ORIGINAL RESEARCH

## Public attitudes toward corneal donation in northern Jordan

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Purpose: The aims of this study were to assess the knowledge and attitude toward corneal donation among Jordanian population and to report the reasons which may influence subject's decision and attitude toward corneal donation.

Methods: A self-designed questionnaire was developed. The participants were asked about reasons for both willingness and unwillingness to donate their corneas. These reasons were stated in the questionnaire and the participants had to express their agreement by one of five options: strongly disagree, disagree, neutral, agree, or strongly agree.

**Results:** A total of 500 participants (218 males and 282 females) completed the questionnaire. The average age ( $\pm$ SD) of the study participants was 32.8 ( $\pm$ 11.7) years. About 67.2% of the subjects were willing to donate their corneas, whereas 32.8% were not willing to do so. The main motive for willingness was doing a good deed by helping others to see. On the other hand, fear of the body being treated badly and that other organ might be taken than the ones specified for donation were the main reasons for unwillingness to donate corneas. The age of participants, gender, and the monthly income did not significantly influence the willingness to donate (P > 0.05). However, the level of education had a significant influence on people's decision to donate their corneas.

Conclusion: Many Jordanians have positive attitude toward corneal donations. Ethical factors need to be addressed to promote for corneal donation. In addition, increasing the awareness of donation and its benefits may help increase the supply of corneal tissues. Keywords: corneal donation, willingness, Jordan

#### Introduction

Corneal blindness accounted for 4% of global blindness, as estimated in 2010.<sup>1</sup> According to the WHO census published in 2018, corneal opacities accounted for 5.1% of the world's blind population and considered the fourth most common cause of blindness globally.<sup>2</sup> Causes of corneal blindness reported in the ophthalmic literature include corneal ectasia, such as keratoconus, bullous keratopathy, corneal dystrophies, xerophthalmia, corneal infections due to Chlamydia trachomatis and other microbial infections, ocular ulceration, and ocular trauma that involve the cornea.

In the Middle East, corneal blindness was listed as the fourth cause of blindness among children after other causes of blindness: retinal degeneration, congenital cataract, and congenital glaucoma.<sup>3</sup> In Jordan, Al-Bdour et al reported in a hospital-based study that corneal opacification was the fourth most common cause of unilateral and bilateral blindness with higher occurrence among patients younger than 25 years old. They also reported that corneal blindness accounts for 13.8% of total cases of blindness in the same study.<sup>4</sup>

Corneal transplantation is one of the most common successful organ transplant procedures performed worldwide to treat corneal blindness and restore vision in affected

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patients. The first successful attempt of human corneal transplant started early in the 19th century by Edward Zirm.<sup>5</sup> Since then, the procedure has been improved by evolving new surgical techniques ranging from full thickness penetrating keratoplasty to partial thickness lamellar keratoplasty that involves removing and replacing of selective damaged corneal layer/s.<sup>5–10</sup> Along with improvements in corneal imaging, surgical instrumentation, and preoperative patient's care, the success rate of the corneal transplantation surgery has been reported to be as high as 80% worldwide.<sup>11–13</sup>

Despite the high success rate of corneal transplantation, the available number of corneal grafts is reported to be lower than the actual need for corneal graft.<sup>14</sup> This issue is documented worldwide in both developed and developing countries and is mainly related to shortage in corneal tissue donation. Al-Bdour et al also pointed that corneal donation is very rare in Jordan and that there is a long waiting list of patients who need corneal graft.<sup>4</sup>

Factors limiting corneal donation have been investigated extensively and attributed mainly to refusal to donation by either the person or their families.<sup>14</sup> Other factors include lack of consent from deceased patients or their relatives, medical contraindications to procurement such as infections or low corneal endothelial cell count, and logistical issues related to approaching deceased patients' relatives.<sup>14–16</sup>

Many reports have addressed knowledge of different populations and their attitudes toward corneal donation.<sup>17–22</sup> Factors that affect subject's decision and unwillingness to corneal donation were determined by other studies, which included insufficient knowledge and awareness of the public about donation; ethical, religious, and cultural issues; and beliefs concerning death and mortality.<sup>15,20,23–26</sup>

To the best of our knowledge, this is the first study to assess the level of knowledge and attitude toward corneal donation among Jordanians, where similar results have not been reported from the population of this study. In addition, factors that might influence the willingness and unwillingness to donate the corneal tissue will be investigated. The findings obtained from the study are of paramount importance to target these issues and act to promote levels of awareness of corneal donation among the public in Jordan, which may improve quality of life among patients with corneal blindness.

