Survey of Canadian critical care physicians' knowledge and attitudes towards legislative aspects of the deceased organ donation system

Sondage concernant les connaissances et attitudes des intensivistes canadiens envers les aspects législatifs du système de don d'organes de donneurs décédés

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Abstract

Purpose We surveyed Canadian critical care physicians who may care for patients who are potential organ donors

to understand their attitudes and knowledge of legislation governing the deceased organ donation system.

Methods We used a web-based, self-administered survey that included questions related to opt-out consent and mandatory referral legislation. Potential participants were identified through membership lists of professional societies and manual searches. We designed our survey

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using standardized methods and administered it in February and March 2018.

Results Fifty percent (263/529) of potential participants completed the questionnaire. A majority (61%; 144/235) supported a change towards an opt-out consent model, and 77% (181/235) stated they believe it would increase donation rates. Asked if opt-out consent would change their practices, 71% (166/235) stated an opt-out model would not change how or if they approach families to discuss donation. Fifty-six percent (139/249) supported mandatory referral laws, while only 42% (93/219) of those working in provinces with mandatory referral correctly stated that such laws exist in their province. Respondents gave variable responses on who should be accountable when patients are not referred, and 16% (40/249) believed no one should be held accountable.

Conclusions While a majority of critical care physicians supported opt-out consent and mandatory referral, many were neutral or against it. Many were unaware of existing laws and had variable opinions on how to ensure accountability. Efforts to increase understanding of how legislative models influence practice are required for any law to achieve its desired effect.

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Résumé

Objectif Nous avons étudié les intensivistes canadiens qui prennent soin de patients potentiellement donneurs d'organes afin de comprendre leurs attitudes et connaissances quant aux lois régissant le système de don d'organes de donneurs décédés.

Méthode Nous avons utilisé un sondage électronique auto-administré incluant des questions liées au consentement implicite avec option de retrait et à la législation de référence obligatoire. Les participants potentiels ont été identifiés grâce aux listes des sociétés professionnelles et par des recherches manuelles. Nous avons conçu notre sondage à l'aide de méthodes standardisées et l'avons administré en février et mars 2018.

Résultats Cinquante pour cent (263/529) des participants potentiels ont complété le questionnaire. La majorité (61 %; 144/235) était en faveur d'un changement vers un modèle de consentement avec option de retrait, et 77 % (181/235) ont déclaré penser que cela augmenterait les taux de don. Lorsqu'il leur a été demandé si l'option de consentement avec option de retrait modifierait leur pratique, 71 % (166/235) ont affirmé qu'un modèle avec possibilité de retrait ne modifierait pas leur façon ou leur intention d'approcher les familles pour parler de don

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d'organes. Cinquante-six pour cent (139/249) étaient en faveur de lois concernant la référence obligatoire, alors que seulement 42 % (93/219) des intensivistes travaillant dans des provinces où la référence était obligatoire ont correctement déclaré que de telles lois existaient dans leur province. Les répondants ont donné des réponses variables quant à l'imputabilité lors de la non-référence des patient, et 16 % (40/249) étaient d'avis que personne ne devrait être tenu responsable.

Conclusion *Alors que la majorité des intensivistes était en faveur du consentement avec option de retrait et de la référence obligatoire, bon nombre n'avaient pas d'avis sur la question ou étaient contre. De nombreux intensivistes ne connaissaient pas bien les lois existantes et avaient des opinions variables sur la façon de garantir l'imputabilité. Des efforts sont nécessaires pour augmenter la compréhension de la manière dont les modèles législatifs influencent la pratique afin qu'une loi, quelle qu'elle soit, ait l'effet désiré.*

The legal framework governing deceased donation in Canada is determined primarily by provincial legislation. These laws apply to the consent model used for deceased donation, to the obligations to refer patients who may become deceased donors, and to what information can be shared with organ donation organizations (ODOs). Many provinces have incorporated elements from high-performing systems, often based on the Spanish model.^{1,2} Nevertheless, variability exists regarding which elements are included in provincial donation and transplantation regulations.³ Little is known regarding the attitudes or knowledge of critical care physicians towards deceased donation legislation, and less is known about how legislation influences clinician behaviours. The last Canadian survey of healthcare worker attitudes towards donation legislation comes from a donation survey in 2006, which included some questions on presumed consent.⁴

