

THE STATE OF KNOWLEDGE ON MEDICAL ASSISTANCE IN DYING FOR MATURE MINORS

The Expert Panel Working Group on MAID
for Mature Minors

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THE COUNCIL OF CANADIAN ACADEMIES**180 Elgin Street, Suite 1401, Ottawa, ON, Canada K2P 2K3**

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This report was prepared for the Government of Canada in response to a request from the Minister of Health and the Minister of Justice and Attorney General of Canada. Any opinions, findings, or conclusions expressed in this publication are those of the authors, the Expert Panel Working Group on MAID for Mature Minors, and do not necessarily represent the views of their organizations of affiliation or employment, or of the sponsoring organizations, Health Canada and the Department of Justice Canada.

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The Expert Panel on Medical Assistance in Dying

Under the guidance of its Scientific Advisory Committee, Board of Directors, and the Academies, the CCA assembled the Expert Panel on Medical Assistance in Dying to undertake this project. Each expert was selected for their expertise, experience, and demonstrated leadership in fields relevant to this project.

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The CCA also recognizes the important contributions of **Yves Beauchamp**, Vice-Principal, Administration and Finance, McGill University (Montréal, QC).

Message from the Chairs

Medical assistance in dying (MAID) has been a topic of public debate in Canada for over 50 years. In 2015, the Supreme Court of Canada opened a new chapter in the debate with its *Carter* ruling, which was followed 18 months later by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. This unprecedented change in the legal landscape — welcomed by some and repudiated by others — reflects an evolving conversation about death and dying that is uniquely Canadian. This conversation continues through the work of the Expert Panel on Medical Assistance in Dying, convened by the Council of Canadian Academies (CCA).

It has been a privilege to serve over the past 18 months as Chairs. More than 40 experts from Canada and abroad, with diverse disciplinary and professional backgrounds, were convened as the Expert Panel while an additional 35 national and international experts served as independent Report Reviewers. The Panel undertook an evidence-based assessment of the state of knowledge surrounding three topics specified in the Act for independent review: MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition. The three reports reflect a broad range of knowledge, experience, and perspective among relevant healthcare professions, diverse academic disciplines, advocacy groups, Indigenous Elders, and from regions where MAID is permitted.

The Expert Panel's work could not have been accomplished without the time and dedication of so many. First, we would like to thank the Panel members themselves, whose exceptional commitment and expert contributions ensured a fair assessment of the evidence. We would also like to express our gratitude to the Report Reviewers, whose detailed and constructive comments improved the depth and quality of each report. Special thanks go to the 59 groups and organizations across Canada affected by or involved in MAID, which responded to our Call for Input and submitted evidence, insight, and stories to enrich the Panel's work. Finally, on behalf of all Panel members, we would like to thank the CCA staff, who worked tirelessly to bring their tremendous research expertise, professionalism, dedication, and good humour to this project, under the guidance of Dr. Eric Meslin, CCA President and CEO.

These reports reflect a particular moment in Canada's history, in the breadth and availability of evidence, and in the evolution of thinking and practice related to MAID. We invite the Canadian public as well as Parliamentarians to engage in a wider discussion about MAID in the weeks and months following release of these reports. It is our hope that the Panel's reports will foster this Canadian conversation.

With our thanks for this opportunity to serve,



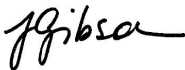
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Message from the President and CEO

Every CCA assessment focuses on a topic of importance to the Sponsor who requested it and to those who await the Expert Panel's findings. Each is unique in its own way. But when the Minister of Health and Minister of Justice referred MAID-related questions to the CCA, we knew we were undertaking one of our most challenging assignments. For obvious reasons, policy topics about how people live and die are especially difficult because they speak to fundamental concepts of human dignity, autonomy, liberty, and suffering; they remind us of long-standing conversations and debates about the rights of patients and the duties of clinicians; and they reflect diverse social norms and cultural perspectives. With respect to MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition, the task is especially daunting given that domestic and international experience is limited and the existing published literature cannot provide a complete picture of MAID as experienced by patients, families, communities, and healthcare practitioners.

This assessment required care, sensitivity, and wisdom to identify what is known and what gaps in knowledge remain to be filled. While no assessment can include every possible perspective, the CCA was mindful of the need to gather abundant expertise for this project: we invited specialists with clinical, legal, and regulatory expertise to the table; we sought authoritative scholars and practitioners from the fields of law, medicine, nursing, mental health, bioethics, anthropology, and sociology; and we included input from Indigenous elders. Drawing on experts from across Canada and other countries, the CCA established a panel of 43 individuals who together reflected the breadth of knowledge and experience required to answer the Sponsors' questions.

Leadership for this Expert Panel was provided by the Honourable Marie Deschamps, our overall Panel Chair, and by three Working Group Chairs: Dr. Dawn Davies, Prof. Jennifer Gibson, and Dr. Kwame McKenzie. I am grateful to all four Chairs for their dedication and commitment to ensuring these reports reflect the considered views and deliberations of Panel members. I am particularly appreciative of the commitment of every Panel member, each of whom volunteered their time in the service of this important task.

I also wish to express sincere thanks to the three Academies — the Royal Society of Canada, the Canadian Academy of Engineering, and the Canadian Academy of Health Sciences — for their support and expert assistance; to the CCA's Board of Directors and Scientific Advisory Committee for their advice and input; and to our dedicated staff for their hard work in support of the Expert Panel.

Finally, I would like to thank the Minister of Health and Minister of Justice for entrusting the CCA with the responsibility to undertake an assessment of such importance to Canada and Canadians. The products of the Expert Panel's work are now in the hands of the Government of Canada, as requested, and will be widely disseminated. It is our hope that this assessment will inform policy discussion and public discussion in Canada and abroad.

A handwritten signature in black ink, appearing to read 'Eric M. Meslin', with a stylized flourish at the end.

Eric M. Meslin, PhD, FCAHS

President and CEO, Council of Canadian Academies

Acknowledgements

Over the course of its deliberations, the Panel reached out to many individuals and organizations that provided valuable evidence, information, and assistance in the development of the reports. The Panel wishes to thank the following people for their participation in an early planning meeting: Jeff Blackmer, Canadian Medical Association; Jennifer A. Chandler, University of Ottawa; Dawn Davies, University of Alberta; Jocelyn Downie, C.M., FRSC, FCAHS, Dalhousie University; Catherine Frazee, O.C., Ryerson University; Jennifer L. Gibson, University of Toronto; Jean Gray, C.M., FCAHS, Dalhousie University; Douglas Ruth, FCAE, University of Manitoba; Janet Storch, University of Victoria; and Randi Zlotnik Shaul, The Hospital for Sick Children.

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Report Review

These reports were reviewed in draft form by reviewers selected by the CCA for their diverse perspectives and areas of expertise.

The Report Reviewers assessed the objectivity and quality of the reports. Their submissions — which will remain confidential — were considered in full by the Panel, and many of their suggestions were incorporated into the reports. They were not asked to endorse the conclusions, nor did they see final report drafts before release. Responsibility for the final content of these reports rests entirely with the authoring Expert Panel Working Group and the CCA.

The CCA wishes to thank the following individuals for their review of these reports:

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Report Review Monitors

The report review procedure was monitored on behalf of the CCA's Board of Directors by three members of the CCA's Scientific Advisory Committee. The MAID Where a Mental Disorder Is the Sole Underlying Medical Condition report review was monitored by **David Castle**, Vice-President Research, University of Victoria; the Advance Requests for MAID report by **Malcolm King, FCAHS**, Professor, University of Saskatchewan; and the MAID for Mature Minors report by **Stuart MacLeod, FCAHS**, Professor Emeritus (Pediatrics), University of British Columbia.

The role of the report review monitor is to ensure that the Panel gives full and fair consideration to the submissions of the reviewers. The CCA Board authorizes public release of an expert panel report only after the report review monitors confirm that the CCA's report review requirements have been satisfied. The CCA thanks Drs. Castle, King, and MacLeod for their diligent contributions as report review monitors.

List of Acronyms and Abbreviations Used in the Reports

| | |
|---------------------|--|
| ACP | Advance Care Planning |
| AED | Advance Euthanasia Directive |
| CAMAP | Canadian Association of MAID Assessors and Providers |
| CAMH | Centre for Addiction and Mental Health |
| CAYAC | Child and Youth Advisory Council at the Alberta Children's Hospital |
| CCB | Consent and Capacity Review Board of Ontario |
| CFCEE | Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie (Belgium) |
| CNCE | Commission Nationale de Contrôle et d'Évaluation (Luxembourg) |
| CPS | Canadian Paediatric Society |
| CPST | Continuous Palliative Sedation Therapy |
| CSPCP | Canadian Society of Palliative Care Physicians |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition |
| EAS | Euthanasia and Assisted Suicide |
| IRER | Immigrant, Refugee, Ethnocultural, and Racialized |
| MAID MD-SUMC | Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition |
| NVVP | Nederlandse Vereniging voor Psychiatrie (Dutch Psychiatric Association) |
| PAD | Physician Aid in Dying |
| PAS | Physician-Assisted Suicide |
| PPC | Pediatric Palliative Care |
| RTE | Regionale Toetsingscommissies Euthanasie (Regional Euthanasia Review Committees), the Netherlands |
| SCEN | Steun en Consultatie bij Euthanasie in Nederland (Support and Consultation on Euthanasia in the Netherlands) |
| SDM | Substitute Decision Maker |
| SLK | Levenseindekliniek (End-of-Life Clinic), the Netherlands |
| VPS | Vulnerable Persons Standard |
| VSED | Voluntary Stopping of Eating and Drinking |
| VVP | Vlaamse Vereniging voor Psychiatrie (Flemish Psychiatric Association) |

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1

Introduction

- **The Charge**
- **Scope**
- **The Expert Panel**
- **Terminology**
- **Evidence Considered**
- **How to Read this Report**

1 Introduction

Canada has become one of a small number of jurisdictions to allow some form of medical assistance in dying (MAID). The Supreme Court of Canada's *Carter v. Canada* decision in 2015 held that an absolute prohibition against physician-assisted death was unjustifiable (SCC, 2015). The landmark ruling was followed by the passage of Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act amended the *Criminal Code* to allow for the provision of MAID under specific circumstances (GC, 2016).

The passage of the Act and the practice of MAID in Canada, however, have not settled public debate. Among the issues under discussion are eligibility criteria and procedural safeguards in the legislation, including the criteria that people under the age of 18 are not eligible for MAID; that it is not possible for a person to consent to MAID through an advance request; and that very few people with a mental disorder as their sole underlying medical condition will meet eligibility criteria for MAID (e.g., that natural death must be reasonably foreseeable). Parliament has called for one or more independent reviews to study the question of prohibiting or permitting MAID to people in the above groups (Section 9.1 of the Act).

To meet their obligation, the Ministers of Health and Justice, on behalf of Health Canada and the Department of Justice Canada (the Sponsors), asked the Council of Canadian Academies (CCA) to conduct independent, evidence-informed reviews of the state of knowledge on MAID as it relates to these three topic areas (mature minors, advance requests, and where a mental disorder is the sole underlying medical condition). The reviews were initiated with a public announcement in December 2016.

1.1 THE CHARGE

The objective of the reviews, herein referred to as the *reports*, was to gather and assess information and evidence relevant to the three topic areas in order to inform a national dialogue among the Canadian public, and between the public and decision-makers. The Sponsors therefore asked the CCA to answer the following general questions:

Main Question

What is the available evidence on, and how does it inform our understanding of, medical assistance in dying (MAID) in the case of mature minors, advance requests, and where mental illness is the sole underlying medical condition, given the clinical, legal, cultural, ethical, and historical context in Canada?

General Sub-Questions

What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for the three topic areas?

*What are the potential impacts on society of permitting or prohibiting requests for MAID for the three topic areas?**

What are the potential risks and safeguards that might be considered related to MAID for the three topic areas?

What are the relevant gaps in domestic and international knowledge and research related to MAID for the three topic areas?

*E.g., Suicide prevention strategies and medical responses; availability and efficacy of palliative care; dementia-related and mental health services and supports; risks to vulnerable populations; discrimination and stigma related to chronological age, dementia and related illnesses, and mental illness; and risks of inducements.

The charge also included sub-questions specific to the three topic areas:

Requests for MAID by Mature Minors

What is the impact of chronological age on the legal capacity to request and consent to MAID?

What are the unique considerations related to mature minors requesting MAID (e.g., mature minors vs. adults and MAID vs. other healthcare decisions)?

Advance Requests for MAID

How is an advance request for MAID similar to or different from advance directives for healthcare under existing provincial/territorial regimes?

*What are the unique considerations to be taken into account depending on when an advance request is made?****

*** That is: 1) before diagnosis; 2) after diagnosis but before onset of suffering; 3) after all of the eligibility criteria and procedural safeguards have been met, except for the 10 day waiting period and the reconfirmation immediately prior to provision of MAID.

Requests for MAID Where Mental Illness Is the Sole Underlying Medical Condition***

What is the impact of mental illness in its different forms on an individual's legal capacity to request and consent to MAID?

*What are the unique considerations related to individuals living with mental illness (including mature minors) requesting MAID where the mental illness is the sole underlying medical condition?*****

*** For certainty, the study is concerned with requests where mental illness is the sole underlying medical condition and does not include circumstances where a person with a mental illness is eligible under the existing law.

**** Both in communities or institutions.

1.2 SCOPE

The reports address the questions set out in the charge. They focus on what is known and not known about MAID as it relates to mature minors, advance requests, and a mental disorder as the sole underlying medical condition. The reports do not provide recommendations to governments. It is also important to note that the reports do not evaluate the provisions enacted by Canada's MAID legislation; a formal review of MAID is required at year five (see Section 10 of the Act). Nor do they revisit the legal arguments and evidence for allowing or prohibiting MAID in general.

1.3 THE EXPERT PANEL

To address its charge, the CCA assembled a multidisciplinary panel of 43 experts from Canada and abroad (the Panel), divided into three Working Groups. Each Working Group focused on one of the three topic areas. The Panel's expertise covered academic, clinical, legal, and regulatory fields from the disciplines of medicine, nursing, law, bioethics, psychology, philosophy, epidemiology, anthropology, and sociology. Each member served on the Panel on a *pro bono* basis as an informed individual, rather than as a representative of a particular community, discipline, organization, or region. The Panel met in person six times from May 2017 through to July 2018 at various locations across Canada. Panel members convened both in plenary and within their respective Working Groups to deliberate over the evidence.

The Panel also organized three parallel sessions to discuss aspects of the charge that intersected with more than one topic area. These sessions examined the social determinants of health relevant to all three topic areas, the relationship between advance requests and mental disorders, and the intersection between mental disorders and mature minors. The result of these sessions informed each of the reports. The Working Groups and various subgroups also held discussions via teleconference as required to advance the reports between in-person meetings.

1.4 TERMINOLOGY

Medical Assistance in Dying

For the purposes of the reports, and consistent with the federal legislation, the Panel uses the term *medical assistance in dying (MAID)*, which, as defined in the legislation, means:

- (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or
- (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

(GC, 2016)

The gathered evidence often used alternative words and phrases, including *euthanasia*, *assisted suicide*, *physician-assisted suicide*, *physician-assisted death*, or *medical aid in dying*. When referring to evidence from other jurisdictions, the reports use the terminology common to the relevant jurisdiction. A table of legal terminology with notes on common usage in other regions is available in Appendix A.

Mature Minor

A *minor* is a person under the age of majority (18 or 19 depending on the province or territory). A *mature minor* is a minor who has the capacity to understand and appreciate the nature and consequences of a decision. The Panel's use of further terminology and nuances related to minors, such as *children*, *adolescents*, *youth*, and *adults*, are explained in this report.

Advance Requests for MAID and Advance Directives

The Panel defines an *advance request for MAID* (AR for MAID) as a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under the circumstances outlined in the request after the person has lost decisional capacity.

ARs for MAID should be distinguished from provincially and territorially regulated *advance directives*, which are documents that “allow a decisionally-capable individual either to designate someone to make decisions about health care on his or her behalf, or to specify types of treatment to be accepted or rejected, should the need arise, or both,” in the event that the individual loses decision-making capacity (Gilmour, 2017). *The State of Knowledge on Advance Requests for Medical Assistance in Dying* explores in detail the possible relationship between ARs for MAID and advance directives.

Mental Disorder and Mental Illness

MAID legislation and the charge use the term *mental illness*. However, the Working Group chose to use the term *mental disorder* to be consistent with current clinical and legal practice. *Mental disorder* is the term used in the two primary classification systems in psychiatry: the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (WHO, 2016) and the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (APA, 2013).

1.5 EVIDENCE CONSIDERED

The CCA has a long-established approach for convening experts and assessing evidence. Throughout the assessment process, the Panel was asked to identify the range of knowledge and evidence relevant to the charge, examine this body of evidence, and interpret it in the form of findings. The Panel recognizes that the breadth of experience is limited, as a small number of jurisdictions permit some form of MAID and fewer still permit MAID in the three topic areas.

Given the complex, interdisciplinary nature of the topics, the Panel recognized the importance of interpreting evidence broadly and included empirical evidence such as peer-reviewed research and grey literature, normative evidence such as bioethical argumentation, and other forms of evidence such as lived experiences. To this end, the Panel identified and assessed evidence that was found in, but was not limited to, peer-reviewed publications from health disciplines, ethics, social sciences, humanities, and law; professional standards and guidelines; regulatory, legislative, and compliance materials; policy documents; and media reports.

Panel members identified evidence in multiple ways. For example, they drew on their respective disciplinary expertise to identify important evidence in their fields, conducted literature searches, and reviewed responses from the CCA's Call for Input (Section 1.5.1). Evidence gathering also included conversation with Indigenous Elders (Section 1.5.2). Literature searches were carried out using search terms that reflected the diversity of terminology that describes MAID domestically and internationally (Appendix A), as well as related concepts and practices. Literature searches were iterative, informed by Panel deliberations, and included examining literature cited by relevant articles and reports.

The Panel acknowledges a number of challenges and limitations associated with assessing evidence from such diverse sources. In addition to varying quality and availability of research, disciplines may also differ in the evidentiary standards

they apply and in the methods of establishing those standards. It was important, therefore, for the Panel to consider the value and quality of the evidence from the standards of their respective disciplines.

The Panel also recognizes that different types of evidence are not necessarily commensurable, and cannot be ordered within a single hierarchy of credibility. Ethical argumentation, empirical medical research, traditional knowledge, and lived experiences, for example, each give understanding, perspective, and nuance to MAID-related issues that no one type of evidence can provide on its own. Moreover, the Panel recognizes that not all questions that matter can be addressed by empirical research; in some cases, an anecdote conveying meaning through lived experience or an argument based on logic may be more relevant to the question.

To the extent that the evidence allowed, the Panel also considered how MAID legislation regarding the three topic areas might impact diverse groups of people. Panel deliberations therefore considered gender, race, ethnicity, ability, socio-economic status, and other factors affecting the determinants of health, including healthcare access and delivery of services.

The reports are a synthesis of knowledge available to the Panel through the academic and policy literature, the CCA's Call for Input, and its diverse interdisciplinary and professional expertise. The Panel's findings provide a lens into what is currently known about MAID with respect to the three topics at issue. They also shed light on relevant values for MAID policy in Canada, including how differences in values may lead to differences in the interpretation of evidence. The final text is the product of a collective effort to engage with these evidentiary and evaluative inputs to address the charge questions. Each report reflects the general view of its Working Group members even if on some points unanimity could not be established. In some situations, even after consideration of available data and Panel discussions, agreement could not be achieved and significant differences of opinion remained, reflecting the complex and conflicted nature of the issues being reviewed; in those instances, such disagreement is reflected in the reports.

1.5.1 Call for Input

As part of the Panel's evidence-gathering activity, a Call for Input was carried out by the Panel over a three-month period beginning in July 2017. In addition to inviting written input from 500 groups and organizations across Canada affected by, or involved in, MAID, the Call for Input was made available online to any interested organizations. Specifically, the Panel asked organizations to:

- (i) describe their main issues concerning requests for MAID in the three topic

areas under study; and (ii) submit, or provide links to, any knowledge they would like the Panel to consider. The CCA received 59 submissions from a wide variety of organizations in the areas of advocacy, medicine, nursing, pharmacy, social work, law, and religion (Box 1.1).

Call for Input submissions were shared with Panel members and reviewed to identify issues related to the three topic areas. Call for Input submissions also identified a range of evidence, including professional guidelines and codes of ethics, additional peer-reviewed articles, surveys of membership of professional bodies, and lived experience testimony, not previously available to, or identified by, the Panel. Where relevant, these sources were included in the body of evidence assessed by the Panel.

1.5.2 Indigenous Elders Circle

An Elders Circle, facilitated by Indigenous Panel members, was held in February 2018 to provide insight into Indigenous perspectives on MAID, particularly with respect to the three topic areas. Six Elders from Métis and First Nations in British Columbia, Saskatchewan, Manitoba, and Ontario offered their knowledge of end-of-life attitudes, practices, issues, and concerns. Notably, the Elders felt that Indigenous Peoples had not been consulted on the issue of MAID. The Panel recognizes that the Elders Circle was limited in scope and representation, and does not constitute consultation with Indigenous Peoples on the topic of MAID. This remains a significant knowledge gap.

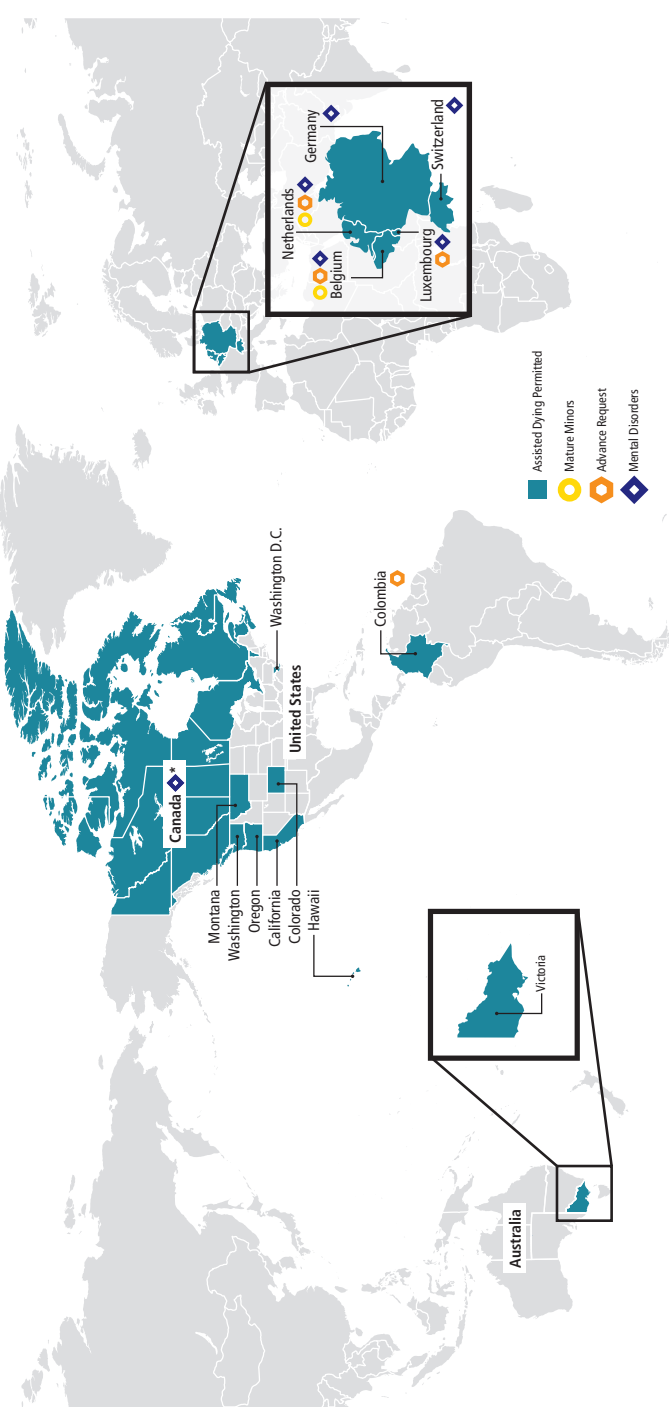
1.5.3 International Experience

The Panel considered the experiences and evidence from other countries that allow some form of assisted dying. In cases where access to relevant documents from other countries was impeded by language, professional translators were engaged.

Assisted dying is legal or partially decriminalized in a small number of jurisdictions (Figure 1.1); areas that allow assisted deaths do so with specific access criteria and safeguards. The Panel considered and assessed critically the international evidence in light of the Canadian healthcare environment, its unique geography and history, and the contemporary political and social policy context within which the MAID conversation is occurring.

Box 1.1**Organizations That Made a Formal Submission to the CCA's Call for Input**

- Addictions and Mental Health Ontario
- Alberta College of Social Workers
- Alzheimer Society of British Columbia
- Alzheimer Society of Nova Scotia
- Association for Reformed Political Action
- Association médicale du Québec
- Association of Registered Nurses of British Columbia
- Autism Canada
- British Columbia College of Social Workers
- British Columbia Humanist Association
- Canadian Association for Community Living
- Canadian Association of MAID Assessors and Providers
- Canadian Bar Association
- Canadian Coalition for the Rights of Children
- Canadian Federation of Catholic Physicians' Societies
- Canadian Medical Association
- Canadian Medical Protective Association
- Canadian Mental Health Association
- Canadian Physicians for Life
- Canadian Psychiatric Association
- Canadian Society of Palliative Care Physicians
- CARP
- Catholic Civil Rights League
- Catholic Health Alliance of Canada
- Centre for Addiction and Mental Health
- Christian Legal Fellowship
- Christian Medical and Dental Society of Canada
- Collège des médecins du Québec
- College of Licensed Practical Nurses of Manitoba
- College of Physicians and Surgeons of Ontario
- College of Registered Nurses of Manitoba
- College of Registered Psychiatric Nurses of Manitoba
- Community Health Nurses of Canada
- Covenant Health
- Dying with Dignity Canada
- Empowerment Council
- Evangelical Fellowship of Canada
- Federation of Medical Regulatory Authorities of Canada
- Institut de planification des soins
- Manitoba Provincial MAID Clinical Team
- National Association of Pharmacy Regulatory Authorities
- Nova Scotia College of Pharmacists
- Nurse Practitioner Association of Canada
- Nurse Practitioner Association of Manitoba
- Ontario College of Social Workers and Social Service Workers
- Ontario Psychiatric Association
- Ontario Shores Centre for Mental Health Sciences
- Ottawa Catholic Physicians' Guild
- Physicians' Alliance Against Euthanasia
- REAL Women of Canada
- Right to Die Society of Canada
- Salvation Army
- St. Joseph's Health Care London
- The Hospital for Sick Children
- Toronto Catholic Doctors' Guild
- Toujours Vivant-Not Dead Yet
- University Health Network
- University of Toronto Joint Centre for Bioethics MAID Implementation Task Force, MAID Advance Request Working Group
- West Coast Assisted Dying



Data Source: Bruns, 2016; GC, 2016; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of DC, 2016; Gov. of Germany, 1998; Gov. of HI, 2018; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of Switzerland, 1942; Gov. of Victoria, 2017; Gov. of VT, 2013; Gov. of WA, 2009; Supreme Court of the State of Montana, 2009

Figure 1.1 Map of the World Showing Places Where Some Form of Assisted Dying is Allowed

This figure represents the understanding of the Expert Panel regarding the status of assisted dying worldwide, given the available knowledge at the time this report was written. Jurisdictions vary in terms of the legal mechanism by which assisted dying is allowed (e.g., through legislation or a court decision), the form of assisted dying that is permitted (e.g., self-administration or physician administration of a lethal substance), and the specific eligibility criteria (e.g., requirement of a terminal illness or a minimum age). For additional information, see Appendix A. The symbols on the map indicate the countries in which assisted dying can be accessed by mature minors, through advance requests, or by people with a mental disorder as their sole underlying medical condition.

*To access assisted dying in Canada, including for a mental disorder, death must be reasonably foreseeable, but this is not a requirement in Belgium, Luxembourg, or the Netherlands.

Rates of uptake vary considerably among, and even within, regions; in U.S. states, which only allow self-administration by patients with a diagnosis of terminal illness, the proportion of deaths attributed to physician-assisted suicide remains under 1% (Figure 1.2). The Panel notes that data collection and reporting procedures vary substantially both within and among jurisdictions. Relevant details and discussion of evidence from foreign jurisdictions are included in the body of the reports.

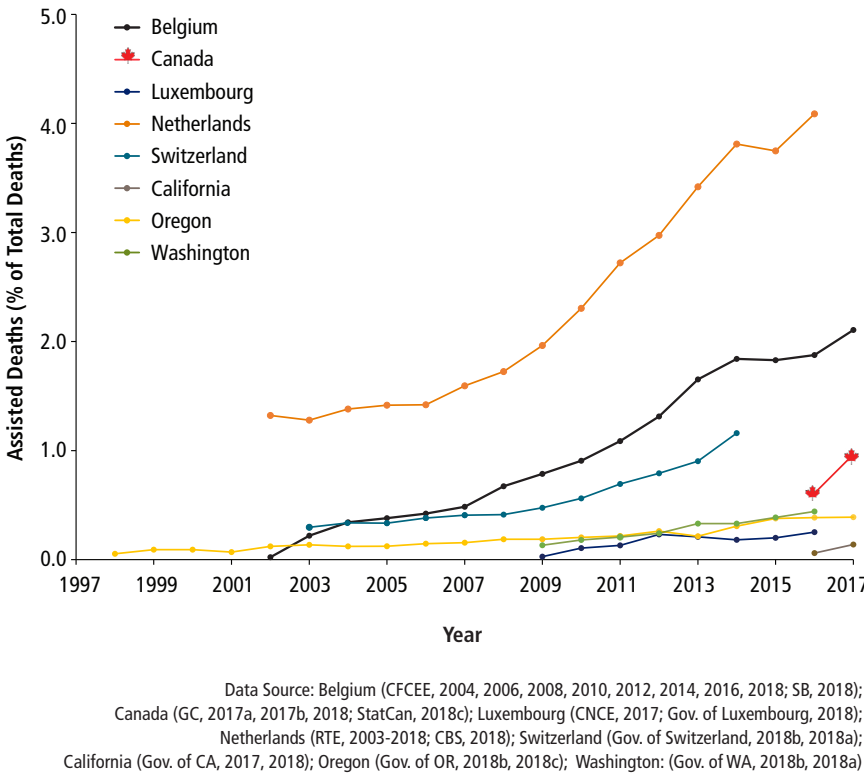


Figure 1.2

Reported Assisted Deaths as a Percentage of Total Deaths per Year by Location

Not all locations where some form of assisted dying is permitted publicly report the number of such deaths each year; data presented in the figure are the best available at this time. Note that assisted dying practices vary among U.S. states; data from individual states are presented where available.

1.5.4 Knowledge Gaps

Direct evidence on the practice of assisted dying in the three topic areas is limited to publicly available documentation from the few countries that allow assisted dying for mature minors, through advance requests, or where a mental disorder is the sole underlying medical condition. However, many of the questions and issues related to the three topic areas identified by the Panel do have an evidence base, often spanning multiple disciplines including law, ethics, medicine, nursing, psychology, psychiatry, and sociology. This evidence forms the core of what the Panel assessed. There are nonetheless knowledge gaps for these issues; where they exist, the Panel identified and factored them into its findings.

1.6 HOW TO READ THIS REPORT

This report is one of three related reports that collectively examine the evidence related to medical assistance in dying: MAID for Mature Minors, Advance Requests for MAID, and MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. Though each report is authored by a different Working Group of the Expert Panel, the three reports have been developed in parallel and benefitted from common discussions across the Working Groups.

These reports can therefore be read independently or as a single body of work. To support this structure the three topic area reports share the same first two chapters: Chapter 1: *Introduction* and Chapter 2: *MAID in Canada: Historical and Current Considerations*. These two chapters provide common information and context relevant to all three reports. The chapters that follow comprise the core of the topic area assessment. Chapters 3 through 5 present context, issues, and evidence specific to the respective topic area. Chapter 6 is a discussion of potential impacts, implications, and safeguards. Each report concludes with its own Chapter 7, which provides summary answers to the charge.

2

MAID in Canada: Historical and Current Considerations

- **How Did We Get Here?**
- **Implementation of MAID in Canada**
- **Provision of Healthcare in Canada**
- **Healthcare Decision-Making**
- **Chapter Summary**

2 MAID in Canada: Historical and Current Considerations

The partial decriminalization of MAID in Canada followed a succession of legal challenges, societal and technological changes, advocacy and scholarly work, and public and professional discussions, some of which began more than 50 years ago. The Panel understands that MAID is a deeply personal topic about which there are differing views on the relevant evidence, and that one's perception about the need for the practice to include mature minors, advance requests, or where a mental disorder is the sole underlying medical condition is informed by life experiences, values, and beliefs. Moreover, Panel members, regardless of their own disciplinary expertise, recognize that clinical, ethical, legal, and societal considerations may be in tension with one another. This chapter provides a context for current discussions of MAID in Canada with the understanding that these discussions will continue to evolve.

The chapter begins with an overview of some pivotal points in this history, along with certain contemporary realities of delivering healthcare services in a culturally diverse and geographically expansive country. The three topic areas also touch on several common considerations — informed consent, decision-making capacity, and decision-making authority — each of which is discussed in the context of MAID in Canada. Given the breadth and complexity of issues, the chapter seeks to provide the reader with a common starting point for thinking about MAID in the three topic areas. It does not purport to be a definitive or comprehensive examination of the historical, social, and political context of MAID in Canada.

2.1 HOW DID WE GET HERE?

The public conversation in Canada about end-of-life decision-making dates back more than half a century. The development of new life-prolonging technology and medical interventions prompted conversations about their use and/or withdrawal among patients, families, clinicians, and institutions. Arnup (2018), citing Smith and Nickel (2003), points out that healthcare in Canada in the post-war years featured new technologies and focused on saving lives, and that “little thought was given to dignity, pain relief or quality of care” of the dying. By the late 1960s, however, the palliative care and hospice movements began to take hold, based on the idea that patients at the end of life required equal clinical attention — albeit of a different kind — even when cure was no longer possible (Mount, 1976; Saunders, 2001; Arnup, 2018). High-profile cases, such as that of Karen Ann Quinlan in the United States, brought public attention to end-of-life discussions about cessation of treatment and quality of life (Martin, 2016).

In 1982, the Law Reform Commission of Canada published a working paper, followed in 1983 by a full report, entitled *Euthanasia, Aiding Suicide and Cessation of Treatment* (LRCC, 1982, 1983). The Commission recommended against decriminalization or legalization of euthanasia or assisted suicide, but did make recommendations to clarify the legal right of a patient to refuse treatment and of a physician to cease treatment that has become therapeutically useless and is not in the best interests of the patient (LRCC, 1983). Nine years later, the decision in the case of Nancy B. in Quebec City affirmed a capable patient's right to refuse life-sustaining treatment even if such a decision led to death (QCCS, 1992).

2.1.1 Sue Rodriguez Challenges the Assisted Suicide Prohibition in Canada

In the early 1990s, Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS), applied to the Supreme Court of British Columbia to have the *Criminal Code* prohibition on assisted suicide declared unconstitutional. After the British Columbia Supreme Court dismissed her application, Ms. Rodriguez appealed to the British Columbia Court of Appeal and, after being unsuccessful there, to the Supreme Court of Canada (SCC, 1993).

The key constitutional rights implicated by the prohibition on assisted suicide were Sections 7 and 15(1) of the Canadian *Charter of Rights and Freedoms* (GC, 1982). Section 7 states that everyone has “the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” Section 15(1) states that every person has the right to “equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.” While actions taken by governments are subject to these provisions, Section 1 of the Charter states they may limit rights insofar as such limits are “reasonable,” “prescribed by law,” and “demonstrably justified in a free and democratic society.” Ms. Rodriguez argued that she would be unable to take her own life without assistance when she no longer had the capacity to enjoy life because of her disease. Ms. Rodriguez stated that, since suicide is legal under the *Criminal Code*, prohibiting assisted suicide discriminates against people with a physical disability that makes them incapable of taking their own life (SCC, 1993).

On September 30, 1993, the Supreme Court of Canada ruled, by a five-to-four majority, that the prohibition against assisted suicide was in accordance with the principles of fundamental justice and as such did not violate Section 7 of the Charter. The Supreme Court also concluded that a violation of Section 15(1) of the Charter would be “demonstrably justified in a free and democratic society” and ruled that the prohibition was constitutional (SCC, 1993).

2.1.2 Public Conversation, Consideration, and Study

Discussions of choice at end of life did not stop after the *Rodriguez* decision. Following a series of papers published by the Canadian Medical Association on assisted suicide and euthanasia in 1993, the Senate of Canada appointed a Special Committee in 1994 to “examine and report on the legal, social and ethical issues relating to euthanasia and assisted suicide” (SSCEAS, 1995). The Committee heard testimony and reviewed letters and briefs from across Canada for 14 months, before publishing a final report in 1995, with a majority recommending against changing the legal status of euthanasia and assisted suicide in Canada (SSCEAS, 1995).

Criminal cases reported in the media across Canada in the 1990s, such as those of Robert Latimer in Saskatchewan and Dr. Maurice G  n  reux in Ontario, inspired further public and private debate (see Deschamps, 2017 for a review of cases). Moreover, Canadians were not insulated from highly publicized international cases, such as those of Dr. Jack Kevorkian in the United States (Martin, 2016). Advocacy groups, such as Dying with Dignity Canada and its Quebec counterpart, Association qu  b  coise pour le droit de mourir dans la dignit  , campaigned for choice at end of life in Canada. Within clinical practice, discussions of appropriate end-of-life care practices and policy development were ongoing (e.g., CFPC, 2012; CMA, 2014).

Academic study of the issues of euthanasia and assisted suicide by scholars in Canada from a range of disciplines, including law, bioethics, philosophy, and history, informed perspectives about the practice (e.g., Somerville, 2001; Downie, 2004; Dowbiggin, 2005; Sumner, 2011). In 2011, the Royal Society of Canada published a multidisciplinary review of end-of-life decision-making that included research on assisted death (RSC, 2011).

In recent decades, legislative attempts to amend the *Criminal Code* to permit euthanasia and/or assisted suicide in limited circumstances were unsuccessful. These attempts came from diverse political parties: Svend Robinson (New Democratic Party, 1992, 1994), Francine Lalonde (Bloc Qu  b  cois, 2005, 2008, 2009), Stephen Fletcher (Conservative Party, 2014), and Nancy Ruth (Conservative Party, 2014) (Butler *et al.*, 2013; Deschamps, 2017).

2.1.3 Quebec Enacts End-of-Life Legislation that Includes Medical Aid in Dying

In 2006, Quebec’s medical regulator, Coll  ge des m  decins du Qu  bec (CMQ), embarked on a three-year process to study appropriate care at the end of life (CMQ, 2009). In November 2009, a working group report concluded that, despite advances in palliative care, there were exceptional cases in which clinical

interventions were ineffective and, in those situations, a patient would have no option but to suffer until death (CMQ, 2009); this position was subsequently adopted by the CMQ (Robert, 2010). In December 2009, the National Assembly of Quebec unanimously adopted a motion to create a select committee of members to study the issue of dying with dignity (Gov. of QC, 2012).

Reporting to the National Assembly in March 2012, the committee noted that opinion had shifted in public polls in support of euthanasia and assisted suicide, and among healthcare practitioners in surveys conducted by professional associations (Gov. of QC, 2012). In June 2014, the Quebec government passed *An Act Respecting End-of-Life Care* (Gov. of QC, 2014), which took effect in December 2015. This Act addresses patients' entitlement to receive the full spectrum of care at the end of life, and includes medical aid in dying. The Quebec eligibility criteria and safeguards are similar, but not identical, to those of the federal statute (Gov. of QC, 2014).

2.1.4 Carter v. Canada Overturns the Blanket Prohibition on Assisted Suicide

In 2011, two family members of Kay Carter (a woman with spinal stenosis who had travelled to Switzerland for an assisted suicide), William Shoichet (a medical doctor willing to participate in physician-assisted deaths), and Gloria Taylor (a woman with ALS) joined with the British Columbia Civil Liberties Association to challenge federal prohibition on physician-assisted dying. In 2015, the Supreme Court of Canada concluded that the challenged provisions of the *Criminal Code* were void insofar as:

[T]hey prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) 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.

(SCC, 2015)

In contrast to the five-to-four decision in *Rodriguez v. Canada* (1993), the *Carter* decision was unanimous (9-0); the decision stated that a blanket prohibition on assisted suicide deprives adults of the right to life, liberty, and security of the person. For the purposes of the reports, it is important to note that *Carter* considered the case of adults with decision-making capacity, and that it made “no pronouncement on other situations where physician-assisted dying may be sought” (SCC, 2015). The Supreme Court confirmed at the same time the role of the criminal law, suspending the declaration of invalidity of the criminal prohibition for one year to allow time for a legislative and regulatory response to the judgment (SCC, 2015).

2.1.5 Bill C-14 and the Partial Decriminalization of MAID

In response to the *Carter* ruling, after study and consultation (e.g., PTEAG, 2015; SJCPAD, 2016b), the federal government introduced Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*. The Act received Royal Assent on June 17, 2016, creating the federal statutory framework for MAID (GC, 2016).

The preamble to the federal MAID legislation takes into consideration the autonomy and intolerable suffering of persons with grievous and irremediable medical conditions who wish to seek MAID; the need for “robust safeguards ... to protect against errors and abuse;” affirmation of the “inherent and equal value of every person’s life” and the avoidance of “negative perceptions of the quality of life of persons who are elderly, ill, or disabled;” the protection of vulnerable persons from “being induced, in moments of weakness, to end their lives;” and the recognition that “suicide is a significant public health issue that can have lasting and harmful effects on individuals, families and communities” (GC, 2016). The preamble concludes:

permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other.

A specific concern of the legislators, as evidenced in the preamble to the Act, was a possible impact of MAID on suicide rates and suicide prevention. Suicide is not a criminal offence in Canada, but assisting a person to end their life is illegal unless the conditions of the MAID legislation are met (GC, 2016). In addition to being a public health issue, suicide prevention is also foundational to the practice of mental health services. Suicide, suicide prevention, and the possible impacts of MAID laws are discussed in detail in Sections 3.2 and 4.2 of *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*.

The legislation provides eligibility criteria and procedural safeguards to establish the parameters of legally permissible MAID in Canada (Box 2.1).

Box 2.1**Eligibility Criteria for Accessing MAID in Canada**

241.2 (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.

241.2 (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 medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

(GC, 2016)

Two independent medical or nurse practitioners must be of the opinion that the person requesting MAID meets all of the eligibility criteria. Furthermore, there must be 10 clear days between the formal request and the provision of MAID, unless the person's death or loss of capacity is imminent. Immediately prior to the provision of MAID, the person must be given an opportunity to withdraw their request and must give express consent to the procedure (GC, 2016).

Thus, mature minors under the age of 18 are not eligible for MAID; competent persons cannot provide valid consent by means of an advance request for MAID; and competent persons with a mental disorder as their sole underlying medical condition will rarely meet all of the eligibility criteria.

2.2 IMPLEMENTATION OF MAID IN CANADA

The best available data indicate that 3,714 people in Canada accessed MAID between December 10, 2015 and December 31, 2017 (GC, 2018). This number includes data from Quebec (but only until June 9, 2017), and excludes data from Yukon, Northwest Territories, and Nunavut. In 2017, MAID deaths represented approximately 1% of all deaths in Canada (GC, 2018).

The most common underlying conditions among those who received MAID in 2017 ($n=1,961$)¹ were cancer (64%), followed by diseases of the circulatory/respiratory system (17%), and neurodegenerative conditions (11%); 51% of recipients were men and 49% women. People ranged in age from 18–45 to over 90 years old, with the largest demographic being 65–70 years of age (Figure 2.1).

New federal monitoring regulations, introduced July 25, 2018, specify reporting requirements and designate a recipient to receive reports from medical and nurse practitioners and pharmacists in each province and territory (GC, 2018). Prior to the introduction of federal monitoring regulations, Health Canada produced three interim reports based on available data from the provinces and territories (GC, 2017a, 2017b, 2018).

1 Excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.

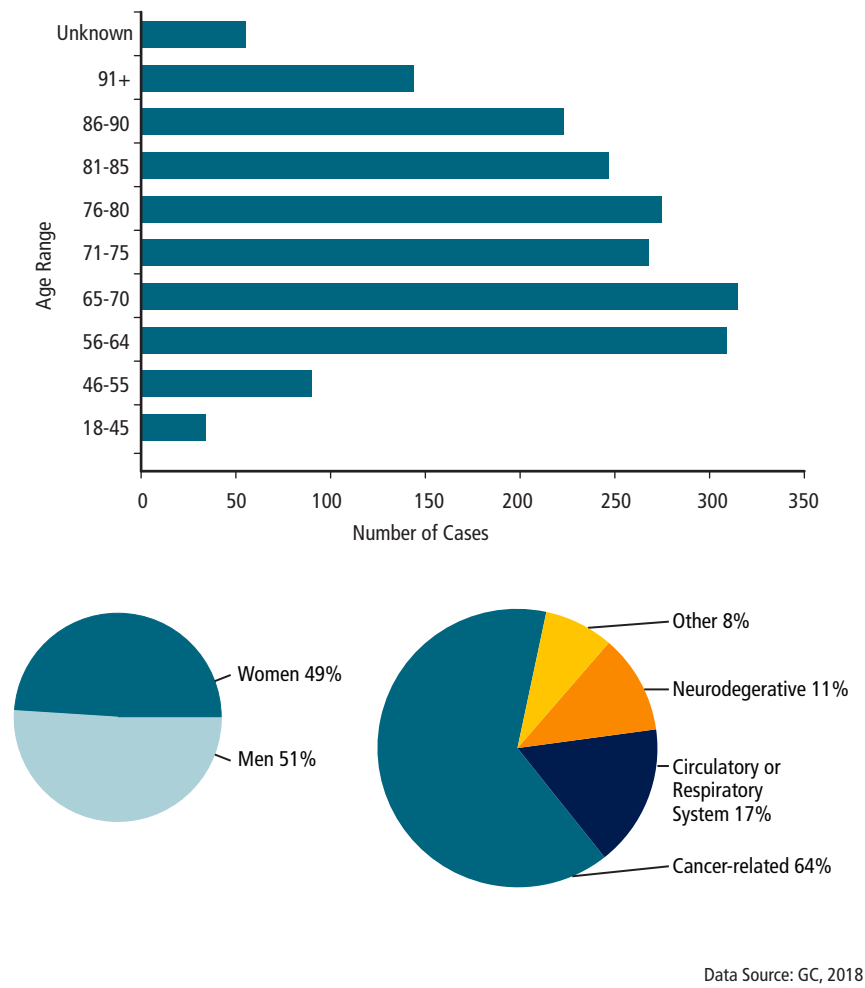


Figure 2.1
Characteristics of Reported MAID Deaths in Canada in 2017
MAID deaths in Canada, as reported to Health Canada in 2017, by age, gender, and underlying medical condition. The figure excludes data from Yukon, Northwest Territories, Nunavut, and Quebec.

In Quebec, *An Act Respecting End-of-Life Care* legislated the creation of a commission that submits an annual activity report, no later than September 30, to the Minister of Health and Social Services (Gov. of QC, 2014). Since its inception, the Commission has published two reports, the first in October 2016 (Gov. of QC, 2016) and the second in October 2017 (Gov. of QC, 2017a). Additionally, executive directors of health and social services institutions, as well as the CMQ (which collects reports directly from individual private practice physicians), are required to publicly report on numbers of MAID requests and outcomes (GC, 2018).

2.2.1 Pending Legal Challenges to MAID Legislation

The British Columbia Civil Liberties Association and Julia Lamb, a 25-year-old woman with spinal muscular atrophy (a progressive degenerative condition), filed a constitutional challenge to the federal Act on June 27, 2016 (BCCLA, 2016). The lawsuit challenges eligibility criteria (reasonably foreseeable death, incurable illness or condition, advanced state of irreversible decline), arguing that the federal legislation unjustifiably limits Sections 7 and 15 of the Charter and is not saved by Section 1 (BCCLA, 2016).

In Quebec, in June 2017, Jean Truchon, a 49-year-old man with cerebral palsy, and Nicole Gladu, a 71-year-old woman with post-polio syndrome, filed a legal challenge against the assisted dying laws in Canada and Quebec (QCCS, 2017a). They argue that the eligibility criteria in the legislation (“natural death has become reasonably foreseeable” and “end of life”) are too restrictive, violate Sections 7 and 15 of the Charter, and cannot be saved under Section 1.

Also in Quebec, Paul Saba, a physician, has variously challenged the validity of the Quebec statute on assistance in dying and the federal MAID law on several bases, including that the current deficiencies in healthcare services prevent patients from giving informed consent. He also claims that the regime is unconstitutional and goes against Quebec’s *Code of Ethics of Physicians* and the *Canada Health Act* (QCCS, 2017b).

In a statement of claim filed with the Ontario Superior Court of Justice, Roger Foley, who has a serious neurological disability, claims that the defendants (his local hospital, local health integration network, and others) have violated his Charter rights by failing to provide adequate and appropriate home care services to relieve his suffering. Additionally, he claims the defendants have offered to provide assisted suicide instead of an assisted life. He also seeks, in part, a declaration that the MAID provisions in the *Criminal Code* are unconstitutional and therefore invalid (ONSC, 2018).

2.2.2 Legal Interpretations of MAID Legislation

In 2017, the Ontario Superior Court of Justice made an *interpretive declaration* regarding the eligibility criterion of a reasonably foreseeable death in the discussion of a case involving a patient seeking MAID (*AB v. Canada (Attorney General)*). Referring to the language used in Canada's MAID legislation, the Court stated:

This language reveals that natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan.

