

5-2016

Attitudes Towards Prenatal Genetics Among Southeast and East Asian Women: A Qualitative Pilot Study

GINGER J. TSAI

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ATTITUDES TOWARDS PRENATAL GENETICS AMONG SOUTHEAST AND EAST
ASIAN WOMEN: A QUALITATIVE PILOT STUDY

by

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ASIAN WOMEN: A QUALITATIVE PILOT STUDY

A

THESIS

Presented to the Faculty of
The University of Texas
Health Science Center at Houston
and
The University of Texas
MD Anderson Cancer Center
Graduate School of Biomedical Sciences
in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF SCIENCE

by

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Houston, Texas

May 2016

ACKNOWLEDGEMENTS

First and foremost, I would like to thank my advisory professor, Sarah Jane Noblin, for her excellent guidance, passion, and support throughout this research process. I would also like to thank the rest of my thesis committee: Dr. Carrie Cameron for her unwavering encouragement and freely shared expertise; Jennifer Czerwinski, for her initiative, dedication, and insight; Dr. Hector Mendez-Figueroa, for his invaluable clinical perspective; and Dr. Susan Peterson, for her thoughtful and critical perspective.

I am also indebted to my classmates in the University of Texas Genetic Counseling Program, particularly the class of 2016 for providing me with incredible memories, advice, and friendship for the past two years. Additionally, I would like to thank all of my supervisors and the program directors of the University of Texas Genetic Counseling Program for challenging me to develop my clinical and research skills even when it seemed impossible for me to do so.

Last but not least, I would like to thank my family and friends, who have been a constant source of support and strength. A special thanks goes to Wade Lanning for his generosity and kindness.

ATTITUDES TOWARDS PRENATAL GENETICS AMONG SOUTHEAST AND EAST ASIAN WOMEN: A QUALITATIVE PILOT STUDY

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Advisory Professor: Sarah Jane Noblin, M.S., C.G.C.

From 2000-2010, the Asian population in the United States grew five times faster than the overall US population. As Asians become incorporated into the US health care system, it is important to recognize cultural differences that may arise between Asian patients and their health care providers. Prior studies show that cultural values influence genetic perceptions within Asian populations. The reputation of the family unit factors into decisions such as pregnancy termination and disclosure of family medical history, and the non-directive model of American genetic counseling conflicts with the historical Asian model of paternalistic health care. Previous studies also provide conflicting evidence regarding correlations between education, acculturation, age, and awareness and perceptions of genetic testing. Recognizing the heterogeneity of the Asian population with regards to acculturation, education, health awareness, and cultural values is vital for tailoring culturally sensitive and appropriate care. The aims of this study were to describe attitudes towards prenatal genetics among Southeast and East Asian women and to explore sociocultural factors influencing those attitudes. 23 Asian women who were members of Asian cultural organizations in the US were interviewed via telephone about their attitudes towards prenatal genetic counseling, prenatal genetic testing, and termination of pregnancy. Responses were transcribed and coded for common themes using a grounded theory approach. Five major themes emerged. Participants had diverse expectations for genetic counselors with regards to emotional support and non-directiveness. Attitudes towards genetic testing and pregnancy termination varied widely and were influenced primarily by religious and spiritual beliefs, risk-benefit analysis, and cultural factors including societal stigma of disabilities, availability of resources, and family authority. These findings may allow prenatal genetic counselors to gain a richer, more nuanced understanding of their Asian patients and to offer culturally tailored genetic counseling.

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INTRODUCTION

From 2000-2010, the Asian population in the United States increased 45.6%, five times faster than the national population (Hoefell, Rastogi, & Shaheed, 2012). As of 2010, the Asian population now accounts for 5.6% of the total United States population, compared to 4.2% in 2000 (Barnes & Bennett, 2002; Hoefell *et al.*, 2012). As Asians become more incorporated into the American health care system, it is increasingly important to recognize cultural differences that may arise between Asian patients and their healthcare providers. Moreover, acknowledging the heterogeneity of the Asian population with regards to acculturation, nationality, socioeconomic status, education level, age, and health awareness is vital for tailoring culturally sensitive and appropriate care.

Cultural values influence perceptions of genetics within Asian populations. Previous studies have shown that Asian patients tend to rely on anecdotal evidence rather than scientific data to understand genetic risks, and that Southeast Asians tend to prefer medication or physical treatment rather than counseling or tests without direct intervention (Learman *et al.*, 2003; Mittman, Crombleholme, Green, & Golbus, 1998). “Saving face,” defined as protecting the collective well-being and reputation of the family unit, also factors into genetic decisions such as pregnancy termination, carrier testing, and disclosure of family medical history (Chin *et al.*, 2005; Glenn, Chawla, & Bastani, 2012; Mittman, Crombleholme, Green, & Golbus, 1998; Wang & Marsh, 1992). In China, the views of partners and spouses take precedence over patient choice with regard to prenatal testing (van den Heuvel *et al.*, 2009). In addition, the non-directive model of American genetic counseling conflicts with the Asian model of paternalistic health care, and the former may lead patients to defer to the counselor’s or doctor’s implied decisions (Chen, Zhao, Zhou, & Xu, 2012; Chin *et al.*, 2005; Mittman, Crombleholme, Green, & Golbus, 1998; Tan *et al.*, 2007; Wang & Marsh, 1992).

While traditional cultural values can lead Asian patients to avoid genetic testing and counseling, studies show a strong positive correlation between education, acculturation, awareness of genetic testing, and positive perceptions of genetic testing (Chin *et al.*, 2005; Pagan *et al.*, 2009; Tan *et al.*, 2007).

Younger Asian patients are motivated to seek genetic testing to prevent the future burden of disease on one's family, contribute to science, and inform their personal health care choices (Chen, Zhao, Zhou, & Xu, 2012; Chin *et al.*, 2005; Glenn *et al.*, 2012). However, studies from Australia and Hawaii, which included participants from China, Malaysia, Japan, the Philippines, and Hong Kong, found that folk beliefs still permeate perceptions of genetics even with diversity in age and higher degrees of education and acculturation (Barlow-Stewart *et al.*, 2006; Eisenbruch *et al.*, 2004; Suzuki, Goebert, Ahmed, & Lu, 2014). These contradictory results present a need to further distinguish between each culture's unique values and experiences that influence genetic understanding and perception.

Confucianism and filial piety are major driving philosophies in Taiwan, Hong Kong, and China (Chien, Su, & Chen, 2013; Leung, 2009; Sleeboom-Faulkner, 2011; Tam, 1994), but the cultural identities of each place differ significantly. Taiwan's official name is the Republic of China, and many people from Taiwan identify as Chinese since they emigrated from China during the Cultural Revolution in the 1960's (Kaeding, 2011). The Hong Kong population is predominantly Chinese, but the cultural identity of the population is complex due to the handover from British to Chinese sovereignty and increasing anti-mainland China sentiments (Kaeding, 2011). However, studies on genetic perceptions do not always distinguish between people from Taiwan, China, and Hong Kong, and instead categorize all of these different groups as "Chinese." This example further highlights the need to distinguish between cultural values and their impact on genetics perceptions.

The historical and cultural experiences of each population may also significantly influence attitudes towards reproductive health care decisions. For example, in China, the "one-child policy" has significantly influenced reproductive decisions in the Chinese population over the past three decades. In line with Chinese government policy and Chinese geneticists' views, the majority of Chinese citizens support the one-child policy as a means of population control despite the personal desire to have more children (Mao, 1998; Su & Macer, 2005). Chinese citizens also support pregnancy termination, sterilization after the birth of a child with a birth defect, and genetic testing for birth defects and rare recessive conditions, (Sleeboom-Faulkner, 2011; Su & Macer, 2005). These actions align with the

Chinese government's campaign to create an "ideal Chinese family" and are generally unconstrained by religion (Sleeboom-Faulkner, 2011). Sex selection favoring males has also been practiced in China, leading to 117 males born to every 100 girls (Pflaker, 2002).

