

Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature

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Abstract

Background. Transplantation is the treatment of choice for organ failure, but a worldwide shortage of suitable organs exists. We conducted a systematic review of qualitative studies that explored community attitudes towards living and deceased solid organ donation to inform strategies to improve organ donation rates.

Methods. Medline, Embase, PsycINFO and EconLIT were searched. Qualitative studies that explored community attitudes towards living and deceased solid organ donation were included. A thematic synthesis of the results and conclusions reported by primary authors was performed.

Results. Eighteen studies involving 1019 participants were identified. Eight themes emerged. The decision to be an organ donor was influenced by (i) relational ties; (ii) religious beliefs; (iii) cultural influences; (iv) family influences; (v) body integrity; (vi) previous interactions with the health care system—medical mistrust, validity of brain death and fear of early organ retrieval; (vii) the individual's knowledge about the organ donation process and (viii) major reservations about the process of donation, even in those who support organ donation.

Conclusions. This review of qualitative studies highlights that seemingly intractable factors, such as religion and culture, are often tied in with more complex issues such as a distrust of the medical system, misunderstandings about religious stances and ignorance about the donation process. Intervention that could be considered includes culturally appropriate strategies to engage minority groups, especially through religious or cultural leaders, and more comprehensively available information about the donation process and its positive outcomes.

Keywords: culture; organ donation; qualitative; transplantation

Introduction

Transplantation is the treatment of choice for severe organ failure. Despite this, and general recognition of organ donation as a global priority, demand for organs outstrips supply in virtually every country in the world [1]. Understanding the reasons why people do or do not donate can help inform policies to address this undersupply.

Previous studies have found a number of specific factors that are certainly associated with positive attitudes to organ donation, including education level, socio-economic status and being young [2–7]. It has also been found that people are more willing to make a living donation to a family member than a donation after death [8–11], while religious reasons were commonly cited as barriers [3, 5, 6, 12, 13].

People beliefs, however, often need to be understood through a broader narrative to uncover the interaction of multiple influences. Qualitative research is able to capture these narratives and their context and therefore helps us better understand the reasons why people hold particular views.

This study aims to synthesize the qualitative research on community attitudes towards living and deceased organ donation and the factors that influence these attitudes.

Materials and methods

Study selection

Studies that explored community attitudes towards living and deceased solid organ (heart, lung, liver and kidney) donation using qualitative data through focus groups or interviews were included. Papers were excluded if they focussed on non-solid organ transplantation, were editorials or reviews or discussion papers that did not elicit perspectives from the community.

Literature search

MeSH terms and text words for community (public and population) were combined with terms relating to organ donation. The searches were carried out in Medline, Embase, PsycINFO and EconLIT (See Supplementary Appendix). We also searched reference lists of relevant studies and reviews, dissertation and thesis databases and transplantation journals.

Included studies were examined for study eligibility by both K.H. and M.J.I.

Comprehensiveness of reporting

There is no universally accepted quality appraisal tool for qualitative research, therefore two reviewers (M.J.I. and K.H.) independently assessed each study for comprehensiveness of reporting, based broadly on the COREQ framework [14], and any disagreement was resolved by discussion. The assessment included details about the research team, the study methods, context of the study, analyses and interpretations (Table 2).

Synthesis of findings

We performed a thematic synthesis of the results and conclusions reported by the primary author. We extracted from each paper all text under the headings ‘results/findings’ and ‘conclusion/discussion’. These were entered verbatim into Hyperresearch 2.8.3 (ResearchWare Inc., Randolph, MA) software. For each paper, two authors (M.J.I. and K.H.) independently coded the text and recorded concepts that focussed on (i) participants’ attitude towards organ donation; (ii) the reasons for participants’ beliefs and (iii) the interpretations given of participant perspectives on

organ donation. A grounded theory [33] approach to analysis was used and further developed through negative case analysis [34]. To achieve a higher level of analytical abstraction, the concepts were examined for similarities, variations and relationships with one another. This informed the development of an analytical schema of themes.

