

A

GUIDE TO DEVELOPING AND SUSTAINING

SPANISH SPEAKING SUPPORT GROUPS

FOR LATINAS WHO HAVE BREAST CANCER



NORTHERN CALIFORNIA CANCER CENTER



GUIDE TO DEVELOPING AND SUSTAINING

SPANISH SPEAKING SUPPORT GROUPS

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SECTION 1: GUIDE FOR SUPPORT GROUP FACILITATORS

SECTION 2: GUIDE FOR COMMUNITY ORGANIZATIONS

SECTION 3: RESOURCES

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NORTHERN CALIFORNIA CANCER CENTER

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The Northern California Cancer Center (NCCC) is an independent, non-profit organization dedicated to cancer research and education. NCCC programs focus on who gets cancer and why, how best to detect and treat cancer, and how to improve quality of life for individuals living with cancer.

Nationally recognized for its community-based cancer research, information service and education programs, NCCC also operates the Greater Bay Area Cancer Registry, the statewide Cancer Information Service (1.800.4.CANCER), and the statewide Breast Cancer Early Detection Program telephone service (1.800.511.2300).

NCCC was founded in 1974 and works with researchers and educators at Stanford University, the University of California—Berkeley, Davis, San Francisco, the University of Southern California, Dana Farber Cancer Center, Harvard University, National Cancer Institute, California State Department of Health Services, and other hospitals, universities and agencies.

If you would like to support NCCC's work, please consider a donation. NCCC is a tax deductible, 501(c)(3) non-profit organization.

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A R T W O R K

There are many Latino and Hispanic cultures in California providing a rich history and variety of art. The symbols we chose to illustrate parts of this book are primarily derived from Aztec, Mayan, and other early Mexican cultures.

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CCC's *Latina Breast Cancer Facilitator Training Project* was initiated in 1997 to help agencies in five San Francisco Bay Area counties develop new Spanish-language support groups and to provide clinical training for support group facilitators.

This Guide, developed both for facilitators and community organizations, is part of a unique and innovative project of the Northern California Cancer Center (NCCC). The project is financially supported by: The William G. McGowan Charitable Fund, The Susan G. Komen Breast Cancer Foundation-San Francisco Bay Area Affiliate, Community Foundation Silicon Valley, Peninsula Community Foundation, and the Royal Barney Hogan Foundation.

The Guide was written primarily by project consultants, Carmen Ortiz, PhD and Debra Ballinger. Dr. Ortiz provided training and support for the participating support group facilitators. Ms. Ballinger provided fund development training and served as the technical assistance consultant for sponsoring agencies participating in this project.

By sharing our experiences, we hope to help additional communities start more support groups in Spanish for monolingual Latinas with cancer. The basic design of this project can be adapted for additional ethnic and racial populations.



HOW TO USE THIS GUIDE

*T*he *Facilitator Training Guide* addresses various aspects of developing and running Spanish-language support groups. Although the Guide provides an understanding of how to develop Spanish-language support groups and offers insights and skills in how to be an effective facilitator, *it should be used as a resource and not in lieu of training*. The Guide can serve as a reference for those interested in developing Spanish-language support

groups as well as for those who already have an established support program. It will be most useful to those who already have some knowledge and experience in cancer work and support group facilitation. Many successful support groups are facilitated by one group leader. However, *the model NCCC used in this Project involved co-facilitators; thus, the general use of the word 'facilitators' throughout the Guide*.

There are three sections in *The Guide*: a Facilitator section, a Community Organization section, and a Resource section. There is some overlapping material between the first two sections, but both sections are important to the stability and long-term operation of a successful support group. Topics covered in the Guide include:

Facilitator Section

- Rationale for support groups.
- Differences between psychosocial support and psychotherapy.
- The basics—infrastructure, location, time, eligibility.
- Stages of group development.
- Facilitator and group models.
- Assessments.
- Group management.
- Common issues and themes.
- Listening and non-verbal communication.
- Crisis counseling.
- Death and dying, closure and rituals.
- Burnout.
- Group process.

Community Organization Section

- Developing an infrastructure for Spanish-language support group programs.
- Fund development.
- Hiring and supervising group facilitators.
- Building community partnerships.
- Strategic planning, outreach and marketing.

Resource Section

- Support Groups
- Organizations
- Publications



In the past decade there have been major strides in increasing public awareness about breast and other cancers. During this same time, the role of psychosocial support in the treatment of cancer has gained increasing attention. For a time the psychosocial needs of a cancer patient were primarily the concern of family and close friends; now, health care professionals recognize the positive effect that participation in a support group can have on the well-being of their patients. Many hospitals and community organizations, particularly in urban and larger metropolitan areas, provide support groups for people with cancer, as well as for their loved ones. Support groups provide a safe place where cancer patients can share their experiences of diagnosis and treatment with others going through the same experience. Research shows that women with breast cancer cope better with the disease when receiving support in addition to cancer treatment.

Latinas, Asian Americans, African Americans and other women of color have few options for participating in support groups. There are many factors for this phenomenon including unique cultural responses to illness, distrust of the medical community, language and cultural barriers, and accessibility to a group. *Two of the most significant barriers to attending a support group for many women of color are language and a lack of understanding or sensitivity to the way different cultures handle life-threatening illness.* Emotional and psychosocial support is critical to the overall well-being of a cancer patient; without it there is often a deep sense of isolation. In a time when the managed care system seriously depersonalizes healthcare, there is a growing sense of urgency that culturally appropriate and sensitive cancer support programs are especially critical for people of color and for immigrants.

NCCC Facilitator Training Project

BACKGROUND

In 1995, the Northern California Cancer Center was asked to bring together agencies and individuals interested in the educational and psychosocial needs of Latinas who have breast cancer. Two working conferences were held in San Francisco in October, 1996 and March, 1997. These were attended by over 200 individuals from Salinas in the south to Santa Rosa in the north.

During these sessions several agencies expressed frustration at their unsuccessful attempts to develop Spanish-language support groups in their communities, while others who had yet to make an attempt, were unsure where to start.

Project Funding

In response to these concerns, NCCC sought support from individuals and foundations to develop this Facilitator Training Project. With grants from The Susan G. Komen Breast Cancer Foundation San Francisco-Bay Area Affiliate, The William G. McGowan Charitable Fund, the Royal Barney Hogan Foundation, the Peninsula Community Foundation, the Community Foundation Silicon Valley, and individual donations, the Northern California Cancer Center initiated the Latina Cancer Support Group Facilitator Training Project.

Latina Facilitator Training Project Goal

The Project's primary goal was to develop Spanish-language cancer support groups for Latinas diagnosed with breast cancer in four or five Bay Area counties through the training of bilingual facilitators. Four agencies located in Union City, San Jose, Pittsburg, and Watsonville agreed to both sponsor and provide the infrastructure for long-term support

of these groups. Each of these agencies already serve the Latino community and have strong ties to other services within that community. Two consultants,* Carmen Ortiz, PhD and Debra Ballinger, were retained to provide training in facilitation, fund development, community outreach, and to assist with organizational infrastructure.

REPLICATION

Spanish-speaking support groups are needed in many locations. It is our hope that this Guide will be used to assist others in serving the needs of Latinas who have breast cancer. The Guide is being distributed through various channels, including the California statewide Breast Cancer Early Detection Program. It is copyrighted with the understanding that approval to duplicate parts or all of the Guide will be granted if a request is made in writing to the Northern California Cancer Center and if proper attribution is made to the NCCC.

While the following facilitator training curriculum was developed specifically for this Project and has numerous cultural references for the Latino population, it is pertinent for developing support groups for other ethnic and racial populations as well. While facilitators need to understand the culture of the women in their support group(s), as this curriculum reflects, the topics, concerns, processes of the group and the characteristics required for facilitators are almost universal. We hope that this Guide will be of assistance to the development of breast cancer support groups for women of California's many diverse communities.

SAMPLE GROUP TOPICS, OBJECTIVES, METHODS and MATERIALS are provided at the end of this Guide. They are the product of another support group project initiated by the Northern California Cancer Center. See Appendix A.

**In 1992, the San Francisco-based Cancer Support Community (CSC) initiated The Latino Outreach Project, offering Spanish-language and culturally appropriate psychosocial services to Latinas diagnosed with cancer. Debra Ballinger was Executive Director of CSC, and Dr. Ortiz was a facilitator. Of the various Spanish-speaking support groups begun in the last decade in the San Francisco Bay Area, only the one initiated by CSC has sustained itself for more than one year. Although CSC has closed, Dr. Carmen Ortiz continues to facilitate the support group meetings. The group has served as a working model, with numerous modifications, for this Project.*

SECTION ONE:
G **UIDE FOR SUPPORT GROUP FACILITATORS**



Carmen Ortiz, PhD

**Technical Consultant to the
Northern California Cancer Center
Latina Facilitator Training Project**

UNDERSTANDING THE NEED



THE NEED FOR SPANISH SPEAKING CANCER SUPPORT GROUPS



A diagnosis of cancer causes many emotions and frequently brings with it invasive surgeries and treatments with disturbing side effects. Women worry about the changes in their bodies, the effect their illness will have on their family and friends, and if they will survive the disease and the treatment.

The lack of Latino health care providers as well as Spanish speaking and culturally sensitive health professionals can turn a difficult experience into a nightmare. While the medical system is difficult to maneuver for someone who is fluent in English, it is almost impossible to navigate for the person whose primary language is one other than English. *The language barrier significantly affects the important first step after a diagnosis—gathering information needed to make informed treatment decisions.*

One of the major reasons that Latinas diagnosed with cancer don't ask questions is because they don't know what questions to ask. While some panic and rush to a decision, an often cold and detached medical establishment intimidates others. As a result, important questions about tumor size, pathology, and treatment options are left unasked. Rather than becoming active participants in their health care, decision-making is turned over to a provider who may or may not take the time to explain (usually through an interpreter, if one is available) what the patient needs to know. Further, the limited supply

of information in Spanish, which would greatly assist individuals in understanding their diagnoses, treatment choices, and treatment side effects, makes this experience even more difficult and traumatic.

