

Parents' attitudes towards children's transplantology

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Abstract

Introduction: Pediatric transplantation is an extremely complex and emotionally difficult area of pediatric medicine. The process of obtaining a pediatric donor by the staff is an extremely delicate topic, and for the family of the deceased child, often an unimaginable and painful process. The aim of the study was to analyze parents' opinions on pediatric transplantology.

Methods: The research survey method was applied using an original survey questionnaire made available electronically using a Google form. The group analyzed included 203 respondents.

Results: The attitude towards making transplant decisions among the respondents was positive. Education, age of parents and number of children did not influence attitudes towards pediatric transplantology.

Conclusions: There is a need for social education in the field of pediatric transplantation and to facilitate access to professional psychological care for pediatric patients and/or their caregivers.

Key words: attitudes, parents, pediatric transplantology.

Transplantology is a field of medicine that saves health and life, and is used in situations where available treatment methods and standards of practice are ineffective. Pediatric patients constitute a special branch of this part of medicine, because the selection of the donor and recipient depends not only on tissue compatibility, but also on the child's weight and height; Unfortunately, there are much fewer organs for pediatric recipients than for adult recipients, and the waiting time for a transplant is significantly longer.

Tissue and organ transplantation is often the only chance for cure for many children. Unfortunately, the limited number of organ donors often prevents effective therapy [1].

Transplant medicine is not only based on the relationship between the doctor and the patient, but has a clear social dimension. Due to making extremely difficult decisions at the time of trauma related to the death of a family member and the need for a holistic approach to the patient, the therapeutic team participating in the process of caring for the potential donor and his/her family often experiences strong stress, sadness or even trauma [2].

The main source of organs are brain-dead patients, but organ donation requires parental consent and the decision-making process, which is often complex and stressful, leads to refusal [3].

In addition, a serious problem is the lack of sufficient public awareness of organ donation, which may cause systemic problems both in declaring a patient's brain dead and in obtaining parental consent to harvesting organs from a deceased child. In Poland, there is "implied consent", which means that a doctor has the right to qualify a child to be an organ donor without asking for the parents' consent; in practice, such consent is asked from both parents after the death of the child [4, 5].

The aim of this study was to analyze parents' opinions on pediatric transplantology; therefore, the topic did not require the consent of the Bioethics Committee.

Methods. The research was conducted between November 21, 2022 and December 5, 2022. The analyzed group consisted of 203 respondents; in the statistical analysis, the group size was sufficient to conduct the study.

The study used a research survey method using an original survey questionnaire sent electronically using a Google form, consisting of 25 single- and multiple-choice questions. The survey was divided into three parts; in Part I, demographic data were collected regarding, among others, age, gender, place of residence, education, religion, fertility/number of children of respondents; Part II included questions assessing the level of knowledge of the respondents, and Part III determined the parents' opinions regarding consent to organ donation. Issues regarding the respondents' level of knowledge and opinions about transplantation were arranged in a well-thought-out scheme, which ensured reliable answers, without the possibility of returning to previous questions and changing the answers. Most of the questions were closed, which enabled the analysis of the collected results and the determination of preliminary correlations.

The inclusion criteria for the study were to having at least one child and the family's residence in Poland. Parents of children with chronic diseases and/or having the status of organ recipient/donor were excluded from the study.

The survey was made available in online support groups for parents: "moms to moms", "active dad" and in private messages to couples with children, asking them to complete the survey and share its link on their social media accounts.

Statistical analysis was performed in the MedCalc v.18 program. Quantitative data were analyzed using the Mann-Whitney *U* test in the case of two independent groups or the Kruskal-Wallis test in the case of three or more groups analyzed. Data distribution was assessed using

the Shapiro-Wilk test. Categorical data were assessed for statistical significance based on the χ^2 test. Statistical significance was determined at $p \leq 0.05$.

Results. 203 respondents took part in the survey, including 184 women and 19 men. Unfortunately, it was not possible to gather a group of comparable size in terms of gender, which significantly limited the possibilities of analyzing the results in this respect. The largest number of respondents, 45 people, were over 47 years of age (22.2%), but the age distribution of the population was relatively even, with the smallest percentage being people between 18 and 23 years of age (8 people). The remaining age options ranged from 15% up to 20% of respondents. Most of the respondents were people living in the countryside (48 people), but apart from the inhabitants of cities with over 500,000 population consisting of a group of 23 people, each group accounted for approximately 20% of the respondents. The vast majority of respondents were people with higher education (completed at least 15 years of education at primary, secondary and university levels), 133 respondents, which accounted for approximately 65.5% of all respondents. Slightly over 30% were people with secondary education (primary and secondary general education, i.e. approx. 10–12 years of education); 8 people declared themselves as having vocational education (primary and secondary education with a vocational profile). The remaining results are presented in the Table I.

