

How Contexts Affect the Willingness of People to Register for the Deceased Organ Donation Program?

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Abstract

Background: The deceased organ donation program is new in the United Arab Emirates (UAE), and to heighten acceptability, a broad understanding of public perspectives thought to be helpful. Therefore, this study aims to explore the extent by which context plays a role in willingness to register for the deceased organ donation program in UAE, Dubai.

Methods: A qualitative methodology was used and this study was gauged by tenets of socioecological model and lay knowledge. Audio-recorded semi-structured interviews were conducted with 17 participants who were recruited purposefully. Then, data was analysed thematically.

Results: Four themes emerged from the dataset including: fear and body integrity, family, relational ties and the identify of recipient, religious conviction and knowledge and personal experiences. Participants feared the whole process, were not aware of the religious outlook and their knowledge regarding the program was scarce. Also, family related factors were major influencer, there should not be overlooked.

Conclusion: Using the socioecological model and lay knowledge helped to unravel contextual factors that affected their willingness to participate. Therefore, enabled developing a holistic understanding of the phenomenon of interest. Responses were mainly stemming from their contexts, hence, awareness campaigns should elucidate people about the technical aspects and address their contextual concerns.

1. Background

Transplantation is the greatest and, frequently, the only life-saving strategy for a patient with end-stage organ failure (Girlanda 2016; Saidi and Hejazii Kenari 2014). Studies have shown that transplantation improves survival rates and the quality of life (Kaballo et al. 2018). Alongside the advancements in surgical techniques and availability of effective immunosuppressive agents, deceased organ donation programs are an important addition in making the organ transplantation more plausible to patients with organ failure (Girlanda 2016). Studies found that there are more than 6000 patients per year while waiting for a transplant, with 10–30% chance of dying while waiting for an organ (Girlanda 2016). Spain has been one of the leading countries in implementing the deceased organ donation program for more than 25 years, with a total number of 4,818 organ transplantations carried out during 2016 as per the National Transplant Organization (ONT) (Govan 2017). This could be primarily due to the opt-out system, where every deceased person is automatically recognised as a potential organ donor unless they signed to opt-out (Govan 2017).

Given the pressing need, the shortage in organs and the importance of organ donation in saving lives of patients; the late Sheikh Zayed Bin Sultan in 1993 paved the way for the organ transplantation in the United Arab Emirates (AINowais 2017). However, it was only in 2010 when the first kidney transplant for an Emirati patient took place (Writer 2010). And in May 2013, the first successful transplantation from a deceased person was performed (Schneider Kayasseh 2014). In 2016, Federal Decree Law No. 5 of 2016 on Regulation of Human Organs and Tissue Transplantation was legislated concerning allowing and

regulating organ transplantation from living people and the deceased ones (Salama 2016). Since then, six deceased donors in UAE donated their organs to spare the lives of 22 patients (12 kidneys, 3 livers, 4 lungs, 2 hearts, and a pancreas) (“Ministry of Health and Prevention,” 2018). The deceased organ donation goes through 6 stages as seen in Fig. 1, and stage 4 is concerned with consenting to donate either by the participant him/ herself or approaching the grieving families (Girlanda 2016; Ralph et al. 2014). However, Agrawal et al (2017), Brown et al. (2010), Elalouf, Pliskin, and Kogut (2020), Parsa et al. (2019) and Ralph et al. (2016), brought to light that registering for the deceased organ donation program is far from being simple.

There are plenty of contextual and situation specific factors that interplay in a complex character, affecting the willingness of people to register for such a program. For example, family ties, parental approval, religious and cultural conflicts and much more were found to be major players in making such a decision (Agrawal et al. 2017; Brown et al. 2010; Elalouf et al. 2020; Parsa et al. 2019; Ralph et al. 2016). Patients or people are complex, therefore the focus in such a sensitive topic ‘deceased organ donation’ should go beyond the biological aspect to include the social determinants, environment and social relations, and recognise that there is an intricate entanglement in the relationship between these factors or elements (Wilson, Holt, and Greenhalgh 2001). However, to be able to understand these subjective, contextually laden factors, lay knowledge has to be unravelled. Lay knowledge is defined as “the ideas and perspectives employed by social actors to interpret their experiences of health and illness in everyday life” (Gabe, Bury, and Elston 2004, p. 135). It is driven by subjective personal concerns, life-situations, and surrounding contexts (Gabe et al. 2004; Popay and Williams 1996). As the deceased organ donation program is new in the UAE, a broad understanding of lay public views may help to identify and explain any factors or barriers for planning and improving the organ donation culture in the society, and render the program more successful. Although plenty of studies were conducted to explore the perceptions of people towards organ donation or deceased organ donation, none were conducted in the UAE, or exploring the extent by which context plays a role in participants willingness to register for the deceased organ donation program in UAE (Dubai).

2. Research Question

To what extent does the context influence people’s willingness to register for the deceased organ donation program in the United Arab Emirates?