Among Latinas, breast cancer is the most commonly diagnosed cancer. Because Latinas are less likely than Caucasians to seek preventive and screening health care services, including clinical breast exams, mammography, and pap smears, a significant number go to their doctors with large tumors and extensive disease.

Several of the reasons why Latinas under-utilize health care services include:

- A lack of knowledge about cancer screening and treatment.
- Lack of health insurance.
- Limited knowledge about cancer related risk factors.
- Fears related to immigration status.
- Mistrust of the medical community.
- Concerns about cost.
- Embarrassment.
- Language barrier.

To complicate matters, the emotional upheaval that takes place following a diagnosis of cancer can create a profound sense of isolation that can be even more devastating for those who have limited access to information and support. Misunderstandings about the illness, difficulty communicating with and understanding one's health care provider, fear of being a burden to family members, and depression are a few of the factors that can increase the suffering of Latinas diagnosed with cancer.

In recent years, research studies have shown that psychosocial support in addition to medical treatment can make a significant difference in the lives of cancer patients. A study by Spiegel and Bloom (1989, Stanford)¹ demonstrated that women with metastatic breast cancer who attended support groups along with medical treatment had less mood disturbance and less maladaptive coping responses than women who received only medical treatment.

Fawzy et al. (1990a and 1990b)^{2,3} looked at early stage melanoma patients and demonstrated that support group participants had significantly improved psychological functioning in comparison to the control group, and at the five year follow-up, group participants had a lower rate of recurrence and mortality. In view of these findings, it becomes important to increase public awareness not only of cancer prevention and early detection, but also of the importance of psychosocial support.

Cancer support groups provide a safe place in which individuals with similar diagnoses can assist one another with mutual support, understanding, caring, and encouragement. The family-like setting facilitates expression of emotions, which frequently are left unspoken in order to protect the important people in one's life. Group members can share their friendship, understanding, fears, and hopes in a compassionate and non-judgmental setting with others going through the same experience. This type of setting allows participants to speak freely about their illness and its effects on themselves and their loved ones without having to put on a "brave front" for family members. For those who find themselves alone and isolated because family and friends are unsure how best to help them through the emotional experience of a cancer diagnosis, a support group becomes very important.

Cancer support groups meet on a regular basis for a specified period of time, with a facilitator who is usually a trained therapist. The facilitator plays a neutral role in the group process, and should be “non-judgmental, sincere, knowing and caring, and one who provides a safe environment in which people can open up and share, and trust that their feelings will not be trivialized, and trust that their disclosures will not leave the room.”⁴

Are Support Groups for Everyone?

Support groups can be very helpful in sorting through the emotional turmoil that comes with a diagnosis of breast cancer. “The goal of a support group is to restore your confidence in the future that the diagnosis of cancer has shattered, to reclaim the control of your life that cancer has stolen from you, and to draw you into a community of understanding people who allow you to connect to others, and to share good and bad news, and to simply recover.”⁴

While support groups appeal to many of us, they do not appeal to all. Reaching out for support is easy for some, hard for others. Not everyone wants to join a support group. Some are not ready, and some may not need a support group. Some will derive greater benefit from one-on-one therapy. At times a group can be stressful—there are difficult topics discussed, such as recurrence, metastasis and dying. Individual needs for talking and sharing change over time, the ages of the women in the group may differ as well as the stages of their disease. These factors alter the group dynamics and may create a shift in the group membership as well as in the appeal of the group to women considering group involvement.

Purpose and Benefits of Cancer Support Groups:

- Provide mutual support and understanding with others undergoing the same experience.
- Provide role models. Veteran group members who are months or years into their diagnosis, and who have successfully come through their cancer experience, can act as role models for newer members.
- Reduce emotional trauma while keeping a sense of hope for the future.
- Decrease loneliness and isolation. Listening to others discuss similar concerns, fears, and hopes can be a source of great comfort and relief.
- Provide a safe, non-judgmental setting in which members can discuss difficult issues.
- Help identify ways in which to manage side effects caused by surgery, chemotherapy, and radiation.
- Provide cognitive restructuring by replacing negative thoughts that increase fear, loneliness, and depression with positive thoughts.
- Instill hope by increasing group member's confidence in her ability to come through cancer treatment and its side effects.
- Increase the sense of altruism among members by allowing them to give as well as receive support, reassurance, and encouragement.
- Increase the sense of accomplishment and joy by allowing members to observe and witness how their support has helped newer members cope.
- For members who live alone or whose family and friends have emotionally withdrawn, the support group offers an immediate support system.
- Increase knowledge about cancer and its treatment.
- Assist members to communicate more effectively with health care providers.

PSYCHOSOCIAL VS PSYCHOTHERAPY



Today, the group approach is widely used by both health care professionals and lay people. Groups for incest survivors, individuals with eating disorders, abusive parents, and alcoholics as well as self-help groups (weight watchers, self-esteem) are a few examples of the kind of groups that are available.

For the most part, groups are composed of six to ten people and meetings are held in a community center, church, office, hospital, clinic, or private residence. Although groups may vary in content and goals, they are alike in that they bring together a group of people with similar problems and coping behaviors.

Despite similarities between psychosocial support and psychotherapy groups, they mainly differ in that a psychotherapy group provides clinical treatment/therapy and a cancer support group does not.

It is important to note for liability reasons that a psychotherapist cannot practice without a license. Although many cancer support group facilitators are licensed therapists, no license is required to facilitate cancer support groups. Psychosocial support is not the same as psychotherapy.

Other differences between psychosocial and psychotherapy groups include focus/task, composition of the groups, and the role of the facilitator/therapist.

FOCUS/TASK

Psychosocial Support Group	Psychotherapy Group
Focus on the here and now.	Focus on past experiences and their influence on present behaviors.
Provide emotional support, reassurance, and education about illness, treatment and its side effects.	Explore long-standing behavioral problems.
Goal is to support group members through cancer experience.	Goal is to improve intrapersonal and interpersonal relations.

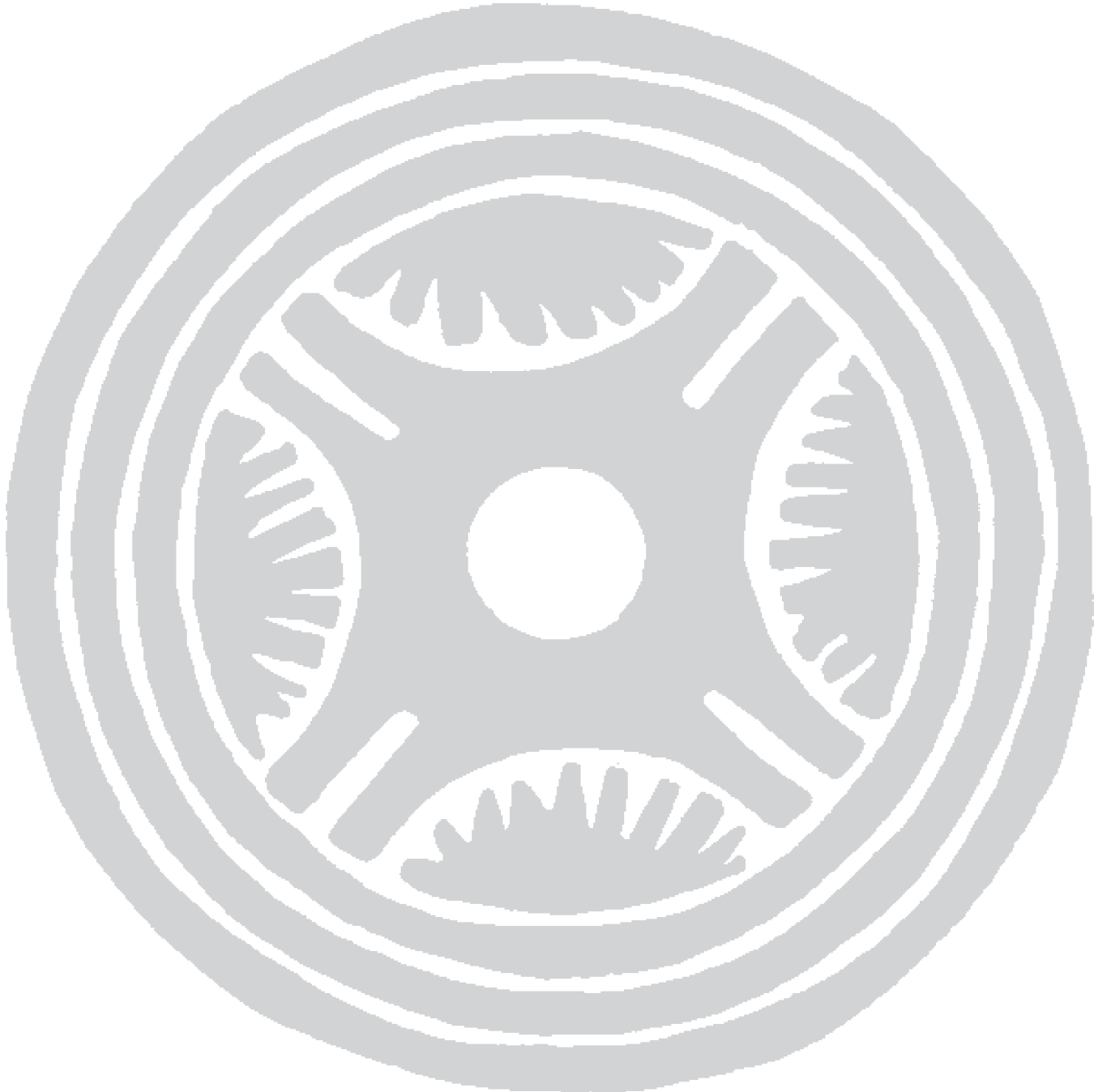
GROUP COMPOSITION

Psychosocial Support Group	Psychotherapy Group
Members are generally well-functioning individuals who may never have needed a support group if they had not had a diagnosis of cancer.	Members have long-standing intrapersonal and interpersonal problems.
Socializing between members is encouraged.	Socializing between members is discouraged.
All referrals are generally accepted into the group.	More selective in who can attend the group.
Absences are expected.	Absences are discouraged and may be interpreted as resistance.

