

Neuroanesthesia and Intensive Care

Brain death diagnoses and evaluation of the number of potential organ donors in Québec hospitals

[Les diagnostics de mort encéphalique et l'évaluation du nombre de donneurs d'organes possibles dans les hôpitaux du Québec]

Réal Cloutier MD,*† Dana Baran MD,‡§ Jean E. Morin MD,*¶|| Raymond Dandavino MD,|| Denis Marleau MD,** Alain Naud MD,†† Robert Gagnon MSc,* Marc Billard MD*

Purpose: Faced with our inability to respond to the growing number of Quebec patients waiting for organ transplants, we sought to determine the number of potential organ donors (OD) in acute care hospitals.

Methods: A retrospective chart review of all acute care, in-hospital deaths in Quebec in the year 2000 was undertaken. Hospital record librarians provided statistics and completed questionnaires on each chart after applying exclusion and inclusion criteria.

Results: There were 24,702 acute care in-hospital deaths reported by 83 hospitals participating in the study on a voluntary basis. Analyzing 2,067 files meeting inclusion criteria, we identified 348 potential OD (1.4% of deaths). In hospitals not providing tertiary adult trauma care, the potential donor rate was 0.99% of all deaths. There were 4.5 times more potential donors in tertiary care adult trauma centers. Brain death was formally diagnosed in 268/348 patients, and organ donation discussed as an option with 230/268 families. Consent for donation was given in 70% of cases, although not all these patients proved to be suitable after evaluation. There were 125 actual donors in Quebec in the year 2000 (18 per million population).

Conclusions: The gap between used and potential donors can be explained by several factors including failure to approach families for organ donation, family refusal, incomplete neurological assessment of patients, and medical unsuitability of some consented donors. There is room for improvement in the identification of potential donors and in the presentation of organ donation as an end of life option to families.

Objectif : Devant l'incapacité de répondre au nombre croissant de patients du Québec qui attendent une transplantation d'organe, nous avons cherché à déterminer le nombre de donneurs d'organes (DO) potentiels dans les hôpitaux de soins actifs.

Méthode : Une étude rétrospective de tous les patients décédés à l'hôpital de soins actifs au Québec en 2000 a été entreprise. Les archivistes des hôpitaux ont fourni les statistiques et rempli les questionnaires sur chaque dossier après avoir appliqué les critères d'inclusion et d'exclusion.

Résultats : Il y a eu 24 702 décès parmi les 83 hôpitaux de soins actifs participants à l'étude. L'analyse de 2 067 fiches répondant aux critères d'inclusion a permis de recenser 348 DO potentiels (1,4 % des décès). Dans les hôpitaux qui n'offrent pas de soins tertiaires pour traumatismes chez les adultes, le taux de donneur potentiel était de 0,99 % de tous les décès. Il y avait 4,5 fois plus de donneurs potentiels dans les centres de soins tertiaires pour polytraumatisés adultes. La mort neurologique a été formellement diagnostiquée chez 268/348 patients et l'option du don d'organe discutée avec 230/268 familles. Il y a eu consentement pour un don dans 70 % des cas, mais après l'évaluation, il n'y a eu en fait que 125 donneurs au Québec en 2000 (18 par million de population).

Conclusion : La différence entre les donneurs potentiels et réels peut s'expliquer par certains facteurs dont le défaut de parler aux familles du don d'organes, le refus de la famille, l'évaluation neurologique incomplète des patients et l'inaptitude médicale de certains donneurs consentants. Il y a matière à amélioration dans la façon d'identifier les donneurs et dans la présentation aux familles du don d'organes comme choix de fin de vie.

From the Transplantation Committee, Québec College of Physicians* Montréal; Directeur conseil, Conseil en Immobilisation et management Inc., Montreal,† Internal Medicine and Nephrology,‡ McGill University Health Centre, Montréal, Québec-Transplant;§ Montréal; Cardiothoracic Surgery,¶ McGill University Health Centre, Montréal; Hôpital Maisonneuve-Rosemont,|| Montréal; Centre hospitalier de l'Université de Montréal St-Luc,** Montréal; Centre hospitalier Universitaire de Québec,†† Québec City; Québec, Canada.

