

Health Communication & the Medical Encounter: Perspectives of Urban African American Women

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ABSTRACT

Effective communication is essential for both a satisfying and productive patient-provider relationship. Ineffective communication can lead to many detrimental patient outcomes including a lack of access to care, an inability to navigate the healthcare environment, a decreased adherence to treatment recommendations, and a lack of patient understanding about disease risk factors, prevention, and management. The Healthy People 2010 initiative recognized the importance of communication by including several health communication-related goals in its objectives. A goal of one of these objectives included increasing the percentage of patients who reported that their care providers have satisfactory communication skills. Researchers can gain insight about those barriers that prevent providers from experiencing effective communication by examining the patients' perspectives about communication. The primary aim of this pilot study was to explore urban African American women's perspectives about the communication utilized during clinical encounters with providers via the use of semi-structured interviews. The semi-structured interviews collected data about a variety of topics including participants' breast cancer-related knowledge, attitudes, beliefs, and practices. Data was also collected about participants' clinical encounter experiences, including their comprehension of health information and their communication experiences with medical providers and other types of health care professionals. Any responses that discussed participants' communication experiences with providers, comprehension of health information, or perspectives about factors that could impede or facilitate communication were selected for analysis.

In addition to the semi-structured interviews, participants also completed two health literacy assessments in order to gauge their health literacy levels. Women were administered the Rapid Estimate of Adult Literacy in Medicine (REALM), a word recognition assessment, and the Short Test of Functional Health Literacy in Adults (STOFHLA), a comprehension assessment. Eligibility criteria included women who: (1) were aged 50 and older, (2) were English-speaking, (3) able to respond to interview questions without assistance, (4) of African descent, (5) were Harlem residents, and (6) had never received a diagnosis of breast cancer. One hundred women participated in the study. Data about the effectiveness of providers' communication skills, patients' abilities to comprehend health information, patients' communication experiences with various types of health care providers, and preferred sources of health information were collected from the interviews. Open-ended questions were utilized to gather information about factors that women deemed as either impediments or facilitators to effective communication with providers. Collected data from interviews were analyzed qualitatively. In addition to information about participants' health literacy scores from the literacy assessments, final results included demographic information, preferred sources of health information, and information about those factors that women viewed as either impediments or facilitators to effective communication with doctors and with other health care providers both in and outside of the medical appointment. Additionally, findings from the qualitative analysis results were utilized in order to inform the creation of health communication recommendations for providers who treat urban African American female patients.

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I. STATEMENT OF RESEARCH TO BE ADDRESSED

With the aging of the baby boomer generation, a large segment of the nation's population will soon be classified as seniors. Population projections cite that the number of individuals aged 65 and older will double in size from 35 to 72 million between the years 2000 and 2030. According to U.S. Census reports, 20% of the population is expected to be aged 65 or older by 2030 (He, Sengupta, Velkoff, DeBarros, 2005). Because of this shifting trend in demographics, it is imperative that efforts are made to address health issues most relevant to this segment of society. As the greatest consumers of healthcare in the U.S., seniors require special attention. Previous research has suggested that studies related to examining and improving quality of and access to care are of particular importance to ensure that older individuals are able to experience the best health outcomes possible.

Because seniors are often more vulnerable to several types of health complications than individuals of younger age groups, research that can assist in reducing specific causes of morbidity and mortality is of significance. A growing body of evidence suggests that an important relationship exists between communication and a number of notable outcomes. Such findings have led to increased attention to the importance of considering the communication skills of providers and the realization that these skills may be central to a patient experiencing a high level of care (Healthy People 2010, 2003).

Effective communication is essential for both a satisfying and productive patient-provider relationship. In order to address issues related to patient-provider communication, it is necessary that researchers gain a clearer understanding of patients' perspectives regarding communication during the medical encounter. A lack of clear communication can result in several detrimental consequences for the patient. Such negative outcomes may include a lack of access to quality

care, a lack of follow-up for necessary care, increased health care costs, and a lack of understanding about disease processes, risk factors, prevention, and management. As well, patients may rate their relationships with their physicians as unsatisfactory, an effect that can lead to distrust and noncompliance with regard to medical instructions. Only with more research can data be utilized to inform and direct efforts toward a greater understanding of the communication practices of patients and physicians. As well, such efforts can assist researchers realize any gaps in communication that may exist (Pfizer Health Literacy).

The current study examined the health communication strategies utilized by providers during medical encounters with senior African American women. Specifically, the purpose of this exploratory study was to examine the perspectives of women in an attempt to understand those factors that impede or facilitate health communication during the medical encounter. Findings from this study are valuable in that they contributed to the already growing body of health communication literature by providing rich qualitative data about the perspectives of urban senior African American women. An examination of study findings will help investigators to identify and clearly contextualize the perspectives of senior African American women regarding medical encounters and to better understand what factors might influence those perspectives.

I.A. STUDY AIMS

The primary purpose of this exploratory study was to examine the communication methods providers utilized during the medical encounters of urban senior African American women. To do this, a qualitative analysis of health communication data was conducted. Specifically, a secondary data analysis was performed on data collected as a part of a larger pilot

study. Findings from analyses will be used in the generation of hypotheses for future studies.

This exploratory study had several aims:

- Aim 1:** To understand urban senior African American women's perspectives about health communication utilized during their clinical encounters with providers.*
- Aim 2:** To explore those factors that either impede or facilitate effective communication between providers and their urban senior African American female patients.*
- Aim 3:** To utilize data from the current study to draft health communication recommendations for providers who treat urban senior African American female patients.*
- Aim 4:** To present descriptive data about the health literacy levels and sociodemographic information of study participants.*

II. BACKGROUND

Communication in health is critical. Effective health communication can dictate the health outcomes that individuals experience, and it is paramount for securing the health of a community. Not only is clear communication central to a successful medical encounter, but it is necessary to convey information that can be utilized in large scale health campaigns, mass media efforts, and the development of online health efforts (Healthy People 2010, 2003).

With regard to individuals, health communication is necessary for the successful exchange of health information in medical encounters. It is a critical element in encounters in which patients are expected to clearly convey their care expectations to providers. The ability of a provider to articulate information and exchange ideas with a patient can have profound effects on that patient's ability to gain access to care systems and effectively navigate the healthcare environment. Patients can take a more active role in decision-making and achieve greater autonomy, and providers can partner together with their patients to obtain the most optimal health outcomes possible (Healthy People 2010, 2003).

Although numerous studies have demonstrated that patient-provider communication is a fundamental aspect of medical care, study findings suggest that patients often experience difficulty comprehending instructions provided during clinical encounters (Weiss, Reed, & Kligman, 1995; Gibbs, Gibbs, & Henrich, 1987). Results from several studies suggest that difficulties occur when providers use complex medical jargon, deliver large amounts of information at once, or do not take steps to confirm that patients understand information provided during appointments. Studies have also revealed that patients often remember less than half of what providers tried to explain during the medical encounter (Ong & de Haes, 1995).

As a result of a growing body of literature, attention to the matter of health literacy and clear communication has reached the national forefront. Several organizations including the American Medical Association (AMA) (American Medical Association Council on Scientific Affairs, 1999), the National Work Group on Literacy and Health (National Work Group on Literacy and Health, 1998), and the Institute of Medicine (IOM) (Institute of Medicine, 2004) have each put forth a call for greater action to educate health care providers and to request that researchers devise and implement techniques that help with clearer communication strategies. One effort to prioritize the importance of clear communication was the Healthy People 2010 Initiative.

Healthy People 2010: Priorities and Strategies for Progress

Healthy People 2010 (HP 2010) was a collaborative effort guided by the Office of Disease Prevention and Health Promotion (ODPHP), an agency under the auspices of the U.S. Department of Health and Human Services (HHS). The Healthy People 2010 initiative was a group of objectives based on a systematic approach to improving health care for the nation. The initiative had two primary goals: to increase the quality and number of years of healthy life for

individuals and to eliminate existing health disparities. These two goals were grouped into over 28 different focus areas (Healthy People 2010, 2003).

The HP 2010 initiative defined health communication as “the study and use of communication strategies to inform and influence individual and community decisions that enhance health” (Healthy People 2010, 2000, pgs. 11-13). The 10 year initiative was set and monitored two times previously, but the 2010 initiative was the first to include a health communication area focus. The inclusion of communication as an area only served to confirm the significance of communication as a topic of interest in the healthcare arena (Healthy People 2010, 2003). As listed in HP 2010, one objective explicitly addressed the communication skills of healthcare providers. The primary focus of this objective was to increase the percentage of patients who reported that their care providers have satisfactory communication skills.

The HP 2010 initiative instituted a number of action steps in order to achieve this objective. Included in these action steps was a call to promote efforts that incorporated the pertinent literacy, cultural, and linguistic factors in interventions that can help improve patient-provider communication. Further steps included requesting that academic training programs place a greater emphasis on training providers to consider those factors particularly when addressing the needs of individuals who may be vulnerable to the most negative health outcomes or have the least access to care and health information. Lastly, and perhaps most importantly, a critical action step to achieve goals of effective communication included assigning researchers with the task of determining exactly what gaps in research currently exist (Healthy People 2010, 2003).

III. FACTORS THAT INFLUENCE HEALTH COMMUNICATION

Before effective health communication strategies can come into play, clinicians must make a concerted effort to learn about their target audience. That is, clinicians can only create and employ effective strategies after they have a clear understanding of each patient's literacy status and cultural background. Research also suggests that certain patient characteristics, including age and gender, can influence the effectiveness of the health communication utilized during the patient-provider interaction.

III.A HEALTH LITERACY

Many individuals encounter limitations when attempting to understand information about disease prevention, treatment, and management during the clinical encounter. Such difficulties need to serve as a red flag for health care professionals. It is critical that physicians realize that, for a number of reasons, they are not always able to successfully convey vital health information to their patients. This inability to effectively relay health information has been especially apparent amongst patients who possess poor literacy. Consistent findings from a number of studies have determined that there is a link between literacy and several health-related outcomes (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

What is Health Literacy?

To specifically examine the relationship between literacy and various health outcomes, researchers have examined findings from large scale literacy assessments and a body of research. Based on these findings, investigators have coined the term "health literacy". Health literacy can be defined as the extent to which an individual has the ability to gather, process, and comprehend health-related information. Health literacy is also linked to one's ability to effectively

understand and utilize certain services that are necessary for individuals to make proper decisions about health (Rudd, Kirsch, & Yamamoto, 2004). Health literacy can be regarded as a constellation of skills that an individual needs in order to negotiate certain demands and function successfully in the health care setting. Such basic skills include not only an individual's ability to read and understand information but that individual's ability to effectively act on health information. Adequate health literacy levels are critical in order for patients to effectively navigate the health care environment. Even with a number of findings that have demonstrated the importance of health literacy, many researchers believe that there is an existing gap between the health literacy skills that patients need to function adequately in the health care environment and the skills that they actually possess. Individuals who possess inadequate health literacy levels may often encounter a number of barriers to effective care.

III.A.1 LITERACY ASSESSMENTS

The National Adult Literacy Survey (NALS)

In 1992, the U.S. Department of Education requested that the Educational Testing Service conduct the National Adult Literacy Survey (NALS), the most comprehensive and largest literacy assessment of its kind. The NALS was able to assess the literacy proficiencies of the country's adult population (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Several of the literacy tasks included in the NALS were health-related in nature. These tasks focused on a myriad of topics including disease prevention, health promotion, safety, drugs, and alcohol. NALS investigators compiled the 191 health-related tasks that were included in the assessment and created a second measure, the Health Activities Literacy Scale (HALS).

Findings from the NALS estimated that between 40 and 44 million U.S. adults, approximately 25% of the population aged 16 and older, were categorized as functionally

illiterate. Additionally, another 50 million individuals were reported to possess marginal literacy skills. According to such findings, approximately 50% of U.S. adults experience some level of limitation in reading and basic mathematical abilities. Of the adults in this 50% who experience limitations, approximately 5% are recognized as possessing some type of learning disability and 15% were not born in the U.S. The overwhelming majority of U.S. adults with limited literacy were born within the U.S.

Several trends also emerged from the data collected from the HALS results. Scores for seniors (aged 65 and older) were much lower than for younger adults (Rudd, Kirsch, & Yamamoto, 2004). Approximately 50% of elderly adults scored within the lowest literacy level of the NALS (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Such low scores revealed that these seniors would experience great difficulty completing even the simplest of health-related literacy tasks. With regard to race, Caucasian adults scored significantly higher than respondents of other racial or ethnic groups (Rudd, Kirsch, & Yamamoto, 2004).

Findings from the NALS assessment were rather revealing. These results suggest that a significant number of U.S. adults are likely to experience serious difficulty when trying to function in the current health care system. Functional health literacy is an individual's ability to read and clearly understand medical instructions, medication bottles, and any type of health-related texts. As well, it also includes an individual's ability to utilize this information in a way that enables the individual to successfully function in the health care setting. The functional health literacy of most U.S. adults is likely to be even worse than the general literacy levels of these adults because functional health literacy is context specific. Such a suggestion posits that even adults who can read and understand information that contains familiar content without

experiencing any type of difficulty may not be able to understand other types of information written at the same level if that information contains health-related material. These adults may struggle because of new terminology or unfamiliar concepts. While the NALS was able to provide a portrait of the literacy proficiencies of American adults, it was not created with the specific intent to assess health literacy (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). The HALS was also not developed specifically to assess health literacy but it provided researchers with important insight about individuals' performances on health-related tasks.

The National Assessment of Adult Literacy (NAAL)

The NALS was not the only large scale assessment conducted to examine adult literacy in the U.S. The 2003 National Assessment of Adult Literacy (NAAL) was another assessment conducted to measure the English literacy proficiency of U.S. adults. The NAAL was administered to over 19,000 adults, aged 16 and older, in U.S. homes and prisons. The assessment was able to assess literacy utilizing the results of literacy tasks that were completed by surveyed adults. This approach differed from previous assessments that tended to rely more on the subjective measures of literacy, such as the self-reports of individuals (Kutner, Greenberg, Jin, & Paulsen, 2006).

Results from the NAAL were utilized to assess health literacy. The scales and tasks utilized in the assessment were constructed based on the definition of health literacy that has also been utilized by the Institute of Medicine (IOM) and the Healthy People 2010 initiative (Institute of Medicine, 2004; U.S. Department of Health and Human Services, 2000). Tasks featured as a part of the NAAL that contained health-related content were grouped together and utilized to create a health literacy scale. The NAAL included 28 health literacy tasks, and these items were developed in order to measure respondents' abilities to locate and comprehend health-related

information and services. The specific tasks featured in this health literacy scale provided real world examples of health-related tasks or information that an individual might actually encounter on a day to day basis (Kutner, Greenberg, Jin, & Paulsen, 2006).

The health tasks featured in the NAAL were specifically utilized to assess health literacy because their content focused on a range of topics related to health. The health tasks were created to assess various aspects of literacy including prose, document, and quantitative literacy. Prose literacy tasks were included to assess the skills and knowledge that an individual would need to be able to locate, understand, and utilize information featured in continuous text, such as sentences or paragraphs. Examples of such texts might include brochures, news articles, or instructions. Quantitative literacy includes the skills and knowledge levels that an individual needs to distinguish and carry out calculations using numbers that are included within the text of printed materials. Examples include the skills needed for an individual to determine a tip for a restaurant bill or balance a checkbook. Lastly, document literacy assesses the knowledge and skills that an individual needs to locate, understand, and utilize information featured in noncontinuous texts. Examples of when such literacy skills are needed includes when individuals read maps or complete applications (Kutner, Greenberg, Jin, & Paulsen, 2006).

In addition to assessing various types of literacy, the tasks featured in the NAAL were structured around three specific areas of health care: clinical, prevention, and the navigation of the health care system. The clinical domain included those activities or tasks that have a focus on the patient-provider interaction, medication, and the diagnosis and treatment of a condition. The prevention domain included those tasks that may be associated with topics such as the prevention of disease, maintenance of health, and engagement in self-care. The navigation of the health care system domain emphasized those tasks or activities that relate to an individual's

comprehension of how the health care system functions as well as an understanding of his or her own rights and responsibilities as a patient (Kutner, Greenberg, Jin, & Paulsen, 2006).

Performance on the NAAL was scored as one of four levels: Below Basic, Basic, Intermediate, and Proficient. The performance levels were used as a way to characterize the literacy abilities of respondents. Using such a categorization enables policy makers, analysts, researchers, and others to assess the performance of the study sample and make predictions about the capabilities of specified groups within the overall study sample. Individuals who scored within the Below Basic literacy range were classified as having the most basic of literacy skills. Adults who scored within this performance level include individuals who may be: (1) nonliterate in English, (2) able to locate easy to identify information in short texts and follow written instructions in relatively simple documents, and (3) able to locate numbers and then use them to perform simple computations (e.g., addition). Adults who score within the Basic performance level typically possess skills to complete simple daily literacy activities. These individuals are usually able to read and comprehend information provided in short texts and simple documents as well as locate quantitative information and then utilize it in simple computations (Kutner, Greenberg, Jin, & Paulsen, 2006).

Adults who score within the Intermediate range are typically able to perform somewhat challenging literacy tasks. These individuals can read and comprehend moderately dense text as well as summarize and make simple inferences. Adults scoring within this range are also able to locate unfamiliar quantitative information and utilize it to solve computations even when the needed mathematical operation is not clearly specified. Adults who score within the Proficient range typically possess the skills needed to perform complicated tasks. These individuals are able to read and comprehend lengthy abstract text as well as make complex inferences. They can

analyze several pieces of information contained in a document as well as locate abstract quantitative information and use it to perform complex multi-step computations (Kutner, Greenberg, Jin, & Paulsen, 2006).

The findings from the NAAL helped to paint a more accurate portrait of adults' literacy capabilities. According to results, over 50% of adults scored within the Intermediate health literacy range. Twelve percent of adults scored within the Proficient range, while 36% scored within either the Basic range or the Below Basic range. When examining NAAL findings by demographic breakdown, overall females scored a higher average level than did males. With regard to race and ethnicity, both Caucasian and Asian/Pacific Islander adults had higher literacy than African American, Latino, American Indian/Alaska Natives or multiracial adults. When examining findings based on age, adults who were age 65 and older received a lower average health literacy score than younger adults (Kutner, Greenberg, Jin, & Paulsen, 2006).

Findings from the both the NALS and the NAAL were instrumental in that they provided researchers with insight about the problem of inadequate literacy. Both the NALS and the NAAL assessments defined literacy as the ability of individuals to utilize both printed and written information in a manner that enables them to develop knowledge, achieve specific goals, and overall function properly in society. This definition of literacy was selected because it emphasized that the concept of literacy is more than an individual's ability to recognize words or comprehend phrases. The definition of literacy emphasizes the notion that one's literacy is also related to his or her ability to use certain skills to achieve a particular objective or accomplish a specific task (Kutner, Greenberg, Jin, & Paulsen, 2006). While both of these large scale assessments provided critical information about general literacy skills in the U.S. adult population, they also helped raise awareness about health literacy specifically.

The topic of health literacy was pushed to the forefront of the research agenda as a result of findings from large scale literacy assessments and research studies. Based on the results of these previous efforts, a number of organizations have adopted a stance in which they support efforts that emphasize the importance of addressing health literacy and its impact on health-related outcomes¹². For instance, the American Medical Association (AMA) Council on Scientific Affairs convened an ad hoc committee that was comprised of experts from a diverse range of fields in order to examine the influence of poor literacy on a number of outcomes. This Council drafted several recommendations that were adopted and incorporated into AMA policy during the organization's annual meeting in June of 1998. The recommendations stated that the AMA would recognize that inadequate patient literacy can act as a significant barrier to the provision of accurate medical diagnoses and treatments. Further recommendations included the fact that the AMA would work to increase the health care community's awareness of the limited literacy levels of many in the nation's adult population. Additionally, recommendations addressed the fact that the AMA does support the creation and implementation of education programs for undergraduate, graduate, and continuing education studies that will help provide education and training about effective ways to communicate with patients with limited literacy levels. The AMA stated that it would encourage the U.S. Department of Education to include questions that collect data about health status, health behaviors, and barriers to effective patient-provider communication in upcoming National Adult Literacy Surveys. Lastly, the AMA emphasized the need for continued funding for research on health literacy from both federal and private sources (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

The Institute of Medicine (IOM) also convened a similar committee. Members of the IOM's Committee on Health Literacy expressed the need for a collaborative effort to address issues related to low health literacy. The Committee determined that low health literacy can have a profound impact on several facets of care (Kutner, Greenberg, Jin, & Paulsen, 2006).

Why Study Health Literacy?

A number of investigators have posited that health literacy can have profound effects on one's access to care, the quality of that care, and the health status that an individual is able to achieve. Adequate health literacy is vital in that it can influence a patient's ability to comprehend health information about a number of topics including disease management, prevention, and health promotion. In order to ensure successful health outcomes, providers must be able to communicate essential health information to their patients in a clear manner (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Prior research findings have revealed that health literacy can greatly influence the quality of communication that occurs during clinical encounters between the patient-provider dyad. Health literacy is important because it can dramatically impact the quality of discussion and dialogue that occurs between the patient and provider and as a result, the nature of the interpersonal relationship between the patient and provider.

Inadequate health literacy can often act as a significant barrier to clear patient-provider communication. Because individuals with low health literacy may experience difficulties completing a wide range of tasks, such problems may impact the quality of communication that occurs during the clinical encounter. Individuals who possess inadequate health literacy may encounter difficulty during medical visits with tasks such as reading and understanding dosage information, test results, information provided on appointment slips or information presented in

health brochures. These individuals may also experience great difficulty conceptualizing levels of risk and processing any written and oral communication that may be provided (Doak, Doak, & Root, 1996; Mayeaux, Murphy, Arnold, Davis, Jackson, & Sentell, 1996). Problems with these and other types of health-related tasks may then result in a breakdown in the communication that occurs between patient and provider.

Another consequence of inadequate health literacy is that patients may be at a greater risk of receiving an incorrect diagnosis as a result of ineffective communication. A patient's health literacy level may not only affect how well the individual is able to understand information, but impact how well the patient is able to convey information about his health status during the provision of medical history to clinicians. Providers may not be able to gather both accurate and comprehensive information during the medical history taking process (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Patients with low health literacy may experience great difficulty verbalizing information about medical concerns (Dorsey, Miller, Parrott, & Thompson, 2003) because they may be unfamiliar with medical concepts and vocabulary (Gibbs, Gibbs, & Henrich, 1987). These individuals may be unable to properly describe medical symptomology to providers (Roter, 2000). Findings from previous reports suggest that less than 50% of the U.S. adult population comprehends frequently used medical terminology. This lack of understanding affects how well patients are able to provide information as well as how well providers are able to collect the information necessary to make accurate and complete diagnoses (Boyle, 1970; Cole, 1979).

Inadequate health literacy can affect communication in other ways. It can prevent patients from actively participating in the clinical encounter. Patients who do not understand health-related information may be less communicative. They may ask fewer questions (Ad Hoc

Committee on Health Literacy for the Council on Scientific Affairs, 1999). As a result of difficulty with comprehension, patients with inadequate health literacy may not understand the importance of sharing vital health information with providers or they may be unable to discern which information (e.g., the presence of certain symptoms) is most relevant (Roter, 2000). When asked about their health status during the history taking process, patients may not know what information they should share with providers. If a provider assumes that a patient who is not vocal or active in discussion is uninterested in improving his or her health, when instead the individual is simply unable to clearly communicate (e.g., clearly convey information about medical status or ask questions to gain information), then the result may be ineffective communication. Providers may make less of an effort to partner with the patient (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). As a result of the breakdown in communication, patients may experience a decrease in levels of self-empowerment (Wallerstein, 1992) and a lack of trust in information provided by physicians during the clinical encounter (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

Efforts to explore the link between health literacy and specific health outcomes are critical because study findings can provide greater insight about this relationship. Continued work will help to reiterate to health care providers the importance of considering the impact of patient health literacy. A primary factor needed in order to achieve effective health communication is for providers to be somewhat knowledgeable about the health literacy levels of their patients. Before a provider can determine if and how (s)he can effectively relay information, the provider must possess an understanding of the patient's health literacy level (Healthy People 2010, 2003). Many physicians rarely consider limited literacy skills during their determination of whether patients understand presented health information or recommendations

about treatment. Previous studies have suggested that many physicians commonly overestimate their patients' literacy levels (Bass, Wilson, Griffith, Barnett, 2002). As well, findings from prior research suggest that clinicians rarely make efforts to determine how well patients comprehend instructions that have been provided during the encounter. One such study determined that clinicians make efforts to determine how well patients comprehend instructions only approximately 2% of the time (Braddock, Fihn, Levinson, Jonsen, & Pearlman, 1997).

Information about providers' lack of awareness regarding patient health literacy levels is somewhat surprising. Providers who are unaware of patient health literacy cannot make efforts to tailor their communication styles to suit the needs of patients who may have inadequate health literacy. However, other research has revealed even more unexpected findings. Other studies have determined that even when physicians are provided with information about patient literacy status, they may be ill-prepared to utilize effective communication techniques with patients (Seligman, Wang, Palacios, Wilson, Daher, Piette, & Schillinger, 2005).

Providers must be proactive about learning about patients' health literacy levels. Patients with inadequate health literacy may not disclose their literacy problems to physicians, either out of shame or embarrassment (Parikh, Parker, Nurss, Baker, & Williams, 1996) or because they do not feel that literacy level is any way linked to health status (Roter, 2000). Patients who have low health literacy also may not always report this issue to providers because they may not recognize that they have inadequate health literacy (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993).

Inadequate health literacy can prevent clear and effective patient-provider communication. Because individuals with low health literacy may experience difficulties completing a wide range of tasks, such problems may impact the quality of communication that

occurs during the clinical encounter. These problems present a great barrier because the current health care system is one in which medical professionals often place great demands on their patients to understand information provided during clinical encounters as well as take the steps to manage their own illnesses. As a result, inadequate health literacy can present a great obstacle to care and disease management (Schillinger, Grumbach, Piette, Wang, Osmond, Daher, Palacios, Sullivan, & Bindman, 2002).

A greater emphasis on the topic of health literacy is critical. Health literacy has been linked to a number of health-related outcomes, including communication. It is imperative that researchers continue to conduct studies that can further elucidate the link between health literacy and communication. Such data will assist researchers in determining how inadequate health literacy can impact the health of individuals.

Findings from previous research have reported that health literacy may be associated with a number of health-related outcomes. Results have suggested that an association exists between inadequate health literacy and a number of adverse health outcomes such as infrequent disease screening practices, disparate morbidity and mortality for a number of diseases and higher rates of hospitalization (Baker, Parker, Williams, & Clark, 1998; Berkman, DeWalt, Pignone, Sheridan, Lohr, Lux, Sutton, Swinson, & Bonito, 2004; Lindau, Tomori, McCarville, & Bennett, 2001). Additional research has reported an independent association between limited health literacy and greater utilization of health care services (Baker, Parker, Williams, & Clark, 1998; Baker, Parker, Williams, Clark, & Nurss, 1997). For their work specifically, Baker and colleagues discovered that low health literacy may also be related to greater utilization of emergency rooms as sources of primary care (Baker, Gazmararian, Williams, Scott, Parker, Green Ren, & Peel, 2004). Inadequate health literacy has been determined to be linked to poor

health status (Williams, Baker, Parker, & Nurss, 1998; Weiss, Hart, McGee, & D'Estelle, 1992; Baker, Parker, Williams, Clark, & Nurss, 1997) and poor self-ratings of health by individuals (Weiss, Hart, McGee, & D'Estelle, 1992). Such findings reveal that inadequate health literacy can have a significant impact on the costs of caring for patients (Kutner, Greenberg, Jin, & Paulsen, 2006). Inadequate health literacy is associated with a number of outcomes, including higher health care related costs (Baker, Parker, Williams, Clark, & Nurss, 1997; Weiss, 1999) for patients, providers, health plans, and the U.S. health care system as a whole (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

Individuals with inadequate health literacy skills may have a decreased likelihood of understanding and recalling the medication recommendations made by health care professionals (Baker, Parker, Williams, Pitkin, Parikh, Coates, & Imara, 1996). They may experience increased levels of difficulty providing the names of their medications as well as any information about these medications (Williams, Parker, Baker, Coates, & Nurss, 1995). As a result, these individuals may take incorrect dosages or dosages at the wrong time and not possess a true understanding of the adverse effects that can result from incorrectly taking medications. Those with poor health literacy may also not realize the importance of seeking suggested follow-up care (Baker, Parker, Williams, 1996). As well, patients with inadequate health literacy may be unable to perform a number of necessary health-related tasks including interpreting charts and test results, making decisions about participation in research, and utilizing medical tools and equipment either for personal or family-related care (Institute of Medicine, 2004). These patients may have to contend with ineffective problem-solving skills (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Williams, Baker, Parker, & Nurss, 1998). Such findings suggest that inadequate health literacy can also affect the treatment that

patients receive and their practices including decisions to seek preventive care (e.g., participate in screening).

Low health literacy can affect other aspects of care including the utilization of certain services (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999), which can lead to noncompliant behavior. A lack of understanding about important information, including recommendations for treatment or screening, may cause patients to not adhere to such requests. In a previous study, researchers found that female patients who possessed low health literacy levels tended to poorly understand mammography. These women also had a greater likelihood of possessing negative attitudes toward the practice of breast cancer screening (Davis, Arnold, Berkel, Nandy, Jackson, & Glass 1996). Additional findings suggest that those individuals with limited literacy may also have a greater likelihood of possessing beliefs that might prevent adequate adherence with medical recommendations (Kalichman, Rmachandran, & Catz, 1999). Individuals who do not understand the significance of such recommendations not only may be noncompliant but they may also not reveal to providers that they have not complied with treatment.

III.B GENDER

Gender can have a great impact on various aspects of the patient-provider interaction. Previous research findings have determined that the gender of the patient can influence the communication process that occurs within the patient-provider dyad during the clinical encounter (Weisman & Teitelbaum, 1989).

Despite the fact that current research has revealed that patient gender can potentially impact factors such as patient adherence, satisfaction, and the quality of communication that occurs during the medical encounter, in past research patient gender was not generally regarded

as a variable of interest that could affect these factors. However, a review conducted by investigator Gabbard-Alley (1995) helped to provide clearer insight about the links between patient gender and health communication. This investigator examined the relationships between patient gender, health communication, patient satisfaction and patient adherence. The investigator's review of the literature helped to provide information about the role of gender in the medical encounter – including its impact on trends in health communication research (Gabbard-Alley, 1995). This examination of communication research determined that patient gender should be regarded as an important variable in the field of health communication research. Hall and colleagues (Hall, Roter, 2002; Hall, Roter, & Katz, 1988) conducted a meta-analysis and determined that gender is a significant variable with regard to specific provider behaviors. The research of these and other investigators revealed the importance of examining the impact of gender on the interactions that occur between patient and provider during the clinical encounter.

Information about the differences in the medical encounter experiences of patients based on gender can provide health care professionals with great insight. Such insight is needed in order to help providers gain a better understanding of the health care experiences that female and male patients may encounter. As a result, this information can help health care professionals better serve their patients.

The communication experiences of female patients and their health care providers are important to consider for a number of reasons. The level and quality of communication between female patients - who are often treated by male physicians - and providers has been frequently criticized in the past. Female consumers of health care have been increasingly pushing for efforts to address this issue. Prior research suggests that women are larger consumers of health

care services than men. An examination of communication between female patients and their providers is also essential because women usually take on the responsibility of managing the health of their family members, including children. Because of this, often their desire and need for health-related information will be greater than that of male patients. As well, as more emphasis is placed on the importance of health promotion and disease prevention for patients, the importance of providing effective communication in order to educate patients about various risk factors and to influence the adoption of key preventive behaviors will increase (Weisman, 1987).

Gender-Based Communication Trends

Researchers have suggested that, when examining issues related to health communication, women should be regarded as an important population of patients. Previous research that focused specifically on general communication patterns in populations revealed the existence of persistent gender differences that are likely also at work during clinical encounters (Weisman & Teitelbaum, 1989). A body of literature, outside of the sphere of medicine and health, has documented the differences in the general communication styles of men and women (Aries, 1996; Dindia & Allen, 1992; Eagly & Johnson, 1990). For instance, findings reveal that in general, women have a greater tendency to reveal more information about themselves during conversations (Dindia & Allen, 1992). As well, women often provide encouragement to others and help to facilitate talk that is warmer and more intimate than men (Hall, 1984). There is also evidence that women make great efforts to equalize their status with that of their partners during conversations, while men do not take such an approach. Males have a greater likelihood of asserting any existing differences in status (Eagly & Johnson, 1990).

Hall has also assessed gender-based differences in non-verbal communication and determined that females are better able to recognize and judge important non-verbal cues, including facial expressions. It was reported that females are better able to use non-verbal behaviors to express emotions. For instance, previous research has suggested that women tend to smile and gaze much more often than their male counterparts (Hall & Halberstadt, 1986).

In prior research, Hall (1984) conducted a review of the literature that focused on gender-based variations in general communication, including speech quantity and non-verbal aspects of communication. As a part of the review, studies that utilized a number of approaches including observations in labs and field settings and analyses of audio recordings were conducted. Hall et al determined that males tended to not only speak more but also at a more rapid pace. As well, males, in comparison to females, were more likely to interrupt discussions, break silences, and make greater numbers of speech errors. Investigators who have reviewed such findings have interpreted that these types of gender-based differences reveal a greater tendency of males to dominate discussions. An additional explanation has posited that females possess better verbal skills than males and that many behaviors that have been exhibited by male participants in previous studies are used as a way for men to compensate for any deficiencies in communication (Weisman & Teitelbaum, 1989).

Communication Characteristics of Female Patients

Previous research has suggested that women are more frequent consumers of health care services than men. This research has revealed that the trend holds even when services that are linked to reproduction such as pregnancy and childbirth are taken into account (Verbrugge & Steiner, 1985; Cleary, Mechanic, & Greenley, 1982). Such research raises several points about

the importance of communication. Although findings that support the existence of a gender difference in the utilization of health care services may not specifically imply that communication issues provide an explanation for females' greater use, one potential explanation for female patients' greater utilization of health services may be that they are more adept at identifying and reporting medical symptoms (Nathanson, 1977). Previous findings have revealed that females disclose more symptoms to their providers in comparison to males, including psychiatric symptoms (Kessler, Brown, & Broman, 1981; Tuetig, Koslow, & Hirschfield, 1981). Much attention has been focused on whether differences in the disclosure of symptoms is linked to a gender role difference in the way that men and women identify symptoms or whether it is associated with the existence of actual differences in morbidity rates between males and females (Nathanson, 1975; Gove, 1984).

A prevailing belief of many medical sociologists is that women experience greater rates of morbidity because certain sociological factors that suppress displays of the sick role in males do not lead to the same type of suppression of such roles in females (Nathanson, 1977; Marcus & Seeman, 1981). As well, it has been surmised that females may report higher rates of illness because the concept of women taking on the sick role has been deemed to be socially acceptable for this group and as a result, it is easier for women to assume this role (Marcus & Seeman, 1981). Such a theory does make the presumption that the sick role behavior has a greater compatibility with the traditional roles of women. Therefore, women may not feel as inhibited as men when either defining or reporting illness (Gabbard-Alley, 1995). Female patients may not feel as restricted as male patients when communicating with providers about health matters during the clinical encounter.

The skill of identifying and reporting medical symptoms by women may be a result of better communication skills (Nathanson, 1977). An additional explanation for females' greater use of health care services is not just that female patients are more willing to assume the sick role but that female patients may often be more easily influenced to utilize more health services by providers who employ persuasive communication techniques during medical encounters (Weisman & Teitelbaum, 1989). These providers may possess ulterior motives. Fisher employed discourse analysis (Fisher, 1988; Fisher & Todd, 1986) to study patient medical interviews that focused on decisions related to women's health including decisions about the use of oral contraceptives, whether or not to perform procedures such as hysterectomies, and decisions related to whether or not Pap tests should be provided. Fisher asserted that in the case of these medical interviews, the providers were not always making efforts to simply convey information to patients. These providers are also trying to persuade patients to make decisions to achieve a certain outcome (e.g., to undergo a hysterectomy) or persuade patients to adopt a certain point of view. Although persuasion as a tool can be considered as a legitimate part of a provider's role, it could be possible that providers persuade patients to a particular way of thinking because of competing interests for the provider, such as financial gain. Such interests could motivate providers to employ certain types of communication behaviors in order to persuade patients to take one action over another. Such assertions suggest that studies that report that physicians often spend more time with women during clinical encounters or offer women greater amounts of information may not always be an indication that both the patient and provider have reached a level of greater understanding. As well, such communication behaviors should also not be viewed as evidence that better decision-making practices regarding care and treatment are being utilized. Whatever the reason for females' greater use of health care

services, their greater use of and exposure to the health care system may result in greater levels of knowledge about health-related issues, and as a result, more effective health communication skills than their male counterparts (Weisman & Teitelbaum, 1989).

Some of the patterns discovered in findings from general communication research have also been discovered to hold true for communication utilized during the medical encounter. Health communication research has determined that women often reveal more information during verbal exchanges with providers than men. Wallen et al (Wallen, Waitzkin, & Stoeckle, 1979) discovered that during clinical encounters, women asked their providers more questions and talked more as compared to men. This finding was similar to the finding of Waitzkin (Waitzkin, 1984; Waitzkin, 1985), who determined that female patients not only talk more during clinical interactions as compared to males, but females also ask a greater number of questions (Waitzkin, 1984; Waitzkin, 1985). This finding does dispute previous research that determines that males speak more than females (Korsch & Negrete, 1972). Some research has attempted to explain the finding that female patients communicate more by suggesting that female patients ask more questions not because they are more effective communicators but because they do not possess as much knowledge as males and therefore have to talk more during clinical encounters in order to clarify information that has been presented. However such findings may be disputed because the fact that female patients may actually talk more because of their greater utilization of health care services, as well as their greater responsibility for the care of their family members, may result in females possessing better information than males (Weisman & Teitelbaum, 1989). The differences in communication between the genders could be linked to the fact that women may have more exposure to different sources of health information than men. As well, such differences could be attributed to factors such as women's

tendencies to take on the help-seeking role, providers offering females greater opportunities to ask questions during encounters, or the possibility that female patients may receive less information (or less clear information) during encounters, and thus must ask questions to clarify information that has been presented (Korsch & Negrete, 1972).

Despite findings that have suggested that male patients are more knowledgeable about health-related matters than females, findings from several studies do not support this belief. Researchers Cooper and Metcalfe (Cooper & Metcalfe, 1979) discovered that females possess greater levels of knowledge about health-related matters than males. Wartman and colleagues (Wartman, Morlock, Malitz, & Palm, 1983) determined that female gender was significantly correlated with greater comprehension of medication instructions. Buller and Buller (Buller & Buller, 1987) suggested that female patients, as compared to their male counterparts, may possess greater knowledge about medical treatments and techniques. This could be linked to the fact women may have greater levels of concern about issues related to health. If such a finding is true, then the greater knowledge that female patients possess may provide them with a greater level of confidence that enables them to request more information during clinical encounters and discuss health concerns at length.

A small amount of evidence has suggested that greater levels of nonverbal interaction also occur between women and health care providers as compared to men (Gabbard-Alley, 1995). Providers should also be aware that female patients have a greater likelihood of possessing more skills with regards to recognizing the non-verbal communication that is conveyed by providers. Therefore, female patients will not only process information that is presented as a part of a provider's dialogue (verbalizations), but also consider the information relayed through a provider's facial expression, tone of voice, and posture. As well, women may

ask questions in order to clarify specific verbal and non-verbal messages that may appear contradictory. For instance, a provider may verbally express a positive affect while conveying a negative nonverbal cue such as frowning. Providers need to make certain to utilize non-verbal cues appropriately (e.g., smiling or using appropriate behaviors when verbalizing empathy) (Weisman & Teitelbaum, 1989). It is also possible that although female patients may receive more communication, it may not be specifically about medical matters. Prior studies suggest that female patients may receive more interactions with providers in the form of affective communication. This research has indicated that often providers of general medicine may express more comfort communicating about feelings with patients who are women than those who are men (Mant, Broom, & Duncan-Jones, 1983; Verbrugge, 1984). Such findings can have important implications for the communication that occurs between patients and providers.

Investigators may believe that women may possess skills that will enable them to better elicit information giving from physicians. As a result of females' skills at properly identifying and interpreting nonverbal behaviors, as well as their greater levels of expressiveness, and their specific types of speech patterns, females may be able to elicit greater amounts of information from providers by reinforcing provider speech and correctly interpreting providers' nonverbal cues. Such speculation helps to explain previous research findings in which women obtain more information from providers and ask more questions than their male counterparts. Investigators suggest that if females are able to state their information needs in a clearer manner than males and utilize approaches that may be more conducive to discussions with medical providers, it is expected that they will likely receive greater amounts of information than their male counterparts (Weisman & Teitelbaum, 1989).

Communication Experiences of Female Patients

A number of studies have been able to provide insight about the experiences of female patients during the clinical encounter. These studies have revealed that female patients are often treated differently than males. Hall and colleagues (Hall, Roter, & Katz, 1988) reviewed 41 studies that examined both verbal and non-verbal aspects of provider behavior during clinical encounters. Studies included in this analysis all focused on communication within the patient-provider dyad (Hall, Roter, & Katz, 1988). The investigators determined that female patients received greater amounts of information and overall more communication (as determined by either total time or the total number of utterances) than male patients. As well, Hall et al found that in a few studies, women received greater amounts of “positive talk” and experienced greater amounts of partnership-building activities. Examples of such “positive talk” included instances in which providers employed humor, expressed approval or offered encouragement. Examples of partnership-building activities included instances in which providers used verbalizations that helped to increase the patient’s level of authority or patient participation in the encounter. The review by Hall et al (Hall, Roter, & Katz, 1988) also found that greater amounts of information provided by physicians was linked to greater levels of patient satisfaction, higher compliance to treatment recommendations, and a greater recall of information and comprehension of one’s health condition (Hall, Roter, & Katz, 1988).

Investigators Hooper and colleagues (Hooper, Comstock, Goodwin, & Goodwin, 1982) studied the effects of a number of patient characteristics (e.g., age, gender, race/ethnicity, and appearance) on several provider communication behaviors including information giving. For this study, interactions between ten patient-provider dyads in an outpatient clinic were observed

using a one-way mirror. Providers in the study were scored on information giving, courtesy, interviewing skills, empathy, nonverbal behavior, provider-initiated interruptions, and the amount of time spent with each patient. Investigators discovered that ratings of both empathy and information giving were significantly higher and the amount of provider-initiated interruptions was greatly reduced when patients were women. Other types of communication behaviors did not tend to vary based on the gender of the patient (Weisman & Teitelbaum, 1989).

Additional research has also suggested that often health care providers communicate more with female patients during encounters than male patients. Evidence suggests that health care professionals, specifically physicians, often experience more verbal exchanges with women than men. As a result, these increased interactions encourage greater communication from women. Investigator Waitzkin (Waitzkin, 1984; Waitzkin, 1985) discovered that female patients received more time, greater explanations, and more general responses from providers during clinical encounters than male patients. As well, Comstock et al (Comstock, Hooper, Goodwin, & Goodwin, 1982) reported that during the patient-provider interaction, ratings assessing provider information giving were substantially higher for female patients as compared to male patients. Comstock and colleagues (Comstock, Hooper, Goodwin, & Goodwin, 1982) discovered that providers spent greater amounts of interview time with female patients in comparison to male patients (Comstock, Hooper, Goodwin, & Goodwin, 1982). If such findings are indeed true, and a specific type of communication bias based on gender does exist, then researchers and health care professionals need to emphasize that greater attention should be placed on gender-based differences in future communication studies (Gabbard-Alley, 1995). Based on such findings, one might suggest that female patients should not experience great difficulty when trying to obtain information and when communicating with providers during clinical encounters.

Though some studies suggest that female patients experience positive clinical encounters, critics who have examined women's health care have asserted that providers often utilize approaches that may adversely affect communication with female patients (Ruzek, 1979). Feminist criticisms about women's health care have targeted communication between female patients and their providers, who are often men, as a source of potential problems during the clinical encounter. Examples of problems include physicians' use of familiar forms of address when talking with female patients (e.g., a provider employing a patient's first name instead of the surname), or when physicians "talk down" to a female patient, belittle a patient's ability to properly utilize medical information, or withhold certain types of technical information from a patient (e.g., information about risks associated with certain procedures or the use of medications). Such examples have been interpreted by many as a provider's way of exerting control both over the clinical encounter and the patient's behavior (Ruzek, 1979; Fisher, 1988). These types of approaches may cause female patients to experience greater levels of dissatisfaction and resentment. As well such approaches may lead to the transmission of less information and the provision of inadequate health care. It is important that researchers determine whether female patients, who although they utilize greater amounts of health care services, may still be provided with a lesser quality of communication (Weisman & Teitelbaum, 1989).

Although prior research has suggested that female patients have more time for communication with providers during such interactions in comparison to men, often the concerns of female patients may not be taken seriously by health care providers. Wallen and colleagues examined 336 audiotaped encounters between male providers and their male and female patients. After observing providers' responses to patients' requests for health information, the

investigators discovered that although female patients asked more questions and were provided with more explanations than males, providers often offered women briefer and less technical responses than those responses offered to men (Wallen, Waitzkin, Stoeckle, 1979). Such a finding posits that the greater degree of health information that women receive may be the result of female patients' requests for information and not because providers volunteer this information. Investigators suggested that such findings indicated a propensity for male providers to withhold medical information from female patients in an effort to maintain some level of the traditional roles often seen in the male-female power relationship. Such an approach by male providers could result in women feeling the need to ask more questions in order to obtain needed information (Gabbard-Alley, 1995). Weisman et al (1989) suggests that health care providers should make efforts to provide adequate responses to female patients' questions with the appropriate amount of technical information. As well, providers should make a point to provide requested information and refrain from disparaging female patients' health information needs as well as their alternative sources of information.

Past research findings suggest that observed differences in communication based on gender may be based to some degree on females' greater communication skills, as compared to males. Such communication also includes the greater quantity of information that female patients receive. Investigators suggest that if females are able to state their information needs in a clearer manner than males and utilize approaches that may be more conducive to discussions with medical providers, it is expected that they will likely receive greater amounts of information than their male counterparts. As well, if females also possess superior skills with regards to non-verbal communication techniques, then they will likely receive greater amounts of information, specifically about a provider's affect (Weisman & Teitelbaum, 1989).

It is important that greater efforts are made to determine the impact of gender on the communication that occurs during the clinical encounter. Although findings for several studies suggest that women may be able to communicate without difficulty because of the skills that they possess in comparison to men, findings from additional research may indicate that women will experience great difficulty especially when conversing with male providers who may attempt to dominate conversations during the clinical encounter. As well, if women are not provided with clear health information, they may be unable to effectively communicate with providers and experience positive health outcomes.

III.C. AGE

The population of seniors is steadily increasing. Estimates by the U.S. Census Bureau have predicted that the population of individuals over the age of 65 years old will comprise approximately 17% of the nation's population by the year 2030 (Adelman & Albert, 1987). Older adults are frequent users of health care services and because of this, providers need to work to address the needs of this segment of the population (Beisecker, 1996). In the U.S., estimates report that individuals over age 65 make more visits to providers annually than individuals in other age groups (United States Department of Health and Human Services, 1982).

The increasing senior population and the greater utilization of healthcare services by older individuals reveal the need for researchers and health care professionals to make greater efforts to examine factors that can impact the health-related needs of seniors, including communication within the clinical encounter (Ryan & Butler, 1987).

As a result of the steadily increasing population in the U.S., health care providers will need to possess specialized communication skills and knowledge that will be necessary in order

to provide care. Such skills will be especially critical for those providers who will be responsible not only for delivering care but also for addressing the long-term care and health promotion needs of older adults. Health professionals must recognize that the needs of these individuals will differ greatly for each individual and over the course of time (Giles, Coupland, & Wiemann, 1990; Shadden, 1988).

Greater research needs to be conducted in order to evaluate how health care providers communicate with senior individuals (Greene, Adelman, Charon, & Hoffman, 1986). The field of communication and aging is quickly emerging as one that will be vital to addressing the needs of seniors. This field will provide critical information that can be utilized to broaden the field of health communication (Nussbaum & Coupland, 1995).

It is especially important that older individuals have access to a health care atmosphere that is supportive (Ryan & Butler, 1987). Findings from prior research suggest that health care for seniors has often been characterized by negativism and antipathy on the part of providers. Such a finding is problematic because most health care providers will have to provide some level of care to senior patients at some point during their careers (Holtzman, Beck, & Ettinger, 1981; Spence, Feigenbaum, Fitzgerald, & Roth, 1968). Therefore, providers will have to acquire the skills needed in order to successfully offer care for senior patients.

Older patients must deal with a number of problems. Older patients may experience age-related changes in both health status and communication skills that result in difficulties during the medical encounter. Communication difficulties that are linked to the physical and cognitive effects associated with increasing age can affect the health care interaction (Ryan & Butler, 1987). For many older adults, even those regarded as healthy, the normal process of aging may result in significant changes in communication skills. Issues related to hearing and vision

impairments, a slower speed of processing information, and various memory issues may adversely affect the communication process (Bayles & Kaszniak, 1987; Kemper, 1992; Nussbaum, Thompson, & Robinson, 1988). Conditions often associated with increasing age, such as dementia or cerebrovascular disease and the use of recommended medications, can result in seriously limited communication skills. As well, problems with communication skills may be linked to the fact that older individuals may experience decreased contact with family, friends, other members of their social circles, and colleagues from their professional worlds. As a result of diminished personal contact or various health reasons, changes in basic social interaction skills can act as a possible barrier preventing effective relationships with providers. Increased knowledge about seniors' communication skills and those strategies that can best help facilitate effective communication can prove beneficial for providers (Ryan & Butler, 1987).

Not only must older patients overcome many of the common physical and health issues associated with routine aging but they must also determine a way to overcome obstacles that are put in place by providers (Ryan & Butler, 1987; Ryan, Meredith, MacLean, & Orange, 1995). Since they are often consulting with providers who may be younger in age, older patients may encounter a number of difficulties. Such obstacles may include the ageist attitudes of health care providers and the impact of intergenerational differences on the patient-provider relationship. Both of these factors can have rather damaging effects on the quality of communication that occurs between patient and provider (Ryan & Butler, 1987).

Often patient-provider relationships are intergenerational in nature. That is, providers may treat patients who are older. This may lead to age-associated variations in communication approaches, including styles and expectations. Any variations that occur because of differences in age between younger and older adults may be related to historical variations in socialization.

Such differences may then impact the intergenerational relationship. Examples of how age differences can impact the relationship are illustrated in instances in which older individuals often expect providers to direct or dominate an interaction (Ryan & Butler, 1987; Greene, Adelman, & Majerovitz, 1996). Younger and older individuals employ different approaches when resolving conflicts and these differences may play out for patients during the clinical encounter (Bergstrom & Nussbaum, 1996).

Intergenerational differences can affect the patient-provider interaction in other ways. Older individuals' expectations that providers will dominate the interaction can have a serious impact on the patient-provider encounter. Certain factors, such as patients' beliefs about sense of control, can influence a patient's communication behaviors. For instance, such beliefs can influence patients' decisions to assert their rights, express opinions and beliefs, and participate in the decision-making process during the clinical encounter. Prior research that examined the role of locus of control (Arntson, Makoul, Pendleton, & Schofield, 1989; Mahler & Kulik, 1990; Woodward & Wallston, 1987) has revealed that older patients often possess a high provider health locus of control and fate locus of control (Arntson, Makoul, Pendleton, & Schofield, 1989). Such research suggests that older patients have a greater likelihood of granting providers authority with regards to decision-making as compared to younger patients (Beisecker, Murden, Moore, Graham, & Nelmig, 1987). As well, such findings have also suggested that older patients may have a low desire for medical-related information and for a sense of control (Woodward & Wallston, 1987). Findings revealed that older patients had a greater likelihood of desiring that their providers make decisions about care (Beisecker, 1988). This can, in turn, impact the quality of the communication in the patient-provider relationship. Observations from prior research also reveal that older patients are often unlikely to request information, participate

in self-care, or talk about emotional issues with providers (Breemhaar, Visser, & Kleijnen, 1990) unless they are offered enough time during the encounter (Beisecker & Beisecker, 1990). If, for these reasons, older patients appear to be less vocal during the encounter and providers are unaware, the providers may incorrectly assume that patients are not interested in their own health.

Older adults often experience barriers to effective communication during the clinical encounter. Ageism can influence some providers to utilize communication approaches that are based on stereotyped expectations when conversing with seniors. Often these providers may not recognize or acknowledge the individual characteristics of their patients. Such an approach may create distance between the caregiver and the care recipient (Ryan & Butler, 1987). Investigators (Nussbaum, Pecchioni, Grant, & Folwell, 2000) assert that there is a great possibility for the influence of stereotypes and ageist attitudes to lead to problems both with the diagnosis and treatment of older patients as well as adversely impact the quality of communication (Shue & Arnold, 2009). The presence of providers' ageist attitudes may work to deny older patients the opportunity for greater empowerment, learning, and improved health status (Greene, Adelman, Charon, & Hoffman, 1986).

The impact of ageist attitudes and certain stereotypes can impact providers' perspectives in a number of ways. In situations in which the physical appearance, voice, or behavior of a patient may convey disability or a frail nature, older individuals are vulnerable to problems because providers may possess several negative expectations (Hummert, 1994; Hummert, Garstka, Shaner, & Strahm, 1994).

Providers may also adopt communication patterns that are somewhat biased because of the influence of ageism. Such patterns employed by providers can include the use of avoidance

(e.g., when providers converse with family members instead of the actual patient). As well, examples include when providers are impatient, use “baby talk” or speak in a high pitched voice while using exaggerated intonations, utilize simplified language, speak to patients in a manner that is too familiar, or shout when speaking with patients (Caporael, 1981; Ryan, Hummert, & Boich, 1995). At times providers may express certain responses to older patients’ conversations including utilizing dismissive and disapproving comments, not listening to patients, and over parenting. Such provider behaviors can also work to reinforce a number of age-stereotyped behaviors by the older patients themselves including passivity, dependency, discussions only about the past or about topics that are out of the realm of the conversation, and withdrawal from activities that may be regarded as socially challenging (Ryan, Hummert, Boich, 1995; Baltes & Wahl, 1996). These communication patterns often give rise to a loss of control, decreasing capability, and increasing feelings of helplessness (Caporael, 1981; Rodin & Langer, 1980).

Although ageism and the biases that result from its impact may not occur as frequently now as in past decades, certain negative expectations about seniors continue to exist. Stereotypes that negatively influence providers may be the products of a provider’s lack of knowledge, lack of contact with a diverse array of seniors, and basic generalizations that are borne out of limited contacts with seniors in certain types of environments. Health care providers may be more vulnerable than the general public to holding ageist beliefs because they frequently interact with a certain segment of the senior population. Providers come in frequent contact with elderly who are sick, confused, or hospitalized more often than those seniors who are more healthy. As a result, it has been suggested that ageist beliefs may be a type of occupational hazard of health care providers and medical school students who may often

encounter older patients who are frail, debilitated, or who suffer from dementia (Ryan & Butler, 1987; Greene, Adelman, Charon, & Hoffman, 1986).

