Published in final edited form as:

J Community Health. 2018 December ; 43(6): 1161–1171. doi:10.1007/s10900-018-0536-7.

Barriers to care in Chinese immigrants with hepatocellular carcinoma: a focus group study in New York City

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Abstract

The incidence of hepatocellular carcinoma (HCC) is rising sharply in the United States and deaths from HCC have increased at the highest rate of all cancers. Though Asians have the highest incidence of HCC of all ethnicities in the US, racial/ethnic minorities, including Asians, have worse survival from HCC. We sought to identify barriers to care in treatment of HCC among affected individuals in the NYC Chinese immigrant community. We held focus groups with Chinese immigrant patients in NYC with HCC. 29 individuals participated in the focus groups. We analyzed focus group data using grounded theory methodology. Barriers to care identified included insurance, money, time, language, residency status, and stigma. The impact of provider bias and culture were also discussed. Knowledge gathering with minority patients with HCC is essential for us to fully comprehend the barriers to healthcare experienced by this community. Future policy and intervention efforts must be founded in this reality.

Keywords

hepatocellular carcinoma; barriers to care; health disparities; immigrants; focus groups

Introduction

In the United States, the incidence of hepatocellular carcinoma (HCC) is rising sharply, and deaths from HCC have increased at the highest rate of all cancer sites [1]. Among all race/ethnicities in the United States, Asians have the highest incidence of HCC [2,3].

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Conflict of Interest: The authors declare that they have no conflict of interest.

Furthermore, Asian Americans are the only group for which cancer is the leading cause of death [4].

The high rates of HCC in Asians is linked to the marked prevalence of chronic hepatitis B virus (HBV) infection in this population. Although all individuals born in the U.S. are routinely vaccinated against HBV, many immigrants from Asian countries have not received the vaccine, and remain at high risk for developing HCC. Because Asians are the fastest growing ethnic group in the U.S., HCC represents a growing health care issue [5,6].

It is well known that racial/ethnic minorities tend to have worse survival from cancer in general [7], and multiple studies confirm that this holds true for HCC [8,9,10,11,12]. While some of this effect is a result of late diagnosis, these survival differences persist even when individuals are matched by tumor stage, due in part to differences in treatment allocation [8,9]. For example, liver transplantation offers the highest survival rate from HCC [13], but minorities, including Asians, tend to undergo liver transplantation less frequently than white individuals [14,15].

The reasons behind this phenomenon are complex and multifocal. Minorities with cancer have been observed to face many barriers to care, including difficulties navigating the health care system, differences in medical beliefs, and fear/mistrust of healthcare providers [16]. But the barriers that minorities face are often ethnicity-specific, thus several researchers have attempted to define the barriers facing the Asian community in particular. A review by Fang et al. summarized the effort to identify barriers to cervical cancer screening in Asian women and identified lack of knowledge, psychosocial beliefs, and structural barriers to care including lack of insurance, language difficulties, and transportation [17]. Studies that employ direct reports from affected community members are especially useful because they allow self-identification of the barriers that they experience. Lee et al exemplify this approach, conducting 19 focus groups in Asian American communities to identify major barriers to accessing general health care [18].

This type of culturally specific attention is deeply needed in the liver cancer community. The largest subgroup of Asian Americans is the Chinese, and New York City is a major destination for immigrants from China [6,19]. Thus, the aim of this study was to utilize focus groups conducted among affected individuals in the NYC Chinese immigrant community to identify barriers to HCC treatment.

Methods

Institutional Review Board (IRB) approval was obtained at both clinical recruitment sites and from the consulting institution involved in the qualitative analysis. Focus groups were planned and conducted based on standard accepted methodology [20]. A set of questions was developed based on review of the literature and on preliminary data obtained from prior experience with focus groups of Chinese American immigrants in NYC. Specific topics included HBV and HCC knowledge, access to treatment services, decision-making around care, attitudes towards Traditional Chinese Medicine, and the presence of social support

networks. Patient perceptions on the receipt of discriminatory care were also specifically explored.

Focus group participants were recruited from the surgical oncology clinics at two large NYC hospitals. Inclusion criteria required that participants were: 1) born outside the United States, 2) of Chinese descent, 3) native speakers of Mandarin, 4) of age greater than 18 years, and 5) had a diagnosis of hepatocellular carcinoma. Meetings were arranged by gender and age to encourage open communication. A separate focus group was dedicated to patients who had undergone liver transplantation, because the experiences and knowledge base of these individuals likely did not reflect that of those who had not undergone transplantation.

Informed consent was obtained from all participants in the study by bilingual staff with previous consenting experience. The nature of the study was explained by the staff and a “teach back” was requested of each subject to ensure understanding. As per the IRB, written documentation was not generated due to focus group questions involving immigration status and the potential risk for any participants with undocumented status.

