

Reflections on a Social Debt: Waiting Lists to be Transplanted

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Abstract

Dying unfairly in the long lists of transplants is the difficult current alternative of thousands of patients waiting for a future life opportunity. From the beginning of the fascinating era of organ transplantation, this cruel reality permanently censures our society. The paradigm of recovering life through the death of another human being is a difficult metaphor to be interpreted by people. We could consider that this symbolic image could be a reason why society would accept the terrible reality of committing a subconscious aggression against itself: 'the unjust death of hundreds of patients'. The objective of this article is to analyse the possible causes of this crisis and propose a change in the strategy of current educational programs, given its statistical inertia to improve public behaviour with respect to organ donation. The main intention is to suggest the review of the global planning of donation and transplant education, seeking to achieve a clear public knowledge of the critical existential dilemma of our time: to recover health and life thanks to the transplantation of organs and tissues.

Keywords: Organ Donation; Waiting Lists; Social Education; Altruism; Non-Cognitive Inhibitions; Sharing

Abbreviations: US: United States; BD: Brain Dead; ECD: Expanded Criteria Donors; DCD: Dead Cardiac Donors; KPD: Kidney Pair Donors Exchange.

Introduction

Since the mid-twentieth century, after a long journey in time, organ and tissue transplants offer unlimited health and wellness potential for the benefit of society. However, the organ shortage crisis creates a permanent and immutable dilemma of uncertainty and hopelessness for those who can benefit from this medical advance with the possibility of receiving the expected transplant. This recurring reality is mainly due to prejudices, ignorance or misunderstandings responsible for the often-ignored negative moral attitude of those who avoid offering a human being the opportunity to live, through the donation of organs, usually from a passed away loved one. The frequent consequence of this conflictive

situation result of inappropriate social behaviour is what we should undoubtedly consider as an 'unfair death'. In general, decisions about organ donation taken at a time during which people do not face the critical moment of the death of a loved one, are very positive. In a survey in the United States (U.S.), 94.9% of adults responded supportively about their intention to donate their organs. However, worldwide surveys showed that people's behaviours change in the face of the death of a loved one. The critical consequences of this attitude are the detriment of the health and well-being of people daily enter the waiting lists to solve with a transplant the terminal failures of a vital organ. This is undoubtedly a moral and ethical problem that requires serious reflections looking for solutions [1-3]. Society has persistently maintained a partial behaviour towards organ and tissues donation. This attitude can obviously suggest that enough recognition of the fundamental principles of donation and organ transplantation through the ongoing and never

modified social educational programs, has not been enough achieved by the public. Most people seem to ignore that organ transplantation not only prevents the possible death of patients on the waiting list, but also provides substantial and necessary economic savings for state's health programs. The increase in kidney transplants will decrease both patient lists, as well as dialysis treatments. The fundamental action of transplant saving thousands of lives also represents, for example, for the dialysis treatment maintenance in the U.S. a saving of approximately \$ 46 billion per year. This result is obviously even more valuable considering that the survival rate after a kidney transplant is twice as high as that obtained by dialysis [4-6]. On the other hand, the shortage of organs has created the possibility that medical groups without ethical-moral scruples and mainly in countries with insufficient socio-economic conditions have developed and exploited intensely the sinister so-called organ market. This inhuman traffic uses poor, defenceless and unprotected people for disproportionate and illegal benefits. In addition to this social injustice, society must clearly know the serious risk that this illegal and unethical-moral medical behaviour can generate for the health and also for the life of those patients who with a significant economic capacity, trying to be recipients of an organ travelled to these tragic human beings market. Organ shortage has developed the so-called organ tourism, a sad negative alternative to the essential principles of social justice and respect for human rights [7].

Altruism and Organ Donation

Since the beginning of the current practice of organ transplantation, ethical-moral altruistic principles have been guiding medical and institutional behaviour of this new and prodigious activity of modern medicine. Altruism is the basis of an action necessary to solve the problems demanded by society, developing all its efforts with the sole interest of being able to complement this requirement. About this definition, different authors have analysed with different criteria the relationship of this fundamental conception of altruism with donation and organ transplantation [8-10]. Basically, altruism should be the essential philosophy that guides people's organ donation decision. This social solidarity conduct has been primarily programmed through the permanent diffusion of the classic slogan the 'Gift that will save someone's life'. Given that education programs have always focused on this motto, a definite interpretation of the real influence achieved at the public level by this predominant educational guide could be of great importance. Several surveys have clearly pointed out that the public is aware of the alternative of donating their organs or those of a family member after death. However, face of grief, a high percentage of people does not remember this commitment and the "gift of life" do not materialize. The persistence of this negative attitude of the families of potential donors, with irreversible results for those in the

