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**ATTITUDES AND KNOWLEDGE ABOUT ORGAN DONATION  
AND TRANSPLANTATION AMONG ASIAN AMERICAN ADOLESCENTS**

**by**

**JOYCE A. TROMPETA**

**DISSERTATION**

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**Submitted in partial satisfaction of the requirements for the degree of**

**DOCTOR OF PHILOSOPHY**

**in**

**NURSING**

**in the**

**GRADUATE DIVISION**

**of the**

**UNIVERSITY OF CALIFORNIA, SAN FRANCISCO**

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**By**

**Joyce A. Trompeta**

## DEDICATION

This dissertation is dedicated to my parents,  
in honor and loving memory;  
to Bailey, Wally, and Buddy;  
and to my husband, Curtis Lee, M.D.,  
whose love, support, patience, and wisdom sustain me.

## ACKNOWLEDGMENTS

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## **ABSTRACT**

### **ATTITUDES AND KNOWLEDGE ABOUT ORGAN DONATION AND TRANSPLANTATION AMONG ASIAN AMERICAN ADOLESCENTS**

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University of California, San Francisco, 2008

The need and demand for kidney transplantation has a significant impact on the quality and quantity of life of Asian Americans who suffer from end-stage renal disease. However, little is known about the attitudes and knowledge regarding organ donation and transplantation among Asian American adolescents. A cross-sectional study design was used to examine the attitudes and knowledge regarding organ donation and transplantation among Asian American adolescents and factors related to willingness to donate and family discussion. A total sample of 121 Asian American adolescents, 16 and 17 years old who identified themselves as having Asian descent of Japanese, Filipino, Korean or Chinese, was recruited from three high schools on the Big Island of Hawaii. Adolescents completed basic demographic information, the Organ Donation Attitude Survey Modified (M-ODAS), the newly developed Organ Donation and Transplantation Knowledge Survey (ODTK), and the Suinn-Lew Asian Self –Identity Acculturation Scale (SL-ASIA). The adolescent’s parent or guardian also completed basic demographic information. Linear regression was performed to examine the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation.



Stepwise multiple linear regressions were performed on those variables of statistical significance obtained from study constructs. Findings revealed Asian American adolescents have positive attitudes about organ donation are knowledgeable about organ donation issues, are willing to donate, and engaged in family discussion. Results indicate that positive knowledge related to general aspects about organ donation and cultural limitations in receiving an organ transplant, a high level of acculturation, and a low level of negative attitudes are associated with and predict willingness to donate ( $R^2 = .402$ ,  $F = 18.86$ ,  $p < .005$ ). Asian American adolescents with approving or positive attitudes will engage in family discussion about organ donation ( $R^2 = .195$ ,  $F = 13.85$ ,  $p < .005$ ). Significant findings from this study suggest the incorporation of organ donation education in high schools is necessary to reinforce and maintain high knowledge and awareness. Asian American adolescents have the influence to raise organ donation awareness with their parents and families.

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## **CHAPTER ONE**

### **INTRODUCTION AND CONCEPTUAL FRAMEWORK**

#### **Background**

The number of Asian Americans on the transplant waiting list has more than tripled from 1993 (1,186) to 2006 (5,886) (Scientific Registry of Transplant Recipients, 2004; United Network of Organ Sharing [UNOS], 2006). The number of new end-stage renal disease (ESRD) cases in Asian Americans increased from 1,227 to 2,970 between 1990 and 1999 (U.S. Renal Data System, 2001). Asian Americans are reported to have ESRD growth rates that are approximately 50 % higher than Caucasians due to the prevalence of type II diabetes mellitus and hypertension (Mau et al., 2003). However, the organ donation rate is far less in Asian Americans compared to Caucasians. In 2005, 2.1% of the nation's organs were procured from Asian Americans compared to 68.2% organs from Caucasians (UNOS, 2006). Because of the marked incidence of ESRD in Asian Americans, the need and demand for kidney transplantation will have a significant impact on the quality and quantity of life and inflate the cost of healthcare of minorities in the future (Churak, 2005; Kasiske, London, & Ellison, 1998).

Racial differences in transplantation rates are seen in the predominantly ethnic population of Hawaii, whose inhabitants have a markedly reduced likelihood of receiving kidney transplants compared with patients living in the continental U. S. (U. S. Renal Data System, 2003). In Hawaii, the incidence of ESRD is 33% higher than the U.S. national average (U.S. Renal Data System, 2005). The TransPacific Renal Network indicated that diabetes mellitus may account for over 55% of ESRD incidence in Asian Americans (Tanner, 2000). As a result, the demand for kidney transplantation is likely to



rise as the relatively young Asian American population ages. However, Asian Americans (Chinese, Japanese, Filipino, Korean) have been reluctant to consent to organ donation (Cheung, Alden, & Wheeler, 1998). Asian Americans appear to be less willing to donate their organs possible due to religious and cultural reasons (personal beliefs, attitudes and knowledge). Cultural influences on the concepts of death and beliefs regarding the sanctity of the human body are possible barriers to obtaining consent for deceased organ donation (Vathsala, 2004).

Asian Americans are the most diverse and the fastest growing of America's ethnic groups, yet relatively little is known about their health status and general health beliefs (Ghosh, 2003). Given the increased number of Asian Americans with ESRD, the growing Asian American populations and subsequent generations of Asian Americans evolving, the conceptual nature of organ donation and transplantation needs to be examined. Few studies have examined the potential sources of kidney donation disparities in Asian Americans, such as, cultural factors, language barriers and health access factors (Lopes, 2004; Mau et al., 2003). These studies found that in many Asian cultures, seeking assistance from others, especially outside their own culture is unacceptable and health care delivery systems appropriately for the ethnically and culturally diverse population may need to be developed to overcome social and cultural barriers.

Empirical literature with Asian American families and adolescents is limited. There is scarce to non-existent literature which explores and focuses on Asian American adolescents' attitudes and knowledge regarding organ donation and transplantation.

It is important to examine adolescent populations and their perceptions on health issues because young people play a key role in helping elders access and understand healthcare (Gollin, Harrigan, Perez, Easa, & Calderon, 2005).

Organ donor research has lacked a strong theoretical foundation (Radecki & Jaccard, 1997). Theoretical frameworks provide a conceptual foundation to understanding one's decision regarding organ donation. Although several theories have been applied towards effectiveness in guiding interventions and educational programs to promote organ donation or to explain human behavior, they have been observed primarily in adult populations from Western culture. Comprehensive review of the literature reveals no theoretically based explanations of the cultural influence in Asian Americans' choice of organ donation. Additionally, researchers who have examined organ donation knowledge, attitudes and beliefs have offered no explicit theoretical basis to their investigations. Most importantly, acculturation theory is nonexistent in the literature which has examined organ donation practices in Asian populations. By knowing the acculturation levels of both adolescent and parents, this theory may help explain or predict the attitudes and knowledge regarding organ donation. Additionally, acculturation theory would be applicable in guiding the development of culturally tailored educational programs to promote organ donation.

Research efforts need to target Asian American teen populations because they have the influence to promote organ donation awareness and to facilitate organ donation discussions and decisions in their families. These teens are faced with their own decision as organ donors when they obtain their driver's license. Once barriers to consent for organ donation can be identified, educational interventions and promotional campaigns

can be designed to overcome these barriers and efforts can be made to increase donation. Thus, the aim of this dissertation study is to explore and examine the attitudes and knowledge about organ donation and transplantation among Asian American adolescents living on the Big Island of Hawaii. Additionally, acculturation levels of Asian American adolescents will be examined in relationship to their willingness to donate and to discuss the issue of organ donation with their families.

### **Statement of the Problem**

Asian Americans are becoming the largest minority group in the United States. The Asian American population is forecasted to increase 213% between 2000 and 2050, compared to the 49% projected increase in the general population (Lugalia & Overturf, 2004). Currently, 26% of Asian Americans in the U.S. are under 18 years of age (Reeves & Bennett, 2003).

Asian-born residents constitute one fourth of the U.S. nation's total foreign-born population. It has been projected that by 2050 approximately 1 out of 10 Americans will have an Asian ancestry (U.S. Bureau of the Census, 1992). The largest concentrations of Asian Americans reside in California, Hawaii and New York. This high level of diversity is surpassed in Hawaii where 71% of the population is of Asian descent and only 26% of the population is Caucasian (Yatabe, Koseki, & Braun, 1996).

According to the national U.S. Renal Data System, the prevalence of ESRD in the U.S. has nearly doubled over the past decade with the sharpest rise in Asian Americans. As a result, the demand for kidney transplantation is likely to rise as the relatively young Asian population ages. In addition, the proportion of Hawaii's elderly population is growing and at a rate above the national average (Mau et al., 2003). Between 1990 and

1999, there was a 62% increase in people over 75 years old and 13% in those 65 to 74 years old (Mau et al., 2003). An increasingly aging population represents a higher risk for age-related health problems, such as, diabetes mellitus, hypertension and ESRD.

Transplantation is less accessible to and less successful in minority groups who are less willing to consent to organ donation. This contributes to issues pertaining to genetic compatibility and difficulty of obtaining a close tissue match in people of different ethnic groups. Human leukocyte antigens (HLA) matching is a well-described factor that contributes to racial and ethnic disparities in kidney transplantation. The distribution of HLA antigens differs among races (Wolfe & Toomey, 2004). A predominantly Caucasian donor pool favors Caucasian recipients and places minorities at a disadvantage (Gaston, Ayers, Dooley, & Drethelem, 1993). Because of differences in, as well as, predominant blood type (blood type B being common in Asians, while the more common blood type O predominates in Caucasians), it is more difficult to make effective matches between donors and Asian recipients (Alden & Cheung, 2000, p.293).

In Hawaii, over 400 people are currently on the transplant waiting list, but fewer than 20% receive a transplant each year and nearly 20% die yearly; the majority of people being Asian Americans (Asian Pacific Islander) (Organ Procurement and Transplantation Network, 2006). There remains a great need for organ donation and studies have suggested that Asian Americans are reluctant to donate (Albright, Wong, Dela Cruz, Abe, & Sagayadoro, 2007; Alden & Cheung, 2000; Cheung et al., 1998).

In order to promote and facilitate organ donation rates in Asian American populations, a body of knowledge that describes Asian American attitudes and knowledge towards organ donation and transplantation is essential so that the approach to

requesting organ donation is performed in a culturally sensitive manner. Additionally, culturally relevant and developmentally appropriate educational programs can be designed to raise organ donation awareness among Asian American populations specifically targeting adolescents.

### **Purpose of Study**

The purposes of this study are: (1) to describe the attitudes and knowledge of organ donation and transplantation among Asian American adolescents attending high school and living on the Big Island of Hawaii; (2) to examine the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents; (3) to determine whether attitudes and knowledge about organ donation and transplantation predict willingness to donate and family discussion about organ donation; and, (4) to examine the effect of acculturation on attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents.

### **Conceptual Framework**

In this dissertation research, the study framework will be based on acculturation theory, the Organ Donation Model (ODM) (Morgan, 2004), and theory in adolescent development. Although acculturation has not been mentioned in any of the published literature which examine organ donation practices, this theory is very important and applicable to understanding organ donation beliefs among Asian American populations. Organ donation decision is being conceptualized as being preventive health behavior and health promotion, whether it is by live donation (which may prevent an individual having

to initiate dialysis) or whether it is by organ donation at the time of one's death to someone on the deceased organ waiting list (which promotes available organs for people from their own ethnic group, including directed donation to a friend or family member with end-stage organ failure). The ODM postulates that willingness to engage in family discussions is a function of willingness to become a donor, which in turn is dependent on positive attitudes toward organ donation, a higher level of knowledge about donation, and positive social norms regarding organ donation.

### ***Acculturation Theory***

The theoretical conceptualization of acculturation is a complex learning process that occurs when individuals and groups come into continuous contact with different societies. Acculturation becomes the way in which an individual incorporates values and behaviors of the new culture into currently held values and behaviors. Involvement in one society does not necessitate a decrease in involvement in another; therefore, individuals can assume a number of acculturation positions (Berry, 1980). On the basis of this theoretical conceptualization, assessment of acculturation entails measurement of identification with the society of origin as well as with the dominant, new society. Such research typically investigates the extent to which ethnic identity persists over time within a dominant majority group context. Thus, acculturation is a critical factor to understand when examining the process of cultural adjustment and adaptation for Asian Americans (Liu, Pope-Davis, Nevitt, & Toporek, 1999).

The acculturation and adaptation process in immigrant families involves changes in family roles, structures and processes. The process of acculturation is an uneven occurrence as people may subjectively identify with their ethnic group and have ethnic

friends, but not speak the ethnic language. One key issue for immigrants is the process of reconciling the cultural differences between their country of origin and their adopted country. This reconciliation often involves discrepant beliefs, practices, behaviors and values by which an individual changes as a result of contact and interaction with another distinct culture (Berry et al., 1986).

A widely accepted and cited framework proposed by Berry (1980) and his colleagues conceptualized individual level of acculturation as a multidimensional process of change that occurs when individuals of differing cultural groups come into continuous contact (Berry, 1992; Berry, 1996; Berry & Kim, 1988; Berry & Sam, 1997). These changes result in a variety of acculturation positions determined according to how individuals deal with two central issues: (1) retention of, or immersion in, an ethnic society other than the dominant society and (2) adoption of, or immersion in, the dominant society. Therefore, individuals and groups can adopt several alternative attitudes or orientations to their heritage and host cultures. For example, if a family from the U.S. moves to Japan, they may adapt to Japanese culture by learning the language (while speaking English at home), eating new foods (while cooking favorite home cooked meals), establishing new relationships (while maintaining old ones), and respecting the Japanese tradition of taking off their shoes upon entering one's home.

Berry (1980) discussed adaptation as a means of dealing with acculturation conflict, which is the conflict people experience when confronting the differences between their culture of origin and the culture of their new environment. An individual's acculturation is related to the way certain questions are answered (Berry, 1980, p.13): first, "Is my cultural identity of value to be retained?" and secondly, "Are positive

relations with the larger (dominant) society to be sought?” Berry (1980) identified four varieties of acculturation based on the potential combination of answers: (1) *rejection* describes those who value their cultural identity and not that of the dominant group; (2) *assimilation* describes those who do value the relationship with the dominant culture; (3) *integration* is when people value cultural identity and seek relations with the dominant culture; and (4) *deculturation* describes people’s rejection of both their cultural identity and the dominant culture. An individual who falls into the category of deculturation may exhibit an alternative lifestyle that may not reflect mainstream society.

Berry and his colleagues further suggest that this paradigm considers individuals who are highly acculturated and have strong ethnic identity as *bicultural or integrated*, those who acculturate entirely into mainstream culture at the expense of ethnic identity as *assimilated*, those who do not acculturate while preserving strong ethnic identity as *separated*, and those who have no strong acculturative pattern or ethnic identity as *marginalized* (Berry, 1980; Berry, Kim, Minde, & Mok, 1987; Berry, Kim, Power, Young, & Bujaki, 1989). This model assumes that acculturation is a fluid, never ending process (Berry et al., 1986).

Members of immigrant families acculturate at different rates. Some research has found that parents’ level of acculturation has effects on family functioning and adolescent adjustment. Investigators have shown that adolescents whose immigrant parents did not adapt to the host culture had more psychological problems than did adolescents whose parents were integrated or assimilated (Koplow & Messinger, 1990). As adolescents attain independence and separate from their families, immigrant parents potentially view this as a rejection of their own culture of origin. In this dissertation study, the theory of



acculturation is an important variable to be examined due to the large multi-ethnic mix in Hawaii. Acculturation theory will help to further explain and predict the organ donation attitudes and knowledge of Asian American adolescents based on their level of acculturation.

### ***Organ Donation Model (ODM)***

Morgan (2004) developed the ODM (See Figure 1) based on existing theories to the field of organ donation research which includes research work from previous studies (Horton & Horton, 1990 & 1991; Kopfman & Smith, 1996; Skumanich & Kintsfather, 1996). These existing models, combined with the Theory of Reasoned Action (Fishbein & Ajzen, 1975), form the foundation of the ODM. Horton and Horton (1990, 1991) reported that knowledge of organ donation facts was found to be related to their attitude towards organ donation and their willingness to donate their own organs or the organs of a deceased loved one. Within the Theory of Reasoned Action, behavior is predicted by intention, which in turn is predicted by attitudes and perceived social pressure.

The ODM has been tested successfully using path analysis of responses from African-American adults (Morgan, Miller, & Arasaratnam, 2003), as well as large multi-ethnic population of adults (Morgan, Miller, & Arasaratnam, 2002). Additionally, another study of African Americans' willingness to donate organs also supported the model (Morgan & Cannon, 2003).

The main assumptions of the ODM include (Morgan, 2004): (1) people who are willing to talk to family members about organ donation will be more willing to become potential organ donors; (2) higher levels of knowledge, favorable attitudes, and favorable social norms will be positively associated with a greater willingness to talk about organ

donation with family members; and, (3) people who have family discussions about organ donation will have higher levels of knowledge, favorable attitudes, and favorable social norms.

Variables examined in the ODM include: (a) altruism and values, (b) knowledge, (c) attitudes toward organ donation, (d) perceived social norms supporting organ donation, (e) willingness/intent to donate, (f) sign organ donor card, and (g) talk to family. The ODM postulates that willingness to engage in family discussions is a function of willingness to become a donor, which in turn is dependent on positive attitudes toward organ donation, a higher level of knowledge about donation, and positive social norms regarding organ donation.

### **Adolescent Development**

The period of adolescence is a critical point of transition. It is a time when our social and intellectual growth changes our lives dramatically. However, what happens in adolescence is in large part determined by what has happened before it (Cunningham & Spencer, 2000; Lerner & Spanier, 1980). In other words, all stages of growth and development are related with early experiences having definite consequences later in life. According to Erikson, the developmental task in adolescence is the exploration of identity. The establishment of a true sense of a personal identity is the psychological connection between childhood and adulthood (Muuss, 1996). In order to acquire a strong and healthy ego identity, a child must receive consistent and meaningful recognition for his or her achievements and accomplishments (Muuss, 1996). Additionally, one's self-orientation is an important outcome of growing up in one's culture and the influence of family (Lerner & Castellino, 2002; Li & Yue, 2004).

The junior high and high school years, middle and late adolescent periods, have been associated with important tasks such as establishing independence from or interdependence with one's family and developing identity (Muuss, 1996). These developmental tasks pose particular challenges for Asian immigrant youths who are adapting to a new cultural environment. Establishing independence from one's parents may be especially challenging because Asian culture emphasizes and prioritizes strong connectedness with family ties and interdependency (Willgerodt & Killien, 2004).

Adolescents are confronted with the issue and decision of organ donation early on when they apply for their driver's license. The subject of organ donation may not have been formally discussed at home, but the adolescent most likely has been exposed to their parents' beliefs towards death and dying.

Because the period of adolescence is marked by the desire for autonomy, development of critical thinking and identity, adolescents may find the concept of organ donation to be challenging, interesting and important to their life and the lives of their family (Muuss, 1996). However, because early adolescents possess the personal fable of being infallible believing they are free from personal harm or death (Elkind, 1990), the issue of organ donation may not be an important decision to make for themselves. The belief in personal uniqueness becomes a conviction that he or she will not die and that death will happen to others, but not to oneself. During middle adolescence, when sensible decision making skills have been acquired, adolescents have an awareness of the consequences of their decision towards organ donation. It is during the later period of adolescence where the adolescent is capable of establishing true rather than self-interested interpersonal relations (Harter, 1999). As the adolescent develops better

cognition skills and becomes more capable of being empathic towards others, the issue of organ donation may have more of an impact.

