Parental attitudes toward pediatric organ donation: a survey

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We conducted a telephone survey of parents in the National Capital Region to assess their intention to donate their child's organs and to provide physicians with information that could help alleviate their concerns about approaching parents for consent. Of 339 parents who agreed to answer questions after being given details of their child's "death" 288 (85%) said that they would be willing to donate their child's organs. The degree of willingness was associated with the certainty of death, altruism and empathy toward children in need of an organ, previous discussion of organ donation with a family member and knowledge of an adolescent or adult child's attitude toward donation. Factors that inhibited the intention to donate included uncertainty of death, insufficient information from medical professionals and fear of mutilation. The child's age was not significantly associated with intention to donate. Concordance between the results and actual donation rates in Canada and the United States supports the generalizability of the survey findings.

Enquête téléphonique auprès de parents vivant dans la région de la capitale nationale sur leur consentement éventuel à donner les organes de leurs enfants si ceux-ci venaient à mourir. On cherche ainsi à fournir aux médecins des informations pouvant leur faciliter la tâche délicate demander le consentement des parents. Des 339 parents qui ont bien voulu répondre aux questions après avoir pris connaissance des circonstances de la mort hypothétique de leurs enfants, 288 (85%) disent qu'ils seraient prêts à donner les organes de ceux-ci. Leur degré d'acquiescement est en raison de la certitude de la mort, de leur altruisme et de leur sympathie pour les enfants qui ont besoin d'organes, de ce qu'ils ont déjà parlé en famille du don d'organes, enfin de la connaissance de l'attitude, devant le don d'organes, de leurs enfants déjà adolescents ou adultes. Militent contre le consentement au don d'organes: l'incertitude de la mort, l'insuffisance des informations données par le médecin, la crainte d'une mutilation. L'âge de l'enfant n'entre pas significativement en ligne de compte. Il est loisible de généraliser à partir de nos trouvailles dans la mesure où elles concordent avec les taux de don d'organes consignés au Canada et aux États-Unis.

Organ transplantation affords a potential cure for end-stage renal disease and liver and cardiac failure and is a promising treatment of cystic fibrosis and diabetes.[1-3] Unfortunately, there is a serious shortage of organs,[4] especially for young children.[2,5,6] As more patients are being referred for transplantation without a comparable increase in the donation rate, the organ deficit is expected to grow.[7]

The shortage may be due to a reluctance by

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physicians to ask for consent rather than a refusal to give consent;[3,8] when families are approached more than 80% agree to donate the organs of a deceased loved one.[9-11] Medical professionals have reported inhibiting factors such as the fear of bothering a grieving family,[12] the fear of refusal[13] and no knowledge of the patient's wishes about donation.[14]

Knowledge of how parents feel about donating their child's organs before a request is made could address the pertinence of the inhibiting factors. If most parents were found to favour donation the physicians' concerns could be alleviated and requests for donation be increased. The available statistics[9-11] show that such an increase would raise the number of donated organs. We developed and tested a questionnaire to determine the intention of parents to donate their child's organs in case of death.

Methods

Subjects

The sample was chosen from the 1988 Ottawa–Hull telephone directory. A Hewlett-Packard 11-C random number program was used to generate two groups of 700 random numbers. The first group indicated the directory page number, and the second group identified the position of the listing on each page. If a business was chosen a new random number was generated for a different listing on the page. We asked any adult resident contacted to participate. People who were not parents were excluded.

A total of 350 parents agreed to participate. Given the parent:nonparent ratio we calculated a parental response rate of 80% using Fowler's procedure.[15] Among those who did not respond the reasons included refusal to participate because of a lack of interest or offence (9%), disconnected telephone service (4%), poor health or a recent death in the family (3%), a language barrier (2%) and unavailability (2%). Eleven parents chose not to complete the interview after hearing the vignette.

More than half (62%) of the subjects were mothers; most of the parents were between 26 and 45 years of age. The children ranged from newborns to adults. When asked about religious affiliation 52% of the subjects said that they were Catholic, 28% Protestant and 4% another denomination; 16% reported no religious affiliation. The socioeconomic status was calculated with the use of a socioeconomic index;[16] a full range was represented, the mean being in the third quartile of the sample population.

Chi-squared analyses, with the Bonferroni correction,[17] were used to compare the various attributes of interest.

Procedure

We developed the questionnaire from information in the literature on the need for and problems with pediatric organ transplantation.[1-14] The final questionnaire was pilot-tested on a random sample of 20 respondents from the overall survey population.

