ACCESS TO CANCER EDUCATION AND SCREENING: A LONG AND DIFFICULT JOURNEY FOR CHINESE IMMIGRANTS IN NEW YORK CITY

by

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ABSTRACT

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by

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Rising cancer incidences, high mortality, and poor survival rates among Chinese Americans have become a great disease burden in the U.S. The purposes of this study are to understand the level of health knowledge, attitude and beliefs towards the causes of cancer among Chinese immigrants in New York City, and to identify their barriers in accessing cancer prevention services. A qualitative, exploratory research methodology based on a grounded theory approach was used. Thirty-nine low-income and medically underserved Chinese men and women participated in 4 focus group sessions and 14 in-depth interviews.

Findings revealed that the concept of "prevention" in the Chinese culture was based on holistic views of health and *yin-yang* balance principles. These beliefs also governed the health behaviors, lifestyle, and daily diet of Chinese immigrants. Many participants in this study misunderstood what actually caused cancer, such as carrying a certain blood type, poor hygiene, or women ignoring their reproductive or natural functions. Ignorance and confusion on risk factors

and causes of cancer resulted in them not engaging in appropriate preventive activities. Many reported lack of health insurance, financial difficulties, as well as embarrassment and modesty as barriers to seeking cancer screening. Common system barriers experienced by participants included red tape and bureaucracy in the health care system, provider insensitivity to their concerns, lack of availability in doctor schedule, long waiting time in clinics, and fragmentation of the medical care system.

Analyzing and comparing data across sub-groups of participants based on age, gender, and dialect spoken uncovered similarities as well as disparities among subgroups on health-seeking beliefs, attitude towards cancer, and cancer screening experiences. This study adds to the sparse literature by providing a better understanding on the cultural attitudes and beliefs towards the causes and prevention of cancer, as well as barriers to cancer screening among Chinese immigrants. It also highlights the importance of cultural sensitivity and relevancy in the design and implementation of effective breast, cervical, and prostate cancer education and screening programs for this population.

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For many Chinese immigrants, access to cancer education and screening is indeed a long and difficult journey for many Chinese immigrants. The data of this study came from powerful and vivid narratives and stories of 39 Chinese men and women. These individuals were much more forthcoming with their personal experience than I had anticipated. I whole heartedly thank them for their time and their openness in sharing their perspectives, experiences, as well as pain and frustrations in accessing health care and cancer services. Publication of findings of this study will insure that their voices will be heard, which hopefully leads to positive changes in the health care system.

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CHAPTER ONE

INTRODUCTION

In the U.S., heart disease is the leading cause of death in all racial/ethnic groups except Asian Americans (US DHHS, 2000). For Asian Americans, cancer is the leading cause of death in both age categories 25-44 years and 45-64 years (Chu, 1998). In fact, cancer has been the leading cause of death for Asian Pacific Islander (API) women since 1980 (National Center for Health Statistics, 1996). National data also show that cancer mortality rate for Asian Americans is rising rapidly. Between 1990 and 1993, the increase in cancer mortality among the API population was greater than any other racial/ethnic group in the U.S. (Ho, 1998). National Center for Health Statistics also reported the API age adjusted death rate was underestimated by approximately 11% (Rosenberg et al. 1999). Therefore, the disparities and distinctions of having cancer as the leading cause of death for Asian Americans are even more striking (Chen, 2005).

Breast cancer is one of the top two cancers for Asian Pacific Islander (API) women and prostate cancer as one of the top five causes of cancer mortality among API males (Chu & Chu, 2005). Breast cancer is the leading site of new cancer cases for Asian American women (ACS, 2005a), whose rates have increased about 1.5% per year (ACS, 2005b). Compared to Caucasians, Chinese Americans have lower rates of cancer incidence at a number of sites, most notably at lung, skin, breast, corpus uteri, prostate, urinary bladder and kidney (Jenkins & Kagawa-Singer, 1994). However, Chinese American males

experience a higher incidence of cancers of oral cavity and pharynx, nasopharynx, esophagus, stomach, and liver. Studies also show that Chinese American women have considerably higher incidence rates for cervical cancer than whites (Olsen & Frank-Stromborg, 1993; Lee, Lee, & Stewart, 1996). Among Asian American subgroups, cancer incidence rates among Chinese were consistently among the lowest (Kwong, Chen, Snipes et al., 2005). However, Chinese have the highest mortality rates for lung and bronchial cancer (34.3 per 100,000) among all Asian subgroups (Kwong et al. 2005)

Cancer rates of ethnic and racial groups often change when members of a group migrate from their native country to another (Frisbie, Cho, Hummer, 2001; Li & Pawlish, 1998; Jenkins & Kagawa-Singer, 1994). Migration studies conducted in many parts of the world show that with successive generations, the offspring of immigrant families experience cancer rates similar to the host country population rather than their native countries (Li & Pawlish, 1998; Jenkins & Kagawa-Singer, 1994; Stanford et al., 1995; Ziegler et al., 1993). One study's findings show that the incidence rate of prostate cancer, a significant cause of mortality in the Chinese American population, is 11.6 times higher in Chinese immigrants in the U.S. than their similar cohorts in China (Yu et. al, 1991). King et al. (1985) studied distinct patterns in rate differentials between Asians and U.S. Chinese and found that U.S. Chinese experience higher mortality for colon/rectum cancer when compared to the homeland population. This study's findings are consistent with the transitional patterns reported for European and Japanese migrants to the U. S. (King & Locke, 1980; King et al., 1985).

Several other studies also show that breast cancer incidences in Chinese and Japanese women after migration to the U.S. are significantly higher than those in their native countries (Yu et al., 1991; Stanford et al., 1995; Jenkins & Kagawa-Singer, 1994). The study of Ziegler et al. (1993) even noted a six-fold gradient in risk of breast cancer with migration patterns. They found that Asian-American women with three or more grandparents born in the West have a 50% higher risk of breast cancer than those with all grandparents born in the East. Immigrants who were born in rural areas of Asia and have a shorter length of stay are at a much lower risk. Another study (Deapen, Liu, Perkins et al., 2002) also found that after immigration, the rate of increase in breast cancer among Japanese-American women surpasses the rate of white women in Los Angeles County. The longer these new immigrants have lived and acculturated in the U.S., the more likely they experience the types of cancers with similar rates found in the American white population. This may be attributed to their exposure to Western lifestyles and their adoption of American dietary patterns and behaviors (Lasky & Martz, 1993; Jenkins & Kagawa-Singer, 1994; Kagawa-Singer, 1995; Ziegler et al., 1993). If this assumption is true, one may expect that the differences in risk between Chinese immigrants and the local white population to gradually diminish over time as the immigrant lifestyle and dietary habit resemble that of local population in the U.S.

Breast cancer rate among Chinese American women has increased 20% in the past 18 years (Lee et al., 1996; Miller et al., 1996). As an aggregate group, Chinese females have lower cancer incidence and mortality rates than

whites for all anatomic sites combined (Jenkins & Kagawa-Singer, 1994). However, these rates are considered to be underestimates because of underreporting of Asian cancer rates (Parker et al., 1997). Despite lower cancer incidence and mortality rates, the survival experience of Chinese women is generally comparable or even poorer than that of whites (Lee, 1998; Lu, 1995; Young et al., 1984). Chinese males also have lower survival rates for cancers of the colon and rectum, liver, pancreas, and prostate than whites.

Minority patients have substantially shorter survival time than whites because they generally present with a more advanced stage of disease, irrespective of the type of cancer (Freeman, 1989; Olsen & Frank-Stromborg 1993). The same is true for medically underserved women who are more likely to have distant metastases when their breast cancer is first diagnosed, because fewer of them have received breast cancer screening (Lee, 1998; Hedeen, White, & Taylor, 1999). Similarly, foreign-born Asian American women diagnosed with breast cancer have a greater proportion of tumors larger than 1cm (Hedeen, White, & Taylor, 1999). API women are very likely diagnosed with cervical cancer at later stages because of the relative lack of Pap smear screening (Jenkins & Kagawa-Singer, 1994). Another study found that Asian American women were 3.7 times more likely than white women to have late-stage breast cancer (Krieger et al. 1997). Therefore, although Asian Americans are less likely to develop cancer and are less likely to die from cancer overall, those who developed cancer have a poor prognosis due to lack of early detection screening (Jenkins & Kagawa-Singer, 1994).

The American Cancer Society publishes a screening guideline for the early detection and treatment of breast and cervical cancers. Women over the age of 40 should screen for breast cancer (breast self-examination, clinical breast examination, and mammogram) and women over 18 should screen for cervical cancer. Screening guidelines also recommend that men over age 50 should screen for prostate cancer. These screening guidelines are shown to be effective in reducing breast cancer mortality (Shapiro et al., 1982). While major efforts are made in the education, screening, treatment, and rehabilitation of cancer in the mainstream world, cancer control efforts targeting the API populations have been inadequate (Jenkins & Kagawa-Singer, 1994). The same is true for poor people and people of color whose adherence to cancer screening guidelines still lag behind, despite a substantial progress in the general population in meeting the national goals of early cancer detection for the year 2000 (U.S. DHHS, 1993; Breen & Kessler, 1994). Asian Americans, as an aggregate group, have the lowest cancer screening rates among all ethnic populations (American Cancer Society, 1997). Asian American women 40 years of age or older report the poorest mammography screening within the past year or two among all other racial/ethnic groups (National Health Interview Survey, 2005).

Breast cancer is the most common major malignancy among several Asian-American female groups (Miller et al., 1996; Jenkins & Kagawa-Singer, 1994; McPhee et al., 1997). Chinese-American and Vietnamese-American women have a much higher cervical cancer rate than whites (Olsen & Frank-

Stromborg, 1993; Lee et al., 1996; Jenkins et al., 1999). Several research groups which specifically studied adherence to breast and cervical cancer screenings among women of different Asian American groups found very low screening rates among these groups (National Health Interview Survey, 2005; Maxwell et al., 2000; Hiatt et al., 1996; Lee et al., 1996; Wismer et al., 1998; Yi, 1996; Lee, 1998; McPhee et al., 1997; Tu et al., 1999). Tang et al. (2000), for example, found that acculturation as measured by age at immigration and use of native and English languages, to be a significant predictor for having a mammogram and clinical breast examination in a sample of Chinese women in senior centers. These studies all concluded that factors such as language, cultural, economic and social barriers contributed to the lack of participation in cancer screening services among Asian American women.

Several studies consistently reported that low socioeconomic status, as measured by education and income, is associated with lower participation in cancer control programs (Katz & Hofer, 1994; Harlan, Bernstein, & Kessler, 1991) and with higher risk of cancer incidence, morbidity, mortality, as well as poor cancer survival (Ward, Jemal & Cokkinides et al., 2004; Bradley, Given & Roberts, 2002; Kagawa-Singer, 1995; Freeman, 1989). Therefore, identifying barriers to health promotion among people with low socioeconomic status can help health care professionals understand why recommended cancer screenings are not being followed. The poor and medically underserved often encounter numerous barriers to preventive health care. These barriers include poverty, substandard and overcrowded housing, crime, lack of resources such as

transportation and child care, as well as lack of knowledge and skills in negotiating the health care system (Langer, 1999).

The poor are often overwhelmed by various situations such as poor physical health, poor living condition, and unemployment. They may not consider preventive health care a priority and engage in cancer screening practices unless they can seek and receive services from health care organizations that are responsive to their specific needs and coping patterns (Hopps et al., 1995). Moreover, cultural beliefs, attitudes, and life experiences also affect an immigrant's reaction to cancer, health maintenance, daily activities, body discomforts, food preference, and various treatment and health practices (Ashing et al., 2003; Lasky & Martz, 1993). These barriers make it very difficult for many medically underserved Asian Americans to access cancer screening services and to seek prompt treatment for cancer (Sadler et al., 1998; Stanford et al., 1995). It is therefore important for health professionals and cancer experts to improve access to services by designing culturally sensitive and consumer friendly programs that meet the needs of the medically underserved population.

Unfortunately, the task of improving Asian American immigrants' access to preventive care is easier said than done. The first and foremost challenge of all is to define what their needs are, because there has not been many studies done on this group. Until very recently, the API population was not identified as a separate minority population group due to their low numbers in the U.S. (Jenkins & Kagawa-Singer, 1994). There is a significant information gap in cancer incidence and statistics on the Asian immigrant population. Furthermore,

very little information is available on the incidences and treatment of various illnesses including cancer among the API population (Lasky & Martz, 1993). If there is any health literature on the API at all, they are focused on documenting the existence and extent of health disparities rather than explaining why these disparities exist (Feinstein, 1993). Even fewer cancer studies have examined psychosocial and cultural variables that may affect access to cancer screening and treatment of specific minority groups such as the Chinese immigrant population. The relatively low incidence of certain types of cancer causes cancer experts, government officials, and the Asian American community to overlook the importance of health promotion and screening services for those types of cancers. It also creates a false impression that API as a group is not at risk because of its low cancer incidence, and that API are capable of taking care of their own needs and therefore do not need cancer screening or cancer support services (Jenkins & Kagawa-Singer, 1994).

The Chinese American population both in the U.S. and in New York City is growing rapidly. According to Census 2000, the Asian American population constitutes about 10% of the New York City's total population of about 8 millions, and the majority of Asian Americans (about 45% or 361,000) are of Chinese origin. The number of elderly Chinese immigrants is also growing drastically because of immigration pattern. The Chinese American population is not only increasing in number, but is also becoming more heterogeneous in its socio-demographic characteristics such as age, income, education, and immigration background (rural versus urban). It is in itself a diverse group with differences in

spoken dialects, levels of acculturation, as well as beliefs and practices toward health, illness, and treatment. A rising breast and prostate cancer incidence rates among the Chinese American population after migration to the U.S. (Yu et al., 1991) and a considerably higher incidence rate for cervical cancer among Chinese American women than whites (Lee, Lee, & Stewart, 1996) have now become a pressing clinical and public health issue. A rising cancer mortality and poor survival rate among Chinese Americans as compared to the general population has also become a great disease burden (Jenkins & Kagawa-Singer, 1994). Cultural beliefs of Chinese immigrants, their unique circumstances of migration, and financial problems may pose significant barriers to cancer screenings and services. Moreover, demographic and cultural characteristics, such as knowledge, attitudes, and behavior to disease prevention, as well as stress and availability of support, may affect their health as well as access to preventive care.

Fortunately, in recent years more and more Chinese immigrants in New York City are seeking cancer education and screening services due to increased outreach activities by community health organizations. Since 1998, the Charles B. Wang Community Health Center, a major health care provider for the Chinese immigrant population in New York City, has provided breast and cervical cancer education and screening services to more than 6,000 Chinese American women. To date, the health center also conducted prostate cancer screenings to more than 500 Chinese American men. However, little is known about the role and preparedness of health care providers and cancer outreach specialists in

delivering cancer education and screening services and whether these services are culturally appropriate for this rapidly growing population. The lack of studies and data on breast, cervical, and prostate cancer screening and treatment among the medically underserved Chinese immigrant population is a major constraint for community health organizations to effectively plan and develop culturally appropriate cancer screening services, health education and outreach programs. Accurate disaggregated data for the Chinese immigrant population are very much needed in understanding their level of cancer knowledge, cultural beliefs and attitudes toward preventive health and cancer screening, as well as their economic, social, and language barriers towards accessing cancer education and services.

The purpose of this study is to fill in the knowledge gap on the medically underserved Chinese immigrants living in the metropolitan New York City area. This study explores the views of health and illness among Chinese immigrants, assesses their level of knowledge on health, prostate, breast and cervical cancer, their beliefs and attitude towards the causes and prevention of these cancer sites, and their cancer screening behavior. This study will also identify demographic and socio-cultural barriers that affect access to cancer education, screening, and services. Information gathered in this study will not only help identify knowledge gaps in cancer control for the Chinese immigrant population, but also highlight the importance of cultural sensitivity and cultural relevancy in the design and implementation of effective cancer education and screening programs. Hopefully, this may in turn promote the concept of early detection and

treatment of breast, cervical and prostate cancer among the Chinese immigrant population as well as improve their access to cancer services.

CHAPTER TWO

THEORETICAL FRAMEWORK

The Health Belief Model and the Systems Model of Clinical Preventive Care, and their related concepts are useful tools in understanding the patients' view on and behavior in preventive health care and cancer screening. They help highlight factors that may influence patients in engaging in health-related behavior, as well as the relationships among and between these factors and various health outcomes. Information based on these concepts provides a framework for studying the patient's perspective and health-related behavior, which in turn helps develop health education and health promotion strategies that are effective to the target population (Lancaster, 1992).

Health Belief Model

The Health Belief Model (HBM) was originally developed by Rosenstock (1974) and Becker, Drachman & Kirschy (1974) to study why people failed to accept disease prevention activities and early detection screening tests. Key dimensions of this model include *perceived susceptibility*, *perceived severity* of illness, and *perceived barriers to* and *benefits of* carrying out recommended health-related behavior such as cancer screening. In order for an individual to take action and avoid a disease such as cancer, he would need to believe that he is personally *susceptible* to the disease even in the absence of symptoms, that occurrence of the disease would have at least some degree of *severity* on certain aspects of his life, that taking an action would be *beneficial* to him by reducing his susceptibility to the disease or by reducing its severity, and that

taking action itself would not be impeded by *barriers* such as cost, transportation, convenience, embarrassment, or other negative factors.

The combined factors of perceived levels of susceptibility and severity, and the perception of benefits and barriers, help predict whether an individual would engage in health-related behavior or not. However, Rosenstock (1974) noted that the combination of these factors might reach a considerable amount of intensity without resulting in actual behavior unless some *instigating events* or *cues* occurred to set the process in action. In the case of health screening, instigating events may be internal, such as experience of symptoms or perception of bodily changes, or they may be external, such as the impact of environmental events or media communication (Strecher & Rosenstock, 1997). Rosenstock (1974) added other variables such as diverse demographic, socio-psychological, and structural variables to the Health Belief Model because these variables may affect an individual's perception of susceptibility, severity, benefits, and barriers, and therefore indirectly influence health-related behavior. However, these additional variables have not been systematically studied.

Rosenstock, Strecher & Becker (1988) later modified the HBM by incorporating *self-efficacy* as an important variable. They argued that in order to effect behavior change, the individual not only has to have an incentive to take action, feel threatened by his current behavioral patterns, and believe that the behavioral change will lead to positive outcome at acceptable cost, he must also feel that he is competent to carry out that change. Self-efficacy, derived from Social Learning Theory, is defined as "the conviction that one can successfully

execute the behavior required to produce the outcomes" (Bandura, 1977, p. 79). It is a sense of self-confidence in one's ability to successfully perform a specific type of action, sometimes over a long period of time. Rosenstock (1990) later modified the concept of self-efficacy and used the *value expectancy* concept to predict health-related behavior. For the individual to practice preventive health behavior, he needs to have "the desire to avoid illness or to get well (value)" (p.40) and believe that a specific health behavior is available for him to prevent illness (expectancy). The concept of self-efficacy in explaining the initiation and maintenance of behavioral change has been supported by a substantial body of literature (Strecher & Rosenstock, 1997).

Janz and Becker (1984) conducted a critical review of various research studies on the Health Belief Model completed between 1974 and 1984. Their review included preventive health and cancer screening behaviors such as breast self-examination, as well as sick-role behaviors such as compliance with medication regimens. They concluded that the component of perceived barriers was the most powerful single predictor of all the HBM dimensions across studies and health behaviors. They found that perceived susceptibility was a stronger predictor of preventive health behavior than sick-role behavior, while the component of perceived benefits was a more powerful predictor of sick-role behavior than preventive health behavior. Perceived severity was the least powerful predictor. The Janz and Becker study (1984) also provided substantial empirical support to the HBM in its role of explaining health behavior pertinent to prevention and behavior in response to symptoms or to diagnosed disease.

While numerous studies have provided empirical support for the Health Belief Model, the model itself is not without flaws. Rosenstock (1990) noted that beliefs themselves are seldom sufficient conditions for action. It is important to find out the constellation of conditions that explain major variations in behavior. In other words, researchers need to specify conditions under which specific beliefs and behaviors are causally related as well as conditions under which they are not. Another limitation of the HBM is that its variables have not been adequately quantified and that the joint relationships among the HBM variables have not yet been tested (Rosenstock, 1990).

Strecher & Rosenstock (1997) suggested that the HBM be tested as a combination of concepts rather than as a collection of equally weighted variables working simultaneously. They concluded that the design of health promotion programs should be based on the knowledge of how many and which members of a target population feel susceptible to a specific disease, their belief of whether the disease constitutes a serious health problem or not, and whether the threat of having a serious health problem can be reduced by engaging actively in health-related behavior at an acceptable cost. Moreover, the extent an individual possesses adequate self-efficacy to carry out the planned action over a long period of time should also be considered in the planning of health promotion programs. Finally, the HBM is highly rational and focuses on individual patient beliefs and attitudes but it does not consider necessary skills, resources, or social support that an individual needs in order to take action.

PRECEDE-PROCEED Planning Framework

The PRECEDE-PROCEED Planning framework proposed by Green & Kreuter (1991) complements the HBM by identifying the skills, resources, or social support needed by an individual in order to perform preventive health behavior and to plan and evaluate health intervention. This framework was initially developed in the 1970s to improve the quality of health education interventions by offering practitioners a systematic planning process (Gielen & McDonald, 1997). The acronym PRECEDE stands for Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation. The model is based on the premise that just as medical diagnosis *precedes* a treatment plan, similarly, educational diagnosis should also *precede* an intervention plan.

The PRECEDE-PROCEED framework consists of a multiple-phase process with the basic notion that health behaviors are complex, multidimensional, and are influenced by a variety of factors (Gielen & McDonald, 1997), namely predisposing, enabling, and reinforcing factors. *Predisposing factors* refer to the motivation to perform a specific health behavior. They include the individual's knowledge, attitudes, beliefs, demographics, personal expectations, preferences, skills, self-efficacy, and health value orientation. For example, patients who believe that cancer is irreversible will see no benefit of knowing about it earlier. *Enabling factors* are antecedents that enable motivation to be realized and affect behavior directly or indirectly through an environmental factor. These factors may include education, programs, services, resources,

convenience, or new skills necessary for initiating and sustaining behavioral and environmental changes. *Reinforcing factors* refer to elements that provide continuing reward or incentive to sustain behavior. They include social support, peer influence, reinforcement by significant others, and encouragement by health care providers. Because health and health risks are determined by multiple factors, efforts to effect behavioral, social, and environmental change must also be multidimensional (Green & Kreuter, 1991). This framework emphasizes the important role of social and environmental factors in determining health behaviors and health outcomes.

Systems Model of Clinical Preventive Care

Building on the HBM and PRECEDE model, Walsh & McPhee (1992) developed the Systems Model of Clinical Preventive Care that contains components of psychosocial, behavioral, communication, and health education theories. This Model is unique in its focus on both patient and physician factors that affect cancer screening. The physician's performance of preventive care activities and physician referral are influenced by predisposing, enabling, and reinforcing factors. *Physician predisposing factors* include physician beliefs, attitudes, prior clinical experiences, concerns for patient embarrassment, and personal health practices. *Physician enabling factors* include training, knowledge of screening recommendations, technical expertise, and the availability of educational tools and materials. *Physician reinforcing factors* include patient satisfaction with the physician's preventive care orientation, communication with other physicians, and peer support and approval.

Both patient and physician factors are independently influenced by other factors such as health care delivery system factors, preventive activity factors, and situational factors (Walsh & McPhee, 1992). *Health care delivery system factors* include access to care, availability of technology and personnel, organizational priorities, reimbursement, and coordination with community resources. *Preventive activity factors* focus on the preventive activity itself and include costs, risks, effectiveness, and efficacy of the activity. *Situational factors* are triggers to health behavior and include internal cues such as symptoms and external cues such as physician encouragement or reminders. All these factors interact with each other in influencing the likelihood of whether any preventive activity is performed or not.

The Systems Model is a useful model in several aspects. First, it focuses on the patient-physician interaction and points out important factors (predisposing, enabling, and reinforcing factors) which influence both patient and physician behavior. The Systems Model also includes situational factors and health care delivery system factors, which are significant in influencing the performance of preventive activities. For this reason, Walsh & McPhee (1992) believe that this model can also be applied to study a variety of preventive care activities or situations. However, the Systems Model has some limitations as well. Although the model describes factors impinging on the physician and the patient at any point of time, it does not describe the time frame or specific steps that the physician or the patient have to consider when carrying out preventive care activities. In addition, the relative importance of different factors for different

preventive care activities is not considered. Also, the model has yet to define which potential barrier as the most important one so that intervention targeting various components of the model may be designed to remove the barriers. Last but not the least, this model focuses on patient-physician interaction but does not address sufficiently the role of family, community, or health care providers other than physicians, in the design and implementation of cancer screening programs for ethnic minorities.

Hiatt et al (1996) believed that no single theoretical model would be sufficient in understanding the diverse cancer knowledge, attitudes, beliefs, and health practices of different culturally and socioeconomically diverse populations. For example, many recent Chinese immigrants lack the concept of preventive care and therefore may have difficulty understanding why certain medical treatment procedures, especially those for early cancer detection, are important. Furthermore, cultural values of ethnic immigrants with respect to modesty and sexuality may partly explain the lack of attention to certain types of cancer (Hoeman, Ku, & Ohl, 1996). Therefore, in order to increase the chance of patients accepting cancer prevention and engaging in screening activities, it is important to involve the target population in all aspects of program planning, implementation, and evaluation (Lasky & Martz, 1993; Walsh & McPhee, 1992).

In summary, the Health Belief Model, Systems Model of Clinical Preventive Care, and their related concepts are all useful tools in identifying different dimensions of patient beliefs and perspectives on preventive health and cancer screening. They help to identify factors (patient and physician factors, as

well as other contextual or system factors) that may influence patients in engaging in preventive health activities and cancer screening behaviors. They are also helpful in revealing the relationships among and between these factors and various health outcomes. It is important to recognize as well that the responsibility for health promotion and education and early detection for cancer does not reside solely on the patient or on the physician. Instead, both the patient and the physician are influenced by many factors including organizational, system, situational, and environmental factors.

Walsh and McPhee (1992) point out that an "ideal" model for clinical preventive care must contain components of psychosocial, behavioral, communication, and health education theories. It is necessary to understand the unique contributions from different disciplines, such as social work, health education, health administration, communication, etc., and define what functions each respective discipline perform in the planning and the implementation of cancer education and screening services. Social workers, for example, can make unique contribution in the clinical setting by attending to psychosocial and system factors and by assisting patients in overcoming organizational, psychosocial, and situational barriers that may affect patient access to needed health services and clinical care. The following sections will review existing literature on (1) culture, health, and cancer; (2) Chinese beliefs and attitudes toward preventive care, cancer and cancer screening; (3) socioeconomic, language, and literacy barriers to cancer education and screening; and (4) physician role in cancer screening and treatment.

CHAPTER THREE

REVIEW OF LITERATURE

Culture, Health, and Cancer

"Culture is a sum of beliefs, practices, habits, likes, dislikes, norms, customs, and rituals." (Spector, 1991, p. 68). Culture is revealed through the unique shared values, beliefs, and practices that are directly or indirectly associated with health-related behavior (Pasick et al., 1996). Kagawa-Singer (1996) defined culture as a tool that operationalizes a specific group's *worldview* into symbols of values, beliefs, and practices that members of a cultural group learn to use to ensure their well-being. Each cultural group is different and unique in defining health and well-being, perceiving the causes of disease, misfortune, and death (Spector, 2002), and identifying appropriate preventive health activities and effective treatment strategies to ensure the survival and well-being of its members (Kagawa-Singer, 1996). Therefore, being familiar with the history, culture, values, beliefs, and practices of ethnic minority individuals can be very helpful in understanding how patients and their families interpret the causes of cancer and the recommended regimen for cancer prevention, screening, and treatment. As Kagawa-Singer (1996) stated, patients will only incorporate recommended medical regimens when these recommendations fit into their belief systems and are relevant to their lives at a specific point in time, and when they see that the changes are worth the effort to try and have the resources to do so.

Health behavior and practice is the outcome of knowledge, attitudes, and beliefs embedded in the context of life circumstances and experiences (Pasick, 1997). Individuals from a specific cultural background may have a very different set of values and beliefs that differ from that of their health care providers. For example, Ma (2000) found that when Mainland Chinese and Taiwanese sought health care, they shared similar cultural barriers including communication difficulties, beliefs about health, health care, and illness, and mistrust in Western health care. Confusion, frustration, and miscommunication experienced by ethnic minority patients are common. It is therefore important for health care providers to differentiate between "disease" and "illness" and understand how they and their patients perceive disease and illness differently. Whereas "disease" is the observable aspects of cancer based on the nosology of the health care system, "illness" is the subjective meaning of the experience related to the disease (Kagawa-Singer, 1996). The meaning attributed to cancer experience is very much dependent upon the patient's and their family's cultural values toward cancer (Kagawa-Singer, 1996) as well as the symptoms they have experienced.

Individuals of different cultural groups and societies embody illnesses in many different ways (Gordon, 1990). Based on a research study in Italy, Gordon (1990) explored the meaning and experience of cancer among women with breast cancer throughout various phases of the illness. The study concluded that culture influences the patient's beliefs on the meaning of cancer, his/her emotional and physical response to treatment, side effects of treatment as

reported by the patient, the perception of pain and attitude toward suffering, death, and dying, patterns of decision making, and patterns of family communication the patient uses to cope with the entire experience. Cross-cultural studies have also shown that culture affects how symptoms are manifested when individuals are in physical, emotional, or psychological pain, when help and services are being sought for physical, emotional, and psychological pain, what healing or treatment procedures are considered acceptable to the individual, what expectations are held by the healer and help-seeker, as well as the meaning ascribed to the return to health or a feeling of well-being (Pedersen et al., 1996; Amodeo & Jones, 1998).

In cross-cultural medical practice, there are often negative or unintended consequences for treatment when the physician provides medical intervention without understanding the patient's perception of illness, treatment, and well-being. Dyche & Zayas (1995) recommend that physicians discuss medical issue with the patient sensitively and collaboratively by being persistent in asking what the patient thinks is wrong and how serious it is, how the illness affects the patient's life, and what the patient thinks can help. In addition, the concept of social support for cancer patients appears to differ in different cultures. Who provides social support, what is considered appropriate and desired, and when it is provided are different in different cultures (Kagawa-Singer, 1996). In oncology practice of Western medicine, emotional support in the form of expression of feeling is often assumed to be important in helping patients cope with cancer (Kagawa-Singer, 1996). However, in many other cultures, material support and

"doing for" the patient is considered more appropriate because the culture stresses emotional support without words (Uba, 1994). In such cultures, talking about dysphoric emotions may create greater distress for the patient because it will not change the situation and is often felt to be detrimental. Therefore, when providing social support to patients, it is important to know what is culturally appropriate and acceptable and what is not in order for intervention to be effective (Kagawa-Singer, 1996).

Although cultural factors can enhance or impede participation in cancer education and control activities, several studies found that they are more likely to be barriers to cancer screening and early detection activities among culturally diverse groups (Liang et al., 2004; Spector, 1991; Kagawa-Singer, 1995; Yi, 1994a). There are many factors influencing the extent to which members of a specific culture participate in cancer prevention and screening. These factors include the patient's birthplace and the level of acculturation or assimilation to the new host society (Hedeen, White, & Taylor, 1999), their cultural attitude towards bodily functions and the power of indigenous healers (McBride et al., 1998), their general and cancer-specific beliefs, their practices concerning health, diet, and access to screening, as well as their expectation concerning the quality of patient-provider interaction and communication in the health care setting (Liang et al., 2004; Olsen & Stromborg, 1993). Underutilization of cancer screening services among ethnic minorities is often attributed to factors such as language difficulties, cultural values and beliefs, and fear of cancer (Hoeman, Ku, & Ohl, 1996). Studies confirm that the unavailability of cancer information in

Chinese language and the absence of culturally specific educational campaigns targeting Chinese immigrant women contribute to a lack of preventive breast health (Lee, 1998; Hoeman, Ku, & Ohl, 1996).

Culture has implications for the design, implementation, and effectiveness of cancer education and intervention in many different ways. Cultural factors play an important role in which a specific population would be identified, targeted, and intervened. Pasick et al. (1996) found that level of acculturation, the extent in which values, attitudes, and behaviors from another culture are being adopted as measured by ethnic and language identification, is associated with different health practices and outcomes. Cultural dynamic also shapes the process and outcome of intervention designed to promote self-care behaviors (Langer, 1999). To implement intervention in a rightful context requires an in-depth knowledge on the meaning of intervention to the target group, its feasibility and acceptance in the target group, and methods being used for community education or media outreach (Pasick et al., 1996). A thorough understanding of the cultural characteristics of the target population as well as how those characteristics affect health behavior is important to insure the success of intervention.

In designing cancer education and health promotion activities, Pasick et al. (1996) recommended “cultural tailoring”, the development of interventions, strategies, messages, and health materials to conform with specific cultural characteristics, rather than “cultural targeting”, the identification of a population subgroup for the purpose of insuring exposure of that subgroup to the

intervention. Pasick et al. (1996) argued that "cultural tailoring" allows health care providers and health educators to move from beneath the surface of race and ethnicity to those factors that directly influence behavior and health. The following sections will outline cultural factors and barriers that specifically affect cancer education and screening activities among the Chinese medically underserved population.

Beliefs and Attitudes toward Preventive Care, Cancer, and Cancer Screening

Cultural values, beliefs, attitudes, and personal experiences affect a person's reaction to illness, health maintenance, daily activities, changes in life, and various health promotion and treatment practices (Lasky & Martz, 1993). In the U.S., health care practice is often guided by scientific, evidence-based, biomedical approach. It is questionable whether this approach to cancer screening and treatment is applicable to working with Chinese immigrants who are seeking health care according to their specific cultural beliefs and personal practice. Lasky & Martz (1993) pointed out that health care professionals need to be sensitive to their own cultural background and health beliefs and how these affect their practice. Otherwise, they may misunderstand their patients, miss valuable diagnostic cues, and encounter higher rates of patient noncompliance with cancer screening guidelines. Therefore, understanding the notion of preventive care and the meaning of cancer in the Chinese culture and the specific health beliefs and practice of the Chinese immigrant population is essential to providing quality cancer screening services and care. It is equally

important to incorporate these specific health beliefs and practices of individuals into service delivery (Varricchio, 1987).

An important first step in cancer education and treatment is to recognize that the American health care system is itself a cultural system that reflects American values, which may be very different from the values in the Asian culture (Kagawa-Singer, 1996). The basic value of the American health care system is founded on Judeo-Christian values, which believes that life is sacred and should be preserved at all cost, that individual autonomous decision-making ability should be emphasized and supported, and that nobody should suffer (Silberfarb, 1982). In contrast, health care value held by many Asians and Japanese Americans is that individual life is not sacred, that the welfare of the group and the community is more important, that decisions are made by group consensus, and that suffering in life is inevitable (Kagawa-Singer, 1996).

Chinese culture has a long history and tradition distinct from that of Western culture. Chinese culture has been strongly influenced by the teachings of Buddhism, Confucianism, and Taoism, which impact the lives of Chinese in a manner unlike of Western philosophies or religions (Uba, 1994; Ino & Glicken, 1999; Chen, 1996). Health care values held by most Asians and Chinese emphasize on harmony, respect, self-control, *yin-yang* balance, other-orientation, interdependency, collectivism, and community (Spector, 1991; Ino & Glicken, 1999) as opposed to Western values that encourage confrontation, independence, and autonomy in individual behavior (Ma, 1999a). Chinese culture, as a way of thinking, appears to influence the state of mind and body,

parent-child interactions, social relationships, individual and group aspirations, and health-seeking behaviors (Wu, 1995).

The basic tenet of Buddhism is that all life is suffering, and that suffering originates from undue desires (Carter, 1994; Ino & Glicken, 1999). This belief is contrary to the basic philosophy of the American health care system that nobody should suffer. Buddhism also believes that all living beings are doomed to ride the "wheel of life" through endless cycles of birth, growth, maturity, aging, illness and death unless they seek the enlightenment of Buddhism (Carter, 1994). Buddhism stresses seeking enlightenment through avoiding undue desires, diligence, and selflessness (Kagawa-Singer, 1996). Therefore, emotional restraint and coping with life's suffering such as cancer for the quality of one's next life have special implications in the Chinese culture (Ino & Glicken, 1999).

