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thesis entitled

PSYCHOLOGICAL AND SOCIODEMOGRAPHIC BARRIERS
TO HEALTH CARE ACCESS OF RURAL WOMEN
DIAGNOSED WITH BREAST CARCINOMA

presented by

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has been accepted towards fulfillment
of the requirements for

MASTER OF ~~SCIENCE~~ degree in NURSING

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Date 8/4/95

DATE DUE	DATE DUE	DATE DUE
Due 6/15/97		
2/10/98		

PSYCHOLOGICAL AND SOCIODEMOGRAPHIC BARRIERS TO HEALTH CARE ACCESS OF RURAL WOMEN DIAGNOSED WITH BREAST CARCINOMA

By

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1995

ABSTRACT

PSYCHOLOGICAL AND SOCIODEMOGRAPHIC BARRIERS TO HEALTH CARE ACCESS OF RURAL WOMEN DIAGNOSED WITH BREAST CARCINOMAS

By

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The purpose of this study was to examine psychological and sociodemographic barriers to health care access of rural Michigan women diagnosed with breast cancer. Structural, financial, and personal health care access barriers were analyzed in a small sample (n=34) of rural women. An index of sociodemographic barriers was constructed from the study model variables, but only rurality, living with others, and marital status were significant. A comparison of the health care access barriers by stage of disease at diagnosis was performed. The relationships among barriers to health care access, stage of disease at diagnosis, and level of depressive symptoms were analyzed. Barriers to health care access were present for all subjects, and barriers increased as depressive symptoms increased. The mean for all barriers was 4.62 (SD 1.51, range 2 to 8). There was a moderate, negative association between depressive symptoms and perceived level of emotional support (r=-.6864, p=.000). Implications for advanced nursing practice included health care access barrier identification and management, holistic approaches to client care, and the importance of assessing for depressive symptoms and perceived level of emotional support.

DEDICATION

This thesis is dedicated to my husband, James E. Emerson, whose boundless love, support, patience, encouragement, and understanding helped me through three of the most challenging years of my life.

ACKNOWLEDGMENTS

I am grateful for the invaluable assistance of two University staff members: Amy Blair, for always being willing to help me find one more article, and Cindy Espinoza, whose superb organizational skills expedited my data collection.

I am also indebted to Dr. Harry Hill, whose expert knowledge of SPSS and ever willingness to help were critical to my statistical analysis, and to Catherine Hunter for her ongoing support.

I wish to thank my Committee members - Gwen Wyatt, Patty Peek, and especially Dr. Barbara Given - for sharing their resources and imparting steady guidance, wisdom, and encouragement to me throughout this project.

Finally, I would like to acknowledge the 34 women of this study whose lives were forever altered by breast cancer. I am deeply indebted to them for their courage to participate in the Rural Cancer Care Study, which has permitted me and others to learn how to help the 150,000 women who will be similarly diagnosed this year.

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INTRODUCTION

Breast cancer will develop in one of eight women in her lifetime, and one out of every thirty-three will die from breast cancer (Bassett & Hendrick, 1994). In 1990, approximately 150,000 new cases were diagnosed in the United States, and more than 44,000 women died from breast cancer (Holleb, Fink, & Murphy, 1991). Carcinoma of the breast is the most commonly diagnosed cancer, and the second leading cause of cancer deaths among women in the United States (Harrington, Feetham, Moccia, & Smith, 1993; "Mammography and clinical breast examinations", 1993).

In Michigan, cancer of the breast is the leading site of cancer diagnosed among women over age 24. According to Michigan Department of Public Health, Office of the State Registrar and Center for Health Statistics, 5,834 women were diagnosed with advanced stage breast cancer during the 1990-1992 period (G. Van Amburg, personal communication, December 9, 1994). Carcinoma of the breast was the underlying cause of death among 1,597 Michigan residents in 1992 (Michigan Department of Public Health [MDPH], 1994).

By the year 2000, the National Cancer Institute's goal is for a 37 percent reduction in breast cancer mortality (Howe, Lehnherr, & Katterhagen, 1994). Likewise, national health objective 16.3 for the year 2000 is to reduce breast cancer deaths to no more than 20.6 per 100,000 women ("Mammography and clinical breast examinations", 1993). This will be a significant challenge in Michigan considering the 1992 age-adjusted mortality rate in this state was well above this goal at 27.3 (MDPH, 1994).

Statement of the Problem

Numerous researchers have estimated that 30% to 50% of breast cancer mortality could be reduced with early detection methods such as performing manual breast examinations and mammography (Bassett & Kendrick, 1994; Harrington et al., 1993; MDPH, 1990; Sochurek, 1988). According to Michigan Department of Public Health (1990), screening mammography plus clinical breast exam can detect breast cancer in 95% of cases. Eighty-five percent of breast cancers detected with mammography can be treated surgically, with chemotherapy, by radiation therapy, or any combination of the three (Sochurek, 1988).

The likelihood of cancer having spread beyond the breast is low and the prognosis good when the size of a primary breast cancer at initial detection is less than 1.5 centimeters in diameter. The five year survival rate for women diagnosed at this stage is more than 90%. However, for approximately 50% of black and white rural Michigan women newly diagnosed in the last 15 years, cancer had already spread beyond the breast at the time of diagnosis (MDPH, 1990). Nationally, 11% of black women and 7% of white women had advanced stage breast cancer with distant sites upon initial diagnosis. The five year survival rate among women with breast cancer that had spread to regional sites is 68%, but drops to 18% for advanced stage breast cancer with distant sites (MDPH, 1990). Advanced stage cancers are the most invasive, most difficult to surgically remove, costliest to treat, and may be unaffected by therapeutic interventions.

Advanced practice nurses may have a significant role in the early detection of breast cancer in their female clients through mammography, comprehensive physical assessment, and careful inventory of each woman's health risks and barriers to care. The purpose of this study was to analyze psychological and sociodemographic barriers to health care access of rural Michigan women diagnosed with breast cancer.

REVIEW OF THE LITERATURE

Conceptual Definition of the Variables

The four primary concepts under study are sociodemographic barriers (structural, financial, and personal), psychological barriers (amount and sources of emotional support, and affective distress), stage of disease at diagnosis of breast cancer, and health care access.

Sociodemographic barriers to health care access were defined as those facts about an individual or her environment which were indicative of her social or economic standing, the status of which may have negatively impacted access to health care. The sociodemographic study variables relating to structural barriers were transportation, traveling more than 25 miles for care, rurality, and absence of a primary care physician. The only variable relating to financial barriers was absence of insurance, Medicare, or Medicaid. The sociodemographic variables relating to personal barriers were age, ethnicity, education, marital status, household income, and the presence of others in the household.

The psychological barriers to health care access in this study were defined as inadequate personal psychosocial support and the presence of affective distress sufficient to cause depressive symptomatology. These subjectively determined factors were 3 of the 9 personal barriers illustrated in Figure 2. The study variables relating to psychosocial support were subject's identification of the number of persons she felt she received emotional support from, and her assignment of the level of emotional support she gained from these supporters, which were gathered using the Family Network grid (Appendix B, page 63). The data for the variable relating to presence of affective distress was gathered from the Center for Epidemiologic Studies Depression Scale (CES-D).

Stage of disease at diagnosis of breast cancer was defined in accordance with the American Joint Commission staging system. According to the American Cancer Society, this system divides all tumors into Stages 0 to IV, based on the size of the primary lesion and the presence of metastases. Stage I is noninvasive, while Stage II is localized to the breast; both are considered early stage disease. Both Stage III and IV may have tumors in the breast of any size plus lymph node involvement; only Stage IV includes metastases to distant organs or lymph nodes (Holleb et al., 1991). Stage III and IV are considered advanced stage disease. In this study, stage at diagnosis was an outcome rather than a barrier; however, the stages were also operationalized as variables. Subjects with all four stages of disease at diagnosis of breast cancer were included in this study.

The definition of health care access that was used to guide the study was meeting the individual's threshold's for acceptability, attainability, accommodation, affordability, and availability of health care services in order to achieve the best possible health outcomes. Acceptability is congruence with the individual's values. Attainability is obtaining needed services. Accommodation is anticipation, recognition, and proactivity to meet the individual's needs. Affordability is acceptable valuation of a service, or a method that renders an otherwise financially inaccessible service accessible. Availability is the existence of necessary personnel and resources (i.e., equipment) to provide a service. This comprehensive definition of access was intended to be a goal more than a reflection of the current state of health care access; further, all of the dimensions of the definition were not measured in this study.

Conceptual Model

Although scores of authors have written about access to health care, the majority of the literature does not offer a framework, definitions, or models of access. Rather, most address only the economic implications of health care access.

One of the first health care access models was published by Aday and Anderson (1974). Based on behavioral theory, the model was dynamic, and acknowledged factors other than ill-health as important in accessing health care. It was driven by three factors: predisposing variables, such as sociodemographic factors and perceptions of care efficacy; enabling variables, such as insurance coverage, cost, and convenience factors; and need, which related to actual health status. The emphasis of the model was largely on structural rather than personal elements. This model remained the dominant model of health care access until issuance of the Institute of Medicine model nineteen years later.

In the last five years, only one author has offered a well-developed definition of health care access having a special focus on women. Puentes-Markides (1992) defined access as an encounter between the client/woman and health care system as a means to better health, be it through personal contact with a health care provider or through the appropriation of information. The author proposed that access occurs as the interaction of many factors related to three fundamental elements: the structure of the health system, the behavior of health professionals, and characteristics of the population seeking care. Puentes-Markides characterized access as "the degree of fit between the clients and the health care system", and assigned health care access the undefined dimensions of availability, accessibility, accommodation, affordability, and acceptability.

In 1993, two important access projects were published. The American

Academy of Nursing (Harrington, Feetham, Moccia, and Smith, 1993) produced a working paper that explored health care access issues for vulnerable populations, as well as those related to the health care delivery system, health care providers, and finances. The paper offered an analysis of access to the current health care system as well as structure and process dimensions that impede health care access, with suggestions for reform of the health care system. This work failed to offer a definition of access, however.

The second project was an even more comprehensive analysis of access and barriers produced by a 17 member committee of experts convened by the Institute of Medicine (IOM). The Committee on Monitoring Access to Personal Health Care Services included Aday who, along with Anderson, designed the 1974 access model. This IOM committee had two charges: to develop a set of indicators for monitoring access to personal health care services at the national level over time, and to assess the current status of health care access in the United States related to five avoidable or improvable health conditions (birth outcomes, vaccine-preventable childhood diseases, early detection and treatment of treatable diseases, reducing effects of chronic diseases, and reducing morbidity and pain through timely, appropriate treatment). Access was defined by the IOM Committee on Monitoring Access to Personal Health Care Services as the timely use of personal health services to achieve the best possible health outcomes (Millman, 1993). Using this definition as a goal more than a guide, a model of access to personal care services was developed (Figure 1); the IOM Committee on Monitoring Access to Personal Health Care Services model was subsequently adapted as the model for this study.

The IOM Health Care Access Model has four components: barriers to health care access, use of health care services, mediators of care, and outcomes of care and services. The model is dynamic and assumes a progression from barriers to outcomes. Participation in the health care system and the impact of structural, financial, and personal barriers on use of health care services are represented. The model was labeled neutrally; that is, there are no value assignments such as "incompetent providers" or "inadequate treatment". Thus, although any of the barriers have the ability to negatively impact utilization (the second component of the model), the fluidity of the model does not accommodate absence or cessation of access. Rather, the model leads the reader to consider potential impacting factors (mediators), and allows prediction or validation of obtained outcomes.

Structural barriers in the model are impediments related to health care provider number, type, concentration, location, or organizational configuration. These are very similar to the structural factors cited by Puentes-Markides (1992). If there is a complete reform of the nation's health care system, the structural barriers cited in this model are likely to be significantly impacted.

Financial barriers are those systemic factors, policies, fee structures, and fiscal management plans that inhibit patient ability to pay for services or discourage providers from treating patients of limited means; they do not refer to the patient's personal financial resources. These barriers would also be likely to be affected by health care reform. Financial barriers are the ones most often cited in the literature, and are used synonymously with the concept of access. Although important, it is clear from the model that they are not the only barriers which impact access.