long lists of life expectancy, should give rise to the analysis of the efficiency of the effectiveness achieved by education at all social levels, by executives responsible for educational and social programs on transplants and organ donation. Altruism has been considered the only ethical basis for donation, representing the 'primus movens' of this purpose; this concept has been identified in some way with the 'Gift of life' and the relationship of this slogan with organ donation has been maintained for a long time. Nevertheless, the basic and irreplaceable notion of altruism should not exclude the alternative of offering to the donor the idea that organ donation is not simply giving, but also the right to receive an organ transplant when needed. In search of ways to modify the shortage of organs, so far not modified by the current educational strategies, might be useful to considered the use of different messages that might convey to society the notion that organ donation means also to sharing a possibility of health and life for all [11,12].

Following the concepts related to the action of community groups motivated by social objectives, established in 1960 by Marcus Olson, it is important to consider their possible relationship with the previously mentioned thoughts on altruism, solidarity and organ donation. Olson has suggested that when a group of people seeks a community benefit, individual members of the community will not contribute with willpower to the community cause if the group does not evaluate individual actions. Personal interest, which does not prevent identification with the mutual cause, becomes the greatest stimulus for the individual's commitment. In accordance with these considerations, efforts to improve educational programs will be extremely important in changing the individual's behaviour toward donation; In this sense, we have proposed in a manner consistent with Olson's theory, a transformation of the slogan, 'Donating is a gift of life' in 'Donating is sharing life' [13,14]. Society must clearly understand that collective actions in organ donation are activities that seek vital resources for the well-being of the community. However, individual participation may somehow conflict with self-interest. Organ donation conforms to this definition because although the benefit to the community is significant, individual incentives for personal participation are low. Disincentives to register as donors include the discomfort of making such a decision, the lack of motivation to officially register, the concerns about burial, the rejection associated with facing death subconsciously representing by organ donation. Regarding these inhibitions towards organ donation, to install in society the ethical-moral concept that signifies the need to give and receive an organ when necessary, we suggest the slogans: 'While we live, we are all potential recipients of a transplant', and 'Our body, at the end of life is a source of health, unique and irreplaceable.' These slogans could be potentially useful for improving social responsibility in the search for a solution to the unfair deaths

of people who wait in vain in the sometimes-tragic waiting lists [15].

Economic Incentives

In recent decades, leading economists have advanced the emerging possibility of developing a highly risky option for society: Financial incentives for improving organ donation. The main justification of this materialistic proposal to use economic resources to stimulate a change in the current insufficient society behaviour towards donation has been based on the persistence of an inexorable dilemma of these times: 'To die waiting for an organ that will probably never come'. Obviously, this suggestion might remove the ethical and moral foundations that have been proclaimed as essential for the practice of organ and tissue transplantation, promoting the risk of critical consequences at the social level putting a price on the passage between life and death that will project the image of an inevitable exploitation of the poor. In any case, the reality is that in this evolved society of the 21st century, which promulgates equality and justice, this proposal of economic use of people for the benefit of others, circulates in the scientific-medical, political and public media with the insistent justification of the humanitarian argument: 'To save lives' [16]. This philosophical-materialist discussion cannot help to request to an answer the question: Who will receive and who will give organs in exchange for money. Are we facing a new and serious social inequality?.

Brain Death

When organ transplantation began to become a common medical practice in the 1960s, doctors and patients ignored that in the future the phantom of organ shortage would eclipse this prodigious activity of current medicine. This ignorance also has included the main protagonist responsible for that always persistent dark reality, an important part of society that still does not understand the magic of being reborn to life through a transplant thanks to an organ provided by a stranger, who already does not exist.

The limits that divide life and death are bleak and vague. Who will say where one ends and the other begins? Since its inception in 1959, the concept of brain death (BD) has been controversial and debated over the years. Several scientists believe that considering what neurological criteria describe the death of a human being exceeds the most advanced possibilities of science [17,18]. The definition of BD represents the equivalent of the step between maintaining a stable biology in a patient with artificial respiration, until establishing the legal diagnosis of death. It is well defined that, although the diagnosis of brain or clinical death has been a transcendent achievement in the current possibility of developing organ transplants, it has also contributed

to respecting the dignity of people by defining the need to suspend the painful and exhaustive harassment of treatments already considered useless. If the technical possibility of maintaining the physiological integrity of vital organs in a patient with BD, whose potential donation alternative is excluded for different reasons, the therapeutic procedures should be suspended [19-21].

