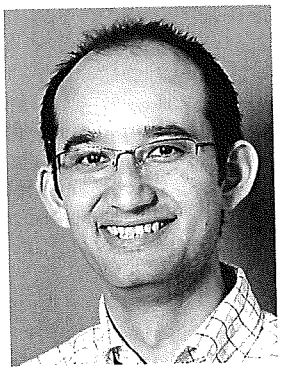
The effectiveness of organ donor policies in 10 European countries: a widening gap?

by Remco Coppen and Roland D. Friele



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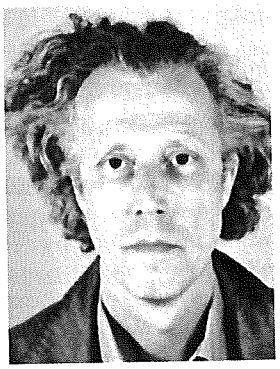

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There is a huge gap between the waiting lists for organ transplantation and the number of organs donated each year. For instance, in the Netherlands over 1300 people are on a transplant waiting list, but only around 200–250 post mortal organ donations are made each year. This means people are waiting over four years to receive a suitable organ, a problem which also exists in other western countries.

Because donor organs are scarce, countries develop organ donor policies. An important aspect of donor policies is the use of consent systems. To retrieve someone's organs, consent is necessary. In general there are two legal systems which regulate consent for an organ donation procedure: informed consent and presumed consent. In an informed consent system, consent is registered, either by signing a document (e.g. codicil) or by registration in a national registry; if the deceased did not register, the next of kin are asked to give consent. In a presumed consent system, consent is assumed and only refusals are registered. As in both systems the group of non-registered persons is much larger than the group of registered persons, the donor pool of presumed consent countries is assumed to be much larger than the donor pool of informed consent countries[1]. Thus, many people assume that a presumed consent system leads to more post mortal organ donations than an informed consent system, and the question is whether this assumption is true.

In 2002 and 2006 NIVEL carried out the second and third evaluation of the Dutch Organ Donation Act. One of the objectives of the Organ Donation Act is to increase the supply of donor organs. Therefore, the evaluation of the Act takes account of the performance of different consent systems.

*) According to the Human Tissue Act of 1961 and the Human Organ Transplants Act of 1989 (U.K.), it is necessary to have a donor's consent to use his organs (explicit consent). However, when his will is not known it is (according to these acts) sufficient to determine that the potential donor did not register an objection against organ donation. Consequently, we conclude that the U.K. had a presumed consent system during the period under review[8]. By implementing the 2004 Human Tissue Act, the UK introduced a formal informed consent system in September 2006.

International assessment of donor procurement

The traditional way of comparing the efficiency of donor procurement between countries is by analyzing the organ donation rates per million inhabitants (PMI). The organ donation rates PMI of presumed consent countries are higher than those of informed consent countries[2]. Earlier studies concluded that in order to compare the efficiency of donor procurement between countries, it is important to adjust the differences in donation rates for differences in donor potential between countries (e.g. [3–5]). Furthermore, many of the differences between the donation rates of countries are explained by discrepancies in the national mortality rates for causes of death relevant to organ donation[3].

In most Western European countries over 80 percent of donors have died following a Cerebral Vascular Accident (CVA) or a (traffic) accident, and most of these were under 65 years of age. Therefore, people who die from these causes form an important pool of potential donors. We found the national mortality rates for CVA and (traffic) accident to be a good proxy to account for differences in donor potential between countries. The adjustment of the donation rates for differences in these mortality rates leads to another outcome variable. We call this variable the donor efficiency rate by proxy (figure 1), which is the rate at which the number of potential donors are converted into actual donors. To calculate the donor efficiency rates by proxy we used the following formula: (national donation rates PMI/national mortality rates relevant for organ donation rates PMI) × 100.

We obtained the donation rates from the national transplant centres. The mortality rates for CVA and (traffic) accidents were obtained from the Health for All database of the World Health Organisation[6]. Because this database is not completely up to date, we had to estimate the mortality rates in some cases. The estimated rates are based on the mortality rates of preceding years.

