# **BMJ Open** Barriers towards deceased organ donation among Indians living globally: an integrative systematic review using narrative synthesis

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#### ABSTRACT

**Objectives** To understand the barriers towards 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 1 January 1994 to 31 December 2021. Participants Individuals of Indian origin living globally. **Results** Eighty-nine studies were included with more than 29000 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 sociocultural constructs. Various sociocultural 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 socioreligious 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 sociocultural 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.

#### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first systematic review on the barriers towards deceased organ donation among Indians living globally, registered with PROSPERO, and published.
- ⇒ Both quantitative and qualitative studies were included to address the aim of the review using integrative approach and narrative synthesis, an appropriate methodology.
- ⇒ 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.
- ⇒ 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.
- ⇒ Studies were limited only to English language, and commentaries were excluded.

#### INTRODUCTION

Since the first deceased organ transplantation performed by Joseph Murray in 1960s, the science of transplantation has witnessed exponential growth.<sup>1</sup> However, the gap between demand and supply of organs has represented a significant challenge,<sup>2</sup> particularly among the Asian population who live both within and outside their continent.<sup>3–5</sup> India located in the South of Asia is the second largest populated country in the world<sup>6</sup> having largest migrating population in Asia,<sup>7</sup> and also has the highest prevalence of diabetes and hypertension.8 Such noncommunicable diseases among Indians9 10 leading them to end-stage organ failure<sup>11 12</sup> increases their need for organs.

While 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,<sup>13</sup> with the Indian national organ donation rate

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Dr Gurch Randhawa; gurch.randhawa@beds.ac.uk less than one per million population (pmp).<sup>14</sup> Reluctance to donate organs among this ethnic population might not be isolated just within Indian border,<sup>15</sup> with evidence suggesting that Indian population from the UK is also disproportionately impacted, where they continue to be over-represented in the recipient waiting list but underrepresented in the donor list.<sup>16</sup> This behaviour is again identified in Canada.<sup>17</sup> 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 synthesise 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 towards deceased organ donation behaviour among this particular population living globally.<sup>18</sup>

#### **METHOD**

#### **Protocol and registration**

This systematic review's protocol has been registered in PROSPERO (CRD42019155274) and also published.<sup>18</sup>

#### 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<sup>19 20</sup> 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 (online supplemental file 1).<sup>21</sup> However, for other resources like Google scholar and the Indian Journal of Transplantation other strategies were employed. All the published papers from 1 January 1994 to 31 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 review).22

The systematic review included studies with individuals of Indian origin living both within and outside India (ie, migrant/first/second generation), aged 18 years and above from varied settings.<sup>18</sup> 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 1 January 1994 (ie, the year when the first law towards organ donation was enacted in India) and 31 December 2021 (ie, 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.

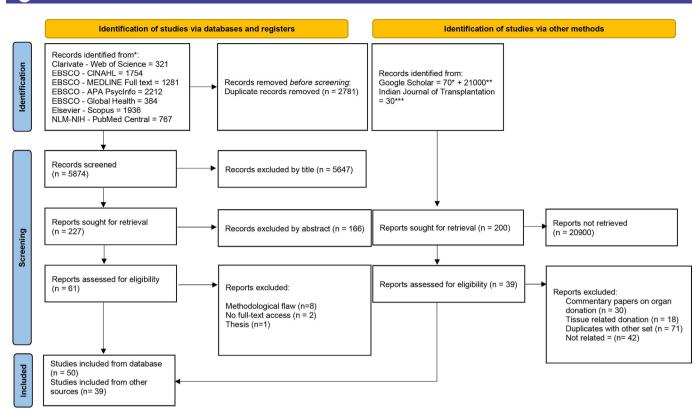
#### Search outcome

Following a stage-by-stage exclusion from 8655 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 8655 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.<sup>23</sup> 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<sup>24–26</sup>; 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.<sup>4 27</sup> 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 were used to critique the rigour of each studies included,<sup>28</sup> also used in other organ donation systematic review.<sup>19 29</sup> Comprehensive reporting on the quality assessment for both cross-sectional and qualitative studies is reported in figures 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 on the quality assessment as mentioned in figures 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.



