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Exploring Asian Indian's Perceptions Regarding Organ Donation

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ABSTRACT

PROJECT TITLE: EXPLORING ASIAN INDIAN'S PERCEPTIONS REGARDING ORGAN DONATION

Organ donation saves many lives and gives many people a second chance at life. With over 123,000 candidates on the organ transplant list, it is crucial to increase organ awareness in an effort to increase organ allocation. The growing Asian Indian population in the United States along with low rates of organ donation in this unique cultural group provides an opportunity to explore perceptions and barriers that may exist. This study will explore the perceptions of Asian Indians regarding organ donation. Findings will provide much needed data for interventions to educate and promote organ awareness in this ethnic group. Increasing organ donation awareness and understanding barriers to organ donation will lead to better outcomes for those on the transplant list.

Sandip Suprai

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EXPLORING ASIAN INDIAN'S PERCEPTIONS REGARDING ORGAN DONATION

by
Sandip Suprai

A project
submitted in partial
fulfillment of the requirements for the degree of
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APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

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CHAPTER 1: INTRODUCTION

Defined as “giving an organ or part of an organ to be transplanted into another person” (Organ procurement of Transplant Network, (OPTN), 2015), organ donation has the potential to save lives. Most commonly donated organs include kidneys, lungs, heart, liver, pancreas, and intestines. The organs donated from one single donor can save up to eight lives (OPTN, 2015). Many times in order to sustain life, organ transplantation is the only option left for many individuals. However, the disparity that exists between the supply and demand of donated organs, leads to a loss of many lives (Gilligan, Sanson-Fisher & Turon, 2012). Based on recent OPTN data, approximately 21 people will die each day while waiting for a transplant in the United States (US). Currently, 123, 358 people are awaiting organs and on the transplant list in the US with this number growing and the number of donated organs declining (OPTN, 2015).

Background and Significance

In 2015 approximately 30,969 people in the US received organ transplants (OPTN, 2016). Fifty-five percent (n=17,791) of the deceased donors were White, 15.5% (n=4,805) were Hispanics, 21.8% (n=6,753) were Blacks, with only 5.4% (n=1,647) of the donated organs being from Asian Americans (AA) (OPTN, 2016). The small percentage of organs from AAs which include Asian Indians, Chinese, Japanese, Korean, and Vietnamese, is disturbing given this population’s rapid growth in the US between 2000 and 2010 (US Census, 2010). The AA population size increased by 43% in the US between 2000 and 2010 (US Consensus, 2010). Among AAs, Asian Indians (AI) are the second largest AA population, with 3.2 million AIs residing in the US (US Consensus, 2010).

As of January 2016, there are 100,680 candidates awaiting a kidney transplant and 14,775 awaiting a liver in the US (United Network for Organ Sharing, 2016). There are

approximately 9,800 (13.4%) AA on the transplant list. American race-ethnic classification includes AIs, Chinese, Filipinos, Japanese, Koreans, Vietnamese, and other Asians from various Asian countries without the ability to break down into the subgroups. Asian Indian's like many other Asian ethnicities are classified under one racial group as Asians. When in reality all these different Asian ethnicities vary tremendously in culture, diet, health and illnesses. For the purpose of this research, the focus will be on AIs.

Asian Indians are more likely to have higher rates of obesity and diabetes compared with other Asian subgroups which puts them at an increased risk of needing a donated organ (Boparai, Davila, & Chandalia, (2011); Lee, Brancati, & Yeh, (2011). An estimated 32 million Asian Indians globally have diabetes, with predictions that this number will double over the next 30 years (Mayo Clinic, 2008). Furthermore, these conditions can lead one to develop coronary artery disease and hypertension which then can lead to chronic kidney disease and other chronic illnesses. Patients who suffer from chronic kidney disease eventually need dialysis and organ transplantation to ultimately regain some quality of life. Also, conditions such as diabetes and obesity can be detrimental to one's life and can lead to fatty liver disease which can lead to chronic liver disease requiring liver transplantation if the liver decompensates (Mayo Clinic, 2014).

With the rising AA population in the United States, it is crucial to understand, that in the coming years the Asian population will have increased number of transplant recipients. The time is now to educate and to learn about the various Asian ethnicities views on organ donation. As the AIs is one of the growing Asian ethnic group with high rates of diabetes and other illnesses that can make this group of population more prone to becoming listed on the transplant list, it is now time to educate in the realm of organ donation. Understanding AIs willingness and perceptions on organ donation can help guide future studies and educational material. In order to bridge the gap between organ

supply and demand, and bring about change along with improvement, it is vital to increase awareness and education in regards to organ donation (Goldstein, Lubezky, Yushkov, Bae & Guarrera, 2012).

Purpose

The purpose of this study is to examine the perceptions regarding organ donation among AIs. The goal is to promote organ donation awareness one race at a time to increase organ allocation. Increasing organ allocation will help many have a second chance at life.

Conceptual Framework: Theory of Reasoned Action

The Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975) was utilized to guide this study. This conceptual framework serves to explain the relationship between a person's beliefs, norms, attitudes, intentions and behaviors and has been used to understand and predict behaviors and willingness to donate organs among African Americans (Jeffres, Carroll, Rubenking & Amschlinger, 2008).

A person's beliefs have a large impact on their attitudes and behaviors. The TRA suggests subjective norms and attitudes predict the behavioral response. Many factors such as with organ donation need to be examined to help predict ones perceptions on organ donation. Attitudes of individuals do change overtime, and by being persuasive and educating individuals many goals can be achieved, such as increasing organ donation allocation by changing attitudes toward organ donation. Subjective norms do play an important factor that can either hinder or promote one to become organ donors. It is vital to understand if individuals care to know if families, friends and religious personnel matter or play a role in determining their beliefs on organ donation. The aim of this study is to identify factors that influence Asian Indians willingness to donate. This study will also shed light on Asian Indians attitudes and beliefs in regards to organ donation.

CHAPTER 2: LITERATURE REVIEW

The following chapter provides a review of the research to date regarding organ donation and the factors related to a person's willingness to donate. The literature regarding minority groups will be explored with a specific focus on Asian Indians. Cultural and religious factors as well as family discussions related to organ donation will be discussed ending with a summary of findings to date.

Cultural views regarding organ donation among Asians

Ancestral beliefs and myths surrounding organ donation can impact one's views on organ donation. Using qualitative focus groups, Wong (2010) examined cultural beliefs and religious factors regarding organ donation among a total of 105 participants of which 34% (n=36) were Chinese, 45% (n=47) were Malay and 21% (n=22) were Indian adults living in Malaysia. The interviews consisted of four different topics: knowledge and awareness, attitudes towards organ transplantation, willingness to donate and the barriers to signing up to become organ donors. The main themes that derived from this study in relation to organ donation across all ethnic groups in this study were as follows: perceived religious prohibition, cultural mythology, fear of disfigurement, fear of surgery, distrust of medical system, and family disapproval. Study findings revealed Chinese Buddhist participants felt their religion supported organ donation whereas the Malay Muslim and Indian Hindu participants felt their religion forbade organ donation. Regarding cultural myths and misperception, Chinese participants believed that deceased people need their complete bodies to enter the spirit world; however, the Hindu participants believed that deceased bodies have to be intact so they can reincarnate for next life. On the other hand, Malay Muslim concerned that the deceased body still can feel pain so they must be handled carefully. In addition, many people in these ethnic groups are worried about body disfigurement. They are afraid that after harvesting the

organs, the bodies would not look good for funeral viewing. Regarding the people's view on distrust of medical problem, majority of people from all ethnic groups trusted the health care professionals and believe that they will do the right things. About the family disapproval, all ethnic participants expressed that the family's consent for them to donate organs are very crucial. Chinese participants added that their elderly parents or grandparents are very superstitious about registering for organ donation because it will bring bad luck and even accelerate their dead.

