

# Attitude of the Saudi community towards heart donation, transplantation, and artificial hearts

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## ABSTRACT

**الأهداف:** لفهم موقف السكان السعوديين نحو التبرع بالقلب والزراعة.

**الطريقة:** أجري استبيان باستخدام استبيان يتناول المواقف تجاه زرع الأعضاء والتبرع في 18 مدينة في المملكة العربية السعودية خلال الفترة من سبتمبر 2015م حتى مارس 2016م.

**النتائج:** اشتمل الاستطلاع على مجموعة 1250 مشاركة. من هؤلاء، حوالي 91% يتفقون مع مفهوم زرع الأعضاء ولكن حوالي 17% لا يتفقون مع مفهوم زرع القلب. ويرفض 42.4% عمليات زراعة القلب لأسباب دينية. وأعرب 43.6% فقط من المستطلعين عن استعدادهم للتبرع بقلبيهم وحوالي 58% سيوافقون على التبرع بأحد أقاربه بعد الوفاة. ما مجموعه 59.7% من المستطلعين يعتقدون أن التبرع بالأعضاء منظم و 31.8% يخشون أن الأطباء لن يحاولوا بما فيه الكفاية لإنقاذ حياتهم إذا وافقوا على التبرع بالأعضاء. حوالي 77% يعتقدون أن القلب يزيل بينما المتبرع على قيد الحياة؛ على الرغم من أن نفس النسبة من المستطلعين يعتقدون أنهم يعرفون ما يعني الموت في الدماغ.

**الخاتمة:** وبصفة عامة، يبدو أن السكان السعوديين يقبلون مفهوم الزرع، وهم على استعداد للتبرع، ولكنهم ما زالوا يحتفظون ببعض التحفظات تجاه التبرع بالقلب.

**Objectives:** To understand the attitudes of the Saudi population towards heart donation and transplantation.

**Methods:** A survey using a questionnaire addressing attitudes towards organ transplantation and donation was conducted across 18 cities in Saudi Arabia between September 2015 and March 2016.

**Results:** A total of 1250 respondents participated in the survey. Of these, approximately 91% agree with the concept of organ transplantation but approximately 17% do not agree with the concept of heart transplantation; 42.4% of whom reject heart

transplants for religious reasons. Only 43.6% of respondents expressed a willingness to donate their heart and approximately 58% would consent to the donation of a relative's organ after death. A total of 59.7% of respondents believe that organ donation is regulated and 31.8% fear that the doctors will not try hard enough to save their lives if they consent to organ donation. Approximately 77% believe the heart is removed while the donor is alive; although, the same proportion of respondents thought they knew what brain death meant.

**Conclusion:** In general, the Saudi population seem to accept the concept of transplantation and are willing to donate, but still hold some reservations towards heart donation.

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The prevalence of heart failure in developed countries ranges from 1% to 2%, rising to  $\geq 10\%$  among those aged  $>70$  years.<sup>1</sup> The increasing survival and the lack of decline in the incidence of patients with heart failure only contributes to the heart failure (HF) epidemic.<sup>2</sup> Patients with HF carry a poor prognosis, with survival estimates post HF diagnosis of only 50% and 10% at 5 and 10 years.<sup>3</sup> Advanced HF accounts for 6-25% of all patients with HF, and is associated with significant costs and resource consumption, secondly foremost to recurrent hospitalizations.<sup>4</sup> The only viable treatment option for these patients are

