Organ donation behaviour: understanding the factors stimulating the decision to register as a potential organ donor: a scoping review in completion of Milestone Two of Mphil/PhD pathway

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Abstract

Background: The demand for organ donors has risen as there is greater improvement in organ transplantation outcome. However, low donation rates have led to a scarcity of organs worldwide. Among potential barriers to organ donation are family rejection when they are not aware of the deceased’s preferences regarding organ donation. To overcome this, countries around the world have developed registers in order to provide a platform for potential donors to record their donation intention. Nevertheless, the process by which an intention to donate an organ becomes a decision and an act of registering has received little attention in the organ donation literature and remains poorly understood.

Objectives: To conduct a scoping review and comprehensively systematically map the literature available to identify factors that influence individual decision making in relation to registering as a potential organ donor and identify key concepts, theories, evidence, or research gaps.

Method: Arksey and O’Malley (2005) five step framework for scoping reviews was applied. The sources searched between May – August 2015 were the Cochrane database for systematic reviews? MEDLINE, CINAHL, EMBASE, PsychINFO, World of Science (W.O.S), and Scopus. The reference lists of relevant articles were also searched.

Results: A total of 457 titles were retrieved with 32 papers meeting the criteria for inclusion in the final review. After discussions with supervisors 10 papers were reviewed to inform the findings section of the Milestone. Analysis of the findings from the 10 papers reviewed showed that factors influencing willingness to register included: altruism, personal benefits, social motivation, and psychological motivation, process of organ donation, religion, and trust.

Conclusion: There is limited literature examining registration as an organ donor particularly from non-westernised countries such as the Southeast Asian region. This suggests that research that explores registration motives and behaviours from a broader cultural perspective is needed, supporting the authors’ intention to complete a study exploring individual donor registration decision-making in Malaysia.

Introduction

Organ transplantation has become a viable and effective treatment for patients with end-stage organ failure (Siminoff et al. 2001). Since 1954 when the first kidney transplant was successfully performed, the demand for organs has escalated rapidly (Ehrle 2008). Currently, many countries have a deficit

Keywords
Organ donor, registration, factors, religious belief, cultural belief, family communication
in the number of organs available for use in transplant operations. Low donation rates have been linked to a lack of public awareness and knowledge about organ donation and transplantation (Siminoff and Mercer 2001); misleading interpretation of religious fatwas or decrees in relation to organ donation (Wakefield et al. 2010); cultural concerns about how the dead body will be treated (Ashkenazi et al. 2015); and mistrust of the healthcare system (Anwar Naqvi et al. 2014). A consistent finding from studies investigating barriers to increasing the number of organs available for transplantation is that family members are more likely to reject the option to donate (when asked) if they do not know the deceased’s preferences or wishes regarding organ donation (Siminoff et al. 2001, 2010; Coppen et al. 2010; Anker and Feeley 2011; Ghorbani et al. 2011; Wang 2011; Hyde and White 2013; Ralph et al. 2014). Therefore, as a means of gathering individual views about posthumous organ donation, countries around the world have developed registers in order to provide a platform for members of the public to record during their lifetime their wishes or intention to become an organ donor after their death (World Health Organization 2009).

This information is recorded on a central database which is usually situated within the organisation responsible for overseeing donation activities within each country (Gomez et al. 2012), for example, NHS Blood and Transplant (NHS BT) in the UK and the National Transplant Resource Centre (NTRC) in Malaysia. This central resource can then be accessed by healthcare professionals who are intending to raise the potential of organ donation with next of kin so that if the registration is not known to the family, this information can be shared.

However, the process by which the intention to donate an organ becomes a decision and an act of registering has received little attention in the organ donation literature and remains poorly understood. Of particular interest to the first author is the situation in Malaysia where both the organ donation and registration rates are very low. To date, less than 1% of a population of approximately 30 million is registered as a potential organ donor, which is the lowest deceased donation rate in the Asia-Oceania region (see Figure 1).

