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Barriers to conversations about deceased organ donation among adults living in the UK: a systematic review with narrative synthesis

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ABSTRACT

Objectives To explore the barriers to conversations about deceased organ donation among adults living in the UK.

Design Systematic review with narrative synthesis.

Data sources PubMed, MEDline via OVID, APA PsycInfo via EBSCO, Web of Science via Clarivate and Scopus via Elsevier, covering studies that were published between January 2006 and December 2023. Searches were conducted on 1 December 2023 and completed on 2 February 2024.

Eligibility criteria Studies published between January 2006 and December 2023, focusing on barriers to organ donation conversations among adults in the UK. Both qualitative and quantitative studies were included, emphasising cultural and generational factors. Non-English studies and those unrelated to the UK were excluded.

Data extraction and synthesis Screening and data extraction were conducted by two independent reviewers using a standardised tool. Quality assessment was performed using Joanna Briggs Institute checklists, evaluating study bias. A narrative synthesis approach was used to integrate findings from heterogeneous studies.

Results 11 studies (6 qualitative, 5 quantitative) with a total of 4991 participants were included. Four main thematic barriers emerged: (1) jinx factor—cultural beliefs associating discussion of death with bad luck; (2) generational impact—younger people were more open but cautious of upsetting parents; (3) ethnic disparities in conversations—varied challenges across diverse backgrounds and (4) cues to action—media and personal experiences prompted conversations. Facilitators included culturally tailored communication and community engagement.

Conclusion Conversations about death and organ donation are often brief and hindered by cultural taboos surrounding death, generational differences in attitudes and the influence of family dynamics. Further research is needed to understand communication patterns better and to tailor interventions that encourage open discussions about organ donation across different ethnic groups.

PROSPERO registration number CRD42022340315.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Comprehensive analysis of cultural barriers, including religion, ethnicity and generational barriers, to organ donation conversations in the UK.
- ⇒ The participants' characteristics are presented as originally detailed in the study, ensuring consistency and fidelity to the original identity as specified by the authors. Integration of both qualitative and quantitative studies provides a diverse range of data, incorporating evidence from both subjectivist and objectivist perspectives.
- ⇒ Limited to UK studies, restricting the generalisability of findings to other settings or countries.

INTRODUCTION

Organ donation offers a life-saving solution for patients with end-stage organ failure, yet demand consistently outpaces supply.[1–3] In the UK alone, approximately 7000 individuals are on the transplant waiting list each year, while only 4000 transplants are conducted, contributing to increased waiting times and mortality.[4] Despite advancements and public awareness efforts, a substantial gap persists between willingness to donate and actual donor registration.[5–7]

To address this issue, the UK adopted an opt-out system, following a global shift towards presumed consent policies. However, family consent remains pivotal, as relatives often retain the right to override presumed consent, particularly when the deceased's wishes were not clearly communicated.[8 9] This underscores the importance of effective family discussions about donation preferences to honour potential donors' intentions.[10]

While extensive research has examined organ donation rates in opt-in vs opt-out systems, fewer studies have explored the interpersonal dynamics that shape family discussions about organ donation.[11–15] In particular, the barriers to these discussions within culturally diverse populations in the UK remain under-researched, despite their critical role in influencing family consent.

Addressing this gap is vital, as evidence from Wales indicates that while the opt-out policy increased donor rates, family refusals persisted when intentions were unclear.[8] Moreover, anticipated regret, cultural beliefs and insufficient awareness significantly influence family consent, particularly when discussions about donation preferences have not occurred.[16 17]

Psychological and societal factors, including fear of death, cultural norms and generational differences, further complicate these discussions.[18 19] Yet, the extent to which these barriers differ across diverse ethnic communities in the UK remains unclear. This systematic review aims to synthesise evidence on the barriers to conversations about deceased organ donation among adults in the UK, with a focus on cultural and generational influences. By addressing these gaps, the review seeks to inform strategies that foster culturally sensitive, open dialogue. Such interventions could enhance public trust, support the opt-out system and ultimately improve donation rates.

