

Exploring the Needs of the Asian and Pacific Islander Population

QUANTITATIVE FINDINGS

May 2025



Asian Family Caregiver Insights

Research Overview

Transcend Strategy Group conducted a nationwide survey of family caregivers who identify as a member of the Asian or Pacific Islander population. Participants experienced the death of a loved one and/or were involved in healthcare decisions for a loved one in the past five years.

METHODOLOGY

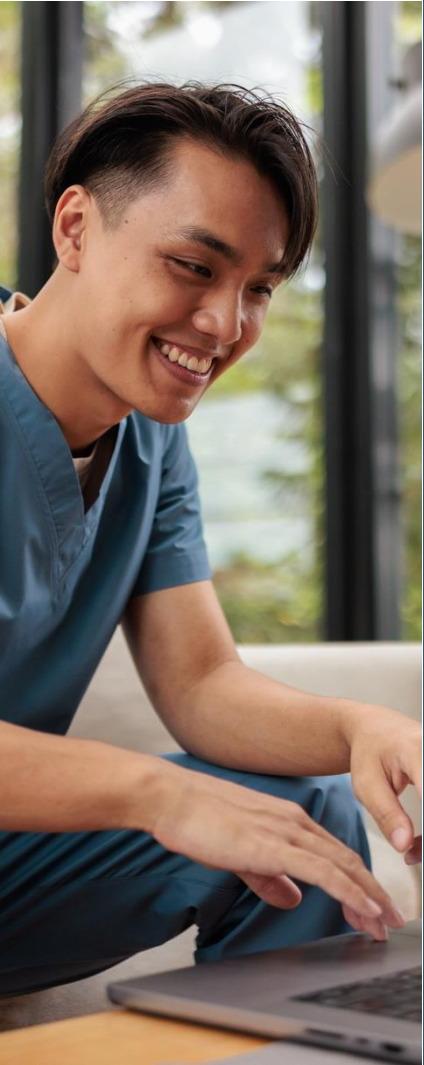
Online surveys with adults ages 25 years and older

SAMPLE SIZE

Showing results from 400 individuals

DATA COLLECTION

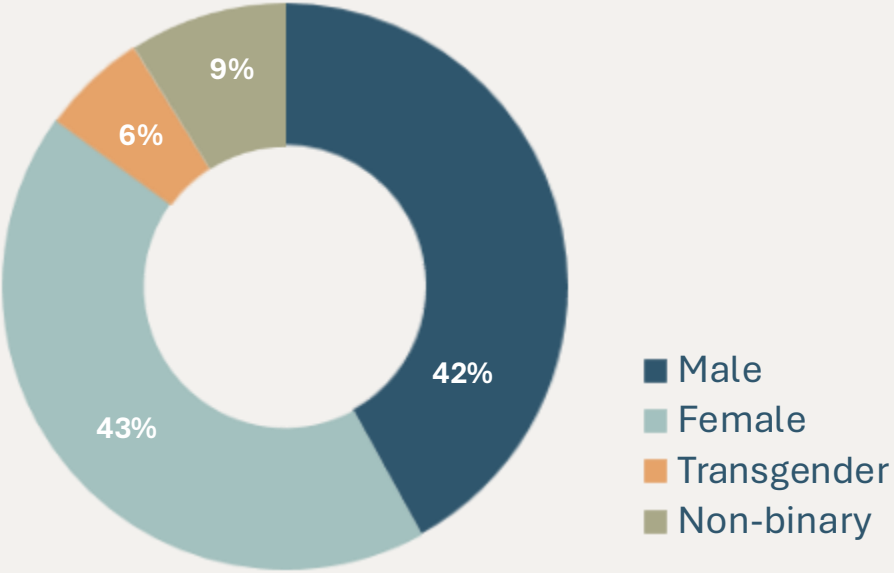
Survey fielded from July through August 2024



Respondent Profile

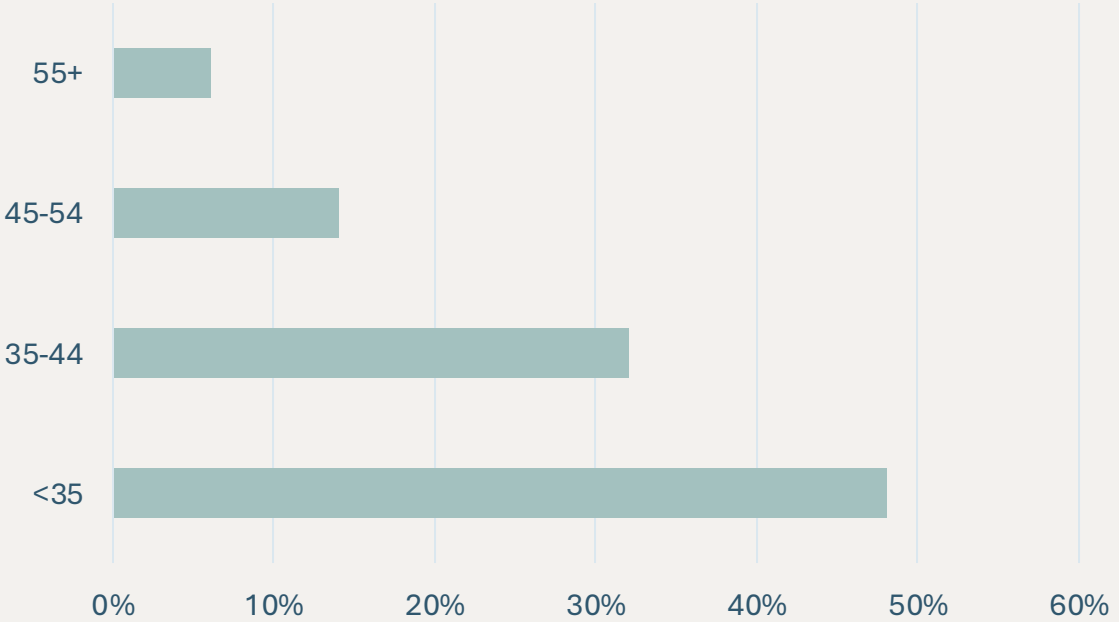
Total Respondent Profile (n=400)

GENDER



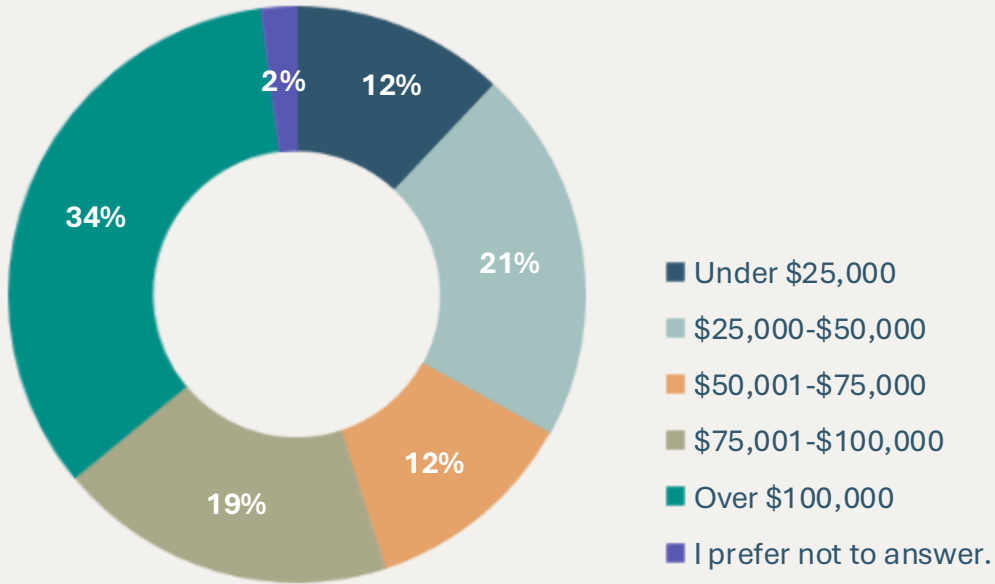
Total Respondent Profile (n=400)

AGE



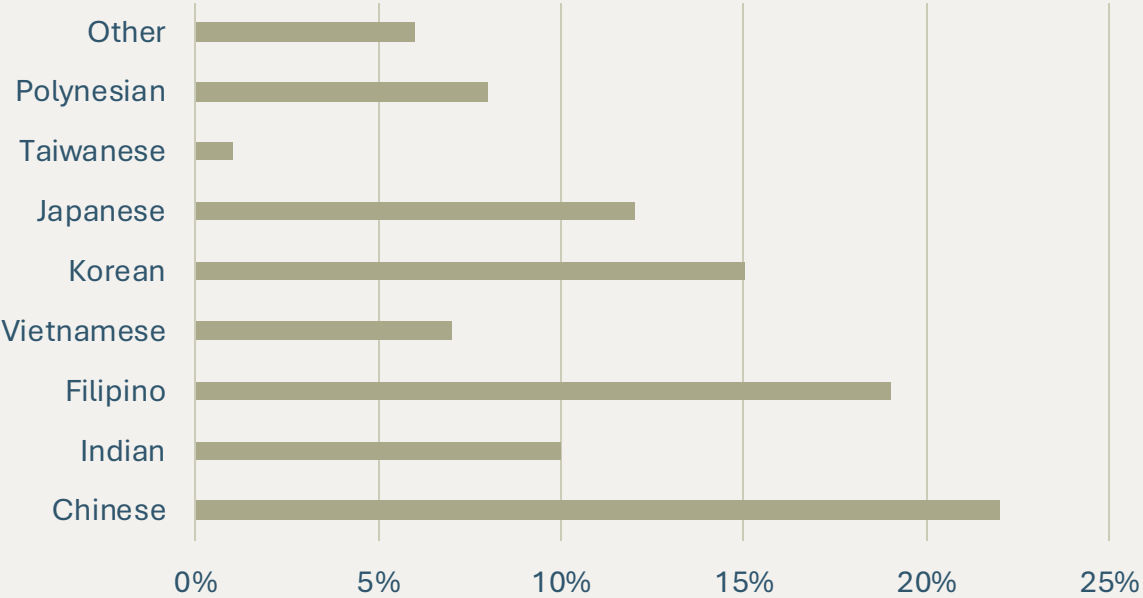
Total Respondent Profile (n=400)

HOUSEHOLD INCOME



Total Respondent Profile (n=400)

IDENTITY

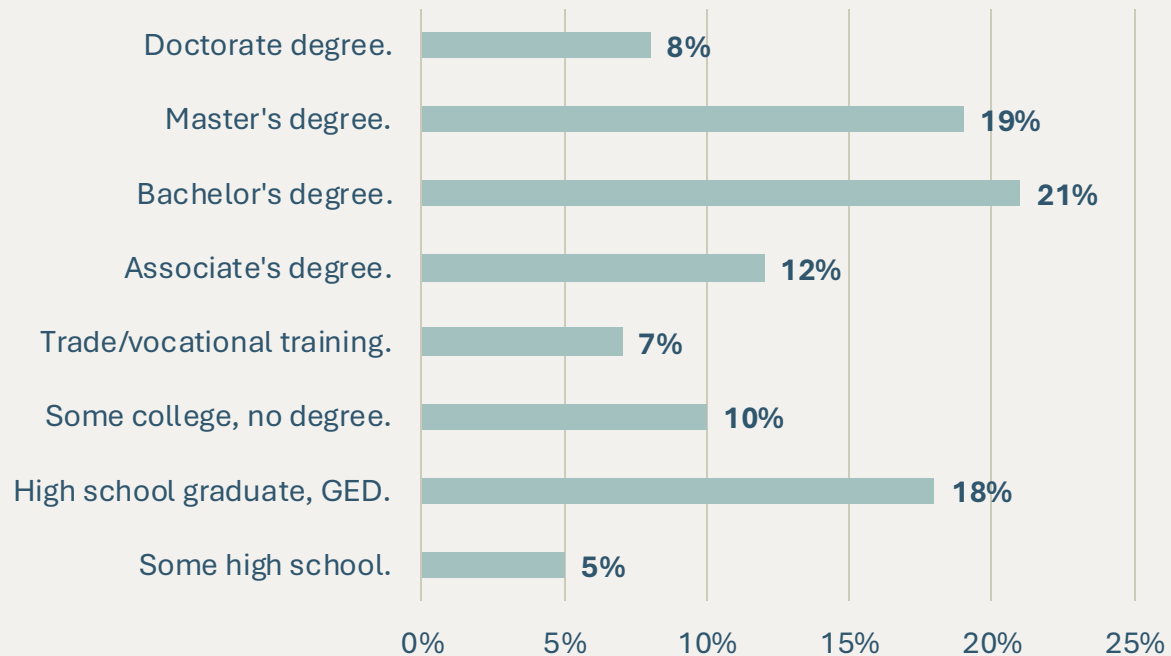


*Hmong and Pakistani were the ethnicity's listed under "other".