In contrast, Taiwan has embraced a democratic government and autonomous society similar to those found in the United States (Ministry of Foreign Affairs, 2015). Taiwan's population also practices several religions such as Buddhism, Taoism, Catholicism, and Christianity, which may affect their views on genetic testing and termination (Chien, Su, & Chen, 2013). Similarly, data from a Hong Kong study show that while Hong Kong Chinese women generally support termination of pregnancy for chromosomal abnormalities and non-medical reasons in early pregnancy, religious background is a significant contributor to negative attitudes toward termination. The majority of women in the study also agreed that termination should not be performed for undesired fetal gender (Leung *et al*, 2004).

An important cultural and historical distinction also lies between people from East Asia and Southeast Asia. Southeast Asians from Vietnam, Cambodia, Laos, Thailand, and other countries between China and Australia have experienced a long and more recent history of war, marginalization, and migration. Their second wave of immigration to the United States in the 1980's was characterized by anxiety, depression, malnutrition, and poor health (Mattson & Lew, 1991). A considerable language barrier and unfamiliarity with health care has hindered access to health care for these groups in the United States. The health beliefs of some highly traditional Southeast Asian groups, which focus on the unity of mind and body, also conflict with several components of the United States health care system. For example, surgery is thought to be a violation of the soul; blood is believed irreplaceable once drawn; pain is defined as a karmic punishment that must be endured rather than treated; and prenatal care is found to be unnecessary since pregnancy is not an illness (Mattson & Lew, 1991). Although these beliefs contrast sharply with the attitudes found in East Asian countries like China, the term "Asian" has been applied broadly in the literature to individuals from both regions, hiding the significant distinctions between belief systems and cultural values as well as further nuances yet to be explored.

Given the diverse social, cultural, and historical experiences among the Asian population, there is a need to distinguish between sociocultural factors affecting attitudes and decisions related to prenatal genetics. The aim of this study was to describe attitudes towards prenatal genetics among Southeast and East Asian women in the United States. Specifically, we aimed to assess attitudes towards prenatal genetic counseling, prenatal genetic testing, and termination of pregnancy, as well as the influence of various sociocultural factors on these attitudes, among Southeast and East Asian women in the United States.

METHODS

Study Design

We conducted semi-structured telephone interviews with women of Southeast and East Asian descent who were members of Asian cultural organizations based in the United States. The study protocol was approved by the Committee for the Protection of Human Subjects at the University of Texas Health Science Center at Houston (HSC-MS-15-0514).

Participants

Eligible women included those who were English speakers, age 18 or older, members of an Asian cultural organization at the school, local, or national level, and who claimed Southeast or East Asian ancestry. This population was chosen as a convenience sample.

Eligible women were invited to participate in the study via an electronic consent form sent by organization leaders through social media platforms, internal listservs, electronic newsletters, and personal emails. Participants provided their full name, organization name, telephone number, age, country of heritage, and digital signature on the consent form. Participants were verbally re-consented prior to the start of the interview. Demographic information was confirmed and supplemented by participant report.

Data Collection

Data were collected through semi-structured telephone interviews. The interviews were all conducted by the same interviewer using an interview guide (Appendix) that facilitated discussion of attitudes towards prenatal genetic decisions. The interview guide consisted of a series of short vignettes describing the discovery of an ultrasound problem during pregnancy, a referral to a genetic counselor, a genetic counseling appointment, and positive genetic test results for a genetic condition. Each vignette was followed by open-ended and close-ended probe questions to assess attitudes towards genetic conditions, genetic counseling, genetic testing, and termination of pregnancy as well as demographic and cultural factors influencing those attitudes. Interviews were audio-taped by the interviewer using a secure digital recorder and transcribed professionally by VoiceBase, Inc. Transcriptions were manually reviewed and edited by the interviewer. They were analyzed with the aid of ATLAS.ti 7 (Barry, 1998; Hwang, 2007) to identify common themes in participant responses across various factors using a grounded theory approach. The major sections of the interview guide were used as a general coding template, and additional codes were added as needed to modify the coding structure. Two of the authors (GT and SN) independently reviewed five transcripts and compared identified themes. They reached concordance of 80% for a subset of transcripts (n=5). The primary author coded the remainder of the transcripts.

RESULTS

Demographics

Demographic characteristics are listed in Table 1. The total number of people who received a consent form is unknown given the online method of recruitment. A total of 26 eligible participants provided written consent to participate in the study. 23 of these participants were reached by telephone

and provided verbal consent to participate in the study. The remaining three participants were not able to participate due to scheduling conflicts. The mean age of participants was 35 years, with a range from 22 to 70 years old. Most participants had private health insurance (21/23), while the remaining two had public insurance. The participants claimed ancestry in a variety of different countries, including mainland China (6/23), Taiwan (5/23), and Vietnam (3/23). There were also participants with ancestry in South Korea, Malaysia, Hong Kong, Japan, Singapore, and the Philippines. Nine of the participants were born and raised in the United States, while 14 had immigrated to the United States, primarily for educational opportunities. The latter group of participants had lived in the United States for an average of 18 years, with a range of years from 5-40 years. All of the participants had a postsecondary education. 12 out of 23 participants had a bachelor's degree and the remaining 11 had an advanced degree. With regards to religion, 10 out of 23 were Christian, with five of those individuals being Catholic and the other five non-denominational, Southern Baptist, Baptist, or unspecified Protestant. Another 10 were atheist; three of those individuals mentioned growing up with Christianity. The remaining three participants were Buddhist, Daoist, or engaged in ancestor worship. 13 participants had never been pregnant nor had children. The remainder had at least one child. Two participants had experienced one or more miscarriages.

Only one participant had personally received prenatal genetic counseling prior to the interview. 13 participants had no knowledge of genetic counseling, while nine were somewhat familiar with genetic counseling through the media, friendships with genetic counselors, or medical knowledge. Of note, seven participants worked in medicine or health care.

Table 1. Demographic Characteristics of Participants

Characteristic	Mean	SD	Range	N=23	
				n	%
Age	35.8	13.3	22-70		
Years in US	Born in US	-	-	9	39%
	18.4	10.8	5-40	14	61%
Insurance	Private			21	91%
	Public			2	9%
Education	Bachelor's degree			12	52%
	Advanced degree			11	48%
Country of ancestry	China			6	26%
	Taiwan			5	22%
	Vietnam			3	13%
	South Korea			2	9%
	Malaysia			2	9%
	Hong Kong			1	4%
	Japan			1	4%
	Singapore			1	4%
	Indonesia			1	4%
	Philippines			1	4%
Religion	Atheist			10	43%
	Christian – Catholic			5	22%
	Christian – non-Catholic			5	22%
	Buddhist			1	4%
	Ancestor worship			1	4%
	Daoist			1	4%
Pregnancy history	G0P0			13	57%
	G1P1			2	9%
	G2P1			1	4%
	G2P2			5	22%
	G3P1			1	4%
	G4P4			1	4%
Familiarity with genetic counseling	No familiarity			13	57%
	Somewhat familiar			9	39%
	Personally experienced			1	4%

Themes

Five major themes emerged from the study. In general, participants had diverse views on genetic counselors and varying amounts of concern for genetic conditions. They tended to pursue genetic testing to obtain information; however, they weighed risks and benefits with regards to genetic testing decisions. Participants had mixed views on termination for lethal and non-lethal genetic conditions. The cultural factors which influenced termination and testing decisions included shame, lack of social and medical support, family pressure, and normalization of termination and genetic testing within society. Religious and spiritual beliefs also influenced prenatal genetic decisions.

