Increasing Dutch adolescents' willingness to register their organ donation preference: the effectiveness of an education programme delivered by kidney transplantation patients

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Background: This study assessed the effects of an educational programme about organ donation delivered by (ex-)patients with a successfully transplanted donor kidney on the willingness of adolescents to register their organ donation preference. Methods: A total of 319 secondary school students were randomly assigned to a control group who received no specific educational information about organ donation or to an experimental group who received a 45-min lesson provided by an (ex-)patient. The lesson consisted of a presentation of basic facts about organ donation, the patient's own experiences with organ donation and a discussion with the students about organ donation and related issues. Results: The educational programme increased the intention of the students to register their organ donation preference. Also, positive outcome expectancies, self-control over the decision, and knowledge increased and negative outcome expectancies decreased. However, it did not lead to a substantially larger percentage of students who intend to register themselves as a potential organ donor. Experimental students were less willing to let their relatives choose to make the decision in the case that they die, but reported being more willing to make the decision themselves through registration. Conclusions: (Ex-)patients with experience with organ donation can successfully encourage adolescents to make a well-considered choice with regard to organ donation registration.

Keywords: adolescents, education, (ex-)patients, organ donation, registration

B ecause of improvements in operation techniques and in medicines to prevent rejection of donor organs, transplantation of a donor organ is often successful and leads to a substantial improvement in quality of life in patients. However, in The Netherlands, as in many other countries, not enough organs are available to meet the growing needs for organ transplants. Consequently, many patients in need of a transplant cannot be helped, and long waiting lists for transplantations exist.1,2

This situation calls for the encouragement of people, and in particular adolescents, to make a decision about posthumous organ donation. At the age of 18 years Dutch adolescents are approached and invited to register their preference with respect to organ donation, including willingness or non-willingness to donate. In general, adolescents have a positive attitude towards organ donation, but there are still specific anxieties, prejudices and misunderstandings that prevent them from registering.1,2

A school-based education programme about organ donation might enable adolescents to make an informed decision about registration. This study examined the effectiveness of such educational information delivered by persons who had received organ transplants in the past.

Only a few studies have examined the effects of health education delivered by persons who have been infected with a specific disease and have experienced its consequences.3,4 Education from people who had experience with a specific disease or health problem brought about more positive attitudes,3 more knowledge3 and a higher intention to perform the desired behaviour.4 One study examined the effects of an education programme about drug abuse carried out by an ex-addict.5

Messages provided by ex-addict educators appeared to reach the target audience effectively. In another experimental study university students were provided with information and positive messages about organ donation.6 They were led to believe that the source of the information and messages was either a patient, a family member of the patient, a physician or an unknown ordinary person. It showed that in cases where an (ex-)patient was believed to be the messenger the increase in intended registration as a donor was as high as when the messenger was believed to be a physician or a family member, and was significantly higher compared with an unknown person.

Explanations for the positive effects of education by people who are directly involved in the issue at hand are that students feel more emotionally involved with a patient,7 the patients are perceived to be more open and honest,5 (ex-)patients do not use complex terminology3 and the communication with the students is informal, which makes social interaction easier.8

In addition, during the interaction there is revelation of myths and displacement of scientific aspects to a more personal level.9

As well as learning how a systematically developed intervention may increase donor organ availability to meet the increasing need for organs, the present study may contribute to our understanding of how to enhance altruistic behaviour to the benefit of public health.

According to the Dutch registration system, which has been in effect since 1998, every citizen in The Netherlands who reaches the age of 18 years receives a registration form with four options from which to choose: (i) registration as a posthumous donor for all organs and tissues or a restricted number of organs or tissues; (ii) registration as not willing to donate; (iii) registration to leave the decision to the next of kin; or (iv) registration to leave the decision to a specific person. The decision is centrally registered.7,8 After the diagnosis of the death of a patient, an authorized health-care provider can verify the patient's wish concerning organ donation.

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Registration is not compulsory. At the time of the assessment in December 2000, 38% of the Dutch inhabitants aged 18 years and older had been registered, of whom 54% had registered their willingness to donate their organs or tissues posthumously.9

Our hypothesis was that education about organ donation provided by persons who received a donor organ themselves will have a favourable influence on the intention to register an organ donation preference, on intended donation choice, and on determinants of these intentions including knowledge about organ donation, positive outcome expectancies, negative outcome expectancies, and social outcome expectancies.

Methods

Education and materials
The intervention was a 45-min lesson provided by five kidney patients during regular school hours. The educators all suffered from a kidney disease, had to undergo dialysis in the past and all carried functioning donor kidneys. Two female and three male patients aged between 44 and 64 years volunteered as educators. They had different levels of education and had different occupations. Prior to the experiment, during two training sessions, the patients were trained to give education on the subject. They were given the opportunity to think about the contents of the education, and they received an instruction manual.

