**ARTICLE DETAILS**

| TITLE (PROVISIONAL) | Barriers toward deceased organ donation among Indians living globally: An integrative systematic review using narrative synthesis |
|---------------------|------------------------------------------------------------------------------------------------------------------|
| AUTHORS             | Vincent, Britzer Paul; Randhawa, Gurch; Cook, Erica                                                               |

**VERSION 1 – REVIEW**

| REVIEWER             | Darlington, Danny                                                     |
|----------------------|-----------------------------------------------------------------------|
|                     | Pondicherry Institute of Medical Sciences, Urology                    |
| REVIEW RETURNED      | 26-Sep-2021                                                           |

**GENERAL COMMENTS**

The authors have done a commendable job of compiling all the work done so far in the knowledge and practice of organ donation among the Indian population.

The authors have made a good effort to highlight the lacunae in the current studies being conducted in India. They have also suggested topics of future research.

Overall, the paper represents a nicely done work with no major flaws. Of course, the statistical part needs specialist evaluation. I have highlighted some minor changes to the text.

Introduction: Adequate. Review justification—adequate

Methodology: Well written and reproducible. Comprehensible to the reader.

Results:

1. With such reluctance, Indians living in India and UK considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [40, 47, 49, 54, 56, 60, 62, 63, 65, 66, 70, 78, 79, 82]. .... Kindly explain what could be the reason for this fear. Kindly also add a brief note on the illegal renal transplantation rackets recently detected in India, which undermine the people's confidence in donating organs.

2. Many people in India think the organs will fetch monetary benefit. Kindly comment on this issue.

3. Similarly, patients who have undergone renal stone surgery or kidney-preserving surgery go on to complain that their kidneys were removed by the surgeon. Kindly comment on these issues and how they can be dealt with.

4. The authors can recommend the policy changes which need to be made in the current system which can improve donation and
optimize transplantation. For eg, there is no central registry on transplantation.

Discussion:

1......Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations .....This section can better if added in introduction for review justification.

Conclusion:

1. ......therefore, this systematic review addressed the barriers toward organ donor registration among Indians in India and UK and also identified gaps both in methodological and research perspectives that merits future research to examine the phenomena of interest from multiple lenses......in both the discussion and conclusion, there are several ideas/thoughts which seem to have been repeated.

The conclusion should be written based on the findings of the review rather than general statements.

Overall grammar-adequate

REVIEWER
Orchanian-Cheff, Ani
University Health Network, Library and Information Services

REVIEW RETURNED
11-Nov-2021

GENERAL COMMENTS
Thank you for the privilege of being able to review this manuscript. The review is about barriers to deceased organ donation among Indians living in India and the UK. I had some concerns in particular with the search strategy presented. As presented, the searches need to be revised. For my review I looked to PRISMA 2020 http://prisma-statement.org/ and the PRISMA search extension http://www.prisma-statement.org/Extensions/Searching.

1. According to both the current PRISMA statement and PRISMA search you need to present all search strategies from all databases. The supplement only includes one search strategy which appears to be for Medline through Ovid, though it is not stated. The strategies from all databases should be copied and pasted exactly as run.

2. Please use the most current PRISMA flow diagram. This was updated for 2020.

3. As per PRISMA search please include the vendors/platforms for each database.

4. Your manuscript states that MeSH terms were identified, but there is no use of MeSH terms in your search strategy as presented. Only keywords were used.
5. Appropriate MeSH terms/subject headings that were missed by your search included “Tissue and Organ Procurement”, India, Health knowledge, attitudes, practice, and Attitude to Health.

6. Your search strategy lacks the appropriate syntax, so it is unclear what fields are being searched. It appears from line 16 and 30 that you are only searching the title and abstract fields. This means you will miss your keywords in the keyword field and subject heading field. It is more appropriate in Ovid Medline to use .mp.

