

Full Length Research Paper

Process of children's organ donation: Factors that intervene in the communication of the healthcare provider

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The possibility of providing aid to individuals through the process of organ donation, so that they may continue living, is an initiative based on altruism and solidarity. The aim of this study is to describe the factors that intervene in the communication of the health care provider with the parents of brain dead children. We have selected papers and information from Web of Science, CINAHL, Science Direct (Elsevier), and PUBMED databases from 2000 to 2013. The principal findings of this study are that brain dead in children has a tough impact on healthcare service teams, cultural and religious aspects of the parents are factors that intervene in the decision making process, and probably the process donation is guided by a sense of solidarity with another in suffering and altruism, parents of children that are waiting for organs are also in a situation of great worry, because the death of their child may occur soon if they do not secure access to an organ which are the underlying constituent emotions and motors of the donor process.

Key words: Organ donor, paediatric intensive care units, decision-making process, communication barriers.

INTRODUCTION

The possibility of providing aid to individuals so that they may continue living through the process of organ donation is an initiative based on altruism (Blum, 2001; Netza et al., 2010) and solidarity (Barbalet, 2006). These values are present in societies that promote and guide

the donation process. The donation process begins when a person freely and voluntarily decides to donate his/her organs.

The Chilean law number 20.413 modifies the law number 19.451 regarding the transplantation and donation

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of organs with the objective of more precisely determining who may be considered a donor. The law establishes that a donor may be any individual who is older than 18 years of age and who has not renounced the possibility of donating before another person or competent organization. In the case of legal minors, this law establishes that organ donation depends on the authorization of parents or legal representatives (BCN, 2010). As a result, the death of an individual from which organs are to be extracted after decease is the starting point of a charitable act of solidarity between survivors and those suffering from illness, with the future goal of saving the life of an individual.

In Chile, a person in the last phase of his/her life becomes a donor subject after a team of assisting medical personnel declares and confirms his/her brain dead (BD). This procedure is corroborated through a series of exams based on available evidence which includes: structural and deep coma of known aetiology and irreversible nature, absence of depressive aspects of the central nervous system by either pharmaceutical or toxic drugs, non-reaction to stimulus, generalized hypotonia, absence of brain stem activity, apnoea, and verification through electroencephalogram confirming the above-listed clinical signs. Communities of medical experts all over the world have generally accepted the above-listed criteria as evidence of BD (Contreras-Ibacache et al., 2012).

Current technological advances allow healthcare professionals to keep people alive despite being gravely ill, granting them the possibility of receiving an effective therapeutic intervention in the form of an organ transplant, which often is the last hope for a significant number of individuals (Caille and Doucin, 2011). This therapeutic use of organs requires that the process of donation, between donor and recipient, necessarily pass through the mediation of an organization of healthcare professionals (Contreras-Ibacache et al., 2012). One of the ethical problems related to this subject, both locally and globally, is the reduction in the rates of organ donation in recent times. This phenomenon not only affects the adult population but also children who die while waiting for an organ, because there are fewer dead organs donors for children (Brierley and Hasan, 2012; Haque, 2011; Tsai et al., 2000). For this reason, both the attitude of health teams collaborating in the detection of potential donors and the training of healthcare professionals involved in the procurement of organs, are relevant factors in helping to increase the levels of organ donation (Ertin et al., 2010).

Even though information about donation is easily accessed across social media, the parents of gravely ill children require that certain information related to the process of donation be directly communicated to them via healthcare teams (de Groot et al., 2012; Martinez et al., 2001), since these healthcare professionals are the ones

that have the level of knowledge necessary to explain clearly the donation process to the BD patient's family members. It is therefore also crucial that at the moment of communicating with parents, the healthcare professionals do everything possible so that the decision to donate a child's organs be both free and autonomous. Healthcare professionals must provide permanent support to the parents, whether the decision to donate be positive or negative in regards to donation. However, healthcare teams are limited in the delivery of information due to some of the following factors: the declaration of BD in children, the state of the potential donation recipient once BD is established, and the way of confronting the family in grief and informing them about the possibility of the donation, which often causes situations of stress and anguish in the teams themselves (Martinez et al., 2001).

In this study, the researchers propose making a review to describe the factors that intervene in the communication of the health care provider with the parents of brain dead child about the possibility of organ donation.

METHODOLOGY

This is a review of literature based on research conducted through the following scholarly databases: Web of Science, CINAHL, Science Direct (Elsevier), and PUBMED from May to July of 2013. The research followed the procedure as shown in Figure 1. The key words searched were: Organ donation, pediatric, factors in family decision-making process, families' decision-making process, factors influencing decision making process, donation d'organe, pediatrie, altruisme, and solidarity. Criteria of inclusion were that the articles were published between 2000 and 2013, in Spanish, French or English. Articles related to adult organ donation, anencephalic individuals, donation of stem cells and gametes, live donation, blood donation, and skin appendages were excluded from the study.

In this article, an exception was made in four articles on donation process (blood donation and adult setting research), due to the relevance of their content relating to the social context of solidarity and altruism in the donative process. Moreover, another article was included regarding organ donation from the perspective of adult intensive care teams, because of its contribution in recognizing the factors limiting communication in the care of BD patients.