Address correspondence to: Dr. Réal Cloutier, Conseil en Immobilisation et Management Inc. 440, boul. René-Lévesque Ouest, bureau 1700, Montréal, Québec H2Z 1V7. Phone: 514-393-4563, ext. 326; Fax: 514-393-4598; E-mail: rcloutier@cim-conseil.qc.ca

Accepted for publication August 30, 2005.

Revision accepted November 25, 2005.

Final revision accepted January 20, 2006.

Competing interests: None declared.

THE number of organ donors in Canada is too small to meet the existing demand. In Québec alone, 815 patients were waiting for solid organ transplants in 2000 and 860 were listed in 2003.¹ Spain is recognized as the country with the highest organ donor rate PMP (33.9)² because of its highly organized donor identification system. In Canada, the rate was 13.3 per million population (PMP) in 2003, whereas in Québec the rate was 19.2.¹

Although actual donor rates are known, there are few studies on the number of potential organ donors in Canada. The only report concerning potential organ donors in Québec hospitals was published in 1991.³ Conducted in 24 hospitals, the study included only those patients most likely to become organ donors (cerebrovascular accident, trauma). In that study, only one out of two eligible patients was identified as a potential donor. In their report published in the summer of 2000, the Advisory Board on organ and tissue donation of Ontario⁴ deplored the lack of data on potential donors in Ontario hospitals. In 2001, the Canadian Institute for Health Information^A published a document using the method of Holt⁵ to estimate the number of potential donors among hospitalized patients in Canada. In April 2001, Baxter (The Urban Futures Institute, 2001)⁶ cast doubt on Canada's ability to attain the organ donor rates of certain countries such as Spain, considered the gold standard, and the United States, given the differences in the causes of death among these countries. He also examined the disparities among rates pointing out that it is difficult to compare them since donors PMP is not calculated in a uniform fashion across countries.

In the context of this debate and considering all these factors, the Transplantation Committee of the College of Physicians of Québec, a subcommittee of the Professional Inspection Committee undertook the present study. The mandate resulted from an agreement with Québec-Transplant who asked the College to assume responsibility for an independent hospital chart review. In return, Québec-Transplant provided the College with all statistics concerning organ donation and financial support for secretarial assistance. A summary appears at: <http://www.cmq.org/DocumentLibrary/UploadedContents/CmsDocuments/transplantationEng.pdf>.⁷

This study had two objectives: a) to establish and report the number of potential donors in all Québec

acute care hospitals compared to the number of donors in the year 2000 and b) to sensitize physicians to the identification of potential organ donors by sending individual hospital results to each Council of Physicians, Dentists and Pharmacists. This study is important because it directly estimates the number of brain dead patients in Québec hospitals and provides a realistic goal for organ donor identification and utilization.

Methods

The study was a retrospective chart review of all deaths that occurred in Québec acute care hospitals between January 1st and December 31st 2000. Patients dying in emergency wards were not included in this study because their charts did not contain diagnostic codes. The study started in September 2000 when documents were mailed to acute care hospitals requesting their voluntary participation. Hospital record librarians provided statistics and completed questionnaires⁷ on each chart after applying exclusion and inclusion criteria (Table I). These data were captured in a database using a software program that automatically checks the validity of entries to reduce the risk of transcription errors. Québec-Transplant provided a separate list for purposes of validation of all phone calls concerning potential donors received from referring hospitals. The secretary of the Transplantation Committee reviewed all the questionnaires supplied by the medical record departments in order to identify potential organ donors (Appendix). When the information supplied was incomplete, copies of progress notes written by doctors, nurses and respiratory therapists in the last 24 hr of the patient's life were requested. With all these data, it was possible to establish the state of consciousness of each patient, and to determine whether or not brainstem reflexes were present including spontaneous respiration. This enabled us to either include or exclude patients as potential organ donors. In controversial cases, the entire Transplantation Committee was consulted and decisions were made unanimously.

Definitions

We defined a *potential organ donor* as any individual under the age of 85 whose trachea was intubated, requiring mechanical ventilation, and in whom brain death was either suspected, anticipated or diagnosed,⁸ and who did not meet exclusion criteria or suffer from hemodynamic instability. A *referring hospital* was defined as the institution placing the initial phone call requesting evaluation of a patient as a potential organ donor by Québec-Transplant. The *consent rate* was the

A Canadian Institute for Health Information. Estimating potential cadaveric organ donors for Canada and its provinces, 1992 to 1998, a discussion paper. Ottawa, 2001: 61.

