Tufts Medical Center Focus Group Study:
Summary Report for Hospital Leadership and Community Members

"Voices from the Boston Chinese-American Community on Wellness, Illness, Cancer and Health Care"

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EXECUTIVE SUMMARY

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Background

Community-based research as a field has matured tremendously in the last decade, and much is currently understood about trends in healthcare access and outcomes in specific sub-populations, whether analyzed by ethnicity, socio-economics, varying education level, or degree of acculturation. The authors of this study acknowledge the previous work of our peers that forms the foundation of published work in this field. It also forms the methodological basis for our project in qualitative research analysis. We undertook this study to specifically examine current cancer attitudes and experience in the Boston Chinese American Community.

Methods

To assess the current attitudes and experience with cancer and issues surrounding the care of family members who had cancer, we held Focus Group Discussions within the community. We made initial contact with a broad array of community members and designed and administered an anonymous questionnaire printed in both English and Chinese. The questionnaire gathered information about participants and their views and experiences with health and cancer. It concluded with an invitation to participate in further research and requested contact information on a separate page for those interested.

From this group we contacted those willing to participate in focus groups. In all, there were 52 focus group participants, 27 female and 25 males who ranged in age from 18 to 80. Twenty six participants self-identified as Cantonese speakers and 26 as primarily English speakers. Participants represented a variety of occupations, and were a highly educated group, with a mean of 15.4 years of education. A series of eight-three hour focus groups were conducted , 4 in English, 4 in Cantonese. Each set of four was further peer-matched into female and males groups between age 50 and 80-plus and younger males between the ages of 18 and 49. This report summarizes the analysis of the data obtained in the focus group study.

Results

An overarching theme which emerged from the analysis of our focus group data was the role of Traditional Chinese medicine and traditional Chinese beliefs about sickness and health. Both foreign born and acculturated American born Chinese participants appear to retain a deep underlying connection

to a traditional Chinese perspective about illness and wellness. They are also quite aware of the Western medical lack of understanding and skepticism about these beliefs and related behaviors. These and other cultural differences along with logistical and financial problems, contribute to the caution many Chinese feel about Western medicine and providers, and to their non-participation in Western medical prevention, care, and clinical trials. Despite this caution, participants seem to have a clear picture of what and how Western medicine and Traditional Chinese medicine can and should work together for the good of the patient and toward solving medical mysteries about disease.

Themes that emerged from our analysis of focus group discussions with community members about wellness and cancer fell into 4 major categories; The first was: Health Paradigms; the second: Cancer and Barriers; the third: Communication; and the fourth: Recommendations for Improved Prevention, Screening and Care. The report summarizes aspects of participants' discussions about these themes, grounding the summaries in direct quotes from the focus group transcripts. In the section on Health Paradigms, we describe participants' health beliefs and behaviors and their views on combining Traditional Chinese Medicine and Western Medicine. The second overarching theme was Cancer, with three main sub-themes about cancer emerging from the data. These consist of participants' thoughts about the most important cancers impacting the Chinese community, their opinions about barriers to cancer care, including concerns about language and interpreters, financial and insurance issues and Chinese' cultural attitudes about cancer. Participants also describe what barriers they believe get in the way of Chinese involvement in cancer clinical trials. In the third section, several subthemes emerged which we grouped under the rubric of Communication. These themes included health information, communicating with health care providers and systems across cultures, and the content of communication about health care.

Recommendations

Many recommendations came from participants who seemed very certain of what needed to be done to better serve the Chinese community—their recommendations were about providers, settings, outreach and some cancer specific suggestions and are outlined in the main text. The following four major areas of recommendations were found and are outlined in the section on Recommendations for ; Improved Prevention, Screening and Care: Educating the Chinese community; Western Providers: Medical Settings—Clinics, Programs and Outreach; and Other Cancer Specific Suggestions

Acknowledgements

Funding for this project was provided by the Tufts Medical Center (MC) Cancer Center Pilot Project Program, made possible by the Cam Neely Foundation for Cancer Care, and several generous Clinical Department Heads within Tufts Medical Center. We gratefully acknowledge this funding as well as subsequent consultant funding made available to us through Tufts MC for the purpose of continuing this study.

We also would like to acknowledge Tufts MC's longstanding interest in the Chinese American community, and its' pioneering programs in "Asian Access", " Asian Community Outreach", and "Interpreter Services" providing linguistic and translational services to non-English speaking patients. We also gratefully acknowledge the dedicated work of those who preceded us at Tufts MC who had and continue to have unwavering levels of commitment to the Asian American community, and whose studies form the foundation of knowledge we here build on. We add the knowledge generated in this study to that continuum of research, community outreach, and education at Tufts MC. It is our hope that the recommendations that emerged from our study will be incorporated into an overarching plan for improving medical services to the Asian American population which surrounds Tufts MC, and improved understanding and respect between the MC and the Chinese American Community in the greater Boston area..

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ABSTRACT

Community-based research as a field has matured tremendously in the last decade, and much is currently understood about trends in healthcare access and outcomes in specific sub-populations, whether analyzed by ethnicity, socio-economics, varying education level, or degree of acculturation. The authors of this study acknowledge the previous work of our peers that forms the foundation of published work in this field. It also forms the methodological basis for our project in qualitative research analysis. We undertook this study to specifically examine current cancer attitudes and experience in the Boston Chinese American Community using a series of 8-three hour Focus Group Discussions, and employing standard Qualitative research analysis techniques.

An overarching theme which emerged from the analysis of our focus group data was the role of Traditional Chinese medicine and traditional Chinese beliefs about sickness and health. Both foreign born and acculturated American born Chinese participants appear to retain a deep-seated underlying connection to a traditional Chinese perspective about illness and wellness. They are also quite aware of the Western medical lack of understanding and skepticism about these beliefs and related behaviors. These and other cultural differences along with logistical and financial problems, contribute to the caution many Chinese feel about Western medicine and providers, and to their limited participation in Western medical prevention, care, and clinical trials. Despite this caution, participants seem to have a clear picture of what and how Western medicine and Traditional Chinese medicine can and should work together for the good of the patient and toward solving medical mysteries about disease.

Themes that emerged from our analysis of focus group discussions with community members about wellness and cancer fell into 4 major categories; The first was: HEALTH PARADIGMS; the second: CANCER AND BARRIERS; the third: COMMUNICATION; and the fourth : RECOMMENDATIONS FOR IMPROVED PREVENTION, SCREENING, AND CARE. This report constitutes our final report summarizing the analysis of the data obtained in the study.

INTRODUCTION

Tufts Medical Center(MC) has an important and special role in the delivery of health care to its Asian American, and especially the Chinese Community. Its strategic location in the heart of the Chinatown neighborhood provides Tufts MC with a unique opportunity to create a successful and exemplary health service for this population. The importance of this special role of Tufts MC is amplified greatly because Boston's Chinatown has become a cultural, religious, and economic "hub" for Asian Americans in New England. The Chinatown community in downtown Boston is an important nexus for various social, religious, and cultural activities, and is the home of many Asian American community organizations. For more than a century, it has been the only "mall" for Asian markets, eateries, herbal pharmacies, acupuncturists, traditional healing art practitioners, Chinese-speaking doctors and dentists, as well as many businesses owned, operated and designed to serve Chinese/Asian-Americans.

Tufts Medical Center and Chinatown have had close ties with one another for many years. Their relationship has gone through different phases for political and other reasons. Over time, Tufts MC gradually expanded into and around Chinatown, and forged relationships with the Chinese–American community. With strong interests in and a commitment to optimal health care delivery of the community, Tufts MC has reached out to the Chinatown neighborhood in varied ways. This has created a tradition of caring for Chinese Americans and a longstanding record of working together in community services. This close relationship has been mutually beneficial, and thus can be the basis for even stronger community care. Nevertheless, various issues working in concert, have at times adversely affected this relationship and also impaired the quality of health care in Chinatown.

