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Informational Seeking Behaviour towards the Decision-Making Experience on Organ Donation Registration: Interview with Registered Organ Donors

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Abstract

Purpose: The purpose of this study aims to understand the information seeking behavior on organ donation that drives individual decision-making in relation to registration. Information seeking behavior on organ donation play a significant part of the development of awareness about organ donation, and ultimately when the right information is shared it would translate to organ donation registration.
Design/methodology/approach: A qualitative study has been conducted and data gathering was via a semi-structured interview among 16-registered organ donors. Purposive sampling method was employed. Data were analyzed using Giorgi's five steps of data analysis.
Findings: Findings showed three psychological concept of information seeking behavior surrounding the decision to register as a potential organ donor in Malaysia; confidence with information resources, informational needs, and judgment about the registration process. The three psychological concepts emerged with eight categories and 18 codes. Part of the research findings discussed that participants were dependent and confident on media resources particularly electronic sources, newspapers, and televisions. They also expressed confidence with the authorized body that look after organ donation matters as the information reliability is crucial when making organ donation registration. Though respondents show efforts when searching for information, when it comes to psychological assurance of the process, majority of them are in view that they assurance about organ removal and transplantation process, thus reading were very much focus around it. On the other hand, information about registration process is also critical as respondents needed to feel that it is effortless for them. This research shows how important an awareness campaign is in promoting organ donation. This research shows how important an awareness campaign is in promoting organ donation.
Research limitations/implications: This is a qualitative study, and as in any qualitative study the generalization and applicability of this study is limited to the context of the registered organ donor only. Further research might use the findings to test the three

psychological concept of information seeking behavior surrounding the decision to register as a potential organ donor using descriptive research. Plus, it is recommended that future research distribute and collect data from whole Malaysia.

Practical implications: These findings have implications for the management of potential organ donor register and suggest the role of authorized body in promoting organ donation. Authorized body such as the National Transplant Resource Centre could improve their future organ donation campaigns by utilizing social media as suggested by the data in the study. Once the authorized bodies recognize that social media advertising can help them improve awareness on organ donation, soon it would potentially gain an increase number on organ donation registration.

Originality/value: There is almost no other area of information discipline such as information seeking behaviors that have induced as much research effort and writing within the organ donation subject. Thus, the role that information seeking behaviors play in the decision to register, as an organ donor is not much understood.

Keywords: Organ Donation, Information Needs, Registration, Decision Making, Experience

Introduction

The continuous success of modern medical technology of organ transplantation has led to escalation of long waiting list of patient who waits for organ donor. However, major setback is poor donation rates that led to a scarcity of organs from donors to patients in need. This is a global issue as there is a big gap between the supply and demand for organs (International Registry of Organ Donation and Transplantation (IRODAT), 2020). This organ shortage scenario is also similar in Malaysia context (MyHealth, 2020; National Transplant Resource Centre, 2017).

One common barrier to organ donation is family rejections when they are not aware of the deceased’s inclinations 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. In Malaysia the National Transplant Resource Centre (NTRC) is responsible for the register. NTRC is accountable to increase the number of people registering as an organ donor on the donor register. To do so NTRC provides information and knowledge regarding organ donation and transplantation. They run national campaigns and educational programs such as the ‘National Organ Donation Awareness Week’ (MyHealth, 2020).

To date, Malaysia has a population of approximately 32.6 million and only 424, 143 people (1.3% of the population) have registered to be a potential organ donor (International Registry of Organ Donation and Transplantation (IRODAT), 2020), while the organ transplant waiting list was recorded as including 21, 826 individuals (National Transplant Resource Centre 2020 per communication). Patient in the waiting list for organ transplantation may have to wait for years before a suitable organ donor can be found. The longer the waiting game for the patient, the greater possibility for medical complications or even death.

There is limited empirical work in Malaysia that explains why people choose to join organ donor registers. 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. Thus, central to this study is to understand the individual information seeking behaviour that drives organ donation registration. An important component that would be of interest within this study is to explore; i) the individual informational needs, ii) the media sources that were used, and iii) the confidence towards the sources of information gained. Therefore, to understand the information seeking behaviour among registered organ donor is needed, thus a qualitative study has been conducted.

Information Seeking Behavior and Organ Donation Registration

Organ donation awareness campaigns play an important role in conveying information to the audience thus it needs to be implemented with effective communication strategies (Morgan, 2006; Morgan et al., 2008; Robinson et. all, 2012; Salim et al., 2012). According to Gurus in public health marketing, Siegel and Doner (1998) stated that communication strategies would determine how information is shared with its target audience and directly promote behavioural change. Similarly, an organ donation awareness campaigns that share the right information should stimulate an individual's intention to become a registered organ donor. These are previous empirical research that has investigated the influence of information and awareness on organ donation registration (Alden & Cheung, 2000; DuBay et al, 2014; Horton & Horton, 1991; Irving et al., 2014, Joshi, 2011; Kopfman & Smith, 1996; Long et al., 2012; Morgan & Cannon, 2003; Morgan et al., 2002; Morgan & Miller, 2002; Parsa et al., 2019; Rasiah et al. 2016, Reubsaet et al., 2001; Robinson et al., 2012; Ryckman et al., 2005; Salim et al., 2012; Schaeffner et al., 2004; Sirois et al., 2005; Weng et al. 2021), where all these studies showed a small to moderate positive influence of organ donation information and understanding towards organ donation registration status.

