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REPORTS OF ORIGINAL INVESTIGATIONS

Nurse knowledge and attitudes towards organ donation and deemed consent: the Human Organ and Tissue Donation Act in Nova Scotia

Connaissances et attitudes du personnel infirmier à l'égard du don d'organes et de la présomption de consentement : la Loi sur le don d'organes et de tissus humains en Nouvelle-Écosse

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Abstract

Purpose *In April 2019, the Human Organ and Tissue Donation Act (HOTDA) in Nova Scotia was modified to incorporate a deemed consent model. In this study, we sought to understand intensive care unit (ICU) and emergency department (ED) nurses' knowledge of and confidence around organ donation and transplantation, experiences with organ donors and recipients, attitudes toward organ donation and deemed consent, and perceived opportunities and barriers to a deemed consent approach in view of the legislative change.*

Methods *We sent an electronic, self-administered survey to all ICU and ED nurses in Nova Scotia. The survey queried respondents on their knowledge of, experience with, and attitudes around organ donation and HOTDA, and opportunities and barriers to the implementation of HOTDA in clinical practice. Survey results were analyzed using descriptive statistics.*

Results *One-hundred and ninety-four nurses responded to the survey. Nearly all (98%) supported organ donation, with 86% having signed an organ donor card to donate organs and/or tissues after death. A considerable majority (89%) also supported the new legislation. Nevertheless, a minority of respondents (13%) believed that deemed consent legislation would be considered a violation of the general principles of freedom and autonomy. The three most identified topics for ongoing training were coordination of the donation process (70%), clinical management of donors (70%), and family issues in decision-making (70%).*

Conclusion *Intensive care unit and ED nurses had positive attitudes toward organ donation, including deemed consent model. The findings should inform educational initiatives in Nova Scotia and beyond to optimize organ donation processes and outcomes.*

Résumé

Objectif *En avril 2019, la Loi sur le don d'organes et de tissus humains (Human Organ and Tissue Donation Act – HOTDA) de la Nouvelle-Écosse a été modifiée pour intégrer un modèle de consentement présumé. Dans cette*

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étude, nous avons cherché à comprendre les connaissances et l'aisance du personnel infirmier des unités de soins intensifs (USI) et des services d'urgence en matière de don et de transplantation d'organes, leurs expériences avec les donneurs et les receveurs d'organes, leurs attitudes à l'égard du don d'organes et du consentement présumé, ainsi que les occasions et les obstacles perçus à une approche de consentement présumé compte tenu de la modification législative.

Méthode *Nous avons envoyé un sondage électronique auto-administré à tout le personnel infirmier des soins intensifs et des urgences de Nouvelle-Écosse. Le sondage a interrogé les répondant.e.s sur leurs connaissances, leur expérience et leurs attitudes à l'égard du don d'organes et de la HOTDA, ainsi que sur les occasions et les obstacles à la mise en œuvre de l'HOTDA dans la pratique clinique. Les réponses au sondage ont été analysées à l'aide de statistiques descriptives.*

Résultats *Cent-quatre-vingt-quatorze infirmières et infirmiers ont répondu au questionnaire. Presque toutes les personnes ayant répondu (98 %) appuient le don d'organes, 86 % ayant signé une carte de don d'organes pour donner des organes et/ou des tissus après leur décès. Une majorité considérable (89 %) soutient également la nouvelle législation. Néanmoins, une minorité de répondant.e.s (13 %) estime que la législation sur la présomption de consentement serait considérée comme une violation des principes généraux de liberté et d'autonomie. Les trois sujets de formation continue les plus fréquemment mentionnés étaient la coordination du processus de don (70 %), la prise en charge clinique des donneurs et donneuses (70 %) et les questions familiales dans la prise de décision (70 %).*

Conclusion *Le personnel infirmier des soins intensifs et des urgences avait une attitude positive à l'égard du don d'organes, y compris du modèle de consentement présumé. Ces résultats devraient éclairer les initiatives éducatives en Nouvelle-Écosse et ailleurs afin d'optimiser les processus et les issues du don d'organes.*

Keywords deemed consent · nursing · organ donation · survey methods

In 2018, 4,351 people in Canada were on a waiting list for an organ transplant and 223 died while waiting for a transplant.[1] With improvements in transplant technology alongside an aging population, more people are needing organ transplants in Canada and this growing demand is resulting in longer wait times for patients in need.[1]

