

Publication

The Role of the Family in Deceased Organ Procurement: A Guide for Clinicians and Policymakers

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Families play an essential role in deceased organ procurement. As the person cannot directly communicate his or her wishes regarding donation, the family is often the only source of information regarding consent or refusal. We provide a systematic description and analysis of the different roles the family can play, and actions the family can take, in the organ procurement process across different jurisdictions and consent systems. First, families can inform or update healthcare professionals about a person's donation wishes. Second, families can authorize organ procurement in the absence of deceased's preferences and the default is not to remove organs, and oppose donation where there is no evidence of preference but the default is to presume consent; in both cases, the decision could be based on their own wishes or what they think the deceased would have wanted. Finally, families can overrule the known wishes of the deceased, which can mean preventing donation, or permitting donation when the deceased refused it. We propose a schema of 4 levels on which to map these possible family roles: no role, witness, surrogate, and full decisional authority. We conclude by mapping different jurisdictions onto this schema to provide a more comprehensive understanding of the consent system for organ donation and some important nuances about the role of families. This classificatory model aims to account for the majority of the world's consent systems. It provides conceptual and methodological guidance that can be useful to researchers, professionals, and policymakers involved in organ procurement.

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