Asian American adolescents already experience the normal developmental challenges while transitioning into adulthood, in addition to being raised to obey and follow the rules and beliefs of their parents. Autonomy and identity formation may be more of a struggle as they transition into adulthood as compared to their friends from the dominant Western culture. The strong sense of filial piety may have been a way of life for Asian American adolescents and they may feel a sense of disrespect to their parents if they were to approach them in discussing sensitive subjects, such as, organ donation. At the same time, these adolescents may have a deep desire for gaining independence in their decision making as they have been exposed to Western culture. Because of their development of critical thinking, these Asian American adolescents may find the need to discuss the choice of organ donation with their parents because of the cultural conflict they may be experiencing.

The choice of organ donation among Asian American adolescents may differ depending upon the exposure to Western culture. It is the second generation Asian American adolescents who may experience the most conflict with their parents as these adolescents have been more acculturated to Western values. Also, these second generation Asian American adolescents who were born in the U.S. may already experience communication and relational difficulties with their parents which may add to the barrier towards promoting the discussion of organ donation. However, if both Asian American adolescent and parents have high levels of acculturation, there may be more willingness to donate as they have both been more acculturated to Western beliefs.

This dissertation study will examine the acculturation levels of Asian American adolescents in Hawaii with their attitudes and knowledge about organ donation and transplantation. Additionally, acculturation will be examined with Asian American adolescents' willingness to donate and engage in family discussion about organ donation. Acculturation is an important factor to consider in examining organ donation practices among Asian American populations.

### **Significance of the Study**

#### ***Impending Kidney Transplant Crisis***

The worldwide incidence of type II diabetes mellitus is expected to double by 2010 (Mitch, 2004). This discouraging data is compounded by estimates that 11% of adults in the U.S. have chronic kidney disease who may require organ transplantation. Asians have a three to four times higher incidence of ESRD compared to Caucasians (Health Care Strategy Unit, 1994) due to the prevalence of type II diabetes mellitus and hypertension. It has been reported that 20% of Asians ages 40 to 49 have type II diabetes mellitus, and by the age of 65 the proportion rises to a third in Asians (Randhawa, 1998).

However, there is growing evidence of racial and ethnic disparities in renal transplantation. In 2002, a total of 14,722 transplants were performed: 8,453 (57%) in Caucasians compared to 579 (3.9%) in Asians. It is evident that the Asian population is at greater risk of diabetes and hypertension than Caucasians which makes them more susceptible to ESRD. As a result, the demand for kidney transplantation is likely to rise as the relatively young Asian population ages.

Renal replacement therapy has shown to improve quality of life in people with ESRD, and renal transplantation appears to produce greater improvements in quality of

life than dialysis (Keown, 2001). Kidney transplantation is also the most cost-saving of all kidney replacement therapy procedures (Renner, 1993), and is cost effective compared to long-term dialysis. Given the higher prevalence of ESRD in Asian Americans and lower organ donation rates, understanding the attitudes and knowledge of organ donation can help to identify barriers to organ donation and develop culturally appropriate organ donation programs.

### ***Barriers to Organ Donation***

The Health Resources and Services Administration launched the Breakthrough Collaborative initiatives in September 2003, which seek among other objectives to reduce the gap between donor pool by improving consent rates (Leichtman et al., 2008). The primary barrier to organ donation for all ethnic groups, including Caucasians, is the denial of family consent at the time of death of their loved one. Lee (1996) reported that in 1992 and 1993, Asians in the U.S. donated 12.4 organs per million population, compared to 27.5 for Caucasians. Although affirmative legislation regarding organ donation exists in the U.S. and most Asian countries, religious, ethnic, and cultural influences on concepts of death and beliefs regarding the sanctity of the human body remain major barriers to obtaining consent for deceased organ donation (Vathsala, 2004). This study will further examine the attitudes and knowledge about organ donation and transplantation among Asian American populations, most specifically adolescents.

Culturally appropriate interventions are needed to raise the awareness of the need for organ donation among Asian American populations specifically targeting adolescents, with efforts in promoting future consent to both living related and un-related organ donation and promoting signed organ donation cards supporting deceased organ donor

donation. These interventions with Asian American adolescents would possibly stimulate family conversation at home regarding organ donation issues. Successful campaigns and educational programs need to incorporate theoretical models, which focus on adolescent development and recognize the values of Asian American culture in order to increase organ donation and transplantation rates.

### **Assumptions**

Based on the ODM (Morgan, 2004), willingness to engage in family discussion is a function of willingness to become a donor, which in turn is dependent on positive attitudes toward organ donation. It is the assumption that people who are willing to talk to family members about organ donation have higher levels of knowledge, favorable attitudes, and will be more willing to become potential organ donors. Additionally, a higher level of knowledge about organ donation and positive social norms regarding organ donation may contribute to willingness to engage in family discussion.

Acculturation theory may help explain the attitudes and knowledge regarding organ donation. Adolescents typically acculturate at a faster rate than their parents and begin to adopt the values and behaviors of the majority culture (Updegraff & McHale, 2006). However, adolescents who were raised in an Asian collectivist culture may find the issue of organ donation a difficult choice to make. The choice of organ donation among Asian American adolescents may differ depending upon the exposure to Western culture and their level of acculturation.

In this dissertation study, Morgan's (2004) ODM has been modified and used as a study framework to specifically examine Asian American adolescents and their attitudes and knowledge about organ donation (See Figure 2). The three variables that relate to

Asian American adolescents' willingness to donate and family discussion about organ donation will be examined: (1) attitude towards organ donation; (2) knowledge of organ donation; and, (3) acculturation level of adolescent.

### **Research Aims**

Aim 1: To describe the attitudes and knowledge about organ donation and transplantation, willingness to donate and family discussion about organ donation among Asian American adolescents.

Aim 2: To examine the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents.

Aim 3: To determine whether attitudes and knowledge about organ donation and transplantation predict willingness to donate and family discussion about organ donation.

Aim 4: To examine the effect of acculturation on attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents.



## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **Introduction**

Life expectancy and quality of life are improved with kidney transplantation compared with maintenance dialysis (Gatchalian & Leehey, 2000). However, in some cultures donating organs would be unthinkable (Woo, 1992; Yuen et al., 1998). Minority groups in the U.S. have a lower rate of organ donation than from the general Caucasian population (Lam & McCullough, 2000). Minority groups in the U.S., including Asian Americans (Chinese, Japanese, Filipino, Korean), have been reluctant to consent to organ donation (Cheung, Alden, & Wheeler, 1998), and yet the number of Asian Americans on the transplant waiting list has more than tripled from 1993 (1,186) to 2006 (5,886) (Scientific Registry of Transplant Recipients, 2003; UNOS, 2006). As of 2003, Asian Americans comprised 5.1% of the total number of patients registered on the National Transplant Waiting List in the U.S. Due to the deficient numbers of deceased donors, there are often discrepancies between the ethnicity of the organ donor and the ethnicity of the organ recipient. Matching a recipient with a donor from the same ethnic group increases the chances of long-term survival (Alden & Cheung, 2000; Weller, Wu & Ferguson, 1987).

Given the predominantly Caucasian donor population in the U.S., ethnic minority ESRD patients are an obvious disadvantage in their chances of receiving a suitable kidney. This situation is compounded by lower levels of organ donation among minority groups due in part to cultural factors. The interplay of culture and the issue of organ donation have been investigated for some minorities living in the U.S. However, few

studies have examined the potential sources of kidney donation disparities in Asian Americans, such as, cultural factors, language barriers and health access factors (Lopes, 2004; Mau et al., 2003). One's health belief culture may contribute to the ethnic disparities seen in transplantation. Some minority groups have a holistic approach to health while placing significance of integrating the individual, family and environment in many ways: physically, socially, psychologically, and spiritually (Churak, 2005). Although several investigations have attempted to explore cultural reasons towards reluctance in organ donation, studies have primarily examined African American and Hispanic groups (Callender, Hall, & Branch, 2001; Morgan, 2004; Park, 1998; Yuen et al., 1998). There have been very few investigations exploring these important reasons in Asian Americans which is a limitation to the existing evidence based literature.

The few studies that did focus on Asian American attitudes and beliefs towards organ donation and transplantation were primarily done in adults (Albright et al., 2005; Alden & Cheung, 2000; Lam & McCullough, 2000; Wheeler, O'Friel, & Cheung, 1994). Therefore, little knowledge is available today about the way young people perceive organ donation and transplantation. By reaching out to young people, willingness to donate organs could be improved in the long term. Future need to examine Asian American adolescents' attitudes and knowledge toward organ donation and transplantation is two-fold: (1) to correct misconceptions by increasing the knowledge of organ donation and transplantation, in preparation for young people to take their own stance concerning their choice; and (2) to promote family discussion of organ donation by young Asian Americans, whereby the whole family would determine their stance on this issue.

This review of literature critically analyzes the existing literature on research that has been conducted to examine the influence of the attitudes and knowledge toward organ donation and transplantation among Asian Americans. The contributions and limitations of this body of literature will be discussed. Additionally, it will recommend potential areas of future research based on identified gaps that will advance our understanding of the underlying causes of low rates of organ donation and promising interventions to promote organ donation and transplantation in Asian Americans.

### **Literature Review**

This following section will review and synthesize the existing body of literature examining Asian Americans and adolescents in relation to their beliefs and attitudes toward organ donation and transplantation. This review is divided into three areas: (1) cultural beliefs and concepts of death; (2) empirical studies of influences on the willingness of Asians to donate organs; (3) family discussion about organ donation and the importance of knowledge about organ donation; and, (4) educational programs promoting organ donation awareness.

#### ***Cultural Beliefs & Concepts of Death***

##### **Beliefs and Attitudes toward Organ Donation**

Attitudes towards concepts and procedures such as brain death and organ procurement may be greatly influenced by cultural perspectives that are rarely mentioned. Organ procurement from patients with brain death is perceived by many Westerners as completely ethical, as it is a common belief that at death, the mind leaves the body (Bowman & Richard, 2003, p.213). The brain is considered the temporary home of the rational and autonomous mind. From this perspective, the brain dies, and the synthesis

between mind and body ends. With this separation of body and mind comes death of the human being in Western society (Lysaught, 1993).

In contrast, most Asian cultures believe a human being is the integration of body, mind, and spirit. Following death, they remain as an integrated whole (Bowman & Richard, 2003). Tanida (1996) suggests that the powerful influences of Shinto and Buddhism in some Asian societies strongly support natural processes and approaches to dying. From a traditional Japanese perspective, the metaphorical center of the body is located in the chest (Tanida, 1996). Removal of an organ from a brain-dead human, especially from the chest, may be perceived as disturbing this integrated unit.

It is believed a dead person goes to the next world as a soul. This soul is believed to have its own body, senses, and feelings similar to a living person; therefore, the dead body must remain whole. If some parts are missing, the soul becomes unhappy in the next world. This philosophy believes the body must be intact after death because the belief is humans become ghosts after death (Kim, Elliott, & Hyde, 2004). Thus, missing an organ for any reason may cause suffering in the afterlife for the spirit of the deceased and would anger the deceased's spirits. Because the deceased person will be transferred into a ghost, that ghost would provoke bad omens for the remaining family members.

Many Asians express rejection or aversion toward the issues of brain death and organ donation and transplantation, especially from the brain dead, as there is a belief that the deceased person would be humiliated by the organ-harvesting process (Kim et al., 2004). Filial piety, or duty to parents, is the most basic and crucial concept of Confucianism and implies that a person's duty is to maintain the body in the same

condition in which it was received from his or her parents, including being intact at death. Therefore, organ donation is discouraged.

Different philosophies and beliefs regarding death and the human body between western and eastern cultures contribute to different perceptions on organ donation. Few studies have examined beliefs and attitudes regarding organ donation in Asian populations. Alden & Cheung (2000) report that very limited empirical information has examined Asian American beliefs, attitudes and behaviors with respect to organ donation. To initiate a more in-depth analysis of this problem, the authors examined potential differences in organ-donor attitudes and behaviors that may exist between Asian Americans and European Americans. Two thousand questionnaires were randomly mailed to households in a predominantly urban area in a western state selected by a professional sampling service with a response rate of 37.6% (Asian American N=250; European American=175). Individuals between the ages of 16 and 60 were included in the analysis (mean age = 41.0 years) which resulted in a final sample of 425 respondents (women, N=263; men, N=158). This study found that, relative to European Americans, Asian Americans hold more negative attitudes toward organ donation. As hypothesized, maintaining body integrity and doctor trust were significant predictors of attitudes toward organ donation for both Asian Americans ( $R^2=.59$ ,  $p<.05$ ) and European Americans ( $R^2=.45$ ,  $p<.05$ ). Although the authors generalized several underlying cultural similarities across all Asian American ethnic groups, this study included primarily higher income level and educated females. Findings cannot be generalized to all Asian American groups as there were differences in Asian American group cell size, with a larger number of Japanese respondents (N=162) and very few Koreans (N=7). The major

limitation to this study was the low response rate of 37.6% despite the financial incentive, which limited its generalizability.

Filipinos are overrepresented on transplant waiting lists, but few become organ donors following their death. Albright et al. (2005) performed a qualitative study to explore the issues that could be linked to the knowledge, attitudes, and cultural beliefs that Filipinos living in Hawaii have toward organ donation. Six focus groups (83% Catholic; 72% women; 52.3 +/- 15 years mean age) comprised of nurses (N=6), physicians (N=12), adolescents (N=11), church members (N=13), organ recipients, and donors (N=15) were interviewed. Qualitative theme analysis methodology identified dominant themes related to organ donation. The most commonly mentioned themes across all groups were awareness of organ donation (38%) and family beliefs (25%). A common statement made by the youth focus group was, “....no one is really educated enough about organ donation.”

The authors did not indicate whether these Filipinos (primarily Catholic women who were in medical and nursing professionals) were first, second, or third generation and whether English was their primary or secondary language. There was no mention of the study's method of sample selection. Additionally, the major limitation of this study was the focus group's large composition of health professionals. However, this is the first study to examine the attitudes and knowledge of Filipinos about organ donation. Future studies need to examine the impact of acculturation on attitudes and knowledge regarding organ donation.

Wheeler, O'Friel, and Cheung (1994) examined the barriers to organ donation among Japanese, Chinese, and Filipinos living in Hawaii by conducting an exploratory

qualitative study. The Organ Donor Center of Hawaii commissioned a private marketing research company to conduct a series of focus group discussions among Asian American groups in order to gather information on attitudes and beliefs about organ donation. Participants in the study (N=29; mean age=30 years) stated that the body should also remain intact to the grave, because the body, as it was on earth, would reunite with the spirit in the afterlife. The lack of knowledge and family discussions were also identified as barriers to organ donation. Limitations to the study's findings included a small sample of highly educated women. Quantitative research will further examine a larger sample of Asian American adolescents (Chinese, Japanese, Filipino, Korean) living on the Big Island of Hawaii, and their attitudes and knowledge about organ donation and transplantation.

Rubens (1996) performed an exploratory pilot study to examine racial differences in organ donation among a sample of racially and ethnically mixed university students. A 64-item questionnaire regarding organ/tissue donation issues was administered to 683 undergraduate students at a state-assisted university in the Midwest. The author found that African American and Hispanic college students had less knowledge about donation than did their Caucasian colleagues (mean age=19 years). However, while African American (N=186) students stated less willingness to donate than Caucasians (N=336), Hispanic (N=64) and Asian American (N=48) students were equally willing to donate as Caucasian students. Irregardless of what ethnic background the students came from, all were equally likely to believe that it is important to communicate their wishes to their families, and equally likely not to have done so. The sample was comprised mainly of Caucasian students and African Americans living in the Midwest. Findings cannot be

generalized across all racial groups. Additionally, there are limitations to the reliability and validity of the instrument used as there was no mention of whether it was developed to meet the sensitivity of cultural issues, such as language and spiritual or religious beliefs. Despite its limitations, this study provides insight on potential racial differences in their willingness to engage in family discussion about organ donation.

In contrast to Rubens' (1996) study, Yuen et al. (1998) found no disparity in the willingness to donate between Caucasians (N=43) and other races (African American N=47; Hispanic N=58; Asian=3; Other=12). The study population consisted of a convenience sample of 163 patients (mean age= 36.5 years; female N=76; male N=24) who were approached for participation while they waited to see a doctor at a family practice center located in an urban city. Individuals who agreed to participate were given a 25-item survey that measured: demographic information; their exposure to, awareness of, and attitudes toward organ donation; and, whether they had signed their organ donor card. All minority groups were equally supportive of organ donation. The results suggested that making it easier for racial minorities to obtain organ donor cards could increase their rates of consenting to donate organs. Although a Spanish version of the survey was available, there was no information given about the instrument. Further research needs to focus on Asian American adolescents and their attitudes toward organ donation and their willingness to donate.

A possible reason for the discrepancy between the studies discussed may be attributed to the differences in the sample characteristics (Asian American groups), age, education level, sample sizes, research designs, and lack of reliable and valid measurements used in those studies. Validity issues are vital when developing



instrumentation in cross-cultural research which can contribute to a stronger research. In the process of understanding the phenomenon, in this case, attitudes and knowledge of organ donation and transplantation among Asians, one must be able to evaluate the truthfulness, precision and dependability of the instruments and measurement methods used to generate the knowledge for evidence-based practice (Higgins & Straub, 2006). Studies have shown that knowledge is also an important predictor of organ donation willingness (Morgan & Miller, 2001; Radecki & Jaccard, 1999). However, few studies have examined the knowledge about organ donation and transplantation, especially in Asian populations and adolescents.

The studies mentioned above lacked reporting psychometric properties of measures used. The threat of unreliable measures has the potential for an increase in measurement error that weakens the relationship between the variables being tested or evaluated. Alden and Cheung (2000), Rubens (1996) and Yuen et al. (1998) did not fully explain or mention the reliability of their measurements. Perhaps that is why Alden and Cheung's (2000) study revealed the unanticipated results of the attitudes toward organ donation between Asian Americans and European Americans. The conflicting results between Rubens (1996) and Yuen et al. (1998) studies may also be attributed to poorly developed measurement tools and different sample characteristics.

This review did not mention instrument development and offered no psychometric properties. The instruments used in these studies had threats to content validity in examining the concepts of attitudes and beliefs toward organ donation. Threats to statistical conclusion validity are serious hazards to research validity (Higgins & Straub, 2006).

Acculturation has not been examined in organ donation literature. In this dissertation study, acculturation levels will be determined and will examine associations with the attitudes and knowledge about organ donation and transplantation, family discussion about organ donation, and willingness to donate among Asian American adolescents.

***Empirical studies of influences on the willingness of Asians to donate organs***

**Impact of Family and Culture**

People's attitudes, beliefs and behaviors are influenced by their cultural background, social norms and religious beliefs (Kim et al., 2004). The decision to donate organs arises from a combination of social and psychological concepts filtered through the personalized experiences of age, gender and further shaped by the cultural practices of the society (Sanner, 1998). Important beliefs regarding organ donation in Asians identified in the literature are: (1) fear of death, (2) the belief that removal of an organ violates sanctity of the deceased, (3) fear of mutilation, (4) desire to be buried whole, (5) dislike of idea of kidneys inside another person, (6) distrust of the medical community, (7) lack of knowledge about the deceased's wishes; (8) concept of brain death, and (9) the idea of donation being against religious conviction (Cantarovich, 2005; Churak, 2005; Rocheleau, 2001; Rumsey, Hurford, & Cole, 2003; Sander & Miller, 2005; Siminoff, Burant, & Youngner, 2004; Woo, 1992).

Lam & McCullough (2000) quantitatively examined the religious and cultural reasons that Chinese-Americans appear to be less willing to donate their organs than other populations. A 43-item questionnaire was distributed to attendees of a non-denominational Chinese-American church in a large urban city. They examined 122

Chinese Americans whose mean age was 41.7 years, who had lived in the U.S. for an average of 17.9 years (religion = 4.1% Buddhist, 72.1% Christian, 23.8% Undecided).

The survey asked about general feelings toward organ donation and Buddhist, Confucian, Christian, Daoist, and other spiritual objections toward organ donation.