**Figure 1** PRISMA flow chart. \*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 *et al.*<sup>126</sup>

#### **Data synthesis**

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This systematic review followed an integrative review with narrative synthesis approach enabling to synthesise complex information towards the phenomena of interest<sup>30</sup>; a methodology also employed in another systematic review on organ donation that reviewed both quantitative and qualitative studies.<sup>20</sup> 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.<sup>31</sup>

First, following the systematic search and quality appraisal, summary data were 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). Second, 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 NVivo V.11. 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.<sup>32–36</sup> Third, 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.<sup>20</sup>

#### **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

	1	2	3	4	5	6	7	8
Adithyan et al, 2017	<b>~</b>	<b>~</b>	~	<b>~</b>	×	~	<ul><li>✓</li></ul>	<ul> <li>Image: A start of the start of</li></ul>
Ahlawat et al, 2013	-	~	~	~	×	×	×	×
Alex et al, 2017	✓	~	~	~	×	✓	✓	✓
Alex et al, 2019	×	×	<b>~</b>	×	×	×	✓	✓
Amaliyar et al, 2019	~	~	×	×	×	✓	×	~
Balajee et al, 2016	-	<ul> <li>Image: A second s</li></ul>	<ul> <li>Image: A second s</li></ul>	<ul> <li>Image: A second s</li></ul>	<ul> <li>Image: A second s</li></ul>	×	× -	× -
Balwani et al, 2015	-	~	~	~	×	×	×	× .
Balwani et al, 2015	~	<b>~</b>	~	<ul> <li>✓</li> </ul>	×	×	×	×
Bansal et al, 2019	~	~	~	~	×	×	×	× .
Bapat et al, 2010	-	~	~	✓	×	×	<b>~</b>	<b>~</b>
Basavarajegowda et al, 2021	~	~	~	~	×	×	×	×
Bathija et al,2017	-	~	~	~	×	~	~	✓
Bharambe et al, 2015	×	~	~	~	×	×	~	~
Bharambe et al, 2016	~	~	~	~	×	×	~	×
Bharambe et al, 2018	~	~	~	~	×	×	~	~
Bharambe et al, 2018	~	~	~	~	×	×	~	~
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	<ul><li>✓</li></ul>	✓	✓	✓	×	×	✓	✓
Deshpande et al, 2018	-	×	×	×	×	×	1	× -
Flower et al, 2013	~	~	~	✓	×	×	~	×
Ghose et al, 2021	×	<ul> <li>Image: A second s</li></ul>	<b>~</b>	×	×	×	<b>~</b>	×
Gupta et al, 2018	✓	✓	~	✓	×	<ul> <li>✓</li> </ul>	✓	✓
Gupta et al, 2021	×	-	~	~	×	*	~	×
Hakeem et al, 2021	~	~	~	~	×	×	~	✓
Huern et al, 2016	<b>~</b>	<b>~</b>	~	<b>~</b>	×	×	<b>~</b>	<b>~</b>
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	~	~	~	~	×	×	~	~
Kalmath et al, 2020	~	~	~	~	×	×	~	~
Karim et al, 2013	~	~	~	~	×	×	~	~
Kaur et al, 2021	<ul> <li>Image: A second s</li></ul>	<ul> <li>Image: A second s</li></ul>	<ul> <li>Image: A second s</li></ul>	<b>~</b>	×	×	<b>~</b>	<ul> <li>Image: A second s</li></ul>

