South Asian Women's Perceptions of Prenatal Thalassemia Screening

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"Approximately 1.5% of the global population are heterozygotes (carriers) of the β-thalassemias" (De Sanctis et al., 2017). Affecting around 125 million people, Thalassemia is the most common genetic disorder worldwide. The National Library of Medicine defines thalassemia as a heterogeneous group of blood disorders affecting hemoglobin genes and resulting in a shortage of the red blood cells that are essential to survival (Bajwa & Basit, 2023). The disease ranges in severity; in more serious cases, carriers may not survive long after birth, or may require frequent blood transfusions throughout their life. Thalassemia is hereditary and at least one parent must be a carrier in order for their offspring to inherit it.

South Asians are genetically pre-disposed to higher susceptibility to thalassemia (De Sanctis et al., 2017). Historically, South Asian society has been largely endogamous; as prominent geneticist Partha P. Majumder notes, Indian society consisted of ranked caste and "little exchange of genes between castes, primarily due to strict social rules of marriage within the caste system" (Majumder, 2010). This limited gene flow has contributed to a significant lack of genetic differentiation among South Asian groups. Inherited diseases, such as thalassemia, thrive in these conditions; continued intermarriage within the same groups only increases the frequency of genetic disease. Consequently, a growing population of South Asian thalassemia carriers is passing the disease onto new generations.

In the light of modern medical treatments, the mortality rate for thalassemia has dropped considerably. Genetic counseling, where healthcare professionals educate families on hereditary risks and help them plan for healthier children, provides a way to eliminate genetic disease like thalassemia completely. However, cultural stigma and limited awareness prevent many families from accessing these resources.

Literature Review

The prevention of genetic disease is not a new concept. In the past, India implemented a mandatory premarital thalassemia screening. Premarital carrier screening is when the genetic histories of a couple are analyzed before marriage in order to see if their potential offspring would be healthy. However, instead of reducing the amount of children born with thalassemia, it merely created stigma, primarily against carrier women (Petrou et al., 2013). Carrier women were labelled unworthy for marriage and motherhood, which led to a fear of carrier testing as a whole (Petrou et al., 2013). Similarly, another study affirmed that being a known carrier of thalassemia disproportionately affected Bengali women's chances to find a suitable partner. As a result, parents simply avoided testing their daughters for genetic disease, believing that it would only harm their ability to find a suitor. The author described this situation as "an inherent conflict between the medically desirable course of action and cultural desirability of an 'unblemished, whole person'" (Chattopadhyay, 2006).

Another strategy used to prevent genetic disease pivots from premarital screening and focuses specifically on prenatal screening. This is the screening of the fetus instead of the parents. Prenatal carrier screening allows families to view all the reproductive options available to them, and to be able to plan a future without genetic disease. In 2022, molecular biotechnology researcher, Hayatul Khairul Rahmat, stated that prenatal screening is the most accurate method to pinpoint genetic disease in utero and to alleviate potential medical burdens upon families (Rahmat et al., 2022). As this technology becomes more affordable, it may prevent families from facing long-term treatment costs altogether. Rahmat and his colleagues emphasize the lack of awareness around prenatal screening as the main factor behind the

continued prevalence of genetic disease. However, their study failed to acknowledge the fact that the stigma associated with prenatal genetic counseling and ethical concerns around the termination of pregnancies diagnosed with lethal and non lethal genetic disease plays a large role in the number of families that choose to use prenatal genetic technologies.

Building upon this gap, many families see genetic counseling, testing and family planning as unethically tampering with the fetus. A 2017 study surveying Asian American women on their perception of prenatal genetic counseling, found that although many participants supported prenatal genetic counseling, they feared societal shame and perception (Young et al., 2017). This presents a major problem where even if a couple wants to undergo prenatal counseling, they may feel unable to pursue it. This is especially pronounced in South Asian society where many of the medical trends and cultural norms may be significantly more conservative than the Western standards. However, this study didn't go in depth to examine the deeper cultural causes of societal shame.

Additionally, there is considerable stigma surrounding individuals with thalassemia and blood disease in general. The stigma surrounding blood disease is especially apparent in South Asian society. In Hinduism, the most practiced religion in South Asia, blood is seen as a symbol of divinity and purity (Kutumbiah, 1956). When one is inflicted with a disease that seemingly affects the 'purity' of an individual's blood, it can lead to harmful stigma and incorrect notions about the people affected.

