

Reasons for organ and tissue donation refusal and opposition: a scoping review

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ABSTRACT

Objective. To map the reasons why individuals oppose or refuse organ and tissue donation, from an international perspective.

Methods. A scoping review was conducted from May 2022 to February 2024 using a three-stage search strategy across five databases and Google Scholar. Data analysis involved categorizing information based on similarities and populations studied.

Results. The analysis included 92 articles and national reports. The data collected were classified into two categories. Category 1 included the reasons why individuals oppose deceased donation: lack of knowledge about the donation process, 22 (16.5%); religious beliefs, 21 (15.8%); fear of mutilation or damage to body integrity, 17 (12.8%); conflicts with health care professionals during hospitalization or distrust of professionals or the organ donation process, 11 (8.3%); and unknown reasons, 11 (8.3%). Category 2 included the reasons why individuals refuse to donate a deceased relative's organs and tissues after the family interview for deceased donation: previous written or verbal expression by the potential donor, 42 (10.1%); fear of mutilation or damage to body integrity, 41 (9.9%); conflicts with health care professionals during hospitalization or distrust of professionals or the organ donation process, 38 (9.2%); religious beliefs, 37 (8.9%); and individual motivations, 36 (8.7%).

Conclusions. This scoping review found that there were two main categories of reasons behind being opposed to or declining organ and tissue donation, with 23 subcategories. By mapping these reasons across international contexts, these findings provide insights for future research and can be used to inform the development of educational initiatives on organ and tissue donation.

Keywords

Health knowledge, attitudes, practice; clinical decision-making; organ and tissue procurement; organ transplantation; tissue transplantation.

Access to transplantation is crucial for individuals with organ or tissue insufficiencies—it offers a chance for survival, and often, an enhanced quality of life (1). However, there is a need for organ and tissue donors, and individuals' decisions to consent to donating are critical. This decision is influenced not only by personal interpretation and experiences related to death, but by the laws, norms, and regulations specific to each country (2).

People approach the topic of organ and tissue donation from different perspectives. They may just think about donation during discussions, surveys, or public activities that promote deceased donation. Or they may only confront the topic while grieving the death of a family member, when they are asked by the health care professionals to decide about donation. Regardless of the scenario, individuals may decide in favor of donation, and follow through by registering this information in

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a governmental electronic registry or verbally expressing wishes or attitudes to their family; or they may decide against it, registering their objection to donating their organs and tissues for transplantation (3). In this context, deciding against or declining donation stands out as a substantial barrier to increasing donation rates and accessing transplants as a therapeutic option.

In recent years, researchers have dedicated their efforts to uncovering the complexities surrounding the decision-making process in different organ and tissue donation scenarios (2). It is important to identify the reasons behind the decision to decline to donate and the attitudes against donation because greater understanding will enable the development of strategies to mitigate their impact, and subsequently, increase the availability of organs and tissues for individuals awaiting transplantations (4). Moreover, cultural, economic, and social factors in each country appear to correlate with decisions and opinions, allowing for a more profound analysis of this matter. Conversely, this direction guides us towards uncovering both converging and diverging points based on region and/or country (2, 5).

Despite years of progress in donation and transplantation research and in the clinical field, the prevalence of people against organ and tissue donation remains a challenging barrier to increasing donation rates, and consequently, to transplantation procedures (6). This is true across countries and differs between people who are sensitized to the topic and approached for donation during their lifetime versus those who are asked to decide in a grief scenario. Therefore, this scoping review sought to map the reasons behind opposing donation and declining to donate a deceased relative's organs and tissues, from an international perspective.

METHODS

We conducted a scoping review that followed the method outlined by the Joanna Briggs Institute (JBI), which was specifically designed for conducting scoping reviews (7). A previous study protocol was developed and registered on the platform Open Science Framework (8). Adherence to reporting standards was maintained by aligning the study with PRISMA-ScR (the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews).

Data sources and collection

To ensure the unique value of our research objective and proposed analyses, comprehensive searches were conducted across

multiple databases including the Cochrane Library, Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Epistemonikos, Open Science Framework (OSF), and the JBI Evidence Synthesis. To the best of our knowledge, no other scoping or systematic review aligning with the specific objective and analysis set forth by our study is available.

The research question and objective were formulated using the Population, Concept, and Context strategy. The *population* comprised individuals questioned about their opinion or decision to donate organs and tissues for transplant, while the *concept* focused on the reasons that prompt people to decline or oppose organ and tissue donation. The *context* encompassed studies conducted in diverse health care settings, including hospitals, intensive care units, and wards, as well as educational institutions such as schools, universities, and public opinion surveys. Additionally, it was extended to include municipal, state, national, and international contexts through national reports. Based on this strategy, the guiding question was, "What are the reasons related to the decision to decline or the opinion against organ and tissue donation?"

To identify relevant studies, our search strategies of databases and additional material were executed in three different phases. These comprehensive searches were conducted collaboratively with a librarian and were designed to identify both scientific articles and gray literature materials. This step was carried out under the supervision of a specialized library science service from a highly qualified institution. The first phase was conducted on 25 May 2022 and constituted the initial search stage. During this phase, general keywords were used on the MEDLINE database via PubMed to identify the most effective search terms. After the keyword selection, the second phase was as a secondary search that commenced on 25 July 2022 and was updated on 20 October 2023 and on 10 February 2024. This phase involved applying the keywords across multiple databases and electronic libraries (ie, PubMed, CINAHL, Embase, LILACS, and PsycInfo) to comprehensively review available literature and consolidating the search strategies as detailed in Table 1.

