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Women's perceptions of mastectomy self-help support group experience

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# WOMEN'S PERCEPTIONS OF A MASTECTOMY SELF-HELP SUPPORT GROUP EXPERIENCE

by

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# ABSTRACT

The number and types of self-help support groups are increasing rapidly. However, there is a limited amount of firm data about these groups. The purpose of this study is to identify women's perceptions of a mastectomy self-help group. The descriptive field study utilized a semi-structured interview schedule with thirteen women who had undergone mastectomy and who had participated in a mastectomy self-help support group. Although the small sample size limits the generalizability of the findings, the participants unanimously felt that the self-help support group experience was, for them, a very positive and beneficial experience. The subjects felt that all women should have the opportunity to participate in a mastectomy self-help support group following a mastectomy. The need for further exploration about the appropriate group structure based on perceived needs and experience was identified.

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## ACKNOWLEDGEMENTS

### "My Support Group"

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# CHAPTER ONE

# INTRODUCTION

## INTRODUCTION

Systematic study of self-help support groups is limited. There are, however, conflicting views of the self-help support group experience. This study aims to identify the perceptions women have of the mastectomy self-help support group.

The experience of mastectomy has great impact on the woman who faces a future of questions about mortality, self-esteem, body image, coping with new family relations and treatment of disease. Altered constitutional states accompany the loss of one or both breasts (King, 1962). This loss, particularly in the American culture, is a highly charged emotional experience, involving for many a deficiency in feelings of sexual allurement. Adjusting to and successful coping with the changes brought on by mastectomy have proven difficult and painful for many women.

Schain (1976) describes problems common to women with breast cancer as: the fear of pain and dying, the physical rehabilitation exercises, the prevention of or treatment of lymphedema, the lack of information about breast prosthesis and reconstruction, the need for financial support for the rehabilitation effort, the employment problems, the sexual attitudes and behaviors, the alterations in styles of dress, the communication with family members and the physician-patient relationship.

One method of coping with the problems associated with breast cancer and the subsequent mastectomy is the self-help support group. Also known as mutual-aid groups, this experience and involvement has been cited (Adams, 1979) as providing one kind of effective rehabilitation for cancer patients. The crisis of cancer is felt to require some type of coping behavior. Although many resources are available to oncology patients, the type of help provided in a self-help support group has been cited repeatedly as making a valuable contribution to the rehabilitation of cancer patients (Adams, 1979; Herzoff, 1979; Yalom, 1977).

The number of health related self-help support groups has increased considerably over the last two decades. There are now more than 500,000 of these groups with a membership exceeding fifteen million people (Ferguson, 1979). Much of the literature describes the group process and functions of the group as perceived by health professionals. Although some authors suggest positive consequences for members from the group experience, none focus on the individual member, nor do they show that the group experience is directly responsible for the outcome they describe; they have neglected consultation with group members about their perception of the group experience.

The growth and proliferation of self-help support groups correlates with the shift in major health problems from acute conditions to chronic illness. At present, over 70% of physician visits are made by people who are chronically ill (Gussow and Tracy, 1978). In spite of the shift in major health problems and the number of people with chronic illness, medical services are still oriented toward acute illness. The dynamics of coping with chronic illness have not been incorporated into the acute treatment model, nor has a continuous form of care evolved. As this current trend in health care shifts to focus on chronic and long term concerns, critical examination of alternative methods such as the self-help support group is essential.

Many conflicting views exist regarding professional opinions of the impact and value of the self-help support groups. Some physicians feel that self-help support groups make a valuable contribution to health care and treatment. People suffering from chronic disease or disability can learn a lot from the experience of others, not necessarily about the disease as such, but about the ways in which life can be made as normal as possible (Williamson and Danaher, 1978). The role and utilization of the "experienced patient" (Borkman, 1976) is sometimes employed by physicians in traditional service. For example, people who have been through a procedure such as a mastectomy or bowel revision often visit with other patients before their similar surgery.

In contrast to this favorable image, other physicians encountered by this author do not feel so favorable about the influence of the self-help support group. For example, one physician states that the mastectomy self-help support group was "just a bunch of women trading symptoms". Some physicians with whom this author has spoken thought that the self-help support groups fostered a dependence and that this dependency had a greater impact than the educative or supportive functions of the group. Hence, these physicians have discouraged their clients from attending self-help support groups.

At this time, the potential risks or benefits of self-help support groups remain unclear. Through the systematic presentation of current literature and the inquiry of women who have participated in the self-help support group experience, this study hopes to clarify the influence of self-help support groups.

# CHAPTER TWO

# CONCEPTUAL FRAMEWORK

## CONCEPTUAL FRAMEWORK

The fundamental concept of symbolic interaction is that people's actions are based on the meaning they ascribe to the events and interactions in their environment (Blumer, 1969). Blumer's work is based on the distinctive approach to human study by scholars such as George Herbert Mead and John Dewey. This framework of viewing people, their life events and their interactions is so simple that very often it is ignored. That is, to understand human behavior and human beings, one must look at and try to understand people's behaviors, environment, and events in that environment, as well as their perceptions of their behaviors, their environment and their interaction with their environment.

