INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI



Order Number 1343700

Information seeking styles and sources of information used by women with breast cancer

Messerli, Patricia Kay, M.S. The University of Arizona, 1991

Copyright ©1991 by Messerli, Patricia Kay. All rights reserved.

U·M·I 300 N. Zeeb Rd. Ann Arbor, MI 48106

A Marine and A services of the services of

NOTE TO USERS

THE ORIGINAL DOCUMENT RECEIVED BY U.M.I. CONTAINED PAGES WITH BLACK MARKS. PAGES WERE FILMED AS RECEIVED.

THIS REPRODUCTION IS THE BEST AVAILABLE COPY.

INFORMATION SEEKING STYLES AND SOURCES OF INFORMATION USED BY WOMEN WITH BREAST CANCER

by
Patricia Kay Messerli

Copyright Patricia Kay Messerli, 1991

A Thesis Submitted to the Faculty of the COLLEGE OF NURSING

In Partial Fulfillment of the Requirements For the Degree of

MASTER OF SCIENCE

In the Graduate College
THE UNIVERSITY OF ARIZONA

1991

STATEMENT BY AUTHOR

This thesis has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this thesis are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the copyright holder.

SIGNED: Patrice Khesseli

APPROVAL BY THESIS DIRECTOR

This thesis has been approved on the date shown below:

Professor of Nursing

 $\frac{0}{100+0}$

Date

DEDICATION

This thesis is dedicated to my husband Tom, who had faith in my abilities; my daughters Enid and Kendall for tolerating my absences so well; and my mother for being my role model and helping me to become the nurse I am today.

ACKNOWLEDGMENTS

I would like to thank my committee chairperson, Dr. Alice Longman, who sustained this long distance effort with a great deal of patience and support. I would also like to thank Dr. Ki Moore and Dr. Carrie Braden for their expert suggestions and guidance.

Finally, I would like to thank the following faculty of Northern Arizona University, Department of Nursing; Dr. Kathleen Huttlinger, Evelyn Cesarotti, Dr. Marianne Yoder, Annie Blackett, and Ruth Nicholls for the endless support, both editorial and emotional, provided to me.

TABLE OF CONTENTS

		Page
	LIST OF TABLES	7
	LIST OF FIGURES	8
	ABSTRACT	9
CHAP	TER	
I.	INTRODUCTION	10
	Purpose of the Study	13 14 14 15 17 21
II.	LITERATURE REVIEW	23
	Self-Care Breast Cancer Information-Seeking Sources of Information Summary	23 25 29 33 36
III.	RESEARCH METHODOLOGY	37
	Primary Pilot Study Setting and Sample Protection of Human Subjects Instrumentation Data Collection Protocol Secondary Analysis Research Design Sample Data Analysis Plan Summary	37 38 39 39 40 40 40 41 43
IV.	RESULTS OF THE DATA ANALYSIS	44
	Demographic Characteristics of the Sample	44
	Results of the Source of Information Checklist	47

TABLE OF CONTENTS--Continued

		Page
	Results of the Information Seeking Style Scale Results Related to Research Questions Summary	47 47 55
٧.	CONCLUSIONS AND RECOMMENDATIONS	56
	Study Sample	56 56 61 62 63
	APPENDIX A: HUMAN SUBJECTS APPROVAL	65
	APPENDIX B: SOURCES OF INFORMATION	68
	APPENDIX C: INFORMATION SEEKING STYLES	70
	APPENDIX D: DEMOGRAPHIC DATA SHEET	72
	REFERENCES	75

LIST OF TABLES

Tab	able	
1.	Educational Level of Subjects	45
2.	Income Levels of Subjects	46
3.	Results of the Sources of Information Checklist (n=25)	48
4.	Results of Information Seeking Style Instrument (n=25)	49
5.	Significant Relationships Between Monitors and Information Seeking Styles	52
6.	Pearson Correlation Coefficient Results of Demographic Variables and Specific Sources of Information (n=22)	53

LIST OF ILLUSTRATIONS

Figure		
1.	Conceptual Framework for Study	19

ABSTRACT

This secondary analysis of data collected in the Self-Help Intervention Project (Braden, Mishel, Longman & Burns, 1990) was undertaken to describe relationships of information seeking styles and sources of information used by women with breast cancer.

The majority of the subjects (n=25) were Anglo, married, had a mean age of 54.72 years, had annual incomes greater than \$30,000, and greater than high school graduate education.

Descriptive statistics were used to analyze the data, using frequencies and percentages for the demographic data. Correlation statistics were used to answer the research questions. A moderate statistical relationship (.6165, p=.001) was found to exist between the variable of marital status and the American Cancer Society as a source of information. Other data reflected low statistical correlations.

Results indicate the need for more research on this topic with larger samples to discover if relationships may be strengthened.

CHAPTER I

INTRODUCTION

Women who are diagnosed with breast cancer face many uncertainties which may ultimately influence how well they cope and adapt to treatments and to adjustments in their everyday life experiences. Among these uncertainties are: 1) the possibility of disfigurement, disability, and even death; 2) the accuracy of information about their condition; and 3) the implications of the various treatments that are available (Rowland & Holland, 1989). The uncertainties reflect a current lack of information with respect to the available treatment alternatives for women with breast cancer.

Most often, women receive information about breast cancer from their primary care physician. In the past, the family or primary care physician made treatment decisions for women with breast cancer after little or no consultation with them as to their alternatives for treatment. With the advent of consumer rights movements, active participation of nurse practitioners in prevention programs, and general public awareness, women are becoming more involved in their own "self-care" and seeking out physicians who are available to them.

The trend for self-care has grown to the current emphasis upon the right to self-control and individual responsibility (Derdiarian, 1986). The consumer movement, self-help movement, and the women's movement were largely responsible for these changing views of how health information is relayed to the consumer (Webster & Lepitz, 1986). These social movements of the 1960s raised questions regarding previously held beliefs of what health care should be and created the impetus for changing the world view of women's health that would directly affect nursing. The world view that "Knowledge is power" has been prevalent since the 1960s. This view uses consciousness raising and self-help approaches to assist women in their search for knowledge regarding their bodies. Increasingly, those who hold this world view are working to create alternatives to the existing health care system. Thus, self-care has developed as an idea which has been integrated into the popular domain (Johnston, 1989). Nurses have also begun to assess the health care situation in their dual roles as consumers and providers of health care.

Rowland and Holland (1989) stated that the problems and fears of breast loss and body image threats have decreased with the advent of new breast-saving treatment techniques. Anxieties have risen regarding the right treatment choices, and subsequent survival likelihood.

The various treatment alternatives that are available and self-care contribute to the need for women to seek information. Nurses play an important role in this information seeking process by promoting opportunities for women with breast cancer to obtain appropriate, and objective information. Seeking information about breast cancer has been viewed as a first step in the path of behaviors that lead

to enhanced health for the individual (Devito, Bogdanowicz & Reznikoff, 1982).

The recent literature indicates that most women obtain information from women's journals, television, famous women, public agencies and other community education projects (Eich, 1985). Along with these sources it is apparent that the American consumer is moving from an illness focus to a health focus. Health education has expanded from the traditional hospital setting to the community where the public media is heavily used. Books, magazines, and television programs are available to all age groups and both sexes. This increase in health-care information combined with other services, such as home health care, ambulatory care, and childbirth alternatives do much to promote self-care by the consumer. These services also have increased options available to patients resulting in a need for decision-making (Dunham, Carter, Keshock, Mondora, Rendano & Torok, 1986).

The question as to "who" seeks information about breast cancer needs to be addressed. Miller and Mangan (1983) described two types of information seekers: blunters and monitors. Blunters are those who do not seek information and seek to distract themselves from adversity, while monitors demonstrate a preference for a large amount of information about perceived threats. In a study of the effects of information and coping styles on adaptation to gynecologic stress, Miller and Mangan identified information seekers (monitors) and information avoiders (blunters). In their discussion, the authors

that a large amount of information may actually magnify patient distress, and patients experiencing distress displayed greater amounts of depression, tension, and dismay during the preparation stage. After the examination was completed, the high information patients showed a decrease in tension, but the depression remained and days afterward continued to have increased levels of discomfort.

Self-care may be facilitated through informed consent, full disclosure of diagnosis and treatment, open communication, and patient information. Of importance is the acknowledgement of the rights of the client who may be harmed by receiving unwanted information. These patients are those who must cope with use of denial; there is nothing gained by offering information to the patient who may not be able to handle it (Cassileth, Zupkis, Sutton-Smith & March, 1980; Derdiarian, 1987).

Purpose of the Study

The purpose of this study was to learn more about the information seeking styles displayed by women with breast cancer. Though there have been studies of information seeking behavior, little material is available about "sources of information" used by women with breast cancer. To gain a better understanding of the sources of information which are used by women to engage in self-help, the purposes of this study were to:

 Describe sources of information regarding breast cancer and its treatment used by women who are undergoing treatment for breast cancer. Describe the relationship between sources of information about treatment options identified as being used by women with breast cancer and their information seeking styles displayed.

