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REVIEW

Cultural barriers to organ donation among Chinese and Korean individuals in the United States: a systematic review

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SUMMARY

Asian Americans have the lowest organ donation registration rates in the United States, and the reason for this is incompletely understood. Aiming to understand the reasons for low organ donation registration rate among Asian Americans, more specifically Chinese and Korean Americans, we conducted a systematic search of databases, websites, and gray literature. Altogether, 34 papers were retained after the assessment of relevance and quality. Commonly reported barriers to organ donation registration among Chinese and Koreans in the literature included lack of knowledge about organ donation, distrust of health-care and allocation system, cultural avoidance of discussion of death-related topics, and desire for intact body mainly stemming from the Confucian concept of filial piety. Strong family values coupled with a cultural reluctance to discuss death-related topics among family members appear to underscore the reluctance to organ donation among Chinese and Koreans. Notably, improved knowledge negatively impacted organ donation intent and religion seemed to play a more important role when making decision about organ donation among Koreans, and the distrust of the allocation system is more prominent among Chinese. This information should be used to inform the development of culturally competent organ donation educational materials.

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Key words
attitude, beliefs, Chinese, knowledge, Korean, organ donation

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Introduction

Organ transplant often represents a life-saving treatment for patients with organ failure. The need for organ transplantation has been increasing steadily, but the number of organ donors has remained stagnant [1–3]. Among all ethnic groups in the United States, Asian Americans have the greatest disparity in demand and supply of organs [4]. Asians, the fastest growing minority group in the United States, currently comprise 8% of the transplant waiting list, but only 2.5% of deceased donors are Asian Americans [5,6]. It is widely reported that racial and ethnic minorities, including Asian Americans, are less likely than Caucasian Americans to register as organ donors, but the reasons for this difference are incompletely understood [7,8].

Queens County, one of the most populated counties in the United States (>2.2 million), consists of 27% Asian population, has one of the lowest donor registration rates in the country (20% vs. national average of 54% currently) [9,10]. The Asian population in Queens includes a large number of Chinese and Korean with a

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significant proportion of these individuals being recent immigrants (47.5% foreign born) [10,11]. Research has shown that Asian American immigrants reported lower acculturation and higher enculturation levels and they continued to be influenced significantly by their native culture [12]. Reluctance toward organ donation is also noted in China and South Korea. In 2017, the deceased donor rate was 3.7 per million population (PMP), 6 PMP, and 10.6 PMP, in mainland China, Hong Kong China, and South Korea, respectively, which is much lower than the United States, where the deceased donor rate is 32 PMP [13].

This systematic literature review aims to review the current knowledge on barriers toward organ donation among Asian Americans, with a focus on Chinese and Korean Americans, by examining studies about organ donation conducted in China and South Korea in addition to the studies done in Western countries. Understanding attitudes and beliefs among Chinese and Koreans regarding organ donation is an essential prerequisite to the development of appropriate interventions to promote organ donation in Chinese and Korean populations in the United States.

Methods

Systematic search

To conduct systematic search in PubMed, specific search strategy and terms were developed with the assistance of an information specialist. Keywords included previous and current phrasing associated with organ donation and our target populations. Medical subject heading (MeSH) and Tiab terms used to search the databases are shown in Table 1. Tiab terms (free text used in titles and abstracts) were also searched to identify articles not yet indexed in PubMed in order to increase the likelihood of locating additional relevant papers [14]. Scoping searches were also conducted in other databases such as EBSCO, Embase, Ovid, Web of Science, and Scopus.

PubMed was initially searched in April 2018 and again in September 2018 to include all recently published literature. Relevant websites and gray literature from sources such as government agencies, universities, associations and societies, and professional organizations were also searched. Experts in the field were contacted regarding recently published or ongoing projects. Finally, the references of the resulting articles were reviewed to identify any additional relevant papers not identified by other search strategy.

The inclusion and exclusion criteria for the selection of articles for review are shown in Table 2. Included were articles that were published from January 1997 through September 2018, related to solid organ donation (living or deceased), evaluated knowledge of and/or attitudes and beliefs surrounding organ donation, focused wholly or in part on the Asian populations of interest (Chinese and Korean), involved either qualitative or quantitative research methods, and written in English. Articles published prior to 1997 were excluded given concerns about the rapid development in the field

Table 1. Search terms for systematic search in PICO format.

Population (P)	Intervention (I)	Comparison (C)/Outcome (O)
"Asian continental ancestry group" [MeSH]	"Tissue donors" [MeSH]	"Barriers" [tiab]
"Asians" [tiab]	"Organ donors" [tiab]	"Attitude" [MeSH]
"East Asians" [tiab]	"Living donors" [tiab]	"Willing*" [tiab]
"Asian Americans" [MeSH]	"Deceased donors" [tiab]	"Knowledge" [MeSH]
"Chinese" [tiab]	"Tissue and organ procurement" [MeSH]	"Trust" [MeSH]
"Koreans" [tiab]	"Directed Tissue Donation" [MeSH]	"Communication" [MeSH]
"China" [MeSH]	"Organ donation" [tiab]	"Culture" [MeSH]
"Taiwan" [MeSH]	"Living organ donation" [tiab]	"Religion" [MeSH]
"Korea" [MeSH]	"Deceased organ donation" [tiab]	"Spirituality" [MeSH]
	"Organ transplantation" [MeSH]	"Beliefs" [tiab]
		"Human body" [MeSH]
		"Body integrity" [tiab]
		"Intact body" [tiab]
		"Complete body" [tiab]

Boolean operator "OR" was used between search terms within each column; Boolean operator "AND" was used to combine search terms of the three columns.

