WOMEN WHO HAVE UNDERGONE MASTECTOMY: THEIR EXPERIENCES MAKING THE DECISION ABOUT BREAST RECONSTRUCTION: A QUALITATIVE STUDY

by

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We accept this thesis as conforming to the required standard

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Abstract

This study was designed to explore post-mastectomy women's decision-making experience in relation to their choosing or refusing breast reconstruction. The literature review clearly illustrates a lack of knowledge about the factors that influence breast reconstruction decision-making. A phenomenological approach was used to guide this qualitative study.

Data were collected via a series of semi-structured interviews from 16 women who had consulted a plastic surgeon regarding breast reconstruction. Of these women 13 underwent breast reconstruction and 3 refused this option. The women ranged in age from 32 to 64 years. Twelve women were married and lived with their partners, one was single, and the remaining three had been married but now lived alone. Most of the women had children.

Decision-making in these women was characterized by an intuitive style as opposed to a logical, systematically-sequenced decision style endorsed by traditional decision theorists. Each woman demonstrated her own unique style of decision-making.

The implications of this study focus on the critical need of post-mastectomy women to be thoroughly assessed, given relevant breast reconstruction information and have follow-up support during their breast reconstruction decision-making process. The emphasis in nursing education should be directed at educating
nurses about the importance of wholeness, knowledge of the factors influencing a woman's choice regarding breast reconstruction and the necessity for understanding the decision-making process itself. Nursing research can play a valuable role in furthering our knowledge about the complex concept of wholeness, the catalytic effect of information on women's behavior with regard to breast reconstruction decision-making, and the significance of intuitive decision-making in relation to breast reconstruction.

Clarissa P. Green, Chairperson
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Symbolizing motherhood, femininity, and sexual attractiveness, breasts are highly valued in our society (Mauldin, 1980; Thomas, 1978). The combination of the loss of such a powerful female symbol and the negative connotations of cancer results in psychological trauma for many women (Maguire, 1975; Renneker & Cutler, 1952). These women often find it extremely difficult to adjust to their changed physical appearance following mastectomy (Cocke, 1977; Miller, Graham, Tepsich & Taylor, 1977). Also Maguire's (1975) study reported that many post-mastectomy women referred to themselves as "second-class", "below standard", "misshapen", "mutilated", "peculiar", "lopsided", "abnormal", and
"so inadequate"--terms which reflect serious damage to their self-esteem (p. 56).

A woman's immediate and future relationships can also be affected by a mastectomy (Bard & Sutherland, 1955; Krumm, 1977; Mauldin, 1980; Rennecker & Cutler, 1952). Due to the personal nature of the breast loss, women tend to feel alone in this experience and, as a result, isolated.

The option of breast reconstruction, an intervention reported to restore feelings of wholeness and self-esteem, is becoming increasingly available to the post-mastectomy population (Kushner, 1982; Zalon, 1978). Even ten years ago, post-mastectomy women were not likely to be restored to normal appearance as a result of breast reconstruction, due to the newness and imperfections of breast reconstruction techniques (Berger & Bostwick, 1984). Cocke (1977) cites figures regarding the incidence of breast reconstruction among post-mastectomy women in the United States:

In a recent questionnaire related to this subject, it was noted that up to mid-1975 only 1,186 reconstructions had been performed. If one used Horton's estimate of 500,000 post-mastectomy patients who are possible candidates for reconstruction, one can see that only 0.2 percent have actually undergone reconstruction (p. 11).

According to Statistics Canada (1980-81) figures, 315 Canadian women underwent total reconstruction of the breast in
1980 to 1981. Of these women, 30 underwent breast reconstruction in British Columbia (Statistics Canada A2-208, 1980-81). Due to the comparatively recent introduction of breast reconstruction as a procedure, all statistics prior to 1980 are of questionable reliability because of the outdated coding used. This coding makes it impossible to determine the actual number of breast reconstruction surgeries performed because they have been grouped with several other breast surgical procedures.

The 1982 to 1983 unpublished figures revealed that 34 women in British Columbia underwent breast reconstruction (Statistics Canada A2-208, 1982-83). The most current unpublished figures from the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures (1983-84) show that 51 women underwent reconstruction in British Columbia in that period.

Two local British Columbia plastic surgeons, who will remain unidentified, reported a marked increase of breast reconstruction surgery in their respective practices. The first plastic surgeon stated that ten years ago he did one breast reconstruction operation per year and is currently performing an average of two reconstructions a month. The second plastic surgeon reported that five years ago he did approximately five breast reconstructions per year; four years ago, 15 reconstruction surgeries; three years ago, 30 reconstructions; two years ago, 40 reconstruction surgeries; and last year, 50 breast reconstructions.
These figures illustrate the growing incidence of breast reconstruction performed in British Columbia, reflecting the increased availability and significance of this treatment option to post-mastectomy women.

Because breast reconstruction is a valid option in the rehabilitative process, there is a need for current, accurate information about this option to be made available to mastectomy patients (Bostwick, 1983; Graham & Turner, 1981; Hunt, 1981). These women have a right to know about the possibility of breast reconstruction even if they have no immediate plans to undergo such surgery. As a professional group, nurses, especially those on surgical units and in cancer treatment settings, interact frequently with mastectomy patients. Given this situation, questions arise regarding the type of knowledge needed by nurses and the role they should assume with potential breast reconstruction candidates.

In order to effectively counsel women who are facing mastectomies, nurses must be knowledgeable of the psychological needs of women after mastectomy, the reasons for increased numbers of breast reconstructive surgeries in recent years, the surgical procedures available, general post-operative care, and the complications which may follow (Rutledge, 1982, p. 470).

While there is a growing abundance of medical literature on the physical nature of this implant surgery that give guidelines
to physicians, there is little on which nurses can draw on. Rutledge (1982) reviewed the nursing literature in relation to this increasingly popular surgical procedure for women and discovered that from 1975 to June 1981 there had been only nine articles written about the nursing care of patients experiencing breast reconstruction. The nursing literature's failure to address this need leaves nurses without direction regarding the type and amount of health care support and intervention needed by women entertaining breast reconstruction.

Within the existing literature on breast reconstruction, the psychological aspects of breast reconstruction are considered important. Both nursing and medical literature, however, devote minimal attention to the process that women go through when seeking information on and making decisions about breast reconstruction. Carroll-Johnson (1982, unpublished) emphasizes this in stating that "there has been a critical lack of data-based research on the psychological factors involved in the decision to pursue breast reconstruction following a mastectomy" (p. 55). The factors affecting a woman's decision to undergo breast reconstruction or refuse reconstruction are largely unknown among this growing population. In order to be pertinent and effective in their care of mastectomy patients, nurses need to know about what factors affect this decision-making process. Because these factors have never been researched, they are based on assumption rather than fact. This knowledge regarding factors
is a vital prerequisite to helping post-mastectomy women make an informed choice about breast reconstruction.

In the limited amount of breast reconstruction literature, the psychological factor most frequently assumed to be related to decision-making is body image (Bostwick, 1983; Clifford, 1979; Goin & Goin, 1981; Needleman, 1979). Authorities on the subject suggest that the way in which women perceive their body image after a mastectomy and the way they feel about this perception are factors in making a choice about breast reconstruction. Cases of post-mastectomy women who refused to accept the loss of their breast but, after breast reconstruction, adjusted and felt satisfied with their body image are cited as examples of this viewpoint (Goin & Goin, 1981; Hugo, 1977; Needleman, 1979).

Whether or not post-mastectomy women also perceive body image as a primary factor affecting decision-making is not known. The need to look at this process through the eyes of the women undergoing it is paramount in developing understanding. Until nurses are aware of the specific needs of this population, nursing care runs the risk of being unsuitable, unsupportive, and inconsistent.

Statement of the Problem and Purpose

The problem under study is the limited amount of knowledge about the decision-making process of post-mastectomy women who consider breast reconstruction. The purpose of this study is, therefore, to describe women's perceptions of their experiences
as they went through the decision-making process related to breast reconstruction. Specifically, factors which influenced this decision-making process are identified and described.

**Definition of Terms**

The following terms have been defined for the purpose of clarifying their meaning in the statement of the problem and purpose.

**Post-mastectomy woman** - A woman who has had her breast(s) removed surgically for treatment of cancer.

**Breast reconstructive surgery** - The surgical implant of a breast prosthesis underneath the soft tissues at the mastectomy site to replace the missing breast(s). This may or may not include a nipple aerolar reconstruction.

**Participant** - For the purposes of this study, (1) a woman over the age of 21 who has had a mastectomy and who has consulted a plastic surgeon and chosen to have breast reconstruction, or (2) a woman over the age of 21 who has consulted with a plastic surgeon but chosen not to have breast reconstruction.

**Decision-making** - "identifying problems for decision, devising alternative courses of action, and choosing an alternative" (A Dictionary of the Social Sciences, 1976, p. 60).

**Factor** - "something (as an element, circumstance, or influence) that contributes to the production of a result" (Webster, 1976, p. 813).
Introduction to This Study's Methodology

The following section explores several basic theoretical assumptions underlying the phenomenological approach to qualitative research. The goal of phenomenology lies in describing experience as it is lived by individuals who determine their own reality (Oiler, 1982). Rist (1979) states that "all knowledge is socially constructed. No information exists outside that produced by individuals within their social and cultural context" (p. 18). When an individual interprets another individual's actions in the context of his own rather than the other's perceptions, he lacks accurate knowledge to understand this person. When the individual is able to grasp the other person's unique viewpoint, however, true and more accurate understanding of the other person is developed (Schutz, 1967).

The role of the researcher in phenomenological research is to be "the major instrument of data collection" (Ragucci, 1972, p. 487). The success of the researcher depends upon the ability to establish rapport and respect with the sample population (Ragucci, 1972) and to conduct each study with an open mind. This prevents the formulation of pre-hypotheses relating to how and why the sample population behaves as it does before the study commences (Lindemann, 1974; Oiler, 1982). The researcher's role within this methodology is one of "discovery, of generating an explanation rather than verifying an imposed theory. Such an approach eschews a preconceived theoretical framework and allows
the study to emerge from the words of participants" (Wilson, 1977, p. 106).

In-depth interviewing is a method used to gather detailed information of the participant's point of view. "Interviewing is both a direct source of information on belief and knowledge systems and a form of vicarious observation to increase case examples of various types of overt behavior" (Pearsall, 1970, p. 346). The traditional focus on reliability and validity of the instrument does not apply in qualitative research and is limited to the reliability and accuracy of the informant's account (Diers, 1979; Oiler, 1982). Pearsall (1970) refers to informants as being 'expert witnesses' because "the selection favours persons who are especially knowledgeable with regard to various activities and bodies of knowledge" (p. 346). The women who participate in the decision-making process regarding breast reconstruction will be the experts in this researcher's study.

Schwartz and Jacobs (1979) contend that suitable and relevant questions are produced from the interaction process between interviewer and informant. "At a later point these are incorporated into the 'interview guide'" (Schwartz & Jacobs, 1979, p. 40). Data analysis generates additional questions which can be used in subsequent interviews to clarify and solidify conceptual categories (Anderson & Chung, 1982). Diers (1979) states that the researcher and her related thoughts, feelings, and perceptions represent another data source. She feels that
involvement with the participants adds richness to the data in terms of the interactions, analysis, and interpretation.

Phenomenology assumes that all investigators have biases which can be controlled through awareness and attempts to analyze the data objectively. However, it is important for phenomenological researchers to realize that their assumptions are not completely objective. This awareness on the part of the researcher "prevents subjective influences from becoming too fixed and rigid" (Davis, 1978, p. 191).

Phenomenological theory guides data analysis which is grounded in the social reality of the participants' experiences (Lindemann, 1974; Oiler, 1982). Data from the interviews are collected and sorted into categories. From these categories, themes emerge which are compared for similarities, differences, and new concepts (Diers, 1979; Oiler, 1982). As a result, it is possible to identify a conceptual framework which acts to guide subsequent collection and analysis of the data (Pearsall, 1970; Simms, 1981; Wilson, 1977). There is no clear-cut separation between coding, data collection, or data analysis in qualitative research. Rather, these three processes overlap continuously throughout every investigation (Glaser & Strauss, 1967). Data collection, coding, and analysis continue until conceptual categories within the data are revealed (Diers, 1979). Clusters of themes in relation to these categories form the theory about the phenomenon under study (Knaack, 1984). The ultimate goal of
data analysis lies in accurate representation of the phenomenon in such a way that the reader experiences it vicariously.

The above characteristics of the phenomenological approach make this method ideal for obtaining data from the participant's point of view. Simms (1981) states that a "fresh perspective" results and benefits a topic area in which important factors have not yet been identified (p. 356). "Phenomenology provides a more perfect fit conceptually with the functions of clinical nursing and with many of the research questions that evolve from clinical practice" (Davis, 1978, p. 187). The preceding discussion clearly demonstrates that phenomenology is a relevant approach to answer the questions posed in this study regarding the participants' decision-making process in breast reconstruction.

Assumptions

1. The two groups of participants are able to identify and are willing to describe factors involved in the process whereby they (1) decided to undergo breast reconstruction, or (2) decided to refuse breast reconstruction.

2. The participants' perception of their decision-making process can be obtained through the accurate reporting of their accounts.

3. An understanding of the participant's decision-making about breast reconstruction can be reached through a phenomenological research approach.
Limitations

The sample was obtained from only two plastic surgeons; therefore, the generalizability of findings will be limited. Time constraints limited the degree to which the richness of data could be completely explored. Sample size was also bound by the limitations of time.

Summary

This chapter presented the problem and purpose of the study and also introduced the methodology. Chapter Two deals with the review of literature which relates to the formation of the study's conceptual framework. The Third Chapter explains how the methodological approach guided the study. Chapter Four presents and describes the accounts given by the women in this study. An analysis of the accounts in relation to the pertinent literature comprises Chapter Five. Chapter Six discusses the summary and implications of the study in terms of nursing practice, education, and research.
CHAPTER TWO

Review of the Literature

In order to explore those theories pertinent to post-mastectomy women who consider undergoing breast reconstruction, this chapter examines theories of body image and decision-making, as well as literature on breast reconstruction. The interrelationship among these three areas will be discussed for the purpose of giving the reader insight into the decision-making process of breast reconstruction. In addition, literature related to mastectomy is presented concurrently with body image and breast reconstruction theory in order to provide additional scope and meaning. This discussion will demonstrate the need behind the present study as well as explain the problem development and purposes of this study.

The breast reconstruction literature is examined for the purpose of exploring factors that may be responsible for a woman's decision to choose or refuse breast reconstruction. Decision-making theory is presented in order to clarify the process women undergo when making a decision regarding breast reconstruction. Both decision theory and research are addressed. Although traditional decision theory is assessed, specific patient decision-making regarding health-related experiences is the primary focus since it is more relevant to the research questions posed in this study.

The literature review illustrates the lack of nursing
research in two major areas; firstly, the actual mechanics of the
decision-making process itself are not explored, and secondly,
the factors that impinge upon a post-mastectomy woman's decision
about breast reconstruction have not been studied. As a result
of these deficiencies, nurses likely lack the knowledge needed to
understand and assist women in their decision-making. It is
hoped that this study may be able to provide additional insight
into the complexities of this decision-making process.

**Body Image Theory**

Theory explaining women's body image provides a framework
for the selection and review of the literature. The theoretical
underpinnings of body image theory are useful in understanding
why the post-mastectomy woman considers the option of breast
reconstruction. Schilder (1950) used knowledge about body image
to explain patient reactions to loss of body parts and related
functions. He defines body image as:

the picture of our own body which we form in our mind . . .
The way in which the body appears to ourselves. We see
parts of the body-surface. We have tactile, thermal, pain
impressions (Schilder, 1950, p. 11).

Norris (1978) states that an individual's unique body image
develops from infancy by sequential steps in differentiation and
that this process is dynamic. "Its goals are manipulation,
mastery and control of relationships with self, others and
environment" (p. 8). Learning about one's body is typically
unstructured since it occurs throughout life as a result of continual exposure to experience (Selekman, 1983). Body image can be called a postural model because it is only through continual changes in position that we come to use our senses fully and establish a sense of our body boundaries (McCloskey, 1976; Schilder, 1950).

Because the attitudes and responses of others help us to define our bodies (Wilson & Kneisl, 1979; Schilder, 1950; Selekman, 1983), social interaction is required to form a concept of body image. The prevailing attitude of society towards breasts is emphasized by Carroll (1981): "Breasts are glorified and emphasized in many aspects of American life; they are not merely functional body parts, but rather are equated with femininity, sexual attractiveness and nurturing behavior" (p. 30).

Society's influence on individual perceptions is clearly illustrated, for example, by the fact that both boys and girls entering puberty are only too well aware that the size and appearance of breasts are important factors in the attractiveness and acceptability of a woman (Small, 1979). Television and magazine advertisements continuously bombard our senses, stressing the sexual qualities of breasts. This attitude regarding the aesthetic importance of breasts may have far-reaching implications for women who lose a breast due to breast cancer.
Loss is the central theme of mastectomy literature and research. This includes the visible loss of the breast, possible loss of arm function and appearance, the lessening of self-esteem with regard to self-concept and sexuality and, overall, the loss of quality of life and possibly the loss of life itself (Asken, 1975; Northouse, 1982; Woods & Woods, 1975).

The alteration of body image caused by a mastectomy automatically triggers feelings of loss. Following mastectomy, a period of grieving for the loss of a loved body part occurs which Kolb (1959) likens to separation from significant others. Denial is a necessary part of the grieving process at first, so that the post-mastectomy patient is not overwhelmed by the discrepancy between her mental body image and actual physical image (Butler, 1976). The depth of the grief reaction relates to the specific value that a woman's breast symbolizes for her. Silberfarb (1977-78) contends that the importance of the breast "depends upon the personality of the individual, the actual functional deficit caused by the loss, the time during one's life, and the situation in which a change in life occurs" (p. 163).

During the crisis period, when confronted with the diagnosis of cancer and the need for treatment, Schilder (1950) claims that a sense of depersonalization may overwhelm the afflicted person. Sourkes (1982) states that fears of losing control and losing one's identity can be expressed in one cancer patient's statement: "I'm afraid of changing so much with this disease
that I won't recognize myself" (p. 35). The mental anguish of losing the sense of a previously intact body image is exacerbated by the feelings of sadness, anger, and despair that are experienced by some post-mastectomy patients. These women are likely to mourn the loss of such psychological attributes as femininity and sexuality along with the lost breast.

Lerman's (1983/1984, unpublished) study attempted to evaluate women's perceived changes in marital and sexual relationships and physical self-concept following breast reconstruction. Sixty-six women were involved in her research and the above changes were measured by an extensive questionnaire which included several standard scales. Her results indicated that "women who had reconstructive surgery reported retrospectively that they had experienced a decrease in feelings of attractiveness, femininity, importance of their breasts and satisfaction with their appearance in clothes following mastectomy surgery and an increase in these subsequent to reconstruction" (p. 66). The multiple losses suffered as a consequence of this marked change in body image are well-evidenced. Therefore, restoration of normal body image is likely to be an important consideration of any woman who contemplates undergoing breast reconstruction. Lerman's study will be examined in further detail in a subsequent section of this literature review.
Body Image and Sexuality

Silberfarb (1984) reports that an alteration in a woman's body image may be accompanied by a "loss of the sense of sexual identity, with a subsequent lowered self-esteem" (p. 821). This alteration in body image can have profound implications for some women's post-mastectomy sexual adjustment. Savage (1981) stresses the complexity of sexuality and its relationship to body image in stating that "interrelated components of the sexual self include ideal body image, body image, self-concept, and self-esteem" (p. 152). Woods and Woods (1975) maintain that a woman's perception regarding the value of her missing breast will likely be "influenced by the extent to which the woman bases her self-worth and acceptability on her appearance" (p. 149). The less a woman is concerned with her physical appearance, she will probably feel less traumatized than if her self-worth is mainly based on other people's reactions to her body (Woods & Woods, 1975).

Women who perceive themselves as deformed following mastectomy are likely to respond to their sexual partner in a withdrawn manner, which in turn may threaten the support given by the spouse (Savage, 1983; Silberfarb, 1984; Woods & Woods, 1975). The vulnerability of post-mastectomy women was further illustrated in a study done by Tarabocchia, Stefanini, Mustacchi, and Milani (1983, unpublished). This research involved 37 post-mastectomy women who ranged in age from 34 to 49, were 18
months post-surgery, and had been married for a minimum of seven years.

Many patients reported that certain difficulties had arisen after mastectomy: an embarrassment to be seen naked . . . and to be touched on the breast by the spouse . . . a feeling of being less sexually attractive for the partner . . . and a need of more affectionate behavior from him . . . (abstract).

Unfortunately, Tarabocchia et al.'s (1983) study has not been published and it is impossible to ascertain how they collected their data and to be sure that their research results are accurate to describe this sample of post-mastectomy women. Not enough studies have been done in the area of post-mastectomy sexuality to replicate the findings of the above study and lend it scientific support.

Both the frequency of intercourse and the level of sexual satisfaction can often decline in women who have undergone mastectomy (Silberfarb, 1984; Tarabocchia et al., 1983). Perhaps a contributory factor is the failure of an external prosthesis to establish any aspect of normalcy in sexual relationships because it is not a permanent part of these women's bodies (Greenberg, 1980; Thomas & Yates, 1977).

Woods and Woods (1975) emphasize that up to their time of writing, "no documentation exists in the literature regarding actual change in frequency of intercourse or orgasmic response
after mastectomy". The majority of articles written on the issue of sexuality of post-mastectomy women appear to be in the form of literature reviews (Silberfarb, 1984; Woods & Woods, 1975) which report only selected findings from some research studies. There is no indication what type of research was carried out and how valid the findings were.

Lerman (1983/1984) measured changes in marital and sexual relations, and physical self-concept in post-mastectomy women who underwent breast reconstruction. Sixty-six women who ranged in age from 30 to 70 years of age participated in the study. Subjects underwent breast reconstruction from 6 months up to 8 years following mastectomy. Scales of sexual and marital relations, feminine attractiveness, and self-concept ratings were used to measure each woman's perception of changes in her sexual and marital relations and physical self-concept at three different periods: pre-mastectomy, post-mastectomy, and post-reconstruction.

The marital relations scale included questions about the frequency and level of conflict in the relationship, perceived stability of the marriage, perceived involvement of the couple with each other, and the amount of affectionate behavior demonstrated between spouses (Lerman, 1983/1984). Items measured on the sexual relations scale consisted of the meaningfulness of breast stimulation during lovemaking for both spouses, the value of sex in the marriage, frequency of sexual intercourse, and the
percent of time that orgasm is experienced by the woman during sexual relations (Lerman, 1983/1984). She used scales that measured feminine attractiveness by asking questions such as the feelings of the woman regarding physical attractiveness and femininity, the value of her breasts in reinforcing these feelings, and the level of satisfaction with her appearance in clothes.

Lerman's research "revealed a significant overlap of the marital and sexual relations and feminine attractiveness scales" (1983/1984, p. 41). She reports that women claimed to have an increase in general marital relations from the period before mastectomy to the period following reconstruction. Lerman posits that the reason for this increase in marital closeness may be due to having to deal with the threat of diagnosis and treatment of cancer. However, there was a significant decrease in the frequency of sexual relations post-mastectomy. Her results pertaining to the decreased amount of sexual relations following mastectomy are supported by Tarabucchia et al. (1983).

As previously mentioned, Lerman's research establishes the link between sexual relations and a woman's feelings of feminine attractiveness. She also reports that there was a significant rise in the level of these feelings following breast reconstruction. Lerman's findings regarding women feeling more feminine and attractive post-reconstruction are well-documented and supported in the breast reconstruction literature (Berger &
Bostwick, 1984; Bostwick, 1983; Goin & Goin, 1981). These results demonstrate the importance of body image and sexuality in women who consider breast reconstruction. The strength of her research lies in the reliability of the measurement scales used, which lend her study validity. Her sample size was also large in comparison to many of the other studies that are explored in this literature review, and as a result, Lerman's findings are more generalizable to the larger population. Unfortunately, she was not able to include a control group in her study, which would have improved the soundness of her experimental design. Finally, her data were retrospective, which could have caused more reported inaccuracies. The importance of Lerman's research cannot be underestimated in terms of addressing the relevant concepts pertinent to women who undergo breast reconstruction. The result of her research succeeds in furthering health professionals' knowledge in this sparsely researched but critical subject.

Self-Concept

As previously noted, there is an intimate relationship between body image and self-concept. A change in body image can, therefore, affect a post-mastectomy woman's self-concept. For this reason, it is necessary to be aware of how a woman views herself in order to know if her view has altered since the mastectomy. This section will define self-concept and demonstrate that the way in which a woman feels about herself may
determine the amount of interest she takes in the possibility of breast reconstruction.


One study which attempted to do this was carried out by Polivy (1977) who measured changes in body image and self-concept in a group of mastectomy patients. She compared a group of 15 women who had undergone mastectomy with two other groups. These groups consisted of 18 women who had had negative biopsies and 11 women who were admitted for various noncancerous operations. All the women were interviewed twice and given an edited version of the Berscheid, Walster, and Bohnstedt Body Image Scale. This measurement scale was administered on three different occasions: before and following surgery, and again after several months had elapsed.

