Consent Systems for Post Mortem Organ Donation in Europe

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Introduction

In the Netherlands, like in many other European countries, there is a considerable shortage of vital organs (hearts, kidneys etc.) for transplantation purposes. While living organ donation is of increasing importance as an alternative source for at least some organs (such as kidneys), the supply is still largely dependent on post mortem organ removal. This has resulted in mounting pressure on public authorities, hospitals and other parties involved to do everything to improve on cadaveric organ donation. However, continuing efforts in the field of general information of the public, education of professionals, and organisational measures at hospital level have had so far no or little effect on the number of transplantable organs. Therefore, the question has been raised whether the consent system for post mortal organ removal (that has been laid down in the Organ Donation Act of 1998) should be changed.

To answer that question an extensive study has been carried out, including a survey of attitudes of the Dutch population on organ donation, an analysis of the practice of organ retrieval in Dutch hospitals, as well as an international comparison of donation rates in order to identify the relative importance of the consent systems (as a factor influencing the availability of organs). The study also included a comparative analysis of the consent systems in ten European countries. The aim of that part of the study was not only to delineate the similarities and differences between the various systems, but also to help in answering the question whether the change from an opt in to an opt out system could raise the number of cadaveric organ donations.

In this article, we present the main results of that comparative part of the study. After a brief introduction of different kinds of consent systems and the main principles and interests underlying them, we will describe the systems in force in ten European countries. Subsequently, we will discuss differences and similarities, with particular reference to the position of the next of kin of the deceased. In our final remarks we will address the question to what extent a change of
Consent system is likely to impact on the number of organs, also taking account of the results of the other parts of the larger research project.

Consent systems in general

There is general agreement that cadaveric organ retrieval is only allowed if some form of consent is available from the deceased or his relatives. This is also reflected in international guidelines and other documents. According to the Additional Protocol to the Biomedicine Convention concerning Transplantation of Organs and Tissues of Human Origin (Council of Europe, 2002), for instance, ‘organs and tissues shall not be removed from the body of a deceased person unless consent or authorisation required by law has been obtained’ and ‘the removal shall not be carried out if the deceased person has objected to it’ (Article 17).2 Basically, two kinds of consent systems can be distinguished: systems of explicit consent and systems of presumed consent. In the former the donor himself has to authorise organ removal after his death (in the form of an advance directive or donor card, or by filling in a form in order to record consent in a national registry). In the latter kind of system, explicit consent is not required: it is sufficient that the deceased person has not objected during his life (according to national law); in that case consent is presumed. Because of its reliance on explicit consent, the first kind of system is also known as an opting in system, while presumed consent systems are characterised as opting out systems.

It is to be noted, that the dichotomy between ‘pure’ opting in and opting out systems represents an oversimplification that fails to recognise the nuances with which these systems function in practice. Usually, consent systems provide for involvement by relatives, either in the sense that they can act as a surrogate and give vicarious consent if the deceased person has not done so himself (opting in systems), or in the sense that they may object even if the deceased person has not registered an objection during his life (opting out systems).

An important operational aspect of consent systems (whether explicit or presumed) is the way the consent or objection is being recorded. A growing number of European countries have established national registries of donors (opting in systems) or non-donors (opting out systems) so that information on the willingness to donate is readily available and easily accessible for health professionals confronted with a potential donor in a hospital or elsewhere. In most cases, such registries have not completely replaced personal documents like donor cards, but they are becoming by and large the most important source of information on donor status. Usually consultation of that source is one of the first steps in the complex process that may result in organ removal post mortem. In order to have maximum