(ONSC, 2017)

The College of Physicians and Surgeons of Nova Scotia has similarly provided a broad interpretation of reasonable foreseeability in its *Professional Standard Regarding Medical Assistance in Dying*, referencing the *AB v. Canada (Attorney General)* case (CPSNS, 2018). Furthermore, an Inquiry Committee for the College of Physicians and Surgeons of British Columbia found a woman had met MAID eligibility criteria “despite the fact that her refusal of medical treatment, food, and water undoubtedly hastened her death and contributed to its ‘reasonable foreseeability’” (CPSBC, 2018).

The College of Physicians and Surgeons of Ontario has two policies requiring physicians who conscientiously object to MAID to make an effective referral for patients who request MAID (CPSO, 2015b, 2016). Several groups and individual physicians challenged these policies, stating they violate one's right to freedom of religion, freedom of conscience, and right to equality. The Ontario Superior Court of Justice (Divisional Court) decided on January 31, 2018 that any infringement on physicians' freedom of religion was justified given its objective of ensuring equitable access to healthcare (ONSCDC, 2018). An application for leave to appeal was filed in the Ontario Court of Appeal on February 20, 2018 (Golding & Rosenbaum, 2018).

2.2.3 MAID Delivery and Regulation

MAID is an exemption in the *Criminal Code* to criminal offenses of homicide and assisted suicide, as long as specific eligibility criteria are met and certain safeguards are followed (Box 2.1). Debates about eligibility criteria for MAID include debates about the scope of criminal law, the prohibitions on causing death that the criminal law contains, and the social norms represented therein. However, MAID is also a medical act, regulated and delivered through the healthcare system, as, by law, only medical and nurse practitioners can provide MAID in Canada. Thus, a brief overview of MAID delivery and regulation in the healthcare system follows.

Provinces and territories are primarily responsible for delivering healthcare services to their residents; however, the federal government has responsibility in providing primary healthcare to certain groups (GC, 2012b). Provincial and territorial healthcare legislation defines the obligations of health authorities, healthcare institutions, and individual practitioners with respect to the delivery of healthcare services. These obligations are set out in legislation regulating, for example, hospitals (e.g., Gov. of NS, 1989) and healthcare consent (e.g., Gov. of ON, 1996). In the case of Quebec, provincial legislation regulates end-of-life care, including MAID (Gov. of QC, 2014). Subsequent to the passage of the federal MAID legislation, Manitoba and Ontario introduced or amended statutes to address implementation (e.g., Gov. of MB, 2017; Gov. of ON, 2017).

Provincial and territorial legislation establishes regulatory colleges that enforce standards of practice and regulate the conduct of professional healthcare providers, such as nurses, physicians, and pharmacists. Colleges enforce standards through the licensing and disciplining of professional members; their purpose is to serve and protect the public, ensuring competency and quality of practice within their professions (e.g., Gov. of BC, 1996a). Quebec has legislation defining codes of ethics for specific professions, such as physicians (Gov. of QC, 2017b). Many regulatory colleges have developed professional standards and policies for the assessment and provision of MAID by their members (e.g., CPSO, 2016; CPSNS, 2018; CRNBC, 2018a).

Hospitals also regulate the practices provided by their institutions and within their facilities, including the provisioning of MAID. There may be public and independent health facilities regulated by different pieces of legislation within a province or territory (e.g., Gov. of ON, 1990a, 1990b, 1990c). Physicians, in law, are generally treated as independent contractors; however, hospitals exert control over the professional conduct of physicians, for instance, by granting or revoking privileges to provide care in their facility. Hospitals hold the authority to hire and regulate the conduct of other healthcare professionals, such as nurses and pharmacists. Many hospitals have developed policies to regulate the provision of MAID (e.g., TOH, 2016).

Professional associations and societies, such as the Canadian Association of MAID Assessors and Providers (CAMAP), the Canadian Society of Palliative Care Physicians (CSPCP), and the Canadian Nurses Association, are organizations of healthcare practitioners and scholars. These organizations seek to provide support, information, and guidance to healthcare practitioners, but do not license members and do not have regulatory authority.

2.2.4 End-of-Life Practices Other than MAID

Though MAID is a novel practice in Canada, subject to eligibility and safeguards prescribed by the *Criminal Code*, it is implemented in a healthcare context where long-standing end-of-life practices exist, such as withdrawing or withholding treatment, continuous palliative sedation therapy, and abstaining from nutrition and hydration. This section briefly reviews their legal status in Canada.

Withdrawing or Withholding Life-Sustaining Treatment

Under Canadian law, people with decision-making capacity clearly have the right to refuse treatment even where that refusal will result in their death (QCCS, 1992). There is no formal requirement in law that refusals be well considered or settled. Mature minors and individuals with a mental disorder who have decision-making capacity may choose to withdraw or withhold life-sustaining treatment, as may their substitute decision makers (SDMs), should they later lose decisional capacity.

Refusals of treatment can be expressed through an advance directive, which may be in the form of written instructions or a chosen SDM. An SDM appointed by operation of a statute (e.g., family member) may decide, on behalf of a patient who lacks decision-making capacity, to withdraw or withhold life-sustaining treatment if they believe it is in accordance with the patient's wishes (where known), or the best interests of the patient (where the patient's prior capable wishes are not known) (see Section 3.3.2 in *The State of Knowledge on Advance Requests for Medical Assistance in Dying*).

Continuous Palliative Sedation Therapy (CPST)

The Canadian Medical Association defines CPST as “complete sedation, with the intent of rendering the patient unable to experience the environment, sensation or thoughts, until the patient dies naturally from the underlying illness” (CMA, 2017). CPST is clearly legal when it does not cause death — that is, when delivered in combination with cessation of artificial hydration and nutrition where death is anticipated within approximately 48 hours (Downie, 2017). Where death is anticipated within two weeks, CPST with the provision of artificial hydration and nutrition is clearly legal (again, it does not cause death) (Downie, 2017). In practice, CPST is generally done without artificial hydration and nutrition. Where death is anticipated within 14 days, the legal status of CPST in combination with cessation of artificial hydration and nutrition is less clear (Downie, 2017); however, it is arguably legal (Downie, 2018b). Where death is not anticipated for some time, the legal status of CPST in combination with cessation of artificial hydration and nutrition is unclear.

Voluntary Stopping of Eating and Drinking (VSED)

Some patients choose to stop eating and drinking, knowing they will die as a result. Competent patients can refuse oral hydration and nutrition (e.g., holding a glass to a person's lips, spoon-feeding) and artificial hydration and nutrition (e.g., intravenous fluids, feeding tube), and advance directives (where applicable in Canada) may also include refusal of artificial hydration and nutrition (Downie, 2017). In some provinces (e.g., Nova Scotia), oral hydration and nutrition can also be refused through advance directives; however, this is less clear in some other provinces (e.g., BCCA, 2015).

VSED has been used in Canada as a pathway to eligibility for MAID. If one stops eating and drinking, their natural death becomes reasonably foreseeable (or, in Quebec, the person reaches their “end of life”). For example, a Quebec man refused food for 53 days and water for 8 days in order to become eligible for MAID (McKenna, 2016). Similarly, a woman in British Columbia refused food and water for 14 days in order to become eligible to receive MAID (CPSBC, 2018).

2.3 PROVISION OF HEALTHCARE IN CANADA

As a first point of contact, primary healthcare services offer immediate care for health problems, routine care, or health information. Family physicians, nurse practitioners, pharmacists, and telephone advice lines can provide these kinds of services. Primary healthcare also provides coordination of specialized services, such as specialist consultation and care (e.g., cardiologists, allergists, psychiatrists) or care provided in hospitals (GC, 2012a).

In 2013, about 29% of people in Canada aged 15 or older reported difficulty in accessing healthcare services, most commonly due to wait times or difficulty securing appointments (Clarke, 2016). In 2016, 15.8% of those aged 12 or older reported that they did not have a regular healthcare provider² (StatCan, 2017). Men aged 18 to 34 were the most likely group to report not having a regular healthcare provider (approximately 33%), whereas men and women over the age of 65 were the least likely group (6.5% of men and 5.3% of women). Self-identified Indigenous people were more likely to report not having a primary healthcare provider (19.2%) compared to the rest of the population (15.8%) (StatCan, 2017). Large geographic distances among communities and low population densities make healthcare more costly in remote areas, resulting in reduced access to services and professionals; this is most pronounced in northern parts of Canada, where visiting professionals or locums provide many

2 Estimates exclude the territories, because the survey did not cover all communities in 2016.

key health services periodically on a short-term basis (NCCAH, 2010). To receive specialized care, patients are often required to leave their home communities by flying to more densely populated centres (NCCAH, 2010; MacIntosh, 2017).

With respect to end of life, access to palliative care also varies across Canada. Access to palliative care and coverage of services such as pharmaceuticals, home care, psychologists, and residential long-term care exist piecemeal across provinces and territories, and are funded through a mix of public programs, private insurance, and out-of-pocket payments by individuals (Carstairs, 2010; Chappell & Hollander, 2011; Verma *et al.*, 2014). Gaps in existing data present challenges in understanding the full extent of this issue (Canadian Cancer Society, 2016). An oft-cited statistic notes that only 16 to 30% of people in Canada have access to palliative care (Carstairs, 2010), though it is based on a study of in-hospital palliative care in Western Canada only (Downie & Lloyd-Smith, 2014). Barriers to access include issues of training and education among healthcare professionals, such as the lack of adequate training in palliative care in Canada (Stonebridge, 2017). In a letter to the Quebec Health Minister dated May 29, 2018, the CMQ raised concerns that, because palliative care and social services are increasingly diverted to those who make a request for MAID, patients may seek to access these services by requesting MAID (CMQ, 2018).

2.3.1 Health and Health Equity in Canada

There are significant disparities in health in Canada. For example, life expectancy is consistently lower than average in regions with high unemployment rates, lower educational achievement, and greater material and social deprivation (PHAC, 2018). Low socio-economic status is also related to higher incidences of chronic disease, such as arthritis, asthma, and diabetes (PHAC, 2018). Studies have demonstrated that immigrant, racialized, and ethnocultural groups face barriers in accessing physical and mental healthcare (McKenzie *et al.*, 2016). Disparities in preventive care such as reduced access to breast cancer screening or mental healthcare, as well as outcomes of care such as lower cancer survival rates, have been reported (Booth *et al.*, 2010; Kumachev *et al.*, 2016; McKenzie *et al.*, 2016).

Such systemic factors (or social determinants of health) are estimated to influence up to 60% of a population's health status (CMA, n.d.). Healthcare access can explain up to 25% of a population's health status, while biology and genetics account for 15% (CMA, n.d.). Social determinants of health include community, housing, food security, physical environment, gender, ability, race, and Indigenous status, among others (PHAC, 2018).

Social determinants can affect the risk of developing an illness, the course and severity of the illness, and the availability of treatment. Stigma and discrimination influence health outcomes, affecting some groups and individuals differently. People with disabilities and their families have reported, for many years, that the healthcare system makes negative assumptions about the quality of their lives (e.g., Stainton & Besser, 1998; Gill, 2000; Drainoni *et al.*, 2006); some health professionals believe life with extensive disabilities is not worth living (Gill, 2000). The need for improved health equity is a fundamental issue in Canada, increasingly enshrined in provincial and territorial legislation. Improving health equity allows people to achieve their full health potential by removing preventable and avoidable systemic conditions that constrain life choices, including choices at the end of life (e.g., Batavia, 2001).

2.3.2 Barriers to Healthcare for Indigenous People

Reconciliation with Indigenous people calls for the provision of services consistent with their cultures and needs. Yet, formal healthcare for Indigenous people in Canada has historically been highly segregated and of low quality (FNHA, 2017; Geddes, 2017). The sharing of responsibilities among federal, provincial, and territorial governments has created a patchwork healthcare system. Payment disputes between federal and provincial/territorial governments can result in delayed access to necessary health services (NCCAH, 2010).

Healthcare inequities experienced by Indigenous people have been well documented (e.g., Loppie *et al.*, 2014; Allan & Smylie, 2015; Hart & Lavallee, 2015; TRC, 2015). Racism continues to create and reinforce disparities (Loppie *et al.*, 2014; Allan & Smylie, 2015), and, as noted in Section 2.3.1, inequitable access to healthcare leads to poor health outcomes (Reading & Wien, 2009). A lack of appropriate and safe healthcare can prevent Indigenous people from seeking treatment (NCCAH, 2010); deficiencies in cultural safety and competence, as well as historical and current abuses, have resulted in some Indigenous people losing trust in the healthcare system (Geddes, 2017). Indeed, the Truth and Reconciliation Commission called for the Canadian healthcare system to recognize the value of Indigenous healing practices and use them when treating Indigenous patients (TRC, 2015).

Indigenous Peoples hold a variety of spiritual views that may inform conceptions of health, death, and dying that are both different from and similar to Western conceptions. Traditional teachings stress the interconnectedness of all of creation, and that humankind is to live in harmony with the natural world (NFB, 2015). In contrast to the positivist (i.e., empirical data-focused) attitudes that dominate modern Western medicine, Indigenous conceptions of health are more holistic in nature (Stewart & Marshall, 2017). For many Indigenous people, connections to family, friends, community, nature, and culture are an

important part of the healing process, suggesting that they may be more receptive to healthcare services based on a theme of interconnectedness (McCormick, 1997). The medicine wheel, for instance, underscores the importance of balance and emphasizes four interrelated forms of health: physical, emotional, spiritual, and mental/intellectual (Dyck, 1996). Some conceptualizations of the medicine wheel also represent the four stages of life in the physical world: birth, youth, adulthood, and death (NLM, n.d.). Many Indigenous people believe in an afterlife and some view the dying process as preparation for the afterlife journey (Kelly & Minty, 2007).

The Indigenous Elders who shared their knowledge and experiences at the Elders Circle (Section 1.5.2) stated that life is sacred and, therefore, death should not be the subject of casual discussion, which risks diminishing life's value. Ideally, individuals make end-of-life decisions as part of a community, embedded in supportive relationships. The Elders felt that allowing MAID for people with mental disorders could be damaging in communities experiencing youth suicide crises. Elders also shared experiences of systemic barriers that prevented them or their loved ones from accurate diagnoses and appropriate treatment. Without basic access to appropriate healthcare and social services in the community, the Elders expressed concern that MAID is a highly inappropriate care option. Consideration of MAID in the three topic areas is a low priority for most Indigenous communities that are also dealing with a lack of clean water, food security, healthcare, and other basic needs. The Elders, while appreciative of the CCA's effort in facilitating the Elders Circle, noted that they do not speak for all Indigenous perspectives. The Panel recognizes that too little input from Indigenous people creates a significant gap in the evidence considered for these reports. It is important to consider the potential needs and concerns of Indigenous Peoples with respect to MAID in the three topic areas.

2.3.3 Culture and End-of-Life Care

Family, ethnicity, religion, workplace, education, as well as other factors contribute to one's cultural experience. Culture can be profoundly influential in how people, both patients and healthcare practitioners, view end-of-life medical care, and death and dying in general (Chakraborty *et al.*, 2017). As a result, one's choice in medical treatment is likely affected by one's personal views on death. While discussions on medical options to prolong life may be appropriate and desirable for some, others may view them as an interference in the natural passage of life (Coolen, 2012). In some cultural traditions, suffering is an essential and spiritually meaningful part of life, and something to be experienced and endured rather than avoided (Searight & Gafford, 2005). Lived experience of racism and historical trauma in the healthcare system also play a role in attitudes towards end-of-life care (e.g., Welch *et al.*, 2005).

Religion and spirituality can be especially important when making end-of-life medical decisions (Chakraborty *et al.*, 2017). Religion may play an essential role in providing meaning and insights into issues of health, medicine, death, dying, and philosophies about an afterlife (O’Connell, 1995). There are diverse perspectives among and even within the faith traditions, which are not homogenous (e.g., orthodox or conservative versus reform or liberal perspectives). This diversity of perspective shapes the opinions that religious people may have about MAID.

The diversity of cultural experiences in Canada influences any examination of the impacts and implications of MAID in the three topic areas. A thorough consideration of these perspectives was beyond the scope of the reports and remains a significant knowledge gap.

2.4 HEALTHCARE DECISION-MAKING

In Canadian law, respect for a person’s autonomy and the protection of their bodily integrity are the core values underlying the principle that decisions made by capable individuals must be respected, and the more specific rule that consent must be obtained prior to treatment (Gilmour, 2017). There are exceptions to this general rule: for example, in some provinces and territories, refusals made by capable minors (Day, 2007) or by capable adults who are involuntarily committed to hospital because of mental disorders may not be followed (Wildeman, 2016). Discussions of healthcare decision-making occur more specifically in each topic area report, but three decision-making concepts are important to clarify for consistency: informed consent, decision-making capacity (as a clinical and legal concept), and decision-making authority.

2.4.1 Informed Consent

Provincial and territorial legislation specifies that informed consent must be:

- related to the proposed healthcare;
- given voluntarily;
- not obtained by fraud or misrepresentation;
- given by a person capable of making the healthcare decision;
- given by a person who has had the opportunity to ask questions about the proposed care and alternatives, and receive answers; and
- given by a person adequately informed to understand the proposed care, including information on the nature of the proposed care, its risks and benefits, and on reasonable alternatives to the proposed care, including non-treatment.

(Gov. of BC, 1996c; Gov. of ON, 1996;
Gov. of PE, 1988; Gov. of YK, 2003a)

Nova Scotia requires hospitals to obtain informed consent to care for patients; however, this statute does not extend to facilities other than hospitals (Gov. of NS, 1989). Quebec requires physicians to obtain informed consent from patients as stated in the *Code of Ethics of Physicians* (Gov. of QC, 2017b) and established in the *Civil Code of Quebec* (Gov. of QC, 1991). Outside Quebec, common law determines informed consent requirements for provinces and territories that do not have explicit legislation and for practices that are outside the scope of legislation on healthcare consent (Wahl *et al.*, 2014).

2.4.2 Decision-Making Capacity

All adults are presumed to have decision-making capacity unless there are reasonable grounds to believe otherwise or unless legislation removes that presumption (Gilmour, 2017). A patient has capacity when they have the ability to understand and appreciate the nature and consequences of their decisions. Capacity refers to the cognitive abilities necessary for sound decision-making — specifically, being able to understand information relevant to making a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of decision). When questioned, capacity becomes decision- and time-specific; it is assessed in relation to the decision to be made and at the time of its implementation. It is not a global determination of the presence or absence of a person's overall decision-making ability (Gilmour, 2017).

Guidelines, policies, and guidance related to capacity and consent are provided by health regulatory colleges, and in some cases by employers (e.g., hospitals, health authorities), experts, scholars, and organizations such as the Canadian Medical Protective Association (CMPA) (LCO, 2017; CMPA, n.d.). There is no universally accepted clinical approach to capacity assessment (Seyfried *et al.*, 2013) and little data on the assessment of capacity in the specific circumstances of MAID (i.e., in the presence of intolerable suffering) (Cartagena *et al.*, 2016). In determining capacity for clinical decisions, healthcare practitioners typically use either a directed clinical interview or a formal capacity assessment tool such as the MacArthur Competence Assessment Tool (MacCAT) (Grisso *et al.*, 1997) or Aid to Capacity Evaluation (ACE) (Etchells *et al.*, 1999).³ Formal capacity assessment tools remind clinicians what dimensions of understanding and appreciation to question; it is then up to the clinician to judge whether a person's abilities fulfil (or not) the criteria laid out in law or policy.

Clinicians determine when a capacity assessment is appropriate (Leo, 1999; Ganzini *et al.*, 2004; Dastidar & Odden, 2011), unless a court has already determined a person is legally incompetent or the person is deemed to lack capacity by the operation of a statute. The purpose of a clinical capacity

3 For a comprehensive list of clinical capacity assessment tools, see Kim (2010).

assessment is to provide a yes/no judgment about whether a specific person can consent to a specific medical treatment (at a specific time, in a specific context) (Charland, 2015).

2.4.3 Decision-Making Authority

Adults with decision-making capacity have legal authority over their healthcare decisions. However, the decision-making authority of minors and involuntarily committed patients, regardless of capacity, is constrained in some provinces and territories (see Chapter 3 of this report and the report *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*). If an adult is found to lack decision-making capacity, the healthcare practitioner must notify and explain this finding to the individual. The next step is to determine whether there is a valid instruction directive, applicable to the medical decision at hand. The healthcare practitioner must identify (or determine) who the SDM is. That may be someone identified by the patient in a written document prior to losing capacity (i.e., a proxy directive) (Dalhousie Health Law Institute, 2017). The SDM may also be a guardian or person appointed by a statute or court. Some provinces and territories have recognized alternative models to substitute decision-making in limited circumstances, such as supported decision-making (e.g., Gov. of BC, 1996d; Gov. of YK, 2003b; Gov. of AB, 2008; Gov. of MB, 1993) and co-decision-making (Gov. of SK, 2000).

If there is no recognized, appointed SDM, most provincial and territorial legislation defines a nearest relative who can act on behalf of the person for the specific treatment decision at hand (e.g., Gov. of BC, 1996c; Gov. of SK, 2015). SDMs act in accordance with the person's prior capable wishes; if unknown, the SDM makes a decision in the person's best interests. For more information on advance directives, see Section 3.3.2 of *The State of Knowledge on Advance Requests for Medical Assistance in Dying*.

CHAPTER SUMMARY

Recent changes in Canadian law have led to the partial decriminalization of MAID. Informed discussions of MAID must consider the complex legislative and regulatory Canadian contexts outlined above, as well as the broader historical context that informs a diversity of perspectives on how best to approach MAID with respect to the three topic areas. The relative significance of healthcare and specialized services regulation, delivery, and access, however, varies across the three topic areas, and considerations of informed consent, decision-making capacity, and decision-making authority will particularly diverge. Indeed, as presented in these reports, MAID as it relates to mature minors, advance requests, and where a mental disorder is the sole underlying medical condition gives rise to distinct issues that interface differently with the various aspects of Canada's healthcare and legal systems.

3

Mature Minors in a Healthcare Context: Legal Considerations

- **Definitions, Terminology, and Sources of Evidence**
- **Concept of a Mature Minor in Canada**
- **Mature Minors and MAID Legislation in Canada**
- **Elements of Informed Consent**
- **Healthcare Consent and Child Welfare Laws Across Canada**
- **Healthcare Decision-Making by Mature Minors in Case Law**
- **Conclusions**

3 Mature Minors in a Healthcare Context: Legal Considerations

Key Findings

Canadian legislation does not provide a definition of a *mature minor* — rather, the Supreme Court of Canada recognizes the common law mature minor doctrine, which defines this population as individuals with the capacity to make an informed healthcare decision but who have not yet reached the age of majority. Quebec law does not recognize the concept of a mature minor, but instead links decisional rights to age ranges.

Patients, parents or guardians, and healthcare practitioners resolve most disputes about mature minors' healthcare. When the courts become involved, the decision whether to give a minor the right to make their own healthcare decision depends on a complex interplay among the following factors:

- the minor's understanding and appreciation of what is proposed;
- the minor's ability to make a voluntary choice;
- the gravity of the treatment decision;
- the expected efficacy and side effects of the treatment and alternatives;
- whether provincial or territorial healthcare consent or child welfare legislation applies; and
- whether this legislation contains any stipulations that might limit the decision-making power of the minor under the circumstances.

Prior to 2009, mature minor court cases suggested that courts would order treatment with a good chance of success even if a mature minor were to refuse it.

A precedent-setting 2009 Supreme Court child protection case gave more weight to a mature minor's decision. It recognized that, although the decision-making abilities of a minor must be assessed with the utmost scrutiny when their healthcare decision will have grave consequences, mature minors should be able to decide.

Although observations and rulings made in mature minor court cases do not explicitly apply to MAID, they suggest that, to be granted the right to MAID, a minor would need to demonstrate the ability to deeply understand and appreciate their situation, and make a mature, independent decision. Their prognosis and availability of any acceptable treatment options might also play a role.

From a legal perspective, apart from legislative requirement, chronological age is not determinative of when a minor has the capacity to make a free and informed decision.

Minors are entitled to fundamental human rights. Given both their perceived vulnerability and dependence, they are also entitled to special considerations and provisions designed for their protection (UN, 1989). A key concern when creating laws for minors is finding a balance between two central goals: keeping them safe from harm and respecting their rights by avoiding unfair and unethical restrictions. A number of questions arise when considering these goals in the context of MAID for mature minors. Since an adult who suffers intolerably from a grievous and irremediable medical condition, and who is in a state of irreversible, advanced decline, can request and receive MAID, is there a reason to exclude a minor who meets the same criteria from accessing MAID? Is it unjust to deny decisionally capable minors access to a service available to adults, only because of their age? Finally, if mature minors in Canada can already make their own decisions about healthcare, including refusing or stopping life-sustaining treatment, why could they not be allowed to choose MAID?

This chapter reviews how mature minors are defined legally in Canada, and the types of healthcare decisions they have been allowed to make when disagreements have arisen and the courts became involved. Situations that require litigation represent a small minority of healthcare situations involving mature minors; usually, decisions are “made cooperatively by the adolescent, physicians and parents in a supportive environment” (Doig & Burgess, 2000). However, reviewing how Canadian law has typically been applied to minors wishing to make serious — and in many cases life-or-death — healthcare decisions enables consideration of how the current law might be applied to mature minors seeking MAID.

There are no available court cases, in Canada or elsewhere, involving a minor wishing to access MAID. Thus, this chapter draws on several court cases in which mature minors wished to refuse potentially life-sustaining treatment. The applicability of these cases is affected by whether one views refusing a life-sustaining treatment and requesting a life-ending treatment as comparable. After considering evidence from physicians and ethicists, the trial judge in the *Carter* case found no ethical distinction between physician-assisted death and other end-of-life practices likely to result in death (BCSC, 2012). The Supreme Court quoted these comments in its *Carter* decision (SCC, 2015). However, the Working Group acknowledges that this issue is not resolved among ethicists, and continues to generate controversy. It is also unclear whether refusing life-sustaining treatment differs from requesting MAID in the case of mature minors versus adults.

3.1 DEFINITIONS, TERMINOLOGY, AND SOURCES OF EVIDENCE

Figure 3.1 explains the terminology that the Working Group uses in this report. *Minors*, *mature minors*, and *adults* are the most important terms to differentiate. Under the law, minors and adults are distinguished by age limits. *Adults* are defined as people who have reached the age of majority and *minors* are defined as people under the age of majority, which is 18 or 19 depending on the province or territory (MacIntosh, 2016) (Table 3.1). The *Criminal Code* (federal law) limits the availability of MAID to those aged 18 or older. Mature minors are not defined by chronological age, but rather by their capacity for decision-making. To have legal capacity, a person must be able “to understand and appreciate the information relevant to a particular decision or type of decision, and the consequences of making that decision (or of not making a decision)” (LCO, 2017). While there is no universally accepted definition of a mature minor, Canadian courts, common law, and health law and policy generally view a *mature minor* as a person under the age of majority with the capacity to make an informed healthcare decision and the ability to act voluntarily with respect to that decision (Gilmour, 2017). In the context of decision-making on life-sustaining treatment, the Working Group was unable to find a person recognized as a mature minor in Canadian courts who was younger than aged 12 (Section 3.6.1) (ONCJ, 1985). Quebec does not recognize the concept of a mature minor, but instead links decisional rights to age ranges (Box 3.1).

This report also uses the term *adolescent*, for which there is no agreed-upon age range. The Canadian Paediatric Society (CPS) states that it is impractical to use a strict age range to define adolescence, and instead “favours a more functional definition based on the biopsychosocial readiness of young people to enter adulthood” (Sacks, 2003). It does, however, recognize that physiological and behavioural developments that characterize adolescence do “correspond roughly” to the age range used by the World Health Organization (WHO) for this population, which is 10 to 19 years (Sacks, 2003). The term *child* is often used in a general way to describe any person under the age of 18 (UN, 1989); using this definition, a child and a minor are equivalent. However, for certain purposes, the WHO uses the age range of 1 to 10 years to distinguish children from adolescents (10 to 19) (WHO, 2013). Finally, though used infrequently in this report, *youth* can refer to young people who are going through a period of transition as they move from childhood to adolescence to adulthood. Although there have been many attempts to define youth based on biology, psychology, social standards, and other criteria, it remains an ambiguous term with an age range that is broad and variable (Gaudet, 2007; Franke, 2010). In its publication on youth and health risks, the WHO places youth in the age range of 10 to 24 years (WHO, 2011).

Taking all of this into consideration, Figure 3.1 explains the Working Group’s use of the terms *children*, *adolescents*, *youth*, *adults*, *minors*, and *mature minors*. The scale to demarcate age (at the bottom of the figure) is intended only as a rough guide except for people who have reached the age of majority (i.e., adults), which, depending on the province or territory, is legally defined in Canada as 18 to 19 years.

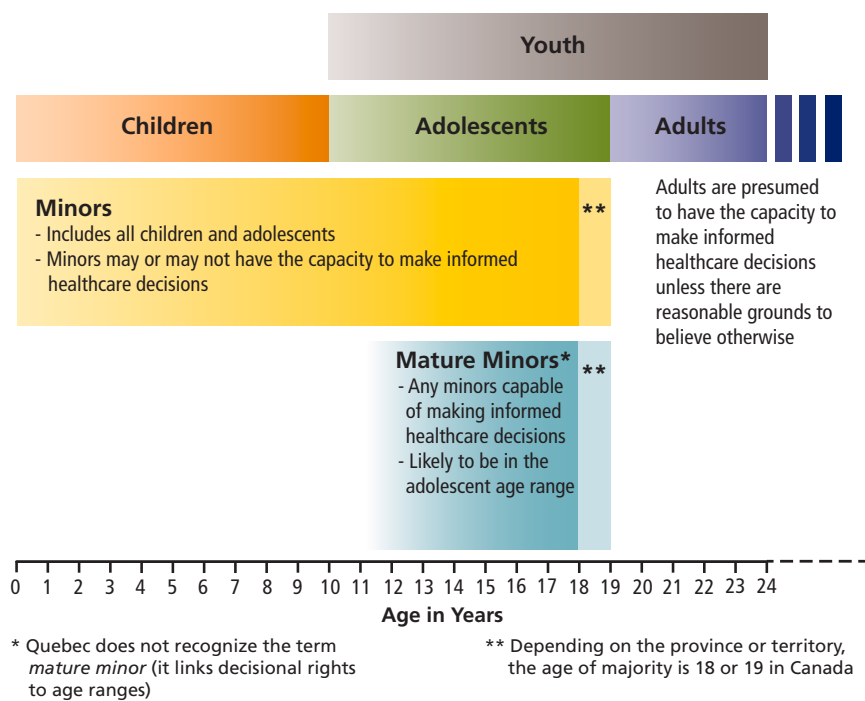


Figure 3.1

Definitions for Terms Related to Age and Decision-Making Capacity

Canadian laws relating to age of majority define minors and adults using a strict age cut-off. Depending on the province or territory, minors become adults when they reach the age of 18 or 19. In contrast, there are no agreed-upon age ranges in the literature for children, adolescents, and youth. For certain purposes, the WHO defines children as aged 1 to 10, adolescents as aged 10 to 19, and youth as aged 10 to 24 (WHO, 2011, 2013). Mature minors are not defined by chronological age, but instead by decision-making ability. Any person under the age of majority with the capacity to make an informed healthcare decision and the ability to act voluntarily with respect to that decision is considered to be a mature minor at common law (Gilmour, 2017). Quebec does not recognize the concept of a mature minor (Box 3.1).

The concept of a mature minor was developed for healthcare, and not for other aspects of social and civil life. In non-medical contexts (e.g., voting, purchasing alcohol, driving), an age cut-off is used. However, the Working Group notes that, unlike in these contexts, denying someone the ability to make healthcare decisions has potential implications for their bodily integrity. Furthermore, the Canadian Coalition for the Rights of Children (CCRC, 2017) argues that the immediacy and finality of some medical situations call for a different approach than in non-medical contexts. A minor can wait until they are, for example, old enough to vote and then continue to enjoy this right for the rest of their lives. In contrast, if a minor were faced with a terminal condition and not permitted to make their own end-of-life decisions, this right would be forever taken from them.

The Working Group acknowledges that its charge was to consider any unique aspects of providing MAID to mature minors. However, for a number of reasons, some of the evidence considered in the report includes studies on *all* minors. First, given that the charge asks about the impact of chronological age on capacity, evidence addressing this topic inevitably considers minors who may not yet demonstrate capacity. Second, in some cases, the age range of participants in a study that is critical to answering the charge may be quite broad, including both children and adolescents. Third, studies are rarely designed to examine minors whose maturity status (under the mature minor doctrine) has already been determined. Thus, some of these participants may be mature minors and others may not; however, this is almost always an unknown variable. These reasons are particularly relevant to the evidence described in Chapters 4 and 5 on the development of decision-making ability, the barriers to pediatric palliative care (PPC), intolerable suffering in minors, and the realities of clinical practice, including the preferences of minors for end-of-life decision-making and the role of families in this process.

3.2 CONCEPT OF A MATURE MINOR IN CANADA

The Supreme Court of Canada has endorsed the common law mature minor doctrine, which recognizes that the healthcare decision-making capacity of minors is not solely determined by age, but also tied to their evolving maturity (SCC, 2009). Under this doctrine, when a minor is able to understand and appreciate the nature and consequences of a treatment decision, they can give legally valid consent to treatment; and healthcare practitioners, therefore, cannot rely on parental consent instead (BCCA, 1999). However, court decisions have discussed the difficulty of defining and identifying maturity, and acknowledged that intellectual capability is only one of several factors to consider (SCC,

2009). Furthermore, some provinces and territories have enacted healthcare consent legislation that applies to minors. In some cases, this legislation imposes restrictions on the ability of minors to consent to healthcare by requiring, for example, a minimum age and/or the concurrence of treating physicians (Gov. of NB, 1976; Gov. of BC, 1996b). Additionally, child protection laws (which can become relevant if a minor or a minor's parents refuse to seek necessary healthcare, resulting in serious and imminent risk to a child's life or health) typically allow a court to authorize treatment that it determines is in the child's best interests when a child has been found in need of protection, even against the parents' and child's wishes (Gilmour *et al.*, 2011). Gilmour *et al.* (2011) argue that, depending on how it is interpreted, a best interests standard may challenge the extent to which the law is committed to respecting the self-determination and autonomy interests of mature minors.

It would be incorrect to state that the best interests standard always applies to minors. In some provinces and territories, legislation or the common law does not permit a best interests argument to override a competent decision by a mature minor, and in others it only allows use of this argument if the minor is under the age of 16 (Section 3.5). When best interests are under consideration, the specific circumstances of each case (e.g., prognosis, treatment efficacy and side effects) are key factors in a court's judgment on a minor's capacity to make a healthcare decision, and whether that decision will be respected. The landmark Supreme Court case of *A.C. v. Manitoba (Director of Child and Family Services)*, discussed below, provides further clarification on this matter.

In the absence of legislation or where it does not apply, with the exception of Quebec's *Civil Code*, the common law mature minor doctrine prevails. Quebec and New Brunswick are the only provinces that set specific ages (14 and 16, respectively) at which minors can make their own contemporaneous healthcare decisions. In Quebec, minors aged 14 to 17 can only make these decisions under certain conditions (Box 3.1). Section 3.5 reviews provincial and territorial healthcare consent and child protection laws for minors.

In addition to the common law mature minor doctrine and provincial and territorial legislation, court decisions on the rights of mature minors may also consider the United Nations Convention on the Rights of the Child (UNCRC), which Canada ratified in 1991. Although there is no legislation explicitly incorporating the UNCRC into Canadian law, Canadian courts have supported its broad principles, and several Supreme Court cases (including *A.C. v. Manitoba*) have cited it for interpretive purposes (Noël, 2015).

Box 3.1**Consent to Healthcare for Minors in Quebec**

Quebec law does not recognize the concept of a mature minor. Instead, it relies on age, dividing minors into two groups governed by different legal regimes for consent to care (Ménard, 2017). For minors under 14 years of age, consent to care is given by the person who has parental authority over them. Minors aged 14 to 17 may consent to care required by their state of health. Neither parental consent nor parental knowledge of the situation is necessary. Parents do not have the right to access their child's medical files, but must be informed if their child will be hospitalized for more than 12 hours (Ménard, 2017).

However, minors aged 14 and older do not have the same degree of autonomy as adults and multiple stipulations limit their autonomy. First, although the *Civil Code* presumes capacity to consent for this age group, if capacity is questioned, the minor must undergo an evaluation to be deemed capable of making free and informed decisions (Ménard, 2017). Second, parental consent may be required "if the care entails a serious risk for the health of the minor and may cause him grave and permanent effects" (Gov. of QC, 1991). Thus, the minor cannot make a decision that will cause them injury. Third, the decision must be in the minor's best interests or it can be overturned. This last stipulation also applies to decisions made by the parents of minors under 14 (Ménard, 2017). Thus, the law in Quebec differs from some other provinces, since it establishes a minimum age at which a minor may be able to provide consent to care.

Two articles of the UNCRC are particularly relevant to mature minors. Article 3 states that "[i]n all actions concerning children, ... the best interests of the child shall be a primary consideration" for courts of law and other authorities (UN, 1989). According to Article 12, children who are capable of forming their own views shall have "the right to express those views freely in all matters affecting [them]," particularly in any judicial and administrative proceedings. Article 12 also states that the views of a child will be "given due weight in accordance with the age and maturity of the child" (UN, 1989). The UNCRC monitoring body, the Committee on the Rights of the Child, interprets this to mean that age limits should not be placed on a child's right to be heard, but acknowledges that, in the healthcare context, legislation to determine a fixed age at which a child can consent to their own care may be appropriate. However, the Committee still recommends giving due weight to the views of younger children who demonstrate the capacity to express informed opinions on their treatment (Paré, 2011). According to Paré (2011), the term *due weight*

“indicates that the child’s wishes will never automatically take precedence, and that the best interests of the child will be an equally important consideration in the final decision.”

The Working Group acknowledges that not all groups in Canada may recognize the concept of a mature minor. For example, many Indigenous groups, including some in Canada, appear to place great value on the independence and autonomy of children, allowing them to make their own decisions and explore their environment freely (Muir & Bohr, 2014). Thus, the idea that minors should not be allowed to make their own healthcare decisions until they have reached a certain level of capacity may conflict with some world views.

3.2.1 Evolution of the Concept of a Mature Minor

Differences in provincial and territorial legislation, combined with the challenge of evaluating a population that falls somewhere between childhood and adulthood, can, in some instances, make it difficult to predict the outcome of cases involving minors. There are many nuances to consider in each individual situation such as the minor’s decision-making capacity and level of maturity, the gravity of the minor’s treatment decision, and whether the healthcare team believes the decision to be in the minor’s best interests. Although the mature minor doctrine has been tested in cases involving life-threatening healthcare decisions (Section 3.6), Mosoff (2012) notes that it did not arise in a life-and-death context. Some of the earliest court cases involved the rights of adolescents to access medical care related to sexual activity or reproduction. In Canada, *J.S.C. v. Wren* clearly expressed the common law principle that minors who have capacity to make informed decisions about their healthcare are entitled to do so. The case involved a minor who had consented to an abortion, but her parents asserted that they should have provided the necessary consent to treatment, and that their daughter could not do so. The court ruled that the minor was decisionally capable and could consent to the abortion. It concluded its judgment with the statement: “We infer that she did have sufficient intelligence and understanding to make up her own mind and did so. At her age and level of understanding, the law is that she is to be permitted to do so” (ABCA, 1986).

What happens when a minor wishes to make a decision that could threaten their life? Before the Supreme Court’s ruling in *A.C. v. Manitoba* (hereafter referred to as *A.C.*), some appellate courts had held that restrictions in child welfare legislation displaced the mature minor rule, such that while a minor’s decisions should be considered, they were not determinative (SCC, 2009). Section 3.6 describes three Canadian court cases that illustrate this type of ruling (ABQB, 2002; ABCA, 2003; BCSC, 2005). However, *A.C.* concluded that, in Manitoba, even though child welfare legislation might have appeared to constrain the

decision of a mature minor under the age of 16, the best interests standard under this legislation should be interpreted such that the choice of an independent, decisionally capable minor must be respected. Given the potential implications of this case for the decision-making power of mature minors in Canada, the next sub-section provides a detailed description.

3.2.2 A.C. v. Manitoba: The Leading Case on Minors' Rights to Make Healthcare Decisions

A.C. is Canada's leading case on minors' rights to make their own decisions about healthcare. Although it arose in the narrow context of child protection proceedings and the particular statutory structure of one province, it is one of the few Supreme Court of Canada judgments on minors and healthcare decision-making. Therefore, the principles it sets out can be applied more broadly. *A.C.* concerned a girl who was almost 15 years old and needed blood transfusions because of gastrointestinal bleeding from Crohn's disease. As a Jehovah's Witness, she refused the transfusions due to her religious beliefs and her parents supported her refusal. Under Manitoba's child welfare legislation, a court order for treatment was granted and blood was administered. *A.C.* and her parents appealed to the Supreme Court, asserting that she was decisionally capable, and the forced treatment breached her rights under the *Canadian Charter of Rights and Freedoms* (Gilmour, 2017).

Under child welfare legislation in Manitoba, children who have been brought into care in need of protection because essential medical treatment was refused are subject to different rules depending on their age. The legislation provides that a court may authorize treatment it considers in the best interests of a child under the age of 16. However, no medical treatment can be ordered without the consent of a child aged 16 or older, unless the court concludes that they lack the ability to understand the relevant information or the consequences of the treatment decision (SCC, 2009).

The Supreme Court noted that child protection proceedings are only invoked in cases of serious and imminent risk to a child's life or health. However, it held that, even where the consequences of refusing treatment would be very grave, the best interests standard in child welfare legislation should not be used to justify automatically displacing a minor's decision. Rather, for the standard to be constitutionally compliant, an adolescent's maturity must be taken into account. The Court stated that, "the more a court is satisfied that a child is capable of making a mature, independent decision on his or her own behalf, the greater the weight that will be given to his or her views when a court is exercising its discretion under [child welfare laws] ... If ... the court

is persuaded that the necessary level of maturity exists, it seems ... necessarily to follow that the adolescent's views ought to be respected" (SCC, 2009). The best interests standard must be interpreted "so that a young person is afforded a degree of bodily autonomy and integrity commensurate with his or her maturity" (SCC, 2009).

The ruling in *A.C.* recognized minors' important rights, at common law and under the Constitution, to make their own healthcare decisions when sufficiently mature and independent, even when these decisions are life-threatening. At the same time, it affirmed the continuing validity of the statutory best interests standard, at least in the limited class of cases where child protection authorities are involved and the minor's life is at stake. It concluded that, due to concerns about the difficulty of determining with certainty whether a minor meets the threshold requirements for decision-making (capacity and voluntariness), consideration of the minor's best interests can still be appropriate when authorized by law. Nonetheless, best interests must take into account the wishes of the mature minor (SCC, 2009).

In the end, however, the Supreme Court of Canada upheld the lower court's decision to authorize transfusions, because it concluded *A.C.*'s capacity to decide about this treatment and her ability to make an independent judgment had never actually been judicially determined. The implications of the Court's decision for mature minors in other contexts are not yet known, but its "strong support for recognizing the authority of decisionally-capable minors, even when treatment refusal poses serious risks to health and even life, make it likely that the same approach will prevail where the consequences are less severe" (Gilmour, 2017). In the experience of the Working Group's clinical members, there is increasing attention in clinical settings to the wishes of capable minors. Even in cases where clinicians do not agree that a minor's decision is the best course of action, that decision should be followed as long as the minor has been deemed decisionally capable.

In summary, the mature minor doctrine and some notable Canadian court cases support the view that minors who demonstrate the requisite intelligence, comprehension, and maturity should be allowed to make their own decisions about medical treatment. However, because of various restrictions in healthcare consent laws and child welfare legislation, the courts have not always granted this power to mature minors. As discussed further in Section 3.6, the courts consider evidence related to a minor's entire set of circumstances before concluding whether they are decisionally capable. Another important element is the minor's prognosis, which affects some judicial decisions in ways that are

not always explicitly stated in a court's ruling. The minor's prognosis and the gravity of the decision at hand will influence the degree of scrutiny applied when a court is assessing the decisional capacity of a minor. When a refusal of treatment carries a significant risk of death or permanent physical or mental impairment, evaluating whether the minor's decision is genuinely independent and based on a real understanding of the decision and its potential consequences, must be particularly careful and comprehensive (SCC, 2009).

A final point on the role of the law is worth noting here. The cases that require litigation involve a dispute that arises when the minor's decision, the parents' or guardians' decision, and the healthcare team's assessment of the minor's best interests do not align. However, most decisions about minors' healthcare never give rise to litigation. Instead, disputes about a minor's capacity or treatment are typically resolved by discussions between the healthcare team and the family. Thus, determining decisional capacity and the voluntariness of minors' decisions are seldom the responsibility of courts (assessing capacity from a clinical perspective is explored in Chapter 4). The Working Group acknowledges the internal processes and procedures for making decisions and resolving conflict at the bedside, but, unlike court cases, these are not publicly available.

3.3 MATURE MINORS AND MAID LEGISLATION IN CANADA

The *Carter* decision referred to competent adults (SCC, 2015) (Section 2.4). As shown in Table 3.1, the age of majority and the age at which people can legally provide their own consent for healthcare vary across provinces and territories in Canada. Prior to the passage of Bill C-14, two key reports provided recommendations on the inclusion of mature minors in Canada's MAID legislation. First, the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, appointed by the provinces and territories, recommended that eligibility for MAID be based on competence rather than age. The Advisory Group stated that an arbitrary age limit for MAID "provides no valid safeguard. Instead, it is important that willing physicians carefully consider the context of each request to determine whether the person has the information needed, is not under coercion or undue pressure, and is competent to make such a decision" (PTEAG, 2015).

A second Special Joint Committee on Physician-Assisted Dying, which included members representing both the House of Commons and Senate, provided a recommendation with two action items. First, it proposed "a two-stage legislative process, with the first stage applying immediately to competent adult persons 18 years or older, to be followed by a second stage applying to competent mature minors" (SJCPAD, 2016a). Second, it called for an immediate commitment by

the Government of Canada to facilitate a “study of the moral, medical and legal issues surrounding the concept of ‘mature minor’ and appropriate competence standards that could be properly considered and applied to those under the age of 18” (SJCPAD, 2016a). Thus, the second part of its recommendation focused on studying *how* to permit access to mature minors, not *whether* to do so. Although the committee members were confronted with differing opinions provided by witnesses and briefs, they did not recommend an outright ban on MAID for mature minors.

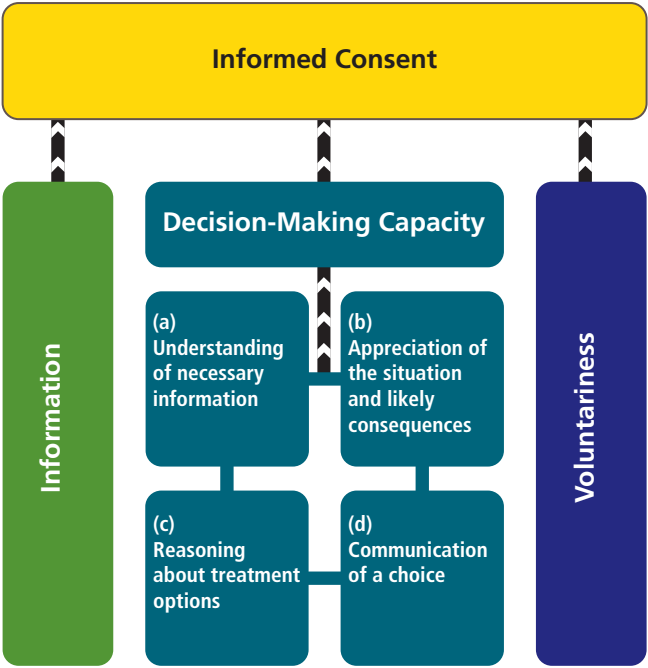
Bill C-14, which received Royal Assent in June 2016, sets out several criteria to define eligibility based on the patient’s health, capacity, ability to make a voluntary request, ability to give informed consent, and age. Bill C-14 states that a person may receive MAID if “they are at least 18 years of age and capable of making decisions with respect to their health” (GC, 2016). Similarly, *An Act Respecting End-of-Life Care* in Quebec states that, to obtain medical aid in dying, a person must “be of full age [i.e., 18 years or older] and capable of giving consent to care” (Gov. of QC, 2014). This age cut-off prohibits access to MAID by minors under 18 everywhere in Canada, regardless of whether they are capable of giving informed consent. In its explanation of the rationale for excluding mature minors from accessing MAID under Bill C-14, the Department of Justice stated that no evidence on the ability of minors to make decisions about ending their lives was presented to the Court during the *Carter* case. It concluded that not enough was known about the risks and benefits of MAID for minors (DOJC, 2016).

3.4 ELEMENTS OF INFORMED CONSENT

The concept of decisional capacity is central to the definition of a mature minor. Capacity is also a key element of informed consent. Aside from situations in which exceptions are granted (e.g., medical emergencies), informed consent must always be obtained before any medical treatment proceeds (Evans, 2016). For adults in Canada, the ability to provide informed consent is presumed unless there are reasonable grounds to believe otherwise (e.g., Gov. of BC, 1996c). This presumption also holds true for minors in some provinces and territories (Section 3.5).

Voluntariness and information disclosure are two other important elements of consent: the patient must make a voluntary choice, free from duress or coercion, and must be provided with information in a way that facilitates understanding (Figure 3.2). Without the ability to give informed consent, the choice must be made on their behalf by an SDM and/or pursuant to an advance directive. For minors, the SDM is typically a parent or guardian (Coughlin, 2018). However, in the case of MAID, substitute decision-making is not permitted under Canadian

law. Patients themselves must request and consent to the procedure (GC, 2016). This section examines the elements of informed consent, and how they are applied to minors making decisions about healthcare.



