

Efficacy of education strategies concerning organ shortage: state-of-the-art and proposals

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Abstract

Introduction: Aim of this study was to review the underlying reasons for organ shortage and the efficacy of current education programs, in order to propose messages to modify socio-psychological feelings to donation.

Discussion: Emotional barriers such as fear of death and mutilation are the major reasons for inadequate organ donation; nevertheless, education programs do not consider these barriers. Concerning non-cognitive factors as donation's inhibitions, phrases 'after death, our body is a unique source of health' and 'throughout life, we are potential recipients of a transplant' should be suggestions for a slogan change. Youth education, starting early, should be well thought out to avoid irrational prejudice to donation. Educational curriculums should be globally established. Education and health stakeholders as well as religious authorities should support this strategy. In search to a long-term solution to the present crisis for society, this teaching strategy should be pedagogically adapted to the socioeconomic characteristics of each region.

Conclusion: Educational options to improve knowledge and attitudes toward organ donation should be carefully planned to prevent 'organ shortage' becoming a permanent and unjustifiable critical health crisis.

KEY WORDS: Cognitive and non-cognitive factors; health education; mortality on waiting lists; organ donation; social behaviour; youth education.

Riassunto

Introduzione: Lo scopo di questo studio è stato quello di fare una revisione di letteratura sulle cause sottostanti la carenza d'organo e l'efficacia degli attuali programmi educativi, con la finalità di proporre messaggi per modificare la sensibilità psicologica e sociale rispetto alla donazione.

Discussione: Le barriere emotive come la paura della morte e della mutilazione sono le ragioni principali per una inadeguata donazione d'organo; nonostante ciò, i programmi educativi non considerano queste barriere. I fattori di preoccupazione di tipo non-cognitivo come le inibizioni alla donazione, frasi come “dopo la morte, il nostro corpo è l'unica fonte di vita” e, “nel corso di tutta la vita, noi siamo potenziali riceventi di un trapianto” dovrebbero essere suggerimenti per un cambio di slogan. L'educazione dei giovani, iniziata precocemente, dovrebbe essere attentamente considerata per evitare pregiudizi irrazionali alla donazione. Offerte formative dovrebbero essere istituite a livello globale. I portatori di interesse sull'educazione e la salute, così come le autorità religiose dovrebbero supportare questa strategia. In cerca di una soluzione a lungo termine per l'attuale crisi della società, questa strategia educativa dovrebbe essere adattata dal punto di vista pedagogico alle caratteristiche socio-economiche di ciascuna regione.

Conclusioni: Le opzioni educative per migliorare la conoscenza ed il comportamento verso la donazione d'organo dovrebbero essere attentamente pianificate per prevenire la mancanza d'organo che rappresenta una permanente ed ingiustificabile emergenza sanitaria.

TAKE-HOME MESSAGE

Conceptual changes in social education programs, a challenge to improve organ shortage.

Competing interests - none declared.

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INTRODUCTION

Current evidence suggests that transplantation from the dead to prolong the life of the living who require a new organ, may be a health guarantee for society; nevertheless, approximately 50% of the world's population has negative feelings toward organ donation, which creates organ shortage and limits this possibility. More than 125,000 individuals in the US currently need a transplant, with 64% of these on a waiting list to which approximately one person is added every 10 minutes; thus, unfortunately only roughly half of these individuals will receive a transplant this year [1]. Organ shortage is a social, psychological, ethical, moral, and political problem, causing patients to 'unfairly' die every day. The unjustifiable truth is that modern day society is denying other humans the chance to carrying on living. With respect to the concept of 'unfair death', it is also true that thousands of individuals die every day due to socioeconomic inequalities [2]. Causes of these deaths are multiple and complex: economic, social inequality, political, and corruption. Conversely, organ shortage may be much simpler to modify; it would be necessary for individuals to acknowledge that they have the right to receive an organ if needed, and also the responsibility upon death, to donate their organs to others who require them. To reach a solution, strategies to modify attitudes toward organ donation should be evaluated and revised [3]. The crucial question should be: why is humanity committing this crime against itself? The main reasons for negative attitudes toward organ donation are cognitive / rational such as ignorance and disinformation, or irrational/non-cognitive such as a fear of death and mutilation. It has been suggested that people's confidence in medical counsels is not always rational. Several studies have shown that illogical attitudes can prevail in patient's agreement with medical advice [4–11]. Currently, organ shortage depends on an individual's elective organ donor registration or to family consent at the time of death of loved ones. Persistent mortality on waiting lists is evidence that legal instruments have not been