#### Methods Study design

A cross-sectional study was performed using a structured questionnaire that was developed to obtain information about attitude toward corneal donation and to identify factors that might affect corneal donation in Jordan. The study was conducted in northern Jordan between September 2017 and January 2018.

#### Participants

The study participants were selected randomly from the general community population in the north of Jordan. Participants aged  $\geq 18$  years were invited to complete a self-administered questionnaire on knowledge of corneal donation and reasons of willingness and unwillingness toward corneal donation. Participants were selected randomly from general public places including shopping malls, bus stations, and universities.

#### Ethics approval

The ethics approval for conducting this study was granted by the Institutional Review Board committee at Jordan University of Science and Technology. Informed written consent was obtained from all participants prior to their participation in the study and all study methodologies complied with the guidelines of the Declaration of Helsinki.

#### Exclusion criteria

People with any abnormal cognitive ability that may affect their logical responses were excluded from the study.

#### The questionnaire

The questionnaire was developed by the research team for the purpose of this study. The questionnaire was initially designed by a focus group that consisted of a group of practicing optometrists and public health researchers. Possible reasons for willingness and unwillingness toward corneal donation were discussed, verified, drafted, and documented.

The questionnaire was then assessed for clarity and ease of comprehension in a pilot group consisting of 25 subjects selected randomly from the general population. Comments and remarks from the pilot group were taken into consideration prior to using the final version of the questionnaire. The data from the pilot group were not included in the final data analysis.

The final version of the questionnaire consisted of 3 parts and included a total of 12 questions: 1) the first part acquires data on sociodemographic characteristics of the participants, such as age, gender, level of education, and economic status; 2) participants were then asked to answer a series of questions related to knowledge about corneal donation; and 3) finally, participants were asked to express their agreement Public attitudes toward corneal donation in northern Jordan

with suggested reasons for willingness and unwillingness toward corneal donation. Participants had to express their agreement with each reason of willingness and unwillingness using a 5-point Likert scale (from 1: strongly disagree to 5: strongly agree). Listed reasons included ethical, religious, and social reasons, which may influence the subject's decision regarding corneal donation.

In order to assess the reliability of the developed questionnaire, a random sample was used for test-retest reliability. Twenty subjects were approached to fill out the questionnaire, and the same subjects were interviewed again after 1 week to assess the intra-subject reliability of answers.

The questionnaire was then administered to a larger sample (n=500) of the population in the north of Jordan. The questionnaire was administered by the same surveyor. A brief explanation of the purpose and significance of the study was introduced to each participant prior to their participation. The surveyor also clarified some concepts related to corneal tissue donation to ensure that all participants had the same level of comprehension of the questions and to establish consistency in acquired responses.

#### Statistical analysis

Data were analyzed using SPSS software version 21.0 (IBM Corporation, Armonk, NY, USA). Descriptive statistics including frequencies and percentages were calculated to summarize the categorical data. Univariate comparisons between attitude toward corneal donation with age and income were done using independent *t*-test, and chi-squared test was applied for the categorical variables (gender and level of education). A *P*-value of <0.05 was considered statistically significant.

#### **Results** Demographic characteristics of participants

A total of 500 participants (43.6% males and 56.4% females) completed the questionnaire. The average age ( $\pm$ SD) of the study participants was 32.8 ( $\pm$ 11.7) years and ranged from 18 to 74 years. Demographics of all participants are shown in Table 1.

## Awareness and general attitudes toward corneal donation

Figure 1 shows that the majority of the participants (88.0%) had heard about corneal donation. Willingness to donate the cornea after death was confirmed by 67.2%, and a higher percentage (82.8%) would encourage people to donate.

Table I Participants' characteristics (n=500)
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Variable	No (%) of respondents
Gender	
Male	218 (43.6)
Female	282 (56.4)
Age group (years)	
18–29	272 (54.4)
30–50	188 (37.6)
>50	40 (8.0)
Smoking	
Non-smokers	542 (70.5)
Smokers	227 (29.5)
Education level	
Illiterate/elementary	44 (8.8)
High school	136 (27.2)
Higher education	293 (58.6)
Bachelor	27 (5.4)
Graduate degrees	
Income (JOD)	
<500	271 (54.2)
500-1,000	178 (35.6)
>1,000	51 (10.2)

Abbreviation: JOD, Jordanian Dinar.

More than half of the participants (54.8%) agreed to report their willingness on the driver's license.

