BMJ Open

Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-056094
Article Type:	Original research
Date Submitted by the Author:	03-Aug-2021
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Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

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Title: Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Abstract

Objectives: To understand the barriers toward deceased organ donation among Indians living globally. However, the studies reviewed were only among Indians living in India and UK, due to methodological issues. Therefore, this review is based only among Indians living in India and UK.

Design: Integrative systematic review using narrative synthesis

Data sources: CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central, Indian Journal of Transplantation and Google scholar.

Participants: Individuals of Indian origin living in India and UK.

Results: Sixty-one studies were included with more than 20,000 participants and quality was assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the participants had knowledge toward organ donation with a positive influence on willingness, the gap between knowledge and willingness was huge, with minimal registration. The findings showed that organ donation behaviour among this particular population is influenced by the complex interactions between the individual and the socio-cultural constructs. Various constructs of the society such as fear and mistrust, family, religion, bodily issues play a vital role. Also, differences in willingness to donate and registration were identified between southern and other regions of India.

Conclusion: Though this study showed the complex relationship, and its influences on organ donation behaviour, lacunae were identified to further understand how such complex interactions determine or inform the behaviour. Also, methodological issues were identified, where this particular population outside India were collectively studied with their neighbouring population which are not homogenous. Studies in India majorly addressed a similar aim using

similar methods which produced repetition of studies leading to lack of diversified, wider, and in-depth research. Therefore, while this systematic review addressed the barriers toward organ donor registration among Indians in India and UK, it also informs various gaps in research and also methodological issues.

PROSPERO registration number: CRD42019155274

Keywords: Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis, Registration

Strengths and Limitations:

1. This is the first systematic review about barriers toward deceased organ donation among Indians living in India and UK, registered with PROSPERO, and published.
2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
3. Included studies that exclusively represented the Indian population and excluded studies that collectively studied with the heterogenous South Asian or Asian population, thereby keeping the rigour of this study and identifying methodological issues involved.
4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. Therefore, both in India and UK, people of Indian origin show higher reluctance to organ donation which is reflected both in registration and consent.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence organ donor registration. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donor registration among the individuals of Indian origin.

Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper insight into the barriers toward organ donor registration among this particular population [17].

The protocol proposed to include Indians living globally [17], but this review represents Indian population living only in India and UK. There had been studies globally that had included Indian ethnic group to examine the barriers of organ donation. However, many of them did not report the results exclusively for Indians but rather combined this population with those from other Asian countries and few had no sufficient findings, therefore excluded. However, on the other side, two studies were included from UK that had the potential to be included. Therefore, this systematic review will address the barriers toward organ donor registration among the Indian population living in Indian and UK, identify gaps in evidence to further research and help stakeholders in furthering strategies to improve organ donation.

Method

Protocol and registration

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published [17].

Systematic search

Search strategy was developed collaboratively with the research team and a subject specialist librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central were utilised along with other sources such as Indian Journal of Transplantation and Google scholar. Key words and MeSH terms related to organ donation were first identified from studies published along with search terms used in other systematic review on organ donation [18,19] and were tested in different combinations in the

forementioned databases. Final search terms and search string was confirmed seeking to capture the most appropriate studies to answer the aim of this review (supplementary file 1).

The systematic review included studies with individuals of Indian origin living both within and outside India (i.e., migrant / first / second generation), aged 18 years and above from varied settings [17]. Cross-sectional and qualitative study design were included as they were mostly employed to understand the barriers toward deceased organ donation. Search strategy was restricted between 1st of January 1994 (i.e., the year when the first law toward organ donation was implemented in India) and 30th of July 2021 (i.e., a recent day before the submission) and was restricted only to studies published in English. However, interventional studies, commentary or opinion papers, studies on blood, bone marrow, body, sperm, and egg donation were excluded alongside any studies which addressed only living donation.

Search outcome

Following a stage-by-stage exclusion from 1,015 studies initially extracted, 61 studies were included in final review (Figure 1). The studies were initially exported to RefWorks (https://refworks.prorequest.com/). Microsoft excel was used to keep a record of studies excluded by duplicates, title, abstract, and full text. All the 1,015 studies were screened by two authors independently and the final 61 studies included were in-agreement with all the authors.

However, during the process, studies conducted among Indians living outside India were identified to be collectively studied as South Asians or with other Asian population. For instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic groups of India [20]. In UK, Indian population was collectively studied as South-Asians [4, 21]. In Malaysia, though sampling was distinguished their results were not sufficiently addressed [22]. However, concerning organ donation, the perspective of deceased organ donation varies even within India's nearest neighbouring country [4, 23]. Therefore, this review

included only the studies which exclusively reported the findings from Indian population, thus making this systematic review address Indians living in India and UK.

Quality assessment

Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the rigour of each studies included [24], also used in other organ donation systematic review [18,25]. Comprehensive reporting on the quality assessment for both cross-sectional and qualitative studies are reported in figure 2. Quality assessment was initially carried out by the primary researcher after which it was reviewed by the other two authors independently. Both the authors along with the primary researcher agreed upon the quality assessment as mentioned in figure 2. The review included all studies; however minimal emphasis was given for those studies that demonstrated only fewer items in the quality assessment checklist.

Data synthesis

This systematic review followed an integrative review with narrative synthesis approach enabling to synthesise complex information toward the phenomena of interest [26], a methodology also employed in another systematic review on organ donation that reviewed both quantitative and qualitative studies [19]. Narrative synthesis primarily depends on words and texts to summarise the findings with four process elements such as 1) systematic search and quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary development, and 4) assessment and interpretation [27].

Firstly, following the systematic search and quality appraisal, summary data was collected for each study, and they were recorded across a table which had information needed to cluster the studies to compare and study across (Table 1). Secondly, with the cross-sectional studies, numerical results from each study were tabulated across a matrix and were compared across to study their relationship in terms of barriers. Later, full synthesis of the four qualitative studies

was undertaken by coding the findings and discussion sections using NVivo11. Codes were then organised into themes to address the barriers appropriately.

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914 (i.e., 1461 in group I; 2453 in group II)	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300 (i.e. 100 from each college)	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	Tertiary care teaching hospital among family members who consented to donate the organs of their loved ones	Quantitative	59	Purposive sampling

Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ donation among dental students based on gender, year of study and religion	Dental college Undergraduate students	Cross-sectional	298	Not specified
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified

Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	9 focus group discussion (i.e. 50 participants) and 8 Semi-structured Interviews	Purposive sampling - Stratified sampling for groups
Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regrading organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8 semi-structured interviews	Purposive
Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding	Medical, dental, nursing students	Cross-sectional	150	Not specified

			organ donation and transplantation, to find out the effect of motivation, towards organ donation				
Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Survey	204	Not specified
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering, and arts and science students in Thirivallur and Chennai	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random

Seethara man et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266 (i.e., 166 paramedics, 100 administrati on staff)	Simple Random Sampling
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600 (i.e. 300 medical; 300 engineering students)	Random
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360 (i.e., 180 undergradu ate and 180 postgraduat e students)	Not specified
Thyagara jan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling
Vijayalak shmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalak shmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitati ve	6 In-depth interviews	Purposive sampling

Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620 (i.e., 375 medical students and 245 nursing students)	Convenient sampling for population and voluntary for participants
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

While comparing and studying across the studies included in the review to understand their relationship, various elements such as what the study is about, type of study, their approach, the findings, study settings, and population studied were also considered. Noblit and Hare (1988) described this as 'Reciprocal translation', also used in other similar methodological approaches [28-32]. Thirdly, full syntheses of both cross-sectional and qualitative studies were studied across to understand the supporting and refuting evidence collectively. For each section of the findings, quantitative studies provided the initial context following which findings from qualitative studies were used to elaborate and explain. With limited qualitative study narratives to support or refute the cross-sectional study findings, they were incorporated into the integration of the findings wherever possible. Both convergent and divergent findings are explained in this review, whereby if divergent findings were identified explanatory factors such as type of study or setting, or population were provided to facilitate better understanding [19].

Findings

Grouping and clustering

Among the 61 studies reviewed, majority (97%) were conducted among Indians living in India (n=59) while other two studies were among people of Indian origin living in UK. Cross-sectional studies (n=57) included various settings such as general community (30%), education institutions (44%) and hospital setting (30%) (Table 1). Qualitative studies (n=4) consisted of in-depth interviews (75%) and focus group discussion (50%) (Table 1). Among the 20,340 individuals involved in the retained studies, 19,900 individuals (97.8%) were from studies

conducted in India. Among the studies conducted in UK, only one study distinguished 107 individuals as Indians, whereas the other with 60 individuals had no evidence on the sample number of Indian participants involved.

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely: 1) knowledge and awareness toward deceased organ donation and registration, 2) willingness and actual behaviour toward deceased organ donor registration, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation and registration

Being the commonest theme studied across, findings showed that knowledge had a positive corelation with willingness and practice [33-38]. Both among Indians in India and UK, younger adults, participants from higher socio-economic status, and with higher education or healthcare education demonstrated higher knowledge toward deceased organ donation [39-51,79] and individuals from southern region of India showed higher knowledge compared to other regions in India [52-57].

Whilst majority of the studies confirmed that almost all the participants had heard about organ donation (Figure 3) and had higher awareness, knew what organs can be donated [35, 47-51, 58-70] and that organs can be donated to anyone [40,52], the knowledge and understanding on brain death was less well understood [43,55,59,60,66,71,72]. A qualitative study from an urban area in the southern region of India also found brain death as a new concept for many and hard to accept among the public [73]. Also, much were not aware about the organ donor card [58, 74-76], where and how to register and obtain an organ donor card [36,44,47,61,62,49,50] - an

important component for organ donor registration. In addition, knowledge on the law that governs organ donation was also found to be low [36,62,75,77,78].

Though a study among Indians living in UK showed that disinterest, emotional distaste, family opposition and religion to be the underlying cause for reluctance to register [79], among Indians living in India, the awareness on brain death, organ donor card, where and how to register are also important factors serving as barriers to individuals who are willing to register [36,43,44,47,49,55,58,60-62,63,71,74-77,80].

Willingness and registration toward deceased organ donation

Greater knowledge showed positive influence on the attitude and willingness across all Indian regions [37,44,75,81-85]. Similar to higher knowledge among individuals from southern region of India, willingness to register, to donate and to accept organs for transplant was also shown to be higher [34,39,40,43,57,59,75,81,83]. However, though knowledge had a positive association toward attitude and willingness, the proportion of individuals willing to register, and actual registration was very low and similar across every study included (Figure 2). Correspondingly, even a study conducted among Indian students living in UK revealed that 55% of the individuals doubted if they would go ahead with registration [79]. With such reluctance, Indians living in India and UK considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [40,47,49,54,56,60,62,63,65,66,70,78,79,82]. On contrary, commonest reasons to donate an organ was to save someone's life, closely followed by elongate someone's life, social commitment, altruistic deed, and that at least their deceased one's organs can live [63,66,74,81,86-88].

Higher proportion of participants were willing to receive compared to donating [34,39,40,59,79,81,83] both among Indians from India and UK. Furthermore, studies revealed

that among those who were willing to donate, majority were only willing to donate specific organs namely eye / cornea and kidneys [40,52,53], which may be related to the knowledge on what organs can be donated [58-63,67-69,71]. Nonetheless, majority of the participants were willing to support and promote organ donation in their region and was similar across India [49,51,74,81,86,87].

Younger adults, participants from higher socio-economic status and participants with higher education or healthcare education demonstrated higher willingness toward deceased organ donation both among Indians in India and UK [23,39,41,42,47,52,79]. However, this was not consistent during the time of actual behaviour. Studies showed that there was almost equal distribution of participants from lower socio-economic status and lower education, who did give consent and actually signed for deceased organ donation [41,77]. However, this conclusion is based only from few studies showed to be similar in north and south of India [41,77].

Familial influence

In-spite of willingness to register for organ donation (Figure 2), larger proportion of individuals have not initiated a conversation or discussed their willingness with their family members, an important behaviour for a successful donation [46,56,59,62,76,82,89,90] - however opted family as the major barriers toward organ donation [40,54,56,60,63,82]. A qualitative study conducted in India and UK revealed the main reasons surrounded a lack of confidence in initiating conversations around sudden deaths, and with these conversations perceived unwelcome by their parents and elders [23,73]. However, another qualitative study conducted among Indian students who were born and grew in UK revealed that they are less concerned of sharing their views compared to their older generations (i.e., mostly migrant generation) and were more willing to discuss their wishes with their families [23], which could be related to

acculturation. On the other side, a qualitative study conducted in southern India among urban living adults suggested that such conversation only occurred when individuals read or viewed such events [73]. Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process [77], making such discussion very important during the crucial decision-making moments.

Willingness to support family members was shown to be higher among healthcare students compared to other students [49,91] and lower among family members from rural areas [81,90]. However, while higher proportion of individuals were willing to support family members for organ donation [34,52,62,75,83], only very few families actually supported this decision when families were approached for consent [73].

Though studies included found no association based on marital status [34,39,83], one study found that unmarried individuals appeared to be more willing to donate compared to married couples [83]. Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared to those unaware of their spouse's opinion [39]. Among the type of family, individuals from 'joint' families had higher knowledge, while willingness to donate was found to be higher among nuclear families [34,42,44].

Fear and Mistrust

Fear on misuse of organs by the healthcare team, revealing lack of trust was the other major barrier reported [23,36,42,49,54,55,59,60,62,63,78,69]. Some participants relate organ donation to organ trafficking and misuse which leads them to fear and mistrust [43,56,81]. A qualitative study also revealed increased ambivalence that while on one side participants perceived organ donation as a noble act, on the other side they were also fearful of organ misuse due to the information that they hear through news and media on organ trafficking and exchange of money for organs [73].

Also in UK, among Indian participants, a mother was afraid to see an organ donor card in his child's wallet as she was thinking if doctors will come to see it, then they may deviate the process toward donation and give less care toward saving her child [23]. In parallel, general population from India also feared pre-mature declaration of death for the need of organs [35,81,91]. However, healthcare population groups were less likely to believe that there will be any premature declaration of death by the doctors [34,62,72].

Religious influence

Overall, majority of the participants favoured organ donation [23,34,40,41,43,52,83,86]. However, when further looked based on religion, different studies showed different religious groups to be more willing to donate compared to individuals from another religious group [39,42,52,64,92], showing no consistency on which particular religion is more supportive or rejective [39,42,46,52,92]. In parallel, a qualitative study conducted among UK university students of Indian descendants showed lack of homogeneity even within one same religion. Some agreed that body needs to be intact for reincarnation, while other participants believed that body and soul are two different entities and that only the soul counts while body is left to decay in this earth [23,78].

However, though there were differences of opinion across and within the religion, majority of the participants agreed that organ donation is not against religious views [34,59,63,73,78,83,86] and also considered religion as the very least barrier toward organ donation [39,54,56,59,73,89,93]. A qualitative study conducted among UK students with Indian origin showed that though individuals felt religion may influence their decision it was not the only factor that that will be considered in such decisions [23]. Yet, favourable opinion of religion toward organ donation was found to be positively correlating with their willingness to donate [34,46].

A Qualitative study conducted in UK with Indian students revealed that younger generations were less bothered about religious views compared to older generations, which could have occurred due to acculturation [23]. Also, participants preferred that religion should not be a criterion based on which allocation can be decided [42,59,86,89] and that organ of a deceased person can be donated to a recipient from any religion [42,59,86,89].

However, during the time of consent, a stakeholder from a qualitative study said that families who were not willing to donate use the concept of religion as a pre-framed reason to decline donation, though none of the religion is against organ donation. In the same qualitative study, public participants from different religious group felt that their religion supports organ donation [73].

Bodily issues

Majority of the individuals from the reviewed studies were not concerned about bodily issues though it has to undergo incisions while explanting [34-36,39,40,52,74,78]. However, on the other side, majority also agreed that it is an individual's complete right to have the organs within the body when dead [43,72]. Whilst majority of individuals were not concerned about incisions in the body, a qualitative study found that in the real time of consent, stakeholders found it easy to get approval for corneal donation and not solid organs as it may have many incisions over the body and disfigure it [63]. In relation to funeral practices involving the deceased body, majority were aware that normal funeral practices can be conducted even after donating organs [34,43,52,72,74,89], contrast findings were also evident [43,49,72]. However, majority opted body disfigurement as one of the least reasons to be a barrier toward organ donation [40,54,56,60,82].

Discussion

To the best of our knowledge, this is the first systematic review that reviewed barriers toward organ donation among Indians in India and UK, while other potential studies were excluded due to methodological issues. Also, this is one of the few systematic reviews in organ donation that used integrative methodology.

While majority in India have heard or are aware of organ donation, and had a positive correlation with willingness, their gap is wide. This indicates that there could be various factors other than knowledge which need to be studied in more detail. Organ donation being more embedded with health behaviour, there is a need to understand the relationship between behaviour and behavioural intention adopting appropriate principles. This aids the specificity of policy and campaigns to address organ donor registration behaviour in the population.

Though gaps identified in majority of the quantitative studies merit qualitative studies, only very few qualitative studies were undertaken in India [72,73,78]. For instance, though majority individuals were willing to be an organ donor, majority have not initiated any such conversation with their family members and considered family to be the major barrier [21,40,54,56,60,82]. However, no further studies were exclusively undertaken to understand how a construct like family interferes in the decision making toward registration and consent. Such studies will aid in developing and testing hypothesis or developing appropriate interventions to increase such conversation with family members. Such conversations play a very important role as the awareness on the willingness of the deceased plays a vital role in decision-making during consent [77]. However, the influence of family can be different among Indians in India and UK as the latter may have influences based on acculturation and enculturation [23,79] while the prior maybe more concerned toward communication issues [46,56,59,73,76,82,89,90].

This review shows that there are various complex interactions that happen in the society where an individual lives rather than just knowledge. Fear and mistrust have shown to influence the

uncertainty in decision-making for a very long time [23,36,42,4954,55,59,60,62,63,69,78] however, studies failed to address how fear influences organ donation, what is the source of fear and how a construct like fear can be addressed. Also, while majority of the studies show influence of religion on organ donation, there is a greater need to understand how a religion influences organ donation in India. Is it the misconception, or the lack of enabling religious community, or reluctance to take such conversation, or lack of information from the religious leaders or their physical practices that does not allow donation? Such in-depth studies need to be undertaken to gain a deeper understanding into the phenomena. Therefore, at the moment, there is a need to study further how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour.

Various factors such as age, sex, education, and socio-economic status showed greater influence on willingness to donate [23,39,41,42,47,52,79]. However, when studies showed that they did not hold true during the time of consent [41,77], they also showed that there is some shift in behaviour during registration and consent making the time period of these two-event having different impact in their behavioural intention and behaviour. This again probes to further the understanding on what happens during the time of consent, and why such a shift is seen in the intention to donate between these two time periods.

Methodologically, studies conducted among the Indian ethnic group outside India were collectively identified as South-Asians or Asians [19,20,94] while they differ culturally, socially, politically, economically, and even religiously [95]. Two studies included from UK in this review have clearly shown such a difference with the neighbouring country (i.e., India, and Pakistan) [23]. Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations

from the same ethnicity [23,79]. This cannot happen without the influence of time elapsed since immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation, perceived discrimination, attitudes / mistrust toward healthcare system, community barriers, socio-cultural influence and many such complex determinants which adds further complexity to the issue of organ donation among such a population. Therefore, such specific research among this community is also needed to address the disproportionate representation between waiting list and donor list from this ethnic population outside the country of origin.

Conclusion

This review showed that majority of the participants from India and of Indian origin hold positive attitude toward registration but show lower willingness and even lower practice of registration. Though this study showed the complex relationship and influences toward organ donation behaviour, lacunae were identified for further deeper understanding into such complex interactions determining the behaviour. There is also a lack of methodological rigour to study this particular population outside India, being collectively studied with their neighbouring population which are not homogenous. Also, within India, majority of the studies employed similar aims and methods leading to repetition of studies rather than diversified, wider, and in-depth research. Therefore, this systematic review addressed the barriers toward organ donor registration among Indians in India and UK and also identified gaps both in methodological and research perspectives that merits future research to examine the phenomena of interest from multiple lenses.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their Global Challenges Research Fund.

Authorship Contribution:

	Vincent, Britzer Paul	Randhawa, Gurch	Cook, Erica
Conception	Yes	Yes	Yes
Design of the work	Yes	Yes	Yes
Acquisition	Yes	Yes	Yes
Analysis	Yes	Yes	Yes
Interpretation	Yes	Yes	Yes
Revision	Yes	Yes	Yes
Final Approval	Yes	Yes	Yes
Accountability	Yes	Yes	Yes

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Data availability: None

Conflict of Interest: None declared.

Patient and Public involvement: None as this is a systematic review

Ethics approval details: Institute for Health Research Ethics Committee from the University of Bedfordshire approved this study (IHREC931).