It is also worthwhile to note that there are contradicting findings in the literature on the influence of organ donation awareness towards organ donation registration status. As evidence, individuals in the Netherlands who have knowledge about organ donation often hold positive attitudes towards organ donation and have a stronger intention to register (Reubsaet et al., 2001). However, an evidence from Poland, reports that knowledge and awareness about organ donation does not necessarily correlate with registration as an organ donor (Perenc, Radochonski and Radochonski, 2012). Similarly, evidence from Malaysia revealed that individuals are aware about organ donor but responded ‘NO’ when asked if they were willing to become an organ donor (Tumin et al.; 2013), suggesting that this provides insufficient reason for individuals to decide to donate.

This raised bigger question globally as well as in local context, Malaysia, where there is many organ donation campaigns run to promote dissemination of the organ donation information, yet, this does not translate into the action of organ donation registration. The organ donation registration rate is still very low and this is often linked back to lack of public awareness and knowledge about organ donation and transplantation in general (Parsa et al., 2019; Rasiah et al. 2016, Weng et al. 2021). The absence of knowledge about the whole process involve in organ donation has become a barrier towards registration decision (Irving et al., 2012). The public frequently referred to myths and misconception (Rasiah et al. 2016, Weng et al. 2021) as this was being framed in fictional television series.

This suggests that even though the public may have awareness about organ donation, awareness alone is not a guarantee of registration. So this raise questions as to whether or not the information dissemination for the purpose of creating awareness was actually sharing the right and sufficient information. Plus, was the platform or media used appropriate enough to reach the intended audience? Thus, this study intend to explore the precise information people needed prior to making the decision to register as a potential organ donor and to understand the sources of information when studying about organ donation.

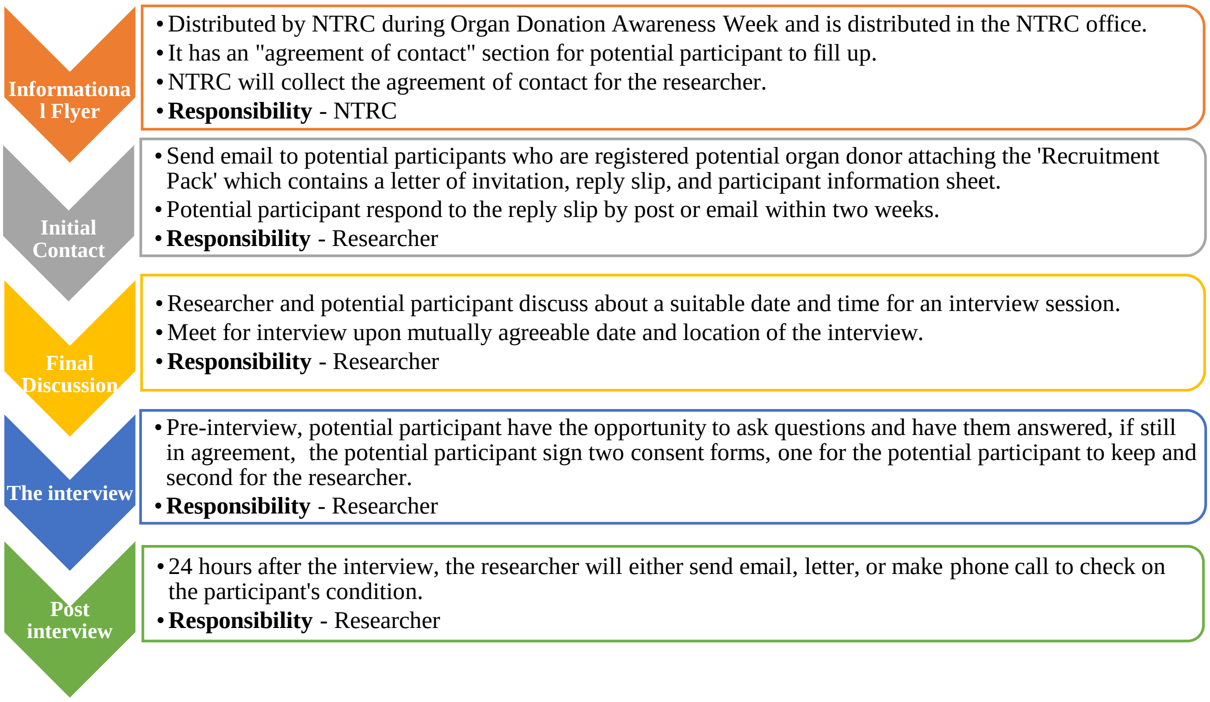
Method

In view of the research aim guiding this study and in order to gain an understanding of the information seeking behaviour prior to making an organ donation registration in real situation, a phenomenological methodology was chosen with the expectation that it would facilitate an in-depth examination aimed at understanding this social phenomena in the natural world (Moustakas, 1994). Furthermore, phenomenology is particularly suited to examining social phenomena when little is known about them (Morse & Field, 1996).

