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A survey of the public attitudes towards organ donation in a Turkish community and of the changes that have taken place in the last 12 years

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Abstract In 1990 we carried out a survey on public attitudes toward organ donation in a Turkish community. We repeated this study 12 years later in order to evaluate the changes that had taken place in the meantime. Using the same questionnaire and method, we repeated the study in a different part of the city with similar socio-economic characteristics as in the former area, which had in the meantime ceased to be our research and training area. The 983 participants were chosen by a random stratified method. Of those interviewed, 57.0% were willing to donate, while 18.3% refused

and 24.7% were uncertain. A total of 52.6% consented to donation. Twelve years later, some public attitudes toward organ donation had changed. Refusal to donate for religious reasons had diminished (16.1% versus 26.2%); uncertainty whether to donate had risen (24.7% versus 15.8%). Attitudes towards organ donation were clearly related to educational level, age and sex.

Keywords Organ donation · Public attitudes · Turkey

Introduction

Solid organ transplantation in Turkey began with two heart transplantations in 1969 and were followed by a live-donor kidney transplantation in 1975. The first cadaveric transplantation was carried out in 1978 [1]. From 1975 to 2001 a total of 5094 transplantations (kidney, liver, heart) were performed in Turkey. Of these, only 27.8% were cadaveric transplantations [2]. There are many reasons for the shortage of cadaveric donors; they are chiefly familial refusal to donate organs and, in a broad sense, public attitudes towards organ donation.

From our study in 1990, we found that religious misconceptions and false beliefs were significant components of negative public attitudes towards organ donation [3]. In the meantime, much has changed in terms of organ donation in Turkey. The National Coordination Center For Organ Transplantation has

been established, and all related sources now gather under this organization. Education has improved, and knowledge, technology, and experience have developed. In order to evaluate whether all this has improved public attitudes towards organ donation, we decided to perform the present study.

Materials and methods

The study was performed in Ertugrulgazi Bursa, Turkey, from January to June 2002. A sample of 983 participants (234 men, 749 women) was randomly chosen on the basis of the household registration cards, with equal distribution between males and females. However, since we performed this study on workdays, we were not able to reach most of the men, which resulted in the participation of three times as many women as men. We designed a questionnaire with six questions on attitudes toward organ donation, and six more on sociodemographic characteristics. The questionnaire was the same as the one that we had used in our 1990 study. Partici-

pants were asked whether or not they had heard of organ donation and transplantation, what the source of that information was, and whether or not they would be willing to donate their own and/or their relative's organs. If they were not willing, they were asked for the reason. Finally, they were asked whether or not they carried an organ donor card. There was no question on the concept of brain death, however, the term "after death" was used in all questions. The questionnaires were filled out in the course of face-to-face interviews by the authors (Table 1)

Results

The mean age (mean \pm SE) was 43.7 ± 0.5 years (range 18–82 years) for the total group; 42.9 ± 0.5 for the women and 46.2 ± 1.1 for the men. A total of 594 participants (60.4%) were aware of organ donation and transplantation. Awareness of organ donation and

Table 1 Public attitudes toward organ donation, questionnaire. For the analysis of data, SPSS software version 9.0 was used. The chi-square test was performed for statistical analysis

1. Age	
2. Gender	(1) Male (2) Female
3. Educational level	(1) Illiterate (2) Literate but not graduated from any school (3) Primary school (4) Secondary School or equal (5) High school and more
4. Profession	(1) Housewife (2) Unskilled laborer (3) Governmental employee (4) Farmer (5) Merchant, skilled laborer (6) Unemployed (7) Other (specify)
5. Your assessment of your own socio-economic status	(1) High (2) Middle (3) Low
6. Do you have any information about organ donation and transplantation?	(1) Yes (2) No
7. From where did you obtain this information?	(1) TV (2) Newspapers, magazines, books (3) Health personnel (4) Friends and relatives (5) Other (specify)
8. Are you willing to donate your organs after your death?	(1) Yes (2) No (3) I don't know
9. Should you not be willing to donate your organs, for which reason?	(1) I do not want to be cut to pieces (2) Because of my religious beliefs (3) I will need my organs in my second life (4) No reason (5) Other (please specify)
10. Which organ would you want to donate?	(1) Eye (2) Kidney (3) Liver (4) Pancreas (5) Skin (6) Bone (7) Heart (8) Lung (9) Whole body (10) Don't know
11. Would you give consent for the donation of your relative's organs after his/her death?	(1) Yes (2) No (3) Don't know
12. Why wouldn't you give consent for the donation of your relative's organs?	(1) I don't want him or her to be cut to pieces (2) Because of my religious beliefs (3) He or she will need his organs in his/her second life (4) Don't know (5) Other (please specify)
13. Do you have an organ donation card?	(1) Yes (2) No

transplantation was found to be strongly related to educational level ($P < 0.0001$); socio-economic status ($P < 0.0001$) age ($P < 0.0001$) and sex ($P < 0.0001$). Lower educational and socio-economic level, increasing age and female sex affected awareness of organ donation negatively. The source of information was mostly the television (56.7%).