The lesson consisted of three parts. Ten minutes were spent presenting basic facts about organ donation and the Dutch registration system; for ~20 min the patient talked about his or her own experiences as a kidney patient, e.g. about problems with his or her kidneys, experiences with dialysis and transplantation; and for 15 min the students were invited to ask and discuss any questions or issues about organ donation and organ transplantation with the patient educator.

Study design
The design of the experiment was a randomized post-test control group. Students were randomly allocated to one of the two conditions. The experimental group received the educational information by the patient while members of the control group completed a written questionnaire to measure their feelings and perceptions with respect to organ donation and registration and received no specific educational information by the patient educator.

Participants
A total of 319 secondary school students at four schools in the south of The Netherlands participated in the study. The education level of the students was either the Dutch HAVO level (higher secondary education level) \((n = 197)\) or VWO level (university preparation level) \((n = 122)\). Fifty-three per cent of the respondents were female. Ages ranged from 15 to 18 years \((\text{mean} 16.5; \text{standard deviation} 0.7)\). Of all respondents, 39% reported to be living in a village and 61% were living in a city. Most participants \((46\%)\) indicated being Roman Catholic, 14% Calvinistic, 10% Dutch Reformed and 30% reported having another or no religion.

Measurements
Effect measurement was informed by the Social Cognitive Theory,10 the Theory of Planned Behaviour,11 and by empirical evidence from research in which predictors of willingness to register as an organ donor were analysed.1,2

Data were collected by means of written questionnaires. Completion of the questionnaire took ~20 min. Data were collected on the following.

Socio-demographic variables. Participants were asked about their age, sex, education, religion and degree of urbanization.

Intention. Two questions measuring intention were included. First, students were asked whether they intended to fill in and send back the registration form. Participant’s reactions were measured on a five-point scale, ranging from ‘fully agree’ to ‘fully disagree’. The second question measured intention for registration choice; students were given the four different registration possibilities mentioned earlier, but classified in a slightly different manner: (i) registration as posthumous organ donor without restrictions; (ii) registration as donor for specific organs or tissues; (iii) registration as not willing to donate; (iv) registration to leave the decision to the next of kin or a specific person; and (v) a fifth option was added: ‘I wouldn’t send back the form’. A dichotomous registration variable was computed to compare participants who explicitly indicated that they would register as potential donors \((1 \text{ or } 2)\) with those who did not \((3–5)\).

Beliefs and attitudes. Relevant beliefs and attitudes related to donor registration were assessed with 27 items. A sample item was: ‘The shortage of organ donors is an important problem’. Statements were scored on five-point scales: ‘fully agree’, ‘agree’, ‘disagree’, ‘fully disagree’ and ‘I don’t know’. To reduce the dataset, factor analysis was conducted. This revealed five factors: anxiety, social outcome expectancies, negative outcome expectancies, positive outcome expectancies and self-control over the decision to donate. These factors accounted for 56% of the total variance and had internal consistencies of 0.75, 0.81, 0.65, 0.62 and 0.58, respectively.

Self-efficacy. Eight statements measuring self-efficacy were scored in a five-point format. A sample item was: ‘I am sure I can fill in the registration form’. Factor analysis revealed one factor (self-efficacy), with an internal consistency of 0.86.

Knowledge. Seventeen yes-or-no statements about prerequisites, procedures and consequences of organ donation and registration were included in the questionnaire. A sample item was: ‘People who smoke can be organ donors’. Factor analysis showed that the knowledge items formed one factor (knowledge) with an internal consistency of 0.71.

A review of the scales is presented in table 1.

Statistical analyses
Data were analysed using SPSS-11 for Windows. Success of randomization was checked on socio-demographic variables. No differences were found except for urbanization: the experimental group was more likely to be living in an urban environment. Therefore, this variable was used as a covariate in subsequent analyses. Intervention effects were tested using analysis of variance. Differences in intention for registration were determined using a \(\chi^2\)-test and logistic regression.

Results

Effect on intention to register
The experimental group and control group differed significantly in their intention to register \([F(1, 315) = 16.24; P < 0.001]\). Students who had been educated by a kidney patient were more willing to fill in the registration form than those who did not receive any education.

Intention for donation choice
Students in the experimental and control condition differed significantly in their choice for organ donation \((\text{table } 2)\) \([\chi^2 (4, 315) = 10.21; P < 0.05]\). More students from the intervention group reported to be willing to donate organs
Four respondents failed to give an answer on this item.

A logistic regression analysis was performed in which intended registration as a donor versus registration as non-donor was the dependent variable, and research condition and degree of urbanization were the independent variables. Although a larger proportion of students in the experimental group chose to become a donor (51% versus 43% in the control group) and a smaller proportion of this group chose to register as non-donor (49% versus 57%), the results were not significant. The lesson of the kidney patient did not lead to a substantially larger number of organ donors.