Many Chinese Americans, particularly immigrants of the older generation, are low income, may lack any or adequate health insurance and often are skeptical about western medicine. These factors have lead to both lack of awareness about and reluctance to participate in preventive screening, clinical trials or some forms of health care. The reason for undertaking this study was to investigate the views and concerns of the Boston Chinese immigrant and Chinese-American community on various healthcare issues, in order to better inform the delivery of health services to this community. Of particular interest were their views on health screening, preventive care and access and delivery of medical and cancer care. Although studies of various ethnic groups might have certain universal findings, such as less than optimal access to screening and healthcare, the underlying reasons for the lack of access might prove to be different among them. This study reports on

the cultural beliefs and traditions specific to this “snapshot” of a Chinese-American community. We believe that the results can provide Tufts MC healthcare planners and providers with insight pertinent to this particular community. On the basis of the findings of this study, the conclusions derived from them and the valuable suggestions of participants in the study, practical recommendations are made with an emphasis on achieving optimal health care of the Boston Asian and Chinese Immigrant and Chinese-American community.

METHODS

To assess the current attitudes and experience with cancer and issues surrounding the care of family members who had cancer, we held Focus Group Discussions within the community. One of our initial assumptions was that there would be reluctance to discuss illness, especially an illness as emotionally charged as “cancer”. In the Chinese American Community, the word “cancer”- both historically and to some degree currently, is equivalent to “death”. To make initial contact with a broad array of community members, we designed and administered an anonymous questionnaire printed in both English and Chinese which gathered the following information: self assessed first language, age, country of origin, acculturation as assessed by English competence and attitudes and experience with cancer illness. There were also questions about where care or cancer treatment or screening had or would be accessed by community members, and why. It concluded with an invitation to participate in further research and requested contact information on a separate page for those interested. [1]

Study investigator, Betty Yau and a team of bilingual volunteers then fanned out across the community to administer the questionnaires at public health fairs, and public community gatherings such as the August Moon Festival. This pool of anonymous questionnaire respondents was used to identify potential focus group participants who would be willing to talk about cancer and about their personal experiences with the disease in themselves, or in family members or close friends. Those expressing interest and providing contact information were contacted, and a subset of respondents ultimately decided to participate in the focus groups.

In order to include the voices of the most recent local neighborhood immigrant population, we conducted half of the eight discussion groups in Cantonese. The two major Chinese languages/ dialects in the Greater Boston areas are Cantonese and Mandarin. From US Census Bureau data and subjective observation, the majority of Chinatown and Greater Boston area immigrant residents that are of Chinese descent are Cantonese speakers, or consider Cantonese their first language. The number of Mandarin speaking immigrants is growing fast, but the growth rate has not outpaced the number of Cantonese

[1] Data from these questionnaires are not included in this report.

speakers as yet. Many Mandarin speakers do not live in or near the Chinatown area. They tend to live in the Northern or the Western parts of Massachusetts although a growing number of Mandarin speakers from Fujian province, China, have in recent years chosen to settle in the cities of Boston and Quincy.

Each of the focus groups was conducted by a trained and experienced facilitator who spoke the language of the focus group participants. In addition, after careful consideration, we decided that to maximize the willingness of participants to discuss their beliefs and experiences openly, we conducted focus groups consisting of participants of similar age, gender, and language, and importantly, facilitated by like-sex facilitators. A series of eight-three hour focus groups were conducted over a period of 1 ½ years between 12/07 and 8/08. Focus groups had a minimum of 6 and maximum of 8 participants, with an even number of English and Cantonese speakers (26 each). Table 1 summarizes our study design, with eight focus groups, 4 conducted in English, 4 in Cantonese. Each set of four was further peer-matched into males between age 50 and 80-plus and younger males between the ages of 18 and 49. The same configuration was followed in the female focus groups, with one comprised of participants between the ages of 50 to 80-plus, the other comprised of women between the ages of 18 to 49.

Table 1: Focus Group Design

18-49 year old Female (English speaking)	50-80+ Female (English Speaking)
18-49 year old Female (Cantonese speaking)	50-80+ Female (Cantonese Speaking)
18-49 year old Male (English speaking)	50-80+ Male (English Speaking)
18-49 year old Male (Cantonese speaking)	50-80+ Male (Cantonese Speaking)

Focus groups were audiotaped using a digital recorder and were translated and transcribed by native language speakers. Three focus group facilitators were recruited. Barbara Bond, EdD, an experienced focus group researcher who has previous experience working with the Chinese community, facilitated the two English speaking, female focus groups. Ann Wong, Chairperson of the Chinese Progressive Association facilitated the two Cantonese speaking female groups, and Doug Ling, Chinese bilingual community activist and consultant facilitated all 4 male groups. The English focus group transcripts were transcribed by an on-line e-transcription company. The Chinese transcripts were transcribed by bilingual translators, who first transcribed the Cantonese conversations in Chinese, and then translated them into English. Each transcript translated into English was read twice by a first and a second Chinese speaking reader. In all, there were five transcribers, all of whom were bilingual and bicultural in Cantonese/ English, were immigrants from Hong Kong or China, and had lived in Boston for between 10 and 20 years. The final transcripts with which investigators worked were all in English.

Qualitative thematic and content analysis was performed with the focus group discussion transcripts by a group of investigators lead by Dr. Barbara Bond and including Dr. Jing Tan, Social Work

Department Faculty from a local University, both of whom have extensive experience in analyzing qualitative and focus group data. Other members of the research group included Stephen C. Lau MD, a physician of Chinese background, who provided input in medical and cultural issues, and helped with interpretation of Chinese language and idiom. Andrea Talis was the Principal Investigator of the study, served as Director of Program Development for the Tufts MC Cancer Center until 2010.

As a group, the investigators began examining the transcripts to define "themes" present in the data. The group met several times to compare notes on the emerging themes and to identify relevant sub-themes. Following recognized qualitative data analysis procedures, , a "master" code book was developed from early readings of the first 3 of the 8 coded transcripts. As coding of transcripts continued , the master code book was augmented by mutual consent of the coders as necessary when coding categories not identified in the earlier version of the codebook was created, and early transcripts were reviewed for inclusion in the early transcripts. Each transcript was read and coded independently by 2 investigators. The preliminary codes were reviewed by a third coder, who reconciled discrepancies between the first and second coder, and established the final codes. At a conference of the three coders, the final codes were adopted.

RESULTS

Focus Group Participant Demographics

Gender of focus group participants was almost evenly divided, with 27 of the 52 participants female and 25 males. Participants were asked to self-identify their first language and their preference for language of focus group participation. Twenty six participants identified as Cantonese speakers and 26 as primarily English speakers. Participants represented a variety of occupations, including: restaurant owners, housewives, retired businessmen, home health aide, lawyer, tai chi instructor, educator, social service providers, financial managers, nurses and realtor. They ranged in age from 18 to 80. They were a highly educated group, 12 had high school educations, 31 were college educated and 9 had post baccalaureate degrees. Table 2 gives more detail on participants' demographics. For Cantonese speaking participants, the high school education indicated was received most likely in their place of origin (i.e. Mainland China or Hong Kong).

