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Factors related to the information needs and desired level of participation of older women engaged in medical decision making

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Factors Related to The Information Needs And Desired Level Of Participation Of Older Women
Engaged In Medical Decision Making

Ronald Ralph Martin

Dissertation submitted to the Eberly College of Arts and Sciences
at West Virginia University
in partial fulfillment of the requirements
for the degree of

Doctor of Philosophy
in Psychology

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ABSTRACT

Factors Related to The Information Needs And Desired Level Of Participation Of Older Women Engaged In Medical Decision Making

Ronald Ralph Martin

Previous research suggests that older adults prefer less information and involvement in medical decision-making scenarios than younger adults. No previous research has empirically explored the factors that might influence the information and involvement preferences of older adults in medical decision-making scenarios. The present study involved an investigation of the influence of four factors on information and involvement needs: the complexity of the medical information, cognitive abilities, attitudes toward medical authority and health locus of control beliefs. Complexity was defined by contrasting reading levels (i.e., medical scenarios written at the 4th- vs. 11th-grade reading level). Cognitive abilities were measured using the Logical Memory subscale from the Wechsler Memory Scale and the following subscales from Wechsler Adult Intelligence Scale – Third Edition: Matrix Reasoning, Digit-Symbol Coding, Vocabulary and Digits Forward and Backward. Attitudes toward medical authority were assessed using an adaptation of a questionnaire developed by Haug and Lavin (1981). Health locus of control beliefs were assessed using the Multidimensional Health Locus of Control scale (Wallston, Wallston, & DeVellis, 1978) and the God Locus of Health Control scale (Wallston et al., 1999). Two, written medical scenarios were used; one involved breast cancer while the other involved cervical cancer. Sixty women, aged 60 years and over, participated in the study. Using Likert-type scales, participants were asked to rate how involved they would prefer to be in treatment and how much information they would prefer regarding nine topic areas (i.e., diagnosis, side effects of treatment, what the treatments do, likelihood of a cure, potential consequences of metastases, what the treatments do inside the body, effectiveness of treatment for other patients, examples of cases of treatment effectiveness and ineffectiveness). Principal component analyses were conducted to yield predictors that were subsequently used in multiple regression analyses. Results revealed that none of the four factors were significantly related to preferences for information in the two scenarios. Similarly, performance on the cognitive variables and manipulations of the complexity of the scenario were not related to preferences for involvement in the two scenarios. However, beliefs that one's health is controlled by external agents (e.g., a Higher Power, chance or powerful others) were related to preferences for less involvement within the cervical cancer scenario. In addition, preferences for less involvement were significantly correlated with decreased tendencies to believe in a patient's rights (i.e., rights to challenge medical authority, obtain information and make medical decisions) in medical settings. Implications of these results and suggestions for future research are provided.

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Factors Related to the Information Needs and Desired Level of Participation of Older Women

Engaged in Medical Decision Making

In everyday life, individuals are continually presented with decision-making situations. Over the course of a day, individuals make decisions about what to wear, what foods to eat, whom to interact with, and what activities to pursue. Given the ubiquitous nature of decision making in everyday life, it becomes a natural area of investigation for researchers. Decision making has been studied in laboratory settings and in everyday contexts. Traditionally, decision-making research took place in experimental settings. The decision-making contexts that were used were highly controlled and far removed from everyday life (i.e., decision-makers were provided with explicit goals as they worked on well-defined problems that occurred in static environments). Typically, the focus of traditional decision-making research was on the decision event. The decision event involves surveying a known and fixed set of alternatives, weighing the probable consequences of each alternative, and then choosing the best alternative based on stable goals and purposes (Orasunu & Connolly, 1993).

As mentioned above, decision-making research also may focus on everyday contexts (e.g., making financial or health decisions). In such contexts, problems are typically ill-structured, and occur in uncertain, dynamic environments. Further, these problems typically involve feedback loops, time stressors, potentially high stakes, the involvement of more than one individual, and shifting, ill-defined, or competing goals for the decision maker (Orasunu & Connolly, 1993). In contrast to traditional decision-making research, the focus of decision making research in everyday contexts does not rest principally on the decision event. Instead, the focus is broadened to include an emphasis on the interaction between the task characteristics and

the attributes of the decision maker (e.g., examining the interaction between various decision alternatives and the values of the decision maker).

Everyday decision making may occur in a wide variety of contexts. One such context involves medical decisions. A considerable amount of research has amassed regarding medical decision making. This is an important area of inquiry for several reasons. First, research studies may facilitate an understanding of the processes that influence medical decision making. Second, the application of research findings regarding medical decision making may lead to more effective decisions that would ultimately benefit patients. Third, research findings may improve the efficiency of medical decision making, in terms of the time and effort that are involved, for all interested parties (i.e., patients and health care professionals). Fourth, one might speculate that if the medical decision-making process was made more efficient, it might ultimately lead to decreased health care expenditures.

Medical decision making is especially relevant among older populations. This is because base rates of medical decision making are likely to be higher among older adults. In support of this proposition, older adults are considerably more likely than younger adults to be required to make medical decisions, as approximately 80% of this segment of the population have at least one chronic health condition (Segal, 1996). Further, people over the age of 65 use 25% of all drugs, account for 30% of all health care expenditures, fill one-third of all hospital beds, and account for 40% of visits to physicians' offices (Schaie & Willis, 1996). Given that older adults are, therefore, highly likely to be involved in medical decision making contexts, a better understanding of decision making among this segment of the population would be useful. One important fact to bear in mind is that older adults do not make decisions in isolation. They often

engage the assistance of others when making decisions. The involvement of other individuals is especially relevant in medical decision making contexts (i.e., older adults typically involve their physicians in the decision-making process).

Traditional and Modern Relationships Between Physicians and Patients

Traditionally, physicians have assumed a paternalistic role in the care of their patients, routinely taking primary responsibility for deciding among treatment options. Currently, however, physicians and patients are more likely to share this responsibility (Zwahr, 1999). This shift in the doctor-patient relationship is largely due to changes within the medical field. Currently, the doctrine of informed consent dictates that individuals have the right to participate in decisions about their medical care. This means that, provided individuals are of sound mind, they have the right to determine what is done to their bodies (Altman, Parmelee & Smyer, 1992). According to Appelbaum and Grisso (1988), physicians are required to inform their patients about the nature of their medical conditions, the proposed intervention, the likely risks, benefits, and discomforts, and any possible alternative interventions (Appelbaum & Grisso). Providing patients with information about their medical conditions and possible treatments allows the patient to make informed decisions and become more actively involved in the decision-making process.

Several beneficial effects have been associated with active involvement in medical decision making contexts (i.e., seeking information and participating in medical decision making). These include self-reports of decreased postoperative anxiety and depression (Morris & Royle, 1987), faster recovery (Wallace, 1986), less concern with illness, improved treatment effectiveness, greater satisfaction with physicians (Brody, Miller, Lerman, Smith, & Caputo,

1989); and a greater sense of control over one's body, health, and life (Hack, Degner, & Dyck, 1994). Given such beneficial effects, one might ask: "How prevalent is an active involvement in medical decision making, given such beneficial effects?" One would hope that most individuals would adopt an active role in medical decision making contexts. However, research indicates that differences do exist in the degree of involvement that is preferred.

Information Needs and Desired Level of Participation in Medical Decision Making

Intra- and inter-individual variability exists with respect to the amount and type of medical information that is desired, as well as the desired level of participation in medical decision making contexts. An individual patient may prefer more or less of certain types of information (e.g., information related to his or her diagnosis or prognosis), and greater or lesser involvement in the treatment decisions that are made. Similarly, groups of individuals (e.g., younger and older adults) also may differ in terms of their information needs and desired level of participation. Numerous research studies have been conducted that facilitate an understanding of the factors that influence information needs and the desired level of participation in medical decision making contexts.

Hopkins (1986) explored the relations between information seeking and various adaptational outcomes among 58 outpatients receiving chemotherapy for breast cancer. Respondents had a mean age of 54.7 years ($SD = 10.58$). The author developed an instrument to measure medical information-seeking, the Information Preference Questionnaire (IPQ). The IPQ required that participants rate on a five-point scale the statements that described their preferences for treatment information. The authors explored the relation between the IPQ and measures of: 1) mood states; 2) level of functioning; 3) chronological age; 4) severity of illness; 5) years of

education; and 6) racial background. No significant relations were observed between information seeking and mood states, functional status, level of education, or racial background. However, the results did reveal that information seeking was negatively related to the participants' age and severity of disease. That is, less information was desired among older patients, and patients whose illness was more severe.

Beisecker (1988) explored the desire for information and input in medical decisions among 106 rehabilitation medicine patients ranging in age from 17 to 85. The authors were interested in studying consumerist attitudes in medical contexts. Consumerist attitudes were reflected in the belief that patients should be active in the physician-patient relationship, and that patients should ask their physicians for information. The author created the Locus of Authority Scale that was designed to determine who the patient felt should make medical decisions (i.e., the patient, the doctor, or both individuals) in 13 areas (e.g., whether to change medications). The author also created the Desire for Medical Information Scale, to determine how important it was for the patient to have information in each of the areas covered in the Locus of Authority Scale. The results revealed that all patients, regardless of age, wanted a great deal of medical information about a wide variety of medical topics. However, as age increased, there was less of a tendency to believe in patients' rights to make medical decisions or to challenge the physician's authority, and more of a tendency to place the locus of authority in the hands of the physician. In contrast, younger patients were more likely than older patients to desire a collaborative role with their physicians in the decision making process. Beisecker also monitored patient-physician communication and found that participants of all ages assumed a passive role. It was concluded that the older adults exhibited congruence between their beliefs about the role

of a patient and their communication with physicians (i.e., passive styles). In contrast, younger adults endorsed consumerist beliefs, but exhibited a passive communication style with physicians.

Ende, Kazis, Ash, and Moskowitz (1989) investigated the desire to be informed and the desire to make medical decisions among a sample of 312 outpatients, aged 18 to 65 years and over. The authors constructed an instrument, the Autonomy Preference Index (API), which consisted of two scales: an eight-item scale measuring information seeking, and a 15-item scale measuring decision making preference. The decision making scale contained three vignettes of varying illness severity (e.g., upper respiratory tract illness represented mild illness severity, whereas myocardial infarction represented severe illness severity). The authors found that although patients strongly wished to be informed, they preferred to leave the decisions to their physicians. The authors further reported no correlation between the patients' decision making and information-seeking preferences. An inverse relation was observed between the desire to be actively involved in the decision-making process and the severity of the illness. In addition, the desire to be informed and make medical decisions was inversely related to age. Results from stepwise regression analyses indicated that 19% of the variance for decision making and 12% of the variance for information seeking could be accounted for using sociodemographic and health status variables as predictors. The authors suggested that other individual characteristics (e.g., cultural background) may be key variables in understanding preferences for decision making responsibility and information.

Beisecker and Beisecker (1990) examined information-seeking behaviors among 106 rehabilitation medicine patients, ranging in age from 17 to 85 years. The authors used the Desire

for Medical Information and Locus of Authority in Medical Decision Making Scales. In addition, the authors observed the communication between patients and physicians to determine the frequency of information-seeking comments made by patients. Results revealed that all patients desired information regarding a wide variety of medical topics but did not exhibit many information-seeking behaviors when interacting with their physicians. Hierarchical multiple regression analyses were performed to investigate to what extent information-seeking communication behavior was related to 17 antecedent variables (e.g., the two scales mentioned above, demographic variables, situational variables such as type of illness, the physician seen, and the length of the interaction). Results revealed that situational variables (i.e., the length of the interaction, the patient's diagnosis, and the specific reason for the patient's visit) were better predictors of information-seeking behaviors than demographic information, the two attitudinal scales measuring information-seeking and decision-making responsibility, or the physician seen.

Degner and Sloan (1992) investigated differences in preferred levels of participation in the selection of treatment options among patients and community-dwelling individuals. The authors recruited 436 newly-diagnosed cancer patients with a mean age of 59 years ($SD = 13.9$ years), and 482 members of the general public with a mean age of 42 years ($SD = 16.4$ years). Two sets of five cards were used to examine decision making preferences. The first set of five cards illustrated the decision-making roles that patients and physicians could assume, ranging from complete patient autonomy (i.e., active role) to a shared responsibility (i.e., collaborative role) to a situation where the physician alone makes the decision (i.e., passive role). The second set of five cards were designed to measure the patients' preferences regarding who would make treatment decisions on their behalf should they become too ill. The options ranged from

complete family autonomy, to a shared responsibility between physicians and family members, to a situation where the physician made the decision alone. Results revealed that among newly-diagnosed cancer patients, 59% preferred a passive role, 29% preferred a collaborative role, and 12% preferred an active role. In contrast, among the general public group, 9% desired a passive role, 27% desired a collaborative role, and 64% desired an active role. Further, most patients (i.e., 51%) and members of the general public (i.e., 46%) wanted their physician and family members to collaborate in decision making matters if they became too ill to participate. An inverse relation was noted between age and the desire for decision-making control in both participant samples. Among the patient sample, females and more highly educated individuals preferred more control. Further, the authors concluded that sociodemographic variables (i.e., age, gender, education) were not very useful in making predictions about which groups would prefer to be more or less active in decision making, as they accounted for only 15% of the variance in participant preferences.

