



# Organ Donation After Death in Québec: Should Family Involvement on Consent Be Restricted?

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Organ Donation After Death in Québec: Should Family Involvement on Consent be Restricted?

Sylvain Bellavance

A Thesis in the Field of History  
for the Degree of Master of Liberal Arts in Extension Studies

Harvard University

March 2020

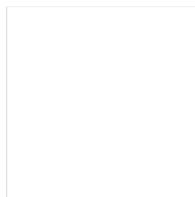


## Abstract

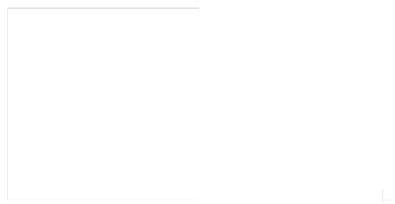
At a time when organ transplantation has become one way to address many health problems, there are not enough organs available to meet demand and many persons are dying worldwide while awaiting a transplant. The province of Québec faces the same challenges and efforts are made every year by Transplant Québec to get individuals to consent to organ donation after death.

More than 40% of the population registered their wishes to donate in one of the two registries available in Québec, and even more expressed their consent for organ donation on their health insurance card, upon renewal. However, reality shows that their sole consent is not enough, and family approval is requested for each organ donation, thereby amounting to a double consent and granting families a veto over the wishes of the deceased.

An analysis of Transplant Québec's Annual Reports, and of a specific set of data compiled for this thesis, reveals that 37% of refusals to proceed with an organ referral are attributable to families' objections and that their reasons for refusing is explained mainly by personal motives and not reasons associated with the deceased. It also reveals that 20% of family refusals concern a donor who had expressed a consent to organ donation, meaning that families overrode the wishes of donors in more than 40 cases of organ referrals in 2018, thereby causing the loss of available organs and, without doubt, costing lives.



This thesis reviews various legal, ethical and practical arguments which support restricting family involvement on consent to organ donation in Québec and, when expressed, giving precedence to donors' wishes. At a time when voices are calling for the introduction of a presumed consent system for deceased donor organ donation in Québec, we conclude that specific restrictions on family involvement are instead required and we propose potential solutions to consider.



## Dedication

To my dear friend, Dr Michel Lallier, a renowned surgeon in pediatric transplantation, whom by his work, dedication to organ transplantation and passionate care for sick children, has always inspired me and made me examine this topic with more than enthusiasm and interest. I hope that my work can contribute to his thinking on the role of families.

To Alain, my partner in life, whose love, support and patience were crucial during this endeavor.

Finally, I also wish to dedicate this work to all those personally concerned by organ donation either because they had to suffer the loss of a loved one or are hoping for the gift of life that organ donation can confer on them or on a member of their family. This thesis does in no way question or doubt the emotional distress, challenges, and values of the former group, although it does take the part of donors and the latter group, whose hopes we have a duty to fulfill.

## Acknowledgments

I am grateful to many persons who motivated me to complete my ALM degree, at a time when work and other life challenges could have convinced me otherwise. To Chuck Houston III, at Harvard Extension School, who first encouraged me to hang on and write my thesis, and Dr Lucie Opatrny, who consistently, but fondly, insisted that I do. Special mentions are also directed to my two older brothers: André, for drawing the path of following intensive studies while working full time and inspiring me to do the same, and René for his contribution in correcting many of my papers.

I also wish to thank Professor Don Ostrowski for his support, not only during the crafting of my thesis proposal, which allowed me to go a step further with the writing of this thesis, but for his continuing assistance thereafter.

Finally, I could not have completed this thesis without the great collaboration of my thesis director, Dr Douglas Wayne Hanto, a renowned transplantation surgeon and a Lewis Thomas Professor of Surgery Emeritus. I am deeply grateful to him not only for sharing his expertise and knowledge about organ donation and transplantation but also for his time and contribution in completing, revising, correcting and improving this thesis.

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## Chapter I.

### Introduction

With progress in medicine, organ transplantation has become one way to address many of the health problems related to organ failure and contributes to saving people or improving their lives. Indeed, around a dozen different organs and tissues can now be transplanted.

All developed countries face a chronic shortage of available organs for transplantation. The number of persons waiting for an organ transplant outnumbers the number of available organs. In the USA, over 120,000 candidates were on the waiting list in 2019.<sup>1</sup> In Canada, close to 3,000 organ transplants were performed in 2018, but 4300 patients remain on the waiting list. More than 220 patients in Canada died in 2018 while waiting for a transplant.<sup>2</sup>

Increasing the number of available organs for transplantation is therefore one of the major challenges in most countries. Indeed, to evaluate their efficiency, countries are rated in terms of the number of donors per million of population (dpmp)<sup>3</sup>. For deceased

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<sup>1</sup> United Network for Organ Sharing, *Transplant Trends*, accessed November 10, 2019, <https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#>.

<sup>2</sup> Canadian Institute for Health Information, *E-statistics Report on Transplant Waiting List and Donor Statistics*, Cumulative Report (2018), accessed November 10, 2019, <http://www.cihi.org/> Table 1A, 2A and 2B.

<sup>3</sup> It is a measure of the total number of organ donors for a given population. It can be expressed for living or deceased organ donors but in this thesis, we will only examine data for deceased donors. Even when expressed for deceased donors, the rate of dpmp can be confusing since it sometimes includes all donors, whether organs recovered were indeed transplanted, while in other instances it includes only donors whose organs have effectively been transplanted.

donors, Spain has been for years the best performer and world leader, averaging around 33-35 deceased dpmp during the early years 2000. Launched in 2007, its “40 dpmp plan” has finally allowed Spain to reach this all-time high in 2016 and to have exceeded it since then, reaching 46.9 dpmp in 2017.<sup>4</sup>

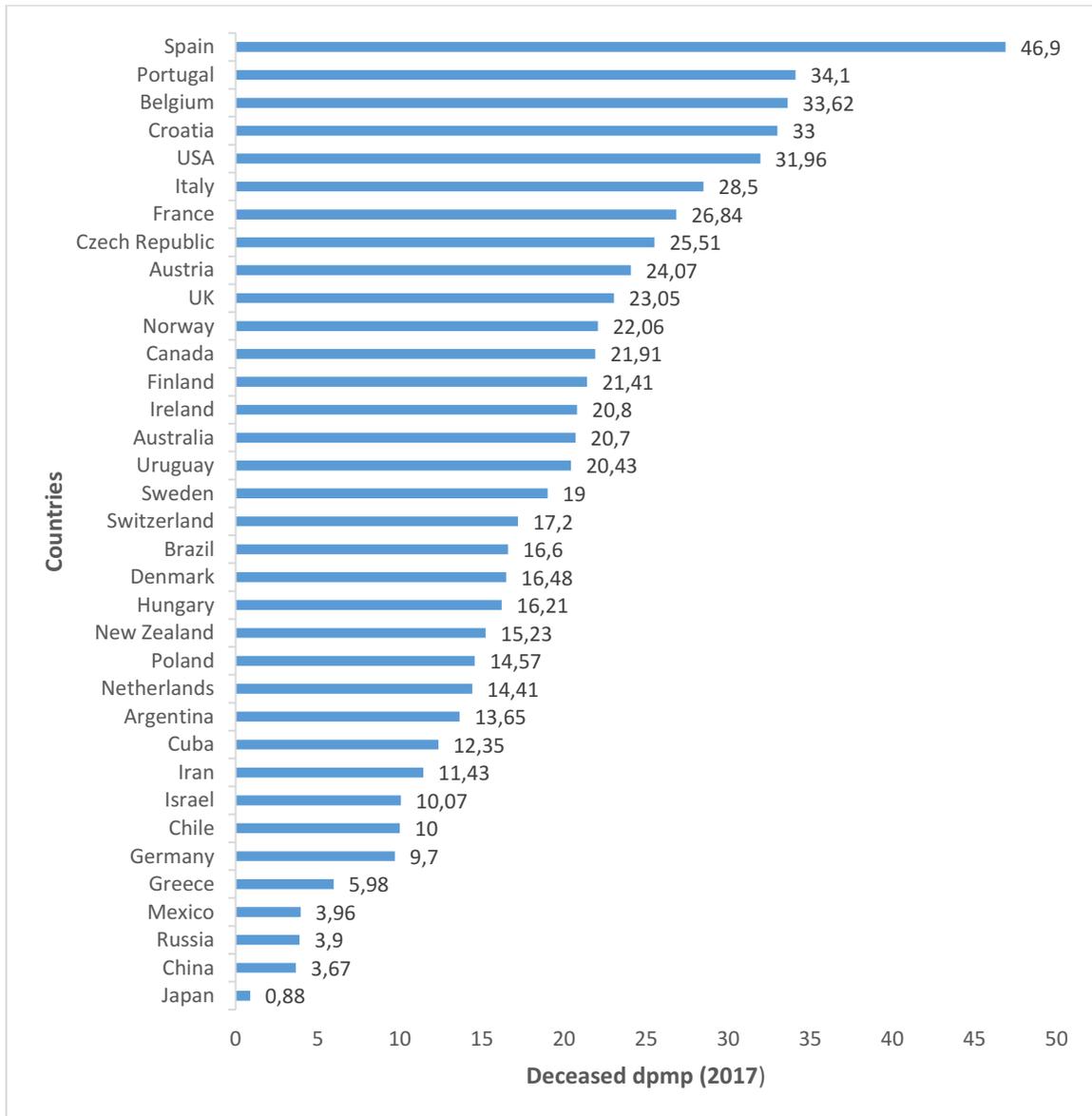


Figure 1: Deceased organ donors per million of population. Various countries, 2017

<sup>4</sup> International Registry in Organ Donation and Transplantation, 2017 database, accessed November 10, 2019, <http://www.irodat.org/?p=database>.

Various changes have been introduced around the world to facilitate both living and deceased organ donation. For years, organ donation systems have been improved through better identification of potential donors, coordination of organ referrals, best practices in obtaining family consent, public promotion of organ donation, expanding the medical criteria for donation, and more.<sup>5</sup> More recently, some countries have been pushing harder than ever to increase the number of available organs by giving various incentives to donors and their families. For example, Israel offers priority points to potential recipients who have family members who have been deceased or living organ donors, to potential recipients who have been living organ donors themselves or who are registered organ donors, and to potential recipients whose family members are registered organ donors. Iran provides monetary compensation or extended health coverage to living unrelated donors and has eliminated the waiting list for kidney transplantation.<sup>6</sup>

### Opt-In or Opt-Out Deceased Donor Systems

For deceased donors, one important issue relates to the type of system that ought to be implemented in order to get people to become an organ donor. Indeed, valid consent must be obtained for organs to be retrieved when death occurs. Therefore, many questions have been raised as to which type of consent system – and which laws and

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<sup>5</sup> Examples of such improvements have been addressed by a Taskforce on organ donation in the UK. Organ Donation Taskforce, *The Potential Impact of an Opt Out System for Organ Donation in the UK* (London: Department of Health, 2008).

<sup>6</sup> Simar Singh, “Organ Donation Programmes across the World,” *NDTV*, August 22, 2017, [online] Available at <https://sites.ndtv.com/moretogive/organ-donation-what-other-countries-are-doing-1297/>.

regulations – would better deal with the consent issue and provide the best results in organ donation.

Although laws and regulations vary in each country, most usually fall into one of the two main categories of informed (opt-in) or presumed (opt-out) consent system.<sup>7</sup> A review of the consent systems in 40 developed countries reveals that in 2009, presumed consent was predominant, being in place in 29 of them.<sup>8</sup> Nowadays, this number has increased since countries like the United Kingdom are about to move to such a system. Presumed consent countries include most European countries as well as others like Argentina and Costa Rica. Informed consent systems may be found in various countries such as the USA, Canada, Australia, and New Zealand.

Over the years, much debate has occurred as to which one of the informed or presumed consent systems is the best solution to improve organ donation. This debate usually takes place in countries with lower organ donation rates. Various studies have fuelled the debate by evaluating the impact of presumed consent systems on organ donation. Many have concluded that presumed consent increases the donation rate.<sup>9</sup> The study of Abadie and Gay included data from 22 countries and concluded that those with

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<sup>7</sup> Informed consent means that an explicit consent to organ donation has been provided by the donor during his lifetime or by his family upon death. On the opposite, presumed consent or “Opt-Out” signifies that each individual is presumed to have consented to organ donation upon death unless he expressly stated otherwise during his lifetime.

<sup>8</sup> Amber Rithalia et al., “A Systematic Review of Presumed Consent System for Deceased Organ Donation,” *Health Technology Assessment* 13, no. 26 (2009): Appendix 1. 47-53.

<sup>9</sup> Alberto Abadie and Sebastien Gay, “The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study,” *Journal of Health Economics* 25 (2006): 613. See also the review of many studies in Rithalia et al., “Systematic Review,” 26-31.

presumed consent laws had a 25-30% higher donation rates than countries with informed consent.<sup>10</sup>

Notwithstanding such positive results, the virtues of presumed consent systems remain questioned by many. Indeed, it is argued that a presumed consent system has the potential to erode trust, undermine the concept of donation and negatively impact organ donation numbers, as the UK Taskforce Report once affirmed.<sup>11</sup> The Taskforce report has been referred to in Canada to argue that the introduction of a presumed consent system was unlikely.<sup>12</sup> For opponents, such a system has limited impact on donation rates and some contend that the Canadian legal and political landscape favor instead the retention of the current opt-in system.<sup>13</sup> As can be seen, the debate is still active.

### Who Really Gives Consent to Organ Donation?

Although informed and presumed consent systems differ, they have at least one point in common: they create the same illusion. They position – or pretend to position – the individual donor at the centre of the organ donation decision’s process. In most informed consent countries, many efforts are made to get individuals to consent, during

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<sup>10</sup> Abadie and Gay, “Impact,” 610.

<sup>11</sup> Organ Donation Taskforce, *Potential Impact*, 34. It must be noted that ten years later, the UK and Scotland have followed Wales and are to introduce presumed consent systems in 2020. <https://www.organdonation.nhs.uk/uk-laws/>. However, the Taskforce Report has been referred to in Canada to argue against the introduction of a presumed consent system.

<sup>12</sup> Irene Ogradnick, “Canada Unlikely to Implement Presumed Consent Organ Donation System, Advocate Says,” *Global News*, May 25, 2012, [online] Available at <http://www.globalnews.ca/canada>. Since then, only the province of Nova Scotia has adopted a presumed consent system, which is set to be introduced in 2020. Nova Scotia, an Act Respecting Human Organ and Tissue Donation, Acts of 2019, s.15(1), accessed November 10, 2019, [https://nslegislature.ca/legc/bills/63rd\\_2nd/3rd\\_read/b133.htm](https://nslegislature.ca/legc/bills/63rd_2nd/3rd_read/b133.htm).

<sup>13</sup> Mark Ammann. “Would Presuming Consent to Organ Donation Gain Us Anything but Trouble?” *Health Law Review* 18, no. 2 (2010): 15

their lifetime, to organ donation in the event of death. Registries are set up for individuals to express their consent<sup>14</sup> or it can also be expressed through the issuance or renewal of driver licenses, health cards or donor's cards.<sup>15</sup> In presumed consent systems, it is also the donor who is presumed to consent to organ donation in the event of death. Focus is again on the individual donor and various vehicles are available to express a refusal, such as non-donor registries.<sup>16</sup>

Though each person seems to be in control of their organs' destiny, research shows, on the contrary, that donor consent is usually not enough. Indeed, the consent of the next of kin or families is not only sought for but can also prevail over the donor's wishes. In presumed consent countries, although individuals are presumed to have consented to organ donation, families must be consulted and may object to organ donation.<sup>17</sup> In informed consent countries such as Canada, families are asked to consent to organ donation, even if the donor has previously registered a decision.<sup>18</sup> Legislation is often poorly drafted and may lead to confusion. Even when legislation is more explicit, other factors such as physician practices can intervene. In the USA, legislation in many states provides that donor's consent is sufficient for organ donation ("first-person consent") and family members do not have a say when such consent has been

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<sup>14</sup> It is the case in countries such as Australia, Canada and the USA. Rithalia et al., "Systematic Review," 47-53.

<sup>15</sup> For Canada, see Kat Tancock, "Organ Donation: What You Need to Know," *Canadian Living*, September 18, 2009, [online] Available at <http://www.canadianliving.com/>.

<sup>16</sup> Rithalia et al., "Systematic Review," 47-53.

<sup>17</sup> Rithalia et al., "Systematic Review," 47-53.

<sup>18</sup> Rithalia et al., "Systematic Review," 47-53.

expressed.<sup>19</sup> But research also suggests that, in many states, this legislation is not enforced and physicians – fearing more about family reactions than about the law – choose in many instances to obtain donor family consent for organ donation.<sup>20</sup>

Because of the involvement of families, organ donation in informed consent systems may then often require a double consent, that of donors during their lifetime and that of family upon death. Some argue that both individual and family consent to organ donation should be defended – the double veto.<sup>21</sup> Others claim that such a situation is entirely unsatisfactory and contributes to organ shortages and to people dying on the waiting list.<sup>22</sup> The ELPAT Working Group on Deceased Donation of the European Society for Organ Transplantation is of the view that “enabling families to overrule

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<sup>19</sup> According to the Uniform Anatomical Gift Act (1987), the donor’s decision to donate was irrevocable and no consent is needed from others after death. Due to the fact that common practices were to ask family for consent, the law was revised and section 8(a) of the Revised Uniform Anatomical Gift Act (2006) now provides that families do not have the power to consent, amend or revoke donation made by donors during their lifetime. The National Conference of Commissioners on Uniform State Laws, “Revised Anatomical Gift Act (2006).” Uniform Law Commission. Accessed November 10, 2019. <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=6705441e-40b7-fbd4-edd5-5748c63fbd79&forceDialog=0>.

<sup>20</sup> Dave Wendler and Neal Dickert, “The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?” *JAMA* 285, no. 3 (2001): 329-333. This study of the organ donation process used by 61 Organ Procurement Agencies in the United States revealed that 31% of them follow the next of kin’s wishes and 21% procure organs only if neither party objects. 48% of respondents ranked the impact on the deceased’s family as the most important factor for organ procurement and only 21% ranked state law as being the most important factor. It remains to be evaluated how physicians’ attitudes have changed since 2009, when the Revised Uniformed Anatomical Gift Act (2006) was adopted. But there is at least one circumstance when the family decision to overrule the wishes of their son to donate his organs was successfully challenged in courts. Manning, Allison. “Family Loses Fight to Keep Son’s Organ from Donation,” *Columbus Dispatch*. Updated July 12, 2013. <https://www.dispatch.com/content/stories/local/2013/07/11/Judge-ordered-family-to-let-brain-dead-son-donate-organs.html>.

<sup>21</sup> T. M. Wilkinson, “Individual and Family Consent to Organ and Tissue Donation: Is the Current Position Coherent?” *Journal of Medical Ethics* 31 (2005): 587-590.

<sup>22</sup> Antonia J. Cronin, “Transplants Save Lives, Defending the Double Veto Does Not: A Reply to Wilkinson,” *Journal of Medical Ethics* 33 (2007): 219-220.

disrespects the wishes of the deceased, can be regretted by families, and contributes to avoidable death and suffering.”<sup>23</sup> Still, others believe that

Many have claimed that “the greatest impediment to organ donation is refusal of family consent.”<sup>24</sup> Among the studies supporting this view, “a 1995 study of families of donor-eligible patients found that 86.5% were asked to donate but only 47.3% gave consent. Other studies have confirmed these findings.”<sup>25</sup> In the UK, it was concluded that “family involvement can affect donation rates. In 2006 in the UK the family refusal rate was 41%...”<sup>26</sup> In 2011-2012, it was shown to be 36%.<sup>27</sup>

Specific data on double consent are also starting to be available. It reveals that in the UK, in 2014-2015, “120 families (12% of approaches) overruled donation from a patient who was a registered donor.”<sup>28</sup> In 2014, in the Netherlands, “families refused organ donation in 6% (11/175) of cases when consent was registered in the DR.”<sup>29</sup>

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<sup>23</sup> D. Shaw et al., “Family over Rules? An Ethical Analysis of Allowing Families to Overrule Donation Intentions,” *Transplantation* 101, no. 3 (March 2017): 485.

<sup>24</sup> Steven L. Gortmaker et al., “Improving the Request Process to Increase Family Consent on Organ Donation,” *Journal of Transplant Coordination* 8, no. 4 (1998): 210.

<sup>25</sup> Laura A. Siminoff, “Factors Influencing Families’ Consent for Donation of Solid Organs for Transplantation,” *JAMA* 286, no. 1 (2001): 71.

<sup>26</sup> Rithalia et al., “Systematic Review,” 3.

<sup>27</sup> Tom Hayes, “Donation and Devolution: The Human Transplantation (Wales) Act 2013,” in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 143.