Like Buddhism, Confucianism is an integral part of Chinese culture and beliefs. Confucianism teaches the importance of family and the virtue of the individual as illuminated by observing the basic relationships of society as well as maintaining social harmony at all levels of society (Spector, 1991; Ino & Glicken, 1999). Filial piety and respect for the elders are central to Confucian thought and practice. Collectivist values in Confucianism emphasize that common good or the pursuits and needs of the community takes precedence over the pursuits and needs of the individual. Collectivist values, as contrary to individualist values in the West, affect health beliefs and health behavior of Asian Americans in many ways (Pasick et al., 1996). First, collectivists see the entire family as the most credible source of health information. Therefore, one models one's health

behavior after family members as opposed to the individualistic perspective which sees health care providers and unrelated others as having greater credibility (Pasick et al., 1996). Most of cancer support services in the U.S. are provided to encourage the individual to be self-sufficient and autonomous in his decision making even when he is sick. However, self-sufficiency and individual autonomy are values that are foreign and perhaps alien to those Asian Pacific Americans who believe in group identity, interdependency, and consensus modes of decision making (Jenkins & Kagawa-Singer, 1994). Therefore, efforts in promoting more individualistic value by health care providers may create discomfort for Asian Americans, because often time problems are shared and discussed among family members (Sue & Sue, 1990). This may result in the patient's resistance to health education and treatment.

Based on psychological theories of individual decision making, the Preventive Behavior Model (Murdaugh & Verran, 1987) combine the concept of *health value orientation* with the concept of *health internal locus of control* in predicting preventive health behavior. *Health value orientation*, as determined by perceived barriers and benefits, is the importance paid to health by the individual and the standard on which health choices are made. *Health internal locus of control* is the belief that health is determined by one's action and by one's rational choice. The design and the implementation of the majority of cancer awareness and education activities in the U.S. are based on these concepts of enhancing the patient's ability to control cancer by engaging in cancer screening activities. However, the Western belief that health is determined by one's effort

is contrary to the Taoism value of the East, which believes that health is a state of spiritual and physical harmony with nature (Spector, 1991). Taoism teaches harmony between human being and nature, and is concerned with the metaphysical and mystical process of "Tao" or the Way (Ino & Glicken, 1999). The person follows the principle of "wu-wei" or non-action, which means that he should always act in accordance with nature and not against it. Taoism promotes the belief that nature has the ultimate authority over the course of one's life and existence (Ino & Glicken, 1999) and that one is not in complete control of nature nor in one's destiny. This "fatalistic view" is reflected in what a group of Chinese women said in a previous cancer study:

> "I do not need to know about preventive health behaviors now because future things are for the future; people do not need to worry about them now because we never know what will be happening in the future" (Hoeman, Ku, & Ohl., 1996, p.526).

In addition, the holistic concept is another important idea in traditional Chinese culture that affects the prevention and treatment of diseases. Chinese tend to view health holistically where the ultimate goal is to harmonize with nature (Chen, 1996). According to Spector (1991), the holistic concept has two major components. First, the human body is regarded as an organism. Local pathological changes such as diseases are always considered in conjunction with other organs and tissues of the entire body rather than being considered alone. Also, special attention is paid to the integration of the human body as an internal organism with the external environment. The onset, development, and change of diseases are considered in conjunction with the social and environmental changes.

Based on this holistic concept, traditional Chinese believe that diseases such as cancer are only “preventable” or “controllable” by maintaining balanced energy levels and eating properly (Hoeman, Ku, & Ohl., 1996). Many Chinese immigrants accept some forms of health measures, such as herbal remedies, acupuncture, and other traditional medical treatments in order to strengthen the body, resist disease, and improve health and physical well-being (Spector, 1991; Ma, 1999). For many immigrant Chinese, Western diagnostic procedures are not used for screening purposes but for a health problem only; therefore they cannot understand why so many diagnostic tests are necessary (Spector, 1991). A Chinese immigrant who has no experience with preventive care may not comprehend the concept of screening for a disease that he or she probably does not have. Therefore, despite the fact that they take some health measures, they may not necessarily accept the Western approach to cancer prevention.

Cancer has a very negative connotation in the Asian American community (Sun et al., 2005; Jenkins & Kagawa-Singer, 1994). Beliefs of what causes cancer may determine what interventions are preferred and appropriate to treat cancer. In more traditional Asian families, cancer is believed to be caused primarily by hereditary defects. This belief can cause the offspring in families with cancer history to be viewed as less “desirable” or “marriageable” (Jenkins & Kagawa-Singer, 1994). Others may believe that cancer is a punishment for transgressions in this life or in past lives. These beliefs may cause Asian immigrants who suspect cancer themselves to delay seeking diagnosis and treatment from a physician (Jenkins & Kagawa-Singer, 1994). Even after they

are diagnosed, they are also less likely to be compliant with treatment recommendations. Beliefs on past transgressions or cancer as a form of retribution may make traditional Chinese families reluctant to admit cancer openly and seek treatment promptly. This reluctance may explain the late stage of diagnosis for cervical cancer among Chinese and Vietnamese women (Jenkins & Kagawa-Singer, 1994).

In the past, only a few studies used the Health Belief Model (HBM) as an explanatory framework in understanding the relationship between cancer beliefs and screening behaviors among Chinese women (Lu, 1995; Hoeman, Ku, & Ohl, 1996; Sadler et al., 1998). Empirical support for the HBM was mixed. Lu (1995) studied barriers to the practice of breast self-examination (BSE) among young Chinese women and found that approximately 50% of these women had no opinion on perceived susceptibility to breast cancer. Although the variable of perceived susceptibility was significantly associated with BSE among Caucasian women (Massey, 1986), this variable was not significant in explaining BSE performance among Chinese women (Lu, 1995).

Misconceptions regarding risk, vulnerability, susceptibility to, and seriousness of cancer are reported among Chinese women. Hoeman, Ku, & Ohl (1996) used the HBM as a framework and conducted a qualitative study with 23 married, educated Chinese women who attended a university clinic. In the area of perceived susceptibility to breast and cervical cancer, they found that these women believed they had a lower cancer risk than American women and therefore associated the need of preventive health behaviors with American

women rather than with themselves. They also believed that cervical cancer was related to early sexual activities among American women, and because they did not engage in high risk behaviors, they did not believe themselves to be susceptible to cancer. With regard to perceived seriousness of breast cancer, only one third of Chinese women in Lu's (1995) study recognized the seriousness of breast cancer, while more than 50% had no opinion or did not consider breast cancer as a serious problem. However, as Lu (1995) noted, items measuring the seriousness of breast cancer in the study instrument focused on areas such as financial burden, marriage problems, and feelings about oneself. However, the social and family impact of illness is a major concern among Chinese women, especially when cancer involves possible death or impairing the functioning of motherhood. Therefore, items relevant to the concerns raised by Chinese women should be included in order for the survey scale to be culturally relevant for this population.

The fear that cancer is fatal prevails in the Chinese culture (Sun et al., 2005; Mo, 1992). For many Chinese patients, the initial immediate reaction when discovering cancer is one of shock, disbelief, disregard, resignation, and withdrawal (Jenkins & Kagawa-Singer, 1994). Sun et al. (2005) studied both American-born and foreign-born Chinese women and found that the perception of a cancer diagnosis carrying a stigma prevails in both groups with more foreign-born women perceive cancer as a terminal disease. Fear of cancer itself, beliefs that thinking about cancer can provoke the onset of cancer, and financial barriers such as cost, are cited as formidable barriers to cancer education and

screening in the Asian American group as they are in other groups (Sadler et al., 1998). Fear of exposure to radiation in mammography screening is another most consistent barrier reported (Bastani et al., 1991). Modesty as a personal factor inhibiting Chinese women from obtaining pap smears is cited as a barrier (Hoeman, Ku, & Ohl, 1996). Mo (1992) also agreed that modesty was a significant barrier. Based on Chinese cultural beliefs on the role of women, their reproductive functions, attention to birthing, as well as other culturally defined role behaviors, fear of exploitation by a health practitioner during Pap smear screening was a factor which impeded Chinese women from seeking preventive gynecological care (Mo, 1992).

With regard to perceived benefits of participating in preventive health behaviors, Chinese women in Hoeman, Ku, & Ohl (1996)'s study cited perceived benefits such as "the avoidance of transferring bad genes to the next generation, the provision of a sense of being personally safe, and the perception that such behaviors were good for reproductive function" (p.527). Although the majority of Chinese women in Lu (1995)'s study did not practice BSE regularly, they recognized the general efficacy of BSE, the efficacy of BSE for themselves, and were comfortable performing BSE. The only significant predictor for BSE practice for this group was perceived competency. Similarly, the study of Bastani et al. (1991) concluded that perceived efficacy of early detection did not significantly predict mammography outcome.

From these studies, it is clear that culture influences beliefs on the meaning and etiology of cancer, concepts of health internal locus of control and

health value orientation, and perceptions regarding risk, susceptibility to, and seriousness of cancer, as well as benefits of and barriers to preventive health behaviors. Health care organizations need to recognize these beliefs and their implications on cancer screening behaviors in order for their services to reach the target population they intend to serve. Empirical support for the Health Belief Model as an explanatory framework for breast and cervical cancer screening behavior among Chinese women is mixed from these studies. More studies on cancer screening activities among the Chinese immigrant population are needed in order to further understand the ramification of their cultural beliefs on their health seeking behavior so as to develop early detection and intervention programs that are effective.

Socioeconomic Barriers to Cancer Education and Screening

Socioeconomic status, race, and ethnicity are often studied simplistically in health literature as static variables controlled in epidemiology, or are treated as the context in health promotion and disease prevention (Pasick, 1997). Concerns remain that current health promotion approaches are not derived nor tested adequately on populations of different cultures and socioeconomic status (Pasick, 1997). Researchers and health care professionals need to consider and address these complex issues in order to develop effective cancer education and screening program for the medically underserved population. Several decades of research studies have consistently found that low socioeconomic status, as measured by income and education, is associated with higher risk of disease incidence, morbidity, and mortality (Fernstein, 1993). Low

socioeconomic status is also associated with higher cancer incidence, morbidity, mortality (Ward et al., 2004; Freeman, 1989; Kagawa-Singer, 1995), and with lower participation in cancer control programs (Katz & Hofer, 1994; Harlan et al., 1991). The overall five-year survival rate of poor Americans for all cancers combined is 10% lower than that of more affluent Americans (Ward et al., 2004). Economic status, regardless of race, acts as a powerful symbol of human conditions and circumstances and explains a higher cancer incidence and lower survival (Freeman, 1991).

Being poor creates economic, social, psychological, access, and information barriers to health care that affect individuals regardless of age, gender, or race (Palos, 1994). Identifying these barriers to health promotion may help health care professionals understand why the poor have a lower rate of compliance with recommended health practices. Barriers the poor experience include poverty, substandard and overcrowded housing, neighborhood crime, chronic malnutrition, lack of enabling resources, knowledge, and skills, illiteracy and innumeracy, provider cultural insensitivity and lack of awareness on patients' coping styles and belief systems, systemic failure to address patients' lack of insurance, and other non-medical impediments to quality health care (Langer, 1999; Freeman, 1989; Reilly et al., 1998).

Jang, Lee, & Woo (1998) studied health-related needs in the low-income San Francisco Chinatown by assessing community perception of health care access and service utilization. They concluded that poverty, limited English skills, and non-citizenship status as significant barriers for Chinese residents to

access and use health care services. In another study, Ma (2000) interviewed Chinese immigrants living in metropolitan Houston and found that cultural and socioeconomic factors associated with access to and utilization of health services. All these factors create competing priorities in the lives of poor individuals which impede them from participating in early detection and cancer screening activities and from seeking treatment when diagnosed with cancer. Sadly, the economically disadvantaged and medically underserved often have health risk factors. The cumulative effect of chronic malnutrition, substandard housing, unemployment, excessive exposure to environmental pollutants, and chronic stress could damage the primary function of the body and affect its inherent ability to defend itself from internal and external stressors (Underwood & Hoskins, 1994). As a result, individuals who are economically disadvantaged become high risk groups for certain types of cancer. They also experience lower survival rates and higher mortality rates as compared with middle-class or affluent Americans (Palos, 1994).

Because of great concern over cost, the poor are often discouraged from seeking state-of-the-art diagnostic examinations or treatments (Bastani et al., 1991). Access to care is another barrier that keeps poor individuals from participating in early detection and cancer screening activities. The “inverse care law” (Hart, 1971) postulated that the availability of good quality medical care tended to vary inversely with the need of the population served. From birth to adult to old age, the medically underserved population experience disease,

illness, and medical care in a different way than the general population do (Reilly et al., 1998) and they encounter numerous barriers to better health care.

Misconceptions of risk, vulnerability, and susceptibility to cancer are also common among the poor (Underwood & Hoskins, 1994). Despite their previous family history of cancer, the poor often think that cancer does not affect those who are healthy and young, or those who are afflicted with other chronic diseases. Therefore, they may not perceive the need for cancer prevention or early detection of cancer (Underwood & Hoskins, 1994). In addition, the poor tend to share a "fatalistic" or "powerless" view (Freeman, 1989). This perception of "powerlessness" seems to have a strong influence on cancer education and cancer care. The poor often report incidents whereby they are told by health care professionals not to concern about changes of their bodies, or made to feel that those concerns are unwarranted, and that their symptoms are of no consequence (Underwood & Hoskins, 1994). When they are not involved in the decision making process, or when they perceive themselves as being incapable of making their own health decisions, they feel that their sense of control is taken away. As a result, they may falsely appear to be ignorant. When cancer is diagnosed, their hope of recovery may be replaced with feelings of hopelessness, pessimism, and fatalism (Underwood & Hoskins, 1994).

The poor are often described as having less accurate information on cancer prevention, early detection, and treatment (Loehrer et al., 1991; Freeman, 1989; Underwood & Hoskins, 1994). Loehrer et al. (1991) interviewed socioeconomically disadvantaged cancer patients to assess their knowledge on

cancer and its treatment and to evaluate their care-seeking behaviors. Although these patients relied primarily on their physicians for cancer information, they had a lot of misinformation regarding cancer. About one-fifth of these patients incorrectly identified the primary site of their cancer, and about one-third of those with metastases identified sites of metastases incorrectly. When asked about how to respond to common cancer-related signs and symptoms, these patients frequently reported inappropriate care-seeking behaviors. This study concluded that when health knowledge of socioeconomically disadvantaged patients was based on incomplete or erroneous information regarding cancer and its treatment, they would seek care inappropriately (Loehrer et al., 1991). Yi (1994b) also concurred that lack of cancer knowledge and low screening behaviors as associated with less educated individuals. On the contrary, having greater knowledge on cancer and taking preventive health measures are associated with employment outside the home and more years of education (Phipps et al., 1999).

Similarly, studies of Asian immigrant women indicated an association between self-reported cancer screening behavior and socioeconomic status, educational level, English proficiency level, and the degree of acculturation (McPhee & Nguyen, 2000; McPhee et al., 1997; CDC, 1992b; Lee et al., 1996). In addition to socioeconomic barriers, medically underserved Asian immigrants also face cultural and language barriers that make them less likely to participate in preventive health screenings or receive cancer education. Tu et al. (1999) found that removing financial barriers does not necessarily increase participation

in mammogram screening by Asian American women. Compared to non-Asians, older Chinese-American women with health insurance (requiring no out-of-pocket medical expense) are less likely to participate in mammogram screening even when they are recommended to do so. This may be attributed to cultural issues pertaining to medical examinations among older Chinese-American women. Other studies also found a variety of reasons for the low rates of breast and cervical cancer screening among Asian American women (Phipps et al., 1999; McPhee et al., 1997; Hiatt et al., 1996). These reasons include lack of knowledge on risk factors and screening procedures, low education level, lack of preventive care orientation, language barriers, preference of Eastern (traditional) medicine, and modesty. While Freeman (1991) argued that ethnic differences in cancer is largely secondary to socioeconomic factors and related issues, non-economic issues such as language, education, and cultural factors are also significant in studying cancer screening behaviors of the Chinese medically underserved population.

Furthermore, Schiffman et al. (1991) found that cancer control educational materials are not effectively disseminated to the medically underserved immigrant populations that comprise a large number of low literate adults. Michielutte et al. (1999) reviewed recent studies on the relationship between health literacy and health care experience. They noted that patients with low reading ability have difficulty accessing the health care system as well as understanding instructions and recommended regimens. The required reading levels for many educational pamphlets on prevention, detection, and treatment of

breast cancer ranged from 9th to 12th grade (Michielutte et al., 1999). As a result, many of these printed health education materials are inaccessible to those who are illiterate, or have low reading skills with an average of 4th reading grade level or below, and also to many individuals who are defined as having "good" reading ability.

While low literacy among American adults could be a result of lack of education, reading and/or comprehension problems, or specific learning disabilities (Michielutte et al., 1999), low literacy among Chinese immigrant groups could often mean reading and comprehension difficulties associated with learning English as a second language as well. Chinese women who have an 8th grade education or less or who do not speak English fluently are less likely to ever have had mammograms than their counterparts who are more educated or speak English more fluently (Centers for Disease Control, 1992a). Another study confirms that the ability to speak English well is significantly associated with breast and cervical cancer screening knowledge and practices (Lee et al., 1996). Therefore, it is important for health care providers to be aware of the low health literacy status of their patients and to explain information clearly so that patients can understand it (Lam, Cheng, & Chan, 2004).

Physician Role in Cancer Screening and Treatment

Efforts to prevent cancer and to reduce morbidity and mortality cannot be effective unless patients adhere to cancer screening guidelines. Gritz et al. (1989) defined noncompliance as encompassing not only the failure of the patient to follow screening guideline as recommended by the physician, but also

the behavior of the physician, physician-patient interactions, and the health care setting in which the patient and the physician interact. In the Chinese culture, physician is an authority figure (Lee, 1998) and his recommendations on cancer screening are very important to this population. Patient adherence to cancer screening guidelines largely depends on the amount of information and support they receive from their physicians, the physicians' knowledge of cancer screening guidelines and their ability to perform screenings or make appropriate referrals, and effective communication between the physician and the patient (Dunkel-Schetter, 1984; Maxwell et al., 2000; Bastani et al., 1991).

In the Maxwell et al. (2001) study, Filipino women were more likely to accept a screening test if recommended by a physician. In another study by Bastani et al. (1991), 75% of participants indicated that they would very likely get a mammogram if their doctor recommended it. However, the same study also found that physicians did not use clinic visits as an opportunity to refer patients for mammograms. Lee (1998) found that only 63% of physicians referred their patients aged 50 and over for annual mammograms, 28% of physicians ordered mammograms once every two years, and only 61% performed Pap smear for their patients. Lack of physician referral is found to be an important factor contributing to the low use of cancer screening among Asian American women (Yu et al., 2001; Harlan et al., 1991; Lee et al., 1999). One main reason is that physicians often focus on chief complaints presented by the patient rather than promoting the concept of preventive health (Lee et al., 1999). Alternatively, physicians are less likely to recommend screening tests when the patient comes

for an unrelated problem (Lee et al., 1999). If the chief complaints presented are not clearly related to cancer, screening would not be recommended. Reluctance to disrobe, especially among Vietnamese and Southeast Asian women, and physician deference to patient's modesty may also contribute to the low referral rate of cancer screening procedures (Bastani et al., 1991).

A heavy reliance upon physicians for information on cancer, cancer screening and treatment, is prevalent among socioeconomically disadvantaged and less educated patients (Loehrer et al., 1991; Dunkel-Schetter, 1984; Yu et al., 2001; Northouse & Northouse, 1987; Liang, et al., 2004). Yu et al. (2001) interviewed 332 less educated Chinese American women and many of them identified doctors (25%) and friends (21.4%) as the source of useful information on how to prevent illness and improve health. Loehrer et al. (1991) interviewed 128 cancer patients from a socioeconomically disadvantaged population to assess their knowledge of cancer and its treatment. Again, 90% of the respondents indicated their physician as the primary source of disease-related information, but 37% reported being less than or only somewhat satisfied with the information they received from their physician, and one third of them expressed the need to get more information.

Northouse & Northouse (1987) reported that cancer patients seek information in order to construct a framework to understand cancer and its treatment. Cancer patients express a strong need for cancer-related information. Health care providers also spend a great amount of time disseminating information during their interactions with patients. However,

physicians should take into consideration that the give and take process of information-sharing between the physician and the patient may be complicated by patients' level of comprehension as well as their preferences of information (Northouse & Northouse, 1987). When physicians intend to provide information and support to patients, they need to understand how cancer patients define the meaning of support, and what they describe as the most helpful and the most unhelpful things.

Dunkel-Schetter (1984) studied seventy-nine cancer patients and asked them to identify helpful and unhelpful behaviors of providers and others. Eighty-one percent of respondents mentioned emotional support (love, concern, understanding, reassurance, encouragement) as the most helpful behavior, 41% indicated informational support as the most helpful (advise, information to solve problem), and 6% mentioned instrumental aid or assistance to them. By the same token, some patients reported that it was unhelpful when physicians provided too little information, or when physicians appeared too cold or too clinical in manner that medical care was provided without any accompanying emotional support (Dunkel-Schetter, 1984). It is clear from this study that support is important to patients. Cancer patients often describe medical care as helpful only when it is provided with emotional and informational support. Physicians are seen as the most effective when they provide a combination of direct assistance, advice or guidance, and emotional support.

From the above studies, we may conclude that the following principles are effective in increasing patient's adherence to cancer control activities and

providing primary care and health screening services for the medically underserved population. First, physicians need to demonstrate genuine interest in the patient's beliefs and attitudes (Langer, 1999; Reilly et al., 1998). They should also enlist the patient's cooperation in formulating service plans. This means that physicians frame health care issues to fit patient's perceptions and their priorities so that patients are more likely to accept and comply with treatments. In addition, physicians need to focus more on the patient rather than the disease. A recent Commonwealth Fund study (Audet, Davis & Schoenbaum, 2006) found that while physicians favor patient-centered care, only 22% of them scored high in incorporating patient-centered care practices such as sending reminder notices for preventive or follow-up care, information from referral physician promptly available, medical records/test results readily available when needed, and patient data feedback to practice.

For many physicians, the notion that illness is equated with challenge inspires them to engage in rational, task-oriented behavior (Amodeo & Jones, 1998). Western medicine itself can be perceived as a culture (Glasser, 2000). However, for patients from non-Western cultures, illness may be viewed as weakness, punishment, or relief from responsibilities (Amedeo & Jones, 1998). Whatever the patient's perspective is, he or she may not be prepared to engage in the behavior expected by the physician. Therefore, physicians need to recognize and understand how the patient's cultural and individual perspectives may affect their decisions on health care and preventive behavior. Although cross-cultural care was perceived to be important in the health care setting, a

large percentage of resident physicians in Weissman et al. (2005)'s study indicated that they were not prepared to provide specific components of cross-cultural care such as caring for patients with health beliefs that are different from Western medicine (25%), new immigrants (25%), and patients whose religious beliefs affect their treatment (20%).

Effective communication between the physician and the patient is essential in promoting patient adherence to preventive health care (Glasser, 2000). However, socio-economic differences and cultural barriers may hinder patients in seeking appropriate care. Taira et al (2001) found that Asians' assessments of the quality of primary care were lower than those of other ethnic and racial groups after adjustment for socioeconomic and other factors. Part of the reason was due to poor quality of communication between physician and patient and the physician knowledge of them as patients. Thus, although Asians were portrayed as better educated, had fewer chronic conditions, and were more likely to be employed in professional or technical occupations than other ethnic groups, they had the lowest primary care performance assessments after adjustments for all of the previously mentioned differences.

Medicine often focuses on the biological and epidemiological factors attributing to diseases. But understanding the socioeconomic contexts in which patients live can help develop appropriate strategies on modifying patient behaviors that are responsible for health risks (Glaser, 2000). Physicians may judge medical regimens on their medical worth, but patients may judge regimens on social priorities (Langer, 1999). Patients often understand a medical regimen

in terms of the way it affects their lives. Therefore, health professionals should understand the protocol in terms of the way it affects the patient's health. Costs of treatments for patients are often expressed in emotional, psychological, and social terms as well as physical and financial ones (Langer, 1999). When designing care and providing services for ethnic minority individuals, physicians need to examine help-seeking behavior as influenced by cultural factors (Ahn, Ngo-Metzger, Legedza et al., 2006; Green, 1999; Pedersen et al., 1996). Physicians should also be sensitive to the socioeconomic barriers encountered by the patient, understand what cultural factors may shape the patient's help-seeking behavior, educate the patient on health maintenance and relevant disease management, and teach the patient how to accomplish certain health care goals (Reilly et al., 1998).

Another principle in effective patient-physician communication is empowering the patient to partner with the physician in actively maintaining and improving health (Reilly et al., 1998). Physicians can help patients cope with the disease by increasing patients' feelings of competence in their ability to manage their disease. Elevating the patient's status within the therapeutic alliance increases the likelihood of participation and improves compliance. One important step in empowering the patient and increasing compliance is that the physician examines his own expectations and understands the role these expectations play in patient-physician alliance (Langer, 1999). Unfulfilled expectations on the part of the physician may lead to labeling the patient as non-compliant and his behavior as inappropriate and unreasonable, while in reality

the behavior displayed by the patient can be completely understandable and acceptable in the patient's context (Langer, 1999). Therefore, managing a therapeutic alliance means developing awareness, sensitivity, knowledge, and skills that encourages physician-patient interaction that is enhanced rather than hindered by differences (Langer, 1999).

Conclusion

The Chinese American population both in the U.S. and especially in New York City continues to grow rapidly. This population is not only increasing in number, but is also becoming more heterogeneous in its socio-demographic characteristics, immigration background, beliefs and practice toward health, illness, and treatment. A rising cancer mortality and poor survival rate, coupled with a low screening rate among Chinese Americans as compared to the general population, has become a great disease burden (Jenkins & Kagawa-Singer, 1994). Therefore, promoting cancer education and screening services for Chinese Americans and improving access to services are becoming pressing clinical and public health issues. Unfortunately, many earliest health promotion and cancer intervention programs often target broad population groups rather than specific minority or cultural groups, although it is the latter group who need the most help in overcoming barriers when accessing preventive care (Pasick et al., 1996).

Barriers to accessing cancer education and screening services and the lack of screening compliance can be attributed to many factors. Sociopolitical and economic deprivation as well as lack of education and knowledge are some

of the barriers that contribute to relatively high incidents of cancer, low survival and high mortality rate among minority groups (Hiatt et al., 1996; Freeman, 1989). Cultural beliefs and attitudes, language barrier, low health literacy, limited access to care, lack of appropriate referrals from physicians, and inadequate patient-physician communication are some of the common barriers Chinese Americans face when accessing to cancer education and screening (Jenkins & Kagawa-Singer, 1994; Batani et al., 1991; Lee et al., 1999).

The Health Belief Model, the Systems Model of Clinical Preventive Care, and their related concepts are useful in identifying factors that influence patient behavior in preventive health and cancer screening activities. However, it is unclear as to what extent these models can be applied to working with Chinese Americans, or what adaptations need to be made in order for the intervention to be effective. Research studies cited in the literature review section focus on four major dimensions of variables that are relevant for this study: (1) the notion of preventive health, illness, and cancer in Chinese culture; (2) beliefs and attitudes toward cancer and cancer screening among the Chinese immigrant population; (3) socioeconomic, language, and literacy barriers to cancer education and screening; and (4) physician role in cancer screening and treatment. Determining the influence of these variables on cancer related behaviors and health outcomes can be complex and challenging. In fact, Kagawa-Singer (1995) point out that separate influences of these variables cannot be extricated from each other. Since these factors are inter-related, an exploratory approach will be employed in this study in order to understand the interdependent nature

of each of these variables and how each variable and their combination influence cancer related behaviors among Chinese Americans. Hopefully, information gathered from this study will shed light on what barriers Chinese Americans encounter when accessing preventive health care, which in turn will help health care agencies in designing programs that are effective in reaching this group.

CHAPTER FOUR

METHODOLOGY

Project Goals and Objectives

The purposes of this study are to understand the level of health knowledge, cultural attitudes and beliefs towards the causes and prevention of breast, cervical, and prostate cancer among medically underserved Chinese immigrant men and women living in the metropolitan New York City area, and to develop a theoretical model on identifying barriers to cancer education and screening activities as well as factors that affect their preventive health behavior. This study is based on the assumption that patterns of health beliefs, health seeking behavior, and the utilization of preventive health and cancer screening services among Chinese immigrants are interwoven into their cultural, socioeconomic, and other aspects of daily lives. This study will be helpful in filling the knowledge gap in cancer education and screening for the Chinese immigrant population and in highlighting the importance of cultural sensitivity and relevancy in the design and implementation of effective breast, cervical, and prostate cancer education and screening programs for this population. A better understanding on care-seeking behaviors and access barriers may also help in the development of culturally relevant programs for the Chinese immigrant population in the U.S., thus improving their access to breast, cervical, and prostate cancer services, and promoting the concept of prevention, early detection, and treatment of cancer.

A total of 39 medically underserved Chinese immigrant men and women living in the metropolitan New York City area participated at this study. The study addressed the following specific research questions:

1. What is the level of knowledge toward breast and cervical cancer among the Chinese women? What is the level of knowledge toward prostate cancer among the Chinese men?
2. What are their cultural attitudes and beliefs on preventive health, and on the causes and prevention of breast, cervical, or prostate cancer? How do these attitudes and beliefs affect their cancer screening behavior? How do they perceive their health risk and their needs of taking action to stay healthy?
3. What are the demographic (such as age, gender, number of years living in the U.S., etc.), ethnic, and cultural factors that may affect their access to breast, cervical, or prostate cancer education and screening services? How do stress and lack of resources affect their access to education and screening services?
4. When they sought breast, cervical, or prostate cancer education and screening services, what were their experiences with health care providers? Had it been easy or difficult for them to discuss their health-related concerns with health care providers? Were there any differences in beliefs, attitudes, and health practices between these immigrants and their providers that may affect patient-provider relationship and communication?
5. What are the organizational and health care system factors that promote or hinder the delivery of cancer education and screening services?

6. What can be done to improve cancer education and screening services for Chinese Americans in New York City? What would be the best way to market screening and educational services to this community?

Research Design – A Qualitative Approach

Denzin & Lincoln (1994) define qualitative research as an interpretive, naturalistic approach to collect and study a variety of empirical materials in their settings such as personal experience, life story, interview, etc. It is an attempt "to make sense of or interpret phenomena in terms of the meanings people bring to them" (p.2). Creswell (1998) sees qualitative research as "an inquiry process of understanding based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting" (p.15). A qualitative, interpretive research methodology is chosen for this study for the following reasons:-

To date, there are very few studies on Chinese immigrants in relation to breast, cervical, or prostate cancer education and screening activities. Therefore, it is important to hear and understand their first hand experiences in seeking cancer education and screening services The social context of their health care experience may differ significantly from that of the more advantaged social groups. A qualitative approach enables us to understand what preventive screening activities, life situations, and health care experiences mean to them, rather than to narrowly define their experiences in categories as in the case of quantitative survey designs. "The commitment to get close, to be factual,

descriptive… constitutes a significant commitment to represent the participants in their own terms… (qualitative studies) faithfully depicting what goes on in their lives and what life is like for them, in such a way that one's audience is at least partially able to project themselves into the point of view of the people depicted" (Lofland, 1971:4). The focus of meaning is central to the "interpretive" approach to social science (Maxwell, 1996). Qualitative approach produces rich and detailed information on a small number of participants through open-ended interviews (Patton, 2002). It also adds depth and meaning at a very personal level of experience.

While the quantitative approach to research has many merits, it tends to oversimplify the complexities of real world experiences and fails to address major and important factors that cannot be easily quantified (Patton, 2002). It is also relatively limited in explaining the complex confluence of psychological, cultural, social, and other systemic factors that lead a person to seek medical attention for a specific problem at a specific time (Zyzanski et al., 1992). On the other hand, a qualitative approach has the advantage of providing a 'holistic', systemic, encompassing, integrated view on the lived experiences of participants and the context in which they interact with the system (Miles & Huberman, 1994). In qualitative studies, greater attention is given to "nuance, setting, interdependencies, complexities, idiosyncrasies, and context" (Patton, 2002, p.60). The influences of the social, economic, cultural, and health care context are taken into consideration. Qualitative data often provide "thick descriptions" that are vivid and nested in a real context (Miles & Huberman, 1994). Therefore,

the voices, feelings, and experiences of participants are heard and understood (Patton, 2002).

The nature of the phenomena on this study does not lend itself easily to quantitative investigation because people do not conceptualize attitudes, beliefs, perceptions, or experiences easily on a hierarchical linear continuum. We may learn more from the participants by asking them to share their experience in the context of an open-ended interview rather than to rate their experience using pre-determined categories. Moreover, in this study, there may be cultural and social barriers to "sharing" among some participants, such as talking about strong negative emotions that may create stress for some participants (Kagawa-Singer, 1996). Fear of cancer itself and the belief that thinking about cancer can provoke the onset of cancer are cited as potential formidable barriers to services among some Asian women (Sadler et al., 1998). An interview led by an experienced and knowledgeable person creates a supportive environment that promotes the sharing of feelings, beliefs, experiences, and problem-solving strategies through exploration, challenge, and clarification (White and Thomson, 1995). In the Sadler et al. study, some women have responded to culturally sensitive and linguistically compatible outreach and educational efforts and have subsequently overcome barriers to services. Based on my previous experiences in conducting focus group interviews with cancer patients, I have also observed participants expressing feelings of relief and comfort when they realize that other participants also share similar experience as theirs.

Qualitative research is specifically oriented toward exploration and discovery by using inductive logic, and is highly appropriate in studying the process (Patton, 2002). A more inductive design allows the important "analysis dimensions" (p. 56) to emerge from themes and patterns found in a small sample of participants. It is best for discovering and exploring an area in depth, and developing plausible hypothesis for future quantitative studies (Miles & Huberman, 1994). Qualitative data can also be used to "supplement, validate, explain, illuminate, or reinterpret quantitative data" (p. 10) gathered from other studies cited in literature. This study aimed at exploring and discovering ways in which Chinese immigrants come to understand breast, cervical, or prostate cancer, how they perceive and seek preventive health services by understanding processes, and the multiple interrelationships among concepts and dimensions that emerge from the interview data.

Grounded Theory Approach

A grounded theory approach (Glaser & Strauss, 1967) was chosen in this study to understand the participants' experiences as rigorously and detailed as possible, to identify concepts and themes that emerge from interview data, and to develop theoretical propositions or present a visual picture of the theory. The grounded theory can be characterized as a "running theoretical discussion using conceptual categories and their properties" (p. 31) which emphasizes on "theory as process…as an ever-developing entity…(that) allows it to become quite rich, complex, and dense, and makes its fit and relevance easy to understand" (p. 32). Grounded theory methodology emphasizes the systematic collection,

coding, and analysis of data in constructing a theoretical model and an abstract analytical schema of the phenomena under study (Creswell, 1998). Based on the principles of grounded theory research, codes, categories, and concepts are developed inductively from transcribed interviews and focus group data. The core themes and salient characteristics of the participants' experiences are identified and compared to theories derived from the literature and health promotion concepts. The constant comparative analysis method is a process of "taking information from data collection and comparing it to emerging categories" (Glaser & Strauss, 1967, p. vii). This method is used to generate categories, properties, themes, and hypotheses on participants' knowledge, attitudes, beliefs, and screening behaviors related to breast, cervical, or prostate cancer and to compare and contrast these themes and concepts to each other. Throughout the study, I repeatedly ask the following questions: What are the general categories and themes that emerge in open coding? When, why, and under what conditions do these themes occur in the interview text? What causes cancer knowledge, beliefs, and behavior of Chinese immigrants? What are the contextual and intervening conditions that influence cancer education and preventive screening behavior? What are the salient issues in patient-provider communication? How do organizational and health care system factors influence health behaviors and health outcomes? What coping or alternative strategies do participants use in accessing quality cancer information and screening services? What are the consequences of these strategies?

As a research method of data collection and analysis, however, the grounded theory approach has some shortcomings (Creswell, 1998; Dey, 1999). While the grounded theory is faithful to everyday realities of a substantive area that is carefully induced from diverse data, Maxwell (1996) warns that trying to fit research data into a pre-established framework or using existing literature and assumptions as a filter of knowledge can distort the way research data is analyzed, resulting in an oversight on other important ways of conceptualizing the study or major implications of research results. The researcher needs to set aside his assumptions or theories as much as he can and be "theoretically sensitive" so that he can conceptualize and formulate a theory as it emerges from the data (Glaser & Strauss, 1967). Therefore, when I conducted this study, I had to be mindful not to impose concepts I read from the literature and existing health promotion models during data collection and initial phase of data analysis.

On the other hand, Wolcott (1995) points out that no researcher is likely to conduct a research without some idea of what s/he is looking for. Theory and citations to the relevant literature help the researcher place the study within some broader contexts. To help me focus, organize, and orient my study, I used "sensitizing concepts" (Patton, 2002) which were derived from health promotion models, research literature, and previous work experience in delivering breast, cervical, and prostate cancer education and screening services. Once the core themes and concepts emerged from interview data, they were compared and contrasted to the literature and existing health promotion concepts and models in order to develop useful theoretical constructs or a dense and rich theory.