Research Questions

- 1. What are the specific sources of information used by women with breast cancer?
- 2. Is there a relationship between specific sources of information used by women with breast cancer and information seeking scores?
- 3. Is there a relationship between the number of specific sources of information used by women with breast cancer and information seeking scores?
- 4. Is there a relationship among the variables of age, marital status, educational level, and the specific sources of information used by women with breast cancer?
- 5. Is there a relationship among the variables of age, marital status, educational level, and the number of specific sources of information used by women with breast cancer?
- 6. Is there a relationship among the variables of age, marital status, eduational level, and the information seeking style score displayed by women with breast cancer?

Statement of the Problem

The Self-Help Intervention Project (SHIP) was a study conducted by Braden, Mishel, Longman and Burns (1990). The secondary analysis

of the data from the pilot study was undertaken to add to the body of knowledge regarding information seeking styles and sources of information used by women with breast cancer and ultimately to help guide nurses caring for these women. Information seeking as a coping mechanism is not a new idea. One may, with increased information, develop cognitive coping skills to meet the change, disability, uncertainty and crises that may accompany the diagnosis of breast cancer (Thomas, 1978). The information gained allows clients to obtain some control over the events that take place. By examining information seeking patterns and sources used by women with breast cancer, one would hope that nurses are able to alter the amount and scope of health related information relayed, adjust the repertoire of sources to more appropriate ones, and ultimately offer alternatives to the information seeker (Lenz, 1984). By learning more about information seeking, improved understanding of the decision-making process used by women diagnosed with breast cancer may be realized. It was for these purposes this secondary analysis of data from Braden et al.'s (1990) study was undertaken.

Significance of the Problem

Cancer is now considered the second leading cause of death of adults, both young and old (Campbell & Forsyth, 1990). In 1990, breast cancer will cause 44,300 deaths, accounting for the second most frequent cause of cancer deaths among women. Breast cancer is a serious, stressful, and life-threatening disease for women.

The American Cancer Society (1990) estimated that there will be 150,900 new cases of invasive breast cancer in 1990. Instead of one out of 19 women developing breast cancer, new figures indicate that one out of 10 women will develop breast cancer (American Cancer Society, 1990; Goodman & Harte, 1990).

Levy (1986) pointed out that there has been no significant change in the death rate from breast cancer in the past 50 years, despite guidelines specific for breast cancer screening and improved treatment for breast cancer. One-half of the women who present with symptoms are diagnosed with disease in the late stages. Risk of breast cancer increases significantly for women after age 40 and again after age 50. These statistics and the implications for nursing practice in the clinical areas of oncology and gerontology present important considerations for professional nursing practice.

Frank-Stromborg (1986) stated health promotion activities are a major, stable force in health care that represent a growing new direction. With this view, there has been increasing attention regarding self-responsibility as a significant factor. Frank-Stromborg (1986), in a study of health promotion activities, found that ambulatory cancer patients demonstrated a strong desire for increasing health potential through health promoting activities. As cancer treatment has extended the years of survival, health promotion activities have gained importance. Further evidence indicates a trend toward adaptation of wellness behavior rather than sick role behavior. The assumption of responsibility for one's own health care may provide patients with an increased sense of control and decreased feelings of helplessness.

The need and value of self-help programs have been recognized by health care professionals. One such intervention project called the Self-Help Intervention Project (SHIP) study has as its purpose the examination of two sets of nursing interventions for women who are receiving treatment for breast cancer (Braden, Mishel, Longman & Burns, 1990). These interventions are educational classes and nurse/case manager education and support. Data collected from the

Conceptual Framework

"Self-care" or managing one's own health has been gaining popularity as a concept. Several reasons for this heightened awareness and attention have been suggested and include: 1) the demystification of the medical profession; 2) consumer demand for increased self-control that is reflected in societal attitudes of anti-authority and anti-technology attitudes; 3) increased educational levels and accompanying life style changes; 4) lay persons' perceived beliefs of abuses in medical care; and 5) lack of availability of some professional services (Levin, Katz & Holtz, 1975).

In the Surgeon General's report, "Healthy People", President Jimmy Carter stated that an emphasis of health be placed on prevention of illness and injury, rather than solely on seeking cures. Califano (1979) stated this document's purpose was to facilitate a second public health revolution, the first of which served to fight infectious disease. Because of research and an increasing body of knowledge,

prevention of illness may be possible. The individual's responsibility for health and health maintenance was highlighted with the following statement: "You, the individual, can do more for your own health and well-being than any doctor, any hospital, any drug, and any exotic medical device" (p. viii).

Fernsler (1986) pointed out that between 200,000 and 400,000 cancer patients each year are treated with chemotherapy and radiation therapy, and frequently most of them are treated on an outpatient basis. Because of this shift from in-patient to out-patient treatment, patients needing treatment assume greater responsibility for their own care and need to maintain the motivation to continue, even when side effects of treatment appear.

The conceptual model used for this study was Orem's Self-Care Practice Model (Figure 1). Orem viewed nursing as a profession which focuses upon the individual's self-care action (Whelan, 1984). Man is viewed by Orem as responsible for his own self-care regarding health needs, and is also responsible for the health care of his dependents. Orem maintained the belief that individuals have the right to choose or not to choose their own health options (Orem, 1980).

Orem (1980) defined self-care as the "practice of activities that individuals personally initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 13). The ability of some patients to meet self-care demands may be taxed by illness and self-care deficits may result. Orem (1985) listed eight self-care

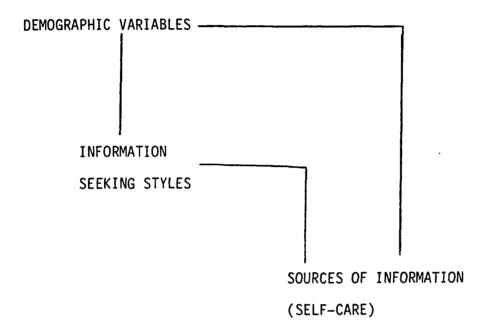


Figure 1. Conceptual Framework for Study of Women with Breast Cancer

---- = Correlation tested in this study

requisites common to all humans. These are: 1) ability to maintain an adequate amount of air; 2) ability to maintain an adequate amount of water; 3) ability to maintain an adequate amount of food; 4) the needs of elimination and excretions are provided for; 5) a balance of activity and rest is maintained; 6) a balance of solitude and social interaction is maintained; 7) hazards or threats to human life, human functioning, and human well-being are guarded against; and 8) human functioning and development is promoted by accounting for the human potentials, limitations, and desire for normalcy.

Self-care deficits exist when the ability of the individual to meet the self-care demand is inadequate. The deficits may be complete or partial (Orem, 1985), and may be due to: 1) lack of knowledge about the situation and/or available self-care activities; 2) inability to perform self-care activities; or 3) malfunction of the individual in a physical or emotional sense due to illness (Dodd, 1988). Seeking information to gain knowledge may be viewed as a part of self-care behavior needed to correct the deficit of lack of knowledge. Nurses, through creativity, knowledge, and individual style need to design appropriate intervention that are meaningful to the client.

Basic conditioning factors such as age, socioeconomic status, marital status, living arrangements, and site and stage of cancer are designated by Orem as contributors to self-care directly or indirectly (Hanucharunkul, 1980). Levin, Katz and Holst (1975) stated ability for self-care assumes an active and educated public, those who are active on their own behalf, and knowledge regarding effective application of health care practices. Hanucharunkul (1989) reported

that the health behavior of self-care has been found to be related to socioeconomic status. Those with higher socioeconomic status also have more resources available to enable self-care, more education that enables understanding of their health state and treatment regimen, and may use available resources more efficiently to meet their needs than those with lower socioeconomic status (Hanacharunkul, 1989).

The process of self-care in Orem's model has phases that includes perceiving a problem, assessing options for action, initiating self-care behaviors, and evaluation of the effectiveness of the self-care action. Goals of self-care theory, according to Orem, include meeting satisfaction of overall self-care requisites, assistance to man in meeting self-care needs, maintenance of the most healthy state, and regulation of therapeutic self-care demands (Orem, 1985). Values assumed by this stance are that nursing provides a service that persons may benefit from when limited in ability for self-care. Man is viewed as a whole, and has the right to participate in self-care through his capacity for decision making (Bromley, 1980).

Summary

The diagnosis of cancer may hold for some stressful and life-threatening implications. Breast cancer involves a significant number of women with no appreciable change in survival in the past 50 years (Levy, 1986). The growing trend of self-determination and self-care may be understood more fully with the knowledge of which sources these women use to gain information. A description of the preferred sources of information and the types of information seeking styles can

influence the clinical interventions and information exchange being planned by nurses or other health care workers.

CHAPTER II

LITERATURE REVIEW

In this chapter information from the existing literature about breast cancer and the concepts of information seeking, sources of information, and self-care is presented. Discussion of how activities of information seeking and knowledge of sources of information used by women with breast cancer affect self-care are discussed.

Self-Care

Goals of self-care theory, according to Orem (1985), include meeting satisfaction of overall self-care requisites, assistance to man in meeting self-care needs, maintenance of the most healthy state, and regulation of therapeutic self-care demands. Values assumed by this stance are that nursing provides a service that persons may benefit from when limited in ability for self-care. Man is viewed as a whole, and has the right to participate in self-care through his capacity for decision making (Bromley, 1980).

Meriney (1990) applied Orem's self-care theory to design an intervention for early recognition and treatment of hypercalcemia related to breast cancer. Meriney stated the client uses knowledge to enable self-care management.

