



The Patient Waiting List Dilemma. Strategies Options to Solve a Social Injustice

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Received Date: November 26, 2018; **Published Date:** November 30, 2018

Abstract

“Organ shortage” still remains a dramatic problem faced by patients awaiting organ transplantation. Getting organs for transplantation depends on people's decisions; thus, public opinion is essential to finding a solution to this problem. Paradoxically, although the mortality of people waiting for organs increases each year, the characteristics of social education programs have remained unchanged. The classic slogan "to donate is to give life" remains solidly valid throughout the world. Several surveys regarding the usefulness of current programmatic strategies to change social attitude toward donation have not demonstrated a definite positive result in changing people's behavior. Fear of death and mutilation, a distrust of medical teams, hostility towards new ideas and religious uncertainties have all been suggested as more relevant barriers to donation than lack of education and information. Education should be used to reshape public opinion about the use of organs for transplantation. However, essentially innovative programs, proposing new suggestions to the public, should be attempted to improve current social response towards organ donation. Society should accept that using organs for transplantation is moral and offers a source of health for everybody. The concept that using the organs of a deceased individual implies sharing a source of health could be, with time and understanding, a social agreement between all members of society.

Suggestions to change people's attitudes towards organ donation and improving organ shortages may include the following catchphrases:

- a. During life, everybody may be a potential organ receptor.
- b. The organs of the deceased are an irreplaceable sources of health; and
- c. The body after death is a chance to “share” health with everyone. A recent survey of medical professionals with university activity has shown that the already defined lack of knowledge in the problem of organ donation and transplants is practically unchanged at the level of current medical education in the universities. Finally, in an attempt to improve the present reality, education in schools, colleges and universities, with programs that consider new encouraging options of social communication, should be seriously evaluated and put into practice by those responsible for international education plans.

Keywords: Organ shortage; Social behavior; Barriers to donation; Waiting list mortality; Medical education; Donation in schools curricula

Abbreviations: UNOS: United Network for Organ Sharing; TTS: The Transplantation Society; UCA: Catholic University of Argentina; ECD: Expanded Criteria Donors; UNESCO: United Nations Educational, Scientific and Cultural Organization

Introduction

The progress obtained by transplant medicine is a reality and holds promise for the future of society. However, the persistent contradiction of "organ shortage" makes this potential benefit uncertain and often unreal [1]. The consequence of this conflicting behavior is that patients on waiting lists are "unfairly" dying every day. A chance for another human to live is denied by many of us, with numerous opportunities for life being lost in intensive care units on a daily basis. Prejudices or indifference prevent us from offering the chance of life from one human to another [2,3]. Several surveys have shown that most people are willing to donate their organs or those of a family member after death. However, when faced with the moment of grief, a high percentage of people fail to remember this commitment and the answer with regard to organ donation is negative. What are the reasons for this behavioral change? As previously suggested, a possible solution to this crisis could be achieved if the right social and educational forces are put into play [4]. Organ donation is certainly a multi-faceted issue that affects potential donors, their families and society as a whole. A relative's refusal with regard to donation is the main impediment to organ donation.

Several factors have been shown to worsen family consent rates:

- a. Institutional responsibility of the organ procurement organizations:
 - i. Requesting organ donation should be done after allowing the family to understand and accept the concept of brain death.
 - ii. The interview with the family must be carried out by a specially trained professional [5,6].
- b. Barriers to donation decision are not effectively evaluated in current global social education programs [7].

Evaluation of current social educational strategy

The notion that organ donation is a 'gift of life' to a stranger, may be questioned as the most important guiding principle of current programs of social education [8,9]. The persistent inadequate response to donation, confirmed by the unchanged lack of organs for transplantation, encourages the evaluation of conceptual change in the message regarding organ donation.

Prolonged unawareness and misinformation have been mostly considered the major causes of the lack of positive responses to the pressing social need for organs, particularly regarding the deceased donor [10,11]. Nevertheless, recent surveys have pointed out the impact that non-cognitive factors represent on the final decision to donate. These studies estimated that subjective barriers play a fundamental role in social conduct towards donation. On the other hand, recent works have suggested that rational factors are not essential for organ donation. Quite the opposite, it has been suggested that psychological feelings such as fear of death, mutilation and a distrust of medical behavior would be the strongest barriers to overcoming the negative attitude of people towards donation [7-12].

