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ORIGINAL ARTICLE

Changes in consent rate, expressed deceased donation decision-making, and family interactions in Israel—a national retrospective cohort study

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SUMMARY

This study aimed to compare the consent rate for deceased organ donation in Israel over two time periods, namely 2004–2009 (2004/9) and 2016–July 2020 (2016/20). Donor and family data were collected from the Israel National Transplantation Center Registry and included donor characteristics, reasons for family consent and refusal, and a subjective assessment of donor coordinator–family interactions. The consent rate increased from 41.6% over the period 2004/9 to 61.8% for the period 2016/20 ($P < 0.0001$). A significant increase in the proportion of Jewish donors was noted (49.8% in 2004/9 vs. 67.5% in 2016/20, $P < 0.0001$), while no increase in the consent rate for the Muslim population was noted. Religious objections as a reason for refusal decreased significantly (37.6% vs. 27.3%; $P = 0.02$), while the proportion of families citing donating as the "right thing to do" increased significantly (7% vs. 26.6%; $P < 0.0001$). Finally, a significant increase in the proportion of very positive DC–family interactions (59% to 78.3%, $P < 0.0001$) was noted. In conclusion, the increased consent rate in 2016/20 was associated with changes in expressed decision-making and donor coordinator–donor family interactions. Additional interventions tailored to all different populations groups need to be developed and further investigated.

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consent rate, deceased organ donation, family interactions, religious beliefs

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Introduction

Organ donation remains the best, and often only, treatment for many patients with end-stage organ failure. However, the gap between those awaiting a transplant and the number of organs available continues to increase, with many patients dying on waiting lists. This gap is expected to increase because of the reported increases in donor age and changes in the causes of brain death (less traumatic brain injury) [1,2]. It is thus essential that every effort be made to optimize the donation process.

The consent rate is the most significant factor limiting the conversion of identified, potential donors to becoming actual donors. Important factors which appear to influence the consent rate include societal beliefs and attitudes regarding organ donation and the family approach, in particular the timing, sensitivity of the requestor, as well as the ability to identify and relate to obstacles raised by a potential donor family [3,4].

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In Israel, which has an opt-in system of organ donation requiring informed consent by the next of kin, a survey covering the period 2004 to 2009 was performed of brain dead/neurologically determined dead (BD/NDD) organ donors and their donor families, including demographic data, the consent rate, reasons for agreeing to or refusing donation, and the quality of interactions with donor coordinators (DCs). The survey demonstrated a consent rate of 46.4%, which is significantly lower when compared with that in many Western countries.

A repeat survey covering the period 2016–July 2020 was recently completed. In the present study, we report on the results thereof, including changes in the consent rate, with particular reference to expressed deceased donation decision-making and the quality of DC–donor family interactions.

Patients and methods

This is a national retrospective cohort study. All potential donors and families approached for organ donation during the two study periods, namely 2004–2009 (2004/9) and 2016–July 2020 (2016/20) inclusive, were included. Data were collected from the Israel National Transplantation Center Registry. As this study did not involve patient identifiable information, the study was deemed exempt by the Institutional Review Board of the Ministry of Health.

Data collection

National-level data collected included the yearly deceased donor consent rate, the percent of Israeli Jews and Muslims on the national transplant waiting list as at the end of 2020, and the percent who underwent transplantation over the period 2018–2020. Donor-level data collected included gender, age at time of death, and population group (Jewish, Muslim, Christian, Druze, or other). Donor family-level data were obtained from those family members actively engaged in decision-making for consenting or refusing organ donation. DCs are required to record the reasons for consenting or refusing from a list derived from local experience with donor families and which includes those most frequently cited in the literature [5,6]. Reasons for consent included saving lives, the right thing to do, leaving a remembrance, fulfilling the will of the deceased, close connection with hospital staff, and close personal connection with organ donation (family member had donated or received an organ). Reasons for refusal included maintaining the integrity of the body, religious beliefs, fulfilling the will of the deceased, preventing unnecessary continued suffering of the deceased, lack of understanding or acceptance of the concept of BD/NDD, and dissatisfaction with hospital staff and/or the donation process. DC-level data collected included a subjective assessment regarding the quality of the interaction between the DC and donor families, which was graded as none/poor/superficial, good, or very good.

