

CANCER SCREENING BEHAVIORS IN OLDER ADULTS: GROUNDED THEORY

A DISSERTATION

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To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewithin a dissertation written by Anne Thomas entitled "Cancer Screening Behaviors in Older Adults: Grounded Theory." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.

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and recommend its acceptance:

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Accepted.

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Associate Vice President for Research  
and Dean of the Graduate School

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## DEDICATION

To my husband, Matthew, and our children Eric Matthew, Nathan Alexander  
and Lauren Elizabeth Joyal.

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## ABSTRACT

### Cancer Screening Behaviors in Older Adults: Grounded Theory

by

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The purpose of this study was to address the knowledge gap regarding older adults' health care decisions occurring after a cancer screening examination was performed. The research question "What phenomena are perceived by older adults to influence their decision not to seek health care following a positive cancer screening examination?" was the domain and primary purpose of the study. Generation of grounded theory regarding older adults' beliefs and perceptions about cancer screening was the ultimate goal.

Formal, unstructured interviews were completed with fifteen older adults who had completed a cancer screening examination and had not obtained further recommended healthcare. Analysis of the interview data was completed using the constant comparative data analysis. The theory of cancer screening behaviors in older adults was generated from these older adults' realities. The theory was then validated by the participants with additional justification from the review of literature.

Data revealed that older adults hold negative perceptions about cancer that

influence their interpretation of the meaning and purpose of cancer screening. These perceptions also influenced their ability to enter the decision making process about their positive cancer screening findings. Developmental life stage, concurrent life events and suspension of the decision making process can pose barriers to the older adult's choice to ultimately obtain recommended follow-up care. The final outcome of the theory is the participant's active choice of health care or health care that has been disease driven, leaving the participant with few options. Implications for nursing involve public education efforts for older adults regarding cancer, cancer screening and normal changes of aging. Mechanisms to routinely include gerontology and geriatric oncology into nursing curriculums must also be addressed. Finally, society must mandate that the health and well-being of the nation's oldest citizens deserves priority research and funding, if there is to be a reduction in the mortality rates of older adults with cancer.



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## CHAPTER I

### THE STUDY PROBLEM

#### Introduction and Rationale

The delivery of health care in the United States is undergoing an unprecedented assessment. The undercurrent of discontent with the health care system is widespread and growing. In 1993, Americans spent more than \$900 billion on health care (Marmor & Mashaw, 1993; Smith, 1993) which is more than any other country in the world (Blendon, 1990; Passell, 1993). Despite these enormous costs, the United States is not among the world leaders in the delivery of preventive medicine or quality service. Approximately 34-36 million people or 13% of the United States population lacks any form of health insurance and many of these individuals have no access or limited entree into the system (Knox, 1993). Hospitals and physician offices turn away one million people a year because they lack insurance (McDermott, 1994).

These figures become even more monumental when addressing common statistics regarding America's older adult. Approximately 12% of the United States citizens are over the age of 65 and nearly 80% of these individuals suffer from at least one chronic illness (U.S. Department of Health and Human Services, 1987). By the year 2000, a staggering 50% of all health care expenditures will be devoted to older adults' medical and health care (U.S. Department of Health and Human Services, 1987). Escalating medical costs by our oldest segment of society is expected to

continue as the baby-boomers come of age. In North America, the United States and Canada will experience a near doubling in the absolute number of older persons over the next three decades (Welch-McCaffrey, 1988).

Experts in oncology are addressing the economic impact that cancer in the older adult will have on the nation's health care system. Approximately 50% of all cancers occur in the elderly population (Crawford & Cohen, 1987; Dellefield, 1988; Clark & McGee, 1992; Yancik & Ries, 1991). The most common sites for cancer in the older adult include the bladder, breast, colon, corpus uteri, lung and prostate. In the United States, there has been a 23% decrease in cancer mortality reported in those under 55 years of age, yet cancer mortality for those over 55 increased by 17% (McCaffrey-Boyle & Engelking, 1993). Sixty percent of all cancer deaths occur in individuals 65 years of age and older (Clark & McGee, 1992). A significant increase in the number of people alive with cancer and newly diagnosed cases could overwhelm the health care system if no appreciable therapy or prevention breakthroughs are found (Yancik & Ries, 1991).

Treatment of cancer is associated with significant costs. Silberman (1993) cites one potential breakthrough in clinical research trials in the treatment of metastatic breast cancer to illustrate the expense of care. The advent of high-dose chemotherapy with autologous bone marrow transplantation costs approximately \$50,000 - \$200,000 (Hillner, Smith & Desch, 1993). If this treatment proves to be efficacious in the treatment of metastatic bone cancer, the immediate implication to the U.S. health system would be a \$1.7 billion annual increase in the demand for service. Silberman (1993) states that looking at this in another perspective equates to \$116,000

for every year of life gained for the breast cancer patient. Consider that breast cancer is only one of many cancers that older people incur and the economic implications of "breakthrough" therapies are staggering.

Older adults can stem the functional disability and exorbitant medical costs from cancer if the disease is detected early before metastasis occurs and when the chance of cure is greatest. Cancer screening is one link in the chain of cancer control which extends from prevention to screening to diagnosis, treatment and rehabilitation (Clark & McGee, 1992). Unfortunately, elders hold many misconceptions about cancer and cancer care that preclude active participation in cancer screening activities (Welch-McCaffrey, 1986). Enhancing the use of cancer screening programs by older adults deserves investigation and should gain societal prioritization as more policy makers become aware of the staggering economic implications that preventive cancer care has for the United States.

#### Significance to Nursing

The older adult population is the most rapidly expanding segment of the United States population and the health care of these individuals has become a national priority (Fleck, 1988). In the near future, the practice of oncology nursing will predominately involve geriatric patients. In providing care for older adults, nurses "must be cognizant of their perceptions of cancer as a hopeless disease, of the health care system as mysterious and frightening, and of money matters becoming a serious and worrisome issue" (Fleck, 1988, p. 217). Age is the most important determinant of cancer risk; the longer a person lives, the more likely they are to develop cancer

(Newell, 1989). The incidence of cancer at the age of 25 is less than one in six hundred but by the age of 70 cancer incidence rises to one in ten (Frank-Stromberg, 1988). The diagnosis of cancer coupled with a chronic illness and residual consequences of other bodily insults that have occurred over a person's lifetime creates a challenging treatment environment for the nurse. Psychological perspectives and coping skills of the older adult also become highly diverse as aging occurs. Nurses, perceiving the older adult as a holistic entity functioning within their environment, need to combine the diverse psyche with complex physiological bodily functioning to formulate an ethical, caring, quality plan of care.

Targeting the elderly with intensive screening and educational programming may reduce the incidence and stage of cancer at diagnosis (Boyle, 1994). Research indicates that early detection of colorectal, breast, prostate, and cervical cancers in the elderly is cost-effective and increases survival (Albert, 1987). The National Cancer Institute estimates that if the percentage of older woman receiving mammograms and breast exams is increased to 80%, mortality in this age group would fall by 30% (Frank-Stromberg, 1988 citing Anonymous, 1987). However, older adults are typically under-represented in cancer screening programs because of lack of knowledge of the purpose of the actual screening itself. The nurse imparts a vital role in the older adult's understanding of cancer screening. As both a client advocate and cancer screener, the nurse can provide educational programs and perform the physical examinations necessary for a complete cancer screening. Cancer prevention education and cancer screening are fully within nursing's scope of practice and does

not require physician referral for the client to obtain care. Thus, typical gatekeeping mechanisms for information and care that abound in our health care system do not preclude the nurse from becoming actively involved in preventive cancer care.

The Oncology Nursing Society's position paper on cancer and the older adult mandates the establishment of a formal framework of nursing care to meet the unique needs of the elderly and "has implications worldwide as action is taken to meet the needs of the forgotten majority with cancer - the elderly" (Boyle, 1994, p. 134). In an editorial, Ash (1986) stated that nurses are the largest group of health care providers and as such need to become knowledgeable about the elderly and the assessment of their needs, serving as a catalyst for the involvement of others. Cancer is a preeminent health care crisis creating an imperative for nurses to lead the challenge in investigating new and innovative early cancer detection and prevention methods for older adults.

#### Aims and Purpose

The purpose of this research was to address the knowledge gap regarding older adults' health care decisions occurring after the cancer screening was performed. Generation of grounded theory regarding older adults' beliefs about cancer screening was the ultimate goal. An interview guide facilitated data collection addressing the research questions.

#### Research Questions

Chenitz and Swanson (1986) state that the primary question asked in grounded theory study is "What patterns can I identify in the problem and how are these



patterns related?" (p. 16). The research question "What phenomena are perceived by older adults to influence their decision not to seek health care following a positive cancer screening examination?" was the domain and primary purpose of the study. Additionally, the following research questions facilitated understanding of the behavioral patterns surrounding the decision making processes of the older adult.

1. What does cancer mean to the older adult?
2. What are the initial thoughts and feelings of the older adult when first told they had positive findings? Have the initial feelings and thoughts changed over a period of time?
3. What are the older adult's expectations of the cancer screening examination?
4. Are there circumstances that prevented the older adult from getting or receiving care after the screening examination?

#### Assumptions

The study of cancer screening behaviors in older adults was based on assumptions about both the method of grounded theory and older adults' life experiences and cancer beliefs. The assumptions regarding grounded theory are explained in detail in the grounded theory methods section. Assumptions regarding older adults and cancer include:

- a. Older adults participating in a cancer screening program have made a conscious choice to seek health care and health information.
- b. Older adults possess unique ideas and thoughts about cancer and cancer

screening.

c. Older adults have an accumulation of life experiences that influence their health behaviors and health choices.

d. Older adults are able to articulate their perceptions and feelings regarding cancer and cancer screening.

### Limitations

The sample size is fifteen and the geographic setting limited to a single urban population in the United States. However, the method of grounded theory allowed the researcher to actively select subjects based on the emergent data in an effort to increase the transferability of the findings. Grounded theory does not have generalizability of study results as its purpose but instead allows for the transferring of variables that are equivalent across contexts (Erlandson, Harris, Skipper, & Allen, 1993, p. 32). All observations made are defined within the specific contexts and the specific time period in which they occurred. Thus, the naturalistic researcher maintains "that not true generalization is really possible; all observations are defined by the specific contexts in which they occur" (Erlandson et al., 1993, p. 32).

Replication of a grounded theory study is problematic to the positivist (nonphenomenologist) because the researcher is an instrument i.e., filter through which the theory is generated (Keffer, 1990). As such, the researcher's perceptions, lived experiences and realities influence the data collection, interpretation and context within which the theory emerges. Erlandson et al. (1993) states that the naturalistic inquirer operates under a different set of assumptions concerning the nature of reality,

epistemology and generalizability. The purpose of naturalistic inquiry is not to replicate but to conduct a study similar to a previous one to allow expansion of the processes and constructed realities of the original study. In short, to seek the initial illumination of the context of the second study from the first. (Erlandson et al., 1993, p. 45). The aim is to develop shared constructions of a particular event thus providing working hypotheses for further research.

### Definitions of Terms

Critical to understanding the study results are the definitions of key events investigated. As such, the context of the definition of terms assists in explaining the cancer event so as to better understand and perceive the participant's reality. Well, older adult is defined as a parameter for inclusion of a participant in the study.

1. Cancer screening: The preliminary step in the early-detection process. Screening does not result in the diagnosis of cancer, but identifies early signs possibly indicating cancer among individuals in an apparently well population (Greenwald, 1992, p. 123).
2. Early cancer detection: The definitive diagnosis of cancer based upon positive physical findings which leads to further investigation from health care professionals (Greenwald, 1992, p. 124). Cancer screening and diagnosis frequently are separated activities, conducted by different health professionals at different physical locations.
3. Cancer screening examination: A head-to-toe physical examination by a certified family nurse practitioner that includes screening for the following cancers: head and neck, oral, lymph, breast, skin, and colorectal. The female examination also includes screening for cervical, uterine and ovarian cancers. The male examination includes screening for prostate and testicular cancers. All screening examinations lasted

approximately 30-45 minutes and were conducted in a large, mobile screening van.

4. Positive cancer screening findings: Physical examination findings that were suspicious for cancer and required further health care. All positive findings were conveyed in writing to the participants at the time of the cancer screening exam along with a copy of the examination results. Participants received a personal copy of the examination results and a summary of the positive findings with the recommended health care before leaving the screening facility.

5. Well, older adult: Women and men age 50 and above who report themselves to be in good health.

6. Lack of recommended follow-up health care: The cancer screening participant did not seek further follow-up health care as recommended by the cancer screening nurse. The cancer screening program's protocol clearly outlines the following sequence of events. The individual with positive cancer screening examination findings receives contact from the cancer screening program via telephone call or postcard two weeks post-cancer screening examination. This contact requests that the client obtain further recommended care as soon as possible. The client is requested to notify the cancer screening program that they have sought care. If the cancer screening does not receive notice from the client within a month following the screening examination, another postcard or phone call is made. If no response is obtained from the client, a certified letter is sent out three months after the initial examination. This letter states that the client had physical examination findings that warranted further evaluation. It further states that this letter is the last reminder that the cancer screening program provides. The letter also states that the program would

appreciate notification if further evaluation by the client is sought. At the end of the third documented notification, the cancer screening program's follow-up is complete.

## CHAPTER II

### REVIEW OF LITERATURE

#### Introduction

Grounded theory research uses an inductive “from the ground-up” approach aimed at understanding how a group of people define via social interactions, their personal realities (Stern, Allen & Moxley, 1982). Artinian (1986) asks the question “What patterns can be identified and how are they related?” As such, the researcher should study an area without any preconceived theory that dictates, prior to research, relevancies in concepts and hypotheses (Glaser & Strauss, 1967, p. 33). Glaser (1978) states that grounded theory is based on systematic generation of theory from data that is systematically obtained from social research.

The researcher enters the investigative milieu without preconceived theories; this does not equate to blind irreverence to informational sources. The researcher needs to become familiar with the general content under study and develop a theoretical sensitivity to the ideas, concepts, constructs and contexts of the topic.

Morse (1994) in a recent editorial about “going in blind” stated:

“Ignorance does not ensure insight. Nor does ignorance ensure theoretical sensitivity. Rather, ignorance is more likely to limit one’s theoretical vision and narrow one’s mind restricting conceivable theoretical options” (p. 3).

Morse reiterates Glaser’s thoughts that the research agenda should remain open and

not preset with a theoretical model in which data will be forced accordingly. It is the astute researcher as an active participant in the qualitative process that can adeptly find the middle ground and formulate the grounded theory by blending formerly acquired knowledge and new realities.

Given the above parameters, this researcher undertook the literature review with several purposes:

1. To review the current literature on cancer in the aged as a broad background to the subject of interest;
2. To review the current quantitative and qualitative studies regarding cancer screening and cancer prevention programs specific to the elderly population. Articles in this particular section of the review of literature were anticipated to be scarce, as the inclusion of individuals over the age of 70 in clinical cancer trials by the National Cancer Institute was recently allowed and many of these trials are not completed.
3. To review the current literature on aging theories with particular focus on the developmental and psychosocial needs of the older adult with cancer and;
4. To review the overall use of health promotion and disease prevention activities specific to older adults.

#### Cancer in Older Adults: Economic Implications

Approximately 50% of all cancers occur in persons over age 65 and the risk for most major cancers increases with age (Webster, 1992; Welch-McCaffrey, 1986).

Cancer in the elderly is the second leading cause of death next to heart disease (Ham & Sloane, 1992). Over 80% of these deaths occur in the 55+ population and one third

occur in the population age 75 and older (List, 1987). The incidence of cancer at age 25 is less than one in six hundred but by age 70 rises to about one in ten (Frank-Stromberg, 1988).

Addressing these figures in the context of the older population as a whole assists in understanding the impact of this disease in the United States. Life expectancy for the average man is 69.9 years and 77.6 years for women and climbing (Dychtwald, 1986). Some demographers predict that average life expectancy at birth will continue to rise in the coming decade, approaching 80 to 85 years by the turn of the century (Greene, Monahan & Coleman, 1992). The numbers of individuals 85 and older are the fastest growing segment of our society, rising at a rate three to four times faster than any other age group. Furthermore, the Census Bureau (1990) predicts that there will be 100,000 centenarians by the year 2000. Women live an average of 7 1/2 years longer than men. Projections from the U.S. Census Bureau (1990) suggest that this trend will continue until leveling off occurs at the year 2050. At that point, life expectancy for U.S. women will be 81 years and for men 71.8 years, a 9.2 year difference (U.S. Bureau of Census, 1990). The proportion of men to women also diminishes in late life until at age 85 it approaches one man for every 3.5 women. Increasingly, the issues of old age are principally issues of the most frail population: women.

Citing economic implications of cancer in the older adult population provides a strong rationale for this study. Dychtwald (1986) purports a glowing fiscal report of the United States elderly population. Persons age 55+ head more than one third of the nation's households and account for more than 30% of the annual income in America.



Dychtwald states that these individuals are long-time money savers and account for approximately 80% of all money in savings and loan institutions in the United States. He estimates that older persons can maintain the same purchasing power as the young on an income of 65% to 80% of their pre-retirement earnings.

However, these statistics are presented as if everyone at age 65 suddenly became unisex creating a highly distorted perspective; particularly when examining income levels of older adults. Given the disproportion of men to women in late life and that 50% of all cancers occur in the 65+ age group consider the following data. The Commonwealth Fund Commission Report documents the extent of elderly wealth misrepresentation (1987). The Commission reported that 81% of the 8.8 million elderly living alone are women, and that singles are nearly five times as likely as couples to be living below the official poverty level for one person (\$104 per week or \$5393 per year). In 1988, elderly women had a median income of \$7103, compared to \$12,471 for men (U.S. Senate, 1990). Among elderly men, 8.5% were below poverty level, while the poverty rate for elderly women was nearly 15%. Among women over age 85, the poverty rate is nearly 22%, compared to 14% for men (U.S. Senate, 1990).

The Commission also estimated that by the year 2020, of the two million poor elderly living alone, 1.5 million will be women. The report concluded that poverty among elderly Americans living alone afflicts primarily widowed women, increases with age and is highest among minorities. These facts have sobering consequences since older women have fewer personal financial resources than men, are much more likely to spend time in a long term care facility or need home health care services, and current health care reimbursement does not meet their needs for financial coverage of

ongoing outpatient care (Greene, Monahan & Coleman, 1992). "Triple jeopardy" - being old, poor and female - characterizes the older adult population in the 21st century.

The economic impact of cancer care could be reduced if researchers and health providers set out a concerted effort to study cancer in the aged and the special educational, psychological and treatment needs of this group. Numerous sources relate the paucity of information related to the special needs of the older adult with cancer (Boyle, 1994; Brower, 1985; Faithfull, 1992; Fleck, 1988, Frank-Stromberg, 1988). This is particularly evident within the last ten years as the research emphasis has seemingly shifted from cancer to other foci: HIV, world population control and other environmental issues. The negative stigma widely attributed to the elderly in the United State's society also impacts the research emphasis on cancer prevention and treatment in the elderly. Clinical consequences of ageism include subtle avoidance of contact, less aggressive cancer therapies, failure to create cancer prevention and treatment programs specific to the needs of the elderly, lack of inclusion in clinical research trials, failure to recognize early cancer symptoms due to confusion with other pathological aging process and others (Boyle, 1994; Fentiman, Tirelli, Monfardini et al., 1990; Holland & Massie, 1987; List 1987).

Fentiman et al. (1990) notes using age limits as a criterion for clinical trial participation often precludes the possibility of formally studying the elderly cancer patient's response to antineoplastic therapy and instead anecdotal notes and case reports are more commonly supported in the literature. Consequently, the best

interests of the elderly as a whole are not supported. Furthermore, given the heterogeneity of biological responses of individuals that occur with aging, case reports and anecdotal notes are not necessarily beneficial for the older adult patient. Applying therapies that succeeded on only one elderly patient should be judiciously practiced. However, Fentiman et al. (1990) reports frequent application of case study reports. Fentiman et al. (1990) states that due to historic exclusion from clinical research trials, elderly cancer patients have received inadequate treatment, untested treatment or even worse, no treatment at all! Until recently, the National Cancer Institute's excluded people over the age of 70 from clinical trials (Given & Keilman, 1990).

There is also a prevalent misconception that older adults are poorly tolerant of antineoplastic therapy, radiation therapy and palliative surgeries (Fentiman et al., 1990; Fleck, 1988; Given & Keilman, 1990). A complexity of factors influences survival rates after the diagnosis of cancer: biological behavior of the tumor, stage of disease at diagnosis, host response, choice of therapy and response and toxicity to the chosen therapy (Given & Keilman, 1990). The variation and relationship of these factors and many others has not been systematically established in the 65+ age group (Goodwin, Samet, Key et al., 1986). Mandleblatt and Fahs (1988) demonstrated that age is a strong determinant of professionals' choices of cancer treatment in elderly, low income women. For most cancer sites, the proportion of patients receiving definitive treatment declines with age and the proportion of patients not given treatment increases (Samet, Hunt, Key et al., 1986).

Aggressiveness of treatment may relate to survival rate of the elderly cancer

patient. In a widely cited research study, Swedish researchers investigated 57,068 cases of breast cancer diagnosed between 1960-1978 and found that women who were 45 to 49 years of age had the best prognosis. Relative survival declined dramatically after age 49 and the worst survival rates were in women age 75+ (Adami, Malker, Holmberg et al., 1986). In another study, elderly breast cancer patients age 75+ were two times more likely to have surgery as their sole treatment as compared to those age 45 and younger (Allen, Cox, Manton & Cohen, 1986). These same researchers noted that 60% of patients under 45 with regional node involvement received adjuvant chemotherapy compared to 27% of those 65 years and older. Age related differences account for differences in the histological presentation of breast cancer. Mucinous cancers are more common in older adults whereas medullary and inflammatory carcinomas are more frequently found in younger women. However, patients over the age of 55 presented with more advanced disease but this proportion did not further increase after age 65. The researchers concluded that differences in treatment responses were specifically associated with the use of adjuvant chemotherapy between the age groups (Allen, Cox, Manton & Cohen, 1986). Despite similar characteristics in regard to laterality, anatomic site and histology, elderly patients were less frequently administered adjuvant chemotherapy in stage II breast cancer.

#### Cancer Screening, Detection and Prevention in Older Adults

List (1987) notes that the elderly are under-represented in most screening and prevention studies creating a serious omission in known risks, benefits and ability to screen the elderly. The review of literature supports List's paucity of information of

cancer screening in the elderly. The overwhelming majority of articles supports limited anecdotal notes and case reports. There is a lack of well documented and/or controlled studies that specifically investigate at the needs of the older adult in relation to prevention and/or earlier detection of cancer (Bostick, Sprafka, Vimig & Potter, 1993).

The National Cancer Institute has set a year 2000 goal to decrease cancer mortality by 50% (Entrekin & McMillan, 1993). To reach this goal, early detection and prevention programs must receive priority. The older adult faces many obstacles toward this end and two are discussed in this paper. The first is the social stigma associated with aging and cancer. Holland and Massie (1987) state that in today's society, the older person who develops cancer faces a dual social stigma. The connotation of being both old and diagnosed with a disease that elicits social recoil may lead to a sense of worthlessness and burden that is detrimental to positive adaptation. Furthermore, these pressures are amplified by changes in the normal life cycle of an older adult: loss of spouse, friends, financial resources, sight, hearing and physical stamina. The major concerns of older adults with regard to cancer are primarily the prevention of disability and improvement of quality of life (Muir Gray, 1985). Therefore, the aim of cancer prevention and early detection measures in this age group must focus on incorporating appropriate preventive measures into current lifestyles. These issues are significant in planning health care for the older adult; if clinical management of these concerns are not addressed, the health care provider can seriously jeopardize client participation thus obtaining less than a desired outcome (Holland & Massie, 1987).

The second major obstacle is the lack of concerted screening and education efforts by a variety of health care providers for older adults. Sawyer (1986) conducted a survey among hospital staff nurses. Sixty-four percent of nurses interviewed did not ask their patients about breast self-examination (BSE) practice. Fifty-five percent of those same nurses were unlikely to teach BSE to nonpracticing patients. Warren and Pohl (1990) conducted a study examining cancer screening practices among 97 nurse practitioners (NPs) in adult primary care settings. Results suggested that NPs were more likely to carry out and recommend screening practices on younger and middle age women as compared to men, more likely to educate younger women than older adults and men, and followed the American Cancer Society guidelines for mammography only 55% of the time. The four primary reasons the NPs cited for not carrying out cancer screening were: 1) not feasible because of practice setting; 2) need an update, do not feel competent; 3) lack of time and; 4) cost factors. These are significant issues when considering that the primary purpose of early detection is to screen persons in ambulatory practice and community settings before the disease advances and requires acute care. Finally, Warren and Pohl (1990) state that the tremendous gender and age gap needs further study as they note serious ethical issues in the care of older adults and men. Health care providers are gatekeeping information and consciously abstaining from preventive practices in a selective and biased manner.

Knowledge regarding cancer screening practices is widely variable among health care professionals. Entrekin and McMillan (1993) surveyed 2,532 nurses in Florida. Results suggested that nurses were most knowledgeable about prevention

and early detection of breast and prostate cancer and least knowledgeable about lung and endometrial cancer. Nurses educated their patients about preventive and early detection practices i.e., BSE, smoking cessation, skin self-examination from zero to 20% of the time. Despite their apparent lack of participation in prevention and early detection, 66% of these nurses believed that cancer prevention is part of the role of the staff nurse.