During the third phase, we expanded the search to include additional materials and gray literature. This involved analyzing the reference lists of studies identified in the second phase using Google Scholar and specific terms: refusal, decline, organ, tissue, donation, donation and transplantation activity report, and national report. To ensure a comprehensive review of available gray literature, we considered the first five pages of search results.

TABLE 1. Search strategies and results (total number of articles/materials)

Database	Search strategy	Results
PubMed	((("refusal"[Title/Abstract] OR ("overrule"[All Fields] OR "overruled"[All Fields] OR "overrules"[All Fields] OR "overruling"[All Fields]) OR "refusal to participate"[MeSH Terms]) AND ("familiarities"[All Fields] OR "familiarly"[All Fields] OR "familiarily"[All Fields] OR "familial"[All Fields] OR "familie"[All Fields] OR "family"[MeSH Terms] OR "family"[All Fields] OR "familial"[All Fields] OR "families"[All Fields] OR "family s"[All Fields] OR "family's"[All Fields])) AND (((("donate"[All Fields]	8035
CINAHL	Decision making AND organ donation AND family refusal	68
Embase	('organ donor'/exp OR 'organ donor') AND (overrule OR overrules OR 'refusal to participate'/exp OR 'refusal to participate') AND family	38
LILACS	decision making AND organ donation	32
PsycInfo	Any Field: decision making AND Any Field: organ donation	304
Google Scholar	'refusal,' 'decline', 'organ,' 'tissue', 'donation', 'donation and transplantation activity report', and 'national database'	150

Study selection

The inclusion criteria for selecting scientific articles and materials from gray literature included various methodological designs, including quantitative and qualitative approaches. We included any material addressing opinions or decisions related to organ and tissue donation in adults and/or children, focusing primarily on deceased donation. Additionally, official documents, institutional manuals, guides, reports, web pages, and other materials, without temporal restrictions according to the JBI method were also included. All languages were considered. Literature reviews, materials unrelated to the topic, and any with restricted access despite attempts to contact authors, as well as any inaccessible materials (eg, due to corrupted internet address), were excluded.

Although the scoping review method does not recommend excluding any type of methodological design, the authors decided to exclude literature reviews to avoid repeating information that would compromise the determination of categories related to the reasons driving opposition to deceased donation while living and behind the decision to decline to donate relatives' organs and tissues.

The study selection process was carried out independently by three authors (SMS, BAR, PCO) with experience in literature reviews pertaining to organ and tissue donation and transplantation. Initially, titles and abstracts were reviewed to identify materials for full-text assessment using the Rayyan tool (9). After the first selection, Mendeley software (Elsevier Ltd) was used for effective review management.

After a comprehensive review of the full-text materials, a total of 92 scientific articles and reports were chosen for inclusion. For data extraction, Microsoft Excel was used to organize data related to the inclusion criteria, specifically on individuals questioned about their opinions or decisions to donate organs and tissues for transplants, reasons for declining or opposing organ and tissue donation, and the context where the research was conducted, such as health care settings (e.g., hospitals, intensive care units, wards), educational institutions (e.g., schools, universities), and public opinion surveys. The Excel spreadsheet was used to organize and group similar findings to discern patterns, categorize results, and record details (i.e., publication years, data collection periods, study countries, primary findings related to the objective of this review, and references).

Statistical analysis

The data collection, data analysis, and results acquisition were performed from December 2022 to March 2024. The number of materials and the detailed data collection and analysis undertaken justified the extended schedule for the development of this scoping review.

The data analysis began with the authors categorizing the materials according to two categories: individuals questioned while alive were grouped into category 1, *reasons why people express in life their opposition to deceased donation*; or after a relative's death, grouped into category 2, *reasons behind the decision to decline to donate relative's organs and tissues after the family interview for deceased donation*.

After categorizing the studies into these two main categories, the authors identified and separated the reasons described in each study, determining the associated causes and reasons.

In other words, each study had its reasons mapped and categorized by occurrence. Finally, all the mapped reasons were grouped by similarity based on frequency to identify subcategories of reasons. To determine this frequency, descriptive statistics were used to calculate both relative frequency (%) and absolute values (*n*). The data from this scoping review are presented through categories, descriptions, charts, and tables.

Ethical approval

Because this was a scoping review, formal review and approval from a research ethics committee were not required. Nevertheless, proper referencing and adherence to copyright regulations were maintained for all materials utilized.

RESULTS

A total of 8 627 publications, including research articles and gray literature, were accessed. Of these, 92 scientific articles and other publications met the inclusion criteria and were included in the review. Figure 1 illustrates the search and study selection process according to the PRISMA-ScR.

