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.

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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

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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 health care 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).

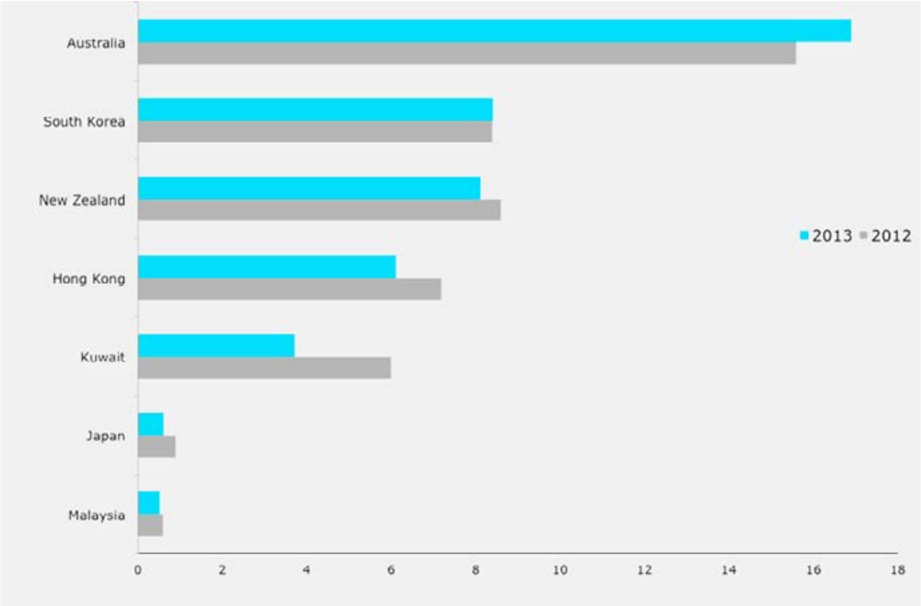

Figure 1. Asia-Oceania Actual Deceased Organ Donors 2012 - 2013 (per million population), (International Registry of Organ Donation and Transplantation 2014)

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 is particularly useful for examining a broadly covered topic to comprehensively and systematically map the literature and identify key concepts, theories, evidence, or research gaps (Arksey and O'Malley 2005; Anderson et al. 2008; Davis et al. 2009; Levac et al. 2010; Daudt et al. 2013). Therefore the aim of this scoping review is to map the literature and identify the evidenced factors that influence individual decision making in relation to registering as a potential organ donor.

Search procedure

In designing the protocol for this review, Arksey and O'Malley (2005) scoping review framework was utilized where the framework outlines a five steps approach as follow:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising, and reporting the result

Step 1: Identifying the research question

The research question guiding this review was developed in Milestone One: What are the factors that stimulate the decision to register as a potential organ donor?

However, reading broadly around this topic to inform Milestone One prompted development of four objectives to provide further structure to the review. The objectives were:

1. To explore the reasons why individuals decide to register as a potential organ donor.
2. To identify what information individuals refer to prior to registering as a potential organ donor.
3. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.
4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.

Step 2: Identifying relevant studies

Developing search terms

From a practical point of view, a search strategy commences with the identification of specific search terms. In order to develop specific search terms for each stage of the search, the PEO format (Bettany-Saltikov 2012) was applied (see Table 1).

Table 1. PEO Format

P	Population and problems
E/I	Exposure / Issue
O	Outcomes and themes

As four objectives had been developed in support of the research question, four stages of searches were carried out using the search terms identified (Table 2). The key words and related synonyms were combined using Boolean operators AND/OR, and truncation '* (Table 2).