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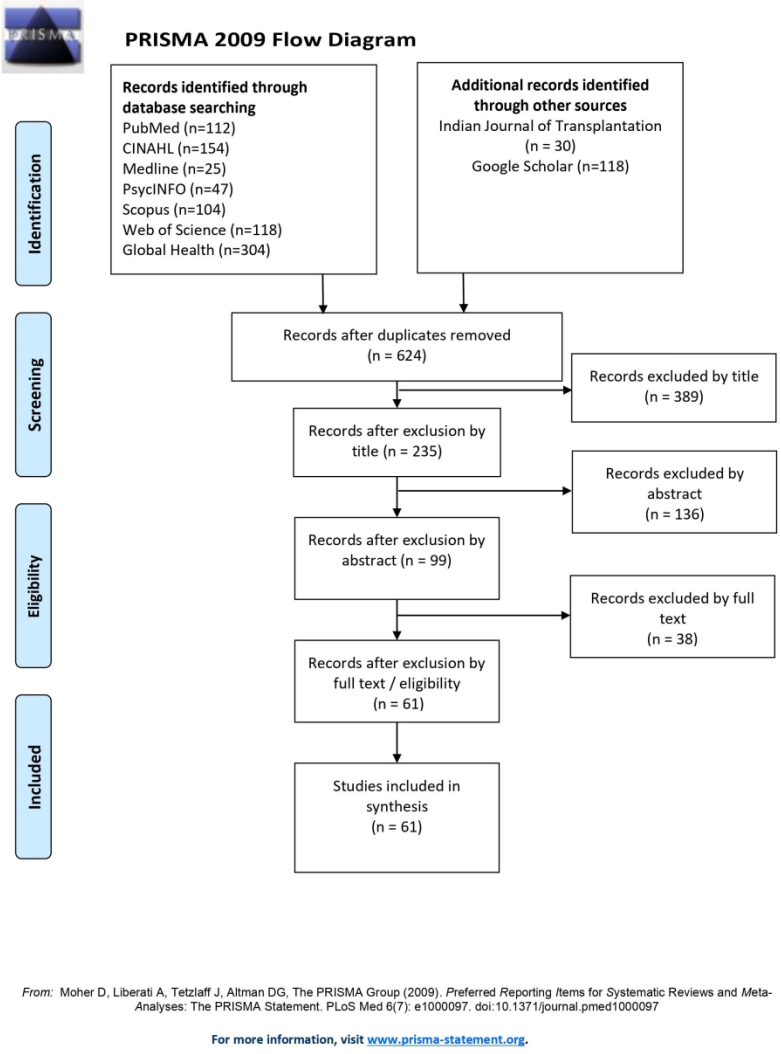

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

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	1	2	3	4	5	6	7	8
Adithyan, Mariappan and Nayana, 2017	✓	✓	✓	✓	×	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	×	×	✓	✓
Alex et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Amaliyar and Patel, 2019	✓	✓	✓	✓	×	✓	✓	✓
Balajee, Ramachandran and Subitha, 2016	-	✓	✓	✓	✓	×	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	×	×	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	×	×	✓	✓
Bansal, Koushal and Mehra, 2019	✓	✓	✓	✓	×	×	✓	✓
Bapat and Kedlaya, 2010	-	✓	✓	✓	×	×	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Bathija, Ananthesh, and Bant, 2017	-	✓	✓	✓	×	✓	✓	✓
Bharambe et al, 2015	×	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	×	×	✓	✓
Bhargavi and Govindapillai, 2019	✓	✓	✓	✓	×	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Darlington, Anitha and Joseph, 2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	×	×	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	×	×	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Gupta et al, 2021	×	-	✓	✓	×	×	✓	✓
Jayabharathi, Devika and Akila, 2019	✓	✓	✓	✓	×	×	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula and Sreeharshika, 2018	✓	✓	✓	✓	×	×	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Kaistha, Kaistha, and Mahajan, 2016	✓	✓	✓	✓	×	×	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Khan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mani, 2016	✓	✓	✓	✓	×	×	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Minz et al, 1998	×	✓	-	✓	×	×	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Mohan and Aswathy, 2019	✓	✓	✓	✓	×	×	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Paul et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	×	×	✓	✓
Rajan, 2021	✓	✓	✓	✓	×	×	✓	✓
Rani et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Ray et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Sachdeva, 2017	-	✓	✓	✓	×	×	✓	✓
Sam et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Singh et al, 2002	✓	✓	✓	✓	×	×	✓	✓
Soni et al, 2018	-	✓	✓	✓	×	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Tamuli, Sarmah and Saikia, 2019	×	✓	✓	✓	×	×	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al,2016	✓	✓	✓	✓	×	×	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	×	×	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

Mentioned ✓ Not mentioned × Unclear -

Quality appraisal for cross-sectional studies

Ref	Vincent et al, 2019	Kennedy, 2002	Gaulter et al, 2013	Misra et al, 2021
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	✓	✓
4	✓	✓	✓	✓
5	✓	✓	✓	✓
6	✓	×	✓	×
7	×	×	×	×
8	✓	×	✓	×
9	✓	×	✓	✓
10	✓	✓	✓	✓

1 Is there congruity between the stated philosophical perspective and the research methodology?
2 Is there congruity between the research methodology and the research question or objective?
3 Is there congruity between the research methodology and the methods used to collect data?
4 Is there congruity between the research methodology and the representation and analysis of data?
5 Is there congruity between the research methodology and the interpretation of results?
6 Is there a statement locating the researcher culturally or theoretically?
7 Is the influence of the researcher on the research, and vice-versa, addressed?
8 Are participants, and their voices, adequately represented?
9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ×

Quality appraisal for qualitative studies

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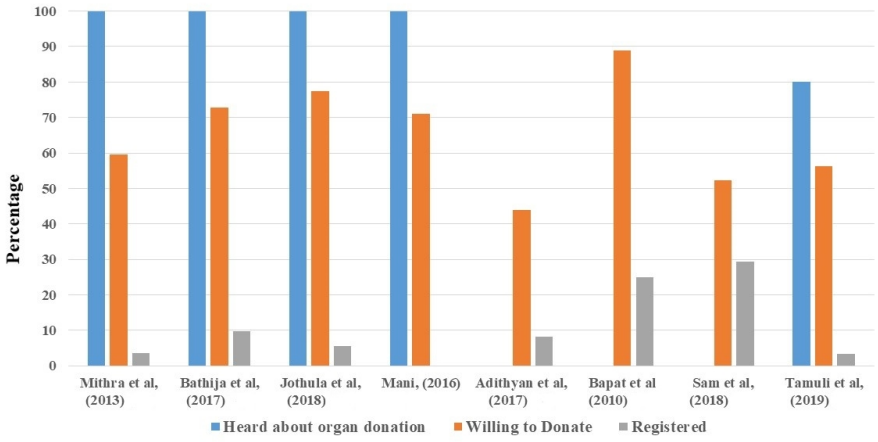

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Search Strategy

1. Organ
2. Tissue
3. Donation
4. ((1 OR 2) AND 3) .ti,ab
5. Consent
6. Regist*
7. Brain Death
8. Deceased
9. Posthmous
10. Donation after Brain Death
11. DBD
12. (5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11) .ti,ab
13. India*
14. South Asia*
15. Asia*
16. (14 OR 15 OR 16) .ti,ab
17. Knowledge
18. Awareness
19. Attitude
20. Perception
21. Practice
22. Barrier
23. Challenge*
24. Cultur*
25. Religi*
26. Famil*
27. Discuss*
28. Sign*
29. Pledge*
30. (17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29) .ti,ab
31. 4 AND 12 AND 16 AND 30
32. Filter year: 1st January 1994 to 30th July 2021

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg. 5
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pg. 5-7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Pg. 5
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg. 6-7
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pg. 6
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg. 5
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Figure 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Figure 2
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg. 13-16
	23b	Discuss any limitations of the evidence included in the review.	Pg. 13-16
	23c	Discuss any limitations of the review processes used.	Pg. 13-16
	23d	Discuss implications of the results for practice, policy, and future research.	Pg. 13-16
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 1
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 1
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 1
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Title page

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

BMJ Open

Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-056094.R1
Article Type:	Original research
Date Submitted by the Author:	07-Feb-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

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Title Page

Title: Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

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As per the order of the authorship

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Keywords: Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis,

Registration

Word count
Abstract: 303
Manuscript: 4192

Title: Barriers toward deceased organ donation among Indians living in India and the United Kingdom: An integrative systematic review using narrative synthesis.

Abstract

Objectives: To understand the barriers toward deceased organ donation among Indians living globally. However, the studies reviewed were only among Indians living in India and UK, due to methodological issues. Therefore, this review is based only among Indians living in India and UK.

Design: Integrative systematic review using narrative synthesis

Data sources: CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central, Indian Journal of Transplantation and Google scholar.

Time period: 1st January 1994 to 31st December 2021

Participants: Individuals of Indian origin living in India and UK.

Results: Seventy-one studies were included with more than 24,000 participants and quality were assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the participants had knowledge toward organ donation with a positive influence on willingness, the gap between knowledge and willingness was huge, with minimal registration. The findings showed that organ donation behaviour among this particular population is influenced by the complex interactions between the individual and the socio-cultural constructs. Various constructs of the society such as fear and mistrust, family, religion, bodily issues play a vital role. Also, differences in willingness to donate and registration were identified between southern and other regions of India.

Conclusion: Though this study showed the complex relationship, and its influences on organ donation behaviour, lacunae were identified to further understand how such complex interactions determine or inform the behaviour. Also, methodological issues were identified, where this particular population outside India were collectively studied with their neighbouring population which are not homogenous. Studies in India majorly addressed a similar aim using similar methods which produced repetition of studies leading to lack of diversified, wider, and in-depth research. Therefore, while this systematic review addressed the barriers toward organ donor registration among Indians in India and UK, it also informs various gaps in research and also methodological issues.

PROSPERO registration number: CRD42019155274

Keywords: Organ donation, Indians, UK, Integrative systematic review; Narrative synthesis, Registration

Strengths and Limitations:

1. This is the first systematic review about barriers toward deceased organ donation among Indians living in India and UK, registered with PROSPERO, and published.

2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
3. Included studies that exclusively represented the Indian population and excluded studies that collectively studied with the heterogenous South Asian or Asian population, thereby keeping the rigour of this study and identifying methodological issues involved.
4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. Therefore, both in India and UK, people of Indian origin show higher reluctance to organ donation which is reflected both in registration and consent.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence organ donor registration. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donor registration among the individuals of Indian origin. Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper insight into the barriers toward organ donor registration among this particular population [17].

The protocol proposed to include Indians living globally [17], but this review represents Indian population living only in India and UK. There had been studies globally that had included Indian ethnic group to examine the barriers of organ donation. However, many of them did not report the results exclusively for Indians but rather combined this population with those from other Asian countries and few had no sufficient findings, therefore excluded. However, on the other side, two studies were included from UK that had the potential to be included. Therefore, this systematic review will address the barriers toward organ donor registration among the Indian population living in Indian and UK, identify gaps in evidence to further research and help stakeholders in furthering strategies to improve organ donation.

Method

Protocol and registration

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published [17].

Systematic search

Search strategy was developed collaboratively with the research team and a subject specialist librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central were utilised. Key terms related to organ donation were first identified from studies published along with search terms used in other systematic review on organ donation [18,19] and were tested in different combinations. Later, for each database, the search terms were then customised seeking to capture the most appropriate studies to answer the aim of this review (supplementary file 1) [20]. However, for other resources like google scholar and the Indian journal of transplantation other strategies were employed. All the published papers from January 1994 to December 2021 were searched from the archives of the Indian journal of transplantation archives to find relevant studies. With regard to google scholar, we searched using two methods. The first one used the word "Organ Donation AND India" in title; and the second one used the say keywords but searched anywhere in the article. However, due to very high number of search results in the second method, we limited the search until we found no further relevant studies (an approach used by other published systematic reviews) [21]

The systematic review included studies with individuals of Indian origin living both within and outside India (i.e., migrant / first / second generation), aged 18 years and above from varied settings [17]. Cross-sectional and qualitative study design were included as they were mostly employed to understand the barriers toward deceased organ donation. For all the databases,

search strategy was restricted between 1st of January 1994 (i.e., the year when the first law toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent day before the submission) and was restricted only to studies published in English. However, interventional studies, commentary or opinion papers, studies on blood, bone marrow, body, sperm, and egg donation were excluded alongside any studies which addressed only living donation.

Search outcome

Following a stage-by-stage exclusion from 3,179 studies initially extracted from the main databases, 31 studies were included in final review along with 40 studies included from other sources (Figure 1). The studies were initially exported to RefWorks (https://refworks.prorequest.com/). Microsoft excel was used to keep a record of studies excluded by duplicates, title, abstract, and full text. All the 3,179 studies along with studies from other sources were screened by two authors independently and the final 71 studies included were in-agreement with all the authors.

However, during the process, studies conducted among Indians living outside India were identified to be collectively studied as South Asians or with other Asian population. For instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic groups of India [22]. In UK, Indian population was collectively studied as South-Asians [4, 23]. In Malaysia, though sampling was distinguished their results were not sufficiently addressed [24]. However, concerning organ donation, the perspective of deceased organ donation varies even within India's nearest neighbouring country [4, 25]. Therefore, this review included only the studies which exclusively reported the findings from Indian population, thus making this systematic review address Indians living in India and UK.

Quality assessment

Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the rigour of each studies included [26], also used in other organ donation systematic review [18,27]. Comprehensive reporting on the quality assessment for both cross-sectional and qualitative studies are reported in figure 2. Quality assessment was initially carried out by the primary researcher after which it was reviewed by the other two authors independently. Both the authors along with the primary researcher agreed upon the quality assessment as mentioned in figure 2. The review included all studies; however minimal emphasis was given for those studies that demonstrated only fewer items in the quality assessment checklist.

Data synthesis

This systematic review followed an integrative review with narrative synthesis approach enabling to synthesise complex information toward the phenomena of interest [28], a methodology also employed in another systematic review on organ donation that reviewed both quantitative and qualitative studies [19]. Narrative synthesis primarily depends on words and texts to summarise the findings with four process elements such as 1) systematic search and quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary development, and 4) assessment and interpretation [29].

Firstly, following the systematic search and quality appraisal, summary data was collected for each study, and they were recorded across a table which had information needed to cluster the studies to compare and study across (Table 1). Secondly, with the cross-sectional studies, numerical results from each study were tabulated across a matrix and were compared across to study their relationship in terms of barriers. Later, full synthesis of the four qualitative studies was undertaken by coding the findings and discussion sections using NVivo11. Codes were then organised into themes to address the barriers appropriately.

While comparing and studying across the studies included in the review to understand their relationship, various elements such as what the study is about, type of study, their approach, the findings, study settings, and population studied were also considered. Noblit and Hare (1988) described this as 'Reciprocal translation', also used in other similar methodological approaches [30-34]. Thirdly, full syntheses of both cross-sectional and qualitative studies were studied across to understand the supporting and refuting evidence collectively. For each section of the findings, quantitative studies provided the initial context following which findings from qualitative studies were used to elaborate and explain. With limited qualitative study narratives to support or refute the cross-sectional study findings, they were incorporated into the integration of the findings wherever possible. Both convergent and divergent findings are explained in this review, whereby if divergent findings were identified explanatory factors such as type of study or setting, or population were provided to facilitate better understanding [19].

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914 (i.e., 1461 in group I; 2453 in group II)	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300 (i.e. 100 from each college)	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a	Cross-sectional	200	Random sampling

				residential area around a tertiary healthcare centre			
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	Tertiary care teaching hospital among family members who consented to donate the organs of their loved ones	Quantitative	59	Purposive sampling
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified

Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ donation among dental students based on gender, year of study and religion	Dental college Undergraduate students	Cross-sectional	298	Not specified
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	9 focus group discussion (i.e. 50 participants) and 8 Semi-structured Interviews	Purposive sampling - Stratified sampling for groups
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death	Medical and nursing students	Cross-sectional	400	Population proportion to size

			criteria and need for organ donation and also to determine the attitude towards the same				
Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regrading organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling
Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8 semi-structured interviews	Purposive

Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Survey	204	Not specified
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	4 FGDs with 48 participants	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified

Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified
Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering, and arts and science students in Thirivallur and Chennai	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random

Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staff	Cross-sectional	266 (i.e., 166 paramedics, 100 administration staff)	Simple Random Sampling
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600 (i.e. 300 medical; 300 engineering students)	Random
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360 (i.e., 180 undergraduate and 180 postgraduate students)	Not specified
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care, hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the	Cross-sectional	193	Lottery method

				outpatient department			
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6 In-depth interviews	Purposive sampling
Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620 (i.e., 375 medical students and 245 nursing students)	Convenient sampling for population and voluntary for participants
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

Findings

Grouping and clustering

Among the 71 studies reviewed; majority (97%) were conducted among Indians living in India (n=69) while other two studies were among people of Indian origin living in UK. Cross-sectional studies (n=67) included various settings such as general community (30%), education institutions (44%) and hospital setting (30%) (Table 1). Qualitative studies (n=4) consisted of in-depth interviews (75%) and focus group discussion (50%) (Table 1). Among the 24,463 individuals involved in the retained studies, 24,023 individuals (98.2%) were from studies conducted in India. Among the studies conducted in the UK, only one study distinguished 107 individuals as Indians, whereas the other with 60 individuals had no evidence on the sample number of Indian participants involved.

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely: 1) knowledge and awareness toward deceased organ donation and registration, 2) willingness and actual behaviour toward deceased organ donor registration, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation and registration

Being the commonest theme studied across, findings showed that knowledge had a positive corelation with willingness and practice [35-41]. Both among Indians in India and UK, younger adults, participants from higher socio-economic status, and with higher education or healthcare education demonstrated higher knowledge toward deceased organ donation [41-57] and

individuals from southern region of India showed higher knowledge compared to other regions in India [58-63].

Whilst majority of the studies confirmed that almost all the participants had heard about organ donation (Figure 3) and had higher awareness, knew what organs can be donated [37,50-52, 64-78] and that organs can be donated to anyone [43,58,77], the knowledge and understanding on brain death was less well understood [46,61,65,66,72,79,80]. A qualitative study from an urban area in the southern region of India also found brain death as a new concept for many and hard to accept among the public [81]. Also, many were not aware about the organ donor card [64, 82-85], where and how to register and obtain an organ donor card [38,,47,50,67,68,52,53,85] - an important component for organ donor registration. In addition, knowledge on the law that governs organ donation was also found to be low [38,68,83,86,87].

Though a study among Indians living in UK showed that disinterest, emotional distaste, family opposition and religion to be the underlying cause for reluctance to register [55], among Indians living in India, the awareness on brain death, organ donor card, where and how to register are also important factors serving as barriers to individuals who are willing to register [38,46,47,50,52,61,64,66-69,79,82-86,88].

Willingness and registration toward deceased organ donation

Greater knowledge showed positive influence on the attitude and willingness across all Indian regions [39,41,,47,83,89-93]. Similar to higher knowledge among individuals from southern region of India, willingness to register, to donate and to accept organs for transplant was also shown to be higher [36,42,43,46,63,65,83,89,91]. However, though knowledge had a positive association toward attitude and willingness, the proportion of individuals willing to register, and actual registration was very low and similar across every study included (Figure 2). Correspondingly, even a study conducted among Indian students living in UK revealed that

55% of the individuals doubted if they would go ahead with registration [55]. With such reluctance, Indians living in India and UK considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [43,50,52,55,60,62,66,68,69,71,72,76,85,87,90,94]. On contrary, commonest reasons to donate an organ was to save someone's life, closely followed by elongate someone's life, social commitment, altruistic deed, and that at least their deceased one's organs can live [69,72,82,89,94-97].

Higher proportion of participants were willing to receive compared to donating [36,42,43,55,65,,89,91,98] both among Indians from India and UK. Furthermore, studies revealed that among those who were willing to donate, majority were only willing to donate specific organs namely eye / cornea and kidneys [43,58,59], which may be related to the knowledge on what organs can be donated [64-69,73-75,79]. Nonetheless, majority of the participants were willing to support and promote organ donation in their region and was similar across India [52,54,82,89,95,96].

Younger adults, participants from higher socio-economic status and participants with higher education or healthcare education demonstrated higher willingness toward deceased organ donation both among Indians in India and UK [25,41,42,44,45,50,55-58]. However, this was not consistent during the time of actual behaviour. Studies showed that there was almost equal distribution of participants from lower socio-economic status and lower education, who did give consent and actually signed for deceased organ donation [44,86]. However, this conclusion is based only from few studies showed to be similar in north and south of India [44,86].

Familial influence

In-spite of willingness to register for organ donation (Figure 2), larger proportion of individuals have not initiated a conversation or discussed their willingness with their family members, an important behaviour for a successful donation [49,62,65,68,84,90,99,100] - however opted family as the major barriers toward organ donation [43,60,62,66,69,85,90,92]. A qualitative study conducted in India and UK revealed the main reasons surrounded a lack of confidence in initiating conversations around sudden deaths, and with these conversations perceived unwelcome by their parents and elders [25,81]. However, another qualitative study conducted among Indian students who were born and grew in UK revealed that they are less concerned of sharing their views compared to their older generations (i.e., mostly migrant generation) and were more willing to discuss their wishes with their families [25,78,101], which could be related to acculturation. On the other side, a qualitative study conducted in southern India among urban living adults suggested that such conversation only occurred when individuals read or viewed such events [81]. Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process [86], making such discussion very important during the crucial decision-making moments.