Thompson, Pitts, and Schwankovsky (1993) explored the factors that may predict desire for involvement in medical decision making among 459 health maintenance organization members, ranging in age from 19 to 98 years. The authors hypothesized that there would be less desire for involvement in medical decisions that required medical knowledge (e.g., which treatments to suggest), and more desire for involvement in scenarios that did not require medical expertise (e.g., deciding which treatment effects are preferred based on one's priorities and values). For example, physicians may be able to decide what treatment options are appropriate for patients to consider, but patients may be in the best position to make decisions about the final treatment selection based on how much they value quality of life versus length of life. In

addition, the authors predicted that younger, female, and better-educated patients would prefer more involvement. The API (Ende et al., 1989) was used to assess desire for involvement in scenarios that require medical expertise. A scale to evaluate desire for involvement in situations that do not require medical expertise, the Desire for Involvement Questionnaire (DIQ), was developed by the authors. The DIQ consisted of four vignettes that described medical problems of varying severity (e.g., stress headaches, a cancerous growth). Each vignette described two treatment choices that were equally appropriate (i.e., to remove the necessity for medical expertise), but differed in the effects exacted upon the patient's lifestyle. Results revealed that patients expressed more desire for involvement in decisions that did not require medical knowledge than they did for decisions requiring such expertise. Further, younger, more-educated patients preferred more involvement than older, less-educated patients on all questionnaires. No gender differences were observed for desire for involvement. The authors concluded that although patients are content to allow their physicians to select medically-appropriate treatments, they do want to be more actively involved in decisions that do not require medical expertise (e.g., lifestyle changes, pain experienced, inconvenience).

Galloway (1994) explored the types of information that were desired by 114 women who were being treated for newly-diagnosed breast cancer. The author developed the Information Needs Questionnaire-Breast Cancer (INQ-BC), which contained the following subscales: Diagnosis, Investigative Tests, Treatments, Physical and Psychosocial. Information needs of all women were high, regardless of the treatment selected. Information needs were greatest for the Diagnosis or Treatment subscales. Marital status, level of education, and level of income were not related to information needs. However, an inverse relation was observed between age and

information needs.

Hack et al. (1994) examined the relations between preferences for involvement in making treatment decisions and preferences for information about diagnosis, treatment, side effects, and prognosis. The authors recruited a sample of 35 women, ranging in age from 32 to 83 years, with stage I and II breast cancer. In designing their study, the authors criticized past research on medical information needs for treating the topic as unidimensional (e.g., asking participants whether they prefer more or less information), and for using crude measures that lack empirical validation. The authors hypothesized that those patients who preferred a more active role would desire a greater amount of detailed information about their illness (e.g., the disclosure of their diagnosis, treatment options and risks involved, explanations of treatment procedures, and information about all side effects and proposed remedies). Preference for involvement was assessed using the card sort procedure described by Degner and Sloan (1992). Information needs for various treatment information (e.g., diagnosis, treatment alternatives, prognostic information) were also assessed via card sort. Patients who desired an active role in choosing their treatments wanted more detailed information about their medical care (i.e., they expressed a desire for more information about their diagnoses, a written copy of their diagnoses, treatment alternatives and associated risks, and treatment procedures). A content analysis of participants' responses revealed that patients preferring a more active role expressed such a desire because it gave them a sense of control over their body, health, and life. In contrast, passive patients felt that although they wanted to be informed of treatment decisions, it was necessary to place faith in their physicians because only their physicians possessed the relevant medical expertise. The results also indicated that age was not associated with preferences for involvement in the decision-

making process.

Davison, Degner, and Morgan (1995) recruited a sample of 57 men with prostate cancer, with a mean age of 71 years, to determine if a relation exists between preferences for involvement in medical decision making and the type of information that was rated as important. Preferences for involvement were assessed using the card sort technique developed by Degner and Sloan (1992). The participants' information needs were explored by soliciting ratings of importance for nine categories of information (e.g., stage of disease, likelihood of cure) that were presented two at a time, in all possible combinations. The nine categories of information were also rated using a Likert-type scale to determine how much information would be desired, ranging from 1 (almost nothing) to 4 (almost everything). The results revealed that most men (i.e., 57.9%) preferred a passive decision-making role, 23% preferred a collaborative role, and 19% desired an active role. The majority of men wanted a little bit to almost no information about the effects of the treatment on unusual sexual activity, and a fair bit to almost everything on the remaining eight categories of information. The participants' information needs primarily concerned disease advancement, likelihood of cure, and types of treatment available.

Meyer, Russo, and Talbot (1995) conducted two studies to examine medical decision making among 94 women, ranging in age from 18 to 88, in response to an unfolding health scenario about breast cancer. In the first study the women were asked to make medical decisions regarding a scenario about breast cancer, and provide rationales for their decisions. Older women made the same decisions as younger women with respect to the treatments selected. However, the older participants sought less information when making their decisions, and made these decisions in less time than younger participants. Older participants were less likely to provide a

rationale for their decisions. Further, when rationales were provided by older adults, they were less systematic than those provided by younger adults. The rationales provided by older participants focused on the need for an immediate decision before the cancer had time to spread, whereas the rationales stated by younger participants tended to focus on the need for second opinions and gaining knowledge about the disease and treatment options. The authors indicated that younger participants adopted Sinnott's (1989) mature decision-making style, whereas older adults tended to adopt a top-down processing approach.

The second study conducted by Meyer et al. (1995) involved a sample of 75 women who had been recently diagnosed with breast cancer. Participants were asked to describe their treatment decisions. In addition, they also were asked to describe the factors that influenced their treatment decisions, and also the degree to which they felt compelled to either make a quick decision, or delay making a decision to provide more time for data gathering, second opinions, and personal reflection. Similar to the first study, the results revealed that older participants took less time than younger participants to make a treatment decision, without seeking much additional information (e.g., second opinions). Again, older participants described their decision-making strategy in terms of needing to make treatment decisions before the cancer had a chance to spread, whereas younger participants characterized their strategy as involving a need for more information.

Luker et al. (1995) investigated the information needs of a group of 150 women, ranging in age from 32 to 84 years, who were newly diagnosed with breast cancer, and a control group of 200 women with benign breast disease, ranging in age from 18 to 70 years. Nine information needs that were identified by Degner, Farber, and Hack (1989) as being important to cancer

patients were evaluated in this study. A questionnaire was developed that presented the nine information needs in all possible pairwise combinations ($n=36$). Participants were asked to indicate which of two information needs in each combination had the greater importance. For both participant groups, information about the likelihood of a cure was ranked as most important, followed by information regarding the spread of the disease and possible treatment options. The next most important items, in descending order of importance, were information regarding: the risk to family members of getting cancer, the side effects of treatment, the emotional impact on family, self-care, and the effect on social life and sexual attractiveness.

Bilodeau and Degner (1996) conducted a study to determine the preferred and actual roles in medical decision making among 68 women with newly-diagnosed breast cancer, and to describe their sources of information and priority of information needs. Role preference was assessed using the card sort procedure described by Degner and Sloan (1992). Participants were asked to rank order their preferred sources of information about their disease. The sources included friends or relatives, brochures, videotapes, physicians, medical journals or textbooks, nurses, newspapers, womens' journals, and television or radio. To assess information needs, participants were asked to rate the importance of nine categories of information that were presented two at a time, in all possible pairwise combinations ($n = 36$). The results indicated that 43% of women preferred, and 57% actually assumed a passive role in medical decision making. This trend was especially true of older women in the sample. Further, although 37% of women preferred to adopt a collaborative relationship with their physicians, only 19% were able to assume such a role. Personal sources of information (i.e., physicians, nurses, friends or relatives) were preferred over written sources of information. Primary information needs included stage of

disease, likelihood of a cure, and treatment options.

Degner et al. (1997) recruited a sample of 1012 women ($n = 210$, aged 70 years and over) with a confirmed diagnosis of breast cancer, to investigate their preferred degree of involvement in medical decision making, the extent to which they felt they had achieved their desired level of involvement, and the types of information they believed to be most important. Preferred degree of involvement was measured using the card sort procedure described by Degner and Sloan (1992). Patients' priorities for nine categories of information were assessed using the identical materials and procedure as outlined above in Luker et al. (1995). Twenty-two percent of women preferred to select their own treatment, 44% wanted to select their treatment collaboratively with their physicians, and 34% desired to delegate the decision to their physicians. Surprisingly, only 42% of women felt that they had achieved their preferred level of involvement in decision making. The results of regression analyses indicated that younger, more highly-educated women desired more control in decision making. Also, women who were closer to the time of diagnosis preferred a less active role. Overall, women older than 50 years were half as likely as women younger than 50 to desire active roles. Further, women older than 70 years were approximately one fifth as likely than women younger than 50 years to desire active roles. Overall, the highest priority information needs involved knowing the chance of a cure, and the stage of the disease. Information regarding sexuality was regarded as least important.

Turk-Charles, Meyerowitz, and Gatz (1997) examined the use of two types of information sources: medical sources (i.e., doctors and nurses), and non-medical sources (i.e., television, newspapers, and friends) among 75 cancer patients, ranging in age from 18 to 81 years. Information seeking from medical sources was measured using the Information Scale from

the Krantz Health Opinion Survey (Krantz, Baum, & Wideman, 1980). This scale contains statements about receiving medical information when interacting with health care professionals (e.g., “I usually don’t ask the doctor or nurse many questions about what they’re doing during a medical exam”). The frequency of seeking information from various non-medical sources was assessed using three items (e.g., when there are shows on television about cancer, do you...). Questionnaires also assessed the patients’ desire for more cancer information, self-perceived knowledge about cancer, and actual knowledge about cancer. The results revealed that information seeking from the medical establishment decreased with age. However, no age differences were observed for non-medical establishment information seeking. The authors suggested that age-related differences in information seeking that are reported in the literature may reflect the failure to consider other sources of medical information (i.e., media and friends). The results of regression analyses indicated that for non-medical information seeking, the patients’ desire for information, self-perceived knowledge, and age were significant predictors. In contrast, for medical establishment information seeking, age and education were the only significant predictors.

Arora and McHorney (2000) investigated the determinants of preferences for participation in medical decision making among 2197 patients with a wide variety of chronic diseases (e.g., hypertension, diabetes, myocardial infarction, congestive heart failure, and depression). Participation preference was measured using a single item “I prefer to leave decisions about my medical care up to my doctor,” with a 5-point Likert-type scale to indicate level of agreement. Patients who “strongly agreed” or “agreed” were categorized as passive, whereas those who “disagreed” or “strongly disagreed” were categorized as active. Logistic

regression analyses were performed using several predictors (i.e., sociodemographic, clinical diagnosis data, and psychosocial variables). The authors hypothesized that more active preferences for involvement would be predicted by: younger age, Caucasian race, female gender, being employed, being unmarried, having a higher socioeconomic status, less health distress, more active lifestyle, more active coping, and greater social support, value on health, and will to function. The authors found that the majority of patients (i.e., 69%) preferred to leave their medical decisions to their physicians. However, certain patient characteristics were associated with preferences for a more active role in decision making. These characteristics included being younger, more educated, and female. In addition, patients of all ages with unsevere hypertension were more likely to prefer an active role than those with severe diabetes and individuals with unsevere heart disease. Further, patients who pursued active coping strategies were more likely to assume active roles in medical decision making than passive copers.

Possible Reasons for Age-Related Differences

The literature reviewed in the preceding section highlights the fact that younger and older adults may tend to seek different amounts of information and levels of involvement in medical decision making contexts. In general, research studies typically indicate that older adults seek less information than younger adults regarding medical problems, and prefer less active roles in the decision making process. The question that arises is: Why does this occur? Authors such as Meyer et al. (1995) have proposed several potential reasons for the age-related differences. However, there has been a scant amount of research that has directly targeted this issue.

Cognitive factors associated with medical decision making. Zwahr, Park, and Shifren (1999) suggested that older adults may be less active in medical decision making due to age-

related declines in various cognitive abilities that are involved in the decision-making process.

What cognitive abilities are involved in medical decision making? According to Appelbaum and Grisso (1988), memory, comprehension, reasoning, and the mental manipulation of information (i.e., working memory) are integral in arriving at medical decisions. In addition, Zwahr et al. proposed that two other cognitive abilities may be involved in the decision making process: verbal ability and perceptual speed (i.e., the speed at which mental operations take place). The author cited the research of Meyer et al. (1995) that indicated that verbal ability (i.e., a composite measure of text memory and vocabulary) explained unique variance in several decision making variables (e.g., the number of treatment options considered). Perceptual speed also may be important in medical decision making, given that Salthouse (1993) reports that perceptual speed accounts for a large percentage of variance in measures of memory, working memory, and reasoning ability. Zwahr et al. reviewed the literature pertaining to cognitive changes across adulthood and found evidence for age-related declines in the cognitive abilities that contribute to medical decision making performance (i.e., text memory, comprehension, reasoning, the mental manipulation of information, and perceptual speed), with the exception of vocabulary skills.

Zwahr et al. (1999) recruited a sample of 102 women, ranging in age from 20 to 79, to assess the role of cognitive abilities and other relevant factors (e.g., prior knowledge, personal experience) in making a medical decision regarding estrogen replacement therapy. Cognitive abilities were assessed via measures of text memory, verbal ability, reasoning ability, working memory, and perceptual speed. Dependent measures included the number of treatment alternatives that were generated, the number of comparisons made among treatment alternatives,

and the quality of the rationales that were provided in support of chosen treatments. The results revealed age-related differences in the measures of cognitive abilities, with the exception of verbal ability. Also, individuals with higher cognitive abilities perceived more treatment options, made more comparisons among treatments, and produced higher quality rationales for their medical decisions. Given this relation between cognitive abilities and decision making, the author suggested that the more passive involvement of older adults in making medical decisions may be due to declining cognitive abilities. It was also reported that personal experience and prior knowledge played minor roles in the decision-making process.