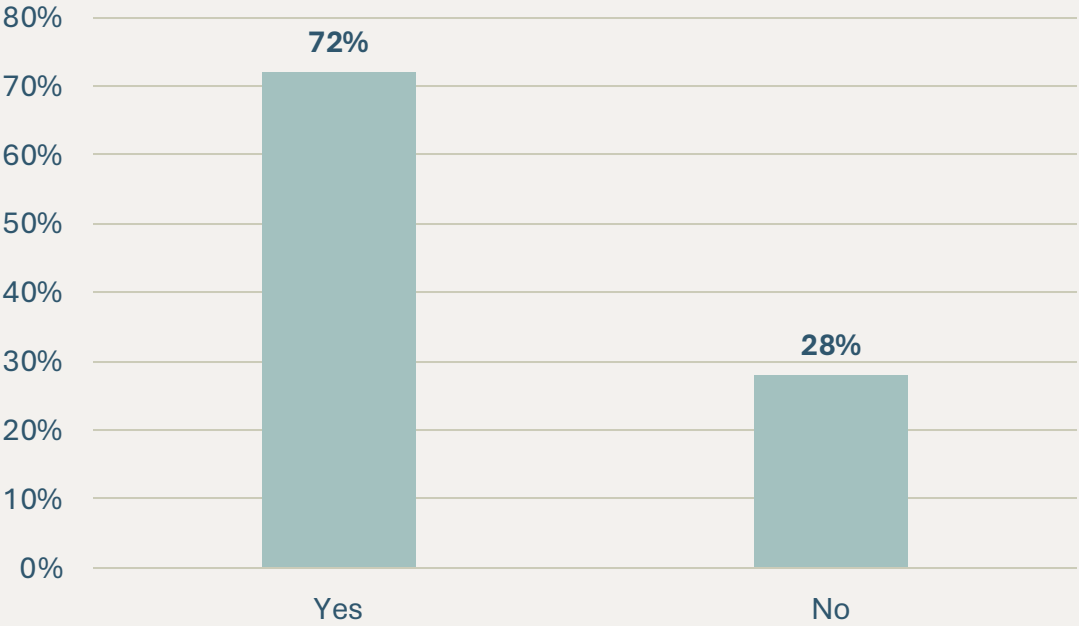
Total Respondent Profile (n=400)

EDUCATION

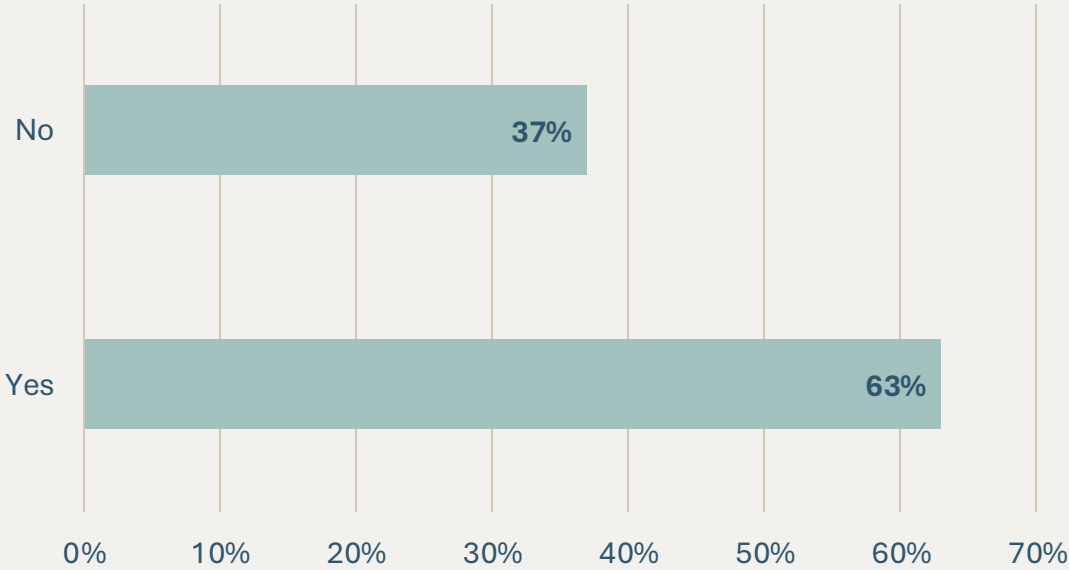


Total Respondent Profile

Experienced the death of a close family member/friend in the past five years.

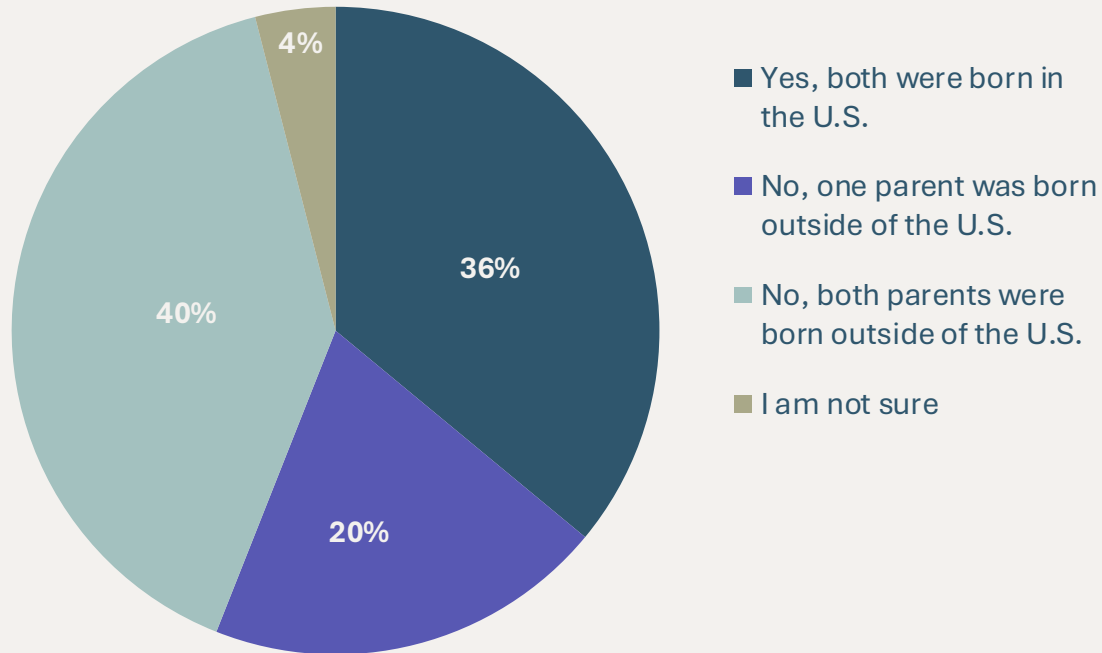


Involved in the healthcare decisions of an aging adult living with a serious illness in the past few years.

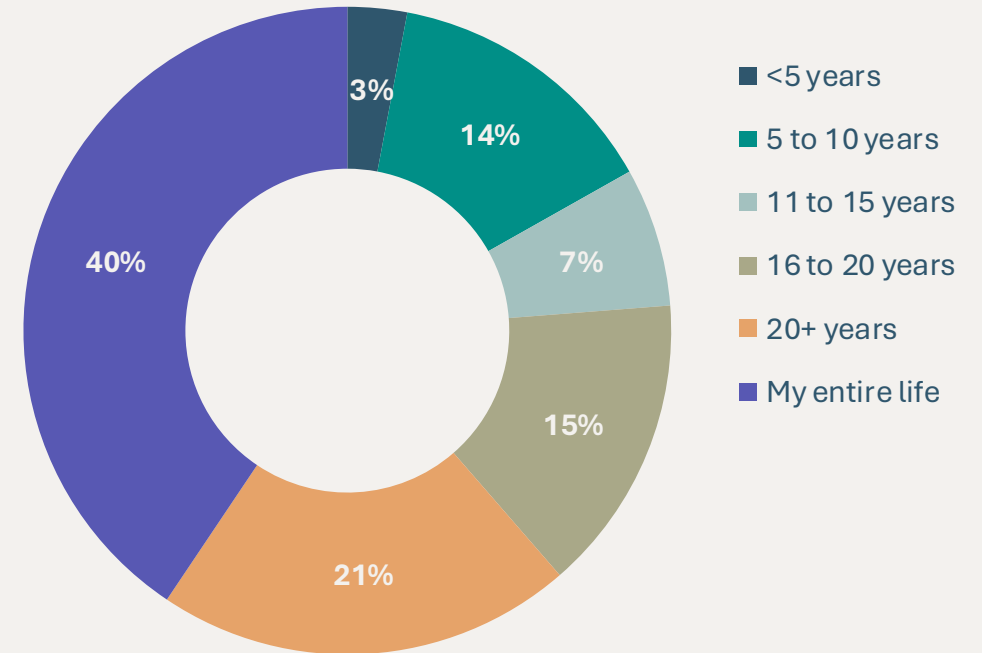


Geographical Background

Were both of your parents born in the United States?



How long have you lived in the United States?