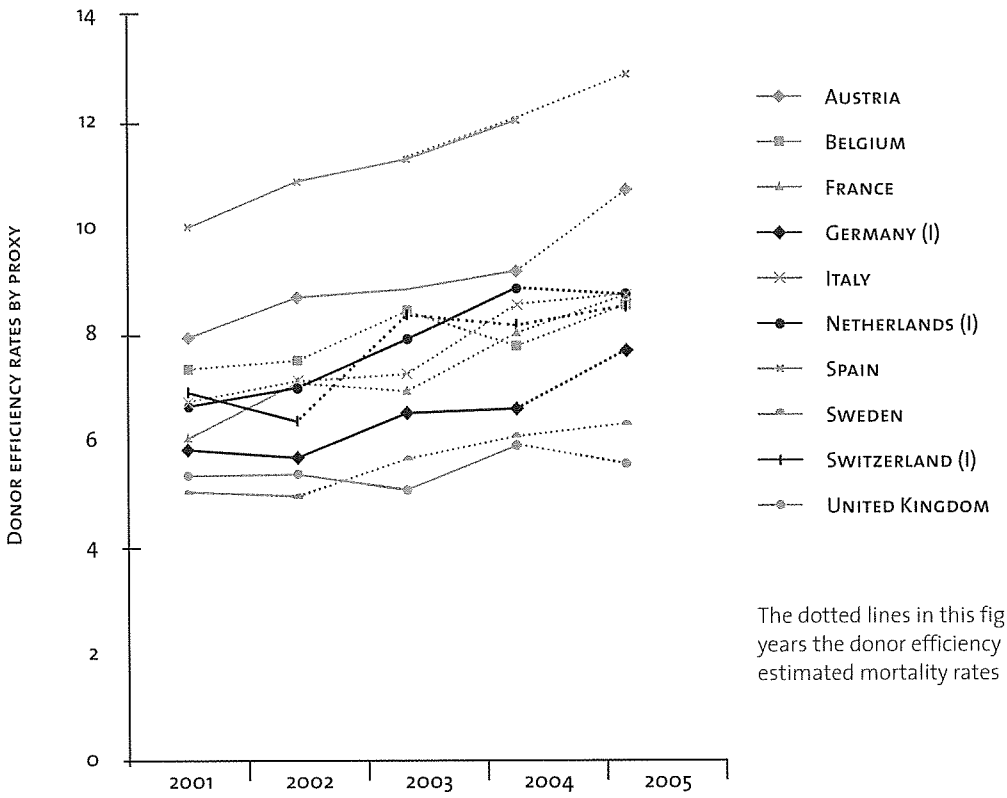
To correct for random fluctuations between years we used the donation and mortality rates for five consecutive years (2001–2005). In order to restrict the number of confounding factors between countries we chose to study only countries which share a similar historical background and have more or less the same status of health care system.

The efficiency of donor procurement in 10 countries

Figure 1 shows the donor efficiency rates by proxy over a five-year period. In this figure the informed consent countries are coloured black. The presumed consent countries are coloured grey. On the one hand, the two countries with the highest donor efficiency rates are Spain and Austria, both presumed consent countries. We see that the slope of these countries has steadily increased over five years. On the other hand, the two countries with the lowest donor efficiency rates (Sweden and the United Kingdom*) also have presumed consent systems. The informed consent countries (Germany, the Netherlands and Switzerland) show average donor efficiency rates. The slopes of these countries have also increased since 2001.

According to our results it would appear that the donor efficiency rates of some countries (i.e. Spain and Austria) increase faster than those of other countries (i.e. Sweden and the United Kingdom).

FIGURE 1
The donor efficiency rate by proxy in 10 European countries (2001–2005)



The dotted lines in this figure mean that for these years the donor efficiency rates by proxy are based on estimated mortality rates

Abstract

Aufgrund des Mangels an Spenderorganen legen Staaten eine Organspendepolitik fest, in der insbesondere geregelt wird, wie die Bereitschaft zur Organspende bekundet wird. Da sich die Mehrheit der Bürger sowohl bei Widerspruchs- als auch bei Zustimmungslösungen nicht registrieren lässt, ist die Anzahl der potenziellen Spender in Ländern mit einer Widerspruchslösung viel höher als in Staaten mit einer Zustimmungsregelung. Daher wird vielfach davon ausgegangen, dass ein Widerspruchsmodell zu mehr Organspenden im Ablebensfall führt. Diese Annahme wurde im Rahmen einer Evaluierung des niederländischen Organspendegesetzes untersucht.