Man's actions in health and disease are based on many things, but a central variable is the way he "sees" or perceives the disease and what accompanies it (King, 1962). People bring complex assumptions or psychological sets to each situation and the understanding of these cognitive processes requires insight into the individual's perceptions. Beliefs, attitudes and values provide continuity from one situation to the next and add structure by defining the course of action open to the individual (Murray, 1938). Situations involving social interaction such as a self-help support group are perceived differently by each individual who has his own reality. One must attend to the individual's perception and interaction with his/her reality.

The self-help literature is limited because the major emphasis is based on professional reflective essays, descriptions and viewpoints of the group process. The group experience or process is assumed by these professionals to be the cause of some behavioral outcomes they describe, leading one to assume a cause and effect condition. This simplistic viewpoint neglects the individual perceptions of the group experience, and hence, ignores the role of the perceptions of group members in shaping their own behavior. Individual member's perceptions of the self-help support group is taken for granted or the professional viewpoint is considered to be more important.

In the literature on self-help support groups little has been written on the meanings people have ascribed to the events and interactions in their environment, including the self-help support group (Adams, 1979; Herzoff, 1979; Gussow and Tracy, 1978; Gartner and Riessman, 1977; Katz and Bender, 1976; Greenberg, 1976; Schwartz, 1974; Dumont, 1974; Garb, 1974; Falknor, 1973). Mastectomy support groups have had even less attention in the literature. In addition, there is little research on self-help support groups, including the mastectomy self-help support group. "When one considers how many people are deeply involved in group events whose meanings they can scarcely comprehend, and then considers how few of these people do research to enlighten themselves and others, it begins to seem likely that the problem lies not with the groups but with the definition and conduct of research" (Mann, R. in The Intensive Group Experience, Rosenbaum, 1976).

The desire for an increase of self-care in health is illustrated by recent consumer demands for more information about health and more involvement in their own health care. Self-care functions have always been performed by individuals and families, but this current increasing trend in health care has its roots in the women's health movement and other activist groups in the 1960's. Clients are beginning to define their rights, as individuals and families, to develop their own definitions of health, their own priorities, their own options and their own risk indicies (Norris, 1979). The question of why self-care is a subject of new or increased public interest since the sixties is not clear, Levin (1979) suggests the following factors influencing this rising interest:

1. the "de-mystification" of primary medical care.
2. "consumerism" and popular demands for increased self-control, related to anti-technology, anti-authority sentiments.
3. changes in life-style and rising educational levels
4. lay concern with regard to perceived abuses in medical care
5. the lack of availability of professional service

Physicians too, are examining alterntive approaches to health care as they begin to recognize that traditional orthodox medicine is not meeting the needs of many people. The San Francisco Bay Area is the forefront of the Holistic Health Movement. For example, pioneers such as John Travis and Tom Ferguson are physicians who do not practice medicine in the traditional sense of the word. Dr. Travis' practice is devoted to promoting wellness rather than treating illness. Dr. Ferguson does not practice clinical medicine, rather, he edits a quarterly journal, Medical Self-Care, (Inverness, California) in an effort to equip people with the tools they need to direct and control their own health care. Dr. Carl Simonton focusses his efforts on cancer patients. His approach, in conjunction with traditional medical treatment such as chemotherapy or radiation, utilizes the client's self-directing and self-healing powers through mental imagery and visualization. This physician thinks that the idea that an individual's behavior can promote and maintain good health has served to popularize the current trend toward self-care and holistic care in today's health care system.

An important basis for health and self-care is the individual's social support system. It is believed that social support provides individuals with opportunities for feedback which may offset deficiencies in communication with the larger community (Caplan, 1976). Individuals within a support network can share experiences, inform others of expectations and provide guides to behavior based on their experiences. Members can also help each other to mobilize psychological resources and master emotional burdens. A close-knit network of family and friends is considered an important self-care practice (Ferguson, 1980).

The family has traditionally provided a social support network for individuals. However, in times of illness, the family's needs also increase, often reducing their resources and their abilities to provide support for individual members. In addition, the changing nuclear and extended family structures have left many people without such social support structures (Nye and Berardo, 1973).

The health care system has provided people with support via diagnosis and treatment of disease and education focused on the pathology and medical treatment. The health care system has been ineffective in providing people with emotional support, especially in the most stressful times. Gartner and Riessman (1977) suggest that the traditional treatment models have become outmoded for meeting the needs of those who suffer from chronic illness.

This author believes that the notion of the self-help support group was conceived as a response to the inability of family and the health care system to provide social support around specific situations. According to others (Gussow and Tracy, 1978; Rosenbaum, 1976) the growth of varied and diverse groups was a response to unmet consumer needs in health care. Katz and Bender (1976) suggest, in contrast, that people join with others in the self-help support group to identify with those in similar situations and to assert themselves. The self-help support groups can serve as a reference group and a vehicle through which members can overcome feelings of isolation and stigma.

Until recently, very little was written about the influence of the social support system on health and illness has had very little research. Although a few studies (James, 1976; Weiss, 1973; Nuckolls, 1972) have been conducted relating social support and health, these studies presented only preliminary evidence of the relationship of social ties on health and illness.

Berkman and Syme (1979) surveyed 6,928 adults in Alameda County, California. Four sources of social contacts were examined: 1) marriage; 2) contacts with friends and relatives; 3) church memberships; and 4) informal and formal group associations. Nine years later, mortality information was collected.