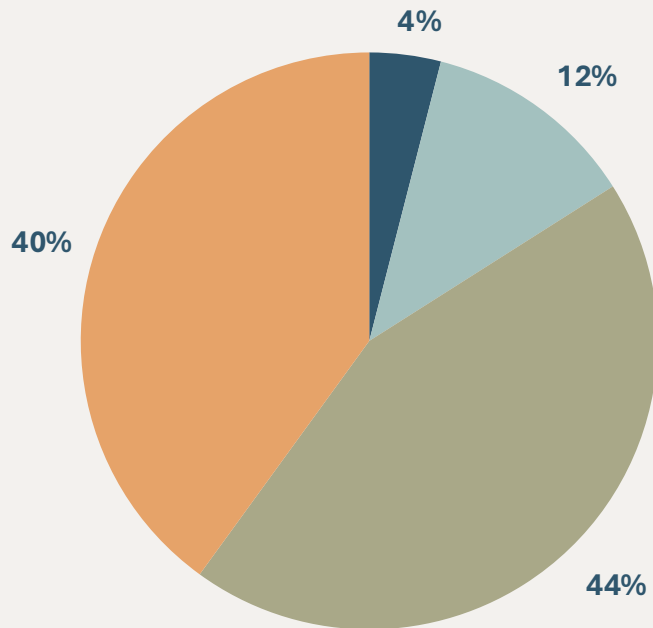




Caregiver Healthcare Experiences

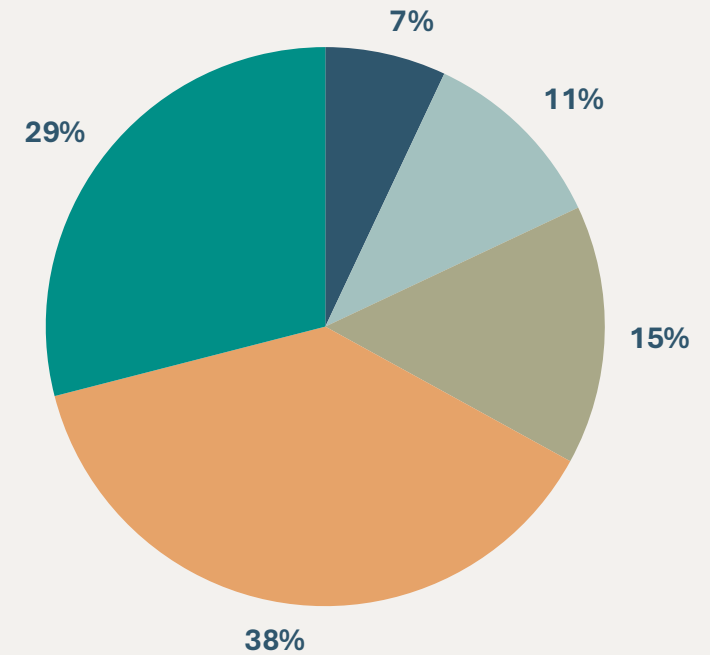
Current Healthcare Engagement

I have a primary doctor that I trust.



■ Slightly Disagree ■ Not Sure ■ Slightly Agree ■ Strongly Agree

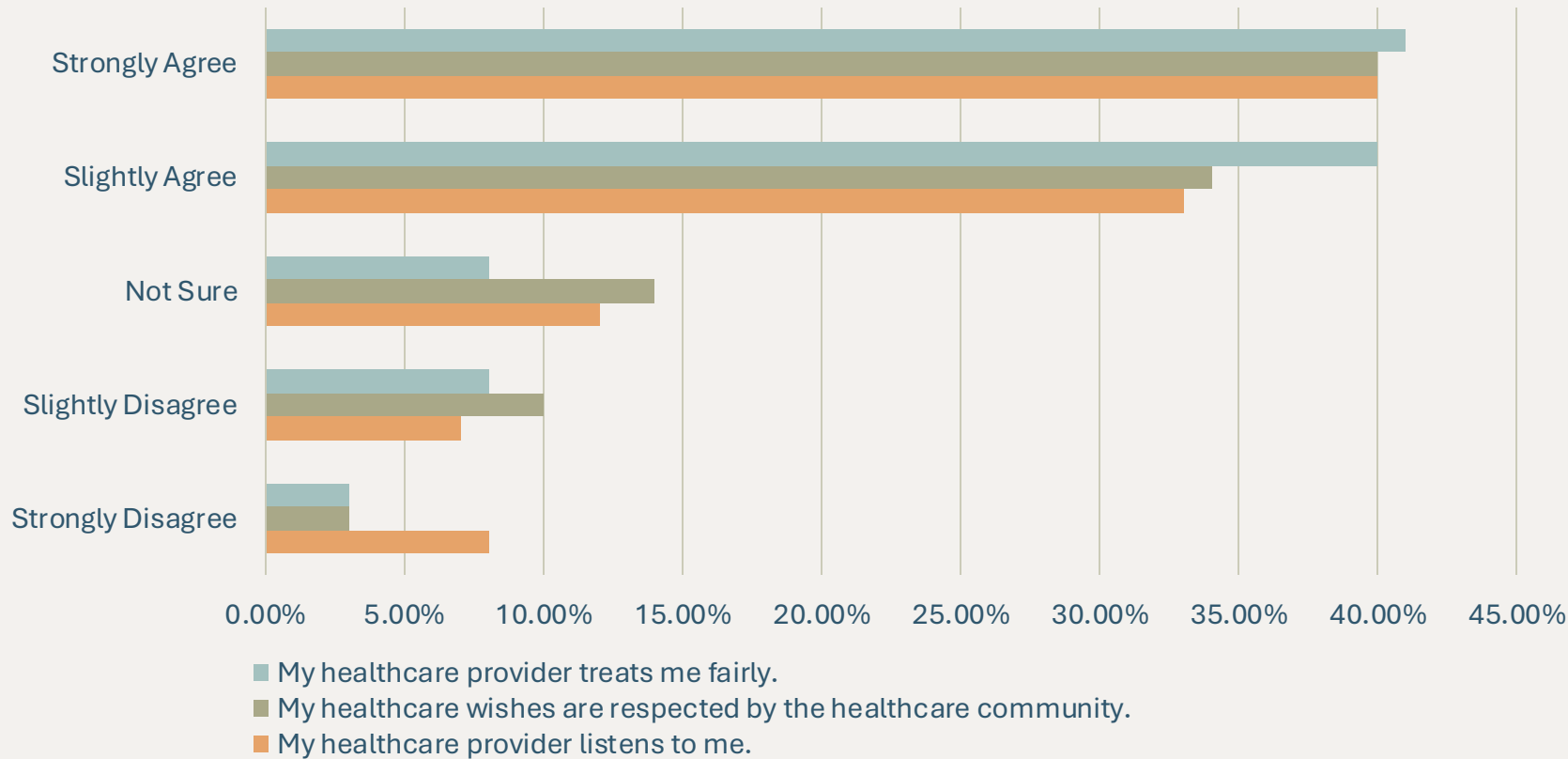
I have access to high-quality doctors.



■ Strongly Disagree ■ Slightly Disagree ■ Not Sure
■ Slightly Agree ■ Strongly Agree

Current Healthcare Engagement

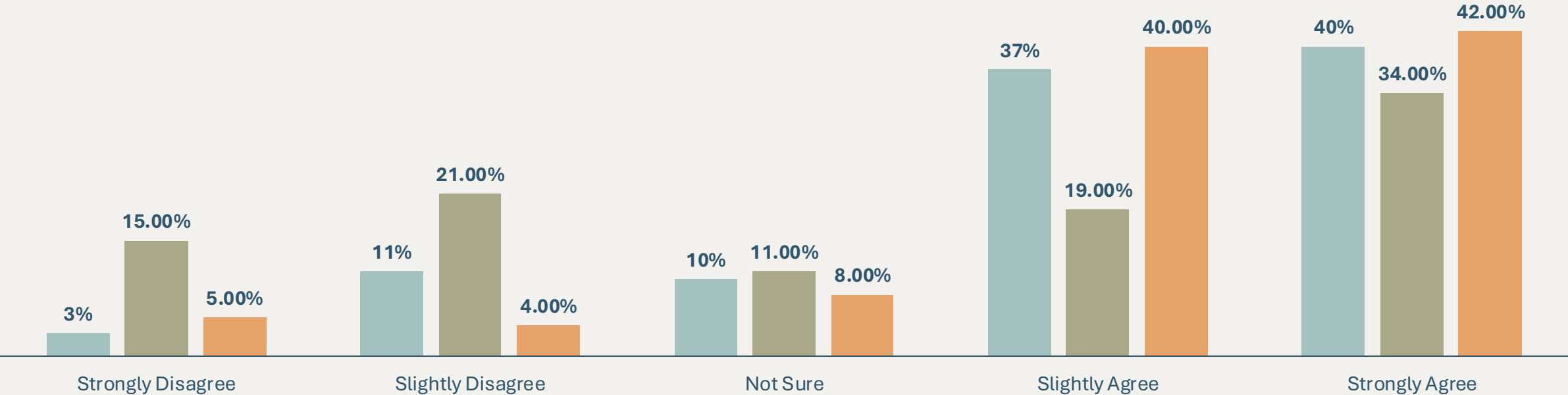
Provider Respect.



There were no significant differences in responses based on age, gender, or ethnicity.

Asian Family Caregivers Generally Have Positive Interactions with Healthcare Providers.

- My healthcare providers offer treatments that respect my wishes and cultural background.
- Healthcare providers ask about my sexual identity.
- Healthcare providers respect my sexual identity.

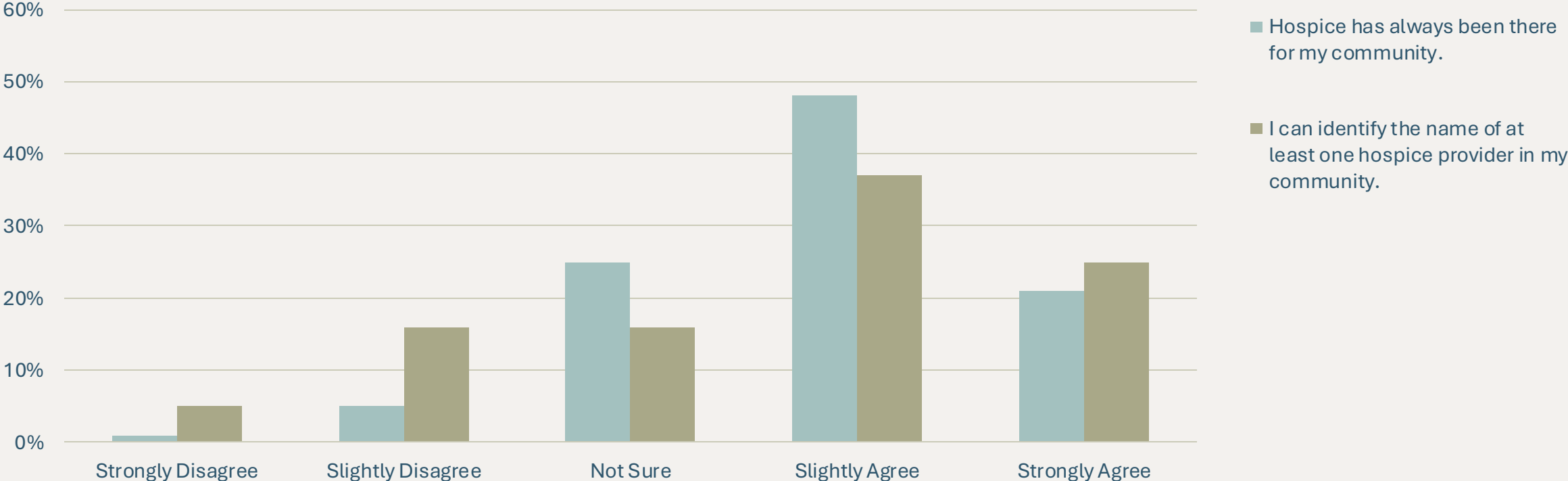




Hospice Perceptions

Many Asian Family Caregivers Are Familiar with Hospice, but There Are Opportunities to Increase Organization Familiarity.

Hospice Familiarity.