7. In line 32 you state that you filtered by date. However, lacking the appropriate search syntax it is not clear which date fields you searched.

8. In the manuscript please state the date the searches were executed for each database.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Dr. Danny Darlington, Pondicherry Institute of Medical Sciences
Comments to the Author:

The authors have done a commendable job of compiling all the work done so far in the knowledge and practice of organ donation among the Indian population. The authors have made a good effort to highlight the lacunae in the current studies being conducted in India. They have also suggested topics for future research. Overall, the paper represents a nicely done work with no major flaws. Of course, the statistical part needs specialist evaluation. I have highlighted some minor changes to the text.

Introduction: Adequate. Review justification-adequate
Methodology: Well written and reproducible. Comprehensible to the reader.
Results:
R1 C1: With such reluctance, Indians living in India and UK considered fear of misuse and family refusal as a major reason, alongside minor reasons like emotional barriers, bodily issues, and religion [40,47,49,54,56,60,62,63,65,66,70,78,79,82]. Kindly explain what could be the reason for this fear. Kindly also add a brief note on the illegal renal transplantation rackets recently detected in India, which undermine the peoples confidence in donating organs.
➢ We have now expanded on the reasons that could have led to fear among the participants within the discussion section and gave reference. However, there has not been much research that has examined fear from a more subjectivist viewpoint and identifies a gap for future research which we acknowledge.

R1 C2. Many people in India think the organs will fetch monetary benefit. Kindly comment on this issue.
➢ Thank you for your comment. Whilst this may be an acceptable reason, we found limited empirical research to support this. This has been found from our further research which we have conducted, and this will be published in the near future.

R1 C3. Similarly, patients who have undergone renal stone surgery or kidney preserving surgery go
on to complain that their kidneys were removed by the surgeon. Kindly comment on these issues and how they can be dealt with.

➢ Thank you for your comment. We were unable to find any evidence regarding this. However, this has been an issue identified in some current fieldwork which we will be publishing in the near future.

R1 C4: The authors can recommend the policy changes which need to be made in the current system which can improve donation and optimize transplantation. Eg, there is no central registry on transplantation.

➢ We have added this to the discussion section informing the need for people to know the procedure for registration and the need for a centralised registry.

Discussion:
R1 C5: Therefore, there is a need to address this population with such specificity in future research that can strengthen the practices even more efficiently. Also, with this population to be the largest migrating population in the world [7] it is important to understand their behaviour outside India. Studies show difference between various migration generations ..... This section can be better if added in introduction for review justification.

➢ Thank you for this comment. We have added this information in the introduction - informing the reader that this is the largest migrating population in the world as well. This was added mainly in the introduction to support the same viewpoint as yours, the need to do this review.

Conclusion:
R1 C6: Therefore, this systematic review addressed the barriers toward organ donor registration among Indians in India and UK and also identified gaps both in methodological and research perspectives that merits future research to examine the phenomena of interest from multiple lenses......in both the discussion and conclusion, there are several ideas/thoughts which seem to have been repeated.

➢ Thank you for identifying this we have now removed this repetitive statement from the conclusion section.

R1 C7: The conclusion should be written based on the findings of the review rather than general statements.

➢ We have drafted the conclusion based on overall findings, informing the gap and the complex interactions that take place toward organ donor decision making.

Reviewer: 2
Ms. Ani Orchanian-Cheff, University Health Network
Comments to the Author:
Thank you for the privilege of being able to review this manuscript. The review is about barriers to deceased organ donation among Indians living in India and the UK. I had some concerns in particular with the search strategy presented. As presented, the searches need to be revised. For my review I looked to PRISMA 2020

R2 C1: According to both the current PRISMA statement and PRISMA search you need to present all search strategies from all databases. The supplement only includes one search strategy which appears to be for Medline through Ovid, though it is not stated. The strategies from all databases should be copied and pasted exactly as run.

➢ Thank you for the comment. In the supplementary file we have now added the search strategy for all the databases used.