The results of this study suggest that social and community ties are associated with lower risk of mortality. Those people with social ties and relationships had a lower mortality rate than people without such ties. This was consistent in all age groups.

Although some research on self-help support groups has been done, pioneer authors describe the concepts and definitions differently. The aim of these groups is frequently to increase insight and problem solving ability. Part of the popularity of currently existing self-help support groups stems from their success in effecting "cures", meeting members needs, as defined by members, over and above the success of approaches in the traditional health care system (Marram, 1978).

Some authors have divided self-help groups into categories as they related to the functions of the group. Gussow and Tracy (1973) have developed a two-dimensional analysis of the functions of self-help support groups. The first type related to the group that provides direct services to patients and their families by providing mutual assistance, education, skills and encouragement. These groups help people deal more effectively with their conditions. The second type of group relates to fund raising, public policy changes and research. The two types of groups are not mutually exclusive, and one type of group can encompass the other.

Levy divides self-help support groups into three categories: 1) groups that help with a life crisis such as colostomy, mastectomy, or parenting without partners; 2) groups for people with permanent, stigmatized conditions such as mental illness, homosexuality and dwarfism; and 3) groups for people with addictions such as drug abuse and obesity.

Katz and Bender (1976) suggested a five-fold system of classification: 1) groups that are primarily focused on self-fulfillment or personal growth; 2) groups that are primarily focused on social advocacy; 3) groups whose primary purpose is to create alternative patterns; 4) "outcast haven" or "rock bottom" groups; and 5) "mixed" types.

Schwartz (1975) described a different type of self-help support that he named the Situation/Transition group. This type of group has five essential factors: 1) they are primarily oriented towards helping members cope more effectively with some shared external event; 2) they have the properties of small groups and meet regularly, usually once a week, for one to two hours, for four to fifteen weeks. There are usually five to fifteen participants; 4) they offer social support, factual interaction with others around the group focus; and 5) they do not encourage or require members to espouse a particular moral or behavioral value system.

A search of the literature indicates there is no well-defined conception of the situation/transition group as an identifiable type having common characteristics, modes of function and problems. Despite superficial differences, most situational groups have a great deal in common with each other and differ from other types of groups in a number of significant ways (Schwartz, 1975).

Regardless of the classification, certain components of self-help support groups are common to all. These include the provision of information by others who have relevant, first-hand experience, the opportunity to be helpful to others, the increased control in maintaining one's health and the identification with others around a shared experience (Marram, 1978; Yalom, 1977; Caplan, 1976; Parsell, 1974; Falknor, 1973; Kemp, 1971; Davis, 1969).

The first function of self-help support groups is usually to provide information. Often the health care professional provides information in medical language; teaching what was learned from books or other health care professionals. However, such professionals usually have not experienced the problems personally. According to Pratt (1976) patients commonly complain that they did not understand what they were told by doctors or other health care professionals. In the self-help support group, in contrast, information is provided by people with similar sets of problems. Members of self-help groups benefit from information provided by patient experts who share strategies they have found useful in coping with their situation.

A second function of these groups is the provision of the opportunity to help others. For example, the patient expert who provides information is also said to benefit by providing that information. Being helpful to others brings people out of a morbid sense of self-absorption (Yalom, 1977). According to Riessman (1965) the person who provides assistance is often the one who improves. He suggests there be a way of transforming recipients of care into dispensers of care (role reversal). The concept of modeling behavior is thus suggested. That is, the experienced "old timer" in the self-help support group has more knowledge and becomes a role model (Borkman, 1976). One of the functions of the self-help support group is allowing for this transformation. The group members with the most experience and knowledge of the situation are placed in positions of teacher or authority. This shift leads to an increased self-esteem, increased sense of wellness, and imparts a feeling of social usefulness (Lipson, 1979; Yalom, 1977). By the end of a members participation in the group, most of the participants are equipped with the experiential knowledge to provide information and care as well as to receive it.

A third function includes increasing individuals control and responsibility for health. Dependence on doctors is thought to be due to a lack of person's understanding of health and disease (Williamson and Danaher, 1978). However, increasing consumer dissatisfaction with medical care has increased people's desire to be in more control of their own health. By providing understandable information and self-help strategies by patient experts, the self-help support group equips its members with the ability to exert control over their own lives through their experience in the group (Lipson, 1980).

Finally, involvement in self-help support groups provides a place in which people with similar problems can share the experience. Recognition of the universality of the problems offers group members ways of dealing with such problems in a safe environment. A condition stigmatized by the greater society is made acceptable and workable in the self-help support group. Concrete, specific and commensensical "know-how" is gained from personal participation and from people who have the same problem. Being able to share and learn from another person who has "been there" has been noted as a special characteristic of the self-help support groups (Lipson, 1979; Marram, 1978). Empathy, understanding and a supportive ambience have also been credited to the group process (Marram, 1978; Parsell, 1974; Falknor, 1974; Kemp, 1971).

The impact of the shared experience, closely linked with the need for this special information, and the opportunity to be helpful to others is believed by many (Levin, 1979; Marram, 1978; Lewiston, 1977; Falknor, 1974; Sagarin, 1969) to be central in helping people adapt successfully to changes in health status.