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Table 2. Assessment criteria.

Inclusion criteria	Exclusion criteria
Country: Relevant studies conducted in all countries to be included Type of donation: Living organ donation, deceased organ donation Ethnicity: Chinese, Korean Age: No restrictions Date: 1997–2018 Language: English Research design: Qualitative and quantitative studies	Type of donation: Nonsolid organ donation (e.g., blood donation, cord-blood donation, sperm and egg donation, bone marrow donation, corneal donation, medical research organ donation) Ethnicity: Other Asians (e.g., Japanese, Indonesian, Malaysian, Vietnamese) Date: Prior to 1997

of transplantation that would potentially impact how organ donation is perceived. Also excluded were papers related to nonsolid organ donation including cord blood, bone marrow, and corneal transplants.

Relevance assessment

The final search in PubMed identified 317 articles (Fig. 1). Of these, 215 publications were excluded after a review of the title and abstract. Full text was retrieved and reviewed for the remaining 102 articles. Thirty-three papers remained after an additional 69 articles were excluded for not meeting the inclusion criteria. In addition, one study was identified by reviewing the references of the resulting articles. Finally, 34 studies were identified and included in this systematic review.

Data synthesis

The preliminary synthesis involved summarizing the reported methods and the results of each study. Papers were then grouped by study population and design (Table 3). Parallel syntheses of the papers in each group were then undertaken to identify the barriers to organ donation. The key barriers identified provided the framework for this systematic review.

Results

Preliminary synthesis

Of the 34 studies included, 25 (74%) were conducted in Asia (mainland China, $n = 12$; Hong Kong China, $n = 6$; South Korea, $n = 7$) and nine (26%) studies were conducted in either the United States ($n = 7$) or Canada ($n = 2$; Table 3). Of the studies that were conducted in the United States, the majority were published approximately 20 years ago, between 1997 and 2001. Two of the seven American studies were qualitative in design and aimed to understand Asian cultures' influence on Asian Americans' health-related behaviors. The remaining five American studies were quantitative in design and compared attitudes and opinions toward organ donation between Asian Americans and Caucasian Americans. The two Canadian studies included were both qualitative studies that explored Chinese Canadians' perspectives on organ donation. Among the 18 studies conducted in China and Hong Kong, one was qualitative study and 17 were quantitative studies that investigated the attitude and willingness of Chinese residents toward organ donation as well as factors influencing their organ donation behavior. The seven studies, including two qualitative and five quantitative analyses, that were conducted in South Korea explored the attitudes and knowledge of South Koreans toward organ donation.

Main synthesis

Attitude, willingness, and registration

Attitude. Chinese and Korean Americans had a less positive attitude toward organ donation compared to Caucasian Americans [15–17]. Many Chinese and Koreans had less positive attitude toward organ donation in part because of Confucian heritage [18–22]. The notion of organ donation stands in direct contrast to the Confucian ideology of filial piety, which states that the body is a gift from one's parents and should be well cared for to show respect to one's parents [18–22]. Concerns about body disfigurement because of organ donation and the wish to be buried intact were prominent among both Chinese Americans and Korean Americans [18,19]. However, these concerns were contradicted by an

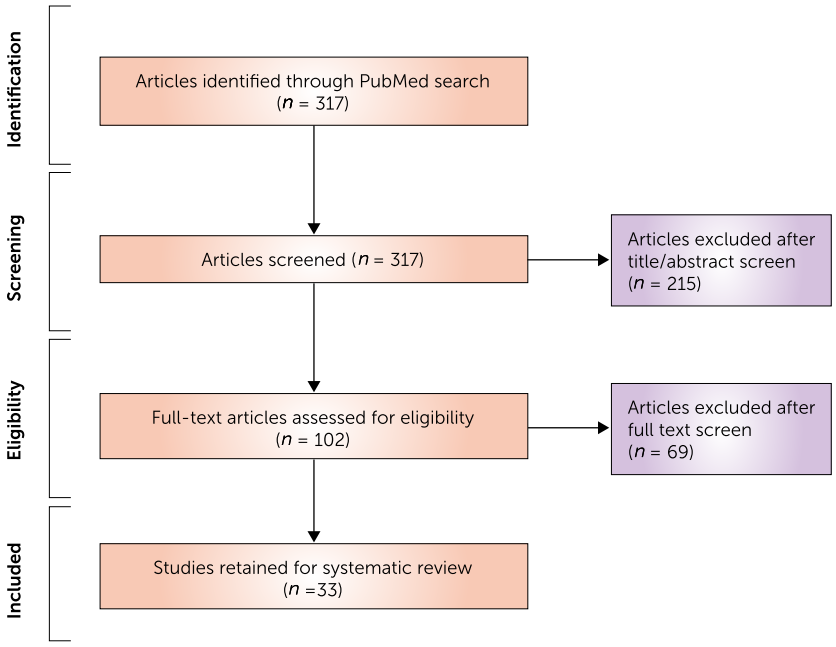

Figure 1 Flow diagram showing exclusion process for studies identified by systematic search in PubMed.

understanding, expressed in studies of Chinese in Canada and Hong Kong, that organ donation is an honorable act that saves lives [22–24]. Studies of health professionals in Korea identified similar mixed attitudes toward organ donation [20,21,25].