Sessions were designed to take approximately 1.5 hours. A \$20 Metro Card to cover travel expenses was provided. All sessions were conducted by two native Mandarin-speaking individuals. Discussions were audiotaped, transcribed in Mandarin, and then translated into English. Three coders, including a native Mandarin speaker, reviewed the final transcripts.

The transcripts were analyzed using Atlas.ti. Inductive analysis techniques were used to conduct content analysis, wherein patterns, themes, and categories arising from the manuscripts were used to generate a coding scheme. Once an initial scheme was agreed upon, transcripts of the focus groups were read again and coded until saturation was achieved.

Results

A total of 29 individuals participated in the focus groups. Participants were confirmed as having been diagnosed with HCC and included a range of disease stages and therapies. One participant requested that her husband remain for the focus group, thus one individual without HCC was included in the discussion. Eight focus groups were held; the groups ranged in size, up to a maximum of nine participants. Ages ranged from 38–79 years (mean 57 ± 3.68 , 95% CI). Participants included 3 women and 26 men, consistent with HCC’s strong male gender predilection. Six groups were held with only men: two consisted primarily of men older than 50 years of age, one session was comprised of younger men, and four sessions included men of mixed ages. One session included only older women, however we were unable to hold a session for younger women due to a lack of candidate participants.

The focus group conversations covered a wide range of topics including a detailed discussion on potential barriers in access to health care. Several definite barriers to care were identified including: Insurance, Money, Time, Language, Residency Status, and Stigma. Discrimination was not generally felt to represent a barrier to care. The impact of Culture

was more complicated, with respondents providing mixed opinions on its role as a barrier. Themes were generally similar between genders and ages, although the low number of participants in some groups limited these comparisons.

Insurance

Across all groups, participants stated the critical importance of insurance coverage to the receipt of medical care (Table 1a). Several participants remarked on the cash price of various blood tests, imaging exams, and medications if uninsured. Some participants lamented that even with insurance, not all prescriptions were covered by their policy, which sometimes led to rationing medications. Many participants also commented on the differing quality of available insurances, noting that Medicaid did not cover some expensive medicines and that there were longer wait times for providers who accepted Medicaid. Despite these frustrations, a few participants noted that it was possible to receive treatment even without the ability to pay.

Money

The high cost of healthcare was a major concern across all focus groups (Table 1b); this theme was related to, but still distinct from, insurance barriers. Even with medical insurance coverage, participants described being burdened by fees, co-pays, and other costs that added up to prohibitive amounts. The high cost of hepatitis B or liver cancer medications specifically was a recurring theme. One participant shared that he relied on family members for financial support.

Multiple participants expressed that these dollar amounts represented a large percentage of their monthly income. Participants also described a vicious cycle wherein illness impacted their work hours, thus leading to lower income, which further exacerbated their ability to receive care.

A few participants expressed feeling a lack of support in the United States compared to in their homeland. Still, some participants were aware that free health care was available at several community health centers.

Time

Another common theme among participants was being unable to dedicate time to seek medical attention (Table 1c). Patients described the burden of having to take time off from work to see a doctor. A few participants specifically described long commute times to Manhattan hospitals as a burden. One participant explained that family members might also be required to take time off from work to accompany the patient to the appointment, or to remain at home as the primary caregiver for children. The difficulty of scheduling appointments during regular business hours was also frequently mentioned.

Particularly in a public hospital clinic, participants stated that several hours might be spent in the waiting room before seeing a doctor, while those with private insurance coverage

experienced shorter wait times. One participant who was retired felt he could only accommodate healthcare appointments because he was no longer working.

Language

Language barriers represented an important issue throughout the focus groups (Table 1d). Although the law requires that interpretation services be available, some participants preferred to bring a friend or family member to interpret and cited this as a barrier to care. Those who were familiar with the hospital-provided telephone interpretation services had mixed feelings. Some expressed satisfaction with the phone interpreters, but more participants expressed frustration. They reported difficulties expressing themselves clearly over the phone and described the situation as “inconvenient.” Many described having difficulty with medical terminology in particular.

Of note, these feelings were not universal, and several participants felt the interpretation services were adequate, especially when interpretation was available in their native dialect.

Residency Status

Focus group participants reported that legal residency status was an important issue among Chinese immigrants in NYC (Table 1e). They explained that lack of documented immigration status created a barrier to healthcare by virtue of precluding insurance coverage. A few participants described how those without legal residency status could still access care at public hospitals. However, one participant explained that even public hospitals required proof of residence, which could be challenging for the undocumented.

Residency status created another barrier to care by prohibiting liver transplantation, an important component in the treatment of liver cancer. One participant described receiving a transplant only when he became a citizen.

Stigma

Many focus group participants described significant stigma against liver diseases in the Chinese community (Table 1f). They described it as a taboo topic; one participant suggested many would be hesitant to discuss their illness because their community might respond in a spiteful way. A few said they knew people who felt ashamed of their diagnosis and isolated themselves to avoid contact with others.

