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PINE STUDY II: Research Article

Knowledge and Beliefs About Biospecimen Research Among Chinese Older Women in Chicago's Chinatown

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Abstract

Background: Enhancing the participation of Chinese older women in biobanking efforts is important for precision medicine efforts, as underrepresented groups risk benefiting less than others from medical advancements in individualized therapies. Focusing on a sample of Chinese older women in Chicago's Chinatown, this qualitative study seeks to describe attitudes toward, and barriers and facilitators of, participation in biospecimen research.

Method: We conducted six focus groups among Chinese-speaking adult women age 45 and above. Focus groups were transcribed, coded, and analyzed for emergent themes.

Results: Forty-seven women participated in focus groups, the majority (66.0%) were age 66 and over and half (50.1%) had less than a high school education. Participants expressed predominantly positive attitudes toward biospecimen research, but also identified multifaceted barriers to participation that included cultural beliefs of the body, perceived physical and privacy risks, as well as perceptions related to aging. Use of minimally invasive biospecimen collection and education to promote awareness of biospecimen research were suggested facilitators to increasing biospecimen research participation.

Conclusions: Culturally and linguistically isolated populations like Chinese older women are at risk of exclusion from advancements in precision medicine. Our findings provide cultural insights for tailoring interventions for Chinese older women to increase knowledge, change attitudes, and increase intention and participation in biospecimen research. We also highlight the need for individual, family, and community level interventions to promote healthy aging among Chinese older women.

Keywords: Health equity, precision medicine—Chinese American—Qualitative research—Women

Introduction

Within the framework of precision medicine—any advancements in technologies, prevention of disease, and treatment options—must seek to take into account individual variability in genes, environment, and lifestyle for each person (1). National calls for precision medicine, such as President Obama's Precision Medicine Initiative (2), aim to develop individualized care for cancers and a range of disease. New headways in our knowledge and understanding of diseases are highly dependent upon biospecimen collection, which provide the source of information for the genomics, proteomics, metabolomics, and epigenomics research necessary for advancing precision medicine (3). However, biospecimens, defined by the National Cancer Institute as "biologic material from people such as tissue, blood, plasma, and urine" (4) and the banking of such tissue and samples, is also a potential propellant of health disparities, if minorities and other underresourced groups continue to be underrepresented in biospecimen research efforts. Limited diversity in study populations may result in fewer samples available to scientists, limited therapeutics for minority-specific tumor pathology, and unequal distribution of the benefits and risks of research (5,6).

Although Asians are the fastest growing immigrant population group in the United States (7,8), they are among the least represented in clinical trials (9) and biospecimen research (10). And in particular, Chinese Americans are a sizeable population at risk of missing out on advancements uncovered by biospecimen research due to their low participation in biospecimen banking. Chinese Americans number over 4.5 million people and constitute the largest Asian American subgroup, accounting for 22.2% of Asian Americans (8). An estimated 76% of Chinese in the United States are foreign-born (11). Although often labeled as the "model minority," (12) Chinese immigrant populations are at high risk for hepatitis B virus (HBV) infection (13) and experience a disproportionate burden of stomach, colorectal, cervical cancer, and HBV-related liver cancer (14). Increasing Chinese American's participation in biospecimen research is necessary for developing optimal care for all Americans.

Few studies have explored Chinese American's participation in biospecimen research. A small body of literature suggests an interplay of cultural beliefs and knowledge driving the lack of participation in biospecimen research. Cultural views such as the sacredness of blood (15), fears of personal injury and harming one's health (16), and fear of discrimination (17) have been identified as barriers. On top of these culturally oriented barriers, a recent research study of Chinese women in Philadelphia found that only 50% of study participants have heard of biospecimen research and the majority could not explain the use of biospecimens (18). On the other hand, facilitators for biospecimen banking participation identified in previous studies include if a family member had a history of the disease (16); if biospecimens would benefit future generations (16,19); if there was direct health benefit to themselves or family member (20); and more positive attitudes toward and greater trust in the health care system (18). A handful of intervention studies among Chinese Americans have also suggested that given the right circumstances, Chinese Americans would be willing to provide biospecimens for research purposes (18,19).