ROLES OF FACILITATOR/THERAPIST

Psychosocial Support Group	Psychotherapy Group
There are fewer boundaries between the leader of a cancer support group and its members than there are in a psychotherapy group.	There are definite boundaries between the leader of the support group and its members.
Although the facilitator's expertise is recognized, the facilitator participates in a similar way to other group members.	A psychotherapist participates in a different way than the group members.
The facilitator is viewed by participants as being a member of the group.	The psychotherapist is viewed by group members as being separate from them.
The facilitator self-discloses.	The psychotherapist rarely if ever self-discloses.
The facilitator conducts home and hospital visits.	The psychotherapist rarely if ever goes on home and hospital visits.
The facilitator may take on a social worker role.	The psychotherapist never takes on social worker role.
The facilitator is process-aware.	A psychotherapist is process-focused, paying attention to how members behave in the group, how they interact with other group members and therapist, and where they sit.
The facilitator is less active in the group.	A psychotherapist takes a more active role during group sessions.
	A psychotherapist confronts group members and offers interpretations
Non-clinical trained individuals can facilitate cancer support groups.	Specialized training and licensing is required.

ESTABLISHING THE BASICS





Before a cancer support group begins, decisions have to be made about where and when the group will meet and the general expectations e.g., number of meetings, participants, and evaluation of progress. Support group developers must secure an appropriate location, decide the time and day of week, size and composition, the duration of each session, and whether the group will be open-ended or closed (see pages 14 and 15). Most importantly, the location of the group should be near public transportation and in the community of those the group hopes to serve.

Although cancer support groups can take place in a variety of settings, it is important that the space feel welcoming and homelike rather than clinical and cold. A “living room” arrangement with comfortable furniture is the ideal setting. Furniture should be set up in a way that allows the participants to have eye contact with one another, as well as give the facilitator(s) an unobstructed view of each member. The space should be free of clutter and noise, and provide enough privacy so that group discussions are not overheard by someone standing outside the door or in an adjacent room. If a living room arrangement is impossible, seating members around a table is an option. The setting can be made homier by placing a nice cloth and/or flowers on the table. Facilitators can provide snacks and refreshments before or after the group meeting. This allows group members to socialize and become better acquainted.

Physical Setting

Cancer support groups can take place in the following locations:

- Hospital.
- Church.
- Community Agency.
- Private Residence.
- Senior Center.
- Social Service Agency.

Of the settings mentioned above, a hospital may be the least desirable because of what it represents to many women diagnosed with cancer. Hospital smells may also cause some women to feel nauseous or sick, especially those receiving chemotherapy.

Time & Day

No one time or day will be convenient for everyone. Consideration should be given to the following:

- Facilitators’ availability*.
- The availability of most group members.
- Travel time for facilitators and group members.
- Walking distance from public transportation to group location.
- Safety issues.

*A facilitator may have another role/employment in addition to leading a support group. This will affect time availability and commitments, and the ability to provide one-on-one support.

Size

Group size can affect both group process and a member's decision to stay in or drop out of a cancer support group.

An overly large group (ten or more) may lead to the following:

- Members may feel overwhelmed.
- Members may leave feeling discouraged or angry because time ran out before they were able to share their cancer story.
- Group participation may diminish and interaction between group members may be compromised.
- Members tend to address the facilitator rather than the group.

Six to eight members are an ideal number. This size of group is manageable and provides everyone the opportunity to share their cancer stories within the time frame of the group.

Since not all participants will stay with the support group, *facilitators should register a slightly larger number (12) to account for attrition and for absences due to:*

- Treatment side-effects.
- Cancer stories that are too overwhelming.
- Fear and anxiety caused by a death in the group.
- An offensive statement inadvertently made by a group member.
- Other factors such as car breakdowns, travel, family, illness, etc.

Duration

A two-hour session provides a group of six to eight women time to share their cancer experiences without feeling rushed. It also allows for a social warm-up before focusing on major themes. *Sessions longer than two hours can result in weariness and fatigue.*

Frequency

The frequency of meetings can vary from once-per-week to every-other-week to once-per-month. Weekly sessions may be too much for newly diagnosed members. With monthly sessions too much can happen between meetings for some people, and issues raised in the previous session may be forgotten. The development of group cohesion is also affected. *A bi-weekly (twice/month) schedule is ideal, giving members time to rest between sessions.*

Open Groups

Open groups may continue indefinitely with changes in membership as participants leaving the group are replaced with new members. One disadvantage of open groups is that group cohesion may be affected if too many members leave at one time. This can result in delays in support of new members. *Preparing the group before bringing in a new member is as important as preparing a new member coming into an on-going group.* Facilitators should review ground rules and the purpose of the support group with each incoming member. Facilitators should also let group members know when a participant has decided to leave the group. One of the advantages of an open group is that a stable core of members usually exists despite dropouts.

Closed Groups

A closed group typically meets for a predetermined number of sessions, and accepts no new participants as members leave the group. Each member is expected to remain with the group until it ends. Members evaluate their progress and decide whether additional meetings are needed.

Group Composition

When starting a cancer support group the tendency is to accept all those who are referred. Although in the beginning accepting every referral may be necessary, it is important to keep in mind that *not all referrals are suitable candidates for a support group*. Thus, assessing who will benefit from a cancer support group experience, and who may impede group process, needs to be carefully addressed in the early stages of group development. Improperly selected participants can have a detrimental effect on the character of a group and on the development of group cohesion.

Although we cannot always predict group behavior based on a pre-group interview, it is nonetheless the best way to determine if a referral is an appropriate candidate for a cancer support group.

The following are examples of inappropriate referrals to a cancer support group:

MAJOR DEPRESSION

- Although depression is a normal response to a traumatic event, women experiencing a major depression may need more than group support to help them through their cancer experience.

- Major depression is twice as common in adult women as men and can be precipitated by severe psychosocial stresses. *Women with major depressive symptoms should be referred to mental health services.*

The signs of major depression include:

- Loss of appetite.
- Sleep disturbance.
- Inability to care for self (not bathing, combing hair etc.).
- Diminished ability to think/concentrate.
- Hallucinations.
- Markedly diminished interest in almost all normal activities.

SUICIDAL IDEATION

Most women diagnosed with cancer want to recover and live a full life. Nonetheless, it is important for facilitators to be aware of signs related to suicide in order to make an appropriate and *immediate* referral.

Risk factors include:

- Major depression.
- Rejection of help.
- A recent suicide attempt or previous history of attempts.
- A family history of suicide attempts.
- Substance abuse.
- Ready access to a lethal weapon.
- Communication of suicidal intent.
- History of poor judgment.
- Social isolation.

An unlicensed facilitator i.e., one who does not have an advanced degree such as LCSW, MSW, MFT, PhD or one without clinical experience should not attempt to provide counseling to a client who is seriously considering suicide. Immediately consult with your supervisor and call 911. Keep the client on the phone or in your office until emergency workers arrive.

SOMEONE WHO IS DYING OR IN THE LAST STAGES OF HER ILLNESS

- Excluding a seriously ill referral may be difficult for facilitators. While group involvement may be inappropriate, facilitators can offer in-home support.

SOMEONE IN CRISIS

- Members and facilitators may get pulled into a crisis intervention mode during group session, taking a significant amount of group time from other members. If this happens, the facilitator may wish to speak with the member outside of the group and provide one-on-one support.

Additional questions to ask when developing a cancer support group are:

- What diagnoses will be included? Breast cancer only? All cancers?
- How many people in the community to be served have cancer? How many cancers are diagnosed each year in the community? How many Latinas are diagnosed with cancer each year in the community?
- Do you want a support group that includes partners of persons diagnosed?
- What age range(s) are to be included? Women 50 and over? Under 50? All ages?
- At what stages of the disease? Early stage? Metastatic? All stages?
- Newly diagnosed women only?
- Latinas diagnosed several to many years earlier?

There are “general” groups that accept various cancer diagnoses and ages. Depending upon the community, the need for a group, and the availability of psychosocial support, a group devoted to a single disease (e.g., breast cancer) may not be advisable.

Advisory Committee

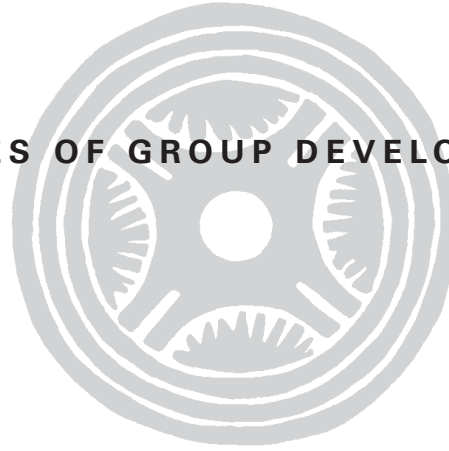
The development of a cancer advisory committee can be an important aspect of support group programs. It may be part of the sponsoring agency’s structure or operate more as an auxiliary to the group. The committee can help insure that the program meets the needs of Latinas diagnosed with cancer as well as create community involvement. We suggested that such a committee be comprised of 10 to 15 individuals who represent the local Latino community, cancer survivors, health and mental health professionals, representatives of the media, and corporations. This number may be revised downward, depending upon the size of the community.