Although many studies have documented the prevalence of thalassemia and the cultural stigma surrounding blood disease and prenatal genetic testing, significant gaps still remain present. Most of these studies focus on individuals living in South Asia rather than immigrants. This opens up many other struggles such as language barriers, systemic discrimination and adjustment to Western healthcare norms. While broad research on Asian Americans exists, it rarely includes South Asian Americans, especially women, despite significant variation in the genetic makeup of populations across Asia. Very few studies explore how Asian American women perceive genetic counseling, and almost none measure how cultural stigma interacts with family expectations and modern reproductive autonomy. These gaps emphasize the need for research in this field.

This study will attempt to bridge the gap by answering the question, how do perceptions about prenatal thalassemia carrier screening differ among first generation South Asian American female immigrants living in the Portland Metropolitan Area in 2025?

I decided to research first generation South Asian Americans because this group is underrepresented in pre-existing research. First generation immigrants face unique adjustment challenges that lower their awareness of medical opportunities. I focused specifically on women because women are underrepresented in medical research, and prenatal carrier screening directly relates with reproductive autonomy. The Portland Metropolitan area provides a medically progressive context, and it was feasible for me to source participants from this area.

As a South Asian woman with thalassemia, I am personally interested in blood disease and cultural stigma. Culturally sensitive research on the South Asian female immigrant perceptions of prenatal thalassemia carrier screening can lead to a better understanding of the barriers preventing minorities from using modern medical technologies. This in turn can lead to impactful awareness and educational campaigns that can create a larger difference, because the research points at what to target. If these campaigns are successful, there will be reductions in the numbers of babies born with genetic disease and public health will improve.

I initially hypothesize that first-generation South Asian American women's perceptions of prenatal thalassemia carrier screening will be affected by not only their pre-existing knowledge on the topic, but also by cultural stigma. I believe that higher awareness will not fully eliminate the stigma, but rather mitigate its influence. I formed this hypothesis by looking at several similar pre-existing studies and trying to fit their results into the context of my study.

I plan on testing my hypothesis by using a mixed methods approach, combining both quantitative and qualitative data. I will use a survey method that uses the Likert Scale and I will conduct structured interviews and then use a thematic analysis on the interview transcripts.

Method

Thalassemia, genetic testing, and sharing one's opinion on healthcare ethics are sensitive topics, and I wanted to make sure that I accounted for that in my study. I researched different ways to acquire the data I wanted without making any participants uncomfortable and settled on a mixed-methods, two-part data collection process: a questionnaire followed by interviews. I wanted my questionnaire to be as uncomplicated as possible so as to not seem daunting to potential participants. I decided on a 7-point Likert scale style questionnaire that would provide the data I needed while not requiring participants to commit a large amount of time or effort. The 7-point Likert scale, developed by Rensis Likert at the University of Michigan, asks participants to rate their agreement with a statement using one of seven choices: "Strongly Disagree," "Disagree," "Somewhat Disagree," "Neither agree nor disagree," "Somewhat Agree," "Agree," and "Strongly Agree." I chose a 7-point scale over the traditional 5-point scale because it allowed for more granular feedback while keeping the simplicity of a multiple-choice survey.

The content of my survey consisted of various statements about thalassemia, genetic testing, and stigma. To ensure there was no bias or unethical phrasing, I connected with Dr. Gakhar at Washington State University. She reviewed my survey, pointed out which statements were problematic or could potentially cause discomfort, and helped me restate them in more considerate language. To acquire participants, I sent out links to an "Intent to Participate" pre-survey in several South Asian community group chats and posted flyers with QR codes in South Asian cultural centers. This pre-survey screened potential participants to make sure they fit my demographic. I asked questions such as, "Did you immigrate to the United States of America from a country in South Asia after you were older than 2 years of age?" and defined South Asia as consisting of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka, and Afghanistan. See Appendix A for a full list of questions. I also used the pre-survey to collect email addresses from all potential participants.

Once I received interest from 20 South Asian women who fit my target demographic, I started reaching out to them using the email addresses they provided. I re-introduced my study, reminded them that they had previously expressed interest, and sent an informed consent form for them to sign. After they emailed a signed copy back to me, I sent them the link to the actual questionnaire. To ensure I would be able to process all of my data in time, I decided to close the survey once I had 35 participants.