assist devices and heart transplantation, the latter of which is standard therapy. Although transplantations offer promising prognosis to recipients, in the last decade heart transplantation has stagnated owing to an increasing demand and a lack of donors. This has fueled interest into the use of ventricular assist devices as a bridge to transplantation or, in selected cases, as a destination therapy. In the last half-century, advances in antibiotics and immunotherapy have been met by an increase in median survival post transplantation from 11-18 days to 11 years.<sup>5</sup> The current concern in heart transplantation now relates to attempting to better match market supply with the ever-growing demand for heart transplantation. The fact that the number of donor hearts available in the US has remained between 2000 and 2700 for the last 15 years, with over 4000 patients on the waiting list, perfectly emphasizes this point.<sup>5</sup> In Saudi Arabia, only 2 cardiac centers perform a total of approximately 30 heart transplantations per year.<sup>6</sup> Data pertaining to requirements for heart transplantation are lacking; however, by extrapolating from US data,<sup>5</sup> we estimate that  $\geq 400$  persons per year require heart transplantation, resulting in over 90% of patients in need of this lifesaving treatment. This lack of supply is likely due to the low rate of donation and shortages in organ donor utilization. Until recently, no study has specifically addressed the need for heart transplantation in Saudi Arabia. Here, we sought to understand the attitudes and willingness of the Saudi populations towards heart donation and transplantation to identify areas that may help bridge the gap between demand and availability of donor hearts.

**Methods.** A survey was conducted involving 1298 individuals in 18 cities across Saudi Arabia (Table 1) using a questionnaire to assess the attitudes towards transplantation and donation. For quality control, the questionnaire was piloted and reviewed by experts in the field of medicine and research prior to study onset. The study was conducted at schools, shopping malls, social events, and family gatherings between September 2015 and March 2016. Participants had to be mentally fit Saudi nationals above 18 years of age. Medical and pharmacy students were trained to coherently ask 32 questions and to note down the 'yes' or 'no' responses. Forty-eight questionnaires were excluded from analysis due to incomplete data.

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**Statistics analysis.** Categorical variables were summarized as numbers and percentages, and numeric data were summarized by mean and standard deviations (SD) or by medians and interquartile range (IQR). Chi-square test or Fisher's exact test was used to determine the association between survey questions and demographic variables. All analyses were performed using SAS/STAT software, version 9.2 (SAS Institute Inc., Cary, NC, USA). A 2-sided  $p$ -value  $< 0.05$  was considered statistically significant.

**Results.** Details pertaining to the respondent demographics are summarized in Table 2. Respondents' perspectives on organ transplantation and donation are summarized in Table 3. Approximately 91% of respondents agree with the concept of all organ transplantation regardless of organ type (with no specification) and that transplantation is a humane treatment that ultimately saves lives. Approximately 17% of respondents do not agree with the concept of heart transplantation, 42.4% of whom rejected it for religious reasons. More than 81% of respondents are willing to donate an organ to a relative, while only 42.5% are willing to donate to a non-relative. However, the proportion of those willing to donate to a non-relative after their own death rises to 70.5%, but only 43.6% are willing to donate a heart. Approximately 58% of respondents would consent to the donation of a relative's organ after death. Of all survey respondents, only 59.7% believe that organ donation is regulated and 31.8% fear that the doctors will not try hard enough to save their lives if they consent to organ donation. Approximately 77% believe the heart is removed while the donor is alive; although, it should be noted that the same proportion of respondents thought they

**Table 1 -** Number of respondents according to cities and regions. A total number of 1250 respondents across 7 regions and 18 cities participated in the survey.

Region	Cities included	Number of respondents (%)
Riyadh Region	Riyadh, Aflaj, Afif	453 (36)
Makkah Region	Makkah, Jeddah, Taif	349 (28)
Southern Region	Abha, Baha	122 (10)
Eastern Region	Dammam, Ahsa, Khafji	115 (9)
Qassim and Hail Region	Buraidah, Onaiza, Bukairiya, Hail	99 (8)
Madina Region	Medina, Yanbu	62 (5)
Tabuk Region	Tabuk	50 (4)

**Table 2** - Demographics characteristics of 1250 respondents.

Demographics	n (%)
Male	620 (49.6)
Female	630 (50.4)
Married	757 (60.6)
<i>Age, years</i>	
Mean $\pm$ IQR15	31.5 $\pm$ 10.5
Range	18-75
<30 years, %	56.4
30-50 years, %	37.6
>50 years, %	6
IQR - interquartile range	

knew what brain death meant. When given the choice between artificial hearts and heart transplantation, a similar proportion of patients preferred a transplant for themselves and for a family member (87% and 90%).