Physicians play a crucial role in recommending and performing cancer screenings in older adults. Unfortunately, physicians, like other health care professionals, lack consistent use of cancer screening recommendation guidelines. An article in Cancer (1985) reported the following results of a survey of physicians' adherence to cancer screening guidelines.

1. Approximately 68% of gynecologists and 11% of all physicians follow the American Cancer Society's guidelines on mammography.
2. Only 8% of gynecologists would consider performing a sigmoidoscopy on their older patients even though many older women receive primary care from their gynecologists.
3. Approximately 75% of all physicians surveyed take Pap smears routinely. Ninety six percent of gynecologists consistently follow the American Cancer Society's guidelines, while 58% of internists and 77% of family and general practitioners perform Pap testing.
4. Approximately 53% of physicians follow the American Cancer Society's guidelines for performing annual digital rectal examinations after the age of 40.

Lack of knowledge by the health care provider regarding normal and abnormal processes of aging accounts for inconsistent use of cancer screening guidelines. Several studies suggest that physicians lack knowledge about normal and physiological changes of aging which may lead to less than optimal therapeutic approaches in the older adult (Goodwin, 1989). This trend will continue until the United States has more trained geriatricians. It is remarkable that although there are more than 50 million Americans over the age of 50, there are still less than 100 fully trained geriatric physicians in the country (Dychtwald, 1986).

Educating older adults about cancer prevention and early detection should, in theory, decrease mortality rates as cancers will be found in their earliest stages when the likelihood for cure is greatest. However, few cancer education programs meet the educational, cancer risk, and life-style needs of older adults (Clark & McGee, 1992; Given & Given, 1989; List 1987; Welch-McCaffrey, 1986). Innovative approaches must be investigated when considering recent cervical, breast and prostate cancer statistics:

\*One fourth of all new case of cervical cancer occurs in women 65+ years of age, yet half of all women in this same age group have not had a Pap smear within the last three years (Power, 1990).

\*Approximately 50% of all new cases of breast cancer are detected in women 65+ years of age but only 16% of all mammograms are performed on women in this age group (Robie, 1989).

\*Thirty-three percent of all prostate cancer patients have advanced disease at the time of initial diagnosis (Mettlin, Jones & Murphy, 1993).

Boyle (1994) states that there are three major obstacles to address



when facilitating change in health seeking behaviors in the elderly regarding cancer prevention and early detection: older adults' attitudinal responses to cancer, their usual functional difficulties as well as those imposed from cancer therapies and their limited health-care access. Attitudinal barriers include lack of knowledge about cancer symptoms, fatalism of cancer, elders' underestimation of cancer risk, and many misconceptions regarding cancer. A study conducted by the American Cancer Society (ACS) revealed that the public markedly underestimates the incidence of cancer in the general population (1990). Rimer et al., (1983) and Weinrich and Weinrich (1986) report that many older adult respondents in their studies did not realize that the elderly were at an increased risk for cancer. Burack and Liang (1986) studied older adult women followed in a university affiliated clinic and found that more than half of the study participants did not believe they had any control over getting cancer and that cancer was unavoidable. While this group tended to underestimate their personal risk for getting cancer, they tended to overestimate the risk for the community. Welch-McCaffrey (1986) reports a rise in misconceptions about cancer in the elderly population. She emphasized tailoring cancer education programs to address the greater misinformation about cancer that occurs with each decade of life.

Some of the same studies also report a lack of knowledge of cancer symptoms among the elderly. Older persons who routinely receive treatment for chronic illnesses may not seek preventive care or confuse the symptoms as part of their current disease process. The respondents in Weinrich and Weinrich study (1986), on the average recalled only one to two of the ACS seven warning signals for cancer. However, the

researchers developed a questionnaire designed to recognize cancer symptoms since the elderly frequently view disease as a normal part of aging. The "Knowledge of Symptoms Questionnaire" incorporated five of the seven ACS warning signals. Study participants increased their ability to recognize causes of symptoms being correlated with various cancers as opposed to simply recalling symptoms.

A recent survey of knowledge, attitudes and personal practices regarding cancer prevention and early detection was performed in a randomly selected population ( $N=4,915$ ) of 25 to 74 year olds in three upper Midwestern states (Bostick, Sprafka, Virnig & Potter, 1993). The results were encouraging as four fifths of the respondents believed cancer to be preventable. Knowledge of warning signs and signals using the ACS seven warning signals was low, particularly among men. The research also suggested an increase since the 1980s in Pap testing and mammography. The researchers felt this was due to high levels of consensus for these specific screening recommendations among policy-making organizations. For instance, the American Association of Retired Persons and four agencies of the U.S. Department of Health and Human Services joined forces in 1991 to launch a major campaign to encourage older women to obtain regular mammograms and to make them aware that Medicare now pays for screening mammograms (Burklow, 1991). Population adherence to colorectal screening is low and may be associated with the lack of national consensus on screening recommendations among the policy-making organizations. Cost of sigmoidoscopy screening is also a significant barrier. The authors note that lack of substantial change will persist:

"until current or new screening tests are clearly proven to be efficacious and made more universally affordable or available, until consensus is reached among policy-making organizations and practicing physicians, and until the general public becomes more knowledgeable regarding cancer prevention and early detection" (Bostick, Sprafka, Vimig & Potter, 1993, p. 83).

Studies indicate older people report cancer symptoms differently than younger adults and seek care at more advanced stages of the disease process (Celenatano, Shapiro & Wiseman, 1982; Holland & Massie, 1987; Ouslander & Beck, 1982). As mentioned previously, most older adults have at least one chronic illness and ingest an average of four prescription medications daily (Ham & Sloane, 1992). Exacerbation of an existing chronic disease can easily be mistaken for cancer related symptoms. Multiple chronic diseases may have overlapping symptoms leading to further confusion. Diseases also present themselves differently in older adult. Infectious processes may not be accompanied by fever; broken bones may lack objective findings or subjective pain responses. Clinically silent cancers are more frequently found in older adults. Hall (1984) noted that although the cancer prevalence in the study group was 12%, autopsies revealed a rate of 25%.

Lack of knowledge of cancer symptoms and common misconceptions about cancer risks contribute to poor participation by older adults in cancer screening programs than in younger age groups (Ouslander & Beck, 1982; Kirscht, Haefner, Kegeles & Rosenstock, 1986; Kane-William & White, 1983; Mandleblatt, Gopaul & Wistreich, 1986). Frank-Stromberg (1986) cites the following obstacles to early

detection of cancer in the elderly: myths regarding unhealthy or demented elderly, lack of accurate health information for the elderly, elders' negative attitudes about cancer, confusion regarding signs and symptoms of cancer, and confusion of aging symptoms with cancer symptoms.

### Psychosocial Characteristics of Older Adults Relative to the Cancer Screening Experience

Physical well-being and acceptance of health care are contingent upon psychosocial health. In late life, many adjustments are necessary to assure continued health of the psyche as the older adult experiences role changes and transitional life experiences while trying to maintain social integration. This researcher believes that role change, life transition and social integration play a critical role in the cancer screening behaviors of older adults. When conducting qualitative research it is important to understand the general context/milieu of the participant's reality i.e., the self-reported well, older adult. Clinical and personal experiences of the researcher have played a primary role in the decision to examine these issues. Each of these topics is discussed broadly and then applied to the available cancer research in older adults.

Roles define a person's relationship to their environment and are comprised of self-concept and self-perception. Self-concept is the cognitive part of the self-perception i.e., how a person views themselves as an individual. Self-esteem is the emotional component of self-perception and refers to judgments that the individual makes about self (George, 1990). It is not clear if self-perception changes with age.

What is clear is how older adults actively try to maintain their self-concept. For an older person whose self-worth and self-concept was based on social roles, role losses have a significant impact. On retirement, older adults find themselves in a world where it is more difficult to reflect the traditional work ethic of achievement, productivity and independence (Davis, 1986, p. 133). Grandparenting, volunteering, and leisure time activities often replace work roles after retirement, although the United States culture does not seem to afford these roles with the status that a paying job or career brings. This adjustment difficulty is most prevalent with the professional world and is a major reason white-collar workers fear and actually postpone retirement more often than blue-collar workers (Davis, 1986). Role conflict and uncertainty can and do occur frequently for the older adult as normal physiologic consequences of aging take hold. This can be a time of great stress or a significant period of intellectual and spiritual growth. All will depend upon past coping experiences and present support systems (Philips, 1989).

The older adult experiences many life transitions. The life event generally considered most stressful in the wake of all others is the loss of a spouse. The average American widow is a 56 year old woman who can expect to live another twenty years after the death of her spouse (Fletcher, 1994). Lifelong roles change immediately, often causing serious problems with self-identity and self-esteem. In a society that functions in dyads, the widow or widower may feel like a "third-wheel" as they begin to adjust and socialize as a new single person. Adjustments may also include serious financial problems, age discrimination with employment and social roadblocks.

Retirement is another transitory life event that for many is their first experience with the impact of aging and precipitates loss in several ways: income, status, intellectual and emotional identity, and every day meaning in life. A stressful retirement has been associated with two predictor variables: inadequate finances and poor health (Bossde, Aldwin, Levenson & Workman-Daniels, 1991). Fletcher (1994) notes that having a stable relationship or a confidant is critical to successful adjustment to retirement. Lack of control over the retirement situation leads to feelings of helplessness, passivity and depression (McGoldrick, 1989). During childhood and adolescence, a person moves toward attainment of an independent and a responsible adult role. An individual's chosen career also subscribes to the attainment of a professional role. When and where does an older adult prepare for the role of retirement? Retirement is facilitated by learning how to use, appreciate and achieve satisfaction from leisure time throughout an employed lifetime (Eliopoulos, 1993).

Social integration is a health promotive and protective activity for many older adults. Although some older adults prefer to disengage from society, studies have indicated that the active, older adult derives more satisfaction from life (Fletcher, 1994). During the middle years, adults are busy with careers and child-rearing. Activities are commonly divided between the home and community/work outside the home. As one ages, a decline in physical exertion occurs bringing social activities closer to the physical home environment (Kelly, Steinkamp & Kelly, 1986). Older adults spend their leisure time in meaningful ways: self-reflection, volunteerism, hobby development and others. This is unlike the middle years where leisure activities are used to "wind

down” or to simply relax. Leisure time is an important social integration tool that older adults used to stay mentally and physically fit. Illness or poor adaptation to a sudden loss typically diminishes leisure time. Diminished leisure time leads to detrimental role functions and poor life transitions; all of which loom deleteriously over health promotion/screening activities.

Given and Keilman (1990) discuss the psychological responses of older adults with cancer and raise important research issues to be addressed in the cancer care of the older adult. They report, and this literature review concurs, that these issues have not been sufficiently studied and believe there is a societal mandate to take action as the “greying of America” occurs. Given and Keilman (1990) ask: 1) Do patients with cancer over the age of 75 require social or psychological care that differs from that provided to elderly people with other chronic disease? 2) How are the decisions and preferences for cancer treatment made by age? 3) Do elderly adults perceive different barriers to using community resources? 4) Is their care different than younger adults? 5) How is the household affected when the older adult has cancer? and many more. Answering these questions are essential to a complete understanding of older adults’ use of cancer prevention and detection services. If older adults perceive cancer treatment as an abysmal prolongation of life without sufficient quality, early detection measures may prove to be clinically insignificant.

Consider the following scenario that this researcher typically found in clinical practice. A 75 year old woman who has a history of longstanding hypertension and painful osteoarthritis has just been diagnosed with breast cancer. She is widowed,

lives alone and is on a meager fixed income. Most of her family lives in another state. Several of her closest friends died from cancer after a long and arduous course of chemotherapy and radiation therapy, only to have minimal prolongation of their lives. She remembers the devastating effect the cancer had economically, psychological and physically on her friends. This is all brought to the treatment table when discussing the patient's therapy. Will her past experiences and present living situation influence her health decisions regarding her cancer? How does her view of aging effect her care? Will her movement through the developmental life stages help or hinder her decision making processes? This researcher's experience has found that these issues are much more important to the older adult than the potential of curing the cancer. However, there is a dearth of information regarding these topics since most literature seeks to describe mortality and morbidity data instead.

Overall, limited studies suggest that older adults with cancer appear to cope better in some psychological domains than their younger counterparts. Maisiak, Gams and Lee (1983) performed a large study comparing older people with cancer, ages 60-97 to younger people with cancer and found that the psychosocial status of the elderly patients was somewhat better than the younger patients. This was in the face of less income and education. The older adult patient was also less likely to be depressed and handled leisure time activities better than the younger subjects. Begg (1990) concluded that elderly patients are less likely to have pressing jobs and family demands, are more likely to have experienced chronic illnesses and to have learned ways of coping, and may be more likely to accept cancer as a natural or expected



occurrence at their stage of life. Gotay (1985) reported that the older adult with cancer experiences less psychosocial disruption than the younger patient.

#### Health Promotion/Disease Prevention Programs for Older Adults

Health promotion for the older adult is a newcomer to the self-care movement and has been typically navigated by younger people. Advocating health promotion in the United States oldest citizens first demands acknowledgement of the following common misconceptions:

- \* Old people are sick and disabled.
- \* Most older people are in nursing homes.
- \* Senility comes with old age.
- \* Old people are unhappy.
- \* People either get very tranquil or very cranky as they age.
- \* Older people have lower intelligence and are resistant to change.
- \* Old people are not able to have sexual intercourse and are not interested in sex anyhow.
- \* There are few satisfactions in old age. (Eliopoulos, 1993, p. 43).

The hallmarks of wellness for many older adults include the ability to remain active, and to maintain desired social interaction and involvement in the community and relationships with family, friends and organizations. Studies demonstrate that older adults need additional information about how to lead healthy lifestyles and that they are willing to make those changes (Gilbert, 1986). However, additional strategies must address long-term cultural biases about aging to stimulate the development of ongoing health promotion programs (Healthy People 2000).

Current health promotion programs often carry another critical bias that deserves careful examination. To date, health promotion programs for older adults have tended to focus on the isolated individual as the target for behavioral change efforts. Dychtwald (1986) notes that poverty, racism, sexism and ageism are usually ignored by many programs. He describes this as an inappropriate focus on a person's responsibility for health as compared to focusing attention on one's response-ability i.e., the capacity for responding effectively to one's personal needs and challenges as posed by the environment. Response-ability necessitates a minimum economic health, without which health promotion efforts are fruitless (Dychtwald, 1986). For the 15% of elderly Americans living at or near the poverty line, ensuring economic health must be considered a prerequisite to conventional health promotion programs (U.S. Bureau of Census, 1990).

Health belief models have tried to theoretically differentiate the philosophical ideas between responsibility and response-ability but are inadequate. Many models do not account for achievement of developmental life stages and self-perception; concepts that this researcher believes are critical in understanding older adults' participation in health promotion activities. Charmaz (1983) studied the relationship between chronic illness and self-care using qualitative methods. She found that a person diagnosed with a chronic illness i.e., hypertension, diabetes or arthritis, ceases to view themselves as they were prior to the illness. This change in self-concept is attributed to the sense that the individual is no longer whole but is less a person than previous, and that the person that once was no longer exists. Most importantly, that

person will never again be the former self. To engage in self-care activities i.e., health promotion and disease prevention, a person must view themselves as worthy of the energy expenditures that self-care entails. The implication of Chamez's work is that persons with chronic disease who have a negative self-esteem are unlikely to provide or seek avenues for self-care. An older adult with a chronic illness who also has cancer has an additional burden to bear. Are these people perceiving themselves as not being worthy enough to seek cancer treatment as they may not have come to terms with the perception of self that was necessitated by a previous diagnosis of a chronic illness?

The implications of chronic illness can also be found in teaching methods used in health promotion and disease prevention programs for older adults. Rimer et al. (1983) reported successful health education programs are those that have addressed the separate and unique needs of the older adult and have sought to meet them. Boyle (1994) urges modification of educational programs for the older adult that considers visual, hearing, cognitive and functional impairments. Modifications in self-examination techniques need to be made in an older adult with a chronic illness such as arthritis. Diminished range of motion caused by the arthritis can interfere with the ability to perform numerous self-screening activities if relying upon traditional teaching methods (Barnes & Thomas, 1990). Making simple modifications in educational programs assure that the majority of common physiological changes of aging are addressed i.e., slowing the pace of presentations, using distinct color contrasts on teaching materials, using concrete illustrations rather than abstract scenarios, and others (Barnes & Thomas, 1990; Kim, 1986). However, research studies

demonstrating the results of these actions are scarce. This lack of research has resulted in many health promotion programs that inadequately address the needs of the older adult population precipitating a lack of funding for creative, innovative programming specific to the older adult.

#### Summary of the Review of Literature

The literature review was undertaken for four basic purposes:

1. To review the current literature on cancer in the aged as a broad background to the subject of interest;
2. To review the current quantitative and qualitative studies regarding cancer screening and cancer prevention programs specific to the elderly population;
3. To review the current literature on aging theories with particular focus on the developmental and psychosocial needs of the older adult with cancer and;
4. To review health promotion and disease prevention activities specific to older adults.

The literature revealed a lack of research in all four areas with acknowledgement of the same from leading experts in the fields of oncology nursing, medical oncology and gerontology. Of particular merit and significance to this study is that many older adults and health providers harbor detrimental age biases, lack knowledge regarding appropriate cancer screening and cancer signs and symptoms in the elderly, and acknowledge that action is imminent in developing acceptable cancer prevention modalities if a national health crisis is to be thwarted.

The population of the United States is greying and the current health care system is unable to provide adequate health coverage and care. As the baby

boomers reach the "golden years", the burden on the nation's economy will be devastating if current trends for health care expenditures of older adults continues. Health promotion and disease prevention programs for older adults that address the major causes of morbidity and mortality must be developed and substantiated with research. The literature review demonstrated that little more than good faith efforts have been the foundation of most of the work investigating cancer prevention and screening in older adults. Thus, the research method (grounded theory) used in this study is appropriate at a time when foundational research is needed to go back to the original question - What are the basic behavioral patterns and phenomena surrounding the cancer screening examination in the older adult?

## CHAPTER III

### PROCEDURE FOR THE COLLECTION AND TREATMENT OF THE DATA

#### Introduction

The purpose of this research was to understand the phenomena perceived by older adults to influence their decision not to seek health care following a positive cancer screening. The review of literature revealed no research regarding this topic area but did provide limited information regarding older adults' lack of use of cancer prevention and detection services. The method of grounded theory was chosen for this study because it allowed this researcher to enter the context of the participant's reality with the ultimate goal of discovering and then unraveling the relationships surrounding the decision making process. The researcher then moved from the empirical to the theoretical to develop a theory of the phenomena; to make sense and order out of the participant's experiences which provides a springboard for further inquiry. Grounded theory methodology was also used because cancer screening behavior and subsequent health care follow-up care are relatively unexplored in the older adult population. Through the constant comparison analysis of categorizing and coding, a theory could be formed which would describe and explain the older adult's beliefs, feelings and health behaviors surrounding the cancer screening examination. This too would lead to propositions which could be tested empirically.

It must be reiterated that entree into the phenomenon of interest was not

blindly pursued. The researcher's assumptions were acknowledged a priori and held in abeyance as each participant shared their perceptions of their experience.

Qualitative research begins by assuming that one can obtain a profound understanding about people and their worlds through ordinary, everyday conversations and observations (Gubrium & Sankar, 1994, p. vii). Gubrium and Sankar (1994) further state that qualitative research has a special use in situations where variables or the very meaning or definition of the issue under study is unknown and where the focus is on the dynamics of the situation. Rubenstein (1994) states that using qualitative methods is the only way to study process and meaning.

#### Grounded Theory Method

The method of grounded theory was first developed by Glaser and Strauss (1967) using the symbolic interactionist philosophy proposed by George Mead.

"Symbolic interactionism posits that humans act and interact on the basis of symbols which have meaning and value for the actors. Examples of symbols include words for an object rather than the object itself, body language which communicates messages to others with or without words.... " (Stern, Allen & Moxley, 1982, p. 203)

Symbolic interactionism rests of three propositions; 1) "human beings act toward things on the basis of the meanings that the things have for them"; 2) "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows"; and 3) these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters"

(Blumer, 1969, p. 2 as cited in Chenitz & Swanson, 1986, p. 5).

Chenitz and Swanson (1986, p. 6) list three reasons why symbolic interactionism has implications for research activities essential to understanding the process of grounded theory.

1. Human behavior, to be understood, must be examined in interaction. The setting, the implication of the setting, and the larger social forces are analyzed.
2. The researcher needs to understand behavior as the participants understand it. Hence, the researcher must "take the role of the other" to understand behavior in the participant's context.
3. In order for the knowledge to be understood and accepted by the researcher's discipline, the researcher, as observer, must translate the meaning derived from the researcher as participant to the language of the research discipline (Blumer, 1969 as cited by Chenitz & Swanson, 1986, p. 7).

By using a symbolic interactionist perspective, grounded theory provides an approach that is useful to conceptualize behavior in complex situations and to understand the impact of new ideologies (Chenitz & Swanson, 1986, p. 7). Creating a new perspective on familiar problems is a primary purpose of grounded theory.

Grounded theory research uses an inductive, "from the ground-up" approach aimed at understanding how a group of people define, via social interactions, their reality (Stem, Allen & Moxley, 1982). Artinian (1986) asks the question "What patterns can be identified and how are they related?" As such, one should "study an area without any preconceived theory that dictates, prior to research, relevancies in



concepts and hypothesis" (Glaser & Strauss, 1967, p.33). Glaser and Strauss state that it is presumptuous to assume that one begins to know relevant categories and hypotheses until data has been collected from field research. Initial hypotheses formation forces the data into categories which may be inappropriate while neglecting other relevant categories. It is through the generation of core variables and categories that the hypotheses formation occurs. In grounded theory, these hypotheses undergo constant reformulating and generating as new data are compiled and analyzed.

The assumption that people order and make sense out of their environment although it may appear disordered and nonsensical to the observer guides grounded theory research (Hutchinson, 1986). The task of the researcher is to discover and accurately conceptualize the essence of the complex interactional process. The resulting theory emerges as an entirely new way of understanding the observations from which it was generated. "It is this understanding that permits the development of relevant interventions in the social environment under consideration" (Hutchinson, 1986, p. 112).

Glaser and Strauss (1967) state that grounded theory formulates two types of theory: formal and substantive. Both are considered mid-range theories. Substantive theory emerges from a substantive or empirical area of inquiry while formal theory develops out of a conceptual area of sociological inquiry (Glaser & Strauss, 1967). Essential to either substantive or formal theory development is the discovery of the core variable. Glaser (1978) calls the core variable the basic social process and describes two components that develop. The first is the basic social-psychological

processes which are a "type of core variable that illustrate social processes as they continue over time, regardless of varying situations" (Glaser, 1978, p. 100). The basic structural process is another type of core variable that illustrates stages, properties and conditions of the structure of the theory (Glaser, 1978; Hutchinson, 1986).

The above explanation alludes to the difference in the sequencing of the qualitative research process as compared to the quantitative. Bowers (1988) states that it is the sequencing of the steps of the qualitative process that distinguishes it from other research methods. The literature review, hypotheses generation, data collection and analysis occur simultaneously rather than in a sequential, distinct order (p. 45). The steps of the process may overlap and occur simultaneously but nonetheless are all completed. Further explanation of the data analysis process will be presented in following sections of the paper.

In summary, Stern (1987, pp. 80-81) offers a succinct overview of grounded theory while noting its departure from other types of research methods:

1. The conceptual framework is generated from the data rather than from previous studies.
2. The researcher attempts to discover dominant processes in the social scene rather than describing the one under study.
3. Every piece of data is compared with every other piece rather than comparing totals of indices.
4. The collection of data may be modified according to the advancing theory; that is, false leads dropped, or more penetrating questions asked as seems appropriate.

5. Rather than following a series of linear steps, the investigator works within a matrix in which several research processes are in operation at once. In other words, the investigator examines data as they arrive, and begins to code, categorize, conceptualize, and write the first few thoughts concerning the research report almost from the beginning of the study.

### Research Setting

The setting for the study was a large metropolitan area in the southwest United States. All study participants were selected from clients seen at a mobile cancer screening clinic owned by a major, national not-for-profit organization. The cancer screening clinic is a nurse-managed center and does not provide medical care. All cancer screening examinations and educational programs encountered by the study participants were conducted by a certified family nurse practitioner. For the convenience of the participants, the unstructured, formal interviews were conducted in each of the participant's homes.

The medical center and the cancer screening clinic were specifically chosen for this study for several reasons. Of significant concern to this researcher was a pressing ethical dilemma that could be encountered when conducting the interview process i.e., should the older adult decide to seek treatment for their positive cancer findings or become distressed from the interview, the researcher needed a referral institution that would accept them regardless of financial status and ability to pay. The medical center had an outpatient, ambulatory care clinic to provide health care for persons without regard to race, creed, gender or ability to pay. Kayser-Jones and Koenig (1994) clearly specify that qualitative research in the elderly must be carefully

contemplated before actual data collection occurs as often the elderly are frail, unable to access support systems or can even become physically ill from the emotional exertion of an interview. Seeking treatment after the interview became a reality in several cases and the participants were referred back to the medical center.