Most participants who spoke about this felt the stigma represented fear, rather than discrimination. Participants verbalized that this fear was based on a lack of understanding of how hepatitis is transmitted.

Culture

Part of the focus group discussions centered on whether cultural factors impacted participants' healthcare choices (Table 2b). Many participants expressed the belief that their

prognosis was linked to fate. Focus group participants also reported a general aversion to surgery among the Chinese immigrant community.

Several questions explored Traditional Chinese Medicine (TCM) and its perceived role in treating liver diseases. Patients voiced mixed opinions on the role of TCM, some stating that it was beneficial in supporting general liver health, and others stating that those with liver diseases should avoid TCM entirely. Nevertheless, a common theme was that the participants felt TCM was not effective at treating liver cancer.

Participants generally voiced respect for their American physicians and stated they were likely to follow treatment recommendations. When asked whether cultural matters consciously factored into medical decision-making, most participants denied any effect.

Provider Bias

Although participants described many other barriers to care, a sense of provider bias was generally absent (Table 2a). Many participants felt that they were treated well by their providers. Several participants voiced that they felt discrimination was not consistent with American culture specifically. Overall, 5 participants stated that they felt some discrimination, whether due to race or because they could not speak English. Of note, only one participant strongly felt definite discrimination.

Discussion

This study draws attention to barriers to care for liver cancer patients in the Chinese immigrant community of NYC, and uses testimony gathered directly from community members to differentiate between barriers that are presumed versus actually experienced.

Lack of insurance was not surprisingly the most concrete barrier for our participants. Insurance represents a pervasive barrier, common to many minorities and disease types, and is well-documented by investigators. For example, in a study of Chinese immigrants, uninsured patients often avoided seeing doctors until the situation became emergent [21]. In HCC specifically, Hoehn et al. showed that patients with Medicare, Medicaid, or without insurance were significantly less likely to have surgery [22].

Importantly, our participants reported that financial barriers, distinct from insurance coverage, were also significant. In NYC, the Chinese have lower median household income and lower per capita income compared to the rest of the population [23]. In a study of Chinese immigrant cancer patients, Gany et al. found that the majority of missed treatment and doctor's appointments were due to the need for financial assistance [24]. This resonated with our finding that even those participants who were insured often struggled with out-of-pocket expenses. Multiple participants expressed that these dollar amounts represented a large percentage of their monthly income. Efforts to reduce disparities must recognize that simply enrolling individuals in insurance programs will not address the financial barriers described by our participants.

Our participants also described time as a distinct barrier. The long or irregular hours often worked by immigrant patients hampered their ability to schedule appointments. Time was intricately linked to financial matters. For example, the need to wait several hours in a waiting room was burdensome because it often led to a day in missed wages. The time demands of a cancer diagnosis are not often discussed or addressed by common intervention programs.

Our study confirms that language barriers are prominent in the Chinese immigrant population. According to 2010 US Census data, approximately 37% of Chinese speakers in New York State speak English “not well” or “not at all.” [25] 60% of the Chinese population in New York City is considered “limited English proficient” [23]. Genoff et al. demonstrated that use of a patient navigator system improved screening rates for breast, cervical and colorectal cancer screening for limited English proficiency patients [26]. Leng et al. suggest system-level approaches to ensure that patients are aware of interpreting resources available [29]. Many of our patients reported mixed experiences with telephone interpreters. Translators should have additional specialization in medical and oncology terminology if they are to effectively overcome the language barrier.

Our study also identified a barrier not previously described in HCC literature: legal residency status. Liver transplantation is the most efficacious treatment for HCC, but is specifically prohibited for those with Emergency Medicaid – typically the only insurance option for undocumented patients needing cancer treatment. As a result, communities with higher rates of undocumented immigrants face a greater barrier to care. Although residency status is difficult to quantify, almost 30% of the non-US citizen Asian population is uninsured [30] and Chinese non-citizens were more than twice as likely as U.S. born Chinese to be uninsured [29]. While some may manage to navigate the bureaucracy of the immigration system and obtain legal status, for most undocumented individuals residency status represents an insurmountable barrier to transplantation. Even if equal access to transplantation was made possible, additional considerations would have to include the cost of life-long immunosuppressive medications. Medical-legal partnerships designed to address immigration status issues could potentially have a positive impact for this population.