Theme 1: Diverse Expectations for Genetic Counselors

One part of the interview guide described a scenario in which a patient attends a genetic counseling session and becomes frustrated at the non-directive approach of the genetic counselor. Participants were asked whether the genetic counselor could have done anything differently to help the patient in the situation.

All participants agreed that a genetic counselor should provide information about testing options, the natural history of conditions, and the risk assessment of a genetic condition to a patient. Some participants approved of a non-directive approach, emphasizing that a counselor's job was to provide information and nothing more, regardless of whether the patient was struggling with her inability to make a decision. A few participants emphasized patient autonomy; one participant who was currently attending medical school said that autonomy should be preserved as it was an ethical principle in medicine. Other participants responded that the patient in the story might have expected direction or recommendations from a counselor because the counselor was considered a medical authority. One participant stated that if a counselor could not make recommendations, it might be helpful to refer the patient to someone who could tell the patient what to do.

Some participants mentioned that this expectation of directiveness might be culturally based. They discussed that medical care within Asian cultures might be paternalistic due to the high status of

medical providers. Participants also mentioned that decisions might be made collectively as a family instead of as an individual. One participant suggested that counselors acknowledge the cultural differences between American and Asian health care systems prior to starting a session in order to prevent frustration from differing expectations. Another suggested that the counselor provide education materials for family members not in attendance in order to help the family make a decision together. A few participants suggested that the genetic counselor facilitate decision making by self-disclosing what the counselor would personally do in the situation without giving specific instructions or recommendations to the patient.

Participants also had mixed views about the need for psychosocial counseling in the form of emotional support. A few participants suggested that the counselor provide emotional support by exploring the patient’s available support system and the patient’s emotions about each decision path. However, a larger number of participants disagreed and suggested that the counselor only stick to numbers and information.

Table 2. Theme 1: Diverse Expectations for Genetic Counselors

Subthemes	Quote	Demographic Factors
Expectation of directiveness from medical provider	“I will say most patients will expect to get a very determinate information from the expert...they are very scared, they are very stressful...[they] expect someone to tell them what will happen exactly.”	38 years old Christian G2P2 China 9 years in US
Facilitating patient decisions through self-disclosure	“...be more like a close friend to patient and say, ‘If I were in the situation, I would rather make this decision. If I were that situation, I would make that decision.’...In that way they wouldn't give words to the patient and say, ‘You should do this.’”	47 years old Atheist G2P2 China 19 years in US
Patient's responsibility to make decision	“You cannot expect a genetic counselor or anybody to give you an advice on what you should do...ultimately the couple has to make a decision. I can't get mad at you for giving me the option.”	30 years old Catholic G0P0 Vietnam 26 years in US

Importance of patient autonomy	“The patient should always be given options. Understand that they have their own autonomy, like, they have a choice in what they can and don't have to do.”	22 years old Atheist GOP0 Vietnam Born in US
Genetic counselors should provide emotional support	“What a genetic counselor could do is go through each option with [the patient]...and have her talk and say maybe what she's feeling about each option. Why she might not want it and why she might want it...in that way it's more like a counseling session.”	27 years old Christian GOP0 Hong Kong 16 years in US
Genetic counselors should not provide emotional support	“Your job is to educate and if they get mad at you guys under this circumstance or if they get upset, there's really nothing you can do.”	30 years old Catholic GOP0 Vietnam 26 years in US
	“A counselor...might not want to go into the level of mentally counseling [sic]...I wouldn't recommend counselors go that deep a level, maybe just the numbers, to start with.”	28 years old Ancestor worship G1P1 Taiwan 5 years in US
Cultural expectation of directiveness from medical professionals	“I think a lot of, particularly immigrant Asians want the doctor to tell them what to do. [...] In America we try to do a more patient participating type of model. And they don't feel confident participating in that, many times.”	63 years old Christian G1P1 China Born in US
	“In Asian culture, the choice factor is less of a thing than it is in American culture... I don't think that in terms of cultural values, women feel that they can just make a choice in independent of consulting...parents, your significant other, a male figure or whatever.”	32 years old Christian GOP0 South Korea Born in US

Theme 2: Genetic Testing Decision Driven by Risk-benefit Analysis

Participants were asked whether they would pursue invasive and non-invasive genetic testing after the discovery of an ultrasound abnormality. The majority of participants expressed interest in pursuing genetic testing to gain information that would help them anticipate preparations necessary for the child's birth, relieve anxiety about the possibility of a problem, or make a decision about pregnancy. However, participants stated that they would weigh the risks and benefits of a number of different factors prior to making a decision about testing.

Participants' responses focused primarily on invasive testing. Several participants mentioned that they would need to compare the numerical risk of harm from invasive testing with the risk of a genetic condition. One participant in particular mentioned that her risk assessment would include advanced maternal age, as her friends had previously received a recommendation for invasive testing from their obstetrician due to advanced maternal age. Other participants considered whether the procedure presented risk to the mother and whether the conditions being tested for by amniocentesis were relevant to a suspected diagnosis. Some participants stated that they would pursue invasive testing only if the conditions were treatable; otherwise the results would not be of benefit as they were not actionable. A few participants stated that they would only pursue testing if it were absolutely necessary as they were unwilling to risk harm to the baby otherwise. Some participants also mentioned that they would account for financial considerations, in particular insurance coverage.

Other participants had more definite answers. Some stated that they would definitely pursue invasive testing as the benefits of information gained from the procedure outweighed any risk of loss due to the procedure; since the baby was already at risk for a genetic condition, these participants considered the risk from the procedure minimal in comparison. One participant said that she would definitely elect testing if the baby was suspected to have a lethal condition. On the other end of the spectrum, some participants mentioned that they would not pursue testing in order to avoid the risk of miscarriage. Others stated that since termination was not an option for religious reasons, they did not see a point in

putting the baby at risk through invasive testing. One participant in particular mentioned that whether or not the baby had a condition, it was her religious duty to take care of the child.

Table 3. Theme 2: Genetic Testing Decision Driven by Risk-benefit Analysis

Subthemes	Quote	Demographic Factors
Risk of disease vs. risk of harm from testing	“I have to probably compare the probability of the disease and the risk of the test.”	38 years old Christian G2P2 China 19 years in US
Financial concerns	“I would want to know as much as possible, unless there were like a limiting factor like cost.”	29 years old Atheist G0P0 Singapore Born in US
	“If it's covered by insurance...that would dictate also how you react to it. Like if someone tells you it's free, you'd be like, ‘Okay, I'll do everything.’ But if you have to pay like \$300 for each test, you'd be like, ‘Okay, well maybe we'll just do the most important ones.’”	27 years old Atheist G0P0 Malaysia Born in US
Conditions that present risk to fetus	“If it endangers the fetus itself...if it's going to go on to birth or if it's just going to die in the womb or something like that. That would definitely be something that should be tested for.”	32 years old Christian G0P0 South Korea Born in US
Relevance of condition being tested	“If it [the test] was for that primary disease, I would definitely do it no matter what the risk was. But if it was for something else...tangentially, I will think twice about having that test.”	27 years old Atheist G0P0 Malaysia 9 years in US
Availability of treatment for condition being tested	“If it [the suspected condition] is curable I would want to do more... further testing. But if it's not curable, let's say, like Down syndrome, then I might just skip the further testing.”	28 years old Ancestor worship G1P1 Taiwan 5 years in US