Across the world, the two main consent models used for deceased donation are the opt-in and opt-out models. In an opt-in model, the individual or their surrogate decision maker (SDM) must give explicit consent for donation. In an opt-out model, often referred to as presumed consent, the individual is assumed to consent for donation unless they have expressed otherwise. No jurisdiction in North America currently operates under an opt-out consent model, though the province of Nova Scotia is preparing to transition towards one.⁵ Mandatory referral, or the legal obligation to refer patients who are potential donors to ODOs, also varies across provinces. Several provinces have clearly stated requirements for mandatory referral of

all deaths, some have no mandatory referral, and others have laws that are somewhat ambiguous.³

Our survey aimed to determine attitudes and knowledge towards deceased donation legislation of Canadian critical care physicians who care for patients who are at the end-of-life and may be eligible to donate organs.

Methods

We conducted a self-administered cross-sectional survey of Canadian critical care physicians. Our survey questions focusing on attitudes and knowledge of deceased donation legislation were embedded in a larger study about deceased donation practices in Canada. Results of our survey on physician non-referral and family override were recently published, and include a more detailed description of the survey development methodology.⁶ Our survey was approved on 6 December 2017 by the Research Ethics Committee of the *Centre Hospitalier de l'Université de Montréal*.

Population and sample size

Our sampling frame included critical care physicians practicing in Canadian institutions caring for patients who may become eligible to donate organs. Potential respondents were identified from the membership list of the Canadian Critical Care Society, supplemented by manual searches of publicly available sources (e.g., hospital websites) and validated by staff at Canadian Blood Services. Responses were included if the respondent reported they were actively practicing critical care medicine with an independent practice license (i.e., not a trainee) and if they were involved in the care of patients who may be eligible for organ donation. Based on recent Canadian surveys, we *a priori* estimated between 300 and 400 critical care physicians would be eligible for this study.⁶⁻⁸ Between 169 and 196 respondents were required for a confidence level of 95% and a 5% margin of error, corresponding to a response rate of 49–56%, which is consistent with previous work in a similar population.⁶⁻⁸ We asked respondents to self-identify if they had a defined donation role, but did not limit the definition of that term. Potential roles could include chair of a local donation committee, formal donor physician status with an ODO, or other self-defined roles.

Survey development

We followed a standardized approach for the design and conduct of self-administered surveys.⁹ We used a modified Delphi approach among the study steering committee and

patient partner. The final survey included items allowing for selection from responses (with a free-text option) and closed answers (binary and five-level Likert scales). Some items were discrete, and some referred to clinical scenarios. The survey was developed and administered in English only. Items pertaining to this manuscript are available as electronic supplemental material (Electronic Supplemental Material [ESM]; eAppendix 1).

Survey validation

The study steering committee members pre-tested the survey for face validity, clarity, and relevance. We then pilot tested the survey on trainees (ten residents and fellows). Reliability and content validity were assessed through test-retest reliability with the same trainees two weeks later. Results of this process were published in a prior report.¹⁰

Survey administration

Our survey was disseminated by email with two reminders sent to non-responders at 14-day intervals. The emails contained links to the online platform (LimeSurvey™). Respondents received no financial compensation for participating in this survey.

Data analysis

All survey responses are reported as descriptive statistics (counts and/or percentages). Denominators were adjusted based on the number of respondents answering individual questions. Per-province descriptive analyses were performed for selected questions based on the presence or absence of mandatory referral laws.³ For province-level analyses, physicians who practice in multiple provinces were included in all provinces in which they practiced; physicians who did not indicate a province of practice were not included. Descriptive analyses according to self-reported donation specialist status were also included. We did not employ comparative statistics as the study was not powered to effectively make these comparisons.