<sup>28</sup> Shaw et al., “Family over Rules,” 482. Also, National Health Service Blood and Transplant, *Annual Activity Report 2014–15*, accessed November 10, 2019, [http://nhsbtmediaservices.blob.core.windows.net/organdonation-assets/pdfs/activity\\_report\\_2014\\_15.pdf](http://nhsbtmediaservices.blob.core.windows.net/organdonation-assets/pdfs/activity_report_2014_15.pdf). Published 2015.

<sup>29</sup> Shaw et al., “Family over Rules,” 483. Also, Dutch Transplant Foundation, Annual report 2014, Leiden, The Netherlands 2015; in Dutch. Accessed November 10, 2019. [https://www.eurotransplant.org/cms/mediaobject.php?file=ar\\_2014.pdf](https://www.eurotransplant.org/cms/mediaobject.php?file=ar_2014.pdf).

Many efforts have been made to understand why families refuse to consent to organ donation. Such efforts have been explained as being of the utmost importance in informed consent countries since while “it is acknowledged that ascertaining the views of the potential donor are important, ultimately it is for the relatives to authorize donation in most cases.”<sup>30</sup> Reasons invoked by families to oppose consent have been scrutinized and have revealed concerns over disfigurement of the body, feelings that the deceased had suffered enough, difficulty in accepting the death, lack of understanding of brain death, concerns over delaying of funerals and more.<sup>31</sup>

Over the years, some have introduced new ways to approach families during this emotionally distressing time by separating the process of information, deliberation and agreement about the retrieval of a potential donor's organs.<sup>32</sup> Others have examined predictors of family decision to consent or refuse donation and there is an overall conclusion that individuals should discuss their wishes with family.<sup>33</sup>

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<sup>30</sup> A. Vincent and L. Logan, “Consent for Organ Donation,” *British Journal of Anaesthesia* 108 (2012), suppl.1: i81.

<sup>31</sup> Vincent and Logan, “Consent for Organ Donation,” i81.

<sup>32</sup> J. De Wispelaere and Lindsay Stirton, “Advanced Commitment: An Alternative Approach to the Family Veto Problem in Organ Procurement,” *Journal of Medical Ethics* 36, no. 3 (March 2010): 180-183.

<sup>33</sup> Thomas E. Burroughs et al., “The Stability of Family Decisions to Consent or Refuse Organ Donation: Would You Do It Again?” *Psychosomatic Medicine* 60 (1998): 156-162.

## Chapter II.

### The Current Situation in the Province of Québec

The province of Québec has been a leader in organ transplantation in Canada. Although the first successful kidney transplants occurred in Europe and the United States in the early 1950's, Canada's first successful kidney transplant between identical twins was achieved in 1958 by Dr. John Dossetor, at the Royal Victoria Hospital in Montréal. In 1963, the first kidney transplant between individuals who were not identical twins was performed at the same hospital.<sup>34</sup>

In 1964, following the death of a young Montréal architect, his family founded the Kidney Disease Foundation of Canada. In 1965 the first lung transplant was attempted at the Montreal General Hospital.<sup>35</sup> Fewer than 6 months after the first heart transplant occurred in Africa, Dr. Pierre Grondin performed Canada's first heart transplant in Montréal in May 1968 and the city was the site of the first liver transplant in Canada in 1970.<sup>36</sup> Organ transplantation then slowed down worldwide because of problems associated with organ rejection in recipients leading to graft loss and in some cases the patient's death. After the discovery of the immunosuppressive drug

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<sup>34</sup> "History of Transplantation in Canada," The Kidney Foundation of Canada – Saskatchewan, accessed November 10, 2019, <https://www.kidney.ca/page.aspx?pid=645>.

<sup>35</sup> "Background," Transplant Québec, accessed November 10, 2019, <https://www.Transplantquebec.ca/en/mission>.

<sup>36</sup> "Il y a 50 ans : Une première greffe cardiaque au Canada," Radio-Canada, *Info*, May 28, 2018, <https://ici.radio-canada.ca/nouvelle/1103120/greffe-coeur-transplantation-institut-cardiologie-montreal-histoire-canada-archives>.

cyclosporine in the early 1980s, there was a marked increase in the number and success of organ transplants.

With the beginning of organ transplantation in the 1960s, concern arose with the attribution of kidneys to potential recipients and in 1970, three transplant surgeons from Montréal co-founded a non-profit organization called Métro-transplantation in order to set attribution rules. With time, the mandate of this body evolved along with the organization of regional centers for organ transplantation and organ donation and the collection of statistics on organ donation.<sup>37</sup> 1984, Métro-Transplantation started to be financed by the ministry of Health and Social Services and later changed its name several times and is known today as Transplant Québec. The mission of Transplant Québec includes the coordination of the organ donation process leading to transplantation, the fair allocation of organs, as well as the promotion of organ donation. A different body called Héma-Québec has been doing the same for tissues.

### The Consent System of Québec

Like most donation systems in North America, the province of Québec relies on an informed consent system where potential donors are asked to consent to organ donation before death. This reality reflects our legal system, which upholds the full autonomy of individuals over their bodies, even after death. This legal principle first originates from section 22 of the Civil Code of Lower Canada, which was adopted in 1971 and repealed in 1994. It read as follows :

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<sup>37</sup> “Background,” Transplant Québec.

**Section 22.** A physician may remove a part of the remains, if in the absence of instructions by the deceased, he obtains the consent of the consort or nearest relative of the deceased.

This consent is not necessary when two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation, and the serious hope of saving a human life.

The death of the donor must be ascertained by two physicians who do not participate in any way in the removal or in the transplantation.

This section of the Code was relied on for years to confirm the right of a person to give instructions for the removal of parts of their body after death. However, in 1994, following a complete recodification of the code, section 22 was replaced by sections 43 and 44 of the Civil Code of Québec, which better recognizes the autonomy of individuals to express their wishes.<sup>38</sup>

**43.** A person of full age or a minor 14 years of age or over may, for medical or scientific purposes, give his body or authorize the removal of organs or tissues therefrom. A minor under 14 years of age may also do so with the consent of the person having parental authority or of his tutor.

These wishes are expressed verbally before two witnesses, or in writing, and may be revoked in the same manner. The wishes expressed shall be followed, unless there is a compelling reason not to do so.

**44.** A part of the body of a deceased person may be removed, if the wishes of the deceased are not known or cannot be presumed, with the consent of the person who was or would have been qualified to give consent to care.

Consent is not required where two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation and the serious hope of saving a human life or of improving its quality to an appreciable degree.

We will further review the “compelling exception” of section 43 in chapter 4. For now, suffice it to say that unless there is a compelling reason not to do so, it is

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<sup>38</sup> Civil Code of Québec, CQLR, c. CCQ-1991, s. 43 and 44.

unambiguous, from a legal standpoint, that the wishes of a deceased must be followed in Québec.<sup>39</sup>

On this basis, many efforts have been made throughout the years to identify the wishes of Quebecers and promote organ donation. First, in 2005, the *Chambre des Notaires du Québec*<sup>40</sup> set up a registry allowing a person to register either a consent or a refusal to authorize the removal of organs upon death. Although this registration is free, it is, however, associated with the execution by a notary of a will or a mandate in case of incapacity, which implies various fees for the person concerned.

Second, in order to better register the wishes of Quebecers and facilitate organ donation, bill 197 was adopted in 2006 by the National Assembly of Québec. This bill provided that when Québec residents were applying to the Régie de l'Assurance Maladie du Québec (RAMQ)<sup>41</sup> for registration, the renewal of registration or the replacement of an health insurance card, they “must indicate in writing if they consent to the removal of organs or tissues for transplantation, do not consent to it or are not ready to make that decision at that time.” The bill also required the RAMQ to record such wishes and allowed a person to consent or revoke their consent verbally or in writing at any time. It

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<sup>39</sup> The review of case law does not provide assistance, as there are no court decisions on what could be seen as a compelling reason.

<sup>40</sup> The *Chambre des Notaires* is a professional order regrouping all notaries practicing in Québec. Like all other professional orders, it has a mission of protecting the public by developing and maintaining the quality and credibility of the notarial practice.

<sup>41</sup> The Régie de l'Assurance Maladie du Québec is the public body having for mission to apply the *Health Insurance Act*. As such, it has the main responsibility of ensuring the remuneration of many health professionals such as physicians but also has other functions such as administering the registry of organ donors.

is interesting to note that this bill insisted again on the principle that the wishes of the donor had to be followed.<sup>42</sup>

Third, in 2010, another bill was adopted to facilitate consent for potential organ donation. Bill 125 replaced bill 197 of 2006 and required the RAMQ to establish and update a consent registry for *post-mortem* removal of organs and tissues, thereby eliminating the requirement to record refusals or indecisiveness of Québec residents, as the 2006 bill provided. The reasons for such a reversal are unclear and may be related to the administrative burden conferred on the RAMQ. But this policy was adopted by the province, notwithstanding the objection of the Chambre des Notaires du Québec which instead supported a registry for both consent and refusal and a merger between its registry and the one to be set up by the RAMQ. It is interesting to note that bill 125 was presented only a month after the filing of a petition by a deputy of an opposition party that called for the establishment of a presumed consent system in Québec.<sup>43</sup> The government's decision to adopt Bill 125 can therefore be seen, then, not only as a rejection of a presumed system of consent but also as a means to better facilitate consent rather than refusals.<sup>44</sup>

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<sup>42</sup> Indeed, a new section 9.1 was added to the Health Insurance Act stipulating that “users are entitled to consent or to refuse to consent to the removal of organs or tissues from their body for transplantation and to have their wishes followed in accordance with the Civil Code of Québec (1991, chapter 64).”

<sup>43</sup> This petition was launched in 2010 and another one followed in 2014. See “Pétition: Don d’organes,” Assemblée Nationale du Québec, 2010, at <https://www.assnat.qc.ca/fr/exprimez-votre-opinion/petition/Petition-411/index.html> and the 2014 petition at “Pétition: Consentement au don d’organes,” Assemblée Nationale du Québec, 2014, accessed at <https://www.assnat.qc.ca/fr/exprimez-votre-opinion/petition/Petition-4577/index.html>.

<sup>44</sup> Recently, on October 8, 2019, a new petition was launched in the National Assembly of Québec, by a deputy from the actual CAQ government, for the introduction of a presumed consent system. See “Pétition : Adoption d’un modèle du “consentement présumé” en matière de don d’organes et de tissus,” Assemblée Nationale du Québec, 2019, accessed at <https://www.assnat.qc.ca/fr/exprimez-votre-opinion/petition/Petition-8073/index.html>. This petition can be signed up to January 8, 2020. It remains to

Hence, since 2010, there are three ways for Quebecers to make their wishes known for *post-mortem* organ donation. First, consent to donate may be registered in the registry set up by the RAMQ (hereinafter the RAMQ registry). Consent can be revoked at any time thereafter. Second, a potential donor can sign a sticker authorizing the removal of organs and tissues upon death and apply this sticker to the health insurance card. The sticker is sent to all Quebecers along with their health-insurance card at renewal time or can be obtained from many health-care institutions. Third, one can have their decision recorded in the Consent Register for Organ and Tissue Donations of the Chambre des Notaires du Québec (hereinafter the CNQ registry).

As shown in Figure 2, registrations in both the RAMQ registry and the CNQ registry have been increasing constantly since their inception. Indeed, in the last 6 years, the number of registrations in the CNQ registry has more than doubled while the number in the RAMQ registry has quadrupled.<sup>45</sup>

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be seen how the government will react to this petition since it is from the same political party who presented the 2010 petition. The government's position will soon be learned of since Bill 399, calling for the introduction of a presumed consent system, has been presented at the National Assembly on November 6, 2019, this time by a deputy of the Liberal party opposition. Mathieu Dion, "Dons d'organes : Les libéraux veulent légiférer sur le consentement automatique," Radio-Canada, *Info*, November 3rd, 2019, <https://ici.radio-canada.ca/nouvelle/1373624/parti-liberal-projet-loi-dons-organes-consentement-automatique>; Leah Henly, "It's a Shame, He Could Have Saved Lives : How Québec Could Make Sure More People Donate Organs," *CBC News*, November 14, 2019 <https://www.google.ca/amp/s/www.cbc.ca/amp/1.5358310>.

<sup>45</sup> The evolution of registrations was based on information included in Transplant Québec Annual Reports as well as information provided by the Chambre des Notaires du Québec.

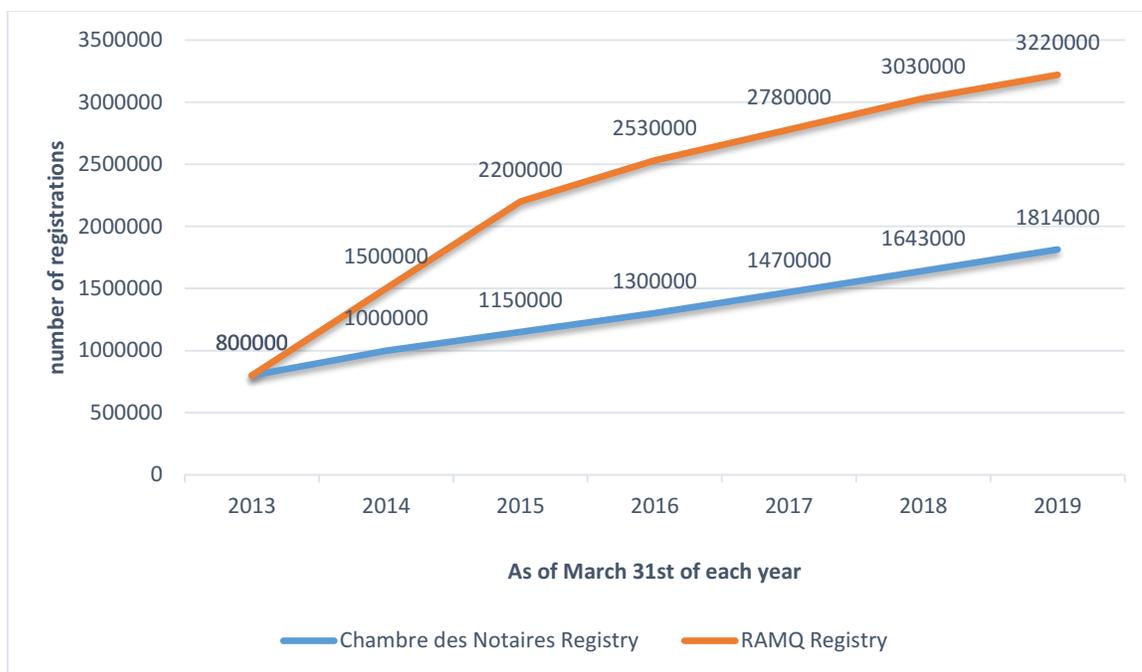


Figure 2: Individual registrations in both organ donor registries (2013 to 2018)

As of March 31, 2019, and out of a population of 8 million, 3.2 million persons had registered their consent in the RAMQ registry. More than 1.8 million had done so in the registry of the CNQ registry, out of which 85% consented and 15% refused to donate an organ.<sup>46</sup> It is not possible to know the extent to which these two registries duplicate the same donors or add some, and there is also no statistics on the number of donors who applied the sticker on their health insurance card. Notwithstanding, Transplant Québec estimates that more than 40% of Quebecers have consented to become potential organ donors.<sup>47</sup>

<sup>46</sup> Contrary to the RAMQ registry which is updated regularly and from which all deceased are removed, the CNQ registry is a sum of all registrations being made year after year and an individual may be counted more than once if such an individual has registered his wishes in more than one notarized document.

<sup>47</sup> Transplant Québec, 2016-2017 Annual Report, 3.

According to Transplant Québec and similarly to what occurs in countries worldwide, the province of Québec faces a shortage of available organs to meet demand. Transplant Québec has been collecting data on organ donation for a few years and its 2018-2019 Annual Report reveals that Transplant Québec has coordinated 755 referrals of potential organ donors, its best year ever, resulting in a total of 164 deceased organ donors, for a rate of 19.5 dpmp.<sup>48</sup> Although 451 persons received an organ transplant, 805 remain on the waiting list and 28 have died while waiting for an organ.

At a time when many countries feel that the shortage of available organs is increasing every year, the situation projected in Québec is described as positive. Indeed, the increase in the registration of potential donors as well as the increase of persons receiving an organ transplantation allows Transplant Québec to project a constant diminution in the number of persons waiting for a transplant and that the year 2021 should see less people waiting for a transplant than people actually transplanted. Although such projection is of great interest, it shows that supply will nevertheless not meet demand. People will continue to die while on the waiting list, which is why many efforts remain to be made to increase organ donation and save more lives. We will better review these projections and the situation in Québec in the next chapter.

### The Confusing Role of Families

Transplant Québec reports also reveal troubling information on organ donation referrals which end up being rejected because of family refusals. In 2018, 198 organ

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<sup>48</sup> Transplant Québec, 2018-2019 Annual Report, 12.

referrals were rejected because of family objections, which is 26% of all referrals.<sup>49</sup>

Considering that most Quebecers surveyed confirmed their intention to donate their organs upon death and that more than 40% of them have registered their consent, such a rate of family refusals seems surprising at the most.

Although many explanations can be given for such refusals, the confusion on the role of families and the negation of the donor's paramount authority for making such a decision certainly contribute to this rate of refusal. There is indeed some confusion as to the role of families in organ donation. As mentioned earlier, the law of the province, as it stood before and as it was later modified, clearly states the principle that a donor's decision must be followed. Bill 125, which introduced Section 2.0.9<sup>50</sup> and a consent form for people willing to register their consent with the RAMQ, indicates that by doing so, people are informed that "consent will be acted upon."<sup>51</sup>

Although the law is clear that a donor's wishes are paramount, the information published contributes to the confusion on the value of a donor's consent and the role of families. Some sources of information confirm the rule set out by the law. Such is the case with the website of the Chambre des Notaires du Québec, which informs potential donors about the Consent Registry for Organ and Tissue Donations of the Chambre des Notaires du Québec and affirms that "thanks to this registry, everyone has the assurance that their wishes will be respected."<sup>52</sup> The website of the ministry of Health and Social

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<sup>49</sup> Transplant Québec, 2018-2019 Annual Report, 3.

<sup>50</sup> Québec, an Act Respecting the Régie de l'Assurance Maladie du Québec, CQLR c. R-5.

<sup>51</sup> Québec, an Act to Facilitate Organ and Tissue Donation (Statutes of Québec, 2010, c. 38).

<sup>52</sup> "Can a Decision Related to Organ and Tissue Donation be Recorded in a Notarized Deed," Chambre des notaires du Québec, accessed November 10, 2019, <http://www.cmq.org/en/registers-testamentary-mandates-search.html>.

services also contains the following indication: “Discuss your wishes with your family. They must respect your wishes.”<sup>53</sup>

On the other hand, other sources of information question this principle or deny it. For example, on the Services Québec website, the Québec Portal, potential donors are informed that “If you want to donate your organs, it is important to inform the members of your family of your decision to ensure that your wishes are respected after your death,”<sup>54</sup> thereby clearly insinuating that families could override their decision. The same is true for Educaloi, a registered charity founded with the mission of explaining the law to Quebecers in everyday language. In answering the specific question, “What if I sign my organ donor card?” the answer provided reveals that “Your signature on an organ donor card lets your relatives know your wishes. The law says that a person's expressed wishes must be carried out unless there is a very serious reason not to do so. To avoid confusion, discuss your wishes about organ donation with your family,” showing again that the donor's wishes serve more as an indicator of its intentions, but that the decision rests with the family.<sup>55</sup>

Although confusion persists in government and other materials, the reality in hospital wards and operating rooms is, however, limpid. It reveals that families are

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<sup>53</sup> Ministry of Health and Social Services, accessed May 3, 2018, <http://www.signezdon.gouv.qc.ca/index.php?informer-vos-proches-en>.

<sup>54</sup> “Organ Donation after Death,” Services Québec – Citizens, accessed May 13, 2018, <http://www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/deces/Pages/don-organes.aspx> (accessed May 13, 2018).

<sup>55</sup> “Donating Part of the Human Body,” Éducaloi, accessed November 10, 2019 <https://www.educaloi.qc.ca/en/capsules/donating-part-human-body> (accessed May 13, 2018).

always asked to consent to organ donation and that organs are not retrieved without their consent, even if the donor has previously expressed his consent or registered it.

As far as physicians are concerned, such a practice can be explained by the fear of acting against a family decision which could then have a negative impact on the perception of the organ donation process and more generally on organ transplantation. Also, or as an excuse, some would argue that the law is not as clear as it sounds and leads to confusion as well. It is therefore recalled that the wishes of a donor must be followed “except for a compelling reason.”<sup>56</sup> Such a wording makes some physicians believe that they must consult with the family before retrieving organs.<sup>57</sup>

On an administrative or operational standpoint, it is also clear that the decision of the family prevails over that of the donor. Indeed, all organ retrievals need to be authorized by a member of the family of the deceased or a member who shows a “particular interest” for the deceased. All appropriate organ donation forms to be completed therefore require the signature of the family.<sup>58</sup>

Transplant Québec’s protocols also provide for such authorization to be obtained from family and no referrals of potential donors will be considered unless such approval is confirmed. Indeed, Transplant Québec procedures requires all organ donation teams to discuss with the family and obtain their decision on organ donation, whether the wishes

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<sup>56</sup> Civil Code of Québec, CQLR c. CCQ-1991, s.43.