#### The association between willingness to donate the cornea and the study variables

The influence of the study demographics on the willingness of the participants to donate their corneas is shown in Table 2. Age, gender, and monthly income did not significantly influence respondents' willingness to donate their corneas after death (P>0.05 for all variables). However, level of education had a significant effect (P=0.00).

## Responses regarding willingness and unwillingness to donate the cornea after death

#### Willingness to donate the cornea

Responses about willingness to donate corneas were investigated by asking participants to express their agreement with clear statement related to willingness. The data from the participants' responses were based on their level of agreement with each statement represented in 5-point Likert scale (from 1: strongly disagree to 5: strongly agree).

Most of the willing participants agree and strongly agree that corneal donation is a gift of vision and that it should be promoted

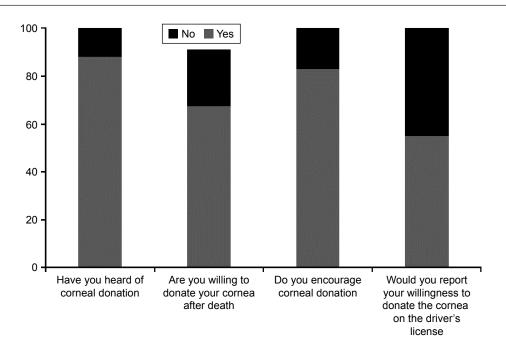


Figure I Awareness and general attitude toward corneal donation among the study participants.

worldwide. Religious beliefs that the life of a person belongs to God and not to the person's family were agreed upon by the majority of willing participants. Although many participants thought that the family of the deceased should be financially reimbursed to promote donation, an equal percentage (26.6%) disagreed on this argument. Table 3 summarizes participants' responses regarding willingness to corneal donation.

### Unwillingness to donate the cornea

Responses regarding unwillingness to donate the cornea were also reported by the participants (Table 4). This table shows that religious issues do not appear to prevent the person from donating the cornea as most of the participants disagree that corneal donation contradicts with religion and also that the person has to be religious to donate the cornea. The two most common

Demographics Willingness to donate cornea after death						
	Willingness to donate, N (%)	Unwillingness to donate, N (%)	P-value			
Total	336 (67.2)	159 (32.8)				
Age (years)			0.316			
18–29	195 (72.5)	74 (27.5)				
30–50	120 (64.5)	66 (35.5)				
>50	21 (52.5)	19 (47.5)				
Gender			0.363			
Male	142 (65.4)	75 (34.6)				
Female	194 (69.8)	84 (30.5)				
Education			0.000			
Elementary	18 (41.9)	25 (58.1)				
High school	76 (56.3)	59 (43.7)				
Bachelors	220 (75.9)	70 (24.1)				
Graduate degree	22 (81.5)	5 (18.5)				
Income (JOD)			0.438			
<500	174 (64.9)	94 (35.1)				
500-1,000	122 (69.3)	54 (30.7)				
>1,000	40 (78.4)	(21.6)				

**Table 2** Characteristics of participants willing to donate their corneas and the influence of study variables (age, gender, level of education, and income) on willingness toward corneal donation

Abbreviation: |OD, |ordanian Dinar.

Reasons for willingness to donate the cornea	Strongly agree, N (%)	Agree, N (%)	Neutral, N (%)	Disagree, N (%)	Strongly disagree, N (%)
Corneal donation is considered to be a gift of vision, ie, help someone to see again	171 (50.4)	149 (44.0)	8 (2.4)	8 (2.4)	3 (0.9)
Organ donation should be promoted in all countries around the world	176 (52.2)	136 (40.4)	22 (6.5)	I (0.3)	2 (0.6)
The benefits of corneal donation outweigh the risk	82 (24.3)	133 (39.3)	102 (30.2)	17 (5.0)	4 (1.2)
Organ donation can be promoted by "presumed consent" method <sup>a</sup>	58 (17.2)	100 (29.6)	93 (27.5)	59 (17.5)	28 (8.3)
Organ donation can be promoted by objective appreciation (financial support) to the family of the deceased	48 (14.2)	94 (27.8)	54 (16.0)	90 (26.6)	52 (15.4)
The life of a person belongs to God and not to his/ her family	138 (40.8)	140 (41.4)	46 (13.6)	(3.3)	3 (0.9)

Table 3 Participants' responses regarding willingness to donate the cornea

Note: <sup>a</sup>Presumed consent means that the consent for organ donation will be assumed unless the deceased has expressed a wish in life not to be an organ donor.

reasons for unwillingness to donate were the thought that the cadaver will be treated badly and the fear of other organs being taken than the one specified for donation. Around 77 participants addressed the lack of awareness of corneal donation as a reason for their unwillingness to donate the cornea and many reported conflict of interest, ie, fear of not treating the ill person well for another person to live or see in the case of corneal donation.

