ABSTRACT

**Objectives:** To know the opinion of senior high school students in public and private schools on the process of donating and transplanting organs and tissues, and their desire to be donors. **Methods:** A descriptive cross-sectional study, conducted from 2004 to 2005, on the opinion/knowledge of senior high school students in public and private schools in the Vila Mariana region of the city of São Paulo, on the process of organ and tissue donation and transplantation. The convenience sample was made up of 140 (81%) students from two private schools and 167 (51%) students from a public school. The project was approved by the Research Ethics Committee of the UNIFESP. **Results:** Data showed that 163 (53.1%) students believe that donation is by presumed consent and 147 (47.9%) that consider that it occurs by informed consent. Of the public school students, 120 (71.9%) believe that transplants are public and free of charge in Brazil versus 94 (67.1%) of the students from private schools. Students know that donations may be made by living or dead donors (121 - 86.4% private schools versus 113 – 67.7% public school). We highlight that 22 (15.7%) of the private school students and 16 (9.6%) of those from the public school believe that the commerce of organs is allowed in Brazil. As to intentions of being a donor, 108 (77.1%) of the private school students declared themselves organ and tissue donors versus 106 (63.5%) from the public school, and 63 (59.4%) from the public versus 61 (56.5%) from the private schools have already informed their families. **Conclusion:** There was no difference in knowledge and opinion among the students from the public and private schools as to aspects regarding donation and transplantation.

**Keywords:** Directed tissue donation /legislation & jurisprudence; Health knowledge, attitudes, practice

RESUMO

**Objetivos:** Conhecer a opinião dos alunos do último ano do ensino médio de escolas públicas e privadas sobre o processo de doação e transplante de órgãos e tecidos e o desejo/vontade de ser doador. **Métodos:** Estudo descritivo, transversal, da opinião/conhecimento de alunos do último ano do ensino médio de escolas públicas e privadas sobre o processo de doação e transplante de órgãos e tecidos na região da subprefeitura de Vila Mariana do município de São Paulo, realizado de 2004 a 2005. A amostra por conveniência foi constituída por 140 (81%) alunos de duas escolas privadas e 167 (51%) de uma pública. Aprovado pelo CEP da UNIFESP. **Resultados:** Os dados mostram que 163 (53,1%) dos alunos acreditam que a doação é presumida e 147 (47,9%) que é consentida. Dos estudantes da escola pública, 120 (71,9%) acreditam que o transplante é público e gratuito no Brasil versus 94 (67,1%) das escolas privadas. Os alunos sabem que a doação pode ser intervivos e doador falecido (121 – 86,4% do ensino privado versus 113 – 67,7% do público). Vale ressaltar que 22 (15,7%) dos alunos da escola privada e 16 (9,6%) da pública acreditam que o comércio de órgãos é permitido no Brasil. Quanto à intencionalidade de ser doador, 108 (77,1%) dos alunos do ensino privado se declararam doadores de órgãos e tecidos versus 106 (63,5%) do ensino público e 63 (59,4%) do público versus 61 (56,5%) do privado já comunicaram à família. **Conclusão:** Não houve diferença de conhecimento e opiniões entre os alunos das escolas públicas e privadas sobre aspectos do processo de doação e transplantantes.

**Descritores:** Doação dirigida de tecido/legislação e jurisprudência; Conhecimentos, atitudes e práticas em saúde
INTRODUCTION
In 1964 the first activities related to organ and tissue transplantation occurred in the city of Rio de Janeiro. Then, in 1965, the first two renal transplants of the country were performed in São Paulo(3).

At that time, treatment by transplantation was not as successful as expected. After a few years, with technological and scientific developments, transplants gained greater credibility and national regulations were established. Thus, in 1997, Law n. 9.434 was promulgated creating the National Transplantation System (SNT – acronym in Portuguese) in Brazil and modifying the type of donations to presumed consent donations. Every legally competent citizen became a donor unless he/she dissented; for this, his/her express will had to be stated on the driver’s license or national registry identification document.

In 1998, due to the great controversy generated by this legislation, a provisional measure was issued adding a paragraph to the Law, transforming presumed consent donations into informed consent donations, i.e., the donor’s family must be consulted for the donation to occur(5).