Personal and cultural barriers inhibit people who need medical attention from seeking it or, once they obtain care, from following recommended

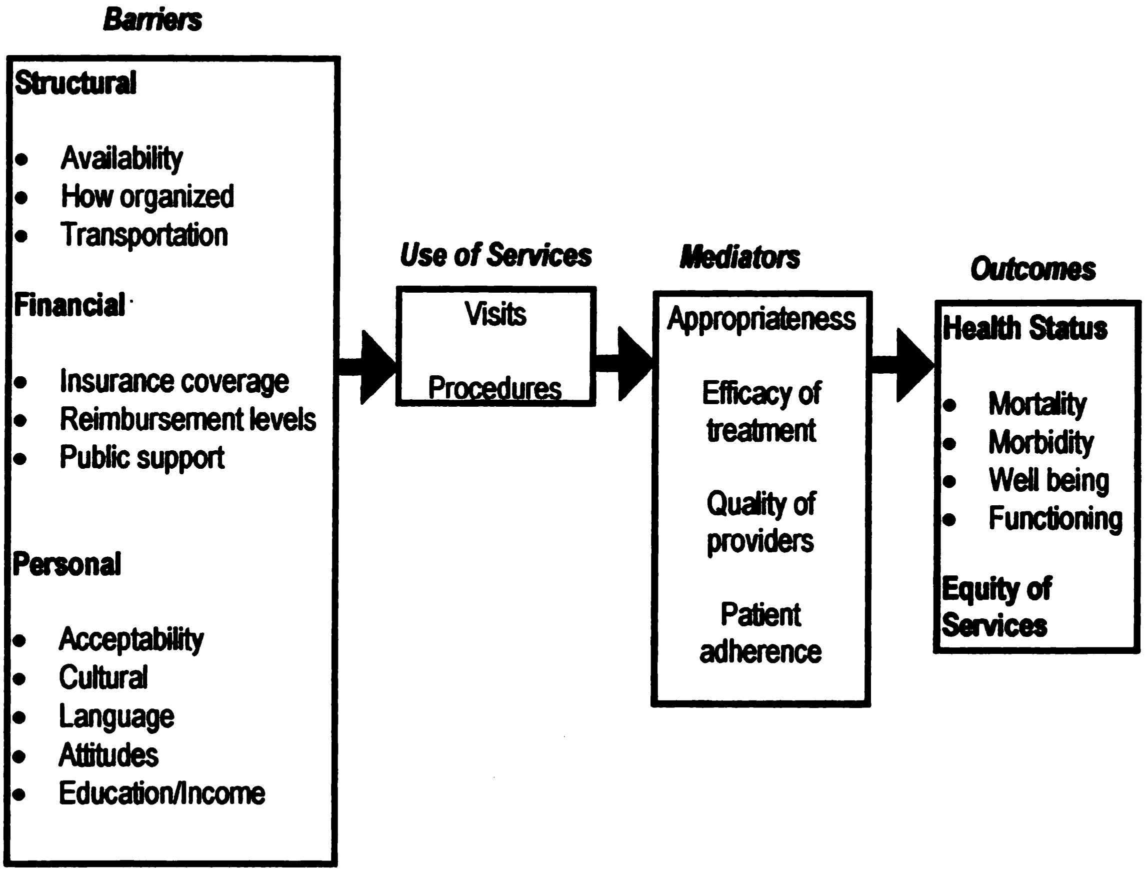

Figure 1. The Institute of Medicine Committee on Monitoring Access to Personal Health Care Services model of personal health care access (Millman, 1993).

post-treatment guidelines. Models by Aday and Anderson (1974) and Puentes-Markides (1992) included this component, though in a less expansive manner. Although these barriers will also be affected by health care reform, the societal demands for increased cultural awareness and sensitivity assure that this element of the model will continue to grow in scope and importance.

The second component is use of services, which is quantifiable and may well be the strongest indicator of the activity level of the barriers which precede it. Although the model was not constructed for reversal of the flow (right to left), this component may also be affected by the mediating component (i.e., failure to return for a recheck due to receiving inappropriate care from a poorly trained provider during the initial visit), and the outcome component (i.e., failure to return for additional orthopedic visits as a result of loss of function and increased pain from treatment received during the initial visit).

The third component, mediators, is similar to another element of Puentes-Markides model (1992), behavior of health professionals. These factors can also curb the use of health care services and diminish desired health outcomes. Appropriateness and treatment efficacy occur when services are selected for which there is high likelihood of benefit, and for which there is a standard of care largely unaffected by variation in practice style. Provider quality is clearly more difficult for the patient to detect and affect when managing personal health services, particularly when treatment options and care sources are limited by issues related to insurance or income. Poor patient adherence to the treatment regimen is often a result of poor communication between the patient and prescriber, due to failure to adequately educate the patient, involve the patient in designing the treatment plan, or take into account the patient's culture, finances, or other influencing factors. Whatever the cause, there often is just one result: poor health outcomes (the fourth component).

It is no secret that there is inequity in health care service availability, and in mortality and morbidity rates. Any single barrier may erode the pathway to optimal health outcomes, the final component of the model. However, multiple barriers may have a compounding effect, akin to the "triple jeopardy" of poverty, rurality, and lack of insurance described by Rowland and Lyons (1989).

The study model (Figure 2) was based on the IOM Health Care Access Model. Much like the IOM Access Model, there are structural, financial, and personal barriers to access; unlike the IOM Model, they are not presented neutrally. The model depicts that the presence of structural, personal, and financial barriers to health care access may lead to a finding of early or advanced stage breast cancer. This study included no research questions or variables regarding use of services or mediators, the second and third components of the IOM Access Model. For this reason, those components were not carried forward in the study model.

Structural barriers in the study model are dependence for transportation, traveling more than 25 miles for health care, residing in a rural county, and absence of a primary care physician. The financial barrier is lack of insurance, Medicare, or Medicaid. Personal barriers are being 35 to 54 years of age, being of noncaucasian ethnicity, having less than a high school education, being married, having a poverty-level income, living with others, not having more than 2 family members or friends for support, receiving inadequate emotional support, and having depressive symptoms. These individual barriers became the primary study variables and the basis for construction of an index of barriers to health care access.

Outcomes, the final IOM Access Model component, was reflected in the study subject's diagnosis of early stage (I or II) or advanced stage (III or IV) breast carcinoma.

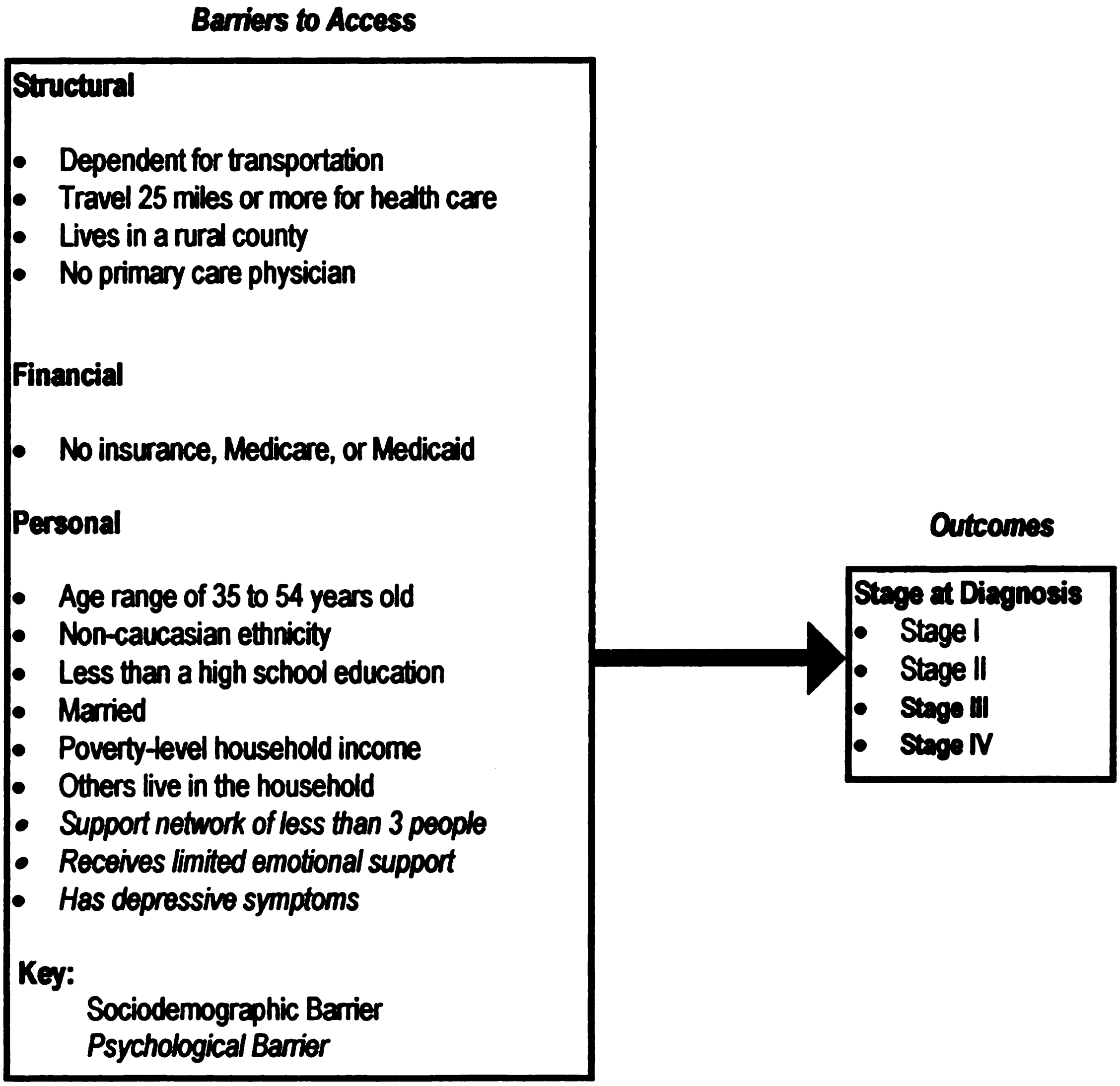

Figure 2. Model of psychological and sociodemographic barriers to health care access of rural Michigan women diagnosed with breast cancer.

Review of the Literature regarding Sociodemographic Barriers to Health Care Access

The sociodemographic barriers were further categorized as structural, financial, or personal barriers. Structural barriers were dependence for transportation, having to travel more than 25 miles for health care, rurality, and absence of a primary care physician. The financial barrier was the absence of insurance, Medicare, or Medicaid. The personal barriers were age, ethnicity, education, marital status, household income, and the presence of others in the household.

Sociodemographic Barriers - Structural

Rurality is often poorly defined in the literature, although much cited. Inconsistent definitions have existed not only in the literature but even within funding and regulatory agencies of the Federal government. This study used the US General Accounting Office definition of urban as more than 99 people per square mile, and rural as 6 to 99 people per square mile. One Michigan county (Keweenaw) met the definition of frontier (less than 6 people per square mile). The four counties in this study are more than 175 miles from Detroit, the only city in Michigan with more than 200,000 people. From the approximate geographic center of each county, residents must travel between 36 and 90 miles one way in order to reach the nearest Michigan city of more than 100,000 people where more sophisticated diagnostic and tertiary care capabilities exist.

One quarter of the population in the United States resides in rural areas. When compared with urban areas, rural areas have few resources and limited possibilities. Linn, Husaini, Witten-Stovall, and Broomes (1989) suggested that rurality is often restrictive, opportunity-poor, offers little hope for economic security or mobility, and that it has greater influence on mental distress and depression than even disruptive life events, such as a diagnosis of cancer.

In contrast to their urban counterparts, rural residents demonstrate lower utilization of health care services as a result of greater distances to travel to providers, lack of a primary care provider, and lower family incomes. In fact, people living in rural areas are more likely to be without a regular source of health care than urban dwellers (Harrington et al., 1993). Hunter et al. (1993) found that, among black and white rural women, black women were more likely to have no primary care provider other than the hospital emergency department. Samet, Hunt, and Goodwin (1990) reported that among the elderly in New Mexico, women who had a family physician were 1.2 times more likely to have breast cancer discovered at a local stage rather than regional or remote. In a study of women who had breast cancer, fibrocystic disease, or no breast disease, less than one-sixth of healthy women lived in rural areas whereas two thirds of the women who had breast cancer were rural dwellers (Jansen & Muenz, 1984).

