
VIII Annual Symposium on Biomedicine, Ethics and Society: "Rethinking Informed Consent: The limits of autonomy"

Mare Knibbe MA, Els Maeckelberghe, PhD.

Centre for Ethics in Care

University Medical Centre Groningen

Correspondence adress:

Expertisecentrum Ethiek in de Zorg

Ant. Deusinglaan 1

9713 AV Groningen, The Netherlands

E-mail: m.e.knibbe@med.umcg.nl; e.l.m.maeckelberghe@med.umcg.nl

Care for donor-autonomy in decisions about living parental liver donation

Securing the autonomy of parents who are willing to donate a part of their liver for their child has been discussed extensively since the introduction of this transplantation technique. In most publications, autonomy is confined to a narrow notion of informed consent: is a parent free, i.e. not coerced, in his/her decision and does s/he have sufficient information.

Observing the donation procedure at the University Medical Center Groningen we explore the ways in which family-involvement in transplantation procedures is shaped. Using semi-structured interviews and observations, we map the moral perspectives of the different care-givers (and receivers) involved in the practice of Living Related Liver Transplantation (LRLT); i.e. parents of the child who needs a transplant and professionals in the transplantation team. This empirical material shows that care for the autonomy of the donors can be found in interactions that are not part of the informed consent procedure in the narrow sense.

Do these observations call for a broader and fuller understanding of informed consent as a process? This option might confuse the relationship between autonomy and informed consent, suggesting the two notions are interchangeable. In this paper, we want to explore another option in which we propose a clearly demarcated, narrow notion of informed consent. Informed consent then becomes a necessary but not sufficient element in the care for autonomy of the donor. In the exploration of this option, we will discuss the relation between informed consent and other forms of care for autonomy.