Pursuing invasive testing only if absolutely necessary	“I want to...get like a fairly definite answer from probably several OBGYNs regarding that there might be an issue with the baby before I have someone stab my belly and subsequently, my baby.”	25 years old Buddhism G0P0 China Born in US
Information gained outweighs risk of procedure	“...your baby's at risk for something, so what harm are you really going to do in putting a slight extra risk when it's already in that kind of situation? I think being a new mom is hard enough, as it is, without any more surprises than necessary.”	27 years old Atheist G0P0 Taiwan Born in US
Influence of religious and spiritual beliefs	“There's no test I need to do, whatever God gave me and that's it. [...] And for the rest of my life, I mean if that's what God gives me, duty, this duty to do.”	48 years old Catholic G4P4 Malaysia 29 years in US
Influence of previous pregnancy history	“Prior to this last pregnancy...I had two miscarriages. I definitely was on edge a lot... I was very cautious and I wanted to get all the possible testing done just to make sure everything was okay, and I needed that validation.”	42 years old Atheist G3P1 Taiwan 15 years in US

Theme 3: Cultural Factors Influencing Genetic Testing Decisions

In order to gauge cultural factors influencing testing decisions, participants were asked how genetic testing decisions may change if the patient in the story were receiving medical care in their Asian country of ancestry. A few participants mentioned that genetic testing would be recommended, possibly strongly, by medical providers. One participant linked this recommendation to the notion that Asian cultures prefer perfect pregnancies. A few participants also mentioned that in their countries of ancestry, genetic testing, including amniocentesis, was recommended by doctors and friends as a standard procedure for getting information about the pregnancy.

Some participants mentioned that there would be different financial considerations with regards to testing in Asia; it would be easier or harder to get genetic testing depending on the country's health care system. One participant noted that the reason financial concerns might be so prevalent for Asian families in America was because they did not have immediate family and support to rely on like in Asia.

A few participants mentioned that a fatalistic attitude might limit genetic testing decisions in Asia, as medical providers may not see the point in doing genetic testing given the pre-existence of a problem. Several participants mentioned that the availability of resources in their countries of ancestry would also affect genetic testing decisions. Many participants discussed that the quality of health care was lower in their countries of ancestry and that extensive testing options may not be available. Most participants stated that genetic counseling was likely not available in their countries of ancestry, and that people were likely not aware of testing options. Since a discussion of genetic testing options may not take place, parents may make more definite decisions about terminating or continuing the pregnancy given their available knowledge. One participant from Vietnam noted that there would typically not be an indication for genetic testing since most of the population generally had children at a young age.

Table 4. Theme 3: Cultural Factors Influencing Genetic Testing Decisions

Subthemes	Quote	Demographic Factors
Paternalism	“I think you would have to get the testing [in Asia]... It's more of an urging, I think, just because, Asian people don't really deal well as a culture, with things that aren't perfect.”	27 years old Atheist GOP0 Taiwan Born in US
Normalization of genetic testing	“A lot of women... They just go straight for [amniocentesis] because they just want to know. And even the younger pregnant women will do that... these days it's pretty standard.”	34 years old Daoist G2P2 Taiwan 21 years in US
Influence of financial resources	“If I were in China... if testing for something is really risky and expensive, and the situation is concerning to be really severe, I would probably just give up [on testing].”	28 years old Atheist GOP0 China 5 years in US
	“In Malaysia... they are socialism. You go to hospital, you pay pretty much nothing, just a little. So it's financially probably less burden. So that will free up the financial issues.”	48 years old Catholic G4P4 Malaysia 29 years in US
Fatalism influences against genetic testing	“From a Chinese family, if you hold onto a more fatalistic perspective... it might not necessarily make sense to go through all that testing and get all that information 'cause, wasn't the little baby meant to come to this world? That's what it's meant to be.”	42 years old Atheist G3P1 Taiwan 15 years in US
	“I don't know how enthusiastic the doctors would be to do the [amniocentesis], knowing what's already happening with the child... like, ‘You already know it's wrong. Why do we have to do this?’”	28 years old Atheist GOP0 Vietnam 22 years in US
Lack of awareness	“Even if it [testing] is available, the demand won't be high probably because the sophistication in the demographic... they're not asking for it, because they don't know to, and they can't.”	30 years old Catholic GOP0 Vietnam 26 years in US

Theme 4: Mixed Views on Termination

Participants were given a set of scenarios in which a patient's genetic testing results showed that the baby had a lethal condition (e.g. trisomy 13), a non-lethal condition (e.g. Down syndrome), and an isolated physical defect (e.g. cleft lip and palate). Participants were asked what would be the appropriate course of action for the pregnancy. Both opposition against termination and support for termination were driven by practical and emotional reasons. One participant declined to answer any termination questions due to unspecified personal reasons.

Several factors contributed to participants' responses about termination. Some participants had definite answers. A few stated that they would terminate in order to prevent the affected child from suffering. In the case of a lethal condition, some participants emphasized that termination would also prevent the child's parents from suffering, as grieving a child who had lived for some time was much harder than grieving a child who had passed *in utero*. Participants also stated that it would be emotionally devastating to spend time with a child knowing that the child would eventually die. Similarly, in the case of a non-lethal condition, participants stated that they would consider termination because the long-term emotional investment required to care for an affected child may have a negative impact on a parent's quality of life.

In contrast, other participants stated that they would continue the pregnancy and accept responsibility for the care of the child even if the child had a lethal condition. Some participants stated that they would continue the pregnancy so that they could develop a parental bond with the baby despite the emotional suffering involved. Religious and spiritual beliefs, including fatalistic beliefs, also influenced participants' decisions against termination.

Other participants had less definite answers and reported that they would make decisions by considering different factors. Participants on the more practical end stated that they would terminate if there was a high rate of mortality. Some also mentioned that they would compare the financial impact of pursuing termination and delivering the baby. One participant stated that she would turn to her support system to help her make a decision. Several participants mentioned that the severity of the condition,

and the subsequent quality of life for the child, would influence their termination decision. Participants stated that they would be more likely to terminate for conditions with greater severity and a lower anticipated quality of life for the child. Some participants also said that they would not terminate if there was an available treatment or cure for the condition, or if they were familiar with the condition.

Participants were also asked separately whether they would terminate for an isolated physical defect that could be corrected by surgery. All participants who answered termination questions stated that they would not terminate for an isolated physical defect because it could be fixed, though a few mentioned taking the financial impact and the severity of the defect into account.

Table 5. Theme 4: Mixed Views on Termination

Subthemes	Quote	Demographic Factors
Practical factors	"[For a lethal condition] I would terminate the baby...because statistically, there isn't a very good chance for even the baby to live for its first year."	27 years old Atheist GOP0 Malaysia Born in US
	"She should...consider the costs involved with any choice that she makes."	27 years old Atheist GOP0 Taiwan Born in US
Preventing emotional suffering	"I will probably still, definitely consider termination... it's not fair for the family, or really the child to come into this world suffering."	42 years old Atheist Taiwan G3P1 15 years in US
	"I think keeping a child and taking care of it, shouldn't be a problem. But after you evaluate your life ten, twenty years from now and you don't like it, I don't really think it's fair to put your spouse through it or the child through it since you're not going to be happy. And if you're not happy, how can you take care of someone else?"	28 years old Atheist GOP0 Vietnam 22 years in US
Familiarity with condition	"If it was something I was familiar with...then I would go ahead with it [the pregnancy]."	27 years old Atheist GOP0 Malaysia Born in US