3. Theoretical And Conceptual Framework:

The social ecological model (SEM), is a theory-based framework focuses on exploring, understanding and addressing the multifaceted and interactive effects of personal and environmental factors (context) on behaviour (Golden and Earp 2012; Stokols 1996). It explores the dynamic interrelations among the various contextual factors of levels (Golden and Earp 2012; Stokols 1996). SEM has five hierarchical levels including individual, interpersonal, community, organizational, and policy/enabling environment, and places a great deal on the interdependence and interconnection between these levels (Golden and

Earp 2012; Stokols 1996). Therefore, it encourages going beyond the biological aspect, or considering individuals and their consciousness as the only controller of actions or behaviours, towards an understanding of the wide range of factors that influence a certain behaviour or act (Golden and Earp 2012; Stokols 1996). Hence, allowing to identify a wider range of contextual subjective factors and influences, while appreciating the interactive nature and that individuals are embedded within larger systems (Burke et al. 2009; DiClemente, Salazar, and Crosby 2011; McLeroy et al. 1988; Sallis, Owen, and Fisher 2008; Stokols 1996). To be able to develop a better understanding of these contextually and situationally specific causative factors, the person who is having a first-hand experience with the context should be involved. The aim is to obtain lay knowledge, and this lay knowledge which is defined as the patient-specific knowledge and is developed through their lived experiences allows to bring to practice patients' own experience with the context which is subjective and diverse, and is stemming from natural settings (Popay and Williams 1996). Using these theoretical and conceptual frameworks lended richness in understanding how contexts affected the willingness of people to sign up for the deceased organ donation program.

4. Methods

4.1 Philosophical paradigm and methodology

To achieve the aim of the study, a qualitative methodology underpinned by an interpretivist paradigm with both subjective epistemology and relativist ontological stances was adopted (Dew and Dabbs 2016; Guba and Lincoln 2000; Lincoln and Guba 1985; Mertens 2014). An interpretivist approach was thought to be the most suitable as this study is mainly aiming at unraveling participants lay knowledge regarding their contexts and the deceased organ donation program, which are diverse, multiple, subjective and complex as seen in the results section (Dew and Dabbs 2016; Guba and Lincoln 2000; Lincoln and Guba 1985; Merriam and Tisdell 2015). This philosophical approach and methodology enables to inductively develop a deep understanding of the phenomenon under investigation from participants' perspective, which is important to achieve the aim of this research (Mertens 2014). Also, the qualitative methodology enables flexibility and preserve natural settings which heightened the chance to capture the complexity of the phenomenon, hence lend richness in understanding (Crotty 1998; Dew and Dabbs 2016; Guba and Lincoln 1994).

4.2 Population, sample size and recruitment

To be able to collect data that will help with answering the research question, a purposeful sampling technique was used (Lincoln and Guba 1985; Merriam and Tisdell 2015). That is due to the fact that the type of knowledge and reality we aim to become acquainted with is residing within people whom are interacting with their context and have heard about the UAE deceased organ donation program, have experienced it or witnessed someone experienced it or a similar program (Lincoln and Guba 1985; Merriam and Tisdell 2015). Since the deceased organ donation program was still relatively new in the UAE, the researchers faced some difficulties with recruitment, therefore snowball sampling was used as

well. Three researchers (A.H, M.S and L.H) invited participants by posting the invitation in various social media platforms (Instagram, twitter, facebook and linkedIn). Ten were recruited initially, and then through snowball sampling another seven joined. Although this was a limitation, the point of saturation was reached with the fifteenth participant, but another two were interviewed to ensure that the recruitment process was not halted prematurely. The same obstacle was seen in other studies regarding the low response rate during the recruitment phases (Fernandes, Bittencourt, and Boin 2015; Gironés et al. 2018). With regards to the sample size, there is no specific consensus about the number participants, as it could vary between 1 to 325 (Dukes 1984; Polkinghorne 1989). Although the phenomenon under investigation is highly sophisticated and diverse, having to remain pragmatic was crucial (Lavery 2008; Van Manen 1990). While recruiting participants, maximum variation was maintained to ensure including a range of participants, therefore capture a divergence of perspectives (Merriam and Tisdell 2015). Hence, individuals falling within different age groups, nationalities, ethnic groups and religions were recruited. All participants were given participant information sheet and signed the consent form before participating as described in the ethics section below.

4.3 Data collection method

Audio-recorded semi-structured interviews (about 60 minutes) using a topic guide derived from literature and the socioecological model were used. Semi-structured interviews were used as they provide data with great depth and breadth, and allow participants to narrate their experiences without being tied down to specific answers, which is important for this research (Morse 1994; Morse and Field 1995). It helped to maintain flexibility, but remain focused on the topic (Bryman 2012). The location, day, date and timing of the interviews were chosen according to the participant's preferences. However, the chosen locations met the following criteria: safe, comfortable, private and free of distractions. Interviews were conducted in different locations ranging between coffee shops and homes of participants. A trial for conducting the interview using the topic guide was done with four participants to ensure that the topic guide will help to capture the appropriate data, free of jargons, clear and understandable. These individuals were excluded from the actual study. Additionally, individual's identities were kept anonymous by using codes (letters followed by numbers), which guaranteed maintaining anonymity and confidentiality of data. When conducting the interviews, participants were first allowed to settle while confirming demographic information, obtaining the consent form if it was not obtained earlier, and then the recording was started, and was completely anonymised.

4.4 Ethical considerations

Subjects were informed fully about the purpose, methods and intended possible uses of the data, what their participation in the study entails and what risks, if any, are involved. Participants were provided with an information sheet including information about the voluntary nature of this study and their right to withdraw from it at any given time. In the participant information sheet, they were informed that findings will be submitted for publication and that their names will be replaced with codes. Moreover, a signed written consent was obtained from each participant before starting the interview. Computers holding data were password protected, and audio-files were password protected and encrypted. The audio-recorded

files were destroyed immediately after the completion of this study. Any paper that might contain personal identifiers was locked in a cabinet.

