support groups protect patients from stress by providing them an opportunity to give and receive support, as well as express their thoughts and feelings about what it means to live with this disease.

The support groups that have been examined come from a variety of theoretical psychological models. In this article, we describe "supportive-expressive group therapy," a therapeutic approach used by David Spiegel and his colleagues at Stanford University (Classen et al., 1993; Spiegel, Bloom, & Yalom, 1981; Spiegel & Spira, 1991). In supportive-expressive group therapy, the aim is to create an environment where patients receive support from one another and can fully

express all their feelings and concerns. Using this model with breast cancer patients in a randomized clinical intervention study, Spiegel found that women who participated in these support groups showed significant improvement in mood and coping skills (Spiegel et al., 1981), reduction in phobic responses and the experience of pain (Spiegel & Bloom, 1983) and, surprisingly, a significant increase in survival time as compared with our control subjects (Spiegel et al., 1989). Currently, numerous studies are underway both in Spiegel's research laboratory and in laboratories around the world to examine the effectiveness of supportive-expressive group therapy for breast cancer, prostate cancer, HIV-infection, lupus and multiple sclerosis.

### *Existential Group Therapy*

Supportive-expressive group therapy is an existentially based therapy that developed out of Irvin Yalom's work (Yalom, 1980, 1995). Many of the most difficult issues faced by cancer patients are existential. The four ultimate concerns outlined in Yalom's book, *Existential Psychotherapy*, are: freedom, isolation, death and meaninglessness. In supportive-expressive groups, these concerns are expressed in a variety of ways.

*Freedom.* The concern of existential freedom has to do with having the responsibility for creating one's life, one's sense of self, and one's place in the world. The diagnosis and treatment of cancer can have a profound effect on the patient's experience of self. The shock of the diagnosis, the confusing choices about medical treatment, and for some patients having to adjust to a radically altered body, leaves patients with the difficult task of having to integrate these changes into her self concept.

Bodily changes can include hair loss as a result of chemotherapy, losing a breast and for some having to adjust to a reconstructed breast, and gaining or losing weight. Each of these changes can leave patients feeling that their bodies are no longer familiar. Accepting their new bodies and integrating them into a healthy and positive view of themselves is an important therapeutic goal.

Both the cancer and its treatment can leave patients with diminished energy and physical abilities. Thus, the old view of oneself as someone with energy and in good physical condition no longer matches reality. The patient may have difficulty integrating this new self which she expresses by pushing far beyond her

present capabilities. Thus, an important goal is to help the patient adjust her internalized view of self so that it more accurately reflects her capabilities.

One major change that requires integration is the patient's new identity as someone who is ill. This change may include a new dependency upon others, which can present a significant challenge to self-esteem.

Accepting responsibility for our lives is one of the consequences of facing existential freedom. Supportive-expressive therapy groups encourage patients to take an active role in their treatment and become partners with their doctors. They learn to be full participants in their treatment decisions, to state what they want and need from their doctors, and to ask questions.

*Isolation.* The awareness of one's existential aloneness comes to the forefront when one is diagnosed with breast cancer. Cancer patients often feel stigmatized and isolated. They have been thrust from the mainstream, endure the constant uncertainty of their disease, are subjected to treatments that may or may not live up to their promise, and are often surrounded by people who don't know how to talk to them. Many patients despair that others cannot truly understand what they are living and consequently feel utterly alone. For the breast cancer patient, joining a breast cancer support group reduces these feelings and provides patients with a place where they are understood. There is often an immediate and surprising sense of camaraderie that is experienced when joining such a group. With time, they can grow secure in the knowledge that the group will be available to them in difficult times. Unlike traditional psychotherapy groups, friendships between group members outside the group are encouraged. Consequently, when the group ends these friendships frequently continue.

Because cancer can isolate patients from family and friends, as well as the community at large, it is important to rebuild these bridges to these essential sources of emotional and practical support. Thus, an important goal of supportive-expressive therapy is to improve communication between patients and important people in their lives. As a culture, we place a great premium on stoicism and maintaining a "positive attitude" no matter how dire the circumstances. However, in order to cope with cancer, patients need an outlet to express the full range of their feelings, despite both internal and external prohibitions. Suppressing these feelings creates a risk that patients will be overwhelmed with feelings of helplessness and

hopelessness as un verbalized pressures build. Ideally, patients should feel that they can be open and honest with those to whom they are closest, and that those people can communicate openly back to them. It is also important for patients to be able to express all their concerns, wishes, and fears without having to worry about protecting others. By reducing barriers created by fear and concern, patients can make full use of their social support system throughout their illness. Thus, the goal of supportive-expressive group therapy is for these patients to be able to express all their feelings, develop group rapport and mutual caring, learn to tolerate intense emotions, and to open the lines of communication with their loved ones.

*Death.* A potentially life threatening illness confronts patients with the reality of their mortality. Concerns of death and dying are often at the forefront of patients' experience, even though they may try hard to keep them at bay. We believe that because these concerns are among the most difficult to face, they are also among the most important.

The confrontation with death provokes deep fear in patients. Rather than avoiding the issue or being left alone with terrifying fantasies of death and dying, patients need a place where their fears can be examined. Addressing death directly reduces fear and anxiety and makes it more manageable. The ability to face death also enables patients to make realistic plans for the future and to complete unfinished business. It can also focus attention to vital issues.

Enhanced quality of life and authentic living are the goals for patients struggling with cancer. With the acceptance and integration of their existential reality, patients can develop greater clarity about personal goals, allowing them to live life as richly as possible, even in the shadow of death.

