

Familial consent/vetoing of organ donation: A systematic review of the contemporary literature.

Abstract

The imminent implementation of an opt-out organ donation system in England has given rise to an abundance of literature exploring the topic. One of the major impediments to organ donation currently, is the issue of familial decision-making upon the death of a potential donor. Familial vetoing of organ donation accounted for 11% of organ donation refusals in 2014-2015 throughout the UK (Hulme et al, 2016). This highlights the need for scientific exploration into the topic. This systematic literature review was undertaken with the specific aims of compiling and analyzing contemporary research which a) explored the reasons why families consent/veto organ donations of deceased relatives, and/or b) suggested or tested possible means to overcome the issue. A multi-database literature search was conducted, with specific inclusion and exclusion criteria, which resulted in seven articles being available for review. As the existing literature was so scant, each article was summarized and individually appraised using appropriate tools. The results of this literature review showed that the main factors involved in familial organ donation decision-making include; presence of an SN-OD during family discussion, type of donor death (circulatory/brain) and the ethnicity of the donor/ donor family. The results with regards to amelioration of organ donation vetoing showed important possible directions for research within the contexts of; education/communication, diversification of familial approach options and nudging theory.

1. Introduction

The topic of organ donation is currently a hotbed of discussion and research throughout the UK (Dallimore et al, 2019; Byrne et al, 2019; Maravia, 2019). Following the 2013 Human Transplantation Wales Act (2013, anaw 5), a new framework for organ donation was implemented, changing organ donor registration from an “explicit consent” to a “presumed consent” system, throughout the country of Wales. This Act, which came into practical effect in 2015, was partly in response to the desperate public need for organ donation in Wales, was the first Act of its kind in the UK, and was influenced by similar legislation throughout other European countries such as Spain and Belgium (Health, Wellbeing and Local Government Committee, 2008; Rithalia et al, 2009). As opposed to the previous system, wherein individuals had to opt-in to donate their organs after death, all eligible adults in Wales are now automatically assumed to be organ donors, unless they specifically choose to opt-out of the ODR. From Spring 2020, this structure will also be adopted in England (National Health Service [NHS], 2019a), and the upcoming change in legislation has given rise to speculation and debate about the efficacy, morality and functionality an opt-out ODR.

A recent study by Noyes et al (2019) highlighted that while the opt-out system implemented in Wales in 2015 *did* correlate with increased organ donation registration, this increase could not be definitively attributed to the Human Transplantation Wales Act, because the rest of Britain also saw a significant increase in consented donors during that period. Noyes speculates that this disputes the idea that an opt-out ODR will increase donation rates. Another issue that has divided opinion on the presumed consent ODR system is centred around the unique diversity of England and its residents. Contention amongst religious leaders regarding the definition of “death” has impacted Islamic belief and uptake of organ donation (Cooper & Kiarans, 2016; Rispler & Duguet, 2018), and those who practice Christianity are also faced with conflicting biblical opinions and low donation rates (Oliver et al, 2011; Munoz, 2018). These are just two examples underlying the wider

discourse regarding how religion plays a part in organ donation rates, and how religious beliefs could cause individuals to disagree with an opt-out ODR.

The functionality of the opt-out system has also been brought into question, due in part to the fact that the approach adopted by the UK so far is a “soft” opt-out. This means that while individuals are presumed to be potential donors, and can even still “opt-in” by providing express consent, this decision can be overruled in the event of their passing, by surviving family members. Relatives of a presumed donor can challenge or veto the donation of organs and can do so even if the deceased had previously given explicit consent (Page et al, 2018). Between April 2018 and March 2019, 79 families overrode a potential donor’s decision to donate (National Health Service Blood and Transplant [NHSBT], 2019), and during the year 2016-2017, there was an increase in familial overrides of organ donation in Wales of over 25% (Noyes et al, 2019). This evidence highlights that familial vetoing is one of the largest impediments to improving organ donation rates in the UK. The literature brings into question the efficacy of a presumed consent system, wherein the family has the final say, and establishes the need to explore the reasons behind the familial organ donation vetoing phenomenon.

1.1. Aims

The purpose of this systematic literature review is therefore to assimilate and evaluate relevant, contemporary research studies that explore the psychological underpinnings of familial vetoing. There are two specific aims of this review, firstly (1) to gain a wider understanding of what factors are associated with a family’s decision to donate or veto donation of organs. Secondly, (2) explore possible measures that could be taken to ameliorate these factors, and thereby improve donation rates in the future.

2. Methods

2.1. Search Strategy

The electronic catalogue search provided by The University of Wales Trinity Saint David was utilised as a tool to gather studies from 13 databases, none of which were excluded from the search criteria. The studies that were eventually selected were retrieved from ProQuest Central (2003-2019), SAGE Premier (2003-2019), BMJ Open (1975-2019) and EBSCO (1998-2019). The specific search terms are shown in Table 1.