5. Data Analysis

5.1 Thematic Analysis

After transcribing verbal data, thematic analysis was carried out as described in Table 1 (Braun and Clarke 2006). Thematic analysis was used because it helped to identify, analyse, report on patterns (themes) and interpret the data (Braun and Clarke 2006).

Table 1
Phases of thematic analysis obtained
from Braun and Clark, (2006).

1.	Steps
2.	Getting familiar with the data
3.	Generating initial codes
4.	Searching for themes
5.	Reviewing themes
6.	Defining and naming themes
7.	Interpretative analysis

5.2 Validity and reliability

As the researcher is the primary data collection tool, measures were implemented to ensure maintaining authenticity of findings and avoid imposing the researcher's perspectives which might mask findings (Lincoln and Guba 1985). To optimise rigor, reflexivity, audit trail, member checks, participants' verifications, ensuring thick descriptions and more techniques seen in Table 2 were utilised (Merriam and Tisdell 2015). Records were transcribed and interpreted immediately (within two days of conducting the interview) to ensure recalling details about the interview. This practice was useful also to ensure introducing amendments to the topic guide to retrieve more purposive information (Lincoln and Guba 1985).

Table 2
Rigor assessment and assurance techniques (Lincoln and Guba 1985).

<u>Rigor assessment parameter</u>	<u>Techniques used to optimize rigor</u>
1) Credibility	<ul style="list-style-type: none"> · Member checks: researchers' and participant's verification of interpretation. · Reflexivity and audit trial: the three researchers reflected on how they affected and were affected by the research, and how all decisions were undertaken. · Thick descriptions · Examine previous research · Competency of researchers: one of the researchers was the research supervisor.
2) Transferability	<ul style="list-style-type: none"> · Thick descriptions · Maximum variations: Selecting a sample that encompass a wide range of cases.
3) Consistency or dependability	<ul style="list-style-type: none"> · Peers examination: researchers verified for each other. · Reflexivity and audit trial
4) Confirmability	<ul style="list-style-type: none"> · Reflexivity and audit trial

6. Results

6.1 Demographic information

The demographic information is summarised in Table 3. All participants were either currently living in Dubai or have lived in the Dubai. Both gender were recruited, where females made up 58.8% of the population, while males made up the rest (41.2%). Participants from nine nationalities, different age groups, educational level, religious beliefs and marital status were included. This variability in demographics ensured getting a wide range of perspectives about the phenomenon under investigation.

Table 3
Characteristics of Demographic Information

Demographic Characteristic		Number
Nationality	UAE	6
	UAE (Biracial, UAE/US)	1
	India	2
	Pakistan	1
	Philippine	2
	Jordan	1
	Egypt	1
	Iraq	1
	United Kingdom	1
	Palastin	1
	Gender	Male
Female		10
Age (Year)	18-29	6
	30-45	7
	46-60	3
	>60	1
Marriage	Married	11
	Single	6
Education	Bachelor	15
	Higher Degree	2
Religion belief	Christian	3
	Hinduism	2
	Islam	12

6.2 Themes

A total number of four themes emerged from the dataset to answer the research questions as delineated below, and these were mapped to the levels of SEM as seen in Fig. 2:

1) Fear and body integrity

2) Family, relational ties and the identity of the recipient

3) Religious conviction

4) Knowledge and personal experience

First theme: Fear and body integrity

Fear which was mapped to the individual level of SEM was found to be a major player in deciding whether or not a person would sign up for the deceased organ donation program. All participants talked about their fear towards registering for the deceased organ donation program. The majority mentioned that it is actually their fear of pain, harm and of the unknown. Also, some participants thought that the word 'deceased' remind them of death which is something they fear. Also, the human body is a sanctifying component for many individuals', and deceased organ donation was perceived as an action that dehumanise or imperil the dignity, identify or individuality of the body.

"It scares me, whenever I see this form, I feel as if I am signing on my death" (Participant 13, Female, 37 years old).

"Someone told me that basically the body feels after death, so you might feel that you're being cut up.. and that.. that scares me. When I die, would I want to feel pain even after I die? NO!" (Participant 9, Male, 26 years old).

"I don't want my body to be cut open and taking stuff from my body after I'm dead. Skin, heart, bones, everything, everything they're taking its mine." (Participant 6, Male, 22 years old)

Participants also talked about the importance of providing care for patient to prevent death. However, due to their mistrust in the healthcare system, they feared that interventions might be withheld, so that patients become eligible for the deceased organ donation program. Or that their organs will be unethically taken out or that they would be intentionally remove before the patient had died, and given to s pecific people due to lobbying.

"I do not trust them to do their best in saving my life if they knew that I have register for organ donation I prefer to die and take everything with me to the grave." (Participant 2, Female, 42 years old)

On the other hand, some participants had an opposing perception, where they thought it is essential for the survival of those who are in need, where it was perceived by some participants as a "noble" act (Participant 6, Male, 22 years old). In fact, these participants thought that there is nothing to lose, so why not to donate.

"I'm not gonna lose anything, I am dead already, instead so many people might have a better quality of life because of my donation." (Participant 7, Female, 19 years old).

Second theme: Family, relational ties and the identity of the recipient

Family, relational ties and the identity of the recipient is a theme that was mapped to all levels of SEM model as seen in Fig. 2. Although the program does not require family permission, some participants talked about the fact that parental authority held the most sway, which is a cultural and religious matter. For participants, it was crucial to please their parents or family members even after death, and this is underpinned by their religious values. Pleasing parents was tied to getting awarded with heaven, therefore their approval was essential even if they were married. In addition, some participants (especially Arabs) talked about the hierarchy in family, where parents hold the highest rank and their decisions and not always negotiable. Another important aspect was wanting to make sure that family members and parents are prepared for this to avoid having them experience intense emotions and react hysterically.