Willingness to support family members was shown to be higher among healthcare students compared to other students [52,102] and lower among family members from rural areas [89,100]. However, while higher proportion of individuals were willing to support family members for organ donation [36,58,68,83,91,101], only very few families actually supported this decision when families were approached for consent [81].

Though studies included found no association based on marital status [36,42,91], one study found that unmarried individuals appeared to be more willing to donate compared to married couples [91]. Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared to those unaware of their spouse's opinion [42]. Among the

type of family, individuals from 'joint' families had higher knowledge, while willingness to donate was found to be higher among nuclear families [36,45,47].

Fear and Mistrust

Fear on misuse of organs by the healthcare team, revealing lack of trust was the other major barrier reported [25,38,45,52,60,61,65,66,68,69,75,85,87,94]. Some participants relate organ donation to organ trafficking and misuse which leads them to fear and mistrust [46,62,89]. A qualitative study also revealed increased ambivalence that while on one side participants perceived organ donation as a noble act, on the other side they were also fearful of organ misuse due to the information that they hear through news and media on organ trafficking and exchange of money for organs [81].

Also in UK, among Indian participants, a mother was afraid to see an organ donor card in his child's wallet as she was thinking if doctors will come to see it, then they may deviate the process toward donation and give less care toward saving her child [25]. In parallel, general population from India also feared pre-mature declaration of death for the need of organs [37,89,102]. However, healthcare population groups were less likely to believe that there will be any premature declaration of death by the doctors [36,68,80].

Religious influence

Overall, majority of the participants favoured organ donation [25,36,43,44,46,58,77,78,91,95]. However, when further looked based on religion, different studies showed different religious groups to be more willing to donate compared to individuals from another religious group [42,45,58,70,103], showing no consistency on which particular religion is more supportive or rejective [42,45,49,58,103]. In parallel, a qualitative study conducted among UK university students of Indian descendants showed lack of homogeneity even within one same religion. Some agreed that body needs to be intact for reincarnation, while other participants believed

that body and soul are two different entities and that only the soul counts while body is left to decay in this earth [25,87].

However, though there were differences of opinion across and within the religion, majority of the participants agreed that organ donation is not against religious views [36,65,69,81,87,91,95] and also considered religion as the very least barrier toward organ donation [42,60,62,65,81,99,104]. A qualitative study conducted among UK students with Indian origin showed that though individuals felt religion may influence their decision it was not the only factor that that will be considered in such decisions [25]. Yet, favourable opinion of religion toward organ donation was found to be positively correlating with their willingness to donate [36,49].

A Qualitative study conducted in UK with Indian students revealed that younger generations were less bothered about religious views compared to older generations, which could have occurred due to acculturation [25]. Also, participants preferred that religion should not be a criterion based on which allocation can be decided [45,65,95,99] and that organ of a deceased person can be donated to a recipient from any religion [45,65,95,99].

However, during the time of consent, a stakeholder from a qualitative study said that families who were not willing to donate use the concept of religion as a pre-framed reason to decline donation, though none of the religion is against organ donation. In the same qualitative study, public participants from different religious group felt that their religion supports organ donation [81].

Bodily issues

Majority of the individuals from the reviewed studies were not concerned about bodily issues though it has to undergo incisions while explanting [36-38,42,43,58,82,87,101]. However, on the other side, majority also agreed that it is an individual's complete right to have the organs

within the body when dead [46,80]. Whilst majority of individuals were not concerned about incisions in the body, a qualitative study found that in the real time of consent, stakeholders found it easy to get approval for corneal donation and not solid organs as it may have many incisions over the body and disfigure it [69]. In relation to funeral practices involving the deceased body, majority were aware that normal funeral practices can be conducted even after donating organs [36,46,58,80,82,99], contrast findings were also evident [46,52,80]. However, majority opted body disfigurement as one of the least reasons to be a barrier toward organ donation [43,60,62,66,90].

Discussion

To the best of our knowledge, this is the first systematic review that reviewed barriers toward organ donation among Indians in India and UK, while other potential studies were excluded due to methodological issues. Also, this is one of the few systematic reviews in organ donation that used integrative methodology. While majority in India have heard or are aware of organ donation, and had a positive correlation with willingness, their gap is wide. This indicates that there could be various factors other than knowledge which need to be studied in more detail. Organ donation being more embedded with health behaviour, there is a need to understand the relationship between behaviour and behavioural intention by adopting appropriate principles. This aids the specificity of policy and campaigns to address organ donor registration behaviour in this particular population.

Though gaps identified in majority of the quantitative studies merit qualitative studies, only very few qualitative studies were undertaken in India [80,81,87]. For instance, though majority individuals were willing to be an organ donor, majority have not initiated any such conversation with their family members yet considered family to be the major barrier [23,43,60,62,66,90]. However, no further studies were exclusively undertaken to understand how a construct like

family interferes in the decision making toward registration and consent. Such studies will aid in developing and testing hypothesis or developing appropriate interventions to increase such conversation with family members. Such conversations play a very important role as the awareness on the willingness of the deceased plays a vital role in decision-making during consent [86]. However, the influence of family can be different among Indians in India and UK as the latter may have influences based on acculturation and enculturation [25,55] while the prior maybe more concerned toward communication issues [49,62,65,81,84,90,99,100]. While majority were willing to be an organ donor [25,41,42,44,45,50,55-58], they were unaware on how to register to be an organ donor [38,47,50,52,53,67,68,85]. Therefore, further campaigns on registration procedure information and centralised registries will enable to improve organ donation in India.

This review shows that there are various complex interactions that happen in the society where an individual lives rather than just knowledge influencing organ donation decision. Fear and mistrust have shown to influence the uncertainty in decision-making for a very long time [25,38,45,52,60,61,65,66,68,69,75,87]. However, studies failed to address how fear influences organ donation, what is the source of fear and how a construct like fear can be addressed. This fear could be due to the news or information that they hear on illegal organ donation and transplants practices around them or any other reasons [105], but not much have been studied why such fear exist among this population.

Also, while majority of the studies show influence of religion on organ donation, there is a greater need to understand how a religion influences organ donation in India. Is it the misconception, or the lack of enabling religious community, or reluctance to take such conversation, or lack of information from the religious leaders or their physical practices that does not allow donation? Such in-depth studies need to be undertaken to gain a deeper understanding into the phenomena. Therefore, at the moment, there is a need to study further

how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour.

Various other factors such as age, sex, education, and socio-economic status showed greater influence on willingness to donate [25,42,44,45,50,55,58]. However, studies showed that they did not hold true during the time of consent [44,86]. This review therefore showed that there is some shift in behaviour during registration and the actual consent. This again probes to further the understanding on what happens during the time of consent, and why such a shift is seen in the intention to donate between these two time periods.

Methodologically, studies conducted among the Indian ethnic group outside India were collectively identified as South-Asians or Asians [19,22,106] while they differ culturally, socially, politically, economically, and even religiously [107]. Two studies included from UK in this review have clearly shown such a difference with the neighbouring country (i.e., India, and Pakistan) [25]. Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations from the same ethnicity [25,55]. This cannot happen without the influence of time elapsed since immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation, perceived discrimination, attitudes / mistrust toward healthcare system, community barriers, socio-cultural influence and many such complex determinants which adds further complexity to the issue of organ donation among such a population. Therefore, such specific research among this community is also needed to address the disproportionate representation between waiting list and donor list from this ethnic population outside the country of origin. Though narrative synthesis is criticised for its lack of transparency, this study has tried to be as transparent as possible to strengthen its validity and credibility of the review and synthesis

[28,108]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are clearly explained in this study to overcome those limitations.

Conclusion

This review showed that majority of the participants from India and of Indian origin hold positive attitude toward registration but show lower willingness and even lower practice of registration. Though this study showed the complex relationship and influences toward organ donation behaviour, lacunae were identified for further deeper understanding into such complex interactions determining the behaviour. There is also a lack of methodological rigour to study this particular population outside India, being collectively studied with their neighbouring population which are not homogenous. Also, within India, majority of the studies employed similar aims and methods leading to repetition of studies rather than diversified, wider, and in-depth research.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their Global Challenges Research Fund.

Authorship Contribution:
All authors BP, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Data availability: None

Conflict of Interest: None declared.

Patient and Public involvement: None as this is a systematic review

Ethics approval details: Institute for Health Research Ethics Committee from the University of Bedfordshire approved this study (IHREC931).

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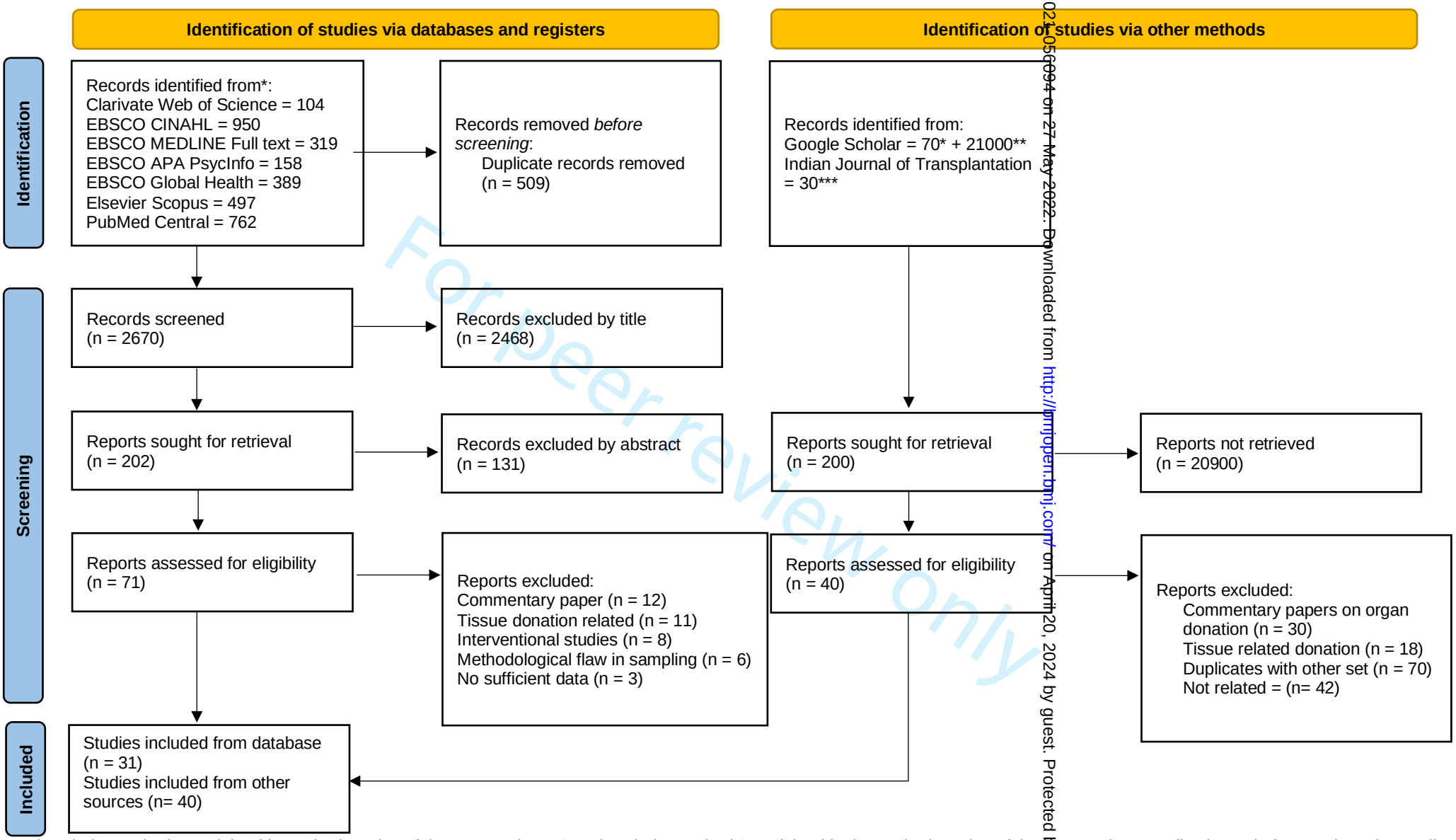
Figure legends / captions:

Figure 1: PRISMA flowchart

Figure 2: Quality appraisal checklist

Figure 3: Graphical representation of studies showing gap between knowledge, attitude, and registration practices.



*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	×	×	✓	✓
Alex et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	×	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	×	×	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	×	×	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Bapat et al, 2010	-	✓	✓	✓	×	×	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Bathija et al,2017	-	✓	✓	✓	×	✓	✓	✓
Bharambe et al, 2015	×	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	×	×	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Darlington et al,2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	×	×	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	×	×	✓	✓
Flower et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Gupta et al, 2021	×	-	✓	✓	×	×	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Jayabharathi et al,2019	✓	✓	✓	✓	×	×	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Kaistha et al,2016	✓	✓	✓	✓	×	×	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Khan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mani, 2016	✓	✓	✓	✓	×	×	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Minz et al, 1998	×	✓	-	✓	×	×	✓	✓
Misra et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Paul et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	×	×	✓	✓
Rajan, 2021	✓	✓	✓	✓	×	×	✓	✓
Rani et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Ray et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Sachdeva, 2017	-	✓	✓	✓	×	×	✓	✓
Sam et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Singh et al, 2002	✓	✓	✓	✓	×	×	✓	✓
Soni et al, 2018	-	✓	✓	✓	×	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Tamuli et al,2019	×	✓	✓	✓	×	×	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al,2016	✓	✓	✓	✓	×	×	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	×	×	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

Mentioned ✓ Not mentioned × Unclear -

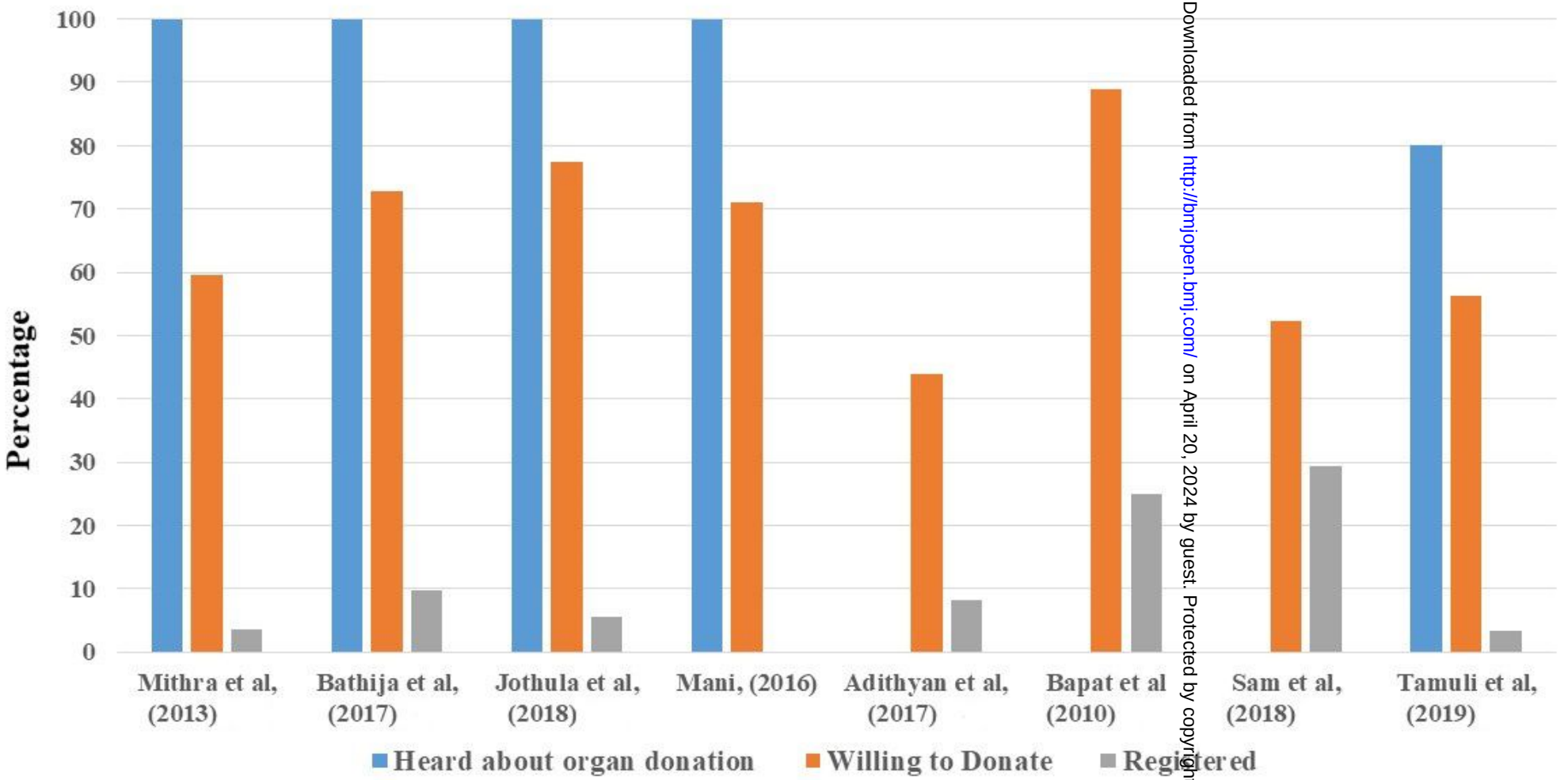
Quality appraisal for cross-sectional studies

Ref	Vincent et al, 2019	Kennedy, 2002	Gauher et al, 2013	Misra et al, 2021
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	✓	✓
4	✓	✓	✓	✓
5	✓	✓	✓	✓
6	✓	×	✓	×
7	×	×	×	×
8	✓	×	✓	×
9	✓	×	✓	✓
10	✓	✓	✓	✓

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objective?
3. Is there congruity between the research methodology and the methods used to collect data?
4. Is there congruity between the research methodology and the representation and analysis of data?
5. Is there congruity between the research methodology and the interpretation of results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research, and vice-versa, addressed?
8. Are participants, and their voices, adequately represented?
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ×

Quality appraisal for qualitative studies



Supplementary I: Search strategy

Database: Clarivate Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ (931356)
2. (ALL) Tissue (2044844)
3. 1 OR 2 (2828541)
4. (ALL) Donation (81986)
5. (ALL) Procurement (35057)
6. (ALL) Donor (452066)
7. (ALL) Registration (142852)
8. (ALL) Pledge (4245)
9. 4 OR 5 OR 6 OR 7 OR 8 (679088)
10. Brain death (93353)
11. Posthumous (2234)
12. Deceased (27866)
13. 10 OR 11 OR 12 (122185)
14. India (1905243)
15. Asia (460895)
16. South Asia (111493)
17. 14 OR 15 OR 16 (2322980)
18. Knowledge (1815596)
19. Attitude (408659)
20. Practice (1974880)
21. Awareness (294873)
22. Perception (704502)
23. Barrier (696152)
24. Challenge (2000813)
25. Religion (121682)
26. Family (1815478)
27. Discuss (3004676)
28. Sign (496082)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 0R 28 (10776639)

30. 3 AND 9 AND 13 AND 17 AND 29 (104)

((((ALL=(Organ OR Tissue)) AND ALL=(Donation OR Procurement OR Donor OR Registration OR Pledge)) AND ALL=(Brain Death OR Posthumous OR Deceased)) AND ALL=(India OR Asia OR South Asia)) AND ALL=(Knowledge, attitudes, practice OR Awareness OR Perception OR Barrier OR Challenge OR Religion OR Family OR Discuss OR Sign)

Database: EBSCO CINAHL Complete < 1994 January to December 2021>

Search strategy

1. TI Organ (12792)
2. TI Tissue (35138)
3. 1 OR 2 (46731)
4. TI Donation (5003)
5. TI Donor (9786)
6. 4 or 5 (14299)
7. AB Knowledge (220735)
8. AB Awareness (72886)
9. AB Attitude (75081)
10. AB Perception (114073)
11. AB Practice (405101)
12. AB Registration (58662)
13. AB Consent (24494)
14. AB Culture (77169)
15. AB Religion (6986)
16. 7 OR 8 OR 9 OR 10 OR 12 OR 13 OR 14 OR 15 (842904)
17. 3 OR 6 OR 16 (950)

TI (Organ OR Tissue) AND TI (Donation OR Donor) AND AB (Knowledge OR Awareness OR Attitude OR Perception OR Practice OR Registration OR Consent OR Culture OR Religion)

