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Michelle Giroux*  
Informing the Future of End-of-Life Care in Canada: Lessons from the Quebec Legislative Experience

There have been numerous and challenging developments respecting end-of-life care in Canada. In Quebec, political consensus and changes in public opinion led to the adoption of end-of-life care legislation. This paper discusses the context and foundation of that reform and reviews its content with the objective of informing the future of end-of-life care in Canada. In the first part of the paper, I explore the balancing of the right to life and autonomy, with a focus on the approach chosen in Quebec by the Legal Experts Panel Report. In Part II, I discuss Quebec’s adoption of An Act Respecting End-of-Life Care, which recognized the precedence of the right to autonomy at the end of life and what it entails. I also highlight the differences between the approaches of Quebec and the Supreme Court in the Carter decision to show how Carter affects the future of the Quebec Act and, conversely, how Quebec’s laws affect the development of federal or provincial and territorial laws as we saw with the adoption of legislation to amend the Criminal Code.

Il y a eu plusieurs défis et changements importants concernant les soins de fin de vie au Canada. Au Québec, l’encadrement des soins de fin de vie s’est effectué suite à un débat social et politique non partisan qui a abouti à un consensus. Ce texte traite du contexte et des fondements de cette réforme et la présente dans le but d’aider au développement et à l’organisation des soins de fin de vie au Canada. Dans la première partie de ce texte, j’explore la recherche de l’équilibre entre le droit à la vie et l’autonomie en mettant l’accent sur l’approche retenue au Québec par le Rapport du comité de juristes experts. Dans la deuxième partie, je discute de l’adoption au Québec de la Loi concernant les soins de fin de vie et des implications qui découlent de la reconnaissance de la préséance du droit à l’autonomie en fin de vie. Je souligne de plus les différences entre l’approche du Québec et celle retenue par la Cour suprême du Canada dans l’affaire Carter. Ces différences sont importantes étant donné que la décision dans Carter affecte l’avenir de la loi québécoise et que, inversement, la loi québécoise affecte le développement de la loi fédérale et des lois provinciales et territoriales, comme ce fut le cas lors de l’adoption des modifications au Code criminel.

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Introduction

I. Evolution of healthcare, social debates and the law: Towards a new balance between the right to life and the right to autonomy
   1. Evolution of health care and of social debates
   2. The evolution of law: A particular focus on the rise of the right to autonomy

II. The Quebec Act Respecting End-of-Life Care: Consecration of a new balance between the right to life and the right to autonomy
   1. Clarifications regarding already recognized practices
   2. Recognition of new end-of-life care
      a. Palliative care
      b. Medical assistance in dying
   3. A health care system for better management of end-of-life care
   4. Measures aimed at increasing knowledge and surveillance of end-of-life care

Conclusion

Introduction

Recently, there have been numerous and challenging developments respecting end-of-life care in Canada. In Quebec, political consensus and changes in public opinion led to the adoption of end-of-life care legislation. This paper discusses the context and foundation of that reform and reviews its content with the objective of informing the future of end-of-life care in Canada.

Fundamental values are at the heart of the matter. From a legal standpoint, the right to life or the sanctity of life must be interpreted in light of the rights to liberty and autonomy. Evolution in the provision of health-care services and in the law increasingly challenge the existing balance between the right to life and the right to autonomy. In this first part of this paper, I explore the balancing of these values, with a focus on the approach chosen in Quebec by the Legal Experts Panel Report. In Part

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1. The word “autonomy” will be used as a synonym of inviolability, which is the word used in the [CCQ] and of liberty.
2. This report is available only in French: Comité de juristes experts, Mettre en œuvre les recommandations de la Commission spéciale de l’Assemblée nationale sur la question de mourir dans la dignité, janvier 2013 [Legal Experts Panel Report].
II, I discuss Quebec’s adoption of *An Act Respecting End-of-Life Care*,\(^3\) which recognized the precedence of the right to autonomy at the end of life.

In *Carter v Canada (Attorney General)*, a February 2015 decision, a unanimous Supreme Court of Canada determined that the criminal prohibition of assisted suicide was too broad. The Court found that the government ought to permit medical assistance in dying, subject to certain conditions.\(^4\) The Court spoke of the ruthless dilemma individuals will face if the law does not establish a new balance between the protection of life at any cost and the liberty of the person. In the first paragraph of its decision, the Court states:

> It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician’s assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.\(^5\)

The Court based its judgement on a number of ideas. On one hand, the Court was sensitive to the evolution of constitutional law. Since hearing the *Rodriguez*\(^6\) case, medical assistance in dying or euthanasia became legally permissible in several jurisdictions.\(^7\) Evidence from these permissive jurisdictions suggests that fears concerning the protection of the vulnerable\(^8\) and slippery slope concerns did not materialize. This evidence suggests that the safeguards implemented by these jurisdictions

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5. *Ibid* at para 1 [emphasis added].
6. *Rodriguez v British Columbia (AG)*, [1993] 3 SCR 519, 1993 CanLII 75 (SCC) [Rodriguez]. It will be recalled that Sue Rodriguez had argued in 1993 that section 241(b) Criminal Code, RSC 1985, c C-46 [Criminal Code] should be declared unconstitutional because it infringed her fundamental rights. Dealing with a degenerative disease (Lou Gehrig’s disease), she would not be able to end her life herself, even when getting to a point where she would not wish to continue it. This would force her to end her own life prematurely in order to avoid causing legal risks to her friends or relatives who would help her commit suicide. The Supreme Court of Canada had rejected her claim, but the decision was close (five judges against four).
7. That is Belgium, the Netherlands, Luxemboug, Switzerland, and the states of Oregon, Washington, Vermont and California as well as Colombia. The province of Quebec can be added to this list and now all Canada.
8. Who is the vulnerable person? One who suffers from mental illness or intellectual disability, or one who would be at risk of not consenting in a free manner (for all sorts of reasons: chronic disease, depression, emotional dependency, etc)?
are effective in protecting these vulnerable groups. The fact that this evidence was not available when Rodriguez was decided was used, in part, to justify revisiting the issue of medical assistance in dying.\footnote{9}