The authors reported a significant finding that Chinese Americans were most willing to donate their organs after their deaths, to close relatives, and then, in descending order, to distant relatives, people from their home country, and then to strangers. Also, Chinese Americans are indeed influenced by Confucian values and to a lesser extent, Buddhist/Daoist and other spiritual beliefs that associate an intact body with respect for ancestors or nature. This was a convincing exploratory study as the participants surveyed were attendees of a non-denominational Chinese American church whose faith and beliefs varied. However, because the sample was not randomized and participants were primarily church attendees from and of Chinese descent, findings have limited generalizability to all Chinese Americans. There is limitation to the instrument's validity and reliability as there was no psychometric properties offered. Additionally, there was biased sample recruitment due to the convenience sampling. Further research will examine Chinese American adolescents, along with other Asian subgroups, in their willingness to donate.

### ***Family Discussion about Organ Donation***

This section will examine studies of willingness to communicate with family members about organ donation. In addition, the concept of knowledge about organ donation and its importance to engaging in family discussion will be addressed.

Morgan (2004) surveyed 311 African-American adults (mean age = 45 years; 59.4% female; 40.6% male; mean income = \$58,000; mean education = college degree) about their attitudes and behaviors regarding family discussions about organ donation. Questionnaires were distributed by various organ procurement outreach managers and African-American community leaders. This study was grounded in the Organ Donation Model. Logistic and multiple regression analyses revealed that the willingness of African Americans to engage in family discussions (as well as their attitude toward these discussions) is predicted by their levels of knowledge about organ donation, their attitudes toward donation, and perceived religious and social norms supporting organ donation. Limitations to this study included high education and income level of African Americans. Future investigation will further examine attitudes and knowledge about organ donation and transplantation in Asian American adolescents with the Organ Donation Model as the study's framework. This research will further determine whether attitudes and knowledge predict willingness to donate and whether Asian American adolescents engage in family discussion about organ donation.

Since family permission is necessary for organ donation to take place, family discussion about organ donation is crucial for increasing the actual organ donation and transplant rate. However, Wu (2008) found that among 298 Chinese young adults (mean age = 20.74 years; female N=171; male N=127), most of them (88%) were reluctant to talk about organ donation with their families. Based on the Theory of Reasoned Action, this study investigated communication within families about organ donation. Psychological factors included intention, attitude, subjective norm, death anxiety, and knowledge.

Wu (2008) recruited participants by convenience sampling on a university campus and public parks in Macao. Participants completed a 10 minute questionnaire (composite of validated instruments used in previous studies) on the spot after signing the consent form. The rejection rate was 17% and a debriefing sheet was provided after respondents completed the survey. The author concluded that death anxiety, but not misconception, significantly lowered the likelihood of family discussion. As the author also hypothesized, subjective norm (the beliefs of people, weighted by the importance one attributes to each of their opinions, will influence one's behavioral intention) was more powerful than attitude in explaining family discussions among Chinese people. Findings suggested that education of improving knowledge about death could be incorporated into general education courses by local schools, in order to reduce misconceptions and stigmas attached to death. There were few limitations identified in this study with the exception of convenience sampling.

### **Importance of Knowledge about Organ Donation**

There is consensus among existing studies that knowledge is an important predictor of the willingness to engage in discussion about organ donation (Guadagnoli et al., 1999; Morgan & Miller, 2002; Radecki & Jaccard, 1999). The implications of this finding are more important because the discussion of a potentially sensitive subject may offend or upset a family member. Few people are likely to take such a risk if they do not have confidence in their own beliefs, attitudes and knowledge about the subject, such as organ donation. Increasing general knowledge about organ donation, and reducing the myths about organ donation, are important to increasing the willingness of individuals to engage in family discussion (Morgan, 2004). In addition, discussion about organ

donation may lessen resistance by family members to the desire of individuals to donate their own organs (Morgan, 2004). A significant barrier to the willingness to donate organs is the potential resistance on the part of family members (Rubens, 1996; Rubens & Oleckno, 1998).

### ***Educational programs promoting organ donation awareness***

The next section of this paper will examine educational efforts in promoting organ donation awareness among young people.

Many people are initially confronted with the issue of organ donation as a teenager when obtaining a driver's license. Gallup (1993) reported that only 36% of young people ages 18 to 24 had received information about organ donation compared to 61% of people older than age 24. Additionally, 34% of young people believed racial discrimination prevented minority patients from receiving needed organ transplants, compared to 27% of people older than age 24. Moreover, most students (69% of Caucasians; 69% of non-Caucasians) were unaware that almost half the patients waiting for organs in the U.S. are from ethnic minority groups (Spigner et al., 1999).

Weaver, Spigner, Pineda, Rabun and Allen (2000) performed a pilot classroom education program to improve knowledge about organ donation and transplantation among a diverse student body of eleventh graders (N=97, mean age=17, 47% female) at an urban high school. The effectiveness of the educational program was evaluated with baseline and follow-up questionnaires. The non-Caucasian group included 49% African American, 17% European American-Caucasian, 12% Asian American, 10% American Indian, 3% Alaska Natives and 3% Middle Eastern.

This pilot study revealed that changes in opinions occurred with equal frequency among students in both treatment (N=36) and control groups (N=36). In regard to opinions at baseline, 92% of Caucasian students had positive opinions about organ donation, compared to 48% of the non-Caucasian students ( $p<0.01$ ). The follow-up survey showed the increase in positive opinions among non-Caucasian students was significantly greater than among Caucasian students ( $p=0.04$ ). Findings from the follow-up survey also showed factual items increased by 18% for the intervention group, compared to 5% for the control group ( $p<0.00$ ). The authors concluded that public educational programs play an important role in increasing organ donation because there are significant causal relationships between: (1) knowledge about organ donation and attitudes towards it; (2) attitudes towards organ donation and willingness to donate; and (3) willingness to donate and the decision to request or carry an organ donor card. However, the major limitation to this study is its findings cannot be generalized to Asian American teens due to the small sample size, nor can it be generalized across all ethnic groups. There was no mention of blinding, randomization, or religious affiliation of each participant. In addition, there was no mention of instrument development or cross-cultural considerations. Despite the limitations, the study indicates the efficacy of an educational program in improving positive attitude, especially for minority students.

Residents of a U.S. Midwestern state were surveyed to determine their knowledge and attitudes toward organ donation. The investigators randomly sent a questionnaire with 36-items regarding issues pertaining to organ donation to 1,000 Ohio residents (mean age = 40 years; female 59.3%; male 40.7%) with a response rate of 39.4%. Sander and Miller (2005) found that respondents as young as 18 not only had

more knowledge and more favorable attitudes toward donation, but were also more willing to consent to organ donation. The authors reported that both knowledge and attitudes were positively associated with willingness as well as commitment to donate, and that health misconceptions represented potential barriers to donation. Limitations to this study included lack of ethnic diversity in the sample (98.7% Caucasian), low response rate, and the newly developed questionnaire's validity and reliability which only assessed deceased organ donation. Despite the limitations, this study suggested that health care providers can play a critical role in educating patients about donation and suggested public education should focus on the knowledge areas about organ donation that show deficits.

Spigner et al. (1999) performed an exploratory study to solicit the opinions of high school students' knowledge and opinions about organ donation and transplantation, focusing on issues of need, availability, and access to organs among ethnic minority groups. A convenient sample of 97 (mean age = 16.5 years) ethnically diverse public high school students were administered a 33-item questionnaire. Proportionately more Caucasian (43%) than non-Caucasian (23%) students believed Asian Americans were disadvantaged in terms of waiting times for kidney transplants ( $p=.08$ ). Among the opinions solicited on organ donation a larger proportion of Caucasian students (60%) compared to non-Caucasian students (28%) reported intention to become a donor ( $p=.002$ ). A surprisingly low percentage (13%) of non-Caucasian high school students had already clearly decided against donation, although 23% of them indicated they "needed more time to think about it" or were "undecided" about organ donation. The study suggests that educational interventions may be a possible mechanism to change



teens' perspectives, knowledge and willingness in relation to organ donation, especially in minority groups.

Sanner (2002) conducted a survey study among 1,447 students ages 15 to 18 in four urban areas in Sweden. Although students looked upon organ transplantation favorably, only 50% were willing to donate their organs, and only 20% the organs of their parents due to the uncertainty about parental opinion on organ donation. Approximately 70% of the students indicated that transplantation issues should be included in the school curriculum. The teenagers felt indecisive and discomfort regarding organ donation after death, but at the same time, viewed organ transplantation as a highly valued act. This discomfort may be connected with the inability for teens to imagine their own death and non-existence, which makes it difficult for them to imagine a difference between the living and the dead. Adolescents often have a perception of immortality which makes them believe no harm can affect themselves or those around them.

### **Summary**

As studies have suggested that Asian Americans are reluctant to donate, health care providers, especially members of the organ procurement organizations, should become more aware about cultural beliefs. By understanding the attitudes and beliefs of individuals, subtle changes in the procurement protocol may allow patients to donate without violating their religious and spiritual beliefs (Lam & McCullough, 2000). These subtle changes may include designating their loved one's organs to be transplanted into someone of their own ethnicity or to a family member or someone they may know who is on the transplant waiting list.

Attitudes, knowledge, beliefs, and behavioral intentions about organ donation can be affected by culturally appropriate health education programs (Callender et al., 2001). These studies suggest by being culturally sensitive to the beliefs, attitudes, and knowledge of Asian Americans concerning organ donation, the educational programs would not come across as directing change, but to support the attitudes of the targeted group and facilitate an awareness to the need of organ donation and its ability to help people of their own ethnic group.

In 1994, the Coalition on Organ and Tissue Donation initiated a national campaign that promotes the slogan “Organ Donation: Share your life. Share your decision.” Li et al. (2001) reported 85% of public citizens and 89% of blood donors did not consent to donation from their family members because the intentions of the deceased relative were unknown. Most people would not object to donating a family member’s organs if they knew that their relative consented to donation (Li et al., 2001). Carrying an organ donation card does not imply automatic donation in a deceased individual because any family member can object to the donation. Very little research has been devoted to encouraging family discussion and facilitating an increase in carrying organ donor cards. There needs to be educational efforts in improving the general understanding of signing organ donor cards, and most importantly, informing one’s family of their decision to become an organ donor at the time of one’s death so that wishes will be abided by the family.

This dissertation research will critically examine the attitudes and knowledge about organ donation and transplantation among Asian American adolescents and the impact of acculturation. This study will further explore willingness and intent to donate,

engaging in family discussion about organ donation, and assessing general knowledge regarding organ donation.

### **Research Gaps**

This literature review has revealed several gaps in the literature. The attitudes and knowledge of Asian Americans toward organ donation and transplantation remain largely unexamined, especially in adolescents. Future aims in research should further examine attitudes and knowledge in Asian American adolescents as they have the influence to promote organ donation awareness and to facilitate organ donation discussions and decisions in their families.

In all of the studies reviewed, the investigators offered no theoretical framework to base their research. Most importantly, the theory of acculturation was never addressed which would be pertinent in studying Asian American cultures. Acculturation is a complex concept that has been defined as changes in behavior and values or movement from the values and social behaviors of one culture to another (Anderson et al., 1993). This emphasis on acculturation is an important theory to include in studies examining the attitudes towards organ donation in Asian populations; most importantly, Asian American adolescents.

Understanding their attitudes and knowledge toward organ donation is the first step in developing effective educational intervention that aims to decrease the organ shortage in ethnic minority populations. After we understand how attitudes, knowledge and acculturation impact Asian American adolescent's willingness to donate and engage in family discussion about organ donation, we will be able to develop culturally sensitive educational programs.

## **Conclusion**

It is evident from the existing literature that culture (personal beliefs, attitudes, knowledge, religion) shapes the minds of Asian Americans in their decision towards organ donation and transplantation. From the studies that have been analyzed, the two common threats to the studies' designs include: (1) small sample sizes, and (2) lack of culturally sensitive instruments that have adequate validity and reliability (with psychometric testing) to measure the attitudes and knowledge about organ donation and transplantation in Asian American populations.

Another threat to external validity is sampling bias, in the form of convenience sampling, as demonstrated by Lam and McCullough's (2000) study examining Chinese Americans at a non-denominational church and Albright's et al. (2005) study of Filipinos whose focus group composition was primarily health care providers.

In addition, the overall body of work has been exploratory using survey methods as seen in several of the pilot studies. Most samples have been small and skewed. Although several studies had good original sample sizes, response rates were low. Findings from studies with low response rates must be interpreted with caution as this may be non-representative of the population being examined.

Because there is lack of research in the area of these diverse Asian American groups and organ donation, there is conflicting data. Alden & Cheung (2000), whose study's sample was primarily Japanese, state Asian Americans are reluctant to participate in organ donation and hold more negative attitudes. However, Lam and McCullough (2000), who primarily examined Chinese Americans, report significant findings from their study which revealed their subjects as willing participants in organ donation after

their deaths, although on their terms (to close relatives, distant relatives, and lastly, to strangers). The rationale for differences between the two studies may be attributed to the research design, instruments used, sample cell sizes of the ethnic groups, and the groups themselves.

Because of the limitations discussed following this literature review, it is too premature to generalize findings. There is limited empirical research that rigorously explores the attitudes and beliefs toward organ donation and transplantation by Asian American sub-groups and in adolescents. Each study lacked fundamental perspectives on the importance of family, a very prevalent concept in Asian culture, as well as, lack of developmental theory in the studies examining adolescents (as the majority of studies' subjects were adults). Most importantly, acculturation levels were not addressed in any of the studies examining organ donation practices in Asian populations. The existing body of literature has yielded mixed findings which may be due to the studies' small, mixed convenient samples of Asian American groups, and the instruments used to measure the variables of interest.

Continued research is needed in further advancing our knowledge in the disparities apparent in organ donation rates in Asian Americans. Because of the increasing concerns about health disparities within the U.S. and globally, this research focus is particularly very timely and needed (Willgerodt & Killien, 2004). In this dissertation study, the gaps will be filled by closely examining the attitudes and knowledge toward organ donation and transplantation of Asian American adolescents, in association with their acculturation level, willingness to donate, and family discussion about organ donation. By knowing Asian American adolescents perceptions about organ

donation, culturally appropriate educational programs may be developed. This is the first study to address the perceptions about organ donation and transplantation of Asian American adolescents, and the first study to incorporate the theory of acculturation into organ donation research.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Research Design**

A cross-sectional design was used to examine attitudes and knowledge regarding organ donation and transplantation, and the impact of level of acculturation on willingness to donate organs among Asian American adolescents living on the Big Island of Hawaii. With approval by UCSF Committee on Human Research (CHR) #H11584-30960-01, adolescents ages 16 and 17 years (junior and senior high school students) who self-identified themselves as being of Asian descent (Japanese, Chinese, Korean, Filipino), and their parent or guardian were recruited to participate in this study . The aims of this research are: to examine and describe the attitudes and knowledge about organ donation and transplantation among Asian American adolescents; to examine the association between attitudes and knowledge with willingness to donate and family discussion about organ donation; and, to determine the effect of acculturation on attitudes and knowledge with willingness to donate and to engage in family discussion about organ donation.

#### **Research Setting Description**

The state of Hawaii's population is approximately 1,275,194 and the population on the Big Island (Hawaii County) is 167,293 (U.S. Census Bureau, 2005). There were 14,577 households out of which 30.6% had children under the age of 18 living with them, with the average household size of 2.70 and the average family size of 3.19. Approximately 26% of the Big Island's population is of Asian descent with

approximately 11,806 adolescents ages 15-19 years. The four largest Asian subgroups include: Japanese (17,716), Filipino (15,726), Korean (828), and Chinese (650).

On the Big Island of Hawaii, study participants were recruited from three high schools: Hilo High School, Waiakea High School and St. Joseph's High School, located in Hilo, Hawaii. Both Hilo and Waiakea High are public schools and St. Joseph's is a private Catholic school.

Hilo High School has a student body of 1,558, ages 14 to 18 years old. There are approximately 350 juniors and 370 seniors. Approximately 25% of juniors and seniors have Asian heritage (C. Masuhara, personal communication, April 22, 2008). It is a public high school with one principal, 2 vice principals, 110 teachers and 6 counselors.

Waiakea High School has a student body of 1,313, ages 14 to 18 years old with approximately 750 juniors and seniors. Approximately 70% of juniors and seniors have Asian heritage (L. Kimura, personal communication, April 21, 2008). It is a public high school with one principal, 2 vice principals, 80 teachers and 6 counselors.

St. Joseph's High School, a private Catholic school, has 143 students ages 14 to 18 years old with 53 juniors and seniors. Approximately 43% of juniors and seniors have Asian heritage (K. Calina, personal communication, April 21, 2008). It is a private Catholic high school with one principal, one vice principal, 18 teachers and one counselor.

### **Human Subjects**

This study was approved by the University of California, San Francisco Committee on Human Research (CHR), the Superintendent of Schools, East Hawaii District, and the three high school principals (See Appendix A: Approval Letters).



### ***Criteria for Sample Selection***

Selection criteria of this study included junior or senior high school students, who were 16 or 17 years of age, who self-identified as Asian American descent (Japanese, Chinese, Filipino, Korean), who resided on the Big Island of Hawaii, English-speaking, and parent/guardian consented to their adolescent's participation in the study. In addition, parent/guardian must also be English-speaking and resides with the adolescent.

### ***Recruitment***

First, driver's education classes (N=2, Hilo High; N=3, Waiakea High) were assessed as avenues to recruit study participants where the primary investigator (PI) presented the research study with a 10 minute PowerPoint presentation. Adolescents were given a Study Support letter signed by the Superintendent of Schools and High School Principal, Study Information letter and a response post card to take home to their parents. Students who were interested in participating in the study returned the postage paid postcard with their names and parent/guardian's names and contact information to the PI within two weeks after receiving study materials. Upon receipt of response postcards with "Yes" circled by interested study participants, the PI mailed a questionnaire packet with a postage paid return envelope which included the parental consent form. Invitation letters for study participation was sent to 500 parents at Hilo High School, 500 parents at Waiakea High School and 55 parents at St. Joseph's High School, all randomly selected by high school administration. Response rates were 1%, 3% and 7% respectively.

Due to the poor response rates from the driver's education classes, a second recruitment was utilized. The PI accessed junior and senior English, Science and Health

classes, Key Club and Japanese Club from Hilo High and Waiakea High to further recruit study participants. Additionally, all junior and senior students at St. Joseph's High School who had Asian descent were gathered in a classroom by the counselor to meet with the PI. Students who were interested in study participation, and who believed parents would consent, were asked to complete the response postcards in class and given directly back to the PI. The research assistant then gave the student a post-paid, addressed envelope which included the signed support letter, study information, parental consent form and questionnaires. Response rates increased to 36% at Hilo High School (N=60), 31% at Waiakea High School (N=48), and 28% (N=6) at St. Joseph's High School.

The Parental Consent Form (See Appendix B) described the potential risks of the study to their adolescent, confidentiality issues and the voluntary nature of research participation. An "Experimental Subjects Bill of Rights" was given to participants. The parent/guardian and adolescent both signed and returned the consent form with the completed questionnaires. The parent/guardian completed a one page demographic questionnaire and the adolescent completed three questionnaires which were mailed back to the PI in a pre-addressed, postage paid envelope.

### *Nature and Size of Sample*

In quantitative analysis of continuous outcome measures, a sample size of 121 would achieve 80% power to detect an R-Squared of .056 (6%) attributed to 1 interaction using an F-Test with a significance level (alpha) of .05 (5%). The interaction tested is adjusted for an additional 2 independent variable(s) with an R-Squared of .09 (9% variance), a close to meaningful "medium" effect (Cohen, 1988).