Despite the evolving, inductive nature of qualitative inquiry and the importance of researchers' receptiveness and openness to the study context (Wolcott, 1995), grounded theory research represents a relatively systematic approach to research with several specific steps of data analysis (Creswell, 1998). One major challenge the researcher faces is determining when categories are "saturated" or when the theory is adequately developed. Dey (1999) warns against "premature closure", the failure to analyze data sufficiently and develop the building blocks of theory. The researcher does not merely describe or report details from the perspectives of participants or subgroups under study. S/he also assumes the responsibility of interpreting what is observed, heard, or read (Strauss & Corbin, 1994). This "interpretive" nature of the grounded theory approach implies that "conceptualizing" or "theorizing" is a challenging and complex process that should be engaged throughout the course of the research study (Strauss & Corbin, 1994).

Selection and Recruitment of the Sample

The sampling plan was intended to recruit a group of medically underserved Chinese immigrant men and women who have directly participated in breast, cervical, or prostate cancer education and screening services. These participants were recruited from the patient population of the sponsoring agency, Charles B. Wang Community Health Center (referred to as "the Agency" hereafter). Additional participants were recruited from community residents who have participated in breast, cervical, or prostate cancer education and screening services at the Agency. I obtained the support and approval to conduct this

research study from the Agency by submitting a proposal on my study to the Agency for review and approval. The Agency then provided a support letter to the Hunter College Institutional Review Board indicating its consent and approval for me to conduct the study at the Agency.

A recruitment letter (Appendix 1) and an information flyer were made available to potential participants at the Agency explaining the purpose of the study and providing information on what participants are being asked to do, how long their participation is expected to last, what incentives they will receive at the end of their participation, how to contact the researcher, and what benefits the study may have for them and for the improvement of services at the Agency. Flyers were posted at various sites of the Agency's bulletin boards as well as made available at the reception desk and patient waiting areas. Recruitment letters and flyers were distributed to potential participants by mail and through Agency staff. Every effort was made to ensure that participation in the study would be voluntary and that no participants should feel any pressure to participate in the study.

The size and the characteristics of the sample were determined by the purposes of the study. A total of 39 participants were recruited for this study. Based on the gender and the primary Chinese dialect the participant speaks, 4 focus groups were formed and 14 in-depth individual interviews were conducted. Five individuals participated both in focus group and individual interviews. Since the goal was not to test a hypothesis or to generalize from a random sample of participants to the entire population as in a quantitative study, the relatively

modest sample size was considered to be appropriate and sufficient for this study.

Stratified purposeful sampling was used to select focus group participants who represent specific patient types or subgroups so as to capture major variations and to facilitate comparisons across subgroups (Miles & Huberman, 1994). Segmented sampling strategy was used to sort different categories of participants into separate groups (Morgan, 1995) in order to identify and analyze the similarities and differences of perspectives across different groups. In this study, group participants who were different in gender, age, preferred spoken dialect, education, income and resource level, and recency of immigration to the U.S. were included in the sample in order to capture variations and differences in beliefs and practice toward health, illness, and treatment, as well as different experiences in accessing to health care and resources. Those who had the same gender and spoke the same dialect (Cantonese or Mandarin) were placed in the same focus group to encourage free sharing of beliefs, attitudes, and experiences.

Two focus groups were formed with Chinese women aged from 25 to 65 who have received breast and cervical cancer education and screening services. One group was constituted of women who speak Cantonese, and the other group of women who speak Mandarin. These women had varied immigration experiences and different length of stay in the U.S. Another two focus groups were formed with older Chinese men aged 50 and over who attended prostate cancer screening activities. Again, one group was constituted of Cantonese

speaking men and the other group Mandarin speaking men. According to statistics gathered by the Agency, participants in breast, cervical, or prostate cancer education and screening services who primarily speak Mandarin tend to be younger in age, relatively new to the country, are unfamiliar with the health care system, and have limited skills in accessing to resources. In contrast, those who speak Cantonese tend to be older, have been living in the U.S. for a longer period of time, and are relatively more familiar with the American health care system and available resources.

The characteristics of the participants in this study were largely consistent with this pattern. Those who speak Mandarin in this study were slightly younger (mean age 55.7) than those who speak Cantonese (57.7) and had been in the U.S. for a much shorter length of time (average 10.7 years) as compared to 21.1 years for the Cantonese speaking group. Fifty percent of Mandarin speaking group self paid for health care while only 9.5% of Cantonese speaking group were uninsured. With limited access to health insurance and health benefits, those who spoke Mandarin reported seeing a physician practicing Western medicine on the average only 2.3 times during the past 12 months while the Cantonese speaking group on average saw a physician 6.2 times during the past 12 months.

Intensity sampling and extreme case sampling methods were used to select participants for in-depth individual interviews. The goal of intensity sampling is to choose participants who can provide rich information and manifest the study phenomenon intensely (Patton, 1990). In this study, those who had

family history of cancer, those who were at different stages of cancer screening and re-screening, and those who had the diagnosis of cancer were selected so that they could share their experience. Several atypical cases were chosen to learn about specific intervening conditions or extreme outcomes that may help improve breast, cervical, and prostate cancer education and screening services. Focus group participants who had either extremely positive or negative experiences in accessing services were also chosen for in-depth individual interviews.

The context, incidents, experiences, and processes were also sampled in this study (Miles & Huberman, 1994). This was based on the strategy of "theoretical sampling" (Glaser & Strauss, 1967), a process in collecting data and developing grounded theory in which the researcher "jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them in order to develop theory as it emerges" (p. 45). The criteria for theoretical sampling are those of "theoretical purpose and relevance" (p.48). Distribution of the characteristics of the sample population were based on these criteria and determined by the scope of research questions. This sampling technique helped generate and define as many properties of the categories as possible. It also helped relate categories to each other and to their properties (Charmaz, 2000).

Characteristics of the Sample

Thirty-nine Chinese men and women participated in 4 focus groups and 14 individual interviews. The majority of participants were low income and medically underserved Chinese immigrants. "Low income" is defined by an

annual income at or below 200% of the federal poverty level. According to the 2004 federal guidelines, an annual household income of $18,850 for a family of four is considered to be at the federal poverty level. “Medically underserved immigrant” is defined by foreign born, linguistically isolated and speak only Cantonese and/or Mandarin rather than English, and medically indigent, under-insured or uninsured. Twenty-one participants were male and 18 were female. The average age was 56.8 years old (range: 25-78 years; standard deviation: 14.9 years). The majority of participants were married (74.4%), 10.3% were divorced, and 7.7% were widowed. All participants were foreign born with an overwhelming majority of participants from China (82.1%). Fifty-nine percent of the sample had an educational level of high school or above, 20.5% attended junior high school, and 20.5% either received elementary school or had no formal education. Only 8% said they spoke English well; 55.2% said their ability to speak English was poor or did not speak English at all. The majority of participants considered themselves as Chinese or Chinese Americans (94.9%) and spoke Cantonese or Mandarin, or a combination of both Cantonese and Mandarin. Approximately three quarters of participants (74.4%) preferred mostly Chinese food, 94.7% observed or celebrated Chinese traditions and festivals, and the ethnic background of their friends were predominately Chinese (94.4%). Therefore, the desire to preserve ethnic identity was very strong in this group, a fact that was reflected in the sociocultural and economic life of Chinese in the New York City.

Approximately 47% of participants were employed and 34% were retired. Over 73% of participants reported their total annual household income to be below $20,000. Approximately 28% privately paid for their health care; only 12.8% had health insurance through their employment, and the rest of the group received government-funded health insurance benefits such as Medicaid, Medicare or Family Health Plus.

Data Gathering Instrument – Individual Interviews and Focus Groups

The Individual interview is a common instrument of data collection in qualitative research (Silverman, 2000) because it yields useful information to answer research questions (Creswell, 1998). Old, fragile, or ethnic minority individuals may feel intimidated if they have to articulate their ideas in public or in a group setting. Therefore, one-to-one interviewing with them will be a better approach for information gathering.

Focus groups are more effective in information gathering when participants are relatively verbal and articulate, and have similarities to share with each other. Moreover, the group process and interaction of group members is intended to stimulate thinking and spontaneous exchanges of ideas, attitudes, and thoughts among its participants (Asbury, 1995; Nyamathi & Schuler, 1990). Focus group interviewing yields rich, detailed experiences and a wide range of perspectives that may not be easily obtained through other methods (Kidd & Parshall, 2000). As a qualitative method, focus groups have many merits. Focus groups can be used to explore new ideas from the participants' own perspectives, particularly among groups of people who are understudied or

poorly understood (Morgan, 1997). Understanding and taking their perspectives into account when planning health promotion programs is important in empowering patients (Basch, 1987). Focus group is also an appropriate method for understanding and developing sensitivity toward the population we serve. Esposito (2000) states that focus group is especially useful in gathering health-related information because it allows immigrant groups to speak out, therefore improving cross-cultural communication in clinical and research settings and enabling health care to be more accessible to non-English speaking immigrants. Without focus groups to elicit valuable information, well-planned efforts by health professionals may fail to address barriers to cancer prevention and early intervention services for hard to reach populations such as new immigrants. Compared to individual interview, candor and spontaneity in a group make focus group a valuable data collection instrument (Carey & Smith, 1994). Synergism created from group interaction may also stimulate new ideas and high levels of energy in discussion. Focus group is also useful in dealing with complex social and sensitive health issues (Basch, 1987). Not only can participants provide in-depth information on complex topics, they can also help us understand the context behind their thoughts and experiences and even generate their own interpretations on topics and issues arise in group discussion (Morgan, 1997).

Using focus groups in exploring perceptions, attitudes, feelings, values, and knowledge of sensitive health topics has been widely documented in the literature (Twinn, 1998; Kreuger, 1994; Basch, 1987). Twinn (1998) used focus groups with Hong Kong Chinese women to evaluate programs and service

development in nursing and health services research. Liang et al. (2004) conducted focus groups with older Chinese women to assess their perceptions of health and illness, knowledge on cancer, beliefs on and barriers to cancer screening, and their healthcare experiences in the U.S. Dignan et al. (1990) used focus groups to explore values on health and disease prevention as well as cancer knowledge among black women and their attitudes and barriers regarding cancer and prevention. Information obtained from these studies (Liang et al., 2004; Dignan et al., 1990) proved to be instrumental in developing effective community-based cancer education and screening programs for minority women. Focus groups were also used to explore nurses' attitude to the care of people with HIV/AIDS (van Wissen & Woodman, 1994) in order to develop programs aiming at reducing risk behaviors attributed to HIV/AIDS (Nyamathi & Shuler, 1990), and to generate knowledge on the effectiveness or generalizability of specific program models (Straw and Smith, 1995).

However, when using the focus group as a data collection tool, one has to be aware of its limitations as well. One should not overlook the effects of "group" in focus group interviews (Asbury, 1995) because they may “provide evidence of ambivalence, inconsistency, conformance, or thinking aloud among informants" (Kidd & Parshall, 2000, p. 294). Agreements and disagreements shape the nature and content of responses. Censoring and conforming occur when participants adjust their responses to the impression of other group members and to their own needs and styles (Carey & Smith, 1994). Such processes raise legitimate concerns on the trustworthiness of focus group

findings (Kidd & Parshall, 2000). The focus group facilitators need to be cautious about the issue of “social loafing", or biases that occurs when participants are trying to be "good research subjects" (Nyamathi & Schuler, 1990). Based on my previous experiences in conducting focus group, it is not uncommon for some Chinese participants to be “polite”, socially conforming, or refrain from expressing views which they consider unacceptable to other group members. To guard against “unproductive” processes or potential setbacks, I laid some ground rules with group participants before discussion began. All participants in the focus groups were told that every one of them is entitled to his or her opinion, that free participation among all group members is strongly encouraged, and that there is no right or wrong response, nor is there any response more desirable than the other. In conducting this study, however, there were more indications of agreements among female participants than male participants. For example, female participants agreed with what other participants said in 45 instances while male participants only indicated their agreements on 6 occasions. Expression of agreement by female participants tend to be gentle as they simply nodded in a supportive tone while attending to the group conversations. Male participants agreed more explicitly while adding their own point of views.

> I agreed with what he said. This related to the traditional beliefs of Chinese culture. I had similar experience too. I see a Hispanic doctor as I can speak Spanish. We tend to be honest and the doctor also likes to ask many questions and we are just like friends. I just tell the doctor whatever concerns I have regarding my prostate and he will treat me accordingly. Chinese are different and their beliefs are traditional based on Confucius thoughts. (D10)

> I agree with the other participant's comment. These celebrity people can receive better treatment than the general public, but I still think it is important that ordinary citizens pay attention to prevent cancer rather than seek treatment at a later stage. (D8)

In this group, many Chinese participants, especially female participants tend to be "polite", and socially conforming. However, there are also occasions when they explicitly disagreed with each other. For example, in the female Cantonese speaking focus group, they debated as to whether Chinese doctors, like American doctors, would remind patients when they were due to get screened:

> B4: You know, I think when you see a Chinese doctor, the doctor doesn't really remind you when to get screening but if you see an "American" doctor, when the time comes, they will give you a call and tell you that it's time for you to be screened.
>
> B3: Chinese doctors do that too. A lot.
>
> B2: Yes, Chinese doctors do that too.
>
> B4: Yeah but not that many of them.
>
> B2: Yes, many do.
>
> B4: American doctors…even before you are due, they will remind you to go.

In the same group, they also debated on whether there was a need to seek a second medical opinion. A couple of patients stated that they might not trust their own doctors and would prefer to see another doctor to prevent misdiagnosis but another patient felt that if the diagnosis was confirmed there was no need to see another doctor to avoid more psychological burden:

> B3: If the doctor is to say that I have this illness, I will not just trust this one doctor. I will go find another doctor or maybe two other doctors to see if there is anything else or get information, a second opinion to

prevent misdiagnosis, to see if there is anything different or not the same diagnosis or misdiagnosis.

B2: Well, if they haven't confirmed your diagnosis, then you can go find more than 2 doctors but if your diagnosis was already confirmed that you have that illness, then there is no point in finding another doctor because for your emotional well-being, it will be a big burden for you.

B4: Not necessarily. If the doctor whom you are seeing now is not good, then going to one or two other doctors…help you get to the bottom of things.

B2: No, if you had a confirmed diagnosis then there's no point in seeing another doctor. But if, let's say, you have liver disease which may lead to liver cancer…then you need to go and see a few other doctors.

B4: Well, I think regardless of what illness you have…

B2: For cervical cancer, it depends on your menstruation situation and what is found. There is no other need to see another doctor.

In the female Mandarin speaking focus group, a patient did not refrain from expressing views which she considered unacceptable to other group members. She admitted openly in the group that she did not attend prenatal care check up:

F: But when you were pregnant, were you told to receive any prenatal care in China?

C1: We all have prenatal check ups when we were pregnant.

C5: I didn't even have a doctor present when I gave birth to my child.

C1: Then you didn't have any regular check up?

C5: No, I didn't go. I was so afraid to see a doctor, and I didn't see one at all.

<<Noise and comment>>

C3: It was pretty much up to the preference of each individual.

Overall, the issue of “social loafing” was not a major concern in these focus groups. The participants were polite but they did not refrain from expressing views which they considered unacceptable to other group members. The effects of “group” appeared to be minimal as agreements and disagreements did not significantly shape the nature and content of their responses. In addition to the issue of conforming, I was conscious of the potential effects of gender difference between the facilitator and the participants. Based on the past focus groups conducted at the Agency, it was observed that group participants of same gender felt more comfortable sharing their private experiences when the group was facilitated by someone of the same gender. For this reason, I recruited two female health education workers to conduct individual and focus group interviews with female participants, while I and another male colleague from the Agency co-facilitated focus group and individual interviews for male participants.

The issue of sidetracking in group discussion due to group dynamics such as commotion, laughters, and giggling, did occur mainly in the female focus groups. Group facilitators were vigilant of and skillful in dealing with sidetracking of the group discussion to irrelevant issues and redirected the group to focus on discussion of the subject areas. Those who tend to dominate in group discussion were reined back, and quiet members were encouraged to speak out. Efforts in soliciting responses from the entire group were made to ensure maximum coverage of the topic. The goal is to explore with the entire group

different possible ways of knowing and understanding that participants could reveal (Holstein & Gubrium, 1997).

In conducting qualitative interviews using a grounded theory approach, Strauss & Corbin (1994) point out that instrument validity and reliability depend largely on the skills of the researcher who does not merely report, but also take responsibility to interpret what is observed, shared or heard. Miles & Huberman (1994) describe the concept of "researcher-as-instrument" and characterize a good “researcher-as-instrument” as one who has knowledge and familiarity with the phenomenon and the setting under study, strong conceptual interests, and good "investigative skills". Being ethnic Chinese and having more than fifteen years of experience working with Chinese immigrants, I have a good understanding of the characteristics and needs of the participants in this study. As the former Health Education Director of a community health center, I am also familiar with the issues of cancer education and screening in the Chinese community as well as the health care context of the study. Throughout the implementation and data analysis stages of the study, I consulted with my colleagues, other health care professionals and cancer experts in the field in order to enhance my conceptual and investigative skills. Consulting with professionals of different disciplines broaden my perspective and skills and help me in conceptualizing and analyzing the data collected in the study.

Interview Guide and its Pilot Test

An interview guide was used to make the interviewing process more systematic and focused, but the interviewers and facilitators were expected to

have flexibility in exploring emerging materials that arose spontaneously in interviews. Prior to conducting focus group and individual interviews, an introductory briefing script was used to explain the research conditions to all participants prior to focus group and individual interviews sessions. The focus group interview guide (Attachment 2A for female participants and 2B for male participants) and the individual interview questionnaire (Appendix 2C for female participants and 2D for male participants) were designed to include several open-ended semi-structured questions that correspond to research questions of this study. Open-ended questions were intended for stimulating and facilitating participants' spontaneity and expansiveness in thinking and responding. If necessary, "probes" (Patton, 2002) or follow-up questions were used to clarify responses and increase richness of responses. While probes were not considered as part of the interview "script", they were readily available for the interviewers as a reminder.

Prior to conducting the interview, each participant was asked to complete a Participant Demographic Data Form (Appendix 3) which contained questions on basic demographic information such as age, gender, country of origin, marital status, income, education, social, family, and health data for statistical and analytical purposes. The introductory briefing script was then read to all the participants. Individual interviews and focus group sessions were conducted in the participants' native dialect. An individual interview lasted for an hour, and each focus group session took approximately two hours. All interviews were audio-taped and later transcribed into English. Incentives including a bakery

exchange coupon and a one-day metrocard were given to each participant at the conclusion of the individual interview or focus group session. The reason for providing incentives is to encourage participation, because focus groups and interviews are often more important to the researcher than they are to the participants (Morgan, 1995).

In 2001, in collaboration with a team of cancer service consultants, health care professionals, and health educators, I conducted a needs assessment study on education activities and services on breast and prostate cancer. Focus group sessions were held with patients, and individual interviews were conducted with health care providers. The 2001 pilot study was instrumental in formulating research ideas for this study. It also allowed me to be more conversant with the scope of the topic and research questions of this study and be familiar with the interview guide. Based on the results of focus group interviews and recommendations from the team of consultants, I revised the interview guide and used the revised version as the skeleton of the focus group interview guide and the individual interview questionnaire for this study. Since the pilot study served as a field test for the interview guide and the questionnaire, there was no need to conduct a pilot study.

Ethical Issues – Plan for Protection of Human Subjects

During the process of data collection and data analysis, the researcher must be mindful of ethical issues and make every effort to protect human subjects. Beauchamp & Childress (1994) describe four moral principles within the framework of biomedical ethics that guide our ethical choices in conducting

research. These principles are: respecting the ability of an autonomous individual to make an informed decision based on the information provided; avoiding harm or risk to those being studied; providing benefits and balancing benefits against potential harm and costs for each individual research participant; and distributing benefits, risks, and costs fairly. In adherence to these principles, I discussed with participants and the Agency any potential risks and benefits of the study. If a potential risk was identified, I took all necessary measures to prevent and minimize the risk. A handout was developed and given to each participant informing them of any relevant information and resources regarding breast, cervical, or prostate cancer education, screening services and mental health support available to them. Talking about cancer and cancer screening experiences could be sensitive and emotional stressful for some participants. Therefore, all participants were told that follow-up or debriefing sessions could be arranged for them if they experienced emotional distress subsequent to participating in a group session or an individual interview. Staff members of the Mental Health Team, the Comprehensive Breast and Cervical Cancer Education and Screening Program, Prostate Cancer Screening Initiative, and the Social Work Department of the Agency are well versed with providing mental health support, social services, and cancer support services for Agency patients. I met with administrators of these units and asked them to be readily available to assist and support any participants of this study if necessary. Such arrangement was stated on the letter of support from the Agency.

Sieber (1992) names privacy, confidentiality, and anonymity as the key ethical principles in research practice. Privacy refers to the participant's "degree of control of the access that others have to them, and to the information about them" (p.45), as well as their need to establish personal boundary against giving sensitive information or receiving unwanted information. Privacy affects their willingness to participate in research and to give honest response. An individual's right to privacy in research is protected by his right to refuse to participate. To protect the privacy of the participants, interviews were conducted in an interview room or conference room of the Agency. There are additional concerns of privacy in focus groups because participants are revealing themselves to each other (Smith, 1995). There is a danger of over-disclosure of personal information by participants due to the synergistic effect of group discussion, especially when the research topic is sensitive or emotionally stressful (Morgan, 1998). To safeguard the privacy of all participants in this study, participants were told that anything discussed during focus group sessions should not be shared with outside individuals. They were also asked not to use real names so that people's identities were protected. Although their participation in discussion was strongly encouraged, their right to remain silent during group discussion or to withdraw from the study at any time was respected. In this study, most of the participants actively participated in group discussion and none withdrew from the study.

Confidentiality refers to the agreement with participants and the Agency on what will be done with the data and may include legal constraint (Sieber,

1992). Participants are more willing to share highly personal information if they are assured confidentiality of data they provided. I took all necessary measures to ensure confidentiality of data collected in the study. Only the interviewers and the staff involved in participant recruitment had access to any contact information on recruited participants. As soon as the transcript was completed, all tapes and recordings were kept in a locked file cabinet for three years to which only the researcher has access. After that, all tapes and recordings will be carefully discarded. During focus group and individual interviews, participants were identified only by their last name or pseudonyms. Names of participants and any other identifying information were either removed or modified in the transcripts to insure confidentiality of participants.

Before an individual or focus group interview started, each participant reviewed and signed a written consent form (Appendix 4A) which stated: (a) the central purpose of the study, (b) that participation is strictly voluntary, (c) that participants have the right to withdraw from the study at any time, (d) that information provided by participants will be strictly confidential, (e) that participant's refusal to participate will not jeopardize the services they currently receive at the Agency, (f) any possible sources of risks or harms associated with the participation in the study, and the expected benefits to the community and to services of the Agency, and (g) a referral source to whom they can turn to in case of problems. Each participant also reviewed and signed an audio tape recording release consent form (Appendix 4B). The form stated: (a) the purpose of audio tape recording of the interview, (b) that any name or other identifying

information will be either removed or modified in the transcript to insure confidentiality, and (c) that information provided by participants will be kept confidential.

When conducting research with ethnic minorities, additional steps have to be taken to ensure that culture, language, and communication do not pose barriers between the researcher and the participants (Sieber, 1992). To enhance the quality of translation, recruitment flyers, focus group interview guide, individual interview questionnaire, and consent documents were translated into Chinese and then reviewed and edited by the researcher. The consent statements were developed in the language compatible with the age and reading level of research participants. Participants' perception of risks and benefits of participating in the study was noted.

From the Agency's perspective, they were concerned about (1) maintaining confidentiality of patient data, (2) the study causing minimal or no interruption to the delivery of clinical services, (3) participants being treated respectfully, and (4) participants' involvement in the study did not jeopardize the services they received from the Agency. Every effort was made to comply with the Agency's policies in reciprocation for its approval and generous support of the study. The Agency was informed of the goal and objectives of the research, its potential benefits to services of the Agency and its patient population, risks or inconveniencies the study might cause, and an action plan to minimize these risks or inconveniencies should they occur.

Data Analysis Procedures

Technical procedures based on the grounded theory approach were used to conduct data analysis for this study (Corbin & Strauss, 1990; Strauss & Corbin, 1998). The analytical process is based on immersion in the data, repeated codings, sortings, and comparisons of data. In essence, the analytical process is iterative in nature. Data analysis began shortly after initial data were collected. Initial data analysis shed new lights on the study phenomenon. Additional research questions and probes were then generated and taken out to the interviews in the next phase of data collection (Miles & Huberman, 1994). Open coding was used to scrutinize interview data that were made up of words, phrases, and sentences (Strauss & Corbin, 1990). The purpose of open coding is to fracture the data so as "to identify some categories, their properties, and dimensional locations" (p. 97). After the interview text was coded and classified, a comprehensive list of 291 codes were generated. The language of the participants also guided the development of code and category labels, which were identified as short descriptors, also known as *in vivo* codes. A category is defined as a unit of information composed of "events, happenings, objects, actions/interactions that are found to be conceptually similar in nature or related to meaning" (p. 102). Within each category, I looked for properties, or subcategories, and data to "dimensionalize" or indicate the location of a property along a continuum. Codes and categories were systematically sorted, compared, and contrasted until they were "saturated" (Strauss, 1987), or until no new codes or categories were produced and all data were accounted for.

The next step of data analysis was axial coding, which was putting data "back together in new ways by *making connections between a category and its subcategories*" (italics in original, Strauss & Corbin, 1990, p. 97). This was done by presenting a logic framework in which a central phenomenon was identified. Then categories of conditions that affected the phenomenon was explored, factors and actions that resulted from the central phenomenon were specified, the broader context and the range of intervening conditions were defined, and the consequences for the phenomenon were delineated (Strauss & Corbin, 1994). In this study, *access to cancer education and screening services among Chinese immigrant men and women* as the central phenomenon was identified. During data analysis, I attempted to present a logical framework for describing this phenomenon and all related themes. I reviewed transcript data, codes, categories, and quotations and made connections between categories, quotations, and the themes related to the central phenomenon. I identified categories of conditions and factors such as knowledge, attitudes, and socioeconomic status that affected the participants' access to cancer education and screening services. I also analyzed the experiences, actions and consequences for having poor access to cancer education and screening services among Chinese immigrants. Finally, I tried to understand how the broader context, such as cultural belief systems and health care delivery systems, influenced the access to cancer education and screening services.

In selective coding, I identified a "story line" and wrote a "story" that integrated the categories in the axial coding framework (Strauss & Corbin, 1990),

which is an "integrative process of selecting the core category, systematically relating it to other categories, (and) validating those relationships and filling in categories that need further refinement and development" (p. 116). Core category is defined in terms of its centrality in relation to other categories, frequency of its appearance in the data, its clarity and inclusiveness, and its theoretical power for a more general theory (Strauss, 1987).

Writing memos is an important step in data analysis and interpretation. This process enriches the analysis process by moving empirical data to a conceptual level, expanding and further refining the data corpus and codes, developing core categories and showing their relationships, and building toward a more integrated understanding of experiences, interactions, and processes (Strauss & Corbin, 1990; Creswell, 1998). I wrote both "analytical memos" consisting of questions, understandings, and insights on the data and emerging concepts, as well as "self-reflective memos", which is my personal reflection on the individual interviews, focus group discussion and group dynamics, and my own reactions toward the participants' narratives (Miles & Huberman, 1994). I wrote notes during data collection and wrote memos throughout data analysis until the end of the study. To maximize its utility, I organized the memos in a systematic manner with the assistance of ATLAS.ti so that they could be retrieved easily for further examination.

According to Miles & Huberman (1994), the researcher's own theoretical orientations, his familiarity with existing literature, and the characteristics of the study phenomenon all affect what concepts and themes are more likely to be

found. However, in developing a conceptual model, I followed the grounded theory approach to the best of my ability to generate categories, concepts, and themes directly from the data and evidence extracted from interview narratives. Themes are then integrated into clusters in order to explain the data in a conceptually coherent manner. It is important that concepts and themes are "sensitizing" and providing a "meaningful" picture by pulling together real examples from the narratives that enable the reader to hear vividly what the participants say in the study (Strauss & Corbin, 1990). I used direct quotes from participants which allowed the readers to understand how various themes and concepts were illustrated in the interviews (Ryan & Bernard, 2000). I used both coding and case study approaches in organizing the data analysis (Royse et al. 2001). The coding approach involves generating codes, categories, and themes across cases from the data and uses these to guide additional analysis. Such coding analyses sweep back and forth across cases to generate common themes and overarching narratives. I also used case studies approach which yielded rich description of individual cases rather than fracturing texts to extract meaning across cases. This approach generated an in-depth portrayal of individuals and their unique experiences. All the procedures described above were intended to make the emerging concepts and themes denser, more complex, and more precise as these concepts and themes were examined constantly and systematically with the data (Strauss & Corbin, 1994).

Use of Data-analytical Software

Because one-to-one interviews and focus group sessions generate a large volume of textual data, computer software programs will help in the analysis of qualitative data in coding, text retrieval, memoing, database management, and a variety of other analysis functions (Zyzanski et al., 1992). ATLAS.ti, a qualitative analytical software program, was used in this study to assist in data analysis. The development of this software program was stimulated by the ideas, terminology, and methodological process associated with grounded theory (Corbin & Strauss, 1990; Strauss & Corbin, 1998). ATLAS.ti is a powerful workbench for qualitative analysis of large volumes of textual data. It offers a variety of tools to explore, manage, retrieve, compare, and resemble pieces from large amounts of data in creative, flexible, and systematic ways (Muhr, 2004). Basic data analysis functions performed by ATLAS.ti include: viewing and comparing text documents, coding and retrieving text passages within documents under certain codes and categories, memoing, sorting of memos and codes into “families’, and exploring and developing concepts via the construction of conceptual frameworks and networks.

I began open coding with the software by first selecting a text message and then ascribing a newly generated code. For axial coding, I connected categories with its subcategories and assigned one or more listed codes to text passages within documents. I continued axial and selective coding by relating existing and newly created codes with the help of a network editor of the software program. One important feature underlying ATLAS.ti is the

“hermeneutic unit”. Everything that is of relevance to one study project is treated as one entity. For example, the transcripts (raw interview data) as well as segmenting of texts, codes, quotations, the developing concepts, the linkages between concepts, the networks formed by the various linked concepts, and the memos attached to texts are all parts of one hermeneutic unit. The immediate advantage is to open the entire study document as one entity. The activation of a hermeneutic unit is simply opening a single file and all associated materials are then activated automatically.

In addition to assisting the researcher in managing large amounts of qualitative data, ATLAS.ti has the capacity of managing annotations, themes, and analytical materials including conceptual relationships that emerge during the process of interpretation. Coding and memoing cover all essential activities aimed directly at the textual level: fracturing text and assembling data files, assigning codes to text, and making comments about text. This software enabled me to accomplish all of these tasks while providing a comprehensive overview of my work in rapid search, retrieval, and browsing functions. Corbin & Strauss (1990) point out that “concepts are the basic units of analysis”. This is where the conceptual level becomes significant as characterized by a shift of the analytical focus from the textual transcript data to the developed concept.

To transition from the textual to the conceptual level, I did the following: After creating a number of codes and attaching them to a number of quotations, I grouped and classified these codes in a systematic and logical manner. This was done with the aid of the software program by grouping codes into “code

families" or "networking" (Muhr, 1991). In this study, many code families were used as attributes for codes. I created a code family that included all the codes that I planned to elaborate or refine later. This grouping of codes reduced the overall complexity emerged in the course of analysis. The main purpose of code families and networks is to systematically visualize, refine and discover the underlying analytical structures suggested in the course of analysis, thus encouraging an exploratory approach to concept development and theory construction. From this, I then constructed concepts and theories based on relationships between codes, quotations, text materials, and memos. This process also allowed me to uncover other relations in the data that were not so obvious before, and I subsequently reverted to data files and primary documents. For example, the aging process appeared to be an emerging theme during the initial stage of data analysis and a key factor that affected cancer screening attitudes and behavior among Chinese immigrants. After I reverted to data files and reviewed interview transcripts, I discovered that the emergence of more physical symptoms and signs of failing health prompted many elderly participants to be mindful of their health and to go for check up and cancer screening.

Computer software programs are helpful tools in performing a variety of unique analysis functions. However, the use of software for qualitative data analysis is not without shortcomings. Kidd & Parshall (2000) point out that certain requirements of the software, such as formatting transcripts and using certain analytical tasks routinely, may distort the underlying context and meanings of the text, thus removing us from engaging and analyzing the data

reflectively. Weitzman (2000) warns that software programs may impose a methodological or conceptual approach which causes us to adapt our research to the software we use rather than the other way around. As a result, we may not change the coding scheme and categories, or organize the information under different categories because we assume that data are fixed or well set by the software program. To avoid losing important data this way, Richards & Richards (1994) suggest that we remain open and flexible in adapting the "powerful" features in data analysis rather than forcing a software program feature that is not appropriate for a particular analytical task. Muhr (2004), the author of the ATLAS.ti, is aware of these potential shortcomings and states that the intent of the design of the software program is not to make the process of text analysis mechanical or rigid, but rather to provide a tool that effectively supports the researcher in the handling of complex qualitative data. The program's author (Muhr, 1991) asserts that "an automatic interpretation of text cannot succeed in grasping the complexity, lack of explicitness, and contextuality of everyday knowledge" (p.350). In other words, the software program cannot perform miracle for research and we still have to have "the ideas and the gifts to do exceptional research" (Muhr, 2004, p. 2).

Issues of Reliability, Validity, and Credibility

Reliability is defined as the extent to which the "measurement procedure yields the same answer however and whenever it is carried out" (Kirk & Miller, 1986, p. 19). In conducting qualitative inquiry, Holstein & Gubrium (1997) contend that we cannot simply expect answers on one instance to replicate

another because they emerge from different circumstances. Reliability in quantitative research is based on the assumption that replication of testing procedure is possible, and that "there is an observable regularity about human experiences that is a function of those experiences and not of the testing procedure" (Sandelowski, 1986, p. 33). However, qualitative study emphasizes the uniqueness of human experience. The "truth value" of qualitative study is to discover the richness and diversity of human experiences as they are lived and perceived by the participants (Wolcott, 1995).

Validity is defined as the extent to which the measurement instrument gives the "correct" answers (Kirk & Miller, 1986), or whether a researcher has measured what the study intends to measure (Wolcott, 1995). The emphasis is on how we rule out plausible alternatives to our interpretations and explanations (Maxwell, 1996). Qualitative study emphasizes the "trustworthiness" of the findings. Angen (2000) uses the term "validation" rather than "validity" to emphasize the continuous process in which the trustworthiness of the study can be determined.

There were several threats to validity in this qualitative study. One main threat to valid description of what the researcher saw and heard was the inaccuracy or incompleteness of data (Maxwell, 1996). Another threat was imposing the researcher's own framework or theory in data interpretation rather than understanding and presenting the perspectives of the participants and the meanings and experiences they described. Over-relying on "elite informants" who are frequently more articulate and more accessible is another concern

(Miles & Huberman, 1994). Since the participants in this study were self identified, they were more connected to the Agency and the community and were more willing and able to share their experiences. Therefore, there is a chance that the validity of findings may be threatened by overweighing these experiences as representing the perspectives of the population (Sandelowski, 1986). Findings based on a small number of "elite informants" may not accurately reflect the experiences of newly arrived immigrants who remain unaware of the services or have cultural or social barriers to and limited understanding of how to access to services. "Holistic bias" is another threat to validity if data are made to look more congruent than they actually are, and when the study conclusions are presented as representing all the data but are actually not (Miles & Huberman, 1994).

The following steps were taken in data collection and analysis to improve reliability and validity of the study. To ensure accuracy and completeness of interview data, special attention was given to the technical quality of the audio recording equipment. All individual and focus group interviews were transcribed by experienced bilingual health educators. Carey & Smith (1994) warn against overdependence on transcribing the verbatim data without incorporating the non-verbal, sequential nature of group interaction or capturing the group effects that are embedded in the data. In order to capture non-verbal data, a co-facilitator was assigned to focus group sessions to record the interviews and take notes on group interaction and group dynamics. All group interaction, group dynamics, and agreements and disagreements among group members that shaped the

nature and content of their responses were coded and analyzed. To capture the essence and richness of data and to increase the validity of interpretations, I met with study team members immediately following each focus group session to solicit their feedback. I also checked for the representativeness of data as well as categories and quotations used to present the data. I checked to see whether descriptions, explanations, or theory on the data were both accurate and complete. Finally, I kept an audit trail (Royse et al. 2001), i.e. a thorough documentation of the steps I took and the decisions I made during data analyses. In this study, ATLAS.ti was used to perform many data analysis functions such as comparing text documents, coding, memoing, sorting of codes into “families”, exploring and developing concepts, as well as managing themes and analytical materials that emerged during the process of interpretation. Therefore, the software program enabled me to systematically document how the data were coded and analyzed and how bias was addressed each step of the process.