Benefits of Hospice Care



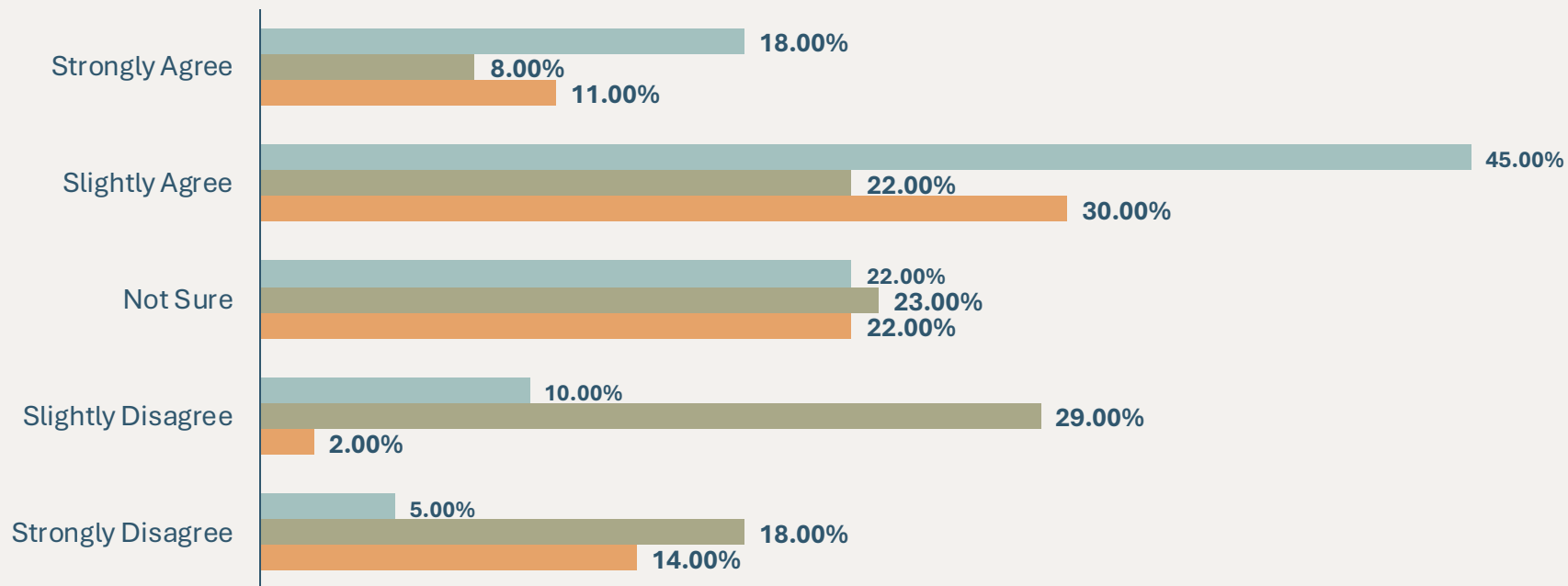
Please rank the following where 1 is most important and 5 is least important	Mean
Hospice can be offered wherever the patient lives.	2.99
Hospice workers can care for my family/friend so I can continue to work.	2.84
Hospice can help me understand what to expect when a person is dying.	3.12
Hospice provides pain management for the patient.	2.89
Hospice provides support to the family of the patient.	3.16

- Chinese and Polynesian respondents found hospice caring for their loved ones so they can continue to work to be most important.
- Indian respondents found hospice providing support to the family of the patient to be most important.
- Filipino and Vietnamese respondents found hospice being offered wherever the patient lives to be most helpful.
- Korean and Japanese respondents found hospice providing pain management to be most important.

Benefits of Hospice Care.

Patient/Provider Hospice Discussions.

- The healthcare community shares information about hospice at an appropriate time.
- Doctors are uncomfortable talking about hospice.
- Doctors bring up hospice too late, waiting until a family is in crisis to offer comfort alternatives to curative care.

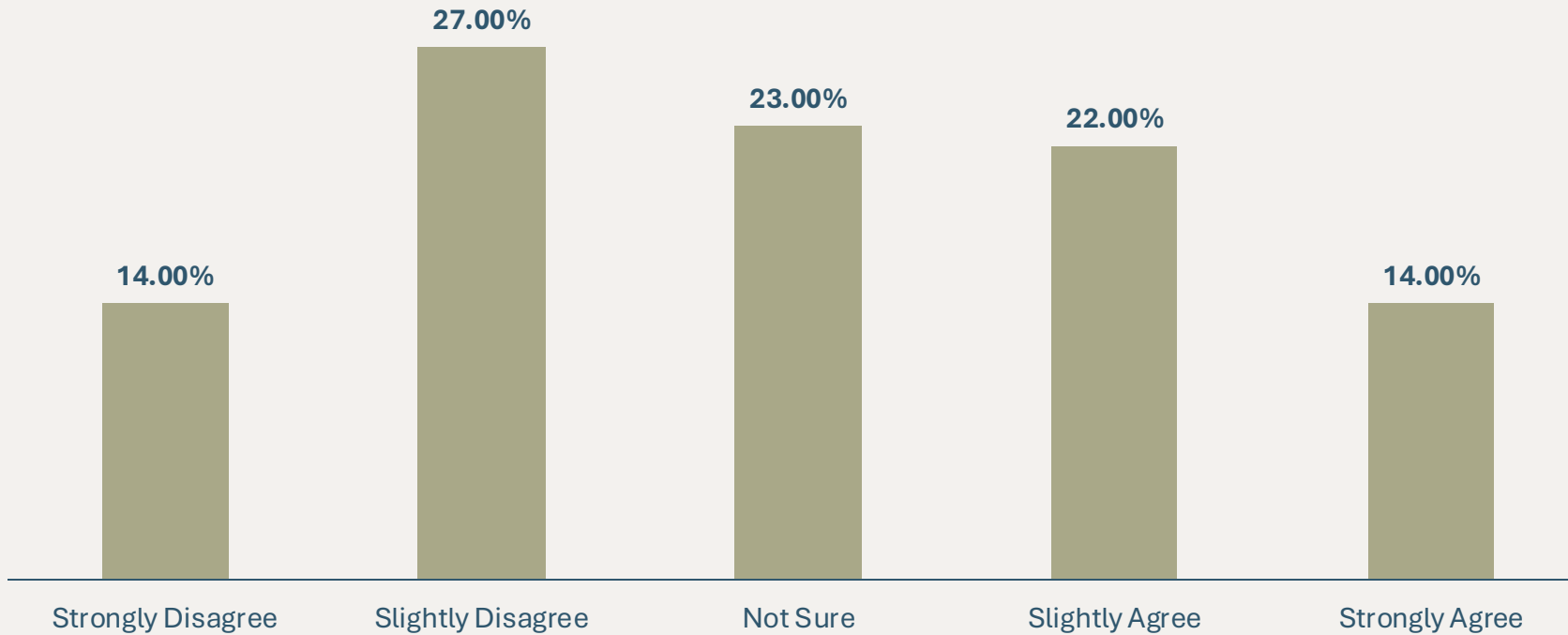


Japanese, Korean, and Indian respondents were **most likely** to feel that doctors bring up hospice too late when compared to other populations.

Benefits of Hospice Care.

Trust in Recommendations.

■ I do not trust doctors when they say it is time to stop curative treatment and think about using hospice.

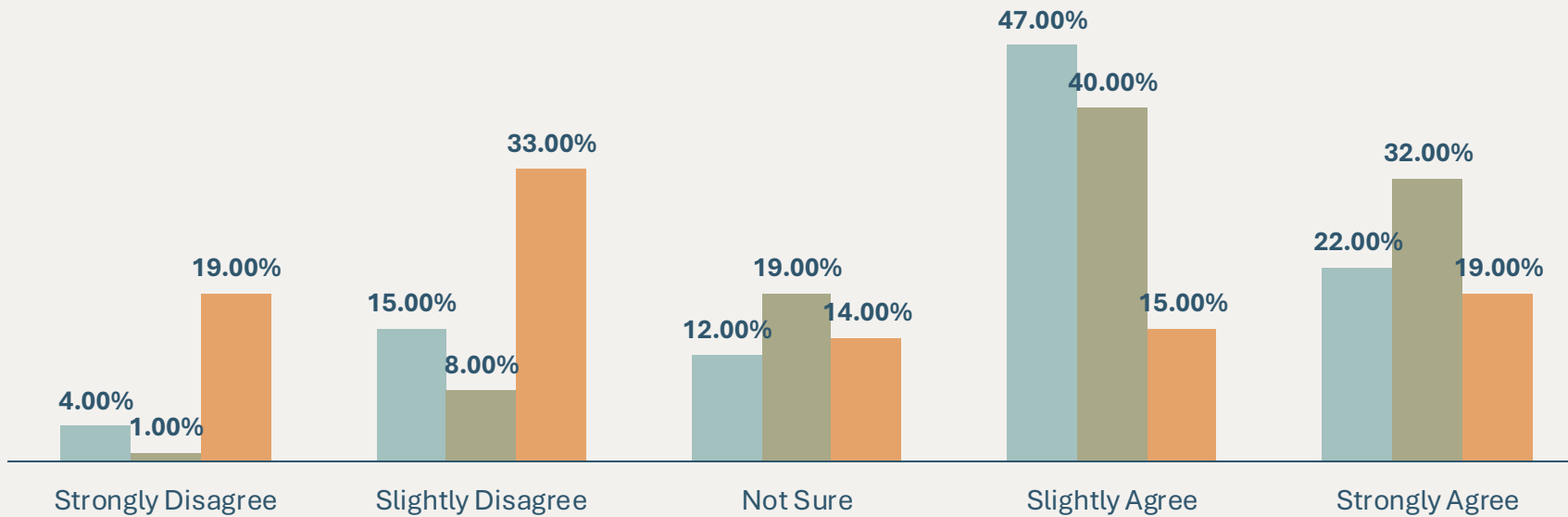


Asian family caregivers under the age of 45 are **most likely** to agree with this statement.

Benefits of Hospice Care.

Personal Hospice Discussions.

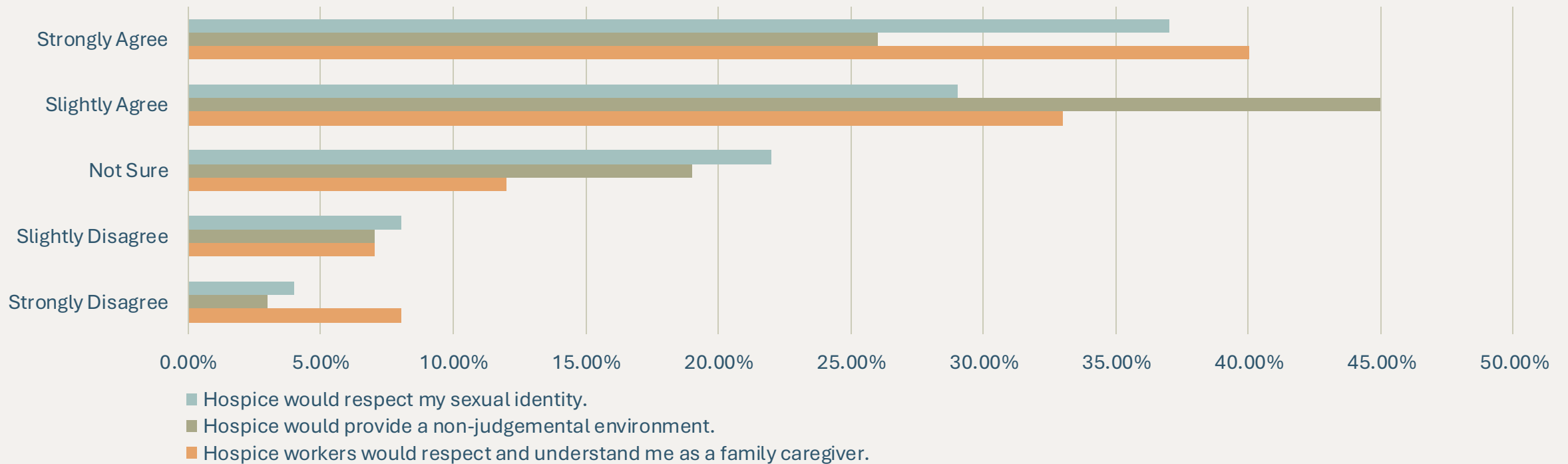
- I would feel comfortable having a conversation with a family member or friend about hospice care if they were terminally ill.
- I would recommend hospice care to a family member or friend who was terminally ill.
- My culture does not think it is appropriate to use hospice.