Although the literature is growing, studies have yet to explore biospecimen participation among Chinese older adults and concerns have been raised about extrapolating findings from studies that have grouped Asian Americans together (21). Many Chinese older adults are disadvantaged in the United States due to cultural, linguistic, and structural barriers and are already vulnerable to low utilization of healthcare services (22). Effective programs promoting biospecimen research participation will need to consider culturally sensitive models tailored toward Chinese older adults. In addition, there are significant health disparities among older Chinese women, including higher rates of chronic disease and disability than men (23), as well as lower preventive health services use (21,24). Although traditional gender roles based on Confucian teachings place emphasis on Chinese women's roles as caretakers of the family, crucial healthcare-related decisions are typically made by male members of the family (25,26). Empowering Chinese older adults, and women in particular, may be key for increasing their participation in research and biobanking. Focusing on a sample of Chinese older women in Chicago's Chinatown, this qualitative study seeks to describe attitudes toward, and barriers and facilitators of, participation in biospecimen research. Findings seek to inform interventions for Chinese older women to increase knowledge, change attitudes, and increase intention and participation in biospecimen research.

Methods

In this qualitative study, we conducted focus groups with Chinese older women in Chicago, Illinois. A community-based participatory approach, in which communities were actively engaged in the research process (27) was used to guide the study development and procedures. A Community Advisory Board (CAB) consisting of representatives from health and social service organizations serving Chicago's Chinese communities as well as cancer survivors and long-standing community advocates, participated in the refinement of research questions, ensured cultural appropriateness of research methods, and served as local gatekeepers to the population of interest (28–30). The Rush University Medical Center Institutional Review Board approved all study protocols and procedures.

Focus group questions in the semi-structured moderator's guide were designed to elicit cultural explanatory models (31,32) of research participation. Within a Cultural Framework of Health (33), cultural explanatory models seek to elicit indigenous conceptions of behaviors and experiences rooted in social, cultural, and historical influences (34). Included are cultural beliefs and values, personal life experiences, as well as biomedical and popular explanations of health and illness. Questions were arranged into three topic areas: (a) attitudes toward biospecimen research; (b) perceived barriers toward donating biospecimen for research; and (c) perceived facilitators for participating in biospecimen research (Table 1). Questions and translations were refined by our Community Advisory Board (CAB) to ensure cultural and linguistic appropriateness.

Recruitment and Data Collection

Women were recruited from flyers distributed at Chinatown community organizations and through word-of-mouth. Eligibility criteria for focus group participants included: (a) female; (b) self-identification as Chinese; (c) ability to speak Cantonese or Mandarin Chinese; (d) being age 45 and older; and (e) residence in Chicago's Chinatown. Study staff screened individuals for eligibility by phone. Between March and April, 2014, trained focus group moderators fluent in Chinese conducted six focus groups, segmented by women's preferred dialect (Cantonese/Mandarin). In total, four focus groups were conducted in Cantonese and two in Mandarin. Focus group ranged from six to eight participants and took place in private rooms at senior apartments or the Chinese American Service League, a social service agency located at the heart of Chicago's Chinatown. Informed consent was obtained prior to the beginning of the focus group session, followed by administration of an anonymous demographic questionnaire. This was followed by a 10-minute slide presentation by the focus group facilitator using the Cancer 101 Biospecimen tool (35) to share basic information about biospecimen research. Women were then asked about their attitudes, perceived barriers and facilitators toward biospecimen research. Focus groups were audio-recorded. Each focus group lasted approximately 90 minutes and participants received a $15 gift card for their participation.