Qualitative research is often criticized as lacking rigor, being subjective rather than objective, producing “soft” data, and lacking generalizability of findings beyond the individuals and circumstances of the study (Perakyla, 1997). However, the “soft” information based on a small sample of participants purposefully and theoretically selected has the potential to describe the phenomenon in all of its complexity and ambiguity with special attention to the context, processes, meaning of events, and uniqueness of experiences of the participants (Zyzanski et al. 1992). Therefore, the “generalizability” of qualitative

study is judged by the development of a theory that can be extended to other cases (Maxwell, 1996). Charmaz (2000) affirms the rigor of the grounded theory approach because it provides a set of clear guidelines for the researchers to collect and analyze data systematically and enables the research process to capture all relevant aspects of the study phenomenon (Corbin & Strauss, 1990).

Nyamathi & Shuler (1990) state that qualitative research is more appropriately assessed by credibility that is enhanced when it is true to life descriptions or interpretations of human experience and may be recognized by those who have such experiences or by those who recognize such experiences after having read about them. A potential threat to the credibility of qualitative study lies in the close relationship between the researcher and the participants (Sandelowski, 1986). To enhance the credibility of this study, detailed responses were solicited from participants in order to yield a more-in-depth analysis (Nyamathi & Shuler, 1990). Probes including elaboration probes, clarification probes, and contrast probes as well as detailed oriented questions were used in the interviews and focus groups to deepen responses to a question, to increase the richness of the data being obtained, and to give cues to respondents on the level of response that is desired. I also obtained immediate feedback on the summary of response from participants at the end of the interviews. In addition, I wrote self-reflective and analytical memos to help identify my own feelings and reactions that may affect my interpretation of the data.

Project Timeline and its Limitations

The project proposal was reviewed and approved by the Dissertation Committee in February 2003. A written approval from the Agency was obtained to conduct the study. The research protocol, research instruments, and informed consent documents were submitted to the Hunter College Institutional Review Board for approval in June 2003. IRB approval was obtained from Hunter College In October 2003. I announced the commencement of the study at the Agency in November 2003 and met with administrators of clinical services to ask for assistance in referring potential participants. The clinical staff of the Agency agreed to make themselves available to assist and support any participants of this study if necessary. The research study team was formed in November 2003 and two training sessions were held for the team members who conducted the interviews and served as research assistants. The study team met and planned on how to distribute recruitment flyers and recruit and register potential participants. Four focus groups were held in January and February 2004. Focus group interviews were taped recorded and transcribed into English text. Debriefing with the study team members were conducted right after each group session to solicit the facilitators' feedback and reactions to the group discussion so as to increase the validity of interpretations. In April 2004, I held another study meeting to discuss the following phase of data collection of recruiting participants for in-depth individual interviews. Fourteen individual interviews were completed before the end of September 2004. All interviews were taped recorded and transcribed into English text. Data analysis began shortly after the

initial data collection phase was completed. I learned the basic functions of ATLAS.ti in spring 2005 and then used the software program to assist in coding, creating quotations, text retrieval, memoing, database management and perform a variety of other analysis functions.

There were a few unforeseeable problems that complicated the process of this study, language being one of them. Translation of study instruments is more complex than mere translation of words. The meaning or semantics of the translation should be comprehensible (Esposito, 2001). Appropriate vocabulary and syntax should be used to make the translation readable and understandable to the participants. Berkanovic (1980) finds that although the meaning is technically the same, differences in the idiomatic quality between Spanish and English versions of interview instruments appear to negatively affect how serious research participants perceive the interview, which result in discrepancies in observed response. All materials of this study were translated into Chinese by the staff members of the Agency who are fully bilingual and have a great deal of medical knowledge and translation skills. They are very experienced in translating research instruments and consent documents for other health and research institutions. Due to limited resources and time constraint, back translation of study materials from Chinese to English was not done. However, as a measure of quality assurance, I edited and proof-read the Chinese translated documents to ensure that the level of language usage is equivalent to the English version both in vocabulary and syntax. Both the Chinese and

English versions of study materials were also reviewed by the research study team members to ensure accuracy in translation.

Not all concepts are universal, therefore not everything is translatable (Jones & Kay, 1992). Kagawa-Singer (2000) notices that many concepts in cancer research in the U.S. may not be conceptually equivalent in other cultural groups. Studies comparing concepts such as suffering, self-concept, social support, family dynamics and expectations, quality of life, and coping styles reveal that these concepts may mean differently in different cultural groups (Kagawa-Singer, 2000). Overlooking these cultural and linguistic differences may adversely affect the quality of data (Twinn, 1998). Therefore, symmetrical translation of cultural symbols and appropriate use of language and specific terms of a study instrument for a specific culture are important in creating a "sharedness of meanings" in which both the interviewer and the participants understand the contextual meaning of specific terms or concepts (Fontana & Frey, 2000). Pilot testing the translated instrument with the target participants serves as a check for both the quality of translation and the practical purpose of administering the instrument. As stated before, the interview guide and questionnaire of this study were field tested in 2001 in a similar project at the Agency.

Individual and focus group interviews were conducted in two major Chinese dialects, Cantonese and Mandarin. It is a challenge to transcribe the sessions in an English script that is clear, accurate, and true to the colloquial of the source language (Esposito, 2001). One of the challenges relates to the

translation of Chinese words for which there is no true equivalence in English. The problem of finding appropriate English words to capture the meaning of Chinese data was a continuing challenge throughout the translation of the data, especially when very colloquial Cantonese was used. In qualitative research, data analysis and interpretation rely heavily on the semantics and exact word usage (Twinn, 1998). Issues in translation raise questions on the extent to which translated data accurately reflect the meanings, feelings, and experiences of the participants. The other challenge is that while there are many spoken dialects, there is only one written Chinese language. The difference in grammatical style and structure across languages as well as across different Chinese dialects may affect the quality of data. Difficulties also arise in translating data when there is little similarity in the grammatical structure of different languages and dialects. This is especially true with the Chinese language whereby tenses and personal pronouns are not used, making it more difficult to make sense of data. Due to limited resources and time constraint, study team members who are proficient in both written Chinese and English languages and are proficient in medical knowledge and translation skills were hired to transcribe the interviews directly into English texts. I then checked for the accuracy and quality of the English transcription by comparing it to the original interview tape. Key findings and quotations of transcribed data were further reviewed and evaluated by an independent certified medical translator to ensure the quality and accuracy of translation.

Finally, the style in responding to questions among Chinese participants could present problems in data interpretation, because often time responses are worded negatively although the participant may agree with the question (Twinn, 1998). On the other hand, some Chinese participants may give socially desirable responses that do not reflect their true response to the question. Therefore, it is important to keep in mind that participants sometimes respond to questions by using familiar "narrative constructs" rather than by revealing their subjective experiences or perspectives. As a result, what they share is something that has been filtered by their language and multi-cultural understanding (Miller & Glassner, 1997). Last but not the least, there could be an issue of trust between the researcher and participants due to social distance and differences in socioeconomic status and literacy skills. Lack of rapport may cause participants not to ask for clarifications even when they do not understand the questions, or to purposely mislead the researcher in their responses. Therefore, I and other study team members spent time prior to the interviews to establish trust and rapport with participants. We also made a conscious effort to be sensitive to the subtle differences and discrepancies in responses throughout the data collection, analysis, and interpretation processes.

CHAPTER FIVE

HEALTH AND DISEASE PREVENTION IN CHINESE CULTURE

Introduction

Each cultural group is unique and different in defining health and well-being, perceiving the causes of diseases and death (Spector, 2002), and using appropriate preventive health measures and treatment approaches to ensure the survival and well-being of its members (Kagawa-Singer, 1996). Cultural beliefs and values not only influence our general behaviors, but also determine our health-seeking behaviors. What we do to promote health is very much a function of our cultural beliefs and values. Understanding the notion of health and preventive care in the Chinese culture, and the specific health beliefs and practice of the Chinese immigrant population are important in providing quality health care to this group. This chapter explores beliefs, values, and perception of Chinese immigrants on health, prevention of disease, and their ways to maintain optimal health and cope with diseases.

Holistic Views of Health and Illness

The holistic concept is an important idea in traditional Chinese culture in maintaining good health and disease prevention. Many Chinese believe that an individual's health or wellness is an integral and holistic composite of mind, body, emotions, and spirit. These holistic aspects of health are interrelated with the environment, family, and social relationships (Ma, 1999a). The meaning of health in the Chinese culture transcends a state of being free of illness or having basic health maintenance. A state of wellness is conceptualized as a

coordinated and integrated way of living, and a balance in the physical, emotional, social, and spiritual development of a person, a family, and a community (Ma, 1999a). Several participants (8) in this study shared this holistic view and defined health as being healthy in the entire body.

> The entire body or your health is very important. Each part of our body is all very important... I feel that every part of my body and every organ can be considered very important to us. For example, our eyes, ears, mouth, nose, if any of these don't feel well, it's not very good. So, health should include the well being of every organ. They are all important to me. What I was born with, all is important. To me, we can't say which part of the body is more important than the other. (I1)

> Health can mean many different things. Being healthy means every part of your body is healthy. Being sick means that you do not feel good, you are not healthy in certain parts, and you feel pain in certain parts of your body. (I8)

Chinese health beliefs and practices are greatly influenced by Taoism, which emphasizes balance and harmony between human mind, body, as well as emotions with one's nature or environment (Ino & Glicken, 1999). To them, optimal health includes both physical and psychological well-being. For instance, one participant considered mind and body as inseparable entities because they influenced each other, and that being physically and emotionally healthy was important for long life and well-being:

> I see being healthy as one - body, and psyche... Psychological state, those things are, for example, depression, not feeling well, feeling down. If you are able to chat and share with friends, it is a sign that you are emotionally healthy... If you are talking about your body being healthy, then it would also mean whether or not you can sleep regularly and cope with life, that you keep up with your mental spirit and that you have the ability to cope with stress. That's what I mean by being "healthy". (B3)

In the Chinese culture, diseases and changes in certain parts of the human body are considered in conjunction with other organs of the entire body

rather than being considered alone. All parts of the body are affected by natural phenomena as well as the social and physical environments, which may include emotions, seasonal conditions, and climatic changes (Ma, 1999a). Therefore, it is important to pay attention to the interaction of our human body with the external environment. The onset and development of diseases such as cancer are considered to be in conjunction with the social and environmental factors such as too much life stress or working too hard. For example, many Chinese immigrant women in Sun et al. (2005)'s study perceived stressful life in the U.S. as a possible cause of their breast cancer diagnosis. Many participants (11) in this study believed that being healthy means being symptom free, the ability to lead a normal life and cope with stress, and function well in every aspect of life:

> A normal life is crucial for health. A normal life that has no stress, no worry or troubles can be considered a healthy one. People grow old easily when they are under too much stress and worry a lot. (I5)

> I think my own health is "so-so" or relatively poor. In terms of my health, if I work for about 8 hours, my hands are numbed and my legs are numbed…My mind gets really tired. Every day I work and go home feeling very tired, therefore I don't think I'm healthy...Well, if one is healthy, one will be able to cope with work stress, regardless of the level of stress…If you're healthy, you can handle it. But if you're not healthy, then you won't be able to. (B2)

> If you are talking about physical health, it means you can sleep normally and cope with life, that you keep your mental spirit and that you have the ability to cope with stress. That's what I mean by being "healthy". (B3)

Collectivist values in Confucianism emphasize that common good or pursuits and needs of the family and the community takes precedence over the pursuits and needs of the individual (Pasick et al. 1996). Many participants considered health as of paramount importance because being sick negatively affected their financial situation and their family. Two participants in this study

commented that their children's needs and future were more important than their own, and that achieving own optimal health was necessary in order for them to take care of their family:

> Health is certainly very important. Health is people's life...I think that my child's needs are more important than mine, because what I've done are all for my child. I tried to stay healthy for the sake of my child. I can't take care of my child if I'm sick, especially we women who spend more time raise children... We can only look after our family and our children if we're healthy. If we are sick, we can't take care of our children... I made an appointment (to receive cancer screening) because I need to stay healthy for my family. (I5)

> Health is very important. My children and grandchildren are living a very good life now. But if I can lead a healthy and happy life, they won't have to worry about me. This is extremely important. (I12)

While participants agreed that leading a stress-free life was important, they also considered life stress as inevitable for first generation immigrants who often live under pressure at work and in every day life.

> Diseases that used to attack the elderly in the past are now beginning to affect middle age persons too. I think it's because we work too hard and we have too much life stress and psychological stress. All these factors are interrelated and are contributing to poor health. (I6)

> Of course, there is a relationship among all aspects of health…I don't know about the others here, but I feel that after I immigrated to the U.S., I have been very unhappy and feel stressed all the time. The feeling of pressure hangs over my head all the time! Even when you are making a lot of money, you are still not happy. If you are under stress all the time, it is hard for you to remain healthy. Stress will eventually make you sick. Sometimes, I told myself not to worry and learn to relax. However, I still feel stressed living in the U.S… I have a language barrier. Maybe because I haven't lived in this country for a long time, I also feel that this is not my home, my country. (Many participants in the focus group agreed) (C1)

> Living in this country is very stressful. I came to America when I was younger. At that time, I was under a lot of pressure and often felt stressed out, but I am adjusting better now. Every elderly should maintain good health so that they may enjoy life. "Health is wealth". (A7)

Health Benefits of Exercising

Based on the holistic concept, many Chinese in this group accepted some forms of health measures such as eating properly, exercising, taking herbal supplements, and other "complementary" medicine measures in order to strengthen the body, resist disease, and improve health and physical well-being. Exercising was one of the widely accepted means to maintain health in the Chinese culture. For instance, two participants indicated that they exercised regularly to stay healthy and prevent illness:

> Basically I think exercising is very important. Exercising can affect us in many ways such as keeping us healthy. Exercising can help prevent many diseases… Exercise can strengthen your body muscle and sharpen your mind. I keep walking and running to keep my body fit. (I14)

> I share the same perspective on the benefit of exercising. Both Western and Chinese medicine believe that exercising is fundamental to health and can strengthen our body. Everyone should exercise from a young age. If the foundation of your body is good, not only can you prevent cancer, you can also prevent other diseases. (D8)

Although participants shared the same belief as Americans in the health benefits of exercising, the ideal exercises for these Chinese immigrants, especially elderly, were ones that could be done on a daily basis, such as stretching and walking, rather than going to a gym and exercising strenuously. These findings were consistent with another study (Chen, 1996) that many Chinese elders believed that it was important to do things based on actual abilities, and that overdoing and underdoing were not considered good for health. When exercising, Chinese elderly preferred gentle types of traditional Chinese movements rather than rigorous exercise such as *Tai ji*.

> Exercising is not just a chore. It really helps relax my body. Those who exercise can feel the difference from the ones who do not exercise regularly. Some may go to the gym and exercise very strenuously but I don't like that. I would rather do it in a relaxed way, exercising gently but yet enough to make me sweat if I wear layers of clothing. That's what I prefer. (I14)

> Not only do I take my medications, I also do other things to stay healthy. I walk about 1-2 hours every day. I live in Brooklyn. I walk about five avenues or 20 blocks…I try not to ride the subway or take a bus, but I walk several avenues, 20 blocks or more every day. This is good for my body and my health. I do not know for sure but I feel that exercising has positive effects on my prostate problem. (D5)

> I will exercise to keep me healthy. I exercise at home. I do not have time to exercise in the park because I have to work... I do stretching both in the morning and before bedtime. If I remember, I will do it 3-4 days a week, about ten or more minutes of stretching. (I6)

Living a Balanced Life

Chen (1996) noted that Chinese American elderly perceived health promotion and disease prevention as "conformity with nature. According to Chen (1996), lifestyle choices of Chinese elderly are based on 3 major principles: harmonizing with the environment, following bliss, and listening to heaven. These beliefs enable the elderly to adjust their daily lives to conform with nature to achieve harmony with the environment, center on family and society, and accept their fate to achieve ultimate well-being. For Chinese elderly, conformity with nature is viewed not as being aggressive or ambitious, but as doing one's best and going with the flow. Once the effort is made, they will accept the outcome peacefully (Chen, 1996). The findings of this study were consistent with the beliefs and views found in Chen (1996)'s study. In addition to walking, stretching, or mild exercising, several participants in this study also emphasized outdoor activities and maintaining a regular routine as ways to maintain good

health. Chinese elderly regarded a full but relaxed daily schedule and an active lifestyle as important ways to achieve life satisfaction and health. Have a routine or a regulated lifestyle that follows natural rhythms, exercising, eating balanced food, enjoying hobbies, and staying active are ways of living a healthy and productive life for the elderly:

> I go to many places everyday and help people translate when they apply for government benefits. I think this routine is good for me because I need to walk a lot. Even though I take the subway or a car, I still need to walk a lot in order to reach my destination…Walking is a good exercise for me and I insist on doing this everyday. Also when I have time, I will practice 18 steps or other fitness movements that I design for myself. I exercise everyday and maintain a regular routine by going to bed early and getting up early. (I4)

> Walk slowly. I usually walk for 45 minutes in the morning after I wake up at 8am or 9am. Then I go back home and drink a cup of coffee or tea and that's it. I will walk to City Hall, then sit and rest at a park nearby, and then I walk back home to drink a cup of coffee or tea. (I13)

> Elderly people should maintain regular activities including eating properly and sleeping well to remain healthy. Time is running out. For the elderly over 60, it is important that they eat, drink and sleep well and they get regular check up. If they don't have cancer, that will be great. (A7)

Tai Ji and *Qi Gong* – Chinese Traditional Exercises

The emphasis of Chinese on moderate outdoor exercise, such as walking, stretching, doing *tai ji,* and exercising in the early morning reflect the concept of harmonizing with the environment (Chen, 1996). Several participants mentioned practicing *tai ji* to maintain health. *Tai ji* is a form of traditional Chinese exercise popularly practiced in the Chinese community. Many Chinese of all ages, especially the elderly, practice this slow, graceful, and relaxing physical activity every day. *Tai ji* emphasizes relaxation, concentration on different parts of the body, and harmony of both mind and body. Those who practice *tai ji* persistently

benefit from it because it is believed to promote free circulation of blood, nourishes all body parts, as well as promotes metabolic activities (Ma, 1999a). For instance, two participants practiced *tai ji* regularly and believed that it helped improve their health:

> I came to the U.S. only for a short period of time but my observation is that Americans don't exercise regularly. That is no good. I have been doing *tai ji* for 25 years. Now my only health concern is my prostate problem. Every elderly should do what they can in remaining physically active. (A6)

> Engaging in physical activity may not directly benefit our prostate condition. For other health problems such as asthma and hypertension, physical activity is important and we have to exercise more. I have been engaging in physical activity and exercising such as practicing *tai ji*, and walking. Regular physical activity keeps us healthy. (I3)

A Chinese elderly participant shared his own experience on how he engaged in many forms of physical exercises including walking, *kung fu*, and *judo* in order to help control his prostate problems. He had been engaging in different forms of sports and exercise for more than twenty years. As a result, he became healthier and the symptoms of his prostate problem had improved:

> First, I walk ten thousand steps every day for at least 2 hours…The simplest way of exercising is walking. One time I walked from Flushing to Chinatown and I met two individuals who became my walking partners. They stopped later and I did not find anyone else as partners. It took 3 and a half hours to walk to Chinatown, through the bridge at 60th Street, then down along 2nd Ave…People can easily walk for two hours. Most people can do that, just as they can go shopping for 2 hours with their spouse. It really depends on your attitude and your motivation…
>
> Then, I had a friend who also had the same surname as mine. He asked me to exercise with him. He asked me to follow him to learn "*kung fu*". In the 50s, it was called "Wong Man Choi" (a type of kung fu). I asked him whether it's good for health and he said yes. Ever since I learned "*kung fu*", I began to feel the benefits of it. Yes, I felt tired especially when I practiced after work. After my friend died, I continued to practice *kung fu* by myself. I still have to see the doctor. But I felt that my condition was better when I compared to my condition in the past…

> Then I learned "*judo*", a form of Japanese wrestling, and I felt even better because I had to exercise my entire body. Practicing *judo* brought a lot of positive changes to my health…I taught other church fellows *judo* so that they can improve their health…I practiced *judo* till I received a black belt in Toyko…yes, many years, more than 10 years. Even now I go to my Japanese friends and practice *judo* with them. (I14)

This participant then talked about learning *qi gong* to improve his health. *Qi* in Chinese is defined as a vital energy or vital breath circulating in the human body (Chen, 1996). To live is to have *qi* in every part of one's body. To die is to be a body without *qi*. To maintain health, there must be a balance of *qi*, neither too little nor too much. The Chinese believe that *qi* as a whole nourishes one's heart and lungs, promotes the circulation of blood and vessels, and enhances respiration (Ma, 1999a). The circulation of *qi* and blood strengthens the internal and external organs of our body. For instance, one participant believed that *qi* must be allowed to flow freely and smoothly through the whole body to maintain good health. He commented that illness or pain emerged when the flow of life energy was interrupted, blocked or became deficient:

> In China, I learned *qi gong* from a popular master. The first thing he taught me was that no one should practice *qi gong* for an extended period of time each day. There was a Chinese saying that "if the *qi* can't get through, you will feel the pain". The *qi* will circulate in your body until it reaches your finger tips. If the *qi* gets stuck, you may feel mild pain. The feeling is unique. It did not take too long for you to master it. You just have to practice many times. That's the way we learned *qi gong*. The *qi* inside your body circulates. Inside our body, there are many tiny holes that fill with *qi*. When *qi* reaches certain parts of your body and gets stuck, you will have pain in that area. Thus, I have different ailments such as my bladder because I had bladder pain. Then I had pain in my urethra because I had stones in my urinary tract… For my entire body, especially my spirit, I feel much better. I am quite persistent in practicing *qi gong*. For example, I told myself to get up at 8am to practice *qi gong* but I did not need to set my alarm clock. I just get up at 8am naturally. Learning *qi gong* is very beneficial to our health…I am satisfied with my health condition now. (I14)

Yin-Yang Balance in Chinese Diet

Many participants emphasized the need for self-care, which explained why they considered exercising regularly and healthy eating as important in their daily lives. The *yin-yang* balance principle, originating in Taoism, reflects all aspects of Chinese life including health promotion and health-seeking behaviors (Ma, 1999a). It is the most fundamental and popular aspect of the Chinese health belief system. The *yin-yang*, or hot and cold balance concept, is a frequently discussed topic among Chinese immigrants. Many Chinese believe that *yin-yang* is present in all living things throughout the universe including human beings. The Chinese diet is based on the *yin-yang* concept, wherein foods and herbs derive are based on the principles of harmony and balance (Ma, 1999a). The strong reliance to traditional health beliefs in *yin-yang* balance and indigenous knowledge of consuming a variety of food to promote health are commonly seen among traditional Chinese. Dietary structures in most Chinese families are balanced oriented and health-related. Diet was considered to be another important means to health. Many participants (12) stressed the need to maintain a proper diet, to limit the intake of fat and cholesterol, and to maintain regularity and moderation in the amount and frequency of daily meals. Two participants noted:

> For all my meals, I will control how much I eat so that I consume less fat and less protein. I will eat more vegetables. If I find out that I have high cholesterol, I will eat less meat. I need to adapt gradually and hope that by paying attention to what I eat, I will achieve better health. (I6)

> I do not overeat. In the morning I drink a cup of tea; in the afternoon a cup of coffee, and a meal at night. I only eat one full meal a day. I live

> with my wife and a son. My wife works and my son goes to school. I am alone at home during the day, so I don't eat lunch…try not to eat too much. For the past 20 years, my weight remains the same, just a few pounds more or less. (I13).

A couple of patients explained that eating less as a measure of "getting rid of toxins in our body" or "cleaning up our body". They believed that it was good in preventing diseases such as cancer.

> I read an article from a Taiwanese professor about dieting in order to get rid of toxins in our body. My wife read it too. We persistently eat brown rice, potato, fruits and vegetables in the morning. We stick to a healthy diet and my wife also does the same. (I4)

> One day a week I will try not to eat. Not even a meal, just drink water. In *qi gong*, it is called "cleaning up your body". It means fasting. It can help clean your internal organs and it's good for preventing cancer. One day a week. (I14)

In the Chinese culture, daily diets are balanced between "hot" and "cold" foods and are used as therapeutic measures either to improve health functions, to prevent or cure ailments, or to adjust to climatic changes (Ma, 1999a). Many Chinese know that certain foods had "hot" or "cold" properties and how these relate to health. They know that "hot" foods are meats, fried foods, greasy food, and spicy foods, with *yang* nature (Ashing et al. 2003). "Cold" foods are leafy vegetables and fresh fruits with *yin* nature. Balancing these two opposite forces has a direct effect on good health, while excesses of either *yin* or *yang* food may result in illness, or more specifically, damage to the stomach and spleen (Ma, 1999a). This reflects the traditional Chinese beliefs that health is a state of physical and spiritual harmony with nature (Spector, 2002) and that diseases are preventable by maintaining this balance in our food intake. Through experience and practice, the Chinese has developed a unique medicinal food system,

wherein food and medicine are combined and cooked for specific purposes, either to cure diseases or to prevent them. They adjust their foods to varying climates and season, and to certain physical changes that occurs in humans (Ma, 1999a). Therefore, choosing to eat the right kinds of food is important to keep the "hot-cold" balance in the body. This belief was illustrated by some participants:

> Not only should you be mindful of the quantity of food you take, you should also do so to the kind of food you eat, what to eat and what not to eat…I do pay attention to the kind of food I eat. Spicy food, for example, upsets my stomach. (I13)

> I avoid fried food, salty food. I would not add salt when I cook. Not very greasy and just a little oil. I am used to eating vegetables. Both the Western trained and Chinese medicine doctors said that tomato and natural food that is red in color such as red potato are very good for your prostate. (I14)

> We should pay attention to what we eat. Greasy food is bad for health and it causes a lot of problems such as coughing… I am very cautious about what I eat… Eat more vegetable and fruits... Drinking soup can enhance health. We make soup everyday, any kind. Vegetable soup, herb soup... I just don't eat food that is high in cholesterol! (I10)

While eating the right food is important, some Chinese were also realistic about what a proper diet can or cannot do in preserving health. One participant pointed out that "nature" ultimately "calls the shot" when it comes to determining life and death:

> Many elder people say you just eat what you should eat and throw away those you should not eat. Don't tell me about what you should eat, or what you should not eat?! You will die when it's your time. Many elder people say the same thing. (I8)

Regulating the Mood

In the Chinese culture, excesses of moods such as joy, anger, anxiety, obsession, sorrow, fear, and horror, as well as external factors such as chill, heat, moisture, dryness, and fire are considered to be causes of illness (Ma, 1999a). The Chinese believe that moods and desires must be moderated or even repressed in order to maintain good health. Many participants shared the belief of keeping a positive outlook and an even temper, having enough rest, developing hobbies, interacting with friends, and reducing life stress as ways to achieve optimal health:

> I think health has to do with one's temperament. Whether you can take it easy or not when you have a health related problem is a reflection of your personality. If you get crazy about too many things or overreact to even minor ailments, it will definitely impact on your well being. (I12)

> In order to be healthy, we should first try not to be too tense and take it easy. We experience a lot of stress living in the U.S. When you are working and you still worry about whether or not you will become unemployed, it will create a lot of stress for you. Too much stress leads to many medical problems. Look at that famous pop star in Hong Kong. She just passed away. I think she could have lived longer, but she had too much stress. When you have too much stress, you will have many medical problems. (A4)

> When we grow old, we need to maintain a pleasant mood and take it easy. Elderly people can get angry and agitated easily. We may argue with others easily and won't let go. For the sake of health, we need to stay calm, be patient, and try not to get angry. (A2)

> It is inevitable that we come across unhappy experience in life, but we should focus on happy things. The fact that your children have all grown up and have a good career is enough to make you happy. The only concern left is how you and your spouse could remain healthy. (A6)

Use of Traditional Chinese Medicine

Yin and *Yang* are believed to be opposite but complementary phenomena. *Yin* represents negative forces such as darkness, coldness, weakness, depression, emptiness, inside, and feminine while *yang* represents positive force such as light, warmth, energy, happiness, fullness, outside, masculine, and anything that has the property of fire (Mo, 1992). The *yin-yang* principle states that every object in the universe contains both *yin* and *yang* – two elements that are the unity of opposites such as outside and inside, sky and earth, hot and cold, growth and decline, etc. (Ma, 1999a). In traditional Chinese medicine, the characteristics of *yin* and *yang* form the foundation of physiology, pathology, prevention, diagnosis, and healing practice (Ma, 1999b). Traditional Chinese medicine believes that *yin-yang* are inseparable. Ma (1999a) studied health beliefs and practices of Chinese residing in Houston, Texas. Many participants of that study explained their emotional and physical illnesses in terms of an imbalance of *yin-yang*. They believed that good health, happiness, peace, and harmony in families and societies are associated with *yin-yang* in good balance.

Practitioners in traditional Chinese medicine use various methods to achieve yin-yang balance and harmony in body and mind (Ma, 1999a). Treatment methods include herbal medicine, acupuncture, massage, *qi gong,* and other alternative remedies. Treatment using traditional Chinese medicine focuses on the entire body rather than parts of the body or symptoms. One third of participants in this study (13) indicated that they visited both Chinese medicine

practitioners and physicians practicing Western medicine. Two participants visited Chinese medicine practitioners (such as traditional healers or herbalists) exclusively for health related issues. Twenty-three percent of participants have seen a Chinese medicine practitioner at least once during the past 12 months.

The popularity of traditional Chinese medicine is based on the assumption that herbal medicines are derived from nature and generally do not lead to adverse side effects (Ergil et al. 2002). The Chinese believe that Western medicine focuses on symptoms of diseases and is therefore more efficacious than traditional Chinese medicine in the treatment of acute diseases such as cancer and heart diseases (Ma, 1999b). But they also believe that Chinese traditional approaches are better for chronic conditions, diet restriction and nutritional care, and general health promotion and maintenance. For example, the Chinese believe that massage can stimulate the circulation of vital energy, *qi*, and blood, which in turn strengthen the immune system and build resistance to illness (Ma, 1999a). Traditional Chinese practitioner focused on the interruption or blockage of *qi*, the driving force of human life. This theory forms the basis for the diagnosis and treatment of illness, as well as for promoting health and preventing illness (Ma, 1999a). Two participants explained why they chose traditional Chinese traditional treatment, herbal supplement, or massage to treat chronic ailments:

> People do a lot of things to stay healthy. For example, I have pain all over my body – minor pain in my hands and legs which makes me very sore especially when I walk more than usual. So I go to massage therapy a lot. (I8)

> I went to China and visited doctors who practiced Chinese traditional medicine for my prostate problem. I suffer from prostate enlargement.

> Having taken western medication for a long time only relieves my symptoms in a limited way. (I14)

Integrated Treatment Approaches

The practice of traditional Chinese medicine is widespread in many parts of the world including China, Hong Kong, Taiwan, and parts of the United States (Ergil, et al. 2002). Ahn et al. (2006) surveyed more than 3,200 Chinese and Vietnamese Americans and found that the majority of them (74%) reported using some form of complementary and alternative medical therapy such as herbal medicine, acupuncture, coining, massage, and cupping. A prominent characteristic of traditional Chinese medicine clinics is that the majority of their patients had already sought Western health care while concurrently seek help from traditional Chinese doctors for the same conditions. For instance, one participant of this study sought both Western health care and traditional Chinese medicine. He believed in the benefits of combining both Chinese and Western treatment methods in order to achieve optimal health outcomes:

> I think it will be good to combine both (Western medicine and Chinese herbal medicine) for optimal results. Chinese medicine may be slower in the diagnosis of illnesses. The Western medicine uses machines and equipment to detect the causes of the illnesses… I don't have time to get physical therapy, but I sometimes use 'massage oil" for my back muscle… Also other people suggested that I take fish oil pills. I bought the pills but I never took it. I may consider taking Vitamin E in the future. I do not have the habit of taking vitamins, but Vitamin E is good for our skin and also our heart. (I6)

Ma (1999a) interviewed a number of Chinese medical practitioners in her study. She illustrated the role of traditional Chinese medicine in the health care of the Chinese community, and how traditional interventions have responded to community health concerns and illnesses such as neurasthenia, insomnia,

fatigue, and loss of appetite. Chinese healing herbs can be used to enrich the blood, enhance vital energy, calm the mind, stimulate appetite, and improve heart function.

> Pain, stress, overwork, grief, and anxiety can often result in sleep disorders. According to traditional medicine, insomnia indicates energy imbalance. Frequent patient complaints are dizziness, headache, restlessness, palpitations, and amnesia. I often prescribe Chinese herbs…for patients with these symptoms to enrich their energy, calm their minds and hearts, and regulate functions of their nervous systems with excellent results. Based on my clinical experience, this approach shows high efficacy in neurasthenic insomnia. These herbs have no side effects. In severe cases, I incorporate acupuncture, meditation, and relaxation exercises, and advise any patients on proper diet, sleeping, and lifestyle changes. (Ma, 1999a, p. 133)

Many Western and traditional doctors have experimented an integrated treatment approach using both Western and Chinese herbal medicine. I visited two community health centers serving predominately Asian Americans and Pacific Islanders in Seattle and Hawaii. Both of these centers offer traditional herbal medicine for their primary care patients. A traditional Chinese doctor in Ma (1999a)'s study explained how he worked with Western-trained doctors in applying Chinese herbal therapy to treatment of cancer patients who just had surgery:

> The primary objective is to reduce the side effects of chemotherapy. One of the most common problems is an abnormal digestive reaction to chemicals, namely, nausea, vomiting, poor appetite, diarrhea, or stomach disorder. I prescribe certain Chinese herbs to enrich the spleen and vital energy, and to nourish the stomach. Many of these patients complain about fatigue and dizziness, symptoms which indicate an imbalance of *yin-yang* body function and structure. I prescribe Chinese herbs to regulate balance of *yin-yang*, enhance the immune system, and prevent the reduction of white blood cells and blood platelets. Some herbal medicines can strengthen the function of fighting cancer cells. (p.133)

Decisions on using herbal medicines are often based on family traditions, professional and quasi-professional recommendations, and history of self medication (Ergil et al. 2002). The Chinese has easy access to health care recommendations from quasi-professionals of traditional herb stores. These stores have been a fixture in China for many years and are also part of any community with a substantial Chinese population. However, using herbal medicine is not without controversies. Main concerns about the use of herbal medicine are adulteration of herbs with pharmaceuticals such as heavy metals, adverse effects of the herbs themselves, and possible herb-drug interactions (Ergil et al. 2002). There are also reported incidences whereby certain stores in American Chinatowns selling prepared Chinese herbal remedies that may contain biomedical pharmaceuticals. Because most of these products do not adhere to labeling guidelines of listing all essential ingredients, there is an increasing possibility of overdosing, drug interaction, or other serious consequences. The concern of herb-drug interactions has been raised, but reports that are directly pertinent to Chinese herbal medicine are scant and often anecdotal. Instances of well-researched and well-documented interactions are also rare in literature (Ergil et al. 2002).

Notion of Preventive Care

As opposed to self-care, approaches to health that involve the healthcare systems, such as regular checkups and screening, were of a lesser importance to participants in this study. When being asked about maintaining health through disease prevention, very few participants mentioned the importance of regular

medical check-up or preventive screening. It is common for Chinese patients not to see a doctor for certain illnesses due to the belief that occasional illnesses can be ameliorated through the use of nonprescription drugs. Some participants and their friends were in denial of their risk of having diseases. They avoided the issue of disease prevention altogether and did not see the need to visit doctors unless they had symptoms. One participant noted:

> Many seniors or even younger people say exercising is too hard for them. If they are sick they just see a doctor and take medication. They said why bother exercising? Just that simple answer! I spoke with several individuals and they gave me the same answer...Yes, they see a doctor when they are sick...They said it's a hassle to go out for exercise for several hours...In our community many individuals are very sick and their conditions are severe. In fact, they may already have the condition but they just don't pay attention to it. For example, they may experience cancer related pain but they just ignore it because they don't have pain. Later on, their condition became much worse. (I14)

Some even believed that talking about seeking medical care could bring on an illness:

> Once I heard it (the disease), the next day, I really did get sick! So, I just don't want them to talk to me about it! (B4) (Three other participants in the focus group also echoed what this participant said).

Summary

Prevention is an essential and important concept in Chinese medicine. In the Chinese culture, prevention includes health promotion as well as balance and harmony in health behaviors, lifestyle, and daily diet. Based on the holistic views of health and *yin-yang* balance principle, the Chinese maintain preventive health through exercising regularly, maintaining a balanced and healthy diet, and the use of herbs and soups to promote health and prevent disease. The Chinese health practices such as exercising regularly and healthy diet is not

controversial or detrimental to health. In fact, these practices are consistent with what the Western medicine is currently advocating in health promotion and disease prevention. Therefore, providers should respect and accept these traditional health practices.