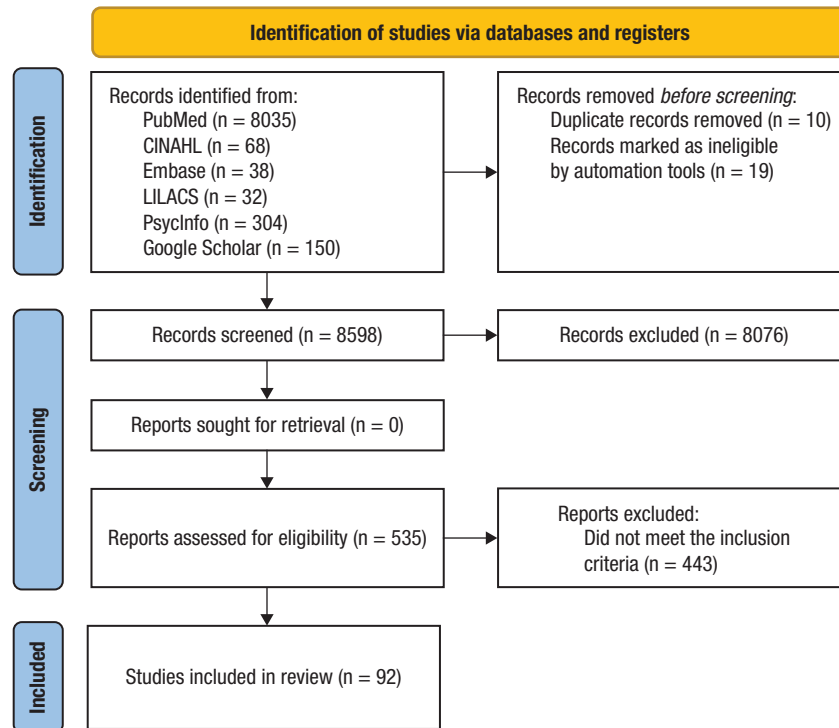
The review analyzed data according to the population studied by each publication. Data were grouped into two main categories: studies that approached the population to investigate the reasons why individuals expressed opposition to deceased donation, and studies that approached family members to investigate the reasons behind declining to donate a deceased relative's organs and/or tissues after the family interview for deceased donation. From the analysis, 23 subcategories emerged describing the reasons for opposing organ and tissue donation or for declining to donate after the family interview for deceased donation. The following summarizes each category and explains the reasons according to the subcategories.

Category 1: Reasons why individuals oppose deceased donation

Category 1 included 28 scientific articles published from 2000 to 2022. The years with the most publications related to public opinion on organ donation were 2016 (5 publications [17.9%]) and 2020 (4 [14.3%]), followed by 2004, 2010, 2014, 2018, and 2022 with two publications each (7.1%). When the data were evaluated by country, Turkey was found to have the most publications related to this category (4 publications [14.3%]), followed by Brazil, Poland, and Saudi Arabia with three each (10.7%), and Morocco and Spain with two each (7.1%). Surveys were used in 22 of the included articles (78.6%), three were cross-sectional studies (10.7%) and three used structured interviews (10.7%). Detailed information on these articles is presented in Table 2.

Regarding the reasons driving individuals to express opposition to deceased donation, 133 statements were identified, among which the most frequent were: a lack of knowledge about the donation process, 22 (16.5%); religious beliefs, 21 (15.8%); fear of mutilation or damage to body integrity, 17 (12.8%); conflicts with health care professionals during hospitalization or distrust of professionals or the organ donation process, 11 (8.3%); and unknown reasons, 11 (8.3%). Table 3 presents all the reasons identified, by classification.

FIGURE 1. PRISMA-Scr flow diagram of included studies



Category 2: Reasons why individuals decline to donate a deceased relative's organs and tissues

Category 2 included 64 publications (59 scientific articles and 5 national reports) published from 1996 to 2023. The years with the most publications were 2014 (6 publications [9.3%]), 2021 (5 [7.8%]), and 2011 and 2018 with 4 each (6.2%). When the data were evaluated by country, Brazil was found to have the most publications related to this category (12 publications [18.7%]), followed by 8 (12.5%) in the United Kingdom, 7 (10.9%) in each Spain and the United States, and 4 (6.2%) in each France and Iran. Regarding study methods, 21 (42.1%) were retrospective studies using data from hospital records (indirect data) and 17 (26.5%) were qualitative studies. Detailed information on these articles is presented in Table 4.

Regarding the reasons behind the decision to decline to donate a relative's organs and tissues after the family interview for deceased donation, we identified 414 responses, the most frequent of which were: previous written or verbal expression by the potential donor, 42 mentions (10.1%); fear of mutilation or damage to body integrity, 41 (9.9%); conflicts with health care professionals during hospitalization or distrust of professionals or the organ donation process, 38 (9.2%); religious beliefs, 37 (8.9%); and individual motivations, 36 (8.7%). Table 5 presents all the reasons identified, by classification.

DISCUSSION

Due to the extent of the study findings, we chose to highlight the five most frequent reasons associated with opposing organ and tissue donation or declining to donate. Subcategories that

were frequently common across both categories are discussed together, considering potential differences, and subcategories that were different are discussed separately. Lastly, a comprehensive discussion of other subcategories based on a global analysis of the study's findings is included.

Lack of knowledge about the donation process

Individuals surveyed often cited a lack of understanding about the donation process as the primary reason for their opposition. The dissemination of information regarding organ and tissue donation emerged as a crucial focus for health authorities. Prior studies have underscored the importance of enhancing the availability and promotion of information concerning the donation process. This entails using media channels to not only educate the public about brain and circulatory death and the current consent framework but also dispelling misconceptions and fears while sharing positive narratives about organ and tissue donation and recipient outcomes. Well-informed individuals are better equipped to make decisions, effectively communicate their wishes to their families, and ultimately, shape community attitudes (10).