Data Analysis

Focus groups were transcribed, translated into English, and reviewed by bilingual/bicultural study staff for accuracy. Members of the research team independently reviewed transcripts to identify initial coding schemes to add to the pre-defined themes derived from the semi-structured interview guide. Schemes were compared and discussed until consensus was reached about a refined higher level coding scheme. Two team members then independently coded each of the transcripts using QSR International NVivo 9 software. Discrepancies in coding were resolved through discussion with the entire team. Thematic analysis of focus group participant responses focused on general agreement among participants and concordance among coders' assessments. As is standard practice in qualitative research, we used qualitative descriptions and exemplar quotes to convey the breadth and strength of agreement with a statement, rather than quantifying responses (36).

Results

Sociodemographic Characteristics of Focus Group Participants

The sociodemographic characteristics of the focus group participants are presented in Table 2. A total of 47 women participated. A majority (66.0%) were age 66 and over, and about half (50.1%) had less than a high school education. All participants were born outside of the United States (76.6% from Mainland China), with 70.0% having lived in the United States for at least 10 years. Most participants (79.5%) have never been diagnosed with cancer. Only 3 women (7.0%) had previously donated biospecimen for research purposes.

Attitudes Toward and Perceptions of Biospecimen Research

Following the 10-minute presentation of the Cancer 101 Biospecimen tool, focus group participants responded to open-ended questions about their opinions of biospecimen research (Table 1). Most responses were positive Table 3. Specifically, women identified that biospecimen research would: benefit research and aging for minority groups such as Chinese; improve research developments for drugs and diseases; enable early diagnosis and treatment; and benefit future generations and others. For example, with respect to the importance of biospecimen research, one participant expressed that "it could help to develop drugs and invent a better way to diagnose." Regarding benefits specific to the Chinese community, one woman noted, "there's a huge difference between Asians and Caucasians" and others cited differences in incidence of hepatitis B and that "sometimes Westerners can adapt to the medication but Chinese don't." At the individual level, participants raised the personal utility of biospecimen research; for example that "it could find out the cancer so you could go get the treatment earlier." Perceived benefits to future generations and to others (eg, "you might not use it if you are fine at this moment, but what if someone needs it") were other positive attitudes that women expressed toward biospecimen research.

Some women had a more negative or neutral opinion on biospecimen research. One such participant identified the possible deleterious effects on individual health, saying, "I'm not very healthy, not willing to draw blood; it would endanger my health." Women also expressed opinions that participating in biobanking research may not be useful to them due to research timelines, describing that "the

Table 1. Qualitative instrument

Attitudes and Perceptions
- Why are biospecimens important in cancer research?
- What are the benefits of donating biospecimens?
- What are the risks of donating biospecimens?
- How does Chinese community perceive biospecimen research?

Barriers
- What are the barriers to recruit Chinese participants in biospecimen research?
- What are the risks of getting involved in this kind research?

Facilitators and recommendations
- How should researchers and community address overcome these barriers?
- What do you think would be the appropriate ways to involve people in biospecimen research in Chinese communities?

Table 2. Sociodemographic Characteristics of Focus Group Participants

	N	%
Age		
46–55	6	12.8
56–65	10	21.3
66 and over	31	66.0
Sex		
Female	47	100.0
Male	0	0
Education (y)		
Less than junior high or 8th grade	21	44.7
Less than high school	3	6.4
High school graduate or GED	8	17.0
Some college, trade, or technical school	3	6.4
College graduate	2	4.3
Graduate school	1	2.1
Income (USD)		
\$0–\$14,999	12	0.0
\$15,000–\$29,999	7	25.5
\$30,000–\$45,999	2	14.9
\$46,000–\$59,999	0	4.3
\$60,000–\$75,999	1	0.0
\$76,000–\$89,999	1	2.1
\$90,000 or more	1	2.1
Marital status		
Married	26	55.3
Widowed	17	36.2
Born outside the United States		
Yes	47	100.0
No	0	0.0
Years in the United States		
0–1	0	0.0
1–3	1	2.1
4–5	3	6.4
6–10	3	6.4
More than 10	33	70.2
Insurance[a]		
Medicare	24	51.1
Medicaid	22	46.8
Private or HMO	5	10.6
No insurance	10	21.3
Country of origin		
Mainland China	36	76.6
Hong Kong/Macau	6	12.8
Taiwan	0	0.0
Vietnam	2	4.3
United States	0	0.0
Other	0	0.0
Language[a]		
Cantonese	44	93.6
Toisanese	6	12.8
Mandarin	6	12.8
English	1	2.1
Have been diagnosed with cancer		
Yes	9	20.5
No	35	79.5
Someone close has been diagnosed with cancer		
Yes	8	19.0
No	34	81.0
Have taken part in a research study		
Yes	3	7.0
No	40	93.0

