

People's Responsibility towards Organ Donation an Unanswered Appeal

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ABSTRACT

People easily agree with the principle of organ donation; nevertheless, when a person dies, their relatives often refuse to honour this agreement. Because of this persistent social conduct, organ shortage is responsible for the rising mortality of patients on organ waiting lists. This sad reality continues despite the ongoing education effort with the enduring slogan: "Organ donation is a gift of life".

The main solutions to this health crisis can be found in:

1. Legal alternatives,
2. Expanding donor acceptance,
3. Education, and
4. Economic incentives.

On the other hand, it should be stated that youths have not yet been sufficiently targeted regarding education on organ donation and transplantation. To prepare young children for their future role in society, schools should incorporate educational concepts about transplantation into their curricula. Educating children about organ transplantation might be, with time, another way to improve social feelings towards organ donation.

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Introduction

Scientific advances in transplantation medicine are impressive, and it is difficult to predict how far they will go this century [1]. Surveys show that most people, when asked, openly agree to offer their organs for transplantation. However, the real experience is that, when faced with the death of a loved one, relatives often refuse to donate [2].

The consequent cruel reality is that such behaviour condemns patients on waiting lists to an "unfair death". This insufficient conduct could be related to the possibility that society, although it has received extensive education regarding transplantation and organ donation, has not been able to identify the essential message: That the advances of science have turned our bodies, essentially after life, into potential sources of survival through organ transplants [3].

It is true that thousands of people die every day because of socioeconomic inequalities [4]. However, the solution to people dying while waiting for an organ is in our hands – society must accept its civic responsibility regarding the dilemma of organ shortage.

Defining the problem. What needs to be solved?

In the last decades, society remains reluctant as regards organ donation. A recent study showed that of the potential deceased donors in the USA, only 42% were used. A similar social behaviour has been observed in Europe. It is important to note that the incidence of refusal to donate in the case of potential deceased donors is no different between developed and undeveloped countries. Undoubtedly a change in the current global educational policy of the authorities of Health and Education, practically worldwide, will be an initial step, fundamental to the achievement of a change of this serious social crisis that means the organ shortage [2, 5, 6].

To change this ambivalence in the public, it is fundamental to search the reasons of this conduct.

An analysis of the different suggestions to modify the factual barriers to organ donation and transplantation highlights targets

- A) The patients and the public
- B) The healthcare professionals

Barriers from the viewpoints of the patients and the public

The inadequate social behaviour concerning organ donation diverges from some principles in the UNESCO declaration about the responsibility of present generations over future generations, where the task of protecting the needs and interests of future generations, particularly through education, is fundamental to the ethical mission of UNESCO [7].

Almost every day, intensive care units are rendered powerless to act because a potential donor cannot be “used” due to family’s refusal. Most of adverse reactions towards organ donation are due to the lack of information, mixed feelings, and prejudice; for example, people are not aware that organ transplantation is an accepted and common part of medical care [8].

Several possible explanations for this denial have been suggested.

- Society in general is not aware that during life we are potential recipients more than we are organ donors [9-11].
- It has not yet been understood that, particularly after death, organ transplantation offers a unique source of health for those who may suffer terminal organ failure [12].
- Doubts about medical diagnosis and treatment: Understanding the concept of “brain death” remains a barrier to accepting the use of a dead person’s organs. It is understandable that without previous reliable information, relatives feel reluctant to believe that their beloved one is dead when they are breathing, and their heart is still beating. Most people have qualms about taking organs from someone whose heart has not stopped beating (“is the patient really dead?”). It is necessary to fully educate society about the significance of brain death, including medical staff. Death should be redefined, with brain death becoming a synonym of death [12,13].
- The media have on some occasions featured stories about criminal organ commerce, without providing proof, and usually unconfirmed news under headlines such as: “The case of a brain-dead patient going home” [14,15].
- In addition, a very common public doubt is the faithfulness of the patient’s medical treatment if the medical staff knows that the patient is a registered organ donor.
- On the other hand, the personal decision to become an organ donor after death or the response of family members to donate a loved one’s organs can generate primary ideas.
- The instinct of preservation.
- The Freudian notion that nobody thinks about their own death until a beloved one dies.
- The old conception that the integrity of the body is mandatory for embarking on the path to eternity.
- It is well known that some people dislike the idea that their organs or those of their beloved may go to strangers [8,16-21].