Polivy's results indicated that while the surgical patients' body image and self-concept did not change, the biopsy patients showed a decline in both categories after being told they did not have cancer. The mastectomy patients showed no decline in body
image and self-concept scores until several months had elapsed. At this time, the scores of all the mastectomy patients were indicative of a loss of self-esteem. These findings may indicate that the mastectomy patients utilized denial as a protective mechanism until they were able to confront the loss of their breast. Polivy's sample groups were small in size, which prevents generalization of her findings to a large population. However, her measurement techniques were scientifically sound and her inclusion of a control group lends her results validity. Her study clearly shows a strong link between a woman's perception of her body image and how she feels about herself.

Another study was conducted by a Swiss plastic surgeon, who instructed women to draw a silhouette of themselves immediately before and after their mastectomy (Timothy, 1977). Their silhouette portrayals appeared normal and realistic at both times. After a few weeks had elapsed the women's drawings became more flattened and male-looking in shape, emphasizing the lack of the breast (Timothy, 1977).

The findings of the above study lend support to Polivy's research by illustrating a time lag between an actual body image change and the accurate perception of that change by the person herself. Unfortunately, Timothy does not specify details of the above study, so the sample size and methods of measurement are unknown. As a result, the validity of the study is questionable and the results can only be construed as based on one
researcher's opinion. It appears that the relationship between changes in body image and timing of decision-making regarding breast reconstruction has not been elucidated. Other authors have made claims, largely unsupported, which are inconsistent with these results.

The writer speculates whether a lower self-concept arising in women several months after their mastectomy affects how women feel and make decisions about breast reconstruction at that time. Carroll-Johnson (1982, unpublished) addresses this issue by claiming that there is a common assumption among health-care professionals that one of the major reasons women seek breast reconstruction is because of a disturbance in their self-concept as the result of mastectomy. The converse belief that women who do not consider breast reconstruction are therefore better adjusted and have reached a higher level of self-acceptance persists, despite the lack of studies to support it. This belief appears to be most firmly entrenched in the early breast reconstruction literature between 1977 and 1981 (Cocke, 1977; Goin & Goin, 1981). Carroll-Johnson (1982) asserts that she was unable to find any valid research studies which tested the above assumption.

It appears that if the mastectomy experience has the potential to lower women's self-esteem, then this experience needs further exploration as a possible factor in the breast reconstruction decision process. The issue of how perception of
body image and self-concept influence a woman's decision-making about breast reconstruction will be explored further in the breast reconstruction section of this literature review.

Carroll (1981) stresses that there is a need for a two- to three-month follow-up for post-mastectomy women, to allow for the body image adjustment that occurs during this time. This may be a crucial time for a post-mastectomy woman to consider her feelings about breast reconstruction. The general literature suggests times that are appropriate for the surgeon to discuss breast reconstruction with the patient. However, it does not give direction as to the relevant time for the woman herself to decide about this surgery. There is a strong possibility that each woman would have a unique perception of the best time for her decision-making. This timing would likely be dependent upon her perception of her changed body image and would have to be individually assessed during the follow-up.

Impact of Prosthesis on Body Image

The preceding sections have illustrated the interrelationship of body image, sexuality, and self-concept. Research findings in the literature also suggest a strong likelihood that the wearing of a prosthesis can adversely affect body image and self-concept in some post-mastectomy women. Perhaps the wearing of a prosthesis does not, as previously claimed, assist women to regain a positive body image and may even have a negative effect on the quality of their lives.
Therefore, feelings related to the prosthesis could be a factor in the decision-making process regarding breast reconstruction.

During the post-operative period following mastectomy, the rehabilitation process focuses on physical recovery and a return to the activities of daily living. The need for the patient to begin wearing a temporary prosthesis is emphasized prior to discharge by health professionals both in practice settings and in the general literature (Silverman & Cohen, 1979). The rationale given for the early wearing of a prosthesis is that the sooner the woman's external appearance is restored to normal, the sooner she will adjust to her loss (Wiesenthal, 1984). Wilson and Kneisl (1979) allege that "the body image extends beyond the physical body. Objects of daily use that are intimately connected with the body surface, such as a cane, clothes, a tattoo, makeup, and jewelry are incorporated into the body image" (p. 250). It is therefore possible that once a woman has adjusted to a prosthesis, it becomes part of her body image. Whether breast prostheses are similarly regarded as part of body image has not been specifically studied. However, the following research dealing with how women feel about their prostheses lends insight into the relationship between prosthesis and body image.

While some women adapt to wearing a permanent prosthesis, a certain number do not. Greenberg (1980) believes that there is widespread dissatisfaction with the available external prosthetic devices. "Many women do not feel at ease while wearing the
irritating, uncomfortable, external substitutes for their missing breast" (p. 1). Downie (1975) found that fifty-six out of a hundred women she interviewed admitted that their prosthesis was uncomfortable because of its heaviness or tendency to slip out of place. Woods and Earp (1978) shared similar findings and reported that three-quarters of the women in their sample who wore prostheses reported difficulties ranging from poor fit to skin sensitivity and pain.

Several authors highlight the inherent imperfections of prostheses (Anstice, 1970; Thomas & Yates, 1977; Winkler, 1976). The more natural gel-like prostheses tend to be expensive. Perfect balance is difficult to attain with a prosthesis if a woman is either very small- or large-breasted. Back discomfort and muscle strain can develop as a result of a poorly balanced prosthesis. Many prostheses do not feel or sound natural when touched. They tend to be hot and irritating to the skin during warm weather and to change position during active exercise.

Contrary to the view that the prosthesis can be incorporated into a woman's body image, Silverman and Cohen (1983) explain why they feel that for some women, the external prosthesis does not alleviate the problem of altered body image:

Although this device may help women feel and look better when clothed, it does not change the internal deformed body image. Since the form feels false and is frequently removed, the patient continues to be reminded that the
breast is absent (p. 142).

Failure to feel comfortable with a prosthesis can lead these women to shun social activities because of self-consciousness. Greenberg (1980) reports that the inability of patients to "wear low-cut sleeveless dresses or bathing suits leads to feelings of social isolation and insecurity" (p. 1). This reclusiveness has negative implications for a woman's perception of her body image and can lead to poor future adjustment (Anstice, 1970; Maguire, 1975). In spite of prevailing practise, some women do not choose to wear a prosthesis.

The following author expresses strong feelings about the inadequacy of any prosthetic device replacing her lost breast and chose her own way of adjusting to her changed body image. Audrey Lorde (1980) poignantly rejects the use of a prosthesis and the idea of breast reconstruction. She states that adjustment to her altered body image could only come from growth within herself.

To imply to a woman that yes, she can be the 'same' as before surgery, with the skillful application of a little puff of lambswool, and/or silicone gel, is to place an emphasis upon prosthesis which encourages her not to deal with herself as physically and emotionally real, even though altered and traumatized. This emphasis upon the cosmetic after surgery reinforces this society's stereotype of women, that we are only what we look or appear . . . with quick cosmetic reassurance, we are told that our feelings are not
important, our appearance is all, the sum total of self
(Lorde, 1980, p. 56).

The option of choosing to go without a prosthesis is not
mentioned in the general mastectomy literature and as such is not
likely to be condoned by the prevailing beliefs of medical care
(Lorde, 1980). Lorde's different point of view is valid and
conveys the importance of assessing the meaning of the breast
loss and body image change from each woman's unique perspective.
It is clear that for Lorde, feelings about her body image
represented an influential factor in terms of her decision not to
wear a prosthesis.

Carroll-Johnson (1982) examined the impact of body image as
it related to women choosing or refusing breast reconstruction.
However, she did not address the important issue of the influence
of the prosthesis as a possible factor in this decision-making
process. The following section explores the relevant literature
regarding breast reconstruction in order to present factors that
are likely to affect a woman's decision to consider breast
reconstruction.

Chronological Developments in
Breast Reconstruction

The literature describes some of the historical developments
in breast reconstruction. It is necessary to know the history of
breast reconstruction in order to put the recent changes into
context. These changes are reflected in society's increasing
acceptance of this surgery. It is interesting to note that when medical technology changes, the underlying rationale also changes to support it.

Letterman and Schurter (1978) claim that the three available methods of breast augmentation and reconstruction are "injectable materials, prosthetic devices, and the use of autogenous tissue transplantation" (p. 243). Unfortunately, tissue transplants and injectable paraffin and silicone produced too many complications to make them worthwhile. "The first implantable prosthetic devices appeared in solid form as handcarved ivory and glass balls" and were used until a preformed sponge made its debut in 1951 (Walsh & Stefanski, 1983, p. 1381). These devices were rejected by the patient's body and caused serious complications. It was the development of the safe silicone prosthesis in the 1960's that made successful breast reconstruction possible in the early 1970's (Walsh & Stefanski, 1983).

Up until a decade ago, reconstruction typically involved multiple procedures because surgical techniques for skin flaps, needed for sufficient skin coverage, had not been perfected. No dependable, safe prostheses were available for restoration of contour, and hospital stays tended to be lengthy (Dowden, Horton & McCraw, 1979). All these factors contributed to the risks of breast reconstruction surgery, resulting in limited numbers of such operations being performed. The past 10 years have seen a surge of research, new surgical techniques, and a concomitant
growing public awareness of the benefits of breast reconstruction.

The trend towards early breast cancer detection, the growing willingness of cancer surgeons to perform less than radical breast surgery, recent developments in plastic surgery and growing public acceptance of other types of cosmetic surgery are helping to make breast reconstruction more feasible, cosmetically pleasing, and less expensive than in the past (U.S. National Cancer Institute & Office of Cancer Communications, 1979).

The primary reason underlying the increase in the amount of breast reconstruction being performed is the development of medical technology. Advances in technology coincided with a shift in focus regarding mastectomy surgery. Traditionally, a radical mastectomy was performed even if a woman had a stage one breast tumour. The advent of the modified radical as the recommended curative surgery during the 70's made breast reconstruction simpler, as there was usually no need for skin grafting. Breast reconstruction following mastectomy for carcinoma is therefore a relatively recent development. Prior to 1976 there are few accounts of this surgical procedure being performed. Mendelson (1980) states,

Twenty-five years ago a woman seeking reconstruction of the breast after mastectomy would, in all likelihood, have been considered highly neurotic or obsessed. Such surgery was
rarely performed, patients being dissuaded from reconstruction, if not on psychological grounds, then on technical grounds (p. 517).

The following statement shows how the change in philosophy has affected public opinion. Teimourian and Adham (1982) cite the U.S. Department of Health and Human Services (1980), "In a public understanding survey on breast cancer . . . it was discovered that nearly 4 out of 10 women would consider breast reconstruction after mastectomy" (p. 322).

In general, most post-mastectomy women will not be able to have immediate reconstruction of their breast at the time of the mastectomy. Reasons for this include the physical shortage or vulnerability of the chest skin, the possibility of recurrence, and the extensiveness of the tumour, which may require radiation or chemotherapy. The waiting period between the mastectomy and the reconstruction usually varies from three months to over a year.

**Traditional Versus Holistic Perspective in Breast Reconstruction**

Breast reconstruction literature shows a marked shift in orientation, depending upon the time it was written. In the 1970's, the emphasis appeared to be on the surgical procedure and outcome of the surgery. A woman was viewed in terms of qualities thought to make her a good risk for surgery. Surgeons were particularly wary of women who were devastated by their mastectomy and whose expectations were considered too high to be
satisfied with a reconstructed breast. This period in time can be referred to as the traditional perspective, which appears to categorize the literature and research published in the 1970's. However, there is also some literature published in the 1980's that reflects this perspective.

The holistic perspective is characterized by an appreciation of a woman's needs as a result of her cancer-mastectomy experience. This psychological orientation is in marked contrast with the physical, technical approach in the 1970's and appears from 1980 to 1985. The switch from a traditional to a holistic approach seems to be related to the ever increasing technological improvements in breast surgery. Again, while most of the literature on breast reconstruction published in the 1980's focuses on a holistic approach, there is not unanimity on this topic. To prevent confusion and to place this information in a chronological context, a distinction is made between traditional and holistic breast reconstruction literature.

Timing

This section presents the topic of the recommended time interval between mastectomy and breast reconstruction. The traditional rationale for delaying reconstructive surgery was expressed by Dinner and Peters (1978):

A woman who has lived with the results of mastectomy will be happier with less than perfect results of the reconstruction compared with the shapeless anterior chest wall that she
lived with following her initial operation. For this reason we encourage a delay in reconstruction for as long as possible (p. 852).

Doctors felt that the few patients who had immediate reconstruction after their mastectomy tended to still be in a period of denial. This often resulted in them being satisfied at first but suffering disappointment in the long-term result because the reconstructed breast was not like their lost breast. In the traditional approach, the timing that was recommended for breast reconstruction following mastectomy was also dictated by the length of time the skin took to heal, in addition to the above psychological considerations.

In the past five years, there is evidence that the psychological focus is not only having an effect, but may actually be changing some of the principles adhered to in the past. As a result, the holistic perspective views breast reconstruction as a part of the rehabilitative process, and not primarily as an intervention for women who cannot adjust to the loss of their breast. This holistic perspective is reflected in the trend towards immediate breast reconstruction at the time of mastectomy. The subject of immediate breast reconstruction will be explored at length in a subsequent section. Interestingly, a recent article by Dinner and Dowden (1984), showed that Dinner, who has been referred to, reflected a shift in his traditional thinking to a more holistic approach. "We would never deny a
patient immediate reconstruction in order to make her live with her deformity for a period of time so that she appreciates the reconstruction more" (p. 810).

**Issues in Breast Reconstruction**

Results of surgery vary from patient to patient. Plastic surgeons emphasize that, at best, a woman will appear normal in a bathing suit or bra. They caution patients that the breast mound will not look as natural as a normal breast when they are nude (Graham & Turner, 1981; Snyderman, 1976). During the consultation with the surgeon, the post-mastectomy woman is typically shown pictures of other women who have undergone reconstruction (Bostwick, 1983; Goin & Goin, 1981; Greenberg, 1980). These pictures depict women who have had fair, average, or good results in order to show them the range of realistic possibilities. Hunt (1981) recommends that his prospective clients also talk to patients who have had both fair and good reconstructive results.

Current medical literature stresses the significance of a positive attitude in women who undergo breast reconstructive surgery in predicting their adjustment to the reconstructed breast (Clifford, 1979; Cocke, 1977; Goin & Goin, 1981; Graham & Turner, 1981). The consultation period between surgeon and patient focuses on building rapport, which facilitates the patient becoming well-informed about the reconstruction procedure.
The initial interview between the patient and the reconstructive surgeon after mastectomy should establish lines of communication that transcend discussion of the obvious, physical deformity and allow the surgeon to develop insight into the patient's emotional status, her expectations from surgery and his chances of meeting her expectations . . . but it is often helpful to begin by asking the patient what she wants to talk about and allowing her the freedom to share her feelings and expectations (Bostwick, 1983, p. 291).

Goin & Goin (1981) also acknowledge the importance of recognizing that the post-mastectomy patient may be dealing with a range of intense feelings such as "depression, wounded self-esteem, decreased feelings of femininity, denial of breast loss, anger at surgeons, and fear of recurrent cancer" (p. 176). They advocate exploring these issues with each patient. Thorough preoperative planning has a positive influence on the final surgery.

Ward (1981) emphatically illustrates the significance of a woman's attitude and associated expectations in determining her acceptance or rejection of breast reconstruction.

A woman can be emotionally and psychologically uplifted after a technically incompetent breast reconstruction. Another woman can be devastated after a perfectly executed reconstruction when she realizes the price she has paid in
terms of added scars. In the eyes of the first woman her new breast is beautiful and in the eyes of the second woman it is hideous (p. 127).

Considering the amount of motivation needed by reconstruction clients, it is not surprising that the actual incidence of breast reconstructions being carried out is low. Rutledge (1982) and Bostwick (1983) claim that only five percent of mastectomy patients undergo breast reconstruction. "Only 25 percent of those who express an initial interest in undergoing reconstructive surgery will eventually request it" (Graham & Turner, 1981, p. 581). The following plastic surgeon expresses a traditional view to explain the above phenomenon. Snyderman (1976) states that

Most women who come to discuss breast reconstruction will elect not to undergo the surgery after having the procedure and the results carefully explained. Unlike the time of their excisional surgery, when they are given little choice, now they feel that their destiny is in their own hands (p. 466).

He feels that if all mastectomy patients were reassured that the emotional trauma they have experienced was normal, in addition to being informed about reconstruction, most of them would decide against this extra surgery.

Factors Involved in Decision-Making

Decision-making theory may be useful in examining and
organizing information about factors that are pertinent to breast reconstruction. The following literature explores factors that may be influential in the breast reconstruction decision-making process. Individual factors likely act to either deter a woman from or encourage a woman towards the idea of breast reconstruction. However, the individuality of each woman will ultimately determine what combination of factors will be responsible for her decision to choose or decline reconstruction.

Controversy about the importance of different factors in the decision-making process abounds in the literature. This lack of agreement among health professionals may be indicative of a critical lack of research-based information on the role each factor plays in this process. One cannot assume that all of the factors presented in this review are relevant to each woman who considers reconstruction. These factors are presented only as guidelines as to what may be important in the decision-making. Only the individual can accurately assess the degree of importance each factor holds in her own decision-making process.

Goin and Goin (1981) state that the following feelings may act as factors to prevent or postpone a woman's decision to undergo breast reconstruction. "For some, fears of cancer recurrence, feelings of guilt and vanity, and anxiety about another operation will interfere. Others will delay because they actually no longer experience the emotional need for reconstruction" (p. 175). Another inhibiting factor implicated
by both traditional and holistic viewpoints is a dearth of consumer knowledge about the possibility of breast reconstruction (Cocke, 1977; Rutledge, 1982). This could be due to a general lack of awareness combined with a negative attitude among some general surgeons (Snyderman, 1976). Surgeons who do not support breast reconstruction may adversely affect the psychological adjustment of some patients. They may insist upon a three- to five-year waiting period or simply tell the patient that she is not a reconstruction candidate without referring her to a plastic surgeon for consultation (Goin & Goin, 1981; Snyderman, 1976). The surgeon's primary fears are that breast reconstruction surgery may activate a local recurrence and that the silicone implants may mask a recurrence if it developed. These traditional medical fears are dissipating somewhat in the light of recent medical evidence showing that immediate breast reconstruction does not have these effects (Bostwick, 1983; Bostwick & Berger, 1984).

Many women give up in despair or are too timid to seek out a second surgeon's opinion. Snyderman (1976) states that additional education would dispel much of the general surgeons' hesitancy about recommending breast reconstruction to their patients.

Bostwick (1983) claims that the women who seek reconstruction have a tendency to focus more on physical appearance and be more distraught by the mastectomy deformity.
These women are, perhaps, more devastated by the loss of their breast than by the threat of cancer (Needleman, 1979; Timothy, 1977).

Women who persistently seek and insist on reconstruction may be the ones . . . we have to be most careful of . . . Because of their intense interest in self-image and breast reconstruction, this group . . . may expect more of the reconstructive surgeon and look to him to make them 'whole' again (Cocke, 1977, p. 12).

Goin and Goin (1981) report that "there was no evidence that these women were particularly 'breast conscious' before mastectomy. Two of them admitted taking particular pride in the shape and appearance of their breasts, but the remainder were surprised by the feelings of devastation which followed their breast amputations" (p. 184).

The lay literature stresses that a woman undergoes reconstruction for mainly restorative reasons (Kushner, 1982; Zalon, 1978). This process of wanting to be 'whole' is tied in with desiring to look normal as they once did. Timothy (1977) asks "where is the vanity in preferring to be like other women?, Where is the vanity in preferring to be the way one was?" (p. 132). "The concern of these women about the integrity of their bodies is not narcissistic, immature, or neurotic, but as natural and appropriate as another person's concern for the loss of an eye or an arm" (Thomas & Yates, 1977). In Harvey (1980),
Wade cites a nurse as saying "the old-fashioned concept that women seek this surgery because they cannot adjust psychologically to their plight is outrageous. People want to feel and look normal" (p. 100). The emotional intensity of the above statements reflect the reactions of women who have felt compelled to defend and justify their decision to undergo reconstruction.

Zalon (1978) feels strongly that breast reconstruction should be available for every mastectomy patient if it meets her physical and emotional needs. She states that "for the many thousands of women who feel deprived and devalued as a person and as a woman by the mastectomies they have undergone ... I believe reconstruction can restore the longed-for sense of wholeness" (p. 136). "I feel my body is back together again. It feels natural and normal which is a feeling that I thought I would never again experience" (Needleman, 1979, p. 75).

Hugo (1977) cites a patient who wrote a letter to him regarding the powerful sense of wholeness that was restored to her through breast reconstruction. "How can I ever thank you enough for the superb reconstructive surgery you did, literally without pain or inconvenience at the time; later followed by a quiet, peaceful state of mind, a self-assurance in becoming a complete woman again" (p. 128).

**Breast Reconstruction Research**

The main thrust of research dealing with breast
reconstruction was developed by surgeons prior to the 1980's. As such, the majority of it was related to the actual surgical techniques used to effect the breast mound and the nipple. As mentioned previously, the interest of plastic surgeons has shifted from the technical to more of a psychological perspective since 1980 (Bostwick, 1983; Goin & Goin, 1981). This rise in concern regarding the psychosocial adjustment of the post-mastectomy woman who desires breast reconstruction appears to be paralleled by refinement of the surgical procedures and innovative techniques that improve upon the aesthetic result of the reconstructed breast. This movement away from the traditional focus to a more holistic perspective was assisted by input from psychologists and psychiatrists (Goin & Goin, 1981; Rowland, 1984).

Nursing literature regarding breast reconstruction emerged in the 1970's, with a focus on explaining the technical surgical techniques used to develop a breast mound. Literature reviews were prevalent during this period and actual nursing research input was extremely limited. This pattern has continued into the 1980's and the only source of research on breast reconstruction to date is an unpublished Master's thesis by Carroll-Johnson (1982). Nursing literature and research in the 1980's continues to emphasize the technical aspects of surgery rather than psychological issues. In general, nursing research tends to deal far more extensively with mastectomy than with breast
reconstruction.

The following section reports the findings of current research in breast reconstruction from other disciplines. Although a variety of breast reconstruction research exists, much of it lacks coherence and as a result the findings are difficult to interpret. There are pitfalls involved in presenting an overview of all the available studies, as many of them contain methodological flaws that seriously affect their usefulness in understanding the decision-making process of women considering breast reconstruction. Therefore, only those studies that have relevance to the factors that influence women making the decision to have breast reconstruction are included. A critical stance has been taken in order to effectively assess the applicability of the research presented. Much of this research deals with the topic of immediate breast reconstruction and as such is characteristic of the holistic focus that now predominates over the traditional approach.

Research shows that undergoing immediate reconstruction can markedly reduce debilitating complications in some post-mastectomy women (Dean & Chetty, 1983; Stevens et al., 1984). Recent research on immediate breast reconstruction following mastectomy contradicts the belief that a woman needs a waiting period before she is able to accept her reconstructed breast (Dean & Chetty, 1983; Logan, 1980; Schain & Wellisch, Pasnau & Landsverk, 1985; Stevens et al., 1984). Logan (1980)
has inserted prostheses at the time of mastectomy in approximately 50 patients. He reports that these patients are less depressed than those who have had only a mastectomy. However, this finding is unsubstantiated by research, as the author did not use any objective method of evaluating his patients' level of depression before or after reconstruction.

Dean and Chetty's (1983) study included 64 women with operable breast cancer who were randomly assigned to two groups, one which underwent immediate breast reconstruction and a control group to whom reconstruction was offered a year later. All immediate reconstruction patients were psychologically evaluated after 3 months and then again in 12 months. The researchers found that a much higher percentage of women in the immediate implant group had returned to work three months after surgery than in the control group, "18 of 27 vs. 12 of 26" (p. 460). The main finding revealed a reduction in "psychiatric morbidity at 3 months after operation predominantly in women with unhappy marriages. This group of women generally have a high psychiatric morbidity after mastectomy . . . and major breast reconstruction appears to prevent much of the morbidity" (p. 461). Of the 31 women in the control group, only 6 underwent reconstruction 12 months after mastectomy, which the researchers think is due to their coming to terms with their physical appearance (Dean & Chetty, 1983).

Stevens et al. (1984) studied 13 women who selected
immediate breast reconstruction and 12 women who delayed reconstruction 3 months to 8 years after their mastectomy. Their findings indicated that the women who underwent immediate reconstruction felt an elevation in mood and a lessening of depressive symptoms following reconstruction. In contrast, "seventy-five percent (9 patients) of the group with delayed reconstruction reported feeling 'deformed' after mastectomy. None of the group with immediate reconstruction had such feelings" (p. 622). The authors stated that "all of the immediate reconstruction patients reported a return to their preoperative sexual functioning except three, who received chemotherapy and experienced a loss of libido early in their chemotherapeutic treatment. Fifty-eight percent (7 patients) of the delayed reconstruction group reported an alteration in their sexual functioning after mastectomy and before reconstruction" (p. 623).

A study conducted by Schain, Wellisch, Pasnau, and Landsverk (1985) assessed the psychological adjustment of post-mastectomy women who had immediate versus delayed reconstruction. Sixty-three women were included in the study and were grouped according to three categories; those women who underwent immediate reconstruction, those who underwent reconstruction less than a year after mastectomy, and those whose reconstruction was delayed more than a year. They were assessed using a questionnaire and several assessment instruments. The results of
this study supported the previous research cited in this discussion.

These data showed that women who underwent reconstruction either immediately or within one year after mastectomy were significantly less likely to report more extreme reactions of distress about the first viewing of their mastectomy than those women who had breast reconstruction more than a year after their original surgery (p. 42).