“Well, I will need to check with my parents, I mean you know how things go (Laughs). You know what, if I tell my mom about this, she would go mad” (Participant 12, Female, 41 years old)

The identity of the recipient of organs was also important to participants, in a sense where they would be willing to donate only if the recipient was a family member, friends or to a person with same cultural or religious beliefs. However, this is not possible in the case of this program.

“No. Unless a family member or a friend needs it.” (Participant 6, Male, 22 years old)

“I would probably do it if it will go to Hindus only” (Participant 16, Female, 56 years old)

Third theme: Religious conviction

Religious conviction is another theme that was mapped to all SEM levels. Religion was found to be a major player in either encouraging or discouraging participants to register for the deceased organ donation program. One of the major issues that was reported by participants is the lack of clear guidance on whether this is acceptable from a religious aspect. Participants mentioned that they are unaware about the current religion's outlook on deceased organ donation. Religious authorities should provide guidance about current practice of end-of-life organ donation and reach to a consensus, since the deceased organ donation religiously still seems to be an area of controversy in all religions. Participants felt that the conflict might be due to the conflict in the values of charity and having to maintain integrity of body and keep it intact.

“What I know that Islam forbid organ donation, and do not allow another Muslim to received organs. If there will be a clear FATWA from the head of FATWA then I have NO issue in donating my organs” (Participant 4, Male, 39 years old).

Fourth Theme: Knowledge and personal experience

Knowledge was mapped to two levels of SEM which are the individual and policy levels. Most participants were not fully aware of all the details regarding the deceased organ donation program, although they have heard about it. In fact, plenty of participants in their responses made it clear that they do not think of the program because they think it is not relevant to them, except the ones who have experienced it or witnessed someone going through the experience. Their limited knowledge and awareness about the program and the whole process seems to have afflicted the decision making regarding whether or not to register for the program. Although organ donation is very beneficial, most participants asked for more clarifications about the program, which is a clear indication that knowledge about the program was scarce. Also, they mentioned that the lack of campaigns to promote the program might also be an issue especially that deciding to sign up for the program is underpinned by numerous and complicated factors which has to be discussed in these promotion campaigns.

*“Health authorities should talk about it, and there has to be more information from many bodies, at least the religious ones, how things will be done, how families will be informed and what if they disagree?”
(Participant 14, Male, 28 years old)*

Several participants reflected on their own experience or the experience of someone they know or close to them with the organ donation. In general, participants felt that this program will be of a great benefit because of their experience or what they have observed while watching someone going through it. In other words, their experience or observation served as a source of knowledge on how useful this program would be for many people.

“Yes, one of my best friends suffered for years from kidney failure and liver failure. And he went abroad to reach a kidney donor in China and to do the operation there. The liver donor was his son he has taken half of his son’s liver and did the operation in Singapore. If this program was available, he might not suffer all these.”(Participant 1, Male, 53 years old).

7. Discussion

7.1 Discussing results in relation to existing literature:

This study intended to explore the extent by which context plays a role in participants willingness to register for the deceased organ donation program in UAE (Dubai).

Although, perception of people about decreased organ donation was studied before, it was mainly explored using quantitative positivist approach, unlike this study (Kennedy 2003; Popay and Williams 1996). Findings brought to light that despite organ donation is a human and noble act, dehumanise the dignity of body, fear of pain, death and the unknown were preventing people from signing up for the program. The same was seen in Shumin et al. (2013), where participants regarded death as an ominous matter, and therefore avoided discussing it (Shumin et al. 2013). Along the same line, participants of this

study were also concerned that there might be some unethical acts related to withholding care or organs trafficking. These concerns are not new, where participants in Kumar (2016), mentioned that they are not signing for the donor cards due to their fear that physicians might hasten their death to be eligible for organ donation (Kumar 2016). Ralph et al., (2014), mentioned that participants in the United States, United Kingdom, South Africa and Spain questioned the standard of medical care provided to donors, and had the same concerns regarding not trusting the organ donation process. Furthermore, similar to our study; participants wanted to know the identity of the recipient, due to their mistrust in the allocation process. Siminoff et al., (2003), mentioned that African American participants believed that "rich or famous" individuals were more likely to be allocated organs than other patients, while Kometsi & Louw, (1999), mentioned that certain ethnic groups are racially discriminated against to mainly supply organs (Kometsi and Louw 1999).

Granting approvals of family members and especially parents is of prime importance, not just in this study, as the same was seen in other studies, where there was a direct connection between the willingness to donate and family support (Alghanim 2010; Mossialos, Costa-Font, and Rudisill 2008; Ralph et al. 2016). In our study, participants felt that their parents approval was a must and not just for the young ones as seen in Ralph et al (2016). This was mainly due to their religious beliefs, as parents blessing is tied to being awarded with heaven. In certain societies such as the one in UAE or the Middle-East, parents hold the utmost power within the family, therefore the rest of family members have to follow, even if this involves donating organ for good deed. In Dodd-McCue et al. (2007), Doering (1996) and López Martínez et al. (2008), parents felt that the responsibility of the donation decision belongs to them. In fact, some mothers strongly advocated that they should make the decision about donating their child's organs (Dodd-McCue et al. 2007; Doering 1996; López Martínez et al. 2008).