The committee can help facilitators in the following way:

- Identify funders.
- Recruit other committee members.
- Conduct support group outreach in the community at large.
- Assist with referrals to the support program.
- Assist in giving credibility to the program.
- Assist in locating a meeting site.
- Ensure that services are culturally appropriate and accessible.
- Assist with fund-raisers.
- Support the work of the facilitators.

For a more thorough discussion of the Advisory Committee, please see the Community Organization Section, Part 2: Creating an Advisory Committee, page 60.

STAGES OF GROUP DEVELOPMENT



All groups, regardless of content and goals, undergo stages of development. These stages are greatly influenced by the facilitation skills of the group leaders and the composition of the group. *Stages described here are based on Dr. Carmen Ortiz' observations and not on empirical data studying the behaviors of cancer patients. (See Reference section, page 45, for additional discussion.)*

Initial Phase

In the beginning stages, while group members are developing trusting relationships with each other, the facilitators take on a more active role. Later, when group cohesiveness is well in place, the facilitators are less active, allowing group process to flow without interruption.

During the initial phase, group participants are involved in getting acquainted with not only group members, but with facilitators. They are learning how a cancer support group functions, whether the group meets their expectations, and how much of their cancer story is safe to disclose.

Facilitators should expect that some members may be tentative, vague, or quiet, and that the level of anxiety during this phase may be high. *A facilitator's goals are to establish a climate of trust and acceptance, encourage self-expression, and provide structure and ground rules.*

Middle Phase

The establishment of relationships characterizes the middle phase. During this time, participants begin to share more of their cancer stories. They are learning to trust and confide in the group as a place where they can experience their grief and loss.

Group members tend to be self-focused rather than group-focused as they begin to discover their identity within the group.

Facilitators should expect some members to become more depressed as their stories of grief and loss unfold. Some may experience a fear of losing control, while others may feel the need to give advice or rescue a member undergoing a difficult moment. *The facilitator's main goal during the middle phase is to facilitate participants through the grieving process by allowing each member to speak about her cancer story without interruptions, and by assisting members in identifying coping skills that will help them through the various stages of their illness.*

Integration Phase

During the integration phase the leadership of the group shifts from the facilitators to the group as a whole. Participants are more group-focused than self-focused, interacting with one another in more direct ways. They understand the grieving process and, as a result, begin to offer constructive support and insights to the group. Most importantly, they begin to integrate into their daily lives their cancer experience and what is learned in the group.

Since leadership is shared by the group, facilitators should expect (and encourage) group members to be less dependent on them. If group cohesion is strong, members will talk about topics other than cancer such as family conflicts, problems parenting children, sexuality, and significant others. Most members will refer to the group as a "second family" and participate in social activities outside of the group. *The facilitator's main goal during this phase is to maintain group cohesion.*

FACILITATING THE GROUP





CHARACTERISTICS OF A FACILITATOR

A facilitator is someone who possesses not only the necessary expertise and training to organize, manage, and facilitate a cancer support group, but the self-awareness and personal characteristics vital in work involving illness, invasive surgeries, treatments with debilitating side effects, overwhelming emotions, and death. It is the facilitators who:

- Validate feelings.
- Encourage self-expression.
- Facilitate the development of group cohesion.
- Assist members in identifying coping skills that will serve them from diagnosis through recovery.

Although breast cancer support group facilitation can be conducted by health/mental health professionals as well as non-clinically trained individuals, *it is imperative that facilitators (regardless of training) understand group process, possess knowledge of the complexities of breast cancer, and understand the physical and psychological impact of a breast cancer diagnosis.*

Facilitation should always be conducted in the language of the participants rather than through an interpreter.

Thus, it is very important that facilitators be fluent in Spanish. Part of the interview process should be conducted in Spanish in order to determine the candidate's fluency. Additionally, many group members may feel more comfortable with facilitators from their own ethnic group.

Survivor versus Non-Survivor

An individual who has never experienced a diagnosis of cancer can be an excellent facilitator. There are advantages, however, to having group facilitators who have battled the disease. These advantages include:

- Group members may feel an instant bond and, as a result, relate more easily with a facilitator who has undergone the same experience.
- Group members may feel more comfortable talking about their feelings and fears with someone "who truly understands".

A facilitator who has experienced cancer may have a better understanding of what it means to live on a daily basis with the fears, anxieties and hopes brought on by a cancer diagnosis.

Personal Characteristics

Regardless of whether the facilitator has had cancer or not, effective facilitators possess personal characteristics important for the successful facilitation of cancer support groups. Although some of these characteristics can be inherently part of the facilitator's make-up, others have to be learned and practiced. The following are a few of the many personal characteristics an effective facilitator possesses:

SELF-AWARENESS

Discovery of one's inner self, although painful at times, is a journey well worth the struggle. Discovery can take place with the help of a trusted friend, a minister, a parent, or a psychotherapist. Facilitators

can begin this process by making a list of the reasons why he/she wants to lead cancer support groups. It is important to consider the motivation, fears, and hopes the facilitator has for those who will participate in the groups. Is the facilitator's motivation overly altruistic? Do the facilitator's fears mobilize or immobilize (her)? Are the facilitator's hopes for the group members realistic or unrealistic?

This self-exploration exercise is important because a facilitator must be genuine and honest with herself as well as with her co-facilitator and group members. This is especially true for facilitators who have had a personal experience with cancer and whose fears and anxieties may be reawakened by group discussions.

A facilitator who has not adequately resolved personal issues will project—consciously or unconsciously—fears, anger, and sadness onto the group. The following can be expected of a facilitator with unresolved issues:

- Abruptly changes the topic when a member is speaking about a particular feeling or fear.
- Does not allow group members to experience the pain of a diagnosis or loss of a breast.
- Rescues a member who is crying or highly emotional.
- Avoids discussions that feel emotionally threatening or that create inner turmoil.
- Does not allow the group to experience the loss/death of a member.

An effective facilitator pays attention not only to the nonverbal behaviors of group members but also to her own. Does the facilitator's heart beat a little

faster when discussing the death of a group member? Does the facilitator hold her breath or experience a flushed feeling when discussing a recurrence? *Knowledge of one's own fears and anxieties can only help in becoming a more effective and understanding cancer support group facilitator.*

WARM AND AFFECTIONATE PERSONALITY

A warm, responsive and professional presentation will assist the facilitator to establish confianza (trust) with group members. Invariably, Latinos will describe a person's personality before they describe their level of expertise. Words such as *amable* (warm), *simpático* (pleasant), and *cariñoso* (affectionate) are frequently used to describe someone who is liked and respected. On the other hand, words such as *frío* (cold), *serio* (overly serious), and *seco* (dry personality) are frequently used to describe someone who is cold and unresponsive.

WILLINGNESS TO DISCLOSE

A 1993 study by Moss, Finney, and Maude-Griffin⁵ found that a group leader's willingness to share her personal experiences with members had a positive effect on the development of group cohesion. *An effective facilitator should be able to share (her cancer story) without monopolizing group discussion and do so in a way that is helpful to group process, i.e., sharing is aimed at helping the group, not the facilitator.*

WILLINGNESS TO LEARN FROM OTHERS

Learning is a life-long process that does not stop once you have finished your training or earned a degree. *An effective facilitator is open and responsive to learning from all those who participate in her cancer support group.*

CULTURAL SENSITIVITY AND AWARENESS

Knowledge of cultural beliefs about health, illness, family, and religion are crucial in understanding the group of people one hopes to serve. Often our perceptions of others are influenced by gross generalizations. It is important to remember that in spite of various cultural similarities, Latino groups vary with regard to duration of U.S. residence, degree of acculturation, language, racial composition, and sociopolitical experience.

It is also important to note that cultural beliefs about the causes of cancer vary among the numerous Latino sub-groups. For example, many Latinos view illness as caused by an imbalance between hot and cold. A cold or the flu may be associated with a sudden change in the weather, walking without shoes, or eating/drinking cold foods.

Folk healers are commonly used to treat Western recognized illnesses as well as folk illnesses such as *susto* (fright), *mal de ojo* (evil eye), and *empacho* (blocked intestines). Folk healers can include the *curandero* (healer), *yerbero* (herbalist), and the *sobador* (masseuse).

While it is important to be aware of these cultural considerations, it is more important to get support members to discuss their own beliefs.

RELIGIOUS SENSITIVITY

For many Latinas religion plays a key role in how they respond to their illness, treatment, and recovery. Regardless of one's own beliefs, it is important to respect the ways in which Latinas incorporate religion into group discussions. Although the majority of Latinas who participate in support groups are Catholic, Latinas from other denominations (e.g., Baptist, Pentecostal, Mormon) also participate.

RESPECT

Respect plays a vital role in Latino culture. Respect for authority, for adults and the elderly, and respect for the formal use of language need to be recognized and understood by those leading Spanish-language cancer support groups. Initial meetings with prospective group members tend to be carried out in a formal manner, changing to a less formal one once *confianza* (trust) is established. Facilitators need to pay close attention to the words and tone of voice used when quieting a member who is disruptive or who is monopolizing group discussion. If the facilitator comes across as disrespectful, she will lose the respect of group members.