	1	2	3	4	5	6	7	8
Khan et al, 2020	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	×	×	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>
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								
Misra et al, 2021 Mithra et al,					×	×		<ul> <li>✓</li> </ul>
2013 Mohan et al,	✓	~	~	~	×	×	~	✓
2019	~	~	~	~	×	×	~	~
Mondal et al, 2016	~	~	~	~	×	×	~	~
Panwar et al, 2016	1	1	~	1	×	×	1	~
Parmar et al, 2016	~	~	~	~	×	×	~	~
Parmar et al, 2021	~	~	~	~	×	×	~	~
Paul et al, 2019	✓	✓	✓	✓	×	×	✓	✓
Poreddi et al, 2016	~	~	~	~	×	×	~	~
Poreddi et al, 2017	~	~	~	~	×	×	~	✓
Pradeep et al, 2019	~	~	~	~	×	×	~	~
Rajan, 2020	~	~	~	~	×	×	~	~
Rani et al, 2020	✓	✓	✓	✓	×	×	✓	✓
Ray et al, 2020	✓	✓	~	✓	×	×	✓	✓
Reddy et al, 2003	~	~	~	~	×	×	~	~
Sachdeva, 2017	-	~	~	~	×	×	~	~
Sam et al, 2018	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	<ul> <li>✓</li> </ul>	×	×	<ul> <li>✓</li> </ul>	✓
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,	• •	• •	• •	• •	~	~	• •	• •
2019 Wong et al, 2011	• √	• √	▼ ✓	• √	×	×	• √	▼ ✓
Yadav et al,	~	~	~	~	×	×	~	✓
2020								

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



Mentioned Not mentioned Unclear

Figure 2 Quality appraisal checklist-quantitative studies.

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	✓	✓	✓	✓	✓	×	×	×	✓	1
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?

<sup>3</sup> Is there congruity between the research methodology and the methods used to collect data?

- <sup>4</sup> 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 ×

Figure 3 Quality appraisal checklist-qualitative studies.

conducted in the UK, there were 1235 individuals in total; however, one study had no evidence on the sample number of Indian participants involved,<sup>27</sup> 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.<sup>17</sup>

#### **FINDINGS**

#### Integration and relationship

Based on the narrative synthesis, findings are described under the following six themes namely: (1) knowledge and awareness towards deceased organ donation, (2) willingness and actual behaviour towards 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 most common theme studied across, findings showed that knowledge had a positive correlation with willingness and practice.<sup>37–44</sup> Both among Indians living in India and outside, younger adults, participants from higher socioeconomic status, and with higher education or healthcare education demonstrated higher knowledge towards deceased organ donation<sup>43–60</sup> and individuals

from southern region of India showed higher knowledge compared with other regions in India.  $^{61-66}$ 

While 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<sup>4 39 44 53-55 67-85</sup> and that organs can be donated to anyone,<sup>46 61 80</sup> the knowledge and understanding on brain death was less well understood.<sup>49 64 68 69 75 86-89</sup> 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.<sup>90</sup> Also, many were not aware about the organ donor card,<sup>67 83 88 91-94</sup> where and how to register and obtain an organ donor card<sup>40 50 53 55 56 70 71 94 95</sup>—an important component for organ donor registration. In addition, knowledge on the law that governs organ donation was also found to be low.<sup>40 71 92 96 97</sup> 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,<sup>58</sup> 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.<sup>40,49,50,53,55,64,67,69–72,86,91–96,98</sup>