Despite mixed feelings, a majority of Chinese and Koreans possessed overall positive attitudes toward organ donation. When surveyed, 76.9% of Chinese health professionals, 80–88.9% of Chinese public (80% in Changsha city, 82.2% in Hunan city, 88.9% in East China), 85.2% of Hong Kong medical students, and 75% of Korean patients' relatives, 85% of Korean nursing students, and 91.2% of Korean health-care professionals, agreed that organ donation is a noble act with positive outcomes and supported organ donation [25–32].

Willingness and registration. Despite the fact that the majority of study respondents held an overall positive attitude toward organ donation, the expressed willingness to donate was markedly low and the actual organ donation registration rate was even lower in Chinese and Koreans even among health professionals. For example, in a cohort of medical students and nurses in Hong Kong, 99% and 96%, respectively, had a self-rated positive attitude toward organ donation, but only 23% of each cohort had signed an organ donor card [27,33]. Similarly, among the general public in Hong Kong, 60.3% of respondents expressed willingness to be organ donors, but only 14.8% had previously registered as organ donors [34]. When compared with Hong Kong residents that had never donated blood, Hong Kong residents that had previously donated blood expressed a significantly higher willingness (81% vs. 53%) and commitment to donate organs (49.9% vs. 22.6%), but the actual commitment to donate was markedly lower than expressed willingness to donate in both groups [35].

In mainland China, the expressed willingness varied greatly between region and study population, ranged from 38.9% to 81.9%. [26,28,31,32,36–40] The expressed willingness to donate was 38.9%, 39.7%, 53.5%, and 73% among the surveyed public in Changsha city, East China, Hunan province, and Beijing city, respectively; 42.2% among general nurses and 33.4% among transplantation nurses; 64.2% among doctors; 62.7% among transplant patients and 50.7% among patients' caregivers; and 64.1% among university students and 81.9% among medical students [26,28,31,32,36–40]. When both expressed willingness and registration rate were examined, 61.3% of the surveyed mainland college students expressed willingness to donate but only 3% of them had actually signed an organ donor card [36].

In Korea, the expressed willingness to donate organs after death among middle school and high school students, patients' relatives, and nursing students was 49.8%, 60.9%, and 73%, respectively [25,30,41]. However, while 49.8% of Korean high school and middle school students reported willingness to become deceased donors, only 0.9% of the students carried donor cards [41].

Table 3. Overview of studies included in the review.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Andresen, 2001 [18]	USA	Qualitative	*N* = n/a; Korean Americans	To explore cultural attitudes toward different aspects of healthcare of patients from Japan, Korea, and India	Koreans had negative views about organ donation because of Confucian heritage of filial piety. Many believed that body is an integral part of nature and that people have their own destiny
Braun & Nichols, 1997 [19]	USA	Qualitative	*N* = 5; Chinese Americans (recent immigrants)	To explore death and dying cultures of four Asian cultures (Chinese, Japanese, Vietnamese, Filipino)	Many interviewed Chinese possessed Confucian beliefs of dying intact and filial piety
Alden & Cheung, 2000 [15]	USA	Quantitative	*N* = 425; Asian American (Chinese 12%, Japanese 38%, Korean 2%, Filipino 7%), Caucasian Americans 42%	To compare and contrast attitudes and cultural beliefs between Asian Americans and Caucasian Americans, and their effects on organ donation behavior	Asian Americans had significantly higher body integrity score, lower sense of community responsibility, lower trust level toward physicians, less positive toward organ donation, less possession of organ donation card, which contributed to lower organ donation rate
Lam & McCullough, 2000 [42]	USA	Quantitative	*N* = 122; Chinese Americans	To explore the religious and cultural reasons of why Chinese Americans are less willing to donate their organs and examine the effects of social distance on willingness to donate	Chinese Americans were more influenced by Confucian beliefs than other religions. Those that agreed with Confucian concept of dying intact as a way of showing respect to ancestors were less likely to donate their organ. Social distance contributed to negotiable willingness. Chinese Americans were most willing to donate to close relatives, then distant relatives, people from same country, and strangers
Thornton *et al.* 2006 [8]	USA	Quantitative	*N* = 883 American high school students; Asian Americans 19% (Chinese Americans 7%), White 25%	To explore ethnic and gender differences in willingness to donate organs among teenagers and determine factors associated with those differences	All participants regardless of race and ethnic had low level of organ donation knowledge. White students were more willing to donate than Chinese (OR 3.03, 95% CI 16–66%)
Bresnahan *et al.* 2007 [17]	USA, Korea, Japan	Quantitative	*N* = 426 college students; Americans *N* = 146, Japanese *N* = 134, Koreans *N* = 146	To investigate willingness of Americans, Koreans, and Japanese to register as organ donors using the theory of planned behavior	Respondents in all three countries showed deficient knowledge about organ donation. American respondents exhibited more positive attitudes, more knowledge, thus more behavioral intention to register as organ donors than either Japanese or Korean respondents. For Korean respondents, knowledge was associated with reluctance to register. And in spite of positive attitudes toward organ donation, most Korean participants declined to take an application to register as a donor