Database: EBSCO MEDLINE With full text Complete < 1994 January to December 2021>

Search strategy

1. TX Organ (1209295)
2. TX Tissue (2836964)
3. 1 OR 2 (3517194)
4. TX Donation (72543)
5. TX Donor (492893)
6. TX Registration (190162)
7. 4 OR 5 OR 6 (702757)
8. TX India (847970)
9. TX Asia (291953)
10. TX South Asia (44218)
11. 8 OR 9 OR 10 (1080319)
12. TX health knowledge, attitudes, practice (119021)
13. 3 AND 7 AND 11 AND 12 (319)

TX (Organ OR Tissue) AND TX (Donation OR Donor OR Registration) AND TX (India OR Asia OR South Asia) AND TX health knowledge, attitudes, practice

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Database: EBSCO APA PsycInfo < 1994 January to December 2021>

Search strategy

1. TI Organ (1723)
2. TI Tissue (2644)
3. 1 OR 2 (4326)
4. TI Donation (1318)
5. TI Donor (1100)
6. 4 OR 5 (2297)
7. KW Knowledge (51470)
8. KW Awareness (19810)
9. KW Attitude (9853)

10. KW Perception (62192)
11. KW Practice (58248)
12. KW Registration (829)
13. KW Consent (4319)
14. KW Culture (34255)
15. KW Religion (11715)
16. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 (234219)
17. 3 AND 6 AND 16 (158)

TI (Organ OR Tissue) AND TI (Donation OR Donor) AND KW (Knowledge OR Awareness OR Perception OR Practice OR Registration OR Consent OR Culture OR Religion)

_ _

Database: EBSCO Global Health < January 1994 to December 2021>

Search strategy

1. TI Organ (5703)
2. TI Tissue (24236)
3. 1 OR 2 (29712)
4. TX Donation (4174)
5. TX Donor (27588)
6. 4 OR 5 (29050)
7. TX Registration (9802)
8. TX Pledge (189)
9. TX Knowledge (157636)
10. TX Awareness (49745)
11. TX Attitude (82125)
12. TX Perception (52839)
13. TX Practice (203547)
14. TX Consent (10210)
15. TX Barrier (57133)
16. TX Challenge (116441)
17. TX Facilitator (5697)
18. TX Religion (6883)

19. TX Culture (195775)
20. 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 18 OR 19 (722134)
21. 3 AND 6 AND 20 (389)

TI (Organ OR Tissue) AND TX (Donation OR Donor) AND TX (Registration OR Pledge OR Knowledge OR Awareness OR Attitude OR Perception OR Practice OR Consent OR Barrier OR Challenge OR Facilitator OR Religion OR Culture)

Database: Elsevier Scopus PUBYEAR > 1993 AND PUBYEAR <2022

Search strategy

---

1. TITLE-ABS-KEY Organ (756450)
2. TITLE-ABS-KEY Tissue (3946763)
3. 1 OR 2 (4390243)
4. TITLE-ABS-KEY Donation (49710)
5. TITLE-ABS-KEY Donor (465356)
6. TITLE-ABS-KEY Registration (204600)
7. TITLE-ABS-KEY Pledge (4315)
8. 4 OR 5 OR 6 OR 7 (693065)
9. TITLE-ABS-KEY India (437307)
10. TITLE-ABS-KEY Asia (352898)
11. TITLE-ABS-KEY South Asia (85909)
12. 9 OR 10 OR 11 (352898)
13. 3 AND 8 AND 12 (497)

(TITLE-ABS-KEY (organ OR tissue) AND TITLE-ABS-KEY (donation OR donor OR registration OR pledge) AND TITLE-ABS-KEY (India OR Asia OR south Asia)) AND PUBYEAR > 1993 AND PUBYEAR <2022

Database: PubMed Central < 1994 January to December 2021>

Search strategy

Search: ((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract] OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract] OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	22-25
	23b	Discuss any limitations of the evidence included in the review.	24-25
	23c	Discuss any limitations of the review processes used.	24-25
	23d	Discuss implications of the results for practice, policy, and future research.	22-25
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary file 1.

PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

BMJ Open

Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-056094.R2
Article Type:	Original research
Date Submitted by the Author:	11-Apr-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

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Title Page

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

Full name of all authors:
As per the order of the authorship

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Authorship Contribution:
All authors BP, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by the Global Challenge Research Fund.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

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Running title:
Barriers to Deceased Organ Donation among Indians globally: An Integrative Systematic Review

Abbreviations:
NCD – Non-Communicable Disease
pmp – per million population

ODR – Organ Donation Rate
JBI - Joanna Briggs Institute's

Conflict of Interest:
None declared.

Word count
Abstract: 300
Manuscript: 4,381

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

Abstract

Objectives: To understand the barriers toward deceased organ donation among Indians living globally.

Design: Integrative systematic review using narrative synthesis

Data sources: CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central, Indian Journal of Transplantation and Google scholar.

Time period: 1st January 1994 to 31st December 2021

Participants: Individuals of Indian origin living globally

Results: Eighty-nine studies were included with more than 29,000 participants and quality of the studies were assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the participants had knowledge toward organ donation with a positive influence on willingness, the gap between knowledge and willingness was huge, with minimal registration influenced by the complex socio-cultural constructs. Various socio-cultural constructs such as fear and mistrust, family, religion, bodily issues play a vital role. Differences were identified in willingness to donate and register between southern and other regions of India. Indian's organ donation behaviour in other geographical locations differed based on the socio-religious background of the country they lived in such as in Malaysia, Canada, and the UK. However, they were collective in decision-making and had complex socio-cultural interference irrespective of the country the individual lived which differed only in their next generations.

Conclusion: Though this study showed the complex relationship, and its influences on organ donation behaviour, lacunae were identified to further understand how such complex interactions determine or inform the behaviour. Also, methodological issues were identified, where this particular population outside India were collectively studied with their neighbouring

population which are not homogenous. Studies in India majorly addressed a similar aim using similar methods which produced repetition of studies leading to lack of diversified, broader, and in-depth research. Therefore, while this systematic review addressed the barriers toward organ donation among Indians living globally, it also informs various gaps in research and methodologies.

PROSPERO registration number: CRD42019155274

Keywords: Organ donation, India, UK, Integrative systematic review; Narrative synthesis, Registration

Strengths and Limitations:

1. This is the first systematic review on the barriers toward deceased organ donation among Indians living globally, registered with PROSPERO, and published.
2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
3. Included studies exclusively represented the Indian population and studies that collectively studied Indians with heterogenous South Asian or Asian population were excluded, thereby keeping the rigour of this study, and identifying methodological issues involved.
4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populous country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes, hypertension, and many other comorbidities [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. This behaviour is again identified in Canada [17]. Therefore, Indian population has demonstrated higher reluctance to organ donation both within and outside the border.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence their organ donation behaviour. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donation among the individuals of Indian origin. Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper

insight into the barriers toward deceased organ donation behaviour among this particular population living globally [18].

Method

Protocol and registration

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published [18].

Systematic search

Search strategy was developed collaboratively with the research team and a subject specialist librarian. Databases namely CINAHL, MEDLINE, PsycINFO, Scopus, Global Health, Web of Science, and PubMed Central were utilised. Key terms related to organ donation were first identified from studies published along with search terms used in other systematic review on organ donation [19,20] and were tested in different combinations. Later, for each database, the search terms were then customised seeking to capture the most appropriate studies to answer the aim of this review (supplementary file 1) [21]. However, for other resources like google scholar and the Indian journal of transplantation other strategies were employed. All the published papers from 1st of January 1994 to 31st of December 2021 were searched from the archives of the Indian journal of transplantation to identify relevant studies. With regard to google scholar, we searched using two methods. The first method used the word "Organ Donation AND India" in title; and the second method used the same keywords but searched anywhere in the article. However, due to very high number of search results in the second method, we limited the search until we found no further relevant studies (an approach used by other published systematic reviews) [22].

The systematic review included studies with individuals of Indian origin living both within and outside India (i.e., migrant / first / second generation), aged 18 years and above from varied settings [18]. Cross-sectional and qualitative study design were included as they were mostly employed to understand the barriers toward deceased organ donation. For all the databases, search strategy was restricted between 1st of January 1994 (i.e., the year when the first law toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent day before the submission) and was restricted only to studies published in English. However, interventional studies, commentary or opinion papers, studies on blood, bone marrow, body, sperm, and egg donation were excluded alongside any studies which addressed only living donation.

Search outcome

Following a stage-by-stage exclusion from 8,655 studies initially extracted from the main databases, 51 studies were included in final review along with 38 studies included from other sources (Figure 1). The studies were initially exported to RefWorks (https://refworks.prorequest.com/). Microsoft excel was used to keep a record of studies excluded by duplicates, title, abstract, and full text. All the 8,655 studies along with studies from other sources were screened by two authors independently and the final 89 studies included were in-agreement with all the authors.

However, during the process, studies conducted among Indians living outside India were identified to be collectively studied as South Asians or with other Asian population. For instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic groups of India [23]. Also, in other countries like the UK and Malaysia, Indian population was collectively studied along with other ethnic groups and the results were not distinctively shown [24-26], therefore eight studies had to be excluded due to these methodological limitations. The

perspective of deceased organ donation varies even within India's nearest neighbouring country [4, 27]. Therefore, this review included only the studies which exclusively reported the findings among Indian population.

Quality assessment

Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the rigour of each studies included [28], also used in other organ donation systematic review [19,29]. Comprehensive reporting on the quality assessment for both cross-sectional and qualitative studies, are reported in figure 2 and 3. Quality assessment was initially carried out by the primary researcher after which it was reviewed by the other two authors independently. Both the authors along with the primary researcher agreed upon the quality assessment as mentioned in figure 2 and 3. The review included all studies; however minimal emphasis was given for those studies that demonstrated only fewer items in the quality assessment checklist.

Data synthesis

This systematic review followed an integrative review with narrative synthesis approach enabling to synthesise complex information toward the phenomena of interest [30], a methodology also employed in another systematic review on organ donation that reviewed both quantitative and qualitative studies [20]. Narrative synthesis primarily depends on words and texts to summarise the findings with four process elements such as 1) systematic search and quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary development, and 4) assessment and interpretation [31].

Firstly, following the systematic search and quality appraisal, summary data was collected for each study, and they were recorded across a table which had information needed to cluster the studies to compare and study across (Table 1). Secondly, with the cross-sectional studies, numerical results from each study were tabulated across a matrix and were compared across to

study their relationship in terms of barriers. Later, full synthesis of the qualitative studies was undertaken by coding the findings sections using NVivo11. Codes were then organised into themes to address the barriers appropriately.

While comparing and studying across the studies included in the review to understand their relationship, various elements such as what the study is about, type of study, their approach, the findings, study settings, and population studied were also considered. Noblit and Hare (1988) described this as 'Reciprocal translation', also used in other similar methodological approaches [32-36]. Thirdly, full syntheses of both cross-sectional and qualitative studies were studied across to understand the supporting and refuting evidence collectively. For each section of the findings, quantitative studies provided the initial context following which findings from qualitative studies were used to elaborate and explain. With limited qualitative study narratives to support or refute the cross-sectional study findings, they were incorporated into the integration of the findings wherever possible. Both convergent and divergent findings are explained in this review, whereby if divergent findings were identified explanatory factors such as type of study or setting, or population were provided to facilitate better understanding [20].

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in	Tertiary care teaching hospital	Cross-sectional	59	Purposive sampling

			potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	among family members who consented to donate the organs of their loved ones			
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ	Dental college Undergraduate students	Cross-sectional	298	Not specified

			donation among dental students based on gender, year of study and religion				
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darbari et al (2020)	Uttarakhand	India	To assess the knowledge on organ donation among undergraduate medical students	Undergraduate medical students	Cross-sectional	197	NA
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Darr et al (1999)	Luton	England	To assess the attitudes on organ donation and transplantation among south Asians	South Asian general public	Qualitative	64	Purposive sampling
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified
Exley et al (1996)	Coventry	England	To examine the religious, cultural, and social context of organ donation	Sikh Asian community members	Qualitative	22	Judgemental sampling
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	58	Purposive sampling - Stratified sampling for groups
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death criteria and need for organ donation and also to determine the attitude towards the same	Medical and nursing students	Cross-sectional	400	Population proportion to size

Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regrading organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Huern et al (2016)	Melaka	Malaysia	To assess the knowledge, attitude, and perception to determine the relationship between various sociodemographic data on knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	72	NA
Jagadeesh et al (2018)	Karnataka	India	To assess the knowledge, attitude, and beliefs toward organ donation and factors affecting willingness to donate	Professional drivers	Cross-sectional	300	convenient sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling

Karim et al (2013)	The United Kingdom	The United Kingdom	To explore the south Asians attitudes toward organ donation	South Asian general public	Cross-sectional	147	Not specified
Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8	Purposive
Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Li et al (2016)	Ontario	Canada	To determine the registration status from deceased organ donation and tissue donation	Migrant population	Cross-sectional	NA*	NA
Loch et al (2010)	Kula Lumpur	Malaysia	To examine the knowledge, attitude, and perception toward organ donation	General public	Cross-sectional	272	NA
Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Cross-sectional	204	Not specified

Mishra et al (2016)	Odisha	India	To evaluate the awareness of organ donation	College students	Cross-sectional	430	NA
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	48	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Morgan et al (2015)	London	England	Identify ways in which minority ethnic group habitus appears to limit attitude and knowledge of the system of organ donation and shape attitude toward registration	South Asian minority ethnic general public	Qualitative	79	NA
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified
Parmar et al (2017)	Gujarat	India	To assess perception of undergraduate students toward organ donation	Undergraduate students	Cross-sectional	100	Randomisation
Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified

Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Pradeep et al (2019)	Nort west of England	England	To explore the attitudes and beliefs toward organ donation	General public	Cross-sectional	593	Convenience sampling
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Randhawa et al (1998)	Luton	England	To examine the influence of religious beliefs, amongst other things, on the extent and directions of public attitudes toward organ donation	South Asian general public	Qualitative	64	Focused sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Reddy et al (2003)	New Delhi	India	To assess the awareness and the attitude of Indian patients, the public, doctors, and nurses toward organ donation	Public, doctors, and nurses	Cross-sectional	990	Randomisation
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering,	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified

			and arts and science students in Thirivallur and Chennai				
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random
Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266	Simple Random Sampling
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600	Random
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360	Not specified
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling

Verma et al (2020)		India	To assess knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	1463	Stratified sampling
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6	Purposive sampling
Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620	Convenient sampling for population and voluntary for participants
Wong et al (2010a)	Klang Valley	Malaysia	To understand the cultural and religious factors limiting organ donation in three ethnic group	Ethnic population	Qualitative	22	NA
Wong et al (2010b)	Klang Valley	Malaysia	To assess public knowledge and attitude with regard to deceased organ donation	General public	Qualitative	22	NA
Wong et al (2011)	Selangor	Malaysia	To explore the knowledge, attitude, perception and barriers toward deceased organ donation	General public	Cross-sectional	259	NA
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

* This study was based on the population data; the findings were based on national Indian population which was 228,879. Since it could over-represent the actual studies, this study sample size is not mentioned in the evidence table but in the notes here.

Findings

Grouping and clustering

Among the 89 studies reviewed; majority (84%) were conducted among Indians living in India (n=75) while other fourteen studies were among people of Indian origin living in the UK (n=8), Malaysia (n=5), and Canada (n=1). Cross-sectional studies (n=79) included various settings such as general community, education institutions and hospital setting (Table 1). Qualitative studies (n=10) used methods like in-depth interviews and focus group discussion (Table 1). Among the 29,385 individuals involved in the retained studies, 27,503 individuals (94%) were from studies conducted in India. Among the studies conducted in the UK, there were 1,235 individuals in total, however, one study had no evidence on the sample number of Indian participants involved [27], and the Malaysian studies had 647 individuals in total. The study participants from the Canadian study were not included since they were information taken from national registry which had around 228,879 Indian individuals.

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely: 1) knowledge and awareness toward deceased organ donation, 2) willingness and actual behaviour toward deceased organ donation, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation

Being the commonest theme studied across, findings showed that knowledge had a positive corelation with willingness and practice [37-44]. Both among Indians living in India and outside, younger adults, participants from higher socio-economic status, and with higher

education or healthcare education demonstrated higher knowledge toward deceased organ donation [43-60] and individuals from southern region of India showed higher knowledge compared to other regions in India [61-66].

Whilst majority of the studies confirmed that almost all the participants had heard about organ donation (Figure 3) and had higher awareness, knew what organs can be donated [4,39,44,53-55,67-85] and that organs can be donated to anyone [46,61,80], the knowledge and understanding on brain death was less well understood [49,64,68,69,75,86-89]. A qualitative study from an urban area in the southern region of India also found brain death as a new concept for many and hard to accept among the public [90]. Also, many were not aware about the organ donor card [67,83,88,91-94], where and how to register and obtain an organ donor card [40,50,53,55,56,70,71,94,95] - an important component for organ donor registration. In addition, knowledge on the law that governs organ donation was also found to be low [40,71,92,96,97].

Though a study among Indians living in UK showed that disinterest, emotional distaste, family opposition and religion to be the underlying cause for reluctance to register [58], among Indians living in India, the awareness on brain death, organ donor card, where and how to register were reported as important factors serving as barriers to individuals who are willing to register [40,49,50,53,55,64,67,69-72,86,91-96,98].

Willingness and actual behaviour toward deceased organ donation

Greater knowledge showed positive influence on the attitude and willingness across all Indian regions [17,41,43,44,50,92,99-103]. Similar to higher knowledge among individuals from southern region of India, willingness to register, to donate and to accept organs for transplant was also shown to be higher [38,45,46,49,66,68,92,99,101]. However, though knowledge had a positive association toward attitude and willingness, the proportion of individuals willing to

register, and actual registration was very low and similar across every study included. Correspondingly, even a study conducted among Indian students living in UK revealed that 55% of the individuals doubted if they would go ahead with registration [58]. With such reluctance, Indians living in India, UK, and Malaysia considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [68,75,79,94,97,100,104,44,105,106,95,107,]. On contrary, commonest reasons to donate an organ was to save someone's life, closely followed by prolong someone's life, social commitment, altruistic deed, and to keep at-least the organs alive [72,75,91,99,104-111].

Higher proportion of participants were willing to receive compared to donating [38,45,46,58,68,99,101,112-114] among Indians living globally. Furthermore, studies revealed that among those who were willing to donate, majority were only willing to donate specific organs namely eye / cornea and kidneys [46,61,62], which may be related to the knowledge on what organs can be donated [67-72,76-78,86]. Nonetheless, majority of the participants were willing to support and promote organ donation in their region and was similar across India [55,57,91,99,109,110].

Younger adults, participants from higher socio-economic status and participants with higher education or healthcare education demonstrated higher willingness toward deceased organ donation among Indians living globally [17,27,43,45,47,48,53,58-61, 108]. However, this was not consistent during the time of actual behaviour. Studies showed that there was almost equal distribution of participants from lower socio-economic status and lower education, who gave consent and actually signed for deceased organ donation [47,96]. However, this conclusion is based only from few studies which showed to be similar in north and south of India [47,96].

Familial influence

In-spite of willingness to register for organ donation, larger proportion of individuals have not initiated a conversation or discussed their willingness with their family members, an important behaviour for a successful donation [52,65,68,71,82,93,100,115,116] - however opted family as the major barriers toward organ donation [46,63,65,69,72,94,100,102], this was identified even among Indians living outside India [27,117]. Qualitative studies conducted in India, the UK and Malaysia revealed the main reasons was their lack of confidence in initiating conversations around sudden deaths, and with these conversations perceived unwelcomed by their parents and elders [27,90,95,4,85].

However, other few qualitative studies conducted among Indians who were born and grew in another country (i.e., UK and Canada) revealed that they are less concerned of sharing their views compared to their older generations (i.e., mostly migrant generation) and were more willing to discuss their wishes with their families [17,27,81,118], which could be related to acculturation. On the other side, qualitative studies conducted in southern India and the UK suggested that such conversation only occurred when individuals read or viewed such events [90,119]. Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process [96], making such discussion very important during the crucial decision-making moments.

Willingness to support family members was shown to be higher among healthcare students compared to other students [55,120] and lower among family members from rural areas [99,116]. However, while higher proportion of individuals were willing to support family members for organ donation [38,44,61,71,88,92,101,118], only very few families actually supported this decision when families were approached for consent [90].

Though studies included found no association based on marital status [38,45,101], one study found that unmarried individuals appeared to be more willing to donate compared to married couples [101]. Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared to those unaware of their spouse's opinion [45]. Among the type of family, individuals from 'joint' families had higher knowledge, while willingness to donate was found to be higher among nuclear families and also was identified to be highly influenced by the family [4,17,38,48,50]. This was a similarity identified in India, Canada, and the UK, showing it to be a collectivist decision making, where involvement of the extended family is identified to be a part of decision making among this population irrespective of the country they live [4,17,38,48,53,117]. And involvement of extended family was identified to be a barrier among Indians in the UK, in this process [4].