Table 1

Exact terms used in initial search

Keyword Combination		
-----	Title contains:	organ
AND	Title contains:	donation
AND	Title contains:	family OR families OR loved ones
AND	Title contains:	consent OR veto OR override OR overrule

2.2. Inclusion and exclusion criteria

This initial search returned 26 papers. The focus of the current study was to evaluate contemporary research, and therefore articles published before 2015, were excluded. Previous systematic reviews and meta-analyses were excluded from the search, as were papers in languages other than English. Due to the relatively small pool of remaining relevant literature, it was decided that research from outside the UK would also be included

in the review. Finally, only peer-reviewed and online accessible articles were selected to be included. This process left 10 articles available for review.

2.3. Review process

Of the 10 remaining articles, only six included subject matter relevant to answering the research aims of the current review and were therefore chosen to be included.

Specifically, these six consisted of primary research which either (1) explored the factors associated with familial vetoing of organ donation, or (2) explored a means to ameliorating this phenomenon. Please see Table 2 for a breakdown of which papers provided evidence for these aims.

Table 2

Papers' contributions to the study aims

Study number/name	Explored factors associated with familial vetoing	Explored a means to ameliorate familial vetoing
1. Taking care of relationships in the intensive care unit: Positive impact on family consent for organ donation (Bocci et al, 2016).		✓
2. Factors influencing the family consent rate for organ donation in the UK (Hulme et al, 2016).	✓	✓
3. A comparative study of effective factors on consent to organ donation among families of brain death victims (Zamani & Abedi, 2015).	✓	
4. Influencing families to respect donor autonomy: Should we nudge families to consent to organ donation? (Sharif & Moorlock, 2017)		✓
5. The Rule of Threes: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK (Morgan et al, 2018)	✓	✓
6. Demographic characteristics of brain death cases in our clinic and causes of family refusal for organ donation (Boran et al, 2019)	✓	✓

2.4 Quality Assessment

The final articles were then scrutinized individually using critical appraisal tools relevant to their study design, to explore their validity, worthiness, and clinical significance. The results of the appraisals are outlined briefly in Table 3 and are explored more thoroughly within the results section (3.2).

Table 3

Quality Assessment of studies using CASP

Study Number	Study design	Appraisal tool used
1	Non-randomised controlled trial	Methodological Index for Non-randomized Studies (MINORS) (Slim et al, 2003)
2	Cross-sectional study	Appraisal tool for cross-sectional studies (AXIS) (Downes et al, 2016)
3	Cross-sectional study	AXIS (Downes et al, 2016)
4	N/A – Narrative review/article	Scale for the Quality Assessment of Narrative Review articles (SANRA) (Baethge et al, 2019)
5	Cross-sectional study	AXIS (Downes et al, 2016)
6	Cross-sectional study	AXIS (Downes et al, 2016)

3. Results

3.1 Overview of studies

Six articles met the inclusion criteria, each with their own merits and methodologies. The differing tools used to appraise each study were justified by the differences in research type or study design. As a whole, the experimental studies looked at data from 5,268 participants, with one study based in Italy (Bocci et al, 2016), one in Iran (Zamani & Abedi, 2015), one in Turkey (Boran et al, 2019) and two based in the UK (Hulme et al, 2016; Morgan et al, 2018). The single non-experimental study was also based in the UK (Sharif & Moorlock, 2017). Participants consisted of family members who had refused or vetoed the organ donation of a deceased relative. All five of the experimental studies used a stratified cluster sampling technique and a variety of data collection methods were used such as questionnaires, interviews and collating national statistics. Three of the studies were local or regional studies, two were conducted using national statistics and one study looked at both regional and national statistics to evaluate an intervention. The articles were all recent, having been published within the last five years. One was published in 2015, two were published in 2016, and one was published each in 2017, 2018 and 2019. Participants' general demographics were only presented within two of the five studies (Morgan et al, 2018; Zamani & Abedi, 2015) and these were contradictory of each other. One purported that gender has no relationship with vetoing behaviour (Morgan et al, 2018), and another suggested that it does (Zamani & Abedi, 2015). Of the six articles, four included an exploration of the possible reasons for familial organ donation vetoing (shown in Table 2), and four articles explored a quantitative method of reducing this phenomenon (shown in Table 2). One article narratively explored a possible method of reducing the phenomenon (Sharif & Moorlock 2017). As there are only six studies available for review in this case, each is individually critiqued in section 3.2.

3.2. Study characteristics

3.2.1. Study 1.

The first study evaluated in the current review was named “Taking care of relationships in the intensive care unit: Positive impact on family consent for organ donation” (Bocci et al, 2016). This study was evaluated in regard to meeting aim 2 of the current review, as it explored a means to ameliorate organ donation vetoing. The appraisal tool used to review this study was the Methodological Index for Non-randomized Studies (MINORS, Slim et al, 2003).

