



Research project summary

Understanding decision making in organ donation: a national study

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- Awarded \$669,375 from the Canadian Institutes of Health Research (CIHR) in January 2018

Transplantation is the only hope for survival for many patients with terminal heart, lung, liver, pancreas and kidney disease and often their only hope for survival. Families of potential organ donors play a central role in the consent process yet little is known about what determines whether or not they consent. Organ donation is a personal decision made by patients and/or their families. As a result, it is expected and appropriate that some families refuse. Amid continuing need for organs and the declining number of organ donors, it is critical that we investigate the factors that influence the decision-making of relatives of potential organ donors. We will investigate relatives of potential organ donor patients' understanding of the process leading to organ donation and their views, beliefs, and motivation for their decisions in regard to organ donation. First, relatives of patients who are potential organ donors will be interviewed to explore their experience, values and beliefs regarding the decision-making leading to organ donation and potential factors viewed to affect their organ donation decision. Second, we will conduct a national telephone survey based on our findings in the first step with patient relatives to test which clinical and behavioural factors are associated with end-of-life decisions in regard to organ donation. This study will identify key factors to help researchers, physicians, decision makers and organ donation organizations develop strategies to support clinicians and families in making informed decisions about organ donation. The project will provide the foundation for developing support to improve family understanding of organ donation process and potentially an improved consent rate that may ultimately lead to a higher number of organs available for transplantation.

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