2004

A Manual On Forming A Support Group For Cancer Patients' Family Members

Amiee P. Sharrock

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A Manual On Forming A Support Group For Cancer Patients' Family Members

By

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Submitted in partial fulfillment of the requirements for the Masters of Arts in Corporate and Public Communication at Seton Hall University 2004
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Acknowledgement

The author would like to take this opportunity to thank those individuals who contributed to making this thesis completion a reality. First, I would like to thank my family for believing and supporting my dreams. To my friends, who supported me throughout my academic years, especially Paul who always made me smile and relax when times were tough. In addition, I would also like to thank Dr. Donald L. Lombardi, my advisor and mentor, who instilled the notion that I am capable of accomplishing above and beyond my expectations.

Most importantly, I would like to remember and give a special thank you to my late sister Denise Sharrock-Devito, who showed me what family and success was all about. She was the reason this thesis was created. Her memory and warm smile will live in my heart forever.
Chapter 1

INTRODUCTION: THE AUTHOR’S JOURNEY

On my way to the hospital cafeteria, I see a door with a sign that reads, “Welcome to the Family Support Room: Please Come In”. I open the door and see a room filled with people sitting silently in a circle with their heads directed to the floor. I am intrigued, so I walk in further and realize everyone is praying. As people raise their heads, I take notice of the exasperation on their faces. Each face has a sad look of confusion, or perhaps fatigue, but they all seem to find comfort in this circle. Someone sees me and offers a tissue as I realize tears are forming in my eyes. I accept the tissue but back away from the group. I am still not sure how to respond. I am wondering what is going on.

As another tissue is offered to me from a flowery blue box, I start to look around and see many tissue boxes. They rest on every flat surface. Tissue boxes are on the bookcase filled with texts about cancer. They rest on the coffee table under the bulletin board lined with information and volunteer lists. A stray box sits on a soft, cozy red couch big enough for someone to lie down on if they need a quick nap. Some tissues wipe away spilled coffee from drips near the ever-brewing pot. And one
Kleenex box is in the lap of a man that was leading the group in prayer.

Now the circle breaks up and people of all ages and backgrounds are talking to one another. Some people are hugging, others are reading books, and some sit in silence and gaze into thin air. The group leader approaches me and asks what my name is since he has never seen me here before. I introduce myself and he welcomes me to the support group for people who have a family member with cancer. He gives me a tour and lets me know about all the support they offer and medical research they have collected about cancer treatments. The room becomes more welcoming, and I quickly start talking with others. Before I know it, someone is hugging me as I tell my story.

Off in the distance, I hear my name being called. faintly at first, but it grows in volume, louder and louder. I look around but I do not see anyone calling my name. Then, I wake up. And I realize, I have been dreaming. This is no group. There is no comfy couch. No hugs. No smell of coffee. I told my true feeling to no one. I am sitting, my neck stiff, in a cold plastic chair, in the corner of a hospital room where, next to me, my sister Denise is lying in bed dying of cancer. My mom calls me to come get coffee with her and I think to myself, "Today I will search again for a support group." But, I
know that my search is endless and finding support for family members in a hospital is next to imposable.

PURPOSE OF THE STUDY: THE AUTHOR’S STORY

On May 4, 2003, my sister Denise Sharrock-DeVito died from melanoma. She bravely battled cancer for three years. My two sisters, mother, Denise’s husband and I were her allies in the fight. During my sister’s fight, she was in and out of hospitals until ten days before she passed away. After she was admitted, she remained to live out her final days, which were the most difficult for everyone. Those days were emotionally and physically draining. In addition to supporting my sister, my family and I battled with everyday life such as who was going to drive back and forth from the hospital and home to let the dog out. It was especially difficult for my one sister who had to balance a work schedule, two kids and a husband at home. Denise’s husband was now left to make all the medical decisions for her and decide who would be at home with their three children when he was not. Of course, we all pitched in and helped each other out. In addition, we relied upon help from friends and extended family to assist us with everyday responsibilities. However, even after all of the support we received, another type of support was missing. The emotional support for my family and me was just not there.
Sure, we had one another to talk with, but some times it was just too hard to talk with someone that was sharing your nightmare. In the hospital in which my sister was a patient, there was no support offered for family members. We visited local churches in the area, and priests were nice enough to talk and pray with us, but no such support was offered in the hospital.

Although my family and I never spoke about it, we all felt the absence of support. We felt it the most when we tried to get a little bit of sleep or when we stood in the hospital hallway praying. It was there when we sat down to eat or smiled at someone as they passed by. Oh, how that support was missed and so badly needed. For example, a support system would have helped us cope better with what lay ahead and would have limited the tension that grew between us. According to Barbara Delinsky’s (2001) book *Uplift: Secrets From the Sisterhood of Breast Cancer Survivors*, a support group is needed:

My support group filled in the cracks when I needed it most. We shared everything together and learned from one another. There was a common bond. I met many gals during this period, and we held nothing back (p. 183).

Becky Honeycutt, diagnosed in 1995 at age 53, also agrees that a support group is helpful: "I believe that developing
a positive comradery with a person who has walked in your shoes can be very helpful and encouraging" (Delinsky, 2001, p. 187).

The purpose of my thesis is to prove how important a support group is for cancer patients' family members. Cancer does not discriminate, never sleeps, and preys upon nearly everyone. The disease not only affects those infected with it, but it affects anyone who cares for that person. How is a family member treated? There is no chemotherapy for worry. There is no radiation to remove stress. There are no pills to swallow to take away the pain. There is no quick operation to cut out the problem and make it go away. There is only the relief in hugs; tears, warm smiles and the comfort of knowing you are not alone.