PATIENCE

Organizing and managing a cancer support program requires patience and endurance. The recruitment of members, establishing group cohesion, and managing the group take time and patience. Too often, in their eagerness to form a group, facilitators may rush someone into joining a support group before she is ready. As a result, she will attend inconsistently or drop out after one or two group sessions. The facilitator is then left feeling frustrated and doubtful about her abilities.

Beginning facilitators, unaccustomed to working with groups, may feel impatient when the session is not going as planned or when a group of diverse women with different problems, difficulties, and living experiences come at her all at once. Patience is required.

SENSE OF HUMOR

Support groups are more than just a place to talk about fears, sadness, and depression. They can be a place of fun and great joy. *Laughter can be a powerful healer.* Funny stories that lead to laughter can have a positive effect on group process, and in bringing members closer together in their struggle and fight against a common disease.

Co-Facilitator Model

Working with individuals diagnosed with cancer can be exhausting both physically and emotionally. While there are several facilitator models, this Project uses a co-facilitator model. *Co-facilitation has several advantages, including sharing the responsibility of facilitating and managing a group. Because the workload is shared, the possibility of burnout is reduced.*

A co-facilitator can also:

- Act as an additional support person after a highly emotional session, or after the death of a group member.
- Provide group members with a different but compatible outlook.
- Can alternate opening, leading, and closing the group.
- Continue the group meetings if one of the facilitators is absent.

A co-facilitator can also reduce the anxiety and nervousness a novice facilitator may feel.

When using the co-facilitator model, we recommend that one of the facilitators have clinical experience as well as experience facilitating groups. Although a license is not required to facilitate support group, we suggest that candidates with an MFCC, MFT, MSW, PhD, or LCSW be seriously considered.

For the successful facilitation of cancer support groups, co-facilitators need to have a mutually respectful working relationship. Unresolved conflicts with a co-facilitator can have a profoundly negative effect on group process. The group will be negatively affected when facilitators:

- Openly disagree with one another.
- Use group time to work out their disagreements.
- Openly contradict or criticize each other.
- Speak badly of the other to group members.

Whenever two or more people work together, disagreements are bound to occur from time to time. Therefore, *open communication and the desire to work out differences are important in establishing a positive working relationship.* As a way of maintaining open communication, facilitators should meet with each other before and after the group sessions.

Before group sessions, the facilitator(s) should discuss the following:

- Issues and themes from the previous session that need further exploration.
- Group members who are having a difficult time.
- Who will open, lead, and close the group.
- Who will fill out the group progress form (see sample form, pages 121).

A group progress form should be filled out during each session. The form is used to record attendance, issues that arise from group discussions, problem members, important issues specific to individual members, and absences. The facilitator who does not lead the group should be in charge of filling out the progress form. Notes are very helpful. Only brief notations should be taken during the group so that the facilitator can remain involved in the group's discussion. More extensive notes can be added later.

After group sessions, the facilitators' discussion should include the following topics:

- Group members who need follow-up.
- Who will conduct follow-up telephone calls and home/hospital visits.
- Absent members and appropriate follow-up.
- Planning of the next group meeting.
- Disagreements and conflicts in the working relationship.

Disagreements, conflicts, and problems in the facilitators' working relationship should be discussed after the group meeting, rather than before, to avoid negative feelings carrying into the group session.

ATTRIBUTES OF A GOOD FACILITATOR

- Neutral.
- Non-judgmental.
- Sincere.
- Culturally sensitive.
- Caring.
- Respectful of differing religious beliefs.
- Respectful of age, authority, informality.
- Patient (patience).
- Sense of humor.
- Knowledge of one's self.
- Warm and affectionate personality.
- Willingness to self-disclose.
- Good listener.
- Willing to learn from others.

BENEFITS OF CO-FACILITATOR MODEL

- Shared responsibility.
- Shared workload.
- Reduced burnout.
- Different outlooks.
- Group can continue to meet if one facilitator is absent.
- Reduces anxiety and nervousness of novice facilitator.
- Facilitate the development of group cohesion.
- Assist members to identify coping skills that will serve them from diagnosis through recovery.



Grief, following a traumatic loss such as the death of a loved one or the loss of one's health or body part, can be both physically and emotionally depleting. Generally, a person's makeup and past experiences with loss will determine how long and how well she copes with grief. For some, recovery may begin days or weeks after a loss. Others may take months and even years to fully recover.

Since people react differently to a loss, it is important for the facilitator to assess during her first conversation with a potential member where the woman is in the grieving process. Women who are still in the shock phase or who feel overwhelmed with medical appointments may not be ready to join a cancer support group. Nonetheless, it is important to offer whatever support is needed even if the invitation to the support group is declined.

A woman may be interested in joining a support group at different times in relation to her breast cancer and treatment.

One-to-one relationship building is critical in the development of psychosocial support programs for Latinas diagnosed with cancer. Establishing *confianza* (trust) should be the facilitator's primary goal with no expectation that the person referred will join the group. The support group should be mentioned as an option if and when the client is ready to participate. Weekly phone calls and home/hospital visits are an excellent way to begin this one-to-one relationship building. During these weekly contacts the facilitator should assess the following:

- Does she understand the cancer diagnosis and treatment recommendations?
- Does she need educational materials?
- How is she doing physically and emotionally?
- How has her diagnosis impacted family members?
- Does she have a strong support system? Does she live alone?
- Does she need transportation or child care services?
- Does she need a wig, a turban, or a prosthesis?
- Would she like a home or hospital visit?

Facilitators should note in their appointment books the dates of surgeries and start dates of treatments. The facilitator can then call the client the day before a surgery to assess level of anxiety, to insure understanding, and to offer support. Calling a few days after treatment begins gives a facilitator an opportunity both to assess if the client is having treatment side-effects and to offer support.

Grief

Often in our society grief is related to sadness. Thus, if a person expresses their grief by crying, we may mistakenly assume that they are grieving appropriately. Grief, however, is more than just one feeling or emotion. Grief is a process that can take days, weeks, or years to resolve. It can manifest itself not only through emotions (e.g., anger, despair, anxiety, rage, guilt, sorrow), but physically as well (e.g., headaches, stomach aches, panic attacks).

Stages of Grief*

SHOCK STAGE

- The initial response to a cancer diagnosis is usually one of shock.
- The shock phase may last for days or even weeks.
- In this phase, the person diagnosed may not feel the full impact of the diagnosis.
- Many feel dissociated from their feelings and from those around them.

Feelings may include:

- Disbelief.
- Panic.
- Numbness.
- Fear.

Physical reactions can include:

- Fatigue.
- Weight loss/gain.
- Nightmares.
- Nausea.
- Dizziness.

DENIAL STAGE

- Once the shock of a cancer diagnosis wears off, a period of denial may follow.
- Some may convince themselves that a medical error has been committed or that their tumor was mistakenly switched with someone else's.
- Many may refuse to speak about their cancer to family and friends.

- Family and friends may deny the cancer diagnosis.
- Many avoid anyone or anything related to cancer.

FEELING STAGE

- As the individual begins to accept the reality of a cancer diagnosis, the mourning process takes over.
- Depression may increase as the individual comes to grip with the loss of her health and/or body part.
- Feelings and emotions may occur together or at different times.
- The goal of the facilitator is to provide support and increase the reality of the loss by allowing members to verbalize their feelings and emotions.
- Facilitators can assist the individual to identify coping skills that will help her through this very difficult time.

Feelings may include:

- Sadness.
- Anguish.
- Despair.
- Fear.
- Guilt.

Physical reactions may include:

- Appetite disturbance.
- Weight gain/loss.
- Nightmares.
- Panic attacks.

*The stages of grief discussed here are based on the writer's (Dr. Ortiz') experience and observations and not on empirical data studying the behaviors of cancer patients.

RECOVERY STAGE

- Feelings are not so intense, and the span between moments of despair is separated by days, weeks, and for some women, months.
- Women begin to integrate cancer into their lives while keeping a sense of hope for the future.
- Others may look at their cancer experience as a turning point propelling them to make changes in their personal and professional lives.

Pre-Group Interview

The main purpose of a pre-group interview is two-fold: to assess where a prospective member is in the grieving process and to begin to establish a trusting relationship. As already stated in the *Setting the Stage* section, group behavior cannot always be predicted solely on a pre-group interview. However, making a personal contact either by telephone or by a home or hospital visit allows the facilitator to determine whether the prospective member is a suitable candidate for a cancer support group. Additionally, and perhaps most importantly, a pre-group interview initiates a relationship between the facilitator and the potential member. Because the concept of *confianza* (trust) is an important one in Latino culture, a pre-group interview allows the facilitator the opportunity to begin working toward developing a relationship of trust. It goes without saying that if a prospective member has an already trusting relationship with the facilitator she will feel less anxious and fearful about joining the group.

Initial referrals can be made by a physician or other health professional, a community agency or service, etc., or women may self-refer. Because the chaos and confusion that follows a diagnosis of cancer can be all consuming, the facilitator should make the initial call rather than wait for the person referred to call about the group. A facilitator, however, should never call a new client without their permission. Therefore, when conducting outreach, facilitators should inform referring parties of their wish to make the initial call. The referring individual can then obtain the client's consent before passing on their telephone number to the facilitator.

Pre-Group Preparation

The purpose of pre-group preparation is to:

- Review with a prospective member the purpose of a cancer support group.
- Explain the role of the facilitators and group members.
- Address myths or misconceptions about cancer support groups.
- Discuss confidentiality.
- Review and normalize common reactions of new members to a group experience.

New members may feel:

- Scared about sharing their cancer stories with a group of strangers.
- Anxious being around others with advanced cancers.
- Nervous before their first meeting.
- Depressed after their first meeting.