Royall, Cordes, and Polk (1997) explored the independent contributions of general cognition, executive control function, age, education, and medication usage, to the comprehension of medical information among 105 elderly retirees, aged 70 years and over. Executive control function was defined as those cognitive abilities that organize basic ideas, movements, or actions into more complex, goal-directed behavior. General cognition was assessed using the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), executive control function was measured using the Executive Interview (EXIT25; Othmer & Othmer, 1994; Royal, Mahurin, & Gray, 1992), and comprehension was measured using the Hopkins Competency Assessment Test (HCAT; Janofsky, McCarthy, & Folstein, 1992). Individuals who failed to reach criterion on the HCAT were given the test again at a lower reading level, thus producing two comprehension scores. The authors conducted separate stepwise multiple linear regressions, using the two comprehension scores as the criterion variables. In both analyses, the predictor variables were entered in the following order: EXIT25, MMSE, age, and education. Both regression models revealed that the addition of MMSE scores

produced a significant change in the variance explained. Further the combination of the EXIT25 and MMSE variables accounted for 71% and 72% of the variance in the two comprehension scores. The addition of the age variable did not reliably produce significant increases in the amount of explained variance (i.e., age was a significant predictor using the first measure of comprehension, but was not a significant predictor using the final measure of comprehension). In both analyses, education failed to significantly contribute to the models. The study conducted by Royal et al. would suggest that information regarding cognitive abilities may be more valuable in understanding certain aspects of decision making performance than demographic information.

Expertise about medical conditions. Older adults arguably possess a greater degree of expertise (i.e., procedural and factual knowledge base) about health-related issues than younger adults (Meyer et al., 1995). This expertise may have accumulated from multiple sources, including personal experience, the experiences of friends and relatives, various media, and other educational sources. It seems reasonable that this expertise would be accessed within medical decision-making contexts. Therefore, older adults may feel that they require less information prior to making medical decisions. The influence of prior knowledge and experience may be seen in the medical decision making process. Meyer et al. (1995) administered a pretest assessment of knowledge about breast cancer to a sample of women who were diagnosed with the disease. Participants were asked to write down everything they knew about breast cancer. Prior knowledge was indexed by the number of words written and the number of expressed ideas that were related to the treatment options contained within the study. Prior knowledge was not greater among older adults. This may have been due to the requirement that participants write their answers (i.e., older adults may have had more difficulty writing their responses due to

chronic conditions such as arthritis). However, while prior knowledge did not predict the amount of information that was desired, it did help to determine the treatment options that were ultimately selected (i.e., pretest beliefs regarding treatment options were strong predictors of the treatment options that were later selected). This prior knowledge persisted in influencing decision making despite the presentation of information regarding additional treatment alternatives.

Health locus of control. One's level of involvement in medical decision making may depend on one's health locus of control. Individuals may believe that their health is more or less under their own control, controlled by external forces (e.g., health care professionals), or due to chance. To the extent that one's health locus of control is externally-based (i.e., unrelated to one's actions), one may be less inclined to desire information or active participation in medical decision-making contexts. To measure health locus of control, Wallston, Wallston, and DeVellis (1978) developed the Multidimensional Health Locus of Control (MHLC) scale which contained the following subscales: internality (IHLC), powerful others (PHLC); and chance (CHLC) externality.

Wallston et al. (1999) recognized that one's health locus of control may be influenced by religious beliefs (i.e., the belief that a "Supreme Being" may determine one's health). Park and Cohen (1992) summarized survey data collected from adults in the United States, indicating that 94% believe in God, 90% pray to God, and the majority actively practice their religion. Further, other studies have indicated that religiosity (i.e., frequency of prayer, religious affiliation, religious devotion) increases with age across adulthood (Bergan & McConatha, 2000; Levin & Taylor, 1997). Recognizing the prevalence of religious beliefs, Wallston et al. developed the

God Locus of Health Control Scale (GLHC) to assess the extent of an individual's belief that God controls his or her health status. Given that religiosity is more prevalent among older adults than younger adults, it is possible that older age groups may be more likely to place their medical decision-making responsibilities in the hands of God. This also may explain, in part, why older adults desire less information and a more passive role in medical decision making contexts.

Complexity and wording of textual medical information. Older adults may desire less information and more of a passive role in medical decision making than younger adults because the information that is presented to them is too complex (i.e., the information is lengthy and written at an advanced reading level with highly technical terms). To illustrate this possibility, consider the medical scenario used by Meyer et al. (1995):

“At your annual physical examination your physician found a lump in your left breast. You were referred to a surgeon after having a mammogram and ultrasound [italics added]. The surgeon discussed the results of these tests with you. The mammogram [italics added] showed greater density within the upper outer quadrant [italics added] of the left breast that could represent some localized dysplasia or lobular hyperplasia (benign breast lumps associated with a fibrocystic, noncancerous condition) [italics added], but there was no radiographic [italics added] evidence for cancer. The ultrasound showed a solid rather than fluid-filled mass [italics added]. The surgeon explained that it was probably not cancer and that most (80%) of such lumps are not cancer. However, the surgeon said that you couldn't know for sure without taking out the lump and sending it to a pathologist [italics added] to examine. The surgeon gave you three choices: One, take the lump out (a lumpectomy - a half day in the hospital with your choice of local or

general anaesthesia) as soon as surgery could be scheduled. Two, wait for a half year or so and then have the surgery when it was convenient. Three, have a needle biopsy (a simple procedure that samples some cells from the lump). However, the surgeon warned that this procedure could only test the cells sampled and not examine the entire lump” (p. 101).

This scenario, which was the shortest of three scenarios used by Meyer et al. (1995), is arguably complex, based on the length of the passage, and the usage of technical medical jargon (i.e., the italicized terms). Increasing the complexity of medical scenarios would arguably place more of a demand on the cognitive resources that are utilized during medical decision making (e.g., memory, comprehension, reasoning, and the manipulation of stored information). Supporting evidence may be drawn from Tymchuk, Ouslander, Rahbar, and Fitten (1988) who presented informed consent vignettes to a sample of 70 elderly adults in a long-term care facility in a standard, simplified, or storybook format. Standard format vignettes were written at a high school reading level. Simplified vignettes featured simplified grammatical structures and words with a higher usage frequency. The storybook format included the same information contained in the simplified format, along with one-page drawings to illustrate a single concept within each vignette. The simplified and storybook vignettes were written at a fifth-grade reading level. A comprehension test was administered following each vignette, and again following an interval of one week. The authors also developed a rating scale that was used to assess the quality of the participants’ decision-making ability. Results revealed that comprehension was significantly better for the simplified and storybook formats upon immediate testing, and at the one-week follow-up. Further, ratings of the participants’ decision making ability were also higher for the

simplified and storybook formats. In general, the study conducted by Tymchuk et al. suggests that increasing the complexity of medical information places greater demands on the cognitive resources of older adults (e.g., reasoning abilities). Previous research has documented that several cognitive abilities that are relevant to decision making (e.g., reasoning, working memory) evidence age-related decline (Zwahr et al., 1999). This may discourage older adults from seeking information and assuming an active role in their medical decision making, when complex information is involved.

The wording of medical information also may influence the medical decision making process. Malloy, Wigton, Meeske, and Tape (1992) recruited a sample of two hundred and one community-dwelling, elderly adults to determine whether the wording of the descriptions of life-sustaining treatments would affect the choices elderly participants made when completing advance directives. Participants were asked if they would accept or reject three life-sustaining interventions (i.e., cardiopulmonary resuscitation, mechanical ventilation, or tube feeding) that were described positively, negatively, or exactly as they appear in a widely-used advance directive. Positive descriptions emphasized the beneficial aspects of the interventions. Negative descriptions highlighted the risks, side effects, and included harsh phrasing. Each participant reviewed each scenario three times with three different descriptions of the interventions. The results indicated that participants opted for the intervention 12 percent of the time when it was worded negatively, 18 percent of the time when it was described in a format that is widely used, and 30 percent of the time when it was described positively. This would suggest that task characteristics that are involved in the decision-making process (e.g., the way the medical scenarios are presented) may influence the decision-making process.

Cohort differences in attitudes toward medical authority. Beisecker (1988) suggested that younger age groups may hold consumerist attitudes regarding the medical profession (i.e., beliefs that physicians are providing a service, and therefore may be questioned). Although no studies have been conducted to address this issue, it is possible that older cohorts may be more likely than younger cohorts to: 1) place a great deal of trust in physicians; 2) have a great deal of respect for the opinions and recommendations of physicians; 3) not question the medical authority of physicians; 4) think of physicians as infallible; 5) strictly obey the orders of physicians; 6) view the medical profession as being highly prestigious; 7) consider physicians as possessing power beyond most other professionals; and 8) consider physicians to be extremely intelligent and thus elite individuals. If these possibilities are generally more characteristic of older cohorts, it may explain, in part, why older adults tend to seek less information and more passive roles in medical decision-making contexts.

Delegation. Older adults may seek less information and adopt more passive roles in decision-making contexts simply because they are more likely than younger adults to delegate tasks to others. Yates and Patalano (1999) suggested that as people age, they are more likely to “commission” others to make decisions for them. The authors suggested that the tendency of older adults to relinquish decision-making responsibility in medical contexts may be due to several factors, including: 1) cohort effects that reflects the traditional, paternalistic relationship between physicians and patients; 2) the suspicion that their personal decision-making skills are diminishing; 3) the amount of effort involved in the decision-making process; 4) economic reasons (i.e., given that older adults may be in a more secure financial position than younger adults, they may be more used to delegating decision-making responsibilities to competent

others); and 5) cultural reasons (i.e., the value of self-reliance in decision making may become less important in North American society as we age).

Conservation of resources. The experience of having an illness or disease is usually associated with a drain on one's mental and physical resources. Leventhal, Leventhal, Schaefer, and Easterling (1993), suggested that health-related strategies used by older adults may change and become more efficient across adulthood. For example, older adults may be less inclined to monitor health problems over lengthy periods of time prior to seeking help from their physicians. A more efficient strategy for older adults may be to access medical attention quickly to avoid unnecessary anxiety and tension that may drain their physical and mental energy. In support of this hypothesis, Leventhal et al. (1993) noted that, in contrast to middle-aged adults, older adults were quicker in seeking medical attention, and sought less information regarding their illness. This would suggest that older adults may conserve their physical and mental energy by quickly turning their medical problems over to their physicians. Further support was provided by Meyer et al. (1995) who found that, in contrast to younger women, older women were quicker in making decisions about their breast cancer treatments, without seeking additional information. The older women explained that they made their decisions quicker and with less information because they did not want to give the cancer time to spread. This strategy would seem to support the notion that the older women were attempting to conserve their mental (i.e., emotional) and physical resources, as the spread of cancer may overtax these resources. Based on these studies, it seems reasonable to assert that older adults may desire a more passive role in medical decision making contexts (i.e., desire less information and a more passive role) to conserve diminishing physical and emotional resources. Seeking information and forming collaborative relationships

with physicians arguably takes time and effort and therefore lengthens the time that illnesses may go untreated. Therefore, lesser involvement in the decision-making process serves to avoid delays to treatment, therefore conserving physical and emotional resources.

The Dynamic Nature of Information Needs and Desired Level of Participation

It is arguable that information and involvement preferences may vary in response to the emotional salience of a medical diagnosis and the recency of the diagnosis. Previous research cited above has indicated that more emotionally salient diagnoses (e.g., diagnoses involving serious threats to health or one's life) may be associated with reductions in medically-related information and involvement needs. Further, individuals who receive a cancer diagnosis may initially exhibit emotional responses (e.g., depression, anger) that may limit their ability to absorb information or take part in medical decision making. Other reactions may include the denial or refusal of a cancer diagnosis which might also lead individuals to seek little or no information or involvement. As time progresses, individuals may experience changes in their readiness and willingness to acknowledge and deal with their diagnoses. In this manner, information and involvement preferences may be described as being dynamic.

Gender Differences Regarding Information Needs and Desired Level of Participation

Previous research indicates that gender differences may exist in health care practices. Women may be more likely than men to consult their general practitioners and make use of health care services (Cleary, Mechanic, & Greenley, 1982; Hibbard & Pope, 1983; Malterud & Okkes, 1998). Further, women may be more proactive than men in alerting others about health problems (Ashton, 1999). This suggests that gender differences may exist with respect to preferences for involvement and information-seeking in medical decision making scenarios.

Among samples of individuals with cancer and other chronic diseases, women have been reported to indicate a preference for more involvement and control than men (Arora & McHorney, 2000; Degner & Sloan, 1992). Similarly, Blanchard et al. (1988) reported that males outnumbered females in groups of adult, hospitalized cancer patients who did not want to participate in medical decision-making. However, when preferences for information are examined, researchers generally have not found evidence for gender differences (Blanchard et al., 1988; Thompson, Pitts, & Schwankovsky, 1993).

Statement of the Problem

Older adults tend to seek less information and participate less in medical decision making than younger adults. This statement regarding the relation between age and preferences for information and involvement is not expressed in absolute terms, as research findings have been mixed. Some studies have indicated that older adults seek less information than younger adults when confronted with medical decisions (e.g., Ende et al., 1989; Hopkins, 1986; Galloway, 1994; Meyer et al., 1995; Turk-Charles et al., 1997). However, other studies have indicated that older and younger adults seek similar amounts of information regarding medical procedures (e.g., Beisecker, 1988; Beisecker & Beisecker, 1990), and aspects of medical decisions that do not require medical expertise (e.g., Turk-Charles et al., 1997). Further, while some researchers have found that older adults seek a more passive role in the decision-making process (e.g., Arora & McHorney, 2000; Beisecker, 1988; Bilodeau & Degner, 1996; Degner et al., 1997; Degner & Sloan, 1992; Ende et al., 1989; Thompson et al., 1993), other researchers have not found age-related differences (e.g., Beisecker & Beisecker, 1990; Hack et al., 1994). Despite the fact that the research findings to date are mixed, the majority of studies indicate that older adults typically

seek less information from their physicians regarding their medical treatments, and desire a more passive role in the decision-making process than younger adults. This tendency has been observed despite the fact that there appear to be advantages to more active involvement in the medical decision making process (Brody et al., 1989; Hack et al., 1994; Morris & Royle, 1987; Wallace, 1986).