There was a clear difference in response according to age. Those aged above 50 years were less likely to accept the concept of organ transplantation (77.5% versus 92.5% for those  $\leq$ 50 years of age;  $p<0.001$ ) and, specifically, heart transplantation (60.6% versus 3.6%;  $p<0.001$ ). These respondents were also less likely to donate to a relative while alive ( $>50$  years of age 57.1% versus  $\leq$ 50 years of age 82.8%;  $p<0.001$ ) or after death (62.0% versus 84.3%;  $p<0.001$ ). No differences were reported in the proportion of patients willing to donate to a non-relative or to donate a heart specifically, which was low across all age groups.

With regard to gender, a similar proportion of males and females accepted the concept of organ transplantation (90.2% versus 93.2%;  $p=0.052$ ), heart transplantation (84.4% versus 81%;  $p=0.2$ ), and organ donation to a relative (80.1% versus 82.3%;  $p=0.3$ ). However, compared with males, females were less accepting of organ donation to a non-relative (47.5% versus 36.9%;  $p<0.001$ ) and heart donation in general (47.5% versus 39.1%;  $p=0.003$ ).

The influence of education level was also assessed. A total of 381 of respondents (31%) had secondary school or lower education, while 853 (69%) had undergraduate or higher education. There was no difference between both groups in the acceptance of organ transplantation (lower education 90.3% versus higher education 92.1%;  $p=0.275$ ) or heart transplantation (lower education 79.95% versus higher education 83.6%;  $p=0.218$ ). There was no difference in the willingness to donate to a relative or non-relative during life or after death; however, there was a significantly lower willingness to donate a heart in the lower education group compared

with those with higher education (38.6% versus 45.6%;  $p=0.024$ ).

**Discussion.** Although the Saudi community accepts the concept of organ donation and are willing to donate, concerns remain on heart donation. Almost a third of respondents expressed a fear that healthcare professionals may make less effort to save the lives of potential donors. This perspective stems from the apparent lack of knowledge regarding both brain death and the state of the donor patient during organ removal, even though clear diagnostic criteria for brain death and policies pertaining to the management of deceased donors exist and are adhered to across Saudi Arabia.

According to 2015 data from the Saudi Center for Organ Transplantation (SCOT), only 30.4% of families to the 332 eligible DBD donors consented to organ donation,<sup>6</sup> a figure that is significantly lower than the 57.8% of survey respondents who would consent if in the same situation. This discrepancy could be due to the approach in questioning, the fact that there was no opportunity to provide graded responses or because the survey simply captures attitudes to hypothetical questions and not real life actions which would be strongly influenced by their emotional state.

A US 2012 National Survey of organ donation attitudes and behavior showed that 94.9% of adults supported organ donation.<sup>7</sup> Almost two-thirds of respondents (60.1%) were registered for donation on their driver's license, 24.2% were open to considering donation, and 15% were hesitant on the concept. A large proportion of family members stated they would consent to organ donation of a relative if they were aware of the relatives wishes, and to a lesser extent (but still considerably high) if unaware of the relatives wishes (96.7% versus 75.7%). These numbers demonstrate a much higher level of support and willingness to organ donation in the US compared with both the SCOT data and the Saudi respondents in our study.

A study in Belgium examined the attitudes to organ donation across 3 generations.<sup>8</sup> Overall, 80.2% of respondents were in favor of organ donation, 60% of whom were 'unconditionally positive', and the remaining 40% 'positive, with reservations'. Acceptance to organ donation decreased with increasing age: from 85.7% in young adults, to 82.6% among parents and 63.6% among grandparents. This pattern is consistent with results from our cohort and are expected because younger generations are perceived to be more open minded of new concepts.