## **Procedure**

Initially, all potential participants who indicated their interest in study participation received a response postcard. Following receipt of response postcard indicating “Yes” for study participation, a questionnaire packet and parental consent form were mailed to the adolescents’ home. Because of the low response rate, the PI returned to the three high schools and presented a 5-10 minute Power Point presentation outlining the purpose and importance of the research study to recruit more potential participants. At the end of the presentation, the research assistant distributed response cards to adolescents who raised their hands in their willingness to participate in the study. After the students completed the response cards with their name and their parent/guardian’s name, the research assistance collected the response card and the student was given a postage-paid, addressed envelope containing the questionnaires, study information, support letter and parental consent forms. Each packet also contained a bright green sheet of paper with instructions for both parent/guardian and adolescent. The response card and questionnaire packets were coded with matching random identification numbers.

Participants were instructed to return the questionnaire packets within two weeks. A telephone call was made by the research assistant, or the counselor at the private high school and the Parent Community Network Coordinator from the two public high schools if the questionnaire was not received after two weeks. After the participant mailed in their completed questionnaire packet, a \$5 Starbucks gift card and a hand-written note on a UCSF note card was mailed to the adolescent in appreciation for their time and effort. In order to further recruit more study participants, the adolescent was sent two \$5 Starbucks gift cards if they personally turned in their completed questionnaires to their

teachers. Additionally, for Key Club members at the public high schools were given one hour community service time.

### **Data Collection Measures**

#### ***Techniques***

Instruments related to organ donation attitude and acculturation used in this study were selected based on their psychometric properties which established validity and reliability (See Appendix C: Data Collection Instruments) (Rumsey, Hurford, & Cole, 2003; Suinn, Ahuna, & Khoo, 1992). However, no knowledge questionnaire regarding organ donation was found. Therefore, a pilot study was conducted to develop knowledge questions pertaining to organ donation and transplantation. Additionally, the pilot study was done to ensure that all questionnaires for adolescents were appropriate for the targeted age group in its comprehension and readability.

Questionnaire packets were either sent to the homes of adolescents, or given directly to the adolescents, and their parent/guardian and instructed to return the completed questionnaires within two weeks. Both parent/guardian and adolescent were asked to sign the Parental Consent Form and return it with the completed questionnaires. The parental measure consisted of a one page 10-item demographic questionnaire which would take approximately 5 minutes to complete. Adolescents were instructed to complete three questionnaires which would take approximately 45 minutes. Adolescent's measures consisted of a 10-item demographic questionnaire, Organ Donation Attitude Survey (ODAS) (20-items), Organ Donation and Transplantation Knowledge Survey (ODTK) (18-items), and Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA) (21-items) (See Table 1: Measurement Time).

## ***Instruments***

Parent/Guardian Demographic Information Survey. The demographic information survey asked the parent/guardian questions related to income, education and years of immigration. This 10-item questionnaire included parent/guardian's age, relationship to adolescent, country of origin, place of birth, residence in Hawaii and adolescent's high school. It is written at fifth grade reading level and takes less than 5 minutes to complete by a parent/guardian (See Appendix C.1)

Adolescent Demographic Information Survey. The demographic information survey asked the adolescent to note their specific Asian nationality(ies), where they were born, religious affiliation and other languages spoken other than English. The detailed list of ethnicities is used by the UNOS registry (UNOS, 2006). There are 10-items which include year in high school, age, gender, place of birth, residence in Hawaii, religious affiliation and spoken languages. It is written at fifth grade reading level and takes approximately 5 minutes to complete by the adolescent (See Appendix C.2).

## **Development of Knowledge Instrument**

### ***Method***

Organ Donation and Transplantation Knowledge Survey (ODTK). Development of the ODTK was conducted in two phases: (1) the development and validation of content of the knowledge scale; and (2) administration of the questionnaire to Asian American adolescents to determine the instrument's reliability and validity. Approval was obtained by UCSF's CHR #H11584-30405-01 prior to instrument development.

### ***Development of the Instrument***

A draft instrument was constructed measuring knowledge based questions pertaining to organ donation and transplantation issues. Following critical review of the literature, several questions were modeled and selected from several questionnaires from previous studies that measured knowledge about organ donation (Morgan & Miller, 2002; Rubens, 1996; Thornton, Curtis, & Allen, 2006; Weaver et al., 2000). Specific items assessed knowledge about diseases contributing to the need for organ transplantation, living organ donation, post-transplantation, and waiting time and race disparities.

The ODTK survey consists of an 18-item self-report type items using a 4-point scale ranging from “strongly agree” to “strongly disagree”: strongly agree (4 points), agree (3 points), disagree (2 points), or strongly disagree (1 point). High scores reflect a high knowledge about organ donation and transplantation issues (See Appendix C.3).

#### *Content Validity*

Following development of the 18-item organ donation knowledge survey, validation of the content was undertaken using several approaches. To ensure that each item addressed what it was intended to measure, clinical and academic experts and a pilot study using focus groups evaluated the items for content validity. These new knowledge questions about organ donation were reviewed by experts in the field of organ transplantation (Nancy Ascher, MD, PhD, UCSF) and adolescent development (Susan Kools, RN, PhD, UCSF). The questionnaire was considered acceptable for a survey of Asian American adolescents’ knowledge level following minor revisions such as re-wording and addition and deletion of several items.

### *Pilot Study*

The purpose of two focus group interviews (N=21) was to evaluate an instrument to examine the knowledge of organ donation and transplantation among Asian American adolescents which is developmentally and culturally appropriate. Adolescents, ages 18 or 19, English-speaking, who self-identified themselves as Asian (American or foreign born) were included in this study. To recruit participants, flyers were posted at local churches and youth group centers. Participants were offered pizza, refreshments and two \$5 movie tickets following study participation.

For the first focus group (N=11; 30 minutes), participants reviewed the ODTK for its content and readability. Open-ended questions were asked in regards to the instrument's clarity of each item and whether items needed to be added or eliminated. There were no revisions needed to be made.

For the second focus group (N=10; 45 minutes), the ODTK was administered to the participants. Following completion of the ODTK, participants were asked whether items were clearly stated. Everyone agreed that the knowledge questionnaire was easily understood and easy to read.

### **Psychometric Properties**

The newly developed ODTK was administered to Asian American adolescents (N=121) in this dissertation study. Psychometric properties of the newly developed instrument were analyzed to determine appropriate reliability (internal consistency) and validity established by factor analysis.

### *Reliability Analysis*

The ODTK was analyzed using item-to-item correlations and Cronbach's coefficient alpha to determine the instrument's internal consistency reliability. Item-to-item correlation and Cronbach's alpha coefficients assess how well items measure a single unidimensional latent construct (Cheng, 2004). Item-to item analysis demonstrates the correlation between the respective items and the summated scale score (without respective item) and coefficient alpha if the respective item was deleted. Because the reliability of individual items affects the size of alpha, items that do not achieve a high correlation are often deleted from the scale (Nunnally & Bernstein, 1994). Therefore, items with an item-to-item correlation coefficient less than 0.3 were discarded to improve scale homogeneity (DeVaus, 2002). Cronbach's alpha coefficient is higher when there is unidimensionality of variances among items. A value of alpha greater than 0.7 is generally required for acceptable internal consistency (Nunnally & Bernstein, 1994). The internal consistency for the two subscales of the ODTK in this study was: .83 for General Knowledge about Organ Donation and .74 for Knowledge regarding Cultural Limitations and Barriers to Transplantation.

### *Construct Validity*

To identify underlying dimensions of the items, common factor analysis (EFA) was performed to address construct validity and to evaluate the internal consistency of the ODTK. There were five steps to conducting the CFA (N=121): model specification, identification, estimating the parameters of the measurement model, evaluating the data-model fit and model modification or respecification to improve the fit (Bollen, 1989).



EFA also specifies information about three sets of parameters: (1) factor loadings; (2) factor interrelationships; and (3) measurement errors (Bryant & Yarnold, 2005).

The EFA with varimax rotation was used to determine construct validity and the structure underlying the newly developed knowledge questions. There were two meaningful factors identified based on the factor analysis. Only items with loadings greater than 0.35 were included into the newly developed ODTK (See Table 2: New Knowledge Items and Factor Loadings). Items 4 (organs for transplant can be bought and sold on the black market in the U.S.), 9 (high blood pressure and diabetes are common diseases in Asians), 10 (it is possible for a brain-dead person to recover from their injuries) and 18 (a matched donor is based on genetics) were dropped as there were no loadings. Items 3 (a rich person has a better chance of getting an organ transplant than an ordinary working person) and 11 (people who choose to donate a family member's organs end up paying extra medical bills) were also dropped because factor loadings were less than 0.35.

The first factor that includes 10 items, General Knowledge about Organ Donation, included items 5, 6, 7, 8, 12, 13, 14, 15, 16, and 17 as they all have positive loadings. The strongest loadings were from items 16 (.742; a patient can receive an organ transplant from a living donor) and 13 (-.724; after a transplant, the person is never healthy enough to return to work or school). Items 6 (types of diseases that lead to the need for transplant are unusual and rare), 12 (organ donors can't have regular funerals because the body is deformed by the removal of organs) and 13 (after a transplant, the person is never healthy enough to return to work or school) have negative loadings. Of the ten items that loaded on this factor, they referred to general knowledge about organ

donation and transplantation which included live organ donation, deceased organ donation and diseases contributing to the need for organ transplantation.

The second factor (two items), Cultural Limitations and Barriers to Transplantation, included items 1 (racial discrimination prevents minority patients from receiving the transplant they need) and 2 (Asians wait longer for kidney transplants than Caucasians/whites). Both of these loadings were positive and referred to cultural limitations for a person receiving an organ transplant.

Knowledge items 6 (-.410, types of diseases that lead to the need for transplant are unusual and rare), 12 (-.678, organ donors can't have regular funerals because the body is deformed by the removal of organs), and 13 (-.724, after a transplant, the person is never healthy enough to return to work or school) were reversed scored. A total score was derived by adding all of the questions from the modified ODAS with scores ranging from 35 to 140, excluding items 1 and 10, as they were excluded by the authors of the ODAS because they were not directly related to opinions regarding organ donation.

Overall, the results from the EFA provided strong support for the reliability and construct validity of the newly developed ODTK. In the analysis, both General Knowledge about Organ Donation and Knowledge regarding Limitations and Barriers to Transplantation were used.

Organ Donation Attitude Survey (ODAS). The ODAS is a 20-item questionnaire which assesses overall attitude toward organ donation and examines the influence of knowledge and religiousness on attitudes toward organ donation (See Appendix C.4). For the purpose of this dissertation study, the ODAS examined the attitudes of organ donation and transplantation among Asian American adolescents.

Rumsey et al. (2003) developed the ODAS which was utilized in their study of 190 undergraduate students (female N=114 / mean age = 20 years / 94% Caucasian; male N=76 / mean age = 20.5 years / 93% Caucasian). This study took place at a small Midwestern university.

The ODAS statements use a 4-point scale ranging from “strongly agree” to “strongly disagree”: strongly agree (4 points), agree (3 points), disagree (2 points), or strongly disagree (1 point). There are three subscales of measurement: (1) Opposing Organ Donation; (2) Approving of Organ Donation; and (3) Potential Organ Donors. The possible range of scores was 18 to 72, with higher scores reflecting a more positive view toward organ donation. Items 2, 13, 14, and 16 were reversed scored: item-2 (my religious beliefs do not support or are against organ donation; item-13 (I believe that organ donation is against my religion); item-14 (I have been taught that organ donation is against my religion; and item-16 (I think that organ donation mutilates or deforms the body). Item-9 (it is important to discuss my wishes for after my death with my family) and item-11 (if needed, I would receive an organ from a person of a different race than myself) were not added to the final score as they did not pertain directly to organ donation.

The ODAS also includes demographic questions regarding age, gender ethnicity, and religious affiliation. Participants were also asked about the frequency of their participation in religious services, their degree of religiosity, and whether they knew any organ donors or recipients.

## **Psychometric Prosperities**

### *Instrument reliability*

The reliability of the ODAS was evaluated in several ways. Split-half reliability utilizing even and odd questions of the ODAS assessed reliability. The split-half reliability coefficient was .82 ( $p < .0001$ ). Reliability was also assessed with Cronbach's alpha (value of .90;  $p < .0001$ ).

### *Instrument validity*

During the development phase of the ODAS, the authors sought experts in the field of nursing and in the fields of the psychological evaluation of religious attitudes. Using the data from all 190 undergraduate students, a common factor analysis (principal factors) with varimax rotation was used to determine construct validity and the structure underlying ODAS. The factor analysis identified three factors: Opposing Organ Donation (67.15%), Approving of Organ Donation (11.84%), and Potential Organ Donors (7.77%). The model explains 87.8% of the variance.

The ODAS scores were then entered into a stepwise regression procedure with gender, religiousness (rating of how religious the person believed him or herself to be), services (number of religious services typically attended in a month), Knew1 (if the participant knew anyone who donated an organ while living), Knew2 (if the participant knew anyone who donated an organ after death), Knew3 (if the participant knew anyone who had received an organ transplant), and Education (if the participant had prior educational experiences regarding organ donations).

The correlations among the variables that were significant related to the ODAS scores were Knew2 (.24) and Education regarding organ donation (.37). Concurrent

validity was established by a highly significant relationship between how religious the respondent indicated he or she was and the number of services that the individual attended each month (.56).

An overall internal consistency of the ODAS was inaccurate to calculate because of how the authors originally calculated the ODAS' overall score. The authors did not calculate several unreported items, several items were not reported as being reversed scored although it was shown as a negative loading factor in their analysis, and several items were not included in their subscales.

Items 2 (my religious beliefs do not support or are against organ donation), 13 (I believe that organ donation is against my religion), 14 (I have been taught that organ donation is against my religion), and 16 (I think that organ donation mutilates or deforms the body) were reversed scored. A total score was derived by adding all of the questions from the ODAS except for questions related to demographics and knowledge regarding receiving an organ, which were not directly related to the opinions regarding organ donation. It is written at fifth grade reading level and takes approximately 15 to 20 minutes to complete by the adolescent.

### ***Modifications***

During the pilot study with the first focus group of Asian American adolescents (N=11) who reviewed the ODTK, the ODAS was also reviewed for its content and readability. Several modifications were made to the ODAS in sentence structure for better comprehension (See Appendix C.5). The following five statements were modified: (1) item-1 modified to state, "I believe there is life after you die", from original statement, "I believe in an afterlife"; (2) item-2 modified to state, "My religious beliefs

do not support or are against organ donation” from original statement, “I have religious objections to organ donation”; (3) item-3 modified to state, “I am knowledgeable about organ procurement” from original statement, “I am knowledgeable about organ procurement and the organ procurement system”; (4) item-16 modified to state, “I think that organ donation mutilates or deforms the body” from original statement, “I think that organ donation is mutilation to the body”; and, (5) item-17 modified to state, “I trust that doctors and hospitals use donated organs as they are supposed to be used” from original statement, “I trust that doctors and hospitals use donated organs as they are intended to be used.”

During the second focus group (N=10), the modified ODAS (M-ODAS) was administered to the participants. Following completion of the questionnaire, participants were asked whether items were clearly stated. Everyone agreed that the questionnaire was easily understood and easy to read. No further modifications were made to the M-ODAS.

For the purpose of this dissertation study, only OOD and AOD subscales were used to examine attitude toward organ donation. The internal consistency was .87 for OOD and .78 for AOD in this study.

Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA). The SL-ASIA is the most extensively used instrument to assess the multidimensionality aspects of acculturation to Western culture for Asian Americans in the U.S. (Ponterotto, Baluch, & Carielli, 1998). The SL-ASIA, a 26-item questionnaire, has been extensively tested and proven to be psychometrically sound (See Appendix C.6).

The validity of the SL-ASIA has been evaluated by concurrent and factorial validation. In terms of concurrent validity, correlations between SL-ASIA scores and demographic information such as self-rating of acculturation and total years range from .41 to .62 (Suinn, Ahuna, & Khoo, 1992). In terms of construct validity, using exploratory factor analysis, Suinn and colleagues (1992) identified the following five factors: (1) Reading/Writing/Cultural Preference [accounting for 41.5% of the variance]; (2) Ethnic Interaction [10.7% of the variance]; (3) Affinity for Ethnic Identity and Pride [6.6%]; (4) Generational Identity [5.8%]; and (5) Food Preference [5.0%]. Cronbach's alpha for the SL-ASIA has ranged from 0.68-0.91 indicating a moderate to good internal consistency (Cohen, 1988). Most importantly, the SL-ASIA is most suitable instrument to assess the level of acculturation of Asian American adolescents because of its attention to friendships, music, movies, food, generational status, and its measurement of parents' ethnic identity.

Respondents use a 5-point scale ranging from 1 (exclusively Asian) to 5 (exclusively Anglo) to answer each item. In scoring the scale, a total value is obtained by summing across the answers for all 21 items. Low scores reflect high Asian identification and low acculturation to Western culture, high scores reflect low Asian identification and high acculturation to Western culture, and a median score of 3 reflects a bicultural individual. It is written at a fifth-grade level and takes approximately 5 to 10 minutes for adolescents to complete. The SL-ASIA was used in this study to examine the acculturation level in Asian American adolescents living on the Big Island of Hawaii (N=121). The internal consistency was .86 in this study (See Figure 3: Study Framework).

## CHAPTER FOUR

### ANALYSIS

The aims of this dissertation study were to examine the attitudes and knowledge about organ donation and transplantation among Asian American adolescents which was performed by descriptive statistics. Linear regression was performed to examine the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation. Stepwise multiple linear regressions were performed on those variables of statistical significance obtained from study constructs. The Asian American adolescent's attitude (Opposing Organ Donation [OOD] and Approving Organ Donation [AOD]) and knowledge (General Organ Donation Knowledge [GODK] and Knowledge about Cultural Limitations and Barriers to Transplantation [CLBT]) were entered into the model as the first step for the effect of those variables on willingness to donate and to engage in family discussion about organ donation. Then, acculturation was entered as the second step to examine the effect on attitudes and knowledge about organ donation and transplantation with willingness to donate and to engage in family discussion about organ donation. (See Table 3: Analysis Plan and Figure 4: Study Framework Findings). All statistical analyses were performed using SPSS 14.0 for Windows (Graduate Student Version).

### Results

#### *Sample Characteristics*

A total of 121 Asian American adolescents were recruited into this study: There were 87 (71.9%) females and 34 (28%) males, ages 16 (N=63; 52.1%) and 17 (N=58;



47.9%). Ninety-eight percent (N=117) of the adolescents were born in the U.S. with 88% (N=103) who were born in Hawaii. Sixty-four (52.9%) adolescents were recruited from Hilo High School, 49 (40.5%) recruited from Waiakea High School, and 8 (6.6%) were recruited from St. Joseph's High School (See Table 4: Adolescent Demographics).

Seventy-nine percent (N=95) of the adolescents self-identified themselves as being mixed race and 42.1% (N=51) self-identified themselves as being two or more of the four Asian subgroups (Chinese, Japanese, Filipino, Korean). Because there were very few adolescents who identified one Asian ethnic group (Japanese N=23; Filipino N=4; Korean N=1), analyses were performed using total sample and ethnic differences were not examined.

Seventeen percent of adolescents (N=21) spoke another language besides English at home, which included 4.1% (N=5) Japanese and 3.3% (N=4) Spanish. Religious affiliations included: 51.6% (N=60) Christian; 10.7% (N=13) Buddhist; 21.2% (N=26) no religious affiliation; and 16.5% (N=22) unreported.

The average age of mothers and fathers was 46.1 years (SD=6.52), and 87% had at least a bachelor's degree and 13% had a graduate or professional degree. Ninety-one percent (N=110) of the parents were born in the U.S. with 72% (N=87) of the parents who were born in Hawaii. Eight-two percent (N=99) of the parents who participated in the study were mostly mothers and 18.2% (N=22) were mostly fathers. Average annual family income showed 75.2% having income above \$47,700, and 14.3% having income below average income (See Table 5: Parent Demographics).

### ***Research Aims***

**Aim 1:** To describe the attitudes and knowledge about organ donation and transplantation, willingness to donate and family discussion about organ donation among Asian American adolescents.