<sup>57</sup> Commission de l’Éthique de la Science et de la Technologie, *Le Don et la Transplantation d’Organes: Dilemmes Éthiques en Contexte de Pénurie* (Québec : Bibliothèque Nationale du Québec, 2004), 11.

<sup>58</sup> Form AH-224A, which applies to all Québec hospitals, must be signed by the family for any Donation by neurological death and it is the same for form LEG-FOR-003.F which applies for any organ donation after cardiocirculatory death.

of the donors are known or unknown. A donor's wishes therefore serve to inform and help convince family to go along with these wishes but will not be enforced unless the family agrees.<sup>59</sup>

This reality therefore amounts to what the literature refers to as the double consent or the double veto, whereby family must consent to organ donation even when a donor has already registered such a consent. As such, it raises the question of the impact of family involvement on consent to organ in Québec.

No data has been compiled before in Québec about the double consent issue and more specifically on the number of cases where family decisions overrode the wishes of the deceased. Gathering and analysing information on the impact of families on consent to organ donation is necessary not only to better appreciate their impact but also the overall compliance and efficiency of the organ donation system in Québec. With a new provincial government elected in 2018 and at a time when proponents of a presumed consent system are again insisting on such a change, such an analysis is now essential.

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<sup>59</sup> "Pronostic and Donation Offer," Transplant Québec, accessed November 10, 2019, <http://www.transplantquebec.ca/pronostic-et-option-du-don>.

### Chapter III.

#### The Impact of Family Refusals to Consent to Organ Donation in Québec

As mentioned in Chapter 2, Transplant Québec portrays a positive picture of the situation of organ donation and transplantation in Québec and forecast that by 2021, the number of persons receiving a transplant should exceed the number of persons on the waiting list.<sup>60</sup> Transplant Québec’s action plan for the period of 2016-2021 targets a level of 25 dpmp by 2021, which would result in 205 effective deceased donors and 650 persons receiving an organ transplant (from living or deceased donors).<sup>61</sup>

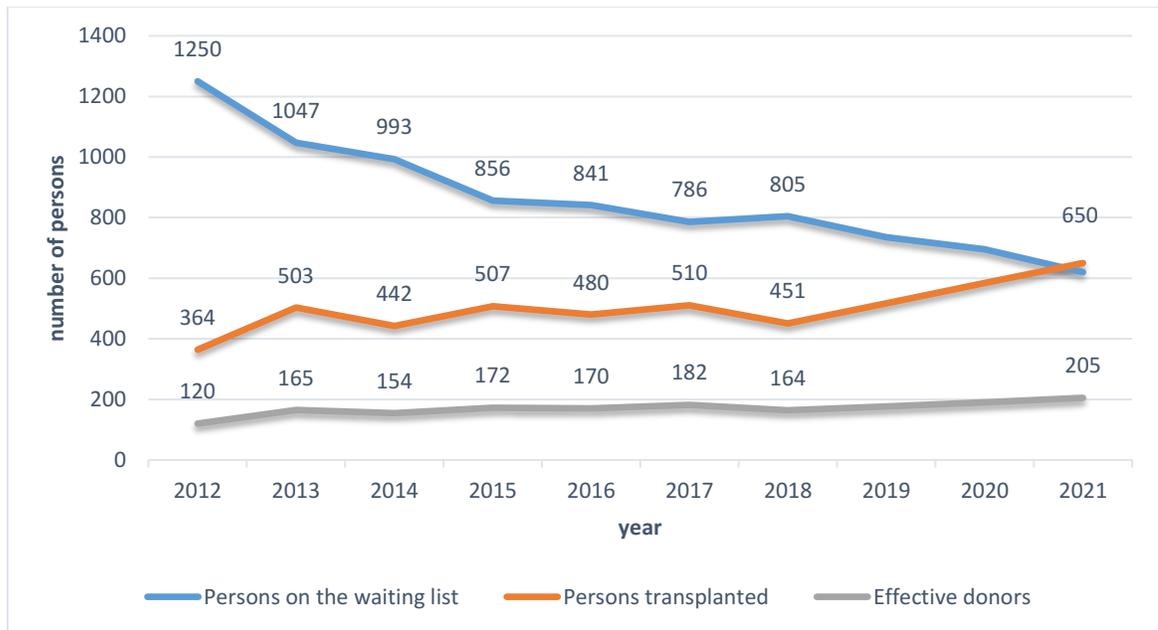


Figure 3: Effective organ donors, persons transplanted and persons waiting for an organ in Québec (2012-2018 and forecast to 2021)

<sup>60</sup> The situation since 2012 is a clear turn of event. Ten years ago, in the 2009-2010 Annual Report, Transplant Québec indicated that the number of persons waiting for a transplant, as of December 31<sup>st</sup>, 2008, had doubled from the previous 10 years, reaching a high of 1202 persons, and was constantly increasing. Transplant Québec, 2009-2010 Annual Report, 16.

<sup>61</sup> Transplant Québec, 2018-2019 Annual Report, 1.

As much as Transplant Québec's projections are encouraging and illustrate that the number of donor referrals is constantly on the rise, two points need to be raised. First, projections are what they are: only projections. Although they seem encouraging, it must be pointed out that these projections were first made by Transplant Québec in its 2016-2017 Annual Report and have already been adjusted downwards. Two years ago, they were based on a trend of constant increases in the number of effective donors whereas the year 2018 revealed instead a decrease from 182 to 164 effective donors. Transplant Québec also projected an increase in the number of persons transplanted whereas the year 2018 showed again a decrease from the year before, from 510 to 451. Also, the number of persons waiting for a transplant has increased from 786 to 805 in 2018, although Transplant Québec had projected a constant decrease before. Even the rate of deceased dpmp for Québec has fallen under the Canadian average, going from 21.7 to 19.5, with a Canadian average at 20.6 dpmp. At first glance, it appears that the main positive data standing out from the results of 2018 is an all-time high in the number of organ referrals, which increased from 664 in 2017 to 755 in 2018, and a decrease in the number of persons who died while on the waiting list, this number going from 54 in 2017 to 28 in 2018, as shown by Figure 4.<sup>62</sup>

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<sup>62</sup> Transplant Québec, 2018-2019 Annual Report, 13.



Figure 4: People dying while on the waiting list (2008-2018)

The 2018 results made Transplant Québec revise its forecast for 2021, aiming for a total of 205 effective donors instead than the 220 projected and for 650 persons to be transplanted instead than the initial 700 predicted.<sup>63</sup> Notwithstanding, Transplant Québec maintains its forecast that by 2021, the number of persons transplanted should exceed the number of persons waiting for a transplant. These projections continue to be justified by a suppose trend, but which seems more difficult to defend, except with respect to the increase in referrals. Such projections are therefore uncertain to say the least.<sup>64</sup>

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<sup>63</sup> Transplant Québec, 2016-2017 Annual Report, 1.

<sup>64</sup> Also, we don't know if the decrease in the number of persons waiting for a transplant is a result of the increase in the number of persons transplanted or is mainly attributable to a diminution in the number of persons being added to the list each year, since Transplant Québec does not release such information. However, the annual reports reveal that the average number of organs transplanted from each effective donor has remained the same at 3,28 organs per donor. Transplant Québec, 2017-2018 Annual Report, 13 and 2018-2019 Annual Report, 13.

Second, one cannot escape from noticing that the increase in the number of refusals and cancellations is as much, and even greater, than the increase in the number of referrals. As a result, although the efforts made by Transplant Québec to improve organ donation may have allowed an increase of referrals, Figure 5 reveals that the number of effective donors grows at a much a lesser rate than the number of referrals.

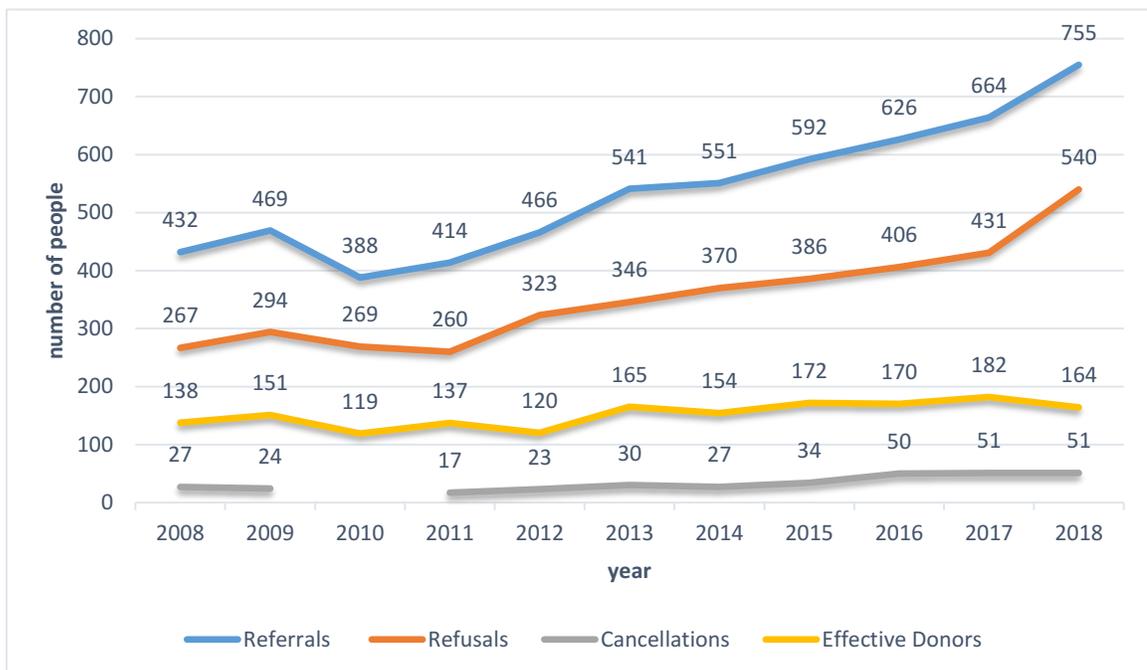


Figure 5: Number of organ donation referrals coordinated by transplant Québec and number of refusals, cancellations and effective organ donors in Québec (2008-2017)

Indeed, from 2008 to 2018, the number of referrals rose from 469 to 755, an increase of 61%. During the same period, the total number of refusals and cancellations

however increased by 86%, from 318 (294 refusals and 24 cancellations) to 591 (540 refusals and 51 cancellations).<sup>65</sup>

As a result, the important increase in the number of organ referrals has not contributed to much of an increase in the number of effective donors, the latter going from 151 in 2008 to 164 in 2018, an increase of only 8%. In 2018, 22% of all referrals resulted in an effective donor while this rate was 32% ten years before, in 2008.<sup>66</sup> Such a result is not only disappointing but particularly surprising when we consider that in the last years, awareness campaigns for organ donation had a tremendous success and the number of people registering their consent has multiplied, as shown by Figure 2.

Trying to better understand the reasons behind the slight increase in the number of effective donors is therefore essential to improve organ donation in Québec. In this regard, a closer look at the impact of families is revealing. We proposed to review this impact over two periods. First, as it stood in 2008 and then, as it evolved afterward, up to 2018.

### Family Refusals in 2008

In this section, we will first draw a picture of family refusals to consent to organ donation back in 2008. To better understand these refusals, we will examine a study conducted at the time on the reasons given by families for their refusals. We will also

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<sup>65</sup> Transplant Québec, 2018-2019 Annual Report, 5 and 12. Over a five years span, from 2014 to 2018, the increase in referrals is 37% compared to an increase of 49% in refusals and cancellations. For 2018 only, the increase in referrals is 14% compared to an increase of 23% for refusals and cancellations.

<sup>66</sup> Even when starting from 2010, the lowest year in the number of referrals and effective donors, the increase in effective donors is 38%, from 119 to 164, compared to an increase of 82% for referrals.

briefly review efforts undertaken by Transplant Québec since that time in order to improve family consents.

As shown in Figure 5, out of 432 organ donation referrals coordinated by Transplant Québec in 2008, 267 were refused for various reasons, which is 62% of all referrals. Transplant Québec's annual reports reveal general information on the motives for the refusals of organ donation referrals.<sup>67</sup> In 2008 such reasons were divided into 4 categories.<sup>68</sup>

1. Family refusals.
2. Unconfirmed neurological death.
3. Medical history, Heart failure, Transmitted diseases.
4. Hemodynamic instability, coroner refusals and other refusals.

The information published indicates that 94 refusals (32% of all refusals) were attributable to family decisions. As shown in Figure 6, family refusals represented, in 2008, the most common reason for refusals.

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<sup>67</sup> Such information is available in the annual reports, but only for refusals and not for cancellations. The difference between the two is that in the latter case, the process of donation has started and the donor has been identified as a potential donor. Cancellations are usually attributable to medical conditions but may also arise when a family changes its decision and refuses to donate. As we will see later, family refusals will be examined and considered only in the context of refusals and not cancellations.

<sup>68</sup> Transplant Québec, 2008-2009 Annual Report, 8.

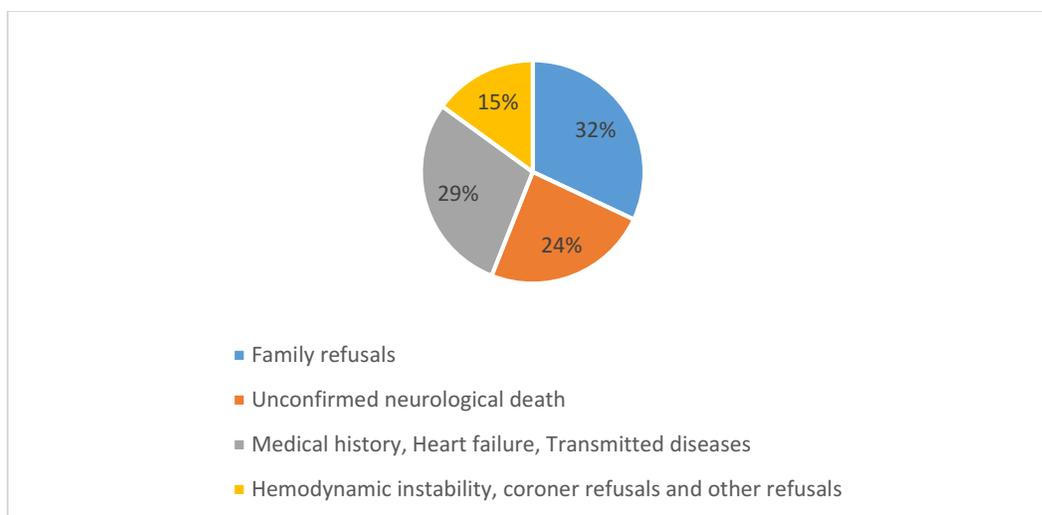


Figure 6: Reasons for the refusals of organ donation referrals (2008)

Transplant Québec’s annual reports do not offer more explanation on the reasons invoked by families to refuse organ donation.<sup>69</sup> However, in 2007, a study was conducted to draw a picture of family refusals in Québec.<sup>70</sup> In this study, 103 cases of family refusals were scrutinized in 11 hospital centers more strategically involved in organ donation. Various data were collected such as the type of approach used to address the issue of organ donation with families (where, when and how) as well as the reasons for family to refuse to donate.

The study found that when the wishes of the deceased were unknown, the decision for family to refuse was explained by reasons associated with themselves and not with the deceased. As shown in Figure 7, 41.2% of family refusals were based on

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<sup>69</sup> Although not being explained in the annual reports, this reason of unconfirmed neurological death is probably attributable to the delays associated with the criteria of neurological death to be met and families not wanting to wait any longer.

<sup>70</sup> Dana Baran, Stephan Langevin, and Carole Lebeau, “Organ Donation. Portrait of Refusal in Québec Families,” *Perspective infirmière* 6 (October 2009): 20-1.

their personal wishes and not those of the deceased compared to 36% of the cases for which family refusals reflected the personal wishes of the deceased. Also, 18% of refusals were explained by the criteria of neurological death and the fact that families did not want to wait for these criteria to be met or didn't want to wait any longer. In 4% of the cases, the reasons to refuse were unknown.

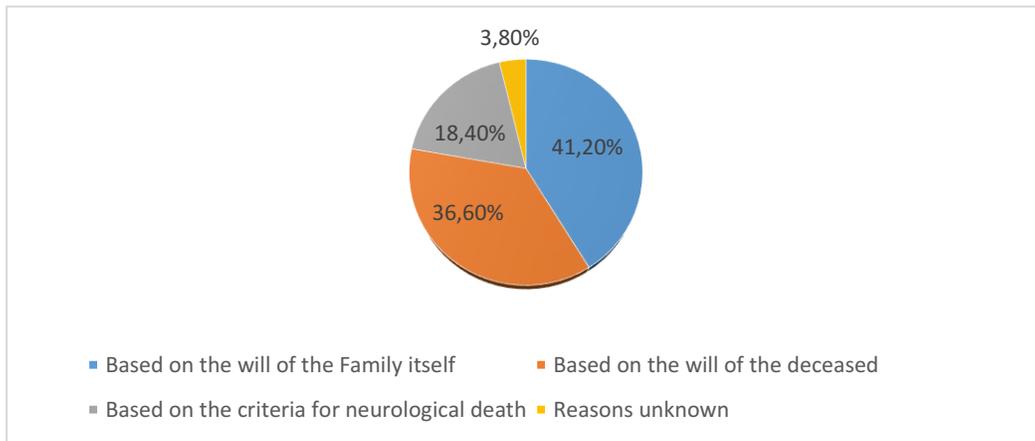


Figure 7: 2007 Study: Reasons for family refusals to consent to organ donation

Reasons associated with the deceased were explained either by their known wishes not to consent to organ donation or their wishes not to be artificially maintained in life. For family refusals associated with their own wishes, the 41.2% of refusals is distributed as follows:

- 14.5% felt uncomfortable making this decision for the deceased.
- 13% objected for contextual, personal or family related reasons.
- 8.4% objected for cultural or religious reasons.

- 5.3% objected because of problems associated with the difficulty to accept the loss of a loved one.

Respondents considered in the study were mainly Caucasians and 44% were the spouse of the deceased. The deceased were generally over 40 years of age and had died of a stroke in slightly more than half of the cases.

Among its conclusions, the study emphasized the fact that a large proportion of refusals were connected to the known or unknown wishes of the donor, thereby stressing the importance to better raise and reinforce public awareness on organ donation.

Because of the impact of families on organ donation, Transplant Québec made various efforts throughout the years to raise awareness among the population, to stress the importance for donors to make their wishes known to their families and to improve the support and approach to families in order to facilitate their consent. Among its various efforts, the following ones can be withdrawn from Transplant Québec's annual reports:

- Multiple awareness campaigns, local community interventions and publications throughout the years to convince donors to register their consent and make their wishes known to their families since according to Transplant Québec, experience demonstrates that family consent is facilitated when the donor wishes are known;<sup>71</sup>
- Specific awareness campaign during the National Week on Organ Donation, in April of each year.
- Annual ceremonies of acknowledgement for families of donors.<sup>72</sup>

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<sup>71</sup> Transplant Québec, 2009-2010 Annual Report, 16.

<sup>72</sup> Transplant Québec 2016-2017 Annual Report, 7.

- Various efforts through Transplant Québec’s Family Committee, such as the diffusion of the 2007 study on family refusals, the review of the method of approach of families at the start of the process of organ donation and the allocation of resources to better answer the need of families.<sup>73</sup>
- The introduction of a nursing initiative with the aim of improving communication with families at the time of donation and consent of families.<sup>74</sup>
- The conduct and follow-up of surveys to collect people’s intentions on organ donation and to follow-up on the impact of awareness campaigns.<sup>75</sup>
- The adoption of strategic orientations, as part as Transplant Québec’s 2010-2014 strategic plan, aimed at increasing the rate of family consent to organ donation.<sup>76</sup>
- The continuing update of the training of health care professionals concerning the approach and communication with families<sup>77</sup> and the granting of education credits.<sup>78</sup>
- The contribution to the launching of the RAMQ registry in 2011 and of the new website “Signezdon” in 2012 which invites the population to consent to organ donation and “Sign in” the registry.<sup>79</sup>

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<sup>73</sup> Transplant Québec, 2008-2009 Annual Report, 10.

<sup>74</sup> Transplant Québec, 2008-2009 Annual Report, 12.

<sup>75</sup> Transplant Québec, 2008-2009 Annual Report, 13.

<sup>76</sup> Transplant Québec, 2009-2010 Annual Report, 6.