In addition, people may not be aware of the tremendous economic impact of transplantation on society’s health care. Improving renal transplantation would lead to a substantial reduction in the expenses generated by the long-term dialytic treatment of patients with end-stage renal insufficiency. This significant reduction in health budgets would allow states to use large sums to solve other vital health and social welfare needs [22-25].

Healthcare professionals’ point of view

- Lack of awareness about the need for transplants for thousands of patients. Transplantation is for many people (including professionals) an uncommon medical practice.
- It is remarkable that only 53% of individuals prepared to donate organs have informed their family of their wish. In addition, the dilemma of increasing waiting lists and patients dying because of organ shortage is not common knowledge.
- Medical teams are untrained in the subject of organ donation because of the insufficient education on this topic.
- ICU doctors need to face several challenges when dealing with a potential organ donor, i.e., the management of brain death and request for organ donation.
- Although the diagnosis of brain death is currently widely

accepted, there are still challenges for medical teams. In addition, studies show that for many doctors, requesting organ donation from the patient’s family is a difficult and often avoided task.

- Increased workloads are leading to a reluctance to participate in the process of organ donation. Several trials focusing on the workload and psychological stress of ICU doctors and nurses when working with brain death diagnoses showed the difficulties they experience. The medical team taking part in this task are also involved in informing families and requesting organ donations.
- As the management of candidates for organ donation is complex (critical care management, the declaration of brain death, the identification and request for organ donation from next of kin), it has been suggested that these patients are best managed in tertiary centres. These centres have professional staff with the expertise and interest in performing these tasks [26-38].
- There is a lack of appropriate training to face the different medical, ethical, and social issues related to organ donation and transplantation. The aptitude of medical teams concerning issues of death and organ donation can make the difference between family’s giving and refusing consent. Families have expressed their dissatisfaction due to inappropriate communication and support when brain death was announced and thereafter when a request for donation was made [39-41].
- Polls performed on the decrease in the number of organ donors evidence the lack of knowledge among different levels of society, including medical teams. Questions on brain death legislation and religious opinions about organ donation were incorrectly answered [42-48].

The followings factors were also reported as barriers for professional participation in organ requests

- Unawareness of the importance of organ donation.
- An ethical-moral disavowal of the responsibility for organ/tissue donation – the rejection of post-mortem mutilation of the body and the potential distress it may cause a distraught family [19,39-41].
- It was suggested that more knowledge among professionals would initiate more cooperation in donation and organ procurement [32].

A significant correlation was observed between doctors in intensive care units and awareness of brain death and organ donation compared to professionals in other hospital units [26-28].

Rational education programs represent the most efficacious solution for this yet unsolved dilemma as they can increase awareness about organ donation-sustaining ethical principles (altruism, equality, fairness). Nevertheless, educational programmes have until now been considered useless and unnecessary [49].

Certainly, this opinion is understandable because while the public seems more aware about transplantation issues nowadays, the organ shortage is increasing every day. As such, one question that must be asked is whether education programmes require a complete modification of their current structure if they are to achieve a fully effective response from the public.

How should be organized a constructive educational project?

This is a long-standing problem that needs to be solved. A realistic and intensive educational program might consider the following priorities:

- Active state participation

- The full participation of all sectors of society
- A well-designed message change

Active state participation

An intensive education activity should be evaluated at all levels of society if a positive outcome of specific education between states and interested partners – the transplantation community, concerned ONGs, schools, and universities – is to be achieved.

The main actions might involve:

- Putting an end to the deficiency concerning donation and transplantation in current educational levels,
- Developing pilot education and information projects on organ sharing and donation, prepared by experts in education, social pedagogy, and legal-ethical-moral and religious principles, and
- Specialising collaboration with the media in a rational and positive way to create public awareness on organ transplantation and enhance public responsibility and human solidarity concerning organ donation.

A principal participation of all sectors of the society

The public needs unambiguous and persistent information concerning organ donation and transplantation. Furthermore, as healthcare professionals have serious deficiencies in their training on transplantation issues, teaching programs in medical schools need to be modified by educators with expertise in organ donation and transplantation problems.

One sector of society that has not been particularly included in transplantation education is the youth.

The importance of educating children has been observed by brilliant educators.