A number of anecdotes that describe the often ageist nature of the clinical encounter with senior patients has been described. Often these anecdotes describe providers' tendencies to make incorrect assumptions about seniors, to discount concerns reported by elderly patients (e.g., dizziness, falls, loss of memory, dentures, etc.) and providers' inattention to psychosocial issues that may be of concern to senior patients. Prior research has also revealed that a number of assumptions are frequently held by providers including beliefs that seniors may have physical and mental health problems that are frequently untreatable (Butler, 1975); that senior individuals are often asexual (Strain, 1981); and that seniors are often overly worried about death (Ward, 1979).

Investigators have recognized that a number of challenges exist within the relationship between providers and older patients. Such challenges include the importance of determining how ageism can confound the patient-provider interaction (Ryan & Butler, 1987), the need to create communication messages that address older patients' levels of dependency while at the same time both recognizing and encouraging independence (Baltes & Wahl, 1996), and the importance of offering a level of provider support for older patients during the clinical encounter (Greene, Adelman, & Majerovitz, 1996). Researchers suggest that a key approach is for providers and researchers to combat negative stereotypes associated with older adults. This can be done by encouraging providers to promote positive attitudes – a step that is a critical component of any effective provider training program (Shue & Arnold, 2009).

Findings from prior studies have offered support for the suggestion that providers behave differently towards patients based on the patients' age. Research that examined ratings of

physician questioning and support revealed that providers offered better questioning and information as well as greater levels of support with their younger patients in comparison to older individuals. Investigators were found to be more egalitarian, patient, engaged, and respectful when interacting with younger individuals as compared to older individuals.

Prior study findings suggest that older patients in one study were not as successful as younger patients in gaining the attention of providers in order to obtain assistance in dealing with their problems. This finding surmises that it was harder for older patients to get their needs addressed as compared to younger patients. As well, these results posit that factors linked to subtle ageism and unequal power dynamics may be at work in these encounters (Greene, Adelman, Charon, & Hoffman, 1986).

It is critical that researchers and providers continue to emphasize the importance of understanding the quality of communication that occurs in patient-provider dyads that include older individuals. One goal for health care professionals and investigators within the field of communication research should be to determine the manner in which various obstacles can negatively impact the relationships between providers and older patients. Researchers and health care professionals need to determine those approaches that can be used to enhance providers' communication skills especially when treating older patients (Ryan & Butler, 1987).

III.D. HEALTH COMMUNICATION & CULTURE

A provider's lack of awareness or acknowledgement of the cultural aspects of communication may lead to barriers that prevent effective information exchange. Cultural aspects in this case do not simply include the fact that patients may not speak or understand English well. Cultural aspects could include those social factors that influence how a patient

understands information and how a patient interacts with his or her provider (Dorsey, Miller, Parrott, & Thompson, 2003). According to Stein and Rowe (1989), culture can be defined as “learned, nonrandom, systematic behavior that is transmitted from person to person and from generation to generation” (Stein & Rowe, 1989).

In order to determine the effects of culture on patient-provider communication, investigators have suggested that specific cultural groups be targeted so that culture-related communication barriers can be clearly identified. Investigators within the field of communication research need to implement specific cultural competence strategies that can enable them to work within the cultural context of a patient’s experiences (Campinha-Bacote, 1994). Suggestions to create approaches that incorporate multicultural communication strategies have included urging providers to learn about other cultures, learn new languages, spend time with members of different cultural communities, or participate in any activities that will increase awareness of other cultures. Such actions will help providers understand that patients often possess a number of different culture-related ideas and beliefs about health (Kreps & Kunimoto, 1994).

With regard to African American patients, it is imperative that physicians consider several factors that can effectively influence the amount and quality of health care that is received. According to Eiser and Ellis, in order for African Americans to receive culturally competent care, providers must consider specific factors that can impact communication. If patients possess different paradigms for illness than their providers because of racial discordance or other reasons, the result may be a significant gap in communication. As well, factors such as a patient’s religion, use of complementary and alternative medicine, and distrust in health care

providers can influence the level of communication that occurs within the clinical encounter (Eiser & Ellis, 2007).

III.D.1. RELIGION

The patient-provider relationship can serve as a therapeutic tool for both the patient and the provider (Brody, 1992). The relationship can help providers gain greater insight about patients' beliefs and practices – particularly those which may play a central role in the lives of patients but which may exist outside the sphere of the medical world (Veatch, 2001). A growing body of literature has led to an increasing awareness about the potential role that religion and spirituality may play in the health care setting (Daaleman, 2004). Such literature reveals trends that consistently suggest that patients' religious or spiritual beliefs can impact various aspects of medical care and health outcomes (MacLean, Susi, Phifer, Schultz, Bynum, Franco, Klioze, Monroe, Garrett, & Cykert, 2003). As a result of this, health care providers should attempt to gain a basic understanding of existing research in the field (Weaver & Koenig, 2006). Religion can be defined as an individual's "personal set or institutionalized system of religious attitudes, beliefs, and practices" or "a cause, principle, or system of beliefs held to with ardor and faith" (Merriam Webster).

Religion can act as a powerful variable by influencing several physical and mental health outcomes, as well as a patient's quality of life (Harris, Gowda, Kolb, Strychacz, Vacek, Jones, Forker, O'Keefe, & McCallister, 1999; Koenig, Cohen, George, Hays, Larson, & Blazer, 1997; Koenig, Hays, Larson, George, Cohen, McCullough, Meador, & Blazer, 1999; Koenig, George, Peterson, 1998; Levin & Chatters, 1998; Strawbridge, Cohen, Shema, 1997), individuals' abilities to adapt to illness, their medical decision-making, and health behaviors and beliefs

(Weaver & Koenig, 2006). As well, a patient's religious beliefs can impact the nature of the patient-provider interaction, including the quality of the communication that occurs within the patient-provider dyad. Based on such findings, it is important that health care professionals recognize that religion can greatly influence the health care experiences of some patients.

Prior research has revealed that religion can greatly influence a number of health-related factors. Additional research has taken a broader perspective by examining not just religion, but also the links between the concept of spirituality and different health-related factors.

Investigators have found it difficult to concretely determine how to best measure dimensions of spirituality and religion. In some investigations, religion is viewed as a one dimensional concept (Gorsuch, 1984; Payne, 1990). After study findings that contended that religion is a multidimensional concept were presented (Gorsuch, 1984; Hilty, Morgan & Burns, 1984; Mitchell & Weatherly, 2000), greater research began to regard religion as a multidimensional construct – one that considers not just the various aspects of religious beliefs but those of religious practices as well (Mansfield, Mitchell, & King, 2002). Religion is critical to many individuals because its doctrines and traditions help provide individuals with a basis for understanding the overall human experience (Daaleman, 2004).

While many studies examine the concept of religion, others also consider the impact of spirituality on health outcomes. Spirituality has been defined as a specific construct that recognizes that individuals may possess faith in some type of divine being or force that can provide individuals with an important sense of meaning and purpose. The sense of meaning and purpose offered by spirituality is not linked to any beliefs or practices that are associated with a specific religion (McBride, Arthur, Brooks, & Pilkington, 1998; Stewart, 1999; Van Ness, 1996). Theologian John Shea has defined the term spiritualities as a group of beliefs, stories, or

practices that individuals use in response to their basic need to find both meaning and purpose (Shea, 2000). These specific stories, beliefs, and practices will not always be necessarily linked to a particular set of religious beliefs, practices, or communities (Van Ness, 1996). With regard to the health care environment, the concept of spirituality is often exhibited by those patients as they try to understand and make sense of their illnesses and by caregivers who will employ spirituality as a part of the approach used to address all of the needs of a patient as a whole (Daaleman, 2004). Although prior research has made distinctions between these terms, for the purposes of this research, the terms religion and spirituality may at times be used interchangeably.

Importance of Inquiring about Religion and Spirituality

Because physicians possess specific knowledge and skills, they are charged with the task of acting as the expert within the patient-provider relationship (Giddens, 1984). However, in addition to the task of providing a level of technical expertise with regard to diagnosis and treatment, the provider must also be aware of the context of the patient's illness experience including any factors that may affect their patients (Mechanic, 1978). Providers must realize the importance of providing knowledge and assistance with factors that may impact a patient's care. Providers need to inquire about factors or at least acknowledge that they can significantly impact care, even if these factors lie outside the realm of medicine.

Efforts to inquire about religion may be regarded as necessary by patients who place a great deal of importance in religion and spirituality. Previous research suggests a number of reasons why providers should make efforts to communicate with their patients about issues related to religion and spirituality (Koenig, 2007). Many patients describe themselves as either

religious or spiritual and because of this, prefer that their providers have some awareness of their religious beliefs (Koenig, 2007). Results from previous Gallup polls indicate the importance of religion in the lives of adults. These polls have revealed that approximately 95% of Americans believe in the existence of God and 42% of individuals report that they attend church services on a weekly basis (Gallup, 1990).

Providers who gain important information about patients' religious beliefs can determine how these beliefs may provide a sense of comfort for patients. Providers who not only inquire about religious beliefs, but who are also able to demonstrate support for such beliefs will help patients be able to more effectively utilize religion and spirituality as powerful coping strategies. For many patients, religion or spirituality can act as a coping mechanism to help them deal with stressful life events. Patients, especially those who have been admitted to a healthcare facility, may feel isolated from their own spiritual communities. Religion can often affect the level of support and type of care that patients receive in a community (Koenig, 2007). For terminally ill patients, religion has often played a vital role by providing individuals with a means of tolerating difficult times during grave illness and providing an important source of meaning to their lives (Branch, Torke, & Brown-Haitheo, 2006). For those patients admitted to health care facilities for care, an inability to obtain support from their religious communities may prove problematic. As a result, these individuals may desire some alternative way of addressing their spiritual needs while in a health care facility, and providers can help to address such needs.

Religion and spirituality can serve as important primary sources of care for some patients. Within the context of the health care environment, both complementary and alternative medicine and end-of-life care have helped to provide what some regard as legitimate uses of religion and spirituality. Both offer a way of incorporating care that is more personal, spiritual, and less

grounded in technology (Daaleman, 2004). Recommendations that seek to improve end-of-life care approaches call for the inclusion of spiritual and religious components, even though findings from previous research do not always agree on how these factors should be addressed in health care settings (Daaleman & VandeCreek, 2000). As well, guidelines created by the Institute of Medicine for palliative care include measures to assess spirituality as a way of examining the emotional status of patients (Institute of Medicine, 1997).

For those who utilize some types of complementary and alternative medicine, religion may often be used as a type of treatment. Complementary and alternative medicine (CAM) has provided a means of incorporating spirituality and religion into medicine (Anderson & Taylor, 2012). Previous research that has assessed the prevalence of CAM modality use has often examined patterns of prayer and faith healing as therapies. A 1993 study that assessed the use of unconventional treatments determined that one-fourth of respondents indicated that they used prayer as a type of medical treatment (Eisenberg, Kessler, Foster, Norlock, Calkings, & Delbanco, 1993). A follow-up study after five years by the same group of researchers revealed an increase in the utilization of prayer for therapy and spiritual healing as a treatment for lung problems, depression, and anxiety problems (Eisenberg, Davis, Ettner, Appel, Wilkey, Van Rompay, & Kessler, 1998). As well, a number of polls have revealed that individuals support findings from CAM-related studies that assess prayer because many U.S. adults possess positive beliefs and attitudes about its effective role in healing. One poll determined that 79% of respondents reported that one's spiritual beliefs can help an individual recover from illness or disease. However, a smaller percentage (56%) of these respondents reported that they believed their faith had helped them during their own times of recovery (McNichol, 1996).

For some individuals, a satisfactory medical experience will only include one in which the physician addresses issues of religion as well as health. Providers may experience better interactions with patients when these beliefs are taken into consideration. Those providers who communicate with patients about religion are able to utilize information offered in patients' narratives and incorporate it into the clinical encounter interaction. Even a brief discussion of the beliefs that are meaningful to the patient can help to build a stronger, more trusting patient-provider relationship (Daaleman, 2004).

Data collected by Mansfield and colleagues (2002) reveal the importance of considering religion because such efforts can aid in the communication that occurs during the clinical encounter and provide a clearer understanding of the expectations that patients possess regarding the health care experience. Health care providers should realize that not only does the faith of patients impact the clinical experience, but patients' beliefs that God can act through physicians during the health care process is also critical. Providers who are both informed and sensitive to their patients' needs can better help their patients benefit from the vast amount of resources that may be available to help with both recovery from illness and the maintenance of health (Mansfield, Mitchell, & King, 2002).

As well, inquiries about religion can also offer providers greater insight about their patients' health-related beliefs and attitudes which can both influence patients' medical decision-making and preferred health practices. In a study conducted by Ehman and colleagues, researchers determined that 45% of outpatient pulmonary clinic patients possess spiritual beliefs that would impact their medical decisions if they were to become seriously ill (Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999). It is important that providers consider factors linked to religion and spirituality because often a patient's lifetime accumulation of beliefs and

practices will greatly influence medical decision-making (Daaleman, 2004). As well, an individual's religious beliefs may at times conflict with recommended medical care (Koenig, 2007). As a result, such beliefs can influence whether or not patients comply with suggested medical treatments. When providers make the effort to inquire about factors such as religion, they may be able to acquire a greater understanding of patients' health-related attitudes. As well, such inquiries may also make patients more comfortable and as a result, open up the lines of communication and potentially lead to greater trust between the patient and provider.

If issues related to religion are not addressed during the medical encounter, patients may be noncompliant with recommended medical regimens. This is especially the case in situations in which beliefs may prevent patients from undergoing certain types of medical procedures because prescribed treatments conflict with an individual's religion. For instance, individuals who practice certain religions may not believe in receiving blood transfusions and this belief may prevent them from complying with treatments recommended by a provider (Panico, Jeng, & Brewster, 2011). For other individuals, a belief that God can cure illness, without the use of medical treatment, may result in individuals who choose not to seek care, either regularly or at all. Patients may not comply with providers' recommendations because they may choose to utilize alternative therapies (e.g., religious practices like prayer) as a form of treatment. Patients whose religions conflict with recommended treatments may not be open to communication during the clinical encounter (Eiser & Ellis, 2007) because they do not feel a personal sense of connection to their providers. If providers are not aware that their patients possess such religious beliefs, either because providers don't inquire or patients do not realize the significance of revealing such information, then providers may inadvertently label their patients as noncompliant and perceive that these patients have no interest in improving their own health. An awareness of

a patient's religious beliefs can offer health care providers greater insight that can be utilized to help initiate communication during the clinical encounter.

Previous literature has suggested that researchers and health care providers need to recognize the importance of addressing religion during the clinical encounter. Findings have revealed that inquiries about religion can offer providers insight about the influence that religion can have on the lives of patients. An additional body of research has also provided information about patients' opinions about whether or not providers should make efforts to inquire about religious beliefs during the clinical encounter.

Prior research has suggested that the majority of patients might be receptive to a general inquiry about their religious beliefs by a provider (Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999). Some patients may actually desire that their religious or spiritual needs be addressed in a direct manner either by their provider (Maugans & Wadland, 1991; King & Bushwick, 1994) or via a referral to some type of pastoral professional (Daaleman & Nease, 1994). Several studies have revealed interesting findings regarding patients' opinions about providers' needs to inquire about their religious beliefs. Maugans and Wadland determined that 30% of 135 surveyed outpatients believed that their providers should discuss religious and spiritual matters with them (Maugans & Wadland, 1991). Work by Daaleman and Nease (1994) discovered that of the 80 patients who were surveyed for their study, 41% believed that physicians should inquire about issues related to religion and faith (Daaleman & Nease, 1994). In their research, Oyama and Koenig determined that 73% of outpatient respondents reported that providers should possess at least a general knowledge of their patients' religious and spiritual attitudes (Oyama & Koenig, 1998).

As well some patients believe that providers should also be willing to go beyond simply inquiring about religious beliefs. Many patients attribute a great healing power to religious activities such as prayer and these patients feel that providers should be willing to pray with their patients (King & Bushwick, 1994). MacLean and colleagues determined that although study respondents did report a general interest in discussing spiritual matters with providers, a minority of patients desired to have spiritual interactions during routine clinical encounters. For office visit settings, less than 20% of respondents desired any type of patient-provider prayer. As well, it was determined that less than 10% of respondents would be willing to forego time devoted to the discussion of medical issues in exchange for time used to discuss spiritual matters. For this study, although a majority of the sample did not indicate an interest in having some type of religious interactions with their patients, investigators found that 66% of respondents believed that their providers should possess a general awareness of their religious beliefs. Thirty-three percent of respondents desired providers to inquire about religious attitudes and beliefs in the office setting.

Patients' wishes regarding inquiry about religious preferences may vary according to when and where this inquiry occurs. Findings regarding provider inquiry about patients' religious beliefs and provider participation in religious activities changed when the medical scenario changed (MacLean, Susi, Phifer, Schultz, Bynum, & Franco, 2003). With regard to situations that involve near death scenarios, 50% of respondents would desire interactions involving active prayer with their providers. Based on findings, MacLean and colleagues surmised that patients' interests in spiritual concerns would increase as severity of illness increases. The investigators found that in situations that involved death and dying – scenarios in which patients must often deal with issues related to faith, coping, and mortality – over half of

respondents desired some level of spiritual interaction with providers (MacLean, Susi, Phifer, Schultz, Bynum, & Franco, 2003). Prior studies have also investigated the religious preferences of gravely ill patients. In one study, Kaldijan and colleagues examined the preferences of 90 inpatients that were living with HIV or AIDS. The investigators discovered that almost half of their respondents (46%) desired to pray with their providers (Kaldijian, Jekel, & Friedlan, 1998). As well, work by King and Bushwick revealed that 77% of 203 interviewed inpatients believed that providers should give consideration to their patients' spiritual and religious needs. For this study, 37% of respondents desired greater discussion about religious matters with their providers.

For patients who have been admitted to hospitals, the desire to communicate about topics of a spiritual nature may be present. These patients may have less access to family, friends, and their religious communities, and therefore desire greater discussion. As well, if patients believe that their health conditions are more serious because they have been admitted to the hospital, this may result in a greater interest in spiritual matters (King & Bushwick, 1994).

Why Providers Do Not Inquire About Religion

Despite the fact that findings from a number of studies have suggested that dialogues about patients' religious beliefs and attitudes may be important, some physicians rarely engage in conversations about issues related to religion and spirituality with their patients (King & Bushwick, 1994; Anderson & Anderson, 1993). As well, providers may not often refer patients to pastoral professionals for assistance (Jones, 1990; Daaleman & Frey, 1998). Providers have offered a number of reasons why they do not discuss spiritual or religious issues during clinical encounters. A provider who wants to address spiritual or religious issues that may be of importance to the patient may feel hesitant to do so because they may believe that they need to play an appropriate role as physician, as well as remain true to their own religious beliefs,

especially if these beliefs are different, while respecting those of the patient (Lo, Quill, & Tulskey, 1999). Providers may have a fear of projecting their own religious beliefs on to patients (Maugans & Wadland, 1991; Jones, 1990) or they may encounter difficulty trying to identify which patients might desire discussion about religious issues (Ellis, Vinson, & Ewigman, 1999). Several other reasons also prevent providers from broaching the topic of religion during the clinical encounter. Some providers may have determined that issues related to religiosity and spirituality should be regarded as a private matter outside the realm of both medicine and the provider's field of expertise (Branch, Torke, & Brown-Haithco, 2006). Providers may be hesitant because of their lack of professional training in discussing spiritual matters (MacLean, Susi, Phifer, Schultz, Bynum, & Franco, 2003) as well as their beliefs that they do not have to take the initiative to start discussions because those patients who wish to discuss spiritual issues will make the effort to self-refer.

Another explanation provided by physicians includes their own lack of any specific spiritual or religious beliefs (Jones, 1990). Providers may not make the effort to initiate conversations about spiritual matters because they feel overburdened during routine clinical encounters because of the competing demands to also address issues related to patient symptoms, psychosocial issues, disease screening and prevention, or a host of other issues (MacLean, Susi, Phifer, Schultz, Bynum, & Franco, 2003). As well, some providers may deem it inappropriate to offer to participate in religious activities with their patients (e.g. prayer) for fear that such offers will be perceived as insincere (Branch, Torke, & Brown-Haithco, 2006). Although some research suggests that a consideration of religious and spiritual matters within the context of healthcare is important, findings have determined that many nonphysicians have questions regarding the ethics of including discussions about spiritual and religious issues in the clinical

encounter (Sloan, Bagiella, VandeCreek, Hover, Casalone, Jinpu, Hasan, Kreger, & Poulos, 2000).

African Americans and Religion

The importance of religion in the lives of African Americans is especially important for health care providers to consider because of suggested links between religion and health. A consideration of the role of religion may help to provide health care professionals with greater insight about the health-related behaviors and beliefs of African Americans and the health outcomes that these individuals experience.

Religion is a significant aspect of African American culture. The importance of religion can be traced back to pre-Emancipation in the southern parts of the nation when slaves' adoption of Christianity provided a source of cohesion for individuals from differing African cultures who were brought together in a foreign environment (Frazier & Lincoln, 1974). The importance of religious practices for this population has been described in previous literature (Stewart, 1999). Religion has helped to guide the creation of a type of black consciousness. For African Americans, religion has played a key role in shaping Black culture (Stewart, 1999).

Previous research has attempted to gain insight about the religious experiences and beliefs of African Americans as well as the importance of religion in their lives (Mansfield, Mitchell, & King, 2002). Investigators who assessed religious involvement determined that elderly African Americans have higher religious involvement in comparison to their White counterparts (Levin, 1994; Levin, Larson, & Puchalski, 1997). Mansfield et al (Mansfield, Mitchell, & King, 2002) and other investigators (Ellison & Sherkat, 1995) have reported that African Americans who reside in rural southern areas of the country often have great levels of church participation. As well, Levin and Taylor (Levin & Taylor, 1997) have discovered more

frequent prayer for adults who possess certain characteristics, namely those who are female, older, married, and/or African Americans (Mansfield, Mitchell, & King, 2002). In a study conducted in Atlanta, many African American patients reported a close and intimate relationship with God and this closeness was often expressed through prayer (Branch, Torke, & Brown-Haithco, 2006). MacLean and colleagues determined that African American race is an important patient characteristic that providers should consider when determining whether to broach issues related to religion. This finding supports the results of other studies that have assessed race-based differences in religiosity (Koenig, 1998; Chatters, Taylor, & Lincoln, 2001).

Providers will often not share the same religious worldviews as their patients or be properly trained to offer spiritual guidance to patients (Branch, Torke, & Brown-Haithco, 2006). Still, there are many steps that providers can take in order to address the issue of patients' religious beliefs and determine how such beliefs can impact care. Even in such situations, the provider can both respectfully and authentically discuss issues related to religion with a patient (Branch, Torke, & Brown-Haithco, 2006). Providers can play a critical role in a patient's health care experience by supporting spiritual and religious beliefs, acknowledging patients' religious perspectives, identifying a patient's spiritual needs, and referring patients to professionals who can properly address patients' spiritual concerns (Koenig, 2007).

Providers need to give full consideration to the role that religion and spirituality play in patients' lives, including their health and the healing processes that they experience (Maugans & Wadland, 1991; Jones, 1990; King, Sobal, Haggerty, Dent, & Patton, 1992). Mansfield et al suggest that providers and other types of health care professionals should not only become more aware of the critical role that these factors play for patients, but also recognize how strong such beliefs may be for patients (Mansfield, Mitchell, & King, 2002). While health care providers are

not clergy or experts within the field of spiritual care, they can still play a key role in helping their patients address spiritual needs or concerns (Koenig, 2007). Some health care professionals suggest that the most effective care for the patient will be offered when providers begin to adopt a perspective that includes not only a consideration of those physical, psychological, and social determinants that affect health, but the spiritual factors that may play a role as well (Institute for the Future, 2000). There has been an increasing awareness that approaches that focus on providing whole person care by regarding health and disease through an integration of body, mind, and spirit may provide patients with more effective care (Graham, Bagley, Kilo, Spann, & Bogdewic, 2004). The utilization of such approaches during the clinical encounter can lead to the development of a more trusting relationship and greater communication between patient and provider.

III.D.2. COMPLEMENTARY AND ALTERNATIVE MEDICINE USE

The utilization of treatments outside of what is typically regarded as conventional medication may have a significant influence on the health of many individuals, including African Americans. Specifically, a belief that various types of complementary and alternative therapies can help to prevent disease or serve as a type of treatment for illness can impact the health outcomes that individuals experience. For many, there is a great belief that treatments outside of the course of conventional medications can provide significant benefits for one's health. Complementary and alternative medicines (CAM) include a wide variety of therapies and practices, many of which do not have to be prescribed by physicians. Although previous research provides support for the fact that patients possess strong beliefs that these types of therapies can offer positive health outcomes, many physicians may not be aware that their patients are utilizing such therapies. This lack of awareness occurs because patients are able to

gain access to several types of these therapies without the permission or authorization of a provider. Many providers may not recognize the importance of inquiring about their patients' use of such therapies. As well, many patients may not inform their physicians of the use of these treatments for a number of reasons. As a result of this nondisclosure, providers are not always aware of the use of such treatments and the result may have an adverse impact on the quality of the patient-provider interaction, including the quality of the communication that patients and their providers experience during the clinical encounter and ultimately the level of care that health care professionals are able to offer their patients.

What is Complementary and Alternative Medicine?

According to the National Center for Complementary and Alternative Medicine (NCCAM), the federal government's lead agency for research in this field, complementary and alternative medicine, referred to as "CAM", is comprised of a diverse selection of products, practices, and health care systems that exist alongside the field of conventional medicine. The NCCAM makes a distinction between the two aspects of care, complementary medicine and alternative medicine. Complementary medicine is that category of medicine which is used in conjunction with conventional medicine treatments. Such an example might include treatments, such as aromatherapy, that are utilized to decrease a patient's level of pain and discomfort after a surgical procedure. Alternative medicine includes treatments which are used in place of conventional medicine therapies. For instance, when a patient who has been diagnosed with cancer opts to follow a special type of nutritional diet instead of choosing to undergo procedures such as surgery or chemotherapy that have been recommended by a conventional physician, this individual is utilizing alternative medicine practices.

NCCAM has divided the various types of CAM practices into four specific groups including: mind-body medicine, biologically-based practices, manipulative and body-based practices, and energy medicine, although these groups at times overlap. NCCAM also investigates whole medical systems which can sometimes cut across the four groupings.

The category of mind-body medicine utilizes several different techniques that seek to improve the mind's ability to influence symptoms and bodily functions. Examples of such approaches include meditation, mental healing, prayer, and those types of therapies that make use of creative outlets including music, art, or dance. Other approaches that were previously categorized within the mind-body classification include cognitive-behavioral therapy and patient support groups. Biologically-based practices include those products or substances that are found in nature including herbs, vitamins, and certain types of foods. Examples include the use of dietary supplements and other remedies that are regarded as natural but whose efficacy may not have been scientifically proven (e.g., the use of shark cartilage as a therapy for cancer).

The category of manipulative and body-based practices focuses on the use of manipulation or controlled force on a joint in order to assist in the restoration of health. Manipulation is often used as a part of several treatments such as massage or chiropractic medicine. Energy medicine includes the utilization of energy fields in order to affect health. One type of energy medicine is biofield therapy which is used to influence the energy fields that penetrate and surround the body. Such examples included qi gong, Reiki, and therapeutic touch (National Center for Complementary and Alternative Medicine, 2006). Although NCCAM categorizes complementary and alternative medicine into four distinct categories, other researchers have categorized this complex array of CAM products, practices, and healing philosophies in a number of different ways. For instance, Grzywacz and colleagues classified

individual complementary medicine modalities into five primary groups instead of four (Grzywacz, Suerken, Neiberg, Lang, Bell, Quandt, & Arcury, 2007).

Whole medical systems are those systems of health care and practice that have developed separately from and earlier than the conventional medicine system that is currently used in the U.S. Homeopathic medicine is an example of such a whole medical system that first originated in Europe. Specifically, the function of homeopathy is to stimulate the body's capacity to heal itself. This is done by giving individuals tiny dosages of very diluted treatments. Larger doses of these diluted treatments would prove harmful by causing illness or producing symptoms. Naturopathic medicine is a whole medical system that seeks to assist the body in its ability to heal itself. Naturopathic medicine involves the use of various modifications in diet or lifestyle in conjunction with the utilization of CAM modalities such as herbal remedies, massage therapy, and joint manipulation. Examples of systems that have originated in non-Western cultures include traditional Chinese medicine (TCM), a whole medical system from China that suggests that diseases and illnesses occur because of interruptions in the flow of qi (energy) or imbalances in certain forces. As a part of TCM, approaches that include the use of herbal remedies, massage, meditation, and acupuncture can help to support healing and restore balance (National Center for Complementary and Alternative Medicine, 2006).

Trends in U.S. CAM Use

It is critical that health care providers gain a greater understanding of the utilization trends of complementary and alternative medicine in the U.S. (Howell, Kocchar, Saywell, Zollinger, Koehler, Mandzuk, Sutton, & Sevilla-Martir, 2006). Greater knowledge about such trends is key because not only can more information about CAM use better prepare providers as

they offer care for their patients, but it can also help improve the level and quality of communication within the patient-provider relationship.

Previous findings have reported that the utilization of CAM therapies has substantially risen in the U.S. over the course of the past twenty years. Such findings report that the percentage of individuals in the U.S. who utilize CAM increased between the years 1990 and 1997 (33.8% to 42.1%) (Eisenberg, Kessler, Foster, Norlock, Calkings, & Delbanco, 1993; Eisenberg Davis, Ettner, Appel, Wilkey, Van Rompay, & Kessler, 1998). Investigators Chao and colleagues determined that approximately 66% of U.S. adults have utilized some form of CAM therapy during their lifetimes (Kessler, Davis, Foster, Rompay, Walters, Wilkey, Kaptchuk, & Eisenberg, 2001). Additional studies that have reported population-based estimates specifically determined that utilization for older adults may range between 30 to 88% of individuals, even higher than the degree of CAM utilization for younger adults (Foster, Phillips, Hamel, & Eisenberg, 2000; Ness, Cirillo, Weir, Nisly, & Wallace, 2005).

One reason for this rise in utilization is an increase in the use of therapies such as herbal remedies, vitamins, and massage therapy (Eisenberg, Kessler, Foster, Norlock, Calkins, & Delbanco, 1993; Eisenberg, Davis, Ettner, Appel, Wilkey, VanRompay, & Kessler, 1998). Previous research suggests that, other than prayer, herbs are the most frequently used type of complementary and alternative medicine among American residents. They are often used as a source of treatment by older adults (Barnes, Powell-Griner, McFam, & Nahin, 2004; Bruno & Ellis, 2005). For herbal products alone, previous reports have projected a yearly market of approximately \$5.1 billion dollars (Kessler, Davis & Foster, 2001) and dietary supplement sales have now surpassed \$200 million dollars a year in the U.S. (Blendon, DesRoches, & Benson, 2001).

Increases in the use of CAM modalities have had great implications on both the medical and economic communities. As a result of increasing CAM use, more than 65% of HMOS provide coverage for at least one kind of complementary and alternative medicine (Landmark Healthcare, 1999). The greater popularity of complementary therapies, as well as the medical community's resistance to many types of these therapies has resulted in increased research that focuses on the efficacy of these therapies and their integration with the use of more traditional Western medicine (Barnett, Cotroneo, Purnell, Martin, MacKenzie, & Fishman, 2003). The rising utilization of these types of therapies has also revealed the need for health care professionals to examine how their use can impact the health outcomes of patients and the nature of the clinical encounter between patients and providers.

Ethnic Specific CAM Use

Care must be taken when examining the results of researchers who investigate the prevalence of CAM utilization in certain populations. An individual's culture and health beliefs can greatly influence that individual's health seeking behaviors (Kleinman, Eisenberg, & Good, 1978; Pachter, 1994; Jasti, Siega-Riz, & Bentley, 2003). Research that seeks to examine the use of CAM modalities among communities is of importance for a number of reasons. Researchers and health care providers may incorrectly make the assumption that only individuals of specific racial and ethnic groups use CAM modalities. As well, based on such assumptions, a profile of a typical CAM user may emerge, and this profile may lead health care providers to make erroneous assumptions about the health care beliefs and practices of their patients.

Despite the fact that many national surveys have indicated that an increase in complementary and alternative medicine use has occurred in the U.S., because racial and ethnic minorities have been under-represented in many of these study samples, more accurate

information is needed. Because of this deficit in data, the profile of the average CAM user that has emerged has suggested that these individuals are likely to be Caucasian, female, middle-aged, and of a higher socioeconomic status. As well this profile suggests that typical users are also likely to be well educated. The use of such a profile can be problematic because it suggests that members of racial and ethnic minority communities do not utilize these types of therapies. Providers need to be aware that members of these communities may possess different views, as compared to Caucasian patients, about illness, utilize different health-related terminology, and have specific types of CAM use patterns (Barnett, Cotroneo, Purnell, Martin, MacKenzie, & Fishman, 2003). If providers are unaware of utilization patterns then they may not address this topic with their minority patients.

Ethnicity and culture may play a key role in determining how an individual practices health self-management. Specifically, one's ethnicity and culture can greatly influence if an individual decides to use and incorporate CAM treatments into his or her own health self-management routine (Arcury, Grzywacz, Bell, Neiberg, Lang, & Quandt, 2007). Culture and beliefs can not only affect one's decision to utilize a CAM modality, but influence which modality an individual decides to try. Certain ethnic or racial groups may prefer to utilize one type of CAM modality over others (Uba, 1993; Kakai, Maskarinec, Shumary, Tatsumura, & Tasaki, 2003). It has been hypothesized that racial and ethnic groups have a greater likelihood of using CAM modalities that are most consistent with their cultural beliefs. Many racial and ethnic populations have a long history of using folk or traditional medicines. Hsiao and colleagues have defined "ethnic-specific" CAM use as the use of a type of CAM modality that is congruent with a specific ethnic or racial group's cultural identity. A determination of which types of CAM modalities are most used by specific racial and ethnic groups is critical because it

can offer health care providers much needed insight about which modalities may be utilized more often by particular groups. Investigations that seek to assess ethnic-specific CAM use can help increase health care providers' awareness of the utilization trends of specific populations (Hsiao, Wong, Goldstein, Yu, Andersen, Brown, Becera, & Wenger, 2006).

Data that has been collected as a part of prior research has helped investigators determine CAM use trends amongst certain ethnic and racial groups. For instance, with regard to certain racial groups, specifically Asian cultures, the concepts of holism, balance, and life energy (chi) may be an important part of the culture, specifically for those who are of Chinese heritage. These individuals may also prefer to utilize medical systems and practices that are founded on these types of concepts (Sung, 1999; Zhang & Verhoef, 2002). Research has determined that some Native Americans often utilize unique traditional healing practices that include shamanism and sacred rituals that may be specific to each tribal community (Rhoades & Rhoades, 2000). For many Latinos, requests may be made to curanderos, espiritistas, and herbalistas for healing treatments (Higginbotham, Trevino, & Ray 1990). Previous research has suggested the use of herbal medicines for treatment and health maintenance in Asian and Latino cultures (Sung, 1999; Kronenberg, Cushman, Wade, Kalmuss, & Chao, 2006; Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005). White populations, as compared to other racial or ethnic groups, may opt to utilize different types of CAM modalities including osteopathic and chiropractic treatments for care (Trotter & Chavira, 1981). As well, for many racial and ethnic groups, aspects of culture like religion and spirituality, can strongly influence the type of CAM that individuals utilize (Rocereto, 1973). For these groups, prayer may be the preferred choice of CAM modality. Investigators have often suggested that certain cultural beliefs about health and proper approaches to health care can lead to ethnic and racial differences in the use of

complementary medicine (Grzywacz, Suerken, Neiberg, Lang, Bell, Quandt, & Arcury, 2007). In order to improve the quality of the patient-provider interaction and the quality of communication, it is imperative that researchers are able to learn more about the utilization trends of certain CAM modalities based on factors that are linked to one's culture, including race and ethnicity.

Information about the CAM use practices of minority populations can help by offering health care providers insight about the health beliefs and practices of their patients. Providers will be able to utilize more effective communication with patients and as a result improve the quality of interactions with patients.

Investigations about trends in ethnic-specific CAM use have revealed a number of diverse findings. The results of many of these studies have varied based on how investigators inquire about CAM use and what types of CAM modalities respondents were questioned about. For example, study findings about the level of CAM use based on ethnicity or race may increase significantly if prayer is offered as a type of CAM modality that respondents can select (Kronenberg, Cushman, Wade, Kalmuss, & Chao, 2006). As well, if investigators do not provide a comprehensive listing of CAM therapies (e.g., if the listing of choices only includes herbal remedies used by certain racial or ethnic groups) then the prevalence of CAM use may be underestimated (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005). For instance, the National Health Interview Survey was not able to provide a comprehensive assessment of folk medicine use when inquiring about survey respondents' CAM use. The survey only inquired about two specific types of folk medicine approaches – curanderismo, which is a traditional Latin or Mexican American folk healing system (Trotter & Chavira, 1981), and Native American healing systems. The survey instrument did not inquire about various other folk medicine

systems including Espiritismo, Shamanism, Santeria, or the use of community healers (e.g., midwives, sobadores, etc.) (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005). As a result of such omissions in the survey instrument, investigators were likely unable to obtain an accurate assessment of true CAM use in the population. Individuals who utilized the types of modalities or approaches that were omitted in the instrument may have simply responded that they did not utilize any types of CAM modalities if their preferred type of CAM modality was not listed amongst survey choices (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005).

African Americans and CAM Use

With regard to African American CAM use, investigators have examined the trends of CAM utilization in this population. The use of home or natural remedies has been a common practice amongst African Americans, particularly the elderly. The use of an herbalist for the provision of natural remedies has been an often used approach by African Americans since the time of slavery (Rocereto, 1973). The use of herbs has also been an important component of many African religions (Levine, 1977). This reliance on herbs followed many Africans to America during the slave trade, with the practice continuing as the primary approach to treatment for Africans even after they had reached America. During the period of the antebellum South, slaves were denied medical care and had to rely on their own means for care (Eiser & Eiser, 2007). Even in the period after slavery, African Americans were unable to access even the most basic of medical care. As a result, members of this community had to develop their own systems of therapies and healing treatments, and often products that were easily accessible were utilized (Pachter, 1994). For these African Americans, deprived of access to standard medical treatments of the time, the use of natural or home remedies as a first approach to care was commonly

accepted. Even when African Americans were provided with access to medical institutions, the often hostile environment that they encountered frequently led them to choose home remedies as a preferred course of treatment (Eiser & Eiser, 2007). Many of the home remedies and alternative health care practices that African Americans continue to use are the result of centuries of oppression and poverty that they have had to endure (Pachter, 1994). As a result of this history, many African Americans will now opt to utilize home or natural remedies before first seeking care from a physician (Eiser & Eiser, 2007).

For many, the tradition of root or faith healing, as it has been called, was passed from generation to generation via the matriarch of each family. In many such homes, a knowledge about the use of roots and the creation of various home remedies is considered to be a basic component of one's "domestic expertise" (Easom & Quinn, 2006). The healing philosophies of the African American community and the treatments that were developed based on traditional beliefs in the community continue to have a powerful role in the health of African Americans in today's society. Often these therapies help to shape the health seeking practices of African Americans, including the self-care behaviors that they adopt (Bailey, 1987).

Despite findings that paint a portrait of a typical CAM user as an individual who is Caucasian, additional studies suggest that many individuals who utilize CAM therapies possess a different ethnic or racial profile. Other research that has investigated CAM use amongst African Americans has suggested that age is an important factor that may influence CAM use in the African American community (Brown, Barnes, Richards, & Bohman, 2007; Cheung, Wyman, & Halcon, 2007). Previous literature determined that before 1980, a profile of the average African American CAM user was a woman who likely resided with her grandparents in areas of the rural South. As well, this profile went on to describe this individual as one who had strong religious

beliefs and whose father was not well educated (Boyd, Taylor, Shimp, & Semler, 2000). Despite this finding, one study that examined use amongst African American female residents of a northern city determined that older participants tended to possess more positive beliefs and utilized CAM therapies more often than younger participants (Cushman, Wade, Factor-Litvak, Kronenberg, & Firester, 1999). Even still, another study suggested that African American women who do not fit this specific profile are also utilizing CAM more frequently. One study that examined the practices of middle class African American mothers determined that participants who were providing care for children with colds often utilized practices that were similar to the practices of White mothers (Patcher, Summer, Fontan, Sneed, & Bernstein, 1998). Participants in this study, like many other young African Americans, may have practices that are influenced by their greater access to the abundance of health information provided on the Internet as well as their greater access to education in general. As a result, younger African Americans may have beliefs and practices that include a broader range of therapies (as compared to older African Americans) that reflect the traditions of African Americans as well as the practices of White individuals. Previous results suggest that no one profile can be used to describe African American users of complementary therapies (Pachter, 1994).

The rich tradition of CAM use continues for many African Americans today. Many of these individuals still rely on the use of natural remedies as a critical first step to healing (Eiser & Ellis, 2007). Results from previous studies suggested that elderly African American women have a greater likelihood of thinking that home remedies are effective for the care of osteoarthritis than elderly White women. As well, African American women in the study were also less likely to have joint-replacement therapy than their Caucasian counterparts (Ibrahim, Siminoff, Burant, & Kwoh, 2001). Findings from a North Carolina based study revealed that

African American participants were 81% more likely to utilize food home remedies as a type of treatment than Caucasian participants (Arcury, Bell, Snively, Smith, Skelly, Wetmore, & Quandt, 2006).

In addition to studies that have investigated the use of home remedies, a number of investigations have also determined that African Americans often opt to utilize another type of CAM modality. Although various investigators categorize CAM modalities in different ways, many include the use of mind-body remedies, such as prayer, as a type of category. Prior research has revealed that African American study participants have a greater likelihood of using such mind-body remedies than their White counterparts (Barnes, Powell-Griner, McFam, & Nahin, 2004). Religion and prayer have been suggested to be a critical aspect of African American culture (Mansfield, Mitchell, & King, 2002; Grzywacz, Suerken, Neiberg, Lang, Bell, Quandt, & Arcury, 2007; Ang, Said, Burant, Siminoff, & Kwoh, 2002). The choice to use prayer as a response to illness may be preferred by African Americans more so than by members of other racial and ethnic groups (Grzywacz, Suerken, Neiberg, Lang, Bell, Quandt, & Arcury, 2007).

Information about African Americans' beliefs surrounding the efficacy of complementary and alternative therapies, as well as how such beliefs might affect health seeking behaviors is critical for health care providers to obtain and understand. It is important that providers have some sense of the importance of various types of CAM modalities in the African American cultural tradition. It is critical that providers possess some level of insight about CAM use because many individuals may not divulge information about the use of such modalities to their health care providers. If providers are not aware of the significant role that such remedies play in the culture of many African Americans, providers may not take the extra step to inquire about

whether or not their patients utilize such treatments (Eiser & Ellis, 2007). Without this information, providers will be unable to clearly communicate and provide effective care during the clinical encounter.

Reasons for CAM Use

Findings from prior research have revealed a number of explanations for patients' use of complementary and alternative medicine. In a study by Chao and colleagues, over 33% of survey respondents who reported CAM use during the previous year stated that their decisions to utilize CAM were based on their beliefs that conventional medicines were ineffective or resulted in many side effects (Chao, Wade, Kronenberg, Kalmuss, & Cushman, 2006).

Additional research reveals several other reasons for CAM utilization. In a study assessing herbal remedy use in older adults, Arcury and colleagues reported that one frequently cited reason for using herbal remedies was because study participants thought that using herbal remedies would be interesting (27.2%). For some individuals, the choice to use herbs is based on the fact that they are often easily accessible. As well, decisions to utilize herbal remedies may be a reaction to media and marketing campaigns that promote the use of such products (Uba, 1993).

The costs of conventional treatments may present a barrier to care. CAM use provides a less expensive alternative to conventional prescription medications (Elder, Gillcrisp, & Minz, 1997). Some investigators have suggested that if older adults are using herbs in place of prescribed medications, it may be because herbs are less expensive than prescription medications (Pagan & Pauly, 2005). For their study, Barnett et al determined that CAM use is often utilized mainly because of a patient's inability to access physicians because of both financial costs and geographical distance from provider (Pachter, 1994).

Participants in one study offered a number of additional reasons for utilizing CAM. These reasons included women's lack of satisfaction with current conventional medications and the influence of various social networks and personal beliefs. The study's investigators determined that female respondents had a greater likelihood of attributing their CAM use to factors such as personal health beliefs more so than to a lack of satisfaction with available conventional medications. Women reported that they utilized CAM because specific remedies were consistent with their beliefs. Many respondents reported that they wanted to utilize what they regarded as more natural approaches to treatment. Those who reported that social influences affected their decisions to utilize CAM revealed that they often adopted the use of these therapies because their family members had used these therapies while they were growing up. Respondents also revealed that information from media sources, including radio and television, influenced their decisions to use CAM (Chao, Wade, Kronenberg, Kalmuss, & Cushman, 2006).

Some investigators have suggested that many patients may use herbal therapies because of a lack of trust in physicians (Astin, 1998). One investigation determined that this was the case specifically for Latino patients. Findings from the work of Barnett and colleagues indicated that many respondents who utilized alternative therapies felt that the use of CAM to manage their own health helped to provide them with a sense of empowerment. This feeling of empowerment occurred especially during those situations when prescriptions recommended by providers led to adverse side effects (Pachter, 1994). Findings from the work of Graham and colleagues suggest that those who use CAM may be individuals who may actively make efforts to improve their health (The National Board of Chiropractic Examiners).

The Importance of Discussions about CAM

In order for health care professionals to provide the best care possible for their patients, it is critical that discussions about the use of complementary and alternative therapies are initiated and continually encouraged by providers. Such discussions are especially important when CAM use is an accepted part of a patient's culture (Howell, Kochhar, Saywell, Zollinger, Koehler, Mandzuk, Sulto, Sevilla-Martir, & Allen, 2006). The use of many types of CAM modalities can lead to adverse health outcomes for patients. Providers can utilize effective strategies to prevent such adverse outcomes when they are aware of patients' CAM use and when they can take the appropriate steps to discuss this use during medical encounters. Such efforts can only occur when patients are willing to disclose their use of CAM modalities and when providers are willing to initiate conversations about such use.

Patients may not always make the effort to initiate conversations about their alternative medicine use (Wheaton, Blanck, Gizlice, & Reyes, 2005). Such findings emphasize the need for proactive efforts on the part of providers (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005). Because patients might not always disclose their CAM use, the onus must be on the provider to collect information from patients about the use of CAM modalities (Kuo, Hawley, Weiss, Balkrishnan, & Volk, 2004). It is critical that providers realize the importance of initiating open conversations about their patients' actual use of herbs and other CAM modalities or even their patients' interest in CAM (Howell, Kochhar, Saywell, Zollinger, Koehler, Mandzuk, Sulto, Sevilla-Martir, & Allen, 2006). If providers are not aware of patients' CAM use, then they will be unable to provide patients with important information about the efficacy and safety of various types of CAM therapies.

The Importance of Patient Disclosure

Greater research is needed to examine both the efficacy and safety of various types of CAM. While herbal products and therapies are often regarded as natural alternatives to conventional health care, the use of such approaches can lead to adverse health outcomes. For many American patients, the use of CAM therapies such as herbal remedies has become popular not only because they are deemed as efficacious but because they are considered as safe as conventional prescription medications (Howell, Kochhar, Saywell, Zollinger, Koehler, Mandzuk, Sulito, Sevilla-Martir, & Allen, 2006). A lack of proper product standardization (e.g., the determination of potential contaminants in products) and therapies that contain mixtures of several different ingredients can lead to the possibility of toxicity exposures in adults and children (Woolf, 2003). Some types of CAM, including herbal products, can have harmful side effects or negatively interact with medications (Wheaton, Blanck, Gizlice, & Reyes, 2005).

More information is needed about CAM use, such as herbal therapy use, because negative reactions to a variety of therapies are likely under reported (Evans, Shaw, Thompson, Falk, Turton, Thompson, & Sharp, 2007; D'Arcy, 1991). Since many individuals regard CAM therapies, such as herbs, to be a natural therapy, any hazardous impacts on health may often go unrecognized (D'Arcy, 1991; Winslow & Kroll, 1998). Because of the possibility of the occurrence of adverse health outcomes, it is essential that patients and providers alike recognize the importance of discussing the use of CAM. If patients do not divulge this information then providers may be unable to attribute the occurrence of adverse health outcomes to the use of CAM therapies. If patients are using these therapies along with or in place of prescribed medications, then the use of CAM could exacerbate an individual's conditions, interfere with the

effects of a prescribed treatment, and as a result, prevent the delivery of effective care (Eiser & Ellis, 2007). As a result, a patient's lack of communication about CAM use could result in the individual experiencing adverse effects.

Reasons for Nondisclosure

Even with such widespread use of CAM modalities, as evidenced by findings from previous research, often patients who utilize CAM therapies do not take the steps to discuss this use with their health care providers. In order for health care professionals to provide their patients with information about CAM use, including its potential dangers, health care professionals must first be aware of their patients' use. If patients do not disclose such information, and providers do not routinely inquire about use then doctors will not have the opportunity to provide effective communication (Eisenberg, Kessler, Van Rompay, Kaptchuk, Wilkey, Appel, & Davis, 2001). Ineffective communication can prove problematic for health care providers by compromising the provision of optimal health care (Hsiao, Wong, Goldstein, Yu, Andersen, Brown, Becera, & Wenger, 2006).

Trends that revealed low disclosure of CAM use have been discovered in the findings from a number of studies. For their study, Eisenberg and colleagues (1993) discovered that 70% of patients did not inform providers about their herb use (Eisenberg, Kessler, Foster, Norlock, Calkins, & Delbanco, 1993). Findings from another study determined that just 45% of African American patients in an urban clinic setting reported that they disclosed their use of herbs to their physicians (Kuo, Hawley, Weiss, Balkrishnan, & Volk, 2004). As well, just 34.9% of African American respondents who completed the 2002 National Health Interview Survey reported that they disclosed their use of CAM modalities to providers. One study discovered an interesting trend with regard to the racial and ethnic backgrounds of patients. Investigators determined that

Hispanics and African Americans were much less likely to reveal their use of CAM to their physicians. Graham and colleagues determined that Hispanics had the highest physician nondisclosure rate (68.5%) about CAM use to providers as compared to that for African Americans (65.1%) and for Whites (58.1%) (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005).

There are many reasons that may influence whether or not patients choose to disclose their CAM use to their providers. Health care staff may not have questioned patients about CAM use because of time constraints or because they may have forgotten to ask about it (Higginbotham, Trevino, & Ray, 1990). Even in instances where language is not a barrier in clinical encounters, English-speaking patients may not choose to disclose their use of CAM therapies because they perceive that their providers will think that this type of treatment is ineffective, they are embarrassed to disclose that they use these treatments or they may not want to be perceived as an unsophisticated patient. As well, some patients do not disclose this use because they think that their provider might object (The National Board of Chiropractic Examiners; O'Connor, 1995).

Results from other studies also determined that those individuals who opted not to inform providers about their herbal remedy use provided several explanations for this decision. These reasons included the idea that providers would not be interested in their use of herbal products, the belief that providers would respond negatively, the perception that providers would be unable (or unwilling) to provide important information about herb use, and the belief that providers thought that herbs were not necessary or needed for conventional biomedical treatments (Adler & Fosket, 1999). Patients may not inform providers about herb use because they may be intimidated by providers and sense that their providers will disapprove of the use of herbal

remedies (Cohen, Cerone, & Ruggiero, 2002). Investigators Howell and colleagues discovered similar findings. For their study, 25.9% of individuals reported that they did not feel that their physicians would be knowledgeable about what herbs were utilized for and 20.5% reported that their physicians would likely tell them to stop using herbs if their physicians knew about their herb use (Howell, Kochhar, Saywell, Zollinger, Koehler, Mandzuk, Sulto, Sevilla-Martir, & Allen, 2006).

If health care professionals are to provide patients with the highest level of care, it is essential that these individuals first possess a thorough understanding of patients' attitudes about CAM use. For those providers who treat African American patients, it is especially essential that these providers possess an appreciation of the importance of home remedies in the cultural history of many African Americans. With such knowledge, health care professionals can then offer patients the most optimal level of care. By understanding the role of these remedies as well as respecting and acknowledging each patient's cultural history and traditions, providers can make effective strides towards building a strong foundation of trust in the clinical relationship. Increased levels of trust can improve the interpersonal relationships between patients and providers and as a result bridge any existing gaps in patient-provider communication (Eiser & Ellis, 2007). Clear patient-provider communication offers one effective strategy that can be employed by health care professionals to decrease the occurrence of adverse health outcomes that may occur as a result of CAM utilization. Those providers who are more receptive to CAM use or even discussing the topic of CAM use may experience more open communication from their patients (Howell, Kochhar, Saywell, Zollinger, Koehler, Mandzuk, Sulto, Sevilla-Martir, & Allen, 2006).

III.D.3. DISTRUST

Investigators have surmised that there is an underlying feeling of distrust between certain populations (e.g., minority groups) and the research and medical establishments. When examining trust, investigators and health care providers must consider the cultural beliefs, attitudes, history, and social issues of these populations and how such factors can affect patient trust and willingness to participate in research (Shavers, Lynch, & Burmeister, 2000). For African Americans specifically, a strong perception of distrust is due in great part to this population's prior experiences within the U.S. health care system. Such distrust in the health care system is a significant problem for African Americans that should be addressed. To fully understand why such distrust exists, researchers and health care providers need only review the history of African Americans in the U.S. (Kennedy, Mathis, & Woods, 2007). The perceptions that many African Americans possess about the country's health care system and many of its social institutions are largely based on the negative experiences that African Americans have had to endure (Blendon, Scheck, Donelan, Hill, Smith, Beatrice, & Altman 1995; Randall, 1995). Such perceptions that are somewhat the result of an often oppressive history in the U.S. frequently translate to feelings of distrust that are directed at health care providers and researchers. This distrust, which can lead to a breakdown in effective communication between the patient and provider, can subsequently result in a number of adverse health outcomes for African American patients.

The Role of Trust in the Clinical Encounter

The health care system is charged with the mission of protecting the interests of both the patient and the provider. The provision of health care presents a unique situation. It can involve the exchange of information in a relationship that is often asymmetrical (Jellinek, 1976). When

the patient and provider enter into a relationship, the provider assumes a role that often has more power than the role of the patient. Because of this, the patient may feel that (s)he is in a vulnerable position. In order to combat such feelings of vulnerability, the factor of trust becomes a critical element in the patient-provider relationship because the patient must believe that the provider will always act in his or her best interest (LaVeist, Nickerson, & Bowie, 2000; Murray-Barcia, Selby, Schmittiel, Grumbach, & Quesenberry, 2000).