Consent to donate is addressed under provincial and territorial statutes pertaining to organ and tissue donation.[2] Prior to 2021, all Canadian provinces and territories operated using an opt-in or "explicit consent" model, whereby an individual expresses their intent to become a donor. In an effort to increase organ and tissue donation, the Nova Scotia government passed modifications to the Human Organ and Tissue Donation Act (HOTDA) on 12 April 2019.[3] When this legislation came into effect on 18 January 2021, Nova Scotia became the first jurisdiction in North America to operate under a deemed consent model wherein every adult Nova Scotian is considered an organ and tissue donor unless they opt out. Under the new legislation, individuals are automatically referred to the provincial donation program at the time of suspected neurologic death or prior to the withdrawal of life-sustaining measures to determine candidacy. Proponents of this approach note that the majority of countries with the highest deceased donor rates worldwide have established deemed consent legislation.[4–6] For example, the highest deceased organ donation rates in Europe are in countries with deemed consent legislation, including Spain (49.6 per million population in 2019), Portugal (33.7 per million population in 2019), Croatia (32.0 per million population in 2019), and France (29.4 per million population in 2019).[6] Nevertheless, this is not case for all countries, such as Chile, where deceased donation rates decreased after the introduction of deemed consent laws.[7] A 2019 poll found that most Canadians support a deemed consent model, with support ranging from 66% in British Columbia, Alberta, and Quebec to 57% in Ontario.[8]

The opportunity to identify and refer patients who are potential organ donors most often arises in the intensive care unit (ICU) following neurologic determination of death or after a decision to withdraw life-sustaining therapy. Donation referrals, however, can also occur in the emergency department (ED) if staff recognize a severely injured patient who is likely to progress toward death in a way that would permit organ donation. As such, ICU and ED nursing staff play a vital role in organ donation management,[9–11] including identifying and assessing potential donors, supporting families, and assisting with logistics.

Several research teams have evaluated the knowledge and attitudes of ICU and ED staff toward organ donation. Although these studies have revealed that nurses have a positive attitude toward organ donation in general,[12–14] special training programs are required to improve their level of awareness.[15] Nevertheless, no study has assessed the views of ICU and ED nurses on deemed consent for organ donation. To address this gap, we sought to understand ICU and ED nurses' knowledge of and confidence around organ donation and transplantation, experiences with organ donors and recipients, attitudes toward organ donation and deemed consent, and perceived

opportunities and barriers to implementation of a legislated deemed consent approach.

Methods

This study was an electronic, self-administered survey. The study was approved by the Nova Scotia Health (NSH) Research Ethics Board (Halifax, NS, Canada). Informed consent was obtained from all participants.

Setting and study population

Nova Scotia Health is the provincial health authority in the Canadian province of Nova Scotia, responsible for delivery of all healthcare services in the province except for children/youth services and some women's services. Healthcare is provided at more than 45 facilities throughout the province and services are organized across four areas based on geography. Intensive care unit and ED nurses employed in all geographic areas (known as Health Zones) were invited to participate in the survey.

Survey development and administration

Survey questions were based on preceding studies of organ and tissue donation including deemed consent[16–21] and methodological and clinical expertise from co-authors (R. U. and S. B., respectively). Specifically, surveys used in prior studies were accessed and reviewed by two team members (R. U. and N. K.) who then selected relevant items for this study. Additional items were created based directly on the Nova Scotia context (e.g., knowledge of organ donation procedures). Draft versions of the survey were circulated to all co-authors and underwent subsequent cycles of review and refinement. No formal reliability or acceptability metrics were assessed. The final survey was categorized into five sections: demographic characteristics (seven questions), experience with organ donation (seven questions), knowledge (12 questions), attitudes toward organ donation and HOTDA (12 questions), and opportunities and barriers (eight questions) to the implementation of HOTDA in clinical practice. We explored attitudes by asking respondents about their overall identification as positive or negative toward organ donation, and their personal preferences with respect to the use of their own body. See Electronic Supplementary Material eAppendix for survey questions.

Survey data were collected and managed using REDCap electronic data capture tools hosted at Nova Scotia Health.[22] Potential respondents were contacted through Nova Scotia Health. Each email notification provided participants with a brief introduction to the survey, including the purpose of the survey and statements about maintaining confidentiality of responses, and the collection and use of anonymized data only. Prior to starting the survey, electronic consent was obtained from all participants. Each survey was identified by a unique online identifier and answers were collected anonymously. Two reminders were sent by email at 14-day intervals. Respondents had the option of entering a prize draw at the end of the survey by providing their name and email. The survey remained open between 6 July 2020 and 31 August 2020.

