SOCIOECONOMIC CONCERNS, FAMILY
ROLES AND RELATIONSHIPS OF THE
BREAST CANCER PATIENT

by

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Date August 31, 1978
The purpose of this study was to explore the socioeconomic needs and concerns of a group of new breast cancer patients and their families with consideration of changes in roles and relationships and patient's feelings about self. The study was conducted in co-operation with the A. Maxwell Evans Clinic, a cancer treatment centre under the direction of the Cancer Control Agency of British Columbia.

The scope of this study was restricted to new breast cancer patients referred to the New Patients Clinic in May, 1978 and their primary care-givers. In this study, the primary care-givers were family members most responsible for the patient's rehabilitation.

The sample consisted of 16 patients and 14 primary care-givers. Two of the patients' primary care-givers were not available at the time of the interview. The sample included patients with breast cancer in Stages 1, 2, 3 and 4.

One interview schedule was designed for the patient and a shorter form for the primary care-giver. An open-ended question about the patients and primary care-givers' greatest concerns were included to identify needs not covered by scheduled topics and to give respondents an opportunity to expand and prioritize concerns.

Socioeconomic change was defined in terms of changes in place of residence, work activities outside the home, family roles and responsibilities, relationships with family and
friends, and feelings about self.

The findings indicated that the area of greatest change was in family roles and relationships. Most primary care-givers were interested in talking to the interviewer about some anxieties concerning their new role as primary care-giver. Some primary care-givers also were interested in more information about how to create a rehabilitative environment for the patient. All patients were generally positive toward the Clinic. Several patients expressed a number of suggestions for improving support services and offered ideas about the attitudes of significant others which affect the patient's sense of well-being and ability to recover.

The researcher makes some recommendations for enhancing and developing supportive services for the consideration of the medical team and the specialized social services department in a cancer clinic. The recommendations include approaches to help families recognize and develop new roles to help the patient recover.
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A special tribute goes to the late Dr. Joe Lagey who through his own illness with cancer perceived the importance of family members support and discussed this concept with the researcher.
"I think I'm used to her mastectomy already, but maybe I'll wake up in the middle of the night and wonder what has happened to us. Is this the beginning of the end?"

Chapter 1

SOCIOECONOMIC CONCERNS AND THE
BREAST CANCER PATIENT

Introduction

"Breast cancer, the leading cause of death for women between the ages of 39 and 44, is still a mystery for the medical profession", said a Canadian Medical Association spokesman at the 1978 cancer conference in Winnipeg, Manitoba. Breast cancer affects approximately 7 out of every 100 women in Canada according to 1975 unpublished figures received from the B.C. Cancer Registry. However, the cause of breast cancer remains unknown and surgeons differ on treatment methods. Surgery, either by the radical mastectomy, the modified radical or the simple mastectomy, is still considered the best method of treatment. Therefore, designing rehabilitation and support programs to meet the total needs of pre-surgical and post surgical breast cancer patients remains a current issue.

The impact of a breast cancer diagnosis and subsequent mastectomy is now recognized in the literature and by the professional team at the A. Maxwell Evans Clinic as an emotional upheaval in the total life situation of the patient and her family. The psychological impact of mastectomy may have traumatic effects upon a few or all facets in the patient's life.

The following exploratory descriptive study is
designed to look at changes which the patient and her family have perceived in the socioeconomic situation of their life since the diagnosis of breast cancer. This study will involve an investigation of the patients' and families' perception of socioeconomic changes, roles and relationships as well as changes in self. This focus will aim to pinpoint some of the needs of patients and families which arise from socioeconomic change. It is hoped that singling out socioeconomic changes and concerns as the major focus of this investigation will have direct practical value to the A. Maxwell Evans Clinic in assessing present support services and planning and implementing further support services to breast cancer patients and their families.
Chapter II

LITERATURE REVIEW

Introduction

There is a growing interest in the medical literature on the emotional impact of breast cancer and mastectomy upon the patient and her family. Until recently, the medical literature has dealt with early detection, screening programs, and controversies over surgical treatment and rehabilitation therapies. The psychiatric and psychosomatic literature contained studies which describe the personality and psychodynamics of the breast cancer patient, or searched for predisposing stressful life events.

The current emphasis has now been placed on the psychosocial aspects of breast cancer and mastectomy and on defining the services and professional roles required to meet patients' needs. There is still very little written on the impact of breast cancer upon the family and significant others.

The purpose of this chapter is to review the medical literature pertaining to the psychosocial experience of women with breast cancer and their families and to look at current approaches to intervention.
I  Predisposing Stress Factors

There have been some questions raised about the influence of social stress and personality in the etiology of breast cancer. Katherine Hurlburt conducted a descriptive study exploring the relationship between life change events using the SRE scale of stressful recent events and the diagnosis of breast cancer in 84 women recently referred to a cancer clinic. Although no causal relationship was found, Hurlburt proposed "that if physicians generally recognized and understood these life change events in women's lives as being significant in terms of adaptive energy that is required to cope with them, their intervention or referral for counselling might very well have important implications for preventive health for women."¹ Snell and Graham conducted a study with 352 women and 670 controls with other diseases of the genitalia to investigate traumatic incidents, e.g. deaths, separations, divorce, unemployment and illness during the 5 years prior to the breast cancer diagnosis.² This research failed also to find a causal relationship between social stressors and breast cancer.

Diagnosis

A. Delay

Hackett conducted a study with 278 patients coming
to a hospital for diagnosis and found that the more advanced the educational background, the sooner the patient came for diagnosis. Some speculation now concerns whether cancer education programs actually reach the person with little educational background. Fisher explored the relationship between the degree of delay in consulting a physician and their perception of "boundary definiteness." Twenty-eight women with breast cancer and 34 with cervical cancer were studied using inkblot tests and personal interviews. Fisher found that in both samples the women who were most independent and self-actualized were likely to delay longest in seeking medical advice. The problem of persuading people to seek early medical consultation was considered to be more complex than providing educational resources.

B. What To Tell The Patient

The issue of how to tell the patient is of great concern to physicians and surgeons helping breast cancer patients.

Bard and Sutherland wrote "the physician should be prepared to spend considerable time with the patient interpreting the need for surgery.... It cannot be emphasized too strongly that an hour of permissive discussion when the diagnosis is established may be more advantageous in the management of the post mastectomy patient than months of psychotherapy during and after convalescence.... A course must always be started between terrifying obscurantism and
equally terrifying and unabsorbable information."  These authors feel that approaching the patient to accept more information than he wants to hear can lead to great problems in the patient's coping ability.

However, Pinschke found that nursing intervention was most effective in an environment of openness and honest sharing about diagnoses and prognoses with cancer patients. Mammaril felt that a nurse's willingness to listen will promote the patient's confidence prior to surgery.

The diagnosis of cancer is often received with shock. Francis felt that the patient's coping resources and skills prior to diagnosis plus adequate support systems will determine her ability to adjust to the shock of diagnosis often followed by denial, anxiety, regression and/or depression.

III The Hospital Experience

Volicer studied a group of patients who were asked to rank in order of degree of impact, their perceptions of stressful events in the hospital experience. Respondents named admission for a life threatening disease as the second most stressful event, admission for possible loss of an organ as third, and the possibility of disfigurement as the sixth most stressful event that could occur with hospitalization. The implication of these findings is that hospitalization for possible mastectomy can be very stressful on three counts for some patients.
IV **Emotional Reactions to Mastectomy**

Bard and Sutherland studied 20 women between the ages of 28 and 68 who were interviewed before and after surgery, and found the response followed three definite stages relating to the time before, during or after the operation. In the first anticipatory stage, all patients reported feeling "shocked" or "panicky". One patient said: "I feel scared I know it has to be done, but I'm afraid of the ordeal, the operation. My hands are shaking just talking about it. I'm scared but I can't say why."\(^{11}\)

For other women, body attractiveness has been the basis of their feelings of self-worth and attractiveness. Another patient said: "If they have to take my breast off, I would feel as though I were losing part of myself, that I'd be disfigured. I'm not afraid of the operation. I'm more afraid of losing that part of myself. I know this has to be taken care of but I'd rather die than to have them take it off."\(^{12}\)

These women often have painful fantasies of themselves as disfigured persons in the community. Another patient expressed a fear of losing a breast as a threat to her relationship with her husband: "I feel it's disgusting in a sense. It seems like you are sexless. That's why I worry about his (husband's) reaction. I feel it would be one of disgust, that he has to sleep with a sexless woman."\(^{13}\)

During the second "operative phase" the patient may project some of her fear and hostility toward hospital staff.
Her view of discharge may be seen with anxieties about not being ready to face others, particularly her family. During the third "convalescent stage" some patients feel depressed and vulnerable to anticipated embarrassments. Roberts et al report that 51% of their sample of mastectomy patients said they were anxious or depressed. Ervin, Healey, Synderman and Akehurst say the predominant emotional reactions to mastectomy are a sense of loss of femininity and disfigurement. Klein and Goldsmith mention many fears associated with mastectomy: fear of major surgery, fears about having cancer and fears of changes in interpersonal marital and sexual relationships. Fear of death is also present but is usually expressed covertly in terms of loss of breast.

V Denial

Peck studied denial in cancer patients who know their diagnosis. Their responses include displacement of concerns, hope giving special powers to the physician, and anger. Peck sees denial of death as an adaptive response to breast cancer. Polivy mentions a great deal of denial was found in breast cancer patients directly after surgery. After a few months of reality, testing the denial defense was found to be no longer necessary.

VI Age and Feelings of Loss

Klein feels that age is a factor in a patient's interpretation of illnesses. The young patient is forced to
confront her own mortality while the older patient is forced
to accept the consequences of old age. Renneker says that
women at the climacteric and women at child bearing age seem
to suffer losses of femininity the most whereas post-menopausal
women seem to suffer least. However, Schoenberg's study of
loss of external organs found that the greater a woman's
emotional investment in her breasts the more likely she was
to suffer loss and depression, regardless of age.

VII Lymphedema (Fluid retention in arm which may result
from mastectomy operations involving the lymph
nodes)

Lymphedema was studied by Healey who found psychosocial
fears concerning self-consciousness of the enlarged arm, changes
in lifestyle, i.e. dancing, playing games, and difficulty in
finding comfortable clothes.

VIII Phantom Breast Sensations

Weinstein who studied 203 women who had mastectomies
found one-third of them experienced a breast phantom sensation.
He found that the longer the cancer had existed, the longer the
sensations lasted. Patients with left mastectomies seemed to
experience sensations earlier than right mastectomies. John
Jarvis' review of the literature on the breast phantom
phenomenon found age at time of mastectomy, mastectomy in
relation to menopause, lymphedema, and post-mastectomy depression
to be the four statistically significant findings that
distinguish the phantom breast group from other mastectomy
patients.
Ambivalence Toward the Remaining Breast

Leis reports the woman's ambivalent feelings toward her remaining breast. On one hand the breast is a remaining sign of femininity and sexual symbol but on the other hand, the breast may be a source of recurrent cancer and creates a problem by unbalancing body symmetry.

Unanswered Questions

Market notes that the breast cancer patient often has many questions which she does not feel are appropriate to ask her doctors. Questions such as how to wear a bra and what bathing suits are available are often left unanswered and create considerable anxiety for the patient. Klein reports that the common misconceptions which patients never question include the belief that cancer always recurs or kills, that the patient is in some way responsible for her cancer and that she will be perceived by others as diseased.

Depression

Ervin reports his personal experience as a surgeon working with mastectomy patients. Ten years ago he lost 3 breast cancer patients by suicide within a few months. He discovered that woman's recovery "from the crisis of mastectomy depends a great deal on the husband's support." He now advocates constant involvement of the husband throughout diagnosis, treatment and rehabilitation even to the point of insisting the husband change her bandages. Sutherland and Orbach found
the depression surrounding surgery for cancer to be centred on the patient's interpretation of the value of the organ. Fear of social unacceptability and future limitations in life activities are often more a source of depression than recurrent disease. Patients who have many unanswered questions about treatment and after effects of surgery, experience more of anxiety than depression. These authors also discuss post-surgical dreams which are often filled with bizarre horror scenes.

XII Self-Esteem

Long studied 26 women between the ages of 20-60 years to explore the effect of anticipated and actual loss of a breast on level of self-esteem. The study concluded that actual loss of breast had a significant effect on self-esteem levels measured by the Tennessee Self-Concept scale. Subjects with high self-esteem were less affected by either anticipated or actual breast loss than subjects with low self-esteem. Polivy attempted to measure changes in body image, self-concept and total self-image in 15 mastectomy patients and two control groups (18 biopsy and 11 surgical controls). The findings indicate that mastectomy patients did show a decline in body image and total self-image, but not until months after surgery. These findings concur with Weisman who found stress was highest in patients two months following the mastectomy.
Effects on Marital and Sexual Relationships

Jamison, Wellisch and Pasnau conducted two systematic studies, one with a sample of 41 women to investigate effects of mastectomy on sexual relationships and the influence of age and another with a sample of their male partners (30 were married and 1 was living common-law) to investigate their adjustment to the mastectomy. The findings of the women's questionnaire indicate that although most women were adjusting to their situation there was some emotional suffering with "suicidal ideation and increased use of alcohol and tranquilizers... age support systems and premorbid functioning may be indicators of the amount and type of intervention needed." Counselling is particularly important before surgery since this time was viewed by most women as the period of greatest anxiety.

The findings of the men's questionnaire indicated that again most men were adjusting to their situation, although a few reported problems in their relationships with their wives. The authors cite "four nodal points" in identifying "good adjustment" in the husband: "involvement of partners in the decision making process, the frequency of hospital visits, resumption of the sexual relationship and the husband's looking at his partner's body after surgery."

Woods explored sexual adjustment to mastectomy. She found that the patient's perception of her post-operative sexual adequacy and desirability depended on pain near the
surgery, perception of partner's reaction, and patient's perception of society's standards of sexual desirability. Grandstaff studied 70 mastectomy patients and their families in a research project involving family and marital counselling. The crucial point in the husband's support of his wife depended on whether his attitude toward the scar was positive or negative. Schoenbert found the greater support in the marital relationship before surgery, the greater the support after the mastectomy. If a woman feels unattractive, she may withdraw which may be interpreted as a rejection by the husband. Schoenbert suggests pre-operative counselling for couples before the mastectomy.

XIV The Family

Klein mentions that the mastectomy may affect the patient's husband and family. The husband may have concerns about his wife's life expectancy and may be unsure of his wife's new needs and expectations of him. If the husband's reaction to uncertainty is withdrawal, the wife may see this as rejection. The children of mastectomy patients may also be frightened by their mother's operation and possible post-operative depression. Anstice says that the whole family should know the patient's problems so that they can give the patient support in a time of physical and emotional healing. Practical helping may involve working out a temporary regime of housework to help her. Fellner indicates that the family can help or hold back the woman from recovering by their own emotional reaction to the patient's illness. Klein says
that families who will not allow negative emotion to be expressed may particularly impede the patient's progress.  