Fear and Mistrust

Fear on misuse of organs by the healthcare team, and lack of trust was the other major barrier reported [55,63,64,68,69,71,72,78,83,89,94,97,104,105]. Some participants relate organ donation to organ trafficking and misuse which leads them to fear and mistrust [49,58,65,99,105]. A qualitative study also revealed increased ambivalence that while on one side participants perceived organ donation as a noble act, on the other side they were also fearful of organ misuse due to the information that they hear through news and media on organ trafficking and exchange of money for organs [90].

Also similar in the UK, among Indian participants, a mother was afraid to see an organ donor card in his child's wallet as she was thinking if doctors will come to see it, then they may deviate the process toward donation and give less care toward saving her child [27]. In parallel, general population from India also feared pre-mature declaration of death for the need of organs

[39,99,120]. However, healthcare population groups were less likely to believe that there will be any premature declaration of death by the doctors [38,71,85,87].

Religious influence

Overall, majority of the participants favoured organ donation [27,38,46,47,49,61,80,81,101,106,108,109]. However, when further looked based on religion, different studies showed different religious groups to be more willing to donate compared to individuals from another religious group [45,48,61,73,121], showing no consistency on which particular religion is more supportive or rejective [45,48,52,61,121]. In parallel, a qualitative study conducted among UK university students of Indian descendants showed lack of homogeneity even within one same religion. Some agreed that body needs to be intact for reincarnation, while other participants believed that body and soul are two different entities and that only the soul counts while body is left to decay in this earth [27,97]. However, among studies undertaken outside India, Indian Muslim participants were identified to be less likely or supportive toward organ donation [4,44,95,106,117]. Qualitative studies from outside India identified that lack of the standpoint of religion as one of the reasons leading to such reluctance and not the individual's opinion [108,117].

However, though there were differences of opinion across and within the religion, majority of the participants agreed that organ donation is not against religious views [38,68,72,88,90,97,101,109] and also considered religion as the very least barrier toward organ donation [44,45,63,65,68,90,115,122,114]. A qualitative study conducted among UK students with Indian origin showed that though individuals felt religion may influence their decision it was not the only factor that that will be considered in such decisions [27]. Yet, favourable opinion of religion toward organ donation was found to be positively correlating with their willingness to donate [38,52].

A Qualitative study conducted in UK with Indian students revealed that younger generations were less bothered about religious views compared to older generations, which could have occurred due to acculturation [27]. Also, participants preferred that religion should not be a criterion based on which allocation can be decided [48,68,109,115] and that organ of a deceased person can be donated to a recipient from any religion [48,68,109,115].

However, during the time of consent, a stakeholder from a qualitative study said that families who were not willing to donate use the concept of religion as a reason to decline donation, though none of the religion is against organ donation. In the same qualitative study, public participants from various religious group felt that their religion supports organ donation [90].

Bodily issues

Majority of the individuals from the reviewed studies were not concerned about bodily issues though it has to undergo incisions while explanting [38-40,45,46,61,91,97,118]. However, on the other side, majority also agreed that it is an individual's complete right to have the organs within the body when dead [49,87]. Whilst majority of individuals were not concerned about incisions in the body, a qualitative study found that in the real time of consent, stakeholders found it easy to get approval for corneal donation and not solid organs as it may have many incisions over the body and disfigure it [72]. In relation to funeral practices involving the deceased body, majority were aware that normal funeral practices can be conducted even after donating organs [38,49,61,87,91,115], contrast findings were also evident [49,55,87]. However, majority opted body disfigurement, but less proportion, as one of the least reasons to be a barrier toward organ donation, both within and outside the borders of India [46,63,65,69,83,100,106,108].

Discussion

To the best of our knowledge, this is the first systematic review that reviewed barriers toward organ donation among Indians living globally. Also, this is one of the few systematic reviews in organ donation that used integrative methodology. While majority in India have heard or are aware of organ donation, and had a positive correlation with willingness, their gap is wide. This indicates that there could be various factors other than knowledge which need to be studied in more detail. Organ donation being more embedded with health behaviour, there is a need to understand the relationship between behaviour and behavioural intention by adopting appropriate principles. This aids the specificity of policy and campaigns to address organ donor registration behaviour in this particular population.

Though gaps identified in majority of the quantitative studies merit qualitative studies, only very few qualitative studies were undertaken in India [87,90,97]. For instance, though majority individuals were willing to be an organ donor, majority have not initiated any such conversation with their family members yet considered family to be the major barrier [46,63,65,69,100,117]. However, no further studies were exclusively undertaken to understand how a construct like family interferes in the decision making toward registration and consent. Such studies will aid in developing and testing hypothesis or developing appropriate interventions to increase such conversation with family members. Such conversations play a very important role as the awareness on the willingness of the deceased plays a vital role in decision-making during consent [96]. However, the influence of family can be different among Indians in India and outside India as the latter may have influences based on acculturation and enculturation [27,58] while the prior maybe more concerned toward communication issues [52,65,68,90,93,100,115,116]. While majority were willing to be an organ donor [27,43,45,47,48,53,58-61], they were unaware on how to register to be an organ donor

[40,50,53,55,56,70,71,94]. Therefore, further campaigns on registration procedure information will enable to improve organ donation in India.

This review showed that there are various complex interactions that happen in the society where an individual lives rather than just knowledge influencing organ donation decision. Fear and mistrust have shown to influence the uncertainty in decision-making for a very long time [27,40,48,55,63,64,68,69,71,72,78,97]. However, studies failed to address how fear influences organ donation, what is the source of fear and how a construct like fear can be addressed. This fear could be due to the news or information that they hear on illegal organ donation and transplants practices around them or any other reasons [123], but not much have been studied why such fear exist among this population.

Also, while majority of the studies show influence of religion on organ donation, there is a greater need to understand how a religion influences organ donation in India. Is it the misconception, or the lack of enabling religious community, or reluctance to take such conversation, or lack of information from the religious leaders or their physical practices that does not allow donation? Such in-depth studies need to be undertaken to gain a deeper understanding into the phenomena. Therefore, there is an urgent need, to study further how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour [124].

Various other factors such as age, sex, education, and socio-economic status showed greater influence on willingness to donate [27,45,47,48,53,58,61]. However, studies showed that they did not hold true during the time of consent [47,96]. This review therefore showed that there is some shift in behaviour during registration and the actual consent. This again probes to further the understanding on what happens during the time of consent, and why such a shift is seen in the intention to donate between these two time periods.

Overall, based on the studies undertaken among Indians living in India, the UK, Canada, and Malaysia, similarities and differences were identified. The willingness and registration behaviour differed according to the geographical location where Indians lived in comparison to their native population. While Indians were considered to have higher attitude and willingness in Malaysia [84,114], Indians living in the UK and Canada were considered to have lower attitude and willingness [17,117]. This could have been due to their respective socio-cultural practices of Muslim major country [i.e., Malaysia] and Christian major country [i.e., Canada and the UK] with Hindu major population [i.e., Indians]. This argument is also supported by a study that compared organ donation willingness between Christian, Hindu, and Muslim major native population [58]. The similarity identified was that, irrespective of their geographical location, this was a collectivist decision and not an individual's decision [4,85,117] with family, fear and mistrust, and bodily issues identified to be the major barrier [44,83,85,95,105,107,108].

Methodologically, studies conducted among the Indian ethnic group outside India were collectively identified as South-Asians or Asians [23-26,106] while they differ culturally, socially, politically, economically, and even religiously [125]. Two studies included from UK in this review have clearly shown such a difference with the neighbouring country (i.e., India, and Pakistan) [27]. Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations from the same ethnicity [27,58]. This cannot happen without the influence of time elapsed since immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation, perceived discrimination, attitudes / mistrust toward healthcare system, community barriers, socio-cultural influence and many such complex determinants which adds further complexity

to the issue of organ donation among such a population. Therefore, such specific research among this community is also needed to address the disproportionate representation between waiting list and donor list from this ethnic population outside the country of origin.

Though narrative synthesis is criticised for its lack of transparency, this study has tried to be as transparent as possible to strengthen its validity and credibility of the review and synthesis [30,126]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are clearly explained in this study to overcome those limitations.

Conclusion

This review showed that majority of the participants from India and of Indian origin hold positive attitude toward registration but show lower willingness and even lower practice of registration. Though this study showed the complex relationship and influences toward organ donation behaviour, lacunae were identified for further deeper understanding into such complex interactions determining the behaviour. There is also a lack of methodological rigour to study this population outside India, being collectively studied with their neighbouring population which are not homogenous. Also, within India, majority of the studies employed similar aims and methods leading to repetition of studies rather than diversified, wider, and in-depth research.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their Global Challenges Research Fund.

Authorship Contribution:
All authors BP, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Data availability: None

Conflict of Interest: None declared.

Patient and Public involvement: None as this is a systematic review

Ethics approval details: Institute for Health Research Ethics Committee from the University of Bedfordshire approved this study (IHREC931).

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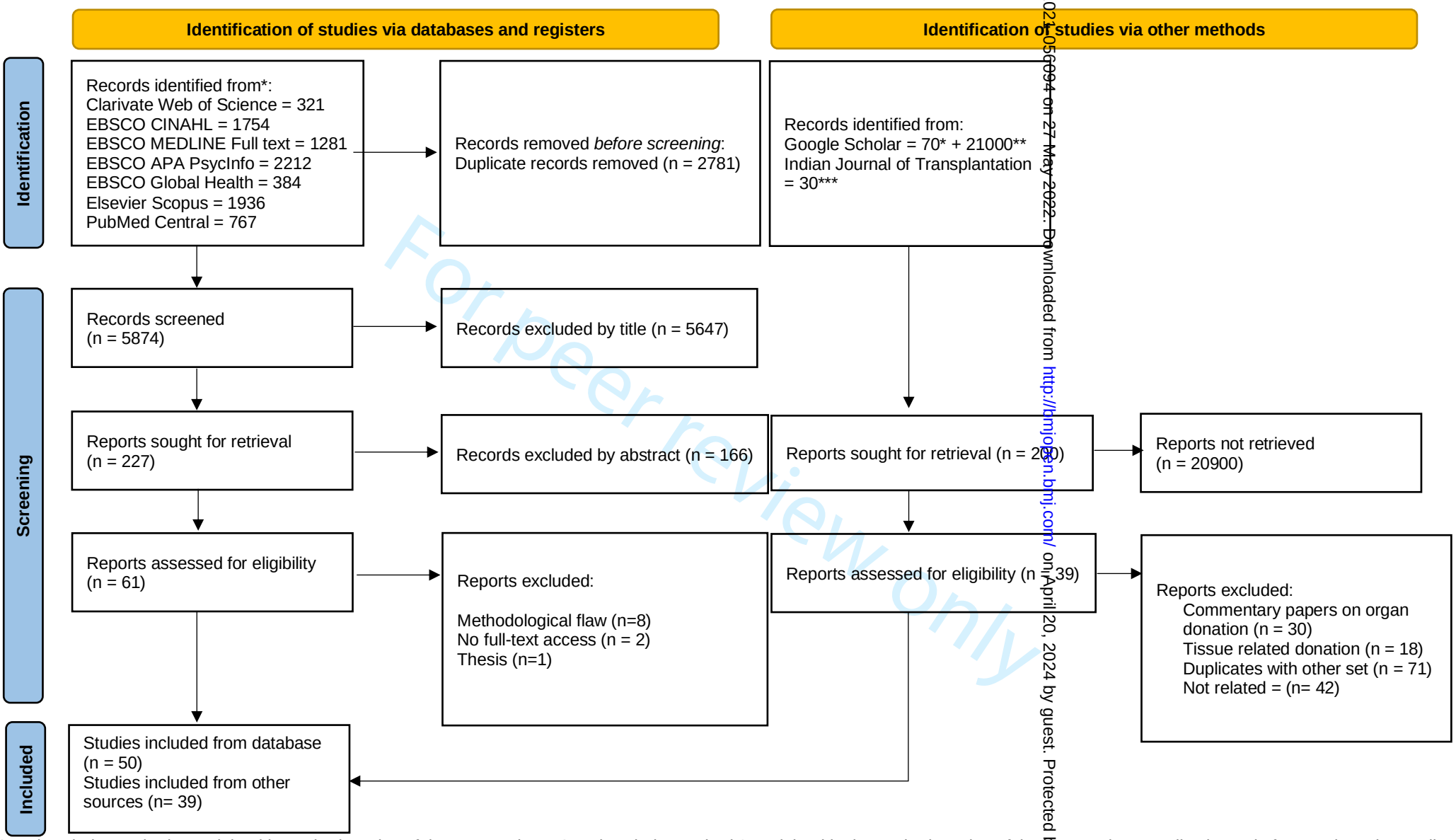
Figure legends / captions:

Figure 1: PRISMA flowchart

Figure 2: Quality appraisal checklist – Quantitative studies

Figure 3: Quality appraisal checklist – Qualitative studies



*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	×	×	✓	✓
Alex et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	×	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	×	×	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	×	×	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Bapat et al, 2010	-	✓	✓	✓	×	×	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Bathija et al,2017	-	✓	✓	✓	×	✓	✓	✓
Bharambe et al, 2015	×	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	×	×	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Darbari et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Darlington et al,2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	×	×	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	×	×	✓	✓
Flower et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Gupta et al, 2021	×	-	✓	✓	×	×	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Huern et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Jagadeesh et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Jayabharathi et al,2019	✓	✓	✓	✓	×	×	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Kaistha et al,2016	✓	✓	✓	✓	×	×	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Karim et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Khan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Li et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Loch et al, 2010	✓	✓	✓	✓	×	×	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mani, 2016	✓	✓	✓	✓	×	×	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Minz et al, 1998	×	✓	-	✓	×	×	✓	✓
Mishra et al, 2016	×	✓	×	×	×	×	×	×
Misra et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Paul et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	×	×	✓	✓
Pradeep et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Rajan, 2021	✓	✓	✓	✓	×	×	✓	✓
Rani et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Ray et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Reddy et al, 2003	✓	✓	✓	✓	×	×	✓	✓
Sachdeva, 2017	-	✓	✓	✓	×	×	✓	✓
Sam et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Singh et al, 2002	✓	✓	✓	✓	×	×	✓	✓
Soni et al, 2018	-	✓	✓	✓	×	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Tamuli et al,2019	×	✓	✓	✓	×	×	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Verma et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al,2016	✓	✓	✓	✓	×	×	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Wong et al, 2011	✓	✓	✓	✓	×	×	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	×	×	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?

✓ Mentioned
× Not mentioned
- Unclear

Ref	1	2	3	4	5	6	7	8	9	10
Vincent et al, 2019	✓	✓	✓	✓	✓	✓	×	✓	✓	✓
Kennedy, 2002	✓	✓	✓	✓	✓	×	×	×	×	✓
Gauher et al, 2013	✓	✓	✓	✓	✓	✓	×	✓	✓	✓
Misra et al, 2021	✓	✓	✓	✓	✓	×	×	×	✓	✓
Darr et al, 1999	✓	✓	✓	✓	✓	×	×	×	✓	✓
Exley et al, 1996	✓	✓	✓	✓	✓	×	×	×	✓	✓
Morgan et al, 2015	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
Wong et al, 2010a	✓	✓	✓	✓	✓	✓	×	×	✓	✓
Wong et al, 2010b	✓	✓	✓	✓	✓	✓	×	×	✓	✓
Randhawa et al, 1998	✓	✓	✓	✓	✓	✓	×	×	✓	✓

1 Is there congruity between the stated philosophical perspective and the research methodology?

2 Is there congruity between the research methodology and the research question or objective?

3 Is there congruity between the research methodology and the methods used to collect data?

4 Is there congruity between the research methodology and the representation and analysis of data?

5 Is there congruity between the research methodology and the interpretation of results?

6 Is there a statement locating the researcher culturally or theoretically?

7 Is the influence of the researcher on the research, and vice-versa, addressed?

8 Are participants, and their voices, adequately represented?

9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?

10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ×

Supplementary I: Search strategy

Database: Clarivate Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ* (4464520)
2. (ALL) Tissue* (2072420)
3. 1 OR 2
4. (ALL) Donation* (92568)
5. (ALL) Procurement* (36067)
6. (ALL) Donor* (471190)
7. (ALL) Regist* (607949)
8. (ALL) Pledge* (5168)
9. 4 OR 5 OR 6 OR 7 OR 8
10. (ALL) “Brain death” (6,922)
11. (ALL) Posthumous* (3317)
12. (ALL) Deceased* (28469)
13. 10 OR 11 OR 12 (122185)
14. (ALL) India* (2374803)
15. (ALL) Asia* (869365)
16. (ALL) “South Asia*” (34481)
17. 14 OR 15 OR 16
18. (ALL) Knowledge (1860768)
19. (ALL) Attitude* (423103)
20. (ALL) Practice* (2018451)
21. (ALL) Aware* (484659)
22. (ALL) Perception* (725428)
23. (ALL) Barrier* (711626)
24. (ALL) Challenge* (1684045)
25. (ALL) Religi* (258116)
26. (ALL) Famil* (2081795)
27. (ALL) Discuss* (4419231)
28. (ALL) Sign* (11546529)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 0R 28
30. 3 AND 9 AND 13 AND 17 AND 29 (321)

((((ALL=(Organ* OR Tissue*)) AND ALL=(Donation* OR Procurement* OR Donor* OR Regist* OR Pledge*)) AND ALL=("Brain Death" OR Posthumous* OR Deceased*)) AND ALL=(India* OR Asia* OR "South Asia*")) AND ALL=(Knowledge* OR Attitude* OR Practice* OR Aware* OR Perception* OR Barrier* OR Challenge* OR Religi* OR Famil* OR Discuss* OR Sign*)

Database: EBSCO CINAHL Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	45587	254692
2	Tissue*	35642	171599
3	1 OR 2	47408	214967
4	Donation*	5126	7255
5	Procurement	733	2440
6	Donor	10046	24599
7	Regist	28751	171623
8	Pledge	906	909
9	4 OR 5 OR 6 OR 7 OR 8	44740	200368
10	India	29146	35077
11	Asia	13516	35961
12	South Asia	1896	3440
13	10 OR 11 OR 12	42022	67778
14	Knowledge	40561	228058
15	Attitude	30320	76214
16	Practice	171844	417435
17	Aware*	16453	106579
18	Perception	47156	116209
19	Barrier	23209	93116
20	Challenge	52643	179284
21	Religi*	7106	20082
22	Famil*	28758	120172
23	Discuss*	12336	525753
24	Sign	60885	1299673
25	Brain Death	811	1176
26	Posthumous	101	157
27	Deceased	725	5381
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	460837	2330155
29	3 AND 9 AND 13 AND 28	697	1057

Database: EBSCO MEDLINE With full text Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	245699	1493730
2	Tissue*	223470	1550014
3	1 OR 2	465190	2862275
4	Donation*	11156	25326
5	Procurement	1825	8302
6	Donor*	58569	260805
7	Regist*	52468	371535
8	Pledge	591	1401
9	4 OR 5 OR 6 OR 7 OR 8	122076	641620
10	India*	79797	128377
11	Asia*	37333	145090
12	South Asia*	3406	9277
13	10 OR 11 OR 12	115447	260763
14	Knowledge	62353	725944
15	Attitude*	44690	132711
16	Practice*	192866	758688
17	Aware*	23266	233256
18	Perception*	73637	238754
19	Barrier*	56399	301446
20	Challenge*	107816	654171
21	Religi*	8586	32213
22	Famil*	62713	341944
23	Discuss*	19872	1196575
24	Sign*	402535	6834667
25	Brain Death	2322	4478
26	Posthumous	201	475
27	Deceased	2643	20262
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	1012657	9432506
29	3 AND 9 AND 13 AND 28	61	1220

Database: EBSCO APA PsycInfo < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	52775	314055
2	Tissue*	2650	33891
3	1 OR 2	55359	344532
4	Donation*	1328	3862
5	Procurement	260	1126
6	Donor*	1103	6196
7	Regist*	4746	41654
8	Pledge	65	479
9	4 OR 5 OR 6 OR 7 OR 8	7304	51337
10	India*	12921	26606
11	Asia*	9722	31810
12	South Asia*	1130	2606
13	10 OR 11 OR 12	22183	55698
14	Knowledge	37077	273907
15	Attitude*	40138	146530
16	Practice*	77921	427695
17	Aware*	12620	117029
18	Perception*	74077	238811
19	Barrier*	12054	74349
20	Challenge*	24193	208260
21	Religi*	18072	57819
22	Famil*	31536	174669
23	Discuss*	7449	675256
24	Sign*	32524	1050671
25	Brain Death	192	383
26	Posthumous	55	451
27	Deceased	211	3514
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	345985	2324405
29	3 AND 9 AND 13 AND 28	1049	1163

Database: EBSCO Global Health < January 1994 to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	34990	281202
2	Tissue*	24264	166199
3	1 OR 2	58782	426568
4	Donation*	851	4044
5	Procurement	276	2063
6	Donor*	5877	26460
7	Regist*	6306	654425
8	Pledge	39	298
9	4 OR 5 OR 6 OR 7 OR 8	13197	94877
10	India*	42961	84021
11	Asia*	11593	56374
12	South Asia*	1307	4386
13	10 OR 11 OR 12	53980	134135
14	Knowledge	21618	146105
15	Attitude*	14175	40544
16	Practice*	32467	149036
17	Aware*	6261	61511
18	Perception*	15315	46000
19	Barrier*	10039	55500
20	Challenge*	18770	113171
21	Religi*	1303	9881
22	Famil*	6241	56096
23	Discuss*	2171	225453
24	Sign*	34744	179950
25	Brain Death	41	179
26	Posthumous	4	29
27	Deceased	238	2971
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	144587	1664816
29	3 AND 9 AND 13 AND 28	5	379

Database: Elsevier Scopus PUBYEAR > 1993 AND PUBYEAR <2022

Search strategy

No.	Terms	Title-Abstract-Keywords
1	Organ*	757636
2	Tissue*	3956065
3	1 OR 2	8523116
4	Donation*	49781
5	Procurement	57632
6	Donor*	465751
7	Regist*	690378
8	Pledge	6915
9	4 OR 5 OR 6 OR 7 OR 8	1214290
10	India*	630668
11	Asia*	614524
12	South Asia*	47204
13	10 OR 11 OR 12	1178235
14	Knowledge	2199485
15	Attitude*	834803
16	Practice*	2961509
17	Aware*	663440
18	Perception*	885170
19	Barrier*	765952
20	Challenge*	2076205
21	Religi*	274948
22	Famil*	776708
23	Discuss*	5121400
24	Sign*	14005232
25	Brain Death	11526
26	Posthumous	7120
27	Deceased	30117
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	24234423
29	3 AND 9 AND 13 AND 28	1936

Database: PubMed Central < 1994 January to December 2021>

Search strategy

Search: ((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract] OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract] OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 4-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 5-6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2 & 3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	24-27
	23b	Discuss any limitations of the evidence included in the review.	26-27
	23c	Discuss any limitations of the review processes used.	26-27
	23d	Discuss implications of the results for practice, policy, and future research.	24-27
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary file 1.