We mailed an introductory letter about 1 week before the interview to inform parents about the study and to explain how their name had been selected. Confidentiality was assured and the voluntary nature of participation emphasized.

The 10-minute interview consisted of an introduction, the presentation of a vignette and questions. The vignette was designed to elicit the intended behaviour of parents confronted with the opportunity to donate their child's organs. We chose intended behaviour as a measure of attitude because of the demonstrated high correlation between intention and actual behaviour;[18] thus, we believe that intention can be a good predictor of future behaviour.[19-21]

In accordance with the theory of attitude–behavioural relations[22] the vignette was matched closely in action (donating) and target (child's organs); to parallel the context it detailed the situation realistically. The parents were told that their child had been in a car accident and had suffered irreversible brain damage (one of the most common ways that children meet the criteria for cadaver organ donation[13]). The interviewers described the child's appearance to make the parents aware that their child would not look dead. The parents were given time to adjust to the "death" before organ donation was discussed with the family.[23,24] Altruism was offered as a reason for donation on the basis of research on donor families.[25,26] In addition, information obtained from studies of the experience of donor families after transplantation was provided to offer some comfort.[25,26]

Immediately before reading the vignette the interviewers warned the parents of its sensitive nature and reminded them again that their response was entirely voluntary. After reading the vignette the interviewers asked the respondents what they would do in this situation and what factors would encourage them to donate or discourage them from donating their child's organs. A 10-point scale, which was explained to the parents, was used to differentiate the responses. A rating of 5 suggested complete uncertainty. Less than 5 indicated an increasing tendency not to donate (0 signifying certainty), and greater than 5 indicated an increasing tendency to

donate (10 signifying certainty). The question about encouraging or discouraging factors was open-ended.

Results

Of the 339 respondents 288 (85%) assigned a value of 6 to 10, suggesting a favourable intention to donate their child's organs; 146 (43%) gave a score of 10 and 142 (42%) a score of 6 to 9 (Fig. 1). In a sample of 339 the chances are 95 out of 100 that the true population figure lies within a confidence interval of 0.038, between 81% and 89%.[15] Of the remaining 51 respondents 27 (8%) did not intend to donate their child's organs (score of 0 to 4), and 24 (7%) expressed complete uncertainty (score of 5).

For the remaining analysis we partitioned the respondents into three groups on the basis of their raw scores. The parents who gave a score of 0 to 5 were put in the "No" group (51), those who gave a score of 6 to 9 were placed in the "Maybe" group (142), and those who gave a score of 10 were entered in the "Yes" group (146). The group labels were chosen on the basis of the definitions of the scores given to the respondents.

A cluster analysis was done to organize the parents' descriptions of the factors that would encourage them to or discourage them from intending to donate their child's organs. Altogether 264 parents

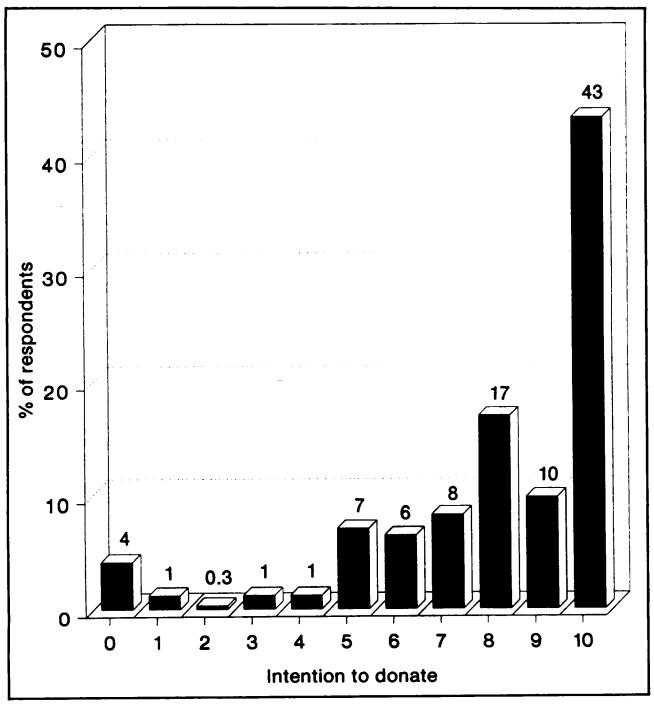

Fig. 1: Intention of 339 parents in National Capital Region to donate their child's organs according to 10-point scale: 5 suggested complete uncertainty, less than 5 indicated increasing tendency not to donate (0 signifying certainty), and greater than 5 indicated increasing tendency to donate (10 signifying certainty).