Statistical analysis

Differences between the two time periods were calculated with the z-ratio for the significance of the difference between two independent proportions. The significance level was set at <0.05. Data were analyzed using SPSS 25 (IBM, Armonk, NY, USA).

Results

National-level data

A total of 754 potential donors were identified in 2004/9 and 699 in 2016/20 (Table 1). This reflects a 15% increase in the number of total reported deceased donors (P = NS). No significant differences between the two periods were noted regarding donor gender, age or proportion of Israeli Jews or Muslims, the latter also reflecting their distribution in the general Israeli public, i.e., 74.2% and 20.9%, respectively. Regarding the national transplant waiting list, as at the end of 2020, 63% of potential recipients are Israeli Jews and 23.8% Israeli Muslims. Regarding the rate of transplantation between the years 2018 to 2020, 58.5% receiving any organ were Israeli Jews, while 22.4% were Israeli Muslims. The remaining individuals on the transplant list

Table 1. Demographic characteristics of total donors for the two study periods.

Parameter	2016–2020	2004–2009	*P* value
Total number	699	754	
Male, *n* (%)	426 (60.9)	448 (61.5)	0.55
Mean age, years	49.3	48.3	0.52
Religion			
Total number with data	562	707	
Jewish, *n* (%)	425 (75.6)	520 (73.5)	0.40
Muslim, *n* (%)	114 (20.3)	120 (16.9)	0.13
Christian, *n* (%)	19 (3.4)	63 (8.9)	0.0006
Druze, *n* (%)	4 (0.7)	4 (0.05)	

and those who underwent transplantation are Israeli citizens who have neither an ethnic nor religious classification and include those with Jewish ancestry deemed non-Jewish by religious law (mainly recent immigrants from the former USSR), Christian non-Arabs and Muslim non-Arabs.

Characteristics of consented donors

The consent rate increased significantly from a mean of 46.4% in the 2004/9 period to 61.8% in the 2016/20 period ($P < 0.0001$; Table 2). No significant differences were noted regarding donor gender or age between the two time periods. The proportion of Israeli Jewish donors for whom consent was obtained increased from 49.8% in 2004/9 to 67.5% in 2016/20 ($P < 0.0001$), while no significant change in the consent rate was noted for the other groups, particularly among the Israeli Muslim population.

Reasons for consent

The commonest reason in both periods was related to "saving lives," although this decreased significantly over the two periods (64% in 2004/9 vs. 38% in 2016/20, $P < 0.0001$), while the reason "the right thing to do" increased significantly (7% in 2004/9 vs. 26.6% in 2016/20; $P < 0.0001$) (Table 3). In addition, the reason "leaving a remembrance" showed a significant increase from 10% in 2004/9 vs. 14.4% in 2016/20 ($P = 0.02$). The only difference between Israeli Jews and Muslims regarding reasons for consent in the period 2004/9 was related to "fulfilling a wish," which was more prevalent among Israeli Jews (18% vs. 1%, resp.; $P = 0.01$). No significant differences were noted between the two groups in the period 2016/20.

Table 2. Characteristics of donors for whom consent was received.