The M-ODAS and newly developed ODTK questionnaires were used to examine the attitudes and knowledge about organ donation and transplantation along with willingness to donate and family discussion about organ donation among Asian American adolescents (See Table 6: Descriptives Summary). The two subscales of the M-ODAS examined attitudes: (1) Opposing Organ Donation (ODD) and (2) Approving Organ Donation (AOD). The two subscales of the newly developed ODTK examined knowledge: (1) General Knowledge about Organ Donation (GODK) and Knowledge regarding Cultural Limitations and Barriers for Receiving Organ Transplantation (CLBT).

For the total sample (N=121), the average scores measuring attitude were 2.01 (SD=.35) for OOD attitude and 2.84 (SD=.31) for AOD attitude. The average scores measuring knowledge were 3.10 (SD=.38) for GODK and 2.49 (SD=.69) for CLBT. The average scores for willingness to donate and family discussion about organ donation were 3.20 (SD=.74) and 3.25 (SD=.70), respectively.

Findings indicate that Asian American adolescents have a high rate of approval for organ donation and they are knowledgeable about general aspects concerning organ donation and transplantation. These adolescents also show a high willingness to donate and to discuss their wishes about organ donation with their families.

**Aim 2:** To examine the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about

organ donation among Asian American adolescents.

Multiple linear regression was performed to examine the relationship between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation. The two attitude subscales of the M-ODAS (OOD and AOD) and the two knowledge subscales of the newly developed ODTK (GODK and CLBT) were regressed independently with willingness to donate (M-ODAS item-10, “I have discussed my wishes for after my death with my family”) and family discussion about organ donation (M-ODAS item-12, “I would be willing to donate my organs to a person of a different race than myself”) (See Tables A & B: Regression Summary).

#### *Willingness to Donate*

Factors related to willingness to donate are OOD (negative) attitude ( $R^2=.219$ ,  $F=33.37$ ,  $p<.005$ ), AOD (positive) attitude ( $R^2=.071$ ,  $F=9.01$ ,  $p=.003$ ), GODK (general knowledge) ( $R^2=.275$ ,  $F=44.66$ ,  $p<.005$ ), and acculturation ( $R^2=.048$ ,  $F=6.01$ ,  $p=.016$ ).

These findings suggest that Asian American adolescents’ willingness to donate is related to their less opposing (OOD) and high approving (AOD) attitudes of organ donation, better general knowledge about organ donation and high level of acculturation.

#### *Family Discussion about Organ Donation*

Factors related to family discussion about organ donation are OOD attitude ( $R^2=.104$ ,  $F=13.85$ ,  $p<.005$ ), AOD attitude ( $R^2=.192$ ,  $F=28.02$ ,  $p<.005$ ), and GODK ( $R^2=.071$ ,  $F=9.04$ ,  $p=.003$ ).

Family discussion about organ donation is related to the Asian American adolescents' less opposing (OOD) and high approving (AOD) attitudes of organ donation (small to medium effect), and general knowledge about organ donation.

**Aim 3:** To determine whether attitudes and knowledge about organ donation and transplantation predict willingness to donate and family discussion about organ donation.

Stepwise multiple regression was performed to examine whether independent variables (attitudes and knowledge) predict dependent variables (willingness to donate and family discussion) of organ donation and transplantation (See Tables C & D: Regression Summary).

#### *Willingness to Donate*

Regression models ( $R^2=.355$ ,  $F=20.96$ ,  $p<.005$ ) reveal that GODK ( $sr^2=.11$ ), OOD ( $sr^2=.09$ ), and CLBT ( $sr^2=.09$ ) are predictors for willingness to donate.

These findings suggest that having positive knowledge about both general knowledge and cultural barriers about organ donation and transplantation, and not opposing organ donation increases Asian American adolescent's willingness to donate.

#### *Family Discussion about Organ Donation*

The stepwise regression model suggest that AOD attitude ( $sr^2=.193$ ) predicts family discussion about organ donation. Model as a whole explained 19% of the variance in family discussion about organ donation ( $R^2=.193$ ,  $F=25.76$ ,  $p<.005$ ).

Findings indicate that positive approving attitudes (AOD) predict engaging in family discussion about organ donation in Asian American adolescents.

**Aim 4:** To examine the effect of acculturation with attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents.

Multiple regression using stepwise method was used to examine the effect of acculturation with attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation (See Tables E & F: Regression Summary).

#### *Willingness to Donate*

In the final model, acculturation was entered along with GODK, OOD and CLBT. The stepwise regression model indicates that four variables (GODK, OOD, CLBT and acculturation) are predictors of willingness to donate. The model as a whole explained 40% of the variance in willingness to donate ( $R^2=.402$ ,  $F=18.86$ ,  $p<.005$ ) which is accounted for by GODK ( $sr^2=.11$ ), OOD ( $sr^2=.097$ ), CLBT ( $sr^2=.069$ ), and acculturation ( $sr^2=.035$ ). When acculturation was entered into the model, it explained an additional 2.2% in willingness to donate ( $R^2\text{change}=.022$ ,  $p=.046$ ).

Findings show that positive knowledge related to general organ donation and barriers, and low level of opposing attitude (OOD) about organ donation affects one's willingness to donate. Additionally, one's higher acculturation level increase's willingness to donate.

#### *Family Discussion about Organ Donation*

Stepwise regression model indicates that only AOD (positive) attitude ( $sr^2=.195$ ) is a significant predictor in family discussion about organ donation.

The model as a whole explained about 20% of the variance in family discussion about organ donation ( $R^2=.195$ ,  $F=13.85$ ,  $p<.005$ ). When acculturation was entered into the model, there was no effect upon family discussion ( $R^2\text{change}=.000$ ,  $p=.938$ ).

Findings show that approval attitude (AOD) affects whether family discussion about organ donation takes place and acculturation does not impact on family discussion.

## **CHAPTER FIVE**

### **DISCUSSION**

Highly acculturated Asian American adolescents reported positive attitudes and were knowledgeable about organ donation. Results suggest that positive attitudes and knowledge about organ donation and transplantation are associated with willingness to donate and engaging in family discussion. Acculturation level of Asian American adolescents affects the willingness to donate, but it does not affect engaging in family discussion about organ donation.

Specifically, Asian American adolescents who have better knowledge concerning general aspects about organ donation and cultural barriers to transplantation, not opposing organ donation, and have high levels of acculturation are more willing to donate their organs. Asian American adolescents who have a positive or approving attitude toward organ donation are more likely to engage in family discussion.

#### **Willingness to Donate**

This study identified significant correlations between a low level of opposing organ donation (negative) attitude and good knowledge (general knowledge about organ donation and knowledge regarding cultural barriers to transplantation) with willingness to donate in Asian American adolescents. Additionally, Asian American adolescents' high level of acculturation was related to an increase in willingness to donate. As for factors predicting willingness to donate, this study found that a low level of opposing attitude toward organ donation ( $sr^2=.097$ ), more knowledge about general aspects concerning organ donation ( $sr^2=.110$ ), more knowledge about cultural barriers to transplantation

( $sr^2=.069$ ), as well as, high acculturation levels ( $sr^2=.035$ ) are predictors for willingness to donate in Asian American adolescents ( $R^2=.402$ ,  $F=18.86$ ,  $p<.005$ ).

Adolescents have greater autonomy to make decisions and act in ways that profoundly affect their health. They continually make choices regarding foods, exercise, learning, consumer purchases, drug use, sexual relations, and smoking (Friedman, 1999; Keating, 1993). Young and middle adolescents are more likely than children to analyze a situation from a variety of perspectives and to anticipate the consequences of decisions. Transitional periods begin at age 12 and between the ages of 15 to 16 years. By 14 to 15 years (middle adolescence), most individuals have acquired sensible decision making skills similar to adults and have increased awareness of the consequences of one's decisions (Steinberg & Cauffman, 1996). Adolescents make choices based on their self-concepts of abilities and values (Simpkins & Davis-Kean, 2005). Adolescents are often open-minded which offers the most opportune time to provide intervention of positive reinforcement. Thus, adolescence is the period in which health care providers can make an influence in facilitating adolescents in making appropriate decisions, especially in the area of organ donation.

This study revealed that Asian American adolescents living in Hawaii, who are highly acculturated, have positive attitudes toward organ donation and transplantation. A low level of negative attitude and high level of positive or approving attitude toward organ donation was associated with their willingness to donate.

Because Asian American adolescents in this study are highly acculturated, they are more westernized in their beliefs as they have adopted values of their society. Their positive attitudes toward organ donation may have been formed and attained by sources



which promote organ donation, influenced by athletic stars such as Michael Jordan who campaigned for organ donation, or from organ donation knowledge learned from school. Perhaps the positive attitudes of Asian American adolescents have been formed by the influence of family who support the concept of organ donation, or they may have known someone who has donated an organ or who has received an organ transplant. It may also be due to the influence of western society's supportive concept of organ donation and its impact upon these Asian American adolescents' decision in their willingness to donate. This is consistent with other studies that found higher level of acculturation is associated with more willingness to donate organs. For example, Pham and Spigner's (2004) study found that Vietnamese Americans who reported living in the U.S. the longest seemed more willing to be an organ donor. Also, Albright et al. (2007) reported that Filipino Americans who were born in the U.S. were 3.5 times more likely to be a designated donor compared with foreign-born Filipinos. Results from this research regarding positive attitudes are associated with willingness to donate and are consistent with other studies that have found attitudes to be a strong predictor of organ donation (Essman & Thornton, 2006; Horton & Horton, 1991; Morgan & Miller, 2001; Radecki & Jaccard, 1999; Siminoff et al., 2004; Tokalak et al., 2006; Weaver et al., 2000).

On the other hand, Asian American adolescents who reported opposing or negative attitudes may be influenced by the traditional Asian beliefs towards death and dying. Because the topic of death or issues pertaining to end-of-life are discouraged to be spoken about in Asian families, perhaps Asian American adolescents have never thought deeply about what happens to the body following a tragic event. Perhaps negative attitudes toward organ donation have been formed by misinformation or myths about the

organ donation process. These factors which contribute to unfavorable attitudes toward organ donation may decrease the Asian American adolescents' willingness to donate.

Improvements in cognition during adolescence shape how adolescents view their social world and themselves; in general, their views of cultural values and society at large tend to become more sophisticated and rational (Craig & Baucum, 2002). Adolescents have an awareness of the consequences of their decision towards organ donation, as they show increasing ability to plan and think ahead (Galotti & Kozberg, 1996). As the adolescent develops deeper cognition skills and becomes more capable of being empathic towards others, the issue of organ donation may have more of an impact. Possibly Asian American adolescents' developing sense of altruism and willingness to help others, along with positive attitudes they have toward organ donation, increases their willingness to donate.

In addition to the positive attitudes toward organ donation, this study's sample of Asian American adolescents also had good knowledge about organ donation. The newly developed Organ Donation and Transplantation Knowledge Survey (ODTK) showed that Asian American adolescents living in Hawaii were knowledgeable about general information concerning organ donation and the cultural limitations for receiving an organ transplant. These findings suggest that knowledge about general aspects concerning organ donation and transplantation increases the willingness to donate and to engage in family discussion. These Asian American adolescents have more exposure to the accepted concept of organ donation in the U.S than perhaps Asian adolescents may have in their country of origin. This study of Asian American adolescents may be knowledgeable about organ donation because they have been posed with the question of

signing an organ donor card upon obtaining their driver's license. Also, driver's education classes have briefly touched upon the subject of organ donation as it relates to the organ donation card.

This study's high knowledge about organ donation among Asian American adolescents reflects very promising efforts by high school educators in promoting organ donation awareness and knowledge among young people. These adolescents will themselves be faced with the decision of organ donation early on when they pursue their driver's licenses. Students, as the current generation, possess the heritage of the past and they are considered to be the source for the future. As Weaver et al. (1999) and Spigner et al. (1999) reported, the opinions of teens are still open for change, and their influence can have an impact in stimulating family discussions pertaining to all aspects of organ donation and transplantation.

Knowledge is also an important predictor of organ donation willingness (Horton & Horton, 1991; Morgan & Miller, 2001; Radecki & Jaccard, 1999). Both qualitative and quantitative studies have shown that people who hold misconceptions about organ donation are far less likely to consent to be potential donors (Morgan & Miller, 2001). Studies have shown significant relationships between knowledge about organ donation and attitudes toward organ donation and willingness to donate (Tokalak et al., 2004; Weaver et al., 2000). Spigner et al. (1999) concluded that high school students are great groups to work with and researchers and educators can make a positive impact on encouraging adequate decision making.

This study's findings are supported by several studies. Sander and Miller (2005) found that individuals with more knowledge about donation were found to have more

favorable attitudes toward donation, and respondents with greater knowledge or more favorable attitudes reported greater willingness to donate. Additionally, Morgan and Miller's (2001) study also found willingness to communicate about organ donation is linked with knowledge about organ donation and attitudes toward organ donation. Several studies also support the positive relationship between better knowledge and more willingness to donate (Meir, Schultz, Kuhlencordt, Clausen, & Rogiers, 1999; Rumsey et al., 2003; Sanner, 2002).

Findings from this research suggest that Asian American adolescents have good knowledge and positive attitudes toward organ donation. A culturally designed organ donation awareness program will reinforce and maintain this knowledge and provide more added education in the area of health promotion tailored to the needs of Asian American adolescents, as these adolescents are at risk for hypertension, diabetes, and childhood obesity which are all contributing factors to end-stage renal disease. Thus, there is a need for the development of educational programs focusing on health promotion and the needs for organ donation.

Although these Asian American adolescents indicate a willingness to donate, this decision must be discussed with their family in the event of an untimely tragic event, otherwise organ donation most likely will not occur due to lack of family consent. As adolescents may simply believe that signing an organ donation card will fulfill their willingness of becoming an organ donor, an educational program should emphasize the need to engage in family discussion and outline its importance.

Educational programs about organ donation awareness should be incorporated into high school curriculums during health education classes and driver's education as

knowledge is a predictor of willingness to donate, especially in Asian American adolescents. A culturally sensitive program is needed to improve Asian American adolescents' knowledge and to maintain the knowledge in order to increase willingness to donate.

This study revealed that a low level of opposing attitudes toward organ donation relates to Asian American adolescents' willingness to donate. A culturally designed organ donation awareness program would provide the opportunity to clarify misconceptions, myths, or fears about organ donation which would increase more positive and approving attitudes toward organ donation; thereby, increasing willingness to donate.

Asian American adolescents in Hawaii revealed high levels of acculturation. High level of acculturation was found to be a significant factor in willingness to donate. Because of the high acculturation, the positive attitudes and knowledge about organ donation may have been formed and acquired from their exposure and upbringing in western culture.

Adolescents typically acculturate at a faster rate than their parents as they tend to adapt more quickly and begin to adopt the values and behaviors of the majority culture before their parents (Agbayani-Siewert, 1994; Baptiste, 1993; Rumbaut, 1994; Uba, 1994; Willgerodt & Thompson, 2005; Ying, 1999). This accelerated level of acculturation may result because of the adolescents' contact with Western values adapted from school and peer relations (Ryan-Arredondo & Sandoval, 2005). Although the acculturation levels of the parents were not measured in this study, 98% of the parents were born in the U.S. with 72% born in Hawaii, suggesting a high acculturation level as

well. These highly acculturated parents may be an influencing factor to the adolescents' positive attitudes toward organ donation. However, this study did not examine parental attitudes and knowledge regarding organ donation. Therefore, it is difficult to make certain conclusions on the impact of parental acculturation on their adolescent's willingness to donate.

The adolescent transition is a crucial period in the development of critical thinking. The Asian American adolescent brings primary experiences to a given social encounter; however, culture is necessary to complete the development of self (Mascolo, 2004). These highly acculturated Asian American adolescents may possess positive attitudes toward organ donation because of their exposure to Western values of being more supportive of organ donation than traditional Asian culture, and they may be exposed to more programs that promote organ donation; therefore, they have more knowledge.

### **Family Discussion**

This study found that positive or approving attitude about organ donation predicts whether family discussion about organ donation takes place, irregardless of the Asian American adolescent's acculturation level. Overall, positive or approving attitude toward organ donation was the most significant finding revealed for Asian American adolescents who engage in family discussion about organ donation ( $R^2=.195$ ,  $F=13.85$ ,  $p<.005$ ). Although these Asian American adolescents are highly acculturated, they may still be strongly influenced by their Asian culture of interdependence in engaging in family discussions. Or, because of the high levels of acculturation, these Asian American

adolescents feel comfortable and open to sharing their approving opinions concerning the concept of organ donation with their parents who themselves are highly acculturated.

Since family permission is necessary for organ donation to occur, family discussions are crucial for increasing the actual organ donation and transplant rate. However, Wu's (2008) study conducted in China found that among 298 Chinese young adults (mean age = 21 years) only 12% had ever talked about organ donation with their families. Less than 2% of the participants were registered organ donors. As the author hypothesized, subjective norm was more powerful than general attitude in explaining the intention to donate and family discussion among Chinese young adults. Findings from this study suggest that Asians with low acculturation levels who hold more traditional Asian culture in their way of life are reluctant to discuss a taboo subject, such as organ donation, with their family and are unwilling to donate. While this study found that 90% of Asian American adolescents had engaged in family discussion about organ donation and 84.3% reported their willingness to donate, these results differ because of the Asian American adolescents' high levels of acculturation.

Adolescents' actions and decision-making are largely influenced by feelings and social influences (Steinberg, 2004). Peer relations are of central importance in the social life of adolescents because they assume a crucial role in certain development functions, such as, emancipation from parental guardianship and affirmation of one's identity (Laflin, Wang, & Barry, 2008). As research has shown, the influence of friends predominates pressuring behaviors (Laflin et al., 2008; Leatherdale, Cameron, Brown, Jolin, & Kroeker, 2006; Lenney & Enderby, 2008; Schad, Szwedo, Antonishak, Hare, &

Allen, 2008). Thus, it is possible that the role of peer pressure may have a causal influence on Asian American adolescents' reported willingness to donate.

The adolescent's emerging need for autonomy and self-definition normally leads to some conflict within the family and an increased need to talk with parents about certain issues (Craig & Baucum, 2002). Although adolescents' ties to the family may become strained, they remain very much influenced by their families because their family unit plays an important role in Asian American life (Dwivedi, 2002).

Although positive attitude about organ donation ( $R^2=.192$ ) was the most significant factor for engaging in family discussion, linear regression revealed that both negative attitude about organ donation ( $R^2=.104$ ) and general knowledge about organ donation ( $R^2=.071$ ) are also associated in family discussion.

The most powerful predictor of family consent to donation is knowledge about a loved one's wishes about organ donation, which in turn is predicated on whether organ donation was discussed with family members (Siminoff, Gordon, Hewlett, & Arnold, 2001). Family discussion of organ donation has been found to double rates of family consent regarding organ donation (Smith, Kopfman, Massi-Lindsey, Yoo, & Morrison, 2004). Siminoff, Arnold and Hewlett (2000) reported that the strongest predictor of consenting or refusing organ donation after a death is the family's response to the request. Those families that initially reacted favorably toward donation were more likely to have previously discussed donation issues with their loved one.

While knowledge predicts willingness to donate, organ donation will not take place unless one's wish is expressed to family members. Organ donation rates can be increased by improving adolescents' knowledge regarding organ donation to promote a



positive attitude in a culturally sensitive manner (Persijn & van Netten, 1997). Most importantly, it is critical that family members are aware of each other's attitudes toward donation.

A culturally designed organ donation awareness program would place emphasis on the importance of sharing one's decision concerning organ donation with family. An educational program incorporated into high school curriculum is an excellent venue to maintain and reinforce the positive attitudes and knowledge about general issues related to organ donation. A culturally tailored organ donation awareness program will address the opposing or negative attitudes as it will allow clarification about facts or myths about organ donation. Most importantly, as Asian American adolescents feel more knowledgeable about organ donation, along with having positive or approving attitudes toward organ donation, family discussions will increase.

