

Margareta A. Sanner

A Swedish survey of young people's views on organ donation and transplantation

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M.A. Sanner
Department of Public Health
and Caring Sciences, Uppsala Science Park,
751 85 Uppsala, Sweden
E-mail: Margareta.Sanner@pubcare.uu.se
Tel.: +46-18-6113564
Fax: +46-18-506404

Abstract The aim of this study is to explore young people's attitudes, beliefs, and knowledge on organ donation and transplantation. A survey was conducted among 1,447 students aged 15–18 years in four urban areas in Sweden. Although students looked upon organ transplantation favorably, only 50% were willing to donate their own organs, and only 20% the organs of their parents. Concerning organ donation, 75% of the students expressed some discomfort. There were significant gender differences. About 70% of the students indicated that transplantation issues should be included in the school curriculum. It

is concluded that teenagers feel irresolution and discomfort regarding organ donation after death, but concurrently see organ transplantation as a highly valued service. One way that this mental conflict can be resolved is through education. Educational programs in school must address this ambivalence and both mediate facts and help students to work through the fear and discomfort associated with organ donation.

Keywords Attitudes · Organ donation · High-school students · Public opinion · Psychology · Discomfort reactions · Knowledge

Introduction

Organ transplantation is totally dependent on people's willingness to donate their organs to others who are in need. Consequently, professionals, patient associations, and voluntary workers have devoted considerable time and energy towards promoting awareness of organ donation and transplantation. These efforts have mostly been directed at the adult population that is assumed able to take a stand, sign an organ donor card, or enter their names into a donor registry. Furthermore, the adult population's attitudes toward organ donation and transplantation are quite well surveyed in many countries [1, 2, 5, 6, 12, 15, 16, 22]. However, little knowledge is available today about the way young people, including teenagers, perceive such issues. Therefore, the aim of this study was to explore teenage attitudes, beliefs, and knowledge on organ transplantation and donation of organs after death.

Because of the increasing gap between supply and demand of organ transplants, much thought has been given to various strategies to break this trend. One such attempt has been to implement special programs designed to inform young people about organ transplantation in schools. It is convenient to use already existing, well-established channels of information and education, especially as ordinary organ donation campaigns are expensive and there is no conclusive evidence that these campaigns are efficient in increasing an individual's willingness to donate [14]. Some programs that educate students of differing age groups have been tested [3, 8, 18, 19, 21]. In Sweden, where the donation rate is lower than ever – 12.1 donors per one million inhabitants in 2001 – there have recently been plans to introduce similar programs concerned with issues in organ transplantation and donation. The results of the present study were intended to be used as a basis for such educational intervention. The goal of the intervention is

twofold: (1) to increase the knowledge of organ donation and transplantation, correcting today's misunderstandings and preparing the students to take a stand regarding donation of their own organs; and (2) spreading this knowledge to the students' family members, which would initiate discussion whereby the whole family would take a stand on this issue. In this way, the number of people who have made known their opinion on organ donation would increase, which is important, as individuals are more willing to donate their own organs than those of a close relative [1, 5, 9, 11, 16].

Material and methods

Students, equivalent to the ninth and 11th grades of high school, who attended 14 different schools in four urban areas in Sweden on an appointed day, were asked to answer a questionnaire administered during normal school hours. The schools were selected to ensure a representative sample concerning socio-economic status. The questionnaires were distributed from May to June 2000 (at the end of the school semester) with the help of the teachers and with permission of the headmasters. Participation in the study was voluntary, and student responses to the questionnaire were kept anonymous.

The questionnaire comprised 24 items that addressed socio-demographic background, information and knowledge of organ transplantation, attitudes toward their own and next-of-kin's organ donation, discomfort reactions at the thought of donating organs, and requests with regard to information on organ transplantation and donation. Most of these questions had been asked in previous studies on adult populations [9, 11, 12, 14]. However, the questions on knowledge/evaluation of organ transplantation were devised in cooperation with a reference group of transplant coordinators, physicians, and representatives of associations of transplant patients. The questionnaire was initially tested on 20 teenage boys and girls and then slightly revised to form the final questionnaire that was used in the present study.