RESEARCH QUESTION

What are the barriers to conversations about deceased organ donation among adults living in the UK?

METHODS

Search strategy and selection criteria

The research team collaborated with the subject specialist librarians with expertise in systematic review methodology. While the strategy was not formally peer-reviewed by a second librarian, it was developed following best practice guidelines and employed robust search techniques to ensure comprehensive and replicable coverage across relevant databases. Each step was documented, and database-specific adjustments were made to refine search precision and guided by previous systematic reviews on organ donation[19–21] (see online supplemental file 1). For each database, the search was limited to studies published from 1 January 2006 to 1 December 2023. This date range was selected to reflect developments following the establishment of National Health Service Blood and Transplant (NHSBT) in 2005. NHSBT's inception marked a significant shift in national policy and public health infrastructure around organ donation, driving academic and policy interest in understanding and addressing barriers to donation. The comprehensive search using the following databases: PubMed (including MEDline full text), MEDline ALL via OVID, APA PsycInfo via EBSCO, Web of Science via Clarivate and Scopus via Elsevier. MeSH terms and key terms relating to the PICC framework (Population—adults; phenomenon of Interest—deceased organ donation; Context—factors influencing conversation; Country—UK) were initially identified and refined through trial searches. Key terms were searched in the title, abstract and keyword fields, except for APA PsycInfo, where terms were searched in the abstract field only.

Studies were included if they involved adults aged 18 years or above, of any gender, residing in the UK, and were published in English between 1 January 2006 and 1 December 2023. Eligible studies comprised quantitative, qualitative and mixed-methods research focused on identifying barriers to conversations about deceased organ donation. Conversely, studies were excluded if they focused exclusively on living donation, tissue, or bodily fluids, involved participants below 18 years of age, were non-peer-reviewed articles, commentary papers, conference reports, media reports, reviews or audits or were published in languages other than English.

A total of 7478 citations were retrieved. Initial duplicate removal using EndNote eliminated 1507 duplicates. The remaining studies were transferred to Rayyan for additional duplicate removal, identifying 430 more duplicates, which facilitated the initial screening of titles and abstracts.

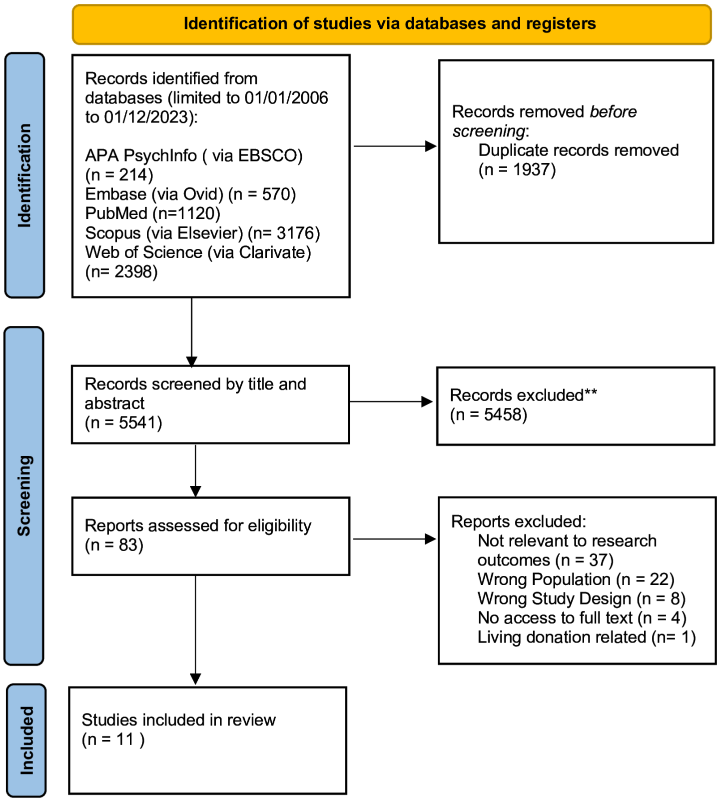
In the first phase, two reviewers (VM and BB) independently screened the titles and abstracts in blind mode. Any disagreements were resolved by a third reviewer (JWF). In the second phase, 83 full texts were retrieved, and screening of citations was conducted independently by reviewers to ensure compliance with the inclusion criteria. Disagreements were resolved by an independent reviewer (JWF). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (figure 1) illustrates the screening process.[22]