Numerous research studies have been conducted to better understand the variables that are related to information seeking and preferred levels of involvement in medical decision making contexts. Previous research has addressed the relations between the desire for information and: mood states and functional status (Hopkins, 1986); actual information-seeking behaviors with physicians (Beisecker, 1988; Beisecker & Beisecker, 1990); the type of information desired (Luker et al., 1995); the time to decision, quality of decisions made, influence of previous knowledge, and health locus of control (Meyer et al., 1995); and the frequency of accessing medical sources of information versus non-medical sources of information (Turk-Charles et al., 1997). Previous research has also addressed the relations between the preferred level of involvement in medical decision making and: the severity of the medical scenario (Ende et al., 1989); the presence or absence of disease (Degner & Sloan, 1992); actual information-seeking behaviors (Beisecker, 1988; Beisecker & Beisecker, 1990); preferred level of involvement, information sources, and priority of information needs (Bilodeau & Degner, 1996); the type of information desired and the extent to which individuals achieved their desired level of involvement (Degner et al., 1997); the degree of medical expertise required to make informed choices (Thompson et al., 1993); and the amount of detailed information desired, as well as the type of information desired (Hack et al., 1994). While the studies cited above have

reported differences between younger and older adults with respect to preferences for information and involvement in medical decision making, the primary focus of these studies was not on age-related differences. Therefore, researchers have been forced to offer post-hoc, tentative hypotheses regarding the reasons for age differences in information seeking and preferred levels of involvement in medical decision making. Several hypotheses regarding these age differences have yet to be investigated. For example, no previous research has investigated whether cognitive performance is related to the amount of information that is desired or the preferred level of involvement in decision making tasks. In addition, no studies have investigated whether one's health locus of control is related to the desire for information and involvement in medical decision making tasks. Further, while studies have suggested that age differences in information needs and desired levels of participation may be related to cohort differences in attitudes toward medical authority, no studies have attempted to address this hypothesis empirically. Finally, no prior studies have determined how information needs and desired levels of participation may be affected by the complexity of the medical scenarios.

In addition to the foregoing, several conceptual and methodological problems have confounded the results of past research that has addressed the desire for information and preferred level of involvement in medical decision making. To date, most studies have conceptualized information seeking as either a categorical variable or continuous variable. In other words, researchers typically have asked either for the types of medical information that are desired, or how much information is desired. From a conceptual standpoint, it is important to realize that both forms of information seeking are informative and useful. Individuals might prefer different types of medical information (i.e., information seeking as a categorical variable),

and different amounts of information within categories (i.e., information seeking as a continuous variable). A more comprehensive understanding of information seeking within medical contexts would be achieved if one would examine the interaction between categorical and continuous measures of information seeking.

From a methodological standpoint, various procedural differences also have confounded the results of past research. For example, Meyer et al. (1995) asked participants to describe their medical decision making process in writing. The authors acknowledged that this may have been more problematic for older participants (i.e., due to arthritis or other conditions that interfere with writing), thus placing them at a disadvantage. Other task characteristics also may have influenced the results of past research. For example, differences in the complexity (i.e., length and reading level) of the medical scenarios that are used in research studies may have influenced preferences for information and involvement in medical decision making. More complex scenarios may have lead older adults to seek less information and involvement in medical decisions as the cognitive abilities involved in decision making evidence age-related decline.

The Present Study

This study examined previously unexplored factors that may influence preferences for information and involvement in medical decision making, while addressing the conceptual and methodological limitations in the extant literature. This research explored the influence of the following factors: cognitive ability; health locus of control beliefs; cohort differences in attitudes toward medical authority; and the complexity of the medical scenarios used. Given the fact that age differences in preferences for information and involvement in medical decision making scenarios have been reported in the majority of the related, previous research, the present study

involved older adults. The decision to examine information and involvement preferences among older participants makes sense from a conceptual standpoint, given that older adults demonstrate some variability in preferences for information and involvement, in contrast to the uniformly high preferences of younger adults. In addition, the present study involved medical scenarios that involve cancer diagnoses among women. This medical context was chosen as the majority of the most relevant, previous research studies on preferences for information and involvement in medical decision making scenarios have employed this context. Therefore, the results of the present study are interpreted in the context of much of the background literature.

Based upon the literature review, the following hypotheses were tested:

- Hypothesis #1: When medical information is more complex, participants are expected to desire lesser amounts of information and levels of involvement when presented with the medical decision-making scenarios.
- Hypothesis #2: Participants with lower scores on the cognitive measures will prefer less information and involvement when presented with the medical decision making scenarios.
- Hypothesis #3: Participants with higher scores on the GLHC scale will prefer less information and involvement when presented with the medical decision making scenarios. In contrast, participants with high scores on the Internality Health Locus of Control scale will prefer more information and involvement when presented with the medical decision making scenarios.
- Hypothesis #4: Participants with lower scores on the measure of attitudes toward medical authority will prefer less information and involvement when presented with the medical decision making scenarios.

Method

Participants

Participants (N = 60) , aged 60 years and over, were recruited from seniors centers and assisted-living complexes in the greater Morgantown area. Prior to data collection, participants were screened according to the following exclusionary criteria: (1) hearing or visual difficulties that would interfere with participation in the study; (2) evidence of gross cognitive impairment as defined by a cutoff score of 20 on the Mini-Mental State Examination (MMSE; Folstein et al., 1975); and (3) evidence of severe depressive symptoms, as defined by a score of 7 or greater on the short form of the Geriatric Depression Scale (GDS; Yesavage, Brink, Rose, Lum, Huang, Adey, & Leirer, 1983). None of the participants who were screened met any of these exclusionary criteria. However, of all the participants who initially agreed to take part in the study initially, one refused to sign the consent form because she believed that her responses might be used to make decisions regarding her medical care. This researcher was not able to convince her that her participation would not affect her medical care or eligibility for any services.

The majority of the sample was comprised of Caucasian participants (n=58), while a small minority of participants were African American (n=2). A summary of the demographic characteristics of the participants is provided in Table 1. Information regarding the health characteristics of the sample are provided in Table 2.

Materials

Two medical scenarios were used in the present study (see Appendices A to D). One was adapted from Meyer et al. (1995) and involved a description of a breast cancer scenario. The

other involved a description of a cervical cancer scenario. Both scenarios were written at two levels of difficulty. Difficulty was measured by using the Flesch-Kincaid grade level index. The difficult versions was written at the 11th grade level, whereas the easier versions was written at the 4th-grade reading level. The length of the scenarios was kept relatively constant (i.e., approximately 200 words), as was the content of the scenarios (i.e., a description of problem and the various treatment options that were available).

Measures

Demographic information. This questionnaire solicited information regarding the participants' age, number of years of education acquired, racial background, self-reported health, and degree of experience with the medical scenarios included in this study (see Appendix E).

Information seeking. Cassileth, Zupkis, Sutton-Smith, and March (1980) developed a questionnaire to determine whether cancer patients would want information in several different categories (e.g., the side effects of the treatments, the effectiveness of the treatments). These categories of information were adapted for use in the present study. Participants were asked to specify the amount of information they would want regarding various aspects of their medical care (e.g., possible side effects of treatments) using a Likert-type scale (see Appendix F), ranging from 1 (no information) to 10 (as much information as possible). After completing each rating, participants were asked to specify the types of information they would want to have within each information category by choosing from one of three statements.

Desired level of involvement. Participants were asked to indicate their preferred level of involvement in response to the medical scenarios by first using a Likert-type scale. The scale ranged from 1 (I prefer to leave all decisions regarding my treatment to my doctor) to 10 (I

prefer to make the final selection about which treatment I will receive). Next, participants were asked to choose one of five statements that best described how involved they would prefer to be (Degner & Sloan, 1992). In both the Likert-type scale and the selected statement regarding decision-making involvement, higher scores indicated a preference for more active roles in medical decision making. These measures are provided in Appendix G.

Health locus of control. Wallston, Wallston, Kaplan, and Maides (1976) developed the 11-item Health Locus of Control (HLC) scale as a measure of peoples' beliefs that their health is or is not determined by their behavior. Using this measure, "health externals" were those individuals who believed that luck, fate, chance, or powerful others determined their health. In contrast, "health internals" were those individuals who believed that their health was determined by their own behavior. This HLC scale was then expanded to include three dimensions of health locus of control beliefs: internality (IHLC), powerful others (PHLC); and chance (CHLC) externality. The result was the Multidimensional Health Locus of Control (MHLC) scale (Wallston et al., 1978). Wallston et al. (1978) investigated the psychometric properties of the three Multidimensional Health Locus of Control (MHLC) scales: the Internality Health Locus of Control (IHLC) scale, the Powerful Others Health Locus of Control (PHLC) scale, and the Chance Health Locus of Control (CHLC) scale. The authors recruited a widely divergent group of persons at a metropolitan airport to gather psychometric data. Of the final sample of 125 individuals, 49% were males, 74% had some college education, and the mean age was 42 years. Two forms of the MHLC were developed: Form A and Form B. Alpha reliabilities for the separate scales ranged from .67 to .77. When the two forms were combined, the reliabilities increased (i.e., .83 to .86). The results also revealed an expected pattern of correlations among

the three scales. The IHLC was not significantly correlated with the PHLC. Further, the IHLC and CHLC were negatively correlated, and the PHLC and CHLC were positively correlated. Test-retest reliability coefficients range from .60 to .70. The authors also reported evidence of convergent validity by concurrently administering another measure of health locus of control. Correlations were examined between the MHLC scales and Levenson's Internal, Powerful Others, and Chance scales (Levenson, 1973; Levenson, 1974; Levenson, 1975). The correlations between the Internal, Powerful Others, and Chance scales were .57, .28, and .80, respectively. Further, the authors reported further evidence of convergent validity by concurrently administering a measure of self-reported health. As expected, health status was positively correlated with IHLC ($r = .40$), negatively correlated with CHLC ($r = -.28$), and did not correlate significantly with PHLC ($r = -.06$).

Wallston et al. (1999) expanded the MHLC to include a religious component. The authors developed the God Locus of Health Control Scale (GLHC) to assess the extent of an individual's belief that God controls his or her health status, and found evidence for the scale's reliability and validity. The GLHC was examined in conjunction with Form C of the MHLC (Wallston, Stein, & Smith, 1994). The psychometric data regarding the scale was obtained using three samples of individuals. Two of the samples included individuals with a confirmed diagnosis of rheumatoid arthritis. The remaining sample was comprised of individuals with a confirmed diagnosis of systemic sclerosis. The majority of individuals across all samples were female, European American, and middle-aged or older adults. Wallston et al. reported that the psychometric properties of the GLHC were sound. Internal consistency estimates ranged from .87 to .94. Test-retest reliability coefficients have been reported to be as high as .70 with an 18-

month interval between administrations. No specific mention was made of the type of validity data that were collected. However, the authors did report that the GLHC was related to other informal measures of religious orientation and activity in a manner that fitted expected patterns (i.e., higher scores on the GLHC were associated with higher frequencies of religious coping, active religious participation, and higher ratings of the importance of religion). In addition, the GLHC scale was uncorrelated with the Doctors and Internality scales for all three samples. The GLHC scale was positively correlated with the Other People scale ($r = .22$ and $.20$ among the rheumatoid arthritis patients, and $r = .22$ among the systemic sclerosis patients). Significant, positive relations were found between the GLHC and the Chance scale ($r = .47$ and $.44$) among the samples of rheumatoid arthritis patients, but not among the sample of systemic sclerosis patients. The scales and corresponding items of the MHLC and the GLHC are provided in Appendix H.

Cognitive measures. Text memory was assessed using the Logical Memory I subtest from the Wechsler Memory Scale-Third Edition (WMS-III; Wechsler, 1997a). This test required the administrator to read two stories to participants. Following the reading of each story, participants were asked to recall as much of the story as possible. The participants' recall was scored for the presence of 25 separate idea units in each story. Possible scores may range from 0 to 50, with higher scores indicating greater text memory.

The WMS-III standardization sample included 1250 individuals, ranging in age from 16 to 89 years. The average consistency reliability coefficient for the Logical Memory I scale was .88 for all ages. Test-retest reliability coefficients were based on a test-retest interval of 2 to 12 weeks. The average stability coefficient for the Logical Memory I subtest was .77 for all ages.

Extensive data regarding the content, construct, and criterion-related validity are contained within the technical manual for the WAIS-III and WMS-III (WAIS-III WMS-III Technical Manual, 1997).

Vocabulary was tested using the Vocabulary subtest from the Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 1997b). This test requires participants to verbally provide definitions for 33 words. Scores may range from 0 to 66. Higher scores are indicative of greater vocabulary skills.

Reasoning was assessed using the Matrix Reasoning subtest from the WAIS-III (Wechsler, 1997b). This test requires participants to engage in four types of nonverbal reasoning: pattern completion, classification, analogy, and serial reasoning. The examinee is required to look at a matrix from which a section is missing, and identify one of five response options that complete the matrix. Scores range from 0 to 26, with higher scores indicating higher reasoning ability.

Working memory was assessed using the Digits Backward subtest of the WAIS-III (Wechsler, 1997b). During this task the examiner verbally presents a sequence of numbers that the participant must repeat in reverse order. Scores range from 0 to 14, with higher scores indicating higher working memory ability.

Processing speed was measured using the Digit Symbol-Coding subtest of the WAIS-III (Wechsler, 1997b). In this task, participants were required to copy symbols that are paired with numbers. Using a key, participants were asked to draw the symbols under their corresponding numbers. The score was the number of symbols correctly drawn within a 120-second time limit. Scores may range from 0 to 133, with higher scores indicating greater processing speed.