Concerning the notion of fear of death as the strong society subconscious challenge for organ donation, it should be noted that fear of death is the concern that most inhibits humans due to a lack of experience with friends or dying patients. This lack of experience generates a significant problem to stimulating the discussion about organ donation with family members, and may also play a significant role in other anxiety disorders [13]. Fear of death remains in the subconscious and reappears with the death of a loved one, which makes the pain even more prominent [14]. The emotional component of fear of death at the time of the decision to donate the body of a loved one is difficult to contest. An alternative would be finding the point at which the fear of death is irrelevant by applying rational arguments [15].

There is very little specific research on treatments for the fear of death, and anxiety about health. The main components of this treatment include exposure to themes related to death, a reduction of safety behaviors, cognitive reappraisal, increased focus on life goals and life enjoyment [16]. In addition, to overcome this deep fear, it will be worth pointing people in the right direction to overcome this ancestral anxiety. The slogan we proposed: "when life is gone, our body persists as a unique and irreplaceable source of health for all", might be a way to overpower this strong non-cognitive and persistent barrier to donation. Educational programs concerning organ donation have not yet considered the fact that non-cognitive emotional reactions may be responsible for the current conflicting people's behaviors towards donation. Due to the significance of these observations, the discussion of the following phrases might be considered in future strategies for social education towards organ donation:

- a. The shortage of organs is a health emergency [17].
- b. Throughout our lives, we are all potential recipients of organs and tissues [18].

- c. The body after death is a unique source of health for all [19].
- d. Organ donation is not giving life, it is sharing life [18-20].
- e. Sharing the body after death should be a tacit social agreement for the common welfare of society [18,20].

An educational strategy that has not yet been used may help to raise awareness about the major barrier to organ donation. Explanations of critical value have been highlighted that can neutralize non-cognitive barriers to alter organ donation decisions [7,17-25]. It has been suggested that to induce people to change their feelings concerning organ donation, multiple positive interventions are necessary. Also, the perception of the benefits of organ donation was mentioned as having the greatest impact on attitudes and intentions [26,27]. Public education programs aimed at overcoming these solidly strong non-cognitive barriers, established in the subconscious of people, might be a challenge to improve this health crisis. These plans should be deeply analyzed by social, psychological and religious experts.

Critical analysis of education campaigns concerning organ donation

General results were accomplished by different education campaigns carried out all over the world, all of which identify donation as a gift of life; this is not always confirmed in different countries, where society achieved a significant progress of organ donation. A study on state of the art of organ donation and transplantation in the USA, performed by the National Kidney Foundation in 1991, stated that the sustained effects of campaigns are generally unknown. It is recognized as an important contention of this essay that the results have unfortunately not been good enough, because the resistance remains unchanged. Even though the public is more aware about transplantation issues, organ shortage is actually increasing. The consequence of this inadequate social awareness and response is that at least twenty-two unreasonable deaths occur on waiting lists every day [28].

With respect to this critical situation, the New Zealand authorities generated an extensive document analyzing all of the structural alternatives and modifications necessary to achieve a positive social behavior towards organ donation [29]. A meta-analysis of four challenge campaigns in 2012 and 2013 undertaken to promote organ donor registrations in New York State was analyzed. Across the 4 campaigns, 107 teams were recruited and 2286 persons registered their consent to donate through the state system. Each team recruited an average of 21 persons, but 40% of teams registered no

individuals [30]. Although a previous poll showed that 85% of Americans approve of organ donation, less than half had made a decision about donating, and fewer still (28%) had granted permission by signing a donor card. Despite the passage of time, from 1995-2002, more than 45,000 people in the United States have died waiting for a suitable donor organ [31].

Information provided by UNOS, corresponding to the evolution of donation and transplants from 1991 to 2017, shows that: a) the patient waiting list grew from 23,198 in 1991 to 115,000 in 2017; b) the number of donors increased from 6953 in 1991 to 16,473 in 2017; and c) the number of transplants increased from 15,756 to 34,770 in the same period [32]. Undoubtedly, these results, registered over 26 years, show that peoples' behavior towards organ donation has unfortunately never been good enough, because the contradiction to donation has remained stable. Even though the public are more aware of transplantation issues, organ shortage is actually increasing. The consequence of this inadequate social response is that an increasing number of quite unreasonable deaths are occurring on waiting lists every day. Considering that nearly all state-level policies to encourage organ donation have had no observable effect on the rate of organ donation and transplantation in the United States, Chatterjee, et al. [33] stated that new policy designs are needed to increase donation rates and curtail the widening gap between organ supply and demand. In addition to this acknowledged disadvantage in worldwide public education programs, media programs often provide very harmful misinformation on the subject of clinical death. In support of the effort of physicians and transplant coordinators at the moment of grief, there should be basic education of the public on this subject [34]. In an aim to solve stagnant organ shortages, different alternatives have been suggested in recent years trying to overcome this serious global health problem.