The study was a non-randomized controlled trial that took place in the 18-bed intensive care unit of a university hospital in Italy. The paper purports that the communicative approach used with families of brain-dead patients is imperative to their decision of whether to veto organ donation or not. A new communication approach was introduced to the unit for all families from 2012, and a before-and-after design utilised to compare whether this intervention affected family consent rates. The pre-intervention period was given as 2007-2012 and the post-intervention period as 2013-2015. The hypothesis of the study was clearly stated as being “changing the approach to relatives could influence factors affecting organ donation refusal.” The previous literature cited in the article supported the hypothesis and research aims well and gave a sound basis for the necessity of the intervention. Both pre- and post-intervention data were collected from the Italian Transplant Coordination system, which provides statistical information for all organ donations on national, regional and individual hospital levels. As well as exploring the effect of the intervention within this study, the authors compared the outcomes to national and regional changes during the same time periods. The study results showed a significant improved consent rate during the post-intervention period within the hospital unit. This was anomalous to the regional and national statistics which showed no significant improvement to consent rates during that period (Bocci et al, 2016). The authors concluded that their communication approach intervention was a successful tool in improving familial organ donation consent.

The research undertaken in this study was replicable and valid, however it could be noted that there was a distinct difference between the time periods explored pre- and post-intervention. The researchers compared five years prior to the intervention to only two years afterwards. This could be excused as the results showed a significant positive outcome, and the authors would have wanted to disseminate the findings and improve donation rates. Nevertheless, it would be pertinent to ensure that the effect of the intervention does not diminish over time, as the communication approach itself evolves. Also, while the authors did compare their own findings with the national average, they failed to provide any estimate of the effect size of their results. This reduces the clinical significance of the study and lessens its validity and real-world applicability.

3.2.2. Study 2

The second study evaluated in the current review was named “Factors influencing the family consent rate for organ donation in the UK” (Hulme et al, 2016). This study was evaluated in regard to meeting aims 1 and 2 of the current review, as it explored reasons given for families’ decisions on organ donation and proposed a means to ameliorate vetoing. This article was appraised using the Appraisal of Cross-Sectional Studies tool (AXIS, Downes et al, 2016).

Although not looking at vetoing behaviour specifically, this study took a positive behaviour perspective, focusing on which factors improve consent, rather than factors which ameliorate vetoing. The aims of the study itself were made clear as being “to identify factors associated with family consent” and “to inform UK practice”, and the study design was appropriate and clearly stated. Sampling was conducted on a national level using the UK NHSBT and was therefore extremely representative of the population. The study utilised parametric logistic regression analyses to explore the reasons given for familial organ donation consent in both circulatory death and brain death scenarios. The results of the

study were also explained concisely, thoroughly and were analysed critically with a high degree of professionalism. The results found that there are a number of factors significantly associated with familial consent for organ donation. Firstly, when considering families of potential circulatory-death donors, the factors significantly associated with consent were; ethnicity of the family, cause of donor death, prior knowledge of donors wishes, and the presence of a specialist nurse in organ donation (SN-OD) during the family approach. Secondly, in regards to brain death donors families, the most significant factors associated with donation consent were found to be; ethnicity of the family, prior knowledge of donors wishes, the timing of the request for organ donation, and the presence of a SNO during the family approach. Interestingly, it was also found that there was a very strong association between consent and the presence of SN-OD, particularly when the SN-OD was the one to make the request for donation. The study concluded that the approach to improving donation rates in the UK is two-fold. The authors purport that by improving the media representations of organ donation, and simultaneously adjusting the way in which families are approached about organ donation, organ donation rates will rise.

This study provides strong evidence for the conclusions it found and was supported by a large body of scientific evidence and relevant previous literature. The scope of the research was far-reaching and has high clinical significance and applicability to real-world implementation of policy.

3.2.3. Study 3

The third study included in this review was titled “A comparative study on effective factors on consent to organ donation among families of brain death victims in Isfahan 2013” (Zamani & Abedi, 2015). This study was evaluated in regard to it meeting aim 1 of the current review, as it explored the factors relating to familial responses to organ donation requests. As with the previous article, this study was framed from a positive perspective, in

that it focused on familial consent rather than familial vetoing, being that both are “two sides of the same coin.” This article was appraised using the Appraisal of Cross-Sectional Studies tool (AXIS, Downes et al, 2016).

The study was undertaken in 2012-2013 and collected questionnaire data asking about reasons for donation decisions from 85 family members of brain death patients in the city of Isfahan, Iran. The participant sample was obtained from the entire population of families of brain death victims during that period and was divided into those who passed from circulatory death and those who passed from brain death. The study then compared factors between the two groups. Although the aims of the study were well defined, there are criticisms to be made about several aspects of the research. The study design was overly complex and the reasons for separating the sample into circulatory or brain death were not justified. This led to the research not fully exploring its initial aims, and instead it simply concentrated on the differences in reason for consent/veto between the two groups. The method of data collection consisted of the researcher going to participants' homes and conducting questionnaire studies, or interviews with those participants who were illiterate. The questionnaires were researcher-created, and there was no example given in the appendices. This is concerning and raises questions about the validity and reliability of the questionnaire. The article presented its data collection method very briefly, and did not clarify whether participants were asked to take part *prior* to the researcher arriving at their home, did not report or discuss any informed consent of participants, and did not provide information on any debrief given to participants following the questionnaire/interview. It could be therefore be suggested that the data collection in this study was not scientifically rigorous or replicable. The results of the study, as mentioned, determined some factors that were significantly related to familial organ donation decisions. These included significant associations between consent for donation and; gender, hospital stay duration, knowledge of donors wishes, donor having a donor card and families' positive opinion of organ donation. However, the results of the study were presented confusingly, with the authors concentrating

on differences between the groups, rather than on the factors themselves, which was the study aim. It was also unusual that demographic information regarding participants' religion was not gathered, considering that the study was undertaken in a relatively theological country. This could have provided interesting insights into the role of religious beliefs in organ donation decision-making and improved the scope of the study.