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Bresnahan *et al.* 2008 [16]	USA, China	Quantitative	*N* = 478 college students; Chinese *N* = 235, Americans *N* = 243	To examine the effects of attitudes and norms on intent to become an organ donor in China and the United States	Respondents from both countries did not differ in amount of knowledge about organ donation. US respondents scored significantly higher measures of attitude, tendency to communicate with family, intention to donate
Molzahn *et al.*, 2005 [23]	Canada	Qualitative	*N* = 15; Chinese Canadians	To explore the values and beliefs regarding organ donation of Chinese Canadians	Sociodemographic characteristics (e.g., older age), general lack of knowledge and communication about organ donation, need for intact body, mixture of beliefs in one person, fear of being hastily treated negatively impacted the participants' view on organ donation. Participants had mix feeling, despite traditional beliefs, some think organ donation is a good deed
Starzomski & Curtis, 2011 [24]	Canada	Qualitative	*N* = 44; Chinese Canadians	To explore Chinese Canadians' values and beliefs on organ donation and transplantation	Most participants had little or no knowledge about organ donation and transplantation but would like to learn more about the topic. Many believed that organ donation is an honorable act. Some believed that the body needs to be buried intact, but many think it is a personal decision, and would not consult religious leader regarding their decision about organ donation
Wu, 2008 [48]	Mainland China	Quantitative	*N* = 298; Chinese public	To examine the psychological factors that influence communication about organ donation with family, which is one of the organ donation-related behaviors that increase organ donation registration, among Chinese young adults	Participants had high intention and overall positive attitude, but only 1.7% were registered donor. Family discussion leads to higher in intention (OR > 1), more positive in subjective norm (OR = 2.34), and lower in death anxiety (OR = 0.41), but only 12% participants had ever discussed organ donation decisions with family (88% had not)

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Wang *et al.*, 2012 [38]	Mainland China	Quantitative	*N* = 2390; Chinese public	To examine Chinese people's awareness and attitudes toward organ donation	90.0% of the participants approved of deceased organ donation whereas only 65.3% of participants approved of living organ donation. 73.0% indicated that they would like to donate their organs postmortem. Only about 6.0% of the participants knew all organs that could be transplanted. Reasons of unwillingness included traditional Chinese values (intact body) 33.1%, afraid donated organs might be sold on the black market 30.2%, incomplete regulations and laws 21.9%
Zhang *et al.*, 2015 [32]	Mainland China	Quantitative	*N* = 1074; Chinese public	To investigate the willingness and attitude of the general public in East China and the factors that affect organ donation	955 (88.9%) participants were in favor of organ donation, but only 426 (39.7%) were willing to donate organs and 648 (60.3%) were not willing to do so. Concerns that participants had included incomplete laws and regulations (27.4%), family opposition (26.4%), and distrust of organ allocation system (25.8%), cultural beliefs that organ donation is against Chinese traditions (15.3%)
Luo *et al.*, 2016 [26]	Mainland China	Quantitative	*N* = 417; Chinese public	To evaluate public attitude and willingness about deceased organ donation and its effects on future voluntary organ donation	Majority of people agreed that organ donation is good. Majority of participants (51.08%) were uncertain about organ donation, while 38.85% were willing, and 10.07% were unwilling. 64.1% of the participants expressed concern about not knowing much about organ donation. 65.3% did not agree with filial piety; only 28.1% thought that body intactness is important. 88.9% of the participants would consider family's willingness, 53.4% influenced by social atmosphere. Participants believed in inappropriate use of organ (74.4%), ineffective use of organ (72.7%), lack of treatment as donor (51.6%)

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Luo *et al.*, 2016 [31]	Mainland China	Quantitative	*N* = 1085; Chinese public	To examine perception and attitudes toward organ donation and to analyze the relationship between knowledge, attitudes, and willingness to donate.	82.2% of public support organ donation, but only 53.5% expressed willingness to donate postmortem. Mean accuracy rate on knowledge evaluation was 71.96%. Knowledge was found to be positively correlated with attitudes of organ donation. Only 1.8% of participants expressed concern about religion and 14.9% cared about body integrity
Hu & Huang, 2015 [28]	Mainland China	Quantitative	*N* = 373; Chinese health professionals, doctor 35.9%, nurse 46.3%, nonclinical staffs 17.7%	To determine the knowledge, attitude, and willingness toward organ donation of health professionals in China because (i) knowledge is positively correlated with donation behavior and (ii) health professionals' attitude and beliefs can influence public's willingness to register	Doctors generally knew more about organ donation and were more positive and willing to donate to strangers than nurse and nonclinical staffs. Top reasons for organ shortage participants believed were traditional views (75.6%) and scarce knowledge about organ donation (59.8%). Reasons for participants' unwillingness to donate were afraid of disfigured body (49.2%), and incomplete law (45%), distrust of medical system (40.2%), traditional values (32.3%)
Xie *et al.*, 2017 [39]	Mainland China	Quantitative	*N* = 566; Chinese transplant nurses	To investigate the attitudes toward organ transplantation and donation among transplantation nurses and to explore the impact factors	Participant's willingness was 33.4% willing, 39.9% were uncertain, 26.7% not willing to donate after death. Only 39.7% of the transplant nurses had received specific training on donation procedures at some time in their career, and 77.1% acknowledged that they would like to receive more training
Ge *et al.*, 2014 [37]	Mainland China	Quantitative	*N* = 320; Chinese medical students	To clarify the knowledge and attitudes toward living and deceased organ donation among Chinese medical students	Only 26.7% participants knew about living donation regulations. Majority of respondents were willing to donate postmortem and living (81.9% and 81.6%, respectively)
Zhang *et al.*, 2017 [40]	Mainland China	Quantitative	*N* = 426; Chinese transplant patients and their caregivers	To investigate the attitudes toward organ donation among renal transplantation patients and their caregivers.	Among the renal patients, 67.4% were willing to donate a living kidney to a close relative, 62.7% were willing to donate organs after death, and 44.4% and 50.7%, respectively, among their caregivers. Participants' age, marriage status, education level, and knowledge were significantly associated with participants' willingness to donate

