

VIEWPOINT

Intimacy or utility? Organ donation and the choice between palliation and ventilation

Aric Bendorf^{*1}, Ian H Kerridge^{1,2} and Cameron Stewart^{1,3}

Abstract

Organ donation after brain death provides the most important source for deceased organs for transplantation, both because of the number of potential organ donors that it makes available and also because of the unparalleled viability of the organs retrieved. Analysis of worldwide deceased organ donation rates demonstrates that all countries with high deceased organ donation rates (>20 donors per million population per year) have high brain death rates (>40 brain deaths per million population per year). This analysis makes it clear that countries striving to increase their deceased organ donor rates to world leading levels must increase the rates of donation after brain death. For countries with end-of-life care strategies that stress palliation, advance care planning and treatment withdrawal for the terminally ill, the adoption of initiatives to meaningfully raise deceased donor rates will require increasing the rate at which brain death is diagnosed. This poses a difficult, and perhaps intractable, medical, ethical and sociocultural challenge as the changes that would be required to increase rates of brain death would mean conjugating an intimate clinical and cultural focus on the dying patient with the notion of how this person's death might be best managed to be of benefit to others.

Introduction

The way we die has changed significantly during the past half-century. Once a sudden and unexpected event, death has become an actively managed and often prolonged process that occurs more often in hospitals than in the community [1,2]. Advances in biotechnology, biomedicine and critical care, in particular, have transformed the

way we die [3-5]. Organ failure, for example, is no longer inextricably linked to death. Patients with end-stage renal disease are routinely dialyzed for many years. The lives of patients with cardiac failure can be prolonged with inotropic and chronotropic therapies, and patients with respiratory failure can receive invasive and non-invasive ventilation in hospital or at home. Also, for more than 100,000 patients per year of the estimated 1.7 million patients worldwide in need of transplant for failing organs [6,7], the transplantation of organs and tissues from patients that have died in intensive care settings provide significant benefits – reducing mortality and morbidity, increasing long-term survival, increasing quality of life and reducing the economic burden of the cost of healthcare for patients with chronic diseases [8].

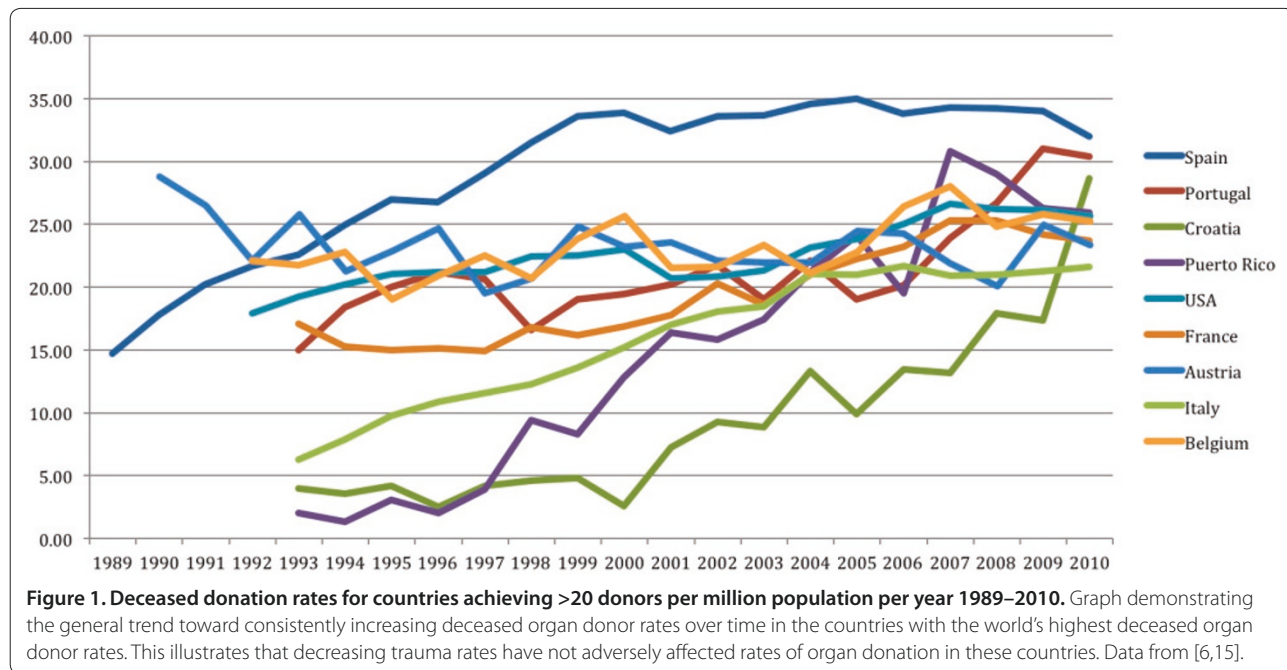
The ICU has therefore come to play multiple important roles in contemporary healthcare – providing access to advanced life support, supporting organ donation and tissue transplantation programs, and providing end-of-life care for those in whom any further treatment is futile [9]. While these functions are generally managed without difficulty, they may, at times, create an unavoidable tension, particularly when intensivists must mediate between professional and social obligations to provide patients with a good death [10,11], to effectively use scarce health resources and to support organ transplantation through the identification and management of people who are, or may become, brain dead.