Japanese respondents were **least likely** to feel comfortable having a conversation with a terminally-ill family member or friend about hospice care.

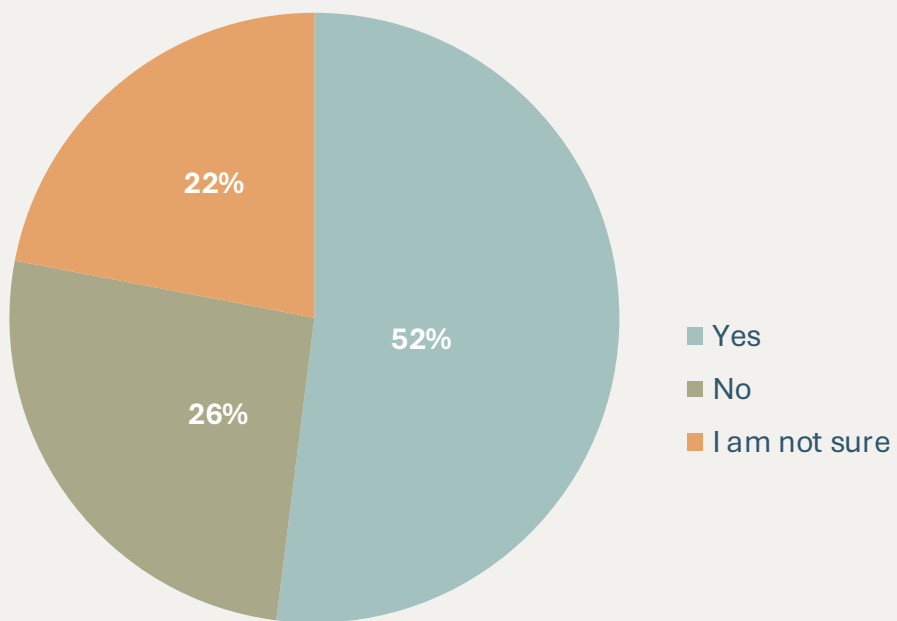
Asian Family Caregivers Generally Feel Respected by the Hospice Community.

Hospice Respect.

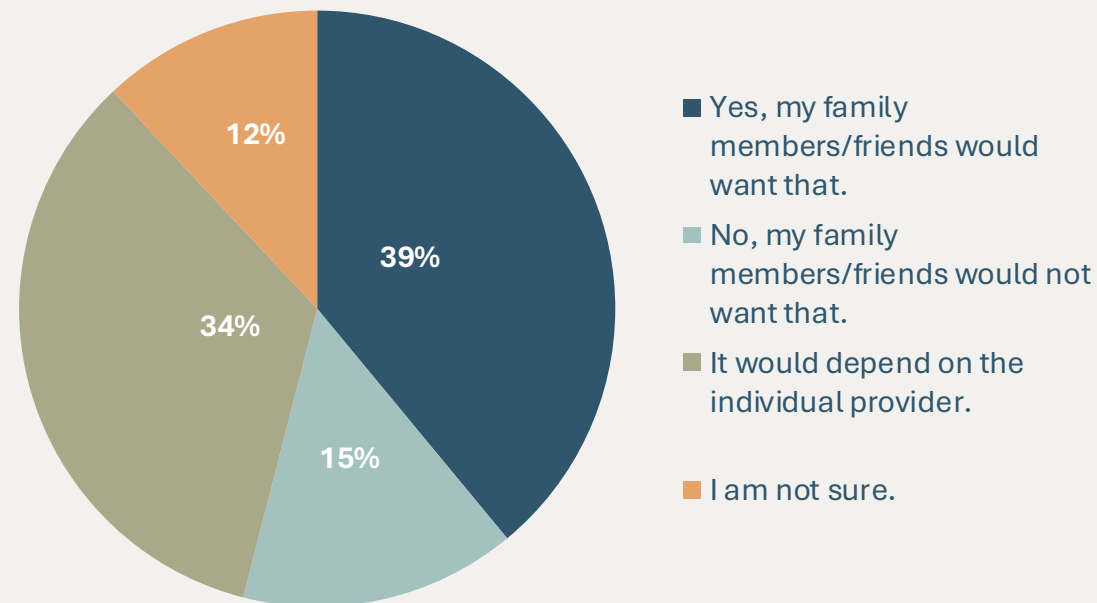


Exploring the Religious and Spiritual Preferences of the Asian Population

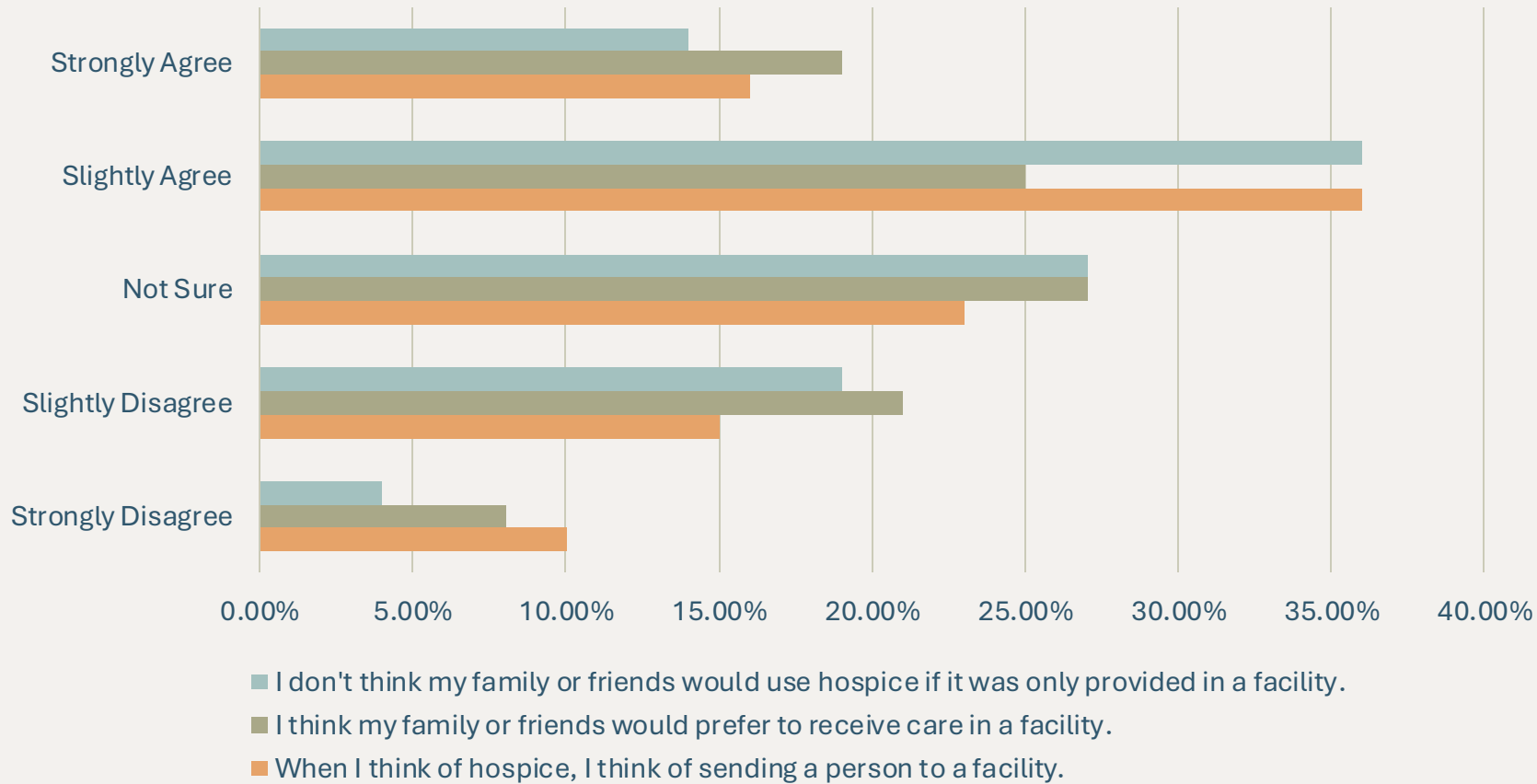
Would you want a spiritual or religious component to hospice care for yourself?



Spiritual component for your loved ones?



Feelings About Facility Usage



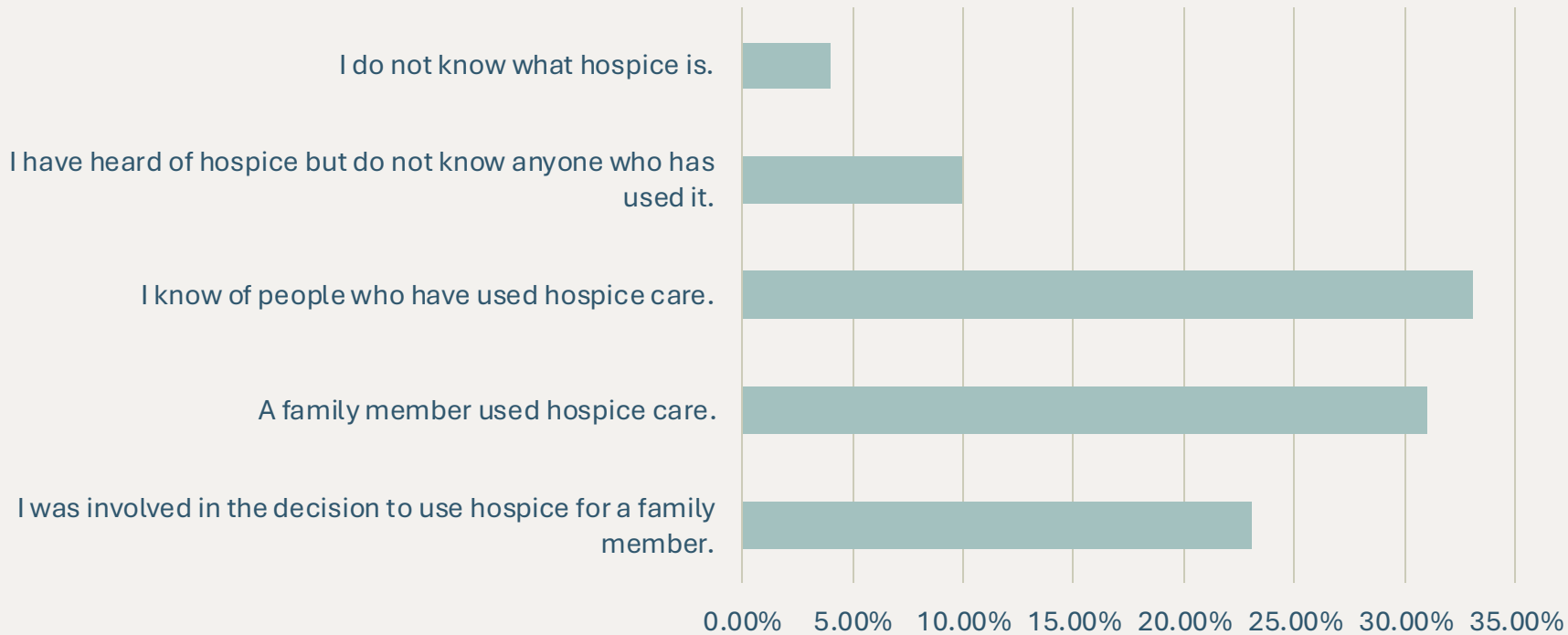
75% of Chinese respondents believe hospice involves sending someone to a facility, **yet only 50%** believe their family or friends would prefer to receive care in a facility.