Religion and beliefs were considered to be major determinants in deciding to register for the deceased organ donation program. The absence of consensus from different religious authorities made participants hesitant and felt uncomfortable to sign up for the program. The same was seen in Ralph et al., (2014), where some families were uncertain about whether their religion espoused donation, and therefore felt conflicted and uncertain about donation (Ralph et al. 2014, 2016). Violating the human body, whether living or dead, is forbidden in various religions (Bruzzone 2008). However, altruism is also an important principle of these religions, and saving a life is placed very highly in various religions (Bruzzone 2008; Oliver et al. 2011; Vuković et al. 2010). In this dilemma, many individuals are still hesitant, where some thought of it as a gift to live (Janahi et al. 2018), and that it is acceptable for people to donate their organs (Shumin, Woo, and Lei 2013; Truijens and van Exel 2019), while others felt that retaining the body intact after death is a religious act such in the case of our study (Truijens and van Exel 2019).

Knowledge is an important cue, as not having a holistic understanding about the organ donation due to the lack of knowledge seems to have an impact. Public exposure to knowledge and information about the deceased organ donation would result not only in disseminating more information about the program, but, also addressing all segments of the society. Hence, more frequent declaration of wishes to donate and render the idea of donation more acceptable (Alghanim 2010; Mossialos et al. 2008). Furthermore,

majority of participants thought that organ donation is not directly related to them. The same was seen in Ralph et al (2016), therefore, raising awareness is important. For example, in Ralph et al (2016), participants felt that they needed to know more about the organ donation process such as timing and length of the potential surgery, what it involves and how the donation affects the appearance of the deceased, organ matching and success rates. However, in our study alongside these, participants wanted to know more about the religious outlook, how to educate their families and more.

7.2 The socioecological model and lay knowledge:

Figure 2 clearly shows the various contextual factors that were identified by participants to play a role in their decision to register for the deceased organ donation program. These were mapped to the various levels of SEM. However, Fig. 2 as well shows the interactive, dynamic and interdependence in relationship between the various levels and contextual factors or elements that influenced their decision (Golden & Earp, 2012; Stokols, 1996). Therefore, these contextual factors are closely tied to each other, and affect each other, and envisaging that there is a unidirectional relationship between them is not suitable. In addition, using the SEM while developing the topic guide helped to unravel data that would enrich our understanding of the lay person's actions in terms of their own logic, knowledge and beliefs that are grounded in the context of people's daily (Williams & Collins, 1995). To illustrate, participants who have talked about granting parental approval, were mainly concerned about their religious and cultural boundaries. In addition, participants clearly expressed that their fear was underpinned by the lack of knowledge or misconceptions. Hence, it is important not to explore these factors in isolation. To improve the organ donation culture in the society, all SEM levels have to be targeted or addressed through awareness campaigns, and to also address people concerns similar to the ones that were unraveled during this study to render this program successful.

It is important to bear in mind that it was not possible to understand the perceptions of people towards the donation without unraveling their lay knowledge. The data that was collected through the interviews was merely a reflection on the program in light of their unique contexts. This is importance because it has an important influence on acceptability, where behaviour and perception were found to be interconnected (Bargh, Chen, and Burrows 1996; Berkowitz 1984; Berkson 1938; Chartrand and Bargh 1999; Dijksterhuis and Bargh 2001; Dijksterhuis and van Knippenberg 1998; Prinz 1990; Vallacher 1993; Woody and Sadler 1998). Perception does not onlt creates an experience of the world, it allows us to act within contexts and environments (Textbook and College 2016). Hence, participants lay knowledge regarding the deceased organ donation program helped us understand what would affect people willingness.

8. Conclusion

The deceased organ donation program is a newly developed program in the UAE. This qualitative study was conducted using a constructivist philosophical position to be able to gains insights to individuals' personal beliefs, opinions and perspectives. This helped to provide a hoslitc understanding of the phenomenon of interest, hence provide future directions to render it a successful program. The usefulness of qualitative research in organ transplantation cannot be overlooked (Dew and Dabbs 2016).

The responses of participants shed light on the need for a proper awareness campaigns about the program. In addition, unless the religious view of deceased organ donation becomes clear and is positive towards it, participation will be scarce. The social context should not be overlooked, where for example family ties in societies such as the United Arab Emirates are essential, and found to play a pivotal role in deciding to donate an organ after death. This is not to say that these results are conclusive, however this study provides a direction for future research on such an important aspect regarding the deceased organ donation.

Declarations

Ethics approval and consent to participate:

Ethical approval was obtained from the institutional Review Board of the Higher Colleges of Technology. Participants were provided with an information sheet including information about the voluntary nature of this study and their right to withdraw from it at any given time. A signed written consent was obtained from each participant before starting the interview. Computers holding data were password protected, and audio-files were password protected and encrypted. The audio-recorded files were destroyed immediately after the completion of this study. Any paper that might contain personal identifiers was locked in a cabinet.

Consent for Publication:

Ethical approval was obtained from the institutional Review Board of the Higher Colleges of Technology. Participants were informed that information gathered will be used in preparing this manuscript for publication purposes. In the participant information sheet, they were informed that findings will be submitted for publication and that their names will be replaced with codes. A signed written consent was obtained from each participant before starting the interview.

Availability of data and material:

Upon request

Competing interests:

None

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Authors' contributions

All authors have contributed equally to the following: planning and designing the study, collecting and analysing the data, and writing the manuscript.