According to the Court, the total prohibition of assisted suicide under sections 241 (b) and 14 of the Criminal Code violates section 7 of the Canadian Charter of Rights and Freedoms\footnote{10} in a way that cannot be justified under section 1. The violation of the right to life lies in the fact that some individuals take their lives prematurely in fear that they will be incapable of doing so at a later time due to the degeneration caused by their disease. There is also a violation of the right to liberty because these individuals are not free to make fundamental health care decisions. Finally, the fact that individuals must endure intolerable suffering in the absence of medical assistance in dying violates the right to security of the person. The Court declined to explore whether the prohibition on assisted suicide also violated the section 15 Charter right to equality. After declaring invalid sections 241 (b) and 14 of the Criminal Code, Parliament was originally granted a 12-month suspension of the declaration of invalidity to amend the law. In January 2016, the Supreme Court extended the suspension of the declaration of invalidity for an extra four months, exempting Quebec from the extension and permitting individual exemptions via an application to superior court of their jurisdiction, according to the conditions mentioned in paragraph 127 of Carter.\footnote{11}

While this decision generally confirms the Quebec approach related to medical aid in dying and gives legitimacy to its law,\footnote{12} some of the Supreme

\footnote{9} On this aspect, the Supreme Court of Canada relies on the exhaustive analysis of the trial judge, Smith J in Carter, supra note 4 at paras 104-107, in particular para 107.


\footnote{11} The federal government filed a motion to the Supreme Court for a six-month extension of the 12-month suspension. This motion was heard on 11 January 2016. See Carter v Canada (AG), 2016 SCC 4, 394 DLR (4th) 1, namely para 7 (Abella, Karakatsanis, Wagner, Gascon and Côté JJ). For the first decision on an individual exemption, see HS (Re), 2016 ABQB 121, rendered on 29 February 2016. The Alberta Court of Appeal has also rejected the appeal from the Attorney General of Canada in Canada (Attorney General) v E.E, 2016 ABCA 155, thus confirming the constitutional exemption granted by the motion judge. It is worth noting that the case concerned a person with a psychiatric condition—a severe conversion disorder—who was nevertheless competent and not terminally ill.

\footnote{12} This was also recently confirmed by the Quebec Court of Appeal in Quebec (Procureure générale) v D’Amico, 2015 QCCA 2138, D’Amico v Quebec (Procureure générale), 2015 QCCS 5556. In this decision, the highest court of the province quashed a judgment of the Superior Court which had concluded that the sections of the Quebec Act, supra note 3, pertaining to medical assistance in dying could not enter into force until February 2016, at the expiration of the suspension of the declaration of invalidity given by the Supreme Court in Carter. However, the case on the motion for declaration of invalidity remains to be heard and decided by the Quebec Superior Court. However, on 12 September 2016 one of the plaintiffs, Lisa D’Amico, had her name removed from
Court’s conclusions bring important nuances to the debate over the regulation of end-of-life decisions and leave some questions unanswered. This paper will highlight the differences between the approaches of Quebec and the Supreme Court, which is important given that Carter affects the future of the Quebec Act and, conversely, Quebec’s laws affect the development of federal or provincial and territorial laws.13

I. Evolution of healthcare, social debates and the law: Towards a new balance between the right to life and the right to autonomy

1. Evolution of health care and of social debates

The Collège des médecins du Québec put the debate about medical assistance in dying on Quebec’s political agenda in October 2008. Its clinical ethics working group’s report specified the following:

Natural death is not such a reliable reference anymore. With medical progress, the moment of death is increasingly becoming the object of a decision. When faced with death, we now can and must make choices. Therefore, new coherent means to understand and frame these choices must be found.14

Advances in medicine have extended life expectancy. New types of care, such as respirators, can make treatment more intrusive than it once was, both during and at the end of life. Death went from a natural phenomenon to a medicalized process. Decisions in this context are now often driven by patient preferences and values, rather than the limits of medicine. Quebec cases dating back to the early 1990s illustrate this shift. In the Nancy B15 and

the current motion as she disagreed with the other plaintiffs’ strategy to also attack the validity of the Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). She has however expressed her intention to file a new motion, see D’Amico v Québec (Procureure générale), 2016 QCCS 4390. It remains to be seen what will happen to these two distinct procedures. To our knowledge, plaintiff Paul Saba did not fill another procedure within the 30 days of the judgment and Lisa D’Amico has still a few days to introduce a new procedure; she has 60 days following the judgment to do so.


Corbeil cases, competent adult patients wished to, respectively, withdraw life maintaining treatments (respirator) and cease nutrition and hydration. They received permission from the Superior Court to do so, despite the fact that death would naturally follow the withdrawal of treatment. These cases, along with changes in medical care and important reports by the Law Reform Commission of Canada and the Special Senate Committee on Euthanasia and Assisted Suicide, set the stage for the important social and legal debates that would follow.

Debates over medical assistance in dying were renewed in Quebec in 2009 with the creation of the Select Committee on Dying with Dignity. The Committee’s March 2012 report contained 24 recommendations, including one stressing the importance of recognizing and regulating medical assistance in dying. In order to implement these, the Minister of Justice created a Legal Experts Panel, whose report was published in January 2013. In June 2013, Bill 52 was presented to the National Assembly of Quebec, followed by a detailed study of this bill in Parliamentary Committee. In spite of a provincial election in the spring of 2014, Bill 52 was rapidly adopted on 5 June 2014. This political consensus thus confirmed public opinion on the matter.