Brain death is the most important method for procuring deceased organs for transplantation, both because of the number of potential organ donors that it makes available and also because of the unparalleled viability of the organs retrieved [12]. But this method, in itself, creates a unique challenge because, where brain death is anticipated, the interests of the patient, and the public benefit that accrues from the organs potentially removed from that patient may diverge, creating tension regarding the most appropriate approach to the management of the patient's death. The successful management of this tension may be the major determinant of the degree to which a country is able to meet its organ donation requirements. The ICU has therefore become the place in which both medicine and society confront a choice

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between increasing organ donation and the provision of a less invasive approach to end-of-life care, where we, collectively, balance the intimacy of a good death and the utility of increased donation rates, through provision of intensive care until brain death occurs.

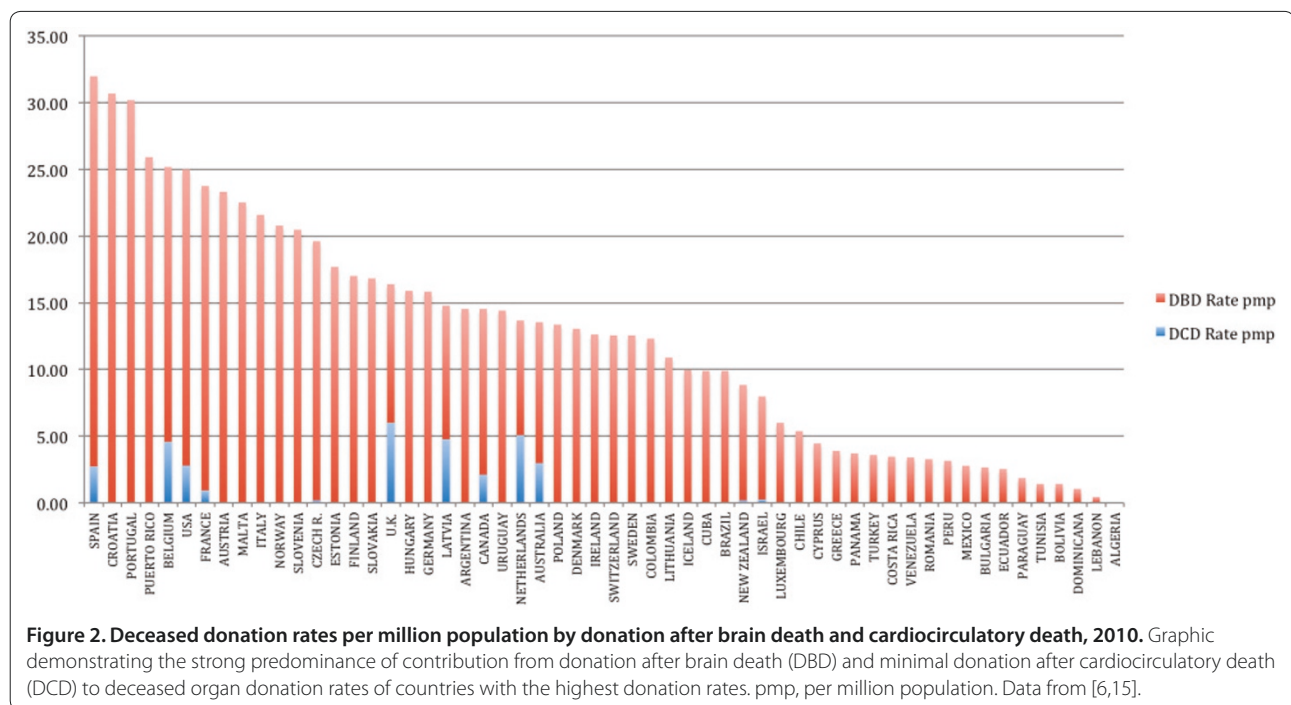
Relationship between organ donation and brain death