While the previous barriers can be thought of as external or structural factors that influence the Chinese community, stigma is a barrier intrinsic to the community due to the psychosocial beliefs surrounding hepatitis and cancer (Figure 1). Our focus group participants described stigma as being widespread in the Chinese community, and that this led to self-isolation. This phenomenon has been noted by other researchers in the field. Cotler et al demonstrate that the stigma in the community is based on Fear of Contagion– which correlates closely with our findings as well [30]. In a survey of Asian immigrants with hepatitis B, 31% of respondents felt ashamed about having HBV and 53% were unwilling to discuss their illness with a friend or family member [32]. Clearly, efforts to overcome the disparity of stigma are fundamentally different than those targeting the logistic/structural barriers discussed above. The San Francisco Hep B Free Campaign demonstrates how overcoming stigma involves culturally-specific programs utilizing respected community members to change perceptions [33].

Interestingly, the Chinese immigrant community of NYC reported that provider bias by American doctors based on race or socioeconomic status was not a major barrier to care. While published reports have linked the perception of racial discrimination to poor cancer outcomes, our participants did not generally report denial of care based on race [34].

Finally, culture, while fundamental to the conceptualization of liver cancer and surgical treatments, was not seen as a barrier to care. Other researchers have commented that cultural fatalism is common among immigrant populations and may interfere with recommended cancer screening strategies [35,36]. However, participants ultimately deferred to their physicians even when their recommendations went counter to cultural beliefs or TCM practices. Lee et al similarly found that most patients used complimentary therapies for a few days, but sought medical help if there was no improvement in symptoms [18].

Our study contributes to the understanding of the multifactorial and intersecting challenges faced by low income people and immigrants in accessing the care they need within our healthcare system. It is unrealistic to expect that sweeping social changes to increase insurance access and reduce consumer costs can be implemented to resolve the barriers identified in our study. Instead, specific, directed interventions to overcome the barriers could include patient navigator and educational programs.

Patient navigator programs have been shown to increase cancer screening and reduce barriers to care, particularly for marginalized populations [37, 38]. Furthermore, race and language concordance between patient navigators and patients has been shown to improve timeliness of care for minority patients with breast cancer [39]. Patient navigator programs designed specifically to serve Chinese immigrant patients at risk for HCC could potentially help patients with insurance issues, connect them to programs that provide free and low cost medication, and help ensure adherence to appointments and treatment.

In addition, culturally specific educational programs have been shown to increase patient knowledge and improve patient outcomes[40,41]. Culture and language specific programs designed to increase knowledge about hepatitis and HCC among Chinese immigrants could potentially reduce stigma, increase early engagement in care, and help improve outcomes for these patients.

Limitations of our study include the modest sample size. Our cohort was comprised of NYC residents, and thus is not necessarily representative of the country as a whole. On the other hand, our results are likely strengthened by the uniformity of the focus groups participants, with participants being Chinese immigrants all under treatment for liver cancer.

In conclusion, our study identifies some of the barriers to liver cancer care encountered by the Chinese immigrant population and demonstrates the need for programs to address these impediments to care. Knowledge gathering with minority patients with HCC is essential for us to comprehend the true barriers to healthcare that are experienced by this community, because future policy and intervention efforts must be founded in this reality.

Acknowledgments

Funding: This study was supported by grant 1R03CA164546-01A1 from the National Cancer Institute (PI Sarpel)