Table 2. Core search terms for each objective and Boolean Operators

Stage	Objectives	Keywords	Boolean Operators
First	1. To explore the reasons why individuals decide to register as a potential organ donor.	P – organ donor E/I – register O - factors, decision	"organ donor" AND register* OR "sign* up" OR record* AND factor* OR determin* OR drive* OR influence* OR motivate* OR perception* OR stimulate* OR thought* AND decision* OR decid* OR "decision making" OR choice*
Second	2. To identify what information individuals refer to prior to registering as a potential organ donor.	P – organ donor E/I – register O – information, decision	"organ donor" AND register* OR "sign* up" OR record* AND information OR data OR evidence OR fact* AND decision* OR decid* OR "decision making" OR choice*
Third	3. To explore whether religious and cultural beliefs play a role in the decision making to register as a potential organ donor.	P – organ donor E/I – register O – religious belief, cultural belief, decision	"organ donor" AND register* OR "sign* up" OR record* AND "religious belief*" OR "spiritual be-lief*" OR faith OR religion OR religio* OR spiritual* OR "cultural belief*" OR culture* AND decision* OR decid* OR "decision making" OR choice*
Fourth	4. To explore whether family communication about a decision to register as a potential organ donor takes place and to determine type of information discussed with the family.	P – organ donor E/I – register O – family communication, decision	"organ donor" AND register* OR "sign* up" OR record* AND "family communication*" OR "family discussion*" OR famil* OR "next of kin" OR relative* OR sibling* OR parent* OR spouse* OR partner* OR wife OR wives OR husband OR communicat* OR discuss* OR talk* AND decision* OR decid* OR "decision making" OR choice*

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 and the first register was established by 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).

Searched procedure

The search terms (Table 2) were conducted on 'All field'. Applying 'All Field' is important in a scoping review as the whole point of scoping the field is to be as inclusive as possible in identifying primary studies for answering the central research question.

Table 3. Inclusion and Exclusion Criteria

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

Table 4. Database

Database	Selection criteria
Cochrane Library	The availability of systematic reviews, technology assessments, economic evaluations and individual clinical trials.
MEDLINE	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.
CINAHL	Offers comprehensive coverage of journals in nursing, midwifery and allied health.
EMBASE	Offers a range of journal articles in biomedicine
PsychINFO	Contains journal articles, books, dissertations and theses in core psychology disciplines, behavioral sciences and mental health.
World of Science (W.O.S)	Provides access to a wide range of field particularly covering science, health, social science, humanities.
Scopus	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.