The second reason that this setting was chosen was due to the researcher's history with the cancer screening program. Before beginning this study, this researcher was a nurse practitioner/screener for the program and developed an interest in the research topic based upon personal experiences with cancer screening in adult day care centers and senior centers. The research question being addressed in this study comes from five years of clinical questioning of the topic.

#### Population and Sample

In qualitative research four types of samples are commonly used: the purposeful sample, the nominated sample, the volunteer sample and the sample that consists of the entire population (Morse, 1989). For this study, a purposive (theoretical sample) was chosen, in that the researcher selected participants according to the needs of the study (Bogden & Biklen, 1982, p.67; Glaser & Strauss, 1967, p. 48). According to Morse (1989), the researcher may initially choose to interview participants with a broad, general knowledge of the topic. As the study progresses and more specific information sought, different participants may be selected. Finally, Morse (1989) suggests to interview participants with atypical experiences so that a range of experiences and the breadth of the concept of the phenomena may be fully understood (p. 119).

Using the previously described parameters, fifteen participants were

interviewed. A family nurse practitioner (FNP) initially performed a retrospective chart review of all potential participants from 1993. She was given the instructions that the potential participants were to have had a cancer screening examination performed at the cancer screening van and had positive findings that required referral for further health care. The second criteria she was given was that the potential participant had not sought care within the recommended follow-up time period. If the person met these criteria, the FNP contacted them to inform them of the study and to secure permission to give their name and phone number to the researcher for further information. The chart review and initial telephone contact was conducted by the FNP to maintain medical record confidentiality per the request of the medical center's Nursing Research Committee.

After receiving a list of names and phone numbers from the FNP, the researcher contacted each of the potential participants. The purpose of the study was verbally explained (Appendix A) and the criteria for participation was reviewed. Criteria selection for participants were:

1. The participant was 55 years old or above and self-reports good health.
2. The participant had a cancer screening examination at the mobile cancer screening clinic and had positive finding(s).
3. The participant did not seek care for the positive results within the recommended time frame. The mobile cancer screening clinic's protocol dictates that three follow-up contacts are made either by phone or certified

letter if the client is unable to be contacted by phone. The follow-up is done at one month intervals. If the client verbally or in written communication state that they have not and/or will not seek further health care the follow-up is considered complete. Follow-up is also considered complete on clients who received a certified letter and did not respond back to the clinic.

4. The participant will agree to note-taking and tape-recording of the interview by the researcher.
5. The participant is able to articulate perceptions relative to the cancer screening examination.
6. The participant was English speaking.

Ideally, it would have been more beneficial to discuss the study and selection criteria face-to-face with the potential participant for several reasons: a relationship between the researcher and the participant could be established and the researcher could better assess the potential participant's ability to articulate ideas and feelings through social talk. Unfortunately, the potential participants lived in wide geographical areas and personal introductions were forestalled until the interview in their home. It took a great deal of explanation and departure from the written "script" (Appendix A) to convince many of the participants that the researcher was not evaluating the mobile cancer screening program but rather to inquire about their thoughts and feelings surrounding the cancer screening experience.

When using the grounded theory method, the richness of the data obtained determines the number of participants i.e., until the researcher elicits major, repetitive

themes of the topic under study (Glaser and Strauss, 1967). After listening and coding the data from the first six interviews several times, clearly physiological age played an important role in the emerging themes. At that point, the researcher attempted to obtain permission for interviews from two 70+ women and one 82 year old woman. This proved to be unsuccessful. The 82 year old woman informed the researcher that the "real reason you're in this study is to get rid of the Medicare funding and that I know you are working for the Clinton administration!" She then went on to tell the researcher that it was odd that anyone would want to find out why old people would go for cancer screening but not go for more care if it was necessary. The woman abruptly ended the conversation shortly thereafter.

The 70+ year old women did not want their voices tape recorded and could not be convinced that the study was not an evaluation of the FNP who performed the cancer screening examination or of the cancer screening program. They both stated they thought it was an odd topic to study and consequently there had to be an ulterior motive. They said that they could not understand why this area of research would be an interest to anyone. One woman stated "Are they (health professionals) just interested in getting our money or do you really care about what we think?" Their statements regarding why the researcher was not permitted to talk with them was the very reason they were notified initially. The meaning of cancer in the older participants seemed to be very different than in the younger participants. The researcher was unable to obtain interviews from additional 70 and 80 year olds and consequently sought interviews from the "young-old", several mid-fifty year old participants, to

determine if the emerging theme was a false lead or a new category needing further investigation and validation. The additional participants validated the new theme.

Saturation of the data must occur to ensure valid and reliable results. Repetitive themes began to emerge after the fourth interview and became apparent by the eleventh interview. At that point, the researcher conducted four additional interviews to validate the findings and to be assured that saturation of the data had occurred. A total of fifteen individuals participated in this study.

#### Protection of the Participants

This study was reviewed and approved by Texas Woman's University Human Subjects Review Committee and by the Human Subjects Review Committee/Nursing Research Committee of the major medical center. Major risks to the participants were not anticipated as a treatment was not applied and the participant was requested to participate in an unstructured, formal interview. Increased anxiety during the interview process was perceived as a minor risk. In the event that the interview process or contact with the researcher prompted a participant to seek medical care for the positive cancer screening findings, arrangements were made to contact the FNP who would then facilitate entry into the medical center's system. The participant was also informed that they could enter the health system of the medical center through the emergency room should they elect not to converse with the FNP. However, this option was not taken by any of the participants.

Each participant was given a participation agreement form to sign (Appendix B) and a consent for audiotaping (Appendix C). The forms included the right to withdraw



from the interview at any time, permission for the interview to be audiotaped and the notice that participation was voluntary without remuneration. A description on how confidentiality would be maintained was also discussed and included:

1. The names and addresses of all participants would be kept confidential by the researcher.
2. Actual names and/or initials would not be associated with reported data.
3. Participants were able to withdraw from the study at any time without consequence.
4. Data from the study will be securely stored in a locked file for a period of 5 years. At the end of this time, the data would be shredded.

The minor risk of the study, increased anxiety, was also included. In addition, each participant was given the researcher's name and telephone number for subsequent contacts if so desired by the participant. Participants were encouraged to ask questions to help their understanding of the research. In retrospect, the actual data collection began at this point in the encounter as many participants would begin to tell stories about their relatives' experiences with cancer.

### Instruments

#### Interview Guide

An interview guide was developed by the researcher for use in the formal unstructured interview process. The questions in the guide were synthesized from the researcher's personal experiences with people that had undergone cancer screening and a number of years in oncology nursing, the review of literature on cancer

screening in older adults and from experiences that people with cancer told the researcher (Appendix D). The interview questions were structured in an open-ended format to facilitate the unstructured formal interview process.

Twelve doctoral nursing students, two of whom were oncology clinical specialists provided initial content validity of the instrument. The original interview guide contained ten questions. After discussion with the expert panel, changes occurred in the wording of several questions and two questions were collapsed into one. The nine question interview guide was then created.

#### Demographic Background Data

A demographic and background information questionnaire was also developed by the researcher. The data compiled reflects key content areas gleaned from the review of literature, personal experiences of the researcher and the expert panel's suggestions. The detailed demographic data form enabled the researcher to obtain a diverse representation of participants in an effort to promote greater transferability of the study's results. All participants answered the questions on the demographic data form without hesitancy except for one area. Inquiring about "family income from all sources" frequently created an uncomfortable moment during the interview process. One participant refused to answer, several jokingly made up a number and told the researcher to record the amount even though it was false, and many others displayed obvious discomfort verbally and nonverbally. Initially, the tape recorder was left in the record mode when obtaining the demographic data as this portion of the session always occurred at the end of the guided interview process. The first three

participants asked to have the recorder turned off during this component of the interview, saying that they did not want that information on tape or in a typed transcript. Due to their obvious discomfort, the researcher did not try to record the demographic data in later interview sessions and found that the participants responded much more spontaneously and honestly.

### The Researcher

Chenitz and Swanson (1986, p. 56) state that the researcher functions as a data collection instrument in grounded theory. Chenitz and Swanson further state (1986, p. 57) that field researchers must attune themselves in a complex social context. Lincoln and Guba (1985) discuss that even though the use of the investigator as an instrument risks the study's objectivity and consistency, the increase in understanding of the subject outweighs the risk. The researcher as an instrument enters the interview encounter acknowledging information regarding the topic under study and tries to hold it at abeyance. This researcher entered the data collection process acknowledging the following a priori knowledge: five years of cancer screening experience; six years experience as a gerontological nurse practitioner; attendance at several extended educational sessions regarding cancer screening at M.D. Anderson Tumor Institute in Houston, Texas; completion of a previous research study investigating educational needs of the elderly in cancer detection and prevention; and an extensive review of literature compiled over at least three years. As Morse (1994) states:

"by the times one gets to thesis or dissertation stage in a program, one's mind

is hopefully not a blank slate; I am not sure how we could imagine erasing all the hard-earned information that has been stored over the years. Thus, if a priori knowledge does produce bias, then valid qualitative research is an unrealistic state and an unattainable goal..... In research the best use of blindness is in group assignments for experimental design" (p. 3-4).

Thus, having a priori knowledge allows the researcher, as a data collection instrument, to hear and understand the interview encounter and the participant's word with more insight and sensitivity than one who is totally outside the situation.

Gathering data using different approaches assists in ensuring trustworthiness as well as diminishing the distortion of the data that can occur with the interview process (Erlandson, Harris, Skipper & Allen, 1993; Glaser & Strauss, 1987). This is particularly true as interviews involve interaction and cooperation. A skilled interviewer is an intuitive listener, knowing when to use silence, to probe further or to bring closure to the subject (Keffer, 1990). Qualitative research also generates large quantities of interview data which may be difficult for the interviewer to manipulate (Marshall & Rossman, 1989). Using interviews alone can create distortions in the data as interviewers can interject personal biases (Marshall & Rossman, 1989, P. 83). Therefore, given the previous experiences of this researcher it was decided that the participants would be actively involved in validating the final theory in an effort to "filter" any biases that may be inadvertently interjected and to increase the trustworthiness of the data.

## Data Collection

### Type of Data Collected

Two methods of data collection were used during the interviews: audio-taping of the interviews and field notes before, during and after the interview. The audiotapes captured the words and feelings of the participant during the interview process. Using the interview guide as a springboard for inquiry, many participants guided their own paths of discussion. The interview questions provided the back drop for many rich personal experiences that contained topics that many participants said they hadn't thought about in years. The audiotapes also allowed the researcher an opportunity to transcribe verbatim the words and expressions shared. Although several participants elected to turn the recorder off, the field notes supplemented the verbal data collection.

Field notes were also taken before, during and after the interview. The researcher followed Merriam's (1988) checklist of elements to record during an observation which included:

1. The setting: What is the physical environment like? What is the context?  
What kinds of behavior does the setting promote or prevent?
2. The participants: Describe who is in the scene, how many people, and their roles. What brings these people together? Who is allowed here?
3. Activities and interactions: What is going on? Is there a definable sequence of activities? How do the people interact with the activity and with one another?  
How are the people and the activity connected or interrelated?
4. Frequency and duration: When did the situation begin? How long does it

last? Is it a recurring type of situation or is it unique?

5. Subtle factors: Less obvious but perhaps as important to the observation are:

- \*informal and unplanned activities
  - \*symbolic and connotative meanings of words
  - \*nonverbal communication such as dress and physical space
  - \*unobtrusive measures such as physical clues
  - \*what does not happen - especially if it ought to have happened
- (Erlandson, Harris, Skipper and Allen, 1993, p. 96).

Prior to entering the participant's house, or in one instance the office building, the researcher took notes regarding the outside environment area - an abbreviated windshield survey of the neighborhood. Notes were also taken during the interview using the criteria above. Very few interviews were completed with only the researcher and the participant physically in the room. Typically, other curious family members, either invited or otherwise, sat in and/or participated in the conversation. Many times, family members interrupted the interview with information they felt was important but the participant forgot to mention. The field notes proved to be invaluable during these interactions because there tended to be incongruencies between the participant's and family member's opinions. The field notes also assisted in corroborating the role of the family in obtaining screening for the older adults as described in the literature review.

Field notes were also taken directly after the interview, usually in the

researcher's automobile. In many instances, a large portion of the data from the interview came after turning the tape recorder off. The researcher's inquiries about family photos, hobbies, etc. seemed to trigger many memories not elicited by the previous interview. In a particular interview that lasted approximately one hour, another thirty minutes was spent en route to the researcher's car in the driveway (parked fifteen feet from the front apartment door) talking about how the participant's chronic illness had effected his entire outlook on life. Cancer was the least of the participant's concerns so he did not bother following up on his screening results. His chronic respiratory illness stifled what was once an active, productive career. He felt that if anything was going to kill him it would be his respiratory ailment, not cancer. All the information he had given the researcher post-interview had direct implications for the information he had previously conveyed. After the researcher left the apartment, she sat in another area of the apartment complex and wrote down the conversation before going home.

#### Data Collection Method

The grounded theory method requires that the researcher simultaneously collect, code and analyze the data from the commencement of the study i.e., the first interview. Therefore writing the data collection method and data analysis sections of a research report can be awkward as one needs to quite literally perform two tasks at once: describe how the data was collected and explain the analysis of findings. To facilitate the reader's understanding of this section, the actual data collection method will be described and the process used for the coding and categorizing. The next

section will discuss the constant comparative technique in detail and present the theory of cancer screening behaviors in older adults.

Interviews were scheduled with each of the participants who met the inclusion criteria. All but one interview was conducted in the participant's home. One interview was conducted during a participant's lunch hour at his work site office because of the convenience of location to the researcher and the participant. Taylor and Bogdan (1984, pp. 87-88) suggest that five issues should be addressed at the beginning of each interview:

1. the investigator's motives and intentions and the inquiry's purpose
2. the protection of the respondents through the use of pseudonyms
3. who has final say over the study's content
4. payment (if any)
5. the logistics of time and place and the number of interviews to be scheduled.

After the appropriate introductions, the above areas were discussed with each participant. All mechanisms of confidentiality and explanation of the rights of the participant were also reviewed. The participant was reminded that the session would be tape recorded and that the researcher would be taking hand written notes (memos) while conversing. The participants were also told that they were able to turn off the tape recorder at any time during the interview. The participant was then asked if they had any questions before the consent form was signed. Many of the participants asked for a copy of the consent forms and these were mailed to them with the



transcript of the interview. The informed consent was then signed.

Before the actual interview started, pleasantries and icebreakers were incorporated to give the participant time to warm up and to become comfortable with the researcher. The researcher felt this was particularly important for two reasons. The interviews needed to be tape recorded, and while casual conversation was occurring the tape recorder was placed by the participant. In essence, they had an opportunity to warm up to the researcher as well as the equipment that was being used. This technique seemed to facilitate more spontaneous questioning than turning on the tape recorder just prior to the interview and placing it by the participant.

Secondly, many qualitative research experts discuss the role of conducting participant observation before the interview, at a time separate from the actual interview, to observe the participant in as natural a setting as possible (Chenitz & Swanson, 1986; Erlandson, Harris, Skipper & Allen, 1993; Morse, 1994). This was not possible in this study due to time constraints of both the participants and the researcher. Therefore, casual conversation allowed the researcher to be introduced to other family members, including pets, to discuss hobbies, take a stroll of the participant's home, etc. Hence, allowing somewhat of a natural, unbiased view of the participant in their surroundings. Lincoln and Guba (1985) suggest that these types of questions "give the respondent practice in talking to the interviewer in a relaxed atmosphere while at the same time providing valuable information about how the respondent construes the general characteristics of the context" (p. 270).

Before describing the actual formal interviews, it is important to become familiar

with basic guidelines that were used to conduct the interviews. As suggested by Swanson (1986) the following parameters were used during the interview.

1. A minimum of 50 minutes to one hour was allotted for each interview.
2. The participant was assured that there were no right or wrong answers to the questions.
3. Social talk opened the interview. The first question from the interview guide was then asked.
4. When all questions on the interview guide had been addressed, the demographic and background data was obtained.
5. Before closing the interview, the participant was asked if he or she had any further questions they would like to ask of the researcher.

All participants were interviewed using a formal, unstructured interview guide (Appendix D). According to Chenitz and Swanson (1986), the formal unstructured interview is most commonly used to collect qualitative data using the grounded theory approach. The interview guide contained a set of brief questions centered on a major theme. The guide provided structure early in the interview. However, the researcher was careful to follow the participant's major concerns or viewpoints as suggested by Swanson (1986). Swanson (1986) also suggested that the initial question asked of the participant should be centered on the major theme of the interview. In this case, the first question of the interview guide asked the participant to describe what cancer meant to them.

The funnel/inverted funnel approach was chosen to facilitate the interview process. Described by Gordon (1975), the interviewer starts with a general question

and follows with more specific questions. This approach is used when the interviewer wants to elicit unanticipated responses, when the respondent is willing to describe detailed descriptions of the event, and when the interviewer wants to avoid imposing their frame of reference on the respondent (Swanson, 1986).

The first eleven interviews were conducted over a three week period of time. The final four interviews were all conducted on the same day approximately two months after the initial eleven interviews. The interviews lasted in length from forty-five minutes to two hours with the average length of time being sixty-five minutes. All interviews were tape recorded for the entire encounter except two. One participant was very eager to "tell my story. I've just got so much you really need to know" and began talking very quickly after just a brief introduction. She requested to turn the tape recorder off "for awhile" during which time she conveyed very personal information about the reasons she went to the cancer screening and fears that she had contracted a communicable disease from her husband. After finishing that portion of the interview, she took control of the tape recorder and turned it on and off as she felt she could. Another participant also reached a point in the interview process where she shared some intimate information about her marriage and her fear of having breast cancer. She was concerned about the impact that cancer would have on her sexuality and her appeal to her spouse. Within a few moments after she began discussing this, she slowly reached over and turned off the recorder. She talked further for about fifteen minutes, allowing the researcher to take notes, but requesting that direct quotes from that portion of the conversation not be used.

These conversations and the feelings that these participants conveyed were very important in validating concepts within the theoretical model. Qualitative research dictates that the researcher allows the participant to describe their own reality using their own methods. For these two women, it necessitated turning off the tape recorder and allowing the researcher to take copious field notes while they shared intimate moments from their lives. Although unable to cite direct quotes in the justification of the model, the audit trail allowed the researcher to paraphrase these conversations.

Memoing, coding and categorizing were completed in between all but the last four interviews by listening to the tapes several times, without the benefit of having the transcription to read. For example, the first interview was completed and its subsequent audiotape was coded, the next interview was completed and its audiotape was analyzed, and so on. The last four interviews were completed all on the same day within an eight hour time frame. Thus, no time was allowed for analysis in between interviews. This technique allowed the researcher to begin discovery of the basic psychologic processes and their related properties relevant to the phenomena.

All interviews were transcribed by the researcher. The subjects were identified on the transcriptions by number and initials only. Transcriptions of the first eleven interviews were done one month after the data collection was completed. The transcriptions of the last four interviews was accomplished approximately one week after the interviews. After all the transcriptions were completed, the researcher then read all the interviews several times for the purpose of transcription checking and additional coding. Suggested by Keffer (1990), the readings were done in the following order for the corresponding purpose.

Purpose

Reading one	Transcribed the interview.
Reading two	Checked the transcription for error and coded feelings revealed by voice intonations.
Reading three	Read the interview for overall content and underlined key phrases.
Reading four	Read all the interviews for key words. Concentrated primarily on the meaning of the words conveyed.
Reading five	Read all the interviews for the theoretical codes.
Reading six	Final reading after theory was developed to "test" the structure and relationships.

Using constant comparative analysis dictates that each interview is coded after completion then compared to those previously formulated in prior interviews.

Listening to the tapes without a transcription assisted the researcher in several ways. The analysis allowed the researcher to initially concentrate on feelings and the subtlety of context brought forth during the interviews and then compare those with the memoing that occurred during the interview. This was important as there was a great deal of information that was given after the tape recorder was turned off in many instances. Secondly, it allowed the researcher to listen critically to her interviewing skills, paying careful attention to intonations of voice and pronunciation. Often older adults will offer "cocktail" or social talk if they are hearing impaired as a adaptive measure in social situations. In one instance, the researcher found that the participant seemed to be answering the initial questions about the consent form in an

inappropriate manner. It was soon discovered that both hearing aids were left in the dining room. The participant "was just too lazy to get up to get them" and did not tell the researcher until the interview started "because you (the researcher) was speaking clearly enough and sitting near enough that I could tell out the lip reading." Many older adults compensate for hearing losses through lip reading and the researcher wanted to evaluate her voice and language carefully on the tape recordings.

Rereading the transcriptions for different purposes assisted in further delineation of codes, categories and themes. It allowed the researcher to "see" the theory building process which became clearer with every reading of the transcript. The audit trail provided further "imaging" of the theory building process. Corbin (1986) describes this diagramming process of memos as visualization of the theory process which allows the researcher to quite literally go back to the roots of the categories and theoretical concepts to begin development of hypotheses.

## CHAPTER IV

### DATA ANALYSIS AND PRESENTATION OF THEORY OF CANCER SCREENING BEHAVIORS IN OLDER ADULTS

#### Introduction

This chapter is divided into two distinct sections. The first discusses the descriptive analysis of the participants' demographic information. The second section begins with an explanation of the trustworthiness of the findings followed by discussion of the technique of comparative analysis as used in grounded theory. The chapter closes with the presentation of the theory of cancer screening behaviors in older adults. Finally, interview data and the literature review provided support and justification for the theory.

#### Participant Characteristics

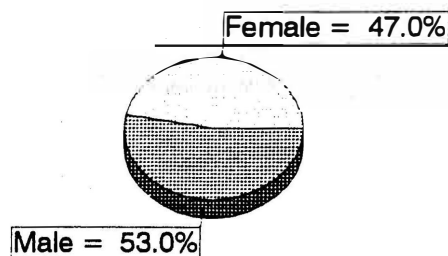
After the interview, all participants completed demographic information consisting of variables found in the review of literature to be most influential in decision processes surrounding participation in health promotion and disease prevention activities. (Appendix E). Eight men and seven women participated in the study (Figure 1). The mean and median age was 62.1 years with a range of 51 to 74 years. Fourteen of the participants were Caucasian and one participant was Black. Educational levels of the participants indicated that two achieved high school diplomas, nine had one to three years of college, three had earned college degrees and one had earned a master's degree (Figure 2). This is substantially higher than

the national average for years of school completed by persons 65+. Only 23.3% of older adults 65+ have college educations (U.S. Bureau of the Census, 1990). In this sample, 87% of the participants had college educations. All but two people had religious affiliations: three participants were Baptists, two were Presbyterian, three were Methodists, three were Catholic and one was Christian.

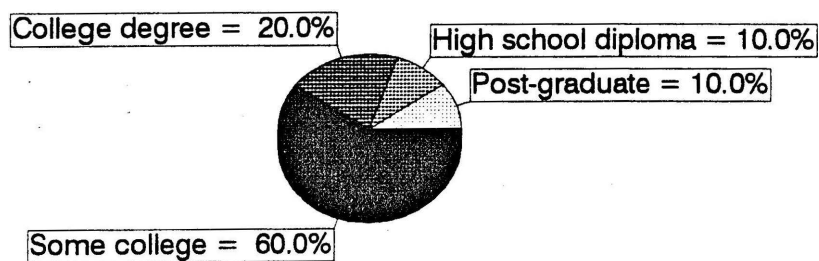
Fourteen of the participants (93%) were currently married and one was widowed. This is higher than the national norm for older adults; 77.6% of older adults are married and 13.9% are widowed with the remaining being divorced or single (U.S. Department of Commerce, 1990). Interestingly, the oldest participant in the study was a widowed, woman of color who resided with her son.

Employment status was difficult to compare to national norms as the median and mean age of the participants was 62 as opposed to 65 years of age. Nationally only 11.2% of older adults 65+ are employed, 0.3 % are unemployed and 88.5% are not considered in the work force (U.S. Department of Commerce, 1990). The majority of participants in this study were employed outside of the home; seven full-time and one part-time. One of the participant's who worked full-time also had a part-time job. Four of the participants volunteered outside the home an average of 25 hours per week (Figure 3).

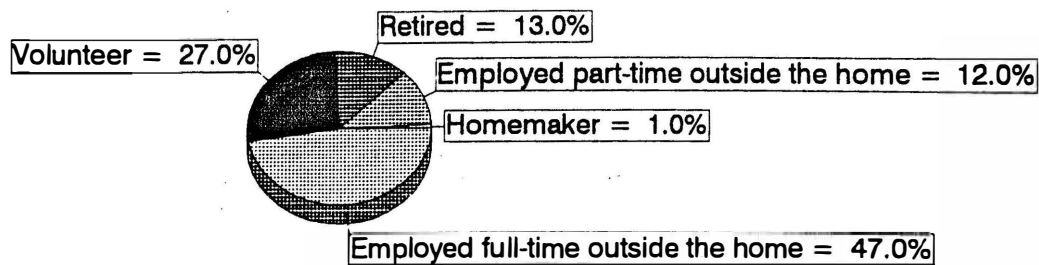




**Figure 1.** Gender of study participants nursing care or home health care



**Figure 2.** Level of education



**Figure 3.** Employment status

Family income data may be skewed due to falsification of income by the participants. This was obviously a very uncomfortable matter to many participants and several admitted to giving the researcher inaccurate information. The median income range for participants was \$40,000 - \$55,000. This was almost twice the national average and may be due to the extended education of most of the participants. In 1988, the national median net worth of older households was \$60,300, which is nearly twice the national average of \$32,700 while the annual median income was \$22,586 for white households and \$13,541 for black households (U.S. Department of Commerce, 1990). No participants were lower than poverty level, one participant refused to answer the question, and one stated their income was "other." The participant who refused to answer the question and the other person that described their income as "other" resided in comfortable, well-decorated houses in upper-middle class neighborhoods.