<sup>77</sup> Transplant Québec, 2009-2010 Annual Report, 13.

<sup>78</sup> Transplant Québec, 2014-15 Annual Report, 2.

<sup>79</sup> Transplant Québec, 2010-11 Annual Report, 3.

- The promotion of new clinician and administrative initiatives with the introduction of the hospital physician coordinator.<sup>80</sup>
- The contribution to the development of a web link for the online registration of consent in the RAMQ registry and web campaigns to promote online registrations.<sup>81</sup>
- In 2013-14 and 2014-15, the annual reports of Transplant Québec's specifically mention their intention to develop strategies and find ways to reduce family refusals.<sup>82</sup>
- The development of a new computer system to collect data.
- The support in the implementation of a mandatory learning module on organ donation in the medical undergraduate programs.<sup>83</sup>
- The adoption of the 2016-2021 strategic plan, with two of the main objectives concerning the support and approach of families.<sup>84</sup>
- And more.

All these efforts are commendable. Unfortunately, we will now see that these efforts generally failed to bring positive results on the impact of family refusals to consent to organ donation.

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<sup>80</sup> Transplant Québec, 2011-12 Annual Report, 4

<sup>81</sup> Transplant Québec, 2012-13 Annual Report, 4.

<sup>82</sup> Transplant Québec, 2013-14 Annual Report, 4.

<sup>83</sup> Transplant Québec, 2015-16 Annual Report, 3.

<sup>84</sup> Transplant Québec, 2016-17 Annual Report, 3.

## The Evolution of Family Refusals since 2008

Reality shows that despite all efforts, families continue to have an impressive impact on refusals to consent to organ donation and thereby on the number of effective donors. Such conclusion can be gathered from the evolution of family refusals within the last ten years, as reported by two sets of information. First, from the data published by Transplant Québec in its annual reports and second, from an exclusive collection of data submitted in the context of this thesis. Each set of information will now be examined separately.

### Transplant Québec Annual Reports

Transplant Québec publishes in each of its annual reports, general information for each organ donation referral which ends up being refused.<sup>85</sup> As previously mentioned, the review of each reports for the period 2008 to 2018 reveals that even if referrals increased significantly, refusals increased at a much greater rate. Moreover, the review of the reasons for refusals indicates that the proportion of family refusals increased at an even greater rate. Indeed, Figure 8 shows that between 2008 and 2018, while the total number of refusals rose from 294 to 540, for an increase of 84%, family refusals increased 111%, from 94 to 198 cases.

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<sup>85</sup> Since 2008, these categories were slightly modified and reasons for refusals are now grouped as follow: 1-Family refusals, 2-Neurological or hemodynamic condition preventing organ donation, 3-Preexisting or actual disease, and 4-Other refusals.

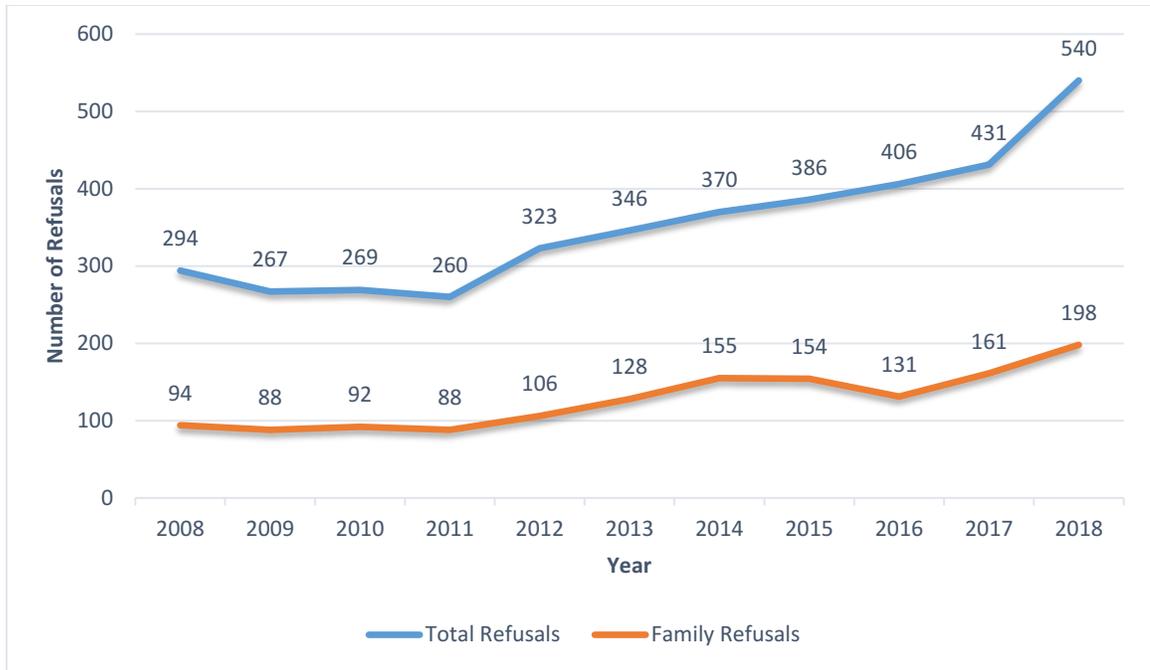


Figure 8: Number of family refusals and total refusals of referrals to organ donation (2008-2018)

The next figure reveals that the proportion of family refusals in 2018 is more important than in 2008, although it reached a peak in 2014 and went down afterward. Family refusals represented 37% of all refusals in 2018, and 26% of all referrals, compared to 32% of refusals and 20% of referrals in 2008.

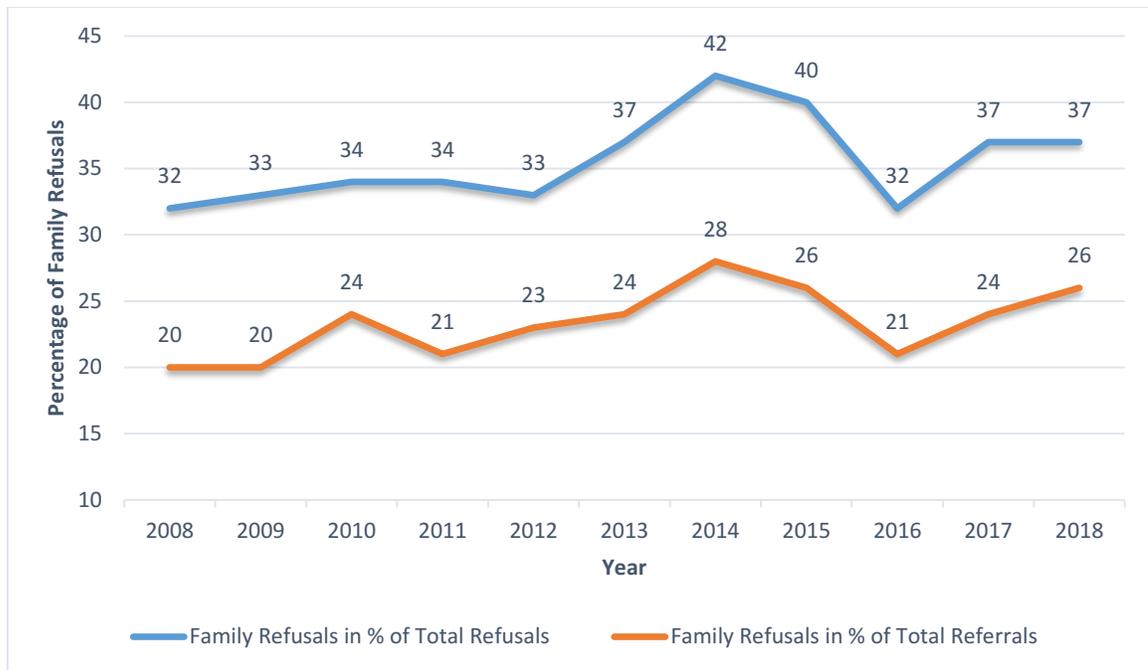


Figure 9: Family refusals in percentage of all refusals and of all organ referrals (2008-2017)

Therefore, after years of efforts to better register donors, to increase information on organ donation, to improve donation rate and to insist on the importance of discussing one's wishes with family, the increase in family refusals seems surprising but is nonetheless a reality. Except for a few years, family refusals account for more refusals than ever before. As we will see next, such conclusion is also put in evidence in the data submitted by Transplant Québec which also offers better information to explain the impact of families.

#### Transplant Québec Exclusive Data Submission

In the context of this thesis, Transplant Québec submitted new data concerning family refusals to consent to organ donation for the years 2016, 2017 and 2018. This data first contains upgraded information on the reasons for each referral refusals and which

were not necessarily available at the time of publication of the annual reports. Therefore, it offers a better view of the reasons for each refusal, which allows us to better identify the ones motivated by family decisions. This data also reveals information as to whether the deceased had registered a consent or a refusal to donate his organ. This will allow to determine the number of times when family refusals either overrode the wishes of the donor to consent or complied with his wishes to refuse to donate.<sup>86</sup>

Looking first at the number of cases of family refusals, we notice that the new data submitted by Transplant Québec reveals, due to the upgraded information available, a higher number of family refusals than the information published in the annual reports. As shown in Figure 10, the impact of family refusals on organ donation is therefore even more important.

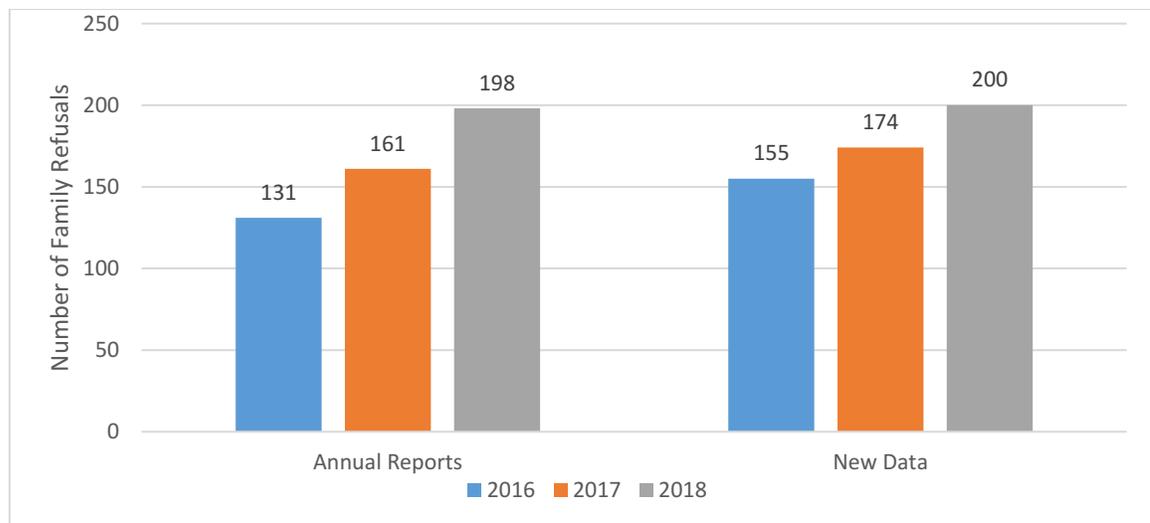


Figure 10: Number of cases of family refusals (2016-2018)

<sup>86</sup> Since the topic of this thesis concerns family refusals, data submitted by Transplant Québec does not contain information on families who consented to donate, either confirming the wishes of a donor to donate or in cases where such wishes were unknown. As for families who would have consented to donate in a case where the donor had expressed a refusal, Transplant Québec confirmed that such a situation happens but only in very rare cases.

Again, the new data confirms that family refusals has an important, even growing impact on consent to organ donation, despite all efforts being made to alleviate the role of families. As shown by Figure 11, the impact of family refusals is so important that in nearly 4 times out of 10, the reason to refuse an organ referral is due to the family's objection to consent to the donation.

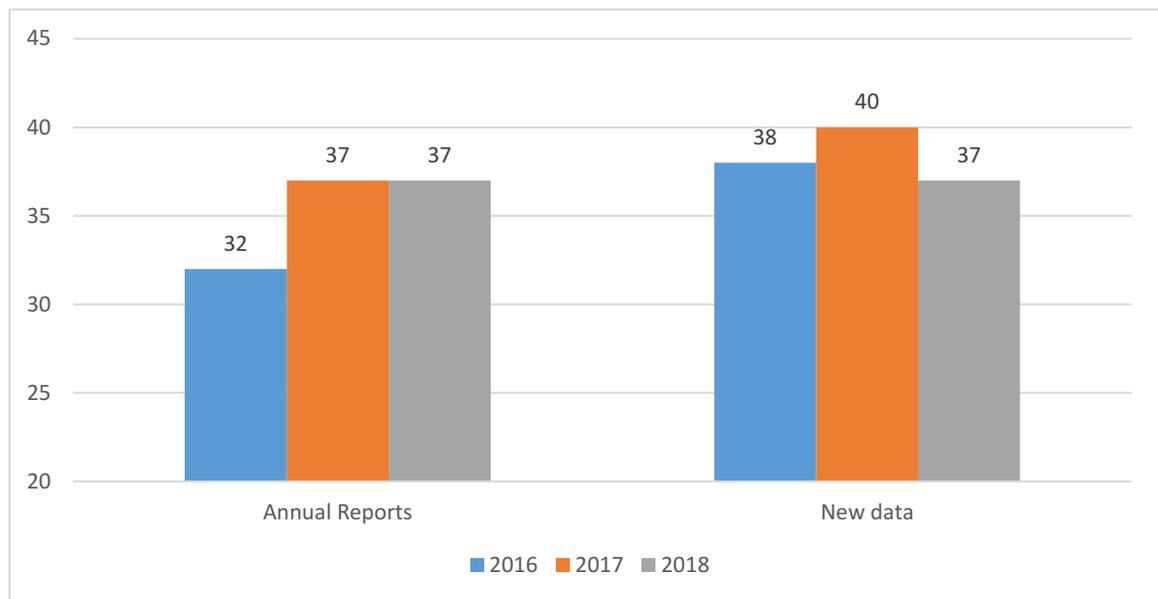


Figure 11: Family refusals in percentage of all refusals (2016-2018)

The number of organ referrals is ultimately limited every year and various efforts are required to reduce to a minimum the number of refusals. It is understandable that the medical history of a patient or that other medical conditions can prevent physicians to accept an organ referral. It seems however less acceptable that so many referrals are being refused because of family's objections.

Data submitted by Transplant Québec reveal exclusive information on the reasons for which families refuse to consent to organ donation. Indeed, such reasons are

mentioned for each referral which has been refused, according to the information obtained from the health professionals involved or the review of the medical file of the deceased. As with the 2007 study mentioned above, we have analyzed and classified such reasons depending if they are based on the known wishes of the deceased -whether such wishes have been registered or simply expressed to their family,- on the wishes of families themselves or on reasons related to the criteria of neurological death.<sup>87</sup>

As shown by Table 1, and similarly to the conclusion of the 2007 study, most of the reasons for families to refuse to consent to organ donation are attributable to their own will and not the will of the deceased. Our analysis shows that the main reasons for family to refuse to consent to organ donation are explained by their own wishes, either it be for personal, cultural or religious reasons or because of their exhaustion or hesitation to consent for the deceased. Another important reason to refuse is due to their reluctance to wait or consent to additional delays for death to occur and allow organ retrieval. In conclusion, in less than 25% of the cases are the refusals based either on the expressed wishes of the deceased or the assumed knowledge by families of the wishes of the deceased.

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<sup>87</sup> The 2007 study was based solely on family refusals in cases where the wishes of donors were unknown. Table 1 also includes refusals to donate expressed by the deceased.

Table 1. Reasons for family refusals to consent (2016-2018)

Reasons	2016	%	2017	%	2018	%
Based on wishes of the deceased						
- Refusal expressed	16		13		9	
- wish not to donate	10		17		33	
- wish not to be maintained in life	3		4		6	
Total	29	19%	34	20%	48	24%
Based on wishes of families						
- Personal reasons	14		17		24	
- Religious or cultural reasons	7		8		4	
- State of shock	9		8		10	
- Exhaustion and wishing end of treatment	14		23		26	
- No family consensus	7		3		6	
- Unknown wishes of deceased and do not want to make decision	10		18		18	
- Wish only comfort care	5		6		1	
Total	66	43%	83	48%	89	44%
Based on criteria for death (DDN or DDC)						
- Difficulty with concept	1				2	
- Too long/Families don't want to wait	31		21		33	
- Family refuse additional delays	1		6		3	
Total	33	21%	27	16%	38	19%
Other reasons	4	3%	11	6%	9	5%
Unknown reasons	23	14%	19	10%	16	8%
Grand Total	155	100%	174	100%	200	100%

## The Double Consent Issue

The new data submitted by Transplant Québec also reveal exclusive information as to whether family refusals are in accordance with the wishes of the deceased or overrule such wishes.

Indeed, in the data submitted, information about the wishes of a deceased to consent or not to consent to organ donation has been recorded for each case of family refusals. Donor's consent to organ donation has been collected in four different ways: registration of consent in the RAMQ registry, registration of consent in the CNQ registry, signature of the RAMQ donor's card or verbal consent given to the medical team just before death. For its part, a deceased refusal to donate has either been collected through the registration of his refusal to consent in the CNQ registry or through a verbal refusal given to the medical team just before death. The following figure distributes family refusals according to each of these situations.

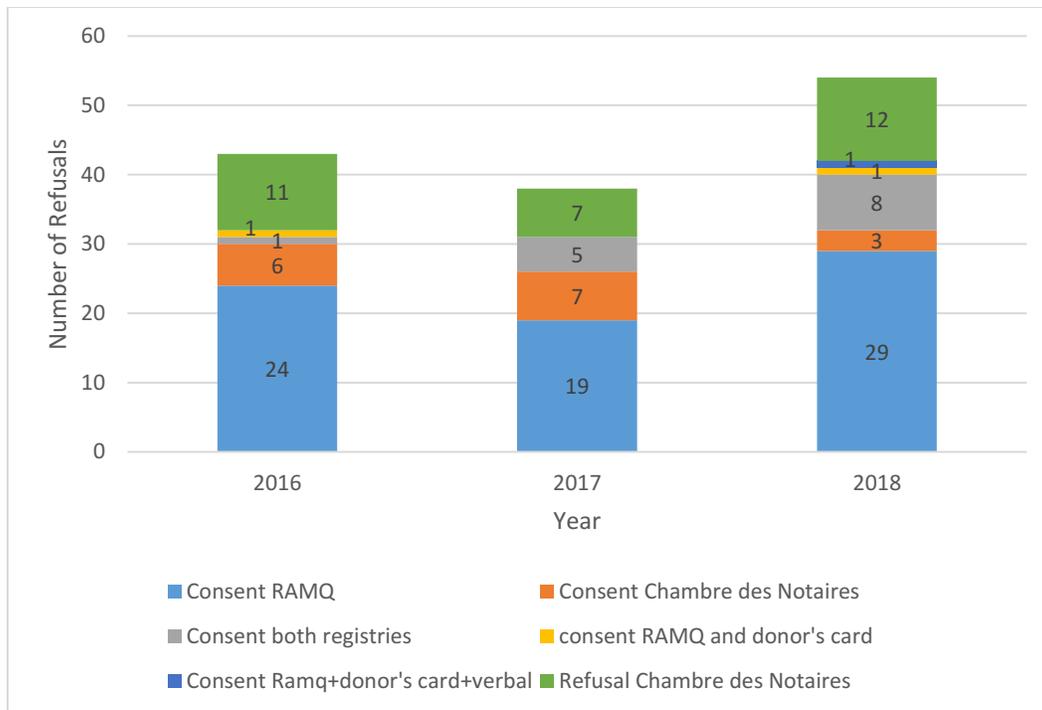


Figure 12: Number of cases of family refusals when the wishes of donors to consent or refuse organ donation were known (2016-2018)

Figure 12 therefore reveals that out of 155, 174, and 198 family refusals, respectively in 2016, 2017, and 2018, there were 43, 38, and 54 cases of family refusals which occurred when the wishes of the deceased were known. It also indicates that in 32, 31 and 42 of these cases respectively, the deceased had indicated their wishes to consent to organ donation, which reveals that in all of these cases, families did in fact override the consent of a donor and refused to consent to organ donation.

It is not possible to determine the impact of family refusals in relation to all referrals for which the deceased expressed their wishes. Indeed, the data submitted by Transplant Québec only include information on referrals which have been refused and not on those which have been accepted by families. However, we could venture the following assumption. Since Transplant Québec reveals that around 40% of the population has

registered its wishes to donate in the RAMQ's registry, it could indicate that out of the 755 organ referrals which occurred in 2018, around 300 of these referrals would concern donors having expressed their wishes. With 42 cases of families overriding such consent in 2018, it would mean that around 14% of all consents registered by donors would have been overridden by their families in 2018. In terms of referrals, it would indicate that more or less 6% of referrals ended up being refused by families who overrode the consent of a donor.