Data Source: Adapted with permission from Ruhe et al. (2015)

Figure 3.2
Abilities Central to Capacity, in Relation to the Components of Informed Consent

3.4.1 Capacity

From a legal perspective, tests for capacity address the mental abilities necessary for decision-making rights, and are time- and treatment-dependent (LCO, 2017). Regardless of a person's age, evaluation of their cognitive functioning in relation to the proposed treatment is the focus of both statutory law (see Table 3.1) and common law tests for decisional capacity (ONSC, 1997; ABQB, 2002). Capacity is defined as a patient's ability to understand the necessary information relevant to the treatment, to reason about treatment options, to appreciate the reasonably foreseeable consequences of their decision, and to communicate their wishes (Ruhe *et al.*, 2015) (Figure 3.2). Cognitive and psychosocial aspects of developing decision-making capacity and processes for assessing capacity are considered in Chapter 4.

3.4.2 Voluntariness

When critical healthcare decisions by mature minors are in question, the issue of voluntariness must not be overshadowed by capacity. The requirement for voluntariness is closely tied to many of the non-cognitive factors that shape the minor's maturity, such as life experience and social environment (Guichon & Mitchell, 2006). In *A.C.*, the Supreme Court of Canada acknowledged that "[t]here is considerable support for the notion that while many adolescents may have the technical ability to make complex decisions, this does not always mean they will have the maturity and independence of judgment to make truly autonomous choices" (SCC, 2009).

Mosoff (2012) discusses the legal challenges of healthcare decisions involving adolescents in life-threatening circumstances: "Dominant ideas about youth suggest that young people are easily influenced and swayed by others because of their family relationships, economic position and stage of development." Mosoff argues that young people are often "seen as too dependent to be certain that an opinion expressed is well-reasoned and truly their own. For example, teenagers often live at home, thus relying on their families for economic and social support" (Mosoff, 2012). This is particularly true for minors under 16 years of age, where "a variety of laws and social norms [e.g., the inability to drive or work full time] make them more dependent on their immediate families and peers in their daily lives than older adolescents" (SCC, 2009). The view that age is directly linked to a minor's independence is reflected in statutory laws that allow court-authorized medical treatment to protect the best interests of minors under the age of 16, as is the case under child protection laws in some provinces and territories (Table 3.1).

Where medical treatment decisions by minors are concerned, court cases have addressed voluntariness in the context of refusing potentially life-saving treatment (SK QB, 1999; ABQB, 2002; BCPC, 2005). These cases illustrate that a focus on cognitive capacity is not sufficient and only addresses one requirement for informed consent. In *Re D(T.T.)*, a 13-year-old boy with osteosarcoma refused surgery and chemotherapy in favour of alternative treatments. The court concluded that the boy was not able to make an informed, voluntary treatment decision, as he was “deeply under the influence of his father,” who provided him with wrong information and controlled his behaviour (SK QB, 1999).

3.4.3 Information Disclosure

As part of informed consent, healthcare practitioners are obligated to discuss the nature and purpose of the proposed treatment, its potential risks and benefits, and available alternatives or options (Evans, 2016). In 1980, the Supreme Court cases of *Hopp v. Lepp* and *Reibl v. Hughes* established requirements for informed consent to treatment in Canadian common law (Bélanger-Hardy, 2017). The rulings created a “reasonable patient” standard of informed consent; that is, healthcare practitioners are required to provide the information that a reasonable person in the patient’s position would need to make an informed decision (SCC, 1980). Furthermore, they must provide this information in a way that facilitates understanding by avoiding ambiguity and jargon, accounting for the patient’s personal circumstances (e.g., their language comprehension or physical state), and ensuring they have a legitimate opportunity to consider all appropriate options (SCC, 1980; ABCA, 2008). For minors, this includes the need for developmentally appropriate information (Harrison, 2004). The standard and scope of disclosure established by these and other cases in Canada are reflected in statutory laws; advice from provincial and territorial colleges of physicians and nurses (e.g., CPSA, 2015; CPSO, 2015a; CNO, 2017; CRNBC, 2018b; CPSNS, n.d.); and clinical advice, such as that provided by the CMPA (CMPA, n.d.).

Patient confidentiality is related to information disclosure. While it may be presumed that patient confidentiality is part of the mature minor doctrine, which would deny a parent or guardian access to a mature minor’s personal health information, the Working Group was unable to find common law cases addressing the extent to which parents are entitled to information about their children. However, statutory law on privacy of health information generally accords mature minors the right to control disclosure of their personal health information, subject to exceptions defined in the legislation. That legislation reflects the autonomy accorded to mature minors under common law to

make healthcare decisions. Despite provincial and territorial differences, the legislation generally provides that a minor's health information cannot be disclosed to someone else without their consent if they have the capacity to make an informed decision about the disclosure (e.g., Gov. of AB, 2000; Gov. of ON, 2004). Thus, the possibility of requests for MAID in pediatric settings raises questions about patient privacy.

As discussed in Chapter 4, pediatric patient care models increasingly recognize the central role of families in the well-being of children (Nicholas *et al.*, 2014). Even if a minor were found to be decisionally capable, there might be tensions related to family interests and patient confidentiality in the MAID context. This might include situations in which parents are opposed to MAID, and the minor wants MAID to occur without their family's knowledge. This scenario also has implications for healthcare practitioners, who might be concerned about how to respond (SickKids, 2017).

3.5 HEALTHCARE CONSENT AND CHILD WELFARE LAWS ACROSS CANADA

In Canada, the rights of mature minors to make healthcare decisions are based in a number of areas of law: provincial and territorial healthcare consent legislation, the common law mature minor doctrine, child welfare legislation, criminal law, constitutional law, and the court's *parens patriae* jurisdiction. The role played by each of these is variable, depending on the context. This section reviews the law on healthcare consent by minors in each province and territory, and discusses its intersection with the mature minor doctrine and child welfare laws.

Laws in Canada generally recognize that the critical factor determining healthcare consent by minors is the ability to understand and appreciate the nature and consequences of the decision and alternatives (SCC, 2009). However, the handling of healthcare decisions by mature minors in provincial and territorial healthcare consent legislation varies on the following issues: (i) whether any specific legislation applies to mature minors; (ii) whether the legislation specifies a minimum age at which minors may be eligible to make their own healthcare decisions; (iii) whether all minors, or minors of a certain minimum age, are presumed to have capacity or presumed to lack it; and (iv) whether the best interests standard can be used to override a decision made by a mature minor. This section summarizes the position of each province and territory on these key aspects. (Detailed information can be found in Table 3.1.)

3.5.1 Presence or Absence of Healthcare Consent Legislation for Mature Minors

Provinces and territories fall into one of three groups in terms of whether their healthcare consent legislation addresses mature minors:

- (i) There is legislation that specifically addresses the conditions under which a minor can consent to healthcare (Yukon, British Columbia, Ontario, Quebec, New Brunswick, and Prince Edward Island).
- (ii) There is no legislation for current healthcare decisions by minors, but the conditions under which minors can specify their wishes for future care are mentioned in the provinces' advance directives statutes (Saskatchewan, Manitoba, and Newfoundland and Labrador).
- (iii) There is no legislation specifically addressing healthcare consent for minors (Northwest Territories, Alberta, Nunavut, and Nova Scotia).

For the second group, legislation in all three provinces states that minors must be at least aged 16 to prepare advance directives. The legislation in Manitoba and Newfoundland and Labrador presumes that minors aged 16 or older have capacity, whereas parallel legislation in Saskatchewan expressly states that a minor must be at least 16 *and* have capacity to make an advance directive. Although the acts do not address contemporaneous healthcare decisions, as Ferguson (2004) states, "it would be odd if minors aged 16 or older were not entitled to make the same treatment decision at the time that treatment was required that they could make in advance."

3.5.2 Age of Consent and Presumption of Capacity

Some provinces and territories address minors in their contemporaneous healthcare consent legislation, and take a purely functional approach to capacity. Yukon, Ontario, and Prince Edward Island presume that, unless there are reasonable grounds to believe otherwise, every person is capable of treatment decision-making, regardless of age. In contrast, British Columbia does not make this assumption and states that consent by a minor is not valid unless the healthcare practitioner communicates with the minor and is satisfied the minor "understands the nature and consequences and the reasonably foreseeable benefits and risks" of the medical treatment in question (Gov. of BC, 1996b). Finally, Quebec and New Brunswick set specific ages (14 and 16, respectively) at which minors are allowed to make their own healthcare decisions. Both provinces presume capacity once these minimum ages are reached. However, the Quebec law includes several stipulations that limit the autonomy of minors aged 14 and older. In contrast, minors aged 16 and older in New Brunswick are subject to the same law as adults, without any additional constraints.

3.5.3 Application of the Best Interests Standard

The healthcare consent legislation in three provinces includes a best interests standard for minors wishing to make their own healthcare decisions. In British Columbia and Quebec, healthcare practitioners must deem that healthcare decisions made by minors (i.e., those under the age of 19 in British Columbia or under 18 in Quebec) are in their best interests (see Box 3.1 on Quebec). In New Brunswick, the same stipulation applies to minors under aged 16; those 16 and over are free to make their own decisions even if their parents or guardians, healthcare team, and the courts view them as contrary to the minor's best interests.

In provinces or territories that either lack healthcare consent legislation for minors altogether, or lack specific requirements for dealing with the issue of best interests, minors can still be protected by other routes, including the common law and child protection legislation (see Table 3.1). Provincial and territorial child protection legislation for healthcare consent is generally triggered when a parent or guardian refuses or neglects to consent to necessary care. However, child protection legislation can also become relevant when a minor, rather than a parent or guardian, declines necessary medical treatment, posing serious risk to life or health. Provincial and territorial child protection laws do not necessarily allow courts unlimited power when dealing with minors who are refusing potentially life-saving treatment (Table 3.1 and discussion of *A.C.* in Section 3.2.2).

Although the best interests standard is embedded in Canadian law and clinical practice involving the healthcare of minors (Coughlin, 2018), in some cases applying the standard may be complex, as the judgments of best interests are informed by values (Diekema, 2004; Birchley, 2016). *A.C.* dealt with this issue by asserting that best interests must take into account the wishes of a mature minor. As discussed in Section 3.6.3, this interpretation provided a way to uphold the minor's constitutional rights by allowing her the opportunity to demonstrate sufficient capacity and maturity to make the healthcare decision in question.

An additional mechanism for protecting minors is the court's right to exercise its *parens patriae* jurisdiction, which describes judicial power to protect those who cannot care for themselves. Its aim has been "to protect minors when there are no parents or guardians to act in the minor's 'best interests', or when the court disagrees with parental decisions made on a minor's behalf" (Ferguson, 2004). However, it is rare that courts must exercise this right due to the existence of comprehensive child protection and substitute decision-making legislation (Ferguson, 2004).

3.5.4 Legislation for End-of-Life Treatment for Minors in Quebec

In contrast to other provinces and territories, Quebec has legislation that specifically addresses end-of-life care for minors. This legislation (*An Act Respecting End-of-Life Care*) includes the eligibility criteria for MAID, which prohibit minors from accessing it (Section 3.3). The Act states that minors aged 14 and older may, respecting the conditions provided by the *Civil Code*, refuse to receive treatment that is necessary to maintain life or withdraw their consent to such treatment. As is the case for adults, the healthcare practitioner must be sure of the free nature of the decision and give the minor all the information needed to make an enlightened decision, especially by informing them of other therapeutic possibilities, such as palliative care (Gov. of QC, 2014).

All decisions rendered by the Quebec courts on the refusal of life-sustaining treatment for a minor follow the same principle: as long as a treatment is available without great burden and that provides a good prognosis, the court will order the treatment. However, when the minor wishes to refuse or discontinue a treatment that provides no therapeutic advantage and solely prolongs suffering, the refusal will be respected, even when that means death.

Table 3.1
Provincial and Territorial Legislation Governing Healthcare Decision-Making by Minors*

| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|------------------|---|---|---|
| British Columbia | 19 <i>Age of Majority Act</i> , RSBC 1996, c. 7, s. 1 | <ul style="list-style-type: none"> • <i>Infants Act</i>, RSBC 1996, c. 223, s. 17, states that a person under 19 may consent to treatment if the healthcare provider is satisfied that the minor demonstrates capacity, and deems the treatment in the minor's best interest. • No minimum age is specified. | <ul style="list-style-type: none"> • <i>Child, Family and Community Service Act</i> RSBC 1996, c. 46. • A child is defined as a person less than 19 years of age. • S. 13(1) includes deprivation of necessary healthcare and parental refusal to consent. • S. 29 states that if a child or a parent refuses to give consent to healthcare that, in the opinion of two medical practitioners, is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's health, a director may apply to the court for an order under this section. |
| Alberta | 18 <i>Age of Majority Act</i> , RSA 2000, c. A-6, s. 1 | <ul style="list-style-type: none"> • No specific legislation for minors' consent to healthcare — common law applies. • <i>Adult Guardianship and Trustee Act</i>, RSA 2000, c. A-4.2. • Permits the appointment of a co-decision maker respecting healthcare if the person is turning 18 within 12 months. | <ul style="list-style-type: none"> • <i>Child, Youth and Family Enhancement Act</i> RSA 2000, c. C-12. • A child is defined as a person less than 18 years of age. • S. 1(2.1) states a child is in need of intervention if they are neglected by their guardian, which includes if the guardian is unable or unwilling to obtain for the child, or to permit the child to receive, essential medical, surgical or other remedial treatment that is necessary for the health or well-being of the child. • S. 22.2(1) If a child who is the subject of a temporary guardianship order or a permanent guardianship agreement or order refuses to consent to essential medical, surgical, dental, or other remedial treatment that is recommended by a physician or dentist, the director must apply to the Court for an order authorizing the treatment. |

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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|--------------|---|---|--|
| Saskatchewan | 18 <i>Age of Majority Act</i> , RSM 1978, c. A-6, s. 2 | <ul style="list-style-type: none"> No specific legislation for contemporaneous healthcare decisions by minors; however, legislation concerning advance medical directives, <i>The Health Care Directives and Substitute Health Care Decision Makers Act</i>, S.S. 2015, c. H-0.002, s. 3, states that any person 16 years of age or older who has the capacity to make a healthcare decision may make a directive. | <ul style="list-style-type: none"> <i>The Child and Family Services Act</i> S.S. 1989-90, c. C-7.2. A child is defined as a person less than 16 years of age, but under s. 18(1) can include a 16 or 17 year old in exceptional circumstances. S. 11 states that a child is in need of protection where, as a result of action or omission by the child's parent, medical, surgical, or other recognized remedial care or treatment that is considered essential by a duly qualified medical practitioner has not been or is not likely to be provided to the child. An agency is only given the rights and responsibilities of a parent when a child is placed in care leaving open whether a child's decision to refuse healthcare could be overridden. |
| Manitoba | 18 <i>Age of Majority Act</i> , RSM 1987, c. A7, s. 1 | <ul style="list-style-type: none"> No specific legislation for contemporaneous healthcare decisions by minors; however, legislation concerning advance medical directives, the <i>Health Care Directives Act</i>, SM 1992, c. 33, CCSM, c. H27, s. 4(2)(a), presumes that a person who is 16 years of age or older has the capacity to make healthcare decisions. <i>The Mental Health Act</i> SM 1998, c. 36, s. 2 states that a person who is 16 years of age or older is mentally competent to make treatment decisions and to consent for the purpose of the Act. | <ul style="list-style-type: none"> <i>Child and Family Services Act</i> SM 1985-86, c. 8. A child is defined as a person under the age of 18 (s. 1). A child is defined as being in need of protection when they are in the care, custody, or control of a person who neglects or refuses to provide proper medical or other remedial care or treatment (s. 17(2)). While s. 25(2) requires the consent to medical treatment of a child 16 years or older, s. 25(3) states that an agency may apply to court for an order authorizing medical treatment when a child 16 years of age or older refuses to consent to an examination or treatment; however, the Act clarifies that, although the court can authorize a treatment that it considers to be in a child's best interests (s. 25(8)), the court cannot do so without the child's consent if he or she is 16 years of age or older unless the court determines that the child is unable to understand the relevant information or the consequences of the treatment decision (s. 25(9)). |

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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|--------------|--|--|---|
| Ontario | 18 <i>Age of Majority and Accountability Act</i> , RSO 1990, c. A.7, s. 1 | <ul style="list-style-type: none">• <i>Health Care Consent Act</i>, SO 1996, c. 2, Sch. A.• S. 4 states that a person is presumed to be capable to make medical treatment decisions. No minimum age is specified.• A health practitioner is not to administer treatment if a person 16 or over has expressed a wish to refuse treatment while capable, but is no longer capable (ss. 21 & 26). | <ul style="list-style-type: none">• <i>Child, Youth and Family Services Act</i>, 2017, SO 2017, c. 14, Sch. 1. [NOTE: while the majority of provisions in this act are in effect, Sections 281-293 and 295-332 in Part X (Personal Information) come into force on January 1, 2020.]• A child is defined as under the age of 18 (s. 2).• S. 74 states that any child (under 16 years of age) is in need of protection if the child requires medical treatment to cure, prevent, or alleviate physical harm or suffering and the child's parent or the person having charge of the child does not provide the treatment or access to the treatment, or where the child is incapable of consenting to the treatment under the <i>Health Care Consent Act</i>, 1996 and the parent is a substitute decision maker who refuses or is unavailable or unable to consent to the treatment on the child's behalf. A child aged 16 or 17 years may only be brought under an agency's supervision or care if the child consents (ss. 77(1) & 82(1)).• The agency is only given the power to make decisions that a parent would otherwise be able to make.• According to s. 110(4), the court must be satisfied that the treatment would be in the child's best interest before authorizing the treatment of an incapable child. |
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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|--------------|--|---|--|
| Quebec | 18 <i>Civil Code of Québec</i> , s. 153 | <ul style="list-style-type: none">• The <i>Civil Code of Québec</i>, CQLR, CCQ-1991.• SS. 14 & 16 state that a minor 14 years of age or older may give consent to medical treatment that is required by the state of his or her health without parental involvements.• A court order is required where a parent or a child over the age of 14 refuses to consent to care required by the state of his or her health when the refusal is not in the patient's best interest. A parent alone can consent if there is a grave danger or threat to integrity.• A court order is also required for a child under 14 if the parent's decision is not in the patient's best interest.• When the care is not required by the state of his or her health, parental consent is required if the care entails a serious health risk and may cause grave and permanent effects.• An <i>Act Respecting End-of-Life Care</i>, RLRQ, c. S-32.0001, s. 5.• 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 <i>Civil Code</i>, a minor of 14 years of age or older, 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.• 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. | <ul style="list-style-type: none">• <i>Youth Protection Act</i>, CQLR, c. P-34.1.• A child is defined as a person under 18 years of age.• For the purposes of the Act the security of a child is said to be endangered if they are neglected, which includes parents failing to give their child the care required for the child's physical or mental health, or not allowing the child to receive such care (s. 38(a)(1)ii).• If the security or development is found to be in danger, the tribunal may instruct that the child receive specific healthcare and health services (s. 91(ii)). |
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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|---------------|--|--|--|
| New Brunswick | 19 <i>Age of Majority Act</i> , RSNB 2011, c. 103, s. 1 | <ul style="list-style-type: none">• The <i>Medical Consent of Minors Act</i>, SNB 1976, c. M-6.1.• S. 2 states that the medical consent law for adults also applies to minors 16 years of age or older. S. 3(1) states that minors under 16 may consent to medical treatment provided that the minor demonstrates capacity and the treatment is in the minor's best interests and continuing health and well-being. | <ul style="list-style-type: none">• <i>Family Services Act</i> SNB 1980, c. F-2.2.• A child is defined as a person less than 19 years of age.• A child may be put under protective care if they are in the care of someone who neglects or refuses to provide or obtain proper medical, surgical, or other remedial care or treatment necessary for the health or well-being of the person or refuses to permit such care or treatment be supplied to the person (s. 31(1)(g)).• The medical examination and treatment of a child is permitted without any consent (s. 32(2)). |
| Nova Scotia | 19 <i>Age of Majority Act</i> , RSNS 1989, c. 4, s. 2 | <ul style="list-style-type: none">• No specific legislation for minors — Common law applies. | <ul style="list-style-type: none">• <i>Children and Family Services Act</i>, SNS 1990, c. 5.• A child is defined as a person less than 19 years of age.• A child is in need of protective services where they require medical treatment to cure, prevent, or alleviate physical harm or suffering, which the parent/guardian refuses or does not provide (s. 22(2)).• S. 61 provides that a court application shall be started when a parent or guardian refuses to consent to the provision of proper medical or other recognized remedial care or treatment that is considered essential by two duly qualified medical practitioners for the preservation of life, limb, or vital organs of a child. The court can then order the treatment including treatment to prevent unnecessary suffering. |

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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|---------------------------|---|---|--|
| Prince Edward Island | 18 <i>Age of Majority Act</i> , RSPEI 1988, c. A-8, s. 1 | <ul style="list-style-type: none">• The <i>Consent to Treatment and Healthcare Directives Act</i>, RSPEI 1999, c. C-17.2.• S. 3(1) states that every person is presumed to be capable of giving or refusing consent to treatment or making a healthcare directive. No minimum age is specified.• S. 20(1) states that any person over the age of 16 years who is capable may execute a directive. | <ul style="list-style-type: none">• <i>Child Protection Act</i>, RSPEI 1988, c. C-5.1.• A child is defined as a person under the age of 18.• S. 9(o) states that a child is in need of protection where they require specific medical, psychological, or psychiatric treatment to cure, prevent, or ameliorate the effects of a physical or emotional condition or harm suffered, and the parent does not, or refuses to, obtain treatment or is unavailable or unable to consent to treatment. |
| Newfoundland and Labrador | 19 <i>Age of Majority Act</i> , SNL 1995, c. A-4.2, s. 2 | <ul style="list-style-type: none">• No specific legislation for contemporaneous healthcare decisions by minors; however, legislation concerning advance medical directives, the <i>Advance Healthcare Directives Act</i>, SNL 1995, c. A-4.1, s. 7, presumes that a person who is 16 years of age or older is competent to make healthcare decisions, whereas a person younger than 16 years of age is not. | <ul style="list-style-type: none">• <i>Children and Youth Care and Protection Act</i>, SNL 2010, c. C-12.2.• A child is defined as a person under the age of 16.• S. 10 states that a child is in need of protective intervention where they are in the custody of a parent who refuses or fails to obtain or permit essential medical, psychiatric, surgical, or remedial care or treatment to be given to the child when recommended by a qualified health practitioner.• Under s. 24 a manager or social worker may consent to necessary healthcare if required without delay.• S. 30 provides a mechanism for court-ordered consent. |

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| Jurisdiction | Age of Majority | Legislation for Healthcare Consent by Minors | Child Protection Legislation on Healthcare Consent |
|---------------------------------|---|---|---|
| Yukon | 19 <i>Age of Majority Act</i> , RSY 2001, c. 2, s. 1 | <ul style="list-style-type: none">• The <i>Care Consent Act</i>, SY 2003, c. 21, Sch. B.• SS. 3 through 6 state that a person may consent to care if the care provider deems that person capable, regardless of age.• Emergency healthcare is not to be provided if the person is at least 16 and expressed a wish to refuse consent (s. 21(2)).• A substitute decision maker will also not give or refuse consent if the recipient expressed a wish while capable and over the age of 16 (s. 20(2)). A person is capable of making a directive if they are 16 (s. 27(1)). | <ul style="list-style-type: none">• <i>Child and Family Services Act</i>, SY 2008, c. 1.• A child is defined as a person who is under 19 years of age (s. 1).• According to s. 21(1), protective intervention is needed if the child is being deprived of healthcare that, in the opinion of a healthcare provider, is necessary to preserve the child's life, prevent imminent serious physical or mental harm, or alleviate severe pain.• S. 33(1) permits court-ordered treatment for healthcare to preserve life, prevent serious physical or mental harm, or alleviate serious pain, even if a capable child is refusing. |
| Northwest Territories & Nunavut | 19 <i>Age of Majority Act</i> , RSNWT 1988, c. A2 | <ul style="list-style-type: none">• No specific legislation for minors — Common law applies. | <ul style="list-style-type: none">• <i>Child and Family Services Act</i>, SNWT 1997, c. 13.• A child is defined as a person who is under 16 years of age.• S. 7(3) states that a child needs protection where the child requires medical treatment to cure, prevent, or alleviate serious physical harm or serious physical suffering, and the child's parent does not provide, or refuses or is unavailable or unable to consent to the provision of, the treatment.• Under s. 31(9) the court can order treatment in the best interests of the child.• <i>Children's Law Act</i>, SNWT 1997, c. 14, S. 39(1) states that a person may apply to the court for an order dispensing with the consent of a parent to medical treatment of a minor that is required by law where the consent is refused or otherwise not obtainable. |

*It might be arguable that a First Nation has legal jurisdiction pursuant to s. 35 of the Constitution to apply its own customs and Indigenous laws to such decision-making. The *Indian Act* s. 88 states that provincial laws are applicable.

3.6 HEALTHCARE DECISION-MAKING BY MATURE MINORS IN CASE LAW

This section reviews some landmark cases, primarily in Canada, which have dealt with the authority granted to mature minors in healthcare decision-making. It is important to note that the driver behind litigation is disagreement between the minor, their parents or guardians, and their healthcare team rather than a questioning of a minor's capacity (MacIntosh, 2016). There is no inherent tendency to question the decision-making abilities of a minor each time a healthcare decision is being made. In examining the court cases that occurred before *A.C.*, a pattern becomes evident. The specific characteristics of each case (e.g., the seriousness of the decision, the minor's prognosis with and without treatment) appeared to influence the court's finding on the minor's capacity to make the decision at hand and whether their decision should be respected. This is demonstrated in the case examples below. However, despite the life-threatening consequences of the decision in question in *A.C.*, the Supreme Court of Canada held that, if a minor can establish that they can exercise mature, independent judgment about the treatment, their decision should be respected (SCC, 2009).

3.6.1 Cases in Which Mature Minors Were Allowed to Make Their Own Healthcare Decisions

Before *A.C.*, the court cases in which minors were deemed decisionally capable and allowed to make their own decisions about medical treatment usually involved one of two situations: (i) the decision *did not* concern a matter of life and death for the minor, but required litigation because someone (usually a parent) disagreed with the minor's decision; or (ii) the decision *did* involve the possibility of death as an outcome and the minor wished to refuse the treatment that could prolong life. The minor's wishes were respected, in part because they had a poor prognosis even with treatment, and the treatment was likely to be painful and traumatic.

J.S.C. v. Wren is an example of the first situation (recall Section 3.2.1) (ABCA, 1986). In this case, a girl described by the Alberta Court of Appeal as a "normal intelligent 16 year old" was recognized as having the authority to consent to an abortion that her parents opposed. *Gillick v. West Norfolk & Wisbech Area Health Authority* in the United Kingdom is another landmark case that illustrates this point (UKHL, 1985). The very principle of a mature minor is considered to have originated from this case, and in the United Kingdom mature minors are sometimes referred to as "Gillick competent" (Lennings, 2015). The case involved a mother who wished to prevent doctors from prescribing contraceptives to girls under the age of 16 without parental consent. The judge's decision

stated that “the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed” (UKHL, 1985). According to Mosoff (2012), in cases such as these, which do not involve life-and-death decisions, it is easier to recognize adolescent autonomy. Another characteristic of these cases is that they involved circumstances in which the courts were asked to determine whether a minor’s consent was (or would be) valid if they *wanted* to receive a particular medical treatment. A related, but separate, issue arises when minors (or their parents or guardians if the minor does not have capacity) do *not want* to receive a given treatment. If refusing the treatment could endanger the minor’s life, child protection laws become relevant, and, if the child is found in need of protection, the courts are required to address whether to order the minor to undergo treatment.

Cases in the second situation (in which seriously ill minors with poor prognoses wished to refuse a potentially life-prolonging treatment) involved L.D.K. (a 12 year old from Ontario) (ONCJ, 1985); A.Y. (a 15 year old from Newfoundland and Labrador) (NL SCTD, 1993); and J.W. (a 15 year old from New Brunswick) (NBCA, 1994). All three cases concerned the refusal of treatment by a minor whose maturity was being considered based on the principles of the common law mature minor doctrine. On religious grounds, all three minors refused chemotherapy, and the accompanying blood transfusions, for leukemia (Downie, 2004). In each case, the prognosis was poor and the treatment refused was burdensome. In all three cases, the courts concluded the minor was decisionally capable and respected their wishes.

For L.D.K. and A.Y., one factor influencing the courts was that the treatment was only expected to have a low chance of slowing the progress of the disease, rather than curing it altogether. The minor’s maturity and experience living with the disease were also taken into account, with the judge noting L.D.K.’s maturity and the court’s order declaring A.Y. a mature minor (Downie, 2004). The doctors involved in J.W.’s case all agreed that he was sufficiently mature to understand the consequences of his treatment refusal, and stated that they would not administer blood or blood products to him, regardless of the court’s ruling, unless he consented. The original decision to place J.W. under the protection of the Minister of Health for two months was appealed, and J.W. was declared a mature minor who could provide his own consent for medical treatment. The appeal judge concluded that “the evidence here is overwhelming that Joshua is sufficiently mature and that, in the circumstances, the proposed treatment [which does not call for blood transfusions] is in his best interests” (NBCA, 1994).

According to Downie (2004), these cases may at first appear to fully embrace the mature minor rule, “but a closer look reveals the possibility of an additional feature of the rule.” Although the maturity of the patient influenced each judge’s decision, decisions were also heavily influenced by — and in L.D.K.’s case, primarily based on — the argument that refusing chemotherapy and pursuing an alternate treatment plan were in the minor’s best interests (Downie, 2004). Thus, the outcomes of these cases were not solely determined on the basis that decisionally capable minors should be allowed to make their own healthcare decisions.

3.6.2 Cases in Which Mature Minors Were Not Allowed to Make Their Own Healthcare Decisions

Before *A.C.*, cases in which courts ruled against allowing mature minors to make their own healthcare decisions involved situations where the minor wished to refuse a treatment that was required to save their life, and the treatment was likely to succeed. Thus, when compared with the situations discussed above, in which the treatment was not likely to be successful, the weighing of burdens and benefits of the treatment differed.

In the early 2000s, several Canadian cases dealt with these circumstances. All involved mature minors with life-threatening conditions who required blood transfusions as part of their recommended treatment, and refused to consent to a transfusion on religious grounds. C.U. (a 16 year old from Alberta) (ABQB, 2000; ABCA, 2003) suffered from dysfunctional uterine bleeding; B.H. (a 16 year old from Alberta) (ABPC, 2002; ABQB, 2002) was diagnosed with acute myeloid leukemia; and S.J.B. (a 14 year old from British Columbia) (BCPC, 2005; BCSC, 2005) was diagnosed with osteogenic sarcoma. All were child protection cases, and the provincial courts ordered transfusions in each one. All three were appealed, but without success; however, in each case, the appellate court did acknowledge that the minor was decisionally capable.

An important difference between these cases and those in which mature minors were allowed to make their own healthcare decisions was the prognosis of the minor with treatment. For B.H., treatment with chemotherapy and blood transfusions offered a 40 to 50% chance of curing her condition and a bone marrow transplant offered a 50 to 65% chance (ABPC, 2002). S.J.B.’s estimated survival rate was 70% if she responded well to the treatment (BCSC, 2005). C.U.’s condition was less life-threatening overall, but could have been fatal without a blood transfusion (ABQB, 2000). Thus, although the treatment would undoubtedly be difficult to endure, particularly for B.H. and S.J.B., there was a reasonable chance that it could save their lives.

In each case, the appellate court dealt with a tension between the common law on mature minors and provincial child welfare legislation, and ruled that the mature minor doctrine was superseded by child welfare laws. C.U. took her case to the Alberta Court of Appeal after it was dismissed by the Alberta Court of Queen's Bench. The Court of Appeal stated:

The mature minor rule does not apply in child welfare proceedings in which a child refuses to consent to essential treatment recommended by a physician. While the court must consider the expressed wishes of a mature child, it is not bound to comply with those wishes. Instead, the best interests of the child govern.

(ABCA, 2003)

Similarly, the judge in B.H.'s appeal ruled that, "while B.H.'s opinions should be considered, they cannot rule the day and should not in this case. ... [I]t is in B.H.'s best interests to have the treatment recommended by the hospital" (ABQB, 2002). In both cases, Alberta's child welfare legislation was viewed as a "complete and exclusive code for dealing with refusal of treatment in circumstances covered by the [legislation]" (ABQB, 2002). The judge in S.J.B.'s case agreed with the rulings for C.U. and B.H., and accordingly dismissed S.J.B.'s appeal (BCSC, 2005). It is important to note that all these cases predate the decision of A.C., which provided a more nuanced interpretation of best interests in the context of life-threatening decisions by minors.

A more recent case from 2017 concerned a 14 year old (known only as Patient X) from Quebec with Hodgkin's lymphoma who was ordered to receive blood transfusions as part of her treatment regime (QCCS, 2017c). The regime was expected to offer a 97% chance of recovery and an 85% chance of recovery with no relapse. In this case, the hospital (McGill University Health Centre) applied for a court order to administer blood after X refused for religious reasons. As discussed in Box 3.1 and Section 3.5.4, the law in Quebec differs from the law in other provinces and territories. Quebec does not recognize the concept of a mature minor and instead has specific legal regimes for consent to care, depending on the age of the minor (under 14 versus 14 to 17). The judge in X's case acknowledged that, while Quebec's *Civil Code* is, in principle, a comprehensive regime, particularly in terms of providing rules for capacity and consent, it does not contain all civil law; thus, it would be wise to consider the Supreme Court's ruling in A.C. Although an assessment of X's maturity was irrelevant under the *Civil Code*, it was nonetheless discussed in the ruling. The hospital doubted X's maturity, noting that her understanding of death was questionable, but a previous assessment by a child psychiatrist had indicated that she was capable of making the decision at hand and the judge agreed.

Ultimately, though, the court authorized the treatment, citing Section 16(2) and Article 33 of the *Civil Code*, which together give the courts the power to override the refusal of care by a minor aged 14 and over, if the care is required by their state of health and would be in the minor's best interests.

3.6.3 Evolving Law Through *A.C. v. Manitoba*

Similar to the cases described in Sections 3.6.1 and 3.6.2, *A.C.* addressed the role that prognosis plays in assessing a minor's capacity. The Court did note that the more grave the consequences of the healthcare decision for the minor, the more searching the scrutiny of their decision-making abilities must be. The Court's comments are consistent with the general law regarding capacity to make healthcare decisions — for adults or minors, it is decision-specific. The degree of understanding and appreciation needed for the capacity to make a particular decision varies with the gravity of the decision (Gilmour, 2017). In the case of minors, another level of complexity is added by the need to assess whether a particular minor can establish sufficient maturity and independence to make the decision. The *A.C.* ruling was precedent-setting in that it acknowledged these complexities, but still recognized the right of minors to make their own healthcare decisions when they are sufficiently mature and independent, even when these decisions could result in death. Furthermore, it was a judgment of Canada's highest court, thus giving it more power to influence future decisions.

Turning to *A.C.*'s constitutional rights — to religious freedom, to life, liberty and security of the person, and to equality, (sections 2, 7, and 15 and of the *Canadian Charter of Rights And Freedoms*) — the Court recognized that forced treatment could breach her rights, but held that the best interests standard in child protection legislation must be “applied in a way that takes into increasingly serious account the young person's views in accordance with his or her maturity in a given treatment case” (SCC, 2009). Taking this approach ensures that “all such constitutional violations can be avoided by allowing someone in [*A.C.*’s] position to attempt to demonstrate sufficient maturity to have her treatment wishes respected” (SCC, 2009). Thus, the Court based the finding of constitutionality primarily on the fact that the best interests standard could be interpreted to allow a consideration of her views and wishes in accordance with her evolving capacities.

3.6.4 Consideration of MAID for Mature Minors in the Current Legal Landscape

Gilmour *et al.* (2011) and Mosoff (2012) note that the courts have consistently intervened in situations where a healthcare decision is life-threatening and a minor makes a decision that medical opinion would argue is not in their best interests. Before *A.C.*, this intervention occurred when the minor was refusing

a treatment that was likely to succeed, regardless of whether the court deemed the minor decisionally capable. It remains to be seen, however, whether the *A.C.* ruling, which gave more weight to the minor's decision, will change this historical trend.

Where might MAID fit within Canada's current legal landscape if it were available to decisionally capable minors? Similar to adult cases pre-*Carter*, much of what case law has to offer concerning the ability of mature minors to make their own healthcare decisions comes from a context that does not necessarily apply to MAID. Although several cases have dealt with healthcare decisions of a life-threatening nature, those mature minors wished to *refuse* a life-sustaining treatment. For MAID, the mature minor would be *requesting* a life-ending treatment. Both of these choices have the same probable or certain outcome (death). In addition, many cases of treatment refusal by minors came to the courts through applications under provincial child welfare legislation. If MAID were authorized for mature minors, it is uncertain what the impact of child welfare legislation would be and, indeed, whether it would be triggered at all.

3.7 CONCLUSIONS

The common law mature minor doctrine, which has been endorsed by the Supreme Court of Canada, recognizes mature minors as individuals who have not yet reached the age of majority, but have the capacity to make an informed healthcare decision. The decision-making ability of a minor cannot be determined using a strict age cut-off or a standard set of criteria; instead, each case must be considered individually. This chapter has focused on cases involving conflict, which can arise when mature minors and their parents disagree, or when a mature minor's decision is at odds with what others consider to be in their best interests. A majority of cases requiring end-of-life decisions for mature minors *do* involve agreement among all parties and most proceed without issue.

The determination of whether a minor is indeed decisionally capable and whether they should be granted the right to make the decision at hand are not two distinct questions. The answers to both are affected by the gravity of the decision (i.e., whether it is life-threatening), the minor's prognosis with and without treatment, and the minor's ability to understand and appreciate their situation. When a minor's wish to refuse a treatment could result in death or permanent impairment, evaluating the independence of this wish, and the ability of the minor to truly appreciate the impacts of their decision, must be particularly careful and comprehensive. Furthermore, for cases that require litigation, the court's ruling will also depend on whether any provincial or territorial healthcare consent or child welfare legislation applies. Some provinces and territories have

enacted healthcare consent legislation that imposes restrictions on the ability of minors to consent to healthcare. In addition, the best interests standard may be applied through provincial or territorial child protection legislation if a minor is refusing to obtain a necessary medical intervention.

How have courts managed to disentangle tension between the mature minor common law and provincial and territorial child welfare legislation in cases where they conflict? Before 2009, case law seemed to indicate that in child protection cases, a court typically overrode a life-threatening healthcare decision made by a mature minor if it did not consider the decision to be in the minor's best interests. In other words, child welfare laws superseded the mature minor doctrine. However, *A.C.*, a precedent-setting 2009 Supreme Court case, gave a more nuanced interpretation of the best interests standard in child protection legislation. It ruled that best interests should be interpreted such that the choice of an independent, decisionally capable minor must be respected. Thus, even if the consequences of refusing a treatment are potentially life-ending, the best interests standard should not be used to justify automatically displacing a minor's decision. Instead, the minor's maturity must be taken into account and, if they are indeed capable of making the decision, they should be given the right to do so, even if it could result in death.

Because mature minors cannot currently access MAID in Canada, this chapter has necessarily relied on cases involving minors' refusal of life-sustaining treatment. These cases reveal what Canadian law says about the ability and the right of minors to make potentially life-ending decisions. The applicability of these cases to MAID depends, in part, on whether one views withholding and withdrawing treatment as ethically distinct from MAID. If it were applied to MAID, mature minor case law would suggest that, to be granted the right to MAID, a minor would need to demonstrate the ability to deeply understand and appreciate their situation, and make a mature, independent decision. Their prognosis and the availability of any acceptable treatment options would also play a role. The next chapter explores other decision-making models that are more inclusive, aiming to support rather than exclude those who might not meet the prevailing *understand and appreciate* test for capacity. It also explores how supported decision-making provides a different framework to apply to the question of whether minors should qualify for MAID.

4

Mature Minors and Healthcare Decision-Making

- **Healthcare Decisions by Minors**
- **Development of Decision-Making Ability:
Cognitive and Psychosocial Aspects**
- **Obtaining Informed Consent from Adolescents**
- **Relational Versus Individualistic Approaches to
Healthcare: Implications for Minors**
- **Conclusions**

4 Mature Minors and Healthcare Decision-Making

Key Findings

Healthcare decisions must be made by a capable, fully informed person exercising free and independent judgment. Decisions with increased risk or complexity incite greater concern over the ability of minors to appreciate the consequences of their choice and to make it voluntarily.

Evolving concepts of autonomous decision-making and patient care acknowledge the uniqueness of minors due to their special relationship with parents or guardians. Thus, minors' healthcare decisions are often intimately connected to the emotions and needs of the family unit.

The cognitive foundations for decisional capacity are in place by early adolescence. Yet, the ability of minors to make critical healthcare decisions cannot be predicated on chronological age alone. It also depends on factors linked to intellectual and psychosocial development, illness experience, and the minor's relationships with their family and healthcare team.

Although their brains are still developing, adolescents may be able to make an informed decision requesting MAID, particularly in a supportive environment. Minors who demonstrate sufficient capacity and maturity are generally able to make other end-of-life decisions, such as withholding or withdrawal of life-sustaining treatment.

While capacity assessments are complex, tools are available or are under development to help clinicians assess adolescent capacity for healthcare decisions and the capacity of patients requesting MAID.

An adolescent's ability to give informed consent is typically more scrutinized in life-threatening circumstances, and must be considered on a case-by-case basis. From an ethical perspective, the relationship of MAID to other end-of-life decisions that mature minors are currently permitted to make continues to be debated.

Being relationally embedded can be compatible with autonomous decision-making. Relational approaches to healthcare recognize that autonomy can be maximized by providing the needed supports from trusted others.

The doctrine of informed consent is firmly entrenched in Canadian healthcare laws and professional practice, designed to ensure that consent is given voluntarily, by properly informed patients with the capacity to consent to the treatment in question. Informed consent embodies both a legal and an ethical concept, and is seen as an interpersonal process in which patients and providers interact as healthcare decisions are made (Grady, 2015). The Canadian Paediatric Society acknowledges that, “the capacity of the paediatric patient to consent to proposed treatment varies with age and circumstances and must be determined on a case-by-case basis” (Coughlin, 2018). However, determining whether a young person is capable of informed consent presents a number of ambiguities and challenges, particularly when a decision has life-or-death consequences. In part, the hesitation to allow mature minors to access to MAID reflects concern over their capacity to appreciate the consequences of this decision, and the ability to make it autonomously.

The Canadian common law test for decision-making capacity centres on cognitive skills. A cognitive focus dominated early research on the development of decision-making ability. However, a spectrum of emotional, social, and situational factors also influences the decision-making process. Furthermore, neuroscience and psychology research does not provide all the answers on capacity in minors. A number of questions related to healthcare decision-making by minors must also be addressed through an ethical lens. In addition, capacity is only one component of maturity and, though it is a necessary condition to accord minors with decision-making authority, it is not sufficient.

This chapter explores a minor’s ability to consent to critical healthcare decisions, through developmental, ethical, and clinical perspectives on the following questions:

- How do different conceptions of autonomous decision-making relate to minors in a medical context?
- What is the relationship between chronological age and decision-making ability?
- Are the cognitive and emotional abilities of a minor sufficient for the capacity to consent to MAID?
- Do the informed consent processes for adults and minors differ with respect to critical healthcare decisions?
- Does the intertwining of minors’ lives and preferences with those of their parents or guardians pose a barrier to autonomous consent to MAID?

4.1 HEALTHCARE DECISIONS BY MINORS

Autonomy, derived from the Greek *autos* (self) and *nomos* (rule), refers to self-determination (Beauchamp & Childress, 2013). A fundamental ethical principle used to guide healthcare practitioners in their therapeutic relationships with patients is respect for autonomy, which centres on a patient's freedom of choice over what happens to their body, health information, and integrity of person (Ells *et al.*, 2011). There is no universally accepted definition of what it means to make an autonomous decision in the field of law (Coggon, 2016) or of ethics (Beauchamp & Childress, 2013). Autonomy is closely linked to the concept of capacity, in that autonomous decisions are made by people with capacity. One way healthcare practitioners must respect patient autonomy is by obtaining informed consent before providing treatment (Beauchamp & Childress, 2013). Of particular relevance to minors is how to reconcile the idea of independent decision-making with appreciation of the social context within which healthcare decisions are made.

4.1.1 Concerns Related to Minors' Ability to Make Autonomous Healthcare Decisions

Healthcare decisions with minimal risk and clear benefits, such as treatment of a local infection, are less likely to incite concerns over minors' capacity than riskier or more complex decisions, such as whether to undergo an experimental cancer treatment (Coughlin, 2018). With increased risk or complexity also comes greater concern over the factors to which minors might be vulnerable during the decision-making process, including external pressure and inaccurate or insufficient information (Guichon & Mitchell, 2006).

One element of autonomous decisions that holds intuitive appeal is authenticity (Kim, 2010). Authenticity of action means that the action should be "consistent with the person's attitudes, values, dispositions, and life plans" (Miller, 1981). In other words, the person should be acting in character. This may be difficult to apply to mature minors since it is questionable whether their core values and life plans are developed enough to stably determine their well-being (Buchanan & Brock, 1989). In fact, one could argue that it might be difficult to apply this element of autonomy to adults as well. Nonetheless, it may still be relevant to consider whether a minor appears to be acting in character, and whether their decision truly reflects their core values and beliefs (SCC, 2009).

Autonomous decisions must also be voluntary, or free from coercion (Beauchamp & Childress, 2013). Whether a minor has sufficient freedom to make a voluntary decision, and thereby provide informed consent, is a key question and area of concern when it comes to deciding whether to allow MAID for this population

(Gilmour, 2017). This stems from the view that minors may be vulnerable to pressure, duress, and manipulation from authority figures, including parents and healthcare teams. While young children generally view authority figures as powerful and obey their requests, adolescents are less susceptible to coercion and more apt to question demands. Nonetheless, given that adolescents likely have less experience than adults with complex life choices, some have questioned whether they truly have the confidence to resist coercive influences when making a serious healthcare decision (Kuther, 2003). However, there are two important counterpoints to this. The first is whether, in trying to protect mature minors from what is perceived as a vulnerable situation, a new vulnerability is created by not respecting their wishes and decisions (Downie, 2018a). The second is that it is overly simplistic and at times inaccurate to state that a decision is not voluntary simply because a person makes it in consultation with family members and healthcare professionals, and considers its potential impact on loved ones (Salter, 2017).

4.1.2 Relational Perspectives on Healthcare Decisions

Patient-centred care has become an essential concept underlying approaches to healthcare policy and practice. For adults, patient-centred care models originated from the idea that patients should be involved in all aspects of decision-making about their health, in ways that recognize their unique preferences, values, and social context. These models have now evolved to consider patients' families and entire clinical care teams (Nicholas *et al.*, 2014). In pediatric settings, care models recognize that, while the patient is at the core, the family is also central to the patient's care. Often referred to as *patient and family-centred care*, this approach incorporates respect for family values and beliefs; effective communication and collaboration among healthcare practitioners, patients, and their families; and the participation of both patients and families in care and decision-making (Keilty *et al.*, 2014). Patient and family-centred care has emerged as a priority in pediatric hospitals across North America (Nicholas *et al.*, 2014).

Ells *et al.* (2011) argue that relational autonomy, a formulation of autonomy introduced by feminist theory (Nedelsky, 1989), is a critical concept that merges the principle of respect for autonomy with evolving patient-centred care approaches. Relational autonomy emphasizes that "all persons are, to a significant degree, socially constructed, that their identities, values, concepts, and perceptions are, in large measure, products of their social environment" (Sherwin, 1998). While relational autonomy does not deny that autonomy ultimately resides in individuals, it rejects the view of autonomous agents as independent, self-interested, and self-sufficient. It recognizes that "much of who we are and what we value is rooted in our relationships and affinities with others" (Sherwin, 1998). Relational autonomy appreciates the interconnectedness of

patients and others who are significant to them, and that, regardless of age, a person's well-being and identity may be intrinsically linked to family members. Choosing to include family, friends, care providers, or other advisors during healthcare decisions can be viewed as a way to foster, not detract from, autonomy (Walter & Ross, 2014).

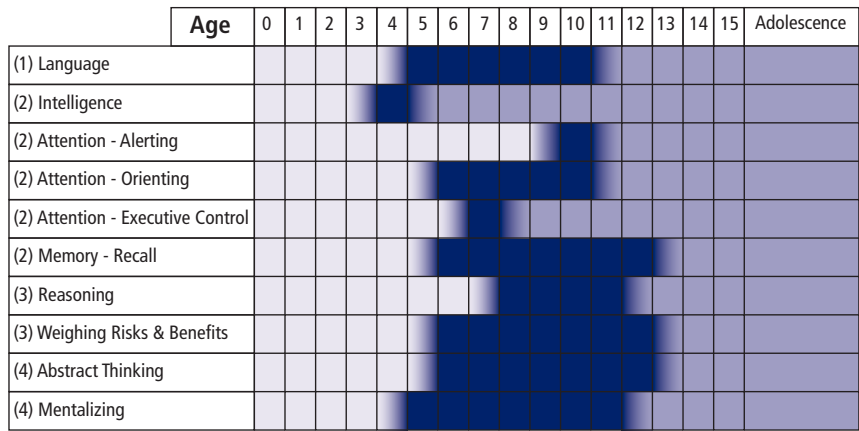
As set out in Chapter 3, Canadian law establishes the extent to which mature minors are able to make autonomous healthcare decisions. However, Friedel (2014) argues that it is misleading to think that a minor's request for euthanasia can ever be completely autonomous, "given that their development is embedded in a variety of relations that influence their perceptions and choices." Healthcare practices that draw upon relational concepts acknowledge that minors are a unique population: they have special relationships with parents or guardians, and their decisions and preferences can be understood in relation to the perspectives of their parents or other significant people in their lives. Parents and guardians have responsibilities, obligations, and interests related to their children, and are significant stakeholders in the results of actions involving them. In most cases, parents or guardians not only care deeply about their children, but are also in a unique position to know their children best (Carnevale *et al.*, 2017). Thus, while the inclusion of others in medical decisions is not unique to minors, it has implications for their healthcare choices, which are intimately connected to the emotions and needs of the family unit. A relational approach also recognizes that the autonomy of adolescents in healthcare settings can either be fostered through the support and guidance of others, or hindered and undermined through oppressive social relationships (Walter & Ross, 2014).