The majority of the participants (80%) owned their home while the remainder rented an apartment. The average number of people living in the household was two with a range from one to four. Only 13% of the participants had a person in the household that required home health care: in one instance the person requiring care was a grown son and in the other circumstance it was a spouse (Figure 4).

Previous review of literature cited in the beginning of this chapter supported the responses to the Health Care Questions (Appendix E). Eighty percent of the participants had primary health care providers. One person had never had a complete physical examination, two had their last examination in the early 1960s, two in the mid

70s, one in the late 80s, three in 1993 and four in 1994.

Surprisingly, none of the participants rated their health as poor (Figure 5) despite that 67% felt they had health problems that directly related to aging and that 67% felt that these health problems could not be resolved. Eleven of the participants related that they had control over their health status. Only two of the participants had a personal history of cancer while eight had a family history of cancer. Within the eight individuals that had a family history of cancer, 75% had multiple first degree relatives who had cancer at some point in their lives. Finally, only one of the fifteen participants had ever received an examination from a nurse practitioner.

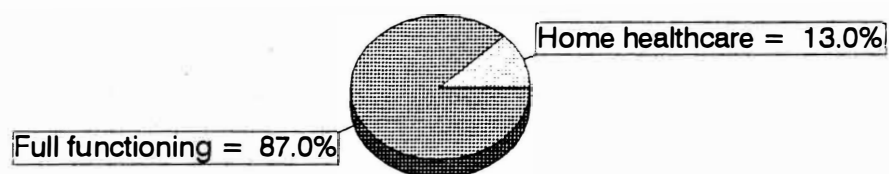


Figure 4. Persons in household requiring home health care

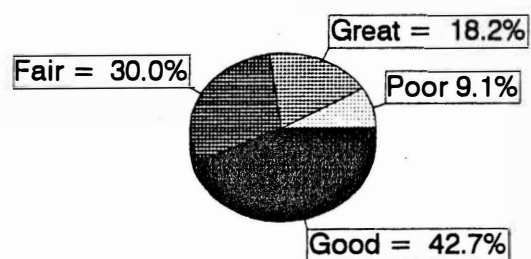


Figure 5. Older adults rating personal health

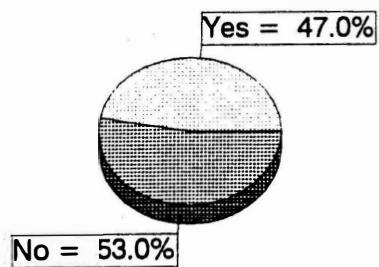


Figure 6. Immediate family members with history of cancer

### Building Trustworthiness of the Data

If intellectual inquiry is to have an impact on human knowledge, either by adding to the overall body of knowledge or by solving a particular problem, it must guarantee some measure of credibility about what it has inquired, must communicate in a manner that will enable application by its intended audience, and must enable its audience to check on its findings and the inquiry process by which the findings were obtained (Erlandson, Harris, Skipper & Allen, 1994, p. 28).

Lincoln and Guba (1985) refer to these combined qualities as trustworthiness of the data. This research study used a combination of writings from Lincoln and Guba (1985) and Erlandson, Harris, Skipper and Allen (1994) to provide evidence for what quantitative research would associate with reliability and validity.

Lincoln and Guba (1985) purport four constructs of trustworthiness: credibility, transferability, dependability and confirmability. Credibility is a term often used interchangeably with "internal validity" and "truth value" and examines the compatibility of the constructed realities of the participants with those attributed to them (Keffer, 1990). Lincoln and Guba suggest several strategies to increase the likelihood of credible findings: prolonged engagement, triangulation, peer debriefing and member checks.

Prolonged engagement is essential to enable the researcher to spend enough time in the context being studied to overcome the distortions that are due to his or her impact on the context, his own biases and the effect of seasonal or unusual events. The researcher spent five years providing cancer screening examinations to older

adults in a variety of clinical settings and across a diverse cultures. The researcher also developed a cancer education curriculum specific to older adults regarding cancer prevention and detection. Hence, a clinically rich background provided numerous experiences from many walks of life; thereby reducing the bias and tunnel vision affect that could occur.

Peer debriefing occurred on several occasions with the certified family nurse practitioner (FNP) for the mobile cancer screening examination, with a colleague specializing in oncology nursing and a colleague who is a FNP in private practice. This process proved to be invaluable as the sessions would bring to the forefront rethinking of the theoretical codes and revisiting the model. The peer debriefers did not recode interviews but instead verbally listened to the "audit trail" compiled by the researcher and offered critical suggestions at key points in the analysis.

Member checks also proved invaluable. One third of the total number of the participants (five) provided feedback on the completed theoretical model. All participants received copies of their personal transcript. The researcher randomly chose five of the participants to also evaluate the model. Each individual received a written description of the model with its corresponding visual representation. A letter accompanied this material stating that the model represented the data analysis of all the interviews completed for the research project, which included their personal contribution. The participant read the description and responded to several questions: 1) Do you think this is an accurate representation of the circumstances surrounding the cancer screening examination? 2) What would you like to change in the model and how? and 3) Should anything be added, deleted or expanded upon in

the model? The participant then received a telephone call from the researcher to discuss their responses to the questions.

The visual representation of the theory (Appendix F) sent to the participants was pictorially more concrete than normally expected in scholarly work. This was done to enhance the understanding of the model, particularly for those individuals that may not be accustomed to abstract thinking. Using common symbols for many of the concepts easily conveyed the overall meaning of the theory and promoted communication for its critique in language that was familiar to both the participant and the researcher.

Two changes in the model occurred after talking with the participants. The first was the representation of "cancer framing." Four out of the five participants suggested "cancer framing" should be given its own "circle" so as not to dilute its importance in the cancer screening experience. Secondly, the majority (three) of the participants suggested that an arrow be drawn back to the "lived experiences" as they indicated they would go back for further cancer screening even if the original health concern was not medically re-evaluated. The next section of the paper contains these descriptions in further detail.

The second construct purported by Lincoln and Guba (1985) is transferability in that inquiry is judged in terms of the extent to which its findings can be applied in other contexts or with other respondents (p. 290). Transferability in a naturalistic setting depends on similarities between sending and receiving contexts; the researcher must provide detailed "thick" descriptions of the data which brings the

reader vicariously into the context being described (Erlandson et al., 1994). Secondly, Lincoln and Guba recommend purposive sampling to enable the data gathering to become as rich as possible regarding the context/event. This researcher provided a detailed written description about the theory to the actual study participants using terms understandable enough for their critique. The description was also given to a peer reviewer enabling her to describe the theory in appropriate detail.

Accomplishment of purposive sampling occurred particularly toward the end of the study. The researcher felt that age of the subject contributed a specific insight in to the cancer screening event and the youngest and oldest participant were then sought.

Dependability and confirmability are the last of Lincoln and Guba's constructs of trustworthiness. Sufficient evidence provides answers to the question "If the study were replicated with the same or similar respondents in the same or similar context, would its findings be repeated?" (Lincoln & Guba, 1985). Using an audit trail facilitates this process. The researcher kept a running account of the research process that included notes about each interview, memos regarding coding procedures, notes regarding the data collection process and copious notes regarding the data analysis process through the writing of the findings. Throughout this "trail" the researcher assigned all participants a number and the only entry containing their initials were on the researcher's copy of the transcript. This was done to ensure confidentiality of the participant.

#### Explanation of Constant Comparative Analysis

The grounded theory method requires that the researcher simultaneously



collect, code and analyze the data from the commencement of the study i.e., the first interview. All interviews were analyzed using the constant comparative technique associated with using the grounded theory method. Recommended by Glaser (1978, 1992) these techniques include open coding, writing and sorting memos, questioning, comparing data and discovering patterns. The constant comparative analysis technique is a circular method that allows the researcher to change focus and pursue leads revealed by the ongoing data analysis (Hutchinson, 1986).

"The aim of the method is the generation of theoretical constructs that, along with substantive codes and categories and their properties, form a theory that encompasses as much behavioral variation as possible"

(Hutchinson, 1986, p. 122).

Concept formation, concept development and concept modification and integration occur sequentially and simultaneously. Glaser and Strauss (1967) purport that comparative analysis emphasizes theory as a process and an ever developing entity. The technique demands sequential formulation, testing and redevelopment of the propositions until a theory emerges that demonstrates integrated and consistent use of the data. The theory must allow for operationalization for testing in quantitative research.

The first step of the constant comparative analysis is concept formation (Stern, 1985). Hutchinson describes this as "level one" coding in which words that describe the action in the setting are coded. These codes are the in vivo or substantive codes stated in words actually used by the participants. "Substantive coding based only on

the data prevents the researcher from the imposition of preconceived impressions" (Hutchinson, 1986, p. 120).

The second step in the analysis is concept development. The level one data are then compared with each other. Through comparisons, categories begin to emerge. Hutchinson (1986) names the categories "level two codes." Some level one codes may be discarded while subsuming others. Connections among the codes are examined for related elements and then subsequently joined (Stern, 1985). During concept development a core variable emerges.

The third step in analysis is concept modification and integration. A combination of academic and theoretical knowledge derives the theoretical construct, or level three codes (Hutchinson, 1986). Theoretical constructs conceptualize the relationships between the three levels of codes "weaving the fractured data back together again" (Glaser, 1978, p. 116). The researcher should continue with concept modification and integration until saturation of the data occurs. Saturation refers to the completeness of all levels of codes when no new conceptual information is available to indicate new codes or expansion of existing ones (Hutchinson, 1986, p. 125). When saturation occurs, the data fit into the established categories and patterns among the interactions are visible. This allows description of behavioral variations and behavioral predications (Glaser & Strauss, 1967; Hutchinson, 1986). It is the complex pattern of constructs which comprise the grounded theory; during this component of data analysis, the researcher describes the conceptual framework. A review of literature then substantiates the emergent theory.

To generate a quality theory, accurate descriptions of the events must be elevated to a theoretical level (Glaser & Strauss, 1967; Hutchinson, 1986, Stern, 1985). Two vital processes to this endeavor are memoing and coding. Quickly and spontaneously performing memoing allows the researcher to record their initial ideas regarding the connections between the data. According to Hutchinson (1986), memos may be long or short and are written without regard to style or punctuation; the emphasis is on conceptualization of ideas. In essence, memoing is a documentation of the thinking process.

Theoretical coding is a technique used during concept modification and integration to further clarify concepts. Glaser (1978, pp. 74-82) states that posing six questions (the six C's) about the data will assist in concept clarification: causes, contexts, contingencies, consequences, covariances, and conditions. Hutchinson (1986) states that questions assessing strategies, dimensions, phases, ranges, and boundaries of the emerging data are also important and provide a structured way to analyze data.

The principle purpose of coding is to discover the basic physiologic processes and their related properties. Hutchinson (1986) suggests four questions to ask of the data to force the researcher to transcend the empirical nature of the data and to think in theoretical terms (p. 122):

1. What is going on in the data?
2. What are these data a study of?
3. What are the basic social and psychological problems with which these people must deal?

4. What basic social and psychological processes help them cope with the problem.

The researcher primarily used Hutchinson's method with clarification from Glaser and Strauss (1986) as needed to facilitate the bridge from empirical coding to theoretical formulation.

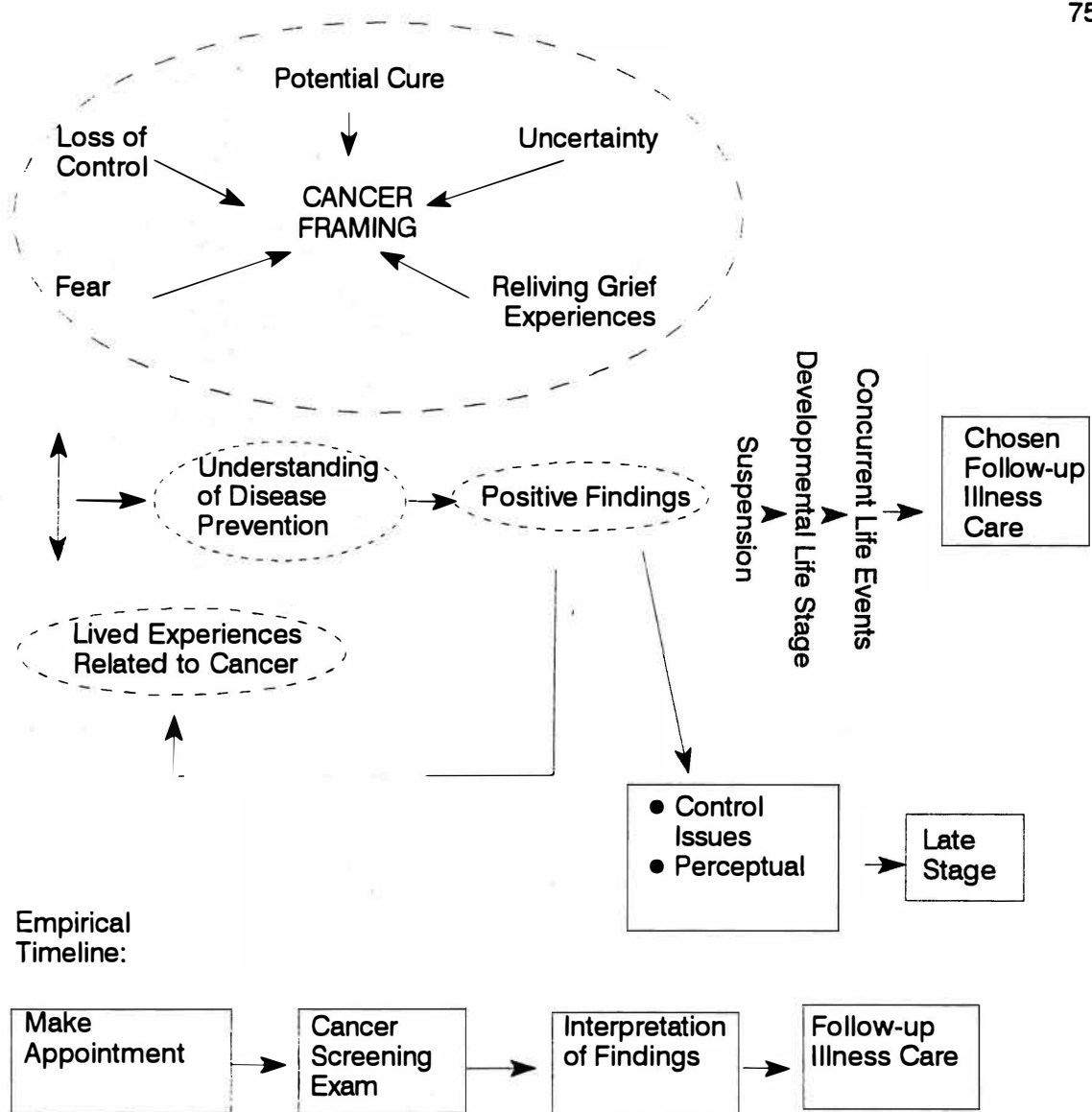
#### Theory of Cancer Screening Behaviors in Older Adults

Qualitative data analysis is a search for general statements about relationships among categories of data; it builds grounded theory (Marshall & Rossman, 1989, p. 112). A theory is an internally consistent group of relational statements i.e., concepts, definitions and propositions, that presents a systematic view about phenomenon (Walker & Avant, 1988) and that is useful in this study for description and explanation. Open codes developed through participant interviews and audiotape transcriptions. Memoing during the interview process substantiated and clarified the codes. The researcher then generated a code list (Appendix G ) with subsequent revision and retesting during each interview. Using the constant comparison analysis technique described previously, the theory of cancer screening behaviors in older adults developed.

#### Formation of the Theory of Cancer Screening Behaviors in Older Adults

The purpose of grounded theory is the systematic generation of theory inductively drawn from raw data (Glaser & Strauss, 1967). Therefore, discussion of the theory of cancer screening behaviors in older adults comprises: 1) defining terms used in the model; 2) describing the concepts, propositions and statements in the

theory; and 3) presenting justification for the model as described in the words of the study participants. The theory is presented initially through citing the interview data derived from the participants and the review of literature provides secondary support. The literature review facilitates understanding and provides additional justification for the concepts and relationships contained within the theory. Figure 7 presents the pictorial conceptualization of the theory.



**Figure 7:** Cancer screening behaviors in older adults

### Statement of the Theory

Cancer screening behaviors in older adults comprises of a complex set of interactive events. Past life events and the individual's coping response to them influence the entire milieu of cancer screening for the older adult. The older adult's resolution of grief responses, past and present experiences with cancer and their understanding of cancer directly influences their perceptions and expectations of the cancer screening examination. Appropriate interpretation of positive findings is dependent upon the culmination of the individual's understanding of the purpose of cancer screening and their past and present experiences with cancer.

The older adult must overcome several barriers before they can actively obtain follow-up care. The first is suspension, or the inability to make a decision based upon numerous psychosocial and economic factors. The second barrier is congruency in the developmental life cycle to actual biological age. The third barrier is concurrent life events. These barriers can present overwhelming obstacles particularly if the positive finding does not present any functional disability and/or interfere with activities of daily living. For the older adult with limited resources, the decision making process is brief. Care is not sought because there are few stable resources that can be accounted for and/or depended upon. Overcoming these obstacles allows the older adult to obtain chosen follow-up illness care. Often, the individual will again seek early preventive care.

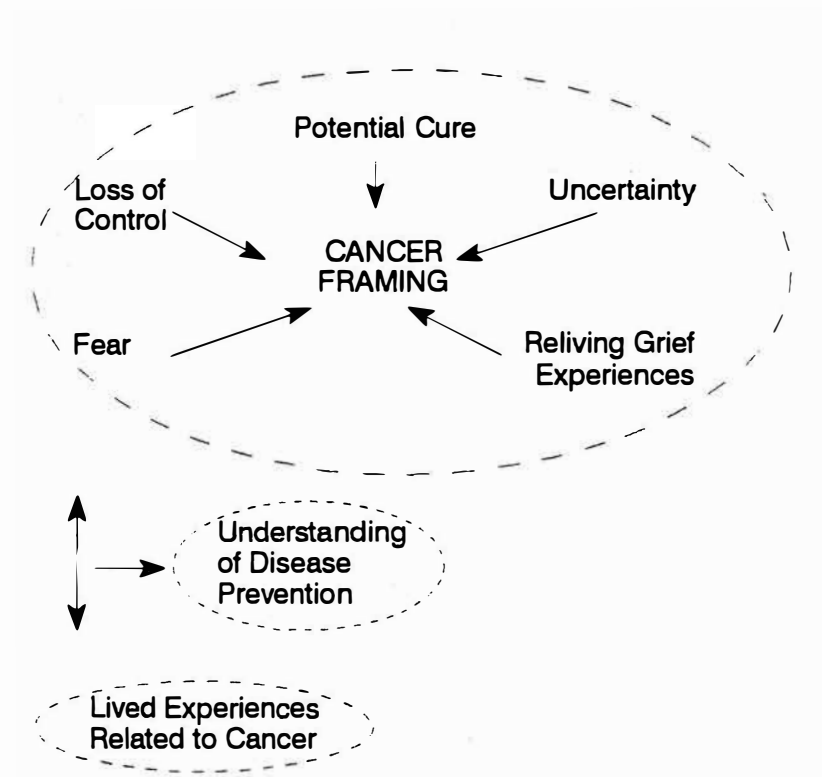
Older adults who do not actively decide to seek further recommended care may be eventually overwhelmed by an accumulation of economic, physical and

psychological life events. These adults may enter the health care system, only at a much later phase in the disease process and incur greatly increased costs emotionally, physically and economically. These individuals do not seek further early cancer prevention and detection services.

### Components of the Theory

Cancer framing is the first major concept and is defined as a set of referents/variables that the individual brings into the decision making process that influences the conscious decision to make the cancer screening examination appointment (Figure 8). These referents are also used as the basis for understanding and interpreting the meaning of the cancer screening examination and disease prevention. They evoke strong, vivid feelings and include five distinct yet overlapping variables: fear, loss of control, potential cure, uncertainty, and reliving of grief experiences. Participants offered these responses when asked "What does cancer mean to you?" and "What were your thoughts and feelings when you made the screening examination appointment; what did you expect?"





**Figure 8.** Cancer framing: Decision referents for older adults

Many participants conveyed uncertainty, fear, and loss of control even if they expressed the hope for cure. Three participants emphatically stated that cancer meant "pain, suffering and death" (P #s 8, 10, & 15) and then continued their thoughts by discussing that there was hope for a cure. However, once "labeled by the disease the mind was never able to go back to a relaxed state of being" (P #8).

"Postponement of death, the inevitable. I don't think there is ever really a cure, just postponement. I guess a few people become "cured" but it seems like you've always got to be extremely vigilant after that. It's not like other diseases where you catch them. Cancer seems to be something that is always there and all that can be done is to make it go dormant" (P#15).

Another participant responded similarly stating:

"Cancer is to me, I still think of it as impure. It think of it as something that you can delay the inevitable but eventually you will succumb to it..... So I think of cancer as something that is very scary. Something that is not selective" (P #1).

This participant went on to describe "not selective" as:

"Well, no matter how healthy you might feel it's something that attacks anyone without discrimination. In other words... I don't necessarily have to have a history of bad health in order for cancer to hit me like it could hit anyone. I no longer felt immune and I felt it could hit me like it could hit anyone."

At the end of the interview, when the recorder was turned off, this participant described several instances where family members had been cured of cancer only to

have a new primary site develop after ten years. He described the emotional blow as devastating and that the lack of control over one's destiny was probably worse than having to battle the cancers. He also noted that the loss of control was a critical issue for him as he grew older. He stated that losses that "old people have can't be made up like when you are young. There isn't enough energy, time and money that will fix some of these things. Sometimes it's pretty hard to get used to all the taking and not seeing the cup filled back up."

Participants described loss of control through stories about developing cancer with a pre-existing chronic disease. All but two of the participants had pre-existing health conditions that involved regular, periodic and occasionally expensive visits to multiple physicians. They collectively voiced the fear that another disease, as one participant stated: "would throw me over the edge physically, financially and emotionally. I just simply couldn't tolerate any more stress. I've lost enough already and I'm not willing to give up anymore. The sicker you get, the more of yourself you lose. Seems like you're at the beck and call of others, particularly the docs." (P #1 from notes following the interview).

Fear and uncertainty were underlying variables surrounding the conceptualization of the screening examination by the participants. The researcher's personal experience with screening older adults provided an interesting perspective into this portion of the interview. Many individuals would enter the screening exam expecting to leave the mobile van with the diagnosis of cancer even though they were asymptomatic and feeling well. Many clients were actually surprised when they

received normal examination findings. Further informal questioning of these same clients revealed that because they were receiving a cancer screening examination they believed they would probably have cancer found before leaving i.e., one could literally "catch" cancer on the screening van. This was just one of many misconceptions that the researcher found.

Participants in this study confirmed many of the researcher's previous informal findings. The fatalistic connotations regarding cancer were particularly evident.

"It's (cancer screening examination) kind of scary because it is the fear of the unknown. I didn't go to my doctor ... they had the mobile van in ( location is deleted for confidentiality purposes) and I just walked in and made an appointment. It's always the fear of the unknown. Are they going to find something or are they not going to find something? You know, then if it is cancer , what then?" (P #2).

Another participant shared:

"Cancer is a scary word. You know, maybe you are more immuned to it than the lay person because you are involved. The profession has a public relations problem. When you say cancer screening no one comes. When you say health screening everyone comes. "He goes on to say, "Believe me, it's anxiety. It's anxiety. The hardest part is waiting for my turn to come. It really is" (P #9).

Even though his relative cancer risk was low, this participant literally believed he would die of cancer in his lifetime due to a significant family history of untimely deaths due to heart disease and cancer. He noted that he went for cancer screenings to get

prepared for the inevitable as there was a person in his home that required home health care and he was responsible for coordinating her care.

Several other participants expressed that they were tense, afraid and uncertain of what would occur. They attributed this to media hype about the incidence of cancer, particularly breast and skin cancers, their personal beliefs about the meaning of cancer, past experiences with people diagnosed with cancer and the uncertainty about how long examination results would take. Several of the women participants felt that breast cancer was inevitable and cited the infamous "one out of every ten women will get breast cancer in their lifetime." "It's just a matter of time. I just don't know when it's going to hit. We don't have any control over this, you know" (P #4).