There were very few differences between the two school grades, and thus the data were collapsed over the two age groups. Only when there were significant differences between the grades, are these differences reported separately. Differences between groups were assessed with the chi-square test (two-tailed). To minimize type I errors, statistical significance was set to $P < 0.01$. For mean values, 95% confidence intervals were calculated. Associations between attitudes were studied by use of Spearman's correlation coefficient.

Results

Description of the students

The response rate was notably high, with only six students refusing to respond. In the ninth grade, 650

students completed the questionnaire, and in the 11th grade, 797 responded. The internal non-response rates on specific questions were low and did not exceed 2% on the items with fixed-response alternatives. On the four open-ended questions, the non-response rates were 8%, 10%, 10%, and 22%. The largest non-response (22%) concerned a question about specific matters on which the students wanted more information.

In the ninth grade, gender was evenly distributed, i.e., 50% male and 50% female. In the 11th grade, it was unequal, with 32% boys and 68% girls. The distribution was uneven because traditionally female educational programs were over-represented. The mean age in the ninth grade was 15.5 (range 14–17) years while in the eleventh grade it was 17.7 (range 16–23) years.

The ethnic backgrounds of the students are described in Table 1. Approximately half the students indicated that they belonged to a church or religious institution. One-third of the 11th-grade students was registered on a course of study preparing them for a trade, and two-thirds were enrolled in a university preparatory program. The gender distribution was the same for both types of educational program.

Knowledge about organ transplantation

Approximately 90% of the students received information on organ transplantation through various television programs. Ninety-eight percent indicated that they had some knowledge on matters of organ transplantation and donation.

More than half the students in the ninth grade and two-thirds in the 11th grade reported that they had discussed issues on organ transplantation and donation in the past. These conversations were limited and had mostly taken place within their family.

In addition to items on the questionnaire that dealt with the heart and kidney, the students knew of some other organs amenable to transplantation, i.e., livers and lungs. On average, they knew of 3.33 ± 0.044 organs. (This was an open-end question with no enumeration of body parts.)

One question concerned the status of the donor and the circumstances under which organ removal is conducted. About 60% in both grades indicated that the donors were deceased persons treated in respirators;

Table 1 Ethnic background. (Question: *Were you born in Sweden?*)

Native background	Ninth grade (%)	11th grade (%)	15–18-year olds according to Statistics Sweden
Born in Sweden, and both parents born in Sweden	73	69	76
Born in Sweden, and one or both parents born abroad	16	16	14
Not born in Sweden	11	15	10

15% thought the donors were 'heart-dead'; and about 25% indicated that they did not know under what conditions an organ removal is conducted.

One open-ended question asked how long the students thought a person would survive with a transplanted heart. There is no simple answer to this question, and it can be seen as a question of attitude as well as one of knowledge. Moreover, many students guarded their responses by indicating that this was really a question about 'believing' and not 'knowing'. The student responses varied from detailed descriptions of factors influencing the survival time to rather elaborate statements about how many survival years they believed could be attained (Table 2). Half the students thought that a person with a heart transplant could live just as long as a 'normal' person, whereas about 10% specified that certain conditions had to be met for a lengthy survival (e.g., that the operation was successful, that the donor had had a young and strong heart, or that the recipient must lead a sound life and take his or her medication regularly).

Most of the students thought that the quality of life of the recipients would be comparable to that of a healthy person, presuming that the transplantation was successful (Table 3).