Table 1 Evidence table	e table						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Adithyan e <i>t al</i> (2017) <sup>115</sup>	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 e <i>t al</i> (2013) <sup>45</sup>	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 <i>et al</i> (2017) <sup>37</sup>	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 <i>et al</i> (2019) <sup>67</sup>	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 <i>et al</i> (2019) <sup>91</sup>	Gujarat	India	To assess the knowledge, attitude, and practice towards organ donation among medical, arts and commerce students	Students from last four semester groups from medical, arts and commerce college	Cross sectional	300	Purposive sampling for centres; Random for participants
Balajee <i>et al</i> (2016) <sup>46</sup>	Pondicherry	India	To assess the awareness and attitudes regarding organ donation among rural people from four villages	General public	Cross sectional	360	Systematic random sampling and random participant selection
Balwani <i>et al</i> (2015) <sup>62</sup>	Gujarat	India	To study the awareness and belief towards organ donation and its Tertiary care centre allocation in chronic kidney disease patients in western India	Tertiary care centre	Cross sectional	85	Not specified
Balwani <i>et al</i> (2015) <sup>62</sup>	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 <i>et al</i> (2019) <sup>47</sup>	Chandigarh	India	To analyse sociodemographic 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 sociodemographic variables	Tertiary care teaching hospital among family members who consented to donate the organs of their loved ones	Cross sectional	59	Purposive sampling
Bapat e <i>t al</i> (2010) <sup>38</sup> Karnataka	Karnataka	India	To understand the awareness, attitudes and belief towards organ donation among post-graduate medical students	Postgraduate medical students	Cross sectional	123	Volunteer sampling
Basavarajegowda <i>et al</i> (2021) <sup>72</sup>	Pan India	India	To study the knowledge difference between the knowledge and attitude about organ donation among blood donors compared with non-blood donors	General public	Cross sectional	803	Purposive sampling
Bathija <i>et al</i> (2017) <sup>63</sup>	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	Postgraduate and medical interns	Cross sectional	300	Not specified
							Continued

	ner						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Bharambe <i>et al</i> (2015) <sup>64</sup>	Maharashtra	India	To assess the knowledge and attitude of the people living in an urban city in India towards organ donation	Outpatient department	Cross sectional	65	Not specified
Bharambe <i>et al</i> (2016) <sup>68</sup>	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 <i>et al</i> (2018) <sup>69</sup>	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 <i>et al</i> (2018) <sup>69</sup>	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 <i>et al</i> (2019) <sup>122</sup>	Kerala	India	To check the level of awareness and attitude of second year medical, dental, and nursing students at Govt. Medical College, Thiruvananthapuram Campus towards organ donation and wholebody donation using a questionnaire-based study.	Medical and nursing students	Cross sectional	177	Convenience sampling
Chakradhar <i>et al</i> (2016) <sup>39</sup>	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 <i>et al</i> (2021) <sup>71</sup>	West Bengal	India	To assess the knowledge, attitude and practices of healthcare professionals towards cadaveric organ donation and to know their awareness regarding legislations pertaining to cadaveric organ donation.	Healthcare professionals	Cross sectional	400	Stratified random sampling
Darbari <i>et al</i> (2020) <sup>82</sup>	Uttarakhand	India	To assess the knowledge on organ donation among undergraduate medical students	Undergraduate medical students	Cross sectional	197	Not specified
Darlington <i>et al</i> (2019) <sup>121</sup>	Tamil Nadu	India	To study the knowledge, attitude and practice towards organ donation	Medical students	Cross sectional	425	Voluntary
Darr <i>et al</i> (1999) <sup>83</sup>	Luton	England	To assess the attitudes on organ donation and transplantation among south Asians	South Asian general public	Qualitative	64	Purposive sampling
Dasgupta <i>et al</i> (2014) <sup>48</sup>	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 <i>et al</i> (2018) <sup>70</sup>	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 <i>et al</i> (1996) <sup>108</sup>	Coventry	England	To examine the religious, cultural and social context of organ donation	Sikh Asian community members	Qualitative	22	Judgemental sampling
Flower <i>et al</i> (2013) <sup>104</sup>	Pondicherry	India	To explore the general publics perceived barriers and facilitating factors of organ donation	General public	Cross sectional	400	Random sampling
							Continued