- “In ancient Greece, Socrates argued that education was about drawing out what was already within the student” [50].
- “The central task of education is to implant a will, and facility for learning; it should produce not learned but learning people. The truly human society is a learning society, where grandparents, parents, and children are students together” [51].
- “No one has yet realized the wealth of sympathy, the kindness and generosity hidden in the soul of a child. The effort of every true education should be to unlock that treasure” [52].
- “Teaching young people about organ transplantation is not notably difficult [53].
- “The organ transplant community has to offer strong inducements for teachers in various settings to take up the task”; “Strong persistent education efforts focused specifically on young people are seem comparatively rare”; “Helping young people understand the facts about transplants early in life increases the chance of them being sympathetic to the idea of organ donation”; “They are also likely to respond to a teacher’s suggestion to find an occasion to discuss this topic with their families or with their peers, thus multiplying the educational effect” [54].
- “Education and information will enhance the value of altruism, protecting people from exploitation and emphasizing the meaning and worth of organ donation” [44].

In John Paul II’s address to the 18th International Congress of the Transplantation Society, he supported the idea of youth education on organ transplantation as a way to improve public sentiment: “There is a need to instil in people’s hearts, especially in the hearts of the young, a genuine and deep appreciation of the need for brotherly love, a love that can find expression in the decision

to become an organ donor”; “I am confident that social, political and educational leaders will renew their commitment to fostering a genuine culture of generosity and solidarity” [55].

Challenging educational programs

On the other hand, some economists support economic incentives to change people’s feelings towards organ donation over education. “Ever since the introduction of the National Organ Transplant Act of 1984, the public has been barraged with what amounts probably to at least a billion dollars’ worth of educational campaigns, and yet the organ donation rate has remained essentially unchanged for the past decade” [49].

Certainly, it cannot be argued that, even though the public seems more aware of transplantation issues nowadays, the organ shortage is increasing every day. Therefore, one may ask whether education programmes on organ donation and transplantation require a complete modification to be more efficacious within the general population.

What is responsible for this situation?

As mentioned, the current message to the people seems to be unsuccessful. From the start, deceased organ donation was structured as a gift that would prevent the death of someone unknown, a real expression of altruism and solidarity.

Global surveys concerning people’s attitude to organ donation have been very positive. Nevertheless, at the moment of the death of a loved one, a great percentage of people fail to remember their support and the answer to organ donation is generally negative [56].

The reasons for this change of attitude are multiple.

Organ donation is a complex and multifaceted issue that affects not only the donor but also their families, organ recipients, and society. The protection of a beloved’s dead body by the relatives may provoke tension when it is released to an unfamiliar person (medical staff). [18].

Changing such attitudes might require renewing the appeal for organ donation through education.

The media is the most influential provider of social information on organ donation and transplantation. Unfortunately, media information usually contains negative news regarding transplantation. The myths frequently propagated by the media include:

- Premature declarations of death
- Transference of personality traits from donor to recipient
- A black market for organs
- Corruption in the medical community
- Bias in the organ allocation system (which allows, for example, celebrities to get transplants first).

These are not the only myths some of the general public hold to be true, and the media is a powerful source of support for them all [14,15].

In contrast, the media does not give enough information on organ shortage consequences and social and health benefits to the people. For example, it does:

- Not acknowledge the increasing number of patients on organ waiting lists
- Not make known the number of people dying every day while waiting for an organ.
- Not make the public aware of the positive attitude of

monotheist religions towards deceased organ donation.

- Use the slogan “A gift of life” as the message to encourage donation as a gift. Decades of unmodified organ shortages must promote the discussion of why, despite such a message, many people still reject the idea of offering the organs of their beloved deceased to a stranger as a gift [20].

It is most likely that a well-informed media campaign, persistently diffused, could change society's attitude towards organ donation and transplantation and improve organ donation. It is also important to evaluate whether the central educational position was insufficiently selected. Several studies and surveys recognized that the level of knowledge of students in colleges and universities and professionals in the field of medicine is inadequate [37,38,43]. In addition, the value of educating school children on transplantation and organ donation has been recognised. Young people are free of prejudice; therefore, they learn new ideas easily. What is more, the transmission by children of new concepts learned at school to their family would be an unprejudiced and clear source of knowledge [53].

Childress affirmed, “Education on organ donation is important to reduce organ shortage” [57]. Well-conducted education and information campaigns would enhance the value of altruism and thus protect people from exploitation and emphasize the meaning and value of organ donation [58].