Figure 1. Asia-Oceania Actual Deceased Organ Donors 2012 - 2013 (per million population), (International Registry of Organ Donation and Transplantation 2014)

Therefore in preparation for undertaking a study exploring the factors that influence organ donor registration in Malaysia the current knowledge base available in the published literature will be scoped.

Choice of Review Methodology

In reviewing published literature, there are various systematic approaches that are available. Each type of review has a different purpose and choosing which review format is appropriate depends on a number of factors including the needs of the writer and the aim of the review. Is the aim to identify theory, review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodology, review literature reporting positivist and/or naturalistic data, or identify policy? For example, scoping review methodol...
Setting inclusion/exclusion criteria

In order to maximise the potential to identify relevant material for review, inclusion and exclusion criteria were established at the beginning of the search process (Table 3). Defining the inclusion and exclusion criteria prior to searching helps improve both the transparency and the rigour of the review by ensuring screening is conducted in a consistent and relatively unbiased manner. The start date for the search was set at 1978 as the focus of this review is to look at registering behaviour conducted in a consistent and relatively unbiased manner. The start date for the search was set at 1978 as the focus of this review is to look at registering behaviour conducted in a consistent and relatively unbiased manner.

Israel in 1978 (Rosenblum et al. 2012). Whilst the minimum age to register as a potential organ donor in most countries is 16 and above (Rosenblum et al. 2012), France and the Netherlands have a minimum age requirement of 12 and 13 respectively. This review will set the minimum registrants’ age at 16 years in line with registration requirements in most countries. Inclusion criteria also include the most common registration methods; e.g. via a donor card, electronic registration, as well as driving licence and passport renewal. Exclusion criteria include: whole body donation, presumed consent and prisoners’ registration.

Database selection

The following databases related to health, social care, psychology and sociology accessed via the University of Southampton library were searched: Cochrane, MEDLINE, CINAHL, EMBASE, PsychINFO, World of Science (W.O.S), and Scopus (Table 4).

Table 3. Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
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<tbody>
<tr>
<td>Those who register as:</td>
<td>Body donation</td>
</tr>
<tr>
<td>Organ donation</td>
<td>Presumed consent</td>
</tr>
<tr>
<td>Tissue donation</td>
<td>Prisoner</td>
</tr>
<tr>
<td>Kidney donation</td>
<td></td>
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<tr>
<td>Blood donation</td>
<td></td>
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<tr>
<td>Egg/sperm donation</td>
<td></td>
</tr>
<tr>
<td>Deceased organ donation</td>
<td></td>
</tr>
<tr>
<td>Participant age – above 16 years old</td>
<td></td>
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<tr>
<td>Time line to search – 1978 to current</td>
<td></td>
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<tr>
<td>Routes to registration:</td>
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<tr>
<td>Electronic register</td>
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<tr>
<td>Donor card</td>
<td></td>
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<tr>
<td>Driving licence</td>
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<tr>
<td>Passport</td>
<td></td>
</tr>
<tr>
<td>Language – Malay, English</td>
<td>Other language</td>
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</tbody>
</table>

Table 4. Database

<table>
<thead>
<tr>
<th>Database</th>
<th>Selection criteria</th>
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</thead>
<tbody>
<tr>
<td>Cochrane Library</td>
<td>The availability of systematic reviews, technology assessments, economic evaluations and individual clinical trials.</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>Medline is the largest and most widely used database in the health sciences. It covers journal articles and other reference types in medicine, dentistry and nursing, including biomedicine, medicine, nursing, dentistry, allied health, pre-clinical sciences and psychology.</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Offers comprehensive coverage of journals in nursing, midwifery and allied health.</td>
</tr>
<tr>
<td>EMBASE</td>
<td>Offers a range of journal articles in biomedicine</td>
</tr>
<tr>
<td>PsychINFO</td>
<td>Contains journal articles, books, dissertations and theses in core psychology disciplines, behavioral sciences and mental health.</td>
</tr>
<tr>
<td>World of Science (W.O.S)</td>
<td>Provides access to a wide range of field particularly covering science, health, social science, humanities.</td>
</tr>
<tr>
<td>Scopus</td>
<td>Is the largest abstract and citation database of peer-reviewed literature. It comprises the world’s research in the fields of medicine, social sciences, and arts and humanities.</td>
</tr>
</tbody>
</table>