Data extraction and quality assessment

The quality of the included qualitative and quantitative studies was assessed using the Joanna Briggs Institute's (JBI) critical appraisal tools.[23] We selected the quality appraisal tool based on its application in prior reviews of organ donation studies.[19 24] The tools evaluate aspects such as methodological quality and relevance.[25] All included studies were independently carried out by two reviewers (BB and VM) using the appropriate JBI checklist. Although the review did not exclude studies based on quality assessment, studies with fewer 'yes' responses on the checklist were assigned less confidence. Conflicts between the two reviewers were resolved through discussions with a third reviewer (CT), ensuring consensus on the quality of each study. The quality assessment results for the included studies are presented in figures 2 and 3).

Data synthesis

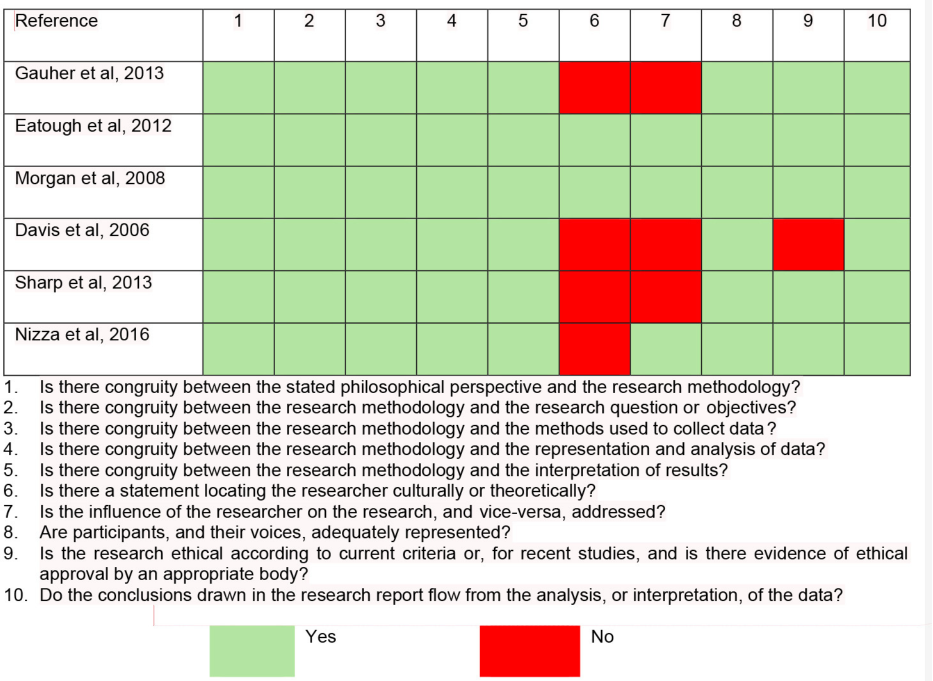
Both qualitative and quantitative studies were included in this review by adopting a narrative synthesis approach,[26] an established approach used by other systematic reviews that included both quantitative and qualitative studies.[19 27] The narrative synthesis followed three steps: (1) grouping and clustering of the included studies into themes, (2) developing textual summary and (3) assessment and interpretation. The studies were included based on a stage-by-stage screening process, after which they were appraised for their quality. The included studies were then segregated based on the study design, and an evidence table



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart.