Table 2: Focus Group Participant Demographics

Language of Group	Gender	# of participants	Age Range of Group	Participant Ages		Education Level	
Cantonese	Female	7	18-49	18-23	1	HS	1
				24-39	3	College	6
				40-49	3	College +	0
Cantonese	Female	7	50-80+	50-59	3	HS	3
				60-69	3	College	4
				70-79	1	College +	
				80+	0		
Cantonese	Male	6	18-49	18-23	0	HS	3
				24-39	2	College	2
				40-49	4	College +	1
Cantonese	Male	7	50-80+	50-59	2	HS	4
				60-69	4	College	3
				70-79	1	College +	0
				80+	0		
English	Female	6	18-49	18-23	2	HS	0
				24-39	3	College	4
				40-49	1	College +	2
English	Female	6	50-80+	50-59	3	HS	0
				60-69	2	College	3
				70-79	1	College +	3
				80+	0		
English	Male	7	18-49	18-23	2	HS	0
				24-39	3	College	6
				40-49	2	College +	1
English	Male	6	50-80+	50-59	3	HS	1
				60-69	2	College	3
				70-79	0	College +	2
				80+	1		

Coding

The master codebook consisted of 20 distinct codes. Twelve of those coded topic areas have been selected as most informative for the purpose of this report. They have been grouped into four categories: observations about “health paradigms”, cancer”,” communication” and “ recommendations” as shown with sub-categories of each in Table 3.

Table 3: Coding Categories—Major Themes and Sub-themes

I. Health Paradigms	II. Cancer	III.Communication	IV. Recommendations
Health Beliefs *Traditional Chinese Concepts of Health and Wellness*	Most Important Cancers for Chinese Community ** Concepts of Cancer* **Causes of cancer* **Attitudes about cancer* **Traditional Chinese Medicine Treatments*	Health Information **Sources of Information* **Lack of Information*	Re. Educational Needs of Chinese ** Basic health education and Dietary education re. disease prevention* **Print information in Chinese/English bilingual format* ** Believing everything you read in the Chinese newspapers* **Information on psychological needs of Chinese people*
Health Behavior **Prevention* **Screening* **Treatment*	Barriers to Cancer Care **Time, language, finances, medical insurance, convenience* **Fears—"Cancer equals death"*	Providers **Following Doctor's Orders* **Eastern/Western Doctors* **Settings and Systems*	Re.Western Providers **Publish doctor's training, specialization and quality of care performance data* **Teach cultural sensitivity to non-Chinese providers* **Outreach out to HMO's and doctors to give info for and about Chinese patients*
Three paradigms **Traditional Chinese Medicine* **Western Medicine* **Combining Chinese and Western Medicine*	Barriers to Cancer Clinical Trials **Being a"guinea pig* **No sense of community* **Few Asians represented in cancer clinical trials*	Communcation ** What to tell/what not to tell* **Trust/mistrust*	*Re. Settings* **Outreach to all Chinese who come to China- town as a hub* **Clinics with multiple specialties in one place rather than patients going all over to see doctors* **Do health education forums in the lobby.* **Be sensitive about how you invite Chinese people into clinical studies*

Reporting Results of Qualitative Data

Qualitative research typically reports results by presenting the major themes and subthemes derived from the data. These themes and sub-themes are then grounded in direct quotes taken from the participants' interviews or focus group transcripts, which illustrate those themes particularly well. In this report, direct quotes from the focus groups are presented in the text in bold, italicized font.

Theme 1: Health Paradigms

Participants in this study demonstrated an awareness and understanding of the different paradigms about health which originated in Chinese culture and in the Western culture in which they now lived. We have grouped three sub-themes which arose from the interviews under the category of health paradigms: "*health beliefs*", " *health behavior*", and "*Ttraditional Chinese medicine and Western medical practice*".

"Health Beliefs"

Traditional Chinese Concepts of Health and Wellness

Traditional Chinese medicine is an ancient system which functions with a specific understanding of what creates and maintains health and a systematic conceptualization about the causes and remedies of illness. Even with much exposure to Western medicine, many Chinese continue to see health and illness through the lens of Traditional Chinese medicine. As one participant said: ***"I think eastern medicine does treat the body as more of a system versus treating entities within the system…"*** Another noted: ***"Chinese people have traditional thinking, believing that herbal medicine can cure a lot of rare diseases."***

Speaking about a basic difference between the Chinese and Western health paradigms, one participant offered this vivid analogy: ***"Western medicine is good for diagnostics. Western medicine focuses on symptoms; Chinese medicine focuses more on treating the root causes…. How does a tree, apparently healthy, have its leaves turn yellow all of a sudden? Chinese will look into the root system to try to find the cause. Western medicine would be quick to prune off a branch rather than treating the roots."***

There are eight guiding principles in traditional Chinese medicine which describe the condition of an individual's health. These are actually four sets of polar opposites: "yin/yang", "cold/heat", "deficiency/excess" and "interior/exterior". The traditional Chinese medicine concept of hot and cold was the concept most frequently mentioned in many of the participant's comments. ***"People use their knowledge of traditional Chinese medicine, about "warm" and "cold" in dealing with day-to-day ailments. If someone coughs for a long time, say, a hundred days, someone may suggest a traditional herbal remedy like the "hundred-day-cough."***

Herbal medicine was one of the aspects of traditional Chinese medicine which participants spoke about in the focus groups. Some were positive and practical: ***" My kids all have medical insurance. Still, I would rather give them Chinese herbal medicine. I just prescribe medication myself."*** There was some disagreement about when and whether herbal remedies were good to use: One participant said**:** ***"Chinese would consult an herbalist when they have small ailments. They would take herbal medicines that only treat the symptoms."*** Another participant commented: ***"For my friend who took herbal medicines, they masked her cancer symptoms. It was too late when she finally turned to chemo***

therapy".

Several participants, however, gave accounts of quite extraordinarily successful experiences they or others have had with herbal treatments, as in this narrative: ***"I have a friend who was diagnosed with cancer of the esophagus at the Guangzho No. 1 Hospital. They gave him papaya tree sap to drink. Now that is a pretty harsh drink to take. Three months after he checked out of the hospital, they could no longer detect any trace of cancer. All the department heads in the hospital gathered to try to figure out what cured the cancer. They asked but he could not remember for sure what he took. He basically took everything that people suggested to him. The point is that he was cured! Even the Health Department sent 10 officials to interview him for three days trying to try to document what medicine he took. They still couldn't figure it out."***

Some believed in herbal remedies but expressed skepticism about the quality of Chinese herbs found in this country*:* ***"My family only uses Chinese medicine that I bring back from China. I don't take what doctors prescribe here. My stomach won't tolerate them. For diarrhea or common cold, I take Chinese over-the-counter drugs. If I don't have what I need, I ask my mother to mail them to me."***

Food and nutrition also play an important role in Chinese beliefs about maintaining health and health restoration, as illustrated in this quote*:* ***"But the Chinese process of preparing food is more than just eating. It is choosing the ingredients. It is choosing the status of the household. Because what happened is that when you prepare a meal, your meal change(s) according to your daily life. Say you have two member(s) who came down with a cold or something. You change your basic meal and you've got to look for ingredients that will help them get better."***

In talking about experiences with dealing with cancer, one participant reported:***"Some people may want to call (me) to find out what kind of food or supplements they can prepare that will help. Like my friend with breast cancer, she called all the time to ask what food she can cook that would help cure the cancer. I told her I didn't know; maybe it would be best to ask a Chinese herbalist. So she did, and together with chemotherapy, she was cured. You can mix Chinese and Western medicine."***

"Health Behavior"

Prevention and Screening

Our focus group discussions with the younger and more acculturated, English speaking participants demonstrated that they had a very real awareness that the "older generation" might never participate in regular cancer screening. We repeatedly heard the pervasive cultural attitude ***"why go to the doctor when you are not sick?".*** Inferred from this attitude, and discussed in several of the focus groups, was also a perception that going to the doctor when you feel well might cause the diagnosis of

something terrible, that might not otherwise be a problem. Younger participants spoke of the belief that for elders, going to a western doctor while healthy might make one sick, or cause a terrible diagnosis that otherwise wouldn't be an issue. While articulating that it would take a lot of education and change in attitude to get the older generation to participate in routine cancer screening programs, the younger and more acculturated participants largely indicated their own openness to and understanding of the advantage of preventive measures and screening programs. However, in the focus group sessions, many of these same younger and more educated Chinese-Americans were *not* up to date on their own cancer screening regiments as they rather sheepishly admitted. So, while clearly the education and intent were altered with acculturation, screening behaviors were still not necessarily optimal in the younger more "enlightened" generation.