Participant Selection and Recruitment

This qualitative study utilized purposive sampling technique to identify and recruit individuals who had registered as an organ donor. Participants were recruited with the helped from the National Transplant Resource Centre (NTRC) in Malaysia. An informational flyer was developed and circulated by the NTRC staff to the public during Organ Donation Awareness Week, which ran from 7th to 13th September 2020 in Kuala Lumpur. The flyer was also distributed by the staff at the NTRC to potential registrants who walked-in to the NTRC office to discuss organ donor registration or to register their organ donation intention. The NTRC staff explained that this study would be taking place in the future and sought the person's agreement to be contacted by researcher to discuss participation in the study. If potential participants agreed to be contacted, they were asked to sign the agreement for contact section on the flyer.

In total, 28 potential participants who had agreed for contact by the researcher. Initial contact with the 28 potential participants was made via personalised email, which included a Recruitment Pack including a letter of invitation, reply slip and participant information sheet. The participant information sheet (PIS) is important, as it is the basis of informed consent, a key ethical principle. The PIS outlined the purpose and conduct of the research. Contact details were provided so that participants could make contact with the researcher if needed. Upon receipt of the email and the necessary information potential participants were asked to respond via the reply slip or email to discuss a suitable date, time and location for an interview. Figure 1 illustrates the recruitment process for registered potential participants.



- Distributed by NTRC during Organ Donation Awareness Week and is distributed in the NTRC office.
- It has an "agreement of contact" section for potential participant to fill up.
- NTRC will collect the agreement of contact for the researcher.
- **Responsibility** - NTRC

- Send email to potential participants who are registered potential organ donor attaching the 'Recruitment Pack' which contains a letter of invitation, reply slip, and participant information sheet.
- Potential participant respond to the reply slip by post or email within two weeks.
- **Responsibility** - Researcher

- Researcher and potential participant discuss about a suitable date and time for an interview session.
- Meet for interview upon mutually agreeable date and location of the interview.
- **Responsibility** - Researcher

- Pre-interview, potential participant have the opportunity to ask questions and have them answered, if still in agreement, the potential participant sign two consent forms, one for the potential participant to keep and second for the researcher.
- **Responsibility** - Researcher

- 24 hours after the interview, the researcher will either send email, letter, or make phone call to check on the participant's condition.
- **Responsibility** - Researcher

Figure 1: Recruitment Process for Registered Potential Participants

Outcome of the recruitment strategies, of the remaining 28 registered donors who had agreed to an interview, 16 participants actually completed interviews. Data saturation was reached after the 16 interviews.

Data Collection

Semi-structured in-depth interviews were conducted with the 16-registered organ donor, three were conducted at a coffee shop, two were undertaken at the participant's home, one at the participant's work place and ten via skype utility. Interviews lasted approximately 45 minutes and were tape-recorded with the consent of the participants. Data was recorded using pseudonyms to ensure anonymity and later it undergoes a full transcription process.

Semi-structured interviews were guided by an interview schedule developed in line with the research aim. This alignment is crucial so as to ensure that the interview questions conform to the research purpose and eliminate unnecessary questions. The interview schedule was developed as broad as possible to let the participant speak freely about the phenomenon they experience. However, there are probing questions set in the interview schedule as a guideline for the further probing whenever necessary. In all interviews, some of the key question posed were; 1) 'Can you tell me about your decision to become a registered organ donor?', 2) 'Can you tell me what drives you to register your intention to become an organ donor?', 3) Can you share what sort of information was important to you when deciding to become a registered organ donor?'

Data Analysis

Transcriptions of the narratives obtained from the interviews were analyzed using Giorgi's five steps of data analysis. First, transcripts were reviewed line by line by researchers to gain a sense of the whole and becoming immersed in the data. Second, on a transcript-by-transcript basis, the data was broken down into 'meaning units' within a psychological perspective. Third, the meaning units are transformed into psychologically descriptive expressions via a process of comparison as a means of grouping meaning units under psychological concepts. Fourth, the researchers began to construct an interpretation of the experience of registering as an organ donor from each interview. Finally, the researchers integrated the results and generate a description of the essence of the information seeking behaviour that drives of registering as an organ donor in Malaysia.

Findings and Discussion

In total, 16 interviews were completed with registered organ donors, including 13 women and three men, aged 26 to 47 years. Eight participants were from urban areas as they lived in close proximity to Kuala Lumpur and the other eight lived in sub-urban/rural area. Two participants were educated to Diploma level, seven participants held a Bachelor degree, and seven participants held a Master's. Through Giorgi's five steps of data analysis, three psychological concepts emerged with eight categories and 18 codes (Table 1). The psychological concept will be interpreted in the following section.

Table 1: Findings: The Three Psychological Concept of Information Seeking Behaviour Surrounding the Decision to Register as a Potential Organ Donor in Malaysia.