Findings from this study revealed that acculturation affects the willingness to donate. However, acculturation did not affect engaging in family discussion about organ donation. An educational program to promote family discussion should target both more acculturated and less acculturated Asian American adolescents.

Findings from this study were not fully supported by Morgan's (2004) ODM, with the exception of positive attitudes. Morgan's (2004) ODM postulates that positive attitudes toward organ donation and a high level of knowledge about donation increases willingness to donate and family discussion. This study did not reveal that the Asian American adolescents' knowledge or willingness to donate contributed to family discussion. This finding may be related to differences in developmental or cultural

beliefs as the ODM was previously supported by a study comprised primarily of highly educated African American adults (Morgan, 2004).

Although this study found that Asian American adolescents are willing to donate and many of them have discussed organ donation with their family, willingness to donate is not related to family discussion. It is possible that the willingness to donate is an individual decision made by the Asian American adolescent and that the decision may or may not be shared with family. If Asian American adolescents are willing to donate, they must engage in family discussion and share their decision; otherwise, the consent for organ donation at the time of death most likely will not be given by the family if they are unaware of their loved one's wish. When family members are confident of their loved one's wishes, they nearly always comply (Morgan & Miller, 2001). The best way to ensure this certainty is to persuade those who are willing donors to discuss the issue with family members. This finding further indicates the importance to educate Asian American adolescents to increase their approval attitude toward organ donation or to increase family discussion.

### **Conclusion**

This study revealed that Asian American adolescents in Hawaii have positive attitudes and knowledge about organ donation and transplantation. The contributing factors to the willingness to donate by Asian American adolescents include: knowledge about organ donation (positive knowledge related to general organ donation issues and cultural limitations and barriers to transplantation); high acculturation level; and, a low level of negative attitudes toward organ donation. Asian American adolescents who have positive attitudes about organ donation are more likely to engage in family discussion.

Understanding of adolescents' attitudes and knowledge enables the development of strategies encouraging donation decision registration and donation decision discussion with family, thereby increasing the likelihood that the donor's wishes will be fulfilled. Significant findings from this study suggest that the incorporation of organ donation education in high schools is necessary to reinforce and maintain high knowledge and awareness and to promote family discussion. The development of a culturally sensitive organ donation educational program would greatly benefit Asian American adolescents in maintaining and reinforcing organ donation awareness, along with focusing on health promotion in the prevention of hypertension, diabetes mellitus and childhood obesity, all of which are risk factors to Asian American adolescents, contributing to end-stage renal disease. A culturally sensitive designed organ donation educational program would also inform Asian American adolescents about the shortage of available organs by people of their own ethnicity who are dying while awaiting organs for transplantation. An organ donation program would lead to increasing organ donation rates and to facilitating the importance of family discussions. Such a program will increase positive attitudes toward organ donation, including increasing knowledge and willingness to donate, all of which lead to engaging in family discussion, as supported by the Organ Donation Model (Morgan, 2004). Asian American adolescents have the influence to raise organ donation awareness with their parents and families.

### **Future Research and Limitations**

This study has some limitations as this is one of the first research reports examining Asian American adolescents' attitudes and knowledge about organ donation and transplantation. Although there was significant association identified with the

attitudes and knowledge about organ donation in relation to willingness to donate and to engage in family discussion, a major limitation was the very high ethnic mix of the study's sample which limits generalizability of findings as there are cultural variations among each of the Asian subgroups. Although efforts were initially made to examine each Asian subgroup individually, the sample sizes were too small. This reflects the changing faces of Asian generations in the U.S. of becoming more mixed with other ethnicities. Out of 11.9 million Asian Americans, 1.7 million, or 14%, are Asian as well as one or more other races (Dariotis, 2002). In Hawaii, 19% of its population is of mixed ethnicity (Health Trends in Hawaii, 2005).

Other limitations also included a small total sample size of more female adolescents and their mothers, which may suggest that females are more likely to participate in surveys concerning sensitive topics. In addition, these adolescents came from high income and educated families.

Future research should focus on adolescent participants with full Asian heritage in order to examine more traditional organ donation attitudes of specific Asian subgroups. Investigations should include comparisons between ethnic groups, for example, Chinese born in the U.S. versus Chinese born in Hong Kong versus Chinese born in Mainland China. Or, more comprehensive cross-cultural and comparative research design studies of Asian Americans who live in Hawaii compared to Asian Americans living in the San Francisco Bay Area that include important variables based on theory or conceptual frameworks. One might examine and compare Filipino and Japanese groups living in Hawaii versus Filipino and Japanese groups living in California. Asian Americans living

in an urban area such as San Francisco may have developed more of a Westernized belief system as compared to Asian Americans living in a more rural, outer-island of Hawaii.

More importantly, longitudinal studies should examine the attitudes and knowledge about organ donation among young Asian Americans following an organ donation awareness presentation. This study design would examine the effect of such a presentation in developing a more formalized culturally tailored organ donation awareness program. Understanding Asian American adolescents' attitudes and knowledge and barriers toward organ donation is the first step in developing effective educational intervention that aims to decrease the organ shortage in ethnic minority populations. What would the impact of a culturally designed educational program regarding organ donation have on Asian American teens? Would young Asian American teens be more inclined to sign and carry an organ donor card upon receiving their driver's license? Would young Asian American teens stimulate discussions about organ donation and transplantation at home? And, how would the Asian American teens influence their parents and families' decision towards organ donation?

This was the first study to utilize the ODAS with a sample of diverse ethnicities. Several items of the ODAS were modified which may have affected reliability of the data. Future studies are needed to further examine the reliability and validity of the original ODAS, including the newly developed ODTK in larger samples of Asian American adolescents and other ethnic groups.

There was an overwhelming initial low response rate when study recruitment materials were initially mailed directly to parents. This low response rate may reflect the parent's own reluctance to address the topic and discussion of a sensitive subject as organ

donation or their suspicion towards the research motives. Reports have cited considerable difficulty recruiting minority participants despite committing considerable time, effort and money to meet recruitment goals, including involvement of community-based advisory committees, school districts and the hiring of local staff (Grunbaum, Labarthe, Ayars, Harrist, & Nichaman, 1996). Another limitation included a self selected sample. These Asian American adolescents who chose to participate in the study may have done so because of their established willingness to donate.

This study's sample consisted of highly acculturated Asian American adolescents. Future investigations should examine adolescents with low acculturation levels to determine traditional Asian culture attitudes and knowledge about organ donation. Future research should include having both Asian American adolescent and their parent complete the ODAS, ODTK, and SL-ASIA. Comparisons between the adolescent and parent's responses should be examined to determine the relationship or concordance of the attitudes and knowledge about organ donation.

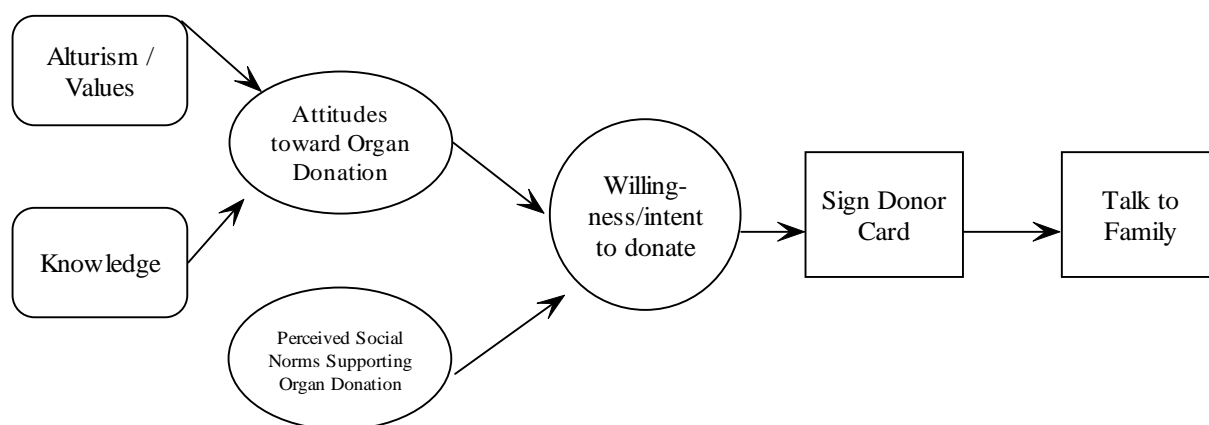
### **Implications for Nursing Practice**

Results of this study suggest the promise of culturally relevant and developmentally appropriate educational programs into school curriculums to continue to raise organ donation awareness among Asian Americans specifically targeting adolescents. In turn, organ donation rates will increase, family discussions about organ donation will take place, and more Asians will be transplanted; thereby, decreasing the number of Asians on transplant lists and dialysis which will decrease long-term medical costs.

The growing transplant waiting lists obligate us to strive to increase the supply of transplantable organs especially in Asian Americans. Currently, there are over 7,700 Asian Americans awaiting an organ transplant in the U.S. (UNOS, 2008). In 2007, only 421 organs were donated from Asian American families (UNOS, 2008). Nurses need to become aware of the cultural barriers that may exist and how they impact upon organ donation consent. There is greater willingness to donate when the potential donor is approached by a healthcare worker who is educated and understands (Norris & Agodoa, 2005). Additionally, the health care practitioners' comfort level with knowing donation criteria and discussing organ donation is associated with an increased patient willingness to donate and family consent rate (Essman & Thornton, 2006; Thornton et al., 2006).

Culturally designed organ donation awareness programs would enhance the care given by health care practitioners to Asian patients who suffer from end-stage organ failure and to Asian families whose loved one has been declared brain-dead. This cultural awareness is important to the role of nurses because they provide the most direct care and have the most personal contact with Asian families. Nurses have the ability to provide the proper knowledge to Asian families concerning all aspects of organ donation and transplantation, most importantly, with cultural respect.

Figure 1:

**The Organ Donation Model**

In: "The Power of Talk: African Americans' Communication with Family Members About Organ Donation and its Impact on the Willingness to Donate Organs,"  
by S. E. Morgan, 2004, *Journal of Social and Personal Relationships*, 21(1), p.115.



Figure 2:

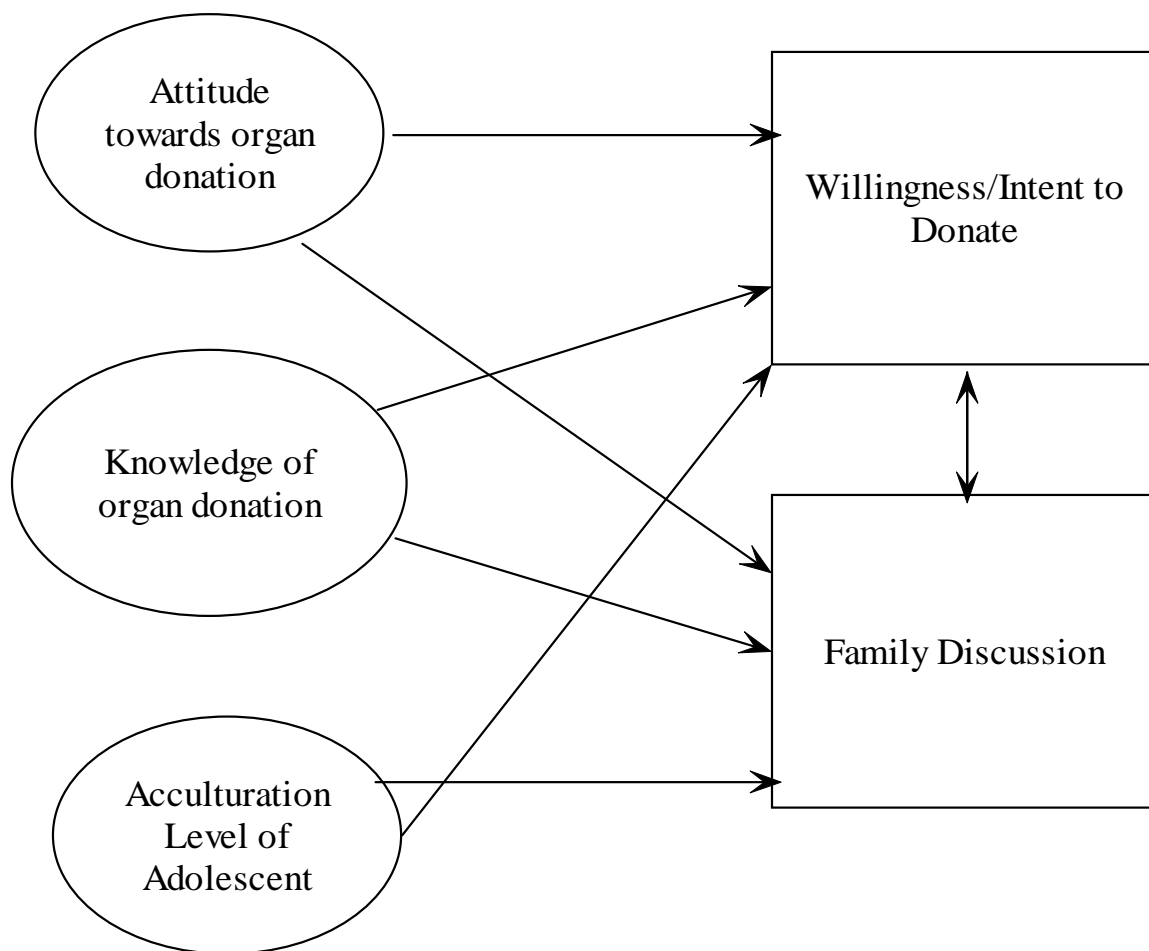
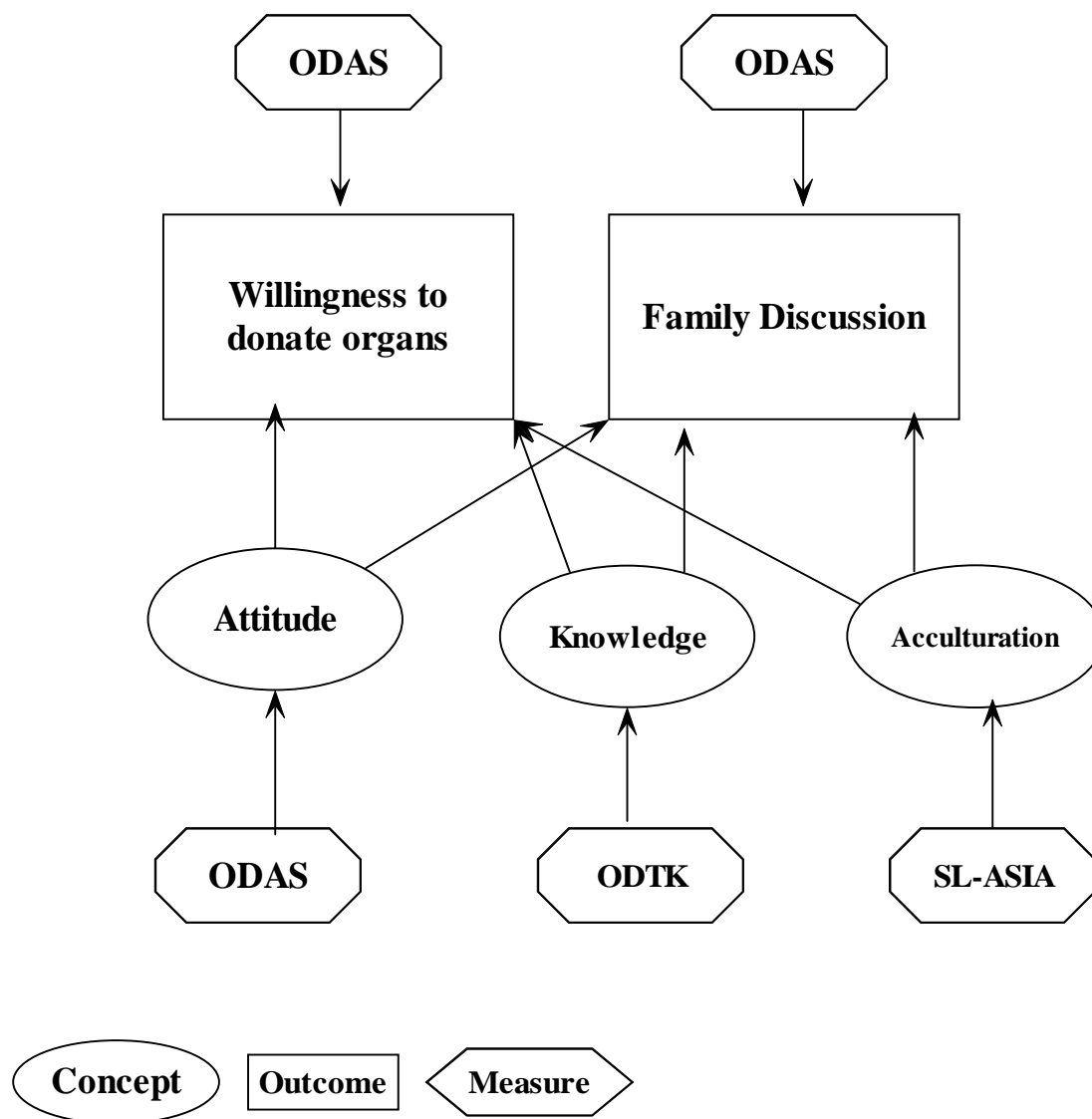
**Organ Donation Model Modified**

Figure 3:

**Study Framework**

Note:

ODAS – Organ Donation Attitude Survey: Opposing OD & Approving OD

ODTK – Newly developed Organ Donation & Transplantation Knowledge Survey:

General Knowledge about OD & Knowledge about Cultural Barriers of OD

SL-ASIA – Suinn-Lew Asian Self-Identity Acculturation Scale

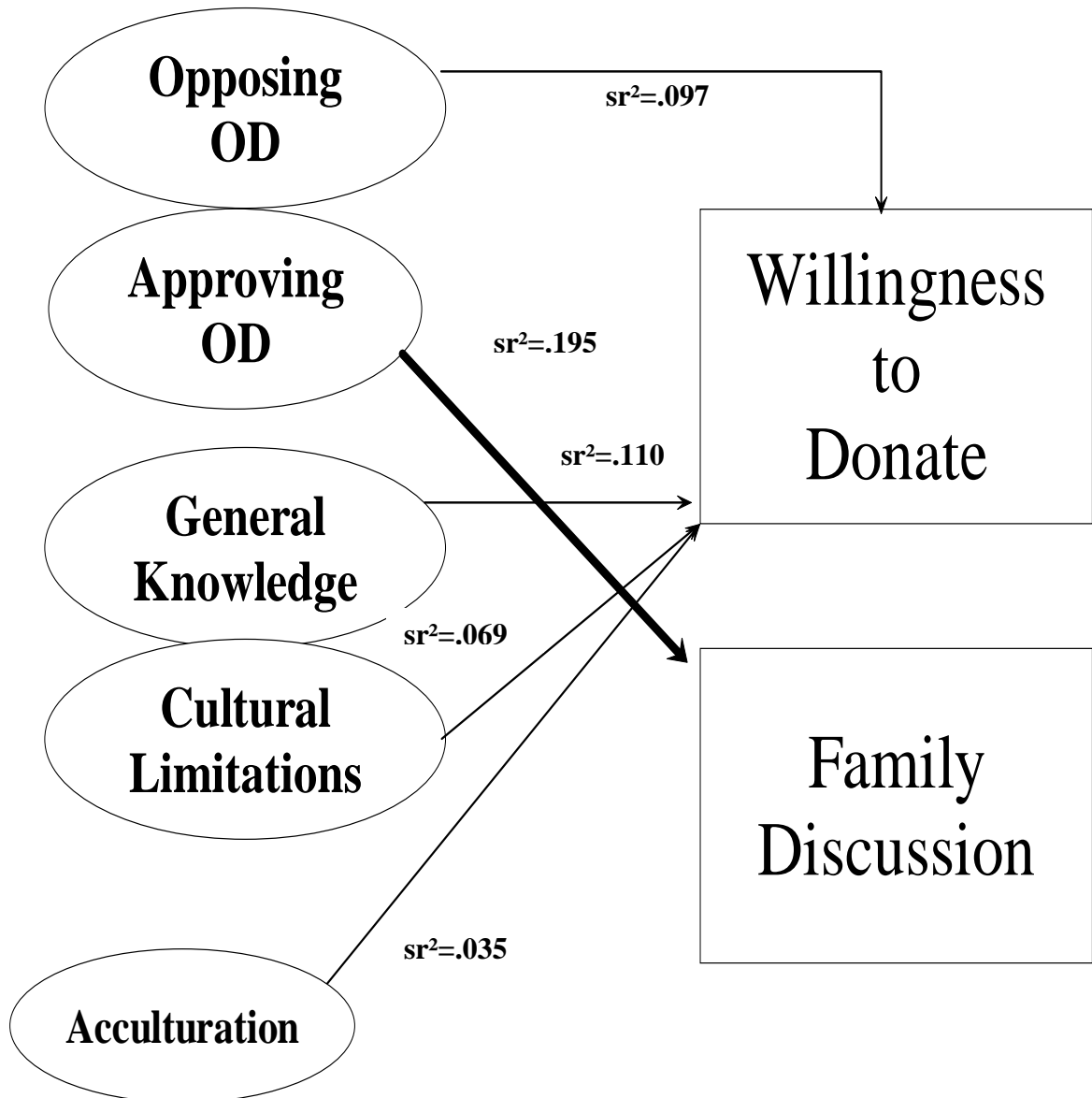


Figure 4:

**Study Framework Findings****Willingness to Donate:**  $R^2=.402$ 

1. positive GODK & CLBT
2. low level OOD attitude
3. high level of acculturation

**Family Discussion:**  $R^2=.195$ 

1. high level AOD attitude

Table 1:

**Measurement Time****Adolescent's Measures**

<b>Concept</b>	<b>Measure</b>	<b>Number of Items</b>	<b>Time</b>
Attitude toward OD	ODAS	20	15-20 min
Knowledge of OD	ODTK (new)	18	10 min
Acculturation	SL-ASIA	26	10-15 min
Demographic Information	Demographic Sheet	10	5 min
<b><i>Main Outcome Variable****</i></b>			
<b><i>Willingness to donate organs****</i></b>	ODAS	3	3 min
<b><i>Family Discussion****</i></b>	ODAS	2	2 min

Total # of items = 73

Total time = 45-55 min

**Parent/Guardian's Measure**

	<b>Measure</b>	<b>Number of Items</b>	<b>Time</b>
Demographic Information	Demographic Sheet	10	5 min

Total # of items = 10

Total time = 5 min

Table 2:  
**New Knowledge Items & Factor Loadings**

<b>Rotated Factor Matrix(a)</b>	<b>Factor 1</b>	<b>Factor 2</b>
Item-16: A patient can receive an organ transplant from a living donor	<b>.742</b>	
Item-13: After transplant, patient is never healthy to return to work or school	<b>-.724</b>	
Item-17: A matched donor is based on blood type and certain health conditions	<b>.689</b>	
Item-12: Organ donors can't have funerals because The body is deformed by the removal of scars	<b>-.678</b>	
Item-15: You can donate certain organs while you are alive & healthy	<b>.677</b>	
Item- 8: People can cause their own disease of needing organ transplant from using IV drugs, drinking too much alcohol	<b>.554</b>	
Item-14: Transplant recipients can live more than 10 Years after a transplant operation	<b>.511</b>	
Item- 7: High blood pressure & diabetes are common causes for people requiring kidney transplant	<b>.506</b>	
Item- 6: Types of diseases that lead to need for transplant are unusual & rare	<b>-.410</b>	
Item- 5: I could need an organ transplant at some time In my life	<b>.373</b>	
Item- 9: High blood pressure & diabetes are common Diseases in Asians		
Item- 1: Racial discrimination prevents minority Patients from receiving transplant they need		<b>.751</b>
Item- 2: Asians wait longer for kidney transplants than Caucasians/whites		<b>.664</b>
Item- 3: Rich person has better chance of getting an organ transplant than ordinary working person		<b>.312</b>
Item-11: People who choose to donate a family member's organs end up paying extra medical bills		<b>.303</b>
Item- 4: Organs for transplant can be bought & sold on black market in the U.S.		
Item- 10: It is possible for a brain-dead person to recover from their injuries		
Item- 18: A matched donor is based on genetics		

Extraction Method: Principal Axis Factoring.

Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 3 iterations.

Table 3:

### **Analysis Plan**

<b>Research Question</b>	<b>Concept</b>	<b>Analysis</b>
1. What are the attitudes and knowledge About organ donation and transplantation and the willingness to donate and family discussion about organ donation among Asian American adolescents?	Attitudes Knowledge Family Discussion Willingness to Donate	Descriptives
2. What is the association between attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents?	Attitudes Knowledge Family Discussion Willingness to Donate	Linear Regression
3. Does attitudes and knowledge about organ donation and transplantation and acculturation predict willingness to donate and family discussion about organ donation?	Attitudes Knowledge Acculturation Willingness to Donate Family Discussion	Stepwise Regression
4. What is the effect of acculturation with attitudes and knowledge about organ donation and transplantation with willingness to donate and family discussion about organ donation among Asian American adolescents?	Attitudes Knowledge Family Discussion Willingness to Donate Acculturation	Stepwise Regression

Table 4:

**Adolescent Demographics**

	<b>Total Sample N=121</b>
<b><u>Age:</u></b>	
16 years old	52.1% (N=63)
17 years old	47.9% (N=58)
<b><u>Grade:</u></b>	
Juniors	55.4% (N=67)
Seniors	44.6% (N=54)
<b><u>Gender:</u></b>	
Females	71.9% (N=87)
Males	28.0% (N=34)
<b><u>Birthplace:</u></b>	
Born in U.S.	98% (N=117)
Born in Hawaii	88% (N=103)
<b><u>High School:</u></b>	
Hilo High School	52.9% (N=64)
Waiakea High School	40.5% (N=49)
St. Joseph's High School	6.6% (N=8)
<b><u>Full Asian Ethnicity:</u></b>	
Chinese	N=0
Filipino	N=4
Japanese	N=23
Korean	N=1
<b><u>Combined Asian Ethnicity:</u></b>	
Mixed Ethnicity **	78.5% (N=95)
>= 2 Asian Ethnicities	42.1% (N=51)
<b><u>Religious Affiliation:</u></b>	
Christian	51.6% (N=60)
Buddhist	10.7% (N=13)
No Religious Affiliation	21.2% (N=26)
Unreported	16.5% (N=22)

**\*\* One of 4 Asian subgroups, along with one or more ethnicities (e.g. Cacaasian, Portuguese, Hawaiian)**

Table 5:

**Parent Demographic Data**

	<b>Total Sample N=121</b>
<b>Parent's age</b>	46.1 (SD=6.52)
<b><u>Gender:</u></b>	
Males	18.2% (N=22)
Females	81.8% (N=99)
<b><u>Birthplace:</u></b>	
Born in U.S.	91% (N=110)
Born in Hawaii	72% (N=87)
<b><u>Education:</u></b>	
Below 9 <sup>th</sup> grade	0.8% (N=1)
9-12 grade	2.5% (N=3)
HS graduate & equivalence	16.8% (N=20)
Some college, no degree	17.6% (N=21)
Associate's degree	21.8% (N=26)
Bachelor's degree	26.9% (N=32)
Graduate/Professional degree	13.4% (N=16)
<b><u>Annual Family Income:</u></b>	
Below \$10,000	1.9% (N=2)
\$15,000 - \$24,999	4.6% (N=5)
\$25,000 - \$35,999	9.3% (N=10)
\$35,000 - \$49,999	14.8% (N=16)
\$50,000 - \$74,999	34.3% (N=37)
\$75,000 - \$99,999	17.6% (N=19)
\$100,000	17.6% (N=19)



Table 6:

**Descriptives Summary****Attitudes / Knowledge / Willingness to Donate / Family Discussion**

	<b>Mean</b>	<b>Std. Deviation</b>
<b>Has discussed own wishes about OD with family</b>	3.25	.70
<b>Willingness to donate organ</b>	3.20	.74
<b>Opposing organ donation (mean)</b>	2.01	.35
<b>Approving organ donation (mean)</b>	2.84	.31
<b>General organ donation knowledge (mean)</b>	3.10	.38
<b>Culturally Related Barriers for receiving OD (mean)</b>	2.49	.70

\*Score Range = 1 - 4

**Acculturation**

	<b>Mean</b>	<b>Std. Deviation</b>
<b>SL-ASIA Language Mean</b>	4.71	.43
<b>SL-ASIA Identity Mean</b>	3.24	1.08
<b>SL-ASIA Friendship Mean</b>	2.49	.73
<b>SL-ASIA Behavior Mean</b>	3.64	.50
<b>SL-ASIA Generation/Geographic Mean</b>	4.50	.62
<b>SL-ASIA Attitude item</b>	2.08	.98
<b>SL-ASIA Acculturation Total</b>	75.51	9.73
<b>SL-ASIA Acculturation Mean</b>	3.60	.46

\*Score Range = 1 - 5

Table A:

**Linear Regression Summary****Dependent Variable: Willingness to Donate (Aim #2)****N=121**

<b>Factor</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>df</b>	<b>F</b>	<b>P</b>
Opposing Organ Donation	.219	-.468	-1.328	-.650	1	33.37	.000
Approving Organ Donation	.071	.266	.217	1.057	1	9.01	.003
General Knowledge About Organ Donation	.275	.524	.726	1.337	1	44.66	.000
Cultural Barriers for Receiving Organ Transplantation	.009	-.096	-.299	.094	1	1.069	.303
Acculturation	.048	.220	.067	.633	1	6.01	.016

Table B:

**Linear Regression Summary**  
**Dependent Variable: Family Discussion about**  
**Organ Donation & Transplantation (Aim #2)**  
**N=121**

<b>Factor</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>df</b>	<b>F</b>	<b>P</b>
Opposing Organ Donation	.104	-.323	-.990	-.302	1	13.85	.000
Approving Organ Donation	.192	.438	.594	1.304	1	28.02	.000
General Knowledge About Organ Donation	.071	.267	.162	.788	1	9.04	.003
Cultural Barriers for Receiving Organ Transplantation	.009	.096	-.085	.271	1	1.080	.301
Acculturation	.001	.034	-.225	.327	1	.133	.716

Table C:

**Stepwise Multiple Regression Summary****Dependent Variable: Willingness to Donate (Aim #3)****N=121**

<b>Predictors</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>sr<sup>2</sup></b>	<b>df</b>	<b>F</b>	<b>P</b>
Overall	.355					3	20.96	.000
General Knowledge About Organ Donation		.349	.318	1.062	.106			
Opposing Organ Donation		-.320	-1.096	-.265	.085			
Cultural Barriers for Receiving Transplantation		-.210	-.393	-.058	.060			

Table D:

**Stepwise Multiple Regression Summary**

**Dependent Variable: Family Discussion about  
Organ Donation & Transplantation (Aim #3)  
N=121**

<b>Predictors</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>sr<sup>2</sup></b>	<b>df</b>	<b>F</b>	<b>P</b>
Approving Organ Donation	.193	.439	.595	1.313	.193	1	25.76	.000

**Excluded variables: Opposing Organ Donation; General Knowledge about OD;  
Knowledge about Cultural Barriers**

Table E:

**Stepwise Multiple Regression Summary****Dependent Variable: Willingness to Donate (Aim #4)****N=121**

<b>Predictor(s)</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>sr<sup>2</sup></b>	<b>df</b>	<b>F</b>	<b>P</b>
Overall	.402					4	18.86	.000
General Knowledge About Organ Donation		.343	.316	1.036	.110			
Opposing Organ Donation		-.331	-1.112	-.302	.097			
Cultural Barriers for Receiving Transplantation		-.220	-.399	-.073	.069			
<b>Acculturation</b>		.149	.005	.472	.035			

Table F:

**Stepwise Multiple Regression Summary**

**Dependent Variable: Family Discussion about  
Organ Donation & Transplantation (Aim #4)  
N=121**

<b>Predictors</b>	<b>R<sup>2</sup></b>	<b>B</b>	<b>95% CI LB</b>	<b>95% CI UB</b>	<b>sr<sup>2</sup></b>	<b>df</b>	<b>F</b>	<b>P</b>
Overall	.195					2	13.85	.000
Approving Organ Donation		.442	.599	1.322	.195			
<b>Acculturation</b>		-.007	-.252	.233	.000			

**Excluded variables: Opposing Organ Donation; General Knowledge about OD;  
Knowledge about Cultural Barriers**

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Appendix A

**LETTERS OF SUPPORT FROM:  
PUBLIC SCHOOLS SUPERINTENDENT  
HILO HIGH SCHOOL  
WAIAKEA HIGH SCHOOL  
ST. JOSEPH'S HIGH SCHOOL**

March 28, 2007

Joyce Trompeta, RN, MS, PNP  
24 Mauna Kea Street  
Hilo, Hawaii 96720

Dear Ms. Trompeta:

**As Principal of St. Joseph's High School**, I am pleased to write this letter of support for your study entitled Attitudes, Beliefs and Knowledge of Organ Donation and Transplantation among Asian American Adolescents that you and Dr. Chen are planning to undertake this upcoming Fall 2007. I am certain that this study has great potential for promoting organ donation consent rates among Asian American families. We will be happy to assist you in recruiting participants by mailing your research participation request to the appropriate families.

Sincerely,

\*\*\*

**Sister Marion Kikukawa  
Principal, St. Joseph's High School  
556 Waianuenue Avenue  
Hilo, Hawaii 96720  
(808) 935-4936**

**\*\*\* Verbal telephone consent on March 28, 2007**



LINDA LINGLE  
GOVERNOR



PATRICIA HAMAMOTO  
SUPERINTENDENT

STATE OF HAWAII  
DEPARTMENT OF EDUCATION  
HAWAII DISTRICT  
P.O. BOX 4160  
HILO HAWAII 96720-0160

May 15, 2007

Joyce Trompeta  
24 Mauna Kea Street  
Hilo, Hawaii 96720

Dear Miss Trompeta,

On behalf of Robert Dircks, Principal of Hilo High School and Kelcy Koga, Principal of Waiakoa High School, we are in support of your proposed research to examine the Attitudes, Beliefs and Knowledge about Organ Donation and Transplantation among Asian American Adolescents, sometime early Fall 2007 (August).

Sincerely,

A handwritten signature in cursive script, appearing to read "Valerie Takata".

Valerie Takata  
Complex Area Superintendent

VT:ba

COMMITTEE ON HUMAN RESEARCH  
OFFICE OF RESEARCH, Box 0962  
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO  
[www.research.ucsf.edu/chr/Apply/chrApprovalCond.asp](http://www.research.ucsf.edu/chr/Apply/chrApprovalCond.asp)  
[chr@ucsf.edu](mailto:chr@ucsf.edu)  
(415) 476-1814

### CHR APPROVAL LETTER

TO: Jyu-Lin Chen, Ph.D.  
Box 0606

Joyce Trompeta, RN, MS, PNP  
Box 0104,

RE: Instrument Development Regarding Knowledge About Organ Donation and Transplantation Among Asian American Adolescents

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

Specifically, the review included but was not limited to the following documents:  
**Organ Donation Consent Form, Dated 3/23/07**

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

**APPROVAL NUMBER:** H11584-30405-01. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

**APPROVAL DATE:** April 26, 2007

**EXPIRATION DATE:** April 26, 2008

**Expedited Review**

**GENERAL CONDITIONS OF APPROVAL:** Please refer to [www.research.ucsf.edu/chr/Apply/chrApprovalCond.asp](http://www.research.ucsf.edu/chr/Apply/chrApprovalCond.asp) for a description of general conditions of CHR approval. In particular, the study must be renewed by the expiration date if work is to continue. Also, prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

**HIPAA "Privacy Rule" (45CFR164):** This study does not involve access to, or creation or disclosure of Protected Health Information (PHI).

Sincerely,



Sharon R. Kaufman, Ph.D.  
Vice Chair, Committee on Human Research

cc:

COMMITTEE ON HUMAN RESEARCH  
OFFICE OF RESEARCH, Box 0962  
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO  
[www.research.ucsf.edu/hr/Apply/chrApprovalCond.asp](http://www.research.ucsf.edu/hr/Apply/chrApprovalCond.asp)  
[chr@ucsf.edu](mailto:chr@ucsf.edu)  
(415) 476-1814

**CHR APPROVAL LETTER**

TO: Jyu-Lin Chen, Ph.D.  
Box 0606

RE: Attitudes, Beliefs and Knowledge About Organ Donation and Transplantation Among Asian American Adolescents

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

Specifically, the review included but was not limited to the following documents:  
**Adolescent/Parent Consent Form, Dated 9/19/07**

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

**APPROVAL NUMBER:** H11584-30960-01. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

**APPROVAL DATE:** September 28, 2007

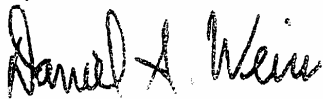
**EXPIRATION DATE:** September 28, 2008

**Expedited Review**

**GENERAL CONDITIONS OF APPROVAL:** Please refer to [www.research.ucsf.edu/hr/Apply/chrApprovalCond.asp](http://www.research.ucsf.edu/hr/Apply/chrApprovalCond.asp) for a description of the general conditions of CHR approval. In particular, the study must be renewed by the expiration date if work is to continue. Also, prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

**HIPAA "Privacy Rule" (45CFR164):** This study does not involve access to, or creation or disclosure of Protected Health Information (PHI).

Sincerely,



Daniel S. Weiss, Ph.D.  
Vice Chair, Committee on Human Research

cc:

Appendix B

**UNIVERSITY OF CALIFORNIA, SAN FRANCISCO  
 ADOLESCENT ASSENT & PARENTAL-GUARDIAN CONSENT  
 TO PARTICIPATE IN A RESEARCH SUBJECT**

**Study Title:** Attitudes, Beliefs, and Knowledge of Organ Donation and Transplantation among Asian American Adolescents

**A. PURPOSE AND BACKGROUND**

Joyce Trompeta, RN, MS, PNP, a doctoral student at the University of California, San Francisco, is conducting a research study to help understand the attitudes, beliefs, and knowledge of organ donation among Asian American adolescents. The ultimate goal is to increase organ donation consent; thereby, decreasing the waiting time on transplant lists. You are being asked to participate in this study because you have an adolescent whose age is 16 or 17 years and you and your adolescent are Asian or of Asian origin.

**B. PROCEDURES**

If you agree to be in the study, the following will happen:

**Parent**

1. You will be asked questions on a questionnaire form about demographic information, such as, your education, family income and native origin. It should take a total of about five minutes to complete this questionnaire. This questionnaire will be done at your home and mailed back to Ms. Trompeta in the stamped envelope or given directly to your adolescent's high school teacher.

**Adolescent**

2. Your adolescent will complete three questionnaires at home. This will take about 45 minutes to complete the three questionnaires: Demographic Information, Organ Donation Attitude Survey, and Suinn-Lew Asian Self-Identity Acculturation Scale.

## **RISKS/DISCOMFORTS**

### **Parent & Adolescent**

3. Emotional distress may result from your adolescent's recounting or perceiving their loss experiences about family and/or friends. Participating adolescents will be reminded that they may stop completion of questionnaires at anytime, and that they do not have to answer all of the questions. You may experience discomfort at the self-reflective and personal nature of questions that ask you about your household income, but you are free to decline to answer any questions you do not wish to answer or decline to participate in the study at any time.
4. Confidentiality: Participation in research may involve a loss of privacy, but information about you and your adolescent will be handled as confidentially as possible. Neither your name nor your child's name will be used in any published reports about this study. Data are coded with the data key kept separately and securely. Completed questionnaires will be stored in locked files at all times.

