Socio-personal profile of teenagers opposed to organ donation

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Abstract

Background. The teenage population has a more favourable attitude towards organ donation than other population groups. Teenagers represent the future of the community and their opinion directly affects other family members and friends. Therefore, teenagers who are in favour of donation become promoters of organ donation in their area of influence. Our aim was to determine the opinion and fears of the teenage population regarding organ donation in order to define the profile of the subgroup, which is opposed to donation.

Methods. We used a random stratified sample according to gender and geographical location of 15–19-year-old adolescents. The attitude towards organ donation was assessed using the questionnaire on psychosocial aspects of donation. The variables were grouped into socio-personal, donation awareness, social interaction, pro-social activities and attitude towards the body. Data were analysed by descriptive statistics, the χ² test, Student’s t-test and a logistic regression analysis.

Results. Seventy-three per cent of teenagers have a favourable attitude towards organ donation. Twenty-seven per cent are undecided or have negative attitudes; the main reason given is fear of apparent death (48%). Variables with statistical significance, which are against donation, are a low level of education (P = 0.0456), no previous experience with organ donation (P = 0.0254), no knowledge of the brain death concept (P = 0.0054) and refusal to accept cadaver manipulation (P = 0.0037).

Conclusion. The profile of the teenager who is opposed to organ donation is one who has only primary schooling or who left school early, is not engaged in pro-social activities, rejects cadaver manipulation and has no knowledge of the brain death concept.

Keywords: attitude; brain death concept; cadaver manipulation; organ donation; teenage population

Introduction

The Spanish population is increasingly better informed about organ donation and transplantation [1], particularly youngsters. Three out of every four (73%) teenagers would be prepared to donate, compared with 65% in the rest of the population [1–3]. The teenagers represent the future of the community and have a direct influence on other family members and friends [3–5]. Therefore, a favourable attitude of the teenager in this matter not only means a positive personal attitude towards donation, but it can also be the determining factor for authorizing donation when faced with the death of a family member. On the other hand, and of no less importance, trained adolescents become quality transmitters, propagators, in their own sphere of influence, which goes beyond the family, of the necessity of active community participation in the whole procedure of obtaining organs [6].

Therefore, one of the prime objectives in the promotion of organ donation is to develop educational programmes for improving the social climate among teenagers regarding donation and transplantation [4,6–7]. These campaigns must be based on teenagers’ prior awareness of the social perception of donation in order to be able to act on the subgroup of those unwilling and on the misconceptions that lead to this unwillingness.

Our aim is to determine the opinion and fears of the teenage population regarding organ donation in order...
to be able to define the subgroup of these adolescents who are opposed to donation.

**Subjects and methods**

A random stratified sample by gender and geographical location was collected from a total of 94,222 teenagers in a Spanish Region aged between 15 and 19 years. The sample was computer-designed using a conglomerated stratification procedure, and included as sampling points the 45 municipalities that make up the Region. The selection of primary units (municipalities) was randomly performed in proportion to the population of every municipality. The secondary units (villages, small towns and cities) were simply selected randomly. The individuals were chosen according to age and sex. The sample error, with a 95.5% confidence level (2 sigma) was estimated at $e \pm 2.2136$. The initial sample selected for these parameters was 210 subjects. The attitude towards organ donation and transplantation was evaluated according to a Psychosocial Aspects of Donation Questionnaire (Appendix). The variables analysed were grouped into: (i) socio-personal: age, sex, municipality (<10 000 inhabitants, between 10 000 and 20 000, between 20 000 and 50 000, between 50 000 and 100 000, between 100 000 and 250 000 and > 250 000 inhabitants) and employment situation (student, employed, unemployed); (ii) donation awareness: prior experience of donation and awareness of the concept of brain death; (iii) social interaction: partner’s opinion on donation and faith in the health system; (iv) pro-social activities: being a blood donor, doing voluntary work; and (vi) attitude towards the body: attitude towards corpse manipulation. This questionnaire was developed by six interviewers of the Regional Transplant Coordination Office in a personal interview. The interviewers standardized their criteria for data collection in a previous pilot study of 300 interviews. The survey was carried out in different ways according to the municipality studied. In municipalities of >10 000 inhabitants, this was carried out by telephone given that >95% of the population has a telephone. In rural municipalities (<10 000 inhabitants), the survey was carried out by face-to-face interview.