The standardization sample for the WAIS-III (Wechsler, 1997b) included 2450 individuals, ranging in age from 16 to 89 years. The sample was stratified on key demographic variables, including age, sex, education level, and geographic region according to U.S. census data (U.S. Bureau of the Census, 1995). The reliability coefficients for the WAIS-III subtests used in this study range from .82 to .93. Test-retest reliability coefficients were based on a test-retest interval of 2 to 12 weeks. The average stability coefficients for the WAIS-III subtests range from the .70s to the .90s. Extensive data regarding the content, construct, and criterion-related validity are contained within the technical manual for the WAIS-III and WMS-III (WAIS-III- WMS-III Technical Manual, 1997).

Attitudes toward medical authority. Attitudes toward medical authority were assessed using an adaptation of a questionnaire developed by Haug and Lavin (1981). Haug and Lavin designed the questionnaire to measure self-reported consumerist attitudes and behaviors towards physicians. This measure includes scales measuring: attitudinal challenges to physicians' authority, behavioral challenges to physicians' authority, belief in the patient's right to information, belief in the patient's right to make decisions, belief in physicians' competence, and belief in medical service. The authors recruited a sample of 466 Caucasian adults, ranging in age from 18 to 91. The authors provided only minimal psychometric data. Specifically, the test-retest reliability for the attitudinal challenge scale was .60 among a sub-sample of 320 adult students. The scales used by Haug and Lavin were adapted for the purposes of this study. Whereas the item content was preserved for the present study, the response format was modified such that participants used a Likert-type scale to indicate their answers. Higher responses on each of the scales indicate a more consumerist attitude. See Appendix I for a copy of this questionnaire.

The SF-12 Version 2.0. Self-reported health was measured using this recently-released, widely-used measure of self-reported health that yields a mental health component score and a physical health component score (Quality Metrics, 2002). The formal scoring criteria were not yet available for this measure. To address this issue, a scoring paradigm was developed such that Likert-type responses were assigned numerical values. Higher scores on the mental and physical health components reflected greater mental and physical self-reported health.

Procedure

Participants read and signed an informed consent form and they were given a copy for their records. Following this, the MMSE and the GDS were administered to determine if the participants were eligible to complete the study. If no exclusion criteria were met, participants completed the demographics questionnaire, followed by the SF-12. Then, the participants were presented with the medical scenarios. Each participant was presented with two medical scenarios (i.e., one breast cancer scenario and one cervical cancer scenario). The ordering of the presentation was randomly assigned such that half the participants were presented with the breast cancer scenario first while the other half of participants were presented with the cervical cancer scenario first. Further, the difficulty of the scenario (i.e., easy versus hard version) was randomly assigned such that each participant was presented with one easy scenario and one difficult scenario. Immediately after reading each medical scenario, participants were asked to complete the questionnaires measuring information seeking and desired levels of participation. Next, participants completed the battery of cognitive assessment instruments in the following order: Digit Span Backwards, Matrix Reasoning, Logical Memory; Digit Symbol Coding, and Vocabulary. Then, the questionnaire regarding the participants' attitudes toward medical

authority was administered, followed by the MHLC and the GLHC.

Results

All analyses were conducted using SPSS, version 10.0. The data were examined for the presence of outliers. Within each variable, those data points that were greater than, or equal to, three standard deviations from the mean were excluded.

Descriptive Statistics and Preliminary Analyses

Prior to conducting the hypothesis-driven analyses, basic descriptive statistics were calculated for the two dependent variables. The mean amounts of information that were preferred by all participants in each category of information (e.g., Diagnosis, Side Effects) are displayed for each scenario in Table 3. T-tests were performed to determine if significant differences existed in the preferred amounts of information based on the scenario. To protect against familywise Type 1 errors, the .05 significance level was adjusted to .006 (i.e., .05 divided by 9). The results, also summarized in Table 3, indicated that the participants desired significantly more information when presented with the breast cancer scenario than the cervical cancer scenario for the following categories of information: diagnosis, what the treatments will do, the likelihood of a cure, the effectiveness of the treatment for others, examples of cases of treatment effectiveness and examples of cases of treatment ineffectiveness. In contrast, no significant differences between the scenarios were found in the participants' desire for information regarding: the side effects of the treatment, the parts of the body that could be effected should the cancer spread, and what the treatments do inside one's body. The level of preferred involvement also was significantly higher in the breast cancer scenario ($\underline{M} = 6.80$, $\underline{SD} = 2.24$) than in the cervical cancer scenario ($\underline{M} = 6.45$, $\underline{SD} = 2.27$), $t(1, 59) = 2.15$, $p = .036$. The number of

participants who preferred each type of information is summarized for the breast cancer scenario in Table 4 and for the cervical cancer scenario in Table 5.

The first hypothesis stated that when the medical information is more complex, participants would indicate a preference for less information and involvement than when the information was less complex. For each scenario, a single-factor (Difficulty) MANOVA was conducted. In these analyses, the independent variable was the difficulty of the scenario, and the dependent variables were the nine ratings of the amounts of information that were preferred (e.g., amount of information about the diagnosis), and the one variable that coded the amount of involvement that was desired. Within the breast cancer scenario, no significant differences were observed, $F(10, 45) = 0.57, p = .83$. Similarly, no significant differences were observed within the cervical cancer scenario, $F(10, 45) = 1.0, p = .46$.

The average amounts of information and involvement were examined for each level of difficulty. The results revealed that participants desired approximately the same amounts of information regardless of the difficulty level in the breast cancer scenario ($\underline{M}_{\text{easy version}} = 9.31, \underline{M}_{\text{difficult version}} = 9.46$) and the cervical cancer scenario ($\underline{M}_{\text{easy version}} = 9.17, \underline{M}_{\text{difficult version}} = 8.93$). Similarly, participants desired equivalent levels of involvement regardless of the difficulty level in the breast cancer scenario ($\underline{M}_{\text{easy version}} = 7.13, \underline{M}_{\text{difficult version}} = 6.47$) and the cervical cancer scenario ($\underline{M}_{\text{easy version}} = 6.27, \underline{M}_{\text{difficult version}} = 6.63$). Therefore, all of the remaining analyses will combine data for the complex and easy versions of the scenarios.

The remaining hypotheses involved predictors of the amount of information and involvement that were preferred. It is not practical to discuss the results for the second, third and fourth hypotheses individually, given that the predictors involved in these hypotheses were all

entered simultaneously into the regression analyses described below. The second hypothesis stated that participants with lower scores on the cognitive measures would prefer less information and involvement than participants with higher scores when presented with the medical decision making scenarios. The third hypothesis stated that participants with higher scores on the GLHC scale will prefer less information and involvement than participants with lower GLHC scores when presented with the medical decision making scenarios. In contrast, participants with higher scores on the Internality Health Locus of Control scale will prefer more information and involvement than participants with lower scores when presented with the medical decision making scenarios. The fourth hypothesis stated that participants with lower scores on the measure of attitudes toward medical authority will prefer less information and involvement than participants with higher scores when presented with the medical decision making scenarios.

Prior to conducting the multiple regression analyses, it was necessary to reduce the number of dependent variables. This was necessary as ten dependent variables were involved. Without reducing the number of dependent variables, ten separate multiple regression analyses would have been required for each scenario (i.e., resulting in twenty multiple regression analyses). Conducting large numbers of regression analyses would increase the chances of committing a Type 1 error. To reduce the number of dependent variables, the average amount of information that was preferred across the nine categories was calculated for each participant. Therefore, two dependent variables were used in the regression analyses: 1) the average amount of information that was preferred; and 2) the level of preferred involvement.

Given the small number of participants in the present study, it also was necessary to

reduce the number of predictors to be used in the regression analyses. Power analyses indicated the need to reduce the number of predictors to approximately six. Therefore, principal component analyses were performed separately on the following sets of variables: the cognitive variables (i.e., Vocabulary, Digits Backward, Logical Memory Score, Matrix Reasoning, Digit Symbol Coding), the attitudes toward medical authority variables (i.e., Attitudinal Challenge to Physician Authority, Patient's Right to Information, Patient's Right to Make Medical Decisions, Beliefs about Physician Competence and Beliefs about Physician Service) and the health locus of control variables (i.e., IHLC, PHLC, CHLC and GLHC). For each principal component analysis, a varimax rotation was specified in order to produce a loading matrix in which the variables "loaded" on only one component. Only those components with eigenvalues equal to 1 or more were accepted. The components were then used as predictors in the regression analyses.

The principal component analysis that was performed on the cognitive variables yielded a single-component solution that accounted for 54.42% of the variance (see Table 6). The principal component analysis on the Attitudes Toward Medical Authority variables yielded two components that accounted for 65.96% of the variance. The loading matrix is outlined in Table 7. The first component may be referred to as a "Patient's Rights" component that involves the right to challenge physician authority, the right to medical information and the right to make medical decisions. The second component may be referred to as an "Evaluative Thoughts Regarding Physicians" component that is comprised of beliefs regarding the competence of physicians and their commitment to service. A third principal component analysis was performed on the health locus of control variables. The results, outlined in Table 8, suggested two components that accounted for 68.00% of the variance. The first component may be referred to

as an “External Health Locus of Control” component that is comprised of variables pertaining to beliefs about external influences on health (i.e., God, Chance and Powerful Others). The second component may be referred to as an “Internal Health Locus of Control” component that is comprised of the variable that describes beliefs about internal influences on health.

As stated above, it was necessary to conduct two multiple regression analyses for each scenario. In one analysis, the dependent variable was an average of the nine ratings of the amount of information that was preferred; in the other analysis, the dependent variable was the rating of the amount of involvement that was preferred. The predictors were the five components resulting from the principal component analyses described above: Cognitive Performance, Patient's Rights, Evaluating Thoughts Regarding Physicians, External Health Locus of Control, Internal Health Locus of Control. The predictors were entered simultaneously. The significance level for entry into the model was set at .05.

Breast cancer scenario. The results indicated that the regression model was not significant when the dependent variable was the average amount of information that was desired, $F(5, 48) = .66$, $p = .65$. The multiple-R-squared value was 0.06. Similarly, the results were not significant when the dependent variable was the preferred level of involvement, $F(5, 51) = 2.19$, $p = .07$. The multiple-R-squared value was 0.18.

Cervical cancer scenario. The regression model was not significant when the dependent variable was the average amount of information that was desired, $F(5, 48) = .77$, $p = .58$. The multiple-R-squared value was 0.07. However, when the dependent variable was the level of preferred involvement, the regression model was significant, $F(5, 51) = 2.89$, $p = .02$. The multiple-R-squared value was 0.22. At the univariate level, two of the components were

significant predictors: the Patient's Rights and External Health Locus of Control. Correlational analyses indicate that higher levels of preferred involvement were significantly correlated with: higher factor scores on the Patient's Rights component ($r = .35, p < .01$); and lower scores on the External Health Locus of Control component ($r = -.27, p < .05$).

Discussion

This findings pertaining to the specific hypotheses stated in this study will first be addressed, followed by a discussion of the more general findings. Finally, the limitations of the present study will be addressed and the need for further research will be outlined.

The first hypothesis stated that participants would indicate a preference for less information and involvement in response to more complex medical information. The results failed to support this hypothesis. Participants desired approximately the same amounts of information regardless of the difficulty level in the breast cancer scenario and the cervical cancer scenario. Similarly, participants desired equivalent levels of involvement regardless of the difficulty level in the breast cancer scenario and the cervical cancer scenario. This finding suggests that the difficulty level of medical information does not influence older women when they indicate their preferences for additional information or involvement concerning breast or cervical cancer. Although previous research suggests that differences in complexity affect the comprehension of medical information (Tymchuk et al., 1988), it is possible that older women may prefer relatively consistent amounts of information and involvement regardless of how complex the information is, or how well they comprehend the material.

This finding (i.e., the non-significant results regarding the difficulty manipulation) may have important implications for physicians and researchers. Physicians may expect that when

presenting older women with initial information about cancer diagnoses, their patients may prefer a good deal of additional information regardless of how the physician initially presents the information (i.e., in a simple or complex fashion). With respect to research, the findings regarding this hypothesis suggest that previous researchers (e.g., Meyer et al., 1995) who have used fairly complex medical scenarios may be more confident that the difficulty level did not greatly influence their participants' stated preferences for information or involvement.

There are several possible explanations for why manipulations to the difficulty of the scenarios failed to produce differences in the participants' desire for information or involvement. First, it is possible that the participants were able to understand the easy and complex scenarios equally well. This was possible given that the mean level of education for the sample was quite high ($M = 14.35$ yrs, $SD = 3.16$ yrs). Second, a high percentage of the sample had personal or vicarious experience with cancer in the past. This may have increased the chances that they had experience with some of the more complex terminology surrounding cancer diagnoses. Third, it is possible that the participants were less concerned with specific details from the scenarios and more concerned with the gist of the material (i.e., that either breast or cervical cancer was involved). If participants were operating at this more general level, they may have paid less attention to more specific, complex pieces of information. Fourth, it is possible that the basis of the difficulty manipulation used in the present study differed from the way difficulty has been conceptualized in previous research. Tymchuk et al. (1988) conceptualized difficulty based on grammatical structure and frequency of word usage. It is possible that other conceptualizations of difficulty (e.g., manipulating the length of the written material or the demands placed on working memory) may be sufficient to produce differences in preferences for information and

involvement.

The hypothesis that participants with lower scores on the cognitive measures would prefer less information and involvement when presented with the medical decision-making scenarios was not supported by the results. This finding suggests that one's cognitive abilities (i.e., the ones measured in this study) may be unrelated to preferences for information or involvement in medical decision making scenarios. Therefore, knowing about the intellectual abilities of a patient may not be a reliable predictor of how much information and involvement would be preferred.

The results regarding this hypothesis stand in contrast to previous literature that suggested that older adults may be less active in medical decision making due to age-related declines in various cognitive abilities that are involved in the decision-making process (Zwahr, Park & Shifren, 1999). The failure to achieve significant results may have occurred for several reasons.