Dodd (1987) stated a person who participates in self-care has knowledge, and health care professionals could use this foundation to build more knowledge and enhance the repertoire of abilities. Dodd

(1982) found in a study of patient self-care behaviors for side effects of cancer chemotherapy that few behaviors were initiated even after perceiving the occurrence of a side effect. These patients were unaware of the self-care behaviors to be used and so endured these side effects. The number of reported self-care behaviors increased as the length of time the patients had received chemotherapy increased. Dodd (1983) viewed quality nursing care for oncology patients as including the facilitation of self-care. Information regarding the drugs, the range of likely side effects, and helpful self-care practices to manage these side effects is imperative for the patient undergoing treatment for cancer (Dodd, 1983).

Self-care has a role in chronic illness as it reduces dependence and gives control of the disability to the client. The patient may use self-care behaviors to substitute or supplement what is offered by health care workers (Levin, Katz & Holtz, 1976). The drive for survival is what these authors stated is the motivating factor toward performance of self-care behaviors. Once these activities of self-direction and self-healing are activated and applied, the focus of the chronically ill may be upon reduction and control of disability and dependency.

Braden (1990a) stated monitoring contributes greatly to enabling skills which in turn contributes to the client's ability to participate in self-care. Those subjects with greater incomes were found to have greater self-help characteristics.

Breast Cancer

Symptoms of breast cancer include the development of a painless mass in the breast, a spontaneous, unilateral, serous, or bloody nipple discharge, and a persistent dermatitis of the nipple or areola. Dimpling of the skin, nipple retraction, change of breast contour, fixation of the mass to the chest wall, swelling or redness of the breast skin or axillary lymph node enlargement may indicate more advanced breast cancer (ACS, 1990). Any lump found in the breast must be evaluated to determine the nature of the mass. Diagnosis may be done by percutaneous needle biopsy or aspiration. Assessment for metastatic disease is done if breast cancer is found.

The development of breast cancer is not considered a chance event and the cause has appeared to be a multiphasic process in which factors of tumor growth potential versus host resistance are involved. There are two peak occurrences of breast cancer. The first is in premenopausal women age 45 to 49 and possibly related to ovarian estrogens. Women who are 50 to 59 years of age have the highest incidence of developing breast cancer. The second peak occurrence, thought to be related to an imbalance of adrenal estrogens, is in women between 65 to 69 years of age (Goodman & Harte, 1990). Because women have a higher ratio of breast cancer development than men (100:1), hormones have long been implicated as a promoter of breast cancer (Goodman & Harte, 1990).

Postmenopausal women who are obese have been found to have a greater incidence of breast cancer. A diet high in saturated fat tends to increase the need for higher levels of biliary steroids to

digest these fats. Biliary steroids after conversion to estrone and estradiol are the fundamental sources of estrogen in postmenopausal women. There have been, however, no conclusive studies that demonstrate a diet low in fat intake will decrease women's chance of developing breast cancer (Goodman & Harte, 1990).

Despite the fact that 75 to 85% of women with breast cancer have no known family history, there is evidence to suggest that women who do have a family history are at higher risk to develop breast cancer. For example, a woman whose mother has had breast cancer, has a risk of 9 to 23% of developing breast cancer herself. A woman who has had two female relatives diagnosed with breast cancer may expect a risk of developing breast cancer of 10 to 50% over a lifetime (Goodman & Harte, 1990).

Personal history of breast cancer is also a primary risk factor. A woman who has been diagnosed with breast cancer in one breast has a 14% chance of developing cancer in the other breast. Other risk factors of breast cancer development, though considered secondary, are history of cystic breast disease, birth of first infant after 30 years of age, early menarche or late menopause, excessive exposure to ionizing radiation, and oral contraceptive use (Goodman & Harte, 1990). Duration of estrogen-replacement therapy may also affect risk of breast cancer. Hulka (1990) found that a risk of 1.5 may be reached after 15 or more years of use.

Treatment choices depend upon the stage of the disease, type of cancer, age, physical condition, patient preferences, and the judgment of the physician. Surgery covers the range from lumpectomy to

radical mastectomy. Other therapies include radiation, endocrine therapy, and chemotherapy which are used according to the choices described previously (Bullock & Rosendahl, 1988). With treatment, the five year survival rate has been estimated at 90%. If noninvasive (in situ) breast cancer has been found, the survival rate has been estimated at 100%. But, with regional spread of the disease, survival rates fall to 68%, and in those with distant metastatic disease, survival rates are 18%. Survival rates are also influenced by tumors which may contain estrogen receptors. Survival rates are increased in women whose tumors contain estrogen receptors, just as the histologic presence of cancer in the axillary node reduces overall survival rate (Goodman & Harte, 1990).

Health professionals often assume that the diagnosis of cancer will result in reactions of shock, disbelief, depression, anger, and fear from the patient. Frank-Stromborg, Wright, Segalla and Diekman (1984) reported that 27% of the patients responding to their study of the psychological impact of cancer actually expressed positive thinking. The remainder of the responses indicated that 29% experienced shock and fear, 16% experienced anger, depression or hopelessness, 9% didn't want to think about it, 7% expressed uncertainty with the future, and the remaining expressed renewed faith (6%) or feelings of doom (6%).

Beyond the impact of receiving the diagnosis, the impact of the treatment for breast cancer may also be multiple and varied. Lifestyle changes such as unemployment, immobility, altered sexual relationship, alopecia, and chronic fatigue were pointed out by Simmons (1984). Simmons also stated that numerous losses; personal, economic, and social are experienced by women with breast cancer. All are associated with lifestyle changes. The possibility of a disfiguring surgery such as a mastectomy coupled with a life-threatening chronic disease may have great personal significance (Brownmuller, 1984; David, Roth & Kuruvilla, 1988). The effects of these losses may result in behavioral changes such as insomnia, inability to concentrate, increased use of alcohol, decreased or loss of appetite, altered daily living activities, and possibly thoughts of suicide (Vinokur, Threatt, Vinokur-Kaplan & Satariano, 1990).

Breast cancer has been classified as a chronic illness, i.e., an illness that may be permanent, leaves a residual disability, caused by a non-reversible pathological alteration, and/or requires a long period of observation, supervision or care (Miller & Nygren, 1978). Breast cancer has gained increasing awareness among American women. A need to disseminate accurate information to overcome fear. depression, panic, and ineffective coping that may result has been made evident. Culturally, our society has considered breasts as highly valued symbols of femininity and nurturing. One must be aware of how these cultural symbols may affect attitudes toward breast cancer (Thomas, 1978). Radical surgery and the ensuing treatment of breast cancer have undergone scrutiny. The original radical mastectomy developed by William Halstead in 1902 has been replaced with a modified procedure (McKhann, 1985). Because of the new approaches in the treatment of early stage breast cancer, women now have choices to make. Cawley, Kosti and Cappello (1990) found that those in the 50 year

old group had a higher satisfaction rate regarding information from the physician than those of women 60 to 70 years old. These authors suspected physicians may have considered older patients less capable of decision making and may behave in a more paternal way to the older group. By ignoring patients' value systems and prohibiting involvement in decision making, the dependency of the patient is fostered and self-responsibility is stifled (Valanis & Rumpler, 1985). Nurses tend to promote self-responsibility by providing information, though they are not often acknowledged as information providers. Dodd (1988) stated that nurses give information in a much more subtle manner than most physicians do and for this reason may not be recognized as frequently used sources of information.

Information-Seeking

The education of patients has been an integral part of comprehensive health care. Because of alternatives in breast cancer treatment, it has become more important than ever for women to be given information, support, and a health care system that is able to meet their needs. No longer do women with breast cancer have just two alternatives, the mutilation of a radical mastectomy or death. Over the course of this century, there has been increasing resistance to radical mastectomy, and women have chosen a less radical approach (Levy, 1986).

As consumers, patients have the right to participate in their health care and to be assisted with decision making. These patients may or may not choose to seek information. Cohen and Lazurus (1979)

identified seeking information as one of the five modes of coping. The task of the patient is to discover if a problem is present and what, if anything, may be done about it. Information can then be used as a mediator for both processes of appraisal and coping. Mediating among the patient, the stimuli, the appraisal, and the coping behavior, information is used by the person to determine the harm, threats, and the resources that may be used to deal with the stressful experience (Derdiarian, 1987).

Valanis and Rumpler (1985) identified three elements needed to make an informed decision: 1) information; 2) appreciation of one's own values; and 3) time. By providing women with information regarding cancer risks, diagnoses, and treatment, decisions may be made by carefully considering the options discovered. Information seeking behavior has been viewed as important for clients to gain knowledge about an existing health condition. Consumers actively seek information as a beginning of the decision making process. Important not only for the decision making process, information seeking has been used to help women regain lost autonomy and gain self-determination (Gadow, 1989).

Just as information seeking may be an individual method of coping, so may there be those who avoid information as a coping mechanism (Cohen & Lazarus, 1979). Informed participation in cancer treatment may be harmful to women with breast cancer who cope with denial or avoid information (Cassileth, Zupkis, Sutton-Smith & March, 1980). These authors also stated that most clinicians were quite

concerned that despair may result if the patient had been provided with detailed information about their disease. Results of Cassileth et al.'s study demonstrated the opposite; patients who are better informed actually expressed a more hopeful outlook. But again, not all patients desire an active role in their medical care. Each patient must be assessed for his/her particular desires.