The level of knowledge questions was assessed based on the percentage of correct answers according to the scoring: very bad (0–30%), bad (30.1–50%), moderate (50.1–65%), good (65.1–85%), very good (85.1–100%).

The scope of answers provided regarding, among others: the definition of death or the possibility of collecting organs from a living donor was on average 90.5% (very good); the respondents' answers regarding the legal status of asking for parents' consent to the removal of a child's organs were well formed. Respondents answered very poorly (the average of correct answers in this regard was 24%) when asked about the legal status in Poland regarding the issue of expressing the will to donate organs during life.

The analysis of the knowledge level index showed no significant differences ($DF = 2$, $p = 0.31$) regarding the result obtained depending on the nature of the work. However, the nature of the work was another factor influencing the response to educational needs in the field of transplantology. People working only physically saw the least need for education, while people combining physical and mental work expressed the greatest need for education in this matter.

Table I. Characteristics of the study group ($n = 203$)

Parameter	Result
Gender	Women 184 (90.5%), men 19 (9.5%)
Age	18–23 years old: 8 (3.9%), 24–29 years old: 43 (21.1%) 30–35 years old: 32 (15.8%), 36–41 years old: 32 (15.8%) 42–46 years old: 43 (21.2%), above 47 years old: 45 (22.2%)
Place of residence	Village: 48 (23.5%), City up to 50,000: 42 (20.7%), City 50,000–150,000: 49 (24.1%), City 150,000–500,000: 41 (20.2%), City above 500,000: 23 (11.3%)
Education	Higher education 133 (65.5%), secondary education 62 (30.5%), vocational education 8 (4%)
Religion	Roman Catholics 170 (83.7%), Atheists 19 (9.4%), Protestants 8 (3.9%), other 4 (2%), no religion 2 (1%)
Type of work	Physical-mental work 93 (45.8%), mental work 86 (42.4%), physical work 24 (11.8%)
The number of children	One child 97 (47.8%), two children 80 (39.4%), three children 16 (7.9%), more than three children 10 (4.9%)
Biological/adopted children	Only biological: 197 (97.0%), only adopted: 5 (2.5%), both: 1 (0.5%)

The assessment of point values obtained in the knowledge test did not show significant differences ($p = 0.08$, $DF = 4$) in relation to the place of residence. In the case of the remaining questions, place of residence was a statistically significant factor determining the answer to the question regarding the presence of a psychologist when asking for consent to organ donation after death. The lack of need for psychological help was expressed significantly more often by respondents from cities with a population of up to 50,000 inhabitants and cities from 50 thousand up to 150 thousand inhabitants.

The analysis of the points obtained in the knowledge test also in the case of education did not show statistically significant differences ($p = 0.3$, $DF = 2$). Education was an important factor determining the answer to the question about the need to intensify education in the field of transplantology in Poland. People with vocational education did not report such a need much more often, while respondents with secondary education significantly signaled this issue.

The respondents' religion was not a factor differentiating the point values of the results obtained in the theoretical test ($DF = 8$, $p = 0.38$ for the entire population, $DF = 2$, $p = 0.07$ for the population after excluding individual results). Orthodoxy, agnosticism and native faith concerned only one representative of a given religion. Moreover, respondents who marked the "hard to tell" option and people who did not declare any religion were isolated cases, therefore these results were omitted in further analysis.

The point values obtained in the knowledge test did not show significant differences ($p = 0.72$, $DF = 5$) in relation to the age groups of the respondents. However, it was an important factor

determining the opinion on the need to intensify education in the field of transplantology in Poland, showing statistical significance both in the case of distribution ($p = 0.003$) and trend ($p = 0.0003$). The analysis did not reveal any significant differences in the remaining questions.

Quantitative assessment of the knowledge index in terms of the number of offspring showed a result close to the level of statistical significance ($DF = 4$, $p = 0.053$). Moreover, post-hoc analysis showed a difference with $p < 0.05$ for respondents declaring having one and three children. Further calculations showed no significant differences in the remaining survey questions.