### **Discussion** Awareness and attitudes regarding corneal donation

Corneal blindness is considered the fourth cause for visual impairment and blindness in Jordan, with corneal transplantation through corneal donation remaining the main treatment for such cases.<sup>4</sup> The current study showed a good level of awareness and knowledge about corneal donation among the studied population. Similar to our findings, high level of public awareness of corneal donation was also reported in many studies around the world.<sup>17,18,21,27</sup>

It has been reported widely that the demand on healthy corneas exceeds the actual supply of donated corneas.<sup>28</sup> Likewise, there is also a lack of corneal supply in Jordan as the Director of Jordan Eye Bank has reported, with local corneal donation increasing to meet 65% of transplant needs in the Kingdom.<sup>29</sup> The low supply of donated corneas is mainly attributed to person's attitude toward corneal donation, which is mainly affected by ethical, religious, and social issues and suggested to be influenced by lack of public awareness of eye donation and its benefits.<sup>17–19,21,25–27</sup>

The current study reported that 67.2% of subjects expressed willingness to donate their corneas and the majority of the participants (82.8%) encouraged others for corneal

Table 4 Participants'	responses	regarding	unwillingness	to	donate the cornea
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Reasons for unwillingness to donate the cornea	Strongly agree, N (%)	Agree, N (%)	Neutral, N (%)	Disagree, N (%)	Strongly disagree, N (%)
Organ transplantation contradicts with religions	7 (1.4)	12 (2.4)	46 (9.2)	43 (8.6)	54 (10.8)
It is important to be religious to donate your cornea	2 (1.2)	11 (6.8)	24 (14.8)	65 (40.1)	60 (37.0)
The cadaver will be mutilated and treated badly	29 (17.9)	76 (46.9)	27 (16.7)	15 (9.3)	15 (9.3)
Fear of other organs being taken than the one(s) specified for donation	40 (24.8)	69 (42.9)	20 (12.4)	17 (10.6)	15 (9.3)
Fear of misallocation of the donated organ <sup>a</sup>	34 (21.3)	51 (31.9)	32 (20.0)	26 (16.3)	17 (10.6)
Fear of not treating the donor the maximum if they know he/she is a donor	25 (15.5)	67 (41.6)	31 (19.3)	28 (17.4)	10 (6.2)
Fear that the religion does not approve organ donation	12 (7.5)	51 (31.7)	42 (26.1)	27 (16.8)	29 (18.0)
Lack of awareness of benefits of donation	11 (6.8)	67 (41.4)	42 (25.9)	34 (21.0)	8 (4.9)
Fear of talking about death and the sanctity of human body	14 (8.6)	60 (37.0)	36 (22.2)	35 (21.6)	17 (10.5)
Existence of conflicts of interests <sup>b</sup>	18 (10.6)	72 (44.4)	36 (22.2)	19 (11.7)	17 (10.5)

Notes: Misallocation means to give the organ to recipients who do not deserve it as much, ie, based on their money, social status, position in the society, or their political connections. Conflict of interests means to kill a person and not treating him/her well for another person to live.

donation. This number falls within the range presented for other populations (41.5%–85%).<sup>27,30–32</sup> Demographic factors, such as the age of participants, gender, and monthly income did not appear to influence the subjects' willingness to donate their corneas after death. This finding agrees with that reported by Tandon et al,<sup>32</sup> who found that the socioeconomic status and monthly income did not influence the willingness to donate the cornea. Similar finding was reported by Yew et al,<sup>22</sup> who reported that only religion and ethnicity influenced the willingness to donate corneas but not gender or age of the participants. This may emphasize on the results reported by McGlade et al that willingness to donate corneas is mainly related to the person's attitude and subjective norms rather than economic or sociodemographic status of the participants.<sup>33</sup>

The current study showed that the level of education was a predictor of awareness and willingness for corneal donation. This is in agreement with a study by Patil et al, who found that the level of awareness among illiterates was significantly lower compared with those who completed higher education.<sup>26</sup> It is obvious in this regard that knowledge is associated with the level of education the person has achieved. Although Jordan is considered a developing country, it has crossed a milestone in the education sector and efforts have been made to increase the level of public access to schools. This is beneficial in terms of increasing the general awareness of the population regarding health issues associated with organ donation.