Results

Literature search and study descriptions

Our search yielded 3498 citations. Of these, 3320 were ineligible after title and abstract review. Of the potentially eligible 178 studies, 18 studies involving 1019 respondents were eligible to be included in the review (Figure 1). Fourteen studies explored factors influencing attitudes towards both deceased and live organ donation. Two studies focussed on attitudes to live organ donation only and two studies

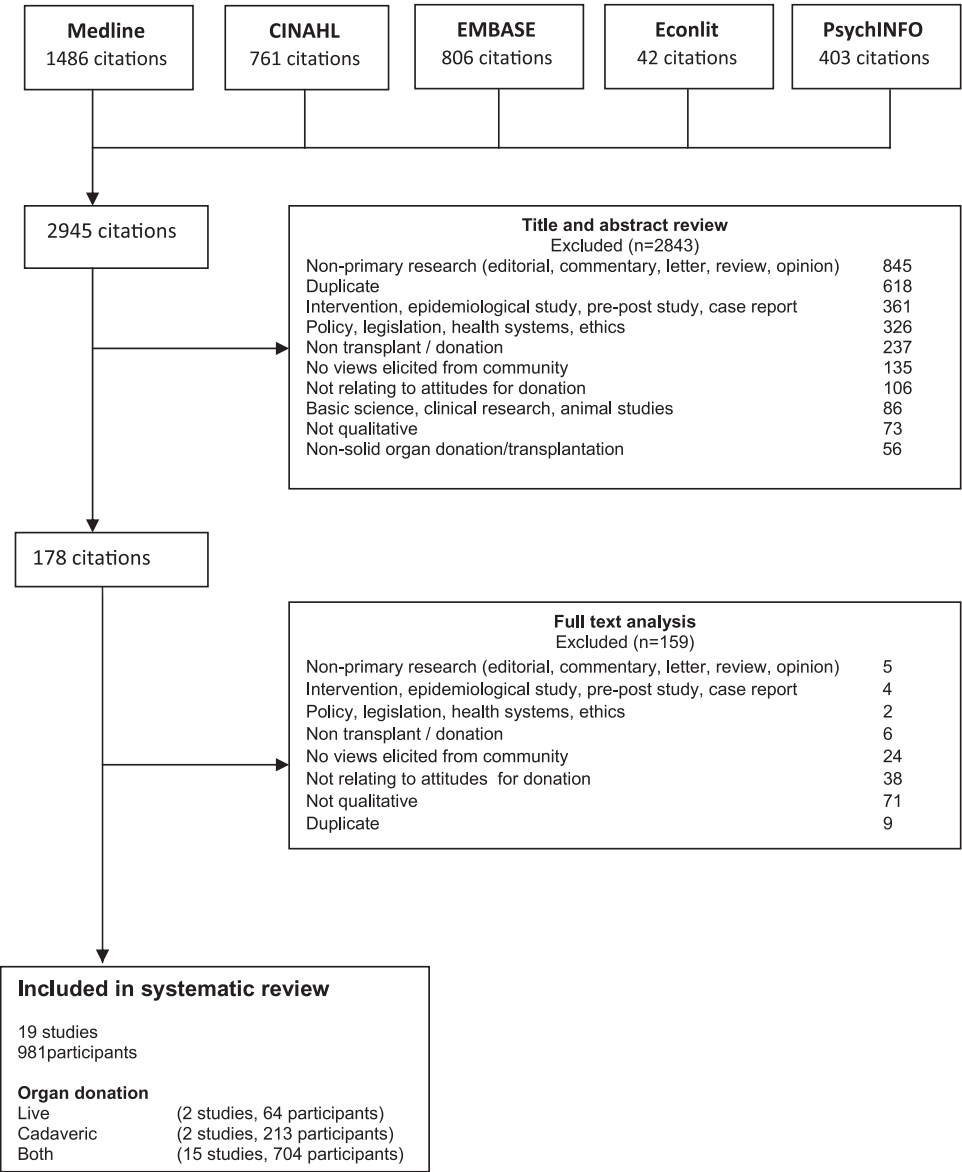


Fig. 1. Search results.

focussed on deceased donation. Six studies employed focus groups, eight studies used interviews and four studies used both focus groups and interviews.