Table 1 Continued	pe						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Gauher <i>et al</i> (2013) <sup>27</sup>	London	Х	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) <sup>80</sup>	Pune	India	To study knowledge and attitude towards 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 <i>et al</i> (2018) <sup>40</sup>	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 <i>et al</i> (2021) <sup>57</sup>	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 <i>et al</i> (2021) <sup>112</sup>	Tamil Nadu	India	To assess knowledge, attitude and perception of organ donation and transplant	Medical students and junior doctors	Cross sectional	966	Not specified
Huern <i>et al</i> (2016) <sup>84</sup>	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 <i>et al</i> (2018) <sup>44</sup>	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 <i>et al</i> (2019) <sup>41</sup>	Tamil Nadu	India	To assess the knowledge and attitude on organ donation among selected community area	Community area	Cross sectional	60	convenient sampling
Joshi <i>et al</i> (2011) <sup>58</sup>	UK	N	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 <i>et al</i> (2018) <sup>92</sup>	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 <i>et al</i> (2020) <sup>73</sup>	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 <i>et al</i> (2021) <sup>54</sup>	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 <i>et al</i> (2016) <sup>110</sup>	New Delhi	India	To determine the knowledge, attitude and practice regarding organ donation	Patient attendants attending out-patient department	Cross sectional	119	Convenience
Kalmath <i>et al</i> (2020) <sup>74</sup>	Karnataka	India	To assess the level of knowledge, preparedness and commitment Youth public towards organ donation.	Youth public	Cross sectional	300	Probability stratified random sampling
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Table 1 Continued	ed						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Karim <i>et al</i> (2013) <sup>4</sup>	UK	NN	To explore the south Asians attitudes towards organ donation	South Asian general public	Cross sectional	147	Not specified
Kaur <i>et al</i> (2021) <sup>118</sup>	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 <i>et al</i> (2002) <sup>90</sup>	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	œ	Purposive
Khan <i>et al</i> (2020) <sup>75</sup>	Jammu and Kashmir	India	To know the knowledge and attitude towards organ donation among the students	Student population	Cross sectional	200	Not specified
Kundu <i>et al</i> (2021) <sup>55</sup>	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 <i>et al</i> (2016) <sup>17</sup>	Ontario	Canada	To determine the registration status from deceased organ donation and tissue donation	Migrant population	Cross sectional	NA*	Not specified
Loch <i>et al</i> (2010) <sup>89</sup>	Kula Lumpur	Malaysia	To examine the knowledge, attitude and perception toward organ donation	General public	Cross sectional	272	Not specified
Lokesh Kumar <i>et</i> <i>al</i> (2021) <sup>94</sup>	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) <sup>116</sup>	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 <i>et al</i> (2018) <sup>120</sup>	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 <i>et al</i> (1998) <sup>65</sup>	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 <i>et al</i> (2016) <sup>105</sup>	Odisha	India	To evaluate the awareness of organ donation	College students	Cross sectional	430	Not specified
Misra <i>et al</i> (2021) <sup>97</sup>	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 e <i>t al</i> (2021) <sup>59</sup> Haryana	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 <i>et al</i> (2013) <sup>61</sup>	Karnataka	India	To assess the perceptions and attitudes of the people seeking healthcare 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
							Continued

Table 1   Continued	led						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Mohan <i>et al</i> (2019) <sup>66</sup>	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 <i>al</i> (2016) <sup>99</sup>	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 sociodemographic factors with the knowledge and attitude towards organ donation	Rural community	Cross sectional	110	Simple random sampling
Morgan <i>et al</i> (2015) <sup>119</sup>	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	62	Not specified
Panwar e <i>t al</i> (2016) <sup>43</sup>	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 <i>et al</i> (2017) Gujarat (2016) <sup>85</sup>	) Gujarat	India	To assess perception of undergraduate students towards organ donation	Undergraduate students	Cross sectional	100	Randomisation
Parmar <i>et al</i> (2021) <sup>60</sup>	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 <i>et al</i> (2019) <sup>111</sup>	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 <i>et al</i> (2016) <sup>81</sup>	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 <i>et al</i> (2017) <sup>49</sup>	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 <i>et al</i> (2019) <sup>106</sup>	Nort west of England	England	To explore the attitudes and beliefs towards organ donation	General public	Cross sectional	593	Convenience sampling
Rajan (2020) <sup>102</sup>	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 <i>et al</i> (1998) <sup>117</sup>	Luton	England	To examine the influence of religious beliefs, among other things, on the extent and directions of public attitudes toward organ donation	South Asian general public	Qualitative	64	Focused sampling
							Continued