Even with this legal protection, organ and tissue donation in Brazil still has a low rate of donors when compared to other places of the world. In Europe, there are approximately 40 donors for every million population (pmp), whereas in Brazil, the number is around five donors for every million inhabitants(5).

The recent publication of the Brazilian Transplant Register highlights a tendency of the number of effective donors to diminish, or at best, to stagnate. In the year 2006, there were 532 donors, which corresponds to 5.8 pmp a year (in 2004 this rate was 7.4 and, in 2005, it was 6.3 pmp)(4).

These data lead one to reflect on the motives that determine low rates of organ and tissue donations for transplants in Brazil, considering that to donate an organ or tissue is considered an act of solidarity that implies preexisting ethical and moral concepts, many of them acquired over one’s lifetime.

Factors that can lead to non-donation include lack of knowledge/information on the process of donation/transplantation, fear of organ commerce, religious beliefs, socioeconomic and educational aspects, gender, racial/ethnic, and generational issues, religious issues pertaining to the postmortem body, suspiciousness and ignorance about diagnosis of brain death, that may generate conflicts as to the whether or not to donate.

Recent studies present determining factors for an individual’s willingness to donate his/her organs and tissues, including political, educational, gender, ethnic, religious, legislative/regulatory issues, as well as the interaction between family members of a potential dead donor and medical professionals(5).

In donation and transplantation, both public and professional education is essential since in this area, more than in any other health-related area, the participation of health care professionals and of society is one of the determining factors for success or failure of transplant programs(3).

This study is based on research of the opinions of senior high school students since, theoretically, they should have received information on many topics, among them donation and transplantation of organs and tissues, and may have already formed an opinion on the subject.

Similar studies show that in Uppsala, Sweden, in spite of having a favorable opinion, only 50% of the high school level students were interested in donating their own organs, and 20% the organs of their parents(6).

In Seattle, USA, a study that evaluated knowledge and opinion among high school students as to the organ and tissue donation/transplantation process, noted that more than 50% of the adolescents did not know how to answer 13 of the 16 research questions(7).

On the other hand, in Torino, Italy, a study was conducted with the objective of assessing the impact of educational programs for high school students on the subject of organ donation in which 76.8% of the teens responded that they are in favor of donation, and approximately 98% appreciated the program and suggested that the experience be extended to other schools(8).

The present study also seeks to obtain subsidies for proposing information campaigns divulging organ and tissue donations/transplants in order to increase the number of donors in Brazil, and carry out orientation through high school pedagogical projects with meetings among those graduating in health-related courses that are a part of the Organ and Tissue Donation League of the Universidade Federal de São Paulo in order to discuss the subject.

OBJECTIVES
To know the opinion of the senior students in public and private high schools on organ and tissue donation and transplantation process, and their desire to be donors or non-donors, and identify the students’ knowledge as to the diagnosis of brain death (BD), legislation regarding transplants in Brazil, criteria for donors, which organs and body tissues can be donated, and the institutions responsible for conducting transplants.

METHODS
This was an exploratory, descriptive cross-sectional study on the opinion/knowledge of adolescents in the
senior year of public and private high schools in the Vila Mariana region of the city of Sao Paulo, from the second semester of 2004 through the year 2005, as to organ and tissue donation/transplantation in Brazil.

The study population comprised senior students from two private high schools with 173 students enrolled during the period, and one public high school with 330 students enrolled during the period.

The sample was formed by convenience, and the only criterion established for study participation was the manifestation of interest on the part of the teens, resulting in 140 (81%) students from the private schools and 167 (51%) from the public school.

The research instrument used was a self-completed questionnaire with closed questions that covered aspects of legislation on organ and tissue donation and transplantation (Annex 1).

The study was approved by the Research Ethics Committee of the UNIFESP and was submitted to the Pedagogical Coordination of the three schools for appreciation; all three agreed to participate in the study.

RESULTS

The study collected the opinions of 307 high school students as to organ and tissue donation and transplantation, showing that this theme is not a part of the normal day-to-day school environment conversations.

Figure 1 shows that students still believe that donation is based on presumed consent, since 163 (53.1%) think that an individual's manifestation of the desire to be an organ and tissue donor should be recorded in his/her identification document, while 147 (47.9%) know that donation is based on informed consent.