Parameter	2016–2020	2004–2009	*P* value
Total consented, *n* (%)	432 (61.8)	350 (46.4)	<0.00001
Male, *n* (%)	265 (62.2)	219 (62.5)	0.73
Age, years	49.8	48.9	0.70
Religion, *n* (%)			
Jewish	287/425 (67.5)	256/520 (49.8)	<0.00001
Muslim	31/114 (27.2)	24/120 (20)	0.19
Christian	16/19 (84.2)	45/63 (71.4)	0.26
Druze	1/4 (25)	2/4 (50)	

Reasons for refusal

The commonest reason in both periods was related to maintaining the integrity of the body, and this was not significantly different over the two study periods (41.9% in 2004/9 vs. 44.4% in 2016/20; $P = 0.46$) (Table 4). Refusal on the grounds of religious beliefs decreased significantly in the latter period (37.6% in 2004/9 vs. 27.3% in 2016/20; $P = 0.02$). Although the numbers are small, there was a significant increase in the proportion refusing donation on the grounds of preventing unnecessary continued suffering of the deceased (4.3% in 2004/9 vs. 5.2% in 2016/20, $P = 0.04$). The significant differences between Israeli Muslims and Jews regarding reasons for refusal were related to (i) objection on religious grounds, which was significantly more prevalent among Israeli Muslims in both study periods (47% vs. 33%, resp. in 2004/9; $P = 0.05$ and 40% vs. 25%, resp. in 2016/20; $P = 0.01$); and (ii) the reported will of the deceased, which was more common among Israeli Jews in both periods (12% vs. 1%, resp. in 2004/9; $P = 0.003$ and 18% vs. 8%, resp. in 2016/20; $P = 0.02$).

Donor family–donor coordinator interactions

Regarding DC assessment of the interactions with donor families for the total group (consenting and refusing

Table 3. Donor family members reasons for consenting to organ donation.*

Reason	2016–2020	2004–2009	*P* value
Number providing reason	525	533	
Saving lives, *n* (%)	199 (38%)	341 (64%)	<0.00001
The right thing to do, *n* (%)	140 (26.6%)	37 (7%)	<0.00001
Leave remembrance, *n* (%)	76 (14.4%)	53 (10%)	0.02
Fulfilling a wish, *n* (%)	76 (14.4%)	80 (15%)	0.81
Previous connection with organ donation, *n* (%)	18 (3.4%)	11 (2%)	0.17
Close connection with hospital staff, *n* (%)	16 (3.0%)	5 (1%)	0.01

*More than one reason could be given by all family members actively engaged in decision-making.

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Table 4. Donor family members reasons for refusing organ donation.*

Reason	2016–2020	2004–2009	*P* value
Number providing reason	161	393	
Maintaining the integrity of the body, *n* (%)	71 (44.4%)	165 (41.9%)	0.64
Religious beliefs, *n* (%)	44 (27.3%)	148 (37.6%)	0.02
Wish of departed, *n* (%)	24 (15%)	38 (9.6%)	0.07
Preventing continued suffering of the deceased, *n* (%)	14 (5.2%)	17 (4.3%)	0.04
Lack of understanding of BD/NDD, *n* (%)	6 (3.7%)	21 (5.3%)	0.42
Dissatisfaction with staff, *n* (%)	2 (1.2%)	4 (1.0%)	-

*More than one reason could be given by all family members actively engaged in decision-making.

families), an assessment of "none/poor/superficial" and "good" interactions showed a significant decrease from 2004/9 to 2016/20 (10% vs. 4%, $P < 0.0001$ and 24% vs. 17.7%, $P = 0.0002$, respectively), while an assessment for "very good" increased from 59% to 78.3% over the same periods ($P < 0.0001$). Regarding consenting families only, an assessment of "very good" showed a significant increase from 76% in 2004/9 to 87% in 2016/20 ($P = 0.0002$), which was associated with a trend for a decrease in the "none/poor/superficial assessment" (4% in 2004/9 vs. 2% in 2016/20, $P = 0.07$) and a significant decrease in the "good" assessment (19% in 2004/9 vs. 11% in 2016/20, $P = 0.0002$).

Discussion

The present study revealed a significant increase in the consent rate for deceased organ donation between the two study periods, which was associated with a significant increase in the number of Israeli Jewish donors. The most recent survey also demonstrated a significant decrease in donor families citing religious beliefs as a reason for refusal and more donor families citing donation as the right thing to do, suggesting a possible change in deceased donation decision-making in Israel. Finally, DCs reported significantly better donor–family interactions.