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19. The Select Committee was composed of deputies from across the political spectrum. It observed end-of-life care practices by travelling to Europe. It organised consultations around Quebec’s major cities. In total, more than 30 experts were met and more than 300 memoirs and applications to intervene were filed. An online survey received over 6000 replies. See final report: National Assembly of Quebec, Select Committee. Dying with Dignity Report, March 2012, online: <http://www.google.com/search?client=safari&rls=en&q=Select+committee+on+Dying+with+dignity+report&oe=UTF-8&gfe_rd=cr&hl=fr&sa=X&as_q=&spell=1&ved=0ahUKEwiHkfme2KLKAhlUdUsD4KHdyfBgQw UILAE>. 20. This panel was composed of Jean-Pierre Ménard (president), Jean-Claude Hébert and Michelle Giroux.
21. Supra note 2.
22. Bill 52, An Act respecting end-of-life care, 1st session, 40th Leg, Quebec, 2013 [Bill 52]. The vote for the adoption in principle on October 29, 2013 is apportioned as follows: Yeas 84, Nays 26, Abstentions 0.
23. The vote for the adoption of Bill 52 is apportioned as follows: Yeas 94, Nays 22, Abstentions 0. The assent took place on 10 June 2014. The entry into force, with the exception of a few sections concerning the advance medical directives register, took place on 10 December 2015. Sections 52, 57, 58, 63 and 64, dealing with the advance medical directives register came into force on 16 December 2015.
2. The evolution of law: A particular focus on the rise of the right to autonomy

Changes in medical care were accompanied by an evolution in both private law and fundamental rights and freedoms. Although the courts have recognized the right to autonomous decision-making in health care over the past several decades, criminal laws respecting the protection of life have remained unchanged since 1892. In order to remedy this discrepancy, criminal law must evolve to respect the right to autonomy, as illustrated by the Legal Experts Panel Report.

In Quebec private civil law, the principle of the inviolability of the person emerged in the Civil Code of Lower Canada in 1971. The right to autonomy has gradually broadened since its enactment. The decision of the Superior Court in 1984 in Canada (Procureur général) v. Hôpital Notre-Dame illustrates the expansion of autonomy. That case involved a forced intervention to remove an iron wire from the oesophagus of a patient who had swallowed it and who preferred dying over being deported to his country in accordance with a decision from immigration authorities. The Courts would today probably reject this compulsory treatment, finding that it is not up to courts or medical professionals to scrutinize the reasonableness of his decision, but rather up to the patient to make judgments on quality of life. The Nancy B and Corbeil cases, which followed a 1989 reform of the law of persons, also illustrate the increasing importance of autonomy in the context of medical decision-making. As noted above, these cases upheld the right of a patient to refuse care, even if death will follow.

However, the right to autonomy was truly consecrated in 1991 during the reform of the Civil Code of Québec. For example of this, not requiring consent in case of emergency is not considered an exception to the rule anymore. Indeed, while consent to treatment was not required in an emergency prior to the amendments, article 13 C.C.Q. now requires

25. Supra note 2 at 21-56.
27. [1984] CS 426, 8 CRR 382.
30. Corbeil, supra note 7.
The Dalhousie Law Journal

consent, even in case of emergency, where it can be obtained in due time. Furthermore, as expressed by the Minister of Justice:

This last provision is intended to both engage the medical practice and enhance respect of the fundamental right of the inviolability of the person by setting, as a principle, the respect of denial of treatment expressed in due time. Despite this, the article establishes that under certain circumstances, the consent, substituted or not, is necessary, even if the person’s consent cannot be obtained in due time; this rule is intended to avoid futile medical care. By these provisions, article 13 is aiming at recognizing a certain primacy of the quality of life on the maintenance of life at all costs, in unacceptable conditions.\(^\text{32}\)

The *Legal Experts Panel Report* also describes the shifting balance between the right to autonomy and the sanctity of life following the adoption of the Quebec and the Canadian charters of rights:

The judicial interpretation given by the Supreme Court to this concept is taking into consideration the evolution of healthcare and the law. It nonetheless moves in the same direction, which is the progressive increase of the right of a person to make crucial and fundamental decisions as he or she chooses, without state interference.... This evolution of the autonomy ... of the person has the effect of mitigating the concept of the sanctity of life, which takes less importance in the end of life when the decision-making autonomy of the person affirms itself in order to allow this person to control the time and the way of dying.\(^\text{33}\)

In short, this evolution in the law must necessarily inform the interpretation of the *Criminal Code*. This is illustrated in *Nancy B*, where the judge, in *obiter*, reassured the physician that he did not have to fear criminal prosecution if he unplugged his patient from the respirator, despite section 14 of the *Criminal Code*, which, prior to *Carter*, prohibited a person from consenting to his or her own death.\(^\text{34}\)

Criminal law must therefore take note of this evolution.\(^\text{35}\) Indeed, as mentioned, the sections regarding the protection of life in the *Criminal Code* have not been modified since 1892, except in 1972 when suicide


\(^{33}\) *Legal Experts Panel Report*, supra note 2 at 203-205 (our translation). It may be recalled that a similar evolution allowed women a greater freedom and security regarding birth control, before the declaration of inoperability of section 251 of the *Criminal Code*, supra note 6 in *R v Morgentaler*, [1988] 1 SCR 30. The administration of justice being within provincial competence, the attorney generals of the provinces and territories no longer applied criminal law, which prohibited abortion under certain conditions, even though criminal law is within federal competence.

\(^{34}\) *Nancy B*, supra note 15 at 366-367.

\(^{35}\) For more details on criminal law, see *Legal Experts Panel Report*, supra note 2 at 21ff.
Informed the Future of End-of-Life Care in Canada: Lessons from the Quebec Legislative Experience

attempts were decriminalized. Faced with inertia in the language of the Criminal Code, courts must interpret the criminal law in a manner that reflects the evolution of private laws respecting individual rights and the public law understanding of human rights:

Traditional values, which inspired the rules of the Criminal Code, must today be interpreted in respect of the new social values, expressed by the Charter and confirmed by the courts. In this context, the emergence of a value such as the decision-making autonomy of a person, or one’s right to self-determination, has a definite impact on the traditional analyses of the Criminal Code’s provisions regarding the protection of life. 36

Although the laws respecting medically assisted dying remained unchanged, shifts in public opinion and the increasing emphasis on autonomous medical decisions may partially explain the few accusations against physicians who have assisted patients in ending their lives. Furthermore, when accusations are made, evidence of the criminal intent of a physician claiming to have acted out of compassion or proof of death causation often becomes very difficult to establish. And finally, when a guilty verdict is reached, sentences are generally minimal and without real deterrent effect. 37 In summary, and as expressed in this excerpt of the Legal Experts Panel Report:

These legal developments reflect an important evolution of social values and of society’s expectations regarding the governance of the end of the life of a person. The actual law practically infiltrates in all the end-of-life process in a direction that goes against the Criminal Code’s philosophy by promoting the affirmation of individual autonomy and of one’s consent…. The Attorney General and the Crown’s prosecutor cannot ignore these developments in the analysis of end-of-life medical practices, because they ought to be considered in this analysis, along with other factors, for the appreciation of the public’s interest in prosecuting. 38

Beyond situations directly involving physicians, there have been several cases of individuals who felt compelled to assist relatives in ending their lives, due to the inertia of criminal law. 39 Although Quebec’s reform

36. Ibid at 204-205 (our translation).
37. See R v Houle, 2006 QCCS 319, 38 CR (6th) 242 [Houle]. The case of Ms Houle, who had helped her son die, may be recalled. Her sentence had only consisted of a three-year probation period. For further detail see ibid at 21-56.
38. Legal Experts Panel Report, supra note 2 at 56 (our translation).
39. Houle, supra note 37. Consider the following quotations from this judgement (our translation): “[77] It is obvious that if the current Canadian regime had allowed Charles to choose to die with dignity, freely and in an informed manner, in a setting which would have guaranteed all the necessary protection, we would not be here today. Ms Houle would not have committed the crime of which she is being accused…. [81] She has committed the crime of which she is being accused in specific and
allows for physicians to medically assist a patient in dying, it will remain an offence for individuals who are not medical professionals to provide assisted dying.

The conception of the protection of life reflected in the Criminal Code of 1892 is difficult to reconcile with modern views which attempt to balance the protection of life with autonomy. The Quebec approach better reflects the evolution of both health care and law. It provides for an evolving interpretation of criminal law, respectful of the evolution of health care and the law, which should now allow medical assistance in dying. For the Legal Experts Panel, the focus on outdated criminal laws became less pertinent given shared jurisdiction over health and provincial powers to regulate hospitals and health professionals. It is against this backdrop that the reform took place.

II. The Quebec Act Respecting End-of-Life Care: Consecration of a new balance between the right to life and the right to autonomy

The Quebec Act,\textsuperscript{40} which is enforced by the Minister of Health and Social Services, provides mechanisms for more options for end-of-life care across the continuum of health care services. As I describe below, the Quebec Act also clarifies actual practices in end-of-life care. It also recognizes new modes of end-of-life care and organizes a system for managing these services. Finally, the Quebec Act provides measures aimed at increasing knowledge and surveillance of end-of-life care.

1. Clarifications regarding already recognized practices

The new law modifies article 11 C.C.Q. to expressly acknowledge a patient’s right to refuse treatment, including life-sustaining care, which is allowed for all patients over 14 years. The law also indicates that the refusal or withdrawal of consent can be expressed by any means:

- Except as otherwise provided by law, a person of full age who is capable of giving consent to care may, at any time, refuse to receive life-sustaining care or withdraw consent to such care.
- To the extent provided by the Civil Code, a minor of 14 years of age or over, and in the case of a minor or a person of full age who is incapable of giving consent, the person who may give consent to care on their behalf may also make such a decision.
- The refusal of care or withdrawal of consent to care may be expressed by any means.

\textsuperscript{40} See Quebec Act, supra note 3 and accompanying text.
The physician must make sure that such a decision is made freely and provide the person with all information needed to make an informed decision, in particular information about other therapeutic possibilities, including palliative care.41

These provisions represent the codification of principles previously recognized in *Nancy B* and *Corbeil*. However, these principles remain difficult to apply, as shown in the 2014 decision *Centre de santé et de services sociaux Pierre-Boucher v. Van Landschoot* case, where a patient’s request to end a treatment was brought to the Superior Court despite clear rulings in the previously mentioned cases.42 In *Van Landschoot*, the Superior Court confirmed that a patient who was rendered quadriplegic in a parachute accident could discontinue all nutrition and hydration. The court also ordered “that Pierre-Boucher Health and Social Services Center, its nursing and medical staff provide appropriate medication to efficiently relieve the pain of Mr. Pierre Mayance in order to allow him a gentle and dignified death.”43 In these decisions, patients are not initially at the end of their life; they wish for life-sustaining treatments to be discontinued. Ending these treatments will, however, cause death in the short term. *Van Landschoot* illustrates the importance of this clarification in the recent legislation in order to reflect the principles recognized by jurisprudence and to avoid unnecessary disputes the next time a competent patient clearly expresses his or her wishes to end a treatment.

The *Quebec Act* also brings two types of changes regarding medical wishes expressed by an individual capable of giving consent, but which apply should that individual become incapable of giving consent in the future. First, article 12 C.C.Q. is modified to give additional weight to previously expressed wishes: “[a] person who gives his consent to or refuses care for another person is bound to act in the sole interest of that person, complying, as far as possible, with any wishes the latter may have expressed....” In contrast, the previous version specified that substitute decision makers’ decisions only required “taking into account, as far as possible, wishes the latter may have expressed....”

The *Quebec Act* also creates a new form of expression for previously expressed wishes: binding advance medical directives (AMD).44 Section 52 of the *Quebec Act* reads:

41. *Quebec Act*, ibid., s 5.
42. 2014 QCCS 4284 [*Van Landschoot*]. See also, available only in French: Isabelle Marcoux et al, “Ce que les professionnels de la santé comprennent des aspects juridiques des soins de fin de vie au Québec” (2015), 1:4 Le médecin de famille canadien 197.
43. *Van Landschoot*, ibid at para 41 (our translation).
44. *Quebec Act*, supra note 3, ss 51ff.
[AMD] are given by notarial act *en minute* or in the presence of witnesses on the form prescribed by the Minister.

At the request of their author, [they can be] recorded in the advance medical directives register established under section 63.