As I waited for participants to finish their surveys, I started working on the interview component. I decided to interview 6 participants to manage my time and pay more attention to their individual responses. To decide which participants would be interviewed, I put all of the

questionnaire respondents into a randomized name picker from wheelofnames.com. I used this tool to randomly pick 6 names and then reached out to them to ask if they would be willing to participate in a 25-minute structured interview. I explained that these interviews would allow for a more in-depth exploration of their thoughts, beliefs, and experiences. I repeated this process until I had 6 willing participants. I sent out another consent form for them to sign and began working with each participant to fit the interview into our schedules. Before conducting any interviews, I sent my list of questions to Dr. Gakhar and got them approved. See Appendix B for the full list of interview questions. I also practiced my introduction and question delivery before my first real interview.

I recorded each interview using meeting software for online sessions or my phone's recording app for in-person meetings. I then used the speech-to-text tool on Google Docs to transcribe each recording. I structured the interviews by placing the most important questions at the beginning to guarantee I received answers to them. To respect both my own and my participants' time, I practiced with a fellow AP Research student to ensure the session stayed around 25 minutes. I decided on 11 questions so participants had roughly two minutes to think about each answer.

Since each interview was transcribed, I conducted a thematic analysis to identify recurring ideas or patterns. I analyzed the questionnaire data by putting it into a Google Sheet, where I calculated the precise numbers for each question and created graphs and tables. I also used a coding program to look for recurring words and themes in the interview transcripts. This helped me generalize the findings and understand the major barriers preventing South Asian immigrant women from getting screened. For example, many participants mentioned a stigma-related barrier, specifically regarding the stigma of being diagnosed with a genetic disease in the South Asian community. I was able to recognize this across the interviews and compare it with the survey results. This process aligns with my research question by acting as a two-step verification process, which helps point toward future research and initiatives. The purpose of my study is to empower South Asian immigrant women to use their resources and be aware of diseases that they and their offspring are susceptible to; this method of data analysis helps me accomplish that.

Findings

Before analyzing my survey data, I grouped all questions into one of four categories: knowledge about prenatal thalassemia carrier screening, attitude towards prenatal thalassemia carrier screening, cultural beliefs and prenatal thalassemia carrier screening and trust in the healthcare system/access to prenatal thalassemia carrier screening. Numbers were assigned to my Likert Scale to turn responses quantitative: Strongly Agree was a seven out of seven, while Strongly Disagree scored a one out of seven.
Descriptive statistics for each construct are presented in Table 1.

Table 1
Descriptive Statistics for Study Variables (N = 34)

Construct Variable	*M*	*SD*
Knowledge about	4.35	0.88

thalassemia		
Attitudes toward screening	5.22	0.34
Cultural beliefs	4.46	1.06
Trust & Access	4.33	0.53
Willingness to get screened	4.38	1.41

The descriptive statistics showed that participants generally held positive attitudes towards the idea of prenatal thalassemia carrier screening (M = 5.22, SD = 0.34). Knowledge about thalassemia (M = 4.35, SD = 0.88), cultural beliefs (M = 4.46, SD = 1.06), trust and access to healthcare (M = 4.33, SD = 0.53), and willingness to pursue screening (M = 4.38, SD = 1.41) all showed moderate average scores.
I conducted a Pearson Correlation Analysis to examine relationships between knowledge, attitudes toward screening, cultural beliefs, trust and access to healthcare services, and willingness to pursue prenatal thalassemia carrier screening.
The results are presented in Table 2.

Table 2

Correlations Between Study Variables

Predictor	***r value***	***t value***	***p value***
Knowledge → Willingness	0.599	4.23	0.00018
Attitudes → Willingness	0.502	3.29	0.00247
Culture → Willingness	0.526	3.50	0.00139
Trust/Access → Willingness	0.592	4.16	0.00022

Knowledge about thalassemia and genetic testing was positively correlated with willingness to undergo screening, $r(32) = .60$, $p < .001$. Attitudes toward prenatal screening were also significantly related to willingness, $r(32) = .50$, $p = .002$. Cultural beliefs demonstrated a significant positive relationship with screening willingness, $r(32) = .53$, $p = .001$. Finally, perceived trust in healthcare providers and access to screening services was significantly correlated with willingness to undergo testing, $r(32) = .59$, $p < .001$.

