

BMJ Open Barriers and facilitators of deceased organ donation among Muslims living globally: protocol for an integrative systematic review using narrative synthesis

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ABSTRACT

Introduction Muslims have been shown to have less favourable attitudes towards organ donation and are less likely to consent to donate their organs. While several studies have been undertaken globally to identify the barriers and facilitators of organ donation, no systematic review has synthesised this evidence to date. Therefore, this systematic review aims to identify the barriers and facilitators of organ donation among Muslims living globally.

Methods and analysis This systematic review will include cross-sectional surveys and qualitative studies published between 30 April 2008 and 30 June 2023. Evidence will be restricted only to studies reported in English. An extensive search strategy will be used in PubMed, CINAHL, Medline, Scopus, PsycINFO, Global Health and Web of Science, as well as specific relevant journals that may not be indexed in these databases. A quality appraisal will be undertaken using Joanna Briggs Institute quality appraisal tool. An integrative narrative synthesis will be used to synthesise the evidence.

Ethics and dissemination Ethical approval has been obtained from the Institute for Health Research Ethics Committee (IHREC) (IHREC987), University of Bedfordshire. The findings of this review will be disseminated widely through peer-reviewed journal articles and leading international conferences.

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INTRODUCTION

There is a wide gap between the number of people who donate organs and the number of patients who require organs, which is recognised as a global phenomenon.¹ In addition, there remains inequity within the available number of donors in terms of ethnicity and religion.²⁻³ In the UK, South Asians are less likely to donate organs when compared with their white British counterparts, with Muslim South Asians shown to have less favourable attitudes toward organ donation and less acceptance of donation.⁴⁻⁶ This finding is not unique to the UK, whereby

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The review uses an integrative narrative synthesis method, which will enable the synthesis of findings systematically from both quantitative and qualitative research.
- ⇒ The review adopts the Joanna Briggs Institute quality appraisal tool, enabling the representation of evidence quality.
- ⇒ The review benefits from more than one reviewer to enhance the credibility of the study.
- ⇒ Studies will be limited to those reported in English, which may exclude some relevant studies.

a similar trend has been identified among the Muslim population who reside in both Arab and non-Arab countries.⁷⁻¹⁴

Global research has revealed the important influence of religion on organ donation decisions. Therefore, understanding the view of organ donation from different religious groups is vital to enable informed decision-making for the public, especially among the Muslim community, whose decisions toward medical care and services have been shown to be driven by the perception of religion.¹⁵⁻¹⁷ In the UK, the All-Party Parliamentary Kidney Group recommended that all organ donation and transplantation service providers should be equipped with an understanding of the religious and cultural aspects of their multiethnic patient population.¹⁸ These policy recommendations demonstrate the need for meaningful and effective public and faith engagement toward organ donation.¹⁹ However, for effective policy and strategies, there is a greater need to understand the barriers and facilitators of deceased organ donation among the Muslim community based on existing evidence.

Research that has examined the barriers to organ donation among the Muslim population living globally has identified a wide range of relevant factors. While the Muslim population is identified to be highly dependent on the scriptures and their religious leaders, the lack of direct counsel from the scriptures, lack of information and inconsistent opinion of the religious leaders have left this particular population in a confused state and undecided about their choice toward organ donation.^{20–22} Other reasons have included the preference to be buried intact, uneasiness toward cadaveric manipulation, ethical concerns and having no control over the organ in the recipient's body once donated.^{6–9} However, among the same population, younger age groups, and individuals with lower levels of religiosity, higher education, awareness of organ shortage and experience with an individual suffering from end-stage organ failure have shown approval toward organ donation.^{10–20}

However, while there is emerging evidence globally that Muslims are less likely to donate organs,^{7–14} there has been no systematic review up to date that has identified and synthesised the evidence on the barriers and facilitators toward deceased organ donation among the Muslim population. Therefore, the aim of the present systematic review is to collate all of the evidence on organ donation among the Muslim community living globally to identify the barriers and facilitators of deceased organ donation. This systematic review seeks to critically appraise existing evidence and provide credible and informative conclusions which can be used to inform stakeholders, researchers, religious leaders and policymakers on how best to improve organ donation among Muslim communities living globally.^{23–24}

Research question:

What are the barriers and facilitators of deceased organ donation among Muslims living globally?

Methods and analysis

Protocol

This protocol follows the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol.²⁵

Inclusion criteria

The criteria for studies to be included in this review will be as follows:

Population

Studies that included adults aged 18 years or above who self-identify as Muslim will be eligible. We will include Muslim adults from both Arab and non-Arab countries since Muslims live in both these regions.