Recent multi-year analyses of deceased donor data from both the Council of Europe and the International Registry of Donation and Transplants have shown that there is a clear division in deceased organ donation performance between those countries that have the highest donation rates and those with lower deceased donation performance [13-15]. This division occurs at approximately 20 deceased donors per million population per year. There are nine countries that consistently achieve donation rates above this level despite having dramatically reduced death rates from the types of rates of trauma that are most commonly associated with organ donation [13]: Spain, Portugal, Puerto Rico, Croatia, the USA, France, Austria, Belgium and Italy (Figure 1). Crucially, each of these countries' high donor rates is due to the high rates of donation after brain death (DBD) and not due to the high rates of donation after cardiocirculatory death (DCD) [16-22] (Figure 2).

While DCD plays an increasingly central role in the organ donor policies in many countries and has contributed to raising organ donation rates in Spain, France, Belgium, the USA, the UK and Australia, DCD strategies are not unproblematic. Although DCD organ recovery and graft survival rates for kidneys and lungs now

approach those of DBD donors in many countries [23,24], recovery rates for other DCD organs – especially livers – remain less than those following DBD [25]. Recovery rates following DCD are also approximately 1.5 times lower, per donor, than DBD and there are some data to suggest that increased DCD donation may come at the expense of reducing DBD donation [26,27]. An international comparison of deceased donation rates demonstrates clearly that the high DBD rates observed in the leading donor countries are directly associated with high rates of brain death (>40 per million population) [28] (Figure 3).

There are many factors that determine whether a person becomes an organ donor and, consequently, many reasons why the deceased organ donor pool may be diminished. Reductions in the rates of traumatic brain injury – specifically, traffic and stroke fatalities together with advances in emergency and critical care – have reduced the numbers of patients reaching brain death criteria and therefore reduced the number of potential organ donors [13,29-31]. Also, while not directly affecting the rates of brain death, the aging of the population and increases in the rates of noncommunicable diseases (that is, diabetes) may serve to reduce the number of organs suitable for transplant. While both upstream and downstream factors – such as consent rates, donor optimization, improved organ preservation, and more rigorous recipient selection – may positively impact upon organ donor rates and transplantation outcomes, the relationship between any of these factors and donation and transplantation outcomes is not straightforward. The impact of end-of-life care and decision-making on rates of brain death and organ donation is even less clear.