**Effects on determinants of organ donation**

Analysis of variance was used to examine the effects of the educational programme on anxiety, social outcome expectancies, negative outcome expectancies, positive outcome expectancies, self-control over the decision to donate, self-efficacy and knowledge (table 3). The experimental group reported significantly less negative outcome expectancies \( F(3, 315) = 4.49; P < 0.05 \), more positive outcome expectancies \( F(3, 315) = 7.47; P < 0.05 \), more self-control over the decision to donate \( F(3, 315) = 27.67; P < 0.001 \) and more knowledge \( F(3, 315) = 41.07; P < 0.001 \) than the control group.

There was an interaction effect of sex with the effects of the intervention on knowledge. More members of the control group would not send back the form and would leave the decision to others (35.6% versus 20.4%). The lesson provided by the kidney patient appeared to enable students to make a decision themselves.

A logistic regression analysis was performed in which intended registration as a donor versus registration as non-donor was the dependent variable, and research condition and degree of urbanization were the independent variables. Although a larger proportion of students in the experimental group chose to become a donor (51% versus 43% in the control group) and a smaller proportion of this group chose to register as non-donor (49% versus 57%), the results were not significant. The lesson of the kidney patient did not lead to a substantially larger number of organ donors.

**Differences between the patients/educators**

Differences in effectiveness between the five educators were tested in multivariate analyses, but no significant differences were found.

### Table 1 Properties of factors from factor analyses

<table>
<thead>
<tr>
<th>Factor (range)</th>
<th>No. of items</th>
<th>Mean (SD)</th>
<th>Eigen value</th>
<th>Explained variance (%)</th>
<th>Cronbach’s α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety (–2/+2)</td>
<td>5</td>
<td>–0.82 (0.77)</td>
<td>2.75</td>
<td>18.67</td>
<td>0.75</td>
</tr>
<tr>
<td>Social outcome expectancies (–2/+2)</td>
<td>4</td>
<td>–0.21 (0.64)</td>
<td>2.77</td>
<td>14.26</td>
<td>0.81</td>
</tr>
<tr>
<td>Negative outcome expectancies (–2/+2)</td>
<td>4</td>
<td>–0.64 (0.77)</td>
<td>2.43</td>
<td>8.77</td>
<td>0.65</td>
</tr>
<tr>
<td>Positive outcome expectancies (–2/+2)</td>
<td>4</td>
<td>0.87 (0.65)</td>
<td>2.18</td>
<td>7.54</td>
<td>0.62</td>
</tr>
<tr>
<td>Self-control over the decision to donate (–2/+2)</td>
<td>2</td>
<td>1.26 (0.76)</td>
<td>1.64</td>
<td>6.76</td>
<td>0.58</td>
</tr>
<tr>
<td>Self-efficacy (–2/+2)</td>
<td>8</td>
<td>0.38 (0.76)</td>
<td>4.02</td>
<td>50.19</td>
<td>0.86</td>
</tr>
<tr>
<td>Knowledge (0–14)</td>
<td>14</td>
<td>8.54 (3.07)</td>
<td>3.09</td>
<td>20.59</td>
<td>0.71</td>
</tr>
</tbody>
</table>

**SD: standard deviation**

### Table 2 Intention to donation choice

<table>
<thead>
<tr>
<th></th>
<th>Not sending back the form (%)</th>
<th>Leaving the decision to the next of kin or a specific person (%)</th>
<th>Not willing to donate (%)</th>
<th>Registering as a donor for specific organs or tissues (%)</th>
<th>Registering as a donor without restrictions (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental group (n = 152)</td>
<td>11.8</td>
<td>8.6</td>
<td>28.3</td>
<td>24.3</td>
<td>27.0</td>
</tr>
<tr>
<td>Control group (n = 163)</td>
<td>17.2</td>
<td>18.4</td>
<td>21.5</td>
<td>22.7</td>
<td>20.2</td>
</tr>
</tbody>
</table>

Note: Four respondents failed to give an answer on this item.

