The Expansion of Medical Assistance in Dying in the COVID-19 Pandemic Era and Beyond: Implications for Vulnerable Canadians

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Submitted: 22 October 2021; Accepted: 5 January 2022; Published: 30 May 2022

DOI: https://doi.org/10.22374/cjgim.v17i2.586

Abstract
In 2015, the Canadian parliament passed a law permitting adults to request Medical Assistance in Dying (MAiD) when they have a grievous, irremediable medical condition that causes unbearable suffering and their natural death is reasonably foreseeable. Following a constitutional challenge, a Quebec lower court, ruled in the Truchon vs. Canada AG case that the restriction to a reasonably foreseeable death is an unjustifiable impingement on the right to life, liberty, and security of the person and the right to equality. In response, the government expanded the MAiD law in March 2021 through Bill C-7 to include those who are not approaching their natural death. Bill C-7 is a potentially harmful approach to justice for vulnerable groups such as the elderly, disabled, or those with chronic illnesses. The COVID-19 pandemic has highlighted serious problems with how we care for the vulnerable members of our society. In this article, we explore what has gone wrong and what has raised serious concerns, while proposing potential options to consider when developing new laws, systems, and processes to improve societal equity.

Résumé
En 2015, le gouvernement fédéral a adopté une nouvelle loi permettant aux adultes de demander l’aide médicale à mourir (AMM) dans certaines circonstances, notamment les problèmes de santé graves et irrémédiables qui provoquent des souffrances insupportables et dont la mort naturelle est raisonnablement prévisible. À la suite d’une contestation constitutionnelle, un tribunal de première instance de la province de Québec a statué, dans l’affaire Truchon c. Procureur général du Canada, que la restriction à une mort raisonnablement prévisible constitue une atteinte injustifiable au droit à la vie, à la liberté et à la sécurité de la personne. En réponse à ce verdict, le gouvernement a modifié la loi sur l’AMM en mars 2021 par l’intermédiaire du projet de loi C-7 pour y inclure les personnes chez qui la mort n’est pas dans un avenir prévisible. Le projet de loi C-7
The expansion of MAiD in the COVID-19 pandemic era

Following the landmark Carter vs. Canada case in 2015, Canadian parliament passed a law permitting capable adults to request Medical Assistance in Dying (MAiD) when they have a grievous, irremediable medical condition that causes unbearable suffering and an irreversible decline of capabilities, with a reasonably foreseeable natural death. While MAiD was originally intended as an exceptional procedure in situations of intolerable suffering in a broad end-of-life context, recent trends indicate that the use of MAiD has steadily increased each year across all Canadian jurisdictions since the law was passed in 2016 (Figure 1). There is evidence that Bill C-7 and future MAiD expansion measures could increase the vulnerability of people who may benefit instead from better access to treatment and palliative care, better supports while living with chronic disease, and better living conditions at home and in long term and chronic care institutions.

Patients usually seek MAiD in Canada because they experience debilitating symptoms that diminish their quality of life, perceived burden on family members and informal caregivers, and loss of dignity. The Health Canada first annual report on MAiD has confirmed reasons that have prompted individuals to choose MAiD (Table 1). Among the 5389 individuals who received MAiD in 2019, the most commonly cited reasons for intolerable suffering that caused them to opt for MAiD were inadequate pain control or fear of this in the future (53.9%), the perceived burden on family or caregivers (53.3%), loss of dignity (34.0%), and isolation or loneliness (13.7%). Similarly, a retrospective chart survey of 250 patients, of which 23.7% had an end-organ failure due to heart failure and/or lung disease, conducted in British Columbia found that illness-related suffering (59.8%), loss of control (52.7%), and fear of future suffering (24.1%) were the most common reasons causing individuals to opt for MAiD.

The limited availability of disability supports and access to palliative care services may play a significant role in the demand for MAiD. Based on the Health Canada first annual report on MAiD, 10.2% of people who received MAiD did not have access to disability supports, and conflicting reports on the availability of these supports exist. The Health Canada first annual report on MAiD stated that 82.1% of 5389 patients receiving MAiD received palliative care, but as many as 16% received palliative care for the first time less than 2 weeks before they chose to die. A total of 18% failed to receive any palliative care prior to receiving MAiD. There may be regional variation in these estimates; for example, a chart review at the Ottawa Hospital found that as many as 39.3% of those who requested MAiD had no palliative care involvement. This emphasizes concerns over the timeliness and quality of these services, while also raising the question of whether better access to palliative care may have mitigated the demand for MAiD.

Keywords: Medical Assistance in Dying, Equity, Equality, COVID-19
Table 1. Reported nature of suffering among people who received MAiD in 2019

<table>
<thead>
<tr>
<th>Reported nature of suffering</th>
<th>No. (%) of 5289 people receiving MAiD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of ability to engage in meaningful activities</td>
<td>4375 (82.1)</td>
</tr>
<tr>
<td>Loss of ability to perform activities of daily living</td>
<td>4209 (78.1)</td>
</tr>
<tr>
<td>Inadequate control of symptoms other than pain (or concern about it)</td>
<td>3039 (56.4)</td>
</tr>
<tr>
<td>Inadequate control of pain (or concern about it)</td>
<td>2905 (53.9)</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>2872 (53.3)</td>
</tr>
<tr>
<td>Perceived burden on family, friends, or caregivers</td>
<td>1832 (34.0)</td>
</tr>
<tr>
<td>Loss of control of bodily functions</td>
<td>1719 (31.9)</td>
</tr>
<tr>
<td>Isolation or loneliness</td>
<td>738 (13.7)</td>
</tr>
<tr>
<td>Emotional distress/anxiety/fear/ existential suffering</td>
<td>253 (4.7)</td>
</tr>
<tr>
<td>Loss of control/autonomy/independence</td>
<td>220 (4.1)</td>
</tr>
<tr>
<td>No/poor/loss of quality of life</td>
<td>199 (3.7)</td>
</tr>
<tr>
<td>Other</td>
<td>32 (0.6)</td>
</tr>
</tbody>
</table>

