

# Comparing Knowledge and Attitudes Toward Deceased Organ Donation Between Registered vs. Nonregistered Donors in Saudi Arabia: A National Assessment

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**Abstract: Background:** Despite the high demand for organ donation, inadequate organ availability remains an issue. Many barriers are associated with this demand-supply gap. Low public awareness, religious beliefs, gap in knowledge, negative attitudes, and cultural justifications are suspect barriers to organ donation. The objective of this study was to compare Saudis' knowledge and attitudes toward deceased organ donation between those who registered as donors and those who are not.

**Methods:** A cross-sectional, study-specific questionnaire was conducted. Through convenient sampling, the questionnaire assessed knowledge and attitudes and compared them among those who registered for organ donations versus those who had not. Independent *t*-test was used to analyze between-group differences.

**Results:** Data was collected from 3,111 individuals with a mean age of 31.4 years (*SD* = 9.7). The result of the independent *t*-test showed a nonsignificant difference in the mean level of knowledge ( $t = 1.2, p = .247$ ) between participants who registered for deceased organ donation and those who did not. The result of attitude indicated a statistically significant difference between the two groups ( $t = -30.5, p < .001$ ).

**Conclusion:** The study revealed that Saudis' knowledge about deceased organ donation may not be driving their decision to register. Attitudes seem to be more influential in shaping that decision. Knowing this, public health practitioners might need to focus on initiatives that shift the public mindset and create a new social norm as opposed to providing facts and information.

**Key words:** Deceased organ donation, knowledge and attitudes, after death organ donation, registration, Saudi Arabia

**Main text:** Organ donation has been saving many lives globally, and its contribution to the overall life years is significant (Schnitzler et al., 2005). Practically, organ donations can take two forms: living or deceased, based on the status of the donor. In the context of the Middle East, living organ donation is dominant, mainly for kidney and partial liver donation (Shaheen, 2009). Despite all efforts from most countries to increase deceased organ donation, inadequate organ availability remains an issue while the demand for organs is much greater than the supply (Marqués-Lespier et al., 2013). Many barriers could explain this demand-supply gap. Factors range from poor health infrastructure to lack of governmental support and low public awareness (Shaheen & Souqiyeh, 2015). Socioeconomics factors, religious beliefs, gap in knowledge, negative attitudes, and cultural justifications are also potential barriers to deceased organ donation (Shaheen, 2009; Shaheen & Souqiyeh, 2005).

Specifically in Saudi Arabia, religion has been influential in shaping public response regarding organ donation. In 1993, a royal decree institutionalized organ donation after clearance from the Council of Senior Scholars, the highest religious body in the country (Shaheen et al., 1995). While organ donation is still a controversial matter among religious scholars, it did gain popular acceptance, especially after one of the prominent members of the Council of Senior Scholars registered to be an organ donor in 2013 (Alriyadhnews, 2013).

Residents in Saudi can register as organ donors through the Saudi Center for Organ Transplantation (SCOT). Early 2021, SCOT worked jointly with Saudi Data and Artificial Intelligence Authority to launch a new service for any adult to register as an organ donor through *Tawakkalna* (Okaznewspaper, 2012).

This phone application is essential for all citizens and non-citizens in the Kingdom, which makes the platform a viable tool to deliver ad-hoc services and announcements. Now, users are prompted to be organ donors via a pop-up message in the app that takes them to the registration process if they opt in (Tawakkalna, 2021). Importantly, this service only concerns organ donation after death, which introduces an additional layer of complexity in the decision-making process.

To account for such complexity, Social Cognitive Theory (SCT) was employed in this study to provide a framework in exploring factors influencing the registration decision. SCT argues that human behavior may be predicted through the interaction of personal, environmental, and behavioral factors (Smelser & Baltes, 2015). Personal factors include cognitive aspects like knowledge, values, self-efficacy and attitude, whereas environmental factors consist of the physical and social environment, such as access and social norms. On the other hand, behavior-related factors emphasize on aspects that include nature, frequency, and intensity of the performed behavior (Smelser & Baltes, 2015). When looking at performing the behavior of registering as a deceased organ donor, Bandura's SCT theory can shed light on contextualized factors that influence this behavior and explain how the behavior can shape and be shaped by personal and environmental factors (DuBay et al., 2017).

In line with the drastic social and sentimental changes around organ donation in Saudi Arabia, comes the need to understand the public response and how organ donation is perceived and practiced. Literature is lacking in this specific area. The available literature is either outdated, foreign, on specific groups (e.g., medical students), or concerns living donation. Therefore, the objective of this study is to compare current Saudis' attitudes and knowledge regarding organ donation after death between those who registered as donors and those who are not. Findings from this study will provide policymakers with insights that can be translated into behaviorally informed policies to optimize organ donations in the country.