Hospice Awareness

Understanding Previous Hospice Experiences

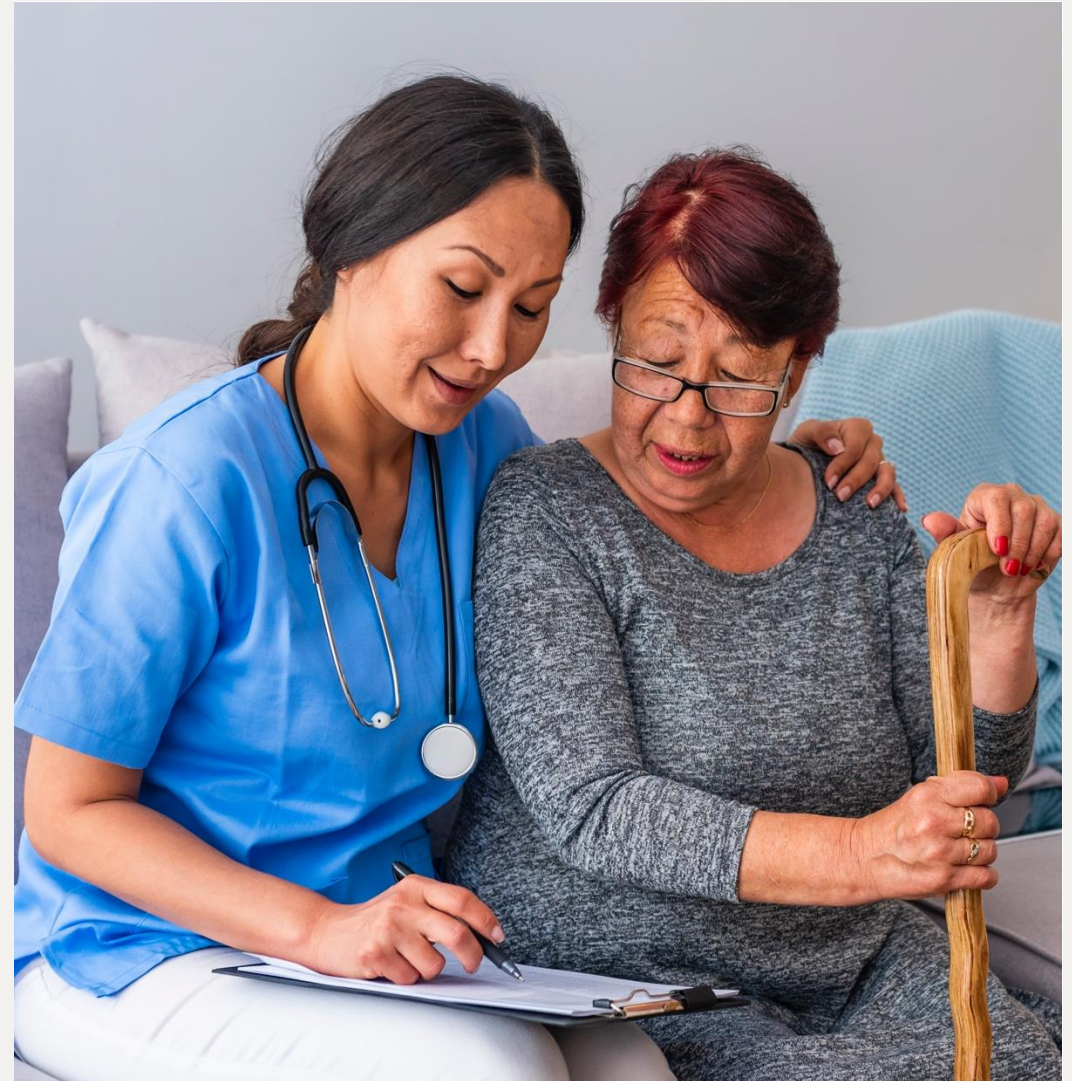
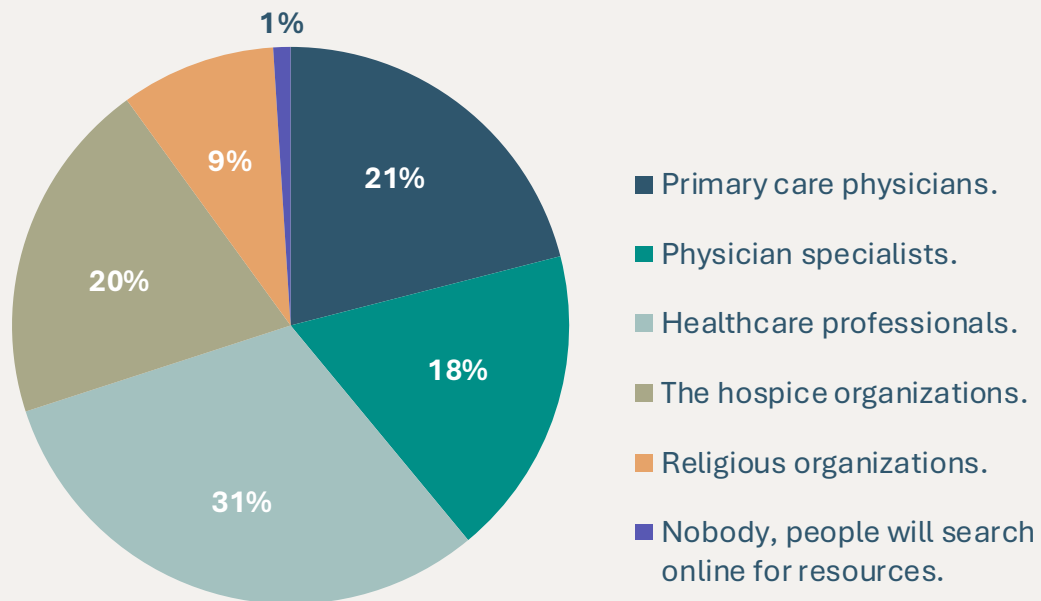
Which of these statements is most true about your exposure to, or use of, hospice care?



Those under the age of 45 were **more likely** to have had a family member who used hospice care services.

Knowledge Sharing in the Asian Community

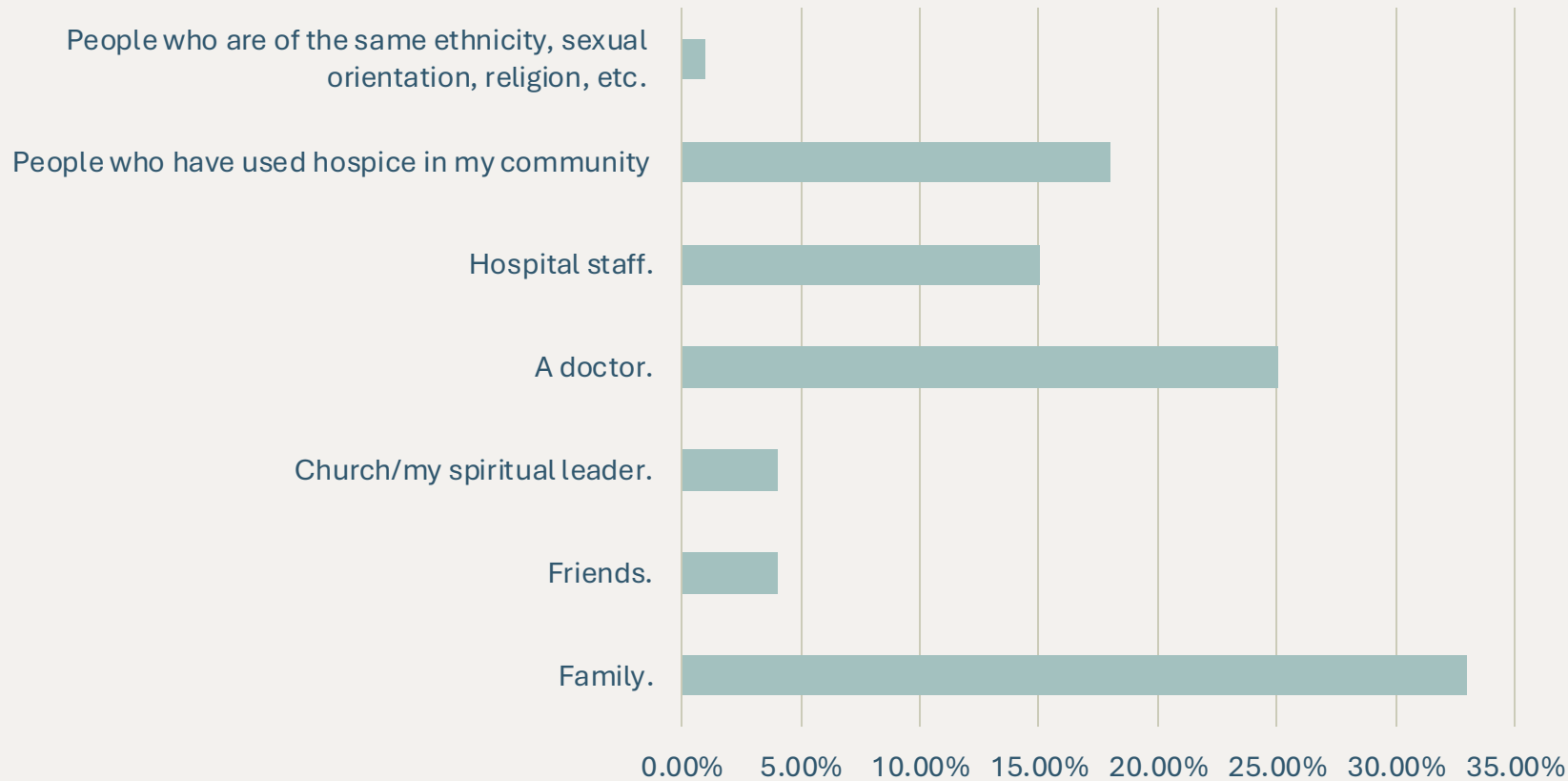
Who should educate the public about hospice?



Who Are the Most Trusted Resources?