Religious beliefs

The second primary reason cited by individuals for opposing donation relates to religious beliefs. The death of a loved one is a profound experience, and the grieving process is uniquely challenging for each family. It can be difficult for individuals who are approached in surveys or at events related to organ donation to fully grasp the intensity of the loss. Religious

TABLE 2. Studies included in the first category of the scoping review (n=28)

Authors (year)	Country	Population	Method
Kecicioglu N, et al (2000)	Turkey	Influential religious figures	Structured interview with a quantitative analysis
Ozdag N (2001)	Turkey	Nursing aid Auxiliary, Health technician, Student nurse, Nurse (enroll. + RN), Midwife, Nurse teacher	Structured interview, prospective, descriptive and semi-analytic study
Conesa C, et al (2003)	Spain	General population (over 18 years old)	Survey
Bilgel H, et al (2004)	Turkey	General population (over 18 years old)	Survey
Conesa C, et al (2004)	Spain	Adolescents (15-19 years old)	Survey
Alam A (2007)	Saudi Arabia	General population (20-60 years old)	Survey
Sasso-Mendes K, et al (2008)	Brazil	General population (17-76 years old)	Prospective, descriptive-exploratory, and monocentric study with structured interviews
Hobeika MJ, et al (2009)	United States	Surgical attendings, surgical residents, and medical students	Survey
Hamouda C, et al (2010)	Tunisia	General population	Survey
Lawlor M, et al (2010)	Australia	General population (over 19 years old)	Survey
Sperling D, et al (2012)	Israel	Organ recipients, organ donors, soldiers, university and high school students, and general population	Survey
Holman A, et al (2013)	Romania	General population (adults)	Survey
Kozlik P, et al (2014)	Poland	Academic students	Cross-sectional study with a questionnaire
Riyanti S, et al (2014)	Malaysia	General population (over 18 years old)	Survey
Wang X, et al (2016)	China	General population (over 20 years old)	Survey
Flayou K, et al (2016)	Morocco	Residents in different departments, nurses, and medical students	Prospective research with a self-administered questionnaire
López-Falcony R, et al (2016)	Mexico	General population (over 15 years old)	Survey
Milaniak I, et al (2016)	Poland	Students (over 16 years old), teachers, and nurses	Cross-sectional study using a single self-report completed by the participants
Balajee KL, et al (2016)	India	General population (over 18 years old)	Community-based cross-sectional study, in person survey
Elsafi SH, et al (2017)	Saudi Arabia	Students of the various departments of anesthesia, clinical laboratory sciences, dental and oral health, emergency medicine technology, biomedical technology, nursing, and respiratory care	Cross-sectional study with a questionnaire
El Hangouche AJ, et al (2018)	Morocco	General population (over 18 years old)	National cross-sectional in person survey
Atamanuk AN, et al (2018)	Argentina	Medicine second-year students	Survey
Tarzi M, et al (2020)	Syria	Patients and visitors (inpatient and outpatient) of the study centers over 18 years old	Survey-based cross-sectional study
Akbulut S, et al (2020)	Turkey	General population (over 18 years old)	Survey
Gelidan AG (2020)	Saudi Arabia	Patients who were visiting the plastic surgery clinics of the study center over 18 years old	Survey
Kobus G, et al (2020)	Poland	Followers of Judaism over 18 years old	Survey
Batista EL, et al (2022)	Brazil	Medical students from Brazilian universities	Web-based survey
Bittencourt PL, et al (2022)	Brazil	General population (over 18 years old)	Survey

Additional information on references is available through the corresponding author.

concerns may become paramount when individuals confront this moment (11-14).

Religions offer diverse perspectives on deceased donation. Although some religions consider organ and tissue donation to be an act of charity and altruism, other religions may impose restrictions or objections based on their doctrines. Moreover, religious beliefs substantially shape individual identity and values, profoundly influencing the decision-making processes. Hence, alignment with these principles holds immense importance when individuals make such crucial life decisions (10, 15). Consequently, fostering inter-religious dialogue and ensuring sensitive, respectful communication of donation-related information are imperative. This approach aims to provide accurate information on the official stance of major religions, honoring personal beliefs while emphasizing the importance of donation (10).

Fear of mutilation or damage to body integrity

The concern regarding the integrity of a loved one's body was frequently cited as a reason for declining to donate a relative's organs and tissues after the family interview. This fear warrants further discussion. Often, this aspect is linked to religious considerations, such as preserving the dignity and wholeness of the body. However, it is essential to consider other aspects. Families need to know that organ and tissue donation may delay the mortuary process; however, this information can instill fear of mutilation or disfigurement, leading to a refusal to donate organs and tissue, possibly a last resort to preserving the body's integrity (10). Although health care professionals may assure the family that the body will be returned with the greatest possible integrity, it may still seem invasive to subject

TABLE 3. Reasons why people express in life their opposition to deceased donation