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Yang *et al.*, 2012 [43]	Mainland China	Quantitative	*N* = 301; Chinese renal patient's relatives	To investigate the attitude toward living organ donation and deceased donation of renal patients' relatives	Among the respondents, 65.5% (*n* = 197) were willing, 26.2% (*n* = 79) were unwilling, and the remaining 8.3% (*n* = 25) were unsure (unsure % lower than other study) about living donation. Negotiable willingness based on social distance was observed. Majority of living donors were related to the recipient, parents (66.5%), spouses (5.7%), and other relatives (4.8%). Attitude of deceased donation and knowledge of living donation procedure were positively impacted living organ donation attitude, while concerns about body mutilation and surgery risks, lack of family discussion negatively impacted it
Zhang *et al.*, 2007 [44]	Mainland China	Quantitative	*N* = 434; Chinese university students	To clarify the knowledge and attitude of Chinese university students	Overall only 50 % of participants were willing to be living donors, and negotiable willingness based on social distance observed. There was a general lack of knowledge and awareness of living donation. Participants were concerned about complications, compensation, and body integrity
Chen *et al.*, 2006 [36]	Mainland China, Hong Kong, Taiwan, Macau	Quantitative	*N* = 922; Chinese university students; Mainland 50.2%, Hong Kong 25.6%, Taiwan 4.2%, Macau 11.8%, other regions 8.1%	To explore knowledge and attitudes about deceased organ donation among university students (mainland vs. oversea)	Overall deceased donation willingness among participants was 61.3% yes, 8.5% no, 30.3% unsure. There was no significant difference in willingness between mainland and oversea students. Majority of participants (90%) would like to know more about organ donation. Top reason for consenting was "save other's live" (93.1%), while top reasons for not consenting were body integrity (47.4%), inappropriate use (35.9%), traditional death ideas (33.3%), family opposition (28.2%)

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Yeung *et al.*, 2000 [34]	Hong Kong, China	Quantitative	*N* = 284; Hong Kong public	To examine the attitude of Hong Kong residents toward organ donation after death	85.2% of the public supported organ donation. And 60.3% of them were willing to donate organs after death, 20.4% were undecided, and 17.4% were unwilling to donate, 1.9% refused to answer the question. Only 14.8% had signed an organ donor card. 10% always carry their donor card. Only 33.3% (54/163) of those that were willing to donate communicated their wish to donate with their family. 85.2% of the respondents would be willing to donate their family member's organ if family have expressed their wish, if not, only 41.1% would be willing to donate their family member's organ. Age and occupation, the traditional belief of being buried whole, altruism, lack of understanding on organ donation and lack of confidence in the professional conduct of doctors affected donation attitude
Li *et al.*, 2001 [35]	Hong Kong, China	Quantitative	*N* = 2245; Hong Kong public, blood donor, *N* = 1227; nonblood donor, *N* = 1018	To examine and compare attitudes and knowledge of organ and tissue donation between general public and blood donor	Blood donors were more aware than the nonblood donors among the general public about the types of organs that can be donated. A significantly higher percentage of blood donors than nonblood donors was willing to donate their organs (81% vs. 53%), and had signed the cards (49.9% vs. 22.6%). Top reasons for not donating were desire for complete body, fear of surgical operation, family objection. And the main reason for not donating family's is uncertainty of the wish

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Boey, 2002 [33]	Hong Kong, China	Quantitative	*N* = 314; Hong Kong nurses	To examine nurses' attitude and commitment to organ donation and identify the relationship between attitude and commitment	96% of the nurses had a favorable self-rated attitude toward organ donation. However, only 23% were actually committed to donate, 55% were undecided (of which 39% were likely to sign in the future, 16% expressed that they would not), 9% wanted to sign a donor card, 13% decided not to sign. Fears of bodily mutilation and medical neglect negatively impacted commitment to donate, while positive attitudinal component of humanity and moral conviction, age (older), and being single positively impacted it
Chung *et al.*, 2008 [27]	Hong Kong, China	Quantitative	*N* = 655; Hong Kong medical students	To study the attitude, knowledge, commitment, and perceived competence and confidence of medical students	99% of the medical students had positive self-rated attitude, 85% had positive assessed attitude. Overall, 23% signed donation card. More senior the medical students had better overall knowledge but still deficient. Only one-third felt competent to consult on organ donation. Knowledge was not correlated with attitude and action. Intact body after death negatively affected both attitude and intention, unease thinking or talking about organ donation after death, objections from family members negatively impacted attitude, convenience for potential donors positively affected action, premature termination of medical treatment for registered organ donors negatively affected action
Tam *et al.*, 2012 [46]	Hong Kong, China	Quantitative	*N* = 362; Hong Kong nursing students	To examine the knowledge, attitude, and commitment toward organ donation among nursing students.	Average attitude score among nursing student was 70.2%, but only 40.6% were registered organ donor. Average knowledge score was 71.8% among the nursing students
Kim *et al.*, 2004a [21]	South Korea	Qualitative	*N* = n/a; Korean health professionals	To explore sociocultural perspectives that influence health professionals' attitudes and perceptions regarding organ donation	Several themes were identified as barriers to organ donation including Confucianism, cultural misunderstandings and myths, commercialization of organs, lack of clarity in the definition of death in the new legislation, and limited medical insurance coverage