R2 C2: Please use the most current PRISMA flow diagram. This was updated for 2020.
We have now updated the PRISMA flow diagram for 2020.

R2 C3: As per PRISMA search please include the vendors/platforms for each database.
➢ We have also now included the databases’ vendors in PRISMA as well as in the search strategy list.

R2 C4: Your manuscript states that MeSH terms were identified, but there is no use of MeSH terms in your search strategy as presented. Only keywords were used.
➢ Thank you for the comments. We have now made the needful changes in the methods section of the main text.

R2 C5: Appropriate MeSH terms/subject headings that were missed by your search included “Tissue and Organ Procurement”, India/, Health knowledge, attitudes, practice/, and Attitude to Health/.
➢ We have now mentioned all the keywords used in the search strategy clearly in the supplementary file.

R2 C6: Your search strategy lacks the appropriate syntax, so it is unclear what fields are being searched. It appears from line 16 and 30 that you are only searching the title and abstract fields. This means you will miss your keywords in the keyword field and subject heading field. It is more appropriate in Ovid Medline to use .mp.
➢ We have updated the search strategy with appropriate syntax (shown in the supplementary file). In some of the database search engines, we did not have the combination of title-abstract-keywords. Hence, we have taken the syntax which covers the maximum and appropriate areas to identify the keywords.

R2 C7: In line 32 you state that you filtered by date. However, lacking the appropriate search syntax it is not clear which date fields you searched.
➢ Thank you for the identification. We have now added the appropriate search syntax for the time period in the search strategy file.

R2 C8: In the manuscript please state the date the searches were executed for each database.
➢ We have now provided dates for the search in the abstract and the main text.

**VERSION 2 – REVIEW**

| REVIEWER          | Darlington, Danny  
Pondicherry Institute of Medical Sciences, Urology |
|-------------------|---------------------------------------------------------------|
| REVIEW RETURNED   | 18-Feb-2022                                                  |

| GENERAL COMMENTS   | The authors have done a commendable job in elucidating the studies in this niche context of organ donation among indian population. Abstract: Adequate  
Keywords: Kindly remove UK, Indians from keywords. Introduction and methods: well written  
Results: adequate  
On contrary, commonest reasons to donate an organ was to save someone’s life, closely followed by elongate someone’s life, social commitment, altruistic deed, and that at least their deceased one’s organs can live [69,72,82,89,94-97].----Kindly rephrase this line. |
..prolong someones life...to keep atleast the organs alive...could be better phrases.

Discussion:
Therefore, at the moment, there is a need to study further how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour.---------Therefore there is an urgent need...wound be better

Conclusion:
There is also a lack of methodological rigour to study this particular population outside India-----this population rather than this particular population

Figures: The seem okay.

Overall, there are no major flaws. The above minor errors can be edited before publication.

REVIEWER
Orchanian-Cheff, Ani
University Health Network, Library and Information Services

REVIEW RETURNED
07-Feb-2022

GENERAL COMMENTS
Thank you for providing all of the search strategies for all of the databases. This makes it much easier to review. I have some minor concerns regarding the search strategies.

1. For all of the databases you have failed to use truncation. For example donation*. Truncation allows the database to find all of the iterations of a word, such as donation, donations.

2. In some of the databases such as CINAHL you are searching some terms in title only and other terms in the abstract only. This would lead to missing relevant citations. Terms should be searched in title and abstract, or all fields to ensure that retrieval is sensitive and complete.

3. In Ebsco Medline you have used textwords but have failed to use subject headings. For example (MH "Tissue and Organ Procurement+”). Searches for systematic reviews should use a combination of keywords and subject headings. You have not used subject headings in CINAHL or APA PsycINFO either.

Without these changes to the search strategies there is no guarantee that you have found all relevant citations on this topic.
allows the database to find all of the iterations of a word, such as donation, donations.”