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References

1. Agrawal S, Binsaleem S, Al-Juhayim MAI-Homrani,A, Abdullah Al-Harbi. Knowledge and Attitude towards Organ Donation among Adult Population in Al-Kharj, Saudi Arabia. *Saudi Journal of Kidney Diseases Transplantation: An Official Publication of the Saudi Center for Organ Transplantation Saudi Arabia.* 2017;28(1):81–9.
2. Alghanim SA. Knowledge and Attitudes toward Organ Donation: A Community-Based Study Comparing Rural and Urban Populations. *Saudi Journal of Kidney Diseases Transplantation.* 2010;21(1):23.
3. AlNowais S. 2017. "Everything You Need to Know about the UAE's Organ Donor Programme." *The National.* Retrieved February 7, 2020 <https://www.thenational.ae/uae/everything-you-need-to-know-about-the-uae-s-organ-donor-programme-1.684548>.
4. Anwar ASM, Tanim, and Jae-Myeong Lee. 2020. "A Survey on Awareness and Attitudes Toward Organ Donation Among Medical Professionals, Medical Students, Patients, and Relatives in Bangladesh." *Transplantation Proceedings* 52(3):687–94.
5. Braun V, and Victoria Clarke. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology.* 2006;3(2):77–101.
6. Brown CVR, Kelli H, Foulkrod S, Dworaczyk K, Thompson E, Elliot H, Cooper, and Ben Coopwood. Barriers to Obtaining Family Consent for Potential Organ Donors. *The Journal of Trauma.* 2010;68(2):447–51.
7. Bruzzone P. 2008. "Religious Aspects of Organ Transplantation." *Transplantation Proceedings* 40(4):1064–67.
8. Bryman A. 2012. *Social Research Methods, 4th Edition.* 4th edition. Oxford; New York: Oxford University Press.
9. Burke NJ, Joseph G, Pasick RJ, Barker JC. Theorizing Social Context: Rethinking Behavioral Theory. *Health Education Behavior: The Official Publication of the Society for Public Health Education.* 2009;36(5 Suppl):55S–70S.
10. Cossé TJ, Weisenberger TM. Words versus Actions about Organ Donation: A Four-Year Tracking Study of Attitudes and Self-Reported Behavior. *J Bus Res.* 2000;50(3):297–303.

11. Crotty M. 1998. "The Foundations of Social Research | SAGE Publications Ltd." Retrieved March 15, 2016 <https://uk.sagepub.com/en-gb/mst/the-foundations-of-social-research/book207972>.
12. Dew M, Amanda, Annette J, DeVito, Dabbs. Harnessing the Power of Qualitative Research in Transplantation. *Am J Kidney Dis*. 2016;67(3):357–59.
13. DiClemente RJ, Laura F, Salazar, Crosby RA. 2011. *Health Behavior Theory for Public Health: Principles, Foundations, and Applications*. 1 edition. Burlington, MA: Jones & Bartlett Learning.
14. Dodd-McCue D, Tartaglia A, and Robin Cowherd. The Role of Women in the Donation Consent Decision: Building on Previous Research. *Prog Transpl*. 2007;17(3):209–14.
15. Doering JJ. Families' Experiences in Consenting to Eye Donation of a Recently Deceased Relative. *Heart Lung*. 1996;25(1):72–8.
16. Dukes S. Phenomenological Methodology in the Human Sciences. *J Relig Health*. 1984;23(3):197–203.
17. Elalouf A, Pliskin JS, and Tehila Kogut. Attitudes, Knowledge, and Preferences of the Israeli Public Regarding the Allocation of Donor Organs for Transplantation. *Israel Journal of Health Policy Research*. 2020;9(1):25.
18. Zélia Zilda Lourenço de Camargo Bittencourt, and Ilka de Fátima Santana Ferreira Boin Fernandes ME, Nascimento. Zélia Zilda Lourenço de Camargo Bittencourt, and Ilka de Fátima Santana Ferreira Boin. 2015. "Experiencing Organ Donation: Feelings of Relatives after Consent." *Revista Latino-Americana de Enfermagem* 23(5):895–901.
19. Gabe J, Bury M, and Mary Elston. 2004. *Key Concepts in Medical Sociology*. First edition. London; Thousand Oaks, CA: SAGE Publications Ltd.
20. Girlanda R. Deceased Organ Donation for Transplantation: Challenges and Opportunities. *World Journal of Transplantation*. 2016;6(3):451–59.
21. Gironés P, Burguete D, Machado R, Dominguez JM, Lillo M. 2018. "Qualitative Research Process Applied to Organ Donation." *Transplantation Proceedings* 50(10):2992–96.
22. Golden SD, Jo Anne L, Earp. Social Ecological Approaches to Individuals and Their Contexts: Twenty Years of Health Education & Behavior Health Promotion Interventions. *Health Education Behavior: The Official Publication of the Society for Public Health Education*. 2012;39(3):364–72.
23. Govan F. 2017. "How Spain Became the World Leader in Organ Transplants." Retrieved February 7, 2020 <https://www.thelocal.es/20170915/how-spain-became-world-leader-at-organ-transplants>.
24. Guba EG, Lincoln YS. "Competing Paradigms in Qualitative Research." In: *Handbook of Qualitative Research*. London: SAGE Publications, Inc; 1994. p.p. 105–17.
25. Guba EG, Lincoln YS. 2000. "Epistemological and Methodological Bases of Naturalistic Inquiry." Pp. 363–81 in *Evaluation Models, Evaluation in Education and Human Services*, edited by D. L. Stufflebeam, G. F. Madaus, and T. Kellaghan. Springer Netherlands.
26. Janahi FK, Al Rais A, Al Rukhaimi M, Khamis AH, Hickey D. 2018. "Public Awareness of Knowledge, Belief, and Attitude Regarding Organ Donation and Organ Transplantation: A National Survey From