"Most Chinese people treat their body like a second-hand car. When you buy a new car, you are more interested in maintenance; but when you have a second-hand car, you tend to ignore regular maintenance and drive it into the ground. If they feel something wrong or rattling, they would take it to a Chinese garage. The garage would say, "I can't tell what's wrong until it actually breaks down. Why don't you bring it back when it breaks down?!"

The above quote from one of the participants conveys a humorous but cynical view of traditional Chinese attitudes about health care intervention and prevention. Participants largely agreed that Chinese people avoid and have many reasons for not attending routine health visits with practitioners on a regular basis. Some of these reasons were lack of or not wanting to "waste" the time and resources, not wanting to know if something is wrong, not wanting to be "jinxed", or as the above quote suggests, believing there was no reason to go to the doctor if nothing is wrong. These additional quotes were typical***:*** ***"Even those with medical insurance, they are still reluctant to go to the doctor's for check ups. They feel that if the results were fine from last year, and they are young, only thirty-something, it would be a waste of time to do the tests again this year."*** And from this individual***: "They tend to reject check-ups because they feel that nothing ever turns up. While they are working, check-ups seem unnecessary; it's only after retirement do they feel necessary to pay attention to their health."*** Another study participant put it like this: ***"We would at least consider the possibility of cancer when we see the symptoms. Otherwise, if we can eat, run, and sleep, we would not suspect anything going on inside even if the cancer is there for a long time"***

In terms of what Western medicine considers preventive care, (i.e. screening examinations) one participant said: ***"The preventive thing—I guess it doesn't really exist in China…they'll say oh there are people that live to be 100 and they just smoke their whole life."*** Similarly, screening examinations were not something the participants felt most older Chinese were even aware of: ***"…well at least when I was growing up there wasn't any kind of awareness of you have to do regular cancer screenings and stuff like that."*** Others without insurance used former Chinese healthcare providers: ***"Before I had***

medical insurance, I had my gynecological check-up every time I went back to China. Once I have medical insurance, I have my check up at the (local health clinic) every year."

Several barriers to Western medical screening of particular note were discussed. One referred to a cultural attitude about modesty ***: "I don' t know if they (Chinese women) go for pap smears because again it's that whole Asian modesty thing. You don't go to a doctor … until you're married, that's when you go and see a doctor (i.e. a gynecologist) because that's when you should be engaging in those types of activities, but prior to that you wouldn't".*** Another was about whether these screenings were necessary or beneficial for Chinese people: ***"Well, personally speaking, I was in my 40s when the subject was brought up by my doctor about screening things, like a sigmoid or colonoscopy and so on, and I think, at that time, I felt 'not me.' Now if there were some instances or facts specific to the Chinese community, my own, that I could identify with, perhaps I would've heeded that advice better than what I did, which was nothing".*** However, another participant turned the lack of information about how certain illnesses affect Chinese people into a self-mandate, saying: **"I know whenever I get an invitation to go for a screening for anything, because there's so little study done in the Chinese population, I'll go."**

"Three Models of Health Care"

Traditional Chinese Medicine and Western Medical Practice

Three models of health care were discussed and used by the participants: Traditional Chinese Medicine, Western Medicine, and a combination of both Chinese and Western medicine.

Traditional Chinese Medicine

Young and old, foreign born and American born, male and female—all participants had used Chinese medicine for their care at various times. Many participants offered testimonials to the curative value of Chinese medicine; this one was typical: ***"My sister-in-law's mother was diagnosed with leukemia and she was treated in the United States for a number of years and the prognosis was not good. So my sister-in-law's father took one year off from his work and took his wife back to China and they found a doctor in China that specialized in leukemia, which I'm thinking is a blood disorder. And they stayed there for a whole year undergoing Chinese herbal treatment. She has been in remission for 7 years now. So whatever it is they did, it worked for them."***

Western Medicine

Western medicine had its place as well in the health care paradigms of participants. These are the ways they described the use of western medicine: ***"I think Western medicine is great if you have to hit the emergency room and they have to do an appendectomy or something like that, you know for the really emergency things".*** One young woman posited the idea of generational differences in relation to

Western medicine. Asked about how she would or had treated her own illness she confided*: **"I would go to the western doctors but I would still let my mom do whatever she feels** (using Chinese medicine) **as long as it doesn't hurt me…"*** Another participant said, ***"Older folks may be more suspicious of Western medicine because they have a long history with Chinese medicine. Younger people have, of course, more trust in Western medicine."***

Study participants also had very clear concepts of what the differences were between the Eastern and Western models of care, especially of cancer care, and articulated their ideas well: ***"Chinese medicine develops more moderately. Western treatments are too severe, they kill all cells, good ones and bad ones."*** Another participant expressed it like this: ***" Eastern medicine treats the body as more of a system versus entities within the system."***

There were many general concerns about how respectful the Western medical system is of Chinese and Chinese-American patients. This was particularly true of those patients who experienced a language barrier to communicating directly with the examining physicians and other providers, but it seemed pervasive even among those Chinese-American patients who were fluent in English. Comments like these indicate the wariness of participants.: ***"Western doctors are not too thorough sometimes. They treat you in assembly-line fashion"***, or ***"Here, you are asked to tell the <u>doctor</u> what's wrong; they don't even bother to find out!"***

In addition to the general experience of immigrants feeling estranged from the medical system, the underlying unfamiliarity with western medicine and attitudes seems to come through the discussions as the perception of being treated as second-class citizens. ***"Here you often get examined by interns; not the chief doctors. It's only if they have questions or cannot prescribe the right medicine that they consult the big doctors. As far as I'm concerned, I don't think the interns know what they are doing. The real doctors won't see me, still they take my money. I want to consult the real doctor so that I get my money's worth! If they want to teach the interns, we should have the choice to reject the intern and demand to see the doctor."***

Other health stories exemplify the mistrust that is present among Chinese-American patients, here in an anecdote told by a younger patient talking about the older generation: ***"They would just follow whatever the doctors told them to do. I can give you an example. My aunt basically complained for years about her stomach and the only reason they finally diagnosed her was when she went to the emergency room and they took an X-ray. I mean basically the physician wasn't really, he was giving her antacids or oh, just do this for your stomach, don't do that, don't eat, you know don't eat this, don't eat that, but by the time that they actually diagnosed her, it already metastasized both to the liver and to the kidneys."***

Combining Traditional Chinese Medicine and Western Medicine

Emerging from almost all the health/illness stories told in the focus groups was a consensus that the third category, that of combining Traditional Chinese medicine and Western Medicine was by far the preference. In fact, anecdotal evidence in our data shows that whether or not Western physicians are aware of it, one or more types of Traditional Chinese medicine is often being used along with the Western physician prescribed treatment. Virtually all of the focus group study participants had something to say about combining Traditional Chinese medicine and Western medicine, sometimes they were enthusiastic about the combination and other times they expressed some caution. ***"…my father uses a combination of Chinese medicine and the Western medication. …like for a cold, if he can feel a cold coming he'll take herbal medicine first, but then he says when it gets really bad, then he'll take Western medicine just because he feels like Western medicine is a lot stronger. It's like stronger on the body so he feels like herbal medicine is better for the body. So he doesn't go to Western until it's—his colds worsen or he's sicker, then he'll go get Western medicine."*** Another health story excerpt: ***"I know someone in China who had liver cancer. They combined traditional and western medicine for his treatment. He lived for five years, more than the others who also had liver cancer in his hospital ward."*** And in cautionary advice from another participant: ***"You need to educate the patients how mixing Chinese and Western medicine may reduce the effectiveness of the medicine. It would not be good."***