A substitute decision maker can only consent to treatment on behalf of an incapable patient if the person incapable of giving consent has not filed an AMD. By contrast, if the patient has an AMD, these wishes must be respected. The only exceptions are when a court "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...."

These welcome changes will facilitate end-of-life care management by medical professionals and family members. It is also hoped that these legislative changes will reduce the taboo associated with end-of-life discussions. Indeed, notwithstanding the fact that jurisprudence has clarified certain rules, decision making by the patient’s representative is often very sensitive and emotional and thus not always effective. *Centre de santé et services sociaux Richelieu Yamaska v. L. (M.)* is a good illustration of disagreement sometimes occurring over care decisions. In this case, a 91-year-old woman in a state of cerebral death, was being kept alive artificially with the help of a respirator. The family disagreed over what their mother would have wished for, and the court confirmed that the patient would have wanted to be disconnected from the respirator to avoid futile medical treatment. The binding power now given to prior expressed wishes will certainly affect how end-of-life issues and disagreements will be handled in the future, if patients do prepare them.

In addition to disagreements between family members, there are cases where it is the family and physicians who are at odds, as exemplified by *Rasouli*. *Lambert et autres v. France*, recently decided by the European Human Rights Court, also exemplifies such disagreements. Both cases

45. *Ibid*, s 61. This section provides that the court may order that these directives be respected. See also the new wording of articles 11 and 15 CCQ.
46. *Quebec Act, ibid*.
48. Under section 62 of the *Quebec Act, supra* note 3, it is important to note that AMD prevail over instructions relating to care expressed in a mandate given in anticipation of a person’s incapacity.
49. *Cuthbertson v Rasouli*, 2013 SCC 53, [2013] 3 SCR 341. In this case, the Supreme Court of Canada concluded that, following the Ontario legal framework, the withdrawal of life support and the administration of palliative care were treatments which required consent, and any issues and disagreements between family members and physicians of the incapable patient with regards to these treatments had to be brought before the Consent and Capacity Board.
50. *Lambert v France* [GC], No 46043/14, [2005] ECHR 185, 62 EHR 2 [Lambert]. In this case,
involved patients in a minimally conscious or chronic vegetative state. The first was being kept alive by a respirator. The other was not but continued to be fed and hydrated. Both cases exemplify the need to bring more clarity to the law to increase respect for autonomy or patients' wishes when expressed before incompetency in an advance directive.

2. Recognition of new end-of-life care
Apart from these clarifications regarding recognized end-of-life practices, the Quebec Act also establishes the right to palliative care and the right to medical assistance in dying.

a. Palliative care
Palliative care is defined as follows:

[T]he total and active care delivered by an interdisciplinary team to patients suffering from a disease with reserved prognosis, in order to relieve their suffering, without delaying or hastening death, maintain the best quality of life possible and provide them and their close relations the support they need.\(^2\)

Although the Quebec Act created a right to palliative care, this type of care was already provided in health-care institutions, palliative care hospices and sometimes even at home. This type of care is not controversial, with the exception of continuous palliative sedation, which is defined as follows:

[C]are that is offered as part of palliative care and consists in administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues.\(^2\)
Prior to the legislative reform, the practice of continuous palliative sedation was not understood or used in the same way by all, with some perceiving it as a form of euthanasia, and others as a form of care. The Legal Experts Report illustrates this confusion:

In the current regulatory environment, certain terminal sedation practices are part of the “slippery slope” area of the application of palliative care. In the absence of a structured framework, this practice is not (or poorly) documented. The criticisms voiced throughout the jurisdictions where terminal sedation is practiced point out a frequent absence of patient consent to this practice. The withdrawal of nutrition and hydration, while the patient is not yet at the stage of his agony where these procedures are justifiable, cause problem.

For example, in the Netherlands, according to a study published in 2004, terminal sedation was preferred to euthanasia by physicians because it did not require consent of the patient, unlike euthanasia.

This confusion prompted legislators to regulate the provision of continuous palliative sedation in order to protect patients. Section 24 of the Quebec Act outlines the preconditions for the provision of continuous palliative sedation:

Before giving consent to continuous palliative sedation, an end-of-life patient or, where applicable, the person who may give consent to care on behalf of the patient must among other things be informed of the prognosis for the illness, the irreversible nature of the sedation and the anticipated duration of the sedation.

In addition, the physician must make sure that the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure.

Consent to continuous palliative sedation must be given in writing on the form prescribed by the Minister and be filed in the patient’s record. (emphasis added)

According to the Legal Experts Panel, “such procedure will prevent terminal sedation from being used as a procedure to bypass the medical assistance in dying rules.”

It remains to be seen whether this procedure will allow for better understanding and control over this type of care, or whether these conditions will limit access to continuous palliative sedation.

53. See namely the results of a survey on euthanasia conducted by the Fédération des médecins spécialistes du Québec, online: <https://www.fmsq.org/en/mediatheque/dap/euthanasie2>. For further detail on continuous palliative sedation, see generally Legal Experts Panel Report, supra note 2 at 248ff.
54. Legal Experts Panel Report, supra note 2 at 254 (our translation, citation omitted).
55. Ibid at 350 (our translation).
Informing the Future of End-of-Life Care in Canada: Lessons from the Quebec Legislative Experience

This is a question not addressed in Carter. Future Canadian legislation could be informed by how Quebec dealt with it.

b. Medical assistance in dying

The Quebec Act also recognizes medical assistance in dying, which is a new form of care. This care is defined as follows:

[C]are consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient’s request, in order to relieve their suffering by hastening death.56

Section 26 provides strict criteria that must be met in order for a patient to obtain medical assistance in dying:

1. be an insured person within the meaning of the Health Insurance Act …;
2. be of full age and capable of giving consent to care;
3. be at the end of life;
4. suffer from a serious and incurable illness;
5. be in an advanced state of irreversible decline in capability; and
6. experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable…. (emphasis added)