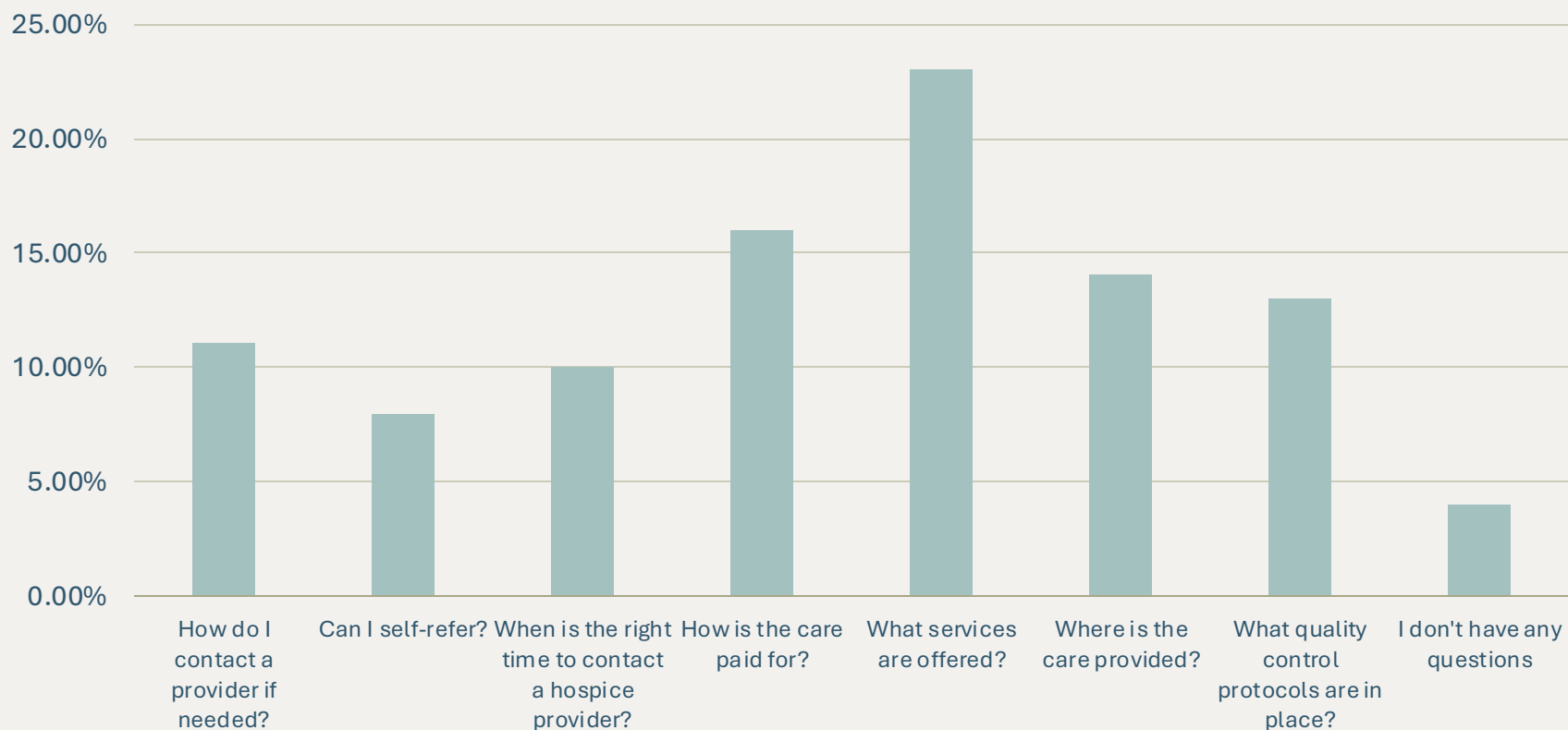
Trusted Recommendations.



- **Chinese** respondents value recommendations from a doctor.
- **Indian, Korean, and Japanese** respondents value family recommendations.
- **Filipino and Vietnamese** respondents value recommendations from people in their community.
- **Polynesian** respondents value recommendations of hospital staff.

Understanding What Information Is Most Helpful

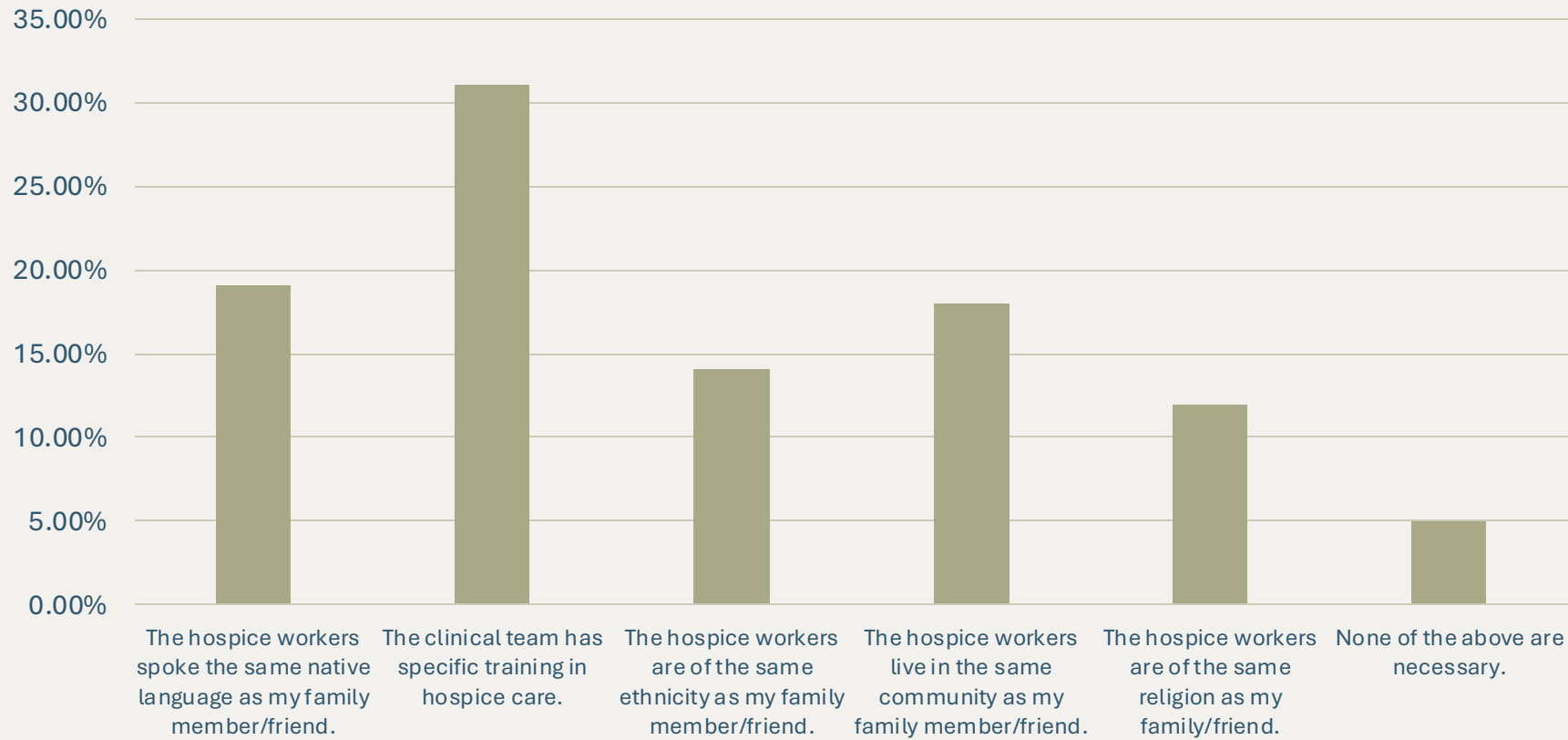
Questions About Hospice.



- **Chinese respondents** are most likely to want to know how hospice is paid for.
- **Indian respondents** are most likely to want to know how to contact a provider.
- **Japanese respondents** are most likely to want to know when is the right time to contact a provider..
- **Polynesian respondents** are most likely to want to know how to contact a provider.

Understanding Previous Hospice Experiences

Which of the following would be necessary for you to feel comfortable using hospice for a family member/friend?



There were no significant differences in responses to this question based on age, gender, or ethnicity.



**National Alliance
for Care at Home**

Research with Asian Community Members

FOCUS GROUP FINDINGS

JUNE 2024

Contents

1. Research Overview
2. Focus Group Findings
3. Appendix: Respondent Profiles



Research Overview

OBJECTIVES

- To understand perceptions of hospice through the lens of adults of Asian descent.

PROCESS

- Two, 75-minute virtual focus groups with a national panel of community members representing a diverse Asian community.

RESPONDENT DEFINITIONS

- 16 respondents, 8 per group
- All participants were between the ages of 46 and 75 and familiar with hospice care.
 - Most have been in a caregiver role and have experienced the death of a loved one.
- 12 were born in an Asian country; 4 were born in the United States.
 - 10 of those born outside of the U.S. have been here for more than 20 years; they have acculturated to the American (“western”) culture while still maintaining their heritage.
 - About half who were born in an Asian country married someone who wasn’t Asian.
- 15 have parents and grandparents born in an Asian country.
- Mix of income levels (about one-third in each category: \$50-\$75K, \$75-\$100K, \$100K+)

RESEARCH DATES

June 27, 2024

KEY INSIGHT Perception

Hospice may not be understood by those of Asian descent because they, or their parents, did not grow up with “institutions” created for elderly care or an end-of-life service called hospice.

“Growing up in the Philippines, we never thought of convalescent hospitals or other facilities. That was non-existent until I came to America.”

“I would not consider sending my parents to a retirement home. We work very hard to keep them with us as much as we can.”

“A first-generation immigrant family has no idea what hospice is, plus, when you’re young, you’re not even thinking about it.”

“When I first saw a retirement facility after I moved to the U.S., I saw residents looking out the window and they looked sad. They were all white people, there were no Filipinos.”

KEY INSIGHT Perception

The Asian ancestry philosophy is to “take care of one’s own.” Even those unable to care for their parent in their home felt as if they would have (should have) in other circumstances. Caring for loved ones at home is expected in their culture.

“You all live together, you take care of each other until you die and that’s kind of how it goes.”

“We try to take care of the family members. The aunts, cousins, it’s like raising a baby, it takes a whole village.”

“It’s unthinkable to not have them with us.”

“It’s not part of our culture to put your elders in a facility, it is our responsibility to take care of our parents, grandparents. But, it is so hard to do that because I am working but no one in our family has ever put someone in a facility.”

Many participants in the focus groups said they would not want to burden their children or grandchildren; they would suggest using a facility for their needs.

KEY INSIGHT Challenge

In general, the primary barrier to seeking healthcare for first-generation (older) adults is the language barrier.

“My parents were born in China, and they don't really speak English. And where we live in Florida, there is not a big Chinese population, so it's very difficult to find someone that they can converse with.”

“My mom speaks only broken English. That would be a reason she couldn't go to a nursing home. If you can't communicate, that's a scary time in your life.”

“My mom didn't speak or read English and they gave her all this paperwork she couldn't understand, so I had to make the phone calls.”

“If someone came to the U.S. in the 1930s or 1940s, they are not going to be able to speak English. It would make all the difference if hospitals could communicate in their language.”

KEY INSIGHT Challenge

A challenge among these participants is variance in opinion/discord within the family unit. All family members want to be involved in the care of the parent; however, siblings have acculturated at different levels, so they often disagree. Within the family unit, some have accepted “Western” thinking and some have not.