Reason	n	%
Lack of knowledge about the donation process	22	16.5
Religious beliefs	21	15.8
Fear of mutilation or damage to body integrity	17	12.8
Conflicts with healthcare professionals during hospitalization or distrust of professionals or the organ donation process	11	8.3
Unknown reasons	11	8.3
Difficulty in accepting the irreversible nature of brain death	10	7.5
Fear of use for commercial purposes or organ trafficking	8	6.0
Fear of causing pain or suffering to the potential donor	5	3.8
Never thought about the subject	5	3.8
Individual motivations	3	2.3
Resentment towards society or fear of social disapproval	3	2.3
Family conflicts that hindered consensus for donation	3	2.3
Discomfort with cornea donation	2	1.5
Unawareness of who the recipient will be	2	1.5
Unawareness of the potential donor's wishes	2	1.5
Lack of financial benefits for the donor	2	1.5
Previous written or verbal expression of the potential donor	1	0.8
Short time for decision-making or long time for body release	1	0.8
Discomfort in deciding	1	0.8
Inadequacy of the donation process	1	0.8
Emotional factors	1	0.8
Concerns regarding living donation	1	0.8
Total	133	100

Additional information on references is available through the correspondent author.

a loved one's body to additional procedures after death. This perspective transcends mere legal assurances of ethical conduct and the importance of body reconstruction; it delves into the realm of personal care and coping with grief (16, 17).

Once again, information dissemination proves crucial, along with legal assurance. Although numerous countries have legislation or recommendations addressing body reconstruction, we propose incorporating these assurances into every country's legal framework, enforceable by law. Safeguarding the respectful return of the donor's body to the family for funeral rituals is recognized as a fundamental human right, deserving legal protection (18, 19). Furthermore, providing adequate support to the family, promoting comfort, and delivering precise information, along with optimizing the time between procedures, are strategies that can facilitate this scenario.

Conflicts with health care professionals during hospitalization or distrust of professionals or the organ donation process

The interaction between health care professionals and patients and their families during a hospital stay is paramount to establishing rapport, trust, and a supportive relationship. Ensuring a high standard of care and emphasizing patient- and family-centered approaches throughout hospitalization and at the end-of-life stage are crucial for professionals. If families experience distrust or discomfort regarding the health care team or notice changes before and after the diagnosis of brain death, their decision-making may be substantially influenced (20, 21). Enhancing the qualifications and training of health care professionals represents an effective strategy to mitigate conflicts.

However, it is essential to tailor these training programs to the specific needs of local populations, considering epidemiology, moral values, religious beliefs, and cultural aspects.

Research suggests that culturally appropriate training that addresses family values (21) and involves experienced and dedicated professionals (22) can greatly benefit these initiatives. However, conflicts among health care professionals may affect perceptions of hospital service quality, potentially compromising relationships among colleagues and affecting donation-related decision-making. Evaluating and identifying areas of weakness in professional relationships is crucial. Mapping services and fostering improved work environments can bolster team confidence, enhance inter-professional relationships, and ultimately, improve patient and family care (23).

Unknown reasons

Some individuals expressed opposition to deceased donation without specifying a motive. This may have been associated with two aspects: first, privacy, that is, an individual's desire to not disclose the reason(s) for a personal life decision; and second, never having been sensitized to deceased donation, and therefore, lacking knowledge of the process and its importance. However, these data allow for assumptions but were challenging to compare, underscoring the need for further investigation (11, 19, 24, 25).

Previous written or verbal expression by the potential donor

The decision not to become a donor is a fundamental right. Although some countries offer registries to formalize the

TABLE 4. Studies included in the second category of the scoping review (n=64)