*Meaning.* Attempting to make meaning out of a cancer diagnosis is inevitable. One of the first questions that is often raised for a patient diagnosed with cancer is "why me?" Some patients struggle with guilt for feeling that they caused the illness or that they haven't done enough. On the other hand, others find that the confrontation with death liberates them from guilt, and they are free to find meaning in the smallest events of everyday life. Because of this, some express gratitude to their illness because they now find life so full and meaningful. Because the future is so uncertain, it is important to help patients think about how best to use the time that is left. This involves becoming clear about their values and life goals. Discussions about life goals can help patients reconstruct the im-

pact of the illness on their lives. This may lead to the development of new goals and perhaps discovering that they want to live and enjoy life more fully in the present.

### *Patient Population*

While supportive-expressive group therapy is relevant to any potentially life-threatening illness, the focus of this article is on using this therapeutic approach with breast cancer. In working with this population, there are several issues for group therapists to consider.

*Type of illness.* There are many different types of cancer and while there are some issues common among cancer patients, each type of cancer also presents unique set of issues for patients. In the case of breast cancer, most patients must undergo disfiguring surgery on their breasts. This often challenges the very core of their femininity and sexuality and contributes to a feeling of being different and alone. When patients with the same disease have an opportunity to share these unique experiences in a supportive environment, they are able to receive a critically important level of understanding. Therefore, it is recommended that whenever possible, patients with the same disease should be placed in one group.

*Stage and severity of disease.* Stage and severity of disease are also important to consider both in forming a group and in the group evolution. Whenever possible it is usually better to form separate groups for primary and advanced breast cancer patients. Even though these primary and advanced cancer patients have some similar concerns, the degree to which they struggle with these issues varies. For example, the fear of death arises for both types of patients. However, for the primary patient there is a strong need to believe that she has been cured and to downplay concerns of dying from the disease. For the advanced patient, concerns of death and dying are unavoidable. If it is not possible to form separate groups or if the group has evolved such that there are patients at different stages of the illness, the therapists must attend to the dynamics that arise when both types of patients are in the group.

*Ethnicity.* Ethnic groups can vary considerably in how they experience having a disease such as breast cancer. It is important to be alert to these differences. For example, traditional Hispanic and Asian cultures value controlling emotions and thus such patients may resist expressing their feelings about the illness..

### *Role of the Therapist*

*Qualifications.* It is advisable to have two therapists co-lead these groups. Between the two therapists, there should be expertise in psychotherapy or group therapy, as well as expertise in working with cancer patients. Because it is not always possible to find therapists who have expertise in both the illness and group therapy, we try to ensure that between the two therapists there is adequate familiarity with group facilitation and the illness.

*Empathy.* The therapists must have the ability to establish rapport, instill confidence in their abilities, and exude warmth and caring. The therapists must be comfortable with facing existential issues, particularly the recognition of their own mortality.

*Boundaries.* Therapists who lead supportive-expressive therapy groups for people with cancer will often experience strong reactions within themselves as the group members deal with profound existential issues. This might present a challenge to sustaining objectivity. While it is important that the therapist be able to maintain the role of therapist, there are times when it might be appropriate or useful to step outside of those usual boundaries. For instance, sometimes it may be appropriate for the therapist to have contact with one or more patients outside of the group. Attending the funeral for a group member or visiting an ill member in the hospital are two examples. When these events occur, it is important to address them in the group in order to ensure that the full meaning of these events are understood.

*Therapist genuineness and transparency.* The existential concerns that are activated by having cancer are fundamental dilemmas of human existence that face us all. The therapist's recognition that "this could happen to me" provides a foundation for the development of empathy and feelings of trust and safety within the group. This recognition also frees the therapist to be emotionally present and thereby helps group members to do the same.

Unlike traditional group psychotherapy, supportive-expressive group therapy does not aim to alter personality traits. Instead, the aim is to share a common experience. At times the therapist might choose to disclose personal information about herself with the intent of deepening the work of the group. The decision to self-disclose must never be based on the needs of the therapist. Instead, it should be made only after carefully evaluating the needs of the group members and determining whether it is clinically appro-

priate. When used appropriately, transparency can help to build an open and trusting environment.

### *Guidelines for Treatment*

*Creation and maintenance of the group.* It is the therapists' responsibility to both create and maintain the group. This includes making initial contacts and arrangements with the potential members, and setting the time and place for the meetings.

In terms of maintaining the group, the leaders must address potential problems such as chronic lateness, unexplained and frequent absences, or any behavior that might disrupt the group. When patients are absent, it is crucial that this be addressed. There is a tendency to worry about absent members, particularly to worry about whether they are ill. Furthermore, if absences are not commented upon and inquired into, it can lead to an underlying fear that one could slip away unnoticed. Therefore, it is important that any absence be followed up by the leader before the next group meeting and whenever possible to explain the reason for any absence at the beginning of the meeting.

*Culture building.* The beginning of any new group undergoes a process of establishing the group norms and thereby the culture of the group. Group norms are the set of implicit or explicit behavioral rules by which a group conducts itself. At a fundamental level, the group norms should contribute to an environment of safety and acceptance. It is the role of the therapist is to ensure that an appropriate set of norms is established. Some of these norms include the following: (a) members should feel free to interact spontaneously and honestly, (b) there should be nonjudgmental acceptance of each another, (c) the focus should be on cancer, (d) meetings should begin on time, and (e) group leaders should be informed of absences.