XV Alternatives to Surgery

The literature also looks into alternatives to surgery as one solution to the trauma and rehabilitation problems of mastectomy.

Cope and Margarey discuss a viable alternative to surgery in modern high voltage irradiation. Cope says "they (women with breast cancer) don't need to be railroaded into having their breast removed".

XVI Intervention

A. Introduction

Klein says that the three goals of rehabilitation for the woman with breast cancer are: one, she must mourn the loss of her breast and accept this loss; two, she must build her self-esteem toward a self-image worthy of admiration and acceptance by others; and three, she must live with the possibility of recurrence for the next 10 years of her life. Klein suggests the first guideline for intervention is open, honest communication about the future, helping her to express her feelings to deal with situational crises and to know what to tell others in her life. The emphasis appears to be on the group approach in helping cancer patients although Dietz feels individual consideration is still primary. The Reach to Recovery Program, a lay organization based on the "self-help"
group concept has been very supportive to women who wish follow-up support from hospital to home provided by someone who has experienced a mastectomy themselves. Parsall talks about the value of patient and family groups led by professionals. Couples groups have also been successful, particularly at the Hospital for Cancer and Allied Diseases in New York, New York, in adjusting husbands to the mastectomy. In helping the patient with the task of rebuilding self-esteem, Dietz proposes the restoration of external appearance and total use of the arm as instrumental in rebuilding the patient's self-image. Millard feels the offer of cosmetic reconstruction before surgery has great power in the patient's psychological adjustment to the operation, even though the breast is not promised to be restored as new. Reconstructing the breast is also a symbol to the patient that the surgeon feels there will be total recovery. Clothing is often mentioned as an issue in rehabilitation. Aves writes an article about the types of swimwear available to post-mastectomy patients.

B. Counselling

The counselling literature discusses the importance of pre-operative counselling. Markel suggests this interview can be a question and answer period to dispel misconceptions. Klein considers this time to be used to discuss changes in family roles and responsibilities. Harrell says the hospitalization period provides an opportunity of involving
Several authors stress the value of family involvement in treatment planning for the cancer patient. The physicians Worby and Babineau wrote about the value of the family interview with cancer patient to "help all family members cope with a mutually shared crisis." Liebman illustrates the value of periodic family case conferences to help family members utilize their full resources in "medical, psychologic, and social support."

C. Professional Roles: The Social Worker; Nurses; General Practitioner; Radiologist and Cancer Clinic Personnel; Surgeon; and the "Team".

Social work research explores the socioeconomic concerns of the cancer patient. Feldman studied 92 employable persons recovered from head/neck rectum/colon and breast cancer to see if there was work discrimination with ex-cancer patients. Although work problems and concerns of patients and their families were prevalent, only one case of discrimination was found. He recommends that counselling resources be developed for patients who would not normally go to a social service agency for help. Topitzer explored a variety of psychosocial factors in 80 mastectomy patients to see if some variables had predictive value for the social worker in helping the patient to adapt for surgery. Patient's ability to cope with other stresses, age, marital status, emotional reaction to her mastectomy and family
reactions) had predictive value although more research was recommended to further investigate these findings. More knowledge about the significant psychosocial factors upon the rehabilitation of the cancer patient will be of great value to the social worker in planning rehabilitation services.

Maguire illustrates in case examples some of the psychological and interrelationship problems faced by rehabilitating breast cancer patients and their families. He recommends that a nurse with special training provide a crucial link between the patient, the family, the hospital and community care teams. Norman discusses the role of the general practitioner in becoming "her partner against cancer" at every stage of illness and rehabilitation.

Radiologists and medical personnel involved in radiation therapy should also recognize the individual fears of patients and their misconceptions. Peck and Boland discovered patients who are referred for radiation post-surgical treatment have many misconceptions which are not clarified by medical personnel. After treatments, fewer than one-third judged themselves improved by radiation although this conception proved to be entirely false as 60% were free from cancer 18-36 months later. The study recommends that cancer clinic personnel should spend time with patients to explore possible doubts about treatment.

Goldsmith writes about the surgeon's role as central
to helping the patient cope with her mastectomy. Although heavy caseloads often prevent surgeons from spending time with their patients, it is crucial that the surgeon know about the patient's fears and possible effects on her family. Ervin routinely gives information interviews to both patient and family members so that he is aware of the family situation.

Post-operative treatment and emotional rehabilitation must be seen as a unit and the team service seems to be one successful approach to treating "the whole person", mind and body. Harrell offers her personal account of her rehabilitation after mastectomy to emphasize the importance of treating both the medical and emotional aspects of recovery:

"Perhaps this sounds overly dramatic but for a woman who has been placed in the starring role it is a drama with a five year run and very little emphasis on the roles that ought to be played... I found that my trivial problems - headache, nausea and pain - were treated aggressively. No one, however, bothered to tell me that my crying spells were not unusual and that they would pass. Consequently, my constant worry was that I was having a nervous breakdown."

The team approach is reported in the literature to be of value in implementing more comprehensive rehabilitation programs for mastectomy patients. Trachtenberg discusses the problems of working with teams. Winick evaluated the Post Mastectomy Rehabilitation Group (PMRG) Team Program at Memmorial Sloan-Ketterering Centre and found 84% of the patients studied resumed
normal activities within the four month post-operative period; 74% returned to work within three months of their mastectomies while 13% experienced moderate or severe emotional stress. Winick found that "doing anything to keep busy" seemed to result in an easier adjustment. The patient's age and physical condition seemed to greatly affect rehabilitation. Ninety-eight percent of the participants studied found this team program to be helpful.

D. Conclusion

Thus, the team approach, involvement of the family, treating the "whole person", and use of self-help and professionally led groups seem to be the currently favoured approaches to rehabilitating the mastectomy patient in the literature. Follow-up care and identification of problems after treatment is over is mentioned as a central issue.

In concluding this review, the researcher notes that although some social work with cancer patients literature was found in this literature search, only two articles deal specifically with breast cancer (other references to social work with patients with all types of cancer may be found in the Bibliography). Moreover, the rehabilitation programs for breast cancer patients seem to develop in hospitals or clinics where the surgery took place, or by medical societies outside treatment centres. The researcher did not find examples of rehabilitation programs for breast cancer patients, specifically in settings like the A. Maxwell Evans Clinic
which provide post-surgical cancer treatments only. However, these two limitations do not prevent the relevance of this review to this study on breast cancer patients and their needs for rehabilitation services, nor draw attention away from the important role of the social worker.
Chapter III

THE PROBLEM FORMULATION

1. The Rationale for this Study

The researcher was interested in the social work role in helping cancer patients and their families cope with the trauma of a cancer diagnosis, treatment, rehabilitation and "cure". In many cases, "cure" implies living with the threat of recurrent disease. Therefore, the researcher felt that an exploratory investigation of family needs concurrently with patient needs might lead to new insights into services which help the family support system to strengthen through a time of stress.

The Maxwell Evans Clinic is aware that new breast cancer patients coming to the clinic for radiation, chemotherapy or hormone post surgical treatment, are undergoing a traumatic experience in their lives. Some of the psychological studies of patients undertaken in the past at this Clinic have led to little insights into intervention approaches. The Clinic wished a more practical focus on patient and family needs which may lead to support service improvement. Hence, the researcher and the Clinic chose socioeconomic concerns as a topic which would lend insights into the patient's current life situation without creating undue stress at an already stressful time for the patient. The ethical question also arose of approaching an area in the
research that is potentially very traumatic without being able to provide immediate clinical intervention. Some of these areas discussed were fear of recurrent disease, death, pain, sexual, and marital relationships. The topic "socioeconomic concerns" would uncover problems of a more practical nature that lend themselves more easily to possible solutions. The researcher felt that this practical focus would have a psychologically hopeful effect on patients who may be in crisis.

2. The Social Work Problem in Need of Research

The importance of family members' involvement is being recognized by all medical and support staff at the A. Maxwell Evans Clinic. The family is being increasingly considered and involved in planning. There is also increasing emphasis on direct service to families and follow-up in the community. As more patients are being cared for at home with community support services, the family is taking a more active role. Therefore, the social work problem in need of research is increasingly one of identifying the needs of family members as well as the needs of patients, to provide a service to the "family system". The current mandate of the social service department involves routine support services to all "out-of-town" patients and families and to those in-town patients and families whose admission forms seem to indicate a socioeconomic problem. Recently, the mandate of the social service department has been expanded to include the person
who is most responsible for the patient's well-being (i.e. the primary care-giver). If a patient dies, the social service department is responsible for helping the primary care-giver resume his normal life. Therefore a current interest of the social service department concerns the potential needs of family members, as well as of patients, which may arise from socioeconomic change or changes in family roles and relationships.

The needs of patients and family members have never been researched at A. Maxwell Evans Clinic, although staff speculate about ways of identifying needs from experiences and observations of patients, as well as brief contacts with family members.

Although the literature supports the notion that family support is crucial to the patient's rehabilitation, there is little information regarding circumstances, activities or relationships in the family which signal a lack of support or a problem requiring assistance. Socioeconomic change may be one source of potential stress which signals a problem in the family support system. The study will investigate this hypothesis by exploring the socioeconomic concerns of family members since the patient's diagnosis. Thus the study will serve as a preliminary investigation of the needs of the family members, particularly those of the primary care-giver.

3. The Purpose of the Study

In summary, the research purpose of this study is to
identify some of the needs of breast cancer patients and their families which arise from socioeconomic change and changes in roles and relationships. This information will improve the planning and implementation of support services to breast cancer patients receiving treatment at the A. Maxwell Evans Clinic.

4. The Research Problem

The research problem which guides this enquiry has been formulated into the following questions: "How has a diagnosis of breast cancer affected the life situation of 16 new breast cancer patients and their families in terms of their socioeconomic situation including employment and family roles and responsibilities?" Under this umbrella question are four specific questions on the socioeconomic life of the patient which outlines this proposed exploration.

1. Are there changes since diagnosis in work responsibilities? (e.g. husband and patient going to work?) in income? in living conditions?

2. Are there changes since diagnosis in social life and relationships outside the family?

3. Are there changes since diagnosis in roles and relationships within the family? e.g.,

 a) Are there changes in children's responsibilities in the family?
b) Who is the primary care-giver in the family? Has the diagnosis changed what he/she does for the patient?

4. Are there changes since diagnosis in feelings about self? (i.e. feelings toward adequacy and attractiveness?)

Changes in the socioeconomic status and in roles and responsibilities may influence relationships within and outside the family and feelings about oneself. As these aspects may affect the kind of support service required, these two areas are also being explored (i.e. 2, 3, 4 above).

The project will identify the areas in the patient's socioeconomic situation which have changed the most and the areas which have created the most concern, in order to rate needs in terms of the patient's priority. This study will also try to identify the relative importance to new patients and their families of concrete services, (e.g. homemaker) and those services offering psychological support or counselling. This information will be of value in assessing the amount, kind and timing of support services needed by the patient and her family as new patients to the clinic. For example, a mother with four children may require immediate concrete services (e.g. homemaker) before she would be able to deal with her own emotional adjustment to treatment.

5. Working Definitions

For the purpose of this study, "the primary care-giver"
is defined as the person who is most responsible for the patient's well-being, particularly in terms of housekeeping and nursing care as well as financial and emotional support.

"Socioeconomic concerns" is defined in terms of finances, employment, housing, transportation, friends and relatives, family life situation and roles and responsibilities.

"Feelings about self" is defined in terms of personal attractiveness, competency in family as a wife and/or mother, ability to be independent, fulfilling others' expectations, and maintaining present level of income and living conditions.

6. **Value Assumptions**

1. Undergoing the trauma of mastectomy and further cancer treatment entitles the patient to any rehabilitation program that will help her regain normal activities and quality of life.

2. If mastectomy and medical treatment affects family functioning, the patient's family members are also entitled to any support programs which will improve their quality of life.

3. The patient should be involved in her own cancer treatment planning and should voice her individual physical and psychological needs to help her rehabilitation.
7. **Independent Variables Which May Affect**

**Perceptions of Socioeconomic Change and Concerns**

**Patient Characteristics**

The patients requested to participate in this study are considered new patients in May, 1978, of the breast outpatient Clinic at the A. Maxwell Evans Cancer Clinic. These patients and their primary care-givers all live in the lower mainland. Age, marital status, number of dependants, employment and present living situation may have some affect on the amount of change and concern they perceive as the result of their diagnosis. The feelings patients have about cancer as an illness, about having cancer themselves, about previous illnesses and about losing a breast may also affect the changes they perceive.

**Family Characteristics**

The family members requested to participate in this study are considered to be the patient's primary "care-givers" by Clinic staff. Age, marital status, employment, present living situation and family relationship to patient may have some affect on the amount of change and concern they perceive as a result of the diagnosis. The feelings of primary care-givers toward cancer as an illness, toward the patient's having cancer, toward the patient's previous illnesses and toward the patient's loss of a breast may also affect the changes they perceive.
Diagnosis and Treatment Plan:

The patients participating in this study have a diagnosis of breast cancer in Stage I, II, III or IV. The possible post-surgical medical treatments planned for these patients are chemotherapy, adjuvant chemotherapy, irradiation or hormonal treatment, administered according to individual patient needs. The stage of cancer and treatment plan may affect the patient's perception of degree of change since the diagnosis. Stage I patients often receive a course of 15 radiation treatments over a period of 3 weeks at which time their treatment is over. Stage II patients may be part of an adjuvant chemotherapy program for one year which may follow a course of 15 radiation treatments. Adjuvant chemotherapy is a precautionary measure which reduces the chances of metastatic spread of a Stage II cancer.

Services Received Prior to Interview

The patients interviewed all have been visited by a mastectomy volunteer from the Mastectomy Volunteer Program sponsored by the Canadian Cancer Society during their hospital stay. Some patients may have received help with arranging accommodation or transportation to treatments from the A. Maxwell Evans Clinic. Some patients may have received home nursing from the V.O.N. branch in their neighbourhood. The services received or not received by patients may influence responses to current socioeconomic needs and the patient's
present attitudes toward cancer treatment at the A. Maxwell Evans Clinic.

**Time Interviewed**

The patients would be interviewed before their treatment at the Clinic begins, during treatment, or after the treatment has ended, depending on the choice of the respondent. As this is a time of upheaval in the patient's life, her perception of changes and concerns may change daily, and certainly may be influenced by their current experience with cancer treatment.