Although these studies have shortcomings, including small subject numbers and a large amount of retrospective data, they lend strong support to the psychological benefit of immediate breast reconstruction for some women (Stevens et al., 1984).

Stevens et al. (1984) dispute the previously held traditional belief that time is required after mastectomy to adjust to the missing breast before reconstruction can even be considered.

There has been concern in the past that immediate breast reconstruction would somehow alter or impede the process of mourning and psychological adaptation to the loss of the breast. Our results suggest that immediate breast reconstruction does not alter this process and that the mourning for the breast loss begins in both groups even before surgery with the anticipation of the breast loss (p. 625).

This research involving immediate breast reconstruction has
important psychological ramifications for women who will be confronted with the need for a mastectomy. One-step implant surgery is likely to significantly reduce the resulting overall trauma for some women.

The remainder of reported research findings deal with factors that appear to influence a woman's decision to consider breast reconstruction. This section provides some substantiated evidence of the validity of the role certain factors play.

The impact of age and subsequent stage of psychosocial development are factors surrounded by controversy. The following authors propose explanations regarding how these factors relate to post-mastectomy adjustment.

Maguire (1975) claims that younger women who led an active sex life and whose breasts represented attractiveness to them are at risk for poorer adjustment after a mastectomy. On the other hand, Goin and Goin (1981) are of the opinion that women who are close to menopause or experiencing menopause may be at a greater risk for having an intense post-mastectomy crisis. This reaction may be caused by their awareness that youth is passing, signifying a lack of time left for fulfillment of earlier plans. Others maintain that adjustment depends upon the significance of the breast to each woman and that age is not a significant factor in the adaptation process (Berger & Bostwick, 1984; Silberfarb, 1977-78).

I found that young women care desperately about being
obliged to live with only one breast . . . but I found that married women care as much, and single women care as much, and older women care as much. Their reactions were all similar. Where the breast is concerned, the emotions are so primal that there are no categories (Timothy, 1977, p. 132).

The above authors base their opinions on interviews of small samples of women and control groups were not included. While these findings are interesting and should be investigated scientifically, they give no clear direction regarding the importance of a particular age when it comes to deciding about breast reconstruction.

Society's preoccupation with youth tends to discriminate against post-menopausal women who desire reconstruction. Stereotyped myths support the notion that middle-aged and elderly women lose interest in sexuality and the desire to look attractive. Timothy (1977) poignantly describes an experience of one woman who phoned a community support service worker to request support prior to her mastectomy. She was asked her age and when she replied that she was fifty-two he asked, "Then why do you care? You're not going to seduce anyone" (p. 132).

Given this prevalent attitude, it is not surprising that women in their fifties and sixties might be reluctant to request breast reconstruction because of fear of being criticized for their vanity. The fact that breast reconstruction is offered to this age group less frequently than women in their 20s, 30s, and
40s indicates that societal prejudice may be an important factor in the reluctance of women over 50 to consider breast reconstruction. Relatives and well-meaning friends may also pressure the breast reconstruction candidate, saying that they accept her the way she is. They cannot understand why she would want to subject herself to more surgery just to get another breast (Goin & Goin, 1981; Timothy, 1977; Zalon, 1978).

Goin and Goin (1981) report a study that explored husbands' attitudes towards breast reconstruction. The findings have implications for the husbands' abilities to give their wives needed support.

The men in this study were well-educated, in relatively high income groups, and lived in a metropolitan area (Los Angeles) where plastic surgery is commonplace. Nonetheless, a large proportion of the husbands were quite negative about the idea of breast reconstruction. They felt that they (and presumably their wives) had had enough of doctors, hospitals, and surgical operations. Another group felt they would give in if their wives were very strongly motivated to have their breasts reconstructed, but showed little spontaneous interest themselves. Only a few men strongly favored breast reconstruction for their wives (p. 171).

Timothy (1977) asked numerous men how significant it would be to them if their partner were to have breast reconstruction. They responded almost unanimously that she should go ahead if it...
was important for her but not to do it for their sakes. Hunt (1981) reports that "it is rare for a husband to urge reconstruction. It is even rarer for a 'significant other' to urge reconstruction" (p. 4). Rowland's (1984, unpublished) results show that "60% of women stated that their husband or significant other was neutral or even opposed to her [sic] desire for reconstruction -- despite having been supportive (85%) following mastectomy" (p. 8). These statements suggest that the decision-making process may be based more on the personal choice of each woman rather than on the influence of significant others.

Clifford (1979) reports that no one knows in any scientific sense what impels a woman's search for restoration or whether it is more likely to be the woman with "impoverished inner resources or the stronger, more assertive woman who seeks breast reconstruction" (p. 22). He interviewed sixty-five women in the process of having reconstruction to determine their motivation.

The women in this study appeared to be reality oriented and the drive for restitution could be considered an effort to achieve a normalcy through the rejection of a physical disability that may be remedial. Women did not seek restitution, for the most part, to solve an inner problem or emotional turmoil. The drive was clearly restorative (Clifford, 1979, p. 32).

The research findings from Clifford's study are valuable in that they represent one of the first attempts to explore the reasons
women chose breast reconstruction from the women's point of view. The findings also cast considerable doubt on the traditional assumptions that these women were psychologically traumatized. Carroll-Johnson's research supports the above findings that women who consider breast reconstruction are no more vulnerable to emotional distress and low self-esteem than other post-mastectomy women. She writes "even though the reasons for reconstruction are primarily psychological (to restore body image, confidence, and the sense of being 'whole again'), no studies to date have been done to evaluate any of these attributes in women who seek this operation" (p. 2).

Carroll-Johnson's (1982) unpublished research was aimed at discovering whether or not a link existed between body image scores and the decision to undergo breast reconstruction. She matched 13 breast reconstruction candidates with a similar group of 12 post-mastectomy patients who chose not to undergo breast reconstruction. Her results "revealed no significant difference between the two groups with respect to body image, gender role definition (masculinity/femininity) and self-esteem" (p. 56).

Both groups of women were found to score positively with respect to body image. Carroll-Johnson reports the interesting finding that with regard to confidence in their general abilities "85% of the breast reconstruction candidates felt very or considerably confident while only 58% of the control subjects rated themselves as high" (p. 47). Unfortunately, the sample size in her study
was very small which makes it difficult to generalize to the larger population of post-mastectomy women who consider breast reconstruction.

A larger research study involving 83 women who underwent breast reconstruction was conducted by Rowland (1984). This study sought to explain women's reasons for considering reconstruction, their expectations of the reconstructive surgery and their response to reconstruction. Rowland's results demonstrated that "women seeking reconstructive surgery were realistic in their expectations, highly motivated, psychologically well-adjusted and high functioning, much like their nonreconstructive peers" (p. 9). Rowland's results supported Clifford's findings, as she discovered that the most frequently stated reasons for choosing to undergo reconstruction were to "1) to be rid of the prosthesis, 2) to 'feel whole again', and 3) to restore symmetry and thus decrease self-consciousness about appearance" (p. 9). Rowland's study appears to be the most rigorous to date in terms of comprehensive, accurate measurement techniques. The patients were evaluated by both a clinical interview and a detailed self-report questionnaire which:

assessed the woman's past psychiatric history, degree of present symptomatology and current level of functioning, and adaptation to mastectomy, including sexual adjustment . . . psychosexual development, current level of psychological and
social function . . . use of and satisfaction with breast prostheses, and knowledge of, expectations of, and motivation for reconstruction (p. 8).

Both pre- and post-operative evaluations were carried out. While the sample size might still be considered small, this study is very important for giving insight into the factors that are influential in the breast reconstruction decision-making process.

What about the women who actually undergo breast reconstruction after considering all the factors that allegedly influenced their decision-making? Clifford (1979) lists the expectations of reconstructive breast surgery patients as "restoration, relief of clothing or prosthetic problems, becoming less self-conscious or embarrassed, improving appearance, improving feelings, improving marital relationships, changing life-style and no expectations" (p. 29).

Perception of the above benefits of reconstruction may well be one of the influential factors that encourage women to undergo breast reconstruction. Examination of the literature and research on breast reconstruction make it clear that the relevant factors influential in the decision-making process can only be complex and very individualistic.

I hope that all those who read this book will keep in mind the cost in pain, time, and money of reconstruction, balance it against the benefit for each patient, and realize that in the end, only the individual patient can know where the
balance lies in her own life. There is no doubt in my mind that reconstruction is an important part of rehabilitation for some patients, excellent palliation for some, and a useless gesture for others (Hunt, 1981, p. 4).

**Decision Theory**

Decision theory is examined in this section in order to understand its relevance to the decision-making process involved in breast reconstruction. An historical overview is given of the development of general Decision Theory, Behavioral Decision Theory, and Psychological Decision Theory. The important role of information in decision-making is also addressed. The organization of this section is useful in terms of placing the theoretical concepts in context with individuals who are faced with health-care decision-making.

The origins of decision-making analysis stem from the disciplines of mathematics and economics (Edwards, 1968; Lee, 1971). Bernouli, a mathematical economist and Bentham, a philosopher economist, are recognized as being instrumental in the initial formulation of decision theory in the eighteenth century (Edwards, 1954, 1968). Hammond, McClelland and Mumpower (1980) state Bernouli believed that "the worth of a decision is determined by the probability of events and their associated utilities" (p. 22) or values. Edwards (1954) cites the following philosophy of Bentham. "Every object or action may be considered from the point of view of pleasure- or pain-giving properties."
These properties are called the utility of the object, and pleasure is given by positive utility and pain by negative utility" (p. 382). The ultimate goal of action was perceived as searching for the maximum utility, whether from a mathematical, statistical, or economic perspective (Edwards, 1954). Both Bernouli and Bentham had a powerful impact on the thinking of nineteenth-century economists.

Lewin was the first person to approach these economic concepts from a psychological perspective. In the 1930's, he described valence (utility) and explored some probability-like concepts (Edwards, 1968). Lewin was reportedly influenced by the mathematician, von Neumann (Edwards, 1968). Unfortunately, the Lewinian formulations were not measurable and as a result, psychological interest in decision processes was not sustained (Edwards, 1968). It was not until von Neumann and Morgenstern published their classic book, Theory of Games and Economic Behavior, in 1944 that the concept of measuring utility emerged (Edwards, 1968). Edwards (1968) states that the authors' claim that men are rational decision-makers "is the historical origin of most psychological research on decision processes since then" (p. 35).

In addition to the key assumption that an individual is always rational, principles of economic theory during this time specified that individuals also know all the available choices and can predict the outcome of all decisions (Edwards, 1954). It
was noted by Edwards (1954) at this point in time that "the
development of the economic theory of consumer's decision-making
... has become exceedingly elaborate, mathematical, and
voluminous" (p. 380). This emphasis on the mathematical
perspective offered limited insight into the behavior of real
people and may have been responsible for psychologists' general
lack of knowledge about economic theory (Edwards, 1954; Lee,
1971).

Edwards (1968) claims that Decision Theory adheres to the
following basic principles:

One, the principle of maximizing expected utility, in
essence asserts that you should choose the action that on
the average will leave you best off. The other, a principle
of probability theory called Bayes' Theorem, is a formally
optimal rule for transforming opinions in the light of new
information, and so specifies how you should process
information (p. 34).

A basic premise of Decision Theory involves the belief that it is
not the actual behavior of decision makers that is valid but the
expectation of what they should do that is all important.
Kozielecki (1981) directs attention to the following limitations
of Decision Theory: "explicitly or implicitly they assume that
optimal decisions are completely determined by the structure of
the task, which renders irrelevant any analysis of either the
cognitive processes or the personality aspects of the decision
maker" (p. 20). Any interpretation of the reasons why decision makers fail to act in a logical manner or consideration of their information processing ability is left entirely up to psychologists (Hammond et al., 1980; Kozielecki, 1981). For this reason, Decision Theory is referred to as a normative or prescriptive theory because it involves the rational choices that an individual should make in a given situation. The following sections on decision-making theory use more of a descriptive, theoretical approach because their psychological focus is on the actual choices real people make, regardless of what they should do (Edwards, 1968; Kozielecki, 1981). It is important to bear in mind, before proceeding further, that the boundaries of mathematical, economical, and behavioral decision theories are not well delineated and overlap considerably.

Behavioral Decision Theory

Edwards, a psychologist who took a special interest in the cognitive aspects of decision-making, demonstrated how his psychology focus could supplement the economists' Decision Theory (Hammond et al., 1980). His article on "The Theory of Decision Making", published in 1954, was a landmark in terms of giving validity and coherence to Decision Theory and establishing the great need for psychologists to become involved in the study of this topic (Hammond et al., 1980). One of Edwards' most important contributions was his empirical research on decision making which was guided by his belief in the "economists' theory
of value and choice" (p. 45).

Edwards searched for a theory to describe the behavioral short-comings of the decision-maker which was in direct contrast with the strictly rational view of man held by decision theorists (Hammond et al., 1980). It was largely through the impetus of Edwards' writings and research that behavioral decision-making theory became established.

**Psychological Decision Theory**

Within an interval of twenty years following the publication of Edwards' influential 1954 paper, two psychologists named Kahneman and Tversky further developed decision-making theory to encompass description, explanation, and prediction of decision behavior (Hammond et al., 1980). According to Hammond et al., the primary goal of Psychological Decision Theory is to "seek the manner in which the processes of memory, perception, and specific varieties of experience lead decision-makers to develop systematic errors in their estimates of the probability and utilities that are the key parameters in decision theory" (p. 11). The psychologist focuses on essential characteristics of the decision-maker which include mental traits that exist in every individual, and personality traits which are unique to each person (Kozielecki, 1981). Janis & Mann (1977) state:

Like Lewin, we see man not as a cold fish but as a warm-blooded mammal, not as a rational calculator always ready to work out the best solution but as a reluctant
decision maker - beset by conflict, doubts, and worry, struggling with incongruous longings, antipathies, and loyalties, and seeking relief by procrastinating, rationalizing, or denying responsibility for his own choices (p. 15).

Janis and Mann (1977) further highlight the human qualities of the decision-maker by citing Abelson's belief that "thinking about vital, affect-laden issues generally involves 'hot cognitions' in contrast to the 'cold cognitions' of routine problem-solving" (p. 45). It is likely that any health-related decision will have some emotional overtones, particularly one concerning breast reconstruction. One wonders if individuals making health-care decisions are even more vulnerable to failure in terms of making a so-called good, rational decision because they are unable to make a cool, logical decision. This logic may be precluded by a lack of health, energy, and time, or other personal factors. The above assertion that an individual's thinking can be influenced by internal emotions which are not dependent on the external environment leads Kozielecki to maintain that this "implies the rejection of the behaviorist notion of man as a reactive system controlled by external stimulation" (p. 23). Psychological theory moves beyond the realm of behavioral decision theory because it involves several general propositions that describe the real behavior of both individuals and groups of people (Kozielecki, 1981). Hammond et
al. (1980) report that this change in thinking from Behavioral to Psychological Decision Theory was the result of a valid amount of empirical evidence demonstrating "that deviations of subjective from objective probability were reliable, systematic, and difficult to eliminate" (p. 23).

Psychological Decision Theory supports the premise that goal-directness is an inborn trait that is possessed by all human decision-makers. Kozielecki (1981) states "goal . . . refers to the person's awareness of a subjective value (utility) he is determined to realize (attain); this awareness guides his behavior" (p. 24). This awareness is fostered by information, which is either collected by individuals themselves through thought processes or is received from the environment as an observation or definite communication (Kozielecki, 1981). According to Kozielecki (1981), goals are perceived as being reflective of a person's physiological and social needs.

In conclusion, while Psychological Decision Theory appears to be more useful in describing the actual realities of human decision making, Hammond et al. (1980) specify that it continues to be aligned with basic Decision Theory.

It still includes probabilities and utilities among its central descriptive terms, and that one of its intended functions is to evaluate, as well as to describe the decision-making behavior of a subject in terms of optimality prescribed by a mathematical (statistical) model (p. 47).
The limitations of this mathematical model are aptly demonstrated by Janis and Mann (1977), who point out that there is no scientific way of combining all the human factors involved in decision-making into a single objective utility measure. Janis and Mann (1977) cite Miller and Starr as stating:

But there is no convenient measuring unit for the utility of an intangible such as dignity. Therefore, even if these other factors can be theoretically expressed in terms of

[subjective] utility the difficulties involved in measuring the utilities prevent the theory [of maximization of utilities] from satisfactorily explaining observed behavior and decision (p. 25).

The preceding section discussed the various theoretical concepts related to general Decision Theory, Behavioral Decision Theory, and Psychological Decision Theory. Given that breast reconstruction is an important psychological issue for those women who consider this surgery, it appears that Psychological Decision Theory is most relevant to the topic under study. This theory appears most likely to accommodate the individuality of women undergoing the decision-making process regarding breast reconstruction and therefore is also congruent with the study's phenomenological focus. It is assumed that knowledge of the underlying principles characterizing general decision theory enhances understanding of critical factors inherent in the decision-making process regarding breast reconstruction.
The following section explores the integral role of information in the decision-making process. Several authors demonstrate methods regarding how individuals process and deal with information related to their decision-making.

**Role of Information in Decision-Making**

The importance of information to the decision-making process is demonstrated by Janis and Mann (1977) who posit that any decision that is made in the best interest of a decision-maker is the result of using vigilant information processing. Sachs (1981) reports that "a decision reached in this manner will have a high degree of stability, that is, it will not be easily challenged by unanticipated outcomes" (p. 114).

This vigilant decision process is characterized by the following seven criteria which the authors feel must be utilized in order to make a good, high-quality decision (Janis & Mann, 1977).

The decision-maker, to the best of his ability and within his information-processing capabilities:

1. thoroughly canvasses a wide range of alternative courses of action;
2. surveys the full range of objectives to be fulfilled and the values implicated by the choice;
3. carefully weighs whatever he knows about the costs and risks of negative consequences, as well as the positive consequences, that could flow from each alternative;
4. intensively searches for new information relevant to further evaluation of the alternatives;
5. correctly assimilates and takes account of any new information or expert judgement to which he is exposed, even when the information or judgement does not support the course of action he initially prefers;
6. re-examines the positive and negative consequences of all known alternatives, including those originally regarded as unacceptable, before making a final choice;
7. makes detailed provisions for implementing or executing the chosen course of action, with special attention to contingency plans that might be required if various known risks were to materialize (p. 11).

Their contention is "that failure to meet any of these seven criteria when a person is making a fundamental decision . . . constitutes a defect in the decision-making process" (p. 11).

Simon (1982) has been influential by questioning the original economic theory that assumed decision-makers knew about every possible course of action, and were also cognizant of the values of every alternative (Edwards, 1968). He presents concepts which are in direct contrast to Janis and Mann's information processing methods in decision-making. Simon believes that people may not always have the time and energy to consider all alternatives when making a decision. In fact, with some daily or simple decisions it would clearly be a waste of
time for the decision-maker to consider all the available information. The following excerpt by Simon (1982) introduces his concepts of satisficing and optimizing, which may well be alternatives to the vigilant strategy previously discussed.

The terms satisficing and optimizing . . . are labels for two broad approaches to rational behavior in situations where complexity and uncertainty make global rationality impossible. In those situations, optimization becomes approximate optimization - the description of the real-world situation is radically simplified until reduced to a degree of complication the decision-maker can handle. Satisficing approaches seek this simplification in a somewhat different direction, retaining more of the detail of the real-world situation, but settling for a satisfactory, rather than an approximate-best decision (p. 417).

Janis and Mann (1977) state that 'satisficing strategy' involves more superficial search for information and less cognitive work than vigilant decision strategy. All that the person has to do is consider alternative courses of action sequentially until one that 'will do' is found" (p. 26). When comparing the ideas of Janis and Mann with Simon's, it is reasonable to postulate that a 'satisficing strategy' would more likely be used on a regular basis than a vigilant strategy. It would be interesting to examine women's decisions regarding breast reconstruction and see if either of the above approaches
to decision-making were used and why.

Lenz's (1984) article demonstrates the critical link between information-seeking and decision-making. Lenz explored the concept of information-seeking in clients as it related to decision-making about health care. She states that:

the provision of information to clients by nurses has received considerable attention in the nursing literature but relatively little cognizance has been given to the active role of clients in seeking and acquiring information that may be instrumental in determining their health behavior (p. 59).

Information can be obtained either overtly by actively seeking it, or in a passive fashion, such as watching television.

Lenz (1984) claims that "the information search process is conceptualized as a subcomponent of the decision process" (p. 61). She concurs with the traditional view held in decision-making theory that the more thorough the information acquisition, the greater the rationality of the decision.

Corbin (1980) supports Lenz by claiming that "information collection and deliberation . . . are geared in part to reducing the subjective uncertainty that characterizes any decision" (p. 59).

During the process of acquiring information, the searcher assesses its adequacy in order to decide whether more information is needed or if the search can be discontinued (Lenz, 1984).
Therefore, a person who determines the information acquired to be inadequate may stop searching, recognizing that the decision will be made under less-than-ideal conditions. Fatigue, boredom, frustration, urgency to take action, and difficulty in extracting information from sources encourage 'premature termination' of search, whereas curiosity, interest, knowledgeable and willing consultants, and strict adherence to predefined goals encourage continuation (p. 65).

Based on the literature, then, it appears clear that information searching, collecting, and processing is viewed as an integral aspect of decision-making. Therefore, it is important to assess the quality of information-seeking among women deciding about breast reconstruction. It will be important to examine the decision-making theorists' belief that a 'good decision' is based on having adequate information and that a 'poor decision' is characterized by a lack of information, and determine if this is applicable to breast reconstruction decisions.

Patient Decision-Making Research

An examination of research on patient decision-making in relation to health care issues revealed a limited amount of literature pertaining to this topic. Information about decision-making tends to focus more on decisions made by health professionals rather than the patients' decisions (Eisenberg, Kitz & Webber, 1983; Howe & Wilcox, 1983; Turner & Kofoed,
The next portion of this discussion addresses the current research on patient decision-making.

A study by Sachs (1981), using the model of vigilant decision-making, evaluated the degree of readiness shown in patients who desired treatment of dentofacial anomalies. For these patients, one of the major psychological factors contributing to their degree of readiness was their wish to improve their appearance.

Patients were asked to express their views about the decision and outline their course of action in coming to a decision. They were given a decision aid which entailed filling out gains and losses for both themselves and others (Sachs, 1981). This study demonstrated that assessing each patient's readiness in terms of her own decision-making process was much more effective than simply labelling them good or bad risks for treatment (Sachs, 1981). Since the literature review suggests that one of the major factors that compelled women to seek reconstruction was their perceived deformed appearance, Sach's study has relevance to breast reconstruction decision-making.

Deatrick's (1984) study dealt with 24 chronically disabled adolescents who were involved in making a decision about elective corrective surgery. These adolescents presented with a variety of diagnoses, "including cerebral palsy, severe burn scars, scoliosis, phalangeal deficiencies and amelias" (Deatrick, 1984).

This research had a qualitative focus and described "the
characteristics, the process, and the evaluation of this decision-making process from the perspectives of both the adolescents and their parents" (p. 18). The goals that the adolescents had for surgery assisted in shaping the meaning of the event and in building a framework for the experience (Deatrick, 1984). Results of this study provide insight into a decision-making process from a patient's point of view. This process is comparable to breast reconstruction decision-making in that none of the surgeries were life-saving, allowing the decision-maker to consider more alternatives.

McClain's (1983) research was directed at the decision-making process among women who were choosing alternative methods for labour and delivery. The three choices examined were birth at home with lay-midwife attendants, birth in the alternate birth centre with a nurse-midwife, and conventional labour and delivery with an obstetrician (McClain, 1983). The author discovered that the women in her study used the following process described by Janis and Mann as 'bolstering'. This involves "decision makers who cognitively strengthen either the preferred (or least objectionable) alternative or the final decision itself. This involves defining or re-defining the risks and benefits of alternatives so that they favour the preferred or chosen alternatives and at the same time disparage the rejected alternatives" (McClain, 1983, p. 1858). The process of bolstering assisted each woman to feel more confident that she
Berger and Bostwick (1984) interviewed eight women regarding their decision-making about breast reconstruction. Although the sample size was very small, these interviews presented specific details about the factors that contributed to each woman's decision to undergo reconstruction. The following excerpt gives insight into the decision-making process of one post-mastectomy woman:

Even 3 years after the mastectomy, when I consulted with a plastic surgeon, I wasn't dying to have this operation. I rationalized my decision for more surgery because of the physical problems I was having. I had developed backaches ... and it [the prosthesis] was hot and such an annoyance in the summer. I was very rational about this whole subject. Certainly I told myself, reconstruction is something you want, just because of the prosthesis and to make your back feel better. So I decided to go ahead for those reasons.

Berger and Bostwick cite numerous examples of such illustrations. Their findings will be discussed further in Chapter Five.

The above concluding section on decision-making clearly reveals a lack of studies pertaining directly to breast reconstruction. Though it is possible to gain insight into the process of patient decision-making from general research articles, it would be more valuable to examine research that
deals directly with breast reconstruction decision-making, as Berger & Bostwick have done. There has been no literature or research available on analyzing the actual mechanics of the decision-making process in women who consider breast reconstruction. It is hoped that the future will provide enlightenment in the form of additional research into the process of decision-making from a patient's point of view. Patient decision-making is a topic of study which has only emerged in the 1980's and has great potential for development in the years to come.