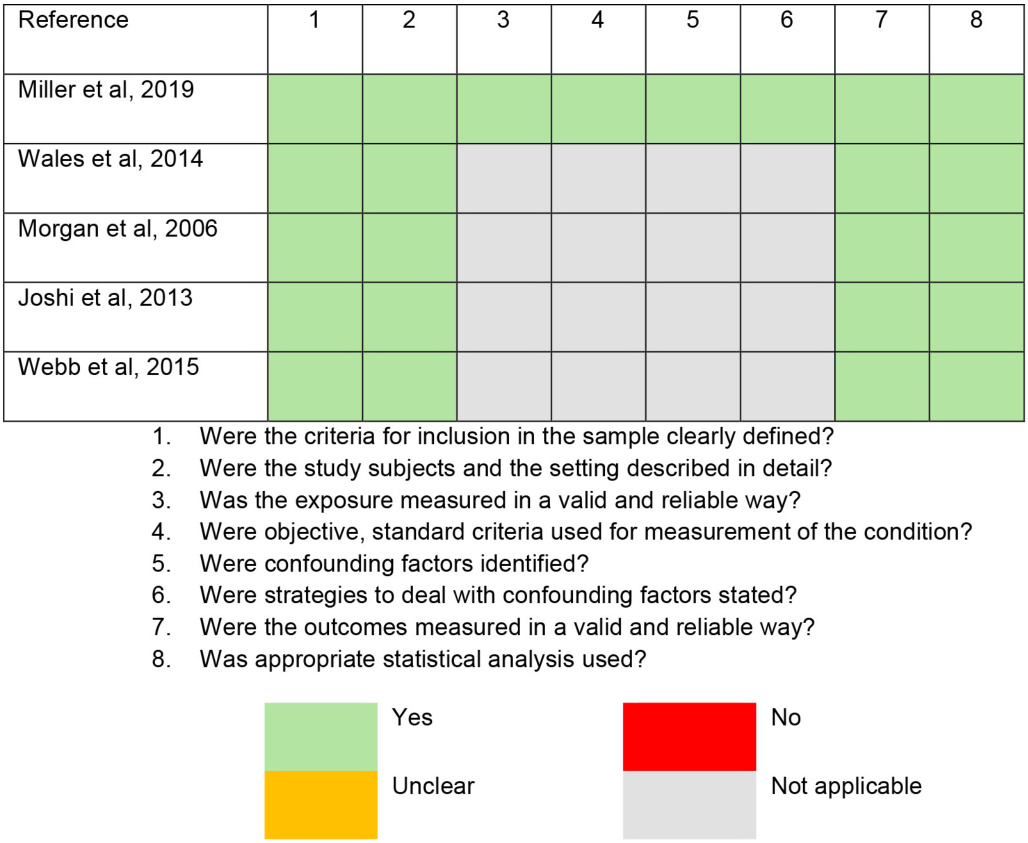


Reference	1	2	3	4	5	6	7	8	9	10
Gauher et al, 2013	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟩	🟩	🟩
Eatough et al, 2012	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Morgan et al, 2008	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Davis et al, 2006	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟩	🟥	🟩
Sharp et al, 2013	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟩	🟩	🟩
Nizza et al, 2016	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩

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 objectives?
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 conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

🟩 Yes 🟥 No

Figure 2 Quality appraisal checklist for qualitative studies.



Reference	1	2	3	4	5	6	7	8
Miller et al, 2019	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Wales et al, 2014	🟩	🟩	⬜	⬜	⬜	⬜	🟩	🟩
Morgan et al, 2006	🟩	🟩	⬜	⬜	⬜	⬜	🟩	🟩
Joshi et al, 2013	🟩	🟩	⬜	⬜	⬜	⬜	🟩	🟩
Webb et al, 2015	🟩	🟩	⬜	⬜	⬜	⬜	🟩	🟩

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 reliable way?
4. Were objective, standard criteria used for measurement of the condition?
5. Were 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?