It is, however, possible to examine specifically the cases of family refusals and determine to what extent they occurred in cases where the deceased have or have not expressed their wishes. Again, if we refer to the years 2016, 2017, and 2018, we know that family refusals occurred in respectively 155, 174, and 200 cases of organ referrals. The following figures therefore reveal that more than 20% of the time, when family

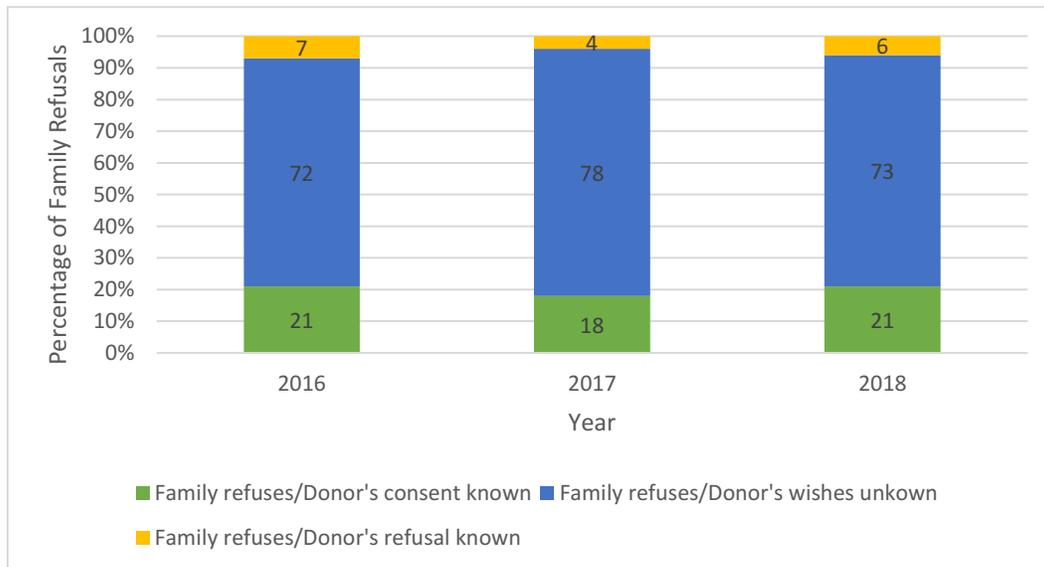


Figure 13: Percentage of family refusals depending on expressed or unexpressed wishes of a deceased (2016-2018)

refused to consent to organ donation, the refusal overrode the wishes of a donor.

Unsurprisingly, Figure 13 reveals that family refusals occur mainly in cases where the deceased have not expressed their wishes, which will be of importance in our discussion in chapter 4. Indeed, it indicates that more than 70% of family refusals relate to deceased who have not expressed their wishes and only 10% of refusals concern deceased who have themselves refused to donate their organs upon death.

It is interesting to look again at the reasons invoked by families who refused to consent, but this time only in cases where donors have expressed their wishes to donate. There are a few cases for which families invoke either a change of mind of the deceased or a knowledge of their wishes which would be contradictory to the wishes registered. However, Table 2 shows that more than half of family refusals are explained either because they are exhausted or, which can be much of the same, because of the delays associated with the criteria of death and the donation process.

Table 2. Reasons for family refusals when donor's consent is known (2016-2018)

Reasons	2016	%	2017	%	20	%
					18	
Based on wishes of the deceased						
- Refusal expressed	1		0		0	
- wish not to donate	0		3		1	
- wish not to be maintained in life	0		1		1	
Total	1	3%	4	13%	2	5%
Based on wishes of families						
- Personal reasons	2		4		6	
- Religious or cultural reasons	0		0		0	
- State of shock	2		1		2	
- Exhaustion and wishing end of treatment	6		10		8	
- No family consensus	1		0		0	
- Wish only comfort care	0		2		2	
Total	11	34%	17	55%	18	43%
Based on criteria for death (DDN or DDC)						
- Too long/Do not want to wait	11	34%	7	23%	15	36%
Other reasons	1	3%	2	6%	4	9%
Unknown reasons	8	25%	1	3%	3	7%
Total	32	100%	31	100%	42	100%

In conclusion, various findings can be drawn from our analysis of family refusals to consent to organ donation. We will propose the following five findings.

1. The rate of family refusals is growing despite all efforts devoted throughout the years to make the wishes of a donor known and followed. It therefore shows that these efforts have not delivered the expected results.
2. Family involvement and the requirement for double consent has a negative impact on organ donation. Indeed, with an average of 35 cases of family refusals per year, when the donor's consent is known, and with a rate of more than 3 organs collected per donor, many more organs could be made available every year for persons waiting for an organ transplantation.<sup>88</sup> In spite of the exact number of organs lost, with people dying every year while on the waiting list, this would suggest, as Antonia Cronin did,<sup>89</sup> that families' involvement in organ donation cost lives also in Québec.
3. Refusals of families to consent is mainly attributable to cases where the wishes of a donor are unknown. Indeed, more than 70% of family refusals were expressed in such a situation, accounting for the refusals of more than a hundred referrals per year.
4. When the wishes of a donor to consent are known, family refusals are mainly attributable to reasons associated with them and not with the deceased, such as personal reasons, the fact that they are exhausted or because of the delays associated with death to materialize.

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<sup>88</sup> Not all donors concerned would have been accepted as referrals since other medical reasons could have prevented the organ donation process. However, the RAMQ mentions that each donation may save up to 8 lives and help restore the health of 40 other persons. See "Consent to Organ and Tissue Donation," Régie de l'assurance maladie du Québec, accessed November 10, 2019, <http://www.ramq.gouv.qc.ca/en/citizens/health-insurance/advance-directives/Pages/consent-organ-tissue-donation.aspx>.

<sup>89</sup> Cronin, "Transplants Save Lives," 219-220.

5. Although the number of family refusals is important and shows a negative impact of families on organ donation, the overall impact of families on organ donation cannot be ascertained. Indeed, with 164 effective donors in 2018, it reveals that families consented to even more donation referrals.

These findings will now better help us address the question as to whether family involvement in the organ donation process in Québec should be restricted.

## Chapter 4.

### Should Family's Involvement Be Restricted

In Chapter 3, we confirmed that many cases of organ referrals are rejected every year because of family refusals to allow the organs of a next of kin to be retrieved. Most family refusals arise in cases where the wishes of a donor are unknown. However, even when the wishes of a donor to donate are known, family involvement still causes, on average, 35 referrals a year to be rejected. Therefore, family involvement generally causes organs to be lost, and lives accordingly.

Based on this conclusion, this chapter will try to determine if family's involvement on consent to organ donation should be restricted, and more specifically in the situation of double consent. Many arguments have been raised both in favor and against the role of families on consent to organ donation and about their capacity to overrule the wishes of a deceased.<sup>90</sup> This chapter will examine this question and in doing so, legal, ethical and practical arguments will be considered.

### Legal Considerations

In a society where the rule of law prevails, the ingenuity of lawyers to raise arguments benefiting their respective clients comes with very few limits. When individual rights are paramount, such as it is the case in most western societies,

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<sup>90</sup> Shaw et al., "Family over Rules," 484-485. In their analysis, the authors considered 6 arguments in favor of families' overrule and 5 against.

individuals can often find grounds for invoking the protection of their rights and freedoms or an infringement of them. The situation in organ donation is not different. Since many persons may be concerned by a decision to donate or not to donate, various legal arguments can be raised to their benefit. Moreover, although most legal systems are based on principles which have been edified throughout centuries if not millenniums, the progress of medicine and transplantation brings new realities to consider (philosophical, ethical and more) and the legal system does not necessarily follow pace, leaving many questions confused and unanswered.

The opposing views of Wilkinson<sup>91</sup> and Cronin<sup>92</sup> offer an interesting example of the legal debate persevering on issues about consent to organ donation and the role of families. For Wilkinson, the right of autonomy implies giving individuals a veto on the use of their bodies, to which Cronin replies that a dead individual is not a person and therefore has no posthumous rights, either to donate or not to donate. For her, even in a situation of posthumous rights, any rights of an individual could not be considered “against the positive rights of the individuals on the transplant waiting list who will die for want of an organ”.<sup>93</sup> As for the role of families, their distress over the loss of a loved one is raised by Wilkinson to suggest that they should have a veto on the decision to donate or not to donate in order to avoid causing them more distress, irrespective of the wishes expressed by the deceased. For Cronin, it seems unreasonable “to suppose that the distress of the family members of the individual who has just died is more important than,

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<sup>91</sup> T. M. Wilkinson, “Individual and Family Consent to Organ and Tissue Donation: Is the Current Position Coherent?” *Journal of Medical Ethics* 31 (2005): 587-590.

<sup>92</sup> Cronin, “Transplants Save Lives,” 219-220.

<sup>93</sup> Cronin, “Transplants Save Lives,” 219.

and should automatically outweigh, the distress of the family members of the individual who is on the transplant waiting list”.<sup>94</sup> The multi-cultural dimension of today’s societies is also raised to justify confronting views on the role of individuals and families since in some cultures “individual’s wishes do not override the family’s, and that it would be inappropriately culturally insensitive to insist that they do.”<sup>95</sup>

Their discussion reveals other interesting points which are stimulating the legal debate on organ donation such as the question of the positive rights to assistance of a potential recipient versus the negative rights against interference of a potential donor or the general public interest in having a strong and viable organ donation system and in avoiding any scandal which could cause a decline in the supply of organs. Also questioned is the extent to which the decision of a donor to express consent on a registry or to tick a box on a form to renew a driver’s license meets or not adequate standards of informed consent. Likewise, arguments can be raised on behalf of the rights of physicians not to override the decision of a family to refuse an organ donation, and so on.

As can be seen, various elements may be considered to determine if the role of families should be restricted. But in each situation the legal answer to this question lies first and foremost on the proper legislation and rules applicable. Therefore, we will examine the legal system in place in Québec in order to determine if the role of families in organ donation should be restricted. Our purpose is not to present a legal opinion but to examine the general legal concepts in order to offer a global picture of the situation as it stands today. In this fashion, we will first address the fundamental rights of individuals in

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<sup>94</sup> Cronin, “Transplants Save Lives,” 219.

<sup>95</sup> Wilkinson, “Individual and Family Consent,” 588.

Québec during their lifetime and determine how such rights evolved or are transformed at the time of death. Considering the confusing status of a deceased, who although being supposedly dead is still maintained alive for the sake of organ retrieval, we will also examine how such status contributes to the legal confusion about the rights of the deceased or those of families.

### The Fundamental Rights of a Person: Autonomy and Self-Determination

Such as it is the case in the mainstream western traditions, the legal system prevailing in Québec grants each individual various fundamental rights and freedoms. Unlike other Canadian provinces where common law prevails, the laws in Québec derive from a civil tradition originating from Roman law. As such, rules of law and rights and freedoms are codified in various texts such as the Civil Code of Québec (the Civil Code) and the Québec Charter of Human Rights and Freedoms (the Charter).

The preamble of the Charter sets the importance to be granted to the dignity of a person:

WHEREAS every human being possesses intrinsic rights and freedoms designed to ensure his protection and development;

Whereas all human beings are equal in worth and dignity, and are entitled to equal protection of the law;

Whereas respect for the dignity of human beings, equality of women and men, and recognition of their rights and freedoms constitute the foundation of justice, liberty and peace;

Whereas the rights and freedoms of the human person are inseparable from the rights and freedoms of others and from the common well-being;

Whereas it is expedient to solemnly declare the fundamental human rights and freedoms in a Charter, so that they may be guaranteed by the collective will and better protected against any violation,<sup>96</sup>

Section 1 of the Charter stipulates that “Every human being has a right to life, and to personal security, inviolability and freedoms. He also possesses juridical personality.”<sup>97</sup> The Charter then expresses various rights and freedoms such as the right to the safeguard of his dignity.<sup>98</sup>

For its part, the Civil Code addresses from the start the rights of persons and section 1 sets the principle that “Every human being possesses juridical personality and has the full enjoyment of civil rights.”<sup>99</sup> The Civil Code then list various personality rights, the first one pertaining to the inviolability and integrity of the person:

10. Every person is inviolable and is entitled to the integrity of his person.

Except in cases provided for by the law, no one may interfere with his person without his free and enlightened consent.<sup>100</sup>

This right of inviolability entails the right of individuals to their autonomy, self-determination and the protection of their body. As personality rights, they are the attributes of a person, as a human being, and allow such a person, during their lifetime, to make their own decision and to have their wishes respected.<sup>101</sup> Therefore, no violation of

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<sup>96</sup> Québec Charter of Human Rights and Freedoms, CQLR, c. C-12, Preamble.

<sup>97</sup> Québec Charter of Human Rights and Freedoms, CQLR, c.C-12, s. 1.

<sup>98</sup> Québec Charter of Human Rights and Freedoms, CQLR, c. C-12, s. 4.

<sup>99</sup> Civil Code of Québec, c. CCQ-1991, s. 1.

<sup>100</sup> Civil Code of Québec, c. CCQ-1991, s. 10.

<sup>101</sup> Since they cannot be separated from the person, personality rights are therefore untransmissible, because extinguishing with death, non-transferable because involving moral interests, elusive because not constituting an economic good and imprescriptible because the right itself cannot be affected by the passage of time, although its exercise is subject to prescription. Édith Deleury and Dominique Goubau, *Le droit des personnes physiques 5<sup>ème</sup> édition* (Cowansville: Éditions Yvon Blais, 2014), 83-84.

this principle can be made without the person's consent, which must be free and informed. Individuals may then refuse a medical treatment or interrupt a treatment, even if it should cause their death.

It is also on the basis of these rights and the need of consent that a person can, under certain conditions, participate in research that could interfere with the integrity of their body, request to right to die in dignity or, in the case of organ donation, choose to alienate a part of their body *inter vivos*. In this latter case, the autonomy of a person to take such a decision is set by section 19 of the Civil Code and is only conditional on the consent of a third party in the case of a minor or a person not able to consent.

19. A person of full age who is capable of giving his consent may alienate a part of his body *inter vivos*, provided the risk incurred is not disproportionate to the benefit that may reasonably be anticipated.

A minor or a person of full age who is incapable of giving his consent may, with the consent of the person having parental authority, mandatary, tutor or curator and with the authorization of the court, alienate a part of his body only if that part is capable of regeneration and provided that no serious risk to his health results.<sup>102</sup>

Therefore, families cannot intervene to override the decision of a person of full age to alienate a part of their body unless it can be demonstrated that the criteria for such alienation is not met.

In conclusion, during their lifetime, personality rights entail individuals to make their own decision and to have their wishes respected, so long as conditions stated by law are met. One cannot be forced to decide against their will and the exercise of such personality rights is protected from the interference of third parties, including families.

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<sup>102</sup> Civil Code of Québec, c. CCQ-1991, s.19.

## Respect of the Body after Death

From a legal standpoint, it is generally acknowledged that since personality rights are the attributes of a person – as a human being – they end with their death. The cadaver is a thing and cannot be granted personality rights. However, the Civil Code grants specific protections to the human corpse and to the wishes of a person after death. Such protection is again based on the principle of inviolability and dignity of a person which continues after death:

Les règles juridiques relatives au corps après le décès reflètent aussi le respect de l'individu comme valeur sociale primordiale et elles indiquent que la personne, même décédée, participe encore d'une certaine façon de la nature humaine. En ce sens on peut dire que même au-delà de la mort, le droit reconnaît à la personne une certaine dignité.<sup>103</sup>

In the 90's, the Civil Code underwent an overall revision and the minister of Justice presented various commentaries to help better comprehend the scope of the changes brought to many sections of the Code. In the section pertaining to personality rights, the commentaries clearly support the principle that the safeguard of the dignity of a person must remain after death:

Le droit d'une personne à la sauvegarde de sa dignité continue même après sa mort : son corps doit être l'objet de soins particuliers.<sup>104</sup>

The Civil Code therefore contains a specific chapter concerning the respect of the body after death. In this chapter, it is stipulated that a person may determine the nature of

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<sup>103</sup> (Translation) *The legal rules relating to the body after death also reflect the respect of the individual as a primordial social value and they indicate that the person, even deceased, still participates in a certain way of human nature. In this sense we can say that even beyond death, the right recognizes the person a certain dignity.* Deleury, *Le droit des personnes physiques*, 39.

<sup>104</sup> (Translation) *The right of a person to the safeguard of his dignity continues even after his death: his body must be the object of particular care.* Ministère de la justice du Québec, *Commentaires du ministre de la Justice, le Code civil du Québec: Un mouvement de société* (Québec: Publications du Québec, 1993), section 37.

their funeral and the disposal of their body<sup>105</sup> or consent to an autopsy after death.<sup>106</sup> It also sets the conditions for the embalmment, the burial or the cremation of a body.<sup>107</sup>

However, the main articles of this chapter deal with the decision of a person to give their body or authorize the removals of organs or tissues therefrom. Sections 43 and 44, which have been referred to in chapter 2, are worth citing again.

**43.** A person of full age or a minor 14 years of age or over may, for medical or scientific purposes, give his body or authorize the removal of organs or tissues therefrom. A minor under 14 years of age may also do so with the consent of the person having parental authority or of his tutor.

These wishes are expressed verbally before two witnesses, or in writing, and may be revoked in the same manner. The wishes expressed shall be followed, unless there is a compelling reason not to do so.

**44.** A part of the body of a deceased person may be removed, if the wishes of the deceased are not known or cannot be presumed, with the consent of the person who was or would have been qualified to give consent to care.

Consent is not required where two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation and the serious hope of saving a human life or of improving its quality to an appreciable degree.<sup>108</sup>

Section 43 clearly states the principle that the expressed wishes of a person with respect to organ donation shall be followed, unless there is a compelling reason not to do so. The notion of “compelling reasons” has not been defined by legislators, nor interpreted by the Courts in the case of organ donation. According to some jurists, such compelling reasons have been viewed as wishes contrary to public order, wishes which

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<sup>105</sup> Civil Code of Québec, c. CCQ-1991, s. 42.

<sup>106</sup> Civil Code of Québec, c. CCQ-1991, s. 46.

<sup>107</sup> Civil Code of Québec, c. CCQ-1991, s. 48.

<sup>108</sup> Civil Code of Québec, c. CCQ-1991, s.42 and 43.

would be impossible to respect, the lack of a potential organ recipient, the poor state of the donor's organs or a change of mind of the donor.<sup>109</sup> Such reasons are therefore associated to objective circumstances and not to the subjective wishes of others. Indeed, the recognition of the right of a person to his autonomy, inviolability and dignity is recognized and enforced in specific ways after death. On the basis of these principles, it can hardly be justified that any third parties, either it be the family of the deceased, the potential recipient, the family of the recipient or the medical team in charge of a potential donor, could have a veto over the decision of the deceased. Most authors would say that there are no legal justifications for such a family veto.<sup>110</sup>

Recently, Louise Bernier offered a different view on the interpretation to be given to the “compelling reasons” exception referred to in section 43 of the Civil Code.<sup>111</sup>

While she acknowledges the legal arguments supporting the autonomy of a person and the restrictive interpretation usually given to section 43, she rightfully points out that in practice, it is the family which makes the final decision to consent or not to organ donation. In view of this contradiction between the law and clinical practice, she proposes a different way to interpret section 43 of the Civil Code, one which takes into consideration the factual context in which it applies. For her, the factual context of organ donation is not only one where shock, pain and sorrow occur but one which is also

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<sup>109</sup> S. Bourassa, « Les droits de la personnalité, » in *Personnes, famille et successions. Collection de droit 2016-2017*, 3, ed. Barreau du Québec (Cowansville: Éditions Yvon Blais, 2016), 66.

<sup>110</sup> Marie Annik Grégoire is one of the main Québec's jurist who strongly supports this view. Marie Annik Grégoire, «Respecter la loi pour sauver des vies,» *Le Devoir*, Octobre 17, 2018, <https://www.ledevoir.com/opinion/idees/539156/don-d-organes-respecter-la-loi-pour-sauver-des-vies>

<sup>111</sup> Louise Bernier, “Organ Donation : Beyond Individual Consent,” *Éthique et Santé* (2018) 15: 142-151.

characterised by the urgency for the family to make a decision, the necessity to maintain or prolonged life to allow organ retrieval and the doubts about the true value, when confronted with reality, of the anticipated wishes of the deceased. For her, this factual context is complemented by other factors such as the values and beliefs of the family, their fear about the integrity of the corpse, their difficulty to understand the concept of brain death, the potential conflicts between family members and also the values and interests of the medical team not to be perceived negatively. Bernier argues that when considering this whole factual context, section 43 offers the flexibility to allow families to override the wishes of a donor.