4.2 DEVELOPMENT OF DECISION-MAKING ABILITY: COGNITIVE AND PSYCHOSOCIAL ASPECTS

Decisional capacity is not simply an intrinsic ability that follows a precise developmental trajectory. Nonetheless, knowledge of cognitive and psychosocial development provides important context for understanding healthcare decisions by youth (Ferguson, 2004). A central question facing research in adolescent decision-making is, even if adolescents were to demonstrate cognitive skills similar to adults, would they be more affected by variables that have an impact on their ability to use these skills, such as emotion or social influence (Klaczynski *et al.*, 2001)? Developmental and behavioural neuroscience research has shown that the answer is *yes*. Adolescents attain cognitive maturity before social or emotional maturity, and the adolescent brain differs from the adult brain in several ways that can affect decision-making, particularly in certain contexts (Steinberg, 2013).

4.2.1 Cognitive Foundations for Decisional Capacity Are in Place by Early Adolescence

The four functional abilities central to capacity (understanding, appreciation, reasoning, and expressing a choice; Figure 3.2) are supported by a spectrum of neuropsychological skills gradually acquired during childhood and adolescence. In a review of neuroscientific and psychological literature, Grootens-Wiegers *et al.* (2017) show that the critical period of development for these skills occurs by the age of 12 (Figure 4.1). The authors therefore argue that, from a strictly cognitive perspective focusing on basic information processing and reasoning, the potential for capacity could be present by age 12.



Adapted with permission from Grootens-Wiegers *et al.* (2017)

Figure 4.1
The Development of Neuropsychological Skills Required for the Four Functional Abilities Relevant to Capacity

Numbers in brackets indicate the ability most linked to each skill (expressing a choice – 1; understanding – 2; reasoning – 3; appreciation – 4). The darkest colouring indicates the critical developmental period.

Studies that examine capacity in laboratory settings are far removed from the daily lives of children and adolescents. Alderson *et al.* (2006b) emphasize that traditional research methods in developmental psychology often involve healthy subjects, use standardized questionnaires, and are “conducted in a cool, detached manner” that might intimidate children and underestimate their actual abilities. Nonetheless, these studies provide some insight into the abilities of adolescents to make healthcare decisions. Steinberg (2013) notes a general pattern across research examining cognitive maturity in various contexts, which suggests that, when emotional and social influences on capacity are minimal, adult-like decision-making abilities are demonstrated by 15 years of age. Similarly, Freyer *et al.* (2006) contend that researchers and professionals across many fields “agree that adolescents 14 years and older should be presumed, in the absence of contrary evidence, to possess the functional competence required to make binding medical decisions for themselves concerning discontinuation of life-prolonging therapy and other end-of-life issues.”

With respect to treatment choices, a limited number of studies have examined capacity in children using all components of the four abilities model, or directly compared the decision-making abilities of various age groups in different treatment scenarios (Miller *et al.*, 2004). In a seminal study that used structured interviews to score all elements of the four abilities model, healthy 14 year olds did not differ from healthy adults in their decision-making abilities with respect to hypothetical treatment dilemmas (Weithorn & Campbell, 1982). Similarly, in a pilot study of pediatric patients at risk for inherited cardiac disease, 12 was the mean age judged to have capacity for diagnostic testing (Hein *et al.*, 2015c).

Together, these data point to the idea that cognitive foundations for mature decisions are generally in place by early adolescence (12 to 15 years of age). Therefore, age should not preclude a minor from providing informed consent to the same healthcare decisions that adults are presumed capable of making. Notably, amendments to Belgian legislation that allow minors to request euthanasia are grounded in the view that capacity for discernment is more important than age when determining eligibility (Section 5.5.1). Investigators have challenged the idea that cognitive development follows an age-predictable trajectory defined simply by a gradual increase in analytic thinking. Instead, dual-process models recognize the co-development and interaction of both analytic and experience-based processing systems, which may explain why age and general intellectual skills can be poor predictors of adolescent decision-making capacity in certain contexts (Stanovich & West, 2000; Klaczynski, 2004). Furthermore, the recognized difference between cognitive and psychosocial maturity has implications for health-related decisions (Steinberg, 2013). As described below, neurological studies have begun to shed light on the interaction of cognition and emotion in adolescents.

4.2.2 Evolving Decision-Making Abilities in Minors Reveal the Importance of Context

Advances in neuroimaging have shown that brain anatomy and activity continue to evolve throughout adolescence, in ways that affect self-control, risk-taking, and response to emotional stimuli (Blakemore & Robbins, 2012). In contrast to fully developed brains, adolescent brains demonstrate a lack of connectivity among regions involved in the control system, reward system, and emotion processing (Grootens-Wiegers *et al.*, 2017).

The prefrontal cortex undergoes a prolonged period of structural changes throughout adolescence and into the early to mid-20s, resulting in a gradual refinement of the neurocircuitry regulating complex decision-making and impulsivity, including functions such as planning ahead and weighing risks and rewards (Steinberg, 2013). Development of impulse control lags behind the maturation of subcortical regions involved in the processing of emotions and rewards, which is thought to promote risky decisions and enhanced emotional reactivity (Mills *et al.*, 2014). In addition, increased reward-seeking behaviour during adolescence is driven by hyper-responsiveness to dopamine in the striatum, a central structure in the reward system (Galvan, 2010). These structural and functional changes translate to a reduced ability for adolescents to show mature judgment in contexts of high emotion or arousal as opposed to contexts of low emotion or arousal (referred to as *hot* and *cold* contexts, respectively) (Blakemore & Robbins, 2012).

Notably, assessing the capacity of adolescents in research settings using hypothetical medical treatment scenarios is unlikely to activate the circuitry responsive to hot contexts (Silber, 2011). Thus, despite cognitive skills that may be comparable to adults, the way that adolescents respond to environmental factors may affect their decision-making abilities, particularly in situations laden with emotion or the influence of peers (Steinberg, 2005). However, a request for MAID would more likely be a well-contemplated decision made with the support of family and a clinical care team, rather than an abrupt, impulsive choice. The CCRC (2017) argues that MAID “is not a spontaneous decision, in which impulse controls are at issue. It is considered, unhurried and reasoned decision making, overseen by medical professionals.” As is the case for adults, adolescents who are provided with the necessary information, and who are in the appropriate environment for making the decision in question, have the potential to give informed consent. Furthermore, while adolescent and adult brains have anatomical and functional differences, capacity is not directly relatable to brain structure. The weight of evidence shows that cognitive elements for capacity, and other maturational features necessary for consent, are likely sufficient prior to the age of 18 (Schwartz *et al.*, 2018).

4.2.3 Informed Consent by Minors Must Consider a Range of Complex Factors

Adolescents must not be understood as a homogenous group in terms of their development, as the pace of cognitive and psychosocial development varies (Steinberg, 2005). Furthermore, during real-life decision-making, significant choices are not made in a social and emotional vacuum, but rather reflect the influences of feelings, values, motivation, experience, and loved ones (Klaczynski *et al.*, 2001; Lansdown, 2005). Some argue that viewing decisional capacity solely as an ability that lies within a person is detrimental to children, as it fails to emphasize the way in which capacity is a product of one's social environment (Ruhe *et al.*, 2016).

Miller *et al.* (2004) propose an integrated model for determining the capacity of children in clinical settings. This model considers several predisposing factors that set the stage for capacity (e.g., cognitive development, prior experience with decision-making in general, parental beliefs about child autonomy, and family cultural and religious values), which then interact with a number of child, parent, clinician, and situational factors. Child factors include experience specific to the decision in question, as well as the current emotional and physical state. Parent and clinician factors centre on communication, support, and behaviour towards the child. Situational factors are related to the nature of the decision.

The role of medical experience in the ability to give informed consent is highly relevant to the MAID context. Freyer *et al.* (2006) note that “clinicians have observed that many minors, especially teenagers who are chronically ill and have acquired considerable medical experience, exhibit significant knowledge and insight about their condition, prognosis, and treatment preferences.” This point was echoed during Belgian parliamentary proceedings prior to the 2014 amendment allowing euthanasia for minors. All witnesses in pediatric medicine agreed that minors with fatal illnesses are capable of exceptional maturity, and may have the capacity to appreciate the implications of a euthanasia request (Van Assche *et al.*, 2018). Qualitative research examining children with chronic or terminal illness has shown that even young children have remarkable knowledge and capacity in relation to their condition, and that experience affects capacity more than age or general ability (Bluebond-Langner, 1978; Alderson *et al.*, 2006b). In a study of 24 children with type I diabetes, children as young as four years old demonstrated an understanding of their disease and an ability to make informed decisions in their own best interests (Alderson *et al.*, 2006a). In contrast, disease experience did not affect the capacity to consent to clinical research in a study of 161 pediatric patients (aged 6 to 18 years) evaluated by a structured assessment tool. However, the authors acknowledge that experience was difficult to define in a diverse study population with a range of medical conditions (Hein *et al.*, 2015b).

In addition to illness experience, the role of family in the healthcare of minors is critical. Salter (2017) argues that it is impossible to answer what is in minors' best interests without acknowledging how their interests are connected to, and partially defined by, those of their parents/guardians, siblings, and broader family unit. According to Salter, for better and worse, "a minor's values, preferences, strengths, and weaknesses are significantly influenced ... by the daily and ongoing nurturing, teaching, disciplining, and modeling (or absence thereof) of parents and families" (Salter, 2017). Ethical views differ on the decision-making authority of minors, some of which are linked to the responsibilities and interests of family. Ross (2015) argues that even if minors demonstrate capacity, parental responsibilities to care for and protect their children still remain. Furthermore, excluding parents from medical choices involving their decisionally capable children ignores the value of the intimate family unit, and the ways in which it can be significantly affected by healthcare decisions (Ross, 2015). In reviewing how empirical findings could be merged with ethical and legal aspects of the debate on children's capacity to consent to clinical research, Hein *et al.* (2015a) support a dual consent procedure (child and parent) for minors aged 12 until the age of majority. See Sections 5.4.2 and 5.4.3 for further discussion of family involvement in the healthcare decisions of adolescents.

4.3 OBTAINING INFORMED CONSENT FROM ADOLESCENTS

Societal attitudes about the need to protect adolescents are ever-present (Mosoff, 2012). Buchanan and Brock (1989) describe the two underlying values at stake in the assessment of a minor's ability to provide informed consent: the patient's self-determination and the patient's well-being. Legal and clinical standards aim to balance the protection of minors from potentially harmful consequences with the preservation of their autonomy, but this poses many challenges (SCC, 2009). This section compares considerations relevant to the informed consent process in adolescents with those relevant to adults.

4.3.1 Approaches to Determine Cognitive Capacity Are Not Defined by Chronological Age

Capacity assessment is inherent to clinician-patient interactions, and healthcare practitioners routinely assess the capacity of minors (Geist & Opler, 2010). Capacity assessment is often implicit; however, in some cases, such as MAID, explicit evaluation of capacity is legally required (GC, 2016). In the *Carter* case, the trial judge's review of the evidence found that "[p]hysicians routinely assess whether their patients are competent and informed and whether their decisions to accept or reject treatment are influenced by depression, coercion or undue influence. The risks of error already accepted in end-of-life practice are low, and can be further reduced through stringent safeguards and monitoring" (BCSC, 2012). Nonetheless, the CPS notes that capacity assessment in pediatric

patients presents a number of complexities related to situational factors and developmental considerations (Coughlin, 2018). In addition, during consultations related to capacity assessment under Ontario's *Health Care Consent Act*, the Law Commission of Ontario "heard that particular attention should be paid to the challenges of assessing the decision-making abilities of youth" (LCO, 2017).

As discussed in earlier sections, statutes addressing healthcare consent among mature minors focus on the decision-specific cognitive skills required for capacity. Similar to adults, there are no formal training requirements or standardized processes for the evaluation of capacity in adolescents. Charland *et al.* (2016) argue that relying on the judgment of individual clinicians, which is an unavoidable aspect of capacity evaluation, is problematic, particularly in challenging cases that inevitably arise in the MAID context. However, there is accessible guidance for capacity assessment in pediatrics (Geist & Opler, 2010; Michaud *et al.*, 2015).

Practical Guidance for Adolescent Capacity Assessment

In general, the age of a patient does not define the core approach to capacity evaluation. Among the most widely cited and extensively tested adult capacity assessment tools is the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (Grisso *et al.*, 1997). The MacCAT-T process is an interview in which information related to the patient's condition is disclosed gradually, accompanied by questions related to their ability to understand, appreciate, reason, and communicate a choice. Understanding is tested by asking the patient to paraphrase information on the condition, and the nature, risks, and benefits of the proposed treatment. Appreciation is assessed by questions that determine whether the patient exhibits not only intellectual understanding of the condition and treatment, but can also apply this information to their own situation. Reasoning and expression of a choice are assessed by questions that focus on motives underlying the treatment decision, including consideration of alternatives and their consequences (Grisso *et al.*, 1997).

While the majority of research on structured capacity assessment tools has focused on adult populations, studies have demonstrated promise for the MacCAT-T as a means to assess the capacity of adolescents to consent to predictive genetic testing, treatment for mental disorders, or treatment for the human immunodeficiency virus (HIV) (Turrell *et al.*, 2011; Chenneville *et al.*, 2014; Hein *et al.*, 2015c; Mandarelli *et al.*, 2017). Thus, it is plausible that guidelines and tools for assessing an adult's capacity to understand the relevant information and appreciate the reasonably foreseeable consequences

of a healthcare decision can apply to adolescents. At this stage, there is a lack of detailed guidelines describing capacity testing for MAID in Canada; however, hospitals are beginning to develop clinical guides to aid practitioners. For example, in its Capacity Assessment Checklist for MAID, Alberta Health Services has developed a detailed series of interview questions to assess a range of factors related to capacity, including the patient's cognitive abilities, mental state, current quality of life, family dynamics, and vulnerability to coercive influences (AHS, 2017). In utilizing this type of comprehensive approach for patients requesting MAID, the questions asked during a capacity assessment could apply to individuals above or below 18 years of age.

While practical guidance related to adolescent capacity assessment does not differ appreciably from guidance for adults, several authors stress that adolescents' sensitivity to context deserves specific attention (Larcher & Hutchinson, 2010; Michaud *et al.*, 2015; Ruhe *et al.*, 2015). Conditions that maximize the capacity for well-contemplated decisions can be provided through support from healthcare practitioners, parents, and others who know the adolescent well (Steinberg, 2013; Hein *et al.*, 2015a). This support includes a trustful relationship between the adolescent and their healthcare team, and a respectful and empathetic environment (Michaud *et al.*, 2015). An additional challenge relates to the fact that healthcare practitioners are typically better trained to focus on the best medical interests, rather than capacity assessment, of minors. Thus, it can be difficult to reconcile medical considerations with the legal requirement that a patient must demonstrate understanding and appreciation, but need not make a *reasonable* choice (Geist & Opler, 2010). In challenging situations, deliberation within a team, which includes the adolescent's primary healthcare practitioners and other practitioners who are not emotionally involved, can reduce the risk of practitioner bias (Michaud *et al.*, 2015).

Assessing the Capacity of Minors Requesting Euthanasia in Belgium and the Netherlands

For MAID specifically, there is no guidance in Belgium or the Netherlands to suggest that approaches to determine the capacity of minors should differ from those for adults. In the Netherlands, the Regional Euthanasia Review Committees Code of Practice (RTE, 2015) states:

In the event of a request from a minor, particular attention will have to be paid to the patient's decisional competence. It is not considered impossible for a minor to be decisionally competent with regard to euthanasia, but the physician and the independent physician will both have to give this matter especially careful consideration.

Given that only 13 minors have received euthanasia in the Netherlands since 2002 and 3 in Belgium since 2014 (Tables 5.1 and 5.2), it is difficult to assess the effectiveness of this approach. Furthermore, it is not known how many minors in Belgium or the Netherlands requested and were denied euthanasia, or the reasons for the denials. However, in the Netherlands, where each case of euthanasia for a minor is publicly available as an individual report, no issues related to assessment of the minor's capacity were discussed, and the primary and consulting physicians were in agreement (RTE, 2018a).

In 2015, a Belgian Supreme Court ruling upheld the 2014 amendment to Belgian's Act on euthanasia allowing minors to request euthanasia. The Court rejected the appellants' argument that the notion of capacity for discernment was new in Belgian medical law and required more specific criteria. It concluded that, while the term had not been widely used, capacity for discernment is analogous to other well-established concepts in Belgian medical law and clinical practice; thus, it can be evaluated using established approaches that consider the circumstances of each minor on a case-by-case basis. The Court ruled that it was not without reasonable justification that the legislature did not provide more specific criteria for determining the capacity of the minor patient (CCB, 2015). Prior to the passing of Belgian legislation legalizing euthanasia for minors, members of the Belgian Royal Academy of Medicine released a document that addresses a number of practical considerations concerning euthanasia for pediatric patients. The document suggests that the minor patient's capacity should be assessed according to the most objective criteria possible. It also suggests to ensure that the euthanasia request is not the result of a lack of understanding related to the disease course or management, a call for help, an indication of depression, the minor's wish to not make their parents unhappy, or relational conflicts (Fonteyne *et al.*, 2013). These considerations related to patient understanding, mental status, and family dynamics are not unique to those under 18 years of age.

4.3.2 Evaluating the Maturity of Minors Adds a Layer of Scrutiny that Is Not Typically Invoked for Adults

Although similar processes are used to assess the cognitive capacities of adults and adolescents, critical healthcare decisions made by the latter are often more intensely scrutinized. It is clear that, when such a decision may lead to a minor's death, cases invoking the mature minor doctrine have considered more than just the individual's cognitive ability to understand the pertinent information and appreciate the reasonably foreseeable consequences of the decision (SCC, 2009; Gilmour *et al.*, 2011). In serious circumstances, such as the refusal of potentially life-saving treatment, an added level of consideration,

which analyzes a minor's maturity in detail, may be applied. The Manitoba Law Reform Commission asserted that "maturity may involve more than an intellectual appreciation of the nature and risks of the medical treatment *per se*. The court may also consider ethical, emotional maturity, particularly in difficult and controversial areas" (MLRC, 1995). Thus, assessment of a minor's maturity includes a broad range of factors. This added layer of scrutiny is not typically invoked for adults, as they are assumed to have the maturity and life experience required to make life-or-death healthcare decisions.

In the Supreme Court of Canada's judgment in *A.C.*, Justice Abella stated that "the evolutionary and contextual character of maturity makes it difficult to define, let alone definitively identify. Yet the right of mature adolescents not to be unfairly deprived of their medical decision-making autonomy means that the assessment must be undertaken with respect and rigour." She acknowledged that determining an adolescent's maturity must include a range of factors that assess "the extent to which a child's wishes reflect true, stable and independent choices" (SCC, 2009).

Determining the ability of an adolescent to provide informed consent often encompasses more than a series of questions about the treatment in question. Broader considerations might address the adolescent's experience in clinical settings, social development, family dynamics, and the ability to express a consistent choice (Geist & Opler, 2010). While close relationships can provide support that empowers an adolescent to make mature healthcare decisions, they can also interfere with their ability to exercise independent judgment. Parents/guardians, other family members, or adults such as teachers or social workers who know the adolescent well may provide information that speaks to an adolescent's maturity, although this information may lack objectivity (Larcher & Hutchinson, 2010; Michaud *et al.*, 2015). Van Assche *et al.* (2018) emphasize that, although pediatricians are constantly evaluating the maturity of their patients, including those at end of life, no standardized approaches are available to assess minors' capacity or psychosocial maturity. Furthermore, "the mere fact that somebody does something frequently, does not necessarily mean that they do it well" (Van Assche *et al.*, 2018).

4.3.3 Treating Mature Minors Differently than Capable Adults in a MAID Context: Factors for Consideration

A key question is whether MAID should be treated differently than other end-of-life decisions that mature minors are generally able to make, such as withholding or withdrawing life-sustaining treatment. When the Supreme Court of British Columbia first heard the *Carter* case, the trial judge found that

the “preponderance of the evidence from ethicists is that there is no ethical distinction between physician-assisted death and other end-of-life practices whose outcome is highly likely to be death” (BCSC, 2012). However, the *Carter* case did not consider the possibility of MAID requests by mature minors. Even in countries where mature minors are eligible for assisted death, the question of this ethical distinction continues to generate strong controversy (Bovens, 2015; Kaczor, 2016). Some argue that there is a fundamental difference between allowing minors to decide to discontinue life-supporting treatment, and allowing them to consent to their deliberate death (Kaczor, 2016).

Within the spectrum of end-of-life decisions, there is also ongoing bioethical debate on the difference between *omission* (not initiating a life-sustaining intervention, which rests on a patient’s negative right to non-interference) and *action* (an act that by itself causes death, which rests on a patient’s positive right to have something provided to them) (Sanchini *et al.*, 2014). There is also debate about what constitutes an act or an omission. For example, is ending artificial nutrition an act (removing a feeding tube) or an omission (no longer supplying nutrition through that tube) (UKHL, 1993)? Where minors are concerned, the precise medical action (or inaction) in question is one of many factors to consider. As discussed in Chapter 3, complex cases involving life-threatening medical choices typically consider the minor’s entire situation, including their prognosis and the availability of other treatment options.

The view that minors deserve added protection in the MAID context is important when considering the informed consent process, and whether it might be different for minors than for adults. If the *approach* to capacity assessment is not age-dependent, then should minors be held to different *standards* than adults? In other words, what would minors be required to demonstrate in order to consent to MAID? In comparing court cases that invoked the mature minor doctrine in Canada and the United Kingdom, Ferguson (2007) cautions against holding minors to standards that even some adults could not meet. These include asking a minor to question her faith (ABPC, 2002), understand ethical arguments related to her medical dilemma (ABCA, 1986), or comprehend the pain, fear, and distress associated with dying (EWHC, 1993). Another aspect of the informed consent process that is critical for minors relates to the involvement of others. This issue is further discussed below.

4.4 RELATIONAL VERSUS INDIVIDUALISTIC APPROACHES TO HEALTHCARE: IMPLICATIONS FOR MINORS

Respect for autonomy includes an obligation for healthcare practitioners to treat patients in a way that fosters the capacity for autonomous decisions (Beauchamp & Childress, 2013). Where children are concerned, it is critical to recognize that the capacity for autonomous decisions originates from, and is shaped by, social interactions. The fact that minors might consider the needs of their parents/guardians or other loved ones when making critical healthcare decisions reflects the way these decisions are often made (Ruhe *et al.*, 2016). As discussed below, relational approaches to healthcare and decision-making are gaining recognition, and can help to recharacterize the interplay between minors and parents/guardians.

4.4.1 Relational Concepts of Autonomy Have Direct Implications for Health Law, Policy, and Practice Concerning Informed Consent

Downie and Llewellyn (2008) contend that relational theory necessitates a reconsideration of traditional approaches to free and informed consent. With respect to capacity, the authors argue that a “relational conception of autonomy allows us to see emotion and relational reasoning as legitimate aspects of competence. It suggests that health law, policy, and practice should see and treat as competent a wider range of decision-makers and decision-making than they do at present.” This includes the involvement of others who are significant to the patient in the decision-making process, and recognition of the view that a competent person might not desire decision-making authority for their treatment decisions. In contrast, a “relational model can entertain a wider range of possible levels and kinds of decisional authority-shifting without concluding that the individual is incompetent and the consent therefore invalid” (Downie & Llewellyn, 2008).

Recognizing the relational aspect of autonomy has implications for the practitioner-patient relationship. Deschamps (2016) maintains that, in the case of MAID, where the relational aspect of autonomy is critical, the ethical and legal foundations of the relationship between healthcare practitioners and their patients must be revisited. This involves the therapeutic alliance, a concept from the field of psychotherapy in which patients and healthcare practitioners collaborate in pursuit of the patient’s well-being, in a way that inherently respects patient autonomy. The therapeutic alliance depends upon mutual trust and respect between the practitioner and the patient (Mead & Bower, 2000). In PPC, for instance, a strong therapeutic alliance is associated with improved patient and family psychosocial outcomes, including greater emotional acceptance of prognosis in patients with an incurable illness (Blazin *et al.*, 2018).

Deschamps (2016) argues that Quebec's legal framework for MAID highlights the relational nature of autonomy. According to *An Act Respecting End-of-Life Care*, the physician administering MAID must verify the persistence of suffering and desire for MAID "by talking with the patient at reasonably spaced intervals given the progress of the patient's condition." The physician must also discuss "the patient's request with any members of the care team who are in regular contact with the patient" and discuss "the patient's request with the patient's close relations, if the patient so wishes" (Gov. of QC, 2014). Thus, Quebec law recognizes the involvement of not just the patient and the administering physician, but also the patient's care team and family. This applies to adult patients, whose relational embeddedness is not a barrier to accessing MAID.

4.4.2 Is Dependence on Others Incompatible with the Right to Make Decisions?

Commonly, minors relate their treatment preferences to the preferences expressed by their parents (Carnevale *et al.*, 2017). Parents must also bear some of the consequences of the treatment choice (Buchanan & Brock, 1989) — a significant issue where MAID is concerned. However, the fact that minors' interests are relationally intertwined with those of their parents does not mean that parents are necessarily coercing their children towards a particular treatment option. Being relationally embedded does not negate one's autonomy (Gibson *et al.*, 2012). Notably, in the Netherlands and Belgium, a requirement for parental agreement is not viewed as incompatible with a minor's consent to euthanasia (Section 5.5.1).

A relational ethics lens recognizes that minors can simultaneously have agency and be dependent. Although there is growing evidence that minors' decisional and participation capacities are often underestimated, the weight given to the voice of the child, particularly younger children who might not demonstrate formally defined decision-making capacity, remains a significant ethical problem with respect to healthcare decisions in general (Carnevale *et al.*, 2015). This point poses a relevant question in the MAID context that, while beyond the Working Group's charge, is important to express. The notion that only those who demonstrate specific mental or emotional capabilities should have access to MAID in Canada means that the opportunity to relieve intolerable suffering from an irremediable condition will be denied to all others — including minors who may be able to clearly express their views but do not meet the criteria for maturity. Thus, there may be grounds to suggest that permitting minors to request MAID only if they demonstrate the adult-like traits expected of mature minors would be unjustified or unprincipled (Singh, 2018).

4.4.3 Recent Shifts in Decision-Making Approaches May Have Implications for Minors

Canadian jurisprudence and legislation have begun to acknowledge “new forms of decision-making status beyond the traditional binary distinction between acting legally independently with no support, and being placed under a substituted authority” (Bach & Kerzner, 2010). This includes a recognition of supported decision-making, a concept grounded in the social model of disability. As described in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), people with disabilities should be enabled and empowered to exercise their legal capacity and make decisions on their behalf (UN, 2007). The UNCRPD, ratified by Canada in 2010, has brought supported decision-making to the forefront. While many disability advocates have interpreted the UNCRPD to mean that all substitute decision-making arrangements should be eliminated, Canada chose not to do so in ratification. Supported decision-making is not legally recognized in most provinces and territories; however, it has been adopted into legislation in Yukon, British Columbia, Alberta, and Manitoba in limited circumstances (Stainton, 2015).

According to the Law Commission of Ontario,

the goal of supported decision-making is to avoid loss of legal capacity through the provision of supports by persons with whom they have relationships of trust and intimacy. It is centred on the insight that for almost all of us, decision-making is a consultative endeavour such that we rely on supports from trusted others in making decisions of various kinds, and seeks to extend this approach to legal decision-making arrangements.

(LCO, 2015)

Grounded in relational autonomy, supported decision-making aims to maximize people’s autonomy, and respect the values, goals, preferences, and decision-making rights of those who would otherwise be excluded based on the prevailing capacity threshold (Bach & Kerzner, 2010; LCO, 2015). Notably, the concept of supported decision-making was developed mainly in the context of people with disabilities, and its application to MAID and minors is unclear. That said, similar to the disability context, the concept may be viewed as a form of reasonable accommodation aimed at facilitating autonomous decision-making by minors in a medical context (Paré, 2011). Figure 4.2 describes how this type of decision-making framework provides an alternate way of thinking about the qualification of minors for MAID.

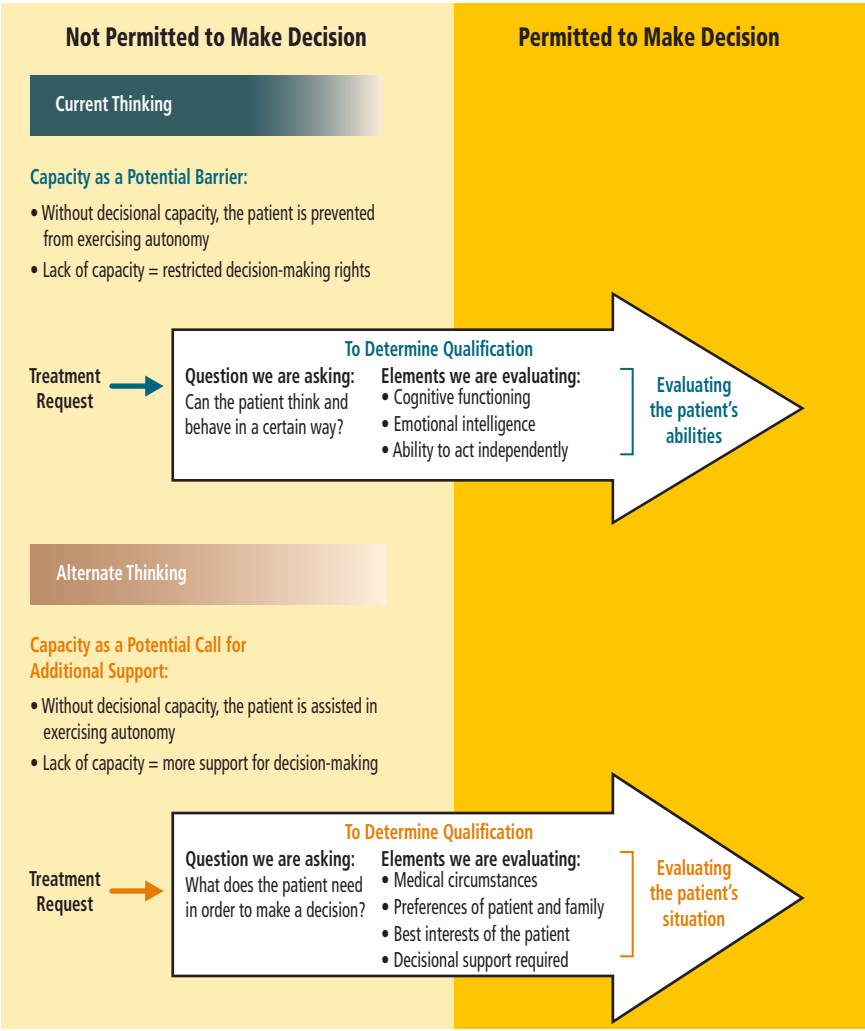


Figure 4.2

Preventing Versus Enabling the Autonomy of Patients

In Canada, minors are able to make their own healthcare decisions if they demonstrate specific abilities that fulfil the criteria for capacity. People with intellectual, cognitive, or psychosocial disabilities must also meet specific criteria to retain decisional authority. This way of thinking focuses on individual attributes as a barrier to decision-making rights, and generally allows minors who are slightly below the age of majority to make critical healthcare decisions. For example, it may grant a 16 year old authority over their end-of-life choices, but deny a 13 year old. An alternative view is that, while lack of decision-making capacity might require a different approach, it should not be seen as an outright barrier to decision-making rights. Instead, it calls for additional supports and a different method of arriving at a decision. In the context of minors, this alternative view leaves room for a minor to make the decision not in isolation, but in consultation with family members and other trusted adults. The entire situation and the preferences of all involved would be considered to determine whether a particular treatment is an appropriate choice for the minor.

4.5 CONCLUSIONS

In its examination of the complexities surrounding healthcare decisions by minors, this chapter shows that autonomous healthcare decision-making can incorporate the relationships of young patients with their parents/guardians and others who are significant to them. While chronological age can provide some generalizations about the development of decision-making skills, it is not an accurate predictor of minors' capacity to provide informed consent for medical treatment decisions. Neurological and psychological data, combined with qualitative research on children with critical illness, demonstrate that some minors have the cognitive and emotional abilities to make critical healthcare decisions, including end-of-life choices. Thus, over time, criteria for informed consent have shifted away from age towards the experience and understanding of the individual, which must be determined on a case-by-case basis.

The existing ways in which capacity is assessed in adults also apply to minors, as is reflected in practical guidance for healthcare practitioners. However, when life-and-death treatment decisions are in question, the ability of adolescents to provide informed consent may be subject to an added layer of scrutiny in which their maturity is assessed in detail. This may be linked to their social environment and life experience (particularly in a medical setting or in relation to their illness). A comprehensive, case-by-case approach used to assess adult patients for MAID may be appropriate for those under the age of 18, although this remains to be examined in practice. A key question concerns the relationship of MAID to other end-of-life decisions that minors are legally able to make. Despite the conclusion of the trial court in the *Carter* case that MAID is no different from other end-of-life decisions for adults, this remains a highly charged topic.

The relational nature of autonomy is critical in the MAID context, and the fact that patients' perceptions and decisions are tied to their social environment is not a concern that applies exclusively to those under the age of 18. Both adults and minors are relationally embedded — a fact that does not preclude access to MAID by adults. The binary conception of individuals as either capable or dependent has been challenged by the recognition that autonomy can be maximized by providing the needed supports.

5

Current Practices in End-of-Life Care for Mature Minors: Canadian and International Evidence

- **Mortality in Minors in Canada**
- **Pediatric Palliative Care**
- **Intolerable Suffering in Terminally Ill Minors**
- **End-of-Life Decisions by Minors:
Clinical Practice**
- **MAID for Mature Minors:
International Experience**
- **Conclusions**

5 Current Practices in End-of-Life Care for Mature Minors: Canadian and International Evidence

Key Findings

Disease-related deaths among adolescents in Canada are rare relative to adults.

Whether MAID for mature minors is permitted or prohibited, more equitable and timely access to pediatric palliative care is critical.

Knowledge gaps among healthcare practitioners may contribute to delayed referrals for pediatric palliative care patients. The absence of pediatric palliative care teams in rural areas also prevents patient access.

Indigenous children face particular challenges in accessing pediatric palliative care. These challenges are related to issues of jurisdictional ambiguity, resources, geography, and colonialism.

There is no evidence that minors experience physical pain differently than adults, or suffer psychologically to a different degree than adults; however, minors may articulate their suffering differently. Seriously ill minors may additionally experience a unique form of suffering when disease thwarts their development of independence.

Cultural values are important considerations in pediatric end-of-life care and MAID because they can influence healthcare decision-making.

There is a paucity of research capturing the voices of dying minors; however, there is evidence that their end-of-life decisions are relationship-based. Adolescents with serious illness can appreciate the complexities of their conditions, and may wish to make healthcare decisions informed by open communication. They also generally want support from their parents and care team.

Although euthanasia for minors is available in the Netherlands and Belgium, the practice is rarely used.

The legalization of euthanasia for minors in the Netherlands and Belgium has been accompanied by an increase in resources devoted to pediatric palliative care.

In Canada MAID is an option for people over the age of 18 whose deaths have become reasonably foreseeable, who are in an advanced state of irreversible decline, and who are suffering intolerably. To explore the idea of MAID for mature minors, the Working Group examines what conditions they might experience that would meet the eligibility criteria of a reasonably foreseeable death and advanced irreversible decline. That is, what fatal conditions might make mature minors in Canada eligible for MAID? The Working Group considers current practices for the easing of suffering and providing end-of-life care for mature minors, and discusses pediatric palliative care (PPC) in Canada. It also asks in what ways, if any, the nature of suffering might differ for minors and adults.

As discussed in Chapter 4, while minors are capable of healthcare decision-making, an important maturity component, which is tied to experience rather than age, requires case-by-case determination. This chapter considers the context of the clinical realities of decision-making. It then explores international jurisdictions that currently permit euthanasia or assisted suicide for those under the age of 18, considering both MAID laws and PPC practices.

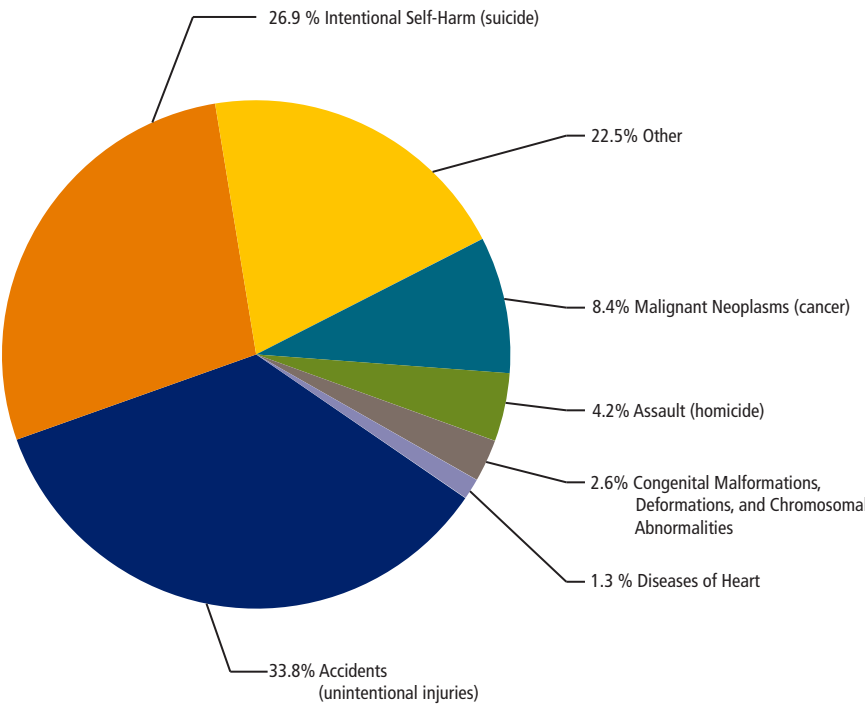
5.1 MORTALITY IN MINORS IN CANADA

Childhood death from disease remains rare in Canada. The majority of deaths of minors aged 15 to 19 years are related to accidents and suicide (StatCan, 2018b) (Figure 5.1).

Childhood cancer is rare, accounting for less than 1% of all new cancer cases. Death from cancer among 15 to 29 year olds is also rare, accounting for less than 0.5% of total cancer deaths in Canada (CCSACCS, 2015). However, cancer was the leading cause of disease-related death for 15 to 19 year olds who died in Canada between 2012 and 2016 (StatCan, 2018b). Cancers of the central nervous system (e.g., glioma), bone and cartilage (e.g., osteosarcoma), and lymphoid and hematopoietic tissues (e.g., leukemia) resulted in the largest number of deaths among the 10 to 14 and 15 to 19 age groups in the same period (StatCan, 2018a).

Figure 5.1 identifies the second-leading cause of death from disease in 15 to 19 year olds as congenital malformations, deformations, and chromosomal abnormalities, and the third-leading cause as diseases of the heart. Many of the diagnoses that make up these categories consist of rare conditions with considerable heterogeneity in the degree of impact on physical, emotional, and social functioning. Thus, some minors with these types of conditions have

significant cognitive deficits that may prevent them from expressing a preference for themselves, regardless of their age, while others are able to partly or fully participate in healthcare decision-making.



Data Source: StatCan, 2018b

Figure 5.1

Leading Causes of Death Among 15 to 19 Year Olds in Canada, 2016

Accidents and suicide are the leading causes of death among adolescents 15 to 19 years old. The leading chronic diseases causing death in this age group include cancer; congenital malformations, deformations, and chromosomal abnormalities; and diseases of the heart. The category “Other” includes all other causes.

5.1.1 How Are Minors Dying in Canada?

Because death among children is rare in Canada, there has been less attention and fewer resources devoted to research on the experiences of, and care provided to, children at end of life (McCallum *et al.*, 2000). However, the few studies that do exist highlight that the majority of deaths of minors in Canada occur in hospital (Widger *et al.*, 2016), with an increasing use of high-intensity interventions, including mechanical ventilation and admittance to intensive care units in the last month of life (Kassam *et al.*, 2016).

Use of these high-intensity interventions sometimes comes with increased suffering and reduced quality of life. Several studies suggest potential room for improvement in the care and symptom management for children with life-threatening illness, particularly as they near the end of life. In one study of 270 children in Canada and the United States with progressive neurologic, metabolic, or chromosomal conditions, 55% were identified by their parents as experiencing pain, and 21% had parent-reported continuous pain. For the patients experiencing pain, 60% of clinicians did not document pain assessments or the administration of medications to treat pain (Friedrichsdorf *et al.*, 2017). A second study, which focused on 50 children in Canada who died from a complex chronic condition (e.g., cancer, heart condition, genetic disorder), found that 32% had no clinically significant symptoms such as pain, fatigue, or nausea documented in their charts during the last month of life, while 14% had one symptom, 20% had two symptoms, and 34% had three or more (Charlebois & Cyr, 2015).

5.2 PEDIATRIC PALLIATIVE CARE

Pediatric palliative care (PPC) is an interprofessional approach to pediatric healthcare that aims to be holistic, addressing physical, psychosocial, and spiritual needs. Because most children are not independent of their parents, PPC often involves family-centred rather than individual decisions. Physical aspects of PPC may include pain and symptom management. Psychologically, the focus may be on coping with the pain and symptoms as well as helping the patient and family manage the complex emotions and existential suffering that accompany life-threatening illness and death, intensified by death occurring early in life. Socially, PPC may help a patient maintain a connection to friends as well as foster relationships with peers experiencing similar health challenges; the team may also help a child maintain a sense of normalcy by encouraging the continuation of daily activities where possible, including participation in school, community, and family life. Finally, PPC may address the spiritual needs of both the patient and family, through age-appropriate conversations

about the meanings of life, death, and legacy, and looking after the needs of the family in bereavement, with a focus on bereaved parents and siblings (Foster *et al.*, 2012a).

Pediatric healthcare practitioners should be familiar with the principles of PPC (AAP Committee on Bioethics and Committee on Hospital Care, 2000). Recent research suggests that care provided through specialized PPC programs is associated with a fivefold decreased risk of the use of high-intensity interventions such as mechanical ventilation, intensive care unit admissions, and death in hospital. PPC provided outside of these specialist teams was no different from receiving no PPC at all (Widger *et al.*, 2018). Other research similarly finds that specialized programs are associated with enhanced quality of life and psychological well-being for the ill child and parents (Remedios *et al.*, 2015; Goldhagen *et al.*, 2016), and reduced pain and other symptoms for the ill child (Charlebois & Cyr, 2015; Osenga *et al.*, 2016).

As of 2012, Canada had 13 PPC programs, located either in hospitals or free-standing hospices offering specialized PPC, compared with 8 programs in 2002 (Widger *et al.*, 2016). While age restrictions vary, most PPC programs accept minors up to 18 years of age although many see patients well into their 20s, especially if there are severe developmental disabilities, or if other circumstances (including imminent death) make a transfer to adult care outside of the patient's best interest (Widger *et al.*, 2016). Conditions leading to referrals for PPC mirror the common causes of death from illness in childhood and include diseases of the nervous system, cancer, and congenital illnesses. Despite the greater availability of programs, patient access remains a significant issue, with only 18.6% of children who might have benefitted from PPC receiving it before death. Furthermore, many children who receive PPC only do so late in their disease trajectory. Of the 431 children who died in 2012 while receiving PPC, 51.3% received it for fewer than 30 days, while 25.5% received it for less than one week (Widger *et al.*, 2016).

Delaying PPC carries a number of risks that have an impact on both the patient and their family:

1. losing the opportunity to promote palliative care principles to the patient and family;
2. being less able to tailor palliative care to the evolving needs of the patient;
3. crisis-oriented management, which exacerbates the sense of vulnerability and helplessness;

4. absence of a framework for preventative, proactive interventions or decision-making; and
5. difficulty in supporting the family's strengths and capacity to cope and in the maximizing quality of the remaining time.

(Hilden *et al.*, 2001)

In Canada, many children are not referred at all, or are referred too late in their illness for specialized PPC teams to offer the full range of services available to patients and families struggling through the process of illness, pain, dying, and bereavement (Widger *et al.*, 2016).

5.2.1 Reconciling MAID and PPC

Many healthcare practitioners have emphasized that it is unethical to provide access to MAID without first ensuring full access to quality palliative care (CPS, 2017). In a 2017 survey of 398 CSPCP members, 119 responded to a question about potential safeguards for mature minors: 89% of respondents agreed with the statement that “robust local palliative care services must be available” as a necessary safeguard before granting MAID to mature minors (CSPCP, 2018). This same survey noted that, so far, the palliative care community has perceived both negative and positive consequences of existing MAID legislation. For example, 17% of 205 respondents replying to a question about the impact of MAID on palliative care access or delivery recognized that MAID had some positive impacts, including more open lines of communication between healthcare practitioners and their patients on appropriate palliative care options. However, 35% of these respondents believed that MAID had some negative impacts on their profession, including taking essential time and resources from the provision of palliative care, and leading to the refusal of some patients to accept pain management out of fear that they may later not be lucid enough to request and/or consent to MAID when the appropriate time arose (CSPCP, 2018).

Many healthcare practitioners believe that, if full access to quality palliative care were provided, it would mitigate the need for MAID (Giglio & Spagnolo, 2014; Cuman & Gastmans, 2017; IRIS, 2017). They argue that good quality palliative care can ease both the physical and mental suffering that lead to requests for MAID and that it is the duty of the physician to “eliminate pain and suffering, not the person with pain and suffering” (Sprung *et al.*, 2018). However, others disagree, noting that in some cases palliative care will never be enough to ease either the physical or mental suffering of a patient, or may simply not be an option that the patient is willing to consider in place of MAID. For example, some adult patients in tertiary palliative care units and hospices in Canada

choose to request MAID despite receiving excellent palliative care (Jayaraman, 2017). Some supporters of MAID also question why mature minors would be forced to wait for “perfect” palliative care to access MAID, when MAID is already permitted for adults in the absence of universally available palliative care.

Many in the palliative care community believe that the presentation of MAID and palliative care as either/or options sets up a false dichotomy. They argue that both can exist and be improved in coordination with each other. Dr. Jeff Myers, Head of the Division of Palliative Care at the University of Toronto’s Department of Family and Community Medicine, notes that “MAID is only a choice if there’s another option” (Morris, 2018). There is indeed room to further develop common ground and promote access to quality palliative care alongside development of MAID legislation. For example, Quebec’s *Act Respecting End-of-Life Care* establishes a regulatory framework for MAID along with patients’ rights to other end-of-life care, including palliative care (Section 2.1.3) (Gov. of QC, 2014). Provision of access to MAID would not obviate the need to continue to pursue full access to quality palliative care.

5.2.2 Identified Barriers to PPC

While quality PPC exists in Canada, access remains an issue for a variety of reasons including inadequate training and a lack of experience among pediatric healthcare practitioners, concerns among parents and guardians who may not understand the full range of benefits offered by PPC, and barriers to care relating to geography.

Knowledge Gaps and Late Referrals

Some knowledge gaps exist among healthcare practitioners, such as equating palliative care with end-of-life care, or lack of professional experience in caring for children with life-threatening conditions (Davies *et al.*, 2008). Childhood death remains rare, and therefore some healthcare practitioners may not recognize when to refer pediatric patients or be aware of the benefits of early referral. Referrals may also be delayed to avoid the perception of failure. Children have overall better rates of survival than adults when faced with cancer. High hopes related to cure and survival may cause parents and healthcare practitioners to only reluctantly turn to palliative care, even though its purpose extends well beyond easing the suffering of the dying (Hilden *et al.*, 2001).

At times, late referrals to palliative care may also come at the behest of parents. Early in a diagnosis and throughout the course of illness, parents often come to know and rely on the primary care team of physicians and nurses. Along with the continuity of care, parents may appreciate the trusting relationship that has developed among them, their child, and the entire healthcare team,

and may fear the introduction of new teams. Parents may fear this change or erroneously equate agreeing to palliative care as giving up on their child (Hilden *et al.*, 2001). This perception of PPC as a last resort misrepresents the role and benefits of palliative care.

Geography

Geography is also a barrier that prevents children with life-threatening conditions in Canada from receiving specialized PPC. Most programs are located in urban centres at tertiary pediatric hospitals. With a dearth of facilities or even healthcare practitioners in their own communities, patients may be forced to transfer to urban centres, drawn away from their families and other support systems to receive the necessary support and treatment of pain or other symptoms. Transfers mean that a patient is excluded from taking part in community life, including attending school, maintaining friendships, and participating in cultural ceremonies. Transfers affect not only the patient but also family members, especially parents and siblings who may experience long-term separations.

There is an ongoing need to ensure access to comprehensive PPC so that patients across Canada may access a similar quality of specialized care (Davies & Shariff, 2016; Widger *et al.*, 2016). Existing specialized PPC programs serve the same wide geographical area as their associated tertiary centres, through telehealth, home visits, and phone calls that support local healthcare practitioners, enabling families to remain at or closer to home (Rapoport *et al.*, 2017). However, healthcare practitioners must be willing and available to provide care locally, and specialized PPC teams need adequate staffing to provide high-quality support at a distance. While PPC teams may be ready and willing to provide support, they are unable to do so if they do not receive referrals or receive very late referrals. A recent study on children who died from cancer in Ontario suggests that living in low-income neighbourhoods or further from tertiary pediatric centres reduces patient access to PPC (Widger *et al.*, 2018). The authors argue that “[t]hese findings are concerning for possible referral bias. These groups may also be less aware of available services or less able to advocate for their needs, despite possibly having a greater need for support and services” (Widger *et al.*, 2018).