Severity of condition	“I think a lot of it depends on the severity of it. Like if they're not even going to really experience life, or will they get the full experience of life anyway?”	27 years old Atheist GOP0 Taiwan Born in US
Possibility of treatment	“I feel if...the medical procedure can intervene and get a better outcome out of it, then, you know, I would take that into consideration and say, ‘Okay, termination may not be the way to go. We can fix this.’”	34 years old Daoist G2P2 Taiwan 21 years in US
	“I think if the baby is not any fatal disease, then there's not a very difficult decision to make. The baby is good, right? It's a good baby. They just have some genetic disease, but that's fixable, right?”	45-50 years old Atheist G2P2 China 20 years in US
Religious and spiritual beliefs	"I am a very pro-life person...from my heart, I believe that every child that is conceived is a gift from God. And every child that dies is still a precious life that he inspired to happen. So I would say that she should go through with the pregnancy."	63 years old Christian G1P1 China Born in US
	“I think she should still give birth to that babyif they could come to the world, they should deserve the time they have in the world.”	28 years old Ancestor worship G1P1 Taiwan 5 years in US
Accepting responsibility for birth of the child	“You made the decision to have a child, you should keep it.”	30 years old Catholic GOP0 Vietnam 26 years in US
Opportunity to develop parental bond	“I don't think I can get myself to terminate her pregnancy, just 'cause at 20 weeks, she already feels the baby in there, you know? So...it might even be a selfish thing, but I would just really want to meet my baby.”	22 years old Atheist GOP0 Vietnam Born in US

Theme 5: Cultural Factors Influencing Termination Decisions

Participants were asked how termination decisions might change if the patient in the story received positive genetic testing results and medical care in Asia. Several major cultural factors influencing termination decisions were identified from these discussions. The majority of participants reported that there was a stigma against children with genetic conditions and disabilities within Asian cultures. Some said that a child with a disability reflected poorly on the reproductive fitness of the child's parents, while others said a disability was a source of shame and embarrassment in social situations. A belief in karma may also foster the view that a child with a disability is receiving a spiritual punishment.

All of the participants who answered termination questions agreed that termination was ultimately a personal choice by the mother or by the mother and father of the baby. However, most participants also discussed that the family, in particular the grandparents of the baby, held authority over the parents of the baby with regards to termination decisions. This was because the baby became the property of the family after a woman married into her husband's family. Some participants also mentioned that the family would pressure or even force a mother to terminate the pregnancy if a child was found to have a genetic condition or birth defect, since a child with a disability would again be a source of shame for the family.

On a similar note, many participants mentioned that they would face social pressure to terminate a child with a genetic condition. According to these participants, not only is termination of affected pregnancies normalized in certain countries, children with disabilities are also seen as a burden upon the family and upon society and are thought to have very little value. On the flip side, a few participants stated that they would receive more social judgment and pressure if they chose to terminate in the United States because of the religious beliefs present in American society. Almost all of the participants noted that there was a distinct lack of social support and medical resources available for children with disabilities in Asia. Some participants connected the lack of resources with a preference toward termination. A few participants anecdotally reported that children with genetic conditions were typically abandoned at hospitals or orphanages because their families could not provide for their needs. Some

participants mentioned that they would keep news of an affected pregnancy hidden from the grandparents of the baby, other family members, and society in general in order to avoid societal and family pressure regarding termination decisions.

Some participants mentioned medical providers in Asia may be paternalistic and encourage patients to terminate an affected pregnancy. However, other participants disagreed, saying that doctors would be non-directive and solely provide information, and that doctors would act very tentatively with regards to patients' decisions. Another participant stated that paternalism in medical care could be found anywhere and could not be ascribed as a cultural factor.

A few participants stated that their religious and spiritual beliefs outweighed cultural factors when making termination decisions, and that regardless of their location or society, they would not terminate the pregnancy as they would still receive support. One participant noted that a patient might receive excessive support after delivering a child with a disability, which could also cause a patient to feel embarrassed or ashamed.

Some participants with Chinese ancestry mentioned that a family may choose to terminate a female fetus while keeping a male fetus regardless of abnormalities. They linked this decision to mainland China's historical one-child policy which limited reproductive choices for new parents, as well as the historical belief that male children had greater value than female children.

Table 6. Theme 5: Cultural Factors Influencing Termination Decisions

Subthemes	Quote	Demographic Factors
Shame and stigma with regards to children with disabilities	“Some people may think that if you have a defect that it's like a punishment for something in your past life...there's a stigma associated with it.”	29 years old Atheist GOP0 Singapore Born in US
	“The shame of having someone like that in your family, or being close to somebody like that...it probably reflects upon you. You know, like, ‘I don't know how healthy your sperm or your eggs are.’	32 years old Christian GOP0 South Korea Born in US
	“In Vietnam...Imperfections, especially physical malformations, physical disabilities are just not acceptable to society...in that situation...you're basically ostracized from your neighborhood, because you have this child.”	28 years old Atheist GOP0 Vietnam 22 years in US
Family makes decisions over individual	“If the family wants to keep it, then they will pressure her to keep it. If the family wants to abort it, they will pressure her to abort it. They will give her pressure.”	45-50 years old Atheist G2P2 China 20 years in US
	“...by the end of the day, it's not just her decision anymore...the grandparents of the baby...they would either say ‘this is what you should do’ or ‘you're doing this.’ Or...in extreme cases they would force her to go through certain surgeries or give up on the baby....Unfortunately, losing a baby is not that hard.”	28 years old Atheist GOP0 China 5 years in US
Social pressure to terminate affected pregnancy	“I think in Korea...more people would just hastily be advised towards terminating the pregnancy if there is even just a hint of a genetic thing.”	32 years old Christian GOP0 South Korea Born in US
	“In Taiwan if this is the situation, the only answer people would tell her is just to terminate the pregnancy...if she doesn't do that, everybody will think she's crazy and stupid or something.”	34 years old Daoist G2P2 Taiwan 21 years in US
Sex selection influences termination decision	“It's totally different in China than in America...I could imagine a family say they want a boy, even though the boy is totally abnormal, they will keep it because it is a boy, you know?...Like, it's by gender, not by anything else.”	45-50 years old Atheist G2P2 China 20 years in US

Lack of resources may lead to termination of pregnancy	“...in China, to have a child with disabilities is really a bad thing 'cause there's not much social support or welfare for the baby...I think it's more likely, I would not choose to have the baby to be born.”	47 years old Christian G2P2 China 19 years in US
	“In Korea...it's really hard to live, or raise kids if they have serious genetic disabilities, or mental problems, or physical problems...that's why people will more lean towards getting abortions.”	25 years old Atheist G0P0 South Korea 10 years in US
Religious and spiritual beliefs outweigh cultural factors	“If I have the same belief in Malaysia, I would say I would make the same choice.”	48 years old Catholic G4P4 Malaysia 29 years in US
	“Personally, I think it has more to do with her perspectives on life and maybe religious affiliation as opposed to where she's living.”	63 years old Christian G1P1 China Born in US

DISCUSSION

The purpose of this study was to assess attitudes towards prenatal genetic counseling, prenatal genetic testing, and termination of pregnancy in an Asian population and describe the influence of various sociocultural factors upon these attitudes. In general, while country of ancestry, age, pregnancy history, and number of years in the United States did not appear to have a strong influence on pregnancy decisions, religious and spiritual beliefs, as well as cultural factors, seemed to subtly influence decisions.