8. **Persons Concerned With This Study**

**The A. Maxwell Evans Clinic Human Support Committee: A Subcommittee**

This committee originated on an ad hoc basis upon the initiative of the late Dr. Joe Lagey, the former director of the research and social policy department of the United Way of Greater Vancouver, who was terminally ill with cancer and receiving treatment at the Clinic. Interested in designing a demonstration and research project involving family counselling with cancer patients, Dr. Lagey called together the Clinic social service director, the Clinic Chaplain, two U.B.C. social work professors, one social work student (myself), the evaluation research director of United Way, a social worker from Family Services of Greater Vancouver, the medical director of the outpatient department at the Clinic and one former
patient, to discuss the feasibility of such a project. Later this committee became recognized as a subcommittee of the Human Support Committee at the Clinic. The evaluation research director of United Way, a member of this subcommittee, has designed a comprehensive framework for a five year project investigating the needs of cancer patients and their families. The subcommittee is therefore interested in the findings of this study and also in the experiences of the interviewer in contacting and interviewing cancer patients and their families. This information will help the committee plan a large scale project of cancer patient and family needs involving men and women, with all types and stages of cancer, and differing prognosis.

Family Services of Greater Vancouver

A family counselling service may be purchased from family services by the A. Maxwell Evans Clinic for a trial period. Family Services, represented on the subcommittee described above, is therefore interested in the concerns and needs of families of breast cancer patients that will result from this study.

The School of Social Work, U.B.C.

The research faculty members at the School of Social Work is interested in exploring the role of the social worker in working with breast cancer patients and their families. Little is known about the family support system in coping
with breast cancer but it is recognized by many medical professionals to be vital to a patient's rehabilitation. Therefore, this research will focus on the socioeconomic life of the family system to explore existing supports in the family and possible needs for services.

The Maxwell Evans Clinic

A. Maxwell Evans Clinical Trials Committee, composed of three doctors and the Clinic Chaplain and the social service department, were actively involved in the problem formulation and design of this research. Their interest has been discussed under the headings "The Problem Formulation" and "The Design".
Chapter IV

THE DATA COLLECTION AND DESIGN

1. The Design Considerations

The purpose of this research is to identify the needs of patients and primary care-givers which result from changes in roles and relationships and socioeconomic change. Therefore, this study is concerned initially with measuring: 1) how much change and what kinds of changes are perceived by new breast cancer patients and their families; and 2) how much concern was felt about each of these changes. Subsequently, the study is concerned with documenting the needs which arise from these changes and concerns.

Therefore, in choosing the design and research instrument, the researcher considered what are the best approaches to measuring socioeconomic change, changes in roles and relationships, and degree of concern relative to these changes, and how to document patient and family needs.

The researcher chose to identify needs firstly through respondents' requests for services and help, and secondly through the interviewer's perception of needs from the findings. Therefore a personal interview was considered the best method of data collection. As the focus is not only quantifying amounts of change and concern but also documenting what these changes are, and how concerns are handled, with or without services, the researcher chose a fundamentally exploratory
design to allow for flexibility in data collection, personal interviewing technique and data analysis. This study is descriptive in design in that the findings will describe how 16 patients and their primary care-givers perceive changes during the time they are coping with a similar experience, i.e. a breast cancer diagnosis, a mastectomy and follow-up treatment, and will note their needs which arise from this experience. There will be no testing of hypothesis or finding causal relationships of the more rigorous explanatory design. Hypothesis for further research will be formulated and clarified from the findings in this study.

2. Sampling Considerations and Design

The Clinic was hesitant to involve patients with poor prognoses and their families in a research study. Breast and cervical cancer patients were suggested as two possible groups of subjects with good prognoses. Due to the diversity of treatment approaches to any one type of cancer, the researcher felt a homogenous sample of one type of cancer would be best for this exploratory study. The fact that breast cancer usually affects women, increases the potential homogeneity of the sample. Thus, breast cancer was chosen as the target population. The outpatient department was interested in a study involving their outpatient breast patients and therefore offered to assist in the selection of the sample.
Procedure in Securing Permission to Interview Patients in the Clinic

The study proposal was presented to the Human Support Committee and then to the Clinical Trials Committee of the Cancer Control Agency of British Columbia for their approval. Once the proposal was passed through these committees, Dr. Ballantyne, Director of the New Out-Patients Clinic at the A. Maxwell Evans Cancer Clinic followed this procedure to secure permission to interview patients:

1. A discussion with Dr. Goodman, Director of the Clinic establishing that the study could take place with patients referred to the A. Maxwell Evans Clinic.

2. A request to the Forms and Documents Committee that the letter to the patient (Appendix C) could be entered in the patient's file for the family and Clinic doctors.

3. A discussion with the Radiotherapy and Medical Oncology Departments that some of their patients would be participating in the study.

4. A discussion with the 5 other New Out-Patient doctors introducing the project and requesting them to select the sample from their new referrals in May 1978 according to the sample criteria.

These procedures, developed for the first time, once established operated successfully and all Clinic personnel involved were well informed.
The sample was selected by Dr. Ballantyne and the five other New Patient Clinic doctors from the approximately 55 new breast patients referred to the New Out-Patients Clinic during the month of May in 1978. The sampling design was stratified to account for Clinical Stage I, II, III and IV. The medical stage of cancer refers to the severity of disease in terms of metastatic spread. Stage I, the earliest stage of cancer, involves no metastases and has the best prognosis. Stage IV patients have a "guarded" or "poor" prognosis, depending on the extent of the metastases and the part of the body the cancer is found.

The patients from Clinical Stages I, II, III and IV, who agree to participate, would compose the sample of 16 patients and their families. The women selected to participate must be living in the lower mainland, have their primary care-giver available for interviewing, have a diagnosis of breast cancer and be considered a new referral to the Clinic in May. The patient could be considered a new patient of the Clinic in May but have received a cancer diagnosis several years before and now be experiencing recurrent disease. Patients not suitable for this study would be excluded at the discretion of Dr. Crawford and Dr. Ballantyne.

The representation of this sample would be in terms of the clinical stages of cancer referred to the Clinic during the month of May. The researcher is aware that the total representation of this group of women as breast cancer patients
is unknown. However, this degree of representation is legitimate in an exploratory-descriptive study. Although the stage of cancer would be taken into account by the sampling design, the demographic and biographical variables would be considered an asset to this exploratory design. This study would explore whether differences in age, marital status, economic status, previous biographical events and the stage of cancer influenced the socioeconomic impact of the diagnosis and the resulting needs for support services.

This project, therefore, would rely on control through the selection of subjects by stage of cancer. Due to this limited attempt at control, this study would not attempt to draw conclusive evidence about causal relationships. However, the findings would identify certain socioeconomic situations which seem to indicate particular needs and services.

The selection of the sample would start May 1, 1978, as new breast cancer patients are referred to the Clinic. New patients would be introduced to this project by their doctor at the New Patients Clinic during one of their initial appointments at the Clinic. The doctor would give to each patient the letter of introduction, found in Appendix A. He would then fill out an information sheet about the patient to be sent to the Social Service Department for the research, found in Appendix C. At this time, the patient's family doctor would also be sent an explanatory letter from the A. Maxwell Evans Clinic outlining the purpose of this study.
found in Appendix B. The patient and her primary care-giver (family member) would be interviewed in separate sessions, once with similar questionnaires, either in her own home or if preferred, at the School of Social Work.

3. Confidentiality

Respondents were assured of confidentiality in the patient's letter of introduction (Appendix A) and by the researcher in person at the time of the interview. The findings have been made anonymous through cumulative totals and generalizing any detailed personal information. If a specific reference is made to one individual's response, the identifying letter of the name has been changed, and no other identifying information is given.

4. Instrument Devised For This Study

The Clinic requested that the researcher compose an original measurement of change and concern without the use of known psychological measurements of anxiety or recent stressful events. The Human Support Committee's subcommittee, the Clinical Trials Committee and the Director of the Clinic's social service department contributed their suggestions and areas of interest during the formulation of the interview schedule.

An interview schedule was composed to form two scales to measure the amount of change and degree of concern perceived by the respondents. One scale measured degree of change
according to respondent's perception of "a great deal, somewhat, or no change" across a number of socioeconomic areas of potential change. The second scale measured the amount of concern or anxiety about any of the changes mentioned or any of the socioeconomic variables of potential change using the same calibration form, i.e. "a great deal, somewhat, and no concern".

The questionnaire was divided into five areas of potential change:

1. Housing and Living Situation
2. Work and Transportation
3. Family Roles and Responsibilities
4. Relationships with Family and Friends
5. Feelings about Self.

Two interview schedules of a similar form were devised, one for the patient and a shorter form for the primary care-giver (found in Appendix E).

Interviewing the primary care-giver is an important part of the design of this study for two reasons. Firstly, an attempt to measure the impact of breast cancer diagnosis upon a patient's socioeconomic situation is incomplete without including the family as a primary source of information. Secondly, the interviewing of a family member will compare changes the patient perceives with changes her family may perceive as well as gain information about changes family members themselves experience as a result of the diagnosis.
Therefore, the interviews with the patient and primary care-giver would take place on the same day, in separate interviews.

**Baseline Data**

As the framework of this study is on the impact of the diagnosis on the socioeconomic life situation of the patient, baseline data will be collected with respect to recent life change events, previous experiences with cancer and other illness, socioeconomic situations, family and work roles, and responsibilities prior to diagnosis. Information will also be collected on past, current and expected cancer treatment from patient perceptions and medical files.

5. **Major Source of Data**

The major source of data is a personal interview of about 1½ - 2 hours in length with the patients and their primary care-givers. Other sources of data were personal interviews with social service and outpatient clinic staff at the A. Maxwell Evans Clinic. The medical information compiled from the files of the 16 patients interviewed may be found in Appendix C.

6. **Administration of the Interview Schedule**

**The Pre-test**

A pre-test of the interview schedule was carried out with two patients and their primary care-givers. The first
lady experienced her mastectomy two years ago, and the second experienced her mastectomy six months prior to her interview. One primary care-giver was a husband and the other an adult son. The primary care-giver interview was changed to allow for a more open-ended response to major concerns, as both primary care-givers emphasized that their main concerns did not centre around socioeconomic change. As a result of this pre-test, the patient interview was changed with respect to the last section as "changes in self" was felt to be a threatening note to end the questionnaire. The phrase "unable to say" was added as the first option to Q. VI 1. to enable a respondent to decline responding if she feels uncomfortable with this topic.

7. Interviewing Procedure

As was previously outlined in the sampling design, a letter (Appendix A) given to the patient during a verbal introduction to the project by her outpatient doctor, mentioned that the researcher would be telephoning in the next week to arrange an interview time. The telephone conversation outline is found in Appendix D. As one visit would be made to each patient and family member, the interviewer tried to arrange the same interview time for both. This would also increase the reliability and validity of a comparison between patient and her primary care-giver.

The interview began with a general introduction to the project followed by a short discussion about who would
like to be interviewed first. Respondents were allowed to transgress from scheduled topics if the interviewer felt the transgression would lead to insights into current changes and concerns.

8. **Data Analysis Design**

Information gathered during the interview will be considered according to the five areas of potential change and concern previously mentioned under the heading "Instrument Devised for this Study." This analysis will attempt to answer the research questions posed under the heading "The Research Problem" of the problem formulation. Any independent variables mentioned under the heading "Independent Variables" which seem to the researcher to influence perception of changes and concerns a great deal, will be noted. Responses to similar questions asked of both patient and family member will be seen as responses from one family system, and described accordingly. Findings from discussions not related to the five areas of potential change will be discussed under separate headings. Some medical information will be summarized in table form. Due to the small sample size, the number of cases rather than percentages will be used to indicate the number of responses to each question.
Chapter V

STUDY FINDINGS

1. Introduction - Problems in Sampling and Data Collection

From the total population of 55 new breast cancer patients referred to this Clinic in May, 23 patients fulfilled the requirements of the sample and were introduced to the project. Of the remaining 32 patients not requested to participate, approximately 27 were living outside the lower mainland. The remaining patients did not fit into the criteria of the sample, or were immediate refusals. Seven of the 23 patients of the sample were not interviewed during the interview period of May 15 to June 15 for the following reasons: two patients could not be contacted by telephone; one family doctor telephoned the researcher to request that his patient be removed from the sample as he felt she would need psychiatric treatment; (This lady was subsequently seen by the Clinic social worker because she was extremely upset. Her prognosis was only fair and her husband was unemployed.) one woman said she would like to be interviewed in July after her treatments were over which would be too late for the researcher; another patient who lived 50 miles away from the Clinic said she was not really interested; another patient wished to be interviewed in several months when her husband returned from a commercial fishing trip; one husband who was not told about the study by his wife refused to participate
when the interviewer arrived at his home as his wife was asleep. The demographic characteristics of the 7 patients described above were not atypical of the rest of the sample according to age, marital status, living situation or prognosis. The researcher assumes therefore that a social situation may have influenced the patient's decision not to participate.

Overall therefore, the patients contacted did not show any hesitancy or resistance to participating in this research project.

The good response rate and participant co-operation was largely due to the careful preparation made by the New Patients Clinic doctors concerning the introduction of this project to the participants.

Sixteen new breast cancer patients were interviewed. In two cases, a family member was not interviewed. In the first case, (Mrs. A.) the husband agreed to the interview but left the house when I arrived to interview him. The researcher was told by his wife that he said "I see no changes so why bother to be interviewed." This case will be also described later in more detail. In the second case, (Mrs. D.) the patient requested that I talk to her alone without any of her family knowing about the visit. The researcher found that there was a problem concerning the mastectomy in this family, which will be discussed later.

In terms of representativeness of the 4 stages of cancer, the patients fulfilling the requirements of the sample
represented a higher proportion of Stage I cancers than found in the total population. Stratification to represent the correct proportions of each stage was therefore not achieved in the time allowed although a sample of each stage is represented.

The following table compares the number of patients in each stage in the total population of new breast patients in May to the number in each stage that were interviewed:
(Data was gathered by the Director of the New Patients' Clinic.)

| TABLE 1 |
|-----------------|-----------------|
| **Total No. of New Breast Patients in May** | **Total No. of Patients Interviewed** |
| Stage 1 = 16 | Stage 1 = 11 |
| 70% |  |
| Stage 2 = 23 | Stage 2 = 3 |
| Stage 3 = 16 | Stage 3 = 1 |
| 30% |  |
| Stage 4 | Stage 4 = 1 |
| Total 100% = 55 | Total = 16 |

As the above table indicates, Stage I is over represented, while Stages II, III and IV are under represented.
2. **Impressions About Interviewing Cancer Patients and Their Families**

Generally speaking, all patients and primary care-givers were interested in talking with the interviewer and asked a variety of questions about clothes, treatment and prostheses. The husbands of the patients seemed somewhat anxious about speaking with me, particularly about the questions I might ask. At the end of the interview, most of the husbands were visibly relieved that the interview had been non-threatening. For example, Mr. E. and Mr. F. interrupted several times with coffee and jokes to see if everything was alright. Interruptions of this kind could be a major source of error as it was difficult for the researcher to return to serious topics after such disruptions. Several patients were also anxious about speaking with me initially, although not to the same extent as their primary care-givers. The two sisters and two daughters who were primary care-givers were noticeably not anxious about being interviewed and confidently related how they were helping. The researcher speculates about the anxiety of husbands with respect to the interview. Some husbands who seemed to be anxious and defensive about their role in this situation, (e.g. Mr. B.) may have felt the researcher was "checking up on them." According to the literature a breast cancer diagnosis affects the husband-wife relationship on many levels i.e. life expectancy, awareness of mortality, sexual relationship and lifestyle. Therefore, this is a very stressful and anxious
time for the husband regardless of the research interview. Allowing patient and family member to discuss anything of present concern reduced participant's anxiety to focus on socioeconomic concerns if this was not their immediate concern, and enabled the interview to run smoothly in a conversational manner. In the researcher's opinion, all the interviews ended in a positive way because the interviewer was willing to discuss any topic which was of individual interest to the participant. Moreover, the researcher spent some time talking about herself to the patient and family which also seemed to reduce anxiety and "break the ice".