To support my survey findings, semi-structured interviews were conducted with six participants. These interviews provided additional context to understand perceptions of prenatal thalassemia carrier screening. Interview responses were coded and grouped into recurring themes based off on patterns across the participant's responses.

Three main themes emerged from the interview data: cultural considerations in genetic decision-making, knowledge and awareness of thalassemia screening, and trust in healthcare providers and access to information

Table 3

Qualitative Themes Identified in Participant Interviews.

Theme	Description
Cultural considerations	Family expectations and community beliefs that influence screening discussions
Knowledge and awareness	Differences in familiarity with thalassemia and carrier screening
Trust and healthcare experiences	Perspectives on communication with healthcare providers

Cultural Considerations

All six participants spoke about cultural or family influences when discussing genetic screening decisions. Participants described how family involvement and community beliefs can influence the conversations about genetic conditions and reproductive decisions. One participant expressed, “In our community people worry a lot about how a serious genetic condition could affect like marriage prospects” (Participant 3).

Knowledge and Awareness

Participants reported varying levels of familiarity with thalassemia and genetic carrier screening. Some participants had prior knowledge due to personal or family experiences, while others showed limited awareness prior to learning about the topic. For example, Participant 1 shared, “I am a doctor, so I am very familiar with thalassemia and carrier screening in general, although I myself never got screened before having kids” (Participant 1). In contrast, Participant 4 stated “I’ve heard of the words before but like, before this study I would not have been able to tell you anything about them” (Participant 4).

Trust and Healthcare Experiences

Participants also discussed their experiences with healthcare providers in the Portland Metropolitan Area and their level of access to information about genetic testing. Their responses included perspectives on how comfortable they felt communicating with healthcare professionals as well as ease in discussing genetic conditions within medical settings. Participant 2 claimed that, “Doctors don’t always understand our community” (Participant 2).

Discussion

The purpose of this study was to examine how first-generation South Asian American women in the Portland Metropolitan Area perceive prenatal thalassemia carrier screening; specifically focusing on how knowledge, attitudes, cultural beliefs, and trust in healthcare systems relate to willingness to undergo screening. The findings show that the perceptions of prenatal carrier screening are influenced by all of the factors listed above interacting with one another. While the majority of participants generally demonstrated moderately positive attitudes toward prenatal screening, cultural beliefs, knowledge levels, and trust in healthcare systems all played a significant role in shaping willingness to pursue genetic testing. These findings support my hypothesis that awareness alone does not fully eliminate stigma surrounding prenatal thalassemia carrier screening but reduce its influence when combined with supportive healthcare environments and culturally sensitive communication.

The quantitative analysis showed statistically significant positive correlations between all four of the predictor variables and willingness to undergo prenatal carrier screening. The knowledge group demonstrated a moderate positive relationship with willingness to pursue screening ($r = .599$, $p < .001$), suggesting that individuals with greater understanding of genetic disease and prenatal carrier may feel more prepared to consider preventative medical technologies. Participants with higher and stronger knowledge scores might have felt more confident about evaluating the potential benefits and drawbacks of prenatal screening. This reduces the uncertainty that could otherwise act as a barrier to screening. This finding aligns with the 2022 study by Hayatul Khairul Rahmat, which emphasized that the lack of awareness about available genetic testing services most significantly contributes to the continued prevalence of genetic diseases such as thalassemia (Rahmat et al., 2022). However, the moderate correlation strength suggests that knowledge alone does not fully explain screening decisions. This illustrates that informational interventions and awareness campaigns may need to be combined with culturally responsive approaches.

Attitudes toward prenatal screening were also positively correlated with willingness to undergo testing ($r = .502$, $p = .002$). Participants who viewed screening as beneficial for family planning or medically useful were more likely to express willingness towards using genetic technologies. This relationship supports the 2021 study conducted by Jennifer L. Young and her colleagues, which indicated that perceptions of medical utility influence preventative health behaviors (Young et al., 2021). Positive attitudes toward screening might demonstrate trust in modern science, scientific advancement or in the value of early intervention. However, the strength of this correlation suggests that attitudes are shaped by surrounding contextual factors, such as ingrained cultural beliefs and perceived social consequences of negative screening outcomes.