Which steps to follow

As suggested, organ donation also emphasizes the value of solidarity in society, highlighting a new social dimension in which donors and recipients integrate a formal need for current medical progress. This social aspect should be one of the elements considered when making decisions about organ donation and transplantation. The value of solidarity encourages the donors, recipients, and others participating in the transplantation process to make responsible decisions.

In the present organ shortage crisis, helping patients who are in a critical stage really shows the social character of humankind. The Catholic *Evangelium Vitae* (no. 101) talks about the proclamation and promotion of life: “The Gospel of life is given to us as a good to be shared with all people: so that all men and women may have fellowship with us and with the Trinity” [59].

Other monotheist religions sustain similar concepts; in Buddhism, for example, there are no rules for or against organ donation, just the wish to relieve suffering as an act of charity.

In any case, the decision for or against organ donation relies very much on individual choice. The death process of an individual is viewed as very important, and a body should be treated with respect. However, there are no beliefs that say the body should be preserved in its entirety [60].

A change of the message should be considered

The lack of change in people's behaviour towards organ donation suggests that the main goal of the education program should be to improve the message to society.

Some proposals for new messages include the following ideas:

- Organ donation means sharing a chance of life with everybody, including our family.
- Organ donations from the deceased represent a vital source of health.
- During life we have more chance of being an organ recipient

than an organ donor.

- Organ donation should be a civic responsibility.
- Organ shortages generate an ever-increasing number of deaths of patients on waiting lists.
- The primary cause of this health crisis is the frequent refusal to allow organ donation, particularly from the relatives of a deceased patient. This negative attitude possibly generates the death of several people.
- Although different legal solutions endorse the possibilities of organ donation, an aspect not yet considered is whether a negative attitude on the part of the society is compatible with the concept of the abandonment of people at risk.
- The use of organs and tissues for transplantation might be a fair agreement as well as a mindful social duty.

Could education lead society to acknowledge a different message?

To evaluate this possibility, surveys and practical experiences have been executed.

Surveys

Executed on well-educated people from five countries: Argentina, Austria, Brazil, France, and Italy.

The conclusion of a study carried out on a panel of well-educated people who have benefited from previous transplantation education programs found:

- They were ready to accept that organ shortage is a serious public health issue, and that transplantation is a useful tool for health care.
- Although people still consider organ donation as a gift, the respondents considered that the slogan “To donate is to share” could generate a greater acceptance of organ donation after the death of a loved one.
- Financial rewards for donors or families of deceased persons are still a subject of controversy.
- The poll showed that adults agreed with the principle of the benefits that might be obtained through early transplantation education programs directed toward school children.
- However, the widespread ignorance of religious precepts concerning organ donation and transplantations, which correlated with a low acceptance rate of the principle of organ donation after death, was unexpected in countries with a long history of monotheist faiths [46].

It was suggested that Church leaders should be included in a task force with representatives of WHO and UNESCO in a combined effort to engineer a comprehensive international education program targeting not only adults but also children.

Practical essay into the education of young people.

To assess the impact of education on organ transplantation in elementary and high schools, 45-minute presentations on the topic were given to 362 school students in Argentina (Buenos Aires) and Canada (Montreal). The issues discussed included history of transplantation, brain death, the donors, waiting lists, and the thoughts of religions on transplantation. At the end of the presentation, the students completed a questionnaire.

- Overall, the students were interested in scientific topics and waiting lists.
- They stated their intention to discuss the topics with parents, friends, or both.
- New concepts were discussed: “During life, we might become organ recipients rather than organ donors”; “The dead body is a source of health”; and “Organ donation means to share life”.

The most important finding of this pilot project was the great interest the young students from two different countries showed regarding organ donation and transplantation. We also observed that 10-year-old children understood basic concepts about organ donation and transplantation [61].

The main difference between this report and previous education strategies on organ donation and transplantation is the concept of new messages. We commented that the deceased human body is a source of life, that during life everyone has a higher chance of becoming a potential organ recipient than an organ donor, and that organ donation is more than a gift – it is to share life.

The aims of these presentations on organ donation and transplantation addressed to elementary and high school students from Canada and Argentina were to assess the students' knowledge about and perception of organ donation and transplantation, to increase their awareness of those topics, including new concepts, and to encourage discussions with their families and friends. These pilot presentations were assessed for their potential use as the basis for an educational program.