Thus, only a person of full age who is competent can formulate a request for medical assistance in dying. Section 51 of the Quebec Act clearly states that such a request cannot be made through an AMD. However some arguments were made during debates on the Quebec legislation to the effect that excluding the possibility of expressing in advance such a request could constitute discrimination and thus be subject of a future constitutional challenge.57 This is a rule which is likely to change in the future. The Court’s decision in Carter does not clearly address this, given the facts before it; it refers only to a “competent adult.”58 Belgium and Luxembourg statutes allow advance medical directives for people finding themselves

56. Quebec Act, supra note 3, s 3(6).
57. See namely Chambre des notaires, Mémoire portant sur le Projet de loi N° 52 Loi concernant les soins de fin de vie, 24 September 2013; Commission des droits de la personne et de la jeunesse, Mémoire à la Commission de la santé et des services sociaux de l’Assemblée nationale—Projet de loi no 52 Loi concernant les soins de fin de vie, CSSS 039, CP PL 52, September 2013, at p 10ff. The Legal Experts Panel would have allowed them, see Legal Experts Panel Report, supra note 2 at 378-386.
58. Carter, supra note 4 at para 4: “We conclude that the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. We therefore allow the appeal.”
in an irreversible coma, but not for people suffering from dementia.  

More recently, the Special Joint Committee Report (Recommendation 7) and the Provincial–Territorial Expert Advisory Group (recommendations 12 and 13) recommended in a similar but not identical way the use of advance directives for medical assistance in dying, on the condition that such requests be made after having received a diagnosis of a grievous and irremediable condition and with the condition that procedural safeguards be put in place to insure autonomous decision.

As to the request for medical assistance in dying, it must be made in the form prescribed by the Minister and provided by a health professional.  

Section 28 of the Quebec Act states that a patient may withdraw his or her request for medical aid in dying “at any time and by any means” and that “a patient may also, at any time and by any means, request that the administration of medical aid in dying be put off.”

The criteria set out in section 26 of the Quebec Act mirror, but only partially, those set out by the Supreme Court of Canada:

We conclude that the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition....

Unlike Quebec’s approach, the Supreme Court does not require the end of life or the advanced state of irreversible decline in capability to access to medical assistance in dying. The end-of-life difference was the subject of some debate before the Parliamentary Committee considering Quebec’s Bill 52, as some argued that the concept of end-of-life should be clarified, while others did not believe in the necessity of requiring this criterion, nor the criterion of the advanced state of irreversible decline in capability. Different views persist and this will need to be fixed for the
future of medical assistance in dying. However, the Supreme Court in *Carter* does not expressly say that one does have to be at the end of life to request medical assistance in dying. The February 2016 *Special Joint Committee Report* goes even further. It does not require that a patient be at the end of life to request medical assistance in dying and would also allow requests from patients with psychiatric conditions.

Quebec’s law also specifies physician obligations with regard to end-of-life care. In particular, section 29 reads as follows:

Before administering medical assistance in dying, the physician must

1. be of the opinion that the patient meets all the criteria of section 26, after, among other things,
   a. making sure that the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure;
   b. making sure that the request is an informed one, in particular by informing the patient of the prognosis for the illness and of other therapeutic possibilities and their consequences;
   c. verifying the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged, by talking with the patient at reasonably spaced intervals given the progress of the patient’s condition;
   d. discussing the patient’s request with any members of the care team who are in regular contact with the patient; and
   e. discussing the patient’s request with the patient’s close relations, if the patient so wishes;
2. make sure that the patient has had the opportunity to discuss the request with the persons they wished to contact.

Finally, once the physician has reached the conclusion that the patient can have access to medical assistance in dying, the opinion of a second physician must be solicited according to paragraph (3) and section 29:

[O]btain the opinion of a second physician confirming that the criteria set out in section 26 have been met.

The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second
medical opinion. The physician consulted must consult the patient’s record, examine the patient and provide the opinion in writing. (emphasis added)

The legislation also contains various rules respecting the functions of the councils of physicians, dentists and pharmacists and the Collège des médecins du Québec. These entities will be responsible for assessing the quality of care provided to patients.

In sum, this legislation reflects the government’s belief that in light of the evolution of medicine and the law, medical assistance in dying naturally fits within the continuum of end-of-life care. This type of care aims to manage heartbreaking dilemmas at the end of life, which would have continued in the absence of such an alternative. However, it is important to note that medical assistance in dying will remain an exceptional form of care to be provided in exceptional cases and will always be subject to an individual’s consent.

Legislation will also need to address whether medical assistance in dying will be available to mature minors, who are individuals under the age of majority but deemed to have sufficient understanding to have capacity for the purposes of medical decision making. The Quebec Act prohibits such access by minors, primarily due to a lack of social and political consensus on this question. Carter, with a general reference to a “competent adult,” did not provide a definite answer to the question. The Court refers to a “competent adult” only and is silent on minors. However, while discussing the issue of vulnerability, without referring explicitly to the mature minor doctrine, the Court mentions “the potential vulnerability of adolescents who are faced with life-and-death decisions about medical treatment,” but acknowledges “the viability of an individual assessment of decisional capacity in the context of that case.” The Special Joint Committee Report recommended “a two-stage legislative process” that would allow medically assisted dying for competent adults now and in three years to mature minors. The Provincial–Territorial Expert Advisory Group recommended that “[a]ccess to physician-assisted dying should... be based on competence rather than age.”

66. Quebec Act, supra note 3, ss 33-35.
67. Ibid, ss 36-37.
68. Carter, supra note 4 at para 116.
69. Ibid. See also AC v Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 SCR 181.
70. Special Joint Committee Report, supra note 13 at recommendation 6. It also urges the Government of Canada to organize a study including general consultations of this issue. As we now know, Bill C-14, supra note 64, does not allow a mature minor to access medical aid in dying.
71. Provincial–Territorial Expert Advisory Group, supra note 13, at recommendation 17. For a
3. A health care system for better management of end-of-life care

The Quebec Act contains several sections regarding health care and social services related to end-of-life care. These rules specify the rights and obligations of patients and medical professionals, and the organization of end-of-life services provided by institutions, palliative care hospices or in private health facilities. Other rules specify the functions of health and social services agencies (replaced by Integrated Health and Social Services Centre or Integrated University Health and Social Services Centre) as well as the functions and powers of the Minister.