Reliving grief experiences was another variable in the cancer frame concept. Information about this variable was expressed primarily after the interviews were over and the participant had time to review their thoughts and ask questions of the researcher. This variable was described in relationship to the others previously mentioned but in the context of grief as it relates to older adulthood. As noted below, eight of the participants shared grief experiences with the researcher as their way of explaining some concepts. It seemed that after the interview, they began to place the grief experience into a different context, a sort of revelation in their psyche. One participant was quiet at the end of the interview. When asked if he had any other thoughts to share he related that he had just realized that he had not really thought about how his friend's death had affected his decision to obtain a cancer screening until this interview. He felt that it wasn't the cancer so much as it was the loss of his

friend that bothered him. The process of going through the cancer screening had made him relive some uncomfortable experiences that he had actively chosen to suppress. Now that the feelings were back, he had to cope with them one more time. It was something he realized he would prefer not to have done.

Another participant who had several friends die of cancer and several others from recent cardiovascular illnesses verbalized similar feelings after the "formal" interview was over. She discussed her method of coping with their deaths. She felt she grieved at the time of the funeral and maintained happy memories but did not dwell on the death experience. She decided that making the cancer screening appointment made her think about many issues regarding her own mortality and also those surrounding her friends' deaths. It was distressing and she worried about her mental stability because it emotionally upset her. She thought the grief process had been completed. She commented that "older people have to get over death because it gets to be a frequent happening as you get up in years."

Other participants described vague feelings of uneasy that they attributed to thinking about their own mortality through reliving grief experiences of significant others' deaths. The recollections seemed to trigger further introspection about priorities of life, the purpose of career goals and other issues that involved family members.

Eight of the participants shared very personal experiences about loved ones, usually family members, who had either died of cancer or were cancer survivors. This was the participants' way of conveying what cancer meant to them. The responses

from this portion of the interview justified distinguishing "lived experiences related to cancer" apart from the cancer framing concept.

Lived experiences related to cancer is the second major concept and is defined as investing emotionally, financially, physically or socially with a significant other who had/has a cancer diagnosis or having a personal diagnosis of cancer before the cancer screening exam. These participants had a positive outlook on cancer and cancer treatment until a significant other underwent cancer treatment. At that point, the potential for cure was obscured, hope was distant and the emotional pain of watching someone die was at times unbearable. Originally this concept was included under the broad concept of cancer framing as part of the "reliving the grief experience" variable. However, when the participants validated the four out of five of the individuals felt it deserved it's own "circle." Their concern was that the concept appeared diluted with the other five referents in the cancer frame. Although difficult to articulate, they felt that those experiences with cancer had colored their entire interpretation of cancer prevention and cancer screening. Many expressed thoughts that cancer screening was useful but were more guarded in its assessment of actually prolonging life or providing additional lead time for a cure.

This was often a sad time in many interviews. It was obviously difficult to express feelings about such a broad topic and many participants would stop for a few moments and then begin by telling their story of cancer with a loved one. Several times the interviews were interrupted because the stories brought back memories that were painful and sad, leading to several tearful moments for the participants. One

participant shared a situation in which several family members then a friend were all diagnosed with cancer:

"Cancer is frightening. I've had some real close friends that had devastating problems with it. I've had a cousin and an uncle both die of colon cancer. The cousin was in his 30s... he only lived about a year. With my uncle he had a colostomy and he lived five or six years but it eventually got all over him. But I had a friend, a real close friend that was just devastated. It's frightening.

didn't feel like that in the past but I have seen so many situations..." (P # 5).

Another participant stated "Cancer, it means disease, suffering, death. I had a good business associate. Yes. He had bone cancer and it was within the last three years. Cancer screening is good, we all need to get checked, but does it really help. I just don't know" (P #10). This participant went on to discuss how he felt cancer was a death sentence particularly after watching a good friend suffer from the disease. The death had negatively influenced his viewpoint on curing cancer and cancer screening.

One of the oldest participants had mixed reactions when discussing cure versus comfort for cancer. She felt she was very positive about cancer therapy despite having lost several friends and relatives to cancer.

"At one time it (cancer) was like a death sentence. But now, well, things have improved and they are doing everything they can for cancer patients to make them comfortable. I had a mother that had skin cancer. She was diagnosed and it was malignant. She went and had treatment and got a clean bill of health in five years which made it very nice. I had a close friend that had breast ..



cancer and she had one of her breasts removed. She took chemotherapy. This was something they were just testing out. And it got to the point where she started feeling bad and she told them and that was it. She just didn't want to go through it anymore. But when she went back to see the doctor they gave her a clean bill of health. And two years later she was diagnosed with a brain tumor..... She had a lot of radiation treatments. We did a lot of praying for her in our church and the tumor shrunk and they keep giving her a clean bill of health again. So she's a survivor" (P #2).

The participant then relates a very lengthy discussion about her sister-in-law previously diagnosed with bone cancer but because of her age she was unable to tolerate the full dose of chemotherapy and the radiation treatments. Bone marrow transplantation was also not an option because of age. She lamented the lack of pain control her sister-in-law had and the poor quality of life that she was enduring.

The third concept, interpretation of cancer screening/disease prevention, is defined as the participant's understanding of the purpose of cancer screening. The older adult's lived experiences and cancer frame blend together and directly influence the understanding, interpretation and acceptance of the cancer screening examination. Only two participants had an accurate perception of the purposes of cancer screening. Both had attended a seminar held at work during the lunch hour regarding the cancer screening program. The program discussed the purposes of early detection and prevention, self-examination techniques for common cancers and the American Cancer Society's Guidelines on cancer screening examination. Interestingly, these two

participants stated they were watching there "positive findings" carefully to ensure rapid treatment if the current symptoms changed! Obviously, health behavior models have attempted to address the above dilemma. Education does not equate into altered health behaviors or clear perceptions of risk.

The above scenario relates to findings that warrant discussion. Individuals have two mechanisms in which to make cancer screening examination appointments with the mobile cancer screening van. One is through a company sponsored health benefit by which the van travels to the corporation or business and the cancer screenings are performed on-site during the employees' work time. The other appointment route enables clients to make individual appointments for screenings held at locations around the metropolitan area. The corporate sponsored health benefit typically includes a seminar about cancer screening or other health promotion/disease prevention topics. The individual "walk-in" client does not receive the benefit of a formalized cancer screening education program prior to their screening examination. Hence, it was found during this study that the participants who signed up for individual appointments via the "walk-in" basis had a distorted idea of what the cancer screening examination would entail. On several occasions, the participants were upset and felt as if they had spent their money unwisely. They had used the screening clinic to obtain medical care even though the informed consent that they signed before the examination was done clearly stated no medical care would be rendered.

One participant had a specific complaint he wanted diagnosed and was quite verbal about not having what he felt was appropriate care.

"I had a specific complaint. There was no immediate evidence of anything serious but I was told by the nurse to go ahead and do follow-up. I would've rather had something done right there... I wanted to know. I was disappointed. I wanted to go in there and get my question resolved (P #9).

An incident occurred where the participant was using the cancer screening van for her primary health care due to her disillusionment with her current physician and lack of funds to go elsewhere. She was having a difficult time finding someone to accept her Medicare assignment and could afford the low cost cancer screening exam. She had noticed an advertisement in the paper about the cancer screening program and thought that was the "next stop for this train" (P #14). However, she was bitterly disappointed when the problem was not taken care of and eventually sought care for her problem from the emergency room at the county hospital.

P #14: "My throat kept getting sore. And I was taking antibiotics and it was still sore. I just wanted to have it checked out"

Researcher: "So you made your appointment for a second opinion?"

P #14: "It was going to be a first opinion because I saw it in the magazine and I thought this was a good idea. ...I was a little disappointed that she wanted to send me to another doctor to get my throat checked to see if I had cancer. I had to pay \$25 (for the cancer screening examination) for that. Then she was going to send me to another doctor that was going to charge me \$28. And I said, wait a minute. This sounds like someone just making money. That's how I felt. But I didn't feel comfortable running back out there because next time

they work on me it'll be \$200 and this is wasn't coming from Medicare. It was all out of my pocket. I just said forget that. ...." (P #14).

Several people had cancer screenings after going elsewhere for care.

Interactions with the health system as a whole and health care providers specifically influenced interpretation of the appropriateness of use of screening facilities. For example, several participants were asked why they chose to have a cancer screening examination performed as opposed to going to a physician for regular care, particularly since they were having symptoms. The following participant highlights many feelings and ideas that others verbalized:

"Well, in most instances I don't think they (physicians) give a thorough exam. One thing, this seemed to be a specialized exam and I had a place that was just a tiny little place by my knee that my hose irritated. It would clear then get irritated. So I went to a skin specialist and she did what she called a cookie cutter and it was just nothing. And I've got these little places that are coming up on my face that are the same thing and I think I got them in Acapulco. But she says they are like a fungus.... she acted like "oh, it's nothing" and I thought "OK, I'm glad to know it's nothing" but she didn't give me an exam or anything. She just basically looked at that one spot and that was it....she just wasn't very interested, period.... But you know the (name of hospital deleted for confidentiality) was much more thorough. I mean good grief, when she put on the rubber gloves and stuck her fingers in my mouth. But it was very good.... "

(P #5)

The vast majority of the participants (14) expressed surprise at the thoroughness of the examination. Even the participant in the scenario with the sore throat remarked about how thorough the exam was despite the fact she was obviously angry with the lack of answers she received. Common misconceptions about cancer and health screenings may keep some elderly away. However, this screening was able to change the minds of several people who were disillusioned with the medical system and hopefully open the door to further preventive care.

Discovery of positive findings was an event that elicited a variety of responses. Positive findings are defined as physical examination findings that were correlated with history taking and cancer risk assessment and felt to warrant referral. Participants explained their feelings about being told they had positive findings through a series of explanations as to why treatment had not been sought as opposed to summing up the experience in a word i.e., surprised or scared. Their responses were facilitated by asking questions four through seven on the interview guide (Appendix D). These particular questions facilitated discussion regarding the participant's thoughts and feelings when first told they had positive findings and the circumstances that prevented them from seeking further recommended health care. The concepts of suspension, developmental life stage and concurrent life events emerged from the interview data (see Figure 9).

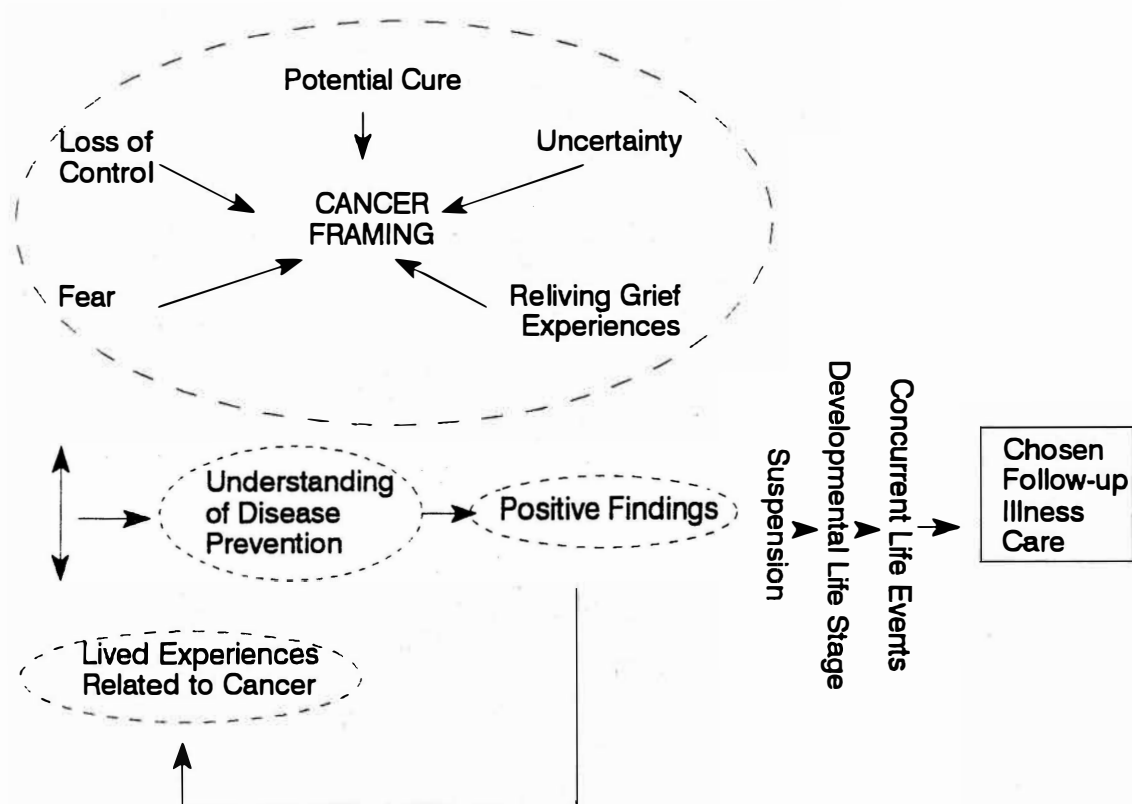


Figure 9. Cancer screening behaviors in older adults

Generally, participants were not surprised or upset about the positive findings because many of them had health concerns about the particular finding prior to the cancer screening exam i.e., they were inappropriately using the screening clinic as a source of inexpensive diagnostic care as opposed to an expensive unreimbursable physician's office visit. These participants also did not seem to feel the health concern was critical because they had personally found it and were self-monitoring its progress.

"I wasn't that worried about it because I told her it was there. I mean it's not like she found it all by herself. I had been watching it changed, but it didn't hurt or bleed so I wasn't worried. She wanted me to go to the dermatologist to have it removed but I really didn't think it was necessary until it became more bothersome" (P #2).

Participants who had not entered the screening examination with symptomatology conveyed only mild concern about the results. Two stated "that it didn't hurt, bleed, or look a awful so why bother with it. I know she's concerned but I really think it's OK" (memos taken for P #4, 6 & 9). They discussed that they were unclear as to the purpose of the screening examination and therefore, did not give credence to the examination findings. They were expecting "something really big to be wrong" despite having no symptoms when entering the examination process.

Overall, participants discussed the significance of the positive findings in what emerged as three conceptual categories: suspension, developmental life stage and concurrent life events. Suspension is the fourth major concept and is defined as the

perceived lack of decision making processes regarding the positive result of the cancer screening examination. Several participants stated that they "just couldn't decide what to do" (P #1, 6, 7, 10). However, in effect their indecision was a decision not to seek further care. They were literally suspended in time trying to come to terms with other life events that were influencing their ability to act. For instance, one participant had three different problems that needed further health care. The first was a small mouth lesion that was excised because she coincidentally needed major dental work done and it was convenient to receive treatment. However, appointments for the other two concerns were not addressed until 6 months after the initial screening exam visit. Hence, whatever benefit that screening could offer was significantly reduced.

"No, I wasn't scared when she told me these things had to be taken care of. Maybe it was because my husband had just gone through a bout of skin cancer that was not advanced disease. I was thinking it was something that I couldn't fix just like that. But I finally made an appointment to get the other two things taken care of... probably prompted by your visit. I waited 6 months because it didn't sound too bad and I was doing other things.... And a number of things happened. My husband went to the hospital. He had a car wreck and my daughter was in the hospital. It was just like this wasn't a priority" (P#12).

Other participants described this waiting period as "allowing things to sink in." During this suspension process, an inventory of resources often occurred. Family,



financial and personal support systems were surveyed relative to the complaint and usefulness to the participant. The resources could then be used if the need presented itself. The participants reported that if the health problem initially presented with physiological impairment the time spent suspended in the decision making process to actively choose health care was shortened.

Concurrent life events was a variable that influenced amount of time the participant remained suspended in the decision making process. The more concurrent life events that were present and given higher priority than the positive cancer screening findings, the more prolonged the decision making process. One participant had significant financial difficulties and needed to wait to receive care until the problem became serious enough for hospitalization. He had been off work for a long period of time and needed to maintain an income for his family. Also highlighted in this interaction was his need to maintain work roles for financial stability (developmental life stage).

"She said even though it was not visible... said that she had detected a bit of blood in my rectum, So even though she said she didn't feel any growths of any kind, I felt that it was serious. I didn't necessarily think it was cancer because years ago I had a diagnosis of diverticulitis and I've been on Metamucil ever since then. And I remember that the doctor told me to get concerned when and if I detected blood in my stool. But I knew how I felt. I felt fine. But I knew it was something I needed to check. I did delay going to have the recommended colonoscopy done but at that time I was without work

and I did have hospitalization. I called for an appointment ..... they billed you up front and you file the insurance... it will be \$325 when you come in. So right then I cancelled the appointment because I had adequate insurance to cover it but there was no way I could come up with \$325. Because I did delay it by the time I went to the clinic I had obvious problems. I wasn't sick but I didn't feel well and I knew something was wrong. And by then I could see the blood" (P #1).

This participant went on to explain that he simply could not make it a priority to put his health first when there were so many other concerns going on in his life.

Unfortunately, his illness required expensive treatment and diagnostic care that long-term will cost him much more than the initial \$325 that he was unable to produce.

When asked why he chose the cancer screening exam as opposed to a regular visit to a health care provider's office he stated "The fact that it was available and I could go... It was something I could do for a minimum amount of money. I'd do it again if it was available and I had the money."

Other participants simply said that their lives were too busy to stop and seek additional care. When questioned about what events were making them busy, most stated that it was their everyday activities of life i.e., coordinating home, family, work and religious obligations that they perceived as obstacles. Interestingly, these same individuals stated that they would make concessions in their personal demands to help others but not to seek care for themselves. This did not appear to be a gender biased statement as an equal amount of men and women reported these feelings.

Developmental life stage was also a variable identified influencing the length of time the participant remained suspended in the decision to actively seek care.

Individuals in their late 50s stated that it was easy not to get follow-up care done because they had "work to blame it on" (P #1, 8, 10 & 15). Clearly maintaining work roles took priority over health concerns and that incapacitation from an illness did not present a viable risk. This was different from the older adults (70+) interviewed. As previously discussed, the researcher attempted to interview several individuals in their late 70s and early 80s. These people refused participation because "These are silly questions to ask. Why would anyone be concerned about this? We are all going to die with something. Isn't it a little late in life to worry about it? Just enjoy the time you have, honey" (potential participant #16). Those comments were exactly the reason the researcher wanted to talk with the individuals. The oldest participant in the study did corroborate the brief conversation the researcher had with the other potential participants.

"Cancer doesn't scare me. I don't have any particular feelings about it. My father had it, my son had it and my brother had it. And I say if you take care of it in time it can be cured. What is there to be afraid of? If it's curable go ahead and take care of it. That's the way I feel. ....I'm going to die of something besides heart failure anyway! There comes a point (in life) where it's just a little too late to worry about exact causes of things. Just accept and go on. We all have to die of something. Does it really matter what it is? Just make it quick and go gracefully" (P #14).

The older individuals seem to be more resolved or at least closer to cognitively thinking about dying whereas the younger older adult (55-65 years old) seemed to be more focused on maintaining work roles, societal and community positions. The mid-older adults (65-75 year olds) could articulate thoughts about reconciling death and becoming satisfied with their inner selves. These participants were retired and many were active volunteers. Leisure time activities were balanced between helping others, quiet self-reflection, and maintaining intergenerational family ties. Much of this information was obtained after the formal interview session by means of discussion about hobbies, family ties, grandchildren and as one participant stated "life's meanings."

In the model, the concepts of suspension, developmental life stage and concurrent life events are labeled perpendicular to the positive findings and chosen follow-up care. This is to indicate that partial or full resolution of these issues must be addressed before chosen health care is actually attained. Noted in many of the participant's lives was a "trigger" that began a domino-like effect towards obtaining health care. For instance, the researchers phone call to inquire about participation in the study "triggered" one participant to make physician appointments. At this point in her life, concurrent life events blocking her ability to obtain care had also resolved. Thus, the dominoes (variables) began to tumble, leading to chosen health care. In another instance where "suspension" was apparent, a physician friend recommended that the participant seek care for a skin lesion that was blatantly cancerous. The participant knew that something was wrong, but was indecisive as to the next course

of action. There were no concurrent life events that would prevent him from seeking care and he felt that he was adjusting well in his pre-retirement years. The impetus to resolve the suspension was a casual remark from his longtime, physician friend.

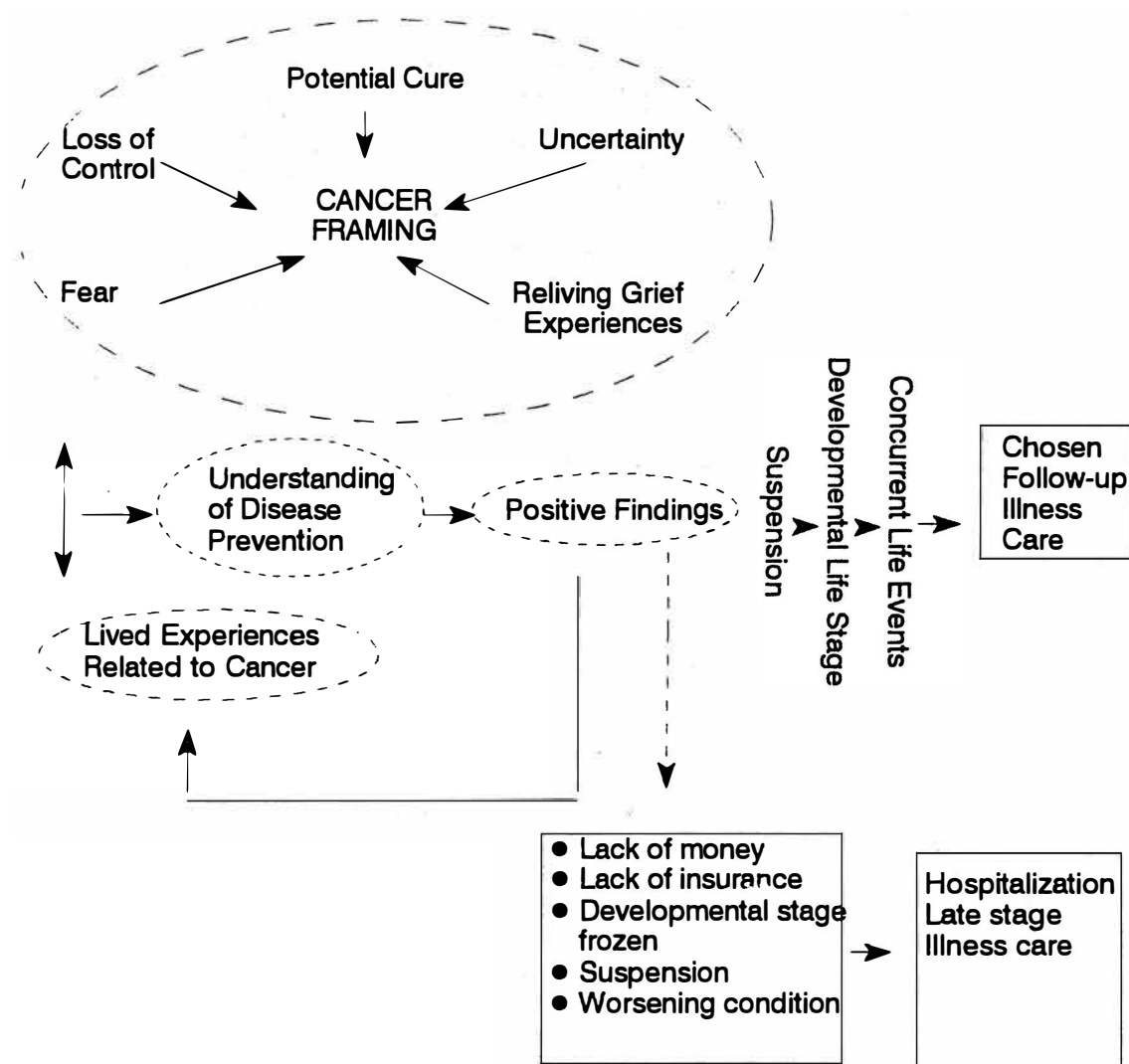
Inability to resolve suspension, concurrent life events and developmental lifestage did not preclude the participants from stating that they would obtain another cancer screening exam. Approximately half of the participants did eventually seek care for their positive findings albeit six months to one year after the initial exam when symptoms had progressed to the point of discomfort or greater concern. However, even though individuals that did not seek care and at the time of the interview had developed changes in their symptoms, they said that they would get another exam. Thus, the arrow on the theoretical model returns to the "cancer frame" experience. Reasons the participants would return for another examination included the thoroughness of the exam, the relatively minor expense and the education and personalized attention they received.

" To go to him (a physician) and getting a complete check-up would probable mean a physical exam and a blood pressure check and that's it. In other words, by going to the doctor you would not be getting anything more than the screening process I went through and it costs a whole lot more. So the time involved with the cancer (screening exam versus the physical exam was better for me and the money involved. It was something I could do quickly for a minimum amount of money" (P #1).

Another participant concurred with these thoughts.

"I thought it was very good and very thorough. She looked at things no doctor had ever checked. It was more than I ever expected. I was pleased with the thoroughness and I would go back again (P #12).

Finally, positive cancer screening examination findings may eventually lead to late stage health care. The individual may not perceive the physical symptom as a problem, allowing the condition to worsen until emergency care is needed. Lack of money and medical insurance, developmental stage stagnation and prolonged suspension can also delay appropriate medical care; hence, the medical condition continues to progress until emergency care is needed. Therefore, persons with positive findings may eventually receive treatment for their disease process (see Figure 10).



