

# Support structures for healthcare professionals involved in medical assistance in dying: Quebec, Canada, and the international landscape

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## Abstract

With the coming into force of the Quebec Act respecting end-of-life care in 2015, nearly 30 Interdisciplinary Support Groups (ISGs) were formed to accompany practitioners and managers in the clinical, administrative, legal, and ethical practice of Medical Assistance in Dying (MAiD). Today, significant variability is observed in the constitution, role and functioning of ISGs. Based on an overview of national and international support structures, we highlight the strengths and challenges of ISGs. This article presents the results of the first phase of research conducted with 245 people involved in the practice of MAiD in Quebec. The objective is to survey current ISG practices in order to contrast them with those of equivalent structures in Canada and around the world. The intention is to guide managers in the development of support structures for their institutions. In summary, ISGs are distinguished by their interdisciplinary constitution, their decentralized nature, and their proximity to the teams in the field. However, their service offer remains largely unknown to caregivers and the general population. This can be explained by the undefined and unlimited nature of their mandate, but also by the gap between the scope of their mandate and the lack of funding they receive.

## Introduction

In Quebec, the Act Respecting End-of-Life Care came into force in December 2015. With this law, this province confirmed the right to receive end-of-life care, including palliative care and Medical Assistance in Dying (MAiD), for people whose condition requires it.<sup>1</sup> The following year, Canada followed suit by legalizing the practice of euthanasia and assisted suicide.<sup>1</sup> In 2021, 3.3% of all deaths in Canada were due to MAiD. With 4.7% of all deaths, Quebec is the second province with the highest proportion of MAiD in the country, just behind British Columbia, which had 4.8%.<sup>2</sup>

In a Quebec Superior Court decision, the criteria of end-of-life and reasonably foreseeable natural death were removed from Canadian and Quebec law in 2021.<sup>3</sup> In Canada, it is anticipated that by March 2023, MAiD will be permitted for people whose only medical condition is a mental disorder.<sup>4</sup> In Quebec, other major legislative changes are expected. Among other things, MAiD could be subject to advance requests, allowing people who are incapacitated by a neurodegenerative disease to use it.<sup>5</sup> These transformations will create new uncertainties and instabilities. They will require renewed adaptation on the part of healthcare institutions, managers, and caregivers.

There is strong public pressure on governments to expand MAiD and on healthcare systems to take on the sheer volume and complexity of it. If the last decade has allowed us to debate the legalization of MAiD and the conditions of its implementation, it is now to be seen whether healthcare systems have had the capacity to support the expansion of the practice, to ensure the rights of patients, without weakening the caregivers' engagement to MAiD.

Although more and more Quebec and Canadian caregivers are becoming involved in MAiD,<sup>2,6</sup> we still know little about their reality of practice. By 2021, it was

estimated that two-thirds of Quebec physicians had experienced at least one situation in which MAiD had been considered by their patient.<sup>7</sup> The increase in the number of people involved in MAiD, coupled with the range of issues that the practice imposes, justifies the importance and relevance of research into the structures designed to support them.

In Quebec, these structures are called, “Interdisciplinary Support Groups” (ISGs). With the implementation of the 2015 law, the Ministère de la Santé et des Services sociaux (MSSS) invited its establishments to set up ISGs to support the caregivers involved in MAiD. Their mandate was to “offer support to interdisciplinary teams in the clinical-administrative process of any MAiD request” and to “offer support to the institution’s decision makers in terms of quality assurance and availability of resources” [free translation].<sup>8</sup>

More than 5 years after their implementation, it is estimated that nearly 30 ISGs have been set up to support caregivers in the clinical, administrative, legal, and ethical practice of MAiD. However, we know nothing about their reality and their support practices that could benefit the others involved in MAiD.

Given the ethical complexity of MAiD, the importance of the mandate given to ISGs and the lack of evidence on the subject, we have undertaken to investigate these support structures. This article presents a mapping of national and international ISG-equivalent

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structures. We explain the research methodology used and present the main findings of the first phase of our study, collected with a mixed on-line survey. We then highlight the strengths and challenges of ISGs by contrasting this support structures with the others identified in the grey and scientific literature. From the perspective of clinical and organizational ethics, we highlight the elements to be considered in the development of a support structure for MAiD in order to guide managers in the development of supporting practices for their institutions. We conclude by outlining the next steps in the research and its potential impact on end-of-life care.

### Support structures for MAiD

Various national and international support structures have been developed in the field of MAiD, but few of them have been the subject of scientific investigation. Table 1 presents structures identified in the grey and scientific literature, as well as their main mandates and characteristics.