References

1. Ryerson AB, Ehemann CR, Altekruse SF, et al. Annual Report to the Nation on the Status of Cancer, 1975–2012, featuring the increasing incidence of liver cancer. *Cancer*. 2016; 122(9):1312–37. [PubMed: 26959385]
2. El-Serag HB. Epidemiology of hepatocellular carcinoma in USA. *Hepatology Research*. 2007; 37(Suppl 2):S88–94. [PubMed: 17877502]
3. Ha J, Yan M, Aguilar M, et al. Race/ethnicity-specific disparities in cancer incidence, burden of disease, and overall survival among patients with hepatocellular carcinoma in the United States. *Cancer*. 2016; 122(16):2512–23. [PubMed: 27195481]
4. Torre LA, Sauer AM, Chen MS Jr, Kagawa-Singer M, Jemal A, Siegel RL. Cancer statistics for Asian Americans, Native Hawaiians, and Pacific Islanders, 2016: Converging incidence in males and females. *CA: A Cancer Journal for Clinicians*. 2016; 66(3):182–202. [PubMed: 26766789]
5. Chen MS Jr. Cancer health disparities among Asian Americans: what we do and what we need to do. *Cancer*. 2005; 104(12 Suppl):2895–902. [PubMed: 16270313]
6. U.S. Census Bureau. The American Community- Asians:2004. 2007.
7. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *Journal of the National Cancer Institute*. 2002; 94(5):334–57. [PubMed: 11880473]
8. Davila JA, El-Serag HB. Racial differences in survival of hepatocellular carcinoma in the United States: a population-based study. *Clinical Gastroenterology and Hepatology*. 2006; 4(1):104–10. [PubMed: 16431312]
9. Sloane D, Chen H, Howell C. Racial disparity in primary hepatocellular carcinoma: tumor stage at presentation, surgical treatment and survival. *Journal of the National Medical Association*. 2006; 98(12):1934–9. [PubMed: 17225837]
10. Artinyan A, Mailey B, Sanchez-Luege N, et al. Race, ethnicity, and socioeconomic status influence the survival of patients with hepatocellular carcinoma in the United States. *Cancer*. 2010; 116(5): 1367–77. [PubMed: 20101732]
11. Kwong SL, Stewart SL, Aoki CA, Chen MS Jr. Disparities in HCC survival among Californians of Asian ancestry, 1988 to 2007. *Cancer Epidemiology Biomarkers and Prevention*. 2010; 19(11): 2747–57.
12. Mathur AK, Osborne NH, Lynch RJ, Ghaferi AA, Dimick JB, Sonnenday CJ. Racial/ethnic disparities in access to care and survival for patients with early-stage hepatocellular carcinoma. *Archives of Surgery*. 2010; 145(12):1158–63. [PubMed: 21173289]
13. Charpentier KP, Cheah YL, Machan JT, Miner T, Morrissey P, Monaco A. Intention to treat survival following liver transplantation for hepatocellular carcinoma within a donor service area. *HPB (Oxford)*. 2008; 10(6):412–5. [PubMed: 19088926]
14. Sarpel U, Suprun M, Sofianou A, et al. Disentangling the effects of race and socioeconomic factors on liver transplantation rates for hepatocellular carcinoma. *Clinical Transplantation*. 2016; 30(6): 714–21. [PubMed: 27027869]
15. Siegel AB, McBride RB, El-Serag HB. Racial disparities in utilization of liver transplantation for hepatocellular carcinoma in the United States, 1998-2002. *American Journal of Gastroenterology*. 2008; 103(1):120–7. [PubMed: 18005365]
16. Guidry JJ, Torrence W, Herbelin S. Closing the divide: diverse populations and cancer survivorship. *Cancer*. 2005; 104(11 Suppl):2577–83. [PubMed: 16258930]
17. Fang CY, Ma GX, Tan Y. Overcoming Barriers to Cervical Cancer Screening Among Asian American Women. *North American Journal of Medicine and Science, Boston*. 2011; 4(2):77–83.
18. Lee S, Martinez G, Ma GX, et al. Barriers to Health Care Access in 13 Asian American Communities. *American Journal of Health Behavior*. 2010; 34(1):21–30. [PubMed: 19663748]

19. Hoeffel EM, Rastogi S, Kim MO, Shahid H. 2010 Census Briefs. U.S. Department of Commerce Economics and Statistics Administration U.S. Census Bureau; 2012. The Asian Population: 2010. <https://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf> [Accessed 26 Sep 2016]