*Activation and illumination of the here-and-now.* An active ingredient in group therapy is working in the here-and-now. Although the inevitable discussion of the history of the disease, its diagnosis and its treatment, is not here-and-now in focus, for example, the therapist can still shift the focus to the present. What feelings come up for the patients as they talk about these issues? Such a question can involve both activation of the here-and-now and the illumination of that experience. Ordinarily, activation of the here-and-now occurs naturally. Identifying the here-and-now experience and working in the here-and-now provides opportunities for members to work with a

problem both experientially and interactively. The illumination of process helps group members reflect on their interactions in the group or their own internal experience. While the aim of supportive-expressive groups is not directed at personality change, illuminating the here-and-now can lead to the achievement of such goals as the reduction of feelings of isolation, improvement of social support, normalization of experience, improvement of coping skills, and greater emotional expressiveness.

*Facilitate supportive interactions.* Facilitating the development of a supportive, accepting and open atmosphere where patients can share all aspects of their experience is a crucial therapeutic task. In early group sessions, the therapist should set the tone of the meetings and function as a role model by offering warmth and understanding. The therapist's empathic comments can serve as a model for supportive behaviors and attitudes among the group members. During the early stage of a group, it is also important to facilitate interaction among the group members so that communication occurs in all possible directions and not through the group leaders. Permitting and even gently encouraging contact outside the group is also appropriate.

*Facilitate the expression of thoughts and feelings.* A diagnosis of cancer stirs up a host of difficult issues and feelings, many of which are actively avoided. Avoiding the expression and examination of threatening thoughts and feelings has deleterious consequences. The notion that a consistently positive attitude is necessary to promote healing is an idea that has been bought by many patients and professionals alike. For these individuals, there is a fear that experiencing any negative or painful feelings or expressing negative thoughts will somehow interfere with healing, and may even cause the disease to progress. Unfortunately, this leaves the patient alone with her most troubling thoughts and terrifying feelings.

Another common fear about expressing difficult thoughts and feelings is that of being overwhelmed or of overwhelming others. The therapist plays an important role in helping patients overcome those concerns. Furthermore, the group provides an ideal place to test those beliefs. The therapist's implicit message that she will not be overwhelmed conveys to the patient that her thoughts and feelings are tolerable to both herself and to others.

*Personal, concrete issues.* One strategy for coping with a potentially life threatening disease such as breast cancer is to try to distance oneself from it.

Speaking about the disease in abstract and impersonal ways is a common strategy patients use to accomplish this unconscious goal. Speaking in general and abstract terms about cancer is all too common among cancer patients. While it gives the illusion that one is talking about the disease, it is also an effective strategy for keeping one's feelings at bay. It also has the negative effect of moving all group members away from their underlying feelings. It is important that the therapists help the members to be specific and, if possible, to find out if it is something that she is in some way experiencing right now in the group. When working on a problem, the more concrete, personal and rooted in the present the patient can be, then the more the patient will be able to identify her underlying feelings, beliefs and assumptions that may have contributed to the problem. Working on a specific problem as it is experienced in the moment can also provide the patient with the opportunity to resolve the problem by enacting the solution in the present.

*Facilitate active coping.* To cope with the reality of their disease, the therapists should encourage the use of active problem-focused coping. With a disease such as cancer, patients can feel that there is little they can do to improve the situation. Coping strategies that involve taking positive steps towards improving their quality of life, understanding their illness and its effect upon them, and taking appropriate steps to deal directly with their disease are highly beneficial to the patient. Encouraging patients to get more involved in their treatment and in monitoring their disease can be very helpful. This includes such actions as: learning about the illness and different treatment options, paying close attention to symptoms, working collaboratively with their doctor or seeking second opinions. For interpersonal or emotional issues, patients are encouraged to identify specific actions they can take to get the support they want from people around them.

*Relaxation and guided imagery.* At the end of each supportive-expressive groups, self-hypnosis (a form of relaxation and guided imagery) is conducted by one of the group leaders. Hypnosis is simply a shift in the focus of attention. Attention is shifted in ways to help patients enter a state of relaxation and calmness, to manage pain, and to consolidate what has been learned in the group. It provides patients with the opportunity to appreciate their current situation, set realistic goals to improve their quality of life, and construct ways to make this transition within the context of their lives. After several guided self-hypnosis sessions, the patients are encouraged to use the

method on their own whenever they want to enter a state of relaxation, manage pain or to work on some issue in their life. The induction is approximately five minutes in length.

### *Conclusion*

In this section, we have presented a brief description of supportive-expressive groups for cancer patients. While a diagnosis of cancer evokes a myriad of emotional responses and radically alters patients' sense of themselves and their future, there are often few places where they can honestly and openly address this experience. Providing a safe and secure environment, where patients can be supported to face the many issues the diseases raises for them, is an important contribution to patients at a critical time in their lives.

#### Dance/Movement Therapy Group for Women with Breast Cancer

The report from this group is based on a research project, funded by the Flow Fund and the Susan G.Komen Foundation and conducted at the Institute of Health and Healing at California Pacific Medical Center, which investigated the effectiveness of dance/movement therapy for the psychosocial and spiritual adaptation of women to breast cancer (Serlin, 1996b).

While recent research on the mind/body connection focuses on physiological or immunological change, there is little research on the effects of physical activity and imagery on these functions.

Both the diagnosis and the treatment of breast cancer can have serious effects on the body image (Dosamantes, 1992; Jamison & Pasnau, 1978; Price, 1992), sense of self and sexuality (Schover, 1994) in women. Physical effects may include a concave torso resulting from the trauma of surgery, restriction in a woman's mobility and a negative body image. Emotional effects may include depression, anxiety, grief, negative self-esteem and quality of life (Ganz, 1992; Greer & Watson, 1987), and the spiritual effects include a decreased sense of control and meaning in life (Crumbaugh & Maholick, 1997; Jenkins & Pergament, 1995).