## **Methods:**

### **Study design, sample, and participants:**

A cross-sectional questionnaire was conducted to explore knowledge and attitudes toward deceased organ donation in Saudi Arabia. A study-specific survey was developed and built into Qualtrics, an advanced online surveying tool (Qualtrics<sup>®</sup> XM). Through convenient sampling and snowballing techniques, the questionnaire was distributed in different social media platforms, such as WhatsApp and Twitter. The penetration of these platforms across all demographic groups in Saudi Arabia is among the highest in the world (Statistics, 2021), which makes this type of sampling efficient and cost-effective. To correct any potential lack of representativeness, demographics were checked mid-way through recruitment and were corrected for any biased distribution. The required minimum sample size based on Krejcie and Morgan (1970) sampling table was 384 participants. However, more participants were targeted to increase power and to account for suboptimal response rates. Eligible participants were adults 18 years and older. Those younger than 18 were auto excluded when answering the age question at the beginning of the questionnaire and their responses were not recorded.

### **Questionnaire:**

A thorough literature review showed that most survey instruments in the topic of organ donation were not designed

specifically to measure aspects of deceased organ donation in general population.

Most of these questionnaires either have mixed questions about living and deceased organ donation or target certain populations such as medical students. Given the considerable different contexts of living versus deceased organ donations and the contrasting decision-making processes involved, a survey instrument was developed to precisely measure knowledge and attitude toward deceased organ donation in the Saudi population.

Multiple expert workshops were conducted to review published questionnaires on the topic. A primary list of items was then generated based on the local cultural and social context. These items were further filtered based on relevancy and importance. The last version was assessed to ensure content and face validity by experts specialized in public health, behavioral science, and sociology. Finally, an Arabic language expert reviewed and edited the items for clarity and lingual accuracy.

A pilot study with 20 randomly selected participants was conducted to assess clarity, content, simplicity, and average duration. Revisions were done as recommended.

### **Questionnaire structure:**

The questionnaire consists of three major sections: (a) sociodemographic; (b) knowledge; and (c) attitudes.

#### **Sociodemographic**

This section includes items about age, gender, nationality, education, socioeconomic status, marital status, parenthood status, and region of residence. Participants answered these categorical items from a drop-down format.

The last two questions asked participants if they are registered as donors (yes or no). If they answered (no), then another question would follow, "Do you wish to register in the deceased organ donation national record?" Responses were captured by one of three choices: willing, uncertain, unwilling.

#### **Knowledge:**

This part asked six true/false statements to assess knowledge of health and administrative aspects about deceased organ donation, such as "The deceased body would be grossly disfigured because of removed organs," and "I can withdraw my registration from the organ donation national record." Each correctly answered item received one point. Therefore, the scale score ranged from 0-6. A higher score indicates a greater level of knowledge.

#### **Attitudes:**

Seven statements measured attitudes, using a 5-point Likert scale (strongly agree- strongly disagree). A sample item asked, "All eligible Saudis should be registered by default as deceased organ donors." The range of the composite score of this scale was 7-35, with "strongly agree" assigned a score of 5 and "strongly disagree" assigned a score of 1. A higher composite score indicates more positive attitudes towards deceased organs donations.

#### **Outcome variables:**

##### **Registration status**

The following item measured participant's registration status: "Are you registered in the deceased organ donation national record" (Yes, No).

##### **Willingness to register**

For those who had not registered, willingness to register was assessed using the following item, "Do you wish to register as donor in the deceased organ donation national record?" Respondents were able to choose one of the provided responses: willing, uncertain, unwilling.

**Ethical Approval:**

This study was reviewed and approved for research with human subjects by Princess Nourah Bint Abdul Rahman University Institutional Review Board (IRB # 21-0316).

**Statistical Analysis:**

This study used SPSS version 23 (IBM) to conduct a descriptive analysis, including frequencies, percentage, means, and standard deviations to describe the sample's demographic characteristics. Two independent-sample *t*-tests were used to detect differences in the mean levels of attitude and knowledge between those who have registered in the national record and those who have not. One-way ANOVA was used to assess the differences in the mean levels of attitude and knowledge based on the willingness to register for organ donation.

**Results:**

The sample size in this study is 3,111 with a mean age of 31.4 years (*SD* = 9.7). Females made 60% of the total sample. Fifty percent of the study sample were single. Two-thirds had a bachelor's degree, and more than 80% reported good or very good economic status. Most participants came from the major regions of Central (46%), Eastern (23%), and Western (21%) Saudi Arabia (Table 1).