The authors closed the article with generic recommendations for further research and provision of information to potential donors' families but struggled to link this conclusion to their own findings. Due to this, and the number of other methodological issues present in the design and procedure, it could be determined that unfortunately this study does not have much ecological validity for explaining reasons behind familial vetoing of organ donation.

3.2.4. Study 4

The fourth article evaluated within the current paper was a narrative review named "Influencing relatives to respect donor autonomy: Should we nudge families to consent to organ donation?" (Sharif & Moorlock, 2017). This study was evaluated in regard to meeting aims 1 and 2 of the current review, as it explored reasons given for families' decisions on organ donation and proposed a means to ameliorate vetoing. The article was appraised using the Scale for the Assessment of Narrative Review Articles (SANRA, Baethge et al, 2019).

Firstly, this article was atypical of the others included in this review, as it did not include an experimental aspect of research. However, the potential bias of a narrative review was mitigated in this case via the use of the aforementioned appraisal tool and a wealth of prior supporting evidence and research. Sharif and Moorlock offered that the justification for publishing their paper was the fact that organ donation rates are severely affected by familial vetoing. This statement is widely supported by the literature and statistics currently available and was also explored in the introduction of the current review. The paper also explicitly stated its purpose, purporting to explore a) the roles of relatives in the discussions about

organ donation, b) how nudge theory (Thaler & Sunstein, 2008) could be applied to the issue of familial vetoing and c) the arguments for and against the application of nudge theory (Thaler & Sunstein, 2008) in this context. The fact that this paper clearly and specifically outlined its aims speaks to the professionalism of the research and the substantial prior investigations of the topic by the authors. Unfortunately, as a narrative review, this article did not include a description of how the authors found their research, and this fact is often used to highlight possible bias. However, the reference list was explored by the current review for similar studies, or for studies by the same few authors and it was found that a wide range of previous literature was used. The consistency of the referencing used throughout the text also showed that the authors attempted to ameliorate their own bias during writing.

The scientific reasoning given by Sharif and Moorlock for why nudge theory could be used to improve organ donation rates is strong and draws upon established and widely accepted psychological knowledge and theory (Thaler & Sunstein, 2008; Hulme et al, 2016). They suggest using a cognitive approach and utilising tools such as motivational interviewing of potential donors' families, and they also explain how nudge theory could be synthesised into this model. Evidence against using nudge theory with donor families is also explored within the article and is given as much credence as the evidence supporting the model. The conclusion of the paper is compelling and provides a credible argument for the recommendations. On consideration of the article, it is reasonable to accept the findings as being a valuable insight into a possible means to ameliorate familial vetoing of organ donation.

3.2.5. *Study 5*

The fifth study included in the current review was named "The rule of three: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK" (Morgan et al, 2018). This study was evaluated in regard to meeting aims 1 and 2

of the current review, as it explored reasons given for families' decisions on organ donation and proposed a means to ameliorate vetoing. The study was appraised using the Appraisal of Cross-sectional Studies tool (AXIS, Downes et al, 2016).

This research study was undertaken on a cohort of families who had vetoed organ donation despite knowing that their deceased relative was on the ODR. The aims of the study were clearly stated as being to identify what factors are associated with familial refusal to donate, and the authors particularly wanted to identify factors that could be changed. The study design was similar to the Hulme et al (2016) paper in that logistical regression analysis was used on retrospective data obtained from the NHS Blood and Transplant service. The sample used in this study was taken from the whole population of UK families who vetoed a donation, even though the deceased was on the ODR, during 2012-2015. This resulted in a sample of 263 participant families in total and was an excellent representation of the target population. Data analyses involved univariable and multivariable logistic regression and the methodological validity of the process was high.

The results of the study found that the main factors associated with familial vetoing of organ donation were; the absence of a SN-OD, the cause of death being circulatory death (as opposed to brain death) and the patient being BAME. The results of the study were adequately described and thoroughly explored by the authors in the text, and the article as a whole was highly legible and reader friendly. This is an important point, as more easily comprehensible studies are more likely to be read and disseminated. The discussion and conclusion of the paper was also supported well by the evidence gathered. Finally, the authors met their initial research aim by providing recommendations for changes that can be made to improve organ donation rates. Taking the whole study into consideration, this research is a valuable contribution to the existing knowledge of organ donation vetoing and could provide a foundation for specific real-world adjustments to healthcare pathways and/or government healthcare initiatives.