Summary

This literature review dealt with the concepts of body image, breast reconstruction, and decision-making. These three topics are helpful in understanding the needs of the post-mastectomy woman, the relevant factors a woman considers in undergoing breast reconstruction, and the process involved in decision-making. Through examination of all three topics, it was hoped that a comprehensive picture could be developed to uncover the pertinent factors that are critical to women who are considering undergoing breast reconstruction.

This literature review also illustrated the relevance of body image theory to the post-mastectomy woman in considering breast reconstruction. This concept is useful for explaining the meaning of the breast loss and the need for some woman to consider options for restoration.
The discussion regarding decision-making presented the history of general decision theory and the concepts that distinguish Decision Theory, Behavioral Decision Theory and Psychological Decision Theory. Of these three theories, Psychological Decision Theory appeared to be the most closely aligned with the phenomenological focus of this study and was thus explored at more length than the other two.

The limited amount of nursing research in relation to patient decision-making from the patient's point of view became evident. Berger and Bostwick provide the only source of direct information regarding the decision-making process of individual women considering reconstruction; however these authors do not have a nursing background.

This lack of research prevents health professionals from examining the relevance of factors pertinent to women who are making a decision about reconstruction. As a result there is no theoretical base to guide nursing practice. Collection of first-hand information from reconstruction candidates would therefore be useful to give direction for improving nursing care for this growing population. It is hoped that the current study will contribute to a greater understanding of the decision-making needs of post-mastectomy women who consider breast reconstruction.
CHAPTER THREE

Methodology

Introduction

As described in Chapter One, this study was directed by the phenomenological approach. This chapter explains in greater detail how the paradigm of qualitative methodology was utilized in this research study. The topics discussed include the selection of participants, data collection, data analysis, and ethical considerations. The researcher was guided by the following authors who describe the phenomenological methodology: Davis (1978), Diers (1979), Lindemann (1974), and Oiler (1982).

Selection of Participants

This study is concerned with the decision-making process of post-mastectomy women who decided either to choose or refuse breast reconstruction after consultation with a plastic surgeon. The initial criterion for selection was involvement of these women with a plastic surgeon for the purpose of seeking information regarding breast reconstruction. This criterion was used because it was felt that any post-mastectomy woman interested enough in breast reconstruction to discuss it with a plastic surgeon would have already gone through a decision-making process with regard to this procedure. The phenomenological approach asserts that women who themselves live the experience of breast reconstruction decision-making are the experts on this topic (Pearsall, 1970). The above two participant groups
represented a convenience sample.

One cannot assume, however, that post-mastectomy women who do not seek contact with a plastic surgeon are not involved in decision-making regarding breast reconstruction. Clearly, this latter group would be an interesting group of women to study, in view of the fact that the majority of post-mastectomy women never see a plastic surgeon. It was deemed beyond the scope of the study however, to include the above group of post-mastectomy women among the participants.

Criteria for Selection

Given that breast cancer is rare in women under 21, this study was limited to those 21 years or older. All participants were to be residents of the Greater Vancouver area and able to speak English.

Selection Procedure

The participants were selected from the private practices of two plastic surgeons. Initial contact with potential participants was made in two different ways. The patients of one plastic surgeon were first contacted through an explanatory letter from their surgeon. Participants were asked in the letter to phone the office nurse and leave their name if they were interested in taking part in the study. The researcher then sent an information and consent letter to these participants. When the participants returned the signed consent form they were then contacted by phone. An interview to take place in the
participant's home was scheduled at a time convenient to her.

The participants who were patients of the second plastic surgeon were initially contacted by the plastic surgeon's office nurse, who explained the study to them. If they expressed interest in participating, they were informed that the researcher would contact them by letter. When the signed consent was sent back the researcher contacted the participant by phone and arranged an interview in her home. In both cases, a complete explanation of the study was given verbally to the participants before the interview.

Characteristics of the Participants

Sixteen participants gave consent and were included in the study. Their ages ranged from 32 to 64 years. Ten of the participants were between the ages of 50 and 60. Two women were in their 30s, two in their 40s, and two in their 60s at the time of the study. All of the participants were Caucasian.

Eleven women were married and lived with their husbands. One woman lived with her common-law husband and another woman had never married. Three of the women, who were not living with a spouse, had previously been married. All but three of the participants had children. Several of these women had children living at home. Ten participants worked full-time and one worked part-time. Six women were volunteers in the Reach for Recovery mastectomy organization.

Thirteen of the sixteen participants had undergone breast
reconstruction. Of these thirteen, two had had only one surgery and had chosen not to have the nipple reconstruction. All other participants had had the nipple reconstruction and undergone from three to twelve breast reconstruction operations.

The breast reconstructions took place from eight months following mastectomy to as much as fifteen years post-mastectomy. The average interval between mastectomy and breast reconstruction was from two to four years. Three participants underwent bilateral breast reconstructions after having had two separate mastectomies.

Data Collection

The data were collected by tape-recorded interviews in the participants' homes. Each woman was interviewed twice; three were interviewed three times. A total of thirty-five interviews were completed. Information disclosed after the tape recorder was turned off was written down immediately following the interview and these field notes also became part of the data.

The interviews averaged 1-1/4 hours. The interview was loosely structured, using two main questions relating to decision-making about breast reconstruction (see Appendix B). The content of these two questions was derived from a review of related literature. The semi-structured interview format was used in order to encourage full expression of the decision-making experience by each participant (Wilson, 1977). This format also allowed the researcher to perceive the information more clearly
from the women's perspective.

New questions were added in the second interview as a result of the knowledge gained through the on-going process of data collection and analysis. The second interview clarified what had been said in the first interview and took account of the events that occurred between the first and second interview. The second interview was facilitated by the rapport established in the first interview between the researcher and participant. By validating themes derived from the accounts of all participants, the researcher was able to refine and clarify abstractions from the data as they emerged (Anderson & Chung, 1982).

As previously mentioned, some participants were interviewed three times, because they took part in a pilot study. This pilot study involved five participants and took place in March and May of 1983. The purpose of this initial study was to refine the study topic and establish a relevant interview guide. All of the participants involved in the pilot study had undergone breast reconstruction. The decision to include participants who had chosen to refuse breast reconstruction following consultation with a plastic surgeon was made after the pilot interviews had been completed. The first round of interviews took place in January and February of 1984. The second set of interviews took place between July and October of 1984.

Rapport developed without difficulty between the researcher and the participants. The women expressed enthusiasm about
contributing to the researcher's knowledge and expressed hope that their experiences would be helpful to other post-mastectomy women considering breast reconstruction.

Construction of Accounts

Qualitative methodology contends that the participants' experience, as presented through their accounts, is their truth (Oiler, 1982). Substantiating the facts in the participant accounts is not as relevant as the ability to understand the experience from the participant's perspective. The meaning of the participant's experience is interpreted through the on-going interplay of thoughts, feelings, and statements from both the researcher and participant.

The interview questions initiated the interaction between the researcher and the participants. One of phenomenology's basic premises is that the researcher's thoughts and actions influence and enrich the data collection (Diers, 1979). Thus, the researcher attempted to monitor her own subjective experience and clarify it in light of the overall meaning of the research process. Assumptions and beliefs held by both the researcher and the participants are acknowledged within the accounts and thus give additional richness to the data (Davis, 1978; Diers, 1979). Regular validation of accounts by the researcher is imperative so that the true meaning of each participant's experience can unfold.
Data Analysis

All tapes were transcribed verbatim following the completion of each interview. In keeping with the phenomenological perspective, analysis of the data was carried out concurrently with data collection. As themes emerged from the accounts they were formed into appropriate categories. Data were then sorted into these categories based on similarities found among all the pieces of information. This resulting analytic framework influenced the interview content, thus reinforcing the interlocking nature of data collection and analysis. The major themes that emerged from initial analysis of the accounts were validated by the researcher, ensuring that the resulting topics were meaningful for all participants (Anderson & Chung, 1982).

The completion of the data analysis process was apparent when no other major conceptual categories were forthcoming from the data (Wilson, 1977). Diers (1979) defines the following characteristics as the "finishing touches to data analysis":

The mental process here is trying to see different instances of events as related, and linking these instances with bigger (more abstract) and bigger concepts -- names which fit all the events within that abstraction. One tries to reduce the volumes of data collected into a meaningful handful of named concepts (p. 115).

This level of conceptualization within the analytic process is articulated in detail in Chapter Four.
Ethical Considerations

This study met the criteria specified by the University of British Columbia's Screening Committee for Research Involving Human Subjects. The rights of the participants were protected in the following ways:

The participants' right to refuse participation was safeguarded by ensuring that interviews could only take place if written consent was given first. A description of the study and details of their expected participation were presented to the participants both in writing and verbally prior to obtaining their consent (Appendix A).

All participants were advised that their participation was voluntary and that they could withdraw from the study at any time. They were assured that withdrawal from the study would have no effect on the treatment they received. Prior to the initial interview, participants were informed that they had the right to decline to answer any questions, to terminate the interview, or to request erasure of any tape or portion of a tape at any time during the study.

The participants were assured that all of the taped material would be kept anonymous and confidential and that all tapes would be erased after completion of the thesis. Transcriptions would be coded with subject identity known only to the researcher. There would be no written material that used names in connection with the study. Access to the data would be limited to the
researcher and her advisory committee.

Finally, the participants were informed that there were no expected risks involved in participating in the study. There were also no financial remunerations. Some participants did acknowledge that they found it beneficial to discuss this experience with the researcher.

Summary

This chapter has outlined how the methodology was utilized in this study. The procedure of selecting participants was also presented. Methods of constructing accounts and data analysis were illustrated, with regard to how they related to the chosen methodology. In addition, the ethical considerations necessary to protect the participants' rights were discussed.

The following chapter will present the participant accounts, which vividly illustrate these women's experiences in making their decisions about breast reconstruction.
CHAPTER FOUR

Presentation of Accounts

Introduction

This chapter focuses on the accounts of the participants, in which they describe their experiences with breast cancer and mastectomy, and their decision about breast reconstruction. Chapter Four highlights the major themes of wholeness versus nonwholeness which recur throughout each participant's decision-making process.

Loss of wholeness is explored first by describing the participants' emotional adjustment to cancer and mastectomy and their experiences wearing a prosthesis. This description is followed by their accounts of their search for wholeness. This includes their decision-making process regarding breast reconstruction and the establishment of the meaning of their cancer experience. Specific aspects of the decision-making process detailed in these accounts include acquiring information, weighing the consequences of reconstruction, and their perception of this surgery.

Regaining wholeness represents the outcome of the participants' decision-making process and is explored next. The women's accounts of their need to justify their decisions and their ultimate recovery which required leaving the cancer experience behind are presented. These themes of loss of wholeness, search for wholeness, and regaining wholeness, then,
serve to add scope to the explanation underlying each participant's decision.

For the purpose of increasing understanding of the participants' decision-making, the women's accounts of wholeness and non-wholeness are introduced by their descriptions of the breast lump discovery, mastectomy and adjuvant treatment experiences. One cannot fully comprehend the significance of each participant's decision until this cancer experience is examined in its entirety.

**Establishing Context**

All participants presented their reconstruction decision within the context of a story, describing their experience with cancer in a narrative form. The beginning of their story was the diagnosis of cancer. Next, the women described their reactions to the prospective treatment plan. The participants' reactions were important because they later influenced their desire to either pursue or refuse breast reconstruction. This encounter with cancer forced these women to re-examine the meaning of their lives.

All participants demonstrated a need for getting the facts straight when they recounted their stories. They had retained a detailed memory of the events that took place during their diagnosis, mastectomy, and adjuvant therapy. Every story was told chronologically, in terms of the participants' life events during the cancer experience rather than specific dates. Several
participants could not remember the exact dates of events and yet their memories of diagnosis, treatment, and coping with cancer were detailed and vivid despite the passage of time.

Stories typically began with the participants' discovery of a breast lump.

P. And this time was just a fluke and I don't know why. It just felt different. I just went like this and there it [the breast lump] was. I thought I never do that. I never undress in front of a mirror. I mean I went in and put my jeans on and I took my brassiere off for some reason or another and there was this lump.

P. I was just taking a bath and putting talcum powder on. I kind of moved in a certain way and just happened to glance down and there was a very tiny lump. It was only 2 cm but was right, almost centre . . . right there. So therefore, if it had been underneath the breast I never would have noticed it.

P. I woke up in the middle of the night and I turned over and felt this lump with my hand and I woke up and shook my husband and said, "Wake up, wake up quick. I've got cancer. . . ." Immediately at that moment I made up my mind that's what it was.

Although the majority of the participants did not do regular
self breast examination, most of the participants discovered their own breast lump either by chance or by self-examination. The remaining participants' breast lumps were discovered by their doctors.

Stories related to the surgical experiences were vividly remembered because of the trauma that the majority of the participants experienced. Several participants believed that their breast lumps were benign because their doctors had reassured them that cancer was unlikely. These women were not expecting to undergo a mastectomy and were therefore, not prepared for the shock of losing a breast.

P. I was told it was not going to come off. The night before I was told it was just a matter of a lump coming out of my breast and under my arm and I would be fine. And then when I came to it [the breast] was gone. And I think that was a shock that I might have got over faster if I was prepared for it.

...............

P. They [the doctors] didn't say, "Well, we'll test it then tell you and then if you have to have it [the breast] removed they'll let you know." It was just that I went in there and they took it [the breast] off and then when I came out and was in recovery I was in shock. I asked the nurse because I kept jumping up and down . . . what was wrong with me and she said, "They
removed your breast," and walked away.

Another part of the cancer stories revolved around the description of chemotherapy and radiation experiences, which necessitated postponement of breast reconstruction until physical recovery was complete. The physically debilitating side effects of these treatments added to the stress these women experienced from the combined assault of cancer and mastectomy.

P. The chemotherapy's hard on you. I lost all my hair and you just feel terrible. When you're taking that and other stuff that they've given you and this is all happening to you, well, you're bound to be depressed.

P. I was frantic as to how I was going to manage when I was physically so ill... I know I tried to climb the stairs one day after I had the cobalt treatment and I couldn't get up the stairs.

The difficulties imposed upon women undergoing adjuvant therapy were influential in their decision regarding breast reconstruction. For some women, this adjuvant therapy inhibited the desire for reconstruction. These women were unable to contemplate any further surgery until the hurdle of adjuvant therapy was behind them. Others were not similarly affected and planned to undergo reconstruction despite their ongoing adjuvant therapy. Participants, therefore, had to contend with the effects of adjuvant therapy while considering breast
reconstruction.

P. I was under chemotherapy for a year and a half and didn't think too much about reconstruction at that point either. The last six months you're fairly wiped out anyway . . . And then it takes you another six months after that to recover.

..............

P. So I still wasn't looking at reconstruction. I was just glad that I was no longer taking chemotherapy and was able to hold down a job and start to feel that I was well again.

..............

P. Then when they told me I had to take chemotherapy for a year . . . well, I was so sick for that year . . . it was bad. I thought of it but that isn't anything. I just wanted them to get over with the chemotherapy . . . I knew I was going to do it [have breast reconstruction] as soon as somebody said O.K.

In addition to reciting stories about discovery of the lump, mastectomy, and adjuvant therapy, the majority of participants placed the events of diagnosis and mastectomy within the context of other concurrent life events, which assisted them in recalling the experience and its associated meaning.

P. And then my doctor happened to be away that day and I was seen by one of his partners . . . his face . . . I
should have known. He tried to excise . . . extract fluid from the lump . . . and he seemed very upset that he couldn't . . . Christmas was coming and I was having a huge engagement party for my daughter and son-in-law. I had my freezer groaning with little quiches and I had all my Christmas shopping done. My friends felt I had a premonition but I didn't.

P. I discovered it [the breast lump] I guess probably in about . . . let me think . . . I would say probably around June and they got the bed about July. Then they cancelled it and then while I was waiting for the bed we'd gone up to Penticton for a little holiday and I was so cranky with the kids and irritable with the hepatitis. Everytime I looked sideways my eyes would hurt and I'd itch all over.

P. Because I'd already had a hysterectomy you see, years before that. I had no reaction to the radiation at all . . . just the chemo but that threw me into menopause . . . There was a lot of stress at that time with moving here and then I lost my job through having it [breast cancer] because I wasn't able to concentrate . . . And since I was the last one hired I was the first one to go.
A key theme to be discussed in this section is loss of wholeness. The participants' perceptions of their wholeness seems to have been a major influence on their decision about breast reconstruction. This perception of wholeness appeared to be both physical and mental. In these accounts, feelings of wholeness seemed to be influenced by the values and feelings each woman had about her breasts. The more her self-esteem and sense of body image were associated with intact breasts, the more likely a woman was to feel a lack of wholeness after her mastectomy. However, there was no way of predicting prior to her mastectomy the degree of loss of wholeness a participant was going to feel.

The majority of participants referred, directly or indirectly, to their wholeness when they talked about the effects of mastectomy on their lives. Of the women who chose breast reconstruction, most claimed they did not feel whole after their surgery, even while wearing a prosthesis. They could not incorporate the prosthesis into their body image because they frequently took it off. On the other hand, two women who decided against breast reconstruction felt a prosthesis was a suitable replacement. These women appeared to have let go of the missing breast and, with the help of the prosthesis, reintegrated their body image into a whole.

The loss of wholeness was a theme that recurred throughout
the participants' adjustment and was then carried on into the decision-making process, which became an all-powerful search for wholeness.

P. No, you are incomplete. Half of you is gone.

P. When this cropped up it just totally destroyed that image of myself of being an attractive female person.

P. And that was my feeling I just, it didn't matter what, I just didn't feel right, there was something wrong with me. No matter where I was I thought about it.

Reflected within the key theme of loss of wholeness are the two subthemes of emotional adjustment to cancer and mastectomy and the prosthesis experience. These important aspects of loss of wholeness will be discussed next.

Emotional Adjustment to Cancer and Mastectomy

This section describes the participants' emotional responses to the loss of wholeness resulting from their encounter with cancer. These reactions include attitudes, feelings, and behaviors. Every participant vividly remembered her feelings in relation to the cancer and breast loss. Although reactions varied in intensity, the majority of participants felt that the emotional experience of having cancer was worse than that of having a mastectomy.

P. The loss of the breast didn't hit me . . . no, it was
the word cancer. Cancer represented death. It was the end. That was the way I felt.

P. Because it was something I couldn't do anything about, no matter how hard I worked or no matter how much I tried. Cancer cells . . . they were in my body and I could not stop them multiplying.

P. Or have I got cancer somewhere else in my body and I really think that was the worst part for me . . . yeah more than the loss. I just wanted them to tell me that everything was going to be O.K. with me and that I was going to be fine.

The presence of fear and helplessness as a result of the diagnosis of cancer was a common theme in the women's narratives.

P. I thought that would never happen to me but it did. I was frightened. So I figured well this was it then. I was going to die and that was all there was to it . . . It was scary. I thought I was in hell . . . and I was paranoid.

P. I went through real roller-coaster feelings, I mean there would be days when I would feel, I am going to beat this . . . I am not going to let this get me down . . . and I'm going to be fine . . . and then other
days ... I mean I'm going to die anyway ... die this horrible death and maybe I should just check out now.

Some women, however, did not present cancer as the most upsetting. For them, the mastectomy was an even more emotionally painful experience.

P. I mean nobody would want to lose an arm or a leg but they probably wouldn't feel any worse losing an arm or a leg [than they would] losing a breast.

P. I guess I was in shock after I had the mastectomy. When I got out of the hospital I was angry. I just felt ripped off ... why me?

One participant acknowledged that the loss of her breast was more traumatic than the potential loss of life from cancer.

P. ... So, no, the fear of losing my breast was much more present than the fear of losing my life to cancer.

She went on to say that the mastectomy might have been too high a price to pay in relation to the quality of her life.

P. In fact if I had not had that [breast reconstruction] as a possibility or as a definite probability I might not have had the surgery because I was so afraid of what it would do to my life.

A variety of behaviors were described as indicative of feelings of grief over the multiple losses suffered because of
the cancer experiences.

P. I'd sit in my room and cry and often I didn't feel like I could tell anybody.

. . . . . . .

P. Like I said it was about a year . . . ten to eleven months I guess before I did smarten up. But all I did was take a lot of pills, aspirins, 292's, or anything I could get my hands on. I'd drink a lot . . . I still drink a lot compared to what I used to before.

In contrast, a few participants claimed that they did not experience a sense of grief as a result of the mastectomy. The following women discussed their feelings in terms of what they did not experience.

P. I just was very, very lucky that I didn't go into any kind of depression. I just couldn't see what the purpose of it would be. It isn't going to help any. . . . and especially after I had been through the cancer clinic and been told there was no need for any treatment . . . that really made me feel very buoyant and positive.

. . . . . . .

P. I never really looked at it as a loss. I looked at it as the breast was secondary . . . To me what was the most important thing was to get rid of the cancer so they got rid of the breast, which was incidental to me.
P. It just didn't bother me. I just felt I was going to have to live with that. . . . You don't bother saying "why me" sort of thing. You know that's happened and you're alive and well and that's the main thing.

............

P. I don't believe I really did grieve . . . It was constantly there . . . you had to either accept it or you would have had to let it bother you. And I accepted it and that was it. Period . . . I know some women don't want to see the scar . . . the first dressing change is traumatic and all of this and I didn't really feel any of that. I knew what it was going to look like and when I saw it my first reaction was that's a fine piece of surgery. It was a beautiful piece of surgery.

This lack of negative reactions revealed a positive attitude that gave these women a different perspective on their cancer and mastectomy experiences. These participants felt that such an attitude may have been instrumental in helping them accept their mastectomy and cancer more easily.

The participants thus described variations in their emotional experiences and attitudes toward cancer and the mastectomy experience. It seemed as if there was a range of grief responses, falling somewhere between the two extremes: feeling "totally traumatized" by the loss of the breast, as
opposed to feeling "relief" that the mastectomy eradicated the cancer.

Prosthesis Experience

The prosthesis experience surfaced as a major subtheme for all of the participants in this study. Depending on the experience she had had with her prosthesis, each woman described it as a strongly negative or strongly positive influence on her attitudes about the mastectomy experience in general. As a result, the prosthesis also appeared to have a considerable impact on the participants' decision-making process regarding breast reconstruction. Feelings expressed in relation to the prosthesis were predominantly negative and focused on the physical uncomfortableness of the breast form. For example almost all the participants complained of how hot the prosthesis was to wear when the plastic material was in contact with their skin. This was especially bothersome in the summer.

P. Your breast form is hot, it's sticky, it's uncomfortable. It rides up, it pulls down.

Several participants acknowledged that they were unable to buy a breast form that fit comfortably. Women who were very small-breasted or large-breasted tended to experience poor fit. The weight of the prosthesis was also a definite disadvantage to those participants who had large breasts. The dead weight of the prosthesis induced shoulder and back aches and a feeling of being off-balance.
P. And another thing was the weight. It always felt like it was pulling your arm down you know so you felt like you were packing an extra weight around.

Other complaints or difficulties expressed were skin irritation and shifting of the form during activity.

P. One of the things that I keep saying is that I hated, I hated the whole business of having to put that prosthesis in every day and take it out and having to deal with it during the day as it sort of slips and makes blisters. It was very awkward.

............

P. Or you're doing exercises in an exercise class and your bra doesn't quite fit the prosthesis or you haven't bothered sewing a lining in . . . oh God, the thing starts to slip - well you know you're in trouble then.

............

P. It was shifting around and then one day at work - I don't wear tight-fitting clothes but I have a dress on that was rather form fitting on top and when I was walking down one of the halls one of the other staff members said to me "Well, you've got one up and one down".

Feelings of self-consciousness added yet another burden to women already bothered by their prostheses' physical limitations.

P. I can remember one evening my husband saying to me
"Be careful how you lean and which side you sit on with people because it's obvious." People just look, especially if they know you've had an operation.

P. If you're going to a recreation centre or keep-fit classes you're changing in one big change room and I always felt very self-conscious especially if there were people who didn't know I'd had the mastectomy. I'd always make sure I was the last person to get changed or hide myself some place where no one would see me or go in the washroom and get changed in there.

P. I was swimming about three times a week right up until I had the mastectomy and then after I didn't do quite so much but I... it was the changing room... dropping this great two pieces. It was like a bean bag you know. That's it, they are so clumsy. Like there was sort of no easy way to grasp the thing and there is a space underneath the changing room door of about two feet I think... Always conscious that people might be offended or shocked.

The women who exercised regularly appeared to experience the most problems with the embarrassment of undressing in public places. Swimming, in particular, presented difficulty due to the tendency of the prosthesis to fall away from the chest causing
the bathing suit to gape when the participant bent over.

Inconvenience was also a stark reality. All participants who underwent breast reconstruction emphasized this; many referred to the prosthesis as a nuisance.

P. You've [got to] take it in, take it out, go take a bath, take it off, change your bra - put it in the pocket, take it out of the pocket.

The prosthesis also limited a majority of the women's freedom of choice in selecting clothing. A large percentage of the participants dressed more conservatively after their mastectomy. Some of the participants found that even with a modified mastectomy there was a depression in the clavicular area where the lymph nodes had been removed. With a radical mastectomy there was a much more noticeable defect. These women tended to wear clothes with higher necklines and ample sleeves to camouflage their asymmetry. Women who did not wear revealing clothing prior to mastectomy were less affected by the limitations of choice in clothing styles when they began wearing a prosthesis.

P. After the operation was over - a lot of my clothes didn't fit. It was a lot to get used to.

P. When I would look at these low-plunging things and think oh - gee how awful - if I could just wear one of those and you really long to wear the dresses that
are. You seem to long to wear them more than you ever did before. You never remember caring that much before.