Cultural background plays an important role on people's view and perception because what individuals are taught to believe to be right and wrong especially after death can have a major effect on the possibility of the person donating their organ upon being declared dead. If individuals are well educated in the realm of organ donation, there more chances those individuals will become organ donors. This can only happen when the community and religious leaders work together to achieve a common goal to help promote organ allocation.

Organ donation views in other ethnicities

Using a quantitative, non-experimental, descriptive, cross-sectional design, Law and McNiesh (2012) investigated barriers to organ donation in a convenience sample of 144 African American adults who were recruited from churches frequented by African Americans in Northern and Southern California. Fifty percent (n=72) held a Bachelor's degree or higher. The 22-item, self-report Bone Marrow Donation Intention Scale (Glasgow and Bellow, 2007) evaluated organ donation perception. Findings revealed church members opinions, recipient's race, and limiting donation to children, were not barriers to organ donation. Participants expressed the importance of educating on organ donation and the positive effects of organ donation leading to help save lives as reasons to want to donate. The convenience sample design limited study findings.

Using a qualitative, grounded theory design, Quick, LaVoie, Scott, Bosch, and Morgan (2012) explored perceptions regarding organ donation among African Americans (n=39), Hispanic (n=27), and White (n=32) low-income high school students in Illinois. The sample included equal numbers of male and female students, aged 16-18 years. The in-person interview included 11 open ended questions based on the Health Belief Model (HBM). Interviews were conducted in 14 small focus groups over a 10-week period. Resultant themes included a general lack of knowledge regarding organ donation and suggested participants were unaware of the severity of the need for organ donation and how to become organ donors. Other findings included myths and medical distrust regarding organ donation. For example, many felt the medical professionals would not do everything possible to save one's life, however would be more interested in harvesting those organs.

Significance of family discussion and organ donation

There is a mismatch with regard to supply and demand of organs. Often, families do not want to donate their family member's organs. Using a retrospective design, Ghorbani et al. (2011) examined reasons behind refusal to donate a loved one's organs. Eighty-one families were contacted and interviewed via phone using the organ procurement units' directory in a hospital in a University Hospital in Iran. Participants (n=72) were between 18-55 years of age with 72% (n=58) male and 38% (n=22) female. Organ donation refusal reasons included: refusal to believe their loved one was brain dead (44%), waiting for a miracle (13.6%), concerns regarding organ trade/unknown organ destination (9.9%), and against religious beliefs (8.6%), unstable family mood (6.2%), unknown donor wishes (4.9%), body integrity after death (3.7%) and fear of objection by other family members (2.5%). Family belief that their loved one was alive and not brain dead was noted as a main theme. In order to increase the instances of organ donation, education must be provided regarding benefits, myths, along with providing a

clear written policy of what process will take place to ensure that the donated organs are properly managed.

Using a quantitative, cross-sectional design, Trompeta et al. (2012) examined the associations of attitudes and knowledge regarding organ donation and the willingness to participate in family discussions about organ donation among 112 Asian American high school students living in Hawaii. The largely female sample (n=87, 78%) were aged 16 - 17 years and self-identified as Japanese, Chinese, Filipino, or Korean. The 18-item Organ Donation and Transplantation Knowledge Survey (Trompeta, Chen, Cooper, Ascher & Kools, 2010), 20-item Organ Donation Attitude Survey Modified (ODAS) (Rumsey, Hurford & Cole, 2003), and the 21-item Suinn-Lew Asian Self-Identity Acculturation scale (Suinn, Ahuna, & Khoo, 1992) were completed by all study participants. Linear regression analysis suggested willingness to donate was associated with level of organ donation knowledge, higher acculturation level, and less opposing attitudes towards organ donation, $p \leq .001$ (significance $p \leq .05$). Findings also revealed that family discussions had a significant ($p \leq .001$) impact on determining ones willingness to donate.

The significant role of religious views on organ donation

Salim et al. (2012) examined whether a culturally sensitive educational program regarding organ donation would increase level of awareness, knowledge, and intent to donate among 182 Hispanic Americans attending one of four Catholic churches in Southern California. The age of the largely female (n=114, 63%) sample ranged between 40-65 years. Findings revealed 20% (n=36) felt religion influenced decision to donate or not, 61% (n=111) felt television played a role in providing organ donation information, 68% (n=124) stated that family would support their decision to donate and whereas post intervention 81% (n=147) felt family would support their decision to donate. A univariate analysis was performed to evaluate the differences on pre and post intervention. There was a statistically significant increase noted after the post intervention in the knowledge

base, from 54% to 70% ($p < 0.0001$), increase perception from 43% to 58% ($p < 0.0001$) and organ donation beliefs from 50% to 60% ($p < 0.0001$). There was no significant difference in the intent to donate post intervention. Study findings suggest familial support, not perceiving that wealthy people will get the transplant and knowing there is a national donation matching program were all positive factors that increased ones intention to become organ donors.

A quantitative study conducted by Hafzalah, Azzam, Testa and Hoehn (2014) explored to see the impact of religious educational intervention on promoting organ donation in Muslim Americans in a city of Illinois, in various mosques, social services offices and at the University of Chicago campus. The participants were all 18 years of age or older and ranged from 18-61, who were English, Arabic, or Urdu speaking. There were two parts to the data collection process. The first step consisted of face to face interviews. Then, a less than a 30 minute intervention took place where participants were educated on organ donation and given a copy of an article from a Saudi journal which emphasized the importance and gave permission for people of Islam to donate. Then the second part of the data collection consisted of a survey. Descriptive statistics revealed that 51% of the respondents were willing to donate. Having a driver's license or, years in the USA did not influence willingness to donate. Being religious did not have an impact on willingness to donate, however not knowing the Islam's stance on organ donation did. Post hoc t-test was conducted to evaluate the findings of post intervention. Post education findings revealed an increase by 3% for the willingness to donate which was not significant, however does demonstrate that the education was somewhat influential. Other influential factors were also studied. Sixty-seven percent ($n=145$) of the participants felt reading on their own influenced their desire to be organ donors, while 44% ($n=73$) felt the concept of "good deed" was a positive factor contributing one to be an organ donor. The factors that contributed to one not wanting to donate were the lack of religious figure

to state it is ok to donate (40%, n=32), disfigurement (33%, n=26) and 8% of the participants (n=6) had medical distrust.