Participants often seemed very clear about when each approach was most useful and under what circumstances: ***"Western medicine is really good at surgeries and stuff like that and then to me it would be (sensible to) take the surgery and then hopefully find something with Eastern medicine or something that helps promote the healing process".*** From another individual; ***"You can use advanced Western medical equipment to make the diagnosis, and treat the disease with Chinese traditional medicine."*** And from another story combining the two health systems: ***"To test for high blood pressure, they now can use Western equipment to measure blood pressure. An herbalist doesn't just rely on pulse taking anymore but uses a blood pressure monitor. He can verify that the blood pressure is high, say 180 over whatever, through the monitor. He will then prescribe herbal medicine as treatment."***

Combining the two approaches seemed to be especially common if the health problem was cancer. ***"I was gonna say that most of the people I know, especially Chinese, who have had cancer, have actually accepted both kinds of treatment. They've accepted the chemotherapy, the radiation or whatever that's been recommended by the physician, as well as practice some form of Chinese medicine, either brewing soups or taking herbs or whatever. So I would say it's a little mixture, at least in this country."*** From another cancer health story, ***"If the western medicine, like chemotherapy, is too strong, it may damage other organs in the body. Chinese medicine is then prescribed to lessen the impact on those healthy organs. Chinese medicine can make the healthy organs stronger".*** And

this story, leaning more towards the advantages of Eastern treatments for cancer***; "The Chinese medicine is effective in a certain way, with the beginning of some of the problems that we face. But, when the cancer is more severe, like a brain tumor or like prostate cancer, you have to do surgery. And the Chinese medicine cannot do surgery. It's just holistic."***

Several of our study participants talked about practitioners from both Western and Chinese traditions beginning to see the good in combining elements of both practices. This is, of course, now the model favored by the NIH/NCI Cancer Center Program, and apparently is also becoming frequently practiced in centers in China; ***"In Zhongshan University, where I was, they have an herbal medicine department in the medical school. Students there sometimes switch from Western to Herbal Medicine; so eastern and western medicines are already being integrated in China."*** Some study participants were clearly proud of the validation of established Eastern traditional methods in combination with Western treatments for optimal outcomes; ***"Like at (a major local hospital) when they give you chemo, you can actually sign-up for acupuncture. So, that it can take the edge off for some people, 'cause you have different reactions. You could get really nauseous, and get sick from it."*** And from another individual interested in combining treatment approaches; ***"…from what I have read, in Hong Kong, there are many universities and clinics with both Chinese and western medicine departments."*** As noted before, one participant noted; ***"There are many more Chinese herbal doctors who use blood tests, x-rays and not just pulse-taking as part of their diagnostic tools. There is this Chinese traditional medicine doctor in Chinatown who uses the same tests before prescribing herbal medicine."***

An interesting example of the lengths Boston's Chinese-Americans are willing to go to pursue combining Eastern and Western medicine was described by this participant; ***"For my parents, they go down to New York to get their exam because it's a one-stop service. They're Chinese people, but they're western educated. They have doctors there that graduated from universities in the United States. They find that if they go through a western institution they have to schedule a month later for a mammogram, another month for cervical, another month for this. Well they can go to one clinic, they have all the diagnostic equipment and they can get everything done within one day. So she (myMom) will sit there with all the Chinese newspapers and all the little old people and they are talking and they'll go from room to room to get all their diagnostics done and then they're told in a week or two you will have your results and they go home."***

There was an overarching belief throughout all the focus groups that combining Eastern and Western medicine would be the best way to approach caring for and curing disease as voiced by this participant; ***"If we can combine Western and Eastern medicine, perhaps we can make some breakthroughs for different incurable diseases."***

Theme II: Cancer and Barriers to Care

The second overarching theme was cancer, with three main sub-themes about cancer emerging from the data: *"Most Important Cancers Impacting the Chinese community"*, "*Perceived barriers to cancer care*", and "*Barriers to participation in clinical trials*".

Most Important Cancers Impacting the Chinese Community

Focus group members identified what they thought were the most important cancers impacting the Chinese community and spontaneously identified what they believed caused cancer. As shown in Table 4 below, more than 10 specific types of cancer emerged from the focus group discussions as having the most impact on the Chinese community. The three most frequently mentioned cancers that emerged as important were lung cancer, liver cancer, and prostate cancer, with gastro-intestinal and breast cancer as close fourths. Focus Group Participants also identified some of the conditions they believed caused these cancers, including: smoking cigarettes, workplace exposure to smoke and greasy fumes from working in Chinese restaurants, changes in diet from Chinese to American, inhaling exhaust fumes, eating too much burnt barbequed meat, as well as bad weather.

Table 4: Comparison: Descending Rank Order of the 10 leading cancers for Asian Men and Women in Massachusetts * and Study Participant's Rank Order

	Males Cancer Regsitry	**Females Cancer Regisry**	**Our Study Participants Rank Order**
1	Prostate	Breast	Lung
2	Bronchus & Lung	Colorectal	Liver
3	Colorectal	Thyroid	Prostate
4	Liver	Bronchus & Lung	Stomach
5	Stomach	Corpus Uteri/Uterus	Breast
6	Non-Hodgkin Lymphoma	Non-Hodgkin Lymphoma	Cervical
7	Oral cavity and pharynx	Stomach	Nasopharyngeal
8	Urinary Bladder	Oral cavity and pharynx	Colorectal
9	Kidney and Renal Pelvis	Ovary	
10	Pancreas	Pancreas	

*The Massachusetts Cancer Registry, Massachusetts Department of Public Health, 2000-2004

Barriers to Cancer Care

Language and Availability of Interpreters as Barriers

One of the most fundamental barriers to care identified by focus group participants was the inability to communicate with doctors due to cultural as well as language differences. The issues concerned the lack of easily available interpreters, or their inability to be reliably present at the critically important interface times with physicians and other medical caregivers. Due to very limited or no English fluency, a lot of Chinese people reported that as patients they need an interpreter when they see

doctors. However, participants noted that patients' access to care at the target hospital can be greatly delayed because of the limited availability of interpreters. ***"If you don't need an interpreter, you can more easily get an appointment. If you do, you may need to wait 2 to 3 months! There are only about 11 or 12 of them running around serving the whole hospital. That's why they often cannot get to all the appointments."***

Whether or not we believe this to be the current circumstance at Tufts MC is of little consequence. That this is a widespread perception in the Chinese-American community surrounding the Institution, is of great consequence. When professional interpreter services are not available, older Chinese adults normally depend on their children as interpreters. One participant commented: ***"It is a hassle if you are sick and you have to rely on your son or daughter to go with you to the hospital."*** They described the other communication issues as those arising from relying on family members who may be younger, of a different gender, or who themselves may not be completely fluent in both languages, or in the physiologic or medical terminology in use in patient/doctor exchanges.