On-going Proposals to Improve Organ Shortage

To solve the problem of organ shortage, certain legal modifications have been developed, fundamentally the so-called presumed consent law. This law determines that when an individual does not certify his or her refusal to be a donor in an official record, it means that he or she is an organ donor. About the effects achieved on social behaviour towards donation in countries in which this law is in force, results are controversial. On the other hand, the negative consequences that the law may have on the public confidence in organ transplantation practises and medical behaviour, should also be measured [22,23].

My personal point of view is that it is difficult to accept that legal measures can modify people's behaviour; People's feelings and conduct can only be modified with examples offered by respected mentors or essentially through rational education. With respect to the changes made in medical practice that seek to overcome the dilemma of organ shortage, significant modifications have been approved with respect to the acceptance criteria of potential donors. Fundamentally, these new criteria and clinical characteristics of potential donors have been extended to deceased and living donors, thus generating the so-called donors with expanded criteria (ECD). The new criterion mainly includes elderly donors, in some centres without considering donors age limits. This criterion also allows donors to be accepted with certain minimum functional clinical alteration conditions. In addition, donors in cardiocirculatory death (DCD) have now been included, identifying a well-defined set of legal medical conditions for its acceptance. A current ethical alternative to consider is patients undergoing intensive treatment, considered useless that are finally suspended with the consent of the family. In this case, the ethical problem involves establishing the time needed to define death. In addition, it is of great importance for the success achieved by this medical advance, the donor exchange program. This program has meant the achievement of successful transplants between related couples immunologically incompatible but compatible each other with the unrelated couples (KPD) [24-26]. Faced with this social dilemma: which represents the shortage of organs, the essential question should be: Why is humanity committing this crime against itself?. The answer to this question is complex. The main factors that influence the negative decision at the time of donation, particularly

in the case of a loved one, are generally motivated by socio-psychological factors that require in-depth analysis.

Cognitive and Non-Cognitive Inhibitions

The main reasons that have always been described regarding negative attitudes towards organ donation have been the so-called cognitive or rational barriers, such as ignorance and misinformation. However, in recent times, several significant studies and surveys have indicated the importance in the decision towards organ donation of inhibitions factors mentioned as non-cognitive or irrational. Fear of death, mutilation, as well as caution and lack of confidence in medical advice, especially in cases where consent for organ donation is required, is suggested as the more important. These significant investigations have given more weight as main responsible for families rejection of donation consent to these non-cognitive or subconscious barriers. In this sense, the following myths and psychological concerns may be instinctively responsible for these barriers to the donation decision:

- The instinct of self-preservation,
- The Freudian notion that no one thinks of dying until a loved one dies,
- The idea that the integrity of the body is obligatory for eternal life,
- Fears related to the diagnosis of brain death [27,28].

Without any doubt, these new data are of great importance in relation to the persistence of organ shortage, mainly because these inhibitory barriers in social behaviour have not been considered in their significance by those responsible for the current public education plans.

Therefore, the need to their evaluation with respect to the development of new educational strategy in the search for positive achievements of the educational programs is essential looking forward to encouraging the current inadequate social response to organ donation [27-29].

Organ Donation Education

The negative reaction when a family receives the request to donate organs from a deceased relative, is a complex social dilemma. This frequent interpersonal event between doctors and relatives in front of a potential donor requires a thorough evaluation. An initial strategy to establish a favourable relationship is to determine the right time to provide emotional support to the family and to provide clear information about the value of positive attitudes towards donation. It is important to note that the participation of professionals with adequate preparation for this difficult function is essential. On the other hand, there is evidence that a positive response to the donation request is gratifying for the donor's family. This positive sequence regarding

the family donation decision has been highlighted in the literature. As well, it has been revealed that families often feel sorry when they refuse donation at the time of the death of a loved one. Educational efforts that attempt to overcome barriers to donation should provide clear public information about their responsibility of the social risks representing by ignorance, misinformation and inappropriate personal behaviour towards organ donation. People should understand that at any time in life they may need an organ transplant and that they should recognize that everyone should have the right to receive an organ if necessary and the duty to be a donor when life ends. In addition, it is important in relation to the behaviours of families at the time they face a request for a deceased relative organ donation, that those responsible for their different monotheistic religions, inform to their faithful that their faiths support organ donation [5,30]. Considering the importance of these factors in social behaviour; as an option to be consider in the review of current public education programs, we propose the discussion of the following concepts at all educational levels:

1. Organ shortage is a health emergency.
2. Throughout our lives, we are all potential recipients of organs and tissues.
3. The body after death is a unique and irreplaceable source of health.
4. Organ donation is meant to share life.
5. Sharing organs after death must be a tacit social agreement for the welfare of society.