Table 2. *Continued*

	N	%
Have donated biospecimen for research		
Yes	3	7.0
No	40	93.0
Someone close has taken part in a research study		
Yes	4	9.5
No	38	90.5

[a] Percentage over 100% due to possibility of checking multiple items.

research might not just take two years, it could be couple decades." Furthermore, one participant mentioned that the lack of reporting back to biobanking participants made research results "irrelevant" and that "participants wouldn't know the report so Chinese would think it's none of his/her business, why do I need to enroll?"

Perceived Barriers of Donating Biospecimen for Research

When asked to identify barriers to recruiting Chinese individuals to donate biospecimen samples for research and the perceived risks of getting involved in biospecimen research, participants noted cultural issues, physical and privacy risks, and various impediments related to old age (Table 4). Regarding cultural values—the notion of the "whole body" was a frequently described barrier to biospecimen donation. For example, one woman explained that "generally the Chinese older adults would prefer to keep the whole body even when they die." Another participant further explained, "if I die now then I can't have an intact body because my gallbladder had been cut a little, and the uterus had been removed as well. I think Chinese really care about this."

Many women expressed that a significant barrier to biospecimen donation was their concern about personal health risks and privacy risks. More than one focus group participant described the possibility of infection as a result of blood donation. For example, women commented about the risk that "if the one who draws your blood makes a mistake then you will have an infection or get some infectious disease" and the risks stemming from "the needle for blood drawing, health of the medical staff, or [the] chance to get AIDS by drawing blood." Privacy concerns were also raised as a potential barrier to biospecimen banking participation, and its connection to the Chinese cultural value of maintaining a good reputation ("saving face"). Women in our focus groups mentioned that Chinese "worry about being seen by someone."

In addition to cultural perceptions of the "whole body" and perceived health and privacy risks, another frequently mentioned barrier to participation in biospecimen research included perceived impediments related to old age. This included perceptions that older adults are frail, too poor of health, and that "older adults have no blood to draw." As one woman described, "personally, I rarely participate. I'm in poor health and only draw blood once a year for check ups." An aging related barrier to biobanking participation is the perception that the blood of older adults is not useful for research purposes: "We all are turning to 80, 90, with high cholesterol. What's the point to analyze these blood? You have no idea how many conditions exist." Another participant expressed, "the older adults are weak and sick." As summarized by a participant, "it's fine for the young people, but the elderly is useless." Along those lines, a related barrier with regard to old age is the perception that research has little usefulness for older adults because they were nearing the end of life and thus, "if it's not useful for older adults, what can you expect from them?"

Perceived Facilitators to Donating Biospecimen for Research

When asked about how researchers can address barriers to biospecimen research participation and recommendations for involving Chinese communities in biospecimen research, our focus group participants identified a number of perceived facilitators and strategies (Table 5). Specifically, participants identified preferred specimen types, compensation, trust building by leveraging word of mouth, importance of increasing education to promote awareness of biospecimen research, and receiving reports or other health service benefits from their participation. Donation of hair or nail biospecimen instead of blood would facilitate participation "because it could regrow" whereas blood "we really have not much left now." One suggestion for the framing of monetary compensation was: "give them compensation to buy something to eat." Gaining trust of the individuals through community contacts and word of mouth was another facilitator. As described by one participant, "it would be better to start with his friend whom he believes, because some seniors are very stubborn." Further, women emphasized expanding education about biospecimen research to inform individuals about the benefits, "You need to explain more to them and let them understand more." Other recommendations made to facilitate participation in biospecimen research included free health check-ups.