TABLE I Inclusion and exclusion criteria

| <i>Diagnoses or conditions</i> | <i>ICD-9 codes (excluded charts)</i> |
|--|--|
| Patients 85 yr and over | |
| Patients in long-term care facilities | |
| Active tuberculosis | 010 to 018 042 to 044 |
| AIDS or HIV infection | 795.8 V02.9 |
| Creutzfeldt-Jakob disease | 046.1 331.5 |
| Syphilis | 090 to 097 V02.5 |
| Uncontrolled bacteremia or septicemia | 038 054.5 140 to 190 |
| Cancer (with the exception of primary brain tumours, basal cell skin tumours, or <i>in situ</i> cancer of organs other than the bladder) | 192.2 to 208 233.7 233.9 238 to 239.9 D09.0 |
| Inclusion criterion | Intubated patient requiring mechanical ventilation in the last 24 hr of life |

ICD = international classification of diseases; HIV = human immunodeficiency virus.

number of family consents obtained for organ donation divided by the number of families approached regarding donation. The *rate of potential organ donors among hospitalized patients* represented the number of potential donors identified by this study divided by the total number of reported death, expressed as a percentage. The *conversion rate* was the number of donors actually utilized, divided by the number of patients who were diagnosed as brain dead.

Statistical analysis

The primary analysis tested the difference between rates of potential donors and the proportion of apnea tests according to three hospital characteristics: the presence of tertiary trauma, the presence of dialysis service, and a location in remote regions. Differences between rates were tested with the Chi-square test with the Yates correction. Results were considered statistically significant at a $P \leq 0.05$.

Results

Eighty three of 93 hospitals (89%) participated in the study: 80 hospitals provided complete information; of these, 31 hospitals had an active local organ and tissue donation committee. The total number of

TABLE II CAUSES OF DEATH

| <i>Causes</i> | <i>n</i> | <i>%</i> |
|--|----------|----------|
| Hematoma, hemorrhage, cerebral edema, cerebrovascular accident, aneurysm | 189 | 54.3 |
| Head trauma, multiple trauma | 72 | 20.7 |
| Encephalopathy/cerebral anoxia | 39 | 11.2 |
| Myocardial infarction | 12 | 3.5 |
| Hanging | 10 | 2.9 |
| Brain tumour | 5 | 1.4 |
| Other causes | 21 | 6.0 |
| Unspecified causes | 17 | 4.7 |

deaths in participating hospitals was 24,702 amongst hospitalized patients, accounting for 93% of all deaths occurring in the year 2000 in acute care hospitals as reported by a special request at the Central bank of data, Ministry of Health and social services Québec (MED-ECHO).⁹ After applying exclusion criteria, 8,973 charts were retained. This number was reduced to 2,067 for final study (8.3% of deaths) after applying the inclusion criterion. A detailed analysis of these charts permitted the identification of 348 potential organ donors. A Glasgow coma scale score¹⁰ was reported in 831 of the 2,067 charts reviewed (40%). The mean age of the 348 identified potential donors was 53 yr. A spontaneous neurological event was responsible for death in 54.3% of the identified potential donors, whereas 72 patients (20.7%) died from head trauma. Several other causes of death were also documented (Table II).

The 348 potential organ donors identified included 148 of the 158 cases retained by Québec-Transplant: the ten cases of patients who died in emergency wards of referring hospitals were excluded from our analysis. Among the 348 potential organ donors, brain death was documented by a physician in 268 cases (77%). In 230 cases (66%), families were approached regarding organ donation, and the consent rate was 70%. A Glasgow Coma Scale score was recorded in 259 of the 348 cases (74%) and 190 apnea tests were performed in the referring hospitals.

A specific analysis of the 268 patients with a formal diagnosis of brain death revealed the following: 205 charts with a documented Glasgow Coma Score (76% of cases), 181 apnea tests (67% of the cases), 205 requests to families (76% of cases) and a consent rate of 73%. The consent rate was similar to the consent rate of 70% for all families approached for donation ($P = 0.44$).