3.2.6. Study 6

The sixth and final study evaluated within the current review was named “Demographic characteristics of brain death cases in our clinic and causes of family refusal for organ donation” (Boran et al, 2019). This study was evaluated in regard to meeting aims 1 and 2 of the current review, as it explored reasons given for families’ decisions on organ donation and proposed a means to ameliorate vetoing. The study was appraised using the Appraisal of Cross-sectional Studies tool (AXIS, Downes et al, 2016).

The study was undertaken as a retrospective exploration of archived data from an intensive care unit in Kahramanmaras, Turkey, and a follow-up telephone consultation with families that had been approached about organ donation. The aims and objectives of the study were explicit in the paper and were justified by appropriate prior research. The methods of the study were good overall, with a strong study design and a likely high reliability. There were some issues in regard to the study methods however, as the authors neglected to explain the specific protocol for the follow-up telephone contact with the participants, and also failed to provide justification for why they chose this method. Any number of confounding variables could affect the responses given by participants over a telephone call, and it was not addressed if there were any standardisation strategies in place. The scientific rigour of this method is questionable, and it could be argued that a more appropriate measure such as face-to-face interviews or even survey research might have been more apt. The results of this study were described well, and the outcomes were split into a) factors associated with consent for organ donation and b) factors associated with veto of organ donation. The study found only one factor significantly related to consenting for organ donation, which was the participants’ desire to help others. Conversely, there were two factors significantly associated with vetoing of organ donation. These were cited as religious beliefs and beliefs about bodily integrity after death.

These results are contrary to the findings of the other studies in the current review, which is a discourse explored in the discussion section (4). The study also included a

measured and fair evaluation of its own limitations and the influence of religious bias with regards to the study's ecological validity. Ultimately, this study provides a valuable insight into an area somewhat lacking in previous literature and contributes to building a strong foundation of knowledge on familial organ donation behaviour.

3.3 Reasons for familial vetoing

Within the 6 studies reviewed, some shared opinion on factors that influence familial organ donation decisions, but there arose an issue whereby some research was conducted with the aim of exploring "consent" and others with the aim of exploring "vetoing". Although it could be argued that both perspectives are the simple inverse of each other, the current researcher chose to separate the two for the purposes of clarity.

Firstly, it was interesting to note that the two most recent of all the articles specifically focused on vetoing, rather than consent. This could suggest a shift in the general understandings of organ donation and the overall acceptance of donation as being "the right thing to do". Briefly, there were five causes found to be related to familial vetoing on the studies; religious belief, body integrity after death, the absence of a SN-OD, the patient having passed via circulatory death, and the patient being BAME. The articles that purported these findings were undertaken in the UK and Turkey and understandably, found differing results as to the most significant factors associated with family refusal.

In the UK, the highest factor related to a family's decision to veto an organ donation was the absence of and SN-OD, which correlates with the inverse findings of the consent studies. However, the study conducted in Turkey found that the most significant factor associated with familial vetoing was their pre-existing religious beliefs. The second highest factor according to this research was bodily integrity after death, which is a topic closely intertwined with religious belief. The difference in findings between these two studies could be attributed the cultural and even demographic differences in the core understandings of

death (Johnson & Westphal, 2018; Watson-Jones et al, 2017). The Turkish study was undertaken on a smaller scale, majority Muslim population, whereas the UK used national statistical data from a much more secular country. However, the Turkish findings were also represented in the UK study which found that, while it was not the top associated factor, a families' ethnic background was one of the three factors most influential in vetoing behaviour. Ethnicity and religion are inextricably linked (Leming & Dickerson, 2020; Johnson & Westphal, 2018; Watson-Jones et al, 2017; Brodwin et al, 2016) and the conclusion that can be made from these studies when taken as a whole is that there are fundamental cultural differences in the reasons for familial vetoing of organ donation.

Relating to this were the final findings from the UK study, namely, that a family's decision to veto a donation was associated more highly with circulatory death than with brain death. This could be due to a number of factors, and the reason cited in the article was that families with a circulatory death donor are often still approached before the deceased has been taken off life support. The Turkish study did not find corresponding evidence. Again, this could link to the psychological knowledge and understanding of the concept of death as being either irreversible, or a step towards a higher plane of existence (Leming & Dickerson, 2020; Johnson & Westphal, 2018; Watson-Jones et al, 2017; Brodwin et al, 2016).

Two of the 6 studies explored familial decision making from the perspective of factors specifically related to consent. One was a large statistical analysis of nationwide data conducted in the UK (Hulme et al, 2016), and the other was a small-scale regional questionnaire-based study completed in Iran (Zamani & Abedi, 2015). The UK study found 3 factors highly associated with familial organ donation consent; presence of a SN-OD, the knowledge of the donors prior wishes and ethnicity of the family. The Iranian study purported that there were four factors significantly correlated with consent; gender of the deceased, length of hospital stay, the deceased having a donor card, and the timing of a donation request. In comparison of the two studies, the face validity of the Iranian article was poor. The research design and methodology were also subpar and therefore, the accuracy of the

results obtained and the relevance to the existing literature is questionable. Due to these issues, the current researcher omitted the results of the Iranian study (Zamani & Abedi, 2015) from this literature review.