**Denial of Change and Concern**

Patients and family members often seemed hesitant to admit concerns and changes throughout the interview. Possibly respondents felt these comments to a researcher would indicate that they were having serious problems or difficulties in "coping". This response may reflect the influence of social desirability on the respondent to show confidence and expertise in handling their own situation. Furthermore, Peck says denial of change or concern is often an effective temporary coping strategy for the patient who wishes to keep her life stable and secure so she may cope with future unavoidable changes in her body in age and health. Therefore the researcher took the possibility of denial of change and concern into account by listening for a respondent's conflicting or ambiguous statements about the same subject. This approach towards
identification of denial formed the basis of defining this concept for the purposes of this study.

As denial was found to be important as an unanticipated variable in this study, a definition was needed for the purposes of data analysis and presenting the findings. A working definition of "denial" would be as follows: the researcher's awareness of a respondent's conflicting or ambiguous statements about the same issue during the interview. This definition of "denial" was therefore not the usual psychoanalytic definition or explanation of this defense mechanism but simply a way of identifying conflicting information collected during the interview. For example, Mrs. M. responded to a question on the interview schedule that she was not concerned about anything and everything was just the same. However, in conversation she mentioned she was not sleeping and was upset because she felt she could not have "company" anymore. Statements like these indicated some denial of change and concern to the researcher. The researcher found that the participants were considerably more involved toward the end of the interview if the researcher spent time to discuss these areas of conflicting statements, and areas of individual interest to the respondent.

The degree of influence of denial on the findings was not possible to measure in this exploratory design. The scalar measures of change and concern in the interview schedule showed little variability possibly because the instrument was not appropriate for the time and situation of these participants.
The comments which indicated changes, concerns and anxiety were recorded for individual cases. However, the degree of concern or amount of change could not be systematically measured for all respondents. Limitations of the interview schedule will be discussed in further detail under the heading "Suitability of the Instrument" in the final chapter.

3. The Interview Schedule

Introduction

Sixteen patients and fourteen primary care-givers, all members of their immediate families, were interviewed in this study. A summary account of the first two sections of the Interview Schedule (Appendix E) (i.e. General Information) and Section I, will be presented to introduce the discussion of the findings. Following this account, the findings of the Interview Schedule beginning at Section II will be discussed under the theme headings of the five potential socioeconomic changes and concerns in the schedule: i.e. II Place of Residence; III Transportation and Work Activities Outside the Home; IV Family Roles and Responsibilities; V Relationships with Family and Friends and, VI Feelings about Self. Reference to the number and kind of responses to individual questions will be noted at the beginning of each section.

In presenting the findings the researcher chose to compromise between individualizing each case without becoming lengthy and showing the trends in all cases. Therefore, a trend analysis is presented under the theme headings, illustrated
by the salient features of each case and the researcher's comments and impressions.

4. **Descriptive Data**

   **General Information**
   - **Age** - The patients' ages ranged from one patient in her thirties, four in their forties, nine in the sixties, to one patient in her seventies.

   **Living Situation and Primary Care-Givers**

   Thirteen patients were currently married, living with their husbands who were their primary care-givers. The three other patients were widows who lived alone. Two of the widows, Mrs. K. and Mrs. P. had sisters as their primary care-givers, while the other, Mrs. G. had her daughter as primary care-giver. Fourteen patients had children ranging in age from 12 to 46. Five patients had children aged 12-22 living at home. Of the nine patients with children not living at home, six patients had children living in the Lower Mainland while three had children living outside the province.

5. **Diagnosis, Treatment and Previous Experience with Illness**

   **A. Diagnosis**

   Thirteen patients found a lump in their breast themselves and eleven went to the doctor as soon as possible. The large number of self-diagnosed patients could be attributed to Breast Self Examination Education Programs. Mrs. K. waited three months until she returned home from a world trip and
Mrs. C. waited over a year, hoping it would disappear. The other three patients went to the doctor for something else, i.e. Mrs. B. for a regular check-up, Mrs. F. for phlebitis, and Mrs. M. for a hernia, at which time the doctor suspected breast cancer. Seven patients experienced a biopsy and then a mastectomy a few days later. Nine patients received the biopsy and mastectomy in one operation. Mrs. I., one of the seven who had two operations, mentioned that she appreciated having a few days to prepare for the mastectomy after her biopsy.

B. Medical Treatment

All sixteen patients experienced a modified radical or simple mastectomy prior to the interview. Two of these patients, Mrs. E. and Mrs. P. were awaiting hospitalization for the removal of the other breast. Eleven patients would be completing a schedule of fifteen radiation treatments over a course of three weeks. By the time of the interview, three patients, Mrs. I., Mrs. L., and Mrs. N., had started radiation treatments and one, Mrs. J., had completed radiation treatments while the remaining seven had not started treatments. Two patients were awaiting results of medical tests before knowing if they required irradiation. Two patients, Mrs. D. and Mrs. A., would be participating in an adjuvant chemotherapy program after radiation treatments. One patient, Mrs. M., had started a hormonal (stilbestrol) therapy program for liver metastases at the time of the interview.
C. Previous Experiences with Cancer and Other Illnesses

In response to the question of this section "Have you or your family member had any previous experience with cancer?" four patients had no previous experience with cancer, while twelve patients knew one or more of their extended family who had cancer. Four patients said they had previous illnesses. Mrs. M. has had a hernia for four years and arrested glaucoma. Three years ago she had a mastectomy and now has diagnosed with liver metastasis. Mrs. J. had two previous major operations, one for a collapsed womb. Mrs. P. had a thyroidectomy and Mrs. I. had a stomach ulcer seven years ago. Twelve patients said they had no previous illnesses. Mrs. F. had a serious chronic phlebitis condition but did not consider this a previous illness.

6. Place of Residence

The following is an account of the responses to Section II of the Interview Schedule on "place of residence".

1. Four patients lived in apartments. Two of these patients were widows who lived alone, and two lived with their husbands in senior citizen retirement homes. The remaining twelve patients were homeowners. The sixteen patients interviewed lived in the following communities: Vancouver, North Vancouver, Burnaby, Richmond, New Westminster, Coquitlam, Maple Ridge, Delta, Langley, Abbotsford and Mount Leyman.
2. During the past two years have you changed your address?  
Yes: 14  No: 2

3. Since you found out you had breast cancer have you changed your address:  
Yes: 0  No: 16
Have you made plans to do so?  
Yes: 2  No: 14
If "Yes" was your decision to move influenced in any way by your discovery that you have breast cancer?  
Yes: 1  No: 15

Comments

In response to the question "How long have you lived in this community?" fourteen patients had lived in the same community from 12 to 46 years. These patients had no current plans to move and the mastectomy did not affect plans to change place of residence. One patient, Mrs. K., was planning to change her place of residence because of her mastectomy. Mrs. K. had been travelling for two years (see Biography) and had not completely moved into her apartment. She wondered if she would be better in an apartment with an elevator as she had concerns about her future health and her energy level.

Mrs. K. knew she had a later staged cancer, (i.e. Stage III) and was anxious about whether "treatment would work". She speculated whether she should stay in her own apartment or move into a senior citizens' complex with communal dining hall and recreational facilities. Mrs. K. was presently very anxious about staying alone in her apartment. Three other
patients had concerns about changing place of residence. Mrs. O. was planning to move back to the Maritimes where she felt more at home and could live a less stressful life. Mrs. C. was selling their home to move back to her old neighbourhood in the same community where all her friends lived. Mrs. G. wants to continue to live alone in her own house and opposes her daughter who feels she would manage more easily in a senior citizens' high rise. Although Mrs. O., Mrs. C. and Mrs. G. did not connect these decisions about place of residence to their mastectomy, the researcher speculates that these three patients are moving towards a greater stability and security in their place of residence to compensate for other changing areas in health.

7. Work Activities Outside the Home and Transportation

A. Work Activities

The following is an account of patients' responses to the section on "work activities outside the home" in the interview schedule:

A. Are you employed outside the home?

Yes: 8 No: 8

B. Do you do volunteer work?

Yes: 2 No: 14

Do you anticipate your treatment will affect your volunteer work?

Yes: 0 No: 2
C. If employed outside the home:

1) What is your job? Description in summary account.

2) For how long have you worked at this job?
   Years: 5 - 19

3) Are you working now?
   Yes: 0    No: 8

   a) If "No" do you anticipate returning to work?
      Yes: 8    No: 0

   b) If "No" does this have anything to do with:
      i) Your present illness:
         Yes: 0    No: 0    NA: 8
      ii) Other recent or current illnesses of your
           or your family members?
         Yes: 0    No: 8
      iii) Previous experiences with cancer?
         Yes: 0    No: 8
         No: Nil

4. If you are currently working or anticipate returning to work:

   1) Will there be a change in hours, job
      responsibilities, work conditions or income?
      Yes: 0    No: 8

      a) If "Yes" could you say more about how this
         change may come about?
         i) Has anyone indicated to you there may be a change?
         Yes: 0    No: 8
ii) Do you anticipate you will feel well enough to continue your present job?
   Yes: 8  No: 0

iii) Do you feel these changes are in any way a result of your illness?
   Yes: 0  No: 8

Comments
In response to the question "Are you employed outside the home?" eight patients responded "Yes". All eight patients had their jobs over five years. The jobs are as follows: a part-time hospital patient-escort; a desk clerk in a hotel; R.N. in a private hospital; a bank department head; dietician in a private hospital; a teacher; head cashier in department store; and a nurse's aide.

Two patients were involved in volunteer work which did not change because of the mastectomy.

All eight patients who were employed were on sick leave and were experiencing a change in lifestyle from going to work every day to staying at home.

All eight patients intended on returning to work with no anticipated changes in work hours, responsibilities, work conditions or income. None of the eight patients knew when they would be returned to work which depended on recovery after treatments. All eight patients showed some concern and anxiety about knowing when they should return to work and
questioned researcher on the effects of treatment so they might be able to estimate time of return for their employers. This concern about returning to work seemed to depend on acceptance of the sick role over the work role, and on their economic situation. Mrs. G. was the only patient who felt she had to work to support herself, and keep her own house. She said "OAP just isn't enough." Mrs. G. was waiting to feel well enough to start her new job in a bank which employed people over 65. However, her daughter was opposed to this job as she felt it was too stressful now and suggested her mother have "some easier" job. Mrs. G. wanted to remain in the work which she knew and did not want a change. She was most concerned about her appearance in her new job and was deciding to wait for a good prosthesis before returning to work.

Mrs. E. and Mrs. H. both worked to supplement the family income but felt some ambivalence about keeping the same job. Mrs. E. who was almost at retirement age (61) was involved in pushing heavy hospital beds at work. She was deciding whether she should look for a lighter job in the same hospital as she liked working there.

Mrs. H. was a full-time nurse and wondered if she could work less hours in order to reduce the stress of her job. Mrs. H. was worried that the stress of working might jeopardize her health.

Three patients, Mrs. E., Mrs. F. and Mrs. I, had difficulty accepting the sick role over the work role. These
patients had also never been seriously ill before which may be a contributing factor to difficulty in adjusting.

Mrs. F. went to work a few hours each day to plan menus, against her doctor's express wishes to keep her off her feet for a phlebitis condition. Her husband said "I can't keep her at home!" Mrs. F. said "I just can't sit at home all day. There are things to be done at work." Her husband explained that "she didn't have to go to work but she's very high strung and needs to be doing something." Mrs. F. indicated to researcher that going to work made her feel that things were getting back to normal.

Mrs. E. talked about her change in lifestyle since on sick leave. She said "I feel stranded", "like an invalid, you know?" She also felt cut off from her friends at work.

Mrs. I., a married teacher with no children, in her 30's, has taught school full-time for the last sixteen years. The diagnosis brought to Mrs. I. a sudden change in lifestyle which according to doctor's orders will be prolonged until September's new school term. This change in lifestyle from "working" to "housewife" is difficult for Mrs. I. to accept and says this change has affected her own work image of herself as a "healthy energetic teacher".

Mrs. J., on the other hand, took the change from work role to sick role more in stride. She has had two other operations before which may contribute to her ease in adjusting. She said "I'm really enjoying my time at home now, they can
just wait for me at work." Although this statement sounds
nonchalent, Mrs. J.'s tone seemed to confirm her anxiety
about when she could return to work.

B. Transportation

The following is an account of patients' responses
to the section on transportation in the questionnaire:

Do you drive a car? Yes: 7 No: 9
a) If "Yes" are you able to drive now?
   Yes: 7 No: 0
b) If "No" does someone drive you?
   Yes: 9
   i) If "Yes" who? Bus or husband or friends?
c) What transportation do you have to your treatments
   at the Maxwell Evans Clinic?
      Husband: 10 Volunteer
      Driver: 4

Comments

In response to the question "Do you drive a car?"
seven of the patients responded "Yes". The operation did not
change their ability to drive nor desire "to go out". The
other nine patients who did not drive, either took a bus or
others drove them a week after the operation. Curtailments
on "going out" were usually connected to self-image rather
than lack of transportation.

However, the findings show that the four patients
who mentioned embarrassment in going out since the operation,
i.e. Mrs. E., Mrs. G., Mrs. L. and Mrs. M., did not drive a car. One may speculate that patients may be more embarrassed by using public transportation and walking than by using their own car, or perhaps these four patients are naturally more timid individuals.

8. Family Roles and Responsibilities

Note: Section IV is also The Primary Care-Giver Interview Schedule. Therefore, the questions in Section IV, Family Roles and Responsibilities, were asked of 16 patients and 14 primary care-givers.

This section is divided into three parts:

A. Main Concerns of Patients and Primary Care-Givers

B. Practical Changes in Daily Activities, Family Roles and Responsibilities

C. Services Received and Services Requested

There were some commonalities in the patients' and family members' responses to the questions "In general could you tell me the main concerns you and your family have at this time?" and "What are the most important changes if any which you have noticed in your family?" Therefore, as this data may indicate differences in the patient's and her family's concerns as well as individual needs and timing of support services, all individual patient responses and their primary care-givers' responses to these two questions will be noted. This listing will be followed by a summary and comparison of patients' and primary care-givers' major concerns and perceptions of change.
A. Main Concerns of Patients and Their Primary Care-Givers

The following is a listing of patients' and their primary care-givers' responses to the questions in Section A of interview schedule under the heading IV, Family Roles and Responsibilities:

1. In general could you tell me the main concerns you and your family have at this time since you found out (or your spouse, daughter, mother) has breast cancer?