Attitudes toward organ donation and transplantation

Fifty percent of the students indicated that they were willing to donate their organs after death (Table 4). Twenty-four percent in the ninth grade and 32% in the

Table 2 Participants' sentiments regarding survival length with a transplanted heart. (Question: *How long in general do you think that a person with a transplanted heart can live?*)

Survival length	%
Normal length of life	49
Normal length of life with qualifications	11
> 15 years	7
10–15 years	6
5–9 years	2
2–4 years	4
< 2 years	2
Shorter lifetime than other people	3
Don't know	16

Table 3 Participants' views on quality of life after a successful transplantation. (Question: *How do you think that people in general get on after a successful transplantation?*)

Quality of life	%
Can live like a healthy person	81
Severe restrictions	6
Need hospital care most of the time	4
Don't know	9

Table 4 Participants' attitudes toward organ donation after death. (Question: *Would you be willing to donate your organs after death?*)

Attitudes	Boys (%)	Girls (%)	Total (%)
Positive	45	54	50
Negative	22	14	18
Undecided	33	32	32

11th grade reported that they had informed their families about their standpoint on organ donation, and 5% versus 10% that they had an organ donor card. However, very few students (2%) had actually had their names entered in the Donor Registry of the National Board of Health and Welfare.

There was an appreciable degree of uncertainty in parental opinion on organ donation. Approximately 60% of the students reported that they had no knowledge about this topic. One-fifth of the students indicated that they would contemplate consenting to organ removal from a parent without knowing that parent's opinion on the matter (Table 5).

Approximately 80% of the students were positive to the notion of receiving a transplant in a life-threatening situation, whereas very few were negative. The values were similar regarding the transplantation event as such.

A large proportion of the students, approximately 70%, thought that organ transplantation issues should be included as part of the school curriculum. Those who did not want to know anything about organ transplantation and donation reported that this subject was too 'disgusting' or boring, or that they did not want to know anything 'just now'. About 80% of those students with a positive attitude to organ donation wanted more information, compared with approximately 50% for those who were hesitant or negative.

Discomfort reactions

In one question, various types of possible reactions of discomfort at the thought of organ donation were listed. The respondents were asked to indicate those reactions that they recognized in themselves (Table 6). Seventy-two percent of the students reported some kind of discomfort at the thought of donating organs. Students

Table 5 Participants' attitudes toward accepting organ procurement from parents. (Question: *If your parents had not indicated their opinion on organ donation, would you as the closest relative accept having their organs removed?*)

Attitudes	%
Positive	21
Negative	32
Don't know	47

Table 6 Types of discomfort among students (Question: *There are different reasons for being hesitant or not wanting to donate one's organs. Even if one is positive toward donating organs, there might be feelings of discomfort. Below are listed some types of discomfort reaction. Please indicate the reactions that are important to you.*)

Type of discomfort	%
Discomfort of a dead body being cut up	39
Discomfort at having one's organs living on in another body	32
Fear of being disrespectful to the dead person	19
Fear of not being dead	17
Fear that resurrection would be negatively influenced	11
Anxiety about desecrating nature	4
Other type of discomfort (usually "nasty")	6
No discomfort at all	15
Cannot answer the question	13

who were undecided gave similar responses to those who were negative, whereas the students with a positive attitude differed from the others in all respects except one, namely, the fear of not being dead during organ removal (Tables 7 and 8). On average, students with negative or undecided attitudes toward organ donation reported more types of discomfort than did those who were positive. This finding might suggest that the number of types of discomfort is a reflection of the intensity of the discomfort.

The most common feeling of discomfort was the thought of the dead body being cut up; the next most common feeling was that the organs would go on living in another person. The third most common was that it would be disrespectful to the deceased person if the body was not left 'in peace'. Twenty-four percent of the students who indicated some type of discomfort were afraid of not being dead when the organs were removed, and 15% thought that an existence after death might be negatively affected if the body was surgically assaulted. A small proportion of students thought that organ

transplantation is against the natural state of things (Table 6).

The answers to one of the open-ended questions showed that 95% of the students thought that the inadequate number of organs available for transplantation was due to scarcity of donors. Firstly, different types of discomfort reactions were indicated as reasons why people do not donate organs. Many students referred to their personal reactions in this respect. Secondly, lack of knowledge on transplantation activities was perceived as an important reason for unwillingness to donate an organ.