Step 3: Study selection

The four stage search strategy resulted in a total of 457 hits (see box A and B of Figure 2). Using the inclusion and exclusion criteria (Table 3) all the 457 titles and abstracts were screened and duplicates removed (see box C, D and E Figure 2). A total of 27 full papers were retrieved and read to check for relevance and further citations. The reference lists of these 27 full papers were reviewed for other relevant publications (using the inclusion...
According to the Arksey & O'Malley’s framework for conducting a scoping review, the data charting process involves extraction of information from individual articles. Therefore the following data was entered into an Excel spreadsheet: author(s), year of publication, study location, aims of the study, methodology/study design, population/sample data collection, sample/participant, and key findings (Appendix 1).

Step 5: Collating, summarizing, and reporting the result

Unlike a systematic review, scoping re-

views do not strive for synthesis of evi-
dence from different studies but for a

thematically coherent presentation that pro-

vides a narrative or description of the exist-
ing literature (Arksey & O’Malley 2005).

As stated by Arksey and O’Malley (2005) scoping reviews should help the reader quickly get a flavour of the main areas of interest and consequently identify where the significant gaps are.

The outcome of this review also points to a need to explore further the role of reli-
gion and culture in the decision to register as a donor, and due to the small amount of literature examining registration as a donor from non-westernised countries, particularly from the Southeast Asian region, a need for research that explores registration motives and behaviours from a broader cultural perspective which limits our knowledge base regarding individual understanding, values, and views.

The following sections in relation to: the process of organ donation were also reported in four out of the 10 studies (Galasis et al. 2008; Murray et al. 2013; Irving et al. 2014). Social motivation appears to refer to the influence of the community at large and/or the people around us that influence the decision to register as a donor. Examples include: familial and peer influence whereby if the family holds a positive view of donation, that positive view supports the decision to register as a donor; or peer pressure whereby an individual with a family member or friend who is registered as a donor is likely to sign up to the donation register as well. Psychological motivation was linked to both positive and negative perceptions of recipients’ pre donation behaviour, for example whether the recipient de-
serves to receive an organ or not was linked to their responsibility to ill people such as recipient’s benefit were likely perceived as smoker and this appears to be part of decision making. Psychological factors linked to both positive and negative perceptions of recipients’ pre donation behaviour, for example whether the recipient deserves to receive an organ or not was linked to their responsibility to ill people such as recipient’s benefit were likely perceived as smoker and this appears to be part of decision making. 

Summary

This scoping review was conducted to comprehensively and systematically map the literature, identify key concepts, and research gaps in relationship to the factors that stimulate the decision to register as a potential organ donor.

Findings from the papers reported have provided some insights into the factors that influence respondents’ willingness or unwillingness to register as a donor. However, none of the studies reviewed provided any information regarding what formal or informal information people refer to in making a decision to register for donation. This is a gap in the knowledge base.

Objective 3: to explore whether religious and cultural beliefs play a role in the deci-
sion making to register as a potential organ donor.

Religious belief is reported as a barrier to donation (Lam and McCullough 2000; Morse et al. 2009; Wakefield et al. 2010) but in Morgan et al. (2008), religious be-
lief is reported to support organ donation and was derived from the perception of the importance of helping others. Of note is that none of the 10 references discussed the influence of culture.

Objective 4: to explore whether family communication about a decision to regis-
ter as a potential organ donor takes place and whether this is formal or informal dis-
cussed with the family.

As indicated in findings above, views regarding organ donation were often shaped by the participants’ families and such views could have either a positive or, more often, negative influence on in-
dividuals’ decisions. Data from three out of 10 studies reported family communi-
cation and opinion about organ donation as important prior to registration as a donor (Galasis et al. 2008; Murray et al. 2013; Irving et al. 2014). However, none of the 10 studies discuss the type of infor-
mation that potential donors share with their family member before and after registration therefore it is unclear as to where the decision to register is shared with family members.