Self-help support groups have developed a special function of bridging the gap between the traditional health care system and individual patient needs by providing information in a safe arena by patient experts and by providing support and validation by peop;e who have shared a similar experience. In addition, self-help support groups often increase the recognition of the role of the family and community in maintaining health, thereby leading to a greater emphasis on the things people do to maintain their own health (Moe, 1978).

The increasing numbers of people participating in and attributing wellness to the group experience suggests that some people have found this experience helpful. However, the ways in which and for whom the self-help support groups are helpful is not completely understood. The popularity of this experience merits more research to document, scientifically, the influence of the self-help support groups.

# CHAPTER THREE

# METHODOLOGY

# METHODOLOGY

This descriptive study is based on the concept of symbolic interaction. The aim of the research is to seek women's perceptions of a mastectomy self-help support group experience. The meaning of the experience of mastectomy and of the self-help support group is thought by this author to evolve from the perceptions the women have for those experiences. In addition, social support has been found to have a positive influence on health (Berkman and Syme, 1979; Ferguson, 1980). However, it is unclear if the type of social support as defined by Berkman and Syme is derived from the self-help support group experience.

The mastectomy support group experience was chosen for study as an example of self-help support group, a situation/transition group, differing from more traditional self-help support groups most notably in the length of time for the group. The function of the mastectomy self-help support group and other self-help support groups appear to be similar. (see page 11 ) For the purposes of this study, the mastectomy self-help support groups are considered to be situation/transition groups and are meant to represent other self-help support groups. The extent to which these mastectomy self-help support groups are representative of other support groups is unknown.

The study began following approval of the proposal by the committee on Human Research of the University of California, San Francisco, the medical directors affiliated with each group, the affiliated institutions and from the women participating in the study. All group members who completed the group experience agreed to participate in this study.

## The Sample and Setting

The sample was drawn from two different groups in Northern California. These groups were identified for the author by the American Cancer Society. Similar to other situation/transition groups as discussed by Schwartz (1975), these groups met once a week for two hours, utilized an open discussion format and the topics for discussion were chosen by the women in the group. Both groups met on a week day afternoon in space provided by the affiliated institution. One group of six women met for 6 weeks, the other group of seven women met for 8 weeks. In the 8 week group, consultants and films were included to provide more factual, concrete information. Both groups utilized professional nurses to facilitate the group process. In one group, the author functioned as a co-facilitator.

The role of the author's co-facilitation involved providing information, referral and feedback. Although there were no apparent substantive differences in the responses of a group members from the two groups, some discussion of the role of co-facilitator is felt necessary to explore the possible implications of that role.

As a result of the facilitation in one group, the members of that group knew the author first as a co-facilitator and second as a researcher. In the other group, the members first and only contact with the author was as a researcher. The women's perceptions of the author may well have been different. The differences in their perceptions may have influenced their responses to the interview questions.

The desire of the participants to please the researcher is also a factor to be considered. This could have been true, however, for any woman, regardless of the group in which she participated. Because of the previous group relationship and ensuing closeness between the group members and group facilitators, the women in the group co-facilitated by the author may have been reluctant to share negative information or perceptions of the group.

## The Interview

A semi-structured interview schedule was utilized. The interview included questions about age, marital status, educational background and occupation (see Appendix B). Information was obtained about the women's perception of the mastectomy self-help support group experience (see Appendix C). For example, questions about past personal experience with mastectomy were obtained in order to identify mastectomy patients need for more information and support. Other questions related to how the women found out about the group, their expectation, their likes and their dislikes and any other comments they wanted to share.

The interviews lasted from one-half to one hour. All interviews were tape recorded in the home of the women or place of her choice. These tapes were later transcribed by the investigator and coded according to common themes. Various categories included demographic data, women's perceptions of the group, their perceptions of their needs and their expectations.

# CHAPTER FOUR

# FINDINGS AND ANALYSIS

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## Demographic Characteristics

The sample of thirteen included women from 33-65 years of age. The variable of age did not appear to be linked to the women's perceptions of the mastectomy self-help support group. Women at both ends of the age spectrum had similar responses to the interview questions.

All but four of the participants were married. Of those four women, two were divorced, one widowed and one recently separated. The relationship of marital status to the women's perceptions of the mastectomy self-help support group is not strong. For example, some of the women's comments were:

> "I don't know how I could have gone through all of this without my husband",
>
> "If I had been married now, I could not have made it through this time",
>
> "Being a widow is a far greater loss than losing my breast".

All of the women had children. Only two had children under ten years old.

Two of the women had full-time jobs. In addition, two volunteered their time, two worked in their husbands' businesses and one conducted her own business in home, on a part-time basis. The others identified themselves as housewives.

Two of the women held master's degrees. Seven of the women held baccalaureate degrees. The remaining four had at least a high school education with some college courses. As a group, the subjects were very well educated.

Five of the women had family members who had undergone a mastectomy. (i.e. grandmothers, mothers, aunts, and sisters) Three of the women had friends who had had a mastectomy. Eight of the women said that they had been able to talk with friends or family about their feelings concerning the mastectomy.

## Time From Discovery of the Lump to Entry into the Group

In 9 of the women, lumps were detected during a physical examination. Only one woman was doing a systematic breast self-examination. The remaining three discovered their lump by noting a visable difference in the breast, by feeling it while washing or while dressing. All of these four women sought medical advise immediately.