The participants' accounts serve to highlight the inadequacies of the prosthesis. It is interesting to note that those participants who chose to have breast reconstruction did not mention any positive aspects of the prosthesis. In marked contrast, all three participants who declined breast reconstruction felt that the prosthesis was primarily beneficial.

R. So the one [prosthesis] that you have now is comfortable.

P. Oh yes, no problem at all. You don't even know it's there. It's as I say, it sort of takes on the warmth of the body and even to touch . . . someone else wouldn't even know. It doesn't feel artificial. You touch one and then you touch the other and you really wouldn't know which is which.

R. No, you seem perfectly content with the prosthesis.

P. Right, right. Except for the money I have to pay for them. It's terrible.

It seems that the way in which a participant perceived and reacted to the prosthesis may have had ramifications for the decision-making process. Women who were unsatisfied with the prosthesis appeared to be more attracted to the option of
reconstruction than were those women who experienced no problems with the prosthesis.

The following section shows how feelings of non-wholeness, dissatisfaction with the prosthesis, and information received about breast reconstruction contributed to an increase in the awareness and readiness of participants to consider breast reconstruction.

Search for Wholeness

Participants described feeling less whole as a result of mastectomy, resulting in feeling less normal. As a result of this the participants' self-esteem declined, which in turn affected the quality of their lives. The trauma associated with this lack of wholeness did not dissipate over time for many of the participants. Instead, it catalyzed a search for wholeness that culminated in the securing of breast reconstruction.

P. I want everything done - I want to feel normal and I don't mind how much surgery I have. I wish to feel a whole person again.

P. But it [lack of natural breasts] did make me feel bad and that's why I wanted to go through with the breast reconstruction . . . Because I felt like I wanted something in the spot where my breasts were and you know, basically that's what I lived for.

All participants appeared to rate themselves as either
feeling whole or lacking in wholeness after their mastectomy. None of the participants reported that this particular feeling changed over the course of time. When women felt a lack of wholeness post-mastectomy this remained consistent. Similarly, those who felt whole following mastectomy continued to feel whole.

Some of the participants chose to proceed with breast reconstruction surgery in spite of feeling whole and, conversely, a participant who refused breast reconstruction claimed she did not feel whole. Therefore, while there was not a consistent link between a lack of feeling whole and the need to pursue breast reconstruction, it appears that the idea of reconstruction was more appealing to those women who did not feel whole with one breast. Those participants who reported feeling devastated by feelings of non-wholeness also seemed to experience the most difficulty accepting the physical experience of the mastectomy scar. It is difficult to know with any certainty whether the women who felt whole with only one breast have a more flexible body image. If so, this may account in part for their being able to incorporate the physical changes from the mastectomy without losing a sense of wholeness.

The following participants who refused reconstruction felt they had no need for it because they continued to feel whole following the loss of their breast.

P. Like I said, I wasn't really that interested ... I
feel quite content the way I am.

P. If he would have come along with the suggestion within the first year, which he didn't... well with this he waited five years... and he said well would you... have you considered it? I hadn't even given it a thought... it wasn't that important to me.

Unlike the above participants, there were women who in spite of feeling whole with one breast underwent breast reconstruction.

P. So I didn't break down or anything and I didn't feel at the time that I was changing psychologically or was having these things like God I'm not whole or whatever so that's why I like to think that I added a new dimension to my psyche.

R. When you had a mastectomy, did it affect your feelings of wholeness? Did you feel sort of any less whole?

P. No, I would have expected to feel that way but I didn't and I can only attribute it to having been flat-chested for so long... I have talked to women who did feel that way and say things like you're half a woman... I just wanted to tell them I was not a side of beef or a piece of meat, I was a woman... But I really sometimes don't think I'm normal in that way.

It is interesting that she expected to feel less whole and
formulated a reason to explain perhaps why she did not have this normal reaction. She seemed to feel that her breasts had never been an important part of her perceived body image in the past. Therefore, she did not feel different either as an individual or as a woman following the loss of her breast.

One participant expressed surprise at how much the loss of a breast affected her sense of wholeness. This lack of wholeness affected her sense of emotional well-being and these feelings overpowered her intellectual sense, which told her she was not a different person after the mastectomy.

P. I seem to be awfully fixated on these little fatty globs on my chest, I don't know. But you know I sometimes wonder if that is normal . . . I don't like to think that I am overly fixated on my breasts or overly concerned with my body, or overly vain, but I seem to have all of that in my make-up.

The mastectomy scar was visually disturbing to several participants and was a continual reminder of their lack of physical wholeness. A common behavior was avoidance of looking into mirrors, to the extent of covering them with a towel while undressing or bathing.

P. No, I guess I never bothered to look in the mirror at it too often . . . and it was a mess.

. . . . . . . . .

P. It just made me feel bad . . . when I came out of the
bath there was a great big mirror there and you saw yourself as you got out. When I had the operation . . . the first bath I'd taken . . . I just about died. I put a towel up over it [mirror] every bath I took after that so I couldn't see myself . . . it even bothered me to look. I couldn't wait to get my brassiere and clothes on . . . It reminded me of one of those one-eyed cyclopes.

One participant who refused breast reconstruction did not feel whole with only one breast. She talked about how she felt when she was not wearing the prosthesis.

P. I feel okay as long as I don't walk around the house . . . as long as I am under the covers, can't see anything.

R. But to look down at yourself, then it bothers you?

P. Yes.

R. Has there been any change at all in as far as your self-esteem is concerned, how you feel about yourself?

P. I don't . . . I never felt the same about myself anymore. Not like I used to.

The powerful drive to regain wholeness was also manifested in the decision of those participants who underwent nipple reconstruction. Almost all women who underwent breast reconstruction talked about the need and right to have their bodies restored to a normal state, as they were before the
mastectomy. They felt strongly that women would not be born with
the potential for developing two breasts and nipples unless they
were meant to have them.

P. 'Cause I mean everybody's got a nipple ... And so I'm
pleased that I had it done.

P. I just want to have two breasts with two nipples with
aerolas that are the same size more or less, with
nipples the same size that are both in the same
direction.

P. I would never have been satisfied just to stay with it
[breast mound] without the rest of it, the nipple. I
would have felt just not as whole as I did before.

P. Like I couldn't believe it when I woke up and saw the
two nipples and everything. I was just dancing all
over the place.

Having a nipple to replace the one that they had lost was
paramount to these women. Participants who underwent nipple
reconstruction needed their reconstructed breast to appear
physically whole before they could feel mentally whole. In
keeping with the different degrees of wholeness felt by
participants, two women were able to feel whole with just the
breast mound and did not require a reconstructed nipple.
While the desire for wholeness was not the sole factor that influences post-mastectomy women to decide in favour of breast reconstruction, it is clear that it was a critical factor for some participants.

P. Well I think when I initially, when the doctor said do I want to go I said O.K. . . And then you start the process . . . because well maybe he can make my life better.

P. I think anything is better than nothing . . . I've got nothing to lose and if anything I'm gaining.

P. That was why I wanted the reconstruction done. It was all part of the process of putting my life back together.

These statements reflect the overall meaning that wholeness made to these women's lives. The following section explores how the participants made sense of cancer in relation to themselves.

Establishing Meaning

An important part of the women's search for wholeness was related to their process of establishing meaning. As the women described their reactions they inferred a search for meaning that took place as they were reacting to and adjusting to the cancer and mastectomy. Part of this "search for meaning" involved comparing cancer to other misfortunes.
P. Because I feel with things like that . . . worse things have happened to other people . . . through life we're all going to get something one way or another and this was perhaps a lot easier than some things . . . It's not like an arm or leg or an eye.

. . . . . . . . .

P. So if it isn't a mastectomy, cancer, it's a heart attack. If it isn't a heart attack, it is something else. There are very few that live right through without having something go wrong.

. . . . . . . . .

P. After awhile you get over the hurt of seeing yourself flat on one side . . . I used to sit and cry for hours but it didn't do me any good so I quit . . . like I say you have to look around and there are a lot of people worse off.

As they compared themselves to other people and other situations, they concluded, "I could be worse off." Meaning was found through putting their situation in perspective with other seemingly worse ones. Their current illness experience was conceptualized according to what they knew within their own lives. No one else but the woman herself could develop this workable personal perspective.

In addition to placing it in perspective with other peoples' experiences, participants looked at the cancer-mastectomy
experience in terms of its relation to their own eventual death. Given cancer's real and imagined link with death, this is not surprising. The women experienced a heightened awareness of the possibility of dying before they had expected to.

P. We all have to die sometime but you know when you've never really had anything seriously wrong with you then you get thinking along those lines and it's depressing. You're not that old.

P. But then if you have to die . . . I always say when my time comes and the good Lord taps his hand on my shoulders and says you're coming, I'm going to say, "I'm coming. I'm coming." I'm not going to argue with Him.

These women responded by appreciating life more fully. They could not afford the luxury of becoming complacent and thinking that there would always be enough time to accomplish life's desired goals. Time and the related quality of life seemed more precious with the realization that they may not live to old age.

P. I think I try harder. I think you're more willing to take each day as it comes . . . know that life is not here forever. You've got to enjoy yourself now today, not put off doing it to next week. If you want to do something you've got to do it now.

Thinking about their own death, then, was an integral part of the
participants' process of discovering the meaning of cancer.

Another facet of finding meaning was to find positive aspects of the cancer experience. Several participants discovered unsuspected strengths in themselves, developed more meaningful relationships with others, or changed their attitude toward life.

P. And I feel because I've had it [cancer] I've met so many nice people involved with the rehabilitation programme ... and if I hadn't had it I wouldn't have ever met all those nice people. And it is special in a way.

P. I also see that people are living in a world that everything is so, [pause] means so much to them, like money and worldly things ... They don't [mean] as much to me ... I'd rather go on a holiday somewhere or go with my husband or be with my family than [have] a spanking new house and [be] sitting in it for myself.

These statements reflect positive aspects of the cancer experience, signifying a change in the participants' perspective.

Clearly, feelings, beliefs, and attitudes were also integral in the participants' search for meaning in their cancer-mastectomy experience. All participants outlined coping strategies that helped them deal with these feelings, beliefs, and attitudes. Creating and utilizing such strategies was a
self-directed process for each woman. Although significant others were acknowledged as helpful, the women believed their instrumental decisions about their lives were made independently.

Every participant was able to articulate exactly what strategies she had used to deal with this stressful period in her life. Resuming everyday activities which she had participated in prior to mastectomy was one of the most basic strategies. The majority of participants also stressed the need for acceptance in living with both cancer and the mastectomy.

P. It is just something you have to accept and you have to live with it, if you don't well, I think you'd be a total wreck.

P. But the way I look at it . . . there are other things that you can die of and that the biggest thing is not to be constantly worrying about it . . . You have to sort of put it in the back of your mind and get on with your life and keep busy.

These two themes of resuming everyday activities and acceptance were emphasized repeatedly throughout the interviews.

The following statements illustrate some of the coping strategies that participants used following the disruption of cancer.

P. . . . get into your regular routine because you're not that sick. Do things and don't dwell on it that much.
P. We are a very close family and if one person has it [cancer] we all give that person support . . . you have to take each day of your life for what it is.

P. Pride in my daughters . . . I think that my family . . . my children in particular, helped me. Just looking forward to things that were happening in their lives. I did have good friends. I had quite an active social life, which helped me.

P. And he [general practitioner] said you won't be ready to wear that for three to six months. I said I'm wearing it [permanent prosthesis] . . . I only knew at that point in time that I was going to that show. I was going, looking as if I was complete and I had to go for my mental attitude as well as my physical attitude. I had to turn up no matter how ill I felt.

All the participants clearly described the meaning and value that these strategies held for them in restructuring their lives.

It was important for these women to receive positive reinforcement from significant others for their efforts in resuming daily life activities. They expressed the need to be treated normally as they were prior to diagnosis. Several participants mentioned that they resented an overly solicitous approach from friends and relatives.
P. I didn't want sympathy. I wanted to lash out . . . I got out the anger by being active all the time. I worked through that phase by having so much to do.

P. Yes, and then some remarks they make and you feel like saying, "I'm not sick." You're not because once you get used to using your arm again you're fine but . . . well, people just don't realize that they're doing it. Certainly not intentionally but it's there.

P. I've been visiting people and [their] tearful relatives or friends [have] come into the room red-eyed . . . ready to pounce on them and hug them and I feel like saying get lost until you straighten out your attitude. But I had the same [experience] thing . . . you don't expect people to be laughing and jumping but those were the people I appreciated because I didn't want to sit and cry all the time. Let them cry at home.

They expressed quite clearly that it was not helpful to be always asked how they were feeling as if people expected them to be terminally ill. In addition, these women seemed eager to share what had been useful for them, especially if they could help somebody faced with the same situation. The above discussion has shown how women used their own resources to
restore normalcy in their daily living. In contrast, the next section illustrates the women's process of reaching for resources outside themselves in the quest for wholeness.

Acquiring Information

This discussion addresses the participants' acquisition of information in response to the search for wholeness. Acquiring information about breast reconstruction was a natural first step in the decision-making process for each participant. Accounts included descriptions of the manner in which they received and dealt with information related to breast reconstruction. Participants fell into two equal groups based on the way in which they received information. One group was routinely given information prior to or following mastectomy by such health professionals as general practitioners, general surgeons, and a nurse. The second group actively solicited information from such sources as magazine and newspaper articles, books, television, health professionals, and volunteers in the Reach for Recovery Organization. All these sources of information for the second group of participants appeared to be of equal influence. The following statements illustrate examples of information acquisition from sources other than health professionals.

P. Well, I think I always knew that there was a possibility to have breast reconstruction because even four years ago there [were] all these articles.
P. Then I read that one with the tummy [breast reconstruction procedure] ... it was about how they take the part of the tummy. Then I was down at my other girlfriend's ... in the States and they had it on their T.V. I watched the doctors talking about it and that's when I asked about it.

Obtaining enough correct information appeared to be a desire of all the participants. Frustration resulted if this need was thwarted.

P. Well, I wasn't given any information. I asked to be referred to a specialist and I was just put off, I knew that you could have breast reconstruction done. I must have read articles on it.

Most participants felt that they had eventually received sufficient credible information about breast reconstruction. Although the credibility of this information was also an important issue for the majority of participants, the issue of credibility is beyond the scope of this paper.

Participants reacted to information about breast reconstruction in two ways. They either chose to do nothing with the information at the time or used it as a way of seeking additional knowledge about breast reconstruction. Those women who dismissed it as an option at the time, usually did so because they were unwilling to go through more surgery, or felt unable to consider breast reconstruction until their adjuvant therapy was
completed.

P. I didn't think of reconstruction at that time or even later. I think my doctor in the clinic mentioned it as being a future possibility and I thought ... yeah, right.

P. I didn't really want anybody else chopping me up again ... so actually it wasn't for a few years or so after ... I don't think that I did think too much of it at that time. It wasn't until I read that article in the paper or in the magazine, I can't remember ... and then there were a few more articles and then that's when I started asking about it when I went to see my doctor [plastic surgeon].

The majority of participants reacted more quickly and positively to the initial information about breast reconstruction. For them it catalyzed immediate action and the beginning of the decision-making process. This strong link between the information and the pursuit of breast reconstruction is illustrated in the following accounts.

P. The minute I knew it [breast reconstruction] was possible the scale went right up to ten. As soon as I knew it was possible that was all I needed to know. I wanted it. That's it.
P. I went to the library and I got books and I got in touch with the cancer society. I got a list of people who had had breast reconstruction and I phoned them and I talked to a lot of people and got their opinion on it . . . six or seven . . . and how happy they were. And I guess it was probably the opinions from talking to these other people that made me all gung ho . . . that really made me feel like I wanna go through with it. 'Cause they were so happy.

P. But I never even thought to ask him [the general practitioner] about it [breast reconstruction] . . . it was him [the general practitioner] that mentioned it to me . . . yeah, I thought it was a good idea. Actually right from the start. Get yourself geared into operations, I guess.

P. I'd be reading everything I could get my hands on if I'd see a magazine or a Chatelaine, anything . . . Everytime I saw it around me . . . these women getting implants and stuff and I'd read stories about it and I thought why not me then. I deserved this . . . and I decided to ask my own doctor.

For some women, the way in which they perceived information proved to be as important as receiving the information. There
appeared to be certain pieces of information or cues that captured the attention of these participants and made them more sensitive to the appeal of breast reconstruction. In fact, these women may have been receptive to the idea of breast reconstruction prior to being diagnosed with breast cancer. The ability to project oneself into a situation that has no practical relevance, and yet identify with the idea of reconstruction reveals a marked sensitivity to such cues.

The following excerpt reflects a heightened awareness on the part of this participant to respond to certain cues about the procedure of breast reconstruction.

P. I had no need, I was just interested, I read it because I was interested - I thought, "Gee, isn't that a neat thing. What a good idea," was all that I thought about at the time.

This statement implies that this participant perhaps thought that if she ever did lose a breast that she might consider the possibility of receiving an implant.

Another participant demonstrated a similar readiness to respond to any information regarding breast reconstruction, although she did so following her mastectomy.

P. I didn't go to a library and search or anything ... But it seemed to me that every time I opened a book it [breast reconstruction] was there facing me.

This sensitivity to cues created a heightened awareness towards
breast reconstruction information and helped to explain why such information was a catalyst for these women.

In marked contrast, the other half of the participants received information on breast reconstruction but did not have the inclination to pursue reconstruction at that time. These participants demonstrated a more low-key response to the information about breast reconstruction and it did not act as a catalyst for decision-making. Some of the participants who underwent breast reconstruction took longer to arrive at a decision than participants who chose to refuse reconstruction. It was not uncommon for several years to elapse before a participant made the decision to undergo reconstruction.

The three participants who decided against breast reconstruction did not respond to the idea of reconstruction with the same trigger response that characterized the responses of so many of the breast reconstruction participants. Rather than respond to the information with excitement, these participants tended to weigh the consequences more deliberately, and to focus on the negative aspects of reconstruction.

P. I'd seen a lady that had had it done in Vancouver, through a friend of mine who was a nurse . . . But the doctor [plastic surgeon] did send me to see another lady . . . and I wasn't too happy with what I'd seen, although the lady was happy with it. But I . . . was disappointed.
In fact, two of these participants acknowledged that if they had not been given information and encouragement by their family doctors they never would have sought out consultation with a plastic surgeon.

What appears to be a critical factor in the decision-making process of many participants is whether or not participants moved toward or away from breast reconstruction after receiving information about it. Perhaps the way in which participants perceived and dealt with given information relates to their style of decision-making. This subject will be addressed in the following section on weighing consequences.

**Weighing Consequences of Reconstruction**

As each account unfolded, it became strikingly apparent that every participant possessed an idiosyncratic approach to decision-making. The unique decision-making style is best characterized by the term true to themselves and is a powerful theme that linked the participant accounts.

Every decision appeared to be characterized by a unique pattern of events that transpired during the decision-making process. While participants could describe the process of making a decision in terms of sequential life events, most experienced difficulty pinpointing the factors which influenced the process, although a few were able to articulate these factors clearly. Others merely acknowledged that the decision had come about. One woman, for example, said that the decision had been made
immediately after she spoke with a mastectomy volunteer who had undergone breast reconstruction. The elusive nature of these factors could be a result of the complex weave of feelings and thoughts that influence the specific action of decision-making. Therefore, it is highly possible that some of the underlying impulses that motivated the decision-making were at an unconscious level.

Time, as a component of decision-making style, pervaded every woman's account. The participants' decision-making time reflected as much variation among individuals as the events characterizing the process of their decision-making. For example, several participants said they made a snap decision while other participants claimed that the time involved in their decision took up to a year.

P. I always wanted it . . . It was mentioned to me when they told me I was going to have my breast off . . . that there was a possibility of having breast reconstruction.

R. You can't remember ever making the decision or . . .

P. Never.

. . . . . . . .

P. I think it was more or less on your mind a lot and I think I just woke up one morning. I'd been thinking about it for quite a few nights and I just woke up one morning and said oh to heck with it, I'm not going to
go through it . . . Just forget about it.

P. Well, actually after he talked to me about it, I really thought that I would go ahead and do it and see it took me a year before I got to doctor [plastic surgeon] to have it done. But I don't know why it took so long. I guess it is just to make up my mind to decide to go ahead with it.

Interestingly enough, while all participants could generally quantify their length of decision-making time by rating themselves on a scale between fast and slow decision-making, the majority were unable to pinpoint the exact amount of time involved. These participants were vague when it came to recalling specific days, weeks, and months in relation to their decision-making time. Some participants were even unclear about the time in their life that this decision took place and were unable to specify the year it took place.

R. When did you first see Doctor [plastic surgeon] after the chemo? Can you remember how many months it was?

P. I honestly don't remember.

R. Do you remember the year?

P. I don't remember whether I was still on chemo or not. I doubt it. Because when you're on chemo you're not thinking of anything else. It's really like that. I can remember when I saw the doctor [the plastic
surgeon].

P. I know I had the first one [consultation with the doctor] about November so it must have been, I think, six months . . . about March. I'm not positive on that . . . could have been.

R. That you first saw Doctor [plastic surgeon], so that would be . . . would that be March of '76?

P. Hmm, it must have been around there.

This phenomenon could possibly be due to the natural process of forgetting some details over a period of time, which is inherent in retrospective accounts. On the other hand, perhaps some participants put time in a different context when making their decision. It appears as if it was more relevant for these participants to recall their decision-making in terms of the life events that centered around their decision.

P. Yes, because this was after my . . . November is the month of my annual check-up and this was when he [the doctor] suggested it [breast reconstruction] and that's also when the report came back . . . my pap test that it was positive . . . and this was working up to this hysterectomy and I thought, "Well, let's wait and see how that goes before I get into something else." Well then I had to have it [the hysterectomy] so that helped to decide as to whether I would check into it further and go back and see whether I would have it done or not.
The sequence of events may well have been more significant to these participants than the length of time each step of the decision-making process had taken.

Participants who acknowledged that theirs had been an instant decision to undergo breast reconstruction appeared to possess less awareness of factors that influenced their decision-making than those women whose decision-making spanned a longer time period. These snap decisions may have taken place outside the participants' consciousness. Perhaps these instant decisions had a more emotional basis, that proved difficult for these women to identify and describe. In contrast, those participants who had taken longer to arrive at a specific decision seemed more likely to engage actively in a deliberate weighing of pros and cons, often characterized by a thinking-through approach.

While time was an enduring part of each participant's unique decision-making style, it appeared to possess a fluid quality. This fluidity was observed with some of the participants, whose perception regarding the timing of events had altered from the first interview to the second.

In addition to time, decision-making about the nipple was a factor that reflected decision-making style. The nipple surgery is optional, therefore the decision to have nipple reconstruction is one that faced every participant who decided to undergo breast reconstruction. Eleven of the participants chose to have the
nipple reconstruction while two participants elected to have the breast mound only. The majority of participants said that they knew either before or after consultation that they desired the nipple reconstruction. Such statements as "It is the icing on the cake," and, "I just assumed the nipple was part of the whole package," were typical.

There was a marked tendency for those women who made snap decisions about having breast reconstruction to decide instantly that they also desired nipple reconstruction. Likewise, participants who took time to deliberate before deciding on breast reconstruction were apt to take time to consider the merits of undertaking nipple reconstruction. Thus, the participants' decision regarding the nipple tended to reflect their decision-making style. The following excerpts highlight the process of decision-making about the nipple.

P. When I just had the prosthesis in and no nipple on the end of it I didn't like it. I wanted it finished.

P. There was no thinking about it . . . I want it done completely . . . What is the point of having half of it done?

It was crucially important for these women to have a reconstructed breast that resembled a normal breast in order for them to feel whole. The following participant was actually more enthusiastic about getting the nipple reconstruction done after
the first interview, which was six months prior to the second interview. She had obviously weighed the consequences and decided that she only needed the convenience of the breast mound and that the aesthetic look of her reconstructed breast was not as important to her as she previously thought it would be.

P. I would say that it was less important. I sort of got all fired up and thought, "Oh this would be the perfect solution," but now I don't think it would make that much difference now. The big thing was having the basic reconstruction done.

Undergoing additional surgery, for the following participant, was a higher price than she was willing to pay for the sake of having the nipple.

P. But if I feel conspicuous I can just take a bandaid and put it over that one . . . I've only done it once . . . That's a lot easier than having the surgery done . . . I think I'd have [the] one taken off before I'd have more surgery done . . . never really considered that. If they could have done it all in one operation maybe . . . but a nipple is a very small thing to be concerned with, I feel.

The following woman's decision-making regarding her nipple was characterized by indecisiveness and she was one of a very few who reacted in this manner.

P. He mentioned it and I said no. And then I said yes. I
didn't know. I went back to him last year and I said, "I think I'm going to get you to put the nipple on it." That's just silly because this side will pop out and then this side wouldn't. That didn't bother me, it wouldn't have bothered anybody, really, except I could see it and nobody else could . . . he wanted to do it.

Another issue that arose for those participants considering nipple reconstruction was a practical consideration.

P. And I thought at the time I might not bother with the nipple except when you wear clothes such as a sun top or whatever it was very obvious that you had one and didn't have another. And so I decided to go all the way and have the nipple.

The nipple appeared to be needed because of the desire for symmetry which likely symbolized normalcy for these participants. Therefore, regaining the lost nipple was a critical issue in the search for wholeness.