RESULTS

Brain death and impact on healthcare service teams

The articles selected prove that it is necessary of addressing the possibility of donation from a multidisciplinary perspective (Siebelink et al., 2012). The information that is available to healthcare teams, at the moment of declaration of BD, is strongly associated with care at the end of life (Siebelink et al., 2012), from the perspective of adequately conserving the organs and protecting the donor. The primary focus of a pediatric

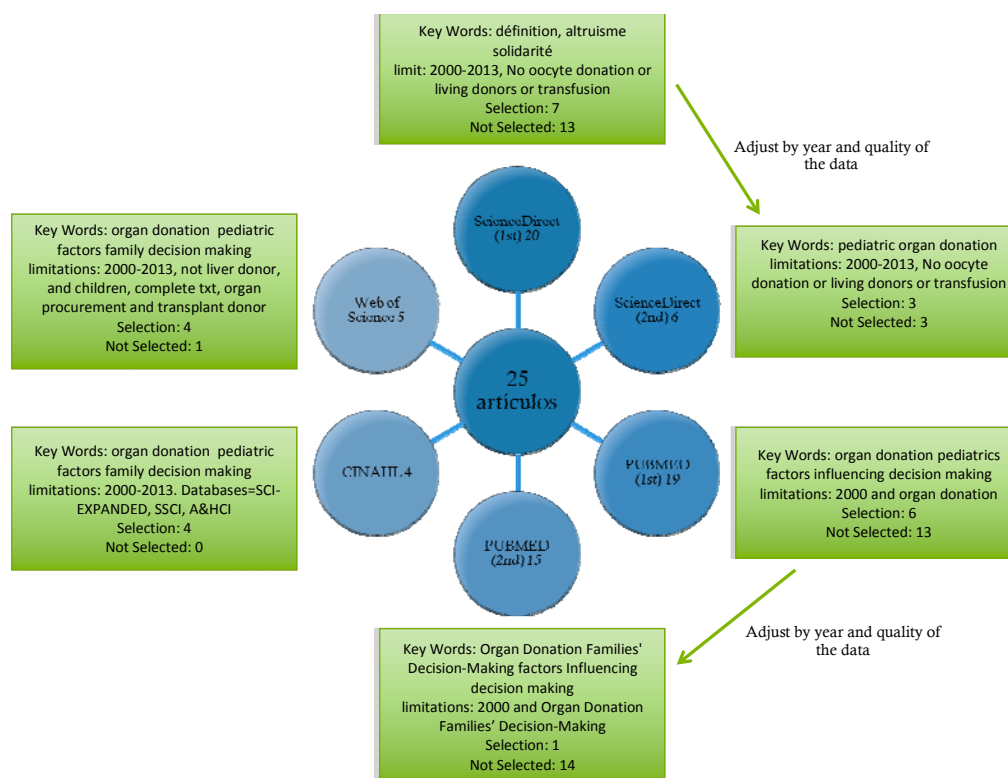


Figure 1. Scholarly database.

intensive care unit (PICU) team is saving lives, one perception is that the duty is to care for the living, when this focus is changed from the dead patient to the potential organ donor (Meyer et al., 2012). When a boy or girl dies and requires that their body be preserved, they become potential donors.

Given this new circumstance, it is a difficult task to initiate a dialogue with the parents about the process of donation, due to the fact that PICU team have few techniques regarding discussing with parents because of the implications of their decision (Floden et al., 2011). Moreover, on many occasions this conversation with the parents, once BD is established, becomes mixed with the grieving process of the treatment team. In numerous cases, the treatment teams are the ones who refuse to ask the question of whether the parents wish to donate organs or not, because they consider it to be a difficult petition, given the emotional weight that the death of a child entails; which also puts a large emotional burden of stress on the team (Biarent et al., 2004).

Moreover, the literature stresses the importance of giving the parents a time period for grieving (Sque et al., 2005), before informing them about the process of donation. The literature also states that once BD is established and declared, it becomes necessary and fundamental to reduce the possibility of coercion in the

process of delivering the information about the donative process, giving the parents time to think and make their own decision in a free and informed manner (Siebelink et al., 2012; Sque et al., 2005). As a result, the first possibility of informing the parents about the process of organ donation for the BD child, belongs to the PICU teams, since they are the ones that have the responsibility of taking care of the child in a situation of grave medical emergency and/or accident (Fraser et al., 2011; Sque et al., 2005; Tsai et al., 2000), and as a result have a preexisting relationship with the parents based on confidence and closeness created during the healthcare provision process.

Various scholars sustain that the PICU teams themselves ought to initiate the dialogue with parents so that the information about the donative process be clear, and without bias, and/or coercive acts (American Academy of Pediatrics, 2010; Siebelink et al., 2012). In this way, healthcare professionals avoid reducing the donor (Contreras-Ibacache et al., 2012) to the state of an object (Baumann et al., 2012), and effectively keep in mind the Kantian imperative to "act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end in itself" (Kant, 2005).