The remaining article (Hulme et al, 2016) provided three main factors associated with consent in order of significance. Firstly, and in concurrence with other studies in this review, the presence of a SN-OD during the family communications was highly correlated with the family's ultimate choice to donate. It could be noted that the presence of an SN-OD is a relatively typical occurrence within the UK, but the studies conducted in Turkey (Boran et al, 2019) and Iran (Zamani & Abedi, 2015) made no mention of a similar provision in their process. This is explored within the discussion section of the current review (section 4). Ethnicity of the donor and donor' families was also highlighted as a significant factor determining consent, which links strongly with the inverse findings of the vetoing behaviour. Finally, the knowledge of the personal wishes of the potential donor emerged as a significant factor for consent according to the Hulme study (2016). This finding was not apparent in those families who declined to donate, suggesting that either a lack of awareness, or an avoidance of the topic could have some impact on organ donation rates.

3.4 Possible measures to tackle familial vetoing

Of the six studies evaluated within this review, five of them expressed opinions on how to tackle familial vetoing of organ donation. Three studies simply made suggestions based upon the evidence gathered in their research (Hulme et al, 2016; Morgan et al, 2018; Boran et al, 2019)), one tested a specific model to reducing familial vetoing (Bocci et al, 2016), and one narratively explored a possible future direction for tackling familial vetoing (Sharif and Moorlock, 2017).

The studies that concluded their paper with recommendations were generally consistent in their conclusions. It was determinable that knowledge surrounding organ

donation is essential in improving donation rates, both on an individual family basis and on a widespread public level. An intervention designed to qualitatively change the communication approach to families was successful in improving consent (Bocci et al, 2016), and the UK-wide SN-OD service also has a beneficial effect overall (Hulme et al, 2016; Morgan et al, 2018). This links to the findings of the singular narrative paper, which also purports that the dissemination of specific knowledge through nudging theory would encourage families to donate (Sharif & Moorlock, 2017). The nudges could be utilised both on an individual scale with families going through the process of organ donation, and on a widespread scale through the use of media and government initiatives.

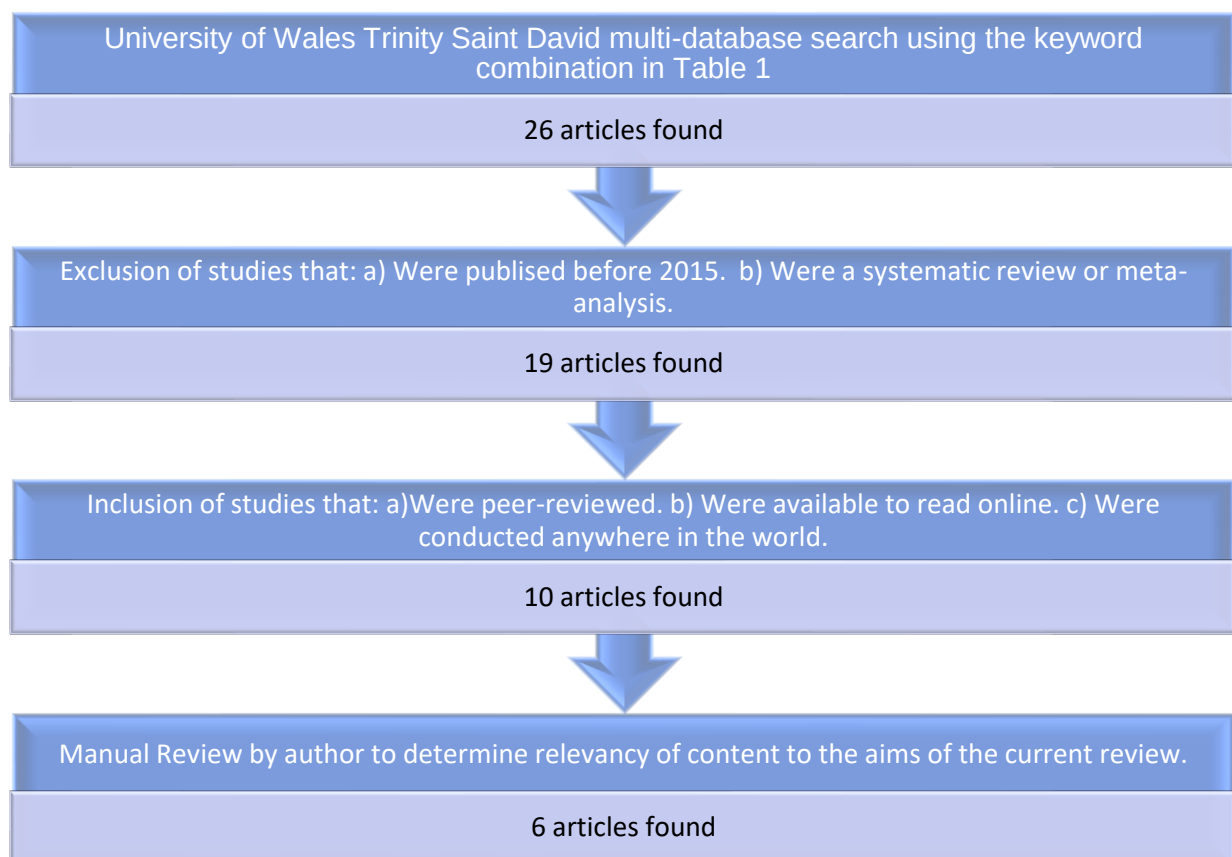
Another of the overarching themes that became apparent throughout this review was the role of ethnicity and religion as an impediment to organ donation, but only the Turkish study (Boran et al, 2019) specifically proposed a feasible means to ameliorate the issue. The authors proposed involving religious leaders in the multi-disciplinary service surrounding organ donation, and simultaneously introducing education provision for said religious leaders about the benefits of organ donation. Reviewed as a whole, these research papers exploring how to ameliorate the familial vetoing issue in organ donation accentuated the links and differences in areas that need to be tackled and provided some insightful possibilities for future intervention.