2. Since the diagnosis what are the most important changes, if any, you have noticed in your family?

(1) Mrs. A. - Stage II

Patient
1. Major concerns: "No Disneyland trip with daughter. Cancelled."

2. Major changes: "None. Shock at beginning, unnatural if it were not?"

No interview with husband, the primary care-giver.

(2) Mrs. B. - Stage II

Patient
1. Major concerns: "Not a darn thing, no sense, no feeling."

2. Major changes: "No".

Primary care-giver: Husband
1. Major concerns: "This hit us like a time bomb, my wife's health."
2. Major changes: "None, carry on pretty much as before."

Mrs. C. - Stage I

Patient
1. Major concerns: "Hard to answer—husband and children have been wonderful, more friends now."
2. Major changes: "Daughter gave up moving into own apartment, 18 year old son naturally lazy, but trying now to help."

Primary care-giver: Husband
1. Major concerns: "Her general well-being."
2. Major changes: "More togetherness, wife gets down a bit, we try to stop those feelings."

Mrs. D. - Stage I

Patient
1. Major concerns: "None"
2. Major changes: "None"

Primary care-giver: Husband
No interview
Mrs. E. - Stage II

Patient
1. Major concerns:
2. Major changes:
Primary care-giver: Husband
1. Major concerns:
2. Major changes:

"How long do you wait for the cobalt treatments? How long before treatments are over? Do not sleep well. Waiting also for prosthesis feeling like invalid."

"Waiting".

"Wife worried and on edge, uptight, you know."

"Wife really upset three days ago, surgeon drew fluid from breast, now not so worried."

Mrs. F. - Stage I

Patient
1. Major concerns:
2. Major changes:
Primary care-giver: Husband
1. Major concerns:
2. Major changes:

"In our age group not as many things are going on; when you have something like this you find out how much your family thinks of you."

"Family shows concern."

"At first anxiety, this is a close family then you do everything you can, grateful that the doctor's found it early."

"Family closer, daughter-in-law cooks every meal next door."
(7) Mrs. G. - Stage I

Patient
1. Major concerns: "Spoiled holiday and when can I return to work? If you cannot support yourself sooner or later you have to sell the house!"
2. Major changes: "Family pretty scared; my brother in Sardis very worried."

Primary care-giver: Daughter
1. Major concerns: "Main concern is whether I will have it."
2. Major changes: "Shocked, educated enough that aware it is not fatal, optimistic."

(8) Mrs. H. - Stage I

Patient
1. Major concerns: "Doubt in your mind, still unreal, it does not seem like it is happening to me. Before the operation, I thought I would go out of my mind with the idea of having cancer. Better now."
2. Major changes: "My husband is helping more than usual."

Primary care-giver: Husband
1. Major concerns: "Shock at the beginning, then you think of wife's comfort, well-being and rehabilitation."
2. Major changes: "Close family now closer still, more intense."
Mrs. I. - Stage I

Patient

1. Major concerns: "Long term survival, knowing the extent of the cancer, future life."

2. Major changes: "None"

Primary care-giver: Husband

1. Major concerns: "My wife getting her head together - adjusting to new shock."

2. Major changes: "None"

Mrs. J. - Stage 1

Patient

1. Major concerns: "Recovery from sickness, hardest on youngest daughter who did more cooking and shopping, shock at beginning, carrying on now."

2. Major changes: "Closer family."

Primary care-giver: Family

1. Major concerns: "Did they get it all out?"

2. Major changes: "Closer family now."
(11) Mrs. K. - Stage III

Patient
1. Major concerns: "Whether treatment will be totally effective, thankful for sister would have found this time very difficult without her."

2. Major changes: "Disruption to sister's life, leaving husband who is not well. Nuisance of clothes because of tenderness."

Primary care-giver: Sister
1. Major concerns: "Shock still, sister always healthy and active; difficult to grasp."

2. Major changes: "I will extend visit until sister starts treatments."

(12) Mrs. L. - Stage I

Patient
1. Major concerns: "The effects of treatment getting prosthesis and getting back to normal."

2. Major changes: "None"

Primary care-giver: Husband
1. Major concerns: "To show love, devotion and togetherness."

2. Major changes: "Always had a good family life and will remain that way."
(13) Mrs. M. - Stage IV

Patient
1. Major concerns: "None"
2. Major changes: "None"

Primary care-giver: Husband
1. Major concerns: "Shock to begin with. We have become well adjusted, wife adjusted and feels her life complete. I know there is no cure for cancer of the liver. There is no reason why you live a certain time."
2. Major changes: "Difficult times ahead, some idea what is involved from doctors. I am going to make everything as agreeable and easy as possible for my wife."

(14) Mrs. N. - Stage I

Patient
1. Major concerns: "Hope treatments will work, not depressed, not worrying."
2. Major changes: "None. Family a bit closer."

Primary care-giver: Daughter (Husband Norwegian and often 'confused' according to patient)
1. Major concerns: "Have they got it all? I have talked to all the doctors."
2. Major changes: "Change in mother's health."
(15) Mrs. O. - Stage I

Patient
1. Major concerns: "I hope my tests are O.K."
2. Major changes: "None"

Primary care-giver: Husband
1. Major concerns: "I believe in doctors, had a broken back half my stomach out. My son is a doctor. All a matter of positive attitude. Radiation is not good for you and it is not necessary."
2. Major changes: "None"

(16) Mrs. P. - Stage I

Patient
1. Major concerns: "Going as strong as ever, walking more, wonder if I should stay with my sister again after operation? She is a very busy, very busy woman."
2. Major changes: "No changes at all."

Primary care-giver: Sister
1. Major concerns: "Want her to get the best of treatment."
2. Major changes: "None"
Comments

Some commonalities were found in primary care-givers responses to the question "What are your greatest concerns?" Thirteen primary care-givers mentioned the patients' well-being. Eight primary care-givers made a reference to their new role in helping the patient. Mrs. G.'s daughter was an exception as she was most concerned about her own chances of getting cancer. Five primary care-givers mentioned the shock of finding out the patient had cancer.

In response to the question "What are the most important changes?" four primary care-givers mentioned the family was "closer". Three primary care-givers were concerned with the patient's anxiety or depression. Mr. F. was concerned about his wife's anxiety, i.e. her going to work when she did not have to go and her sitting up at 3 a.m. doing crossword puzzles. Mr. I.'s concern was that his wife "get her head together". Mr. C.'s concern was about his wife "getting down" and his trying to "stop those feelings". Mr. M. on the other hand, recounted how amazingly well his wife was handling this situation and seemed to consider her an inspiration in dealing with "tough times ahead". All 14 primary care-givers said there were no major changes in family activities, roles and responsibilities. The following commonalities were found in patient's responses to "What are your greatest concerns since you found out you have cancer?":
Seven patients were concerned about their treatments and rehabilitation;
Five were concerned about family roles and responsibilities and relationships with family and friends;
One had socioeconomic concerns; and
Three said they had no concerns.

In response to the question "What are the most important changes if any you have noticed in your family?" these commonalities were found;

Three patients said family roles and responsibilities had changed;
Two patients mentioned their families were showing concern;
Two patients said their family was closer; and
Nine patients said there were no changes.

A comparison of the concerns and changes noted by the patient and those noted by her family

Patient concerns seem to be short-term future oriented focussing on anticipation of treatment, effectiveness and returning to normal daily activities. Family concerns, on the other hand, seem to be long-term future oriented, focussing on their new role in helping the patient fully recover, and on the patient's long-term prognosis.
Practical Changes in Daily Activities,
Family Roles and Responsibilities

The following is an account of patients' and primary care-givers' responses to the table and questions in the interview schedule which would indicate a change in family responsibilities. The patient and her family member response to the table was identical in every case.

Table II  Please indicate the responsibilities of each family member and others before the diagnosis.

Note: If patient and primary care-giver both did same job, both were counted. Therefore tables do not add up to 16 for each responsibility but rather to how many were involved in each responsibility for all 16 households.

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Primary Care-Giver</th>
<th>Children</th>
<th>Neighbours</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Earning income</td>
<td>8</td>
<td>10</td>
<td>-</td>
<td>18</td>
</tr>
<tr>
<td>2.</td>
<td>Sitting down to pay bills</td>
<td>9</td>
<td>7</td>
<td>-</td>
<td>16</td>
</tr>
<tr>
<td>3.</td>
<td>Washing dishes</td>
<td>12</td>
<td>6</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>4.</td>
<td>Meals</td>
<td>16</td>
<td>2</td>
<td>-</td>
<td>18</td>
</tr>
<tr>
<td>5.</td>
<td>House cleaning</td>
<td>16</td>
<td>2</td>
<td>-</td>
<td>18</td>
</tr>
<tr>
<td>6.</td>
<td>Shopping (Groceries)</td>
<td>10</td>
<td>8</td>
<td>-</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>(Supplies)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Yard work</td>
<td>8</td>
<td>10</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8.</td>
<td>Volunteer work</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>Making arrangements for social visits for the family</td>
<td>12</td>
<td>2</td>
<td>-</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td><strong>TOTALS</strong></td>
<td>93</td>
<td>49</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
Is there some area of change in responsibilities which is not on this table? Yes: 0  No: 16
If "Yes" please add it to the table as "Other".

Table III  Please indicate responsibilities of each family member and others after the mastectomy during the second week home from the hospital.

<table>
<thead>
<tr>
<th>TABLE III: AFTER DIAGNOSIS:</th>
<th>Patient</th>
<th>Primary Care-Givers</th>
<th>Children</th>
<th>Neighbours</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Earning income</td>
<td>8</td>
<td>10</td>
<td>-</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>2. Sitting down to pay bills</td>
<td>9</td>
<td>7</td>
<td>-</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>3. Washing dishes</td>
<td>7</td>
<td>10</td>
<td>2</td>
<td></td>
<td>19</td>
</tr>
<tr>
<td>4. Meals</td>
<td>8</td>
<td>7</td>
<td>3</td>
<td></td>
<td>19</td>
</tr>
<tr>
<td>5. House cleaning</td>
<td>6</td>
<td>9</td>
<td>3</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>6. Shopping (Groceries)</td>
<td>5</td>
<td>10</td>
<td>2</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>(Supplies)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Yard Work</td>
<td>6</td>
<td>11</td>
<td>3</td>
<td>1</td>
<td>21</td>
</tr>
<tr>
<td>8. Volunteer work</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>9. Making arrange-</td>
<td>12</td>
<td>2</td>
<td></td>
<td></td>
<td>14</td>
</tr>
<tr>
<td>ments for social visits for the family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTALS</td>
<td>63</td>
<td>67</td>
<td>13</td>
<td>2</td>
<td>146</td>
</tr>
</tbody>
</table>

3. Do you feel you will be able to carry on your regular household responsibilities and chores? The same as before the diagnosis?

15 patients  14 primary care-givers
Nearly as well?  1 patient  0 primary care-givers
Not as well?  0 patient  0 primary care-givers

4. If changes were noted in the above table:
   a) How concerned are you right now about each of these changes?
      Not at all?  16 patients  12 primary care-givers
      Somewhat?  0 patients  1 primary care-giver
      A great deal?  0 patients  0 primary care-givers
   b) Are you concerned about the above responsibilities?
      More:  0  The same:  16 patients and 14 primary care-givers or Less:  0
      than before your wife's, etc. (or your) diagnosis?
      If more is this concern connected to your wife's, etc. (or your) illness?
      Yes:  No:  N.A. All respondents

5. Could you tell me which of the family changes we have talked about is of most concern to you now? Next? Etc.
   All respondents mentioned their perceptions of change in Part A of Section IV.

Comments
During the first two weeks after the mastectomy, families re-organized responsibilities away from the patient towards husbands and/or children, sisters, friends or neighbours. By the time of the interview, usually two to four weeks after
the mastectomy the family said that responsibilities were returning to normal.

**Patients Living with their Husband and Children.**

Five patients lived with their husbands and children. Four husbands and children said they were doing more in household chores at the time of the interview. Mrs. A. denied there were any changes in family responsibilities. However, she later mentioned her daughter was helping with cleaning. Mrs. C.'s daughter postponed plans to leave home so she could look after the household for a few weeks after her mother's operation.

Mr. C. was doing all the cleaning in preparation for selling the house and their son was doing yard work and "trying to help" which amazed Mrs. C. Mrs. C. slept in in the mornings and took an afternoon nap. At the time of the interview, she was still recovering from the operation of two weeks ago, but was starting to cook the meals.

**Couples**

Seven patients lived with their husbands who were their primary care-givers. Four patients noticed a change in their husbands helping with cleaning while three patients noticed no change. Mr. L. cooked and washed the dishes for the evening meal. Mrs. F. traded meals for dish washing with her daughter-in-law next door.
Mr. N. kept house for himself while his wife was staying with her daughter during treatments. Couples tended to notice less change than families with children in household responsibilities, possibly because there is less to do in households of two people.

The Widows

The three widows lived alone, with primary care-givers living with their own families.

Mrs. K. stayed with her friend for two weeks after her operation until her sister arrived from the Interior, at which time she moved back to her own apartment. Mrs. P. stayed with her sister who lived nearby for two weeks and then returned to her own apartment. Mrs. G. was visited each day by her daughter who cooked some of her meals and did the shopping.

In response to the question "Will you be able to carry on your regular household responsibilities and chores?" 15 patients and all 14 primary care-givers responded "the same as before diagnosis". One patient, Mrs. H., said "nearly as well" and seemed to the researcher to be an immaculate house-keeper. All patients and primary care-givers responded "Not at all" to the question "How concerned are you right now about changes in family roles and responsibilities?" The patients' and family members' response to the table noting
changes in responsibilities consistently jibed. Therefore, patient and primary care-giver are aware of the same changes in family responsibilities. Fifteen patients and fourteen primary care-givers said they had no major concerns about changes in their daily practical family responsibilities because they felt changes were temporary. One respondent, Mrs. K.'s sister, had a major concern about practical household responsibilities. She worried about whether Mrs. K. could manage on her own during treatments when she returned to the Interior to nurse her sick husband.

Although both primary care-giver and patients' responses would indicate no change in role and responsibilities, the details of family life given to the researcher indicated considerable changes in responsibilities taken by other family members. This discrepancy may indicate denial as a means of coping with change, or may be a way of keeping the interview away from a painful discussion of private family concerns.