Authors (year)	Country	Population	Method
Durand-Zaleski I, et al (1996)	France	Families who had been asked for their consent to organ procurement during the year 1994	Semi-structured interview with qualitative analysis
Bonnet F, et al (1997)	France	Questionnaire filled in by the physicians after the interviews of the relatives of brain-dead patients	Prospective study
Kometsi K, et al (1999)	South Africa	Black African families who were interviewed for organ donation	Semi-structured interviews with qualitative analysis
Tsai E, et al (2000)	Canada	Data collected from hospital records (indirect data) related to pediatric context	Retrospective study
Yong BH, et al (2000)	Hong Kong	Data collected from hospital records (indirect data)	Retrospective study
Martínez JM, et al (2001)	Spain	Data collected from hospital records (indirect data)	Retrospective study
Siminoff LA, et al (2002)	United States	Organ procurement coordinators who conducted the interview for organ donation	Retrospective study with a structured instrument
Verble M, et al (2002)	United States	Family members involved in the decision process related to organ donation	Retrospective study with a semi-structured instrument for in person interview
Rodrigues JR, et al (2003)	United States	Family members involved in the decision process related to organ donation	Retrospective study with a semi-structured interviews via telephone
Ashkenazi T, et al (2004)	Israel	Data collected from hospital records (indirect data)	Retrospective study
Tandon R, et al (2004)	India	Family members involved in the decision process related to cornea donation	Structured interviews
Frutos MA, et al (2005)	Spain	Data collected from hospital records (indirect data)	Retrospective study
Frutos MA, et al (2005)	Spain	Data collected from hospital records (indirect data)	Retrospective study
Bellali T, et al (2006)	Greece	Family members involved in the decision process related to organ donation in pediatric scenario	Semi-structured interview with qualitative approach
Barber K, et al (2006)	United Kingdom	Data collected from hospital records (indirect data)	Retrospective study
Bellali T, et al (2007)	Greece	Family members involved in the decision process related to organ donation in pediatric scenario	Semi-structured interview with qualitative approach
Siminoff LA, et al (2007)	United States	Family members involved in the decision process related to organ donation	Structured interview with qualitative approach
Sanner MA, et al (2007)	Sweden	Family members involved in the decision process related to organ donation	Open interviews with qualitative analysis
Martínez JS, et al (2008)	Spain	Family members involved in the decision process related to organ donation	Structured interviews with qualitative analysis
Moraes EL, et al (2008)	Brazil	Family members involved in the decision process related to organ donation	Qualitative research based on the situated-phenomenon structure
Sotillo E, et al (2009)	Venezuela	Data collected from hospital records (indirect data)	Retrospective study
Baran D, et al (2009)	Canada	Data collected from hospital records (indirect data)	Retrospective study
Moraes EL, et al (2009)	Brazil	Family members involved in the decision process related to organ donation	Qualitative phenomenological approach
Dalbem GG, et al (2010)	Brazil	Data collected from hospital records (indirect data)	Retrospective, documentary study
Fernandes M, et al (2010)	Brazil	Data collected from hospital records (indirect data)	Cross-sectional descriptive study
Beca I, et al (2011)	Chile	Data collected from hospital records (indirect data)	Case report
Ghorbani F, et al (2011)	Iran	Family members involved in the decision process related to organ donation	Retrospective study with interviews via telephone
Dehghani S, et al (2011)	Iran	Family members involved in the decision process related to organ donation	Cross-sectional descriptive study with structured interviews
Saviozzi A, et al (2011)	Italy	Data collected from hospital records (indirect data)	Retrospective study
Rodríguez-Villar C, et al (2012)	Spain	Transplant coordinators who conducted the interview for organ donation	Survey
Morais M, et al (2012)	Brazil	Family members involved in the decision process related to organ donation	Descriptive cross-sectional study
Ira GG, et al (2012)	Brazil	Family members involved in the decision process related to organ donation	Qualitative study using a descriptive exploratory design
Verble M, et al (2013)	United States	Potential donor's family	Telephone interview with a structured instrument
Pessoa JLE, et al (2013)	Brazil	Data collected from hospital records (indirect data)	Correlational cross-sectional study
Mahdavi-Mazdeh M, et al (2013)	Iran	Data collected from hospital records (indirect data)	Retrospective study
Lawlor M, et al (2014)	Australia	Family members involved in the decision process related to organ donation	Qualitative study with a semi-structured interview
Pompeu MH, et al (2014)	Brazil	Family members involved in the decision process related to organ donation	Qualitative study with a structured interview

(Continued)

TABLE 4. (Cont.)

Authors (year)	Country	Population	Method
Le Nobin J, et al (2014)	France	Data collected from hospital records (indirect data)	Retrospective study
Shaw D, et al (2014)	United Kingdom	Data collected from hospital records (indirect data)	Retrospective study
Kumar V, et al (2014)	India	Family members involved in the decision process related to organ donation	Prospective study with structured interviews
Hermann KC, et al (2014)	Brazil	Data collected from hospital records (indirect data)	Retrospective study
Knihs NS, et al (2015)	Brazil	Family members involved in the decision process related to organ donation	Exploratory, descriptive, qualitative research with a phenomenological approach using a semi-structured interview
De Groot J, et al (2015)	Netherlands	Family members involved in the decision process related to organ donation	Qualitative study with a semi-structured interview
Hénon F, et al (2016)	France	Data collected from hospital records (indirect data)	Retrospective study
Shaw D (2016)	United Kingdom	Data collected from hospital records (indirect data)	Overview of the national report
Lee A, et al (2017)	China	Data collected from hospital records (indirect data)	Retrospective study
Can F, et al (2017)	Turkey	Family members involved in the decision process related to organ donation	Semi-structured interview with quantitative and qualitative approach
López JS, et al (2018)	Spain	Family members involved in the decision process related to organ donation	Observational study with a validated instrument
Molina MI, et al (2018)	Colombia	Data collected from hospital records (indirect data)	Overview of the national report
Mojtabae M, et al (2018)	Iran	Data collected from hospital records (indirect data)	Retrospective study
Moraes EL, et al (2019)	Brazil	Family members involved in the decision process related to organ donation	Qualitative study, social phenomenology as the theoretical reference, with interviews
Yeşilbaş O (2020)	Turkey	Family members involved in the decision process related to organ donation	Structured interview
Schmidt S, et al (2020)	Germany	Data collected from hospital records (indirect data)	Retrospective study
Darnell W, et al (2020)	United States	Family members involved in the decision process related to organ donation	Qualitative study with semi-structured interviews
Siminoff LA, et al (2021)	United States	African American family members involved in the decision process related to organ donation	Data collected from hospital records (indirect data) and interviews with a qualitative approach
Leblebice M (2021)	Turkey	Data collected from hospital records (indirect data)	Retrospective study
Santos DC, et al (2023)	Brazil	Data collected from hospital records (indirect data)	Retrospective study
National Health Service - Blood and Transplant (2018)	United Kingdom	Data collected from hospital records (indirect data)	National report
National Health Service - Blood and Transplant (2019)	United Kingdom	Data collected from hospital records (indirect data)	National report
National Health Service - Blood and Transplant (2021)	United Kingdom	Data collected from hospital records (indirect data)	National report
National Health Service - Blood and Transplant (2022)	United Kingdom	Data collected from hospital records (indirect data)	National report
National Health Service - Blood and Transplant (2023)	United Kingdom	Data collected from hospital records (indirect data)	National report

Additional information on references is available through the corresponding author.

decision to be a donor (opt-in consent model) or not become a donor (opt-out consent model), in other countries, it is left to the family to be informed and to make the decision (2, 3, 26).