This research used a traditional quantitative approach combined with a phenomenological qualitative approach (Miles & Huberman, 1984) to assess mood, coping, body image and spirituality.

### *Description of the Group*

The group consisted of 12 weekly sessions in an outpatient setting. Women were referred by hospital physicians, and through active recruitment in the community. Each woman received an initial telephone screening, followed by 45-minute interviews and a battery of pre- and post-self-report measures. During the second year, the women received a Rorschach with the interviews, and the third year the interviews were focused on postgroup experiences of change. Approximately 10 women completed each group; a high rate of attrition was due to the taxing effects of chemotherapy and surgery.

The method used was a form of movement therapy called kinaesthetic imagining, a process by which movement makes images explicit (Serlin, 1996a). Although certain props are used to amplify the imagery, such as music or drawing, the theoretical basis of the group is existential-integrative and symbolic.

Like the supportive-expressive groups at Stanford University, this group is existentially based. By that, it is meant that the group is experiential, focuses on the here-and-now, emphasizes support and connection and encourages authenticity. This existential base is important, because as the alternative and complementary health movement spreads, there is a push to make all interventions standardized and manualized. Standardizing an intervention has the advantage of allowing for comparative research, and for training health professionals to repeat the program in new locations. An existentially-based group takes issue with this form of standardization, however, since it is based on the principle that the imagery and material arise from the participants and the group itself, and are not imposed by an "authority." These groups empower participants to develop their own healing imagery, and would suggest only general structures in which material or imagery can develop. Self-empowerment and self-acceptance of each person is considered to be crucial for healing, so group members are encouraged to initiate ideas, confront each other and/or the leader and discover spontaneity. All of these qualities are stifled by an overly structured group. In addition, if a Type C personality for cancer patients does exist, then cancer patients need to learn to express anger, take risks, and be authentic and not more compliant (Temesk, 1987).

The issues faced by these women are death, isolation, freedom and meaning, like in the Stanford supportive-expressive groups. Therapeutic goals are less

about symptom reduction than about the meaning or quality of their lives. The women are called "participants" instead of "patients," and the work is not called "treatment," which is a description still from the old authoritarian medical model. It is more important that the participants struggle genuinely with these issues than that they are given solutions. In fact, one of the group goals is to help women move from an externally-dependent to an internal locus of control, and take charge of their own decisions, healing rituals, and power (Tarrier, Maguire, & Kincey, 1983).

In addition, these groups are existential in that the participants are encouraged to form relationships with each other outside the group, especially to create healing rituals for each other. The therapist also tends to be more sharing, especially when the issue arises of whether she has had breast cancer or has faced serious illness. Finally, the groups are existential in their integrative quality. By integrative, we mean that the group follows its own organic process, rather than being a cut-and-paste program of visual imagery, body exercises, and meditation. In kinaesthetic imagining groups, imagery, meditation, and movement are all combined as the process of telling and bearing witness to members' stories develops.

What is different about these groups from the Stanford model, however, is that the groups are not only verbal. Because so much emotion and psychological material is carried in the body and the unconscious, especially in an illness like cancer, non-verbal, symbolic and ritual forms of expression are particularly appropriate (Serlin, 1993).

### *Results*

Trends from the self-report data were encouraging; significant improvement was found on the fatigue, vigor and tension subscales, while depression and anxiety decreased (McNair & Lorr, 1971).

However, while a quantitative approach may tell us something about the efficacy of certain interventions on certain variables, it does not tell us anything about the quality of suffering, the nature of the woman's experience or the meaning of her illness. For this information, a qualitative approach is needed.

In addition, the quantitative approach has some serious drawbacks. For example, due to recruitment difficulties, we were unable to develop a control group. We were unable to account for the significant number of intervening variables between group sessions; women were feeling better after each

session, but not necessarily over the 12 sessions. In fact, many of the women underwent surgery or chemotherapy during the group, and would feel better or worse depending upon the course of their illness. A number of the women found the spirituality scale and its reference to church or higher powers not descriptive of their experience of spirituality, just as they did not find the body image scale, normed on women with eating disorders, to be descriptive of the mutilating and de-sexualizing experiences of undergoing treatments for breast cancer (Secord & Jourard, 1953)

Yet we observed profound changes happen each week. We saw women who were initially sitting outside the circle move into the center and assume leadership roles, we saw faces radiant with energy after moving and we saw sunken torso's and helplessness/hopelessness turn into erect torso's and confident steps. We saw women who were disconnected from themselves and others begin to connect. We began to wonder whether we needed to be asking different questions, or asking them differently. So we listened as well as we could; we helped them discover what music moved them and what kinds of movements, and what images emerged from these movements. We gathered those images by drawing them, by enacting them in rituals, by describing them in interviews, and by videotaping. We asked different questions, as in focus groups or exploratory qualitative research. We tested those questions with each group, approximating a close representation of their experience. The questions were grouped into questionnaires, which are currently being piloted as test instruments. Documentation of these groups gave rise to the following stories, images, and meaning of these women's experiences of an arts medicine group process.