However, not many hospitals, if any, offer such a support group. Through this thesis, I will prove that every hospital that treats cancer should have a support group for cancer patients' family members.
RESEARCH QUESTION

Should every hospital that treats cancer have an on-site support group for the patients' family members? This examination will determine if a support group would be beneficial to the cancer patient, family members, and hospital staff. Also, this study will present a manual with guidelines for establishing and maintaining a support group.

OBJECTIVE

The objective of this study will be to prove that hospitals should have and maintain a support group for the family members of cancer patients. I will direct my attention on several points during the course of this examination. The first point will determine why cancer needs to have a support group for family members. I will briefly show the rise of people infected with cancer over the years. My second point will be a close study probing the effectiveness of support groups. I will demonstrate that support groups help patients cope with cancer, help family members deal with the stress caused by this illness, and help hospital staff more effectively do their jobs. My final point will examine why a support group is needed on-site, and the means by which a hospital can effectively create one.
DEFINITION OF TERMS

Breast Cancer: potentially life-threatening malignancies that develop in one or both breasts.

Cancer: is when certain cells in the body become abnormal and grow without control, destroying normal cells.

Chemotherapy Treatment: is a drug that is combined with other drugs to cause a toxic effect upon cancer, usually interfering with cell reproduction. Most chemotherapy medication is given intravenously but oral drugs may be added.

Emotional Support: support given to people that increases their self-esteem and emotional health.

Group Leader: a person who leads or facilitates a support group.

Hospital Staff: doctors, Nurses, Administrators and hospital volunteers.

Leukemia Cancer: is a progressive, malignant disease characterized by large numbers of immature white blood cells that resemble lymphoblasts. These cells can be found several organs in the body.

Melanoma Cancer: is a malignant skin tumor that involves skin cells that produce pigment (melanin). Melanoma is an aggressive cancer that can spread very rapidly.

On-Site (hospital setting): a support group found within a hospital building.

Radiation Treatment: uses a high dosage of localized radiation on malignant tumors, destroying the cancer cells in the treated area.

Support Group: a group of two people or more formed to talk about feelings on a particular topic and gain help when needed.

Support Room: a room used specifically for support meetings.

Terminal-illness
LIMITATIONS

This study will be limited to the exclusive focus on cancer. Other illnesses, which are equally important, will not be researched. The research I utilized for this thesis represents the years of 1976 through 2000 due to the five-year cycle of the reported issuance of cancer statistics. Also, this exploration will stay within the parameters of family members. Patients themselves will be peripherally examined but only in the way they pertain to family members. Information on support groups for family member within a hospital setting is limited and the author concludes more research needs to be conducted. Support groups will be investigated in a general sense. Findings will then relate back to the overall effectiveness of support groups. In addition, the author’s survey did not include hospital staff members. Moreover, surveys did not target only people who had a family member with a terminal illness.
SUBSIDIARY QUESTIONS

In completing this discussion of the necessity for support groups, the following subsidiary questions will be examined.

1. Why cancer?

2. Why is a support group necessary?

3. Will a support group help patients cope with cancer?

4. Will a support group help family members?

5. Will a family member who receives support help extend the life of a patient with cancer?

6. Why should the meeting place for the support group be on-site in the hospital?

7. Why is the hospital responsible for funding a support group?

8. Who should facilitate the support group?

9. How does the hospital create an effective support group?

10. Will a support group also benefit the employees of the hospital?
Chapter 2

CANCER'S ROOT

When the war on cancer was declared in 1971, cancer was believed to be one disease. Research since then has shown that in fact cancer is more than 100 diseases, many of which also have subtypes that require different treatment regimens. The growth in knowledge about cancer biology and genetics that has accompanied this evolution and the insights and interventions that have derived from it "are perhaps the greatest success of the national cancer effort since passage of the National Cancer Act" (Freeman, 1999, p. 8).

Prior to the National Cancer Act of 1971, research was being done on cancer. For example, in the 1960s and a generation earlier, chemotherapy and surgery made inroads into treating certain types of cancer. However, many of the common kinds of tumors such as lung, colon, prostate and breast seemed to be as refractory to treatment. Although the National Cancer Act allowed for more funding to be created and the need for conducting more cancer research become prevalent, since in the 1960s alone 267,582 Americans succumbed to various forms of cancer. It was not until the 1980s that the pieces of the puzzle came together
for researchers: "the picture that emerged showed definitely that damage to both halves of a cell's brain conspired to create cancer" (Weinberg, 1996, p. 247).

In a time that preceded the 70s to the present lies the start of the discovery of what appears to be the causes of cancer. As early as the 1850s, researchers had discovered a defining conclusion about how cancer cells originated. Researches were able to determine that cancer cells arose directly from the normal cells of the organs.

In the 1920s Dr. Otto Warburg developed an entirely new way of posing the cancer quest. Warburg felt that the real solution to cancer lay within the chemistry of the cell. He determined that cancer cells could grow and divide without oxygen, something normal cells cannot do. Thus, he developed the theory that providing the body with more oxygen will kill off, prevent or slow down the growth of the cancer cells. Although Warburg's findings would ultimately be found inconclusive at best it served as the foundation for other researchers to make the true discovery of cancer's cause.
WIDESPREAD IMPACT OF CANCER

It is estimated that 1.33 million new cases of cancer will be diagnosed in 2004. According to a report issued by the National Cancer Institute, the news regarding the incidence of cancer in the United States is mixed. According to President George W. Bush, in 2002 each day 35,000 Americans were diagnosed with some form of cancer and 15,000 died (Press Release 16 December 2003 www.whitehouse.gov). While the death rates of the four most common cancers--lungs, breast, prostate, and colorectal--continued to decline in the late 1990's, overall death rates increased through 1990 before becoming stable from 1998 through 2000. Without a doubt, instances of cancer continue to affect our society.