The data were analysed by descriptive analysis, the $\chi^2$ test for analysis of the contingency tables with analysis of residues and Cramer’s of Fisher’s exact test if necessary, and the Student’s $t$-test. For the multiple risk study we used a multivariate analysis by means of logistic regression analysis. A $P$ value <0.05 was considered significant.

**Results**

The survey was conducted between December 1998 and April 1999. Of the 214 teenagers initially selected four were excluded because they did not want to answer the important questions of the questionnaire, which left 210 valid interviews, 108 of which were males (51%). Seventy-three per cent of the teenagers have a positive attitude towards organ donation. In the group with a favourable attitude, the reasons for this attitude were principally solidarity (72%) and reciprocity (32%). Twenty-seven per cent are undefined or have a negative attitude towards donation, the reasons, for these attitudes were principally the fear of apparent death (48%) (Figure 1).

![Fig. 1. Reasons given by teenagers opposed to organ donation. The total sum of percentages exceeds 100% due to the fact that some of the respondents gave more than one reason against organ donation.]
As for the variables that influence opinions on organ donation, no significant differences are observed for age, sex and geographical localization. Level of schooling influences opinion: those with primary schooling or below have a more negative attitude towards organ donation and transplantation than those with secondary schooling or above ($P = 0.0456$). Also, students have a more favourable opinion than those who work or are unemployed ($P = 0.0132$) (Table 1).

As far as awareness variables are concerned, a significantly more favourable opinion is observed among those having prior first-hand experience with organ donation and/or transplantation ($P = 0.0254$) and those aware of the brain death concept ($P = 0.0054$).

With regard to social interaction, a more negative attitude towards donation is noted in those whose partner’s opinion is unknown or negative, but the differences are not significant ($P = 0.221$). Faith in the health system does not influence opinions on donation in this age group. As for the variables concerning pro-social activities, we see that those who are, or are prepared to be, blood donors ($P < 0.0001$) and those engaged in voluntary and social welfare activities ($P = 0.0419$) show a more positive attitude towards organ donation than the rest.

Finally, with regard to attitude towards the body, those not opposed to cremation and/or autopsy after death are seen to have a more favourable attitude towards donation ($P = 0.0037$) (Table 1).

In a multivariate analysis the variables that are important in the attitude towards organ donation were employment situation (RR = 1.795), having a favourable attitude towards blood donation (RR = 1.579), knowledge of the brain death concept (RR = 2.379) and a positive attitude towards cadaver manipulation (RR = 2.373) (Table 2).

**Discussion**

The teenage population is the population subgroup most predisposed to the donation of organs [1,3], which in our series exceeds 70%. However, 27% are opposed
to organ donation or undecided, which coincides with the rate of family refusals, currently almost 20–30%. When assessing the reasons for being opposed to donation we see that almost 50% are afraid of apparent death, which is clearly related to no knowledge of the brain death concept [15].

Martinez et al. [1], in a study on the Spanish population, found that younger individuals have a more favourable attitude towards donation of their own organs, although some authors show the opposite [9]. As for sex, most authors agree that having a favourable attitude towards donation is not influenced by the person’s sex, although some studies show a slightly more favourable predisposition in females [10]. Östergren et al. [10] conducted a survey on 6440 18 year olds and found that the females had a significantly more positive attitude towards donation. There are no differences for age or sex in the teenage group in our series.

The level of education is fundamental. Subjects with a high level of education have more favourable attitudes towards science and medicine, and specifically more positive attitudes towards organ donation [2–3,11–12]. Our results show that the higher the adolescents’ level of education the more positive their attitude, and that those who have left school early have a more negative attitude. Gabel et al. [11], in a study in Sweden on 2758 young male soldiers and their attitude towards cadaveric organ donation and transplantation, states that they have a positive attitude towards cadaveric organ donation, whereas the less intellectual are also less positive, due particularly to a lack of knowledge on the subject, which makes it necessary to inform youngsters in order to promote a positive attitude towards donation. It is important to assess socio-economic and cultural roles in donation [11–12].

Information on organ donation and transplantation is fundamental [4,6–7,13–14]. As observed by Martín et al. [2] in 1991, a great many subjects (65%) express the desire to receive more information, the young subgroup (18–30 years) being those who request it most. This information must include the brain death concept [15], as fear of the possibility of an apparent death and of being declared dead prematurely for the sole purpose of extracting organs is, as we have seen, a very important obstacle to organ donation [2,16]. The main problem lies in the fact that some sectors of society neither accept nor understand this concept [15,17].