Participants' mean score of knowledge was 2.7 (*SD* = 1.0, range: 0-6), while their mean score for attitude was 22.6 (*SD* = 4.8, range: 7-35). Most participants (70%) were not registered as deceased organ donors. Among those 70% who were not registered (*n* = 2,177), 32.5% were willing to register, and 38.0% were uncertain (Table 2).

The result of the independent *t*-test in Table 3 shows a nonsignificant difference in the mean level of knowledge ( $t = 1.2$ ,  $p = .247$ ) between participants who registered for deceased organ donation and those who did not. However, results from the attitude scale indicated a statistically significant difference between the two groups ( $t = -30.5$ ,  $p < .001$ ). Registered participants report a statistically significant higher level of attitude than those who were not registered (Table 3).

The one-way ANOVA reveals an overall significant difference among participants regarding their level of knowledge based on the willingness to register for deceased organ donation (Welch = 24.5,  $p < .001$ ). Participants who were willing to register as well as those who were uncertain had the highest level of knowledge. Another one-way ANOVA shows an overall significant difference among participants regarding their level of attitude based on willingness (Welch = 1368.8,  $p < .001$ ). Participants who were willing to register for deceased organ donation had the highest level of attitude among the three groups (Table 4).

**Discussion:**

The objective of this study is to compare Saudis' attitudes and knowledge regarding organ donation after death between those who registered as donors and those who are not. While findings from this study showed that 70% of participants are still unregistered, two thirds of those who had not signed up are willing or uncertain to register as donors. Knowledge does not seem to affect the decision as much as attitudes do.

According to a global review of donor registries, the percentage of donors varies widely from 0.01% to 40%. The number of registered donors reported in Arab countries in this review is in the lower extreme (Rosenblum et al., 2012), while the US and Spain are the highest countries with deceased organ donors, 38.03 and 37.97 donors per million population respectively (GODT, 2020). According to our study, Saudi

Arabia's deceased donors would be 1.87 donors per million population.

These figures highlight the shortage of donors in the region and in Saudi Arabia despite the widening supply-demand gap (Christmas et al., 2008). Globally, low registration is more prominent in countries where explicit consent is required to register in the program compared to countries that adopt a presumed consent with the option of opting out. For example, Australia reports nearly 100% of registered donors as they utilize an opt-out approach (Johnson & Goldstein, 2003; Rosenblum et al., 2012). Such global variation warrants for a closer examination of the socioecological model in each country.

In our study, most of those who had not registered reported that they were willing to register or were uncertain at most. Only a minority bluntly rejected donation. These results are promising and reflect the importance of developing effective behavioral interventions to translate intentions into actions as many people are "nudgable". Decision-making aides can help increase the numbers of donors. A study by Sallis et al. (2018) conducted a field experiment measuring the effect of persuasive messages with reciprocal altruism and social norms. The study found that reciprocal messages, such as "If you needed an organ transplant would you have one? If so, please help others," worked well in increasing registration. Collective efficacy and the expression of individual's reciprocity positively influence willingness to donate one's organs (Mossialos et al., 2008). In addition, empirical evidence suggests altruistic and prosocial motives as potential interventions to inform, persuade, and motivate actions (Robitaille et al., 2021). In fact, research shows that prosocial attitudes positively correlate with a favourable attitude towards organ donation (Falomir-Pichastor & Frederic, 2013).

Moreover, current findings demonstrate that knowledge around organ donation did not differ between registered and non-registered respondents; however, attitudes did. This suggests that provision of factual information might not drive participation in organ donation. Instead, interventions might want to improve attitudes for those who are uncertain about their decision and could enhance the choice architecture for those who are willing to donate. A large body of research shows that the intention-action gap can be bridged by implementing cost-effective behavioral interventions (Thaler & Sunstein, 2008), particularly in the domain of organ donation (Beraldo & Karpus, 2021; Reinhart et al., 2007; Robitaille et al., 2021). Deedat et al. (2013) explain that multiple interventions could reinforce and build on each other. When attitudes are negative, interventions might focus on changing attitudes by targeting prosocial motives, altruism, collective efficacy, moral norms, religious and social beliefs. However, when intentions are already made, such as the segment of participants who expressed willingness to donate, interventions might focus on simplifying the actual registration process.