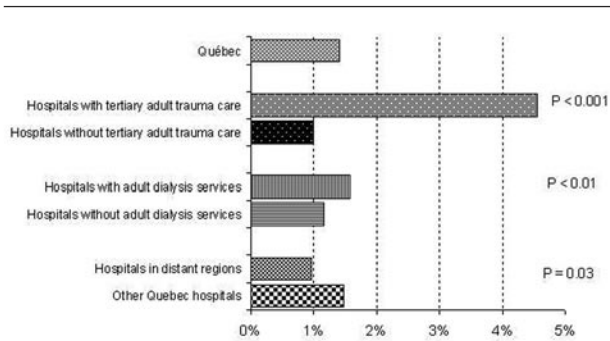


FIGURE 1 Rate of potential donors in Québec as a function of hospital type.

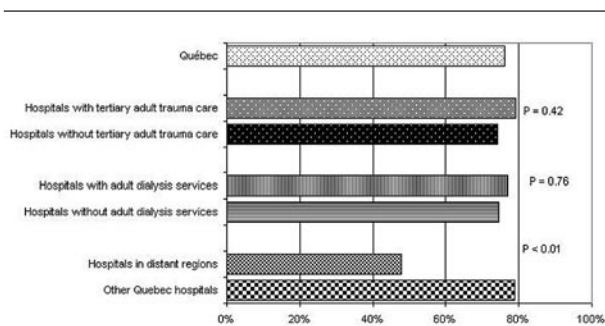


FIGURE 2 Percent of apnea tests done in referring hospital patients in case of diagnosed brain death.

Apnea tests were documented in 204 of the 2,067 charts analyzed. One hundred and ninety tests were done in the 348 cases of identified potential organ donors, and 181 tests were done in the cohort of patients formally diagnosed as brain dead.

The potential organ donor rate among hospitalized patients who died in acute care institutions was 1.41% for all causes of death combined (Figure 1). The rate in the 78 hospitals not offering tertiary trauma care was 0.99%. It was 4.5 times higher in the four hospitals providing adult tertiary trauma services. The rate was also higher than average in the 28 hospitals offering adult dialysis services (1.58%; $P < 0.01$). The potential organ donor rate in the 27 hospitals in distant regions was not different when compared to other Québec hospitals (0.96% *vs* 1.47%, $P = 0.03$). The conversion rate among hospitalized potential donors was 46% (125 utilized donors/268 documented cases of brain

death).

The number of apnea tests done in the hospital of origin in cases of documented brain death was not statistically significant when comparing different types of hospitals, except for hospitals in distant regions where statistically fewer apnea tests were performed (Figure 2).

The four tertiary care adult trauma centres had a total of 38% of all potential donors. Fifty-nine percent of all cases were concentrated in the ten hospitals that each had a donor potential of ten or more; 76% of the cases were in the 19 hospitals that had a donor potential of five or more.

Discussion

Our chart review established that most physicians adequately documented neurological signs permitting the identification of brain death in most cases. However, there is room for improvement in certain centres where incomplete information was recorded on the level of consciousness and other pertinent neurological signs. Physicians in trauma intensive care units are most sensitized to the identification of potential organ donors. Other physicians, however, do not always have a clear notion of how to diagnose brain death, or when and how to perform an apnea test. This may be explained by the small number of cases of brain death in most Québec hospitals.

Our data also suggest that more families should be approached regarding organ donation when brain death is diagnosed (only 77% of cases). The consent rate of 70% is higher than the 54% observed in the study of Sheehy *et al.*,¹¹ but could still be improved. The estimated consent rate in our study closely parallels the intentions of Quebecers reported in a Léger & Léger survey published in 1999^B indicating that 66% of those polled would agree to donate their organs.

The mean age of the potential donors was 53 yr, whereas the mean age of donors actually utilized by Québec-Transplant was 43 yr. This age discrepancy might be explained by a tendency of physicians to exclude patients from consideration based upon age alone.

The potential donor rate of 0.99% in hospitals without tertiary trauma care services is a new and interesting observation since it reflects the situation in the majority of hospitals. The higher potential donor rate in tertiary trauma centres (4.5%) is consistent with the study of Christiansen *et al.*¹² who identified the provi-

B Léger & Léger. Attitudes des Québécois face au don d'organes. Montréal, Léger & Léger, Survey realized with 1,005 persons at the Québec-Transplant demand. April, 1999: 16.