Although such a proposition is certainly interesting, we feel that this interpretation does not accurately reflect the purpose of section 43 and the intent of the legislator. We feel that Bernier's proposition is more an attempt to give meaning and justification to the conduct of families and the medical team than to give meaning to the exception specified in section 43 and its purpose. For the sake of resolving a contradiction between legal rules and clinical practices, she insists on attributing sense to a reality which we believe is faulty at its core and should not be qualified otherwise. We are of the view that the exception of "compelling reasons" must receive a restrictive interpretation, one which is consistent with the intent of the legislator. In this regard, the commentaries of the Justice minister when reviewing section 43 in 1994 were clear. The goal was not only to recognize the autonomy of a person to consent or not to organ donation but precisely to prevent families from overriding his decision.

L'article 43 précise que, sauf motif impérieux, il doit être donné effet à la volonté exprimée du défunt. Cette règle vise à éviter que la volonté du défunt ne soit mise de côté par celle de ses proches.<sup>112</sup>

The foregoing review of the fundamental rights of a person during lifetime and of the specific provisions relating to the protection of the body after death is sufficient for us to reiterate the principle that in the province of Québec, the wishes of a person on organ donation must be respected after death and that families are not authorized to override such wishes. However, to better support this conclusion, it is interesting to have a brief look at the legal debate surrounding the status of a person after death in order to better determine if this debate could support or refute the family veto on consent to organ donation.

#### Are the Living Ruling on the Dead?

As previously mentioned, the principle that personality rights are attached to a person as a human being and end with their death has not prevented legislators to grant certain protection to the human corpse and to the wishes of a person after death. For many, it is difficult to reconcile these two realities from a civil law standpoint. Since personality rights are attached to a human being and are therefore not transmissible to others, it appears that no one could claim any such rights on behalf of the deceased. On the other hand, if a corpse is a thing, who does it belong to and how can they take a decision about it? The Civil Code is structured in a way that clearly distinguishes persons from things. However, the progress of medicine and the development of organ

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<sup>112</sup> (Translation) *Article 43 states that, unless there are compelling reasons, the expressed will of the deceased must be given effect. This rule is intended to prevent the wishes of the deceased from being put aside by those of his family.* Ministère de la justice du Québec, *Commentaires du ministre de la Justice, le Code civil du Québec: Un mouvement de société* (Québec: Publications du Québec, 1993), section 43.

transplantation has brought attention to the difference between the human being as a subject and his corpse as an object.<sup>113</sup>

A debate has therefore occurred about the status of deceased and their corpse and some authors have proposed to confer a hybrid status to the cadaver which could then be seen as a “residual person” or a “legally half-person.”<sup>114</sup> It is important to emphasize that the practical interest of this theory has more to do with the necessity to determine the rights of the living rather than those of the deceased, which is relevant for our discussion on the role of families in organ donation.

En d’autres termes, l’intérêt pratique que pose l’existence, ou la non-existence, des droits de la personnalité du cadavre se situe au niveau de l’action des membres de la famille. Les héritiers vont-ils agir au nom du défunt, ou ne pourront-ils agir qu’en leur nom personnel? Faut-il rapporter la preuve d’un préjudice subi personnellement par le cadavre, ou au contraire, la preuve d’un préjudice familial, que subissent personnellement les héritiers?<sup>115</sup>

Over the years, the courts had to determine the rights of action of heirs and families on various issues concerning the deceased. Such has been the case on issues concerning the protection or violation of the personality rights of the deceased such as their image, honor and reputation. Such has also been the case on issues regarding the wishes of the deceased with respect to the disposal of their corpses or their funerals.

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<sup>113</sup> Anne Saris, «Le sort du cadavre : Le règne des vivants sur les morts,» in *Développements récents en succession et fiducies*, ed. S.F.C.B.Q. (Cowansville : Éditions Yvon Blais, 2014). Marlène Lacroix, « Le Code civil du Québec....en chair et en os, » in *Les oubliés du Code civil*, ed. Gabriel-Arnaud Berthold (Montréal: Les Éditions Thémis, 2014).

<sup>114</sup> Générosa Bras Miranda, «La protection posthume des droits de la personnalité,» *Les Cahiers de propriété intellectuelle* 19, no. 3 (2007) : 804.

<sup>115</sup> (Translation) “*In other words, the practical value of the existence, or non-existence, of the personality rights of the deceased is at the level of the action of the members of the family. Will the heirs act on behalf of the deceased, or will they be able to act only in their own name? Is it necessary to prove the personal offense suffered by the body, or, on the contrary, the proof of an offense suffered by the heirs personally?*” Lacroix, «En chair et en os,» 27.

Générosa is one author who carefully reviewed the grounds which would allow heirs or families to act in circumstances involving the deceased.<sup>116</sup>For her, their potential rights of intervention can be summarized as follow:

1. Although one court case concluded that the personality rights of the deceased were transferred to their heirs, such a theory must be dismissed in view of subsequent law changes and court interpretations. Rights of personality of the deceased are not transferable to heirs.
2. If an action to claim damages for the violation of a personality right has been brought by the deceased before death, such action is transferable to heirs as part of the patrimony of the deceased.
3. Since the Civil Code provides that “heirs are seized of the rights of action of the deceased against the author of any infringement of his personality rights or against the author’s representatives,”<sup>117</sup> heirs are therefore entitled to claim the protection, the forbiddance or the interruption of any *post-mortem* violation to the rights of the deceased. This is not a transfer of the personality rights of the deceased but instead a transfer of a right of action. For Générosa, "Plus qu'un droit, il faut y voir le *devoir, imposé à chaque génération, de veiller au respect de la dignité humaine de leurs prédécesseurs.*"<sup>118</sup> On this basis, heirs can claim the respect of the physical integrity of the cadaver based on the protection granted to the deceased and their wishes, such as those concerning the arrangement of

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<sup>116</sup> Bras Miranda, « Protection Posthume,».

<sup>117</sup>Civil Code of Québec, c. CCQ-1991, s.625.

<sup>118</sup> (Translation) *More than a right, we must see the duty, imposed on each generation, to ensure respect for the human dignity of their predecessors.* Bras Miranda, «Protection Posthume,» 815.

funerals, the disposal of the corpse or the alienation of parts thereof in the case of organ donation. In various cases, the Courts have determined the rights of heirs to enforce the wishes of the deceased, such as the wish to be incinerated instead than buried, even if it required the exhumation of the corpse. It has also been clearly recognized that heirs may intervene for the protection of the moral integrity of the deceased which may occur in the case of a violation of their image, name, memory, Honor or dignity.

4. Finally, families – and not only heirs –, may intervene based on a violation of what could be referred to as their own personal right to the protection of their “feelings of family affection.” Such a possibility is derived from the right to the respect of their privacy which would include the right not to suffer from a violation of the fundamental rights of the deceased. Violating the name, honor or dignity of the deceased therefore amounts to an attack against the feelings of family which would then allow them to act. Such personal rights of families have been inspired by the thoughts of French jurists and have been defined as the “right of family affection” or the “right to family memories.”<sup>119</sup>

Based on this review it appears clear to us that the living cannot be said to be ruling over the dead but instead that the dead are somehow maintained alive by allowing heirs and families to protect their image, honor and dignity after death.<sup>120</sup> Whenever

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<sup>119</sup> In one case, the Court ordered a cemetery who had lost the urn containing the ashes of their father to pay damages to the 6 children. *Robert c. Cimetière de l'Est de Montréal Inc.* (1989) R.R.A. 124 (C.S.) See also Lacroix, «En Chair et en Os,» 27-28.

<sup>120</sup> It is true to say that the right to family affection is a subjective right conferred on them and not on the dead, which is regrettable according to Bras Miranda. We are however of the view that this does not confer priority to the living over the dead since it is through the dignity of the dead that any right of affection of families will be considered.

families are successful in their claim is precisely when they act in accordance with the wishes and dignity of the deceased. In the context of consent to organ donation, it can therefore be said that any role of families could not be justified on the basis of their own wishes but in view of the protection and enforcement of the deceased wishes and dignity.

When applying the legal considerations reviewed in this section to the question at hand concerning the right of Québec's families to intervene in the case of organ donation, we reach the following conclusions:

1. When individuals have expressed their wishes to donate their organs, it appears clear that these wishes must be respected. This is supported as much by the duty to respect their fundamental rights, by the need to observe the specific provisions of the Civil Code concerning organ donation and the protection of these wishes, as well as by the impossibility for third parties to override these wishes as we have seen that any claim or personal rights of families can only be exercised in a manner which protects the dignity of the deceased.<sup>121</sup> Therefore, compelling reasons not to follow the wishes of deceased to donate their organs could not be justified by the distress of families as it appears clear that the revision of section 43 aims at preventing them from overriding the wishes of the deceased. In chapter 3, we have indicated that when the wishes of a person to donate are expressed, family refusals are mainly attributable to reasons associated with them and not with the deceased. Hence, there are no legal justifications for such a rebuttal of

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<sup>121</sup> Some are also of the view that families who override the wishes of the deceased could be declared unworthy of inheriting. Christine Morin, «Respect du corps après le décès,» in *Droit des Personnes Physiques*, ed. Collection Théma (Montréal : LexisNexis, 2015) 5/12.

the deceased wishes and family's involvement in this situation should be restricted.<sup>122</sup>

We believe that compelling reasons not to follow the wishes of the deceased must lean on other objective elements such as the ones mentioned earlier such as the poor conditions of his organs, the lack of a potential recipients and so on.

Family's intervention should be restricted to cases where it can be demonstrated that donors had a recent change of mind and failed to appropriately revoke their consent to donate. In such a situation, we are of the view that the refusal would not amount to a compelling reason not to follow the wishes expressed by a donor but instead finds grounds on the fact that section 43 allows a person to revoke their wishes and families could then provide evidence in this regard. We believe that such a situation will be very rare.

2. When individuals have expressed their refusal to donate their organs upon death, we believe that the same legal principles of autonomy and self-determination apply to protect this decision unless there is a compelling reason not to do so. In this regard, it could be more conceivable to find objective circumstances which could provide compelling reasons not to follow such wishes. Such reasons could

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<sup>122</sup> In an interview on organ donation, a renowned transplant surgeon related one of his experience when a family invoked the fact that, had the donor knew his decision to donate his organs upon death would have caused distress to his mother for days, he would not have chosen to donate. As much as this reason can be indirectly associated with the donor himself, we believe it cannot serve as a compelling reason to override his decision or the legal principles of autonomy and self-determination. Also, in a charming story revealed by a physician who addressed the question of organ donation with her dying father and her mother, we learn that although the mother is informed of her husband wishes to donate his organs, she tenderly informs him of her intention not to follow his wishes, to which the loving husband accepts to let her decide on the issue. As charming as this story may be, we believe that donors who are so advised and willing to leave it up to their spouse or next of kin to decide, should in that situation refrain from registering their wishes to donate or revoke such wishes. Rebecca L. Sudore, "Can We Agree to Disagree," *JAMA* 302, no. 15 (2009): 1629.

be explained by the right to life of a potential recipient.<sup>123</sup> As we have seen, the preamble of the Québec Charter provides that rights and freedoms granted to a person are inseparable from the rights and freedoms of others and from the common well-being. Could this serve as a basis, in some cases, to override a decision of a deceased not to donate? While there is certainly more potential success to this argument, we believe this would remain very difficult because the right to the inviolability and integrity of a person should again take precedence. Indeed, some would argue that when body integrity is considered, a refusal to donate is even more powerful than a consent to donation.<sup>124</sup>

3. For individuals who have not expressed their wishes, it appears clear from a legal point of view that the consent of families cannot be disregarded in such a situation. Indeed, the consent to donate rests, in the case of a minor, on the person having parental authority or, in the case of a person of full age, on the person who has or would have been qualified to give consent to care: the spouse or, if there are no spouse or the spouse is prevented from giving consent, a close relative or a person who shows a special interest in the person.

However, the fact that families must consent does not mean that their involvement should not be restricted. Indeed, we believe that families should take a decision only having the interests of the deceased in mind and not their own motives or interests. Families should therefore be asked about the wishes of the deceased or

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<sup>123</sup> Let's take the example of two brothers involved in a road accident, one of which dies and the other needs a new organ to survive. Assuming he could be a recipient, could such a circumstance be argued as a compelling reason not to follow the refusal to consent of the deceased, which could have seen things differently in these circumstances and would have wanted to save his brother's life?

<sup>124</sup> Shaw et al., "Family over Rules," 486.

what they could have been and not about their own wishes. Such an example of restriction on the role of families can be seen in some presumed consent system such as the one introduced recently in the province of Nova Scotia where a substitute decision-maker can only reverse the decision of the deceased or his deemed decision if he provides information that could convince a reasonable person that the individual would have decided otherwise.<sup>125</sup> We believe that such a restriction on the role of families could also be introduced in an informed consent system like the one in Québec, for donors who have not expressed their wishes.

In conclusion, on the basis of the review of the legal principles governing personality rights as well as organ donation in Québec, it is our view that consent to organ donation must rest first and foremost with the person concerned and that family's involvement should be restricted as mentioned above.

### Ethical Considerations

Again, the progress of medicine and the advent of organ transplantation has made ethicists debate organ donation as much, if not more, than lawyers.

It was clinical medicine with its growing ethical problems and new types of conflict situations that obliged philosophers to once again address “substantive ethical questions” by applying “principles to particular situations” instead of just practicing metaethics”. The topic of organ transplantation is a very good example of what the reanimation of ethics

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<sup>125</sup> An Act Respecting Human Organ and Tissue Donation, Nova Scotia Legislature, Acts of 2019, ch. 6, s.15(1), accessed November 10, 2019, [https://nslegislature.ca/legc/bills/63rd\\_2nd/3rd\\_read/b133.htm](https://nslegislature.ca/legc/bills/63rd_2nd/3rd_read/b133.htm). Section 15(1) provides that “where a substitute decision-maker provides information that would lead a reasonable person to conclude that an individual would have made a different decision respecting donation after death than the decision recorded in the Registry or deemed under Section 11, the substitute decision-maker may consent or refuse on behalf of the individual in accordance with that information.

by medicine could resemble. It is not only a current and controversial subject of applied ethics, namely medical ethics, but is also concerned with a subject from the heart of philosophy, which has been rejuvenated by the possibilities of modern medicine.<sup>126</sup>

Ethical considerations are fueling many interesting debate on issues at the core of organ donation and transplantation such as the organ shortage and ways to address it, the end of life and the paradigm of brain death, the physical integrity of the body, the status of the deceased, the expectations of recipients, their moral obligations to take good care of the gift they received and so on. Whether family's involvement in organ donation should be restricted or not must also be examined through ethical lens.

Some have argued that “ we have a powerful moral duty to respect a person's wishes about what should happen after her death...”<sup>127</sup> For others, once the donor is deceased, it is more appropriate to be sensitive to the needs of the family and consider the distress the loss of a loved one is causing. It would then be morally wrong to retrieve any organs without their consent.<sup>128</sup> Again, this debate revolves around the status to be given to the deceased and, specifically in the case of brain death, to the problem of seeing a love one which is legally dead but maintained alive and breathing. This problem has brought some authors to suggest a third category for the status of existence, one which “puts human in a new and ambiguous realm between life and death” and which would amount to the zombification of humans.<sup>129</sup> Still, others claim that the ethical debate

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<sup>126</sup> Tobias Eichinger, “Brain Death, Justified Killing and the Zombification of Humans – Does the Transplantation Dilemma Require New Ways of Conceptualizing Life and Death?” in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 9.

<sup>127</sup> Michael B. Gill, “Presumed Consent, Autonomy, and Organ Donation,” *Journal of Medicine and Philosophy* 29, no. 1 (2004): 44.

<sup>128</sup> Wilkinson, “Individual and Family,” 23.

should not rest on the donor's side and any moral decision on organ donation should favor the persons who are waiting for an organ transplant to save their lives.<sup>130</sup>

For some, Western philosophy and culture with its “secular tradition that is based on rationality and the Enlightenment” provides the basis for answering moral and ethical questions concerning organ donation. In this regard, the influence of philosophers as Descartes and the idea of the separation of personality and identity certainly endorses the medical possibilities coming from organ transplantation, as the corpse is seen as a source of organs and other valuable materials. But the Kantian respect for autonomy also supports our western tradition that one should not be obligated to consent to organ donation after death. Organ donation is seen as an act of giving and therefore an altruistic deed.<sup>131</sup> Others would oppose that altruism implies a form of self-sacrifice which is absent in the case of *post-mortem* organ donation and that we should instead refer to the concept of solidarity which goes with the idea that cooperative actions entails mutual benefits and obligations.<sup>132</sup> Still, others argue that “making one's own organs available for donation after death is in fact a moral duty.”<sup>133</sup>

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<sup>129</sup> Eichinger, “Brain Death,” 15.

<sup>130</sup> Cronin, “Transplants,” 219.

<sup>131</sup> Sabine Wöhlke, Julia Inthorn, and Silke Schicktanz, “Organ Transplantation in the Face of Donor Shortage –The Role of Body Concepts for Donation Willingness. Insights from a Survey with German Medical and Economics Students,” in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 25.

<sup>132</sup> Diana Aurenque, “Why Altruism is not a Convincing Argument for Promoting Post-mortem Organ Donation: Responsibility and Solidarity as Key Concepts,” in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 65.

<sup>133</sup> Katherine Mendis, “Organ Transplantation in the Face of Donor Shortage - Foundations of a Duty to Donate Organs,” in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 51.

Although western tradition serves as a basis, it has been rightly pointed out that it would be wrong to assume that the western medical paradigm has been adopted by all citizens of the western industrialized world.

The increasing understanding of modernity, its post and late versions in their complexities, provides a necessary framework to reject such a simplistic assumption of *Western* culture as something that is homogenous, solely scientific, secular, and rationality-based. Instead, moral and political pluralism based on self-determination, as well as a critical assessment of scientific pragmatism, are in themselves leading paradigms. Hence, cultural factors have diverse sources and various forms of expression must be expected when citizens hold a position towards complex social practices such as organ donation. In summary, culture comprises convictions, values, and codes of behavior as well as lifestyle practices, which have been acquired and are transmitted to future generations.<sup>134</sup>

It is therefore crucial to examine Québec's specific situation, and more specifically its culture, tradition and values to better provide ethical answers as to whether family's involvement in organ donation should be restricted or not. Once again, our goal is not to propose a philosophical essay but rather to assess what are the main ethical elements to consider on this issue as well as the values and attitudes of Quebecers. For doing so, we will consider the thinking of a few expert committees and will also examine the results of polls conducted in the last years.

#### What Does Québec Want?

This question has been raised over the years by Anglo-Canadians from other provinces in order to better understand Quebecers and what has been referred to as *la différence québécoise*. It is now well recognized that the province of Québec is by itself a

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<sup>134</sup> Wöhlke et al., "The Role of Body Concepts," 28.

distinct society in many ways. Quebecers are influenced as much by their French and British heritage as by the American culture in which they live. When asked which is their predominant culture, Quebecers will divide themselves almost equally into each of these three founding cultures.<sup>135</sup>

In *Le Code Québec*, Jean-Marc Leger and his colleagues dress the seven differences which makes Quebecers unique. They point out that our uniqueness is not as pronounced as we might believe, 71% of our perceptions, attitudes and behaviors being much like other Canadians. However, they argue that the remaining 29% can make the whole difference. Keeping this in mind, it is therefore interesting to gather the values of Quebecers on social issues like organ donation and medical aid to dying.

The Initial Work of the Commission de l'Éthique de la Science et de la Technologie

The government created the Commission de l'Éthique de la science et de la Technologie (the Commission) in 2001 in order to critically assess the development and applications of science and technology and to co-ordinate a reflection on the related ethical issues for Québec's society. In the context of organ shortage, one of the first position papers of the Commission focused, in 2004, on the ethical questions surrounding donation and transplantation of organs in Québec. From the onset, the Commission laid the fundamental ethical values involved.

Altruism, solidarity, and beneficence are values that the Commission believes in, both for individuals and society, and that are fundamental in organ donation. However, it recognizes that these values cannot be universally defined; symbolic representations of life, death, the body, the individual's place in the universe, and spiritual belief systems underpin

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<sup>135</sup> Jean-Marc Léger, Jacques Nantel, and Pierre Duhamel, *Le Code Québec: les sept différences qui font de nous un peuple unique au monde*, (Montréal : Les Éditions de l'Homme, 2016).

values like respect for physical integrity or freedom of choice, which cannot be ignored or dismissed in the context of organ donation. In this sense, the Commission believes that some leeway exists in terms of respect for physical integrity, as long as organs are removed only with the free and informed consent of the donor or family, the priority being the donor's autonomy and freedom of choice. In the context of organ donation, it is a matter of a gift of the self, of a part of one's body to another person, leading to an "eternal debt," but one which can be acknowledged by the recipient in several ways.<sup>136</sup>

Although the Commission gives priority to the donor's autonomy and freedom of choice, it is of the view that this autonomy is not absolute and that "other values and principles offset autonomy: beneficence, nonmaleficence, solidarity, and justice, to name just a few."<sup>137</sup> In its review of the informed consent system in place in Québec, the Commission acknowledges the fact that most physicians deem it mandatory to obtain consent from the donor's family before beginning the organ donation process, even if the deceased have expressed their wishes to donate. However, relying on limited source of information showing that families rarely reverse the decision of a donor,<sup>138</sup> the Commission refers to values of respect, autonomy and trust to reiterate the importance of raising the subject of organ donation with families. For the Commission, respect requires that those "who approach the family about organ donation remain neutral and do not

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<sup>136</sup> Commission de l'Éthique de la Science et de la Technologie, *Position Statement – Organ Donation and Transplantation: Ethical Dilemmas Due to Shortage* (Québec : Bibliothèque nationale du Québec, 2004) 5.