The length of time from discovery of the lumps to surgery varied, depending on the diagnostic process. For example, one woman's mastectomy followed a two year history of multiple breast lumps that were benign biopsy. Some women sought second opinions. In many cases, surgical removal of the breast immediately followed a positive biopsy. The women's perceptions of their experiences, during this varied time period, and things they learned and discussed were not brought up during the interview.

It is also unknown what, if any, support, information or opportunity for discussion of their feelings took place in the immediate post-operative hospitalization. However, the majority of women were referred to the mastectomy self-help support group by nurses and Reach to Recovery volunteers during their hospitalization. Two of the women's physicians referred them, two received information about the group in the mail and three actively sought out the group experience.

The length of time from surgery to participation in the mastectomy self-help support group varied from five weeks to two years. The reason for the difference in experience is unknown. Some of the women expressed regret at not participating in the group sooner. One group had been cancelled and was rescheduled at a later date. Two of the women expressed great disappointment when this happened.

> "When the group was cancelled I was terribly disappointed. I tried to find another group but there just wasn't any. So I had to wait until the group was rescheduled. It was a very difficult time for me"

<u>Perceived Needs</u>

Inquiry was made about the women's needs and related expectation of the group. Three major expectations of the group experience were identified. They are: Discussion of Feelings About Mastectomy, To Receive More Information About Mastectomy and Cancer, Comparison of Oneself to Others in the Group. A fourth, The Opportunity to be Helpful to Others was identified in the literature, but only supported by two of the women. In addition, two major categories related to the group functions had to do with the length of time from the surgery to the group and the women's past personal experience with mastectomy.

1. <u>Discussion of Feeling about Mastectomy</u>

Example: "I wanted to discuss my concern with other women who had also had a mastectomy; I wanted to talk about the treatment, the fears and deal with the loss."

"I wanted to talk with others who had been there".

Although eight of the women said they had been able to talk about their feelings about mastectomy, six identified a need for the discussion of their feelings about mastectomy. This became an expectation of the group experiences. This need to discuss the feelings associated with mastectomy appears to be a first priority for women whose mastectomy occured less than seven months prior to entry into the group. (see Table 1). In addition, women who had no past personal experience with mastectomy via family members or friends seemed to perceive a greater need to discuss their feelings than women who had past personal experience with mastectomy. (see Table 2). This was identified by women who had close friends and family with whom they could talk and share their feelings, and by women who described themselves as "open". Despite their opportunity to discuss their feelings with friends and family, women with no past personal experience perceived a need to discuss their feelings especially with others who had "been there". The opportunity to discuss their feelings about the mastectomy is of particular importance for women whose mastectomy was less than seven months and who had no past personal experience with mastectomy (see Table 3).

2. <u>To Receive More Information About Mastectomy and Cancer</u>

Examples: "I didn't know where to start to look for a prosthesis",

"I wanted to talk about cancer. Most people can't or won't talk about it",

"I really wanted to know about when the lump started and some possible cures".

Information about mastectomy was identified by most of the women as their most important need, but it was of particular importance to the women whose surgery was more than seven months prior to her participation in the group.

In addition, women who had past personal experience with mastectomy seem to perceive less of a need to discuss their feelings and more of a need for specific, concrete information (see Table 2). It seemed that these women had already discussed and confronted their own feelings about mastectomy, but had not learned the particular problems associated with mastectomy such as changes in clothing, prosthesis, reconstruction or treatment.

3. Comparison of Oneself to Others in the Group

Examples: "I thought I could tell how I was doing by comparing myself to other women in the group",

"I wanted to see how other women handled this".

To compare oneself was only identified by three of the women in the study but was considered by this author to be emerging theme not identified in the literature. These women described assessing their own progress and health as it related to other women in the group. Their past perceptions of health no longer seemed adequate and possibly they perceived a need for a new method of determining health and illness. Again, their perception is the key to understanding their behavior.

4. The Opportunity to Help Others

Example: "I thought that since my mother had been through mastectomy, and I been through it, maybe I could help someone else".

Helping others was identified by only two of the women. This finding did not strongly support the literature (Yalom, 1977, Riessman, 1965). It was expressed only by women who had had surgery more than seven months prior to participation in the group.

Table I

Relationship of Time from Post-Operative Surgery and Perceived Needs.

| Perceived Need | Time Less than 7 months N=9 | Time More than 7 months N=9 | Total |
|---|---|---|---|
| Discussion of Feelings | 6 | 0 | 6 |
| Receipt of Information | 4 | 3 | 7 |
| Comparison of Oneself to Others | 2 | 1 | 3 |
| Opportunity to be Helpful to Others | 0 | 2 | 2 |

N does not equal 13; some women gave more than 1 answer

## Table II

### Relationship of Past Personal Experience with Mastectomy* and Perceived Needs

| Perceived Needs | Past Personal Experience with Mastectomy | | |
|---|---|---|---|
| | Yes<br>N=7 | No<br>N=6 | Total<br>N=13 |
| Discussion of Feelings | 1 | 5 | 6 |
| Receipt of Information | 5 | 2 | 7 |
| Comparison of Self to Others | 1 | 2 | 3 |
| Opportunity to be Helpful to Others | 2 | 0 | 2 |