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

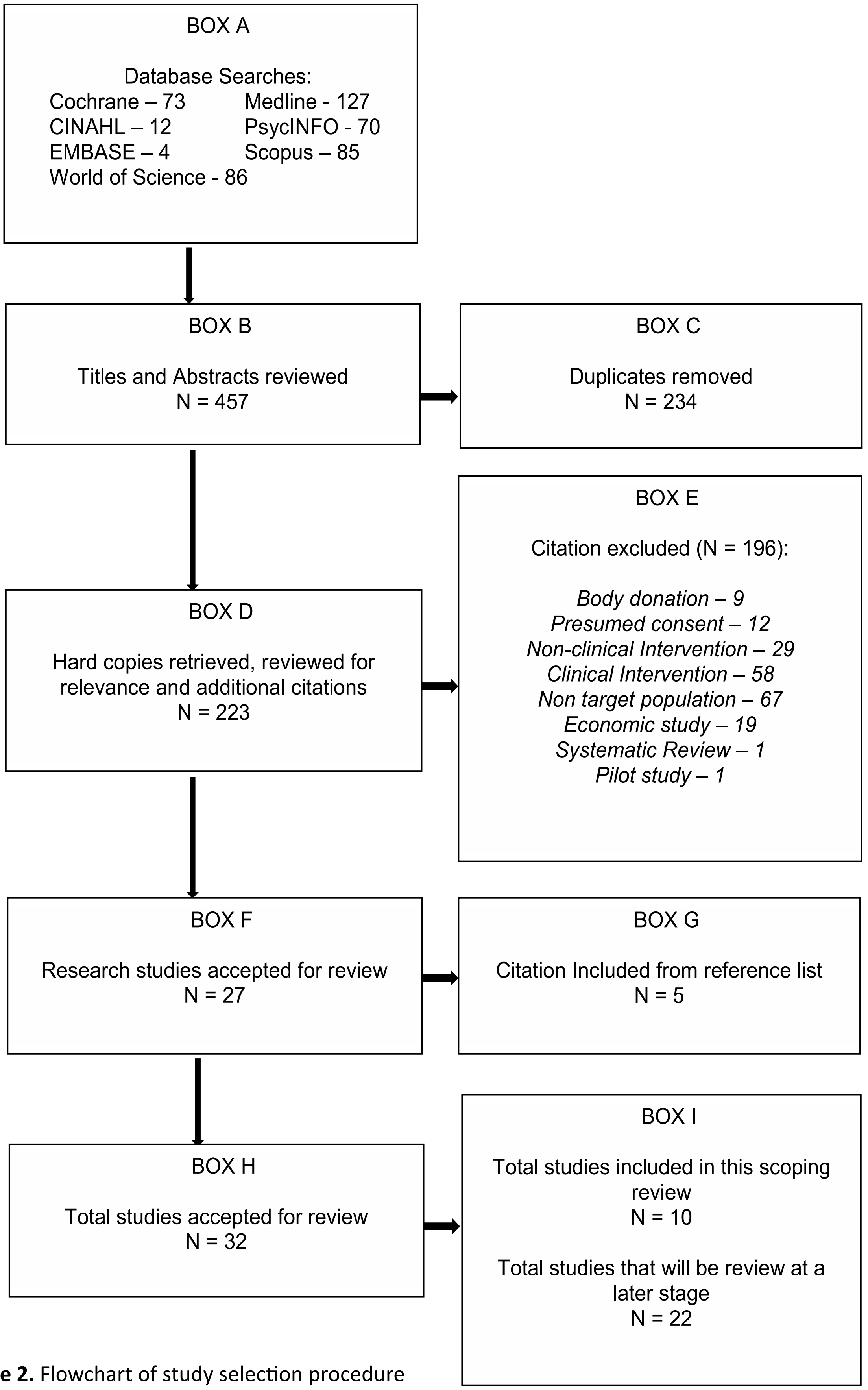

Figure 2. Flowchart of study selection procedure

and exclusion criteria as in Table 3) which resulted in an additional 5 citations to be included (see box G of Figure 2). A total of 32 papers met the criteria for inclusion in the final review however, after discussion between the authors regarding the number and focus of papers gained and the necessary limited word count for Milestone Two, only those papers which report on the central aim of participant reported reasons influencing registration/non-registration were reported in Milestone Two. The remaining 22 papers will be reviewed during development of the research proposal (Milestone Three) as they focus on the use of theoretical frameworks proposed for predicting registration behaviours.

Step 4: Charting the data

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, and method of data collection, sample/participant, and key findings (Appendix 1).

Step 5: Collating, summarizing, and reporting the result

Unlike a systematic review, scoping reviews do not strive for synthesis of evidence from different studies but for a thematic construction that presents a narrative or description of the existing literature (Arksey and 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.

With the aim of informing Milestone Three the literature will be collated in the following sections in relation to: the country in which the study was completed, the methodology applied and the populations sampled. The findings section will summarize the reported factors or concepts underpinning the decision to register as a donor. The findings section is structured using the objectives for this review which were to: explore the reasons why individuals decide to register as a donor, identify the information individuals refer to prior to registering as a donor, explore the role of religious and cultural beliefs in registering as a donor, and the role of family communication in registering to be a donor.

Collating the studies: country of origin

All of the selected papers were written and published after 2008 as countries across the globe have sought to understand the factors that influence the continuing gap between supply and demand. From the 10 papers reviewed, five studies were carried out in the USA, two in the UK, one in Greece and two in Australia. Thus, there is limited literature examining registration as a donor from non-westernised cultures and no research found from the Southeast Asian region. This suggests that research that explores registration motives and behaviours from a broader cultural perspective is needed.

Collating the studies: design, method, and data collection

The dominant research design applied in the retrieved studies was quantitative with six surveys and one intervention study. Two studies applied qualitative approaches. Of the six surveys, two (Cohen and Hoffner 2013; Murray et al. 2013) employed a standardized tool for data collection, the Organ Donation Attitude Scale (ODAS) (Parisi and Katz 1986). Four studies (Galanis et al. 2008; Hyde and White 2011; Joshi 2011; Feeley et al. 2014) employed questionnaires that were either self-constructed or developed in collaboration with clinical experts. The two studies that adopted qualitative approaches collected data via interviews (Morgan et al. 2008) and nominal group technique (Irving et al. 2014). Thus, there is limited literature examining registration as a donor from a naturalistic perspective which limits our knowledge base regarding individual understanding, values, and views.

Collating the studies: participants

The participants identified in the reviewed studies were from the following populations: university students (Morgan et al. 2008; Studts et al. 2010; Hyde and White 2011; Joshi 2011; Cohen and Hoffner 2013; Murray et al. 2013), customers exiting the Department of Motor Vehicles (DMV) offices in state of New York (Feeley et al. 2014), and the general public (Galanis et al. 2008; Irving et al. 2014; Webb et al. 2015). Seeking public participation in donation studies is justifiable because it is the public who are going to register and become a donor. However there may be limitations in seeking a student only sample as this group falls within the age range least likely to register.