Cultural beliefs demonstrated a significant positive correlation with willingness to pursue screening ($r = .526$, $p = .001$). Although the quantitative data suggests that cultural perceptions and beliefs do not bar families from pursuing screening entirely, the qualitative interview responses indicated that cultural expectations may complicate decision-making processes. My participants frequently spoke about the role of family, marriage expectations, and perceived

judgment from their community when discussing genetic conditions. For example, one participant shared their concerns about how genetic diagnoses and procedures might influence social perceptions and their family's reputation. This reflects themes present in the 2013 study conducted by referenced in my literature review that stated that stigma surrounding hereditary conditions heavily influence reproductive decision-making (Petrou el al., 2013). When a culture has norms emphasizing family reputation or social expectations, it may create conflict between medically recommended actions and 'socially acceptable' behavior.

Trust in healthcare providers and access to screening resources also demonstrated a moderately positive relationship with willingness to undergo prenatal carrier screening ($r = .592$, $p < .001$). Participants who reported greater trust in healthcare professionals or easier access to screening services were more likely to express willingness to pursue testing. The interview data provided additional context for this finding, as many participants discussed communication barriers or uncertainty about whether the majority of healthcare providers fully understood the cultural background of an immigrant. Based on the findings, worries about cultural misunderstanding frequently contribute to hesitation when considering genetic counseling services. This suggests that improving provider cultural competency may help increase confidence in screening programs and reduce perceived barriers to participation.

The qualitative interview results supported the quantitative findings by helping to identify three recurring themes: cultural considerations in thalassemia screening decision-making, variation in knowledge and awareness of thalassemia screening, and trust in healthcare providers. All of the participants described how family expectations and community beliefs can influence the conversations surrounding reproductive decisions, in a negative way. Even among the individuals who expressed positive attitudes toward screening, social stigma remained a large concern. This supports previous research suggesting that stigma associated with genetic disease may persist even when individuals understand the medical benefits of testing (Young et al., 2021). Interview responses also demonstrated the variability and differences in knowledge levels. This reinforced the quantitative finding that the level of awareness is not uniform across participants and depends on a multitude of factors. The differences in familiarity with medical terminology among the interview participants suggest that access to culturally appropriate educational resources about healthcare may play a role in shaping perceptions of screening.

These findings have important implications for public health communication and healthcare accessibility. Increasing awareness about prenatal carrier screening may improve understanding of thalassemia and genetic disease prevention, but informational efforts alone may not fully address cultural concerns related to stigma or family expectations. It is impossible to fully change cultural norms that have been ingrained for generations, but educational initiatives that collaborate with community organizations or cultural leaders may help ensure that information about genetic screening is communicated in ways that respect cultural values. Healthcare providers will also benefit from additional training on culturally sensitive communication practices, particularly when discussing delicate topics related to reproductive health and genetic testing. In general, improving patient-provider trust may increase comfort when discussing genetic risk factors and reproductive decision-making options.

Several limitations should be considered when interpreting the results of this study. The relatively small sample size (N = 34) limits the generalizability of my findings, as the results may not represent the perspectives of all first-generation immigrant South Asian American women. Additionally, participants were recruited from a single geographic region, which may influence perceptions due to regional healthcare accessibility or cultural community dynamics. All of the participants in my study also received some form of tertiary education which may skew results, as not all first-generation immigrant South Asian American women have access to education beyond high school. Self-reported survey responses and interviews may also introduce response bias, as participants may have selected answers that reflect socially acceptable or politically correct views rather than their actual personal beliefs. Furthermore, while correlation analysis is able to identify relationships between variables, it does not necessarily establish causation. Additional research using experimental or longitudinal designs would definitely help clarify causal relationships between cultural beliefs, knowledge, and screening decisions.

Future research should expand on this study by including larger and more diverse participant samples across multiple geographic regions and even beyond immigrants in the United States. Additionally, comparative research examining differences between first-generation and second-generation immigrants may provide further insight into how cultural adaptation and assimilation into western healthcare norms influences perceptions of genetic testing. Additional qualitative research exploring how families discuss genetic risk may also contribute to a more complete understanding of how stigma develops and how to reduce it. Further investigation into culturally responsive and sensitive educational strategies will help identify effective methods for improving awareness of prenatal screening for thalassemia without reinforcing the cultural stigma associated with genetic disease.