Of the participants, 560 (57.0%) claimed to be willing to donate their organs for transplantation, while 180 (18.3%) said they were not, and 243 (24.7%) were uncertain. There were no preferences regarding any specific organ. Of the participants, 425 (75.9%) were willing to donate their whole body. In our former study, 50.5% of the participants were willing to donate their organs, while 33.7% were not, and 15.8% were not sure. During the following 12 years, willingness to donate an organ had not changed significantly, but unwillingness had decreased, and the level of uncertainty had risen. These differences were found to be statistically significant ($\chi^2 = 69.11$; $P < 0.0001$). Reasons for refusal to donate organs were as follows: no reason (40.0%); fear that their body would be cut into pieces (31.7%); religious beliefs (16.1%); the belief that they would need their organs in their second life (2.8%); more than one reason (9.4%). In the 1990 study, we had found the proportion for religious beliefs to be 26.2%, and fear that their body would be cut into pieces 43.8%. The number of people refusing organ donation for these reasons had in the meantime diminished, but refusal for no reason had risen (40.0% versus 23.1%).

There was a significant correlation between willingness to donate, and age, sex and educational level. The younger were more favorable of organ donation than the elder (55.9% versus 52.5%; $\chi^2 = 16.794$; $P = 0.002$). Willingness to donate organs was higher among males (67.5% versus 53.7%; $\chi^2 = 27.026$; $P < 0.0001$). Of the

illiterate group, 42.5% expressed a desire to donate their organs. The same desire was expressed by 55.5% of the group with primary-school education and by 66.3% of the participants with secondary school or higher education. For the females, low educational level was the main reason for less willingness to donate organs. We had found similar results in our former study. We found no significant relationship between socioeconomic status and willingness to donate organs ($\chi^2 = 5.050$; $P = 0.282$).

A total of 517 participants (52.6%) said they would consent to donating relatives' organs. Some 164 (16.7%) would not give their consent, and 302 (30.7%) were uncertain. Formerly, the percentage of participants who would not give their consent had been 1.8 times higher, and the number of those who were uncertain was 1.8 times lower than it is currently. Furthermore, the participants were unwilling to donate their own or their relative's organs for approximately the same reasons. These reasons being as follows: no reason (54.4%); fear that the relative's body would be cut into pieces (22.8%); religious beliefs (9.5%); the belief that one would need ones organs in one's second life (5.7%); all other reasons (7.6%). Of those who were willing to donate their own organs, 82.8% (464/560) said they would also donate a deceased relative's organs. Only 25 (4.5%) declined and 71 (12.7%) were uncertain. Only 17 participants (1.7%) carried a signed donor card. The distribution of participants according to their awareness and willingness to donate organs, and, furthermore, some socio-demographic variables are shown in Table 2.

Discussion

In spite of improvements in graft and patient survival rates, the number of cadaveric organ transplantations

Table 2 Distribution of participants according to their awareness and willingness to donate organs; some socio-demographic variables

Socio-demographic variables	Awareness of organ donation (%)	Willingness to donate organs (%)	
		One's own organs	One's relative's organs
Age (years)			
15-34	70.6	55.9	51.4
35-54	57.9	59.7	54.2
55 and over	52.5	52.5	50.7
Sex			
Male	72.2	67.5	61.1
Female	56.7	53.7	49.9
Educational level			
Illiterate	35.0	42.5	37.5
Primary school	54.9	55.5	53.4
Secondary school or higher	82.9	66.3	57.3
Socio-economic status			
High	65.4	57.4	46.8
Middle	62.9	57.2	54.4
Low	30.9	54.3	54.3