However, Chinese health practice does not include diagnostic testing and medical checkups that is common in Western medicine. Some Chinese may therefore consider annual check up and diagnostic tests as “unnecessary”. Cultural competence in health care requires health providers to have a broad knowledge as well as being open and receptive to cultural beliefs and health of the populations they serve. Unfortunately, very few Chinese Americans discussed their use of complementary and alternative medical therapy with their clinicians for fear of disapproval, or because medical providers did not initiate the discussion (Ahn et al., 2006). Therefore, health providers not only need to be aware of traditional Chinese belief on health promotion, they also need to educate patients the importance of Western medical practices and diagnostic procedures so that they may understand within their respective cultural framework the importance of early detection and treatment of diseases.

CHAPTER SIX

CHINESE ATTITUDE AND VIEWS TOWARD CANCER

Introduction

Our cultural values, beliefs, attitudes, and personal experiences affect our reaction to illness and our presumptions on what causes cancer. Beliefs of what causes cancer may in turn determine what interventions are preferred in cancer prevention and treatment. It is important for health care professionals to incorporate these specific health beliefs and practices of individuals into service delivery (Varricchio, 1987) by understanding the meaning of cancer in the Chinese culture and the attitudes and beliefs of the Chinese immigrant population toward cancer screening. This chapter will present the beliefs and values of Chinese immigrant participants towards cancer, their perceived cause of cancer, how they react to a cancer diagnosis, and their attitudes and experiences towards cancer screening.

Negative Attitude towards Cancer

Cancer has a very negative connotation in the Asian American community (Jenkins & Kagawa-Singer, 1994). The fear that cancer is fatal prevails in the Chinese culture (Mo, 1992). Liang et al. (2004) studied a group of older Chinese women on their attitudes and beliefs of cancer. They found that the subjects' notion of prevention or early detection of cancer was countered by a sense of grim fatalism. Cancer is often considered as a fatal disease which, from a Chinese fatalistic perspective, has no cure. Many participants in this study confirmed this belief and considered cancer as fatal. They associated cancer

directly with death because unlike other chronic conditions, they did not know if cancer could be cured.

> I know if diabetic patients follow their regimen - eat what they should eat, do not eat what they shouldn't eat - they won't die, they can be treated. But I don't know about cancer. I don't know if cancer can be cured. (I8)

Some participants in Liang et al. (2004)'s study also expressed a sense of powerlessness towards illness or cancer and were ready to accept their "fate". Traditional Chinese believe that the highest acceptance of God is "listen to heaven and follow fate". When unfortunate events happen, the individual should try his or her best, be positive, and leave the outcome to God (Chen, 1996). Two participants in this study believed that there was no way to prevent cancer. As a result, they felt powerless and had no control in their lives:

> Life is very unpredictable. Even though you have a lot of money, your life may end suddenly. So it doesn't matter whether you have money or not... it is your fate that determines whether you have cancer or not. (I2)

> For us women, we can be cautious about many different things, but when it comes to cervical cancer, even you are cautious about personal hygiene, you cannot avoid getting cancer. (C5)

For many Chinese patients, the initial immediate reaction when diagnosed with cancer is that of shock, disbelief, disregard, resignation, and withdrawal (Jenkins & Kagawa-Singer, 1994). The majority of participants in this study (18 participants) reported feelings of fear when they first heard about cancer. One participant recalled:

> I was scared. Life is very precious... I was scared when I felt something hard in my breast during self-examination. So I went to see a doctor again. She told me it was just the bone and there was nothing wrong…I was scared when I saw the doctor, because I was afraid that the doctor didn't know whether it was a bone or something else. I couldn't tell from self-examination and I was afraid the doctor couldn't tell from examining

> me by hands either. But the doctor said that area is not the breast. It was the chest bone…But now I'm getting old and starting to have health problems, I am scared. A casual remark about me being sick would be enough to make me anxious. (I5)

Several participants were sympathetic when they heard that someone has cancer. This participant said:

> Why some have cancer and not the others? I think it's a pity (tragedy) to have this disease. You will die and your life will cut short if the doctor can't cure you. I think it's a misfortune to die like this…I feel sad when I heard that someone had cancer. I was thinking that it would be such a pity for a person who was so young, looked so pretty to have cancer. I was thinking what she could have done differently… I hope that the doctor can cure her. I hope the doctor can provide good treatment for her and make her live longer, give her a chance to see more in this world. I hope that everyone is healthy. (I8)

The reason participants reacted with fear and anxiety to the diagnosis of cancer was because they knew very little about cancer and how cancer progressed. They participated in cancer screening and followed the doctor's instruction to get further testing. Because the doctor did not explain to them how cancer could be treated, they felt panicky and did not know what to do when diagnosed.

> I have a friend who came here and had a Pap smear. As soon as she had cancer screening done, she was told that there was a lump in her cervix. She was told to quickly see a doctor for further testing... But at the time when she heard that, she was scared. The doctor did not explain to her exactly how her illness would progress… She was told very little and she got so scared that she did not know what to do. (B3)

Other participants (6) in the study felt very anxious when they heard about cancer, 3 others were in denial or did not want to face it at all, and only 2 felt indifferent about cancer. For instance, two participants commented that many people did not want to accept the fact that they had cancer because they were afraid. Many knew what they needed to do but chose to ignore it or make

excuses so that they did not have to deal with it.

> I know that many seniors do not care about cancer. They said they were old. If they got cancer, they just died and it's not a big deal. That's what they told me when I talked to them. They said they would die one day anyway, so why bothered?! But I said, "what if you do not die immediately but have to suffer a long and painful death as a result of cancer?" They then said they were old and they would die anyway. They asked why they still had to watch their diet at their age. They said, "If you are only allowed to eat certain things but not other things, what pleasure is left in life?" (I4)

> Of course I hope it (cancer) won't happen to me. I just don't know why it happens...People may not want to know that they have cancer. Many people avoid the issue and not want to deal with it... Other people are afraid to face it. If they find out that they have cancer, it's hard for them to accept the fact... I think this is why many people know what they need to do but say they are busy and have no time. (I1)

Not only would patients be in denial and avoid dealing with the diagnosis of cancer, family members might also withhold information from the patient rather than openly discuss screening results with the patient. For instance, one participant indicated that his children did not tell him what the tests were for until they received a negative result:

> Last time when the doctor suspected that I had prostate cancer, my children didn't tell me the truth. The doctor told them (the children). They didn't tell me. Not until we received a negative result from the tests. My children told me the reasons why those tests such as a biopsy were needed. It was because my blood level (PSA index) increased too fast. (I12)

<u>Positive Attitude toward Cancer</u>

The belief that thinking about cancer can trigger the onset of cancer (Sadler et al., 1998) was cited as a major barrier to cancer education and screening in the Asian American communities. However, when participants of this study were asked about whether they believed that thinking or finding out about cancer could induce the onset of cancer, surprisingly none of them shared

this view. They disagreed that talking or thinking about cancer would itself bring bad luck or lead to cancer. Five participants reported that they were calm when they heard about cancer, and 6 felt that they had control over what they could do to cope with cancer and were psychologically prepared for it. For instance, two participants indicated that they cared about their health very much, and that they would do whatever they could to fight the disease:

> Sometimes people tend to ignore these things. They don't want to deal with it until they experience symptoms. I'm not like that. Perhaps everyone's perspective and opinion are different. Perhaps what is important to me is not necessarily important to others. I think being healthy and not being sick is very important because it affects me in many different ways... I went to Hong Kong to see my friends every few years. They don't want to talk about health issues. The health care system in Hong Kong is also different. So, it seems to me that only when they have illness or when they feel sick, then they seek medical care. If they feel fine and do not have any symptoms, they will not make an appointment to check whether they have cancer or not... For me, if I know, then at least I can be psychologically prepared, which is better than, oh, I have cancer, what now? The latter would be very scary to me. (I1)

> I will not avoid talking about it (cancer). It's very normal to talk about it. A normal topic, just like 'how are you today?' 'How is the weather today?' 'Do you feel good today?'...As I said, I don't want to have cancer. But if I have it, I'm very practical and I will seek treatment. (I12)

Several participants (5) were open when they talked about cancer. Some participants (8) affirmed that that cancer screening was a preventive measure. They considered cancer screening as a tool for early detection and treatment:

> For cancers such as breast cancer or cervical cancer, treatment in general was very effective. Therefore, there is no need to be overly concerned or scared when we heard about being diagnosed with cancer. Early detection and treatment of prostate cancer in its early stage was also important and effective. It would be a concern if one is diagnosed at a late stage. (I3)

> Depending on your medical condition and your willingness to learn new information and knowledge, it is important to be informed about your

> condition and be diagnosed and treated in the early stage of the disease. Prompt treatment can take care of a lot of problems. (I4)

One participant commented that while she was open to talk about cancer, others might not be ready to discuss it at all:

> Some people may not want you to talk to them about cancer… If you meet someone who doesn't want you to talk about cancer, we should not talk about cancer with them. We should respect them. (I6)

Perceived Seriousness of and Susceptibility to Cancer

With regard to perceived seriousness of breast cancer, only one third of Chinese women in Lu (1995)'s study recognized the seriousness of the disease, while more than 50% had no opinion or did not consider breast cancer as a serious problem. The findings of this study were consistent with Lu's (1995) study. Approximately one third of participants (12) in this study believed that cancer was a very serious disease because when cancer was detected, it was usually at a late or advanced stage. For instance, some participants believed that cancer could progress quickly and drastically without much warning. When patients found out that they had cancer, the disease had already progressed.

> Cervical disease is complicated. Therefore, we need to get Pap smear. Without the screening, it will be too late when we find out and it will be life threatening. That's why I often tell other people to go and get screening... In my own opinion, cancer is more serious and more important than other diseases. Because if you have diabetes and you follow the doctor's advice "eat what you should eat, stay away from those kinds of food you shouldn't eat", then your condition can be stabilized. But cancer cannot be cured. (I8)

> There are some people who find out too late when they have a certain illness … For instance, I have a friend who gets a physical check-up every year. But a year ago during a physical examination in August, the doctor told her to return the following month after she had her period. As soon as she returned for follow-up, the doctor said that her ovaries already had a big, a really big tumor. And she had to be admitted to the hospital

> immediately for surgery. It's just so scary… I get check up every year, but still how come as soon as you find out, the condition is already so serious? (B3)
>
> If you have other medical issues, it is not a problem as long as you receive proper treatment and know how to take care of it. But if one has cancer, it's difficult. Even the most advanced medical technology cannot buy more time for a few more years. Look at those celebrities who were fighting cancer. They were rich and had money but yet they still died of cancer. For this reason the stress of having cancer is high. (A5)

Many participants believed that cancer was a very serious problem and knew that many individuals at their age had cancer. However, only one third of them felt that they were susceptible to having cancer. Many more female participants (11) than male participants (2) believed they were. Inadequate knowledge or misconceptions on the cause of cancer might give these participants a false sense of security about their low susceptibility of cancer. For instance, one participant believed that since she attended screening examination regularly, she would be immune from cancer:

> There are many women who have breast cancer or cervical cancer... Because many people have cancer at my age, I'm scared. But I don't think I'll have cancer because I attend screening examination and I'm healthy. (I5)

Because of inadequate knowledge on the causes of cancer, some participants, on the other hand, believed that they were totally vulnerable to developing cancer. Two participants commented:

> Everyone has cancer cells inside her body. It is a matter of time whether or not they develop into tumors and beyond…. I do not know whether I have it or not…I heard that it is easy for women over 40 to get such disease, is it true? (I8)
>
> I think breast and cervical cancers are disorders of the hormonal system and your blood type is related to these problems... I read that from some Japanese medical journals. They said if you have blood type B, you are

> more likely to have hormonal problems. I don't know the reasoning behind it because the article did not explain further on this. However I found that more individuals with cervical tumor have blood type B…I consider myself high risk because I have blood type B. (I6)

Perceived Cause of Cancer

When asked about cancer, many participants (12) did not know or were not sure about the causes of cancer, although they learned that cancer was quite prevalent in the Chinese community. One participant was very concerned about the fact that many people had cancer. She raised many questions about what caused cancer and what could be done to prevent it:

> I'm not sure how cancer came about. I'd want to know what causes it so that I can prevent it. I'm not even sure why so many illnesses are cancer related. How come it's so easy to get cancer? Medical professionals tell you not to eat this or do that. But really, is it true that we can prevent it? I don't quite want to accept cancer but we have no choice... Of course I hope that it will not happen to me, but I just don't know why it happens. Sometimes we learn about cancer from the media or other sources. We learned that a lot of people have it. It's just hard to understand why. (I1)

Some male participants were confused about the difference between prostate related problems such as prostatauxe (prostate enlargement) and prostate cancer. They wondered whether prostatauxe would eventually turn to prostate cancer and asked what they could do to prevent or treat cancer. For instance, one participant had a long history of prostate enlargement and saw many doctors. He raised many questions with his doctors about his prognosis and potential complications of prostate enlargement. But he was frustrated because his questions were not thoroughly answered:

> Speaking of my own experience, I have prostate enlargement for more than 30 years. I saw many doctors in major hospitals in Nanjing and they all knew me. Before I saw a doctor, I read books about prostate problems. I even took some notes when I read them. The doctors

> wondered why I knew so much about the illness. I told them that I read a lot of books because I had prostatauxe. But after all these years of learning about the disease, I still don't know why men develop prostatauxe. This is one of the reasons why I come to this meeting. I don't fear anything but prostate cancer… Doctors cannot tell me if my prostatauxe will develop into cancer. What will be the symptoms? I do not have cancer now, but knowing how to prevent cancer is important. What should I do if I develop prostate cancer? I asked all these questions but so far I haven't got clear answers. Every doctor I saw recommended having the mass on my prostate removed. Will surgery guarantee that I will not have prostate cancer? This is a tough question. But what can be sure is that removing the prostate can postpone the development of cancer. In the U.S., the "electrical cut" is a very advanced technique and has gone through many years of testing. But you still never know what will eventually happen and it's hard to say. (A6)

When participants were unclear about the cause of cancer, they speculated. For instance, two participants were puzzled as to what actually caused cancer:

> Why does cancer happen? I'm always asking. Is it due to genetic factor? Is it because of poor hygiene? Is it due to poor diet or something else? I'm not sure. I am just guessing. Why some people have cancer and some do not? (I8)

> My aunt has breast cancer... She is never married. I wonder how she would have got breast cancer if she is never married. (B2)

<u>Misconceptions, Confusion, and Incorrect Assumptions</u>

Misconceptions about the cause of cancer were found in several studies of Chinese and other ethnic groups (Liang et al. 2004; Maxwell et al. 2000; Ashing et al. 2003; Mo, 1992). For instance, breast cancer is considered a "dormant and contagious disease" caused by "breathing polluted air" (Mo, 1992). In another study, "breast trauma" such as "pressure on the breasts" or the "use of wired bras" will lead to the development of breast cancer (Ashing et al. 2003). Medical professionals had educated patients on common risk factors, such as

genetics, family history, and poor diet, that might lead to cancer. A few participants in this study learned that genetics and poor diet were risk factors for cancer. However, many still had misconceptions, confusion, and incorrect assumptions about the causes of cancer.

Common perceptions among participants on the causes of cancer included: genetics, sexual indulgence, and unhealthy diet and cooking habits. One third of participants (12) believed that cancer ran in the family. For instance, some participants believed that genetics played a role in cancer formation.

> Is it because of genetics? Is it because her mother had it too? ... When cells mutate and become abnormal, they develop into cancer… I don't know… My relatives also had cancer, so I think maybe I will have it too. (B4)

> From what I read from the newspapers and magazines, I learned that heredity is a contributing factor to prostate related problems. Since my father had prostate problems, I am especially concerned about myself and I am vigilant of my prostate problems… I am not a medical professional. I am just an ordinary person. However, I am eager to learn more about the disease. My knowledge on cancer is still limited. I think family genetics is a key factor. If your father had prostate cancer, you would be at a higher risk of having prostate cancer. (I4)

Although some participants suggested the role of genetics in cancer development, others were unsure that genetics played a role while some others attributed cancer to unfounded causes. For example, one participant believed that every person had both normal and cancer cells in the body; that when she became extremely tired and exhausted, she could get cancer easily because the normal cells in the body could not recognize or fight cancer cells:

> Because when you get cancer, there is usually a genetic predisposition... You don't have to be scared because all of us live with cancer cells. When you are healthy, the normal cells can identify the cancer cells and overcome them... When you are extremely tired because of work or when your body is too exhausted, you may get cancer easily. Genetic factors

> are predisposing factors. Therefore, if your have a family history of cancer already but you still don't pay attention to your health, such as working too much and getting too tired, then you are prone to have cancer. (B2)

Both male and female participants regarded excessive sexual activities as a contributing factor to cancer. Two female participants believed that cervical cancer was caused by promiscuity and sexual indulgence:

> Cervical cancer? Perhaps because they have been fooling around? (I2)
>
> Some people said it is because you have done something shameful, and then you became inflicted... which leads to cervical cancer. (I5)

Cancer is believed to be 'contagious" (1992). Sometimes participants were confusing the causal factors of cancer with sexually transmitted diseases. One participant believed that physical contact during doctor's examination might spread cancer:

> Another way is through physical contact, yes, when doctors are touching you during the examination. But talking about it won't spread cancer. (I12)

Male participants too attributed prostate cancer or prostate related symptoms to uncontrolled sexual urge and desires, too much sex, and sexual indulgence. This notion of "conserving energy" and "suppressing pleasure seeking desires", especially "sexual desires", as a way of preserving health is a hallmark of Taoist and Buddhist philosophies.

> Some said being sexually active, lack of control, or sexual indulgence make one prone to prostate cancer. (I4)
>
> Some may not care about having prostate enlargement. They must be very sexually active because they "stimulate" their prostate a lot by engaging in sex too often. (I14)
>
> From what I read from this brochure, three factors accounted for prostate enlargement... one's sexual urge, sexual desire, and too much sex.

> These are the three major risk factors attributing to prostate enlargement. However, we still do not know what the primary cause is. (D2)

Some participants made up their own "theory" on the causes of cancer because they were confused about risk factors and causes of cancer. For example, one participant concluded that a woman whom she knew developed breast cancer shortly after she gave birth because she had "cold and excessive breast milk left in her breast". According to her "theory", the breast milk was "frozen to tiny particles" and became lumps in her breasts, which in turn caused her to develop breast cancer. This participant's theory reflected the Chinese belief of balancing "hot" and "cold" elements in one's body. Once this balance was upset, one was prone to illness.

> I heard a story about a woman who just gave birth to a baby. When her baby drank too much breast milk while she had a cold, cancer developed in her breast but she did not know about it… I've got another friend who had too much breast milk and her baby couldn't finish it. She caught a bad cold and her breast milk was "frozen to tiny particles", forming a mass in her breast. After she migrated to the U.S., she had a mastectomy. Nobody knew what she had. Some said it was breast cancer. Some said it was just a tumor. In fact, she had breast surgeries in both the U.S. and China. She said it was because she had "cold and excessive breast milk left in her breast" which became lumps. (I5)

The following two participants believed that women who did not breastfeed, or did not use their reproductive or "natural" functions, such as child bearing, were at a higher risk of having cancer. While there is some basis in medical literature regarding the association between breast cancer, child birth, and breastfeeding, the belief of this participant also reflected the Taoism value of health being a state of physical harmony with nature (Spector, 1991). Taoism believes that nature has the ultimate authority over the course of life (Ino &

Glicken, 1999) and one should always act in accordance with nature and not against it.

> As for breastfeeding, I have seen people who did not breastfeed and later developed breast cancer. They didn't use their body the way it was made for... This is a form of imbalance in the natural body function. When you upset the balance, the metabolism becomes abnormal. My friends didn't breastfeed. They used baby formula. (C1)

> I have heard but am not sure if there is any medical evidence to prove it, that more and more women now have cancer because of the use of birth control. For example, in the old times, women had 8 children and their reproductive organs were used in the way "nature" made it for…Women then did not use birth control and therefore they did not have cancer. Nowadays, many women use various birth control methods, which conflict with the body system and its normal function. This will gradually lead to the development of diseases. Environmental factors and stress in life also contribute to cancer… women are not giving birth to babies enough or using their reproductive system frequently enough. As "God" created women, they are supposed to use their breast for breastfeeding and their uterus for the fetus to grow. All these natural functions of women are being neglected. I believe it will come back as a form of "punishment". I am not sure whether this theory of mine is scientific or not but I heard a lot of people talking about it. (C3)

Traditional Chinese believed that the formation and progression of diseases are associated with social and environmental changes. Based on this holistic concept, traditional Chinese believe that diseases such as cancer are only "preventable" or "controllable" by eating properly and maintaining balanced energy levels (Hoeman, Ku, & Ohl., 1996). Cancer is believed to be triggered by eating unbalanced, frozen, preserved, or raw food (Mo, 1992). Several participants in the study shared this belief and stated that unhealthy cooking and poor eating habits might be a causal factor for cancer:

> Chinese people ate "a lot of" food which is not so healthy. These food have a lot of salt. They are not fresh. (C3)

> It depends on whether or not you pay attention to your health, whether or

> not you have regular physical activity, adhere to your diet and not eat too much fried food. There was a Chinese saying that fried food is no good (toxic) for our health. Therefore, if you don't control your diet and eat too much oily and fried food, you are not only more likely to have prostate cancer, but are also prone to have other medical problems. (I4)

Chinese health beliefs and practices emphasize balance and harmony among human mind, body, and emotions with one's nature or environment (Ino & Glicken, 1999). Mind and body are considered inseparable entities because they influence each other. Being emotionally imbalanced may put someone at a higher risk of developing diseases. For instance, one participant believed that being chronically unhappy, such as feeling depressed or anxious, would contribute to breast or cervical cancer.

> I thought that you are more prone to having breast cancer if you are chronically unhappy, anxious or depressed… I just feel that when one is unhappy, it's easier to catch any illness. We don't know for sure how people get these diseases (breast cancer and cervical cancer), but I think that they are somewhat related to our mental conditions. Our emotion does not just affect our chances of getting cancer but also many other diseases as well. (C1)

Some participants in this study had misconceptions about the causes of cancer. They believed that blood type and poor hygiene were associated with the development of cancer:

> There are four different types of blood in human beings. There are some blood types that cause people to get sick easily… Well, I read about this theory and I looked back at my family. Some of my family members have cancer. So, I thought it (cancer formation) is related to blood type because my younger sister and I do not have the same blood type. So, I think it depends not only on your own mental well being but also on your blood type. (B4)

> You have cancer because your personal hygiene may not be so good. Therefore, you may be affected. (I1)

> For women, we can be cautious on many different things, but as for

> cervical cancer, even if you are cautious about personal hygiene, you cannot avoid having it. (C5)

A participant believed that poor immune system was a factor associated with cancer. He used an analogy of the Civil War in China to illustrate his argument:

> Being weak in our body! Just like the Red Army in China, it depends on whether or not you have an adequate force of army. If the Red Amy had enough armed force to win the battle, it would not need to escape to "Yin On" (a province in China to which the Republic of China retreated during the Civil War). Similarly this is how we get cancer. Yes, our immune system becomes weak and then you will get sick easily. (I14)

Summary

The findings of this study confirms that culture influences beliefs and attitudes towards cancer, as well as perceptions regarding the cause, risk, susceptibility to, and seriousness of cancer. Participants in this study reported both positive and negative attitudes toward cancer. Contrary to the findings of Sadler et al. (1998)'s study, most of our participants did not believe that thinking, talking, or learning about cancer could lead to bad luck or trigger the onset of cancer. In fact, several participants reported being calm when they first heard about cancer, because they believed that they had control on what they could do to deal with cancer and were psychologically prepared for it. This could be explained by the fact that participants in this study were recruited from the patient population who attended cancer screening. The fact that they went for cancer screening in the first place reflected that they had overcome the taboo of cancer, and were willing and ready to deal with the possibility of a "positive" result. Therefore, going for cancer screening can also have the positive effect of

helping the patient cope with the initial shock and anxiety related to the diagnosis of cancer. In addition, going for cancer screening also empowers the patient by making him or her feel good about the decision of seeking screening before experiencing symptoms and giving them a sense of control by detecting the disease at an early stage. As a result, many participants believed that cancer screening was a preventive measure and considered it a priority in life.

Only a few participants in this study recognized the role of genetics and unhealthy diet as risk factors for cancer. Many others held misconceptions, confusion, and incorrect assumptions about the cause of cancer. Common misconceptions about the causes of cancer included: having a certain blood type, poor hygiene, cancer being “contagious”, and women ignoring their reproductive or natural functions by using birth control or not breastfeeding their babies. Ignorance and confusion on the risk factors and causes of cancer will put them in a disadvantaged position because they do not know what to do prevent or treat cancer. Therefore, it is important for health care providers to recognize that misconceptions exist and to educate the community so that the public is properly and adequately informed of the true causes of cancer as well as ways to prevent and treat it.

CHAPTER SEVEN

SOCIOECONOMIC AND CULTURAL BARRIERS TO CANCER EDUCATION AND CANCER SCREENING

Introduction

The majority of participants in this study were low income, uninsured or under-insured Chinese immigrants who spoke little or no English. Approximately three quarters of participants (73%) reported their total annual household income to be below $20,000. Only half of them were employed and 34% were retired. Approximately 28% privately paid for their health care. Only 12.8% had health insurance through employment. The rest of the group (59%) received government-funded health insurance benefits such as Medicaid, Medicare or Family Health Plus. All participants were foreign born. Only 8% said they spoke English well; 55.2% said their ability to speak English was poor or did not speak English at all.

The poor and the socially deprived often encounter numerous barriers to preventive health care. Several research studies reported association between socioeconomic status and poor participation in cancer control activities (Katz & Hofer, 1994; Harlan, Bernstein, & Kessler, 1991) with a higher risk of cancer incidence, morbidity, mortality, as well as poor cancer survival (Ward et al., 2004; Bradley, Given & Roberts, 2002; Kagawa-Singer, 1995). Therefore, identifying the barriers low income and medically underserved individuals face will help health care professionals reach this population more effectively. This chapter will describe the socioeconomic and cultural barriers that Chinese immigrants experienced in accessing cancer education and cancer screening. The findings

will also show how Chinese immigrants perceive cancer as compared with other health problems, how they perceive the benefits of cancer screening, what make them go for cancer screening for the first time, and their perceived barriers to cancer information and cancer screening.

Perceptions of Health Problems

The majority of male participants in this study considered prostate-related problems as more important (18 participants) than other health problems that affected Chinese American men. The majority of female participants rated cervical (5 participants) and breast cancer (8 participants) as more important than other health problems. Many believed that these problems were common in the Chinese community because many Chinese suffered from them:

> Cancer seems to be quite prevalent nowadays. There are more incidents of cancer these days, a lot more. It seems to me that 80% of those who died of diseases are cancer related. Men and women died because of cancer such as laryngeal or lung cancer. These diseases seem to be more prevalent. (I1)

> I think gynecological health is important for women… I hope I would not have any women's health problem, whether it is the cervix or the breast. Women at my age have so many problems…. If my menstrual period is not normal, I will immediately worry about my health. I heard a lot about this from others. Therefore, I worry about myself. (C5)

> Prostate cancer is also common. Prostate problem is very common among Chinese elderly men and they have varying degrees of concerns on this problem. Some suffer from prostate enlargement…Many elderly urinate frequently at night and wake up several times. This problem affects the quality of their sleep. (I4)

> Prostate problem is quite prevalent. Quite a number of people that I met have prostate related problems… it affects especially those who are getting old. I know quite a few people who have prostate problems. (I13)

Although these participants recognized that cancer was more common, they knew very little about the disease. Two participants commented that many

Chinese did not have any cancer knowledge or an interest in learning more about cancer until they got sick themselves:

> Perhaps in the past, people did not want to say they had cancer. Maybe they didn't even know that they had cancer. You did not hear it much in the past. It is rather common to hear about people being diagnosed with cancer now. (I1)

> People do not know how exercising may affect prostate problems. If they do not know about their prostate problems, they may not even know that they could have prostate cancer... They are not interested in finding out about cancer even though you try to give them more information. So, many Chinese are uninformed about health issues... They are not motivated to find out more. They also do not understand what would happen to them if they have health problems. They wait until they get sick... In fact, most people know very little about cancer. They simply ask why they have cancer. They are really ignorant…people need education…They have limited medical knowledge. Only when they have heart disease, they will speak to a doctor to learn more about heart disease. For those without heart disease, they have no understanding about heart disease. (I14)

Perceived Benefits of Cancer Screening

Only half of the total participants (19) of this study were compliant with annual cancer screening activities. Nonetheless, the majority of participants who were compliant with annual cancer screening (12) showed positive attitude toward cancer screening. For example, one participant affirmed that cancer screening was important for maintaining health:

> I understand that it is important to maintain health and prevent disease. I don't want to wait until I'm sick, and then find out what I need to do to take care of myself. For me, if I am healthy, I feel good. (I1)

Another participant who considered cancer screening very important sought preventive care even though it cost her money:

> I take my health seriously. Many people do not go for annual screening. They get screening after more than a year, but I go. I used to go to a private doctor for screening. Although it costs me more than $100 or so, I

> still go ... I think health is very important. I'll definitely go (to cancer screening) when I receive the reminder letter (I8).

Many participants (18) in this study understood the benefits of early detection of cancer. For instance, two participants commented that preventive screening was necessary to early detection and treatment of cancer. They reported feeling relieved when they found out that their screening result was negative:

> I was relieved after the examination. I would be scared if something went wrong. I felt good when I found out that I was fine after the re-screening…I think it is better to receive regular screening and check-up. We have very advanced medical technology in the U.S. It's easier to treat if it (cancer) is detected early. Doctors can do nothing if the patient is too old or has been sick for too long. If detected earlier, doctors can do something to treat it. (I5)

> This is the reason why you get the screening. If the result was normal, you would be relieved. If something abnormal was found, you could follow the doctor's instruction and get immediate help. If you really had cancer, you went for the surgery and received treatment immediately. Therefore, the emphasis on disease prevention is important and I support that. If not, you get treatment at a later stage of the disease and you would suffer more. Your family will also be stressed. (I4)

While the majority of participants recognized the benefits of preventative measures, one participant commented that cancer screening could not be effective unless one paid attention to other preventative measures as well:

> I don't think screening can help much if we do not pay attention to our health. For example, if you smoke several cigarettes every hour, screening may not help. We need to find out what causes cancer and what we need to do in our daily life. That is very important. (I14)

<u>Reasons for Cancer Screening</u>

When being asked what made people go for cancer screening the first time, only one third of participants provided specific reasons. Very few

participants (6) mentioned that they went for cancer screening the first time because they were referred by a health care provider. Several other participants (6) were prompted by personal heath concerns or symptoms. A couple of patients were concerned about their risks of having cancer because of family history.

> It's for my own health... Since I started menstruating, I always have heavy bleeding every month. People said once you got married, you should have lighter bleeding during your menstrual period. Yes, I did not have my period during pregnancy. But once my child reached a month old, I had heavy period again. Since then, my period has been heavy because of imbalance of my hormone. Therefore, I am eager to get a check up… I heard about screening guideline for women over 40. I come for cancer screening because of my health condition. (I6)

> Maybe because I'm approaching 60, I have had problems with my prostate gland in recent years. But it's no big deal. I just have some urgency in urination. Therefore, I am very interested in participating in this screening event... I am concerned about my health. (I11)

Increased Access through Low Cost/Free Screening

Some participants in this study, especially the elderly, had health insurance which allowed them to access cancer education and screening services at no or little cost. But all participants agreed that free or low cost screening services was a major factor in promoting cancer screening in the Chinese community.

> We didn't have this (screening service) in the past. It's much better now. In the past we had nothing, just health benefits from the union... basically they all have health insurance. They know that they need to get screening... Everyone knows that if they are low income, they still can get the services. (I2)

> Yeah, I knew before I came. I asked the person, "I'm undocumented, is it ok?" She said "yes". They helped me and the service was free. I said to her that usually only those with Medicaid could get screening, but undocumented persons are not eligible for Medicaid. Therefore, I usually do not get regular check-up at all. I told myself it's too good to be true that

> I can receive free service. So I followed her advice and came to the health center for cancer screening. (I8)

> Cost is very important. I really appreciate the services provided by the health center…The health center cares about the health of Chinese women... They have free screening services for us, women without health insurance... I always wanted to get a check up but others told me that it was expensive, say I had to pay $350. So I did not get a check up right away, until I read the newspaper. Oh, it was so good to get free services... In the past I didn't see a doctor because it was expensive. In China, the service is paid by the government. Here in the U.S. you worry that you will get sick and do not have money to see a doctor. Making money is hard. I feel the invisible pressure. I was worried. But now, since I know this place that I can come for check up, I feel more relieved. (C5)

Encouragement from Peer and Friends

In Ashing et al. (2003)'s study, a Chinese cancer patient indicated that she was afraid to tell her friends about her diagnosis. She believed that they would fear catching the illness from her and therefore they kept a distance from her. In this study, however, peer encouragement was reported to be an important factor in getting participants to cancer screening. Many participants indicated that they received general health and cancer screening information through friends and peers. A casual conversation with friends may also provide valuable cancer information for these participants:

> I had a chat with my friends and naturally we talked about our needs for cancer screening... we were going to get screening and attend workshops. One of my friends was very resourceful and she lived in Queens. She received care at a community hospital and she talked about this too… I heard from my friend that she had irregular menstrual period and heavy bleeding. She was not married and she also attended the screenings. (I6)

> My friends in the U.S. said we should get screening examination... I work in a garment factory and we chat a lot. My coworkers asked me, "Do you want to get cancer screening?" So all I heard about getting free check up was from my colleagues. I'm rarely sick after coming to the U.S. I have

> never been admitted to a hospital. If I have a common cold, all I need is to take some over the counter medications. But my friends told me that I should get screening examination regularly because I am getting old... My other friends do not have health insurance, we now can tell them where they can go to get free services too! (I5)

More female (12) than male participants (3) heard about cancer through their friends. For instance, one woman found out that many of her friends had been diagnosed with cancer:

> She said she felt very bad. She was in China... She did not have any symptoms…after a routine examination, she was found to have a tumor but it was not malignant. She then went for surgery. She is relatively healthy now. I heard a lot of cases like this one...I also have another friend who came from WenZhou and she is very pretty…I asked her why she was so skinny. She told me that she had cervical cancer and had a hysterectomy. It was done here. Her husband came and wanted to have children with her. Now her uterus was taken out, how can they have a baby? That's why she is so skinny. Her life is very miserable. Nevertheless, she recommended me to get a screening examination. (C5)

Participants learned from their friends the benefits of getting cancer screening services. Because they received good services, they in turn took an active role in spreading the word and sharing with friends their positive experiences in seeking cancer screening services. They believed that their testimony on the services would be enough to persuade their friends to go for screening as well. Two participants reported:

> My co-worker in the garment factory suggested that I come to this center. She told us that staff members from the health center often went to garment factories to promote screening services. Then she took me here. I made an appointment at the front desk and came back for screening two weeks later...My coworkers will trust what I tell them more than what the staff at the clinic does. They asked me if I did the screening and I said "yes". I said the service here was great and staff members were very helpful and patient. Screening is very important for women. One of my friends did it later and she was also very satisfied with the service. She said what I told her was true. She didn't know how to get to the health

> center. I told her what transportation she needed to take... So we always tell people, "Come on, there is free screening at the health center. The service at the heath center is very good." That's what I usually tell other people in the garment factory. The most important internal organ for women is the cervix. Cervical related disease is complicated and therefore we need to go for check-ups. Without attending regular screening, when you find out that you have cancer, it is often too late. It could then cost your life. That's what I often tell other people. (I8)

> I receive medical services here. I have been here only for about a month. At that time, I didn't have too many friends. After that, I mentioned my experience to a couple of friends. They also came here for screening…I share with others how I feel when I go through the exam and what the services are like. I have real experience. I will tell other people what's good about the program and it will sound convincing for them. It is the best way to share these information, through word of mouth (C3)

For participants of this study, especially female individuals who work in garment factories, the "word of mouth" approach appeared to be an especially effective method in promoting cancer screening services in the Chinese community. For others, outreach efforts by health educators who went to the factory to promote cancer screening services also produced good results. In one instance, several garment workers were recruited by a health educator to attend screening services at the health center.

> I asked her (the health educator), "How do you know about this factory?" She said her friend told her about this place. I ran into her the other day in the factory and she seems very happy. She said, "It is good seeing you again!" I asked her why she hasn't come for such a long time. She said she has been very busy lately and that's why she could not come until today. Later on she signed up several people for the screening. We have many workers here, more than 70 people. (I8)

<u>Cancer Education through Mass Media</u>

In this study, very few participants (4) reported that they heard about cancer and cancer screening services through attending health education workshops or reading health brochures.