C. Services Requested and Services Received

The following is an account of patients' and primary care-givers' responses to questions on services received and services requested:

6. Have you or your family had any of the following services (if "Yes" name the service, who provided this service and when).
<table>
<thead>
<tr>
<th>Service</th>
<th>Patient</th>
<th>Primary Care-Giver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Household help</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Information services</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Counselling: Individual</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Groups with other patients and families</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VON Home Nursing</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Mastectomy volunteers</td>
<td>16</td>
<td>0</td>
</tr>
</tbody>
</table>

Did you receive these services when you wanted them?

**Patient:**
- Yes: 16
- No: 0

**Primary Care-Giver:**
- 0

Would any of the above services be helpful to you now?

**Patient:**
- 6
- 10

**Primary Care-Giver:**
- 1
- 13

If "Yes" which service would be most helpful? Next? Etc?

**Patients:**
1. Clinic transportation service 2
2. Earlier notification about treatment 2
3. Pre-operative counselling 2
4. Share experiences with other patients 4

**Primary Care-Givers:**
1. Share experience with other primary care-giver 1

**Comments**

In response to the question "What services have you
received? all sixteen patients said they were visited by a 
Mastectomy Volunteer while they were in hospital and found 
this service very helpful. Four patients interviewed were 
receiving Clinic's transportation service and were very 
grateful for this. Three patients received medical information 
about their doctors at the Clinic which they found very 
helpful. Three patients said they received VON home nursing. 
To the question "Did you receive these services when you wanted 
them?", all sixteen patients responded "Yes". In response to 
the question "What services would be helpful?" ten patients 
responded "None". Mrs. A. and Mrs. B. were considering using 
the Transportation service. Mrs. E. and Mrs. K. wished the 
Clinic would let them know earlier when treatments would start 
because they felt they had to stay at home to wait for the 
telephone call, and could not make any short term plans. Mrs. 
D. and Mrs. H. both mentioned the most stressful time for them 
was before the mastectomy and they would have appreciated 
pre-operative counselling.

Thirteen primary care-givers felt they did not need 
any services or more information. Mr. M. felt he would like to 
talk to other family members in the same situation. These 
patients felt that the mastectomy volunteer did not quite meet 
this need because they had already successfully recovered.

9. Changes in Relationships with 
Family and Friends

The following are patients' responses to questions
in Section V, Changes in Relationships with family and friends, found in the interview schedule.

1. Since you found out that you have cancer do you find that your relationships have changed with any of the following:

   Yes: 8       No: 8

   Spouse  
   Child  
   Parent  
   Doctors  
   Friends  
   Relatives  
   Other (Specify

If "Yes" could you tell me any more about this? Responses found in "Comments".

2. Do you see any more or less of your friends now?

   More: 10      Less: 3       About the same: 3

   If more, who usually initiates these contacts?

   Spouse: 0      Self: 0     Friends: 16
   Other: 0

   i) Is this a change?

      Yes: 16       No: 0

   ii) If "Yes" could you tell me more about it? Responses found in "Comments".

   If "Yes" to any change above, are you concerned or worried about these changes? A great deal: 0       Some: 0

   Not at all: 16

   a) If concerned are you worried about these changes

      More: 0      The same: 0      Less: 0
      NA: 16

      than before diagnosis?
3. Have you been able to handle these changes without serious difficulty? NA: 16 Yes: 0 No: 0

4. Do you feel your own behaviour has changed, e.g. more irritable, more cheerful toward any of the following:

Spouse
Child
Parent
Doctors
Friends
Relatives
Other (Specify)

If "Yes" could you tell me any more about this?

i) To what extent do you see these changes as connected to your illness? A great deal: 0 Somewhat: 0 Not at all: 0 NA: 16

ii) Do you have any concern about these changes in your behaviour? No concerns: 0 Some: 0 A great deal: 0 NA: 16

5. Have you told any of your family, friends or work associates you have cancer?

a) Your children Yes 14 No 0 NA 2
b) Brothers-Sisters Yes 8 No 0 NA 8
c) Parents (if alive) Yes 1 No 4 NA 11
d) Neighbours Yes 13 No 3 NA 0
e) Colleagues at work Yes 6 No 2 NA 8
f) Supervisor at work Yes 6 No 2 NA 8

"I would now like to talk about who has helped you deal with the kinds of changes we have been discussing in this interview."
6. If possible, in order of importance, list those who help and indicate how they help you (do not read list):

<table>
<thead>
<tr>
<th>First Choice</th>
<th>Second Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>Doctors: 15</td>
</tr>
<tr>
<td>Child</td>
<td>Clergyman and</td>
</tr>
<tr>
<td>Parents</td>
<td>Friends: 1</td>
</tr>
<tr>
<td>Doctors</td>
<td></td>
</tr>
<tr>
<td>A. Maxwell Evans</td>
<td></td>
</tr>
<tr>
<td>Clinic Staff</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
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<tr>
<td>Clergyman</td>
<td></td>
</tr>
<tr>
<td>Relatives</td>
<td></td>
</tr>
<tr>
<td>Other (Specify)</td>
<td></td>
</tr>
</tbody>
</table>

7. Regarding the person(s) who help(s) you most now, is this the same person(s) who helped you most before the diagnosis?

   Yes: 13  No: 3

(If "No" specify who helped most before - Helped myself)

If "Yes" have you noticed a change in things (he/they) do for you now?

   Yes: 3  No: 13

Comments

In response to the question "Since you found out that you have cancer do you find that your relationships have changed with any of the following?" eight patients responded "Yes". However, the other eight patients who said "No" also mentioned changes in their relationships with others. Therefore all 16 patients noticed some change in this area. All 16 patients said they were concerned "Not at all" about any of these changes.
Relationships with Primary Care-Givers

Four wives, Mrs. E., Mrs. F., Mrs. J., and Mrs. L., said they felt closer to their husbands who were their primary care-givers. A description of these four cases follows.

Mr. E. had told Mrs. E. she was a "wet blanket" and he was going to "put her in the drier" before he took her out. This statement had become a family joke as I heard it twice from Mr. and Mrs. E. Mr. E.'s joking manner was a great morale booster to Mrs. E. who seemed quite depressed to interviewer.

Mrs. J. told me her husband said "Now get with it, quit feeling so sorry for yourself" which had been a turning point in her depression about the operation. She was now helping him with remodelling the house.

Mr. L. said the answer was a great support to Mrs. L. who said had cried when she looked at the scar and seemed anxious and depressed at the time of interview.

Mrs. F.'s husband asked to see the scar the minute she came home from hospital saying "come on, I want to see it". His attitude was a great support to Mrs. F. who did not want to look at herself and did not until several days after her husband saw the scar.

Mrs. C. and Mrs. D. who had not shown the scar to their husbands, were both about the same age, 48-49 and pre-menopausal. The mastectomy was creating some changes in their relationships with spouses. Mrs. C. felt "it was more
my decision" and she "just was not ready" to show her husband the scar. For two weeks post mastectomy, Mrs. C. was on tranquilizers, as her doctor felt the experience would be emotionally upsetting. The doctor had told Mrs. C. not to be alarmed by her depression as this was natural. Mrs. C. gave researcher the impression that she had been depressed before the operation. A week after the mastectomy Mrs. C. went to a party and people mentioned how much better she looked. Both husband and wife told me of this incident. Her husband was very supportive and said "it will take time." The mastectomy seems to have improved Mrs. C.'s relationships with family and friends and particularly with her husband.

Mrs. D. has not shown the scar to her husband and has not had sexual relations since her mastectomy six weeks ago. She had her ovaries removed during the same week and explains the situation as "my husband is leaving me alone until I get better." This explanation is only speculation on Mrs. Martin's part as she has not discussed with her husband why he is "leaving her alone". She seems to be quite concerned about how to handle this situation. She described her marriage several times as "like a rock" explaining that the two operations may have affected her sexual relationship but certainly not her marital relationship. She seemed to separate these two areas clearly in her mind. Mrs. D. also mentioned she was worried about frightening her 12 year old daughter who was very concerned about her mother.
The three widows seemed anxious about being dependent on their primary care-givers for too long and each mentioned they were concerned about imposing on their busy lives. Mrs. P.'s second mastectomy was affecting her relationship with her sister. She was deciding whether she should impose on her again by staying with her for two weeks after her second operation. Mrs. K. who did not want to stay alone in her apartment, was concerned about keeping her sister from her sick husband. The researcher speculates that the longer the primary care-giver is requested to provide help the more anxious the single person becomes about creating an imposition.

Four patients, Mrs. A., Mrs. F., Mrs. I., Mrs. M., were frustrated by the fact they could not do more and were becoming someone for people to "fuss over". Mrs. I. mentioned that "her mother and sister telephoned daily to see if she was all right" which annoyed her. Mrs. M. told researcher she has to tell people who telephone "just do not worry, I am perfectly all right."

Mrs. F. says "my husband spoils me does anything I want" which seemed to upset her. Mrs. A. said "my children tried to pamper me, but I would not sit still." The researcher speculates that this annoyance may be connected with discomfort of the sick role and some role-reversal on the part of family members who, in taking the role of mother and nurse, may make the patient anxious. Moreover, although cancer is a serious
disease, the recovery after mastectomy is usually rapid with few serious complications. Therefore the patient may not feel sympathy for her illness is warranted although she does need some understanding of her fears about having breast cancer.

Three patients, Mrs. F., Mrs. H., and Mrs. I. mentioned their difficulty in "not overdoing" and becoming tired. The husbands of these patients seemed aware of this concern and felt responsible to monitor their wives' activities, which seemed to change their relationships. Mr. H. asked the researcher whether he was doing too much or too little in the house and seemed anxious about his new role. His wife who had five children, two still at home, was an excellent house-keeper, baked bread every week and kept 2½ acres of garden and forest. Currently Mrs. H. was anxious, particularly about the garden. She was frustrated also with her sore arm and tended to "overdo it". Mr. H. felt responsible for allowing her to rest but he did not want to treat her as an invalid. This role was a difficult one for Mr. H. who never had done housework or gardening before. Mrs. H. recognized that her husband was a great support to her in this way by doing some of the work she "wanted to get done".

Nine patients perceived this experience as bringing them closer together as a family. Three patients mentioned this experience also brought them closer to other people. Mrs. H. said "I always was the strong one people came to me
for help. Everyone at church was floored. This experience has been a learning experience for me and has brought me closer to people." In response to the question "Do you see more or less of your friends now?" ten said "more" and three said "about the same" and three said "less". Of the ten who said "more" their friends were initiating more of the contacts and this was a change.

Mrs. A. and Mrs. J. both said "I did not know how many friends I had." Of the three patients who were seeing less of their friends, Mrs. M. could not have big dinner parties because of nausea. She said "I love company and feel badly that I cannot have people over." The two other patients, Mrs. G. and Mrs. I., were seeing less people because they were not working. All sixteen patients responded "not at all" to the question "Are you concerned about any of these changes in relationships?"

In response to the question "Do you feel your own behaviour has changed" all sixteen patients responded "No".

Generally speaking, all sixteen patients had the impression that they told everyone about their cancer diagnosis. On specific questioning, several persons were identified as not being told. Mrs. A., Mrs. D., and Mrs. I. did not tell their husbands' mothers because they were "too old" and the diagnosis would worry them. Mrs. A. did not tell her father for the same reason. Mrs. C., Mrs. D., and Mrs. P. did not tell their neighbours who they did not know
too well. Mrs. I. did not tell her principal or some of her teacher colleagues for fear of jeopardizing her employability.

All fourteen mothers told their children.

In response to the question "List those who help you if possible in order of importance" all 16 patients listed their families and primary care-givers first, 15 patients' second choice was their doctor and Mrs. H. chose her clergyman.

In response to the question "Regarding the person who helps you most now is this the same person who helped you before the diagnosis?" 13 responded "Yes" and the three widows responded "No" specifying "myself" as the person who helped before. Three patients, Mrs. E., Mrs. F., and Mrs. H., noticed a change in things primary care-givers did for them now specifying that families showed more concern.

10. Feelings About Self

The following are patient responses to questions in the interview schedule on changes in feelings about self.

1) How much would you say your feelings about yourself have changed toward any of the following:

   a) feelings of personal attractiveness?
      Unable to say: 0  Not at all: 10
      Somewhat: 6  A great deal: 0

   b) Feelings of being competent within and outside the home?: 0
c) Ability to be independent?: Somewhat: 1

d) Feelings towards fulfilling others' expectations and being responsible?: Somewhat: 1

e) Feelings of being able to maintain present level of income and living conditions?: 0

f) Other (specify)?: 0

If somewhat or a great deal which of the above concerns you the most? Next? NA = X

2. Of all your concerns which we have mentioned in this interview, what would most likely help with at this time? Three patients said help with prosthesis; 13 patients said "no help needed".

3. Would you like to add any further comments?

   No: 7  Clinic very helpful: 9

   Comments

   In answer to the question "How much would you say your feelings about yourself have changed?" six patients felt their feelings of personal attractiveness had changed somewhat. Mrs. E. also felt her feelings about ability to be independent and fulfilling others' expectations had changed somewhat. No other changes in feelings about self were mentioned when the question was asked directly but several people reported changes in feelings about self during the course of the interview. Mrs. C. commented that
she got more upset about other things than her health, such as bursting into tears over selling the house. Mrs. I., in talking about her work role, also mentioned that she always had an image of herself as strong and healthy which had now changed. Mrs. L. said she felt "uncomfortable" with herself and had not gone to church since the mastectomy because as she says "people are so inquisitive, particularly the young ones". Mrs. E. said she felt embarrassed and said she would not go out to play bingo until she got a prosthesis.

In response to the question "Of all your concerns which we have mentioned in this interview what would you like help with most at this time?", three patients, Mrs. E., Mrs. F., and Mrs. L., mentioned help with the prosthesis, the other thirteen patients said they did not need any help.

In response to the question "Do you have any further comments?", seven patients said "no" and nine said "yes", commenting that they were "very happy with the Clinic's treatment of them as patients." Mrs. K. added "this was the first time a doctor ever shook my hand."

This concludes an account of patient and family members' responses to the interview schedule.

11. **Degree of Concern and Amount of Change**

Although the interview schedule's measure of degree of concern or change was not reliable, the researcher feels a subjective account of the researcher's perception of degree of anxiety may be useful. The researcher felt that eight patients perceived more changes and were generally more
anxious about their situation than the other patients. This greater anxiety was indicated to the researcher in the following ways: Mrs. C. said she was more upset and tearful about other things recently and was on tranquilizers. Mrs. D. said she was very anxious about treatments and said she "hated that place" in reference to the Clinic.

The three husbands of Mrs. E., Mrs. F., and Mrs. I., said their wives were unusually "highstrung" and "uptight" and these three patients mentioned many concerns to the researcher. Mrs. K. and Mrs. L. mentioned having dreams, waking in the night and said they were anxious about treatment effectiveness. The profiles of these eight patients do not appear similar in any way, although all eight mentioned difficulty in either adjusting to loss of a breast or loss of good health. The researcher speculates that this anxiety may be attributed to the attitudes of these eight patients toward the value of their breasts and good health prior to diagnosis and surgery. This association has been mentioned in the literature. However, as this study did not explore the value of the breast to the patient prior to surgery, this idea is still pure speculation. Possibly these eight patients were naturally more inclined to be anxious than the other eight patients.