# Factors influencing the willingness of participants toward corneal donation

In this study, more than half of the participants (67.2%) were willing to donate their corneas after death. Corneal donation was considered as a "gift of sight" by all the willing participants. The motive for corneal donation was being a good person and doing good deeds. On the contrary, 22.8% of the participants were unwilling to donate their corneas after death. This finding appeared to be related to some ethical, religious, and social factors, which influenced their decision regarding corneal donation.

### Ethical issues related to corneal donation

Several ethical issues were agreed upon among participants. The most commonly cited reason for unwillingness to donate is the fear of treating the cadaver badly. This reason was followed by fear of other organs being taken other than the one specified for donation. The third reason was "misallocation" of the donated organ. That is, to prioritize people with high socioeconomic status or to people who do not deserve the transplant, ie, their medical case is not urgent for transplantation. In other words, the term "favorism" may decide who takes the organ and who does not. This is reflected by the fear of participants to donate their organs and corneas in particular. These issues can be solved by a set of guidelines under the supervision of a team of medical practitioners who can decide the suitability of candidates assigned for transplantation. Therefore, increasing professional performance in hospitals is very important to gaining trust inside and outside the hospital and improving corneal and organ donation rate.<sup>34,35</sup>

## Religious and social issues related to corneal donation

This work has highlighted the knowledge of participants about the relationship between the process of organ donation and religion. It appeared that most of the participants disagreed that organ donation and transplantation contradict with religion, and that the person has to be religious in order to donate. Participants believed that all religions including Islam, Christianity, and Judaism encourage helping and caring for others. Therefore, donating a cornea to a blind person would help that person to see again and live his/ her life normally. In a study by Ali et al,<sup>36</sup> a significant correlation was reported between the participants' attitude to donate and their knowledge that it is allowed and supported by religion. In Saudi Arabia, the main and strongest influence for organ donation reported by general population was that Islam supported the concept of transplantation through helping others.<sup>37</sup> Other religions such as Christianity and Judaism also supported organ donation, and Christianity, eg, was reported to be have a positive influence toward organ or corneal donation.<sup>38</sup>

Although not stated clearly in this work, being a member of a family affected the person's actions. The person may have the will to donate but the influence of the parents on the person's decision is beyond his will. Objection by the family was one of the reasons the participants cited for unwillingness to donate in other reports.<sup>27</sup> This is a very important issue especially in Arab countries such as Jordan where family ties are very strong and the adults obey, consult, and usually agree to what their parents say or decide even when they are above 18 years old. The other argument is concerned with females, who in some cultures inside Jordan are still dominated by their parents or older males in their household. Therefore, their decision to donate the cornea could be influenced by their families. However, many participants (40.8%) agreed that the body belongs to God not to the family and this is why they were willing to donate their corneas. This may indicate the person's autonomy regarding this issue.

Lawlor and Kerridge<sup>39</sup> suggested another social perspective regarding corneal donation. The authors reported that families of the deceased agreed to donate internal organs but not the external ones that are apparent like the eyes. The reason behind their refusal was mostly due to superficial disfigurement of the dead, ie, disruption of beauty and loss of person identity. The same authors reported that of all body parts, the eyes represent a social interaction among people and this may explain the lower rate of eye donation compared with other organs, eg, kidney, liver, or heart, and the lack of adequate corneal donation to meet the demand.<sup>40</sup>

Basic knowledge of corneal donation and its benefits appeared to have a significant influence in the person's willingness for corneal donation.<sup>21,41</sup> This was also confirmed by Ackuaku-Dogbe and Abaidoo,<sup>42</sup> who reported that the main attributor to corneal donation was the awareness and knowledge of the procedure and its benefits.

#### Conclusion

To the best of our knowledge, this study is the first study to address attitudes toward corneal donation in Jordan. The study showed that participants demonstrated high level of awareness about corneal donation and most of them were willing to donate their corneas. The main reason for willingness was doing a good deed by helping others. Whereas fear of the body being treated badly was the main reason for unwillingness to donate, the main source of knowledge about corneal donation reported was the media and healthcare personnel and higher levels of education. This study emphasized on the need to implement public educational programs to increase the awareness of corneal donation and to encourage official registration of willing donors. Thereby, this may reduce the misconception related to corneal donation and increase the supply of local donor tissues.

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#### Disclosure

The authors report no conflicts of interest in this work.

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