During the initial research stage, we noted that none of the body image scales we explored had developed their items from descriptions gathered from women. Therefore, we attempted to gather these descriptions during our interviews. We analyzed the transcripts with the use of five independent raters, each of whom did a content analysis of the interviews. Choosing the themes which recurred most in the analyses, we converted them into a Likert scale of 100 items, which we are now in the process of validating. Preliminary categories which emerged from this process pointed to more essential dimensions of embodiment, such as statements like "My body betrayed me" or "My body is my enemy" to "My body is my friend." Also, descriptions suggest a form of spirituality which is based in the body and emotion, rather



than a transcendent spirituality. For example, the interviews yielded statements like: “My body is a way of knowing,” or “I feel more connected with myself, with others, and with a larger force.” We are in the process of validating these items into a one-page scale. Next, we noticed that the bodies and use of space changed dramatically during the sessions. Interested to document these changes, we videotaped the first, middle and last sessions of the second year’s groups, and looked for patterns of change from baseline profiles. Using a Laban-based scale (Ullman, 1984), we tracked salient dimensions on which we noticed change, and are developing a second part of a body-image scale which is based on movement observation. This system is also in process of validation, and we are collecting data at this point. We hope, when the validation process is complete, to have a body image scale which is unique to the experiences of women with breast cancer, which can show significant change over time in descriptions and observations that are connected intimately to their own words and narratives, and which can therefore accurately reflect their experiences.

### *Narratives*

The following is a vignette from an interview which reflects the use of narrative, case study (Aldridge, 1994) and ritual in the creation of healing rituals:

Well, the work is for me—at, you know, just a very deep level. What I find in this work is that somehow the work allows for a deep, spaciousness within me and a deep movement in me and therefore what happens is that because of the expansion I become more of who I’m supposed to be in this world...

It gives spaciousness to my cells so it allows them to breathe and allows them to flow more freely and then it gives spaciousness to my spirit because all of a sudden I’m free and joy or pain or whatever comes out.

And again, that’s where the healing is—is that we don’t have to be anything. We can just become who we are and who we’re meant to be.

This person related her experience to becoming aware of herself as a woman in a new way:

...somehow I think this related to healing the planet and healing the female on the planet. Somehow I think...we’ve given up something in the planet in being female, maybe the lack of connection, maybe the getting so involved in our own lives, the struggles that we have to deal with on a daily basis, you know, the single parenthood or working in the world. For me, it’s having to be all—being a single mom and a professional and so forth but maybe the nourishment I didn’t get from my mom but somehow this work has gotten me more in touch with my feeling. Therefore I can become more the woman that I want to be or that I am supposed to be ...and also in doing that I have become more connected with women and seeing how much I need women.

When I asked her to describe the healing ritual we did for her, she tells the following story:

Oh, the Halloween and the Bad Girl. One of the things for me that happened as a result which was tremendously impactful for me is that, well, it started with the dance when we were dancing with the scarves on that one day I was in there and what I got in touch with was how when I was a young girl, I kind of shut down, I think, to my femininity...and I got really back in touch with that in the group, in the going back and remembering even when I was in first grade ...about how I ... loved to dance and I was in this recital and, for some reason, something happened in the recital that I somehow remember my father saying I was fat or something like that, that I would never dance again and in the group I got in touch with that pain through some kind of movement that we did...and then afterwards you said why don’t you take this scarf and have the people hold it...and dance behind it and so what happened to me was I felt really protected...with the scarf there, very safe with the people in the room and then danced my dance and out of that it freed up really in me the desire to dance and move, the fun that I had doing it, the joy and the love that comes into my life from it and...also the essential woman that has been there that is...really afraid to come out because...it was always bad to be that way and bad to be interested in sensuality and sexuality and so, as a result of that, the Halloween thing

was we were supposed to come as our bad girl...so I came all dressed in black, black leather jacket, black top, black bottoms and just really felt I could be my awful self or the other self that's in there that's part of me as well. And in doing that it just freed up really who I am because now I'm so much more embracing of all that part of me and none of that is bad and it's more fun...We've all been good girls...and I've never looked at it that way. It seemed like all of us in the group had that bad girl that we were really thrilled at allowing to get in touch with and to let out and that we always felt...that we had to be good girls all our lives.

Reflecting on her experience, this woman understood more about the meaning of her illness:

Well, what is cancer? Cancer is a cell that's lost. Its nucleus takes over, right? and it goes out of control. Well, I think that's what's happening is that as people we're out of control. We don't connect. It's a power kind of society and ...we need more support and more connections from each other...that's what happens in illness, you need people. I mean you can't do it by yourself. And you realize your own lack of control and I think that's true and I think also in this society ...as the stress is created and we have to do more and more and the technological revolution...is that we deplete our immune systems and therefore allow these opportunistic diseases to come in and being connected with people and having...the rituals gives more support and then therefore we don't ...allow these diseases to come in...it's something I need in my life to keep me healthy, keep me centered and keep me on my own path—these healing circles and its beautiful work.

Not only did she eloquently describe her own experience in words, but she also drew pictures which conveyed a strong sense of the experience. The following are images from her, and from other group members, which give a sense of the group process and the creation of healing images and rituals (see Figures 1, 2 and 3).



Figure 1. This is me (points). The sultry jet. I don't remember much about growing up except one time I was dancing as the Jet—it was anti-feminine. Black leather.

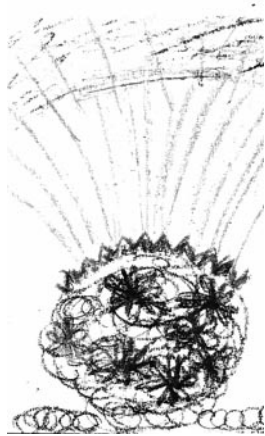
### The Healing Stories Project

Images and stories are powerful tools in the healing process, and particularly address the symbolic part of the supportive/expressive dimension of group experience. Scientists have recently documented the effect of the emotions on the immune system (Pert, 1997), as well as the effect of expression on the healing process (Pennebaker, 1990), but it was obvious to our research team that the sharing of stories during the group and during the interview process was an important part of the group's effect.