Table 1 Continued	ed						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Rani <i>et al</i> (2020) <sup>76</sup>	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 <i>et al</i> (2020) <sup>77</sup>	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 <i>et al</i> (2003) <sup>113</sup>	New Delhi	India	To assess the awareness and the attitude of Indian patients, the public, doctors and nurses towards organ donation	Public, doctors, and nurses	Cross sectional	066	Randomisation
Sachdeva <i>et al</i> (2017) <sup>103</sup>	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 Cross attendant of a government sectional hospital	Cross sectional	450	Convenience sampling
Sam et al (2018) <sup>100</sup> Tamil Nadu	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 <i>et al</i> (2018) <sup>50</sup>	Puducherry	India	To determine the knowledge, attitude and practice regarding organ donation	Urban community members	Cross sectional	257	Random
Seetharaman <i>et al</i> (2020) <sup>78</sup>	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 <i>et al</i> (2002) <sup>42</sup> Uttar Pradesh	<sup>2</sup> Uttar Pradesh	India	To study level of awareness in hospital staff about transplantation, Hospital staffs 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 <i>et al (</i> 2018) <sup>101</sup>	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 incentivisation	Medical and Engineering students	Cross sectional	600	Random
Swamy <i>et al</i> (2020) <sup>56</sup>	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 <i>et al</i> (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 <i>et al</i> (2019) <sup>51</sup>	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 programme 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
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Table 1 Continued	ed						
Author (s) (year)	Study site	Study country	Aim	Study setting	Study design	Study sample size	Sampling technique
Thyagarajan <i>et al</i> (2020) <sup>98</sup>	Tamil Nadu	India	To assess the police officers' knowledge of the organ donation process and their practice towards it.	Police officers	Cross sectional	627	Purposive sampling
Verma <i>et al</i> (2020) <sup>88</sup>		India	To assess knowledge, attitude and perception toward organ donation	Undergraduate medical students	Cross sectional	1463	Stratified sampling
Vijayalakshmi <i>et al</i> Karnataka (2015) <sup>33</sup>	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 <i>et al</i> Karnataka (2016) <sup>se</sup>	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 <i>et al</i> (2019) <sup>87</sup>	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	Q	Purposive sampling
Vincent <i>et al</i> (2019) <sup>96</sup>	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 e <i>t al</i> (2010) <sup>95</sup> Klang Valley	Klang Valley	Malaysia	To understand the cultural and religious factors limiting organ donation in three ethnic group	Ethnic population	Qualitative	22	NA
Wong <i>et al</i> (2010b) <sup>107</sup>	Klang Valley	Malaysia	To assess public knowledge and attitude with regard to deceased organ donation	General public	Qualitative	22	NA
Wong <i>et al</i> (2011) <sup>114</sup>	Selangor	Malaysia	To explore the knowledge, attitude, perception, and barriers toward deceased organ donation	General public	Cross sectional	259	NA
Yadav et al (2020) <sup>79</sup>	Haryana	India	To determine the knowledge and attitude of faculty members of a university	Faculty members	Cross sectional	170	Not specified
*This study was ba sample size is not n	sed on the popul: nentioned in the	ation data; th evidence tab	*This study was based on the population data; the findings were based on national Indian population which was 228879. Since it would over-represent the actual studies, this study sample size is not mentioned in the evidence table but in the notes here.	379. Since it would over-repr	esent the act	ual studies	this study

### Willingness and actual behaviour towards deceased organ donation

showed Greater knowledge positive influence on the attitude and willingness across all Indian regions.<sup>17 41 43 44 50 92 99–103</sup> 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.<sup>38 45 46 49 66 68 92 99 101</sup> However, though knowledge had a positive association towards 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.<sup>58</sup> 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.<sup>44 68 75 79 94 95 97 100 104-107</sup> On contrary, the most common 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.<sup>72 75 91 99 104–111</sup>