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Kim *et al.*, 2004b [20]	South Korea	Qualitative	*N* = 9; Korean health professionals (one transplant surgeon, three organ transplant nurse coordinators, two ICU nursing unit managers, two ICU nurses)	To identify and analyze Korean health professional's attitude and knowledge of organ donation and transplantation	Surgeon and transplant coordinators were more knowledgeable regarding brain death and the organ procurement process than ward or unit nurses. Only surgeon knew the difference between PVS and death. Attitude of the health professionals was mixed and somewhat negative. Negative views stemmed from beliefs that organ transplantation is recycling, witness of lack of respect and objective approach toward the deceased from their medical colleagues
Kim *et al.*, 2006 [25]	South Korea	Quantitative	*N* = 292; Korean nursing students	To determine Korean nursing college students' knowledge of and attitudes toward brain death and organ donation	73% of students were willing to donate their own organs, but only 51% would donate their family members' organs. Overall positive attitude toward organ donation (71% thought it comforts bereaved family, and 85% thought that it increases life of quality of recipient). There is general lack of knowledge, but knowledge was not significantly correlated with attitude
Jeon *et al.*, 2012 [29]	South Korea	Quantitative	*N* = 170; Korean doctor *N* = 61, nurse *N* = 109	To evaluate the knowledge and attitudes of health-care professionals to the concepts of brain death and organ retrieval	12.4% were registered to donate organs. Participant's average knowledge score was 11.17/14 points; average attitude score of brain death organ donation was 36.7/54 points. 27.6% had discussed with my family about organ donation
Lee *et al.*, 2017 [30]	South Korea	Quantitative	*N* = 92; Korean patients' relatives	To examine the attitude of patients' relatives toward organ donation after brain death	75% had positive thoughts about organ donation. Participants willingness to donate self's body and relatives' body were 60.9% yes, 27.2% undecided, 12% no versus 38.1% yes, 44.6% undecided, 17.3% no, respectively. Reasons for rejection to donate included bodily concern (34.7%) and disrespect of hospital staff (15.2%)

Table 3. Continued.

Author, Year	Country	Study design	Participant demographics (sample size, ethnicity)	Objective	Main results/outcome
Chung *et al.*, 2015 [41]	South Korea	Quantitative	*N* = 323; Korean grade school students	To explore the knowledge and opinions of deceased organ donation among middle and high school students in Korea, and determine factors associated with willingness to become an organ donor	161 (49.8%) were willing to become a deceased donor, 88 (27.2%) not willing, and the remaining 74 (22.9%) were uncertain about it. Only three (0.9%) students carry a donor card. Students were correct on an average of 2.43 plus and minus 0.88 of four questions. And only 36.9% (119/323) of Korean students had received public organ donation-related information within the past year. Factors affected willingness included age, gender, cohesive family environment, family discussion
Kim *et al.*, 2018 [47]	South Korea	Quantitative	*N* = 115; Korean police officers	To evaluate the knowledge and attitude of police officer toward brain death and organ donation since they are the first responders	35.6% reported religious affiliation. Mean score for knowledge of brain death was 7.37/11 points. Mean score for attitude toward brain death and organ donation was 13/16 points. Correlation between knowledge and attitude toward organ donation was positive (P = 0.029)

Willingness to donate and registration rates were comparably low among Asian Americans. Caucasian Americans appear to be more willing to donate compared to Chinese Americans (OR 3.03, 95% CI 16–66%) [8]. Among surveyed Chinese Americans, only 23% of the participants were willing to be designated as organ donors on any form of identification, and only 4.9% of them were organ donors [42].

The expressed willingness to donate appeared to be influenced by the degree of social distance to the intended recipient [28,42]. Chinese Americans' willingness to donate was 95.9%, 84.4%, 46.7%, and 45.9% for close relatives, distant relatives, people from same country, and strangers, respectively [42]. A similar decline in the willingness to donate with increase in social distance was noted among Chinese health professionals; 82.8%, 42.1%, and 15% were willing to donate to family members, relatives and friends, and strangers, respectively [28].

The approval rate and expressed willingness for living organ donation were lower than that of deceased organ donation and more dependent on social distance [28]. Overall, 60.1% of health-care professionals and 90% of the public in China approved of deceased donation compared to 48.5% and 65.3%, respectively, for living donation. [28,38] The expressed willingness for living donation among Chinese ranged from 44.4% to 81.6%, and it decreased with increase in social distance. [37,40,43,44] For example, 62.4% of surveyed university students would only donate to relatives, only 28.3% would donate to friends and relatives, 5.5% would donate to volunteers of organ procurement organizations, and 3.8% would donate to someone unknown [44]. In fact, the majority of living kidney donors in China was related to recipient, such as parents (66.5%), spouses (5.7%), and other relatives (4.8%) [43]. One possible explanation for this varying willingness based on social distance is that the need of family is prioritized in these cultures [15,42].

Across the identified literature, the low registration rates among Chinese and Koreans were attributed to four key barriers: (i) lack of knowledge, (ii) distrust toward the health-care system, (iii) lack of communication and discussion about organ donation, and (iv) traditional, cultural, and religious beliefs.

Barriers to organ donation

Knowledge. Lack of knowledge was commonly cited as the reason for organ donation refusal. [32,36,38,45] There is a general lack of awareness and knowledge about organ donation and transplantation independent of ethnicity [8,16,23,24]. Knowledge assessments on organ donation reveal that American high school students answered more than half of the questions incorrectly, regardless of race/ethnicity [8]. Chinese and American university students' knowledge of organ donation was similarly limited [16]. Similarly, most Chinese Canadians interviewed said they knew little about organ donation, but they would like to know more about the medical procedures involved, the state of the body after donation, and the registration process [23,24].

