Frail Connections: Legal and Psychiatric Knowledge Practices in U.S. Adjudication over Organ Donations by Children and Incompetent Adults

MARIE-ANDRÉE JACOB
Cornell University

1. Introduction

Reproductive as well as organ transplant technologies are often debated today in the language of “gift-giving” and “saving life”. One example of the latter is the emerging expression “saviour sibling,” used by the medical professions in reference to an embryo conceived and selected by its parents specifically to be an organ or tissue donor for an ill sibling. The category and rhetoric of gift-giving, on their part, are not new to the realm of organ donations among family members (Simmons et al. 1977; Thomson, 2001; Franklin et al., 2003). But if the technologically assisted conception of a child for purposes of organ donation is relatively recent, the use of children as organ suppliers is not. This paper traces a number of U.S. cases involving children and also incompetent adults as organ donors for a family member. Inspired by Mariana Valverde’s approach, I focus on aspects that, instead of being located under the label of “the principles,” pertain to the evidence and rhetoric used in legal texts (Valverde, 2003a). Today, much of legal and bioethical literature is devoted to the substantive values – e.g. deontology, utilitarianism, communitarianism – that inform and should inform the debates on organ transplantations. However, very little attention is paid to the manner in which these debates and discussions unfold – for example, on their rhetorical style or their use of evidence. In reaction to this, I wish to investigate how legal actors come to argue, determine and reform what is good, acceptable, or illegitimate use of medical technologies, and how they explicate and provide justification to their knowledge. This paper tries to employ this general method of inquiry, while examining the narrow issue of organ procurement from the bodies of children and incompetent adults. This paper looks at the law as it articulates and reorders so-called “new” problems provoked by organ transplant technology, and more particularly, as it integrates psychiatric knowledge in its thinking about these problems. As if the decisions were artefacts or “works of fiction,” (Kahn, 1999, 126) I devote considerable time to investigating their style and format. I also look at their surface, and at what is considered mundane in them.
In the second section of this paper, I outline the conditions of twentieth century U.S. law that arguably made it porous to social sciences and psychiatric evidence in the first place. I will modulate this view with Gunther Teubner’s idea of the law as a self-referential system (Teubner, 1993). In order to illustrate the theoretical moves I make in the first section, I describe and analyse a number of cases. First, I examine the earlier cases in the area, which condemn organ donations involving minors, and then move on to describe one of the features that contributed to normalizing donations by minors and incompetents in case-law: the use of psychiatric experts. As will be seen, these cases interest me for the way they build-up and deploy a certain rhetoric. Subsequently, I analyse how psychiatrists came to be recognized as experts in organ donation cases. I end this paper by asking and attempting to respond to a question that cannot be overstated: did psychiatric expertise really have a genuine impact on the law in cases involving children and incompetent adults as organ donors?

But before that, I would like to start with a caveat, and a note on my use of terminology. The limitations of this paper are clear. It reviews U.S. cases exclusively; hence it does not pretend to offer an international or comparative perspective on the utilization of psychiatrists in organ donations adjudication. The methodology favours the microscope over the telescope. Yet, by looking closely at a number of cases from one jurisdiction, the paper may offer some groundwork for future comparative studies focusing on the types of evidence used in organ donation law and policy. In terms of terminology, in this paper I try – not without difficulty- not to feed the reader with dramatic images. I want to avoid speaking of ungrateful children who refuse to offer a gift to a vulnerable ill sibling, and alternatively, of fragile incompetent individuals who are being exploited by a vampire-like medical community and cruel family members for whom ends justify all means. The subject is a sticky matter, which has its proponents and opponents, and attracts much media and academic attention. Therefore, in the literature, the positions advocated follow polarized patterns, which often lead to sterile debates. The subject matter also has its own jargon, which makes itself available for both “proponents” and “opponents”. This jargon includes the following bipolar lexicon:

- **Persons**: organ donors/givers/heroes vs organ suppliers/providers/sources;
- **Relations**: donation/gift/exchange vs harvest/salvage/pluck/recycle/steal;
- **Objects**: gift/"gift of life"/donations vs spare parts/matters/replacement parts.

The lexicon available for anyone who wants to write about this subject is roughly limited to these. The use of words, from one group or another, inevitably drags the writer in one clan or another. Interestingly, those at the receiving end of the transplant world seem immune from either colourful or insolent depictions. They are termed “donees,” “hosts,” or “recipients” more...