> There are many workshops at senior centers. They invite doctors and nurses to talk on various topics, including topics on prostate related problems. I attended those workshops at the senior center before. (I4)

But more participants (15) reported receiving their cancer and health information through local ethnic media such as newspapers or radios. Ethnic specific media such as newspapers and radios was considered by many participants as an important source in obtaining information on cancer screening services. Chinese immigrants read ethnic specific newspapers and listen to Chinese radio stations. They receive health information through these media channels. These media activities are usually quite effective in promoting cancer education in the Chinese community.

> Sometimes, I heard community workers talk about it (cancer screening) on the radio. I also read about it in newspapers. (I1)

> I read newspapers and got helpful health information. Then I came to the health center to learn more. In the Chinese communities of NYC, health education and promotion are quite comprehensive and in-depth. (I4)

> We often get a lot of information from newspapers or medical magazines. We do not need a doctor to explain that to us...They always say men over 60 are likely to have prostate problems. The level of severity is different for each individual. How do prostate problems arise and develop? What can we do to cope with prostate problems? Taking medication, surgery, or do we need other treatments? Newspaper articles cover all these topics. We can find a lot of health information in major newspapers. Every newspaper, such as the World Journal, has a health section and I sometimes do news clipping. For example, there is a newspaper article regarding a certain medication. In fact, about 4 years ago, I read the details of that same medication in the newspaper. I learned that this medication was good in treating cancer and I had been taking it…I often read the newspapers to learn more about prostate related issues. (I3)

> Publishing articles on the prevention of prostate cancer is helpful. I read about that in the newspapers before. As you said, being well informed is quite important. Once we have some basic medical information, it would be easier for us to understand more complicated issues such as prostate cancer…We then could be more vigilant of the signs and symptoms of

prostate cancer. (I4)

Sometimes, news of celebrities battling with cancer helps raise public awareness to the disease. Eight participants became more aware of the issue when they heard about certain politicians, singers, actors and actresses being diagnosed of cancer. For instance, one participant learned about the development and treatment of prostate cancer by reading articles on cancer experiences of the former New York City mayor and his police commissioner.

> The first time I knew about prostate cancer was when former Mayor Giuliani was diagnosed with prostate cancer. His father had prostate cancer too. Around that time, there were a lot of news coverage on his illness and whether it was necessary for the mayor to have surgery or not. At that time I did not have symptoms but I started to pay attention to my prostate. I wondered why people got prostate cancer and others did not. Later, I read a news article and found out that the Police Commissioner also had prostate cancer. I thought even these powerful people were not immune to prostate cancer, so the public should really be aware of the signs and symptoms of the disease too. (A5)

Another participant pointed out that people in general are interested in the lives of popular stars. They paid more attention when pop stars shared their own experience on fighting cancer. Therefore, she believed that cancer education through publicizing stories of cancer experiences of celebrities was effective in disseminating cancer information:

> There are many new young singers, actors, and actresses in Hong Kong who are also very well known in the Chinese communities in the U.S. If one of these popular stars goes for cancer screening and encourages the public to do the same, I am sure that a lot of us will listen. I think everyone will support the idea of getting a popular star to help raise cancer awareness. I think this will be an effective approach… Many people in the community may suffer from the same disease, but I don't know them… Since I don't know them, I do not care much about it…But if it is someone who is well known, it is different. You see that they are young but yet they have cancer. They could have a bright future but it's unfortunate that they have the disease... In general, people are interested in the lives of celebrities... I think people are naturally curious. If you don't

> know the person, then you would not care. If you know that this person is so young and talented, you feel that it will be a loss if he/she dies young. (I1)

Several participants reported obtaining health and cancer information from health talks or radio programs hosted by doctors and nurses. But clinics are not the only ones which use mass media to get the message across. Companies which market nutritional supplements and natural products also do infomercials in newspapers and on the radio. Chinese community residents could be easily confused between health information that has reliable and scientific evidence and advertisements of health products which sometimes give misleading or false information. Two participants mentioned that they came across advertisements of health products in the media:

> The main problem is that there are ads in the newspapers about many different types of supplements that can be used to treat your prostate problem. I am not sure about the efficacy of these products. Who knows? That's what these big companies sell. They market many types of products. (I3)

> I heard of a supplement that could be used to improve your liver functioning... But the radio station also broadcasted a disclaimer saying that they did not endorse the product... They said that those messages were simply infomercial from a company. I do not believe those "health messages"... I trust my doctor. I would take medications if my doctor asked me to do so. Those infomercial exaggerated what these supplements could do as if they were "magical pills". I would not believe that. (I13)

Barriers to Cancer Screening

Ma (1999) noted in her study that despite a high prevalence of health problems in the Chinese community, Chinese tend to underuse the U.S. health care system and preventive services. This low utilization rate may give health professionals a false impression that there is an absence of need among the

Chinese immigrant populations. Instead, underutilization of preventive health services by Chinese Americans is a reflection of their barriers in accessing health care, rather than the absence of needs. Barriers to cancer screening reported by the majority of participants in this study were lack of health insurance, high costs of health care, and cultural barriers such as embarrassment and modesty.

Lack of Medical Information & Concept of Prevention

Many Chinese immigrants are poorly informed of cancer, its prognosis, and treatments. One reason was that their health care providers did not explain to them about cancer. While the participants in this study received health information from friends, peers, workshops, outreach activities, and mass media, none of them indicated that they learnt about cancer directly from their doctors during clinical visits. Lack of understanding of their illness and being poorly informed of diagnosis and treatment in general are significant barriers that prevent many Chinese from seeking preventive care. For instance, one participant asked his doctor about urination problems but did not get a clear answer:

> Regarding my urination, usually after a few hours I have the urge to pee. Some urine will come out but it's hard to control. After a few dribs, the urination stops. I wonder whether I have regulatory problems in my urethra. Is it because I am getting old that my urination slows down? I really don't know. I don't understand. (I3)

Lack of concept on prevention for health care is another barrier that causes Chinese immigrants not to seek cancer screening. Many Chinese tend to utilize medical services only when they experience acute illness or pain. For

instance, some participants pointed out that their friends did not go for cancer screening because they did not feel anything wrong or have any symptoms. They considered attending preventive screening “unnecessary”.

> They said that if they don’t have any problems, why see a doctor? I know some people who think this way. But the issue is: you really don’t know. They may say “I don’t have any symptoms and I don’t need a check-up. If I see the doctor, they can’t do much for me”. What can I say to them? It may seem unimportant to them... They may not have the motivation to know more or maintain their health. They may not know what to do or how to get more information... Some may think it’s too much trouble to get check up. They may even ask why you have to see a doctor if you have no symptoms. They don’t think the doctors can do much. Many people have this attitude. Some don’t think they need to prepare themselves for the worst. (I1)

> They often wait until they are sick. Then they see a doctor... When they are sick and see a specialist, then they will get a check up. In general Chinese consider seeking medical care a taboo. If they are not sick, they are not used to going to a hospital to get screening. Hospitals provide these services. The services are there… But the Chinese are not used to seeking medical services unless if they are sick. (I6)

Other participants commented that their friends were afraid of positive results. They were either in denial or did not care about getting cancer screening.

> They may be afraid of knowing the screening results. If they don’t go see a doctor, they think they are healthy… They are lying to themselves. Like an ostrich burying its head in the sand, they don’t want to know. It is also because they do not feel anything wrong with their body. (C3)

> My friend said she’s afraid. Another person I knew said that she was very healthy and didn’t need to go for a check-up. (C1)

> When you were young, you didn’t know much about cancer. I didn’t know about cancer before. But after I came to the U.S., I heard more about cancer. When you are offered a free check up and you don’t bother to take advantage of it, then you don’t appreciate what you have (free screening services). (C5)

Rising Health Care Cost and Lack of Health Insurance

Recent immigrants who do not speak English are at a greater risk for poor health due to economic hardship and financial difficulties (McPhee & Nguyen, 2000). It was not surprising that many participants in this group identified having health insurance or affordable care as critically important factors for them to receive health care and cancer screening. Chinese and other Asians are among groups who were the least likely to have employer-provided health benefits, the most prevalent form of health insurance in the U.S. today. Many of them work in small ethnic businesses, such as garment factories, restaurants, construction industries, and other service occupations which provide low pay, no health insurance coverage, and hardly any employment benefits. The working poor are not qualified for different kinds of health insurance benefits sponsored by the government either. For instance, some participants pointed out that working poor like themselves were at a higher risk of poor health because they could not afford a doctor's visit, nor did they have health coverage through government funded health insurance or employment.

> If you are elderly, you are eligible for different health coverage. You have regular check up every six months. But "no one cares" about us. We have nothing. When you are sick, then you go see a doctor. (C1)

> Many Chinese do not have health insurance. If it's not free, they can't afford the services. They work and earn very little. The cost of screening services is high. Therefore, they do not have the option of getting health service. Health care cost is very high…if the medical care costs them a hundred or more but they are earning more or less the same in a week, then of course they will not pay to see the doctor. (I13)

> People don't know whether they are healthy or not because they don't seek medical care. They have no health insurance. They don't want to

> spend money on seeing a doctor. So they don't know their health condition. They do not know whether they have illness or not. (C1)

> She didn't have any health insurance because her husband's income was over the limit (above the eligibility requirement for low cost health insurance) …Her husband said, "Well, we can't worry about it unless if we really have to face it." …Now, I think lack of health insurance has the biggest impact on this group of people. They say if your income is very low, then you can get help from the government... But if your income is not high or low and you don't have health insurance through your employment, you are not eligible for government help either. It is really tough for this group of people. (B3)

Lack of health insurance not only causes the poor not to participate in screening activities but also makes it difficult for many others to comply with re-screening or obtain additional follow-up services. Because of concerns over cost, the poor are often discouraged from seeking state-of-the-art diagnostic examinations or treatments (Bastani et al., 1991). For instance, one participant understood her needs for annual cancer screenings but indicated that she postponed her follow-up appointment when she needed to pay out of pocket:

> I heard of it (cancer screening) for a long time but I didn't go because I was poor. I did not want to spend any money on it... I put it off for a long time because I didn't have insurance and I didn't want to pay out of my pocket. It would cost me a lot of money. I went to the health center to get screening as soon as I got the insurance card... It's good to know there was free service. However, if I needed to pay, I might not be able to come in October. I would probably postpone my visit and do it later due to financial reason. But I would definitely come if it's free… It is not necessary that I have the screening once a year. I might try to get it every 1.5 to 2 years… My income is low. I work in a factory and I do not have health insurance… I do not earn a lot of money. I would not get screening if I have no coverage. (I5)

Another participant said that he preferred receiving comprehensive and thorough diagnostic check-up. However, his concerns on the cost of state-of-the-art diagnostic tests made it difficult for him to seek further testing:

> They will charge me for an x-ray. I have not gone for the x-ray yet. I can't afford it. Even registration alone will cost me $50. The examination will cost more. So I just let it go…Those Chinese who go for screening are usually low-income people. They want to know their health condition better when they get a check-up. The procedure only involves drawing some blood. We do not draw blood for prostate screening in China. Here (in the U.S.) they can tell if I have prostate cancer based on blood test results. I prefer getting more tests but I can't afford it. I think further tests are necessary because it helps determine whether I have cancer or not… Getting treatment for prostate cancer is also a problem for me because the cost is too high. (I7)

The "inverse care law" (Hart, 1971) postulated that the availability of good quality medical care tended to vary inversely with the need of the population served. From birth to adulthood to old age, the poor experience disease, illness, and medical care in a different way than the general population do (Reilly et al., 1998). For instance, one participant suspected that his doctor did not check his prostate because the service was not covered by his health insurance:

> The major issue is that your doctor may not check your prostate during examination if the service is not covered by your health insurance. If your union health benefit covers the service, then your doctor will do a more thorough check-up during an outpatient visit. (D2)

Undocumented immigrants face additional barriers when they seek medical care or cancer screening services. First, they are not willing to be identified within the service systems, for fear of deportation (Ma, 1999a). These immigrants survive in their own indigenous communities, live below poverty level, and receive no services from the public domain, despite their high vulnerability to diseases and disabling conditions due to poor working environments and overcrowded living conditions. One participant said she knew many people who worked at garment factories had no insurance. Due to lack of health insurance and undocumented status, they would not seek medical care from a hospital.

> Those who work in the garment factory are undocumented and they seldom travel out of state. Those with the (insurance) card can go to the hospital. The doctor will tell them everything they need to know. People working at the garment factory are usually undocumented or old. They cannot work in the restaurant because they don't understand English. (I5)

Undocumented individuals tend to seek medical services from private unlicensed practitioners who lack advanced diagnostic equipment and are incapable of treating acute or serious illnesses. A participant in this study admitted that she visited an unlicensed practitioner who sent her blood samples to the laboratory in a hospital through illegitimate channels:

> Some of my friends' income is just above the poverty level and they are not eligible for government funded health insurance. They also cannot afford to purchase their own health insurance... I used to do annual physical examination at a private doctor's office. It is a private doctor and her office is on East Broadway. The "doctor" is not licensed. I asked her where she sent the blood test if she didn't have a license. She said she had connections with someone at a hospital and she could get lab result from there. The result was sent from the hospital but not from her. (I6)

Since there is no accountability in the chain of custody of the blood samples, the samples could be adulterated or be mixed up in the process, causing potential risks of misdiagnosis to patients.

Cultural Barriers – Embarrassment and Privacy

Cultural beliefs such as modesty on the topics of sexuality, reproductive organs, and the body may contribute to the delay or failure to participate in cancer screening (Mo, 1992; Lum; 1995). Modesty is cited as a barrier inhibiting Chinese women from obtaining Pap smear (Hoeman, Ku, & Ohl, 1996). Based on Chinese cultural beliefs on the role of women in the society, their reproductive functions as well as other culturally defined role behaviors, fear of sexual exploitation by a health provider during Pap smear screening was a factor which

impeded Chinese women from seeking gynecological care (Mo, 1992). The findings of this study were consistent with previous studies. Several female participants (39%) shared these beliefs and felt embarrassed when they received cancer screening on their reproductive organs. This cultural barrier inhibited them from discussing issues and concerns with their providers openly during cancer screening. One participant affirmed this belief:

> I always thought that seeing a doctor for these kinds of health issues (breast and cervical cancer) is embarrassing… I just feel uncomfortable (Other participants in the focus group smiled and nodded). I don't know how to discuss this with the doctor. (B4)

Compared to female participants, only two male participants (10%) shared the same reticence. For instance, one participant heard from his friends that they felt embarrassed and uncomfortable when their doctors touched their genital organs during prostate cancer check-up:

> Since prostate cancer check-up is performed on your reproductive organ, people feel uncomfortable letting the doctor examine their genitals… They feel embarrassed and uneasy when they ask for a digital rectal examination to check their prostate. (I4)

Several male participants commented that Chinese were relatively traditional and conservative in sex. One participant commented that while he was open talking with his doctor about his concerns on prostate related issues, he also noticed that most Chinese did not do so because they were more traditional in their thinking:

> This attitude is typical of the traditional beliefs of Chinese culture. I had similar experience too. I saw a Hispanic doctor because I could speak Spanish. We were open and talked about many things. My doctor asked many questions and we were like friends. I told him my concerns about my prostate and he would give me treatment. Chinese were different and their beliefs were conservative and more influenced by Confucius

thoughts. (D10)

Some participants associated prostate problem with sexual indulgence. This assumption made them uncomfortable discussing their prostate problem directly with their doctor. Unless they were asked specifically about their prostate, they would not bring up the subject themselves. For instance, one man commented that the doctor would ask his sexual behavior and sexual relationships, but he would feel uncomfortable if he had to bring up the subject with his doctor:

> I think many Chinese are still relatively traditional when it comes to this subject. If the doctor does not ask you specifically about this problem, you may not want to take the initiative to bring up the subject of whether you have sex or not. You will not tell the doctor directly about this. If the doctor asks you specifically about this issue, then you will tell him… Will you tell the doctor about your condition and what happens between you and your wife? I don't think so. I read newspapers and magazines and learn about the relationship between prostate and sex. Often times, the doctor will not ask you these questions. You will not tell the doctor about these issues either. I think this reflects that Chinese in general are conservative in their attitude on sex. (D5)

Because of cultural barrier, several female participants preferred seeing female doctors for women's health problems. They believed that female doctors could understand their concerns and feelings better. In turn, they could communicate better with female doctors.

> Well, of course, a female doctor... I always prefer seeing a female doctor. I think it is easier for me to talk to a female doctor. (B3)

> I am worried about coming to the health center for women's health because I may see a different doctor each time. If it happens to be a male doctor, then I will be really scared…I probably would give up seeing the doctor because …when I see a male doctor, I don't know what I should say… I prefer seeing a female doctor... there are many things that I don't feel comfortable discussing with a man. (B2)

> It is easier for us to communicate with each other...You feel

> differently…your feelings…a woman's feelings… it's not the same when you share your feelings with a man. (B6)

There are exceptions to this view. For instance, only one woman said that seeing a doctor of the opposite gender was not a problem for her. She would pick a doctor who had skills and professional ethics over one of the same gender:

> I think it depends on what you think is more important. If you think you will feel more comfortable seeing a female doctor, then you see a female doctor... I would pick a doctor who is good. It doesn't matter to me if the doctor is a male doctor. (B4)

By and large, the doctor's gender is not a problematic issue for male participants in this study. They claimed no preference on the doctor's gender but that might be because most urologists are men. For instance, one male participant also believed that the doctor's professional skills and ethics are more important than his or her gender:

> Most urologists who treat prostate problems are male. A male patient will not have any problem seeing a male doctor. I also do not have any problem seeing a female doctor. This is their professional practice. The doctor will expect me to bring up these issues…Since they are specialized in treating these medical problems, I will bring up my questions to them. Similarly, there are male obstetricians who deliver babies. Therefore, I don't think gender is an issue. (D8)

Summary

The majority of participants in this study considered cancer-related problems as more important compared to other health problems that affected Chinese immigrants. They believed that cancer was common in the Chinese community because many Chinese suffered from it. Although they recognized that cancer was more common in recent years, they knew very little about the

disease. About half of the participants were compliant with annual cancer screening activities. For those who were compliant with annual cancer screening, they showed positive attitude toward cancer screening. Many participants also understood the benefits of early detection of cancer.

When being asked what made them go for cancer screening the first time, only one third of participants could provide specific reasons, namely personal health concerns, family history of cancer, or referrals from a health care provider. Participants described a number of factors that helped promote cancer screening in the Chinese community. One important factor was to improve access to screening by providing low cost or free screening service. Peer and friend encouragement also acted as an impetus for Chinese immigrants, especially women, to get cancer screening. Many participants indicated that they received general health and cancer screening information through friends and peers. Therefore, the “word of mouth” approach appears to be an effective method in promoting cancer screening services in the Chinese community, especially for female individuals who work in garment factories. In addition, some regarded that having celebrities talk about their own experiences also helped promote cancer awareness.

While many participants received health and cancer information from friends, peers, mass media, workshops and outreach activities, none indicated that they heard about cancer directly from their doctors during clinical visits. Lack of health education from primary care providers and lack of prevention orientation for health care services were cited as barriers for participants. Other

major barriers to cancer screening included lack of health insurance, concerns about cost of health care, as well as and cultural barriers such as embarrassment and modesty. In addition to socioeconomic and cultural barriers, many Chinese also experienced frustrations with the health care delivery system and communication issues with their health care providers. Physician-related factors and health care delivery system factors will be discussed in the following chapter.

CHAPTER EIGHT

SYSTEM BARRIERS TO CANCER INFORMATION AND CANCER SCREENING

Introduction

The Systems Model of Clinical Preventive Care (Walsh & McPhee, 1992) is unique in its focus on both patient and physician factors that affect cancer screening. Both patient and physician factors are influenced by other factors such as health care delivery system factors. The previous chapter described patient factors due to education level, low socioeconomic status, and cultural barriers that affected cancer knowledge and cancer screening behavior. This chapter will explore physician-related factors and health care delivery system factors that affect the perceptions and behaviors of Chinese immigrants.

Perception of Quality Health Care

The quality of health care patients receive is important because patients rely on doctors and other health care workers for treatment and health related information. One participant commented:

> I think the service in the U.S. is incredibly good. Health care is important for us to maintain health because I do not know anything about health. With help from my doctors and other health care workers, I then know more about how to remain healthy, what I should eat and what I should not eat. I would not know how to maintain health without any help from them. (I8)

Patients regard the quality health care as good when their doctors are kind, thoughtful, and attentive to their needs and concerns. Chinese immigrants who participated in this study felt the same. In our current health care environment, doctors have competing demands and busy schedule. Therefore,

patients especially appreciate doctors who are willing to spend time listening to their concerns. For instance, some participants compared their health care experience in China with that of the U.S. They were very impressed with the enthusiasm of the American doctors and the quality of care they provided:

> I felt that overall the doctors were pretty good. Their attitudes were better than those in China. When I walked in, I was so afraid and worried. They calmed me down and told me not to worry…Their attitude was very good. They helped me relax and told me step by step about how to do the breast self examination. I was thankful to all the doctors who were so kind to me. I was so nervous that my hands were shaking at that time. They held my hands gently and comforted me. They told me that I looked nervous during the examination and it wouldn't help. I was so touched that I began to cry. (C5)

> When they talked to me, they were thorough and patient. I kept telling her that I didn't hear her, so she repeated what she said. I felt that she was really nice. She was very patient. She said to me, "Take your time". I was a little scared in the beginning. She said it (the procedure) was no big deal and it wouldn't hurt. She asked me not to be afraid. I considered her service very good, very well thought out... It was good. It (the mammogram) was taken by a non-Chinese technician. She did not speak Chinese but she was very considerate. (I8)

Many Chinese have limited health knowledge and health literacy. They are not familiar with the health care system in the U.S. Therefore, navigating through a relatively complex health care system consisting of primary care doctors and specialists can be confusing to them. Patients are often puzzled and perplexed when they have to be seen by different doctors for the same condition. They prefer seeing a doctor who knows their condition well, has all of their medical records, and can take care of any and every medical problem they have. They also think that communicating and coordinating care between their family doctor and specialists are important. One participant noted:

> My family doctor has my medical record and knows my condition... he

> knows what medications I take. I think this is good because you don't have to look around for another doctor. You only have to see your family doctor. I think it is better because your doctor has your record. You go back to see the same doctor every year for physical check-up. Your doctor has your medical record, x-ray results, etc. I think it is better that your doctor has all your screening results and other reports… I didn't have to wait long to see the specialist. My family doctor called the specialist and then I just went... After I saw the specialist, he sent the report to my family doctor. He let my family doctor know the size of my prostate…They communicated with each other...If the specialist did not communicate with my family doctor, I would not get good care. (I13)

To Ask or Not to Ask – Communication Barrier

Maintaining good communication with the family doctor and knowing that the doctor is fully aware of your health status and concern make the patient feel relieved and relaxed. Unfortunately, this was seldom the case for our Chinese participants. In this study, only two participants reported good communication with their doctors, but nine participants reported having problems communicating with their doctors. Language and communication difficulties are major barriers to accessing health care services among Chinese immigrants (Ma, 1999a). Despite the long length of stay in the U.S. (average = 15.7 years), the majority of participants in this study were monolingual Chinese. As indicated earlier, only 8% of participants said they spoke English well; 55.2% said their ability to speak English was poor or did not speak English at all. Those who were limited in their English abilities were either elderly or had little formal education. Language barriers and low education level were two major factors affecting health-seeking behaviors of Chinese immigrants and the quality of care they received.

The majority of participants in this study routinely visited Chinese-speaking doctors for health care. Naturally, very few of them expressed

language difficulty when visiting the doctors. But ironically, although both the patient and the doctor spoke the same language, patients were still frustrated about not being able to discuss with their doctors more fully about their needs and concerns or their health problems, primarily because the doctors had no time for questions or discussions with their patients. Not being able to ask questions coupled with unfamiliarity with medical terminology can adversely affect the treatment process and health outcomes. A study by Ashing et al. (2003) confirmed that many Chinese had concerns about their communication with their doctors. In this study, one participant commented:

> If you are talking about patient's rights and doctor's responsibilities, our situation is far from ideal. Doctors can only marginally fulfill their responsibilities because they do not work hard enough. I don't believe doctors have magic. American doctors tend to spend time assessing the patient's conditions thoroughly. At least these doctors will listen to you and hear your concerns. I have real feelings and legitimate concerns. The doctor needs to understand my concerns and feelings in order to treat me adequately. Sometimes the doctor may think that I am nagging. I ask myself why I can't talk about my condition and feelings if I have legitimate concerns. For example, tolerance of pain is different for everyone. How can he assess the level of pain, whether it is painful to death, very painful, or painful? How can he use a machine to detect my level of pain? I think I am more aware of my pain to tell the difference between needle pain and chest pain. I know it better than anyone else. If the doctor does not ask clearly but just jump to conclusion, he may cause harm to the patient… Sometime I do not want to argue with the doctor or to upset him because I still need a prescription from him. What I can do is to find another doctor. After a few visits, I may switch to another doctor again... I went to the New York Eye and Ear Center to treat my dizziness. I did not know anything about my condition and it was hard for me to communicate with the doctor there. So I can only see a Chinese doctor. (I4)

In the Chinese culture as in many others, physicians are perceived as authority figures (Lee, 1998). Not asking questions also reflects Chinese cultural values that focus on harmony, respect the authority, self-control, tolerance,

politeness, and avoidance of confrontation. Valued behaviors such as assertiveness and directness in Western cultures are foreign in Chinese culture, whereas patience, compassion, and selflessness are essential to the achievement of a good life (Ma, 1999a). To maintain harmony with the social environment, Chinese patients, especially the elderly, do not openly challenge their health care providers, even when they disagree (Chen, 1996). The Chinese value of consideration for others causes patients to withdraw their ideas if they believe they would inconvenience others. Like many other elderly patients, the participant whom we previously quoted did not want to displease the doctor even though he disagreed with him. He also felt that he had very limited health care choices because he could only see a Chinese doctor due to language barrier. Several participants in this study shared the same view. They noticed that doctors were very busy. They tried to be considerate and not to be rude. As a result, they did not ask questions even though they wanted to find out from the doctors about their concerns:

> If I am not feeling well, then I will ask. If I don't have any problem, then I will not ask. (I2)
>
> I have heavy bleeding during my menstrual period. I did not ask the doctor about it. The doctor was busy doing the examination and I was not comfortable asking her so many questions. (C5)
>
> I noticed that they (the doctors) were very busy. When you asked them questions, they seemed impatient and they were not willing to answer. (C2)
>
> I do not have sufficient information about what to do next...The doctor seems too busy to explain anything to us... We generally do not want to ask questions. Doctors will not have time to listen to us. Doctors always have a full schedule. Therefore, they have no time to listen to us. He only examines you and then schedules the next appointment for you. If every patient talks for 20 minutes, the doctor will not be able to see everyone.

> The ideal situation is that the doctor can talk with us, but he has no time and he will not allow us to talk more. (A3)

> A good doctor usually has many patients. After the test, they do not talk much, maybe just a few words. Then, they will send you away. (D8)

Most Chinese patients chose not to raise questions because they wanted to be considerate to the doctor. But for some other patients who did ask their doctors questions, they were met with criticism and ridicule in return. Two participants stated that when they asked their doctors questions, they were either told that their questions or concerns were unimportant, or at times they were criticized for asking.

> I wanted to come here for screening. Before I registered, I asked a lot of questions. A female staff said to me, “Why do you have so many questions?”... I came for breast cancer screening. I felt a lump near my underarm, something like a “secondary” breast. I asked the doctor. She said, “Why do you have so many questions?”... So, I said, “How come there is “an additional thing” here (points to the underarm area)? If it is breast cancer, wouldn’t it grow in the actual breast and not over there? (Laughed) “So, why do you have so many questions?” (B2)

> Last time I went to see a doctor because I had a common cold and a stomach problem. The doctor kept asking whether I had a cold. I said the cold was gone but I had a stomach problem. He then said I seemed to have a lot of problems. I asked him what he really meant and why he said I had so many problems. He asked why I kept asking him questions and I said I just wanted to find out more. I did not understand what the doctor was saying. So I asked him to repeat. He said, “You have a problem with your hearing?” I told my wife what happened. She said she also had similar experience with the same doctor. I heard that this doctor had treated many other patients much worse. (A5)

Patients suffer serious consequences if doctors do not take the time to explain things to them, or do not allow them to ask questions. For instance, one participant mentioned that her friend almost died and had to be hospitalized immediately. Apparently she took the doctor’s advice to receive an injection but

had no idea about possible side effects of the shot.

> Seeing how everyone (health care providers) was so busy…I didn't want to be rude and interrupt their work... But my friend had a bad experience. She had heavy bleeding during her menstrual cycle. So, she went to see a doctor. Her doctor said, "It doesn't matter. I will give you a shot." Then, after the injection, she went home. After a short while, her family found out that she was not well. She almost lost consciousness. Then she called her doctor. Her doctor said, "You better call an ambulance immediately." She was immediately taken to the hospital. By then, she almost died…if you just saw this doctor and simply took whatever the doctor said (without asking questions)…it would be very dangerous. (B3)

Many participants expressed frustration about doctors not answering their questions or not explaining things to them. They were often made to feel that their questions were trivial. Some decided not to argue with the doctors because they did not want to displease their doctors. There were a few others who believed that they did have the right to ask questions or learn about their condition. One participant noted:

> Many Chinese see the doctors but just let the doctors tell them what to do. Patients have their rights. They have the right to ask the doctor questions. I also find out that many Chinese doctors do not tell patients about their diagnosis. They will not tell you the diagnosis if you do not ask. Maybe they want to refrain themselves from telling you the wrong things. It is ridiculous if they do not tell patients their diagnosis or what's wrong with the patient… Some doctors are very "smart" and they do not tell. Maybe they think they cannot be held accountable if they do not tell the patient their diagnosis… Chinese patients tend to be passive and they are afraid of asking questions. Maybe it is because they have low self-esteem. They think that because they are not doctors, they do not ask or assert their rights. Although the Patients' Bill of Rights is displayed clearly everywhere, I am not sure how many patients actually read it. (I4)

Not having proper communication with health care providers was the most frequently mentioned source of frustration for participants when they sought health care and cancer information. On the other hand, listening to patient needs and concerns and encouraging patients to ask questions not only

increased patient satisfaction but also helped patients understand their condition better, which in turn improved patient compliance to the medical regimen.

Too Busy and Impatient

Taira et al. (2001) found that after adjustment for socioeconomic and other factors, Asians had the lowest primary care performance assessments among all ethnic groups. Compared to whites, Asians had lower scores for communication with primary care doctors. In the same study, doctors were found having very low knowledge of their Asian patients. The findings of this study were consistent with another study (Taira et al. 2001) that participants had poor communication with their doctors. Many participants in this study perceived doctors as busy, inpatient, sloppy, and uncaring. They complained that doctors, especially those in private practice, were extremely busy because they needed to see many patients every day. Medicaid reimbursement rate for the doctor's visit in a private office is much lower than that of government affiliated clinics or federally qualified community health centers. Many private health care providers in the Chinese community tend to see a large number of patients every day to support their practice. One participant complained about his doctor being very inpatient, sloppy in his examination, and was rushing patients in and out:

> When my friends finish seeing the doctors, they just leave (without asking a question). The doctors do not explain what they have done for you… Some doctors are not compassionate to their patients because they probably have seen too many patients... they are so inpatient when they are in session… I brought my mother to a doctor. When I got there, they just said, "That's it. Where? Just tell me about here (a particular part of the body). I am not checking there (other parts of the body)." (Laughter) I'm like: "Are you kidding me? How could doctors be like that? I know older people are chatty, but still they should not be treated like this. If you say this part hurts, the doctor just focuses on this part. You can't talk

> about other places that hurt or it hurts over there. He won't listen…I think there are doctors who really care about you and are willing to communicate with you. Some doctors don't have that motivation. After they finish checking, they just want to rush you out. (B4)

What appeared to matter most to participants was not their doctors' reputation or skills. Rather, they preferred seeing a doctor who was compassionate, patient, and willing to listen to their concerns. For instance, one participant was very unhappy with his doctor who was quite popular but saw many "customers" every day. He preferred seeing a doctor who had good reputation and was patient and thorough in his examination:

> It is better not to see those doctors who are very popular and busy. Since these doctors are so popular, they have many "customers". These doctors tend to be cursory in their examination. I was recommended by someone to see a doctor for my asthma. I only went to see this doctor once or twice. The doctor only spent five to ten minutes with me. I prepared what to tell the doctor about my status and symptoms and how I felt. However, the doctor was very inpatient to what I said... If a doctor does not fully understand my status and concerns and makes the diagnosis quickly, I will not pick this doctor... I would rather pick someone who may not be as popular but are highly regarded by other patients and will take the time to examine their patients. My current doctor is quite popular. I find that I have to wait for a long time for an appointment. I have to wait even more in the exam room. The doctor only spends less than 10 minutes with me. He used his finger to examine my prostate and then ask me to leave. (I4)

Lack of Trust

As a result of lacking communication with the doctor, patients often expressed a great sense of distrust regarding their doctor's professionalism and integrity. Several participants believed that they were "cheated" by doctors who performed check-ups superficially and casually. They were also unsure if certain medical procedures were really medically necessary. For example, one participant questioned the doctor's examination procedures and believed that

certain procedures were either done in a sloppy manner or were medically unnecessary. As a result, he concluded that he was being exploited by the doctor:

> The doctor already knew my blood pressure level and whether I had problems with breathing or not. He did the examination superficially. Did he scam me? I really don't know. When he checked my blood pressure, he did not even ask me to take off my clothes. If it is blood pressure check-up, I can understand. But if they had to check my breathing, I couldn't quite understand why they did not ask me to take off my clothes. I usually wear many layers of clothing in the winter and they did not ask me to take off my clothes. They must be scamming me! They already know my condition. In China, quality medical care means doctors examine their patients carefully to find out if there are any minor changes in the patient's condition. If he heard some noise from my chest, he did not know whether it came from my lungs, or whether it was one piece of clothing rubbing against the other. If they examined me like this, they must be cutting corners. They said they used x-ray to check whether or not you had pneumonia. And then they said you were fine. I could have confronted him but I did not. Because they have a machine to check your colon, they will persuade you to go for a colonoscopy so that they can bill you. Many doctors in Chinatown are like that, but we still need to count on them to get the care. They have poor ethics and they just want to make more money. I am not against them making money. If they are not working for money, then what are they working for? But then they are also too unethical. (I3)

Some participants believed that services they received from private doctors would be more comprehensive if they had good insurance coverage. They would get reminders when they were due for screening appointments. On the contrary, low income people believed that they received sub-standard care because of lack of health insurance.

> I think my doctor is quite responsible. She will remind me when I will be due for my annual screening. Maybe it's because I have private health insurance, my doctor will recommend me to get more comprehensive screening services. Low-income people can't afford private health insurance. (I6)

When you get screenings by a private doctor, the doctor is good and

> reads your results more carefully. When you call a public clinic and say that you want to get a check-up, they say, "checking for what?" I don't know (laughed). They cannot perform ultrasounds here? You have to go elsewhere to get it. It takes like 3 months (to be screened). By then, you'll be dead...Right! Three months, they said. They just see if there is a time slot for you. Then they say they will call you. (B5)

For uninsured or under-insured low-income Chinese, the main concern is health care cost. It will be a big financial burden for them if they are asked to see the doctor several times for the same concern or symptom. Therefore, they question as to why it is necessary to see a doctor many times for the same illness. Lack of communication with the doctor is the main factor attributing to such misunderstanding. When patients are uninformed about the necessity or the importance of certain procedures in the treatment process, they begin to question the intent of the doctor's recommendation. Several participants mentioned that doctors simply asked them to return for follow-up appointments without explaining to them about the treatment process and procedures. They then assumed that doctors were simply seeing them for more money, and that they were often over-charged and exploited:

> After you see them (the doctors) and you probably don't even have an illness, they say "see you next time"… Once I went to see a doctor and I probably did not have any illness… But he told me to come back 4 to 5 times to check for the same thing. He wanted to be paid. He would collect money for doing the same thing. (B4)

> The majority of doctors in Chinatown are for money...The doctor told me that mayor Giuliani had a PSA test. His PSA level was 5 and the mayor went for surgery. I did not think that surgery was necessary in my case. I think that when the doctor wants you go for surgery, he would exaggerate your PSA result several times... the doctor asked me to go for surgery too. At that time I learned that prostate problem was very common among elderly men. Therefore, I went for surgery. But the question was: after the surgery, the biopsy result was normal. How could he explain the fact that my PSA level was abnormally high before? That was the problem.