The feedback from our data shows clearly that the time-lag in obtaining a scheduled appointment with associated interpreter-service translators available is not the only issue. Once scheduled, these long-awaited appointments with interpreter support for patients can be problematic. We are all familiar with the wait time associated with busy clinics. Patients are often not seen at the appointed hour, sometimes hours later than the appointment time scheduled. This leads to interpreters who cannot be everywhere at once, and cannot predict how they will cover the scheduled appointments which are likely to be quite disparate from the appointment times assigned to multiple patients in multiple clinics with multiple doctors. One participant said, ***"I showed up but the interpreter did not".*** Sometimes it is the doctors' delay that causes a cascading problem with interpreters. "If each doctor is late for 2 to 5 minutes, the interpreter's schedule for the whole day will be affected." One focus group member wryly quipped, ***"For those Chinese patients who do not speak English, they cannot even complain when something goes wrong. I can't yell at the Caucasian staff in Chinese. He'll just think I am nuts. If I knew English, I would be complaining to everyone in sight. But I don't speak English well—that is the killer."***

<u>*Financial Issues and Medical Insurance as Barriers*</u>

Financial status and medical insurance also play important roles in many Chinese people's access or lack of access to cancer and other types of care. For most immigrants who do not have insurance when they first came to US, it is confusing and difficult to know how to apply for insurance. For older adults, it may be just too hard to get health insurance. What we typically heard regarding these issues was: ***"if they don't have the means to pay for it, they may reject treatment and just buy over-the-counter herbal remedies."*** It was noted that the many people who work long hours in Chinese restaurants and laundries usually do not have insurance provided by their employer. Thus, people who do not have insurance or a

primary care physician, have huge barriers to receiving preventive care information, screening services and cancer care.

Focus group participants expressed the notion that the Massachusetts mandatory medical insurance system has not magically solved all the issues. ***"If a problem is found, you may get stuck with an exorbitant bill. You may rather just take some Chinese herbal medicine yourself and delay getting medical attention."*** Some participants even felt that Mass mandatory care has created some additional complications and paperwork. One person said, ***"before, I only had to pay $3 per doctor visit. Now, with mandatory care, I would have to pay $25 per visit. That doesn't even count the cost of medication."***

Underlying Issues in Cancer Care

Focus group participants thought that an underlying issue in barriers to cancer treatment for Chinese were cultural attitudes about cancer: Many stated that Chinese are afraid of cancer. They believed that Chinese people do not go for screening because ***"(t)hey are more scared of knowing than not knowing"*** They further held that Chinese people believe it is their "fate" or "bad luck" to have cancer. This results in a tendency to give up fighting if they know they have cancer, because they believe there is no hope for survival. In addition, several other barriers to cancer care and participation in cancer clinical trials were described as presented below.

Other barriers to care named included, *lack of time*, *lack of information*, and *lack of trust*. Regarding lack of time, they explained that the many Chinese immigrants who work in the Chinese restaurants, work long hours for little pay and barely have time to get their children, let alone themselves, to the doctor. One participant said that many Chinese are what he called ***"medically illiterate—they do not understand basic anatomy, do not know how bodies function, not what good health practices are".*** Therefore, he and others explained, they may do nothing proactive or preventive regarding general health. Several participants asserted that ***"some people who have cancer may never get diagnosed because of this confluence of the lack of time, information and trust."***

Barriers to Participation in Cancer Clinical Trials

The biggest fear noted in regard to questions about participation in cancer clinical trials, was the Chinese perception that it meant being a "guinea pig", or a "lab rat." One participant said that ***"Chinese in general lack confidence in any new treatment and believe that every drug has a certain level of toxicity".*** If toxicity and side effects of a new drug or new treatment cannot thoroughly be explained, they will not try a new drug.

Another fascinating barrier to participation in clinical treatment trials arose in several of the focus groups. Some expressed it as "collective selfishness" or "lack of altruism". One woman said ***"That is American to sacrifice for the good of strangers, Chinese don't"***. When asked if that was

specific to new immigrants who by necessity are more focused on survival issues-food, shelter, work- she asserted, ***"No, even more acculturated and educated Chinese won't participate"***.

"No sense of community" was another explanation of why Chinese do not participate in clinical trials. Said one participant, ***"In the Chinese community I don't feel like there's that sense of community where you feel like there's something you could do here that might potentially benefit another person in terms of medicine."*** The traditional Chinese attitude of not wanting to "get involved" was also said to prevent people from participating in clinical trials. One man said: ***"my wife even told me not to come to this focus group."*** In addition, "***lots of rules and criteria and too much paperwork for documentation",*** impede Chinese participation in clinical trials.

In addition, there is a new awareness of the need for Western providers to recruit Chinese-American patients to research trials. Several participants asserted that it was not until recently that attention was paid to Asians as participants in clinical trials. Some people said that they would try a clinical trial only if there was no other options. ***"Since they are dying anyway",*** said one group member, ***"they may take the approach of treating a dead horse as if it were a living horse."*** Several participants voiced the opinion that younger people with a stronger sense of survival, and a greater awareness of how clinical trials might benefit future Chinese cancer patients, might well be more receptive to clinical trials when there are be no effective treatments to be found.

Theme III: Communication

We found several subthemes which we grouped under the rubric of communication. They were about "health information", "communicating with health care providers and systems" and "the content of communication about health care".

Health Information

Sources of Information

Participants complained that there were few reliable sources of health care information available to Chinese residents in their native language. ***"There are many Chinese nutritional supplements or medicines, especially those that claim to have the power to bring you back from certain death! There really aren't too many sources of more authoritative and objective information*** *(in Chinese)****."*** Several participants felt that this contributed to their lack of participation in screening programs. ***"You need more education in Chinese. You need to change their*** *(Chinese people's)* ***behavior more towards prevention. We must promote more annual check-ups".***

According to many participants, Chinese newspapers were frequently the source of medical information relied upon by many older Chinese and newer immigrants. Some of the published

information is not well-vetted for content accuracy, and some isn't designed to be educational at all. ***"Chinese need to be educated to not trust the drugs they advertised in newspapers for every possible ailment."***

"Word of mouth" was another common source of medical information. ***".. my cousin had a back problem and he didn't wanna go to the American doctors. He said, Oh, I heard someone in New York can just pop it back into place or just fix it right away."*** [2]

Regarding information about cancer, one participant said: ***"I don't think there's a lot of education out there until it actually comes up in your life. So I'm, I myself I don't really know what treatments are available. You hear about things but I mean if you were to ask me what treatments are available for certain types of cancer, I probably wouldn't be able to tell you."***

Providers and Settings

Eastern and Western Doctors

There were many comments comparing Eastern and Western practitioners, some of which have been reported in other sections of this report. Additional critical comments referred to how Western doctors fell short in their patient care approach. ***"Often times you get examined by so many interns; everyone wants to poke at you and check you out. It gives the patient a bad impression or feeling that he's being experimented on."*** A frequently voiced criticism of Western doctors was their lack of understanding and respect for traditional Chinese medicine, as reflected in these comments. ***"The whole mistrust of western doctors to eastern medicine is also a pain in the ass to deal with too. Most of the time you talk "I mean when is there an opportunity for them to actually have a true discussion with you about a whole set of treatments versus let's just fix that cancer in your arm versus how did you get the cancer in your arm or even wondering, you know yeah, you got cancer, let's fix it in the arm but then yeah there's also a worry that it'll spread and stuff like that. But western medicine has such a focus on body parts and things like that, that's what always bothers me about talking to these guys and then it's a fight about Chinese treatments."to these guys, they don't even wanna talk to you about the potential of doing something alternative sometimes and especially with cancer where it really is a scary thing."***

However, there were also some positive comments about a few Western doctors who seemed sensitive to and respectful of cultural differences. These are typical. ***"We were very fortunate that my father found a doctor that treated me and my brother, and he was a very good person, understood that***

[2] This is a troubling notion to the authors of this study, given the alienation and mistrust that many less acculturated residents feel for Western Society, as well as in Institutions providing Western Medical Treatment. It perhaps speaks to a need for frequent and accessible educational workshops and screenings where more accurate information gets out into the community.