First, it is possible that participants held the belief that their cognitive abilities were adequate to manage their preferred amounts of information and involvement. Regardless of their actual cognitive abilities, participants may have operated on the optimistic belief that they were capable of handling the information and involvement. Second, it is possible that some participants were aware of specific cognitive deficits (e.g., memory difficulties) but stated preferences for high levels of information and involvement anyway. This may have occurred because participants were aware of the hypothetical nature of the study. Third, it is possible that there was not enough variability in cognitive performance within the present sample. The likelihood of a restricted range of cognitive performance (i.e., average or better performance) was increased given that

participants were community dwelling and able to meet criteria on the MMSE. It is possible that the inclusion of participants with lower cognitive functioning may have produced significant findings.

Partial support was found for the two-part hypothesis that higher scores on the GLHC would be associated with preferences for less information and involvement while higher scores on the IHLC would be associated with preferences for more information and involvement. The results from the regression analyses indicated that neither of the MHLC components (i.e., the Internal Health Locus of control component and the External Health Locus of Control component) predicted a significant amount of variance in the ratings of the amount of information that was desired in either scenario. This suggests that one's beliefs about who or what controls one's health are not related to preferences for information. Individuals who believed that their health was controlled by themselves, a Higher Power, powerful others or chance were all equally likely to state preferences for large amounts of information. Although neither of the MHLC variables were significant predictors of the amount of information that was preferred in either scenario, the External Health Locus of Control component was a significant predictor of the amount of involvement that was preferred in the cervical cancer scenario. Participants who preferred to be less active in choosing among treatment options were more likely to endorse beliefs that their health was controlled by external agents (e.g., a Higher Power, chance, or powerful others). For example, this would suggest that individuals who place their health in the hands of a higher power prefer less involvement in certain medical decision-making scenarios. Although the participants preferred a good deal of information about their medical problems, they chose to place their health in the hands of external agents while working

collaboratively with their physicians.

Partial support was found for the hypothesis that participants with lower scores on the attitudes toward medical authority variables would prefer less information and involvement when presented with the medical decision making scenarios. The results indicated that the attitudes toward medical authority components (i.e., Patient's Rights and the Evaluative Thoughts Regarding Physicians) did not explain a significant amount of variance in the ratings of the amount of information that was desired in either scenario. However, the Patient's Rights variable was a significant predictor of the amount of involvement that was preferred in the cervical cancer scenario. Preferences for less control were significantly correlated with decreased tendencies to believe in a patient's rights (i.e., rights to challenge medical authority, obtain information and make medical decisions). This suggests that older women who hold more traditional views regarding medical authority may prefer less involvement in similar medical decision-making scenarios. These women may be more likely to defer to their doctors. In contrast, older women who hold more of a consumerist view in medical contexts will prefer to be more actively involved in the treatment of cervical cancer.

General Discussion

Preferences for Information

The results from previous research have been mixed regarding preferences for information among older adults in medical decision-making scenarios. Whereas most studies have typically found that older adults prefer less information than younger adults (e.g., Ende et al., 1989; Hopkins, 1986; Galloway, 1994; Meyer et al., 1995; Turk-Charles et al., 1997), a smaller subset of studies indicate that older adults may prefer large amounts of information (e.g.,

Beisecker, 1988; Beisecker & Beisecker, 1990). The results from the present study support the less-prevalent finding that older adults may desire significant amounts of information in medical decision-making scenarios. This desire for information makes intuitive sense. Gathering information would allow an individual to build his or her knowledge base regarding the disease (i.e., the more information the better). Presumably, one would be able to make better decisions regarding one's illness after acquiring more information.

The desire to increase one's knowledge base also may be considered as a form of coping response. Specifically, it is possible that information gathering serves as a mechanism to reduce the anxiety that would understandably accompany a newly-acquired cancer diagnosis. In the face of such a diagnosis, individuals would likely be plagued with questions concerning prognosis, life expectancy and chances of survival, among others. Not knowing the answers to such questions would arguably be highly anxiety provoking. Therefore, acquiring knowledge would serve the purpose of reducing the ambiguity and uncertainty about the illness (i.e., making the unknown known).

Another reason for the participants' preferences for large amounts of information may be related to the use of heuristics. A heuristic may be defined as an internal decision-making guideline or "rule of thumb" that may be used to direct behavior in recognizable situations. Heuristics allow individuals to bypass the mental processing that is associated with weighing the pros and cons regarding potential decisions. For example, when buying a car, rather than weighing the pros and cons of different makes, the heuristic "buy American" may be applied to facilitate the decision-making process. In this manner, the use of heuristics conforms to a "top-down" approach to problem solving and decision-making (Sinnott, 1989). In response to cancer

diagnoses, the older women in the current study may have used a heuristic to guide their preferences for amounts of desired information. Given the results, the heuristic may have been “If I have a serious medical problem, I want all the information I can get,” or “I want to be highly informed.”

The desire for a great deal of information has implications for health care professionals. Physicians may expect that their older female patients will want to be maximally informed regarding their cancer diagnoses. Therefore, physicians may choose to create educational resources to accommodate these information demands. The educational materials may include more of the types of information that were deemed to be desirable in this study (e.g., regarding diagnosis, side effects), while offering less of the types of information that were considered to be less desirable (e.g., examples of cases of treatment ineffectiveness). However, physicians should not assume that all of their older, female patients will prefer large amounts of information. It is likely that the amount of information that is preferred will depend on several factors. For example, the individual’s characteristic coping style may influence the information preferences of some patients. Some individuals may adopt an emotion-focused coping response and prefer lesser amounts of information. Other individuals may prefer a problem-solving coping response and request more information. The amount of information that is preferred also may depend on how recently the information regarding the potential cancer diagnosis was conveyed. It seems reasonable that initially, some older female patients may experience denial or shock and consequently ask for little information. Eventually, as these individuals accept their cancer diagnoses, their desire for information may change or evolve. Specifically, more information may be preferred with the aim of increasing one’s knowledge regarding the illness and preparing

for future decision-making responsibilities.

Most preferred categories of information. The vast majority of the participants were most interested in obtaining information about the following: diagnosis, side effects, what the treatments will do, the likelihood of a cure, the effects if the cancer should spread, what the treatments would do internally, and the effectiveness of treatments for other patients. These categories of information seem to address a basic set of concerns regarding a cancer diagnosis and subsequent treatment. In contrast, participants were less interested in learning about examples of actual cases where the treatment was either effective or not effective. Anecdotal evidence (i.e., comments made by a small subset of study participants) during data collection suggested that participants felt that there were too many variables that might distinguish them from other treatment recipients. Therefore, the participants seemed to believe that such information would not be personally relevant. Further, the results clearly indicated that across both cancer scenarios, participants were least interested in obtaining information regarding treatment failures. This may suggest that participants would attempt to maintain an optimistic mindset regarding cancer diagnoses by focussing on the positives and avoiding negative information. The tendency to focus on the positive and avoid negative information may be viewed as a coping response. Previous research by Blanchard-Fields and colleagues suggests that older adults tend to use a variety of coping responses, including avoidance or denial, especially as the emotional salience of a problem increases (Blanchard-Fields & Camp, 1990; Blanchard-Fields, Chen & Norris, 1997; Blanchard-Fields, Jahnke & Camp, 1995).

Preferred level of detail. The present findings suggest that participants were interested in having their physicians do more than just verbally describe and explain their illness. The desire

for additional, detailed information was evident within certain topic areas. For example, participants were interested in seeing visual material (e.g., X-rays, plastic models of the human body) in order to help them understand their diagnoses. Mathematical descriptions (e.g., percentages, odds ratios) also were desired when dealing with concerns about treatment effectiveness or the effects of metastatic disease processes. Further, the majority of participants indicated that summaries from professional journals would be helpful in learning about the likelihood of a cure. In contrast, participants preferred less-detailed information in response to certain topic areas (e.g., case examples of treatment successes and failures). For these topic areas, participants appeared to be satisfied with verbal explanations from their physicians or no information at all.

Differences based on cancer scenario. The results indicated that participants preferred slightly less information for the cervical cancer scenario in virtually every category of information (i.e., the exceptions being information regarding the effects if the cancer should spread). This finding may be explained by taking into account the developmental stage(s) of the participants. Given that participants were screened to include individuals who were aged 60 years or over, it is safe to assume that child-bearing was no longer relevant (i.e., the participants would have already had children and were most likely post-menopausal). Therefore, the participants may have felt that their internal, reproductive organs would be easier to “sacrifice” if it meant increasing their chances of survival. Anecdotal evidence (i.e., comments from a small subset of participants) supported this line of reasoning. Preferences for larger amounts of information regarding breast cancer suggests that, despite advanced age, the participants were invested in their outward appearance. This makes sense, given that external sex characteristics

(i.e., breasts) likely contribute to a sense of womanhood and female identity. Therefore, surgical procedures involving the breast (i.e., lumpectomies, mastectomies) would likely be highly undesirable. This would likely lead participants to want as much information as possible in order to make better-informed decisions. The desire for more information in breast cancer scenarios than cervical cancer scenarios also may reflect epidemiological findings regarding the survival rates for the two diseases. The American Cancer Society reports that in the year 2002, approximately 203 500 women in the United States will be diagnosed with breast cancer. Of those women, 40 000 will die from the disease. In contrast, approximately 13 000 new cases of cervical cancer are expected to occur in the United States in the year 2002, with 4100 deaths resulting from the disease (American Cancer Society, 2001).

Preferences for Involvement

One might expect that preferences for information would closely parallel preferences for involvement in scenarios involving cancer diagnoses. In other words, individuals who want to be highly informed might be expected to desire highly-active roles in making decisions regarding treatment options. The results of the present study indicate a different picture. Participants appeared to want as much information as possible but they did not want to be maximally involved in choosing among different treatment options. Instead, they seemed to want to share the decision-making responsibility with their physicians. On a scale that described their preferences for involvement that ranged from 1 (I prefer to leave all decisions regarding my treatment to my doctor) to 10 (I prefer to make the final selection about which treatment I will receive), the participants indicated average preferences in the 6 to 7 range. Previous research indicates that as adults age they may be more likely to commission others to help them make

important decisions (Yates & Patalano, 1999). The average preferred level of involvement in the present study may reflect this general trend. However, it is important to recognize that comments regarding age changes or differences are not possible given the design of the present study.

Given that the average rating fell in the 6 to 7 range, it was clear that although participants wished to share the decision-making responsibility with their physicians, they wanted the balance of control regarding treatment options to stay in their favor. The desire to retain the balance of control regarding treatment decisions (and the desire to be highly informed) may reflect a preference for what lifespan developmental researchers (e.g., Brandstädter & Wentura, 1995) have termed “primary control.” Primary control refers to an individual’s need to have a direct impact on his or her environment. Preferences for this type of control are suggested to be age-invariant (Brandstädter & Wentura). This active stance would likely be associated with beneficial health outcomes. As stated earlier, numerous beneficial effects are associated with active participation in medical decision making contexts (i.e., seeking information and participating in medical decision making), including decreased postoperative anxiety and depression (Morris & Royle, 1987), faster recovery (Wallace, 1986), less concern with illness, improved treatment effectiveness, greater satisfaction with physicians (Brody, Miller, Lerman, Smith, & Caputo, 1989); and a greater sense of control over one’s body, health, and life (Hack, Degner, & Dyck, 1994).

Limitations of the Present Study

One of the limitations of the present study involves weaknesses in generalizability of the findings. For example, with respect to populations, the results are generalizable to women who are: between the ages of 60 and 90, Caucasian, not reporting symptoms of depression and not

evidencing gross signs of cognitive impairment. These specific parameters limit the generalizability of the findings to other groups of individuals. With regards to settings, the present findings would not be generalizable to real-life scenarios involving cancer diagnoses. Given that this experiment involved a hypothetical exercise, it is possible that participants' responses were not indicative of how they would actually behave in a parallel, real-life situation.

It also is possible that the difficulty of the medical scenarios (i.e., easy versus hard versions) was not manipulated in an optimal way. The present study based the differences in difficulty on the reading level of the medical scenarios. Although the decision to focus on reading level was based on procedures found in previous research, this objective index of difficulty may not have been sufficient in producing qualitative or subjective differences in the way the scenarios were experienced by the participants.

Another limitation of the present study involves the small number of participants. Sixty participants were recruited to participate which limited the power of the statistical analyses.

Summary and Recommendations for Future Research

Findings from the present study suggests that women over the age of 60 are likely to prefer to be highly informed regarding most aspects of a diagnosis of breast or cervical cancer. Identifying predictors of information needs among this segment of the population may be a futile endeavor given the uniformly high desire for information. When considering treatment options, this population appears to be willing to share responsibility with physicians while still preferring to retain the balance of decision-making control. Preferences regarding the degree of involvement appear to be related to beliefs about who or what controls one's health, and one's attitudes toward medical authority. Overall, these findings offer a preliminary understanding of

some of the factors that may influence information and involvement preferences of older women in medical decision-making contexts. In addition, the present findings spark additional questions that may be investigated in future research.

Given that one of the major limitations of this study involved weaknesses in the generalizability of the findings, future research studies might involve more diverse sample populations. For example, samples may be recruited that feature a broader range of cognitive functioning and a wider variety of racial/cultural backgrounds. In addition, gender effects also may be examined in parallel studies that involve cancer diagnoses that are relevant to men (e.g., prostate or testicular cancer). Future studies also might involve a more diverse set of medical scenarios and possibly real-life scenarios involving cancer diagnoses.

Future research also may examine the effects of alternative indices of difficulty and complexity (e.g., changing the length of the scenarios or the demands placed on memory). These manipulations may be more effective in yielding differences in the preferred amounts of information and involvement.

In order to better understand the variables that influence participants' preferences for information and involvement in medical decision-making scenarios, researchers may ask participants to engage in "think-aloud" protocols as they consider their responses. This approach may be useful in identifying additional factors (e.g., the use of heuristics) that may influence information and involvement preferences.