Most students know that organ donation in Brazil is not mandatory, regardless of the school they attend (162 – 97.0% private versus 139 – 99.3% public). Additionally, they believe that transplants can occur with living and dead donors (121 – 86.4% private versus public 113 – 67.7%). It is noteworthy that 18 (12.9%) of the students from private versus 41 (24.5%) from public schools think that the transplants only occur with dead donors (Figure 2).

As to the need for the diagnosis of brain death (BD) that defines a potential donor, 227 (73.9%) of the students know that BD is an absence of blood flow with a loss of cerebral functions.

As to financing for transplants, data show that 120 (71.9%) of the public school students and 94 (67.1%) of those in private high schools believe that transplants are public and free of charge in Brazil, and 30 (21.4%) of the private school students believe the treatment is paid for by the patient.

Data show that about half of the students know that there is a National Transplant System (SNT) in the country that coordinates all activities related to this treatment (84 – 50.3% in public schools versus 73 – 52.1% in private schools).

Furthermore, results show that, even with publicity campaigns on donation and transplants, 22 (15.7%) of the private school teens and 16 (9.6%) of those from public schools believe that the commerce of organs is allowed in Brazil (Figure 3).

Figure 1. Opinion of senior high school students about requirements to be donor in Brazil. Vila Mariana, city of Sao Paulo, 2005

Figure 2. Opinion of senior high school students about situations when it is possible to donate organs and tissues for transplant. Vila Mariana, city of Sao Paulo, 2005

Figure 3. Knowledge of senior high school about the question “Is commerce of organs allowed in Brazil?”. Vila Mariana, city of Sao Paulo, 2005
Students know that a donation from a living donor cannot occur between strangers (106 – 63.5% in public versus 59 – 42.1% in private schools). Nevertheless, it was noted that among teens from the public school, 25 (15.0%) believe that husbands/wives, 19 (11.4%) mothers, and 14 (8.4%) fathers cannot be living donors versus 27 (19.3%) husbands/wives, 15 (10.7%) mothers, and 8 (5.7%) fathers opined by the private school students.

Considering only those who know that transplants between living individuals exist, in public schooling, 82 (49.1%) know that bone marrow can be transplanted, 54 (32.3%) the liver, and 143 (85.6%) the kidneys. In private schools, 82 (58.6%) answered that bone marrow, 45 (32.1%) liver, and 127 (90.7%) kidneys can be donated by living donors.

Students believe that the main organs that can be donated are the heart (154 – 92.2% public and 129 – 89.3% private), kidneys (163 – 97.6% public and 138 - 98.6% private), and liver (122 – 73.0% public and 114 – 81.0% private).

Figure 4 shows that 108 (77.1%) of the students in private schools declared themselves organ and tissue donors versus 106 (63.5%) in the public school. More than half of these affirmed that they had already informed their families about their desire to donate their organs and tissues (63 – 59.4% public versus 61 – 5.5% private). Among the donors who had not yet informed their families, 43 (40.6%) were in public schools and 41 (38.0%) in private schools, while 48 (28.7%) of the public and 27 (19.3%) of the private school students declared themselves non-donors.

**Figure 4.** Intentionality of senior high school students as to being donors or non-donors of organs and tissues. Vila Mariana, city of São Paulo, 2005

Results show that a large part of the teens interviewed believe that the best way to obtain information on donation and transplantation of organs and tissues is through lectures given at schools (109 – 73.6% private versus 109 – 65.3% public).

**DISCUSSION**

Since 1997, with the establishment of the SNT with its own organization, activities have been conducted by the State Centers of Notification, Procurement and Distribution of Organs – CNCDO (acronym in Portuguese). These centers are responsible for the control of notification and distribution of organs and tissues, based on technical rosters for each organ (9-11).

The transplant program in Brazil has been recognized for its growth in the number of transplants and by public investment in the specialization of its teams. The number of solid organ transplants performed in 1997 was 2127, and increased to 3916 in 2001. Additionally, in Brazil, the Unified Health System – SUS (acronym in Portuguese) finances more than 95% of the transplants carried out and also subsidizes all immunosuppressive medications (1).

At present, according to data from the Brazilian Register of Transplants, the official organ of the Brazilian Association of Transplants – ABTO (acronym in Portuguese), the general total of transplants performed was 8563 during the first semester of 2006 (4).