Data analysis

Survey results were analyzed as descriptive statistics. Where possible, variables were transformed for ease of interpretation in the following ways: 1) dichotomizing agreement scales, 2) collapsing response categories where responses totaled less than 5% of the sample into adjacent categories, and 3) dropping the "other" or "neutral" response categories. Pearson Chi square tests were used to test for statistical differences between two categorical variables using only valid (nonmissing) values. Statistical analyses were performed using IBM SPSS Statistics for Windows (IBM Corp., Armonk, NY, USA) with statistical significance set at $P < 0.05$.

Results

One-hundred and ninety-four nurses responded to the survey. Table 1 presents respondent demographics. Most were $\leq$ 55 yr of age (83%) and identified as a woman (92%). More than half served a rural population (58%). Of those who responded, less than half (46%) had received training, at some point in their career, on organ donation issues. Sixteen respondents stated they have a formal role as a nurse donor coordinator.

Experience with organ donation and transplantation

Respondents' experience with organ donation and transplantation is presented in Table 2. Nearly one-quarter stated that either they or someone close to them had been an organ donor (23%) and that they or someone close to them had been an organ recipient (25%). Most nurses (76%) had cared for a potential organ donor in their professional practice; of those, 46% had cared for one to two donors and 20% had cared for three to five donors in their last three years of employment. Most nurses (72%) had cared for an organ transplant recipient; of those, 26% had cared for one to two and 25% had cared for three to five recipients in the past three years.

Table 1 Respondent demographics

Variable	Nurses (N = 194)	
	n/total *N*	%
Age		
< 35 yr	79/194	41%
35–55 yr	81/194	42%
> 55 yr	34/194	18%
Gender		
Man	14/194	7%
Woman	179/194	92%
Prefer not to answer	1/194	1%
Religion		
Christian	113/193	59%
No religion	61/193	32%
Prefer not to answer	12/193	6%
Other	7/193	4%
Zone		
Central	75/194	39%
Eastern	47/194	24%
Northern	15/194	8%
Western	57/194	29%
Population served		
Rural	112/194	58%
Suburban	18/194	9%
Urban	64/194	33%
Years of experience		
< 5 yr	58/194	30%
5–15 yr	68/194	35%
> 15 yr	68/194	35%
Ever received training for organ donation issues		
Yes	83/179	46%
No	96/179	54%
Formal role as nurse donor coordinator		
Yes	16/194	8%

Table 2 Experience with organ donation and transplantation

Variable	*n*/total *N* (%)
Have you, or has anyone close to you, ever been an organ donor?	
Yes	45/193 (23%)
No	138/193 (72%)
I don't know	10/193 (5%)
Have you, or has anyone close to you, ever received an organ transplant?	
Yes	48/193 (25%)
No	143/193 (74%)
I don't know	2/193 (1%)
Are you, or is anyone close to you, currently waiting for an organ?	
Yes	20/193 (10%)
No	168/193 (87%)
I don't know	5/193 (3%)
In your professional practice, have you cared for a potential organ donor?	
Yes	147/193 (76%)
No	46/193 (24%)
If yes, what is the number of potential organ donors you cared for in the last 3 years?	
0	20/147 (14%)
1–2	67/147 (46%)
3–5	29/147 (20%)
6–10	16/147 (11%)
> 10	15/147 (10%)
In your professional practice, have you cared for an organ transplant recipient?	
Yes	139/193 (72%)
No	54/193 (28%)
If yes, what is the number of transplant recipients you cared for in the last year?	
0	24/139 (17%)
1–2	36/139 (26%)
3–5	34/139 (25%)
6–10	24/139 (17%)
> 10	21/139 (15%)

Attitudes toward organ donation

Table 3 presents attitudes around organ donation and HOTDA. One-hundred and seventy seven responded to this section of the survey. Nearly all who did (98%) support organ donation, and 86% had signed an organ donor card to donate organs and/or tissues after death. There was widespread awareness among nurses that HOTDA was coming into effect in Nova Scotia (87%), and high support for this new legislation (89%). Few nurses (7%) opposed or strongly opposed HOTDA. All respondents who opposed HOTDA cited ethical concerns, with nine of these respondents indicating that deemed consent is a violation of an individual's rights.