🟩 Yes
🟧 Unclear
🟥 No
⬜ Not applicable

Figure 3 Quality appraisal checklist for quantitative studies.

was also developed (table 1). A summary of findings for each of the included studies was then drafted, following which the data was coded for interpretation. When interpreting the findings, both converging and contrasting findings were looked for between the studies. If there were findings that contradicted, they were then looked further into the studies such as their demography, participant age, gender or the immigration generation to give further details on what could have contributed to the differences.[19 27 28]

The protocol for the review was registered with PROSPERO (CRD42022340315) (available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD4202234031518).

Findings

Grouping and clustering

Among the 11 studies reviewed, 6 were qualitative, involving focus groups and interviews, 4 were quantitative based on structured questionnaires and 1 used focus groups to inform questionnaire generation and presented quantitative findings from the questionnaire. Nine studies identified the participants with various ethnic or cultural backgrounds. We have used the same descriptors as presented by the authors of the studies included and refrained from making any additional grouping to ensure consistency and fidelity to the original classifications (table 1).[16 29–38] The total number of participants in these eleven studies was 4991. Among the studies that identified ethnicity/cultural identity, 1903 individuals were identified as Indian, Pakistani, Bangladeshi, black British Caribbean, black Caribbean, black African other black, and Polish living in the UK.

Integration and relationship

Using narrative synthesis,[26] the findings from the 11 studies are organised under four themes: (1) jinx factor, (2) generational impact, (3) ethnic disparities in conversations and (4) cues to action.

Jinx factor

A significant reticence towards discussing death was evident both in qualitative and quantitative studies. Many participants preferred not to discuss death at all,[32] highlighting a pervasive cultural inhibition against addressing mortality directly. Death was often referred to as the “elephant in the room” (White British, female)[36] with participants feeling uncomfortable and reluctant to think/discuss dying, “We don’t like to think about death, it’s too final.” (African Caribbean, anonymous).[33] Discussing one’s own mortality was regarded as taboo, with many believing that contemplating death would bring bad luck. “Yeah, I’d be happy to just fill out the form and then just like not think about it [laughs]… it’s kind of that… jinxing kind of your destiny, that occurred to me just then as well…” (White British, female)[36] and this thought of jinxing was statistically significant among those who opted out and those who were not sure of their

Table 1 Evidence table of included studies

Study	Aim	Participants	Study design	Data collection method	Participants (n)	Sampling technique	Study participants' racial/ethnic identity as identified in the study
Davis and Randhawa[33]	Investigate attitudes and religious influence on organ donation among black communities in specific UK boroughs.	Black residents in Lambeth, Southwark, Lewisham	Qualitative	Focus groups	11	Purposive	Africans, Caribbeans, and black others
Eatough *et al*[37]	Explore brain donor relatives' experiences.	Adults who consented to brain donation of a relative/friend.	Qualitative	Semistructured interviews	19	Purposive	Not mentioned clearly
Gauher *et al*[31]	Understand attitudes towards organ donation among UK Indian and Pakistani students.	Indian and Pakistani university students	Qualitative	Focus group and semistructured interviews	4 groups, 58 interviews	Stratified (focus groups), purposive/ convenience (interviews)	Indian and Pakistani
Joshi[30]	Examine organ donation attitudes and behaviour of young adults in the UK, with focus on South Asians.	Adult college/university students in the UK.	Cross-sectional	Survey	439	Purposive	Indian, Pakistani, Bangladeshi, white, black, Chinese and other
Miller *et al*[16]	Assess opt-out legislation impact on organ donation intentions and test National Health Service myth-busting intervention.	Residents of Scotland, England, Northern Ireland	Cross-sectional	Focus groups and survey	1202	Opportunistic	General public from Scotland, England and Northern Ireland
Morgan *et al*[29]	Investigate kidney donation attitudes by ethnicity for recruitment insights.	Attendees of four general practices in Lambeth Primary Care Trust.	Cross-sectional	Survey	1536	Purposive	Black Caribbean, black African, Indian, Pakistani, Bangladeshi, other Asian, mixed ethnic, other black and other ethnic minorities
Morgan *et al*[34]	Study ethnicity and willingness to register as a donor, focusing on identity.	Adults from multiethnic areas in SE London	Qualitative	Semistructured interviews	14	Purposive	Black British Caribbean
Nizza *et al*[36]	Explore non-donors' motives and cognitive/ affective factors in organ donation decisions.	Non-religious British women (20–35 years) without chronic conditions	Qualitative	Semistructured interviews	4	Purposive	White British women
Sharp and Randhawa[35]	Investigate deceased organ donation knowledge/attitudes among the Polish community in Luton/ Dunstable.	Recent and postwar Polish migrants	Qualitative	Focus groups, interviews	1 group, 7 interviews	Purposive	Polish
Wale *et al*[38]	Explore the associations between a wish to donate, discussion experiences and knowledge among hospice care staff.	Hospice doctors, nurses, assistants	Cross-sectional	Survey	74	Convenience	Not mentioned clearly
Webb *et al*[32]	Identify reasons for support versus low registration/consent rates for organ donation in England.	Adult residents of England.	Cross-sectional	Survey	1549	Probability	White, black and minority ethnic, and other/not stated ethnicity