Attitudes in relation to background and some other factors

There were significant gender differences. As shown in Table 4, the girls were more often in favor of donating their organs ($P < 0.0001$), and the same was true regarding organ transplantation as such ($P < 0.0001$). Nevertheless, the female students reported feelings of discomfort at the thought of donation (78%) more often, compared with the male students (65%) ($P < 0.0001$). The female students had talked more frequently about transplantation issues with others ($P < 0.0001$) and had informed their family about their standpoint on organ donation ($P < 0.0001$) more often than the male students. Finally, female students reported more often that they knew their parents' opinion on organ donation ($P < 0.0001$).

The only significant differences between the two school levels were that older students expressed their standpoints on donation more frequently ($P = 0.002$) and that more older students were donor-card holders ($P = 0.001$).

Table 7 Types of discomfort among students expressing some degree of discomfort

Type of discomfort	Positive (%)	Undecided (%)	Negative (%)	Total (%)
Discomfort of a dead body being cut up	48	57	57	54
Discomfort at having one's organs living on in another body	36	46	52	44
Fear of being disrespectful to the dead person	20	39	27	27
Fear of not being dead	27	18	23	24
Fear that resurrection would be negatively influenced	10	20	18	15
Anxiety about desecrating nature	4	8	4	5
Mean no. of discomfort reactions, confidence interval (95%)	1.065 ± 0.041	1.734 ± 0.059	2.054.00 ± 0.091	1.453 ± 0.034

Table 8 Discomfort in relation to attitudes toward organ donation

Discomfort reactions/attitudes toward organ donation	Discomfort (%)	No discomfort (%)	Don't know (%)
Positive	61	29	10
Negative	87	1	12
Undecided	82	2	16
Total	72	15	13

Native background was related to willingness to donate both one's own ($P=0.0001$) and parents' organs ($P=0.003$), to receive organs ($P<0.0001$) and to regard organ transplantation as a positive event ($P=0.0001$). Students born in Sweden and who had parents that were born in Sweden were in favor of organ transplantation and donation to a greater extent than students who were not native Swedes or whose parents were born in another country. There were no differences in attitude towards the transplantation issues in relation to religious affiliation.

The 11th-grade students who were enrolled in university-training programs took a more favorable stance in all transplantation issues than those enrolled in trade-preparation programs ($P<0.0001$).

The students who assumed that organ removal would be conducted on deceased patients who had been declared 'brain dead' were more often in favor of donating their own ($P=0.01$) and their parents' organs ($P=0.001$) than those who believed that the operations were conducted on 'heart-dead' patients. They were also more often in favor of donation than students who indicated that they did not know the nature of the death. Another finding was that those students who assumed that the quality of life ($P=0.001$) and the survival time of transplant patients were as high as for the 'ordinary' population ($P<0.0001$) were more often willing to donate their own organs.

Regarding their attitudes towards transplantation and donation, there were no significant differences between the students who personally knew an organ recipient and those who did not, even if there was a tendency among the former to be more in favor.

A fair degree of congruity was noted between the four questions on attitudes toward organ transplantation and donation. Thus, if students were in favor of donating their own organs, they also tended to accept donation from a parent ($r=28$), to receive an organ themselves ($r=249$), and to view organ transplantation as a positive event ($r=256$).

Discussion

Representativeness

The ninth-grade students were representative of this school level on such variables as age, gender, and ethnic background (Statistics Sweden). In the 11th grade, however, there was an over-representation of female students and students in university preparatory programs (Swedish Board of Education). One reason for the biased sample was that the traditionally female trade programs, including hair dressing and childcare, were over-represented in the schools that participated in the study. It is also suspected that more boys than girls took

the opportunity to skip some lessons during the last days of the semester, when the survey was conducted. According to Statistics Sweden, a slightly higher proportion of students in the 11th grade who participated in the study was not born in Sweden. Choice of program, gender, and ethnic background were all factors that covaried with attitudes toward organ transplantation. Taking part in university preparatory programs and being female were related to attitudes that were more in favor of transplantation, whereas not being born in Sweden was related to less positive attitudes. Thus, some caution must be observed when the results are generalized to all Swedish 11th-grade students. However, the overall trends should be valid.