20. Krueger RA, Casey MA. Focus groups: A Practical Guide for Applied Research. SAGE Publications, Inc; 2015.
21. Ma GX. Between two worlds: the use of traditional and Western health services by Chinese immigrants. *Journal of Community Health*. 1990; 24(6):421–37.
22. Hoehn RS, Hanseman DJ, Jernigan PL, et al. Cincinnati Research in Outcomes and Safety in Surgery (CROSS). Disparities in care for patients with curable hepatocellular carcinoma. *HPB (Oxford)*. 2015; 17(9):747–52. [PubMed: 26278321]
23. Asian American Federation. [Accessed July 2016] Profile of New York City's Chinese Americans: 2005–2007. 2009. <http://www.aafny.org/cic/briefs/chinese2009.pdf>
24. Gany F, Ramirez J, Chen S, Leng JC. Targeting social and economic correlates of cancer treatment appointment keeping among immigrant Chinese patients. *Journal of Urban Health*. 2011; 88(1): 98–103. [PubMed: 21246300]
25. MLA Language Map Data Center. Data center results. New York: <https://apps.mla.org/> [Accessed 26 Sep 2016]
26. Genoff MC, Zaballa A, Gany F, et al. Navigating Language Barriers: A Systematic Review of Patient Navigators' Impact on Cancer Screening for Limited English Proficient Patients. *Journal of General Internal Medicine*. 2016; 31(4):426–34. [PubMed: 26786875]
27. Leng J, Lee T, Sarpel U, et al. Identifying the informational and psychosocial needs of Chinese immigrant cancer patients: a focus group study. *Support Care Cancer*. 2012; 20(12):3221–9. [PubMed: 22531877]
28. Clough J, Lee S, Chae DH. Barriers to health care among Asian immigrants in the United States: a traditional review. *Journal of Health Care for the Poor and Underserved*. 2013; 24(1):384–403. [PubMed: 23377740]
29. Huang K, Carrasquillo O. The role of citizenship, employment, and socioeconomic characteristics in health insurance coverage among Asian subgroups in the United States. *Medical Care*. 2008; 46(10):1093–8. [PubMed: 18815516]
30. Robbins AS, Cox DD, Johnson LB, Ward EM. Persistent Disparities in Transplantation for Patients with Hepatocellular Carcinoma in the United States, 1998 through 2007. *Cancer*. 2011; 117(19): 4531–9. [PubMed: 21448933]
31. Cotler SJ, Cotler S, Xie H, Luc BJ, Layden TJ, Wong SS. Characterizing hepatitis B stigma in Chinese immigrants. *Journal of Viral Hepatology*. 2012; 19(2):147–52.
32. Wu H, Yim C, Chan A, Ho M, Heathcote J. Sociocultural factors that potentially affect the institution of prevention and treatment strategies for prevention of hepatitis B in Chinese Canadians. *Canadian Journal of Gastroenterology*. 2009; 23(1):31–6. [PubMed: 19172206]
33. Yoo GJ, Fang T, Zola J, Dariotis WM. Destigmatizing hepatitis B in the Asian American community: lessons learned from the San Francisco Hep B Free Campaign. *Journal of Cancer Education*. 2012; 27(1):138–44. [PubMed: 21748476]
34. Taylor TR, Williams CD, Makambi KH, et al. Racial discrimination and breast cancer incidence in US Black women: the Black Women's Health Study. *American Journal of Epidemiology*. 2007; 166(1):46–54. [PubMed: 17400570]
35. Vrinten C, Wardle J, Marlow LA. Cancer fear and fatalism among ethnic minority women in the United Kingdom. *British Journal of Cancer*. 2016; 114(5):597–604. [PubMed: 26867159]
36. Jun J, Oh KM. Asian and Hispanic Americans' cancer fatalism and colon cancer screening. *American Journal of Health Behavior* 2013. 2013; 37(2):145–154. (10).
37. Natale-Pereira A, Enard KR, Nevarez L, Jones LA. The role of patient navigators in eliminating health disparities. *Cancer*. 2011; 117(15 suppl):3543–3552. [PubMed: 21780089]
38. Battaglia TA, Roloff K, Posner MA, Freund KM. Improving follow-up to abnormal breast cancer screening in an urban population. A patient navigation intervention. *Cancer*. 2007; 109(2 suppl): 359–367. [PubMed: 17123275]