Higher proportion of participants were willing to receive compared with donating<sup>38</sup> <sup>45</sup> <sup>46</sup> <sup>58</sup> <sup>68</sup> <sup>99</sup> <sup>101</sup> <sup>112–114</sup> 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,<sup>46</sup> <sup>61</sup> <sup>62</sup> which may be related to the knowledge on what organs can be donated.<sup>67–72</sup> <sup>76–78</sup> <sup>86</sup> Nonetheless, majority of the participants were willing to support and promote organ donation in their region and was similar across India.<sup>55</sup> <sup>57</sup> <sup>91</sup> <sup>99</sup> <sup>109</sup> <sup>109</sup> <sup>110</sup>

Younger adults, participants from higher socioeconomic status and participants with higher education or healthcare education demonstrated higher willingness towards deceased organ donation among Indians living globally.<sup>17 27 43 45 47 48 53 58-61 108</sup> However, this was not consistent during the time of actual behaviour. Studies showed that there was almost equal distribution of participants from lower socioeconomic status and lower education, who gave consent and actually signed for deceased organ donation.<sup>47 90 96</sup> However, this conclusion is based only from few studies which showed to be similar in north and south of India.<sup>47 90 96</sup>

#### **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<sup>526568718293100115116</sup>—however opted family as the major barriers towards organ donation,<sup>46 63 65 69 72 94 100 102</sup> this was identified even among Indians living outside India.<sup>27 117</sup> 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 (ie, UK and Canada) revealed that they are less concerned of sharing their views compared with their older generations (ie, mostly migrant generation) and were more willing to discuss their wishes with their families, <sup>17 27 81 118</sup> 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.<sup>90 119</sup> Also, during the time of consent request, unknown will of the deceased showed to be a significant challenge during the decision-making process,<sup>96</sup> 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 with other students<sup>55 56 100 120</sup> and lower among family members from rural areas.<sup>99 116</sup> However, while higher proportion of individuals were willing to support family members for organ donation,<sup>38 44 61 71 88 92 101 118</sup> only very few families actually supported this decision when families were approached for consent.<sup>90</sup>

Though studies included found no association based on marital status,<sup>38 45 101</sup> one study found that unmarried individuals appeared to be more willing to donate compared with married couples.<sup>101</sup> Also, participants who were aware of their spouse's approval opinion, they were more willing to donate compared with those unaware of their spouse's opinion.<sup>45</sup> 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.<sup>4 17 38 48 50</sup> 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 decisionmaking 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.<sup>4</sup>

#### Fear and mistrust

Fear on misuse of organs by the healthcare team, and lack of trust was the other major barrier reported.<sup>55 63 64 68 69 71 72 78 83 89 94 97 104 105</sup> Participants from several studies relate organ donation to organ trafficking and misuse which leads them to fear and mistrust.<sup>49 58 65 99 105</sup> 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.<sup>90</sup>

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 towards donation and give less care towards saving her child.<sup>27</sup> In parallel, general population from India also feared premature declaration of death for the need of organs.<sup>39 99 120</sup> However, healthcare population groups were less likely to believe that there will be any premature declaration of death by the doctors.<sup>38 71 85 87</sup>

### **Religious influence**

Overall, majority of the participants favoured organ dona-tion.<sup>27 38 46 47 49 61 80 81 101 106 108 109</sup> However, when further looked based on religion, different studies showed different religious groups to be more willing to donate compared with individuals from another religious group,<sup>45 48 61 73 121</sup> showing no consistency on which particular religion is more supportive or rejective. <sup>45</sup> <sup>48</sup> <sup>52</sup> <sup>61</sup> <sup>121</sup> 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.<sup>27 97</sup> However, among studies undertaken outside India, Indian Muslim participants were identified to be less likely or supportive towards organ donation.<sup>44495 106 117</sup> Oualitative 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.<sup>108</sup>