effective in solving this crisis. Different alternatives have been suggested in the forward search for a solution to this dilemma [6]. Organ transplantation symbolizes the change of death into life. Undoubtedly, people's knowledge and acceptance of this metaphor should be sustained by decision-makers of the State health authorities and education strategies. One way to accomplish this aim is to encourage individuals to accept that after death the body is a unique source of organs, which can be used when terminal organ or tissue failure can end our lives. The objective of education should be to convince individuals to acknowledge that during their existence they have the right to receive an organ if needed, and also have a duty to be a donor at the end of their life. In addition, individuals should know that all monotheistic religions accept life after death following organ donation. In the quest of this achievement, we have proposed changes from the classical slogan: 'donation is the gift of life' to 'to donate is to share life' and 'during life we are all potential transplant recipients'. Actions to improve educational programs would be extremely important in changing individual's conduct toward donation. Government and private health and social service organizations should be involved in the solution to this public problem [12, 13]. It is critical that information regarding donation and transplantation is not susceptible to confusing interpretations. The united network for organ sharing (UNOS) stated that in 2017 the number of deceased donors in the US was 10,281, representing an increase of 3.1% as compared with 2016, and of 27% since 2007. Moreover, UNOS have stated that a record number of organs have already been donated in 2018 pointing out that current acceptance of extended criterion donors (ECDs) partially explains this statistical progress [14]. In 2004, Stratta et al. remarked that deceased donors over the age of 50 had increased from 21% to 30% in the last 10 years. Patients waiting for a kidney transplant at that time had risen by 260%, while deceased donor transplants had increased by only 16%. The authors highlighted that organ donation and transplants statistics should be evaluated

following the acceptance of ECDs (previously named marginal or suboptimal donors), since ECDs were systematically rejected by transplantation teams at that time [15]. We have also emphasized that educating the youth regarding transplantation and donation is a valuable strategy to attempt to change social behavior. This alternative, carried out in schools, colleges, and universities, has not yet been attempted globally in a stable way by the States responsible for education. Its systematic application in the search for a change in the critical attitude of society toward organ shortage is a rational alternative supported by studies on youth psychology [16]. Aim of this study was to review the underlying reasons for organ shortage and the efficacy of current education programs, in order to propose messages to modify socio-psychological feelings to donation.

DISCUSSION

The underlying reasons for organ shortage

It has been considered that willingness to donate is universally conditioned by cognitive factors such as cultural, religious, and altruistic beliefs. Moreover, psychology disciplines have revealed that non-cognitive factors may be mostly responsible for refusal to donate organs [17].

Cognitive factors

Several rational explanations for the social behavior toward organ donation have been suggested:

1. There is only partial awareness of how common organ transplantation is [18].
2. Thought process that a transplant may be needed during their life is absent [13].
3. Transplants and organ donation modify the perception of the body and of life and death [19].
4. The likelihood of a transplant is dependent on the socioeconomic environment of the patient [19].
5. The use of deceased organs and tissues

should be accepted as a health insurance [20].

6. Universities in the field of medicine have not developed relevant programs on transplantation [21–25].
7. Barriers regarding the diagnosis of brain death among physicians were analyzed in areas with low (LDR) and high donation rates (HDR). The LDR doctors were doubly resistant to initiate the diagnosis when confronted with a case of clinical death [26].
8. The low donation rate is mainly due to ignorance and/or bad social information and non-acceptance of a non-traditional concept of death. Many health professionals misunderstand the legal definition of brain death [27].
9. The public ignores the fact that organ transplantation can reduce health budgets. It should be underlined that transplantation generates economic benefits; an example is the cost savings of kidney transplantation versus the increasing costs of chronic hemodialysis [28, 29].