In addition, rural women are less likely to have readily accessible transportation and assistive community resources to obtain mammography or other preventive health services. Hartley, Quam, and Lurie (1994) reported that rural dwellers were more likely to travel distances of more than 25 miles for a physician visit. In rural Michigan, obtaining preventive health services may entail more than an hour's drive. Eleven Michigan counties have no mammography equipment, and in nine there is no hospital. Fewer interactions with the health care system result in less opportunity for ongoing health screening and illness prevention, which may prolong the interval between tumor development and detection (Samet et al., 1990). Taken in combination, these factors may delay care, which results in progression of the disease and higher mortality (Hartley et al.).

Sociodemographic Barriers - Financial

Hunter et al. (1993) found that rural black women were less likely than rural white women to have insurance or other sources for defraying medical care costs. In addition, rural residents are less likely to have employment opportunities that include employer-paid health insurance (Hartley et al., 1994). Rural health insurance policies are seven times as likely as urban policies to have a deductible, while providing less coverage and consuming a higher proportion of the family income to pay the premiums. Rural dwellers are less able to afford private insurance or the copayments and deductibles for public or private insurance (Given, Given, & Harlan, 1994; Harrington et al., 1993). Thus, rural residents are more likely than their urban counterparts to rely on Medicaid or other public assistance, and spend a higher proportion of their income on health care (Harrington et al., 1993; Hartley et al., 1994).

Sociodemographic Barriers - Personal

Although many of the sociodemographic barriers have appeared in the literature, few have been analyzed in the context of health care barriers for rural women. As such, the literature includes general findings about the barriers individually or collectively, but with little emphasis regarding the impact on rural women.

One rural dweller in six lives in poverty (Anderson, 1993; Given et al., 1994), and rural dwellers are more likely to have lower median incomes than urban dwellers. In Michigan, rural dwellers earn on average $10,446 less per year than their urban counterparts (US Bureau of the Census, 1994). Friedman (1994) reported barriers to access as race (noncaucasian), social class and culture (those other than caucasian, middle-class, English-speaking people with Christian values and traditions), gender (female), and age (the very young and the elderly).

Age is often cited as a barrier but the exact age range considered to be a barrier is not specified. Michigan Department of Public Health identified breast cancer as a leading cause of death for rural women in Michigan who are between the ages of 35 and 54 (P. DeGuire, personal communication, July 10, 1995).

Hunter et al. (1993) found that, among rural black and white women under 50 years of age, black women had lower household incomes; were more likely to have never married; and were less likely to have a high school education.

Moritz and Satariano (1993) reported a number of other relevant findings, such as the likelihood of getting breast cancer increased with age. Perhaps their most interesting finding, however, was a risk factor for women who lived with others. Women living with a spouse were twice as likely to be diagnosed with advanced stage breast cancer than women who lived alone; women living with someone other than a spouse were 1.7 times as likely to be diagnosed with advanced breast cancer than women who lived alone. Lack of emotional support and having less than three close friends or relatives were contributory findings in this study. Women who had never been married were less likely to be diagnosed with advanced disease than any other group, and were more likely to use formal health services, resulting in more interactions with the health care system. It was proposed that women who are married or live with others may be caregivers to others or more focused on tending to the needs of others, and relegated their own needs as less important. As such, they may have higher levels of personal stress from their caregiver role, defer their own needs for routine examination and screening, and allocate the household health care dollars to the care of others rather than themselves.

Other researchers have similar findings. Ulbrich and Bradsher (1993) reported that unmarried caucasian women who live alone report better physical health than those who live with others. Ross, Mirosky, and Goldsteen (1990) noted that marriage protects men's psychological well-being and physical health more than it does women, and protects men more from death. They reported the positive effects of marriage declined between 1972 and 1986, especially for women, and that recent studies show a weaker association between marriage and well-being than did earlier studies.

Nayeri, Pitaro, and Feldman (1992) and Ernster, Sacks, Selvin, and Petrakis (1979) found wide variations cancer incidence by marital status patterns when people of all colors and sexes were considered. For women 35 to 64 years old, Ernster et al. (1979) found the lowest incidence of breast cancer and other hormone-regulated tumors in separated, divorced, and widowed white females and in separated black females.

It is important to note that not all studies have derived these same findings or adopted this study's posture that marriage can be a barrier to health care for rural women; others have drawn opposite conclusions. In response, researchers proposed that the conflictual conclusions about the effects of marriage may be due to differences in the characteristics of the population under study, staging techniques, or definitions (Nayeri et al., 1992), misclassification of marital status information on tumor registries, treatment files, and other sources of information (Goodwin, Hunt, Key, & Samet, 1987), or omissions and reporting discrepancies (Ernster et al., 1979). In the absence of standard definitions, there is not a common interpretation of status for common law marriage, separation, marriage between people of the same sex, and other configurations. Patients may also perceive that it is more socially acceptable to report one status rather than another.

Women often become caregivers to a first-degree relative who suffers an injury or illness. According to Robertson, Elder, and Skinner (1991), caregiving can be time-consuming, stressful, and, when not reciprocated, a burden. Kiecolt-Glaser et al. (1987) noted that the simple presence of a partner is not equivalent to a supportive relationship. Fox, Harper, Hyner and Lyle (1994) reported that women with cancer are less content with their relationships with males than are healthy women. Moreover, marital distress can render the immune system less effective and inhibit the body's ability to fight cancer. Fox et al. (1994) and Kiecolt-Glaser et al. (1987) found that a relationship of poor marital quality was a significant predictor of depression and lowered immune competency. Loneliness and helplessness are also associated with immune suppression (Fox et al., 1994).

Preston and Dellasega (1990) reported on the effects of marriage on women over 65 years of age. They found that, of married and unmarried men and women, married women were in the poorest health and the most vulnerable to stress. Wives experienced dramatic changes in the marital relationship as a consequence of becoming a caregiver. Since many older women are unlikely to develop independent identities or to have worked outside the home, whatever recognition, socialization, and financial security the wives had was largely achieved through their husbands. Thus, wives experienced serious threats to self-concept, role performance, and interdependence needs that resulted in poorer health and higher stress.

Since there are only women in this study, being female is not a study variable. However, being female is associated with a special set of barriers to health care. In a study of Caribbean and Latin American women, Puentes-Markides (1992) reported that women's barriers to accessing the health care system are dependent upon variables such as women's status in the specific culture and society to which they belong, their ethnicity, control of decision-making, socioeconomic standing, the society's degree of social investment in women, and the position of women in the labor force. She further noted that the health care needs of women are perceived as almost exclusively related to their reproductive roles or are often defined in male terms. Without consideration and integration of female experiences of health and illness, the health care system is unable to respond to women in a culturally appropriate and gender-sensitive manner, which serves as a barrier. Women are less likely to use health care services that fail to accommodate their needs or that are deemed personally unacceptable (Puentes-Markides, 1992).

Review of the Literature regarding Psychological Barriers to Health Care Access

The psychological barriers in this study were lack of people to provide emotional support, lack of adequate emotional support, and presence of depressive symptomatology. Each was further categorized as a personal barrier within the study model.

Psychological Barriers - Personal

No studies were found in the literature that directly examined psychological barriers to health care access. Although the issues of depression and social support are otherwise widely reported, their association with health care access is presently absent from the literature. One research team (Revicki & Mitchell, 1990) reported the absence of such research as they reported their own findings regarding the relationship between social support and psychological distress in rural populations.

Bieliauskas (1984) reported on the linkage between depression and cancer, often noted as a "chicken-or-egg" phenomenon; that is, was the depression present after the diagnosis of cancer was made, or was the depressive syndrome present before and perhaps contributory to the development of cancer? In a review of existing research, Bieliauskas found that a "chronic depressive-like state of distress" in up to 40% of patients with cancer is identified as either a risk factor or prevalent symptom in studies demonstrating either a premorbid or concomitant association between psychological depression and cancer, but clinical depression was not associated with either. The author also reported that inefficient coping styles are measured in studies of depression in cancer patients, appearing as behaviors that either increase the risk of cancer (i.e., smoking) or decrease the chance of detection (i.e., failure to report symptoms).

Personality traits may impact effectiveness of coping styles. Jansen and Muenz (1984) determined that women with breast cancer were more depressed, less aggressive, less demonstrative, and less able to express anger or other negative emotions than women with either fibrocystic or no breast disease. Women in their study with breast cancer described themselves as timid, non-assertive, non-competitive, and as keeping anger inside. Marital status, too, may be a factor. Ross et al. (1990) reported that, when levels of emotional support and household incomes were equivalent, there were higher levels of depression in nonmarried people than married people.

Others have noted that women report higher levels of depression in general, with the highest levels noted in rural and black women with low family incomes and few friends (Linn et al., 1989). Rural women also fared worse on the dimensions of depression that are most sensitive to socioenvironmental contingencies, such as hope for the future, self-worth, happiness, and satisfaction with life.

In this study, the presence of depressive symptomatology is considered a barrier in that it may reduce the likelihood of seeking health care services, as well as negatively impact the patient's effectiveness in the health care system once entry occurs (Linn et al., 1989).

Social support is yet another important issue, but that is not widely reported on for rural populations. In their study of the rural elderly, Revicki and Mitchell (1990) reported that social isolation was associated with an increased risk for depression. In addition, they found that financial limitations, poor physical health, loss of family members and friends, and transportation problems placed the rural elderly at greater risk for social isolation and low social network involvement, resulting in depression and low self-esteem.

The presence of friends or family members as sources of emotional support remains important to women. Ulbrich and Bradsher (1993) found that stress did not result in psychological distress in older women with confidants available with whom they could discuss their problems. Linn et al. (1989) found that the size of the woman's friendship network was more indicative of social support availability and thus mental health, since people select their friends largely on the basis of perceived availability of social support from them, whereas the extended family network into which one marries or is born contains both supportive and unsupportive individuals. This study also found that rural black women had the least number of supportive friends and the largest number of unsupportive relatives. The importance of social support to women's health was further underscored in a study by Moritz and Satariano (1993), where it was reported that women with less than 3 close friends or relatives were more likely to be diagnosed with advanced stage breast cancer.

Review of the Literature regarding Stage of Disease at Diagnosis of Breast Carcinoma

For the most part, the literature does not analyze or specifically report on findings of early stage breast cancer; early stage disease is considered part of the staging continuum but not the primary object of study. Rather, the literature with emphasis on health care access tends to focus on initial diagnosis of advanced stage disease, since this reflects a failure of utilization (such as a failure of the client to utilize the health care system, or a failure of the health care provider to utilize standard health maintenance and cancer screening protocols) or inappropriate, ineffective diagnosis or treatment.

In this study, advanced stage breast cancer is an outcome, a result of barriers to health care access. However, an issue outside the scope of this study would be whether a diagnosis of advanced stage breast cancer is also a barrier to further health care access, perhaps due to the costs of care, or high rates of morbidity and mortality, or other factors.

Findings of advanced stage breast cancer are often reported in association with other barriers. Liff, Chow, and Greenberg (1991) observed that rural breast cancer patients had more advanced disease and were diagnosed at later stages than urban cases, due to barriers such as limited access to health care, fewer cancer prevention activities, and decreased receptivity to health resources in a population with lower educational achievement and limited knowledge of preventive care.

Several researchers (Hunter et al., 1993; Liff et al., 1991; Moritz & Satariano, 1993) have noted the association between advanced stage disease at diagnosis and lower household incomes for caucasian women. Hunter et al. (1993) reported that rural black women are more likely to have advanced stage breast cancer upon initial diagnosis than rural caucasian women.

As previously noted, Moritz and Satariano (1993) found that the likelihood of being diagnosed with advanced disease increased with age, and that advanced stage breast cancer was more likely to be found in women who did not have at least 3 people to provide emotional support to them and who judged themselves to generally receive little emotional support.