Studies were conducted in the UK, Canada, USA, South Africa, Malta and Australia. Many of the studies included respondents from specific minority groups and focussed on barriers to donation (Table 1).

Comprehensiveness of reporting of included studies

The comprehensiveness of reporting of the included studies is described in Table 2. All studies provided respondent quotations, details of sample sizes and a range and depth of insights into attitudes to organ donation. Twelve studies described the setting for data collection.

Synthesis of findings

Eight main themes emerged from the synthesis of the studies. These were relational ties, religious beliefs, cultural beliefs, family influence, body integrity, interaction with the health care system, knowledge and information about donation and the significant reservations for the support that many gave for organ donation.

Relational ties

Many participants were willing to donate a kidney to a family member or friends, even if they would not consent to deceased donation nor provide a living donation to somebody they did not know.

I couldn't understand anyone who could let their brother or their sister or their mother, father, continue to suffer or even possibly die when it's within their means to help them. When you love someone that's what you do. (Respondent) [12]

Religious beliefs

For some, religious faith encouraged donation as it fitted within the altruistic belief system provided by the religion.

Our religion says do not waste things; if they [organs] can be utilized and used for the good of other people, then that item should not be thrown away. (Respondent) [31]

Others believed that donation was not encouraged within their religion. Respondents from the same religion often held different beliefs depending how they interpreted the edicts of their faith. Many believed more discussion on donation was necessary and felt that religious leaders should take a definitive stance on the topic.

A large number of participants expressed their belief that Islam forbids organ donation, on the basis of statements from the Qur'an and traditional Islamic literature. (Author) [15]

Some respondents felt organ donation was 'playing God' and believed no one should intervene if a person was 'meant' to die. But, the most common religious objection to organ donation was the need to maintain body wholeness

after death. Many believed their body needed to be 'whole' to enter the next life. Others also believed that they did not 'own' their body, but rather it belonged to their God, and were therefore unable to donate.

I don't want half of my body buried and half to go to heaven. (Male Respondent) [19]

After you die, you may go to another world. If you don't have an eye, you cannot see. (Respondent) [27]

Cultural beliefs

Cultural and religious beliefs were at times interchangeable but some participants held strong culturally specific beliefs which were not linked to any particular religious stance. These beliefs generally concerned broader issues around health care, death and dying. Often these were based on superstition, including beliefs that discussing death or signing a donor card would lead one's own death.

Black people in general didn't like to talk about death and were very private about particular matters. (Author) [20]

Some cultures believed that the spirit transferred from the donor to the recipient and others discussed the need for ancestral approval before donation, so that the remaining family did not lose ancestral protection in the future. Others highlighted the importance of particular rituals to do with the grieving process and that organ donation was seen to interfere in this process [26]. Some spoke about the change in traditional cultural beliefs over time and how younger generations were deciding to become donors.

Family influence

Views regarding organ donation were often shaped by the participants' families. Such influences could have either a positive or, more often, negative influence on individuals' decisions.

I personally have no objection but my father does, so I am not sure (Respondent, Female, 20) [15]

Some felt they had to ask permission from family members. Some also felt that a definite decision, from family members regarding donation, would ensure that loved ones were not burdened later with a difficult choice. Some felt that organ donation would interfere with the grieving process for families.

Body integrity

Many had strong beliefs about body wholeness in death unrelated to any religious stance. Sometimes they were apprehensive about the organ removal process and worried that their family would be traumatized about the thought of their body being 'cut up'.