has not reached the desired level, and the number of patients on the waiting lists is increasing rapidly. Shortage of cadaveric organs for transplantation is a global problem [4, 5]. Informing, educating about organ donation and motivating the population to donate is an essential tool for solving this problem. Since the late 1980 s, some attempts have been made to increase the cadaveric organ transplantation rate. However, the rate is still very low and amounts to only about one third of all solid organ transplantations that were performed during last 25 years [2], i.e. 57 cadaveric transplantations per year for an average population of fifty millions. In the previous year, 306 cadaveric solid organ transplantations were performed. The number of cadaveric donations is about 0.5 pmp/year, and there are 6563 patients (5931 kidney, 430 liver, 155 heart, 31 heart and lung, 16 pancreases) on the waiting list for a cadaveric organ transplantation. Data on identified potential donors and the percentage of refused retrievals are not available. Transplantation teams face many obstacles, but the most difficult one is the lack of cadaveric organs. The key to organ supply is to promote awareness of organ donation and the willingness to donate. Many factors influence public attitudes towards organ donation. Beside socio-demographical characteristics such as age, sex, educational and economic status, religion and superstition play an important role in the willingness donate organs [3, 6]. In our former study we had found that awareness of organ donation was highest among well-educated young males of high socio-economic status. This is confirmed by this study; however, awareness of organ donation and transplantation has in the meantime fallen from 85.6% to 60.4%. Willingness to donate one's own or a relative's organs had not changed during these 12 years; however, refusal to donate had also decreased, but the number of participants uncertain whether or not to donate ones own or a relative's organs has risen. This implies that the people who had formerly refused organ donation in the 1990 study shifted to the category of those without opinion in the 2002 study. The most impressive shift in opinion took place in the categories "religious beliefs" and "fear of being cut into pieces". In a study, the vast majority of religious Turkish people claimed that organ donation was an honorable humane act that was acceptable according to Islamic beliefs [7]. The Supreme Board of Religious Affairs stated by its decision dated March 6, 1980, that organ transplantation is lawful. It seems that this verdict has successfully reached the audience and has been accepted.

The main source of information on donation and transplantation is still the television. In many studies on knowledge, attitudes and behavior in various matters of health, the primary source of information for the Turkish people is the television. During the past years, there has been widespread publicity and television news

coverage on organ donation and transplantation [8, 9]. If this mass-media communication opportunity could be used in a broader sense and within the principles of enter-educate methods it would be more effective.

On the other hand, however, it is very sad to learn how inefficiently health personnel is spreading information. For 88,666 medical doctors, 113,526 nurses and midwives and 46,382 health technicians it should not be difficult to be more efficient. In a study [10], 98.3% of Turkish physicians claimed to approve of organ transplantation, but only 23.1% had an organ donation card. Thirty percent stated they would not donate their relative's organs. The difference between brain death and vegetative state was known by 66.2%, and only 75.0% had been informed on transplantation during their medical education. Another study [11] showed that 27% doctors and 11% nurses were willing to donate. The need for training and education on the spot, particularly in the areas of identifying brain death, caring for potential donors, providing family support, executing the request process and harvesting organs was clearly defined in the same study. Recently, the Turkish Ministry of Health National Organ Coordination Center made an attempt to improve brain-death patient identification and organized in-service training courses for health personnel. In six cities (Ankara, Istanbul, Izmir, Antalya, Adana and Kayseri) Regional Organ and Tissue Transplantation Centers were established. The Organ and Tissue Transplantation Services Regulation was accepted in June 2000, and 6 months later, an Organ Donation Campaign had begun. With this regulation, all 29 Organ Transplantation and Donation Centers in the country were connected to The National Coordination Center and were responsible for informing The National Center on the amount of patients on their waiting list, the number of cadaveric donations and the number of performed transplantations. In all Organ Transplantation and Donation Centers, Brain Death Committees were established. Four specialist medical doctors of various branches (neurosurgery, neurology, anesthesiology and cardiology) are members of this committee. Their responsibility is the confirmation of brain death patients according to current international medical norms. (Turkish Law #2238 On the Harvesting, Storage, Grafting and Transplantation of Organs and Issue. Article 11: In connection with enforcement of this law, the state of medical death is established unanimously by a committee of 4 physicians comprising a cardiologist, a neurologist, a neurosurgeon and an anesthesiologist by applying the current rules, methods and practices of the country.) According to Article 14 of the above mentioned law, permission from the next-of-kin is needed for harvesting organs of a brain-dead person who has not donated his organs. The article describes next of kin as any of the following: Spouse, mother or

father, adult children, sister or brother. This article is amended by Law #2594, dated 21.01.1982. The amendment is as follows:

In the case of aforesaid persons, where the next of kin do not exist or cannot be located, and termination of life has taken place as a result of an accident or due to natural causes and is not in any way related to harvesting and according to the conditions stated in Article 11, organs and tissues can be transplanted into persons whose lives depend on them without permission from the donor's next-of-kin.

The Turkish public's attitudes towards organ donation are the same today as they were twelve years ago.

Some minor changes have taken place, but they are insignificant. Opinions have shifted from refusal to donate to uncertainty. We have a very long way to go in promoting public awareness and willingness. At this point, organ donation and transplantation issues, beside the other important health problems we face, may be seen as a luxury for our country, but in the very near future, with the current increasing rate of terminally ill patients, this issue will become our major concern.

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