Discussion

Participants in this qualitative study of women in Chicago's Chinatown expressed their attitudes toward, and perceived barriers and facilitators of, participation in biospecimen research. To our knowledge, our study is among the first to explore attitudes and perceptions of biospecimen research participation specifically among Chinese older women in the United States. Following an introductory presentation of biospecimen research, we found that focus group participants held predominantly positive attitudes toward biospecimen research, as women believed that participation in biospecimen banking would benefit research and aging for minority groups such as Chinese; improve research developments for drugs and diseases; enable early diagnosis and treatment; and benefit future generations and others. However, numerous barriers were identified as well—including cultural beliefs regarding the "whole body," perceived physical and privacy risks, as well as perceived lack of direct benefits and useful blood as related to aging. Facilitators to participation noted by focus group participants included collection of non-blood specimen types, financial compensation, trust building by leveraging word of mouth, increasing education to promote awareness of biospecimen research, and receiving reports or other health service benefits from participation in biospecimen research.

Several cultural beliefs illuminated in this study—such as Chinese traditional values of the preciousness of blood and the intact body—support cultural beliefs identified in prior studies. For example, a qualitative study of biospecimen donation for cancer research among Chinese, Vietnamese, and Hmong in California reported the special significance that Chinese regard for the balance of blood in the body (15). Traditional beliefs that blood is nonrenewable (37) in conjunction with traditional beliefs that blood is intertwined with the flow of life energy (qi) have been identified as sources of culturally based reservations about blood donation (38). However, beliefs about how blood loss may affect the flow of qi are not the only cultural beliefs that may impact participation. Studies on barriers to

Table 3. Attitudes toward and perceptions of Biospecimen Research

Themes	Subthemes	Representative Statements
Positive	Minority aging has specific trajectories	"Sometimes Westerners can adapt to the medication but Chinese can't. Doing the research by these samples would be a benefit for us." "The benefits are because different races have different kinds of disease, Asians may have more cases of Hepatitis B. While Caucasians would not have more cases of skin cancer than Chinese. Different races would have different cases." "Each race has their common disease; for instance, Chinese are more likely to have nasopharynx cancer, while Mexicans have breast cancer the most. They are different so different research would be needed to develop a new drug that works for each specific group."
	Drug research	"There's a huge difference between Asians and Caucasians, so if you study the morbidity of some kind of disease, it could come out that kind of medicine works for some people, but not for Caucasians." "It could be used as the statistics in medical research, for example, to understand the hereditary disease or gene for the specific group. According to this, it could help to develop the drug for this specific group."
	Disease research	"Of course it's useful; research always needs to be step by step. Without these materials and information, how can the research be done?" "It is important about the biospecimen, it could understand what kind of disease would happen under a certain circumstance, it could help to develop drugs and invent a better way to diagnose."
	For future generations	"As far as I am concerned, the purpose of the research is to benefit the future generation, different kinds of people would use that personalized something. So I don't think it matters, it's not a big deal." "I would like to say you should support the public service, you might not use it if you are fine at this moment, but what if someone needs it, yours could be used by others. I think this is really a benefit to others, benefit to the future, so everyone should support this."
	Genetic	"Some are hereditary, for example what disease the parents have, the children might have a higher chance to get the same disease." "It analyzes everyone's race and genes, to see the differences."
	Diagnosis	"It could find out the cancer so you could go get the treatment earlier, and if I have dementia I could find out earlier." "It could help diagnose the disease and know what medication should be used." "The benefit is you could know your health condition."
Negative	On health	"The older adults would think it's not good to lose some blood, which would make them skinnier. They think the blood is for maintaining life, it would need supplements to gain it back." "It hurts and mostly it's because I'm not very healthy, not willing to draw blood; it would endanger my health."
Neutral	No impact on the individual	"Not many Chinese would participate because the research result is irrelevant. The participants wouldn't know the report so Chinese would think it's none of his/her business, why do I need to enroll?" "Because it's research, you wouldn't know the result if your blood's been drawn; and the research might not just take two years, it could be couple decades." "It's for research, so the result won't come out immediately, I might not accept it."

organ and tissue donation among Chinese have illuminated related beliefs about the body, such as the importance of having an intact body for reincarnation and the afterlife, and as a sign of filial piety and respect for ancestors (39).