Section 2 of the Quebec Act sets out the organizing principles that guide in the “provision of end-of-life care”:

1. respect for end-of-life patients and recognition of their rights and freedoms must inspire every act performed in their regard;
2. end-of-life patients must be treated, at all times, with understanding, compassion, courtesy and fairness, and with respect for their dignity, autonomy, needs and safety; and
3. the healthcare team providing care to end-of-life patients must establish and maintain open and transparent communication with them.

With respect to patient rights, section 4 of the Quebec Act provides that “[e]very person whose condition requires it has the right to receive end-of-life care, subject to the specific requirements established by this Act.” Subject to the availability of resources, a person will have access to this care in an institution, in a palliative care hospice or at home. In addition, no one can refuse end-of-life care to a person “for previously having refused to receive certain care or having withdrawn consent to certain care.” A patient dissatisfied with his or her end-of-life care may file a complaint through existing mechanisms, but such complaint must now be treated as a matter of priority.

similar position alleging discrimination for not allowing minor to get access to medical aid in dying, see Commission des droits de la personne et de la jeunesse, supra note 57.

72. Quebec Act, supra note 3, ss 7-12.
74. Ibid, § 16.
76. Quebec Act, supra note 3, see ss 17-18 and 19ff.
77. Ibid, § 4.
78. Ibid, § 6.
79. Ibid, § 48. See also, available only in French: Le Protecteur du citoyen, Mémoire du Protecteur du citoyen présenté à la Commission de la santé et des services sociaux dans le cadre des consultations particulières et auditions publiques sur le Projet de loi no 52, Loi concernant les soins de fin de vie,
The Quebec Act also addresses conscientious objections by physicians who object to providing end-of-life care. In this case, a mechanism is set out in order to find another physician to provide medical assistance in dying. A physician who refuses for conscientious reasons must notify and forward the medical assistance in dying request form to the executive director of the institution (or of the local authority) in which he practices, or to any other person designated by the executive director. The person in charge must then find another physician to provide this care.

As mentioned, the legislation also creates rules pertaining to the organization of end-of-life care in institutions. Specifically, section 7 of the Quebec Act stipulates the obligation to offer end-of-life care in a way that is complementary to the other care provided to the patient, and in a manner that promotes a multi-disciplinary approach and collaboration between the various care providers. There are also rules clarifying the location where care will be offered. Each institution has the obligation to adopt a policy regarding end-of-life care. The institution’s organizational plan must provide for “a clinical program for end-of-life care.” Section 10 adds that “[t]he code of ethics adopted by an institution...must have due respect for the rights of end-of-life patients.” These measures certainly will improve the quality of available information for patients and thus ensure better communication between patients and medical professionals.

The new law also contains a series of measures aimed at improving communication between the patient and the medical body and the consideration of a person’s wishes. The effectiveness of these measures remains to be proven. All of these aspects could be useful to other provinces and territories for their law reform on end-of-life care.

septembre 2013.

80. Quebec Act, ibid, s 31. See also Code of ethics of physicians, CQLR c M-9, r 17, s 24: It is a similar rule as in the case of a refusal to perform an abortion for reasons of conscience or belief. However, the physician who refuses to perform medical aid in dying does not have to find a physician who will do it; he or she has to notify the responsible person in the institution to which he or she refers and a physician will be found that way. This procedure ensures a better protection of a physician’s conscience.

81. Quebec Act, ibid, s 31.

82. Ibid. See ss 11-12, regarding the obligation to offer an individual room to a patient in the last days of his life.

83. Ibid, s 8.

84. Ibid, s 9.

85. See Quebec Act, supra note 3, ss 2, 8, 9, 29.

86. See Part II-1 Clarifications regarding already recognized practices, above, for more on this topic.
4. Measures aimed at increasing knowledge and surveillance of end-of-life care

The Quebec Act establishes the Commission sur les soins de fin de vie, which will monitor end-of-life care. The Commission is made up of eleven members, two of whom are to be jurists, appointed for a mandate of five years, with one renewal permitted. The mandate of this Commission is quite broad, with section 42 stipulating that "the Commission is to examine any matter relating to end-of-life care". Among other things, its mandate includes the evaluation of the implementation of the Quebec Act in a global way for all end-of-life care. The Commission may "refer to the Minister any matter relating to end-of-life care that needs the attention of or action by the Government" and, conversely, the Minister may give the Commission additional mandates. The Commission will be required to submit a report to the Minister on the state of end-of-life care every five years, as well as an annual activity report.

The Commission is also responsible for overseeing, after the fact, "the specific requirements relating to medical aid in dying." Physicians who provide such care will have to advise the Commission within 10 days.

The Provincial-Territorial Expert Advisory Group recommended establishing "a pan-Canadian Commission on End-of-Life Care to provide system oversight and to report to the public." It might not prove necessary to create such a national entity if each province and territory has its own system of oversight like the one that exists in Quebec. Nevertheless, what is needed is collaboration between the different levels of governments to make sure that Parliament can have access to the information across the country. In that sense, recommendation 16 of the Special Joint Committee Report is of interest.

Conclusion

Quebec’s legislative approach respecting end-of-life care is broad and offers, within a continuum of care, several options, including palliative care and medical assistance in dying, which should be available in a complementary way. On the basis of the dignity of the patient, the legislation was legitimized by the Supreme Court of Canada in *Carter*.

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87. *Quebec Act*, supra note 3, s 39. For further details on how the Commission will operate, see ss 40-41.
88. *Ibid*, ss 42ff. No exhaustive analysis will be made.
89. *Ibid*. See also s 44 regarding solicitation of external opinion and the commission of research, studies or expertise.
90. *Ibid*, s 42. See also s 47.
The Quebec Act offers a balance between social/political consensus and fundamental rights and values. Its short history shows that it is helping to shape the future of end-of-life care across Canada. Some elements remain fragile, considering the contentious issues inherent to end-of-life debates. The fact that a patient may choose between various types of care enhances autonomy even when medical assistance in dying is not the chosen option. Gloria Taylor herself confirms the importance of choice in the context of end-of-life care:

My present quality of life is impaired by the fact that I am unable to say for certain that I will have the right to ask for physician-assisted dying when that “enough is enough” moment arrives. I live in apprehension that my death will be slow, difficult, unpleasant, painful, undignified and inconsistent with the values and principles I have tried to live by…\(^93\)

This suggests that some people would not hesitate to prematurely jeopardize their own life, and are prepared to do so in difficult conditions, thereby infringing their dignity.