The establishment of the SNT made Brazil stand out as one of the countries with the highest number of transplants performed. The country has, in terms of investment, the largest public organ and tissue transplant program in the world. The Unified Health System (SUS) is responsible for 92% of the transplants carried out in Brazil.

According to data available from the SNT portal, in 2003 there were 12710 transplants conducted in Brazil. Of these, 8544 were performed by the Unified Health System – SUS, whereas in 1995, a total of 4122 transplants were done, representing an increase of 107% in the number of transplants performed by the public system. However, by November 2004, the waiting list for transplants had reached the number of 63600 patients (12).

The SNT has recognition on the part of the Brazilian society, patients, and transplant community. This merit is a result of actions on the part of the Brazilian Ministry of Health in this area by prioritizing a national transplant policy as well as clear and objective management of the system aiming to increment this activity in the country (13).

Despite the progress in number of transplants performed in the country, educational measures merit greater public investment since the limited knowledge on the part of the population as to the process of donation and transplantation of organs and tissues can be one of the factors explaining the low rates of donations per million population found in Brazil.

The legislation that created the SNT and modified the type of donation adopted in the country to presumed consent in 1997, despite having been converted back

A study carried out by the Unifesp undergraduate Nursing research grant holders in 2002, showed that 47.7% of the students in Nursing, Medicine, Biomedicine, Speech Therapy, and Ophthalmic Technology knew that donation occurred by informed consent and 43.8% did not know how to answer the question(14).

There is similarity in the opinions of the graduating students and those still in high school, showing that publicity campaigns and the inclusion of content relating to organ and tissue donation and transplantation in health care professional training, do not seem to have reached the objective of transmitting knowledge and information on organ donations and transplants.

Despite surveys having included the lack of knowledge on the part of the population on the concept of BD, data seem to show the opposite. A survey conducted with family members of dead donors of the city of São Paulo who had gone through the experience of donating the organs and tissues of their deceased loved ones, showed that 66.7% of them had no doubts as to the diagnosis of BD, and among those who did have uncertainties, 73.9% were able to clarify these doubts(13).

A study carried out with district attorneys, judges, chronic renal disease patients, professionals from the technical transplantation team, and the general public interviewed on the street on the inefficacy of legislation in impeding the commerce of organs and tissues reported that “80% of those interviewed think that the Brazilian Law, in allowing organ donations from non-related living donors, enables remunerated donations or the commerce of organs”(15).

The author further points out that, besides the phantom of kidney merchandizing between living non-related individuals, the Brazilian legislation has not been sufficient to prevent possible ethical-legal deviations.

The study shows that approximately half of the senior high school students of three schools from the Vila Mariana region of the city of São Paulo are not acquainted with the National Transplant System, and after applying the research instrument, the students had questions as to how it works, as they knew it existed but did not understand its purpose.

Law n. 9.434 of February 4, 1997, expands the criteria for living donor donations, allowing any legally capable person to donate, for transplant, one of his/her double organs, as long as this donation does not compromise the donor’s health and is without payment. Also, its scope of intervention covers knowledge of brain death verified in any location of national territory and the determination of the destination of the tissues, organs, and parts removed(16).

Data show ignorance as to legislation pertaining to living donor transplants, and calls attention to the difference in percentages of non-donations between mothers and fathers in both groups.

Another important aspect of the study deals with the intentions to donate organs and tissues on the part of senior high school students from two private schools and one public school of a neighborhood in São Paulo that proved to range from 63.5 to 77.1%. However, about 40% did not inform their families as to their desire, since in informed consent donation, only the family can authorize post-mortem donations. In a population-based study in Brazil about the intention of donating organs, 52% of the 3519 individuals interviewed had the intention of donating their organs, and among these, only 58% had informed some relative as to their desire. Most (80%) families authorize organ donation after the death of a loved one who had previously manifested this desire(16).

A study conducted with 69 family members of deceased donors by the Organ Procurement Organization of the Universidade Federal de São Paulo (Unifesp), 63.2% of the family members had prior knowledge of the desire of their deceased loved one to donate organs and tissues, and 36.8% did not know. Among those who were aware of the donor’s wishes, 90.5% stated that this was important for the decision making process(15).

In this way, it is necessary to emphasize the importance of communicating the decision about organ and tissue donation to family members, provide lectures in clubs, universities, unions, factories, or any other venue where an interest in the subject is expressed; public education is needed by means of community, academic, religious, and medical programs, especially among minority groups, as well as training of educational coordinators, generally health care professionals, college students, and volunteers(17).