*Contact with grandmother, mother, aunt, sister or close friend

**The total does not equal 13; some women gave more than 1 answer

## Table III

### Relationship of Time from Post-Operative Surgery, Past Personal Experience with Mastectomy* and Perceived Needs

| | Past Personal Experience With Mastectomy N=7 | | No Past Personal Experience With Mastectomy N=6 | |
|---|---|---|---|---|
| | Less than 7 months | More than 7 months | Less than 7 months | More than 7 months |
| Perceived Needs | | | | |
| Discussion of Feelings | 1 | 0 | 5 | 0 |
| Receipt of Information | 3 | 2 | 1 | 1 |
| Comparison of Self to Others | 0 | 1 | 2 | 0 |
| Opportunity to Help Others | 0 | 2 | 0 | 0 |

*Contact with grandmother, mother, aunt, sister or close friend

**The total does not equal 13; some women gave more than 1 answer

## Group Characteristics

The importance of the meaning the group had for each women was discussed earlier in the paptel. The following characteristics help to elucidate a clearer image of the influence of the mastectomy self-help support group. Although the characteristics of the group as percieved by the women are similar and related to their expectations of the group, they do reveal the view of the mastectomy support group as seen by the women in the groups. These characteristics are listed below:

1. a safe place to talk
2. an open environment, where one can say anything
3. a place to share the experience of mastectomy
4. a place where one can identify with others who have had a mastectomy
5. receipt of specialized information
6. an opportunity to be helpful to others

The safe environment for the mastectomy self-help support group was named consistently as the characteristic of the group experience the women liked most. This environment, according to the women, gave them an opportunity to learn more about mastectomy through the discussion of their feelings of the experience and the sharing of knowledge and specific information about the strategies of living with mastectomy. This "open" environment afforded them more freedom to share their feelings about the mastectomy. In summary, women were satisified with the group if it met their expectations.

## Dislike of the Support Group Experience

Some of the women had negative perceptions of the group. One of the negative perceptions related to the group stucture. For example, three women did not like the open discussion format. They would have preferred a more stuctured, lecture-type setting. Four other women in one group expressed a sense of depression as it related to the downhill course of another group member.

## Relationship of the Findings to the Conceptual Framework

The findings of this study are consistent with literature presented earlier in the paper. For example, the family has been noted as a provider of social support (Ferguson, 1980). However, in times of mastectomy, women perceive a need to discuss their feelings with other women who have had a mastectomy. Others fear overburdening their already troubled family. A fairly typical example is expressed in the following comment"

> "My husband has been through so much already. I just can't discuss my fear about cancer with him now. It's not fair".

Although many of the women in this study named their family as a source of social support, they also perceived a need extending beyond the capability of a loving, supportive family. Thus, the type and quality of support provided in the mastectomy self-help support group may be a determining factor in how a woman and her family cope with the stress associated with a mastectomy.

In addition, the health care system has been providing support in the form of diagnosis and education focussed on the disease and medical treatment. However, following mastectomy, most of the women in this study perceived a need for more education focussed on the special information about the life changes following a mastectomy. These findings are consistent with the assessment of others (Marram, 1978; Gartner and Riessman, 1977) that the traditional treatment model is inadequate for meeting some long term health care system, self-help support groups have been successful by meeting some members long term health related needs.

The findings of this study are consistent with the literature which identifies support group characteristics and functions, among them, the provision of specialized information, the opportunity to be helpful to others, discussion of the shared experience and a safe, open environment of the self-help support group (Marram, 1978; Yalom, 1977; Caplan, 1976; Parsell, 1974; Falknor, 1974; Kemp, 1971; Davis, 1969).

However, one other function, an increased sense of control over one's health (Lipson, 1980; Williamson and Danaher, 1978) was not named by the participants in this study. Although some women enjoyed what they describe as "learning to deal with doctors," this theme did not emerge as a central, consistent function of the group. One must be careful about the inference that having more information about their diagnosis, their surgical procedure and their treatment, and hence, their health, that these women would be able to exert more control over their own health care. For example, decreasing dependency on doctors, increasing communication with doctors or simply increasing communication with other health care professionals may or may not follow participation in self-help support groups.

## Emerging Themes

Some themes not identified in the literature emerged from this study. The perceived need to "cope" with having a mastectomy was identified by many of the participants in this study. The literature also suggests some form of coping behavior is learned from the group process (Adams, 1979; Lipson, 1979; Marram, 1978; Parsell, 1974; Falknor, 1974; Kemp, 1971). The methods and mechanism of coping are unclear. Is an underlying purpose of the mastectomy self-help support group to help women to "cope" with mastectomy? Can the exchange of information and discussion about mastectomy within the self-help support group facilitate this "coping?" Although the women in this study did find the mastectomy self-help support group a beneficial and positive experience, no one used the word "cope".

Comparing oneself to another women who had a mastectomy was suggested by three women as a measure of how well she was "coping". Her progress (coping?) can be checked by using others as a yardstick. Borkman's (1976) concept of the "experienced patient" suggests that people involved in self-help support groups serve as role models for other group members. One wonders if this learning from others in the same situation facilitates "coping".