Context/settings

Studies from all settings will be eligible, including those in the community, workplace, residential and hospital settings. These places were identified from many relevant studies where the general public was studied. Studies reported in languages other than English will be excluded.

The Declaration of Istanbul took place in the year 2008 when more than 100 countries in the world signed the summit to enable an ethical and legal practice of organ donation around the world.²⁶ Therefore, this systematic review will search for studies from 30 April 2008 to 30 June 2023 (planned date of search).

Study designs

Qualitative and quantitative studies have been used to examine barriers and facilitators of organ donation.^{27–28} This review will include quantitative (only cross-sectional surveys) and qualitative studies. Experimental designs and intervention studies will be excluded.

Concept

This review will include studies and concepts related to deceased organ donation.

Outcome of interest

To identify the barriers and facilitators, several related outcome issues from other studies such as knowledge, awareness, attitude, perception, practice, perspectives, behaviour, registration, consent, barrier, challenges, discussion on organ donation, morals, belief, religion and cultural influence, and other factors influencing organ donation and organ pledge will be used. Any concepts related to inhibiting or stopping an individual from organ donation behaviours will be identified as barriers.

Exclusion criteria

The exclusion criteria for this study are as follows:

1. Studies that have included Muslim participants in the sample but have not clearly distinguished the findings of the Muslim population from other included religious participants.
2. Intervention-based studies (ie, trial-based, experimental studies) on organ donation.
3. Commentary papers on organ donation among Muslim population.
4. Papers published that are based on the views of religious leaders, as a similar literature review has recently been published.²²
5. Articles that have not been peer reviewed.
6. Studies which were undertaken with Muslim individuals below 18 years of age.

Search strategy

An extensive search strategy has been developed by the research team, which has been informed by previous systematic reviews exploring the attitudes of specific populations in organ donation,^{8–29–32} with the support of an information librarian specialist. The search terms used are provided in online supplemental file 1. Keywords will be searched using the titles, keywords, abstracts, full text, subject headings and Medical Subject Heading terms as appropriate to allow for a comprehensive search.

Information sources

Based on previous systematic reviews in organ donation,^{8 29–32} we will search for published research using the databases PubMed via US National Library of Medicine National Institute of Health; CINAHL, Medline with full text, Global Health and PsycINFO via EBSCO; Scopus via Elsevier; and Web of Science via Clarivate. We will also include journals that may have relevant research but are unlikely to be indexed in these databases (eg, *Saudi Journal of Kidney Diseases and Transplantation*, *Journal of Experimental and Clinical Transplantation*). We will also include any relevant dissertations, search from references and relevant reports. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart will be used to illustrate the study selection process.²⁵

Data management and selection process

The studies extracted from the databases will be exported to Rayyan (<https://www.rayyan.qcri.org>), a free web and mobile app, which enables to expedite the initial screening of duplicates, title and abstracts. Titles and abstracts will first be independently blind double-screened by two reviewers (AA-A, BPV) to remove any ineligible records. All full-text papers will then be retrieved and blind double-screened by two reviewers (AA-A, BPV) to determine if the remaining studies meet the required inclusion criteria. All reasons for exclusion will be recorded. Any discrepancies will be resolved through discussion or the inclusion of a third reviewer (GR/EC/RF).

Data collection process

The review team will use a standardised data charting form to extract the data from the included studies. The data extracted will include: (1) study details (eg, author(s), year of publication, country of origin), (2) a description of methods used (eg, aims of the study, inclusion/exclusion criteria, study design, setting/context, recruitment strategy, sample size and characteristics including ethnicity, religion, age, sex, socioeconomic status, instruments used (eg, topic guide/questionnaires)), and finally (3) main findings such as concepts and evidence related to barriers and facilitators of organ donation. This list is not exhaustive and may be subject to refinement. The template will be piloted on a subsample of three studies by two reviewers before use to ensure consistency, where any adaptations or refinements made will be reported. All extracted data will be verified for accuracy by a second reviewer. Any disagreements will be resolved by a consensus or, where necessary, a third reviewer (EC/GR/RF).