Main findings

Objective 1: to explore the reasons why individuals decide to register as a donor.

The aim of this study was to map out the reported reasons behind registering a decision to become a potential organ donor. Therefore the 10 selected papers were read and factors that were reported as influencing respondents' willingness to register or not register as a donor were identified and categorised under the headings: reasons for registering and reasons for not registering and then subcategorised into concept groups, for example altruism, benefits etc (see Table 5). Four of the 10 retrieved studies reported altruistic behaviour as a key influence on the decision to donate (Morgan et al. 2008; Feeley et al. 2014; Irving et al. 2014; Webb et al. 2015). Altruistic deeds were most influenced by the desire to voluntarily save life and help to improve the well-being of the recipient.

Table 5. Factors that influence the decision to register or not register as donor

Factors for registering:	Factor for not registering:
1. Altruism a. Saving lives b. Desire to help others 2. Benefits a. Self-benefits b. Reciprocal benefit c. Avoidance of waste 3. Social/Societal motivation a. Family support b. Peer pressure c. Religion 4. Psychological factor a. Perception about transplant recipients' behaviour b. Emotional appeal c. Personal experience d. Own decision to donate e. Process of organ donation	1. Psychological factor a. Perception about transplant recipients' behaviour 2. Trust a. Mistrust of the system b. Belief in black market 3. No reason

It is interesting to note that most persons who reported altruism as the reason to sign the registry also expressed certain benefits linked to registration, such as: i) self-benefit expressed as feeling pride and satisfaction after registering as a donor; ii) reciprocal benefits expressed as the registrant feeling proud of their intention to donate with the outcome that the recipient would enjoy improved quality of life; iii) avoidance of waste expressed as the view that it was wasteful if organs were not utilised for transplantation.

Social/societal motivational factors were reported in four out of the 10 studies (Galanis et al. 2008; Morgan 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 deserves to receive an organ or not was linked to their responsibility to illness such as someone with lung complication were likely perceived as smoker and this appears to be part of decision making (Hyde and White 2011). Interestingly, emotional appeal, which provides a narrative story about an organ donor and a recipient who had underwent transplantation stimulates the decision to register (Studts et al. 2010) as does if individuals knew someone who was waiting for a transplant, own decision to donate, and process of organ donation were also outlined as factors that influenced registration to become a donor (Galanis et al. 2008; Joshi 2011; Feeley et al. 2014; Irving et al. 2014).

Objective 2: to identify what information individuals refer to prior to registering as a potential organ donor.

None of the 10 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 decision 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 belief 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 register as a potential organ donor takes place and to determine type of information discussed 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 individuals' decisions. Data from three out of 10 studies reported family communication and opinion about organ donation as important prior to registration as a donor (Galanis et al. 2008; Murray et al. 2013; Irving et al. 2014). However, none of the 10 studies discuss the type of information that potential donors share with their family member before and after registration therefore it is unclear as to whether the decision to register is shared with family members.

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 on two of the specific objectives, thereby we have identified a gap in the knowledge base in relationship to: what type of information is referred to by individuals prior to making a decision to register as a donor, and whether the family are aware of the decision of their family member to be a donor.

The outcome of this review also points to a need to explore further the role of religion 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. These deficits in the current knowledge base support the first author's intention to undertake a study exploring the factors that stimulate the decision to register as a potential organ donor in Malaysia.

References

Abouna GM (2008) Organ shortage crisis: problems and possible solutions. Transplantation Proceedings 40(1): 34-8

Anderson S, Allen P, Peckham S and Goodwin N (2008) Asking the right questions: scoping studies in the commissioning of research on the organisation and delivery of health services. BMC Health Research Policy And Systems 6: 7

Arksey H and O'Malley L (2005) Scoping studies: towards a methodological framework. International Journal of Social Research Methodology 8(1): 19-32

Bettany-Saltikov J (2012) How to do a systematic literature review in nursing: a step-by-step guide. Maidenhead: McGraw-Hill/Open University Press.