Donor audits of deaths in Israel consistently demonstrated consent rates for donation after BD/NDD well below those in many other countries. To assess factors affecting decision-making in organ donation, a representative survey of the Israeli population was performed in 2001 and found that the commonest reason for refusal was related to religious objections [7]. Religion plays an important role in the lives of the Israeli population. Thus, 39 percent of Israeli Jews report observing all or most Jewish religious laws and customs and are guided by the advice of their religious Orthodox leaders in every aspect of their daily lives. In addition, in times of severe stress, such as may occur following a BD/NDD declaration, many traditional Israeli Jews also seek reassurance from their religious leaders that their decisions are compatible with their belief system. For many years, religious parties in Israel opposed recognizing BD/NDD and dissuaded the public from donating organs until further requirements were met. These reservations were addressed by the Brain-Respiratory Death Determination Law which was passed by the Israeli parliament in 2008 following prolonged discussions between representatives of the medical community and the Chief Rabbinate, and implemented in 2009 [8]. The changes made to the new Law, which have previously been described [9], led the Council of the Chief Rabbinate to formally accept BD/NDD as an indication of death for all legal and religious purposes, removing Jewish-legal barriers for organ donation. This was followed by a national public relations campaign, including publication of the Law on the internet where the changes made to the BD/NDD declaration were detailed and the support of the Chief Rabbinate emphasized. The passing of the Law also led elements of the Orthodox community to express their unequivocal support to promote organ donation in their local communities and synagogues, as well as in the mainstream media. This was considered particularly important as local religious authorities are typically respected and most trusted within their own communities. The present study suggests that these initiatives may have a resulted in a possible change in decision-making, in that a significant decrease in the proportion of donor family members citing religious grounds as a reason for refusal was noted over the two study periods, from 38% to 27% ($P = 0.02$). This was associated with an increase in the proportion of Jewish donors, from 49.8% to 67.5% ($P < 0.0001$), which accounted for the change in the total consent rate. It should be stated that despite the initiatives mentioned above, there remain spiritual leaders within the ultra-Orthodox communities who are totally opposed to the

concept of BD/NDD so that their followers will not consent to organ donation.

A corresponding change in the consent rate among the Israeli Muslim population, 68% percent of whom say religion holds a particularly important place in their lives, was not evident and remained low over the two study periods (20% and 27.2% in 2004/9 and 2016/20, respectively; $P = 0.384$). Similar low rates of consent have been reported among ethnic minority families in the UK, namely 33%, compared with 61% among white donors [10]. In this regard, a recent review on the Islamic perspective on organ donation and transplantation reported that Muslims from a number of countries, including Spain, Poland, South Africa, the UK, and the USA, were more reluctant to donate their organs compared with adherents of other faiths [11]. The authors identified religious obstacles as being a central consideration in Muslim decision-making. This was also evident in our study where refusal on religious grounds was significantly more prevalent among Israeli Muslims than Jews and did not change significantly over the two study periods. An important role for religious leaders in fostering positive attitudes toward organ donation among the Muslim population has been suggested [11]. It is therefore clear that in Israel increased engagement with the local Muslim community is essential and that additional and appropriate culture and religion-specific interventions and reinforcement by leading Imams need to be implemented.

Regarding societal attitudes and decision-making, the most recent survey showed a significant increase in the proportion reporting organ donation being the "right thing to do." In this regard, the recent yearly campaigns of the National Transplantation Center have placed particular emphasis on consenting to organ donation being normative social behavior. Another factor possibly impacting societal attitudes is related to a clause of the Organ Transplantation Law of 2008 which granted prioritization in organ allocation to candidates who have either been registered as organ donors for at least 3 years prior to being listed as candidates or have given their consent for actual organ donation of their deceased next of kin or have been nondesignated living kidney or liver-lobe donors [12]. The impact of this clause was associated with a preliminary increase in signees to the national registry. It was interesting to note that most families were willing to share the reason for consenting to donation with the DC, while far fewer were forthcoming regarding the reason for refusal. This too may reflect a developing positive social climate for donation where refusal to donate might be perceived as less acceptable.