Review of the Literature regarding Health Care Access

A plethora of health care access issues have been presented thus far; however, a few additional considerations remain. Access to basic health services can be difficult for rural residents (Howe et al., 1995). Rural communities have been shown to have poor access to health care services, fewer cancer prevention and early detection programs, and decreased receptivity to health resources (Given et al., 1994; Liff et al., 1991; MDPH, n.d.). Many rural residents are poorly educated and do not practice prevention or early detection behaviors that could identify cancer at an early stage (Given et al., 1994). Women with poverty-level incomes have a lower five-year survival rate from cancer (American Cancer Society, n.d.; Liff et al., 1991), partly because they are less likely to seek or afford early breast cancer detection (particularly mammograms) and are less likely to know how to assess and limit their risks for developing cancer.

Persons living in rural areas have the most problems with access to and utilization of physician services (Given et al., 1994; Harrington et al., 1993; Hartley et al, 1994), since the availability of physicians in rural areas is half the national average. The 1991-92 American Academy of Physicians' Committee on Rural Health noted that half of the 500 US hospitals that closed between 1980 and 1990 were rural, a trend which has continued (Anderson, 1993). Following rural hospital closure, physicians often leave the area (Friedman, 1994). This results in a lack of access to hospital and physician care and an increased risk for preventable illnesses. Closure of rural hospitals has been identified as a factor limiting health care access for the rural poor (Given et al., 1994).

Shortcomings in the Literature

It would appear from a review of the literature that access is a relatively recent issue for examination. Within health care literature, there is no standard definition of access or of barriers to it; in fact, access is largely left undefined though widely cited as a health care issue. There are few examples in the literature of works that comprehensively explore the dimensions of health care access. No studies were found that comprehensively examined access issues of rural women.

More often than not, access is noted in the literature by its absence rather than its presence. In many studies, access was eliminated as a problem when there was documented use of services. Few gave thorough consideration to access as a factor when free services went unused. Issues ascribed to be financial barriers to access appeared frequently in the literature, but usually were tilted toward reimbursement rather than client access. There were no studies that systematically examined the impact of depression or psychosocial factors on access. Most of the literature addressing either depression or psychosocial issues is based in the psychotherapeutic realm where substantial pathology exists.

As a profession, nursing has been slow to research and publish access-related studies. Prior nursing contributions to the barriers-to-access discussion were anecdotal and published in non-research based journals. Recently, more nursing research has appeared in the literature and, for the most part, provides the only source of holistically-oriented studies. In the future, it is hoped that advanced practice nurses will have the opportunity to methodically examine and report on the access barriers they are so uniquely qualified to research. With improved identification and analysis of barriers to health care access, additional methods of reducing or eliminating barriers can be implemented throughout the health care delivery system.

Discussion of and Rationale for Proposed Study

Based upon the review of the literature, it is clear that no studies have been reported that address psychosocial and sociodemographic barriers to health care access for rural women. In addition, health care access is an emerging area of interest in light of the many proposals to reform the nation's health care system.

The task of reducing breast cancer in rural women is of such importance that each barrier in this study could be the focus of an individual study. However, this study identified particular psychological and sociodemographic barriers, with the intent of directly quantifying the barriers that are present for each subject, and examining their relationship to the stage at which her cancer was diagnosed and her level of distress.

The most compelling access issue of the study, however, is not related to data to be collected but rather to facts about the study participants. The Institute of Medicine's Committee on Monitoring Access to Personal Health Care Services asserts that a finding of advanced stage breast cancer upon initial diagnosis is, in itself, an indicator of health care access impediment (Millman, 1993). Some of the women in this study had such a degree of impediment that there was no tumor detection until the disease had been established in the breast, lymph nodes, and even other organs. It is beyond the scope of this study to determine precisely how and why each woman's tumor detection was delayed, but it is clear that barriers to access limited the subjects' entrance to or persistence within the health care system, with severe consequences.

The barriers and relationships are important to identify and quantify to the larger community of advanced practice nurses. These additional cues supplement the repertoire of the advanced practice nurse, improving her ability to identify women in her practice with substantial access barriers. Incorporation of this information within advanced nursing practice promotes health, prevents disease, facilitates education of clients and their families in the primary care setting, permits more thorough education of select women about breast health, maximizes health screening opportunities during routine office visits, and emphasizes the importance of reducing or controlling as many barriers as possible.

Research Questions

The questions to be answered in this study include:

1) What are the most frequently occurring sociodemographic barriers to access among subjects? (index)

2) How do the number of access barriers for women with stage I and II breast cancer compare to those of women with stage III and IV breast cancer?

3) What is the relationship between the number of access barriers and stage of cancer at diagnosis?

4) Based on the Center of Epidemiologic Studies Depression Scale (CES-D), what is the relationship between the number of access barriers and depressive symptomatology?

5) Based on the CES-D Scale, what is the relationship between the stage at diagnosis and depressive symptomatology?

METHODS

The population for this study was women who agreed to participate in the Rural Partnership Linkage for Cancer Care project (Grant Number 1 R01 CA56338), part of the Rural Cancer Care Study funded by the National Cancer Institute and initiated in 1992 by Michigan State University researchers Barbara A. Given, PhD, RN, FAAN and Charles W. Given, Ph.D. The subjects resided in one of four rural counties in western Michigan (Allegan, Barry, Cass, and Van Buren) when diagnosed with cancer. Subjects from that project were accepted into this study if they were female, had a recent diagnosis of breast cancer, had relatively complete subject data, and had signed a human subject consent form.

Field Procedures and Data Collection

The data that was analyzed in this study was gathered during the first wave of the Cancer Care Project from two instruments (telephone interview and self-administered instrument) and the medical records of the subjects. Subjects were advised that the study would occur in four waves, each consisting of a telephone interview and self-administered instrument. The first wave of data collection occurred at the time of enrollment in a nursing case management intervention, followed by three other waves of data collection at ninety day intervals for the next twelve months.

Using the first instrument, trained interviewers conducted telephone interviews with each subject and her family caregiver. The interviewers were trained through role playing, taped mock interviews, and real taped interviews with feedback, and were provided a detailed interview procedure and policy manual to outline procedures and policies and to ensure quality. In addition, interviews were reviewed monthly with quality assurance and consistency indicators. The telephone interview lasted about thirty to forty minutes and gathered information regarding a wide range of aspects of each subject's life three months before and as a result of their diagnosis with cancer. Information was gathered regarding the patient's ability to carry out activities of daily living and health care, use of health services and cancer therapies, sociodemographics, employment, health insurance, use of transportation services, and personal expenditures and finances. The portions of the telephone instrument used in this study appear as Appendix A.

The second instrument, a self-administered questionnaire completed by the subjects, contained a variety of scales. The scale from that instrument that was used in this study was the Center for Epidemiologic Studies - Depression Scale (CES-D), a measure of subject depressive symptomatology. The instrument was mailed with a postage-paid return envelope to each subject upon completion of the first instrument. Follow-up calls and reminder letters were placed to those failing to return the instrument within three weeks. The portion of this instrument that was used in this study appears as Appendix B. Data from both the telephone and self-administered instruments was manually entered in a computerized database.

A complete pathology report documenting each subject's stage of disease at diagnosis was collected from the medical record.

Data collection for this study was done directly from the Cancer Care Project telephone interview instrument, self-administered instrument, and stage-at-diagnosis pathology report, or from printouts of this information. Data were collected on a set of forms designed by the author, and subsequently entered into SPSS Studentware for analysis.

Protection of Subjects

The Rural Cancer Care Study was approved by the Michigan State University Committee on Research Involving Human Subjects; permission to proceed with data collection appears as Appendix C.

Informed consent was obtained from all participants, with the assurance that information provided would be treated confidentially and their identities held anonymous. The informed consent for the Rural Cancer Care Study included the right to withdraw from the study at any time. A copy of the Subject Consent Form appears as Appendix D.

On March 24, 1995, the University Committee on Research Involving Human Subjects approved the application for this study to reanalyze data gathered in the Rural Cancer Care Study, which appears as Appendix E. During data collection and analysis, each subject was assigned a unique identifier for tracking purposes and to further obscure her identity.

Operational Definitions, Instrumentation, and Scoring

There were a variety of instruments used to initially collect the study data. Although several data sets were constructed during the course of the analysis, the final set was consistently scored using 0 to indicate that the criteria for a barrier to health care was not met, 1 to indicate the criteria for a barrier was met, and 9 to indicate the data were missing.

Operational Definitions, Instrumentation, and Scoring of Psychological Barriers

The psychological barriers to health care access in this study were defined as inadequate psychosocial support and the presence of affective distress sufficient to cause depressive symptomatology. Three study variables measure these personal barriers.

Data for the psychosocial support variables were gathered using the

Family Network grid within the telephone instrument [page 9, item 11 of the 4/24/94 version]. Telephone interviewers asked each subject to identify up to 10 family members she felt she received emotional support from; the interviewer recorded the names on the Family Network grid. A barrier was considered to be present if there were 0, 1, or 2 supporters; there was no barrier present if there were 3 or more supporters.

The subject was then asked to assign a value from 1 (none or very little) to 5 (a great deal) to reflect the level of emotional support she felt she received from each supporter. These scores were summed, and a mean calculated for each subject. In addition, all subjects' scores were summed and a mean derived for the sample. A barrier was considered to exist if the subject's mean was less than that of the sample. The data for the variable relating to presence of depressive symptomatology was gathered from the Center for Epidemiologic Studies Depression Scale (CES-D), a 20-item, self-reporting scale. The four depressive factors and specific symptoms measured by the scale are: depressed affect (could not shake off the blues, felt lonely, felt depressed, had crying spells, felt sad, thought life a failure, felt fearful), positive affect (felt as good as other people, felt hopeful about the future, was happy, enjoyed life), psychomotoric or somatic and retarded activity (bothered by things, poor appetite, trouble concentrating, everything was an effort, sleep was restless, talked less than usual, could not get going), and interpersonal (people were unfriendly, people disliked me).

The CES-D scale has been widely used in a variety of populations, including women (Stommel et al., 1993). The internal consistency of the instrument is greater than .90 (Cronbach's alpha and Spearman-Brown coefficients), and test-retest correlations range from .32 for 12 months to .67 for 4 weeks. Moderate convergent validity is shown with the Hamilton and Raskin scales (r values of .44-.56), and significantly higher with other scales. For discriminant validity, there is low, negative correlation with the Marlowe Crowne Social Desirability scale (r=.18) (Radloff, 1977; Shaver & Brennan, 1993; Stommel et al., 1993).

In this study, the CES-D was part of the self-administered instrument [page 2-4, items 1-20]. The CES-D uses a Likert response scale (3=almost all of the time, to 0=rarely or none of the time), with direct scoring of all items except 4, 8, 12, and 16, which are reverse scored. Scores on the instrument of 16 or more establish the presence of depressive symptomatology but not a clinical diagnosis of depression (Radloff, 1977). Each subject's CES-D was scored, and a barrier was considered to exist if the score was 16 or more.

Operational Definitions, Instrumentation, and Scoring of Sociodemographic Access Barriers

Sociodemographic barriers to health care access were defined as those facts about an individual or her environment which are indicative of her social or economic standing, the status of which may negatively impact access to health care. Variables relating to structural barriers were transportation, absence of a primary care physician, rurality, and traveling more than 25 miles for care; the variable relating to financial barriers was absence of insurance, Medicare, or Medicaid; and the variables relating to personal barriers were ethnicity, education, marital status, household income, the presence of others in the household, and age.

Except for distance traveled by the subject to the provider, all sociodemographic data was collected from the telephone interview instrument.

Operational Definitions, Instrumentation, and Scoring of Structural Access Barriers

Transportation status [page 30, item 7a] was considered to be a barrier if there was dependence for transportation. As such, the response selections "someone else usually drives" and "others always drive" were barriers, and "drives self" was not.

If a subject named a primary care physician [page 45, item 5a], a barrier was not considered to exist. A barrier was considered to be present, however, if no physician was identified.

Subjects residing in Allegan, Barry, Cass, or Van Buren county [page 6, item 6] were considered to have a barrier for rurality. The other counties that subjects reported residing in were determined to be rural or nonrural based on the average number of residents per square mile. Counties with 99 people or less per square mile were considered rural and thus positive for a barrier.

Distance from primary care was considered to be a barrier if the primary care physician's city address [page 45, item 5a] was more than 25 miles round trip from the city address of the subject [page 2, item 2]. Michigan Department of Transportation county road maps were used to calculate the distances, and figures were rounded to the nearest whole number. If the physician and subject addresses included the same city, the distance was recorded as 5 miles (non-barrier).