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
other materials			

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

BMJ Open

Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-056094.R3
Article Type:	Original research
Date Submitted by the Author:	27-Apr-2022
Complete List of Authors:	Vincent, Britzer Paul; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Randhawa, Gurch; University of Bedfordshire Faculty of Health and Social Sciences, Institute for Health Research Cook, Erica; University of Bedfordshire - Luton Campus, Department of Psychology
Primary Subject Heading:	Health policy
Secondary Subject Heading:	Health services research
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, ETHICS (see Medical Ethics), TRANSPLANT MEDICINE

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Title Page

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

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Funding sources: This systematic review is part of a PhD studentship funded by the Global Challenge Research Fund to the principal investigator Britzer Paul Vincent, a PhD scholar at the Institute for Health Research, University of Bedfordshire, UK.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

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Running title:
Barriers to Deceased Organ Donation among Indians globally: An Integrative Systematic Review

Abbreviations:
APA – American Psychological Association
EBSCO – Elton B Stephens Company

JBI - Joanna Briggs Institute's
NCD – Non-Communicable Disease
NIH – National Institute of Health
NLM – National Library of Medicine
ODR – Organ Donation Rate
pmp – per million population

Conflict of Interest:
None declared.

Word count
Abstract: 308
Manuscript: 4,404

Title: Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis.

Abstract

Objectives: To understand the barriers toward deceased organ donation among Indians living globally.

Design: Integrative systematic review using narrative synthesis

Data sources: CINAHL, MEDLINE Full-Text, PsycInfo, Scopus, Global Health, Web of Science, and PubMed Central, Indian Journal of Transplantation and Google scholar.

Time period: 1st January 1994 to 31st December 2021

Participants: Individuals of Indian origin living globally

Results: Eighty-nine studies were included with more than 29,000 participants and quality of the studies were assessed using Joanna Briggs Institute's critical appraisal tool. Though majority of the participants had knowledge toward organ donation with a positive influence on willingness, the gap between knowledge and willingness was huge, with minimal registration influenced by the complex socio-cultural constructs. Various socio-cultural constructs such as family, fear and mistrust, religion, and bodily issues play a vital role. Differences were identified in willingness to donate and register between southern and other regions of India. Indian's organ donation behaviour in other geographical locations differed based on the socio-religious background of the country they lived in such as in Malaysia, Canada, and the UK. However, they were collective in decision-making and had complex socio-cultural interference irrespective of the country the individual lived which differed only in their next generations.

Conclusion: Though this study showed the complex relationship, and its influences on organ donation behaviour, lacunae were identified to further understand how such complex interactions determine or inform the behaviour. Also, methodological issues were identified, where this particular population outside India were collectively studied with their neighbouring

population which are not homogenous. Studies in India majorly addressed a similar aim using similar methods which produced repetition of studies leading to lack of diversified, wider, and in-depth research. Therefore, while this systematic review addressed the barriers toward organ donation among Indians living globally, it also informs various gaps in research and also methodological issues.

PROSPERO registration number: CRD42019155274

Keywords: Organ donation, India, UK, Integrative systematic review; Narrative synthesis, Registration

Strengths and Limitations:

1. This is the first systematic review on the barriers toward deceased organ donation among Indians living globally, registered with PROSPERO, and published.
2. Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
3. Included studies exclusively represented the Indian population and studies that collectively studied Indians with heterogenous South Asian, or Asian population were excluded, thereby keeping the rigour of this study, and identifying methodological issues involved.
4. Findings are based on the quality of each studies appraised using appropriate tools, and the assessment is also made available to the view of the readers.
5. Studies were limited only to English language, and commentaries were excluded.

Main text

Introduction

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth [1]. However, the gap between demand and supply of organs has represented a significant challenge [2], particularly among the Asian population who live both within and outside their continent [3-5]. India located in the South of Asia is the second largest populated country in the world [6] having largest migrating population in Asia [7], and also has the highest prevalence of diabetes and hypertension [8]. Such non-communicable diseases (NCD) among Indians [9, 10] leading them to end-stage organ failure [11, 12] increases their need for organs.

Whilst the need for organ donors is high among the Indian population, the actual number of donors remain too low to satisfy the number of recipients on the waiting list [13], with the Indian national organ donation rate (ODR) less than one per million population (pmp) [14]. Reluctance to donate organs among this ethnic population might not be isolated just within Indian border [15], with evidence suggesting that Indian population from the United Kingdom is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but under-represented in the donor list [16]. This behaviour is again identified in Canada [17]. Therefore, globally, Indian population has demonstrated lower organ donor registration and consent both within and outside the border.

There have been a larger number of studies conducted among the Indian population living globally to understand the factors that influence their organ donation behaviour. However, to date, there has been no systematic review conducted to synthesize the available evidence to understand the barriers toward organ donation among the individuals of Indian origin. Therefore, a systematic review was proposed with an aim to address this gap to gain a deeper

insight into the barriers toward deceased organ donation behaviour among this particular population living globally [18].

Method

Protocol and registration

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published [18].

Systematic search

Search strategy was developed collaboratively with the research team and a subject specialist librarian. Databases namely CINAHL, MEDLINE Full-Text, APA PsycInfo, and Global Health were accessed through EBSCO platform, Clarivate for Web of Science, Elsevier for Scopus, and US National Library of Medicine – National Institute of Health for PubMed Central were utilised. Key terms related to organ donation were first identified from studies published along with search terms used in other systematic review on organ donation [19,20] and were tested in different combinations. Later, for each database, the search terms were then customised seeking to capture the most appropriate studies to answer the aim of this review (supplementary file 1) [21]. However, for other resources like google scholar and the Indian journal of transplantation other strategies were employed. All the published papers from 1st of January 1994 to 31st of December 2021 were searched from the archives of the Indian journal of transplantation to identify relevant studies. With regard to google scholar, we searched using two methods. The first method used the word "Organ Donation AND India" in title; and the second method used the same keywords but searched anywhere in the article. However, due to very high number of search results in the second method, we limited the search until we found no further relevant studies (an approach used by other published systematic reviews) [22].

The systematic review included studies with individuals of Indian origin living both within and outside India (i.e., migrant / first / second generation), aged 18 years and above from varied settings [18]. Cross-sectional and qualitative study design were included as they were mostly employed to understand the barriers toward deceased organ donation. For all the databases, search strategy was restricted between 1st of January 1994 (i.e., the year when the first law toward organ donation was implemented in India) and 31st of December 2021 (i.e., a recent day before the submission) and was restricted only to studies published in English. However, interventional studies, commentary or opinion papers, studies on blood, bone marrow, body, sperm, and egg donation were excluded alongside any studies which addressed only living donation.

Search outcome

Following a stage-by-stage exclusion from 8,655 studies initially extracted from the main databases, 50 studies were included in final review along with 39 studies included from other sources (Figure 1). The studies were initially exported to RefWorks (https://refworks.prorequest.com/). Microsoft excel was used to keep a record of studies excluded by duplicates, title, abstract, and full text. All the 8,655 studies along with studies from other sources were screened by two authors independently and the final 89 studies included were in-agreement with all the authors.

However, during the process, studies conducted among Indians living outside India were identified to be collectively studied as South Asians or with other Asian population. For instance, a study conducted among Indo-Canadians in Canada included all neighbouring ethnic groups of India [23]. Also, in other countries like the UK and Malaysia, Indian population was collectively studied along with other ethnic groups and the results were not distinctively shown [24-26], therefore eight studies had to be excluded due to these methodological limitations. The

perspective of deceased organ donation varies even within India's nearest neighbouring country [4, 27]. Therefore, this review included only the studies which exclusively reported the findings among Indian population.

Quality assessment

Appropriate critical appraisal tools from Joanna Briggs Institute (JBI) were used to critique the rigour of each studies included [28], also used in other organ donation systematic review [19,29]. Comprehensive reporting on the quality assessment for both cross-sectional and qualitative studies, are reported in figure 2 and 3. Quality assessment was initially carried out by the primary researcher after which it was reviewed by the other two authors independently. Both the authors along with the primary researcher agreed upon the quality assessment as mentioned in figure 2 and 3. The review included all studies; however minimal emphasis was given for those studies that demonstrated only fewer items in the quality assessment checklist.

Data synthesis

This systematic review followed an integrative review with narrative synthesis approach enabling to synthesise complex information toward the phenomena of interest [30], a methodology also employed in another systematic review on organ donation that reviewed both quantitative and qualitative studies [20]. Narrative synthesis primarily depends on words and texts to summarise the findings with four process elements such as 1) systematic search and quality appraisal, 2) grouping and clustering of the studies reviewed, 3) text summary development, and 4) assessment and interpretation [31].

Firstly, following the systematic search and quality appraisal, summary data was collected for each study, and they were recorded across a table which had information needed to cluster the studies to compare and study across (Table 1). Secondly, with the cross-sectional studies, numerical results from each study were tabulated across a matrix and were compared across to

study their relationship in terms of barriers. Later, full synthesis of the qualitative studies was undertaken by coding the findings sections using NVivo11. Codes were then organised into themes to address the barriers appropriately.

While comparing and studying across the studies included in the review to understand their relationship, various elements such as what the study is about, type of study, their approach, the findings, study settings, and population studied were also considered. Noblit and Hare (1988) described this as 'Reciprocal translation', also used in other similar methodological approaches [32-36]. Thirdly, full syntheses of both cross-sectional and qualitative studies were studied across to understand the supporting and refuting evidence collectively. For each section of the findings, quantitative studies provided the initial context following which findings from qualitative studies were used to elaborate and explain. With limited qualitative study narratives to support or refute the cross-sectional study findings, they were incorporated into the integration of the findings wherever possible. Both convergent and divergent findings are explained in this review, whereby if divergent findings were identified explanatory factors such as type of study or setting, or population were provided to facilitate better understanding [20].

Table 1: Evidence table

Author (s) (Year)	Study Site	Study Country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan et al, (2017)	Kerala	India	To assess the knowledge and attitude of medical students regarding organ donation	Final year Undergraduate Medical students	Cross-sectional	194	Not specified
Ahlawat et al, (2013)	Chandigarh	India	To assess the attitude of healthcare professionals employed in intensive or emergency care units of our hospital towards organ donation, and the influence of various factors on willingness for self-organ donation after death	Health workers in intensive units	Cross-sectional	361	Not specified
Alex et al, (2017)	Karnataka	India	To assess the knowledge and attitude regarding organ donation and transplantation among the medical students	Medical college	Cross-sectional	510	Convenient sampling
Alex et al, (2019)	Pan India	India	To assess the general public's knowledge and attitude towards organ donation over two decades	General public	Cross-sectional	3914	Not specified
Amaliyar et al, (2019)	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last 4 semester groups from medical, arts and commerce college	Cross-sectional	300	Purposive sampling for centres; Random for participants
Balajee et al, (2016)	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from 4 villages	General public	Cross-sectional	360	Systematic random sampling and random participant selection
Balwani et al, (2015)	Gujarat	India	To study the awareness and belief towards organ donation and its allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross-sectional	85	Not specified
Balwani et al, (2015)	Gujarat	India	To determine the knowledge, attitude, and practice regarding organ donation in western India	Adult participants from a residential area around a tertiary healthcare centre	Cross-sectional	200	Random sampling
Bansal et al, (2019)	Chandigarh	India	To analyse socio-demographic profile of the decision makers for organ donation in	Tertiary care teaching hospital	Cross-sectional	59	Purposive sampling

			potential deceased donors//To determine the level of awareness regarding organ donation in decision makers and the correlation with the socio-demographic variables	among family members who consented to donate the organs of their loved ones			
Bapat et al (2010)	Karnataka	India	To understand the awareness, attitudes, and belief towards organ donation among post-graduate medical students	Post-graduate medical students	Cross-sectional	123	Volunteer sampling
Basavarajegowda et al (2021)	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared to non-blood donors	General public	Cross-sectional	803	Purposive sampling
Bathija et al, (2017)	Karnataka	India	To investigate the knowledge and attitude towards organ donation among post-graduates, and interns; to know the reasons for donation one's organs	Post-graduate and medical interns	Cross-sectional	300	Not specified
Bharambe et al, (2015)	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Out-patient department	Cross-sectional	65	Not specified
Bharambe et al, (2016)	Maharashtra	India	To study the knowledge and attitude of a medical student doing internship with regards to organ donation	Medical college internship students	Cross-sectional	43	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of healthcare professionals from a rural part of India regarding organ donation	Healthcare professionals attending a medical association meeting	Cross-sectional	32	Not specified
Bharambe et al, (2018)	Maharashtra	India	To assess the knowledge and attitude of people from a rural part of India regarding organ donation.	Rural community members	Cross-sectional	201	Not specified
Bhargavi et al, (2019)	Kerala	India	To check the level of awareness and attitude of 2nd year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and whole-body donation using a questionnaire-based study.	Medical and nursing students	Cross-sectional	177	Convenience sampling
Chakradhar et al, (2016)	Telangana	India	To assess and compare the knowledge, attitude, and practice regarding organ	Dental college Undergraduate students	Cross-sectional	298	Not specified

			donation among dental students based on gender, year of study and religion				
Da Silva et al (2021)	West Bengal	India	To assess the knowledge, attitude, and practices of health-care professionals toward cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross-sectional	400	Stratified random sampling
Darbari et al (2020)	Uttarakhand	India	To assess the knowledge on organ donation among undergraduate medical students	Undergraduate medical students	Cross-sectional	197	Not specified
Darlington et al, (2019)	Tamil Nadu	India	To study the knowledge, attitude, and practice towards organ donation	Medical students	Cross-sectional	425	Voluntary
Darr et al (1999)	Luton	England	To assess the attitudes on organ donation and transplantation among south Asians	South Asian general public	Qualitative	64	Purposive sampling
Dasgupta et al, (2014)	West Bengal	India	To ascertain the knowledge and attitude of the people regarding organ donation and to elicit the determinants of their knowledge and attitude in an urban community of west Bengal	Slum area residents	Cross-sectional	110	Simple random sampling
Deshpande et al, (2018)	Maharashtra and Madhya Pradesh	India	To determine the knowledge, attitude, and practice of pharmacy students about organ donation	Pharmacy college	Cross-sectional	160	Not specified
Exley et al (1996)	Coventry	England	To examine the religious, cultural, and social context of organ donation	Sikh Asian community members	Qualitative	22	Judgemental sampling
Flower et al (2013)	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross-sectional	400	Random sampling
Gauher et al, (2013)	London	The United Kingdom	To determine the attitude towards organ donation among Indian and Pakistan students	Medical and Non-Medical students	Qualitative	58	Purposive sampling - Stratified sampling for groups
Ghose et al (2021)	Pune	India	To study knowledge and attitude toward organ donation among medical and nursing students with objectives to determine level of awareness about death criteria and need for organ donation and also to determine the attitude towards the same	Medical and nursing students	Cross-sectional	400	Population proportion to size

Gupta et al, (2018)	Jammu & Kashmir	India	To assess the awareness and attitude of medical students regrading organ donation	Medical college Undergraduate students	Cross-sectional	280	Not specified
Gupta et al, (2021)	Maharashtra	India	To assess the pre-existing understanding beliefs, perception, and attitude, about deceased organ donation	College teachers and Students	Cross-sectional	80	Purposive sampling
Hakeem et al (2021)	Tamil Nadu	India	To assess knowledge, attitude, and perception of organ donation and transplant	Medical students and junior doctors	Cross-sectional	996	Not specified
Huern et al (2016)	Melaka	Malaysia	To assess the knowledge, attitude, and perception to determine the relationship between various sociodemographic data on knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	72	Not specified
Jagadeesh et al (2018)	Karnataka	India	To assess the knowledge, attitude, and beliefs toward organ donation and factors affecting willingness to donate	Professional drivers	Cross-sectional	300	convenient sampling
Jayabharathi et al, (2019)	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross-sectional	60	convenient sampling
Joshi et al, (2011)	The United Kingdom	The United Kingdom	To investigate the organ donor attitudes and donor card behaviour of young adult UK citizens with particular focus on those of South Asian origin	Higher education institutes in the UK	Cross-sectional	382	Purposive sampling
Jothula et al, (2018)	Telangana	India	To assess the knowledge, attitude, and practice towards organ donation among medical students	Medical college Undergraduate students	Cross-sectional	160	Not specified
Kachappillil et al (2020)	Kerala	India	To assess the attitude of general population towards organ donation residing in a rural community	General public	Cross-sectional	100	Convenient sampling
Kadam et al (2021)	Maharashtra	India	To study the knowledge and attitude of first-year medical students towards organ donation.	First year medical students	Cross-sectional	130	Not specified
Kaistha et al, (2016)	New Delhi	India	To determine the knowledge, attitude, and practice regarding organ donation	Patient attendants attending out-patient department	Cross-sectional	119	Convenience
Kalmath et al (2020)	Karnataka	India	To assess the level of knowledge, preparedness, and commitment towards organ donation.	Youth public	Cross-sectional	300	Probability stratified random sampling

Karim et al (2013)	The United Kingdom	The United Kingdom	To explore the south Asians attitudes toward organ donation	South Asian general public	Cross-sectional	147	Not specified
Kaur et al (2021)	Punjab	India	To know the knowledge, attitude, and practices regarding organ donation among medical students of Punjab	Medical students	Cross-sectional	380	Not specified
Kennedy et al, (2002)	Kerala	India	To study the attitudes and beliefs about organ donation in India from the perspectives of the doctors and the public	Doctors and public	Qualitative	8	Purposive
Khan et al (2020)	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation amongst the students	Student population	Cross-sectional	200	Not specified
Kundu et al (2021)	Chhattisgarh	India	To investigate the willingness to become an organ donor and the religious and cultural attitude of healthcare professionals	Medical and paramedical students	Cross-sectional	630	Not specified
Li et al (2016)	Ontario	Canada	To determine the registration status from deceased organ donation and tissue donation	Migrant population	Cross-sectional	NA*	Not specified
Loch et al (2010)	Kula Lumpur	Malaysia	To examine the knowledge, attitude, and perception toward organ donation	General public	Cross-sectional	272	Not specified
Lokesh Kumar et al (2021)	Tamil Nadu	India	To determine the awareness of organ donation concerning organ donation amidst the rural population and to assess the attitude towards the organ donation	Rural public	Cross-sectional	203	Two stages random sampling
Mani, (2016)	Tamil Nadu	India	To identify the perceptions and practices related to organ donation in a rural population of Tamil Nadu, India	Rural population	Cross-sectional	100	Simple random sampling
Meghana et al, (2018)	Karnataka	India	To assess the knowledge of organ donation among the final year medical, dental, and nursing students and to study the attitude, religious beliefs of the healthcare professionals regarding organ donation and transplantation, to find out the effect of motivation, towards organ donation	Medical, dental, nursing students	Cross-sectional	150	Not specified
Minz et al, (1998)	Chandigarh	India	To find out the extent of awareness and attitudes, to help us formulate a further plan of action	Healthcare professionals	Cross-sectional	204	Not specified