A departure from previously reported perceptions of biobanking in China, we found that the biospecimen research views expressed by Chinese older women in our focus groups were largely positive in nature and there was lack of explicit mistrust of the medical establishment or of researchers. In contrast, a survey of Chinese patients (n = 648) and the general public (n = 492) in urban and rural Shanghai investigating attitudes toward providing consent for storage and use of leftover biosamples revealed low willingness to donate, in part due to extreme public distrust in their local medical institutions (40). One possible explanation for the lack of mention of distrust in our focus groups may be that most of our focus group participants have resided in the United States for some time—80% have lived in the United States for over 10 years. Many Chicago Chinatown residents have had very few, or no encounters with the United States health care system (22). Additionally, a population-based study of Chinese older immigrants in Chicago suggested high levels of trust in physicians in clinical encounters (41), so attitudes toward medical institutions among Chinese in the United States may be more conducive toward biobanking research participation than they are in China.

Our study among Chinese elder women revealed preferences for less invasive approaches to biospecimen collection and a focus on avoiding risk. More acceptable, and less invasive approaches than blood collection that have been noted in prior studies include observation and pulse taking, as noted in hepatitis B-related focus groups among Chinese American community members and leaders (16), and saliva and urine, as noted in a survey of n = 295 Chinese Americans in San Francisco (19). A recent study by using semi-structured interviews among 30 Chinese elderly in Houston found that safety, side effects, and invasive study procedures were the primary concerns related to participation in clinical research (42). Although the study in Houston focused on attitudes toward clinical research participation and almost half of study participants held a college or advanced degree, the similarity in concerns raised by Chinese older adults in that study and the Chinese older women in our study suggest overarching concerns about safety. We found that perceptions of risks from the mistakes and health of medical staff was a prominently expressed barrier to participation in biospecimen research, this despite the overall perceived benefits of biospecimen research and no mention of distrust toward the

Table 4. Perceived Barriers of Donating Biospecimen for Research

Themes	Subthemes	Representative Statements
Cultural issues	Whole body	"The older generation of Chinese would think they need the whole body even if they die." "There's a saying in Cantonese, which might be bad but not as important as in the past, is 'dying without being intact'. And now I'm just like this, if I die now then I can't have an intact body because my gallbladder had been cut a little, and the uterus had been removed as well. I think Chinese really care about this. So I teach my children not to turn into that." "Westerners feels different, they would think it's just a dead body once they die, they would prefer to donate it to save others. But generally the Chinese older adults would prefer to keep the whole body even when they die."
	Saving face	"Chinese are concerned about saving face, and everything relate to "blood" they would lose interest." "They worry about being seen by someone. Chinese regard face as an important part."
Risk	Physical	"The risk is pain, swelling, or you might get an infection." "If the one who draws your blood makes a mistake then you will have an infection or get some infectious disease." "The problem is taking your tissue or skin which might scratch you, and if it's blood then you might get an infection." "The needle for blood drawing, health of the medical staff, or [the] chance to get AIDS by drawing blood."
	Privacy	"Maybe some lose privacy [because they] would be known by someone." "Those who are well educated have more privacy and they don't want others to know."
Old age	Poor health	"It's useless even if the blood had been drawn. We all are turning to 80, 90, with high cholesterol. What's the point to analyze these blood? You have no idea how many conditions exist. What's the purpose for the blood drawing?" "Personally I rarely participate. I'm in poor health and only draw blood once a year for check ups."
	Useless body	"Older adults have no blood to draw." "Older adults don't have extra blood to draw. The blood from the healthy people could be functional; the older adults are weak and sick." "It's fine for the young people, but the elderly is useless."
	Limited personal usefulness	"The elderly would think they are too old to see the result come out, so it's not useful for them." "If it's not useful for older adults, what can you expect from them?"