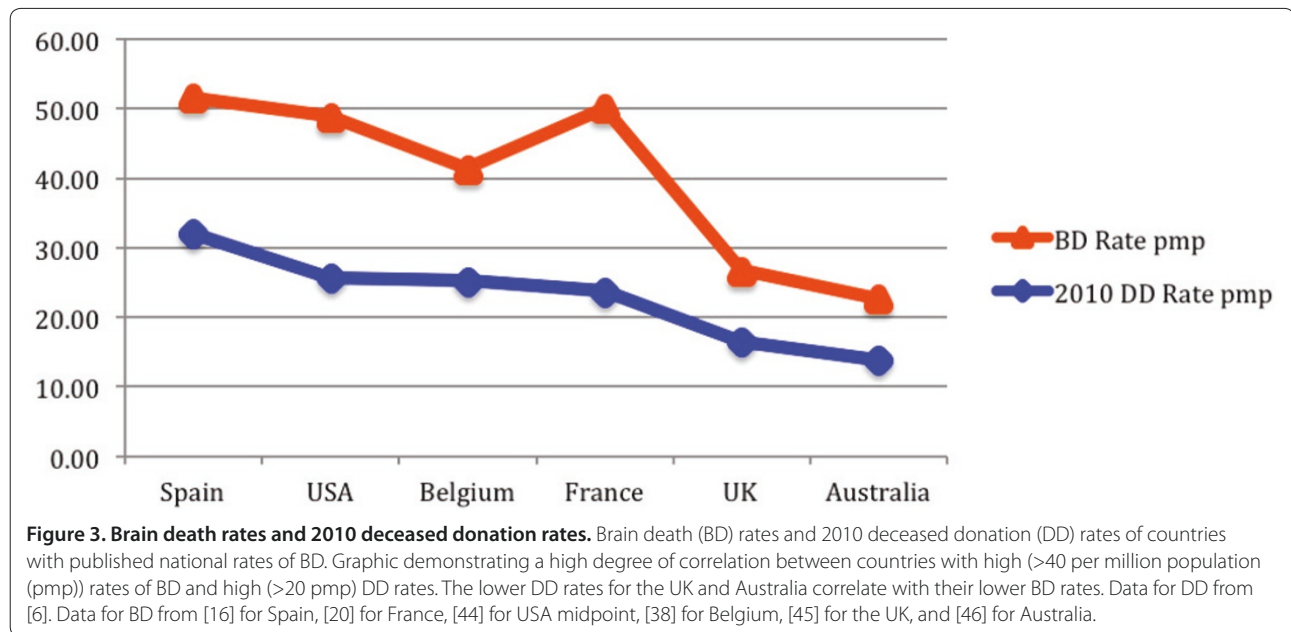
While there is some literature dealing with end-of-life practices in ICU settings [32-34], there is much less literature that makes explicit the tension between palliative care and organ donation and it remains unclear why there are such significant differences in rates of brain death in developed countries when the factors that lead to brain death are likely to be broadly equivalent in these countries and other metrics that one may expect to be salient, such as the number of ICU beds per capita, appear to have little influence on brain death rates or organ donation rates [35]. One possibility is that the high rates of brain death observed in all countries that have high deceased donor rates may be related to more aggressive interventional approaches to end-of-life care that are part of these countries' standard treatment protocols in intensive care [36-38]. Conversely, developed countries with lower rates of brain death – such as Australia, where brain death is normally only formally diagnosed when the potential donor's family has agreed to donation [39] – may approach end-of-life care less aggressively, may stress treatment withdrawal and palliation for cases in which treatment is deemed to be futile, may be less likely to emphasize the value of intensive care admission and cardiorespiratory support, and may be less likely to seek a diagnosis of brain death.

Cultural and religious factors affecting death management

Different approaches to end-of-life care and different social conventions regarding what is and what is not

appropriate or acceptable during life's final moments are likely to reflect cultural values, religious beliefs, legal norms and medical practices. Collectively, these may determine the extent to which technology is integrated into death's approach and arrival, the specific point at which society considers a person to be well and truly dead, and the use of heroic measures, including intensive care. These approaches to end-of-life care are critically important with regard to the success of organ donation and transplantation programs because they will determine when and how frequently brain death is used as the criterion by which death is declared. In cultural settings where aggressive intensive care is not the norm, patients are less likely to progress through to a diagnosis of brain death. Where faith traditions privilege bodily integrity, cosmological integration, rapid burial, or prolonged rituals of grieving (as may be the case with both eastern and Abrahamic faith traditions), there may be less support for the application of biotechnology at the end of life and for organ donation.