### Table 3 Significant effects failed to give an answer on this item

<table>
<thead>
<tr>
<th>Factor (range)</th>
<th>Experimental group [mean (SD)]</th>
<th>Control group [mean (SD)]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative outcome expectancies (–2/+2)</td>
<td>–0.56 (0.74) (n = 154)</td>
<td>–0.39 (0.68) (n = 165)</td>
</tr>
<tr>
<td>Positive outcome expectancies (–2/+2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boys</td>
<td>1.02 (0.69) (n = 79)</td>
<td>0.65 (0.68) (n = 91)</td>
</tr>
<tr>
<td>Girls</td>
<td>0.97 (0.56) (n = 75)</td>
<td>0.95 (0.54) (n = 74)</td>
</tr>
<tr>
<td>Self-control over the decision to donate (–2/+2)</td>
<td>1.39 (0.73) (n = 154)</td>
<td>1.02 (0.73) (n = 165)</td>
</tr>
<tr>
<td>Knowledge (0–14)</td>
<td>7.88 (2.28) (n = 98)</td>
<td>6.60 (2.70) (n = 99)</td>
</tr>
<tr>
<td>HAVO</td>
<td>8.91 (2.20) (n = 56)</td>
<td>6.18 (2.64) (n = 66)</td>
</tr>
</tbody>
</table>

**SD: standard deviation**

Posthumously. However, in addition, a larger proportion of the students in this group did not want to donate organs after death in comparison with the control group. More members of the control group would not send back the form and would leave the decision to others (35.6% versus 20.4%). The lesson provided by the kidney patient appeared to enable students to make a decision themselves.

A logistic regression analysis was performed in which intended registration as a donor versus registration as non-donor was the dependent variable, and research condition and degree of urbanization were the independent variables. Although a larger proportion of students in the experimental group chose to become a donor (51% versus 43% in the control group) and a smaller proportion of this group chose to register as non-donor (49% versus 57%), the results were not significant. The lesson of the kidney patient did not lead to a substantially larger number of organ donors.
Discussion

The present study examined the effectiveness of an education programme about organ donation for students in secondary schools delivered by patients who carried a transplanted donor organ (kidney). The results revealed that educational information given by patients increased the intention of the students to return a registration form, but did not lead to a substantially higher percentage of students who intend to register as a potential organ donor. It did enable students to make a decision about organ donation: the relatives were less often left to choose. The intervention also increased positive outcome expectancies, decreased negative outcome expectancies, increased self-control over the decision and, finally, increased knowledge.

How would one explain the fact that the intervention did not significantly increase the intention to register as an organ donor? Particularly because of the fact that the intervention had significantly decreased the students’ fear of being a donor and negative outcome expectancies, and increased social outcome expectancies, positive outcome expectancies and self-control over the decision to donate, one would expect all these attitude changes to have resulted in a significantly higher intention to register as a potential organ donor. One explanation may be that, after the intervention, the students had not yet discussed the issue of organ donation with significant others. Earlier research has indicated that the opinion of significant others (parents) about the issue of organ donation has an important impact on youngsters’ decisions about organ donation.1,2,12–14 Effect measures were taken 1 week after the intervention, which left little time to discuss organ donation with parents or friends. In particular, parents seem to be a key reference for students, as they realize that their parents will be the persons to be involved in decision making after their death. A second explanation could be that students were not ready to make a decision yet, while they may have perceived that there was plenty of time to make a decision (mean age was 16.5 years, while decision to make one’s preference known is requested at 18 years of age).

The effects found in this study correspond largely to the effects found in other studies in which people with experience of a specific disease or health problem provide education.3–6 However, some marginal notes have to be made with respect to the results. First, an unfavourable consequence of the study design was that several classes at the same school participated in the experiment at differing times and days. Students of different classes who already participated in the study may have talked with others who were yet to participate in the study. It is unclear whether this may have benefited or disfavoured the results.

Furthermore, only short-term effects of the intervention have been examined. The effect measurements took place ~1 week after the intervention. It may be that effects disappeared after a certain period due to a backsliding effect. But the opposite, a sleeper-effect, may have been more likely to occur; i.e. the possibility that on certain variables more effects would have been found after a longer period of time. This may have caused an underestimation of effects. The lesson by the patient has a positive effect on perceptions of self-control, outcome expectations and knowledge on organ donation.

We acknowledge J. van Hooff, E. Schaeken and A. Reubsaet, who helped to create positive conditions for the execution of the study. We also thank J. André, M. Brants, L. Van Dijke, J. W. Duizings and J. de Jong for participation in the training and for providing the lessons to the students. The intervention and the study were supported by a grant from the Institute HEALTH, University of Maastricht, The Netherlands.

Key points

- Does health education for adolescents delivered by persons who experienced the consequences of a disease and treatment (organ transplantation) enhance altruistic behaviour to the benefit of public health?
- Education of adolescent on organ donation by (ex-) patients increases intention to register their organ donation preference.
- Education of adolescent on organ donation by (ex-) patients has a positive effect on perceptions of self-control, outcome expectations and knowledge on organ donation.
- (Ex-) patients can be effective educators on issues related to their health problems.
- An education programme about organ donation provided by (ex-) patients is likely to be a successful method to stimulate adolescents to make a well-considered choice with regard to organ donation.

References


Received 4 March 2004, accepted 6 September 2004