During the course of our groups, we noticed some



Figure 2. It was incredible being in the circle. I felt the energy. I have strong faith in all of us healing each other. It was exquisite; thank you everyone. Fire in these bones struggling to become free to stay free. Move lady move. I have to remember to breathe and move.



*Figure 3.* This is kinda like darkness, a lot of sadness. Breath came into my body. I get energy from our sisterhood. I wanted to do a summersault and I'm scared to death of summersaults. Expansion, dark, pain, fear. Breath gives way to swirling, twirling, leaping. Do I dare feel great?

distinctly different phases which the women went through during their healing process. There was the first shock of diagnosis, and the denial, anger and grief of the accompanying reactions. Then there was a stage of treatment, which might include radiation, chemotherapy and surgery. This stage was often accompanied by extreme physical and mental exhaustion, as well as isolation, fear, helplessness and hopelessness. Following this stage was the stage of recuperation, which might include a range of emotions from hope and transformation to dread and anticipation of recurrence. Finally, the re-entry stage, in which the women prepared to re-enter the workforce or family life, was often accompanied by a desire to normalize and leave the illness behind.

These stages began to fall into somewhat regular patterns. We noticed, for example, that women from the early part of the process often became activists or leaders, participating in community cancer events or helping other women with breast cancer. This activism was an important part of their healing process. Women from the re-entry stage, on the other hand, might no longer want to identify as "breast cancer survivors," and "get on" again with their lives. For them, moving on with their lives was important for their healing. The issues, therapeutic goals and even group dynamics of each of these stages were noticeably different.

One way these stages can be described is through a mythological perspective. Based on observations

from the breast cancer group, groups called *Body and Metaphor*, *Story as Healing*, and then the *Healing Stories* project at California Pacific Medical Center explored the effect of illness on group members in terms of their personal mythology. The work of Joseph Campbell (1949) and Maureen Murdock (1990) formed the basis of this work. Campbell's Hero's Journey model was used, and divided into four quadrants; the "call" to the journey, the "outer" or physical challenge, the "inner" or spiritual challenge and "re-birth" or re-entry. Music, movement, art and storytelling allowed the participants to explore whatever issue of illness they were having, and put it into context as if it were a chapter in their overall personal mythology (Feinstein & Krippner, 1988).

Most of the group members had dealt with the physical challenge and were now dealing with the "inner challenge" quadrant, which is the journey into the unknown, the belly of the whale and the descent into hell. A number were in the rebirth quadrant, as they struggled to make profound changes in their lives, or to "normalize" back into the workforce or family life.

By identifying with characters in favorite stories, participants were able to compare the way they understood illness or challenges in their lives with the way these mythological heroes handled challenges. This process allowed them to explore or to reframe their experiences, and to assess the effectiveness of their approach.

By becoming aware of the cyclical nature of process, as well as common elements they could share with others, release and relief would arise and a sense of hope was reinstilled. The images they drew guided them to stories from within themselves that came from a deep level, exposing blocks and clues to releasing resistance to living a healthier and fuller life.

#### A Workbook-Journal: An Alternative Approach for Providing Psychosocial Support to Rural Women with Primary Breast Cancer

Women diagnosed with breast cancer require immediate and continuing education and psychosocial support. Support groups have become increasingly popular as an efficient and effective method for providing educational and emotional support to women undergoing treatment for breast cancer (Berglund, Bolund, Gustafsson, & Sjoden, 1994; Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Felic, Goldman, & Kennedy, 1979; Heinrich & Schag, 1985; Johnson,

1982; Mahon, Cella, & Donovan, 1990; Spiegel & Bloom, 1983; Spiegel et al., 1981, 1989; Spiegel, Flynn, & Heard, 1996; Telch & Telch, 1986). In rural communities, however, where women diagnosed with breast cancer may have to travel great distances to receive treatment, access to this type of support is limited. Given the isolating nature of their geography and the decrease in educational and medical services available in rural areas, rural women with breast cancer require an alternative venue through which they can access disease and treatment-related information and psychosocial support.

One group of breast cancer patients and providers in a rural county in the Sierra Nevada Foothills of California approached researchers at the Psychosocial Treatment Laboratory at the Stanford University School of Medicine with a proposal for an alternative method for offering support to cancer patients in rural areas. This project was funded by the Breast Cancer Research Program of the University of California Community-Initiated Research Collaboration pilot grant 3AB-1301. Together, the Sierra-Stanford Partnership was formed in an effort to bring their idea to fruition and test its feasibility and effectiveness. From the community members' experiences in struggling with and providing care for breast cancer in this rural mountainous region, and the Stanford researchers' experience in developing and testing psychosocial interventions for women with breast cancer, the Sierra-Stanford Partnership worked to develop an intervention which was appropriate for and accessible to women who live in rural communities, and which followed the principals of a research-based therapy for cancer patients (Spiegel et al., 1981).

#### *History and Background of the Intervention*

The idea for this intervention began in a rural breast cancer support group called *La Loba*. During a series of meetings, these women began to articulate why the group was so meaningful to them. Their list included sharing breast cancer treatment information, discovering other breast cancer resources, preparing for treatment by talking with other women who had already been through surgery, chemotherapy or radiation, having a forum for expressing anxieties and fears about cancer and recurrence, observing other coping strategies, knowing that they weren't alone and the ability to help other women with breast cancer. This process caused them to lament the fact that so few women they knew with breast cancer in their

community were able to benefit from what the group had to offer, and motivated them to consider ways of overcoming the barriers rural women face in accessing support and education about breast cancer.