Future Directions

The goal of this study was to answer the research question: *How do perceptions about prenatal thalassemia carrier screening differ among first-generation South Asian American female immigrants living in the Portland Metropolitan Area in 2025?* The findings indicate that willingness to pursue prenatal thalassemia carrier screening is shaped by the interaction of knowledge, attitudes, cultural beliefs, and trust in healthcare systems. While prior research usually singles out a lack of awareness as the primary barrier to genetic screening, the results of this study show that it is not only awareness that accounts for decision-making processes. Instead, perceptions of prenatal thalassemia screening seem to emerge from a complex mix between cultural identity, family expectations, perceived social consequences, and confidence in healthcare providers and institutions. By examining these interacting variables, this study contributes to a more complete understanding of how cultural context influences the use of preventative genetic technologies among immigrant populations.

Before collecting data, my expected end result of this study was to find out whether cultural stigma meaningfully influences reproductive decision-making related to thalassemia. My initial hypothesis proposed that higher knowledge levels would correlate with greater willingness to pursue prenatal screening, but that stigma would also influence perceptions even when the participant was well informed about thalassemia and genetic testing. The results supported the hypothesis, but also revealed a more nuanced relationship between variables than I had

originally expected. Although the correlations that were observed were statistically significant between knowledge, attitudes, cultural beliefs, trust in healthcare, and willingness to pursue screening, since the strength of these relationships was moderate, it leads me to believe that no single factor independently explains decision-making behavior. Instead, the findings indicate that willingness to engage in prenatal carrier screening is influenced by overlapping social, cultural, and informational considerations.

One important implication of this study is that increasing awareness about thalassemia alone may not substantially increase screening participation and overall public well being unless the educational initiatives also address cultural concerns related to stigma and reproductive autonomy. Previous research has emphasized informational deficits as a primary explanation for low screening rates, particularly in developing regions. However, this study suggests that within immigrant populations, knowledge works hand in hand with concerns about social perception, family reputation, and perceived cultural expectations. This finding builds upon prior literature by demonstrating that cultural beliefs continue to influence medical decision-making even in increasingly medically progressive environments such as the Portland Metropolitan area. As a result, public health interventions that focus exclusively on distributing scientific information and facts overlook the social barriers behind low participation in preventative genetic screening.

The results of this study highlight the importance of culturally responsive healthcare communication. Participants frequently referenced concerns about whether healthcare providers truly understood the cultural context surrounding genetic disease and reproductive decisions. This illustrates that improving provider cultural sensitivity may strengthen patient-provider trust and increase comfort discussing sensitive topics such as reproductive autonomy. Healthcare practitioners, public health educators, and genetic counselors may benefit from these findings when thinking of how best to connect with their patients. Training programs that incorporate cultural awareness when discussing hereditary conditions could improve communication quality and increase the likelihood that patients feel respected and safe when navigating loaded medical decisions.

Policy implications may also emerge from this research. Public health agencies should consider implementing targeted educational initiatives that collaborate with South Asian cultural organizations, religious institutions, or community leaders to ensure that information about prenatal carrier screening is presented in a culturally sensitive manner. Rather than presenting screening as just a medical intervention and an invasive procedure, framing genetic counseling as a tool that supports informed decision-making might reduce concerns related to stigma or societal judgment. Policies that support access to translated educational materials, culturally sensitive counseling services, and affordable screening technologies may help combat the structural barriers related to healthcare participation among immigrant populations.

Further research may also explore differences between first-generation and second-generation South Asian Americans. Second-generation individuals may experience different levels of cultural integration and familiarity with Western healthcare systems, potentially influencing perceptions of prenatal genetic screening. Comparative studies between generational groups could reveal whether cultural stigma surrounding blood disorders persists across generations or whether assimilation into Western medical frameworks alters attitudes toward genetic testing.

Understanding generational differences could inform the development of outreach strategies that better reflect the needs of specific communities.

Overall, this research contributes to the broader academic conversation about the intersection of cultural norms and healthcare decision-making. By demonstrating that perceptions of prenatal thalassemia carrier screening are shaped by the interaction of knowledge, cultural beliefs, and trust in healthcare institutions, this study expands on existing research that often focuses primarily on informational barriers. The findings suggest that future public health initiatives should consider both informational and cultural factors when designing interventions aimed at increasing participation in genetic screening programs and improving health literacy.