Psychological Concept	Categories	Codes
Confidence with information	Dependent on electronic resources	1. Confidence in trusted online resources 2. Confidence in official religious body online resources 3. Confidence in religious online blogs

resources		4. Confidence with viral online information; particularly social media
	Confidence with the traditional mass media	5. Confidence with the information shared in the newspaper 6. Confidence in TV advertisements, movies and TV series
	Confidence with authority	7. Confidence with the organ donation governing body 8. Confidence with the talk, seminar, or booth set up by governing body 9. Confidence with an official statement from a Mufti
	Positive assurance from social connection	10. Confidence with information shared by friends. 11. Superior or employer is an organ donor
Informational needs	Assurance of the process	12. Assurance of the organ removal and transplantation process 13. Assurance of the process involved in authorizing donation
	Verification of the value	14. Convinced that religion allow organ donation 15. Knowing the type of organ that can be donated
Judgement about the registration process	Overcome uncertainty of the registration process due to visibility	16. Knows that the registration process is effortless 17. A booth set up anywhere to approach the public, it is visible and accessible
	Knowing a number of registration platform	18. Acknowledge that registration is possible online

Psychological Concept 1: Confidence with Information Resources

The participant of this study, they were first stimulated with a signal of the need to acquire knowledge around issues surrounding organ donation. The stimulation may have arisen when they first came across booth or attended a talk session about organ donation. Once they are stimulated, decision is made to actively seek for more information surrounding the matter of interest. This then lead to information searching behaviour, which maybe a personalize method such as talking to family and friends, or impersonalized method like the use of printed material or media. Whether it is personalize or impersonalize method, this reflects the participant's preference on the sources of information.

The key issue brought up by most of the participants when they discussed about information resources is on their dependency towards online resources. For example when participants had questions regarding religious support for organ donation, electronic resources played a key role in providing the necessary information to guide decision making:

> "Only from the websites. First, I looked and read from the pamphlet I received from the talk. However, since I would like to know more, I did further reading from online resources. I started goggling and reading about the fatwa/dalil from JAKIM as obviously religious information is from JAKIM website only. Then, I went into

> their website too, the National Transplant's website. I read again in the National Transplant's website, mmm… I was curious and I would like to know what you can do while you are still alive, and what are the benefits of organ donation." (Registered Participant 1, 243-248)

As well as religious or donation specific resources, social media including blogs and Facebook was influential in not only supplying information but also stimulating cognitive readiness toward organ donation.

> "In many social media, especially Facebook, there were a lot of discussions surrounding the issue of whether it is illegal or not to donate organs. Thus, this fatwa council has made a statement that organ donation is not harmful to the deceased. So, when I read it, I was like 'oh, ok, organ donation is legal then'. So to me, by right, if the religious man or the pious says it is not violating Islamic rules, then it should not be a problem for me to go on with donating organs after death." (Registered Participant 3, Line 103-108)

> "I kept seeing in the FB wall where people shared the link on the awareness & campaign about organ donation… Plus I can also recall, I think in the last few years there were also official statements by the mufti, so I was moved to and get more interested around organ donation." (Registered Participant 16, Line 39-42)

Information gained from social media such as Facebook is now a key-influencing factor and yet it is unclear exactly what information was being shared and if the information provided was robust.

Whilst participants drew on social media and electronic resources, traditional mass media also played a role in influencing the decision to register. Examples of traditional mass media are newspapers, television and radio. Mass media has the ability to reach wide audiences with strong and influential messages (Wakefield et al., 2010; Irving et al., 2014). Participants reported reading newspapers, listening to items on the radio, or watching TV. The overriding impact of sources of information for those participants who registered was that the media triggered an emotional reaction that stimulated information seeking behaviours or the act of registration.

> "I have been reading about organ donation from articles in newspapers. However, usually information shared in a newspaper is statistical figures. Therefore, I wanted to know more. I also browsed through sites looking for Islamic perspectives on this. I also obtained brochures and pamphlets." (Registered Participant 15, Line 72-75)
>
> "I was really impressed when I heard the story of one of the organ donors in a radio. He has donated one of his kidneys to a child. Before that the child was in a very critical condition. He is not as active as other children of that age are. When there was someone who was willing to donate an organ to him, now the boy can live the life he could have like other children." (Registered Participant 12, Line 46-50)

Additionally, when deciding to register as a potential organ donor, the reliability and trustworthiness of sources of information was reported by participants as influential. For example, participants believed that online resources must be governed by the organization that oversees organ donation registration in Malaysia, the National Transplant Resource Centre (NTRC):

> "The National Transplant Resource Centre was the organizer itself, thus we believed that it is a trusted body which looks after organ donation, and they should know better and the information shared… was accurate… so it convinced us, so that was why I made the decision to immediately sign up. There is no need to refer to anything else. I believed the information shared." (Registered Participant 2, Line 186-190)

> "I don't think it was necessary to do that because I felt that the National Transplant is the right source to refer to. Because they have the authority, I guess. I mean they are the authorised body that overlooks organ donation activities in Malaysia. So I don't think I should look from elsewhere." (Registered Participant 6, Line 123-126)

NTRC staffs were perceived to be 'experts' and that the information they provided could be trusted. As representatives from a governing body, they are potential resources for communicating information about organ donation to the public and they should be taking up the role as opinion leaders by building trust with potential registrants to increase the number of intention registration in the organ donation register. Overall, NTRC is the authorized body that oversees organ donation throughout Malaysia: they act as a continuous information centre for the community on organ donation and transplantation. The NTRC coordinates donor registration and runs organ donation and transplantation awareness programs.