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### Aim(s) of study

- **Transplantation Registration**
- **Data Collection and Design**

### Sample

- **Age**: 17 – 65
- **Gender**: 121 male, 344 female

### Design, data collection and design.

- **Data collection**: Questionaire
- **Data Analysis**: Descriptive analysis

### Main Findings

- **Reason for registering**: Self-benefit was a stronger predictor than other-benefits. Examples of self-benefits are pride and satisfaction.

### References

**Overview of the studies relating to the factors that stimulates the decision to register as a potential donor.**

<table>
<thead>
<tr>
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<td>To determine the relative influence that self-benefit or other-benefit perceptions exert on people’s organ donation decisions.</td>
<td>Age = 18 – 29 Gender = 45 male, 86 female</td>
<td>Design: a survey research design. Data collection: Questionnaire Data Analysis: Descriptive statistics</td>
<td>Reason for registering: not registering. No reason. Individual is unsure why they or he did not register as a donor.</td>
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<td>Galanis, Sparsos, Katokorinis, Velonakis, and Kallikerinou (2008) (Greece)</td>
<td>To examine the influence that self-benefit perceptions exert on potential bone marrow donors.</td>
<td>N = 356 (250 registered and 115 not registered potential bone marrow donors.) Age = not reported Gender = not reported</td>
<td>Design: a survey research design. Data collection: Questionnaire Data Analysis: Descriptive statistics, logistic regression</td>
<td>Reason for registering: Had discussion with family and gain support. Peer pressure, Personal experience (relative or friend in need of BM and the respondent is a regular blood donor)</td>
</tr>
</tbody>
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### Appendix 1

#### Overview of the studies relating to the factors that stimulates the decision to register as a potential donor.

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<td>N = 356 (250 registered and 115 not registered potential bone marrow donors.) Age = not reported Gender = not reported</td>
<td>Design: a survey research design. Data collection: Organ Donation Attitude Scale (ODAS) Data Analysis: Hierarchical regression analysis and T-test</td>
<td>Reason for registering: altruistic benefit, personal experience</td>
</tr>
</tbody>
</table>
Irving, Jan, Tong, Wong, Craig, Chadban, Rose, Cass, Allen, and Howard (2014) (Australia)

Title: What factors influence people’s decisions to register for organ donation? The results of a nominal group study.

N = 114

Design: qualitative research design. They were 13 nominal groups that are separated by age category.

Reason for registering: Saving lives, own decision to donate, family opinions, benefit to recipients, process of organ donation.

Joshi (2011) (UK)

Title: Whose decision is it? Organ donation attitudes among young UK South Asians

N = 382

Design: a survey research design.

Reason for registering: moral reasons (the right thing to do), personal reasons (someone you know need it), and emotional reasons (image of those in need).

Reason for not registering: not understanding about the topic, disapprove of donation.

Murray, Millor, Daysou, Wakefield, Homeewood (2013) (USA)

Title: Communication and Consent: Discussion and Organ Donation Decisions for Self and Family.

N = 267 (200 community volunteered, 67 university students)

Design: a survey research design

Reason for registering: Prior discussion and gaining support from family influences registration decision.

Reason for not registering: Religion, desire to help others.


Title: Decisions to register for the National Marrow Donor Program: rational vs emotional appeals.

N = 102

Design: an experimental research design (testing and intervention)

Reason for registering: Those who received EA has higher tendency to register.


Title: Factors affecting the decision to grant consent for organ donation: A survey of adults in England

N = 1549

Design: a mixed method research design

Reason for registering: altruistic, reciprocal benefit, avoidance of waste.


Title: In their own words: the reasons why people will (not) sign an organ donor card.

N = 78 family-pair dyads. (33 partner-spousal dyads, 30 parent-child dyads, 15 other dyads (sibling, stepparent))

Design: a qualitative research design

Reason for registering: Religion, desire to help others.

Reason for not registering: Mistrust, belief in black market, deservingness issue.