It is important to note that although pre-group preparation is necessary, the facilitator should not overwhelm the prospective member with too much information. A facilitator should be able to explain the purpose of the group and assess the referred person's readiness to participate without bombarding her with too much information.

Facilitators should keep in mind that a new member may not remain with the group despite pre-group preparation. Pre-group preparation, however, allows the facilitator to convey a positive message about the support group and assists her in anticipating one or more of the reactions listed above, all the while reassuring the new member that these are temporary and should decrease after a few sessions.

Excluding a prospective member should be done with sensitivity in an honest and direct manner by clarifying how the individual's expectations differ from the group's. Exclusion does not mean she cannot join at a later time. Provide one-on-one to this person or refer her to an appropriate service. It is important that she not be left without support.

Intake Form

Facilitators should complete an Intake Form (sample, page 123) on each person referred to the support group. Most of the information needed to complete the form should be collected in the course of the conversation with the prospective member. *Facilitators should avoid asking numerous direct questions in order to keep the pre-group interview from seeming like an interrogation. Keep the discussion as conversational as possible.*

The information collected can be used to determine:

- If a group will be for breast cancer, only.
- The most common type of cancer in your groups.
- The age of most of your group members.
- The number of early versus late diagnoses.
- Where most women in your group are being treated and by whom.
- The number of low-income members.
- Who most often refers women to the group.
- If referrals are made from only a few people.



*A*s already mentioned in previous chapters, how well a group comes together is dependent upon a number of factors: group characteristics, environment, and the experience and motivation of the facilitators. In addition to the concepts and issues already discussed, facilitators should consider the following regarding the successful management of cancer support groups.

Group Cohesion

Group cohesion, although a complex and abstract concept, is an important one to understand. Studies (Yalom, 1995)⁶ indicate that groups that have a high degree of cohesiveness tend to have members who are more open to support from others, are more willing to listen, self-disclose more often, and value the group goals more highly. As a result, cohesive groups have a higher rate of attendance, participation, and mutual support among its members.

The manner in which group cohesion develops is not set in concrete. Instead, it is a fluid process that can take days, weeks, or months. While some groups come together easily, others take more time, and still others never quite achieve a sense of stability and solidarity.

The facilitators' role in the development of group cohesion is an important one. *If facilitators are unable to provide a safe space and a sense of trust and belonging among members, the development of group cohesion will be greatly affected.*

First Meeting

How well a group develops is highly influenced by what takes place during a member's initial meeting. Because individuals come into a group unsure of what to expect or how they might help others, it is important to take a few minutes at the beginning of each session to orient new members to the purpose of a cancer support group. Thus, with each new member facilitators should:

- Restate the purpose of the group.
- Review group norms/rules.
- Identify personal goals.
- Identify common fears.
- Define confidentiality.

A participant will not return if she leaves her first group session feeling out of place, unwelcome, or confused as to the purpose of the group.

The Check-In Model

An individual who is naturally shy begins a cancer support group with a certain amount of anxiety and uneasiness. Someone who is generally insecure may feel scared and anxious about how she will be accepted, and perhaps doubt her ability to be of help to others undergoing the same experience. For someone coming into an already established group where members have been meeting for some time, the experience of entering such a group can be especially difficult. Despite individual differences, it is safe to assume that everyone entering into an unfamiliar situation will feel some degree of anxiety.

The check-in model is a way to ease someone's entrance into a cancer support group without feeling the pressure of saying more than she is willing at a first meeting. Although everyone is required to participate, each is allowed to say as much or as little as she chooses, allowing her to transition into the group at her own pace.

Each participant is asked to say who she is, when she was diagnosed, the type of cancer she has, her treatment history, and how she is feeling physically and emotionally. This process is repeated at each session for the following reasons:

- It puts everyone's cancer story out in the open.
- Each time a member repeats her cancer story she adds a little more detail.
- Group members need to remember their cancer experience before they can come to grips with their grief and loss.
- It promotes group interaction by inviting members to ask questions of one another.
- Self-disclosure is important in the development of group cohesion.
- Members learn how to trust and confide in each other.
- Repetition helps members reframe their cancer experience.
- Topics of discussion evolve out of a member's cancer story.

Once members know each other well, check-in takes less time and is primarily focused on the physical and emotional well-being of each member rather

than the specific details of each cancer experience. At this time, the facilitators and/or group members can introduce specific topics for discussion or a guest can be invited to speak to the group.

Member Type

Each member brings into a group characteristics, values, and familial histories that will influence how much or how little she will participate in group discussions. Because the success of a cancer support group depends on the participation of all of its members, the facilitator needs to stay alert to any problem or conflict that may interfere with group cohesiveness as well as the promotion of interaction between group members.

Although it is important for the facilitators not to lose sight of the group as a whole, it is nonetheless important to know each member and how she may or may not be interacting with others. *It is the role of the facilitators to reconnect or engage those who are having difficulties as well as set limits with others who may be monopolizing group discussions.*

Member types can include:

- The talker.
- The chronic complainer.
- The help-rejecting member.
- The self-righteous member.
- The interrupter.
- The silent one.
- The advice giver.
- The rescuer.

Absences and Dropouts

Facilitators should expect to have absences and dropouts in the normal course of a cancer support group. You can expect a member to miss one or several meetings due to the debilitating effects of her illness. Others who return to work may not have the time or energy to continue in the group. Still others have received all they have needed from the group and feel no need to continue. *However, because the early development of group cohesion is greatly influenced by the stability of its membership, frequent absences and turnover can have an adverse effect on the facilitators, group members, and on group process.* Thus, it is important for the facilitators to conduct extensive follow-up to determine the reasons for absences and dropouts.

The one-to-one relationship building does not stop once an individual becomes a member of the group.

Weekly or biweekly contact by telephone or a home visit will give the individual the opportunity to disclose a problem or conflict she is unwilling to bring up in the presence of other group members. This contact will also allow facilitators to stay connected with group members too ill to attend a session or those who have dropped out for one reason or another.

Possible reasons why a group member may miss a meeting include:

- Feels overwhelmed or frightened by the cancer stories of participants, especially those with more advanced cancers.
- May still be in the shock or denial phase.
- Group may not meet her expectations.
- Takes an instant dislike to another member or facilitator.
- Wants to keep her diagnosis a secret.
- Effects of surgery, chemotherapy or radiation.
- The death of a member.
- A recurrence.
- Transportation problems.
- Childcare problems.
- Major depressive episode.
- Other family problems.
- Work pressures.
- Other illness.



A cancer support group is a place for members to express the feelings, fears and hopes that they are unable to express elsewhere. Thus, issues and themes that surface during group discussion will be guided in part by how safe and comfortable members feel in the group. Useful, supportive, and helpful discussions will not take place without that feeling of safety. Members will hold back, sharing very little of their cancer experience and its impact on their lives.

Prior to establishing group cohesion and safety, members' concerns about surgery, treatment options, and side effects of treatment dominate group discussions. Once members feel the group is a place where they can freely express all their feelings, more in-depth issues and themes unfold.

The following are examples of the common issues and themes that emerge during different stages of the illness.

After the Diagnosis

For most women, a cancer diagnosis causes a myriad of overwhelming feelings. For Latinas unable to speak or understand English, a diagnosis of cancer can be even more devastating.

It is the time immediately following a diagnosis of cancer when English-speaking and non-English speaking women most need the support from facilitators.

Since women tend to cope better when they fully understand what is happening to them, it is important that they receive simple and practical

information about their diagnosis and recommended treatments. The facilitator may be called upon to help with this, as well as to assist Latinas in communicating more effectively with those who are attempting to help (e.g., health care professionals, social services). Such assistance greatly reduces the encompassing fear and confusion that many Latinas experience. This is a potentially difficult role as the facilitator must be careful not to take on the role of the physician. Interpreting medical data or providing medical explanations can be difficult. It may be appropriate and beneficial to do this with the physician.

The following are examples of common themes and issues that may arise following a diagnosis of cancer:

- The "Why me?" question.
- The "What did I do to cause my cancer?" question.
- Fear of dying.
- Concerns regarding surgery and other treatment.
- Concerns about node dissection.
- Concerns about making the right surgery and treatment decisions.
- A sense of "loss of control" over their bodies.
- The need to deny the illness.
- Questions to ask their physicians.
- Fears about communicating effectively with physicians.
- Financial impact of cancer.
- The social attitude toward people with cancer.
- How to speak to children about cancer.
- How this will affect the spouse/partner.

After Treatment Begins

After chemotherapy and/or radiation begins, issues and themes tend to be centered on the effectiveness and side effects of treatment. The following are examples of the more common issues and themes that arise after treatment begins:

- Changes in body image.
- The effectiveness of chemotherapy and radiation.
- Dealing with side effects of surgery, chemotherapy, and radiation.
- Stress-reducing techniques.
- The effectiveness of alternative treatments.
- The impact of hair loss.
- Concerns about being a burden on family members.
- Concerns and questions about diet and nutrition.

Once Treatment Ends

During the first few weeks after a diagnosis of cancer, medical appointments, surgeries and other treatments may distract a group member from the full impact of a diagnosis of cancer. Once treatment ends, however, and the attention of family and friends diminishes she may ask, "Now what?" During this time she may begin to experience new worries as a result of having less medical attention. She may also begin to feel the full impact of a cancer diagnosis.

Issues and themes that arise after treatment ends may include:

- Post-treatment depression.
- Feelings of loneliness and helplessness.

- Fear of recurrence.
- Mourning physical loss.
- Concerns about nutrition.