Non-cognitive factors

Current surveys have not distinguished donors from non-donors with respect to the role of cognitive factors in donation decisions. Conversely, these polls have shown that non-cognitive factors such as a fear of death and mutilation had a significant influence on the attitude of non-donors [9].

The decision to donate after death awakens fears, prejudices, and misunderstandings such as:

1. The instinct of self-preservation [7].
2. The Freudian notion that nobody thinks of dying until a loved one dies [30].
3. The idea that body integrity is mandatory to eternal life [31].
4. Fears concerning brain death diagnosis [10, 11, 32].
5. It has been remarked that the negati-

ty toward donation is the consequence of myths and psychological concerns developed at the moment of decision [33, 34]. Morgan et al. suggested that rational factors are not essential for organ donation. On the contrary, psychological feelings such as a fear of death and mutilation, and distrust in medical behavior, have been suggested as decisive barriers to donation [31, 32]. Moreover, it had been remarked that certain individuals believe that it is bad luck to make any reference to death [33].

Educational programs regarding donation have not considered until now the emotional non-cognitive reactions responsible for the conflicting behaviors toward donation.

To consider the importance of these concerns, we suggest discussion of the following phrases:

- a. Organ shortage is a health emergency [35].
- b. The body after death is a unique source of health for everyone [36].
- c. Sharing the body after death should be a tacit social agreement for the common welfare of society [36, 37].
- d. Organ donation is not giving life; it is sharing life [36, 37].
- e. Throughout our lives we are all potential organ and tissue recipients [38].

Evaluation concerning feelings toward donation showed a higher score for fear of death related to a lack of experience with dying friends or patients. Undoubtedly, this lack of experience generates a significant problem with respect to the encouragement of discussion about organ donation with family members. Coherent explanations that can neutralize non-cognitive barriers have been highlighted as being of critical value in modifying organ donation decisions [39–48]. These concepts regarding psychological aspects, often based on ancestral background, are deserved of study by social, psychological, and religious experts. The solution to overcoming these non-cognitive barriers and modifying the conditioned negative attitude towards donation is public education specifically address-

sed to this subject; a possible benefit to the people that has not yet been used. An educational program considering rational and subconscious barriers toward donation will help to save the lives that are currently lost daily [32, 42, 49].

The message to the public has been inadequate

For decades, public education regarding organ donation has relied on the concept of altruism; the 'gift' that will save someone's life. Several surveys have shown that individuals are open to donating their organs or those of family member after death; however, at the moment of grief, a high percentage fail to remember this commitment, and the 'gift' of life does not come to fruition [50–51]. The media often covers sensationalistic news sustaining the following myths:

- a. Premature declaration of death [51].
- b. Transference of personality from donor to recipient [52].
- c. Criminal black market [53].
- d. Corruption in the medical community [54].
- e. Celebrities getting transplants first [55, 56].

A well-designed media campaign may have an influence on improving society's knowledge. The collaboration between transplant experts and journalists has been proposed to correct misinformation regarding donation and transplantation news [57]. Teaching basic concepts of organ donation and transplantation has been a matter of interest for decades; nevertheless, the results to date are inadequate and neither worldwide organ donation nor procurement has improved. With respect to medical education, multiple polls have shown a severe lack of knowledge on the subject [3, 20–26]. Aiming to modify prejudices and barriers that inhibit the use of the body after death should be well planned, with the main focus given to youth education, beginning with children in schools [58, 59].

Youth education on organ donation and

transplantation

The rationale of this proposal is that young people are free of prejudice and able to learn new ideas; sometimes effortlessly as compared with adults. Modern psychology suggests that childhood is the best developmental stage to begin prevention programs against harmful prejudices. In addition, new ideas learned in school can be a way to transfer knowledge to their families [60, 61]. In Argentina and Canada, an educational program detailing the essential steps of donation, procurement, and allocation of organs was carried out. Evaluation of the understanding of this methodology in young people from 12 to 16 years old was surprisingly positive. Answering a questionnaire after the class showed that students from different socioeconomic levels had a clear understanding of the concepts taught and a coherent interpretation of the problem [61]. These experiences may highlight the importance of the opportunity of a universal and stable transplantation curriculum in youth education. It should include new forms of the message to change the behavior toward organ and tissue donation [61].