Personen, die infolge eines Schlaganfalls oder (Verkehrs-)Unfalls sterben, stellen eine bedeutende Gruppe potenzieller Spender dar. Viele Unterschiede bei den nationalen Spenderzahlen lassen sich anhand der nationalen Mortalitätsraten bei für Organspenden relevanten Todesursachen erklären. Daher ist es notwendig, die Spendezahlen um Unterschiede bei den relevanten Mortalitätsraten zu bereinigen. Als Ergebnis dieser Anpassung erhält man einen Ersatzindikator für die Effizienzrate der Organspenden, der mit folgender Formel berechnet wird: (nationale Organspenden je Mio. Einwohner/für Organspenden relevante nationale Mortalitätsraten je Mio. Einwohner) × 100.

In einer juristischen Analyse der Systeme zur Willensbekundung zeigen Gevers et al., dass sich die verschiedenen Modelle in der Praxis viel stärker ähneln als angenommen. Dies wird auch von unseren Ergebnissen bestätigt, da sie darauf hindeuten, dass die unterschiedlichen nationalen Effizienzraten bei Organspenden nicht auf die jeweiligen Widerspruchs- oder Zustimmungsregelungen zurückzuführen sind. Deshalb gelangen wir zu dem Schluss, dass eine Widerspruchslösung keine höheren Spenderaten gewährleistet.

Wie lassen sich dann aber die Unterschiede bei den Spendeneffizienzraten zwischen den einzelnen Ländern erklären? Neben Widerspruchs- bzw. Zustimmungssystemen setzen Staaten noch weitere politische Maßnahmen, um Organspenderaten zu steigern. Es besteht Grund zu der Annahme, dass die umgesetzten politischen Maßnahmen von Land zu Land variieren.

Schließlich scheint auch eine Kluft zwischen den einzelnen Staaten bei der Spendeneffizienz zu entstehen. Hier stellt sich die Frage, ob sich diese Kluft vergrößert.

Discussion

In a legal analysis of consent systems Gevers et al. [7] point out that in reality the different consent systems are much more similar than is assumed. They established that next of kin are also asked for consent in presumed consent systems and they concluded that this reduces the potential effect of presumed consent systems.

Our findings confirm this conclusion, implying that the differences in the performance of organ donor policies are not caused by a difference in consent systems between countries. Presumed consent countries do not automatically have higher donor efficiency rates than informed consent countries. Both those countries with the highest donor efficiency rates and those with the lowest donor efficiency rates are presumed consent countries. Moreover, in a similar vein to some successful presumed consent countries, informed consent countries are also showing increasing donor efficiency rates. Therefore, we conclude that presumed consent does not guarantee higher donation rates (see also[3]).

When consent systems do not explain the differences in donor efficiency rates between countries, how can we explain these differences? Besides consent systems, countries also implement other policy measures to increase organ donation rates. Examples of such policy measures are:

- optimising the process of organ donation in hospitals: e.g. by training the medical staff (with regard to identifying potential donors or asking for consent) or by implementing quality management programmes for organ donation,
- increasing the donor pool: e.g. by non-heartbeating donation or accepting older donors;
- through public advertising: e.g. (selling) mass media campaigns.
- We have reason to believe that there are differences between countries in the implemented policy measures. However, there is a lack of concrete information available on the extent to which these policy measures are implemented in the countries studied.

As the donor efficiency rates of some countries seem to increase faster than those of other countries this may point to differences in the effectiveness of the policy measures. An interesting question is whether a gap is appearing between those groups of countries and whether this gap is widening. ■

Reference List

1) Johnson EJ, Goldstein D. Medicine: Do defaults save lives? Science 2003; 302:1338-1339.
2) Gimbel RW, Strosberg MA, Lehrman SE, Gefenas E, Taft F. Presumed Consent and Other Predictors of Cadaveric Organ Donation in Europe. Prog Transplant 2003; 13(1):17–23.
3) Coppen R, Friele RD, Marquet RL, Gevers JKM. Opting-out systems: no guarantee for higher donation rates. Transpl Int 2005; 18:1275–1279.
4) Roels L, Cohen B, Gachet C. Countries' donation performance in perspective: time for more accurate comparative methodologies. American Journal of Transplantation 2007; 7:1439–1441.
5) Stogis S, Hirth RA, Strawderman RL, Banaszak-Holl J, Smith DG. Using a Standardized Donor Ration to Assess the Performance of Organ Procurement Organizations. Health Services Research 2002; 37(5):1329–1344.
6) www.euro.who.int/hfadb. 2007.
7) Gevers J, Janssen A, Friele R. Consent systems for Post Mortem Organ Donation in Europe. Eur J Health Law 2004; 11(2):175–186.
8) Janssen A, Gevers J. Explicit or presumed consent and organ donation post-mortem: does it matter? Medicine and Law 2005; 24:575–583.