medical and scientific community. One potential explanation is that sensationalized stories of medical malpractice in China, which have contributed to erosion of trust between doctors and patients in China (43,44), may have also impacted risk perceptions in the United States.

Before we discuss implications of our qualitative study, key study limitations should be noted. First, the data represented a convenience sample of Chinese older women in the Chicago Chinatown area. As all focus group participants were foreign-born, and most have resided in the United States for over 10 years, generalizing study findings to US born Chinese Americans and more recent immigrants requires caution. However, based on existing population-based studies of Chinese immigrant older adults in Chicago, acculturation levels of Chinese immigrants tended to be lower than other ethnic/racial groups (45). Another limitation is that these focus groups were conducted after presentation of a Cancer 101 Biospecimen tool. However, there is not a native term for "biospecimen" in the Chinese language (15), so an introductory presentation was needed. Introduction of biospecimen definitions and concepts enabled women to have a basic understanding of the topics at hand that they can react to and discuss. A third limitation is that most of our focus group participants were Cantonese speaking from the Southern regions of China—which reflect the demographic composition of Chicago's Chinatown. However, China is a vast country with regional cultural differences so additional studies of attitudes and perceptions toward participation in biobanking research are needed among diverse Chinese populations. Studies on genetic testing among Chinese for example, have highlighted differences in barriers to genetic testing by region, language, ethnicity, and religious beliefs (46).

Despite the above limitations, our findings have important practical and policy implications. First, our findings provide cultural insights for tailoring interventions for Chinese older women to increase knowledge, change attitudes, and increase intention and participation in biospecimen research. Existing interventions to promote biospecimen research participation among this population have included educational seminars on biospecimen collection and opportunities to provide blood onsite at health education events (16,19). Results from our qualitative study suggest that additional opportunities for increasing the cultural appropriateness of health education strategies could include leveraging family, peer, and other social networks; emphasizing benefits to future generations and duty to others; and addressing misconceptions about physical risks and aging, as well as fears about medical mistakes and contamination that may have been heightened by media outlets. Additionally, to address the hesitation surrounding blood expressed by our focus group participants, efforts to increase awareness about biospecimen research participation may want to highlight advancements in minimally invasive biospecimen collection procedures, such as dried blood spot sample methods that collect drops of blood from a simple finger prick (47). Leveraging research findings suggesting no increase risk for adverse donor reactions in old age (48) may also help in the messaging for interventions geared toward promoting biospecimen research participation.

However, the several perceived barriers we identified in this study related to aging—the perceptions that older adults are too old, too frail, and don't have "useful" blood due to their health conditions—may require individual, family, and community level interventions that address stereotypes and older adults' self-image. It has been postured per modernization theory (49) that economic growth and