Attitudes toward transplantation activities: ambivalence

The students had a high opinion of the quality of life and survival for individuals who had undergone successful transplantation. They were in favor of transplantation in general and could see themselves as recipients should such a situation arise. Knowledge about the conditions of organ removal (e.g., retrieving organs from 'brain-dead' donors) and which organs can be transplanted are regarded as quite good.

However, students' attitudes toward supporting transplantation activities by donating their organs, or especially a relative's organs, were less positive. This ambivalence – expressing high appreciation of an activity and at the same time not being prepared to support it – suggests the possibility that psychological discomfort plays an important part. Three of four students also reported different kinds of discomfort. Figure 1 pictures this ambivalence.

Reactions of discomfort were most common with the negative and undecided students but were frequently mentioned by the positive students as well. A majority thought that people's fear and discomfort were the major reasons for the lack of organ transplants. Discomfort at the thought of having one's body cut up was the most frequent category. It has been suggested [10] that this form of discomfort might be connected with the inability to imagine one's own death and non-existence, and hence an inability to imagine a difference between the living and the dead. Thus, the dead body is ascribed qualities that only the living individual possesses. The feeling of immortality is especially strong in young people and might make it difficult to arrive at a standpoint on what operations may be conducted on the body after death. Next in frequency was the discomfort of knowing that one's organs would be surviving in another person. This might be interpreted as a belief that all organs must be left alone when the body is buried or cremated, so that the person can 'rest in peace'. Several

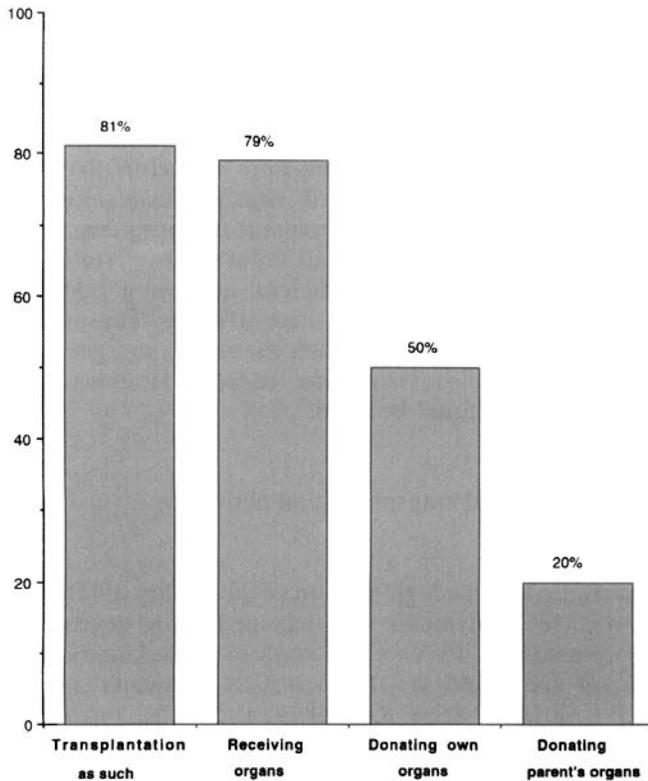


Fig. 1 Proportion of the 1,447 high-school students with a positive attitude toward various issues associated with organ transplantation

student comments brought up this subject. This is closely related to beliefs that the resurrection or an existence after death would be affected if one gave away one's organs. Believing in re-incarnation was indicated as an influential factor in this context. Thus, this category seems to reflect some hesitance about the real meaning of death, i.e., an existential irresolution. One of the boys wrote: "I know what it is to be alive, but not what it is to be dead."

Another interpretation of this category is that one did not want to be part of another person's body. Such comments were also frequent. Here the concern seems to be that through the transplanted organ the donor would influence the recipient and vice versa [13]. Several of the students indicated that this issue was what they wanted to know more about, preferably from persons with transplanted organs.