Many of these concepts related to psychological aspects are often based on ancestral backgrounds and must be studied by social, psychological and religious experts to find a clear understanding and acceptance by the public [31].

Organ Donation Education at Schools

To modify prejudices and barriers that inhibit organ donation after death, well-planned education on this subject for young people should be started in primary schools. Educational programs initiated in schools might play an important role in a positive evolution in social behaviour towards organ donation. The education of young people in this area will be a positive strategy to improve public knowledge and their support in the donation of living and deceased donor organs [32-35].

Changing the message and focusing especially on young people, is a potential resource to solve this serious social dilemma. Shoenberg, stressed that teaching young people about organ transplantation is not particularly difficult. He noted that helping young people understand problems related to donation and organ transplantation will increase their comprehension of its importance. This educator stressed that the goal is for young people to multiply the

educational effect by discussing the donation with their families and classmates. Consequently, education about organ donation for young people, which begins in primary school and continues at secondary and university levels, has been suggested as a promising method to change attitudes and social behaviour with respect to organ donation. The main reason for this proposal is that in general young people are free from prejudice and can learn new ideas more easily than adults. Current psychology suggests that childhood is the best stage of life, to prevent the development of social prejudices. It has also been emphasized that children who learn new ideas in school can transfer them to their families [36-38].

Organ Shortage and Health Economics

Concerning the economic influence of organ shortages in state budgets, this issue has been clearly pointed out in the literature. The relationship between the effects of insufficient success represented by the lack of organs and its consequences for the general management of people's health has also been observed.

The behaviour of society is a basic human mechanism that balances not only the problem of loss of life, but also the serious economic consequences of this crisis. Different technical possibilities have been suggested, which can reduce the serious economic consequences generated by insufficient organ donation. Current advances in the preservation of organs through new solutions, and particularly with the use of pulsatile machines, could improve the prognosis of transplantation, particularly in the case of organs from ECD and not only in the case of renal transplantation. It has been estimated that progress in the preservation of organs could save billions of dollars to the health system and could also reduce costs in many aspects of the transplant procedure [39,40]. Among the serious consequences on health economics due to inappropriate social behaviour towards organ donation, it is interesting to note that the dialytic treatment of end-stage renal failure in the U.E. it currently exceeds \$ 48 billion per year. Kidney failure treatment uses 6.7% of the total Medicare budget to serve less than 1% of the covered population. In fact, it has been hypothesized that if organ donation remains stagnant and an increasing number of patients will need dialysis, then the cost of treatment could reach \$ 1 billion per decade. Axelrod et al. compare the costs and survival of patients between transplantation and dialysis; all transplant options were associated with better survival rates compared to dialysis. On the other hand, the authors concluded that kidney transplantation is profitable considering all types of donors, despite the higher costs for marginal organs or ECD or the innovative practices of KPD [41-47].

Final Thoughts

The basic value of justice and equality should motivate the execution of any action that could generate modifications to the critical problem of organ shortages. Any strategy to combat and improve organ shortage should depart from the basic concepts of autonomy, non-maleficence, beneficence and justice. However, we should not exclude the alternative of giving people the idea that donating is not simply the decision to give but should also be the right to receive an organ donation if they need it. That was the intention of our suggestion that 'Donating is not giving, giving is sharing [15,48]. The dilemma of organ shortage requires offering to the people the knowledge that organ and tissue transplantation represents for them a possible medical solution at any time in life. Inadequate educational results consequence of public and professional education never reviewed is the major cause of the current insufficient attitude of people towards organ donation. In recent decades, several attempts have been made to resolve the persistent crisis of organ shortage, through political and medical-legal proposals, establishing new acceptance criteria particularly for the acceptance of donors and recipients, often crossing the medical red lines respect the ancient Hippocratic criteria 'Primum non nocere'. These extreme efforts are uncertain from an ethical point of view, but analytically they are morally justifiable, based on the essential objective of saving lives. However and perhaps inexplicably a change option that has not yet been tested is the review and implementation of public education programs, which might allow society to judge in a positive way their attitudes towards organ donation. A fundamental objective of the proposals suggested in this document is an analysis of the programmatic structure of current social education plans towards donation, to consider changes in its philosophy and strategy. This simple proposal might be a possible initial way to solve this serious medical, political and social dilemma that globally it affects us. Trying this path will certainly not be difficult and trying it can be a valid effort that consciously elaborated will be the possibility that society deserves to be tested for the benefit and respect of people.

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