Unquestionably, we have made major strides against cancer since the passage of the National Cancer Act in 1971, yet more than 13,000 people in the United States still die each day from the diseases we collectively call cancer. The annual national death toll from cancer "exceeds fatalities from all wars fought by the United States in the last century" (Freeman, 1999, p. 6).
THE "C" WORD: CANCER, FAMILIES AND HIDDEN VICTIMS

Cancer is a scary thing. Whether it affects oneself, or one's family members indirectly, this wide-ranging disease will attack one in every four persons. As difficult as the process of contracting the malady is upon the victim, often forgotten is his or her family members and cancer's adverse affects upon them and their respective and collective lives.

Initially, cancer victims' families perceive themselves as being purposely excluded from the care process. This creates a significant sense of tension between them and the hospital staff caring for the victim, thus leading to the family members' emotional problems. The family members' initial challenge is to adapt to the seemingly unbelievable situation confronting them. As they must continue to deal with the every day needs of their healthy family members— they, at the same time, must begin to cope with the uncertainties of the victim's life expectancy and physical and mental comfort levels. Toward the end, a host of emotions converges upon the family members as they at once experience the inability to communicate well and the soon-to-be feeling of eternal loss.
The Random House Webster's Dictionary tells us that the word emotion comes from the Old French word, esmovoir, and the Middle French word emouvoir, to stir up, and the Latin word exmovere, to move away, disturb. The evolution of the word in modern Western culture has led the Collegiate to define it as "a psychic and physical reaction (as anger or fear) subjectively experienced as strong feeling and physiologically involving changes that prepare the body for immediate vigorous action" (p. 638). Denial, anger, fear, stress and anxiety, depression, guilt and loneliness are many of the emotions experienced by family members of those suffering with cancer. Ironically, such stress might possibly be responsible for eliciting cancer and other diseases within these family members themselves if they are not mentally and/or emotionally adjusted. A Canadian family physician, Gabor Mate (2003), has published a book entitled When the Body Says No: Understanding the Stress-Disease Connection, in which he attempts "to prove that there is a link between emotions and personality and the emergence of cancer, multiple sclerosis, ALS, rheumatoid arthritis and other diseases" (p. 2).

Consequently, family members may feel helpless and even resentful over what's going on. When a child has cancer, parents may fear letting him or her out of sight.
An adult cancer patient's young children may not understand all the upheaval around them. Older children may feel guilty because they want to go on with their normal lives. Family members may even feel anger at the patient for getting sick, and then feel angry with themselves for even thinking that way. An example case is as follows:

When one member of a family has cancer, the whole family is affected and, in fact, psychologists consider these family members to be 'secondary patients'. Cancer affects an entire family, not only because there are genetic links to cancer and cancer risk but also because when one member of a family has cancer the whole family must deal with the illness. If you or a loved one has been diagnosed with cancer, help for the entire family may be in order (Delinsky, 2001, p. 35).
HELPING CANCER'S HIDDEN VICTIMS: THE SUPPORT GROUP

Support groups for cancer victims are relatively common. Traditionally, they were nearly exclusively designed for the victims, with their cancer counterparts meeting, talking and assisting each other through a most trying circumstance. However, lost within this dynamic was the family of the victims, the impact the disease had upon them and the value they represented through their inclusion in the process that proved beneficial for both themselves and their beloved victim family member. Study after study has shown how beneficial support groups for cancer victims' families can be. For example, a study was conducted that revealed:

...families that achieved rather than ascribed role-assignment methods before the onset of cancer, families with older children who could adopt expanded role functions, and families with more interspouse communication experienced less disruption, less role conflict, and less strain over time. (Journal of Psychological Oncology, Vol 3(2), Sum 1985. pp. 1-14. Journal)

Interestingly, families facing a member with cancer confront the situation in unique ways. Some may adopt the illness as their theme, while others adopt the more traditional and, to some, reassuring family life as their theme.
Nonetheless, when someone falls ill with cancer, the family is suddenly faced with a whole new set of challenges. They have to provide emotional support and share in gathering information and making decisions about treatment, provide physical care at home, and deal with insurance companies. Even though only the individual with cancer actually has the disease, the psychological effects of the illness extend into the family. In the book *Surviving Cancer Emotionally: Learning How to Heal*, it is revealed that family and close friends should be treated as "second-order patients, people who do not suffer from the disease yet are subject to many of the same psychological consequences" (Granet, 2001, p. 170).

In the past, hospital staff professionals treating the disease have tended to consider family members as merely reactants to the outcome of the disease. Now more studies are being shown that family members also are profoundly affected by the disease and as needy of attention and care as the patient. As discussed, in more detail, prior to each individual will react emotionally to and cope with the news a loved one has cancer differently. One of the most important factors determining the emotional reaction to cancer in a loved one is the relationship to the individual with cancer.
Studies have shown that all members of the family share some sense of emotional crisis. In studies conducted on spouses or life partners, it has shown that they suffer through the same pain as the cancer patients themselves. Moreover, the spouse or life partner's psychological suffering may actually worsen over time. For a parent of cancer patients who are children, the experience of cancer can be devastating. In addition cancer has profound effects on children. Children often feel left out of the decision-making process. Sometimes when children are included in the process they often worry that they bear the responsibility for causing the cancer. Obviously, care and nurturing is needed not just for the patient but for the family members as well.