Knowledge and confidence around organ donation

More than half of respondents (58%) were strongly confident or somewhat confident in introducing the subject of organ donation in a clinical setting. Nearly three-quarters (72%) were strongly confident or somewhat confident in their understanding of donation after circulatory death (DCD) and more than half (59%) were strongly confident or somewhat confident in their understanding of donation after neurologic death (NDD). There was a significant relationship between previous training on organ donation and confidence in introducing

Table 3 Attitudes toward organ donation

Variable	*n*/total *N* (%)
Have you decided to donate your organs and/or tissues at the time of your death?	
Yes, any/all organs or tissues	143/177 (81%)
Yes, but only specific organs or tissues	20/177 (11%)
I have not made a decision about this yet	10/177 (6%)
No, I am not donating any organs or tissues	4/177 (2%)
Have you signed an organ donor card that gives permission for organs and/or tissues to be donated after death?	
Yes, I have signed	10/177 (6%)
No, but I am planning to sign	3/177 (2%)
No, I am still thinking about whether to sign	3/177 (2%)
No, I will not sign	
Have you discussed this decision with your family or the individual who would act on your behalf in the event of a medical emergency?	
Yes	163/177 (92%)
No	14/177 (8%)
In general, do you support or oppose organ donation?	
Strongly support/support	174/177 (98%)
Strongly oppose/oppose	1/177 (1%)
Don't know	2/177 (1%)
The Human Organ and Tissue Donation Act will come into effect late 2020. Are you aware of this legislation?	
Yes	154/177 (87%)
No	23/177 (13%)
Do you support or oppose HOTDA?	
Strongly support/support	158/177 (89%)
Strongly oppose/oppose	12/177 (7%)
Don't know	7/177 (4%)

HOTDA = Human Organ and Tissue Donation Act

the subject of organ donation in a clinical setting ($P < 0.001$) and understanding of NDD ($P = 0.04$). Nurses with or without training had a similar level of confidence in their understanding of DCD ($P = 0.29$).

Opportunities and barriers

Table 4 presents barriers and opportunities for organ donation and deemed consent legislation. The three most common barriers were a lack of familiarity with the referral process (63%), unknown wishes of the deceased (62%), and family refusal for organ donation (57%). Other notable barriers included reluctance to approach the topic of donation (51%); racial, ethnic, and/or religious perspectives on organ donation (43%); and lack of time to discuss donation with the patient's family (41%).

Table 4 Barriers and opportunities for organ donation and deemed consent

Variable	*n*/total *N* (%)
Barriers	
Lack of familiarity with the referral process	123/194 (63%)
Deceased wishes unknown	121/194 (62%)
Relatives refused permission for organ donation	111/194 (57%)
Reluctance to approach the topic of donation	98/194 (51%)
Racial, ethnic, and/or religious perspectives on organ donation	83/194 (43%)
Lack of time to discuss donation with the patient's family	79/194 (41%)
Lack of supports for referral process	70/194 (36%)
Deceased expressed intent to not be a donor	47/194 (24%)
Perception that clinicians will provide "suboptimal care" to potential donors	47/194 (24%)
Difficulty declaring brain death or circulatory death diagnosis not confirmed	45/194 (23%)
Which of the following do you agree with?	
No concerns - this a great idea which is long overdue	112/194 (58%)
Increased relatives refusing to allow organs to be procured from a loved one means a law is required to prevent that from happening	32/194 (17%)
Deemed consent will be considered a violation of the general principles of freedom and autonomy	26/194 (13%)
Infrastructure for organ donation is more important than legislation	21/194 (11%)
Campaigns targeting feelings and emotions are more effective than legislation	14/194 (7%)

Table 5 Identified topics for further training

Variable	*n*/total *N* (%)
Coordination of donor process	136/194 (70%)
Clinical management of donors	135/194 (70%)
Family issues in decision-making	135/194 (70%)
Donor identification	132/194 (68%)
Communication skills	130/194 (67%)
Donor referral	128/194 (66%)
Family grief counseling	119/194 (61%)
Brain death	107/194 (55%)

Twenty-six (13%) respondents thought that deemed consent legislation would be considered a violation of the general principles of freedom and autonomy. Only 11% of respondents agreed that infrastructure for organ donation is more important than legislation, and 7% felt that campaigns targeting feelings and emotions are more effective than legislation.

Respondents were asked about their roles and responsibilities with respect to organ donation. The majority of nurses believed that conveying the importance of organ donation (71%) and identifying potential organ donors (72%) were consistent with their professional role. Just under half (44%) also saw discussing consent with family as part of their role. Only six respondents (3%) felt it was not within their role to support organ donation. Table 5 presents the respondents' preferences for further training. The three most common topics for training were coordination of the donation process (70%), clinical management of donors (70%), and family issues in decision-making (70%).