Even if the Quebec government has struck a balance between autonomy and competing values, maintaining this balance will require constant vigilance. The monitoring Commission, health-care institutions and professional associations must take this responsibility very seriously.\(^94\) The guiding principles of the Quebec Act can assist in this sense.\(^95\) The legislation adopts an approach centered on the patient and this should help prevent unnecessary litigation over end-of-life decisions between family members or between family members and health professionals.\(^96\)

\(^{93}\) Carter, supra note 4 at para 13.


\(^{95}\) Quebec Act, supra note 3, s 2 states: “The provision of end-of-life care is to be guided by the following principles: (1) respect for end-of-life patients and recognition of their rights and freedoms must inspire every act performed in their regard; (2) end-of-like patients must be treated, at all times, with understanding, compassion, courtesy and fairness, and with respect for their dignity, autonomy, needs and safety; and (3) the healthcare team providing care to end-of-life patients must establish and maintain open and transparent communication with them.”

\(^{96}\) Lambert, supra note 50. This conflict will have lasted more than two years, that is since the beginning of 2013, when Vincent Lambert’s physicians wanted to obtain cessation of treatment by using the collegial procedure provided for by the Law no 2005-370 Law of 22 April 2005 on patients’ rights and the end of life (called The Leonetti Law). It also took many procedures and judgments to
Furthermore, even if it was not necessary for the purpose of resolving *Carter*, the Supreme Court nevertheless dealt with the division of powers and opined that “[h]ealth is an area of concurrent jurisdiction” and that “aspects of physician-assisted dying may be the subject of valid legislation by both levels of government, depending on the circumstances and focus of the legislation.”\(^{97}\) Several recommendations of the Special Joint Committee Report are asking for a collaborative approach between the Government of Canada and the provinces and territories on the issue.\(^{98}\) It is to be hoped that such a perspective will avoid constitutional debates over the *Quebec Act* and future provincial and territorial laws and help to constructively build the response for end-of-life care for every Canadian. As governments embark on discussions of law reform, the questions they must deal with should be resolved in light of the needs of individuals at the end of their lives.

During the editing of this paper, Parliament adopted legislation to amend the *Criminal Code*.\(^{99}\) The eligibility criteria are very similar to the Quebec legislation in many aspects.\(^{100}\) Medical aid in dying is

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97. *Carter*, supra note 4 at para 53. The Supreme Court of Canada rejected the argument of interjurisdictional immunity with regard to health.

98. Special Joint Committee Report, supra note 13. See also Provincial-Territorial Expert Advisory Group, supra note 13, recommendation 2: “Provinces and territories should collaborate and coordinate with all relevant organizations and institutions as soon as possible to ensure the smooth and timely implementation of physician-assisted dying in Canada.”

99. *Bill C-14*, supra note 64. Since the objective of this paper is to present the Quebec legislative experience, we will not elaborate on or discuss this recent amendment, but we could not remain silent about it.

100. Section 241.2 sets out the eligibility criteria which are less restrictive than those of the Quebec legislation. They are also expressed differently than in the *Carter*, supra note 4 decision. Section 241.2 reads as follows:

1. A person may receive medical assistance in dying only if they meet all of the following criteria:
   a. they are eligible—or, but for any applicable minimum period of residence or waiting period, would be eligible—for health services funded by a government in Canada;
   b. they are at least 18 years of age and capable of making decisions with respect to their health;
   c. they have a grievous and irremediable medical condition;
   d. they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
   e. they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

2. A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
   a. they have a serious and incurable illness, disease or disability;
   b. they are in an advanced state of irreversible decline in capability;
   c. that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
   d. their natural death has become reasonably foreseeable, taking into account all of their
available to persons over 18 years, who “have a grievous and irremediable condition,” who have made a free and informed request, and who are “in an advanced state of irreversible decline in capability” that causes them “physical or psychological suffering that is intolerable” and which cannot be alleviated “under conditions that they consider acceptable.” The debate was polarized, especially on the question of the interpretation of the moment when one can access medical aid in dying.

As to the possibility of requesting medical aid in dying in advance directives or for allowing it to minors or to mentally ill persons for that sole reason, the Preamble of Bill C-14 invites Parliament to continue to explore these avenues in the future.

Depending on the interpretation that will be given by courts to this new piece of legislation, the Quebec Act might need to be adjusted. This is a clear example of the rapid changes legislation can prompt. The Quebec statute which was breaking new ground before Carter is now dragging behind with respect to the conditions associated with access to medical assistance in dying. Nevertheless, the cautious way in which Parliament established eligibility showed the influence of the legislative experience and the democratic debate that occurred in Quebec, which has and continues to inform the future of end-of-life care in Canada.

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101. The Quebec legislation is more restrictive since it limits access to persons with an “illness,” whereas the federal statute refers to: “illness, disease or disability.”

102. The Quebec legislation is more restrictive as it requires that a person ought to be at “the end of life.”

103. Compare the similarities of sections 241.2 (2)(c) of Bill C-14, supra note 64 and 26(6) of the Quebec Act, supra note 3.

104. As defined in Bill C-14, supra note 64 § 242.2 (2)(d): “their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.” This section is clearly less restrictive than the Quebec Act, supra note 3 which refers to “end of life” and there is a debate as to whether it meets the criteria established by Carter. We are of the opinion that the wording of this section provides enough flexibility for the courts to manage the specific circumstances of each case and take into account the most delicate situations. We are of the opinion that it does not infringe the Charter, supra note 10, and if it does, we think it is justifiable in a democratic society under its section 1 given the political debates that led to the adoption of the amendments to the Criminal Code.