**Figure 10.** Late stage illness care

Participant #1 had such an experience. Due to lack of control over his money situation, inability to recognize the importance of early intervention and a prolonged decision making process, he ultimately received tertiary medical intervention for a serious, advanced stage disease. He reports that this was not something he had anticipated and thought that the current health care system encouraged such actions. Unfortunately, he is quite accurate in this perception.

Participant #14 is another individual whose decision not seek follow-up care will quickly catapult her into a hospital setting although she felt as if that were not going to happen. Her lack of financial resources and her worsening condition will combine to eventually overwhelm her physical being. The day of the interview, the researcher could see ominous signs of pathology. Interestingly, this was also the participant who said that everyone must die of something; why should one worry about the exact cause? She conveyed that death was a natural and inevitable part of life and that her time would be near. Consequently, her developmental stage had not stagnated and the researcher does not believe she was in prolonged suspension. Instead, she had made a very conscious decision not to seek care.

#### Overview of the Theory of Cancer Screening Behaviors in Older Adults

Cancer will occur in three out of four families in the United States and adjusted survival rate for normal life expectancy of individuals with cancer is approximately 50% (Clark & McGee, 1992). Cancer will enter the lives of all individuals albeit through illness of friends, family members or working with individuals with cancer. Sooner or later, many individuals will encounter a loved one, typically an older adult, with cancer and begin to experience the overwhelming feeling of inadequacy when trying to seek



quality health care targeted for older people.

Older adults have not been under-represented in morbidity and mortality rates of cancer. Substantial documentation supports the rise of cancer incidence and mortality with age. However, the older adults are poorly represented in cancer prevention and screening endeavors. When inclusion of older adults is targeted for cancer prevention programs, follow-up of study results has been limited. What happens to the older adult diagnosed with cancer at a screening examination? Do they seek health care or present at the health care provider's office after delaying additional treatment? The research that has been conducted on cancer screening follow-up in the older adult has typically been in university, teaching-hospital settings where resources can be unlimited both for the medical community and the patient. What happens to the older adult with limited access to such settings? Has the health care system in effect limited access to care before it even begins? Is it contributing to the overall mortality rate in older adults with cancer?

The older adults interviewed for this study addressed these questions and many more. Specifically they were asked to describe their behaviors surrounding the cancer screening examination. Their collective responses formed the basis of the following propositions of the theory of cancer screening behaviors in older adults:

1. The older adult enters the cancer screening event in a "cancer frame" which is influenced by feelings of fear, potential cure, uncertainty, grief, and loss of control.
2. The older adult's "cancer frame" is strongly influenced by their lived experiences related to cancer and is unique to the individual.

3. The older adult's culminated lived experiences with cancer can alter their understanding of disease prevention and their understanding of the meaning of positive examination results.
4. Acting on positive cancer screening examination findings requires the older adult to deliberately cope with developmental and concurrent life events if recommended health care is to be attained.
5. Older adults will eventually succumb to medical care for the positive cancer screening examination findings due to the overwhelming, cumulative result of physical, social, psychological and economic life events.
6. Older adults with early, positive cancer screening examination findings may seek additional cancer screenings due to lack of understanding of the purpose of disease prevention.

### Summary

The theory of cancer screening behaviors in older adults was developed using grounded theory methodology. Memos and actual interview data presented above facilitate illustration and description of the concepts, propositions and behaviors surrounding the cancer screening event. The research questions guided theory development and were answered through the conceptualization of the theory. The final step in grounded theory is to justify and support the model using the literature. Through this process, the actual words, feelings and thoughts of the older adult participants will be used to stimulate further research in an area that lacks consistent attention and value from many oncology and geriatric experts: cancer screening.

## Justification of the Theory of Cancer Screening Behaviors in

### Older Adults: Review of Literature

Prefacing entree into the cancer screening event are a multitude of attitudes and beliefs that older adults hold as truths to their realities and cancer. Importantly, one must be cognizant that these beliefs, truths and attitudes become acquired through a lifetime of experiences. Changing preconceived beliefs is unrealistic and occasionally detrimental to the health and well-being of the older adult. However, acknowledgement of these issues is salient to the understanding of how an older adult places meaning to cancer and the cancer screening examination and the value of its results. Understanding of these issues then helps the health care provider understand the frame of reference in which the older adult bases their decision making processes.

### The Cancer Frame

The participants in this study expressed numerous thoughts and feelings about cancer that clustered into a concept called cancer frame. Contained within the cancer frame are the following: loss of control, potential cure, reliving grief experiences and fear. The literature indicates that these are common attitudes about cancer that often interfere with older adults' decisions to seek early detection and treatment measures. Clark and McGee (1992) state that attitudes and beliefs about cancer in the public are affected by individual experience, cultural heritage, religious beliefs, family and societal attitudes, education and present circumstances. The poor, the elderly and the poorly educated often have the least accurate information about cancer prevention, detection and treatment (Clark & McGee, 1992, p. 202). The

authors also state that despite increasing public awareness of the curability of cancer, there is still widespread belief that cancer is fatal and deters early diagnosis and treatment.

Loss of control over one's life choices are a paramount concern for the older adult. Most older adults have one or more chronic illnesses and more than one-third have a serious disability that limits activities of daily living (Eliopoulos, 1993). Older adults fear that additional insults to an already diminished physiological functioning will lead to further dependence upon significant others and the health care system (Greene, Monahan & Coleman, 1992). In the current cohort of older adults, experiences with cancer are understandably varied leading to misinterpretations regarding treatment and treatment outcomes. Many older adults recall the decades when few antiemetics were available for chemotherapy patients and other chemotherapeutic side effects were perceived as worse than cancer itself. In a cohort of elderly that has lived through some of the world's worst economic times, global disasters and world conflicts loss of control and asking for help is commonly viewed as difficult and shameful. For many elders, depending upon others for support, particularly one's children is not desirable and must be avoided (Eliopoulos, 1993).

Loss of control, uncertainty and fear are all emotions and concepts that are found in many theories of aging. Frequently, these three emotions have very negative connotations for older adults because their additive effect can lead to functional and emotional disability, particularly if cancer is the involving disease process.

Havinghurst's (1963) activity theory of aging supports the need for the older adult to

stay in control of their life and remain active. Declining health, loss of roles, reduced income, diminished social interactions and other obstacles should be avoided; maintaining an active middle-aged lifestyle is priority despite the noticeable change in physiological age. These perceptions coupled with the common myths regarding cancer in the elderly i.e., disability, death, pain, and uncertainty, negatively distort the cancer frame even in the wake of positive experiences with cancer.

Uncertainty is another important component of the cancer frame. Uncertainty was conceptualized in this study as being unsure about the future and emerged as underlying statements regarding labeling, anxiety, prospects of institutionalization, feelings of isolation and others. Participants described this as "needing extreme vigilance" to "being labeled despite being cured." Uncertainty produced a level of anxiety about the future which caused psychological discomfort upon entering the screening examination process. Anxiety, in this study, is a feeling of apprehension to a nonspecific or unidentifiable threat and is produced during periods of uncertainty. The participants discussed the possibility that anxiety could prohibit them from further screening or receiving follow-up care.

Anxiety and "cancer worries" have been associated with reductions in self breast-examination frequency (Alagna, Morokorr, Bevet & Reddy, 1987) which can reduce the likelihood of repeated mammogram screenings (Lerman et al., 1990) and produce longer delays in seeking medical attention for possible cancer symptoms (Greenwald, Becker & Nevitt, 1978). Extreme levels of distress can also interfere with adherence behaviors. Distress following the diagnosis of hypertension has been

related to poor medication compliance in the elderly (MacDonald, Sackett, Haynes & Taylor, 1984). In a widely cited study, Gray (1985) identified a variety of beliefs in older adults that affect participation in early detection practices: fear of death, isolation, institutionalization, dementia, failure, feelings of immediacy, a fatalistic attitude and worthlessness.

Circumstances that may prompt all of these feelings are typically negatively oriented and ultimately lead to uncertainty. Any alteration, negative or positive in the human condition necessitates change. For the older adult, change can be a frightening and deleterious phenomenon. Many older adults can compensate for the numerous physiologically and psychological insults that a lifetime of living brings as long as they maintain homeostasis. Any situation that remotely appears to alter current living situations produces anxiety at varying levels. The mechanisms through which the person responds to the stress influences the likelihood of engaging in positive and negative health care behaviors. Thus, the decision making cycle for adaptive health behavior is increasingly more complex in the older adult than in the younger person.

Reliving grief experiences was another component of the cancer frame. Grief was defined as changes in thinking, feelings and behaviors that occur as a direct consequence of actual or perceived loss of a loved one, valued object, status or identity (Clark, McGee & Preston, 1992, p. 67). Many of the participants in this study perceived their cancer frame and the decision making process as influenced by experiences of losses of significant others through cancer deaths. However, they also discussed the process of reliving the grieving experience as it might relate to what

they could encounter if the cancer screening findings were positively identified as cancer. The researcher thought this concept would all be encompassed under "reliving grieving processes" but the participants validated that this was a separate and distinct issue. In other words, they were anticipating their own grief through their experiences with others and could not come to terms or cope with this without "reliving" the initial experience. Articulation of this was difficult by the participants but their feelings were very strong regarding this issue.

Articulation of these responses may have been influenced by and directly related to several factors relative to the cancer screening event: unresolved and/or dysfunctional grief processes and presence of and/or potential of cumulative losses. Both of these issues are directly related to developmental tasks of maturity as described by Havinghurst (1972), Lieberman and Tobin (1983) and Erikson (1959). Common to all three theories is the belief that older adults must reexamine life experiences and integrate them into perceptions of their current selves. Kaufman (1986) states that older adults continually reconstruct their personal histories so they can interpret their current experiences in a way that supports an ageless self. Through this reexamination process, older adults can acknowledge details about prior experiences that are unflattering or unresolved. Transforming life situations enables older adults to feel in control of their own destinies in late life as opposed to succumbing to the cumulative physiological and psychological insults of aging. Lieberman and Tobin describe this as investing in self-continuity, self-integrity and self-identity which is essential to an older adult's psychological survival (1986).

### Lived Experiences with Cancer

Lived experiences with cancer is an important preface to the decision making process of obtaining follow-up health care after a positive cancer screening examination. Encompassed within this concept was a multitude of factors surrounding a personal bout of cancer or those surrounding cancer diagnosis, therapy and survival or death of a significant other. Of particular significance to the participants in this study were recurrence of the cancer after a long period of remission, ability to maintain a current standard of living, pain encountered from the disease process and the treatment regime, and the psychological impact on self, family and friends. The ultimate status of these factors i.e., successful coping or dysfunction, directly influenced the cancer frame.

The impact of the factors noted above are discussed in the literature as to their effect on obtaining cancer therapies or on outcome statistics of cancer treatments of older adults (Balducci, Beghe, Parker & Chausmer, 1991; Bostick, et al., 1993; Valentine, 1986). Likewise, many articles infer that previous experiences with cancer patients influence older adults' participation in cancer screening (Boyle, 1994; Greenwald, 1992; Fallcreek, Muchow & Mockenhaupt, 1992). However, no research studies specifically examining the impact of cancer experiences in older adults relative to seeking cancer screening examinations or outcomes of care was found.

Vranicar-Lapka, Barbour-Randall, Trippon, Coffou et al. (1992) examined oncology patients' significant others responses to a proposed cancer prevention and detection program. The mean age of the 245 predominately white participants was 47



years old. Using the Health Belief Model, the authors constructed a questionnaire to collect information regarding the willingness of patients and their significant others to participate in a cancer prevention and detection program, as well as the expectations of the program's design. Over 80% of the respondents stated that they would participate in a cancer screening examination and 79.6% believed that a cancer screening program would detect cancer early. However, only 66.1% indicated that cancer screening was actually beneficial in curing cancer, while 24.5% responded that they did not know. A significance difference was found between individuals who had no familial or personal history of cancer and those who had either a personal history of cancer or a family member with the disease. Persons with a familial/personal history of cancer thought that cancer screening would detect the disease earlier than those without a personal/familial history of cancer. Replication of this study in an older adult population is necessary to determine if perceptions about the efficacy of cancer prevention clinical correlates with obtaining care after positive screening examination results.

Lived experiences with cancer and cancer framing culminate as reference points in the decision making processes surrounding the participant's making the cancer screening examination appointment. These perceptions are then carried through to influence the understanding of what the cancer screening examination entails as well as an understanding of the concepts of disease prevention and screening.

### Understanding of Disease Prevention

Cancer screening and early detection are two different processes that are interdependent. Screening is simply the preliminary step in the diagnostic process; it does not diagnose cancer but instead allows the screening participant information that evaluates their risk and/or need to seek further diagnostic care (Greenwald, 1992). Screening is the application of history taking, physical examinations and other tests and procedures to detect risk factors, asymptomatic disease and unreported conditions. Screening is typically performed on a presumed asymptomatic population. Early detection is accomplished when risk factors or previously undetected symptomatology indicates the need for further diagnostic processes.

Misunderstanding of the purposes of screening may lead to poor follow-up of further health care. Several participants in this study were blatantly angry because the nurse screener did not offer a definitive diagnose for symptoms that they presented with. This represents a lack of understanding in two important areas: 1) the participant entered the screening examination process with known pathologies; hence, screening is not the appropriate source of health care but instead early detection and diagnostic procedures are necessary; 2) the participant expected a definitive diagnosis, whatever the outcome, during a screening examination. Definitive diagnosis are never part of screening criteria but instead belong in the detection process that is further "down the line" in the treatment of cancer. Consequently, the participant perceived that their time and money had been wasted and further distrust in the health care system was expressed.

The previous review of literature supports that older adults hold many misconceptions about cancer, enter the diagnostic process at later stages than younger adults, and lack understanding of early cancer symptoms but does not examine their beliefs regarding the cancer screening examination or the purposes of early detection. Likewise, volumes of literature exists regarding general aspects of cancer prevention and screening in younger adults, but few current data are available regarding utilization of services and attitudes towards and knowledge of cancer prevention and detection (Bostick, Sprafka, Vimig & Potter, 1993). In an extensive review of literature, Bostick and others (1993) report that most population-based studies focused on a restricted number of screening tests or cancers (Center for Disease Control, 1989; Harlan, Bernstein & Kesser, 1991; Makuc, Freid & Kleiman, 1989; Polednak, 1990) but not attitudes or knowledge about cancer prevention.

The older adults' understanding of the purposes of screening is also influenced by their chronic disease states. Heart disease is the number disability of persons over 65 years of age, followed by cancer, stroke, arthritis and diabetes (Kelley, 1989). Consider that the majority of older adults suffer from at least one chronic disease state and it becomes easily understood why symptomatology of any kind is present at a screening examination. Should the concept of screening become an oxymoron in the older adult? Faithfull (1994) states that examination of health perceptions and screening behaviors are only one aspect of secondary health promotion. If screening is to benefit the older adult, the reality is that society must make a priority of health education on all fronts for this segment of the population. Chronic illness and the disabilities that typically accompany them are part of the intrinsic being of the older

adults. The government can "mandate" screenings for older adults (Healthy People 2000) but to effectively implement these objectives necessitates a value on educating the older adult that is currently absent in the U.S. society. Screening must be personalized relative to the chronic illnesses incurred by the older adult; this takes additional time and money as the most effective screenings may be part of a visit to the health care provider for the chronic disease condition. Unfortunately, Medicare and Medicaid have not given full credence to the value of preventive health care in older adults. Hence, the battle is in essence lost before it ever begins.

#### Interpretation of the Findings: The Positive Cancer Screening Examination Result

The majority of adults in this study were not overwhelmed or surprised when told they had positive examination results. In retrospect, this is due to these same individuals entering the examination process with known complaints that had been present for varying lengths of time. Reiterating previous literature at the expense of redundancy, older adults misinterpret cancer symptomatology often presenting with distant metastasis at the time of initial diagnosis. This has been, in part, due to lack of understanding of normal versus abnormal changes of aging, education levels, family and social support networks and others.

Three other concepts particularly identified in this study as effecting the ultimate decision of seeking health care for the positive findings are suspension, developmental life stage and concurrent life events. Suspension, the perceived lack of a conscious decision regarding the positive cancer screening examination findings, was influenced by a number of variables: fear, uncertainty, lack of trust in the medical system, and the combination of the consequences of concurrent life events and

developmental life stage.

Greenwald (1992) corroborates the variables included in the concept of suspension through illustration of a specialized cancer screening facility. The screening facility enjoyed a favorable reputation and offered an extensive battery of tests and history-taking which concluded with a physician exam. The entire screening process took about three hours for a minimal cost. The center provided neither definitive diagnosis or treatment but instead patient's with positive results were told that they were to consult their own physicians immediately for further care. Nearly 25% of patients with positive findings did not act on the center's advice for four months or longer and about 16% never took any action. For these people, advantages gained from early detection were reduced if not entirely lost because of delay of action or total inaction (Greenwald, 1992, p. 131). Greenwald states that interviews with the people that delayed action or to no action explained that they were afraid to find out if they actually had cancer, had weak relationships with the broader medical system, or were unable to acceptable medical practice. Furthermore, the automated, impersonal nature of the screenings seemed to reinforce preexisting negative experiences i.e., people felt like they were just another number. Many participants in this study expressed alienation with their personal physicians, expressing a lack of compassion and listening skills even though they felt they were receiving competent care.

When the older adult's well being is threatened, biological, psychological and social processes of aging are inextricably woven creating a complex decision making

process. Inherent in this process is the accomplishment or work towards the older adult's developmental tasks. Developmental tasks are the challenges and adjustments that must be met in response to life experiences that are part of an adult's continued growth through the life span (Eliopoulos, 1993). These tasks are discussed within the framework of theories of aging. Narrow foci of many of the theories of aging necessitates the use of several theories to explain the descriptions of the participants in this study as they relate to the cancer screening examination process. Erikson (1963) defines the challenge of late life as the acceptance of past experiences and life's meaning. This gives the older adult ego integrity that facilitates adjustment and coping to the realities of aging and mortality. Dysfunction during this process can lead to feelings of anger, bitterness, depression, and inadequacy or despair.

Influencing the outcome of ego integrity or despair is Peck's (1968) work detailing the specific challenges.

1. Ego differentiation versus role preoccupation: The older adult develops satisfaction from one's self as a person rather than through parental or occupational roles.
2. Body transcendence versus body preoccupation: The older adult finds psychological pleasures rather than becoming absorbed in health problems imposed by aging.
3. Ego transcendence versus ego preoccupation: The older adult achieves satisfaction through reflection on one's past life and accomplishments rather than preoccupation with the finite number years

left to live.

The third theory of aging used to explain the participant's responses and resulting theoretical framework is Lieberman and Tobin (1983). Late life challenges are met with the older adult trying to maintain self-continuity. Different from other theorists, Lieberman and Tobin state distance from death instead of time from birth accounts for the variability in functioning of the aged. Their studies have shown that there are psychological forerunners to death that occur even before physical changes are evident.

Achievement of developmental life tasks is seldom formally discussed in any of the literature regarding cancer screening and treatment in the older adult. Albeit peripherally, many authors elude to maintaining work roles and family social structures as a necessity to appropriate coping in older adults but omit other developmental tasks such as self-reflection. In this study, the oldest participants questioned the value of the researcher's need to study the topic of interest, commenting that it seemed silly and even strange. The younger participant's were ever bent towards maintaining careers, family responsibilities and social roles; they did not have the time to investigate the positive results until the pathology was so overwhelming that an emergency room visit ensued. Is this a different developmental place in life? Are the oldest participant's more resolute in the aging process and consequently not as concerned about the longevity of life but what havoc medical care may place upon them? Knowing that they had positive findings, irregardless of the diagnosis, allows the older participants time to think, self-reflect and ponder the consequences of their

decisions before actually taking action. The decision making process is suspended while the benefits and costs are carefully weighed. Many of the older participants, particularly the one that validated the theoretical model, shared these sentiments.

"Honey, we are all going to die. Does it really matter what it's from. Get to the place (in life) where there's content ... nobody gonna take that from me" (P #14).

Finally, concurrent life events is the third concept involved in the interpretation of the positive cancer screening findings. Variables cited within this concept included: crisis with other family members, financial/insurance burdens, and work related commitments. The family has an important role in the cancer care continuum from prevention through diagnosis and beyond. It is within the context of the family that behavioral repertoires are learned that can be either healthful or injurious with respect to cancer (Philips, 1989). The role of the family in secondary prevention of cancer has not been investigated to any substantive degree, primarily because secondary prevention usually concerns utilization of professional services, which is typically an individual effort; at least as it is perceived by the medical community (Philips, 1989).

It is commonly accepted that the health or illness of one family member significantly impacts the entire family unit. This premise lies at the heart of family systems theory yet it is one of the most commonly overlooked and underassessed factors when referring an individual for health care or developing a treatment plan. In this study, none of the participants felt their symptomatology warranted rapid diagnostic assessment particularly in the wake of several other family crises that they perceived as more urgent. One participant had two immediate family members in the



hospital, another had one that she was caregiving from a recent hospital discharge and two more had caregiving responsibilities to individuals living in the household. Hence, cancer screening's effectiveness may be related to the additional insult that the family system can tolerate.

Directly influencing the decision within the family system was the availability of adequate insurance coverage and "up-front" money for additional health care. Several of the participants reported long periods of unemployment that resulted in substantial lack of income and insurance. Several others reported that although their income was sufficient to meet everyday needs, a devastating illness could quickly diminish life savings due to additional insurance and co-payment costs. Difficulty was cited in finding physicians that would accept Medicare payment or bill for services as compared with fees due at the time of treatment. Therefore, care would be sought only when functional ability was impaired.

Lack of insurance and financial concern is a common thread surrounding the cancer treatment decision making process. Economic disadvantage is a special risk factor for virtually all chronic diseases, including cancer (Underwood, Hoskins, Cummins, Morris & Williams, 1994). Furthermore, these authors define medical disadvantage as the lack of healthcare insurance or insufficient resources to cover healthcare costs. The American Cancer Society's (ACS) (1989) summative report on cancer and the poor indicated that economically disadvantaged Americans are often forced to accept substantially substandard healthcare services and endure assaults on their personal dignity when seeking preventive care and treatment for cancer.

Underwood et al. (1994) reports that the testimonies of the individuals at the ACS hearings reported fragmented, impersonal, and symptomatic care and that the individuals were discouraged from seeking state-of-the art care due to costs. The testimonials also indicated that the poor were discouraged from being concerned about changes were occurring in their bodies and they had difficulty communication their needs and concerns. The majority of the individuals giving the oral testimony were middle and older adult men and women of ethnically diverse backgrounds.

The concerns reported are similar to those that older adults report in the typical health care encounter (Barry, Crescenzi, Radovsky, Kern & Steel, 1988). When the older adult does enter the health care system they are particularly vulnerable to poor-quality care. Sui (1987) reviewed 24 studies published since the 1970s to assess the quality of medical care received by older adults in community settings, nursing homes and private physician offices. He concluded that there are problems in the quality of care older adults receive. Less time is spent with the older adult during the patient visit despite the higher complexity of the illness, elderly patients develop more iatrogenic complications during hospitalization, adverse drug reactions in inpatient settings were commonly due to the administration of unnecessary medications and others. Approximately 50% of all visits to the physicians' offices are made by the older adults. Older adults are by far the biggest consumers of healthcare, accounting for more than 25% of all prescriptions written, 33% of all hospital beds occupied, and 30% of all health bills paid. (Dychtwald, 1986). It is easy to understand why older adults may choose not to fight the system if they are being asked to seek care for what they perceive as a minor inconvenience i.e., positive cancer screening results.

Follow-up care for the positive cancer screening examination results is obtained only when the older adult perceives the benefits of facing numerous obstacles to outweigh the risks of the attempt. The literature did not attempt to delineate if one of the proposed concepts, i.e., suspension, developmental lifestage or concurrent life events, was more significant than the other in helping to break the barrier to care. Nor did the participants attempt to prioritize these issues. Instead, they validated the conceptualization with their words, stating it seemed to be a accumulation of variables that determined their willingness and ability to seek care.

## CHAPTER V

### SUMMARY AND RECOMMENDATIONS

#### Introduction

The research question "What phenomena are perceived by older adults to influence their decision not to seek health care following a positive cancer screening examination?" was the domain and primary purpose of the study. Grounded theory methodology was used to explore the phenomena surrounding the cancer screening event. Fifteen, well older adults were interviewed regarding their perceptions of the event. The theory of cancer screening behaviors in older adults was developed using the theoretical concepts that emerged from the interview data. The theory was then validated by the participants and the review of literature. This research study examined several variables and used different strategies heretofore not found in the literature: 1) the examination of the phenomena surrounding the decision not to seek health care following a screening examination as compared to other studies that have investigated factors effecting lack of care following diagnostic examinations; 2) the development of theory specific to older adults' perception of the cancer screening event; 3) the use of grounded theory methodology to investigate the research questions; and 4) the formation of the conceptual categories of suspension and development life stage as influencing decision making process.

Implications of the study's results should be addressed to nursing and health care professions and at the larger whole of society. The nursing profession responds to and is born out of society's need for holistic, quality, effective nursing care.

However, the decisions that the government, hence, society mandates regarding health care objectives, reforms, economic costs, etc. directly impact the route by which nursing can expend its efforts. In a health-care (illness) system that subsidizes illness and acute care disproportionately to preventive/health promotion, mass prevention campaigns cannot be effective if there is a lack of government and third party reimbursement for the basic screening tests incurred by the majority of the participants. For example, in 1991, years after the clinical effectiveness of mammography had been demonstrated, the Omnibus Reconciliation Act of 1990 enabled Medicare to begin paying for a portion of the cost of screening mammograms for women 65+ (Bright, 1993).