Summary of the Literature

Based on the current literature, many studies have been conducted on various racial groups. One study done in Iran hospital examined Iranians reasons behind refusal to donate a loved ones organs (Ghorbani, et al., 2011). A study done in Malaysia studied Chinese, Malay Muslims and Asian Indians (AIs) and the effects of ancestral beliefs and myths regarding organ donation (Wong, 2010). Law and McNiesh (2012) studied barriers in African Americans in Norther and Southern California to organ donation. Furthermore, a study evaluated Asian American high school students who self-identified themselves as Japanese, Chinese, Filipino and Korean who live in Hawaii. This study discussed the importance of family discussion and willingness to donate (Trompeta et al., 2012). Quick, Lavoie, Scott, Bosch, and Morgan (2012) investigated barriers in African Americans, Hispanics and White high school students in Illinois. While another study done in Illinois evaluated Muslims and the influence of religious leaders and intent to donate organs. Salim, Berry, Ley, Schulman, Navarro, Zheng and Chan (2012) examined the effect of organ donation education after religious services.

Very little research to date has examined the perceptions of organ donation among Asian Indians. This is concerning given the high likelihood of AIs requiring a donated organ versus the overall low donation rates in this race-ethnic group. Hinduism and Sikhism are two religions many AIs practice and very little data is available on these religious groups regarding organ donation. Based on this literature review, other ethnicities have benefited from getting educated on organ donation. Family discussions had a big impact in the various populations in the literature review. By conducting this study, more data will help to understand the views of the Asian Indians and will help to guide future studies and/or educational programs to increase organ donation awareness.

CHAPTER 3: METHODOLOGY

Research Question

This study aimed to answer the following research questions:

1. What are the perceptions of organ donation among Asian Indians (AIs)?
2. Do their perceptions regarding organ donation predict willingness to donate?

Study Design

A quantitative, non-experimental, descriptive, cross-sectional design was utilized to evaluate the perceptions of the Asian Indians regarding organ donation. Prior to any data collection, human subjects' approval was obtained from California State University of Fresno along with written permission from the two study sites (Sikh temple, Fremont, CA and Hindu Temple, Sunnyvale, CA).

Sample/Setting

All adults, self-identifying as AI, over the age of 18 who were able to speak and write English, were invited to take part in this study. Participants were recruited using convenience sampling from two temples in the Silicon Valley. The setting for this study included a Sikh Temple in Fremont, California and a Hindu Temple in Sunnyvale, California. For purpose of this research study, AI was defined as individuals who were from the country of India or had ancestors from India.

Recruitment

Participants were recruited by placing fliers in places most local Indian grocery stores, fliers were put up to spread the news about the study that will be conducted at the temples. There was an incentive of \$10 gift cards from Starbucks, Jamba Juice and Baskin Robbins. The participants after completing the surveys were entered into a drawing. The drawing was done at the end of the three month data collection and ten participants were granted the prize. (*See Appendix B for recruitment flyer*)

Data Collection

Data was collected on Sundays and Wednesdays, at the Fremont Sikh Temple and at the Sunnyvale Hindu temple both in the Silicon Valley, CA region, from 8 am to 4 pm. Data was collected over three month period. Data was collected at the temples via paper and pen.

Flyers (*See Appendix B*) at both of the temples and local Indian grocery shops to spread the word of the surveys was done to market more individuals to participate in this valuable study. For both of the temples, permission was given by the head priest and presidents. On the days of the survey, a booth was set up, with some chairs and a banner alerting and reminding all the members of both of the temples that study is taking place and to ask for volunteers to help participate in this study.

Measures and Demographics

Perceptions of organ donation were assessed using a modified version of the Bone Marrow Intention Scale (Glasgow & Bello, 2007). after obtaining permission from the author of this tool which is a 37-item Likert Scale, which was modified after obtaining permission to do so, from a 60-item Likert Scale for the purposes of this study. This scale is a reliable and a valid tool that has been used in previous studies to evaluate the perceptions of African Americans on organ donation and even on perceptions specifically on bone marrow transplantations, (Law & McNiesh, 2012; Glasgow & Bello, 2007). Four additional questions were added to the study to help guide future studies of this sort which sought to understand a little more of individuals perceptions on organ donation and factors such as family discussions, personal desires to donate and what factors prevent one from donating ones organs. Demographic data was also collected which entailed: Gender, age, religion, educational level, marital status, organ donor history and socioeconomic status. There were a total of 16 demographic questions.

The full Bone Marrow Intention Scale questionnaire is in Appendix C (See appendix C). Responses on this scale range from -3 (not at all / disagree / extremely bad) to +3 (very much / strongly agree / extremely good). For the purpose of this study, responses were coded such that a 1 was equivalent to a -3 while 7 was equivalent to +3.

Data Analysis

Participant characteristics and perceptions of organ donation data were entered into SPSS version 19.0 for Windows (IBM, 2010). An analysis of the data was conducted using descriptive statistics including, frequencies, percentages, means, and measures of central tendency.

CHAPTER 4: RESULTS AND DISCUSSION

A total of 244 participants completed study questionnaires. However, for the purpose of this paper, findings will only be reported on the 215 participants with both complete demographic and organ donation data.

Participant characteristics

The mean age of this sample (N=215) was 36.7(SD=10.5) years (range 19-78). The majority of the sample were male (63%, n=136), married, (72.1%, n=155). Ninety one percent of these respondents were born in India (90.7%, n= 195). Sixty-five percent (n=138) of the participants were fluent in Hindi. Forty percent of the participants (n=86) had stated occupations in the computer/technical industry, while 34.7% (n=74) of the participants were teachers or /professors, and 20.2 % (n=43) of the participants worked in the health care field or / medical industry. (*Please see Table 1 for all participant demographic results.*)

Findings

The findings of this study are being reported in certain themes that were extracted from the data collected. Participants were asked questions regarding organ donation and how much of an impact the participants families, partners, friends, religious leaders had on their willingness to donate. Some questions were aimed at discovering if providing education and knowledge in the realm of organ donation would increase the participant's willingness to donate. Other questions were asked to see if the participants willingness to donate to the rich, elder, or other races had any effect on their decision to become donors.

Opinions of partners/family

Approximately 74% of the participants (n= 158) want to do what the respondents partner thinks they should do. Indicating that the opinions of the participant's partners matter. (BMIS question #1). When asked directly if the participants partners opinion

about whether they should donate organs is important to them, 73% of the participants (n=156) stated their partners opinions mattered (BMIS question #3) When asked if they think their partner would approve of them donating organs, 81% of the participants (n=153) very much or likely are to approve. (BMIS question #11).

Participants were questioned in general how much do they want to do what their family thinks they should do 42.5% of the participants (n=91) are likely to do what their family would want them to do. And 35% of the participants (n=74) very much would want to do what their family thinks they should, (BMIS question #21). Furthermore, participants were asked if their families would approve of them donating their organs, and 66% of the participants (n=142) felt their families would approve of them donating organs. (BMIS question #7). Participants were also asked if their families opinion whether they should donate is important to them and the participants (n=164) 76% of them responded the families opinion is very much and likely important.