decision.[16] Participants did not want to talk about death as they described it to be too final, "We don't like to think about death, it's too final." (Caribbean, female, 31–44 years, FGD)[33] or act as a jinx "I'd be happy to just fill out the form and then just like not think about it [laughs],…when we just then spoke about that …it's kind of that…Jinxing kind of your destiny" (White British, female).[36] Hence, the avoidance behaviour driven by the belief in the jinx was a notable barrier to open conversations about death.[36]

Generational impact

Generational differences in attitudes towards discussing deceased organ donation were identified among the UK-born participants of Indian, Pakistani and Bangladeshi (also commonly referred to as South Asians) origin. One of the studies showed that participants from India and Pakistan respect the views of their parents also while demonstrating a greater willingness among the younger generation to engage in family discussions compared with their elders, "With organ donation in our generation, we are generally less tied to things and generally more willing to argue [than older people]" (Indian, male).[31] However, parents often exclude children from these decisions to protect them.[37] In the view of cultural norms to consult family for decisions and the importance of family consent in Pakistan, younger generations expressed the need for open family discussions before making decisions.[31] However, compared with the white population, a higher proportion of discomfort was identified among the young Pakistani and Bangladeshi participants regarding conversations on organ donation with their parents (6% of white population vs 18% of Indians vs 52% of Pakistani/Bangladeshi).[31] The importance of family consent before making any decision among Pakistani families was mentioned by a participant: "I do pay a lot of attention to what my parents and … older brother say. Their views… would probably have a huge impact on my views of organ donation" (Pakistani, male), and the fear of causing discomfort to parents as mentioned by another participant "You don't want to cause them grief and it could be regarded as disrespect if they don't agree" (Pakistani, female) imposes a higher barrier among the younger generation from Pakistani origin in discussing organ donation with their parents.[30 31]

Additionally, despite holding organ donor cards, 9% of white participants, 22% of Indian participants and 46% of Pakistani/Bangladeshi participants fear their decision would be overridden by their parents or spouse, undermining the effort among South Asian participants to initiate such conversation.[30] In parallel to this, around 75.7% and 64.5% of hospice care staff also believed such discussions would distress patients and their relatives, respectively, leading 65.3% of staff to discuss deceased organ donation only if initiated by the patient or family members.[38] Conversations were often avoided with elderly or terminally ill individuals, who were perceived as too old or ill to make such decisions.[37] Additionally, misconceptions that organ donation would physically harm the deceased and upset the family deterred discussions.[37]

Ethnic disparities in conversations

Individuals from Indian, Pakistani, Bangladeshi, black, black British, Caribbean or African backgrounds are less likely to engage in conversations about organ donation due to various barriers, while white participants were more likely to engage in these discussions.[29 30 32 38] A quantitative comparison found that 6% of white participants, 18% of Indian participants and 52% of Pakistani/Bangladeshi participants believed discussing organ donation with their parents would upset them, deterring such conversations.[30] Additionally, despite holding organ donor cards, Pakistani/Bangladeshi participants feared that their decision had a higher potential to be overridden compared with Indian and white participants, undermining the efforts to build the conversation, especially among South Asians.[30] Another study indicated that British Africans had the highest proportion who never discussed organ donation, followed by South Asians and Caribbeans.[34] These findings underscore ethnic disparities in organ donation conversations. However, ethnicities were not uniformly classified/defined across the various studies included in the present review.