Mishra et al (2016)	Odisha	India	To evaluate the awareness of organ donation	College students	Cross-sectional	430	Not specified
Misra et al (2021)	Haryana	India	To understand the beliefs and knowledge of a rural community toward organ donation and the identification of barriers for organ donation	Rural public	Qualitative	48	Simple random sampling
Misra et al (2021)	Haryana	India	To assess awareness about brain death and attitude towards organ donation in a rural community setting.	Rural public	Cross-sectional	947	Simple random sampling
Mithra et al, (2013)	Karnataka	India	To assess the perceptions and attitudes of the people seeking health care in tertiary care centres towards organ donation in Mangalore, India.	People seeking general healthcare as outpatients	Cross-sectional	863	Simple Random Sampling and convenient sampling
Mohan et al, (2019)	Tamil Nadu	India	To establish the role of perceived awareness, family support, perceived individual value, and religiosity on organ donation intention	Public	Cross-sectional	247	Convenience sampling
Mondal et al (2016)	West Bengal	India	To assess the knowledge and attitude of people towards organ donation in a rural community of West Bengal and to study the association of socio-demographic factors with the knowledge and attitude towards organ donation	Rural community	Cross-sectional	110	Simple random sampling
Morgan et al (2015)	London	England	Identify ways in which minority ethnic group habitus appears to limit attitude and knowledge of the system of organ donation and shape attitude toward registration	South Asian minority ethnic general public	Qualitative	79	Not specified
Panwar et al (2016)	New Delhi	India	To assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation	General public	Cross-sectional	352	Not specified
Parmar et al (2017)	Gujarat	India	To assess perception of undergraduate students toward organ donation	Undergraduate students	Cross-sectional	100	Randomisation
Parmar et al (2021)	Gujarat	India	To assess the awareness among subjects regarding body donation and cadaveric dissection and their willingness to donate body	Patients	Cross-sectional	130	Not specified

Paul et al, (2019)	West Bengal	India	To understand the knowledge, attitude, and practice pattern of organ donation among the participants and to find out the association between the knowledge of organ donation with selected variables of interest	Urban field practice area of medical college	Cross-sectional	206	Not specified
Poreddi et al (2016)	Karnataka	India	To assess Indian undergraduate nursing students' attitude, knowledge, and willingness to donate organs	Nursing students	Cross-sectional	267	Non-probability convenience sampling
Poreddi et al, (2017)	Karnataka	India	To assess the knowledge, attitude, and willingness to donate organs among the general population	Patients attending outpatient department	Cross-sectional	193	Lottery method
Pradeep et al (2019)	Nort west of England	England	To explore the attitudes and beliefs toward organ donation	General public	Cross-sectional	593	Convenience sampling
Rajan (2020)	West Bengal	India	To assess the knowledge and attitude regarding blood and organ donation among adolescents	Adolescent population	Cross-sectional	100	Non-probability purposive sampling
Randhawa et al (1998)	Luton	England	To examine the influence of religious beliefs, amongst other things, on the extent and directions of public attitudes toward organ donation	South Asian general public	Qualitative	64	Focused sampling
Rani et al (2020)	New Delhi	India	To assess the knowledge ad attitude of general population towards organ donation	General public	Cross-sectional	1089	Purposive non-probability sampling
Ray et al (2020)	West Bengal	India	To assess the knowledge and attitude of certain populations like medical students with respect to organ donation	Medical students	Cross-sectional	134	Random sampling
Reddy et al (2003)	New Delhi	India	To assess the awareness and the attitude of Indian patients, the public, doctors, and nurses toward organ donation	Public, doctors, and nurses	Cross-sectional	990	Randomisation
Sachdeva et al, (2017)	Delhi	India	To assess knowledge, attitude, and practice regarding organ donation / tissue donation among adult visitors of a government hospital in Delhi, India	patient or accompanying attendant of a government hospital	Cross-sectional	450	Convenience sampling
Sam et al, (2018)	Tamil Nadu	India	To assess the awareness and attitude regarding Organ Donation among final year students of medical, dental, engineering,	Medical, dental, engineering, and arts and science students	Cross-sectional	486	Not specified

			and arts and science students in Thirivallur and Chennai				
Sarveswaran et al, (2018)	Puducherry	India	To determine the knowledge, attitude, and practice regarding organ donation	Urban community members	Cross-sectional	257	Random
Seetharaman et al (2020)	Maharashtra	India	To evaluate the knowledge, attitudes, and beliefs of licensed medical doctors and undergraduate medical students	Medical doctors and students	Cross-sectional	532	Non-probability convenient sampling
Singh et al, (2002)	Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, brain death, and organ donation, as well as factors that may be associated with this awareness	Hospital staffs	Cross-sectional	266	Simple Random Sampling
Soni et al, (2018)	Madhya Pradesh	India	To understand correlation between knowledge and attitude towards organ donation among medical and non-medical students and identify barriers to deceased organ donation; to look into participants perception for adoption of presumed consent policy in Indian context; and understanding the acceptance of donor acknowledgement in the form of organ incentivization	Medical and Engineering students	Cross-sectional	600	Random
Swamy et al (2020)	Karnataka	India	To assess the awareness and attitude of the young graduates in medical and engineering streams	Medical and Engineering students	Cross-sectional	400	Not specified
Swani et al (2020)	Uttarakhand	India	To know the awareness, perceived threat and factors affecting the willingness to donate organs	first-and second-degree relatives of deceased	Cross-sectional	166	Complete sampling
Tamuli et al, (2019)	Assam	India	To determine awareness and knowledge of educated (Undergraduate and postgraduate students) population towards organ donation; To find out factors impeding the organ donation program in this part of the country; To observe differences between findings of Undergraduate students and postgraduate degree holders (faculty)	Undergraduate and postgraduate students	Cross-sectional	360	Not specified
Thyagarajan et al (2020)	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice toward it.	Police officers	Cross-sectional	627	Purposive sampling

Verma et al (2020)		India	To assess knowledge, attitude, and perception toward organ donation	Undergraduate medical students	Cross-sectional	1463	Stratified sampling
Vijayalakshmi et al, (2015)	Karnataka	India	To investigate nurses' attitude towards organ donation	Nurses directly involved in patient care at a tertiary care hospital in South India	Cross-sectional	184	Non-probability convenience
Vijayalakshmi et al, (2016)	Karnataka	India	To assess the gender differences in perceptions and attitude of general population toward organ donation	Relatives of patients attending the outpatient department	Cross-sectional	193	Lottery method
Vincent et al (2019a)	Pondicherry	India	To understand the subjective views on barriers in the process of deceased organ donation among the stakeholders and their suggestions to improve in a government tertiary care teaching hospital	Transplant unit stakeholders	Qualitative	6	Purposive sampling
Vincent et al (2019b)	Pondicherry	India	To assess the knowledge, attitude, and perception on organ donation among undergraduate medical and nursing students	Under-graduate medical and nursing students	Cross-sectional	620	Convenient sampling for population and voluntary for participants
Wong et al (2010a)	Klang Valley	Malaysia	To understand the cultural and religious factors limiting organ donation in three ethnic group	Ethnic population	Qualitative	22	NA
Wong et al (2010b)	Klang Valley	Malaysia	To assess public knowledge and attitude with regard to deceased organ donation	General public	Qualitative	22	NA
Wong et al (2011)	Selangor	Malaysia	To explore the knowledge, attitude, perception, and barriers toward deceased organ donation	General public	Cross-sectional	259	NA
Yadav et al (2020)	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross-sectional	170	Not specified

* This study was based on the population data; the findings were based on national Indian population which was 228,879. Since it could over-represent the actual studies, this study sample size is not mentioned in the evidence table but in the notes here.

Findings

Grouping and clustering

Among the 89 studies reviewed; majority (84%) were conducted among Indians living in India (n=75) while other fourteen studies were among people of Indian origin living in the UK (n=8), Malaysia (n=5), and Canada (n=1). Cross-sectional studies (n=79) included various settings such as general community, education institutions and hospital setting (Table 1). Qualitative studies (n=10) used methods like in-depth interviews and focus group discussion (Table 1). Among the 29,385 individuals involved in the retained studies, 27,503 individuals (94%) were from studies conducted in India. Among the studies conducted in the UK, there were 1,235 individuals in total, however, one study had no evidence on the sample number of Indian participants involved [27], and the Malaysian studies had 647 individuals in total. The study participants from the Canadian study were not included since they were information taken from national registry which had around 228,879 Indian individuals [17].

Findings

Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely: 1) knowledge and awareness toward deceased organ donation, 2) willingness and actual behaviour toward deceased organ donation, 3) familial influence, 4) fear and mistrust, 5) religious influences, and 6) bodily issues.

Knowledge and awareness of deceased organ donation

Being the commonest theme studied across, findings showed that knowledge had a positive corelation with willingness and practice [37-44]. Both among Indians living in India and outside, younger adults, participants from higher socio-economic status, and with higher

education or healthcare education demonstrated higher knowledge toward deceased organ donation [43-60] and individuals from southern region of India showed higher knowledge compared to other regions in India [61-66].

Whilst majority of the studies confirmed that almost all the participants had heard about organ donation and had higher awareness, knew what organs can be donated [4,39,44,53-55,67-85] and that organs can be donated to anyone [46,61,80], the knowledge and understanding on brain death was less well understood [49,64,68,69,75,86-89]. A qualitative study from an urban area in the southern region of India also found brain death as a new concept for many and hard to accept among the public [90]. Also, many were not aware about the organ donor card [67,83,88,91-94], where and how to register and obtain an organ donor card [40,50,53,55,56,70,71,94,95] - an important component for organ donor registration. In addition, knowledge on the law that governs organ donation was also found to be low [40,71,92,96,97]. Though a study among Indians living in UK showed that disinterest, emotional distaste, family opposition and religion to be the underlying cause for reluctance to register [58], among Indians living in India, the awareness on brain death, organ donor card, where and how to register were reported as important factors along with family and religion among individuals who were willing to register [40,49,50,53,55,64,67,69-72,86,91-96,98].

Willingness and actual behaviour toward deceased organ donation

Greater knowledge showed positive influence on the attitude and willingness across all Indian regions [17,41,43,44,50,92,99-103]. Similar to higher knowledge among individuals from southern region of India, willingness to register, to donate and to accept organs for transplant was also shown to be higher [38,45,46,49,66,68,92,99,101]. However, though knowledge had a positive association toward attitude and willingness, the proportion of individuals willing to register, and actual registration was very low and similar across every study included.

Correspondingly, even a study conducted among Indian students living in UK revealed that 55% of the individuals doubted if they would go ahead with registration [58]. With such reluctance, Indians living in India, UK, and Malaysia considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [44,68,75,79,94,95,97,100,104,105,106,107]. On contrary, commonest reasons to donate an organ was to save someone's life, closely followed by prolong someone's life, social commitment, altruistic deed, and to keep at-least the organs alive [72,75,91,99,104-111].

Higher proportion of participants were willing to receive compared to donating [38,45,46,58,68,99,101,112-114] among Indians living globally. Furthermore, studies revealed that among those who were willing to donate, majority were only willing to donate specific organs namely eye / cornea and kidneys [46,61,62], which may be related to the knowledge on what organs can be donated [67-72,76-78,86]. Nonetheless, majority of the participants were willing to support and promote organ donation in their region and was similar across India [55,57,91,99,109,110].

Younger adults, participants from higher socio-economic status and participants with higher education or healthcare education demonstrated higher willingness toward deceased organ donation among Indians living globally [17,27,43,45,47,48,53,58-61,108]. However, this was not consistent during the time of actual behaviour. Studies showed that there was almost equal distribution of participants from lower socio-economic status and lower education, who gave consent and actually signed for deceased organ donation [47,96]. However, this conclusion is based only from few studies which showed to be similar in north and south of India [47,96].

Familial influence

In-spite of willingness to register for organ donation, larger proportion of individuals have not initiated a conversation or discussed their willingness with their family members, an important

behaviour for a successful donation [52,65,68,71,82,93,100,115,116] - however opted family as the major barriers toward organ donation [46,63,65,69,72,94,100,102], this was identified even among Indians living outside India [27,117]. Qualitative studies conducted in India, the UK and Malaysia revealed the main reasons was their lack of confidence in initiating conversations around sudden deaths, and with these conversations perceived unwelcomed by their parents and elders [4,27,90,95].

However, other few qualitative studies conducted among Indians who were born and grew in another country (i.e., UK and Canada) revealed that they are less concerned of sharing their views compared to their older generations (i.e., mostly migrant generation) and were more willing to discuss their wishes with their families [17,27,81,118], which could be related to acculturation. On the other side, qualitative studies conducted in southern India and the UK suggested that such conversation only occurred when individuals read or viewed such events [90,119]. Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process [96], making such discussion very important during the crucial decision-making moments.

Willingness to support family members was shown to be higher among healthcare students compared to other students [55,56,100,120] and lower among family members from rural areas [99,116]. However, while higher proportion of individuals were willing to support family members for organ donation [38,44,61,71,88,92,101,118], only very few families actually supported this decision when families were approached for consent [90].

Though studies included found no association based on marital status [38,45,101], one study found that unmarried individuals appeared to be more willing to donate compared to married couples [101]. Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared to those unaware of their spouse's opinion [45]. Among the

type of family, individuals from 'joint' families had higher knowledge, while willingness to donate was found to be higher among nuclear families and also was identified to be highly influenced by the family [4,17,38,48,50]. This was a similarity identified in India, Canada, and the UK, showing it to be a collectivist decision making, where involvement of the extended family is identified to be a part of decision making among this population irrespective of the country they live [4,17,38,48,53,117]. And involvement of extended family was identified to be a barrier among Indians in the UK, in this process [4].

Fear and Mistrust

Fear on misuse of organs by the healthcare team, and lack of trust was the other major barrier reported [55,63,64,68,69,71,72,78,83,89,94,97,104,105]. Participants from several studies relate organ donation to organ trafficking and misuse which leads them to fear and mistrust [49,58,65,99,105]. A qualitative study also revealed increased ambivalence that while on one side participants perceived organ donation as a noble act, on the other side they were also fearful of organ misuse due to the information that they hear through news and media on organ trafficking and exchange of money for organs [90].

Also similar in the UK, among Indian participants, a mother was afraid to see an organ donor card in her child's wallet as she was thinking if doctors will come to see it, then they may deviate the process toward donation and give less care toward saving her child [27]. In parallel, general population from India also feared pre-mature declaration of death for the need of organs [39,99,120]. However, healthcare population groups were less likely to believe that there will be any premature declaration of death by the doctors [38,71,85,87].

Religious influence

Overall, majority of the participants favoured organ donation [27,38,46,47,49,61,80,81,101,106,108,109]. However, when further looked based on religion,

different studies showed different religious groups to be more willing to donate compared to individuals from another religious group [45,48,61,73,121], showing no consistency on which particular religion is more supportive or rejective [45,48,52,61,121]. In parallel, a qualitative study conducted among UK university students of Indian descendants showed lack of homogeneity even within one same religion. Some agreed that body needs to be intact for reincarnation, while other participants believed that body and soul are two different entities and that only the soul counts while body is left to decay in this earth [27,97]. However, among studies undertaken outside India, Indian Muslim participants were identified to be less likely or supportive toward organ donation [4,44,95,106,117]. Qualitative studies from outside India identified that lack of the standpoint of religion as one of the reasons leading to such reluctance and not the individual's opinion [108,117].

However, though there were differences of opinion across and within the religion, majority of the participants agreed that organ donation is not against religious views [38,68,72,88,90,97,101,109] and also considered religion as the very least barrier toward organ donation [44,45,63,65,68,90,114,115,122]. A qualitative study conducted among UK students with Indian origin showed that though individuals felt religion may influence their decision it was not the only factor that that will be considered in such decisions [27]. Yet, favourable opinion of religion toward organ donation was found to be positively correlating with their willingness to donate [38,52].

A Qualitative study conducted in UK with Indian students revealed that younger generations were less bothered about religious views compared to older generations, which could have occurred due to acculturation [27]. Also, participants preferred that religion should not be a criterion based on which allocation can be decided [48,68,109,115] and that organ of a deceased person can be donated to a recipient from any religion [48,68,109,115].

However, during the time of consent, a stakeholder from a qualitative study said that families who were not willing to donate use the concept of religion as a reason to decline donation, though none of the religion is against organ donation. In the same qualitative study, public participants from various religious group felt that their religion supports organ donation [90].

Bodily issues

Majority of the individuals from the reviewed studies were not concerned about bodily issues though it has to undergo incisions while explanting [38-40,45,46,61,91,97,118]. However, on the other side, majority also agreed that it is an individual's complete right to have the organs within the body when dead [49,87]. Whilst majority of individuals were not concerned about incisions in the body, a qualitative study found that in the real time of consent, stakeholders found it easy to get approval for corneal donation and not solid organs as it may have many incisions over the body and disfigure it [72]. In relation to funeral practices involving the deceased body, majority were aware that normal funeral practices can be conducted even after donating organs [38,49,61,87,91,115], contrast findings were also evident [49,55,87]. However, majority opted body disfigurement, but less proportion, as one of the least reasons to be a barrier toward organ donation, both within and outside the borders of India [46,63,65,69,83,100,106,108].

Discussion

To the best of our knowledge, this is the first systematic review that reviewed barriers toward organ donation among Indians living globally. Also, this is one of the few systematic reviews in organ donation that used integrative methodology. While majority in India have heard or are aware of organ donation, and had a positive correlation with willingness, their gap is wide.

This indicates that there could be various factors other than knowledge which need to be studied in more detail. Organ donation being more embedded with health behaviour, there is a need to understand the relationship between behaviour and behavioural intention by adopting appropriate principles. This aids the specificity of policy and campaigns to address organ donor registration behaviour in this particular population.

Though gaps identified in majority of the quantitative studies merit qualitative studies, only very few qualitative studies were undertaken in India [87,90,97]. For instance, though majority individuals were willing to be an organ donor, majority have not initiated any such conversation with their family members yet considered family to be the major barrier [46,63,65,69,100,117]. However, no further studies were exclusively undertaken to understand how a construct like family interferes in the decision making toward registration and consent. Such studies will aid in developing and testing hypothesis or developing appropriate interventions to increase such conversation with family members. Such conversations play a very important role as the awareness on the willingness of the deceased plays a vital role in decision-making during consent [96]. However, the influence of family can be different among Indians in India and outside India as the latter may have influences based on acculturation and enculturation [27,58] while the prior maybe more concerned toward communication issues [52,65,68,90,93,100,115,116]. While majority were willing to be an organ donor [27,43,45,47,48,53,58-61], they were unaware on how to register to be an organ donor [40,50,53,55,56,70,71,94]. Therefore, further campaigns on registration procedure information will enable to improve organ donation in India.

This review showed that there are various complex interactions that happen in the society where an individual lives rather than just knowledge influencing organ donation decision. Fear and mistrust have shown to influence the uncertainty in decision-making for a very long time [27,40,48,55,63,64,68,69,71,72,78,97]. However, studies failed to address how fear influences

organ donation, what is the source of fear and how a construct like fear can be addressed. This fear could be due to the news or information that they hear on illegal organ donation and transplants practices around them or any other reasons [123], but not much have been studied why such fear exist among this population.

Also, while majority of the studies show influence of religion on organ donation, there is a greater need to understand how a religion influences organ donation in India. Is it the misconception, or the lack of enabling religious community, or reluctance to take such conversation, or lack of information from the religious leaders or their physical practices that does not allow donation? Such in-depth studies need to be undertaken to gain a deeper understanding into the phenomena. Therefore, there is an urgent need, to study further how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour.

Various other factors such as age, sex, education, and socio-economic status showed greater influence on willingness to donate [27,45,47,48,53,58,61]. However, studies showed that they did not hold true during the time of consent [47,96]. This review therefore showed that there is some shift in behaviour during registration and the actual consent. This again probes to further the understanding on what happens during the time of consent, and why such a shift is seen in the intention to donate between these two time periods.

Overall, based on the studies undertaken among Indians living in India, the UK, Canada, and Malaysia, similarities and differences were identified. The willingness and registration behaviour differed according to the geographical location where Indians lived in comparison to their native population. While Indians were considered to have higher attitude and willingness in Malaysia [84,114], Indians living in the UK and Canada were considered to have lower attitude and willingness [17,117]. This could have been due to their respective socio-

cultural practices of Muslim major country [i.e., Malaysia] and Christian major country [i.e., Canada and the UK] with Hindu major population [i.e., Indians]. This argument is also supported by a study that compared organ donation willingness between Christian, Hindu, and Muslim major native population [58]. The similarity identified was that, irrespective of their geographical location, this was a collectivist decision and not an individual's decision [4,85,117] with family, fear and mistrust, and bodily issues identified to be the major barrier [44,83,85,95,105,107,108].