The abovementioned educational measures were mentioned by the students who participated in the study, since they manifested interest in receiving orientation through lectures on the subject.

**CONCLUSION**

Study data allow one to conclude that most of the senior students in public and private high schools of the Vila Mariana region of the municipality of São Paulo:

- know that organ and tissue donation is not compulsory and are acquainted with donor criteria, but half of them believe that they should record their wish to be a donor in a document; they also know that the donation can be done with living donors, deceased donors, and
that among living individuals, no donation can occur between strangers;
• know the definition of brain death and which organs can be donated, but as to tissues, there are still questions as to removal of skin and bones, especially regarding disfiguring the body of the deceased donor;
• most declared that they are donors, and more than half of them have already informed their families.

Youth people need systematic information, transmitted through discussions in school environments. This desire was reported verbally after the discussions that occurred at the end of the survey in each classroom in order to answer questions. Televised messages did not affect the general public since even though the teens demonstrated a relative knowledge of the donation/transplant process, they still had not communicated to their families their wish of becoming a donor or not.

REFERENCES
### Annex 1. Research Instrument

1. Is organ and tissue donation compulsory in Brazil?  
   A ( ) Yes  
   B ( ) No

2. Are donations possible between living individuals?  
   A ( ) Yes  
   B ( ) No

3. To be a donor, a person must:  
   A ( ) Leave a [written] statement declaring whether or not he/she is a donor  
   B ( ) Record his/her wishes regarding becoming a donor on the identification document or driver’s license  
   C ( ) Be on a list at institutions responsible for transplants  
   D ( ) Nothing is necessary since transplants are mandatory in Brazil  
   E ( ) Inform his/her family or guardian as to this desire, since they are the ones who will provide the necessary authorization for the transplant

4. What is brain death?  
   A ( ) It’s when a person is in a coma  
   B ( ) It’s when there is no more blood flow to the brain, and the person loses his/her normal functions  
   C ( ) It’s when all body organs stop functioning  
   D ( ) It’s when the heart stops beating

5. In what situation is it possible to donate organs and tissues?  
   A ( ) Between living individuals  
   B ( ) From deceased to living individuals  
   C ( ) Both answers are correct  
   D ( ) None of the alternatives above

6. Mark which organ(s) and tissue(s) can be donated:  
   ( ) Heart  
   ( ) Kidneys  
   ( ) Liver  
   ( ) Pancreas  
   ( ) Cornea  
   ( ) Lungs  
   ( ) Bone  
   ( ) Skin  
   ( ) Bone marrow  
   ( ) Heart valves  
   ( ) Intestines

7. Which organs can be donated from a living donor?  
   ( ) Kidney  
   ( ) Liver  
   ( ) Bone marrow

8. In living donor transplants, who cannot donate?  
   A ( ) Father  
   B ( ) Mother  
   C ( ) Husband or wife  
   D ( ) A stranger/unknown person

9. Do you know if there is a National Transplant System in Brazil that coordinates activities related to this treatment?  
   A ( ) Yes  
   B ( ) No

10. In Brazil, transplants are:  
    A ( ) Public and free of charge  
    B ( ) Privately financed  
    C ( ) Performed only if the patient has a health insurance plan  
    D ( ) None of the above

11. Does legislation on organ and tissue donation and transplantation in Brazil allow organ commerce (payment)?  
    A ( ) Yes  
    B ( ) No

12. Do you think the person who receives the transplant is cured completely and does not need to go to continue seeing a doctor?  
    A ( ) Yes  
    B ( ) No

13. How did you learn about organ and tissue donation and transplants?  
    ( ) Internet  
    ( ) Newspapers and magazines  
    ( ) At school  
    ( ) Information campaigns on TV  
    ( ) My family  
    ( ) My friends  
    ( ) Books  
    ( ) Other

14. What is the best way to convey information on organ and tissue donations?  
    ( ) Lectures  
    ( ) Pamphlets  
    ( ) As a science subject  
    ( ) Other

15. Are you a donor?  
    A ( ) Yes  
    B ( ) No

16. Have you informed your family about your decision?  
    A ( ) Yes  
    B ( ) No