(78%) reported encouraging factors. They were given by 94% of those in the "Yes" group, 82% of those in the "Maybe" group and 33% of those in the "No" group. The factors most frequently reported were "To save another life" (by 164 [62%]) and "Certainty of death" (by 98 [37%]).

Discouraging factors were reported by 119 parents (35%); they were given by 70% of those in the "No" group, 43% of those in the "Maybe" group and 15% of those in the "Yes" group. The discouraging factors most frequently cited were "Uncertainty of death" (by 65 [55%]), "Not enough information from medical staff" (by 23 [19%]) and "Fear of mutilation" (by 12 [10%]).

Of the parents 231 (68%) did not know how many children in Canada needed an organ transplant, 302 (89%) overestimated the number of potential recipients who die before transplantation, and 288 (85%) overestimated the proportion of deaths in which organ donation is appropriate. More than two-thirds (70%) of the parents overestimated the likelihood that they would be approached if their loved one met the criteria for cadaver organ donation. Only 48 respondents (14%) knew someone who had donated or received an organ.

The age, sex, socioeconomic status and religion of the parents and the age of their children did not significantly relate to the parents' intention to donate. Only 156 (46%) of those who reported a religious orientation knew their religion's policy on organ donation. Of those, 120 (77%) said organ donation was favoured, and 36 (23%) said it was only slightly or not favoured.

The association between discussion of organ donation with family members and intention to donate was significant ($\chi^2 = 9.69$, 2 and 339 degrees of freedom [df]; $p < 0.008$) (Fig. 2). In the "No" group an equal number of parents indicated that they had or had not discussed organ donation. In the "Maybe" group the parents were 1.5 times as likely to have discussed it. In the "Yes" group they were almost three times as likely to have done so.

Awareness by the parents of their adolescent or adult child's attitude toward organ donation was significantly related to intention to donate ($\chi^2 = 12.88$, 2 and 172 df; $p < 0.002$). (The number of respondents is smaller because only parents of adolescents or adult children were asked this question.) Although most of the parents in the "No" and "Yes" groups reported being aware of their child's attitude (57% and 62% respectively) 66% in the "Maybe" group were not aware of it (Fig. 3).

Discussion

The large proportion of parents who expressed an intention to donate indicates that most parents,

when asked, are in favour of donating their child's organs. Although intention to donate will not perfectly predict parental behaviour because of social desirability, this is less of a problem with telephone surveys than with face-to-face interviews because of greater anonymity.[27] The similarity in the proportion of parents in this study who indicated an intention to donate (85%) and the actual proportion of families who consent when asked (over 80%)[9-11] supports the assumption that social desirability did not significantly influence our results. Moreover, there is evidence that the study sample is representative of the population in the National Capital Region since the socioeconomic data and the age of the parents were similar to the 1986 census data for that region.[28] A comparison of other demographic variables was not possible, as the census data did not give that information.

This study is unique because intention rather than global attitude, a characteristic of previous research,[29,30] was measured. The correlation between intention and actual behaviour has been found to be high,[18] whereas the correlation between global attitude and behaviour has been low.[31,32] Our study is also unique because it provides physicians with information not previously available on parental attitudes toward pediatric organ donation. Transplantation is more difficult among children than among adults because of (a) a shortage of donors, especially children under 10 years of age,[5] (b) fewer options to overcome this shortage[33] and (c) greater hesitation by health care professionals to approach parents because of the inappropriateness of early death.[34] However, regarding the last reason we found that the child's age did not influence the parents' intention to donate.

Helping of others is a prominent factor in the decision to donate,[25,26] as demonstrated in our study. This reason is also congruous with the guidelines of the American Hospital Association (AHA) for notifying donor families of their options. The AHA reports that donation is often a consolation and not an imposition to grieving next of kin.[24] Health care professionals who approach parents for consent must emphasize the altruistic aspects of donation.