Religion is another decisive factor [18]; an important figure that has apparently contributed to the omission or discouragement of donations is the traditional doctrine of resurrection of the body, in particular the idea of keeping the body intact after death. Thus, attitude towards the body is another factor, as non-donors or those with an unfavourable or negative attitude towards donation are more afraid of disfigurement [1,15].

The geographical factor is important in that it is usually associated with population density, health infrastructures, per capita income and socio-cultural level [8]. This influence is not confirmed in our series, possibly due to the influence of other factors on these age groups.

The experience with organ donation and transplantation is one of the factors that has most helped to promote it. The positive social idea that has emerged in recent years is the direct acquaintance of transplant patients. Although in interviews on the subject of donation some of the interviewees are reluctant to be donors, if it turns out that they have a neighbour, friend or relative who has undergone transplantation, knowledge of both the therapeutic success and the circumstances that made the transplant possible often leads to a favourable decision regarding donation [8]. Being engaged in pro-social activities and giving blood is considered to indicate an altruistic view of life [15] and usually predisposes to organ donation, as seen in our series.

Informing the family of the willingness to be a donor encourages discussion among relatives, which appears in the literature as one of the mainstays of a decrease in family refusals [15]. In our study, awareness of one’s partner’s opinion is also important for determining to donation.

Table 2. Variables that influence attitudes towards organ donation and transplantation in teenagers (logistic regression multivariate analysis)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Regression coefficient (β)</th>
<th>Error standard</th>
<th>Odds ratio (CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment situation:</td>
<td></td>
<td></td>
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<tr>
<td>Employed—unemployed (n = 49)</td>
<td>0.02803</td>
<td>0.216</td>
<td>1</td>
<td>0.0167</td>
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<tr>
<td>Student (n = 161)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>In favour of blood donation:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>No (n = 55)</td>
<td>0.4964</td>
<td>0.1407</td>
<td>1</td>
<td>0.0068</td>
</tr>
<tr>
<td>Yes (n = 155)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Attitude to cadaver manipulation:</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Against (n = 148)</td>
<td></td>
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<tr>
<td>No (n = 62)</td>
<td>0.86423</td>
<td>0.3289</td>
<td>2.4 (4.58–1.1)</td>
<td>0.0057</td>
</tr>
<tr>
<td>Yes (n = 118)</td>
<td>0.3444</td>
<td>0.4115</td>
<td>1</td>
<td>0.006</td>
</tr>
</tbody>
</table>

Note: Odds ratio (CI) is calculated using logistic regression, with 95% confidence intervals.
Some studies report that a mistrust of the health system influences an unfavourable attitude towards organ donation [8,15,17]. In our age group we found no statistical association in the predisposition towards organ donation.

The educational campaign to be carried out on adolescents in our environment will centre on the last two school years (15–16 year olds) of primary schooling, given that in Spain it is obligatory to attend school until the age of 16 and therefore we can have easy access to this subgroup. The general bases of theses campaigns are going to be the same as those we have used on children in previous campaigns [4,19–22], and which are essentially three types: those carried out in small groups of teenagers (maximum 25); the use of positive stimuli avoiding any negative situation which an adolescent could later associate with organ donation and transplantation; and encouraging the undertaking of group activities related to organ donation and pro-social activities. A fundamental point which blends into our study, is the content of the talks and activities, which should not be limited simply to concepts of organ donation and transplantation, but we should introduce three other important conceptual fields: (i) a clear and comprehensible explanation of the concept of brain death; (ii) a workshop on the handling of the dead body dealing in a natural way with terms such as autopsy and incineration; and (iii) a workshop with the participation of patients with transplants to whom adolescents can ask about concerns and get to know the experiences of these people. This last section could be carried out through visits to transplant areas in the hospital, an activity already undertaken in our country by the Dr López Navidad group with good results [6].

In conclusion, the profile of the teenager opposed to organ donation is one who has only primary schooling or who left school early, is not engaged in pro-social activities, rejects cadaver manipulation and has no knowledge of the brain death concept.

Conflict of interest statement. None declared.