Operational Definitions, Instrumentation, and Scoring of Financial Access Barriers

A barrier to health care access was considered to exist if the subject had no third-party payment source or governmental plan to assist with health care expenses. As such, a barrier existed for those without insurance and who were not enrolled for Medicare or Medicaid [page 101, item 7]. Subjects with some type of insurance coverage or who received Medicare or Medicaid were not considered to have a barrier; however, it is acknowledged that, in actuality, this group still may have difficulties accessing care.

Operational Definitions, Instrumentation, and Scoring of Personal Access Barriers

A barrier is considered to exist of the subject's ethnicity is other than caucasian [page 5, item 4].

Those who responded that they had "no formal school", "grade school", or "some high school" [page 5, item 3] were considered to have a barrier. All other responses were considered non-barriers.

Marital status [page 5, item 5] is considered a barrier if the response is "married"; all other responses (divorced or separated, widowed, or never married) are not considered barriers.

Household income [page 101, item 5] at or below poverty level (as established by the US Bureau of Census) was considered a barrier. Those with incomes exceeding poverty level were not considered to have a barrier.

Subjects who had others present in their households [page 6, item 8] were considered to have a barrier. Those living alone did not.

Subjects between the ages of 35 and 54 at the time of their entry into the Cancer Care Study were considered to have a barrier; those of any other age were not.

In summary, the variables identified in the study model (Figure 2) were considered to be the barriers for this study, and comprised the barrier index. Each response was determined to fall into one of three categories: that it met the criteria of a barrier, it did not meet the criteria of a barrier, or that the response was absent.

Operational Definitions, Instrumentation, and Scoring of Stage of Disease at Diagnosis of Breast Cancer

For some analysis, the specific stage of disease at diagnosis was used as the category for analysis. For those analyses where combined-stage analyses occurred, subjects whose pathology reports determined at least one Stage III or Stage IV breast carcinoma were considered to have advanced stage breast cancer. Those with Stage I or Stage II were considered to have early stage breast cancer.

Research Design and Data Analysis Plan

This was a descriptive explanatory study, derived from survey research. It quantified rural women's barriers to health care access (independent variable) and examined relationships between barriers, stage of cancer at diagnosis (dependent variable), and level of depressive symptomatology of the subjects (independent variable). There was no pilot study or pretest for this study.

Once tabulated, data was entered into SPSS Studentware, which was then used to perform the correlational and analysis functions. Excel was used to generate the tables and figures. Data analysis was tailored for optimal response to the research questions. Frequencies (question 1: most frequently occurring barriers), chi square (question 2: comparison of number of barriers for advanced stage versus early stage disease at diagnosis) and Pearson correlations (questions 3, 4, and 5: relationships between number of barriers, depressive symptoms, and stage of disease at diagnosis) were prepared in order to answer the study's research questions; means and standard deviations were also calculated for the data. Other analytical functions were performed on the study's data as well, but did not offer additional insights or permit alternative conclusions.

RESULTS

On 04/12/95, data from the Cancer Care Project were collected at the Family Care Study offices on the campus of Michigan State University. Between 08/19/93 and 03/15/95, the 34 women with breast cancer who had enrolled in the Cancer Care Project became the sample for this study.

During data collection, it was determined that a variety of factors resulted in some data remaining irretrievable. The telephone instrument was modified as the study progressed, resulting in the modification or elimination of some items. Two interviews were not completed; one subject became too ill, and the other became angry and refused to complete the interview. There were repeated response refusals to two items (household income and whether unrelated adults lived with the subject). As a result, complete data sets were available on only 19 of the 34 subjects (56%), with 6% of the total data falling in missing data/refusal categories.

The sample (Table 1) was composed of a homogenous group of rural middle-aged, educated, married caucasian women with insurance and moderate incomes who lived with others in their households. They were independent for transportation, lived close to and have a primary care physician, and were diagnosed with early stage breast cancer. They have family members who support them emotionally but to an inadequate degree, and show depressive symptomatology. Every subject in the study had at least 2 and as many as 8 of the barriers under examination.

Presentation of Answers to Research Questions

Research Question One

The first research question asked for the most frequently occurring sociodemographic barriers to health care access among subjects; the frequencies are displayed in Table 2. There was a range of 2 to 6 sociodemographic barriers per subject, with the mean falling at 3.82

Table 1. Frequency of Variable Occurrence in Sample, and Percent of Sample Affected

Variables	% of Sample	n*
STRUCTURAL		
Independent for transportation	82	28
Have a primary care physician	91	31
Lives in a rural county	**94**	**32**
Travels < 25 miles for health care	80	24/30
FINANCIAL		
Has insurance, Medicare, Medicaid	94	32
PERSONAL		
Caucasian ethnicity	97	33
High school graduate or higher	85	29
Married	**67**	**23**
> poverty-level household income	70	21/30
Others live in the household	**82**	**28**
Age < 35 years old or > 54 years old	56	19
Has depressive symptoms	**50**	**15/30**
Has a support network of > 3 people	96	26/27
Receives more emotional support than the mean	59	16/27
STAGE AT DIAGNOSIS		
Stage I	41	14
Stage II	38	13
Stage III	3	1
Stage IV	16	6

Key:

Sociodemographic variable

Psychological variable

Barrier to health care access

* From a total sample of 34 unless otherwise indicated

Table 2. Research Question 1: The Most Frequently Occurring Sociodemographic Barriers to Health Care Access

Barriers	% of Sample	n*	$\bar{x}$	SD	Range
STRUCTURAL					
Dependent for transportation	18	6			
No primary care physician	9	3			
Lives in a rural county	**94**	**32**			
Travels more than 25 miles for health care	20	6/30			
FINANCIAL					
No insurance, Medicare, and/or Medicaid	6	2			
PERSONAL					
Non-caucasian ethnicity	3	1			
Less than a high school education	15	5			
Married	**67**	**23**			
Poverty-level household income	30	9/30			
Others live in the household	**82**	**28**			
Age 35 through 54 years old	44	15			
Total Sociodemographic Barriers			3.82	1.15	2 - 6
Total Barriers			4.62	1.52	2 - 8

Key:

Barrier present for more than 50% of subjects

* From a sample of 34 unless otherwise indicated

(SD 1.15). Barriers to health care access were identified for every subject in the study. The barriers with the highest frequencies and that affected more than half of the sample were rurality (94% and a structural barrier), living with others in the household (82% and a personal barrier), and being married (67% and a personal barrier). The high frequency of rurality is not unexpected, since the Rural Cancer Care Study collects data from four rural counties. It is also not unexpected that a subject who is married would have others living in the household, particularly a spouse. The percentage of women who are married (67%) is slightly lower than the national average (73%)(US Bureau of the Census, 1994); however, given the small sample size, this may not be a variance of significance.

Research Question Two

The second question asked how the number of access barriers for women with stage I and II breast cancer compared to those of women with stage III and IV breast cancer. This information is provided in Table 3. When combined, the women with stage I and II breast cancers had fewer sociodemographic and psychological barriers (mean of 4.59; SD 1.57, range 2-8) than the grouping composed of women with stage III and IV disease (mean of 4.71; SD 1.28, range 3-7). When both barrier configurations (structural, financial and personal; sociodemographic and psychological) are compared by chi-square, the differences between the means were not significant at the 95% confidence level with 3 degrees of freedom.

Table 3. Research Question 2: Comparison of Number of Barriers to Health Care Access of Stage I and II versus Stage III and IV

Stage at Diagnosis	n	$\bar{x}$	SD	Range
I & II	27	4.59	1.57	2 - 8
III & IV	7	4.71	1.28	3 - 7

Research Question Three

The third question addressed the relationship between the number of access barriers and stage of cancer at diagnosis. Table 4 contains data by barrier type (structural, financial, and personal, as well as psychological and sociodemographic). A Pearson correlation revealed no statistical difference in the relationship diagnosis ($r=.0293$, $p=.869$). Since there was only one subject diagnosed at the Stage III, statistics for that stage (mean, standard deviation) were not meaningful.

In summary, the stage with the highest number of total barriers was IV (mean of 4.83, SD 1.35, range 3-7), followed by I then II. Stage IV subjects had the highest mean for structural barriers (followed by Stage I then Stage II) and psychological barriers (followed by Stage II then Stage I). Stage I subjects accrued the highest mean for sociodemographic barriers (followed by Stage II then Stage IV), and Stage II had the highest mean for personal barriers (followed by Stage IV then Stage I). Additionally, it was noted in Table 3 that women with advanced stage breast cancer had more barriers (mean of 4.71, SD 1.28, range 3-7) than did women with early stage disease (mean of 4.59, SD 1.57, range 2-8). Despite the absence of statistical significance, there may be clinical significance in the pattern for total barriers, structural barriers, and psychological barriers to be highest at Stage IV, and for the presence of the inverse relationship between stage and sociodemographic barriers.

Table 4. Research Question 3: Comparison of the Number of Barriers to Health Care Access by Stage at Diagnosis

Barriers	**Stage I** **n=14**	**Stage II** **n=13**	**Stage III** **n=1**	**Stage IV** **n=6**
STRUCTURAL				
Dependent for transportation	4	1	0	1
No primary care physician	0	1	0	2
Lives in a rural county	14	11	1	6
Travels > 25 miles for health care	3	2	0	1
Total Structural Barriers	21	15	1	10
Mean	**1.5**	**1.15**	**1**	**1.67**
Standard Deviation	0.5	.62	-	0.75
Range	1 - 2	0 - 3	-	1 - 3
FINANCIAL				
No insurance, Medicare, Medicaid	1	1	0	0
PERSONAL				
Non-caucasian ethnicity	1	0	0	0
Less than a high school education	3	1	0	1
Married	10	10	1	2
Poverty-level household income	5	3	0	1
Others live in the household	11	12	1	4
Age 35 to 54 years old	5	6	1	3
Has depressive symptoms	5	7	0	3
Support network of < 3 people	0	0	0	1
Receives limited emotional support	3	4	0	4
Total Personal Barriers	43	43	3	19
Mean	**3.07**	**3.31**	**3**	**3.17**
Standard Deviation	1.48	.98	-	1.14
Range	1 - 6	2 - 5	-	1 - 4
TOTAL - ALL BARRIERS	65	59	4	29
Mean	**4.64**	**4.54**	**4**	**4.83**
Standard Deviation	1.54	1.60	-	1.35
Range	2 - 8	2 - 8	-	3 - 7
PSYCHOLOGICAL - Total Barriers	8	11	0	8
Mean	**.57**	**.85**	**0**	**1.33**
Standard Deviation	.68	.56	-	.55
Range	0 - 2	0 - 2	-	1 - 2
SOCIODEMOGRAPHIC - Total Barriers	57	48	4	21
Mean	**4.07**	**3.69**	**4**	**3.5**
Standard Deviation	1.16	1.2	-	.96
Range	2 - 6	2 - 6	-	2 - 5

Research Question Four

The fourth question in this study asked about the relationship between access barriers and level of depressive symptomatology, based on the CES-D score. Table 5 depicts the total number of barriers and the CES-D scores that were 16 or more, which are considered barrier-level. The Pearson correlation for this relationship showed no statistical significance (r=-.0780, p=.661). However, there was a significant finding between two personal barriers: CES-D score and the perceived level of emotional support. A moderate, negative relationship (r=-.6864, p=.000) was noted with Pearson correlation. This finding infers that as the perceived level of emotional support decreased, depressive symptoms rose.

Thirty of the subjects completed the CES-D scale, scoring in a range from 2 to 39. The mean score for all subjects was 16.67 (SD 10.26), which falls within the range for depressive symptomatology. However, the mean score for the 15 subjects with CES-D scores of 16 or more was 25 (SD 7.46). There was a relationship between CES-D score and the number of barriers; as the number of barriers rose, the frequency of CES-D scores above 16 rose.

Research Question Five

The fifth question addressed the relationship between the stage at diagnosis and level of depressive symptomatology (CES-D score), also shown in Table 5. There was no statistically significant correlation of CES-D score with stage (r=.1707, p=.335). Of the 30 subjects who took the CES-D instrument, 12 (40%) were Stage I; 13 were Stage II (43%); 1 was Stage III (3%); and 4 were Stage IV (13%). Based on these occurrences, a similar distribution might be expected to occur in those with CES-D scores above 15. The results did not bear this out, however; Stages II and IV were over-represented (47% and 20% respectively), while Stages I and III

were under-represented (33% and 0% respectively). It is also noteworthy that of the four subjects who did not take the CES-D instrument, 2 had Stage III disease and 2 had Stage IV.