Cues to action

Despite identifying barriers to conversations about deceased organ donation, this review also identified cues to action. Deceased organ donation was not typically part of regular conversations,[32] due to the barriers mentioned above. However, conversations about organ donation were often triggered by exposure to movies, advertisements or media featuring organ donation.[35] The absence of such exposure was said to hinder these conversations, as mentioned by a participant: "I haven't seen much about [organ donation] myself or heard about it or seen much publicity." (Pakistani, male, medic)[31] and that media could be used, especially in Bollywood movies in India: "I think [the media] could [make more impact]… Indian movies, especially because Bollywood is huge" (Indian, male, non-medic).[31] In another study, it was reported that shifting the discussion from one's own death to another person's death facilitated the conversation, reducing the negative impact of jinxing.[36] Discussions were possible between white couples during everyday domestic activities,[37] though this was not seen between parents and their children or people from other ethnic communities. One interesting concern among the young population identified in a qualitative study was that the primary barrier to cues to action was not an unwillingness to discuss organ donation, but rather a lack of understanding and experience on how to start such conversations: "I don't think its awkward to bring up the topic,… it's just I don't see … how the topic will come out…" (Indian, female, medic).[31]

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

DISCUSSION

This systematic review aimed to identify the barriers to conversations about deceased organ donation with family members among adults living in the UK. During the screening process, many identified studies addressed general barriers or influencing factors affecting the willingness to become an organ donor.[39–41] There is a notable dearth of research specifically investigating the barriers to conversations about deceased organ donation with family members in the UK. In most studies, this issue was addressed merely as one of the survey questions and lacked in-depth analysis to identify the factors influencing these barriers in the UK context or at least the pattern of communication. Consequently, only 11 studies met our inclusion and exclusion criteria that answered the research question of this review.

In most countries, including the UK, regardless of whether an opt-in or opt-out policy is employed for deceased organ donation, a soft approach is followed.[11 42] In this system, the final consent for organ donation is sought from the next-of-kin of the potential deceased donor. Within such a framework, prior communication of an individual's intent to donate or not to donate is crucial for facilitating swift, clear, decisive and empowering decision-making during emotionally challenging times.[43] Research has demonstrated that early conversations with family members about one's wish to donate organs significantly streamline the donation process. Conversely, the absence of such discussions has been shown to impede or delay decision-making during critical moments.[44 45]

However, while talking about one's own death is somewhat normalised in Western contexts, such as discussing death/funeral insurance plans,[46 47] this is contrary to practices in many countries where the UK's diverse ethnic heritage population is from.[48 49] Especially among Asians, Caribbeans, Africans and Arabs, discussing one's own death is often seen as uncomfortable, taboo or as potentially bringing bad luck, hastening death or acting as a jinx, leading to being highly reluctant to talk about death and organ donation with family members.[30–33 37] However, when conversations initiate, individuals typically start by assessing whether there is consensus among family members,[50 51] which may prove challenging when individuals perceive resistance from the parents. While participants in the included study experienced differing opinions with their parents, Indian participants were more inclined to engage in further discussion before deciding. In contrast, Pakistani participants placed a stronger emphasis on parental and family influence and were often more comfortable aligning with their family's views.[31] Hence, such variations based on the cultural, religious and social context are to be considered in campaigning strategies to encourage/promote conversations on organ donation within families.