Results

Respondents

We approached 550 potential respondents between 26 February 2018 and 26 March 2018; 21 respondents did not meet the inclusion criteria. The response rate was 50% (263/529), of which 95% (249/263) of respondents answered at least one question and 89% (235/263)

completed the entire survey. The demographics of the participants are detailed in Table 1. Ninety-one percent (226/249) of respondents were affiliated with academic institutions and 13% (33/249) worked in pediatric intensive care units. Twenty-one percent (53/249) of respondents self-reported having a formal role as a donation specialist in their hospital or institution.

Attitudes towards opt-out consent

Nationally, 61% (144/235) of respondents agreed or strongly agreed with a possible change towards an opt-out consent model, 19% (44/235) were neutral, and 20% (47/235) disagreed or strongly disagreed. Figure 1 shows responses across the different provinces. Seventy-seven percent (181/235) of respondents believed that an opt-out consent model would increase donation rates, and 4% (9/235) thought it would decrease donation rates. Seventy-one percent of respondents (166/235) stated that an opt-out consent model would not change the likelihood that they would approach the SDMs of a patient who is a potential donor. Twenty-five percent (59/235) stated it would increase their likelihood of approach, and 3.4% (8/235) stated it would decrease their likelihood of approach.

Attitudes towards model of initial approach

We asked respondents if those seeking consent from SDMs of patients who had previously registered consent for donation should “inform the family that donation would proceed” instead of framing the discussion as a new consent discussion. Responses varied (Table 2), with 46% (108/235) stating they strongly agreed or agreed, 39% (92/235) strongly disagreed or disagreed, and 15% (35/235) were neutral.

Mandatory referral legislation

Respondents were asked about the existence of mandatory referral legislation in their province. Overall, 42% (93/219) of respondents working in provinces with mandatory referral (Table 3) correctly stated that their province had mandatory referral. This proportion varied across provinces (Fig. 2). No respondent incorrectly stated that their province had mandatory referral when it did not (Fig. 2).

Fifty-six percent (139/249) of respondents stated mandatory referral laws should be in place, 32% (79/249) said they should not, and 12% (31/249) did not know. There was variation in the level of support for mandatory referral across provinces; physicians in Manitoba, Newfoundland and Labrador, Nova Scotia, and Ontario expressed majority support for mandatory referral, while respondents in other provinces were either mixed or did not

Table 1 Characteristics of survey respondents

	n	%
ICU population ^a		
Adult	216	86.7
Pediatric	33	13.2
Type of ICU (all that apply)		
Trauma ICU	119	47.7
Neuro or neurosurgical ICU	144	57.8
Cardiothoracic ICU	101	40.6
Coronary care unit	32	12.9
Medical unit	81	32.5
Surgical unit	75	30.1
Mixed unit (surgical and medical)	231	92.8
Number of ICU beds		
0 to 5	1	0.4
6 to 10	24	9.6
11 to 15	44	17.6
16 to 20	44	17.6
21 to 30	79	31.7
> 30	57	22.8
Prefer not to respond	10	4.0
Age group		
≤ 30	0	0.0
31 to 40	86	34.5
41 to 50	92	36.9
51 to 60	54	21.7
61 to 70	16	6.4
≥ 71	0	0.0
No response	1	0.4
Province (territory) of practice ^b		
Alberta	23	9.5
British Columbia	21	8.4
Manitoba	13	4.9
New Brunswick	3	1.2
Newfoundland and Labrador	5	2.0
Northern Canada (Northwest Territories, Nunavut, and Yukon)	0	0.0
Nova Scotia	12	4.8
Ontario	86	34.6
Prince Edward Island	0	0.0
Québec	78	31.6
Saskatchewan	10	4.2
Academic affiliation		
Yes	226	90.7
No	21	8.4
No response	2	0.8
Years of independent practice		
0–5	61	24.5
6–10	63	25.3
11–15	44	17.7
> 15	81	32.5

Table 1 continued

	n	%
Self-reported role as a donation specialist ^c		
Yes	53	21.3
No	196	78.7
Physician defined role as a donation specialist in the institution		
Yes	170	68.3
No	79	31.7