39. Charlot M, Santana MC, Chen CA, et al. Impact of patient and navigator race and language concordance on care after cancer screening abnormalities. *Cancer*. 2015; 121:1477–1483. [PubMed: 25565151]
40. Friedman AJ, Cosby R, Boyko S, et al. Effective Teaching Strategies and Methods of Delivery for Patient Education: A Systematic Review and Practice Guideline Recommendations. *Journal of Cancer Education*. 2011; 26(1):12–21. [PubMed: 21161465]
41. Two Feathers J, Kieffer EC, Palmisano MA, et al. Racial and Ethnic Approaches to Community Health (REACH) Detroit Partnership: Improving Diabetes-Related Outcomes Among African American and Latino Adults. *American Journal of Public Health*. 2005; 95(9):1552–1560. [PubMed: 16051927]

Figure 1.

Table 1

Barriers to care experienced by focus group participants

a) Theme: Insurance	
Subtheme	Quotes
Insurance is a barrier to care (15)	"They won't see you without insurance, so for people with our disease, insurance is the most important thing." "If you don't have health insurance, there's simply nothing you can do to get treatment."
Being uninsured leads to delays in care (3)	"Some people don't have insurance in the U.S., they can't afford an exam, so they just delay and delay..."
Healthcare is prohibitively expensive without insurance (5)	"If you don't have the insurance...one scan is a couple thousand dollars!" "It seems that my type of medication, my two types of medication, cost about a thousand dollars. Without health insurance, I simply wouldn't be able to take them." "Without insurance...liver cancer will cost you a lot! (laughing)"
Healthcare is expensive even when insured (3)	"If [the medication] is not covered then I don't want it. I hold back, or I eat less of it." "if they don't cover it, then there's no medication, and you don't use the medication." "they don't cover this thing, they don't cover that thing. If they don't cover it...then how can you dig up money to buy that thing?"
The quality of insurance varies (7)	"It was so miserable, us low-income people, our insurance is rotten." "Most of us have government insurance...it won't give you good medicine, it gives you regular medicine. If you purchased your own [insurance], the kind that you spend several hundreds to buy and pay every month, then that will give you good medicine."
b) Money	
Cost is a barrier to care (18)	"...it'll take more than hundred dollars. Who has that kind of money to see the doctor?" "You go outside to get examined/tested, it seems that it all costs ve or six hundred [dollars]. A lot of people say...then forget it."
Healthcare takes up a large percentage of income (4)	"...the money we make is very, very little. Then the rent is expensive, and [commodity] prices are high." "I had to pay more than \$200 because it was \$60 to see the doctor, then add on those things—the blood test... they de nitely have to send it to New Jersey to do the laboratory test. Two hundred dollars, and as far as we're concerned, it's almost half...a week's wages are already gone." "I had to put out a few hundred dollars every month. The wages they get from work...these burdens just become too big. That is, as long as they can endure it, they'll just endure it. They'll endure it to a certain level, endure it until they can't anymore, and when they get to the hospital, it'll be too late."
High cost of screening and treatment for hepatitis B (6)	"30 pills...30 days...that thing is more than one thousand US dollars!" "...when it comes down to it, I couldn't deal with [paying] that money, so I stopped [taking the medication]. Two years after stopping, [the cancer] came back and it was disastrous." "the vaccine costs about \$200 to \$300."
In China neighbors help each other, but US is more individualistic (2)	"In America [if] you have no money, it's hard to go even an inch (i.e. make any progress), right? In mainland China, for example, I could still borrow your bicycle, [but] in America..." "In America you have to depend on yourself. You're pitiful—if you're starving to death at home, it's your own problem."
Vicious cycle: being sick affects your ability to work and make money to pay for healthcare (2)	"With this [disease], your ability to work is weakened."
c) Time	
Must take time off work to go to appointments (4)	"You need to reject any work that you may have on the day of the appointment...you don't make that one day's money." "But I didn't have the ultrasound...the doctor requested that I go get it, but I didn't do it...there's every kind of reason. There's work-related reasons, time-related reasons, [there are] many aspects." "Obstacles to making appointments, the most crucial point is...how to put it...Chinese people...[some] work in restaurants, sometimes in an outside state, not necessarily in New York, and only rest one day per week." "If you were to tell me to skip a day, I would lose my job. I wouldn't give up the job in order to get my health examined...[But now that] I know I have this kind of disease, I would've gotten my health examined the rst time around. I could go nd another job, this is the most important thing."
Waiting room times are long (5)	"The wait time it's too long." "You generally need half a day." "Once, I came at eleven o'clock. By the time I nished seeing the doctor it was already four o'clock." "Because we're retired, although we need to wait for a long time—you have to wait here for 3 or 4 hours—but we're retired, [so] it doesn't matter."

a) Theme: Insurance	
Subtheme	Quotes
	"[If] you want it to be fast, going to see the doctor, it'll take more than a hundred dollars. Who has that kind of money to see the doctor? [We're] retired, we only have four or ve hundred dollars [per month] of retirement income, so we'd rather be here and wait."
Difficult to get appointments at times that are convenient for people who work long hours (e.g. restaurant industry) (5)	"There's the money problem on the one hand, [and] although it's a big problem, there's also [the issue of] time—the time they spend working, those times in Chinese restaurants...the tests have to be compatible with their work hours. They need to work. [If] the timing isn't compatible, they don't have any alternative." "When they go, the clinic is already closed."
d) Language	
Not speaking English is a barrier to care (16)	"Language is a crucial point." "Not understanding English, you're just like a blind person." "It doesn't depend on the doctor. It depends on the interpreter, right?" "Something's gotta get lost during translation compared to direct communication." "Because my English isn't very good/clear, every time I come to the hospital...I have to nd a translator to come with me. I think it's so troublesome."
Phone translation is inadequate (7)	"if [the interpreter] were right next me, then I would speak directly...I would be able to speak more. But sometimes you nd it difficult to express things clearly over the phone, right?" "The expressions were simple, very simple, you can't ask things in detail."
Medical terminology causes particular problems (3)	"When talking normally [to ordinary people] and you say something a little bit wrong, everybody will still understand. But going to the doctor is different...language is a crucial point. [When] seeing the doctor language is a really important element." "We can handle simple conversations, but when it comes to difficult medical knowledge, then we may not understand." "They don't know some of the specialized terms."
e) Residency Status	
Lack of documentation limits availability of healthcare (6)	"they didn't immigrate [legally] to America and they don't have any documentation, they don't have any health insurance." "A lot [of people] are undocumented, they have no way of paying money to go get an exam, medical treatment, they don't even know whether or not they're sick." "When I finally got citizenship, [they] gave me a liver transplant."
Can be difficult to get proof of residence even if legal status not required (2)	"You have to provide two types of [identi cation] materials—one proof of address and one proof of income. ... But some proofs of address...[for] those of us who came over without documentation, there's no chance of buying a house."
f) Stigma	
Stigma exists surrounding liver disease (9)	"Some [of my] friends are very conservative, they don't want to talk about it." "A lot of people don't want others to know that they have had liver transplant...or that they are sick. I have a friend... because when I was on the waitlist I was asking around...and then there was this friend's husband. He didn't want other people to know, so he didn't go out that much either. So...I asked him about it because we were friends, but he didn't say anything to others. Some people are like that." "Someone more shy may not want others [to know]. There's a typical case I know...he/she just didn't want anyone to know and just stayed home after the surgery."
Stigma is about fear of contracting hepatitis (5)	"They're afraid of the infection, it's not discrimination." "Some people are just scared [of the disease]." "Their meaning is that, ai-ya, this person now has hepatitis B, and then others, ai-ya, don't be in close contact with that person. They are scared that they will be infected." "Because everyone is very responsible for their own health. They don't necessarily have expert knowledge about this, and of course, it's out of a defense mentality." said "And then there was this person, he heard that I had hepatitis B, and then he asked me to wait outside and called my wife in, asking me to wait outside. He almost didn't want to shake my hand, (laughing), it was like that. I thought to myself, is it that serious? When I was in the hospital, even the doctor shook my hand, and it was ne (more laughing)...I don't think shaking hands will pass it on." "Yes, there are those, such as older sisters or relatives, wherever you go, take chopsticks, bowls, and immediately wash them, washing, to disinfect them. You sit in a spot, and they wipe it. Heh heh. They actually don't understand it...[If] you have liver disease I don't shake your hand. Won't even dare come close to you, as if you are a crazy person. They're all scared of your type. Heh, liver disease, heh, don't get close to him."