Legal modifications to donation consent

Legal instruments such as the promulgation of presumed consent laws have been established and/or projected for endorsement in various countries. With regard to this possible legal solution to organ shortage, it is important to note that the first presumed consent law was promulgated in France (Law Caillavet n°76-1181, 22 December 1976). The French experience to date shows that this law was not used over time. Therefore, a modification of this law has recently been promulgated in France. Nevertheless, faced with the critical situation of organ shortage, several countries have sanctioned this law looking for a solution to the crisis. However, useful results of this legal measure are not yet clearly defined

[35]. Regarding the efforts to identify legal solutions to modify human behavior, it has been suggested that “the gap between organ demand and supply is forever widening. It is essential to review ethical facets of every new law, strategy or policy initiated to increase the organ donation. Ethical reflections of organ donation quandaries promote and advance this field in a bioethical manner that ultimately benefits humanity and the well-being of the society” [36]. On this matter, any ethical and educational efforts to changing societal behavior should be well thought-out as the change will only be achieved by conscious and effectively planned education that is directed to a given purpose.

Modification to donor acceptance criteria

The persistent and painful health crisis represented by patient mortality on the waiting list has required to the medical community to recommend a number of modifications of the established donor acceptance medical criteria. One important change in medical measures has been the acceptance of donors that are currently known as expanded criteria donors (ECDs). These donors have been previously known as marginal or sub-optimal, because long-term results may be lower than those that have currently been achieved. These donors do not respond to the classic acceptance criteria that potential organ donors should be completely healthy. ECD are aged 60 years or older or over 50 years with at least two of the following conditions: a history of hypertension, serum creatinine >1.5 mg/dl or cause of death from cerebrum-vascular accident. Although the long-term results are lower than those obtained with non ECD, currently called “standard donors”, ECD decreased the potential mortality of patients remaining on waiting lists [37-39].

Economic incentives

The proposal of an Economy Nobel prize, considering that legal economic incentives to both living and deceased donors will be a substantial measure to improve society accomplishment to organ donation, has gained significant global motivation. Supporters of this proposal considered that no matter how controversial, the possibility that economic incentives can save lives is stronger than any other type of decision [40,41]. Among the moral and ethical risks concerning a global acceptance of this proposal, the social challenge that placing a price on a human body may present has been highlighted, as this could generate a dramatic social inequality between the poor and the rich [42]. On the other hand, analyzing the conflicting argument that the sale of organs would probably only be accepted by poor people, several authors stated that this argument is disputable on ethical

grounds. They stated that poor individuals should not be deprived of an income that is useful to them, particularly when their organs might save the lives of those who desperately need them [43,44].

Following this controversial proposal, it is necessary to mention the opinion of the Working Group on Incentives. This group considered that the discussion of incentives has been focused on two areas:

- a. Whether or not there are ethical principles that justify the current prohibition.
- b. Whether incentives would do more good than harm. Considering that the major potential advantages of a regulated system of incentives for donation are increased organ availability for candidates on the waiting list combined with the provision of benefits for donors or donor families, the group proposes a clear legislation and national framework, strong governmental control and safe and transparent procedures and screenings. Finally the group stated that donor and recipient protection is the most important factor. The single greatest threat to a regulated system of incentives for donors would be that dishonest individuals or groups would seek to subvert that regulation for personal gain, a risk that applies to any legal enterprise [45].

Current social education impact on organ donation and transplantation

Strikingly, as has been remarked upon by different authors, a more adequate education strategy is a possibility to change people’s behavior toward organ donation; this has never been generated by any institution responsible for social education programs with regard to this critical subject. The contradiction is that the success of organ transplantation is growing simultaneously with the progression of waiting lists and patient mortality. Almost inexplicably, society’s education methodology has remained practically unchanged over time. Improving all levels of society education may change the critical organ shortage situation. A methodological change based on modifications of the message to society may be one way to deal with this dilemma. It is crucial that leading medical societies performing organ transplantation worldwide, as well as the World Health Organization, UNESCO and the chief representatives of the main religious beliefs, should be concerned with a change in the classic social education programs.