Miller and Mangan (1983) discussed two types of information seekers: blunters and monitors. Blunters are those who do not seek information and must seek to distract themselves from adversity, while monitors demonstrate a preference for a large amount of information about threats. In their study of the effects of information and coping styles on adaptation to gynecologic stress, Miller and Mangan (1983) identified the information seekers (monitors) and the information avoiders (blunters). These authors found that a large amount of information may actually magnify patient distress, and these patients displayed higher levels of depression, tension, and dismay when After the examination preparing for a gynecological examination. was completed, the high information patients demonstrated decreased tension, but the depression remained and continued to demonstrate increased levels of discomfort more than the low information group. Miller and Mangan (1983) reported that while studies have demonstrated that individuals prefer information they can use to control an aversive event, this information is not always stress reducing. Also, patients who were given choices had reduced behavioral, physiological, and subjective displays of distress, independent of an informed or uninformed choice. Miller, Summerton and Brody (1988) stated seeking information is used to reduce uncertainty, rather than to control it. Braden (1990b) found evidence that association with the monitoring information seeking style has been used to reduce uncertainty rather than enabling self-help. Results of Braden, Mishel, Longman and Burn's (1990) pilot study supported this notion, as no significant relationship was found between monitoring behavior and self-help.

Seeking information was identified by Friedman (1980) as a principal mechanism among the coping mechanisms listed. Information sought included disease, treatment, and prognosis information to counteract anxiety and fear (Garrison, Abner, Oakley & Hagan, 1983). In the study conducted by Garrison, et al., an increase in seeking information following diagnosis of cancer was found. Information seeking was described by DeVito, Bogdanowicz and Reznikoff (1982) as an important first step in the sequence of steps that ultimately enhances overall health of the individual.

Scott and Eisendrath (1985/86) stated that information seeking was only a moderately effective coping strategy. It may bring only situational relief, but may not provide any effects that may be enduring. The most effective coping strategies cited by the authors were confrontation, where action is based upon understanding of the problem; redefinition, a reframing of the problem to a more positive view in manageable doses that may allow greater sense of control; and finally compliance, the ability to continue and tolerate treatment with a minimal amount of discomfort.

Knowledge is sought to fill gaps and rid one's self of uncertainty, disharmony, and the unknown. The diagnosis of cancer may

create great uncertainties and tax the limitations of modern medicine (Cassileth, 1989). Hopkins (1986) stated information seeking facilitated patients' appraisal of threatening situations; problems that may create stress are identified and problem resolution strategies may be initiated.

Lenz (1984) identified major background variables that may influence information seeking behavior. These include sociodemographic data such as age, socioeconomic status, marital status, ethnicity, and sex. Age was found to negatively correlate with search for information and the extent to which this search is carried out. The elderly are the least likely to seek information. Those with higher socioeconomic status were more likely to seek information than those with a lesser income. Reasons offered were higher cognitive skills, greater status, and a belief system congruent with that of the health profesfewer interest in health matters. sional. greater constraints, and greater access to social networks. Those with a lower socioeconomic status are more likely to rely on personal rather than professional sources of information.

Sources of Information

Sources of information about advances and lack of advancement in the treatment of cancer have been readily available through written media such as newspapers and magazines, and through verbal media such as television, video, professionals, family, and friends (Cassileth, 1989; Frank-Stromborg, 1986; Valanis & Rumpler, 1985). From these modalities, the public has gained a great deal of knowledge regarding

the treatment and prognosis of cancer. Information from friends, neighbors and public figures with cancer coupled with open communication regarding cancer has given the public a general idea of cancer survival and percentages of those personally known who survive the disease. Because of this, media statements regarding advances in cancer treatment may be viewed with suspicion (Cassileth, 1989).

Hopkins (1986) found a statistically significant relationship between age and information seeking and between illness severity and information seeking. Hopkins (1986) stated that older patients may have had more faith in physicians and less expectations of participating in the decision making process. Coping through avoidance by those with more severe illness was a possible reason for the negative relationship of illness severity and information seeking (Hopkins, Sources of verbal information found to be used by Hopkins 1986). (1986) were the oncologist, health professional or patient on television, the oncology nurse, volunteers from cancer organizations, family, friends, the surgeon, acquaintances working in the medical field, other patients, other health professionals, and neighbors or casual acquaintances, respectively. Sources of written information were, in order of the most to least used, the oncologist or nurse in the office, newspaper, magazine articles, popular books about cancancer organizations, hospital personnel, radiation center cer, personnel, surgeon, and finally friends and co-workers (Hopkins, 1986). Garrison, Abner, Oakley and Hagan (1983) studied sources of information used by cancer patients; 13 of the subjects (n = 75) had breast cancer. Overall, results were that 38% of the patients responding had read

cancer literature prior to the diagnosis of cancer. Material was obtained from magazines, clinics, physicians' offices, hospitals, libraries, and health personnel. Magazines were the most frequently listed source of information. Also found were that lay publications were the most often used source of information prior to the diagnosis of cancer. Material read at the time of diagnosis or after the diagnosis was more likely to be professional, patient oriented material (Garrison, et al., 1983).

Cawley, Kostic and Cappello (1990) in their study of women who chose conservative surgery and primary radiation for early stage breast cancer found 74% cited the physician as the primary source of information and 23% received information from nurses. Reportedly, several of their subjects independently sought out information from friends, the library, the American Cancer Society, and pamphlets.

Eich (1985) identified magazines, news articles, radio, television talk shows of health developments as sources of information used by women with breast cancer. She stated as a result of this information, patients are able to assume a more active role in personal health care rather than seeking out the physician or nurse to answer questions regarding breast cancer treatment.

Dodd (1982) studied patient self-care for side effects of cancer chemotherapy. Patients in this study cited themselves as the most frequent source of information for self-care behaviors needed to deal with side effects. Physicians, family and, finally, nurses were listed next in order of most frequent to least frequent. Dodd (1982) expressed concern that nurses may not be providing information, or may be

providing information that is not recalled for later use. She stated this pattern must be assessed and reversed to maintain quality care.

Ward, Heidrich and Wolberg (1989) found breast cancer patients cited the physician as the most frequent source of information. Family, friends, clinic handouts, nurse, media, clinic, video tapes and, finally, scientific journals were included as some of the more important sources of information. Significant to these authors, was the fact that people or verbal sources of information were more important to most of the participants than written sources. The authors stated that the tendency to substitute impersonal media in place of a more personal one to one approach may not be consistent with the desires of the patient.

Summary

Trends related to self-care in women who have breast cancer require increasing skills in decision making. Information empowers not only decision making, but also provides understanding of potential problems. That individuals seek and gain information to make decisions is compatible with nursing theories such as Orem's (1985) that emphasize patients' abilities to participate in decision making, make independent choices, and the need of nurses to provide health information to assist clients. The patient may be viewed in a more positive light as an active seeker rather than a passive recipient of health information, and nursing may be viewed as an information source rather than a sole educator of health information.

CHAPTER III

RESEARCH METHODOLOGY

The setting and sample, protection of human subjects, instrumentation, and data collection protocol employed for the Self-Help Intervention Project, the primary pilot study, are described in the first section of this Chapter. The sample, research design, protection of human subjects, and plan for data collection for the secondary analysis are described in the second section. The plan for data analysis is also described.

Primary Pilot Study

<u>Setting</u> and Sample

The pilot sample consisted of 25 women who were beginning a course of treatment for breast cancer. Identification of women who met the study criteria and recruitment was accomplished through referral by staff nurses at one of several treatment sites with a personal or telephone contact by study personnel. Names of potential subjects who would be entering into treatment within one to two weeks were supplied by the treatment sites. A field worker then contacted the potential subject and invited her to participate in the project. The criteria for inclusion in the study included fluency in English, age 18 years or older, and a diagnosis of breast cancer.

Protection of Human Subjects

The subjects were invited to voluntarily participate in the study. The project was submitted to the University of Arizona Human Subjects Committee and the project was exempt from review (Appendix A).

To ensure protection of human subjects, the following occurred. The study was presented personally to each prospective subject by The purpose a field worker for the purpose of introducing the study. of the study was presented as one helping health care professionals learn more about what assists women obtain the best effects from breast cancer treatment, and what helps cancer patients during the experience The project expectations of three data collections or measurement occasions, the need of some subjects to voluntarily attend self-help classes, voluntary independent study, and/or voluntary weekly contact with a nurse case manager were explained to each subject. The subjects were informed that participation was voluntary, that there were no hazards or cost beyond time involvement, that they could withdraw at any time, that their questions would be answered and all information would be treated with anonymity to ensure confidentiality. Only those on the collaborative research team and staff would have access to the data. No identifying information was kept with the data. Raw data were stored in a locked file and shredded as the data were entered on a computer tape and stored.

Instrumentation

Sources of Information, was measured by a 16 item checklist completed by the subjects during the pilot data collection period. Scoring of this checklist provided two kinds of variables, the type of source used was scored by dummy coding each source as 1, having been selected, and 0, not having been selected, and the number of sources used, scored by summing the number of sources checked as having been used (Appendix B).