there were cultural differences, and had a lot of sensitivity." And from another participant about his family's provider, ***"My father and I both see the doctor that my grandmother sees. She's seen her for at least 15 years. And she just pays attention to everything and she's open to all types of medicine too, she understands that the makeup of the Asian community is very different so she welcomes all these herbal medicines too. She doesn't say this is the only way. She's 'hey if it works for you then don't stop'. She's very open to that."***

Following Doctor's Orders

Many participants voiced the somewhat contradictory opinion that Chinese patients will basically do whatever the doctor they go to tells them to do; ***"Like my friend who has breast cancer, she trusts that a doctor's instructions, having come from a professional, should be correct. So she follows them. As far as how much she actually understands, I would say about 30 to 40%. That's what it sounds like from what she tells me."*** They also believe that this was related to a reluctance to face a diagnosis like cancer directly. ***"Yes. It is also about the ability to rationalize. Most patients would say, 'I'll go along with whatever the doctor says; why worry more than necessary? If you think that's best, that's fine. I don't really care how I am treated'. Since cancer is serious, the patient may not have the spirit to really get into understanding the illness anyway."***

Some study participants told stories about how following doctors orders without question ended up in negative consequences for some Chinese patients. ***"They would just follow whatever the doctors told them to do. I can give you an example. My aunt basically complained for years about her stomach and the only reason they finally diagnosed her was when she went to the emergency room and they took an X-ray. I mean basically the physician wasn't really, he was giving her antacids or oh, just do this for your stomach, don't do that, don't eat, you know don't eat this, don't eat that, but by the time that they actually diagnosed her, it already metastasized both to the liver and to the kidneys."***

Settings and Systems

Probably the most frequent criticism of the Western medical system had to do with the long waits for appointments, and the disorienting need to go to many buildings and locations within the Institution to see multi-disciplinary specialists. Both of these issues greatly contribute to the sense of powerlessness and confusion that many feel in seeking access to healthcare.

Regarding the access to care and appointments: ***"I tried to make an appointment at (this hospital). They told me there was none available for 3 months. When the appointment time came, I was told the doctor went on vacation! Now I have switched to Hospital X, and I have been able to see a***

doctor much sooner. I used to go to this hospital; now I go to Hospital (X) instead. It's just so much faster." From another study participant; ***"My girl friend recently needed to see a doctor. They cannot schedule an appointment for 2 months. When I was in New York City, the wait was at most 2 days. I don't know if there are not enough doctors here or what."***

Others found ways to deal with the scheduling problems or had positive experiences in the hospital that the speakers above found lacking. ***"I think some of that has to do with who the PCP is; like for example my previous PCP, he's always busy so I've seen him maybe like twice ever and I usually just deal with the nurses for regular checkups, not exactly cancer or anything."*** It may be that some of the frustration we recorded in the transcripts had to do with misunderstandings about scheduling urgent care visits for an acute problem, versus scheduling routine check-up appointments, as exemplified by this comment from one participant: ***"That depends on your personal experience. It is your opinion. I think (the target hospital) is better. The doctors are good. I had a friend who had cancer; they operated on him very quickly and followed up with chemotherapy. He had very good care and follow-up."***

There were several comments which indicated dislike and unfamiliarity of Chinese patients with the Western system of medical care in general. ***"I don't like how everything goes through the family doctor here in the U.S. If there is something wrong, I would like to have diagnoses from 2 or 3 doctors in order to get a full picture. They don't let you do that here. The doctors are not perfect. Ultimately, you need to make a decision yourself, whether to have surgery or not. No doctor can guarantee success. But here, you don't have the option. It's a hassle to switch doctor."*** Comments also reflected confusion about requesting necessary appointments, and making the actual arrangements for them individually; ***"Sometime your family doctor tells you to do a certain cancer screening for your annual physical, along with blood tests and EKG. But for most women, you have to request gynecological or other specialized check-ups. It's sometimes difficult to get an appointment."*** Once specialist appointments are achieved, some Chinese patients feel rushed, or not properly attended to for their medical problem; ***"They're, you know, they have to do assembly line,… but then I just don't feel like you should treat other people like a piece of meat either;…and the difficulty of seeing specialist is as usual everybody wants to see the specialist so you know their time is only what you see him for all of 5 minutes, do your stuff and see you later?"***

Finally issues that arose almost constantly in focus group discussions were about how people experienced care in Western Medical settings and the issue of the scatter and distance between departments and the multi-disciplinary specialists and equipment that cancer care often requires. Even for Westerners who are used to having to go to multiple buildings and sites, and who speak the language and can potentially follow hospital signage, there are well-studied reasons to implement things like navigator programs to assist patients get from one appointment to another, and to cluster appointments so

as to minimize how many times a patient has to come to the institution. For foreign-speakers, it is easy to imagine the overwhelming prospect of getting to the institution and to the correct location for the first clinic appointment a patient has. But then add to that being seen by English-speaking providers and attempting to communicate about ones' health through an intermediary, and subsequently having patients sent on their way to another building/department/provider in the same institution, still with only an English verbal set of confusing directions in terms of how to navigate themselves there![3] Our study indicates that this overwhelming logistical issue is a huge barrier to healthcare access.

Communication Across Cultures

What to tell/what not to tell

Some participants expressed a commonly held belief that Chinese preferred not to have doctors be direct in discussing a terminal illness like cancer, but not because they do not want to know the truth, rather because of the impact some ways of conveying information may have on the patient's will to live. For example: ***"For terminal cases especially, doctors here (Western medical practitioners) are too explicit about when the patient may die. Basically, if they tell you six months, you can expect to die in two."*** One person told this story illustrating what happens when you bluntly tell Chinese people the truth about the prognosis of a terminal illness: ***"Last September, I had a patient who was diagnosed with cancer. From the day he was diagnosed, he never smiled again. I asked him to share with me his feelings. Even though I could not solve his problem, I thought I could help provide some comfort. He told me he was very depressed. His prognosis was for 6 months; but he only lasted a month and a half. It deteriorated very quickly. For three weeks he was able to bathe himself; then the next week he could not even get out of bed. We had to lift him off the bed to bathe him. The next week we could only give him sponge baths. We could not untangle the knots in his mind."*** Interestingly, there were also discussions in many of the Focus Groups about whether or not family members would convey a terminal diagnosis to (for example) an elderly family member. There were strong opinions on the reasons for this that we feel boiled-down to: "Chinese people give up whenever you talk about death."

Study participants in general also felt that doctors here did not always really explain things in a way that Chinese patients could understand. As one person said: ***"A patient doesn't exactly always know what a doctor tells him about the illness. He just follows doctor's order and goes through the treatments."*** Another explained*:* ***"The doctors would say something and then we'd go home and try to figure out what to do because it wasn't clear. You know the doctors say like, "do this, do this, do this." But did they really have the patients' interest in mind or were they just solving a problem?"***

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[3] For example, there are no appropriate-language printed materials that show patients how to get to the radiation department, much less a friendly navigator who speaks their language, to escort them, offering reassurance and relief to already alienated patients.

Trust/Mistrust

The issue of trust came up frequently in many of the participants' comments. They found trust to be both critical in the doctor/patient relationship and hard to achieve. ***"to find a new doctor was a very, very difficult process to sort of build that kind of trust with the doctor and that *who would understand why you didn't do what you didn't do, or why you did what you did. That took a very long time."*** Regarding being referred to see a specialist by their PCP, one participant believed it undermined the doctor/patient relationship. ***"The issue is trust. Like I just made a relationship with you and now you're telling me to take off to go look for some other stranger. I'm not gonna deal with that. Why do I need to do that?***" Some participants spoke about the relationship between culture and trust: ***"That that's why they (her parents) would trust the Chinese doctors more because they know what their body type is like and they're familiar with their lifestyle and there's definitely a better communication level there. Whereas the American doctor, they don't know – like I don't eat the same thing you do why should I trust you? You don't know what my life is like."*** And understandably, ***"I don't think they (Chinese doctors) have to convince anybody initially. I don't know if they're more caring, but there's already initial trust – an understanding of what they're saying."***

RECOMMENDATIONS

Theme IV: Recommendations

The last theme arising from the data were the many recommendations which came directly from participants themselves. They seemed very certain of what needed to be done to better serve the Chinese community—their recommendations were about providers, settings, outreach and some cancer specific suggestions and are outlined here. These four major sub themes are described below.