Discussion

To our knowledge, this study represents the first to understand ICU and ED nurse's knowledge, confidence, attitudes, and experiences around organ donation and transplantation in the context of an impending deemed consent model. We found high support of organ donation among ICU and ED nurses with many having cared for (potential) organ donors or transplant recipients. One key finding was the need for additional education and supports. Barriers to organ donation included a lack of familiarity with donation processes, family refusal, and a reluctance to approach the topic of donation with families. Approximately, half of respondents had some form of organ donation training yet wanted future training in terms of coordinating the donation process, clinical management of donors, family issues in decision-making, donor identification, communication skills, donor referral, and family grief counseling.

Previous literature has identified health professional education as an important component of successful organ donation programs, with the assumption that education increases knowledge of the organ donation system and process. In our study, only 46% of respondents had received training in organ donation-related issues, despite evidence to suggest that training may influence behavior with respect to donation outcomes. For example, a Swiss study of ICU staff showed that training in donor identification, NDD, and clinical management of donors was a significant predictor of consent rates for organ donation.[21] In this study, the three most common topics identified for further training were coordination of the donation process, clinical management of donors, and family issues in decision-making. These align with a previous needs assessment undertaken in Canada to inform development of a deceased donation education program.[23] Indeed, research has shown that training of ED staff on organ donor identification and management, specialized training on approaching families for donation discussions, and having a trained nurse in the ICU to provide additional family support are all associated with improved donation outcomes.[11,24]

Given their roles in the ICU and ED, nurses' attitudes toward organ donation and deemed consent are a critical piece of increasing donation rates and ensuring deemed consent models are optimized in each setting. If a patient is not identified and referred as a potential organ donor, the family will not be approached, and consent will never be a possibility. In the present study, nearly all nurses had a favorable attitude toward organ donation in general, which confirms previously published data.[12–14] The large majority also indicated they support or strongly support HOTDA. This is notable because nurses who have positive attitudes around organ donation show better practice (clinical competence, actions) when it comes to organ donation-related tasks,[25] whereas those with negative attitudes can influence people away from donation or generate distrust in the process.[26] With respect to deemed consent, varying perceptions have been reported across jurisdictions, with approximately 59% of ICU nurses supporting an opt-out system in Austria[27] but only 32% of nursing students supporting deemed consent legislation in Spain.[28]

This study has a number of limitations. First, we do not have a denominator of the number of nurses working in ICUs and EDs in Nova Scotia, which limits our ability to compute a precise response rate. Based on internal health authority information, the average number of ICU and ED nurses in Nova Scotia in the study timeframe was 1,124. Therefore, our response rate appears to be somewhere around 17%. We also have no way to determine the representativeness of our sample, further complicated by susceptibility to nonresponse bias. That is, our respondents may have had greater interest and experience in organ donation than nonresponders, and therefore may have had greater knowledge and more positive attitudes. In fact, $>$ 70% of respondents were confident in their understanding of DCD and nearly 60% were confident in their understanding of NDD. This is much higher than found in a prior Canadian study of ICU and ED nurses.[23] Conversely, it may be possible that nurses in this study were overly confident in their understanding of the concepts of neurologic and circulatory death; we did not test their specific knowledge of these concepts so are unable to investigate the extent to which their purported

understanding was accurate. Despite these limitations, this study sheds new insight into ICU and ED nurses' attitudes around deemed consent legislation and the training and related supports they feel they need as this new legislation is rolled out. Indeed, this study is a starting point to understanding ICU and ED providers' perspectives on HOTDA and further work, including qualitative inquiry, should be done to generate more in-depth understanding of providers' perspectives and experiences.

Conclusion

This study shows overall positive attitudes of ICU and ED nursing staff toward organ donation, including a deemed consent approach. Nurses identified numerous barriers and opportunities with respect to organ donation, as well as areas for further training as HOTDA is implemented. These areas relate to understanding the processes and procedures of organ donation as well as communicating with families around decision-making related to donation. These findings should inform educational initiatives in Nova Scotia and beyond to optimize organ donation processes and outcomes.

Author contributions *Robin Urquhart* contributed to all aspects of this manuscript, including study conception and design; acquisition, analysis, and interpretation of data; and drafting the article. *Nelofar Kureshi*, *Jade Dirk*, *Matthew Weiss*, and *Stephen Beed* contributed to the conception and design of the study and the interpretation of data. *Nelofar Kureshi* contributed to the acquisition and analysis of data.

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