It is not clear from the accounts whether or not each participant used a pattern of decision-making that reflected all other personal decision-making. The possibility exists that the participants used a style that was unique for their decision regarding breast reconstruction. Another explanation could be that they used a past decision-making style combined with a newer, modified style. One needs to look beyond a participant's breast reconstruction decision style to her past decisions to
fully comprehend her over-all decision-making style.

**Perception of Surgery and Surgeon**

The search for wholeness encompassed the issue of surgery. The attitudes to surgery of participants who underwent breast reconstruction differed considerably from participants who chose to refuse this surgery. Every participant who underwent breast reconstruction tended to perceive the positive aspects of surgery and minimize or deny the risks.

P. It would be different this time because they weren't going internal really. They were doing external things to me, cutting me and just putting an implant in. They weren't looking for cancer so it would be a whole psychological[ly] different operation as well.

P. Couldn't see any barrier, anything negative about the whole thing . . . plunge headlong if I get to feeling positive about something. I just get all excited about it.

P. It is such a minor surgery. They just slit open and they try and use the slit that you already have and just put an implant in and sew it back up.

P. But when they convinced me it was just [a] simple procedure technically speaking . . . inserting the
implant and sewing me up and that would be it. That really was what helped me to be convinced to go ahead and have the surgery. Some women acknowledged the risks of surgery but their desire for reconstruction outweighed their fears.

P. Only that I didn't want another operation because I had gone through another very traumatic operation . . . Well, once I psyched myself up, oh well I'll go through with it and have it done and get it over with. That's just it. To me no operation is a small operation you know. I don't like them . . . I would never put myself through that [breast reconstruction adjustment] just for another, almost cosmetic thing and to me that is not important. It is just not worth the . . . whole thing.

.............

P. If I thought there was any reason for taking a chance I would not have had it done. But I was looking for a doctor to tell me, "No, it's not [a risk]."

.............

P. The only thing that scared me ever was if I did stir up any cancer that was there but then you can't think like that because if I thought it was there it might come. . . . I thought maybe if they cut but then I figured I got rid of it with the chemotherapy.

The following accounts illustrate the powerful impact of the
participants' perception of surgery on the decision-making process. For example, this optimism persisted despite a lack of good results following the first surgery.

P. There was a very good chance that it [breast reconstruction] would work this time. It was worth it to do it once and wasn't too bad to recover from . . . only infected . . . fairly simple, yeah sure, go ahead with it.

. . . . . . . .

R. How did you deal with the setbacks when you had the setbacks?

P. I don't think I had any setbacks.

R. So . . . they [two implants] went hard and like . . .

P. Oh, well that.

. . . . . . . .

R. And that time you hemorrhaged?

P. Well, those things happen.

These women appeared to take the surgical complications in stride and were not threatened.

Some of the participants who underwent reconstruction were prepared to go through any number of surgeries to attain their personal goals. One participant had five breast reconstruction surgeries. Another participant had more than ten separate operations to reconstruct her breasts over an eight-year period.

P. No, it was like I'll just keep, I will do this
[surgery] until I'm happy with the result or until he [the plastic surgeon] tells me that's as good as it is going to get and then I'm going to have to learn to be happy with that result.

... 

P. He [the plastic surgeon] said that doesn't look right and I said, "No . . . it looks a bit higher than the other [breast]" . . . "Maybe I had better lower it, eh?" and I said, "Well, sure . . . just like buying ice cream."

In marked contrast, those participants who decided against having breast reconstruction viewed surgery as traumatic. For them the risks far outweighed any perceived benefits. It was difficult for these women to contemplate undergoing surgery without a guarantee of satisfactory results.

P. In the meantime I'm not going to be a guinea pig, it's not worth it. You see they've got to cut my back, take a piece from my back, bring it around to the front . . . you go back about twice or three times.

... 

P. And another reason . . . your body changes as you get older. Mine's already changed. I've had different sized prostheses since I started, about four of them . . . what are you going to do, keep turning back and having more surgery done? . . . In my case my good
breast would have to be made smaller to match and that
didn't appeal to me . . . having my good breast touched
in any way . . . Yeah, one good one is better than
nothing I guess.

. . . . . . . .

P. The hysterectomy came along and so there you go from
one to another. You figure this is enough . . . It was
more surgery . . . It's not even an artificial limb
. . . other people if you don't tell them they don't
even know.

These participants never acknowledged any positive aspects of
reconstructive surgery.

Perception of surgery appeared to be affected by their
perception of the surgeon on the part of those participants who
underwent reconstruction. The more positive a participant felt
about her surgeon, the greater confidence she expressed in the
benefits of breast reconstructive surgery. In these women's eyes
the breast reconstructive surgeon was frequently endowed with
magical powers and, as such, was worthy of absolute respect and
admiration. These women placed great faith in their surgeons.
This trust in the surgeons' ability appeared to create a bond
between doctor and participant that contributed to a teamwork
relationship. Although the strength of the bond varied among
breast reconstruction participants, they all expressed
satisfaction with the relationship between themselves and their
surgeon.

P. I didn't even know where he was going to get the skin from. It didn't bother me a bit . . . I was just in his hands. Just as if he was God.

...............

P. And when I went to him [the doctor] like I said, the guy could ask me to jump off the Lions Gate Bridge and I would. He was just, his whole attitude, and the way he dealt with me as a human being and someone who had a disfiguring operation done. The way he explained it and everything and didn't tell me that it was all going to be wonderful afterwards, but it wasn't going to be anywhere near what I looked like then.

...............

P. I believe he's [the doctor] magic. I really do and . . . I think that he can just do everything perfectly.

...............

P. He [the doctor] has got the most excellent personality, I figured, as soon as my husband and I talked to him. First interview; I knew I had it made with him. I trusted him completely . . . If he could do another operation on me I wouldn't worry about it.

The amount of trust shown by the participants appeared to be directly related to the number of surgeries they had undergone. Those women who underwent multiple, repetitive breast
reconstructive operations were more likely to demonstrate absolute trust by putting their surgeon on the same level as a demigod. Perhaps this high degree of trust assisted them in persevering through numerous surgeries over an extended course of time.

Conversely, those women who refused breast reconstruction surgery tended to perceive the surgeon on a more neutral basis. There was no need for them to establish a relationship with their surgeon, as the breast reconstruction participants had.

It is apparent that the participants’ perception of surgery was consistent with the choice they made. Those women for whom the anticipated results outweighed the risks, underwent reconstruction. Those participants who could not justify the surgical risks declined the surgery. Regardless of the conclusion, all participants went through a decision-making process. Weighing the consequences in terms of need for surgery and perception of the surgeon was an important step in the process.

Indeed, the powerful dynamics of the patient-doctor relationship cannot be underestimated when a participant's decision-making process is assessed. Throughout the weighing of consequences, variations in personal decision-making style were evident. It is critical that these factors be assessed in the context of the meaning that each participant attaches to her decision.
The participants dealt with such complex issues as establishing meaning of the cancer experience, acquiring information about breast reconstruction, weighing the consequences, and placing the surgery into context for themselves during their search for wholeness. With these issues behind them, they were able to make a decision about choosing or refusing breast reconstruction. Regaining wholeness was the final step of the women's decision-making process and focused on defending the decision and recovery from the cancer-mastectomy experience.

Regaining Wholeness
Defending the Decision

Although the decision to undergo breast reconstruction was made by the individual participant, it was also obvious that the beliefs and values of friends and relatives had impact on the individual woman in her decision-making. For the majority of women who underwent breast reconstruction, the influence of significant others occurred primarily after their decision was made. The resulting need to defend their decision was a recurrent theme throughout the accounts. This section addresses this defense and its effect on the participants.

Nuclear family members were perceived as more supportive than extended family members. Husbands and boyfriends, in particular, offered the greatest support for the women's decisions. Almost without exception, they emphasized to the
participants that it was their own decision. The partners felt strongly that the women should not undergo breast reconstruction for them and offered their support regardless of the decision they made. All the children of the participants, with the exception of two from different families, were enthusiastic about their mothers undergoing reconstruction.

P. And they [family] thought that [breast reconstruction] was a good idea because I thought it was.

P. Whatever I wanted. Now of course we [husband and I] discussed the pros and cons and everything else like that but it was whichever way I wanted it because I was the one that had to undergo the surgery.

P. But he [husband] really was very cool about it [breast reconstruction] . . . either way was fine.

Friends and acquaintances were much more likely than close family members to ask the participant to explain her rationale for having breast reconstruction. The unsolicited comments of friends and acquaintances were frequently viewed as intrusive and unsupportive.

P. Oh, I've got lots of static from a variety of people.

P. . . . Why at your age do you want to be bothered having something like that? . . . I don't really figure I'm that old yet . . . Made me quite mad.
P. ... in fact my father-in-law ... he said things like ... and you get sick leave for this? ... because it was sort of a frivolous sort of thing and of course a lot of older people feel that way ... and they ask you if it's safe and you explain to them that you're going to a medical doctor that's doing it ... most people have no idea ... frustrations of wearing a prosthesis and how it can take years off your life.

P. Oh, one daughter. She just couldn't stand it. She thought that I was playing with fire [having breast reconstruction] ... she thought leave well enough alone - that it was okay the way I was and I said, "You think I'm okay but I don't."

P. One of my friends said to me, "You didn't need this operation," and I sat them down and I said, "Well, I think I need it," and after I'd explained it to them about the whole bit - being uncomfortable, being too heavy on one side they said, "Well, I'm glad you explained it to me" ... if you say you're going in for breast reconstruction, they say it's like going in for a face-lift ... they think you're being vain by even considering it.

The validity of comments about breast reconstruction was
judged by the participants on the basis of the experience of the person who made the comment. Women with experience made fewer comments and were perceived with more credibility. Conversely, non-supportive comments came more frequently from women with no personal experience with loss of a breast. Not surprisingly, their comments were seen as less valid.

P. From people that never had the mastectomy who say, "Oh, I wouldn't do that to my body [have breast reconstruction]," I just think, "Oh well, don't talk to me about it. You don't know what you're talking about."

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P. I'm sure that if I had had a hand removed and had been given the choice of having a hand as a prosthesis attached to my remaining limb I don't think anyone would have nearly given me the flack for it that I got for having a breast ... I would try to tell people why and they didn't want to know. That made it worse. I was somehow perverse, I mean sick. Something is wrong with you. You are so hung up on your breasts and sex too ... I mean how can you deal with people like that. I stopped trying.

................

P. Wouldn't really matter to me what they thought anyway ... It is what I wanted. It's my life. I
wasn't harming anybody by doing it.

. . . . . . . . . .

P. It was something I was doing because I wanted to do it and I felt right about doing it against all the advice and comments of so many of my friends and I just decided I was right and I was going to do it and they could all piss off . . . it was for my own benefit and I knew that I was doing it for me and I knew perfectly well why I was doing it . . . I justified it several ways and then decided that it really didn't matter a damn what the reason was as long as I felt better about myself.

Participants expressed anger and disappointment when they talked about the non-supportiveness of friends. They coped with this challenge from others by continually justifying their decision to themselves, dismissing their friends' influence and taking responsibility for their own decision. Participants limited the risk of encountering criticism by controlling discussion of the topic of breast reconstruction and by talking to individuals who were perceived as open-minded or who brought up the subject. A few participants were supported in their decision to pursue breast reconstruction by all of their friends and colleagues in addition to their families.

Both groups of participants were able to articulate a rationale for their decision.
P. I think it's basically . . . happiness and I don't like to be sick or different . . . Because I thought it was good that they could do something.

P. I have an appreciation for the human body and for its lines which beautify - for the way it ought to be.

P. Yeah, that's the big thing, you're not confronted visibly every day with the fact that you've had cancer, which nobody can run away from but nobody wants to be constantly reminded of it.

P. We all have to have a certain amount of self-esteem to function. And you're no good to anybody else if you don't have it . . . And so if it's something like this that means that you're going to have better self-esteem, then it [breast reconstruction] is something that you need because we're not just physical beings, we're emotional beings and physical, as well as spiritual, so you're involving all parts of your life.

P. I think you should do what you feel like - like you want done and I mean even if I - if they told me I was to get cancer, like this is before I had the reconstruction even if this was cancer in my back I
would still have gone on and had the breast reconstruction. Because I feel like life is too short and if you really feel like you want something why not go for it?

P. Like my daughter says - maybe it's vanity and I said it is not. I says if I had my finger cut off I'd want that back . . . I just wanted to have everything that everybody else had.

P. So with something like reconstruction or with cancer, to have to live with what I consider mutilation, why should you have to do that? Why should you have such a lousy time? If for a brief period of discomfort you can forget about it.

P. I don't know where I'd be now . . . to live with it [mastectomy]. But I don't think I would be as happy as I am now. I would still be searching for this or wanting it done.

Most participants stated several reasons for undergoing this surgery.

The three participants who decided against having breast reconstruction described their rationale as follows.

P. Well, there's just too many things for me against it.
... Too many ifs ... I thought no, at this stage of
the game it's not for me. It's not right.

P. I'm not really sorry that I made that decision. I'm
not comfortable this way but who's to say I'd be
comfortable the other way [with breast
reconstruction]? I had heard from another cousin of my
husband who knew a lady that had both breasts done and
she had terrible pain. I heard that after, but that
sort of helped me along in thinking that I made the
right decision ... a few of them [friends] said to me
when I was going to have it done, "I'm glad you changed
your mind and didn't."

P. And my own doctor said that she's glad I didn't go
through with it because they are not very successful.

It was apparent from their accounts that women who declined
breast reconstruction surgery were not challenged or required to
defend their decision to the same extent as those who chose
surgery. All participants who declined breast reconstruction
received support from family, friends, and doctors. The primary
reason endorsed by these significant others was the belief that
these women had been through enough trauma. Participants
acknowledged that the support of their significant others was
helpful, although they stood firm in their convictions that they
alone were responsible for the decision.

The major difference between the two groups of participants was the amount of justifying they felt compelled to do. The increased amount of justification required of women who chose breast reconstruction appears consistent with the elective nature of the procedure.

In addition, it is likely impossible for women who have two intact breasts to really know what the experience of losing a breast is like for post-mastectomy women. Not surprisingly, all the participants who declined breast reconstruction stated that they could understand why breast reconstruction would be an important part of the rehabilitative process for other post-mastectomy women. The very fact that they sought out consultation with a plastic surgeon provides support for the belief that they were open-minded enough to identify with some of the concerns of the breast reconstruction participants.

Recovering

The following section addresses only the participants who underwent breast reconstruction. For these thirteen women, the process of regaining wholeness was symbolized by the physical restoration of their missing breast and the resulting ability to let go of the cancer experience and get on with leading normal lives. All participants recited numerous benefits of the restorative surgery. The most predominant benefit cited can be described as regaining a sense of wholeness. Restoration of
wholeness was a powerful theme recurrent in the description of these women's decision-making process. Becoming whole again was associated with feelings of happiness and well-being.

An important part of regaining a sense of wholeness was looking and feeling normal. Dressing without restrictions also gave the participants a feeling of being normal. This feeling of normalcy appeared to be an integral part of being able to acquire a sense of wholeness. Because feelings of wholeness and normalcy appeared to be inseparable for the participants, it is difficult to ascertain which one developed first after reconstruction.

P. I think when you look normal that also helps you to feel more normal.

. . . . . . . .

P. I'm pleased. I think if you ask [the plastic surgeon] before he even took the bandages off - I told him it was beautiful because I had a mound there . . . Oh I enjoyed it. "It's better in all ways," I said. We enjoy the sun and the things I can wear, whatever, I'm just the same as everybody else.

Another asset of breast reconstruction which tied in with feeling normal was the disappearance of the self-consciousness previously associated with the mastectomy and prosthesis.

P. And I can even go and change in a changing room with other women now . . . whereas before I couldn't take my clothes off in front of other people . . . Because you
look so different and even if you are well-adjusted I don't think you can do it because you look weird. You don't want people staring. Nobody wants to be seen as a freak.

Feeling normal again was critical in assisting many of these participants in regaining their self-esteem.

Happiness and surprise that the reconstructed breast could make such a difference in their lives is well illustrated in the following statements.

P. As soon as I woke up [following surgery] I was just so happy. It just felt wonderful. Just like being reborn again.

P. I'm much happier since it's been done. It's made a great deal of difference. I didn't think it would make that amount of difference but it has . . . Well, I just thought I wanted to feel more complete . . . more as a whole person. But I am totally happy.

P. I think it's a very positive piece of surgery that you don't realize how positive it is until after you've had it.

P. I never thought having one [breast] made any difference. . . . I think it's being made whole again.
It is like you don't really mind losing the breast but instead of being 100 percent you're 98 percent. The intensity of these women's feelings shown in describing their pleasure with the results of breast reconstruction was striking.

Convenience also was mentioned repeatedly as a primary reason for choosing breast reconstruction. Participants remarked on the sense of freedom and relief at giving up their burdensome prosthesis.

P. To be able to get up in the morning and to be able to put on a bra and not pin rubber boobs on.

P. Well I had said before that you know I wasn't unhappy before, it just felt so much nicer afterwards, that I never thought really that it would make that much difference. Except for being more comfortable. Not having to wear a bra all the time with the prosthesis in it.

P. Yeah, no it wasn't really going to change my life. I mean to change my life immeasurably . . . It was going to be something that was good to do and put it back the way it was kind of thing and also be a lot more convenient.

This convenience suited these participants' active life styles and also reinforced their feelings of normalcy.
A further important theme was loss of the constant physical reminder of the cancer experience. This constant reminder was associated with worry and focusing on the negative aspects of cancer as a disease. The women cited this factor as a critical one. It provided both a rationale for having reconstruction and was a beneficial effect of the surgery.

P. When you have the reconstruction you've always got something there. And you're not constantly reminded of having cancer.

... . . . . . . .

P. You don't even think about it [cancer and mastectomy] unless somebody brings up the subject. I just feel like I was before . . . It is just that you feel more normal.

From the following accounts it appears as if several of the participants had succeeded in putting behind them the whole trauma of their cancer experience.

P. I'm just very grateful that I'm well and that I can feel this well because as I said three years ago I didn't think I'd be able to look this far ahead and be enjoying life the way I am today. So I am very, very grateful for that.

The majority of participants felt that breast reconstruction made it possible to get on with their lives.

One of the overriding feelings that emerged from the
participants' accounts was exuberance. This excitement about the benefits of breast reconstruction was reflected in their eagerness to talk about their experiences, in the words they used and in their non-verbal expressions. They were thrilled at the physical and mental transformation brought about by breast reconstruction.

The powerlessness of the breast reconstruction experience is best documented through the following statements:

P. I had two doctors [at the cancer clinic] look at the implant and I said I feel like a million dollars and I said it should be done for every woman that wants it done.

P. I said to [the plastic surgeon], "One thing I'm disappointed about . . . it's not like a new dress that I can go home and show off. I can't show it [reconstructed breast] off." I was so delighted . . . I was absolutely thrilled.

Every participant who underwent breast reconstruction stated that she would recommend the surgery to any woman who desired it.

P. I still don't understand how women don't. Why not every single breast cancer patient is in there getting reconstructed.

The participants' strong belief in the benefits of this constructive surgery never faltered during the entire
decision-making and outcome phase.

**Summary**

This chapter addressed the participants' decision-making process regarding breast reconstruction. The major themes that pervaded the participants' accounts and influenced the decision-making process were the initial loss of wholeness and the search for and restoration of wholeness.

The participants needed to start at the beginning of their cancer experience and recite stories describing diagnosis, mastectomy, and adjuvant therapy. This enabled them to anchor the cancer experience and assist the researcher in understanding their reasons for considering breast reconstruction. All the participants put the cancer-mastectomy experience in the context of other life events in order to establish the personal meaning of the cancer experience for themselves.

Another theme that continually characterized the participants decision-making was a uniqueness in style. Factors that appeared to have the greatest impact on the decision to choose or refuse reconstruction were the participants' perceptions of wholeness, feelings about the prosthesis, perceived benefits versus risks of surgery, and the acquisition of information.

These factors influenced each participant's degree of readiness to consider breast reconstruction. The participants who chose to decline breast reconstruction were more likely to
have maintained a sense of wholeness, accepted the prosthesis, and not responded to breast reconstruction information as intensely as those who chose reconstruction. For those who chose breast reconstruction, a characteristic quality was their excitement in response to information about breast reconstruction.

Another major difference between the two participant groups was that those women who chose reconstruction perceived only the positive aspects of surgery, in contrast to the women who declined reconstruction, who perceived surgery as negative and risky. In addition, women who declined breast reconstruction were not required to defend their decision to the same extent as those who underwent this surgery. All participants stated that they were satisfied with the outcome of their decisions.

Finally, it seems evident from these accounts that this decision-making process is amazingly complex. These women experienced difficulty identifying the pertinent factors that influenced their decision-making about breast reconstruction. It is only through the richness and depth of these accounts that a degree of insight and understanding into this decision-making process can be attained.

The following chapter will interpret the significance of the participant accounts in relation to the literature review presented in Chapter Two.
CHAPTER 5

Discussion of the Findings

This chapter discusses the findings of this study in relation to current professional and lay literature. The purpose of this discussion is two-fold. Firstly, it seeks to promote insight into factors influencing whether women choose or refuse breast reconstruction. Secondly, it demonstrates how the decision-making process in breast reconstruction can be further understood by exploring a woman's perspective. The literature review presented in Chapter Two concluded that scientifically sound research related to the decision-making process in breast reconstruction was scarce, thereby substantiating the need to study women's actual experience in making a decision regarding breast reconstruction.

The major themes recurring throughout the mastectomy and breast reconstruction literature also emerge in this study. Three additional themes, however, not as clearly articulated by the professional literature, arose from these findings. It is the researcher's intent to detail these three themes: wholeness, the doctor-patient relationship, and decision-making. Although other findings are recognized as important, they will not be highlighted in as much detail.

Additional literature and research will be utilized in this discussion, including literature presenting a feminist perspective on women's experiences with breast reconstruction.
The purpose of this study was to examine and describe women's perceptions of the decision-making process regarding breast reconstruction. The conceptual framework for this discussion of findings will focus on the three major themes: wholeness, the doctor-patient relationship, and the decision-making process. These key themes were presented in Chapter Four.

Loss of Wholeness

Women Who Underwent Breast Reconstruction

The majority of the 13 women who underwent breast reconstruction described feelings about their loss of wholeness following mastectomy. These feelings were expressed in such terms as lacking completeness, lacking normalcy, not feeling right, or feeling unlike themselves. Loss of physical wholeness appeared to cause a profound sense of psychological loss that affected their self-concept.

The women reported feeling a decrease in general confidence, self-esteem, and physical attractiveness. Feelings about the mastectomy site varied in intensity from repugnance toward their incision site and lack of breast to being only occasionally bothered by it. Others wished that symmetry could be restored to them because they felt unbalanced.

Several women felt that their femininity was decreased as a result of feeling less whole. This decreased sense of femininity inhibited their sexual expression, which reduced sexual
satisfaction with their partner. The negative effect on self-esteem arising from feelings of a lack of wholeness was well validated in the lay literature. Van de Walle's book, Falling from Grace (1984), poignantly expresses her anguish over the loss of wholeness following mastectomy.

... I have been told
I would get used to it
I have been told that according to the shrinks I'll first find anger then grief and eventually acceptance.
I smile and nod.
Fear roams through the hours
erupts at night in violent seizures
shame forever
averts my eyes from mirrors.
Pain at times
almost becomes a pleasure.
A terrible and new territory.
I wander there alone ... (p. 24).
Lack of bodily wholeness is described by Snyder (1984) when she says:
I felt like such a nonwoman and hated myself for not being able to intellectualize out of that feeling ... I'd catch a glimpse of my naked self in the mirror ... it just never
stopped being a surprise. It was such a shock that I'd gasp and then cry . . . (p. 40).

The importance of wholeness was illustrated by Stolar's (1978) unpublished survey of mastectomy volunteers. She instructed the volunteers to "rank order their feelings of concern, at the time of surgery, with respect to femininity, mothering (nurturing), sexuality, wholeness and beauty" (p. 8). The volunteers not only stated that wholeness followed by femininity was the most important for them but maintained that wholeness was the major concern of women they counselled.

The following statement by Spletter (1982) is consistent with predominant views found in the lay literature, which support breast reconstruction as the solution to a woman's lack of wholeness following mastectomy:

Interest in breast reconstruction is not a sign that a woman is vain or trying to turn into a sex symbol. It is a sign that she wants to regain a natural, normal body contour and restore what psychologists call body integrity (p. 164). This statement reflects the thoughts expressed by most women in the study. Their need to restore wholeness was their need alone and was prompted by the desire to regain their sense of self.

Clifford's (1979) research further supports Spletter's viewpoint by illustrating that a woman's sense of femininity goes beyond her sexual feelings.

Concepts of femininity were not necessarily related to
concerns about sexuality; most frequently an inner sense of femininity seemed to be involved. These women stressed their own views of femininity rather than the views of others about their femaleness predominated (p. 25).

Fear of loss of wholeness started for some women preoperatively, as illustrated by Parker (1978).

My God, am I going to have a mastectomy, then a hysterectomy? . . . Are they going to chop away at my body? . . . I don't want to live by being chopped into little pieces. One year we'll take this, and another year we'll take that (p. 59).

Despite the fact that several women experienced a preoperative fear of losing their breast, the majority of women appeared relieved at the thought that they would be receiving effective treatment for cancer. Prior to surgery, the majority of women were unable to predict the pervasive and powerful effects that a lack of wholeness would have on their lives.