A survey in Iran involving 93 teachers found that 86% favored organ donation, with 70% open to

**Table 3** - Respondent perspectives on organ transplantation and donation.

Question	Response	n	(%)
Do you think the concept of organ transplantation is acceptable?	Yes	1149	(91.5)
	No	107	(8.5)
If no, is it for religious reasons?	Yes	47	(44.8)
	No	57	(54.3)
Do you think organ transplantation is humane?	Yes	1205	(96.9)
	No	38	(3.1)
Do you think the concept of heart transplantation is acceptable?	Yes	1029	(82.6)
	No	216	(17.3)
If no, is it for religious reasons?	Yes	86	(42.4)
	No	117	(57.6)
Do you know someone who has had an organ transplantation?	Yes	568	(45.2)
	No	688	(54.7)
Do you know someone who has had a heart transplantation?	Yes	167	(13.3)
	No	1086	(86.6)
Do you know someone who is waiting for an organ transplant?	Yes	334	(26.7)
	No	917	(73.2)
Do you think organ donation saves lives?	Yes	1203	(96.1)
	No	49	(3.9)
Do you think organ donation is regulated?	Yes	731	(59.7)
	No	493	(40.3)
Do you have a heart problem?	Yes	83	(6.6)
	No	1164	(93.2)
Do you have a relative with a heart problem?	Yes	705	(56.5)
	No	543	(43.5)
Have you ever donated blood?	Yes	1138	(90.8)
	No	112	(8.9)
Would you donate an organ while alive to a relative?	Yes	1015	(81.2)
	No	234	(18.7)
Would you donate an organ to a non-relative whilst alive?	Yes	530	(42.5)
	No	718	(57.5)
Would you donate a heart?	Yes	543	(43.6)
	No	703	(56.4)
Would you donate an organ to relative after your death?	Yes	1045	(83.3)
	No	209	(16.7)
Would you donate an organ to a non-relative after your death?	Yes	883	(70.5)
	No	370	(29.5)
Would you consent to the organ donation of a relative whilst they are alive?	Yes	498	(40.1)
	No	744	(59.9)
Would you consent to the organ donation of a relative after his death?	Yes	721	(57.8)
	No	527	(42.2)
Do you think that doctors would try less to save your life if they are aware that you are a registered organ donor?	Yes	397	(31.8)
	No	851	(68.2)
Do you think that the body is treated respectfully by doctors and nurses after organ donation?	Yes	1016	(81.5)
	No	230	(18.5)
Would you donate money to support an organ transplantation?	Yes	1131	(90.3)
	No	122	(9.7)
Do you think the heart is taken from a person after their death?	Yes	274	(21.9)
	No	977	(78.0)
Do you think the heart is taken whilst the person is alive?	Yes	960	(76.7)
	No	292	(23.3)
Have you heard of brain death?	Yes	1167	(93.0)
	No	88	(7.0)
Do you know what brain death means?	Yes	951	(76.1)
	No	299	(23.9)
Have you heard of artificial hearts?	Yes	737	(58.8)
	No	515	(41.1)
If needed for yourself, would you prefer heart transplantation?	Yes	1090	(87.3)
	No	159	(12.7)
If needed for yourself, would you prefer an artificial heart?	Yes	361	(31.6)
	No	782	(68.4)
If needed for a family member, would you prefer heart transplantation?	Yes	1131	(90.5)
	No	118	(9.4)
If needed for a family member, would you prefer an artificial heart?	Yes	391	(34.2)
	No	750	(65.7)

donating their organs after death.<sup>9</sup> Little exposure to patients with chronic disease, lack of trust in organ donation networks, and diagnosis of brain death were associated with respondents who were less willing to donate an organ. The results reported herein and the lack of knowledge regarding brain death highlighted by our survey suggest that use of educational programs should be a primary consideration for any initiatives aimed at building trust in the organ donation system.

However, not all global data are as supportive of organ donation. A 2012 study in Greece showed that, despite knowledge of brain death, only 48.3% of respondents expressed a willingness to donate an organ, with only 3.8% registered as donors.<sup>10</sup> Over half of respondents were afraid of the procedure and would feel guilty about consenting to the organ donation of a relative. Respondents' profession or level of education had no influence on these attitudes, demonstrating that the negative perception of organ donation in this region may be deeper than poor education alone. The study also showed that women (odds ratio 1.95), people under 30 years of age (odds ratio 2.4), and parents (odds ratio 1.2) were more willing to donate. Similarly, data from our cohort showed that women had a greater willingness to donate a heart.