> "The speaker from NTRC did mention about organ donation from the perspectives of Islam. Before this I really thought that organ donation is prohibited and against our belief. But after listening to the talk then I understood it is not wrong in my religion." (Registered Participant 7, Line 48-51)

Participants expressed the importance of information dissemination by a trusted governing body such as NTRC, but also the need for such bodies to support the discussion around religion. This is a key issue due to the important role a participant's belief system has in deciding to register as an organ donor. Trusted sources therefore included the mosque, church, and Jabatan Kemajuan Islam Malaysia (JAKIM). JAKIM is a body that oversees Islamic development, ensuring standardization of the legal and administrative aspects relating to Islamic affairs, law and education throughout Malaysia. To reach a decision as important as donating an organ after death, it is vital for a person to have complete information and that information should come from a reliable source, especially when it involves religious matters. Dependability of JAKIM was mentioned by most participants and this corresponded to the importance of religion in making the organ donation registration decision. If we can focus to the two trusted websites; JAKIM and NTRC were mentioned a number of time, which conveys the importance of a trusted and reliable websites that is control by an appropriate authority.

Psychological Concept 2: Information Needs

An individual information needs is often the start of psychological state for information seeking behaviour. When we have certain information needs that are not being met yet, it drives certain level of curiosity and we begin to seek information in various sources. This category, informational needs, it links closely with the previous category discussed earlier, information seeking behaviour. Informational needs were expressed by some of the participants of this study to convey their psychological curiosity of wanting to be certain of the organ donation values and the desire to know about the organ donation process.

Participants discussed their need to know and to understand how the process of organ donation works and to verify the value of organ donation from religious perspective. A lack of knowledge was a barrier and has delayed organ donation registration, as knowledge deficits were usually linked to key concerns and feelings of anxiety.

> "I would like to get all sorts of Information. Information about benefit, about what organ can we donate, and… what else? Mmm… maybe on the processes involved. The process of how the transplant will take place… whether… I thought that when they… like when we die because of an accident… during the post-mortem they would straight away take my organ if I were a registered organ donor. Whereas, in the website it mentioned that post-mortem and transplant is a separate process. Therefore, it is a different process. It is not what I thought, that during the post-mortem the doctor could remove an organ for donation purposes. Moreover, only from reading on the website, I knew that the doctor would I have to ask the permission of the family and it is not only based on our decision. Right? Even if we had signed up as a registered organ donor, when we die, the family will be asked first, and if the family does not allow it then it will not happen. From reading, I also know that we can either donate all organs, or we also get to choose which part to donate. Yes, that is it. These were all sorts of information I needed." (Registered Participant 1, Line 263-274)

Overall participants were poorly informed about key donation actions, for example: how organ removal is performed, and how the dead body is handled after the removal process. Thus, information seeking behaviour were driven to uncover these.

> "I was actually referring to the way they perform the surgery at the time when health care personnel are removing the organ from the deceased body. I was also interested to know how they put it back together after the removal of an organ. I was really worried about it, maybe because my mom has put it in my mind, that organ removal for donation is painful and the healthcare personnel will do it carelessly as they would not bother to sew together the remains neatly." (Registered Participant 8, Line 95-100)

> "All this information is necessary for me to know prior to making the decision to register. I was curious, as I really wanted to know what our religion's stance about it is and how the removal process would take place. And what would happen to my body after the organs were removed?" (Registered Participant 12, Line 192-194)

How the dead body is treated post donation is a concern discussed in the global literature (Andy et al., 2015; Ashkenazi et al., 2015; Cotrau et al., 2019; Febrero et al., 2019; Irving et al., 2014; Morgan et al., 2008b; Salim et al., 2010; Sanner, 2006; Siminoff et al., 2010; Sun, 2015; Sque et al., 2005; O'Carroll et al., 2011; Wakefield et al., 2010). A lack of knowledge or a misconception of bodily integrity, particularly on the organ donation operation and treatment of the body post organ removal procedure, was a factor in registration decisions in this study and is reported elsewhere (Wong, 2011; Riyanti et al., 2014; Tumin et al. 2014). Misconception arises because of a lack of correct information about organ donation processes.

By nature, organ donation topic has greater complexity compared to any other pressing healthcare need. As for the participants of this study, all of them persistently mentioned that religious concerns play a significant role much more than other psychological concern. The informational needs of participants in this study were reported as needing to know whether or not religious teaching supported organ donation, but also the detail of what actually happens when you become a donor. These informational needs led to participants seeking information from varied sources, both traditional and contemporary.

Psychological Concept 3: Judgement about the Registration Process

Registered organ donor in this study expressed the influence of organ donation registration only because they know where to go and the sites were more convenient to them. This is in line with many previous studies that look into why people do not register where one of the key reason; does not know how to do it and have no idea of where to go to register.