When surveyed, 61.4% of the Chinese public reported not knowing much about organ donation, and when tested, <50% were able to accurately answer questions about organ allocation [26,31]. Even medical and nursing students and health-care professionals in China were shown to have limited knowledge regarding organ donation [27,28,37,39,46]. Hong Kong nursing students and medical students in clinical clerkships were only able to answer approximately two-thirds of the questions on organ donation assessment accurately, but this was already better than preclinical medical students who were only able to answer a third of the questions correctly [27,46]. Despite gaining knowledge about organ donation with medical education, less than a third of senior medical school students felt competent in counseling patients about organ donation [27]. This is probably related to the near-complete absence of education about organ donation in the medical curriculum. Only 22.4% physicians and 39.7% transplantation nurses reported ever having taken training courses about organ donation, while more than three quarters (77.1%) of health-care professionals would like to receive more training [28,39].

Among the Korean health professionals interviewed, only the transplant surgeon was able to explain the distinction between a persistent vegetative state (PVS) and brain death [20]. Korean nurses and emergency personnel such as police officers as well as nursing and grade school students performed relatively poorly on organ donation knowledge evaluations [25,29,41,47].

Improved knowledge is positively correlated with positive attitudes toward organ donation. [28,29,47] And both increased knowledge and positive attitude should in turn increase willingness and commitment to donate [17]. Notably, this was not true among Koreans. Increased knowledge had no effect on willingness to donate among Korean grade school students and it was associated with an increased reluctance to register as an organ donor among Korean college students [17,41].

Trust in health-care system. Asian Americans had a lower level of trust toward physicians compared to Caucasian Americans [15]. Fear of physicians procuring organs hastily and inhumanely appeared to be a recurrent concern among both Chinese Canadians and Korean health-care professionals [20,23]. Moreover, it appeared to be the primary reason to refrain nearly half (49.2%) of the Chinese health-care professionals from donating organs [28]. There was also a widespread concern about insufficient and early termination of treatment for registered organ donors among both Chinese and Koreans [21,25,26,33]. Approximately half (51.6%) of the surveyed Chinese public and 15% of Hong Kong nurses believed donors would receive less thorough treatment while two-thirds (67%) of surveyed Korean nurses were afraid of being misdiagnosed as being brain dead [25,26,33].

In addition, concerns about incomplete laws and regulations about organ donation were noted and more examined and prominent in mainland China than Korea and Hong Kong China [21,26,28,32,38]. Among interviewed Korean health professionals, some reported fear of organ commercialism and immature organ transplant system in Korea [21]. Among surveyed Chinese health-care professionals and public in mainland China, many (42% and 27.4%, respectively) expressed concerns about the incomplete nature of organ donation laws and regulations, distrust in the allocation system (40.2% and 30.2%, respectively) including concerns about organs being sold on the black market and favoring the wealthy and celebrities [26,28,32,38]. These concerns appear to have a significant detrimental impact on organ donor registration [36].

Communication and discussion. Discussions about organ donation appear to be positively associated with the intention to register as an organ donor, but these discussions are often frowned upon culturally given concerns that discussions of death/dying can evoke bad luck [17,19,23,34,41,48]. Caucasian Americans were more likely than Chinese Americans, and native Chinese and Koreans, to share their donation wishes and discuss organ donation with their families [8,16,17]. Only 12% of surveyed Chinese said they had discussed postmortem organ donation with their family [48]. Similarly, in Korea, only 27.6% of surveyed health-care professionals and 25.9% of surveyed grade school students had discussed organ donation with their family [29,41]. These discussions with families was low (33.3%) even among individuals who expressed willingness to donate [34]. This reluctance is likely cultural and a recognition that families are unlikely to view the decision to become an organ donor favorably [32,38]. This is a particularly challenging barrier given that the overwhelming majority (88.9%) consider family consent to be necessary [26].

Communication of organ donation wishes is crucial when it comes to time for the family to provide consent for the donation of a loved one's organs. Among the Chinese Canadians interviewed, most thought that organ donation was a personal decision, and it would be difficult to make this decision on behalf of the family member [24]. Lower expressed willingness to donate relatives' body when compared to donating one's own had been demonstrated in several studies among both Chinese and Koreans (China 38.85% vs. 16.07%, 33.4% vs. 28.2%, Hong Kong 50% vs. 42%, Korean 60.9% vs. 38.1%) [26,30,35,39]. The main reason for refusal to donate family's body was uncertainty of the wishes of the deceased person [35]. When family member's wish was not known, only 41.1% of the participants would be willing to donate their family member's organs, whereas if the donation wish was known, donation was twice as likely (85.2%) [34]. Similar consideration and adherence to the deceased person's stated wishes regarding organ donation had been demonstrated in other studies [26,35].

Cultural, traditional, religious beliefs. Both Chinese and Korean cultures emphasized the importance of maintaining the body intact [18,19,21–24] and keeping the body complete appeared to be the most common reason provided for not consenting to organ donation for both Chinese and Koreans [15,25,28,30,33,35,36,38]. In addition to the concept of filial piety from Confucian ideology, another idea cited to explain the reason for maintaining an intact body after death was the importance for the afterlife and rebirth. [21–23] Some people thought dying with an incomplete body would be a curse and would prevent one from resting in peace [21–23]. Other than the importance of being buried whole, many Chinese and Koreans also reported general fear and disgust toward the organ procurement procedure and body disfigurement, which negatively impacted willingness to donate [24,27,33]. In addition, a belief of predetermined destiny and concerns about how organ donation interferes with traditional burial and death rituals also prevented many Chinese and Koreans from donating [21,22,24]. However, with economic and social development, these beliefs have become less influential. In a more recent study conducted in China, 65.3% of the respondents did not agree with filial piety and only 28.1% of the respondents thought that body intactness

was important [26]. In another, only 15.3% of the participants felt that organ donation is against Chinese traditions [32].