Cohen EL and Hoffner C (2013) Gifts of giving: the role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors. Journal of Health Psychology 18(1): 128-38

Daudt HM, Mossel CV and Scott SJ (2013) Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. BMC Medical Research Methodology 13(48)

Davis K, Drey N and Gould D (2009) What are scoping studies? A review of the nursing literature. International Journal Of Nursing Studies 46(10): 1386-400

Feeley TH, Reynolds-Tylus T, Anker AE and Evans M (2014) Reasons for (not) signing the state registry: surveying Department of Motor Vehicles customers in New York state. Progress in Transplantation 24(1): 97-105

Galanis PA, Sparos LD, Katostaras T, Velonakis E and Kalokerinou A (2008) Factors that influence Greeks' decision to register as potential bone marrow donors. Transplantation Proceedings 40(5): 1271-4

Hyde MK and White KM (2011) A comparison of registered and unregistered organ donors' perceptions about transplant recipients. Clinical Transplantation 25(3): 444-449

International Registry of Organ Donation and Transplantation (2014) Final Numbers 2013.

Irving MJ, Jan S, Tong A, Wong G, Craig JC, Chadban S, Rose J, Cass A, Allen RD and Howard K (2014) What factors influence people's decisions to register for organ donation? The results of a nominal group study. Transplant International 27(6): 617-624

Joshi MS (2011) Whose decision is it? Organ donation atitudes among young UK South Asians. Psychological Studies 56(1): 86-97

Lam WA and Mccullough LB (2000) Influence of religious and spiritual values on the willingness of Chinese–Americans to donate organs for transplantation. Clinical Transplantation 14: 449-456

Levac D, Colquhoun H and O'brien KK (2010) Scoping studies: advancing the methodology. Implementation Science: IS 5: 69

Morgan SE, Harrison TR, Afifi WA, Long SD and Stephenson MT (2008) In their own words: the reasons why people will (not) sign an organ donor card. Health Communication 23(1): 23-33

Morse CR, Afifi WA, Morgan SE, Stephenson MT, Reichert T, Harrison TR and Long SD (2009) Religiosity, anxiety, and discussions about organ donation: understanding a complex system of associations. Health Communication 24(2): 156-64

Murray L, Miller A, Dayoub C, Wakefield C and Homewood J (2013) Communication and consent: discussion and organ donation decisions for self and family. Transplantation Proceedings 45(1): 10-2

Parisi N and Katz I (1986) Attitudes toward posthumous organ donation and commitment. Health Psychology 5(6): 565-580

Rosenblum AM, Li AH, Roels L, Stewart B, Prakash V, Beitel J, Young K, Shemie S, Nickerson P and Garg AX (2012) Worldwide variability in deceased organ donation registries. Transplant International 25(8): 801-11

Studts JL, Ruberg JL, Mcguffin SA and Roetzer LM (2010) Decisions to register for the National Marrow Donor Program: rational vs emotional appeals. Bone Marrow Transplant 45(3): 422-8

Wakefield CE, Watts KJ, Homewood J, Meiser B and Siminoff L (2010) Attitudes toward organ donation and donor behavior: a review of the internation literature. Progress in Transplantation 20(4): 380-391

Webb G, Phillips N, Reddiford S and Neuberger J (2015) Factors affecting the decision to grant consent for organ donation: A survey of adults in England. Transplantation 99(7): 1396-402