Participants of this study have certain judgement about how easy the registration process is which lead them to sign up. A stress free access and convenience to the participants played a significant role in the decision to register as an organ donor. As spoken by participants in this study, knowing that registration process was easier since there are either booths located at event space, public places or event online, has eased up their registration experience.

> "Plus, an added point is that they have a representative at their booth that handle registration straight away. Therefore, it was easy. You don't have to go elsewhere to do it." (Participant 2, Line 110-112)

> "Emm there were booth for registration. I think it was a collaboration program between a few agencies. Because as far as I can remember there were Mufti (religious man) which I think is from the Islamic Department, there were people from the Nephrology Department, and I think there were NTRC booth." (Participant 4, Line 76-79)

While Participant 6 has demonstrate how medium of registration other that the traditional way as describe earlier has influence her to register. To her registration was easy as she discovered it can be done online and the link for registration was available in the blog she has been reading. The information shared on the blog that she was reading provide sufficient information, which make her aware of how and where to register her donation intention.

> "It is properly written by Ustaz Saiful Islam where he explained about where to go if reader wanted to register, and he even provide a link of the National Transplant website." (Participant 6, Line 49-51)

> "Well since I don't have to go elsewhere to register, plus I don't have to do extra work like googling about it, you know the registration process, so I just click on the link and register. It was easy." (Participant 6, Line 57-59)

Likewise, Participant 16 did not take too long to sign up her organ donation intention. She straightaway registers herself when she found a link on social media that she browsing. This has eases her intention registration process.

> “So basically I registered, as there was this one day I saw a link… a direct link to register online... I straight away signed up myself... Make it easy for me. If not... I will still procrastinate.” (Participant 16, Line 42-44)

Ideally, it is significant for Malaysia to have a working registration system where people could feel like registering organ donation intention is just a step away. This could indirectly increase the number of registered organ donors as well as actual donors. This is evident as many participants of this study felt that the availability of representative or accessibility of NTRC’s booth has ease their registration process. This emphasis that they do not want to take extra effort to explore if there are other ways to register their organ donation intention.

Malaysia should take initiatives to follow the example of countries who has successfully increase organ donation rates by having a more effective organ donation system. As an example, in the UK and US, they have a flexible registration system where people often prompt with the choices to become an organ donor through various means such as the ordinary organ donor registry form, on the websites, when applying or renewing driving licenses, and when applying of new or renew passport. However, we have to acknowledge that now all system, be it a traditional or computerized system, there is no guarantee that everyone would respond positively by becoming a registered organ donor, and however effort such as this should be in place to improve the organ donation system.

The key to success for Malaysia organ donation registration at the moment is to focus on having a system in place for all generation. It should be a system, which could reach traditionalist who prefer manual registration at booth. This means a booth set up should be available at many public spaces like malls, public transport stations, or even religious facilities. Extra effort should be in place to work in collaboration with mosque, churches, and temples, as these places is where you will commonly see older generation, who could probably prefer traditional or manual registration. Nevertheless, NTRC should also take the opportunity with the advancement of technology, to have an online registration platform. Links should be visible not only in NTRC’s website, but others such as Ministry of health websites, public and private hospitals websites, and other government agencies website which provide service to public such as for driving license and passport renewal.

Conclusion

There is almost no other area of information discipline such as information seeking behaviours that have induced as much research effort and writing within the organ donation subject. Thus, the role that information seeking behaviours play in the decision to register, as an organ donor is not much understood. Through increased publicity, via both electronic media and traditional mass media within communities, and empowering various official bodies that has authorities over organ donation matters should directly improve organ donation registration rate. The attitudes toward organ donation will become more positive, and thus increase the potential number of donations.

Findings from this study indicate that making important decisions requires relevant and accurate knowledge, as this knowledge would serve as a basis for managing uncertainty and ambiguity. Cognitive readiness required that participants acknowledged the gaps in their knowledge, which stimulated a motivation that led to information seeking behaviours (Wilson, 2000; Fletcher, 2004). Information seeking behaviour is a feature of being cognitively ready to engage in the registration or non-registration decision. A study conducted in Iran where 85 students from various universities in Hamadan city were interviewed found that cognitive readiness influenced registration decisions (positively or negatively) and that cognitive readiness was directly related to the quality of knowledge available and the level of understanding of participants (Parsa et al., 2019).

In the course of seeking information, participants may have interacted with different information sources, and the key sources discussed were computer based (the Internet) and manual information system (newspaper, pamphlet, television). The availability of Internet has allowed social media to be a powerful tool to spread awareness and encourage action (Cameron et al., 2013). Nevertheless, social media can also influence unethical practices by disseminating incorrect information (Miller et al., 2016), such as myth and taboo in the territory of organ donation activities. The availability of information and access to knowledge supports autonomous decision making as individuals can seek out information supporting their goals in life (Wilson, 2000; Hofstede, 2001; Fletcher, 2004). Whilst use of the Internet and traditional media was clearly a way in which participants gained access to the questions and concerns they may have about organ donation, there was an internal driver to seek information, and there were also pertinent external influences that influenced participants' decision-making.