Finally, future studies may involve larger sample sizes. This would enhance the power of statistical analyses, thus improving the chances of detecting other predictors of information and involvement needs.

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Table 1

Demographic Data for the Study Sample

	Number (Percentage)		Mean (s.d.)	Range
Age (years)				
60-69	18	(30.0)	-	
70-79	20	(33.3)	-	
80-89	20	(33.3)	-	
90+	2	(3.3)	-	
Total sample	-	-	75.10 (8.21)	
Race				
Caucasian	58	(96.7)	-	
African American	2	(3.3)	-	
Education (years)				
<7	0	(0.0)	-	
7-10	5	(8.3)	-	
11-12	19	(31.7)	-	
>=13	36	(60.0)	-	
Total sample	-	-	14.35 (3.16)	
MMSE (maximum 30 points)	-	-	27.73 (1.82)	

	Number (Percentage)	Mean (s.d.)	Range
Logical Memory I Task *		18.58 (6.73)	5 to 38
Digits Backward Task **		6.27 (1.95)	3 to 12
Matrix Reasoning Task ***		8.90 (5.47)	4 to 22
Digit-Symbol Coding Task ****		51.15 (13.85)	12 to 92
Vocabulary Task *****		43.15 (12.04)	19 to 64
GDS		0.93 (1.13)	

N = 60 participants

* = Raw scores used. Possible range of scores was 0 to 50

** = Raw scores used. Possible range of scores was 0 to 14

*** = Raw scores used. Possible range of scores was 0 to 26

**** = Raw scores used. Possible range of scores was 0 to 133

***** = Raw scores used. Possible range of scores was 0 to 66

Table 2

Descriptive Statistics Regarding Participant Health Characteristics

	Number (Percentage)	Mean (s.d.)
Personal experience with breast cancer	12 (20.0)	-
Vicarious experience with breast cancer	56 (93.3)	-
Personal experience with cervical cancer	0 (0.0)	-
Vicarious experience with cervical cancer	15 (25.0)	-
Number of doctor visits in past year	-	6.02 (6.49)
Health self-rating*	-	1.97 (1.01)
Rating of relationship with doctor**	-	4.60 (0.67)
Rating of communication with doctor***	-	4.48 (0.85)
Rating of satisfaction with visit length/physician's attention****	-	4.32 (0.89)
SF-12 Physical health self-rating+ (derived)	-	16.92 (3.37)
SF-12 Mental health self-rating++ (derived)	-	21.18 (3.18)

* Rating scale that ranged from 1 (very good) to 5 (very poor)

** Rating scale that ranged from 1 (highly negative) to 5 (highly positive)

*** Rating scale that ranged from 1 (very poor) to 5 (very good)

**** Rating scale that ranged from 1 (disagree strongly) to 5 (agree strongly)

+ Possible scores ranging from 5 (poor physical health) to 21 (good physical health)

++ Possible scores ranging from 5 (poor mental health) to 25 (good mental health)

Table 3

T-tests for Differences Between the Scenarios in the Mean Amount of Information Preferred by Category

	Breast	Cervical		
<u>Category of Information</u>	<u>(M) (s.d.)</u>	<u>(M) (s.d.)</u>	<u>t value</u>	<u>Sig.</u>
Diagnosis	9.68 (0.65)	9.53 (0.79)	2.87	.006*
Side effects	9.63 (0.69)	9.51 (0.84)	2.62	.01
What the treatments do	9.43 (0.81)	9.12 (1.17)	4.32	<.001*
Likelihood of a cure	9.75 (0.63)	9.58 (0.89)	2.82	.006*
Parts of body affected if cancer spread	9.60 (0.74)	9.58 (0.77)	0.90	>.05
What treatments do inside your body	9.43 (0.89)	9.25 (1.10)	2.65	.01
Treatment effectiveness for others	9.47 (0.78)	8.96 (1.38)	4.65	<.001*
Examples of effective treatment	9.29 (1.00)	8.13 (2.49)	5.06	<.001*
Examples of treatment failures	7.78 (2.95)	7.07 (2.98)	4.77	<.001*

Note. Participants indicated how much information they preferred for each category of information, using a scale which ranged from 1 (no information) to 10 (as much information as possible).

* = significant at the .006 level

Table 4

Number and Percentage of Participants Preferring Each Type of Information in Breast Cancer Scenario

Type of Information	Number	(Percentage)
Diagnosis		
I want to hear my diagnosis, but do not want it explained to me.	0	(0.0)
I want an explanation of my diagnosis, including a description of the type of cancer.	5	(8.3)
I want an explanation of my diagnosis, including the type of cancer, location of cancer (by showing me an X-ray and having the location of illness illustrated on a plastic model of the human body), and extent of disease progression.	55	(91.7)
Side Effects		
I do not want an explanation of the treatment side effects and how to remedy them.	0	(0.0)
I want an explanation of the MOST LIKELY treatment side effects and how to remedy them.	9	(15.0)
I want an explanation of ALL possible treatment side effects and how to remedy them.	51	(85.0)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Breast CancerScenario

Type of Information	Number	(Percentage)
What the Treatments Will Do		
I do not want any information about what the treatments will do.	0	(0.0)
I want a description of what the treatments will do, including an explanation of how the treatment will affect my body.	7	(11.7)
I want a description of what the treatment will do, including an explanation of how the treatment will affect my body, and the beneficial and harmful effects of the treatment.	53	(88.3)
Likelihood of a Cure		
I do not want any information about the likelihood of a cure.	0	(0.0)
I want my doctor to give me his/her opinion regarding the likelihood of a cure.	10	(16.7)
I want my doctor to give me his/her opinion regarding the likelihood of a cure. Further, I would like to have summaries of relevant information from medical journals or cancer research institutes.	50	(83.3)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Breast CancerScenario

Type of Information	Number	(Percentage)
Effects if Cancer Should Spread		
I do not want any information about the parts of my body that could be affected.	0	(0.0)
I would like my doctor to mention what parts of my body could be affected.	13	(21.7)
I would like my doctor to mention what parts of my body could be affected, how they would be affected, and what it would do to my chances of survival.	47	(78.3)
What Treatments Do Inside My Body		
I do not want any information about what the treatments will do inside my body.	0	(0.0)
I want a description from my doctor about what the treatment will do inside my body, including an explanation of the organs, tissues, and systems that will be affected.	11	(18.3)
I want a description from my doctor about what the treatments will do inside my body, including an explanation of the organs, tissues, and systems (e.g., gastrointestinal, pulmonary) that will be affected, whether or not the effects of the treatment are reversible, and how the treatment will affect my day-to-day life.	49	(81.7)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Breast CancerScenario

Type of Information	Number	(Percentage)
Effectiveness of Treatment for Other Patients		
I do not want to know how effective the treatment has been for other patients.	2	(3.3)
I want to know what percentage of people are helped by the treatment.	14	(23.3)
I want to know what percentage of people are helped by the treatment. I want to know how much improvement has been noted in people who have received the treatment in the past. I also want a description of the factors that either improve or worsen the chances that the treatment will be effective (e.g., the patient's age, the stage of the disease).	44	(73.3)
Examples of Cases of Effective Treatment		
I do not want any information about the effectiveness of the treatment.	2	(3.3)
I want a description from my doctor about a few cases where the treatment has been effective.	20	(33.3)
I want a description of as many cases as possible where the treatment has been effective. I would like to read about examples of people who have been successfully treated. I would like to see pictures of the cancer site before and after treatment. I would like the opportunity to talk with people who have been successfully treated.	38	(63.3)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Breast CancerScenario

Type of Information	Number	(Percentage)
Examples of Cases of Treatment Failure		
I do not want any information about the effectiveness of the treatment.	7	(11.7)
I want a description from my doctor about a few cases where the treatment has NOT been effective.	24	(40.0)
I want a description of as many cases as possible where the treatment has NOT been effective. I would like to read about examples of people who have NOT been successfully treated. I would like to see pictures of the cancer site before and after treatment. I also would like the opportunity to communicate with other people who have NOT been successfully treated.	29	(48.3)

Table 5

Number and Percentage of Participants Preferring Each Type of Information in Cervical Cancer Scenario

Type of Information	Number	(Percentage)
Diagnosis		
I want to hear my diagnosis, but do not want it explained to me.	0	(0.0)
I want an explanation of my diagnosis, including a description of the type of cancer.	6	(10.0)
I want an explanation of my diagnosis, including the type of cancer, location of cancer (by showing me an X-ray and having the location of illness illustrated on a plastic model of the human body), and extent of disease progression.	54	(90.0)
Side Effects		
I do not want an explanation of the treatment side effects and how to remedy them.	0	(0.0)
I want an explanation of the MOST LIKELY treatment side effects and how to remedy them.	13	(21.7)
I want an explanation of ALL possible treatment side effects and how to remedy them.	47	(78.3)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Cervical CancerScenario

Type of Information	Number	(Percentage)
What the Treatments Will Do		
I do not want any information about what the treatments will do.	0	(0.0)
I want a description of what the treatments will do, including an explanation of how the treatment will affect my body.	10	(16.7)
I want a description of what the treatment will do, including an explanation of how the treatment will affect my body, and the beneficial and harmful effects of the treatment.	50	(83.3)
Likelihood of a Cure		
I do not want any information about the likelihood of a cure.	0	(0.0)
I want my doctor to give me his/her opinion regarding the likelihood of a cure.	15	(25.0)
I want my doctor to give me his/her opinion regarding the likelihood of a cure. Further, I would like to have summaries of relevant information from medical journals or cancer research institutes.	45	(75.0)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Cervical CancerScenario

Type of Information	Number	(Percentage)
Effects if Cancer Should Spread		
I do not want any information about the parts of my body that could be affected.	0	(0.0)
I would like my doctor to mention what parts of my body could be affected.	16	(26.7)
I would like my doctor to mention what parts of my body could be affected, how they would be affected, and what it would do to my chances of survival.	44	(73.3)
What Treatments Do Inside My Body		
I do not want any information about what the treatments will do inside my body.	0	(0.0)
I want a description from my doctor about what the treatment will do inside my body, including an explanation of the organs, tissues, and systems that will be affected.	18	(30.0)
I want a description from my doctor about what the treatments will do inside my body, including an explanation of the organs, tissues, and systems (e.g., gastrointestinal, pulmonary) that will be affected, whether or not the effects of the treatment are reversible, and how the treatment will affect my day-to-day life.	42	(70.0)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Cervical CancerScenario

Type of Information	Number	(Percentage)
Effectiveness of Treatment for Other Patients		
I do not want to know how effective the treatment has been for other patients.	2	(3.3)
I want to know what percentage of people are helped by the treatment.	19	(31.7)
I want to know what percentage of people are helped by the treatment. I want to know how much improvement has been noted in people who have received the treatment in the past. I also want a description of the factors that either improve or worsen the chances that the treatment will be effective (e.g., the patient's age, the stage of the disease).	39	(65.0)
Examples of Cases of Effective Treatment		
I do not want any information about the effectiveness of the treatment.	3	(5.0)
I want a description from my doctor about a few cases where the treatment has been effective.	30	(50.0)
I want a description of as many cases as possible where the treatment has been effective. I would like to read about examples of people who have been successfully treated. I would like to see pictures of the cancer site before and after treatment. I would like the opportunity to talk with people who have been successfully treated.	27	(45.0)

(cont.)

Number and Percentage of Participants Preferring Each Type of Information in Cervical Cancer Scenario

Type of Information	Number	(Percentage)
Examples of Cases of Treatment Failure		
I do not want any information about the effectiveness of the treatment.	6	(10.0)
I want a description from my doctor about a few cases where the treatment has NOT been effective.	35	(58.3)
I want a description of as many cases as possible where the treatment has NOT been effective. I would like to read about examples of people who have NOT been successfully treated. I would like to see pictures of the cancer site before and after treatment. I also would like the opportunity to communicate with other people who have NOT been successfully treated.	19	(31.7)

Table 6

Component Matrix for Cognitive Variables

Variable	Component
Digits Backward	.65
Logical Memory	.68
Vocabulary	.72
Matrix Reasoning	.86
Digit Symbol Coding	.75

Table 7

Rotated Component Matrix for Attitudes Toward Medical Authority Variables

Variable	Component 1	Component 2
Attitudinal Challenge	.71	.16
Right to Information	.66	-.32
Right to Make Decisions	.82	.06
Beliefs about Physician Competence	.15	.87
Beliefs about Physician Service	-.12	.88

Table 8

Rotated Component Matrix for Health Locus of Control Variables

Variable	Component 1	Component 2
Internality Health Locus of Control	-.01	.99
God Locus of Health Control	.64	.05
Chance Health Locus of Control	.85	-.08
Powerful Others Health Locus of Control	.76	.01

Appendix A

Breast cancer: Complex version

At your annual physical examination your physician found a lump in your left breast. You were referred to a surgeon after having a mammogram and ultrasound. The surgeon discussed the results of these tests with you. The mammogram revealed a greater density within the upper outer quadrant of the left breast that could represent some localized dysplasia or lobular hyperplasia, but there was no radiographic evidence for cancer. The ultrasound showed a solid rather than fluid-filled mass. The surgeon explained that it was probably not cancer and that most (80%) of such lumps are not cancer. However, the surgeon said that you couldn't know for sure without removing the lump and sending it to a pathologist to examine. The surgeon gave you three choices: One, undergo a lumpectomy (a half day in the hospital with your choice of local or general anaesthesia) as soon as surgery could be scheduled. Two, wait for a half year and then have the surgery. Three, undergo a needle biopsy in order to obtain a sample of a portion of the cells from the lump, bearing in mind that the surgeon warned that this procedure could only test the cells sampled and not examine the entire lump.