12. Other Findings

A number of other findings were discovered during
the interviews which were not connected to specific questions in the schedule.

**Old Depressions**

The researcher found that in talking about the mastectomy patients brought up sources of depressions in the past.

Mrs. P. told the researcher about the heart attack of her husband, the almond poisoning of her brother and the sudden death of her brother-in-law as if the mastectomy related to other losses and endings and was just another thing to cope with in life.

**Recognition of Mortality**

Mrs. M. (who had liver metastasis) and the widows Mrs. G., Mrs. K., and Mrs. P., wished to tell the researcher about their lives and showed old pictures of themselves with husbands and children, rather than talk about their mastectomy experience. The researcher felt this was an indication that these ladies were spending some time looking back over their lives and experiencing a sudden awareness of mortality and past endings. This finding may also indicate a certain degree of denial.

**Breast Phantom and Loss**

Three patients, Mrs. E., Mrs. F., and Mrs. L seemed to particularly express their feelings of "loss" after the
mastectomy to the researcher.

Mrs. L. who was quite heavy breasted mentioned she experienced phantom limb sensations in her missing breast. Mrs. L. said she had cried and felt "really bad" about herself on first returning home from hospital, which seems to indicate a deep sense of loss. Mrs. E. and Mrs. F. also quite heavy breasted mentioned difficulty with the other breast in creating a lopsided, unbalanced feeling about themselves, which indicated their sense of loss. These three patients were very concerned about how soon they could wear a prosthesis. The other 13 patients did not express this specific anxiety about obtaining a prosthesis.

**Denial**

Denial of changes and concerns seemed to be in evidence most strongly in two cases, Mrs. A. and Mrs. B., who both had Stage II cancers with "guarded" prognoses. As was previously mentioned, "denial" may be an effective coping strategy to help patients adjust to future changes in health. Their diagnoses and "guarded" prognoses may be connected to their denial of changes or concerns at the time of the interview. A synopsis of the interviews with Mrs. A. and Mrs. B. and her husband, follow to illustrate the interviewer's perceptions of denial in these two cases.

Mrs. A.

**Case Synopsis:** Mrs. A.'s main concern was that treatment
will delay holidays and she will not be able to take her 14 year old on a promised trip to Disneyland. "There is no change in this family at all" she says. "I was out digging in the garden the day I was out of hospital." My husband says "there is no change so why bother to be interviewed." Mrs. A. later said she notices a change in feeling closer to her family. She said, "The children showed a great deal of concern." Mrs. A. said "the children attempt to pamper me but gave up because I would not sit still." She later said after the scheduled interview was over that her 21 year old daughter was helping with some cleaning, cooking and shopping. Mrs. A. sees more of her friends now: "I did not realize how many close friends I had."

She feels a slight change in personal attractiveness but no other changes in self. She adds "I'm very healthy now, the muscles hurt in my arm but it's just a matter of time." Mrs. A. added she does not get down because she "just gets up and does something." Mrs. A. has a Stage II cancer with a guarded prognosis. Interviewer had impression denial was allowing her to remain cheerful and carry on as if everything were back to normal although she was aware she would be having treatments for one year. Also, interviewer felt husband must be under some stress because he originally said he would like to be interviewed and then changed his mind. The researcher had the impression he was not involved at this time in his wife's recovery, which she appeared to want to handle herself.
Mrs. B.

Case Synopsis: Mrs. B.'s response to "What is your main concern?" was: "not a darn thing - no sense, no feeling." Her husband did the cooking her first week out of hospital but after that she carried on as normal. Mrs. B. impressed upon me the fact that there were no changes except "her son calls often." Interviewer had impression Mrs. B. also a Stage II cancer patient, took a similar approach to denial as Mrs. A. although the interview with Mrs. B. took place later, seven weeks after mastectomy.

Primary Care-Giver Interview:

Synopsis: Mr. B.'s main concern is his wife's health, and whether treatment will be successful. He says "they claim they can fix it - it's still up in the air you know." He adds: "This hit us like a time bomb - I just hope that my wife is taken care of by this bomb shell (cobalt)!" As far as changes in family roles and responsibilities, Mr. B. says "we carry on pretty much as before - I do more of the dishes and shopping though. She's not in any pain at all, no pain whatsoever - feels nothing really."

Interviewer had impression husband was actively involved in patient's recovery, seemed to put words to Mrs. B.'s feelings and recognized her denial of changes at this time.

The Next Stage - 10 Months after the Mastectomy

Mrs. O. had her mastectomy in August 1977 and was
returning to the Clinic for follow-up tests for possible recurrent disease. At the time of interview, she was waiting for the results from these tests. Mrs. O.'s major concerns focused around a search for causality in order to change her lifestyle and diet and thus remain healthy. Mrs. O. had decided in the last few months that it was the bacon fat in her diet and many changes in residence that caused her breast cancer. Therefore, changes in her life currently involved a decision to modify her diet and move back to her home in the Maritimes, where the life was familiar and less stressful.

13. The Independent Variables Which Seemed to Influence Perceptions of Socioeconomic Change and Concerns, as previously posed in the problem formulation.

The treatment plan proposed and time of interview

The seriousness of the diagnosis, either Stage I, II, III or IV, did not seem to influence perceptions of socioeconomic change. However, the patients' current experience with treatment did seem to influence perception of change and degree of concern.

The ten patients interviewed before their radiation treatments seemed to be the most anxious, to have the most socioeconomic concerns and to be future oriented, anticipating the end of treatment. Mrs. K., Stage III, and Mrs. E., and Mrs. F., Stage I, had socioeconomic concerns and also mentioned problems with sleeping. The four patients, i.e.
Mrs. I., Mrs. L., Mrs. M., and Mrs. N., interviewed during treatments seemed to be generally less anxious than patients awaiting treatment. Mrs. N. said "you just take each day at a time." The two patients, Mrs. G. and Mrs. J., interviewed after tests and/or treatment, seemed the least anxious about medical concerns and were thinking more about the long range future. Mrs. G. was wondering when and if she should return to work. Mrs. J. said "I just hope I do not have to go through all this again"; and was planning to return to normal activities at her own speed. Therefore the respondents' perceptions of current socioeconomic concerns seem to be influenced by the time interviewed in terms of treatment.

Previous Experience with Cancer

In response to the question "Have you or any family member had any previous experience with cancer as an illness?", 12 patients responded "Yes". Three fathers, two mothers, four brothers and sisters, four aunts and uncles, two grandmothers and one nephew were mentioned by patients as having cancer. Mrs. P.'s mother died of breast cancer, and this may affect her perception of herself "going stronger than ever." Mrs. M.'s father-in-law died of liver cancer and this experience may affect her attitude "I am fine, do not worry." These two patients took more of an optimistic stance about their illness treatment and their socioeconomic situation than Mrs. E. or Mrs. K., who had no previous experience with cancer.
**Previous Illnesses**

Women who had no previous illness or serious operations before seemed to be more uncomfortable with the sick role, and with having cancer. They also perceived more socioeconomic concerns. Therefore perceptions of socioeconomic change seem to be influenced by previous experience with illness.

Three patients responded "Yes" to the question "Have you experienced any previous illnesses?" Mrs. M. had experienced a hernia and glaucoma, Mrs. J., a collapsed womb, and Mrs. P., a thyroidectomy. These patients seemed to adjust more easily to the sick role and to be less anxious about their socioeconomic situation than the 13 patients who had not experienced previous illness. Mrs. H., who had never been ill, said "I have always been the strong one. It is still a shock this cannot be happening to me."

The primary care-givers of Mrs. J., Mrs. M. and Mrs. P. seemed to also adjust and adapt more easily to the patients' sick roles than Mr. H. who had never known his wife to be ill.

**Living Situation and Age**

The three widows who lived alone seemed to show the most concern about their socioeconomic situation. Their concerns were future oriented. Mrs. K.'s concerns lay with future housing, Mrs. G.'s concerns with potential employability, and Mrs. P.'s concerns with finding something to fill her life since her husband's death. All three widows expressed some
fears about imposing too long on their primary care-givers, who did not live with them, but on whom they were temporarily dependent. This anxiety created stress on their relationships with primary care-givers and added anxiety to their socioeconomic situation.

Mrs. I., the married school teacher in her thirties without children, had a unique socioeconomic concern about her future employability and life expectancy.

The women in their 40's and 50's and early 60's, living with husbands and children seemed somewhat anxious about their socioeconomic situation, particularly if they were employed, even though they were aware of their families' support. The cancer diagnosis seems to have brought to this age group a sudden awareness of mortality and possible change in employability, life expectancy, sexual attractiveness and lifestyle with their husband in future retirement.

Women in 60's or 70's living with husbands in a retired quiet lifestyle adjusted with the least socioeconomic change or concern to the diagnosis and treatment of breast cancer. As Mrs. M. said "at our age (79) you begin to accept these things." Mr. B. said "things go on pretty much as before." Patients in this age group seem already to have some acceptance of mortality. Patients' concerns centred more around feelings of personal attractiveness, their appearance, and social concerns about people looking at them or others worrying too much.
Services Received Prior to Interview

The services received or not received by patients did not seem to influence the universally positive attitude of patients toward the Clinic staff. Although Mrs. D. said she "hates the place", she explained it was not the people, psychological reaction to going there for treatment.
Chapter V

SUMMARY AND RECOMMENDATIONS

1. Summary

The purpose of this study was to identify some of the needs of breast cancer patients and their families which arise from socioeconomic change and changes in roles and relationships after the mastectomy. As research with cancer patients is relatively new at the Clinic, the exploratory nature of this study was stressed in the problem formulation. The design allows for needs to be identified through requests for service by the respondents themselves and through the researcher's perceptions of needs from personal interviews about socioeconomic changes and concerns. This exploration of the needs of breast cancer patients will improve the planning and implementation of support services to breast cancer patients and their families by the professional team at the A. Maxwell Evans Clinic.

The scope of this study was restricted to considering new breast cancer patients referred to the Clinic in May, 1978 and their primary care-givers. The sample was stratified to allow for representation of the four stages of cancer. Two patients in the sample had received a cancer diagnosis before. One of these patients was experiencing recurrent disease. The remaining 14 participants were experiencing their first diagnosis and treatment of cancer.
The focus of the study was the perception of the patient and the primary care-givers of socioeconomic change, changes in roles and relationships in their family and their feelings about self. The interview schedule gathered demographic and medical information, perceptions of diagnosis and treatment, perceptions of changes in place of residence, changes in work roles, income and transportation, changes in family responsibilities, relationships with family and friends and feelings about self. The main source of data was the interview schedule and information gathered by the director of the New Patients Clinic from patient files. All patients and primary care-givers were interested in talking with the researcher and had a variety of questions to ask of the researcher. The respondents' level of involvement seemed to improve toward the end of the interview if the researcher took time to discuss what was of pressing interest or concern to the respondent regardless of the interview schedule. The findings from responses to the interview schedule indicated that all patients and primary care-givers perceive some changes in socioeconomic situation and/or roles and relationships, but these changes were perceived to be minor and of only a moderate degree of concern. Family members and patients agreed on the number of practical changes in their daily family roles and responsibilities and no respondent said he or she was "very concerned" about these changes. As mentioned in the literature review, breast cancer patients
often use denial as a coping strategy particularly in the first month after the mastectomy. Therefore, denial, as defined for this study, was given consideration in interpreting the findings. However, this design does not offer a way to measure the degree of influence of denial on the findings. The researcher reports that eight patients showed a greater degree of anxiety than the others as indicated by their comments about not sleeping, dreaming, taking tranquilizers and being generally upset. The researcher recognized that although these patients did not have similar profiles they all indicated a difficulty in adjusting to loss of a breast or to loss of good health. The researcher speculates whether the value of the lost breast may be associated with post-mastectomy anxiety. This association is mentioned in the literature.

All patients and primary care-givers who needed practical services were recieving them and at the time they were needed. A few patients and primary care-givers mentioned needs for emotional support services. All patients were very pleased with the treatment they received from the staff at the A. Maxwell Evans Clinic.

2. **The Suitability and Limitations of the Instrument**

The interview schedule's focus on socioeconomic concerns and changes in roles and relationships to identify patient needs was successful for three reasons. Firstly, as
breast cancer patients usually have a favourable prognosis, their thoughts are usually focused towards rapid rehabilitation and a future daily life without disability. Therefore, discussing concerns about socioeconomic changes, changes in roles and relationships and feelings about self seemed to be relevant to their needs. Secondly, this focus was also non-threatening for breast cancer patients who may not wish to discuss their psychological adjustment to mastectomy. If patients wished to talk about their emotional adjustment, they did so voluntarily. Thirdly, socioeconomic change and family roles and relationships is relevant to the social service department's mandate. Therefore, as a social work study, this research identified needs from the social work perspective at the Clinic. In this way, needs and services recommended from this study will have a recognizable base from which to consider practical applications of the findings.

However, the structured interview schedule had two limitations in this exploratory study. Firstly, the responses to the two scales which measured degree of concern and amount of change across the areas of socioeconomic change resulted in little variability. Possibly the scalar measures were not suitable for the time and situation of these respondents. Some recognized scalar measures of anxiety such as the Spielberger Anxiety Scale, would have been useful to complement open-ended questions on degree of concern.
Secondly, a more loosely structured schedule focused on the same topics, would have lent more easily to the conversational interview style which the researcher found essential for this kind of exploratory study.

3. **Conclusions**

1. The majority of patients and primary care-givers felt their families were "closer" as a result of this experience. The researcher concludes that families may often strengthen and see the need to strengthen to maintain an unchanging stability through the stress of a cancer diagnosis and treatment.

2. Denial is often a noticeable strategy for patients and primary care-givers to handle this stressful experience.

3. Widows seem to have the most socioeconomic concerns and experience the most anxiety about change. These patients also fear that future needs may eventually be impositions on their primary care-givers. The primary care-givers did not indicate to the researcher or to the patient that they felt imposed upon. The researcher concludes that single persons and widows have unique concerns from patients who live with their primary care-givers.

4. All 11 husbands interviewed felt responsible and concerned about their wives' rehabilitation. These husbands were involved in a temporary role-reversal in the home and 8 seemed to the researcher to be somewhat uneasy with this change. One husband asked researcher if what they
were doing was enough or should they do more. Another husband said it would be helpful to talk to other primary care-givers in the same situation. The researcher concludes that the husband as primary care-giver wants to be involved in helping the patient in recovery and that some are uncertain about the best way to do this.

5. All patients seemed to find waiting for the mastectomy operation and then waiting for Clinic cancer treatments the two most stressful time periods. Most patients do not seem to be aware that the Mastectomy Volunteers can help with pre-surgical counselling as well as post-surgical rehabilitation. The researcher concludes that "waiting for treatment" is a problem for some cancer patients.