One of the most important components of a strong therapeutic relationship is trust (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). More and more, researchers and health care professionals have begun to recognize the importance of regarding trust as a key aspect of health care. In previous reports, the concept of trust has been described as a patient's expectation that health care providers (e.g., doctors, nurses, etc.) will act in a manner that clearly demonstrates that the needs and interests of patients are priorities. Trust can be regarded as a multidimensional concept that incorporates a patient's perceptions of the provider's technical abilities, interpersonal skills, and the degree to which the patient believes that his or her best interests are placed above all else (Hall, Dugan, Zheng, & Mishra, 2001; Thom, Ribisl, Stewart, & Luke, 1999).

It is important that investigators are able to gain a clearer understanding of the effects of patient trust, particularly among poor and underserved populations. The presence of trust can be a critical indicator of the quality of the relationship (Sheppard, Zambrana, & O'Malley, 2004). A decrease in trust can result in less patient and provider satisfaction, patients' greater disenrollment from care, and ultimately a negative health status (Thom, Ribisl, Stewart, & Luke, 1999; Mechanic & Schlesinger, 1996). Trust has been identified as a critical determinant and predictor of patient compliance to suggested treatments and the practice of certain protective

behaviors, as well as a determinant of the duration and quality of relationships with providers (Thom, Ribisl, Stewart, & Luke 1999; Sheppard, Zambrana, & O'Malley, 2004; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). Trust may be linked to the extent to which patients decide to seek care and cultivate long lasting relationships with health care providers and health insurers (Hall, Dugan, Zheng, & Mishra, 2001; Thom, Ribisl, Stewart, & Luke, 1999).

Trust and African Americans

The presence of trust is a critical issue in the relationships of all patients and their providers. However, because of the unique history of African Americans in the U.S., this population may experience greater levels of distrust in the health care system than members of other racial groups. The issue of distrust for many in the African American community is grounded in the long and difficult history of this group in America (Kennedy, Mathis, & Woods, 2007).

Although the nation's population is culturally diverse, and many minority populations have experienced racism, the African American experience is one that has been built on slavery, segregation, and racism. African Americans have been victims of experimentation during slavery, medical abuse and misuse, exploitation, and institutional racism. As a result, many in the community have developed a profound sense of distrust towards health care providers and these individuals now frequently face the U.S. health system with apprehension, doubt, and at times, animosity (Randall, 1995). Results from the work of Blendon and colleagues reported that 42% of African American participants in their study were more likely to state that the nation's health care system needs to be rebuilt as compared to White participants (Blendon, Scheck, Donelan, Hill, Smith, Beatrice, & Altman, 1995). Many in the community have expressed fears about being treated like a guinea pig if they participate in clinical research while

others believe that health care providers may not, whether intentionally or unintentionally, treat their minority patients like their White patients (Lake, Snell, Perry & Associates, 2003).

In order for researchers and health care professionals to gain insight into why distrust can present such a barrier for African Americans in the health care system, they must first comprehend the extent of previous injustices and medical abuses (Randall, 1995). Such knowledge will offer health care professionals a critical perspective of the impact that this abuse has had on African Americans including their perceptions of the health care environment.

African Americans and a History of Medical Abuse

A review of numerous reports has revealed a long history of medical abuse dating back to America's antebellum period. Reports have revealed that testing of a smallpox vaccine was performed when two hundred slaves of Thomas Jefferson were inoculated with the vaccine. Reports of further abuse and medical atrocities were common during slavery. There have been reports that slaves often believed that physicians killed slaves or allowed them to die so that their bodies could be utilized for dissection. Beliefs also circulated that the bodies of slaves were exhumed and sold to medical schools for teaching. Additionally, reports from literature have suggested that physicians frequently abused and exploited slaves for their own gain. One report reveals that the highly revered Dr. Marion Sims, who is regarded as the father of gynecological surgery, perfected some of his surgical approaches on slaves.

The Tuskegee Syphilis Study

Abuses in research and medicine for African Americans were not solely restricted to the era of slavery. Post-slavery abuses in research also occurred and the most egregious example was the Tuskegee Syphilis Study (Randall, 1995). The Tuskegee Syphilis study is one of the most widely recognized examples of abuse in medical research. For this infamous study,

conducted by the U.S. Public Health Service between 1932 and 1972, investigators withheld medical treatment for syphilis from approximately four hundred African American men. The focus of the study was for investigators to observe the natural progression of disease in a sample of African American men. Even after penicillin was utilized as the accepted standard of care for syphilis treatment, investigators continued to withhold treatment from the study participants in order to observe the effects of disease (Adams, 2003). The failure of study investigators to treat the study participants with penicillin even after the efficacy of this treatment was determined has been cited in previous reports as an accepted and even positive study approach that was employed by investigators (Olansky, Simpson, & Schuman, 1954; Shafer, Usilton, & Gleeson, 1954). In 1969, a panel was convened by the Centers for Disease Control and Prevention to review the specifics of the study. The panel voted to allow for the study's continuation, without any type of modification to study protocol, until its endpoint, i.e., until all subjects were deceased (Thomas & Quinn, 1991). The Tuskegee Syphilis Study was eventually stopped after public outrage began when the study's details were made available to the public (Shavers, Lynch, & Burmeister, 2000).

For many, the Tuskegee Syphilis study has come to represent a blatant example of government racism. In his book "Bad Blood", author James Jones asserts that for many African Americans, this study became a symbol of racism and of mistreatment by the medical community (White, 2000).

Prior studies have helped investigators gain insight about the true impact of the Tuskegee Syphilis Study on African American patients and their trust in medical research and the health care system as a whole. Previous research has attempted to examine the impact of low levels of trust on a number of outcomes including participation in research studies. Shavers and

colleagues utilized data collected from mail and telephone surveys to determine what types of barriers might hinder African American participation in research. The investigators specifically examined study participants' knowledge of the Tuskegee Syphilis study and how such knowledge might impact trust in health care and willingness to participate in research.

Findings revealed that 81% of African Americans and 28% of White respondents reported knowledge of the Tuskegee Syphilis Study. For 51% of African Americans and 17% of White respondents, knowledge of the Tuskegee Syphilis Study resulted in lower levels of trust of researchers. As well, 46% of African Americans and 34% of White participants reported that their knowledge of the Tuskegee Syphilis study would influence future decisions regarding participation in research. Of those individuals who reported that such knowledge would affect their future participation in research, 49% of African Americans and 17% of White respondents stated that they would not participate in research studies in the future. Findings from the work of Shavers and colleagues provide important evidence to support the suggestion that even today knowledge of the Tuskegee study likely impacts the beliefs and perceptions of many African Americans.

The legacy of the Tuskegee Syphilis study has often been used as a metaphor for the abusive and unethical treatment of African Americans in research (Shavers, Lynch, & Burmeister, 2000). This legacy has had a profound impact, and investigators believe that it has greatly influenced the beliefs and attitudes of many African Americans regarding the nation's health care system and the scientific establishment. A number of researchers have posited that the Tuskegee Study has contributed to a sense of widespread distrust in the African American community and affected many individuals' willingness to enroll in disease prevention programs and research studies (El-Sadr & Capps, 1992; Bateman, Kardinal, Lifsey, Gralla, Washington,

Scroggins, & Allen, 1993; Jones, 1992). Investigators suggest that many individuals may be reluctant to participate or refuse participation because they fear the possibility of abuse by unethical researchers (Kressin, Meterko, & Wilson, 2000).

Medical mistreatment and exploitation of African Americans continued to occur in the years following slavery. Although the Tuskegee Syphilis Study represents one of the most infamous examples of post-slavery abuse among African Americans, and it is symbolic of African Americans' pervasive distrust of the research establishment, there have been other examples of medical abuse that are not as well known. A number of reports provide information about previous cases of medical misuse and abuse of minority and disenfranchised groups. These cases also help to provide explanations for the high levels of distrust in the African American community (Randall, 1995; Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997; Washington, 1995).

During the early 1960s, the United States Public Health Service, in conjunction with the American Cancer Society and the New York-based Jewish Chronic Disease Hospital of Brooklyn conducted a research experiment in which live cancer cells were injected into 22 chronically ill patients, all of whom were African American. These individuals were not aware that they had been injected with the cells, and therefore they could not have consented to have such a procedure performed. By not informing patients about the study and obtaining their consent, the investigators unethical approaches to research resulted in the mistreatment of patients.

Even after the Civil Rights Movement of the 1960s, African Americans still experienced blatant discrimination and the end result for these individuals with regard to health has often been either access to poor quality of care or no access to care at all. Study results that reveal

gaps in mortality or morbidity rates between African Americans and other racial groups suggest that such variations may indeed be the result of discrimination and racism. For instance, certain groups may not have access to care or be informed about the use of important treatments at the same rate as other groups.

Though all patients should be assured that they will receive the best medical care available, the presence of discrimination and institutional racism does not always allow African Americans and other minority patients to possess such assurances. Such barriers can have long lasting impacts on those individuals who perceive that they are the victims of discrimination and racism. A legacy of racist health care, combined with the current influence of discrimination and institutional racism can work to reinforce African Americans' feelings of distrust toward the U.S. health care system.

Although a number of instances of abuse have been perpetrated against African Americans, most individuals may not be aware of the details of many of these abuses, except for those that have gained more attention, such as the Tuskegee Syphilis Study. However, even without individuals' knowledge of the specifics of each of these abuses, all of these instances of abuse and exploitation are a part of the collective Black consciousness that greatly impacts the ways in which African Americans respond to and communicate with researchers, physicians, and the health care system as a whole. For many African Americans, fear and distrust of the nation's health care system has been a natural response to the history of abuse and experimentation that has occurred. This fear has consequently shaped the perspectives of many in the African American community. Such perspectives often deter many African Americans from accessing health care, participating in research studies and participating in a number of other activities including organ donation. As a result, it is critical that researchers and health care professionals

acknowledge this fear and distrust and the adverse effects that these feelings can have on various aspects of care including patient-provider communication (Randall, 1995). The impact of distrust in the African American community can lead to a breakdown in the communication between providers and their patients.

Distrust in Research

A number of previous studies have attempted to assess levels of trust in patients as well as explore those factors that may impact patients' trust in their health care providers. Investigators Boulware and colleagues conducted a cross-sectional telephone survey in an effort to examine participants' willingness to participate in blood or organ donation. As a part of the study, investigators also assessed participants' trust levels in providers, medical institutions, and health insurance plans. Boulware and colleagues analyzed the responses for 118 respondents (49 African American and 69 White respondents) and determined that overall most of the respondents expressed trust in their physicians (71%) and hospitals (70%). However, it was discovered that African American respondents had a lower likelihood of trusting their physicians in comparison to White respondents. As well, African American respondents had a greater likelihood of reporting that they trusted their health insurance plans in comparison to White respondents. Boulware et al (2003) also noted that as compared to White respondents, African American respondents had a greater likelihood of reporting that they were concerned about issues related to personal privacy as well as the possibility of exposure to harmful experimentation in medical institutions (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003).

The results of the Boulware et al (2003) study are revealing. Race-based differences in trust regarding specific health care entities may be the result of the divergent cultural experiences of individuals. Such experiences can greatly influence the levels of interpersonal and

institutional trust that individuals experience. Interpersonal trust is linked to specific direct personal experiences that patients have with others including a personal physician. However, institutional trust is based more on an individual's overall general perceptions of professional institutions and organizations. For this type of trust, these perceptions are based on personal experiences and information about secondhand experiences, as well as social cues such as discussions with others, information presented in the media, and protective measures that are developed to prevent discrimination (Hall, Dugan, Zheng, & Mishra, 2001; Goold & Klipp, 2002). For African Americans specifically, the issue of trust is unique because these individuals have been victims of both interpersonal and institutional discrimination. As a result, both personal and institutional relationships are critical for African Americans, and they may be dramatically impacted by concerns about potential discrimination (Blendon, Scheck, Donelan, Craig, Smith, Beatrice, & Altman, 1995). Boulware et al's suggestion that African Americans had a lower likelihood of reporting trust in providers than White study respondents supports previously published findings that have explored racial variations in perceptions of the patient-provider relationship. As well, the findings of Boulware and colleagues may reflect the fears that many African Americans may have about interpersonal race-based discrimination (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Study findings that reveal that patient-provider racial concordance is positively linked to perceptions of quality of care and patient satisfaction provide support for the idea that fear of racial discrimination in interpersonal relationships with providers can affect trust (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; LaVeist & Nuru-Jeter, 2002).

Boulware and colleagues have suggested an explanation for their study findings. The investigators surmise that for specific individuals, feelings of distrust may increase depending on

the setting. For those settings, such as during a clinical encounter, where one's race or ethnicity cannot be easily concealed, distrust may increase. Conversely those who serve as administrators for health care insurance plans are rarely in direct contact with patients; therefore, these individuals might not always have information regarding a patient's race. In such scenarios where there is no direct contact, levels of distrust may be lower (Fiscella, Franks, Gold, & Clancy, 2000). For African Americans, a feeling of racial anonymity may increase their trust in health plans. If increased trust levels are associated with less concerns about discrimination based on race, individuals' trust of health care plans may be adversely impacted by policies that call for the provision of race or ethnicity data about insurance plan enrollees (Perot & Youdelman, 2001).

The results of other research provide additional support for the finding that many African Americans possess low levels of trust for health care providers. For their work, Halbert and colleagues (2006) analyzed data that was collected as a part of a telephone survey that was administered to examine the health care experiences and characteristics of a racially diverse sample of adults (Halbert, Armstrong, Gandy, & Shaker, 2006). Study investigators determined that African Americans were significantly more likely than Whites to state that they had low trust in their health care providers.

Trust in the patient-provider relationship is necessary in order to help ensure that effective communication occurs between individuals. Prior research reveals that there is an association between trust and communication in the patient-provider interaction. The findings of Halbert and colleagues (2006) posit that individuals who have providers who communicate well (e.g., via the utilization of direct and empathetic communication) may experience increases in levels of patient trust. For the work of Halbert et al, this finding was reported for African

American and White patients. Such findings suggest that those efforts that focus on improving provider behaviors, such as efforts that lead to effective partnership-building and subsequently more effective communication, may result in improvements in trust for African Americans and Whites (Thom, 2000). As well it is likely that the converse is true. Greater trust may also result in more effective communication.

Additional research has also helped to provide some insight about the role of trust in the patient-provider relationship. In their research, investigators Sheppard and colleagues conducted focus groups of prenatal and postpartum women who attended community public prenatal care programs. The investigators discovered that several factors were determined to be associated with the presence of greater trust in patient-provider relationships that include low income women. Upon analysis of collected data, investigators devised a model that included the most common themes discovered regarding patient trust. They discovered that several factors were determined to be associated with the presence of greater trust in patient-provider relationships including: effective communication, demonstrated caring by the provider, perceived competence of the provider, and continuity of the patient-provider relationship. Such factors are important to recognize because they may then affect various other outcomes that patients experience including levels of satisfaction with care and patients' adherence to providers' recommendations for care. The work of Sheppard and colleagues was critical in that it helped to address existing gaps in the literature by providing an examination of patient trust among low income and minority populations (Sheppard, Zambrana, & O'Malley, 2004).

Greater research needs to be conducted in order to provide insight about the role of trust within the clinical encounter. This is of particular importance for those providers who treat African American patients. Without additional information about the role of trust in the patient-

provider relationship, as well as the recognition of this role by health care providers, patients may not experience effective communication with their providers nor be able to obtain quality care. An emphasis on the role of trust and its impact on the interpersonal relationship between patients and providers is necessary. This emphasis is especially critical for patients who belong to those communities of individuals who may experience difficulty trusting health care professionals and the overall medical establishment. If providers are able to achieve greater levels of trust with their patients, and offer more effective communication, the result may be that providers can offer their patients more comprehensive information, more accurate diagnoses, and better care.

III.D.4. RACIAL CONCORDANCE

The issue of patient and provider race is an important one to examine when considering factors that may impact the health outcomes that patients experience. Findings from health disparities research have been rather telling, in that such studies often suggest that minority patients do not experience the same health outcomes as their White counterparts. Several studies have determined that in the U.S., often the overall health care quality that individuals experience differs based on patients' racial and ethnic backgrounds (Smedley, Stith, & Nelson, 2002; Mayberry, Mili, & Ofili, 2000; LaVeist, Nickerson, & Bowie, 2000).

It is critical that investigators examine the impact of patient and provider race for a number of reasons. An examination of the role of race in the clinical encounter can help investigators to determine if, and how, race impacts the nature of the clinical interaction. It can provide information about whether or not factors such as race influence the type and quality of care that patients receive from providers. Such research can also provide investigators with

information about how the factor of race can not only influence how providers behave during clinical encounters, but possibly influence the health-related practices of patients. It is important for investigators to examine the role of race because prior studies suggest that this factor can greatly impact the quality of communication that occurs between patients and providers.

An exploration of the impact of patient and provider race may help to provide critical insight about health disparities. Although a number of explanations have been suggested to explain the existence of health disparities, the root causes of these differences in health outcomes are not clear (Clancy & Stryer, 2001). Findings from studies have revealed that minority patients, in comparison to their White counterparts, have often reported that they have experienced a lower quality of relationships with their providers (Blanchard & Lurie, 2004; LaVeist, Nuru-Jeter, & Jones, 2003). Such reported differences in quality are speculated to be based somewhat on providers' racial or ethnic backgrounds (Saha, Arbelaez, & Cooper, 2003).

Previous research has posited that patients who are members of racial or ethnic minority groups tend to utilize less health care services than Caucasian patients. These findings suggest that minority patients may tend to be less satisfied with the care that they receive when compared to White patients (Blendon, Aiken, Freeman, & Corey, 1989). A number of studies have reported that individuals who are members of minority populations are more likely to have decreased access to care, in comparison to White individuals (Council on Ethical and Judicial Affairs, 1990; Blendon, Aiken, Freeman, & Corey, 1989; Lillie-Blanton, & Alfaró-Correa, 1995), and to utilize less available health care resources (Lillie-Blanton & Alfaró-Correa, 1995; Esarce, Epstein, Colby, & Schwartz, 1993). Such findings are important to address and many investigators suggest that differences in factors such as health care insurance coverage cannot adequately explain the reasons for these disparities (Council on Ethical and Judicial Affairs,

1990; Esarce, Epstein, Colby, & Schwartz, 1993). As a result, it is imperative that researchers examine those other factors, including patient and provider race, which may contribute to the existing gap between health outcomes experienced by minority and White patients. Patient and provider race may be important to consider because in those instances where patients and providers share the same race, especially for certain groups such as African Americans, patients may not experience negative health outcomes. In these cases, racial concordance may work to prevent the occurrence of adverse outcomes.

A report of the Institute of Medicine that focused on racial and ethnic disparities in health care recommended that several facets of the patient-provider relationship may contribute to existing disparities in the nation's health care system (Institute of Medicine, 2003). Many of the studies that attempt to examine such disparities have often examined specific technical aspects of care, including a patient's receipt of certain diagnostic tests, medical procedures or treatments (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003). However, emerging literature has now begun to link various interpersonal aspects of care with a variety of health outcomes including continuity of care. Included in these interpersonal aspects of care is patient-provider communication (Kaplan, Greenfield, & Ware, 1989; Stewart, 1995).

Previous research has provided support for the fact that both patient and physician race can impact the quality of the patient-provider relationship (Saha, Arbelaez, & Cooper, 2003). Patients who belong to the same racial group as their providers are said to be in racially concordant relationships, whereas when the race of the patient and provider differ, the relationship is described as racially discordant. A number of studies have revealed that many minority patients, specifically African Americans, often prefer to receive care from providers who are of the same race. Several studies have often reported that patients believe that

physicians who share the same race provide a better level of interpersonal care than physicians who do not share the same race as the patient (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Saha, Taggart, Komaromy, & Bindman, 2000; Saha, Komaromy, Koepsell, & Bindman, 1999).

An examination of race is important because racial discordance may contribute to health disparities by influencing whether certain (i.e., minority) patients receive an equal quality of care as other (non-minority) patients. If the race of the patient and provider differ, this may subsequently lead to negative health outcomes for patients who may be treated differently – whether intentionally or unintentionally – because of their race. Providers may exhibit certain biases and treat patients who are of another race differently. As well, these patients may not feel comfortable during the clinical encounter because of differences in race. As a result, patients may not seek necessary care or communicate openly with providers and they may experience a variety of health disparities, including less optimal care as a result.

An examination of the link between racial concordance and the nature of patient-provider interactions can provide important information for health care professionals. Previous research has suggested that racial and ethnic concordance may affect the encounter in a number of ways including influencing the quality of communication that occurs during health visits. Greater insight about the impact of racial concordance can help researchers and health care professionals determine how concordance may positively impact the quality of communication that occurs during the encounter. Physicians and patients who share the same race or ethnicity may share similar cultural beliefs, values, and experiences. Such similarities are likely to allow the patient and provider to feel more comfortable, and as a result, communicate more effectively with each other. Despite such suppositions, findings from previous studies have attempted to refute this

idea. These findings have suggested that differences based on socioeconomic status, and not race or ethnicity, are the actual causes of communication barriers between patients and their providers (Pendleton, 1980; Wasserman, Inui, Barriatua, Carter, & Lippincott, 1984). The work of Cooper-Patrick et al (1999) does not support such assertions. The investigators found that minority patients, including African Americans, experienced less participatory visits with White physicians than with physicians who shared the same race or ethnicity, regardless of educational attainment (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999). The work of Cooper-Patrick et al (1999) was important in that it provided evidence that existing ethnic and racial differences between patients and their providers can act as barriers to effective communication and the creation of partnership-building efforts (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Cooper & Powe, 2004).

As well, findings from other studies have provided support for the fact that racial concordance can positively impact the encounter. Investigators have suggested that racially concordant patient-provider dyads may experience better interactions during the clinical encounter because these individuals may possess somewhat similar ideas about health and illness. Findings that support this idea include those instances in which the patient and provider shared similar explanatory models of disease and expectations about care. Such similarities often led to improved communication (Lin, 1983).

The Link Between Racial Concordance and Health-Related Outcomes

Findings from previous studies have proven valuable by helping to offer insight about the link between racial concordance and various health-related outcomes. Such findings support the assertion that concordance can positively impact the health of patients in a number of ways.

A previous examination of health services utilization revealed that patients in racially concordant relationships with providers had a greater likelihood of utilizing necessary health services and more health services. As well, those in racially concordant relationships also had a decreased likelihood of postponing or delaying seeking care (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003). Patients and providers in racially concordant dyads may experience more effective communication. In their work, investigators Cooper-Patrick and colleagues (1999) determined that patients who had racially concordant relationships with their providers tended to rate their providers as much more participatory than did patients who were in racially discordant relationships (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999). Cooper-Patrick et al (1999) also discovered that providers in concordant relationships may employ greater partnership-building communication with patients (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999). It has been reported that minority patients often report a specific personal preference for providers who are of the same race (Saha, Taggart, Komaromy, & Bindman, 2000). Such individuals also report greater levels of satisfaction with provided care when they are members of racially concordant patient-provider dyads. This finding is especially prevalent among African American patients (Saha, Komaromy, Koepsell, & Bindman, 1999).

Investigators Saha and colleagues conducted a study to determine if racial concordance between the patient-provider dyad has an effect on the level of satisfaction that patients experienced. As well, researchers focused on determining the effect of racial concordance on patient utilization of health care (Somnath, Komaromy, Koepsell, & Bindman, 1999). For their study, Saha et al (2003) analyzed data collected from the Commonwealth Fund's 1994 Minority Health Survey. This national telephone survey utilized a sample of noninstitutionalized adults.

The responses of more than 2200 White, African American, and Latino adults who stated that they had a regular clinician were evaluated. The survey collected data on a number of topics including various demographic variables, usual sources of care, utilization of health care services, and health status (Saha, Arbelaez, & Cooper, 2003). Investigators determined that African American study participants who had African American physicians had a greater likelihood of rating their physicians' service as excellent when compared to African American participants who were not in racially concordant relationships. African Americans in racially concordant pairs were more likely to state that they had obtained the necessary preventive care and all other necessary health care during the year prior to the study. The findings of Saha and colleagues were critical because they suggested that racial factors can have an important influence on the patient-provider relationship. Saha and colleagues determined that African American patients were more satisfied with the medical care they received from African American physicians as compared to care from physicians who were not African American. A similar trend was also seen amongst patients of other racial groups (Somnath, Komaromy, Koepsell, & Bindman, 1999).

Prior research findings have also determined that racial concordance can positively impact the nature of the interpersonal interaction between the patient and the provider. It has been suggested that racial concordance can lead to more effective communication between the patient-provider dyad. Previous research has revealed that African American patients also rated African American physicians as providing higher quality care including exhibiting better listening and communication skills, displaying respect towards patients, involving patients in the decision-making process, and being accessible (Blanchard & Lurie, 2004; Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003) as compared to physicians of other races.

Investigators determined that for African Americans, a strong link was discovered between racial concordance and participants' positive ratings of factors that impact the overall nature of the patient-provider interaction. Such findings suggest that African American physicians may experience more amicable relationships with African American patients than physicians who are not African American. These successful interpersonal relationships (and likely resulting effective communication) may be the result of the cultural similarities and like experiences that both parties share. Such experiences can lead to greater levels of trust and understanding between the patient and the provider (Gamble, 1997).

For their study, investigators Cooper and colleagues (2003) compared the communication between patients and their providers in race concordant pairs with the communication between patients in race discordant pairs. Findings from the study demonstrated that patient-provider dyads in race concordant pairs had visits that were 2.2 minutes longer in duration compared with dyads in race discordant pairs. As well, investigators discovered that visits between race concordant pairs featured dialogue that was characterized by a much slower speech speed for patients and providers than in visits between race discordant pairs. Investigators also determined that patients who shared the same racial background with their providers reported more satisfaction with their visits and rated their providers as utilizing more participatory approaches (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003).

Health care providers and patients often perceive that the length of a clinical encounter is linked to the quality of care provided (Wiggers & Sanson-Fisher, 1997). Often when clinical encounters are longer, patients are likely to state that they experience less difficulty talking about problems and making decisions. Patients are often more satisfied with the amount of time that they have with physicians (Howie, Porter, Heaney, & Hopton, 1991). Within the context of race,

length of clinical encounter may be of specific importance because a number of studies have reported shorter encounters and decreased satisfaction with the time spent in clinical encounters for those African American patients who have physicians of another race (Rosenheck, Fontana, & Cottrol, 1995; Gross, Zyzanski, Borawski, Cebul, & Stange, 1998).

Racial Discordance

Prior research has revealed the existence of prevalent racial, ethnic, and social disparities in the U.S. health care system (Blendon, Aiken, Freeman, & Corey, 1989; Esarce, Epstein, Colby, & Schwartz, 1993; Carlisle, Leake, & Shapior, 1997; Andrulis, 1998), and some investigators have suggested that racial discordant relationships may provide a partial explanation for some of these disparities (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003). A number of studies have examined whether barriers that exist in cross cultural patient-provider relationships may contribute to existing health care disparities (Saha, Arbelaez & Cooper, 2003). Minority patients who are in racial or ethnic discordant relationships tend to rank the level and quality of interpersonal care offered by providers or the care offered by the health care system as a whole, as more negatively in comparison to White patients (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Somnath, Komaromy, Koepsell, & Bindman, 1999; Gross, Zyzanski, Borawski, Cebul, & Stange, 1998). The end result for these patients may be a decreased likelihood of obtaining needed care because of feelings of dissatisfaction. Decreased care received by patients may then lead to increases in health disparities for a number of outcomes.

Racial discordance in a patient-provider relationship can also sometimes affect the actions of the provider. Evidence from studies has also suggested that providers often stereotype patients during the clinical encounter (Van Ryn & Burke, 2000; Schulman, Berlin, Harless,

Kerner, Sistrunk, Gersh, Duber, Taleghani, Burke, Williams, Eisenberg, & Escarce, 1999).

When a difference in race or ethnicity exists between patients and provider, providers may be more likely to display some type of bias during the encounter. The perceptions and assumptions that many providers possess about social or cultural norms can sometimes unintentionally affect their relationships with patients. As well, health care providers might intentionally tailor their behaviors to address any cultural variations in patients' expectations for the care that they receive. Both such intentional and unintentional behaviors by providers may be influenced by a number of social and cultural stereotypes (Van Ryn & Burke, 2000). A belief in certain stereotypes may affect how physicians interpret their patients' symptoms, how they predict what behaviors they think patients will display, and the type of medical decisions that physicians make (Schulman, Berlin, Harless, Kerner, Sistrunk, Gersh, Duber, Taleghani, Burke, Williams, Eisenberg, & Escarce, 1999).

As well differences in the race of patients and their providers may adversely affect the clinical encounter in another manner. Physicians may not stereotype or exhibit bias towards patients of a different race; however they may still experience less than optimal interactions. Physicians may not clearly comprehend their patients' ethnic and cultural models of disease or how these factors influence an individual's attributions of symptoms. Physicians may not always be aware of their patients' expectations regarding care. If providers do have certain expectations, these ideas may differ from that of their patients, and such discrepancies can then act as a barrier to effective communication and partnership-building efforts (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999).

Providers who are in race concordant relationships with patients, particularly African Americans, should recognize that the racial similarities that exist between the two parties can

help providers build strong partnerships with their patients. Racial concordance can help to increase a patient's involvement in the decision-making process regarding medical care. As well, such similarities may help to provide patients with a greater sense of trust, an outcome which can lead to patients experiencing greater levels of satisfaction. The end result for patients and providers in racially concordant relationships can be an improvement in the quality of the interpersonal communication that occurs between both parties. Although it is not reasonable to expect that all patients will always be in racially concordant relationships with their providers, during those instances in which both parties share a similar racial or ethnic heritage, it is important that providers recognize the benefits that can result from such concordant relationships.

IV. METHODOLOGY

The pilot study "Breast cancer knowledge and health literacy levels of African American women in Harlem, New York" was funded in part by Columbia University's Center for the Active Life of Minority Elders. The focus of this pilot grant was to assess the health literacy levels and breast cancer knowledge, attitudes, beliefs, and practices of a sample of urban senior African American women.

Although the primary focus of the pilot study was to assess health literacy and breast cancer-related variables, the study also examined the patient-provider communication experiences of participants. Several open-ended questions included in the interview were able to capture information about a number of topics including participants' health information needs, health communication experiences, and preferred sources of information. Participants were asked to recall their clinical encounter experiences and to specifically discuss their previous

experiences communicating with their providers. Individuals were able to discuss any factors that they deemed as either facilitators or barriers to effective communication with their physicians, nurses, or other health care professionals. Information about patient-provider communication was obtained via the use of a semi-structured interview. Responses to those questions that inquired about communication experiences were assessed and selected for analysis. As well, any other comments that addressed facilitators or barriers to effective communication were also selected for analysis. These comments were included even if they were in response to questions that did not specifically inquire about communication. For the purpose of this dissertation, a secondary analysis of the responses to these qualitative patient-provider communication questions was performed utilizing thematic analysis.

IV.A. STUDY RECRUITMENT

A recruitment site was secured at The Hamilton Grange Senior Center, located in Central Harlem. The center provides activities and two meals a day for community members who are age 60 and older. Special permission has also been granted to some individuals who are younger than 60 years of age to attend the center for meals and participate in daily activities. The center's catchment area includes 125th Street to 155th Street (from the Hudson River on the West to the Harlem River on the East). The center's Director estimated that approximately 175 to 200 seniors are served breakfast and lunch each week.

The Hamilton Grange Senior Center is located in the basement level of Convent Avenue Baptist Church. The Center's design includes one large open space that is filled with numerous tables. Those who attend the center sit at these tables all day while participating in activities or eating their meals. The Center's space also includes a kitchen and serving area and the offices of

the Director, an Activities Coordinator, and other support staff. In addition to these rooms, the Center has two locker rooms, a large room that is used for storage, and a small vacant office. While participant recruitment and screening occurred in the large open area, all interviews were conducted in the small vacant office in order to provide participants with privacy during their interviews.

During the course of the study, the center's Director provided the project interviewer with permission to post study flyers at the site. The Director also provided information about the study to attendees during his lunchtime announcements. The project interviewer, who was on-site three to four times a week, met with women and provided information about the purpose of the project. Interested individuals were then screened to determine eligibility. In order to participate, individuals had to meet seven specific criteria. The participants had to: (1) be female, (2) be age 50 and older, (3) be able to speak English, (4) be able to respond to a face-to-face interview without assistance, (5) be a Harlem resident, (6) identify as Black or of African descent (African, African American, Caribbean, etc.), and (7) have had no previous diagnosis of breast cancer. Women who met these criteria were informed that participation involved the completion of two short literacy assessments and an interview. They were also advised, before signing the study's consent form, that the time commitment was approximately one hour and thirty minutes to complete both assessments and the interview. During the consent process, women were informed that they did not have to complete the two literacy assessments if they were not comfortable and they could skip any questions on the semi-structured interview that they did not wish to answer. As well, all women were informed that they would receive a twenty-five dollar incentive upon completion of the assessments and the interview. Those who

chose to skip questions during the interview or who did not wish to complete one or both assessments were still provided with the full incentive amount.

The recruitment strategy for the study utilized convenience sampling, a method that provides an economically feasible strategy that can be utilized in research that is exploratory in nature. This nonprobability sampling strategy provided a sound approach without incurring expensive costs – in terms of finances and time – that may be associated with random sampling (Statpac). Since the project was a pilot study, convenience sampling provided a practical approach.

The study interviewer distributed flyers to center attendees. Attendees were approached by the interviewer and provided with information about the study. Individuals who expressed an interest in the study were quickly screened to determine their eligibility. Individuals who were deemed eligible either agreed to participate in the interview at that time or scheduled an interview at a later date if they were not available at that time. Because the interviewer was in attendance at the center on multiple days each week for several hours each day, she was often accessible to attendees of the center during several blocks of time throughout the week. This increased availability helped to make scheduling more convenient for the interview and the participant. Although several attendees were initially not interested in participation when first invited, many changed their minds and opted to participate. Often these individuals approached the interviewer and asked to participate despite the fact that they had initially refused participation. A few such women mentioned that they decided to participate because they became more open to the idea of participating after seeing the interviewer in the center so often. The women mentioned that they became more comfortable with the interviewer's regular presence at the center.

Once women who were deemed eligible decided to participate, they were invited into the private office that was provided by the center's Director. The interviewer provided information about the purpose of the pilot study and again informed each woman about the study's time commitment and incentives. If women were still interested in participation, they were asked to review and sign the study's consent form. In order to ensure that each woman understood the form, the interviewer read sections of the form out loud and then asked if the women had any questions. Once all questions were answered, the women were then asked to sign the consent form. Women were asked to complete two literacy assessments before completing the semi-structured interview. Participants were asked if the interviewer could record their interviews. Those who agreed to have the session recorded were asked to sign a consent form to allow recording. All participants except one woman granted permission to record the interviews. For those individuals who had consented to have their sessions taped, audio recording devices were turned on only after the completion of the two literacy assessments and before the commencement of the interview.

IV.B. STUDY INSTRUMENTS

The Rapid Estimate of Adult Literacy in Medicine (REALM)

The initial part of the interview session involved the completion of two validated literacy assessments. Participants were first asked to complete the Rapid Estimate of Adult Literacy in Medicine (REALM), a word recognition assessment that takes approximately three minutes to complete. To complete the REALM, participants were given a laminated sheet that contained 66 words. The participants were then asked to read the words out loud. The assessment is not timed; however if participants appear to have difficulty pronouncing a word, they should be

prompted to take a guess or given the option to skip the word. Participants received one point for each correctly pronounced word. Participants could earn between a minimum 0 points (no words were pronounced correctly) and to a maximum score of 66 points (all words were pronounced correctly). Final scores were then totaled and converted into a corresponding grade reading level. According to the assessment's scoring guidelines, final scores are equivalent to the following grade levels: 0 to 18 points (3rd grade and below reading level), 19 to 44 points (4th-6th grade reading level), 45 to 60 points (7th-8th grade reading level), and 61 to 66 points (high school reading level) (Davis, Long, Jackson, Mayeaux, George, Murphy, & Crouch, 1993).

The Short Test of Functional Health Literacy in Adults (STOFHLA)

Participants were then asked to complete the Short Test of Functional Health Literacy in Adults (STOFHLA), an assessment that employs a modified cloze procedure. Participants were asked to read passages in which every fifth to seventh word was omitted. Four multiple choice options were provided and the participant was asked to use the context of the words of the surrounding phrase to select one of the four multiple choice words to fill in each blank. According to the STOFHLA's instructions, participants should be instructed to select the one word that makes the sentence "make the most sense". The protocol for this assessment did not require that participants read out loud to the interviewer. The STOFHLA is used to measure one's ability to read and understand prose passages. The first passage is about patient preparation instructions for an upper gastrointestinal tract radiograph series, and the second passage includes an excerpt from a "Rights and Responsibilities" section of a Medicaid application. The STOFHLA is a shortened version of the original Test of Functional Health Literacy in Adults (TOFHLA), which assesses both reading comprehension and numeracy skills and takes 22 minutes to complete. Although participants are given 7 minutes to complete the

STOFHLA, instructions state that participants should not be informed that the assessment is timed. To score the assessment, participants receive one point for each correct response. All points are added, and the total is converted into a corresponding health literacy level. According to the assessment's scoring guidelines, final scores are assigned to one of three health literacy level categories: 0 to 16 points (inadequate health literacy), 17 to 22 points (marginal health literacy), and 23 to 36 points (adequate health literacy) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

The Semi-Structured Interview

After the completion of the literacy instruments, the semi-structured interview was conducted. At this point in the session the recorder was turned on if the participant provided written consent. The interview assessed the participant's breast cancer-related knowledge, attitude, beliefs, and practices. The interview assessed basic knowledge about breast cancer risk factors, screening recommendations, diagnosis, and treatment. The interview also inquired about participants' screening practices (mammography, clinical exam, self-exam) as well as attitudes about the effectiveness of screening. Demographic information collected included age, highest completed year of education, household income, nativity status, age of relocation to New York (for those born outside of the city), and preferred language. Data was also collected about participants' family history of cancer, access to health care, and communication experiences during medical encounters. Participants were asked about preferred sources of health information, medication use, and adherence to medication instructions.

For this exploratory study, the responses from specific open-ended questions about health communication featured in the semi-structured interview were transcribed and qualitatively analyzed. Only individuals' responses that focused specifically on participants' comprehension

of health information and communication experiences during clinical encounters were selected for analysis.

V. DATA ANALYSIS

Qualitative analysis was selected as the method of analysis because it is often the preferred approach when exploring a relatively new field of research. Qualitative methodologies can provide valuable insight into often misunderstood or complex aspects of an issue (Dorsey, Miller, Parrott, & Thompson, 2003). The use of a qualitative methodology can provide rich data that is often the basis of hypothesis generation for future research. Such an approach is preferred in instances when investigators need to conduct an in-depth exploration of one's feelings, experiences, and perceptions about a particular topic (Weiss, 1994). With regard to the current exploratory study, the use of a qualitative methodology provided participants with an opportunity to give detailed information about their medical experiences. Data from the first-hand accounts of participants provided insight into the perspectives of participants and the perspectives of other individuals (e.g., friends, family) they may know. The use of the women's first-hand accounts about the clinical encounter experience is of particular importance because research suggests that often patients and their physicians perceive aspects of the medical encounter differently. While providers may think that they are effectively communicating and meeting their patients' health care needs, patients may believe that providers are not putting their interests first. As a result of such discrepancies in perceptions, it is critical that both parties of the patient-provider dyad be able to gain a greater understanding of what the other party believes (Cegala, Gade, Lenzmeier, & McClure, 2004). Only with direct information from participants can researchers gain insight about any obstacles to clear communication during the clinical encounter. Such information can

then be utilized to address goals set forth in the Healthy People initiatives that focus on improving provider communication skills.

In addition to the qualitative analysis of factors that impact health communication, study findings included sociodemographic data, health literacy scores, and participants' preferred sources of health information.

V.A. THEMATIC ANALYSIS

Before any analyses were conducted, the transcripts for all study participants were reviewed in their entirety so that the study's coder could become thoroughly familiarized with the content of the transcripts. All interview responses for each study participant were reviewed repeatedly. After this step was completed, the data were sorted and all passages that were relevant for analysis were highlighted. Although the interviews collected data about a number of topics including breast cancer-related knowledge, attitudes, beliefs, and practices, all of the collected data were not included in the analysis. The initial readings of the transcripts in their entirety revealed that only responses to certain questions were relevant for analysis. The focus of the analysis was to examine those participant responses that pertained to patient-provider communication. Specifically, in order to address the aims of the study, an analysis was conducted of responses that mentioned or discussed factors that might impact the quality of communication between a patient and provider or factors that could influence the nature of the clinical encounter between these two parties.

For the purposes of this exploratory study, data collected from two specific open-ended questions that inquired about patient-provider communication experiences were the focus of analysis. Responses from these questions were transcribed and analyzed qualitatively.

Responses for the following questions were analyzed:

- 1) Do you ever have any problems talking to your physician or nurse during medical appointments? Do you ever have any problems understanding the health information provided when you are talking with your doctors or nurses? By health information, I mean medication instructions, information about medical procedures, etc.? If “yes” please tell me more about this.**
- 2) In general, have you ever had problems understanding or reading information provided to you in a medical setting? For this question, don’t just think about when you are talking directly to your doctor or nurse. Think about any problems that you have understanding any information in a hospital or clinic. This includes problems reading signs in the hospital, health brochures, treatment instructions, or completing hospital forms. If “yes”, please tell me more about this.**

In addition to those questions that specifically inquired about a participant’s perceptions about communication during the clinical encounter, any responses given by participants that mentioned factors that might impact patient-provider communication or influence the nature of the encounter between a patient and provider were also highlighted for inclusion in the analysis. If there were responses discovered that commented on communication – even if these responses were given as direct answers to questions that had not inquired about communication – then these responses were included for analysis.

This approach was utilized because as interviews were conducted, it was noted that several study participants discussed their communication experiences with providers in response to questions that had not specifically inquired about communication during their clinical encounter experiences. For instance, if a participant was asked a question that requested that she name risk factors for breast cancer, and her response included information about the difficulties she experienced talking with health care providers during medical appointments, the portion of this response that focused on the patient-provider communication experience was marked by the coder and selected for analysis. Such a response was selected for inclusion because it could

reveal a factor that could ultimately impact the quality of communication during the clinical encounter.

Once all relevant sections were highlighted for analysis, the selected responses for each participant were grouped together for further review so that a thematic analysis of data could be performed. The coder then performed several readings in order to review all selected responses. These relevant responses were grouped into a table and listed based on which respondent made the comment. The coder next began the process of reading all responses again in order to determine the existence of themes or general patterns in the data. With each reading of the data, the coder began to note which patterns occurred most often amongst all of the responses. At this point after repeated readings, the coder had become more familiar with the data.

According to findings from previously conducted literature, several factors have been suggested to impact the effectiveness of communication between the patient and the provider. Such findings suggest that a patient's health literacy level, culture, age, and gender can all impact communication within the patient-provider dyad in some manner. With regard to culture specifically, this concept can be comprised of several elements, but for the purposes of this research, aspects of an individual's culture that might impact health communication include: the use of complementary and alternative medicine, an individual's religious or spiritual beliefs, levels of trust in the health care provider and/or health care system as a whole, and an individual's racial concordance with his or her provider.

Based on findings from previous literature before any analyses were conducted, it was hypothesized that the following factors would be reported by study participants as those that often impact communication between patients and their providers:

- 1) Patient's Health Literacy**
- 2) Patient's Complementary and Alternative Medicine Use**

- 3) **Religion (Patient's Religious or Spiritual Beliefs)**
- 4) **Patient's Distrust**
- 5) **Racial Concordance Between a Patient and a Provider**
- 6) **Patient's Age**
- 7) **Patient's Gender**

A Review of the Raw Data

As a result of findings from previous research, the coder reviewed the raw information included in the tables and examined the data for the presence of the previously seven listed factors. As well, in addition to looking for mention of the previously listed seven factors, any responses that focused on other factors that could impact some aspect of patient-provider communication were also tagged for inclusion in data to be reviewed and analyzed.

In order to complete the next stage of the thematic analysis, it was necessary for the coder to thoroughly familiarize herself with the raw data for each study participant or unit of analysis. At the beginning of this stage, the coder reviewed and summarized all data for each study participant in order to reduce the available raw information. During this step of the process, the coder repeatedly reviewed data and then summarized it. The primary aim was for the coder to – both consciously and unconsciously – use these activities as methods to process the data. By reading and rereading each transcript, highlighting excerpts of the raw data and then creating an outline of highlighted passages for each study participant, the coder was able to successfully reduce the raw data. As well, this process was critical in that it further increased the coder's familiarity with the data by creating a comprehensive picture of all of the available raw data (Boyatzis, 1998).

The Identification of Themes

The next phase of the analysis included the identification of themes. Once the coder was thoroughly familiarized with the data, she began the preliminary process of looking for existing

themes or patterns within the data. At this stage it was not necessary to begin the interpretation process. Instead the coder was mainly tasked with the responsibility of reading the raw data in order to determine which themes were present.

Analysis of the data revealed the discovery of a number of themes. As suggested by the findings from previous research, the previously discussed seven factors that were discovered in literature reviews were also discovered in an examination of data. The following themes were discovered in the data:

- 1) Patient's Health Literacy**
- 2) Patient's Complementary and Alternative Medicine Use**
- 3) Religion**
- 4) Patient's Trust and Confidence in Health Care Professionals**
- 5) Race and Culture**
- 6) Age (Patient and Doctor)**
- 7) Gender (Patient and Doctor)**

One primary difference should be noted in the list of factors discovered in previous research and the patterns of data that emerged in this study's analysis. Although a review of findings from previous literature suggested that other factors such as "Racial concordance" can have an impact on the communication that occurs between a patient and provider, an examination of data collected for this study revealed that this factor was not reported by the women in this sample.

Although findings from prior studies suggest that racial concordance between a patient and provider can positively influence the nature of the exchange between these two parties, women in this study did not cite this as a factor that impacted their experiences during the clinical encounter. Instead participants mentioned that "Cultural" concordance (i.e., a shared culture between the patient and provider), more so than "Racial" concordance, can impact communication. With regard to race, participants did not report that it was important for a patient and provider to share the same racial or ethnic background. Instead with regard to race or

culture, the responses of these participants focused on describing the influence that one's race or culture might have on certain health-related attitudes, beliefs, and practices. Therefore, instead of utilizing the title "Racial concordance", the coder opted to utilize the theme title of "Race and Culture". Any responses that discussed "Cultural concordance" were included within the overall theme of "Race and Culture".

A repeated examination of the relevant participant responses revealed that certain topics or themes were mentioned by participants. In addition to those seven factors from the literature review that were hypothesized to impact the quality of patient-provider communication, a review of the data revealed the presence of a number of additional themes in participants' comments. Several trends emerged from the data. A list of these themes and a description of each is featured below.

- 1) **Doctor's age** – Participants commented about the age of their doctors and suggested that the doctor's age may help or hinder the communication that occurs during the clinical encounter
- 2) **Patient's age** – Participants commented about their own age and suggested that patient's age may in some way impact the nature of the clinical encounter experience.
- 3) **Health care professionals (HCPs) should use scare tactics to convey information to patients** – Participants suggested that a way to effectively convey health information to patients should include the use of some type of scare tactics.
- 4) **Doctor's provision of information** – Participants commented about whether (or how) doctors provided information during the encounter, and if so, the manner in which the information was provided.
- 5) **Other health care professionals (HCPs) may provide assistance to patients** – Participants commented about instances in which health care professionals (e.g. nurses, pharmacists, etc.) other than doctors, have provided some type of assistance with the comprehension of information during or after a clinical encounter.
- 6) **Doctor's provision of time** – Participants commented about whether or not a doctor provided adequate time during a clinical encounter.

- 7) **Doctor's busy schedule** – Participants commented about their doctors' heavy patient loads or stated that doctors are often too busy.
- 8) **Doctor's respect of patients** – Participants commented about whether or not their doctors displayed respect during the clinical encounter.
- 9) **Patients should feel comfortable during the clinical encounter** – Participants commented about instances when they have or have not felt comfortable during a clinical encounter.
- 10) **Doctor's ego** – Participants commented about their doctors' displays of egotistical behaviors during the clinical encounter.
- 11) **Doctor's need for control** – Participants commented that doctors may at times intentionally act in a manner that ensures that they have control over the patient or the clinical encounter.
- 12) **Doctor's demeanor** – Participants commented about some aspect of a doctor's personality or demeanor, and in some cases suggested that a doctor's demeanor may impact the nature of the clinical encounter.
- 13) **Doctor's gender** – Participants commented about a doctor's gender, and suggested that gender may help or hinder the communication that occurs between the patient and doctor during the clinical encounter.
- 14) **Patient's gender** - Participants commented about a patient's gender, and suggested that gender may help or hinder a patient's desire to seek care or impact the interaction that occurs between the patient and doctor.
- 15) **Doctor is unaware of patient's difficulty understanding information** – Participants suggested that doctors may not realize that some patients do not understand the information that is presented during a clinical encounter.
- 16) **Patient's demeanor, attitudes, and beliefs can influence their health care practices** – Participants commented about some aspect of their own demeanor, attitudes, or beliefs and suggested that these factors could impact the health care practices that they adopt and ultimately their clinical encounter experiences or their health outcomes.
- 17) **Health literacy** – Participants commented about difficulties that they experienced understanding health information provided by doctors during a clinical encounter or from other sources because of their limited education or some other factor that was associated with their own backgrounds.
- 18) **Patients experience difficulties understanding information** – Participants commented that for a variety of reasons - not just due to their own limited educations

- they have experienced difficulties understanding health information provided during a clinical encounter or from other sources.
- 19) **Patient's trust and confidence** – Participants commented about their trust or confidence (or lack of) in doctors or the overall health care system.
 - 20) **Patient's reluctance to seek care** – Participants commented about instances in which they were hesitant to seek care even when they needed to see a doctor.
 - 21) **Patient's fear** – Participants commented about the fear they experienced about receiving care or communicating with their doctors.
 - 22) **Patient feels intimidated** – Participants commented about intimidation that they may have experienced during a clinical encounter or during any other type of health care interaction.
 - 23) **Patient's difficulty remembering information** – Participants commented about instances when they experienced problems remembering information that was provided during the clinical encounter.
 - 24) **Religion and spirituality** – Participants commented about their religious or spiritual beliefs, attitudes, or practices.
 - 25) **Complementary and Alternative Medicine (CAM) use** – Participants commented about their use or knowledge of complementary and alternative medicines.
 - 26) **Race and culture** – Participants commented about their own (or their health care professionals') racial or cultural backgrounds and suggested that these factors could impact patients' health outcomes or the patient-provider interaction.
 - 27) **Patients will make efforts to review additional information** – Participants commented about the fact that they will make an effort to seek out and review health information if it is available.
 - 28) **Patients want more health information** – Participants commented about the fact that they would like to receive more health-related information from various sources.
 - 29) **Patients must advocate on behalf of others or have others advocate for them** - Participants reported that they have had to advocate for others who do not understand information provided during the clinical encounter or who need assistance with health-related matters. Participants commented about receiving assistance from others with health-related matters, including understanding health information.
 - 30) **Patient's compliance with medical recommendations** – Participants commented about whether or not they followed their doctors' medical recommendations.

While prior research findings have revealed that a patient's gender can often influence the quality of communication between a patient and provider, a review of the interview responses from this sample of women revealed that most participants did not report that a patient's gender was a factor that might affect patient-provider communication, either negatively or positively. As well, only one comment was made about the factor "Doctor's gender". Because very few participants commented about the factors of "Patient's gender" and "Doctor's gender", the theme was renamed "Gender" and included responses that made reference to both patient and provider gender. As well, because few responses were provided for each of the categories "Doctor's age" and "Patient's age", these two categories were combined under the general title "Age".

A review of the raw data revealed that numerous responses could be categorized under more than one theme. For instance, if a participant's response mentioned how egotistical some doctors are, and in the same comment also mentioned that doctors have hectic schedules, this comment was categorized as "Doctor's ego", "Doctor's busy schedule", and "Doctor's provision of time".

The Revision of Themes

All relevant responses that were selected for inclusion in the analysis were first organized according to participant. After a list of preliminary themes was drafted, the coder next re-grouped these responses based on different topics or theme categories. Although a review of the participants' responses revealed the presence of numerous themes in the raw data, upon further examination, the coder recognized that several of these themes appeared to overlap in meaning. As a result of the similarities between the themes, many of the theme categories were combined. A new list of combined themes with revised titles then emerged. The table below includes a list

of several themes that were grouped together because of their similarity in nature, and renamed as one theme. Additionally, because some categories contained so few participant responses (e.g., “Doctor’s Age” and “Patient’s Age”), these themes were combined under one category that was then renamed.

TABLE 1: REVISED THEMES

Grouped Themes	Revised title for combined themes
Doctor’s age	Age
Patient’s age	
Health care professionals (HCPs) should use scare tactics to convey information to patients	Doctor’s provision of information
Doctor’s provision of information	
Other Health Care Professionals (HCPs) may provide assistance to patients	
Doctor’s provision of time	Doctor’s provision of time
Doctor’s busy schedule	
Doctor’s respect of patients	Respect
Patients should feel comfortable during the clinical encounter	
Doctor’s ego	Doctor’s demeanor
Doctor’s need for control	
Doctor’s demeanor	
Doctor’s gender	Gender
Patient’s gender	
Doctor is unaware of patient’s difficulty understanding information	Doctor is unaware of patient’s difficulty understanding information
Patient’s demeanor, attitudes, and beliefs can influence their health practices	Patient’s demeanor, attitudes, and beliefs

Health literacy	Patient's comprehension of information
Patients experience difficulties understanding information	
Patient's trust and confidence	Patient's trust and confidence
Patient's reluctance to seek care	Patient's reluctance to seek care
Patient's fear	
Patient feels intimidated	
Patient's difficulty remembering information	Patient's difficulty remembering information
Religion and spirituality	Religion and spirituality
Complementary and Alternative Medicine (CAM) use	Complementary and Alternative Medicine (CAM) use
Race and culture	Race and culture
Patients will make efforts to review additional information	Patient's use of additional information
Patients want more health information	
Patients must advocate on behalf of others or have others advocate for them	Advocacy during the clinical encounter
Patient's compliance with medical recommendations	Patient's compliance with medical recommendations

An analysis of data determined that a few themes that emerged in a review of the data were not always specifically mentioned as those that would either impede or facilitate effective communication between patient and clinician. These themes include: (1) Patient's use of additional information, (2) Advocacy during the clinical encounter, and (3) Patient's compliance with medical recommendations. These themes will not be explored at length. However, because many participants mentioned these topics during their responses they will be discussed briefly.