The results of these essays showed that young students are open to learning about organ donation and transplantation and accepting and discussing new notions. These pilot studies suggested that education on organ donation and transplantation, when adapted to students' ages and regional sociocultural characteristics, might be of value to the effort to change attitudes towards organ donation. Education will help students work through the fear and discomfort that the subject of organ donation might present. Knowledgeable students could share information with friends and families.

Parent involvement in these programs

In early childhood organ donation education programs, there should be a frequent exchange of information between close relatives and schools. Parental involvement is important during the early years of school life and is of extreme importance on issues related with transplantation. It has been suggested "that it is desirable, according to most of the respondents, to inform parents that this lesson is being given. This finding seems to imply that when parents are informed about a lesson taking place, they should also simultaneously receive information about the subject; this could serve as an aid for family discussions at home. Therefore, we think that school can serve as a basis for initiating these family discussions, and we already know how important it is for these discussions to take place in a non-crisis situation" [62].

Participation of the community

Public and private schools need to be open about education on organ donation and transplantation programs. In collaboration with other organizations, they would provide the community with the best programs for children and their families. As mentioned, "A communitarian approach to the problem of organ shortage entails changing the moral culture so that members of society will recognize that donating one's organs, once they are no longer of use to the donor, is the moral (right) thing to do" [48].

Final remarks

Education could be the route to promoting a culture more accepting of organ donation, thus alleviating the "organ shortage" crisis. Current community barriers and disinformation should be considered when assays are performed in the attempt to develop a different approach to society. A new well-thought-out message should be addressed to all society levels, particularly to medical professionals and youth. Schools should incorporate concepts

about organ donation and transplantation into their curricula to better prepare young children for their future role in a society that will require full understanding of an urgent dilemma: People are dying unnecessarily because of organ shortage. Educating children about organ transplantation could be the key to changing social opinion, and a stimulus for modifying the current public information models.

Previous experience has shown that children can understand basic notions about transplantation.

The following steps should be taken for a promising development of this program:

- Incorporation of the program in regular school curricula
- School teachers fully accepting the new instructed notions
- An integrated and enthusiastic education protagonist team
- The support of the transplantation community
- The active participation and support of states and churches.

In addition, and certainly of importance, it should be stated that current laws regulating organ donation have not resolved the existing health emergency. It has therefore been suggested that education efforts and efficient legal reforms could change present society's unsatisfactory behaviour. Undoubtedly, changing people's negativity towards donation would preserve the lives of those dying unnecessarily every day while on endless waiting lists. The practice of transplantation requires a specific legality. In addition, organ donors should have clear social knowledge of the subject as well as a complete acceptance of the legal and practical procedures.

It is important to recognize that several authors have proposed well-defined educational and legal medical proposals. In 1968, Dukeminier said, "Society must face the fact that cadaveric organs can save human lives, perhaps their own. To achieve this goal requires the decision to advance in the policy of preserving life, or to remain paralyzed by its taboos" [63].

Other authors have come up with ideas and suggestions of real value over the years: "The rescue of a person in danger of death, when the action does not involve personal risks, is a legal responsibility".

It has also been stated that, faced with the present organ shortage emergency, states should generate radical ethical-legal solutions, respecting the concept that they would apply only when "help" is being provided without the intention of reward or financial compensation [64]. In the US, for example, almost none of the state's policies on organ donation have completely solved transplantation needs. Chatterjee considered that new policy designs are necessary to increase donation rates and reduce the widening gap between the supply and demand for organs [65].

Conclusions

The technical and scientific evolution of organ transplants over the last 50 years have been remarkable. Furthermore, the magic paradox of a family deciding to donate the organs of a deceased loved one to avert the death of another, a stranger, is a clear image of superb social conduct.

Nevertheless, the ongoing organ shortage and its critical consequence – the increasing number of deaths of those on transplant waiting lists – clearly shows that current situation needs to change. If the social, educational, and legal attempts to modify the present situation have not led to a substantial change, then it is necessary to invent new strategies that will achieve a more significant social acknowledgement of the gravity of this crisis.

New proposals that might develop critical peoples doubts and complex reaction, require Expert discussions are needed on how to alleviate the doubts and complex reactions of those against organ donation and attain conscientious social acceptance, as well as pedagogical methods to increase people's understanding of this vital issue.

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