Thirty-seven percent of the participants (n=78) in general, want to do what their friends think they should do. (BMIS question #14). When asked if their friends would approve of them donating organs, 71% of the participants (n=151) stated that their friends would very much approve. (BMIS question #20).

Within the Asian Indian (AI) population based on the findings above, families, partners and friends play a vital role. The opinions and views of these important people in the participant's life can effect their willingness to donate or not to donate. It is necessary to include AI families, partners and friends in the educational intervention.

Education/ knowledge on organ donation

When participants were asked if knowing more about organ donation would encourage them to donate, approximately 81% of the participants (n=176) agreed it would be beneficial (BMIS question #4). Patients were asked again if they knew more about organ donation, would they be more likely to donate organs and 52% of

participants (n=111) strongly agreed and 30% (n=64) very likely agreed. (BMIS question #19). Similarly, when participants were asked in general about Asian Indians knowing about organ donation and if that would encourage them to donate and approximately 83% of the participants (n=180) strongly agreed or very much agreed. (BMIS question #6). Participants were also asked if Asian Indians know about organs, they will be more likely to donate their organs and 43% (n=92) strongly agreed and 27.6% (n=59) likely agreed.

Furthermore, participants were asked if saving someone's life by donating organs is good or bad, 96% of the participants (n=206) answered extremely good/very good. (BMIS question 5). Participants were also asked how they viewed helping another person by donating their own organs and 86% of the participants believe it was extremely good and very good. (BMIS question #23). Seventy-three percent of the participants (157) believe organ donation is extremely good and 17.7% of the participants (n=38) believe it's very good. About 4.7% of the participants (n=10) were neutral and 1.4% of the participants (n=3) believed it was extremely bad. (BMIS question #18). Participants were asked if they donate their organs it may not help someone, and 42.1% of the participants (n=90) strongly disagreed, 17.8% (n=38) didn't know and 15.9% (n=34) strongly agreed. (BMIS question #29).

The findings in the realm of knowledge and education suggest that knowing about organ donation and getting the appropriate education would increase ones willingness to donate. Although, majority of the participants understand that donating organs will help save another's life, the participants believe if they are given the education on organ donation, it will encourage them to donate.

Religious views/impact on decision to donate or not

When participants were asked in general how much they want to do what their fellow temple members think they should do, 54% of the participants (n=103) replied very much or likely. (BMIS question #13). Interestingly, 48% of the participants (n=104)

stated their fellow temple members opinions about whether the participant should donate is important to them. However, 21 % of the participants (n=45) did not feel the temple members opinions mattered. (BMIS question #8). When participants were asked if their temple would approve of them donating organs, 46.2% of the participants (n=98) stated their temple would very much approve and 25.5% of the participants (n=54) would most likely approve. About 18.4% of the participants (n=39) were neutral or didn't know. (BMIS question # 27).

The findings suggest that approximately fifty percent of the participants do value the opinions of religious leaders on organ donation. This is important to note when developing any educational interventions. Religious leaders can have a positive impact if they are involved in teaching and encouraging AI to donate.

Donating to elders, other races or the rich

When asked if the participant would be willing to donate to a different race, 81% of the participants (n=194) stated they were extremely likely or very likely to donate to a different race. (BMIS question #10). Thirty-five percent of the participants (n=77) do not worry that their organs will go to a different race than the participant. However, approximately 41% of the participants (n=89) worry very much or very likely worry that their organs will go to a different race than their participants. (BMIS question #17).

When asked if participants believed if important or famous people would get organs first before ordinary people, approximately 35% of the participants (n=75) stated they strongly disagreed, while 19.5% of the participants (n=42) were neutral and about 29% of the participants (n=63) strongly agreed or very much agreed with this statement. (BMIS question #12). Twenty-eight percent of the participants (n=61) strongly disagreed that they believed that their organs would go to a white person before an Asian Indian, while 38 % of the participants (n=82) were neutral. There was a 10 % of the participants (n=23) who strongly agreed to this statement. (BMIS question #15). When asked further,

if the participants worry that a white patient might receive their donated organs before an AI and 34% (n=72) stated it strongly did not worry them. (BMIS question #31).

Participants were also asked if they would prefer to only donate organs to children and 36% of the participants (n=78) strongly agreed or very much agreed to this, while 20% (n=43) strongly disagreed and 22% (n=27) were neutral. (BMIS question #16). Thirty-six percent of the participants (n=78) strongly disagreed when asked if they would not give organs to a very old person, while 23.7% of the participants (n=51) were neutral. (BMIS question #2) Participants were asked if they would not mind giving their organs to a very elderly person and 32.7% of the participants (n=70) strongly agreed, while 22.4% of the participants (n=48) likely agreed and 18.7% of the participants (n=40) somewhat agreed and 14% of the participants (n=30) didn't know.

When asked if they would prefer to only give their organs to close friend or family member, 32.6% of the participants (n=70) strongly disagreed or likely disagreed. However, 28.4% of the participants (n=61) were neutral and 18% of the participants (n=39) strongly agreed. (BMIS question #24). On the other hand, when asked if the participants were willing to give their organs to a stranger, 65% of the participants (n=140) strongly agreed, 17.7% of the participants (n=38) likely agreed and 10.7% of the participants (n=23) were neutral. (BMIS question #25).

Participants were asked if they wouldn't mind giving their organs to whoever needs it and 65.9% (n=141) strongly agreed, 17.8% (n=38) mostly likely agreed. (BMIS question # 30).

The findings pertaining to different race other than Asian Indians or the age to whom these participants would donate to, didn't matter. Majority of the participants didn't believe race or age would effect their willingness to donate. This is important to understand and should be included in future educational interventions as some did

although not many were concerned about donating to other races or that other races would get donation prior to the Asian Indians.

Other

Participants were asked if the concern of taking care of their children in the next 12 months would make it difficult for them to donate an organ and approximately 62% of the participants (n=135) strongly/agreed to this statement. (BMIS question #9). When asked if they prefer to only give organs to a person who does not use drugs, 53% (n=163) strongly agreed. This question was asked again but this time asking if they wouldn't mind giving their organs to a person who uses drugs and 44.9% of the participants (n=96) strongly disagreed. (BMIS question #34).

The participants were asked if it is most up to the participant whether to register to become an organ donor or not. The results indicated 54% of the participants (n=115) strongly agreed, 23.9% of the participants (n=51) likely agreed. (BMIS question #36). The participants were finally questioned, on how much control they believe they have over registering to become an organ donor within the next twelve months. Sixty-four percent of the participants (n=138) believe they had complete control.

Discussion

Based on the findings, families, partners and friends have an influential impact on the Asian Indian participants of this study. Family and partners opinions are important and can shape ones decision on wanting to or not wanting to donate. Having the knowledge and education will encourage participants to want to donate. Involving religious leaders in the teaching process can also increase the AI population's willingness to donate.

CHAPTER 5: Conclusion

The overall findings of this study suggest that Asian Indians (AIs) do have a willingness to donate their organs after death. Participants value what their families or partners opinions are regarding organ donation. Therefore, education regarding organ donation must include the whole family. This study also suggests that the importance of having the knowledge and education in the realm of organ donation would help AIs be more willing to donate.