Table 5. Research Questions 4 and 5: Comparison of Stage at Diagnosis, Number of Barriers to Health Care Access, and CES-D Score > 15

Study ID	Stage	Number of Barriers	CES-D Score*	n	$\bar{x}$	SD	Range
		2		2	12	2	10 - 14
23	2	3	**30**				
		3		6	10	11.6	2 - **30**
13	1	4	**20**				
31	2	4	**24**				
33	2	4	**23**				
		4		7	14.7	7	7 - **24**
30	1	5	**39**				
8	2	5	**18**				
32	2	5	**16**				
17	4	5	**20**				
		5		10	14.8	9.5	3 - **39**
6	1	6	**19**				
27	4	6	**17**				
		6		2	18	1	**17 - 19**
16	1	7	**38**				
2	2	7	**22**				
25	4	7	**30**				
		7		3	30	6.53	**22 - 38**
20	1	8	**36**				
11	2	8	**23**				
		8		2	29.5	6.52	**23 - 36**

Boldface = barrier-level score

nd = no data

Interpretation of the Findings

It is important to first acknowledge the limiting effect the small sample size had on the characteristics and on meaningful analysis of the data. The very small number of women in the study with advanced stage breast cancer also hindered the analysis of this group. Although there were no findings of statistical significance in this study, a repetition of this study with a larger sample may well yield statistically or clinically important results. The larger issue of health care access for rural women deserves continued exploration, particularly considering the near-absence of such studies in the literature.

Within the study model, personal barriers occurred most frequently, followed by structural then financial barriers. This may have been explained by the size of these categories; they were the largest, with personal containing 9 of the 14 study variables and structural containing 4. The high frequencies for the rurality (structural), living with others (personal), and marital status (personal) also pushed these barrier categories forward. Although most of these barriers were well documented in the literature, it is unclear from this study if these specific barriers have other particular significance in this population. Examination of other barriers was hindered by low frequencies; for example, with only one noncaucasian in the study, no relative conclusions could be drawn.

The first research question proposed that an index of sociodemographic barriers to health care access could be constructed from the most frequently-occurring sociodemographic barriers. Rurality, living with others, and being married were the only barriers that affected at least 50% of the sample; however, these three barriers would provide few cues for identification of clients who may have substantial health care access barriers. An index which also included psychological barriers would be more likely to more meaningfully capture barrier status.

The increase in depressive symptoms with number of barriers was one of the more interesting study findings, and one with clear implications for the advanced practice nurse. However, the third psychological barrier (less than 3 people in each woman's emotional support network, as reported in the literature) was not strongly supported in this study.

The primary variable in the structural barriers was rurality. Dependence for transportation and traveling for health care were poorly supported. One-third of the women with stage IV disease (2 of 6) reported not having a primary care physician. Since this information was gathered after the diagnosis of cancer, it is unknown if they did not have a primary care physician, or if they switched their primary care to oncologists and other physicians since being diagnosed. Although of small scope in this study, it would be worthy of future study in other breast cancer populations.

Since most of the subjects had some type of insurance, the financial variable did not bear much useful information. Since the barrier was constructed in such narrow terms (presence or absence of insurance, Medicare, or Medicaid), only those with no coverage whatsoever were captured. No data was collected about the type of therapy each women was receiving, based on her insurance status. Although complete absence of coverage is an important factor in accessing health care, the presence of insurance, Medicare, or Medicaid does not assure freedom from barriers. A more comprehensive focus on coverage may have yielded more illuminating data.

One of the controversial positions in this study was consideration of marriage as a barrier to health care access for rural women. Although the majority of the women in the study were married, this study did not firmly establish whether marriage served as barrier to the women or was simply a demographic commonality among them. As previously reported, researchers take stands on both sides of this issue, but little scientific study has been directed specifically toward rural women. There are anecdotal reports of rural husbands who refused to call a physician for their ailing wives, but who summoned a veterinarian immediately for a sniffle in their prized bull. Without bigger, direct studies of rural women's access, the issue remains unclear.

The findings regarding relationship between the number of access barriers and stage of cancer at diagnosis (third research question) were not as complete as possible since data for some of the subjects was missing. The small sample size and limited number of subjects with advanced disease made it difficult to draw meaningful conclusions regarding barrier substantiation, parallels with published literature, or consistency with the study model.

The study model and definition of health care access were used with moderate success. Useful comparisons were gained from examination of both the psychological/sociodemographic barrier grouping and the structural/financial/personal grouping. The study model was found to be effective in identifying some barriers to access in a rural sample, and in identifying trends that may be worthy of further examination in a larger study. With respect to the study definition of health care access, the study and model addressed affordability (insurance and income), accommodation (distance to care, transportation, educational level), acceptability (congruence with rural values, ethnicity), and attainability and availability (presence of a primary care physician). The personal issues of depression and emotional support certainly may impact attainability, but many other factors may have a more direct effect. Notwithstanding, this definition of health care access was useful and worked well with the study model.

DISCUSSION

Discussion, Assumptions, and Limitations

The small sample size and limitations it imposed on the study have already been discussed. The results of this study are not generalizable to any other population. It is hoped, however that as the Rural Cancer Care Study continues and additional subjects are added to the population, there will be ongoing opportunities for analysis of barriers to access.

The US Bureau of the Census poverty level used for this study was $14,335. Due to the data assignment to a category by range, there may have been inaccurately assigned data. All members of the $10,000-$14,999 household income range were considered to have an income equal to or less than poverty level, although there may have been subjects whose incomes were above $14,335 but less than $14,999. Thus, it is possible that the actual number of subjects with household incomes of $14,335 or less was overattributed.

It is assumed that the subjects were capable of responding, and that they did so in an honest, accurate manner. It is certainly possible, however, that information that could not be readily substantiated in the medical record (such as whether one was truly a high school graduate or had a particular level of income) was incorrect.

It is further assumed that certain factors can act as barriers to health care access, and that the barriers make a difference in one's health outcomes. A related caveat is that interaction with the health care system and visits to a primary care provider (or utilization, the center portion of the IOM model) lead to positive health outcomes. However, it is possible that this study's subjects' failure to achieve the best possible outcome was related to other factors outside the scope of this study, such as error in diagnosis or physician delay in treatment initiation. Although the subjects reported having a primary care physician to whom they had made visits in the last 3 months, it is possible that they did not have a primary care physician before they were diagnosed or had failed to routinely visit their primary care provider.

The original proposal anticipated that the study data would be collected within 3 months of each subject's initial diagnosis of cancer. One of the limitations of this study was that only 9 of the subjects were initially interviewed less than 3 months after diagnosis, and 2 had completed the self-administered instrument containing the CES-D by then. As such, the personal and structural factors and levels of depression measured may have related to the phase of learning to cope with their cancer diagnosis (or, in some cases, recurrence) rather than being an indicator of ongoing barriers or a depressive state that may have kept them away from or ineffective within the health care system.

The CES-D instrument classically inquires about subjective affective status "in the last week". The directions to the subjects in this study asked that they respond about their feelings "within the past month". It is not known if any of the instrument's psychometrics are altered with this difference in timeframe.

Implications for Existing Literature

This study had no statistically significant findings to add to the existing literature but did note some patterns that were consistent with those previously reported in the literature. The more important contribution that this study may make, however, is to create a greater awareness of the barriers to health care access for a segment of our society who are nearly invisible - rural women - at a time when health care reform is underway.

Further refinement of the health care access barrier index should also occur. Although the study's original proposal was to develop an index based upon the sociodemographic barriers, it is clear from this work that psychological barriers play a key role as well and must also be included in the index.

The study model may be a useful tool for further barrier analysis, as well as for clinical practice. The health care provider who is oblivious to or uninformed about barriers that clients may be experiencing will be at a great disadvantage in helping clients to identify, reduce, manage, or eliminate them. The model serves as a quick reminder that barriers come in many forms, and have serious consequences. Others must be encouraged to continue the exploration, identification, analysis, management, eradication, and reporting of findings regarding barriers to health care access.

Implications for Advanced Nursing Practice and Primary Care

This study presents additional cues to the advanced practice nurse to identify and evaluate barriers to health care access that his/her rural female clients may be experiencing. Although study barriers were not determined to be predictive in this study, the presence of several barriers for any woman in the rural primary care setting is deserving of assessment and management or elimination.

This study highlighted the importance of identifying psychological barriers. Half of the women in this study perceived that they received limited emotional support, and reports of affective distress rose with the number of barriers. Additional emotional support can come from having or developing a confidant, strengthening the family support network (burying old grudges, re-establishing contact, making time for building better family relationships), better understanding, strengthening, or repairing the marriage dyad (eliminating as much negativity, dysfunction, and stress in the relationship as possible; understanding that the marriage relationship may influence the way in which a woman responds to menopause; encouraging her efforts to establish her own identity as a woman in addition to that of a wife), involvement in shared-interest groups (church, crafts, social organizations, volunteer work), support groups (spousal abuse, cancer survivors), or acquisition of a pet. The client may benefit from improving her stress management skills, changing her coping style, or increasing her physical exercise. There must be ongoing efforts to actively reduce the barriers in anticipation that depressive symptoms will diminish as well.

The advanced practice nurse can assess the levels and sources of support each woman feels she has in her life. The advanced practice nurse can make regular evaluations of the woman's depressive symptoms using the CES-D scale or other instruments, performing a thorough clinical assessment, referring for assessment, or initiating or referring for treatment. The client's level of depressive symptoms may simply require ongoing monitoring and assuring that the woman feels free to discuss her concerns, or more aggressive treatment. The holistic advanced practice nurse recognizes the importance of emotional support to the client's emotional health, and works to identify support sources in the woman's family circle, home, and community. S/he must also educate the client about the intertwining of support and depression, help her to identify symptoms in herself and, when necessary, encourage her to seek treatment.

Clinically, the advanced practice nurse will use the roles of educator, advocate, clinician, assessor, counselor, researcher, and change agent to address structural, financial, and personal barriers. For example, some women in this study had high levels of depressive symptoms or very low levels of emotional support. The advanced practice nurse who holistically views the client and family and who makes the time to listen to clients can better interpret the meaning of these findings to the client's life. Strategies can then be planned and implemented to minimize, manage, or eliminate them to the extent possible.

Barriers such as ethnicity, age, or gender are "fixed"; that is, they would be impossible to change. However, the advanced practice nurse can help women to identify and educate them about their barriers and risks.

Some barriers may be more amenable to change. A woman without transportation may infrequently receive care at a clinic 40 miles from her home because she is unaware of a closer site. The advanced practice nurse can assist the patient in selecting an alternate care source; check with the county transit system or other carrier to learn the routes, cost, days and times of operation, and method of access; and provide complete transition of medical records and care information to the new care manager and facility, including the barriers to health care access that have already been identified.

Other barriers may be identified through history-taking or ongoing information-gathering. Determinations regarding who is living with the client, how many others she has caregiving responsibilities for, and her assessment of her relationships can occur in the course of any office visit and provides valuable information about actual or potential barriers. Modifying these barriers may involve more personal or financial resources than the woman may have, or she might not be interested in making any changes at this time. The advanced practice nurse should assess these issues with the woman at risk, educate her, provide her with information about community resources that she may be unaware of, and convey a willingness to discuss or assist the woman in making changes not as a part of one office visit but as a function of her ongoing care.

There is little the advanced practice nurse can do to alter the woman's income status. However, a low-income client may be able to pay less for health care services if assisted by the advanced practice nurse to apply for special programs, or educated about participation in sliding scales or other fee defrayment methods. The advanced practice nurse should be familiar with other resources in the community and, when referrals are necessary, refer to other health care providers who will accept the client's financial or insurance status.

The advanced practice nurse can gather information about the impact of underinsurance or uninsurance on the lives and health of his/her clients and advocate for change within his/her clinic, county, state, and nation.