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References

Alden, D.L. and Cheung, A. H. S. (2000). Organ donation and culture: A comparison of Asian American and European American beliefs, attitudes, and behaviors, *Journal of Applied Social Psychology*, 30, 293-314.

Andy, H., Abdul Rahim, M. H. and Lyndon, N. (2015). Penerimaan kempen pendermaan organ dalam kalangan masyarakat Islam di Malaysia: Satu kajian pendapat awam, *GEOGRAFIA: Malaysian Journal of Society and Space: Themed issue on Attitudinal and Institutional Dimensions of Malaysia's Development,* 11(8), 110-123.

Ashkenazi, T., Lavee, J. and Mor, E. (2015). Organ donation in Israel--achievements and challenges, *Transplantation*, 99(2), 265-6.

Cameron, A. M., Massie, A. B., Alexander, C. E., Stewart, B., Montgomery, R. A., Benavides, N. R. Fleming, G. D. and Segev, D. L. (2013). Social Media and Organ Donor Registration: The Facebook Effect, *American Journal of Transplantation*, 13, 2059-2065.

Cotrau, P., Hodoson, V., Vladu, A., Daina, C., Daina, L. G., and Pantis, C. (2019). Ethical, Socio-Cultural and Religious Issues in Organ Donation, *Maedica*, 14(1), 12-14.

DuBay, D. A., Ivankova, N., Herby, I., Wynn, T. A., Kohler, C., Berry, B., Foushee, H., Carson, A. P., Redden, D. T., Holt, C. and Siminoff, L. (2014). African American organ donor registration: a mixed methods design using the theory of planned behavior, *Prog Transplant*, 24(3), 273-83.

Febrero, B., Rios A., Lopez-Navas, A., Martinez-Alarcon, L., Almela-Baeza, J., Sanchez, J., Parrilla, J. J., Parrilla, P. and Ramirez, P. (2019). Psychological profile of teenagers toward organ donation: a multicentric study in Spain, *European Journal of Public Health*, 29(6), 1011–1018.

Fletcher, J. D. (2004). Cognitive readiness: Preparing for the unexpected. Alexandria, VA.

Hofstede, G. (2001). *Culture's Consequences: Comparing Values Behaviors, Institutions, and Organizations across Nations*. 2nd edn.: Thousand Oaks, CA: Sage Publ.

Horton, R. L. and Horton, P. J. (1991). A model of willingness to become a potential donor, *SocialScience & Medicine*, 1037-1051.

International Registry of Organ Donation and Transplantation (IRODAT) (2020). Final Numbers 2019.

Irving, M. J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., Allen, A. D., Craig, J. C., Wong, G. and Howard, K. (2012). Factors that influence the decision to be an organ donor: a systemic review of the qualitative literature, *Nephrol Dial Transplant*, 27, 2526-2533.

Irving, M. J., Jan, S., Tong, A., Wong, G., Craig, J. C., Chadban, S., Rose, J., Cass, A., Allen, R. D. 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, M. S. (2011). Whose Decision is it? Organ Donation Attitudes among Young UK South Asians, *Psychological Studies*, 56(1), 86-97.

James W. (2012). A sequential decision framework for increasing college students' support for organ donation and organ donor registration. The Organization for Transplant Professionals.

Kopfman, J. E. and Smith, S. W. (1996). Understanding the audiences of a health communication campaign: A discriminant analysis of potential organ donors based on intent to donate, *Journal of Applied Communication Research*, 24, 33-49.

Long, S. D. et al. (2012). When families talk: Applying interpretative phenomenological analysis to African American families discussing their awareness, commitment, and knowledge of organ donation, *Journal of the National Medical Association,* 104(11-12), 555-563.

Miller, D., Sinanan, J., Wang, X., McDonald, T., Haynes, N., Costa, E., Spyer, J., Venkatraman, S. and Nicolescu, R. (2016). *How the World Changed Social Media*. Gower Street, London: University College London.

Morgan, S. E., Miller, J. and Arasaratnam, L. (2002). Signing cards, saving lives: An evaluation of the worksite organ donation promotion project. *Communication Monographs*, 69, 253-273.

Morgan, S. E. and Miller, J. K. (2002). Communicating about gifts of life: The effect of knowledge, attitudes, and altruism on behavior and behavioral intentions regarding organ donation. *Journal of Applied Communication Research*, 30, 163-178.

Morgan, S. E. and Cannon, T. (2003). African Americans' knowledge about organ donation: Closing the gap with more effective persuasive message strategies, *Journal of the National Medical Association*, 95, 1066-1071.

Morgan, S. E. (2006). Many Facets of Reluctance: African Americans and the Decision (Not) to Donate Organs, *Journal of the National Medical Association*, 98(5), 695-703.

Morgan, S. E., Harrison, T. R., Afifi, W. A., Long, S. D. and Stephenson, M. T. (2008). In their own words: the reasons why people will (not) sign an organ donor card, *Health Commun*, 23(1), 23-33.

Morgan, S. E., Stephenson, M. T., Harrison, T. R., Afifi, W. A. and Long, S. D. (2008b). Facts versus 'Feelings': how rational is the decision to become an organ donor?, *J Health Psychol*, 13(5), 644-58.