A number of factors may mitigate against the application of intensive and invasive technology during end-of-life care (and therefore the diagnosis of brain death), including: Do Not Resuscitate orders and advance care planning that limits the provision of invasive treatment; professional reluctance to provide futile care; policies that restrict admission of futile cases into intensive care; availability of ICU resources; increased social and political support for palliative care and services that enable death in community settings; sociocultural attitudes against the



application of invasive technologies at the end of life; and increasing public and professional emphasis on ensuring that people with terminal illness have a good death.

A difficult choice: intimacy versus utility

To increase rates of organ donation in countries which privilege advance care planning and treatment withdrawal over aggressive treatment in intensive care – particularly in patients with severe brain injury – policy-makers and health professionals confront a difficult choice. The measures necessary to increase rates of brain death, and thereby the availability of transplantable organs, would require fundamental changes in clinical care at the end of life – changes that may appear inconsistent with accepted norms surrounding what constitutes appropriate care at the end of life and the appropriate management of a good death.

One option available to countries with low deceased donation rates is to try to raise rates of brain death by redefining what is considered appropriate treatment in end-of-life care – specifically, to normalize the widespread application of technology at the end of life and to continue cardiorespiratory support in patients who currently have treatment withdrawn as part of the active management of their dying [40]. The impact of such a move (as has been recently proposed in the UK [41,42]) would be profound – increasing expenditure at the end of life, increasing ICU admission rates and the number of ICU beds required, privileging intensive care over palliative and chronic care, readjusting our expectation of advance care planning to accommodate interventions that maximize organ donation potential, adjustment of

public health policies to encourage hospital-based and intensive care, and changing social attitudes and expectations regarding where and how we should die. Each of these strategies requires fundamental changes to our attitudes and expectations regarding the way in which we die. Each would also represent a major policy reversal from efforts in most common law countries, which in recent decades have generally rejected moves toward presumed consent legislation and have aimed to decrease levels of unwanted end-of-life interventions and to increase the effectiveness of advance care planning for treatment limitation [43].

The other option is to accept lower brain death rates and constrained numbers of deceased organ donors as a consequence of maintaining approaches that limit end-of-life interventions and futile care and that encourage advance care planning, treatment limitation and dying in community and hospice settings.

One of these options is concerned primarily with the best interest of the dying patient while the other sacrifices some degree of intimacy in dying for the social utility of organs and tissues. Moreover, it conjugates a previously singular sanctity of focus on a peaceful, minimally intrusive pathway to death for a more aggressive and mechanical approach that views a patient's death not just as an unfortunate tragedy but also as a potential utility to helping others.

Clearly it is important to continue research into strategies that may increase the recruitment of organ donors and raise rates of consent for donation, into methods for optimizing organ and patient outcomes following DCD, and into the emergent sciences that may ultimately

reduce our reliance upon organ donation. At this point, however, the evidence is clear – only through increasing the diagnosis of brain death can countries realize the numbers of deceased organ donors needed to best meet the demand for organs for transplantation. We believe it is time to put aside the idea that we can significantly increase deceased organ donation rates without significantly increasing brain death rates. Doing so will enable the public and professional debate to move to where we believe it should be – a discussion about what we are prepared to do and what we are prepared to give up, in order to expand our transplantation programs.

Abbreviations

DBD, donation after brain death; DCD, donation after cardiocirculatory death.

Competing interests

The authors declare that they have no competing interests.