Information Seeking Styles was measured by using the instrument (ISS) adapted from one used by Miller and Mangan (1983). The responses to this eight item visual analogue instrument were grouped into each of two subscales, blunters and monitors. The individual subject's monitor score and blunter score was determined by totaling the monitor score and the blunter score from each subscale (Appendix C). The internal consistency reliability of the Information Seeking Styles scale estimated by Cronbach's Alpha was =.73, std. item coefficient =.72 for the monitoring subscale and =.63, std. item coefficient =.63 for the blunting subscale (Braden, personal communication, December 10, 1990). Interpretations from this instrumentation must be made with caution due to an internal consistency reliability score less than the .7 criterion. The purpose of the instrument is to identify blunters and monitors.

Data Collection Protocol

Subjects were given three data collection instruments, which included a Demographic Data Sheet (Appendix D), a checklist for

identification of sources of information used (Appendix B), and an instrument used to identify information_seeking styles (Appendix C).

Questionnaires were completed in the presence of a trained data collector or privately by the subject. The completed questionnaires were kept in a file in a locked office. The data collected were entered into a computer by research assistants. A master list of subjects was maintained by the research coordinator.

Secondary Analysis

Research Design

The present study, the secondary analysis of the initial data from the Self-Help Intervention Project (SHIP) pilot study, used a descriptive design. This was chosen since further information is needed regarding preferences of sources of information used by women with breast cancer and information seeking styles displayed. The data analyzed were those obtained at the first of two data collection periods.

Sample

The convenience sample for the secondary analysis included . 25 subjects. Criteria for inclusion in the study were:

- 1. Female, age 18 years or older.
- 2. Fluent in English.
- Diagnosis of breast cancer, and beginning a course of treatment.

Data Analysis Plan

The data collected from the subjects were copied onto a subdirectory file to be analyzed. The data analysis plan addressed the following research questions:

- 1. What are the specific sources of information used by women with breast cancer?
- 2. Is there a relationship between specific sources of information used by women with breast cancer and information seeking scores?
- 3. Is there a relationship between the number of specific sources of information used by women with breast cancer and information seeking scores?
- 4. Is there a relationship among the variables of age, marital status, educational level, and the specific sources of information used by women with breast cancer?
- 5. Is there a relationship among the variables of age, marital status, educational level, and the number of specific sources of information used by women with breast cancer?
- 6. Is there a relationship among the variables of age, marital status, educational level, and the information seeking styles score displayed by women with breast cancer?

Descriptive statistics were used to analyze the demographic data.

Research question #1 was analyzed through use of frequencies and rank ordering to describe the specific sources of information used by women with breast cancer.

Research question #2 was analyzed by adding total monitor scores and total blunting scores. Each subject's monitor score and blunting score was analyzed with a Pearson correlation coefficient to determine if a relationship exists between specific source of information and information seeking styles as determined by the monitoring and blunting scores.

Research question #3 was analyzed using Pearson correlation coefficient to test if a relationship exists between the number of sources of information used by women with breast cancer and the information seeking style scores.

Research question #4 was analyzed using Pearson correlation coefficient statistics to determine relationships among the variables of age, marital status, educational level, income level, with the specific sources of information used by women with breast cancer.

Research question #5 was analyzed using Pearson correlation coefficient statistics to determine if a relationship exists among the variables of age, marital status, educational level, income level, with the number of specific sources used by women with breast cancer.

Research question #6 was analyzed using Pearson correlation coefficient statistics to determine if a relationship exists among the variables of age, marital status, educational level, income level, with the information seeking style scores of monitor or blunter displayed by the subject.

Summary

The research methodology for both the primary study and this secondary analysis were reviewed. A descriptive design was used to explore the sources of information used by women with breast cancer, and if a relationship exists with information seeking styles of monitor and blunting as examined through the monitor and blunter scores. Also examined was if demographic variables have a relationship with the number of specific sources of information used, the actual specific sources used, and the information seeking style score of the subjects. Criteria for inclusion of the subjects in the secondary analysis were described. The protocol for protection of human subjects in this secondary analysis was discussed in relationship to the primary study. Last, the data collection protocol employed in the primary study and the data analysis plan for the secondary study were described.

CHAPTER IV

RESULTS OF THE DATA ANALYSIS

The results of the Demographic Instrument, Source of Information Checklist, and Information Seeking Styles scale are presented in this Chapter. The results related to the research questions are also presented.

Demographic Characteristics of the Sample

The age range of the 25 subjects was 36 to 72 years of age with a mean age of 54.72 (s.d. = 11.08). The majority of the subjects were married (n=16, 64%); one subject (4%) was separated; seven (28%) were divorced; and one (4%) was single, never married. Twelve subjects were unemployed, five subjects (29%) were employed part-time, six subjects (24%) were employed full-time and two subjects (8%) did not respond to this question. Table 1 presents the frequencies and percentages of the educational level of the subjects. The majority (n=20, 80%) of the subjects had an educational level higher than high school graduate. Table 2 presents the frequencies and percentages of the subjects' income levels. A majority of the subjects (n=14, 56%) had an income of \$30,000 or greater.

Twenty-one of the 25 subjects had no family history of breast cancer. There were 21 subjects who were Anglo; three who were Hispanic; and one who was Black. Eleven (44%) of the subjects had no other history of chronic illness; 11 (44%) reported a history of

Table 1. Educational Level of Subjects

Educational Level	Frequencies	Percentages (%)	
8th Grade or Less	0	0	
Some High School	1	4	
High School Graduate	4	16	
Trade/Business School	2	8	
Some College	8	32	
College Graduate	2	8	
Graduate/Professional Degree	8	32	
TOTAL	25	100	

Table 2. Income Levels of Subjects

Income Level	Frequencies	Percentages (%)	
Below 10,000	2		
10 - 19,999	3	12	
20 - 29,999	5	20	
30 - 39,999	3	12	
40 - 49,999	4	16	
50 - 59,999	3	12	
Above 60,000	4	16	
Missing Data	1	4	
TOTAL	25	100	

one chronic illness; and three (12%) of the subjects reported a history of two other chronic illnesses.

Results of the Source of Information Checklist

The results of the Source of Information Checklist are presented in Table 3. A "yes" answer indicated by a check mark signified the source was used for information about breast cancer treatment. The subjects responded affirmatively to as many actual sources of information they used.

Results of the Information Seeking Style Scale

The Information Seeking Style Scale has two seeking styles, those of a monitoring style and those of a blunting style. For this study, each subjects' total monitoring and blunting scores were used for the correlations. Subjects were not identified individually as only a monitor or blunter, as it is recognized that monitors and blunters may each exist on their own continuum.

Results Related to Research Questions

Question #1. What are the specific sources of information used by women with breast cancer? By rank ordering of the data presented in Table 4, the surgeon was identified by 24 (96%) of the subjects as a source of information followed by the chemotherapy physician/nurse who were used by 19 (76%) of the subjects. Magazines were used by 17 (68%) of the subjects and were the third most frequently used source

Table 3. Results of the Sources of Information Checklist (n=25)

Source of Information	Frequencies	Percentages (%)	
Surgeon	24	96	
Chemotherapy Physician/Nurse	19	76	
Radiation Physician/Nurse	13	52	
Counselor/Therapist	3	12	
Family	9	36	
Friends	16	64	
American Cancer Society	11	44	
National Cancer Institute	7	28	
Arizona Cancer Center	10	40	
Cancer Information Groups	3	12	
Cancer Support Groups	9	36	
Books	8	32	
Audiotapes/Videotapes	5	20	
Television/Radio	13	52	
Newspaper	12	48	
Magazines	17	68	

Table 4. Results of Information Seeking Style Instrument (n=25)

Subject Monitor Score	Subject Blunter Score		
277.00	107.00		
220.00	367.00		
360.00	30.00		
205.00	171.00		
346.00	144.00		
107.00	37.00		
360.00	105.00		
232.00	194 . 00		
185.00	61.00		
270.00	276.00		
317.00	115.00		
58.00	227.00		
378.00	12.00		
341.00	78.00		
202.00	107.00		
102.00	193.00		
243.00	46.00		
380.00	235.00		
212.00	26.00		
213.00	180.00		
53.00	102.00		
271.00	113.00		
104.00	219.00		
363.00	6.00		
336.00	110.00		

of information. Friends followed and were used by 16 (64%) of the subjects. Radiation physician/nurse were equal with television/radio and were the fifth most frequently used. Each were used by 13 (52%) of the subjects. Twelve (48%) of the subjects indicated the newspaper as a source of information. The American Cancer Society (n=11, 44%) and the Arizona Cancer Center (n=10, 40%) were ranked as the eighth and ninth most frequently used source of information. Cancer support groups (n=9, 36%) were ranked as the tenth source as information and were equal with family (n=9, 36%). Books (n=8, 32%) were the 12th source of information. The American Cancer Society (n=7, 28%) was ranked 13th, audiotapes/videotapes (n=5, 20%) were ranked 14th, and finally counselor/therapist and cancer information groups (n=3, 12%) were tied as the least identified source of information used by women with breast cancer. None of the subjects added any sources of information in the "other" category.