To be honest with you I do care what happens to my body after I die, I may be dead but it's still my body and I want it to look right and be treated right. (Respondent, Female) [30]

Table 1. Qualitative studies on community attitudes to organ donation

Authors	Study reference	Country	<i>n</i>	Population	Minority group, Yes/No	Data collection	Donor type	Research topic
Alkhawari <i>et al.</i>	[15]	UK	141	Indo-Asians	Yes	Interviews and focus groups	Live/deceased	Attitudes to organ donation and transplantation
Alvaro <i>et al.</i>	[16]	USA	52	Muslims in the UK	Yes	Focus groups	Live	Barriers and opportunities for living kidney donation
Benghu <i>et al.</i>	[17]	Africa	48	Spanish-Hispanics in Arizona	No	Interviews	Live/deceased	Cultural norms and social structures and their influence on organ donation
Corlet	[18]	Canada	60	Zulu traditional healers and religious leaders	No	Focus groups	Live/deceased	Attitudes to organ donation and transplantation
Davis <i>et al.</i>	[19]	UK	120	Donors, non-donors and ambivalent	Yes	Focus groups	Live/deceased	Awareness and attitudes to organ donation
Davis <i>et al.</i>	[20]	UK	120	Black African/Caribbean	Yes	Focus groups	Live/deceased	Influence of religion on organ donation and transplantation
Exley <i>et al.</i>	[21]	UK	22	Black African/Caribbean	Yes	Interviews and focus groups	Live/deceased	Attitudes and beliefs on organ donation
Fahrenwald <i>et al.</i>	[22]	USA	21	Sikh community	Yes	Semi-structured interviews	Live/deceased	Sociocultural perspective on organ donation
Griffin <i>et al.</i>	[23]	USA	12	American Indian adults in an Indian Reservation in South Dakota	Yes	Face to face, interviews with Knowledge	Kidney live	Factors that influence relatives decision about kidney donation
Lauri	[24]	Malta	57	African American dialysis patient's care givers	No	Focus groups	Deceased	Social representations the public has of organ donation
Moloney <i>et al.</i>	[25]	Australia	29	General community	No	Focus groups	Live/deceased	Contradiction between endorsement and donation
Molzahn <i>et al.</i>	[26]	Canada	14	General community	Yes	Interviews	Live/deceased	Values and beliefs on organ donation
Molzahn <i>et al.</i>	[27]	Canada	39	Canadian aboriginals	Yes	Interviews and focus groups	Live/deceased	Beliefs on organ donation
Molzahn <i>et al.</i>	[28]	Canada	40	Chinese Canadians	Yes	Interviews and focus groups	Live/deceased	Beliefs on organ donation
Morgan <i>et al.</i>	[30]	UK	14	Indo-Canadians	Yes	Interviews	Live/deceased	How ethnicity shapes perceptions of identity and belonging that underpin organ donation
Morgan <i>et al.</i>	[29]	USA	156	Caribbean descent in London	No	Interviews	Deceased	Reasons for not signing an organ donor card
Randhawa	[31]	UK	64	General community—family pairs	Yes	In-depth interviews	Live/deceased	Examining the influences to attitudes on organ donation
Wittig	[32]	USA	10	Asians in the UK	Yes	Interviews	Live/deceased	Cultural care beliefs, meanings and practices regarding organ donation
				African American women in Southern USA				

Table 2. Comprehensiveness of reporting for included papers

Study	[15]	[16]	[17]	[18]	[19]	[20]	[21]	[22]	[23]	[24]	[25]	[26]	[27]	[28]	[29]	[30]	[31]	[32]
Personal characteristics																		
Researcher identified	•													•			•	
Credentials									•			•	•					•
Occupation												•	•					•
Sex												•	•				•	
Experience and training									•			•	•					
Relationship with participants	•																	
Participants selection																		
Sampling	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Method of approach	•	•			•		•	•	•	•	•	•	•	•	•	•	•	•
Sample size	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
No. and reason for non-participation	•												•	•		•		
Setting																		
Setting of data collection	•	•					•	•	•			•	•	•	•	•	•	•
Presence of non-participants		•																•
Description of sample	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•
Data collection																		
Interview guide	•	•	•				•	•	•				•	•	•		•	•
Repeat interviews	•											•						
Audio/visual recording	•			•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Field notes	•											•						•
Duration	•				•	•		•	•	•	•	•	•		•	•		•
Data or theoretical saturation	•											•						
Transcripts returned to participants											•		•					•
Data analysis																		
No. data coders		•			•	•		•					•					
Description of coding tree															•			
Protocol for data preparation and transcription			•			•		•			•	•	•		•	•		•
Use of software										•	•	•	•	•	•			•
Reporting																		
Respondent quotations provided	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Range and depth of insight into attitudes to organ donation	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Range and depth of insight into cultural diversity	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•	•