### **C. BENEFITS**

There will be no direct benefit to you from participating in this study. However, the information you provide may help health professionals better understand how to best approach Asian American families in requesting organ donation and to promote organ donation.

### **D. COSTS**

There will be no costs to you as a result of taking part in this study.

### **E. PAYMENT**

Your adolescent will receive a \$5 Starbucks gift card following completion of the questionnaire.

## F. QUESTIONS

You can talk to the researcher about any questions or concerns you may have about this study. Please contact Joyce Trompeta, RN, MS, PNP at (808) 989-8836 or by e-mail at: [trompetaj@surgery.ucsf.edu](mailto:trompetaj@surgery.ucsf.edu)

Or, for Hilo High & Waiakea High students, you may contact Ms. Eileen Wagatsuma, E. Hawaii District Resource Teacher at (808) 933-0938 or by email at: [Eileen\\_Wagatsuma@notes.k12.hi.us](mailto:Eileen_Wagatsuma@notes.k12.hi.us)

Or for St. Joseph's High students, you may contact Mr. Kulani Calina, SJHS Counselor at (808) 935-4936 ext.230 or by email at: [tkalina.sjhscounselor@gmail.com](mailto:tkalina.sjhscounselor@gmail.com)

**If you have any questions, comments, or concerns about taking part in this study,** first talk to the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the Committee on Human Research, UCSF's Institutional Review Board (a group of people who review research to protect your rights). You can reach the CHR office at (415) 476-1814, 8am to 5pm, Monday through Friday (Pacific Standard Time). Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

**G. CONSENT**

You will be given a copy of this consent form to keep.

**H. PARTICIPATION IN RESEARCH IS VOLUNTARY**

You have the right to decline to be in this study or to withdraw from it at any point without penalty or loss of benefits to which they are otherwise entitled.

**If you don't want to be in the study, just indicate "no" when mailing back the stamped addressed postcard, and don't sign this form.**

**If you want to be in this study, please sign your name below. You will also need to have your parent/guardian sign their name below.**

\_\_\_\_\_  
Adolescent's Signature

\_\_\_\_\_  
Date

Age \_\_\_\_\_

\_\_\_\_\_  
Parent/Guardian's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Adolescent's Name (please print)

**High School: (Please Circle)**

- Hilo High School
- Waiakea High School
- St. Joseph's High School

**Grade: (Please circle)**

- Junior
- Senior

\_\_\_\_\_  
Signature of Person Conducting Research

\_\_\_\_\_  
Date

Appendix C**UNIVERSITY OF CALIFORNIA, SAN FRANCISCO****EXPERIMENTAL SUBJECT'S  
BILL OF RIGHTS**

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

- 1) To be told what the study is trying to find out,
- 2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice,
- 3) To be told about the frequent and/or important risks, side effects, or discomforts of the things that will happen to me for research purposes,
- 4) To be told if I can expect any benefit from participating, and, if so, what the benefit might be,
- 5) To be told of the other choices I have and how they may be better or worse than being in the study,
- 6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study,
- 7) To be told what sort of medical treatment is available if any complications arise,
- 8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study,
- 9) To receive a copy of the signed and dated consent form,
- 10) To be free of pressure when considering whether I wish to agree to be in the study.

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 476-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, Box 0962, University of California, San Francisco, CA 94143.

Call 476-1814 for information on translations.



Appendix D.1:

**PARENT/GUARDIAN DEMOGRAPHIC INFORMATION**  
**\*\*YOUR INFORMATION WILL REMAIN CONFIDENTIAL\*\***

**Age:** \_\_\_\_\_ **Gender:** Male \_\_\_\_\_ Female \_\_\_\_\_

**Relationship to your adolescent:**

- Mother
- Father
- Grandparent
- Guardian

**Education level (please circle):**

- Less than 9<sup>th</sup> grade
- 9<sup>th</sup> – 12<sup>th</sup> grade, no diploma
- High school graduate (includes equivalence)
- Some college, no degree
- Associates Degree
- Bachelors Degree
- Graduate or professional degree

**Annual Family Income (please circle):**

- Less than \$10,000
- \$10,000 - \$14,999
- \$15,000 - \$24,999
- \$25,000 - \$34,999
- \$35,000 – \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000

**Were you born in the United States?** YES \_\_\_\_\_ NO \_\_\_\_\_

**If yes, what state were you born?** \_\_\_\_\_

**If no, your country of origin:** \_\_\_\_\_

**Year of immigration to the U.S.:** \_\_\_\_\_

**How long have you lived in Hilo?** \_\_\_\_\_

**If you are not a Hilo native, where did you live before moving to Hilo?**

\_\_\_\_\_

**Adolescent's name:** \_\_\_\_\_

**High School (please circle):**

- Hilo High School
- Waiakea High School
- St. Joseph's High School

*THANK YOU VERY MUCH FOR YOUR PARTICIPATION!*

Appendix D.2:

**ADOLESCENT DEMOGRAPHIC INFORMATION**

**Name (please print):** \_\_\_\_\_

**Ethnicity/Race:** (Check all origins that apply)

**Do you have mixed ethnicities:** YES \_\_\_\_\_ NO \_\_\_\_\_

**ASIAN:**

- ☐ Chinese
- ☐ Filipino
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese
- ☐ Asian Indian/ Indian Subcontinent
- ☐ Asian: OTHER (list): \_\_\_\_\_

**NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER:**

- ☐ Native Hawaiian
- ☐ Guamanian or Chamorro
- ☐ Samoan
- ☐ Other Pacific Islander (list) \_\_\_\_\_

**WHITE:**

- ☐ European Descent
- ☐ Arab or Middle Eastern
- ☐ North African (NON-Black)
- ☐ White: OTHER \_\_\_\_\_

**BLACK/AFRICAN AMERICAN:**

- ☐ African American
- ☐ African (Continental)
- ☐ West Indian
- ☐ Haitian
- ☐ Black or African American: OTHER \_\_\_\_\_

**HISPANIC/ LATINO:**

- ☐ Mexican
- ☐ Puerto Rican (Mainland)
- ☐ Puerto Rican (Island)
- ☐ Cuban
- ☐ Hispanic/Latino: OTHER \_\_\_\_\_

**AMERICAN INDIAN/NATIVE ALASKAN:**

- ☐ American Indian  
☐ Eskimo  
☐ Aleutian  
☐ Alaska Indian  
☐ Alaska Native: OTHER \_\_\_\_\_

**High School (please circle):**

- Hilo High School
- Waiakea High School
- St. Joseph's High School

**(Please Circle)**

- Junior
- Senior

**Age:** \_\_\_\_\_ **Gender:** Male \_\_\_\_\_ Female \_\_\_\_\_

**Were you born in the United States?** YES \_\_\_\_\_ NO \_\_\_\_\_

**If yes, what city and state were you born?** \_\_\_\_\_

**If no, your country of origin:** \_\_\_\_\_

**Year of immigration to the U.S.:** \_\_\_\_\_

**How long have you lived in Hilo?** \_\_\_\_\_

**If you are not a Hilo native, where did you live before moving to Hilo?**

\_\_\_\_\_

**Religious affiliation (please specify):**

\_\_\_\_\_

**Do you speak any other languages besides English?** YES \_\_\_\_\_ NO \_\_\_\_\_

**If yes, please list:**

\_\_\_\_\_

Appendix D.3:

**Newly Developed Knowledge Questionnaire**

**Organ Donation & Transplantation Knowledge Survey (ODTK)**

1. Racial discrimination prevents minority patients from receiving the transplant they need
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
2. Asians wait longer for kidney transplants than Caucasians/whites
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
3. A rich person has a better chance of getting an organ transplant than an ordinary working person
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
4. Organs for transplant can be bought and sold on the black market in the U.S.
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
5. I could need an organ transplant at some time in my life
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
6. The types of diseases that lead to the need for transplant are unusual and rare
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

7. High blood pressure and diabetes are common causes for people to require a kidney transplant
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
8. People can cause their own disease of needing an organ transplant from using IV drugs, drinking too much alcohol
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
9. High blood pressure and diabetes are common diseases in Asians
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
10. It is possible for a brain-dead person to recover from their injuries
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
11. People who choose to donate a family member's organs end up paying extra medical bills
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
12. Organ donors can't have regular funerals because the body is deformed by the removal of organs
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
13. After a transplant, the person is never healthy enough to return to work or school
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

14. Transplant recipients can live more than 10 years after a transplant operation
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
15. You can donate certain organs while you are alive and healthy
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
16. A patient can receive an organ transplant from a living donor
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
17. A matched donor is based on blood type and certain health conditions
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
18. A matched donor is based on genetics
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

### Appendix D.4:

## Organ Donation Attitude Survey (ODAS)

*Organ donation occurs when someone has suffered brain death. The organs (such as, kidney, pancreas, heart, liver, etc) are taken from the person who has suffered brain death. The family volunteers that person's organs to help others.*

Religious affiliation: \_\_\_\_\_

Participation in religious services: \_\_\_\_\_ times per month

I view myself as ..... 1 2 3 4 5 6 7 8 9 10  
Not religious Very religious

I know someone who donated an organ while they were still living      YES      NO

I know someone who donated an organ after they died	YES	NO
---	-----	----

I know someone who has received an organ transplant	YES	NO
---	-----	----

I have received education about organ donation in general	YES	NO
---	-----	----

**Please answer the following questions using these choices: (please CHECK)**

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Agree
- ☐ Strongly Agree

1. I believe there is life after you die
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
2. My religious beliefs do not support or are against organ donation:
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
3. I support organ donation
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
4. I would agree to an organ transplant, if my life were in danger without one
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree

5. I am willing to have my organs donated after my death
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
6. I have signed an organ donor card on the back of my driver's license
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
7. I know someone who has signed an organ donor card on the back of his/her driver's license
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
8. It is important to discuss my wishes for after my death with my family
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
9. I have discussed my wishes for after my death with my family
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
10. If needed, I would receive an organ from a person of a different race than myself
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
11. I would be willing to donate my organs to a person of a different race than myself
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree



12. I believe that organ donation is against my religion
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
13. I have been taught that organ donation is against my religion
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
14. I think that organ donation is a safe, effective practice
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
15. I think that organ donation mutilates or deforms the body
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
16. I trust that doctors and hospitals use donated organs as they are supposed to be used
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
17. I think that doctors would try just as hard to save my life whether or not I plan to be an organ donor
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
18. In general, I think that organ donation is a good thing
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

19. Organ donation is consistent with my moral values and beliefs
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
20. Racial discrimination prevents minority patients from receiving the transplant they need
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
21. Asians wait longer for kidney transplants than Caucasians/whites
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
22. A rich person has a better chance of getting an organ transplant than an ordinary working person
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
23. Organs for transplant can be bought and sold on the black market in the U.S.
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
24. I could need an organ transplant at some time in my life
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
25. The types of diseases that lead to the need for transplant are unusual and rare
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

26. High blood pressure and diabetes are common causes for people to require a kidney transplant
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
27. People can cause their own disease of needing an organ transplant from using IV drugs, drinking too much alcohol
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
28. High blood pressure and diabetes are common diseases in Asians
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
29. It is possible for a brain-dead person to recover from their injuries
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
30. People who choose to donate a family member's organs end up paying extra medical bills
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
31. Organ donors can't have regular funerals because the body is deformed by the removal of organs
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
32. After a transplant, the person is never healthy enough to return to work or school
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

33. Transplant recipients can live more than 10 years after a transplant operation
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
34. You can donate certain organs while you are alive and healthy
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
35. A patient can receive an organ transplant from a living donor
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
36. A matched donor is based on blood type and certain health conditions
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
37. A matched donor is based on genetics
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

### Appendix D.5:

### Modified Organ Donation Attitude Survey (M-ODAS)

*Organ donation occurs when someone has suffered brain death. The organs (such as, kidney, pancreas, heart, liver, etc) are taken from the person who has suffered brain death. The family volunteers that person's organs to help others.*

Religious affiliation: \_\_\_\_\_

Participation in religious services: \_\_\_\_\_ times per month

I view myself as ..... 1 2 3 4 5 6 7 8 9 10  
Not religious Very religious

I know someone who donated an organ while they were still living      YES      NO

I know someone who donated an organ after they died	YES	NO
---	-----	----

I know someone who has received an organ transplant	YES	NO
---	-----	----

I have received education about organ donation in general	YES	NO
---	-----	----

**Please answer the following questions using these choices: (please CHECK)**

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Agree
- ☐ Strongly Agree

1. I believe there is life after you die
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
2. My religious beliefs do not support or are against organ donation:
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
3. I support organ donation
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
4. I would agree to an organ transplant, if my life were in danger without one
  - Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree

5. I am willing to have my organs donated after my death
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
6. I have signed an organ donor card on the back of my driver's license
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
8. I know someone who has signed an organ donor card on the back of his/her driver's license
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
8. It is important to discuss my wishes for after my death with my family
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
9. I have discussed my wishes for after my death with my family
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
10. If needed, I would receive an organ from a person of a different race than myself
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
11. I would be willing to donate my organs to a person of a different race than myself
  - ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

12. I believe that organ donation is against my religion
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
13. I have been taught that organ donation is against my religion
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
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14. I think that organ donation is a safe, effective practice
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
15. I think that organ donation mutilates or deforms the body
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
16. I trust that doctors and hospitals use donated organs as they are supposed to be used
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree
17. I think that doctors would try just as hard to save my life whether or not I plan to be an organ donor
- ☐ Strongly Disagree
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18. In general, I think that organ donation is a good thing
- ☐ Strongly Disagree
  - ☐ Disagree
  - ☐ Agree
  - ☐ Strongly Agree

19. Organ donation is consistent with my moral values and beliefs
- Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree
20. Racial discrimination prevents minority patients from receiving the transplant they need
- Strongly Disagree
  - Disagree
  - Agree
  - Strongly Agree



Appendix D.6:

**Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA)**

**INSTRUCTIONS:** The questions which follow are for the purpose of collecting information

about your historical background as well as more recent behaviors which may be related to your

cultural identity. Choose the one answer which best describes you.

**1. What language can you speak?**

- a. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
- b. Mostly Asian, some English
- c. Asian and English about equally well (bilingual)
- d. Mostly English, some Asian
- e. Only English

**2. What language do you prefer?**

- a. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
- b. Mostly Asian, some English
- c. Asian and English about equally well (bilingual)
- d. Mostly English, some Asian
- e. Only English

**3. How do you identify yourself?**

- a. Oriental
- b. Asian
- c. Asian-American
- d. Chinese-American, Japanese-American, Korean-American, etc.
- e. American

**4. Which identification does (did) your mother use?**

- a. Oriental
- b. Asian
- c. Asian-American
- d. Chinese-American, Japanese-American, Korean-American, etc.
- e. American

**5. Which identification does (did) your father use?**

- a. Oriental
- b. Asian
- c. Asian-American
- d. Chinese-American, Japanese-American, Korean-American, etc.
- e. American

**6. What was the ethnic origin of the friends and peers you had, as a child up to age 6?**

- a. Almost exclusively Asians, Asian-Americans, Orientals
- b. Mostly Asians, Asian-Americans, Orientals
- c. About equally Asian groups and Anglo groups
- d. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
- e. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups

**7. What was the ethnic origin of the friends and peers you has, as a child from 6 to 18?**

- a. Almost exclusively Asians, Asian-Americans, Orientals
- b. Mostly Asians, Asian-Americans, Orientals
- c. About equally Asian groups and Anglo groups
- d. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
- e. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups

**8. Whom do you now associate with in the community?**

- a. Almost exclusively Asians, Asian-Americans, Orientals
- b. Mostly Asians, Asian-Americans, Orientals
- c. About equally Asian groups and Anglo groups
- d. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
- e. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups

**9. If you could pick, whom would you prefer to associate with in the community?**

- a. Almost exclusively Asians, Asian-Americans, Orientals
- b. Mostly Asians, Asian-Americans, Orientals
- c. About equally Asian groups and Anglo groups
- d. Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
- e. Almost exclusively Anglos, Blacks, Hispanics, or other non-Asian ethnic groups

**10. What is your music preference?**

- a. Only Asian music (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
- b. Mostly Asian
- c. Equally Asian and English
- d. Mostly English
- e. English only

**11. What is your movie preference?**

- a. Asian-language movies only
- b. Asian-language movies mostly
- c. Equally Asian/English English-language movies
- d. Mostly English-language movies only
- e. English-language movies only

**12. What generation are you? (Circle the generation that best applies to you):**

- a. 1<sup>st</sup> Generation = I was born in Asia or country outside the U.S.
- b. 2<sup>nd</sup> Generation = I was born in U.S., either parent was born in Asia or country outside the U.S.
- c. 3<sup>rd</sup> Generation = I was born in U.S., both parents were born in U.S., and all grandparents born in Asia or country outside the U.S.
- d. 4<sup>th</sup> Generation = I was born in U.S., both parents were born in U.S., and at least one grandparent born in Asia or country outside the U.S. and one grandparent born in U.S.
- e. 5<sup>th</sup> Generation = I was born in U.S., both parents were born in U.S., and all grandparents also born in U.S.
- f. Don't know what generation best fits since I lack some information.

**13. Where were you raised?**

- a. In Asia only
- b. Mostly in Asia, some in U.S.
- c. Equally in Asia and U.S.
- d. Mostly in U.S., some in Asia
- e. In U.S. only

**14. What contact have you had with Asia?**

- a. Raised one year or more in Asia
- b. Lived for less than one year in Asia
- c. Occasional visits to Asia
- d. Occasional communications (letters, phone calls, etc.) with people in Asia
- e. No exposure or communications with people in Asia

**15. What is your food preference at home?**

- a. Exclusively Asian
- b. Mostly Asian food, some American
- c. About equally Asian and American
- d. Mostly American food
- e. Exclusively American food

**16. What is your food preference in restaurants?**

- a. Exclusively Asian food
- b. Mostly Asian food, some American
- c. About equally Asian and American
- d. Mostly American food
- e. Exclusively American food

**17. Do you**

- a. read only an Asian language
- b. read an Asian language better than English
- c. read both Asian and English equally well
- d. read English better than an Asian language
- e. read only English

**18. Do you**

- a. write only an Asian language
- b. write an Asian language better than English
- c. write both Asian and English equally well
- d. write English better than an Asian language
- e. write only English

**19. If you consider yourself a member of the Asian group (Oriental, Asian, Asian-American, Chinese-American, etc., whatever term you prefer), how much pride do you have in this group?**

- a. Extremely proud
- b. Moderately proud
- c. Little pride
- d. No pride but do not feel negative toward group
- e. No pride but do feel negative toward group

**20. How would you rate yourself?**

- a. Very Asian
- b. Mostly Asian
- c. Bicultural
- d. Mostly Westernized
- e. Very Westernized



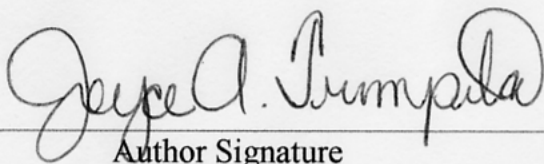
**26. There are many different ways in which people think of themselves. Which ONE of the following most closely describes how you view yourself?**

- a. I consider myself basically an Asian person (i.e. Chinese, Japanese, Korean, Vietnamese, etc.). Even though I live and work in America, I still view myself basically as an Asian person.
- b. I consider myself basically as an American. Even though I have an Asian background and characteristics, I still view myself basically as an American.
- c. I consider myself as an Asian-American, although deep down I always know I am an Asian.
- d. I consider myself as an Asian-American. I have both Asian and American characteristics, and I view myself as a blend of both.

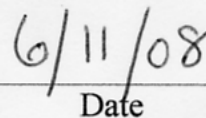
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