Appendix 1

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

Authors, Year, Country, Title	Aim(s) of study	Sample	Design, data collection and analysis	Main Findings
Cohen and Hoffner (2013) (USA) Title: Gifts of giving: the role of empathy and perceived benefits to others and self in young adults' decisions to become organ donors	To determine the relative influence that self-benefit perception or other-benefit perceptions exert on people's organ donation decisions.	N = 131 university students Age = 18 – 29 Gender = 45 male, 86 female	Design: a survey research design. Data collection: Organ Donation Attitude Scale (ODAS) Data Analysis: Hierarchical regression analysis and T-test	Reason for registering: self-benefits was a stronger predictor than other-benefits. Examples of self-benefits are pride and satisfaction.
Feeley, Reynolds-Tylus, Anker, and Evans (2014) (USA) Title: Reasons for (not) signing the state registry: surveying Department of Motor Vehicles (DMV) customers in New York state	To understand motives associated with donor registration.	N = 1325 customers exiting 18 DMV offices in 9 counties in New York State. Age = 18 – 91 Gender = 667 male, 658 female	Design: a survey research design. Data collection: Questionaire was generated by the researcher in response to the literature Data Analysis: Descriptive statistics	Reason for registering: alturistic benefit, personal experience Reason for not registering: No reason. Individual is unsure why she or he did not register as a donor.
Galanis, Sparos, Katostaras, Velonakis and Kalokerinou (2008) (Greece) Title: Factors that influence Greeks' decision to register as potential bone marrow donors.	To examine the factors that influence the decision to be registered as potential bone marrow donors.	N = 565 (250 registered and 315 not registered potential bone marrow donors.) Age = not reported Gender = not reported	Design: a survey research design. Data collection: Questionaire Data Analysis: Descriptive statistics, logistic regression	Reason for registering: Had discussion with family and gain support, Peer pressure, Personal experience (relative or friend in need of BMT and the respondent is a regular blood donor)
Hyde, White (2010) (Australia) Title: A comparison of registered and unregistered organ donors' perceptions about transplant recipients.	To examine the influence of perceptions about transplant recipient's previous behaviour on the decision to register as organ donor.	N = 465 (university student = 283, community members = 182) Age = 17 – 65 Gender = 121 male, 344 female	Design: a survey research design. Data collection: Questionaire Data Analysis: Chi-Square, ANOVA, MANOVA	Reason for registering and not registering: Potential donor's perception about transplant recipients' behaviour influences donation registration decision.

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.	To determine the relative importance of individual factors that influence willingness to register as organ donor.	N = 114 Age = 18 - 25 (n = 34), 26 - 49 (n = 42), 50 and above (n = 38) Gender = 56 male, 58 female	Design: qualitative research design. They were 13 nominal groups that are separated by age. Data collection: Nominal group technique and ranking Data Analysis: Descriptive statistics	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	To investigate the organ donor attitudes and donor card behaviour of young adult with particular focus of South Asian origin.	N = 382 Age = 17 - 31 Gender = 164 male, 218 female	Design: a survey research design. Data collection: Questionaire Data Analysis: Descriptive statistics, Factor analysis	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, Miller, Dayoub, Wakefield, Homewood (2013) (USA) Title: Communication and Consent: Discussion and Organ Donation Decisions for Self and Family.	To examine factors that influence individual's willingness to donate organ.	N = 267 (200 community volunteered, 67 university students) Age = not reported Gender = 68 male, 199 female	Design: a survey research design Data collection: Organ Donation Attitude Survey (ODAS) Data analysis: Binary logistic regression, ordinal logistic regression	Reason for registering: Prior discussion and gaining support from family influences registration decision.
Studts, Ruberg, McGuffin, Roetzer (2010) (USA) Title: Decisions to register for the National Marrow Donor Program: rational vs emotional appeals.	To compare the efficacy of a rational appeal (RA) with emotional appeal (EA) as methods of increasing the intention to register.	N = 102 Age = not reported Gender = 47 male, 55 female	Design: an experimental research design (testing and intervention) Data collection: Medical students were assigned to 2 groups. 1 group received RA questionaire (statistical information about the need for stem cell donors) and the other received EA questionaire (narrative story of a donor and a recipient). Data Analysis: t-Test, Multivariate logistic regression	Reason for registering: Those received EA has higher tendency to register.
Webb, Phillips, Reddiford, Neuberger (2015) (UK) Title: Factors affecting the decision to grant consent for organ donation: A survey of adults in England	To explore the factors influencing personal decision to donate.	Focus group: 24 couples and 14 small family groups (the finding were used as a basis for the questionaire) N = 1549 Age = 18 24 (199), 25-34 (362), 35-44 (334), 45-54 (261), 55-64 (173), and 65 and above (220) Gender = 678 male, 871 female	Design: a mixed method research design. Data collection: Focus group and online survey Data Analysis: Multiple ordinal regression	Reason for registering: Altruistic, reciprocal benefit, avoidance of waste.
Morgan, Harrison, Afifi, Long, Stephenson (2008) (USA) Title: In their own words: the reasons why people will (not) sign an organ donor card.	To explore the reason 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)) Age = 18 – 67 Gender = 45 male-female dyads, 26 female-female dyads, 5 male-male dyads, 2 not reporting dyads.	Design: a qualitative research design. Data collection: Dyadic interview Data Analysis: Open coding and developed themes or concepts. Using Ethnograph (a qualitative software) to assist the analysis.	Reason for registering: Religion, desire to help others, Reason for not registering: Mistrust, belief in black market, deservingness issue.