4. Discussion

In conclusion, this review was undertaken in order to evaluate and critique the current literature regarding familial consent/vetoing of organ donation. Specifically, the author wanted to achieve two aims; to explore the factors associated with familial consent/vetoing of organ donation and to explore possible approaches that could ameliorate the issue. The method involved a systematic literature search to find peer-reviewed, recent articles which met the inclusion and exclusion criteria. Please see Figure 1 for an overview of the literature search process. The search resulted in only six articles being included in this review, and these were then critically appraised on an individual level using the appropriate tools.

Figure 1

Flowchart of the systematic review process



On reflection of the research topic as a whole, it is pertinent to recognise the very small amount of relevant contemporary research available. Considering that there is a large discrepancy between organ donation need and provision on a global level, and also considering the fact that familial vetoing has been long-established as one of the main factors in causing this discrepancy, it is disconcerting that more studies have not been undertaken. It was also interesting to note that within those studies which looked at the reasons given for familial consent/vetoing; only quantitative data was analysed. This highlights a possible shortage of in-depth semantic research exploring the reasoning of those who refuse to donate, and it could be beneficial to call for further qualitative exploration into this topic.

Another finding of this review was that the differences between familial vetoing and familial consent were ambiguously determined. Some looked at one perspective, and some looked at the other perspective. Although they could both be considered the inverse of one another, it was found that the different approaches in the research methods did produce some differing outcomes. Namely, those exploring vetoing behaviour showed links with religion and the type of death a donor had, and the studies focusing on consent behaviour did not. Oppositely, the research undertaken from a consent perspective found that the personal prior wishes of the donor were influential, and the research from a vetoing perspective did not. This divergence could hinder further understandings of family decision-making, and it might be pertinent to suggest that future research attempts to consolidate the evidence, by exploring both facets simultaneously.

Finally, the studies included in this review coincidentally represented research conducted in a number of countries and thereby highlighted the relationship between familial organ donation decision-making and families' ethnicity and cultural beliefs. Alongside the shortage of organs that is seemingly universal at present, there is a significant need for donation of organs from BAME donors (NHS, 2019b). Studies conducted in Muslim countries showed much higher evidence of religion having an impact on donation decisions, linked

with beliefs about death and that BAME donor families are more likely to refuse a donation. From this, it might be concluded that constructing a more diverse pathway for potential donor families, perhaps with the input and inclusion of religious figures, could improve consent rates and shorten waiting lists for the people in desperate need of organs.

6. Limitations

The author declares no conflicting interests but recognises that this review did have some limitations. Firstly, the project was undertaken by only one person, heightening the likelihood of bias. Secondly, the heterogeneity of the studies being reviewed was poor, which made it difficult to come to meaningful conclusions. This could be addressed in future by repeating the process at a time when more research is available. Finally, there was a possibility of publication bias, which is a common effect with systematic literature reviews in general and could not be reasonably avoided.

5. References

Baethge, C., Goldbeck-Wood, S. & Mertens, S. (2019). SANRA – A scale for the quality assessment of narrative review articles. *Research integrity and peer review*, 4(5).

Bocci, M.G., Alo, C., Barelli, R., Inguscio, S., Prestifilippo, A., Di Paulo, S., Lochi, S., Fanfarillo, M., Grieco, D., Maviglia, R., Caricato, A., Mistraletti, G., Pulitano, S., Antonelli, M. & Sandroni, C. (2016). Taking care of relationships in the intensive care unit: Positive impact on family consent for organ donation. *Transplantation proceedings*, 48, 3245-3250.

Boran, O., Oksuz, H., Soylu, D., Urfalioglu, A., Bilal, B., Orak, Y. & Urfalioglu, S. (2019). Demographic characteristics of brain death cases in our clinic and causes of family refusal for organ donation. *Yogum Bakim Derg*, 10(1), 1-6.

Brodwin, M. G., Siu, F. W., Hernandez, E. J., & Pebdani, R. N. (2016). Death and Dying: Basic Concepts, Disability and Five Cultural Views. *Rehabilitation Professional*, 24(2).