5.2.3 Identified Barriers to PPC for Indigenous Children

Many Indigenous people, including children, struggle with equitable access to healthcare and other social services. Two of the principal factors that create barriers are jurisdictional ambiguity over the provision of services and geography, particularly for those living on reserves and/or in remote locations.

Jurisdictional Ambiguity and Jordan's Principle

Health discrimination is a part of life in many Indigenous communities. On average, the services received by Indigenous people, and their overall health outcomes, rank far below those of the average Canadian (NCCAH, 2013). These inequities are rooted in racism, colonialism, and continuing government policies that discriminate against Indigenous people (Loppie *et al.*, 2014) (Section 2.3.2). The result of these historical and present-day policies is a complex interplay between the federal and provincial and territorial levels of government in the delivery of health services to Indigenous people, one that has frequently resulted in jurisdictional ambiguity over the financial responsibility for the provision of healthcare (Moffatt & Cook, 2005; NCCAH, 2011). This ambiguity has resulted in disputes leading to delayed access to necessary healthcare for First Nations and Inuit children, typically until issues of payment could be resolved, resulting in a system in which “the needs of the governments were prioritized over considerations for the child’s safety or well-being” (Blackstock, 2009).

In 2007, Jordan’s Principle was legally mandated in an effort to solve the problem of jurisdictional ambiguity in cases of delivery of health and social services to First Nations and Inuit children. Jordan’s Principle was named for Jordan River Anderson, a Norway House Cree Nation child born with complex medical needs. Jordan’s condition required a long-term hospital stay, and he was only cleared by his medical team to return to his home community and family at the age of two. This return, however, would require Jordan to receive healthcare, which caused a long-term dispute between the governments of Manitoba and Canada over who would pay for his care — care that would have been delivered to a non-Indigenous child. While both governments continued to dispute responsibility for Jordan’s care, he remained in hospital waiting for a resolution. Jordan died in hospital on his fifth birthday, having never lived in Norway House (Blackstock, 2009).

While there have been other cases like Jordan’s among Indigenous children, his case captured the national spotlight (FNCFCSC, 2005). Jordan’s Principle resolves that the interest of the child must come before any payment dispute between the federal and a provincial or territorial government. When a payment dispute arises over any service to a First Nations or Inuit child — one that is normally provided to any other child — the government of first contact must pay the bill and any jurisdictional disputes must be resolved later (Blackstock, 2009).

However, there has been a failure to fully implement the provisions of Jordan's Principle across Canada. In 2016, the Canadian Human Rights Tribunal found the Government of Canada continued to discriminate against First Nations and Inuit children and their families, and it ordered Indigenous and Northern Affairs Canada to take measures to immediately implement the full meaning and scope of Jordan's Principle (CHRT, 2016).

Healthcare on Reserves and/or in Remote Locations

Geography remains a significant barrier in accessing PPC especially for those in remote, non-urban settings. The location of most PPC units in urban centres can be an especially formidable challenge in the case of Indigenous children. Reserves and remote communities, including Northern fly-in communities, face enormous physical and financial hurdles in accessing care. Conditions of poverty on reserves, including lack of electricity, clean water, and affordable and healthy food, mean that Indigenous children do not have even the most basic necessities for health, let alone the conditions needed for specialized medical care (Bourassa & Bendig, 2015; Caxaj *et al.*, 2018). Reserves and remote communities also lack staff to provide PPC. In many cases, communities are served solely by nurses and nurse practitioners who are often subject to high rates of turnover, may be working beyond the scope of their practice, or may not be licensed to provide certain specialized services (Goraya, 2016). Therefore, a scarcity of equipment, staff, financial resources, and basic utility services all preclude the provision of palliative care to Indigenous children.

Due to these barriers, transfer for care among Indigenous adults and children remains common. In these cases, patients are removed from home communities to receive long-term care in more urban settings. However, Bourassa and Bendig (2015) warn that "[t]he stress and holistic impacts associated with relocation need to be taken seriously, and relocation should be questioned as a valid option in order to ensure that the benefits and harms are balanced." In some cases, both rare and ideal, cooperation between healthcare facilities and Indigenous providers is achieved in a way that allows patients to stay in their home communities, but these examples also speak to the lack of resources in remote communities. A poignant case report by Darlene Grantham (2010), a clinical nurse specialist, is discussed in Box 5.1.

Box 5.1**The Case of Gentle Waters**

Samantha Serene Rose Stevenson, Gentle Waters, a child from the Peguis Reserve in Manitoba, was diagnosed with leukemia at seven years old. The Peguis Reserve lies 100 kilometres north of Winnipeg. Because of the reserve's location and her condition, Samantha spent much of her time over the next three years in Winnipeg receiving chemotherapy, radiation, and — finally, when those failed — a bone marrow transplant. The transplant was followed by months of isolation to protect her immune system, as well as a number of painful side effects and extreme fatigue. In the absence of friends who were far away, Samantha asked her nurse to be her best friend. Despite all efforts, Samantha's leukemia returned. She was offered the choice to undergo another transplant, and her parents entrusted her with the decision. Samantha decided to forego treatment and asked if she could return home to spend her remaining time with her family, friends, and dog. At the time, palliative care was not provided at Peguis Reserve, and no physicians near the reserve were trained to deal with Samantha's issues. In spite of the obstacles, the Winnipeg transplant team offered to support the health team on the reserve by phone, and promised to visit if needed. Through this cooperative effort, Samantha was allowed to spend her final days in the way she most wished. She died surrounded by her family at 10 years of age (Grantham, 2010).

The purpose of MAID is to end intolerable suffering in people who are declining and whose death is reasonably foreseeable. Similarly, the goal of palliative care is to anticipate and relieve suffering in the face of a life-threatening condition. Unfortunately, provision of even the highest-quality palliative care through a specialized team long before death may not erase all suffering experienced by a minor. However, if MAID for mature minors were to be permitted, it is critical that minors are not left feeling that MAID is their only option, when living in a different location or receiving an early referral to a specialized PPC team could reduce suffering to a more tolerable level and ensure effective support is provided to the entire family.

5.3 INTOLERABLE SUFFERING IN TERMINALLY ILL MINORS

As well as meeting the current minimum age of 18, accessing MAID in Canada requires someone to have a “grievous and irremediable medical condition” (GC, 2016). The prospective patient must experience intolerable physical or mental suffering because of the illness, disease, or disability (GC, 2016). Suffering, however, is defined by many as a subjective phenomenon that can only be

characterized as intolerable by the person experiencing it. In the opinion of noted physician Cassell (1991), who wrote extensively on the subject, suffering is “the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person.” Suffering “involves some symptom or process that threatens the patient because of fear, the meaning of the symptom, and concerns about the future. The meanings and the fear are personal and individual, so that even if two patients have the same symptoms, their suffering would be different” (Cassell, 1999). While physical pain is not necessarily interchangeable with suffering, its presence, and the failure to relieve pain, can contribute to one’s suffering (Strang *et al.*, 2004).

Any determination around the eligibility of mature minors to receive MAID would need to take into consideration whether the nature of suffering among minors is unique, and whether minors experience physical and psychological suffering in ways that differ from adults.

5.3.1 Physical and Psychological Suffering and Chronological Age

Aside from newborns, whose pain-modulating systems have not fully matured and may thus experience pain more intensely, there is no evidence to suggest that children experience physical pain differently than adults (Hatfield, 2014). Recent research suggests that hospitalized pediatric patients may often be undertreated for pain (Birnie *et al.*, 2014). Common physical symptoms among children with advanced diseases nearing end of life include difficulty breathing, nausea and vomiting, itching, fatigue, difficulty sleeping, and general weakness (Michelson & Steinhorn, 2007). Research has highlighted the high symptom burden in children with advanced cancer where, over a period of nine months, 104 children or their parents completed 920 symptom surveys, in which 48% indicated moderate to severe distress from pain and 37% had significant irritability (Wolfe *et al.*, 2015).

Psychologically, many of the symptoms experienced by adults at end of life are also experienced by adolescents. These symptoms can include “depression, sadness, anxiety, nervousness, worry, guilt, loneliness, and fear” (Foster *et al.*, 2012a). Among adults wishing to access MAID, many cite loss of dignity, loss of self-determination, and fear of becoming a physical, financial, or emotional burden to their family as the primary reason for requesting assistance in dying (Ganzini *et al.*, 2007). Straddling the line between childhood and adulthood, adolescents may exhibit some of these same existential fears. While most adolescents may not have full autonomy, including total control over decision-making or financial independence, they may have nevertheless experienced enough autonomy to be aware of its loss. Severely ill adolescents may find their development and their emergence into adulthood thwarted by disease, and that

is a unique experience among this age group. Just as they find themselves taking on more responsibilities, making more decisions, and relying increasingly on their peer groups in forming identity, severely ill adolescents may experience increased reliance on their parents for their care. According to Hilden *et al.* (2001):

The unique psychosocial issues for dying adolescents — which relate to the normal developmental tasks of this time of life — include greater focus on physical appearance, reversal of developing independence, lack of control, loss of self-confidence, social isolation, disruption of future plans, and desire to be listened to by their care providers.

Even within the subset of adolescents, these experiences can be further broken down. Flavelle (2011) notes:

In early adolescence (10–14 years), illness most significantly affects the development of self-image and peer relations. In middle adolescence (15–17 years), illness often leads to a compromised sense of autonomy and interferes with attraction of a partner. Towards the end of adolescence (≥ 18 years), illness may disrupt career aspirations and affect family planning.

Understanding of suffering and death is directly related to individual experience. For example, a minor who has cancer, spent a substantial amount of time in hospital for treatment, and formed relationships with other pediatric patients, some of whom may have died, will likely exhibit an understanding of death far beyond that of a healthy person of the same age (Bluebond-Langner, 1978; Curtin, 2001).

5.3.2 Expressions of Suffering by Minors

The ways in which minors articulate or express their suffering may differ widely by age. Adolescents may become withdrawn from their families, but choose to express their fears to a confidante in their peer group or healthcare team. Children tend to hold out hope throughout much of their illness, often until shortly before death. Children of all ages may express concerns over time, such as a lack of interest in planning for the future or a hurry to get things done as quickly as possible so as not to waste remaining time (Bluebond-Langner, 1978). The healthcare team must be open to providing opportunities for children and adolescents to express their suffering in various ways and to provide developmentally appropriate emotional support. However, knowledge

gaps exist in understanding the spectrum of emotions that children with life-threatening conditions may experience and their coping mechanisms during the course of their illness (Foster *et al.*, 2012a).

In addition to dealing with the ramifications of their own illness, pediatric patients often show concern for the needs of their family, in particular their parents and siblings. Pediatric patients seek to shield their parents from pain, just as parents seek to do so for their child. Terminally ill minors may practice *mutual pretence* — an unspoken arrangement where they avoid talking about their condition with loved ones, and sometimes their healthcare team, in an effort to keep them nearby and maintain the established order, wherein doctors heal and parents protect (Bluebond-Langner, 1978).

While research on the emotional lives of minors facing end of life is limited, what is consistent in the research on PPC is the need to include minors in discussions about their disease, treatment options, and end-of-life care. Providing age-appropriate information and context is key, as is allowing minors to be active participants and decision-makers in their care when they choose to be. Adults should also allow children to express their fears and frustrations, and support them in the “grief work” of dying (Bartholome, 1993). Like adults, children seek honesty and openness, and may raise questions on life’s meaning, personal legacies, and existence of an afterlife. These questions should be answered openly and as they arise (Bluebond-Langner, 1978).

5.4 END-OF-LIFE DECISIONS BY MINORS: CLINICAL PRACTICE

The binary view of minors as either incapable and requiring protection or as agents capable of acting on their own is not always realistic with respect to clinical experience (Carnevale *et al.*, 2015). In practice, the unique circumstances of each situation, and the characteristics and experience of each patient, are considered in a patient- and family-centred approach to care (Newman *et al.*, 2014).

There is a lack of information on the clinical realities of adolescents in end-of-life contexts. Hinds *et al.* (2005b) acknowledge the need for more research on dying pediatric patients and their families, regarding both clinical practice and the ways in which critically ill young people make end-of-life decisions. Published studies rarely capture the voices of pediatric patients at end of life. Instead, they tend to rely upon retrospective medical record reviews and reports, or

perspectives from care teams or parents (Hinds *et al.*, 2007). Berger (2012) notes that current studies focus on how parents make end-of-life decisions for their children, rather than how capable adolescents make decisions for themselves.

5.4.1 The Role of Culture in Healthcare Decision-Making for Minors

In her landmark study, *The Private Worlds of Dying Children*, Bluebond-Langner (1978) states: “The death of a child poignantly underlines the impact of social and cultural factors on the way that we die and the way that we permit others to die.” She explains that death is not simply a biological process, but an experience that has strong social and cultural dimensions as well. The death of children, often rare and jarring, engages social relationships (Bluebond-Langner, 1978). Cultural values are also important considerations in pediatric end-of-life care and MAID because they can influence healthcare decision-making. Culture can be difficult to define. It can include one’s religion, language, ethnicity, and race, and can also be viewed more broadly as “shared patterns of learned values, beliefs, and experiences of a group that provide a sense of identity and guide individuals, often unconsciously, in their thoughts, actions and decision-making” (Srivastava, 2014).

Although current Canadian healthcare approaches place a high premium on respect for autonomy (Nicholas *et al.*, 2014), and Canadian health law and policy grant many rights to minors with capacity (Gilmour, 2017), prioritizing autonomy may, at times, conflict with the personal values of some patients and their families. For example, some cultures may view the focus on autonomy to be isolating to the patient. This is true of cultures where entire families, or even communities, often participate in decision-making (Gilbar & Miola, 2014). For some cultural groups, preventing harm may be considered the most important principle, and therefore directly addressing death or terminal illness might be avoided to protect the emotional state of the patient (Searight & Gafford, 2005).

How Death Is Discussed

In some cultures, the sharing of a poor medical prognosis or “bad news” can be seen as inappropriate, or even burdensome and unkind to a terminally ill patient (Kwak & Haley, 2005; Searight & Gafford, 2005). Cultural issues surrounding disclosure can prove even more challenging or complex within the pediatric context where parents, guardians, and extended families are intimately involved in caregiving for the patient, and may have differing views on what is in the best interest of the patient. Parents, regardless of cultural background, may seek to control the flow of information from healthcare practitioners in an effort to protect their children, or because of their own inability to discuss death with their child (Srivastava, 2014).

While the inclination of some parents may be to avoid any discussion of death, research shows that these discussions can at times be beneficial for both the child and their parents. A 2004 study of parents who had a child die of cancer found that of 429 parents, 147 (34%) spoke to their child about death, and none regretted doing so. Almost one-third of the parents who had avoided any discussion of death reported that they regretted the decision. Feelings of regret were most likely among parents who sensed that their child was aware of their imminent death, and parents of older children (Kreichbergs *et al.*, 2004).

To address the diverse range of beliefs among patients in Canada, healthcare practitioners must be sensitive in how they deal with patients. Practitioners must make an effort to understand the culture and values of their patients and families while also keeping in mind their professional responsibilities. As Srivastava (2014) suggests, healthcare practitioners may allow families to disclose information in a way they see fit, but also discuss with them how a patient might benefit from knowing all they can about their illness. They must also make clear that, if asked direct questions by a patient, they will answer them truthfully (Srivastava, 2014). Although parental/family involvement is potentially a culturally and emotionally sensitive subject, minors have a right to their health information and, in certain circumstances, mature minors may even be allowed under Canadian health information laws to keep this information confidential. In other words, not only would their parents be uninvolved in their healthcare decision, they would be unaware that any health intervention had occurred (Jackson *et al.*, 2014). However, this would be unlikely in the case of a terminal illness, and more common in situations, for instance, where mature minors may wish to keep their sexual health and activity private.

Attitudes Towards the Medical Community

Cultural experience and/or history can play a role in personal attitudes towards the medical community in general. In Canada, some Indigenous patients may not trust the medical community due to systemic racism and past traumas (TRC, 2015). Within the pediatric context, this can be especially true of Indigenous families who have experienced the residential school system, as well as the *Sixties Scoop* (Kelečević, 2014). In both cases, Indigenous children were taken from their families and placed in institutional settings where abuse and neglect were pervasive, and the government argued that its decisions were made in consideration of the “best interest” of the child (TRC, 2015).

The trauma of this recent history remains and can potentially influence Indigenous views of best interest and authority, including entrusting the care of terminally ill children to hospitals and healthcare workers. For example,

in the case of J.J., an 11-year-old Mohawk girl who was diagnosed with acute lymphoblastic leukemia, her mother, identified as D.H., decided 11 days into J.J.'s chemotherapy to halt the treatment in favour of traditional healing practices. J.J.'s oncologist found that she "lack[ed] the maturity even of typical children her age and did not have the capacity to understand the details of her complex therapy" (ONCJ, 2014). Thus, she was deemed incapable of making informed decisions and her mother was named her SDM. Physicians caring for J.J. had asserted that her treatment, if completed, could have a 90 to 95% chance of curing her cancer. The Hamilton Health Sciences Corporation challenged Brant Family and Children's Services' decision to not intervene on the basis that it was not in J.J.'s best interest. However, the judge ruled that J.J. was not in need of protection and that her mother was practising her Indigenous right in pursuing a course of traditional medicine (ONCJ, 2014). At the time of the verdict, both J.J. and D.H. had left the jurisdiction, possibly indicating not only D.H.'s mistrust of the medical system, but also a distrust of the judicial system to respect her decision, or rule in favour of her daughter's best interest. When J.J.'s cancer later returned, D.H. agreed to pursue chemotherapy in addition to traditional Indigenous healing practices. All parties were in agreement that this course of action was in J.J.'s best interest (MacIntosh, 2017).

5.4.2 End-of-Life Care and Decisions Are Inherently Relationship-Based

In an exploration of the decision-making process in which adult patients request euthanasia in the Netherlands, Dees *et al.* (2013) conclude that a "patient's request for euthanasia entails a complex process that demands emotional work by all participants. It is characterised by an intensive period of sharing information, relationship building and negotiation in order to reach agreement." The authors argue that the needs and values of all participants (patients, families, and care providers) should be acknowledged in a framework of shared decision-making, and that open communication about end-of-life decisions should be initiated early in the palliative care trajectory (Dees *et al.*, 2013). Notably, a consultation of Canadian healthcare practitioners revealed that, in their experiences with end-of-life care, a relational, family-centred approach was needed regardless of the patient's age, "where the dying person was not the only person towards whom care was provided, nor were their wishes the only ones taken into consideration" (Cartagena *et al.*, 2016). Thus, many of the issues relevant to end-of-life care and requests for MAID by mature minors are not unique to this age group.

Hinds *et al.* (2005a) interviewed 20 patients between the ages of 10 and 20 who had recently participated in one of three end-of-life decisions: (i) whether to forego life-sustaining treatment in favour of symptom management only,

(ii) whether to enroll in a Phase I trial, or (iii) how to deal with their level of resuscitation intervention. In addition to demonstrating an understanding and appreciation of complex medical decisions and the inevitability of dying, the patients almost universally reported that their choices were relationship-based. When contemplating decisions, participants thought about their relationships with others, including family, hospital staff, and even future, unknown patients who might benefit from Phase I trial results. This altruism may reflect the maturing effect of a life-ending illness, and may be valued by critically ill adolescents and their parents as a way to seek something good in an otherwise profoundly tragic situation (Hinds *et al.*, 2005a; Solomon & Browning, 2005).

A relational approach is critical when considering the burden of end-of-life choices. While mature minors have decision-making authority, they are not operating in total isolation. Many studies have shown that, in coming to a decision, adolescents desire the support of their parents and care team. In a study of 40 adolescent cancer patients between 12 and 18 years, 65% preferred active roles in their medical treatment decisions. Yet, most participants indicated that parent and clinician support was needed and appreciated, and recognized that situational factors, such as the gravity of the decision, would influence the supports required (Weaver *et al.*, 2015). In a systematic narrative review of decision-making in adolescents with cancer, Day *et al.* (2016) found that adolescents welcomed parental involvement. These studies suggest that adolescents facing serious illness can appreciate the complexity of healthcare decision-making and, even if making the final choice independently, may prefer the help of others as they deliberate.

5.4.3 Relationship-Based Approaches to End-of-Life Decisions Must Not Overshadow Patient Needs

The Canadian Paediatric Society's position statement on advance care planning (ACP) for pediatric patients notes that, if the goals of the patient and family members do not align, a family-centred approach may pose difficulties. For healthcare practitioners, the challenge is to consider the pediatric patient both in isolation and as part of a family unit (Tsai, 2008). Referring to end-of-life decision-making in its position statement on treatment decisions, the Canadian Paediatric Society states:

Although the impact on the family — such as the burdens and harms they might experience — must be considered in end-of-life decision-making, these interests should not be allowed to override those of the child or adolescent. It is essential that the decision to use life-sustaining treatment be guided by the best interests of the patient.

(Harrison, 2004)

In most terminal illness contexts, the minor makes a decision in agreement with their parents and care team. In scenarios where a level of resuscitation status or withholding/withdrawing treatment are in question, all parties tend to pursue the same care objectives: to improve the time remaining with good symptom control, and to achieve a quality of death (Valdez-Martinez *et al.*, 2014).

5.4.4 Communication and Trust Are Critical During End-of-Life Care for Minors

A systematic review by Valdez-Martinez *et al.* (2014) of research addressing the decision-making process when children's cancer treatment is no longer curative identified six overarching themes relevant to clinical practice:

- the flow of information to inform decision-making;
- disclosure of prognosis;
- the process by which doctor-child/parent relationships were developed;
- biomedical aspects and child/family preferences;
- alternatives of treatment, preferences, and objectives and goals of their preferences; and
- barriers and facilitators to decision-making.

Within these themes, communication and trust were considered paramount. Parents and children wanted their clinical care team to be invested, listen well, be open to discussion, provide clear explanations, and provide thoughtful care. Even when the prognosis was poor, young people did not want information to be softened (Valdez-Martinez *et al.*, 2014).

Communication can have a profound impact on the way in which minors' capacity to give informed consent is fostered or hindered (Mårtensson & Fägerskiöld, 2008). Freyer *et al.* (2006) describe communication as a bidirectional process, which includes medical information that is accurately conveyed by care providers, and an opportunity for the adolescent patient to share thoughts, feelings, and preferences.

In a study on end-of-life decision-making for adolescent oncology patients, information exchange was rated as the most important factor. Adolescents and parents wanted honest information about disease status and likelihood of survival, and stressed the value of ongoing communication about patient and parent decision-making preferences, as well as accessibility of the healthcare team to discuss both previous and upcoming decisions (Hinds *et al.*, 2001). In a study of 17 young people (aged 14 to 21) with cancer, the majority (75%) believed it was appropriate to discuss end-of-life preferences well before death was imminent, either when healthy or at various points in their disease process (Jacobs *et al.*, 2015). Studies show that ACP documents such as *Five Wishes*®

or *Voicing My Choices*TM, which were adapted or created to aid children and adolescents in expressing their wishes for end-of-life care, may help initiate such conversations and help adolescents communicate their preferences (Wiener *et al.*, 2008; Wiener *et al.*, 2012). Thus, adolescents favour direct information and open communication in relation to end-of-life decisions. Furthermore, when communication related to palliative care and end-of-life issues is encouraged, the congruence between patients and their families is increased (Lyon *et al.*, 2009).

5.4.5 Requests for MAID by Adults Aged 18 to 25 in Canada

Between January 1 and December 31, 2017, there were 34 cases of MAID among people aged 18 to 45 (GC, 2018).⁴ Since the number of requests for MAID is not well documented across the country, it is unclear how many patients in the youngest age group (18 to 25) may have requested but were rejected, or requested but did not receive MAID. As of June 2017, the Working Group was aware of two 18-year-old cancer patients in Manitoba who requested MAID, but one patient declined to proceed while the second patient received approval but died before MAID could be arranged (K.Widger, personal communication, 2017).

5.4.6 The Number of MAID Requests by Mature Minors Is Likely to Be Small

In May 2016, a month prior to the passage of Bill C-14, a survey of pediatricians and pediatric subspecialists conducted through the Canadian Paediatric Surveillance Program (CPSP) asked how often respondents engaged in exploratory conversations or received explicit requests for MAID by minors or their parents over the past year. The survey had a 40% response rate (1,050 out of 2,597), and 35% of respondents stated that they provide end-of-life or palliative care. Some respondents did not comply with the request to answer based on experiences only over the past year, and instead reported the cumulative incidence over their careers. Respondents reported exploratory discussions about MAID with 60 pediatric patients, and explicit requests for MAID by 17 pediatric patients. In these cases, the majority of patients were between 14 and 18 years old. In addition, parent-initiated exploratory discussions or explicit requests for MAID were reported for 419 and 91 patients, respectively. In these cases, the patients involved were more commonly newborns, infants, or children aged 1 to 13 (CPSP, 2016).

4 The Third Interim Report on Medical Assistance in Dying does not include data from the territories (Yukon, Northwest Territories, and Nunavut), due to small numbers and associated privacy concerns. Data specifying the age ranges of persons receiving MAID also exclude Quebec. Where available, data from Quebec used throughout the report are from either Quebec's Commission of End-of-Life Care or compiled from individual health and social service institutions in the province and from the Collège des médecins du Québec and not from official records of the provincial government. Therefore, official data for specific age ranges in Quebec were not available.

Notably, according to these CPSP findings, parental requests for MAID for their children outnumber requests by minors themselves by five to one. Similarly, pediatricians and pediatric specialists in the Netherlands report that requests for MAID are much more common from parents, even when considering ages where minors are old enough to ask for themselves (Vrakking *et al.*, 2005; Bolt *et al.*, 2017). Thus, in Canada, the number of MAID inquiries or requests from minors themselves is likely to be small, but by no means trivial. Indeed, the CPS notes that, “[g]iven the evolving legislative landscape, it is reasonable to anticipate that such questions will increase in the near future” (CPS, 2017). Some argue that the small number of young people who might access MAID is not the issue; rather, the ability to help even one person, or the peace of mind that comes from having MAID as an option, provides sufficient rationale to make its implementation worth the effort (Guichon *et al.*, 2017).

5.5 MAID FOR MATURE MINORS: INTERNATIONAL EXPERIENCE

The Netherlands and Belgium are currently the only two jurisdictions where euthanasia and assisted suicide (EAS) is permitted for minors. In both countries, safeguards have been implemented to strike a balance between protecting a group often perceived as vulnerable, and recognizing that their desire to pursue euthanasia may be similar to that of adults should their suffering become intolerable.

5.5.1 Including Minors in MAID Laws in the Netherlands and Belgium The Netherlands

Euthanasia was codified in Dutch legislation in 2002 with the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (Gov. of the Netherlands, 2002). The Act formally codified the practice that had been taking place in the Netherlands for decades. The practice of euthanasia developed through professional guidelines and judicial decisions (RTE, 2015). The Royal Dutch Medical Association (KNMG) appointed a commission in 1985 to study a number of special issues related to euthanasia, including the cases of minors and newborns (Box 5.2). The final decision to include mature minors in the Dutch legislation was made in 2002 (Lewy, 2011). The legislation related to mature minors, including the categorization of ages and the need for parental consent, followed pre-existing Dutch legislation related to age, medical treatments, and decision-making, as set out in the Dutch Civil Code (Janssen, 2002).

While the Act allows euthanasia for patients who are 12 years of age or older, additional requirements must be met in the cases of minors. First, a minor must be “deemed to be capable of making a reasonable appraisal of his own

interests” (RTE, 2015). Patients between the ages of 12 and 16 must have the consent of their parents or guardians to access euthanasia. Those aged 16 to 18 must consult with parents or guardians during the decision-making process; however, parents and guardians do not have the right to veto the decision in cases where the patient and their doctors deem euthanasia appropriate (RTE, 2015).

Between 2002 and 2017, the Regional Review Committees (RTE) reported 55,872 notifications of euthanasia, of which 11 involved minors. As of August 2018, two additional cases were reported, bringing the total to 13: 11 aged 16 to 18, 1 aged 14, and 1 aged 12 (RTE, 2018a). In all documented cases, the patients’ families were involved in the process and accepted the patients’ decisions (RTE, 2018a). Table 5.1 lists the medical conditions that precipitated these cases.

Table 5.1
Reported Dutch Cases of Euthanasia for Minors

| Year | Age at Death (Years) | Condition |
|------|----------------------|----------------------|
| 2003 | 17 | Leukemia |
| 2004 | 17 | Astrocytoma |
| 2005 | 12 | Rhabdomyosarcoma |
| 2008 | 17 | Rhabdomyosarcoma |
| 2008 | 17 | Leukemia |
| 2015 | 16 | Leukemia |
| 2015 | 17 | Glioma |
| 2016 | 17 | Metastatic melanoma |
| 2017 | 16–18 | Ewing’s sarcoma |
| 2017 | 14 | Epithelioid sarcoma |
| 2017 | 16 | Renal cell carcinoma |
| 2018 | 16–18 | Rare form of cancer |
| 2018 | 16–18 | Leiomyosarcoma |

All Dutch cases of euthanasia for minors reported to the RTE between 2002 and August 2018 are listed above. Thus far, every minor patient reported to have undergone euthanasia in the Netherlands was suffering intolerably from terminal cancer. Statements and explanations about cases involving minors are documented online by the RTE (RTE, 2018a). For select cases, additional details regarding the exact age and type of cancer were obtained from personal correspondence with the RTE.

Box 5.2**The Groningen Protocol**

Although it has not been written into law, the Groningen Protocol deals specifically with euthanasia in the context of severely ill newborns with a prognosis determined to be hopeless. Authorized as a national guideline by the Dutch Association for Paediatric Care in 2005, the protocol states that both parents and the medical team must be in full agreement to proceed with euthanasia in these cases (Verhagen & Sauer, 2005; IEB, 2014). Since the implementation of the Groningen Protocol, cases of physician-assisted deaths among infants under the age of one have decreased, likely related to both the introduction of legal criteria governing the practice, as well as earlier and improved pre-natal screenings (ten Cate *et al.*, 2015).

Belgium

Euthanasia was legalized in Belgium in 2002 with *The Belgian Act on Euthanasia of May 28th 2002* (Gov. of Belgium, 2002), and in 2014 the law was amended to include all minors with capacity to judge, regardless of chronological age (Gov. of Belgium, 2014). Capacity to judge refers to having the “full ability to judge the situation and the full weight of the request for and consequences of euthanasia” (Van Gool & De LaPeliere, 2017). Belgian legislators (based on evidence provided by specialists in pediatric medicine) determined that age alone was not enough to assess capacity and that restricting euthanasia based on age would unfairly infringe upon the rights of minors who are fully capable of understanding the decision-making process surrounding euthanasia and the consequences of the decision (Van Assche *et al.*, 2018). Belgian minors do face additional safeguards when requesting euthanasia. People under the age of 18 must be terminally ill, dying in the short term, and experiencing unbearable suffering. This is in contrast to adults whose illness need not be terminal, only serious and incurable. A mental disorder alone is not considered a sufficient criterion for minors, as it is for adults. Repeated requests must come directly from the patient who must exhibit the capacity to fully understand their request and its consequences. The case must be assessed by a team of physicians and a psychiatrist and/or psychologist, and final approval must be granted by the parents (Gov. of Belgium, 2014).

The amendment to include eligibility for capable minors in Belgium’s Act on euthanasia generally had strong public support. Prior to the amendment, a 2011 survey found that pediatric physicians in the Flanders region generally supported physician-assisted dying for minors. Of the 124 physicians who had provided

care to a patient between the ages of 1 and 17 who died in 2007 to 2008, 69% favoured extending the right to a physician-assisted death to minors in certain circumstances (e.g., 26.6% favoured age limits, 61% favoured a requirement for parental consent) (Pousset *et al.*, 2011). Despite this support, when the Belgian amendment was passed in 2014, it faced strong opposition from groups that included religious organizations, and some healthcare practitioners including pediatricians and palliative care specialists (Samanta, 2015).

Critics of the amended law accused Belgian legislators of passing the amendment without significant public consultation. In February and March 2013, academic experts from fields including pediatric oncology, ethics, and law were heard during Senate discussions (Van Gool & De LaPeliere, 2017); however, a group of 160 pediatricians were denied a request to delay the vote (Collectif des pédiatres, 2014). Representatives from religious and other philosophical organizations were barred from addressing the Senate on the matter and a group of Belgian pediatric nurses voiced their concerns that the new law interfered with the role of pediatricians in end-of-life decision-making (Friedel, 2014). Lawmakers and supporters of the revised legislation argue that age cannot be used as a predictor for decision-making capacity, and therefore age restrictions on euthanasia are arbitrary and discriminatory to decisionally capable children (Samanta, 2015).

Since 2014, there have been three reported cases of pediatric euthanasia in Belgium: two in 2016 and one in 2017. The patients were aged 17, 11, and 9 (CFCEE, 2018). Table 5.2 lists the medical condition that precipitated these cases.

Table 5.2
Reported Belgian Cases of Euthanasia for Minors

| Year | Age at Death (Years) | Condition |
|------|----------------------|-----------------------------|
| 2016 | 17 | Duchenne muscular dystrophy |
| 2016 | 9 | Glioblastoma |
| 2017 | 11 | Cystic fibrosis |

All Belgian cases of euthanasia for minors reported to the Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie between 2014 and 2017 are listed above. Additional information was retrieved from *The Washington Post* (CFCEE, 2018; Lane, 2018).

5.5.2 The Number of EAS Requests by Minors in the Netherlands and Belgium, and Reasons for Requests or Refusals

Currently, no systematically collected data are available on the total number of EAS requests by minors in either the Netherlands or Belgium, the reasons and/or medical conditions precipitating requests, or the number of refused requests. This represents a major research gap in current understanding of MAID and mature minors. However, in a 2012 survey, 6% of Dutch pediatricians stated that they had at some point in their career received a request for assisted death from a patient under the age of 18; 1% had received such a request in the last two years; 5% had performed euthanasia on a minor during their career; and 0.6% had done so in the last two years. Finally, 14% of Dutch pediatricians reported ending the life of a minor at the request of parents and without the explicit request of the child (Emanuel *et al.*, 2016).

In a national survey of 276 Dutch pediatricians (with a 62% response rate), 81% of respondents reported that they could conceive of assisting in the death of a minor, regardless of age and/or competency, but were more reluctant if parents did not agree with the minor's request or death was not imminent. Ultimately, pediatricians stated that their decision to provide physician-assisted dying would be driven by the duty to relieve suffering in cases where palliative care no longer proved sufficient (Bolt *et al.*, 2017). Most of the pediatricians in the study did not support two of the key criteria in the Dutch act on euthanasia: the age limit and the need for an explicit request to come from the patient rather than the parents (Bolt *et al.*, 2017).

5.5.3 Other Jurisdictions

In addition to Canada, Belgium, and the Netherlands, competent adults in Switzerland, Luxembourg, Colombia, Germany, and several U.S. states can access either physician-assisted dying and/or euthanasia. The state of Victoria in Australia legalized assisted dying in November 2017, and the practice is set to begin in mid-2019 after an 18-month implementation period. In each of these jurisdictions, only adults over the age of 18 are permitted to access assisted dying or euthanasia (Figure 1.1).

Debates on euthanasia have been held for decades in many other countries, including the United Kingdom and France. While the Working Group was unable to review the totality of material from every country, it did exercise due diligence by examining a breadth of information from jurisdictions with restricted euthanasia (no access for minors) and those in which euthanasia or assisted dying has been debated but ultimately not legalized or decriminalized.

Material reviewed included peer-reviewed articles, news articles, books, proposed legislation, and selected parliamentary/senate reports. The evidence came primarily from English language sources.

The research revealed no relevant information on the rights of minors to access assisted dying or euthanasia outside of Canada, the Netherlands, and Belgium. While the Working Group cannot definitively say that the issue has not been discussed within other jurisdictions, there are no documented English language reports that reference the issue of assisted dying for mature minors in any of the restrictive jurisdictions where assisted dying is otherwise allowed or has been debated.

5.5.4 PPC in the Netherlands and Belgium

A concerted effort has been made to improve the general state of palliative care in Dutch medical facilities since the passage of euthanasia and assisted dying laws. These efforts have been driven in part by views that a euthanasia policy is only equitable and responsible if it is offered alongside accessible, well-developed palliative care options (Lewy, 2011). However, in the case of PPC, knowledge in the field is still lacking. A 2015 study of Dutch guidelines related to PPC found that the evidence and recommendations in the field were sparse, and that literature related to adult palliative care continues to be the main body of evidence informing pediatric cases (Knops *et al.*, 2015). As a result, minors may continue to suffer from symptoms of terminal illness in ways that adults may not. The authors of the study note that progress in PPC has been slow due to both the complexity of PPC and the rarity of cases. Citing the relationship between palliative care and EAS legislation, the authors state: “It seemed odd that this specific part of end-of-life care received so much attention, while there were no formal guidelines available for palliative care for children in the Netherlands” (Knops *et al.*, 2015).

Similar to the Dutch experience, federal funding for palliative care increased in Belgium with the introduction of assisted dying. Between 2002 (the year euthanasia was legalized) and 2007, federal spending on palliative care resources increased by 72% with the majority of the increase directed towards palliative care provision at home (Chambaere *et al.*, 2011). Since 2009, palliative care teams are to be licensed by the Belgian national health system and any physician treating a child requiring palliative care can request the service of the team in the child’s home. These teams support both local healthcare teams, as well as parents, in providing support to children (Van Gool & De LaPeliere, 2017).

In Belgium and the Netherlands, a steady increase in funding for palliative care services and an increased professional interest in palliative care have been linked to assisted dying legislation (Chambaere *et al.*, 2011). Evidence has shown that, in countries with both quality palliative care and assisted dying, both practices can co-exist and complement each other, rather than one practice replacing another (Dan *et al.*, 2014; Hanson, 2016).

5.6 CONCLUSIONS

In describing the current practices and state of end-of-life care in Canada for mature minors, the Working Group draws upon evidence from Canada, as well as Belgium and the Netherlands — the only jurisdictions where assisted dying is allowed for people under the age of 18. The international evidence is admittedly limited, confined to two jurisdictions with only 16 cases of assisted dying among minors. Despite the limitations, the evidence can still provide some insights that can inform policy discussions.

This chapter relies largely upon clinical and ethical evidence to inform its findings. Any decision about extending MAID to mature minors should be informed by how end-of-life decisions are made in the clinical setting by patients, their families, and their healthcare teams. While the capacity of seriously ill minors to make end-of-life decisions has been demonstrated, it is often the case in practice that their choices are relationship-based and that minors value the input of their families and healthcare teams, along with their autonomy.

PPC is a necessary part of any discussion related to MAID for mature minors. While access to PPC in Canada has improved in recent years, it is still far from the goal of reaching every patient who might benefit from it. Full access to PPC is limited by late referrals, a lack of knowledge within the medical community of the full benefits that PPC can offer, and the concentration of PPC teams and facilities in urban centres, which often prevents patients in rural or remote regions from accessing care. These barriers only increase in the case of many Indigenous pediatric patients, who, in addition to often living in remote locations, are also limited by a complicated and inequitable healthcare system.

The relationship between PPC and MAID is of vital importance. The suffering of terminally ill children can be just as significant as that of an adult. While PPC may not be able to relieve all forms of suffering in every case of illness, some healthcare practitioners believe that offering full and timely access to quality PPC might mitigate the need for MAID for mature minors in many cases. In both Belgium and the Netherlands euthanasia legislation was accompanied by increased funding for, and training in, palliative care services.

6

MAID for Mature Minors: Impacts, Safeguards, and Policy Considerations

- **Potential Impacts of Permitting or Prohibiting MAID for Mature Minors**
- **Safeguards and Policy Considerations**
- **Conclusions**

6 MAID for Mature Minors: Impacts, Safeguards, and Policy Considerations

Key findings

Evidence on potential impacts of MAID for mature minors, though limited, is skewed towards the impact on healthcare practitioners, and does not address the potential impacts on patients and their families.

There are a paucity of opinions and voices from young people on the subject of MAID. Research supports the notion that discussions of end-of-life options empower young patients and can provide some relief to parents.

No evidence was found to suggest the irremediability of mental disorders prior to the age of 18.

No evidence was found on the psychological impact that extending eligibility for MAID to mature minors might have on family members.

Evidence that directly assesses the societal impacts of MAID for mature minors is not available. However, based on discussions among organizations and groups that have reflected on the question, impacts that must be carefully considered include those on pediatric palliative care and on minors with disabilities or mental health issues.

There is a general view that minors need heightened protection. However, protecting those who may be perceived as vulnerable and respecting their autonomy are not mutually exclusive considerations. While it is critical to protect people from exploitation, it is also critical to protect them from exclusion by ensuring that they are listened to.

Belgium and the Netherlands have safeguards regulating access to euthanasia for minors with capacity; however, they are not necessarily transferable to Canada. These safeguards include parental consent and/or consultation during the decision-making process, specific medical criteria for eligibility, and assessment by an interprofessional healthcare team that incorporates a psychiatrist and/or psychologist.

This chapter highlights critical issues for Canadian policy-makers to consider if they were to revisit MAID legislation. Extension of circumscribed access to MAID for mature minors in Canada would have to consider all impacts of an emotionally charged practice that is not legislatively permitted in most countries. As a consequence, the Working Group draws potential impacts from a wide

body of knowledge, including the attitudes and opinions of those who would be affected by legislation allowing or denying MAID for capable minors; the personal experiences of care providers, patients, and families in the pediatric setting; and, in many cases, ethical and legal arguments. The Working Group also considers submissions from the Call for Input, existing legislation in countries that permit MAID for capable minors, and the current Canadian legal framework and clinical guidelines related to healthcare for people below the age of majority. Stakeholder attitudes and opinions, however, must at times be interpreted with caution and are not necessarily an indicator of the ideal path forward.

6.1 POTENTIAL IMPACTS OF PERMITTING OR PROHIBITING MAID FOR MATURE MINORS

Mature minors are adolescents who have demonstrated the capacity to make decisions about their healthcare, and are able to provide free and informed consent to treatment. Yet, MAID legislation in Canada explicitly excludes anyone under 18 years of age from accessing a medically assisted death. The Government of Canada views requests by mature minors as having unique considerations (GC, 2016). The preamble to Bill C-14 recognizes “the interests of vulnerable persons in need of protection” (GC, 2016). One method of protecting people from being coerced to end their lives using MAID is to exclude them from accessing MAID at all; however, this exclusion may give rise to legal challenges. Excluding mature minors from MAID also means that someone who is a few months short of their 18th birthday, but meets all other eligibility criteria, is not able to access a medically assisted death, regardless of how reasoned and thoughtful their request may be, whether their family supports the request, and whether their healthcare team is willing and able to provide such assistance.

6.1.1 Impacts on Mature Minors

As discussed in Section 5.4, limited research exists on the experiences of children and adolescents with terminal illness (Tomlinson *et al.*, 2007). This gap, combined with the small number of minors who have accessed euthanasia internationally, makes it difficult to speculate on how the inability or ability to legally request MAID would affect mature minors. At this point, there is also a lack of consultation with minors themselves. The limited evidence available is highlighted below.

The Suffering of Mature Minors

While there are no published studies of mature minors who have accessed MAID, reports from Belgium and the Netherlands show that patients turned to euthanasia when death from incurable illness (cancer, muscular dystrophy, or cystic fibrosis) was expected in the short term (CFCEE, 2018; RTE, 2018a). All documented cases in the Netherlands involving 12 to 18 year olds indicate that patients were suffering from terminal cancer following attempts at a number of different treatments, and exhibiting many symptoms of end-stage disease. These included loss of mobility, pain, fatigue, inability to eat and swallow, nausea, weakness, weight loss, and shortness of breath. Thus, it appears that, within the current Dutch framework, mature minors who receive euthanasia perceive their suffering at the end of a terminal illness to be intolerable. In all reported cases, parents were involved in the decision leading to euthanasia and supported the request (RTE, 2018a).

As noted in Chapter 5, while adolescents may face some unique psychosocial issues, their physical and emotional suffering at end of life is similar to that of adults. Thus, a key question is whether mature minors should have equal access to the potential benefits that MAID could provide, such as an end to intolerable suffering, control over their own death, and the peace of mind gained from knowing that MAID is available. If mature minors are indeed equally entitled, there must be justification as to why they would be denied access (Guichon *et al.*, 2017). The human rights implications of either allowing a potentially vulnerable group to access MAID, or denying access to capable patients based on age alone, are important to consider. There is, however, a lack of input from minors themselves on this issue. Rights-based arguments can be articulated by referring to Canada's national and international human rights commitments (MacIntosh, 2016; Bond, 2018).

While analyses of potential legal challenges are beyond the scope of this report, the issue of rights can also be examined through the lens of suffering.

During his consultations as a member of the External Panel on Options for a Legislative Response to *Carter SCC*, Professor Benoit Pelletier noted a common message from advocates of physician-assisted death: "suffering is suffering, regardless of the age of the person suffering" (SJCPAD, 2016b). The CCRC (2017) echoes this point:

There is no evidence that the intolerable suffering of mature minors, who are equally aware of their current condition and what they face in the future, is any more tolerable than that of the similarly situated capable person over 18 years of age. Palliation is available as a choice

for adults, as it is for minors, and there is no reason to assume it is any more or less a means to alleviate intolerable suffering based on age alone. Whatever the opinion of legislators or health care-providers, the Supreme Court of Canada has ruled that palliation is not sufficient to alleviate suffering in all cases. Therefore, the only remaining legal and ethical question is one of whether to deny equal access to that which is a fundamental right and benefit to those dying and suffering without hope.

The CCRC also refers to debates that compare MAID to less fundamental, deferred rights such as driving, arguing that MAID is a fundamental right under Section 7 of the *Canadian Charter of Rights and Freedoms* that cannot be deferred. In other words, “[t]he right to choose when to end intolerable suffering by the mature minor with an irremediable medical condition (i.e., a reasonably foreseeable death) is not an instance of ‘wait to become an adult and you too will have this right.’ The right is not deferred, it is forever denied” (CCRC, 2017).

Guichon *et al.* (2017) provide two scenarios to illustrate the inequitable situation created by the denial of MAID to mature minors: in the first case, a person under the age of 18 who is suffering intolerably with a grievous and irremediable medical condition, and dependent on life-sustaining treatment, can choose to withdraw the treatment if deemed capable. In the second case, if the same young person enduring intolerable suffering is not dependent on life-sustaining treatment, they are denied access to MAID. Here, “[t]he difference between the two cases is the dependence on life-sustaining treatment, not the degree of suffering, or the maturity of the minor” (Guichon *et al.*, 2017).

End-of-Life Decisions by Mature Minors

Wiener *et al.* (2012) note that adolescents with terminal illness face “an exceedingly difficult and contradictory challenge: they are dying yet it is their nature and developmental need to want to live.” However, if the adults caring for them avoid conversations that acknowledge death, pediatric patients can feel isolated and fearful (Stillion & Papadatou, 2002). It can be empowering for adolescents with cancer to voice their opinions about end-of-life care with their families, and these discussions can promote openness, honesty, and trust among patients, parents, and caregivers (Lyon *et al.*, 2013; Walter *et al.*, 2013).

In the United States, research that guided the development of an ACP document for adolescents and young adults with serious illness, called *Voicing My Choices*TM, shows that allowing young people to articulate their end-of-life care preferences contributed to their sense of independence and purpose, and provided some

comfort to parents in knowing the wishes of their children. However, terminally ill youth participating in the study identified questions about life-sustaining treatment as more stressful to answer than those related to spiritual thoughts and wishes. The authors suggest that this may indicate uncertainty among youth about how to make medical treatment decisions at end of life (Wiener *et al.*, 2012).

Mature Minors' Opinions on MAID

At the Alberta Children's Hospital, the Child and Youth Advisory Council (CAYAC) comprises 25 to 30 children and youth aged 12 and over, with diverse cultural backgrounds and health experiences (Alberta Children's Hospital, 2017). In a consultation on the possibility of MAID for capable minors, CAYAC members related potential benefits of MAID to the freedom of choice and ability for mature minors to control their own lives, as well as fulfilling their right to reduce their pain and suffering, including the peace of mind that availability of MAID would offer. The risks of allowing MAID for mature minors centred on notions that minors might not think about or be properly able to grasp long-term consequences, maturity would be difficult to assess, and conflict could arise within families. The added complexities of youth with mental health issues were also noted, and participants felt that the option for MAID could either increase or decrease youth suicide. Out of 17 CAYAC members who answered a question about whether a mature minor should ever be eligible to request MAID, 10 (59%) said *yes*, 3 (18%) said *no*, and the remainder were unable to definitively answer. CAYAC members were more supportive of MAID for mature minors with terminal illness than for other conditions. Most members felt that, if MAID requests by mature minors were permitted, parental awareness or agreement would be needed (Alberta Children's Hospital, 2016).

Youth Leaders from the Holland Bloorview Kids Rehabilitation Hospital in Toronto echoed the importance of giving youth a meaningful role in decision-making on their medical treatment as well as in the development of health policies that affect young people. Interviews conducted in September 2017 with three Youth Leaders asked for their thoughts on youth participation in clinical care and on MAID for mature minors. Although these leaders were over the age of 18 at the time of the interviews, they had significant experience in dealing with pediatric healthcare systems when they were minors⁵ (Carnevale, 2017).

5 Holland Bloorview supports the participation of Youth Leaders in systems-level discussions that may affect young people living with disability, medical complexity, illness, and injury. The views expressed by the Youth Leaders, however, do not necessarily reflect those of the hospital.

Along with emphasizing the need for youth to have their voices heard and valued in relation to their healthcare, Youth Leaders spoke eloquently about the need to stop categorizing all youth with disabilities as vulnerable. They recalled their own experiences of being encouraged by their parents to take an active role in medical conversations and decisions, and they credited those experiences with helping them develop the power to advocate on their own behalf as children and youth, and now as adults (Carnevale, 2017).