However, it can be difficult to achieve because in many occasions, the caregivers (PICU) get attached to patients in such a way that could make prompting organ donation conflicting. When this happens, PICU members can even fail to give the proper information about the donation to the parent's patients. So in this case, the parents are the only ones responsible for the decision making either to donate the organs of their deceased children or not. A policy that would require a mandatory request to consent in organ donation may alleviate the stress of caregivers (Tsai et al., 2000). It is also important to point out that the leadership exercised by any of the members of the PICU team may become either a positive or a negative factor in the decision to donate the organs of the dead brain child, according to their management of the situation and engagement with the donation request (Fraser et al., 2011). Another aspect that requires mentioning is the separation of tasks inside healthcare service, with different teams diagnosing BD, performing the transplant, and carrying out the procurement process. These three teams are key actors in the delivery of information, the transparency of the donation process, and in respect to the decision of the parents or legal guardians to donate (Martinez et al., 2001; Tsai et al., 2000). To improve this process, the separation of tasks is also essential for the team members themselves.

Important psychosocial aspects

Some scholars argue that cultural and religious aspects of the parents are factors that intervene in the decision making process, influencing them to accept or deny the request for the donation of organs. The misconception of the caregivers about the different cultures and religions beliefs may inhibit the request of organ donation. Contrary to popular belief, there are few religions that prohibit the organ donation, which is why it is important that the participants in the organ request process must be well-informed and knowledgeable about various cultural, ethnic, and religious perspectives (Tsai et al., 2000). For this reason, PICU teams, in both transplant and procurement (American Academy of Pediatrics, 2010), should keep in mind such factors when they consider the enrolment of a BD child in the process of organ donation (Cochat et al., 2004; Tsai et al., 2000).

Parent's motivations for organ donor process

In studies regarding donation, it is mentioned that both altruism and solidarity are the principal reasons for deciding to donate organs (Baughn et al., 2006; Cochat et al., 2004; Duboz et al., 2012; Meert et al., 2007; Schneider et al., 2004).

In a study carried out by Morris et al. (1992), it was established that the principal reason parents have for accepting organ donation on the part of their children, was not only that another child might die, but also was to avoid that other parents might have to live through the loss of a child (Biarent et al., 2004; Rodrigue et al., 2008). These motivations are clearly related to the values of altruism and solidarity.

Finally, the act of donating is an act of service to another, which can improve the health of a person who is seriously ill and is at risk of losing his or her life. This service is guided by a sense of solidarity with another in suffering and altruism, which are the underlying constituent emotions and motors of the donative process. The parents that donate their children's organs after BD is established may be saving the life of another child. This possibility gives them a certain kind of solace, because they find that there may be some redeeming aspect resulting from the tragedy they are currently experiencing (Biarent et al., 2004).

The solidarity exercised by parents who donate organs demonstrates the changeability of human circumstances, the fragility of life, and serves as a reminder of the interdependence of human beings (d'Houtaud, 2008). In effect, organ donation is a social device that is directly related to individuals' solidarity with those in suffering, because the saving of any one person necessarily requires the aid of another (d'Houtaud, 2008).

DISCUSSION

The organ donation process requires teams trained in the topics of donation and transplantation, since it is the main purpose of this training to endow the teams with the skill to respectfully and professionally approach a family of a boy or girl with BD. The organ donation request is always made during a moment of great difficulty, and many times the family is experiencing a situation of crisis that demands special treatment and handling; all the needs and questions of the family members, who have lost a young loved one, must be thoroughly considered. Despite these difficulties, however, the request is an imperative, since the parents are the ones who have to make the decision regarding the acceptance or denial of a petition for the donation of organs, and not the treatment team.

The necessity of differentiating treatment teams from transplant teams builds confidence in healthcare professionals; also this differentiation decreases the possibility of coercion in the parent's decision-making process. The health care team of the potential donor may feel very strong emotions and discomfort with the idea to make an approach with a proven family. To avoid this stress is important to consider the separation of tasks in the same health team so that each member knows which task should be performed when proposing the donation to

the child's family with BD. In the logic of organ donation, what is being sought is the improvement of the health of a sick boy or girl through a resource which must be extracted from the body of another child that has died. As a result, healthcare professionals are responsible for respectfully carrying out this act of care, supplying it with all the necessary attentions and honouring the donor as a person (although he or she is dead), so that the child may not be considered simply an object. For this reason, until the moment that the body is delivered to the parents, it must be treated with all due dignity.

Organ donation certainly improves the survival of thousands of people but it can also be experienced positively. It is an emotionally heavy demand for both the child's parents and for the healthcare team. An adequate training and support enable caregivers to perform this process for the benefit of all who are concerned. The possibility of being a donor carries with it an underlying value - a sense of social responsibility for a total stranger - since the final recipient is normally unknown to the deciding parents. There is a will to help others that are also experiencing grief and tragedy, because the parents of children that are waiting for organs are also in a situation of great worry, because the death of their child may occur soon if they do not secure access to an organ.

Conclusion

Finally, the BD and the impact on healthcare service teams, parent's psychosocial aspects and parent's motivations for organ donor process are three new lines for the next step to follow with a qualitative study.

Conflict of Interest

The authors have not declared any conflict of interest.

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