The current findings disagree with the literature discussing knowledge as an important determinant of organ donation registration (Alghanim, 2010; El-Shoubaki & Bener, 2005; Mossialos et al., 2008). These authors argue that lack of knowledge impacts the decision-making; therefore, providing people with information would increase acceptance and registration. Other research argues that information campaigns promoting donation are not as effective in changing attitudes and perceptions and have a relatively low effect on actual behavior (Deedat et al., 2013; Jasper et al., 1991; Terbonssen et al., 2015). In the present study and in the context of Saudi Arabia, it seems that organ donation is driven by sentimental factors, not pure

logic. This insight should be the basis for future policies and interventions.

#### Limitations:

Findings should be considered in light of some limitations. The design of this study cannot prove any causal relationships between attitudes and registration. It is possible, however unlikely, that people developed positive attitudes after the registration as a way to solve any cognitive dissonance. That said, the decision to be an organ donor is not a light, casual one, so we assume that attitudes precede behavior in this case. Another limitation concerns recruitment. Sampling was convenient which might have introduced selection bias. To address this risk, tremendous efforts were done to include a large national sample size across all demographic groups.

#### Future Research :

To get a better understanding of the decision-making process around organ donation, experimental research is recommended to empirically test the causal effect of different types of behavioral interventions. Some relevant determinants of organ donation registration that could potentially be examined empirically in future research are affective reactions (activating the sense of pride, joy, altruism, and happiness), moral norms (emphasizing that donating is the right thing to do), and social norms (highlighting the increasing popularity of registration) (Falomir-Pichastor & Frederic, 2013).

#### Conclusion:

The context of deceased organ donation in non-Western countries is rare to find. This study offers unique insights on this important topic. Main findings demonstrate that attitudes, not knowledge, might have more important role in people's decisions to become organ donors. In addition, it seems that many people are not completely rejecting organ donation. Thus, well-designed behavioral interventions can be utilized to encourage willing or uncertain citizens to register. Public health initiatives should be designed with these insights in mind to save lives and costs.

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Appendixes:

Tables

Table 1. Demographic Characteristics

Variable	N = 3,111	%	Mean	SD
Age	-	-	31.4	9.7
<b>Gender</b>				
Female	1,863	59.9		
Male	1,248	40.1		
<b>Marital Status</b>				
Single	1,550	49.8		
Married	1,445	46.4		
Divorced/Widowed	116	3.8		
<b>Nationality</b>				
Saudi	2,950	94.8		
Non-Saudi	161	5.2		
<b>Education</b>				
High School or Less	277	8.9		
Diploma	196	6.3		
Bachelor	1,965	63.2		
Graduate Degree	673	21.6		
<b>Economic Status</b>				
Poor	170	5.5		
Good	1,253	40.3		
Very Good	1,285	41.3		
Excellent	403	13.0		
<b>Do You Have Children? (Only for non-singles)</b>				
Yes	1,261	80.8		
No	300	19.2		
<b>Region</b>				
Central	1,422	45.8		
Eastern	716	23.0		
Western	654	21.0		
Southern	143	4.7		
Northern	176	5.6		

Table 2. Descriptive Analysis of Main Study Variables

Variable	N = 3,111	%	Mean	SD
Knowledge	-	-	2.7	1.0
Attitude	-	-	22.6	4.6
<b>Registration Status</b>				
Yes	934	30.0		
No	2,177	70.0		
<b>Willingness to Register</b>				
Willing	707	32.5		
Uncertain	836	38.4		
Unwilling	634	29.1		

Table 3. Independent Sample t-tests for Knowledge and Attitude by Registration Status

Variables	t	p	Mean		95% CI	
			Registered	Unregistered	Lower	Upper
Knowledge <sub>a</sub>	1.2	.247	1.7	1.8	-.002	-.0
Attitude	30.5	.001 <sup>&lt;</sup> ***	25.9	21.2	-4.9	-4.4

<sup>a</sup>: Transformed variable using inverse method. \*\*\* (p-value is less than .001)

Table 4. One-way ANOVA for Knowledge and Attitude by Willingness to Register

Variable	Willing Mean (SD)	Uncertain Mean (SD)	Unwilling Mean (SD)	Welch a	p
Knowledge <sub>b</sub>	1.8 (.07)	1.8 (.07)	1.7 (.10)	24.5	.001 <sup>&lt;</sup> ***
Attitude	23.8 (3.5)	21.1 (3.3)	18.4 (3.9)	1368.8	.001 <sup>&lt;</sup> ***

<sup>a</sup>: Welch test was used because of homogeneity assumption violation. <sup>b</sup>: Transformed variable using inverse method. \*\*\* (p-value is less than .001)