Limitations

Study results were limited by several factors. The study had largely English speaking sample from 2 temples in the South Bay. Therefore, the findings can't be generalized to other populations of AIs such as the non-English speaking AIs. Furthermore, this study was conducted in Silicon Valley in Northern California and can't be generalized to the rest of the AIs in the United States. There was no measure of acculturation.

Future Implications

This study is one of the first to examine the perceptions of AIs in the US. This study is a passageway to guide future studies and to help develop educational material to help increase organ donation awareness in the AI population. Future research should focus on conducting surveys in both Hindi and Punjabi which would be beneficial and will help researchers understand the perceptions of those AIs who don't speak English. Distributing BMIS and demographic survey to South Asian Public Health Association (SAPHA) would be informative and would help to generalize to other areas of the US.

Based on study findings, encouraging family discussions and religious leaders involvement will be effective method to help to promote organ donation. Educating the

AIs on organ donation will definitely lead to positive outcomes. Teaching and informing on what exactly organ donation is and how to register will also be beneficial.

By increasing organ donation awareness in one of the growing Asian population in the US, it will help to increase allocation in this AI group. Reaching out one race at a time to increase organ donation awareness to help increase organ allocation will help many have a second chance at life.

References

- Asian American Health Initiative, (2005). Who are Asian Americans? Retrieved from:
<http://www.aahiinfo.org/english/asianAmericans.php>
- Boparai, J., Davila, H., & Chandalia, M. (2011). Cardiovascular disease in Asian Indians living in the United States. *Current Cardiovascular Risk Reports*, 5(3), 240-245
- Fishbein, M.A. & Ajzen, I. (1975). *Belief, attitude, intention and behavior: an introduction to theory and research*, Reading, MA, Addison Wesley
- Ghorbani, F., Khoddami-Vishteh, H., Ghobadi, O., Shafaghi, S., Louyeh, A., et al. (2011). Causes of family refusal for organ donation. *Transplantation Proceedings*, 43(2), 405-406.
- Gilligan, C., Sanson-Fisher, R., & Turon, H. (2012). The organ donation conundrum. *Progress in transplantation* 22(3), 312-316.
- Glasgow, M., & Bello, G. (2007). Bone marrow donation: Factors influencing intentions in African Americans. *Oncology Nursing Forum*, 34(2), 369-377. Retrieved from:
<http://search.ebscohost.com.libaccess.sjlibrary.org/login.aspx?direct=true&db=rzh&AI=f=20095;1-1999&site=ehost-live>
- Goldstein, M., Lubezky, N., Yushkov, Y., Bae, C., & Guarrera, J. (2012). Innovations in organ donation. *The Mount Sinai Journal of Medicine*, 79(3), 351-364.
- Hafzalah, M., Azzam, R., Testa, G., & Hoehn, K. (2014). Improving the potential for organ donation in an inner city Muslim American community: The impact of a religious educational intervention. *Clinical Transplantation*, 28(2), 192-197.

- Jeffres, L., Carroll, J., Rubenking, B., & Amschlinger, J. (2008). Communication as a predictor of willingness to donate one's organs: An addition to the theory of reasoned action. *Progress in Transplantation*, 18(4), 257-262.
- Law, D., & McNiesh, S. (2012). Exploring barriers to organ donation in the African-American communities of California. *Journal of National Black Nurses' Association: JNBNA*, 23(1), 59.
- Lee, J., Brancati, F., & Yeh, H. (2011). Trends in the prevalence of type 2 diabetes in Asians versus Whites results from the United States national health interview survey, 1997-2008. *Diabetes Care*, 34(2), 353-357.
- Mayo Clinic. (2008). Why Is there such a high incidence of diabetes among Asian Indians?. *ScienceDaily*. Retrieved May 4, 2016 from www.sciencedaily.com/releases/2008/02/080229112210.htm
- Mayo Clinic (2014). Nonalcoholic fatty liver disease. Retrieved from: <http://www.mayoclinic.org/diseases-conditions/nonalcoholic-fatty-liver-disease/basics/definition/con-20027761>
- Morning, A. (2001). The racial self-identification of south Asians in the United States. *Journal of Ethnic and Migration Studies*, 27(1), 61-79.
- Organ Procurement and Transplantation Network (2016). Data. Retrieved from: <https://optn.transplant.hrsa.gov/converge/latestData/rptData.asp>
- OPTN (2015) National data. Retrieved from: <http://optn.transplant.hrsa.gov/converge/latestdata/viewdatareports.asp>

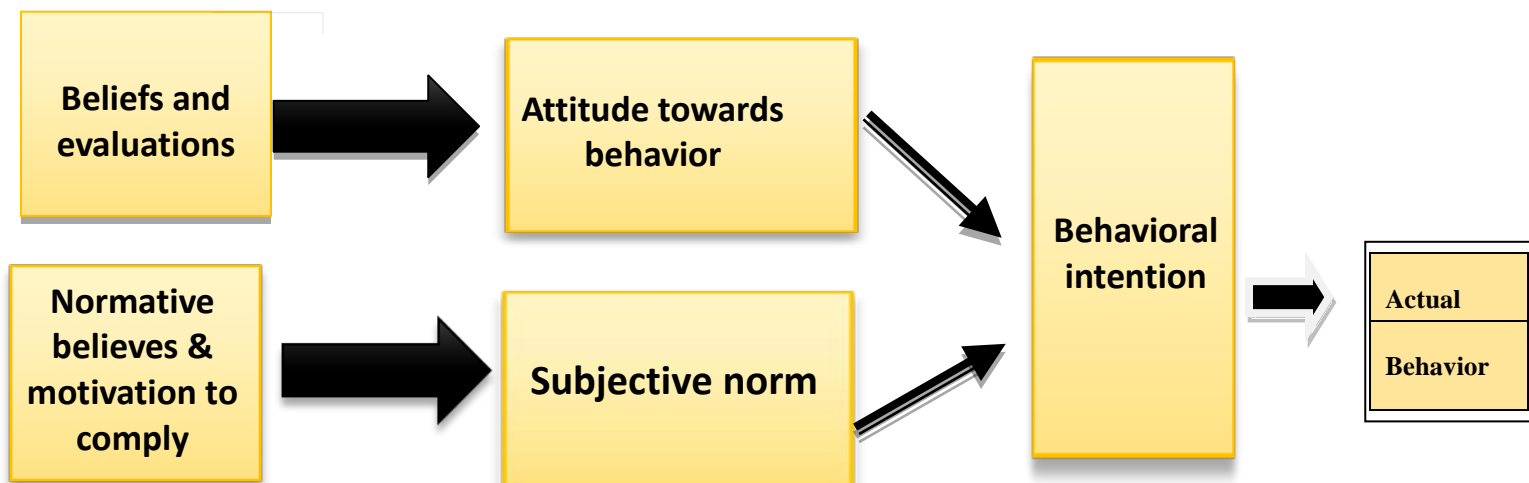
- Quick, B., LaVoie, N., Scott, A., Bosch, D., & Morgan, S. (2012). Perceptions about organ donation among African American, Hispanic, and White high school students. *Qualitative Health Research, 22*(7), 921-933.
- Rumsey, S., Hurford, D., & Cole, A. (2003). Influence of knowledge and religiousness on attitudes toward organ donation. *Transplantation Proceedings, 35*(8), 2845-2850.
- Salim, A., Bery, C., Ley, E., Schulman, D., Navarro, S., et al. (2012). A focused educational program after religious services to improve organ donation in Hispanic Americans. *Clinical Transplantation, 26*(6), E634-E640.
- Suinn, R., Ahuna, C., & Khoo, G. (1992). The suinn-lew asian self-identity acculturation scale: Concurrent and factorial validation. *Educational and Psychological Measurement, 52*(4), 1041-1046.
- Trompeta, J., Cooper, B., Ascher, N., Kools, S., Kennedy, C., et al. (2012). Asian American adolescents' willingness to donate organs and engage in family discussion about organ donation and transplantation. *Progress in Transplantation, 22*(1), 33.
- Trompeta, J.A, Chen. J.L, Cooper. B., Ascher, N., & Kools, S. (2010). Development of the organ donation and transplantation knowledge survey for use in Asian American adolescents. *Transplant Proc.*2010; 42(5): 1427-1431
- United Network for Organ Sharing (UNOS), (2016). Waiting list candidates by organ type-All states. Retrieved from: [https://www.unos.org/data/transplant-trends/#waitlists_by_organ+state+All States](https://www.unos.org/data/transplant-trends/#waitlists_by_organ+state+All+States).
- U.S. Census Bureau. (2010). Asian Population: 2010. Retrieved from www.census.gov/prod/cen2010/briefs/c2010br-11.pdf