A third emergent theme is the notion of limited time for group involvement. This has not been addressed in the literature. Although traditional self-help support groups are on-going, Schwartz (1975) describes the situation/transition group as lasting four to fifteen weeks in duration. How the number of weeks for the group experience is determined is not explained. The groups in this study were six and eight weeks in duration. Neither of the group facilitators could explain how the number of weeks was determined. One wonders if learning and "coping" can take place within the given time frame allowed.

Perception of disease and what accompanies it leads to actions in health and disease (King, 1962). The mastectomy self-help support group influences the participants perceptions of their disease through the group functions just described. The opportunity to share the experience of mastectomy and learn from others who have had a mastectomy, to learn concrete information and strategies for dealing with life following a mastectomy, in an open and safe environment, allows many the opportunity to discuss and confront their feelings about the disease. This awareness that others too, have to "cope" with the same problem, that they are not alone in this experience, changes peoples assumptions and psychological sets. Their beliefs, attitudes and values grow from this experience and provide the women with a structure that defines their course of action (Murray, 1938). Individual members perceptions of the self-help support group is indeed important for understanding peoples' ability to shape their own behavior and reality.

### Limitations

The small sample size limits the generalizability of the results of the study of these mastectomy self-help support groups to other mastectomy self-help support groups.

This descriptive design lends itself to inferences and functional relationships rather than casual relationships, because of the lack of control of the variables.

Although both groups were similar in characteristics and function, the possible hidden differences in the groups are unknown. The possible influence of the author's co-facilitation in one group and not in the other is also unknown. Other potential factors influencing the women's perceptions of the mastectomy self-help support group are not apparent, but again, there is no control for the variables in this study.

# CHAPTER FIVE

# DISCUSSION

# DISCUSSION

The most significant finding of this study is that women appear to be unanimous in the positive feelings about the mastectomy self-help support group. For a greater understanding of this perception, more information and further study is required. For example, if the women perceived the mastectomy self-help support group as positive, does that imply that the women feel better about themselves or can "cope" better with their mastectomy experience? Other areas requiring more information are listed and discussed.

People receive social support in various ways including the family and health care providers. The women in this study did feel that they needed support beyond that provided by family and health care providers during their mastectomy experience. The importance of a strong social support network for health has been discussed. The type of social support received from friends, family and group affiliations as defined by Berkman and Syme (1979) is said to decrease mortality rates. It is unknown if the social support received in the mastectomy self-help support group is as influential as the groups discussed by Berkman and Syme. Further inquiry in this are is essential.

A third area requiring indepth research is in the area of time. There are two important dimensions of time in relation to the self-help support group experience. The first dimension is the difference in the needs and perceptions women have at differing post-mastectomy periods. The length of time from surgery to the group was related to women's perceived needs (see Table I). Women whose participation in the self-help support group was less than seven months post-mastectomy perceived a greater need to discuss their feelings. Women who participated in the group later than seven months post-mastectomy perceived a greater need for concrete, specific information. Should self-help support groups be structured differently in order to meet these two types of needs, i.e. discussion of feelings about mastectomy and receipt of concrete information about mastectomy? This would mean that the type of support group recommended to clients would be determined by the number of months since their mastectomy.

The second dimension of time relates to the number of weeks appropriate for the mastectomy self-help support group. Investigation into the criteria for chossing the appropriate number of sessions, the length of time for each session and the frequency of sessions is needed for the mastectomy self-help support group to be a more meaningful experience.

## Implications for Nursing

Another significant finding of this study was that with the exception of one women, none of the participants did a regular breast self-examination. Even those subjects who had close contact with a women who had had a mastectomy did not do a systematic breast self-examination. Although this was not an expected findings, the implications are far reaching. Why were those women not doing breast self-examinations? Inquiry was not made in this area, but further research must uncover this information. In addition, nurses must reinforce to their clients in all settings the importance of doing a systematic, monthly breast self-examination.

Within the acute post-operative period, nurses are key health care providers for women following surgical removal of the breast. Nurses have the opportunity to provide women with emotional support, allow for and encourage verbalization and discussion of their feelings, and provide the necessary information when appropriate. Although this time may be too stressful for many to take in information, a printed handout could be provided, with information about mastectomy self-help support groups (if they are available).

Nurses are often the ones to discover the perceived needs of our clients. Collaboration with other members of the health care team is essential. Reach to Recovery volunteers were said to be a positive influence on the recovery period of women in this study. Nurses have a responsibility to refer clients to Reach to Recovery volunteers, nurses, psychologists, clergy, social workers and other professionals as needed.

### Implications for Health Policy

There is a lack of available mastectomy self-help support groups. For example, in the city of San Francisco, the only mastectomy self-help support group began in April 1980 without professional facilitation. This group is threatened due to lack of funds.

This lack of mastectomy self-help support groups may be due to any number of reasons. For example, since the public is often unaware of the availability and potential usefulness of these groups, they may not participate in them. Although many of the women in this study were referred by professionals, there is the possibility that professionals in other geographic locations are unaware of or not supportive of self-help support groups and hence, do not recognize the potential merits of self-help support groups. In addition, because there is little research to support the thesis that self-help support groups are effective means of facilitating the "coping" for some people, many professionals are reluctant to refer clients to this experience. Only further documentation and research can help.