These topics will be included as those that health care providers need to take into consideration when developing the best strategies for clear communication in order to provide effective care for patients.

Once the preliminary themes were discovered, the coder then returned to a review of the data and again searched for the presence of themes. This step involved editing, rewriting and the reconstruction of the statements that comprised the initial themes. At this point, the coder began to include, along with the revised themes, statements about what types of information should be excluded. That is, the revised themes included rules that would be used by the coder when applying the themes to the raw data. These rules were used as an indication of what pieces of information the coder could or could not include as a part of a theme. This step of determining qualifications or exclusions for identifying themes is a key step in the code development process – the process used to identify the presence of themes in the data. For instance, an example of a statement of qualification or inclusion could be “Code this theme as present if the study participant reports that she personally has experienced this event. A participant’s description of the event happening to other individuals or groups should also be considered and should be coded.” The next step in the analysis included the development of a code based on the researcher’s theory.

V.B. THE CREATION OF THE CODE

Once the themes were drafted and revised, the next step involved the creation of a code. At this point, the code should be reviewed and rewritten so that it can then be applied to the available raw data. According to Boyatzis, the creation of a good code is critical when conducting thematic analysis. A quality code will be one that is comprised of five elements:

1. *A label (i.e., a name)*
2. *A definition of when the theme concerns (i.e., the characteristics or issue constituting the theme)*
3. *A description of how to know when the theme occurs (i.e., indicators on how to “flag” the theme)*
4. *A description of any qualifications or exclusions to the identification of the theme*
5. *Examples, both positive and negative, to eliminate possible confusion when looking for the theme (Boyatzis, 1998)²⁹⁴.*

Codes were constructed based on the revised list of themes. As codes were constructed, it was noted that when determining the presence or absence of a theme, the definition of the theme had to be revised. For many participant responses, often a participant reported about a personal experience. However, participants also reported about the experiences of other individuals (e.g. family members, friends, etc.) when responding to questions. In these situations, despite the fact that the participant did not report a personal experience, the response was still considered as relevant during the review of the raw information. Although these responses did not discuss the participants’ personal experiences, the responses provided important information about the health-related perceptions and experiences of other individuals. For example, if a participant reported that she has never had problems understanding information during a medical appointment, yet her sibling always experiences problems because doctors use language that is too difficult for the sibling to understand, this response would be included for analysis.

As a result of this revision in the definition of themes, the codes were revised to include participants’ responses about their personal experiences as well as the experiences of other individuals. Additionally, because study participants often reported about experiences with nurses, pharmacists, and other types of health care professionals, as well as experiences with doctors, at times the definitions for the codes might include the use of general, more encompassing terms such as “health care professional” or “health care provider” (HCP).

Employing Boyatzis’ definition of what five elements constitute a quality code, several codes were constructed based on reviews of the raw data. A description of each of the five elements that comprise each code is included in the Appendix. The resulting list of labels for each code is featured below:

- 1) Age
- 2) Doctor’s Provision of Information
- 3) Doctor’s Provision of Time
- 4) Respect
- 5) Doctor’s Demeanor
- 6) Gender
- 7) Doctor is unaware of patient’s difficulty understanding information
- 8) Patient’s demeanor, attitudes, and beliefs
- 9) Patient’s comprehension of information
- 10) Patient’s trust and confidence
- 11) Patient’s reluctance to seek care
- 12) Religion and spirituality
- 13) Complementary and Alternative Medicine Use
- 14) Race and Culture
- 15) Patient’s Difficulty Remembering Information

VI. RESULTS

TABLE 2: STUDY PARTICIPANT AGE DISTRIBUTION

AGE RANGE	PERCENT OF STUDY PARTICIPANTS
50 – 59	31%
60 – 69	28%
70 – 79	31%
80 – 89	6%
91 – older	4%

VI.A. RACE & AGE

One hundred women participated in the pilot study interviews. The minimum age requirement for participation was 50 years old. The average age of the study sample was 65.64

years old. With regards to the study sample’s breakdown by age categories, 31% of the participants were between 50 and 59 years old. Twenty-eight percent were between the ages of 60 and 69, while an additional 31% were aged 70 to 79 years old. Another eligibility criterion for study participation was racial self-identification as “Black” or “of African descent”. As a result of this criterion, all participants were Black. However, all of the participants did not identify as “African American” specifically. Of the one hundred participants, 3 women identified as both “Black” and “Latina”. As well, 8% of participants identified as either “West Indian” or “Caribbean”, and 2% identified as “Other”. Women who selected “Other” identified as both “Black” and another race (e.g., White, Native American).

TABLE 3: MARITAL STATUS AND HOUSEHOLD COMPOSITION

MARITAL STATUS		
	Single / Never Married	28%
	Married / Living with Spouse or Partner	17%
	Divorced / Separated	24%
	Widowed	31%
HAVE CHILDREN		
	Yes	69%
	No	31%
HOUSEHOLD COMPOSITION		
	Nuclear (Father, Mother, Children)	5%
	Extended (Nuclear w/ Friends and Relatives)	2%
	Woman and Children	15%
	Woman and Children Extended	4%
	Alone	49%
	Woman and Spouse (Partner)	11%
	Other	14%

VI.B. MARITAL STATUS & HOUSEHOLD COMPOSITION

An additional criterion for participation included a residence requirement. Since one aim of the original pilot study was to examine the breast cancer-related knowledge, attitudes, beliefs, and practices of Harlem residents, all participants were required to reside in the geographical area of Harlem, New York at the time of their interviews. A review of data collected about birthplaces revealed that even though all participants were residents of Harlem, many of the participants were not born in Harlem or even in the state of New York. Forty-four percent of the participants were born in states throughout the South.

Collected study data provided key information about factors such as marital status, educational attainment, and employment status of individuals within the study's sample. With regard to marital status, 28% of women in the sample were single, 17% reported that they were either married or living with a partner, 24% identified themselves as divorced or separated, and the majority (31%) reported that their spouses were deceased. Information about marital status was important, but data collected about participants' household composition was also valuable. This data provided information about the potential support systems of each participant. For instance, a participant's reported marital status of "single" might suggest that the participant lives alone or does not have receive a lot of assistance within the home with basic chores or activities of daily living (e.g., eating, bathing, dressing etc.). However, additional information about household composition may disprove this assumption. That is, a participant who is "single" may not necessarily live alone. This individual may live in a home with children, siblings, other extended family members, or roommates. The members of the household may provide assistance to the participant with regards to the administration of medication, comprehension of

medical information, and other tasks that are essential to complete in order to address an individual’s health care needs.

Sixty-nine percent of the sample reported that they have children. Almost half of individuals in the sample (49%) reported that they live alone, while 15% reside with children, 11% with a spouse or partner, and 5% reported that their household consists of a nuclear family structure. These individuals reside with a spouse or partner and children. Two percent reported that they live with other family members (e.g., siblings, parents, etc.) and 4% indicated that they live both with their children and other relatives (but not with a spouse or partner). Fourteen percent of participants also indicated that their household composition was classified as “other”. These participants reported that they reside with siblings, roommates, or rent rooms to boarders.

TABLE 4: EDUCATION AND EMPLOYMENT STATUS

EMPLOYED		
	Yes	22%
	No	78%
EMPLOYMENT STATUS		
	Part-time	10%
	Full-time	12%
EDUCATION		
	Did Not Complete High School	29%
	High School or GED	31%
	Vocational Certificate	7%
	Some College	17%
	Bachelor’s Degree	9%
	Master’s Degree	3%
	Other	4%

VI.C. EDUCATION

The average number of years of education completed was 12.38 years. Seventy-one women reported that they had completed at least the twelfth grade. Seventeen percent of

participants had completed some college courses, 9% of the sample reported earning a Bachelor's degree while another 3% reported that they had earned a Master's degree. Since almost three quarters of the sample had completed at least twelve years of education, one might assume that comprehension of health-related information would not present a problem for the participants in the study.

VI.D. EMPLOYMENT STATUS

An assessment of employment status revealed that just 22% of participants reported that they were employed in some capacity, either in a part- or full-time position, at the time of the interview. Seventy-eight percent of women were not employed. Despite the fact that the average age of the sample was 65.64 years old, many of the women who were not working did not consider themselves to be retired. In fact, 31% of participants who were not working reported that they wished to return to work but they were unable to for various reasons (e.g., the inability to secure employment, presence of a health condition, etc.) they were unable.

Women reported current employment in the fields of maintenance and housekeeping, home healthcare, childcare, education, and clerical work. Specific examples of positions that were reported included: assistant teachers, babysitters, cashier, administrative assistants, housekeeping, home health care, telephone technicians, and transportation dispatchers. Although the types of reported positions did not vary extensively, the lifetime positions reported by participants were rather diverse. Women reported that the work that they regarded as their "career positions" or "lifetime" employment was often different than the types of current positions that they held. Examples of career positions that were reported included: accountants, beauticians, biologists, business managers, data entry workers, factory workers, food service

workers, stenographers, EKG and X-ray technicians, home health care aides, nurses, housekeepers, and administrative assistants.

VI.E. INSURANCE STATUS & ACCESS TO CARE

In an effort to obtain some insight about access to care, participants were asked to provide information about enrollment in insurance plans. Ninety-one percent of the sample reported that they have some type of health insurance. Sixteen percent stated that they have private insurance. Another 24% of respondents reported that they are enrolled in Medicaid, while 35% reported enrollment in Medicare. Sixteen percent of women selected “Other” as their type of insurance. Those in this category included women who may belong to some type of subsidized program at specific hospitals. Although these findings indicated that the majority of women in the sample are enrolled in some type of insurance and therefore have access to care, the fact that women have insurance is not an indication of whether or not they utilize insurance and actually seek medical care when necessary.

Another question that addressed access to care inquired about whether or not participants currently have a regular doctor. One finding revealed that an overwhelming majority of the women in the sample (85%) reported that they have a regular physician. This finding is of particular importance because previous research has suggested that many U.S. adults may not have a regular primary care physician and instead rely on the use of emergency rooms as a source of care. Despite this finding, it is still important to note that participants’ access to a regular physician is not necessarily an indication that they will actually seek out care. Though women have regular providers, a number of factors may still deter or prevent them from seeking care.

VI.F. INCOME

The average reported annual income for study participants was \$20,248.00. Participants provided an estimate of all income sources that they received (e.g., Social Security, pensions, full or part-time employment etc.). Women not only provided information about their average income, but they also indicated the number of people who were supported by this reported income. The average number of individuals who were supported by the average annual income was 1.83 individuals. When asked if they would be able to rely on other family members for financial support if necessary (such as during an emergency situation), 61% of the women indicated that they would not be able to rely on others “at all”, 14% reported that they would be able to rely on others “slightly”, and 25% selected the response “very little”.

VI.G. HEALTH LITERACY ASSESSMENTS

In order to assess the health literacy levels of the study sample, each participant was asked to complete two assessments, the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Short Test of Functional Health Literacy in Adults (STOFHLA). The REALM is a word recognition tool that provides a relatively quick assessment of one’s health literacy level. The STOFHLA, which requires more time to complete, offers a means of assessing reading comprehension.

Rapid Estimate of Adult Literacy in Medicine (REALM)

One hundred participants completed the REALM. Participants received one point for each correctly pronounced word. A score of 0 indicated that the participant did not pronounce any words correctly while a maximum score of 66 indicated that all words were pronounced correctly. The scoring guidelines for this assessment indicated that the final scores should be

assigned to one of four categories. According to the assessment's scoring guidelines, each category of scores is equivalent to a certain grade's reading level. Individuals who score between 0 and 18 points have a reading level that is equivalent to 3rd grade or below. Those whose scores fall within this range will experience great difficulty reading materials that are written at the easiest level. These individuals may have to rely on verbal information that is delivered repeatedly, illustrations, and visual or auditory sources (e.g., videos, audio recordings) of information in order to understand. Those who score between 19 and 44 points typically read at a fourth to sixth grade level. Individuals scoring within this range typically rely on sources of information that are written for an audience with low literacy levels. Individuals who score between 45 and 60 points read at a seventh to eighth grade level. These individuals tend to struggle with most educational materials that are available to patients. Finally, those who score between 61 and 66 points on the assessment are categorized as having a reading level that is equivalent to high school. Individuals who score within this range are able to read most patient educational materials without great difficulty (Davis, Long, Jackson, Mayeaux, George, Murphy, & Crouch, 1993).

**TABLE 5: RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE
(REALM) SCORES (n=100)**

PARTICIPANT RESULTS PER CATEGORY	RAW SCORE FOR REALM	EQUIVALENT READING LEVEL	LITERACY SKILLS BASED ON GRADE LEVEL
2 %	0-18 points	3 rd grade and below	<ul style="list-style-type: none"> ▪ Unable to read most materials written for low literacy levels ▪ Comfortable with materials that use illustrations or information presented using audiotapes or videotapes ▪ May need to have repeated verbal instructions
11%	19-44 points	4 th to 6 th grade	<ul style="list-style-type: none"> ▪ Will need to utilize materials written for low literacy levels ▪ May experience difficulty reading certain types of information including labels on prescription bottles
36%	45-60 points	7 th to 8 th grade	<ul style="list-style-type: none"> ▪ May experience difficulty with most types of educational materials provided for patients ▪ Will feel comfortable utilizing materials written for low literacy levels
51%	61-66 points	High School	<ul style="list-style-type: none"> ▪ Will not experience difficulty reading most educational materials that are available (Davis, Long, Jackson, Mayeaux, George, Murphy, Crouch, 1993)

Of a total maximum score of 66 points that could be earned, the average score for the study sample was 56.19 points. Participants' scores ranged from 10 to 66 points. Assessment results indicated that just 2% of participants scored within the 3rd grade and below category (0-18 points). As well, 11% scored within the 4th to 6th grade category (19-44 points), 36% scored within the range of 7th to 8th grade (45-60 points), and 51% of the sample scored within the high school category (61-66 points). A review of the REALM's scoring guidelines revealed that the average score of 56.19 is equivalent to a 7th to 8th grade reading level. This category describes

individuals who will likely struggle with the majority of patient educational resources that are available. Those who score within this range may encounter some difficulty understanding many available materials and as a result, they will likely not be offended by materials that are prepared using terminology that is geared towards individuals who have lower literacy levels.

Short Test of Functional Health Literacy in Adults (STOFHLA)

Ninety-eight participants completed the STOFHLA. All participants completed the REALM, yet two participants did not elect to complete the STOFHLA. Although the participants did not provide an explanation for why they did not want to complete the assessment, their reasons may have included the fact that the STOFHLA takes longer to complete and the participants did not want to take the time to complete the assessment. Because the assessment required that individuals read passages and select responses to fill in the blank, the assessment may have had the appearance of a test. This may have discouraged the two women from participating. Women may also have believed that they would not be able to select the correct responses, and they did not want to reveal this to the study interviewer so they refused to complete the assessment. Scores for this assessment can range from 0 points (no correct responses) to a maximum of 36 points (all responses were correct). Scoring guidelines for the STOFHLA reveal that the final scores are grouped into one of three categories: 0 to 16 points (an indication of inadequate health literacy), 17 to 22 points (marginal health literacy), and 23 to 36 points (adequate health literacy).

Those categorized as having inadequate health literacy levels may experience some degree of difficulty when trying to read the simplest of health-related information such as that included on prescription labels or reminder slips for medical appointments. A classification of marginal health literacy indicates an ability to perform very simple tasks without much difficulty.

However individuals who are categorized as having marginal health literacy do experience problems when comprehending more complicated health information such as that included in brochures or instructions about certain medical procedures. Lastly, those categorized as having “adequate” health literacy typically do not experience great difficulty understanding most health information. These individuals can complete most health-related tasks without problem (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

TABLE 6: SHORT TEST OF FUNCTIONAL HEALTH LITERACY IN ADULTS (STOFHLA) SCORES (n=98)

PARTICIPANT RESULTS PER CATEGORY	RAW SCORE FOR STOFHLA	HEALTH LITERACY LEVEL	SKILLS BASED ON HEALTH LITERACY LEVEL
17.4%	0-16 points	Inadequate Health Literacy	<ul style="list-style-type: none"> ▪ Likely to misread even the simplest of health-related materials (e.g., information on medication bottle labels)
12.2%	17-22 points	Marginal Health Literacy	<ul style="list-style-type: none"> ▪ Able to read the simplest of health-related materials without problem ▪ Likely to experience difficulty reading more complicated health-related materials (e.g., brochures, instructions for medical procedure preparation, etc.)
70.4%	23-36 points	Adequate Health Literacy	<ul style="list-style-type: none"> ▪ Able to complete most of the general tasks needed in order to successfully navigate the health care system (Baker, Williams, Parker, Gazmararian, & Nurss, 1999)

Of a total of 36 points that could be earned, the average score for the study sample was 26.22 points. Participants’ scores for this assessment ranged from 1 to 36 points. Assessment findings indicated that 17.4% of participants scored within the inadequate health literacy range (0-16 points). As well, 12.2% scored within the marginal health literacy range (17-22 points), and 70.4% scored within the adequate health literacy range (23-36 points). According to the scoring guidelines, a mean score of 26.22 indicates marginal health literacy. This categorization describes individuals who would likely experience problems understanding health information

that may be regarded as somewhat complicated (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

Comprehension of Health Information

A qualitative analysis of data revealed the presence of several key trends. This analysis yielded findings that can be utilized by health care professionals to help guide the provision of health information for patients. Such data will be presented as a part of the results of the thematic analysis. In addition to these findings, responses to a number of questions asked during the interview also provided critical information that can offer health care professionals greater insight about the types of difficulties that patients experience when trying to comprehend health-related information and communicate with their providers. Participant responses also offered information about which types of approaches may prove most effective for health care professionals when providing information during clinical encounters. While collected data helped to provide reasons why participants may experience difficulty comprehending information in various types of healthcare scenarios, the data also provided information about which factors likely did not hinder communication for the women in this sample.

Although findings from health literacy research have provided evidence to support the assertion that language often acts as a major impediment to the comprehension of health information for patients, for this study language did not likely impact the participants' abilities to understand. Just 5% of the women in the sample reported that they speak a language other than English. Women who indicated that they were bi- or trilingual reported that they also spoke Spanish, Portuguese, or French. Because all of the women in the study had a strong grasp of English, it appeared that an inability to clearly understand English would not impact comprehension for women in this sample. This finding is especially relevant to health literacy

and patient-provider communication because women in this sample who reported that they experienced some degree of difficulty when communicating with their providers did not attribute this difficulty to the fact that they had any difficulty understanding English.

Study participants admitted that they had experienced varying degrees of difficulty understanding information provided to them because of problems comprehending certain words. This difficulty was illustrated by participants' responses to certain questions asked during the interview sessions. When asked the question "*Do you ever have problems understanding health information because you do not know what certain words mean? That is, are words used in hospitals or any types of health information ever too hard for you to understand?*", 61% of participants responded "yes". When asked to elaborate on their responses, for these participants, the reported difficulties were linked specifically to the use of complex medical terminology used during clinical encounters or during the course of their visits to health care facilities.

Fifty-six percent of study participants reported that they have generally experienced problems comprehending health-related information for a variety of reasons. Several women discussed instances in which they have experienced great difficulty trying to understand the instructions for medications. An additional complaint offered by study participants was that physicians often speak too quickly during the clinical encounter and as a result, participants are unable to clearly understand some of the information that has been provided. Several of the women revealed that they had to make specific requests during medical appointments that their physicians use "plain English" when discussing any types of health-related issues. For these women, the use of complex terminology posed a significant problem.

Participants were asked to rank the general degree of difficulty that they experienced when communicating during their clinical encounters. Although many participants reported

problems with the comprehension of information, findings suggested that this difficulty may not have impacted the participants' abilities to communicate. When asked about difficulty communicating with providers, seventy-two percent of participants replied that it is "not at all" difficult to communicate with their health care providers. However, 28% of participants reported that they had experienced some degree of difficulty when communicating with providers. These individuals selected either "slightly" (11%), "moderately" (8%), or "quite a bit" (9%) as the degree of difficulty that they experienced when communicating with their doctors or nurses.

Study findings also indicated that despite problems with communication, participants felt that they received explanations about information from their providers. Seventy-eight percent of participants stated that their providers usually took time to provide explanations. The fact that many providers make an effort to provide explanations certainly benefits patients who experience difficulty comprehending information. An even more important discovery was that 92% of women revealed that they ask physicians questions when they do not understand. This finding was of particular importance for this sample of women, many of whom reported that they have experienced problems comprehending information. The fact that the vast majority of women revealed that they will take the initiative and ask physicians questions in order to better understand is critical for investigators to know. This finding revealed that women in the study will take the necessary steps to ensure that their health information needs are met. If providers are aware of this, they can make certain to tailor their medical appointments to take advantage of participants' practices of asking questions. Providers can make certain to offer a designated amount of time to all patients so that they can ask questions.

VI.H. MEDICATION USE

Participants were also questioned about their medication use. Although responses suggested that the study participants experienced difficulty understanding some information, findings did not suggest that the majority of participants experienced problems understanding medication-related information. Data revealed that 74% of participants reported that they were using some type of medication. For those individuals who reported medication use, almost two-thirds of these individuals (69%) indicated that they were generally able to understand the instructions for taking their medications.

Many study participants reported that they regularly seek out assistance from a number of sources during those instances when they are unable to comprehend the instructions for taking their medications. Fifty-eight percent of participants reported that they have asked either a nurse or doctor questions when they did not understand medication directions. Forty-eight percent of participants have asked other individuals (e.g., pharmacists, family members, friends, etc.) for assistance while another 46% reported that they have tried to understand instructions by conducting their own research. Such efforts included searching for information on the Internet, in medical dictionaries, or in sources such as the “Physician’s Desk Reference”. One finding that was rather troubling was that almost one fourth (23%) of those in the sample who utilized medications admitted that although there have been instances in which they did not understand medication instructions, they made no efforts to ask someone for assistance or search for information in order to understand how to correctly take their medications. These individuals simply took their medications and hoped that they were following the proper instructions.

Collected data about medication utilization helped to reiterate the need for health care professionals to provide medication instructions in a clear manner for all patients. Participants’

reports that they did not always seek assistance even when they were fully aware that they did not understand instructions indicated the critical need for patients to have access to comprehensible information about their medications. The finding that 75% of individuals reported that they take medications on their own, without the assistance of family members or home health aides, also helped to reiterate this need for clear information because participants may not be able to rely on the help of others when deciphering the instructions for their medications. It is imperative that patients possess a thorough understanding of how to properly take their medications, especially since findings from this study suggested that it is possible that many women may not be able to receive assistance with the administration of their medications on a daily basis.

The problems that many participants experienced taking their medications were not always associated with the comprehension of instructions. Participants occasionally skipped their medications because they either forgot to take them or they did not have their medications. Participants indicated that they did not have their medications at times because they forgot to refill prescriptions, could not afford refills, or because they may have unexpectedly stayed away from home overnight and did not have their medications on hand with them.

VI.I. PREFERRED SOURCES OF INFORMATION

**TABLE 7: PARTICIPANTS' PREFERRED SOURCES OF HEALTH INFORMATION
(n=100)**

SOURCE OF INFORMATION	YES
NO	
DOCTOR 20%	80%
TELEVISION 15%	85%
RADIO 77%	23%
PEOPLE (FAMILY, FRIENDS, ETC.) 21%	79%
MAGAZINES 13%	87%
NEWSPAPERS 31%	69%
PUBLIC TRANSPORTATION 47%	53%
COMPUTERS 89%	11%
OTHER SOURCES 49%	51%

VI.I.1. Television Programs

Data was collected about participants' preferred sources of health information. An analysis of collected data provided critical information about the health information needs of participants. Such information can prove valuable for health care professionals who are greatly interested in determining the most effective manner to in which to convey information to patients as well as the sources of information preferred by older urban African American women.

As expected, an often reported source of health information was the participant's physician. An overwhelming majority (80%) of participants reported that they usually obtained health information from their doctors. Aside from doctors, many of the women interviewed also

reported that they have utilized additional sources in order to satisfy their information seeking needs.

Eighty-five percent of study participants reported that they have relied on television as a source of health information. Women who reported that they utilize this medium also indicated the types of programs that often served as a source of health information. Eighty-one percent of women have obtained health information from TV news programs, 70% from various talk shows, and 43% reported that they have utilized “other types” of programming for health information. Specifically, examples of “other types” of reported programming included news magazine programs such as “60 Minutes”, “Dateline”, and “20/20”. Other participants reported a preference for TV shows or networks that often present shows with a health-related focus including CNN (Dr. Sanjay Gupta’s show), the Discovery Channel, Lifetime, and PBS.

Study participants also indicated that they have used other types of TV programming as a means of obtaining information. Women reported that they have learned from watching fictional dramas that contained health-related storylines (e.g., if a character in a TV show is diagnosed with cancer), shows that focused on nutrition-related topics, and documentaries. A few of the women indicated that they have also learned about topics by watching programs about celebrities. For example, a few women talked about the information that they were able to learn about lung cancer by watching a program about the life of Dana Reeve, the wife of actor Christopher Reeve, who had succumbed to the disease.

VI.I.2. Television Commercials

Sixty-three percent of those who reported TV as a source of information indicated that they obtained health information from television commercials. Participants offered a number of examples including commercials by sponsors such as: AARP, the American Cancer Society,

Medicare, and various pharmaceutical companies. Although some participants were unable to actually provide the names of the organizations or companies that sponsored commercials that they have seen, these women were able to recall the subject matter addressed in the commercials. Examples of commercial topics mentioned included those that focused on breast cancer, arthritis, diabetes, osteoporosis, menopause, smoking, and gastroesophageal reflux disease.

VI.I.3. Radio Programs

Forty-seven percent of respondents indicated that they used radio as a source of health information. Specifically, of those who have utilized radio, 41% obtained information from radio news programs, and 23% gained information from radio commercials. Participants offered examples of programs that provided information including those that featured weekly shows about health-related topics such as holistic care options. Some participants mentioned that many of the religious-based stations often included health-related programming for their audiences.

VI.I.4. Family and Friends

When study participants were asked about individuals who have provided health information, the women revealed that they sought information from several sources, in addition to their physicians. Seventy-nine percent of women reported that they often turned to other individuals for assistance. Sixty-three percent of participants have requested information from family members (primarily siblings and children) and 77% reported that they have asked friends for information.

VI.I.5. Magazines

Many study participants indicated that they rely on various types of written sources for their health-related information. Eighty-seven percent of those in the sample reported that they have utilized articles in magazines for this purpose. Several of the magazines most frequently

cited included those that focus on addressing news stories that are of specific interest to members of the African American community. Examples of such magazines include: “Ebony”, “Jet”, “Essence”, and “Body & Soul”. Participants also mentioned that they have obtained information from other magazines including: “O (Oprah) Magazine”, “AARP Magazine”, “Fitness”, “Newsweek”, “New York Times Magazine”, “Prevention”, “People Magazine”, “Self”, and “Women’s Health”. In addition to these periodicals, a few participants also mentioned that they read religious-based literature such as “Awake” and “Watchtower” (magazines distributed by Jehovah’s Witnesses) for health information. A few participants reported that they have obtained information from academic medical journals. Study participants also indicated that they have obtained information about a multitude of topics from magazines including information about diabetes, cancer, and holistic medicine.

One surprising finding was that more of the study participants reported that they obtain health-related information from magazines and television than from their doctors. Such a finding is important for health care providers to consider because physicians who wish to relay information to patients need to realize that the use of television programming and magazines or approaches that use similar formats (e.g., videos and booklets with a magazine-like format) may present the most effective means of conveying information.

VI.I.6. Newspapers

Sixty-nine percent of participants utilized newspapers regularly as a source of health information. Participants provided examples of newspapers that they have used as sources including: “The New York Times”, “The New York Daily News”, “The New York Post”, and “USA Today”. Several participants also mentioned local free neighborhood papers that were available in the community such as “The Amsterdam Weekly”.

VI.I.7. Public Transportation Advertisements

Study participants reported that they have obtained health-related information from advertisements featured on various modes of public transportation including buses and subways. Women provided examples of such advertisements including those that focused on diabetes, nutrition, cancer, hypertension, smoking, the importance of preventive care, and stroke and HIV/AIDS prevention.

VI.I.8. Computers

Although participants reported the use of various sources for health information, one that was not utilized as often for this sample was the Internet. Less than a third (18%) of respondents reported that they used computers regularly. Only 11% of these respondents reported that they seek out health-related information from the Internet. Of the 11%, only a few individuals reported that they used specific search engines such as Ask.com, Google, or Yahoo to search for terms when they needed information. Participants also mentioned that they have utilized websites such as WebMD and DrWeil.com. The WebMd.com website provides a source of credible and timely information about a vast array of health subjects (WebMD website). DrWeil.com is the site of physician Dr. Andrew Weil. The site provides information about the principles of integrative medicine and offers alternative approaches to care that emphasize the mind, body, and spirit (Andrew Weil MD website).

VI.I.9. Other Sources of Health Information

Participants also reported a number of other sources that they did not mention during responses to previous questions. In addition to magazines and newspapers, women reported that they utilized other written sources of information such as brochures, leaflets, and medical reference books. The women obtained these resources from a variety of places including health

food stores, health fairs, church events, neighborhood seminars, and libraries. When discussing specific individuals who tended to provide information, in addition to family, participants often received information from members of their churches, community groups, senior centers, and exercise classes (e.g., yoga, swimming, etc.). Additionally, one participant disclosed that she obtained a great amount of health information from movie storylines. As with the source of TV that was reported by other women, for this woman the information presented in movie storylines often helped to increase her awareness of specific health topics (e.g., breast cancer).

VII. STUDY FINDINGS: THEMATIC ANALYSIS

In addition to the analysis of the data captured in participants' responses about health information needs, information seeking practices, and experiences during the clinical encounter, a thematic analysis was also conducted. This qualitative analysis of participants' responses to specific questions was conducted in order to assess the quality of communication between the participant and her provider. Responses to selected questions that assessed patient-provider communication experiences were reviewed as well as any responses that examined patient-provider interactions. A description of the thematic analysis process is included in the methodology section. Included in this description is a discussion about the code creation process.

Findings from the thematic analysis revealed the presence of several themes that were discovered within the responses of the study participants. Each of these themes was selected because according to participants in the sample they have, in various ways, impacted the quality of communication that occurs in general between patients and providers. As well, participants' responses suggested that these themes were integral in impacting the nature of the patient-

provider interaction during clinical encounters of those in the sample. Several themes were discovered during the thematic analysis. Each of these themes will be discussed at length. The list of themes included:

- 1) Doctor's Provision of Information
- 2) Doctor's Provision of Time
- 3) Doctor is unaware of patient's difficulty understanding information
- 4) Doctor's Demeanor
- 5) Patient's demeanor, attitudes, and beliefs
- 6) Patient's comprehension of information
- 7) Patient's trust and confidence
- 8) Patient's reluctance to seek care
- 9) Patient's difficulty remembering information
- 10) Respect
- 11) Religion and spirituality
- 12) Complementary and Alternative Medicine (CAM) Use
- 13) Race and Culture
- 14) Age
- 15) Gender
- 16) Patient's use of additional information
- 17) Advocacy during the clinical encounter
- 18) Patient's compliance with medical recommendations

VII.A. THEME: PATIENT'S TRUST AND CONFIDENCE

The theme of trust was mentioned by several study participants. A number of study participants commented about their lack of trust in their health care providers and the health care system as a whole. Not only did participants comment about their levels of trust in their doctors' medical knowledge, but they also discussed their trust in providers' technical abilities. One participant commented on her own lack of trust in her doctor's abilities when discussing whether or not her doctor or nurse provided time to explain health-related information.

“Yes [the doctors provide time to explain information], but I don’t place that much confidence in them though. (1026)”

When asked if her doctor provided adequate information, another participant replied,

“No [the doctor does not provide adequate information]. I don’t trust him, my primary care doctor. (1046)”

What is most interesting about these comments is that neither of the women was directly asked about their levels of trust in their providers. They were asked about their doctors’ provision of time or information but gave unsolicited comments about their levels of trust instead. Such findings are not unexpected because the results of prior research support findings that suggest that many African Americans possess low levels of trust in health care providers. Researchers Halbert and colleagues analyzed data that was collected as a part of a telephone survey that examined the health care experiences and characteristics of a racially diverse sample of adults and determined that African Americans were significantly more likely than Whites to state that they had low trust in their health care providers (Halbert, Armstrong, Gandy, & Shaker, 2006).

One participant mentioned that she does not rely on physicians to provide her with information because many physicians do not have enough time to stay up to date with current research findings because of their busy schedules. For this participant, only doctors who work at certain types of medical facilities such as teaching hospitals may take the time to keep abreast of recent research findings. If the participant does not believe that her doctors are knowledgeable about current research, instead of asking them for information, she indicated that she will take the initiative to research topics on her own if she ever has difficulty understanding information.

“I can go to the internet or since I’m a scientist, I go to PubMed, New England Journal of Medicine. I can find out a whole lot of things. I figure out things for myself that’s why I say, I don’t place a lot of confidence in them because most of them are so busy with patients. Maybe some of them go to continuing education, but overall I’d say unless they are working in a for

instance, some of the doctors at Columbia [Presbyterian] or are in private practice, so they're constantly going to seminars, presenting seminars, they're in classes teaching medical students. Unless they're in that kind of environment most doctors...I don't put confidence in them. I know more about what's going on than they do because they don't have the time. (1046)"

This participant's comments suggested that she does not trust that most doctors are as knowledgeable as they should be unless they happen to be employed at certain types of health care facilities.

The same participant again returned to the theme of trust later in the interview. She tried to explain why she doesn't trust the health care establishment. Her lack of trust in physicians is not only based on her lack of confidence in their medical knowledge and abilities. This participant believes that many providers who work in the health care establishment are not to be trusted because they do not truly care about the needs of the patient. For this participant, doctors are driven more by financial incentives than a true desire to provide care for the patient.

"Doctors only want to make money so that they can pay for their house in Malibu and put their kids through college. You don't have to do what anyone says. You don't have to do what the medical establishment says. You can make your own decisions. You don't have to do what doctors say. You don't have to do what the nurses say. They don't care about the patient. They just want to do what they can to make money. That getting money is the most important thing and not necessarily the patient's health. Doctors don't care if patients live or die. (1046)"

Another participant echoed these sentiments. She suggested that many doctors are often more interested in profit than actually providing appropriate care for those who may need it.

When discussing her perceptions about the medication prescribing habits of doctors, the participant discussed why she does not always like to take the medications that doctors recommend.

"Well I understand the information and as far as medication goes, it's not every medicine that they give me that I take, when they tell me to take it...I don't always take it [prescribed medicine], especially for blood pressure. Why should I take it? He [doctor] keep giving me blood pressure medicine. When the visiting nurse was coming, they never find me with no pressure. Also the fact that I know that they had on television several times, lately they're saying

they find a lot of doctors are being paid to prescribe medicine to people and the person don't really need it. And they [doctors] got a interest in the stock market you know what I'm saying? So you keep buying this stuff and sending their stock up and you taking something that you really don't need okay? And he himself when I told him point blank that my nurses can't understand how you keep diagnosing me with pressure and I don't have no pressure. And he says 'I'm the doctor. I'm the doctor.' (1026)”

The participant's comment suggests that she suspects that doctors will prescribe medicine to a patient because of the financial payoff and not because a patient is actually exhibiting actual symptoms of a disease. With regard to medication recommendations, providers should be aware of patients' beliefs about the use of medications. In order to build an effective relationship, the first discussions between providers and patients about any new medications can represent an opportunity for the provider to gain insight into the patient's values and determine which, if any of these values, may influence whether or not the patient may be receptive to complying with medication recommendations. Such knowledge is important for providers to possess because often a patient's beliefs, views, and preferences about a provider's medication prescribing habits can greatly influence a patient's medication compliance. In situations in which patients think that a provider's decision to prescribe a certain medication is influenced by factors (e.g., the influence of pharmaceutical companies) other than the primary goal of improving the patient's health, the patient may be unlikely to adhere to the provider's recommendations regarding medication or care and less likely to fully trust their providers' motives.

The belief that doctors and the medical establishment do not care about helping the patient was again mentioned. The participant insinuated that doctors and the medical establishment actually prefer to keep patients ill because they are able to profit from patients' ill health. This participant expressed rather strong sentiments about her lack of trust in doctors' motives.

“It is actually cheaper to keep people having diabetes. There was an article in the New York Times. It is very very expensive to have preventive education for diabetes. It’s just cheaper to go ahead and let them start taking medicine. The drug companies and the doctors can make a lot of money from amputations, blindness, and all the money they make from insulin, drug companies and all this kind of stuff. It would be better for people to not have to suffer and get preventive education but it’s more profitable for them to just have diabetes and get their feet cut off. Drug companies, hospitals. Just like [Memorial] Sloan Kettering Cancer Center. They don’t want to find a cure for cancer. Because they’re not going to ever close down Sloan Kettering Cancer Center. They don’t want to close it down. They don’t care one iota. Nobody who says that they’re trying to help you – insurance companies, pharmaceutical companies, medical suppliers, hospitals, nurses, doctors – they want their paychecks. They want to make as much profit as they can. As much money as they can. So that’s why each person has to take trust in their own health. You have to do your own research. You have to sit down and meditate until that still small voice inside of you decides that this is what you need to do. And the best medicine is prevention. (1046)”

Although this theme focused on the comments of participants that mentioned issues of either trust or distrust, the vast majority of comments that were related to this topic focused on participants’ lack of trust in providers or the health care establishment. Only one participant (1062) commented positively about her trust in her provider by directly stating that she trusted her physician. What is of particular interest with regards to the theme of trust is that although no questions in the interview directly inquired about the issue of patients’ trust levels, study participants made several comments about this topic. This occurred even when participants were asked about completely different topics. Future research that investigates the topic of trust should be certain to directly ask about levels of trust in providers and health care system as a whole. If individuals in future investigations are directly asked about the topic and allowed to give a little time to consider the issue, then researchers may be able to collect even more comprehensive information about potential barriers to trust in the patient-provider relationship.

A consideration of patient distrust is critical because this factor can affect various elements of the patient-provider interaction including the quality of the communication utilized during the encounter. Without adequate trust, patients and their providers may experience a

breakdown in communication which may subsequently lead to a diminished quality of care for patients. Patients may not comply with the medical recommendations if they do not possess trust in their providers' abilities, knowledge, or motives or if they feel their providers do not place the provision of quality care for patients above all else.

VII.B. THEME: RELIGION AND SPIRITUALITY

The topics of religion, spirituality, or faith were mentioned numerous times by study participants. Some study participants commented about the role that God plays in their lives and suggested that their religious beliefs or practices might impact the care that they receive or the health outcomes that they experience in some manner.

During interviews, participants frequently commented about the role that religion plays in their lives. For these women, certain religious acts can assist doctors in the provision of care. Although these participants recognize the importance of a doctor's care, they also suggested that effective care would not be possible without the inclusion of religion in some aspect of the healing process.

“God does the work, the healing. Doctors can help but God works through the doctor. They can use the knowledge of God. The doctor helps but God heals. (1001)”

This same individual again emphasized the importance of including religion in the healing process. For this participant, both religion and conventional medicine are equally important aspects of effective care.

“You go first to the doctor and through the doctor and through faith, through faith all can work. (1001)”

When one participant was asked her opinion about what types of treatments are most effective when treating cancer she reported that although the use of medication is critical,

religion is also a necessary component of care. As with the previous participant, this woman indicated the importance of combining conventional medicine from a physician with aspects of religion in order to achieve optimal care.

“You have to take your medicine or God can’t heal. Stay in touch with the doctors and things. (1021)”

When discussing her treatment for a past illness, yet another woman provided a description of a recent treatment regimen that she had utilized that incorporated the healing power of religion in combination with other conventional treatments.

“Medication, pills. I had surgery. I don’t remember about the pills – it’s been a while...I belong to church so I used prayer. (1037)”

All of these women indicated that the provision of care by a physician is necessary but it is also the added element of religion or spirituality that is needed in order to obtain successful treatment.

Although some study participants recognized the importance of incorporating religion with medical care in order to achieve optimal health outcomes, other participants did not acknowledge the role of medical care as a critical component of treatment. Instead, these participants emphasized the role of religion in patients’ lives and how it is critical for healing, even more so than the receipt of medical care from a provider. For these participants both conventional medicine and religion have helped in the provision of care; however the role of religion is regarded as more important than conventional medicine. One participant commented about the importance of religion during several points during the interview. When discussing a previous illness she commented:

“God healed me. I don’t know what I had but God healed me. (1021)”

When asked what type of care (in general) a woman would have to seek if she was diagnosed with breast cancer, the same participant commented about which approach would

provide the most effective type of treatment. She commented about the role of God in the healing process.

“She’d have to go and get on her knees and pray. God heals...God do the healing. The devil ain’t going to try to heal nobody. He’s going to try to keep you down. Cause God is a healer if you got faith. God can heal anything. (1021)”

During another section of the interview, this same participant also revealed that it is critical for individuals to realize that although God can heal, God can also cause illness. When asked to list risk factors for breast cancer, the participant commented that cancer could be the result of a punishment from God *“because God rules the world (1021).”*

For other participants in the study, religion alone was a necessary component of effective health care. For these individuals, conventional medical care is not necessary. One participant commented on the power of prayer or the belief that prayer can lead to positive health outcomes. For this woman, one must possess a strong belief or faith in order for prayer to be an effective method of healing. This woman’s comment suggested that prayer can be an effective treatment alone, not always necessarily in combination with other forms of medical care.

“Some people say they have been healed through prayer. In fact, I have a friend up in Massachusetts, Boston. She said she was healed years ago of cancer through prayer and she’s still around today and she don’t have it [cancer]. You have to believe in those things. If you strongly believe in those things, it will work for you but if you don’t believe it won’t work. (1038)”

One participant recalled a previous medical situation in which prayer provided an effective form of healing for her family. This participant even took the step of pointing out the efficacy of prayer to the doctors who provided care for two siblings. In two different instances, prayer provided positive results for the woman’s family. This participant’s response also suggested that religion is a key element in the healing process. For this participant, it is not only the faith of patients that matter, but the faith of providers may also help with the healing process.

“Prayer is the key, prayer is the answer. I’m a firm believer in that. Even with my sister being very blessed. She was surrounded by a physician who was very spiritual, who had a spiritual base and it was an Afro-American doctor, and I think that made a lot of difference. And there was this incident that occurred. The doctors had to stop and go to see who was in control. You know what I mean with me praying for my sister? And this has happened on two separate incidents with two sisters...Praying through the situation they [the doctors] were able to see the results right then. And I told them [the doctors] now you have something that you can go back and share with your colleagues because I said we’re a praying family and I said prayer works. I can’t get away from that. (1016)”

This participant reported that she had witnessed two separate incidents in which religion and prayer had led to positive health outcomes for relatives. For this woman, religion alone was important for effective care.

Beliefs that are similar to those of the aforementioned participants (1021, 1016) are not uncommon. Complementary and alternative medicine utilization has provided a means of incorporating spirituality and religion into medicine. Previous research that has assessed the prevalence of CAM modality use has often examined utilization patterns of various types of CAM therapies that are classified as mind-body therapies including prayer and faith healing.

One participant commented that it is important to both recognize and respect the role of religion in health care. As previously suggested, some of the participants commented that although religion works in conjunction with medical care, religion is the most important element in the healing process. For this participant religion should be used in combination with medical care, although it is likely a more critical part of healing.

“There have been reports, there have been documents of it. I mean I have seen things like this that have been reported. You know, miracle healing. First and foremost you know I’m a very spiritual person and I believe that. Let me just say that we have it all wrong. We go to get spiritual help after everything else has failed. So for example, that should be our first choice. We go to God, we get spiritual guidance, we pray about it, then we go to the doctor. And hopefully, when you are dealing with somebody in the medical profession, doctor - male or female - that he or she has that knowledge themselves or you know that have some kind of spirituality that they’re believing in because that plays a part. That’s the first person you go to. Like the woman in the Bible, she spent all of her money going back and forth to the doctor and

everything and nobody helped her. And when Jesus passed by she just, she was healed. Yeah, I am a firm believer and a big proponent of God healing and miraculous healing. (1016)”

For this participant, it was important that patients turn to religion as a first step in the healing process, instead of seeking care from a physician. This participant emphasized that when patients do decide to seek care, they may experience more effective outcomes if the doctor who provides the care also possesses some type of spiritual or religious beliefs. Although some patients may feel a greater sense of comfort if their providers also possess similar types of spiritual beliefs, this will not be the case for all providers because many will either possess different religious beliefs than their patients or possess no religious beliefs at all. Even if providers do not share the same spiritual beliefs as their patients, the patients can still experience an effective clinical encounter. Providers who display an authentic understanding of patients’ beliefs will be able to achieve a more effective interaction with their patients. Even in cases where providers do not directly participate in religious or spiritual events, such as prayer, the mere act of bearing witness to a patient’s religion or faith is frequently a therapeutic act in itself. Providers who are able to express beliefs, feelings, or ideas that are in line with their own values, while respecting the beliefs of patients who follow different religious traditions, will likely be able to achieve an interaction that utilizes effective communication while allowing the patient a level of dignity.

A provider’s knowledge of patients’ perspectives about religion can help to provide potential explanations for patients’ health-related attitudes and behaviors. For instance, those who believe that God has ultimate control over all aspects of their lives, including health and mortality, may not always adhere to providers’ treatment recommendations if they think that their actions will have no real impact on the health outcomes that they experience since God makes all decisions. Patients who exhibit a strong external locus of control may be less likely to

follow suggested medical recommendations if they believe that their own actions will not make a difference in the health that they experience. Providers who wish to offer patients the most effective care should make an effort to determine how religious beliefs and practices can impact patients' health-related beliefs and practices.

Even with this finding about locus of control, such beliefs about religion may not always determine the health-related decisions that patients will make. For instance, for their study, Branch and colleagues did not find that patients' religious beliefs prevented terminally ill patients from seeking care. The investigators discovered that patients benefitted greatly from their faith. The strong religious beliefs of these patients did not deter them from either obtaining treatment or expressing a desire to live. For these patients, religion played a vital role by providing them with a means of tolerating difficult times during grave illness while providing an important source of meaning to their lives at the same time (Branch, Torke, & Brown-Haithco, 2006).

Participants in the current study held similar beliefs about the power or control that God has over health. When commenting on the important role of religion in healing, one participant revealed that she believed that it is God alone who has the power to heal. As well, the participant revealed that she believes that God has ultimate control over her health, even if she decides to seek medical care.

"I'm a person that I don't worry about those kinds of things. I give it to the hands of God. I don't think about breast cancer because if I did, I would worry myself to death. (1063)"

The participant later continued,

"There's no use in worrying because God has everything under control. He's going to do what he wants to do anyway. Sometimes you get healed from it and sometimes you don't. Even if you go to the doctor, if God says 'No' the doctors can't do you no good. (1063)"

For one participant, religion would not just serve as a source of healing. In the face of a diagnosis of a grave illness such as cancer, her religious beliefs would help to sustain her. For this woman, religion would provide a primary means of coping during a medical crisis. This sentiment, that religion should be used as a source of strength and coping, was expressed by other participants as well.

“I’m a firm believer that I don’t like to upset people. And my belief in the Lord he has brought me tremendously far because like in the ‘60s, I had spinal meningitis and I don’t know if you know what that is. They had told my mother I’d be dead by the morning and ain’t I here? From where I come from, my foundation, my belief in God, all of this is why I would want to keep it to myself [if diagnosed with cancer] and just take it to the master and let me and the master deal with it. I wouldn’t tell my family. I wouldn’t like to worry people and then another thing too, you never know how people are going to react so I’d just leave that between me and the master. (1026)”

VII.C. THEME: COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) USE

The use of various forms of complementary and alternative medicine (CAM) was discussed by several study participants. A number of participants commented generally about different types of CAM therapies or they discussed their personal use of these therapies. In previous research, religious or spiritual practices have often been regarded as a type of CAM remedy that is classified within the category “mind-body” therapies. This category is one that was named by the National Center for Complementary and Alternative Medicine. Although religion and prayer are classified as a type of “mind-body” CAM remedy, for this study religion was classified as a distinct theme and not included within the categorization of complementary and alternative medicine. Many participants did discuss the role of religion or spirituality in care, and as a result of this, “Religion and Spirituality” was considered separately from other types of CAM therapies.

Although some participants reported that they do not utilize complementary and alternative medicine, for others the use of various CAM modalities comprised a large part of their health care practices. This finding is not unexpected because for many African Americans one type of CAM therapy, the tradition of root or faith healing, as it has been called has been passed from generation to generation via the matriarch of the family (Eiser & Ellis, 2007).

A number of study participants commented on the potential for CAM therapies to provide an effective form of care. Some participants reported that complementary and alternative medicine therapies should be considered as possible treatment options if these therapies are a part of an individual's culture, and if these therapies are found to be effective. One participant recounted such a story.

“It all depends on one's culture. If it works. If it works [you should use it]. (1016)”

Previous studies that have assessed prevalence of CAM use in various populations have determined that individuals cite numerous reasons for utilizing different types of CAM modalities (Chao, Wade, Kronenberg, Kalmuss, & Cushman, 2006). Despite these findings, responses from some of the participants from the current study suggested that the use of alternative therapies may not always present the best course of treatment. The use of home remedies that have not been scientifically proven to be effective may result in patients experiencing adverse health outcomes instead of an effective course of treatment.

“There was a nurse and she had a lump in her breast and she found it. She talked to her grandmother about it. Her grandmother told her to go use some camphorated oil to rub on it. But it never went away. The doctor took her breast off because she had cancer. She did what her grandmother said. And this is what I mean. Some of these old wives' tales you have to look at them very deeply. And something like that, she should have known. But I guess grandmother knows best. It got worse and she went to see about it. (1092)”

It is critical that individuals who make the decision to utilize certain home remedies exercise extreme caution. These individuals may choose to use remedies that have not been subjected to

rigorous scientific testing that can provide evidence that their use can offer some type of health benefit.

According to the participant's report, the nurse in her story chose to utilize a remedy that did not provide an effective course of treatment. The nurse opted to use camphorated oil despite the fact that she had received some degree of medical training for her profession and therefore likely possessed some level of knowledge regarding effective treatment options for cancer. Findings from prior research have suggested a number of reasons why individuals might opt to utilize CAM therapies. Reports have revealed that many individuals prefer to use CAM therapies because they are effective, less expensive than prescription medications, and because these individuals are often unsatisfied with prescription medications and other more conventional forms of treatment (Chao, Wade, Kronenberg, Kalmuss, & Cushman, 2006; Elder, Gillcrisp, & Minz, 1997). Chao and colleagues determined that participants in a previous study utilized CAM as a result of various social networks and because the remedies were consistent with their personal beliefs. Many respondents reported that they wanted to utilize CAM because they wanted to use what they regarded as more natural approaches to treatment. Those who revealed that social influences affected their decisions to utilize CAM reported that they often adopted the use of certain therapies because their family members had used these therapies in the home while they were growing up (Chao, Wade, Kronenberg, Kalmuss, Cushman, 2006).

For the nurse mentioned in the study participant's story, her decision to utilize the camphorated oil may have been linked to the fact that this remedy was one that had been utilized by her grandmother as a treatment for various maladies. As a result of the nurse's social network, she may have decided to use the oil in the hopes that it would provide some type of cure instead of following her provider's medical recommendations.

The responses of other participants also revealed the individuals' desires to learn more about different types of CAM treatments. When responding to a question that asked a participant to define different types of cancer treatments, the participant attempted to define radiation therapy. As a part of the response, the participant explained that radiation not only attacks cancer, but the healthy organs in the body. She offered an explanation for why individuals might prefer to use alternative therapies such as herbs.

“There are certain herbs for everything. And I believe there's certain things like even for fertilization. There's certain things that's written in the word that all we have to do is go and get that particular item and it'll be done. Just like my daughter has asthma, there's certain stuff that we can put together to stop the asthma. Like shark oil and a few other items that you put in the shark oil and you give it to the child three times a day. And they will never have another asthma attack. It's the same thing. I think with cancer, there's a way you know to get rid of it or prevent it but the thing is to have the wisdom and the knowledge [about which remedies are effective] and also know where to find [the remedy] ...So therefore if we don't have the wisdom and the knowledge of what it is and [where it is] ..., then we, you know we're stuck because knowledge is power. (1035)”

For this participant, CAM therapies offered an effective course of treatment. However, the individual noted that it is important that information about various CAM treatments be made available for those who want to use these treatments. Individuals who are interested in CAM may not be informed about what types of natural remedies are suggested for certain health conditions, as well as where to locate the ingredients to create these remedies. Without proper information, individuals who are interested in exploring various types of CAM use will not know where to seek out necessary CAM therapies.

The use of complementary and alternative medicine may result in adverse health outcomes for some patients, not because the therapies are ineffective or harmful, but because the use of CAM therapies may cause some patients to not comply with their doctors' medical recommendations. Patients may rely on the CAM therapies and not opt to take doctors' prescribed medications. Further, those who do not comply with medical recommendations may

not disclose this noncompliance to their providers. As a result, patients may experience adverse health outcomes and providers may inadvertently link such outcomes to the medicines that they prescribed, unaware that the patients may be using alternative therapies that are responsible for the adverse outcomes.

At the end of one interview, after the tape recorder was turned off, a study participant (1012) relayed a story about a friend's previous experience with CAM therapies. The participant reported that she had previously given a female friend some herbs for a very large lump that had grown under the friend's arm. The participant asked the friend not to tell anyone – not even her physician - that she was taking the herbs. As well, the participant also told the friend to tell her physician that she was still taking the medications that had been prescribed by the physician. The participant reported that the friend's lump shrunk to the size of a dime after the herb use. The friend informed the participant that not only was her physician happy with the outcome but the physician reported that the friend would no longer need surgery. This announcement was surprising because the physician had insisted earlier that surgery was necessary. Despite the positive health outcome in this case, the physician was never made aware that the prescribed medications were not the reason for the lump's reduction in size. It is unfortunate that the friend did not reveal her noncompliance because the physician was likely under the false impression that his medical recommendations alone were effective and solely responsible for the lump's smaller size. Although the herbs may not have caused the reduction, the misinformed physician never had the opportunity to try and determine what led to the positive health outcome.

Such responses reveal the importance of patient disclosure of CAM use. Although the individual in the story who was described by the participant (1012) did not experience any type of adverse health outcomes, others who use CAM therapies to augment or substitute their

prescription use may experience negative health outcomes. In order for health care professionals to provide their patients with information about CAM use, including its potential dangers, health care professionals must first be aware of their patients' use. If patients do not disclose such information and providers do not routinely inquire about use, then doctors will not have the opportunity to provide effective communication about CAM use. Ineffective communication about CAM use during medical encounters can prove problematic by compromising the provision of optimal health care.

Another participant also relayed a story about a friend who had utilized a CAM remedy yet failed to disclose this use to her provider. Although the friend experienced a positive health outcome, the woman did not want to reveal her CAM use to her physician because she thought that the physician would not believe that the CAM therapy had actually been effective.