**AUTHOR RESPONSE** - The updated search strategies have used truncations appropriately in all the databases used.

2. “In some of the databases such as CINAHL you are searching some terms in title only and other terms in the abstract only. This would lead to missing relevant citations. Terms should be searched in title and abstract, or all fields to ensure that retrieval is sensitive and complete.”

**AUTHOR RESPONSE** - The updated search strategies have used the combination of title and abstract according to the feasibility of the databases. In several databases it was not possible to search title and abstract in one same time. Therefore, for those databases, the search was undertaken separately for each, and the final number studies were combined for extraction.

3. “In Ebsco Medline you have used textwords but have failed to use subject headings. For example (MH "Tissue and Organ Procurement"). Searches for systematic reviews should use a combination of keywords and subject headings. You have not used subject headings in CINAHL or APA PsycINFO either.”

**AUTHOR RESPONSE** - The updated search strategy now has used the combination of SU / MH according to the respective database.

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Reviewer: 1
Dr. Danny Darlington, Pondicherry Institute of Medical Sciences

**Comments to the Author:**

The authors have done a commendable job in elucidating the studies in this niche context of organ donation among Indian population.

**Abstract:** Adequate

**Keywords:** Kindly remove UK, Indians from keywords.

**Introduction and methods:** well written

**Results:** adequate

“On contrary, commonest reasons to donate an organ was to save someone’s life, closely followed by elongate someone’s life, social commitment, altruistic deed, and that at least their deceased one’s organs can live [69,72,82,89,94-97].----Kindly rephrase this line. ..prolong someones life...to keep atleast the organs alive...could be better phrases.”

**AUTHOR RESPONSE** - The changes were made in the manuscript.

**Discussion:**

“Therefore, at the moment, there is a need to study further how the interaction of the individuals with such a complex socio-cultural and institutional structures influences the organ donation behaviour.-----

----Therefore there is an urgent need...would be better”

**AUTHOR RESPONSE** - The changes were made in the manuscript.
Conclusion:
“There is also a lack of methodological rigour to study this particular population outside India-----this population rather than this particular population”

AUTHOR RESPONSE - The changes were made in the manuscript.

Figures: The seem okay.

Overall, there are no major flaws. The above minor errors can be edited before publication.

**VERSION 3 – REVIEW**

| REVIEWER           | Orchanian-Cheff, Ani                             |
|--------------------|--------------------------------------------------|
| University Health Network, Library and Information Services |

| REVIEW RETURNED | 13-Apr-2022 |
|-----------------|-------------|

| GENERAL COMMENTS | Thank you for revising your manuscript. It is much better than before. However, there are still some deficiencies related to the search. As per PRISMA-S in addition to the names of the databases searched, please also include the platform for each. For example, for CINAHL the platform is EBSCO. For Medline you are using PubMed. Thank you for including all search strategies as run. There is one remaining methodological flaw: in the databases that use subject headings such as CINAHL and PsycINFO you have only used key word searching and have not employed subject headings. A systematic and comprehensive search would utilize both key words and appropriate subject headings. |

**VERSION 3 – AUTHOR RESPONSE**

Reviewer: 2

Ms. Ani Orchanian-Cheff, University Health Network

Comments to the Author:

Thank you for revising your manuscript. It is much better than before. However, there are still some deficiencies related to the search. As per PRISMA-S in addition to the names of the databases searched, please also include the platform for each. For example, for CINAHL the platform is EBSCO. For Medline you are using PubMed.

RESPONSE: This has been updated now in the PRISMA flowchart, the manuscript and supplementary file.

Thank you for including all search strategies as run. There is one remaining methodological flaw: in the databases that use subject headings such as CINAHL and PsycINFO you have only used key word searching and have not employed subject headings. A systematic and comprehensive search would utilize both key words and appropriate subject headings.

RESPONSE - The updated search strategy now has used the combination of SU / MH according to the respective database.