Adoption was the last factor analyzed in the context of the survey questions and was not a statistically significant variable ($DF = 2$, $p = 0.73$). In addition, one respondent marked the answer indicating having both adopted and biological children and was therefore excluded from further analysis.

Parents' attitudes towards pediatric transplantology turned out to be favorable; 202 respondents consented to the transplantation of a fragment or the entire organ to their child, only 1 person did not express such consent. 189 (93.1%) respondents answered that there was a need for the presence of a psychologist when providing information about the death of a child. The remaining 14 (6.9%) people did not consider it an important issue.

A similar question regarding the participation of a psychologist when asking for consent to organ donation after death showed that 85.2% of respondents believed that the psychologist should participate in the conversation, and 14.8% did not recognize such a need.

If a child is diagnosed with brain death and the doctor asks about the possibility of organ donation, 69% of respondents would agree to donate organs from their own child, 15.3% would agree, but only for selected organs, while 9.9% of respondents would agree if the child also consented while alive; 5.8% would not consent regardless of the circumstances.

The need for psychological care for the pediatric recipient's family was indicated by 177 (87.2%) respondents, and the lack of such a need was expressed by 26 (12.8%) respondents. As many as 95.6% of respondents reported the need to consult a psychologist when caring for the family of a pediatric donor.

Table II identifies significant statistical correlations between variables along with the degree of significance described.

Discussion. The attitude of parents regarding pediatric transplantology may be reinforced by the level of knowledge of the Polish society regarding the current legal status and ethical standards, which may be reflected in research conducted in 2020 among the residents of Gdańsk, where only 33% of respondents presented a high level of knowledge about the legal conditions in the field of organ transplantation. Important factors determining correct answers to the question about legal aspects were higher education (44.5% of people with the highest score) and younger age of respondents (50% answered correctly in the 18–29 age group) [6]. This study did not show any

significant differences in the level of knowledge about transplantology depending on the records. Perhaps the group of parents is quite a homogeneous group in terms of knowledge about legal and medical conditions regarding transplantology. This may be due to the fact that people having children, contact with health care professionals seems to be more frequent, which allows you to become familiar with and familiar with the medical staff. It should be noted, however, that the general results, both from available publications and from this study, still indicate a relatively low level of knowledge about transplantology in the Polish society. The median of correct answers in the parent population was only 42.9%.

The insufficient level of public knowledge is reflected in numerous scientific studies. Czaplińska *et al.*, when examining the level of knowledge about organ transplantation, showed that as many as 79.4% of respondents rated their level of knowledge as satisfactory or lower, and the average level of knowledge was 2.6. A statistically significant correlation between the sense of knowledge and its reflection in the theoretical test was demonstrated (Pearson correlation $r = 0.3$, $p = 0.01$) [7]. Also in studies conducted in Austria and Switzerland, the level of young people's knowledge regarding organ donation was insufficient [8].

Research shows that even in medical fields there are no classes promoting favorable attitudes towards transplantology. Almost every fifth nursing student declared that the above-mentioned

Table II. Significant statistical correlations

P-value	Data
1. Opinion on the need to provide psychological care to the child donor's family, broken down by gender $p = 0.04$	Women: Yes 178 (87.5%), No 6 (3%) Men: Yes 16 (8%), No 3 (1.5%)
2. Respondents' opinion on the participation of a psychologist during a conversation with a doctor regarding consent to organ donation after death, broken down by place of residence $p = 0.04$	Yes: 173 (85.2%), No: 30 (14.8%) Village: Yes 44 (21.7%) City up to 50,000: Yes 30 (14.8%) City 50,000–150,000: Yes 41 (20.2%) City 150,000–500,000: Yes 38 (18.7%) City above 500,000: Yes 20 (9.8%)
3. Opinion of the respondents regarding the need to intensify education in the field of transplantology, broken down by the type of work $p = 0.036$	Yes: 193 (95%), No: 10 (5%) Physical work: Yes 21 (10.3%) Mental work: Yes 80 (39.4%) Physical-mental work: Yes 92 (45.3%)
4. Opinion of the respondents regarding the need to intensify education in the field of transplantology, taking into account education $p = 0.015$	Yes: 193 (95%), No: 10 (5%) Vocational education: Yes 6 (3%) Secondary education: Yes 61 (30%) Higher education: Yes 126 (62%)
5. Parents' opinion on the need to intensify education in the field of transplantology, broken down by the age of the respondents $p = 0.0003$	Yes: 193 (95%), No: 10 (5%) 18–23 years old: Yes 6 (3%) 24–29 years old: Yes 37 (18.2%) 30–35 years old: Yes 31 (15.3%) 36–41 years old: Yes 31 (15.3%) 42–46 years old: Yes 43 (21.1%) Above 47 years old: Yes 45 (22.1%)

classes were not available at their university during their education [9].