Similar legislation must be undertaken for cervical, prostate and colorectal screening if cancer screening in the elderly is to begin to approach a comprehensive examination. The National Cancer Institute, Division of Cancer Prevention and Control (1992) has formulated cancer control objectives for Healthy People 2000. Included in the objectives are the screening goals: 1) increase to 80% or more women ages 40+ who have ever received a clinical breast exam and mammogram within the preceding one to two years; and 2) increase to 50% or more people age 50+ who have received a fecal occult blood test and 40% or more of those who have received a proctosigmoidoscopy. It is interesting to note that a woman age 65+ is eligible to

receive partial reimbursement for the screening mammogram from Medicare but will receive no reimbursement for the clinical breast examination, proctosigmoidoscopy and fecal occult blood test unless pathology is present at the time of screening. Is "screening" an oxymoron in the elderly? Proctosigmoidoscopy examinations cost on average of approximately \$250 - \$400. This is a substantial amount of money to request of an older adult on a fixed social security income who has an average of four prescription medications to purchase every month. It is another example of the government's ability to place "priority" on disease prevention in a climate where illness and acute care are clearly the mainstay of the health care system.

The United States government has traditionally been divergent in its approach to cancer prevention. Massive education efforts are currently underway to stem the rise of cigarette smoking now understood to cause the majority of all lung cancers either by direct inhalation of the carcinogens or through passive smoking exposure. The Community Intervention Trial for Smoking Cessation (COMMIT) was initiated by the National Cancer Institute (NCI) in 1988 and is the largest smoking intervention study in the world, involving over two million people (Bright, 1988). The NCI receives federal dollars that in part are due to taxpayer's monies. Other prevention measures include the Surgeon General determination on cigarette packages that "Smoking can be hazardous to your health." This message has recently been replaced with more specific messages i.e., "Smoking by pregnant women may result in low birth weight, fetal injury or premature birth; Cigarette smoking contains carbon monoxide; and others (Chen & Minton, 1989). However, the federal government still continues to

spend an ever increasing, sizable amount of money on tobacco subsidies for the United States tobacco farmers. This bizarre, political undertow continues to erode the national cancer prevention efforts, sending a mixed message to the public and health care professionals.

#### Recommendations for Society

The overall economic burden of cancer to the United States was an estimated \$104 billion in 1990. The burden was measured as \$35 billion for direct medical cost incurred for cancer prevention, diagnosis and treatment; \$12 billion for morbidity costs from economic losses caused by days lost from productive activity because of illness-related disability; and \$57 billion for mortality costs from lost economic output measures by loss in earnings because of premature death of productive individuals (Brown, 1990 as cited in Bright, 1993). Chen and Minton (1989) state that the public has never been more aware of the approximately 200 diseases generically classified as "cancer" nor more educated about actions it can take to reduce the risks of cancer (p. 47).

The public in general may have a better understanding of cancer and cancer risk reduction but the current literature and this research study do not support that the public has knowledge regarding who is at highest risk for cancer and who incurs the highest mortality rates from the disease. Bright (1993) provides a synopsis of recent public health initiatives for cancer prevention and control. The majority of the efforts are directed toward the younger adult/adolescent and/or unspecified age groups. Few national programs are specifically targeted towards the elderly adult and even fewer are targeted toward the proportion of the elderly that are at highest risk for poor.

cancer outcomes: minority, economically disadvantaged women. Five year survival rates are lower for the economically and medically disadvantaged, and cancer mortality among the poor is significantly higher than among people with incomes above the poverty line (ACS, 1990). Contributing to this trend are issues regarding access to care, treatment limitations, and negative attitudes of health care providers toward the impoverished, older adult.

The federal government and the national cancer research institutes must account for blatant negligence of older adults in clinical trials and in funding of programming specific to older adults. The greying of America is upon this society and the problem can no longer be relegated to another generation of politicians and researchers. The economic costs of such ignorance is staggering and will only be compounded if allowed to continue. It is not enough to purport objectives as in Healthy People 2000 if realistic mechanisms are not able to support efforts for attainment. Recent public opinion supports increased emphasis and spending on issues of concern to older adults (Blendon, 1988), and as the baby boomers come of age, the nation will demand it. A national agenda for cancer care in the aged must be formulated with the financial backing to enact it. To date, the rhetoric simply continues.

Access to care mitigates many older adults' decision making processes to obtain follow-up diagnostic care. The participants in this study cited this as one factor in their decision making process as well as their lack of trust in the medical system in general. Funding must be made available to create innovative programs for older adults which promote screening and diagnosing in the same physical location



adults which promote screening and diagnosing in the same physical location conveniently located to the older adult population it is trying to reach. As previously cited in the literature, the majority of screening programs are separate and distinct from the diagnostic process and require that the participant use several facilities to complete the treatment process. Many comprehensive cancer screening and prevention programs are located in large, government funded research institutions. Older adults may find these institutions difficult to access due to geographical location and/or lack of transportation. Likewise, their well documented distrust and hesitancy with the medical system would only be compounded with the need to enter a large, intimidating institution for a screening examination.

The participants in this study indicated a broad acceptance of the mobile cancer screening concept. Large research institutions could obtain private and government grants to provide outreach programs to older adults via mobile cancer screening services. In this way, coordination of services would be provided through the large institution leading to cost-effective, comprehensive, quality care. This concept would also provide access to older adults as potential research study participants, providing a more representative sample than what may have occurred previously.

#### Recommendations for Nursing Education

This research study provided insight into the behaviors surrounding the cancer screening examination of the older adult and the perceptions that older adults hold as truths about the meaning of cancer. Specifically identified were: 1) participants experienced age- biased care from health professionals; 2) numerous social and

3) older adults hold misconceptions about aging and the purposes of cancer screening, detection and treatment. Each of these areas is amenable to nursing education and patient education.

Nurse educators must take a two-pronged approach to address these issues. The first is to integrate content into nursing school curriculums regarding gerontology not simply geriatrics. Geriatrics is the study of older adults using a illness-health model; its concentration is typically on narrowly focused illness care. Gerontology is the broader study of older adults to include their physical, psychological and social being. Through studies in gerontology, age biases can be addressed, interventions to stem such biases promoted, and advocacy for the older adult introduced and practiced. Dispelling misconceptions about aging and caring for older adults is critical if health promotion is to be commonplace for this age group. Value of the wisdom and the experiences that the older adult embodies must be internalized before health care providers i.e., nurses give credence to providing routine screening and health promotion for a population that incurs the majority of chronic illness.

Nurses, in general, do not have encounters with older adults in the community setting as part of their work functions. The majority of beds in the United States' hospitals are occupied by older adults and the majority of nurses are employed as staff nurses on a medical surgical unit in a hospital (AJN, 1994). Consequently, the image the nurse has of the older adult may be skewed towards one of a demanding, confused and ill patient that comprises the majority of the nurse's time during his or her shift. Nurse educators must take their students into community settings, long-term care facilities, adult day cares centers and foster grandparent programs to provide a

her shift. Nurse educators must take their students into community settings, long-term care facilities, adult day care centers and foster grandparent programs to provide a more rounded clinical experience and to allow the fledgling nurse to develop a better understanding of how well most older adults can actively function despite the physiological insults that aging brings. Many nursing curriculums provide a geriatric health care elective but if the elective is not selected by the student, minimal time is formally spent teaching about the older adult. Understandably then, the classroom and didactic content that is allocated typically addresses acute care issues, and are consequently illness focused because that is what the new graduate will encounter in the hospital setting.

Bias sensitivity games (Marte, 1991) and interdisciplinary undergraduate and graduate forums must be advocated (Boyle, 1994). Nurses and other health professions must be educated together as the care an older adult needs is frequently multidisciplinary and multifaceted. Allow older adults to come into the classroom to teach, share and impart the wisdom of their years. Older adult community and national role models need to be held as the norm of aging as opposed to the exception. Models to integrate health promotion with chronic illness need to be developed specific to the older adult with subsequent testing and utilization. All these interventions necessitate an innovative approach by nurse educators who will be trail blazers for the next century. There is a wealth of articles written about the need for educating nurses and other health professionals about older adults. However, only a handful of resources offer practical, cost effective interventions.

Finally, nurse educators must develop and test outcomes of cancer screening

and early detection programs specific to the older adult. This study demonstrated that older adults hold many misconceptions about aging, health promotion, purposes of cancer screening, cancer symptomatology and treatment. These perceptions were cited throughout the initial literature review and again in the literature used to justify development of the theory of cancer screening behaviors. However, many authors continue to cite references that are more than five years old because new research is not being conducted. The newer articles do not address intervention studies but instead call for a national agenda to make cancer screening programming specific to older adults.

Nurse educators have the academic background and capabilities to develop innovative programs that can be used in diverse settings. Small descriptive pilot projects previously conducted can be used as springboards for larger intervention trials (Barnes & Thomas, 1990; Faithfull, 1994; Zabalegui, 1994). Equipped with knowledge about curriculum development, healthy and pathological aging, geriatric oncology and nursing needs of older adults, the nurse educator is ideally positioned to lead the front in program development and outcome research. Boyle (1994), a leading nurse expert in geriatric oncology, states that oncology nursing will soon include geriatrics as its subspecialty due to the overwhelming number of older adults that will develop cancer as the baby boomers come of age.

Oncology clinical specialists have started the charge through formulation of the Oncology Nursing Society's position paper on cancer and aging (Boyle, Engelking, Blesch, Dodge, Sama & Weinrich, 1992). However, the message needs dissemination in non-specialty nursing journals such as the American Journal of Nursing, Nursing

Times and RN. Every nurse is caring for older adult patients and many of these patients have or will develop cancer. The cancer education message must be broadly addressed outside the realms of oncology nursing to nurses and older adults in community and non-oncology based settings.

What should the research and the education message about cancer in the older adult purport? This research study was conducted due to the uninvestigated experiences of older adults in relation to the cancer screening examination. Specifically, it sought to describe the events, feelings and experiences surrounding the decision not to seek health care following a positive finding during the cancer screening examination. To justify the proposed research questions, this researcher evaluated numerous articles discussing older adults' morbidity and mortality rates, misconceptions of aging and cancer, lack of utilization of preventive services and health and socioeconomic data. The majority of the articles described the findings in context of the experiences of younger adults or theoretical knowledge regarding the aging process not through the actual lived experiences of the older adult. Conducting research is a prerequisite to understanding the older adults' lived experiences with cancer (Boyle, 1994). Understanding of the older patient's biopsychosocial distress related to cancer is not known (Given & Keilman, 1990). Numerous psychosocial concepts were proposed in the theory of cancer screening behaviors that older adults report as contextual and decision making variables for seeking health care following a positive cancer screening examination. The developmental life tasks of old age necessitate introspection and integration of the self for appropriate adaptation to the

aging process. Strategies for cancer symptom management and interventions are imperative but not at the expense of the psychological needs of the older adult.

Skillfully developed research must address not only quality, physical cancer care issues but also the emotional and psychological agendas that may play a significant role in recovery. Boyle (1994) states that the delineation of caregiver burden and the identification of novel interventions for emotional support for the patient, family, and extended family are of the utmost importance. The family is becoming increasingly more visible in the lives of older adults as economic and social agendas of the United States change. Multigenerational families are becoming the norm, and children are providing care for elderly, ill parents at an unprecedented rate (Boyle, 1994; Eliopoulos, 1992; Hogstel, 1994). Elderly patients hold negative perceptions of the health care system and will often refuse hospitalization despite grave physical conditions (Barry, Crescenzi, Radovsky, Kem & Steel, 1988). Understanding of the phenomenon surrounding the emotional impact of caring for an ill, older adult in a multigenerational home is essential. The expense of long-term care is unaffordable and/or unacceptable to many families and older adults. Hence, the preference to care for the sick at home is ever increasing (Ham & Sloane, 1992).

Research is just one area of priority of nurse educators. The other is the development of cancer education programs specific to older adults. Traditional teaching and evaluation methods are not adequate when teaching older adults. Innovative curriculum designs need to be developed and tested (Barnes & Thomas, 1990). Teaching models for the older adult should be created. Older adult peer teaching, proficiency testing for cancer self-examination skills, use of anatomical

methods that could be used in new curriculums. Use of nationally recognized older adult role models should also be sought to get the cancer prevention message out. One participant in this study sought additional prostate cancer screening because he learned Telly Savalas had died from prostate cancer metastasis.

Older adults are fighting their own misconceptions about aging and cancer and therefore need to be shown that prevention of cancer can promote quality of life. Dispel the myth that health promotion in old age is not important (Rubenstein, 1989). This can be accomplished through messages given by older adult role models that are cancer survivors. Powerfully spoken words by well respected, nationally known older adults have an unknown but seemingly positive impact on an older adult's choice to change health behaviors. Also, curriculums must address the normal signs of aging and compare and contrast them to the common cancer symptomatology. It is this researcher's opinion that the American Cancer Society's seven warning signals provide little guidance for the older adult. For instance, people are to notice a change in a mole or skin lesion. Most older adults have numerous sun and/or occupational induced changes on their skin surface along with normal age related lesions i.e., seborrheic keratoses and solar lentigines. These lesions, although harmless, often grow larger or smaller, fall off the skin and grow back and can become cosmetically undesirable. This is a "change in a mole or skin lesions" but it is perfectly benign. Confusion ensues and the older adult may simply give up trying to perform skin self exam because of frequent, normal changes. Thus, the small, insidious basal cell carcinoma may develop unabated because of the slow clinical change that is

characteristic of the disease.

### Summary

This research study described the phenomenon surrounding the older adult's decision not to seek health care following a positive cancer screening examination. The theory of cancer screening behaviors in older adults was developed and addressed numerous psychosocial concepts and several economic variables that were substantiated by both the participants and the literature review. Unique to this theory was the inclusion of developmental life stage as it influences the decision making process. Little has been reported in oncology, education or motivation theory literature regarding the role of developmental life tasks.

Discussion regarding generalization of the findings is commonly noted in quantitative studies. However, the goal of grounded theory is transferability, in which the burden of demonstrating the applicability of one set of findings to another context rests more with the investigator who would make that transfer than with the original investigator (Marshall & Rossman, 1989, p. 145). Sufficient trustworthiness of the data in this study facilitates transferability of the data to ambulatory cancer screening clinics for older adults and to cancer screening for older adults albeit with some degree of ethnic bias. The fifteen participants in this study were predominately white, well-educated, middle class men and women. Hence, although poverty and other socioeconomic conditions cut through gender and ethnic barriers, it has been noted that rural, poverty stricken, minority older adults have been under-represented in the cancer literature and in cancer research studies in general (Boyle, 1994; Coward, Bull, Kukulka & Galliher, 1994). Therefore, the theory of cancer screening behaviors in



cancer literature and in cancer research studies in general (Boyle, 1994; Coward, Bull, Kukulka & Galliher, 1994). Therefore, the theory of cancer screening behaviors in older adults has been justified and validated by primarily a homogeneous population of white, older adults. Further testing of the theory should be conducted in participants to include diverse socioeconomic, ethnic and racial backgrounds.

Development of theory using the grounded theory method provides a rich tapestry from which hypotheses can be developed. This research has provided a theoretical framework to launch further investigation into the phenomenon surrounding the cancer screening event. In particular, further investigation needs to be conducted regarding the influence of developmental life stage and accomplishment of subsequent tasks on the meaning of cancer and cancer screening decision processes in older adults. This was an area of conceptual development that has not been adequately addressed in older adults. Further investigation also needs to be conducted to describe the relational statements within the theory and clarify the concepts.

The development of the theory of cancer screening behaviors is a small step towards understanding the phenomena surrounding the cancer screening examination in older adults. Hypotheses testing can now be conducted in quantitative studies with the potential of broad applicability to older adults in numerous walks of life. The economic and societal implications of the greying of America is monumental. If cancer morbidity and mortality rates continue at their current pace, and many leading experts predict they will (Greenwald, 1992), oncology in older adults will take unprecedented priority on the federal agenda. Cancer survival will become a public

issue and public decisions may ultimately affect the progress in improving cancer survival more profoundly than private ones (Greenwald, 1992, p. 202). The policymakers that regulate the nation's health care choices must be availed of information regarding older adults that is more than case studies and anecdotal notes. The oncologic imperative is a critical one (Boyle, 1994). Ash (1986) reminds us: "As the single largest group of health care providers, nurses must become knowledgeable about the elderly and the assessment of their needs and serve as a catalyst for the involvement of others."

The coming of age of the elderly has arrived. Nurses must be on the forefront of developing new curriculums for cancer screening in the elderly, creating public awareness that promotes positive images of the elderly and developing research and implementing subsequent outcomes that address the issues surrounding the older adults' decision making processes during the cancer experience. The tasks ahead are monumental but the unresolved consequences are ominous. Nurses can meet this challenge and provide the impetus to revolutionary change in oncology care for the older adult.

## REFERENCES

- Adami, H.O., Malke, B., Holmberg, L., et al. (1986). The relation between survival and age of diagnosis. New England Journal of Medicine, 315, 559-563.
- Alagna, S.W., Morokoff, P.J., Bevet, J.M., & Reddy, D.M. (1987). Performance of breast self-examination by women at high risk for breast cancer. Women and Health, 12(2), 29-46.
- Albert, M. (1987). Health screening to promote health for the elderly. Nurse Practitioner, 12, 42-58.
- Allen, C., Cox, E., Manton, K., Cohen, H. (1986). Breast cancer in the elderly: Current patterns of care. Journal of the American Geriatrics Society, 34(9), 637-642.
- American Cancer Society. (1989). Cancer and the poor: A report to the nation. Atlanta: American Cancer Society.
- American Cancer Society. (1990). Cancer and the socioeconomically disadvantaged. Atlanta: American Cancer Society.
- American Cancer Society. (1990). Public attitudes toward cancer and cancer tests. CA - A Cancer Journal for Clinicians, 30(2), 92-98.
- American Journal of Nursing. (1994). RN population grows to 2.2 million: Nurses age a bit but work more. American Journal of Nursing, 94, 68-70.
- Artinian, B. (1986). The research process in grounded theory. In C. Chenitz & J. Swanson (Eds.), From practice to grounded theory: Qualitative research methods in nursing (pp. 16-23). Menlo Park: Addison-Wesley.
- Ash, C.R. (1986). Cancer care for the elderly. Cancer Nursing, 9, 229.
- Balducci, L., Beghe, C., Parker, M., & Chausmer, A. (1991). Prognostic evaluation in geriatric oncology: Problems and perspectives. Archives of Gerontology and Geriatrics, 13, 31-41.
- Barnes, S., & Thomas, A. (1990). A modified cancer education program: Effect on cancer knowledge and beliefs in the elderly. Cancer Nursing, 13(1), 48-55.

Barry, P., Crescenzi, C., Radovsky, L., Kern, D., & Steel, W. (1988). Why elderly patients refuse hospitalization. Journal of the American Geriatrics Society, 36, 419-424.

Begg, C., Cohen, J., & Ellerton, J. (1980). Are the elderly predisposed to toxicity from cancer chemotherapy? Cancer Clinical Trials, 3(2), 369.

Blendon, R.J. (1990). Satisfaction with health systems in ten nations. Health Affairs, 9(2), 185-192.

Blendon, R. J. (1988). The public's view of the future of health care. JAMA, 259, 3587-3593.

Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs: Prentice-Hall.

Bogdan, R., Biklen, S. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn & Bacon.

Bossde, R., Aldwin, C.M., Levenson, R., & Workman-Daniels, K. (1991). How stressful is retirement? Findings from the normative aging study. Journal of Gerontology, 46(1), 9-14.

Bostick, R., Sprafka, M., Vimig, B.A., & Potter, J.D. (1993). Knowledge, attitudes and personal practices regarding prevention and early detection of cancer. Preventive Medicine, 22, 65-85.

Bowers, B.J. (1988). Grounded theory. In B. Sarter (Ed.). Paths to knowledge: Innovative research methods for nursing (pp. 33-59). New York: National League for Nursing.

Boyle, D.M. (1994). Realities to guide novel and necessary care in geriatric oncology. Cancer Nursing, 17(2), 125-136.

Boyle, D.M., Engelking, C., Blesch, K.S., Dodge, J., Sama, L., & Weinrich, S. (1992). Oncology Nursing Society position paper on cancer and aging: The mandate for oncology nursing. Oncology Nursing Forum, 19, 913-933.

Bright, M.A. (1993). Public health initiatives in cancer prevention and control. Seminars in Oncology Nursing, 9(3), 139-146.

Brower, H.T. (1985). Do nurses stereotype the elderly? Journal of Gerontological Nursing, 11, 26-28.

Brown, M.L. (1990). The national economic burden of cancer: An update. Journal of the National Cancer Institute, 82, 1811-1814.

Bruhn, J. (1991). Health promotion and clinical sociology. In H. Reach & J. Bruhn (Eds.), Handbook of clinical sociology. New York: Plenum Press.

Burack, R.C., & Liang, (1986). Early detection of cancer among older women (Research report). Washington, D.C.: Andrus Foundation.

Burklow, J. (1991). New campaign urges older women to get mammograms. Journal of the National Cancer Institute, 83(21), 1533-1534.

Celenatano, D., Shapiro, S., & Weisman, C. (1982). Cancer preventive screening behavior among elderly women. Preventive Medicine, 11, 454-463.

Center for Disease Control. (1989). Trends in screening mammograms for women 50 years of age and older: Behavioral risk factor surveillance system. MMWR, 38, 137-140.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health and Illness, 5(2), 169-195.

Chen, M., & Minton, J. (1989). The most favorable societal climate for cancer prevention. Health Values, 13(6), 47-50.

Chenitz, C. & Swanson, J. (1986). From practice to grounded theory: Qualitative research in nursing. Menlo Park: Addison-Wesley.

Clark, J., & McGee, R. (Eds.). (1992). Oncology Nursing Society: Core curriculum for oncology nursing (2nd ed.). Philadelphia: W.B. Saunders.

Clark, J., McGee, R., & Preston, R. (1992). Nursing management of responses to the cancer experience. In J. Clark & R. McGee (Eds.), Oncology Nursing Society: Core curriculum for oncology nursing (2nd ed., pp. 67-77). Philadelphia: W.B. Saunders.

Commonwealth Fund Commission on Elderly People Living Alone (1987). Old, alone and poor. Baltimore, MD.

Corbin, J. (1986). Coding, writing memos and diagramming. In W.C. Chenitz & J.M. Swanson (Eds.), From practice to grounded theory (pp. 102-120). Menlo Park: Addison-Wesley.

Coward, R.T., Bull, C.N., Kukulka, G., & Galliher, J.M. (Eds.). (1994). Health services for rural elders. New York: Springer Publishing.

Crawford, J., & Cohen, H.J. (1987). Relationship of cancer and aging. Clinics in Geriatric Medicine, 3, 419-432.

Dellefield, M.E. (1988). Informational needs and approaches for early cancer detection in the elderly. Seminars in Oncology Nursing, 4(3), 156-168.

Derby, S.E. (1991). Ageism in cancer care of the elderly. Oncology Nursing Forum, 18, 921-926.

Dychtwald, K. (Ed.). (1986). Wellness and health promotion for the elderly. Rockville: Aspen.

Eliopoulos, C. (Ed.). (1993). Gerontological nursing (3rd ed.). Philadelphia: Lippincott.

Entrekin, N., & McMillan, S. (1993). Nurses' knowledge, beliefs, and practices related to cancer prevention and detection. Cancer Nursing, 16(6), 431-439.

Erikson, E. (1959). Identity and the life-cycle. In Psychological Issues, Monograph No. 1 (p. 166). New York: International Universities Press.

Erlandson, D., Harris, E., Skipper, B., & Allen, S. (1993). Doing naturalistic inquiry: A guide to methods. Newbury Park: Sage.

Faithfull, S. (1992). Chemotherapy for elderly people. Nursing Standards, 6, 25-28.

Faithfull, S. (1994). Negative perceptions. Nursing Times, 90(1), 62-65.

Fallcreek, S., Muchow, J., & Mockenhaupt, R. (1994). Health promotion with rural elders. In R.T. Coward, C.N. Bull, G. Kukulka, & J.M. Galliher (Eds.), Health services for rural elders (pp. 182-202). New York: Springer Publishing.

Fentimann, I.S., Tirelli, U., Mondardini, S., et al. (1990). Cancer in the elderly: Why so badly treated? Lancet, 335, 1020-1022.

Fleck, A. E. (1988). Economic issues in the care of the elderly cancer patient. Seminars in Oncology Nursing, 4(3), 217-223.

Fletcher, K.R. (1994). Health promotion. In M.O. Hogstel, Nursing care of the older adult (3rd ed.) (pp. 92-116), Albany: Delmar Publishing.

Frank-Stromberg, M. (1988). Future projected trends in the care of the elderly individual with cancer, and implications for nursing. Seminars in Oncology Nursing, 4(3), 224-231.

Frank-Stromberg, M. (1986). The role of the nurse in early detection of cancer: Population sixty six years of age and older. Oncology Nursing Forum, 13(3), 66-74.