Exploring knowledge of the subject in well-educated individuals and doctors

To assess the usefulness of the present social programs to improve organ donation and evaluate personal

viewpoints with regard to new proposals on the educational strategy, a group of well-educated individuals was surveyed some years ago. A questionnaire was presented to 2321 university students and staff members who would have been likely to benefit from previous information campaigns; this was undertaken in five universities in two South American and three European countries (Argentina, Brazil, France, Italy and Austria).

Organ shortage was considered by the respondents as a serious public health issue. However, there was a widespread ignorance of religious precepts concerning transplantation that contributed to the low acceptance rate of organ sharing after death. Financial rewards for donors or their families remain controversial. There was a general agreement that there is a need for early educational programs in schools. Most people still consider organ donation to be a gift, but many would now agree to readily share body parts after death. This survey, in 2007, showed that well-educated people, including medical doctors, retained little knowledge of organ donation. The negative impact of ignorance surrounding religious precepts indicated the need for specific information by Church leaders. On the other hand, a significant positive result of this survey was the high acceptance rate of educational programs in schools [10]. The results of this study confirmed different surveys carried out in different universities at that time. Currently, in the Catholic University of Argentina, we are conducting a survey to assess the knowledge of medical professionals regarding the persistent problem of organ shortage. We

will perform a preliminary analysis of the results to evaluate the present knowledge of medical professionals on the organ donation crisis and compare this with previous surveys.

The interviewed professionals are undertaking post-graduate studies in different medical areas. The methodology of the survey consisted of the evaluation of two questionnaires. The first, pre-information questionnaire, aimed to evaluate the individuals' knowledge about donation and transplants of medical professionals in a country that was developing a national transplant program since 1979 [46]. The second of the questionnaires aimed to evaluate the response and acceptance by the respondents of the essential concepts proposed in this manuscript, particularly the impact of cognitive and non-cognitive factors as inhibitory barriers for donation and the suggested new slogans for the promotion of donation at all social levels. The respondents were 159 professionals, 88 females (55.35%) and 71 males (44.75 %). The average age was 37 years (range 27-64). The results obtained in this survey show that the insufficiency of medical education in transplantation issues in Universities, has remained, unfortunately without major changes over the years (Tables 1&2). In general, the positive answers expressed in the after class questionnaire show the importance to establish teaching programs on donation and transplants in medical education [46-51].

1. Do you know the causes of organ shortage?		
Yes	92	58%
Not	64	40.5%
Not answer	3	1.5%
2. Can you mention them?		
Lack of education	47	29.55%
Organ shortage	36	22.64%
Myths ⁽¹⁾	21	13.2%
Insufficient medical knowledge	17	10.7%
Not know	9	5.66%
Religion	7	4.4%
Misinformation	5	3.14%
Family refusal	4	2.51%
State inefficiency	3	1.88%
3. Would you be an organ donor?		
Yes	148	93.08%
Not	11	6.92%
4. Would you donate the organs of a deceased loved one?		
Yes	145	91.2%
Not	14	8.8%
5. Mention the conscious or subconscious fears for which you would not be an organ donor.		
Not answer	59	37%

None	52	32.4%
Myths ⁽¹⁾	39	24.2%
Lack of education	7	4.3%
Family refusal	3	1.5%
Religion	1	0.6%
<i>(1) Myths: Fears, prejudices, organ trafficking, concern of medical behavior</i>		

Table 1: Questionnaire Pre-Class.

1. Do you after the lecture, better understand the problem of organ donation?		
Yes	156	98.11%
Not	3	1.89%
2. What factors do you think are the most important barriers to organ donation: cognitive or non-cognitive?		
Non-cognitive factors	89	55.9%
Cognitive factors	43	27.1%
Both	26	16.4%
Not know	1	0.6%
3. Do you accept the concept that our body, after life, is a unique and irreplaceable source of health?		
Yes	156	98.11%
Not	3	1.89%
4. Would you disseminate these concepts to your family and your social environment?		
Yes	157	98.74%
Not	2	1.26%
5. What do you consider useful to modify the social behavior towards donation: Education or legal instruments?		
Education	146	91.82%
Both	13	8.18%
6. Was this class useful for you?		
Yes	158	99.37%
Not	1	0.63%

Table 2: Questionnaire Post-Class.

Youth education on organ donation and transplantation

The need to focus organ donation education at an early age, beginning with primary school and followed by intensification at the college and university levels, has been cited as a useful alternative to achieve a change behavior towards organ donation [52]. The rationale of this proposal is that young people are free of prejudice and able to learn new ideas, sometimes more easily than adults. Modern psychology suggests that childhood is the best stage of life to begin prevention programs against harmful prejudices. In addition, new ideas learned in school can be transferred to their families [53]. In public school in Argentina (>1000 students, from different socio-economic areas) and Canada (140 students, from a single private school), an educational program on essential concepts of organ donation, procurement, and organ allocation was carried out.