Methodologically, studies conducted among the Indian ethnic group outside India were collectively identified as South-Asians or Asians [23-26,106] while they differ culturally, socially, politically, economically, and even religiously [124]. Two studies included from UK in this review have clearly shown such a difference with the neighbouring country (i.e., India, and Pakistan) [27,58]. Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations from the same ethnicity [27,58]. This cannot happen without the influence of time elapsed since immigration, immigrant generation (i.e., first, second, or higher), acculturation, enculturation, perceived discrimination, attitudes / mistrust toward healthcare system, community barriers, socio-cultural influence and many such complex determinants which adds further complexity to the issue of organ donation among such a population. Therefore, such specific research among this community is also needed to address the disproportionate representation between waiting list and donor list from this ethnic population outside the country of origin.

Though narrative synthesis is criticised for its lack of transparency, this study has tried to be as transparent as possible to strengthen its validity and credibility of the review and synthesis

[30,125]. The PRISMA flow chart, search strategy, data synthesis and analysis methods are clearly explained in this study to overcome those limitations.

Conclusion

This review showed that majority of the participants from India and of Indian origin hold positive attitude toward registration but show lower willingness and even lower practice of registration. Though this study showed the complex relationship and influences toward organ donation behaviour, lacunae were identified for further deeper understanding into such complex interactions determining the behaviour. There is also a lack of methodological rigour to study this population outside India, being collectively studied with their neighbouring population which are not homogenous. Also, within India, majority of the studies employed similar aims and methods leading to repetition of studies rather than diversified, wider, and in-depth research.

Funding sources: This review is led by the principal investigator Britzer Paul Vincent who is a PhD scholar at the Institute for Health Research, University of Bedfordshire funded by their Global Challenges Research Fund.

Authorship Contribution:
All authors BPV, GR & EC contributed to – conception of the study, design of work, data acquisition, data analysis, data interpretation, writing of the article, final approval, and accountability of the study.

Acknowledgement: We would like to thank our librarian Mr. David Abdy from Institute for Health Research, University of Bedfordshire for his contribution with the development of the search strategy.

Data availability: None

Conflict of Interest: None declared.

Patient and Public involvement: None as this is a systematic review

Ethics approval details: Institute for Health Research Ethics Committee from the University of Bedfordshire approved this study (IHREC931).

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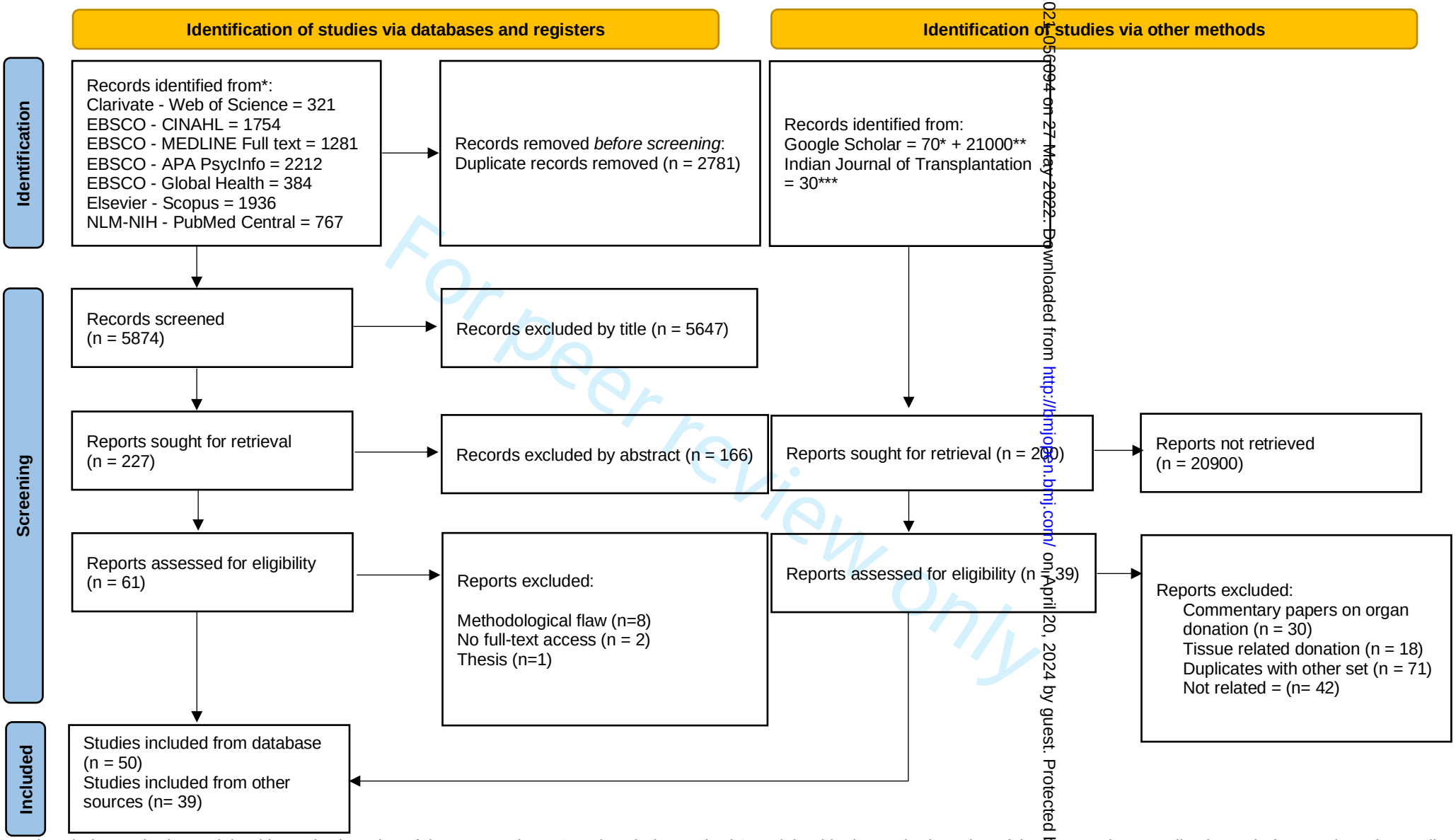
Figure legends / captions:

Figure 1: PRISMA flowchart

Figure 2: Quality appraisal checklist – Quantitative studies

Figure 3: Quality appraisal checklist – Qualitative studies



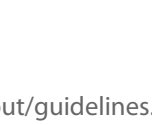
*Google scholar method 1 explained in method section of the manuscript; **Google scholar method 2 explained in the method section of the manuscript; ***Indian journal of Transplantation – All issues were manually searched from 1994

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Ahlawat et al, 2013	-	✓	✓	✓	×	×	✓	✓
Alex et al, 2017	✓	✓	✓	✓	×	✓	✓	✓
Alex et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Amaliyar et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Balajee et al, 2016	-	✓	✓	✓	✓	×	✓	✓
Balwani et al, 2015a	-	✓	✓	✓	×	×	✓	✓
Balwani et al, 2015b	✓	✓	✓	✓	×	×	✓	✓
Bansal et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Bapat et al, 2010	-	✓	✓	✓	×	×	✓	✓
Basavarajegowda et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Bathija et al,2017	-	✓	✓	✓	×	✓	✓	✓
Bharambe et al, 2015	×	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018a	✓	✓	✓	✓	×	×	✓	✓
Bharambe et al, 2018b	✓	✓	✓	✓	×	×	✓	✓
Bhargavi et al, 2019	✓	✓	✓	✓	×	✓	✓	✓
Chakradhar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Da Silva et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Darbari et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Darlington et al,2019	✓	✓	✓	✓	✓	✓	✓	✓
Dasgupta et al, 2014	✓	✓	✓	✓	×	×	✓	✓
Deshpande et al, 2018	-	✓	✓	✓	×	×	✓	✓
Flower et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Ghose et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Gupta et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Gupta et al, 2021	×	-	✓	✓	×	×	✓	✓
Hakeem et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Huern et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Jagadeesh et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Jayabharathi et al,2019	✓	✓	✓	✓	×	×	✓	✓
Joshi, 2011	✓	✓	✓	✓	✓	✓	✓	✓
Jothula et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Kachappillil et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kadam et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Kaistha et al,2016	✓	✓	✓	✓	×	×	✓	✓
Kamlath et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Karim et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Kaur et al, 2021	✓	✓	✓	✓	×	×	✓	✓

	1	2	3	4	5	6	7	8
Khan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Kundu et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Li et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Loch et al, 2010	✓	✓	✓	✓	×	×	✓	✓
Lokesh et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mani, 2016	✓	✓	✓	✓	×	×	✓	✓
Meghana et al, 2018	✓	✓	✓	✓	×	✓	✓	✓
Minz et al, 1998	×	✓	-	✓	×	×	✓	✓
Mishra et al, 2016	×	✓	×	×	×	×	×	×
Misra et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Mithra et al, 2013	✓	✓	✓	✓	×	×	✓	✓
Mohan et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Mondal et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Panwar et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Paramr et al, 2021	✓	✓	✓	✓	×	×	✓	✓
Paul et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2016	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2017	✓	✓	✓	✓	×	×	✓	✓
Pradeep et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Rajan, 2021	✓	✓	✓	✓	×	×	✓	✓
Rani et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Ray et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Reddy et al, 2003	✓	✓	✓	✓	×	×	✓	✓
Sachdeva, 2017	-	✓	✓	✓	×	×	✓	✓
Sam et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Sarveswaran et al, 2018	✓	✓	✓	✓	×	×	✓	✓
Seetharaman et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Singh et al, 2002	✓	✓	✓	✓	×	×	✓	✓
Soni et al, 2018	-	✓	✓	✓	×	✓	✓	✓
Swain et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Swamy et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Tamuli et al,2019	×	✓	✓	✓	×	×	✓	✓
Thyagarajan et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Verma et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al, 2015	✓	✓	✓	✓	×	×	✓	✓
Vijayalakshmi et al,2016	✓	✓	✓	✓	×	×	✓	✓
Vincent et al, 2019b	✓	✓	✓	✓	✓	✓	✓	✓
Wong et al, 2011	✓	✓	✓	✓	×	×	✓	✓
Yadav et al, 2020	✓	✓	✓	✓	×	×	✓	✓

1. Were the criteria for inclusion in the sample clearly defined?
2. Were the study subjects and the setting described in detail?
3. Was the exposure measured in a valid and realistic way?
4. Were the objectives, standard criteria used for measurement of the conditions?
5. Were the confounding factors identified?
6. Were strategies to deal with confounding factors stated?
7. Were the outcomes measured in a valid and reliable way?
8. Was appropriate statistical analysis used?



Mentioned
Not mentioned
Unclear

Ref	1	2	3	4	5	6	7	8	9	10
Vincent et al, 2019	✓	✓	✓	✓	✓	✓	×	✓	✓	✓
Kennedy, 2002	✓	✓	✓	✓	✓	×	×	×	×	✓
Gauher et al, 2013	✓	✓	✓	✓	✓	✓	×	✓	✓	✓
Misra et al, 2021	✓	✓	✓	✓	✓	×	×	×	✓	✓
Darr et al, 1999	✓	✓	✓	✓	✓	×	×	×	✓	✓
Exley et al, 1996	✓	✓	✓	✓	✓	×	×	×	✓	✓
Morgan et al, 2015	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
Wong et al, 2010a	✓	✓	✓	✓	✓	✓	×	×	✓	✓
Wong et al, 2010b	✓	✓	✓	✓	✓	✓	×	×	✓	✓
Randhawa et al, 1998	✓	✓	✓	✓	✓	✓	×	×	✓	✓

1 Is there congruity between the stated philosophical perspective and the research methodology?

2 Is there congruity between the research methodology and the research question or objective?

3 Is there congruity between the research methodology and the methods used to collect data?

4 Is there congruity between the research methodology and the representation and analysis of data?

5 Is there congruity between the research methodology and the interpretation of results?

6 Is there a statement locating the researcher culturally or theoretically?

7 Is the influence of the researcher on the research, and vice-versa, addressed?

8 Are participants, and their voices, adequately represented?

9 Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?

10 Do the conclusion drawn in the research report flow from the analysis, or interpretation, of the data?

Mentioned ✓ Not mentioned ×

Supplementary I: Search strategy

Database: Clarivate for Web of Science <1 January 1994 to 31 December 2021>

Search strategy

1. (ALL) Organ* (4464520)
2. (ALL) Tissue* (2072420)
3. 1 OR 2
4. (ALL) Donation* (92568)
5. (ALL) Procurement* (36067)
6. (ALL) Donor* (471190)
7. (ALL) Regist* (607949)
8. (ALL) Pledge* (5168)
9. 4 OR 5 OR 6 OR 7 OR 8
10. (ALL) “Brain death” (6,922)
11. (ALL) Posthumous* (3317)
12. (ALL) Deceased* (28469)
13. 10 OR 11 OR 12 (122185)
14. (ALL) India* (2374803)
15. (ALL) Asia* (869365)
16. (ALL) “South Asia*” (34481)
17. 14 OR 15 OR 16
18. (ALL) Knowledge (1860768)
19. (ALL) Attitude* (423103)
20. (ALL) Practice* (2018451)
21. (ALL) Aware* (484659)
22. (ALL) Perception* (725428)
23. (ALL) Barrier* (711626)
24. (ALL) Challenge* (1684045)
25. (ALL) Religi* (258116)
26. (ALL) Famil* (2081795)
27. (ALL) Discuss* (4419231)
28. (ALL) Sign* (11546529)
29. 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 0R 28
30. 3 AND 9 AND 13 AND 17 AND 29 (321)

((((ALL=(Organ* OR Tissue*)) AND ALL=(Donation* OR Procurement* OR Donor* OR Regist* OR Pledge*)) AND ALL=("Brain Death" OR Posthumous* OR Deceased*)) AND ALL=(India* OR Asia* OR "South Asia*")) AND ALL=(Knowledge* OR Attitude* OR Practice* OR Aware* OR Perception* OR Barrier* OR Challenge* OR Religi* OR Famil* OR Discuss* OR Sign*)

Database: EBSCO for CINAHL Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	45587	254692
2	Tissue*	35642	171599
3	1 OR 2	47408	214967
4	Donation*	5126	7255
5	Procurement	733	2440
6	Donor	10046	24599
7	Regist*	28751	171623
8	Pledge	906	909
9	4 OR 5 OR 6 OR 7 OR 8	44740	200368
10	India*	29146	35077
11	Asia*	13516	35961
12	"South Asia*"	1896	3440
13	10 OR 11 OR 12	42022	67778
14	Knowledge	40561	228058
15	Attitude*	30320	76214
16	Practice*	171844	417435
17	Aware*	16453	106579
18	Perception	47156	116209
19	Barrier*	23209	93116
20	Challenge*	52643	179284
21	Religi*	7106	20082
22	Famil*	28758	120172
23	Discuss*	12336	525753
24	Sign	60885	1299673
25	"Brain Death"	811	1176
26	Posthumous	101	157
27	Deceased	725	5381
28	**SU** Organ Donation	191	
29	**SU** Tissue and Organ Procurement	437	
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	460837	2330155
31	3 AND 9 AND 13 AND 28	697	1057

Database: EBSCO for MEDLINE With full text Complete < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	245699	1493730
2	Tissue*	223470	1550014
3	1 OR 2	465190	2862275
4	Donation*	11156	25326
5	Procurement	1825	8302
6	Donor*	58569	260805
7	Regist*	52468	371535
8	Pledge	591	1401
9	4 OR 5 OR 6 OR 7 OR 8	122076	641620
10	India*	79797	128377
11	Asia*	37333	145090
12	"South Asia*"	3406	9277
13	10 OR 11 OR 12	115447	260763
14	Knowledge	62353	725944
15	Attitude*	44690	132711
16	Practice*	192866	758688
17	Aware*	23266	233256
18	Perception*	73637	238754
19	Barrier*	56399	301446
20	Challenge*	107816	654171
21	Religi*	8586	32213
22	Famil*	62713	341944
23	Discuss*	19872	1196575
24	Sign*	402535	6834667
25	"Brain Death"	2322	4478
26	Posthumous	201	475
27	Deceased	2643	20262
28	**MH** Organ Donation	13951	
29	**MH** Tissue and Organ Procurement	19560	
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	1012657	9432506
31	3 AND 9 AND 13 AND 28	61	1220

Database: EBSCO for APA PsycInfo < 1994 January to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	52775	314055
2	Tissue*	2650	33891
3	1 OR 2	55359	344532
4	Donation*	1328	3862
5	Procurement	260	1126
6	Donor*	1103	6196
7	Regist*	4746	41654
8	Pledge	65	479
9	4 OR 5 OR 6 OR 7 OR 8	7304	51337
10	India*	12921	26606
11	Asia*	9722	31810
12	"South Asia*"	1130	2606
13	10 OR 11 OR 12	22183	55698
14	Knowledge	37077	273907
15	Attitude*	40138	146530
16	Practice*	77921	427695
17	Aware*	12620	117029
18	Perception*	74077	238811
19	Barrier*	12054	74349
20	Challenge*	24193	208260
21	Religi*	18072	57819
22	Famil*	31536	174669
23	Discuss*	7449	675256
24	Sign*	32524	1050671
25	"Brain Death"	192	383
26	Posthumous	55	451
27	Deceased	211	3514
28	**SU** Organ Donation	729	
29	**SU** Tissue and Organ Procurement	619	
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	345985	2324405
31	3 AND 9 AND 13 AND 28	1049	1163

Database: EBSCO for Global Health < January 1994 to December 2021>

Search strategy

No.	Terms	Title	Abstract
1	Organ*	34990	281202
2	Tissue*	24264	166199
3	1 OR 2	58782	426568
4	Donation*	851	4044
5	Procurement	276	2063
6	Donor*	5877	26460
7	Regist*	6306	654425
8	Pledge	39	298
9	4 OR 5 OR 6 OR 7 OR 8	13197	94877
10	India*	42961	84021
11	Asia*	11593	56374
12	"South Asia*"	1307	4386
13	10 OR 11 OR 12	53980	134135
14	Knowledge	21618	146105
15	Attitude*	14175	40544
16	Practice*	32467	149036
17	Aware*	6261	61511
18	Perception*	15315	46000
19	Barrier*	10039	55500
20	Challenge*	18770	113171
21	Religi*	1303	9881
22	Famil*	6241	56096
23	Discuss*	2171	225453
24	Sign*	34744	179950
25	"Brain Death"	41	179
26	Posthumous	4	29
27	Deceased	238	2971
28	**SU** Organ Donation	475	
29	**SU** Tissue and Organ Procurement	313	
30	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29	144587	1664816
31	3 AND 9 AND 13 AND 28	5	379

Database: Elsevier for Scopus PUBYEAR > 1993 AND PUBYEAR <2022

Search strategy

No.	Terms	Title-Abstract-Keywords
1	Organ*	757636
2	Tissue*	3956065
3	1 OR 2	8523116
4	Donation*	49781
5	Procurement	57632
6	Donor*	465751
7	Regist*	690378
8	Pledge	6915
9	4 OR 5 OR 6 OR 7 OR 8	1214290
10	India*	630668
11	Asia*	614524
12	"South Asia*"	47204
13	10 OR 11 OR 12	1178235
14	Knowledge	2199485
15	Attitude*	834803
16	Practice*	2961509
17	Aware*	663440
18	Perception*	885170
19	Barrier*	765952
20	Challenge*	2076205
21	Religi*	274948
22	Famil*	776708
23	Discuss*	5121400
24	Sign*	14005232
25	"Brain Death"	11526
26	Posthumous	7120
27	Deceased	30117
28	14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27	24234423
29	3 AND 9 AND 13 AND 28	1936

Database: US National Library of Medicine National Institute of Health for PubMed Central < 1994 January to December 2021>

Search strategy

Search: ((((Organ[Title/Abstract] OR Tissue[Title/Abstract]) AND (Donation[Title/Abstract] OR Donor[Title/Abstract])) AND (Knowledge[Title/Abstract] OR Awareness[Title/Abstract] OR Attitude[Title/Abstract] OR Perception[Title/Abstract] OR Practice[Title/Abstract] OR Registration[Title/Abstract] OR Consent[Title/Abstract] OR Barrier[Title/Abstract] OR Challenges[Title/Abstract] OR Religion[Title/Abstract] OR Culture[Title/Abstract]))) AND ((India OR South Asia OR Southeast Asia OR Asia[MeSH Terms])

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg. 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg. 1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg. 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg. 3-4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg. 4-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg. 4 -5
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary file & PRISMA 2020
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 5-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg. 5-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	NA
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	NA
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg. 6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	NA
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg. 6-7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1, Pg. 5-6
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Quality appraisal: Figure 2 & 3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	24-27
	23b	Discuss any limitations of the evidence included in the review.	26-27
	23c	Discuss any limitations of the review processes used.	26-27
	23d	Discuss implications of the results for practice, policy, and future research.	24-27
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg. 2
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg. 2
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg. 4
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg. 25
Competing interests	26	Declare any competing interests of review authors.	Pg. 25
Availability of data, code and	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary file 1.

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
other materials			

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

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