The decision to consent to organ donation may also be influenced, or even altered, at the time of the family approach. In Israel, DCs, who are trained and overseen by the National Transplantation Center, are present in all hospitals. The DCs, who accompany donor families from the time of potential donor identification, are charged with the identification of potential organ donors, ensuring their optimal medical management and the family approach. The latter is made following the BD/NDD declaration, usually together with dedicated organ donation physicians, who are present in all Israeli intensive care units. Their ongoing training is provided by the National Transplantation Center regarding all aspects of the donation process with particular emphasis on the family approach. In 2014, many newly appointed DCs expressed concerns regarding approaching potential donor families in particular situations. These included families who had perceptions of their loved one having received poor hospital care, families with divergent views regarding organ donation and families with strong religious beliefs against organ donation. In response to this, a simulation-based training program was introduced in 2014, an intervention which has been associated with significant increases in consent rates [13]. The training consisted of day-long interactive group workshops, overseen by the principal investigator (T.A.). Professional actors played family members in simulated clinical settings which were devised by the authors (T.A. and J.C) with special emphasis on those situations previously identified as causing uncertainties and dilemmas. This was followed by video-assisted feedback where DCs received personalized suggestions regarding appropriate responses to the scenarios. These videos and the lessons learned continue to be shown and referred to in the DC ongoing training program. Since the commonest reason for refusal in Israel was related to religious objections, an additional resource available to the DCs during the family approach was developed and is widely utilized. This involved the possibility to call upon the assistance of authoritative religious leaders, either in person at the hospital or via a 24/7 hotline. In this regard, every effort was made to contact a family's local religious leader, whom they knew and with whom they shared religious beliefs, or if not possible, with a recognized national leader representing their belief system. The offering of faith or religious support to donor families is not a new concept and has previously been described [10]. However, what may be unique in Israel is that all those who agreed to provide religious support underwent a training program by leaders in their respective areas of expertise which

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included medical, legal, religious, and psychosocial aspects of BD/NDD and organ donation. Taken together, the results of these interventions, i.e., DC training programs and religious support, may have contributed to the reported significantly improved interactions with donor families noted in the repeat survey and possibly to the change in the consent rate.

Over recent years, other important interventions have been introduced impacting the donation process. These include the Organ Transplantation Law of 2008, which declared organ trade and trafficking to be a criminal offence and banned the performance and reimbursement of organ transplantation anywhere outside of Israel if performed contrary to the law of that country [14].

This study has limitations. We did not investigate whether there was a change in the number of observant and/or traditional compared with secular Jewish families who consented to organ donation. However, the significant increase after many years of stagnation together with an apparent decreased emphasis on religious objections suggests that the initiatives may have played at least some role in the change. Second, no pre- and postassessment testing was performed following the simulation-based training program. Third, the DC–donor family interaction assessment was subjective in nature. In this regard, it is important to state that the majority of the 21 active DCs in Israel have been employed in this position for >8 years so that they were able to compare the interaction to the previous survey. Finally, it is not possible to determine which if any of the interventions described here have had an impact on the observed changes.

In conclusion, this study demonstrated a significant increase in the consent rate for deceased organ donation which was associated with a significant increase in the proportion of Jewish donors. In addition, changes were demonstrated in expressed deceased donation decision-making and in the quality of donor coordinator–donor family interactions, both of which may have contributed to the findings of this study. Additional interventions tailored to all different populations groups need to be developed and further investigated.

Authorship

TA: participated in research design and in the performance of research. JC and TA: participated in data analysis. JC and TA: wrote the article.

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Conflicts of interest

The authors declare no conflicts of interest.

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