Educating populations about the donation process remains a pivotal strategy, not only to boost donation rates, but to facilitate decision-making among family members. Understanding the wishes of the individual, when discussed during their lifetime, aids the family in decision-making, whereas uncertainty can lead to heightened distress and a greater likelihood of refusal (27). This association was suggested by our study findings—the primary reason for refusal among interviewed families was the previously expressed intention of the potential donor.

Individual motivations

Families who underwent family interviews for deceased organ donation and decided to decline cited different individual

motivations. These motivations are related to the unique experiences and personal beliefs of each family. They are intimate aspects linked to decision-making, especially in the face of grief, pain, and suffering, compounded by the demand for decision-making (28, 29).

Comprehensive discussion regarding the other subcategories

Among the classifications related to reasons for opposing or declining organ and tissue donation, some reasons that were mentioned in one category did not appear in the other. For example, in category 1, refusal due to “belief in miracles or potential donor’s recovery” did not appear, and in category 2, “never thought about the subject,” “concerns regarding living donation,” and “lack of financial benefits for the donor” were

TABLE 5. Reasons behind the decision to decline to donate relatives' organs and tissues after the family interview for deceased donation identified in the scoping review

Reasons	n	%
Previous written or verbal expression of the potential donor	42	10.1
Fear of mutilation or damage to body integrity	41	9.9
Conflicts with healthcare professionals during hospitalization or distrust of professionals or the organ donation process	38	9.2
Religious beliefs	37	8.9
Individual motivations	36	8.7
Family conflicts that hindered consensus for donation	31	7.5
Difficulty in accepting the irreversible nature of brain death	27	6.5
Lack of knowledge about the donation process	27	6.5
Little time for decision-making or long time for body release	26	6.3
Unawareness of the potential donor's wishes	24	5.8
Fear of causing pain or suffering to the potential donor	21	5.1
Unknown reasons	16	3.9
Resentment towards society or fear of social disapproval	13	3.1
Discomfort in deciding	10	2.4
Belief in miracles or potential donor's recovery	7	1.7
Fear of use for commercial purposes or organ trafficking	6	1.4
Unawareness of who the recipient will be	4	1.0
Inadequacy of the donation process	4	1.0
Emotional factors	3	0.7
Discomfort with cornea donation	1	0.2
Total	414	100

Additional information on references is available through the corresponding author.

not mentioned. Concerns about living donation may not apply to the scenario of a deceased donor, and further research is necessary to determine this relationship or to define whether this was a casual finding (30). Regarding the classification of “never thought about the subject,” even if a family member has never considered the issue, when confronted with it, a decision is necessary. Thus, it is not reported as a reason for declining to donate a relative's organs and tissues (11, 19, 28).

The last classification, which was mentioned in surveys of individuals but does not appear in the 414 mentions from studies regarding families who underwent interviews is the “lack of financial benefit for the donor.” Another study indicated that when people were confronted with the idea of organ and tissue donation, direct payment as an incentive for decision-making was not seen as a good strategy. Strategies such as financial assistance with funeral arrangements and donations to charity by health care institutions were viewed positively in the study (10). However, there is a broad discussion surrounding this topic and the major recommendation is to incentivize donation with neutral costs and with no financial reward (1, 4, 31).

Understanding the reasons why individuals decline or are opposed to organ and tissue donation is crucial. This information will not only help us develop strategies to increase donation rates but also contributes to scientific, clinical, and ethical advancement in how we support families. By comprehending these aspects, we can enhance the quality of care provided to families during bereavement and the process of facing death. This ensures that when families are faced with the decision of organ and tissue donation, they do not feel pressured or overwhelmed. Instead, they can be guided to make a sound decision that allows them to avoid any negative effects from the experience (15, 21, 27).

It is important to consider that research conducted in real-world environments is distant from organ and tissue donation. Surveys that collect people's thoughts on organ and tissue donation may prompt individuals to contemplate death and its possibility; however, their responses will likely be closely related to their current life situation and social context. There is a certain difficulty in accessing the concept of finitude amid life and daily routines.

When studies address family members who have undergone interviews for deceased donation, they reflect not only a rational reason for the decision but also the experience of coping with grief and mourning. The context changes, priorities change as well; it is no longer about the context of life but rather the context of death. Therefore, the reasons for decision-making also change, being associated with care and the stages of mourning that each person experiences differently.

Understanding these differences can foster the development of actions and strategies that are more valid and contribute not only to increasing donation rates but also ensuring that health care systems are ethical and transparent regarding transplantation. Moreover, quality information should be disseminated in a manner that considers the diversity of the population. Thus, decisions regarding organ donation and whether to register as a donor or non-donor can be made in an informed manner, without persuasion or pressure. If they are well-informed, family members confronted with the need to decide for or against organ donation while mourning will experience greater comfort and respect, and will make the best decision for themselves (15, 21, 25).

Limitations

This scoping review had some limitations. It incorporated national reports from a single country and context, potentially

impacting the interpretation of the data. Other limitations of the study relate to the lack of standardization in the language used when addressing the reasons why people decline or oppose organ and tissue donation. The authors of each study used different descriptions, compromising the ability to identify all relevant articles in the field. Furthermore, despite being meticulously structured, the search strategies may not have been sensitive enough to identify other studies and materials from different regions of the world.