I'd sign, but my wife and children object. The children don't like to see daddy cut up. (Respondent, Male) [18]

Some would not donate as they believed that organ donation precluded an open coffin at their funeral, especially if corneas (eyes) were donated.

I would not donate my eyes, ever, because of the ceremony prior to cremation when people come to the funeral to see the body. I don't want to not have any eyes. (Respondent) [31]

Interaction with the health care system

Some participants expressed a distrust of the organ donation system and process, sometimes based on previous negative experiences with the health care system. Participants questioned the validity of brain death and were suspicious of health care providers making such decisions. Some believed organ donors would not receive proper care in hospital as health care personnel would only be interested in 'harvesting' their organs or remove organs prematurely. Some believed donor bodies would not be treated with dignity and respect. Others were concerned their organs might go to 'undeserving' recipients or be used for research purposes rather than saving lives.

How fast is the decision made? Are you really dead? Who makes the decision? (Respondent) [18]

... They'll start gutting you up like a deer. (Respondent) [29]

These opinions were often pronounced in minority populations where potentially a sense of marginalization from the health care system underpinned a refusal to donate.

Sorry to say, but we all think it's for the whites and not us because whenever we see pictures on TV about people receiving transplants they are always white. So we think we are not part of a culture who needs donors or organs. (Respondent, Female aged 18–30 years, African) [19]

Level of knowledge and information on organ donation

Lack of knowledge about organ donation and the process involved was often reported as a barrier. Participants frequently referred to 'urban myths' or discussed how donation was framed in fictional television shows. Many mentioned that they would like more information about the donation process.

A number of people expressed concern about the lack of information available concerning organ donation. Over

time, 'urban myths had been translated into what people perceived to be correct information and had subsequently resulted in fears about donation. (Author) [19]

One study, though, indicated that participants would still choose not to donate even if they had more information about the process, as their belief system did not support donation [18].

Participants' reservations despite positive beliefs

In many studies, organ donation was seen as a 'gift' to society, a way of demonstrating respect for 'your fellow man' and many participants were willing to be living donors, particularly for their families. Despite this positive attitude, it was not uncommon for significant reservations to be held about deceased donation. Within each 'theme' above, there were both positive and negative influencing factors with each one having the ability to tip the balance in either direction when being weighed and measured during the decision-making process regarding organ donation (Figure 2).

Overwhelmingly ... people cited the amazing potential of organ donation to help people who are suffering ... However, these same people went on to voice serious misgivings about organ donation, especially about institutions and individuals involved with the process of organ donation. (Author) [29]

Discussion

We identified eight major themes regarding community attitudes towards organ donation. Many made decisions

regarding organ donation based on personal beliefs (religious, cultural, family, social and body integrity), levels of knowledge about organ donation and previous interaction with the health care system. Many maintained positive attitudes to organ donation despite significant reservations about the organ donation process. Resistance to donation tended to be less in the case of living donation for family.

There are some limitations in this study. Although we set out to synthesize community attitudes to organ donation, 13 of the 18 included papers were specifically designed to elicit barriers to organ donation from ethnic or cultural groups with previously known low donation rates. Consequently, the results of this review are perhaps skewed towards the negative influences on the organ donation process.

Previous research tells us that religious beliefs are often associated with being a non-donor [3, 5, 6, 12, 13]. In this study, we find that some religious beliefs could also be positive influences and where negative beliefs were present, these often stemmed from uncertainty or misrepresentation of religious edicts. One solution would be for the transplant community to more actively engage religious leaders, especially when it has been reported that, across the major religions, there are very few cases where organ donation can be seen to be inconsistent with religious edicts [35]. Religious leaders could be made available in hospitals to assist families in making decisions regarding organ donation and potentially debunk misperceptions. Staff members who have a role in approaching families to request consent for donation could also be more effective through awareness programmes and resources about religious concerns.