<sup>137</sup> Commission de l'Éthique de la Science et de la Technologie, *Position Statement*, 37.

<sup>138</sup> The Commission relied on communication with healthcare workers and a statement from the Danish Council of Ethics stating " it is essential for the debate on organ transplantation to make it clear that such clashes are confined to a very small number, so that in general the next-of-kin cannot be said to constitute a hindrance to organ donation when the deceased has given consent. Nor, then, is it possible to blame the unmet need for organs on any such conflict between the deceased and the next-of-kin." As we have seen, our analysis on the impact of families shows a different reality.

present consent as the expected decision”<sup>139</sup> and autonomy implies that “families must be able to make informed decisions, whether for or against donation.”<sup>140</sup>

Keeping these assumptions in mind, the Commission recommended in 2004 the *status quo* with respect to the informed system of consent in place in Québec, which consent was then expressed by signing a declaration of consent to donate and sticking it on the back of the health insurance card at the time of renewal. In his report, the Commission rejected other initiatives on consent such as a presumed consent model, a mandated choice or even the set-up of a consent registry which the Commission believed offered fewer benefits than risks and drawbacks since “even with a registry in place, people would still have to notify their family members, since healthcare workers will in all likelihood continue to request the family’s consent before proceeding.”<sup>141</sup>

As we can see and notwithstanding the priority claimed to be given to the autonomy of the deceased, the Commission does nothing to give priority to the consent given by the donor and alleviate the role of families but on the contrary reaffirms such a role “out of respect for families and their needs.”<sup>142</sup> These findings of the Commission certainly seem awkward today when we realize the success of the registries in Québec and the impact of families on consent to donation. But even back in 2004, the inclination of the Commission for the involvement of families does not seem well supported by the values and attitudes of Quebecers.

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<sup>139</sup> Commission de l’Éthique de la Science et de la Technologie, *Position Statement* 44.

<sup>140</sup> Commission de l’Éthique de la Science et de la Technologie, *Position Statement* 45.

<sup>141</sup> Commission de l’Éthique de la Science et de la Technologie, *Position Statement*, 42.

<sup>142</sup> Commission de l’Éthique de la Science et de la Technologie, *Position Statement*, 42.

Indeed, in its consultation process, the attempts of the Commission to gather the feelings and values of the population on the question of consent were dim to say the least.<sup>143</sup> In the workshops consultations, many of the players engaged in the process of donation raised the importance of respecting the decision of the deceased, without the Commission really emphasizing this feeling in its report.<sup>144</sup> Also, a mini-survey conducted for the Commission revealed that 55% of the population surveyed approved of a presumed consent system and 67% of a mandatory declaration.<sup>145</sup> People were not surveyed about the idea of setting-up a registry on organ donation or about the role of families but considering the rate of approval expressed for mandated choice, the vast majority would have certainly approved of a registry which, like the mandatory declaration, supports the principle of the autonomy of a person.

#### Surveys on the Attitudes and Values of Quebecers

The predisposition of the Commission for the role of families seems surprising considering the results of an extensive poll conducted among all Canadians two-years before. In April 2002, Health Canada retained the firm Environics to conduct a survey to examine the awareness and attitudes of Canadians on organ donation. The final report published in June 2002 revealed the following results:

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<sup>143</sup> The two-stage consultation conducted by the Commission was in the form of workshops with informed players engaged in the process of donation and in the form of a call to Quebecers for written opinions. In its report, the Commission recognized that the second part of its consultation was unsuccessful and didn't provide much assistance. To offset this lack of involvement of the population, a mini-survey containing four questions was conducted but with only one question pertaining to consent.

<sup>144</sup> Commission de l'Éthique de la Science et de la Technologie, *Rapport de consultation sur les enjeux éthiques du don et de la transplantation d'organes- Résultats des entrevues de groupes et du mini-sondage réalisé dans le cadre de l'enquête Statmédia, Printemps 2004* (Québec: Bibliothèque nationale du Québec, 2004) 18.

<sup>145</sup> Commission de l'Éthique de la Science et de la Technologie, *Rapport de Consultation*, 82.

- 93% of Canadians strongly or somewhat approve of organ donation and strong approval is significantly higher in Québec;
- 40% of Canadians and 52% of Quebecers said that they had signed a donor's card;
- 44% of Canadians have decided to become organ donor and Quebecers are more inclined to have made that decision. 83% of those who had decided to become an organ donor said that they had discussed their wishes with their family;
- When questioned about the conflict between the wishes of the deceased and those of the family, 66% of Canadians wrongfully believe that the wishes of the deceased have legal precedence. Notwithstanding what reality is, 90% of Canadians, Quebecers alike, believe that it should take legal precedence over those of the family.<sup>146</sup>

Surveys certainly offer valid information on opinions and values of a given population and with such a strong rate of support for putting the wishes of the deceased above those of family, it supports the idea of limiting family's involvement in consent to organ donation when the deceased have already expressed their choices. Also, it must be pointed out that the opinions and values expressed in this survey by Canadians and Quebecers are not isolated. Indeed, the questions about what is and what should be the role of families on consent to organ donation have been reiterated in four different surveys conducted between 2001 and 2010. These surveys reveal consistent results, the

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<sup>146</sup> Health Canada, *Organ and Tissue Donations: Awareness, Knowledge and Advertising Recall – Final Report*, (Environics Research Group, June 2002), <https://professionaleducation.blood.ca/sites/msi/files/Survey-Donation-Recall.pdf>.

view of the population on the priority to be given to the wishes of the deceased over those of the family receiving more or less a 90% rate of approval.<sup>147</sup>

### An Evolution of Thinking on the Role of Families?

The fact that Quebecers' fundamental social values revolve around the principle of self-determination and the autonomy of individuals to decide for themselves was made even more obvious in the consultations held on the issue of dying with dignity. At the end of 2009, after a public debate on euthanasia and surveys showing that most Quebecers were in favor, the National Assembly of Québec adopted a motion creating a Select Committee to Study the Issue of Dying with Dignity. To assist the Select Committee in its consultation, the Commission published a discussion paper raising various ethical questions on the issue. On this occasion, we believe the Commission strengthened its views on the principle of self-determination as a fundamental value of Quebecers to act upon.

L'autonomie morale – comprise comme autodétermination – est la capacité d'une personne à agir conformément à ce que lui dicte sa conscience ou sa raison, et donc à déterminer elle-même les règles morales auxquelles elle se soumet. Le premier document produit par la Commission sur le « mourir dans la dignité » a montré que l'autonomie morale est une valeur phare dans notre société. Elle est également mise en avant dans les chartes des droits et libertés du Canada et du Québec, de même que dans la jurisprudence.

Par conséquent, il tombe sous le sens que la capacité de décider pour soi et d'être maître de ses choix de vie subsiste lorsqu'il est question de déterminer les conditions de sa fin de vie. Pour certains, cela va jusqu'à inclure le choix du moment de la mort. En effet, selon quels critères peut-

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<sup>147</sup> Canadian Council for Donation and Transplantation, *Public Awareness and Attitudes on Organ and Tissue Donation and Transplantation Including Donation After Cardiac Death – Final Report*, (Environics Research Group, December 2005); Canadian Blood Services, *Views toward Organ and Tissue Donation and Transplantation – Final Report* (Ipsos Reid, July 2010), 31. <https://profedu.blood.ca/sites/mtsi/files/Views-Toward-OTDT-Final-Report-2010-07-221.pdf>.

on refuser à une personne lucide demandant l'euthanasie ou une aide au suicide de l'obtenir?<sup>148</sup>

After an exhaustive two years consultation, the Select Committee released its report in March 2012. In this report, the Select Committee had the opportunity to reflect on the social values of Quebecers.

First, the decline of religious practice in recent decades and the changing morals of society, increasingly centred on the development of individual freedoms and respect for personal autonomy, have changed the way we view end of life and death. In the past, society was more homogeneous and subject to various authorities. Death had a different meaning then, mainly because of religious references. But the expiatory suffering of yesteryear has lost its meaning, resulting in the unwillingness to tolerate prolonged suffering. Personal autonomy, inviolability and integrity, along with pluralistic values, have become the cornerstones of society. In view of this, we believe a person can choose to conduct his life according to his own personal values and beliefs.<sup>149</sup>

Among the questions raised by the select Committee in its consultation, it is interesting to note the attention given to the potential impact of euthanasia on family's grieving. Much like the situation in organ donation, consideration was given to the feelings of families and the Committee received different views on this matter. It revealed that for some, "euthanasia can make it easier for families to grieve by making those final days more peaceful and humane." For others, "euthanasia is a violent method that in no

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<sup>148</sup> (Translation) *Moral autonomy - understood as self-determination - is the capacity of a person to act in accordance with what his conscience or reason dictates to him, and thus to determine for himself the moral rules to which he submits. The first document produced by the Commission on "dying with dignity" has shown that moral autonomy is a key value in our society. It is also put forward in the charters of rights and freedoms of Canada and Québec, as well as in the case law. Therefore, it comes to the sense that the ability to decide for oneself and to be in control of one's life choices remains when it comes to determining the conditions of one's end of life. For some, this goes to include the choice of the moment of death. Indeed, according to what criteria can one refuse to a lucid person asking for the euthanasia or a help to the suicide to obtain it?* Commission de l'Éthique de la Science et de la Technologie, *Document de réflexion - Mourir dans la dignité : Sept questions sur la fin de vie, l'euthanasie et l'aide au suicide*, (Québec : Bibliothèque nationale du Québec, 2010), 10.

<sup>149</sup> Select Committee on Dying with Dignity, *Report* (Québec: Bibliothèque et Archives nationales du Québec, 2012), 48.

way helps the grieving process.” Even more, the fact of contributing “to the patient’s process of asking for help to die is bound to leave scars on the family, including perhaps a sense of guilt.”<sup>150</sup> From these comments, we realize again that many are adamant to pay more attention to the feelings of families than to those of the individual concerned. Notwithstanding, the Committee recommended that legislation be amended to recognize medical aid in dying as an appropriate end-of-life care and fixed criteria to be met to agree to such a request, no criteria being based on the wishes of families.<sup>151</sup>

Also, with the view that a patient’s condition could deteriorate with time and that they could become incapable of making a decision regarding end of-life, the Committee recommended that advance medical directives be not only recognized but legally binding. In this regard, the Committee specifically acknowledged the fact that families and health practitioners do not always respect advanced medical directives and it is exactly in order “to ensure people’s wishes are respected” that it proposed that they be binding, thereby clearly expressing the precedence of the patient’s wishes over those of their family.<sup>152</sup>

Following the report and another vast public consultation, the Act Respecting End-of-Life Care was adopted by the National Assembly of Québec in 2014.<sup>153</sup> The province of Québec became the first Canadian province to offer medical aid to dying and remains today a precursor on proposed changes to be brought to better recognize and enforce this right to self-determination.<sup>154</sup>

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<sup>150</sup> Select Committee, *Report*, 66.

<sup>151</sup> Select Committee, *Report*, Recommendation 13, 82.

<sup>152</sup> Select Committee, *Report*, 41-43.

<sup>153</sup> An Act Respecting End-of-Life Care, (R.S.Q., ch. S-32.000).

Not all recommendations of the Committee were approved and introduced into law and many ethical issues remain to be resolved. With respect to advanced medical directives, some recommendations were put aside but a registry of medical directives has been set-up and the law confers on the tribunals the ability to either order that the instructions relating to care expressed in those directives be carried out or that they may be invalidated “if it has reasonable grounds to believe that the author of the directives was not capable of consenting to the care at the time of signing the directives or that the directives do not correspond to the author’s wishes in the present situation.”<sup>155</sup> Although different from the recommendation of the Committee that they be legally binding, it nevertheless allows the wishes of a person to die with dignity to be respected and that any objection be based not on the wishes of others but on the proof that the patient’s wishes had changed or were flawed.

Among the ethical issues remaining after the adoption of the Act Respecting End-of-Life Care, was the possibility for a patient requesting medical aid to dying to also consent to the donation of organs. Once more, the Commission was asked to consider this issue and it is again interesting to note the evolution of its thinking. Indeed, the

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<sup>154</sup> In September 2019, the Superior court ruled that both the Federal and Québec laws were putting unconstitutional barriers for some vulnerable patients and forcing them to endure harsh physical and psychological suffering, because one of the conditions to get medical aid in dying required that their natural death be imminent. Tu Thanh Ha and Kelly Grant, “Québec Court Strikes Down Restriction to Medically Assisted Dying Law, Calls it Unconstitutional,” *The Globe and Mail*, September 12, 2019, <https://www.theglobeandmail.com/life/health-and-fitness/article-Québec-court-strikes-down-parts-of-laws-on-medically-assisted-death/>. In October, the government of Québec confirmed that it would not appeal the judgment and would broaden the scope of the law. At the Federal level, this issue gave rise to a debate during the general election held in October 2019, but the leader of the Liberal party, who was finally elected with a minority government, had confirmed that he would not appeal the judgment if elected. Tommy Chouinard, « Aide médicale à mourir: Québec accepte d’élargir l’accès, » *La Presse*, October 3, 2019, <https://www.lapresse.ca/actualites/politique/201910/03/01-5243905-aide-medicafe-a-mourir-Québec-accepte-delargir-laces.php>.

<sup>155</sup> An Act Respecting End-of-Life Care, s.61.

Commission resorted again to values of autonomy, dignity, justice and well-being in its discussion and considered the impact of such a decision on the family, but this time only insisted that family should “ideally be informed.”

Le bien-être de la famille et celui des proches passent par la connaissance et l’acceptation des intentions du donneur. La famille devrait idéalement en être informée. Cependant, rien dans la Loi concernant les soins de fin de vie n’oblige le patient qui demande l’aide médicale à mourir à informer ses proches de sa décision, et encore moins à obtenir leur consentement. Il pourrait vouloir garder confidentielle sa volonté de faire don de ses organes, ce qui pourrait bouleverser sa famille et ses proches. Pour leur bien-être, il serait important que le donneur en discute préalablement avec eux.<sup>156</sup>

The Commission then made a firm recommendation for health care centers to ensure that medical providers respect the autonomy of the patients and their wishes to donate their organs.<sup>157</sup> In our view, individuals who have expressed their consent to donate after having requested medical aid to dying should not be treated differently than individuals who have expressed such a decision while in good health. We understand that the former might have had a better opportunity to discuss their decision with family, but in the same fashion, the wishes of the latter should be acted upon notwithstanding their family wishes. We believe this better reflects the values of Quebecers on the issue.

Such attitude was evidenced again in a web survey conducted for Transplant Québec at the end of 2018. Although it reveals that 69% of potential donors confirmed

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<sup>156</sup> (Translation) *Knowing and accepting the wishes of a donor favors the well-being of the donor’s family and those close to him. The family should be ideally informed. However, nothing in the act respecting end-of-life care requires the patient who request medical aid in dying to inform those close to him, or even less to obtain their consent. He could keep confidential his wishes to donate his organs, which could upset his family and those close to him. For their well-being, it would be important for the donor to discuss it with them.* Commission de l’Éthique de la Science et de la Technologie, *Supplément - Enjeux éthiques liés au don d’organes en contexte d’aide médicale à mourir*, (Québec : Bibliothèque nationale du Québec, 2016) 19.

<sup>157</sup> Commission de l’Éthique de la Science et de la Technologie, *Supplément – Enjeux Éthiques*, 24.

having taken steps to make their wishes known to their families, more than a third of those who did not discuss their wishes gave for a reason that it does not concern them.<sup>158</sup>

The values of Quebecers, and Canadians outside of Québec, on the role of families in the context of consent of organ donation can also be gathered to some extent from the public discourse on organ donation. In this regard, it is interesting to note the results of a systematic content analysis of the articles published in English-language newspapers addressing family veto between 2000 and 2016. It concludes that family veto on consent to organ donation was framed predominantly as something that should not be allowed and most publications called for changes. According to the authors of the analysis “the concept of a family’s overriding a deceased person’s expressed wish to donate was characterized as “terribly wrong,” “a shame” and “tragic.”<sup>159</sup> We are of the view that this adequately reflects on the values of Canadians on this issue and that the same analysis in French newspapers could only have brought similar or even stronger results for Quebecers.

In conclusion, similarly to the conclusions reached in the previous section, we believe that from an ethical standpoint, when a person has expressed their consent to donate their organs at death, those wishes shall be respected and family’s involvement shall be limited to situations where it can be demonstrated that the wishes of the donor

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<sup>158</sup> Transplant Québec, “92% of Quebecers Support Organ Donation: Transplant Québec Wants to Do More to Encourage Citizens to Register as Donors!” Press Release, February 19, 2019, [http://transplantQuebec.ca/sites/default/files/2019-02-19\\_communique\\_officiel\\_f.pdf](http://transplantQuebec.ca/sites/default/files/2019-02-19_communique_officiel_f.pdf).

<sup>159</sup> Samantha J. Anthony, Maeghan Toews, Timothy Caulfield, and Linda Wright, “Family Veto in Organ Donation in Canada: Framing within English-Language Newspaper Articles,” *CMAJ OPEN*, 5(4). E768-E772.

have changed afterwards. The values of Quebecers would not allow such a consent to be revoked solely based on the wishes of families themselves.

For individuals who have not expressed their wishes, we believe again that consent must then rest on families but in taking this decision, they should be restricted to determine what the deceased would have wanted and not what they themselves wish for.

Finally, when a person has refused to consent to organ donation we believe that the values of Quebecers also require that such wishes be respected although it would be thinkable to refer to values of solidarity to override such a decision since it entails the principle that “l’homme n’a pas de droits, il n’a que des devoirs envers les autres.”<sup>160</sup>

### Practical Considerations

The idea of restricting family’s involvement on consent to organ donation seems even more understandable when various practical arguments are considered. The patterns already adopted by Quebecers, the investments made in the actual consent system, the efforts devoted to organ donation and transplantation all concur to go one step further to improve our consent model by restricting family’s involvement.

Regarding patterns and behaviours, all surveys demonstrate that the level of awareness and support of Quebecers for organ donation is very important. Moreover, it shows that they generally take action to express their wishes. The survey conducted for Transplant Québec in October 2018 also confirms this reality. The results indicate that

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<sup>160</sup> (Translation) *Man has no rights, he has only duties towards others.* See in J.M. Mantz, “Transplantations et greffes d’organes et de tissus: Le point sur la question,” *Les Journées Strasbourgeoises*, p. 124, when referring to the philosopher Vladimir Jankelevitch.

92% of respondents are Favorable to organ donation and that 77% would accept donating their organs at death.<sup>161</sup> Also, 70% of those who would accept to donate their organs have taken actions to make their wishes known, thereby representing 54% of all respondents.<sup>162</sup>

Figure 14 shows that when questioned about the measures taken to express their wishes, the respondents having made their wishes known indicate that not only are they knowledgeable about the measures available to express their wishes, but they are in fact making use of them.