ICU = intensive care unit. ^a No respondents reported practice with both pediatrics and adult population; ^b This question allows multiple responses (three respondents answered they practiced in two different provinces and one respondent indicated zero provinces); ^c Donation specialist not defined in the survey, left to respondent discretion

Fig. 1 Support by province for consideration of an opt-out organ donation consent model **Table 2** Approach of substitute decision maker of patients with previously expressed consent

When an eligible donor is found to have registered their intent to donate, should the approach by the organ donation organization change from “seeking consent” to “informing the family that donation will proceed.” (n = 235)

Strongly disagree	27	11.5 %
Disagree	65	27.7%
Neutral	35	14.9%
Agree	82	34.9%
Strongly agree	26	11.1%

support these laws (Fig. 2). Among the 139 respondents who supported mandatory referral laws, the majority believe that these laws improve donation rates (86%, 118/139) or encourage improvements to the donation system (89%, 123/139). Supporters also agreed that these laws provide legal justification for family or SDM approaches (73%, 101/139), and clarify when an approach of the family was appropriate (67%, 92/139).

Of the 79 respondents who opposed mandatory referral laws, the most frequently cited reason was that it forces physicians to approach SDMs in situations they may judge to be inappropriate (80%, 63/79). They also cited concern that if a referral was not done there could be potential legal exposure either for the physician (43%, 34/79) or their hospital (39%, 31/79). Some (30%, 24/79) did not believe that mandatory referral was effective in increasing donation rates.

Table 3 Provinces of respondents with and without mandatory referral legislation^a

	No mandatory referral law enacted at time of survey	Mandatory referral law enacted at time of survey
Provinces	New Brunswick, Newfoundland and Labrador, Nova Scotia, Saskatchewan	Alberta ^b , British Columbia, Manitoba, Ontario, Québec ^b

^a Provinces with no respondents in the current survey not reported; ^bClassified as having mandatory referral despite some ambiguity in legislation (see discussion). Adapted from Zavalkoff *et al.*³

Fig. 2 Awareness of current provincial mandatory referral legislation. Blue bars: percent of correct responses from respondents in provinces with mandatory referral laws. Red bars: percent of

correct responses from respondents in provinces without mandatory referral laws. Grey bars: percent of incorrect responses (e.g., stating that a province did not have mandatory referral laws when they did)

Respondents gave variable responses regarding who should be held accountable in case a referral was not made according to mandatory referral legislation. The hospital was the most frequently chosen (59%, 148/249), followed by the department/service (44%, 111/249), and the individual physician (40%, 99/249). Sixteen percent (40/249) thought that no one should be held accountable for a missed referral.

Donation physicians

Responses from physicians who did and did not self-identify as donation physicians are presented descriptively in eAppendix 2 (available as ESM). Figure 4 shows responses to mandatory referral and opt-out consent questions between these two groups.

Discussion

Our survey provides an overview of Canadian critical care physician attitudes towards deceased donation legislative issues. A slight majority of our respondents reported support for opt-out consent and mandatory referral, though a substantial number of expressed neutral or negative opinions towards these laws. Many respondents also reported being unaware of the mandatory referral framework in which they work. These results are an important indicator of the attitudes of a key stakeholder group in the deceased donation process.

The legislative framework of a donation and transplantation system performance may influence the success of that system.² As a country with federally mandated but provincially administered healthcare, Canadian physicians are governed by a variety of legal mandates. This variability is about to increase with the introduction of reforms to the Nova Scotia system that

Fig. 3 Preference for mandatory referral laws. Light blue bars represent the percent of responses in favour of mandatory referral laws and light red bars represent the percent of responses not in favour of mandatory referral laws

include opt-out consent for deceased donation, with implementation scheduled to begin in 2020. Despite being employed by other countries for decades, opt-out has not been consistently associated with an increase in donation rates,^{11,12} and it is unclear what its impact will be in a North American context.