Incorporation of slef-help support groups into the mainstream of the health care system is another important area of concern. Although many self-help support groups are initiated and maintained without professional facilitation, the mastectomy self-help support groups studied utilized professional nurses and space provided by the affiliated institutions. In an era of economic turmoil, self-help support groups that depend on professional and institutional support will be threatened without evidence that this experience is beneficial and cost-effective. At present, third party payers do not cover self-help support groups. Research that explores it's value is essential.

A breast screening center seems to this author the most likely place to incorporate a mastectomy self-help support group. In such a setting, all women could be made aware of the support group as another service provided by the center. All women could be given this information prior to diagnosis or surgery, and this avenue would be open to any women with or without a physician referral. In a breast screening center, all women could be followed and informed of different treatment alternatives as indicated. More extensive research could be done to validate our current treatment modalities and necessary improvements in group structure could be based on individual member's needs. For example, women could be referred to groups based on their similarities, beyond the mastectomy, such as age, marital status and treatment of disease. The establishment of categories of needs and experiences could be designed so that the mastectomy self-help support group is most meaningful for the members.

## Implications for Future Research

The small number of mastectomy self-help support groups currently available severely limits the investigators ability to obtain an adequate sample. Validation of this study through replication with a larger sample of women is necessary.

It is also important to seek the reasons for the small number of mastectomy support groups available in the San Francisco Bay Area. An interview with health professionals aimed at identifying their perceptions of a mastectomy self-help support group may provide additional information.

Following these studies, the comparison of mastectomy self-help support groups could identify similarities and differences in the group experience. For example, the length of time appropriate for the group could be explored. Women involved in mastectomy self-help support groups could be compared with women not involved in such an experience. The mastectomy self-help support group could be compared with other self-help support groups, perhaps based on the group typologies described in literature.

Finally, a study seeking information about who engages in mastectomy self-help support groups and at what time in their post-operative recovery period they chose to do so could be studied. This information may reveal concrete ways in which the support group experience could be modified to be as meaningful and effective as possible.

## Conclusions

The perceptions of women in this study about the mastectomy self-help support group reveal important information on the influence of the group. This study suggests that the mastectomy self-help support group experience is a viable and effective method of learning and sharing feelings about, and possibly adjusting to mastectomy. This supports the work of Adams (1979).

This research has revealed that there is a large area of unknowns surrounding the self-help support groups and further study is needed to provide a scientific foundation. Only research will provide the information necessary to add to our current knowledge and truly influence our perception of the mastectomy and other self-help support group experience.

# APPENDICES

## APPENDIX A

## DEFINITION OF TERMS

Self-Help Support Group (also self-help group, support group, mutual-aid group, mutual-help) - any group of people who have come together to share the same experience, who have similar sets of problems, and shared or common goals. The purpose of the group is decided on by the members, but it's concerns usually include sharing of information by people who have had the experience and learned from it, and the provision of support.

Self-Care - any activity an individual performs to maintain and/or promote his/her own health.

Mastectomy Self-Help Support Group - a group of women who have had the surgical removal of one or both breasts. The purpose of the group is to meet with other women who have had a mastectomy to share this experience.

Social Support System (or network) - one or more significant others who provide a buffer for a person during a vulnerable period brought on by the acute crisis of illness or life transition.

Experienced Patient - any person who has learned from personal experience the necessary resources to deal effectively with a health related problem.

Life Transition - a new maturational or situational experience that necessitates a change in personal development.

## APPENDIX B

## FACE SHEET

Name:

Address:

Phone:

Age:

Marital Status:

Children (with ages):

Occupation:

Educational Background:

Date of Diagnosis:

Date of Surgery:

Any Complication:

## APPENDIX C

## INTERVIEW GUIDE

1. When did you first discover the lump in your breast?
2. How did you discover it?
3. What did you do when you first discovered the lump?
4. Has anyone in your family had a mastectomy?
5. Have you any friends who have had a mastectomy?
6. Have you any close associates? Is there someone you confide in?
7. Have you discussed your feelings about your Mastectomy with anyone?
8. How did you find out about the group?
9. What did you expect from the group?
10. What keeps you coming to the group?
11. Would you recommend the group experience to other women who have had a mastectomy?
12. What did you like the most about the group?
13. What did you like the least about the group?
14. Is there anything else you would like to talk about that I haven't asked about?

# APPENDIX D

## UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

## CONSENT TO BE A RESEARCH SUBJECT

Ms. Nancy Steiger is a nurse-researcher who is working on her graduate degree in family health care nursing. Her thesis project is an exploration of how women who participate in mastectomy self-help support groups perceive the group. If I have any further questions, Ms. Steiger can be reached at 333-7030.

If I agree to participate, I will be interviewed for about one hour in my home or place of my choice. The conversation will be tape-recorded. The questions asked will concern my personal experiences and my feelings about the group.

The interview is confidential and all precautions will be taken to safeguard my anonymity. The names of participants might be revealed on the tape recordings, but will be deleted on the transcription and the tapes will be erased when the study is complete.

Participation in research is voluntary. I have the right to refuse to be in the study without penalty or jeopardy. I have the right to withdraw from the study at any time. I may refuse to answer any of the questions.

There may be no benefit to me from participation. The investigator may learn more about self-help support groups and that information may help people.

SIGNATURE ______________________________

DATE ______________________________

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