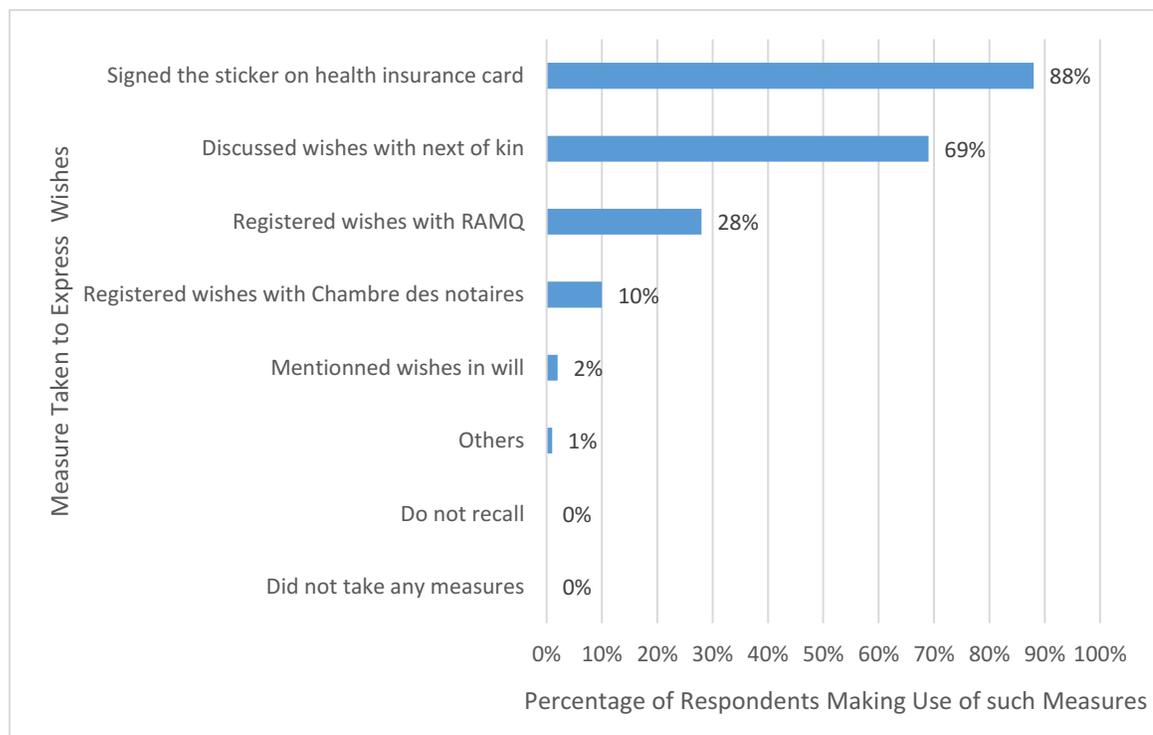


Figure 14: Measures taken by respondents to make their wishes to donate known

<sup>161</sup> Transplant Québec, “92% of Quebecers Support Organ Donation,” Tableaux du sondage, accessed November 10, 2019, [http://transplantQuébec.ca/sites/default/files/2019-02-19\\_tableaux\\_sondage\\_leger\\_ppt.pdf](http://transplantQuébec.ca/sites/default/files/2019-02-19_tableaux_sondage_leger_ppt.pdf).

<sup>162</sup> Which represents 801 respondents among the 1515 who answered the survey.

The answers to the survey also indicate that respondents have well answered the public call to make their wishes known since they had, on average, made use of two of these measures to express their wishes, which is why the total of answers exceed 100%.

Therefore, having clearly understood the consent system on organ donation and taken action to express their wishes by using the measures put at their disposal, we believe once again that those wishes should be acted upon and that families should not be able to easily override such wishes.

To the same extent, the investments, both financial and in human resources, dedicated to organ donation in Québec offer another practical argument to improve our consent model system by restricting family's involvement. Such investments are not limited to the setting-up, maintenance and administration of the government's consent registry every year but also to the investments made to have Quebecers express their wishes on the sticker provided at the time of renewal of their health insurance card. We can also add the investments made through hospitals and Transplant-Québec to gather and act upon these wishes and the investments dedicated to repeated ad-campaigns to invite Quebecers to make their wishes known. Again, it is regrettable and awkward to realize that notwithstanding all the time, efforts and money invested in making Quebecers express their wishes, such wishes can be put aside by families and the latter's decision prevails. We believe the deceased wishes are paramount and that family's involvement must be restricted to make sure that decisions are made in accordance with the deceased expressed wishes.

A third practical reason to improve our actual consent model by restricting family's involvement on consent to organ donation is supported by the evidence that our consent system works, although we can do better. As we have seen, Quebecers are favourable to organ donation and registrations are increasing every year in both the CNQ and RAMQ registries. Regarding the latter, an assessment of the effectiveness and performance of the RAMQ concluded in 2016 that the rate of registration exceeded government's expectations, with more than 30% of the population covered having registered their consent.<sup>163</sup> Registrations have continued to increase thereafter and, as shown in Figure 14, many Quebecers are sticking their consent on their health insurance card and making their wishes known to family. Moreover, the number of organ transplantations was on the rise in the last years and the number of persons waiting for a transplant is slowly decreasing.

Indeed, the main problem with our consent system has to do with the negative impact of families, which has been acknowledged worldwide and has been further demonstrated for Québec in Chapter 3.<sup>164</sup> It is with this finding in mind that we must act to improve the consent system by restricting family's involvement in some ways. Not doing so would contribute to the continuing loss of available organs and could also lead to Quebecers deserting the idea of registering their consent if they feel that it becomes useless because of the priority given to the wishes of their families.

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<sup>163</sup> BDO Canada, *Rapport sur l'application de la loi constitutive de la Régie de l'assurance maladie du Québec*, (Québec, 21 juin 2016), <http://www.ramq.gouv.qc.ca/SiteCollectionDocuments/citoyens/fr/rapports/rapp-application-loi-constitutive-ramq.pdf>.

<sup>164</sup> Meaghan Toews, and Timothy Caulfield, "Evaluating the family veto of consent for organ donation," *CMAJ* 2016, 188: E436—7; Michael Robinson, "Mourning Families Increasingly Blocking Organ Donations of Loved Ones," *The Star*, June 16, 2019, <https://www.thestar.com/news/gta/2016/06/16/mourning-families-increasingly-blocking-organ-donations-of-loved-ones.html>; Rachel Naylor, "Hundreds of Families Block Organ Donation," *BBC News*, October 19, 2017, <http://www.bbc.com/news/health-41671600>].

In conclusion to this Chapter, many arguments can be raised both in favor and against the role of families when consent to organ donation is concerned. However, our research and analysis concur to support the view that there happens to be as much practical arguments than legal and ethical ones to restrict family's involvement on consent to organ donation in Québec. Introducing such restrictions would not only be in conformity with the fundamental rights of potential donors but would also be ethically acceptable and practically justified. Most importantly, such restrictions would reduce the number of organ referrals being refused by families, would increase the number of organs available for transplantation and would save lives.

## Chapter V

### General Conclusion and Potential Solutions to Consider

With the progress of medicine, many lives can now be improved through organ transplantation. Many times, it also offers a unique opportunity to save people's lives. Unfortunately, and despite all efforts made, all countries continue to face a chronic shortage of available organs for transplantation as the number of persons waiting for organ transplants outnumbers the number of available organs. Regrettably, year after year, people die while waiting for an organ. Such is the case for the province of Québec, where 54 potential recipients died in 2017 and 28 in 2018, while on the waiting list.

Increasing the number of organs available for transplantation is one of the main challenges of health systems around the world. The evolution of living donation is certainly a great way to increase the availability for some organs. However, *post-mortem* organ donations remain the principal source for organ supply and all countries have been intensifying their efforts to increase their rate of deceased donors per million of population, which is one the main indicator to measure the effectiveness of an organ donation system. With a rate of 19,5 dpmp in 2018, the province of Québec is in the average of Canadian provinces, but still well below countries like France or the United States, whose rate are at 26 and 32 dpmp respectively, or Spain, which is seen as the all-time champion at 46 dpmp.

Improving the rate of organ donation requires multiple efforts. For many, the solutions lie mostly in the planning and operation of the donation system which can offer,

more than the type of consent system itself, better hopes for increasing the number of organs available. Focused is then placed on matters such as specialists training, infrastructure, systems for coordinating donation process and so on.<sup>165</sup> For others, the type of consent system can make a difference and presumed consent is often seen as a key to improve donation rate since countries with presumed consent systems often show a better organ donation rate than countries with informed consent.<sup>166</sup> However, consent systems cannot simply be divided between these two as there are a whole variety of sub-systems in between, going from a soft presumed consent system to a hard informed consent system, the differences revolving among other things on the importance to be given to the wishes of the deceased and on the role of families.

Although we agree that improving organ donation rates requires more efforts than just working on consent, it should not mean to set it aside, as efforts are also required on the issue of consent in order to improve organ donation. Even if a debate remains as to which consent system is the best, one conclusion is more obvious than ever: when addressing the issue of consent, the greatest impediment to organ donation lies in the refusals of families to consent to organ donation.

In this regard, this thesis addressed the impact of families on consent to organ donation in the province of Québec, which has been a leader in organ transplantation in Canada. More specifically, this thesis examined the impact of requesting family consent in cases where the deceased have already expressed their wishes on organ donation, thereby amounting to a double consent, or what is referred to as family veto.

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<sup>165</sup> Hayes, "Donation and Devolution," 145.

<sup>166</sup> Abadie and Gay, "Impact."

Through the review of Transplant Québec's annual reports for the last ten years, as well as from an analysis of a special set of data produced by Transplant Québec for the years 2016 to 2018, we have come to the clear conclusion that families have a negative impact on consent to organ donation in Québec. Indeed, two hundred cases of organ referrals have been refused by families in 2018, amounting to 37% of all refusals. Among these refusals, families overrode the consent given by the deceased in 35 cases on average in each of the last three years and the reasons for overruling such consent are mainly based on motives associated with their own wishes and not those of the deceased. Therefore, it has been clearly demonstrated that in Québec, families have a negative impact on consent to organ donation, which causes lives to be lost.

Based on this conclusion, we have suggested the idea of restricting family's involvement on consent to organ donation and have identified many legal, ethical and practical considerations which militates in favor of restricting their role. First, both the fundamental rights of the deceased to self-determination and inviolability, as well as the specific provisions of the Civil Code and other laws pertaining to organ donation, clearly support the conclusion that there are no legal grounds for families to override the wishes of a donor as the exception of "compelling reasons not to do it" could not be justified by their own wishes or based on their distress or exhaustion with the organ donation process. With respect to the decision of a deceased to refuse organ donation, rare circumstances may offer an opportunity to challenge such a refusal under the compelling reasons exception but it remains doubtful that such an attempt would be successful. Secondly, values such as moral autonomy, altruism and solidarity as well as opinion and attitudes of Quebecers on integrity all offer ethical justifications for limiting the role of families.

Finally, all efforts and investments dedicated to gathering the wishes of individuals on organ donation and to registering these wishes offer practical arguments to act upon them without letting families intervene to the contrary. Indeed, only in cases where the deceased have not expressed their wishes or when it can be demonstrated that such wishes have changed overtime could family intervene. However, even in these circumstances, we are of the view that family's consent or refusal should be supported by what the deceased would have wanted and not by their own wishes.

Having concluded that family's involvement on consent to organ donation should be restricted, the question remains as to which limitations and restrictions should be introduced. It was not the purpose of this thesis to determine such restrictions as this issue requires more research. Nonetheless, we wish to identify a few potential solutions for questioning.

First, it is necessary to briefly address the possibility of putting in place a presumed consent system as some are presently advocating for, seeing in such a system the solution to increase organ donation rates.<sup>167</sup> It is not our goal to review the pros and cons of presumed consent systems as this debate has received notable attention and research over the years and continues to do so. As much as there are studies showing that countries with presumed consent system perform better in organ donation, others attribute their performance to other factors. We would limit our view on this issue by saying that we are doubtful about the advantage of putting in place a presumed consent system as a solution to restricting family's involvement on consent to organ donation, since it seems to us that their role can only be amplified in such a system. Indeed, even if a registry

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<sup>167</sup> As mentioned in Chapter 2, a new petition and Bill 399 has been recently presented in order to introduce a presumed consent system in Québec. See note 41.

remains in place for people to register their consent and not only their refusal, it seems to us that a presumed consent system is bound to make less people registering their consent because it would be deemed anyway. Putting in place a presumed consent system would therefore not alleviate the role of families but give them even more of a say and increase the chances of referrals being refused by them.<sup>168</sup>

Such as been demonstrated in Chapter 3, where data reveals that family refusals occurred in 200 organ referral cases in 2018, it was shown that 42 of those refusals occurred in cases of registered donors, representing 20% of all family refusals and 6% of all organ referrals. Therefore, family refusals have predominantly occurred in cases where the deceased have not expressed their wishes, which should be most of the cases in a presumed consent system. An analysis of the impact of family refusals in the UK in 2011-2012 also indicates that the rate of family refusals is much more important when the wishes of the deceased have not been expressed. Indeed, the familial rate of refusal stood at 7% when donors have expressed their wishes but increased to 52% when such wishes have not been expressed.<sup>169</sup> As is rightfully suggested by Hayes, “this would be of concern to an opt out system which operates on the basis of silence being equated with consent.”<sup>170</sup> Therefore, simply putting in place a presumed consent system would be

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<sup>168</sup> As mentioned earlier, England and Scotland changed their consent system and will introduce in 2020 a presumed consent to organ donation, while maintaining at the same time a registry for those who would like to register either their consent or their refusal to organ donation. We believe that the role of families has not been reduced since information released continue to stress the importance for potential donors to discuss their wishes with family in order for them to be consulted, to support or to accept their decision. NHS Blood and Transplant, “Organ Donation,” accessed November 10, 2019, <https://www.organdonation.nhs.uk/uk-laws/>.

<sup>169</sup> Hayes. “Donation and Devolution,” 148-149.

<sup>170</sup> Hayes. “Donation and Devolution,” 148.

insufficient to reduce the negative impact of families on consent to organ donation and other solutions must be examined.

One such solution could be to turn to a first-person consent system such as the one in place in the USA. In such a system, the donor's wishes are paramount and must be respected. Only in cases where such wishes have not been expressed may consent rest on families which would then act as the first person to consent. Priority is therefore given to the donor's designation and supported not only by legislation but mainly by the approach and practice of Organ Procurement Organizations (OPO's). As mentioned earlier, organ donation legislation in the USA not only provides that the consent of a donor is irrevocable and no other consent is required but also that families do not have the power to consent, amend or revoke a donation made by donors during their lifetime.<sup>171</sup> As much important than legislation is the necessity to adapt to the philosophical change and modify the approach with families, leaving the traditional model of asking them for consent and implementing instead the new model of reaffirming the donor's designation. The experience of many states revealed that applying the new approach proved to be difficult at first for OPO's staff who felt uncomfortable going against the wishes of families and had to deal with their opposition or threat of legal action. As mentioned by one OPO's executive, "We were nervous after the first case. We were prepared for families to take their story to the media. We were prepared for bad press and even prepared to be sued. We had our crisis plan in place, but we never had to use it."<sup>172</sup>

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<sup>171</sup> See note 19.

<sup>172</sup> Karen Sokohl, "First Person Consent OPOs Across the Country are Adapting to the Change," *UNOS Update*, First of a Three Part Serie, September-October 2012, 2, [https://www.unos.org/wp-content/uploads/unos/registires\\_combined.pdf](https://www.unos.org/wp-content/uploads/unos/registires_combined.pdf). As mentioned earlier in note, there is only one circumstance where the family overruling of their son's wishes to donate was successfully challenged in the courts, which indicates that the fear initially suggested has not materialized.

Thereafter, first person consent expanded throughout the USA and is not only well perceived and applied today but seen as having contributed to increasing organ donation rates, the USA now having an enviable rate of 32 deceased dpmp, one of the best in the world.

Changing the philosophy behind the role of families could therefore be done in Québec too. Attitudes and behaviors must be changed first. In this regard, the process followed by Transplant Québec and hospitals should not be to search for the consent of families but should instead be limited to consult them about any change of mind of the deceased. The forms presently used should be modified accordingly to better support such a limited consultation of families and not make them believe that their own consent is also required. The confusion existing in various government websites must be corrected accordingly and ad-campaign should better focus on the limited role of families and the fact that they should not overrule the decision of the deceased, whatever their motives or distress.

Legislation can also be changed to limit the role of families. Part of the actual confusion may be explained by the uncertainty associated with the compelling reasons exception of the Civil Code. Modifying the specific sections concerned by emphasizing the principle that families are to intervene only to provide evidence of a change of mind of the deceased can only contribute to improving the consent system and change behaviors. Tougher legislation modifications may also be considered to prohibit families from overriding the decision of the deceased or to prevent medical team from giving priority to the wishes of families over those of the deceased, such as it is the case in the United States with first-person consent laws. Even if families' objections are not

challenged in courts, the existence of such tougher legislation may however better motivate families to respect the wishes of the deceased.<sup>173</sup>

Other alternatives to enforce the wishes of the donor and restrict the role of families would be by improving the registration system. In this regard, many innovative solutions have been advanced. For example, the registration system could be changed by requiring every person registering their wishes to also identify the name of a next of kin who has been informed about their wishes and could act as a main respondent. Such a solution has already been referred to in 2003, in the workshops held during the consultation of the Commission on organ donation. Such a designation could also be added on the sticker affixed on the back of the health insurance card. A similar solution would be for donors to appoint a designated second consentor who would uphold the donors' decision after death.<sup>174</sup> Others, have proposed to make the registration systems more flexible, either by allowing each registrant to indicate in advance if it would be acceptable or not for a relative to overrule their decision or by letting registrants record a short message to be sent to their families either upon registration or after death, if donation becomes an option.<sup>175</sup> In both cases, it would provide another clear indication of the wishes of the deceased and would further incite families to respect such wishes. Other solutions may include the regular renewal of the wishes indicated on the registries, which

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<sup>173</sup> Shaw et al., "Family over Rules," 486. The authors do not recommend adopting such a "hard-line approach" and recommend other strategies. However, it is our view that tougher legislation can serve as a deterrence and should be considered in the strategies put forward.

<sup>174</sup> J. De Wispelaere, and L. Stirton, "Advance Commitment: Rethinking the family Veto Problem in Organ Procurement," in *Organ Transplantation in Times of Organ Shortage: Challenges and Solutions*, ed. Ralf J. Fox et al., International Library of Ethics, Law and the New Medicine 59 (Switzerland: Springer, 2016), 157.

<sup>175</sup> Shaw et al., "Family over Rules," 486.

would give even more strength to such wishes and would multiply the opportunities to communicate one's wishes with families. Also, mandatory registration may be considered if it includes restrictions on the role of families.

In cases where the deceased have not expressed their wishes, some of the restrictions mentioned above could still be introduced. Although family consent would be required in such a case, it is still possible to change the approach to families, the process for obtaining consent and the legislation which applies in order to inspire families to better make a decision based on what would have been the wishes of the deceased. One such example can be derived from the restrictions implemented in Nova Scotia's upcoming presumed consent system, which will take effect in 2020. As mentioned earlier, this new system will allow families to consent to or refuse organ donation only in cases where information about the wishes of the deceased is provided and would lead a reasonable person to conclude from this information that the wishes of the deceased were different from its recorded wishes or his deemed consent.<sup>176</sup> It shows that such restriction on the role of families can be implemented both in an informed or presumed consent systems and it will be worth to follow the impact of such restrictions on the rate of family refusals in Nova Scotia.

Finally, on another note, potential solutions may also focus on ethical reciprocity instead than on restrictions. Such reciprocity could translate into actions supporting a donor's family during the process of organ retrieval or giving family members some level of priority in the allocation of organs if they ever come in need of a transplantation themselves. Any potential solutions should also be supported by ad-campaigns which

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<sup>176</sup> An Act Respecting Human Organ and Tissue Donation, Nova Scotia Legislature, Acts of 2019. s.15(1). [https://nslegislature.ca/legc/bills/63rd\\_2nd/3rd\\_read/b133.htm](https://nslegislature.ca/legc/bills/63rd_2nd/3rd_read/b133.htm).

must also continue to focus on the factors influencing families when making a decision<sup>177</sup> or on ethically promoting either their altruism, solidarity or duty to donate.<sup>178</sup>

As can be seen, there are various potential solutions to consider when determining how to define the role of families on consent to organ donation and how to better abide by the wishes of a donor. Such solutions should not be judged negatively, as actions taken against families, but must instead be seen constructively, as measures adopted in sympathy for the individual donors and for those potential recipients who could benefit from the gift of life that organ transplant can confer. A Brazilian study once concluded that many families who overruled the wishes of their loved one came to regret it afterward and that even in cases when a deceased had not registered his wishes, 50% of families who refused donation would subsequently permit it in similar circumstances.<sup>179</sup> Therefore, more has to be done to identify solutions and determine the ones which would be the most appropriate in the circumstances, when keeping in mind the need to improve organ donation, the necessity to respect the autonomy of the deceased, the importance of supporting families through their grieving and the need to maintain a strong and reliable donation system. However, maintaining the *status quo* cannot be an option.

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<sup>177</sup> Lee Shepherd, and Ronan E. O'Carroll, "When Do Next-of-kin Opt-in? Anticipated Regret, Affective Attitudes and Donating Deceased Family Member's Organs," *Journal of Health Psychology* 2013, 19:1508-17.

<sup>178</sup> Katherine Mendis, "Foundation of a Duty to Donate," Aurenque, "Why Altruism Is Not a Convincing Argument"; Jennifer A. Chandler, and Vanessa Gruben, "The Ethics of Persuasion: Evaluating the Ethical Limits on Attempting to Persuade Families to Donate the Organs of Deceased Family Members," in *Ethical Issues in Pediatric Organ Transplantation*, ed. R. A Greenberg et al, (Ottawa: Springer International Publishing Switzerland, 2016), 63.

<sup>179</sup> Shaw et al., "Family over Rules," 485. M. Morais et al., "Families who previously refused organ donation would agree to donate in a new situation: a cross-sectional study," *Transplant Proc.* 2012;44:2268-2271

## Chapter VI

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