The role of international organizations responsible for health and education

For the success of an educational program, a joint activity promoted by the World Health Organization (WHO), international education institutions, scientific societies, and religious leaders would be of great value. The WHO and the Transplantation Society have already developed an intense legal and ethical interest in solving the serious problem of organ commerce and transplant tourism [62]. It is without doubt that a similar action of these leading institutions in solving potential educational problems responsible for a health crisis due to inappropriate social behavior would be of significant interest.

Economic incentives to donate

Considering that our transplant system based on altruism is inadequate to save lives, it has been proposed that incentive pilot trials

should be considered [63]. Matas and Hays stated that the educational policy in the US has had little effect on organ donation; and for that reason, they suggested that organ donation be financially beneficial for donors as a solution to this serious problem [64]. With respect to this proposal, it should be considered that any strategy with economic incentive to donate risks the generation of a new type of social injustice and inequality [65]. In addition, there has been criticism of the current educational programs, and the methodology is considered ineffective and a needless economic investment [66, 67]. It is interesting to highlight that none of these authors suggested any substantial modifications to the current educational methodologies to achieve a more positive societal response to organ donation.

Perspectives and proposals

It has been stated that millions of dollars have been unsuccessfully spent on education regarding organ donation. Consequently, it has been suggested that there is a need for controversial measures such as economic motivations as an incentive to living and deceased donors [64–67]. The contradiction is that the success of organ transplantation is growing simultaneously to the growth of waiting lists and patient mortality. Almost inexplicably, society's education methodology has remained practically unchanged over time [68]. Improving related education of all levels of society may offer a possibility to change critical organ shortage. We have considered that a methodology change based on modification of the message to society may be a way to challenge this stagnant dilemma. As we have previously discussed, it should be of importance to consider within new educational plans the complex mentioned barriers to donation. Research conducted in the US has demonstrated that rational factors have less influence on individual's behavior than non-rational variables such as a fear of mutilation or death and a lack of confidence in physicians [32]. An evaluation of the influence of cognitive factors and personal ways of thinking may modify individual's current undefined behavior toward

donation. Psychological inhibitions have not been defined in informative messages. An educational program developed by experts in sociology, psychology, and theology would be essential to prevent the inadequate behavior of society and the tragic consequences of organ failure. The absence of positive attempts to modify human behavior concerning organ donation suggests a scientific stalemate for crisis resolution by the main protagonists. A change in philosophy policies regarding organ donation and transplants requires a critical discussion between States responsible for education and international health and education organizations. The need to focus on related education at an early age, starting with elementary school, followed by intensification at university level has been addressed. This analysis can condition more concrete criteria in every effort to obtain a change in social behavior toward donation, since persistence of the current reality remains an unanswered uncertainty [69–71]. Finally, current results of organ transplantation show an extraordinary improvement in long-term graft and patient survival, with daily scientific advances; nevertheless, the number of patients dying on the increasing waiting lists continues to rise. It is a persistent reality that the ambiguous society participation in organ donation corresponds to the partial ignorance or misunderstanding of what organ transplantation currently represents. Recently, it has been highlighted

regarding potential donors: ‘if a potential donor’s questions were not answered or if they were confused, they may abandon the process without a realistic understanding of the risks and benefits of donating’ [72]. Changing the message and focusing particularly on the young could be a way toward a solution to this serious social dilemma. Shoenberg considered that teaching young people about organ transplantation is not particularly difficult. He noted that helping young people to understand the problems surrounding organ donation and transplantation will increase their understanding of its importance [73]. The goal is that young people will discuss donation with their families and peers, which will multiply the educational effect. Intense and persistent educational efforts focused specifically on young people are relatively rare, and consequently led this educator to suggest in 1991 that the transplant community must offer strong stimuli that induce professors in various places to assume such a task [73].

CONCLUSION

Although the current public education programs towards organ donation have managed to bring to light the importance of this new medico-social resource, the persistence of organ shortage and the progressive increase in mortality on waiting list evidences the need to analyze their results and to consider alternatives encouraging to a greater public understanding of the relevance of organ donation.

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