The Youth Leaders all acknowledged the complexity and sensitivity of MAID. They expressed the belief that a person's decision to pursue MAID is an individual one, and that age alone is a flawed standard by which to decide who may or may not be eligible. They described their experiences interacting with very mature young people, and their own realizations that one does not suddenly become more knowledgeable or mature on an 18th birthday. One Youth Leader spoke of the need to ensure that a minor would never feel obligated to choose MAID, while another expressed concern for larger societal implications (Carnevale, 2017).

Coercion in the MAID Context

In a MAID context, no studies compare the pressures faced by minors versus adults, or the relative sensitivity of minors to their social environment. However, a 2016 survey answered by 1,050 of 2,597 Canadian pediatricians and pediatric subspecialists on their interactions with minors or their families addressed the concern that MAID requests from mature minors might result from explicit parental pressure. Respondents reported that, over the past year, parent-initiated MAID conversations among 14 to 18 year olds were rare, accounting for only 11% of exploratory discussions and 9% of explicit MAID requests by parents on behalf of their children (CPSP, 2016). Thus, based on one study, there is no evidence to suggest that there is a risk of parents of adolescents over age 14 of playing a coercive role in pressing their child to choose MAID.

As discussed in Section 6.1.2, studies of dying children and their families have commonly reported that parents hold out hope until the very end as they struggle to accept the imminent death of their children. Bovens (2015) argues that minors may in fact be acutely aware of their parents' difficulty in letting go, and request palliative care over euthanasia for that reason. Additionally, the author suggests that pressure from an adult child on a dying parent is also a possibility, and that pressure to undergo MAID is likely to be even greater on older people than on minors. The Right to Die Society of Canada also addresses the weight given to the vulnerability of minors, arguing that, while minors may "awaken 'protective' feelings in others," they "have not signed a duty-to-live contract with the universe, any more than adults have" (RDSC,

2017). In *A.C.*, the Supreme Court recognized that, despite concerns over their intrinsic vulnerabilities, some adolescents possess the maturity to make autonomous, potentially life-ending medical decisions (SCC, 2009).

Mature Minors and Mental Health

A critical issue that bridges considerations in two of the topic areas for this assessment is the possibility of MAID requests by mature minors whose sole underlying medical condition is a mental disorder. This highlights a broader question about the potential mental health implications of extending the eligibility of MAID to mature minors.

Organizations that responded to the Call for Input alluded to mental health in relation to MAID eligibility for mature minors. Permitting MAID requests by mature minors whose sole underlying medical condition is a mental disorder would incite concerns related to the protection of young people with mental health issues (OCPG, 2017). Allowing mature minors to request MAID in any context is associated with uneasiness over the normalization of suicide as a solution to suffering, and what message this might send to troubled youth (ARPA, 2017), particularly when considering the epidemic of youth suicide in some Indigenous communities (CH, 2017). Whether and how MAID eligibility for mature minors might affect the mental health of young Canadians is unknown at this point, nor has it been studied in countries where capable minors are legally eligible for euthanasia (Belgium and the Netherlands).

The Working Group found virtually no evidence on MAID for mature minors where a mental disorder is the sole underlying medical condition. There are two major reasons for this. The first relates to time for treatment efforts. When one considers the natural history of psychiatric conditions that begin in childhood, it is highly unlikely that a mental disorder would be deemed irremediable before a capable minor reaches the age of majority (age 18 or 19 in Canadian jurisdictions). The second reason relates to the structural and functional changes that occur in the brain during development, as discussed in Section 4.2. It is improbable that a mental disorder would be considered incurable in a developing brain. Discussion of MAID for unique populations with mental disorders, including mature minors, can be found in the report *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*.

Healthcare for Minors with Disabilities

Concerns about the vulnerability of minors with disabilities in healthcare contexts may be compounded compared with minors in general (IRIS, 2017), as they are more likely to have suicidal thoughts (Moses, 2018), be in the child welfare

system (Lightfoot *et al.*, 2011), and live in poverty (CACL, 2013). A number of factors, including perceived parental support, can influence the self-worth of children and adolescents with intellectual, developmental, or physical disabilities (Antle, 2004; Jones, 2012). DeLoach and Greer (1981) propose that children born with physical disabilities experience disability-related stress when they are old enough to recognize and internalize the social stigma surrounding disability. Using data from the Statistics Canada Community Health Survey, Branscombe *et al.* (2016) conclude that adolescents with disabilities are a vulnerable group in Canada, one that perceives discrimination associated with their condition. Perceived discrimination was generally associated with lower life satisfaction, even more so among adolescents who reported low levels of belonging to their local community.

The Working Group found little Canadian evidence on the experiences of disabled children and/or children in the welfare system with end-of-life care, and no literature at all that explicitly discusses their relationship to MAID. A report by Ontario's Provincial Advocate for Children and Youth suggests that youth in residential care (which includes secure mental health settings and treatment centres, custody facilities, group homes, youth shelters, and foster homes) are often deprived of the ability to make a variety of choices, ranging from simple decisions on what to wear, to more complex healthcare decisions (Provincial Advocate for Children & Youth, 2016). In the words of an anonymous youth cited in the report:

What always frustrated me with the plan of care process was that staff at the facility would draft a plan then bring it to me to review afterwards. I was never actually included in the development process. I was just kind of there for the review piece at the end.

International evidence supports the idea that disabled children and children in care are often not engaged in their own healthcare decision-making and that their views are less likely to be listened to than other children. In the United Kingdom, evidence suggests that the pace of including disabled children in healthcare decision-making has been slower than for non-disabled children, and there is often little effort to communicate with children who have very limited or no speech (Franklin & Sloper, 2009). In the United States, Strassburger (2016) notes that, in the case of youth in care, “[c]aseworkers, judges, foster parents, and others routinely make decisions ‘in the child’s best interest’ that counteract the actual wishes of the child.” He goes on to state that “[a]llowing youth to make their own decisions would empower them and make them more likely to cooperate with their treatment plans.”

Disability rights organization *Toujours Vivant-Not Dead Yet* (TV-NDY) expresses concern over the possibility of access to MAID by mature minors, stating that “ill and disabled children often grow up in families where non-disabled parents see their lives as burdensome, tragic, a disappointment of their hopes for the future, and ‘not worth living’” (Hasbrouck, 2017). TV-NDY points to blogs by people with disabilities since childhood who recall a lack of positive role models (Haynes, 2015) and feelings of shame that were only later replaced by the realization that what needs to change are the views of society (Hitselberger, 2017).

Disability-related stress should not be linked solely to a person’s impairments. A growing body of evidence — with adults and minors — highlights that disability should be understood as an interplay between a person’s impairments and the physical and social accommodations available in their environment (Carnevale *et al.*, 2006; Gibson, 2016). This view points to the importance of focusing not on the potential vulnerability of a particular group, but rather on the fact that society should provide the means (whether through policies or programs) to ensure that every individual is supported, respected, and listened to.

6.1.2 Impacts on Families

The important role of family dynamics in end-of-life decisions is not unique to mature minors or to MAID. However, some considerations, related to the role of parents as protectors of their children and the emotional burden of relinquishing that role, may be particularly relevant for the families of mature minors seeking MAID. While there is a lack of research on the impacts on families following the assisted death of a minor, studies have addressed the complexities of parent-child relationships when a child is critically ill and the impact of a child’s death on their parents and siblings.

Parental Involvement in a Minor’s End-of-Life Care

Given that cure is the primary goal of treatment for children with cancer, and parents often feel and act upon a responsibility “to leave no stone unturned” (Bluebond-Langner *et al.*, 2007), it can be difficult for all those involved in caring for pediatric oncology patients to accept non-curative options (De Graves & Aranda, 2002). According to Hinds *et al.* (2005b), “[r]especting parents’ hopes while grounding them in the unfortunate reality of a terminal diagnosis is a delicate and important balance.”

While parents of mature minors would not be making the choice to request MAID on behalf of their children, in most cases it is unrealistic to view minors’ end-of-life decisions as completely detached from their parents’ emotions and

preferences (Carnevale *et al.*, 2017). Situations involving critically ill minors extend beyond the weighing of the risks and benefits that apply in other circumstances in which there is hope for recovery — and will have an inescapably tragic impact on those involved. When parents do have a role to play in their children's end-of-life decisions (as they do in Belgium and the Netherlands), allowing a child to die through legal means such as withdrawal of life support may present “a powerfully paradoxical tragic dilemma. Although legal norms indicate that it is socially permissible, everyone knows that this means then having to struggle to live with such a choice. Knowing that it is legal may not reconcile the torment of conscience that will ensue” (Carnevale, 2007).

This torment of conscience for parents is alluded to in an open letter signed by 160 Belgian pediatricians opposing the extension of euthanasia to capable minors in Belgium. The care of seriously ill children was deemed complex enough, even without the need to confront the difficult choice of active euthanasia. The signatories felt that extending the law to capable minors and asking for parental agreement with their child's euthanasia request would only increase parents' unimaginable pain and stress (Collectif des pédiatres, 2014; Friedel, 2014).

Family Stress Surrounding the Death of a Child

Talking to a terminally ill child about death is unimaginably difficult for parents, yet some express regret over not doing so, particularly if the child was aware of their impending death, or if the child was older (Kreicbergs *et al.*, 2004). Furthermore, hearing about their child's end-of-life care preferences can provide some relief to parents (Wiener *et al.*, 2012). While parents often have difficulty accepting a child's terminal diagnosis and facing discussions of death, some still consider hastening the child's death. In a study of parents whose children died of cancer, 19 of 141 (13%) considered requesting a hastened death, and 5 (4%) explicitly asked a clinician for medication to end the child's life. Parents were more likely to consider asking for hastened death if their child was experiencing pain. When the same parents were asked in retrospect about circumstances under which they would have considered discussing hastened death for their child, the most-cited reason (chosen by 34% of respondents) was their child's uncontrollable pain (Dussel *et al.*, 2010). Thus, the physical suffering of a child is a major source of distress for parents of dying children. MAID could therefore provide comfort to families in knowing their loved one did not have a prolonged and painful death. Based on their experience providing MAID to an adult patient, Quinn and Detsky (2017) suggest that MAID relieved stress on the patient and family, by removing all of the uncertainty and agonized decision-making associated with the dying process.

Family Bereavement

Hinds *et al.* (2005b) note that “[a]lthough preventing a child’s death is the overall priority for health care systems, facilitating a ‘good death’ is a priority for the health of bereaved families and affected health care providers.” The circumstances surrounding the death of a child influence the intensity of parental grief (Meij *et al.*, 2008). Based on parental accounts, most children dying of cancer experience considerable suffering from at least one symptom (Wolfe *et al.*, 2000). Parents who believe their child experienced severe pain and discomfort report lasting images and protracted feelings of anguish (Contro *et al.*, 2002). The death of an adolescent is recognized as a particularly complex issue, in light of the tensions that can arise in the parent-child relationship as the child develops independence and maturity. Davies (2001) suggests that parents who feel they failed to understand their adolescent child may experience a heightened sense of guilt following the death.

A number of survey-based studies show that the death of a child can have profound impacts on bereaved siblings. Within the first year of bereavement following the death of a brother or sister from cancer, the majority of siblings experience personal changes (e.g., withdrawn behaviour, changing interests or goals, greater maturity and leadership qualities), and some may experience changes in relationships with family or friends (Gerhardt *et al.*, 2011; Foster *et al.*, 2012b). Years later, bereaved siblings report that the death of their brother or sister has lasting impacts on their perceptions and life decisions, and that circumstances surrounding the death can have long-term effects. Those who recall a lack of social support prior to and following the death are more likely to report self-assessed anxiety two to nine years later (Eilertsen *et al.*, 2013). Bereaved siblings who report being dissatisfied with communication by parents or healthcare practitioners around the time of death, an inability to prepare for their sibling’s death, and a lack of opportunity to say goodbye, score higher on measures of psychological distress and lower on measures of social support over a decade later (Rosenberg *et al.*, 2015).

Studies exploring the effects of MAID on bereaved families have not involved minors who accessed MAID. Quantitative research in the Netherlands and the state of Oregon compared the impacts on family and friends following the death of loved ones by MAID or natural death. This work suggests that MAID does not have negative effects on the grief or mental health of surviving family and friends, and, in some respects, is associated with better coping. The reduction in stress was attributed to better preparation for death, more open discussion about dying, and the ability to say goodbye (Swarte *et al.*, 2003; Ganzini *et al.*, 2009). Qualitative studies in Switzerland and the states of Oregon and Washington describe the difficulties faced by bereaved family members

following the assisted suicide of a relative. These include moral dilemmas that began during the decision-making process and continued following the death, isolation during the bereavement period due to the need for secrecy regarding the circumstances of the death, and concerns over the social stigma associated with suicide (Starks *et al.*, 2007; Gamondi *et al.*, 2013). However, there is no evidence that consequences of suicide for young people would conflate with those for MAID.

6.1.3 Impacts on Healthcare Practitioners

The responsibility of assessing patients and providing MAID currently rests with healthcare practitioners. Thus, the potential emotional burden on practitioners involved in MAID for mature minors is important to consider. However, the Working Group emphasizes that this potential burden would not necessarily affect access to MAID. Research describing the impact of providing MAID on healthcare practitioners in Canada is limited, nor are there any international studies that describe the impact of providing MAID to mature minors. Some insight, however, can be drawn from surveys of child healthcare practitioners, MAID assessors and providers, and qualitative studies of care teams working with dying patients.

Healthcare Practitioner Views of Mature Minor Eligibility and Provision of MAID to Mature Minors

In a straw poll of 600 delegates at the Canadian Medical Association's 2017 annual meeting, 67% were in favour of access to MAID by mature minors (Picard, 2017). In a survey of 135 active MAID assessors and providers (of which 79 responded), 82% answered that they would be willing to assess mature minors for MAID and 70% would be willing to provide MAID to a mature minor deemed eligible (CAMAP, 2017). However, the idea of actively ending the life of a young person is distressing to many clinicians in pediatric settings. In a CPS-Attitudes survey of 1,979 Canadian Paediatric Society members, 486 answered a question about whether mature or emancipated minors should be eligible for MAID in some circumstances. Of these, 46% answered *yes*, while 33% answered *no*, and the remainder answered *maybe* or were undecided. Yet, when asked if they would personally participate in the medically assisted death of a young person they believed to have full capacity to consent, if it were legal, only 19% of 412 respondents answered *yes*. Many respondents who chose to add comments reported feeling uncomfortable with the concept of MAID for children and noted that MAID is contrary to the principles of pediatric care (CPS, 2016). There have been no published surveys documenting the views of other healthcare practitioners, including nurses and pharmacists, on the specific issue of MAID for mature minors.

While it is premature to evaluate the impact on healthcare practitioners, these data indicate that there may be specific concerns for pediatric healthcare practitioners, and increased distress for practitioners involved in MAID for mature minors. The passage of federal MAID legislation did not directly address the issue of the rights of conscientious objection among healthcare practitioners. Instead, rights of conscience and refusal among healthcare practitioners and faith-based institutions continue to be adjudicated at the provincial and territorial level as governments make efforts to address patients' and physicians' rights (Kelsall, 2018). In some provinces such as Ontario, physicians who refuse to consider requests for MAID must provide an effective referral, that is to take "positive action to ensure the patient is connected in a timely manner to another physician, health care provider, or agency who is non-objecting, accessible and available to the patient" (CPSO, n.d.). The Ontario Superior Court of Justice Divisional Court upheld this requirement following a challenge led by the Christian Medical and Dental Society (ONSCDC, 2018).

As the above survey results indicate, practitioner support for mature minor access to MAID can be highly variable depending on the group of respondents. Furthermore, even targeted surveys may not fully capture the most informed viewpoints (e.g., not all Canadian Paediatric Society members would have clinical experience with children at end of life) (CPS, 2016). This highlights the need to consult with healthcare practitioners who are caring for severely disabled or terminally ill children and youth in their daily practice, a need echoed in the Canadian Paediatric Society's position statement on MAID (CPS, 2017).

Healthcare Practitioner Stress and Grief

Most terminally ill adolescents and their parents have close relationships with their care providers (Freyer, 2004). In referring to treatment decisions for children with life-threatening or life-limiting illness, Bluebond-Langner *et al.* (2010) describe the extraordinary difficulty faced by physicians and parents, where the "pain they feel does not just come from empathy or sympathy. It also derives from their roles as physicians and parents — to care for and protect." Studies of caregivers working with dying children have found that the emotions and grief reactions of physicians and nurses are influenced by the extent of the relationship with their patients and the type of death experienced (Kaplan, 2000; Papadatou & Bellali, 2002). Since no studies have specifically addressed the impacts on healthcare practitioners of providing MAID to mature minors, it is not known whether they might be greater than the impacts of providing MAID to adults. The Working Group also notes that peer-reviewed studies examining these impacts tend to be problem-based.

An interview study of physicians in Canada who provided MAID identified key challenges. One concerned colleague relationships, which were strengthened with other MAID providers but strained when colleagues objected to MAID, in some cases leading to a hostile working environment. The other challenges identified, increased workload and inadequate financial compensation, might be less applicable to MAID for mature minors given that the number of requests from minors would likely be small (Khoshnood *et al.*, 2018). MAID providers in Canada have also identified positive impacts of providing MAID to adult patients. Two physicians' experiences with an adult patient described a "peaceful death" that was "the right care, for the right patient, at the right time" (Quinn & Detsky, 2017). Other physicians have described similar experiences providing MAID, in which they did not feel distress, but were moved and gratified by their role in helping patients have loving, peaceful deaths (Porter, 2017; Proudfoot, 2017). Where mature minors are concerned, it is not known if finding practitioners to provide MAID would be a challenge.

Qualitative studies have described the profound impacts on primary care physicians in the Netherlands with personal experience in providing euthanasia or assisted suicide to adults. Many physicians cited the need for a direct clinical relationship with the patient to perform euthanasia, which also led to feelings of loss. Some reported feeling tension about the procedure itself and the potential reaction of families, pressure from society or relatives to provide euthanasia, and a lack of time to cope with the trauma of performing it. Others noted how supportive and thankful patients' families could be, and felt relieved and satisfied that they had been able to do something for the patient (van Marwijk *et al.*, 2007; Dees *et al.*, 2013).

In an effort to minimize and/or manage MAID providers' stress and grief, in-hospital programs have been developed in Canada. For example, The Ottawa Hospital's resiliency program for staff members connected to the provision of MAID offers support before, during, and after the implementation of MAID, and collects data to monitor well-being and inform future practice (HSO, 2017). Similar programs, tailored for the particular circumstances, could help deal with the potential impacts on pediatric providers if MAID for mature minors were permitted.

6.1.4 Societal Impacts

Evidence that directly assesses the societal impacts of prohibiting or permitting requests for MAID by mature minors is not available. At this stage, some insight regarding the potential broader implications can be drawn from organizations or groups that have considered the possibility of MAID for mature minors, and discussed the issues that are central to them in this context. Thus, in some cases the potential societal impacts are informed by advocacy positions.

Pediatric Palliative Care

The possibility of extending MAID eligibility to mature minors has brought PPC issues to the forefront. As discussed in Section 5.2, many children who might benefit from PPC in Canada are either not receiving it or are referred too late in the course of their disease. The Canadian Paediatric Society Bioethics Committee states that, “[t]o meet this critical need, paediatric palliative care specialists need more support, and community-based physicians, nurses and home care providers need enhanced education and skills development.” In addition, the Committee emphasizes the “invaluable wisdom and experience” of palliative care practitioners, and maintains that palliative care must be made available to all patients and families facing advanced illness, even those considering MAID (CPS, 2017).

The opinions of palliative care physicians in Canada on allowing mature minors to request MAID are mixed. In a survey of 398 CSPCP members, 192 answered a question on which statement best represented their views on the eligibility of mature minors for MAID. Of these, 42% chose “mature minors should never have access to MAID,” 47% chose “mature minors should only be granted access to MAID after necessary safeguards to reduce harm are in place,” and 11% chose “other” (CSPCP, 2018).

MAID has the potential to positively or negatively affect palliative care in Canada in a number of ways, most of which apply to patients of any age. These possible impacts were conveyed in the CSPCP’s survey discussed above, as well as in its 2016 submission to the Special Joint Committee on Physician-Assisted Dying. Potential negative impacts include the possibility of misconceptions that associate palliative care with hastened death (CSPCP, 2016), a diversion of time and resources to MAID rather than palliative care, the decline of effective palliative care by patients fearful of losing capacity to consent to MAID, and a damaging impact on the atmosphere within treatment centres (CSPCP, 2018).

Potential positive impacts include improved awareness and more open dialogue about palliative care in both clinical settings and communities, increased comfort among practitioners and patients in discussing end-of-life options, and empowerment of patients to consider a broader range of choices at end of life (CSPCP, 2018). These impacts could be relevant to patients, their families, and care teams in both pediatric and non-pediatric settings.

Societal Viewpoints on the Capabilities of Minors

As discussed in Chapter 4, while a number of factors must be carefully considered on a case-by-case basis when determining capacity in life-and-death circumstances, some minors are capable of making autonomous end-of-life decisions. Salter (2017) contends that neurological and psychological data addressing the ability of adolescents to make health-related decisions can be used to support both sides of the argument, and thus do not resolve the issue. On the one hand, it can be argued that adolescent brain function and behaviour are incompatible with mature decision-making because adolescents may be able to understand the risks and relevant factual issues, but lack the ability to fully understand the long-term implications of their decisions or the emotional control to make mature choices (Cherry, 2013). On the other hand, healthcare decision-making contexts, in which adolescents are supported by a care team and family members, are not conducive to the impulsive behaviour promoted by peer influence and high emotion or arousal (Steinberg, 2013). Consequently, policy-makers would need to address widespread concern about the capacity of minors to give informed consent to MAID, which, according to some, must be treated differently than all other medical procedures when considering approaches to capacity assessment (ARPA, 2017; TCDG, 2017).

The Physicians' Alliance Against Euthanasia takes the view that "an adolescent might be able to explain perfectly the risks and benefits associated with the decision being considered, but still be unable to judge adequately how to apply this theoretical knowledge" (PAAE, 2017). Thus, it proposes "greater scrutiny of such choices made by young adults, up to the age of at least 21 and perhaps 25" (PAAE, 2017). Similarly, REAL Women of Canada argues that "adolescence is a time of exceptional turbulence, experienced by individuals who ... have not lived long enough to acquire the knowledge to weigh the credibility of the arguments for or against assisted suicide and to understand the value of their own life, not just for themselves personally, but for others as well" (REAL Women of Canada, 2017).

The Right to Die Society of Canada rejects the view that adolescents do not have the life experience to have sufficient perspective on their situation:

If ‘perspective’ means having had numerous experiences similar to the current problem, an adult may not be any more qualified than an adolescent. Some people live most of their lives in almost-perfect health, then suddenly fall victim to a catastrophic illness. In terms of innocence and inexperience, they are on a par with similarly-stricken teenagers or children.

(RDSC, 2017)

Evidence discussed in Chapter 4 supports the notion that adolescents who have disease experience show remarkable insight into their condition and end-of-life decisions, and may exhibit a maturity beyond that demonstrated by healthy subjects in many neuroscientific or psychological research studies (Day *et al.*, 2016).

In response to the Call for Input, several organizations noted that, if MAID were extended to mature minors, it would incite major concerns about their vulnerability and society’s obligation to protect them (CACL, 2017; CCRL, 2017; CHAC, 2017; CHNC, 2017; CLF, 2017; EFC, 2017). Such discussions tend to focus on concerns about protecting minors who might not have the life experience or stable identity to make the choice to die, or might be overly susceptible to influence by others. Some believe minors are more likely than adults to base decisions on social expectations, and are more sensitive to implicit or explicit pressure. For example, even if their parents do not raise the subject, minors might feel pressure to request MAID to lessen the emotional or financial stress on their families (Kaczor, 2016; CHNC, 2017; IRIS, 2017).

Considerations Related to Vulnerability

The Working Group emphasizes two aspects of vulnerability: one is that an individual will be exploited, while the other is that they will be excluded. Thus, part of protecting potentially vulnerable patients is to ensure that they are listened to. Similarly, Downie (2018a) argues that, while the goals of respecting autonomy and protecting the vulnerable are typically presented as a dichotomy in the MAID context, they overlap in reality. Discussions of vulnerability often focus on how the inabilities or characteristics of certain groups make them susceptible to outside influence and restrict their alternatives. However, it is also imperative to consider society’s treatment of groups that are frequently described as vulnerable. This treatment may decrease the likelihood that some groups have their wishes followed, have adequate support and resources for

certain aspects of their healthcare, or have trust in healthcare practitioners (Downie, 2018a). From a legal standpoint, the Canadian Bar Association supports this argument for mature minors, asserting that they are less likely to “engage counsel to argue their position,” particularly if ill (CBA, 2017). Thus, it can be reasoned that minors are liable to have their end-of-life preferences disregarded (Section 3.6.2), which could lead to unnecessary suffering.

This view recognizes vulnerability as a social construct, and calls for social responsibility to support all people in advancing their interests, rather than labelling certain groups as incapable and further limiting their choices (Paré, 2011). Part of this responsibility includes attentiveness to how any patient, not just certain populations, can have their options restricted, and their capacity, voluntariness, or access to healthcare threatened. In this way, autonomy is not in opposition with protection of the vulnerable. Rather, the interests of perceived vulnerable groups can be advanced *through* respect for and promotion of autonomy (Downie, 2018a).

6.1.5 Summary of Key Issues for Groups that Might Be Affected by MAID for Mature Minors

Figure 6.1 summarizes key issues for groups that might be affected by prohibiting or permitting MAID for mature minors. For mature minors, these issues would include their suffering, the impacts on their rights, how the MAID process fits with their circumstances and wishes, and the impact of their end-of-life decisions on their family. For third parties (particularly healthcare practitioners and family members), considering MAID for mature minors would create the potential for burdens and moral distress, but also for comfort and relief from suffering. The general concerns of healthcare practitioners about support related to the emotional or practical aspects of MAID, as well as conscientious objection, might also arise in the mature minor context. The emotional impact of their loved one’s end-of-life decision is central for family members. At the societal level, there are concerns about what might precipitate MAID requests by mature minors, and how these could be related to the adequacy or availability of healthcare and social supports. There is also concern that allowing MAID for mature minors might stigmatize groups with added vulnerabilities, such as adolescents with disabilities, whereas prohibiting it might discriminate against mature minors.

In deciding whether to allow MAID for mature minors and, if so, whether to restrict its use to particular situations, policy-makers would need to address the alleviation of suffering, protection of the vulnerable, and respect for autonomy, which are not mutually exclusive. This triad of considerations, however, is not unique to mature minors.

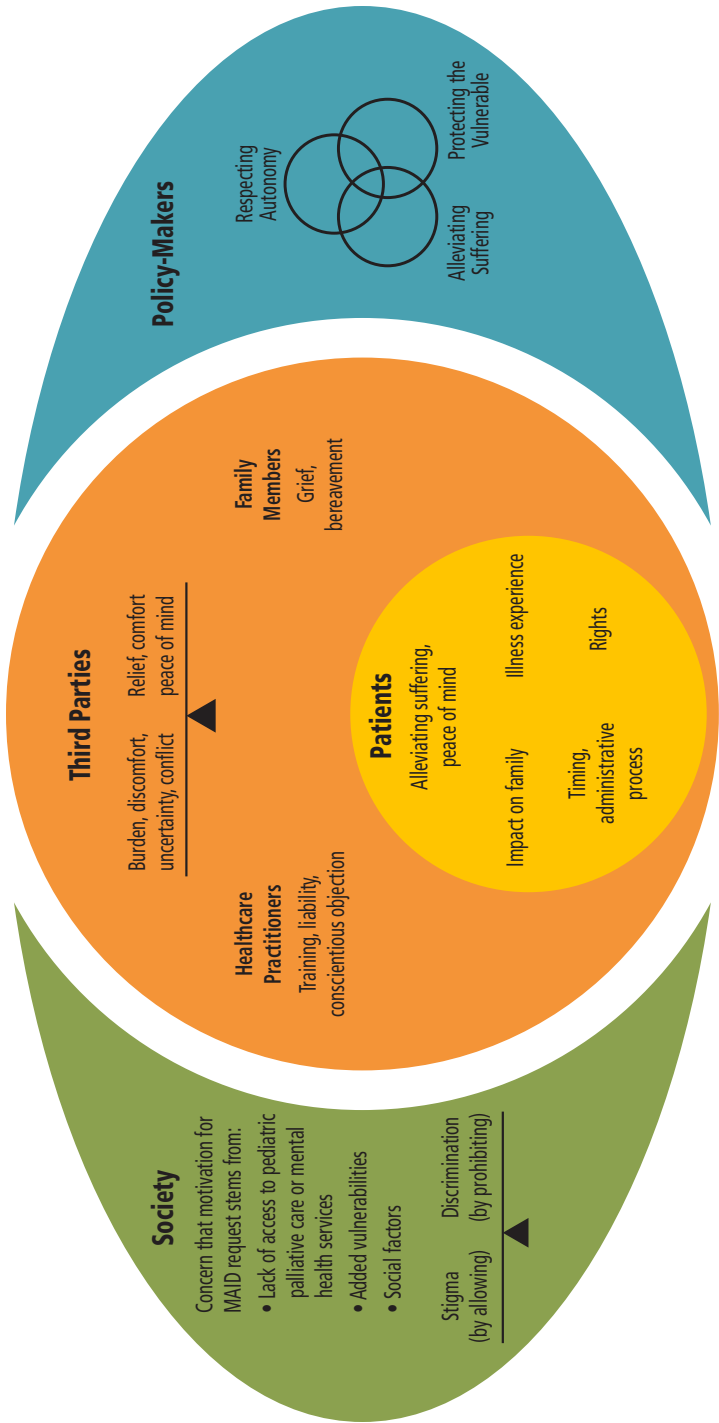


Figure 6.1
Key Issues for Groups that Could Be Affected by MAID for Mature Minors

6.2 SAFEGUARDS AND POLICY CONSIDERATIONS

Mature minors in Canada already have the ability to make healthcare decisions that may hasten their death, by consenting to the withholding or withdrawal of life-sustaining treatments. Although in some rare instances, cases may go to court when there is a dispute between minors and other interested parties over a potentially life-threatening decision, generally, this type of decision-making does not require that mature minors meet a list of additional safeguards beyond those already applicable to adults. Based on the eligibility criteria under the current Canadian legislative framework, if mature minors were permitted to request MAID, those who qualified would have limited life expectancy and intolerable suffering. Therefore, the question of protecting their healthy future, which might arise in some cases of treatment refusal, would not apply. Nonetheless, as noted in Section 6.1.4, the view of minors as a group deserving of heightened protection is a widely shared concern. From this viewpoint, if the ability to request MAID were extended to those under the age of 18, eligibility criteria would have to be weighed against providing sufficient safeguards to protect a potentially vulnerable group. Yet, there is also a concern that, if MAID were permitted for mature minors under additional safeguards that are too restrictive, this would limit eligibility of people who would otherwise qualify.

Drawing from jurisdictions where EAS is permitted for capable minors (Belgium and the Netherlands), as well as the positions and opinions of relevant organizations or groups, the Working Group identified a number of safeguards and policy considerations that might apply to MAID for those under the age of 18. Table 6.1 summarizes the eligibility and procedural due care criteria for minors in Belgium and the Netherlands.

There are a variety of views on what possible inclusion of mature minors in MAID legislation could look like. The Expert Panel of the Royal Society recommended that existing legislation related to mature minors and healthcare decision-making should also apply to assisted dying, but provincial and territorial governments should clarify their existing laws on mature minor consent for end-of-life decision-making through their respective healthcare consent and child protection legislation (RSC, 2011; MacIntosh, 2016). Bond (2018) contends that the rulings in *A.C.*, as well as a number of provincial court cases in which a minor refused potentially life-saving treatment (discussed in Chapter 3), provide important guidance related to MAID eligibility and safeguards for mature minors. Rather than focusing on age, the courts considered the complete circumstances of the minors involved, including their capacity, maturity, medical situation, family dynamics, and the emotional and physical impact of further medical intervention. The author argues that this type of framework both protects potentially vulnerable minors and upholds the autonomy of those suffering from grievous and irremediable disease.

Table 6.1
Summary of Eligibility and Procedural Due Care Criteria for Euthanasia and Assisted Suicide in the Netherlands and Belgium

| Age-Based Eligibility Criteria | Other Eligibility Criteria | Procedural Due Care Criteria for Capable Minors | Mental Disorder or Advance Request-Related Criteria for Capable Minors |
|---|--|--|---|
| The Netherlands <ul style="list-style-type: none"> • Adults • Capable minors 16–18 years of age (if parent(s) and/or guardian have been consulted) • Capable minors 12–16 years of age (if parent(s) and/or guardian(s) agree with the minor's request) | <ul style="list-style-type: none"> • Patients aged 12 and over must demonstrate "unbearable suffering" with "no prospect of improvement" • Act does not have any provisions requiring terminal illness or related to patients' proximity to death • Patient must be capable of a voluntary and well-considered request (but no requirement for written request) | <ul style="list-style-type: none"> • Physician must follow the adult due care criteria, and adhere to the conditions of parent/guardian involvement | <ul style="list-style-type: none"> • Written advance requests permitted for patients 16 years of age or older no longer capable of expressing their will but, prior to reaching that state, were deemed capable of making a reasonable appraisal of their own interests • No provisions for any age group restricting access to somatic diseases/disorders nor provisions related to proximal death (but RTE Code of Practice includes cautions related to psychiatric disorders); therefore, minors with mental disorders as sole underlying medical condition are not explicitly excluded |
| Belgium <ul style="list-style-type: none"> • Adults • Emancipated minors (16–17 years old, autonomous, and capable as determined by a judge) • Non-emancipated minors (without age restriction) with capacity for discernment, provided that parent(s) and/or guardian(s) agree with the request of the minor | <ul style="list-style-type: none"> • <i>Legally competent adults and emancipated minors:</i> medically futile condition of constant and unbearable physical or mental suffering, resulting from a serious and incurable disorder caused by illness or accident • <i>Non-emancipated minor children with capacity for discernment:</i> medically futile condition of constant and unbearable physical suffering resulting from a serious and incurable disorder caused by illness or accident, that will result in death in the short term • Patient must be capable of a written, voluntary, well-considered, repeated request that is not the result of any external pressure, and must be conscious and competent when making the request | <ul style="list-style-type: none"> • Physician must follow the due care criteria for adults and emancipated minors, ensure that parent(s)/guardian(s) agree with the request, and perform a second consultation with a child psychiatrist or psychologist | <ul style="list-style-type: none"> • Minors with capacity for discernment are not eligible for euthanasia via advance request or where a mental disorder is the sole underlying medical condition |

Data Source: Gov. of Belgium, 2002, 2014; RTE, 2015

Others argue that, if MAID were extended to this group, additional safeguards, such as those that exist in Belgium and the Netherlands, should be implemented in Canada. The CPS recommends that, if future legislation were to permit capable minors access to MAID, “[g]overnments at every level [should] develop policies and procedures to safeguard young people from possible risks, harms or abuses of MAID, given their unique vulnerabilities” (CPS, 2017). Beyond federal legislative efforts, safeguards could also be implemented by provincial and territorial legislatures, as well as by those who deliver healthcare, including through professional regulatory bodies and clear hospital guidelines. The College of Physicians and Surgeons of Ontario argues that, regardless of what position the federal government decides to take on MAID for mature minors, “careful consideration needs to be given to the challenges facing clinicians in interpreting and applying legislation and efforts made to ensure that any resulting legislative provisions are clear” (CPSO, 2017).

6.2.1 Chronological Age and Capacity

In the Netherlands, children are eligible to request euthanasia beginning at the age of 12, whereas in Belgium, children face no age restrictions as access to euthanasia is based on one’s capacity to make serious healthcare decisions and to understand their implications. In Belgian practice, the requirement for capacity and a written request by the patient would exclude very young patients from accessing euthanasia (Friedel, 2014). In both jurisdictions, legislation on consent to euthanasia by minors is consistent with legislation on healthcare consent by minors (Janssen, 2002; Pousset *et al.*, 2011). In contrast, legislation in Canada regulating chronological age and healthcare consent varies by province and territory (Section 3.5), precluding the adoption of a single resolution satisfying criteria of all provinces and territories.

Given the lack of consensus on the age of majority in Canada, it is perhaps unsurprising that a lack of consensus remains on whether chronological age should limit access to MAID. A 2015 Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying report recommends that “[a]ccess to physician-assisted dying should not be impeded by the imposition of arbitrary age limits” and “eligibility for physician-assisted dying is to be based on competence rather than age” (PTEAG, 2015). In the CPS-Attitudes survey (Section 6.1.3), 398 out of 1,979 CPS members answered a question about eligibility criteria if MAID were extended to include mature minors. Of these respondents, 55% said that eligibility should be based on individual capacity, 22% said it should be regulated by a minimum age requirement, and the remainder were unsure (CPS, 2016, 2017).

In Canadian society more generally, the population is divided on MAID for mature minors. In a 2016 online survey conducted by the Government of Alberta, 54% of 12,575 respondents stated that people under 18 years of age should be able to access MAID as long as they show the maturity and capacity to make and understand the request (Gov. of AB, 2016). To this end, some recommended the creation of national standards to help determine capacity among minors (Gov. of AB, 2016). Currently, no standard process is used across Canada to assess capacity in a minor. The Community Health Nurses of Canada warn that “[a]n inconsistent and subjective process of assessing can be problematic as physicians may rely more heavily on their own discretion and judgement in the decision of whether the mature minor is a candidate for MAID, rather than objective criteria” (CHNC, 2017). The Working Group notes that provincially there are professionals in healthcare and other fields who are specifically trained in capacity assessments. The need for a consistent approach in evaluating who might qualify for MAID has implications for practitioner training that are still emerging, and would have more implications if MAID for mature minors were to become a reality.

6.2.2 Involvement of Parents, Healthcare Practitioners, and Other Experts

The CPS recommends that, if capable minors were eventually granted access to MAID, “[p]rocedures for assessing a minor’s personal capacity to make health decisions rest with the patient’s clinical team and parents, in consultation with other designated experts (e.g., bioethicists, psychologists, psychiatrists)” (CPS, 2017). This recommendation mirrors the framework implemented in Belgium, where children requesting EAS are subject to an enhanced evaluative process that includes the opinion of a child psychiatrist or psychologist (Gov. of Belgium, 2014). However, within the Belgian context, psychiatrists and psychologists called upon to make capacity assessments in minors require no special qualifications or expertise in areas of end-of-life care, or competencies in working with terminally ill minors. Without special expertise in these areas, Van Assche *et al.* (2018) argue that they may not be any more qualified to assess a terminally ill minor for capacity than any other type of clinician, and that the term “psychologist” in the Belgian legislation is too broad to be meaningful in the case of judging capacity for euthanasia requests by minors.

Clinicians involved in the MAID process should have a clear understanding of the capacity that would be required when assessing MAID eligibility for mature minors, and when providing MAID. The College of Physicians and Surgeons of Ontario asks “whether there should be specific professional competencies or areas of expertise and experience that are required as prerequisites for clinician involvement,” and whether any such prerequisites might risk limiting

the number of providers who may be willing or able to provide access to MAID (CPSO, 2017). These are both important questions to consider in any proposed expansion of MAID to mature minors, and in light of the current context of pediatric healthcare for seriously ill minors in Canada.

Pediatric healthcare in Canada relies upon an interprofessional approach that includes a team of health professionals, including a psychologist and/or social worker. Child/adolescent psychiatrists are also increasingly available to offer team and family consultation, and psychosocial professionals are integrated into the healthcare team, developing an intimate knowledge of a young person's history over time. The advantage of this approach is that, in the event of a MAID request by a minor, a psychiatrist or a psychologist called upon to make a determination of maturity or capacity would likely be familiar with the case and have access to interprofessional team members. Therefore, they would be able to make an informed opinion based on knowledge of the patient and the medical and psychosocial situation, including family dynamics, or the patient's emotional development (Kazak & Noll, 2015). This approach has the potential to limit anticipated harms, including specialists introduced too late in the patient's disease trajectory and who may not know the entire case history, or young patients who may be withdrawn from, or be distrustful of, a newly introduced clinician in an interview setting or who may not feel comfortable with a new specialist who is there solely to judge their capabilities (Michaud *et al.*, 2015; Van Assche *et al.*, 2018).

The requirement for parental consent recognizes the family as a decision-making unit, and reflects elements of a supported decision-making approach (MacIntosh, 2016). It has been argued that the supported decision-making model provides a valuable perspective on minors' consent to healthcare, as it balances concerns over respecting their autonomy with protecting them from both exploitation and exclusion (Paré, 2011). Yet, supported decision-making is not the same as a requirement for parental consent. Alderson (2017) cautions that preserving the interests of the intimate family during healthcare decision-making by providing parents with too much discretion may lead to parents overriding the interests of their sick children. Notably, the Belgian and Dutch requirements for parental consultation or agreement are not consistent with the mature minor concept; they do not reflect current legislation for other health decisions or for clinical practice in Canada. The Working Group also cautions that, in some cases, involving parents in a minor's healthcare decision could have a negative impact on, or prejudice minors who are in abusive or troubled relationships with their parents.

A small sampling of Canadian youth shows that they also favour additional safeguards for their protection. Consultation with 17 members of the Alberta Children's Hospital CAYAC revealed that many members in favour of MAID for capable minors cited a need for decisions to be supported by multiple members of their care team, other professional experts (e.g., social workers, clinical ethicists, psychologists, counsellors), and their parents and siblings (Alberta Children's Hospital, 2016). However, as noted earlier, one consideration of this potential safeguard is the additional burden on parents of terminally ill children, who already face difficult and complex choices about end-of-life care. The option of euthanasia may put parents in the painful position of granting their child permission to die (Collectif des pédiatres, 2014).

The Right to Die Society of Canada warns that caution must be exercised when considering parental consent as a truly effective safeguard due to the instinctive urge of parents to save their child at almost any cost. This urge might prevent some parents from acting as partners in a mature minor's decision-making process (RDSC, 2017).

6.2.3 Medical Criteria for MAID Requests by Mature Minors

In the CPS-Attitudes survey, 301 CPS members who replied *yes* or *maybe* to the question of whether mature or emancipated minors should be eligible for MAID in some circumstances answered a follow-up question on which circumstances. These respondents were more likely to favour MAID eligibility for mature minors with progressive or terminal illness (96%) or intractable pain (46%), while there was less support for disability (29%) or mental disorders that the patient finds intolerable (8%) (CPS, 2016). Clinician views are important because clinicians would be responsible for providing MAID to mature minors if it were permitted.

The views of many healthcare practitioners in Canada are consistent with current international safeguards in Belgium, where mature minors requesting euthanasia must have a terminal illness causing intolerable physical pain. While mature minors with a mental disorder as the sole underlying medical condition are not explicitly excluded from Dutch euthanasia legislation, there are no reported cases of access to euthanasia for this reason. Adolescents and young adults are particularly susceptible to mental disorders such as depression and schizophrenia (CMHA, 2017). There are potential treatment options for a number of mental disorders, and restrictions on MAID for mental disorders may further help to ensure that these options are sought. This safeguard might also help ensure that MAID does not lay the groundwork leading to the normalization of suicide, particularly for this age group, which can be prone to

risky decision-making if not provided with the needed supports. As previously noted in Section 5.1, between 2012 and 2016, suicide remained the second-leading cause of death for people aged 15 to 19 in Canada (StatCan, 2018b).

6.2.4 Access to Palliative Care

It has been suggested that, as well as procedural safeguards for MAID for mature minors, there should be broader safeguards to help potentially mitigate the need for MAID among mature minors. As Section 5.5.4 points out, the decision to extend euthanasia to minors in Belgium was passed in conjunction with legislation that provided additional funding to increase access to, and training in, palliative care (Cohen-Almagor, 2009). Rather than furthering the divide between proponents of palliative care and supporters of euthanasia, the Belgian experience has increased communication between the two, and brought palliative care specialists into the euthanasia process through consultation (Cohen-Almagor, 2009). As also noted in Chapter 5, adequate PPC is not only care that is well funded, but also care that is timely and available locally, either in hospital settings or by specialized home care teams. Respondents to the CSPCP survey stressed the need for education on PPC for prospective patients and their families, and for healthcare practitioners who must be taught to recognize the appropriate timing for introducing PPC, the full range of services that PPC offers, and its potential effectiveness (CSPCP, 2018).

6.3 CONCLUSIONS

In describing the potential impacts of allowing or disallowing access to MAID by mature minors on the groups and individuals most directly implicated (patients, their families, and healthcare practitioners), this chapter has drawn upon legal, ethical, human rights, medical, and social arguments. It has also looked at impacts on society as a whole. However, it is difficult to fully capture these impacts in the absence of an existing regime in Canada of MAID for mature minors. Although the experiences of Belgium and the Netherlands provide important information, they are not directly transferable to the Canadian context. In the same way, while international examples of safeguards for a regime of EAS for mature minors can provide guidance for developing them in Canada, unique circumstances in the Canadian context would need to be considered.

Any decision-making in this area should take into consideration the views of all Canadians, gathered through national consultation exercises, and most importantly, the voices of youth themselves. At this time, there is a paucity of youth voices, including those of terminally ill youth, disabled youth, Indigenous youth, and youth in care.

7

Conclusion

- **Answering the Charge**
- **Final Thoughts**

7 Conclusion

This report answers the charge given to the CCA by the Ministers of Health and Justice, on behalf of the Sponsors, Health Canada and the Department of Justice Canada, as they relate to MAID for mature minors. As the main question of the charge requests, the report gathers available evidence to inform understanding of MAID for mature minors, within the clinical, legal, cultural, ethical, and historical context in Canada. The charge also includes a number of specific questions, the answers to which are summarized below in the same order as they were addressed in the preceding chapters.

7.1 ANSWERING THE CHARGE

What is the impact of chronological age on the legal capacity to request and consent to MAID?

The ability of minors to make end-of-life decisions cannot be predicated on chronological age alone. While decisional capacity has a developmental component, minors must not be understood as a homogenous group in terms of their development because cognitive and psychosocial development varies. Furthermore, the capacity to make healthcare choices is also a product of factors that are not dictated by chronological age, such as social and cultural environments and personal experience with illness and medical settings.

Nonetheless, neuroscientific and psychological research examining decision-making abilities over the course of development can provide important context. This research has supported the idea that adolescents attain cognitive maturity before social or emotional maturity. Chronological age can provide some insight, such as the fact that the cognitive foundations for decisional capacity are typically in place by early adolescence, and other maturational features necessary for informed consent are likely present before the age of 18. However, capacity cannot be equated with developmental generalizations about brain structure and function. Factors unique to each person must be considered on a case-by-case basis. Thus, criteria for informed consent have shifted away from age and towards individual experience and understanding. Similarly, the Supreme Court has recognized that chronological age is not determinative of when a minor has the capacity to make a free and informed decision.

What are the unique considerations related to mature minors requesting MAID (e.g., mature minors vs. adults and MAID vs. other healthcare decisions)?

Legislated approaches to the presumption of decisional capacity vary across Canada (Table 3.1). However, by adulthood, there is a legal presumption of decisional capacity that can only be rebutted in the presence of contrary evidence. Under common law, those under the age of majority must demonstrate capacity and maturity to be deemed a mature minor with a right to make their own healthcare decisions. This in itself subjects minors to a layer of scrutiny that is not typically invoked for adults. The scrutiny may be intensified under life-threatening circumstances that incite greater concern about the factors to which minors might be vulnerable during the decision-making process.

In part, the hesitation to allow access to MAID by mature minors reflects uncertainty about their ability to fully appreciate the consequences of this decision, and to make it without impulsiveness. Research has shown that some minors have the cognitive and emotional abilities to make critical healthcare decisions, including end-of-life choices. However, it is important to consider minors' unique context and how their capacity for well-contemplated decisions can be maximized. A healthcare environment that respects the patient's voice, and is grounded in communicative, supportive, and trusting relationships, may facilitate a minor's ability to provide valid informed consent.

Whether a minor has sufficient independence and maturity to make certain healthcare decisions autonomously, and therefore satisfy the voluntariness element of informed consent, is a key area of concern in considering whether to allow MAID for this population. What constitutes an autonomous healthcare decision does not have a single answer. A relational conception of autonomy acknowledges that capacity for autonomous decisions originates from, and is shaped by, social interactions. This conception also appreciates that the decisions and preferences of minors can be understood in relation to the perspectives of parents or guardians and other significant people in their lives; this reflects the way that healthcare decisions are often made. Everyone is relationally embedded to some degree, but this does not negate their autonomy or ability to provide informed consent.

According to some views, parental and societal responsibilities to care for and protect children mean that minors should not necessarily have full authority over critical healthcare decisions. Although most decisions about minors' healthcare

never give rise to litigation, Canadian case law has determined that whether minors will be given the right to make their own healthcare decisions depends on a complex interplay of a number of factors. Thus, courts have considered the complete circumstances of the minors involved. The Supreme Court's decision in *A.C.* provides important guidance to ensure that the decisions of mature minors are respected and followed. Even if a best interests test were applied, the mature, independent decision of the minor should be respected.

Perceptions of minors as vulnerable, and societal attitudes about the need to protect them, are central to the MAID discussion. These concerns, which may be magnified for children with disabilities or mental disorders, tend to centre on the potential exploitation of minors in the MAID context. However, disability and vulnerability can be understood as an interplay between a person's impairments and the accommodations available in their environment; this points to society's role in ensuring that everyone is heard and supported.

One question related to MAID and mature minors is whether MAID should be treated differently than other healthcare decisions that mature minors are typically permitted to make, particularly those that are likely to result in death. Despite the *Carter* conclusion that MAID is no different from other end-of-life decisions, this remains a highly charged topic. Furthermore, the exact medical course of action is one of many factors at play in complex cases of mature minors who wish to make life-ending choices. Legally and clinically, there is a need to consider a minor's entire medical and social situation.