Table 5. Perceived Facilitators to Obtaining Biospecimen for Research

Themes	Subthemes	Representative Statements
Specimen type	Non-blood	"I'm fine with donating hair or nail, but not blood." "First of all it hurts, secondly it's not good. I could accept all ways except drawing blood." "Our body is made from blood, it gets dried out when you get old, and nothing's left in it. The younger ones are fine because it's all about metabolism, it could be supplemented by eating. But it's different for us older adults. I won't participate. Hair is fine because it could regrow. But for the blood, we really have not much left now, that's why we will feel dizzy."
Compensation	Monetary	"Of course, it would be good if you would have any compensation to motivate them. When one named Ms Huang come interview me and asked me to introduce more participants to her, I said: 'Sure, as long as they heard of $15 compensation, they will be very active.' If you have nothing beneficial, no one will respond. So even though it's just a little bit, it would be very helpful." "For example, if you took their time to do an interview with them, then give them compensation to buy something to eat; they would be very happy. It's much better than nothing, otherwise people will just turn their backs on you."
Community	Building trust	"It would be better to start with his friend whom he believes, because some seniors are very stubborn, whatever you say they just can't listen to you. You must be someone that knows him." "It must be someone she trusts, then what she said would be useful." "People would always like to accept from the people that are well educated, then they could recommend to their acquaintance… if it's their friends or relatives say: "It's very useful. Just take some hair and you will know your health condition, you could know how to improve your health. Why not?" Maybe it would raise their interest like that."
Focusing on health benefits	Health education workshops	"You need to explain more to them and let them understand more." "If you mail the notice to announce the focus group like this, some people would be active if they have time." "…promote on the newspaper, people will join if someone sees it and feels it's a benefit for him. So no matter if it is newspapers, flyers, or focus group it's fine. But I'm not sure how many people will attend focus groups, I will go if I have time."
	Free check-up	So as your research now, it's free and not required to provide a lot of things. It would be perfect if we would know the results if we provide the sample." "It would be better to get a report afterward." "If it's a free check-up that people could get their report then maybe they would willing to participate." "At lease they would know their situation, like the changing of the cancer cell, then it might get more people enrolled."

westernization, and the accompanying changes in family structures and values, have contributed to the declining perceived contributions and social status of older adults. And according to stereotype internalization theory, exposure to these negative stereotypes have affected how older adults view themselves, leading to beliefs of inadequacy and low-self esteem (50). Formation of negative self-image may also be exacerbated by high prevalence of elder abuse in Chinese populations, ranging from 0.2 to 64% according to a recent global review (51,52).

Considering aging as a social construct (53), interventions for increasing biospecimen research participation may also want to consider strategies for promoting self-esteem and self-image. Social workers, health educators, and patient navigators providing individual support to older adults are often already engaged in this work. However, programs geared toward nurturing multigenerational relationships, developing older adults' social support networks, and community education to promote positive views of aging may be warranted as well. Improving attitudes of health care providers toward older adults, and specifically reducing stereotypes and biases against elders, may also call for gerontology training for all health-care professionals (54). More broadly, policy measures to promote biospecimen research among Chinese older women is one of healthy aging—ensuring adequate provision of community and health services for the aging population.

The need for enhancing the participation of underrepresented groups in biospecimen research increases as individualized therapies come into focus. The Precision Medicine Initiative in the United States requires large cohorts of individuals willing to share electronic medical record and genomic data (55) but underrepresented groups risk benefitting less than others from medical advancements. It has been suggested that precision medicine efforts can result in diagnostic or therapeutic mistakes in a multiethnic society if we do not achieve representative precision medicine and capture genomic variances (56). As China is the most populous nation in the world, biobanks in China may hold promise. However, most Chinese biobanks have only been recently been established (57) and due to fragmented ethical and legal regulatory systems (40), face significant impediments to academic exchange in international efforts. Thus, the culturally appropriate education and community outreach needs, as well as training and policies ensuring adequate provision of community and health services for the aging population as described above, will be pivotal for helping to mitigate biospecimen research participation barriers toward equal contribution to sciences among all population groups.

Conclusions

This qualitative study of the attitudes and perceptions of biospecimen research participation among Chinese older women found predominantly positive attitudes toward biospecimen research, but also identified multifaceted barriers to participation and potential facilitators for increasing biospecimen research participation. Many Chinese older women are disadvantaged in the United States due to cultural, linguistic, and structural barriers and are vulnerable to poor health and limited health care utilization (22). Underrepresentation in biospecimen research has the potential to perpetuate health disparities. Nevertheless, these challenges represent tremendous opportunities for community stakeholders, researchers, health professionals, social service agencies, and policy makers to improve the health and well-being of Chinese older women and to reduce health inequalities in this vulnerable population.

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Conflict of Interest

None.

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