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<sup>38</sup> <sup>68</sup> <sup>72</sup> <sup>88</sup> <sup>90</sup> <sup>97</sup> <sup>101</sup> <sup>109</sup> and also considered religion as the very least barrier towards organ donation.<sup>44</sup> <sup>45</sup> <sup>63</sup> <sup>65</sup> <sup>68</sup> <sup>90</sup> <sup>114</sup> <sup>115</sup> <sup>122</sup> 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.<sup>27</sup> Yet, favourable opinion of religion towards organ donation was found to be positively correlating with their willingness to donate.<sup>38</sup> <sup>52</sup>

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

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.<sup>90</sup>

#### **Bodily issues**

Majority of the individuals from the reviewed studies were not concerned about bodily issues though it has

to undergo incisions while explanting.<sup>38-40 45 46 61 91 97 118</sup> 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.<sup>49 87</sup> While 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.<sup>72</sup> In relation to funeral practices involving the deceased body, majority were aware that normal funeral practices can be conducted even after donating organs, <sup>38</sup> <sup>49</sup> <sup>61</sup> <sup>87</sup> <sup>91</sup> <sup>115</sup> <sup>115</sup> <sup>115</sup> <sup>115</sup> <sup>115</sup> <sup>115</sup> <sup>115</sup> also evident.<sup>49 55 87</sup> However, majority opted body disfigurement, but less proportion, as one of the least reasons to be a barrier towards 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 towards 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.<sup>87 90 97</sup> 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.<sup>46</sup> <sup>63</sup> <sup>65</sup> <sup>69</sup> <sup>100</sup> <sup>117</sup> 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<sup>27 58</sup> while the prior maybe more concerned towards communication issues.<sup>52,65,68,90,93,100,115,116</sup> While majority were willing to be an organ donor,<sup>27 43 45 47 48 53 58-61</sup> they were unaware on how to register to be an organ donor.<sup>40 50 53 55 56 70 71 94</sup> Therefore, further campaigns on registration procedure

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.<sup>27 40 48 55 63 64 68 69 71 72 78 97</sup> 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,<sup>123</sup> 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 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 sociocultural and institutional structures influences the organ donation behaviour.

Various other factors such as age, sex, education and socioeconomic status showed greater influence on willingness to donate.<sup>27 45 47 48 53 58 61</sup> However, studies showed that they did not hold true during the time of consent.<sup>47 96</sup> 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,<sup>84 114</sup> Indians living in the UK and Canada were considered to have lower attitude and willingness.<sup>17 117</sup> This could have been due to their respective sociocultural practices of Muslim major country (ie, Malaysia) and Christian major country (ie, Canada and the UK) with Hindu major population (ie, Indians). This argument is also supported by a study that compared organ donation willingness between Christian, Hindu and Muslim major native population.<sup>58</sup> The similarity identified was that irrespective of their geographical location, this was a collectivist decision and not an individual's decision<sup>4 85 117</sup> with family, fear and mistrust, and bodily issues identified to be the major barrier.<sup>44 83 85 95 105 107 108</sup>

Methodologically, studies conducted among the Indian ethnic group outside India were collectively identified as South-Asians or Asians<sup>23–26 106</sup> while they differ culturally. socially, politically, economically and even religiously.<sup>124</sup> Two studies included from UK in this review have clearly shown such a difference with the neighbouring country (ie, India and Pakistan).<sup>27 58</sup> 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,<sup>7</sup> it is important to understand their behaviour outside India. Studies show difference between various migration generations from the same ethnicity.<sup>27 58</sup> This cannot happen without the influence of time elapsed since immigration, immigrant generation (ie, first, second or higher), acculturation, enculturation, perceived discrimination, attitudes/ mistrust toward healthcare system, community barriers, sociocultural 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.<sup>30 125</sup> 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 towards registration but show lower willingness and even lower practice of registration. Though this study showed the complex relationship and influences towards 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.

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