Morse J. and Field P. (1996). *Nursing Research: The application of qualitative approaches*. Cheltenham: Nelson Thornes Ltd.

Moustakas, C. E. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: SAGE Publications, Inc.

MyHealth, K. K. M. (2020). Derma Organ. Available at: http://www.myhealth.gov.my/derma-organ/ (Accessed: 21 Mac 2020).

National Transplant Resource Centre (2017). Statistik Derma Organ. Available at: http://www.dermaorgan.gov.my/statistik-derma-organ/ (Accessed: 10 October 2020).

O'Carroll, R. E., Foster, C., McGeechan, G., Sandford, K. and Ferguson, E. (2011). The "ick" factor, anticipated regret, and willingness to become an organ donor, *Health Psychol*, 30(2), 236-45.

Parsa, P., Taheri, M., Rezapur-Shahkolai, F. and Shirahmadi, S. (2019). Attitudes of Iranian students about organ donation: a qualitative study, *BMC Medical Ethics*, 20-36.

Perenc, L., Radochonski, M. and Radochonski, A. (2012). Knowledge and attitudes of Polish university students toward organ donation and transplantation, *Psychol Health Med,* 17(6), 667-73.

Rasiah, R., Manikam, R., Chandrasekaran, S. K., Naghavi, N., Mubarik, S., Mustafa, R. and Pushparajan, S. (2016). Deceased donor organs: What can be done to raise donation rates using evidence from Malaysia?, *Am J Transplant*, 16, 1540–1547. pmid:26602367

Reubsaet, A., Brug, J., van den Borne, B and van Hooff, H. (2001). Predictors of organ donation registration among Dutch adolescents, *Transplantation*, 72, 51-56.

Riyanti, S. et al. (2014). Organ Donation by Sociodemographic Characteristics in Malaysia, *Asian Social Science*, 10(4).

Robinson, D. H. Z., Perryman, J. P., Thompson, N. J., Amaral, S. and Arriola, K. R. (2012). Testing the utility of a modified organ donation model among African American adults, *Journal of Behavioral Medicine,* 35(3), 364-374.

Ryckman, R. M., van den Borne, B., Thornton, B. and Gold, J. A. (2005). Value priorities and organ donation in young adults, *Journal of Applied Social Psychology,* 35, 2421-2435.

Salim, A., Schulman, D., Ley E. J., Berry, C., Navarro, S. and Chan, L. S. (2010). Contributing factors for the willingness to donate organs in the Hispanic American population, *Arch Surg*, 145(7), 684-689.

Salim, A., Bery, C., Ley, E. J., Schulman, D., Navarro, S., Zheng, L. and Chan, L. S. (2012). A focused educational program after religious services to improve organ donation in Hispanic Americans, *Clin Transplant*, 26(6), E634-40.

Sanner, M. A. (2006). People's attitudes and reactions to organ donation, *Mortality*, 11(2), 133-150.

Schaeffner, E. S., Windisch, W., Freidel, K., Breitenfeldt, K. and Winkelmayer, W. C. (2004). Knowledge and attitude regarding organ donation among medical students and physicians, *Transplantation*, 77, 1714-1718.

Siegel, M. and Doner, L. (1998). *Marketing public health: Strategies to promote social change*. Maryland: An Aspen Publication.

Siminoff, L. A., Traino, H. M. and Gordon, N. (2010). Determinants of family consent to tissue donation, *J Trauma*, 69(4), 956-63.

Sirois, B., Sears, S. and Marhefka, S. (2005). Do new drivers equal new donors? An examination of factors influencing organ donation attitudes and behaviors in adolescents, *Journal of Behavioral Medicine,* 28, 201-212.

Sque, M., Long, T. and Payne, S. (2005). Organ donation: key factors influencing families' decision-making, *Transplant Proc*, 37(2), 543-6.

Sun, H. J. (2015). A study on the development of public campaign messages for organ donation promotion in Korea, *Health Promotion International*, 30(4), 903–918.

Tumin, M., Noh., Mohd Satar, N., Chong, C. S., Lim, S., Abdullah, N. and Ng, K. (2013). Organ donation in Muslim countries: the case of Malaysia, *Ann Transplant*, 18, 671-6.

Wakefield, C. E., Watts, K. J., Homewood, J., Meiser, B. and Siminoff, L. A. (2010). Attitudes toward organ donation and donor behavior: a review of the international literature, *Progress in Transplantation*, 20(4), 380-391.

Weng, L. C., Chiang, Y. J., Huang, H. L., Tsai, Y. H., Chen, K. H., Wang, W. S. and Lin, M. H. (2021). Factors associated with registration for organ donation among clinical nurses, *PLoS ONE*, 16(2): e0247424. https://doi.org/10.1371/journal.pone.0247424

Wilson, T. D. (2000). Human information behavior, *Informing Science*, 3(2), 49–55.

Wong, L. P. (2011). Knowledge, attitudes, practices and behaviors regarding deceased organ donation and transplantation in Malaysia's multi-ethnic society: a baseline study, *Clin Transplant*, 25(1), E22-31.