Group Cohesion

Once group cohesion is established, issues and themes become more personal in nature. Group members disclose more openly and share more intimate information about themselves and their families. Issues and themes that arise may include the following:

- Impact of diagnosis on family and friends.
- Long-standing family conflicts.
- Body image and sexuality.
- Fear of dying.

After the group has been meeting for several months and the need for personal expression is not so high, the facilitator can begin group discussions with a quick check-in followed by the introduction of a specific topic or issue. Topics can be introduced by the facilitators, a group member, an educational video or guest speaker. Topics may include the following:

- Using illness as a catalyst for positive change.
- Assertive communication with physicians.
- Nutrition.
- Non-cancer related topics.
- Relaxation techniques.
- How to speak to children about cancer.



*L*istening is a more subtle and sometimes more difficult skill than speaking. When someone says, “You’re a good listener,” it generally means that you listen with attention and interest. This conveys to the speaker, verbally as well as non-verbally, that you are alert and focus on the speaker’s feelings, message, and ideas.

Since the majority of the facilitator’s time is spent listening to others speak about their illness, she needs to be alert and observant not only to what is being said, but how. If the facilitator appears disinterested or is busy taking notes rather than listening, there will be little movement in the group, and a limited exchange of ideas and feelings.

LISTENING SKILLS

- Stay focused versus drifting away.
- Place total concentration on the speaker.
- Suspend judgment.
- Hear the total message versus selective listening.
- Listen with respect.
- Accept speaker’s message even if different from your own.
- Verify comprehension.

APPROPRIATE RESPONSES

Clarify: Ask questions about what was said to ensure understanding.

Paraphrase: Restate in different words what has been said.

Summarize: List main points of discussion.

Offer feedback: This allows the listener an opportunity to let the speaker know she was heard as well as how you feel about what has been said.

Relay: Pass an idea, message, or topic from one group member to another.

Reinforce: Verbally confirm and validate the speaker’s feelings. This motivates the person to continue speaking.

Ask open-ended questions as a way to elicit new information, allowing the speaker to go deeper into an issue or topic.

Nonverbal Communication

When we speak, it is not only our words that convey a message, but also our body language. In fact, most of us make assumptions of others based upon their physical appearance, body movements, gestures, and facial expressions.

For most people nonverbal communication is an unconscious process. Thus, it is important for facilitators to pay attention to the nonverbal messages they may be communicating to group members.

Equally important is the facilitator's attention to the nonverbal messages conveyed by group members. The success of a support group depends on the participation and contribution of all of its members. If one or several members are staring out a window, it is up to the facilitator to reconnect them in a way that does not make them feel singled out or uncomfortable.

FACIAL EXPRESSIONS

- Can convey what a participant feels about group process, other members, topic of discussion, and facilitators.
- Can show discrepancy between verbal and nonverbal communication. For example, a member may smile when talking about illness and death.
- Can convey understanding, fear, sadness, and confusion.
- Can show the effects of a cancer diagnosis.

EYE CONTACT

- Eyes are a powerful means of communicating.
- In eyes, we can see affection, love, anger, sadness, or empathy.
- How much one is willing to look directly into the eyes of another is culturally influenced.
- In some cultures, direct eye contact is disrespectful while in others the reverse is true.
- Generally, too much eye contact (staring) or too little (ignoring) can create problems.
- With time, facilitators should come to understand each group member well enough to know the level of eye contact she feels most comfortable with.



CRISIS COUNSELING

A crisis can be brought about by any traumatic event that causes a person to experience an uncommonly strong physical, cognitive, emotional, or behavioral reaction. Symptoms can begin immediately following the trauma or months/years later in the form of major depression, flashbacks and nightmares.

Physical reactions can include:

- Chest pain.
- High blood pressure.
- Dizziness.
- Tremors.
- Sleep disturbance.
- Chills.
- Difficulty breathing.
- Rapid heart beat.
- Nausea/vomiting.
- Profuse sweating.
- Fatigue.
- Diarrhea.

Cognitive reactions can include:

- Decreased alertness.
- Mental confusion.
- Impaired memory.
- Nightmares.
- Impaired concentration.
- Slowed thinking.
- Disorientation to person, place and time.
- Disruption in logical thinking.

Emotional reactions can include:

- Panic.
- Major depression.
- Suicidal ideation.
- Anxiety.
- Hopelessness.
- Shock.
- Anger.
- Mania.
- Fear.
- Grief.

Behavioral reactions can include:

- Withdrawal.
- Decreased appetite.
- Hypervigilance.
- Excessive silence.
- Paranoia.
- Substance abuse.
- Excessive laughing.
- Hyper/hypoactivity.

In cancer work, crisis counseling is used as a defusing process to lessen the psychological impact of a diagnosis and treatment of cancer. The main goal is to help the individual talk about her feelings and reactions to a diagnosis in a supportive and caring manner. *How strong a reaction someone will experience depends on the type of trauma, the person's coping abilities, emotional stability prior to the trauma, and her support network.*

Crisis counseling can take place via the telephone or face to face. When providing crisis counseling over the telephone, facilitators should maintain a caring and supportive tone. Eye contact, facial and body language appropriate to the conversation and active listening are maintained in a face to face counseling session.

The phases of crisis counseling are as follows:

- **Ventilation of feelings.** The first phase of crisis counseling allows the person in crisis an opportunity to express her emotions. If the person is highly agitated, the facilitator may want to calm the person prior to eliciting feelings. When the person begins to speak, the facilitator should interrupt as little as possible. Opened-ended rather than yes and no questions should be asked. Occasionally, the facilitator may use expressive words that convey understanding of the person's feelings.
- **Opportunity to verbalize their cancer story.** The facilitator gives a person in crisis not only an opportunity to express emotions, but also an opportunity to verbally tell her cancer story. This may include when and where the person was when they received the cancer diagnosis and their first reaction to the news. It allows the person to reconstruct and integrate the trauma as well as face the reality of her diagnosis.
- **Normalization of feelings and symptoms.** Once the person in crisis has had sufficient time to express her feelings and verbalize her story, the facilitator should take time to normalize the person's stress response. Many individuals will feel enormous relief by simply hearing that what they are experiencing is a normal reaction to a traumatic event.
- **Identifying coping skills.** It is important to assist the person in identifying coping strategies that will help her through the crisis. Coping strategies can include those the person has successfully used in the past or new coping strategies suggested by the facilitator or other group members.

RESOURCES

The resource phase involves providing the person in crisis with resource numbers, educational materials and, if necessary, referrals to other agencies (e.g. mental health). If appropriate, an invitation to the cancer support group can be offered at this time. A brief description of the support group should be given along with general information about location, transportation, and time.

FOLLOW-UP

A telephone or home visit should follow two to three days after initial contact regardless of the person's decision to attend the support group. The main purposes for follow-up contact are to insure that the person is moving through the crisis, to answer questions about the disease, and to assist in resolving any lingering issue or problem.



The death of a group member can be a trying and intense experience causing a vast array of emotions. For some, the loss of a group member can be a terrifying experience pushing to the surface their own fears about dying. For others, the emotional reaction will be one of relief—relief that the deceased member is no longer suffering from the devastating effects of her illness.

Responses to Death

Responses to the death of a group member can be physical, emotional, and behavioral. For most, it is a combination of all three. Physical responses can include stomach upset, tightness in chest/throat or dizziness. Emotional responses can include sadness, depression, guilt, and fear. Behavioral responses are dependent on the impact of the loss. Those especially affected may choose to leave the group while others may miss a few sessions immediately following a death before returning.

How a group member responds to a death depends on:

- A member's personal perceptions about death.
- Stage of the deceased's disease.
- The number of years into the member's own recovery.
- Degree of affectionate bond to the deceased.
- Whether or not she has the same type of (breast) cancer as the deceased.
- The number of losses she has experienced.
- Religious beliefs.

Processing the Death of a Group Member

Although processing the death of a group member can be a difficult and draining experience for many facilitators, the loss has to be acknowledged and discussed. *Ignoring or denying the effects of a death may have a severe impact on the group members left behind.* It is important that they be given an opportunity to adequately express their grief. How long the deceased had been a member of the group and the group's affectionate bond to the deceased will determine the length of time it will take to move the group through this difficult period.

Because there is no right or wrong way to grieve, each member's personal experience with grief needs to be respected and acknowledged. Despite these differences, the goals of grief processing are essentially the same for all group members.

The goals of grief processing include:

- **Accept the reality of the loss.** Group members may deny the loss by avoiding the group or any discussion about the loss. Verbalizing the loss breaks the denial and makes it more real.
- **Experience the pain of the loss.** Members may avoid experiencing the pain of a loss by leaving the group or by avoiding sessions. If their feelings are denied their pain may resurface at another time.
- **Adapting to deceased member's absence.** Members who sat next to the deceased or those who had a close relationship with the deceased member have to adjust to the void the loss has created. Once this accommodation of feeling has been accomplished they can begin to establish more affectionate bonds with other members.

Facilitators' Response to Death

It is important for facilitators to keep in mind that they too are impacted by the death of a group member. Too often facilitators exclude themselves by intellectualizing the processing of grief. Rather than sharing their feelings with the group and fully participating in the closure ritual, they rigidly adhere to their facilitating role. A facilitator who is unable to process her own grief may:

- Project her sense of loss onto the group.
- Feel afraid to become emotionally involved with group members.
- Not be able to recognize a member's need for additional support.
- Avoid any expression of grief.

Generally, it takes the group two to three sessions to move through the grieving process. Once verbal processing is completed, the facilitator can provide the members with some sense of closure by performing a ritual. The following is one example:

- Burn sage to cleanse the physical space.
- Light a candle(s) to provide guidance and enlightenment.
- Place a photograph of the deceased next to the candle.
- Stand or sit in a circle with hands together.
- Begin ritual with words and/or a prayer honoring the gathering and the deceased.