Conclusions

This scoping review was able to map the reasons behind declining or opposing organ and tissue donation and it provides an international overview. The two categories mapped in the review yielded 23 subcategories of reasons. These findings contribute to the literature and knowledge base by comparing the different studies and countries that have addressed organ and tissue donation. These findings may also be the basis for reflecting on how health authorities can develop strategies to provide the public with accurate information (and debunk misinformation) on organ donation, ultimately increasing the number of those who donate and those who receive transplants. We expect that this study will impact future research and assist in strategy development and educational materials to gain wider support for organ and tissue donation.

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Razones de la negativa y la oposición a la donación de órganos y tejidos: una revisión exploratoria

RESUMEN

Objetivo. Elaborar un mapa de las razones por las que las personas se oponen a la donación de órganos y tejidos o la rechazan, desde una perspectiva internacional.

Métodos. Entre mayo del 2022 y febrero del 2024, se llevó a cabo una revisión exploratoria mediante una estrategia de búsqueda en tres etapas en cinco bases de datos y Google Scholar. El análisis de los datos consistió en clasificar la información en función de las similitudes y las poblaciones estudiadas.

Resultados. Se incluyeron en el análisis 92 artículos e informes nacionales. Los datos recopilados se clasificaron en dos categorías. La categoría 1 incluía las razones por las que las personas se oponen a la donación de órganos de una persona fallecida: falta de conocimiento sobre el proceso de donación, 22 (16,5%); creencias religiosas, 21 (15,8%); temor a la mutilación o al daño a la integridad del cuerpo, 17 (12,8%); conflictos con los profesionales de la salud durante la hospitalización, o desconfianza hacia los profesionales o el proceso de donación de órganos, 11 (8,3%); y razones desconocidas, 11 (8,3%). La categoría 2 incluía las razones por las que las personas rechazan la donación de los órganos y tejidos de un familiar fallecido después de la entrevista con la familia para la donación tras el fallecimiento: manifestación previa por escrito o verbalmente por parte del posible donante, 42 (10,1%); temor a la mutilación o al daño a la integridad del cuerpo, 41 (9,9%); conflictos con los profesionales de la salud durante la hospitalización, o desconfianza hacia los profesionales o el proceso de donación de órganos, 38 (9,2%); creencias religiosas, 37 (8,9%); y motivos personales, 36 (8,7%).

Conclusiones. Esta revisión exploratoria puso de manifiesto que existían dos categorías principales de razones para oponerse a la donación de órganos y tejidos o rechazarla, que incluían 23 subcategorías. Mediante la elaboración de un mapa de estas razones en diversos contextos internacionales, estos resultados proporcionan una perspectiva para las investigaciones futuras, así como un fundamento para la elaboración de iniciativas educativas sobre la donación de órganos y tejidos.

Palabras clave

Conocimientos, actitudes y práctica en salud; toma de decisiones clínicas; obtención de órganos y tejidos; trasplante de órganos; trasplante de tejidos.

Motivos para oposição e recusa à doação de órgãos e tecidos: revisão de escopo

RESUMO

Objetivo. Mapear os motivos que levam à oposição ou recusa à doação de órgãos e tecidos a partir de uma perspectiva internacional.

Métodos. Uma revisão de escopo foi realizada entre maio de 2022 e fevereiro de 2024, usando uma estratégia de busca em três estágios em cinco bases de dados e no Google Acadêmico. Para realizar a análise dos dados, as informações foram categorizadas segundo semelhanças e populações estudadas.

Resultados. A análise incluiu 92 artigos e informes nacionais. Os dados coletados foram classificados em duas categorias. A categoria 1 incluiu os motivos que levam as pessoas a se oporem à doação de doador falecido: falta de conhecimento sobre o processo de doação, 22 (16,5%); crenças religiosas, 21 (15,8%); medo de mutilação ou perda da integridade do corpo, 17 (12,8%); conflitos com profissionais de saúde durante a internação ou desconfiança em relação aos profissionais envolvidos no processo de doação, 11 (8,3%); e motivos não informados, 11 (8,3%). A categoria 2 incluiu os motivos que levam à recusa dos familiares de doar os órgãos e tecidos de um parente falecido após a entrevista de doação: vontade do potencial doador manifestada em vida de forma verbal ou por escrito, 42 (10,1%); medo de mutilação ou perda da integridade do corpo, 41 (9,9%); conflitos com profissionais de saúde durante a internação ou desconfiança em relação aos profissionais envolvidos no processo de doação, 38 (9,2%) crenças religiosas, 37 (8,9%); e motivos pessoais, 36 (8,7%).

Conclusões. Esta revisão de escopo indicou a existência de duas categorias de motivos principais para a oposição ou a negativa dos familiares de doar órgãos e tecidos de um ente falecido, com 23 subcategorias. O mapeamento desses motivos no âmbito internacional oferece *insights* para pesquisas futuras e serve de base para iniciativas educacionais sobre doação de órgãos e tecidos.

Palavras-chave

Conhecimentos, atitudes e prática em saúde; tomada de decisões clínicas; obtenção de órgãos e tecidos; transplante de órgãos; transplante de tecidos.