> That's the reason why I said if the doctors in Chinatown wanted you to have surgery, they somehow exaggerated your PSA results so that they could admit you to the hospital for surgery. (I3)

> Last year I needed to travel overseas but no flu vaccine was available at the health center or at the senior center. Therefore, I asked around and found a place where I could get the shot. Do you know how much they charge me for that? When I received the bill, it was about $160... They are still sending me bills. I didn't know that they would charge me that much. I saw the bill and they charged me $160! So, I cannot say that this doctor was ethical. (D9)

Uninsured patients were not the only ones who believed that they were overcharged, exploited, or scammed by their doctors. Patients who had government-funded health insurance, such as Medicaid or Medicare, were also skeptical of the necessity of certain treatment procedures. One participant who had insurance believed that examination and treatment for things that she did not complain about was medically unnecessary. In fact, she questioned why her doctor had to check on so many things:

> If you're not sick but you are seeing a doctor only for health screening, it will cost about $1,000 or at least a few hundred… if all the doctors in the world are so kind hearted, then it would not be an issue. But some doctors actually take advantage of you and they scare you … I ask to check for one thing but they check for other things as well…and it never ends…I do have insurance, but I am very much against doctors milking the system by ordering one test after another. One will think that the doctor may be committing a fraud. If you think I have a problem, you should just give me medication, right? (B3)

Due to poor communication and mistrust with doctors, several participants in this study questioned the integrity of their doctors and concluded that they were taken advantage of by their providers. For instance, one participant saw an urologist but felt that the doctors did not really care about him but saw him just for money:

> I want to emphasize that whether the doctor is good or not depends on his or her professional ethics… When you see a cardiologist for check-up, it usually costs you one or two thousand dollars. For a minor thing such as examining your colon costs you one or two thousand dollars. Most of the time, they are more concerned about making money but they do not really care about you… In the past 7 years, I have seen many doctors for my prostate problems… All the doctors, except for a non-Chinese doctor, are no good and I am not satisfied with any of these doctors. (D7)

Another participant then gave an example of his urologist charging Medicare for an ultrasound that was never performed. He concluded that he was being exploited by the doctor and considered this doctor unethical:

> I have known a doctor whose office is on Canal Street. He is very popular and has many patients…he's affiliated with a good hospital. He is young and has publications related to urology. I went to see this doctor. I understand some English. I used my Medicare card. After the visit, I received a bill from Medicare that listed the items charged by the doctor. Quite often this doctor only saw me for a routine visit. But every time I checked the bill I noticed that some services, such as ultrasound, were never rendered to me but were billed to Medicare. I know what an ultrasound was like and what the procedures involved. The test was never performed but was sent for billing. Other patients who do not know English will probably not check the bill. They may not know that they are charged for an ultrasound. Medicare pays for it anyway and they do not pay anything out of pocket. Sometimes I wonder whether I should report the doctor for Medicare fraud, or whether I should file a complaint against him. I did not. This doctor is very popular, but he is really unethical. If the services were not rendered, then why should they be billed? (D7)

Scheduling of Doctor Appointments and Long Waiting Time

In the health care environment, both patient and physician behaviors are independently influenced by factors such as the health care delivery system (Walsh & McPhee, 1992), access to care, reimbursement, and government regulations. Chinese patients encounter systemic barriers to health care as do members of other ethnic groups. Systemic barriers such as long waiting time, lack of availability in the doctor schedule, high costs, inconvenience, and

fragmentation of the health care system, are common experience to many of our Chinese participants, especially new immigrants. Many study participants (14) considered the healthcare system in the U.S. as not user-friendly. They complained about the long wait for the next available appointment and doctor's hours not fitting their work schedule. Lack of immediate availability in the doctor's schedule and not having after work hours appointments made it difficult for many to attend cancer screening or get medical care. For instance, one participant described the red tape she went through when she went to a public hospital. Before she could even schedule a doctor's visit, she had to get a clinic card, but it took her 3 trips to the hospital just to get registered:

> Last year, I wanted to register at a public hospital because I didn't have insurance at the time. I went 3 times but still couldn't get a clinic card. The first time, I waited on line for a long time. At the end of the day, they told me that I needed to go to another office. I came back a second time, I went early to the hospital but the office was closed because of hospital holiday. The third time, I went again and when I got there, a staff told me that I had to go to a different office first. After waiting there for a long time, they told me that I had to see a head nurse first. So, I had to wait on another line again to see the head nurse... After seeing the head nurse, I went back to the office again to register for the visit. But when I went to the clinic, it was already 12:00 noon and the clinic was closed for lunch. I went to that hospital three times just to get a clinic card. I felt so frustrated. I took a day off from work every time. So, finally I went to the manager. He said, "There's nothing that we can do. Come early next time." I said to the manager that I got there since 8:00 in the morning! … I originally thought that I would get better service at a public hospital but ...I went 3 times and waited for a whole day each time just to get the clinic card. I did not even get to see the doctor yet! If I were acutely ill and I had to go to this hospital, I would be dead by the time they got to me! (B2)

Other participants complained that appointment time did not fit their work schedule and that waiting time during the visit was also too long. Lack of accessibility after work hours made it impossible for many Chinese immigrants to

seek preventive screening because they could not afford taking a lot of time off from work. Two participants noted:

> This year, I couldn't find an appointment at the health center that fit my schedule, so I switched to another place for my check up. There is no Sunday appointment at the health center... Sometimes even when I take a day off to go to my appointment, when I get to the clinic, I still have to wait for a long time to be seen. This can be very annoying. This affects my job because I have to take time off in order to keep the appointment. Because of this concern, some people just don't go for check up… Sometimes seeing the doctor just takes 2-3 minutes. But then you have to wait half a day just to see the doctor.... It happened to me in the past. I saw the doctor just for a short while but had to wait 1-2 hours, so I was upset... I hope that I can make an appointment on Sunday because it is my day off. It won't affect my work and I can wait to be seen if I have to. There is nothing that I can do about it... If the center is open on Sundays, many of us will be able to participate in screenings since most of us do not work on Sundays. If I can schedule an appointment on Sunday, I will come... Many Chinese are very busy and have to work. (I1)

> The waiting time was very long. The appointment was for 9:30 a.m. and I was there (the hospital) on time. I should be seen on time. The reality was that the appointment was at 9:30 a.m. but I didn't get to see the doctor until 11a.m. It happened twice. I also had appointments at another hospital ... I was referred to this hospital for specialty follow up because of family history… They referred me to get an X-ray. I waited for a long time even though I was on time for my appointment. The examination took only 10 minutes. However, you had to spend a half day there just waiting. (C3)

Aside from the long waiting time during doctor's visits, other participants complained about the lack of immediate availability of triage appointments, especially when they were experiencing acute symptoms.

> Annual screening is sometimes not enough. For instance, I go for check up every year. In year 2001, I had a lump. A year later I did the check-up again and I had two more! ... If you need to get an ultrasound or other tests at this hospital or any other government-funded hospitals, you need to make an appointment…But the wait for the next available appointment is at least 3 to 6 months. If you really have an illness but you have to wait 3 months, you will die before an appointment is available. (B2)

> The doctor who had cytological equipment gave me the same physical

> examination again. I had to wait two to 3 months for the cytological test appointment. This really bothered me. I was referred to the cytologist in December the year before (2002). I was scheduled to have the cytological test in late March the following year and got my report in April. It took 5 months to complete the entire process: scheduling appointment, completing the test, and obtaining the result. The process took too long. If it were cancer, I might not have lived that long. Fortunately, prostate cancer progresses slowly. Otherwise, I might not have lived to see the result of the test. (A6)

Referrals, Follow-up, and Screening Results

The American biomedical model tends to isolate and compartmentalize ailments. This model emphasizes on specialization which results in fragmentation in its service delivery design. It not only conflicts with the holistic views of health and illnesses in the Chinese culture (Ma, 1999a), but also causes confusion to Chinese patients when accessing necessary medical care. Liang et al. (2004)'s study reported that Chinese immigrants were used to a different healthcare system in their home countries. In China, patients do not need to obtain physician referrals prior to a specialist visit, nor are they required to make advanced appointments or wait for weeks or months to see a doctor. This is very different from the referral system in the U.S., which involves an extra step of getting approval from primary care doctors in order to see a specialist. Several participants in this study complained about having to wait too long before being able to meet with specialists to discuss their health concerns. One participant noted:

> They want you to register and then be put on a waiting list…I went there in person and I tried to schedule an appointment to see a specialty doctor. I waited for months but still not get a slot. By the time they got to me, I probably would be dead. (B4)

As compared to middle class patients who often initiate and coordinate

their own medical care, socioeconomically disadvantaged and less educated patients often rely heavily on physician referral for cancer screening and treatment (Liang et al., 2004; Loehrer et al., 1991; Yu et al., 2001; Dunkel-Schetter, 1984; Northouse & Northouse, 1987). Physician recommendations based on cancer screening is very important to this population, which has little concept of preventive health care to begin with. In addition, patient adherence to cancer screening guidelines largely depends on the amount of information and support they receive from physicians, and the physician's ability to perform cancer screening. For instance, one participant learned about breast self-examination directly from her doctor. She followed the doctor's instructions and went to the hospital when she felt something went wrong:

> The doctor teaches me how to do breast self-examination every month to detect breast cancer. If I notice something "like a mass" in the breast, I should go to the hospital immediately. So, of course I will do it and get screened each year. The doctor teaches me how to it. (B6)

However, this woman was atypical in this study group. Only 4 participants (10%) reported that their physicians performed cancer screening or they got a referral from their physicians to receive cancer screening. This finding was consistent with results from other studies, which found that lack of physician referral was an important barrier for the low use of cancer screening among Asian American women (Yu et al., 2001; Harlan et al., 1991; Lee et al., 1999). Two male participants were convinced that primary care doctors or internists should routinely perform prostate examination as part of physical examination for elderly men:

> These days, primary care doctors examine their patients superficially.

> They said the examination was comprehensive. They looked at your eyes casually and commented you had big eyes and that was it. They did not perform digital (finger) rectal examination. The internists that I knew did not perform the digital rectal examination...not if I get my physical check up from doctors who were specialized in that area. If you saw an internist or a cardiologist, they would not check your prostate…The family doctor or internist should know that they need to check your prostate. They should do so especially when they see elderly patients. They just don't do it nor do they care about it. That's the problem. (I3)

> I notice that a comprehensive physical examination may not include prostate cancer screening. I suggest that full physical exam for males should include prostate check-up because most of the time, patients may not ask for it. They may feel embarrassed…The situation is very different for female patients. Annual check up for female patients usually includes breast examination. We should learn from that practice. Prostate cancer screening is very important for male patients, just as breast cancer screening is important for females. Therefore, if breast cancer screening is an integral part of preventive care for female patients, then annual examination for male patients should include prostate check-up. (I4)

Another complaint reported by several participants was that they did not receive the report or screening results after they attended the screening. For those who received a report, they were not told what to do next or whether they needed to return for additional visits. This made it harder for them to receive further treatments or necessary follow-up services.

> After the screening, the report indicated that I have an enlarged prostate. It did not tell me what I should do next, when I should come again for another examination, or what I need to do. (A1)

> They were supposed to give you a report. Instead they just told you to call back in a few days. A few days later, you called the doctor and he said your screening result was negative. They did not even give me the written report. That is not right?! I think the doctor should give me the report after the test... I used Medicare to see the doctor and the doctor was already reimbursed by Medicare. The doctor should be responsible for my care and give me the report. But he didn't. (D8)

Summary

The findings of this study were consistent with previous studies on the

importance of patient-doctor communication and relationship. In the Murray-Garcia et al. (2000)'s study, Asian Americans were significantly less satisfied with physician performance than whites, blacks, and Latinos (Murray-Garcia et al. 2000). In the same study, Chinese people were even more dissatisfied than other Asian groups on communication with physician, discussions focusing on prevention, and physician accessibility. Taira et al. (2001) also found that Asians had the lowest primary care performance assessments among all ethnic groups. Compared to whites, Asians had lower scores for communication with primary care doctors.

Many Chinese patients in this study experienced similar difficulties in their communication and relationships with their health care providers. First, Chinese immigrants had limited health knowledge and health literacy. They also did not understand how the American health care system worked. Therefore, navigating a relatively complex health care system consisting of primary care doctors and specialists could be a challenge for them. Very few participants expressed language difficulty when they saw the doctors. However, many of them were frustrated about not being given the opportunity to communicate with doctors adequately or to express their health concerns. They complained about doctors being extremely busy and had no time to listen or explain things to patients.

While participants sensed that their doctors had no time for them, many chose not to ask their doctors questions because they did not want to displease or inconvenience the doctor. Some chose not to argue with their doctors, even though they disagreed with them. They just moved on and found another

provider if necessary. Those who asked questions were met with arrogance, ridicule, or insensitivity by their doctors. A few participants believed that they had the right to ask questions and learn about their condition. But because of negative experiences, many participants concluded that their doctors were sloppy, uncaring, money-hungry, or even unethical. Because the doctors did not take the time to explain to patients the purpose for follow-up visits, some patients questioned were skeptical of the necessity of repeated visits for the same illness. Others believed that examination or treatment performed in certain areas other than their primary concern was unnecessary. Growing mistrust between patient and doctor was by and large a result of poor communication as well.

Access barriers to the health care delivery system such as red tape and bureaucracy, lack of availability in doctor schedule, long waiting time in clinics, high costs, and fragmentation of medical care system, were typical stumbling blocks Chinese immigrants come across. Many participants in this study considered the American healthcare system inconvenient and not user-friendly. They complained about the long wait for a the next available appointment and that clinic hours conflicted with their work schedule. They also complained bitterly about spending hours at the clinic waiting to be seen. These system barriers turned many Chinese immigrants away from seeking preventive screening. In addition, the emphasis on specialization and fragmentation of care in the service delivery design confused and frustrated Chinese participants who had little understanding of the American health care system. This lack of understanding hindered their access to necessary services. Several participants

also complained about the long wait for an appointment with the specialists especially when they were symptomatic and had a specific health concern. Others complained that their primary care doctor did not perform preventive screening for them or failed to refer them for screening.

Patients are more satisfied with their care when their doctors are kind, thoughtful, and attentive to their needs and concerns. Patients do understand that doctors have competing demands and busy patient schedule. But they still need their doctors to spend time listening to their concerns and answering their questions. In general, a doctor who spends time explaining things to patients are perceived as providing a higher quality of care compared to another doctor who do everything else the same but does not communicate well with patients. Patients who understand more about their health issues are also more likely to trust their doctor's judgment and recommendations and are more inclined to follow the medical regimen. Therefore, it is important that health care providers listen to the patient's needs and concerns and take the time to educate the patient on the necessity or importance of certain procedures in the treatment process, as it helps increase patient satisfaction and improves their adherence to preventive check up and screening.

CHAPTER NINE

HEALTH CARE AND CANCER EXPERIENCES OF CHINESE AMERICANS – SIMILARITIES AND DIFFERENCES AMONG SUB-GROUPS

Introduction

Most sociological studies on Asian Americans on the topic of cancer used quantitative methodology to identify factors such as level of acculturation, socioeconomic status, and education barriers that might associate with cancer incidence and mortality rates. Other studies assessed the level of adherence to cancer screening guidelines among the poor and people of color (U.S. DHHS, 1993; Breen & Kessler, 1994; Freeman, 1991). Only a few studies used qualitative research to learn about cancer screening and cancer experiences of Asian Americans (Ashing et al., 2003; Liang et al., 2004). Many studies were done on Asian American women on their level of adherence to breast and cervical cancer screenings (Yu et al., 1991; Jenkins & Kagawa-Singer, 1994; Standford et al., 1995) but very few were done on Chinese American males. Some studies focused on sub-groups of Asian Americans. For example, some studies assessed the participation rate in cancer control programs among Asian Americans of low socioeconomic background, as measured by their education and income (Katz & Hofer, 1994; Harlen et al, 1991). A few other studies focused specifically on Asian American elderly (Liang et al., 2004; Tang et al., 2000; Chen, 1996).

Previous studies on similar topics tended to consider Chinese as a homogeneous and aggregate group and overlooked intra-group or subgroup variations. This qualitative study is unique not only because there is little

research done on Chinese immigrants on their attitudes towards seeking cancer screening, but also because the methodology of this study also revealed rich data on sub-group differences. Stratified purposeful sampling was used to select subgroups so that variations among subgroups may be captured and comparisons could be made. Segmented sampling strategy was used to sort participants into separate groups (Morgan, 1995) so that similarities and differences of perspectives across different groups may be identified. In the recruitment process, conscious efforts were made to enroll participants representing variations in gender, age, preferred spoken dialect, education, income and resource level, as well as number of years living in the U.S. Diversity in demographic and socioeconomic background of participants reflects not only a wider spectrum of cultural beliefs and practice toward health, cancer, and treatment, but also differences in experiences when accessing health care services and resources.

The sampling design of this study allowed the researcher to capture variations of health care and screening experiences of Chinese immigrants based on their gender, age, spoken dialect, and insurance status. Therefore, this study found not only similarities, but also variations in health-seeking beliefs, health service utilization, and preventive and cancer screening behaviors among these subgroups. This chapter will discuss similarities and variations of participants experience on health care and screening based on differences in age, gender, and spoken dialect.

Aging – Raising Awareness and Consciousness

Aging appeared to be an instigating event that prompted many Chinese elderly to go for check up and cancer screening. The emergence of more physical symptoms, bodily changes, and signs of failing health served as wake up calls for many elderly to be mindful of their health and to utilize preventive health care and screening services. Several participants in this study confirmed that getting older and frailer made them realize that they were more at risk for chronic and serious health problems. Stories of many elderly falling ill to various ailments also made them feel very anxious about their health:

> To be honest with you, when I was young, I wasn't that keen on getting medical care. I was young then and I did not have any problems. But when I reached old age, I told myself that if I was not being proactive, I would not know what might happen to my body. I became more anxious about my health. (I1)

> When I was young and healthy, I was not worried about my health. But now I'm getting old and have many health problems. I am scared. (I5)

> I've been a coward. I am worried about getting sick. I have no choice but to get a check up. What if I have a disease? ... I am afraid of being sick. Now no matter what, I definitely go for a regular check up because of my age. I have heard a lot of elderly people doing the same. (C5)

Many elderly understand that as they get old, they are prone to develop various types of illness. Therefore, it is important that they go for check up regularly. For instance, one participant compared his body to a 'broken machine' which needed regular check up:

> When people are getting older, their bodies are like broken machines. Wear and tear of our body is to be expected. People may not realize what underlying problems they have. When they start having symptoms, it is usually too late. Having a routine check-up on your blood pressure, blood sugar, and prostate is very important. I usually go for an examination every six months. (A6)

Another elderly participant shared the same view. He commented that when he grew older, his body was like an old car that needed tune up and repairs. Therefore, attending annual screening was like getting a car inspection every year so that he might find out which part of his body needed to be fixed:

> An annual examination will tell you what is working in your body and what is not …Our body is like an old car which needs regular check-up. If some parts are worn out, they needed to be repaired. If your have high blood pressure, you need to find a way to control it… Especially when you are in your 50s and going on to 60, you may have health problems sooner or later. Therefore, it is important that you do something. If you don't have any health problems, God blessed you…But since I am getting old, I need to be mindful of my health. The health center provides screening services including blood tests, and I take advantage of it to find out whether I have any problem or not. I may not have any problem now. But if I do, I will find out sooner. The doctor told me that if we know about problems at an early stage, it is usually easier to treat. (A4)

Stress and Lifestyle Differences between Male and Female

Compared to male participants, more female participants believed that being happy and leading a stress-free life were very important to maintaining optimal health. Female participants tended to emphasize a holistic view and defined health as being both physically and psychologically well. They tend to believe that "mind" and "body" were inseparable entities because they influenced each other, and that being physically and emotionally healthy was important for long life and well-being. However, many women reported being under stress all the time. Sources of stress included living in America and having to endure hardships resulted from cultural and language differences as well as stress at the workplace. One possible reason for this difference between male and female participants' perception of life stress was that more female participants in this

study were still working. Seventy-two percent of female participants were gainfully employed, while only 25% of male participants were working. Male participants were much older (mean age 68.1) than female (mean age 43.6). The majority of male participants (65%) were retired. Naturally, the psychological pressure of working women juggling with responsibilities at home was far greater than men who were retired and had leisure time to engage in stress-reduction activities such as exercising and socializing.

In the Chinese culture, the values governing family life and responsibility are influenced by Confucianism thoughts, which emphasize common roles and proper relationships among family members (Ma, 1999). Within the family, caring for parents and young children is of paramount importance especially for women. A Chinese woman would sacrifice her needs if it would benefit the family as a whole. Work and family are two major factors that affect a woman's life. A decent job that guarantees a stable income not only brings better material life to the family but also causes less financial and psychological pressure on the woman, thus resulting in better health. However, a woman cannot maintain a good job without being healthy enough to perform well at work. Domestic life is essential to being happy in life, which greatly impacts on the woman's physical health. Diseases like cancer affect family members' relationships tremendously. Being sick also means not able to take care of family, especially children. For instance, one participant described her struggle between responsibilities at work and at home. She felt that her life was always torn between demands on both ends:

> I need to go to work. I am married and have children. If my children behave and our finance is good, then I will feel good. One's finance affects one's life. If you don't have money, you will be under stress. We need to work because it's not like we can sit home and wait for someone to put food on our table. So work and family affect our life…If your physical health is not so good, it can have an adverse effect on your job. Then the financial stability of the family will be affected. When your financial situation is not good, your psychological well being will also be negatively impacted. So everything is inter-related. If our financial situation is stable, then my life and everything else is good. (I1)

The prevailing role of women as nurturers, and the cultural and gender socialization demands of Asian women to be caregivers and not dependents (Ashing et al., 2003) create tremendous pressure to the woman's life. Two female participants shared this view and indicated that their role as nurturers in the family demanded greater responsibilities and made their life more stressful, especially when they were experiencing physiological changes or illnesses:

> Don't you know that as a woman, you have to take care of your family and work? There is just not enough time in a day to take care of all the responsibilities in life... As a result, you experience more psychological stress. Often times you get sick when you are under that much pressure. (B3)

> When you are in your 40s, you are already over the hills…Your strength, your environment, and your health all change for the worse as a result of aging. Throughout different life stages, we experience lots of physiological changes in our body. But even when we are going through changes, we still have to take care of the family and our responsibilities in life. But if we stop putting our health first, our life will soon be over. (B2)

In terms of seeking health and cancer information, there were no noticeable gender-based differences. Both male and female participants obtained health information through attending educational workshops and reading health brochures. However, more female than male participants heard about cancer and the benefits of getting cancer screening services from their

peers. Women tend to talk to their peers more about health issues. Because many female participants worked full time, the workplace (the factory) provided a forum for these women to share information and experiences. This venue was mostly lacking in male participants. For the purpose of designing outreach activities, it seems that asking female patients to “bring a friend” or to “spread the word” would be a particularly effective method of promoting cancer screening services.

Gender-based Differences on Attitude towards Cancer and Screening Activities

While female participants were more concerned by the stresses they experienced in life, male participants were more concerned about their actual likelihood of being diagnosed with cancer. Because male participants were older in age and tend to be frailer than the female participants, there were good reasons why they should be more concerned about serious illnesses such as cancer. Both groups recognized cancer as a serious illness. More female participants reported feeling shocked and sad when they first heard about cancer, while male participants reported more subdued feelings. This is consistent with the traditional role of Chinese male who are expected to be stoic, poised, and emotionally reserved especially in times of crisis. There was no major difference between the genders in the perceived causes of cancer. However, female participants also considered poor hygiene and psychological stress as potential causes to cancer whereas male participants did not believe so.

Both male and female participants showed both positive and negative attitudes toward cancer and cancer screening activities. Female participants identified more factors that prompted them to seek cancer screening than male participants. For example, women considered encouragement from peer and friends, low cost or free services, as well as receiving follow-up letters and reminders, as positive factors that prompted them to get cancer screening. Female were also able to name more barriers to cancer screening, such as lack of health insurance, lack of availability in doctor schedule, long waiting time in clinics, as well as feelings of embarrassment. Since many female participants were working poor, lack of health insurance was a major obstacle for them in accessing preventive medical services.

Lack of communication with medical providers and not able to ask questions were experienced by both male (8) and female participants (9). In this study, male participants had a higher level of education than their female counterpart. Forty-eight percent (48%) of male were college graduates but only 11% of female completed college. Therefore, male participants tend to have a better understanding of their medical condition and what it took to deal with their problems. For instance, one participant described the functions of PSA test, biopsy, and magnetic resonance imaging in diagnosing prostate cancer. His description showed that he was knowledgeable of his condition and related diagnostic procedures:

> I had a biopsy several years ago. It was very painful and caused bleeding, very painful. It is easier to have blood tests several times a year, but it will be a hardship to have a biopsy several times a year. If your PSA test result is more than 4, you can repeat the blood tests

> several times. However, it is not possible that you go for a biopsy so many times. Without a biopsy, you may not really know whether you have prostate cancer or not. Someone mentioned earlier about using "magnetic resonance imaging" to detect prostate cancer. Based on what I read in the literature, it is still unclear as to whether magnetic resonance imaging can accurately detect prostate cancer. There is no test or procedure except for a biopsy that can accurately diagnose prostate cancer. You can only find out whether you have cancer cells or not through biopsy tests. If you find cancer cells, then you have cancer. This is what we need to deal with. Many people have prostate enlargement and it may or may not lead to prostate cancer. We do not know. Prostate enlargement and prostate cancer are two separate things. (D7)

Male participants in this study resided in the U.S. much longer (average 20.3 years) compared to female participants (average 9.6 years). Therefore, men tended to be more familiar with the American medical system than women. However, although male participants were better educated and had been in this country longer, when it comes to seeking medical care, they reported essentially the same obstacles as female participants. Nevertheless, since male participants had a higher education level, they were more articulate in expressing their concerns to their medical providers. They were also more critical of their providers, especially on the quality of care they received, and the doctor's integrity and professionalism.

Comparison of Health Care Experience by Spoken Dialect

There were demographic and socio-economic differences between participants who spoke Mandarin and those who spoke Cantonese. The Cantonese-speaking group had been in the U.S. for a much longer time (average 21.2 years) than the Mandarin-speaking ones (average 10.7 years). Fifty percent of the Mandarin-speaking group were ineligible for any health insurance and therefore had to pay for their health care, while only 9.5% of the Cantonese

group paid for their health care privately. In other words, Mandarin-speaking participants were less accessible to preventive care services than their Cantonese-speaking counterpart due to lack of health insurance. This explained why the Mandarin-speaking group visited a Western-trained doctor less frequently (only 2.3 times every year) than the Cantonese-speaking group (6.2 times every year).

In terms of access to information and resources, those who spoke Cantonese received health and cancer information through friends and family more often than those who spoke Mandarin. Both groups considered Chinese local media as an important means in obtaining health information. The Mandarin-speaking group indicated that they maintained optimal health by keeping a positive outlook on life and going for regular check-up, while the Cantonese-speaking group stated that learning new things and getting up-to-date medical information were important for maintaining health. Although the Cantonese-speaking group had been in the U.S. longer as compared to those who spoke Mandarin, there was no noticeable difference in their perceived risk, susceptibility, and severity of cancer. Both groups reported feeling scared when they first heard about cancer. However, more Mandarin-speaking participants reported feeling of powerlessness and anxiety when they reacted to a cancer diagnosis, while more Cantonese-speaking participants reported a sense of being in control and confidence in winning the battle with cancer. This finding was consistent with studies that concluded that the medically underserved and the poor (the Mandarin-speaking group) harbored a “fatalistic” or “powerless”

view in the prevention or early detection of cancer (Underwood & Hoskins, 1994; Freeman, 1989). On the subject of perceived cause of cancer, the Mandarin-speaking group perceived poor diet as a potential cause for cancer, while the Cantonese-speaking group believed that genetics and sexual indulgence as potential causes of cancer. Because all participants in this study were patients who attended preventive medical service at the health center, obviously they regarded attending cancer screening as a priority in life.

When asked about what participants thought would be important in improving cancer screening services, the Mandarin-speaking group, being more socially deprived and had less access to health care, indicated that low-cost or free screening services as a top priority. On the other hand, the Cantonese-speaking group, who had health insurance and better access to health care, regarded regular referrals from doctors and reminding calls to patients as important factors in promoting cancer screening services in the Chinese community.

With regard to the quality of care they received, Mandarin-speaking participants were generally more satisfied with their doctors and were more appreciative of the care they received. But the Cantonese-speaking group, which were mostly insured and had a higher usage of health care services, were less satisfied with their providers and more critical of the services they received. Even though their insurance paid for the care, Cantonese-speaking participants were more skeptical of their providers' professional conduct and billing practices. They also had more concerns on cancer screening procedures and treatments.

There was no major difference in recommendations on how cancer screening services could be improved in both groups, except that the Mandarin-speaking group suggested holding more targeted community outreach at appropriate service locations to promote cancer education and screening services.

Summary

Qualitative data analysis conducted on the entire sample of participants provided a general view of how cancer education and preventive services were perceived and utilized by Chinese immigrants as a group. However, analyzing and comparing data across sub-groups of the sample offer additional insight. In comparing similarities and differences among different sub-groups based on age, gender, dialect spoken, and health insurance coverage, the study uncovered a wealth of information on health-seeking beliefs, attitude and emotional reactions towards cancer, health service utilization, and preventive and cancer screening experiences among different subgroups. Findings in this study dispel the general assumption that Chinese American is a homogeneous group. Therefore, when designing and delivering health care services, it is important to bear in mind the diversity of this immigrant population and their disparity in cancer knowledge, attitude, and service seeking behaviors.

However, analysis of data based on subgroups is not without limitations. The sample size of the entire study and in each sub-group is very small, making the apparent differences in the findings statistically insignificant. When assessing the demographic characteristics of sub-groups, it becomes obvious that the gender-based differences in cancer attitudes and experiences is a

function of other factors such as age, education level, employment status, and length of stay in the U.S. Similarly, the differences based on groups that speak different dialects can be explained away by factors such as differences in the number of years living in the U.S., health insurance status, as well as frequency of doctor visits. These limitations affect the externality validity and generalizability of sub-group findings. Therefore, the findings on sub-group similarities and differences should be interpreted cautiously and treated as suggestive rather than as definitive.

CHAPTER TEN

ACCESS TO CANCER EDUCATION AND SCREENING – MAKING A FUTURE PATH

A Long and Difficult Journey

The American Cancer Society publishes a screening guideline for the early detection and treatment of breast and cervical cancers. Women over the age of 40 should screen for breast cancer (breast self-examination, clinical breast examination, and mammogram) and women over 18 should screen for cervical cancer. Screening guidelines also recommend that men over age 50 should screen for prostate cancer. These guidelines appear to be straight forward enough for everyone to follow. But as indicated in the findings of this study, many Chinese participants experienced numerous barriers to cancer education and screening. The fact that they were poor and had little financial resources, limited or no health insurance coverage, spoke little or no English, were poorly informed of diseases and prevention strategies, and limited understanding of and access to the health care system, all posed significant obstacles in their quest for quality preventive health care. In addition, when they finally got to be seen, they were often met with red tape and bureaucracy in the health care system, as well as insensitivity and arrogance from providers. Therefore, screening guidelines are mere rhetoric when the doors to cancer education and screening were closed to them. And for those who were able to negotiate the health care system, their journey in seeking care remained a long and difficult one. The following case vignettes represent several participants' experiences in their odyssey for health care:

A Quest for Cure that Went Astray

Although prostate problem is common among elderly men and prostate cancer is usually treatable, men who suffer from prostate problem such as prostate enlargement or prostate cancer could lead quite a miserable life. This is because the prostate affects urinary functions, continence, and sexual performance. If symptoms such as frequent urination or urine retention go untreated or are inappropriately addressed, it could greatly affect one's quality of life and normal daily functioning. The following is a story of an elderly man who sought treatment for his prostate problems. He did everything he could, including going along with the doctor's recommendation and went for surgery after surgery, even though sometimes he did not quite understand the rationale behind it. But yet, after several invasive procedures and surgeries, he still ended up with the same symptoms. Although he could be a complicated case of having failures in the whole urological system with involvement in his prostate, bladder, and urethra, it was, however, apparent that he was unclear as to why surgeries were warranted in the first place, and how come after repeated operations, he still experienced the same symptoms! The journey that he went through is sadly a typical experience of what an immigrant, who is often poorly informed of his ailment and of the options available to resolve his medical problems:

> In the past when I had health benefits from the union, I used to get an annual check up. At some point as I grew old, my prostate became enlarged and I had to urinate more frequently. My PSA level fluctuated. Sometimes it was 6, other times it was 4, and another time it was 8. Then I began to experience urinary retention. Instead of urinating more frequently, I also had difficulties urinating and had blood in my urine. … I went for a check-up again, my PSA level was 6. The PSA result was inconclusive for prostate cancer, but I suspected that I might have

> prostate cancer. So I went to the doctor again for my urine retention problem. The doctor put a catheter in to help me pee. After that he told me to go for surgery because my PSA had increased to 26...
>
> When the doctor did the biopsy, the result was negative for prostate cancer. The surgery was done anyway. That's why I said they exaggerated my PSA results to make a case so as to lure me into surgery…They also made a hole in my lower abdomen. I found out that other surgeries could be done on either the urethra or the bladder…They operated on my lower bladder… Before my first surgery, I used to pee many times during the day. After surgery, I could hold off peeing for more than 3 hours. My condition was better initially after my prostate was removed. A year later, I had a relapse. In the beginning, I did not pay too much attention to it. But suddenly I had difficulties peeing again, then suddenly I became incontinent of urine, and my pants were all wet. I made an emergency visit to the doctor. They put in a foley catheter again to help me pee, and I had yet another surgery. After a year, I had the same old problem again… I went for another surgery at a hospital. After the operation, my condition was fine in the beginning. Still my urethra was too small… In the same year I had the same old problem of urine retention. Then I had another procedure at a hospital and I had another tube. It was a mess. Most likely my first surgery was not done properly and therefore I had a relapse…They did not find the problem. I asked whether I had cancer or not and they said it was not cancer. (I3)

Two Countries, Two Systems

Participants who came from China had health care experience from two different health care systems, one in their country of origin, and one in the U.S. Because both systems have different sets of screening guidelines, diagnosis, treatment process, and treatment outcomes, it may create confusion for patients, especially when they have to seek follow up care in the U.S. for a pre-existing condition that was once treated in China. One participant talked about her experience of cancer screening services in the U.S. as compared to that in China. She also talked about her diagnosis and treatment of "hyperplasia of mammary glands", a condition which was considered as "pre-cancerous" in China which required treatment. Her experience with the medical system in

China was very different, and in her mind somewhat more “superior”, than that of the U.S.