Evaluation of the understanding of this critical subject in children aged from 10 to 16 years was remarkable. A

questionnaire performed after the class showed that pupils from different countries and socioeconomic levels clearly understand the concepts explained with a coherent interpretation of the problem. The teaching attempt comprised a one hour explanation of the basic concepts of transplantation, including history, end stage organ failure, waiting lists, brain death, organ donors, the opinion of individuals of monotheist faiths, and different messages to the public. The level of understanding of the pupils with regard to previously unknown topics was significantly similar considering ethnical, cultural and socioeconomic differences in both groups. These experiences suggest that the acceptance of similar teaching programs about organ donation by young children might be accepted by those in different socioeconomic communities [54-56]. These youth education attempts suggest that a universal transplantation school curriculum, with messages that might change critical social behavior toward organ and tissue donation, should be actively considered by state officials responsible for education and public health [56,57].

Discussion

Undoubtedly, organ and tissue transplants constitute one of the most important achievements of current medicine. The contradiction is that this outstanding medical success is growing simultaneously with the progression of waiting lists and patient mortality. The sinister ghost of organ shortages has been maintained, practically unchanged, for decades. In a critical search for solutions, several authors have made reasonable analyses of the invariable structural methodology of social education programs, envisaging rational changes to the real barriers that inhibit people's motivation to donate. Nevertheless, almost inexplicably, society's education methodology has remained practically unchanged over time, with its programmatic strategy being primarily based on the slogan "Donation is the gift of life". It is interesting to note that except for proposals of incentives to donation, no author has suggested changing the structural characteristics of current educational plans to improve peoples' behavior toward donation [45, 58-61].

Considering that improving education at all levels of society should offer the possibility to change the current organ shortage dilemma, we propose a change based on the substantial modification of the strategy that is currently being used with society. In the last decade, different researchers in social psychology have suggested that rational factors have less of an influence on individual behavior with respect to organ and tissue donation than non-rational variables such as a fear of mutilation or death and a lack of confidence in doctors [24,62]. The absence of positive attempts to modify human behavior with respect to organ donation suggests a scientific stalemate for the resolution of crises on the part of the main protagonists.

A change in policy regarding organ donation and transplantation requires a critical discussion between the groups responsible for education and international health and education organizations. Psychological inhibitions have not been defined in educational messages to people. An instructive program developed by experts in sociology, psychology and theology would be essential to modify the inappropriate behavior of society and the tragic consequences of this procedural failure. Our preliminary experience in the carry out poll, showed a surprising lack of information from doctors working in a country that has developed a national transplant program, under a law, in the last 40 years [46]. As well, regarding the potential causes of organ shortage is also of interest to highlight the high percentage of medical insufficient knowledge mentioned by the participants. On the other hand, the post-class questionnaire showed that a one-hour talk,

mentioning a previously unknown topic such as cognitive and non-cognitive barriers, and different slogans addressed to society, show up a significant adherence to these concepts by the survey participants. Finally, we also estimate that as Schoenberg already stressed in 1991, education of the young, starting in elementary school, might be of potential social utility if more efficient educational measure is established in a universally rational way.

Conclusions

In conclusion, it is worth mentioning the main proposal suggested for a potential improvement of social educational programs on organ donation:

- a. People must be taught through educational programs that the lack of organs is a social responsibility causing an increasing number of "unjust deaths" of patients on waiting lists.
- b. Subconsciously, non-cognitive factors which are responsible for social barriers to donation should integrate possible modifications to the current social educational programs.
- c. International surveys showed that the following slogans, which could neutralize non-cognitive factors towards donation, might be included in educational programs:
 - i. Donating is not giving life to somebody, it means sharing life with everybody,
 - ii. While we live, we are potential recipients of a transplant; but we can primarily only be organ donors after death,
 - iii. When life is gone, our body is a unique and irreplaceable source of health. The results obtained worldwide showed that current educational strategies have not exceeded a defined level of acceptance to organ donation. The persistent organ shortage is an acute health crisis. Unfortunately, we must accept that an insufficient social behavior towards donation is a major responsible for a daily unjust death of patients on the waiting lists throughout the world. A thorough analysis of the causes of organ shortage, and any alternative to achieve their change, is an unavoidable obligation of the responsible of current health and education programs regarding organ donation and transplantation worldwide.

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