"I read a lot about it [CAM therapies] and being from the Caribbean we used to use a lot of herbal stuff. Let's say you have a cold. Instead of going to the doctor just for a cold, you know, we have bush or seaweed that you can get from your garden or any place it might be growing in your yard. We take that and we boil it as tea in the morning for colds. I know that there are things that people use but personally I don't know what I would use for that. The most that I'll use is something called choryla. I think over here they call it Circe or something like that. That is something very bitter and we use that. I have a friend who says that she was diagnosed with some cancer and she used this thing that we call aloe, aloe vera. We have it in the Caribbean growing in the yards. She said she used that and something very very bitter. She said she used that and then after going back to the doctor, the doctor didn't find what was there. She said it had disappeared. It wasn't for breast cancer I think it was in the uterus... And she said she used it like medicine daily, 2 or 3 times a day on a regular basis and she said it helped. The doctor asked her what she used but she wasn't willing to tell the doctor. She didn't know whether the doctor would have believed her so she didn't worry to tell him. (1073)"

Although the provider in this story was not informed about what type of CAM therapy the patient utilized, the patient's disclosure about the fact that she had used some type of CAM remedy was important because at least the provider was not under the false impression that his recommended treatments had resulted in the positive health outcome.

Health care staff may not question patients about CAM use because time constraints may prevent inquiries or because they may forget to ask about its use (Higginbotham, Trevino, & Ray, 1990). Patients may not choose to disclose their use of CAM therapies because they may perceive that their providers will think that these types of treatments are ineffective, they are embarrassed to disclose that they use such treatments, they may not want to be perceived as an unsophisticated patient, or because they think that their providers might object (The National Board of Chiropractic Examiners; O'Conner, 1995).

The experiences reported by many of the participants in the current study are not surprising based on findings from prior research which have revealed an interesting trend with regards to patient disclosure. Investigators have posited that Hispanics and African Americans may be much less likely to reveal their CAM use to their providers (Graham, Ahn, Davis, O'Connor, Eisenberg, & Phillips, 2005).

For providers who treat African American patients, it is important that providers have some sense of the importance of various types of CAM modalities in the African American cultural tradition. An awareness of the patterns of use of these modalities is critical because often many individuals may not divulge information about use to their health care providers. If providers are not aware of the significant role that such remedies play in the lives of many African Americans, providers may not inquire about their patients' use of these therapies (Eiser & Ellis, 2007). As a result, when individuals do experience positive health outcomes, but fail to disclose the possible causes of these outcomes (e.g., herb utilization), health care providers may be misinformed about the true level of efficacy of the treatments that they recommended.

VII.D. THEME: RACE AND CULTURE

The theme of “Race and culture” was used to categorize participants’ responses that discussed how the factors of race and culture might impact patients’ health-related beliefs, attitudes, and practices and ultimately the health outcomes that patients experience. This categorization was also utilized when participants commented about how race and culture might influence how patients understand and act on health information.

An examination of the role of race in the clinical encounter can help investigators determine if, and how, this factor can impact the nature of the clinical interaction including the communication that occurs within the patient-provider dyad. It can also provide information about whether this factor influences the quality of care that patients receive from providers. Findings from such an examination can also provide key information about how race and culture can not only influence how providers behave and interact with patients, but also potentially impact the health-related behaviors of patients. As well, an understanding about the influence of race and culture in the patient-provider dyad can provide clues about how these factors may contribute to existing health disparities.

One participant’s comments about race and culture suggested that these factors impact the care that patients receive in various ways. The participant suggested that patients who possess beliefs that may be culturally-based may adopt certain health-related practices as a result of these beliefs. The participant suggested that a patient’s race or culture can influence how the patient interacts with his or her provider. Consequently such interactions can adversely impact the care that the patient receives.

“Latin women, men they don’t want [anyone] to touch them. And some of our American women they don’t even want some doctors, depending on the doctors, to touch them. It’s their idea and I’m not trying to downplay it because this is what they’ve been taught. But it’s also hindering in

some ways. Because the knowledge is out there. You don't have to pay for it, you just go. You can get a free mammography and there isn't any reason for a woman not to take care of your own body. You take care of it.... But some people they try old wives' salves on this and this and that. I guess we will eventually get people to do more for themselves. (1092)"

For this participant, patients' culturally-based beliefs and fears about being touched may result in the receipt of suboptimal care. Patients may not be able to receive thorough physical examinations or participate in preventive care practices that require that they be touched.

Although it has been suggested in the literature that patient-provider racial concordance can positively impact the clinical encounter, for some participants, a shared cultural heritage is as important. Those patients who share a similar cultural background with their physicians may share a greater level of comfort within the relationship which can lead to better communication. Participants in the current study commented about the importance of cultural concordance within the clinical encounter.

"Say for instance I'm African American and my doctor is African American. Okay so I'm talking to him and I discover, well my family is from the South, he doesn't have to be from the South. It seems like they open up more to the doctor culturally if he understands, you don't have to be Black. But you have to understand a little bit about the culture. Culturally, if you're Southern and the doctor is Southern. I think that opens up where people could feel more comfortable and especially with something as serious as breast cancer. Or if they have a woman, a nurse or someone that they could relate to. I'm Black and the doctor could be White but they could have an idea of that culture and they could react to that. It doesn't have to have anything to do with color. (1087)"

Cultural and racial concordance between a patient and provider can have a positive impact on a patient's clinical experience. Physicians and patients who share the same race or ethnicity may share similar beliefs, values, and experiences. Such similarities are likely to allow the patient and provider to be more comfortable and as a result, communicate more effectively with each other. Greater social distance, or in some instances a greater cultural difference, between two parties can lead to increased communication problems.

The issue of culture was again broached when one participant associated certain attributes to patients based on the patients' cultural backgrounds. Although cultural concordance was suggested as a predictor of positive interactions between patients and providers, some participants commented about the adverse impacts of culture. For one participant, a patient's culture could adversely influence an individual's information-seeking and health communication practices. This participant suggested that patients who live in the Southern part of the United States might be less likely to be assertive and to ask questions during the encounter. This participant did not attribute such personal characteristics to the patient's race specifically, but to the patient's culture.

“Down in the Southern part, they do not ask questions. More in the North they ask questions. But down South they don't ask questions. Whatever the doctor says, like I said I would go, this is the way you know some people in the South, you know, whatever the doctors say they just take it at face value. Maybe for the elder persons in the South and some of the young people. They just don't like to ask questions. I can't explain it really. Maybe like they don't understand what the doctor is saying because they [doctors] don't break it down in terms, on the level just like if you go to church and this preacher is preaching a text, and he don't break it down to explain to you what he is talking about, you don't know what he's talking about. If the doctor don't break it down to the patient to say you know “such and such” in our language then they [patients] would not understand what they're [doctors] talking about. (1075)”

For this participant, the perception of Southern culture was associated with a number of characteristics. The participant suggested that Southerners are unlikely to understand information provided by doctors and to question doctors during the encounter. The participant also posited that Southerners are less aggressive and, as a result, less likely to obtain and understand the health information that they need as compared to patients from other geographic areas of the U.S., especially individuals from the Northern U.S.

The responses of study participants also yielded interesting opinions about race and health. Some study participants suggested that the race of patients can influence health-seeking

behaviors and practices. For instance, when discussing possible risk factors for breast cancer, one participant suggested that some African Americans may not seek out care or participate in preventive care because they are afraid and uneducated. For this participant, African Americans' lack of participation in care is not based primarily on financial constraints or an inability to pay for care, but also the fear that exists for many within the African American community.

"I think Black people are not wanting to really go through with everything and the fear. And not being educated. A lot of Black people are not financially able to get exams like Caucasians. I guess family history. Some Black people are afraid. There's a fear. It's not that they [Black people] are not able – there's a fear. (1097)"

Although many African American patients may be aware of the importance of screening, they may still choose to not participate in any preventive measures because they may be fearful of what their doctors may actually discover with regards to their health. For these women, screening may not be regarded as a way to discover and treat a disease early, but as a way to find out earlier that they have a disease – news that would be unwanted for almost any woman. This lack of participation in screening may occur even for women who may be aware of the risks for certain types of diseases. One participant in the study suggested that race specifically may affect some women's likelihood of having a breast exam performed.

"...and as far as breast exam goes for women, ain't too many Black women still are going for it. Even though you see a lot of stuff highlighted on the TV and it's telling you different things, trying to educate you, it's still not happening. One thing is this tremendous fear that, you know, 'Well nothing is bothering me, I feel alright you know what I'm saying.' So why go looking for trouble in other words? Why am I going to go stir up and go looking for trouble, ain't nothing bothering me. My mother used to say 'If it don't trouble you leave it alone. Don't bother with it. Don't try to fix it'. (1026)"

One participant, who is originally from the Southern U.S., suggested that African Americans may not be as open as other racial groups to talking about health and disease.

Although the participant also mentioned her cultural background, she associated a lack of dialogue about health to race, not specifically culture.

“Not to my knowledge. People don’t talk. I’m from the South. People really don’t talk about it now. We as a Black race don’t talk about diseases, and I think we should. (1010)”

Another participant who possessed similar beliefs commented that African Americans do not always take the necessary steps to obtain care in a timely manner. Often by the time individuals obtain care, any disease or condition that is present may have advanced. The participant suggested that younger African American women will not always take advantage of preventive care, even when the women have health insurance. In those situations where preventive care such as mammograms are provided at no cost, some African American women still may not utilize screening.

“Health insurance and not getting medical attention. Black women and Black men with the prostate cancer. Well men are hard to go to the doctors. You have to push them to go but because a lot of people don’t have the health insurance and the health insurance is a nationwide crisis - it’s not just Black women. For some reason we [Black women] don’t go and there’s so many clinics and things out here but we don’t avail ourselves to what’s out here for us. We don’t take advantage of it. So a lot of times when they detect it, it’s too far gone. Black women, I think more so Black women. They just don’t seek the medical attention or I don’t know [if women are getting mammograms]. (1094)”

Participants’ beliefs that African American patients do not utilize medical services to the same degree as patients of other racial backgrounds echoed the findings of prior research. A number of studies have revealed that differences in health status and utilization of health care have continued to persist based on race. Findings from previous investigations have indicated that members of minority groups often make use of health services less often than Whites. This relationship continues even after variables such as income and insurance have been controlled. It is important that investigators examine those factors, in addition to an individual’s ability to pay, that can help explain differences in health utilization and existing health disparities (Blendon,

Aiken, Freeman, & Corey, 1989; Andersen, Giachello & Aday, 1986) Although some participants suggested that African American women do not take the necessary steps to obtain appropriate care, a few believe that African American women are now beginning to take the initiative when it comes to their own health. African American women are taking a more assertive stance regarding how they communicate during clinical encounters. This increased participation in the clinical encounter and assertiveness may positively impact the effectiveness of communication between patients and providers as well as the care that these women receive because providers are paying more attention to the wishes of these patients. Responses from study participants suggested that many African American female patients are taking a more active role in their health care not only because they are more assertive, but because they are now more well-informed and therefore better equipped to do so. Participants suggested that African American women are more empowered and willing to demand that their needs be met by their doctors. African American women are taking a stronger stance and taking greater control of their health.

“I think that honestly a lot has changed where people are more educated in the illnesses and the symptoms and the signs and we as individuals, especially Black women, are more assertive in what we feel and what we want so that when we go to the hospital and the doctors, we’re no longer just sitting back, allowing anyone to just say ‘Well this is this and this is that’. We are saying now, ‘No listen! Stop! You must investigate what I’m saying and if you don’t we will seek our medical attention elsewhere’. And we spread that around, like don’t go to that physician because he’s not listening and that person is not listening to what we are saying. We are being more assertive and we are more informed by way of other people, computers, television. We are just more knowledgeable now, so we are taking more control of ourselves and our health (1028).”

Although the responses of some participants suggested that African American patients are now becoming more empowered regarding their health, other participants disagreed. There was a belief amongst some participants that many African American patients may experience ill health because they seek care only when a medical condition has progressed to a point where its symptoms are affecting their day to day activities. These delays in obtaining care may be linked

to the fact that many African American patients do not place a great importance on conventional medical care, instead preferring to utilize alternative therapies.

“It’s become very prevalent among Black people, especially Black women. And you find the same thing with the Black men. Most of them don’t even, they don’t go for their prostate cancer to get it checked, and when they do go then it’s too late. So it’s something that I would say among Black people as I said because we tend to not, I don’t think Black people as a whole, in general, believe too much in doctors, doctors, doctors. And I think we’re more quicker to take a remedy, especially from the West Indies. If this is wrong or your stomach hurts or something, go out in the backyard and pull a few leaves. So they’re not thinking conscientiously about going to no doctor...(1026)”

Some African Americans may not comply with a doctor’s medical recommendations because these recommendations may conflict with cultural beliefs that they possess. Study participants relayed accounts of instances where specific beliefs may have prevented patients from seeking necessary medical care. In response to a question that asked for the definition of the term “chemotherapy”, one participant conveyed her family’s beliefs about cancer and treatment. This response suggested that some individuals may not comply with a doctor’s medical recommendations because of certain beliefs about treatments for diseases such as cancer that may prevent individuals from obtaining critical care.

“[Chemotherapy] is basically a radiation treatment that they give you once if they find that you have cancer. And when you say that too, it comes to mind what my mother told me. ‘If they ever tell you I got cancer tell them don’t touch me, don’t touch me.’ She was a diabetic but then she had a lot of other complications. For one thing, we still got a lot of strong headed Black people where if the doctor tells them one thing, but they’re going to do another. Well that was my mother. She used to tell me ‘If they ever tell you I got cancer, tell them don’t touch me, don’t touch me. And don’t cut me don’t do nothing to me. Just leave me alone because I want to go back to my God the way he sent me here.’ She would say ‘And another thing, the minute they open you up, cancer spreads.’ And this lady that just died from cancer she was in Memorial Sloan Kettering and she refused to let them touch her. They couldn’t operate or nothing. They couldn’t do anything for her. She flatly refused to. And this was an educated woman. Okay. We’re talking about an educated woman and she refused to let them touch her. But no more than when my son told me, she went to the doctor and they told her she had cancer. And she said ‘No’. She refused. They talked about chemo, she refused that. They talked about cutting her, she refused that...She said ‘No’, she don’t want it. This wasn’t an illiterate person or a person with a 6th grade education. This is a person that you talking about that had a Master’s degree

and PhD. I don't think she was even quite 60. They diagnosed her in November and she died December 16th. Very soon after she found out, she died. It had to have been advanced. That's what I told my son because he was so upset behind it. And I told him 'Well I guess she chose. She probably was of the same thought like how your grandmother always say that if they touch you, once the air hit it, the cancer spreads like wildflowers.' (1026)"

The participant believes that many individuals, specifically African Americans, possess certain cultural beliefs that adversely affect health. The idea that cancer can spread if the body is cut, or beliefs that prevent individuals from obtaining care, may be ones that are held more often by African Americans as compared to members of other races. If such beliefs are disproportionately held by members of this racial group, providers must become aware of these beliefs so that they can effectively address them during clinical encounters.

It is critical that investigators examine the impact of patient and provider race for a number of reasons. In addition to an assessment of the impact of cultural or race-based beliefs, attitudes and practices on health outcomes, an examination of the impact of racial or cultural concordance is also necessary. Although participants in this study did not specifically emphasize the role of racial concordance in their own relationships with their providers, prior research suggests that racial concordance is associated with a number of outcomes (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson, & Ford, 1999; Saha, Taggart, Komaromy, & Bindman, 1999).

While findings from previous studies have examined the relationship between racial concordance and various outcomes, findings from this study also emphasized the importance of examining cultural concordance. Such findings suggested that investigators should consider the role of cultural concordance in the patient-provider relationship and the impact that this factor may have on the quality of interpersonal communication that occurs during the clinical encounter. This is of particular importance because although racial concordance might be

preferred by some African American patients, it is likely not feasible since there are not enough African American physicians who are currently practicing medicine. That is, there are not enough African American physicians available to guarantee that all or even most African American patients would only be seen by African American providers. However, the provision of cultural concordance within patient-provider dyads may be a much more achievable goal. Although Southern African American women may not be able to be paired with African American providers, it may be possible for them to be paired with providers who are from the South. This commonality in culture could help to lead to more effective communication between patient and provider.

VII.E. THEME: PATIENT'S RELUCTANCE TO SEEK CARE

During the interviews, several study participants often discussed the concept of fear and other factors that might cause them to become reluctant to seek any type of care, receive treatments, or request information during clinical encounters. Because these comments all focused on reasons why individuals might be hesitant to seek care or actively participate in the clinical encounter, numerous comments were categorized under the theme "Patient's reluctance to seek care".

The topic of patient fear was mentioned several times by study participants during the interviews. Although participants also discussed the fact that overall African Americans may be more fearful of seeking care and discussing health topics as compared to members of other racial groups, participants also commented about how fear can impact patients' decisions to go for care. Study participants discussed fears about seeking care or participating in preventive screenings. Some of these individuals experienced great trepidation, not because of an illness or

medical problem that they were currently experiencing, but because of what might be discovered during a future medical appointment or screening visit. For these participants or their family and friends, just the possibility of discovering some type of medical problem caused individuals to experience great fear.

“I think that breast cancer results because a lot of women are afraid. I’ve talked to many women who don’t go... believe it or not, and it’s free now [the mammogram]. They’ll say I felt something here and I’m afraid to go [to the doctor or for a mammogram]. So fear and not doing anything would increase your chances. I’ve talked to so many women and I’ve even started a lecture one day. We were sitting in the clinic and I was telling them that fear is your worst enemy. They’re usually a group of women who are afraid of doctors, who don’t do anything [go for checkups]. And then when they find out they have it[a disease], they’re devastated. You know you have to really think of your body as a temple and do the best that you can to care for it. (1084)”

Some participants recognized the benefit of screening in the case of cancer or other diseases. These individuals realized that the early discovery of disease might increase the chance for effective treatment and therefore increase the chance for a successful recovery. Even with this knowledge, these individuals were still hesitant to go for screening. For these participants, or other individuals who they know, the possibility that they may have some type of disease caused them to experience tremendous fear and worry. In situations where treatments might be successful, participants reported that they or others might worry that the disease would always recur and as a result, this constant worry would adversely impact the quality of their lives.

“If I discover something the next time I have the clinical [exam] I have breast cancer. So what can I do? Are they going to take the breast off because it’s not bad? But then my life would change because I am a worried person. I would be worried. But if I discover [the cancer] and they say ‘Oh you really have it bad’, I think I would be so much depressed and so much worried. I think that if I do not have help to make myself better, I would make myself worse and I would be gone soon. If I have something, I definitely am a kind of person when I have to have a lot of psychological support to keep going. I think I would just give up easily. I think I would. Some people say ‘No I can do it.’ I don’t think I would be that type of person. I would just go [die]. If you have somebody’s support, you would be okay, you would keep going, you have more time. I couldn’t do it. (1047)”

According to one participant, many individuals would prefer not to know if they have a disease. Some individuals might actually prefer to discover that they have a disease when it is has advanced. For these individuals, a late diagnosis would mean that they would die quickly and not have to endure a long period of suffering.

“If I had cancer I would want it to be fast. I would not want to suffer. A woman had it on her pancreas and she lost weight over and over again. And the friend with stomach cancer. He’s suffering too. He had convulsions. He was taking medicine, the cancer was growing back. It was just stressful because he don’t have a life. He’s suffering you know? I rather be like my friend, she had breast cancer, she found it late but it was fast. If I find it early or I have breast cancer and you have to take a piece of the breast cancer or they have to take a breast off and I would be cured [that would be okay]. But I would be worried anyway because even if they take your breast off that says to me the cancer’s gone. Next thing is it comes back. (1047)”

“I would always think it would come back. All the time when you feel something you have to go and check it out. I accept it more when they give it to you [providers deliver the news that you have cancer] and you go fast, 1,2,3. You have the cancer, you discover it, and any chance of survival is gone. I think if they find it early you’ll always think that it will come back early... When you have cancer and you have a treatment you go back and forth, back and forth, you don’t have a life. You are very limited. (1047)”

Some individuals are fearful of discovering that they may have a disease so they will not participate in screening or seek care even if they suspect that something is wrong. These individuals may wait until a condition has worsened before they will make the decision to seek care. It is only when they experience a great amount of pain or other symptoms that affect their daily activities that they will then make the effort to seek some level of care.

“Because a lot of women, and I’m not saying it because I just moved uptown, a lot of women in Harlem don’t take care of their body like they should. Especially when it comes to mammograms and things. I came from midtown Manhattan. But to me down there people took more time to take care of themselves than the women up here. To me they act like they going to miss something if they go take a mammogram or something. They’re not interested and they don’t think it’s as serious as it is. Like they said, if you get a mammogram they can catch it. A lot of women don’t realize how important that is, and they need people to go around telling them. Especially these women in the projects across the street, Drew Hamilton [public housing], they don’t take care of themselves physically like they should...A lot of women are scared. They ain’t busy doing nothing. It ain’t like they got a job or nothing. They just running around drinking beer and stuff. But they’re just scared. A lot of women are scared. Even if you think about

somebody trying to say you got a lump in your breast, the first thing they going to say is 'Cancer'. They going to be scared to check it out then the lump get bigger. That's how it was with my friend. It got so sore that she had to tell me about it. And I was like 'No go fix yourself. Just go to the doctor.' I went with her. We cried together and everything. And it wasn't nothing. It hurt. But they got to realize they got to go check it out before it gets to a lump or anything. A lot of women to me, I don't even see them taking the time to self-exam...But these women in Harlem. It's these women uptown. To me, they're just so lazy. They don't want to go to the doctor to take care of anything. They wait until they really really get sick before they will really honestly go to a doctor. Like I said, once a year it's my birthday present to me to go to a doctor. They don't do things like that. They got to wait until something is falling out before they will go to a doctor. But it's like that. Like I said they don't realize the importance of it. And maybe if they get a little bit more brochures and read about it more. I think brochures will help. A lot of people read more than you think. When it comes down to that, a lot of people will read them. That's a serious thing. (1022)"

One participant reported that some individuals are not able to cope well with the news of a diagnosis of a disease such as cancer. She discussed one friend's experience. Once the friend received her diagnosis, she refused to accept it. The friend would not return to the hospital for any type of treatment. To this participant, her friend refused to go for treatment because she was afraid and in denial.

"I have a friend who's diagnosed with breast cancer. She's 58 and she has not been back. She is in denial. I believe she's afraid to go back. She acts like it's nothing to worry about. She's going to make it through this without having any more [medical attention]. I guess she feels maybe if she goes back, it will put more worry on her so she's just denying it. When I see her, I'm like 'You didn't make another appointment?' [She says] 'No.' 'Well what are you going to do?' 'I don't know, I guess I'm going to do nothing.' She won't tell me why. It's like she feel it's just going to disappear. [The participant's friend thinks] 'I'm not going to think about it, I'm not going to worry about it, I'm not going to do nothing'. I don't know why she, she's 58 years old and knows better. She did a mammogram. They seen a lump. They told her to come back. She hasn't gone yet. I don't understand her logic, and I talk to her. I told her I would even go with her. In her family, they tried to get her to go. They couldn't make her and she's just walking around like it's okay. (1070)"

Patient fear was also illustrated by participants' responses that discussed their fears of undergoing a medical procedure or participating in screening because they held the belief that the experience would cause them to experience actual physical pain. Some participants, who actually acknowledged and recognized the benefit of participating in breast cancer screening,

still expressed great trepidation about having a mammogram because of the physical pain that the experience might cause.

“I went to the Avon Pavilion at Columbia and last year when I went I didn’t have no problem. In fact I didn’t know she was finished. The first experience I had a colored lady that did it, and it was the most horrible experience for me because she kept like clamping the thing down so hard that I was in pain. Then I went and there was a young girl up at Avon and as I said I didn’t feel anything. And this time too, it wasn’t so bad but then I went in December for a checkup because they had seen like a little spot but it wasn’t cancer. But they wanted to follow-up on it to make sure. So when I went back I went to Radiology this time and that hurt. I’m going to tell you. It hurt. Because the way they clamp that thing down. That’s what I think get a lot of people discouraged too in going for it [a mammogram]. Because I know quite a few friends that I spoke to. They don’t like it, they call it the ‘titty crusher’. So they tell me I ain’t going for that titty crusher. It’s unbearable. Because even though it’s for a few minutes, it seems like a long time. (1026)”

One woman experienced a sense of fear because she received information about a procedure that she was about to undergo. It is expected that patients who are uninformed and who do not know what to expect from a procedure might be hesitant to receive treatment because they are afraid. However, for this participant, her fear resulted from the fact that she felt that she was too well informed. After learning the details of the procedure that she was to undergo, she was too afraid to proceed.

“When the doctor tried to explain to me about the knee procedure, I had to ask questions about that. I didn’t understand the procedure so much because of what he said he was going to use. I always thought that when they replaced it [knee], it would be with something like plastic I guess. But he said something about tin or something. Whatever it was, it [the material the doctor wanted to use for the surgery] didn’t seem pliable to me. I guess he explained it to me at the time to my satisfaction or dissatisfaction. I never had it done so I guess pretty much I wiped it out of my mind. It just seemed a little coarse, not his description but the procedure itself, what he was going to do. I guess sometimes you think you want to know something step by step and sometimes it’s better that you don’t. So it could’ve just been that. If I was a medical professional then the procedure (description) would have probably been right on but since I’m a lay person it just seemed like it was horrible. And I’m thinking to myself, ‘He’s going to do that to my knees?’ I’m going to be worse off than I was when I walked in. (1086)”

Participants were also reluctant to go for care because of feelings of intimidation that they sometimes experienced. Participants commented about instances in which they or other

individuals felt intimidated by their doctors or other health care providers. These participants admitted that they did not ask questions even in instances when they did not understand information that was provided during appointments. These feelings of intimidation affected the individuals' information-seeking habits. An example of such a scenario was illustrated in the statement of one participant who disclosed that feelings of intimidation sometimes prevented her from requesting information during past medical appointments.

“Sometimes you’re intimidated by doctors. You don’t want people to think that you’re stupid. If you think that they’re a lot smarter than you are, sometimes you don’t ask questions. Sometimes you don’t ask questions because you’re afraid to ask, you don’t really want to know the answer at that particular time. (1086)”

Other participants in the study admitted that they were reluctant to go for care because they simply did not like doctors and only visited their providers when they could no longer avoid it.

“I’m not a doctor person. I only go to the doctor when I can’t help it. I’m not a person who when they get their little finger hurt they go to the doctor. I’m not that kind of person. I go to the doctor when I can’t help it. (1075)”

Participants' reluctance to seek care or participate in screening, as well as their fear of asking for information from providers, can serve as significant obstacles to effective communication within the clinical encounter. An individual's feelings of intimidation, fear of revealing her lack of knowledge, or fear of experiencing pain, can ultimately impact the health outcomes that the individual experiences. If providers are aware that patients may be experiencing such attitudes towards care, these individuals can make a greater effort to tailor their approaches when providing care.

VII.F. THEME: PATIENT'S DEMEANOR, ATTITUDES, BELIEFS, AND PRACTICES

Many participants reported that certain aspects of their demeanor, attitudes, and beliefs have been able to impact the health care practices that they adopt. For instance, participants' reports of certain habits (e.g., the tendency to always ask their doctors questions when they don't understand information) may result in a better understanding of health information and therefore better health outcomes. Those participants who reported that they take the initiative during clinical encounters and request clear explanations when they do not understand information can gain a better understanding of medical recommendations and what they need to do in order to successfully follow these recommendations.

Several participants disclosed that they have adopted the practice of always asking for explanations when they do not understand information that a doctor has provided. These individuals take the initiative to question their providers, obtain the information they need, and are therefore better prepared to act on the health information. Based on their responses, it appeared that these participants did not let feelings of intimidation deter them from seeking information. Examples of such practices were reported by a number of participants.

"I ask the doctor to not use medical words that I can't understand. (1003)"

"Yes I make them [doctors] explain it [information] to me. (1091)"

"Say for instance he give me some medicine and he says you have to take this two or three times a day so I say 'Can you go back and explain it?' And what I do I write it down myself because sometimes I don't understand. And sometimes he use words and I don't understand what he's saying and I say 'Can you tell me what that means? Could you break it down?' And sometimes he might break it down and sometimes he might not. (1093)"

"When I don't understand I usually ask them to explain it, to write it down. I ask them to write the names down that they're talking about because sometimes they say a name that I don't know what the name is. It be like about 20 letters in the name. It could be medicine or even just like a problem with me. And they'll say a word and I don't know what it is and I want them to write it down so I can go look it up. And I can do research on it myself. (1045)"

Some study participants reported that they always made certain to ask questions during clinical encounters when they did not understand information provided by a doctor. For these participants, the practice of insisting that doctors explain information in a clear manner or repeatedly until the participants understood was one tactic that they employed often.

“I’ve learned not to let them rush me and when they want to give me medication I want to know what the side effects are. Yes it’s the rush job. Yes I tell them to slow down and explain it to me and I ask questions too. Because I speak softly, my doctor talks over me sometimes but I always ask questions. (1061)”

“Yes [I have problems understanding] that’s why I have them go over and over it. (1093)”

“Usually when my doctor prescribes a medication, I always ask what the side effects are and why should I take it and for how long. Because a lot of people just accept what their doctor tells them. They sit there, they don’t ask any questions...I will ask questions. (1084)”

“Sometimes but I always tell them to please explain or run that back by me again. Like even when I go to the doctor and he’s telling me whatever he thinks is wrong and then he says well here’s this prescription. I never accept until he explains to me what it is, why I need it, and what is the side effects. (1083)”

Those participants who insisted that doctors provide clear explanations about health topics were likely to have left the encounter feeling more informed than those who did not. Participants who have adopted the practice of questioning health care providers when they did not understand likely received more information that was simplified for easier comprehension. These participants may have also felt more empowered because they took the initiative to question the doctor and made an effort to improve their own health. Such habits, when adopted by all patients, can lead to more effective communication.

Some participants reported that they did not ask questions even when they did not understand the information provided by their doctors. While these participants admitted that they should have made a greater effort to assure that they understood information, others did not acknowledge that it may be important for them to ask their doctors questions when they did not

understand. Participants who reported that they needed more health information in order to clearly understand, acknowledged that they may not have always made the effort to obtain information from other sources in order to understand. As a result, participants who possessed such attitudes about information-seeking may have experienced a multitude of problems during the clinical encounter.

“I’m the type of woman where I don’t ask anybody questions because I don’t know what kind of answer they’ll give me. So I just leave it alone. (1027)”

“I think it’s my fault. I would imagine if I was to go to the computer there’d be tons and tons of information available. So it’s there, it’s just that I’ve never had a need to look for it. (1067)”

“Many patients don’t ask questions because they’ve been conditioned not to. Like the doctor is always right. And a lot of people have some feeling that he [the doctor] knows it all. He’s just a human being. You know you should ask questions when it come to your body. (1084)”

The practices of participants can impact the care that they receive and the quality of communication that they experience with their providers. Those participants who were content to not ask questions, even when they acknowledge that they did not fully understand the health information that was provided, likely experienced some degree of confusion regarding what actions they were supposed to take in order to achieve optimum health.

Some participants suggested that patients have to go beyond simply asking their doctors questions during the clinical encounter. For these participants, the most effective clinical experience will occur only when patients actively participate in the encounter. These participants suggested that those patients who prepare for the encounter have a greater likelihood of better understanding health information and of having more positive interactions with their providers as a result.

“I won’t go to a doctor that I can’t talk to. My primary happens to be an oncologist. I always do my homework before I come and you have a little bit of information so that opens the dialogue up. And they [doctors] generally will begin to talk to you. If you just sit there and you don’t say anything, they won’t say anything. But my experience has been that when you start to

dialogue with a doctor intelligently, then the doctor will sit down and talk to you. I don't have any problems with that. (1042)"

"You know I've been pretty lucky as far as my health is concerned. I go with a laundry list[of questions for the doctor], and I tell him what I want. What I expect him to do. So far so good. (1091)"

"I always make a list of questions that I can ask when he [the doctor] is talking. Then he gives me a chance to ask questions. (1061)"

"What I will say in their [doctors'] defense, it [effective communication] also required me knowing what to ask my doctors and required me insisting that my doctor's listening to what I am saying and how I am feeling as opposed to them telling me. (1028)"

Findings from previous studies support the importance of active participation during the clinical encounter. Investigators Greene et al (1986) suggest a number of approaches that can be employed by patients of all ages who wish to have their concerns and health care needs addressed. The researchers suggest that patients should always take a written list of questions to medical appointments. As well, patients should make a point to state their concerns and agenda at the start of the encounter and be willing to repeat their concerns if they are not addressed properly by providers (Greene, Adelman, Charon, & Hoffman, 1986)⁸². Providers should also recognize the importance of a patient's active participation in an encounter and be certain to accommodate patients' requests for information. This includes the provision of a designated time during each appointment during which patients are allowed to ask their providers questions.

The attitudes of participants could have also impacted their communication experiences. Participants who believed that their actions could positively impact health in some manner made greater efforts to understand the information provided by health care professionals. Conversely, those participants who possessed the attitude that medical interventions or treatments would make little difference in their health outcomes might not have adhered to doctors' recommendations. The attitudes of these participants, who believed that they had no control over

their health, might have led to participants not receiving appropriate care and attention. One participant relayed a story about a friend who had been diagnosed with an illness but who made no efforts to have a recommended surgical procedure, possibly because the friend may have thought that her own efforts would prove futile and not impact her health.

“I was downtown and she was up in the Bronx. When I would go up there, I asked her what she’d want me to do and she would say, ‘Bring me so and so’ and as I said, the first can [of food] she told me to bring, I saw it sitting there on the shelf, but I didn’t let her know that I saw that. I said ‘I’m going now, what do you want me to bring you when I come back?’ and she’d say ‘Oh you can bring me so and so.’ And that wasn’t even her intention [to use the food that I brought]. But she tried to pretend that she was using it but she wasn’t using anything. She wasn’t even eating...if my doctor told me that I needed to go and have an operation then I would have went. I wouldn’t have laid around and let it turn to cancer. I would’ve went and did just what he told me to do. If he said take an operation, I would have gotten that operation. (1017)”

Although the participant believed that her friend should have been more proactive and obtained necessary care, the friend – for whatever reason – elected not to seek the care that had been recommended by her physician. Many individuals who possess an external locus of control believe that their actions cannot change the health outcomes that they will experience. The participant’s friend may have held the belief that she had no control over her own health. For this friend, she may have believed that her health status would remain the same and her prognosis would remain bleak even if she decided to follow her doctor’s treatment recommendations and go for care. Such attitudes can cause individuals to be unwilling to openly communicate with providers or comply with medical recommendations.

VII.G. THEME: DOCTOR’S PROVISION OF TIME

Although a number of patient-related factors impact the quality of the patient-provider interaction, there are also doctor-related factors that can impact the nature of the clinical encounter. When discussing the quality of patient-provider communication, several participants

commented about the amount of time allowed for medical appointments. Although participants reported that some doctors attempted to make an effort to address patients' concerns and provided adequate information, several study participants also commented about doctors' inabilities to provide adequate time during clinical encounters. Doctors may be unable to allot extra time because they do not have the time or they may actually have time but be unwilling to devote the time to converse with their patients.

"No [my physician doesn't usually take time to explain information]. I don't even ask because, well it depends on the doctor. You say you've worked at Columbia? Up there, everything seems to be, time seems to be very very important to the doctors there. And it's more important to them to get through say 5 patients than sit down and explain things that are going to happen or the things that are happening or what's been said, that type of thing. (1088)"

"When they [doctors] try to explain the results or something, when a result comes back and they want to talk to you about it and they start talking, it's like 'I don't know what you're saying. You got to tell me.' A lot of doctors are in a hurry. They don't want to really sit down and talk with you. I ask questions. (1060)"

"Because he [my doctor] ain't got the greatest of patience like my other doctor did. And then nowadays it's like a sweatshop when you go to these doctors. You're in and out and it look like they don't really spend no pile of time with you no more. And unfortunately my [previous] doctors are retired. (1026)"

Some participants commented that they may not always be allotted a sufficient amount of time because their doctors were expected to work quickly in order to see each of their patients and not because their doctors did not wish to provide the time to patients.

"My doctor is one little busy man. He'll run over there from Harlem and the office will be full and in three minutes, the office will be clean. He'll get you out of there. (1017)"

"No [the doctor or nurse does not always take time to explain information] I just got this doctor. I just went to her once....They said she was the best doctor there but she was always busy. Sometimes she couldn't see you. So I just got another doctor. (1069)"

Many participants commented that they understood some doctors' inabilities to provide adequate information because doctors' overcrowded schedules allowed little time to devote to each patient. For these individuals, doctors were unable to address the needs of patients because

they had to contend with heavy patient loads, not because doctors were unwilling to spend more time with patients.

“Most of the time [my doctor or nurse explains information to me]. I understand when they’re really backed up and busy. And it doesn’t take that long for them to do it [explain]. (1042)”

“Yes I will sit there and take a little time with me and let them explain it. I don’t think it’s the doctor, I think it’s just the schedule. (1019)”

“I think the doctor was very busy so he didn’t take the time to explain anything. (1073)”

“Well I think that doctors are overloading patients. And I think that a doctor with close to over 40 patients that’s ridiculous. They give less than 5 minutes. You don’t have the time to rattle things off. So when they tell you things, you got to go back and ask again because they didn’t take enough time to explain it. And I think they would like to be more of a giver but the time doesn’t allow them to do it. I think it comes down to the time. (1019)”

One participant commented that she will often not even make the effort to ask a question if she thinks that the doctor is busy. For this woman, her decision to not ask questions was based in part on her fear of having her questions ignored by her provider. The participant reported that she would feel angry if she were to ask questions but receive no response because the provider was busy.

“Doctors don’t have time to do all of that conversation with people because they got 20 patients waiting in their office for them and so that makes it extremely difficult. When you see people, when you walk in and sign in and you see 5 patients and you know, and it’s an hour past your time. You know that the person is backed up. Sometimes you don’t say what you have to say because of that. I think it’s more that you don’t want to be rejected and if I ask you a question and you [the doctor] just sort of fluff it off [ignores question] then I’m going to get angry about it and so then I just won’t bother to say anything. I’ll say something the next time that I come. I’ve never had anything that was vital or real serious serious that I thought that it couldn’t wait. But that’s the health profession now. It’s very difficult to deal with even if you have insurance because a lot of doctors are too swamped and they take too many patients because the insurance companies are paying so little to them. In order for them to meet their expenses and pay all their college loans, they have to double up on their patient load and it doesn’t help. (1042)”

The participant’s comment suggested that she realizes that many doctors often have very busy patient schedules. As well, she also recognizes that increased patient loads may not solely be the fault of providers but a necessary action in order for providers to increase their incomes so

that they can pay for their expenses. However, even with this realization, the participant admitted that she might feel rejected or offended if her provider did not take time to answer her questions. To avoid such feelings, her solution included not asking questions, even during those instances when she might actually need some information.

There were very few instances in which participants reported that they believed that their doctors did provide enough time. One participant (1042) reported that the time usually provided by her doctor is usually more than enough to allow her to ask questions and have all of her concerns addressed. However, this participant's situation was not representative of most patients. The participant admitted that she likely received such a great amount of time during her appointments because she has had a professional relationship with her doctor for more than fifteen years. Not only did the doctor provide sufficient time during the encounter, but she also usually took the participant to her office immediately following appointments so that they could speak more. The participant admitted that although she generally received more than enough time, she believed that if she had not known the doctor for so long, she probably would not have had the opportunity to ask questions or meet with the doctor after the encounter. The woman also revealed that she believed that other patients who had the same doctor did not receive as much time during clinical encounters because they have not known the doctor as long. The participant had spoken with others who are patients of the same doctor and they reported that they did not receive enough time to speak with this doctor, either during the appointment or afterwards. Unlike the participant, the other patients also reported that the doctor did not talk much or ask them many questions during clinical encounters. After conversing with other patients, the participant realized that she did not represent the physician's normal standard of care. The finding that the participant received adequate time and opportunity for discussion is linked

primarily to the fact that the participant had such a long professional relationship with her doctor. The doctor did not provide this level of care for all of her patients.

In situations in which doctors are too busy to spend enough time with patients, one solution may include the use of other health care professionals as a support system. One participant suggested that nurses and their skills are not utilized effectively by doctors and the health care system as a whole. Nurses can help to relieve doctors' heavy patient loads by not only providing patients with information but also additional time.

“A lot of times you walk out of that office, he [the doctor] done told you a lot of information about something that you may have problems with such as your gall bladder. [The doctor might say] ‘I want you to have a glass of milk 3 times a day to put a spin on your stomach or something like that. I want you to get this medicine and take it 2 times a day.’ See those things the nurse could spend a little time with you, sit in that office and explain to you. But the doctors have to do all that. It’s not fair, nurses should be able to do that. She [the nurse] shouldn’t just have to run and get the napkins and wipe the patient and do that kind of stuff. She has a lot of experience. They could use the nurses to lighten up on some of the things they need because when they be explaining to you what’s going on, the nurse be right there in front of you. She has learned a lot over the years being in the room with that doctor. But they only use them as horses in the hospital, they don’t use them as professionals. I think they could do a lot more with that. And I wish it comes to that because one person can’t do all of that you know? And the doctor, in our society where the ratio must be about, what is it, about 100 patients in our society for each doctor you know? We don’t have a lot of doctors in the United States. So we need to find better ways to use them. To use the doctor so you don’t tie him up on everything. (1019)”

Participants' comments suggested that, despite the fact that they recognize the health care industry's demands on physicians, it is still critical that providers make efforts to offer patients adequate time during the medical appointments. Additional time, whether provided by physicians or other types of health care professionals, can provide patients with the chance to ask questions and obtain important information.

The provision of adequate time during a clinical encounter is important because health care providers and patients may perceive that the length of a clinical encounter is linked to the quality of care provided. Often when clinical encounters are longer, patients are likely to state

that they experienced less difficulty talking about problems and making decisions. As well, patients are often more satisfied with the amount of time that they have with physicians (Carcaise-Edinboro & Bradley, 2008).

VII.H. THEME: DOCTOR'S Demeanor

Although patient demeanor has been suggested as one factor that impacts the nature of the clinical encounter, the provider's demeanor was also mentioned as a factor that can greatly influence the patient-provider interaction. While there are aspects of a provider's demeanor that can help to create effective communication between the patient and provider, study participants often emphasized those aspects that adversely impacted communication.

A provider's technical skill is comprised of several key elements including the ability to properly conduct physical examinations. Providers are also charged with the task of gathering, evaluating, and interpreting data in order to make a proper diagnosis and provide proper treatment. These skills are critical but they are not the only important elements that providers must consider when trying to ensure a high level of clinical competence. In order to gain a patient's cooperation with care as well as obtain patient satisfaction, providers must possess adequate interpersonal skills (Hays & DiMatteo, 1984). A provider's conduct, including the technical and interpersonal behaviors that he or she displays during the encounter, is one of the most significant predictors of patients' overall satisfaction with medical care (Doyle & Ware, 1977). It is critical that providers recognize that how they communicate with their patients is as important as what they communicate.

A number of study participants discussed the influence of a provider's demeanor on the patient-provider interaction. The individuals suggested that when providers do not display compassion, patients may experience difficulty communicating.

“My original doctor was on maternity leave. My original doctor was more compassionate. The one I have now she is not compassionate at all so I think we got off to a little [bad] start there... (1070)”

Doctors may not always realize that they are displaying an unpleasant demeanor. When employing methods that seek to motivate patients to adopt healthy behaviors, doctors have to use care to not display behaviors that may appear demeaning to the patient. For one participant who perceived that her physician was speaking to her in a rude manner, the physician’s style of communication only served to create a breakdown in the communication within the relationship. The doctor’s comments made her feel uncomfortable instead of serving as a source of motivation, which was likely the doctor’s intention.

“Okay personally sometimes when my doctor talks to me I don’t like the way she talks to me number 1. She makes me feel very uncomfortable. Okay when she tells me about the smoking and my weight. And once I come back [for another visit] and to me I have like improved she said I can do better but she never say ‘You did great’ you know what I’m saying? So it was like a turnoff to me. The way she talks to me. She notice a little bit and then she says ‘Oh you can do better you only lost 8 pounds’ and I’m like ‘But I lost something’. I’m not coming back with an extra eight pounds you know what I’m saying? And um it’s like to me, it’s like she talks down , maybe she talks down to me to [so that I can] do better but it doesn’t make me feel good inside you know? (1093)”

A visit to the doctor can be a negative experience for some participants if they feel that they are not receiving support during the clinical encounter. Providers should recognize that communication during the clinical encounter should be used as a source of encouragement for patients, not just as a way to provide health information. Communication has a pivotal role in helping patients and providers establish rapport and build trusting relationships, and it provides physicians with a way to offer patients support and motivation both through verbal and nonverbal means. Providers’ use of behaviors that display empathy and understanding (Williams & Weinman, 1998) rely on effective communication. Patients who feel as though they are supported, as well as those who are actively involved in the decision-making processes regarding

their care, may experience greater adherence to medical recommendations (Carcaise-Edinboro & Bradley, 2008) and greater satisfaction with the clinical encounter experience.

Some of the participants believed that their opinions were totally disregarded by their providers. For these individuals, a provider's disregard could be considered as a sign of disrespect and result in a breakdown in the relationship. One woman discussed the impact that her doctor's demeanor had on her own attitudes about the clinical encounter. For this individual, the doctor's tendency to not listen to her and not offer a variety of treatment options resulted in the participant experiencing feelings of sadness and frustration.

"I'm down when I come back from my doctor I'm always down. She [the participant's daughter] said 'you're always coming back [from your doctor] and you're always complaining'. And she said 'you look like you feel down'. She said 'Why don't you just change your doctor'? Your doctor's supposed to make you feel good but every time you come back you know [you feel bad]'. And I'll say [to the daughter] 'Oh she [the doctor] told me to take [some medicine] and...I'm not taking anything because I'm sick of her'. And that's my attitude. That's my attitude. I feel like she [the doctor] doesn't support me. What I don't like is when I ask her 'Is there anything else I can take besides taking medicine?' Because you know I do it a different way. If I really don't need this medicine [can I do it another way?][But the doctor says] 'No this is the way you're going to do it.' You know that's a turnoff. You can't tell me what I'm going to do. If I'm asking you a question, is it a different way besides taking a pill every day? I don't like to take a pill every day. Could I go to the herb store or is there something that I can do different? (1093)"

Doctors who do not support patients' decisions or display compassion may encounter significant barriers that can hinder communication. Findings from previous research have strongly urged providers to make greater efforts to exhibit compassion and empathy when caring for patients and attempting to understand patients' perspectives (Association of American Medical Colleges, 1998; Meryn, 1998). If providers utilize warmth and openness when communicating and express interest in their patients, they may be able to establish rapport with patients. As a result, patients may be more open to communicating and willing to try practices (e.g., screening) that have been suggested by a provider (Kim, Kaplowitz, & Johnston, 2004).

Patients may refuse to actively participate in the encounter or instead opt to seek out other doctors who can provide a better experience. To one participant, a doctor's indifferent attitude during one clinical encounter not only affected communication, but was a probable indication of racism. In order to resolve the situation the participant decided to change physicians.

“Well I changed doctors because I didn't like her [the doctor's] attitude. She seemed very indifferent. Once I asked her what my blood type was and she said I didn't need to know that and I said 'What did you say?' Suppose I have to go to the hospital for an emergency. I changed doctors and reported her. She was very indifferent. I think she was racist. (1084)”

Even though the participant may have had no other reason to believe that the physician was racist, because the physician displayed such an air of indifference, the participant assumed that this behavior must be an indication of racism. If the physician had just answered the participant's question, the woman may not have switched to another physician.

Individuals who perceive that they are not being respected by doctors may not actively participate in the clinical encounter. When doctors do not take the complaints of patients seriously, patients may shut down and refuse to talk openly. One participant who was offended by a doctor's demeanor and comments no longer disclosed symptoms during encounters to her provider and admitted that she did not comply with medical recommendations. To this participant, her relationship with her provider was one that was not equal. The doctor wanted the participant to listen but was not willing to grant the participant the same level of courtesy.

“Because they [doctors] really don't want to hear what you have to say but they really want you to hear what they have to say. I went to the doctor a few months ago and she said something to me that really struck me. She said to me, 'You have anything to tell me other than the same old stuff?' My arm could be falling and I wouldn't tell her about it because she said that comment. And I have done it. I just looked at her. And I agreed with her. I did have some pain. But I kept it to myself. The only time I would mention it to her is that it really got so bad that I couldn't take it anymore. A lot of what you perceive as pain and discomfort, they [doctors] make it seem as like really it's not very important. But any pain to a patient is important. And I think that maybe a doctor should look at it that way. Or what they'll do is say 'Here take this.' Maybe it

[medication] doesn't make you feel any better but they don't want to know about it. If it doesn't make me feel any better, I just keep it to myself. I don't tell [the doctor]. What for? I'll stop taking it. Eventually I may tell them [that I stopped taking it]. I have been in a situation where a doctor has given me a medication just recently and that was it – there was no follow-up. The doctor did not say 'Well has this medication worked for you? How are you feeling using it?' He wrote me a prescription and that was the last I heard of it. I guess it was [working] to a certain extent but that's not the point. If you give your patient some type of medication, you follow up. You say 'Well how are you doing with that?' You don't just say 'How are you doing?' It's 'How are you doing with the medication? How is that? Is that helping you or hurting you?' (1088)"

The participant's tendency to shut down in response to her physician's indifferent behavior may eventually lead to the participant suffering unnecessarily. By not disclosing the symptoms that she experienced, including pain, the participant was not able to obtain the care that she needed. As well, the participant's decision to not disclose all of her symptoms could have led to the physician experiencing great difficulty when trying to provide an accurate diagnosis. This silence on the part of the participant could have made the physician's job much more difficult and ultimately hurt the health of the participant, who may have had to unnecessarily suffer through physical discomfort because she did not want to talk to her physician. As a result of a physician's demeanor, the participant may have received substandard care for some time simply because she did not like her physician and did not speak up to address this issue with her provider.

A provider's consideration of the impact of his or her own demeanor on the clinical encounter experience is vital. A review of the findings from patient-provider communication research support the assertion that factors such as expressions of anger or disagreement by a provider or the use of a negative tone by either the patient or the provider have been determined to be negatively linked to patient satisfaction (Freemon, Negrete, Davis, & Korsch, 1971). Investigators Carter et al determined that displays of tension by providers or patients during discussions about patient history were negatively linked to satisfaction. As well, when providers

displayed antagonism during the physical exam or during the end of the clinical encounter, a negative association with patient satisfaction was also discovered (Carter, Inui, Kukull, & Haigh, 1982).

One participant recounted a story about her interactions with a nurse. The participant, who now has a good relationship with a nurse at her health care facility, was not always able to communicate effectively with this provider. The nurse's terse tone of voice and seeming disregard for the participant's concerns about her own health resulted in a difficult relationship between the two individuals. However, once the nurse began to listen to and consider the concerns of the participant, the two individuals were able to build a better professional relationship.

"Sometimes they [nurses] get nasty. Well when they get nasty I get nasty too. The tone of voice they use. Like one time my pressure was up one time, and I knew it was up. And I had this tendency of going to the hospital a lot. And she [the nurse] says 'You know you come in the hospital a lot because you live by yourself.' And I said 'Well that wasn't the point, I'm coming here because I don't feel well.' And this particular day I know my pressure was up because I felt like I was going to pass out. And that was in the afternoon and I told her. And she said, 'How can you tell when your pressure is up?' I said 'I know it's up... 'Well somebody's got to do something.' And then she said 'Just come on in the hospital you know and we can check your pressure and see whether your pressure is up'. And when I went in the hospital, my pressure was so high. And she looked at me and she said 'Your pressure is really up like you say.' I said 'I know it was up.' And she couldn't understand how I knew my pressure was up. She couldn't really understand how I knew my pressure had went up. And I knew it was up because of the way I felt. She looked at me so strange and I guess she say [to herself] 'How did she know that her pressure was up?' And ever since that day, me and her, me and that nurse we were like this [crosses fingers indicating a close relationship]. We were real good friends... She's real nice. She's nice now. (1027)"

Some participants suggested that sometimes physicians may intentionally behave in a way that is not conducive to a supportive patient-provider relationship. These participants commented that doctors may conduct clinical encounters in a way that ensures that they can maintain some level of control or power over their patients. Providers may utilize certain behaviors in order to make patients feel as those they are less educated or knowledgeable. Such

findings are not surprising because a body of literature suggests that an unequal division of power within the patient-provider relationship is not uncommon. Historically, health care providers have often been perceived, and have perceived themselves, as paternalistic in nature (Parsons, 1951) taking on the role of making decisions for patients.

Sociologist Eliot Freidson suggested that within the patient-provider relationship, there is often a conflict or clash of beliefs and attitudes between the patient and provider because of different expectations that each of the individuals has. This model of the patient-provider interaction describes the patient-provider pair as a relationship comprised of a superordinate and a subordinate. Providers represent the dominant party in the dyad and are often able to maintain this position of power by employing a number of techniques (Freidson, 1961).

One participant surmised that doctors may intentionally use complicated medical language in order to maintain more power within the patient-provider relationship. Doctors' needs to control the relationship, by using technical medical language or similar techniques, can at times result in patients not being able to properly convey their medical concerns because patients are confused about the information that is being presented (Greene, Adelman, Charon, & Hoffman, 1986).

“Doctors have a tendency to be up there while they keep the patient down here. There’s a large gap between what they know and what the patient knows going in. So if the doctor keeps you on that level, you don’t know anything when you go in his office. That’s why you’re there. If he keeps you on that level then you won’t even be able to help him with whatever it is that you have. They ask you a few questions sometimes but they don’t always ask the right questions or they don’t always ask what’s on your mind about what you have because you know your body a lot better than they do. Sometime you just have worries, other times you actually have a problem that you would like the doctor to get to – to address in terms that you can understand and deal with. And sometimes that is a problem. Because sometimes doctors like to play God and you know, you can’t question God. And doctors sometimes are the same way. So they should be more on an equal basis with the patient. Because after all, the patient hires the doctors, the doctor doesn’t hire the patient. So the patient should be more in control of what the doctor says and does than the reverse. (1086)”

Another participant echoed similar sentiments. This participant suggested that some doctors may not truly care about the welfare of their patients. According to this participant, doctors are only concerned about whether they can maintain a certain level of power or control over their patients. For this participant, patients are, in a sense, powerless to participate in decisions about maintaining their own health because they do not have the proper medical training or knowledge needed to make their own decisions about their health.