**Women Who Refused Breast Reconstruction**

Although the women in this study have been separated into two groups for purposes of discussion, the findings reflected an overlap between both groups regarding feelings about wholeness. There were women who professed to feel psychologically whole and went on to have breast reconstruction; conversely, others who experienced some degree of loss of wholeness refused this surgery. From this it appears that lack of wholeness, although a
critical factor in determining whether a woman may consider breast reconstruction, is not the sole predictor of a woman's decision to choose or refuse this surgery.

Perhaps the fact that so few women go on to have reconstruction may be an indication that, despite a transitory loss of wholeness, most of these women resolve their negative feelings regarding loss of wholeness. It is difficult to know whether acceptance of being single-breasted can be equated with feeling whole. The general literature focuses on women experiencing adjustment problems and fails to provide conclusive information on this topic. Information related to the wholeness resolution process in women who do not consider breast reconstruction would thus be invaluable to health professionals. We might ask: Why are some women's self-concepts more vulnerable to loss of wholeness than others? How can health professionals assess whether a woman's loss of wholeness is transitory or of a more permanent nature?

Search for Wholeness

Similar to the majority of women in this study, women portrayed in the lay literature initially expected to adjust to their mastectomy, given time. However, when complete acceptance was not forthcoming, their resulting search for wholeness developed into an urgent, compelling need.

Jean Zalon's statement reflects this great need for wholeness and epitomizes the value assigned to wholeness by the
lay literature.

I was the one who was dissatisfied, still angry and rebellious at the mutilation of my body, still aching with incompleteness. Most of the time, of course, I hid that ache. Over the years I had learned to push the dissatisfaction to the back of my mind . . . But the whole point was that it really wasn't necessary -- not anymore . . . All I wanted to do was to get back where I started, look the way I had once looked (1978, p. 32).

According to the findings of this study which support the lay literature, loss of wholeness was the most powerful influence on those women who chose to undergo breast reconstruction. The professional literature, however, does not emphasize the degree to which wholeness, in relation to other factors, affects decision-making regarding breast reconstruction.

The wholeness needs of those women who underwent breast reconstruction differed markedly from each other. This was manifested in the type of surgical result each woman desired. Spletter (1982) stresses the important point that "our expectations, priorities, and feelings about our own bodies can make a major difference in our decisions" (p. 141). This was found to be the case with those women who had had more than four breast reconstruction surgeries. They tended to be more perfectionistic and desired a reconstruction that appeared as much like a normal breast as possible. A few women in the study
stated that they would keep on having surgery if better results were possible, but their plastic surgeons felt that everything that could safely and reasonably be done had been done. This attitude is clearly illustrated in these women's comments about their breast reconstruction.

As far as I am concerned . . . I will continue to have more surgery as long as it makes me feel better or as long as I feel it is necessary (Berger & Bostwick, 1984, p. 177).

. . . . . . . . . .

I would really like a nipple that sticks out more; this one is flat. You know the truth? [whispers] Deep inside myself, I am very happy that I did it, but I'm afraid that if I let the doctor see that, he will stop working on me to make it better (Snyder, 1984, p. 135).

Another striking feature of the women who searched for wholeness was their tenacity in pursuing this goal. Obstacles such as resistance of significant others and health professionals, extensive amounts of surgery, and physical complications were frequently encountered. In spite of all these inhibiting factors, these women were articulate and assertive in achieving their goal of restoration by breast reconstruction. Both professional and lay literature record this phenomenon. One wonders if women who undergo breast reconstruction are more equipped with the skills necessary to achieve their personal goals than women who choose to refuse reconstruction. It is also
possible that the very process of obtaining breast reconstruction, which is not as acceptable to society as wearing an external prosthesis, further develops a woman's assertiveness, thus shaping her responses.

Sandelowski's (1981) portrayal of health is significant for those women who chose to undergo breast reconstruction. She states: "Health is the ability to change because we choose to, because we experience pain with what we are at present, and not because someone else wants us to change" (p. 93). She contends that, "health is finding pleasure from our own bodies, pleasure that we give ourselves or allow others, men or women, to give us" (p. 93).

Those women in the study who underwent reconstruction played a critical role in their own health management by exchanging their disfigurement and its association with illness for a beneficial feeling of wholeness and health.

The three women who consulted with a plastic surgeon and eventually declined reconstructive surgery obviously initiated more of a search for alternatives than the general population of post-mastectomy women, who never see a plastic surgeon. For two of these women, the search for wholeness ended following one consultation with the plastic surgeon. The other woman who declined reconstruction consulted with the plastic surgeon three times before she decided against surgery.

Although the vast majority of women choose to wear an
external prosthesis or have breast reconstruction, a third course of action exists. This alternative also represents a search for wholeness and involves a woman's decision to remain single-breasted without wearing a prosthesis. This last alternative is not endorsed by society as an option or presented in the professional literature. Not surprisingly, no woman in this study mentioned the possibility of presenting herself to society as a single-breasted woman.

This option is, however, chosen by some women, as illustrated by Audre Lorde (1980) in her book, *Cancer Journals*. She presents a feminist perspective on the meaning of her breast loss and indicates how she feels the issue needs to be resolved in order to promote individual growth.

I would lie if I did not also speak of loss. Any amputation is a physical and psychic reality that must be integrated into a new sense of self. The absence of my breast is a recurrent sadness, but certainly not one that dominates my life. I miss it, sometimes piercingly. When other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham. But I believe that socially sanctioned prosthesis [*sic*] is merely another way of keeping women with breast cancer silent and separate from each other (p. 16).
Lorde acknowledges the pain invoked by loss of wholeness. However, she sees the solution to restoring wholeness as inside one's self rather than through the cosmetic solutions of a prosthesis or breast reconstruction.

The emphasis upon physical pretense at this crucial point in a woman's reclaiming of her self and her body-image ... encourages women to dwell in the past rather than a future. This prevents a woman from assessing herself in the present, and from coming to terms with the changed planes of her own body. Since these then remain alien to her, buried under prosthetic devices, she must mourn the loss of her breast in secret, as if it were the result of some crime of which she were guilty ... It encourages a woman to focus her energies upon the mastectomy as a cosmetic occurrence, to the exclusion of other factors in a constellation that could include her own death (p. 57).

Lorde rejected the stereotypic pressure of society to return immediately to her previous outwardly sexually attractive appearance by covering up her supposed defect. She worked through this crisis in terms of her own life experience in order that she could come to a full acceptance and appreciation of her one-breasted state. She urges other women to do the same.

Another example of this choice, Paula Armel (1981) expressed the following reality during her decision about wearing a prosthesis following her mastectomy.
I wonder why I haven't seen more women going public. If one in 14 women has breast cancer, and 90 percent have mastectomies, there are a lot of single-breasted women, yet we don't dare admit it. I decide then, to myself, that I want to try not wearing a prosthesis (p. 22).

Armel supports Lorde's conviction that acceptance of one's altered body, is the critical healing force in coming to terms with a mastectomy.

In view of society's entrenched bias about what is appropriate post-mastectomy behavior for the cancer patient, it is highly likely that women who refuse to use a prosthesis will be denied support from health professionals and that this alternative will not even be discussed as an option.

Lorde (1980) makes the point that at one time pregnancy in women was concealed because it was not socially acceptable for women to expose their private and embarrassing condition to the public. Snyder (1984), Spletter (1982), and Zalon (1978) all cite experiences of criticism from friends and health professionals during their quest for reconstruction. However, a change in prevailing attitudes has been noticeable in breast reconstruction literature, as evidenced by the shift from traditional views to a more holistic focus. Given the non-static nature of societal beliefs, the current stigma towards the option of declining to wear a prosthesis will hopefully lessen in the
Regaining Wholeness and Recovery

Every woman in this study who felt a lack of wholeness preceding breast reconstruction felt that her sense of wholeness had been completely restored through reconstruction surgery. This regaining of wholeness was a powerful theme in these women's accounts. Both the lay and professional literature claim that even women who get only fair reconstruction results are happy because it is a vast improvement over having a flat chest. This claim is consistent with the assertions of women in this study who underwent breast reconstruction surgeries. The following excerpt from Harvey (1980) who cites Wade clearly illustrates the striking difference that breast reconstruction makes in the lives of women who make the transition from non-wholeness to wholeness.

I felt as if a shade had been raised, the darkness of fear and anxiety left me almost entirely ... I have almost forgotten what happened to me ... I feel normal, and I feel pretty, and it shows not only on my chest but in my face and in my heart (p. 100).

All of the women who underwent breast reconstruction named two major benefits of this surgery; firstly, restoration of their wholeness and the dramatic change in their self-concept and secondly, their ability to put the fear and sadness of the cancer experience behind them. They were able to accomplish this largely because the grim physical reminder of the breast loss was
gone. This allowed these women the freedom to start living again, most with new priorities in life as a result of their cancer experiences.

Snyder (1984) describes the anger frequently invoked by the cancer experience:

One of the most insidious side effects of cancer is the impotent anger felt by the individual. Taking as positive a step as reconstructive surgery helps enormously to alleviate that rage. It cannot negate the experience, but it can certainly create a sense of having more control in an otherwise victimizing situation (p. 52).

One can envision the tremendous sense of release that breast reconstruction gave this woman, enabling her to put the cancer-mastectomy experience in a meaningful perspective for her. The women in the study were all able to identify with the feeling that breast reconstruction was something that they had chosen to do that symbolized for them, perhaps, the victory of not only regaining their sense of wholeness but also creating a more defined sense of self in the process.

By the same token, it is just as important for a woman to refuse the option of reconstruction if it is not a relevant choice for her. Every post-mastectomy woman knows what the best alternative is for her, once she considers the options available in relation to her own needs.

The following definition of health is broad enough to
encompass and validate a woman's reasons for choosing a prosthesis, breast reconstruction, or to be single-breasted as an adaptive response to the loss of wholeness after mastectomy. Sandelowski (1981) cites Ullman who defines health as "striving for a 'peace' that allows us to 'sit and listen to what is inside of [us] without influence'" (p. 93). All participants demonstrated in the accounts that they had listened to their inner feelings and made their own decision about breast reconstruction in relation to what felt comfortable for them. In addition, personal growth as a result of experience with the life and death issue of cancer was realized by most participants, regardless of the choice they made. Perhaps this is part of the self-actualization process that Lorde so eloquently describes in The Cancer Journals.

The Doctor-Patient Relationship

Establishing Rapport

The powerful impact of the doctor-patient relationship is a striking theme in the accounts of the women who underwent breast reconstruction. The findings indicate that there is a tendency for a woman who undergoes reconstruction to perceive her surgeon as a god-like person endowed with special qualities, if not magical powers. Schain (1980) offers the following explanation to explain this phenomenon.

There still exists strong support . . . for the conviction that the physician remains singularly the authority in
medical management ... The fear of death and the desire to live, along with the belief that the physician has special power withheld from ordinary people, cause the average person to believe that the physician has more going for him than expertise alone, and often perceives [sic] him as larger than life (p. 1036).

It is possible that mastectomy patients are vulnerable to this phenomenon because of the trauma of their surgery and the fear of impending death, and therefore respond by perceiving their physicians as a person with special powers. The following statement by a breast reconstruction patient clearly illustrates her strong belief in the power of her surgeon.

If I needed to have my head severed, and he was going to do it, I would go into the surgery with all of the confidence in the world. That is how much faith I have in him ... He demonstrated his support by always having time to explain anything that I wanted to know ... (Bostwick & Berger, 1984, p. 197).

Each woman in the study felt that her plastic surgeon was empathetic, understanding, and supportive regardless of whether or not she underwent reconstruction. The women who refused breast reconstruction after only one consultation, however, did not express any thoughts that the doctor’s capacities transcended ordinary human abilities, but stressed that he was supportive, informative, and appeared competent. The woman who refused
reconstruction after seeing the plastic surgeon for three consultations was more outspoken than the above women in her praise of the plastic surgeon's empathy and caring. This woman stated that if she ever changed her mind about having the surgery she had a lot of trust in this surgeon and would want him to do it.

It seems clear from these findings that the amount of rapport developed between patient and doctor was at least partially a function of the length of time they spent together. There also appears to be a link between the complexity of the surgical procedures and the amount of respect each woman felt for her plastic surgeon. For example, the woman who underwent 12 operations to have her breasts reconstructed was more enthusiastic in describing her plastic surgeon as a superior being than was a participant who had had a one-stage breast reconstruction. Time was not the only factor, however; it appears that other influences were present and these, too, warrant explanation. These factors involve the participants' need to see the plastic surgeon as magical and powerful and will be explored later.

Examination of the therapeutic relationship helps to further elucidate the doctor-patient relationship. Bostwick (1983) and Goin and Goin (1981) stress the importance of a therapeutic relationship with clients who consider breast reconstruction.

Carl Rogers (1951) developed the theoretical concepts of
Client-Centered Therapy and lists principles of the ideal therapeutic relationship:

The therapist sees the patient as a co-worker on a common problem.
The therapist treats the patient as an equal.
The therapist is well able to understand the patient's feelings.
The therapist always follows the patient's line of thought (p. 53).

The above principles emphasize the effectiveness of respect and empathy in establishing a foundation for good rapport between health professionals and their clients, a claim that is well-documented in the general health-care literature as well (Butler, 1976; Maguire, Tait & Brooke, 1980; Silberfarb, 1977-78). Rogers claims that genuineness and unconditional warmth, which are communicated on a non-verbal level, are the essence of an effective relationship between therapist and client. The findings in this study reveal that the women perceived their plastic surgeons as having the therapeutic qualities that characterize Roger's Client Centered Therapy. Berger and Bostwick (1984) cite a woman who talks about these personal qualities. Like one of the study women, this woman had previously had contact with a plastic surgeon with whom she could not relate.

When I met him, I liked him immediately. He has a gentle,
patient, loving personality... I chose him because he was recommended, he had ability, and he had a good bedside manner that revealed real love and concern... Most doctors are brilliant. Unfortunately, most brilliant people do not have a human side of love and compassion for people because these qualities don't seem to come in the same combination. So when you do find compassion and talent in a surgeon, you really want to latch on to him and enjoy your association because he is a rare find (p. 203).

The admiration that post-mastectomy women felt toward their doctors is interesting. After all, as Sandelowski (1981) asserts, society perceives men as "being less sensitive, less expressive, less nurturant, and less emotional than women" (p. 84). Corea (1977) explains why male doctors might experience difficulty building a rapport with their women patients.

By their behavior, women sometimes appear to confirm the sexist views of male physicians. They come from a social caste foreign to men. There are cultural differences. Women have been conditioned to freely acknowledge their emotional difficulties and express their feelings. To men trained in the stoicism of the masculine stereotype, this may appear to be hysterical behavior (p. 78).

Given this inherent difference in the social conditioning of men and women, it makes sense that Stevens et al. (1984) discovered that all of their patients stated how glad they were
to have a female plastic surgeon.

They unanimously described a certain empathy that they felt from the female plastic surgeon that they felt would be difficult to obtain from a male physician . . . When the male surgeons seemed to focus equally on cosmetic and surgical concerns, the patients experienced them as more helpful and caring (p. 624).

Further, the very nature of a woman's feelings about her breasts is likely to invoke associations such as sexual activity or breastfeeding. Therefore, a male physician is likely to automatically trigger self-protection in any patient when he becomes the authority and takes charge of her breast. It is interesting that this phenomenon did not take place for most of the women in the study. This is likely due to the woman's belief that the plastic surgeon perceived her as an individual with special needs and planned his surgical interventions accordingly.

The women also viewed their plastic surgeon as competent, which is a quality commonly identified as a male trait (Sandelowski, 1981). A need for trust in her plastic surgeon's competency was an important element in the bonding process between each woman and her surgeon, especially if she decided to undergo reconstruction.

One explanation that offers insight into understanding the powerful level of rapport between these women and their plastic surgeons comes from viewing the surgeon's behaviors from a
feminist perspective. Demetrakapoulos (1983) makes reference to the following feminine qualities: "receptive, empathetic . . . preservative," which appear to correlate with the supportive, nurturing behaviors shown by the plastic surgeons to their women patients (p. 21). Women would more likely be able to identify with this behavior since it embodies the way they have been conditioned to relate to others.

It appears that there was a harmonious blending of both feminine and masculine traits in the plastic surgeons which likely created the rapport between themselves and their patients. Sandelowski (1981) cites Bem as saying that individuals who show a combination of male and female traits are "androgynous" and "may be more adaptable in a variety of contexts than either 'masculine or feminine' males and females" (p. 91). Given this, it is important to recognize that a post-mastectomy woman is more likely to form a rapport with a plastic surgeon who possesses both masculine and feminine traits than a surgeon who demonstrates either masculine or feminine characteristics only.

Creating a Demi-God

Women who undergo breast reconstruction invest power in the plastic surgeon. It appears that some degree of rapport between the woman and her plastic surgeon was necessary in order for the woman to endow him with god-like powers. The greater the perceived rapport between the woman and her doctor, the greater likelihood that she would put him on a pedestal when describing
their interaction. Such behavior has been noted in other women undergoing breast reconstruction. Berger and Bostwick (1984) and Snyder (1984) cite the following women as examples of this.

After every operation I think that I will never go through this again ... But then after a little while I reconsider ... If my plastic surgeon came in today and said that he wanted to operate again next week to make them more symmetrical, I'd say okay (Berger & Bostwick, 1984, p. 177).

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My first implant was too high, round and firm in the beginning. At first I was afraid to go back to the surgeon ... Last time he said, "This is not a good enough result. So we're doing it over" ... I was glad that he recognized the problem. I thought I would just have to live with it that way (Snyder, 1984, p. 134).

Both women appear to have automatically accepted their plastic surgeon's definition of a good result from breast reconstruction. The second excerpt shows the patient taking no responsibility for communicating her concerns to the surgeon. She had learned to expect him to take full responsibility and to be all-knowing when it came to fulfilling her needs.

Johnson (1978) contends that physicians are accorded high status in our society. Patients, however, usually define themselves as having low status and this results in them feeling and acting powerless in the doctor-patient relationship. The
above researcher discusses how status relates to power.

Two things happen when a person has high status. First, the high status itself can form a base of power with which the person can influence. This is a form of legitimate power. Second, high status can give people greater leeway in how they influence others . . . Sometimes high status and high power are synonymous, since high-status people often possess the other determinants for power use: resources, expertise, and confidence (p. 304).

The power of the physician also emanated from his perceived prowess as a surgeon. The women had almost unlimited confidence in the ability of their plastic surgeon to operate on them. This supreme trust appears to have been established during the consultation period, well in advance of the first breast reconstruction. Once in place it never wavered, despite complications which affected a few of the women in this study. They appeared willing to undergo any amount of risk and repeated surgery to correct the complication. Thus, both the findings of this study and the literature reveal numerous examples of the powerlessness of post-mastectomy women versus the powerfulness of their surgeon.

One can speculate as to whether this fascinating process can be totally explained by the power differential between surgeon and patient, or whether additional factors are operating. Why would women willingly and eagerly submit their bodies to be
altered surgically, knowing all the inherent risks? A pertinent factor appeared to be the women's ability to minimize these surgical risks. From what is known about the importance of wholeness, it is likely that the need for restoration was so compelling that it influenced their attitude, making the option of surgery more attractive. Cognitively supporting the preferred decision, while rationalizing the rejected option as even less attractive is referred to as 'bolstering' by Janis and Mann (1977). These women, then, effectively utilized the bolstering process. This fact was evident in their negative perception of going through life with one breast as compared to the anticipated joy of having their breast restored.

The concept of cognitive dissonance further explains the women's attitudes toward the perceived trauma of surgery for the purpose of breast reconstruction. Sandelowski (1981) quotes Festinger:

Whenever we are confronted with choices, we are likely to experience dissonance or a discordance between what we believe and know to be true about the choices, and alternative explanations of the truth about the choices . . . In some way, the person has to either change his/her beliefs to accord with his/her actions, or rationalize or justify the existing belief to reduce the disharmony created by being exposed to a contrary belief. Disharmony or discordance is uncomfortable and therefore motivates a
person to do something about it in order to create cognitive consonance (p. 10).

Another finding that could be the direct result of women experiencing cognitive dissonance and reacting to it by bolstering is their tendency to elevate the surgeon to the status of a demi-god. This makes sense when one considers that a woman is not likely to feel secure letting anyone alter her body who is not perceived as extremely competent. Fears about the inherent risks of breast reconstructive surgery are thus minimized if the women perceived their surgeons as having magical, super-human powers. The ability to minimize inherent risks was seen most clearly in those women who underwent multiple surgeries.

Although women's accounts in both this study and the literature appear to support the power differential between surgeon and patient, the women themselves did not seem to perceive it. The majority of women who underwent multiple reconstruction procedures tended to perceive the relationship between themselves and their plastic surgeon as a team effort, in which they both worked together to achieve the desired goal of restoring breast contour. At times, the relationship appeared to be more of a mutual needs sharing experience, rather than a strictly collaborative effort aimed at meeting the woman's needs. One can surmise that the woman's needs might include the need for intense interest and involvement on the part of the plastic surgeon, while the plastic surgeon might need to create
as perfect a breast as possible. These complementary needs could therefore be fulfilled.

This discrepancy between the woman's image of the powerful doctor versus her perception of their teamwork relationship can perhaps be explained by the following factors. Although each woman had no control over the end result of the reconstruction, she could decide on the amount of surgery she would eventually undergo. In addition, there is a strong likelihood that the empathic relationship between the woman and her surgeon would reduce feelings of powerlessness on her part and at the same time enhance the teamwork quality of their relationship.

To reiterate, the women's compelling need for wholeness and their ability to envision regaining it through breast reconstruction is a powerful factor in their desire to undergo this surgery. Every woman in the study emphasized the positive aspects of reconstruction over the negative multiple losses invoked by the mastectomy. They appeared eager and excited about each step of the reconstructive procedure. Sandelowski (1981) states that "motivation is also a reflection of self-esteem and belief in the ability to control one's destiny" (p. 9). This belief characterizes those women who believed in the value of breast reconstruction for themselves.

The Decision-Making Process

Professional literature related to decision-making was explored to gain insight into the findings on decision-making.
As stated in Chapter Two, the available professional literature revealed a paucity of information related specifically to decision-making about breast reconstruction. The majority of health-care research on women's decision-making focuses on the decision to deliver or abort in the event of an unwanted pregnancy. Given the moral implications of abortion, this experience was thought to be too dissimilar to the breast reconstruction decision to be useful.

As an alternative, feminist literature that explored possible ways that women perceive and conceptualize events in the world around them was drawn on. Insight into these cognitive processes enhanced understanding of women's decision-making process. This literature was particularly helpful in interpreting the findings of this study, given the fact that most of these women did not appear to follow a systematic process.

This finding stands in direct contrast to the traditional view held by psychological decision theorists, who maintain that an individual can only make a good decision if a specific rational procedure is adhered to. To reiterate from Chapter Two, Janis and Mann (1977) proposed a model of "vigilant decision-making" that included seven steps and contend that these steps are a critical part of any decision-making process.

The findings reveal that participants completed some of these steps to varying degrees but omitted others. The majority of women appeared to miss out entire steps of the above logical
deliberation process and then arrive at an almost instantaneous conclusion. They could not articulate the decision process, only that they always knew they desired breast reconstruction from the beginning.

The women in the study who decided to undergo reconstruction appeared to have made up their minds before they consulted with a plastic surgeon, whereas the women who refused this surgery did not make up their minds until after talking with the plastic surgeon. It would be interesting to know if women who do not seek out a plastic surgeon make up their minds to reject breast reconstruction in the same convincing and spontaneous manner as some of the women who chose this surgery.

One wonders if it is possible for women to go through the steps of the traditional decision-making process at a subconscious level. Perhaps, too, the retrospective nature of this study may have made it difficult for the women to recall the steps in their decision-making. Another factor to consider is that individuals not accustomed to describing their decision terminology would have difficulty articulating their experience in these terms.

The data suggest, however, that many of these women did not use any systematic decision-making process. This vigilant process is above all rational, and one speculates how often people actually have the time or motivation to think through the decision process so clearly. The assertion by decision theorists
that a decision is good or bad based on such arbitrary criteria appears too simplistic to have complete validity for decisions with the emotional impact of breast reconstruction surgery. The fact that every woman was satisfied with her decision and specified that she would make the same decision if she were given the opportunity again, suggests that the vigilant decision-making process was not required to arrive at a satisfactory outcome.

Perhaps, what might appear to be a rational decision to one person may not appear so to another individual. Given this emphasis on rationality, do risks exist in the form of unexpected setbacks or post-decisional regret for these women who do not use a vigilant model of decision-making? There may be existing decision processes that explain the nature of these findings more effectively than those patterned after such a rigid, traditional model. The feminist literature gives direction for examining the concept of intuition in women's thinking by suggesting that women draw on intuition when arriving at a decision.

Rational Versus Intuitive Decision-Making

In Ebony (1979), Poussaint states "all people have the potential for intuition, but women have probably used it more" (p. 104). She reasons that intuition is fostered culturally in women because they are socialized to rely on their emotions and experiences while men are encouraged to be more analytical.

Authors such as Fee (1983) maintain that society's values promote the belief that intuitive thinking is synonymous with
being female. The following excerpt illustrates the marked contrast between the perceived rationality of men and the perceived irrational and intuitive nature of women.