Similarly, cultural sensitivity to issues such as apprehensiveness to discuss death among certain groups or individuals and the importance to many of death rituals may

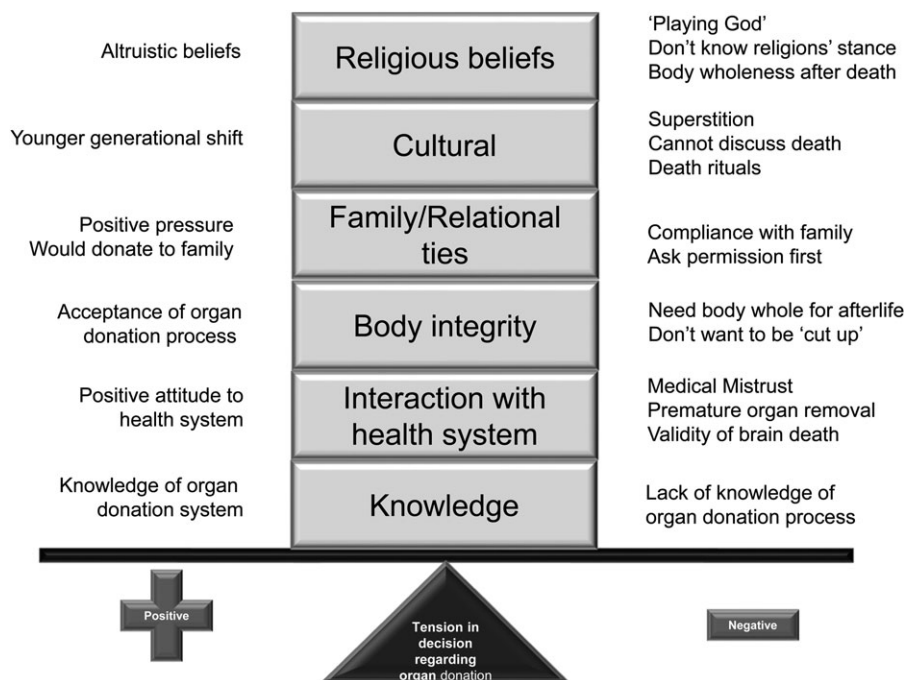


Fig. 2. Balance of attitudes to organ donation.

improve dialogue regarding organ donation. Studies have shown that engaging some minority groups in the health care system and creating a sense of belonging and ownership can improve compliance with health interventions [36]. As a consequence, efforts should be made to create positive interactions within the health care system, especially for minority groups, to improve donation rates.

Although many qualitative studies have found that higher socio-economic status and education were associated with a stronger willingness to be an organ donor [2, 3, 5], little can be discerned directly from these studies as to the reasons why. However, issues of alienation, as highlighted in relation to ethnic minorities, and of ignorance are likely to be at play. This suggests that programmes to better engage disadvantaged communities particularly through targeted information campaigns would be worth considering. Some of the strong reservations held, even among those with generally positive views towards donation, such as concerns that agreeing to donation would discourage doctors from caring so much about saving their lives in an emergency or that it would result in the premature removal of their organs or indeed prevent them from having an open coffin at their funerals, are examples of very real barriers that can be readily addressed through information.

The organ donation decision is a complex one, based strongly on personal beliefs. There are some factors, such as religious and cultural beliefs, that are seemingly intractable and are often cited as reasons for a refusal to donate. In this review of qualitative studies, it is shown that these have often been found to be tied in with more complex issues such as a distrust of the medical system, misunderstandings about religious stances and ignorance about the donation process. Interventions to better engage the community, including disadvantaged and minority groups, to foster trust and provide information represent promising opportunities of promoting organ donation in the future.

Supplementary data

Supplementary Appendix is available online at <http://ndt.oxfordjournals.org>.

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