US Department of Health and Human Services. (2015). The need is real: Data. Retrieved from: <http://www.organdonor.gov/about/data.html>

Wong, L. (2010). Factors limiting deceased organ donation: Focus groups' perspective from culturally diverse community. *Transplantation Proceedings*, 42(5), 1439-1444.

APPENDICES

APPENDIX A: Conceptual Framework



APPENDIX B: Recruitment Flyer



Exploring perceptions of Asian Indians regarding organ donation

Study Purpose:

The purpose of this study is to explore the perceptions of Asian Indians on organ donation. The goal is to get a better understanding of this population's views on organ donation to help increase organ awareness and increase organ allocation

Who can participate?

You may qualify for this research study if you meet the following criteria: a) be 18 years of age or older; b) be able to read and write in English; c) self-identify as Asian Indian; d) attend the Fremont Sikh Temple or the Sunnyvale Hindu Temple; e) or receive the email link via SAPHA in order to participate. Participants will not be excluded based on gender.

When and Where?

The research study will be conducted from September to November. Time and dates are to be announced. The research study will take place at both the Fremont Sikh Temple in Fremont, CA and at the Sunnyvale Hindu Temple, in Sunnyvale, CA and via online thru South Asian Indian Public Health Association.

What do the participants have to do to participate in the study?

Participants who choose to participate in this study will complete a questionnaire and demographic data sheet. Completion of the questionnaire takes 10-15 minutes approximately. Participants will be able to enter a raffle drawing for 10 \$10 gift cards to Starbucks, Baskin Robbins or Jamba Juice, after the completion of the questionnaire. For any questions or concerns please email Sandip Suprai at ssuprai@gmail.com or Dr. Goyal at deepika.goyal@sjsu.edu.

APPENDIX C: Consent to Participate in a Research Study

TITLE: Exploring Asian Indian's perceptions regarding organ donation

INVESTIGATOR: Sandip Suprai, NP-BC, MSN, BSN, Doctoral Student

PURPOSE: The purpose of this study is to explore the perceptions of Asian Indians on organ donation. The goal is to get a better understanding of this population's views on organ donation to help increase organ awareness and increase organ allocation.

PROCEDURES: You are being asked to fill out a Likert-scale questionnaire on organ donation along with some open ended questions to help the nurse researcher better understand the Asian Indians views on organ donation. This will take approximately 10-15 minutes. You will also be asked to complete a demographic data sheet. These are the only requests that will be made of you.

POTENTIAL RISK

& DISCOMFORTS: There is a slight risk that a person may become upset/emotional when completing the form on organ donation. The nurse researcher and another colleague will be available for any support if needed. A resource sheet is attached for more information on organ donation and contact information of the researcher for further support, questions or concerns.

POTENTIAL BENEFITS:

The participant will have an opportunity to discover his/her stance on organ donation and will bring about organ donation awareness.

CONFIDENTIALITY: Your name will never appear on any survey. No identity will be made in the data analysis. All written materials and consent forms will be stored in a locked file in the researcher's home. Your responses will only appear in data summaries.

RIGHT TO

WITHDRAW: Your participation is voluntary. You may refuse to participate and withdraw from the study at any time.

SUMMARY OF RESULTS:

A summary of the results of this research will be given to you at no cost upon request

COMPENSATION: For your time and participation, you will be able to qualify to

enter a raffle drawing for \$10 gift cards to Starbucks, Jamba Juice or Baskin Robbins.

**VOLUNTARY
CONSENT:**

I have read the above statement and understand what is being asked of me. I understand that my participation is voluntary and that I am free to withdraw my consent at any time for any reason. On these terms, I certify that I am willing to participate in this research project.

I further understand that should I have any further questions about my participation in this study, I may call Sandip Suprai (510-378-2958)/email at ssuprai@gmail.com or Deepika Goyal at deepika.goyal@sjsu.edu and will be given a chance to talk in confidence to the researcher.

APPENDIX D: Bone Marrow Intention Scale Tool (Modified Version)

Please read carefully!

People have many thoughts about organ donation. I would like to know **your** opinion about organ donation. Please answer several questions using a rating scale from -3 to +3, where -3 means you strongly disagree, -2 means you disagree, -1 means you somewhat disagree, means 0 means you are in the middle or you are unsure of how you feel, +1 means you somewhat agree, +2 means you agree, and +3 means you strongly agree. Please put a circle around the number that best describes your opinion.

For example, if you are asked to rate a certain food on a scale from -3 to +3, “Samosa’s at the new restaurant are good,” and you agree the food is good, then you would circle the number +2 like this:

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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For example, if you are asked to rate a certain food on a scale from -3 to +3, “Samosa’s at the new restaurant are good,” and you strongly disagree, then you would circle the number -3 like this:

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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You may be asked to use other rating scales such as “extremely unlikely to extremely likely” or “not at all to very much”. If you have any questions, feel free to ask the nurse researcher to assist you. In completing the questionnaire, please remember the following:

- There are no right or wrong answers. I am interested in your opinion.
- Please put a circle around the number that best describes your opinion.
- Please answer all the questions - do not leave any question blank.
- Do not write your name on any page.