George, L. (1990). Social structure, social processes and social psychological states. In R.H. Binstock & L. George (Eds.), Handbook of Aging and Social Sciences (3rd ed.). San Diego: Academic Publishing.

Gilbert, S. (1986). Health promotion for older Americans. Health Values, 10(3), 38-46.

Given, B.A., & Given C.W. (1989). Cancer nursing for the elderly: A target for research. Cancer Nursing, 12, 717-7.

Given, B.A., Keilman, L. (1990). Cancer in the elderly population: Research issues. Oncology Nursing Forum, 17, 121-123.

Glaser, B.G. (1978). Theoretical sensitivity. Mill Valley: The Sociology Press.

Glaser, B., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Publishing.

Goodwin, J. (1989). Knowledge about aging among physicians. Journal of Aging and Health, 1(2), 234-243.

Goodwin, J., Samet, J., Key, C., Humble, C., Kutviet, D., & Hunt, C. (1986). Stage at diagnosis of cancer varies with the age of the patient. Journal of the American Geriatrics Society, 34(1), 20-26.

Gordon, R. (1973). Interviewing: Strategies, techniques and tactics. Homewood, Illinois: Dorsey Press.

Gotay, C. (1985). Why me? Attributions and adjustments by cancer patients and their mates at two stages in the disease process. Society of Science and Medicine, 20(8), 825-831.

Gray, J.A. (1985). Education for health in old age. In J. A. Gray (Ed.), Prevention of disease in the elderly (pp. 200-220). London: Churchill Livingstone.

Greene, V.L., Monahan, D., & Coleman, P. (1992). Demographics. In R. Ham & P. Sloane, Primary care geriatrics (pp. 3-16). St. Louis: Mosby.

Greenwald, H.P. (1992). Who survives cancer? Berkeley: University of California Press.

Greenwald, H.P., Becker, S.W., & Nevitt, M.C. (1978). Delay and noncompliance in cancer detection: A behavioral perspective for health planners. Milbank Memorial Fund Quarterly, 56, 212-230.

9 Gubrium, J.F., & Sankar, A. (Eds.). (1994). Qualitative methods in aging research. Thousand Oaks: Sage.

Hall, S. (1984). Special considerations in older patients. Geriatrics, 39, 74-78.

Ham, R., & Sloane, P. (1992). Primary care geriatrics (2nd ed.). St. Louis: Mosby.

Harlan, L.C., Bernstein, A.B., Kessler, L.G. (1991). Cervical cancer screening: Who is screened and why? American Journal of Public Health, 81, 885-890.

Havinghurst, J. (1963). Successful aging. In R.H. Williams, C. Tibbetts & W. Donahue (Eds.), Processes of aging. volume 1 (pp. 299). New York: Atherton Press.

Hillner, B.E., Smith, T.J., & Desch, C.E. (1992). Efficacy and cost-effectiveness of autologous bone marrow transplantation in metastatic breast cancer. JAMA, 267, 2055-2061.

Hogstel, M.O. (Ed.). (1994). Nursing care of the older adult (3rd ed.). Albany: Delmar Publishing.

Holland, J., & Massie, M. (1987). Psychosocial aspects of cancer in the elderly. In H. Cohen (Ed.), Cancer I: Clinics in geriatric medicine (pp. 533-539). 3(3).

Hutchinson, S. (1986). Grounded theory: The method. In P. Munhall & C. Oiler (Eds.), Nursing research: A qualitative perspective (pp. 111-130). Norwalk: Appleton-Century-Crofts.

Kane-Williams, E., & White, J. (1983). Community-based cancer education for the elderly. Progress in Clinical and Biological Research, 130, 113-122.

Kayser-Jones, K., & Koenig, B. (1994). Ethical issues. In J.F. Gubrium & A. Sankar (Eds.), Qualitative methods in aging research (pp. 15-32). Newbury Park: Sage.

Kaufman, S.R. (1986). The ageless self: Sources of meaning in late life. Madison, WI: University of Wisconsin Press.



Keffer, M.J. (1990). Ethical decisions in nursing: The do-not-resuscitate decision. Unpublished doctoral dissertation, University of Illinois, Chicago.

Kegeles, S., & Grady, K. (1989). Behavioral dimensions. In D. Shottenfeld & J. Fraumeni (Eds.), Cancer epidemiology and prevention. Philadelphia: Saunders.

Kelley, W.N. (Ed.). (1989). Textbook of internal medicine. Philadelphia: J.B. Lippincott.

Kelly, J.R., Steinkamp, M.W., & Kelly, J.R. (1986). Later life leisure: How they play in Peoria. The Gerontologist, 12(11), 3.

Kim, K. (1986). Response time and health care learning of elderly patients. Research in Nursing and Health, 9, 233-239.

Knox, W. (1993). The impact of health-care reform on the cancer patient. Cancer (supplement), 72(9), 2850-2853.

Leininger, M. (1985). Ethnography and ethnonursing: Models and modes of qualitative data analysis. In M. Leininger (Ed.), Qualitative research methods in nursing (pp. 33-71). New York: Grune and Stratton.

Lerman, C., Rimer, B., Trock, B., Balshem, A., & Engstrom, P. (1990). Factors associated with repeat adherence to breast cancer screening. Preventive Medicine, 19, 279-290.

Lewis, M. (1985). Older women and health: An overview. Women and Health, 10, 1-16.

Lieberman, M., & Tobin, S. (1983). The experience of old age: Stress, coping, and survival. New York: Basic Books.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Beverly Hills: Sage.

List, N.D. (1987). Perspectives in cancer screening in the elderly. In H.J. Cohen (Ed.), Clinics in Geriatric Medicine (pp. 433-445). Philadelphia: W.B. Saunders.

Loeb, E. (1987). Special problems of cancer care for the elderly. Primary Care, 14(2), 281-291.

Makuc, D., Freid, V., & Kleinman, J. (1989). National trends in the use of preventive health care by women. American Journal of Public Health, 79(1), 21-26.

Mandelblatt, J., & Fahs, S. (1988). Cost effectiveness of cervical cancer screening for elderly low income women. JAMA, 259(16), 2409-2413.

Mandelblatt, J., Gopaul, I., & Wistreich, M. (1986). Gynecological care of elderly women: Another look at the Papanicolaou smear testing. JAMA, 256(3), 367-371.

Marmor, T., & Mashaw, J. (1993, July 6). Health-care reform costs: Rumor is scarier than reality. Los Angeles Times/Washington Edition, p. A11.

Marshall, C., & Rossman, G.B. (1989). Designing qualitative research. Newbury Park: Sage.

Marte, A.L. (1991). Experimental learning strategies for promoting positive staff attitudes towards the elderly. Journal of Continuing Education in Nursing, 22, 73-77.

Masiak, R., Gams, R., & Lee, E. (1983). The psychosocial support status of elderly cancer outpatients. In P. Engstroms, P. Anderson, & L. Mortenson (Eds.), Advances in cancer control: Research and development (pp. 395-399). New York: Alan Liss.

McCaffrey-Boyle, D., Engelking, O. (1993). Cancer in the elderly: The forgotten priority. European Journal of Cancer Care, 2, 101-107.

McDermott, K. (1994). Healthcare reform: Past and future. Oncology Nursing Forum, 21(5), 827-832.

McGoldrick, A. E. (1989). Stress, early retirement and health. In K.S. Markides & C.L. Cooper (Eds.), Aging, stress and health. New York: John Wiley & Sons.

Merriam, S. (1988). Case study research in education: A qualitative approach. San Francisco: Jossey-Bass.

Mettlin, C., Jones, G., & Murphy, G. (1993). Trends in prostate cancer care in the United States 1974-1990: Observations from the patient care evaluation studies of the American College of Surgeons Commission on Cancer. CA - A Cancer Journal for Clinicians, 43, 83-91.

Miller, D. (1981). Principles of early detection of cancer. Cancer, 47(5), 1142-1145.

Miller, M. (1991). Factors promoting wellness in the aged person: An ethnographic study. Advances in Nursing Science, 13(4), 38-51.

- Morse, J. (1994). Going in "blind." Qualitative Health Research, 4(1), 3-5.
- Morse, J. (1989). Strategies for sampling. In J. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (pp. 117-131). Rockville: Aspen.
- Morse, J.M. (Ed.). (1991). Qualitative nursing research: A contemporary dialogue. Newbury Park, London: Sage.
- Muir Grey, J. (ed). (1985). Prevention of disease in the elderly. New York: Churchill Livingstone, 1-17.
- National Cancer Institute, Division of Cancer Prevention and Control. (1992). Annual report. Bethesda, Maryland: National Cancer Institute.
- Newell, G.R., Spitz, M.R., & Sider, J.G. (1989). Cancer and age. Seminars in Oncology, 16, 3-9.
- Ory, M.G. (1984). Health promotion strategies for the aged. Journal of Gerontological Nursing, 10, 31-37.
- Ouslander, J., & Beck, J. (1982). Defining the health problems of th elderly. Annual Reveiw of Public Health, 3, 55-83.
- Passell, P. (1993, May 16). The nation: To health, from wealth. The New York Times, p. 4.
- Peck, R. (1968). Psychological developments in the second half of life. In B. Neugarten (Ed.), Middle age and aging (pp. 88-92) Chicago: University of Chicago.
- Philips, B.U. (1989). The forgotten family: An untapped resource in cancer prevention. Family and Community Health, 11(4), 17-31.
- Polednak, A.P. (1990). Knowledge of colorectal cancer and use of screening tests in persons 40-74 years of age. Preventive Medicine, 19, 213-226.
- Power, E.J. (1990). Cervical cancer screening in elderly women. JAMA, 262, 2966.
- Public Health Service. (1990). Summary of healthy people 2000: National health promotion and disease prevention objectives. Washington, D.C.: American Public Health Association.
- Rimer, B., Jones, W., Wilson., M., Bennett., D, & Engstrom, O.P. (1983). Planning a cancer control program for older citizens. The Gerontologist, 23(4), 384-389.

Robie, P.W. (1989). Cancer screening in the elderly. Journal of the American Geriatrics Society, 37, 888-893.

Rubenstein, L. (1991). Targeting health advocacy efforts toward the older population. Cancer, 68, 2519-2524.

Rubenstein, R.L. (1994). Proposal writing. In J.F. Gubrium & A. Sankar (Eds.), Qualitative methods in aging research (pp. 67-81). Newbury Park: Sage.

Samut, J., Hunt, W.C., Key, C., Humble, C., & Goodwin J. (1986). Choice of cancer therapy varies with age of patient. JAMA, 255(24), 3385-3399.

Sawyer, P. F. (1986). Breast self-examination: Nurses aren't assessing their clients. Oncology Nursing Forum, 13, 44-48.

Silberman, G. (1993). Cancer palliation: Economic and societal implications. Cancer Treatment Reviews, 19 (supplement A), 97-102.

Siu, A. (1987). The quality of medical care received by older persons. Journal of the American Geriatrics Society, 35, 1084-1091.

Smith, L. (1993, May 17). The coming healthcare shakeout. Fortune Magazine, 70-75.

Stern, P. (1985). Using grounded theory methods in nursing research. In M. Leininger (Ed.), Qualitative research methods in nursing (pp. 149-160). New York: Grune and Stratton.

Stern, P., Allen, L., & Moxley, P. (1982). The nurse as grounded theorist: History, purposes, and uses. The Review of Philosophy and Science 7(1), 200-215.

Stern, P. N. (1987). Grounded theory methodology: Its uses and processes. In S.R. Gortner (Ed.), Nursing Science Methods: A reader (pp. 79-88). Regents: University of California.

Survey of physicians attitudes and practices in early cancer detection. CA, 35, 197-213.

Swanson, J. (1986). The formal qualitative interview for grounded theory. In C., Chenitz & J. Swanson, From practice to grounded theory: Qualitative research in nursing (pp. 66-78). Menlo Park: Addison.

Taylor, S.J., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: John Wiley.

Underwood, S.M., Hoskins, D., Cummins, T., Morris, K., & Williams, A. (1994). Obstacles to cancer care: Focus on the economically disadvantaged. Oncology Nursing Forum, 21(1), 47-52.

U.S. Bureau of the Census. (1990). Current population reports. Series p-20, No. 433, Washington, D.C.: Bureau of the Census.

U.S. Bureau of the Census, U.S. Department of Commerce (1990). Projections of the population of the United States by age, sex and race 1988-2080. Current Population Reports Population Estimates and Projections, series p-25, No. 1018, Washington, D.C.

U.S. Department of Commerce. (1990). Statistical abstract of the US 110th ed: Washington, D.C.: Bureau of the Census, 37.

U.S. Public Health Service and Administration on Aging. (1984). Aging and health promotion: Market research for public education. Contract No. 282-83-0105, SRA Technologies.

U.S. Senate. (1990). Aging america: Trends and projections, serial 101-j, Washington, D.C.: U.S. Government Printing Office.

Valentine, A. (1986). Behavioral dimensions in cancer prevention and detection. Seminars in Oncology Nursing, 2(3), 200-205.

Vranicar-Lapka, D., Barbour-Randall, L., Trippon, M., Wild, L., Coffou, B., Grace-Louthen, C., Hausen, V., & Schaeffer, C. (1992). Oncology patients' and their significant others' responses to a proposed cancer prevention/detection program. Cancer Nursing, 15(1), 47-53.

Walker, L.O., & Avant, K.C. (1988). Strategies for theory construction in nursing (2nd ed.). Norwalk: Appleton & Lange.

Warren, B., & Pohl, J.M. (1990). Cancer screening practices of nurse practitioners, Cancer Nursing, 13, 143-151.

Webster, J. (1992). Sociodemographic and attitudinal changes affecting cancer care. In J. Clark & R. McGee (Eds.), Oncology Nursing Society: Core curriculum for oncology nursing (2nd ed., pp. 195-204). Philadelphia: W.B. Saunders.

Weinrich, S. & Weinrich, M. (1986). Cancer knowledge among elderly individuals. Cancer Nursing, 9, 301-307.

Welch-McCaffrey, D. (1988). Geriatric oncology: Nursing concerns. In Proceedings of the Fifth International Conference on Cancer. London, 43-45.

Welch-McCaffrey, D. (1986). To teach or not to teach? Overcoming barriers to patient education in geriatric oncology. Oncology Nursing Forum, 13, 25-31.

Yancik, R., & Ries, L. (1991). Cancer in the aged: An epidemiological perspective on treatment issues. Cancer, 68, 2502-2510.

Zabalegui, A. (1994). Barriers to health: Cancer screening, older people. Nursing Times, 90(1), 59-61.

## APPENDICES

## APPENDIX A

## ORAL EXPLANATION TO PARTICIPANTS

Hello, (name of prospective participant), my name is Anne Thomas and I am a doctoral nursing student at Texas Woman's University. I am a registered nurse who is conducting a research study about cancer screening in older adults to help understand what that experience was like. This study has been approved by the Human Subjects Review Committee at Texas Woman's University and the Nursing Research and Publication Committee at (insert name of medical center). I am particularly interested in the experiences of men and women over the age of 55 who had positive results from the screening examination and were referred for additional health care but did not have further care given. The nurse screener with the Cancer Screening Program has given me your phone number as you indicated to her that you are interested in participating in the study.

The reason I am calling you is to find out if you would be interested in talking with me about your thoughts and feelings regarding the cancer screening examination. We would need to plan on allowing about one to one and a half hours for the interview. The interview consists of a few general questions. There are no right or wrong answers. Our discussion will be tape recorded and I will be taking hand written notes. The purpose of doing this is so I may interpret our conversation accurately and transcribe the interview. After the interview is transcribed, it will be shared with you to verify its accuracy. The audiotapes will not be shared with anyone but you. Your participation in this study will be completely anonymous and you will not be



identified in the written results of the study.

If you agree to be interviewed, I would like to come talk with you in your home if that is convenient for you. Also, should you agree to participate, there will be two consent forms to sign. The first indicates your willingness to participate in the study and the second allows permission to tape record the interview. I will bring the forms when we meet. Also, please be assured that you may choose to withdraw from this study at anytime without consequence. Finally, as this study will not be applying any experimental treatment and will simply be asking you to share your thoughts and concerns about your cancer screening examination, no untoward or harmful effects to you are anticipated. However, should discussion of the cancer screening examination prompt you to seek the further follow-up care that was originally recommended, you will be referred to the nurse screener with the Cancer Screening Program for further assistance.

Is there anything you would like to ask before deciding?

Would you have some time available this week?

I will call you the evening before to confirm the appointment. Should you need to cancel or change the appointment, please call me at home (---)---.

Thank you, (name of participant). I have enjoyed talking with you and look forward to meeting with you next week.

## APPENDIX B

## CONSENT TO PARTICIPATE IN RESEARCH

Texas Woman's University  
Denton, Texas

Anne C. Thomas, MSN, RN, CS, ANP, GNP  
Dr. Patsy Keyser - Supervising Professor

I have read a description of the study about cancer screening in older adults. I understand that the interview will be audio-taped, that my name will not be used in any release of information in the final research report, that I am free to withdraw from the study at any time without giving a reason, and that I will receive a copy of the findings of the completed study.

I understand I will not be monetarily compensated by Texas Woman's University, (name of the medical center), or the researcher in the study.

I have been given the opportunity to ask questions about the study and they have been answered to my satisfaction.

I also understand that if I have any concerns about the way this research is being conducted, I may contact the Texas Woman's University Office of Research and Grants Administration at (817)898-3375.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**APPENDIX C**

**CONSENT TO AUDIOTAPE**

## CONSENT FORM C

## TEXAS WOMAN'S UNIVERSITY

We, the undersigned, do hereby consent to the recording of our voices and/or images by \_\_\_\_\_, acting on this date under the authority of the Texas Woman's University. We understand that the material recorded today may be made available for educational, informational, and/or research purposes; and we do hereby consent to such use.

We hereby release the Texas Woman's University and the undersigned part acting under the authority of Texas Woman's University from any and all claims arising out of such taking, recording, reproducing, publishing, transmitting, or exhibiting as is authorized by the Texas Woman's University.

## SIGNATURE OF PARTICIPANTS

\_\_\_\_\_  
Date

Signature: \_\_\_\_\_

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of its contents.

\_\_\_\_\_  
Authorized representative of the  
Texas Woman's University

\_\_\_\_\_  
Date

APPENDIX D  
INTERVIEW GUIDE

1. What does cancer mean to you?
2. When you first chose to have a cancer screening examination performed, you may have had some ideas or thoughts and feelings about what that exam was like and what you expected. Can you describe some of those feelings? Did those feelings change over time?
3. What were your expectations of this examination?
4. When you were told that you had positive findings (interviewer will specify type of positive findings) what did you think and feel? Did those feelings change over time?
5. At the time of the exam, the nurse discussed the need for further health care. What were some of the thoughts and feelings that were on your mind at that point?
6. How do you feel now?
7. What were the circumstances that prevented you from getting care after your screening exam?
8. Is there anything else you would like to share about your experience?
9. Is there anything you would like to ask me?

APPENDIX E  
DEMOGRAPHIC DATA COLLECTION FORM

Background Interview

1. Age: \_\_\_\_\_
2. Gender: M F
3. Race: Caucasian Black Hispanic Asian Indian Other  
\_\_\_\_\_
4. Highest level of education: \_\_\_\_\_
6. Marital status: S M W D
7. Employment status:  
 Employed part-time outside the home (hrs/week) \_\_\_\_\_  
 Employed full-time outside the home \_\_\_\_\_  
 Volunteer (hrs/week) \_\_\_\_\_  
 Retired \_\_\_\_\_  
 Retired from primary occupation but employed outside of the home \_\_\_\_\_  
 Homemaker \_\_\_\_\_  
 Other \_\_\_\_\_
8. Principle wage earner in household \_\_\_\_\_
9. Family income before taxes from all sources  

___ \$10-15,000	___ \$40-55,000
___ \$15-25,000	___ \$55-75,000
___ \$25-40,000	___ \$75,000+
10. Is this income sufficient for your needs? Y N
11. Place of residence  
 house (own)  
 apartment/house (rental)  
 supervised retirement living center  
 children's or other relative's home
12. Number of people in household \_\_\_\_\_
13. Persons in household requiring nursing or home health care? Y N  
 relationship to the participant \_\_\_\_\_

### Health Care Questions

14. Y N Do you have a primary health care provider?
15. When was the last time you had a complete physical examination? 19\_\_\_\_\_
16. How would you rate your health?
- \_\_great  
\_\_good  
\_\_fair  
\_\_poor
17. Y N Do you have medical insurance?  
If yes - Is the insurance sufficient for your needs? Y N
18. Y N Do you feel you have control over your health status?
19. Y N Do you feel the health problems you have can be resolved?
20. Y N Do you feel the health problems you have are directly related to aging?
21. Y N have you ever had a physical examination by a nurse practitioner?
22. Y N Do you have a history of cancer?  
If yes - Type\_\_\_\_\_ Year diagnosed\_\_\_\_\_
23. Y N Does anyone in your immediate family have a history of cancer ?

Person/Relationship

Type of Cancer

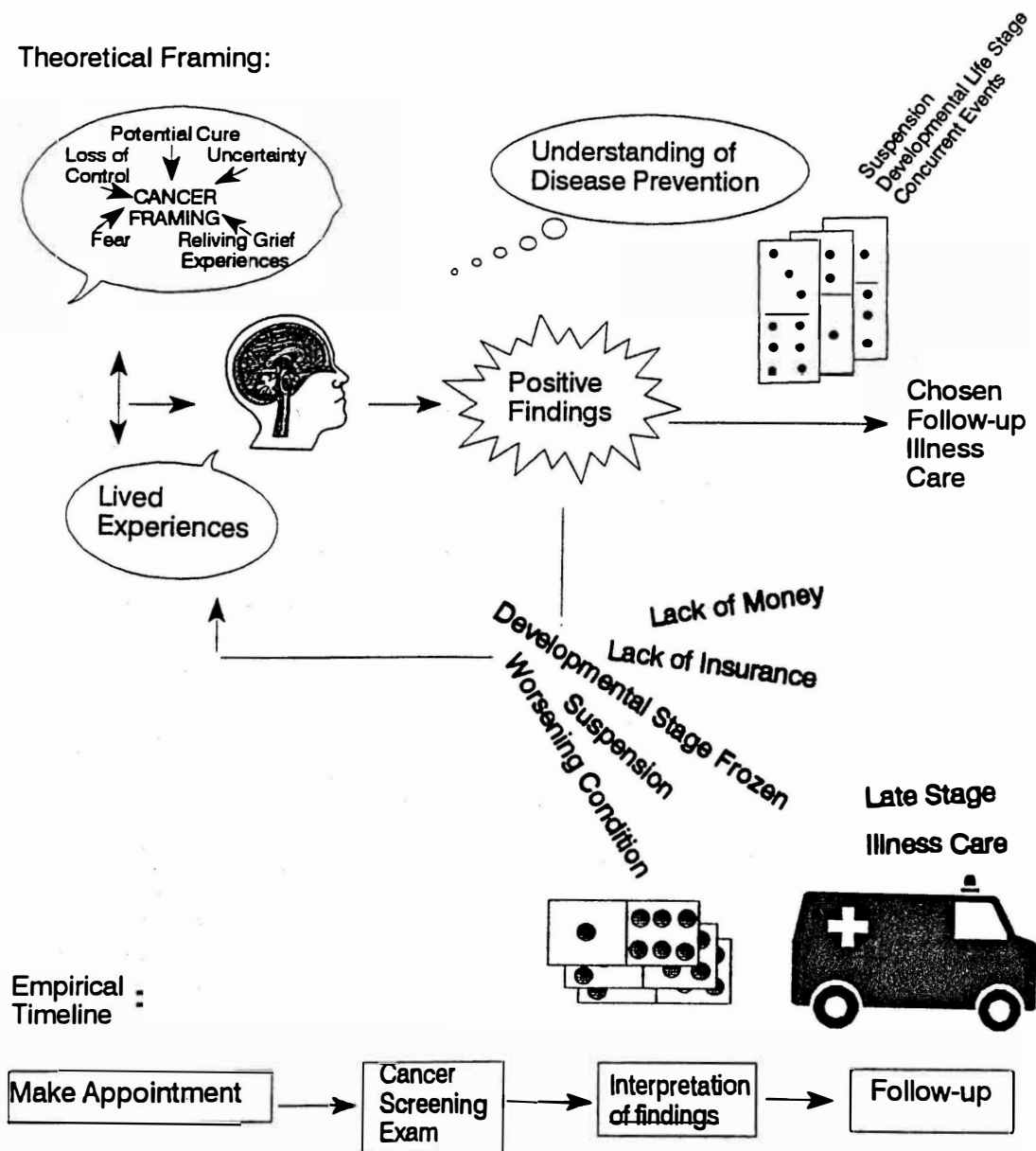
- 1.
- 2.
- 3.
- 4.

## **APPENDIX F**

### **Participant's Representation of the Theory of Cancer Screening Behaviors in Older Adults**



## Theoretical Framing:



**Figure 7.** Cancer screening behaviors in older adults

## APPENDIX G

## Coding List

1. Precursors

incurable	fear
death	inevitable
suffering	grief
deterioration	uncertainty
untimely	finality
conditional cure	guarding

2. Findings

confirmatory	uncertainty
scared	denial
control	relief
ambivalence	distrust

3. Decisions

lack of knowledge	priorities
perceived seriousness	external influences
lack of resources	unknowing
delay	eventuality