Man is seen as the maker of history, but woman provides his connection with nature; she is the mediating force between man and nature, a reminder of his childhood, a reminder of the body, and a reminder of sexuality, passion, and human connectedness. She is the repository of emotional life and of all the nonrational elements of human experience (p. 12). Sherif (1979) claims that this stereotypic notion that women and men think differently is based solely on the perceived biological superiority of man. She sees the male as "receiving high ratings on a variety of characteristics denoting competence, emotional maturity, and resourcefulness, and the female receiving high ratings on traits suggesting warmth, nurturance, and expressiveness" (p. 157).

The following conclusions are made in the article entitled "Female Intuition" in Ebony (1979):

Intuitive thinkers, then, are the opposite of systematic, or scientific minds. Whereas scientific conclusions use linear, organized thought based on universal modes of rational reasoning, intuitive conclusions result from some stored pool of cues. Such people solve problems by trial and error, and their wisdom springs from the amalgam of their life's experience (p. 102).
It appears that the traditional rational model of "vigilant
decision-making" was designed by and for male decision-makers.
Perhaps women who made instant decisions about wanting breast
reconstruction were relying on more of an intuitive model to
arrive at the best decision for themselves. For these women,
their decision represents an emotionally-charged commitment to
having their wholeness restored.

Both the literature regarding intuition and the findings of
this study support the fact that cues from the environment were a
critical factor in the decision-making process for some women.
Women who made intuitive decisions were more sensitive on an
unconscious level to environmental cues regarding breast
reconstruction. It appears as if these women were continually
processing information but were not aware of it. When the women
talked about the meaning of these cues, their words were
emotionally laden.

These environmental cues acted more as a catalyst for those
women who chose breast reconstruction on an intuitive level than
for those women who chose reconstruction by utilizing a rational
model of consciously weighing the pros and cons of their
decision. According to the findings, those women who chose
breast reconstruction were more likely, as a group, to favour an
intuitive over a rational model of decision-making when compared
to those who refused reconstruction. Intuitive decision-making,
then, is characterized by a heightened sensitivity to
environmental cues, emotionally-based feelings in connection with the decision, and a snap or instant decision which does not allow for an analytical weighing of consequences.

The following statement by a woman interviewed by Berger and Bostwick (1984) illustrates how she may have been influenced by intuition in her decision to pursue breast reconstruction. She was originally attracted to the idea of reconstruction following exposure to several cues associated with this surgery. She was fearful of others interpreting her desire for reconstruction as solely based on vanity. Therefore, she felt compelled to give other reasons regarding her need for reconstruction. Afterwards, this woman acknowledged that the wish to appear normal and feel good about her appearance again were the real reasons underlying her decision.

Then, I started to pick up an article here and an article there on breast reconstruction and every time I turned on the T.V. there was Phil Donahue or someone else talking about it, and I would say . . . Maybe people will think I'm vain, or they will think: 'Why did she do that? She was perfectly fine the way she was' . . . Certainly, I told myself, reconstruction is something you want, just because of the prosthesis and to make your back feel better . . . Later, . . . I realized that to be totally honest, I wanted to look good again (p. 166).

Another woman made a quick decision to undergo breast
reconstruction after receiving information in the Reach to Recovery program and meeting women who were enthusiastic about having had reconstruction themselves. "Why not me? Why shouldn't I do this? I want to be 'whole' again" (Berger & Bostwick, 1984, p. 196). Both of these women's experiences echo the decision-making experiences of the women in this study.

It is important to bear in mind that a woman making a decision about breast reconstruction is not limited to using only an intuitive process or only a rational decision-making process. In Luker's (1975) study of abortion and the women's decision not to use birth control, she contends that the decision process can have both rational and intuitive elements. She claims that the women used a rational model in that their decision-making was designed to effect their personal goals. Luker maintains that even if a participant's decision is not considered rational from a health professional's perspective, its validity is recognized for that individual. She goes on to state that the choices in the decision process "are not always explicit or clearly articulated: in perhaps the majority of life situations, this calculation of the 'risks of life' is a subtle, intuitive, continuing process" (p. 78). According to the findings, several women appeared to utilize both an intuitive and rational type of reasoning when making their decision.

One should not assume that even if a woman appears to act more intuitively in a decision such as breast reconstruction,
which may have emotional overtones, that she would not make other
daily decisions using a more systematic style. It is impossible
to know, as previously mentioned, if individuals own a
characteristic decision style or if their decision styles change
in relation to situational factors. We do not know what kind of
decisions use which model and to what degree an individual uses
the rational and/or intuitive model. Factors that influence
adherence to specific models have not been studied.

McMillan (1982) claims that, contrary to society's
stereotypic perspective, a case cannot be made supporting the
superiority of rational thought over intuitive thought.
The view that a particular accomplishment or skill depends
upon intuition does not suggest that such knowledge excludes
thought and sustained effort. To define a judgement as one
based on intuition draws attention to the way in which the
facts of a particular situation strike the agent and states
that this way of seeing things originates, in a sense,
solely with him. Consequently, his ideas and judgements are
not reducible to a straightforward description of the
situation about which he is thinking . . . The distinction,
then, between scientific or 'rational' knowledge and
intuitive knowledge is a question not so much of different
reasoning processes or theories of knowledge as of the
peculiarly different roles which the notions of learning and
teaching assume in the two contexts (p. 41).
It is interesting that the importance of intuition, as reflected in the findings, confirms to some degree that the way in which society has conditioned women to think has been validated. This excerpt by McMillan stresses the value and need for both types of reasoning in our society.

Although there were similarities in the decision style among women in the study, it is critical to note that every woman's style was unique. Berger and Bostwick (1984) found this to be true among the 8 women they interviewed about undergoing breast reconstruction. All of these women revealed a different style of decision-making.

**Weighing the Consequences**

The mechanics of weighing consequences in decision-making are described in professional literature. This literature specifically utilizes a rational model of decision-making. This model was explored in the literature review under Psychological Decision Theory and "assumes that individuals perceive options, assign values to these various options, choose one option as preferable to another, and then act to implement that choice in behavioral terms" (Luker, 1975, p. 78). The above theory appears to have more practical relevance for the findings of this study than the cumbersome model of vigilant decision-making. However, both these models of decision-making share the view that a thorough analysis of alternatives is deemed necessary in order to effect the best decision. This process was more easily observed
in those women who were able to articulate a method of weighing consequences. It is helpful to speculate that other women in this study likely weighed available consequences as well, but did so unconsciously, in an intuitive manner.

Although the following theory is aimed at teaching effective decision-making to nurses in clinical situations, it can be applied to decision-making in breast reconstruction. Ford, Trygstad-Durland, and Nelms (1979) state that there are three major criteria for analyzing alternative solutions. "These are desirability, probability, and personal risk taking" (p. 85). These authors explain that desirability, which has its origins in utility theory, is the criterion that measures the individual's preference for an alternative. Subjective probability is the rating that the individual places on the likelihood that the alternative will be successful. Risk represents an individual's analysis of the alternatives in terms of hazards versus benefits of a particular problem situation (p. 92).

The authors contend that these criteria are then ranked numerically in terms of available alternatives in order to assign a priority in relation to their comparison with each other. Generally, the alternative representing the highest level of desirability with the greatest probability and lowest amount of risk is selected as the best decision.

In the findings, all the women were able to refer in some
way to these three important elements of decision-making. In keeping with their unique decision-making style, all participants perceived these elements differently. For those women who desired reconstruction, the desirability of breast reconstruction was always judged to be the most important alternative while the risks were minimized. Conversely, the women who refused breast reconstruction consistently ranked risk as the most important criterion in their decision-making, thereby making desirability the lowest ranking element. The women who underwent reconstruction ranked probability of successful outcome as high priority because they felt that the surgery would successfully achieve their desired goal. On the other hand, those women who rejected the idea of surgery felt strongly that breast reconstruction would not be helpful or successful for them. The applicability of Ford et al.'s (1979) theoretical concepts regarding the assessment of alternatives are clearly relevant to the findings of this study. These concepts assist in interpreting the women's decision-making behavior in a meaningful way.

Summary

This chapter discussed the findings of this study in relation to the current literature. The major finding involved the women's general lack of adherence to the traditional model of vigilant decision-making. The role of intuitive thinking was found to be relevant to the women's decision-making regarding
breast reconstruction. The variability of each woman's
decision-making process was emphasized. Additional key findings
involved the importance of wholeness in the women's decision to
consider breast reconstruction and the significance of the
doctor-patient relationship to those women who underwent
reconstruction. The present study offered additional insight
into understanding the complexity of the decision-making process
in women who consider breast reconstruction. Chapter Six
presents conclusions from the findings and discusses the related
implications for nursing practice, education, and research.
CHAPTER SIX

Summary, Conclusions, and Implications for Nursing

Summary of the Study

This study was implemented to describe and explore women's decision-making process in choosing or refusing breast reconstruction. Current scientific evidence clearly reveals that breast reconstruction is a reasonably safe and effective alternative to an external prosthesis for post-mastectomy women. Because of recent advances in surgical techniques, this surgery is increasingly available as a treatment option.

However, existing knowledge regarding pertinent factors that influence a woman's breast reconstruction decision-making is extremely limited. The literature reflects minimal nursing research on the subject of breast reconstruction. The majority of nursing research continues to focus on mastectomy and on the technical aspects of reconstructive surgery, neglecting to deal with the associated psychological concerns of breast reconstruction. This insufficient theory base likely results in nursing care that stops short of meeting the needs of this patient population.

The phenomenological approach was selected to guide this study because of its focus on examining participants' experience from their unique perspective. This methodology relies on participant accounts which reflect the meaningful interaction of informants and researcher. The richness of the data is enhanced
by the simultaneous data collection and analysis processes. This methodological approach enabled the researcher to explore how women decide whether or not to have breast reconstruction. In addition, the phenomenological perspective was consistent with nursing's focus on the value of the individual and his or her need for quality care.

The literature on body image, mastectomy, and breast reconstruction was reviewed for the purpose of enabling the researcher to identify pertinent issues that might have relevance for post-mastectomy women. Specific factors alleged to influence the breast reconstruction decision were examined. The literature review substantiated the need for additional sound research in the topic area. Literature related to decision-making was explored to ascertain if it would be helpful in interpreting and understanding women's decisions about breast reconstruction.

The data were collected through a series of semi-structured interviews with 16 women over a four-month period. All interviews were audiotaped and then subsequently transcribed verbatim. The concurrent data collection and analysis ensured validation of emerging themes from the participant accounts. These themes were examined for similarities and differences and then clustered to form major concepts. These concepts were instrumental in condensing the data and clarifying its overall meaning in terms of the breast reconstruction decision-making process.
Participants began their accounts by telling their cancer-mastectomy stories and how they made sense out of this experience in terms of their own lives. The women described their experiences in light of the factors that influenced their decision to choose or refuse breast reconstruction. The most pervasive overall theme was wholeness which was manifested in the subthemes of loss of wholeness, search for wholeness, and regaining of wholeness. In this study, most women who chose breast reconstruction felt less whole than those women who refused reconstruction. This lack of wholeness was evidenced in decreased self-esteem and a perceived lack of normalcy. All women who underwent breast reconstruction expressed negative feelings about their prostheses in terms of discomfort, its lack of convenience, and its inability to restore feelings of wholeness to them.

This loss of wholeness acted as a catalyst that began the search for wholeness. Acquiring information was a critical component of this search. Some participants were informed of breast reconstruction by health professionals. Others actively sought and obtained this information from a variety of sources.

The regaining of wholeness was an exceptionally powerful event for the women who underwent breast reconstruction. They were amazed at how quickly their sense of normalcy and self-concept were restored. One of the major benefits was the new-found ability to put the cancer experience behind them now
that they were not constantly reminded of their breast loss.

Although all participants described similar feelings about wholeness versus non-wholeness, their interpretation of information reflected their personal beliefs about the value of breast reconstruction. Therefore, a key theme that emerged was the unique decision-making style that characterized each woman's account. One of the most striking components was the variation in the length of time it took each woman to make her decision. Weighing of consequences was an important part of the decision-making process and involved focusing on the benefits versus the risks of reconstruction.

For those women who chose reconstruction, another major theme was the powerful nature of the doctor-patient relationship. The plastic surgeon was frequently endowed with magical, god-like powers and this, in turn, inspired the women's confidence to such an extent that it appeared to diminish fear of risks involved in reconstructive surgery. The women who refused reconstruction did not endow the physician with such power and were unable to minimize these risks. In fact, they felt that the risks associated with surgery outweighed any benefits offered by breast reconstruction.

Finally, despite the type of choice made, every participant defended her decision as the right one for her.

In addition to examining the findings of this study in terms of the current literature on body image, breast reconstruction,
and decision-making, women's literature dealing with mastectomy, breast reconstruction, and decision-making was explored to enrich the researcher's understanding of these issues from a feminist perspective. This proved to be a relevant perspective because the mainstream scientific literature on decision-making, focusing as it does on a male model of logical, rational decision-making, proved to be inapplicable to the process of the women's decision-making in breast reconstruction. Clearly, it is important to understand the divergent perspectives represented by these two sources in terms of women's needs in breast reconstruction decision-making.

Conclusions

The findings can be summarized by the following statements:

1. Each woman in this study demonstrated a unique decision-making style when making a decision about breast reconstruction.

2. Intuitive thinking was a prominent characteristic of the breast reconstruction decision-making experience for the women.

3. Information about breast reconstruction acted as a catalyst for initiating the process of breast reconstruction decision-making.

4. A feeling of non-wholeness was the most powerful and influential factor for the women choosing to undergo breast reconstruction.
5. Among the women who chose breast reconstruction, the prosthesis was strongly criticized in terms of its inability to restore wholeness.

6. The women who refused breast reconstruction felt more whole after mastectomy than did those who chose to undergo reconstruction.

7. The women who underwent reconstruction minimized the surgical risks of breast reconstruction and frequently endowed the plastic surgeon with magical, god-like powers.

8. The women who refused breast reconstruction perceived the risks of any surgery as a decisive factor in their rejection of this option.

9. The women who underwent breast reconstruction experienced the need to defend their decision.

**Implications for Nursing Practice**

The findings of this study suggest a number of specific implications for nurses who provide care to post-mastectomy patients. These implications are pertinent throughout all phases of the nursing process and reflect the needs of clients making a choice about reconstruction.

As nurses, it is critical to be aware that every post-mastectomy woman may be involved in the breast reconstruction decision-making process at any point following her surgery.

This study directs nurses to understand the inherent
differences between a logical versus an intuitive style of
decision-making in order to be more sensitive to a patient's
needs. Given that each woman has a unique decision-making style, it is important to thoroughly assess this decision process in relation to past health-related issues.

The nurse can be invaluable in facilitating a woman's decision-making process and in being supportive and helpful as the patient clarifies what she needs from health professionals. In addition, the decision-style manifested in the woman's approach to the breast reconstruction decision needs to be examined. This assessment would address such questions as: Does a woman tend to use a logical, systematic decision style? Does she favour more of an intuitive approach? Or does she integrate elements from both?

Another implication involves the critical role that information plays in initiating a woman's consideration of breast reconstruction. Because of their interaction with numerous health professionals in hospital and clinic settings, nurses can function in an effective liaison capacity to dispense and clarify information about breast reconstruction. The findings of this study direct nurses to give post-mastectomy women specific information relating to the surgical procedures available for breast reconstruction, the timing of reconstructive surgery following mastectomy, possible complications versus likely benefits, and characteristics of the post-operative experience.
It is imperative that women be informed about breast reconstruction during the follow-up period after their mastectomy, regardless of whether or not they require adjuvant treatment. A woman who has been fully informed is likely to feel more in control of her life. This is important, given the feelings of loss of control experienced by cancer patients.

Nurses need to be attuned to the fact that information about reconstruction acts as a catalyst for some women, compelling them to pursue breast reconstruction immediately. As well, they need to know that some women will not respond initially but will later express interest, and other women will never consider this treatment option at all. Once women are made aware of the option of breast reconstruction, it should be stressed that it is their choice alone whether or not to seek out a plastic surgeon.

It is the nurse's responsibility to ask patients what they know about breast reconstruction and explore their prior sources of information. The nurse can then modify her explanation of breast reconstruction to best meet the unique needs of each patient.

Even though many turn down the option of breast reconstruction, it is important for a woman to be given the facts about available alternatives and assured of a nurse's availability for future discussion of breast reconstruction if the patient so desires. Snyder (1984) suggests that nurses would enhance the effectiveness of their information-giving role if
they were to offer follow-up support to those patients who later undergo reconstructive surgery.

The process of telling a woman about the alternative of breast reconstruction serves to convey the message that health professionals would support any decision the woman chooses to make.

Berger and Bostwick (1984) agree, stating that "equipped with this information, women, we hope, will be able to more effectively influence their own destinies and play an active role in their own health care" (p. 2).

Given that a woman's perception of her wholeness is a valuable indicator of how she may adjust to wearing a prosthesis and consequently respond to the idea of breast reconstruction, another implication involves understanding each woman's sense of her wholeness. The concept of wholeness appears to be reflected through the interrelated concepts of body-image, self-concept, and sexuality. Therefore, these three topic areas must be explored in the nurse's assessment of a patient's perception of her wholeness. Such coping strategies as avoiding looking at oneself in the mirror when undressed, continued apprehension regarding sexual intimacy, and a large degree of self-consciousness while wearing a prosthesis should alert nurses to factors which may signify a patient's lack of wholeness.

The ability to carry out a non-threatening assessment of a woman's feelings about the intimate subjects of body-image,
self-concept, and sexuality requires a great deal of sensitivity on the part of the nurse. It is imperative that such an assessment is done with empathy and respect for the client. With patients who do not initiate discussion of their fears and concerns, the nurse may need to take the lead in facilitating such a discussion. Nurses need to have worked through their own feelings about their own body image and sexuality in order to feel comfortable when exploring these topics with their clients.

The tendency of the women who underwent reconstruction to criticize the inadequacy of a prosthesis in terms of its inability to restore wholeness supports the need to understand how each woman's prosthesis experience affects her sense of wholeness. This understanding can be reached by exploring the client's feelings regarding her prosthesis. The importance of a woman's experience with her prosthesis cannot be underestimated in terms of her decision to choose or refuse reconstruction. Women who continue to lack wholeness in spite of the prosthesis require additional support from nurses because of society's predominant belief that an external prosthesis is all that is required for long-term adjustment.

The following implication deals with those women who underwent reconstruction and minimized the surgical risks while attributing god-like powers to their plastic surgeon. Although it is important that these patients be realistically informed of the facts about breast reconstruction, it is imperative for
nurses to both accept and support their need for downplaying risks and elevating the surgeon's powers.

Given the recognized importance of the doctor-patient relationship, it is critical that nurses communicate to patients their right to competent, sensitive medical care. Nurses can give support to breast reconstruction candidates by assisting them in locating plastic surgeons, while emphasizing the importance of establishing rapport with the surgeon, and of seeking several consultations if necessary.

This process could be facilitated, as Winder and Winder (1985) suggest, by helping women to compile relevant questions for the plastic surgeon. By actively taking part in the consultation process, women are less likely to assume the traditional submissive role and a more meaningful, constructive doctor-patient relationship can be established.

Finally, because women who underwent reconstruction were compelled to defend their decision to significant others, the issue of negative attitudes towards breast reconstruction should be explored in a supportive manner with these patients (Pfeiffer & Mulliken, 1984; Winder & Winder, 1985).

The conclusions of this study present guidelines for a specific nursing role which should facilitate better understanding and meeting of the needs of post-mastectomy women who consider breast reconstruction.
Implications for Nursing Education

The importance of educating nurses to understand the needs of post-mastectomy women who consider breast reconstruction is obvious. Nursing education should stress the value of perceiving each woman's experience as unique and meeting her needs. This will help students avoid making assumptions and generalizations that will compromise the quality of their nursing care.

A major need exists for course material to include information on general patient decision-making in relation to health-care issues. Since the findings support that it is an integral part of the breast reconstruction decision, it would be highly relevant for nursing education, for example, to address the topic of intuition and its effect on decision-making.

In addition, the vital role that information plays should be examined. The significance of the nurse's role in dispensing information to breast reconstruction patients should be emphasized.

The importance of post-mastectomy women being able to make an informed choice about breast reconstruction cannot be stressed enough in nursing education and is best summed up by Harvey (1980) who cites Grandstaff as stating that "an informed decision is the best decision, regardless of what your options are" (p. 102).

The conclusions of this study also direct nursing educators to provide theory pertaining to the topic of wholeness and
non-wholeness. Such content should be explored using contemporary literature on women's health issues.

Nursing curricula should focus not only on the technical procedure of breast reconstruction with its inherent risks, but also the psychological factors which influence a woman's decision to choose or refuse reconstruction. A positive attitude toward these women should be encouraged by educators, given that the majority of women who choose breast reconstruction are "realistic in their expectations, highly motivated, psychologically well-adjusted and high functioning, much like their non-reconstructed peers" (Rowland, 1984, p. 9). This would help to dispel the prevalent bias which sees women who request breast reconstruction as maladjusted in some way and to ensure that nurses are attuned to the real needs of this patient population.

According to the literature and the findings of this study, nurses frequently do not take advantage of their unique opportunities to talk to post-mastectomy women. As a result, critical issues such as alteration in body image and self-concept, adjustment, and sexuality are neglected during the provision of nursing care. Such avoidance behavior on the part of nurses is likely to be construed as non-supportive by these women. Certainly, there is a clear mandate for nurse educators to support the use of rigorous psychosocial assessment when working with post-mastectomy patients. Carroll (1981) claims that if such assessments were utilized over a follow-up period of
at least several months, nurses would be alerted to the 20% of women who experience adjustment problems following mastectomy.

Thus, nursing education can play an instrumental role in improving nursing care for post-mastectomy women involved in breast reconstruction decision-making.

Implications for Nursing Research

The findings of this study suggest several areas for additional research.

More information is needed about factors that influence women to choose or refuse breast reconstruction, to expand on the findings of this exploratory study. Future studies should involve greater numbers of participants for the purpose of eliciting a wider range of experiences which will enhance the richness and generalizability of the findings. Carroll-Johnson (1982) addresses the importance of research in this area by stating:

the role of the nurse and other health-professionals in facilitating decision-making for the individual woman will be dependent upon further clarification of the factors related to adjustment to the loss of a breast and the role of breast reconstruction in a mastectomy patient's physical and emotional rehabilitation (p. 73, unpublished).

Secondly, as Carroll-Johnson (1982) claims, additional research is needed to develop more relevant, accurate, and discriminating tools for measuring body image. Since body image
alteration through mastectomy is a key factor in women feeling non-whole, such tools would be useful for evaluating women's perception of their wholeness.

Because this study deals only with women who sought consultation with a plastic surgeon, it would be invaluable to investigate a group of women who decided to refuse the option of breast reconstruction without having consulted with a plastic surgeon. How would this group of participants compare with women who undergo reconstruction in terms of their perception of their own wholeness? According to the literature findings, this group of women would be very important to study in view of the relatively limited number of women who actually undergo reconstruction.

The issue of the prosthesis experience calls for examination of this within the overall context of wholeness. It would be useful to conduct research into the factors that determine whether post-mastectomy women perceive their prosthesis as an asset or a detriment in regaining wholeness. Knowing the process that leads women to accept their prosthesis would assist nurses in facilitating adjustment for those who experience difficulty.

The findings of this study support the need for continued investigation into the dynamics of the decision-making process in women who consider breast reconstruction. Nursing research is needed to help clarify and conceptualize this vital thought process so that decision-making, especially intuitive
decision-making, can be better understood. Although the whole concept of intuition may not be amenable to scientific scrutiny, it would be worthwhile to instigate research in this area in order to validate the intuitive process for both nurses and patients.

In view of the fact that this study and the majority of studies reported in the literature are retrospective in nature, it would be useful to study women who are currently in the process of deciding about reconstruction.

Lastly, there is a need for further study of the importance of information in relation to the decision-making process. The catalytic role that information plays in decision-making requires investigation to establish a clearer understanding of how it influences women differently.

In conclusion, this study has demonstrated the significance of viewing women's experience in making the decision to choose or refuse breast reconstruction, and indicates a need for further research with regard to the pertinent factors that influence a woman's choice about breast reconstruction. It is hoped that further understanding of the issues faced by women considering breast reconstruction will enrich and guide nursing care for this patient population.
Reference List


Female intuition. (1979). Ebony, 34(11), 100-104.


APPENDIX "A"

Information and Consent Form

My name is Anne Claydon. I am a registered nurse presently enrolled in the graduate nursing program at the University of British Columbia. I am interested in learning how nurses can help women who have had mastectomies and are considering breast reconstruction. If you agree to participate in this study, I will arrange for an interview at your convenience in your home.

The questions I will ask will be related to such topics as where you first learned about breast reconstruction, what you saw as the disadvantages and advantages in breast reconstruction and what factors caused you to undertake or refuse breast reconstruction. I would welcome any ideas of how this decision has affected your life.

I would like to interview you twice. Both interviews would be tape recorded, but every effort will be made to avoid the use of identifying names on the tape. You may refuse to answer any question during the interview. The tape will be kept confidential with the exception of myself and my thesis advisors. Excerpts of the interview may be included in written reports of my study but no names will be used. The tapes will be erased when my thesis is completed. The purpose of recording the interviews is to enable me to carefully examine your ideas and concerns and to compare them with the ideas of other participants.
APPENDIX "B"

Sample Questions for Initial Interview

1. What prompted you to seek consultation with a plastic surgeon about breast reconstruction?

2. What factors about breast reconstruction influenced your decision to have reconstruction?

3. What factors about breast reconstruction influenced your decision to refuse reconstruction?