Introduction

Welcome back to the ISODP Journal Watch, April 2023 Edition!

This edition has an emphasis on ethical issues and how to improve a systems response to the needs of diverse populations. Two articles on ethical controversies surrounding interpretation of the dead donor rule, an evaluation of the rights of indigenous people in the changes of a consent model, and a review of socio-cultural factors that influence pediatric donation consent rates. Other topics covered include a review of quality improvement indicators in donation and a retrospective review of adverse events during pediatric apnea testing.

As always this set of articles represents a small sample of the breadth of exciting work going on in the field of donation science and ethics research. The included articles were generated from teams working in North America, the UK, and China, and of course the excellent reviews include work gathered from across the world. Together the international donation research community continues to generate knowledge and analyses that will help us all create better systems to honor the wishes of those who wish to donate.

Thanks as always to Amina Silva for keeping us organized and to Stéphanie Larivièrre for her work formatting and distributing the Journal Watch.

Looking forward to the next edition in June.

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Does Controlled Donation after Circulatory Death Violate the Dead Donor Rule? | Read article

Nielsen Busch and Mjaaland
The American Journal of Bioethics, February 2023
Corresponding author: Emil J. Nielsen Busch - emiljb@uio.no

Pragmatic Aspects of Controlled Donation after Circulatory Death and Ethical Considerations for Alternative Approaches | Read article

Morrissey, P.
The American Journal of Bioethics, February 2023
Corresponding author: Paul Morrissey - pmorrissey@lifespan.org

These related articles, both from a recent issue of The American Journal of Bioethics, represent two provocative ethical analyses of the dead donor rule (DDR) in relation to controlled donation after circulatory determination of death (cDCD). Busch and Mjaaland argue cDCD of abdominal organs does not violate the DDR. Quoting from Robertson’s 1989 original formulation of the DDR, the authors claim that the DDR requires only that organ recovery not cause the death of the patient. This claim is not how many clinicians and ethicists currently understand the DDR, which is generally cited as requiring the patient to be determined dead prior to organ recovery. They then explore the implications of this distinction in the practice of abdominal normothermic regional perfusion. In his article, Morrissey restates his position from 2012 that recovery of kidneys before even the withdrawal of life-sustaining therapy would not be the proximate cause of death and therefore would not violate the DDR.

While neither of these articles represents the mainstream of ethical thought around the DDR, it is important for donation system experts to think about the implications of these arguments for their own programs in the context of the laws and societal norms of their region. The DDR has been and will be a cornerstone principle of ethical donation systems, but that does not mean that interpretation of aspects of the DDR is not up for some debate.
The rights and interests of First Nations, Métis, and Inuit in debates over deemed consent legislation for deceased organ donation in Canada: calls to action

Tait, C.
The Lancet Regional Health - Americas, February 2023

Corresponding author: Caroline Tait - caroline.tait@ucalgary.ca

This article, published in The Lancet Regional Health – Americas, examines the need to adapt deemed consent legislation (often referred to as presumed consent) in the Canadian province of Nova Scotia to the needs of the varied Indigenous populations living in the province. In doing this analysis Dr. Tait broadens the scope to emphasize the historic and current inequities these populations face in gaining access to any type of care, including dialysis and listing for transplantation. These multiple issues contribute to a mistrust of the Canadian healthcare system and government in general in many members of these populations which may be amplified by programs such as deemed consent. She also points out the unique legal status of Canadian First Nations, Indigenous, and Métis (FNIM) peoples who have rights accorded to them under national and international treaties. She ends with a call to action to create and fund a dedicated body that would explore the needs of FNIM within the donation and transplant system. These issues are relevant to any system navigating how to ensure that their system respects the specific concerns of the diverse populations within their jurisdiction.