Even if the female students indicated uneasiness more frequently than the male students, they were often more willing to serve as organ donors, regarded organ transplantation as a positive event, and generally discussed such matters more often than their male counterparts. Teenage girls, as a rule, are more mature than boys of the same age. This gender difference in maturity may account for girls expressing more responsibility to those

who are suffering physical ailments, or have greater capacity to exhibit feelings of empathy and compassion.

The finding that students on the university preparatory programs were more often in favor of organ transplantation and donation than students in the trade preparatory programs is in accordance with evidence that adults with higher education are more often in favor of organ transplantation than those with lower education. This difference in view is probably related to a greater openness and confidence in scientific development and medical progress in people with a higher education. Such an argument might also explain the attitudes of young people of foreign origin. However, this subgroup is very heterogeneous.

Comparison with the adult population

There is a scarcity of studies on the adult population's assessment of quality of life and survival and on their knowledge of the conditions of transplantation surgery. In general, however, adults have the same high opinion of organ transplantation as students and have shown their willingness to be organ recipients [9, 12].

In the adult Swedish population, the proportion of people who are in favor of organ donation has varied between 60% and 68% during the past decade [9, 12]. These values can be compared with the 50% value found in the present study. There are no indications that the attitudes of the Swedish population would generally have become less positive than they were earlier [7]. It is more probable that young people are indecisive and feel considerable discomfort regarding organ donation after death. Adolescents are in the midst of a period of rapid physical development, and their search for identity is intense. The donation of organs is, in a sense, an intrusion in a progressing bodily change and might be experienced as a disturbing and threatening event. Moreover, there are few young people of this age range that have a consistent and distinct perspective of life and death. This may lead to a fear or hesitance of accepting anything experienced beyond what is traditionally done with the body after death.

The adult population seems to feel discomfort, regarding organ donation, comparable to that of these young students. In a previous study, 65% of a representative sample of Swedish persons aged 18 to 75 years [9] indicated at least one reaction of discomfort parallel to the ones demonstrated here.

Time for a shift in strategy

There is evidence that the positive and negative substrates underlying donor attitudes and behavior are bivariate rather than bipolar [4, 10], which serves as the

basis of the ambivalence. The eventual attitude depends on the relative forces of these counteracting and promoting factors. Only when the psychological discomfort is weak does the strength of altruism and rational deliberations based on empirical facts have any significance for the willingness to donate. For many people, most of the feelings of discomfort are apparently an initial and normal reaction and tend to fade when confronted with facts and the possibility of helping fellow beings. For others, however, anxiety is too great to allow thoughts about death, and even less, to envision the cutting and removal of organs from a dead body. The implication, then, is that these individuals block information on the topic or even distort or misrepresent any such information, in an effort to escape cognitive dissonance [10]. Thus, the negative and undecided students in this study were less motivated in acquiring information about organ transplantation at school than were the positive students.

Donation campaigns as well as public education have focused largely on imparting facts, but seldom on helping people work through their anxiety. The results of the traditional campaigns have not been encouraging [17, 20]. It is perhaps easier to explain, e.g., legal rules, logistics, and surgery techniques, than to help people come to terms with their partly subconscious and not

always clearly articulated uneasiness. Yet, this is evidently what is needed. The best and simplest way for people to work through their feelings is for them to formulate their reactions into words, which helps them to scrutinize their underlying motives and drives. This would be best accomplished in conversation, where many varied views and reactions might be discussed. The multiplicity of the field of organ transplantation offers unique possibilities to highlight questions that are important to young people, as it brings a series of existential questions to a head: views on life and death, identity, nature and culture, and altruism. It should be manageable to accomplish an educational program that includes both information and emotional support to small, heterogeneous groups in a school environment. The teachers who would guide such groups of students should have good knowledge of potential student reactions. In addition, they should have worked through their own views in order not to confound their reactions with those of their students. With such a model, the risk of evoking uncontrolled anxiety would be minimized.

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