Based on current trends, it is likely that 150,000 women will be diagnosed with breast cancer this year. Considering the survival rate for those with early stage breast cancer is five times better than that for late stage cancer, strategies for self-examination and practitioner screening and early detection in the primary care setting are extremely important. One of the goals for women's health in this nation should be elimination of the finding of advanced stage breast cancer upon initial diagnosis. We can only achieve that goal if we identify and aggressively work to reduce or eliminate the barriers for women to health care access. One method with relevance to this study would be for the advanced practice nurse to teach every female client about breast health, self breast examination, disease risk factors, and the importance of reporting abnormalities quickly. Another tactic is to diligently follow established protocols for health maintenance and cancer screening for every female client in the advanced practice nurse's practice.

Access barrier management can be a tool for empowerment of the rural woman. In working with the woman to identify her real or potential barriers, the advanced practice nurse can help her develop strategies for minimizing or eliminating these barriers whenever possible.

The advanced practice nurse is the optimal provider within the health care system to be a client advocate in the identification and management of barriers to access. As an assessor, s/he develops a data base for each person, including sociodemographic and psychological factors. As a clinician, s/he optimizes every interaction each woman has with the health care system, educates her regarding her health management and wellness, and does not lose sight of the woman's advocacy needs and assessment as she develops a management plan with - not for - the woman. S/he educates other members of the health care team who may not see or understand the barriers to access that are present for this and other women.

This study offers support for the advanced practice nurse's practice paradigm; that is, remain sensitive to who your patient is, treat her respectfully, and meet her at her presenting level of coping and capability. Explore with her how her culture, role in her family, or ethnicity may shape her views, treatment options, and wellness. Access includes meeting the woman's individual threshold for acceptability, attainability, accommodation, affordability, and availability; if her threshold is not met, not only her health but that of her family may suffer, since women are often responsible for arranging and assuring receipt of health care services for other family members. Thus, a system that shuns female participation or access is likely to negatively impact the health of not only the woman, but all those for whom she has a caregiver role. As new health care systems are developed under national health care reform, the advanced practice nurse's unique knowledge, perspective, and abilities as a change agent are ideal for designing a system that identifies and eliminates access barriers.

The advanced practice nurse is ideally suited for leading continued research regarding barriers to health care access.

Recommendations for Further Research

Virtually any aspect of health care access barriers is amenable to discovery, and it is critical to continue further analysis with larger samples. Any one of the 14 health care access barriers in the study is worthy of research. Careful documentation of the factors in a rural woman's life, perhaps through personal, focused interviews, that kept her from seeking health care or that made her impotent within the system must be systematically documented, evaluated, and ultimately eliminated or reduced. Based on the results of this study, it would be useful to conduct more detailed analysis of the relationships among perceived emotional support, living arrangements, and level of depressive symptoms. Longitudinal studies of rural women, their health care, and barriers - especially any psychological indicators - would be invaluable.

Another component from this study that would be useful to examine in larger samples is the pre-diagnosis presence or absence of a primary care physician for women with advanced stage breast cancer.

It would be interesting to repeat this study using a larger sample of rural women. It would be even more compelling to concurrently gather data from rural areas throughout the state, and compare health care access barriers of the groups.

There are few research dollars aimed at women, much less rural women with access problems, although they make up a significant portion of the population of every state; this de-emphasis of female research must stop. No doubt there is more known about the laundry detergent buying habits of rural women than about their health care knowledge and access barriers. Little has been scientifically documented about rural Michigan women, how they may compare to their urban sisters, and the health promotion and wellness practices of each. Michigan Department of Public Health has a wealth of data about Michigan women, but there has been little scientific inquiry about their health risks or even if residency in one rural county (i.e., where there is no hospital or other health care source that has made a serious commitment to not just staying in business but in actively improving the health of the community) may put women more at risk than another. This invites further research.

A final suggestion is that the study's definition of health care access, the study's model, or the three elements of the IOM barriers to access model (financial, structural, and personal) and utilization mediators be systematically evaluated, perhaps through the study of preventable diseases and illnesses. This information would help in refining, supporting, or completely revamping the definition and the models, lending additional fundamental knowledge about access and barriers to future researchers, and assisting us as a nation to recognize and minimize factors that discourage Americans from accessing the health care system, promoting wellness, and preventing disease.

The advanced practice nurse is ideally and uniquely prepared to design, lead, and participate in research activities, generating new knowledge and improving the practice of all levels of health care providers.

APPENDICES

APPENDIX A

Telephone Instrument

APPENDIX A
Telephone Instrument

CANCER IV

RURAL CANCER CARE STUDY

WAVE I PATIENT TELEPHONE

TELEPHONE PACKET (PATIENT)

"Rural Partnership Linkage for Cancer Care"

Grant #1 R01 CA56338
Funded by the National Cancer Institute

CURRENT FEELINGS

These questions ask about how you feel, and how things have been with you <u>within the past month</u>. For each question, read the statement then circle the one answer that comes closest to the way you have been feeling during the past month. Do not spend too much time on any one statement.

EXAMPLE

DURING THE <u>PAST MONTH</u>, HOW MUCH OF THE TIME ...

have you eaten breakfast? (CIRCLE ONE)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

DURING THE <u>PAST MONTH</u>, HOW MUCH OF THE TIME ...

1. were you bothered by things that usually don't bother you? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

2. have you not felt like eating; had a poor appetite? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

3. have you felt that you could not shake off the blues, even with the help of family or friends? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

4. have you felt that you were just as good as other people? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

5. have you had trouble keeping your mind on what you were doing? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

DURING THE PAST MONTH, HOW MUCH OF THE TIME ...

6. have you felt depressed? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

7. have you felt that everything you did was an effort? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

8. have you felt hopeful about the future? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

9. have you thought your life has been a failure? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

10. have you felt fearful? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

11. has your sleep been restless? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

12. have you felt happy? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

13. have you talked less than usual? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

14. have you felt lonely? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

15. have you felt people were unfriendly? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

DURING THE PAST MONTH, HOW MUCH OF THE TIME ...

16. have you enjoyed life? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

17. have you had crying spells? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

18. have you felt sad? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

19. have you felt that people disliked you? (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

20. could you not get "going?" (circle one)

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME

Please circle one response for each item that represents how you feel about each statement.

21. In uncertain times, I usually expect the best. (circle one)

STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE

22. If something can go wrong for me, it will. (circle one)

STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE

23. I always look on the bright side of things. (circle one)

STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE

24. I'm always optimistic about my future. (circle one)

STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE

APPENDIX B

Self-Administered Instrument

APPENDIX B
Self-Administered Instrument

CANCER IV

RURAL CANCER CARE STUDY

Wave I

The answers you give to these questions are very important in helping us to better understand the experiences dealing with cancer. You should try to mark the response which is most like your own feelings and experiences. Your answers will be of great help to us and we want to remind you that the answers you give are strictly confidential.

If you have questions, please call Cindy Espinosa or Charles W. Given at (517) 353-0306 or toll free at 1-800-654-8219.

We appreciate the time that you spend answering these questions and we value the answers you give. Your help is the most important factor in our efforts to learn more about patients dealing with cancer.

Please complete and return this booklet in the self-addressed stamped envelope by ______________________________. Thank you.

SELF-ADMINISTERED BOOKLET (PATIENT)

"Rural Partnership Linkage for Cancer Care"

Grant # 1 R01 CA56338
Funded by the National Cancer Institute

ID __ __ __ __/INT __
Date __ __/__ __/__ __

SCREENING CANCER PATIENT NAME AND ADDRESS

1. **Name of Patient:** ______________________________
2. **Address of Patient:** ______________________________

   ____

   ____
3. **Telephone:** (____)________________________
4. **Name and phone number of contact person if unable to reach patient:**

   Name: ______________________________

   Relation to patient: ______________________________

   Telephone: (____)________________________

   Location: ______________________________

   ____

ID __ __ __ __/INT __
Date __ __/__ __/__ __

Prior to interview-- Enter date (month, day and year) and interviewer number on each page, if indicated.

SOCIODEMOGRAPHIC INFORMATION FOR CANCER PATIENT

1. Sex of patient: (check one) ____ Male (1) ____ Female (2)

2. What is your birthdate? (write in)

__ __/__ __/__ __
Month/ Day /Year

3. What is your highest level of education completed? (check one)

_____ No formal education (1)
_____ Completed grade school (2)
_____ Completed some high school (3)
_____ Completed high school (4)
_____ Completed some college or technical training (5)
_____ Completed college (6)
_____ Completed graduate/professional degree (post baccalaureate degree) (7)
_____ NA/Refused (9)

4. What is your race or ethnic background? (check one)

_____ Caucasian/White (1)
_____ African American/Black (2)
_____ Mexican American/Hispanic/Chicano (3)
_____ Native American/Alaskan (4)
_____ Oriental/Asian/Pacific Islander (5)
_____ Other (6) (specify ______________________________)
_____ NA/Refused (9)

5. What is your marital status? (check one)

______ Never married (1)
______ Married (2)
______ Divorced/Separated (3)
______ Widowed (4)
______ NA/Refused (9)

(GO TO NEXT PAGE)

6. In which county do you live? (check one)

_____ Allegan (1)
_____ Barry (2)
_____ Berrien (3)
_____ Branch (4)
_____ Calhoun (5)
_____ Cass (6)
_____ Eaton (7)
_____ Ionia (8)
_____ Kalamazoo (9)
_____ Kent (10)
_____ Ottawa (11)
_____ St. Joseph (12)
_____ Other (specify ______________________________) (13)
_____ NA/Refused (99)

7. When was the month and year you moved to this county? (write in)

_____/_____
Month/Year

Now we are going to ask you questions about who lives with you, and about persons who might help you.

8. Who lives in your household with you? (check all that apply)

a) ___ No one-- lives alone (1)
b) ___ Spouse (2)
c) ___ Your children or step-children (3)

If c was checked, then:

(c3A) How many children under 13 years of age?
_____(write in number)

(c3B) How many 13 to 17 years of age?
_____ (write in number)

(c3C) How many 18 years or older?
_____ (write in number)

d) ___ Any other children under 18 years of age (4)

If d was checked, then:

(d4A) How many children under 13 years of age?
_____(write in number)

(d4B) How many 13 to 17 years of age?
_____ (write in number)

(GO TO NEXT PAGE)

ID __ __ __ __/INT __
Date __ __/__ __/__ __

FAMILY NETWORK

11. Now I would like you to think about all your living relatives; parents, brothers, sisters, children, step-children, nieces, or nephews. We would like to know how much they support you emotionally, and how much they help with physical care, help around the house or with shopping or transportation. The same relative may help with one or both. Please tell me the relationship of the relative to you, how far they live from you (if they live in your home, let me know), and then how much they help you emotionally and with physical care. You can say that they help a great deal, quite a bit, some, a little, or very little to none.

(Interviewer: Ask patient for first relative, initials, and relationship to patient. Proceed with all relatives patient reports.)

INITIALS	RELATIONSHIP TO PATIENT	DISTANCE IN MILES 1 = Lives in my household 2 = Less than 10 miles 3 = Between 10 & 50 miles 4 = More than 50 miles	HOW MUCH EMOTIONAL SUPPORT DOES THIS PERSON PROVIDE TO YOU? 1 = None or very little 2 = A little 3 = Some 4 = Quite a bit 5 = A great deal	HOW MUCH PHYSICAL HELP DOES THIS PERSON PROVIDE TO YOU? 1 = None or very little 2 = A little 3 = Some 4 = Quite a bit 5 = A great deal
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5
		1 2 3 4	1 2 3 4 5	1 2 3 4 5

12. Please tell me the month and year you were diagnosed with your cancer. (write in)

____/____ Month/Year

____ NA/Refused (9)

(Interviewer: For all of the following questions, if patient was diagnosed in the past three months, then preface questions that follow with: "Since your diagnosis ...." If diagnosis was <u>more than</u> three months ago, then preface questions that follow with: "In the past three months ...")

7) TRANSPORTATION

7a. Three months ago, with regard to getting to places outside of walking distance, i.e., going to the doctor's or grocery shopping away from your neighborhood ... (check one)

___ Did you drive yourself? (1)
___ Did someone drive you (i.e., taxi, e-train, relative, or friend)? (2)
___ Others have always driven me. (3)
___ NA/Refused (9)

7b. Currently, with regard to getting places outside of walking distance, i.e., going to the doctor's or grocery shopping away from your neighborhood ...