1. In general, how much do you want to do what your partner (husband, wife, boyfriend, girlfriend) thinks you should do?

Not at all	-3	-2	-1	0	+1	+2	+3	Very Much
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2. I would not want to give my organs to a very old or elderly person.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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3. My partner's (husband, wife, boyfriend, girlfriend) opinion about whether I should donate organs is important to me.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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4. Knowing more about organ donation might encourage me to donate my organs.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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5. To me, saving someone's life by donating my organs is:

Extremely Bad	-3	-2	-1	0	+1	+2	+3	Extremely Good
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6. Knowing about organ donation may encourage Asian Indians to donate organs.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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7. My family would approve of me donating my organs.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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8. My fellow temple members' opinions about whether I should donate organs are important to me.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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9. The concerns of taking care of my children in the next twelve months would make it difficult for me to donate an organ.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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10. I would donate my organs to someone who is a different race than me.

Extremely unlikely	-3	-2	-1	0	+1	+2	+3	Extremely likely
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11. I think my partner (husband, wife, boyfriend, girlfriend) would approve of me donating organs.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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12. If I donate organs, I believe important/famous people will get my organs first before regular/ordinary people

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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13. In general., how much do you want to do what your fellow temple members think you should do?.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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14. In general, how much do you want to do what your friends think you should do?

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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15. If I donate my organs, I believe it may go to a white person before an Asian Indian.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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16. I would prefer to only give my organs to children.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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17. The possibility that my organs will go to someone who is a different race than me worries me.

Not all	All	-3	-2	-1	0	+1	+2	+3	Very Much
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18. I believe donating organs is:

Extremely Bad	-3	-2	-1	0	+1	+2	+3	Extremely Good
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19. If I knew more about organ donation, I would be more likely to donate my organs.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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20. My friends would approve of me donating my organs.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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21. In general how much do you want to do what your family thinks you should do?

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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22. My family's opinion about whether I should donate organs is important to me.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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23. Helping another person by donating my organs is:

Extremely Bad	-3	-2	-1	0	+1	+2	+3	Extremely Good
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24. I prefer to only give my organs to a close friend or family member.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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25. I would give my organs to a stranger if they needed it.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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26. The possibility that important/famous people get organs first before regular/ordinary people worries me.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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27. My temple would approve of me donating bone marrow.

Not at All	-3	-2	-1	0	+1	+2	+3	Very Much
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28. I would not mind giving my organs to a very old or elderly person

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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29. If I donate my organs, it may not help someone.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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30. I would not mind giving my organs to whoever needs it.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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31. The possibility that a white patient might receive my donated bone marrow before an Asian Indian worries me.

Not at all	-3	-2	-1	0	+1	+2	+3	Very much
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32. I prefer to only give my organs to a person who does not use drugs.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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33. Donating organs is:

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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34. I would not mind giving my organs to a person who uses drugs.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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35. If Asian Indians know about bone marrow, they will be more likely to donate their bone marrow.

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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36. It is mostly up to me whether or not I register to become an organ donor:

Strongly Disagree	-3	-2	-1	0	+1	+2	+3	Strongly Agree
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37. How much control do you believe you have over registering to become a organ donor within the next twelve months.

No Control	-3	-2	-1	0	+1	+2	+3	Complete Control
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Please circle your response.

38. What is the best way to get information to you about bone marrow donation?

- a. Radio
- b. Television
- c. Pamphlets
- d. Flyers on bulletin boards
- e. Hearing from someone who donated their bone marrow
- f. Other _____

Please write in your answers below

39. Have you spoken to your family about your wishes to be an organ donor, if something were to happen to you? Please explain.

40. If there was nothing that could be done to save your life, are you willing to donate your organs? Please explain.

If you are not an organ donor, what are some reasons that prevent you from becoming a donor? (if you are a registered donor please write not applicable)

APPENDIX E: BONE MARROW INTENTION SCALE RESULTS

1. In general, how much do you want to do what your partner (husband, wife, boyfriend, girlfriend) thinks you should do?

Response	<i>n</i>	%
1(not at all)	6	2.8
2	5	2.3
3	3	1.4
4	16	7.4
5	27	12.6
6	83	38.6
7 (very much)	75	34.9

2. I would not want to give my organs to a very old or elderly person.

Response	<i>n</i>	%
1(strongly disagree)	67	31.2
2	11	5.1
3	16	7.4
4	51	23.7
5	42	19.5
6	16	7.4
7 (strongly agree)	12	5.6

3. My partner's (husband, wife, boyfriend, girlfriend) opinion about whether I should donate organs is important to me.

Response	<i>n</i>	%
1(not at all)	14	6.5
2	3	1.4
3	3	1.4
4	21	9.8
5	18	8.4
6	91	42.3
7 (very much)	65	30.2

4. Knowing more about organ donation might encourage me to donate my organs.

Response	<i>n</i>	%
1(strongly disagree)	3	1.4
2	2	.9
3	0	0.0
4	12	5.6
5	22	10.2
6	53	24.7
7 (strongly agree)	123	57.2

5. To me, saving someone's life by donating my organs is:

Response	<i>n</i>	%
1(extremely bad)	1	1
2	0	0.0
3	0	0.0
4	6	2.8
5	2	.9
6	33	15.3
7 (extremely good)	173	80.5

6. Knowing about organ donation may encourage Asian Indians to donate organs.

Response	<i>n</i>	%
1(strongly disagree)	2	.9
2	1	.5
3	3	1.4
4	10	4.7
5	20	9.3
6	64	29.8
7 (strongly agree)	116	53.4

7.

8. My family would approve of me donating my organs.

Response	<i>n</i>	%
1(not at all)	8	3.7
2	5	2.3
3	4	1.9
4	20	9.3
5	36	16.7
6	68	31.6
7 (very much)	74	34.4

9. My fellow temple members' opinions about whether I should donate organs are important to me.

Response	<i>n</i>	%
1(not at all)	45	20.9
2	3	1.4
3	1	.5
4	35	16.3
5	27	12.6
6	67	31.2
7 (very much)	37	17.2

10. The concerns of taking care of my children in the next twelve months would make it difficult for me to donate an organ.

Response	<i>n</i>	%
1(strongly disagree)	10	4.7
2	6	2.8
3	4	1.9
4	42	19.6
5	17	7.9
6	50	23.4
7 (strongly agree)	85	39.7

11. I would donate my organs to someone who is a different race than me.

Response	<i>n</i>	%
1(extremely unlikely)	8	3.7
2	1	.5
3	2	.9
4	20	9.3
5	10	4.7
6	49	22.8
7 (extremely likely)	125	58.1

12. I think my partner (husband, wife, boyfriend, girlfriend) would approve of me donating organs.

Response	<i>n</i>	%
1(not at all)	14	6.5
2	0	0.0
3	1	.5
4	23	10.7
5	24	11.2
6	63	29.3
7 (very much)	90	41.9

13. If I donate organs, I believe important/famous people will get my organs first before regular/ordinary people

Response	<i>n</i>	%
1(strongly disagree)	55	25.6
2	20	9.3
3	7	3.3
4	42	19.5
5	28	13.0
6	28	13.0
7 (strongly agree)	35	16.3

14. In general, how much do you want to do what your fellow temple members think you should do?

Response	<i>n</i>	%
1(not at all)	32	15.0
2	4	1.9
3	3	1.4
4	22	10.3
5	40	18.7
6	55	25.7
7 (very much)	58	27.1