“Okay I had one physician...So he gave me a prescription and he said this is the way I want you to take your medicine now. And what he wanted me to do was decrease it over time. He said you take 9 this week, and 8 this week, and 7 this week. I haven’t seen him since. The result is that it was sort of detrimental to me because the less I took, the less of the medication made my condition worse. But see it really didn’t matter to him. He said, ‘These are my instructions. You do this’. I was just to do it. He gave it to me and said ‘Here do this’ and then he left. That was it. Then he left. I don’t mean he left the room. He left the country. He left the hospital. I guess he sort of passed my chart on to the next doctor but then by that time like I could hardly walk. I was in a great deal of pain. It was just like, I felt just like I did before I began the medication. I said all that to say that doctors do not really - some doctors not all - do not really care about what happens to the patient as long as his instructions are followed. Like I said it’s that power. [Doctors think] ‘I have a certain amount of power and I’m going to use it’. And because most patients don’t have a medical background, they almost have no choice but to do what this person has told you to do. I did it for a while [what the doctors said to do]... (1088)”

One participant discussed an experience when she believed that a doctor purposefully utilized complex medical jargon so that the doctor would not have to really interact with her. This participant suggested that the doctor may have used complicated language in an effort to humiliate or belittle her or because he did not want to take the time to truly interact with her.

“But I know when my daughter was having a baby, the doctor like to talk over your head you know. And when you ask them a question they tell you some jargon which they’re sure you don’t understand but they do it so they can get rid of you quickly and make you feel like a fool. I know they do that a lot. Like you’re not supposed to question them about your ownself. Oh back home [Jamaica] they’re terrible. Oh Lord have mercy. You’re not supposed to ask them any questions. It’s a third world country. (1032)”

Another participant reported that many doctors intentionally utilize complex terminology with patients because they are egotistical and want to impress or “show off” for patients. This

participant suggested that doctors should stop trying to impress patients and instead utilize language that is simplified and easier to understand.

“Doctors egos are so large. They use all the terminology that they were given in school. That doesn’t mean anything to me. Unless I went to medical school an ‘ectomy’ or any kind of ‘ectomy’ means nothing to me. Sometimes I think they use words that you are not going to understand on purpose. To show you how much they know. I don’t want to know how much you know. I want to know how I am. I don’t want to know whether you know what a certain word means, I want to know what it means. So come down a little, come down to my level. (1088)”

Studies suggest that providers often listen and respond in a selective manner when communicating with patients. Providers may focus specifically on listening to the information that patients offer about certain topics including symptoms that will assist them in making a medical diagnosis (Kern, 1979; Mishler, 1984) instead of listening to all of the information that a patient provides. By focusing efforts on obtaining information that they deem important for making a medical assessment, providers can be guilty of ignoring what they regard as extraneous issues, including those issues that patients may mention during the encounter such as problems with family members or financial problems (Greene, Adelman, Charon, & Hoffman, 1986).

VII.I THEME: PATIENT’S COMPREHENSION OF INFORMATION

One of the greatest barriers to effective patient-provider communication is a patient’s inability to understand the health information that is presented during the clinical encounter. If patients are unable to understand the information, they are likely unable to actively participate in the encounter. Providers may then incorrectly conclude that these patients are uninterested in improving their own health. As well, patients who are unable to comprehend information are likely to experience difficulties effectively acting on health information and successfully navigating the health care environment.

An emphasis on patients' comprehension of information and their health literacy levels is of great importance because so often an individual's ability to access care depends in large part on his or her ability to adequately understand written and oral information. An individual's health literacy can have a profound influence on the patient's experiences during the clinical encounter.

Individuals may experience difficulties understanding information for a variety of reasons. For some study participants, interview responses indicated that they attributed their problems with comprehension to their own limited education, while other individuals emphasized the role that other factors can play with regard to comprehension. Study participants commented on the difficulty that they experienced understanding the information discussed during encounters with physicians. For some participants, their problems understanding were linked to the fact that they had not attained a high level of education and therefore could not understand the doctor.

"I'm not all that educated... (1059)"

"I think it's because of the language...the doctors they are high education and I am low education so it's not easy [to understand]. (1062)"

"Some of them [patients] have a certain educational language to where they don't even comprehend the English reading and writing too much. (1032)"

One participant who experienced difficulties understanding and who also attributed her problems to her limited educational level, indicated that her problems with comprehension were only exacerbated by the feelings or nervousness and anxiety that she experienced during medical appointments.

"When I do [have problems understanding] I ask them to repeat themselves. I think it's because of me. That's what I'm thinking. They tell me like they should. I don't think it's the words so much but me trying to figure them. When I try to apply whatever they're saying, it's harder for

me to understand. When they're talking to me, it's hard for me to understand. It's because I'm scared and not concentrating. When I go to the doctor, my pressure goes up before I get there. (1064)"

In such a circumstance, it may be true that the doctor was actually providing information in what the woman believed was a format that was easy to understand, yet the participant could not understand because she had not attained a certain level of education. However, several study participants did not attribute the problems with comprehension of information to their own limited education. These participants suggested that any difficulties with comprehension were associated with the doctor and how this individual provided information.

Study participants provided many examples of instances during which they have experienced some level of difficulty understanding either verbal or written health information at some point during their visits to health care facilities. For some, the greatest difficulties were experienced when they were conversing with health care providers. Participants' responses revealed that they often encountered significant challenges because doctors utilized complex medical terminology when consulting with the participants during medical appointments.

"Yes [I have problems understanding] medical terms. (1085)"

"It's just hard to understand the words sometimes. I don't know what they mean when they try to tell me about my health problems. (1098)"

"Language they would use. I can't understand what they are talking about. I'm not a doctor. (1014)"

"The doctor was explaining to me about my husband and I didn't understand. He had a stroke so he [the doctor] was trying to explain some things to me. I couldn't quite grasp it. (1053)"

"Words they say [are hard to understand]. I ask them [doctors] to break it down and explain it to me. The words were definitely too hard and too big. I say 'I don't understand what you're saying, can you please tell me so that I can understand it?' (1051)"

The comments about comprehension problems from participants were not surprising because findings from previous reports suggest that less than 50% of the U.S. adult population comprehends frequently used medical terminology. This lack of understanding affects how well patients are able to provide information about symptoms that they may have experienced and how well providers are able to collect the information necessary to make accurate and complete diagnoses (Boyle, 1970; Cole, 1979).

A number of study participants commented that they experienced difficulty specifically understanding information that pertained to the use of medications.

“Sometimes it [a medication’s instructions] has to be explained more. I just have medicine that you take once a day. (1013)”

“I have problems understanding information about side effects and interactions with other medicines that I might take. (1098)”

“They have to elaborate a little more because you don’t understand what it’s for, what it’s going to do, the medicines they’re prescribing for you. (1053)”

Other study participants revealed that they experienced confusion specifically when consulting with doctors about test results.

“I [had problems understanding] when I was taking a test or something. The instructions to prepare for a test like a colonostomy. How you take it [medicine] or frequency. What you can eat or not during the period when you’re preparing for it. I ask for clarification on that. (1094)”

“[I have problems] Probably understanding the different tests for blood sugar. I asked the doctor to explain. (1004)”

Participants commented that they simply wanted to understand exactly what their test results meant. Though providers may have attempted to explain results in a simplified manner (e.g., by reporting that a test result was “good” or “bad”) some participants still wanted to have test results translated and explained in a comprehensive yet still comprehensible manner.

“When I go and have certain tests like I went and had this test for the circulation. They was explaining something like the leg circulation. I didn’t understand it. I asked my doctor and he tried to explain it to me. But I still didn’t understand it. He told me it was nothing. He said it came out good. But I wanted to know because my leg cramps all the time and is numb so it has to be some reason for it. But he said ‘Circulation is good’. I’m going to go to the foot doctor and let them check it out. (1090)”

Although the participant who relayed this account was still confused about the symptoms that she suffered after the doctor repeated that her test results were good, the woman still wanted a second opinion from another provider. However, the woman’s doctor had erroneously believed that he had explained the test results to the woman’s satisfaction.

Inadequate health literacy can act as a great obstacle to proper disease management (Institute of Medicine, 2004). Past research suggests that individuals with poor health literacy who have been diagnosed with an illness may not possess an adequate understanding of their conditions and the steps that they need to follow in order to manage their diseases (Schillinger, Grumbach, Piette, Wang, Osmond, Daher, Palacios, Sullivan, & Bindman, 2002). This lack of understanding about one’s illness can cause a patient to experience a number of adverse health outcomes. The potential for patients to then experience an inability to follow recommendations is especially critical because in the context of today’s health care system, one where advances in research can result in a greater degree of self-management demands on patients, inadequate health literacy can act as a primary barrier to effective treatment for patients, as well as prevent the comprehension of medical instructions provided by clinicians (Institute of Medicine, 2004).

“Sometimes I don’t understand a lot of the stuff that they have now. But I just don’t say nothing. I just don’t understand what the doctors are saying to me and the medicines, my diabetes. I don’t really understand that and I have diabetes. I just don’t understand and I don’t read a lot what I’m supposed to eat. My sugar be high. I don’t know what to do half the time but I know I’m not supposed to eat sugar. (1057)”

For several study participants, the difficulties with comprehension were not always attributed to their own level of education or a provider’s verbal use of complex terminology

during appointments. Several responses revealed individuals' specific difficulties understanding written information that was provided in the medical environment. Participants reported that information included in resources (e.g., brochures) that are supposed to assist patients and serve as references often proved difficult for some patients to understand.

"Sometimes they [doctors] will try to state something right but then it's written so with these extremely big words and I really can't follow through what actually they're trying to emphasize or get over. In the magazines sometimes. Or even some at the drug store they have these, I call them health books, and some of the terminology is a little difficult to understand. (1026)"

"Sometimes when you read the information, it's the wording, how they word it, sometimes it's words that I don't understand and then that mean the whole sentence is messed up for me because I don't quite understand it. (1055)"

[Referring to information in breast cancer brochures] "The information uses words that are too hard to understand and the information doesn't always give definitions of the words. (1099)"

"You might not understand what a brochure is saying so they have to break it down into human terms, laymen terms. (1053)"

"Sometimes the words are so long and they're describing like if you have 'gas' it will say 'gastroblahblah'. Like right I have some sort of stomach, to me it's just like nausea or something and the doctor says it's something 'reflux' and that it says GERD [gastroesophageal reflux disease]. Give me GERD but all of those other words you give me. Medical terms I don't really understand but if it's just in laymen's terms [I can understand]. (1085)"

A number of study participants reported that they experienced significant challenges when completing various types of hospital forms. For these individuals, the questions featured on forms were not always explicitly clear with regards to the type of information that health care providers wanted to collect. Some participants were unable to successfully complete these forms without obtaining some assistance from friends, family, or hospital staff or first making several errors on the forms.

"I need a pencil with an eraser when I fill out the forms. I always need it because when I read back I can see the mistakes. (1064)"

"The filling out a form. I don't quite understand what they want me to do. Sometimes I don't understand. (1075)"

“Most times I understand the forms that I’m filling out because when I’m filling the form out and they give it to me, if it’s something I don’t understand, I’ll take it back to the desk or wherever and I’ll ask a question. Then they’ll tell me what it is and I can go ahead and fill it out. (1055)”

“When I’m filling out applications [admissions forms], I don’t understand everything what they asking and I ask the nurse or somebody what they mean. (1090)”

“Filling out the forms. I don’t ever fill out the forms. Someone does it for you. Someone in hospital always helps me fill it out. (1063)”

“Sometimes you have to ask questions on the forms, whether they want this or that. I don’t always know. (1095)”

“Insurance, it’s like it’s a lot of words and it’s like what are they trying to say? I have to read a lot. Most forms you have to read so much. It’s the medical words I would say that I have problems with. (1067)”

Study participants provided examples of different types of written forms or information that they had difficulty understanding while at a health care facility. When asked to provide an example, one participant remarked that she had problems understanding the *“autopsy report of her daughter (1009).”* Another disturbing finding that was revealed was that participants reported that they had problems understanding other types of important paperwork such as consent forms. Participants admitted that they had signed forms to give consent to have a procedure performed without truly understanding the content on the forms. This is particularly problematic because should some type of adverse event occur as a result of a procedure, the participant might not understand that her signature was used as an indication that she was aware of any risks associated with undergoing the procedure.

“The forms that you sign to give consent. I don’t understand most of that. Sometimes I might have signed one and really not understood everything that was on it. (1098)”

“When my daughter had her baby. I didn’t understand when they give you the form that you have to sign [to have the epidural]. And also what they were going through because she had to have a caesarean and before then there was a complication with the sonogram that they were giving her and the baby’s heartbeat. They [doctors] running around and saying things and you don’t know what they’re talking about. So you have to ask them what’s going on. I had to sign

the form because she was under 18 at the time so I had to sign everything. After they explained what it was, I understood it. To tell you the truth I didn't even know anything about epidurals because I didn't have none of that when I was having my babies. I didn't know anything about that. (1060)"

"I don't understand some of the information in the health brochures. And information that they put on those forms that tell you how to get ready for different procedures. The hardest information that I have seen is information on those forms that ask you for your permission to have some procedure done. The forms that ask for your signature – they tell you all the risks of having something done. That information is really hard. How do they expect us patients to understand all that? (1099)"

Findings from prior research have determined that patients with low literacy who provide signatures on forms for participation in research or to receive treatment, including surgery, may not be able to give full informed consent because they do not always understand what they are signing (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Low health literacy can influence the issue of legal liability when patients who have signed an informed consent form yet do not understand information about a treatment then experience some type of adverse health outcomes as a result of the treatment (NCQA Reviewer Guidelines for the Accreditation of Managed Care Organizations, 1995).

One participant discussed issues that she experienced while trying to understand the details of a medical procedure that she needed to have performed. Although the participant reported that she had undergone a procedure for ulcers, she did not understand what type of procedure had been performed on her own body.

"When I had ulcers, I don't have no idea what was written or what procedure they did for me. What they wrote down. And he [my doctor] gave me a referral to go to another doctor and whatever he wrote on the referral, I had no idea. But if I had to read it on the paper he wrote, I'd have no idea what was said. Some of the words I can't even pronounce. When I went where he referred me to, they explained what it was that the doctor said I was coming for. Because I had no idea. I figured once I get there, they'll tell me. The referral was to the doctor. It was for him to understand. But it was still concerning me and I wanted to know what it was. I knew what he explained to me (about the procedure) but I didn't know if what he explained to me was the same as what was written on the paper. (1060)"

Participants indicated that when they were unable to understand questions asked on medical intake or admissions forms, then they might not have always provided accurate information (e.g., information about allergies, relevant medical history, etc.) that was important for the health care professionals who were responsible for providing an accurate diagnosis and effective care.

“I had pneumonia. When I read the [admissions] form, I didn’t understand some of the words like sputum. (1061)”

“Uh, one of the things that bothered me when I had a slight pneumonia and I went to the doctor and I was hurting and some of the information I can’t remember the word, I know about bronchitis and stuff like that. I had to stop to remember things from high school. And I thought ‘What is this?’ And I thought that old man over there [referring to an older gentleman who was also sitting in the waiting room] probably don’t know what they’re talking about. [The information was difficult] for me to fill out on the admittance form. (1061)”

“Hospital forms. They ask you for the medication that you’re taking and you write down the medication and the times you’re taking it. And then they ask you ‘Why are you taking this?’ And you write that you were taking something else before but the doctor changed it. Then they asked ‘Why did he change it?’ I don’t know why he changed it. (1076)”

Several study participants reported that they experienced numerous difficulties understanding questions on forms and determining the type of information that was being requested on admissions forms. One participant recounted a story about the great difficulty she experienced understanding and completing hospital forms. Questions featured on the forms that were apparently clear to health care providers caused great confusion for this woman.

“[I have problems] Trying to read the signs or filling out forms. Staring and trying to read it over to see, to get the understanding of it, you know, the meaning [forms]. Sometimes the way the sentences are. The way the questions are put to you. Now I went to one place and I asked a question there and they asked whether I was allergic to any medications. So I wrote on the form, ‘I have a reaction for most medications that I’ve taken.’ So when the doctor came in with the [forms], the secretary had just circled everything. So he came in with an attitude. ‘You don’t have any business here if you’re allergic to this that and the other and you circled everything’. [I told the doctor] ‘I didn’t circle anything. I wrote up there that I have reactions. I didn’t say anything about being allergic’. So then he started asking me questions, ‘Well are you allergic to penicillin?’ I said ‘I don’t know. I haven’t had any penicillin.’ ‘Then you’re not allergic to it then. You put down no.’ How in the devil can I put down no if I haven’t had it? See that’s what

I'm talking about. Sometimes the way things are worded. It was on there, reactions or allergic to medications. And it had a whole bunch of medication. So I didn't mark anything. I just wrote up there, 'I have a reaction to most medications.' That means that when I take a medication, it reacts on me and it's not just common side effects. It's the rare side effects. I had went through cholesterol drugs from A down to Z and every one of them, even without the statins [class of cholesterol drugs], that reacted on me. It's just a reaction. Sometimes they say the side effects will go away but sometimes they don't go away... You'd be surprised about all the medications can do. So that's why even now, my doctor that I have now, when I tell her about the medication and everything, she doesn't push me to have the medication. If I tell her I have pain. Medications I just can't cope with. (1074)"

Another commonly reported complaint by participants centered on the fact that women experienced problems understanding information provided in various places in clinics and other types of medical environments. For instance, participants commented on problems they experienced understanding information featured on the signs in medical facilities.

"Like I read a sign but I don't know what they mean [flyers posted in the hospital]. Medical words. (1050)"

"Yeah it's hard to understand the information on signs sometimes. I don't know what the words mean all the time. Like if I see words that they use for the x-ray department. Words like radiology. The words for the departments are hard to understand. (1100)"

Other participants also commented on difficulties that they had experienced understanding the information included on signs and in other sources in medical facilities. However for these individuals, the problems experienced were not because of complex medical terminology but the result of the small font that was utilized on signs or in other sources of written information. For these participants, the small font size was not always appropriate, especially for older patients or for those who suffer from visual impairments.

"Sometimes reading the signs. Because half the time I can't see. I need to get thicker glasses. Because everything, after a while, it comes all together like one big black ink spot. The words are too small. I can't see it. (1049)"

"Sometimes I have problems even seeing the words because the print is so small. I also have problems understanding what's in those health pamphlets. The nurses give you papers sometimes for you to get ready for some kind of procedure and it's hard to read those papers too. (1099)"

One participant talked about problems that she experienced understanding information during clinical encounters because of auditory impairments. This participant suggested that the issues she experienced were the result of her doctor speaking quietly and not her own physical impairment. The study's interviewer noted that the participant did likely have difficulty hearing because the interviewer had to speak very loudly when talking to the woman. However this participant insisted that she did not need the assistance of a hearing aid.

“One thing I don't like about my doctor. I have a hearing problem but I don't need a hearing aid. And he mumbles to me. He won't speak up. I used to argue with him and he spoke up. Then he started mumbling again. (1030)”

For certain participants a lack of understanding was in no way linked to the use of complex medical terminology by providers or in written materials. Instead, the issues that they experienced were associated with how a physician spoke during an encounter. Participants reported that doctors who spoke with accents were often hard to understand.

“My doctor is Italian so sometimes her accent is very thick. (1072)”

“I don't understand foreign doctors often. (1005)”

“It has nothing to do with even educational levels. Sometimes it's just the accent that you don't understand. (1032)”

For a few study participants, the difficulties that they experienced understanding information were the result of a provider's handwriting that was difficult to read.

“When they write prescriptions, I don't understand that [the handwriting]. (1009)”

“The words used or even the doctor's writing. Their handwriting is terrible. (1005)”

It is critical that efforts are made to examine the various reasons why patients may experience difficulty understanding information. Although the comprehension of medical terminology is a major reason why patients experience difficulty during clinical encounters, as

reported by participants in the current study, there are a multitude of additional factors that can impact a patient's ability to understand information in the health care environment. A continued examination of these factors is critical, because so often an individual's ability to successfully access care depends in large part on his or her ability to adequately understand any written and verbal information that is provided.

VII.J. THEME: DOCTOR'S PROVISION OF INFORMATION

Another common theme that was discovered in the responses of study participants focused on health care professionals' provision of information. Although many participants mentioned that they experienced difficulty understanding information, a number of participants also commented about whether or not doctors provided adequate information. These participants discussed the manner in which information was provided, if enough information was provided, and how a provider's style of delivery could impact how well information was understood by participants.

When asked if participants believed that their doctors provided adequate information during the clinical encounter, several participants reported that their health care professionals did make efforts to provide information. The responses suggested that these participants were satisfied to some degree with information that was provided by doctors.

"Yes my doctor explains everything and when I don't understand I ask questions. (1072)"

"When he explain me something and I don't understand, I ask him to [explain] and he make it easy to understand. I can say two, three times. 'Doctor I don't understand. Can you please tell me again, can you please tell me again?' And he'll tell me until I get it to understand. I ask until he make it easy to understand. (1062)"

"Mine is pretty good. Most of them are pretty good. I never had really a difficult time. Because sometimes they use terms and you have to bring them back down to Earth. (1040)"

"He speaks in plain English. (1044)"

“During appointments with doctor. I don’t understand the names of drugs all the time. The names on the drug bottle [generic]. My doctor explains it to me. (1004)”

“They’re very clear about what they say to me. They break break it down. I don’t have to ask, can you give it to me in laymen’s terms. Okay? They understand and don’t want to have to repeat it. So I guess that’s why they give it to me the right way. (1039)”

Although a number of participants were satisfied with their doctors’ provision of information, as many were dissatisfied with the manner in which information was delivered. Still, despite this dissatisfaction, women did reveal that their providers clarified information if asked. One participant discussed a situation when she had experienced a problem understanding the information supplied during medical appointments. Although this woman did not understand what her doctor was saying, when she asked the doctor to simplify his language, he altered the manner in which he delivered information. By modifying the way in which he spoke, the doctor was able to provide information in a clear manner which helped the participant better understand.

“Sometimes they talk but generally I’m like, I don’t have no idea [what they are saying]. [I say] ‘Listen you have to tell me in plain English’. I usually do that. So and then I understand because when they start doing that I stop them and tell them to talk to me in plain English. They have done it quite a few times. And I’ll be like, ‘Look you have to talk to me like I’m 5 years old.’ This was a general checkup and the doctor was talking and he was just using words and I was like ‘What are you talking about?’ So I said, ‘Look you’ve got to talk to me just like I’m 5 years old but I don’t know what you’re saying.’ I had no idea what he said. So then he kind of laugh and then he broke it down to where I could understand it. He wasn’t annoyed. He kind of laughed. I think he realized it also when I said that. I said ‘I don’t know what you’re talking about and I’m not taking anything [medication] until I know what it is.’ He was explaining something I was supposed to take with this long name. (1040)”

For this participant, even though she was unable to understand the information provided by her doctor, once she made the effort to point out that his language was too complicated, he immediately modified the manner in which he presented information.

Despite the fact that many of the study participants reported that they were satisfied with their doctors’ provision of information, a number of women in this study reported that their

doctors did not always adequately provide or explain information during clinical encounters.

Unlike the participant mentioned previously (1040), these participants were not always able to receive a follow-up explanation that helped to clarify information.

“It was very difficult because anytime I asked him or said anything to him, he’d say ‘You need to take off the weight.’ He [the doctor] didn’t explain anything. (1074)”

Some of the participants who reported that they had not received adequate information from their doctors indicated that they sometimes received information from other types of health care professionals (HCPs) including patient advocates and nurses. Although these individuals may not have been satisfied with the information provided by their doctors, they were able to receive assistance from another source within the health care facility.

“I go to the Brown building [at Harlem hospital] and when you finish with the doctor, they send you in the little room and get my prescription. He’ll sit down, whatever they call him [patient advocate], and explain everything to you even though I know what it is. (1051)”

“Yes sometimes they have a word on that I may miss. They got so many words. I think, ‘What is this? Or what is that?’ First I’ll call and ask to speak to the nurse because the doctor is always busy. The nurses on the floor I’ll ask. (1015)”

Some participants revealed that they no longer depended on physicians to provide information at all, but instead relied primarily on certain HCPs to provide assistance so that they could better understand health information. Many of these women who sought information from other types of HCPs reported that they would specifically seek out their pharmacists in order to obtain information.

“They [doctors] give you the prescription and that’s it but when you go to the drug store, that’s when they print out, they print out cards with the name of medication, the dosage, and all of the side effects. (1026)”

“The pharmacist explains it too. He always explains. (1051)”

“The pharmacist told me you got to ask and he told me don’t try to figure out nothing yourself. When it come round to your health. You got to ask. (1051)”

Participants commented on those instances when doctors specifically referred patients to other health care professionals for information. According to these participants, the patients may not have always been able to obtain information easily from these individuals. The doctors who referred patients to these other health care professionals may then have been under the false impression that once a patient left the medical appointment, she received information without any difficulty because of their recommendations that the patient obtain assistance from a nurse or other type of HCP. However, patients may have been referred to additional individuals and had to take several steps (visiting more than one or two health care professionals) before they were finally able to obtain the information that they needed.

“He’ll [my doctor] say okay you can just go to her [nurse] she’ll explain everything to you. And then the nurse will send me to someone else, you know like if I have to take a test. Like if I have to bring a stool if I want to know what day and how do I do it. She [nurse] never explains it to me, she always sends me to someone else. (1093)”

Another participant experienced frustration because her doctor had not provided all of the information that she needed in order to properly understand her treatment plan for diabetes. She had to obtain information from another health care professional so that she could gain a better understanding.

“When I was diagnosed being a diabetic. I had to take insulin. So she [the doctor] didn’t explain to me how to administer it to me. How to give me my own shots. And I’m thinking to myself ‘Does she think I just know this? I don’t know.’ She told me how many units to use, how to use the needle, but not where to stick it. She didn’t tell me I could stick it into the thigh, she is only saying my stomach but she’s not telling me where in my stomach. So when I left her office I had to ask a nurse where and she tell me you can go in your thighs. Oh well why didn’t she [the doctor] tell me? She was too busy telling me about the pills more than what to do with that insulin. She didn’t tell me more and I was like really upset so I just left her office. I didn’t want to talk with her any longer. I just left and talked to the nurse. The nurse was more helpful. (1070)”

Although the participant reported that there were aspects of the treatment plan that confused her (i.e., where in the body to inject the needle for insulin), she did not offer a reason

why she did not ask her doctor to provide more information about the instructions for insulin.

The participant did not report that she had revealed her confusion to the provider during the clinical encounter. Instead, she left the encounter with feelings of dissatisfaction about the care that she had received and sought assistance from another individual.

Another participant emphasized the importance of physicians providing enough information. This participant experienced difficulties that were associated with the fact that she did not have enough information, not because she did not understand the information that was provided.

“I have some of the best doctors in NYC. My doctors are just some of the best but that doesn't negate the fact that I have had problems in the past. I felt that they did not understand or investigate my complaints, my needs. And they did not thoroughly explain to me the side effects. That was one of the major issues. Medications now, they cure one thing but they have a tendency to interfere with something else. It's not the language. I didn't misunderstand. I just felt that I wasn't given enough information that would better serve me as well as the doctor. In order for my treatment to be effective, it requires me understanding what the doctor's saying, also understanding the medication, understanding the importance of taking all the medication and also the side effects so that when things happen to me as a result of the medication I don't get anxious thinking that something else is wrong. You may not understand that but sometimes when you take medication it brings on another symptom. (1028)”

For this participant, an important part of her satisfaction with provided care was associated with whether or not she was well-informed about all aspects of her care, including her medication and any potential side effects that could occur as a result.

In many instances, patients who indicate that they experience better communication from their doctors including clearer instructions about medication use (Williams, Parker, Baker, Parikh, Pitkin, & Coates, 1995; Jolly, Scott, & Sanford, 1995; Spandorfer, Karras, Hughes, & Caputo, 1995) and greater counseling (Tarn, Heritage, Paterniti, Hays, Kravitz, & Wenger, 2006) about their medications have an increased likelihood of adhering to recommendations from providers than their counterparts who do not receive such communication or explanations. These

individuals may be more likely to adhere to recommendations because they possess an understanding about their medications and as a result possess knowledge about how to take them (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

Researchers Tarn and colleagues determined that often providers do not communicate either effectively or at all about many of the key elements that are important for proper medication use. Investigators speculated that this lack of proper communication may contribute to patients' misunderstandings about both the need for medications and the proper directions for medications. The end result may be that patients do not take medications properly (Tarn, Heritage, Paterniti, & Hays, Kravitz, & Wenger, 2006).

The provision of adequate amounts of information by providers is important because it can also help to address patients' concerns about health. This is especially true for those individuals who may have a serious illness.

“Explaining because if you’re diagnosed with cancer it doesn’t always mean it’s a total death sentence. Also explain that it don’t always mean right away that you have to lose a breast because that’s another reaction. They feel as though I got a lump, that means cancer, next thing you know I’ve lost a breast. Also like someone was explaining to me, when they diagnosed her, her right bust swole up and then she says it wasn’t really hurting but then she noticed that the right bust shrunk and the left bust is swollen up now and the right bust got completely smaller. You know and she was like a heavy chested woman like myself. She said what she read, it never really explained why something like that happened. (1026)”

According to some participants, for patients who receive news of a diagnosis of some kind (e.g., cancer), the availability of proper information can help to ease individuals' concerns and calm any fears.

When study participants were unable to obtain either enough or any information, they sometimes experienced great frustration. One participant reported that such feelings caused her to change physicians and seek out care from another provider.

“Yes – with previous doctors, they don’t explain it as they should have, and especially the last doctor that I left, he didn’t explain anything. He did not explain anything. I asked him questions and when I complained about certain things, all he did was sit up there and tell me I’m too fat and all of this. And that’s when he’s pushing medications at me and I told him I couldn’t take the medications. They had me bloated you know and he’d say ‘Oh you’re too fat, you need to lose 70 pounds and everything.’ I looked at him the last time he said that and that’s when I told him I want another doctor. (1074)”

It is critical that providers make every effort to address patients’ needs, because resulting frustration can lead to patients switching providers. This issue is particularly critical because of greater competition in the medical marketplace amongst physicians. Providers need to develop and utilize skills that can often provide patients with a sense of satisfaction about the care that they receive. Otherwise, the result for the provider may be a reduced patient load (DiMatteo, Hays, & Prince, 1986).

One participant suggested that doctors are willing to provide information, but only if patients take the additional step of specifically requesting it. All doctors may not take the time to voluntarily offer patients information unless a request is made. For this participant, if the patient does not make the effort to ask questions then the doctor will not make the effort to provide information.

“...they only provide enough information as you ask them. If you go there asking them information then they will [explain things] but if you have a 15 minute or 5 minute thing [appointment] and you’re out the door with no questions...Then you release the doctor to see that next patient. So I mean if I have questions yes [I will ask them] and if this a doctor that can’t answer questions for me you know about my body and my concerns that I have, this is a person that I wouldn’t want to see. (1016)”

Another participant reported similar perceptions about the provision of information during the clinical encounter. For this participant, doctors should be willing to make the effort to provide information even if patients do not ask questions because doctors are likely aware that patients do not understand much of the health information that they provide during visits.

“I’ve had doctors that didn’t explain what was the medication or the name of something they had diagnosed me with. I’ve had that. And then I’ve also had doctors that was considerate and sat down and explained the process or the procedure or the name to even what it was and what kind of medication you’re gonna take through the whole process. There’s some out there that do it and some out there that don’t. You know they don’t take the time out there to do stuff like that. A lot of times people don’t ask questions...those doctors know that we don’t know those names. They know we don’t know that. I think they should explain it more. They could give us some more inside information on it instead of us having to ask because most of the time we don’t ask. But we see that name and we just pass it by. So yes they can give us a little more information on it without us asking because they know certainly that we don’t know what that is. You know? (1045)”

One woman reported that she may not have received information even if she made the effort to ask questions. The woman’s comment suggested that she likely did not receive information because her doctor was unable to answer her questions yet did not want to disclose his lack of knowledge to the woman.

“If you ask questions. He’s [the doctor] not going to go into it. You know like sometimes I may say something and it’s like it don’t even exist [like I didn’t ask the question]. I’ll ask ‘Why am I getting this sharp pain in my leg?’ No answer. You know? Which I find out when I went to wound care is that there’s still a lot that they don’t know about diabetes... And if you ask them why, they can’t answer you, they honestly can’t answer you. And I heard him one time. He was telling this young intern ‘Well there’s a lot of things that we don’t know where the diabetic is concerned.’ So none of them really have no answers. (1026)”

One area of research that has been examined in the field of communication is patient uncertainty and provider disclosure of information (Greene, Adelman, Charon, & Hoffman, 1986; Danziger, 1978). During the medical encounter, patients seek information from their providers because of a high level of uncertainty about their health. Although providers may also be uncertain, they often do not reveal this to patients. Providers’ control of information as well as the maintenance of patients’ uncertainty allows the provider to retain power (Greene, Adelman, Charon, & Hoffman, 1986). Although the study participant had not suggested that the provider was intentionally withholding information in order to maintain some sense of control

over the encounter, she suggested that the provider may not have possessed the knowledge necessary to answer her questions, yet for some reason he did not reveal his uncertainty to her.

VII.K. THEME: RESPECT

Important aspects of communication such as a provider's ability to listen and demonstrate some degree of respect during the medical visit are examples of communication elements that are critical to the provision of effective care. The use of such behaviors can help to greatly increase a patient's level of satisfaction. Respect can be expressed by providers who show that they are attentively listening to their patients as well as expressing the most appropriate nonverbal behaviors (Cole & Bird, 2000; Coulehan & Bloch, 1992). As well, respect can be illustrated during those instances when a provider possesses different beliefs (e.g., religious or health-related) from a patient, yet still makes the effort to acknowledge the patients' beliefs.

For some participants, the theme of respect was an important one that was often discussed in interview responses. Participants commented about doctors' displays of respect and also emphasized instances when a doctor displayed some type of disrespectful or uncaring attitude toward a participant. As well, participants' comments illustrated instances during which they felt uncomfortable because of a provider's actions.

One participant, who reported that her doctor often left her waiting for long periods of time before an appointment, believed that her doctor did not respect her time. Despite the fact that patients were kept waiting, the doctor did not appear apologetic. As a result of her frustration, the participant "fired" her doctor and sought care elsewhere.

"I just fired her. I'm getting a new one. She didn't seem to care enough. And she was always nonchalant and I'd go there and sit between 2 and 3 hours before she'd see me. It was disrespectful of my time. Someone just gave me a new one Sunday [new doctor]. (1082)"

Another participant discussed her perceptions about doctors who exhibited disrespect in another way. This participant believed that doctors do not always take the time to truly listen to their patients. When doctors do not take their patients' opinions into consideration, patients may be left with the beliefs that their doctors do not regard their (patients') opinions seriously, and this disregard may potentially result in patients not receiving proper diagnoses and care.

"I think that it is extremely important that we as patients know what to ask our doctors and what to know a little bit about how we feel because in a lot of cases, when you go to doctors, especially doctors in Harlem and you tell them how you feel, most times instead of them trying to investigate what you're saying, they try to tell you how you are feeling. They don't understand that a lot of times, we as women, especially women of color, we know our own bodies so even if we may not be able to explain it in medical terms, we can just in laymen terms say 'Well I'm not feeling well this way or this way' and a lot of times, especially in Harlem, doctors don't really do thorough investigations. They like to put us in a certain category that if you say you feel tired right away they say 'Oh you have chronic fatigue syndrome' as opposed to saying 'Oh let me take your blood and make sure that your blood cells are such and such and such' and I think that if more of the physicians that were in Harlem were like the old time physicians, then I think a lot of us would get better care, health care. I really do. I think that a lot of the illnesses that a lot of times that we are diagnosed with and they say 'Oh you wait too long'. I don't think that that is always the case. I think that in some cases, not all, but I think in some cases when we go to the doctor and explain to them how we're feeling, as opposed to them investigating what we say, they put a label on us and say this is what you should have and sometimes that is simply not the case. (1028)"

Participant responses also revealed that doctors do not always exhibit a caring demeanor or bedside manner during clinical encounters. One participant reported that her provider did not take the time to complete a thorough examination during one medical appointment. For this individual, the perception that her doctor did not appear to have a real interest taking the time to provide her with quality care made her want to submit a complaint to the doctor.

"Supposedly I can't say yes because the one I was talking about who didn't give me the [breast] exam, didn't even take my clothes off. I just saw him for the first time and I guess I'm going to write him and tell him he shouldn't get paid [the doctor didn't complete the exam]. He opened my mouth. Finish. Looked in my eye. And how can you examine somebody's breast or anything with their clothes on. He almost took my blood pressure with all my things on. You have to have the arm exposed. So this guy was not good. Definitely I'm not going back. I can't even get an answer from him. He took urine from me three weeks ago. What did my urine show? What was the results? And nobody's picking up the telephone. If I call before 9 [a.m.] and let it ring 8 or

9 times no one answers. I call at 10 [a.m.] no one answers. I call at 3 [p.m.]. No answer. I don't want to go down to 110th Street and spend car fare and then he's not in. He never said 'Roll up your sleeves' [when he tried to check her blood pressure]. I just felt like he thought 'Well here she comes, I've got to do her. So let me do it and get it over with. Like he wasn't 'How are you? Are you having a nice day?' He didn't have any personable. What's that word? Bedside manner. None of that. And people need that today. (1065)''

This participant perceived that she had been disrespected because not only was she unable to get information regarding her test results, but she was unable to get in touch with her health care professionals at all. As well, she believed that her doctor did not provide a high level of care.

One participant's negative experience during a mammogram appointment resulted in her refusal to return for future screenings. This woman believed that she had been disrespected by the technician who performed the mammogram. In order to prepare for the procedure, the woman was asked to disrobe. When the woman asked the technician to close the blinds in the windows after she had disrobed, the technician refused. Although the participant felt uncomfortable having the blinds open and repeatedly expressed this, the technician responded that the blinds did not have to be closed because they were on a high floor and no one could see into the windows.

"I ain't been [to get a mammogram] in a while. Years. It's been years though. Because I'm like this. If I go somewhere and the window is open, not the window open but the blinds are open. I don't care if it's high up or not, close them up, make me feel comfortable. I won't go back there. I could be up high and there's nothing there. But if the windows are open. Make me feel good. It's like this is your office and you are on the high floor. To you it's okay, but if I'm your patient, the windows are open and I'm like 'Close them' and [you say] 'Ain't nobody there' I don't care if they are there or not. Make me happy. Close the blinds up. At that place, the state building, it's [the blinds are] open so I never went back. I need to feel comfortable. They got blinds and they don't want to close them up. I'm the patient, make me feel comfortable. If I tell you something [and they say] 'Can't nobody see you'. I know that but make me feel comfortable. I don't want to go back. I haven't been back in about 15 years. (1051)''

"When I go for my physical. You don't know how I feel or what I'm going through. They should respect that. They don't respect that. (Interviewer asks 'Did you ask them at that time to shut the blinds?') That's why I wouldn't go back there. Yeah [I asked about the blinds] and they wouldn't do it. [The technician said,] 'Nobody can see you. Nobody can see you.' [I said] 'I

know that's just how I am.' (Interviewer 'If they had shut the blinds would you have gone back?') 'Yes'. (1051)''

For this participant, the technician's refusal to accommodate her requests was a clear indication of disrespect. As a result, the participant opted to not return to that health care facility for screening again. Although the participant did not state that she has never returned for a mammogram at any other facility, she did report that she has not had a mammogram in years. Her negative experience with the technician may have contributed greatly to her not going for her annual mammogram. This delay in seeking care may have possibly impacted her attitudes about participation in preventive care. This one negative experience, specifically the technician's perceived disrespect, may have significantly affected the participant's attitudes and health-seeking practices and ultimately the health outcomes that she may have experienced.

VII.L. THEME: DOCTOR IS UNAWARE OF PATIENT'S DIFFICULTY UNDERSTANDING INFORMATION

Another interesting theme that was discovered in the examination of the participants' responses was the belief that not only do many patients not understand much of the health information provided by doctors, but their doctors are probably unaware of this lack of understanding. According to these participants, it would be especially difficult for providers to address this barrier if patients do not inform their doctors of their difficulties comprehending information. Study participants suggested that even though many patients are fully aware that they do not understand information that may have been provided during a clinical encounter, these individuals will often not make the effort to reveal these difficulties to their providers.

"They [patients] say 'uh-huh, uh-huh' [indicating understanding]. They [patients] don't be fully understanding what they [doctors] are saying. But they'll [patients] always agree on every little thing that they [doctors] say to them [patients] and it's like they're [patients] in a blank. They [patients] don't know zilch. (1050)''

“Doctors always talk over your head. They use words that are hard to understand. Sometimes I can’t even write the words down because I don’t know how to spell these words. The doctor will just keep talking and I know that I look confused. I don’t say anything though. (1100)”

“I don’t think that he even knows that I don’t understand a lot of what he says. He uses such big words. I ask him questions but sometimes it’s so much that I don’t understand that I don’t even bother. I just get tired of trying to understand. (1099)”

“The information is hard to understand and the doctors don’t ask if I understand it. I don’t always ask questions either so maybe they don’t know that I don’t understand. (1098)”

One participant mentioned that if patients do not take the step to disclose their lack of understanding, their providers will be unaware of their difficulties and will not make any efforts to tailor the manner in which they [doctors] provide information.

“I feel like they rush patients all the time. I think they want to help their patients but I don’t think that they even know that they use words that patients don’t understand. I don’t think it’s because doctors don’t care, they just don’t get it – that we don’t understand half of the stuff that they are saying. They try to give us the information but if the patient doesn’t say anything, you know that he [the patient] doesn’t understand, the doctor will keep right on talking and using all those words. (1099)”

The participant suggested that doctors should be able to recognize when patients don’t understand information. Even during those instances when doctors are not aware of patients’ confusion, doctors should not make the assumption that patients who do not ask questions have a firm grasp of any information that has been provided. A patient’s silence during a medical appointment can sometimes serve as an indication that the patient may be confused.

Participants indicated that they may not have always revealed their lack of understanding to doctors because the women did not want to frustrate their doctors. These women believed that their doctors would think that they were not intelligent or would think badly of them in some way.

“[I didn’t ask questions] Because I didn’t think that I would understand even if he did explain. And I didn’t want to frustrate him. I didn’t want him to know that I didn’t understand. (1100)”

“But it’s so hard. I don’t understand that. Sometimes I don’t say anything because I hate for them to think I’m stupid you know and then I’m old. I just guess at what I’m supposed to do sometimes. I think that’s what he [the doctor] meant or she meant. I try. I just try, but I don’t understand a lot of this medical stuff and the new things they have out now. I just go on each day until the Lord calls me home. (1057)”

“You’d be surprised that a lot of people don’t understand the things that are said to them. Some people will not ask questions. And I’ve heard people say, ‘I wasn’t going to sit up in there and ask that question. You know for them [doctors] to know how dumb I was.’ I said ‘Well honey I ask questions, because he’s the doctor and I’m not. And if they are the doctor they are supposed to know that and answer that.’ So I ask. Sometimes they’ll tell you and sometimes, you know depending on who the doctor is, some of them do not have patience. Some doctors have very little patience. They’re steady talking and asking questions, and you’re trying to ask questions and they stand up and open the door trying to get you out. They [some women] didn’t want the doctor to know how dumb they were. Don’t be afraid. You’re not the doctor, they’re the doctor. They had to learn. So you’re supposed to ask. If you don’t understand, ask them to explain. Tell them to give it to you in simple English, something you can understand. Because no we do not understand all those words. I don’t understand all those words either but if you ask them to give it to you in simple English. Tell them, ‘Break it down to me’. You know? (1074)”

Some participants revealed that they have not always divulged the problems that they experienced when trying to understand because they were too confused by complex medical language to even formulate questions. These individuals may not have even made an effort to ask a question because they did not know what questions they should have asked.

“If I don’t understand something I won’t ask because I won’t know how to put it to them for them to understand. Because I might jumble it or whatever. There have been times when they [doctors] have asked if I have questions and I didn’t understand. I didn’t ask questions. I said ‘No.’ I don’t say anything. I don’t say anything. (1069)”

For participants who did not understand the information that was provided enough to ask questions, one solution that they devised was to find other ways to obtain clear and comprehensible information. One approach often involved asking other individuals (e.g., family, friends, other health care professionals) to provide an explanation about information that may have been provided earlier by a physician but that may have been too difficult to understand.

“I don’t think that my doctor tries to explain the information to me. He just talks but doesn’t stop to think that maybe I don’t understand. Maybe he doesn’t know that I don’t understand. I don’t let him know. I’m usually so confused when I am talking to him. Sometimes I ask

questions but sometimes I am so confused that I don't say anything. I just ask one of my kids when I get home. (1100)"

"I ask questions sometimes, but sometimes I just get tired because it seems like there's a lot that I don't understand. I don't want to hold the doctor up and keep asking questions. I will leave and then ask someone else – my family members and friends - to explain stuff to me. (1099)"

Although participants disclosed that they have not always revealed their confusion about the information that has been offered by their physicians, many of these women suggested that it is still up to the physician to take some steps in order to ensure that their patients understand.

In addition to the previously discussed themes, three more themes, "Age", "Gender", and "Patient's Difficulty Remembering Information" were discovered amongst the responses of study participants. Although these additional themes did not occur very frequently in the data collected for the current study, findings from prior research suggest that these factors may impact the nature of communication within the patient-provider dyad.

VII.M. THEME: AGE

The topics of "Patient's age" and "Doctor's age" were not mentioned often by study participants, but previous literature suggests that these factors may impact certain aspects of the patient-provider interaction. With regard to "Doctor's age", one participant reported a preference for older physicians. For this individual, a physician's age could impact the nature of the clinical encounter by improving the patient's ability to communicate with the physician. The participant expressed her preference for an older physician because older physicians communicate differently – more effectively - than their younger counterparts. This participant believed that older doctors tend to take more time with their patients than younger doctors, and as a result of this increased time, older doctors are able to devote more time to providing explanations about information.

“I got my old doctor and I can talk. These younger ones, they don’t talk to you like the older ones. They don’t have that much time. (1033)”

Although the theme of “Patient’s age” was not discussed by many participants, a few individuals offered this factor as one that could impact the nature of the clinical encounter. Research has revealed that older adults may ask few questions during encounters, provide less important information to doctors, and behave less assertively than their younger counterparts (Ryan & Butler, 1987). As well, communication on the part of the provider may be influenced by the age of the patient. Adelman and colleagues suggest that physicians are often more condescending or abrupt when conversing with older patients, as compared to younger patients (Adelman & Albert, 1987). If a patient feels that the provider is behaving in a manner that is not warm and friendly, for whatever reason, (s)he may be unwilling to actively participate in the medical encounter, including providing appropriate information needed for diagnosis and participating in decisions about care.

A few participants suggested that the older age of a participant could impact an individual’s ability to communicate with her provider. One study participant referenced her older age and suggested that it might have affected her ability to understand information during previous clinical encounters.

“But it’s so hard. I don’t understand that. Sometimes I don’t say anything because I hate for them to think I’m stupid you know, and then I’m old. (1057)”

Another participant explained how her mother’s older age adversely affected the mother’s ability to communicate during medical appointments.

“...when my mother come back from the doctor all she can tell me is ‘My pressure was good’ but she cannot tell me what the doctor said because she cannot understand anything he [the doctor] said to her. But she’s not going to sit there and say, she’s 81, she’s not going to say ‘What? What do you mean about that?’ She don’t understand anything. (1093)”

One participant suggested that changes are needed in the provision of information in order to accommodate the general needs of older patients.

“I would like them when they put out the brochures to put them in large print, large print. When we get older we need help. Put words and put the meaning of them. That would help a lot. Then we wouldn’t have to run and look for a dictionary. (1076)”

Many older adults, even those regarded as healthy, often discover changes in the effectiveness of their communication skills that have developed over time. These changes may be linked to normal hearing and vision impairments and problems processing information that may be associated with the normal process of aging, including memory loss (Bayles & Kaszniak, 1987; Kemper, 1992; Nussbaum, Thompson, & Robinson, 1988). Such factors can have a dramatic impact on both the quantity and quality of communication that occurs between patients and providers.

VII.N. THEME: GENDER

Although both patient and provider gender are two factors that have been discussed in the literature, the majority of the participants for this study did not cite either as key factors that impacted their interactions with their doctors. Only one participant commented about the influence of provider gender. For this individual, her provider’s gender might have impacted her desire to seek care. This study participant reported that she was apprehensive to have a colonoscopy performed because her doctor was male. Although the participant revealed that she was afraid to have the procedure performed, the fact that her physician was male also served as a major deterrent to her participation in preventive care.

“I can talk to my doctor about certain things. I got a man doctor but about certain other things. I’m supposed to get a colon test but I don’t want to go. I don’t want a man going up my rectum. So I haven’t went to take that one yet. But maybe I should. I think I should. But I’m scared. (1057)”

The participant's comment suggests that she feels as though she can communicate with her provider, but only about certain topics. Her comment suggested that her reluctance to speak openly with her doctor about more, possibly sensitive, topics is likely influenced by the fact that her doctor is male. The participant may have preferred a female provider simply because of her reason for the clinical visit – a colonoscopy. Investigators Kerssens et al (1997) revealed that preferences for a certain gender tend to be greater for the specific health-related professions that have an increased likelihood of dealing with issues that are regarded as intimate in nature or psychological problems, including gynecologists and general practitioners. As well, in many types of medical encounters, including those that involve gynecological exams, female providers are often seen by their patients as more attentive and informative in comparison to their male counterparts (Weisman, 1987). Other investigators have also suggested that female gender concordant patient-provider dyads will experience the most effective communication in certain instances. Such instances include situations in which patients are receiving treatment for certain gender-specific conditions or when patients seek care for medical conditions of a highly personal nature (Weisman & Teitelbaum, 1985). Because the participant mentioned that she was hesitant to go for a colonoscopy because her provider was male, she may have been reluctant to seek care because of the intimate nature of the examination.

A review of participants' responses also revealed a comment about the impact of patient gender on the receipt of care. One participant suggested that male patients are likely to delay or avoid seeking care. The participant commented that male patients in comparison to their female counterparts often have to be motivated to see physicians.

"...not getting medical attention. Black women and Black men with the prostate cancer. Well men are hard to go to the doctors. You have to push them to go... (1094)"

The reluctance of these individuals to go for regular care can impact their ability to build effective relationships with their providers. The participant's suggestion that it is difficult to motivate men to seek care from doctors is supported by previous research. Study findings have revealed that women are greater consumers of health care services than men. Female patients' greater utilization of health care services has led investigators to infer that females are more adept at identifying and reporting medical symptoms (Nathanson, 1977). Some study findings posit that women may be more likely to seek care from a provider than men and report higher rates of illness because the concept of women taking on the sick role has been deemed to be socially acceptable for these individuals. As a result, it may be easier for women to assume this role. Such a theory does make the presumption that the sick role behavior has a greater compatibility with the traditional roles of women. Women may not feel as inhibited as men when either defining or reporting illness (Gabbard-Alley, 1995).

VII.O. THEME: PATIENT'S DIFFICULTY REMEMBERING INFORMATION

For some participants, the greatest barrier to the comprehension of health information was not just the difficulties they experienced obtaining information. Participants also experienced significant problems retaining this information once it had been provided by a physician. One study participant who commented about problems that she experienced remembering the information provided by her physician reported that she employed different approaches in order to overcome this barrier. The participant revealed that she used information that had been written down by doctors or other health care professionals as a way to retain important health information. For this woman, a reliance on written information provided an effective strategy for retaining information.

“When the doctor tells me, it [information] goes in but by the time I go get my prescription which might be a week or so later [I don’t remember], I ask the pharmacist and he gives good information. He even writes it out. For medicine sometimes I forget when the doctor tells me but I ask the pharmacist. (1076)”

“And then the doctor will say I know you might not always remember this and he’ll get the nurse to type it out and then I have it. (1076)”

For many older patients, certain medical conditions and the medications prescribed to treat these conditions may result in memory problems and impair the individuals’ abilities to communicate clearly. Conditions that are often associated with increasing age, such as dementia, can adversely affect the quality of communication that occurs within the patient-provider dyad (Ryan & Butler, 1987). As well, older age itself may cause patients to experience problems with the retention of information. Providers need to be aware that older patients may need extra assistance when trying to remember information.

In addition to the themes previously discussed, there were additional themes discovered in participants’ responses that could have impacted the nature of their clinical encounters. Although these themes were not always suggested as those that would specifically facilitate or impede patient-provider communication, they should be considered in a discussion about effective communication. As well, it is critical that health care professionals examine these themes when devising future strategies that can improve communication within the patient-provider dyad.

VII.P. THEME: PATIENT’S COMPLIANCE WITH MEDICAL RECOMMENDATIONS

Study participants discussed the topic of compliance during the interview. Women related stories about instances in which they had been noncompliant with their providers’

medical recommendations. A lack of compliance could impact communication - even if the participant felt that she had a good reason for not following recommendations.

Participants offered a number of reasons why they elected to not comply with a provider's recommendations. Participants admitted that they did not follow recommendations because they believed that a suggested dosage was ineffective or could result in adverse side effects. One participant who had stopped taking her medication revealed that she preferred the use of alternative remedies as a treatment option for most conditions. Some participants elected to stop taking medications because of pain or inconvenience. Participants also revealed that although they sometimes disclosed this lack of compliance to their providers, often there were also instances in which they did not disclose their noncompliance.

A similar finding was discovered in the response of another participant who was taking insulin. The participant decided to change her medication dosage because she did not agree that the recommended treatment was the best option for her. When asked if she had ever stopped taking her medication, the participant provided an explanation for her noncompliance.

"It wasn't because I forgot and it wasn't because I didn't understand, it was because I didn't want to. Because I'm on a scaling insulin schedule where every time that I eat I have to check my blood sugar and give myself a shot of insulin. This is every time. So the nutritionist has me on six small meals a day. So this means I'm sticking myself constantly and constantly sticking myself with insulin. No I think that's just too much insulin during the course of the day. Then I take two different types of insulin. One is during the day and one is at night. Just too much insulin. (1070)"

VII.Q. THEME: PATIENT'S USE OF ADDITIONAL INFORMATION

Another theme that emerged from the analysis was that many study participants reported a desire to not only better understand the information that their doctors provided, but they also expressed a desire to obtain additional sources of information.

For some individuals this willingness to review more information was associated with a need to better understand information that may have already been provided by their doctors. Others expressed a wish to obtain additional information because they wanted to learn more about a specific topic. These individuals already possessed an understanding of the information given during a clinical encounter, but they were interested in reviewing additional sources of information in order to further their understanding of a particular topic.

With regards to the type of information desired, participants reported that they were willing to utilize a variety of types of resources including written information such as medical dictionaries and brochures. As well, women in the study revealed that they often relied on family and friends for supplemental information. Participants revealed that they often made the effort to seek out sources of information including resources distributed at health facilities and at sites around the community (e.g., health fairs, church meetings, etc.). Women in the study reported that they would make an effort to obtain information that was available at no cost, but they were also willing to pay for sources of information.