An example of an overstressed family member with no support is found in Roger Garnet's text *Surviving Cancer Emotionally: Learning How to Heal*. Garnet (2001) describes a husband named Seth:

Seth had a life that was, if anything, too full. Besides working a never ending week to keep his business prosperous, he coach his daughters' soccer teams, volunteered at an inner-city homeless shelter and was an avid Knicks Fan. Seth was always overworked but energized by his various involvements. That all changed when
Seth’s wife, Danielle, was diagnosed with cancer. Although determined to be the quietly competent hunter who could do anything, Seth soon found himself overwhelmed. It was all he could do get the kids out of bed and through the door to school, keep his business functioning and accompany Danielle on each of her many medical appointments. And, as Danielle went through the predictable cycle of emotions accompanying her disease, Seth sat up many nights listening to Danielle’s fears, worries and discussing treatment options. Soon Seth found himself short-fused at work, thin-skinned with his daughters and uninterested in the Kicks.

One morning while he was sitting in the waiting room of the radiation oncology center where Danielle was receiving her initial treatment, Seth struck up a conversation with another man the same age. It turned out they were both Knicks fans and both had wives with uterine cancer. The talk soon went from batting averages to their mutual frustrations over being working husbands whose wives had cancer.

“You Know”, said Seth’s newfound
acquaintance, a bunch of us get together for dinner at the little downtown restaurant on Tuesday nights. It's great. The food's good, but the important thing is that we can talk about what's going on and I find it really helps to know I am not alone in this mess. Why don't you come?

Seth did. He found it helped him enormously to discover other men in precisely the same situation. He was able to express many of the feelings he had been hesitant to share with Danielle, determine that he was stronger than he realized. (p. 170)

Seth's story is a story that can be told over and over again by mouths of many different people. Again each person feels that same emotional and physically drained when a loved one is battling cancer. When trying to do it on your own as Seth did can and will overwhelm you. Having a support group to lean on helps cope with ones day-to-day frustrations, may help deal with what lies ahead and most of all, it develops a sense of security knowing others are going through the same thing as you. Moreover, if a family member receives support it will help relieve the stress and enable them to better assist their family member with cancer. Dr. Yalom, an American group psychotherapist, can
be found in Keith Nichols & John Jenkinson’s (1991) book *Leading a Support Group*. Dr. Yalom, who has studied support groups for many years, states that people in support groups benefit from seven factors: 1) *cohesion* -- a powerful sense of belonging and acceptance; 2) *universality* -- discovering that one’s feeling and experiences are to be found in similar form amongst others in the group; 3) the *instillation of hope*; 4) the *corrective recapitulation of the family group* -- that is belonging again in a ‘family’ of a group where reality testing honest feedback is possible; 5) *imitative behavior* -- people can learn vicariously simply listening and watching while another member goes through his difficulties which are then discussed; 6) *intellectualization* -- the growth of knowledge and understanding of one’s own psychology; and finally, 7) *catharsis* -- the opportunity to express and share feeling with others (pg. 65-67).

A study conducted in 1989 by Stanford University psychologist Dr. David Spiegel found that women with advanced breast cancer who attended weekly support groups lived an average of eighteen months longer than those who did not participate in such groups. Dr. Spiegel’s study goes to show the positive impact support groups have. If people living with the life threatening disease who attended weekly support groups lived longer then those who
did not, makes it apparently clear developing support
groups for family members will enable them to reap the
positive fruits the cancer patents have.

In conclusion, during the past decade research on
support groups have been focused primarily on patients with
the illness and only recently, during the past several
years, more studies are being done on how necessary
support groups are for family members as well as patients.
Evidence-based study has shown that structured group
intervention for family members improve psychological well-
being, reduce anxiety and depression, and even lead to the
extended life of the patient cancer. Obviously, the
benefits of a support group for the patients and patients' 
family members have been substantiated.
Chapter 3

SURVEY ANALYSIS

Description of the Survey

This survey was given to ninety-eight randomly selected participants. The survey was not biased and was not given to any individuals with known prior experience with cancer patients. The survey consisted of ten statements regarding the establishment of an in-house support group for family members with a terminally-ill relative in the hospital. The responses were ranked with five measurements in which a surveyor could indicate their responses: “Strongly Agree, Agree, Neutral, Disagree, and Strongly Disagree.”

Purpose of the Survey

The purpose of this survey was to determine if a support group should be part of every hospital’s facility strategy. Individuals were surveyed to find out if they would benefit from such a support group and if they felt the hospital should be responsible in providing one. The author realized in this research that terminal illness of family members in hospitals touched well over half of all
the people surveyed. And the responses have given good reasons and solid data support, for the writer's main goal of establishing the aforementioned in-house support groups.
STATEMENT 1

A support group for patient's family members should be part of any healthcare facility's strategy when offering services for terminally-ill patients.

The results of this statement reveal that almost 100 percent of the individuals agree that a support is needed. Specifically, 72 percent strongly agreed. Another 21 percent agreed. Only 3 percent disagree with the statement and 4 percent were neutral.

Over 90 percent of people surveyed strongly agreed or agreed that a support group for patient's family members, which leads the author to conclude her theory is correct; a support group for patient's family members is clearly needed.
STATEMENT 2

Hospital staff members should be trained on ways to support families of terminally-ill patients.

The survey data states that over 90 percent of people polled agreed that hospital staff members should be trained on ways to support family members with terminally-ill patients. Only 3 percent disagreed with the statement and 5 percent were neutral.

Out of all people surveyed 92 percent strongly agreed or agreed with statement two. This reveals that it is almost essential for hospital staff to be trained in ways to deal with family members with terminally-ill patients. Moreover, the author believes that providing training to hospital staff members would only decrease the family members stress and form a stronger relationship with the hospital staff members.
STATEMENT 3

Every hospital should have a central, consistent location for support groups for the family members of terminally-ill patients.