15. In general, how much do you want to do what your friends think you should do?

Response	<i>n</i>	%
1(not at all)	32	15.0
2	12	5.6
3	6	2.8
4	35	16.4
5	50	23.5
6	46	21.6
7 (very much)	32	15.0

16. If I donate my organs, I believe it may go to a white person before an Asian Indian.

Response	<i>n</i>	%
1(strongly disagree)	61	28.4
2	5	2.3
3	3	1.4
4	82	38.1
5	20	9.3
6	21	9.8
7 (strongly agree)	23	10.7

17. I would prefer to only give my organs to children.

Response	<i>n</i>	%
1(strongly disagree)	43	20.0
2	8	3.7
3	6	2.8
4	47	21.9
5	33	15.3
6	48	22.3
7 (strongly agree)	30	14.0

18. The possibility that my organs will go to someone who is a different race than me worries me.

Response	<i>n</i>	%
1(not at all)	77	35.8
2	9	4.2
3	1	.5
4	20	9.3
5	19	8.8
6	38	17.7
7 (very much)	51	23.7

19. I believe donating organs is:

Response	<i>n</i>	%
1(extremely bad)	3	1.4
2	1	.5
3	2	.9
4	10	4.7
5	4	1.9
6	38	17.7
7 (extremely good)	157	73.0

20. If I knew more about organ donation, I would be more likely to donate my organs.

Response	<i>n</i>	%
1(strongly disagree)	2	.9
2	0	0.0
3	3	1.4
4	9	4.2
5	24	11.3
6	64	30.0
7 (strongly agree)	111	52.1

21. My friends would approve of me donating my organs.

Response	<i>n</i>	%
1(not at all)	9	4.3
2	0	0.0
3	4	1.9
4	27	12.8
5	20	9.5
6	66	31.3
7 (very much)	85	40.3

22. In general how much do you want to do what your family thinks you should do?

Response	<i>n</i>	%
1(not at all)	7	3.3
2	3	1.4
3	3	1.4
4	14	6.5
5	22	10.3
6	91	42.5
7 (very much)	74	34.6

23. My family's opinion about whether I should donate organs is important to me.

Response	<i>n</i>	%
1(not at all)	9	4.2
2	0	0.0
3	2	.9
4	12	5.6
5	28	13.0
6	78	36.3
7 (very much)	86	40.0

24. Helping another person by donating my organs is:

Response	<i>n</i>	%
1(extremely bad)	4	1.9
2	3	1.4
3	5	2.3
4	10	4.7
5	9	4.2
6	31	14.4
7 (extremely good)	153	71.2

25. I prefer to only give my organs to a close friend or family member.

Response	<i>n</i>	%
1(strongly disagree)	49	22.8
2	21	9.8
3	4	1.9
4	61	28.4
5	15	7.0
6	26	12.1
7 (strongly agree)	39	18.1

26. I would give my organs to a stranger if they needed it.

Response	<i>n</i>	%
1(strongly disagree)	7	3.3
2	1	.5
3	0	0.0
4	23	10.7
5	6	2.8
6	38	17.7
7 (strongly agree)	140	65.1

27. The possibility that important/famous people get organs first before regular/ordinary people worries me.

Response	<i>n</i>	%
1(not at all)	48	22.4
2	14	6.5
3	13	6.1
4	40	18.7
5	20	9.3
6	36	16.8
7 (very much)	43	20.1

28. My temple would approve of me donating organs.

Response	<i>n</i>	%
1(not at all)	6	2.8
2	2	.9
3	1	.5
4	39	18.4
5	12	5.7
6	54	25.5
7 (very much)	98	46.2

29. I would not mind giving my organs to a very old or elderly person

Response	<i>n</i>	%
1(strongly disagree)	11	5.1
2	8	3.7
3	7	3.3
4	30	14.0
5	40	18.7
6	48	22.4
7 (strongly agree)	70	32.7

30. If I donate my organs, it may not help someone.

Response	<i>n</i>	%
1(strongly disagree)	90	42.1
2	9	4.2
3	12	5.6
4	38	17.8
5	10	4.7
6	21	9.8
7 (strongly agree)	34	15.9

31. I would not mind giving my organs to whoever needs it.

Response	<i>n</i>	%
1(strongly disagree)	6	2.8
2	5	2.3
3	1	.5
4	17	7.9
5	6	2.8
6	38	17.8
7 (strongly agree)	141	65.9

32. The possibility that a white patient might receive my donated organs before an Asian Indian worries me.

Response	<i>n</i>	%
1(not at all)	72	34.0
2	30	14.2
3	9	4.2
4	36	17.0
5	6	2.8
6	24	11.3
7 (very much)	35	16.5

33. I prefer to only give my organs to a person who does not use drugs.

Response	<i>n</i>	%
1(strongly disagree)	21	9.8
2	2	.9
3	8	3.7
4	24	11.2
5	12	5.6
6	32	15.0
7 (strongly agree)	115	53.7

34. Donating organs is:

Response	<i>n</i>	%
1(strongly disagree)	7	3.3
2	5	2.4
3	3	1.4
4	10	4.7
5	3	1.4
6	20	9.5
7 (strongly agree)	163	77.3

35. I would not mind giving my organs to a person who uses drugs.

Response	<i>n</i>	%
1(strongly disagree)	96	44.9
2	10	4.7
3	4	1.9
4	29	13.6
5	10	4.7
6	31	14.5
7 (strongly agree)	34	15.9

36. If Asian Indians know about organs, they will be more likely to donate their organs.

Response	<i>n</i>	%
1(strongly disagree)	2	.9
2	2	.9
3	1	.5
4	17	7.9
5	41	19.2
6	59	27.6
7 (strongly agree)	92	43.0

37. It is mostly up to me whether or not I register to become an organ donor:

Response	<i>n</i>	%
1(strongly disagree)	4	1.9
2	3	1.4
3	1	.5
4	22	10.3
5	17	8.0
6	51	23.9
7 (strongly agree)	115	54.0

38. How much control do you believe you have over registering to become an organ donor within the next twelve months.

Response	<i>n</i>	%
1(no control)	5	2.3
2	3	1.4
3	4	1.9
4	24	11.3
5	39	18.3
6	63	29.6
7 (complete control)	75	35.2

TABLE 1: Participant Characteristics

Demographic	<i>n</i>	<i>%</i>
Gender		
Male	136	63.3
Female	78	36.3
Education Level		
Less than high school	4	1.9
High school graduate	17	7.9
Some college education	37	17.2
College graduate	78	36.3
Graduate degree	77	35.8
Marital Status		
Single	56	26.0
Married	155	72.1
Widowed	0	0.0
Separated	4	1.9
Religion		
Hindu	98	45.6
Sikh	113	52.6
Jain	1	0.5
Christian	3	1.4
Occupation		
Health care / Medical	43	20.2
Computer / Technical	86	40.4
Teacher / Professor	74	34.7
Other Professional	9	4.2
Country of birth		
India	195	90.7
United States	14	6.5
Nepal	1	0.5
UAE	1	0.5
United Kingdom	4	1.9
Language		
Hindi	138	64.8
Punjabi	64	30.0
Tamil	6	2.8
Urdu	3	1.4
Telugu	1	0.5
Gujarati	1	0.5