202 words

Flesh-Kincaid grade level = 10.8

Appendix B

Breast cancer: Simplified version

Your doctor found a lump in your left breast during your physical checkup. He ordered two tests. He then sent you to see a surgeon. The surgeon discussed the results of these tests with you. One of the tests showed a firm area on the left breast that could be a harmless lump. There was no proof of cancer from the X-rays. Another test showed a solid lump. The surgeon explained that it was probably not cancer. He also said that most of these types of lumps are not cancer. To be sure, the lump would have to be taken out. Then the lump would be sent to another specialist for more tests. The surgeon gave you three choices: One, take the lump out as soon as surgery could be set up. You would spend a half day in the hospital. You would have a choice of being awake for the operation while getting medication to stop the pain, or being asleep for the operation. Two, wait for a half year and then have the surgery. Three, let the doctors use a needle to check some of the cells from the lump. However, the surgeon warned that the third procedure does not test the entire lump, only the cells that are taken.

212 words

Flesh-Kincaid grade level = 4.5

Appendix C

Cervical cancer: Complex version

Following your gynecological exam, you were informed that the results from your Pap smear indicated the presence of dysplasia (meaning abnormal cells) in the tissue of your cervix. Your doctor ordered a biopsy, and found evidence of cancerous cells. A second test called a conization was then performed. Your doctor reviewed the results and then referred you to an oncologist for staging and treatment options. The oncologist examined the test results and concluded that the malignant cells were located only in the first layer of cells lining the cervix, and not in the deeper tissues of the cervix. This is called Stage 0 cervical cancer, otherwise known as carcinoma in situ. The oncologist informed you about the various treatment options. The options depend on one's age and physical health. One, undergo a loop electrosurgical excision procedure to remove the abnormal tissue. Two, allow the surgeons to perform the excision using laser surgery. Three, have cryosurgery in order to kill the malignant cells. Four, undergo a total abdominal or vaginal hysterectomy to remove the cancerous area, cervix, and uterus. Some of these procedures may be done on an outpatient basis, whereas others would require inpatient status.

195 words

Flesh-Kincaid grade level = 10.9

Appendix D

Cervical cancer: Simplified version

Recently, you went to the doctor for a gynecological exam. The doctor did a Pap smear to check the cells around the opening to your womb. The doctor found some cells that were not normal. He ordered a test to check a small number of cells. The test results showed some cancer cells. A second test was done to check more of the cells. Your doctor looked at the results and sent you to see another doctor who specializes in cancer. This doctor told you that the cancer cells were on the surface, not down deep. He told you that your type of cancer is in the early stage. The doctor told you about the different kinds of treatment. The treatment options depend on your age and how healthy you are. One, the surgeons could take out the cancer cells by using a thin wire. This wire uses electricity to cut. Two, the surgeons could use lasers to take out the cancer cells. Three, the surgeons could freeze the cancer cells to kill them. Four, the surgeons could cut out the area with the cancer. This might mean cutting out the opening to the womb or the whole womb. Some of these treatments would not require you to stay overnight at the hospital. Others would require you to do so.

220 words

Flesh-Kincaid grade level = 4.6

Appendix E

Participant #: _____

DEMOGRAPHICS QUESTIONNAIRE

Please ask if you are unsure of how to answer any of the questions.

Age: _____ years

Education (please indicate the number of years of education you have completed): _____
years

Racial Background (circle one):

Caucasian
African American
Hispanic
Asian
Other

(specify) _____

In general, my health is (circle one):

Very good
Fairly good
Average
Fairly poor
Very poor

Have you ever been diagnosed with breast cancer? (circle one) yes no

If yes, please indicate when you were diagnosed, what treatments you have tried, and how effective each treatment was.

Have you ever known **someone else** who has been diagnosed with breast cancer? (circle one)

yes no

If yes, please indicate when she was diagnosed, what treatments she tried, and how effective each treatment was.

Have you ever been diagnosed with cervical cancer ? (circle one) yes no

If yes, please indicate when you were diagnosed, what treatments you have tried, and how effective each treatment was.

Have you ever known **someone else** who has been diagnosed with cervical cancer? (circle one)

yes no

If yes, please indicate when she was diagnosed, what treatments she tried, and how effective each treatment was.

Appendix F

Instructions: Imagine that you are faced with the situation described in the medical scenario and answer the following questions.

How much information would you like to have about **your diagnosis**? (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I want to hear my diagnosis, but do not want it explained to me.
- ☐ I want an explanation of my diagnosis, including a description of the type of cancer.
- ☐ I want an explanation of my diagnosis, including the type of cancer, location of cancer (by showing me an X-ray and having the location of illness illustrated on a plastic model of the human body), and extent of disease progression.

How much information would you like to have about **all the possible side effects of the available treatments**? (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want an explanation of the treatment side effects and how to remedy them.
- ☐ I want an explanation of the MOST LIKELY treatment side effects and how to remedy them.
- ☐ I want an explanation of ALL possible treatment side effects and how to remedy them.

How much information would you like to have about **what all the treatments will do?**
(Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about what the treatments will do.
- ☐ I want a description of what the treatments will do, including an explanation of how the treatment will affect my body.
- ☐ I want a description of what the treatment will do, including an explanation of how the treatment will affect my body, and the beneficial and harmful effects of the treatment.

How much information would you like to have about **the likelihood of a cure?**
(Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about the likelihood of a cure.
- ☐ I want my doctor to give me his/her opinion regarding the likelihood of a cure.
- ☐ I want my doctor to give me his/her opinion regarding the likelihood of a cure. Further, I would like to have summaries of relevant information from medical journals or cancer research institutes.

How much information would you like to have about **what parts of the body could be affected should the cancer spread?** (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about the parts of my body that could be affected.
- ☐ I would like my doctor to mention what parts of my body could be affected.
- ☐ I would like my doctor to mention what parts of my body could be affected, how they would be affected, and what it would do to my chances of survival.

How much information would you like to have about **exactly what the treatment will do inside your body?** (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about what the treatments will do inside my body.
- ☐ I want a description from my doctor about what the treatment will do inside my body, including an explanation of the organs, tissues, and systems that will be affected.
- ☐ I want a description from my doctor about what the treatments will do inside my body, including an explanation of the organs, tissues, and systems (e.g., gastrointestinal, pulmonary) that will be affected, whether or not the effects of the treatment are reversible, and how the treatment will affect my day-to-day life.

How much information would you like to have about **how effective all the treatments have been for other patients?** (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want to know how effective the treatment has been for other patients.
- ☐ I want to know what percentage of people are helped by the treatment.
- ☐ I want to know what percentage of people are helped by the treatment. I want to know how much improvement has been noted in people who have received the treatment in the past. I also want a description of the factors that either improve or worsen the chances that the treatment will be effective (e.g., the patient's age, the stage of the disease).

How much information would you like to have about **examples of cases where the treatment has been effective?** (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about the effectiveness of the treatment.
- ☐ I want a description from my doctor about a few cases where the treatment has been effective.
- ☐ I want a description of as many cases as possible where the treatment has been effective. I would like to read about examples of people who have been successfully treated. I would like to see pictures of the cancer site before and after treatment. I would like the opportunity to talk with people who have been successfully treated.

How much information would you like to have about **examples of cases where the treatment has NOT been effective?** (Circle one number)

1 2 3 4 5 6 7 8 9 10

No information

As much information
as possible

Place a check mark beside ONE statement that best describes your preference:

- ☐ I do not want any information about the effectiveness of the treatment.
- ☐ I want a description from my doctor about a few cases where the treatment has NOT been effective.
- ☐ I want a description of as many cases as possible where the treatment has NOT been effective. I would like to read about examples of people who have NOT been successfully treated. I would like to see pictures of the cancer site before and after treatment. I also would like the opportunity to communicate with other people who have NOT been successfully treated.

Appendix G

Instructions: Imagine that you are faced with the situation described in the medical scenario. Please make one mark across the line at the point that best describes how involved you would be in choosing a treatment option.

1	2	3	4	5	6	7	8	9	10
I prefer to leave all decisions regarding my treatment to my doctor									I prefer to make the final selection about which treatment I will receive

Imagine that you are faced with the situation described in the medical scenario. Place a check mark (T) next to the statement that best describes how involved you would be in choosing a treatment option.

_____ I prefer to make the final selection about which treatment I will receive.

_____ I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.

_____ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.

_____ I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.

_____ I prefer to leave all decisions regarding my treatment to my doctor.

Appendix H

Multidimensional Health Locus of Control (MHLC) Scales

Internal Locus of Control (IHLC)

If I become sick, I have the power to make myself well again.

1	2	3	4	5	6
strongly					strongly
disagree					agree

I am directly responsible for my health.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Whatever goes wrong with my health is my own fault.

1	2	3	4	5	6
strongly					strongly
disagree					agree

My physical well-being depends on how well I take care of myself.

1	2	3	4	5	6
strongly					strongly
disagree					agree

When I feel ill, I know it is because I have not been taking care of myself properly.

1	2	3	4	5	6
strongly					strongly
disagree					agree

I can pretty much stay healthy by taking good care of myself.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Powerful Others Health Locus of Control (PHLC)

If I see an excellent doctor regularly, I am less likely to have health problems.

1	2	3	4	5	6
strongly					strongly
disagree					agree

I can only maintain my health by consulting health professionals.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Other people play a big part in whether I stay healthy or become sick.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Health professionals keep me healthy.

1	2	3	4	5	6
strongly					strongly
disagree					agree

The type of care I receive from other people is what is responsible for how well I recover from an illness.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Following doctor's orders to the letter is the best way for me to stay healthy.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Chance Health Locus of Control (CHLC)

Often I feel that no matter what I do, if I am going to get sick, I will get sick.

1	2	3	4	5	6
strongly					strongly
disagree					agree

It seems that my health is greatly influenced by accidental happenings.

1	2	3	4	5	6
strongly					strongly
disagree					agree

When I am sick, I just have to let nature run its course.

1	2	3	4	5	6
strongly					strongly
disagree					agree

When I stay healthy, I'm just plain lucky.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Even when I take care of myself, it's easy to get sick.

1	2	3	4	5	6
strongly					strongly
disagree					agree

When I become ill, it's a matter of fate.

1	2	3	4	5	6
strongly					strongly
disagree					agree

God Locus of Health Control (GLHC)

If my [condition] worsens, it is up to God to determine whether I will feel better again.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Most things that affect my [condition] happen because of God.

1	2	3	4	5	6
strongly					strongly
disagree					agree

God is directly responsible for my [condition] getting better or worse.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Whatever happens to my [condition] is God's will.

1	2	3	4	5	6
strongly					strongly
disagree					agree

Whether or not my [condition] improves is up to God.

1	2	3	4	5	6
strongly					strongly
disagree					agree

God is in control of my [condition]

1	2	3	4	5	6
strongly					strongly
disagree					agree

Appendix I

Attitudes Toward Medical Authority

Indicate how your level of agreement or disagreement with the following statements by using the following scale:

- 1 = disagree strongly
- 2 = disagree somewhat
- 3 = neutral
- 4 = agree somewhat
- 5 = agree strongly

Attitudinal Challenge to MD Authority		(Circle one number from 1-5)				
R1.	Obedience and respect for what doctors tell you is most important.	1	2	3	4	5
2.	Relying on your own judgment and making your own decisions about what doctors tell you are most important.	1	2	3	4	5
R3.	If doctors would discuss less with patients and tell them straight out what to do, everybody would be better off.	1	2	3	4	5
4.	If doctors would discuss matters more with patients before acting, everybody would be better off.	1	2	3	4	5
5.	In making health decisions, the doctor ought to take a patient's opinion into account.	1	2	3	4	5
R6.	The doctor ought to have the main say-so in deciding what to do about a person's health problems.	1	2	3	4	5
7.	It's all right for people to raise questions with doctors about anything they tell you to do.	1	2	3	4	5
R8.	Every person should have complete faith in doctors and do what they tell you without a lot of questions.	1	2	3	4	5

Indicate how your level of agreement or disagreement with the following statements by using the following scale:

- 1 = disagree strongly
- 2 = disagree somewhat
- 3 = neutral
- 4 = agree somewhat
- 5 = agree strongly

Belief in Patient's Right to Information

(Circle one number from 1-5)

1.	If a patient asks to read his own medical records, they should be given to him	1	2	3	4	5
2.	Doctors should be required to explain the reasons for any treatment or prescription they recommend to a patient	1	2	3	4	5
3.	Doctors should make completely clear to a patient the risks for any treatment or operation.	1	2	3	4	5

Belief in Patient's Right to Make Decisions

(Circle one number from 1-5)

1.	If no contagious disease is involved, a patient should be allowed to leave the hospital even though his doctor does not agree.	1	2	3	4	5
2.	A patient should make the final decision whether to go along with the doctor's advice even if the decision is to refuse treatment.	1	2	3	4	5
3.	When a person is in the last stages of a terminal illness that cannot be cured, the patient or his family should decide if further treatment should be continued.	1	2	3	4	5

Indicate how your level of agreement or disagreement with the following statements by using the following scale:

- 1 = disagree strongly
- 2 = disagree somewhat
- 3 = neutral
- 4 = agree somewhat
- 5 = agree strongly

Belief in MD Competence

(Circle one number from 1-5)

1.	People do not know how many mistakes doctors really make.	1	2	3	4	5
R2.	Today's doctors are better trained than ever before.	1	2	3	4	5
3.	No two doctors will agree on what is wrong with a person.	1	2	3	4	5
R4.	Doctors will do everything to keep from making a mistake.	1	2	3	4	5
5.	Many doctors just do not know what they are doing.	1	2	3	4	5
6.	Doctors are put in a position of needing to know more than they possibly can.	1	2	3	4	5

Belief in MD Service

(Circle one number from 1-5)

1.	Doctors act like they are doing you a favor by treating you.	1	2	3	4	5
2.	Many doctors treat the disease but have no feeling for the patient.	1	2	3	4	5
R3.	Most doctors take a real interest in their patients.	1	2	3	4	5

Note. R = Reverse coded.