Genetic Counseling

Participants had conflicting and diverse attitudes towards the role of a genetic counselor. While all participants agreed that the counselor should provide thorough and objective information to a patient, participants disagreed on whether a non-directive or directive approach would be more appropriate with regards to facilitating patient decisions. Those who emphasized autonomy and discouraged directiveness tended to be younger with no known pregnancy history, while those who encouraged directiveness tended to be older and had already had children. According to the latter group of participants, a directive approach may engender trust in the counselor as it would show the counselor's expertise. Patients may also have a lot of anxiety and stress over making a decision due to their disparate knowledge level, and direction from a provider may validate and relieve those feelings. Many participants suggested that patients could have a cultural expectation for directiveness from a medical provider given the historically paternalistic health care provided in Asia. This paternalistic approach has been described in previous studies (Chin *et al.*, 2005, Hayashi *et al.*, 2005; Mittman, Crombleholme, Green, & Golbus, 1998), one of which suggested an association between older ages and preference for paternalistic health care among Asian patients (Chin *et al.*, 2005).

Participants who suggested a compromise between non-directive and directive counseling in the form of self-disclosure generally worked in the medical setting. They may have had an increased awareness of the complexity of the problem. Since the quality of relationships in Asian cultures tends to be based on degrees of familiarity (Chen, 2003), Asian patients may be less inclined to disclose medical

information or engage in a counseling session with a stranger. Self-disclosure, though often discouraged in genetic counseling clinical training programs, may be a way to develop rapport with an Asian patient and facilitate culturally tailored counseling.

A similar conflict arose when discussing whether it would be appropriate to provide psychosocial counseling in the form of emotional support. The two participants who suggested that genetic counselors provide emotional support were both Christian, and it is possible that their religious beliefs influenced their views. Other participants, spanning all religions, ages, countries of heritage, and pregnancy histories, opposed the idea of emotional support and strongly suggested that the counselor only provide information to a patient. In fact, participants were generally confused when probed about emotional support systems for pregnancy decisions. They expressed that they tended to rely on health care providers solely for information and recommendations, while they sought emotional support from family or spouses only as needed. Participants also stated that receiving clear information, and sometimes recommendations, was a means of relieving anxiety and stress caused by the uncertainty of pregnancy. This has implications for the clinical genetic counselor who has been trained to address psychosocial issues. For Asian patients, providing psychosocial support through a filter of information may be more effective than the more classical psychosocial approach which addresses emotions directly, unless there are explicit signs that the patient will engage in the session beyond the information portion.

Genetic Testing

Most participants stated that they would pursue some form of prenatal genetic testing, whether it was non-invasive blood screening or invasive testing like amniocentesis. The decision to pursue testing was primarily driven by the need for information. Participants sought information for a variety of reasons, including a diagnosis by which to make pregnancy decisions or to prepare for the birth of a baby with disabilities. Genetic testing decisions primarily depended on a risk-benefit analysis of several different factors, including the risk of harm to the baby, the probability of a genetic condition, the benefits of information, relevance of conditions being tested for, the availability of treatment for

conditions, and religious and spiritual beliefs. A previous study in Japan showed similar factors for decision making regarding genetic testing, including the risk of harm to fetus, risk of harm to mother, procedural details, and details about the conditions being tested for (Skirton *et al.*, 2008). The cost of genetic testing was also a common concern among participants in this study. This knowledge may help genetic counselors address concerns of high priority for Asian patients, including the financial burden of testing and the benefits and limitations of information gained from genetic testing.

In the current study, there did not appear to be a trend toward or away from genetic testing in relation to age, country of ancestry, or number of years in the United States. However, a history of pregnancy issues and religious and spiritual beliefs did contribute to decision making. The two participants who had experienced miscarriages stated that they pursued invasive testing with their most recent pregnancies because they were anxious about losing the pregnancy due to an undiagnosed condition. This finding conflicts with a previous study which found that women were less likely to pursue amniocentesis if they had a history of miscarriages (Ellman *et al.*, 2003). However, that study only included women of advanced maternal age who were undergoing *in vitro* fertilization, and their decisions may have been influenced by other factors besides their history of miscarriage. The study also did not look at associations between its subjects' ethnicities and testing decisions. Additionally, the participants in our study may have sought information as a means to relieve their anxiety, which is another finding in this study.

A few Christian participants were opposed to invasive testing for religious reasons and stated that the results from invasive testing would not change pregnancy decisions related to termination. Interestingly, this finding is consistent with studies done on the Latina population (Hunt & deVoogel, 2005; Seth *et al.*, 2011). This may not be surprising given that the majority of the Latina population is Catholic, and at least one of the participants who gave that answer in this study was also Catholic. However, as religious and spiritual beliefs are not factors typically associated with decision making in the Asian patient population, it is important to note that they may still influence decisions for certain members of the population.

Another spiritual belief that influenced testing decisions was fatalism, or the belief that events are pre-determined. Fatalism is part of the traditional Asian worldview and has previously been shown to be a barrier to Asian patient participation in cancer screening services (Glenn, Chawla & Bastani; Kwok & Sullivan, 2006). In the current study, participants of various religions, including Christianity, ancestor worship, and atheism, cited fatalism as a reason not to seek genetic testing, as information from testing would not lead to a change in the baby's condition, in current medical management, or in pregnancy decisions.

In contrast to influences against testing, some participants said genetic testing was commonplace in Asian cultures, and that testing may be recommended by doctors. This may be a consequence of the desire for information, combined with historical government policy mandating testing and a traditionally paternalistic health care system (Hayashi *et al.*, 2000; Sleeboom-Faulkner, 2011; Su & Macer, 2005). For example, China has had historical reproductive policies requiring carrier screening and screening for birth defects (Su & Macer, 2005). This mindset could still influence doctors today, especially those who lived through and experienced such policies, and they may unconsciously recommend similar pregnancy measures for patients. One participant with Taiwanese ancestry mentioned that testing would be recommended because of the pressure to have a perfect baby. Another participant, also with Taiwanese ancestry, mentioned that invasive testing was a standard procedure for women even if they were considered low-risk, because it was a social norm and a general desire to get as much information as possible about the pregnancy. Again, this may tie into social pressure to have a perfect baby and to take action against an affected pregnancy. The normalization of genetic testing and paternalistic approach to healthcare in Asia may contribute to a patient's expectation for directiveness and testing recommendations in a genetic counseling session.

Termination

Participants expressed differing views with regards to termination for a lethal defect and for a non-lethal defect of variable severity. Religious and spiritual beliefs again influenced decision making in

these cases, with Christian beliefs and fatalism serving as motivation not to pursue termination. Participants with Christian beliefs stated that every life deserved a chance, while those motivated by fatalism stated that the baby was meant to be. A previous study among women in Hong Kong similarly found that religious belief was a significant factor for a negative attitude toward termination (Leung *et al*, 2004). In contrast, many participants also viewed election of termination as a means to prevent the suffering of both child and family, especially in the case of a lethal condition. Other factors influencing termination decisions included the parents' eventual quality of life, familiarity with and severity of a condition, availability of treatment, and various cultural factors discussed in the next section. Participants who emphasized parental quality of life in decision making had no history of pregnancy and were generally in their late 20's; it is possible that their current status as an independent young adult contributed to their answers.

All participants who answered termination questions agreed that they would not terminate for a physical defect that could be corrected by surgery, despite the use of cleft lip and palate as a case example. Cleft lip and/or palate historically has a stigma in Asian cultures (Cheng, 1990). In general, participants viewed "fixable" conditions with available treatment as more acceptable since action could be taken against them. This is consistent with a previous study which showed that Southeast Asian patients view physical interventions and medication as effective treatments over counseling or indirect intervention (Mittman, Crombleholme, Green, & Golbus, 1998).

Cultural Factors Influencing Genetic Testing and Termination Decisions

Participants discussed a number of cultural factors that could influence testing and termination decisions. One major factor was the lack of financial, social, and medical resources available in Asian countries, as well as the lack of exposure to individuals with disabilities, which might lead a patient to terminate a pregnancy. Many participants also discussed the shame and stigma of disability within Asian society, which was usually accompanied by social and family pressure to terminate an affected pregnancy. In addition, participants mentioned that family members, in particular grandparents, tend to

have authority over individuals with regards to pregnancy decisions. All of these factors are interrelated, and the findings are consistent with several other studies about attitudes towards disability among Asian populations.