The parent's confidence in the diagnosis of brain death appears to play an important role in the decision of parents to donate. The certainty and uncertainty of death constituted the most frequently reported encouraging and discouraging factors. The concept of brain death can be difficult for parents to understand when life signs such as respiration, continued digestion and heart beat are present. Simmons, Fulton and Fulton[25] found that many family members are bound to an "instant" notion of death and are reluctant to make a decision until that instant has occurred. Batten and Prottas[26] reported that almost 40% of donor families had difficulty in understanding brain death and needed a firm declaration of death by the physician before they would donate. The data from these studies and ours indicate that it is imperative for physicians to explain

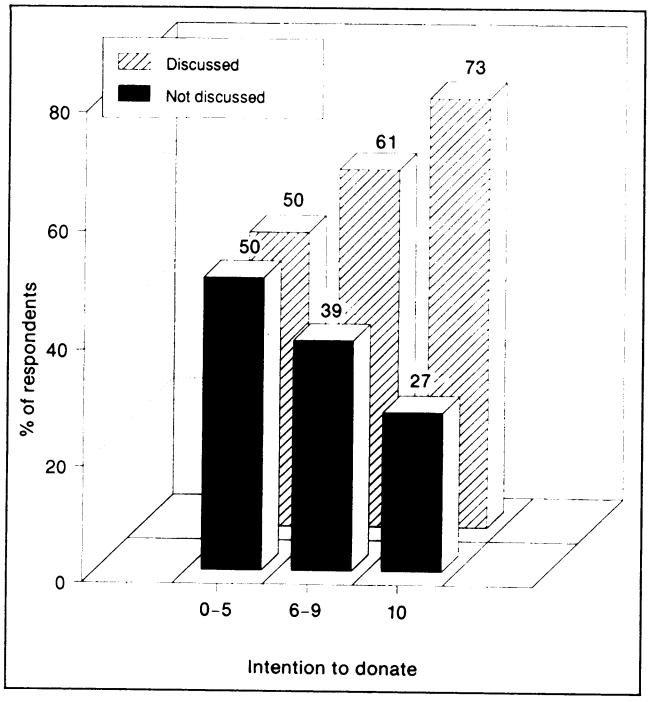

Fig. 2: Intention to donate child's organs in relation to previous discussion of donation with family member.

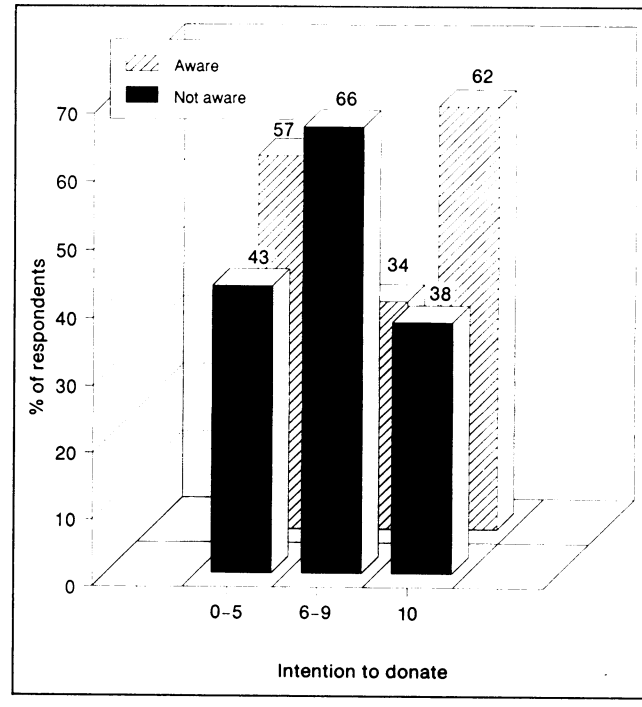

Fig. 3: Intention to donate child's organs in relation to awareness of adolescent or adult child's attitude toward organ donation.

brain death clearly and to emphasize the impossibility of error in declaring a child's death.

Although most parents reported little personal experience or knowledge of issues related to transplantation most still indicated a favourable attitude toward donation. The combination of a favourable attitude and the lack of awareness, in particular the parents' overestimation of the frequency with which physicians initiate the request, contributes to the shortage of pediatric organs. Apparently parents assume that they will be asked in appropriate donor situations; this suggests that when they are not asked, which is often the case,[3] they will not offer to donate because they do not think it is feasible.

It is important for parents to be aware of their adolescent or adult child's attitude toward organ donation; most of the parents who thought that they would donate their child's organs but had some doubt were unaware of their adolescent or adult child's wishes. Family members should be encouraged to discuss their feelings about donation if the donor shortage, particularly in the pediatric population, is to be overcome. In addition, family discussion is necessary, because although organ donor cards are legal documents the decision to donate is usually left to the next of kin.[23,25]

Most of the parents in our study were in favour of donating their child's organs if the need were to arise. As the results were in accordance with actual rates of donation in Canada[9,10] and the United States[11] they may be generalizable. These positive feelings may help to alleviate some of the concerns physicians have about the appropriateness of requesting organs and provide them with greater confidence that, given an optimal request situation, most parents will agree to donate their child's organs.

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