Question #2. Is there a relationship between specific sources of information used by women with breast cancer and information seeking scores? Munro's (1986) strength of correlation coefficient was used to establish the meaningfulness of the correlation. A correlation of 0.26-0.49 is considered a low correlation; 0.50-0.69 is considered a moderate correlation; and any relationships greater than .70 are considered a high correlation (Munro, Visintainer & Page, 1986). The significance level was set at 0.10. No meaningful statistically significant relationships were found to exist between blunter scores

and sources of information used by women with breast cancer. The Arizona Cancer Center was found to have a moderately meaningful statistical relationship with the monitor scores (Table 5). Television/Radio, Video/Audio Tapes, and the Newspaper were found to have low statistical relationships with the monitor scores.

Question #3, Is there a relationship between the number of specific sources of information used by women with breast cancer and information seeking styles scores? No meaningful statistical relationship was found with the blunter scores of the subjects. The monitor scores when correlated with number of sources used by women with breast cancer demonstrated a low statistically meaningful relationship (.43, p=.022).

Question #4, Is there a relationship among the variables of age, marital status, educational level, and the specific sources of information used by women with breast cancer? Of the demographic variables studied, only income was found to have a meaningful relation—ship with the surgeon as an information source and was a statistically low relationship (Table 6). There were no statistically meaningful relationships found between the chemotherapy doctor/nurse and the demographic variables. The radiation doctor/nurse category of information source for women with breast cancer had a low statistically significant relationship with the demographic variables of work and education. The counselor/therapist had a low relationship with the demographic variables of education. No other meaningful relationships

Table 5. Significant Relationships Between Monitors and Information Seeking Styles (n=2)

	Arizona Cancer Center	Television/ Radio	Video/Audio Tapes	Newspaper
Monitor	.6465	.4548	.3862	.4564
	p=.001	p=.017	p=.04	p=.016

Table 6. Pearson Correlation Coefficient Results of Demographic Variables and Specific Sources of Information (n=22)

	Age	Marital Status	Work	Education	Income
Surgeon	05	.14	.19	.29	.35
	(p=.8)	(p=.5)	(p=.4)	(p=.2)	(p=.1)
Chemotherapy	25	.22	.09	.01	21
Doctor/Nurse	(p=.2)	(p=.3)	(p=.7)	(p=.95)	(p=.3)
Radiation	05	06	.4	.49	.07
Doctor/Nurse	(p=.797)	(p=.762)	(p=.06)	(p=.01)	(p=.76)
Counselor/	05	03	.27	.35	11
Therapist	(p=.9)	(p=.9)	(p=.2)	(p=.9)	(p=.6)
Family	23	.24	.23	.33	18
	(p=.3)	(p=.3)	(p=.3)	(p=.13)	(p=.4)
Friend	.08	01	.07	.37	06
	(p=.7)	(p=1.0)	(p=.8)	(p=.07)	(p=.8)
American Cancer Society	43 (p=.03)	.48 (p=.01)	.19 (p=.4)	.20 (p=.3)	06 (p=.8)
National Cancer Institute	16 (p=.4)	.38 (p=.06)	.18 (p=.4)	.26 (p=.2)	17 (p=.43)
Arizona Cancer Center	.04 (p=.8)	27 (p=.2)	.06 (p=.8)	.26 (p=.2)	.40 (p=.05)
Cancer Information Groups		25 (p=.2)	033 (p=.9)	.03 (p=.9)	.03 (p=.9)
Cancer Support Groups	08 (p=.7)	06 (p=.8)	07 (p=.8)	.33 (p=.1)	.19 (p=.4)
Books	20	.07	.09	.47	.02
	(p=.4)	(p=.7)	(p=.7)	(p=.02)	(p=.9)
Audio/Video-	14	.01	.29	.26	.11
Tapes	(p=.5)	(p=.9)	(p=.2)	(p=.2)	(p=.6)
TV/Radio	.30	.30	.30	19	20
	(p=.15)	(p=.15)	(p=.17)	(p=.4)	(p=.4)
Newspaper	.37	.21	.10	18	01
	(p=.07)	(p=.3)	(p=.2)	(p=.4)	(p=1.0)
Magazines	.19 (p=.4)	.32 (p=.12)		19 (p=.4)	16 (p=.5)

were found. The family, cancer information groups, audio/videotapes, TV/radio and magazines as information sources of women with breast cancer had no statistically meaningful relationships with the demographic variables studied. Friend as an information source had a low statistically meaningful relationship with the education demographic The American Cancer Society as an information source variable. correlated negatively with age, and positively with marital status, each having a low statistically meaningful relationship. The National Cancer Institute had a low meaningful relationship with marital status. The Arizona Cancer Center as an information source had a low meaningful relationship with the income variable. The cancer support groups and books as an information source for women with breast cancer each had a low statistically meaningful relationship with the education demographic variable. The newspaper as an information source demonstrated a low statistically meaningful relationship with age.

Question #5, Is there a relationship among the variables of age, marital status, educational level, and the number of specific sources of information used by women with breast cancer? The number of sources used by women with breast cancer was found to have low statistically meaningful relationships with the variables of work (.32, p=.07) and educational level (.35, p=.06).

Question #6, Is there a relationship among the variables of age, marital status, educational level, and the information seeking style score displayed by women with breast cancer? No meaningful statistical relationships were found with the blunter scores of women with breast cancer. The monitor scores of the subjects used in this

study were found to have low statistically meaningful relationships with age (.48, p=.01) and income (.41, p=.03).

Summary

The results indicated women in this study were an average age of 54 years, married, educated post-high school, and had an income of greater than 30,000 dollars per year. Low statistical relationships were found between variables of age and income with the monitoring population. The only moderate statistically meaningful relationship found was between the American Cancer Society as a source of information for women with breast cancer and marital status. Low relationships were found to exist among the number of sources of information used by women with breast cancer and the demographic variables of work and education. The monitor scores as an information seeking style had low correlations with video/audiotapes, newspapers and TV/radio as sources of information. The demographic variables studied had low and no moderate or higher statistically meaningful relationships with varied sources of information used by women with breast cancer.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

Discussion of the study sample and research questions are presented in this Chapter. Limitations of the study, recommendations for further study and implications for nursing are also discussed.

Study Sample

Based upon the results of the demographic data collected, a majority of the women with breast cancer in this sample were Anglo, married, with an educational level greater than high school, and an income level of greater than \$30,000. The subjects had a mean age of 54.72 years and the majority had no previous family history of breast cancer. All of the subjects had experienced surgery for diagnosis and treatment of their breast cancer at least once. Four of the subjects reported having chemotherapy, but 15 of the subjects did not provide information regarding chemotherapy treatment. Fourteen of the 25 subjects had received radiation treatment for cancer.

Research Questions

Question #1 asked what are the specific sources of information used by women with breast cancer. The major source of information identified by the subjects in this sample was the surgeon followed by the chemotherapy/nurse. Magazines were the third most frequently

used source of information, and friends were fourth. Television/radio and radiation physician/nurse tied for fifth most frequently used source of information. The seventh most frequently used source of information was the newspaper. The American Cancer Society, the Arizona Cancer Center, and cancer support groups tied with family respectively were the eighth, ninth, and tenth most frequently used source of information. Books were the 12th followed by the American Cancer Society (13th) and audiotapes/videotapes which were 14th. The least identified source of information was counselor/therapist.

As each of the subjects had a surgical procedure related to the diagnosis and treatment of breast cancer at least once, it is expected the surgeon would be identified as a source of information regarding information and its treatment. It is unclear from the data collection instrument used for this study if the women sought out the surgeon as a source of information or if it was provided as a matter of course by the surgeon. The same question may be asked regarding identification of the chemotherapy doctor/nurse as the second most frequently used source of information. Did the women in this sample seek information from these sources or is providing information part of the routine? It is clear more subjects may have had a contact with a chemotherapy doctor/nurse than indicated in the demographic It would also have been useful for the purposes of this study to separate chemotherapy doctor and chemotherapy nurse as sources of information. There was not a category that identified a nurse solely as a source of information regarding breast cancer or its treat-Magazines are readily available and frequently contain ment.

information regarding breast cancer, especially the experiences of famous women. This may be used by women with breast cancer as a private, possibly inspirational source of information.

Only four of the 25 women identified a family history of breast cancer. This might explain why family was a source of information by only nine of the subjects. It would have been interesting to find out from the 16 women who identified friends as a source of information, if any of these friends had a personal or family history of breast cancer. Did the subjects identify family and friends because of social support provided or actual information regarding breast cancer and its treatment? It was unexpected that the American Cancer Society, the National Cancer Institute, the Arizona Cancer Center, and cancer information groups should be used so little as information sources as evidenced by the data supplied by these subjects.

Inconsistencies of information regarding breast cancer and its treatment may possibly explain why the newspaper was only identified by 12 subjects as a source of information. It would be helpful to know how many of these subjects read the newspaper regularly.

The seeming lack of availability of audiotapes/videotapes would explain somewhat the low use by these subjects as an information source. It would not be expected for counselor/therapist to be rated low as a source of information for breast cancer and its treatment. It would be reasonable to expect this source to be rated higher if the question asked the subjects to identify sources of coping or support.

Question #2 asked if there is a relationship between information seeking styles and specific sources of information used by women with breast cancer. Due to the majority of low scores of the blunter subscale of the information seeking style scale, it is not unexpected that there were no statistically significant relationships found. The Arizona Cancer Center was the only source of information found to have moderate relationship with the monitoring scores. Low relationships were found to exist among newspaper, television/radio, and video/audiotapes as sources of information with the subjects' monitor scores. These low relationships may be due to the limited sample size and the greater number of correlations carried out on these data.