“You know a lot of times you don’t understand the lingo when you’re really reading things. And then you have to go back and reread it or go to a dictionary or when I don’t understand what a medication is, I bought a drug book. And I also have a copy of the physician’s prescription book. That big thing. It’s old but when they give me a particular prescription, I’ll go there and look up that particular drug and see what it is. And when I’m reading the material if I have to look up words in a medical dictionary or journals or something then I do that. So it’s difficult a lot of time. I don’t always do it but when it gets to the point where I feel it’s important then I’ll do that. (1042)”

“Yes I look stuff up, I’ll even go to the library to get some understanding. Then I’ll go pay somebody to help me with it. I’ll go to one of these, what do you call somebody who understands both sides of it and explain it to me and tell me my alternatives? I’ll spend enough money to do that. I will do that because if I don’t get it in a library I have to have enough information to feel comfortable. (1019)”

VII.R. THEME: ADVOCACY DURING THE CLINICAL ENCOUNTER

A review of interview responses revealed that the concept of patient advocacy was one that was mentioned several times by study participants. Not only did participants recount instances during which they provided assistance understanding information or navigating the health care environment, but women also provided examples of times when they had to rely on others in order to successfully seek care.

Although this theme is not one that appeared as frequently as others, it is still a critical one for health care professionals to consider when determining how to create the most effective health communication recommendations for providers. Examples of this theme included a comment that described a participant's experience when trying to obtain health information from a provider. Although this participant experienced a great deal of difficulty, she relied considerably on her daughter. During medical appointments, the participant did not always understand instructions provided by her physician, but her daughter usually accompanied her during her visits to the physician in order to ask questions.

Participants also provided examples of situations in which they provided assistance to, or advocated for, other individuals who were unable to obtain or understand information. One participant mentioned that she had to advocate on behalf of family members so that they could obtain information that was simplified.

"I have advocated on my family's behalf for things to be explained to them in a way that they would understand it. It has happened I wouldn't say often but it has happened during my sister's last hospitalization you know. I advocated for her. (1016)"

Another example of advocacy was illustrated by a participant's story of how she obtained clear information for her mother. This woman previously accompanied her mother to appointments but is now unable to do so because she does not have any time to take off of work.

The participant provided an example of how she has been able to obtain information from the doctor.

“My mother is 81 years old. I send a note with her. Because every time my mother has a doctor’s appointment, because I had accumulated so many days on my job I used to go with my mother to the doctor. Now I can’t go. I send a note to her doctor. I say ‘Please do not put medical terms’. I just want to know what my mother can eat and what she don’t supposed to eat and how much sodium that she can have because I want to make sure I’m doing the right thing. So she’s taking a note to her doctor. So she’s taking a note today to the doctor. That’s what I was telling her, ‘Don’t forget to give the note to the doctor’. (1093)”

This participant has devised a strategy that can help her obtain information for her mother. Without this approach the participant’s mother would likely have been unable to obtain necessary health information that is easy to understand. The participant reported that she had to employ this tactic several times because her mother had experienced difficulty conveying information about what the doctors said during previous encounters.

“When I send a note with my mother, when my mother come back from the doctor all she can tell me is ‘My pressure was good’ but she cannot tell me what the doctor said because she cannot understand anything he said to her. But she’s not going to sit there and say, she’s 81, she’s not going to say ‘What? What do you mean about that?’ She don’t understand anything so now I have to send a note. (1093)”

VIII. DISCUSSION

Although one of the primary aims of the original pilot study was to assess participants’ breast cancer-related knowledge, attitudes, beliefs, and practices, participants also provided a rich source of information about several additional topics. One such topic that was often addressed during interviews was the quality of communication that occurred between patients and their providers. Participants provided valuable insight about their experiences during clinical encounters including information about the communication experienced within the patient-provider dyad. While participants discussed those factors that helped to improve communication, they also presented information about the barriers that they encountered when

trying to communicate with providers in a variety of health care settings. An examination of responses that focused on participants' perspectives about the dynamic between patients and providers revealed important data that can now be used to inform the drafting of communication recommendations. Interview responses revealed that although participants reported that they often encountered significant barriers when trying to communicate with providers, the women also suggested ways in which providers could more effectively communicate with patients. It is important to note that although many of the recommendations offered by participants discussed suggestions for physicians specifically, because so many of the participants also talked about communication issues experienced with nurses, physicians' assistants, and other types of health care professionals, the more encompassing terms of "health care provider", "provider", or "health care professional" is used throughout the recommendations.

Providers who either wish to improve communication with patients or avoid the occurrence of a breakdown in communication may wish to review the medical recommendations that have been drafted based on the data collected from the current study's interview responses. Although providers who adopt the strategies listed in these recommendations cannot be guaranteed that they will not encounter difficulties when communicating, those who do choose to follow these recommendations may experience improved communication. Since the recommendations are based on the real world experiences of patients, it is critical that health care professionals take note and, if feasible, make efforts to incorporate such suggestions into their strategies for the provision of care for patients.

VIII.A. PROVIDER RECOMMENDATIONS

Findings from the pilot study revealed several interesting trends in the data. An examination of the responses of study participants determined that health care providers may

wish to consider several recommendations that were offered by study participants. Participants offered a number of recommendations that providers can adopt in order to provide more efficient and effective care for their patients. According to participants, these recommendations may be able to assist providers and patients by improving both the quality and amount of communication that occurs during clinical encounters. Many of the study's participants suggested that physicians and other types of health care providers need to perform a thorough assessment of their patient populations before they can truly gain a clearer understanding of the needs of their patients. Such an assessment will assist providers by revealing which, if any, literacy, cultural or other types of barriers to communications may exist. Although participants offered a number of suggestions, most providers will not need to adopt all of these in order to see improvements in the care that is offered. However, many of the participants suggested that it is critical that each provider will need to determine which of the recommendations (s)he may need to follow in order to improve the quality of communication that occurs with each patient during medical visits.

Although participants suggested a variety of communication recommendations for health care providers to consider, a number of these recommendations were offered more frequently than others during the course of the interviews. Those offered most often were selected for discussion. Several of these recommendations may appear similar or to overlap somewhat in content. Despite the fact that the content of many recommendations may contain similar information, they have been listed separately in case health care providers who review this information only choose to review only one or a few of the listed recommendations. The use of similar content in the explanations for several of the recommendations will ensure that important information is not missed by providers who are not able to or who do not choose to review each of the listed recommendations. The most frequently offered recommendations are listed below.

TABLE 8: PATIENT-PROVIDER COMMUNICATION RECOMMENDATIONS

<i>Recommendation 1</i>	Providers should inquire about patients' complementary and alternative medicine use.
<i>Recommendation 2</i>	Providers should inquire about patients' religious and spiritual beliefs.
<i>Recommendation 3</i>	Providers should consider the impact that race, ethnicity, and culture can have on the clinical encounter.
<i>Recommendation 4</i>	Providers should consider the impact that a patient's age can have on the clinical encounter.
<i>Recommendation 5</i>	Providers should determine if patient-provider gender discordance can impact a patient's desire to seek care.
<i>Recommendation 6</i>	Providers should take steps to ensure that patients can retain the information that has been provided.
<i>Recommendation 7</i>	Providers should take steps to ensure that patients can properly understand the health information that has been provided.
<i>Recommendation 8</i>	Providers should take steps to ensure that patients have access to enough health information.
<i>Recommendation 9</i>	Providers should offer a variety of resources in order to help patients better understand health information.
<i>Recommendation 10</i>	Whenever possible, providers should try to offer patients extra time during medical appointments.
<i>Recommendation 11</i>	Providers should use a variety of approaches in order to offer effective care and meet the demands of heavy patient loads.

<i>Recommendation 12</i>	Providers should make every effort to ensure that patients are comfortable during clinical encounters.
<i>Recommendation 13</i>	Providers should always exhibit a positive and caring demeanor.
<i>Recommendation 14</i>	Providers should work to build a partnership with their patients.
<i>Recommendation 15</i>	Providers should try to determine the reasons why some patients may delay or even refuse to seek care.
<i>Recommendation 16</i>	Providers should work to ensure that patients do not feel afraid or intimidated during clinical encounters.
<i>Recommendation 17</i>	Providers should ask patients if they would like to invite friends or family members to participate in their medical care.
<i>Recommendation 18</i>	Providers should prepare patients for the interactions that they may have with other health care professionals.
<i>Recommendation 19</i>	Providers should become a cheerleader for their patients.
<i>Recommendation 20</i>	Providers need to consider additional approaches when treating patients who experience difficulty communicating because of problems understanding English.

Recommendation 1: Providers should inquire about patients' complementary and alternative medicine use.

In order for health care providers to communicate effectively with their patients, providers need to be aware of patients' health-related beliefs, attitudes, and practices. Doctors

should make a specific effort to ask their patients if they utilize any types of complementary and alternative medicine (CAM). An awareness of the different types of CAM therapies that patients utilize is critical for providers because such knowledge can impact the quality of communication that occurs between patient and provider. Providers should be aware of the CAM therapies that patients may be utilizing especially before they prescribe medications or offer patients different treatment options. Patients may not always disclose their use of various CAM therapies for a variety of reasons, including the fact that they believe providers will frown upon such use, and this nondisclosure can affect adherence to recommended conventional therapies. Therefore, it is critical that providers take the step to directly inquire about patients' use of such therapies. Patients may be more willing to be open and to discuss their use of such therapies if directly asked.

Obtaining information about these types of remedies may be somewhat tricky if health care providers do not attempt to ask about CAM use in the most effective way. In order to gather accurate data about CAM use trends amongst certain patient populations, providers must first be certain that they understand the definition of what constitutes a CAM therapy. As well, providers must possess a general knowledge of the types of CAM therapies that are available to patients, especially those therapies that may be preferred by patients in the communities that providers serve.

When providers inquire about patients' use of various types of therapies, they should be certain to employ terms that patients recognize and provide patients with a clear and simple definition of what the term "complementary and alternative medicine" means as well as examples of what approaches constitute CAM use. For instance, providers may want to use other terms in addition to the term "complementary and alternative medicine" when discussing

CAM utilization with patients. Patients may not realize that when they use “natural”, “family”, “food”, or “home” remedies as treatment options, these remedies are regarded as CAM therapies. As a result, when asking patients about CAM use, providers may wish to employ a variety of terms instead of solely asking about “complementary and alternative medicine” use. Use of this term may prove to be too confusing for patients. The result may be an underestimate of patients’ true use.

Providers need to become familiarized with as many types of CAM therapies as possible. When collecting data about a patient’s CAM use, providers need to offer a comprehensive list of therapies as well as offer patients the opportunity to report the use of therapies that may not be included on the list. Without this approach, providers will be unable to obtain the most accurate information about their patients’ CAM use. If a provider inquires about a patient’s CAM use, but only offers three or four examples of CAM therapies, the provider may not be able to gather the most accurate information. As well, if only a few examples are given by providers and these examples are not therapies used by the patient, then the patient may not feel that the question applies to him or her. For instance, if a patient utilizes various types of energy medicine, yet examples of energy medicine are not listed as examples of CAM therapies when a provider inquires about use, the patient may incorrectly report that (s)he does not use any type of CAM, when in fact the patient does. Unless a provider or some other health care professional takes the time to read or provide a comprehensive list of CAM therapies to patients either during the actual clinical encounter or at some point during their visits to a health care facility, the patients may not understand that some of the approaches to care that they use at home (e.g., biologically based remedies such as herbs) are actually classified within the realm of complementary and alternative medicine.

In order to collect the most accurate data possible, providers should try to stay abreast of the CAM utilization trends of patients who live within the communities that the providers serve. A review of studies conducted within the field of CAM research, as well as inquiries about patients' CAM use, can help providers to stay informed about patients' preferred types of CAM use. According to prior investigators who have coined the term "ethnic specific" CAM use, certain racial and ethnic groups may be more likely to use certain CAM therapies. Providers should be certain to learn what types of CAM are used most often by specific racial and ethnic groups. For instance, if a provider's patient load is comprised primarily of Latino patients, the provider may want to make a particular effort to investigate research findings in an effort to learn about CAM therapies that are used most often by members of this community. However, providers must also use particular care to not focus on inquiring about certain remedies solely because a patient is a member of a racial or ethnic group because doing so may cause the provider to obtain inaccurate or incomplete information. Providers should be certain to not only ask individuals about therapies simply because patients are members of specific racial or ethnic groups. For instance, if a patient is Asian American, providers should not just make assumptions and ask that patient about CAM therapies that may often be used by Asian Americans. Providers should still make certain to ask about a variety of types of CAM so that the providers can have a true understanding of the utilization trends of the patients in the communities that they serve.

Although inquiries about patient CAM use can offer providers valuable information about patients' health-related attitudes, beliefs, and practices, providers may believe that because of time constraints, it may not always be feasible to inquire about this topic. An inquiry about CAM use may take more time than doctors are willing to provide. To help address this issue, doctors can make the decision to only inquire about this topic during a patient's first visit when

information about the patient's medical history is requested. A follow-up inquiry about CAM use can then occur every 6 months or annually based on each provider's preference and time availability. Such follow-up inquiries would enable the provider to gain information about any changes in CAM use trends or attitudes about CAM use for patients. As well, these periodic inquiries can serve as a reminder to patients that it is important to discuss the use of CAM therapies during clinical encounters. If patients believe that their doctors are open to learning about their CAM use, patients may be even more willing to initiate the conversation about the subject and disclose their use even when providers do not inquire about the topic.

Providers must also determine how they wish to ask about CAM use. Questions about use can be included on hospital admissions forms. It may be more effective for a physician or other health care professional to ask the patient in person instead of via the use of a form because then the patient will have the opportunity to ask any necessary questions once the provider broaches the subject. The provider can make certain to provide a clear explanation of what types of remedies are included in different CAM classifications. If providers question patients in person, then this approach will offer patients more opportunities for conversations about CAM use. Additionally, when inquiring about CAM use, providers may also want to collect information that will enable them to gain insight about utilization trends. Such questions may include asking patients about the types of CAM therapies they have used in the past, which therapies they currently use, why they decided to try CAM therapies, why they may have stopped using a certain therapy, and if they always disclosed their use of CAM to their providers. As well, patients who admitted that they have not always disclosed their CAM use can have the opportunity to have a candid exchange and offer reasons for their decisions to not disclose this information. Discussions about CAM use also provide physicians and other health care

professionals with the chance to distribute literature. Information about the importance of disclosing use and topics such as the potential interactions that CAM can have with other medications can be highlighted in this literature.

Recommendation 2: Providers should inquire about patients' religious and spiritual beliefs.

Providers should be cognizant of the religious and spiritual beliefs of patients as well as how such beliefs can impact the interaction between the patient and provider. Providers should recognize the influence of religion and spirituality on patients' health-related attitudes, beliefs, and practices. Although some providers may contend that religion and spirituality are topics that should be regarded outside the realm of medicine and health, findings from previous literature suggest that these factors can indeed influence the nature of the patient-provider interaction.

With regard to communication recommendations, it is essential for health care providers to recognize the importance of religion and spirituality in the lives of many patients. Doctors may wish to determine the most optimal approach to employ when inquiring about patients' religious or spiritual views and then utilize such information to determine the best ways to address the health care needs of their patients. Providers need to consider if and how they should inquire about each patient's beliefs and determine if and how patients would like them to utilize such information as it relates to the provision of health care (e.g., if patients desire referrals to pastoral professionals, the provider to participate in prayer, etc.). Doctors can ask patients about their religious or spiritual beliefs as a part of the medical history taking process. Such questions can be included on hospital admissions forms or in the actual conversation about the patient's medical history with the provider. If providers ask if patients want to provide information about

their religious or spiritual beliefs during the history taking process in an unobtrusive manner, they can utilize the opportunity to explain to patients that such information is important for some patients to disclose because these patients may wish for a provider to possess some knowledge about their beliefs. As well, the doctor can also explain that it is not necessary for patients to reveal information about their religious beliefs unless the patients feel that a doctor's knowledge of their religious views will be relevant or useful in the provision of effective care in some manner. By asking patients during the history taking process, providers offer patients the opportunity to reveal the degree of importance that they place on religion. Such questions can give patients the chance to reveal any preferences that they have regarding the role of religion in their care and help patients realize that it is okay to broach the subject of religion within the context of the clinical encounter.

Providers who recognize the importance of considering the role of religion within health care must determine the best way to proceed during those instances in which patients may possess strong beliefs but the providers either have religious beliefs that differ or if the providers possess no beliefs at all. In these situations, a provider should determine the most effective ways of acknowledging and respecting patients' beliefs without revealing his/her own. These providers may benefit greatly from knowledge about their patients' beliefs because under certain circumstances, including instances where patients often seek out spiritual support or guidance during life and death scenarios, providers can be better prepared to address the needs of patients. Information about religion or spirituality can help providers determine if they will need to make referrals for pastoral professionals for patients, if patients prefer to have members of their own religious support groups present, or if patients have other beliefs that can impact the type of care

that they receive. For instance, a patient may want to reveal that his religious views prohibit him from receiving blood transfusions.

Some patients may feel a greater connection to those providers who simply take the step to inquire about their religious or spiritual beliefs even if the beliefs of the providers differ from those of the patients. For these patients, just a provider's acknowledgement or awareness of their religious or spiritual beliefs may serve to build a stronger relationship, foster a greater sense of trust, and as a result improve communication.

Providers can use the initial encounters that they have with new patients as an opportunity to collect this type of information. Providers can then continue to inquire about this information periodically. Such inquiries can help to maintain updated information, as well as offer patients occasional opportunities to discuss religion or spirituality. It is essential that providers make an effort to inquire about beliefs and practices regularly. By making intermittent inquiries, providers can convey the importance of discussing religion and spirituality especially as these topics pertain to the provision of effective care and capture information about any changes in patients' beliefs should they decide to adopt different religious views and practices.

By offering patients additional opportunities after the first medical appointment to discuss religion and spirituality, providers may be perceived by their patients as individuals who are willing to discuss matters that are personally important to patients. Once providers take the step to inquire about patients' religious views, patients may then begin to feel comfortable enough to bring up the issue during other visits – even during visits when providers have not taken the initiative to broach the subject. When patients recognize that doctors are at least acknowledging their beliefs, they may develop a deeper sense of trust in their providers, be more willing to communicate openly and actively participate in encounters, and make greater efforts to

seek needed care. Inquiries about religion and spirituality will help patients realize that there is a link between religion and health. As well, patients will recognize that some information about their personal views may be of use to the individuals who provide their care.

Recommendation 3: Providers should consider the impact that race, ethnicity, and culture can have on the clinical encounter.

Although issues related to race and culture can affect the patient-provider relationship in a variety of ways, patients may not feel comfortable bringing up issues that may be related to these topics. As a result, providers need to stay abreast of research findings that explore the link between race and ethnicity and those factors that can impact the nature of the clinical encounter (e.g., the link between race and factors such as patient satisfaction, patient communication, etc.). The knowledge gained from these findings can be used by providers to properly structure the clinical encounter. For instance, if findings from research suggest that race and/or culture can affect various aspects of the clinical encounter such as the dynamic between patients and providers, providers should take this information into consideration. If providers suspect that patients' racial or cultural backgrounds may be linked to their health-related knowledge, attitudes, beliefs, and practices, then providers should investigate the impact of these factors and determine how such information can influence the nature of the patient-provider relationship.

Providers should examine the roles that racial and cultural concordance can play in the clinical encounter. For many patients, a shared racial or cultural heritage with their providers can have a positive impact on the patient-provider relationship. Patients may have a greater likelihood of feeling more comfortable when they communicate with an individual with whom

they share certain commonalities. Even in instances when the patient and provider do not share the same race or culture, the provider can determine if any other types of commonalities exist between the two parties. Providers can build upon existing commonalities in order to create a strong and trusting relationship and make patients feel more comfortable. For instance, although a patient and a provider may not share a racially or culturally concordant relationship, if they share some commonality – such as they both possess a shared passion (e.g., a hobby) or they are both from the same area of the country - the provider may want to touch upon or even emphasize these common interests in an effort to make the patient feel comfortable and as a result, more willing to open up to communication during the clinical encounter. This approach can be utilized as a way of putting patients at ease especially in situations in which the parties have experienced problems communicating.

Although study findings suggest that an individual's race or culture can impact their attitudes, perceptions, and practices, it is still important that providers use great care not to stereotype patients solely based on race or culture. Providers should not assume that because a patient is of a certain race or ethnicity that (s)he will possess certain beliefs or attitudes.

Providers need to also recognize any types of biases that they (the providers) may possess and make a concerted effort not to exhibit these biases. It is always important for providers to tailor the clinical encounter in such a way that all patients are most comfortable (e.g. simplified information for someone with inadequate health literacy levels). However, if patients suspect that their providers are tailoring their communication based on any stereotypes or biases, the result may be a decline or even a total shutdown in the communication between the patient and provider. As well, if patients suspect that they are being treated in a particular way because of their racial or cultural backgrounds, they may also withdraw from interactions with their

providers. Although providers should be aware of potential links between race and various patient-related factors, providers must use care not to stereotype patients or allow any biases to impact the manner in which they interact with or provide care for patients.

It should be stated that providers should recognize that in those situations in which providers and patients share the same race or culture, these shared factors may not offer a guarantee that the patient is comfortable. Even if racial or cultural concordance exists, the provider may still have to utilize other techniques – such as the provision of clear information, displays of empathy, or even directly asking the patient how (s)he feels – in order to ensure that the patient is comfortable and receptive to openly communicating during the clinical encounter.

Recommendation 4: Providers should consider the impact that a patient's age can have on the clinical encounter.

Providers should be aware of barriers to communication that may exist for certain groups of patients, specifically older patients. Providers should be cognizant of common age-associated factors that can impact the encounter as well as consider potential barriers that might be specific to this age group. Visual, auditory, and cognitive impairments that are associated with advancing age may cause older patients to experience great difficulty obtaining, understanding, and retaining information. Those conditions associated with memory loss (e.g., dementia), as well as the problems associated with the effects of medications utilized to treat these conditions, may also cause older patients to experience problems more frequently than their younger counterparts. When treating older patients who may deal with such impairments, providers

should not only offer information verbally, but also offer written sources of information to patients. The provision of written sources that can be taken home will help patients retain and reinforce any information provided during the clinical encounter.

As recommended for patients who may experience difficulty retaining information, older patients should be provided with written information (e.g., fact sheets, brochures, etc.) that is easy to understand. These patients should also be provided with printed information that contains a summary of the appointment's medical findings. Such information can then be shared with other individuals (e.g., family or other individuals) who may act as caregivers and provide older patients with the opportunity to reference information at a later time. Information such as blood pressure readings, test results, or preparation activities for certain procedures should be printed and given to patients at the conclusion of their appointments. Such information can be shared with others and make it unnecessary for the patient to rely on memory alone in order to correctly recall information presented during clinical encounters. These types of approaches can help to assure that patients are well informed and help to decrease the demands that are placed on older patients by the health care industry.

Providers should be certain that any information (e.g., brochures, hospital signs, printed information sheets, etc.) that will be utilized by older patients is printed using a large font that is appropriate for individuals who may have visual impairments. As well, when providing information verbally, providers should be certain to speak clearly and at an appropriate volume, especially for patients suspected to have experienced hearing loss.

If it will benefit the patient, providers may also talk to older patients about the possibility of inviting a family member or friend to the clinical encounter. Patients who experience difficulty understanding or recalling information will be able to turn to this individual for

assistance. These individuals can then serve as a convenient and valuable information resource when the patient does not understand. Providers should also offer brochures or pamphlets during the visit, as well as a listing of credible websites that provide clear and comprehensible information. By providing brochures, pamphlets, or fact sheets providers can then at least be assured that after patients leave their medical encounters, they would have some resources on hand. Additionally, patients should always be presented with additional alternative sources of information. For those who do not have access to the internet or who do not prefer this source as a means of obtaining information, providers should offer a list of current phone numbers of organizations that can provide free or inexpensive resources.

It is also important to note that because individuals in this segment of the U.S. population are the greatest consumers of health care, they also likely utilize more medication than their younger counterparts. Providers should take great care to ensure that older patients are able to manage their medications without difficulty. Providers should offer clear information about the names of medications (including generic alternatives), instructions regarding dosages and schedules for medications and if possible, a short blurb about why a drug may have been prescribed (e.g., hydrochlorothiazide is a drug that is used to treat high blood pressure). If feasible, it may also prove useful to offer pictures of prescribed medications. Such information could help patients keep their medications organized. Although this information is generally provided by the pharmacists who actually fill the prescriptions, older patients should have access to this information at the end of the medical appointment. When patients leave the clinical encounter, they should have some level of knowledge about the medications that they have been prescribed including the names and functions of medications and not have to wait until they visit a pharmacy to obtain this information.

Recommendation 5: Providers should determine if patient-provider gender discordance can impact a patient's desire to seek care.

In situations in which doctors need to perform procedures that may be regarded as intimate in nature (e.g. colonoscopy) or discuss topics that are sensitive, a lack of gender concordance between a patient and provider may prove problematic. If patients and providers do not share the same gender, providers should be willing to directly ask their patients if a difference in gender is going to result in any types of problems. Providers' direct inquiries about gender may be especially important because some patients who may have an issue with gender discordance may not voice their concerns. Instead they may delay when they seek care or they may choose not to go for care at all. For instance if a male patient, who has a female provider, feels uncomfortable receiving a prostate exam, he may not reveal his discomfort to his provider. He may simply choose not to have the exam performed without disclosing the reason. As well, when providers need to discuss topics that may be regarded as intimate in nature, they should consider that gender may act as a potential barrier to effective communication and the provision of effective care. Such situations may require that providers consult with patients about any discomfort that they may feel if their patients do not share the same gender. When providers make recommendations to patients to obtain care (e.g., specific types of exams), providers should also directly ask the patient if differences in gender will present any problems. This is especially important when providers have to refer a patient for care. Before referring a patient to another provider, physicians should ask patients if gender will possibly affect the patient's comfort level. A primary care physician who refers a female patient to a male gynecologist may

be unaware that this female patient is uncomfortable being examined by a male. When this patient presents for care, she will undoubtedly be very uncomfortable and possibly unsatisfied with the care that she receives, even if she receives proper medical attention. Providers should recognize that for some, provider gender may result in a patient's delay in seeking care or refusal to obtain any care at all. Those patients who do decide to obtain care may still experience discomfort.

Providers need to ask about the issue of gender discordance because patients may not be willing to volunteer this information during the clinical encounter. Patients may be too embarrassed, uncomfortable, or even afraid to have certain procedures performed by providers of a different gender yet hesitant to admit their discomfort. As a result, these patients may be labeled as "noncompliant" by their providers if they do not go for care or actively participate in the clinical encounter and regarded as patients who have no interest in improving their own health.

Even if gender discordance does not pose a problem for patients under general circumstances, if providers adopt the habit of asking patients during those occasional instances when gender discordance may pose a potential problem, patients may then be more willing to disclose this discomfort when they do actually experience unease because of discordance. These patients may then be willing to report their discomfort even during those instances when providers do not directly ask them. This is particularly important because it is critical that patients be able to take the step to reveal their discomfort about gender discordance if and when the situation actually arises.

Recommendation 6: Providers should take steps to ensure that patients can retain the information that has been provided.

Patients who are unable to retain the information provided by a physician will likely experience great difficulty communicating during the clinical encounter. Providers should be aware of problems that patients experience retaining information. Providers who wish to have patients who are well informed about information concerning their own health should take steps to help ensure that their patients can remember information that has been presented during the clinical encounter. Providers should offer patients clear and comprehensible sources of written information (e.g., fact sheets, brochures, instructions about patients' health plans, activities, and prescribed medications, etc.) that can help to reinforce any health information that physicians may have already delivered during a medical visit. For patients who wish to obtain additional information about a specific health topic, providers should also make an effort to offer examples of credible websites that provide accurate information. As well, for patients who do not have internet access or who do not prefer to use the internet, providers should also provide a list of up to date phone numbers of organizations that can provide resources for patients at little or no cost.

For those patients who may find it difficult to remember information reported during the clinical encounter (e.g. test results, blood pressure readings, etc.) physicians should print this information and provide it to patients to reference at a later date. By providing the patient with written findings from the clinical encounter, the patient will be able to track his or her own health progress and provide this information to family members or caregivers rather than trying to rely on memory alone to recall important information. In addition to offering written resources,

providers should make certain to repeat important information to patients during medical visits and speak at a slower pace. Providers may also wish to offer patients other types of aids that can assist with the retention of information. For instance, the provision of instructional videos that can teach patients how to administer medications (e.g., inject insulin) or prepare for medical procedures will help to reinforce any verbal information that was provided during the clinical encounter.

Recommendation 7: Providers should take steps to ensure that patients can properly understand the health information that is provided.

Providers must truly understand the role of health literacy and how it can impact the nature of clinical encounters. It is critical that providers recognize that patients often experience great difficulty understanding medical jargon. Patients who have limited education frequently have problems understanding complex terminology. However, even those individuals who have attained higher levels of education (e.g., college educated) might experience problems understanding medical language because literacy is context specific. Individuals who may be educated and understand topics such as computer science or economics, may still experience problems understanding medical-related terminology because they have not been educated about health-related topics. Providers cannot assume that because a patient has attained a high level of education, (s)he will understand medical information. With regards to patients who have not been able to attain a high level of education, providers must also use care not to use complex language – whether medical in nature or not.

It is critical that providers recognize that although patients may not understand much of the information offered during a medical visit, for a variety of reasons, these patients may fail to disclose this lack of understanding. Providers should determine the most effective strategies to use to determine when patients have difficulties understanding. Providers can offer patients the opportunity to ask questions and disclose any problems that they may have understanding information.

Providers may find it more effective and faster to directly ask patients if they have questions instead of waiting for patients to disclose their lack of understanding. Those who choose this option should be willing to offer patients more than one chance to ask questions because patients may be unwilling to disclose any confusion during the initial opportunity offered by providers. Offering patients a second opportunity to discuss any difficulties with comprehension may put them at ease and make them more likely to open up. Providers can first make patients comfortable by asking their questions in an unobtrusive manner. For instance, when talking to a patient, a physician might state “I know that this may be a lot of information to understand or the information may be hard to understand. Please feel free to ask me any questions if you have them, and I will be happy to explain and help you understand.” Even if the patient does not reveal any problems the first time that the physician states this, the physician can repeat the statements at a later time during the medical visit or follow-up with a quick question such as “Do you have any questions about any of the information that I have given you today?”

The provision of more than one opportunity to discuss any difficulties with comprehension is critical because some patients may not admit any problems the first time that they are asked. Patients may remain silent or even reply to providers’ questions with a response of “No” when asked if they have any problems understanding. Providers should recognize that

for some individuals, a patient's silence or even a direct response of "No" should not always signify that the patient truly understands. Asking a patient about any problems with comprehension more than one time may make the patient feel more at ease and comfortable, and as a result, more willing to open up the lines of communication. For those patients who are not willing to reveal such difficulties, providers can determine alternative solutions.

Health care providers can take further steps to help ensure that patients do not experience difficulties understanding medical-related information. Providers can review the language utilized on forms provided in their offices for clarity. It is critical that patients understand forms such as informed consent documents so that they understand any risks associated with procedures as well as hospital admissions forms so that patients provide accurate medical histories. If providers utilize complex medical jargon when collecting information, they may not be certain that they are obtaining correct information from patients. Without accurate information, providers may be unable to make accurate diagnoses.

Comprehension of information about medication is also of great importance. Not only must patients understand what medications they are taking and the purposes of each, but it is also important that patients understand how to take their medications. Instructions about when to take medications, as well as information about side effects and possible interactions with other drugs, should be easy for patients to understand. Although providers may expect that patients will always have this information offered to them in a clear format from other individuals such as pharmacists, patients may not always understand information about medications provided in pharmacies (e.g. information leaflets that accompany prescriptions). If clear information is not provided by pharmacists, and if patients do not make the effort to ask pharmacists questions about medications, then patients may take medications incorrectly. To avoid the possibility of

medication errors, health care providers should offer patients some degree of information about medications that will be prescribed before patients leave the medical appointment.

Providers can also utilize certain tools (e.g., software programs) to determine if the language utilized in written documents such as fact sheets or brochures is written at too high of a reading level before distributing information to patients. Use of such approaches can help to assess the educational level of text that is used in written documents. As well, providers can try to assess the clarity of the language used on forms or in written resources by using focus groups to provide feedback or by field testing documents and asking a small selected group of test subjects to review materials and offer feedback before the materials are put into widespread use. Such steps will enable providers to employ procedures that can examine brochures or other sources of written information and determine if the text used to compose the documents is too difficult to understand. Additionally, in an effort to help patients both understand and retain information, providers should offer patients some sort of health information materials that they can take with them to review after the clinical encounter. Information provided should be clear and comprehensible so that patients and those who may be able to provide assistance (e.g. family) to patients experience no difficulty reviewing information.

Although the provision of sources of written information can prove beneficial for many patients after the clinical encounter is over, providers must also recognize that they must still employ approaches to help patients during the actual encounter. Providers should use care to ensure that they repeat the most important information when talking directly to the patient. As well, patients should be provided with verbal instructions for any types of procedures or medical tasks. Although the use of printed materials to provide this information can serve as a means to reinforce verbal information and as an important reference material for later review, the use of

verbal instructions is especially important for patients who may not be able to read well or at all. By offering information verbally, providers can be assured that they know that their patients have directly received information, and providers do not have to rely on the possibility that the patient will take the time to review written information at a later date. As well, the use of written information cannot be emphasized enough. If providers do opt to provide printed materials, all information must be written at an appropriate grade level that is not too high so that patients who may have low health literacy levels can understand.

Another approach includes the use of certain strategies by providers when trying to teach patients how to properly perform certain activities such as the administration of insulin. By utilizing a “teach back” approach, providers offer information about a procedure and demonstrate how to perform it. The provider then asks the patient to demonstrate or “teach back” the activity. This allows the provider to actually observe the patient performing the activity and then the provider can offer feedback. Such an approach can help to assure the provider that the patient is equipped with whatever skills are needed to perform the activity.

Recommendation 8: Providers should take steps to ensure that patients have access to enough health information.

While information that is both clear and comprehensible is vital for patients, it is also important that patients are able to obtain adequate amounts of information. Providers should recognize that not only is it critical to offer information that is easy to understand but patients should be provided with enough information so that they can effectively communicate and participate in medical decision-making during visits.

Those providers who are able should make an effort to offer patients more information during clinical encounters. For instance, if any extra time is available, physicians can offer to explain medical terminology or concepts mentioned during the clinical encounter. Although doctors' busy schedules may prohibit them from dedicating a large amount of time to the provision of what may be deemed as excess information during the encounter, doctors can take other steps to help ensure that patients obtain the information that they need. Doctors should offer to provide resources such as brochures, the names of reliable resources, and information about where such resources can be obtained. Although the internet can offer a seemingly endless supply of information, not all websites provide valid and reliable information. A number of patients may experience problems discerning which sites may be credible. Some patients may have access to the internet yet they may not prefer to use this as a source of information. As well, those patients who do not own computers or have access to the internet may experience difficulties obtaining accurate sources of written information at little or no cost. Providers should be prepared to have a list of resources that can assist patients. Such resources should include a listing of books, brochures, and websites, as well as phone numbers for organizations for those patients who do not use the internet.

Results from this study indicated that many participants desired access to additional information in order to better understand certain health topics. A number of participants revealed that they would be willing to review additional sources of information if they felt they needed to obtain a better understanding of a topic and if these sources were made available to them. Several of the participants revealed that they have often visited libraries to obtain information or even book stores in order to purchase resources. Those individuals who could not afford to buy any items from book stores admitted that they sometimes visited stores and copied

information from medical books or other types of resources into their personal notebooks in an effort to obtain additional information about a topic of interest. For these study participants, a common theme in their responses was that they were greatly interested in obtaining additional information, and they were willing to use this information. These individuals were interested enough that they were willing to travel to places (e.g., book stores) where they could to access information at little or no cost.

Recommendation 9: Providers should offer a variety of resources in order to help patients better understand health information.

Health care providers should make every effort to ensure that their patients understand and retain the information that has been provided during medical appointments. The use of simplified medical language is one approach but there are other steps that providers can take to assist their patients. Many patients may wish to have access to some type of reference or resource material that can offer additional information about specific health-related topics. Providers should offer written sources of information for patients to review at a later date. These sources should use clear and comprehensible language that is easy for all patients to understand. Providers should also be ready to offer patients recommendations for other resources (e.g., brochures, references, websites, etc.) that also use language that is clear and comprehensible. Providers or other designated individuals who may have more time to devote to the task can obtain brochures or other resources from reputable health organizations, medical associations, or pharmaceutical vendors. Educational materials that contain information about a wide variety of

topics including medical conditions, medication dosage schedules and side effects, or treatment options are all important for patients to have.

The provision of health fact sheets, medical dictionaries, or easy to understand brochures that include simple diagrams and glossaries can assist patients with comprehension after they have left their medical appointments. Such resources are critical because they can assist patients as they try to review medical information offered during appointments. Findings obtained from a review of this study's data revealed that study participants often relied on additional sources of information (outside of the verbal information provided by a physician) when they did not understand the information that was provided during a medical visit. Participants reported that they often made efforts to research information, utilize resources such as medical dictionaries or pharmacy resources, ask family or friends for help, or seek information from various health care professionals such as pharmacists in order to obtain needed information.

Several participants also revealed that they have made multiple trips to bookstores in order to better understand health information. Although some reported that they purchased medical dictionaries or other resources, many participants could not afford to do this. Those who could not afford to purchase books revealed that they would often take a pen and paper into a store and copy information from books. As well, a few individuals also reported that they would request the assistance of friends or family or visit libraries in an effort to access additional free information.

The provision of some type of resources can also be of assistance to other individuals (e.g., friends, family) who may help patients to better understand important information about diagnoses, prevention, and treatment. If patients are not able to recount and explain the information given during a clinical encounter, easy to understand pamphlets that patients can

take home can provide an important resource for those caregivers and other individuals who assist patients with a variety of health-related tasks such as explaining health information, scheduling appointments, and administering medications.

In addition to using simplified language and distributing written resources, providers can also provide brief documentation about the most important information discussed during the encounter. This information should be typed out instead of handwritten so that patients do not experience difficulty or confusion when reading information. For patients with visual impairments, the font utilized should be large enough to read without difficulty. Although many providers might assert that such a step is not feasible because of the time constraints imposed on most providers, it may be possible to provide written documentation quickly. For instance, if a physician notes that a patient has high blood pressure, in addition to telling the patient the blood pressure reading, the provider may also want to use a preprinted sheet that features information about blood pressure categories. The sheet could provide a short passage with a breakdown of blood pressure ranges so that the patient understands the range within which his or her reading falls (e.g., pre-hypertensive range or hypertensive range). The provider or another designated individual (e.g. nurse) can then fill in the section with the patient's blood pressure reading and date so that the patient will not forget the reading and so that the patient can have a means of tracking the readings over time. As well, the provider can type out two or three sentences that pertain to the patient so that the form will provide important information but also be tailored specifically to the patient.

An example of such a preprinted sheet might be structured in the following way. A provider might use a sentence such as "Today your blood pressure was _____ / _____. This reading indicates that you have hypertension or high blood pressure. I am going to recommend

that you take certain steps to help lower your blood pressure.” The provider can then include options such as: (1) prescribing a certain drug, (2) asking the patient to return for a follow-up reading or requiring that (s)he check his/her blood pressure regularly, and (3) reviewing brochures that will be provided, or asking the patient to begin an exercise regimen and to modify eating habits. The rest of the sheet, which already includes general information about blood pressure that will be included on the sheets of all patients who receive the form, can include recommendations for lowering one’s blood pressure, as well as a listing of one or two phone numbers and credible websites that a patient can use to obtain additional information. Although such a step might appear time consuming, if a series of sheets that are specific to different conditions have already been drafted, then the physician can add the extra lines of text that are specific to each patient. Patients can then leave the encounter with the sense that they have some level of accurate information about their own health. The provision of this information can help patients better understand and recall what was stated by the provider during the clinical encounter and better equip them to discuss this information with family members or other individuals at a later time. If it is not practical for providers to compose information to be included on the preprinted forms, other individuals can be designated to complete this task after the medical appointment ends. A nurse or other health care professional can review patient information (e.g. blood pressure) and fill this information in on the form.

Printed sheets containing information that is specific to each patient can help patients in a number of ways. For example, patients who leave a doctor’s office with a written prescription may not even be able to read the name of the medicine that has been prescribed for them. Some patients who have handwritten prescriptions may know the names of drugs that they have been prescribed (and the drug’s functions) only after they pick up medications from a pharmacist who

usually provides printed information sheets about the functions, side effects, and dosage scheduling of medications. Findings for this study revealed that several women complained that they often experienced great difficulty when trying to decipher a physician's handwriting. Patients reported that they have received handwritten prescriptions and although the name of the drug was written on the prescription, they had no idea what medicine they had been prescribed. They were only able to read the prescription name after receiving information from the pharmacy. Information about other important topics can also be included on preprinted sheets. If a patient has received a referral for a certain procedure (e.g., biopsy) then the preprinted sheet could include the name of the procedure as well as a short passage that describes or defines the procedure and what steps should be taken by the patient in order to prepare for the procedure. This recommendation is important because a few women discussed instances in which they had actually had some type of surgical procedures performed on their bodies. These women admitted that although they had actually undergone some type of procedures, they had no idea what the actual procedures entailed or even the names of the procedures. The woman did know what body parts were involved in the procedures (e.g. "I had something done to my stomach") but that was all the information that they could offer.

If possible, patients may also benefit if providers can offer other types of resources including visual aids such as charts and graphs that can help to explain information. For instance, a physician who has to perform any type of medical procedure on a patient may find it helpful to use anatomical drawings when explaining what steps will be taken during the procedure. As well, the use of videos that can either explain medical conditions or serve as a source of instruction (e.g., how to take medication such as injecting insulin or how to prepare for a procedure, etc.) may also assist patients with the comprehension of vital health information.

For providers who feel comfortable and who have enough time, the use of blackboards or dry erase boards may also provide an effective means of communicating basic health information or even help to convey what steps providers intend to take in order to perform certain medical procedures.

In addition to the provision of a variety of resources such as health brochures, medical dictionaries, or videos, health care professionals may also wish to provide patients with other strategies that can help patients not only retain information but maintain the flow of the clinical encounter. If it is economically feasible, providers can offer patients simple tools that can assist them during the clinical encounter. When a patient first signs in for a medical appointment, health care staff can provide the patient with a pencil and paper so that the individual can write down questions as (s)he thinks of them. While patients are waiting to be seen, or even during the course of the appointment, they may think of questions that they want to ask their physicians or nurses. If patients are not allowed to ask their questions right away because they have not begun their appointments or because they are in their appointments but their doctors are talking, the patients may often forget what they wanted to ask. By writing down their questions as they think of them, patients can remember to ask their questions before they leave the health care facility. As well, those providers who note that patients are writing during the clinical encounter can use this as a cue that they should take a minute during the encounter and provide the patient with time to ask any questions. Health care providers who adopt such a strategy (even if they do not see patients writing questions) can take a moment at the end of the clinical encounter and ask patients to read any questions that they may have written down. As well, if time does not allow for this approach during the actual clinical encounter, the provider can direct the patient to another individual (e.g. a designated nurse, patient navigator, health educator, etc.) after the

appointment and this individual can assist the patient by answering questions, addressing any concerns, or writing down the patients' questions so that the questions can be relayed to a physician later for follow-up.

Other approaches have also been utilized in order to help providers convey information to patients and to improve the patient-provider interaction. For instance, the use of toolkits at health care facilities around the nation have been determined to provide an effective means of improving communication during clinical encounters. In an effort to address communication barriers encountered by patients, health care professionals at Boulder Community Hospital developed a tool kit for their patient population. This communication tool kit was developed in an effort to address a multitude of communication-related barriers that patients might face during a visit to a health care facility. Items contained in the kit were included to help patients address issues related to language, hearing deficits, or even issues related to ventilator use that might prevent patients from speaking. The kit, referred to as the On the Spot Communication Toolkit, consists of tools that can be used to assist patients with issues related to vision, hearing, and speech. As well, items included in the kit may be of assistance for those patients who do not speak English either well or at all. Examples of items featured in the kit include both word and picture boards (in several different languages), an amplifier to help patients hear better in noisy environments, writing boards with instructions for patients who may have communication or physical limitations, word translation cards, and several other tools (e.g., a guide for hearing aids) that could be of assistance to both patients and staff. Providers who have access to resources, both financial and staff-related, could help to create such kits that contain tools that benefit a particular patient population. Such kits could be tailored to assist patients in certain communities who have to deal with frequent obstacles. For instance, a kit may only contain

tools that assist with language translation. These providers, as a result, may experience a patient population that encounters less communication barriers. If patients in a provider's population tend to experience issues related to vision or hearing deficits more so than to issues related to a lack of knowledge of English, then the provider should focus on building a toolkit that will help to address these types of barriers (vision, hearing). For providers who may not have the financial resources to develop and distribute such kits, one potential solution could be to seek assistance by applying for grants from foundations or agencies whose focus is to address certain health conditions or issues related to health literacy. The provision of written documents, including brochures and sheets that summarize findings from a patient's medical visit, or other resources such as toolkits can prove to be effective approaches that can help patients better understand and retain important information given during medical appointments. Still even the use of all of these approaches cannot offer providers the guarantee that their patients will understand information that has been offered during clinical encounters. For providers who still possess doubts about their patients' level of comprehension, the most important step for any provider to take is to simply ask the patient if (s)he understands.

Recommendation 10: Whenever possible, providers should try to offer patients extra time during medical appointments.

In addition to providing patients with necessary information, it is also important that providers make an effort to offer patients adequate time during the clinical encounter. Physicians often face enormous demands on their time because of heavy patient loads. With such demands many providers, even if they would like to, may not be able to realistically

guarantee that they can extend the length of the clinical encounter for every patient. Although many physicians who have heavy patient loads may not find such an option feasible, those who are able to offer their patients even one or two minutes more of time discover that their patients may be more satisfied with the quality of the encounter. Extra time can be used to provide patients with an opportunity to ask questions and to allow physicians more time to provide information. Such additional time can also enable providers to take more time during the encounter so that patients do not feel as though they are being hurried or rushed. Whether extra time is used to answer patients' inquiries or to simply slow the pace of the encounter, patients are likely to feel more satisfied with their medical interactions, and as a result, more likely to communicate with their health care providers. The provision of extra time will enable providers to employ vital communication techniques that can help patients retain information such as the repetition of important information and a slower speed of speech during the encounter. Both of these approaches, in conjunction with patients' greater levels of comfort because they have been provided with more time, may help to improve communication during the clinical encounter.

Providers who do not feel that they can realistically extend the length of the medical encounters can take the step of adopting other strategies in order to provide patients with more time. Providers can offer patients the opportunity to meet with other health care providers after the medical appointment. Doctors can select individuals including nurses, health educators, or patient navigators to provide blocks of time so that patients can feel free to just walk in and discuss any concerns that they may have.

Recommendation 11: Providers should use a variety of approaches in order to offer effective care and meet the demands of heavy patient loads.

Doctors are often under intense pressure to treat and address the medical needs of a large number of patients daily. It may not always be feasible for a doctor to offer greater assistance by providing more time or information to a patient. Doctors may not always be able to effectively and successfully meet all of the demands of their patients on their own. In an effort to ease the burden of heavy patient loads, doctors should attempt to utilize the services of other health care providers as much as possible. Doctors can assign certain duties to other types of health care providers who possess the knowledge to provide information or assistance. Such individuals can be specifically assigned the task of answering patients' questions and helping to explain basic concepts about a variety of conditions. Findings from this study indicated that many participants believed that doctors often fall behind schedule because they do not make proper use of the manpower (i.e., nurses) that is available to them to assist with responsibilities and lessen their workloads.

If financial resources allow, individuals such as nurses, patient navigators, or health educators can be hired for the specific purpose of assisting patients with their questions and health information needs. Such health care professionals can assist patients with other tasks that may prove problematic including the completion of hospital forms or scheduling future medical appointments. These individuals can also help direct patients to resources (including other health care professionals who may be able to provide needed services) or locate sources of information that may be of assistance to patients. Those health care professionals assigned with these tasks can offer patients information about health conditions, answer specific questions, or act as a

liaison and convey patients' concerns back to their doctors so that these concerns can be addressed at a later date. The provision of staff that can help patients more effectively navigate the often complicated health care system will likely make patients more receptive to seeking out care and more open to communicating with health care professionals.

Doctors can hire personnel who will be charged with certain responsibilities or assign these tasks to health care professionals who are already employed by the facility. One approach to address this issue could include the use of a designated individual who can meet with patients after each clinical encounter or at a time that is convenient for the patient in order to address any concerns. This individual could not only be assigned with the task of answering patients' questions but also recording patients' concerns, and then relaying this information along with any questions to the patients' doctors. Such a strategy would help patients experience greater satisfaction with their health care experiences because they would have the opportunity to focus on discussing any issues of concern. This approach could also prove effective because such designated individuals could inform doctors about any difficulties or confusion that patients experienced – confusion that patients may have failed to reveal to their doctors during the actual clinical encounters. Once doctors are aware of their patients' difficulties, the doctors can then determine the best way to address any problems and convey necessary information to patients.

Meetings with designated health care professionals after clinical encounters or at other times that are convenient can offer patients the chance to collect their thoughts and ask for information without feeling rushed or hurried. As well, this post-appointment meeting would also allow patients the opportunity to address any concerns that may have arisen during the appointment or review any questions that patients may have written down during the actual appointment but did not ask either because they forgot or were afraid or intimidated in some

way. If such an approach is deemed feasible, the designated health care professionals should allow patients the opportunity to either schedule appointments or either just walk in when the patient has the time.

Physicians who are unable to designate such tasks to other health care providers can offer patients other ways to ask questions or provide feedback. Physicians can offer patients the opportunity to ask questions or make suggestions electronically via email or set up a website specifically to handle this purpose. For those patients who do not have internet access, physicians can set up a phone number that will be used for the sole purpose of offering patients a voicemail that they can call and leave messages. Patients can call in to ask questions or make comments and if they would like to be contacted, they can leave their contact information for a follow-up call. For those patients who would like to provide feedback, but who prefer to have a bit more anonymity, a different – more “old fashioned” - approach could include the use of an actual suggestion box for patients. Such an approach would provide a very cost-effective means of obtaining patient feedback. Providers could place suggestion boxes in the office for patients. The boxes, which would remain locked and anchored down in locations throughout an office (e.g., waiting room, bathrooms, or in each examination room so that no one could see a patient put a form in the box), would provide each patient with the chance to write a note to his/her provider. The patient could make requests of certain providers (e.g., “You often use words that are too hard to understand. Can you please use words that are easier to understand?”). As well, forms can be printed for use with the suggestion box that offer patients the option to include their providers’ names (if more than one provider practices at a location). Patients could choose to include their own names on forms or be provided with the chance to make an anonymous comment. Patients who complete forms for the suggestion boxes can be offered the chance to

have someone contact them to discuss their comments at a later time or during their next visit. Patients who wish to be contacted would be informed that they have to provide their names and contact information. Because forms may contain private information (e.g., names, contact numbers) the boxes used to collect recommendations would have to remain locked and anchored down so that they could not be removed from the site. Boxes that are not anchored down would have to be put away and stored in secured sites (e.g., locked cabinets) at the end of each work day.

The use of suggestion boxes, phone lines, websites, or health care professionals who can provide extra time could help providers collect information that could be used to identify certain gaps in services. Although patients may comment on problems that are commonly experienced in many health care practices (e.g., long waits for an appointment, heavy patient loads) collected information may also reveal problem areas of which providers may not have been previously aware. For instance, if a large percentage of notes indicate that providers speak too quickly or use language that is too difficult to understand, providers can then realize that they may need to simplify the language that is used during the clinical encounter or slow the pace at which they deliver information.

Recommendation 12: Providers should make every effort to ensure that patients are comfortable during clinical encounters.

One of the most effective ways to improve communication during the clinical encounter is for providers to help their patients feel comfortable. Those patients who experience a greater level of comfort during the encounter may have a greater likelihood of communicating openly

with their providers. There are many steps that providers can take in order to help patients feel comfortable.

Providers can employ a variety of techniques to help patients achieve a certain level of comfort. The use of habits such as making certain to welcome or greet patients properly (e.g., addressing the patients by their surnames so as not to appear too informal) or even asking how each patient is doing are fast and simple gestures that can help put a patient at ease. Providers should be aware of the demeanor that they exhibit because patients who believe that their providers are not displaying a positive or pleasant demeanor (or a “good bedside manner” as one study participant remarked) may not be open to communicating during the encounter. As well, when providers do not exhibit positive gestures, such as smiling, patients may perceive that such behaviors are too impersonal. The result may be a shutdown of communication. If the provider is not aware that his/her demeanor has been perceived as rude or cold because the patient has not revealed this perception, the provider may not alter his/her demeanor, and the patient may not be interested in actively participating in the clinical encounter.

Another strategy that can be utilized to help patients experience greater comfort is to ensure that they are provided with adequate opportunities to discuss any concerns that they may have without feeling hurried or rushed. Providers can try to build in a few extra minutes into each clinical encounter so that patients can have the chance to ask questions. If this increase in the length of the clinical encounter is not feasible, then providers may want to devise other ways that patients can have their concerns addressed. Providers may be able to utilize other qualified members of the health care staff who can meet with patients, provide health information, answer questions, or record and convey questions to patients’ doctors.

Providers should make an effort to take note of those instances in which patients display feelings of fear, intimidation, or unease. Even if patients do not verbally express that they are experiencing such feelings, providers should still pay attention to each patient's nonverbal communication. Cues such as certain types of facial expressions or other body language can serve as indicators that a patient is scared, confused, or uncomfortable. Providers should be aware that even a patient's silence can be an indication of an individual's discomfort.

It may not be feasible for providers to always directly ask patients if they are feeling intimidated or uncomfortable, but physicians can devise other ways of determining if patients are experiencing these types of feelings. Providers can make it a part of their routine to occasionally ask patients if they are okay, even if the patient does not display outward signs of discomfort. As well providers can take specific steps to help ensure that patients do not experience any negative feelings. Providers can make a concerted effort to utilize a patient-centered approach during appointments. Patients who feel that they have built a true partnership with their providers may be more willing to openly communicate with their physicians. These patients may also be more willing to inform their providers when they actually experience any feelings of fear, intimidation, or confusion.

Recommendation 13: Providers should always exhibit a positive and caring demeanor.

It is essential that physicians and other health care providers recognize the impact that their demeanor can have on the clinical encounter. Even though physicians may possess excellent technical medical skills, if a patient does not believe that a provider is displaying a

demeanor that is personable, (s)he may not be satisfied with the care that is provided. Patients who are not satisfied may not, in turn, be willing to actively participate in the encounter.