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Appendix

I: Psycho social aspects of donation questionnaire
1. Age Years
2. Sex
   Male
   Female
3. Marital status
4. Municipality of residence
5. Education
   - Literate or less
   - Primary
   - Secondary
   - Other:
6. Current employment situation:
   - Employed
   - Student
   - Seeking first employment
   - Unemployed
   - Other:
7. Profession
8. Do you have children?
   - Yes
   - No
9. Do you know anyone among your relatives or friends who has donated organs, needed or had a transplant?
   - Yes
   - No
   - Do not know
10. Indicate by which means you have received information on organ donation (more than one answer possible)
    - Television
    - Radio
    - Daily press
    - Magazines, weekly supplements
    - Conversations with friends
    - Conversations with relatives
    - Hoardings, posters
    - Professionals in the medical sector
    - Schools or other educational centres
    - None
    - Other:
11. Do you consider your information on organ donation to be . . .?
    - Good
    - Average
    - Scant
    - Poor
    - Inexistent
12. What is your opinion of people who donate organs?
    - I think they are extraordinary people
    - I think they are good people
    - I find it normal, nothing more
    - I do not like it
    - These are bad people
    - Other:
13. What is your opinion of the following statement: ‘The present need for transplant organs is fully covered’
    - Totally true
    - Only partly true
    - Not true; there is a shortage of organs
    - Do not know
14. Would you donate your organs?
    - Yes, and I have a donor card
    - Yes, but I do not have a donor card
    - No, I would not donate my organs
    - Do not know
15. For which of these reasons would you donate your organs? (Indicate those you think necessary)
    - It is a moral obligation
    - Out of solidarity
    - To give life after death
    - For religious reasons
    - Because it is free
    - Reciprocity (to do for others what I want others to do for me)
    - Other: please specify:
16. Conversely, if you are not a donor, for which of the following reasons? (Indicate those you think necessary)
    - No money is paid
    - Rejection of the idea of corpse mutilation
    - Fear of organs being taken before death really occurs
    - For religious reasons
    - I do not wish to give a reason
    - Other: please specify
17. Are you a blood donor?
    - Yes, regularly
    - Yes, occasionally/or I gave once
    - No, but I am prepared to
    - No, and I do not wish to
    - Do not know
18. Do you participate in non-governmental organizations, voluntary work or social activities?
    - Yes, regularly
    - Yes, occasionally
    - No, and I am not going to
    - No, but I would be prepared to
    - Do not know
19. Of the following options regarding your own or a close relative’s death, indicate those with which you agree?
    - I wish to be cremated
    - Yes
    - No
    - I wish to be buried
    - Yes
    - No
    - I agree to an autopsy
    - Yes
    - No
20. In your opinion, can a person with brain death recover and live a normal life?
    - Yes
    - No
    - Do not know
21. Do you trust your family doctor?
    - Fully
    - Quite a lot
22. When finally, like everybody else, your turn has come to die and your attitude towards donation is positive, what organs would you be prepared to donate? (More than one answer possible)
   - Lungs
   - Heart
   - Liver
   - Kidneys
   - Pancreas
   - Other:

23. How do you think transplant waiting lists should be organized?
   - Those officially recognized as donors should have preference when needing a transplant
   - Organs should only be adjudicated to patients for serious reasons and in emergency situations
   - Preference should be given to those who have been on the waiting list longest
   - Do not know

24. How do you think the distribution of transplant organs should be arranged?
   - Every community should have preferential use of the organs given by their own donors
   - The organs generated in each community should be pooled for use nationwide
   - All organs should be pooled for use throughout Europe
   - Organs should be pooled for use worldwide
   - Other:

25. With regard to religious beliefs, do you consider yourself . . .?
   - A practicing Catholic
   - A non-practicing Catholic
   - Of a non-Catholic religion
   - An agnostic
   - An atheist
   - Other:

26. Which of the following statements do you think is the opinion of the Catholic Church regarding organ donation and transplantation?
   - It is in favour of organ donation and transplantation
   - It is against organ donation and transplantation
   - It has not expressed an opinion
   - Do not know

27. Do you know your partner’s attitude towards organ donation?
   - Yes, it is positive
   - No, I do not
   - Yes, it is negative
   - I do not have a partner
   - Do not know

28. With regard to donating the organs of a deceased person, when do you think the next of kin should be asked for permission?
   - Only when the opinion of the deceased is not known
   - The next of kin should always be asked for permission
   - The opinion of the deceased on the matter should be respected
   - No previous permission should be necessary
   - Other

29. How would you consider legislation that grants the state access to the organs of a deceased person without the need for previous permission?
   - As a great gesture of solidarity
   - As an abuse of authority
   - As an efficient means of not wasting organs that are lost in vain
   - As an offence to the relatives of the deceased
   - Other: please specify

30. Who do you consider should contact the next of kin to seek permission for organ donation?
   - The doctor who treated the patient
   - Medical staff from the hospital
   - Administrative staff
   - A professional from the transplant coordination network
   - Someone else. Who?