Messaging strategies in organ donation campaigns, such as "Save someone… by telling your family you want to be an organ donor",[52] are designed to encourage individuals to initiate conversations with family members. However, research suggests that people, particularly younger individuals, feel more comfortable discussing organ donation with siblings than with parents, who typically hold the authority to provide consent for deceased organ donation.[51] This insight indicates that campaigns could benefit from more targeted messaging, emphasising specific actions and guidance to ensure conversations reach those with decision-making authority.

A study in Asia indicated that seeking information from healthcare professionals or individuals with lived experiences improved comfort in talking about death more than media sources.[53] However, participants from the included studies were not able to see much about deceased organ donation around the community where they live, making it harder for such conversations.[35 36] Therefore, enhancing the visibility of the lived experiences of donor families using media platforms could positively impact conversations about organ donation,[54] rather than celebrities, adding a genuine emotional dimension to the topic. However, it is crucial to assess the effectiveness of media campaign content and identify messaging strategies that resonate with culturally diverse populations.[55] Therefore, while the young generation are willing to talk about organ donation, providing ideas on how to initiate a conversation, rather than only facts to debunk the myths, could be a valuable resource to promote conversation on death and organ donation. It is essential to encourage or normalise conversations about organ donation, as many countries ultimately base decisions on the next-of-kin's word, where prior conversation with family would be helpful to give consent for deceased organ donation.

One of the limitations of the studies included is the variation in how participants were grouped by ethnicity. According to the 2021 UK Census, ethnic communities in the UK are categorised as: (1) Asian or Asian British, (2) black, black British, Caribbean or African, (3) mixed or multiple ethnic groups, (4) white and (5) other ethnic groups.[56] In one of the included studies,[31] participants were clearly grouped as Indians and Pakistanis, reflecting their different national, cultural and religious backgrounds, which led to distinct findings for each group. In contrast, other studies combined Indians, Pakistanis and Bangladeshis,[29] or grouped Pakistanis and Bangladeshis together,[30] without distinguishing between them, considering their social, cultural and religious differences. Additionally, in some studies, participants were classified simply as 'black and minority',[32] while others used more specific categories, such as 'black Caribbean', 'black African' and 'other black'.[29 34] These inconsistencies in ethnic grouping present a challenge, as they risk overlooking important sociocultural and religious differences that may influence attitudes and behaviours. This issue was also highlighted in a previous systematic review on organ donation, which found that South Asian populations were often treated as a single, homogeneous group, despite significant sociocultural and religious diversity within the community.[19] Consequently, a limitation of the present review's findings is the reliance on inconsistent ethnic categories used across the published studies, which restricts the accuracy and depth of the data and may overlook those important socially constructed nuances.[57]

Both quantitative and qualitative studies were combined in one review by following an established narrative synthesis.[26] While narrative synthesis is often criticised for its lack of transparency and subjective bias, we have used the actual quotes recorded in the included qualitative studies to strengthen the findings. This study should also be taken with the limitation that the evidence is restricted by UK studies only. A broader global scope could provide more evidence on the barriers to conversations on death and deceased organ donation from various ethnic populations.

CONCLUSION

This study highlights the barriers to discussing deceased organ donation with next-of-kin and stresses that campaigns should address specific details to support these conversations. The findings point to the need for further research in the UK into barriers and communication patterns with next-of-kin, as conversations on death and organ donation vary significantly across different communities. Evidence suggests that while such topics are difficult to approach, understanding these differences could help tailor interventions more effectively. Enhanced visibility of organ donation could improve individual understanding and awareness. However, it remains unclear whether it directly influences conversations with next-of-kin about deceased organ donation.

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Contributors SW: conceptualisation (equal), writing—original draft (lead), formal analysis (lead) and writing—review and editing (equal). JWF: conceptualisation (equal), writing—original draft (lead), formal analysis (supporting) and writing—review and editing (supporting). CT: conflict resolution in methodology (lead) and writing—review and editing (equal). VM and BB: screening literature search (equal) and writing—review and editing (supporting). BPV: guarantor, conceptualisation (equal), writing—original draft (supporting), writing—findings, review and editing (equal). Penelope.ai was used to check the manuscript for BMJ Open criteria.

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