Hoover *et al.* described the experiences of parents of children qualified as organ donors in intensive care units in the United States. Protection of the body and assistance in dying peacefully were identified as factors significantly influencing decision-making regarding organ donation after a child's death. Parents were asked to formulate recommendations for clinicians, which demonstrated the need for empathy, a clear explanation of the situation and intensification of educational activities [10].

In a study conducted in China among donor families, as many as 72.6% of respondents admitted that they were not provided with sufficient emotional, informational and material/financial support which seems to be one of the factors determining of consent to organ donation [1].

Moreover, it has been proven that urban residents are more willing to be organ donors than rural residents; people with higher education are more aware of the need for transplantation and are much more willing to donate an organ. The main factors contributing to young people's willingness to be a donor were a social environment providing support and the willingness to fulfill their last will after death. The main factors influencing the respondents' reluctance to donate organs resulted from low awareness of transplantation or misconceptions about organ donation [11].

The research coincides with the Italian results, which highlighted the need to raise awareness, promotion and social education regarding organ donation in order to dispel misconceptions [3].

The above data correlate with the results of the research conducted – as many as 93.1% of parents indicated a strong need for a psychologist's participation when providing information about the child's death and when asking for consent to organ donation after death (85.2%). During the analysis of the results obtained, as many as 95.5% of parents indicated the need to provide psychological care to the pediatric donor's family; 85.2% of respondents declared a strong need for a psychologist's participation when providing information about a child's death and when asking a doctor for consent to organ donation after death. Women significantly more often indicated the need for psychological support ($p = 0.04$).

The nature of the respondents' work was also a factor influencing the declaration of educational needs in the field of transplantology. People working physically more often indicated the lack of need to intensify promotional activities related to health promotion with a statistical significance of $p = 0.036$. This may be due to the fact that, apart from the level of knowledge, which is quite

uniform in the society, self-awareness regarding the social dimension of the issue of transplantation is also important. This topic requires social research because previous publications ignored these issues.

The respondents' attitude towards transplantation may be determined by their current professional situation. This was demonstrated by research from the Center for Social Research conducted in 2016, revealing the reluctance to donate organs after death was twice as high in such groups as service workers (12%), unemployed people (8%) and among people in a bad financial situation (10%) [12]. It is possible that the data presented resulted from an insufficient level of knowledge and individual beliefs and values that guided society.

Education was also a significant factor determining the answer to the question about the need to intensify education in the field of transplantology ($p = 0.015$). People with vocational education clearly more often did not recognize such a need, while respondents with secondary education significantly signaled this need, being more favorable to the implementation of educational activities in this area.

However, this work has several limitations. The most important of them is the different size of groups as regards gender, education or type of work. This means that responses to a given topic may not reflect the exact distribution of opinions among these subgroups. Moreover, many opinions were similar in individual groups, which made the analysis of the factors that determine the answer to the question much more difficult. Therefore, further research is necessary on a larger number of respondents which will reflect the demographic structure of Poland based on current statistical data.

The collected results can be used to develop materials promoting organ donation on social media with a large reach. The issue of organizing sports and cultural events promoting transplantology also has great potential. Even though awareness about transplantology has been increasing over the years, there are still no activities in this area that would be noticed by the public.

Health education, especially in the context of awareness-raising and social education, still remains a significant area of medical activities in order to provide maximum access to reliable information regarding promotion and prevention, which in the long run will certainly influence attitudes towards transplantology.

Future research should also focus on developing the best possible methods of communication with the patient's family and determining the impact of the introduced educational activities aimed at the entire society. It seems necessary to

develop training for health care workers involved in the transplantation process and psychological support for donor families.

In conclusion, the attitude of parents towards making transplant decisions is positive and most respondents are favorable to donating their children's organs after death. The level of education, age of parents and number of children did not influence social attitudes towards pediatric transplantology. Education was an important factor determining the need to intensify education in the field of transplantology. People with primary and secondary education with a vocational profile did not report such a need much more often, while respondents with primary and secondary education with a general profile reported this to a significant extent ($p = 0.015$). There is a need for social education in the field of pediatric transplantation and psychological support for the families of pediatric donors.

Conflict of interest

The authors declare no conflict of interest.

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