Question #3 asked if there a relationship between the number of sources of information used by women with breast cancer and information seeking style scores. Due to the majority of low scores of the blunter scale, it is not unexpected that correlations would not exist. The lack of correlation is very likely due to the blunter characteristics of not wanting information as a coping mechanism, as results identified few sources of information.

The monitor scores of the subjects demonstrated a low statistically meaningful relationship with the number of information sources used by women with breast cancer. If a larger sample size were obtained, it would be expected the relationship would be strengthened. Because of the monitor characteristic of needing a greater amount of information, it would be expected that a greater number of sources would be sought out.

Question #4 asked if there a relationship among the variables of age, marital status, educational level, and the specific sources of information used by women with breast cancer. A majority of the subjects had incomes of greater than \$30,000 and identified the surgeon as a source of information, therefore it was not surprising to find the correlation that existed. It is possible with a larger sample size the correlation may be the strengthened, or otherwise altered as the characteristics of the subjects change. The lack of relationship between the chemotherapy doctor/nurse and the demographic variables may be related to the time line of this study, the women may have not recognized information given by the chemotherapy doctor/nurse as new information, especially if options had already been discussed with the surgeon.

The friend as an information source was found to have a low relationship with education. The relationship found may be due to those with higher education are probably friends with persons of higher education, and have knowledge of more resources. The lack of moderate or higher relationships among the variables and the various sources of information identified by women with breast cancer may be related to the small sample size and the great amount of correlations needed. It would be expected that those with higher levels of education and income levels would use more professionally generated sources of information, while those with lower education levels may use more public sources, such as television, radio, and friends. It is possible with a larger, and more diverse sample size, a stronger and greater relationship may be discovered.

Question #5 asked if there a relationship among the variables of age, marital status, educational level, and the number of specific sources of information used by women with breast cancer. The relationship found among the number of sources of information with income and work was not unexpected. Those with greater incomes would have more financial resources to access greater information and those employed would have greater contact to potential sources of information.

Question #6 asked if there is a relationship among the variables of age, marital status, educational level, or income level, and the information seeking style score displayed by women with breast cancer. No significant statistical relationships were found to exist. As expected, a low relationship was found between the variables of age and income with the monitoring group. Women with higher incomes would possibly have greater access to more sources. With a larger sample of monitors, this relationship would likely be strengthened.

Limitations of Study

The limitations of this study may have affected the outcomes of the research questions. A larger sample with a greater representation of both blunting groups and monitoring groups would improve the ability to ascertain the existence of relationships examined in this secondary analysis. Lack of discrimination of true sources of information, especially the separation of physician sources from nurse sources may also alter the outcome of this secondary analysis. During data collection for the primary study, subjects reacted to the source

of information checklist questioning whether they had ever seen a nurse when seeing the chemotherapy or radiation doctor.

The weakness of the Information Seeking Style Scale with its poor reliability places the results in questionable light. This writer questions if persons move in and out of both monitoring and blunting styles depending upon the day and circumstance the subject is approached. Upon first hearing of the diagnosis of breast cancer, a blunting style may be displayed but, with the passage of time, the style may alter to that of a monitoring style to meet the patient's need for information.

Recommendations for Further Study

- Recommendations for further study include using a larger sample, hopefully to gain a more equal number of monitors and blunters.
- 2. It is also recommended that a more diverse population be used to include a greater ethnic representation and greater income spread.
- 3. Further studies in this area of information seeking styles coupled with sources of information are needed, not only for women with breast cancer, but also other acute populalations, i.e., preoperative patients.
- 4. Further studies are needed to explore the role nurses play as a source of information, and how nurses are perceived by the patient as a source of information.

- 5. Further studies are also needed to explore if indeed patients may be separated into two groups of information seekers, blunters and monitors.
- 6. It is recommended that with further studies the Source of Information Checklist be altered so nurses may be more clearly identified by subjects as specific source of information or not.

Implications for Nursing

The implication for nursing may be to remove the standard practice of providing reams of information regarding breast cancer and its treatment to every patient. The ability to assess and acknowledge two information seeking styles would enable nurses to truly deliver individualized care, based upon the patient's needs.

Nurses also need to investigate their own methods of delivering patient education, to assess why it is so little recognized by the public. This information will enpower nurses and improve their image as professionals. The public needs to be informed about the availability and expertise of nurses as sources of information. More research needs to be done in the area of information seeking and learning the sources of information used by women with breast cancer.

Summary

Chapter Five presented a discussion of the results of this secondary analysis. Recommendations for further studies, if carried out, may confirm the results of this study and avoid possible errors discussed previously. It is recommended that nurses continue to offer

information to patients as needed, and also educate the public about their availability as likely sources of information. Nurses must continue to assess their patients' response to information offered and must individualize what is offered based on this response.

APPENDIX A

HUMAN SUBJECTS APPROVAL

UNIVERSITY OF ARIZONA COLLEGE OF NURSING

MEMORANDUM

TO:

Patricia K. Messerli

P.P. Box 1123

Flagstaff, Arizona 86002

FROM:

Carolyn Murdaugh, Ph.D., R.M., F.A.A.N. Director of Clinical Research

DATE:

October 3, 1990

SUBJECT: Human Subject's Approval for Thesis Research

Your research, "Information Seeking Styles and Sources of Information used by Women with Breast Cancer, has received prior approval as part of a larger study entitled *Life Quality, Self-Help and Self-Care Among Women Having Received Radiation Treatment for Breast Cancer: A Follow-up Study". The project was approved as an exempt one and requires no further approval for secondary analysis of data.

Best wishes with your research.

CM:dbr



THE UNIVERSITY OF ARIZONA TUCSON, ARIZONA 85721

COLLEGE OF NURSING

December 10, 1990

Patricia Messerli Northern Arizona University Department of Nursing Nursing Sciences, Bldg., Rm 211 Flagstaff, AZ 86011

Dear Pat:

I am happy to provide this statement of permission for your use of the data from the SHIP pilot study. The data specifically include responses on the Sources of Information Checklist, Information Seeking Styles and the Demographic Information Sheet. The internal consistency reliability of the two scales, monitoring and blunting, that make up the Information Seeking Styles Questionnaire as evidenced by Cronbach's Alpha was =.73, std. item =.72 for the Dentist subscale for monitoring and =.63, std. item =.63 for the Dentist subscale for blunting. The other subscale responses for monitoring and blunting (Hostage, Airplane, Work) were too low to be considered suitable for data analysis.

Thank you for your interest in using this data for your own research. I am looking forward to hearing the results of your study.

Sincerely,

Carrie of Strawn

Carrie Jo Braden, Ph.D., R.N. Principal Investigator, S.!!.I.P.

APPENDIX B

SOURCES OF INFORMATION

SELF-HELP INTERVENTION PROJECT: BREAST CANCER TREATMENT

SOURCES OF INFORMATION

Coc	le #
Dat	e
From which of the following sources have you received in about breast cancer and its treatment? (Check all that a	
Your Surgeon	
Your Chemotherapy Doctor/Nurses	
Your Radiation Doctor/Nurses	
Therapist or Counselor	
Family Members	
Friends	
American Cancer Society	
National Cancer Institute	
Arizona Cancer Center	
Cancer Information Groups (e.g., I Can Cope)	
Cancer Support Groups (e.g., Can Surmount or Reach To Recovery)	Control of the last of the las
Books from Public Library or Bookstore	
Audiotapes or Videotapes	
Television/Radio	
Newspaper	
Magazines	

APPENDIX C

INFORMATION SEEKING STYLES

DATE:	I	D #:
T:		
	ISS	
some dental work d making your mark o	nat you are afraid of the dentist a lone. Read each of the following a on the line, the degree to which ea we about you in this situation:	nd indicate, by
(M1) I would ask t	the dentist exactly what he/she was	going to do.
Not true about me		True about me
(B1) I would take	a tranquilizer or have a drink bef	ore going.
Not true about me		True about me
(B2) I would try t	to think about pleasant memories.	
Not true about me		True about me
(M2) I would want	the dentist to tell me when I woul	d feel pain.
Not true about me		True about me
(B3) I would try t	co sleep.	
Not true about me		True about me
(M3) I would watch sound of his	all the dentist's movements and l	isten for the
Not true about me		True about me
(M4) I would watch	n the flow of water from my mouth tood.	o see if it
Not true about me		True about me
(B4) I would do me	ental puzzles in my mind.	
Not true about me		True about me

APPENDIX D

DEMOGRAPHIC DATA SHEET

SELF-HELP INTERVENTION PROJECT: BREAST CANCER TREATMENT

DEMOGRAPHIC DATA

		Code #	
Age:		Date:	
Marital Status (Check One)		Working/School (Check	One)
Married		(2) Full Time	
Separated		<pre>(1) Part Time (0) None</pre>	
Divorced Widowed		(U) None	
Single/Never Married			
Education (Check One)		Gross Family Income (Check One)	
(1) 8th Grade or Less		(7) \$60,000 & Above	
(2) Some High School(3) High School Graduate		(6) 50,000 - 59,999 (5) 40,000 - 49,999	
(4) Trade/Business School		(4) 30,000 - 39,999	
(5) Some College		(3) 20,000 - 29,999	
(6) College Graduate(7) Graduate or		(2) 10,000 - 19,999 (1) Below 10,000	
Professional Degree		(1) Delow 10,000	
Date of Diagnosis of Breast	Cancer:		
<pre>Type of Surgery(s): (Check all that apply)</pre>		Date Done	
Radical Mastectomy or Modified Radical			
Partial Mastectomy			
Local Excision (Lumpectomy)			
<pre>Type of Treatment(s): (Check all that apply)</pre>		Approximate Date Treat Completed:	ment
Chemotherapy			
Radiation Hormone Therapy			
Who Lives at Home With You?	(Check all th	at apply)	
Husband Children Other Family	(Ages)	Friends Other	

Family History of	Breast Can	<u>cer</u> (Check all	that apply)			
	Mother	Sister(s)	Paternal Grandmother	Maternal Grandmother		
Age at Diagnosis:						
Ethnic Origin:						
(1) White (2) Hispanic (3) Black (4) Native American (5) Oriental (6) Other						
List of other chronic illnesses/diseases:						
Insurance Coverage (Check One)						
(1) Blue Cross/Bl(2) Commercial In(3) HMO-e.g. Inte(4) Medicare	surance-e.g	. Aetna (6)	AHCCCS Self-Pay Other (Specify)		

Briefly describe how you discovered that you had breast cancer.