“Face” is a vital concept in Chinese culture, in which individuals are judged on their ability to act according to societal norms. “Face” is not only associated with individual behavior but also with the behavior of family members, and “losing face” means to suffer severe shame and embarrassment as well as judgment from society (Chiu, Yang, Wong, Li, & Li, 2012). Having a child with a genetic condition and associated disabilities could be a strong source of shame for the family, as it may imply that the parents have poor reproductive fitness. It could also negatively affect the mental health of the parents or primary caregivers, who may begin to internalize the shame that they feel and slowly lose confidence in their own worth to society (Chiu, Yang, Wong, Li, & Li, 2012). In addition, the stigma of a disability may pass quickly from an affected individual to the rest of the family, and so the family may try to ostracize or outcast the affected individual to protect their own “face” or social status (Chiu, Yang, Wong, Li, & Li, 2012). Thus, having a child with a disability or genetic condition not only means embarrassment to the family, but also the loss of a support network that may be vital to functioning in society. The fear and anticipation of such an event may motivate a couple to elect termination in order to stay protected within the family network. Historical government policies encouraging the creation of a “perfect family” through termination of affected pregnancies, sterilization after delivery of a child with a defect, and mandatory genetic testing for recessive conditions and birth defects may further contribute to a decision to terminate a pregnancy (Sleeboom-Faulkner, 2011; Su & Macer, 2005). These factors may explain why grandparents or other family members may pressure a couple to terminate an affected pregnancy.

Other Asian cultures have a similar concept as “face” and similar associations with stigma and disabilities. The effect of stigma may also extend beyond the family network. In Vietnam, when caregivers are stigmatized for “burdening” society with a child with a disability, they seek to minimize the shame that they feel, and so they tend to withdraw from society and limit their social interaction

(Ngo, Shin, Nhan, & Yang, 2012). One participant in the current study mentioned that she was aware of a family member in Singapore with a disability who was “kept inside the house” to avoid shame for the family. This kind of mindset leads to a lack of social exposure to disabilities in society, and thus to the absence of advocacy efforts which could lead to the creation of resources that may help individuals with disabilities (Scior, Addai-Davis, Kenyon, & Sheridan, 2012). One study showed that Asian families in the United States were less likely to try to access available resources and could not be counted on to support other families because of their insular methods for managing affected individuals (Choi & Wynne, 2000). Thus, for couples with affected pregnancies, it may be difficult to continue the pregnancy given the numerous cultural barriers which feed each other in a vicious cycle. The fear of “losing face” may also affect a risk assessment for a genetic condition in a medical setting, as a patient may be less likely to disclose embarrassing information about an affected family member. It may be helpful for genetic counselors and other medical providers to be aware of these factors when counseling Asian patients on termination decisions, while also keeping in mind that Asian patients may seek direction for information but not for emotional issues.

Although participants mentioned normalization of testing and recommendations for genetic testing within Asian cultures, not many participants discussed paternalism from medical providers in the context of termination. Religious and spiritual beliefs, family authority, social pressure, and available resources were the main factors influencing termination decisions. While one participant worried that doctors in Asia might encourage abortion, another provided anecdotal evidence that doctors were non-directive when it came to major pregnancy decisions. Another participant stated that a paternalistic approach to medicine could occur anywhere regardless of the country or culture, and so it is unclear whether paternalism affects termination decisions as much as genetic testing decisions.

A few participants from China mentioned that sex selection may influence termination decisions, stating that if the fetus was a boy, the family may keep the pregnancy even if affected, but if the fetus was a girl, even an unaffected girl, the family may terminate the pregnancy. Historically, Chinese parents have valued male children over female children (Pflaker, 2002); it is possible that being a male might

ameliorate the “loss of face” or stigma associated with disability. This may factor into termination decisions after disclosure of the baby’s sex from genetic testing, and it will be important for genetic counselors to be aware of this.

With the exception of sex selection, cultural factors influencing testing and termination decisions, as well as attitudes towards prenatal genetics, did not differ among participants based upon their country of ancestry. Distinguishing between attitudes from different regions of Asia was an initial motivation for this project. It is possible that this trend could not be teased out due to the limitations of the study discussed below, including the skewed and limited sample of participants.

Limitations

There are several limitations to this study. First, the findings of this study are not likely to be generalizable to the Asian population at large, as only 23 participants were interviewed in total. Three individuals were interviewed twice because the original recordings of their interviews were lost, and they may have changed their responses from the first interview.

All participants were recruited from cultural organizations for Southeast and East Asian individuals. Given their memberships in these organizations, they may have had a pre-existing interest in cultural issues and thus a higher interest in participating in the study. In addition, due to time constraints and logistical difficulties, participants were not selected to maximize demographic variation in the study population. All of the participants were well-educated and had a college degree or an advanced degree. Part of the selection criteria was that participants had to be English-speaking, which skewed the study population toward individuals who were likely highly acculturated and educated. Although income was not specifically assessed in the study, it is likely that most participants were relatively affluent as only two participants had public insurance. Additionally, most participants in the study had Christian beliefs or were atheist, and so there was little to no diversity in religious and spiritual beliefs that could have a significant effect on attitudes.

The interview guide consisted of a series of short vignettes followed by probe questions instead of direct questions about attitudes towards genetics. While the interview guide was piloted with six individuals prior to the start of the project, some of the probe questions may have been leading or confusing. The interviews also may not have exactly followed the interview guide and the study may be hard to reproduce. Depending on participant responses, the conversation may have gone down a different path or required clarifications of questions or answers. In addition, the interview questions were all hypothetical, and so they may not reflect what a participant's true attitudes towards prenatal genetics, although some participants related the questions back to their own experiences with pregnancy. Of note, over half of the participants had never experienced pregnancy.

Participants discussed cultural factors by comparing a hypothetical patient's prenatal care and prenatal genetic decisions in Asia and the United States, and the difference in location may not have corresponded exactly to differences in culture and society. Cross-cultural studies have recommended indirect approaches to communication as a way to approach the Asian population due to cultural values of "saving face," shame, and the importance of familiarity within relationships (Chen, 2003; Storti, 1994); thus, an indirect approach may have been more effective than a direct approach in gleaning information about participant attitudes and motivations. However, given the highly acculturated sample, participant answers about cultural factors could depend on which aspects of their culture they had individually chosen to incorporate in their lives in the United States rather than reflecting the global effect of cultural values upon attitudes towards prenatal genetics.

Conclusions and Future Directions

This study has implications for the clinical practice of genetic counselors. While the findings of the study may not be generalizable, it is important to note that for Asian patients, information and recommendations may serve as more effective ways to provide psychosocial support over a discussion of emotions. Directive counseling could relieve anxiety and stress with regards to the uncertainty of pregnancy and pregnancy decisions as well as foster trust in a counselor's expertise. Genetic counselors

may consider using self-disclosure as a way to connect with an Asian patient, given the importance of familiarity in relationships within Asian cultures. Counselors should also note that the cultural factors of shame, social stigma, family pressure, and availability of resources may all contribute to decision making for a pregnancy. In particular, a patient may also not disclose information about affected family members for fear of “losing face,” thus leading to an inaccurate risk assessment. A family may also view conditions associated with long-term care and mental disabilities as less acceptable than isolated physical defects which can be corrected. Counselors could anticipate these factors when discussing genetic conditions and testing and termination options. Although direct emotional support may not be an effective psychosocial strategy, incorporating discussion of cultural factors into the education portion of the session could be beneficial for patients. It could also be helpful to provide educational materials for a patient who seeks approval for a decision from family members who are not present at a session. Counselors should also recognize that religious and spiritual beliefs, as well as fatalistic perspectives, may override other factors in decision making and tailor their session accordingly.