In evaluating statement three, one finds that 49 percent of all people surveyed strongly agree that every hospital should have a central, consistent location for support groups for that family members for terminally-ill patients. Moreover, 42 percent of people survey agreed with statement three and 6 percent of respondents were neutral. Only 3 percent of people surveyed disagree and zero respondents strongly disagree.

In total 91 percent of respondents agreed that every hospital should have a central, consistent location for support groups for the family members of terminally-ill patients. The large percentage of people that agree with statement three clearly indicates that developing a support
group within a hospital is something most people will utilize. The author believes that because 91 percent of respondents agreed with statement three, it clearly reinforces that such a support group is vital to every hospital.
STATEMENT 4

It is comforting for you to talk to others who have a family member with the same illness as your family member.

The results of survey four reveals, 83 percent of surveyors strongly agreed or agreed that they find comfort in talking with others who have a family member with that same illness as their family member. Only 2 percent of respondents disagree with the statement and 1 percent strongly disagreed. Fourteen percent of respondents felt neutral about the statement.

Since only 3 percent of respondents disagreed that they would find comfort in talking with others who have a family member with the same illness as your family member, proves the author's theory that people find comfort in talking with others who have a family member with the same terminal-illness. Therefore, the author feels developing a
support group for family members who have a loved with a specific terminal illness will allow them to feel comfort in knowing that they are not alone and others are suffering through the same experience.
STATEMENT 5

A sense of comfort can be garnered from talking to someone who has been/is going through the same experience as you.

The survey data states that over 85 percent of respondents agreed or strongly agreed that a sense of comfort can be garnered from talking to someone who has been/is going through the same experience as you. Only 4 percent of people surveyed disagreed and zero surveyed strongly disagreed with the statement. Eight percent of respondents were neutral with the statement.

Over the majority of people surveyed strongly agreed or agreed with statement five—clearly shows that comfort is garnered from talking to someone who has been/is going through the same experience. The author believes that if people feel comfort in talking with someone else who is going through the same experience as then, developing a support group for terminally-ill family members will create
an comforting environment for people to talk with others who are going through the same experience.
Statement 6

Any healthcare facility providing services to the terminally-ill should be responsible for providing support not only to patients but also to family members.

The data in statement six reveals that 78 percent of people surveyed strongly agreed or agreed that any healthcare facility providing services to the terminally-ill should be responsible for providing support not only to patients but also to family members. Seven percent of respondents disagreed and zero percent strongly disagreed with statement six. Fifteen percent were neutral.

Since over half of the percentage of people surveyed strongly agreed or agreed with statement six, clearly proves that a hospital should provide support for family members. The author believes that the high percentage rage of surveyors strongly disagreed or agreed with the statement because they know what a positive impact support groups can have.
Family members should be provided with as much information as possible about a patient's disease.

In evaluating statement seven, data reveals that 93 percent of respondents strongly agreed or agreed that family members should be provided with as much information as possible about a patient's disease. Only 3 percent of people surveyed disagreed and zero percent strongly disagreed with statement seven. Moreover, four percent were neutral with this statement.

With an outrageous number, 93 percent, of people surveyed strongly agreed or agree that family members should be provided with as much information as possible about a patient's disease. This reinforces that people want to understand what their loved ones are facing. This clearly shows how close loved ones want to be involved with their
family member's challenges. Furthermore, when loved ones becoming involved new emotions are presented to them. Hence there is a need for a support group for family members, which allow them to understand their emotions and find support among others that are going through the same experience.
STATEMENT 8

Most hospitals probably provide clear direction for finding appropriate support groups.

The survey data states that 14 percent of surveyors strongly agreed that most hospitals probably provide clear direction for finding appropriate support groups and twenty-one percent of respondents agreed. Twenty-eight percent of respondents strongly disagreed or disagreed that hospitals provide clear direction for finding appropriate support groups. A large percentage, 37 percent, of people surveyed seemed to be neutral about this statement.

Within this data statement the percentages of people polled showed there as no majority of numbers that swayed one way or another. In fact, all of the total percentages of given choices fall within about eight percent of one another. This leads the author to believe that hospitals have not given clear direction to people who are trying to find appropriate support groups.
STATEMENT 9

Social workers and mental health professionals should have the lead role in providing counseling to family members through the services of a support group.

In evaluating statement nine more than half, 63 percent, of respondents strongly agreed or agreed that social workers and mental health professionals should have the lead role on provide counseling to family members through the service of a support group. Only 10 percent of people surveyed strongly disagreed or disagreed with this statement. Twenty-seven percent or surveyors were neutral about this statement.

In general, over half of the percentage of respondents strongly agreed or agreed with statement nine. This leads the author to believe that social workers and mental health professionals should have the lead role when providing counseling to family members through the service of a support group.
STATEMENT 10

Social workers and mental health professionals are usually more effective when they work "one-on-one" with particular families and specific maladies.

The results of survey ten reveals - 63 percent of respondents strongly agreed or agreed that social workers and mental health professionals are usually more effective when they work "one-on-one" with particular families and specific maladies. Four percent of people polled disagreed with the statement and zero percent strongly disagreed. Thirty-three percent of surveyors were neutral with this statement.