- The facilitator hands a photo of the deceased to the group member on her left who speaks about how the death has impacted her, what the member meant to her, and what she will miss most about the deceased. The photograph is passed from one member to another until everyone (including facilitators) has had an opportunity to speak.
- Close ritual with words and/or a prayer with hands together.

Usually verbal processing followed by a ritual is sufficient to move most members through the grieving process. Facilitators, however, may need to provide additional one-to-one support to members who continue to experience a difficult time.

Occasionally, a referral to a mental health agency may be necessary when the group member needs something more than group and individual support.

Processing the death of a group member can be an intense emotional experience. At times, a loss may bring up unresolved grieving issues, as well as fears about recurrence and of our own death. This is especially true for group members who are newly diagnosed, and for those who have the same cancer as the deceased member.

It is imperative that new members not be brought into a group in the middle of grief processing. Rather, the facilitator should wait until the group has sufficiently worked through their grief and after the closure ritual takes place.

RECOGNIZING AND UNDERSTANDING BURNOUT





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orking with women diagnosed with cancer can be a rewarding experience; it also can lead to burnout and stress if group facilitators do not pay close attention to their own physical and emotional well-being. Facilitators have to cope not only with the psychological reactions and physical ailments of group members, but also with their own feelings of vulnerability and mortality aroused by being with seriously ill patients, some of whom will die.

Initially, facilitators may feel fired up, excited, and willing to give tremendously to group members. Emotional overload takes place when they give until there is nothing left to give. It can happen to anyone who over-extends herself. *Those who work with seriously ill patients are especially vulnerable.*

Definition of Burnout

Burnout: physical or emotional exhaustion from long-term stress. A pattern of emotional overload is at the heart of the burnout syndrome.

The Effects of Burnout

The ability to be supportive and understanding when sharing in someone's cancer experience is a commendable trait. There is, however, such a thing as too much caring. Therefore, it is important to maintain a healthy psychological distance between yourself and the women in your group. When this emotional detachment is combined with genuine caring, burnout is avoided. The physical and psychological price of caring too much can lead to:

- Emotional and physical exhaustion.
- Sleep disturbance/insomnia/nightmares.

- Difficulty awakening.
- Tension/difficulty relaxing.
- Chronic fatigue.
- Lack of appetite/overeating.
- Reduced personal accomplishment.
- Low self-esteem.
- Decrease in the quality of work.
- Negative attitude about the group and its members.
- Callous and cold attitude.
- Extended coffee and lunch breaks.
- Earlier quitting time.
- Increased absenteeism.
- Negative impact on life outside of work, family and friends.
- Resignation.

Facilitators may take on an attitude of cold indifference and become emotionally distant from the people whose needs and demands feel too overwhelming, reaching a point where they are unable to provide the appropriate help, support, and comfort to those in their groups. Reduced personal accomplishment can lead to:

- Negativity about oneself, cancer work and others.
- Feelings of distress and guilt.
- A sense of inadequacy.
- Decreased self-esteem.
- If depression is severe enough, one can burnout on life.

Internal Factors

What a facilitator brings to a work situation is just as important as what the work situation brings out in the facilitator. Examples of what a facilitator brings to her work are:

- Motivation.
- Self-esteem.
- Needs and wants.
- Self-confidence.
- Value system.
- Emotional expressiveness.
- Fears.

Internal factors determine how well or how poorly one handles the external sources of physical or emotional stress, and assists us in understanding why one individual may experience burnout in a particular work environment while another individual will not. This is not an attempt to put blame on certain personality types; instead, it is a way to understand what makes one more susceptible to burnout and stress.

At high risk for burnout are facilitators who:

- Have been unable to work through the death of a significant other.
- Have difficulty with loss.
- Are under pressure to perform.
- Are expected to do more than their share.
- Have difficulty setting limits, being assertive, saying no.

- Have a tendency to over-extend themselves.
- Do not get along with the co-facilitator.
- Have a low frustration level.

Esteem and Confidence

If you do not like the person that you are and you continuously question your abilities or are overly self-critical, you will be more susceptible to burnout and stress. Low self-esteem and confidence can result in the following:

- Cancer work will feel difficult and overwhelming.
- You will be less assertive in your dealings with group members and co-facilitator.
- You will defer too often and, as a result, feel powerless.
- Setbacks become major issues. Instead of learning from your mistakes, you use them to confirm your worst fears.

Understanding Your Limits and Responsibilities

It is not only important how you feel about yourself, but how well you know and understand your skills, talents, strong points and weaknesses. The inability to recognize your limits will result in the following:

- Increased likelihood that you will exceed your limits.
- Inability to recognize when to stop, when to say no, and when to make changes.
- Over-involvement with group members and their families.

Emotions

Group sessions will at times elicit strong feelings of anger, sadness, and frustration. Those unable to deal with their feelings in a constructive way will either vent their feelings inappropriately or turn them inward. Facilitators who themselves have battled cancer can become fearful about their own health and mortality when listening to others speak about their illness.

Fear will be more pronounced when there is a recurrence in the group, when a member reports metastasis, or when there's a death. Facilitators who become overly fearful may fail to confront their own feelings; deny or avoid feelings of fear by blocking or becoming numb; or abruptly change group discussion to something less threatening:

External Factors

There are numerous external factors that can contribute to burnout. This chapter focuses on three factors: work environment, working relationship with co-facilitator, and working relationship with supervisor.

WORK ENVIRONMENT

The work environment itself may be a source of burnout. The following are a few examples of external factors related to work environment that can lead to burnout:

- Too much work, not enough time.
- Too many demands from group members, co-workers, and supervisors.
- Cramped work space.

- Lack of appreciation from supervisor.
- Lack of support from supervisor.
- Lack of control over the scope, quality and quantity of work.
- Lack of input on policy that affects one's job.
- Lack of mental health days in work schedule.

WORKING RELATIONSHIP WITH CO-FACILITATOR

Conflicts with one's co-facilitator can be a great source of stress. This, in turn, can have a profound effect on group process.

Conflicts will arise when co-facilitator:

- Does not do her share of the work.
- Has a bad attitude about life.
- Has power issues.
- Does not take constructive criticism well.
- Has trouble relating to others.
- Openly contradicts or criticizes you in front of group members.
- Has difficulty working as a team.
- Is overly competitive.
- Is unwilling to ask for help or share her feelings.
- Views co-facilitator as a rival rather than as a partner.

WORKING RELATIONSHIP WITH SUPERVISOR

Supervisors are in a unique position to shape and influence the facilitator in either a positive or negative way. They can easily hasten or alleviate burnout and stress by their actions or non-actions.

Burnout can occur when:

- Negative feedback predominates.
- Positive feedback is minimal or non-existent.
- The facilitator is taken for granted.
- There is little trust or faith in the skills of the facilitator.
- There is little trust or faith in the skills of the supervisor.
- Supervisor is moody and irritable most of the time.
- Supervisor is too busy to check in with facilitators.
- Supervisor has difficulty listening to complaints.

Preventing Burnout

The cost of burnout can be high in terms of facilitator turnover and productivity. Therefore, it is crucial for both facilitators and supervisors to watch for the signs and symptoms of burnout. It is important to remember there are methods for coping with stress and burnout that can help and should be incorporated into all psychosocial support programs.

Facilitators as well as supervisors should periodically review this chapter. Doing so will help them more readily identify the signs and symptoms of burnout.

On a personal level, each facilitator can avoid burnout by being honest and open with both the co-facilitator and the supervisor. It is okay to ask for help and to admit one is having a difficult time. If one is feeling helpless and frustrated as a result of performing the same job in the same way each day, it is important to try doing the job differently. Look and see what can be changed and what is fixed and cannot change.

The following are examples of what a facilitator can do to lower the risk of burnout:

- Set clear and precise goals.
- Develop a list of specific goals and steps needed to achieve them.
- With co-facilitator and supervisor, develop a work plan that is manageable.
- Make positive changes in the way job duties are handled.
- Concentrate on the positive.
- Acknowledge own accomplishments.
- Focus on what can be modified rather than on what cannot be changed.
- Nurture the working relationship with the co-facilitator.
- Praise and recognize the accomplishments of the co-facilitator.

Individuals who are strong in body and spirit can best prevent becoming a victim of burnout.

Taking care of oneself first and foremost is an essential prerequisite to giving support and comfort to those diagnosed with cancer. Fortunately, there are many constructive and positive ways of coping with burnout and stress. The following are a few examples. Keep in mind that what works for one person may not for another.

- Don't wait for nice things to happen, make them happen.
- Bring positive people into one's life.
- Talk to a supportive family member, friend, co-worker.
- Learn to relax, physically as well as mentally.
- Leave work at the office.

- Take time to visit with one's self.
- Write out feelings.
- Allow self time to blow off steam.
- Be self-observant.
- Take breaks. Even a short pause can help one regain a sense of calm.
- Do not skip lunch. If possible, leave the work area.
- Go for a walk; read a suspenseful novel.
- Develop a life outside of cancer work.

For some, the ability to rest and relax comes easily. For others it is a much more difficult task. Either way burnout can be prevented by listening to one's body and most importantly, by making time for oneself. You may want to try:

- Meditation.
- Exercise.
- Full body massage.
- Guided imagery.
- Sports.
- Prayer.

Saying Goodbye

It is important to take action before burnout gets the best of the facilitator. Unfortunately, most of us wait until the problem is out-of-hand before making changes. If, despite all efforts, the work environment has not improved or the facilitator continually runs into obstacles, it may be time to think about changing jobs. Saying goodbye to cancer work should be viewed not as a failure but as a way of taking care of oneself.

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