The influence of religion on organ donation was relatively minimal in comparison to cultural and traditional beliefs among the Chinese. Chinese Americans were generally more influenced by Confucian values and, to a lesser extent, by Buddhist, Daoist, Christian, and other religion and belief systems [42]. Moreover, in recent studies, the majority (60–85%) of Chinese in mainland China reported being nonreligious [28,31,34,37,46,48]. Among the surveyed Chinese public, only 1.8% felt that organ donation was against their religion [31]. In addition, those that were religious generally did not base their decisions regarding organ donation on religious beliefs and would not consult religious leaders when making these decisions [24].

Religion played a more important role in Koreans [30]. Most Koreans surveyed, except the police officer and student cohort, were affiliated with a religion, only a portion of them reported having no religion (39.1% of public, 34% of nursing student, 53.9% of middle and high school student, 64.4% of police officers) [25,30,41,47]. Among surveyed patients' relatives, 41.3% thought that religion was an important factor when making decisions about organ donation [30].

Discussion

This systematic review identified a number of consistent themes regarding barriers to organ donation among Chinese and Koreans. Organ donation was acknowledged as a noble and altruistic act that saves lives. However, positive attitudes toward organ donation and expressed willingness to donate were not translated into actual commitment to donate. One explanation for the discrepancy was a lack of knowledge regarding organ donation among Chinese and Koreans. The majority of people in these demographics—including health-care professionals—were not familiar with organ donation, and many expressed the wish to learn more about organ donation indicating opportunity for education.

Another barrier identified was distrust toward the health-care system, which included concerns about hostile organ procurement by medical personnel, early termination and insufficient care for donors, and perceived unfairness of the allocation of the organs. Distrust in the allocation system among Chinese and Koreans might be caused by the newness of recently established organ donation and transplantation regulations and laws.

In addition, there were barriers to organ donation created by cultural, traditional, spiritual, and religious beliefs specific to Chinese and Koreans. A cultural avoidance of discussing topics related to death led to a general reluctance among Chinese and Koreans to talk about organ donation. However, communication about organ donation with family was crucial to improving organ donation rates. Individuals took into consideration the family's attitude regarding organ donation when deciding whether to register as organ donor. If the family knew the deceased person's wishes regarding organ donation, the family would most likely respect those wishes.

Another cultural barrier that was commonly mentioned in the literature was the importance of maintaining intact body. The origin of the idea of maintaining bodily integrity was difficult to pinpoint. Confucian beliefs were often cited in discussions of why Chinese and Koreans wish to maintain intact bodies. The Confucian concept of filial piety dictates that one's body is a gift bestowed by one's parents, thus one should take good care of the body and return the body intact upon death as a way of showing respect to parents and ancestors. Organ donation prevents one from returning a complete body and is therefore not acceptable to those who hold this belief. Some people thought dying with an incomplete body is a curse that would prevent one from resting in peace and interfere with one's rebirth. However, these beliefs are becoming less prevalent among both Chinese and Koreans over the years.

Notably while Chinese and Koreans shared some common barriers such as lack of knowledge and communication about organ donation, distrust toward health-care system and strong desire to maintain intact body, some barriers were specific to each population. For example, among Koreans, improved knowledge negatively impacted organ donation intent and religion seemed to play a more important role when making decision about organ donation, while the distrust of the health-care system is more prominent among Chinese. These findings suggested that improving organ donation rate in Chinese and Korean Americans will require educational efforts specifically tailored to each Asian subpopulation. For example, educational interventions for Koreans should enlist religious leaders to articulate values of organ donation while educational efforts in Chinese should address the issue of trust toward the allocation system.

In addition, findings in more recent studies showed that some of the traditional and cultural ideas, such as burying intact and filial piety, have become less influential suggesting generational differences and that younger

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individuals are potentially more open to organ donation. Given that both Chinese and Korean cultures possess strong family values, an educational effort that focuses on improving awareness of organ donation among younger individuals and encouraging them to initiate this discussion within the family may positively impact organ donation rates. However, this approach does not appear to have been well studied, and the absence of efforts using this approach in the literature underscores the need for further research in this area.

Strengths and limitations

This review is a synthesis of a small number of articles. Both quantitative and qualitative studies were included, which means studies differ in their design, measure, and study population. These differences prevented precise comparison. However, inclusion of both types of studies enabled a more detailed and in-depth understanding of the topic. Some of the studies included were limited in interpretive content reflecting a challenge to research in this area.

This systematic review aims to explore the barriers to organ donation in Chinese and Korean Americans as a distinct group. One reason why research effort in this area has had limited success is that many studies done in the United States studied Asian Americans as a group. Asian Americans are a diverse population that includes Americans of East Asian, Southeast Asian, and South Asian descent. Even though the Chinese culture is the dominant influence of many Asian countries, there are still clear cultural differences between Asian groups [15]. Therefore, studying Asian Americans as a group has provided limited understanding of the barriers to organ donation among Chinese and Koreans. Studying Asians as distinct groups is crucial to understanding barriers and creating effective interventions to increase organ donation rates.

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Conflicts of interest

The authors of this manuscript have no conflicts of interest to disclose.

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