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Donation as an Ethical Commitment in End-of-Life Care

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Thousands of patients are waiting for the phone call announcing that they may have a chance to live longer, better, or just to live. Organ donation has changed the lives of millions by pushing the limits of medical treatment; limits that transcend the death of one person and extend the life of another. Not surprisingly, several ethical considerations arise in this complex scenario, which represent the substance of the recently developed international standards that this paper comments on.

Donation and Transplantation in the Global Landscape

Organ transplantation depends on the availability of human organs. Their scarcity means there is a waiting list of almost 60,000 in the European Union (EU) (Council of Europe 2012) and over 118,000 in the USA (Organ Procurement and Transplantation Network 2013). It has been estimated that 12 patients die on the waiting list each day in the EU. Recent statistics show that deceased donation rates vary dramatically, from 35.2 per million population (pmp) in Spain to 0.6 pmp in Japan, with many countries not registering any deceased donation activity at all (DOPKI 2009). Comparisons are also difficult when organisations only provide minimal figures about transplantation results.

Diversity in organ donation and transplantation rates activities in the EU is highlighted by data collected within several EU-funded projects (DOPKI 2009). Variability in rates of donation after death between EU Member States is not seemingly due to differences in mortality rates or in public support for organ donation. On the contrary, differences in the organisational approach might be the underlying reasons for these variations (DOPKI 2009).

The disparity between supply of, and demand for, transplantable organs has triggered a wide variety of initiatives, as discussed at The Third World Health Organization (WHO) Global Consultation on Organ Donation and Transplantation, held in Madrid on March 23 to 25 of 2010, where there was a call for a comprehensive national strategy based on self-sufficiency in transplantation (WHO 2011).

Implementing the Concept of Self-Sufficiency

As specified in the Madrid Resolution, self-sufficiency means the capacity to meet patients' transplantation needs founded on each country's own resources, aiming to foster the adequate provision of organ and transplantation services to a given population, including international cooperation when appropriate. Self-sufficiency implies the maximisation of donation, making donation possible in all circumstances of death, a principle already stressed in the WHO Guiding Principles for the transplantation of human organs, tissues and cells (WHO 2010).

The Madrid resolutions develop many recommendations and requirements regarding emergency and intensive care departments, by increasing skills, awareness, collaboration, and support for donation from the deceased. Equally important is the definition of their critical role in better identifying possible and potential donors and the elaboration of standards, unambiguous guidance and protocols on how to manage the dying process. Hence, donation must be included as part of end-of-life care and is regarded as the responsibility of all healthcare professionals involved.

The Critical Pathway for Organ Donation After Death

Donor detection is the key factor preceding the step of organ referral. Up to 60 percent of patients with a devastating brain injury derived from stroke, trauma, or cardiac arrest die after family members and clinicians, given the poor prognosis, decide that further treatment is futile, without considering donation (Sprung et al. 2003). Outcomes after these decisions are very difficult to predict with certainty, and in the face of value-

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laden decisions and prognosis, treatment-withdrawal practices vary widely (Decato et al. 2013). However, it is surprising that there are practically no published studies regarding the number of brain deaths in these pathologies.

A systematic approach to the process of donation from deceased persons will help populations to define actions, roles and responsibilities in both donations after brain death (DBD) and donations after circulatory death (DCD). The critical pathway delivered in the Madrid Conference of 2011 (Transplantation 2011) is:

- a) To provide a common systematic approach to deceased donation;
- b) To create a common trigger to facilitate the prospective identification and referral of potential deceased donors and precipitate the deceased donation process, and
- c) To provide common procedures to estimate potential organ donation from deceased persons and to evaluate performance in the process of donation after death (Domínguez-Gil et al. 2011).

The pathway stipulates that any patient with a devastating brain injury, i.e. Glasgow Coma Scale below 5 (Council of Europe 2010) or with circulatory failure, who is apparently suitable for organ donation, must be considered for organ donation as part of end-of-life care. Above all, the dead donor rules must be respected (Transplantation 2011), that is, patients may only become donors after death, and the recovery of organs must never cause a donor's death (De Vita et al. 2007).

It is strongly recommended to refer every case to transplant coordinators for further evaluation, in order to inform families about donation when futility of treatment is independently decided by the team in charge (De Vita et al. 2007); Daly et al. 2006).

Option to Donate as Part of End-of Life Care

Giving and receiving are inherent to human life, and organ donation and transplantation are based on these cornerstones of survival. These basic survival mechanisms are developed within a relational context and specific cultural conditions. Based on these principles, organ and tissue donation means gifting one's heritage to whoever needs it.

The option of organ donation must be considered as an integral part of endoflife care and occurs as the culmination of two processes: the ending of a patient's life and the gaining of permission for donation from the patient or the patient's family (Daly et al. 2006). Donation cannot occur outside this context, and thus understanding endof-life issues and committing to a caring request process are essential.

However, this is a complex and extremely stressful situation for all those involved, which demands total honesty and respect. Easier said than done! (Masnou and Pont 2012; Truog et al. 2008; Shafer et al. 2008).

Hence, the ability to provide sensitive and technically competent care to dying patients and their families is a prerequisite to the success of all donation programs (Truog et al. 2008; Jacoby et al. 2006).

Professional education in precisely how to manage these difficult situations with empathy and tact is full of gaps (Pont et al. 2008), making ethical discussion even more complex and necessary. Lack of adequate training to raise awareness in medical staff has been shown to be the cause of lower donor detection and referral rates (Hart et al. 2012). The literature reviewed consistently shows that where the process was coordinated and managed the consent rates were improved (Shafer et al. 2009; Shafer et al. 2008).

Summary

- Quality end-of life care is "best provided through the collaborative practice of an interdisciplinary team to meet the physical, emotional, social and spiritual needs of the person and their family" (Canadian Hospice Palliative Care Association 2002);
- Improving end-of-life care and increased organ donation are essential goals formally recognised by healthcare professionals and by society at large;
- The option of donation is an ethical commitment in end-of-life care.

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