Our findings describe an understudied patient population and suggest that there is a large and nuanced spectrum of factors that Asian-American women take into account when making decisions about genetic counseling, genetic testing, and termination of pregnancy. Religious and spiritual beliefs, cultural factors, and risk-benefit analysis play a role in influencing prenatal genetic decisions across a wide spectrum of ages, pregnancy histories, and countries of ancestry. The influence of cultural factors may differ depending on the society in which a patient receives health care. Recognizing these diverse factors will be important for tailoring prenatal genetic counseling sessions to a patient’s individual needs. Future studies can be performed to quantify the association between the various factors described in the study and specific pregnancy decisions.

APPENDIX

INTERVIEW GUIDE

1. Introduction

Hello, my name is [researcher]. How are you today? I'm calling you about the research study you read about/signed up for on ___[date listed on consent form]___. Do you remember reading about this? I am trying to look at if people who were raised with the beliefs and traditions of different countries make different kinds of decisions about going to the doctor when they are pregnant. Would you mind taking 45 to 60 minutes to speak with me?

2. Introductory questions

How are you doing today? How are your children doing? How is your family doing?

3. Rationale for the study

I'm a student at the University of Texas genetic counseling program. Genetic counselors are part of the medical team and they help people understand what genetic testing is and help people make decisions related to genetics. I grew up in an Asian household. My parents are from Taiwan, and they worked hard to teach me about the traditions and values that they grew up with. These included hard work, humility, and honoring authority. While I was in my first year in clinic here, when I was observing some counseling sessions, I noticed that I was being taught to approach patients very differently, in a way that would not really be appropriate in a clinic in Taiwan. This led me to think whether there were other differences that we could learn about, that would help us provide better counseling and better care to Asian patients in a medical setting. I'm talking to you and a few other women to try to get your insight on topics related to genetics and pregnancy. I really want your stories to be heard so that we can help doctors and nurses understand the women in your community and provide better experiences for the community. Before we begin, I wanted to get a little bit of information about you.

4. Demographic questions

- **Ethnicity:** It says here on the consent form you filled out that your native country or heritage country is [country/countries listed on consent form]. Is that correct?
- **Age:** Could you tell me how old you are?
- **Acculturation:** Were you born in the United States? (If no: How long have you lived in the United States? How many years has it been since you left [native country]?)
- **Religion:** Do you believe in any particular religion? Would you mind telling me what it is?
- **Pregnancy history:** Are you pregnant right now? Is this your first child? How many children do you have?

5. Explanation of questionnaire

I'm going to be telling you a story broken up into four parts. The story is based on an experience I had in clinic. I'd like to talk to you about these stories with you after each part. Maybe you might wonder what the person in the story should do, or what advice you might tell the person in the story. I understand that you may need some time to decide on your own response. I may also ask you some questions after your response to help me get a better understanding of your feelings. Before we begin, do you have any questions for me?

6. First Story: Problem with Pregnancy (ultrasound)

Our story centers around Ms. Lee, a patient who is a lot like you: [list patient's age, country of origin, acculturation details]. Ms. Lee was 20 weeks pregnant, and she was at her OB/GYN or doctor's office to get an ultrasound to scan every part of the baby's body. Have you heard of ultrasounds? [pause] They're a machine that lets you look at a picture of the baby inside the mom. Well, when the doctor got that picture of the baby, the doctor told her that there was a problem with the baby, and that the baby might have some problems after it was born. The doctor said that it could just be a physical defect, but it could also

affect the baby's mind and brain. It could be a condition that ran in Ms. Lee's family, but it was hard to tell with the picture from the ultrasound. Ms. Lee wasn't really sure what to do about this problem.

Follow up questions to first story:

- What would you say the next step would be for her?
- "You'd tell Ms. Lee....?"
- What do you think Ms. Lee needs in this situation? Emotional support, information, care from her family?
- Who else do you think Ms. Lee should talk to about this situation?
- How do you think the situation might be different if Ms. Lee were in [home country]?

7. Second Story: Genetic Counseling

The doctor suggested that Ms. Lee go see a genetic counselor, who's a specialist that explains genetic conditions, tests, and risks, because the problem on the ultrasound could be related to something genetic. That's what I'm training to do in school right now. A genetic change is a change that affects our body and changes parts of our body and mind. Sometimes these changes happen by chance when the baby is being created, such as Down syndrome or cleft lip and palate, and sometimes these changes are passed down from the parents to the baby, such as sickle cell disease or thalassemia diseases which affect the blood.

Follow-up questions to second story:

- Have you heard about, or do you know of, any genetic conditions in pregnancy you would be worried about for her? It could be something passed down through her family or something that happens by chance, like a physical defect.
- Which people in her life, like family members or anyone else, should Ms. Lee talk to before making any decisions about going to see the genetic counselor?
- What kinds of questions do you think she should ask the genetic counselor? What information do you think she needs?

- What kinds of decisions do you think Ms. Lee needs to make right now, before going to see a genetic counselor?
- Ms. Lee ended up going to see the genetic counselor. However, she didn't show up to her first scheduled genetic counseling appointment; the genetic counselor ended up seeing her on a rescheduled date. What do you think she was feeling or thinking about when she decided not to go the first time?

8. Third Story: Genetic Testing

At the appointment, the genetic counselor explained to Ms. Lee that she could get genetic testing for the pregnancy. The testing could give a better idea of whether or not the baby had a genetic condition and what type of genetic condition it was. The genetic counselor explained the different genetic things that could happen in pregnancy and what could or couldn't be done about them. The counselor also explained what genetic conditions might be dangerous to the mother, the baby, or both. Ms. Lee asked the genetic counselor what she should do. The genetic counselor said that it was Ms. Lee's choice and it seemed like Ms. Lee got more and more frustrated every time the genetic counselor said that.

Follow up questions to third story

- Is there anything you think the genetic counselor could have done differently to help Ms. Lee in this situation?
- Are there any conditions or problems with the pregnancy you think Ms. Lee should get the baby tested for? For example, we can test to see if the baby has Down syndrome and other conditions that happen by chance, and we can also test the baby for specific conditions that run in Ms. Lee's family.
- Some genetic tests just require a blood sample from the mother, but some of them need to take a little bit of fluid from around the baby which has some risks associated with it...do you think this would affect Ms. Lee's answer?
- How do you think the situation would change if Ms. Lee were in [home country]?

- Which people in her life, like family members, should she talk to before making any decisions about testing?

9. Final Story: Termination

Ms. Lee decided to get genetic testing and found out that the baby had a genetic condition that might cause problems in the baby's life. For example, a baby with trisomy 13 would be born with severe physical defects and intellectual disability.

Follow-up questions to final story

- What do you think she should do about her pregnancy? (Do you think it is appropriate for her to terminate the pregnancy?)
- What if she found the baby had a condition that runs in her family [can use example from interviewee] instead of trisomy 13?
- Do you think the answer would change if it were a physical defect that could be corrected by surgery?
- Who should she talk to after finding out about this news?
- Who does she need to talk to before making a decision about the next step?
- How do you think the decision would change if she were in [home country]?

10. Ending comments:

Thank you so much for taking the time to speak with me today. I can't thank you enough for providing your insight, and I'm sure that the conversation we had will help us to provide better health care to the [native country] community in the future. I hope health and happiness guide you and your family forward into the future.

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