Educating the Chinese Community:

1) Targeted basic health education about cancer and screening is needed

2) Host educational workshops in Hospital Lobby and Conference Rooms makes Institution familiar to Community Members.

- a) Provide opportunity for community members to observe *building signage, clinic locations,* and *educational materials* in Chinese.
- b) More print information should be available in Chinese/English bilingual format
- c) Need to address the issue of reliability/quality of educational sources and content:
  - i. Not believing everything you read in the Chinese newspapers" or
  - ii. "Use the Chinese newspaper for health education dissemination."[4]

3) Put out more information on psychological needs of Chinese people

Western Providers

4) Advertise/create Chinese-language promotional materials providing professional information about doctor's training, specialization and quality of care performance data. If providers are bilingual highlight that; [5]

5) Help facilitate hiring and licensing of additional bilingual providers;

6) Require validated cultural sensitivity curriculum and training to all hospital staff and providers

7) Educate western providers about Traditional Chinese Medicine so that they can discuss and understand the TCM approaches that many Chinese use;

8) Be sensitive to non-English-speaking people who qualify for clinical studies

a) Make certain to have interpreter support in thoroughly explaining the study and patient eligibility;

b) When clinical trial/study is complete, be certain to give feedback about study results and express gratitude for their participation.

One person expressed their disappointment about research studies this way:

"But if you're a guinea pig, I mean that's okay, but I really wanna know that I made a difference or I didn't make a difference. I think I would like to see, "Well, we tested you and 15 of your colleagues, and this is what came up. And thank you." But I never got any feedback on anything."

Medical Settings: Clinics, Programs and Outreach

9) Organize multi-disciplinary Asian Cancer clinics (and other disease centered clinics) in one location rather than having patients sent all over the hospital to see doctors of several specialties related to cancer care.[6]

10) Patient navigators are used in cancer centers across the country. Hire and train Asian navigators to help take patients to the next appointment/clinic they need to go to and to do other patient support and outreach.

11) Utilize already existing excellent Chinese-language print material and web sites from other cancer centers which have already made this investment (San Francisco, Davis, and Minneapolis)

12) Reach out to HMO's and doctors to give info for and about Chinese patients and TCM

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[4] Older Chinese read the Chinese newspaper daily like eating rice, deapite access to the internet.

[5] Useful only for the educated Chinese American public. Others would probably not understand nor care about most of these kinds of information.

[6] The Breast Health Multidisciplinary Clinic is one model that could be used. Another model suggested by one participant was built on that of a Chinese hospital:

"In Guangzhou, China, hospitals often hold health forums in the lobby and provide disease screening in Saturday or Sunday afternoons. They cover different cancers or diseases. If you want to learn about a particular cancer, you can go and listen. They are all free; some are sponsored by drug companies. You'll learn where some diseases come from, etc."

13) Do more studies specifically involving dialogue with the Chinese community; implement suggestions and what data shows would improve care.

14) Do multiple types of outreach to all Chinese who come to Chinatown as a hub for Chinese goods, services and resources.

15) Fill as many positions as possible within the Asian Cancer Clinic (and Medical Center) with qualified bilingual Chinese staff and medical practitioners.

16) Hire a dedicated Chinese interpreter who is permanently assigned to the Cancer Center and present at all Asian Cancer Clinics, and assign a Chinese bilingual social worker to these clinics.

17) Provide various forms of Traditional Chinese Medicine at the Asian Cancer Clinic (and other clinics).

18) Provide health education forums, health fairs, and free screenings in the lobby so community members become familiar with the Hospital.

19) Provide effective signage and clinic names in Chinese so participants feel empowered to navigate their way to different areas of the hospital.

<u>Other Cancer Specific Suggestions:</u>

20) Work on addressing the stigma of cancer in the Chinese community

21) Teach about cancer as a disease that can be stabilized

22) Address the resignation to cancer as just "bad luck"

23) Provide data specific to the cancers most common in the Chinese community and provide clinic/physician information to facilitate use of clinics by Chinese community.

Several of these attitudes are summarized in the following comment from a participant:

> ***"Yeah, and I think (what to do) before you get to even building those support groups, is to take away the stigma to a lot of the things, like cancer. Because, again if our culture says, "Oh, we don't like to talk about it." And if you can take that stigma away, that you know – why I convey to them the value of communicating that to the public, that there are success stories, there are options."***

Another participant said:

> ***"I think the problem is this: besides time constraint or whether people would want to learn about cancer, we resign to the fact that it's just bad luck that one gets cancer. It is so hard to detect and cure. If I have a sore throat, or whatever, and I read somewhere that it's one of the symptoms of cancer, I may resign to the fact and not want to learn more about it. So what's the point of trying to learn how to identify cancer?"***

Finally, one participant gave this sage advice:

> ***"People may not come to a workshop. You need to give yourself enough time to do outreach. Don't get discouraged when you roll the talks out and no one comes. It will take time for people to learn about and accept what you have to offer."***

CONCLUSION

For many Asians and Asian Americans the health issues raised by the dichotomy between Western Medicine and Traditional Chinese Medicine have become compelling in the setting of delivering health care in the West to individuals immigrating from these Asian cultures. Seemingly at odds with one another, the East/West approaches to health and illness, treatment and cure, create unique challenges for the provision of care and prevention. As study collaborator Betty Yau, MBA, has so aptly said "the end-behavioral response of Chinese Americans may be the same (eg avoidance of screening procedures, or avoidance of doctors in general) as individuals from other cultures, but the underlying attitudes that cause the behavior are unique and must be correctly understood to be targeted appropriately for the successful delivery of health care in Chinese-American Communities".

If we listen to the voices of our participants we hear several strong messages regarding how to reach Chinese immigrants and Chinese Americans in health care delivery systems. One very clear message is that Traditional Chinese Medicine is their framework for understanding health and illness. There is little we can add to the excellent recommendations made by study participants, summarized here. Participants wanted a setting that would incorporate and offer the best of both Western and Traditional Chinese Medicine, would respect Traditional Chinese medicine as a health framework; that would provide consistent and readily available language interpretation if needed; offer truly culturally competent care from all providers, and respect them as unique individuals as well as people who come from a distinct cultural background. This would mean having bilingual, bicultural health care providers as well as readily available language interpretation with non Chinese speaking providers, who could understand and accommodate their cultural and everyday realities. They also wanted help provided for understanding and navigating the current, complex system of medical care and especially cancer care; and asked for outreach to educate people about health and facilitate their access to medical care. Last, they wanted clinical studies that address the diseases most important to their communities and include members of those communities in the studies and give results of those studies back to the community in respectful and timely fashion.

It is important to note that these are the comments and voices of the Chinese community through a small and perhaps unusually highly educated group of informants. We are well aware that there are many more voices to be heard in the Chinese community and certainly in other Asian communities in the Greater Boston Area (such as Vietnamese, Korean, Cambodian, etc), who use the services of the Chinatown neighborhood and could be reached by the Tufts MC. We

hope that these findings will encourage the Tufts MC to continue to explore these voices and develop programs and services to meet the needs of these communities in the most comprehensive and culturally inclusive ways possible. We conclude this report with our great thanks and deep gratitude to the participants for the thoughtful and frank conversations they shared with us and hope that we have represented their views and voices well.