What are the potential implications for individuals and other affected persons, including their families, care providers, and health professionals, related to MAID for mature minors?

To consider the potential implications of permitting or prohibiting MAID for mature minors, the Working Group drew upon a wide body of knowledge. Under legislation that permits euthanasia for minors in Belgium (since 2014) and the Netherlands (since 2002), 16 cases have been documented. This number is too small to inform future outcomes in other jurisdictions. Furthermore, the paucity of voices from terminally ill minors who may eventually be eligible to access MAID precludes a full understanding of how they may be affected by any change in the legislation, and what they view as either positive or negative consequences of permitting or prohibiting MAID for mature minors.

Allowing mature minors, as recognized under common law, to access MAID would provide them with an increased range of end-of-life choices and a certain degree of control over their death. However, one unintended consequence

might be that some terminally ill minors feel pressure to request MAID as a means of protecting their families from continued financial and/or emotional distress. The implications might be even more pronounced for minors with added vulnerabilities, including those who are disabled and/or living in the child welfare system. While there is no information directly related to MAID requests by minors in these categories, evidence shows that they struggle more routinely to have their voices heard in healthcare decision-making.

Another concern is that allowing mature minors to request MAID might also normalize suicide among young people, especially those who struggle with mental disorders and may be considered vulnerable. However, rather than focusing on the inabilities of certain groups, it is important to recognize vulnerability as a social construct generated by society's treatment of these groups. Thus, there is a social responsibility to support those who may be perceived as vulnerable by facilitating their ability to make informed, autonomous decisions, rather than diminishing their rights and limiting their options.

No evidence exists on how MAID eligibility for mature minors could affect families. Although this matter has not been sufficiently explored within a pediatric context, it is likely that individual outcomes would be dependent on a number of variables, including family dynamics, available social supports, and belief systems and culture. Choosing to help a child die may create pain and stress for some parents, but others might find release in helping their child to end their suffering and fulfil a final wish. While some studies explore the relationship between assisted dying and the grief of families, this research is limited to adults.

Finally, the majority of studies that have assessed the impact of MAID on healthcare practitioners have focused on adult patients, and these results cannot simply be transferred into the pediatric context. Since pediatric healthcare practitioners often develop close long-term relationships with their patients, a patient's death can involve an emotional burden for the healthcare team. Yet, it is not known whether this burden would be greater for mature minors than for adults, and whether practitioners providing MAID to mature minors would need different supports than those currently being developed for practitioners providing MAID to adults. Compared with healthcare practitioners' views of MAID for adult patients, surveys of those in the pediatric medical field indicate a greater unease about the prospect of providing MAID to minors, and a greater unwillingness to participate in the process. However, it is not yet known whether finding practitioners willing to provide MAID to mature minors would be a challenge.

What are the potential impacts on society for permitting or prohibiting mature minors' requests for MAID?

The view that minors are in need of heightened protection is a widely shared concern. Despite research demonstrating that some minors are capable of making critical healthcare decisions, including end-of-life choices, some argue that minors as a group (particularly those who are negatively affected by social determinants of health) are too vulnerable to be given the ability to request MAID. However, part of protecting potentially vulnerable patients is to ensure that they are listened to. Thus, it has been argued that, rather than denying healthcare choices to groups frequently labelled as vulnerable, society must provide the accommodations to ensure that everyone is protected not only from exploitation, but also from being ignored and excluded.

Denying MAID to mature minors would pose a potential future legal challenge if a case were to be brought forward in which a mature minor argued that their constitutional rights were being denied. Any such challenge, or change in current MAID legislation, might require courts or policy-makers to re-examine prevailing views of children and their capabilities, and the overlapping considerations of protection from harm and respect for autonomy.

Permitting mature minors to request MAID might also have clinical impacts related to the potential for MAID to either weaken or strengthen PPC services in Canada. In Belgium, the Netherlands, and Quebec, passage of assisted dying laws have included additional legislation to provide increased funding for palliative care services. Therefore, on the one hand, allowing MAID for mature minors might result in increased funding for PPC, or at least improve awareness of PPC services, in part by opening the lines of communication between healthcare practitioners and patients on difficult end-of-life topics including suffering. On the other hand, MAID might have a negative impact on palliative care services by diverting resources away from palliative care, leading the public to conflate palliative care with hastened death, and causing patients to decline pain management because they wish to maintain the capacity to consent to MAID.

What are the potential risks and safeguards that might be considered related to MAID for mature minors?

Given the unique considerations related to minors in a healthcare context, the issue of safeguards for MAID is critical. While safeguards for MAID must provide sufficient protection to the group in question, safeguards that are too restrictive might limit the eligibility of people who would otherwise qualify. Safeguards may be put in place by federal legislation, provincial and territorial legislation, or the healthcare sector through its professional and/or regulatory bodies. No evidence has established that a minimum age would be an effective safeguard for protecting those who are incapable of making an informed, voluntary decision about MAID.

Additional safeguards that might be considered include specific medical criteria for the eligibility of mature minors, and an expanded medical team to determine capacity in minors. In Canada, pediatric healthcare already relies upon an interprofessional approach that includes psychologists and social workers, as well as child/adolescent psychiatrists who may consult with medical teams and families. In the event of a MAID request, these psychosocial professionals, who are already integrated in the healthcare team, might benefit from an existing familiarity with the patient, and their particular circumstances, when making a determination of maturity or capacity.

Parental consent exists as a safeguard for minors requesting euthanasia in Belgium and the Netherlands. This safeguard recognizes the patient and parents or guardians as a decision-making unit in pediatric healthcare. While it is intended to protect children, this safeguard might also pose a risk to children who have troubled relationships with their parents, or to parents who view the decision to grant their children permission to access MAID as unbearable. Others argue that parental consent is not truly an effective safeguard, as some parents with the natural inclination to save their child at any cost might be unable, under any circumstances, to agree to their child's request.

Finally, proponents of increased access to palliative care argue that universal PPC, supported by additional resources, can act as a potential safeguard. According to them, before any extension of MAID to mature minors, PPC should be available in a timely manner and locally, whether in hospital or at home. While none deny that PPC should be an option available to everyone who needs or wants it, critics argue that PPC will never be a substitute for MAID and that these two options are not mutually exclusive.

What are the relevant gaps in domestic and international knowledge and research related to MAID for mature minors?

The Working Group identified a number of gaps in domestic and international knowledge and research; if available, this evidence would inform the issue of MAID for mature minors.

First, there is a paucity of evidence that captures the voices of youth, who would be most affected by the prohibiting or permitting of MAID for mature minors, and of the families, in particular the parents and siblings of terminally ill youth and bereaved families. Internationally, minimal information exists on cases of euthanasia for minors, and none on the families in Belgium and the Netherlands who have gone through the process. Evidently, this particular lack of knowledge relates to the very small number of cases, as well as protecting the private and personal nature of the decision-making process, the experience itself, and subsequent experience of bereavement.

Second, there is little available evidence that documents the views of minors who may be perceived as particularly vulnerable, including those with disabilities, Indigenous youth, and/or those in the child welfare system. These voices have been historically excluded, leaving gaps in knowledge.

Third, few clinical studies have focused on the health issues of youth, including their experience with suffering, end-of-life care, and palliative care. It proved difficult to find quality studies on young people generally, and even more difficult to find studies specific to adolescents, the age range most likely to fit the definition of a mature minor. While this report cites survey and academic literature that explores the experiences of pediatric physicians, it lacks the views of others working in pediatric healthcare teams, especially nurses who are often intimately involved in care. The scarcity of documented cases of EAS for capable minors limits the experiential knowledge of providing MAID to this group.

Fourth, another gap in knowledge relates to Canadian case law. While courts have addressed cases of minors wishing to withhold or withdraw potentially life-saving or life-prolonging treatment, there have been no cases of minors wishing to request MAID.

Finally, the available data in Canada on MAID have many gaps. For example, data collection remains uneven across provinces and territories, and basic information on how many MAID requests have been denied, and the reasons

for denial, is lacking. There is limited information on the youngest patients requesting MAID. Data are available in the 18 to 45 age range, but little is known about patients aged 18 to 25, including the number of requests made, and how many were granted or denied.

7.2 FINAL THOUGHTS

Canada and Canadians are grappling with the question about whether to extend MAID to mature minors in an increasingly diverse society that is also being exposed to changing ideas about death and dying. The provision of MAID to “vulnerable” groups such as mature minors is a charged issue, and some ethical debates remain unresolved, including whether MAID should be on a spectrum with other life-ending healthcare decisions. Although the Working Group examined a wide body of evidence covering clinical, developmental, ethical, legal, and regulatory perspectives, it concludes that the many gaps in knowledge described above make it difficult to arrive at definitive answers in some cases. Any deliberation on whether to permit currently excluded groups to request MAID must weigh the available evidence, ensure full consultation with Canadian society, especially those groups most likely to be affected, and consider appropriate safeguards and supports.

Several critical issues are relevant to the question of whether to permit mature minors to request MAID, including whether MAID would ever be appropriate for mature minors with mental disorders as the sole underlying medical condition. Additional considerations include how to address the requirements for respecting individual autonomy in health-related decision-making, promoting equity, and alleviating intolerable suffering while also taking every care to prevent harms to mature minors. These issues are not mutually exclusive, and will therefore have a number of overlapping considerations. As discussed throughout this report, a central concern surrounding potential MAID eligibility for mature minors is that this group is in need of heightened protection, and is often perceived as vulnerable. Yet, vulnerability includes two aspects that must be considered together: protection from exploitation and protection from exclusion.

If MAID for mature minors were permitted, a number of safeguards would need to be considered to respond to this group’s unique end-of-life concerns. One potential safeguard might be to increase the availability of PPC services to reduce the possibility that a minor will choose MAID because PPC is unavailable.

This report demonstrates that mature minors are developing autonomy within a relational context, which is extremely important to their decision-making. Thus, other potential safeguards might reflect a relational approach to healthcare decision-making that involves the patient, their family (parents or guardians), and an interprofessional healthcare team. Age, while certainly a factor, is not the most important variable in determining capacity for informed consent. Moreover, the issue of age in Canada is complicated by the fact that Quebec law does not recognize the mature minor doctrine. This made it difficult for the Working Group to move forward with considerations of providing access to MAID for minors in Quebec through the mature minors focus used in this report.

The fact that only two jurisdictions allow EAS for minors, and that cases remain extremely rare within those jurisdictions, means little is known for certain about the practice. While the examples from Belgium and the Netherlands can provide insight, significant knowledge gaps remain. There is also a paucity of evidence from Indigenous people on the relevance and implications of the mature minor doctrine, as well as MAID for any age, for their communities. The views of young people on allowing access to MAID for mature minors are critical to inform the discussion and debate on this issue. At this point, their voices have not been adequately consulted or heard.

References

References

- AAP Committee on Bioethics and Committee on Hospital Care (American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care). (2000). Palliative care for children. *Pediatrics*, 106(2), 351-357.
- ABCA (Alberta Court of Appeal). (1986). *J.S.C. v. Wren*, 1986 ABCA 249 (CanLII). Edmonton (AB): ABCA.
- ABCA (Alberta Court of Appeal). (2003). *U.(C.)(Friend of) v. McGonigle*, 2003 ABCA 66 (CanLII). Edmonton (AB): ABCA.
- ABCA (Alberta Court of Appeal). (2008). *Martin v. Findlay*, 2008 ABCA 161. Edmonton (AB): ABCA.
- ABPC (Alberta Provincial Court). (2002). *Alberta (Director of Child Welfare) v. B.H.*, 2002 ABPC 39. Calgary (AB): ABPC.
- ABQB (Court of Queen's Bench of Alberta). (2000). *C.U. v. Alberta (Director of Child Welfare)*, 2000 ABQB 626 (CanLII). Edmonton (AB): ABQB.
- ABQB (Court of Queen's Bench of Alberta). (2002). *H. (B.) v. Alberta (Director of Child Welfare)*, 2002 ABQB 371 (CanLII). Calgary (AB): ABQB.
- AHS (Alberta Health Services). (2017). *Capacity Assessment Checklist for Medical Assistance in Dying*. Edmonton (AB): AHS.
- Alberta Children's Hospital. (2016). *CAYAC Consult on MAID for Mature Minors*. Calgary (AB): Alberta Health Services.
- Alberta Children's Hospital. (2017). About CAYAC. Retrieved October 2017, from <http://fcrc.albertahealthservices.ca/youth/cayac/about.php>.
- Alderson, P., Sutcliffe, K., & Curtis, K. (2006a). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91(4), 300-303.
- Alderson, P., Sutcliffe, K., & Curtis, K. (2006b). Children's competence to consent to medical treatment. *Hastings Centre Report*, 36(6), 25-34.
- Alderson, P. (2017). Children's consent and the zone of parental discretion. *Clinical Ethics*, 12(2), 55-62.
- Allan, B. & Smylie, J. (2015). *First Peoples, Second Class Treatment: The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada*. Toronto (ON): Wellesley Institute.
- Antle, B. J. (2004). Factors associated with self-worth in young people with physical disabilities. *Health & Social Work*, 29(3), 167-175.
- APA (American Psychiatric Association). (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. Washington (DC): APA.
- Arnup, K. (2018). *Family Perspectives: Death and Dying in Canada*. Ottawa (ON): The Vanier Institute for the Family.
- ARPA (Association for Reformed Political Action). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.

- Bach, M. & Kerzner, L. (2010). *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities Through Law, Policy and Practice*. Toronto (ON): Law Commission of Ontario.
- Bartholome, W. G. (1993). Care of the dying child: The demands of ethics. *Second Opinion*, 18(4), 25-39.
- Batavia, A. I. (2001). The ethics of PAS: Morally relevant relationships between personal assistance services and physician-assisted suicide. *Archives of Physical Medicine and Rehabilitation*, 82 (Suppl 2), S25-S31.
- BCCA (British Columbia Court of Appeal). (1999). *Van Mol v. Ashmore*, 1999 BCCA 6 (CanLII). Vancouver (BC): BCCA.
- BCCA (British Columbia Court of Appeal). (2015). *Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91 (CanLII). Vancouver (BC): BCCA.
- BCCLA (British Columbia Civil Liberties Association). (2016). *Lamb v. Canada Case Documents*. Vancouver (BC): BCCLA.
- BCPC (British Columbia Provincial Court). (2005). *Director of Child Welfare v. S.J.B.* 2005 BCPC 0105. Vancouver (BC): BCPC.
- BCSC (British Columbia Supreme Court). (2005). *B. (S.J.) v. British Columbia (Director of Child, Family and Community Service)*, 2005 BCSC 573 (CanLII). Vancouver (BC): BCSC.
- BCSC (British Columbia Supreme Court). (2012). *Carter v. Canada (Attorney General)*, 2012 BCSC 886. Vancouver (BC): BCSC.
- Beauchamp, T. L. & Childress, J. F. (2013). *Principles of Biomedical Ethics* (7th ed.). New York (NY): Oxford University Press.
- Bélanger-Hardy, L. (2017). Chapter 14: Informed Choice in Medical Care. In J. Erdman, V. Gruben & E. Nelson (Eds.), *Canadian Health Law and Policy* (5th ed.). Toronto (ON): LexisNexis Canada.
- Berger, R. S. (2012). Including adolescents and young adults in decisions at the end-of-life. *Journal of Student Nursing Research*, 5(1), 12-18.
- Birchley, G. (2016). Harm is all you need? Best interests and disputes about parental decision-making. *Journal of Medical Ethics*, 42(2), 111-115.
- Birnie, K. A., Chambers, C. T., Fernandez, C. V., Forgeron, P. A., Latimer, M. A., McGrath, P. J., ... Finley, G. A. (2014). Hospitalized children continue to report undertreated and preventable pain. *Pain Research and Management*, 19(4), 198-204.
- Blackstock, C. (2009). *Jordan's Story: How One Boy Inspired a World of Change*. In *Aboriginal Children's Health: Leaving No Child Behind - Canadian Supplement to the State of the World's Children 2009*. Toronto (ON): UNICEF Canada.
- Blakemore, S. J. & Robbins, T. W. (2012). Decision-making in the adolescent brain. *Nature Neuroscience*, 15(9), 1184-1191.

- Blazin, L. J., Cecchini, C., Habashy, C., Kaye, E. C., & Baker, J. N. (2018). Communicating effectively in pediatric cancer care: Translating evidence into practice. *Children (Basel)*, 5(3), 40.
- Bluebond-Langner, M. (1978). *The Private Worlds of Dying Children*. Princeton (NJ): Princeton University Press.
- Bluebond-Langner, M., Belasco, J. B., Goldman, A., & Belasco, C. (2007). Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *Journal of Clinical Oncology*, 25(17), 2414-2419.
- Bluebond-Langner, M., Belasco, J.B., & DeMesquita Wander, M. (2010). "I want to live, until I don't want to live anymore": Involving children with life-threatening and life-shortening illnesses in decision making about care and treatment. *Nursing Clinics of North America*, 45(3), 329-343.
- Bolt, E. E., Flens, E. Q., Pasman, H., Willems, D., & Onwuteaka-Philipsen, B. D. (2017). Physician-assisted dying for children is conceivable for most Dutch paediatricians, irrespective of the patient's age or competence to decide. *Acta Paediatrica*, 106(4), 668-675.
- Bond, J. (2018). A minor issue? The shortcomings of the eligibility requirements for medically assisted death in Canada. *Appeal*, 23, 41-64.
- Booth, C. M., Li, G., Zhang-Salmons, J., & Mackillop, W. J. (2010). The impact of socioeconomic status on stage of cancer at diagnosis and survival: A population-based study in Ontario, Canada. *Cancer*, 116(17), 4160-4167.
- Bourassa, C. & Bendig, M. (2015). *Experiences of First Nations, Inuit, and Metis people with Advanced Cancer Illness and at the End-of-Life*. Winnipeg (MB): Canadian Virtual Hospice.
- Bovens, L. (2015). Child euthanasia: Should we just not talk about it? *Journal of Medical Ethics*, 41(8), 630-634.
- Branscombe, N., Daley, A., & Phipps, S. (2016). *Perceived Discrimination, Belonging and the Life Satisfaction of Canadian Adolescents with Disabilities*. Halifax (NS): Dalhousie University.
- Bruns, F., Blumenthal, S., & Hohendorf, G. (2016). Assisted suicide in Germany: Medical diagnoses and personal reasons of 117 decedents. *Deutsche Medizinische Wochenschrift*, 141, e32-e37.
- Buchanan, A. E. & Brock, D. W. (1989). *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, United Kingdom: Cambridge University Press.
- Butler, M., Tiedemann, M., Nicol, J., & Valiquet, D. (2013). *Euthanasia and Assisted Suicide in Canada*. Ottawa (ON): Library of Parliament.
- CACL (Canadian Association for Community Living). (2013). *Assuring Income Security and Equality for Canadians with Intellectual Disabilities and their Families*. Toronto (ON): CACL.
- CACL (Canadian Association for Community Living). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.

- CAMAP (Canadian Association of MAID Assessors and Providers). (2017). *CAMAP Survey Results August 2017*. Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Canadian Cancer Society. (2016). *Right to Care: Palliative Care for All Canadians*. Toronto (ON): Canadian Cancer Society.
- Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1), e48-e60.
- Carnevale, F. A. (2007). The birth of tragedy in pediatrics: A phronetic conception of bioethics. *Nursing Ethics*, 14(5), 571-582.
- Carnevale, F. A., Campbell, A., Collin-Vézina, D., & Macdonald, M. E. (2015). Interdisciplinary studies of childhood ethics: Developing a new field of inquiry. *Children & Society*, 29(6), 511-523.
- Carnevale, F. A. (2017). *Medical Assistance in Dying: Exploring Potential Implications for Paediatrics*. Paper presented at 2017 Canadian Association of Paediatric Health Centres Annual Conference: Engaging Children, Youth and Family: Are You Ready to Move Beyond Good Intentions?, Montreal (QC).
- Carnevale, F. A., Teachman, G., & Bogossian, A. (2017). A relational ethics framework for advancing practice with children with complex health care needs and their parents. *Comprehensive Child and Adolescent Nursing*, 40(4), 268-284.
- Carstairs, S. (2010). *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Ottawa (ON): The Senate of Canada.
- Cartagena, R. G., Thompson, A. K., Katebian, K., Lemmens, T., Geist, R., Schipper, H., ... Handelman, M. (2016). *Understanding the Relationship Between Suffering and Capacity at the End-of-Life: A Pilot Study*. Toronto (ON): Law Commission of Ontario.
- Cassell, E. J. (1991). Recognizing Suffering. *Hastings Center Report*, 21(3), 24-31.
- Cassell, E. J. (1999). Diagnosing suffering: A perspective. *Annals of Internal Medicine*, 131(7), 531-534.
- Caxaj, C. S., Schill, K., & Janke, R. (2018). Priorities and challenges for a palliative approach to care for rural Indigenous populations: A scoping review. *Health and Social Care in the Community*, 26(3), e329-e336.
- CBA (Canadian Bar Association). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CBS (Centraal Bureau voor de Statistiek). (2018). Deaths; Underlying Cause of Death (shortlist), Sex, Age. Retrieved September 2018, from <http://statline.cbs.nl/statweb/publication/?vw=t&dm=slen&pa=7052eng>.
- CCB (Cour Constitutionnelle de Belgique). (2015). *Arrêt n° 153/2015*. Brussels, Belgium: CCB.

- CCRC (Canadian Coalition for the Rights of Children). (2017). *Medical Assistance in Dying in Canada: Denial of Rights to End Intolerable Suffering of Mature Minors*. Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CCRL (Catholic Civil Rights League). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CCSACCS (Canadian Cancer Society's Advisory Committee on Cancer Statistics). (2015). *Canadian Cancer Statistics 2015. Special Topic: Predictions of the Future Burden of Cancer in Canada*. Toronto (ON): Canadian Cancer Society.
- CDC (Centers for Disease Control and Prevention). (2017). Underlying Cause of Death 1999-2016 on CDC Wonder Online Database. Retrieved May 2018, from <https://wonder.cdc.gov/ucd-icd10.html>.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2004). *Premier Rapport aux Chambres Législatives (2002–2003)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2006). *Deuxième Rapport aux Chambres Législatives (2004–2005)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2008). *Troisième Rapport aux Chambres Législatives (2006–2007)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2010). *Quatrième Rapport aux Chambres Législatives (2008–2009)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2012). *Cinquième Rapport aux Chambres Législatives (2010–2011)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2014). *Sixième Rapport aux Chambres Législatives (2012–2013)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2016). *Septième Rapport aux Chambres Législatives (2014–2015)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFCEE (Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie). (2018). *Huitième Rapport aux Chambres Législatives (2016–2017)*. Brussels, Belgium: Chambre des Représentants et Sénat de Belgique.
- CFPC (College of Family Physicians of Canada). (2012). *Position Statement - Issues Related to End of Life Care*. Mississauga (ON): CFPC.
- CH (Covenant Health). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CHAC (Catholic Health Alliance of Canada). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.

- Chakraborty, R., El-Jawahri, A. R., Litzow, M. R., Syrjala, K. L., Parnes, A. D., & Hashmi, S. K. (2017). A systemic review of religious beliefs about major end-of-life issues in the five major world religions. *Palliative and Supportive Care*, 15, 609-622.
- Chambaere, K., Centeno, C., Hernandez, E. A., Van Wesemael, Y., Guillen-Grima, F., Deliens, L., & Payne, S. (2011). *Palliative Care Development in Countries with a Euthanasia Law*. Vilvoorde, Belgium: European Association for Palliative Care.
- Chappell, N. & Hollander, M. (2011). An evidence-based policy prescription for an aging population. *HealthcarePapers*, 11(1), 8-18.
- Charland, L. C. (2015). Decision-Making Capacity. Retrieved November 2017, from <https://plato.stanford.edu/archives/fall2015/entries/decision-capacity/>.
- Charland, L. C., Lemmens, T., & Wada, K. (2016). Decision-making capacity to consent to medical assistance in dying for persons with mental disorders. *Journal of Ethics in Mental Health, Open Volume*, 1-14.
- Charlebois, J. & Cyr, C. (2015). Quality indicators for paediatric palliative care. *Paediatric Child Health*, 20(3), 145-147.
- Chenneville, T., Machacek, M., Tan, R., Lujan-Zilberman, J., Emmanuel, P., & Rodriguez, C. (2014). Decisional capacity among youth with HIV: Results from the MacArthur Competence Tool for Treatment. *AIDS Patient Care and STDs*, 28(8), 425-432.
- Cherry, M. J. (2013). Ignoring the data and endangering children: Why the mature minor standard for medical decision making must be abandoned. *Journal of Medicine and Philosophy*, 38(3), 315-331.
- CHNC (Community Health Nurses Canada). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CHRT (Canadian Human Rights Tribunal). (2016). *First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada (for the Minister of Indian and Northern Affairs Canada)*. Ottawa (ON): CHRT.
- Clarke, J. (2016). *Health at a Glance: Difficulty Accessing Health Care Services in Canada*. Ottawa (ON): Statistics Canada.
- CLF (Christian Legal Fellowship). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CMA (Canadian Medical Association). (2014). *CMA Policy: Euthanasia and Assisted Death*. Ottawa (ON): CMA.
- CMA (Canadian Medical Association). (2017). *CMA Policy: Medical Assistance in Dying*. Ottawa (ON): CMA.
- CMA (Canadian Medical Association). (n.d.). Health Equity and the Social Determinants of Health. Retrieved June 2018, from <https://www.cma.ca/En/Pages/health-equity.aspx>.

- CMHA (Canadian Mental Health Association). (2017). Fast Facts about Mental Illness. Retrieved November 2017, from <https://cmha.ca/media/fast-facts-about-mental-illness/>.
- CMPA (The Canadian Medical Protective Association). (n.d.). Good Practices Guide: Informed Consent. Retrieved December 2017, from https://www.cmpa-acpm.ca/serve/docs/ela/goodpracticesguide/pages/communication/Informed_Consent/informed_consent-e.html.
- CMQ (Collège des médecins du Québec). (2009). *Physicians, Appropriate Care and the Debate on Euthanasia: A Reflection*. Montréal (QC): CMQ.
- CMQ (Collège des médecins du Québec). (2018). *Objet: Accès à des soins palliatifs de qualité au Québec*. Montréal (QC): CMQ.
- CNCE (Commission Nationale de Contrôle et d'Évaluation de la loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide). (2017). *Quatrième rapport à l'attention de la Chambre des Députés (Années 2015 et 2016)*. Grand Duchy of Luxembourg: Ministère de la Santé.
- CNO (College of Nurses of Ontario). (2017). *Practice Guideline: Consent*. Toronto (ON): CNO.
- Coggon, J. (2016). Mental capacity law, autonomy, and best interests: An argument for conceptual and practical clarity in the court of protection. *Medical Law Review*, 24(3), 396-414.
- Cohen-Almagor, R. (2009). Euthanasia policy and practice in Belgium: Critical observations and suggestions for improvement. *Issues in Law & Medicine*, 24(3), 187-218.
- Collectif des pédiatres. (2014). Extension de la loi relative à l'euthanasie: Une lettre ouverte de pédiatres. Retrieved October 2017, from <https://collectiefpediaterscollectifdespediatres.wordpress.com/lettre-ouverte/>.
- Constitutional Court of Colombia. (2014). *Judgment T970/14. Writ of Protection of Fundamental Rights Submitted by Julia Against Coomeva E.P.S.* Bogotá, Colombia: Constitutional Court of Colombia.
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics & Adolescent Medicine*, 156(1), 14-19.
- Coolen, P. R. (2012). Cultural Relevance in End-of-Life Care. Retrieved October 2017, from <https://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care>.
- Coughlin, K. W. (2018). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics & Child Health*, 23(2), 138-146.
- CPS (Canadian Paediatric Society). (2016). *Attitudes and Beliefs of Canadian Child Health Practitioners Regarding Medical Assistance in Dying for Paediatric Patients*. Ottawa (ON): CPS.
- CPS (Canadian Paediatric Society). (2017). *Medical Assistance in Dying: A Paediatric Perspective*. Ottawa (ON): CPS.

- CPSA (College of Physicians & Surgeons of Alberta). (2015). *Advice to the Profession: Informed Consent for Adults*. Edmonton (AB): CPSA.
- CPSBC (College of Physicians and Surgeons of British Columbia). (2018). *Final Disposition Report of the Inquiry Committee: File no. IC 201-0836*. Vancouver (BC): CPSBC.
- CPSNS (College of Physicians and Surgeons of Nova Scotia). (2018). *Professional Standard Regarding Medical Assistance in Dying*. Halifax (NS): CPSNS.
- CPSNS (College of Physicians & Surgeons of Nova Scotia). (n.d.). *Professional Standard and Guidelines Regarding Informed Patient Consent to Treatment*. Halifax (NS): CPSNS.
- CPSO (College of Physicians and Surgeons of Ontario). (2015a). *Policy Statement #3-15: Consent to Treatment*. Toronto (ON): CPSO.
- CPSO (College of Physicians and Surgeons of Ontario). (2015b). *Policy Statement #2-15: Professional Obligations and Human Rights*. Toronto (ON): CPSO.
- CPSO (College of Physicians and Surgeons of Ontario). (2016). *Policy Statement #4-16: Medical Assistance in Dying*. Toronto (ON): CPSO.
- CPSO (College of Physicians and Surgeons of Ontario). (n.d.). *Fact Sheet: Ensuring Access to Care: Effective Referral*. Toronto (ON): CPSO.
- CPSO (College of Physicians and Surgeons of Ontario). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- CPSP (Canadian Paediatric Surveillance Program). (2016). *2016 Results - Canadian Paediatric Surveillance Program*. Ottawa (ON): Canadian Paediatric Society and Public Health Agency of Canada.
- CRNBC (College of Registered Nurses of British Columbia). (2018a). *Scope of Practice for Registered Nurses — Part 5: Medical Assistance in Dying*. Vancouver (BC): CRNBC.
- CRNBC (College of Registered Nurses of British Columbia). (2018b). Practice Standards: Consent. Retrieved July 2018, from <https://www.crnbc.ca/Standards/PracticeStandards/Pages/consent.aspx>.
- CSPCP (Canadian Society of Palliative Care Physicians). (2016). *Submission to Special Joint Committee on Physician-Assisted Dying: January 27, 2016*. Surrey (BC): CSPCP.
- CSPCP (Canadian Society of Palliative Care Physicians). (2018). CSPCP Member Survey October 2017: Medical Assistance in Dying (MAiD) - Results February 2018. Retrieved March 2018, from <https://www.cspcp.ca/wp-content/uploads/2018/02/CSPCP-MAID-survey-report-Feb-2018.pdf>.
- Cuman, G. & Gastmans, C. (2017). Minors and euthanasia: A systematic review of argument-based ethics literature. *European Journal of Pediatrics*, 176(7), 837-847.
- Curtin, C. (2001). Eliciting children's voices in qualitative research. *American Journal of Occupational Therapy*, 55, 295-302.

- Dalhousie Health Law Institute. (2017). Advance Directives. Retrieved November 2017, from http://eol.law.dal.ca/?page_id=231.
- Dan, B., Fonteyne, C., & Clement de Cley, S. (2014). Self-requested euthanasia for children in Belgium. *The Lancet*, 383(9918), 671-672.
- Dastidar, J. G. & Odden, A. (2011). How do I determine if my patient has decision-making capacity? *The Hospitalist*, 8.
- Davies, A. M. (2001). Death of adolescents: Parental grief and coping strategies. *British Journal of Nursing*, 10(20), 1332-1342.
- Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philip, J. C., ... Kramer, R. F. (2008). Barrier to palliative care for children: Perceptions of pediatric health care workers. *Pediatrics* 12(2), 282-288.
- Davies, D. & Shariff, M. (2016). *Canadian Paediatric Society's Submission To The Special Joint Committee On Physician-Assisted Dying*. Ottawa (ON): Canadian Paediatric Society.
- Day, D. C. (2007). The capable minor's health care: Who decides? *Canadian Bar Review*, 86(3), 379-420.
- Day, E., Jones, L., Langner, R., & Bluebond-Langner, M. (2016). Current understanding of decision-making in adolescents with cancer: A narrative systematic review. *Palliative Medicine*, 30(10), 920-934.
- De Graves, S. & Aranda, S. (2002). Exploring documentation of end-of-life care of children with cancer. *International Journal of Palliative Nursing*, 8(9), 435-443.
- Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Elwyn, G., Vissers, K. C., & Van Weel, C. (2013). Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliative Medicine*, 27(1), 27-37.
- DeLoach, C. & Greer, B. G. (1981). *Adjustment to Severe Physical Disability : A Metamorphosis*. New York (NY): McGraw-Hill.
- Deschamps, P. (2016). L'autonomie personnelle: Individuelle ou relationnelle? Regard sur l'aide médicale à mourir [Personal autonomy: Individual or relational? A look at medical assistance in dying]. *Cahiers francophones de soins palliatifs*, 16(2), 12-20.
- Deschamps, P. (2017). *Les soins de fin de vie: Repères éthiques, juridiques et sociétaux*. Montréal (QC): LexisNexis.
- Diekema, D. S. (2004). Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics*, 25(4), 243-264.
- Doig, C. & Burgess, E. (2000). Withholding life-sustaining treatment: Are adolescents competent to make these decisions? *Canadian Medical Association Journal*, 162(11), 1585-1588.

- DOJC (Department of Justice Canada). (2016). Medical Assistance in Dying: Questions and Answers. Retrieved November 2017, from <http://www.justice.gc.ca/eng/cj-jp/ad-am/faq.html>.
- Dowbiggin, I. (2005). *A Concise History of Euthanasia: Life, Death, God, and Medicine*. New York (NY): Rowman & Littlefield.
- Downie, J. (2004). *Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada*. Toronto (ON): University of Toronto Press.
- Downie, J. & Llewellyn, J. (2008). Relational theory & Health law and policy. *Health Law Journal* (Special Edition), 193-210.
- Downie, J. & Lloyd-Smith, G. (2014). The making of a myth: Unreliable data on access to palliative care in Canada. *Health Law Review*, 22(3).
- Downie, J. (2017). End of Life Law and Policy. In J. Erdman, V. Gruben & E. Nelson (Eds.), *Canadian Health Law and Policy* (5th ed.). Toronto (ON): LexisNexis Canada.
- Downie, J. (2018a). *Providing MAID to Vulnerable, Indigenous, Homeless & Frail Elderly Populations*. Paper presented at 2nd Annual Medical Assistance in Dying Conference, Ottawa (ON).
- Downie, J. (2018b). An alternative to medical assistance in dying? The legal status of voluntary stopping eating and drinking (VSED). *Canadian Journal of Bioethics*, 1(2), 48-58.
- Drainoni, M.-L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access: Consumer perspectives. *Journal of Disability Policy Studies*, 17(2), 101-115.
- Dussel, V., Joffe, S., Hilden, J. M., Watterson-Schaeffer, J., Weeks, J. C., & Wolfe, J. (2010). Considerations about hastening death among parents of children who die of cancer. *Archives of Pediatrics & Adolescent Medicine*, 164(3), 231-237.
- Dyck, L. E. (1996). An analysis of Western, feminist, and Aboriginal science using the Medicine Wheel of Plains Indians. *Native Studies Review*, 11(2), 89-102.
- EFC (Evangelical Fellowship of Canada). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Eilertsen, M. E. B., Eilegård, A., Steineck, G., Nyberg, T., & Kreicbergs, U. (2013). Impact of social support on bereaved siblings' anxiety: A nationwide follow-up. *Journal of Pediatric Oncology Nursing*, 30(6), 301-310.
- Ells, C., Hunt, M. R., & Chambers-Evans, J. (2011). Relational autonomy as an essential component of patient-centered care. *International Journal of Feminist Approaches to Bioethics*, 4(2), 79-101.
- Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA*, 316(1), 79-90.

- Etchells, E., Darzins, P., Silberfeld, M., Singer, P., McKenny, J., Naglie, G., ... Strang, D. (1999). Assessment of patient capacity to consent to treatment. *Journal of General Internal Medicine* 14, 27-34.
- Evans, K. G. (2016). *Consent: A Guide for Canadian Physicians*. Ottawa (ON): Canadian Medical Protective Association.
- EWHC (High Court of Justice - Family Division). (1993). *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386. London, United Kingdom: EWHC.
- Ferguson, L. (2004). *The End Of An Age: Beyond Age Restrictions For Minors' Medical Treatment Decisions*. Ottawa (ON): Law Commission of Canada.
- Ferguson, L. (2007). Uncertainty and indecision in the legal regulation of children: The Albertan experience. *Canadian Journal of Family Law*, 23(2), 159-214.
- Flavelle, S. C. (2011). Experience of an adolescent living with and dying of cancer. *Archives of Pediatrics & Adolescent Medicine*, 165(1), 28-32.
- FNCFCSC (First Nations Child and Family Caring Society of Canada). (2005). *Wen De: We are Coming to the Light of Day*. Ottawa (ON): FNCFCSC.
- FNHA (First Nations Health Authority). (2017). Our History, Our Health. Retrieved September 2017, from <http://www.fnha.ca/wellness/our-history-our-health>.
- Fonteyne, C., Clement de Clety, S., & Dan, B. (2013). *Réflexions éthiques sur la fin de vie et l'euthanasie chez le mineur d'âge [Ethical Reflections on End-of-Life and Euthanasia in Minors]*. Brussels, Belgium: Belgian Royal Academy of Medicine.
- Foster, T., Bell, C. J., McDonald, C. F., Harris, J. S., & Gilmer, M. J. (2012a). Palliative nursing care for children and adolescents with cancer. *Nursing: Research and Reviews*, 2, 17-25.
- Foster, T. L., Gilmer, M. J., Vannatta, K., Barrera, M., Davies, B., Dietrich, M. S., ... Gerhardt, C. A. (2012b). Changes in siblings after the death of a child from cancer. *Cancer Nursing*, 35(5), 347-354.
- Franke, S. (2010). *Current Realities and Emerging Issues Facing Youth in Canada: An Analytical Framework for Public Policy Research, Development and Evaluation*. Ottawa (ON): Government of Canada Policy Research Initiative.
- Franklin, A. & Sloper, P. (2009). Supporting the participation of disabled children and young people in decision-making. *Children & Society*, 23, 3-15.
- Freyer, D. R. (2004). Care of the dying adolescent: Special considerations. *Pediatrics*, 113(2), 381-387.
- Freyer, D. R., Kuperberg, A., Sterken, D. J., Pastyrnak, S. L., Hudson, D., & Richards, T. (2006). Multidisciplinary care of the dying adolescent. *Child and Adolescent Psychiatric Clinics*, 15(3), 693-715.
- Friedel, M. (2014). Does the Belgian law legalising euthanasia for minors really address the needs of life-limited children? *International Journal of Palliative Nursing*, 20(6), 265-267.

- Friedrichsdorf, S. J., Postier, A., Andrews, G. S., Hamre, K. E. S., Steele, R., & Siden, H. (2017). Pain reporting and analgesia management in 270 children with a progressive neurologic, metabolic or chromosomally based condition with impairment of the central nervous system: Cross-sectional, baseline results from an observational, longitudinal study. *Journal of Pain Research*, 10, 1841-1852.
- Galvan, A. (2010). Adolescent development of the reward system. *Frontiers in Human Neuroscience*, 4(6), 1-9.
- Gamondi, C., Pott, M., Forbes, K., & Payne, S. (2013). Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: A qualitative study. *BMJ Supportive & Palliative Care*, 5, 146-152.
- Ganzini, L., Volicer, L., Nelson, W. A., Fox, E., & Derse, A. R. (2004). Ten myths about decision-making capacity. *Ethics*, 5(4), 263-267.
- Ganzini, L., Goy, E. R., & Dobscha, S. K. (2007). Why Oregon patients request assisted death: Family members' views. *Journal of General Internal Medicine*, 23(2), 154-157.
- Ganzini, L., Goy, E. R., Dobscha, S. K., & Prigerson, H. (2009). Mental health outcomes of family members of Oregonians who request physician aid in dying. *Journal of Pain and Symptom Management*, 38(6), 807-815.
- Gaudet, S. (2007). *Emerging Adulthood: A New Stage in the Life Course — Implications for Policy Development*. Ottawa (ON): Government of Canada Policy Research Initiative.
- GC (Government of Canada). (1982). *Canadian Charter of Rights and Freedoms*. Ottawa (ON): GC.
- GC (Government of Canada). (2012a). About Primary Health Care. Retrieved April 2018, from <https://www.canada.ca/en/health-canada/services/primary-health-care/about-primary-health-care.html>.
- GC (Government of Canada). (2012b). Canada's Health Care System. Retrieved October 2017, from <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/canada.html>.
- GC (Government of Canada). (2016). *Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*. Ottawa (ON): GC.
- GC (Government of Canada). (2017a). *2nd Interim Report on Medical Assistance in Dying in Canada*. Ottawa (ON): Health Canada.
- GC (Government of Canada). (2017b). *Interim Update on Medical Assistance in Dying in Canada June 17 to December 31, 2016*. Ottawa (ON): Health Canada.
- GC (Government of Canada). (2018). *Third Interim Report on Medical Assistance in Dying in Canada*. Ottawa (ON): Health Canada.
- Geddes, G. (2017). *Medicine Unbundled: A Journey through the Minefields of Indigenous Health Care*. Victoria (BC): Heritage House Publishing Company Ltd.

- Geist, R. & Opler, S. E. (2010). A guide for health care practitioners in the assessment of young people's capacity to consent to treatment. *Clinical Pediatrics*, 49(9), 834-839.
- Gerhardt, C. A., Fairclough, D. L., Grossenbacher, J. C., Barrera, M., Gilmer, M.J., Foster, T. L., ... Vannatta, K. (2011). Peer relationships of bereaved siblings and comparison classmates after a child's death from cancer. *Journal of Pediatric Psychology*, 37(2), 209-219.
- Gibson, B. E., Carnevale, F. A., & King, G. (2012). "This is my way": Reimagining disability, in/dependence and interconnectedness of persons and assistive technologies. *Disability & Rehabilitation*, 34(22), 1894-1899.
- Gibson, B. E. (2016). *Rehabilitation: A Post-Critical Approach*. New York (NY): Taylor and Francis.
- Giglio, F. & Spagnolo, A. G. (2014). Pediatric euthanasia in Belgium: Some ethical considerations. *Journal of Medicine and the Person*, 12, 146-149.
- Gilbar, R. & Miola, J. (2014). One size fits all? On patient autonomy, medical decision-making, and the impact of culture. *Medical Law Review*, 23(3), 375-399.
- Gill, C. J. (2000). Health professionals, disability, and assisted suicide: An examination of relevant empirical evidence and reply to Batavia (2000). *Psychology, Public Policy, and Law*, 6(2), 526-545.
- Gilmour, J., Harrison, C., Asadi, L., Cohen, M. H., & Vohra, S. (2011). Treating teens: Considerations when adolescents want to use complementary and alternative medicine. *Pediatrics* 128(Supplement 4), S161-S166.
- Gilmour, J. M. (2017). Legal Capacity and Decision-Making. In J. Erdman, V. Gruben & E. Nelson (Eds.), *Canadian Health Law and Policy* (5th ed.). Toronto (ON): LexisNexis Canada.
- Goldhagen, J., Fafard, M., Komatz, K., Eason, T., & Livingood, W. C. (2016). Community-based pediatric palliative care for health related quality of life, hospital utilization and costs lessons from a pilot study. *BMC Palliative Care*, 15(73).
- Golding, L. & Rosenbaum, D. C. (2018, March 13). Ontario Court Upholds Requirement that Physicians Provide an Effective Referral, and Comments on the Legal Status of CPSO Policies, *Fasken Knowledge Health Bulletin*.
- Goraya, J. (2016). Access to Health Care on Aboriginal Reserves. Retrieved February 2018, from <https://ppgreview.ca/2016/04/06/access-to-health-care-on-aboriginal-reserves-2/>.
- Gov. of AB (Government of Alberta). (2000). *Health Information Act, R.S.A. 2000, Chapter H-5*. Edmonton (AB): Gov. of AB.
- Gov. of AB (Government of Alberta). (2008). *Adult Guardianship and Trusteeship Act, SA 2008, c.A-4.2*. Edmonton (AB): Gov. of AB.
- Gov. of AB (Government of Alberta). (2016). *What We Heard: Medical Assistance in Dying*. Edmonton (AB): Government of Alberta.

- Gov. of BC (Government of British Columbia). (1996a). *Health Professions Act, RSBC 1996, c 183*. Victoria (BC): Gov. of BC.
- Gov. of BC (Government of British Columbia). (1996b). *Infants Act [RSBC 1996] c. 223*. Victoria (BC): Gov. of BC.
- Gov. of BC (Government of British Columbia). (1996c). *Health Care (Consent) and Care Facility (Admission) Act*. Victoria (BC): Gov. of BC.
- Gov. of BC (Government of British Columbia). (1996d). *Representation Agreement Act, RSBC 1996, c. 405*. Victoria (BC): Gov. of BC.
- Gov. of Belgium (Federal Government of Belgium). (2002). *Loi relative à l'euthanasie [The Belgian Act on Euthanasia as of 28 May 2002 (Unofficial Translation published in Ethical Perspectives, 9(2-3), 182-188)]*. Brussels, Belgium: Federal Ministry of Justice.
- Gov. of Belgium (Government of Belgium). (2014). *Loi modifiant la loi du 28 mai 2002 relative à l'euthanasie, en vue d'étendre l'euthanasie aux mineurs*. Retrieved August 2018, from http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&table_name=loi&cn=2014022803.
- Gov. of CA (Government of California). (2015). *End of Life Option Act*. Sacramento (CA): Gov. of CA.
- Gov. of CA (Government of California). (2017). *California End of Life Option Act 2016 Data Report*. Sacramento (CA): California Department of Public Health.
- Gov. of CA (Government of California). (2018). *California End of Life Option Act 2017 Data Report*. Sacramento (CA): California Department of Public Health.
- Gov. of CO (Government of Colorado). (2016). *Colorado End-of-Life Options Act*. Denver (CO): Gov. of CO.
- Gov. of Colombia (Government of Colombia). (2015). *Resolution Number 00001216 of 2015*. Bogotá, Colombia: Ministry of Health and Social Protection.
- Gov. of DC (Government of the District of Columbia). (2016). *Death with Dignity Act of 2016*. Washington (DC): Council of the District of Columbia.
- Gov. of Germany (Government of Germany). (1998). *German Criminal Code*. Berlin, Germany: Federal Ministry of Justice.
- Gov. of Germany (Government of Germany). (2015). *Beschluss des Bundesrates, Gesetz zur Strafbarkeit der geschäftsmäßigen Förderung der Selbsttötung [Act to Criminalize Commercial Assisted Suicide]*. Berlin, Germany: Gov. of Germany.
- Gov. of HI (Government of Hawaii). (2018). *Our Care, Our Choice Act*. Honolulu (HI): Gov. of HI.
- Gov. of Luxembourg (Government of the Grand Duchy of Luxembourg). (2009). *Act of 16 March 2009 on Euthanasia and Assisted Suicide*. Luxembourg, Grand Duchy of Luxembourg: Ministry of Health.

- Gov. of Luxembourg (Government of the Grand Duchy of Luxembourg). (2018). Deaths by Age Group and Sex. Retrieved September 2018, from https://statistiques.public.lu/stat/TableViewer/tableViewHTML.aspx?ReportId=12884&IF_Language=eng&MainTheme=2&FldrName=2&RFPPath=96.
- Gov. of MB (Government of Manitoba). (1993). *The Vulnerable Persons Living with a Mental Disability Act, CCSM c. V90*. Winnipeg (MB): Gov. of MB
- Gov. of MB (Government of Manitoba). (2017). *The Medical Assistance in Dying (Protection for Health Professionals and Others) Act, CCSM, c. M92*. Winnipeg (MB): Gov. of MB.
- Gov. of NB (Government of New Brunswick). (1976). *Medical Consent of Minors Act, SNB 1976, c M-6.1*. Fredericton (NB): Gov. of NB.
- Gov. of NS (Government of Nova Scotia). (1989). *Hospitals Act, RS 1989, c. 208*. Halifax (NS): Gov. of NS.
- Gov. of ON (Government of Ontario). (1990a). *Public Hospitals Act, R.S.O. 1990, c. P.40*. Toronto (ON): Gov. of ON.
- Gov. of ON (Government of Ontario). (1990b). *Private Hospitals Act, R.S.O. 1990, c. P.24*. Toronto (ON): Gov. of ON.
- Gov. of ON (Government of Ontario). (1990c). *Independent Health Facilities Act, R.S.O. 1990, c. I.3*. Toronto (ON): Gov. of ON.
- Gov. of ON (Government of Ontario). (1996). *Health Care Consent Act, SO 1996, c. 2*. Toronto (ON): Gov. of ON.
- Gov. of ON (Government of Ontario). (2004). *Personal Health Information Protection Act, S.O. 2004, c. 3, Sched. A*. Toronto (ON): Gov. of ON.
- Gov. of ON (Government of Ontario). (2017). *An Act to Amend Various Acts with Respect to Medical Assistance in Dying, SO 2017, c.7*. Toronto (ON): Gov. of ON.
- Gov. of OR (Government of Oregon). (1997). *The Oregon Death With Dignity Act*. Salem (OR): The General Assembly of the State of Oregon.
- Gov. of OR (Government of Oregon). (2018a). *Oregon Death with Dignity Act: Data Summary 2017*. Salem (OR): Oregon Health Authority.
- Gov. of OR (Government of Oregon). (2018b). Death Data. Retrieved May 2018, from www.oregon.gov/oha/ph/BirthDeathCertificates/VitalStatistics/death/Pages/index.aspx.
- Gov. of PE (Government of Prince Edward Island). (1988). *Consent to Treatment and Healthcare Directives Act, RSPEI 1988, c. C-17.2*. Charlottetown (PE): Gov. of PE.
- Gov. of QC (Government of Quebec). (1991). *Civil Code of Quebec, SQ 1991, c.64*. Québec (QC): Gov. of QC.
- Gov. of QC (Government of Quebec). (2012). *Select Committee on Dying with Dignity: Report*. Québec (QC): National Assembly of Quebec.