In 2013, the National Health Services Blood and Transplant reported the most common concern towards organ donation was a fear that hospital staff may not try their best to save lives if the patient is a registered donor.<sup>11</sup> This sentiment was echoed by 31.8% of respondents in our cohort.

Additional studies, specific to the population in Saudi Arabia, have also been conducted. One study showed that only half of 22 surveyed intensivists (across 4 hospitals in Riyadh) appreciated the high success rate of modern organ transplantation and a quarter were unaware of the role of SCOT.<sup>12</sup> They believed that the shortage of organs was secondary foremost to family refusal; a stance that is reflected in our cohort in which 42.2% of respondents admitted they would refuse to consent to the organ donation of a relative. The shortage in knowledge pertaining to the role of SCOT among intensivists highlights the need for education beyond the patient level. A separate study involving Saudi men showed that these individuals were even more unaware of SCOT, with 41.5% having never heard of its existence.<sup>13</sup> Although over 90% of these Saudi men understood the need for organ donation, only 42% would donate an organ after death. Almost a third feared that organ donation contradicted their religious beliefs, a notion that was just as pronounced in our survey (44.8% of respondents).

Several factors must be considered for future initiatives aimed at addressing the shortage in organ supply. Public awareness can be raised through traditional and social media campaigns. Implementing an opt-in or opt-out strategy at the time of obtaining national identification cards or drivers licenses should help boost the pool of available donors, and has proven effective in other countries.<sup>5</sup> An innovative national program in Spain has been met by a successful increase in the number of donor hearts, making it one of the world's leading nations for heart transplantations. The rate of heart transplantations in Spain has risen from 10 performed in 1984 to >230 performed per year since 1992.<sup>14</sup> Spain is the only country with a sustained increase in organ donation since 1990 and a rise from 550 organ donors in 1990 to 1546 in 2007.<sup>15</sup> This success has been attributed to optimizing processes for early identification of brain death, accurate referral of potential donors, use of hospital-based transplant coordinators to educate families on the importance of donation, a centralized single transplant waiting list, and implementation of quality assurance programs to monitor the patient's progress.<sup>15</sup> Adopting some of these approaches in our region will surely help improve current transplantation programs.

There is a clear shift in the attitudes of the Saudi community towards organ transplantation, with the younger generation seemingly more accepting of change and who are willing to donate an organ once given sufficient information and reassurance of the processes. Further awareness is needed to stress the importance of organ donation in the region, and the impact this has on the survival of patients with debilitating diseases. Emphasis should be placed on the concept of saving lives, which is recited in the Quran and is supported by the decree (Fatwa) of the Council of Senior Scholars (no. 99 dated 6/11/1402 A.H) granting permission for organ donation and transplantation.<sup>16</sup> Future efforts should be directed towards increasing public awareness by dispelling current misconceptions about the organ donation process.

**Study limitations.** The strength of our study is that it included several regions of the Kingdom of Saudi Arabia and a similar proportion of each gender. Although a wide range of age groups were involved, older age groups are not well represented which is a study limitation. This is the only study that specifically addresses the attitudes towards heart donation. The main limitation of our study is that data were collected using questionnaires requiring specific 'yes' and 'no' responses, and therefore fails to capture people actions.

In conclusion, with the growing burden of heart failure and advanced disease there is an increasing need for heart transplants and donation. The Saudi community accepts the concept of transplantation and are generally willing to donate; however, many still have some reservation towards heart donation. More effort is required to dispel current misconceptions, increase the awareness, and work with regulators to identify their role and expand the pool of donors in Saudi Arabia. Aligning these initiatives with current policies will help increase heart donation rates and curb the growing gap between supply and demand.

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