- the United Arab Emirates." *Transplantation Proceedings* 50(10):2932–38.
27. Kaballo MA, Canney M, Williams PO'Kelly,Y, Conall M, O'Seaghdha, Peter J, Conlon. A Comparative Analysis of Survival of Patients on Dialysis and after Kidney Transplantation. *Clinical Kidney Journal*. 2018;11(3):389–93.
 28. Kennedy I. Patients Are Experts in Their Own Field. *BMJ: British Medical Journal*. 2003;326(7402):1276–77.
 29. Kometsi K, Louw J. Deciding on Cadaveric Organ Donation in Black African Families. *Clin Transplant*. 1999;13(6):473–78.
 30. Kumar L. Brain Death and Care of the Organ Donor. *Journal of Anaesthesiology Clinical Pharmacology*. 2016;32(2):146–52.
 31. Lavery SM. Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*. 2008;2(3):21–35.
 32. Lincoln YS, Guba EG. 1985. *Naturalistic Inquiry*. 1st edition. Beverly Hills, Calif: SAGE Publications.
 33. López Martínez JS. María Jesús Martín López, Barbara Scandroglio, and José Manuel Martínez García. 2008. "Family Perception of the Process of Organ Donation. Qualitative Psychosocial Analysis of the Subjective Interpretation of Donor and Nondonor Families." *The Spanish Journal of Psychology* 11(1):125–36.
 34. McLeroy KR, Bibeau D, Steckler A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Health Educ Q*. 1988;15(4):351–77.
 35. Merriam SB, Tisdell EJ. 2015. *Qualitative Research: A Guide to Design and Implementation*. 4 edition. San Francisco, CA: Jossey-Bass.
 36. Mertens D. "An Introduction to Research." In: *Research and Evaluation in Education and Psychology: Integrating Diversity With Quantitative, Qualitative, and Mixed Methods*. Thousand Oaks: SAGE Publications, Inc; 2014. p..p. 1–45.
 37. Mertens DM. 2014. *Research and Evaluation in Education and Psychology: Integrating Diversity With Quantitative, Qualitative, and Mixed Methods*. 4 edition. SAGE Publications, Inc.
 38. Morse JM. 1994. *Critical Issues in Qualitative Research Methods*. SAGE.
 39. Morse JM, Peggy AF. 1995. *Qualitative Research Methods for Health Professionals*. SAGE Publications.
 40. Mossialos E, Joan Costa-Font, and Caroline Rudisill. Does Organ Donation Legislation Affect Individuals' Willingness to Donate Their Own or Their Relative's Organs? Evidence from European Union Survey Data. *BMC Health Services Research*. 2008;8(1):48.
 41. Oliver M, Woywodt A, Ahmed A, and Imran Saif. Organ Donation, Transplantation and Religion. *Nephrology Dialysis Transplantation*. 2011;26(2):437–44.
 42. Parsa P, Taheri M, Rezapur-Shahkolai F, and Samane Shirahmadi. Attitudes of Iranian Students about Organ Donation: A Qualitative Study. *BMC Medical Ethics*. 2019;20(1):36.

43. Polkinghorne DE. 1989. "Phenomenological Research Methods." Pp. 41–60 in *Existential-Phenomenological Perspectives in Psychology*, edited by R. S. Valle and S. Halling. Springer US.
44. Popay J, Williams G. Qualitative Research and Evidence-Based Healthcare. *J R Soc Med.* 1998;91(Suppl 35):32–7.
45. Popay J, and Gareth Williams. Public Health Research and Lay Knowledge. *Social Science Medicine.* 1996;42(5):759–68.
46. Ralph A, Chapman JR, Gillis J, Craig JC, Butow P, Howard K, Irving M, Sutanto B, Tong A. Family Perspectives on Deceased Organ Donation: Thematic Synthesis of Qualitative Studies. *American Journal of Transplantation: Official Journal of the American Society of Transplantation the American Society of Transplant Surgeons.* 2014;14(4):923–35.
47. Ralph AF, Alyami A, Allen RDM, Howard K, Craig JC, Chadban SJ, Irving M, Tong A. Attitudes and Beliefs about Deceased Organ Donation in the Arabic-Speaking Community in Australia: A Focus Group Study. *BMJ Open.* 2016;6(1):e010138.
48. Saidi RF, Hejazii Kenari SK. Challenges of Organ Shortage for Transplantation: Solutions and Opportunities. *International Journal of Organ Transplantation Medicine.* 2014;5(3):87–96.
49. Salama S. 2016. "Passed: UAE Organ Transplant Law – and What It Means." Retrieved February 7, 2020 <https://gulfnews.com/uae/health/passed-uae-organ-transplant-law-and-what-it-means-1.1896013>.
50. Sallis JF, Owen N, Fisher EB. 2008. "Ecological Models of Health Behavior." p..p. 465–85 *Health behavior and health education: Theory, research, and practice, 4th ed.* San Francisco: Jossey-Bass.
51. Schneider Kayasseh E. Organ Transplantation in the United Arab Emirates: Legal, Ethical and Historical Aspects. *Electronic Journal of Islamic Middle Eastern Law (EJIMEL).* 2014;2(8):1–23.
52. Shumin X, Woo SMu-Lian, and Zhang Lei. Strategies for Changing Negative Public Attitudes toward Organ Donation in the People's Republic of China. *Patient Preference Adherence.* 2013;8:25–30.
53. Siminoff LA, Renee H, Lawrence, Arnold RM. Comparison of Black and White Families' Experiences and Perceptions Regarding Organ Donation Requests. *Crit Care Med.* 2003;31(1):146–51.
54. Stokols D. Translating Social Ecological Theory into Guidelines for Community Health Promotion. *American Journal of Health Promotion: AJHP.* 1996;10(4):282–98.
55. Truijens D, Job van, Exel. Views on Deceased Organ Donation in the Netherlands: A q-Methodology Study. *PloS One.* 2019;14(5):e0216479.
56. Van Manen M. 1990. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.* 2nd edition. Albany, N.Y.: State University of New York Press.
57. Vuković M, Moljević N, Katanić N. Dragan Krivokuća, Vesna Vuković, and Zoran Milosević. 2010. "Cadaveric Organ Transplantation and Religion." *Medicinski Pregled* 63(7–8):575–78.
58. Wilson T, Tim Holt, and Trisha Greenhalgh. Complexity and Clinical Care. *BMJ.* 2001;323(7314):685–88.