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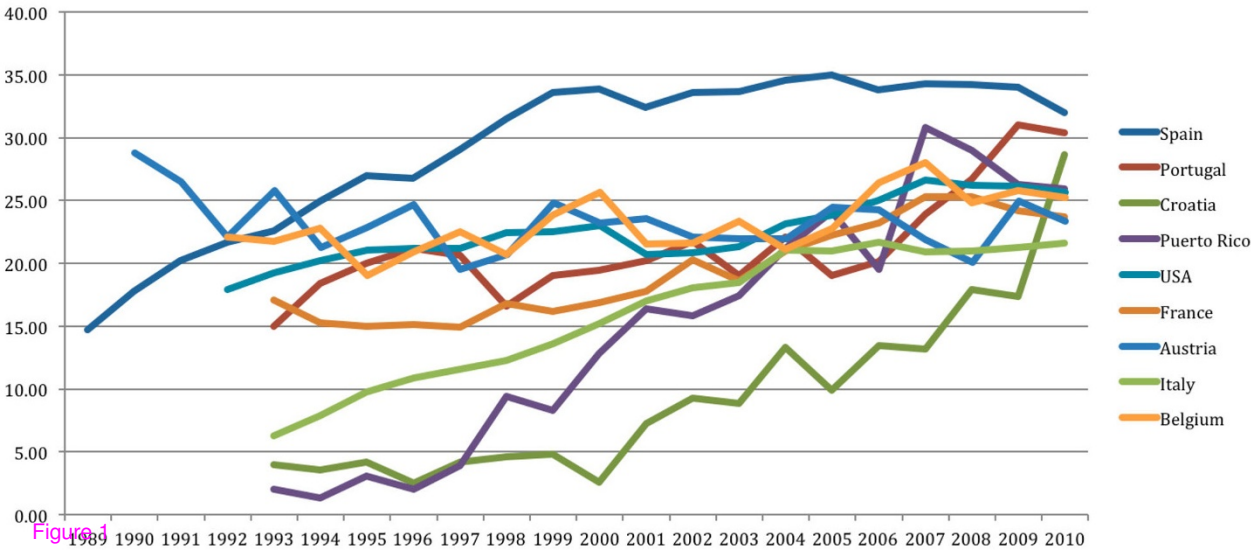


Figure 1

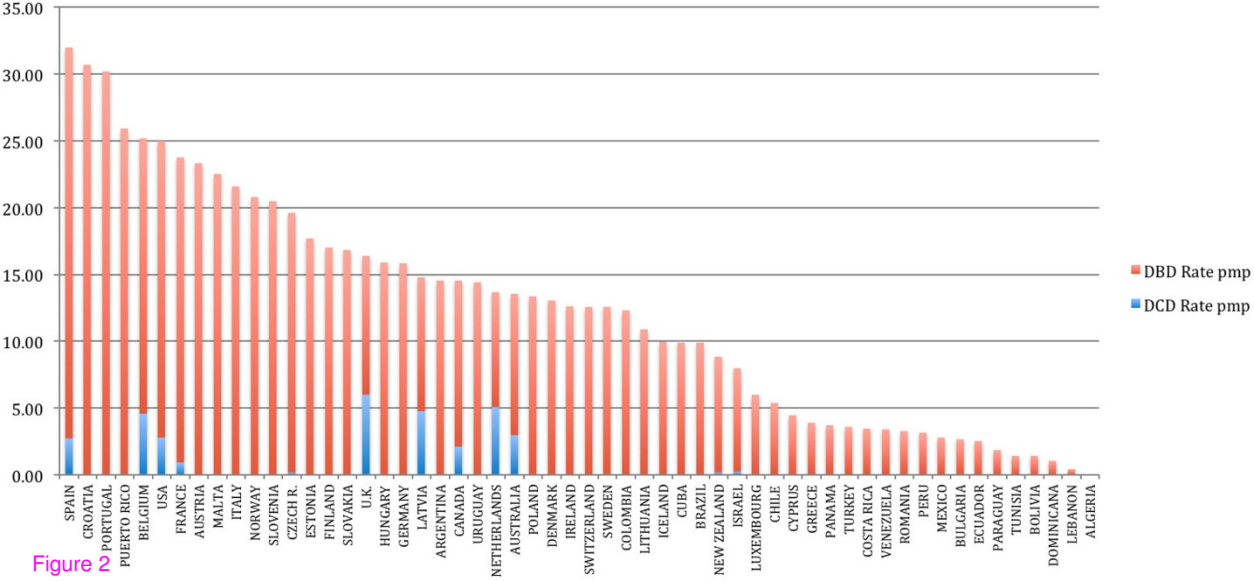


Figure 2