The significance of this study lies in its examination of how minority populations engage with preventative medical technologies. The body of literature looking at disparities in healthcare is growing and this study adds to it. The results highlight the importance of culturally responsive healthcare communication and suggest that future research should continue exploring how social norms influence medical decision-making processes. By identifying the ways in which cultural stigma, knowledge, and trust overlap with one another, this research provides a base for future investigations seeking to improve health literacy and access to genetic counseling services while reducing the prevalence of hereditary blood disorders.

References

1. Bajwa, H., & Basit, H. (2023). *Thalassemia*. Nih.gov; StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK545151/
2. Chattopadhyay, S. (2006). 'Rakter dosh'—corrupting blood: The challenges of preventing thalassemia in Bengal, India. *Social science & medicine*, *63*(10), 2661-2673.
3. De Sanctis, V., Kattamis, C., Canatan, D., Soliman, A. T., Elsedfy, H., Karimi, M., ... &
4. Angastiniotis, M. (2017). β-thalassemia distribution in the old world: an ancient disease
5. seen from a historical standpoint. *Mediterranean journal of hematology and infectious*
6. *diseases*, *9*(1), e2017018.
7. Kutumbiah, P. (1956). The concept of heart and blood vessels in ancient Hindu medicine. *Journal of Indian Medical Heritage*, *1*(1), 11-20.
8. Majumder, P. P. (2010). The human genetic history of South Asia. *Current Biology*, *20*(4), R184-R187.
9. Petrou, M., Old, J., Traeger-Synodinos, J., Galanello, R., & Angastiniotis, M. (2013). Prevention of thalassaemias and other haemoglobin disorders. *Thalassaemia International Federation Publications*, *2*, 113-116.
10. Rahmat, H. K., Fajrian, A., & Ma'rufah, N. (2022). Preventing Genetic Diseases
11. Through Genetic Counseling to Build a Harmonious Family: a Narrative Review. In
12. *International Conference on Islamic Guidance and Counseling* (Vol. 2, pp. 110-119).
13. Young, J. L., Mak, J., Stanley, T., Bass, M., Cho, M. K., & Tabor, H. K. (2021). Genetic
14. counseling and testing for Asian Americans: a systematic review. *Genetics in Medicine*,
15. *23*(8), 1424-1437.

Appendix A

I know what thalassemia is.

I understand why prenatal thalassemia carrier screening is done.

I would not want my child to marry someone with thalassemia.

I feel confident in my understanding of genetic testing in general.
Prenatal thalassemia carrier screening is important for expecting parents.

I believe screening can help families make informed decisions.
I would consider getting prenatal thalassemia carrier screening if I was expecting a child.
I trust that screening results are accurate.

My cultural or family beliefs influence my views on genetic testing in a positive way
I feel comfortable talking about genetic conditions within my family.
I feel that genetic testing services are easy to access in my community.

Language barriers prevent me from fully understanding genetic testing.
I would need more information before deciding to get screened.
I know where to go if I want to get tested.

I feel comfortable asking doctors questions about genetic screening.
I believe healthcare providers understand the needs of South Asian immigrants.
I am open to learning more about prenatal thalassemia carrier screening.
Living in the Portland Metropolitan Area makes me more open to preventive health care like genetic testing.

Appendix B

What have you heard about thalassemia or thalassemia carrier screening?

How familiar do you feel with prenatal genetic testing in general?

How do you feel about prenatal thalassemia carrier screening?

What factors would make you more or less likely to get screened?

In what ways do your cultural or family beliefs shape your views about genetic testing?

How comfortable do you feel talking about genetic conditions in your family or community?

How would you describe your experiences with healthcare providers in the Portland area?

Do you feel healthcare providers understand the needs of South Asian immigrant women? Why or why not?

What challenges or worries might you have about getting prenatal carrier screening?

Are there any things that might make it difficult for people in your community to get tested?

What information would help you feel more confident about genetic testing?

How would you prefer to learn about prenatal thalassemia screening or modern medical technology in general (doctor, community groups, online, etc.)?

Do you feel that living in the Portland Metro Area affects how you think about preventive health care or genetic testing? If so, how?