___ Do you drive yourself? (Go to question 8) (1)
___ Does someone drive you (i.e., taxi, e-train, relative, or friend)? (Go to 7c) (2)
___ Others have always driven me. (Go to 7c) (3)
___ NA/Refused (9)

7c. Is this due to your ... (check one)

___ Cancer or cancer treatment (Go to 7d) (1)
___ Other health problem(s) (Go to 7d) (2)
___ NA/Refused (9)

7d. If someone helps you with transportation ... (check all that apply)

___ primary caregiver (1) (Go to 7e)
___ paid family (2) (Go to 7g)
___ paid friends/others (3) (Go to 7g)
___ paid professional (4) (Go to 7g)
___ unpaid family (5) (Go to 7f)
___ unpaid friends/others (6) (Go to 7f)
___ unpaid professional (7) (Go to 7f)
___ NA/Refused (9)

7e. If the **primary caregiver** helps with transportation ...

(1) In the past week, how many times did he/she help with transportation? (write in)

______ Times per week

(2) Approximately how long in minutes each time did he/she help with transportation? (write in)

______ Minutes each time

(Interviewer: If patient doesn't know, then ask them to estimate as best they can.)

(GO TO NEXT PAGE)

3d. On how many of these visits did someone go with you? (write in)

___ Times someone went with patient

4. In the past three months or since you were first diagnosed with cancer, have you visited a laboratory for tests? (check one)

___ Yes (Go to 4a) (1)
___ No (Go to 5) (2)
___ NA/Refused (9)

4a. Please list the city in which the laboratory was located: (write in)

City: ______________________________

4b. Excluding time for other stops, from the time you left home until you returned home, how long did a typical visit take? (write in)

___ Hours

4c. In the last three months or since you were first diagnosed with cancer, how many times have you visited this laboratory? (write in)

___ Times

4d. On how many of these visits did someone go with you? (write in)

___ Times someone went with patient

5. In the past three months or since you were first diagnosed with cancer, have you visited a primary care physician? (check one)

___ Yes (Go to 5a) (1)
___ No (Go to 6) (2)
___ NA/Refused (9)

5a. Please list the name and city in which the primary care physician was located: (write in)

Name: ______________________________

City: ______________________________

5b. Excluding time for other stops, from the time you left home until you returned home, how long did a typical visit take? (write in)

___ Hours

5. Considering all these sources of income, what was the combined household income of all household members in 1993? (Please indicate gross income, before deducting taxes.) (check one)

Household Income Categories:

___ 0 - 4,999 (1)
___ 5,000 - 9,999 (2)
___ 10,000 - 14,999 (3)
___ 15,000 - 19,999 (4)
___ 20,000 - 24,999 (5)
___ 25,000 - 29,999 (6)
___ 30,000 - 34,999 (7)
___ 35,000 - 39,999 (8)
___ 40,000 - 44,999 (9)
___ 45,000 - 49,999 (10)
___ 50,000 - 59,999 (11)
___ 60,000 - 69,999 (12)
___ 70,000 - 79,999 (13)
___ 80,000 - 89,999 (14)
___ 90,000 and over (15)

(Go to question 6)

6. In 1993, did you receive ...

6a. Food stamps? (check one)

___ Yes (Go to 6b) (1)
___ No (Go to 6d) (2)
___ NA/Refused (9)

6b. How much in food stamps per month? (write in)

$____________ (Go to 6c)

6c. For how many months did you receive food stamps? (write in)

___________ Months

6d. Winter heat assistance? (check one)

___ Yes (1)
___ No (2)
___ NA/Refused (9)

7. Do you currently have health insurance? (check one)

___ Yes (Go to 7a) (1)
___ No (Go to question 17) (2)
___ NA/Refused (9)

(GO TO NEXT PAGE)

APPENDIX C

University Committee on Research Involving Human Subjects Approval of the Rural Cancer Care Study

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University Committee on Research Involving Human Subjects Approval of the Rural Cancer Care Study

MICHIGAN STATE
UNIVERSITY

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
225 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

March 14, 1995

TO: Charles Given
B108 Clinical Center

RE: IRB#: 91-277
TITLE: RURAL PARTNERSHIP LINKAGE FOR CANCER CARE

REVISION REQUESTED: N/A
CATEGORY: FULL REVIEW
APPROVAL DATE: 03/06/95

The University Committee on Research Involving Human Subjects'(UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

APPENDIX D

Subject Consent Form

APPENDIX D
Subject Consent Form

MICHIGAN STATE UNIVERSITY
Rural Cancer Care Project

CONSENT FORM

The project in which we are asking you to participate is designed to learn more about the delivery of a nurse focused network of supportive cancer care directed to families residing in the rural community.

Patients receiving cancer care in the rural area will be interviewed by a member of the Rural Cancer Care Project research staff. The interviews will take approximately 45-60 minutes to complete (4 times per year). Patients will also be asked to complete a short written questionnaire (4 times per year) and have their medical records reviewed.

If you are willing to participate, please read and sign the following statement:

1. I have freely consented to take part in a project of Cancer Care to Patients and their Family Members conducted by the Michigan State University Colleges of Nursing and Human Medicine, Department of Family Practice, Cancer Center of Michigan State University, the Kalamazoo Clinical Oncology Programs and the Kalamazoo Center of Medical Studies.

2. The project has been described and explained to me and I understand what my participation will involve.

3. I understand that participating in this project is voluntary.

4. I understand that I can withdraw from participating at any time without penalty or any adverse impact on the care to which I am otherwise entitled by calling 1-800-654-8219.

5. I understand that professionals (physicians and nurses) who provide care to me will not have access to my responses to phone interviews or questionnaires.

6. I understand that no immediate benefits will results from taking part in answering the questionnaire, but I am aware that my responses may add to the understanding of health care professionals of the experience of cancer care in a rural area and may influence future family care.

7. I understand that the care provided as a part of the Rural Cancer Care Network will be according to a plan of cancer care determined by my physician(s). Benefits in coordination and availability of care is expected.

8. I understand that the nurse providing care will work in collaboration with my physician(s) and keep my physician(s) informed of my progress to ensure coordinated care.

9. I understand that my treatment plan and appropriate medical information from my medical record will be shared with referral services (i.e., skilled home care agencies, hospices) if a referral is made.

10. I understand that the results of the project will be treated in strict confidence and my name will remain anonymous from any reports or publications. I understand that within these restrictions, results can, upon request, be made available to me.

11. I request that my medical records be made available to Dr. Charles W. Given, Professor, Family Practice, Michigan State University.

12. I understand that a member of the project staff may wish to inquire about my group health insurance policy benefits to understand what benefits are available to me and compare these to what I am presently using. I authorize the Health Care Financing Administration to release information about myself to the aforementioned parties for the purposes of the research project, entitled "Rural Partnership Linkage for Cancer Care," in which I am a participant. The information to be released will include admissions to hospitals, nursing homes, and other health care facilities, the respective length of stay for these admissions and all health care costs paid by Medicare including physician services. This consent is effective until such time that I withdraw my authorisation.

For more information concerning the research and research-related risk of injuries, I may contact Dr. Charles W. Given, the investigator in charge at (800) 654-8219.

In addition, I can contact Dr. Donald Batts at (616) 384-9491 if I have any questions regarding patient's rights in research studies.

I, the undersigned, state that I understand what is required of me is a participant and agree to take part in this project.

Signed ______________________________

Date ____________________

Please print name ______________________________
Last name First name M.I.

Address ______________________________

____

Date of Birth ______________________________

Social Security Number ______________________________

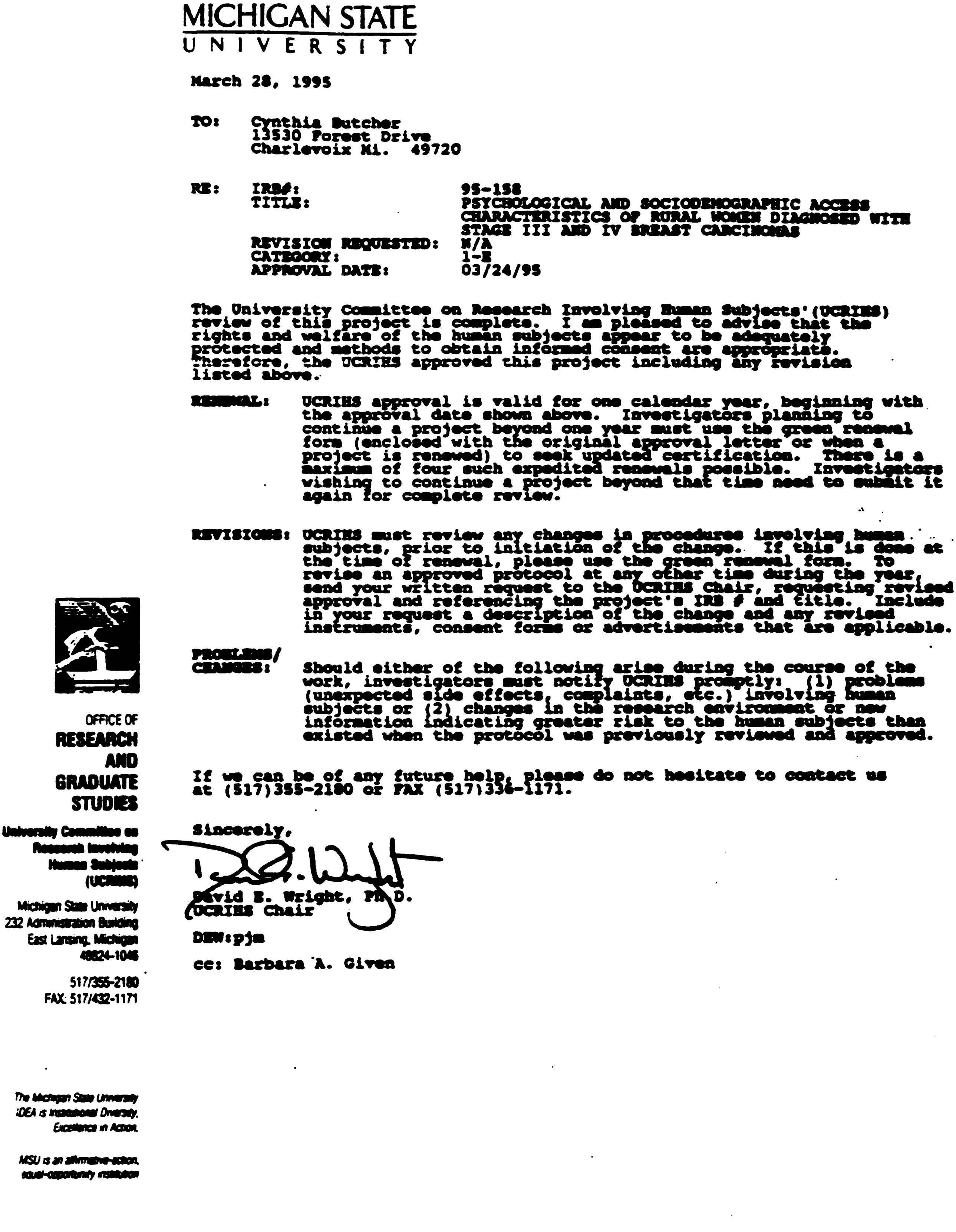
Health Insurance Claim Number ______________________________

ks:133:consent
8/12/94

APPENDIX E

University Committee on Research Involving Human Subjects Approval of this Study

APPENDIX E
University Committee on Research Involving Human Subjects Approval of this Study



MICHIGAN STATE
UNIVERSITY

March 28, 1995

TO: Cynthia Butcher
13530 Forest Drive
Charlevoix Mi. 49720

RE: IRB#: 95-158
TITLE: PSYCHOLOGICAL AND SOCIODEMOGRAPHIC ACCESS CHARACTERISTICS OF RURAL WOMEN DIAGNOSED WITH STAGE III AND IV BREAST CARCINOMAS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 03/24/95

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Barbara A. Given

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
232 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

The Michigan State University
IDEA is Institutional Diversity:
Excellence in Action.

MSU is an affirmative-action,
equal-opportunity institution.

LIST OF REFERENCES

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