Since a large percentage, 63 percent, of people surveyed strongly agreed or agreed with statement ten, which leads the author to believe her assumption is correct. Social workers and mental health professionals would be more effective when working with family members that are dealing with a particular terminal-illness.
The following final three charts display the survey's age demographic, the gender of people polled and the number of people surveyed who have had cancer or know someone who has.
People whom cancer has affected

32% Yes
68% No
Chapter 4

A MANUAL ON FORMING A SUPPORT GROUP FOR CANCER PATIENTS' FAMILY MEMBERS

The purpose of this manual is to be a guide for people who are starting a support group from scratch for cancer patients' family members in a hospital setting. It is not building a not a handbook of cut and dry rules. Remember, they are no right ways or one style in the creation of a support group. So, one is not expected to do everything the way it is described here. Draw what you need and leave the rest, for each support group will develop differently.

HOW SUPPORT GROUP CAN BE SUCCESSFUL

A patient family members support group is effective when members understand one another's needs and can work together to try to meet them. In successful support groups, members help each other rather than relying on a facilitator. When a group is working well, members can sustain their feeling of connectedness to other group members even when they do not agree on issues. Ideally, a group culture develops and people feel bonds of intimacy, commitment, acceptance, understanding and safety. This
lays the groundwork for group members to feel a sense of unity and build trust with one another. Thus, allowing each group member to talk confidently about his or her story and listening to others in the group. In addition, members start sharing information based upon personal experience and offering emotional support through empathy and understanding.

MEMBERSHIP: CHOOSING BETWEEN OPEN-ENDED OR CLOSED

Unfortunately, there is not a lot of information that tells if open-ended groups or closed groups are more effective in meeting members' needs. However, there are a few tips to keep in mind when establishing if the group should have an open-ended or closed membership.

Open-ended groups meet on a regular basis -- weekly or once/twice a month and follow a very informal meeting format. The group accepts new members at any time, which can be very helpful for people who just found out their loved one has been diagnosed with cancer. However, maintaining an effective open group requires occasional evaluation about how well the group is meeting members' needs, since there will always be a fluctuation of different members. Groups that have a regular process for evaluation will be more likely to stay effective.
Closed membership groups will usually have time or membership restrictions. Each section usually has a prepared topic and usually meets for six to twelve weeks. The membership restriction generally occurs for new members after the second meeting. Closed groups often create a very safe and close-knit atmosphere for members very quickly. It is easier to create safety and closeness when you know who will be at every meeting and how long you will be together.

When designing a support group within a hospital setting, an open-ended support group would work best. A hospital environment has a daily high volume of new patients with family members. In addition, a patient’s stay at a hospital varies and can be as short as four days or as long as five months; therefore, a close-ended support group would not work. Creating an open-ended support group for family members, new and old, would allow future members not have to wait for a new group to start-up; instead, they can enter and group and receive support when needed.
DETERMINING GROUP SIZE

Groups function most effectively for discussions when there are six to eight members. However, an acceptable range is from a minimum of five to a maximum of twelve. When a group membership drops below four members, the group cannot work very well and when it grows beyond ten members it becomes difficult to work on individual issues. But, this does not mean that a group should not meet if there are not enough people. If there is less then four members that show up during a session use the time to build on each person's own goals.

LENGTH AND FREQUENCY OF A MEETING

There is no accepted correct practice regarding frequency of a support group meeting. It will vary on what type of membership, close or open-ended, one's group will be. In addition, determining the frequency of meetings will also be evaluated by how much progress the group is making and what goals were set forth.

For the purpose of this thesis, an open-ended membership will be used, and meetings should take place everyday since they will be conducted in a hospital environment. The norm for an open-ended membership support group would be once a week not everyday. In fact, by holding meetings everyday one can run into a risk. The risk
here is that the group can itself become a way of life rather than a means to a better one. However, when developing a support group of patients' family members in a hospital, different factors are set into place -- volume of people, high turnover rate of different members and most of all, family members that have a loved one in the hospital. They need a lot of support since they have to deal with many issues, and the meetings many be the only support.

The length of time a support group should meet is about 1-1½ hours. This span gives time for meeting, greeting, settling down, work, summing-up, closure and goodbyes, with time available somewhere in the middle if people have something they really need to work out. Less time than this and something is likely to suffer. A feeling of being under time pressure can get in the way and affect the group adversely.
ESTABLISHING GROUP GOALS

Once the focus of the group is clearly defined, group goals should be established. Goals emerge from the purpose and are usually stated as specific actions or activities of the group. One typical goal is to decrease the sense of isolation of loneliness people sometimes experience.

Three group goals that should always be addressed are...

- To learn from and provide encouragement to one another
- To develop coping skills
- To provide a safe, trusting, accepting place where confidentiality is ensured

By using these goals as basic guidelines each group will create a supportive atmosphere. Other goals can be determined by each, individual group.
SETTING THE GROUND RULES

When developing a family member support group it may be helpful to lay a few ground rules. These rules are created to provide a safe, informal but structured environment for sharing and learning from each other. In addition, the rules define acceptable group behavior and may prevent offensive comments or actions and limit constant complaining. In a closed group environment, rules will be discussed and voted on by members. A facilitator can draft the rules when the group is getting started. The opposite takes place in an open-ended membership. The facilitator will create the rules that will enable all members to feel safe and comfortable at the meeting. These rules should be general, like "What is discussed here, stays here". These meeting rules should be reviewed at every meeting for the benefit of new members.
CREATING THE GROUP ENVIRONMENT

The physical setting of the hospital-based support group is crucial. The group room must do everything to counter the sterile, cold atmosphere of the hospital. This can be accomplished with a few simple ideas. The room should be warmly lit with non-hospital lights. The walls should not be white but have an earthy, warm color. Seats should also be warm and comfortable, a couch or two will create a feeling of welcome and a place to lounge or lie down. During a meeting seats should be arranged in a circle so everyone can make eye contact with the person who is speaking. This environment will lead to a successful support group.
THE GROUP FACILITATOR’S SKILLS

A group can only be as successful as the group facilitator’s skills. The following are tips that any facilitator or leader needs to keep in mind to be successful. This list can be found in Pat Kelly’s (2000) book Cancer Self-Help Group: A Guide (p. 85-90).