Cooper, J. & Kierans, C. (2016). Organ donation, ethnicity and the negotiation of death: ethnographic insights from the UK. *Mortality*, 21(1), 1-19.

Dallimore, D. J., McLaughlin, L., Williams, C., & Noyes, J. (2019). Media content analysis of the introduction of a “soft opt-out” system of organ donation in Wales 2015-17. *Health Expectations*, 22(3), 485-495.

Downes, M., Brennan, M., Williams, H. & Dean, R. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, 6(12).

Health, Wellbeing and Local Government Committee. (2008). *Inquiry in Presumed Consent for organ donation*. Retrieved from:
<https://www.assembly.wales/Laid%20Documents/CR-LD7192%20-%20Report%20by%20the%20Health,%20Wellbeing%20and%20Local%20Government%20Committee%20on%20its%20inquiry%20into%20Presumed%20Consent-30072008-94336/cr-ld7192-e-English.pdf>

Hulme, W., Allen, J., Manara, A.R., Murphy, P.G., Gardiner, D. & Poppitt, E. (2016). Factors influencing the family consent rate for organ donation in the UK. *Anaesthesia*, 71, 1053-1063.

Johnson, D. O., & Westphal, C. G. (2018). Addressing Religious or Cultural Opposition to Brain Death Diagnosis. *Journal of Hospice & Palliative Nursing*, 20(3), 252-259.

Leming, M. R., & Dickinson, G. E. (2020). *Understanding dying, death, and bereavement*. Cengage Learning.

Maravia, M. U. (2019). Re-examination of the Fatawa on Organ Donation in Light of Current Medical Research. *Ethics*, 2(1).

Morgan, J., Hopkinson, C., Hudson, C., Murphy, P., Gardiner, D. McGowan, O. & Miller, C. (2018). The rule of threes: three factors that triple the likelihood of families overriding first person consent for organ donation in the UK. *Journal of the intensive care society*, 19(2), 101-106.

Munoz, M.G. (2018). Christian bioethics, brain death, and vital organ donation. *Christian Bioethics: Non-Ecumenical Studies in Medical Morality*, 24(1), 79-94.

National Health Service (2019a). *What is the organ donation system in England?* Retrieved from: <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/faq/what-is-the-opt-out-system/>

National Health Service (2019b). *Organ donation and ethnicity*. Retrieved from: <https://www.organdonation.nhs.uk/helping-you-to-decide/organ-donation-and-ethnicity/>

National Health Service Blood and Transplant. (2019). *Organ Donation and Transplantation: Activity Report 2018/19*. Retrieved from: <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/transplant-activity-report/>

- Noyes, J., McLaughlin, L., Morgan, K., Walton, P., Curtis, R., Madden, S., Roberts, A. & Stephens, M. (2019). Short-term impact of introducing a soft opt-out organ donation system in Wales: Before and after study. *BMJ Open*, 9(4), 1-9.
- Oliver, M., Woywodt, A., Ahmed, A. & Saif, I. (2011). Organ donation, transplantation and religion. *Nephrology Dialysis Transplantation*, 26(2), 437-444.
- Page, N., Higgs, G. & Langford, M. (2018). An exploratory analysis of spatial variations in organ donation registration rates in Wales prior to the implementation of the Human Transplantation (Wales) Act 2013. *Health & Place*, 52, 18-24.
- Rispler, C. & Duguet, A.M. (2018). Debates in Islamic bioethics on how to increase organ donations: between presumed consent and explicit consent. *Ethics, Medicine and Public Health*, 7, 88-94.
- Rithalia, A., McDaid, C., Suekarran, S., Myers, L. & Sowden, A. (2009). Impact of presumed consent for organ donation on donation rates: a systematic review. *British Medical Journal*, 338, 1-8.
- Rudge, C.J. (2018). Organ Donation: Opting in or opting out? *British Journal of General Practice*, 68, 62-63.

Sharif, A. & Moorlock, G. (2017). Influencing relatives to respect donor autonomy: Should we nudge families to consent to organ donation? *Bioethics*, 32, 155-163.

Slim, K., Nini, E., Forestier, D., Kwiatkowski, F., Panis, Y. & Chipponi, J. (2003). Methodological Index for Non-randomized Studies (MINORS): Development and validation of a new instrument. *ANZ Journal of surgery*, 73(9), 712-716.

Thaler, R. & Sunstein, C. (2008). *Nudge: Improving decisions about health, wealth, and happiness*. New Haven: Yale University Press.

Watson-Jones, R. E., Busch, J. T., Harris, P. L., & Legare, C. H. (2017). Does the body survive death? Cultural variation in beliefs about life everlasting. *Cognitive science*, 41, 455-476.

Willis, B.H. & Quigley, M. (2014). Opt-out organ donation: on evidence and public policy. *Journal of the Royal Society of Medicine*, 107(2), 56-60.

Zamani, F. & Abedi, H.A. (2015). A comparative study on effective factors on consent to organ donation among families of brain death victims in Isfahan, Iran in 2013. *Journal of emergency practice and trauma*, 1(1), 13-18.