This spontaneously generated list closely parallels many of the goals of supportive-expressive group therapy. The task for the Sierra-Stanford Partnership, therefore, was to search for a different method of providing psychosocial support to women in rural communities. One woman in the rural support group talked about the benefits of using a journal to help her understand her own reactions, causing us to consider a written medium. While there are many written materials on breast cancer, the ones recommended and available to these rural women contained either too much information or not enough. None contained or communicated the feature highlighted most by women when they describe the benefits of support groups: shared personal experiences. Was there a way to translate the principles and benefits of a support group into a written form, which would be low cost and easily disseminated to women, but which also included the sense of shared personal experiences?

#### *Major Aims*

In this preliminary study of the Sierra-Stanford Partnership pilot project, we had two major aims: (a) To develop a written psychosocial intervention, which was based on the principles of Supportive-expressive Group Therapy, was somewhat interactive, and was appropriate and accessible to rural women with primary breast cancer, and (b) to recruit women with primary breast cancer who lived in rural areas to participate in a randomized clinical trial of the effects of this intervention upon psychosocial functioning.

#### *Methods*

*Subjects.* Subjects for recruitment into the clinical trial were women with biopsy-proven primary breast cancer who lived in one of seven rural counties in the Sierra Nevada Foothills of California. Recruitment was headquartered in the Sierra Nevada Cancer Center in Grass Valley, California. This hospital is affiliated with Mercy Hospital in Sacramento, California, 55 miles away. There were 67 women newly diagnosed with primary breast cancer at this cancer center during a 13-month period from June 1, 1997 to July 31, 1998. In addition, since 80% of the members of *La Loba* joined the group *after* they finished their

treatment for breast cancer, we also decided to target women who were nearing completion of their medical treatment for primary breast cancer, as this is an additional time of crisis (Cordova et al., 1995). We identified 28 women who were within 3 months of completion of their treatment during the same time frame. Forty-two women were referred to the trial from smaller clinics and practices in the surrounding California counties of Amador, Sierra, Placer, El Dorado, Sutter and Uba. In order to be considered for participation they could not be suffering from any other life-threatening illness, had to be fluent in English, at least 18 years of age, and had to be able to give informed consent.

*Materials and measures.* The materials used for the development of the intervention included pooled information from existing references of breast cancer treatment and side effects, experiences shared by members of *La Loba*, and material from formal and informal interviews of breast cancer patients, family members and breast cancer care providers in the seven rural counties listed above. The intervention, a workbook-journal, was written by the partnership (MAK), and a graphic artist designed all illustrations and layout.

The main outcome measure for the aim of recruiting rural women to participate in a clinical trial was the number of women diagnosed with primary breast cancer or nearing completion of their treatment for primary breast cancer during the above time frame who agreed to participate in a randomized trial of the psychosocial effects of the new intervention. The trial involved a baseline interview and psychosocial assessment, randomization to either the workbook-journal condition or the traditional educational materials condition, one 3-month follow-up assessment, and a request for feedback from the study participant on the materials received.

### *Procedure*

We called our intervention a “workbook-journal” (Kreshka, 1997). It is entitled: “One in Eight: Women Speaking to Women.” It is a soft-cover, spiral bound, 77-page workbook, with text, graphics, space for making lists and space for expressing oneself through words and artwork. It is structured with chapters which were chosen based upon Supportive-expressive Treatment manuals (Classen et al., 1993; Spiegel & Spira, 1991) and concerns most frequently raised in the rural support group, *La Loba*. Each section con-

tains information about that topic communicated through text, drawings and bulleted lists. An essential and unique feature of this publication is the inclusion of personalized stories and short quotes from women living with breast cancer in these rural communities. Some quotes describe a hurdle, some share emotions and others suggest coping strategies. All are intended to communicate to the reader that there are other rural women with breast cancer who have experienced some of what she is going through. The quotes are anonymous, but the age, role in the community and time living with breast cancer of the woman speaking are identified. There is a large reference section at the end of the workbook which includes descriptions and contact information of both local and national breast cancer resources. There are two pockets in the workbook for the reader to store cancer-related materials she collects on her own. Finally, every workbook created for this pilot contained a blank note card and a ribboned package of lavender seeds, a small gift from the women of *La Loba* to the reader of workbook.

We called the publication a workbook-journal to encourage women to use it: write, color, scribble, paste, etc. The spiral-bound format, sturdy paper and pockets also encourage use. The graphics, drawings, space for lists and thoughts are all attempts to reach out to the reader from the page, and to create a sense of interacting with the information and experiences described within. The graphic artist lived in Nevada County, California, and worked in conjunction with *La Loba* in creating her drawings. The title, “One in Eight: Women Speaking to Women,” combines the incidence of breast cancer as of the writing of the intervention, with the suggestion that the experience of breast cancer is shared. The personal stories and quotes create the sense of being spoken to by other breast cancer survivors. Throughout the workbook-journal, suggestions are made for different methods of expressing, understanding and coping with breast cancer: drawing, sculpting, collecting, gardening, dancing, singing and writing.

The content of the workbook-journal was gleaned from numerous medical, research-based and lay sources, and was edited by oncologists, radiologists, nurses, psychologists, psychiatrists, social workers and breast cancer patients. It is not inclusive and it clearly states that it is not intended to be a medical resource and cannot replace medical consultation. Like a support group, it is intended as a support re-

source or a guide for helping women manage their breast cancer treatment.

The personal stories and quotes were taken from formal and informal interviews with women with breast cancer in the seven rural counties identified above. Some stories also came from the women of *La Loba*. All women gave permission for their stories or quotes to be used and were assured of their confidentiality.