> I believe that I am at risk for breast cancer and that’s why I have been participating in cancer screening at the health center for the last 3 years. I am very concerned about my health. I was diagnosed of “mammary gland fibroma” (breast fibroid) in China when I was 20 years old. One time when I took a bath and touched my breast, I felt something. The lump was like a ball rolling inside my breast. I went to see a doctor and found out I had mammary gland fibroma. This was believed to be a precursor of breast cancer. But it was not cancer yet because the lump in my breast moved… I had surgery and was hospitalized for 10 days. Then, the doctors suggested that I had regular check up thereafter…
>
> When I was in the hospital, they did a biopsy to test if my breast lumps were benign or malignant. After the test, the doctor told me that the result was negative. However, there were six other patients who had the same abnormality in their breasts. Four had fibroma. I was lucky because mine was just benign. They even let me look at the size of both breast fibroids, one was bigger and the other was smaller…
>
> In China, the Chinese government had no specific cancer screening guidelines nor assumed any responsibilities of offering testing… Whether you get preventive health care depends on whether your ‘employment unit’ offers gynecological check up or not. My “unit” provided screening services on breast and cervix… In the U.S., there is no diagnosis called “hyperplasia of mammary glands” (HMG). The diagnosis for breast abnormality in this country is just whether there is cancer or not. In China, there is more follow up once a patient is diagnosed of HMG… They would tell you whether you had HMG and asked you to take medication to control hyperplasia. …I believed those diagnosed with breast cancer or with breast problems might also have had HMG That’s why in China, after taking the x-ray, they would tell you if you had HMG or not. If you did, they asked you to take medications to eliminate hyperplasia in the breasts…
>
> The doctors in China asked me to take herbal pills. Some patients took them but I did not. I didn’t think “hyperplasia of mammary glands” was a big problem. I don’t like taking herbal pills. A few of my co-workers also have HMG. In China, they tell you whether your HMG is “prolific” or not. Patients can actually see the extent of HMG level from x-ray films. The doctor can show you which part of your breast has HMG. If you have a serious case of HMG, you need to take medications. My coworker took the pills and her HMG decreased drastically…On the contrary, Western-based medical system has no specific treatment or medications for

> HMG… These herbal pills can be picked up in the hospital in China, but in the U.S, those medications are not available. In China, both Chinese medicines and Western medicines are available in the hospital.
>
> In the U.S., after taking an x-ray, we were only told if we had cancer or not, or if we had other abnormality in our breasts. There was no "transitional" stage, such as before cancer developed… Here in the U.S., they did not tell me the exact problem of my breast…In China, doctors tell you whether you have HMG. They said that women with HMG have higher risks of developing into breast cancer. They then prescribe medicine to you. (C1)

A Pathfinder's Account on a 'Miracle Cure'

Many participants experienced nothing but frustration, anxiety, fear, and confusions when seeking health care services. A few participants in this study could not find a satisfactory treatment for their condition. So they decided to create their own path by looking into alternative treatment options. The following is an account of a male participant who embarked a journey to China years ago, looking for inspiration, enlightenment, and alternative treatment methods for his health condition. Eventually he was able to find his own path of integrated healing approaches which worked miraculously to 'cure' the ailments that he suffered:

> I had prostate problems for a long time and I tried many medications. Then I went to China and tried to find out from Chinese traditional medicine what I could do with my prostate problems… I visited well-known practitioners of Chinese traditional medicine… I was then introduced to a Buddhist monk in the mountains of ChengDu. This old monk taught me a special exercise called "prostate exercise" to strengthen my prostate. Western doctors may think that this is absurd… But I have taken western medications for a long time and it can only help my problem in a limited way… Exercising can prevent cancer. In China, there was a saying that "*qi gong* can prevent cancer"… Exercising can strengthen our immune system and the cancer cells won't attack our body…The Chinese doctor told me to practice *qi gong* and "exercise" my prostate. He said these methods were effective in treating my prostate problem…

> It was quite simple. Every time we practice *qi gong*, we can exercise our bladder as well. Hold it tight and then relax. They called it "bladder exercise". After each bowel movement or urination, you "exercise your bladder" by contracting your abdomen muscles and then relaxing it. The movement looks like the gesture of men having orgasm during sexual intercourse. They said it was good for your prostate. If one does not care about having a large prostate, this person must be sexually active because he has lots of exercise in his prostate… Since I learned about this "prostate exercise", I practice it almost every day. I can now do it everywhere even when I am outside. I can even show it to you.
>
> When I returned from China, I saw my urologist for a check-up. Two years in a row, my doctor was surprised to find that my prostate has shrunk to its original size. He said I looked much younger, more like a 30-year-old man. I told the doctor that I wanted to cut down my medication and asked whether it would be okay or not. The doctor said it was up to me… The doctor said he could not feel my prostate when he did a digital rectal examination. I told him what I did when I was in China. I also told the doctor about the "theory" of exercising the prostate. (I14)

This participant also went on to learn other types of exercise that benefited his health, such as *kung fu* and *judo*. He also learnt about food groups that were known to be rich in antioxidant and had been persistent in exercising and eating a healthy diet. As a result, not only did his symptoms of prostate enlargement and arthritis disappear, he was also healthier in general.

Improving Access to Care

As described in previous chapters, Chinese immigrants face numerous barriers and challenges when seeking cancer information and screening services. At the end of each individual interview and focus group session, participants were asked what improvement they would like to see so that cancer education and screening would become accessible to Chinese immigrants in New York City. The following is a summary of recommendations made by the participants of this study:

Educational Material

Participants of this study believed that educational brochures on diseases and illnesses should contain both key health information as well as illustrative diagrams. The print should be big enough for easy reading. Posters containing health information should be displayed in public areas and community based locations (such as bus stops and subway stations) so as to maximize the public's access to health information.

With regard to the content of cancer education handouts, male and female participants had different opinions as to what topics they were most interested in learning. Chinese women wanted to receive educational material on broad women health issues, such as menopause, as well as breast, cervical and ovarian cancers. However, Chinese men were only interested in learning more about prostate problems, such as general information on prostate enlargement and prostate cancer, the course and the prognosis of the condition, its signs and symptoms, different treatment options and their risks and effectiveness, as well as prevention strategies.

Patient Education and Outreach Activities

Many participants in this study believed that the Chinese population in general was poorly informed of diseases and illnesses as well as prevention and treatment strategies. Therefore, there is a great need for health education in the Chinese community. Many regarded ethnic mass media, such as Chinese newspapers and radio programs, as instrumental and effective means of disseminating health information and reaching a large audience. However, they

also consider educational seminars and workshops as indispensable. Health information workshops and seminars have the advantage of discussing an issue in a small group setting, a venue that many Chinese prefer especially when they have specific questions on the topic.

Several participants suggested that workshops, seminars and community events be held in the evening and on weekends so as to accommodate working people. Lack of transportation is often cited as a barrier for access to health care. Participants suggested conducting community outreach by bringing educational events to the work place (such as garment factories) and to communities where newly arrived immigrants (who are also the most needy and the least educated in health care) resided. They also suggested using the 'word of mouth' and 'bring your friends' approaches as effective methods of recruiting for event participants.

As for educational topics, in addition to health related issues, there is also a need to educate the public on patient rights and responsibilities. Several participants were outraged by what appeared to be 'unethical professional conducts' and 'inappropriate billing practices' of some medical providers. Instead of walking off and finding another doctor, patients need to be educated on proper complaint and grievance channels and procedures so that any allegation of mistreatment or exploitation may be properly addressed and investigated.

Free or Low Cost Screening

Health education activities are only window dressings unless if they are

coupled with robust actions to make preventive services available and accessible to the target population. As indicated earlier, many Chinese Americans are recent immigrants and ineligible for state and federally supported health care assistance. Although they may recognize the importance and benefits of cancer screening, they have no means to pay for the services unless if it is offered to them free of charge or at an affordable rate. Therefore, the majority of participants of this study would very much want to see more free and low-cost screening and follow-up services available for low income individuals and families. They also felt that there should be an emphasis on "no questions asked" on participants' immigration status, due to fear for apprehension and deportation of the undocumented population.

Many participants in this study complained bitterly about not receiving a copy of the screening results in the mail. Often times, providers assumed that there was no need to inform the patient of the results unless if the test came back positive or there was a need for follow up care. However, what they failed to realize was that from the patient's point of view, 'no news' is not necessarily 'good news'. Waiting for an extended period of time and not knowing the outcome of the screening could provoke unnecessary fear and anxiety on the part of the patient.

On the other hand, there were patients who received a notice of 'positive result' in the mail with no further instructions or recommendations, leaving them to wonder and ponder as to what to do next with a new found diagnosis. This practice is as irresponsible as dropping a bomb at someone's door and walking

away. Obviously, if there is an abnormal finding in a screening result, the only ethical and responsible thing for any health care provider to do is to contact the patient and schedule for a clinic visit so as to discuss with the patient the test result, its implication, as well as any treatment options available.

Information Hotline and Service Referral Center

Many participants in this study expressed a great need for a central clearing house where they may obtain health information and service referral. This makes a lot of sense especially because the immigrant population is very unfamiliar with the local health care delivery system and resources available in the community. Therefore, having a hotline (similar to the 1-800-HelpNet hotline for inquiry of mental health services) to answer questions on health issues and provide information on services available based on medical need and geographical location would help non-English speaking immigrants tremendously in locating and accessing services.

Some participants suggested the need for a comprehensive service center whereby people could just walk in to make inquiries, receive health counseling, and obtain health care service referrals. A service center which has health education, screening activities and referral services all under one roof and all health care resources at its disposal will certainly save the poor and the indigenous population the grief of being kicked around and getting lost in the bureaucratic maze of the health care delivery system.

Provider Sensitivity and Cultural Training

Over the past decades, although the American health care system has

made major advances in medical and biomedical technology and treatment, the human aspect of care often receives little attention. This is reflected in inadequate communication between patients and health care providers on diagnosis, medical procedures, and pharmacological or surgical treatments. Many participants of this study did not have an adequate understanding of diseases or diagnostic and treatment processes. The health care delivery system, as well as the role of primary care providers versus that of the specialists, are all very foreign to this population who are used to a different medical system in their country of origin. Naturally, they looked to their medical providers for information, advice, and guidance especially when they had specific health concerns. When that need for information and education was not adequately met, they became frustrated and even distrustful of the provider and the health care system.

Doctors should understand the need of immigrants for information and be sensitive to their concerns. They should provide their patients the necessary education that helped them understand Western concepts of diagnostic test and screening services so as to ensure patient compliance. Improving communication between doctor and patient also has the benefit of increasing patient satisfaction with the services and building a trustful relationship.

Clearly Chinese immigrants have varying beliefs in and perceptions of health and illnesses. These beliefs and perceptions are often reflected in their strong adherence to a holistic approach with traditional beliefs in *yin-yang* balance, hot-cold principle, medicinal foods, self-diagnosis, and alternative

treatment practices. Health care providers should keep an open mind and be more aware of the traditions and cultural beliefs of Chinese immigrants concerning wellness, illnesses, and cancer. They must include their patients' perception of health in the assessment and implementation of health care. In order to adequately understand and provide health care to the patients, medical providers should be sensitized to their patients' cultural beliefs, health practices, traditional Chinese medicine, and alternative treatment approaches.

Some traditional Chinese still rely on alternative or complementary healing practices that tend to care for the whole person, taking into consideration their social, mental, emotional, and spiritual well-being. Many participants in Ma's (1999a) study believe that Chinese medicine is more appropriate for treatment of chronic conditions, and these beliefs guide patients' decisions and choices in treatment. Gordon (1996) also pointed out that these therapies should be used to complement, not replace, conventional medical treatments. Providers serving Chinese immigrants need to be more aware of alternative therapies their patients may be using so that they can respond appropriately to questions raised by their patients, as well as help them develop an integrated, effective therapeutic plan.

About This Study and Beyond

Past studies on the cultural views on health care and cancer of Chinese immigrants are few and far between. What are even rarer are studies done in this area on this population using a qualitative rather than a quantitative study approach. Therefore, this research project is unique in the sense that it is one of the first, if not the only, studies which uses qualitative methods to explore and

describe the cultural beliefs, service seeking behaviors, and system barriers of Chinese immigrants. In studying phenomena such as cultural values as well as motivations and inhibitions behind human behaviors, qualitative methods are far more appropriate than quantitative ones, because the former have the advantage of revealing rich and vivid descriptive information which give a three dimensional image to the issues rather than a flat and linear account that quantitative methods usually produce.

This study adds to the sparse literature by contributing to a better understanding on the level of health knowledge, cultural attitudes and beliefs towards the causes and prevention of cancer, as well as barriers to cancer education and screening among the medically underserved Chinese immigrant men and women living in the metropolitan New York City area. The study is based on the assumption that patterns of health beliefs, health seeking behavior, and the utilization of preventive health and cancer screening services among Chinese immigrants are interwoven into their cultural, socioeconomic, and other aspects of daily lives. Therefore, this study is helpful not only in filling the knowledge gap in cancer education and screening for the Chinese immigrant population, but also in highlighting the importance of cultural sensitivity and relevancy in the design and implementation of effective breast, cervical, and prostate cancer education and screening programs for this population. Finally, the study is able to fulfill its goal by exploring and unraveling the participants' cultural beliefs on health related issues and health care, what factors that motivated or inhibited their health seeking behaviors.

With regard to the choice of data collection methods, the researcher used both individual interview and focus group sessions as vehicles for data collection with the assumption that some participants might feel uncomfortable disclosing personal experiences in a group setting. Therefore, individual interview sessions were added to supplement the presumed 'shortcoming' of focus group sessions. But surprisingly, the focus group method turned out to be equally effective in soliciting data as individual interviews. Once an atmosphere of openness was created in a group session, participants had no problem at all sharing very personal and intimate experiences with other group members. In fact, with appropriate guidance and facilitation by staff members, group members were more willing to share their experiences with each other than in a relatively more 'sterile' individual interview session. Subjects that one participant brought up might trigger other participants to recall similar or different views or experiences of their own. This 'mutual stimulation effect' was also lacking in individual interviews. Some long and illustrative quotations and unique stories of personal experiences cited in this study were actually collected through focus group sessions. Despite the sensitivity of the research topics, group sessions still turned out to be equally productive in yielding rich descriptive information as compared to individual interviews.

When it comes to data analysis and coding procedures, however, the group method was also more superior in yielding efficiency and expediency. In order to capture the intense experiences of the participants, the researcher had to painstakingly review each and every transcript in order to identify similarities

and differences in themes and perspectives. Going through transcripts of focus group sessions took far less time than doing the same for transcripts of individual interviews. In fact, focus group summaries enabled the researcher to identify common themes even more quickly. Given the numerous advantages of the focus group method, researchers for future qualitative studies should seriously consider using focus groups as a major data collection tool.

Another interesting aspect of a qualitative study lies in the fact that there is no presumptive answer to the research question, i.e. study hypothesis. In fact, information continued to emerge and evolve throughout the data collection, coding, and analysis processes. When reviewing the data on health care seeking behaviors of the participants, the researcher realized that it would have been even more revealing if the health seeking behaviors of the participants prior to emigration was known. This is because the participants' health care seeking behaviors in their country of origin will provide a good reference point for comparison to their health care seeking behaviors in the U.S. For example, if participants did not have the habit of going for preventive check up in either country, then perhaps the participants' lack of motivation in actively seeking preventive health care could be more of a reflection of the deep-rooted cultural belief of not seeking care, rather than the result of systematic barriers which deterred the participants from accessing health care in this country. The 'pre-existing health seeking behaviors' of Chinese participants prior to immigration to the United States would be an interesting subject for future researchers to explore.

As discussed in the previous chapter, there are limitations inherent in the design of this study. This study used a small purposeful, stratified sample of subjects. Therefore, the generalizability of the findings of this exploratory qualitative study to the entire population of Chinese immigrants is limited. Furthermore, the fact that participants were individuals who were already attending educational and health screening activities illustrates the fact that this is a skewed sample who do not represent the larger population of Chinese immigrants at all. In fact, they represent the 'cream of the crop' who are already better informed and more resourceful than an average Chinese immigrant living in New York City. However, if these participants are still confused and perplexed with various health care issues and have tremendous difficulties accessing the health care system, one could only imagine how many mountains of systemic barriers an average Chinese immigrant has to overcome before quality preventive care can be obtained. For these immigrants who are socially deprived and poorly educated, the road to accessing quality health care will be long and their journey arduous and trying. One could only hope that with a better understanding of their care-seeking behaviors and access barriers, more culturally relevant programs could be developed for the Chinese immigrant population so that they may have better access to preventive health services.

APPENDIX 1

RECRUITMENT LETTER

Dear Patient,

If you have participated in breast, cervical, or prostate cancer education and screening services at the Charles B. Wang Community Health Center, you are being invited to participate in a dissertation research study conducted by Kenny Kwong, Health Education Manager of the Health Center and a doctoral student at the City University of New York Graduate School and University Center. The study is sponsored by the Health Center.

The purposes of the study are to explore how Chinese Americans perceive the causes of cancer and their health risks, to understand their needs of cancer education and screening services and how they act to meet their needs, and to find out what services need to be expanded to meet the needs. You will be asked to attend an individual or group interview that lasts for about an hour and a half. You will be asked to share your personal experience in cancer education and screening services. Approximately forty men and women will participate in the study. To protect your privacy, the interview will be conducted at an interview room or conference room of the Health Center. All interviews will be audio taped for recording and analytical purposes only. You will be asked to give your consent for participating in the study and for audio tape recording of the interview. If you refuse to give your consent of if you do not want to be taped, you will not be able to participate in the study.

Please understand that your participation in the study is voluntary, and that if you wish to withdraw from the study or leave, you may do so at any time. If you withdraw from the study, this will have no effect on your relationship and services with the Health Center. All information you provide will be kept confidential. If you are participating in a group interview, you may know some of the group participants from the Health Center. Therefore, your participation won't be completely confidential. There are limits to confidentiality. The research staff members are mandated to report to the proper agency suspected child abuse, and any indications that you are in imminent danger of harming yourself or other. The study will be conducted at the Health Center. Therefore, it may be possible for the Health Center staff to know who is participating in the study. All materials and data will be kept in a locked file cabinet for three years to which only the researcher has access and after that these materials will be destroyed.

There is potential risk to you for your participation. The study may raise painful or difficult issues, and that you may experience stress and minor discomfort during your participation. If this occurs, you may withdraw from the study. You will receive a list of resources at the end of the interview to assist you should you need them.

To show appreciation for your participation, you will receive a bakery coupon and a $4 metrocard at the end of the interview. You may not receive any other direct benefits from participating in the study, but that your participation may help others by increasing the knowledge and understanding on how to improve and expand cancer education and screening services for Chinese Americans. Some general information on the results of the study in the form of aggregate data will be provided to the Health Center to improve cancer education and screening services for Chinese Americans. You will not be identified by name or other identifying information in these aggregate data.

If you are interested in participating in the study or if you need more information, please contact Kenny Kwong at (212) 379-6988 or Brenda Wan at (212) 966-0461. If you have questions about the study, you can contact Kenny Kwong at (212) 379-6988 or his faculty advisor Dr. Irwin Epstein at (212) 452-7030. You should contact the Hunter College Office of Research Administration at (212) 772-4020, if you have questions regarding your rights as a participant.

Thank you!

APPENDIX 2A

Focus Group Interview Guide for Female Participants

Breast and Cervical Cancer as Health Problems among Chinese American Women

1. What do you consider to be the most important health problem among Chinese American women? How is breast and cervical cancer compared to this health problem?

Attitudes, Beliefs, and Preventive Health Practices

2. What comes to your mind when we talk about "health"? What keeps us healthy? What would you do to stay healthy?

(Probe: Does the notion of health involve physiological, mental/spiritual, cultural, social, or personal aspect? Preventive health or remedial treatment? Use of Western medicine, Chinese/herbal medicine or alternative therapy?)

3. What comes to your mind when you hear about "cancer"? What causes breast and cervical cancer? Do you see yourself as being at risk for breast and cervical cancer? Do you believe that thinking or finding out about cancer could provoke the onset of cancer?

(Probes: beliefs and attitudes towards cancer, personal life experience, etc.)

4. The American Cancer Society recommends various screenings for the early detection and treatment of breast and cervical cancer. Women over the age of 40 should screen for breast cancer (Breast self-examination, clinical breast examination, and mammogram) and women over 18 should screen for cervical cancer (Pap smear).

Have you heard about these screening guidelines before you came to the U.S. (for immigrant participants only)? Do you believe what these cancer screenings do for your health? What screening services have you received? What makes you go for breast and cervical cancer screening the first time?

(Probes: Prior cancer knowledge, having symptoms, encouragement by family and friends, physician's advice, free-or-low cost services, educational workshops and information, newspaper report or radio announcement, etc.)

5. How many of you come back for breast and cervical cancer re-screening every one or two years? What makes you come back to the Health Center for re-screening?

(Probes: Physician's advice and encouragement, reminder letter/phone-call from the Health Center, free or low-cost services, peace of mind in early detection, education through workshops and local media).

Access Barriers to Breast and Cervical Cancer Education and Screening Services

6. We all have responsibilities and priorities in life. Keep in mind all the things that are important to you, how important it is for you to receive breast and cervical cancer screening services in your life?

(Probe: Responsibilities and priorities in life among Chinese immigrants and among those with limited resources or family support?)

7. Are there reasons/things that make it difficult for you or someone you know to come for workshops, screenings, re-screenings, or follow-up? If so, what are they?

(Probes: Too busy, family responsibilities, long waiting time to get the screening or follow-up appointment, concerns about the costs and follow-up, know little about breast or cervical cancer, unable to communicate well with doctors, radiology technicians, fear of being exposed to radiation, etc.)

Experiences with Health Care Providers

8. How was your experience with health care providers such as doctors, nurses, health educators, and radiology technicians when you seek breast and cervical cancer education and screening services? Has it been positive or negative? Why?

(Probes: Health care experience in country of origin, receive enough information from doctors and health educators, health care providers from the same cultural background, language and interpreter issue, etc.)

9. What concerns do you have regarding breast and cervical cancer and related issues? Has it been easy or difficult to discuss these concerns with health care providers? Why?

(Probes: Do not know what and how to ask, not given enough time to address these concerns with the provider, etc.)

Suggestions on Breast and Cervical Cancer Education and Screening Services

10. We would like to improve breast and cervical cancer screening and education services for Chinese American women in New York City. Which services do we need to improve on? Why? How would these services be provided?

11. What would be the best way to tell someone you know (spouse, family members, friends, coworkers, etc.) about screening and educational services?

(Probes: Setting up an information center, organizing support groups, one-to-one outreach and contact, community workshops, outreach through newspapers and radios, etc.)

Closing Inquiry

12. Our group session is almost coming to a close. Is there anything you would like to say? How was it talking about breast and cervical cancer? Any last thoughts or comments on this topic? [Close]

APPENDIX 2B

Focus Group Interview Guide for Male Participants

Prostate Cancer as Health Problem among Chinese American Men

1. What do you consider to be the most important health problem among Chinese American men? How is prostate cancer compared to this health problem?

Attitudes, Beliefs, and Preventive Health Practices

2. What comes to your mind when we talk about "health"? What keeps us healthy? What would you do to stay healthy?

(Probe: Does the notion of health involve physiological, mental/spiritual, cultural, social, or personal aspects? Preventive health or remedial treatment? Use Western medicine, Chinese herbal medicine or alternative therapy?)

3. What comes to your mind when you hear about "cancer"? What causes prostate cancer? Do you see yourself as being at risk for prostate cancer? Do you believe that thinking or finding out about cancer could provoke the onset of cancer. What do you think?

(Probes: beliefs and attitudes towards cancer, personal life experience, etc.)

4. The American Cancer Society recommends that men over the age of 50 should screen for the early detection and treatment of prostate cancer. Have you heard about this screening guideline before you came to the U.S. (for immigrant participants only)? Do you believe what cancer screening do for your health? What screening services have you received? What makes you go for prostate cancer screening the first time?

(Probes: Prior cancer knowledge, having symptoms, encouragement by family and friends, physician's advice, free-or-low cost services, educational workshops and information, newspaper report or radio announcement, etc.)

5. How many of you come back for prostate cancer re-screening every one or two years? What makes you come back to the Health Center for re-screening?

(Probes: Physician's advice and encouragement, reminder letter/phone-call from the Health Center, free or low-cost services, peace of mind in early detection, education through workshops and local media).

Access Barriers to Prostate Cancer Education and Screening Services

6. We all have responsibilities and priorities in life. Keep in mind all the things that are important to you, how important it is for you to receive prostate cancer screening services in your life?

(Probe: Responsibilities and priorities in life among Chinese immigrants and among those with limited resources or family support?)

7. Are there reasons/things that make it difficult for you or someone you know to come for workshops, screenings, re-screenings, or follow-up? If so, what are they?

(Probes: Too busy, family responsibilities, long waiting time to get the screening or follow-up appointment, concerns about the costs and follow-up, know little about prostate cancer, unable to communicate well with doctors, etc.)

Experiences with Health Care Providers

8. How was your experience with health care providers such as doctors, nurses, health educators when you seek prostate cancer education and screening services? Has it been positive or negative? Why?

(Probes: Health care experience in country of origin, receive enough information from doctors and health educators, health care providers from the same cultural background, language and interpreter issue, etc.)

9. What concerns do you have regarding prostate cancer and cancer related issues? Has it been easy or difficult to discuss these concerns with health care providers? Why?

(Probes: Do not know what and how to ask, not given enough time to address these concerns with the provider, etc.)

Suggestions on Prostate Cancer Education and Screening Services

10. We would like to improve prostate cancer screening and education services for Chinese American men in New York City. Which services do we need to improve on? Why? How would these services be provided?

11. What would be the best way to tell someone you know (spouse, family members, friends, coworkers, etc.) about screening and educational services?

(Probes: Setting up an information center, organizing support groups, one-to-one outreach and contact, community workshops, outreach through newspapers and radios, etc.)

Closing Inquiry

12. Our group session is almost coming to a close. Is there anything you would like to say? How was it talking about prostate cancer? Any last thoughts or comments on this topic? [Close]

APPENDIX 2C

Individual Interview Questionnaire for Female Participants

1. What do you consider to be the most important health problem among Chinese American women? How is breast and cervical cancer compared to this health problem?

2. What comes to your mind when you hear about "health"? How important is it for you to stay healthy? What would you do to stay healthy? (Probe: Does the notion of "health" involve physiological, mental, spiritual, cultural, social, or personal aspect? Preventive health or remedial treatment? Use Western medicine, Chinese herbal medicine or alternative therapy?)

3. What comes to your mind when you hear about "cancer"? What causes breast and cervical cancer? Do you see yourself as being at risk for breast and cervical cancer? Do you believe that thinking or finding out about cancer could provoke the onset of cancer? (Probes: beliefs and attitudes towards cancer, personal life experience, etc.)

4. The American Cancer Society recommends various screenings for the early detection and treatment of breast and cervical cancer. Women over the age of 40 should screen for breast cancer (Breast self-examination, clinical breast examination, and mammogram) and women over the age of 18 should screen for cervical cancer (Pap smear). Have you heard about these screening guidelines before you came to the U.S. (for immigrant participant only)? Do you believe what these cancer screenings do for your health? What screening services have you received? What makes you go for breast and cervical cancer screening the first time? (Probes: Prior cancer knowledge, having symptoms, encouragement by family and friends, physician's advice, free-or-low cost services, educational workshops and information, newspaper report or radio announcement, etc.)

5. Have you come back for breast and cervical cancer re-screening every one or two years? What makes you come back to the Health Center for re-screening? (Probes: Physician's advice and encouragement, reminder letter/phone-call from the Health Center, free or low-cost services, peace of mind in early detection, education through workshops and local media).

6. We all have responsibilities and priorities in life. Keep in mind all the things that are important to you, how important it is for you to receive breast and cervical cancer screening services in your life? (Probe: As an immigrant, responsibilities and priorities in life, limited resources or family support?)

7. Are there reasons/things that make it difficult for you or someone you know to come for workshops, screenings, re-screenings, or follow-up? If so, what are they? (Probes: Too busy, family responsibilities, long waiting time to get the screening or follow-up appointment, concerns about the costs and follow-up, know little about breast and cervical cancer, not able to communicate well with doctors or radiology technicians, fear of being exposed to radiation, etc.)

8. How was your experience with health care providers such as doctors, nurses, health educators, radiology technicians when you seek breast and cervical cancer education and screening services? Has it been positive or negative? Why? (Probes: Health care experience in country of origin, receive enough information from doctors and health educators, health care providers from the same cultural background, language and interpreter issue, etc.)

9. What concerns do you have regarding breast and cervical cancer and related issues? Has it been easy or difficult to discuss these concerns with health care providers? (Probes: Do not know what and how to ask, not given enough time to address these concerns with the provider, etc.)

10. We would like to improve breast and cervical cancer screening and education services for Chinese American women in New York City. Which services do you think we need to improve on? Why? How would these services be provided?

11. What would be the best way to tell someone you know (spouse, family members, friends, coworkers, etc.) about screening and educational services? (Probes: Setting up an information center, organizing support groups, one-to-one outreach and contact, community workshops, outreach through newspapers and radios, etc.)

12. Is there anything that you would like to say before we finish our interview? How was it talking about breast and cervical cancer? [Close]

APPENDIX 2D

Individual Interview Questionnaire for Male Participants

1. What do you consider to be the most important health problem among Chinese American men? How is prostate cancer compared to this health problem?

2. What comes to your mind when you hear about "health"? How important is it for you to stay healthy? What would you do to stay healthy? (Probe: Does the notion of "health" involve physiological, mental/spiritual, cultural, social, or personal aspect? Preventive health or remedial treatment? Use Western medicine, Chinese herbal medicine or alternative therapy?)

3. What comes to your mind when you hear about "cancer"? What causes prostate cancer? Do you see yourself as being at risk for prostate cancer? Do you believe that thinking or finding out about cancer could provoke the onset of cancer? (Probes: beliefs and attitudes towards cancer, personal life experience, etc.)

4. The American Cancer Society recommends that men over age 50 should screen for the early detection and treatment of prostate cancer. Have you heard about this screening guideline before you came to the U.S. (for immigrant participant only)? Do you believe what prostate cancer screening do for your health? What screening services have you received? What makes you go for prostate cancer screening the first time? (Probes: Prior cancer knowledge, having symptoms, encouragement by family and friends, physician's advice, free-or-low cost services, educational workshops and information, newspaper report or radio announcement, etc.)

5. Have you come back for prostate cancer re-screening every one or two years? What makes you come back to the Health Center for re-screening? (Probes: Physician's advice and encouragement, reminder letter/phone-call from the Health Center, free or low-cost services, peace of mind in early detection, education through workshops and local media).

6. We all have responsibilities and priorities in life. Keep in mind all the things that are important to you, how important it is for you to receive prostate cancer screening services in your life? (Probes: As an immigrant, responsibilities and priorities in life, limited resources or family support?)

7. Are there reasons/things that make it difficult for you or someone you know to come for workshops, screenings, re-screenings, or follow-up? If so, what are they? (Probes: Too busy, family responsibilities, long waiting

time to get the screening or follow-up appointment, concerns about the costs and follow-up, know little about prostate cancer, not able to communicate well with doctors, etc.)

8. How was your experience with health care providers such as doctors, nurses, and health educators when you seek prostate cancer education and screening services? Has it been positive or negative? Why? (Probes: Health care experience in the country of origin, receive enough information from doctors and health educators, health care providers from the same cultural background, language and interpreter issue, etc.)

9. What concerns do you have regarding prostate cancer and related issues? Has it been easy or difficult to discuss these concerns with health care providers? (Probes: Do not know what and how to ask, not given enough time to address these concerns with the provider, etc.)

10. We would like to improve prostate cancer screening and education services for Chinese Americans in New York City. Which services do you think we need to improve on? Why? How would these services be provided?

11. What would be the best way to tell someone you know (spouse, family members, friends, coworkers, etc.) about screening and educational services? (Probes: Setting up an information center, organizing support groups, one-to-one outreach and contact, community workshops, outreach through newspapers and radios, etc.)

12. Is there anything that you would like to say before we finish our interview? How was it talking about prostate cancer? [Close]

APPENDIX 3

PARTICIPANT DEMOGRAPHIC DATA FORM

1) What is your gender?
   a) Male
   b) Female

2) How old are you? _____

3) What do you consider yourself to be?
   a) Chinese American
   b) American
   c) Chinese
   d) Other, specify _____

4) In what country were your born in?
   a) China (Mainland)
   b) Taiwan
   c) Hong Kong
   d) Southeast Asia
   e) The United States
   f) Other, specify: _____

5) How many years have you been living in the United States? _____

6) What is your marital status?
   a) Currently married
   b) Widowed
   c) Divorced
   d) Living with a partner (not legally married)
   e) Separated
   f) Single, never married
   g) Refused

7) What is your highest level of education?
   a) No formal education
   b) Elementary school
   c) Junior high school
   d) High school graduate
   e) College Graduate
   f) Other, specify _____
   g) Refused

8) Including yourself, how many people live in your household? _____

9) Are you currently working?
   a) Employed
   b) Unemployed
   c) Retired
   d) A homemaker
   e) Other, specify _____

10) Which of the following best describes your total household income in the year 2002, that is, your income and the income of all family members living with you?
   YEARLY
   a) <$10,000
   b) $10,000 - <$20,000
   c) $20,000 - <$30,000
   d) $30,000 - <$40,000
   e) $40,000 - <$50,000
   f) $50,000 or more

11) What language/dialect do you speak comfortably?
   a) Cantonese
   b) Mandarin
   c) English
   d) Other, please specify _____

12) What would you say about your ability to speak English?
   a) Fluently like a native
   b) Well
   c) So so
   d) Poor
   e) Not at all

13) What kind of food do you prefer?
   a) Mostly Chinese food
   b) Both Chinese and American food
   c) Mostly American food
   d) Other, please specify: _____

14) Do you observe or celebrate Chinese festivals and traditions?
   a) Yes
   b) No

15) What is the ethnic background of your friends?
   a) Mostly Chinese
   b) Mostly other ethnic minorities
   c) Mostly Caucasians

16) If you need health care, how would you pay for it?
   a) Self-pay
   b) Medicaid
   c) Medicare
   d) Family Health Plus
   e) Health insurance plan through employment
   f) Other health insurance, specify _____

17) Do you see Chinese medicine practitioners or physicians practicing Western medicine for your health care?
   a) Only Chinese medicine practitioners, such as traditional healers or herbalists
   b) Only physicians practicing Western medicine
   c) Both Chinese medicine practitioners and physicians practicing Western medicine

18) Where do you usually receive your health care?
   a) Outpatient clinic or health center
   b) Local hospital
   c) Hospital emergency room
   d) Private doctor
   e) No single place
   f) Other, specify: _____

19) During the past 12 months, how many times have you seen a physician practicing Western medicine about your health? _____

20) During the past 12 months, how many times have you seen a Chinese medicine practitioner such as a traditional healer about your health? ____

21) In general, would you say your health is?
   a) Excellent
   b) Very good
   c) Good
   d) Fair
   e) Poor
   f) Don't know

APPENDIX 4A

STATEMENT OF INFORMED CONSENT

You have been selected to participate in this dissertation research study because you have participated in breast, cervical, and prostate cancer education and screening services at the Charles B. Wang Community Health Center (Health Center). This study is conducted by Kenny Kwong, a doctoral student at the City University of New York Graduate School and University Center. The study is sponsored by the Health Center.

The purposes of the study are to explore how Chinese Americans perceive the causes of cancer and their health risks, to understand their needs of cancer education and screening services and how they act to meet their needs, and to find out what services need to be expanded to meet the needs. Approximately forty Chinese men and women will participate in the study. You will be asked to attend an interview that lasts for about an hour and a half. You will be asked to share your personal experience in cancer education and screening services. To protect your privacy, the interview will be conducted at an interview room or conference room of the Health Center. The interview will be audio taped for recording and analytical purposes only. You will be asked to give your consent for participating in the study and for audio tape recording of the interview. If you refuse to give your consent or if you do not want to be taped, you will not be able to participate in the study.

Please understand that your participation in the study is voluntary; and that if you wish to withdraw from the study or leave, you may do so at any time and you do not need to give reasons for doing so. If you withdraw from the study, this will have no effect on your relationship and services with the Health Center.

There is potential risk to you for your participation. The study may raise painful or difficult issues, and that you may experience stress and minor discomfort during your participation. If this occurs, you may withdraw, or stop, or not answer the question. You will receive a list of resources at the end of the interview to assist you should you need them.

All information you provide will be kept confidential. If you are participating in a group interview, please refrain from speaking to others about what is said within the group. Please do not use real names so that people's identities are not revealed. You may know some of the group participants from the Health Center. Therefore, your participation won't be completely confidential. There are limits to confidentiality. It may be possible for the Health Center staff to know who is participating in the study. The research staff members are mandated to report to the proper agency suspected child abuse, and any indications that you are in imminent danger of harming yourself or other. As soon as the transcript is completed, all tapes and recordings will be kept in a locked file cabinet for three

years to which only the researcher has access. After that, all tapes and recordings will be carefully discarded. Your name and any other identifying information will be either removed or modified in the transcripts to insure confidentiality of subjects

To show our appreciation for your participation, you will receive a bakery coupon and a $4 metrocard at the end of the interview. You may not receive any direct benefits from participating in the study, but that your participation may help others by increasing the knowledge and understanding on how to improve and expand cancer education and screening services for Chinese Americans. Some general information about the results of this study will be provided to the Health Center to improve the services. This information will describe the level of cancer knowledge and beliefs and summarize barriers to cancer screening and education among the Chinese immigrant population. Only aggregate data will be presented in any reports or publications developed from this research.

If you have any questions about the study, you can contact Kenny Kwong at (212) 379-6988 or his faculty advisor Dr. Irwin Epstein at (212) 452-7030. You should contact the Hunter College Office of Research Administration at (212) 772-4020, if you have questions regarding your rights as a participant or if you feel you experienced a research-related injury.

I am offered to answer all the questions I had on the study and what I am expected to do. I have read the above contents or have the above contents read to me. I understand the information and I agree to take part in the study. I am asked to sign two copies of the form and keep one for my record.

_____ _____

Signature of the Participant Date

_____ _____

Signature of the Researcher Date

APPENDIX 4B

AUDIO TAPE RECORDING RELEASE CONSENT FORM

Researcher: Kenny Kwong, CSW

Title of the Study: Knowledge, Attitudes, and Barriers towards Breast, Cervical, and Prostate Cancer Screening and Education among the Medically Underserved Chinese Immigrant Population in New York City

As part of this project, an audio tape recording will be made of you during your participation in the research study. The audio tapes will be transcribed into English by the research team for analytical use in the research project. In any use of the audio tapes, your name or any other identifying information will be either removed or modified in the transcript to insure confidentiality. You cannot be anonymous in the study. These tapes will be kept for three years like all other data and after that they will be destroyed. If you do not want to be taped, you will not be able to participate in the study.

I have read the above contents or have the above contents read to me. I understand the information and I give my consent for audio tape recording of the interview and the use of audiotapes as indicated above.

_____ _____

Signature of the Participant Date

_____ _____

Signature of the Researcher

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