- Gov. of QC (Government of Quebec). (2014). *An Act Respecting End-Of-Life Care, SQ 2014, c. 2*. Québec (QC): Gov. of QC.
- Gov. of QC (Government of Quebec). (2016). *Rapport annuel d'activités: 10 décembre 2015 — 30 juin 2016*. Québec (QC): Commission sur les soins de fin de vie.
- Gov. of QC (Government of Quebec). (2017a). *Rapport annuel d'activités: 1er juillet 2016 — 30 juin 2017*. Québec (QC): Commission sur les soins de fin de vie.
- Gov. of QC (Government of Quebec). (2017b). *Code of Ethics of Physicians, CQLR c M-9, r 17*. Québec (QC): Gov. of QC.
- Gov. of SK (Government of Saskatchewan). (2000). *The Adult Guardianship and Co-decision-making Act, SS 2000, c. A-5.3*. Regina (SK): Gov. of SK.
- Gov. of SK (Government of Saskatchewan). (2015). *The Healthcare Directives and Substitute Healthcare Decision Makers Act, c. H-0.002*. Regina (SK): Gov. of SK.
- Gov. of Switzerland (Government of Switzerland). (1942). *Swiss Criminal Code*. Bern, Switzerland: Swiss Confederation.
- Gov. of Switzerland (Government of Switzerland). (2018a). Suicide assisté selon le sexe et l'âge. Retrieved September 2018, from <https://www.bfs.admin.ch/bfs/fr/home/statistiques/sante/etat-sante/mortalite-causes-deces/specifiques.assetdetail.3742886.html>.
- Gov. of Switzerland (Government of Switzerland). (2018b). Nombre de décès et taux de mortalité selon les principales causes de décès, la nationalité et le sexe. Retrieved September 2018, from <https://www.bfs.admin.ch/bfs/fr/home/statistiques/sante/etat-sante/mortalite-causes-deces/specifiques.assetdetail.3742888.html>.
- Gov. of the Netherlands (Government of the Netherlands). (2002). *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*. Amsterdam, The Netherlands: Ministry of Justice; Ministry of Health, Welfare, and Sports.
- Gov. of Victoria (Government of Victoria). (2017). *Voluntary Assisted Dying Bill 2017*. Melbourne, Australia: Legislative Assembly of Victoria.
- Gov. of VT (Government of Vermont). (2013). *An Act Relating to Patient Choice and Control at End of Life*. Montpelier (VT): General Assembly of the State of Vermont.
- Gov. of WA (Government of Washington State). (2009). *Washington Death With Dignity Act*. Olympia (WA): Gov. of WA.
- Gov. of WA (Government of Washington). (2017). Vital Statistics 2016 Highlights. Retrieved May 2018, from www.doh.wa.gov/DataandStatisticalReports/VitalStatisticsData/Death/DeathTablesbyYear.
- Gov. of WA (Government of Washington). (2018a). *Washington State Department of Health 2017 Death with Dignity Act Report Executive Summary*. Olympia (WA): Washington State Department of Health.

- Gov. of WA (Government of Washington). (2018b). Death Tables by Topic: Table C2 - Leading Causes of Death for Residents. Retrieved September 2018, from <https://www.doh.wa.gov/DataandStatisticalReports/HealthStatistics/Death/DeathTablesbyTopic>.
- Gov. of WA (Government of Washington). (2018c). *Death With Dignity Act Report*. Olympia (WA): Washington State Department of Health.
- Gov. of YK (Government of Yukon). (2003a). *Care Consent Act, SY 2003, c. 21*. Whitehorse (YK): Gov. of YK.
- Gov. of YK (Government of Yukon). (2003b). *Decision-Making Support and Protection to Adults Act, SY 2003, c. 21*. Whitehorse (YK): Gov. of YK.
- Grady, C. (2015). Enduring and emerging challenges of informed consent. *The New England Journal of Medicine*, 372(9), 855-862.
- Grantham, D. (2010). A rainbow named Samantha (Gentle Waters). *Journal of Palliative Care*, 26(1), 32-33.
- Grisso, T., Appelbaum, P. S., & Hill-Fotouhi, C. (1997). The MacCAT-T: A clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services*, 48(11), 1415-1419.
- Grootens-Wiegers, P., Hein, I. M., van den Broek, J. M., & de Vries, M. C. (2017). Medical decision-making in children and adolescents: Developmental and neuroscientific aspects. *BMC Pediatrics*, 17(1), 120.
- Guichon, J. & Mitchell, I. (2006). Medical emergencies in children of orthodox Jehovah's Witness families: Three recent legal cases, ethical issues and proposals for management. *Paediatrics & Child Health*, 11(10), 655-658.
- Guichon, J., Mohamed, F., Clarke, K., & Mitchell, I. (2017). Autonomy and beneficence in assisted dying in Canada: The eligibility of mature minors. *Alberta Law Review*, 54(3), 775-831.
- Hanson, S. S. (2016). Pediatric euthanasia and palliative care can work together. *American Journal of Hospice & Palliative Medicine*, 33(5), 421-424.
- Harrison, C. (2004). Treatment decisions regarding infants, children and adolescents. *Paediatrics & Child Health*, 9(2), 99-103.
- Hart, M. A. & Lavallée, B. (2015). Colonization, Racism, Social Exclusion and Indigenous Health. In L. Fernandez, S. MacKinnon & J. Silver (Eds.), *The Social Determinants of Health in Manitoba* (2nd ed.). Winnipeg (MB): Canadian Centre for Policy Alternatives Manitoba Office.
- Hasbrouck, A. (2017). NDY Canada Explains the Dangers to Disabled Children of "MAID" Expansion to Minors. Retrieved March 2018, from <http://notdeadyet.org/2017/08/ndy-canada-explains-the-dangers-to-disabled-children-of-maid-expansion-to-minors.html>.
- Hatfield, L. A. (2014). Neonatal pain: What's age got to do with it? *Surgical Neurology International*, 5, S479-S489.
- Haynes, M. (2015). Do We Need Disabled Role Models? Retrieved March 2018, from <http://blog.aidis.org/do-we-need-disabled-role-models>.

- Hein, I. M., De Vries, M. C., Troost, P. W., Meynen, G., Van Goudoever, J. B., & Lindauer, R. J. (2015a). Informed consent instead of assent is appropriate in children from the age of twelve: Policy implications of new findings on children's competence to consent to clinical research. *BMC Medical Ethics*, 16(1), 76.
- Hein, I. M., Troost, P. W., Lindeboom, R., Benninga, M. A., Zwaan, C. M., Van Goudoever, J. B., & Lindauer, R. J. (2015b). Key factors in children's competence to consent to clinical research. *BMC Medical Ethics*, 16(1), 74.
- Hein, I. M., Troost, P. W., Lindeboom, R., Christiaans, I., Grisso, T., van Goudoever, J. B., & Lindauer, R. J. (2015c). Feasibility of an assessment tool for children's competence to consent to predictive genetic testing: A pilot study. *Journal of Genetic Counseling*, 24(6), 971-977.
- Hilden, J. M., Himelstein, B. P., Freyer, D. R., Friebert, S., & Kane, J. R. (2001). End of Life Care: Special Issues in Pediatric Oncology. In K. M. Foley & H. Gelband (Eds.), *Improving Palliative Care for Cancer*. Washington (DC): National Academy Press.
- Hinds, P. S., Oakes, L., Furman, W., Quargnenti, A., Olson, M. S., Foppiano, P., & Srivastava, D. K. (2001). End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: Research to evidence-based practice guidelines. *Cancer Nursing*, 24(2), 122-134.
- Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005a). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23(36), 9146-9154.
- Hinds, P. S., Schum, L., Baker, J. N., & Wolfe, J. (2005b). Key factors affecting dying children and their families. *Journal of Palliative Medicine*, 8(Supplement 1), S70-S78.
- Hinds, P. S., Brandon, J., Allen, C., Hijjiya, N., Newsome, R., & Kane, J. R. (2007). Patient-reported outcomes in end-of-life research in pediatric oncology. *Journal of Pediatric Psychology*, 32(9), 1079-1088.
- Hitselberger, K. (2017). #DisabledAndUnashamed: The Power of Owning Disability. Retrieved March 2018, from <http://www.claimingcrip.com/2017/08/disabledandunashamed-power-of-owning.html>.
- HSO (Health Standards Organization). (2017). Leading Practices: A High Quality Care Pathway for Patients Requesting Medical Assistance in Dying (MAID). Retrieved June 2018, from <https://healthstandards.org/leading-practice/high-quality-care-pathway-patients-requesting-medical-assistance-dying-maid/>.
- IEB (European Institute of Bioethics). (2014). *Euthanasia of Newborns and the Groningen Protocol*. Brussels, Belgium: European Institute of Bioethics.
- IRIS (Institute for Research and Development on Inclusion and Society). (2017). *Concerns with Expanding Access to Medical Assistance in Dying: A Review of Evidence*. Toronto (ON): IRIS.

- Jackson, M. K., Burns, K. K., & Richter, M. S. (2014). Confidentiality and treatment decisions of minor clients: A health professional's dilemma & policy makers challenge. *SpringerPlus*, 3(1), 320.
- Jacobs, S., Perez, J., Cheng, Y. I., Sill, A., Wang, J., & Lyon, M. E. (2015). Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. *Pediatric Blood Cancer*, 62, 710-714.
- Janssen, A. (2002). The new regulation of voluntary euthanasia and medically assisted suicide in the Netherlands. *International Journal of Law, Policy and the Family*, 16, 260-269.
- Jayaraman, J. (2017). Should palliative care physicians get involved with MAID. *BC Medical Journal*, 59(3), 147.
- Jones, J. L. (2012). Factors associated with self-concept: Adolescents with intellectual and development disabilities share their perspectives. *Intellectual and Developmental Disabilities*, 50(1), 31-40.
- Kaczor, C. (2016). Against euthanasia for children: A response to Bovens. *Journal of Medical Ethics*, 42(1), 57-58.
- Kaplan, L. J. (2000). Toward a model of caregiver grief: Nurses' experiences of treating dying children. *Journal of Death and Dying*, 41(3), 187-206.
- Kassam, A., Sutradhar, R., Widger, K., Rapoport, A., Pole, J. D., Nelson, K., ... Gupta, S. (2016). Predictors of and trends in high-intensity end-of-life care among children with cancer: A population-based study using health services data. *Journal of Clinical Oncology*, 34(2), 236-242.
- Kazak, A. E. & Noll, R. B. (2015). The integration of psychology in pediatric oncology research and practice. *American Psychologist*, 70(2), 146-158.
- Keilty, K., Nicholas, D. B., Sappleton, K., & Karmali, K. (2014). Paediatric Patient-Centred Care at SickKids: Advancing Child & Family-Centred Care. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centred Care: Ethical and Legal Issues*. New York (NY): Springer.
- Kelečević, J. (2014). Ethical and Legal Issues in Patient and Family-Centered Care: Canadian First Nations, Metis and Inuit People. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centered Care: Ethical and Legal Issues*. New York (NY): Springer.
- Kelly, L. & Minty, A. (2007). End of life issues for Aboriginal patients: A literature review. *Canadian Family Physician* 53, 1459-1465.
- Kelsall, D. (2018). Physicians are not solely responsible for ensuring access to medical assistance in dying. *CMAJ*, 190(7), E181.
- Khoshnood, N., Hopwood, M.-C., Lokuge, B., Kurahashi, A., Tobin, A., Isenberg, S., & Husain, A. (2018). Exploring Canadian physicians' experiences providing medical assistance in dying: A qualitative study. *Journal of Pain and Symptom Management*, 56(2), 222-229.

- Kim, S. Y. H. (2010). *Evaluation of Capacity to Consent to Treatment and Research*. New York (NY): Oxford University Press.
- Klaczynski, P. A., Byrnes, J. P., & Jacobs, J. E. (2001). Introduction to the special issue: The development of decision making. *Journal of Applied Developmental Psychology*, 22(3), 225-236.
- Klaczynski, P. A. (2004). A dual process model of adolescent development: Implications for decision making, reasoning, and identity. *Advances in Child Development and Behaviour*, 32, 73-123.
- Knops, R. R. G., Kremer, L. C. M., & Verhagen, A. A. E. (2015). Paediatric palliative care: Recommendations for treatment of symptoms in the Netherlands. *BMC Palliative Care*, 14, 57.
- Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *New England Journal of Medicine*, 351(12), 1175-1186.
- Kumachev, A., Trudeau, M. E., & Chan, K. K. (2016). Associations among socioeconomic status, patterns of care and outcomes in breast cancer patients in a universal health care system: Ontario's experience. *Cancer*, 122(6), 893-898.
- Kuther, T. A. (2003). Medical decision-making and minors: Issues of consent and assent. *Adolescence*, 38(150), 343-358.
- Kwak, J. & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45(5), 634-641.
- Lane, C. (2018, August 6). Children Are Being Euthanized in Belgium, *The Washington Post*.
- Lansdown, G. L. (2005). *The Evolving Capacities of the Child*. Florence, Italy: UNICEF - Innocenti Research Centre.
- Larcher, V. & Hutchinson, A. (2010). How should paediatricians assess Gillick competence? *Archives of Disease in Childhood*, 95(4), 307-311.
- LCO (Law Commission of Ontario). (2015). *Legal Capacity, Decision-making and Guardianship: Interim Report*. Toronto (ON): LCO.
- LCO (Law Commission of Ontario). (2017). *Legal Capacity, Decision-making and Guardianship: Final Report*. Toronto (ON): LCO.
- Lennings, N. J. (2015). Forward, Gillick: Are competent children autonomous medical decision makers? New developments in Australia. *Journal of Law and the Biosciences*, 2(2), 459-468.
- Leo, R. J. (1999). Competency and the capacity to make treatment decisions: A primer for primary care physicians. *Primary Care Companion Journal of Clinical Psychiatry*, 1(5), 131-141.
- Lewy, G. (2011). *Assisted Death in Europe and America: Four Regimes and Their Lessons*. New York (NY): Oxford University Press.

- Lightfoot, E., Hill, K., & LaLiberte, T. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children and Youth Services Review*, 33(11), 2069-2075.
- Loppie, S., Reading, C., & de Leeuw, S. (2014). *Aboriginal Experiences with Racism and its Impacts*. Prince George (BC): National Collaborating Centre for Aboriginal Health.
- LRCC (Law Reform Commission of Canada). (1982). *Euthanasia, Aiding Suicide and Cessation of Treatment (Working Paper 28)*. Ottawa (ON): LRCC.
- LRCC (Law Reform Commission of Canada). (1983). *Euthanasia, Aiding Suicide and Cessation of Treatment: Report #20*. Ottawa (ON): LRCC.
- Lyon, M. E., Garvie, P. A., McCarter, R., Briggs, L., He, J., & D'Angelo, L. J. (2009). Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics*, 123(2), e199-e206.
- Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2013). Family-centered advance care planning for teens with cancer. *JAMA Pediatrics*, 167(5), 460-467.
- MacIntosh, C. (2016). Carter, medical aid in dying, and mature minors. *McGill Journal of Law and Health*, 10(1), S1-S33.
- MacIntosh, C. (2017). The Governance of Indigenous Health. In J. Erdman, V. Gruben & E. Nelson (Eds.), *Canadian Health Law and Policy* (5th ed.). Toronto (ON): LexisNexis.
- Mandarelli, G., Sabatello, U., Laponi, E., Pace, G., Ferrara, M., & Ferracuti, S. (2017). Treatment decision-making capacity in children and adolescents hospitalized for an acute mental disorder: The role of cognitive functioning and psychiatric symptoms. *Journal of Child and Adolescent Psychopharmacology*, 27(5), 462-465.
- Mårtensson, E. K. & Fägerskiöld, A. M. (2008). A review of children's decision-making competence in health care. *Journal of Clinical Nursing*, 17(23), 3131-3141.
- Martin, S. (2016). *A Good Death: Making the Most of Our Final Choices*. Toronto (ON): Harper Perennial.
- McCallum, D. E., Byrne, P., & Bruera, E. (2000). How children die in hospital. *Journal of Pain and Symptom Management*, 20(6), 417-423.
- McCormick, R. (1997). Healing through interdependence: The role of connecting in First Nations healing practices. *Canadian Journal of Counselling*, 31(3), 172-184.
- McKenna, K. (2016). Doctor-assisted death obtained by Sherbrooke man who starved himself to qualify. Retrieved July 2017, from <http://www.cbc.ca/news/canada/montreal/sherbrooke-man-hunger-strike-death-1.3529392>.

- McKenzie, K., Agic, B., Tuck, A., & Antwi, M. (2016). *The Case for Diversity: Building the Case to Improve Mental Health Services for Immigrant, Refugee, Ethno-cultural and Racialized Populations*. Calgary (AB): Mental Health Commission of Canada.
- Mead, N. & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature. *Social Science & Medicine*, 51(7), 1087-1110.
- Meij, L. W. D., Stroebe, M., Stroebe, W., Schut, H., Bout, J. V. D., Van Der Heijden, P. G., & Dijkstra, I. (2008). The impact of circumstances surrounding the death of a child on parents' grief. *Death Studies*, 32(3), 237-252.
- Ménard, J.-P. (2017). *Consent to Medical Care for Minors Under Québec Law*.
- Michaud, P. A., Blum, R. W., Benaroyo, L., Zermatten, J., & Baltag, V. (2015). Assessing an adolescent's capacity for autonomous decision-making in clinical care. *Journal of Adolescent Health*, 57(4), 361-366.
- Michelson, K. N. & Steinhorn, D. M. (2007). Pediatric end-of-life issues and palliative care. *Clinical Pediatric Emergency Medicine*, 8(3), 212-219.
- Miller, B. L. (1981). Autonomy & the refusal of lifesaving treatment. *Hastings Center Report*, 11(4), 22-28.
- Miller, V. A., Drotar, D., & Kodish, E. (2004). Children's competence for assent and consent: A review of empirical findings. *Ethics & Behavior*, 14(3), 255-295.
- Mills, K. L., Goddings, A. L., Clasen, L. S., Giedd, J. N., & Blakemore, S. J. (2014). The developmental mismatch in structural brain maturation during adolescence. *Developmental Neuroscience*, 36(3-4), 147-160.
- MLRC (Manitoba Law Reform Commission). (1995). *Minors' Consent to Health Care*. Winnipeg (MB): MLRC.
- Moffatt, M. E. K. & Cook, C. (2005). How can the health community foster and promote the health of Aboriginal children and youth? *Pediatrics and Child Health*, 10(9), 549-552.
- Morris, C. (2018). Maureen Taylor, UofTMed Physicians on End of Life Care in the Era of Assisted Dying. Retrieved June 2018, from <https://medicine.utoronto.ca/news/maureen-taylor-uoftmed-physicians-end-life-care-era-assisted-dying>.
- Moses, T. (2018). Suicide attempts among adolescents with self-reported disabilities. *Child Psychiatry and Human Development*, 49(3), 420-433.
- Mosoff, J. (2012). "Why not tell it like it is?": The example of P.H. v. Eastern Regional Integrated Health Authority, a minor in a life-threatening context. *University of New Brunswick Law Journal*, 63, 238-252.
- Mount, B. M. (1976). The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution. *Canadian Medical Association Journal*, 115(119-121).

- Muir, N. & Bohr, Y. (2014). Contemporary practice of traditional Aboriginal child rearing: A review. *First Peoples Child and Family Review*, 9(1), 66-79.
- NBCA (Court of Appeal of New Brunswick). (1994). *Pole v. Region 2 Hospital Corporation*, 1994 CanLII 4470 (NB CA). Fredericton (NB): NBCA.
- NCCAH (National Collaborating Centre for Aboriginal Health). (2010). *Access to Health Services as a Social Determinant of First Nations, Inuit, and Métis Health*. Prince George (BC): NCCAH.
- NCCAH (National Collaborating Centre for Aboriginal Health). (2011). *The Aboriginal Health Legislation and Policy Framework in Canada*. Prince George (BC): University of Northern British Columbia.
- NCCAH (National Collaborating Centre for Aboriginal Health). (2013). *An Overview of Aboriginal Health in Canada*. Prince George (BC): University of Northern British Columbia.
- Nedelsky, J. (1989). Reconceiving autonomy: Sources, thoughts and possibilities. *Yale Journal of Law & Feminism*, 1(1), 7-36.
- Newman, C., Rapoport, A., & Sangha, G. (2014). Ethical Conflicts That May Arise When Caring for Dying Children. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centred Care: Ethical and Legal Issues*. New York (NY): Springer.
- NFB (National Film Board). (2015). *The Faith Project: Aboriginal Spirituality*. Ottawa (ON): NFB.
- Nicholas, D. B., Keilty, K., & Karmali, K. (2014). Paediatric Patient-Centred Care: Evidence and Evolution. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centred Care: Ethical and Legal Issues*. New York (NY): Springer.
- NL SCTD (Supreme Court of Newfoundland and Labrador). (1993). *A.Y., child of P.Y. and J.Y.*, 1993 CanLII 8385 (NL SCTD). St. John's (NL): NL SCTD.
- NLM (U.S. National Library of Medicine). (n.d.). The Medicine Wheel and the Four Directions. Retrieved October 2017, from <https://www.nlm.nih.gov/nativevoices/exhibition/healing-ways/medicine-ways/medicine-wheel.html>.
- Noël, J.-F. (2015). The Convention on the Rights of the Child. Retrieved July 2018, from <http://www.justice.gc.ca/eng/rp-pr/fl-lf/divorce/crc-crde/conv2a.html>.
- Nys, H. (2017). A Discussion of the Legal Rules on Euthanasia in Belgium Briefly Compared with the Rules in Luxembourg and the Netherlands. In D. A. Jones, C. Gastmans & C. MacKellar (Eds.), *Euthanasia and Assisted Suicide: Lessons from Belgium*. Cambridge, United Kingdom: Cambridge University Press.
- O'Connell, L. J. (1995). Religious dimensions of dying and death. *The Western Journal of Medicine*, 163(3), 231-235.
- OCPG (Ottawa Catholic Physicians' Guild). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.

- ONCJ (Ontario Court of Justice). (1985). *Re L.D.K. (An Infant)*, 1985 *CanLII* 2907 (ON CJ). Toronto (ON): ONCJ.
- ONCJ (Ontario Court of Justice). (2014). *Hamilton Health Sciences Corp. v. D.H.*, 2014 *ONCJ* 603. Ottawa (ON): ONCJ.
- ONSC (Ontario Superior Court of Justice). (1997). *Koch (Re)*. 33 *O.R. (3d)* 485 [1997] *O.J. No. 1487*. St. Catharines (ON): ONSC.
- ONSC (Ontario Superior Court of Justice). (2017). *A.B. v Canada (Attorney General)*, 2017 *ONSC* 3759 (*CanLII*). Toronto (ON): ONSC.
- ONSC (Ontario Superior Court of Justice). (2018). *Foley v. Victoria Hospital London Health Sciences Centre et al.* (Court File No. CV-18-592072). Toronto (ON): ONSC.
- ONSCDC (Ontario Superior Court of Justice (Divisional Court)). (2018). *The Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, 2018 *ONSC* 579 (*CanLII*). Toronto (ON): ONSCDC.
- Osenga, K., Postier, A., Dreyfus, J., Foster, L., Teeple, W., & Friedrichsdorf, S. J. (2016). A comparison of circumstances at the end of life in a hospital setting for children with palliative care involvement versus those without. *Journal of Pain and Symptom Management*, 52(5), 673-680.
- PAAE (Physicians' Alliance Against Euthanasia). (2017). Submitted as Part of of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Papadatou, D. & Bellali, T. (2002). Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatric Nursing*, 28(4), 345-353.
- Paré, M. (2011). Of minors and the mentally ill: Re-positioning perspectives on consent to health care. *Windsor Yearbook of Access to Justice*, 29(1), 107-125.
- PHAC (Public Health Agency of Canada). (2018). *Key Health Inequalities in Canada: A National Portrait*. Ottawa (ON): PHAC.
- Picard, A. (2017, August 23). CMA Poll Finds Rising Support for Medically Assisted Death, *The Globe and Mail*.
- Porter, C. (2017, May 27). At His Own Wake, Celebrating Life and the Gift of Death, *The New York Times*.
- Pousset, G., Mortier, F., Bilsen, J., Cohen, J., & Deliens, L. (2011). Attitudes and practices of physicians regarding physician-assisted dying in minors. *Archives of disease in childhood*, 96(10), 948-953.
- Proudfoot, S. (2017, September 1). The Doctor Who Took on Death, *Maclean's*.
- Provincial Advocate for Children & Youth. (2016). *Searching for Home: Reimagining Residential Care*. Toronto (ON): Office of the Provincial Advocate for Children and Youth.
- PTEAG (Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying). (2015). *Final Report*. Toronto (ON): PTEAG.
- QCCS (Superior Court of Québec). (1992). *Nancy B. v. Hotel-Dieu de Québec*, 1992 *CanLII* 8511 (QC CS). Québec (QC): QCCS.

- QCCS (Superior Court of Québec). (2017a). *Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)*. Montréal (QC): QCCS.
- QCCS (Superior Court of Québec). (2017b). *Saba c. Procureure générale du Québec*, 2017 QCCS 5498. Montréal (QC): QCCS.
- QCCS (Superior Court of Québec). (2017c). *Centre universitaire de santé McGill (CUSM-Hôpital général de Montréal) c. X*, 2017 QCCS 3946 (CanLII). Montréal (QC): QCCS.
- Quinn, K. L. & Detsky, A. S. (2017). Medical assistance in dying: Our lessons learned. *JAMA Internal Medicine*, 177(9), 1251-1252.
- Rapoport, A., Williams, R., Davis, P., Van Clieaf, J., Widger, K., Naipaul, A., ... Salminen, R. (2017). *Bridging the Gap: The Paediatric Advanced Care Team (PACT) Community Outreach Nurse Practitioner Model*. Paper presented at Canadian Foundation for Healthcare Improvement CEO Forum 2017, Toronto (ON).
- RDSC (Right to Die Society of Canada). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Reading, C. L. & Wien, F. (2009). *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. Prince George (BC): National Collaborating Centre for Aboriginal Health.
- REAL Women of Canada. (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Remedios, C., Willenberg, L., Zordan, R., & Philip, J. A. M. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliative Medicine*, 29(3), 223-230.
- Robert, Y. (Collège des médecins du Québec). (2010). *Sortir de l'impasse: Une réflexion sur les appropriés*. Montréal (QC): Collège des médecins du Québec.
- Rosenberg, A. R., Postier, A., Osenga, K., Kreicbergs, U., Neville, B., Dussel, V., & Wolfe, J. (2015). Long-term psychosocial outcomes among bereaved siblings of children with cancer. *Journal of Pain and Symptom Management*, 49(1), 55-65.
- Ross, L. F. (2015). Theory and practice of pediatric bioethics. *Perspectives in Biology and Medicine*, 58(3), 267-280.
- RSC (Royal Society of Canada). (2011). *The Royal Society of Canada Expert Panel: End-of-Life Decision Making*. Ottawa (ON): Royal Society of Canada.
- RTE (Regional Euthanasia Review Committees). (2015). *Code of Practice*. The Hague, the Netherlands: RTE.
- RTE (Regionale Toetsingscommissies Euthanasie). (2017). *Regional Euthanasia Review Committees Annual Report 2016*. The Hague, the Netherlands: RTE.
- RTE (Regionale Toetsingscommissies Euthanasie). (2018a). *Uitspraken Over Minderjarigen*. Retrieved July 2018, from <https://www.euthanasiecommissie.nl/uitspraken-en-uitleg/1/1-minderjarigen/documenten>.

- RTE (Regionale Toetsingscommissies Euthanasie). (2018b). *Regional Euthanasia Review Committees Annual Report 2017*. The Hague, the Netherlands: RTE.
- Ruhe, K. M., Wangmo, T., Badarau, D. O., Elger, B. S., & Niggli, F. (2015). Decision-making capacity of children and adolescents—Suggestions for advancing the concept's implementation in pediatric healthcare. *European Journal of Pediatrics*, 174(6), 775-782.
- Ruhe, K. M., De Clercq, E., Wangmo, T., & Elger, B. S. (2016). Relational capacity: Broadening the notion of decision-making capacity in paediatric healthcare. *Journal of Bioethical Inquiry*, 13(4), 515-524.
- Sacks, D. (2003). Age limits and adolescents. *Paediatrics and Child Health*, 8(9), 577-578.
- Salter, E. K. (2017). Conflating capacity & authority: Why we're asking the wrong question in the adolescent decision-making debate. *Hastings Center Report*, 47(1), 32-41.
- Samanta, J. (2015). Children and euthanasia: Belgium's controversial new law. *Diversity and Equality in Health and Care*, 12(1), 4-5.
- Sanchini, V., Nardini, C., & Boniolo, G. (2014). The withholding/withdrawing distinction in the end-of-life debate. *Multidisciplinary Respiratory Medicine*, 9(1), 13.
- Saunders, C. (2001). The evolution of palliative care. *Journal of the Royal Society of Medicine*, 94, 430-432.
- SB (StatBel). (2018). Deaths - Open Data. Retrieved June 2018, from statbel.fgov.be/en/statistics/opendata/datasets/population/deaths/.
- SCC (Supreme Court of Canada). (1980). *Reibl v. Hughes*, 1980 2 SCR 880. Ottawa (ON): SCC.
- SCC (Supreme Court of Canada). (1993). *Rodriguez v. British Columbia (Attorney General)*, [1993] 3 SCR 519, 1993 CanLII 75 (SCC). Ottawa (ON): SCC.
- SCC (Supreme Court of Canada). (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [2009] 2 SCR 181, 2009 SCC 30 (CanLII). Ottawa (ON): SCC.
- SCC (Supreme Court of Canada). (2015). *Carter v. Canada (Attorney General)*, [2015] 1 SCR 331, 2015 SCC 5 (CanLII). Ottawa (ON): SCC.
- Schwartz, Y., Williams, T. S., Roberts, S. D., Hellmann, J., & Zlotnik Shaul, R. (2018). Adolescent decision-making in Canadian medical contexts: Integrating neuroscience and consent frameworks. *Paediatrics & Child Health*, 23(6), 374-376.
- Searight, H. & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physician*, 71(3), 515-522.
- Seyfried, L., Ryan, K. A., & Kim, S. Y. H. (2013). Assessment of decision-making capacity: Views and experiences of consultation physicians. *Psychosomatics*, 54, 115-123.

- Sherwin, S. (1998). A Relational Approach to Autonomy in Health Care. In S. Sherwin (Ed.), *The Politics of Women's Health*. Philadelphia (PA): Temple University Press.
- SickKids. (2017). *Submission to the Council of Canadian Academies on Behalf of the MAID Working Group at The Hospital for Sick Children*. Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.
- Silber, T. J. (2011). Adolescent brain development and the mature minor doctrine. *Adolescent Medicine: State of the Art Reviews*, 22(2), 207-212.
- Singh, H. K. (2018). *Medical Assistance in Dying (MAID) for Minors in Canada: Considering Children's Voices (Masters Thesis)*. Montreal (QC): McGill University.
- SJCPAD (Special Joint Committee on Physician-Assisted Dying). (2016a). *Report of the Special Joint Committee on Physician-Assisted Dying*. Ottawa (ON): Parliament of Canada.
- SJCPAD (Special Joint Committee on Physician Assisted Dying). (2016b). *Special Joint Committee on Physician-Assisted Dying: Evidence. PDAM Number 005, Tuesday, January 26, 2016*. Ottawa (ON): Government of Canada.
- SK QB (Saskatchewan Court of Queen's Bench). (1999). *T.T.D., Re. Saskatoon (SK): SK QB*.
- Smith, S. L. & Nickel, D. D. (2003). Nursing the Dying in Post-Second World War Canada and the United States. In G. Feldberg, M. Ladd-Taylor, A. Li & K. McPherson (Eds.), *Women, Health, and Nation: Canada and the United States since 1945*. Montréal (QC): McGill-Queen's University Press.
- Solomon, M. Z. & Browning, D. (2005). Pediatric palliative care: Relationships matter and so does pain control. *Journal of Clinical Oncology*, 23(36), 9055-9057.
- Somerville, M. A. (2001). *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide*. Kingston (ON): McGill-Queen's University Press.
- Sprung, C. L., Somerville, M. A., & Radbruch, L. (2018). Physician-assisted suicide and euthanasia: Emerging issues from a global perspective. *Journal of Palliative Care*, 33(4), 197-203.
- Srivastava, R. H. (2014). Culture, Religion, and Family-Centered Care. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centered Care: Ethical and Legal Issues*. New York (NY): Springer.
- SSCEAS (The Special Senate Committee on Euthanasia and Assisted Suicide). (1995). *Of Life and Death - Final Report*. Ottawa (ON): Parliament of Canada.
- Stainton, T. & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability*, 23(1), 57-70.
- Stainton, T. (2015). Supported decision-making in Canada: Principles, policy, and practice. *Research and Practice in Intellectual and Developmental Disabilities*, 3(1), 1-11.

- Stanovich, K. E. & West, R. F. (2000). Individual differences in reasoning: Implications for the rationality debate? *Behavioral and Brain Sciences*, 23(5), 645-726.
- Starks, H., Back, A. L., Pearlman, R. A., Koenig, B. A., Hsu, C., Gordon, J. R., & Bharucha, A. J. (2007). Family member involvement in hastened death. *Death Studies*, 31(2), 105-130.
- StatCan (Statistics Canada). (2017). *Health Fact Sheets: Primary Health Care Providers, 2016*. Ottawa (ON): StatCan.
- StatCan (Statistics Canada). (2018a). *CANSIM Table 13-10-0142-01. Deaths, by cause, Chapter II: Neoplasms (C00 to D48)*. Ottawa (ON): StatCan.
- StatCan (Statistics Canada). (2018b). *CANSIM Table 13-10-0394-01. Leading Causes of Death, Total Population, By Age Group*. Ottawa (ON): StatCan.
- StatCan (Statistics Canada). (2018c). *Table 17-10-0008-01 Estimates of the Components of Demographic Growth, Annual*. Ottawa (ON): StatCan.
- Steinberg, L. (2005). Cognitive and affective development in adolescence. *Trends in Cognitive Sciences*, 9(2), 69-74.
- Steinberg, L. (2013). Does recent research on adolescent brain development inform the mature minor doctrine? *Journal of Medicine and Philosophy*, 38(3), 256-267.
- Stewart, S. L. & Marshall, A. (2017). Counselling Indigenous Peoples. In S. L. Stewart, R. Moodley & A. Hyatt (Eds.), *Indigenous Cultures and Mental Health Counselling*. New York (NY): Routledge.
- Stillion, J. M. & Papadatou, D. (2002). Suffer the children: An examination of psychosocial issues in children and adolescents with terminal illness. *American Behavioral Scientist*, 46(2), 299-315.
- Stonebridge, C. (2017). *Palliative Care Matters: Fostering Change in Canadian Health Care*. Ottawa (ON): The Conference Board of Canada.
- Strang, P., Strang, S., Hultborn, R., & Arner, S. (2004). Existential pain - an entity, a provocation, or a challenge? *Journal of Pain and Symptom Management*, 27(3), 241-250.
- Strassburger, Z. (2016). Medical decision making for youth in the foster care system. *The John Marshall Law Review*, 49, 1103-1154.
- Sumner, L. W. (2011). *Assisted Death: A Study in Ethics and Law*. Oxford, United Kingdom: Oxford University Press.
- Supreme Court of the State of Montana. (2009). *Baxter v. Montana*. Helena (MT): Supreme Court of the State of Montana.
- Swarte, N. B., van der Lee, M. L., van der Bom, J. G., van den Bout, J., & Heintz, A. P. M. (2003). Effects of euthanasia on the bereaved family and friends: A cross sectional study. *BMJ*, 327(7408), 189.
- TCDG (Toronto Catholic Doctors' Guild). (2017). Submitted as part of the CCA Expert Panel on Medical Assistance in Dying Call for Input.

- ten Cate, K., van de Vathorst, S., Onwuteaka-Philipsen, B. D., & van der Heide, A. (2015). End-of-life decisions for children under 1 year of age in Netherlands: Decreased frequency of administration of drugs to deliberately hasten death. *Journal of Medical Ethics*, 41(10), 795-798.
- TOH (The Ottawa Hospital). (2016). *Corporate Policy: Medical Assistance in Dying*. Ottawa (ON): TOH.
- Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., Wrathall, G., & Sung, L. (2007). Challenges to participation in paediatric palliative care research: A review of the literature. *Palliative Medicine*, 21(5), 435-440.
- TRC (Truth and Reconciliation Commission of Canada). (2015). *Honouring the Truth, Reconciling for the Future: Summary of the Final Report of the Truth and Reconciliation Commission of Canada*. Winnipeg (MB): TRC.
- Tsai, E. (2008). Advance care planning for paediatric patients. *Paediatrics & Child Health*, 13(9), 791-796.
- Turrell, S. L., Peterson-Badali, M., & Katzman, D. K. (2011). Consent to treatment in adolescents with anorexia nervosa. *International Journal of Eating Disorders*, 44(8), 703-707.
- UKHL (United Kingdom House of Lords). (1985). *Gillick v. West Norfolk and Wisbech AHA [1985] UKHL 7*. London, United Kingdom: UKHL.
- UKHL (United Kingdom House of Lords). (1993). *Airedale N.H.S. Trust v. Bland [1993] 2 WLR 316*. London, United Kingdom: UKHL.
- UN (United Nations General Assembly). (1989). *Convention on the Rights of the Child*. New York (NY): UN.
- UN (United Nations General Assembly). (2007). *Convention on the Rights of Persons with Disabilities. A/RES/61/106*. New York (NY): UN.
- Valdez-Martinez, E., Noyes, J., & Bedolla, M. (2014). When to stop? Decision-making when children's cancer treatment is no longer curative: A mixed-method systematic review. *BMC Pediatrics*, 14(124), 1-25.
- Van Assche, K., Kasper, R., Vanderhaegen, B., & Sterckx, S. (2018). 'Capacity for discernment' and euthanasia on minors in Belgium. *Medical Law Review*, *In press*.
- Van Gool, S. & De LaPeliere, J. (2017). Euthanasia in Children: Keep Asking the Right Questions. In D. A. Jones, C. Gastmans & C. MacKellar (Eds.), *Euthanasia and Assisted Suicide: Lessons from Belgium*. New York (NY): Cambridge University Press.
- van Marwijk, H., Haverkate, I., van Royen, P., & The, A. M. (2007). Impact of euthanasia on primary care physicians in the Netherlands. *Palliative Medicine*, 21(7), 609-614.
- Verhagen, E. & Sauer, P. J. J. (2005). The Groningen Protocol - euthanasia in severely ill newborns. *The New England Journal of Medicine*, 352(10), 959-962.

- Verma, J., Petersen, S., Samis, S., Akunov, N., & Graham, J. (2014). *Healthcare Priorities in Canada: A Background*. Ottawa (ON): Canadian Foundation for Healthcare Improvement.
- Vrakking, A. M., van der Heide, A., Arts, W. F. M., Pieters, R., van der Voort, E., Rietjens, J. A., ... van der Wal, G. (2005). Medical end-of-life decisions for children in the Netherlands. *Archives of Pediatrics & Adolescent Medicine*, 159(9), 802-809.
- Wahl, J. A., Dykeman, M. J., & Gray, B. (2014). *Health Care Consent and Advance Care Planning in Ontario: Legal Capacity, Decision-Making and Guardianship*. Toronto (ON): Law Commission of Ontario.
- Walter, J. K., Rosenberg, A. R., & Feudtner, C. (2013). Tackling taboo topics: How to have effective advanced care planning discussions with adolescents and young adults with cancer. *JAMA Pediatrics*, 167(5), 489-490.
- Walter, J. K. & Ross, L. F. (2014). Relational autonomy: Moving beyond the limits of isolated individualism. *Pediatrics*, 133(Supplement 1), S16-S23.
- Weaver, M. S., Baker, J. N., Gattuso, J. S., Gibson, D. V., Sykes, A. D., & Hinds, P. S. (2015). Adolescents' preferences for treatment decisional involvement during their cancer. *Cancer*, 121(24), 4416-4424.
- Weithorn, L. A. & Campbell, S. B. (1982). The competency of children and adolescents to make informed treatment decisions. *Child Development*, 53(6), 1589-1598.
- Welch, L. C., Teno, J. M., & Mor, V. (2005). End of life care in black and white: Race matters for medical care of dying patients and their families. *Journal of the American Geriatric Society*, 53, 1145-1153.
- WHO (World Health Organization). (2011). *Sixty-Fourth World Health Assembly Provisional Agenda Item 13.16 — Youth and Health Risks: Report by the Secretariat*. Geneva, Switzerland: WHO.
- WHO (World Health Organization). (2013). Definition of Key Terms – Consolidated ARV Guidelines, June 2013. Retrieved January 2018, from <http://www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/>.
- WHO (World Health Organization). (2016). International Statistical Classification of Diseases and Related Health Problems 10th Revision. Retrieved July 2017, from <http://apps.who.int/classifications/icd10/browse/2016/en>.
- Widger, K., Davies, D., Rapoport, A., Vadeboncoeur, C., Liben, S., Sarpal, A., ... Siden, H. (2016). Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study. *CMAJ Open*, 4(4), E562-568.
- Widger, K., Sutradhar, R., Rapoport, A., Vadeboncoeur, C., Zelcer, S., Kassam, A., ... Gupta, S. (2018). Predictors of specialized pediatric palliative care involvement and impact on patterns of end-of-life care in children with cancer. *Journal of Clinical Oncology*, 36(8), 801-807.

- Wiener, L., Ballard, E., Brennan, T., Battles, H., Martinez, P., & Pao, M. (2008). How I wish to be remembered: The use of an advance care planning document in adolescent and young adult populations. *Journal of Palliative Medicine*, 11(10), 1309-1313.
- Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., & Osherow, J. (2012). Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*, 130(5), 897-905.
- Wildeman, S. (2016). Consent to Psychiatric Treatment: From Insight (Into Illness) to Incite (A Riot). In J. A. Chandler & C. M. Flood (Eds.), *Law and Mind: Mental Health Law and Policy in Canada*. Toronto (ON): LexisNexis Canada.
- Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., ... Weeks, J. C. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine*, 342(5), 326-333.
- Wolfe, J., Orellana, L., Ullrich, C., Cook, E. F., Kang, T. I., Rosenberg, A., ... Dussel, V. (2015). Symptoms and distress in children with advanced cancer: Prospective patient-reported outcomes from the PediQUEST study. *Journal of Clinical Oncology*, 33(17), 1928-1935.

APPENDIX A: ASSISTED DYING TERMINOLOGY IN JURISDICTIONS WORLDWIDE

| Jurisdiction | Year Allowed | Terminology | Definition | Notes |
|---------------------------|--------------|---------------------------------------|--|---|
| Victoria, AUS | 2019 | Voluntary Assisted Dying | The administration of a voluntary assisted dying substance and includes steps reasonably related to such administration. | The Voluntary Assisted Dying Bill was passed in 2017, and will come into power June 19, 2019 at the latest. |
| Hawaii, USA | 2019 | Medical Aid in Dying | Not explicitly defined; a qualified patient may request and obtain a prescription for medication that they may self-administer to end their life in a humane and dignified manner. | The Our Care, Our Choice Act was signed into law on April 5, 2018, to take effect on January 1, 2019. Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |
| District of Columbia, USA | 2016 | Death with Dignity | The request and dispensation of covered medications to qualified patients seeking to die in a humane and peaceful manner. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |
| California, USA | 2016 | End of Life Option: Aid-in-Dying Drug | A drug determined and prescribed by a physician for a qualified individual, which the qualified individual may choose to self-administer to bring about his or her death due to a terminal disease. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |
| Canada | 2016 | Medical Assistance in Dying | The administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death. | |
| Colorado, USA | 2016 | Medical Aid-in-Dying | The medical practice of a physician prescribing medical aid-in-dying medication to a qualified individual that the individual may choose to self-administer to bring about a peaceful death. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |

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| Jurisdiction | Year Allowed | Terminology | Definition | Notes |
|--------------|--------------|---|--|--|
| Colombia | 2015 (1997) | The Fundamental Right to Die with Dignity | The procedure to address the request to exercise the fundamental right to die with dignity is not explicitly defined. | The Ministry of Health and Social Protection issued a regulation on the fundamental right to die with dignity in 2015. The legal judgment that first recognized such a right in Colombia occurred in 1997. |
| Quebec, CAN | 2014 | Medical Aid In Dying | Care 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. | |
| Vermont, USA | 2013 | Patient Choice at the End of Life | Not explicitly defined; physicians are allowed to prescribe medication to a patient with a terminal condition for the purpose of hastening the patient's death if they meet certain criteria, but may not be involved in the administration of the medication. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |
| Montana, USA | 2009 | Physician Aid in Dying | Not explicitly defined; in physician aid in dying, the patient — not the physician — commits the final death-causing act by self-administering a lethal dose of medicine. | The provision of physician aid in dying is permitted through the Supreme Court of the State of Montana ruling that found a terminally ill patient's consent to physician aid in dying constitutes a statutory defense to a charge of homicide against the aiding physician when no other consent exceptions apply (Supreme Court of the State of Montana, 2009). Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |

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| Jurisdiction | Year Allowed | Terminology | Definition | Notes |
|-----------------|--------------|---|---|---|
| Luxembourg | 2009 | Euthanasia and Assisted Suicide | <p>Euthanasia: The act performed by a physician, which intentionally ends the life of a person at the express and voluntary request of that person.</p> <p>Assisted Suicide: a doctor intentionally helps another person to commit suicide or to provide another person with the means to that end, at the express and voluntary request of the latter.</p> | |
| Washington, USA | 2008 | Death with Dignity | Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |
| The Netherlands | 2002 | Termination of Life on Request and Assisted Suicide | <p>Termination of Life on Request: Not explicitly defined.</p> <p>Assisted Suicide: Intentionally assisting in a suicide of another person or procuring for that person the means [thereto].</p> | Termination of Life on Request is commonly referred to as <i>euthanasia</i> and <i>assisted suicide</i> (EAS). |
| Belgium | 2002 | Euthanasia | Intentionally terminating life by someone other than the person concerned, at the latter's request. | The Belgium Act only refers to euthanasia; however, assisted suicide is not expressly prohibited in criminal law. Both are practised and are commonly referred to as <i>euthanasia</i> and <i>assisted suicide</i> (EAS). The Federal Control and Evaluation Commission on Euthanasia has stated that it considers assisted suicide to fall within the definition of euthanasia, and has approved cases of assisted suicide in Belgium as meeting legal requirements (Nys, 2017). |
| Oregon, USA | 1997 | Death with Dignity | Not explicitly defined; an adult who qualifies may make a written request for medication that the patient may self-administer to end his or her life in a humane and dignified manner in accordance with the law. | Physician Assisted Death (PAD) or Physician Assisted Suicide (PAS) are commonly used in the American media. |

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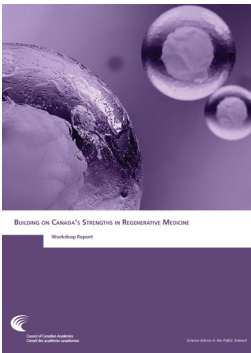
| Jurisdiction | Year Allowed | Terminology | Definition | Notes |
|--------------|--------------|-------------------|---|--|
| Germany | – | Assisted Suicide | Not explicitly defined; suicide is exempt from criminal punishment, as is aiding suicide. However, killing a person at the express and earnest request of the victim (“mercy killing”) is a criminal offence. | A 2015 law makes it illegal to assist in suicide for commercial intent. Relatives or other persons closely related to the patient who are only involved as non-business participants are exempt. |
| Switzerland | – | Assisting Suicide | Not explicitly defined. | Art. 115 of the Swiss Criminal Code (1942) states: Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty. |

Sources: Constitutional Court of Colombia, 2014; GC, 2016; Gov. of Belgium, 2002; Gov. of CA, 2015; Gov. of CO, 2016; Gov. of Colombia, 2015; Gov. of DC, 2016; Gov. of Germany, 2015; Gov. of HI, 2018; Gov. of Luxembourg, 2009; Gov. of the Netherlands, 2002; Gov. of OR, 1997; Gov. of QC, 2014; Gov. of Switzerland, 1942; Gov. of Victoria, 2017; Gov. of VI, 2013; Gov. of WA, 2009; Nys, 2017; Supreme Court of the State of Montana, 2009

Table of terminology and legal definitions used in euthanasia and assisted suicide law around the world, including notes about commonly used terms in local media and academic literature when different from the official legal terminology.

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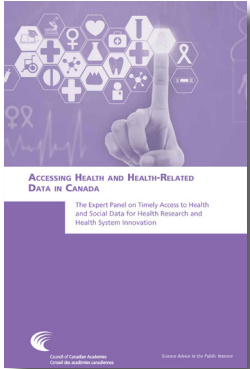
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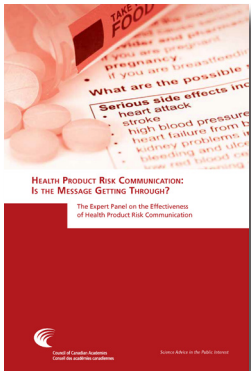
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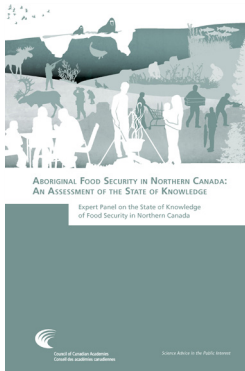
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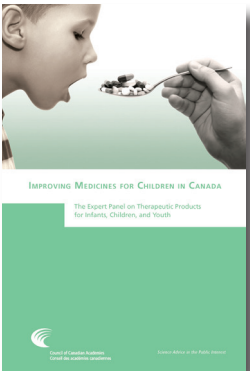
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