Table 2

Explored themes which participants felt were generally not a barrier to care

a) Culture	
Fatalism in Chinese culture (11)	After being diagnosed, I always felt that, live or die, it's fate." "[They would say] 'If it's my time to go, it's my time to go; if the heavens want you to die then you will die.' "If you have it [cancer], just leave it to fate, right? We're in our 70s. Just let it go. There's nothing you can do. If it's destined to come it will come, right?"
Aversion to surgery in traditional Chinese culture (6)	"The Chinese try to avoid surgeries." "Why do Chinese people avoid surgeries? Humans have innate Qi. If you cut a person open, you're letting the Qi out...It completely relies on your Qi, your own Zhen Qi (vitality). Surgeries will let out the Zhen Qi." "This gentleman had a point, though, in that surgery will hurt your Yuan Qi (vitality). This is true. You can't deny it." "I said, can you if possible not operate? Chinese people are scared of surgeries—it would be ideal if you don't need to operate. But the doctor said you have to have the surgery. And so I could only listen to the doctor, right?"
Traditional Chinese Medicine has some role but will not cure liver disease (3)	"I'd say, Chinese medicine has its own pros [and] Western medicine has its own pros, but you need to prescribe the right medicine for an illness." "Traditional Chinese Medicine and Western medicine differ in their philosophies... They are not in conflict... There's no such thing as which is bad, which is good; each has its own strengths" "If in the beginning, there's something wrong with your liver, like hepatitis, in amimation and so on... then TCM can help your liver to a certain degree. But it's very difficult with cancer." "When I am out of strength, or having back pain, or stomach ache and things like that, TCM may cure you. You take some and you regain your strength, and improve in all aspects. But once you get cancer, what can TCM do? Can it get rid of your cancer? No way. Cut it out or have a transplant, these are the ultimate ways." "They see Chinese doctors, [for] ordinary illnesses. But if [one] has cancer, the majority goes to Western doctors, [they] don't see Chinese doctors." "If you have cancer and you take TCM, you will surely end up dead. If you cut it out or have a transplant, you will not die. TCM will not cure you, it just prolongs your life a little."
Cultural factors do not play a role in medical decisions (7)	"No, no. This is the same everywhere. To prolong the life, right? Nobody is going to say 'Ah, I'm not going to get a transplant because of my culture.' There's no such cases. No such cases. There are many people getting liver transplants in China too. I know. Many liver transplants in China, and Taiwan, and Mainland China...may cases. No cultural considerations like this. That doesn't exist." "This, this has nothing to do with culture. This is de nitely linked to medical...Liver transplant can prolong your life. What else is there? It has nothing to do with culture."
b) Provider Bias	
Feeling of being discriminated against due to race or language (5)	"There's de nitely some discrimination."
Treated well in US, not discriminated against based on race or economic status (11)	"I feel that people here are really nice. I am very satisfied." "They don't separate Chinese from Non-Chinese." "Of course, they see us all equally" "This I haven't [experienced]; I haven't felt this at all. On the contrary, I've felt that, although I don't have any money, seeing the doctors here, as long as I ask the questions I want to ask on a given day, the doctor will answer all my questions one by one... the doctors, their [sense of] medical ethics is beyond words."
Discrimination is not consistent with American culture (4)	"The American [doctors], they're not like that." "It seems that when it comes to equal treatment, America is doing a wonderful job." "No. I didn't feel this way either. I should say American hospitals are doing great in this area. They don't have this racial concept. They treat diseases and save people's lives, right? You come and you are regarded as a patient [no matter who you are], and treated according to the protocol of the hospital, right? This is their system...the whole system functions to treat your disease. Racial discrimination and the sort are nonexistent here."