TABLE III Estimate of potential donors per million population

348 potential donors × 70% consent rate = 243 consented donors
 243 consented donors × 85% utilization rate = 207 donors
 207 donors for 7 400 000 inhabitants = 27.9 donors per million

Note 1: This calculation includes hospitalized potential donors only.
 10 cases from emergency wards in 2,000 are excluded from this estimate

Note 2: The 85% utilization rate is based on statistics from Québec-Transplant (utilized donors/consented donors)

sion of trauma care as one of five characteristics predictive of the number of potential donors. Using our information on donor distribution, we have recently trained a group of in-house organ donor resource nurses who are working in the 20 Québec hospitals with the greatest organ donor potential. This initiative will hopefully lead to better donor identification in the future. Almost 8% of potential donors were found in distant regions which is an important observation that should not be neglected. Only a few hospitals (31) had active organ and tissue donation committees of the 83 participating hospitals.

Based on our results, it is theoretically possible to achieve a rate of approximately 28 donors PMP (Table III), which would permit Québec to have 200 donors per year (135 in 2000). The conversion rate of 46% observed in Québec is comparable to the rate reported by Sheehy *et al.*¹¹ but is, of course, far from optimal.

The Professional Inspection Committee transmitted the results of the present study to each participating hospital providing the Council of Physicians, Dentists and Pharmacists with a profile of their hospital, as well as a copy of the overall report.⁸ In addition, specific recommendations were made to each hospital to help physicians better identify potential organ donors. These recommendations were based on the analysis of charts from the individual hospitals.

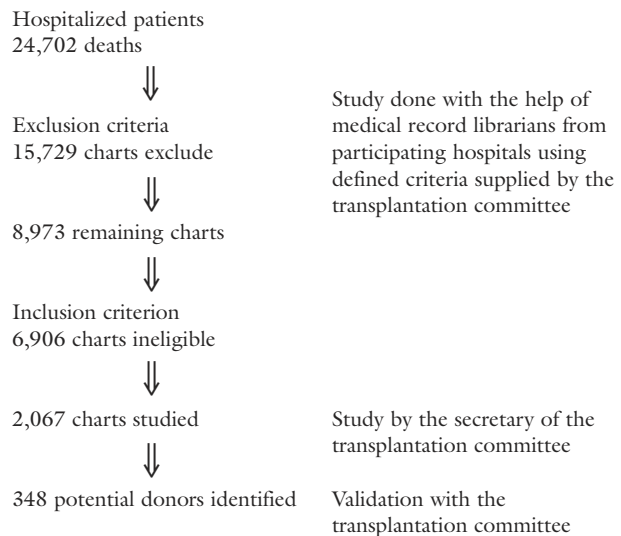
The present study has certain limitations: it is a retrospective chart review relying on the collaboration of hospital record librarians; in addition, it depends on local research tools (local data bank MED-ECHO), the accuracy of coding the charts, and the quality and quantity of information in the hospital records. A total of 40/2,047 charts (1.9%) reviewed were considered to be incomplete, and were reviewed in detail by the Transplantation Committee in an effort to classify patients as accurately as possible.

Despite several limitations, we believe that this study is important because it addresses the issue of organ donor potential in a direct manner, helping us to establish a realistic target for organ donation in the province of Québec. With the publication of these data, the Québec College of Physicians hopes to play a leading role in the analysis of organ donor potential in Canada, and to suggest ways in which more organ donors can be identified and utilized.

Acknowledgements

We were able to conduct this study with the invaluable collaboration of all Québec hospitals, especially hospital record librarians, and with the support of Québec-Transplant. The Transplantation Committee extends special thanks to Donald Langlais, Anthony d'Amicantonio and Micheline Lyras (Québec-Transplant), Lisa Goulet (McGill University Hospital Centre) and Isabelle Brunet (Québec College of Physicians). We are also grateful to Dr. Sam Shemie for his collaboration and to Dr. Dana Baran for the English translation of this article.

APPENDIX Steps for the identification of potential donors



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