#### *Recruitment of Rural Women with Breast Cancer*

One of the Sierra-Stanford Partners (RM) was employed as an oncology social worker at the Sierra Nevada Cancer Center. In that role, she routinely visited every woman newly diagnosed with breast cancer to educate her and assess her need for services. Beginning in June 1997, she began to end her visits with a description of the clinical trial testing the effectiveness of the workbook-journal. She answered questions, offered a pamphlet describing the study, and asked permission for the woman to be contacted by a research interviewer. To avoid a conflict of interest in providing services and to maintain confidentiality, she had no further role in the research assessments of patients for whom she might potentially provide social services.

Patients who expressed an interest in the study were immediately followed-up by a clinically skilled research interviewer (PD). Patients who were hesitant or unsure about participating in a research trial, were contacted again about 2 weeks later, by phone or in person, by the research interviewer. She reviewed the procedure for participation, educated the woman about her rights as a research participant and answered any questions about the project. If the woman was still unsure, the research interviewer asked permission to contact her again in the future, and then repeated the above process. At any time, if a woman stated she did not wish to participate in the research, no further contact was initiated.

Our research interviewers (RM, PD) were respected breast cancer care providers in Nevada County. In order to recruit other provider groups to refer breast cancer patients to the study, they traveled to each surgical and oncologic group practice in the recruitment area. At each location, they gave a presentation describing the goals of the research, the funding source and the criteria for and details of patient participation. They then worked with each medical group to set up a referral system that was conve-

nient for them based upon their staff and patient load. These referral networks were strengthened by occasional phone calls to troubleshoot, support and thank these medical groups for referring patients to the project.

#### *Results*

Through a strong collaboration between rural community members and Stanford University researchers we were able to create a written intervention which follows the principles of research-based therapy and is attractive and inviting. It is full of information while being easy to read, communicates personal struggles and successes of other rural women with breast cancer, invites readers to include their own information and experiences and is accessible to rural women with breast cancer. "One in Eight: Women Speaking to Women" was produced in October 1997 and is currently being pilot tested in a randomized clinical trial in Nevada County.

Of the 67 women who were either newly diagnosed with and/or treated for primary breast cancer at the Sierra Nevada Cancer Center during our study period, 10 were ineligible to participate in our clinical trial of the effectiveness of the workbook-journal on psychosocial functioning. Of the remaining 57 women, 40 (70%) agreed to participate, while 17 (30%) declined. Of the 28 women within 3 months of ending treatment for primary breast cancer, one was ineligible for the study and 23 of the 27 remaining women (85%) agreed to participate. Forty-two women were referred from other oncology and surgery practices in the surrounding counties. Of these 10 were ineligible, and the remaining 32 all entered the study. In sum, out of a total of 137 women referred to the study, 95 (82%) agreed to enroll in our clinical trial.

#### *Discussion*

The goals of this preliminary Sierra-Stanford Partnership pilot project were to create a psychosocial intervention which was research-based, culturally sensitive, and accessible to rurally isolated women, and to test our ability to recruit a sample of rural women with breast cancer to participate in a randomized clinical trial of its effectiveness. We created a workbook-journal that contained the major features of support groups in a written and graphic format, which included personal experiences of rural women coping with breast cancer, and which could be easily handed

or mailed to a woman in any rural location. We then successfully recruited 85% of identified eligible patients in seven rural counties to participate in our clinical trial.

Our workbook-journal is an attempt to overcome barriers to support and education about breast cancer in rural environments by translating some of the most powerful features of support groups into a written format. By compiling many resources into one easy to read volume, it may reduce the time rural women spend researching and tracking down the resources they need. The inclusion of personal stories and quotes of other rural women makes this a unique publication, and approximates the feeling of shared experiences. While this publication can not take the place of actual, mutual sharing with another woman with breast cancer, for rurally isolated women or for women who do not feel comfortable sharing in a group setting, the workbook-journal may be an alternative method for receiving information and support about breast cancer.

Recruiting rural women to participate in a research project was a challenge. Our community partners discovered that, in order for these rural women to feel comfortable, many needed several personal contacts with our research team. It was not uncommon for the research interviewers to drive 25 miles down dirt roads to visit with a woman and discuss the research in person in order for her to feel comfortable joining the study. In addition, only a handful of women had ever participated in a research trial before, increasing the contact time spent in educating women about the nature of a clinical trial and about their rights as a research participant. There was a lower level of familiarity with aspects of informed consent and a higher level of suspicion about how the results would be disseminated and how confidentiality would be maintained.

As a result, the relationships that our community research interviewers developed with potential research participants was *critical* in our ability to recruit the majority of these rural women into the trial. Relationships developed with other cancer care providers in surrounding counties were also vital in establishing and maintaining other medical group referral sources. Our experience with this project suggests that in order to involve rural communities in a research trial, the research team needs to both incorporate skilled community members in the recruitment process, and spend time forming relationships both

with potential participants, as well as referring providers.

Another important feature of our success in recruiting rural women was the level of clinical skill of our research interviewers. Both were skilled cancer care providers with backgrounds in nursing and social work. They were also long-time members of these rural communities, and were known both personally and professionally. They utilized a great deal of clinical skill in approaching women for the first time about the research and in follow-up contacts. They maintained a careful balance between giving women room to think, ask questions, and say "no," and pushing them to identify fears or anxieties about being part of a research project. There was as much clinical skill required for recruitment as there was for the psychosocial interview assessments.

We are now conducting a 3-month follow-up assessments on all participants in our clinical trial of the psychosocial effects of the workbook-journal to determine if this intervention is similar in its effects to other support group interventions. We will use subject feedback and psychosocial outcome to revise our intervention for a more wide-spread test of its effectiveness. We have demonstrated that rural women with breast cancer, even those who have never participated in any type of research, can be successfully recruited into a randomized clinical trial which is relatively short and noninvasive.

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