1. **Listening for Meaning**—by listening one will be able to help the speaker recognize his or her feeling. Only when the speaker is fully aware of those feelings and able to manage them.

2. **Noticing Cues**—much of communication is non-verbal, so it is important to pay attention to other messages one can receive through body language and the hesitation or tone in ones voice.

3. **Clarifying or Paraphrasing**—sometimes understanding what the speaker is trying to say may be difficult, it is important to test your understanding. This can be done by, restating in your own words what you believe the speaker has said.

4. **Using Silence**—many people not comfortable with silence and feel the need to fill the void however it can be very effective when used properly. Silence can help slow down discussion and allow groups members to gather their thoughts.
5. Ask open-ended questions - asking open-ended questions, such as "can you talk about how you would like the group to help with this problem?" will invite the speaker to continue the discussion and explore different or complex issues.

6. Validating Experiences and Strength - when a speaker tells their story the facilitator can show that they have listened by affirming the messages the person has conveyed.

7. Bridging or Linking - the group leader or facilitator can use bridging or linking to help new people connect with the group and each other.
EVALUATING A GROUP MEETING

A facilitator should be sure to regularly evaluate the group meetings he or she leads. The checklist below can be a helpful guide to make sure the group is on-target and growing in a way that will help its members. Immediately after a meeting, running down checklist and jotting down the proper responses can help a facilitator learn about himself or herself and the dynamics of their group’s most recent meeting. This checklist can be found in Pat Kelly’s (2000) book Cancer Self-help Groups: A Guide (p. 33-35).

**Group Leader Checklist**

<table>
<thead>
<tr>
<th>Communication Skills</th>
<th>ok</th>
<th>Need to do more</th>
<th>Need to do less</th>
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<tbody>
<tr>
<td>Keep a constant discussion going</td>
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<td></td>
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<tr>
<td>Being brief and concise</td>
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<tr>
<td>Drawing out others</td>
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<tr>
<td>Listening generously</td>
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<tr>
<td>Thinking before speaking</td>
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<tr>
<td>Not interrupting</td>
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</table>

<table>
<thead>
<tr>
<th>Observation Skills</th>
<th>ok</th>
<th>Need to do more</th>
<th>Need to do less</th>
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</thead>
<tbody>
<tr>
<td>Being aware of tension in the group</td>
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<tr>
<td>Being aware of the energy level</td>
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<tr>
<td>Being aware of who is talking to whom</td>
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<tr>
<td>Being aware of the interest level</td>
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<tr>
<td>Sensing the feelings</td>
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<tr>
<td>Being aware of who is not talking</td>
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<td></td>
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<tr>
<td>Being aware of anyone who is left out</td>
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<tr>
<td>Being aware of issues the group is avoiding or being distracted by</td>
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<tr>
<td>Being aware of silence</td>
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<tr>
<td>Problem-Solving Skills</td>
<td>ok</td>
<td>Need to do more</td>
<td>Need to do less</td>
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<tr>
<td>Recognizing a problem</td>
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<tr>
<td>Stating problem clearly</td>
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<td></td>
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<tr>
<td>Asking for ideas, opinions and responses</td>
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<td></td>
<td></td>
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<tr>
<td>Giving ideas</td>
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<td></td>
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<tr>
<td>Summarizing the discussion</td>
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<tr>
<td>Clarifying the issues</td>
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<tr>
<td>Making a decision</td>
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<tr>
<td>Implementing the decision</td>
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</table>

<table>
<thead>
<tr>
<th>Morale-Building Skills</th>
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<th>Need to do more</th>
<th>Need to do less</th>
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</thead>
<tbody>
<tr>
<td>Showing Interest</td>
<td></td>
<td></td>
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<tr>
<td>Getting others involved</td>
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<tr>
<td>Creating linkages</td>
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<td></td>
<td></td>
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<tr>
<td>Getting agreement</td>
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<tr>
<td>Ensuring a safe, democratic, open process</td>
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<tr>
<td>Appreciating others' idea and abilities</td>
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<tr>
<td>Recognizing individual contributions</td>
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A GUIDE FOR FACILITATORS DURING A MEETING

The following checklist can also be used by a facilitator. By running down this list the facilitator can evaluate how well they are communicating during a group meeting. Below is simple list of what to do and what not to do. This checklist can be found in Pat Kelly's (2000) text *Cancer Self-Help Groups: A Guide* (p. 104). If a leader finds they are checking off too many items from the "Don’t" column, they will soon realize that they are taking over the support group. This will not create an effective environment.

Do's and Don’t for a Facilitator

<table>
<thead>
<tr>
<th>Do</th>
<th>Don’t</th>
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<tbody>
<tr>
<td>Participate</td>
<td>Take over</td>
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<tr>
<td>Provide information</td>
<td>Lecture</td>
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<tr>
<td>Encourage everyone to talk</td>
<td>Pressure</td>
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<tr>
<td>Empathize</td>
<td>Focus on yourself</td>
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<tr>
<td>Clarify people's feelings</td>
<td>Prevent members from doing so</td>
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<tr>
<td>Let members explore</td>
<td>Rescue people</td>
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<tr>
<td>feelings</td>
<td></td>
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<tr>
<td>Protect members from hostility</td>
<td>Block expression of anger</td>
</tr>
<tr>
<td>Support and balance different views</td>
<td>Take sides</td>
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</tbody>
</table>
Prepare an agenda
Use structure and predictability to reduce anxiety
Acknowledge group tension
Use humor to reduce stress or being people together
Encourage members to explore questions

Insist on following the agenda
Substitute structure for control
Avoid tough issues
Use humor to distract or avoid
Assume you need to have answers
HOLDING A MEETING

The following guidelines are necessary tools for when holding a meeting.