Prior to our survey, there was no recent data regarding what Canadian physicians believed about a potential opt-out consent model. In a 2006 survey of healthcare workers (not physician specific), 59% of respondents strongly or somewhat supported an opt-out consent model,⁴ suggesting stable support among critical care physicians 12 years later. In our survey, only 4% of respondents thought opt-out might decrease donation rates. Despite this support, more than two thirds (71%, 166/235) stated opt-out consent would not change—notably not increase—the likelihood that they would approach families of potential donors. This suggests that respondents may not understand the mechanism of how opt-out could influence donation rates. While opt-out could influence consent rates once the consent donation is initiated, that discussion depends on timely referral and an approach of the family or SDM. Even in an opt-out consent model, if patients who are potential donors are not identified and referred to the ODO, there is no possibility they progress to become actual donors. Likely, jurisdictions considering opt-out implementation will need to continue to focus on methods to ensure proper identification and referral.

Mandatory referral laws received mixed support from respondents, with provincial variation. Additionally, fewer than half of physicians working in a mandatory referral province correctly identified the existence of the law, with variability by province. This is despite multiple reports—including from high-performing systems in Spain and the United States—that highlight mandatory referral likely has

a larger impact on donation system performance than opt-out consent models.^{11,13}

Reasons for the lack of recognition of mandatory referral laws are unclear. One potential issue is the lack of clarity of existing legislation. In Québec, for instance, the law states that all potential donors should be referred to the ODO for verification if the patient had registered a desire to become an organ donor. Nevertheless, the law stipulates that hospitals should then “send to such an organization, *if the consent has been given*, any necessary medical information concerning the potential donor and the organs or tissues that may be removed” (emphasis added).¹⁴ This wording could suggest that if the patient has not registered consent, the treating team should not transmit any medical information to the ODO to facilitate screening for eligibility. In the absence of guidance from the ODO, physicians may choose not to approach patients who were in fact eligible, a behaviour reported frequently in another section of this same survey.¹⁰ Clarification of these laws and how laws should influence practice are potential targets for knowledge translation efforts if improved compliance is desired.

We also found that critical care physicians varied in their opinions of who, if anyone, should be held accountable if clinicians and hospitals fail to adhere to mandatory referral requirements. Policy makers will need to consider the best methods to ensure compliance, especially considering the recent report of a national meeting on the importance of donor identification included a call for comprehensive audits of potential donors.³ While direct causal links cannot be confirmed based on existing literature, audit and feedback processes are reported as a key component of high-performing programs and are the only way to verify compliance with mandatory reporting legislation.^{13,15}

Fig. 4 Responses from respondents with or without self-identified role as donation physician

Strengths and limitations

Our survey was rigorously developed. Our sampling frame was comprehensive, and we obtained a reasonable response rate. Nevertheless, some limitations are to be acknowledged. First, there is a possibility that non-respondents had different attitudes or behaviours towards donation than respondents. Of note, a high number of respondents had self-reported formal roles in the donation system. The design of our study did not allow for meaningful comparative statistics between donation-focused physicians and other respondents, but responses to most questions between the two groups were within the

sampling margin of error. Also, questions regarding opt-out consent models were likely highly theoretical for respondents, as likely few if any had ever worked in such a system. The lack of clarity regarding how opt-out consent may impact their practice could have been from unfamiliarity with such a system or from questions that did not provide adequate context for respondents. Finally, all forms of donation are infrequent events for an individual clinician in Canada, which may limit an individual's knowledge of the legislation supporting the system. Nevertheless, the survey's goal was to understand the attitudes of respondents as a group, so this variability would only add to the global understanding of intensive care physician attitudes as whole.

Conclusions

Our survey found that, while a majority of critical care physicians supported opt-out consent and mandatory referral, a substantial number were neutral or against these laws. Many were unaware of existing laws and had variable opinions on how to ensure accountability. These results suggest that there is a significant opportunity for outreach to the critical care physician community regarding deceased donation legislation. Stakeholders can use these results to support methods that encourage compliance with existing mandatory referral legislation and incoming opt-out. Future laws that alter donation consent and referral practices should be drafted clearly and communicated to the clinicians who are significantly impacted by those changes.

Author contributions Matthew J. Weiss and Michaël Chassé contributed to all aspects of this manuscript, including study conception and design; acquisition, analysis, and interpretation of data; and drafting the article.

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