*More than one could be selected, therefore the total exceeds 100%.
*Data from the Government of Canada.2

Existential suffering associated with living environments and poor health care experiences may also result in individuals opting for MAiD.12-14 An example was a 42-year-old man with VACTERL syndrome, a non-random association of birth defects that affects multiple anatomical structures, who, despite having the option to receive physician-recommended medical interventions that could keep him alive, declined treatment and requested MAiD in 2020 largely due to previous negative healthcare experiences.12 Another recent example was a 35-year-old man suffering from Fabry disease who chose MAiD in January 2021.13 His decision to receive MAiD appeared to be associated with the deplorable conditions in the long-term care (LTC) home he resided in.13 These squalid conditions have since caused the Retirement Homes Regulatory Authority to revoke the operating licence of this LTC home along with five others.13 These cases raise concerns about the prioritization and provision of MAiD in circumstances without first addressing the failure of care standards. Situations such as these also highlight the need for future research directed towards understanding the gaps in care amongst people who opt for MAiD.

The SARS-CoV-2 2019 (COVID-19) pandemic has highlighted serious disparities in how we care for vulnerable members of our society – and such members may be more likely to opt for MAiD. Members of the Canadian Association of MAiD Assessors and Providers have reported that since the onset of the pandemic, more individuals have inquired about MAiD and that COVID-19 restrictions have accelerated the timelines of individuals’ medically assisted deaths.14 Residents in LTC facilities, which have made up a majority of all reported COVID-19 deaths in Canada, are particularly vulnerable.15 LTC homes lacked the basic testing capabilities, hygiene processes, and personal protective equipment needed for infection prevention and mitigation, even after they were identified as COVID-19 hot spots.16 Before the pandemic, a meta-analysis of 16 cross-sectional studies found that residents of LTC institutions had worse quality of life than community-dwelling individuals.17 The impact of LTC institutionalization on the quality of life of individuals has likely only worsened with the isolation and illness of the pandemic.18 For example, in October 2020, a 90-year-old woman, who was described as being exceptionally social and energetic, elected to receive MAiD as she did not want to suffer through another lockdown in her LTC home.14 These trends during the COVID-19 pandemic should be seen by legislative bodies as an urgent call toward action for improving the quality of care in LTC, reducing the need for lockdowns, enhancing the quality of life amongst vulnerable individuals, and providing community support so individuals can live at home longer.

Expanding access to MAiD outside the end-of-life context may increase the proportion of vulnerable Canadians, such as those with disabilities, who receive MAiD. Following a constitutional challenge, a Quebec lower court ruled in the Truchon vs. Canada AG case that the restriction to reasonably foreseeable death is an unjustifiable infringement on the right to life, liberty, and security of the person and the right to equality.19,20 Parliament, responded in March 2021 with a new MAiD law that removed the legal safeguard that restricted MAiD to those who have a reasonably foreseeable death, and introduced a second track access system for persons who are not approaching their natural death, de facto for persons who have a disability.21-23

An analysis of 1027 Canadians with disabilities found that increased anxiety, stress, and despair were associated with negative financial effects of COVID-19, increased loneliness, and decreased feelings of belonging.24 There is concern that the increased strain on support services and the disproportionate impact on vulnerable populations as a result of COVID-19 may result in even more people with disabilities with non-foreseeable deaths opting for MAiD.
The expansion of MAiD in the COVID-19 pandemic era

In light of the legal expansion of MAiD eligibility, the legislative branches of government and health systems need to understand and support vulnerable populations (Figure 2, Central Illustration). We have to conduct research to better understand gaps in care, support, and services. We must realize that Canada has significantly underfunded social support spending compared to other economically similar countries, which was recently shown in the 2020 Organization for Economic Cooperation and Development Social Spending update, and acknowledge this impact on health outcomes. Additionally, all decisions pertaining to MAiD should be made in consultation with the best available evidence, while ensuring that proper safeguards are in place to protect our vulnerable populations. Lack of rigorous research, inadequate social support funding, poor living conditions, and inadequate access to care and support will continue to put individuals at risk. Consequently, if we fail to act promptly, we may find more people, particularly society’s most vulnerable, opting for MAiD.

The COVID-19 pandemic has exemplified how disparities and despair could be alleviated with adequate support and services. As the MAiD practice continues to grow, we need to insist that our legislative branches of government and health systems critically evaluate opportunities for improved services rather than further expanding MAiD. This should include a detailed assessment of the underlying reasons why people opted for MAiD, and how these underlying reasons should be addressed with better health care, social supports, disability services, and other measures that promote dignity in life, so that individuals do not seek to access a government-funded and health system-provided assisted death. It is important that we learn from our experiences in the COVID-19 pandemic context, while also adjusting our laws, systems, and processes to improve social justice and protect those who are in situations of heightened vulnerability.

Author Contributions

HGCV conceived the work, reviewed the literature, and wrote and edited the manuscript. SW reviewed the literature and wrote and edited the manuscript. TL reviewed the literature and wrote and edited the manuscript. All authors approved the manuscript for submission.

Conflicts of Interest

The authors declare no competing interests.

Funding

HGCV received research funding from the Canadian Institutes of Health Research and the Heart and Stroke Foundation of Canada.

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