REFERENCES

- American Cancer Society (1990). Cancer Facts and Figures 1990, Atlanta, GA: ACS, pp. 6-10.
- Braden, C. (1990a). A test of the Self-Help Model: Learned response to chronic illness experience. <u>Nursing Research</u>, <u>39</u>(1), 42-47.
- (1990b). Learned self-help response to chronic illness experiences: A test of three alternative learning theories. Scholarly Inquiry for Nursing Practice, An International Journal, 4(1), 23-41.
- Braden, C., Mishel, M., Longman, A. & Burns, L. (1990). A self-help intervention project (SHIP) in breast cancer treatment.

 <u>Innovations in Oncology Nursing</u>, 6(2), 1, 8, 19.
- Bromley, B. (1980). Applying Orem's self-care theory in enterostomal therapy. American Journal of Nursing, 80(2), 245-250.
- Bullock, B. & Rosendahl, P. (1988). Pathophysiology. Boston, MA: Scott, Foresman and Company.
- Campbell-Forsyth, L. (1990). Patients' perceived knowledge and learning needs concerning radiation therapy. <u>Cancer Nursing</u>, <u>13(2)</u>, 81-89.
- Cassisleth, B. (1989). The social implications of questionable cancer therapies. Cancer, 12(5), 1247-1250.
- Cassileth, B., Zupkis, R., Sutton-Smith, K. & March, V. (1990). Information and participation practices among cancer patients.

 <u>Annals of Internal Medicine</u>, 92(6), 832-836.
- Cohen, F. & Lazarus, R. (1979). Coping with stress of illness. In Stone, G., Cohen, F. & Adler, N. (Eds.), <u>Health Psychology</u>. San Francisco, CA: Jossey-Bass, pp. 217-224.
- David, A., Roul, R. & Kuruvilla, J. (1988). Lessons of self-help for Indian women with breast cancer. <u>Cancer Nursing</u>, <u>11</u>(5), 283-387.
- Derdiarian, A. (1987). Informational needs of recently diagnosed cancer patients: A theoretical framework, Part one. <u>Cancer Nursing</u>, 10(2), 107-115.

- Devito, A., Bogdanowicz, J. & Reznikoff, M. (1982). Actual intended health-related information seeking and health locus of control. Journal of Personality Assessment, 46(1), 63-69.
- Dodd, M. (1982). Assessing patient self-care for side effects of cancer chemotherapy-Part I. <u>Cancer Nursing</u>, <u>5</u>(6), 447-451.
- (1983). Self-care for side effects in cancer chemotherapy:

 An assessment of nursing interventions-Part II. Cancer Nursing 6(2), 63-67.
- in radiation therapy patients. Heart and Lung, 16(5), 538-544.
- _____ (1988). Patterns of self-care in patients with breast cancer. Western Journal of Nursing Research, 10(1), 7-24.
- Eich, S. (1985). Promising early breast cancer treatment, without mastectomy. <u>Cancer Nursing</u>, 8(1), 51-58.
- Fernsler, J. (1986). A comparison of patient and nurse perception of patients' self-care deficits associated with cancer chemotherapy. Cancer Nursing, 9(2), 50-57.
- Frank-Stromborg, M. (1986). Health promotion behaviors in ambulatory cancer patients: Fact or fiction? Oncology Nursing Forum, 13(4), 37-43.
- Frank-Stromborg, M., Wright, P., Segalla, M. & Diekman, J. (1984).

 Psychological impact of the "Cancer" diagnosis. Oncology

 Nursing Forum, 11(3), 16-22.
- Friedman, B. (1980). Coping with cancer: A guide for health professionals. Cancer Nursing, 3(4), 105-110.
- Gadow, S. (1989). An ethical case for patient self-determination. Seminars in Oncology Nursing. 5(2), 99-101.
- Garrison, J., Abner, J., Oakley, M. & Hagan, P. (1983). Accessibility and utilization of educational materials for cancer patients. Oncology Nursing Forum, 10(2), 60-62.
- Goodman, M. & Harte, N. (1990). Breast cancer. In Groenwald, S., Frogge, M., Goodman, M. & Yarbo, C. (Eds.), <u>Cancer Nursing: Principles and Practice (2nd Ed.)</u>. Boston, MA: Jones and Bartlett Publishers.

- Hanacharunkul, S. (1989). Predictors of self-care in cancer patients receiving radiotherapy. <u>Cancer Nursing</u>, <u>12</u>(1), 21-27.
- Hopkins, M. (1986). Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. <u>Cancer Nursing</u>, 9(5), 256-262.
- Hulka, B. (1990). Hormone-replacement therapy and the risk of breast cancer. <u>Ca-A Cancer Journal for Clinicians</u>, 40(5), 289-295.
- Johnson, J. & Kelly, A. (1990). Recovery from breast cancer: A wilderness experience. Oncology Nursing Forum, September/October, 17(5), 691-695.
- Lazarus, R. (1979). Psychological stress and the coping process. New York, NY: McGraw-Hill.
- Lenz, M. (1986). Breast cancer treatment alternatives: The patient decision making process. Health Values, 10(1), 16-21.
- Levin, L., Katz, A. & Holtz, E. (1976). Self-care lay initiatives in health. New York, NY: Prodist.
- Mayo, L. (1956). Problems and challenge. In <u>Guides to Action in Chronic Illness</u>. New York, NY: National Health Council, pp. 331-358.
- McKhann, C. (1985). The changing role of surgery in the treatment of breast cancer. <u>Seminars in Oncology Nursing</u>, <u>1</u>(3), 176-180.
- Miller, S. & Mangan, C. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: Should the doctor tell all? <u>Journal of Personality and Social Psychology</u>, 45(1), 223-236.
- Miller, S., Summerton, J. & Brady, D. (1988). Styles of coping with threat: Implications for health. <u>Journal of Personality and Social Psychology</u>, <u>54</u>(1), 142-148.
- Munro, B., Visintainer, M. & Page, E. (1986). Statistical methods for health care research. Philadelphia, PA: J. B. Lippincott Company.
- Orem, D. (1980). Nursing: Concepts of practice (2nd Ed.). New York, NY: McGraw-Hill.
- _____(1985). Nursing: Concepts of practice (3rd Ed.). New York, NY: McGraw-Hill.

- Ray, C., Fisher, J. & Wisniewski, T. (1986). Surgeons' attitudes toward breast cancer, its' treatment and their relationship with patients. <u>Journal of Psychosocial Oncology</u>, <u>4</u>(1/2), 33-43.
- Rowland, J. & Holland, J. (1989). Psychological care of the patient with cancer. In Holland, J. & Rowland, J. (Eds.), <u>Handbook of Psycho-Oncology</u>. Oxford Press, Oxford.
- Scott, D. & Eisendrath, S. (1985/86). Dynamics of the recovery process following initial diagnosis of breast cancer. <u>Journal of Psychosocial Oncology</u>, 3(4), 53-66.
- Simmons, C. (1984). The relationship between life change losses and stress levels for females with breast cancer. Oncology Nursing Forum, 11(2), 37-41.
- Thomas, S. (1978). Breast cancer: Psychosocial issues. <u>Cancer Nursing</u> 1(1), 53-60.
- U. S. Department of Health, Education and Welfare (1979). Healthy people: The Surgeon General's report on health promotion and disease prevention. Washington, D.C., U. S. Government Printing Office.
- Valanis, B. & Rumpler, C. (1985). Helping women to choose breast cancer treatment alternatives. <u>Cancer Nursing</u>, <u>8</u>(3), 167-175.
- Weisman, A. (1976). Coping behavior and suicide in cancer. In Cullen, J., Fox, B. & Isam, R. (Eds.), Cancer: The Behavioral Dimension. New York, NY: Raven Press, pp. 331-358.
- Whelan, E. (1984). Analysis and application of Dorothea Orem's Self-Care practice model. <u>Journal of Nursing Education</u>, <u>23</u>(8), 342-345.