Quality assessment

A critical appraisal will be conducted on all included studies using the Joanna Briggs Institute (JBI) quality appraisal tool.³³ The JBI is a reliable tool used previously to assess the trustworthiness, relevance and results of published papers in the field of organ donation.⁸ This tool has separate checklists for cross-sectional and qualitative

studies. AA-A will undertake the quality appraisal, and BPV will verify the appraisal ratings. Disagreements will be resolved by a consensus, or where necessary a third reviewer (GR/EC/RF) will be approached. While no studies will be excluded based on the quality of the study, the appraisal will be made available to the readers to facilitate their judgement on the credibility of the findings.⁸

Data synthesis

Since this review will include both quantitative and qualitative studies, a narrative synthesis will be adopted. The narrative synthesis approach to data synthesis has been adopted and used appropriately in several other systematic reviews in organ donation.^{8 34} Narrative synthesis involves four steps, namely: (1) systematic search and quality appraisal, (2) grouping and clustering of included studies, (3) developing a textual summary of included studies, and (4) assessment and interpretation.³⁵ Before the data synthesis, the studies will be grouped based on the study design, such as quantitative and qualitative. The narrative will be first made for the quantitative studies, followed by the qualitative studies. For quantitative studies, all outcome measures will be identified (eg, knowledge, attitudes, willingness and behaviour). For qualitative studies, the result sections of the study will be coded, and a summary will be made for each study. A summary of all studies will integrate the findings, which will be segregated based on appropriate themes.

Patient and public involvement

None.

Ethics and dissemination

This review has been approved by the Institute for Health Research Ethics Committee (IHREC) (approval number: IHREC987), from the University of Bedfordshire. The findings from this systematic review will be used as part of the PhD research programme for the principal author.

The findings will be shared widely with academic and practitioner audiences through peer-reviewed journal articles, conferences and relevant organ donation committees. We will also share important findings with stakeholders, including relevant government and non-government organisations.

DISCUSSION

Several studies have shown religion to be a barrier toward organ donation globally.^{8 29–34 36} The Muslim population, in particular, have been identified as highly reluctant with less favourable attitudes towards organ donation behaviour and consent.^{7 37 38} While several studies have been undertaken among the Muslim population globally to understand their barriers, there has to date been no systematic review that has synthesised this evidence. With a lack of a systematic review in this area of organ donation, there is currently potential for repeating the same research and creating redundancy of evidence, wasting

resources such as funding and time, which could potentially lead to a slower pace in identifying the real gaps in research and moving forward to newer and more focused evidence regarding barriers and facilitators of organ donation among the Muslim population.

This systematic review will therefore serve several purposes, from practice to research. This systematic review will identify patterns of barriers and facilitators of organ donation among Muslims living globally, both in Arab and non-Arab nations and communities. This will evaluate whether the barriers are similar across countries or vary even within the Muslim community based on their country or ethnicity, such as Arab and non-Arab Muslims. This will also facilitate identifying existing research, evidence and gaps from where further research can be developed, thereby not wasting resources such as funding and time over the redundancy of information. The outcome of this review will also inform religious leaders and stakeholders on the potential strategies needed among this particular population.

This review will use appropriate methods used in evidence synthesis that involves reviewing both quantitative and qualitative approach. A most common and credible method used in such evidence synthesis is narrative synthesis as per Popay *et al.*³⁵ which has been used in other systematic reviews that used both quantitative and qualitative studies in organ donation.^{8 34} All of the stages in the study will be undertaken by more than one researcher. This investigator triangulation will improve the quality and credibility of the findings, an approach used by several systematic reviews.^{8 30 34} While there are several quality appraisal tools used in systematic reviews, JBI quality appraisal tool enables reviews of both cross-sectional and qualitative studies and also allows every reader to assess the quality of each study used in the review in the supporting graphical representation as used in another systematic review on organ donation.⁴ However, while the researchers have attempted to ensure the study is reliable, valid, authentic and credible, there are some limitations which are noteworthy. Limiting studies to those only published in English may exclude potentially relevant evidence and lead to language bias.³⁹ Further, while this review aims to study the Muslim population living globally, Muslims are not a homogeneous group; thus, there may be differences in relation to behaviour and perception within the Muslim population. Therefore, the findings of this study should also be taken with caution given that this 'sound same' but heterogenic population by practice may affect the findings based on various social and institutional structures in various countries.

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protocol for publication and PROSPERO registration, drafted the ethics application form and developed the search terms. GR, EC and RF were involved in various stages such as gaining the funding as a collaboration with the University of Bedfordshire, England and Hamad Medical Corporation, Qatar; and reviewed and suggested amendments for the PROSPERO registration, ethics submission, protocol and search terms.

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Competing interests None declared.

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

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