59. Writer S. 2010. "UAE's First Kidney Transplant on Child a Success - Eb247 - The Business of Life - Health And Fitness - Emirates24|7." Retrieved February 7, 2020
<https://www.emirates247.com/eb247/the-business-of-life/health-fitness/uae-s-first-kidney-transplant-on-child-a-success-2010-05-02-1.239322>.

Figures



Figure 1

The Process of Deceased Organ Donation (Girlanda 2016; Ralph et al. 2014).

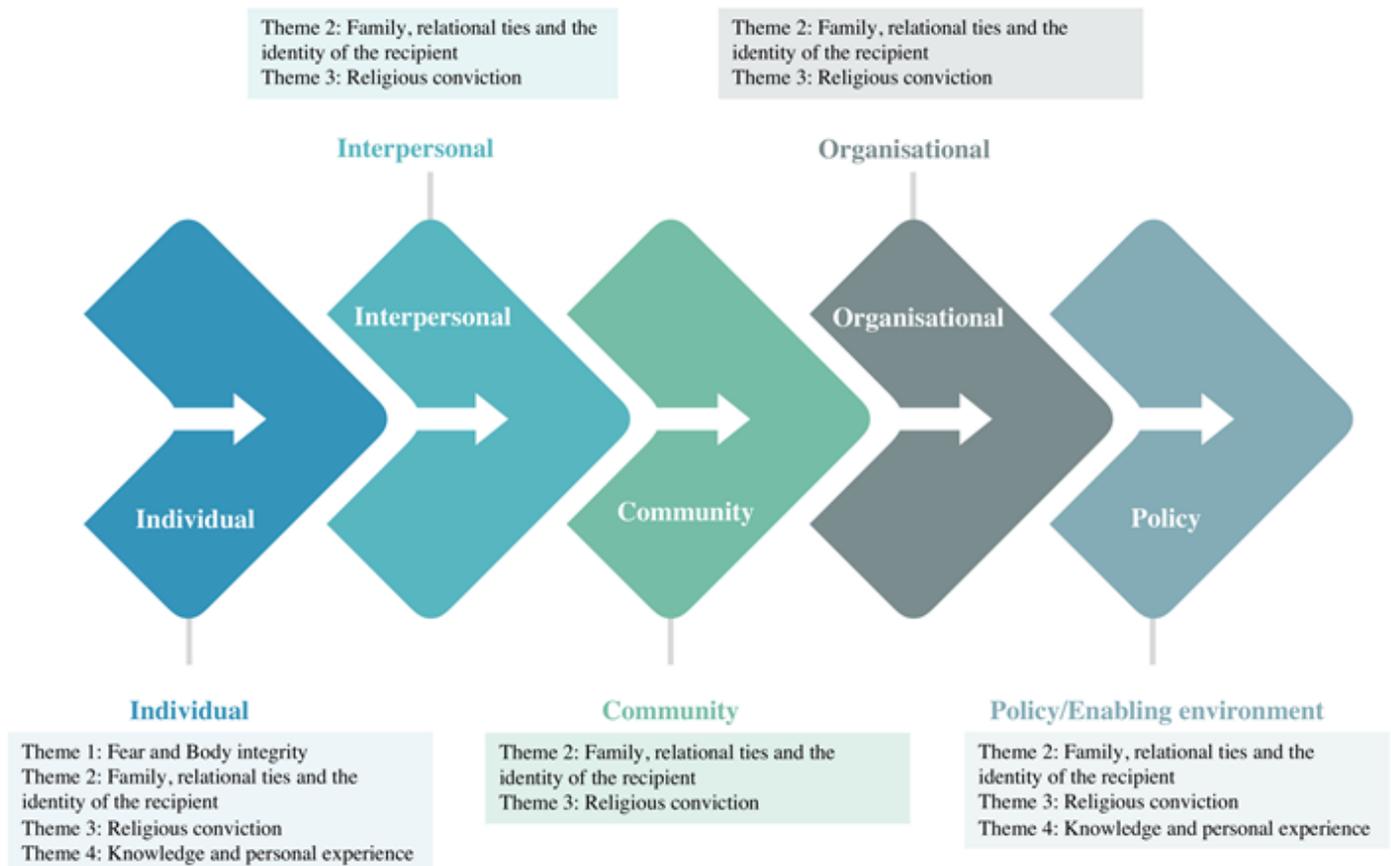


Figure 2

Socioecological Model