“My fight was with my younger brother who’s very old-fashioned. My mom lives with him, and she’s not in good health and soon will not be able to go upstairs without a risk of falling. But he said he will take care of her. I know it’s not a good thing to put her in a nursing home, but for her safety it may be a better choice than staying in the house.”

KEY INSIGHT Consideration

No opposition to hospice care provided in the home exists. They also believe their loved ones would accept care provided in the home. However, hospice care provided in a facility would not be ideal unless it was absolutely needed.

“The first time I went through hospice care, I absolutely agree that it is a cultural difference why people don’t seek that care. But, once we used hospice, we understood and were confident in how they took care of her and communicated with us every day.”

“The concept of home hospice care is a really good fit for the Asian community because of their desire to be at home with their families.”

“There is something comforting about being at home at the very end of their life.”

“I used to think it was a place but a lady from church had hospice care at her home and it was compassionate.”

KEY INSIGHT Consideration

Besides care provided in the home by a family member, no other alternative end-of-life care was discussed (except a non-medical doula in CA). Those of Asian descent appear to have a lack of knowledge of hospice rather than a lack of interest in using it.

“I don’t think any culture really knows a lot [about hospice] until you need it, do they?”

“I don’t feel there’s a disconnect with the Asian culture as long as you know it is available. It’s just a matter of comfort and being informed about it.”

“In my Filipino family, we have never thought about hospice or talked about it. It would have to be offered at the very end because we want to die at home.”

KEY INSIGHT Consideration

The hospice experience needs to be close to their normal experiences. “Outsiders” should ideally be their ethnicity or understand their culture. Culture similarity increases their comfort and trust with the care.

“I feel like a lot of people would be more comfortable if their hospice catered to their ethnicity somehow. It’s a time when you’re very vulnerable and you want as much comfort as you can get.”

“You don’t let outsiders come take care of you because it’s disrespectful. You all live together and take care of each other until you die.”

“The hospice care should be given by someone they can connect with and feel comfortable with.”

“An Asian meal service for the hospice patient and the family [would be nice], because having those familiar flavors is very important.”

KEY

INSIGHT

Physician/Medical Needs

Many said they prefer physicians with a high level of education rather than being influenced by choosing one of the same race or ethnicity.

“In the Philippines, doctors were very well respected.”

“It is a challenge because I don’t want to choose a provider for my dad based on ethnicity. We want to choose based on how capable they are.”

“I would choose someone who has gone to medical school at Johns Hopkins or Harvard, not someone who went to college in another country or a place I’ve never heard of.”

“Where they went to school, their credentials, and their specialty are important.”

“It’s probably better if the doctor isn’t Asian because an Asian doctor would expect me to speak and understand the language, but I don’t.”

KEY INSIGHT

Physician/Medical Needs

Some mentioned that the “Eastern” philosophy is to try home remedies first. However, not much was said about Western versus Eastern medicine. Nobody said they would avoid Hospice because it is “Western” thinking or “Western” medicine.

“Asian countries have different processes. We take care of our own and mostly we try to do remedies at home rather than go to the doctor.”

“The Asian view on healthcare is a little bit different, where you don’t want to go see a doctor. You use your own Chinese medicine to take care of things.”

“My mom trusts the Chinese medicine. She was trying her herbal medicine and acupuncture.”

“The Western medical system is very patriarchal, very downward oriented, telling you what to do and you go and do it. But hospice is completely different, it’s more like we’re here to help you.”

“To my new generation, I don’t know if race matters as much as what will work.”

KEY INSIGHT

Physician/Medical Needs

Some first-generation Asian Americans want a healthcare provider of the same culture to make them feel more comfortable. A common language is a significant bridge to building trust. Some older adults have difficulty with the medical vocabulary and understanding the descriptors used for specialists.

“They still always sought out an Indian or Chinese doctor. I think it was just the comfort level.”

“This is somebody who’s like them. It’s not just language, it’s the nuances and just a comfort level from that shared cultural experience.”

“My mom didn’t have the vocabulary to express herself in English.”

KEY

INSIGHT

Physician/Medical Needs

Those of Indian descent are more likely to seek (and find) well-respected Indian healthcare providers.

“It wasn’t the language because they were educated in English. I grew up in my head thinking Asian doctors are better. I noticed that when I was picking a doctor, I would automatically go for the Asian name.”

KEY INSIGHT

Education

Comments indicate that hospice needs to be explained in terms of how care is provided in the home, how the decision-making stays with the family unit, and how their cultural wants are respected.

“There should be a book about hospice explaining what to expect—the ABCs of what it is. It’s new to us, we weren’t brought up with it.”

“The great fear is my parents are going to lose control over what they like to eat, the TV shows they want to watch, things that keep them alive that make their day interesting.”

“My parents want that feeling of family and support of their own culture. If I knew that hospice care specifically catered to Asians by Asians, it would almost be a good substitute for those of us who do not have a large Asian family here.”

KEY INSIGHT

Education

Comments indicate a lack of knowledge regarding how hospice is paid for or how it works. They suggest websites or online videos (YouTube or social media) to provide education.

“Does it cost money? Who pays for it?”

“The insurance said they would no longer pay for his dialysis, so they basically pulled the plug on him and sent him home to die. They set up a hospital bed at home and I took care of him, and an aide came to the house.”

“I would think the insurance company could provide some information.”

“I want to know the duration of how long and if insurance covers it. What is the process?”

“I want to look [at videos] at my own pace and educate myself. Direct me with links to a website to learn more.”

“Hospitals are doing a good job giving information, but if [the patient] is not in a hospital, you would be lost.”

KEY INSIGHT

Education

Primary physicians and insurance companies are referral and educational sources, but online sources are increasingly influential. The theme of their comments is that patients should be proactive and search for information.

“Our Facebook community of [adults aged] 55 plus has daily posts of someone asking for a healthcare recommendation.”

“Unless you have an appointment, you can’t just call your doctor to ask a question. I would talk to friends. I would Google the American Cancer Society if the question was about cancer.”

“I do my due diligence getting information before talking to the doctor. But you have to be careful of misinformation online or through social media.”

“I think doctors should want to provide hospice information but more than likely we will have to go home and Google for information.”

KEY INSIGHT

Education

From an information-sharing perspective, they would like to hear about hospice through their social networks (churches, community groups, etc.). They seek guidance from friends made in those social circles and shared on social media.

“Hospice people should reach out to Asian influencers, such as bloggers, or people on social media.”

“In the large cities, Seattle, San Francisco, LA, New York, Chicago, there are relatively large Asian communities, so there are a lot of community agencies that help the Asian population navigate the system. That’s another resource that can be very helpful.”

“My mom’s church group would come over and have Bible study. They were all Chinese-speaking. She would get referrals--medical or dental.”

“Our place of worship is where everyone goes. That is where my parents meet other people their age and get recommendations for doctors that would work best with them. Obviously, most of them are Asian and whom they could relate to.”

Recommendations

- Help Asian families understand that hospice care in the home can meet their cultural needs of providing family care for their loved ones.
- Educate the social referral and information-sharing sources Asian community members would trust, such as cultural organizations/centers, churches, public services/agencies, social groups, etc.
 - Make information accessible throughout the Asian community.
 - Offer information in many languages.
- Educate the medical referral sources, such as Asian physicians and specialists; they can promote the synergy between Eastern and Western beliefs when using hospice care.
- Have specific hospice cultural education on insurance and hospice websites.

Appendix: Respondent Profiles

GROUP 1: June 27, 2024 @ 5:30pm

Name	Gender	Age	Years in US	Birth Location	Parents' Birth Location	Grandparents' Birth Location	Made care decisions for someone	Relationship with person made decisions for	Experienced death of loved one	Household Income
Connie T	Female	65 to 74	More than 20 years	Eastern Asia (China)	Eastern Asia (China)	Eastern Asia (China)	No		Yes	75-100k
Eddie L	Male	55 to 64	More than 20 years	SE Asia (Philippines)	SE Asia (Philippines)	SE Asia (Philippines)	Yes	Family member	Yes	75-100k
John K	Male	45 to 54	More than 20 years	SE Asia (Pakistan)	SE Asia (Pakistan)	SE Asia (Pakistan)	No		Yes	50-75k
Karen R	Female	75+	Born in USA	United States	United States	United States	No		No	75-100k
Mark C	Male	45 to 54	Born in USA	United States	Southern Asia (India)	Southern Asia (India)	Yes	Family member	Yes	100k+
Michelle C	Female	45 to 54	More than 20 years	SE Asia (Philippines)	SE Asia (Philippines)	SE Asia (Philippines)	No		Yes	100k+
Rebekah W	Female	55 to 64	More than 20 years	Eastern Asia (South Korea)	Eastern Asia (South Korea)	Eastern Asia (South Korea)	Yes	Friend	Yes	75-100k
Silveria J	Female	45 to 54	11 to 15 years	SE Asia (Philippines)	SE Asia (Philippines)	SE Asia (Philippines)	Yes	Spouse	Yes	50-75k

Appendix: Respondent Profiles

GROUP 2: June 27, 2024 @ 7:30pm

Name	Gender	Age	Years in US	Birth Location	Parents' Birth Location	Grandparents' Birth Location	Made care decisions for someone	Relationship with person made decisions for	Experienced death of loved one	Household Income
Anita M	Female	55 to 64	More than 20 years	Southern Asia (India)	Southern Asia (India)	Southern Asia (India)	No		No	50-75k
Anthony G	Male	65 to 74	Born in USA	United States	Eastern Asia (China)	Eastern Asia (China)	Yes	Self	Yes	75-100k
Danny E	Male	65 to 74	More than 20 years	Eastern Asia (Hong Kong)	Eastern Asia (Hong Kong)	Eastern Asia (Hong Kong)	Yes	Family member	Yes	75-100k
Jeff Y	Male	55 to 64	More than 20 years	Eastern Asia (Hong Kong)	Eastern Asia (Hong Kong)	Eastern Asia (China)	Yes	Family member	Yes	75-100k
Ling L	Female	55 to 64	More than 20 years	Eastern Asia (Hong Kong)	Eastern Asia (China)	Eastern Asia (China)	Yes	Family member	Yes	50-75k
Nancy B	Female	45 to 54	5 to 10 years	SE Asia (Malaysia)	SE Asia (Malaysia)	SE Asia (Malaysia/India)	Yes	Family member	No	100k+
Shirley K	Female	45 to 54	Born in USA	United States	Eastern Asia (China/Japan)	Eastern Asia (China/Japan)	Yes	Family member	Yes	100k+
Tess H	Female	45 to 54	More than 20 years	SE Asia (Philippines)	SE Asia (Philippines)	SE Asia (Philippines)	Yes	Family member	Yes	50-75k

All respondents have heard of hospice care, palliative care and holistic care.

Acknowledgements

We would like to express our sincere gratitude to all those who contributed to this research project. Our deepest thanks go to Transcend Strategy Group, whose partnership was invaluable throughout the study. We also appreciate the support and guidance of the Diversity Advisory Council's research sub-committee whose contributions were essential to the successful completion of this work.

- Karen Davis-Pritchett
- Aparna Gupta
- India Harris-Jones
- Kevin Mann
- Nicole McCann-Davis
- Dr. Cynthia Pan
- Nikkie Preston

Finally, we acknowledge the participants and collaborators who generously shared their time and insights, making this research possible.





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