6. Patients mentioning the value of talking to other patients going through the same experience were usually patients who had met other patients in the transportation service or at the hospital and found this helpful. The researcher concludes that if patients are already finding other patients to talk about concerns, a need has been identified.

4. Recommendations

1. Future research needs to be conducted to explore the unique concerns of the widow and single person in the face of a cancer diagnosis. This study should also involve the stress on the relationship between the single person and primary care-giver.

2. More research needs to be done to investigate the role
of denial in helping and/or hindering cancer patients to adjust to diagnosis, treatment and rehabilitation.

3. More research is needed to investigate the influence of the value of the lost breast on the patient's rehabilitation and relief from anxiety after surgery.

4. A study of primary care-givers and patients of different types of cancer with the focus "What are the best activities and attitudes for the primary care-giver (and family) to have in order to help the patients?" would be most useful.

5. A weekly telephone follow-up from the social work department to patients waiting for their treatments to start would alleviate their general anxiety. This telephone call may also serve to answer questions which seem to occur to patients while they are resting at home.

6. The patient who is waiting for surgery would be reassured if she were informed routinely about the pre-surgical counselling service of the mastectomy volunteers sponsored by the Canadian Cancer Society. The surgeon's nurse could be responsible for informing patients.

7. A voluntary group ideally for all new breast patients beginning treatment at the Clinic would have an educational rather than a therapeutic focus for patients who wished to share concerns and questions about changes in family roles and relationships, socioeconomic change, and changes in health and feelings about self with other patients in
the same situation. As all patients mentioned some changes in roles and relationships, the researcher feels that a need has been identified. The mastectomy creates feelings of loss and anxiety in many patients. The group would help patients to accept these feelings as part of their natural adjustment and return to normal daily activities.

These needs for support are now often left to the family's responsibility who may not know how or be allowed to help by the patient.

If the group were led by a social worker, this may help to broaden the role of the social worker to someone who deals with education as well as family and socioeconomic problems.

A support group for breast cancer patients would also serve to identify needs for extra counselling and help which would not be identified through socioeconomic problems on the admission forms of local patients.

8. A long-range demonstration and research project to voluntarily involve ideally all primary care-givers of breast patients, particularly husbands, and patients in an educational program about the primary care-giver's role and how one can best help the breast cancer patient with her unique needs for rehabilitation. Some educational advertising would probably be necessary to encourage husbands to participate.


6. Ibid.


12. Ibid., p. 661

13. Ibid., p. 662

14. Ibid., pp. 662-663


33. Klein, p. 1662.

34. Ervin, p. 42.


37. Polivy, p. 77.


42. Ibid.

43. Wellisch et al, p. 543.


46. Schoenbert, p. 120.
47. Klein, p. 1661.


53. Cope, p. 269.


61. Akehurst, p. 182.


63. Markel, p. 1678.

64. Klein, p. 1664.


73. Goldsmith, p. 1672-1675.

74. Ervin, p. 75.

75. Markel, p. 1676

76. Harrell, p. 676


79. Ibid.

80. Wellisch, 432-436.
SELECTED BIBLIOGRAPHY


Jackson, D. "On the Question of Family Homeostasis." Psychiatric Quarterly Supplement. 31 (1957): 79-86.


Magarey, Christopher J. and Todd, Peter B. "The Doctor and the Patient in Early Breast Cancer Diagnosis." Australian Family Physician. 6 (March 1977): 243-244, 248-249, 251.


Dear

A research project to discover some of the experiences and needs of new breast cancer patients to the A. Maxwell Evans Clinic and their families is being undertaken under the auspices of the Social Service Department of the A. Maxwell Evans Clinic.

We are concerned to discover what changes, if any, have to be made in daily living and planning for patients and their families. At the present time there is very little known in this area and, of course, such information is essential for the planning of services for patients. We are asking you to help us acquire this information and, therefore, would like to interview you and a member of your family in separate sessions, regarding your experiences. Of course, all information is confidential.

We will be contacting you by telephone within the next week to arrange appointment times and hope you will be interested in participating with us.

Yours truly,
APPENDIX C

PATIENT INFORMATION FOR RESEARCH PROJECT
(given to Out-Patient doctors to fill out for researcher)

NAME ____________________________________________

ADDRESS _________________________________________

PHONE NUMBER ____________________________________

PRIMARY CARE-GIVER ________________________________

DIAGNOSIS _________________________________________

PROGNOSIS _________________________________________

STAGE _____________________________________________

TREATMENT TO DATE OR SCHEDULED FOR THE FUTURE:

<table>
<thead>
<tr>
<th>TYPE</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>SURGERY</td>
<td></td>
</tr>
<tr>
<td>CHEMOTHERAPY</td>
<td></td>
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<tr>
<td>RADIOTHERAPY</td>
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<tr>
<td>OTHER</td>
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</tbody>
</table>
APPENDIX D

TELEPHONE CONTACT TO ARRANGE INTERVIEW TIME
(with people who gave prior consent)

Hello Mrs.___________. This is Margot Jessup calling. Did Dr.__________ tell you about my study with new mastectomy patients? I am calling to see if you would like to participate in this study? Do you have any questions about this study or about myself? Have you talked the study over with your (primary care-giver)? Would he/she like to participate also? I would like to talk with you both, individually, if this is convenient with you. What time would be the best to interview you and your (primary care-giver)? Would you like to be interviewed at your home or another place (e.g., Clinic after 4:30 p.m., U.B.C. until 5:00 p.m., or interviewer's home)? Thank you very much. See you on__________. Bye.
INTRODUCTION  (to be read by the interviewer to the interviewee)

The Clinic is interested in learning more about the changes that you see in your life since you found out that you have breast cancer. You can help us to improve service to other patients who are newly diagnosed and their families. You and your family's help are very important to us. The changes we are thinking about have to do with work, place of residence, changes in yourself and family responsibilities, as well as new concerns you and your family may be having at this time.

In participating in the interview, you are not required to answer any questions with which you are not comfortable.

Schedule I - The Patient Interview Schedule

General Information

1. Name: ________________________________

2. Address: ________________________________

3. Marital Status: ________________  Years Married: _________
4. Members in Immediate Family and Age and Employment:

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Present Employment</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

Note: *Those living with patient **Primary care-giver

5. Ethnic Background and Language Spoken at Home:

6. Religion:____________________

I Diagnosis, Treatment and Previous Experience with Illness

To begin this interview I will ask a few questions about your treatment.

A. Diagnosis

When did you first know you had breast cancer?

Date:____________ What happened at this time?________

B. Treatment

____________ Biopsy? Date:____________
Mastectomy? Date: 

Who told you and how? 

1st Appointment at Cancer Clinic - Date? 

C. Previous experience with cancer and other illnesses.

Have you or any family member had any previous experience with cancer as an illness?

Previous illnesses 

Is your treatment complete now? Yes: No:

If "No", how much longer is it expected to last?

II Changes in Place of Residence

I would like to ask you now about your place of residence.

Open:

Are you a resident of ________________________ ?

1. For how long have you lived in the city (or district of _________)? Years: _______ Months: _______

2. During the past two years have you changed your address? 

   Yes: _______ No: _______

3. Since you found out you had breast cancer have you changed your address? 

   Yes: _______ No: _______

Have you made plans to do so? 

   Yes: _______ No: _______

If "Yes", was your decision to move influenced in any way by your discovery that you have breast cancer?
III  Changes in Work Activities Outside the Home and Transportation

Now I would like to ask you about work activities outside the home and transportation.

A. Work Activities

A. Are you employed outside the home?

Yes: _______ No: _______

B. Do you do volunteer work?

Yes: (specify) _______

No: ______________________

Do you anticipate your treatment will affect your volunteer work?

Yes: (specify) _______

No: ______________________

C. If employed outside the home:

1) What is your job? ________________________________

2) For how long have you worked at this job?

Years: _______ Months: ______________________

3) Are you working now?

Yes: _______ No: _______

a) If "No", do you anticipate returning to work?

Yes: (When?) _______

No: ______________________

b) If "No", does this have anything to do with:

i) Your present illness?

Yes: _______ No: _______

ii) Other recent or current illnesses of yours or family members?

Yes: _______ No: _______
iii) Previous experiences with cancer?

Yes:_________ No:_________

iv) Other? (Specify)

______________________________

______________________________

4) If you are currently working or anticipate returning to work:

1) Will there be a change in hours, job responsibilities, work conditions or income?

Yes:_________ No:_________

a) If "Yes", could you say more about how this change may come about?

i) Has anyone indicated to you there may be a change?

Yes:_________ No:_________

ii) Do you anticipate you will feel well enough to continue your present job?

Yes:_________ No:_________

iii) Do you feel these changes are in any way a result of your illness?

Yes:_________ No:_________

B. Transportation

Do you drive a car? Yes:_________ No:_________

a) If "Yes", are you able to drive now?

Yes:_________ No:_________

b) If "No", does someone drive you?

Yes:_________ No:_________

i) If "Yes", who? ________________________________
c) What transportation do you have to your treatments at the Maxwell Evans Clinic?

IV New Family Concerns, Roles and Responsibilities

Note: This Section is also Schedule II - The Primary Care-Giver Interview

I would now like to ask about any effects that finding out you (or your spouse, daughter, mother, etc.) has breast cancer may have had on family activities and responsibilities as well as new concerns you and your family may be having at this time.

A. Major Concerns and Perception of Changes

1. In general, could you tell me the main concerns you and your family have at this time, since you found out (or your spouse, daughter, mother) has breast cancer?

2. Since the diagnosis, what are the most important changes, if any, you have noticed in your family?

B. Practical Changes in Family Roles and Responsibilities

We have a list of practical changes which people have often experienced. We wondered if any of the following changes apply to you?

A. Please indicate by writing in "All", "Most", "Some" or "None", the share of responsibilities of each family member and others before the diagnosis.

For "Children" and "Others" please indicate name as well as the share of responsibility.
## TABLE A: BEFORE DIAGNOSIS

<table>
<thead>
<tr>
<th>Patient</th>
<th>Spouse</th>
<th>Children</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Earning Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Sitting down to pay bills</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3. Washing dishes</td>
<td></td>
<td></td>
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<tr>
<td>4. Meals</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. House cleaning</td>
<td></td>
<td></td>
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<tr>
<td>6. Shopping (Groceries)(Supplies)</td>
<td></td>
<td></td>
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<tr>
<td>7. Yard work</td>
<td></td>
<td></td>
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<tr>
<td>8. Volunteer work</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>9. Making arrangements for social visits for the family</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>10. Other</td>
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</tbody>
</table>

Is there some area of change in responsibilities that is not on this table?

Yes:_________ No:_________

If "Yes", please add it to the table as "Other".

B. Please indicate by "All", "Most", "Some" or "None" the share of responsibilities of each family member and others after the diagnosis. For "Children" and "Others" please indicate name as well as share of responsibility.
TABLE B: AFTER DIAGNOSIS

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Spouse</th>
<th>Children</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Earning Income</td>
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<tr>
<td>10. Other</td>
<td></td>
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</tbody>
</table>

3. Do you feel you will be able to carry on your regular household responsibilities and chores?
   The same as before the diagnosis?
   Nearly as well?
   Not as well?

4. If changes were noted in the above table:
   a) How concerned are you right now about each of these changes?
      Not at all?
      Somewhat?
      A great deal?
   b) Are you concerned about the above responsibilities:
      More:_______ The Same:______ or Less:_______
      than before your wife's, etc. (or your) diagnosis?
If more is this concern connected to your wife's, etc. (or your) illness?

Yes:______  No:______

5. Could you tell me which of the family changes we have talked about is of most concern to you now? Next? Etc.

C. Services Received and Services Requested

Now I would like to say a word about services.

6. Have you or your family had any of the following services: (If "Yes", name service, who provided this service and when)

a) Transportation:

b) Household help:

c) Information services:

d) Counselling: Individual:

Family:

e) Groups with other patients and families:

f) Other:

7. Did you receive these services when you wanted them?

Yes:______  No:______

8. Would any of the above services be helpful to you now?

Yes:______  No:______

If "Yes", which service would be most helpful? Next?

Etc.  __________________________________________________________

____________________________________________________________
V Changes in Relationships with Family and Friends

Now I would like to talk about any effects that finding out that you had breast cancer might have on your relationships with your family and friends.

1. Since you found out that you have cancer do you find that your relationships have changed with any of the following:

   Yes No

Spouse
Child
Parent
Doctors
Friends
Relative
Other (Specify)

a) If "Yes" could you tell me any more about this?

2. Do you see any more or less of your friends now?

   More: ________ Less: ________ About the same: ________

a) Who usually initiates these contacts:

   Spouse: ________ Self: ________ Friends: ________ Other: ________

   i) Is this a change?

      Yes: ________ No: ________

   ii) If "Yes" could you tell me more about it?

3. If "Yes" to any change above are you concerned or worried about these changes? A great deal: ________

   Some: ________ Not at all: ________
a) If concerned are you worried about these changes:

More:______ The same:______ or Less:______

than before diagnosis?

Have you been able to handle these changes without serious difficulty?

Yes:______ No:______

4. Do you feel your own behaviour has changed, e.g. more irritable, more cheerful toward any of the following:

Yes No

Spouse
Child
Parent
Doctors
Friends
Relatives
Other (Specify)

a) If "Yes" could you tell me any more about this?

i) To what extent do you see these changes as connected to your illness?

A great deal:______ Somewhat______

Not at all:______

ii) Do you have any concern about these changes in your behaviour?

No concerns:______ Some:______

A great deal:______

I would now like to talk about who has helped you deal with the kinds of changes we have been discussing in this interview.
6. If possible in order of importance, list those who help and indicate how they help you (Do not read list):

Spouse
Child
Parent
Doctors
A Maxwell Evans Clinic Staff
Friends
Clergyman
Relatives
Other (Specify)

7. Regarding the person(s) who help(s) you most now: is this the same person(s) who helped you most before the diagnosis?

Yes:_______ No:_______ (If "No" specify who helped most before)

If "Yes", have you noticed a change in things (he/she) do for you now?

Yes:_______ No:_______

VI Changes in Feelings about Self

I would like to ask you a few questions about your feelings about yourself.

1. How much would you say your feelings about yourself have changed toward any of the following:

a) feelings of personal attractiveness

Unable to say Not at All Somewhat

A great deal

b) feelings of being competent within and outside the home

c) ability to be independent
d) feelings toward fulfilling others' expectations and being responsible

e) feelings of being able to maintain present level of income and living conditions

f) other (specify)

If somewhat or a great deal, which of the above concerns you the most? Next?

2. Of all your concerns which we have mentioned in this interview, what would you most like help with at this time?

This questionnaire is to help the Maxwell Evans Clinic improve its service to patients and families.

3. Would you like to add any further comments?
   Do you have any questions you wish to ask me?
   Thank you very much for your participation.