- Be there early to welcome new and old members and hand out nametags.

- As participants to sign-in so one can keep track of the members.

- Have a table set up near the entrance with some refreshments and print materials, brochures, newsletters or articles you want to share.

- Arrange the chairs so that everyone can see one another since eye contact encourages communication.

- Always start on time and get going.

- The facilitator should introduce him or her self and ask the members of the group to go around and introduce themselves. This will make new members feel welcome.

- Keep the environment of the group informal, warm and welcoming.

- Keep the purpose of the meeting in mind: to create a connection with others who are experiencing the same situation. In addition, it will encourage member's ideas about what the group should be and do.

- Put together a meeting plan or agenda and write it down on a flip chart ahead of time. Post the agenda
where everyone can see it and ask if anyone wants to add to it.

- Seek professional speakers to come and talk with the group from time to time on different topics.

- Make sure that everyone has a chance to speak and no one is left out. If there is someone in the group that is shy and is not speaking, make sure that he/she has a chance.

- Do not be bound by the agenda if the meeting is taking another turn go with it.

- Do not let one person monopolize the meeting since they could hard the structure of the group. If one person is monopolizing the meeting seek to move on by saying, “Thanks for sharing with us, I really hope that it has been helpful to you.”
Chapter 5

CONCLUSION

I think the most amazing fact I discovered writing this thesis was realizing how young the treatment of cancer actually is. As my survey statistics have shown, everyone knows someone who has had cancer. As I type these words right now, I think of a friend who told me his mother-in-law was diagnosed with breast cancer today. The most astounding fact: the serious treatment of cancer is only thirty-three years old. Such a short time. Not even a lifetime. About one third of a lifetime, with today’s technology. The key date is 1971, the year the United States Government passed the National Cancer Act. Because of this act, cancer -- only treated by chemotherapy and surgery and only thought to be one disease -- became the disease we understand today. In 2004, we know that cancer is more than 100 diseases. We know that cancer has subtypes that require different treatment regimens. And we know this thanks to a law that funded a massive amount of research and brought into the light of day, a disease that lurked in the dark, silently killing us from the inside out. We have come a long way in thirty-three years. At least that is what one would think.
In thirty-three years of research medical science has reached a point, believe it or not, that it is estimated that 1.33 million new cases of cancer will be diagnosed in 2004. Thought that number might be lower, I imagine. It is not. It is high. And it is growing. Regretfully, there is a good chance you, the reader, will know someone in your world who is diagnosed this year. With all this research, you would think things would be better for cancer patients. It is. Treatments are better, more improved, with greater chances of success, by cancer is not cured.

Amazingly, this is how far we have come treating patients with cancer. The question which prompted my thesis is simply this: If we are nowhere near ridding cancer itself for a patient, how far have we come treating the family members of patients? And being a family member of a patient, which I related to you in Chapter one, I know from personal experience and now from the research I have conducted, family members need support and funding for research to learn how best they can cope with cancer in their lives.
RECOMMENDATIONS

Generally, doctors who are treating a patient only treat the physiological aspects of the body; however, now some doctors and researchers are looking at how support groups extend the lives of patients. Discussed in Chapter two Dr. David Spiegel a psychologist at Stanford University formed a support group for breast cancer patients. These were not ordinary patients or newly diagnosed or in the middle of treatment. These patients were terminal. All hope was gone. It was only a grim waiting game. Believe it or not, Dr. Spiegel's support group that had the patients meet with others, talk about concerns, realize they are not alone, prolonged the patients' lived an average of eighteen months longer than those who did not participate in such groups. Now, more and more doctors are realizing the need, the imperative, to treat the body, the mind, and the spirit of a patient. With that being said, why wouldn't a patient's family member benefit from a support group? They, too, are carrying the burden of cancer on their shoulders. And wouldn't it help a patient to have their husband/wife, father/mother, sister/brother, aunt/uncle being treated along with them? Wouldn't it also prolong the life of the patient and of course ease the burden of the family member? The answer to this question is a resounding "yes." This thesis clearly argues this
point. And the writer recommends that all hospitals provide such support to family members, with support groups located on-site.

**FINAL THOUGHTS**

Odds are that some time in the future I will be in a hospital like I was for my sister Denise. Odds are that a family member, a friend, or maybe even myself might some day be diagnosed with cancer. I can hope that as I walk back from the cancer treatment wing, I will see a bulletin board. On that board will be a flyer with directions to the hospital support group for cancer patients' family members. I will take the elevator. Follow the signs. Turn a corner and come to a door.

I will open the door and inside I will see everything I have written about and you have read in this thesis. There will be softly lit lamps. Tables with cancer-coping pamphlets. I will smell coffee in the air. Comfy couches will invite me to sit. There will be blue walls and a plush carpet. It will be a room like no other in the white sanitary hospital.

I will enter. A group will be forming, the chairs in a circle. I will sit, talk with a facilitator, drink some coffee. I will rest, take a breather, talk with others who are coping with cancer, express the feelings that I have
been keeping inside, and I will slowly know, deep in my
heart, that I am not alone. If my thesis has brought me or
anyone else one step closer to making this dream a reality
in every hospital that treats cancer, than this thesis
journey I have taken, for myself and Denise, will all have
been worth it.
BIBLIOGRAPHY