READ ARTICLE
Quality improvement tools to manage deceased organ donation processes: a scoping review

Silva, A., et al.
BMJ Open, February 2023

Corresponding author: Amina Silva - asilva@cheo.on.ca

In this scoping review published at BMJ, the authors investigate the quality improvement tools that have been developed for deceased organ donation processes (both NDD and DCD). After throughout search of published and unpublished data, a total of 40 references were considered relevant for that investigation. A variety of tools were found (e.g., checklists, algorithms, flow charts, charts, pathways, decision tree maps, and mobile apps) that were used to help manage the various steps of the deceased organ donation process. The QI tools identified were focused on potential donor identification, donor referral, donor assessment and risk, donor management, withdrawal of life-sustaining measures, death determination, organ retrieval and the overall organ donation process. According to the existing literature, the use of QI tools can support the practice of healthcare professionals involved directly and indirectly in organ donation cases. Still, the existing evidence lacks details in the report of methods used for the development, testing and impact of these tools.
Willingness of intensive care unit patients’ family members to donate organs: A cross-sectional study

Chen, Y.-C., et al.

Medicine, January 2023

Corresponding author: Chi-Lun Tsai - poclal888@gmail.com

The authors of this cross-sectional design study investigated the willingness of the family members of hypothetical patients in ICUs suffering from an irreversible condition to sign an organ donation consent form in a medical center in southern Taiwan. The participants (n= 110) demonstrated a highly positive attitude toward organ donation and most of them (79.1%) were willing to donate organs. Additionally, family support, attitude, and knowledge of organ donation were predictors of the variance in willingness to sign consent. Aspects leading to families’ refusal to organ donation are complex and difficult to tackle, however, this study adds to the existing literature to provide evidence that can be used by healthcare professionals to consider family support and education to help fulfilling donation opportunities.

READ ARTICLE
Cultural and other beliefs as barriers to pediatric solid organ transplantation

Wray J., et al.
Pediatric Transplantation, December 2022

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The authors reflect on the important subject of cultural implications for donation as well as for those pediatric patients waiting for a transplant. Notably, the authors separate the discussion of ethnicity and race versus culture and religion. As expected, this review highlighted the paucity of evidence focusing on cultural barriers. The authors rely on similar questions in adult literature. Among cultural barriers, examples included superstitions around death, beliefs that illness is God's will and must therefore be accepted and a belief in fate. Importantly, the authors also highlight potential strategies to alleviate these barriers such as enhanced culturally appropriate support, respect/sensitivity/open-mindedness of professionals in relation to culture and religion, and working with Faith leaders to increase awareness about donation and transplantation. The authors conclude that one of the largest barriers is health professionals' lack of awareness and knowledge about the specific beliefs of different groups and the failure to deliver culturally competent care. This work is an excellent step towards a better understanding by healthcare professionals.
Adverse Events During Apnea Testing for the Determination of Death by Neurologic Criteria: A Single-Center, Retrospective Pediatric Cohort

Sveen, W.N., et al.
Pediatric Critical Care Medicine, February 2023

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The authors at Cincinnati Children’s reviewed deaths at their institution over 7 years retrospectively. After identifying 58 patients undergoing 105 apnea tests. To note, apnea testing is protocolized at this centre with an in-line flow-inflating bag using PEEP. They identified 21 adverse events (20%). As expected, the most common events were hypotension (15/105 [14%]) and hypoxia (4/105 [4%]) with the impression that these were more common when patients were in higher respiratory settings to begin with. These vital sign deviations were transient. Only 5% of tests were aborted due to instability. There were four situations with new pneumothoraxes, found incidentally, and none were clinically significant. Further, no patients experienced arrhythmias or cardiac arrest. The risk of cerebral blood flow changes related to hypercapnia has been a controversy related to apnea testing. This study found no significant difference between pre- and ICP values, though many patients did not have ICP probes and ICP values when measured were already high pre-testing. Overall, the findings are important to help counsel families and staff when preparing for routine apnea testing for the purpose of death determination by neurologic criteria. Also, these findings may help minimize the controversy associated with apnea testing.