A provider's displays of empathy, compassion, and other positive behaviors are essential elements of effective communication. Although a provider's medical skills are important, patients may place an equal, if not greater value on a provider's behavior. Providers should display behaviors that convey respect. Patients should never feel as though they or their opinions are being disrespected in any way. Not only is it essential for providers to be cognizant of the verbal language that they utilize but they must also be aware of the nonverbal behaviors that they exhibit. Even behaviors such as smiling or similar types of gestures can help patients experience greater comfort and reassurance and feel as though their providers are conveying a caring demeanor. Although these types of behaviors are not a reflection of a provider's medical skills, knowledge, and technical expertise, the utilization of such behaviors can dramatically impact the degree of satisfaction that patients experience. In turn, patient satisfaction can positively influence the quality of communication within the patient-provider dyad. Providers should also be certain to be aware of patients' expressions and other nonverbal behaviors and make efforts to address those instances when patients appear angry, uncomfortable, or appear to experience other negative reactions.

In order to achieve the most effective communication, providers should make every effort to help patients feel comfortable during the clinical encounter. Providers should always greet patients with a positive demeanor and appropriately address patients by name. Providers should always refer to patients by their surnames regardless of age unless a patient gives the provider permission to use his or her first name. Providers should respect patients' personal beliefs and practices (e.g., religious beliefs, use of complementary and alternative medicine therapies, etc.).

Efforts should also be made by providers to respect patients' time and if patient appointments start later than anticipated, apologies should be offered by staff for any delays. Displays of respect are essential during the clinical encounter because if patients do not perceive that they or their beliefs are being respected, they will likely be unsatisfied with their exchanges with providers even if the patients are actually provided with a high level of quality care.

Recommendation 14: Providers should work to build a partnership with their patients.

It is important for providers to realize that communication during the clinical encounter will likely be most effective when providers make an effort to partner with their patients. Although providers may feel the urge to take control of the clinical encounter, they must realize that their relationships with their patients should be regarded as a partnership. Findings from this study revealed that several of the participants believed that doctors often intentionally employ various approaches in order to exert some sense of control over the encounter. For instance, participants suggested that providers may utilize complex medical terminology intentionally in order to control the flow of the encounter. Even if this is not the true intention of many providers, the fact that some patients even possess such a belief is important for providers to recognize. During those instances in which providers do not try to completely control the flow of the medical encounter, patients may feel that they are being respected and that their concerns are being heard by providers. Providers should make every effort to simplify the language that they utilize. This approach will help providers as they attempt to partner with their patients and employ a patient-centered approach. The use of a patient-centered approach during the clinical

encounter will provide the patient with the assurance that the relationship is one that is egalitarian. Providers who are able to partner will help their patients feel that they are not only being respected but that their concerns are actually being heard. As a result, patients may be more likely to actively participate in the encounter.

If patients believe that providers are disrespectful, egotistical, or controlling, then patients may not be interested in making the effort to communicate during clinical encounters. Even in circumstances where providers do not display such blatantly negative behaviors, providers should not assume that their behavior or demeanor is acceptable to patients. A physician who provides quality care, yet does not display a positive demeanor may still be rated as unsatisfactory by patients. This may occur even if a provider's demeanor is not overtly rude. Such a physician may not be preferred by patients because this individual may not make an effort to employ behaviors that may be construed as more positive in nature – behaviors that will make patients feel more comfortable.

It is important for providers to display overt behaviors and utilize body language that indicates a pleasant or personable demeanor. Providers should be certain not to frown or express other types of nonverbal behaviors that indicate negative emotions otherwise such behaviors may adversely impact patient satisfaction. Even if providers do not utilize such behaviors, they may still have to take the specific step of displaying behaviors, such as smiling or other gestures, that indicate a level of warmth. These behaviors are indicative of a positive demeanor and are necessary in order for patients to feel comfortable.

Recommendation 15: Providers should try to determine the reasons why some patients may delay or even refuse to seek care.

There are a number of reasons why patients may be hesitant to seek care. Providers must first be aware of these reasons before they can attempt to address them. Providers need to determine the best way to obtain such information. Those who make the effort to ask patients if they have ever experienced any problems when going for care or during the course of a medical appointment may experience improved communication with their patients. Physicians can ask about these problems either during the medical history taking process during a routine appointment or at some point during the patient's initial visit to a physician. Such inquiries can help a physician begin a dialogue and provide patients with the opportunity to expose any types of barriers to care that they may have experienced. Even if patients do not have any specific problems to report when they are first asked by providers, just the act of a physician inquiring can help to start a conversation. As well, such an inquiry can provide patients with the sense that their physicians are concerned about their well-being and interested in what they have to say. Even if patients do not report that they have experienced any difficulties when they are initially asked, if they do experience problems at a later time, the patients may be open to initiating conversations and discussing barriers they encounter when seeking care at a later time because they feel that their doctors will be open to listening to them. Patients may even be willing to bring up such barriers when they have not been asked. Physicians can then incorporate information obtained from inquiries about certain patients' experiences regarding barriers to receipt of care or effective communication periodically into their usual line of questioning for all patients.

Providers can also make it a habit to ask patients who have to cancel appointments or who do not show up why they missed their appointments. Providers or other designated staff members (e.g., front desk receptionists, medical clerks) can contact patients to make sure that they are okay and ask why they missed their appointments. If providers adopt this protocol then patients may be willing to provide information about barriers that they may have encountered (e.g., no transportation, no child care, etc.) that caused them to miss their appointments. Some patients may also offer information on other types of barriers that prevented them from obtaining care (e.g., a patient's fear of seeking care, etc.) that health care professionals may not have anticipated.

Recommendation 16: Providers should work to ensure that patients do not feel afraid or intimidated during clinical encounters.

When patients experience feelings of fear or intimidation during the clinical encounter, they may be less likely to communicate with their providers. Providers should make an effort to take note of instances in which patients display such feelings. Even if patients do not verbally express this, providers should still note that a patient's silence can be an indication of that person's level of discomfort or fear.

Physicians should recognize that many patients experience some degree of fear when attending medical appointments. Those who are able to address concerns and calm a patient's fears will likely have patients who are satisfied with the quality of care provided and able to communicate more effectively. Some patients may be reluctant to receive medical treatment or participate in other types of health-related activities such as screening simply because they are

afraid. Patients who are uninformed and who do not know what to expect during a clinical encounter may experience a great sense of apprehension about seeking care. One study participant commented that she sometimes does not go for mammograms because it hurts too much to have her breasts “crushed”. Patients may refuse to have certain procedures, such as mammograms or surgeries, performed because they are afraid that these procedures will cause them to experience physical pain.

It may not be feasible for providers to always directly ask patients if they are feeling intimidated or afraid in some way, but providers may be able to devise other ways of determining if such feelings exist. Providers can also take designated steps to help ensure that patients do not experience such negative feelings. They can make a concerted effort to partner with the patient. If patients feel that they have an egalitarian relationship with their providers, then they may be more willing to open up and inform their providers when they are experiencing feelings of fear or intimidation.

Providers can combat such feelings of patients by effectively communicating with their patients. When physicians provide patients with clear and comprehensible information about various medical topics, including what to expect during a medical procedure, physicians can help to allay some of the fear and hesitation that patients may possess about the unknown. In such a circumstance, effective communication does not merely involve providing easy to understand information. Physicians must be certain to provide adequate amounts of information to their patients. It is also important that physicians try to empathize with the feelings that patients may be experiencing. The use of a caring and considerate approach by physicians can be utilized to help put patients more at ease.

Although the provision of information is important, in some cases, physicians must utilize their judgment and determine what amount of information is sufficient depending on the patient. For some patients who may not be prepared to have all of the details of a surgical procedure provided to him or her, too much information may also lead to feelings of fear and result in patients who may refuse to have certain procedures performed. One participant in the study recounted an instance in which she was making plans to have a knee replacement procedure performed. However, these plans changed once the patient was provided with detailed information about the procedure. For this participant, the doctor's detailed and graphic description of the procedure frightened her. As a result of this fear, she changed her mind and decided not to have the procedure performed.

Recommendation 17: Providers should ask patients if they would like to invite friends or family members to participate in their medical care.

Since it is the provider's primary responsibility to provide quality care for patients, the provider must be willing to work with the patients to ensure that this is accomplished. One approach that will enable physicians to achieve such a goal is to not only work with patients but their friends and family members. By including those individuals who provide assistance to patients, providers can tap into an extremely important resource. Taking the step to allow or even invite patients' friends or family members to participate in the encounter, when the patient grants permission for the provider to extend such invitations, can help providers ensure that patients are receiving assistance even after the clinical encounter is over.

Several participants from this study revealed that they have advocated for friends or family or had others advocate on their behalf. These individuals discussed instances in which they have attended medical appointments in order to assist family. As well, some participants recounted situations in which they have received assistance from others during clinical encounters. As a result of study findings, and the comments that participants made about the importance of family members advocating for patients during clinical encounters, providers may wish to ask patients if they would like to invite others (e.g., friends, family, etc.) to participate in the medical appointment. As well, providers can offer to speak with these individuals (in person, via phone, or email if these are viable options) if patients wish. Although such an offer may be time consuming for providers, offers to speak with family members may be especially important for those patients who obviously experience difficulty understanding or recalling information. Such efforts on the part of providers can help to improve communication. As well, if friends and family participate in the encounter, because the patient is not the only individual who will receive health information, (s)he can rely on others to serve as information resources. These individuals can explain or recount information when the patient does not understand or cannot recall information that has been presented during a clinical encounter.

This step of including a patient's friends or family is an important one for patients who may need the assistance of others including elderly patients, those with visual and auditory impairments, or those who may have experienced great difficulty with comprehension. Such a step may not be necessary for all patients. Inclusion of additional individuals in a patient's care can prove valuable because these individuals can help patients effectively obtain care and comply with medical recommendations. As well, the inclusion of patients' family and friends in the clinical encounter can help patients better understand information related to medical

symptoms and conditions and ensure that patients take the steps necessary to experience positive health outcomes.

Recommendation 18: Providers should prepare patients for the interactions that they may have with other health care professionals.

Some study participants expressed a degree of frustration during those instances when they were referred by their regular physicians to other providers for care. For these participants, the frustration that they expressed was related to several issues. A lack of effective communication by their regular physicians about exactly what type of care these participants were expected to receive often resulted in a sense of confusion. Some participants reported that their primary care physicians had not adequately explained the type of procedure or care they (patients) were to receive as a result of any referrals that were made. Although some participants who were confused about referrals did still seek care, some were unable to explain exactly what type of care they had received. Even study participants who reported that they had actually had surgeries performed could not always explain the nature or even recall the name of the procedure that had been performed.

Some participants expressed great annoyance because they assumed that appointments to specialists would result in an extended relationship with these providers. That is, because primary care physicians had not provided adequate information about the role that patients' specialists would play, participants expected to see specialists several times after certain procedures (e.g. surgical procedures) had been performed. For some participants, the fact that they were able to see surgeons only once or twice after having surgery performed caused them to

experience great consternation. Some of these participants had expectations that they would continue to go for more than one follow-up visit after surgery and when this did not occur, the participants were annoyed and confused in the lack of communication about what to expect. Several expressed frustration that they felt as though they had just been abandoned by their surgeons. One participant's statement suggested that she felt slightly abandoned by her surgeon because she no longer saw the individual after her surgery was performed. Her comments even suggested that she wasn't certain if her surgeon cared about her outcome because the surgeon had never been in touch with her again. The participant did not realize that after a follow-up visit or two with her surgeon, her plan of care may not have required that she have any more appointments with this physician.

Physicians should also consider an additional recommendation for patients who are referred for care or who may have to communicate with a team of health care providers. Patients and their caregivers should be informed that based on the situation, the patient may have to receive care from several different providers. As a result, patients and their family members should be aware that they may have to communicate the same information to a number of different individuals in order to receive the best care. For instance, a patient who has a stroke and who suffers from seizures as a result may have to provide his or her medical history to physicians who treat stroke, those who treat seizures, several nurses, (and once the recovery process begins) occupational and physical therapists, social workers, and nutritionists. Patients and their family members who are not aware that they will have to recount information several times for each of these health care professionals may experience great frustration. In order to avoid this, providers should inform patients so that patients know what to expect with regards to the process of receiving care. Unless patients are informed that they may have to recount the

same information repeatedly to different health care providers, the patients may become annoyed and believe that communication has broken down because they may perceive that their providers have not listened to the information that they have already provided several times. Patients who are properly informed about the steps that they need to take in order to navigate the health care system and receive care will then not be dissatisfied with their clinical encounters.

Recommendation 19: Providers should become a cheerleader for their patients.

Patients may not always believe that their providers are motivated enough to make the effort to improve communication and offer a higher quality of care. If patients believe that providers are not willing to take the necessary steps needed to improve communication (e.g., provide more time, hire a professional interpreter, etc.) and ensure that their patients are receiving optimal care, the result may be a breakdown in the interaction that occurs during clinical encounters. Patients may believe that their providers are not doing what is needed to ensure that they receive a high quality of care and that they do not encounter barriers to effective communication.

Although a number of recommendations can be offered for providers who wish to improve the amount and quality of communication that occurs during the clinical encounter, the most critical point that health care professionals must remember is that providers should always serve as cheerleaders for their patients. Such efforts can help to boost morale, strengthen partnership building efforts, and increase trust between the two parties. In order to achieve this goal, health care professionals can choose to adopt several types of strategies. For instance, providers can offer patients positive reinforcement for those individuals who are able to achieve

certain clinical goals (e.g., lose weight, lower cholesterol levels, etc.) even if patients are only able to take small steps towards achieving a goal. For this study, one participant recounted an instance when her physician told her that she was too fat. Although the woman had worked hard to lose a few pounds, she had been unable to lose the total amount of weight recommended by her physician. When the participant attended a medical appointment and was admonished by her physician, she became angry. The participant reported that instead of congratulating her on what she had been able to lose, the physician criticized her for what she did not lose. This interaction resulted in the patient later having a strained relationship with her provider – one that suffered because of a breakdown in communication after the patient admitted that she stopped actively participating in appointments with this provider as a result of the provider's comments.

Providers can help their patients prepare for health care encounters and make certain to inform their patients that they should not be afraid to ask questions about their own health. Providers should stress that their patients be willing to advocate for themselves during clinical encounters. Providers should inform their patients that they should always be willing to speak up in order to obtain necessary care and be prepared with questions to ask. Most importantly, providers need to assure patients that their active participation in clinical encounters is a vital aspect of effective care. Patients must be assured that when they actively communicate with their providers and participate in medical decision-making, they will be able to obtain optimal care.

Providers should be willing to make every effort to improve communication during clinical interactions with their patients. Some providers may believe that they should not be held solely responsible for improving communication because patients must be active participants in their own care. It is essential that providers recognize that they are indeed responsible for

providing optimal care for their patients and the use of effective communication practices will enable the providers to do so. The onus to improve communication should not be solely on the provider; however the provider should recognize that by following certain steps that can positively influence communication, (s)he can play a major role in impacting the interaction that occurs during medical appointments between patients and providers.

Recommendation 20: Providers need to consider additional approaches when treating patients who experience difficulty communicating because of problems understanding English.

Although the issue of language was not a reported barrier for the participants in this study because eligibility criteria mandated that women speak English in order to participate, it should be noted that patients whose first language is not English may often report the factor of language as a barrier to effective communication. Since difficulty understanding as a result of language was not reported as a barrier for this sample, study participants did not list this factor as one that impacted their interactions with their providers. Providers who serve patient populations that consist of bi- or multilingual patients may find it useful to further research this topic. An important initial step will include an assessment of the needs of the community that is being served. Providers first need to determine the languages that are preferred by individuals in the patient population. Approaches to address communication issues could include the use of professionally trained medical interpreters, the provision of written materials (health information, medical forms, etc.) in languages besides English, or suggestions for websites or phone lines that provide information in languages other than English. As well, another approach might include

the use of communication toolkits that contain lists or flashcards that contain translations of commonly used medical words. For instance a flashcard for Spanish speakers might include the translation “eye” = “ojo”.

One barrier that may actually impact the participants in this study population is not specifically a patient’s language but a patient or provider’s use of either “slang” or colloquialisms during conversation. If either party in the relationship does not understand the other’s use of such jargon, then a breakdown in communication may result. If providers do not understand a patient’s language because of this, then they (providers) should be certain to clarify understanding by directly asking the patient to explain any confusing terms. Conversely the same recommendation must be made for patients. Providers should avoid the use of such jargon unless they are certain that their patients will understand because if their patients do not understand the use of certain phrases, the patients may not be willing to disclose this lack of understanding to providers. Whenever patients experience any level of uncertainty - whether because of the use of “slang” or the use of complex medical terminology - they should always be urged by providers to ask questions during such instances in order to obtain needed clarity.

Providers should be willing to adopt tactics that can help to improve the quality of communication with their patients. There are a variety of techniques and approaches that providers can employ in order to address the issue and it is important that providers determine which approaches can prove to not be only effective but feasible based on their patient loads and available resources. Although findings from the pilot study resulted in several communication recommendations by participants, providers need to determine which of the proposed suggestions will work most effectively for their specific patient populations. Providers should note that while employing some of the suggested recommendations may specifically assist

patients who have inadequate health literacy, the use of these recommendations will also likely help to benefit all patients by improving various aspects of communication during the clinical encounter.

VIII.B. STUDY STRENGTHS

While the responses of study participants provided a rich source of data, because the eligibility criteria for participation in the pilot study only included individuals from a select pool, the recommendations offered for providers may not prove to be effective for all patients. Health care professionals who provide care for African American women who are at least age 50 may experience the greatest benefit from adopting these recommendations because eligibility criteria restricted participation to individuals who possessed these characteristics. In addition to age, gender, race, language, and place of residence, study criteria also mandated that women who participated could not have received a diagnosis of breast cancer. In an effort to gain a true understanding of women's knowledge of breast cancer-related topics, those women who had received a previous diagnosis of breast cancer were unable to participate. During the course of the pilot study, investigators identified both strengths and limitations with regard to the study's design and implementation.

Findings from the pilot study will be able to assist investigators who wish to further explore patients' clinical experiences, including the quality of patient-provider communication that occurs during encounters. In addition to collected data that can be used to inform investigations about effective communication, the study was also able to inquire about participants' levels of knowledge about breast cancer, as well as their attitudes, beliefs, and practices. While this data is not central to the focus of the dissertation, it was collected as a part

of the original pilot study. As well, the collected data about participants' breast cancer-related knowledge, attitudes, beliefs, and practices (KABPs) is a critical source of information for researchers who wish to examine these topics in future studies. A review of the data about participants' breast cancer-related KABPs will certainly assist investigators who wish to pursue this topic further, especially amongst study samples that consist of aging urban African American women.

In addition to the fact that the pilot study provided a wealth of data with regard to KABPs, the study also possessed a number of other strengths. Although the study's limited budget restricted the number of staff available to work on the study, the fact that only one individual was charged with the task of interviewing all subjects did not limit the study. During the first few weeks of study recruitment, the interviewer was on-site to conduct interviews approximately two to three days a week for a few hours each day. However, once the interviewer was able to increase her availability, she was on-site for four days a week, for 6 to 7 hours a day. Although all of this time was not spent interviewing participants, it was used to recruit participants. By increasing her time at the senior center, the interviewer was able to provide potential participants with more information about the study and more opportunities to participate in the interview at their convenience. In addition to providing more interview slots, the interviewer's frequent presence at the center served another, more important function. It helped to provide center attendees with a great sense of trust. When the interviewer first started to attend the center, she was often rebuffed by some women who she approached and invited to participate in the study. Although many attendees would initially refuse participation, the interviewer would generally wait for approximately two weeks and then approach the same attendees again who had initially declined. Occasionally these women would again refuse

participation, but often the same women who had initially been so abrupt in their refusal to participate changed their minds and agreed after they were approached again. A frequent response by “initial refusers” (women who declined participation when first invited) was that because they had (in the words of one participant) “gotten used” to the interviewer being at the center and felt more comfortable with her presence, they were usually more open to hearing about the study and participating when approached a second or even third time. Since the interviewer had made an effort to establish a regular presence at the senior center, the center attendees became accustomed to being approached and offered information. Eventually many of these attendees, who initially appeared to be uninterested, agreed to not only hear more about the study but to participate as well. By making certain to be in attendance at the senior center regularly, the interviewer was able to help attendees become more comfortable with her presence and eventually build rapport and establish a level of trust.

An additional strength of the study was the recruitment strategy that was employed by the interviewer. Several approaches were utilized in order to recruit individuals for study participation. Not only did the interviewer post flyers around the senior center that included basic information about study participation and her contact information, but the center’s Activities Coordinator frequently distributed flyers to attendees when passing out information about activities that were available at the center. The center’s Director also regularly made announcements either in the mornings or during lunch time about center events. Included in these regular announcements was information about study participation. If the interviewer was present at the center when these announcements were being made, then the Director would always introduce and identify the interviewer to the center’s attendees. If the interviewer was not present at the center when announcements were being made, then the Director still provided

brief information about the study and directed attendees to either seek out the center's Activities Coordinator or locate a posted study flyer in a designated section on the "Activities Bulletin Board" in order to obtain additional information.

All interviews were conducted by the same individual. Although an initial limitation of the study was that the budget did not allow for a large number of staff, this limitation was eventually considered a strength. Since all interviews were conducted by the same individual, the protocol utilized to recruit participants and conduct interviews was the same for each participant. The use of one individual to conduct all interviews helped to ensure that all participants were exposed to the same protocol during the study interview process. Since the interviewer displayed the same demeanor when speaking with participants and did not deviate greatly from the study's specified protocol, it is likely that all participants had a similar experience during both the recruitment and the interview processes.

One aspect of the interview protocol required that the interviewer record the responses of study participants. In an effort to ensure that the interviewer accurately and completely recorded all interview responses, participants were asked if they would allow their interviews to be audio recorded. By recording responses, the interviewer was able to maintain the flow of the questions and keep her focus on the interview questions and responses without taking too much time to write responses. If the interviewer had to take the time to write all responses, this process would have been too time consuming and increased the amount of time needed to conduct interviews. By recording responses to questions, the interviewer could then take time at a later date to transcribe recordings and review responses. To ensure that all information was recorded accurately, two different recorders were used. This approach ensured that if one recorder malfunctioned, the other recorder was able to serve as a backup and capture information. The

interviewer also recorded notes during the interview sessions. All participants were informed that audio recording the interview sessions was not mandatory. Women were offered the option to have their interviews recorded and all but one participant agreed to have her session recorded. As a result, responses were able to be accurately recorded and reviewed. The transcripts of interview sessions helped to provide investigators with an accurate record of participants' responses.

With regard to the interview sessions, the interviewer took several steps in order to best accommodate participants. Since the interviewer was present for most of the week, the schedule of participants could be accommodated. As well, the interviewer was provided with a small room where interviews could be conducted and participants could be afforded with a great deal of privacy so that they could answer questions honestly. Participants were offered refreshments during the course of the interview and also offered the time to take a break if they wished. While participants were instructed that the interview process could last approximately 1 hour or so, those who wished to speak longer were allowed to do so. Many of the women were willing to spend between 1 to 2 hours with the interviewer. The interviewer did not end the sessions if participants were still answering questions or talking about their clinical experiences after the allotted hour had passed. Instead, each participant was allowed with all the time that she needed to complete the interview. Although many of the interviews lasted a greater length of time and required more time to transcribe, the result was a greater amount of information that discussed the communication experiences of the participants. In order to ensure that participants could take their time and not have to rush through the session, the interviewer made a considerable effort to not schedule any interviews back to back. Spacing out the interviews provided each participant with extra time in case their session exceeded the allotted time.

The pilot study was exploratory in nature, and because of this study participants were allowed a bit of flexibility with regards to their participation in the interview. With regards to time constraints, although participants were instructed during the consent process of the study that the interviews were expected to last a certain amount of time, participants were allowed to take as much time as needed to respond to interview questions. Because of the flexibility allowed for participants, the responses of many of these individuals were rather comprehensive. Such comprehensive responses were able to provide valuable information about factors that impact patient-provider communication that may not have been examined at great length in previous research and that may not have been previously considered by the study's investigator.

In an effort to ensure that the study investigator captured the most accurate data possible, several of the questions that focused on assessing the communication experiences of participants were presented in more than one format. That is, a question that inquired about a participant's level of difficulty understanding sources of health information during medical visits might be asked in two different ways in order to make certain that the participant both understood the information that the question was asking and provided a complete response. For instance, one question in the interview asked participants, "*Do you always understand the information that your doctor or nurse provides for you?*" Participants who answered "No" to this question were then asked to explain their responses. This question was utilized to capture problems that participants might experience when trying to understand information presented by a health care professional during a clinical encounter. However, those participants who responded "Yes" to this question may still have experienced difficulty understanding health information in some other setting in the health care environment and not specifically during a medical appointment. To capture information about participants' experiences understanding information outside of

their medical appointments, the interview also included another question that was used to assess experiences in other environments throughout the health care setting. Participants were also asked, *“In general, have you ever had problems understanding or reading information provided to you in a medical setting? For this question don’t just think about when you are talking directly to your doctor or nurse during an appointment. Think about any problems that you have understanding any information in a hospital or clinic. This includes having problems reading signs in the hospital, health brochures, treatment instructions, medication instructions, or hospital forms – like insurance forms - that you complete when you register for a medical visit.”*

Although this question is much longer in length, it was useful in that it may have been able to capture information about participants’ difficulties understanding information throughout the health care setting (e.g., reading signs in the hospital) and not specifically information that focused on problems experienced during medical appointments. Participants who responded “Yes” to this question were then asked to explain their responses. Although the use of similar questions resulted in longer interviews for participants, additional questions also helped to ensure that investigators were able to collect accurate data about participants’ experiences. The use of just one question may have led participants to only respond about difficulties that they experienced during their actual medical appointments. However, the use of a second, more comprehensive, question helped to ensure that participants also responded about difficulties that they experienced understanding health information in medical environments outside of the actual clinical appointment. As well, a number of participants, when answering the first question may have responded with just one example of an instance when they did not understand information. However, by the time the participants were asked the second question, they usually had recalled more examples, and they then included these examples in their responses to the later question.

An additional strength of the pilot study was that the interview that was utilized inquired about a number of topics in addition to the communication experiences of participants. Participants were asked questions that assessed their breast cancer related knowledge, attitudes, beliefs, and practices. As well, other sections of the interview focused on assessing participants' health literacy levels, medication use and adherence, and preferred sources of health information. The data collected can offer a valuable source of information by providing investigators with insight about which resources patients are likely to rely on when they need assistance comprehending information or when they need additional information.

The pilot study's findings will help to provide a valuable source of information about the health literacy levels and the patient-provider communication experiences of a sample of aging urban African American women, a segment of the U.S. population which has encountered increasing health disparities. This study is of great value because this particular segment of the population has often not been the focus of studies that examine patient-provider communication during the clinical encounter. Collected data from the interview responses will not only provide critical insight about the experiences of these individuals, but data can also be used to inform the development and implementation of future programs that will seek to address comprehension and communication barriers that patients may experience. An examination of pilot study data can help to guide investigators who seek to conduct larger scale studies that focus on examining variables including health literacy, patient-provider communication, or the breast cancer-related knowledge, attitudes, beliefs, and practices of African American women. Lessons learned from the current study can also be applied to larger scale studies that seek to examine study samples that are comprised of individuals who possess other eligibility criteria (e.g., race, gender, etc.).

VIII.C. STUDY LIMITATIONS

Although the study did possess several strengths with regards to its design and implementation, there are also limitations that need to be considered. The information captured by participants' responses can help to provide insight about clinical encounter experiences, including barriers and facilitators to effective communication, but such information must be validated. The use of other types of qualitative methodologies such as focus groups can help to serve this purpose. The use of focus groups comprised of center attendees who also meet the pilot study's eligibility criteria will help the study's investigator determine if the study's findings accurately represent the views of women who attend the center as well as other African American female residents of Harlem who meet a specific age criterion. By conducting focus groups and presenting group participants with the findings from the semi-structured interviews, researchers will be able to determine if other African American women who reside in the central Harlem area will confirm the results of this study. Discussions that will allow focus group participants to review the pilot study's reported facilitators or barriers to effective communication and offer feedback about these factors will help the study's investigators to validate findings from the current study. An important next step for this pilot study should include the use of research activities that can help to validate the data collected during the interviews. Once this is completed, further activities can include the step of having investigators conduct larger scale studies that also seek to explore the communication experiences of patients.

An additional limitation of the pilot study was the number of staff available to conduct the study. Because of limited funds, only one interviewer was available to meet with participants. This individual also served as the recruiter of the study's participants. Although the availability of only one individual to conduct interviews could be considered as a limitation

to the study's implementation, once the interviewer was able to spend more time on site at the center, the issue of limited staff did not appear to be problematic. The interviewer's greater availability at the center helped to speed up the recruitment process and allow participants increased flexibility when selecting their interview times. As a result, more participants were able to be recruited and interviewed each week.

Once the interviewer began to spend greater amounts of time at the center, she was able to interact more with attendees. This increased interaction – whether in the form of helping participants with their extracurricular activities or even simple tasks such as carrying the lunch trays of individuals who had mobility issues – helped the interviewer to build a greater sense of trust with the attendees. The interviewer's frequent presence at the center helped her to build relationships with the attendees and as a result likely helped with recruitment. As attendees grew more comfortable with the interviewer's presence and became more trusting, they would sometimes take the initiative to approach the interviewer and ask questions about this study. This action even occurred with attendees who had initially rebuffed the interviewer when they were approached about study participation. Many who had expressed no interest in the study or even flatly refused to participate changed their minds and agreed to participate once they spent more time in the center in the presence of the interviewer. Such findings reveal that although the issue of limited staff could be regarded as a limitation, it can also be considered as a strength of this study.

Another potential limitation to the study is that the findings from the current study may not be generalizable to all patients. The small sample size and the fact that the sample was not representative impacted the study's generalizability. As well, it is important to note that participants in this sample were residents of only one geographic area in Manhattan. Individuals

who possess other characteristics (e.g. race other than African American, or different age, place of residence, medical history, etc.) may not report the same facilitators or barriers to care as the participants in this study sample. In order to determine if factors that impact communication may differ for other individuals, additional studies should be conducted. Future research efforts may replicate the current study by using the same eligibility criteria and data collection instruments or investigators may choose to modify the eligibility criteria. By opening up the study participant pool to individuals who are younger, male, from different racial backgrounds, and who may reside in other geographical areas of Manhattan or even other boroughs, researchers may be able to determine if these reported barriers are specific to patients with the selected eligibility criteria or if these barriers can impact all patients and prevent effective communication. By repeating this study with other participants, researchers will be able to inquire about the clinical encounter experiences of a wide variety of patients and determine what barriers to communication may exist for other patients.

Although the drafted communication recommendations may prove beneficial for those who provide care for patients who possess certain characteristics (i.e., the eligibility criteria of participants in the current study) the barriers reported by study participants may not be ones that are experienced by all patients. For instance, although the women in this study reported that they may at times either delay seeking care or refuse care altogether because they are afraid of experiencing physical pain (e.g., from a mammogram), other patients (who are not African American, 50 and older, etc.) may not report similar fears. As a result, efforts should be made to conduct similar studies with different eligibility criteria.

An additional limitation of the study was that the population of individuals who participated in the interview only offered a patient's perspective of the clinical encounter. Future

endeavors may benefit from also considering the perspectives of health care providers, who serve individuals in this community, as well as family members and friends who act as advocates and assist patients during clinical encounters. Such research efforts can include the use of qualitative approaches such as interviews or a focus group methodology. By including information collected from health care providers, investigators can determine if providers' perspectives about clinical encounter communication experiences match those of patients.

Another issue for investigators to consider is that although the data collected from the interviews provide valuable insight about the patient perspective, the data may not be totally complete. That is, while participants appeared at ease and willing to talk during the interviews, all of the participants may not have been totally forthcoming about all of the difficulties that they have encountered. For instance, when asked to provide examples of situations in which the participants experienced problems with comprehension or communication, participants may not have been comfortable speaking honestly about situations that would expose their lack of knowledge about health topics, including topics related to their own health status. Participants may not have been willing to admit to the interviewer that they did not understand certain information because such a disclosure would reveal their limited knowledge. As well, participants may have been more likely to focus on barriers to communication caused by providers and not barriers that may be patient-related. Some participants may have had the tendency to focus on communication problems caused by providers' actions, while trying to downplay their own roles in issues related to communication. For example, one participant who had difficulty answering questions during the session because she could not hear the questions, disclosed to the interviewer that she did have some degree of hearing loss. Despite the fact that the participant admitted her auditory impairment, when asked about her communication

experiences with her provider, one of her chief complaints was the fact that her provider spoke “too low” during medical appointments. The woman did not discuss the fact that her difficulty hearing information and communicating with her provider may have been the result of her hearing loss. The woman was not willing to admit that her own auditory impairment likely contributed to her difficulty with comprehension. Instead she attributed most problems that she experienced to the fact that her provider “refused to speak up”.

IX. FUTURE DIRECTIONS

The current pilot study was able to collect data that can be used to inform the design and implementation of future investigations that seek to examine patient-provider communication. Although the information captured by the interviews will be of great assistance to those investigators who wish to explore these topics further, there are a few additional steps that need to be taken. As discussed previously, findings from the current pilot study need to be validated. Qualitative methodologies such as the use of focus groups are one approach that can help to address the issue of validation.

Despite this limitation, findings from the study will prove valuable for researchers interested in examining health literacy and patient-provider communication. Collected study data also provided information about patients’ preferred sources of information and medication use and adherence. Although the dissertation focused on exploring those factors that impact communication during clinical encounters, the responses of participants were also able to provide great insight about other critical topics that are relevant to the provision of optimal care.

Despite the fact that all captured data from the original pilot study was not included as a part of the dissertation’s findings, collected data from the interviews also revealed valuable

information about participants' breast cancer-related knowledge, attitudes, beliefs, and practices. Findings from the data that focus on these topics can also serve as a valuable source of information for investigators. For instance, a review of data indicated that although participants possessed some level of knowledge about breast cancer-related topics, several participants were unsure as to what the correct screening recommendations were for self-exams and mammograms (e.g., recommended frequency of practices and age to start screening, etc.). As well, many of the participants still did not possess a thorough knowledge of topics related to prevention or treatment. For instance, while participants could properly define the term "mammogram", most could not give a definition of other terms such as "lumpectomy", "chemotherapy", or "radiation therapy". Such a finding might be expected, particularly amongst a sample of women who had never been previously diagnosed with breast cancer. These women might not possess an understanding of different types of treatments for cancer. Still because of the age of the members of the sample, it might be expected that more of the individuals would be more knowledgeable about the recommendations for various types of screening including self-exams, clinical exams, and mammograms. An additional study finding that does need to be addressed in future research is the fact that the majority of women could not provide a clear yet simple definition of the term "cancer". Most women could offer some type of descriptor such as the fact that cancer as a disease is "serious" "bad", "scary", or "frightening" but these individuals were unable to give any type of a response when asked the question "*What is cancer?*"

With regard to future health education efforts, this finding needs to be addressed because women – especially those in this age group - cannot be expected to effectively take the necessary steps to prevent a disease that they cannot even define. Another section of the interview included a series of questions that were utilized to assess participants' knowledge of risk factors

for breast cancer. Results from this section of the interview can also prove valuable for investigators. A large percentage of participants were unsure about risk factors for breast cancer. Many indicated that they believed that breast cancer was caused by a hit to the breast, a punishment from God, or even the Devil's work. Programs that can help to educate women about risk factors need to be developed and implemented for future education programs. A particular emphasis needs to be placed on the development of strategies that can help women to learn more about those factors that have been deemed by investigators and the results of research studies as ones that have a greater likelihood of increasing a woman's risk of developing the disease.

Although the focus of the dissertation was to examine factors that impact communication, an examination of those responses that assessed participants' cancer-related knowledge, attitudes, beliefs, and practices (KABPs) can also assist investigators who wish to gain a more thorough understanding of the facilitators or barriers to effective patient-provider communication. Greater exploration of such factors may, for instance, help investigators realize that if patients do not possess attitudes or beliefs that will motivate them to participate in screening or possess an accurate knowledge of risk factors for breast cancer, then the result may be a breakdown in communication within the patient-provider dyad. Those patients who do not understand screening recommendations or who may become intimidated because they may be frightened or they may not understand breast cancer-related information may also experience barriers to communication.

A preliminary review of data revealed that future research efforts may wish to not only continue to assess factors that impact communication but to also focus on further assessing the breast cancer-related KABPs of women, particularly older African American women. Data

collected from research efforts that continue to examine either the breast cancer-related KABPs of older African American women or the communication experiences of these individuals will assist investigators by providing the data needed to design and implement effective health education programs. Such initiatives can then be used to educate individuals about prevention and treatment as well as teach them how to either avoid or effectively overcome those barriers that may impact the quality of communication that they have with their providers.

It is also critical that any future efforts that examine the topics of breast cancer and effective patient-provider communication for African American women also explore other topics that were touched upon but not explored in depth in this study. For instance, although participants were never directly asked about the issue of trust and how it impacts their perceptions of providers and the health care establishment, this topic was raised by several participants in their responses to questions that were asked about other topics. For instance, although one participant commented about a physician's provision of information, she also made comments about her level of trust in this individual. Her unsolicited comment about trust indicates that this is a topic that participants may be interested in discussing and therefore needs to be further explored.

Another topic that should be explored is the amount of resiliency that participants displayed when attempting to have their health care needs met. Although a number of the participants reported that they wished to have more health-related information about topics so that they could obtain a better understanding of their own health care needs, many revealed that they were not always able to acquire this information from their doctors, nurses, or even literature that was available at their health care facilities. As a result of this dearth in information, participants often commented that they took any steps necessary in order to acquire

this information. Participants provided examples of instances when they would seek out information from family, friends, and other health care professionals (e.g., pharmacists). A great number of the women reported that they would make an effort to research topics on their own so that they could be better informed. These women would attend community lectures, health fairs, and exercise classes in order to pick up brochures about a variety of health topics. Several women indicated that they would go to the library and check out or make copies of books that contained needed information. As well, a number of women also admitted that they could not always afford to purchase health-related books from bookstores. When they needed information they would simply go to the store, select a book of interest, and then take a pencil and pad so that they could write down information from the book. While the women indicated that they would have preferred to be able to purchase the book, by copying relevant information from the book the women still felt as though they were able to obtain the information that they needed. These practices, along with other examples of resiliency that participants provided, suggest that this is a topic that should be further explored in any future investigations that examine the patient communication experiences or the health-related knowledge, attitudes, beliefs, and practices of urban African American women.

X. CONCLUSION

One of the primary goals of the health care industry is to provide a high level of quality care for its patients. Although this objective calls for providers to ensure that patients receive the care that they need, a number of factors can work to prevent patients from participating in preventive practices or obtaining necessary medical attention. Several such factors are able to

impact the receipt of preventive care or treatment by adversely affecting the quality of communication that occurs during the clinical encounter. As a result, providers and their patients may experience either a poorer quality of communication or decreased communication. This breakdown in patient-provider communication within the health care setting can result in a number of negative outcomes for patients including: (1) medication errors, (2) greater levels of patient pain, (3) increased misdiagnoses, (4) treatment errors, (5) longer hospital stays and (6) even a greater risk of death. Although communication problems can lead to several dire consequences for patients, providers can address these issues by first, determining the causes of communication breakdown and second, adopting strategies that can help to address or even prevent communication problems.

While strategies to address communication issues may include the utilization of at least one of the recommendations offered by the pilot study participants, many providers may not always be willing to follow such recommendations. For instance, the recommendation that patients be provided with additional time during the clinical encounter may cause some providers to experience great frustration. The addition of new techniques to a provider's toolkit of skills and practices may not always be feasible especially if the providers are already dealing with tremendous pressures to treat a large number of patients each day. The use of approaches such as a slower speed of speech, repetition of information, or communication with family or friends who may be in attendance during an appointment may first appear time consuming. However, providers who are able to adopt at least one of these approaches may experience a noticeable improvement in communication and the ability to provide improved care.

Many who work in the health care field may believe that the provision of effective communication should not solely be the responsibility of the health care provider. However, it is

imperative that such individuals recognize that providers may be better prepared to handle this task than patients. Providers can initiate and put into practice those strategies that are critical for ensuring that patients receive optimal care. Patients can learn approaches that will help them actively participate in decision making and as a result, more effectively communicate with their providers. Still, even with patients taking such actions, providers are in the best position to guide clinical encounters and therefore help to guarantee that the interactions that occur during such encounters employ strategies that can help to ensure the utilization of effective patient-provider communication.

Since the factors that can impact the clinical encounter interaction between patient and provider, and as a result the quality of communication that the two parties experience, varies according to each patient, it is critical that health care providers make an effort to examine this topic further. As reported by participants in the current pilot study, findings revealed a number of reported barriers and facilitators to effective communication with providers. Although the factors discussed by participants in this study may be those that primarily impact the interactions of patients who are female, African American, Harlem residents who are least 50 years of age, it is critical that investigators make efforts to further explore such findings. Factors such as patient-provider gender discordance, the impact of race and culture on the clinical interaction, and patients' religion and spiritual views were all offered as potential barriers to effective communication. Although findings for this study need to be validated, the results of this study have revealed valuable data that can be used to improve communication within the patient-provider dyad. As well, findings from the current study can be used in the generation of hypotheses for larger scale studies. Investigators who wish to explore this topic further may wish to repeat this study while employing different eligibility criteria for participation. By

allowing the use of different criteria in future studies, investigators and health care providers will be able to gain a clearer picture of factors that may impact the clinical encounter experiences of patients who possess a variety of characteristics – not just the characteristics of those individuals who participated in the pilot study.

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APPENDIX A

DATA COLLECTION INSTRUMENTS

Test of Functional Health Literacy in Adults

Short Test of Functional Health Literacy in Adults (STOFHLA)

STOFHLA

**Large Print Version
English, 14 point font**

Short Test of Functional Literacy in Adults
STOFHLA
READING COMPREHENSION

HAND PATIENT THE READING COMPREHENSION PASSAGES TO BE COMPLETED. FOLD BACK THE PAGE OPPOSITE THE TEXT SO THAT THE PATIENT SEES ONLY THE TEXT.

PREFACE THE READING COMPREHENSION EXERCISE WITH:

“Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which of those 4 words should go in the blank, which word makes the sentence make sense. When you think you know which one it is, circle the letter in front of that word, and go on to the next one. When you finish the page, turn the page and keep going until you finish all the pages.”

STOP AT THE END OF 7 MINUTES

PASSAGE A: X-RAY PREPARATION

PASSAGE B: MEDICAID RIGHTS AND RESPONSIBILITIES

PASSAGE A

A1	(1)	(0)
a.		
b.		
c.		
d.		

A2	(1)	(0)	A3	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A4	(1)	(0)	A5	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an _____ stomach when you come for _____.

- | | |
|-----------|--------|
| a. asthma | a. is. |
| b. empty | b. am. |
| c. incest | c. if. |
| d. anemia | d. it. |

The X-ray will _____ from 1 to 3 _____ to do.

- | | |
|---------|-----------|
| a. take | a. beds |
| b. view | b. brains |
| c. talk | c. hours |
| d. look | d. diets |

A6	(1)	(0)	A7	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A8	(1)	(0)	A9	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A10	(1)	(0)	A11	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

- a. little
- b. broth
- c. attack
- d. nausea

- a. toes
- b. throat
- c. toast
- d. thigh

with coffee or tea.

After _____, you must not _____ or drink

- a. minute,
- b. midnight,
- c. during,
- d. before,

- a. easy
- b. ate
- c. drank
- d. eat

anything at _____ until after you have _____ the X-ray.

- a. ill
- b. all
- c. each
- d. any

- a. are
- b. has
- c. had
- d. was

A12	(1)	(0)
a.		
b.		
c.		
d.		

A13	(1)	(0)	A14	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A15	(1)	(0)	A16	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

THE DAY OF THE X-RAY.

Do not eat _____.

- a. appointment.**
- b. walk-in.**
- c. breakfast.**
- d. clinic.**

Do not _____, even _____.

- | | |
|------------------|-------------------|
| a. drive, | a. heart |
| b. drink, | b. breath. |
| c. dress, | c. water. |
| d. dose, | d. cancer. |

If you have any _____, call the X-ray _____ at 616-4500.

- | | |
|----------------------|----------------------|
| a. answers, | a. Department |
| b. exercises, | b. Sprain |
| c. tracts, | c. Pharmacy |
| d. questions, | d. Toothache |

B17	(1)	(0)
a.		
b.		
c.		
d.		

B18	(1)	(0)	B19	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B20	(1)	(0)
a.		
b.		
c.		
d.		

B21	(1)	(0)	B22	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B23	(1)	(0)
a.		
b.		
c.		
d.		

Sub-Total

PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I _____ to provide the county information to _____ any

- | | |
|----------|--------------|
| a. agree | a. hide |
| b. probe | b. risk |
| c. send | c. discharge |
| d. gain | d. prove |

statements given in this _____ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the _____ to get such proof. I _____ that for

- | | |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion | b. entertain |
| c. iron | c. understand |
| d. county | d. establish |

Medicaid I must report any _____ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges

B24	(1)	(0)	B25	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B26	(1)	(0)	B27	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B28	(1)	(0)	B29	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B30	(1)	(0)
a.		
b.		
c.		
d.		

B31	(1)	(0)	B32	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

within _____ (10) days of becoming _____ of the change.

- a. three
- b. one
- c. five
- d. ten

- a. award
- b. aware
- c. away
- d. await

I understand _____ if I DO NOT like the _____ made on my

- a. thus
- b. this
- c. that
- d. than

- a. marital
- b. occupation
- c. adult
- d. decision

case, I have the _____ to a fair hearing. I can _____ a

- a. bright
- b. left
- c. wrong
- d. right

- a. request
- b. refuse
- c. fail
- d. mend

hearing by writing or _____ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you _____ TANF for any family _____, you will have to

- a. wash
- b. want
- c. cover
- d. tape

- a. member,
- b. history,
- c. weight,
- d. seatbelt,

B33	(1)	(0)	B34	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B35	(1)	(0)	B36	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

_____ a different application form. _____, we will use

- a. relax
- b. break
- c. inhale
- d. sign

- a. Since,
- b. Whether,
- c. However,
- d. Because,

the _____ on this form to determine your _____.

- a. lung
- b. date
- c. meal
- d. pelvic

- a. hypoglycemia.
- b. eligibility.
- c. osteoporosis.
- d. schizophrenia.

Short Test of Functional Health Literacy in Adults (STOFHLA)

Joanne R. Nurss, Ph.D., Ruth M. Parker, M.D., Mark V. Williams, M.D., & David W. Baker, M.D., M.P.H

TOFHLA is a measure of a patient’s ability to read and understand health care information, their functional health literacy. TOFHLA Numeracy assesses their understanding of prescription labels, appointment slips, and glucose monitoring. TOFHLA Reading Comprehension assesses their understanding of health care texts such as preparation for a diagnostic procedure and Medicare Rights & Responsibilities.

Date ____ / ____ / ____

Name _____ M ____ F

Birthdate ____ / ____ / ____ Age ____ SSN or ID# _____

Hospital or Healthcare Setting _____

City, State _____

Short Form Administered: _____ English _____ Spanish

STOFHLA – Score

**TOFHLA Total Score:
Reading Comprehension Raw Score (0-36)**

Functional Health Literacy Level:

0 – 16 -- Inadequate Functional Health Literacy	<input data-bbox="1198 1619 1416 1671" type="text"/>
17 – 22 -- Marginal Functional Health Literacy	<input data-bbox="1198 1688 1416 1740" type="text"/>
23 – 36 -- Adequate Functional Health Literacy	<input data-bbox="1198 1757 1416 1810" type="text"/>

STOFHLA: Reading Comprehension
Scoring Key

14 Point Font

Passage A	Passage A	Passage A	Passage B	Passage B	Passage B
A1 a	A6 a	A12 c	B17 c	B24 d	B33 d
A2 b	A7 c	A13 b	B18 a	B25 b	B34 c
A3 d	A8 b	A14 c	B19 d	B26 c	B35 b
A4 a	A9 d	A15 d	B20 b	B27 d	B36 b
A5 c	A10 b	A16 a	B21 d	B28 d	
	A11 c		B22 c	B29 a	
			B23 a	B30 c	
				B31 b	
				B32 a	

Rapid Estimate of Adult Literacy in Medicine

Patient name _____ Date of birth _____ Reading level _____

Date _____ Clinic _____ Examiner _____ Grade completed _____

List 1

Fat
 Flu
 Pill
 Dose
 Eye
 Stress
 Smear
 Nerves
 Germs
 Meals
 Disease
 Cancer
 Caffeine
 Attack
 Kidney
 Hormones
 Herpes
 Seizure
 Bowel
 Asthma
 Rectal
 Incest

List 1 score _____

List 2

Fatigue
 Pelvic
 Jaundice
 Infection
 Exercise
 Behavior
 Prescription
 Notify
 Gallbladder
 Calories
 Depression
 Miscarriage
 Pregnancy
 Arthritis
 Nutrition
 Menopause
 Appendix
 Abnormal
 Syphilis
 Hemorrhoids
 Nausea
 Directed

List 2 score _____

List 3

Allergic
 Menstrual
 Testicle
 Colitis
 Emergency
 Medication
 Occupation
 Sexuality
 Alcoholism
 Irritation
 Constipation
 Gonorrhea
 Inflammatory
 Diabetes
 Hepatitis
 Antibiotics
 Diagnosis
 Potassium
 Anemia
 Obesity
 Osteoporosis
 Impetigo

List 3 score _____

Raw score _____

Directions:

1. Give the patient a laminated copy of the REALM form and score answers on an unlaminated copy that is attached to a clipboard. Hold the clipboard at an angle so that the patient is not distracted by your scoring. Say, "I want to hear you read as many words as you can from this list. Begin with the first word in List 1 and read aloud. When you come to a word you cannot read, do the best you can or say, 'blank' and go onto the next word."
2. If the patient takes more than five seconds on a word, say "blank" and point to the next word, if necessary, to move the patient along. If the patient begins to miss every word, have him or her pronounce only known words.
3. Count as an error any word not attempted or mispronounced. Score by marking a plus (+) after each correct word, a check (✓) after each mispronounced word, and a minus (-) after words not attempted. Count as correct any self-corrected words.
4. Count the number of correct words for each list, and record the numbers on the "Score" line. Total the numbers, and match the score with its grade equivalent in the table below.

Scores and Grade Equivalents for the REALM Questionnaire

Grade equivalent

Raw score	Grade range
0 to 18	Third grade and below; will not be able to read most low-literacy materials; will need repeated oral instructions, materials composed primarily of illustrations, or audio or video tapes
19 to 44	Fourth to sixth grade; will need low-literacy materials, may not be able to read prescription labels
45 to 60	Seventh to eighth grade; will struggle with most patient education materials; will not be offended by low-literacy materials
61 to 66	High school; will be able to read most patient education materials

APPENDIX B

CONSENT FORM

Columbia University Medical Center Consent Form

Medical Center Institutional Review Board: 212-305-5883
Consent Form #: CF-AAAJ7950 Copied From: CF-AAAI1369

Attached to Protocol: IRB-AAAB5709

Principal Investigator: Robert Fullilove (ref5)

IRB Protocol Title: Breast cancer knowledge and health literacy levels of African-American women in Harlem, New York

Consent Number: CF-AAAJ7950

Participation Duration: 1 hour

Anticipated Number of Subjects: 300

Contact

Dionne Otey Project Director Co-Investigator
Telephone: 917 570-7638

Robert Fullilove Assoc Prof Of Clinical Principal Investigator
Telephone: 212-740-7292

Research Purpose

To assess the health information needs of urban African-American women.

Information on Research

The purpose of this study is to learn more about the health education needs of urban African-American women. We will also try to determine what things influence women's attitudes and whether or not women decide to participate in activities that might help to improve their health. Collected information will be used to create easy to understand health brochures and guidelines that healthcare staff can use to help them when they talk to patients. You are able to participate in this study because you live in Harlem. To be eligible to participate, you must also be: female, age 50 & older, of African-American descent, and you must not have been diagnosed with breast cancer in the past.

This study will include 300 participants. Women who participate in this study will be asked to complete two very short surveys and participate in an interview that will ask about their knowledge, attitudes, and opinions about certain types of

health activities. If you participate, you will also be asked questions about how well you understand the kinds of health information that your doctor or nurse gives you. Because we ask that you complete two surveys and an interview, you will be asked to give permission to have your interview audiotaped so that your responses can be recorded more accurately. If you do not wish to have your interview taped, you will still be able to participate in this study. If you do give permission to have your interview taped, we will ask you to sign a second audiotape consent form.

Risks

Participation in this study should not lead to any serious risks. If you find that any of the questions asked or topics discussed are upsetting in any way, you can choose to stop the interview or you can refuse to answer certain questions. You can also stop the interview and reschedule it for another time. Any information that you reveal during the interview sessions will be kept completely confidential. Any collected information will only be reported as a part of group results. Any specific information reported by you will in no way be linked to your name specifically.

Benefits

There is no direct benefit to you for participating in this study. The information that you give may help doctors learn to communicate better with their patients, and as a result, provide better care for patients in the future.

Alternative Procedures

You do not have to participate in this study if you are not interested. You have the option of stopping the interview session at any time if you no longer wish to participate. You can also stop the interview at any time and reschedule it for another time if you wish.

Confidentiality

All records will be kept in locked file cabinets and will be kept confidential to the extent permitted by law. Collected data will only be available to research staff. If any of the data collected as a part of this study is used for scientific publications or presentations, your name will not be used. All information kept on computer databases will be protected with passwords. No identifiers or names will be used in databases.

Compensation

You will be paid \$25 for the completion of two short surveys and an interview. You will receive \$5 for the completion of the 1st survey, \$5 for the completion of the 2nd survey, and \$15 for the completion of the interview. Payment will be made by a check or money order that you will receive 3-5 days after the completion of your session.

Voluntary Participation

Your participation in this study is completely voluntary. You can refuse to participate and you may stop participation once the interview has begun. You have the right to withdraw from this study at any time. You will be notified of any significant new findings that may relate to your willingness and desire to continue participation in this study.

Additional Information

Statement of Consent

I voluntarily consent to participate in the study. I have thoroughly read this consent form and understand the nature and the purpose of the study. I have fully discussed the study with the investigator or study staff, have had the opportunity to ask questions and have received satisfactory answers. The explanation I have been given has mentioned both the possible risks and benefits to participating in the study and the alternatives to participation. I understand that I am free to not participate in the study or to withdraw at any time. My decision to not participate or to withdraw from the study will not affect my future care or status with this investigator. I understand that I will receive and may keep a copy of this signed and dated consent form. By signing and dating this consent form, I have not waived any of the legal rights that I would have if I were not a participant in the study.

Questions

The study Co-Investigator, Dionne Otey, MPH, is available to answer any questions that you may have about the study. Ms. Otey can be reached during the day at (917) 570-7638. You can also contact the study's Principal Investigator, Dr. Robert Fullilove at (212) 740-7292. If you have any questions about your rights as a participant in this project, you can call the Institutional Review Board at (212) 305-5883.

Signature

Study Coordinator

Print

Name _____ Signature _____ Date _____

Study Participant

Print

Name _____ Signature _____ Date _____