As shown in Table 1, some structures (eg, Support and Consultation on Euthanasia in The Netherlands, Life End Information Forum, *Comité científico interdisciplinario para el derecho a morir con dignidad*) offer referring physicians the availability and expertise of a second assessor to ensure that the legal criterion of independence is met. Some structures take the form of communities of practice (eg, American Clinicians Academy on Medical Aid in Dying, Canadian Association of MAiD Assessors and Providers, ISG Community of Practice, AMM-Quebec Community of Practice), some are supported or funded by the state (eg, Support and Consultation on Euthanasia in The Netherlands, Life End Information Forum, Canadian Association of MAiD Assessors and Providers, ISG Community of Practice), some are enshrined in law (eg, Support and Consultation of End of Life in New Zealand), while others are bottom-up initiatives (eg, American Clinicians Academy on Medical Aid in Dying, Canadian Association of MAiD Assessors and Providers, AMM-Quebec Community of Practice). There are also national and regional models, centralized or decentralized by jurisdiction, region, or locality. In sum, the Canadian and international initiatives identified provide a point of comparison on support structures. However, given the multiplicity of applicable cultural and legislative contexts, the transferability of models remains limited.

### Methodology

We conducted a mixed method, multi-phase study to describe current ISG practices, to critically analyze them and to make recommendations for the improvement of those practices considered to be supportive. The specific objective of the first phase of our study (here reported) was to create an inventory of the practices and issues experienced in the field by the participants. Before being launched, the study was approved by the Scientific and Research Ethics Committee (REB) of the CISSS de Laval.

All those involved in the practice of MAiD in Quebec were invited to complete a mixed on-line questionnaire with 38 open and closed questions, divided into 5 sections (demographics, reality of ISGs, needs and issues, innovation and supporting practices, and participation in the community of practice<sup>2</sup>). Participants may be part of the public healthcare system, private clinics, or palliative care homes. These people were reached by healthcare institutions, MAiD communities of practice, Quebec network for palliative and end-of-life care research, and College of physicians. Before accessing the questionnaire, respondents were required to electronically sign the research consent form. The data were subjected to convergent mixed-method analysis including statistical and descriptive thematic analysis.<sup>36</sup> Statistical Package for the Social Sciences (SPSS) software was used for statistical data analysis and NVivo-12 software was used for qualitative content analysis. Citations from participants are anonymized and participants assigned by a rank number (eg, P1 and P2).

### Results

Two hundred and forty-five people completed the entire questionnaire. The majority of the sample was composed of nurses (25%), physicians (25%), and managers (23%). It also included social workers, pharmacists, spiritual care workers, psychologists, occupational therapists, and family partners. However, no legal representatives participated in the research. All respondents were involved in MAiD practice, 44% were members of an ISG and 33% were part of the ISG Community of Practice.

The research shows that most institutions respected the initial composition of the ISGs proposed by the MSSS, by including a coordinator, a physician, a nurse, a pharmacist, and a social worker.<sup>33</sup> However, some ISGs consisted of a single coordinator, while others included psychologists, spiritual care workers, medical specialists, ethicists, lawyers, patients, or family partners.<sup>3</sup>

In addition to representation by discipline, several participants suggested that the ISGs should be representative of the missions of the institutions. To counterbalance the hospital-centric nature of the ISGs, they suggested including representatives from long-term care facilities and local community service centres.

One of the highlights of our study was that many participants were actually unaware of the existence of ISGs or the services they offer before completing the questionnaire, even though they are regularly involved in MAiD practice. These are physicians, nurses, and social workers and work mainly in institutions where ISGs are also identified as less active. Otherwise, ISGs are better known by physicians than by other caregivers, and they are also better known by palliative care physicians than by general practitioners and specialists. Finally, they are little or unknown to teams in the community (family medicine groups, private medical clinics), compared to those in public hospitals and institutions.

**Table 1.** Summary of support structures and main characteristics.

Support structures	Country/State/Province	Main mandate	General observations
Support and Consultation on Euthanasia in The Netherlands Life End Information Forum	Netherlands <sup>9-13</sup>	Provide a second independent assessor	First support structure in the world; government funding Web site: <a href="https://www.knmg.nl/advies-richtlijn/scen/over-scen.htm">https://www.knmg.nl/advies-richtlijn/scen/over-scen.htm</a> Only available in Flanders; low government funding
Support and Consultation of End of Life in New Zealand	Belgium <sup>12,14-17</sup>	Provide a second independent assessor	Consultations on MAiD and palliative care Web site: <a href="https://leif.be/home/">https://leif.be/home/</a>
<i>Comité científico interdisciplinario para el derecho a morir con dignidad</i> Doc2Doc	New Zealand <sup>18,19</sup>	MAiD coordination Support and information	Interdisciplinary, including patient partner; list of evaluators, providers, and experts Information and communication to the population Ensuring quality of MAiD and physician training
American Clinicians Academy on Medical Aid in Dying	Colombia <sup>20</sup>	Provide a second independent assessor Physician-to-physician support	Free and confidential telephone line Web site: <a href="https://www.compassionandchoices.org/dzd2022">https://www.compassionandchoices.org/dzd2022</a>
Programme Death with Dignity	United States <sup>21</sup>	Support and information for all caregivers Referral system for patients	Bottom-up initiative; community of practice; certified trainings for caregivers Operates with donations and fundraising activities Web site: <a href="https://www.acamaid.org/">https://www.acamaid.org/</a>
Canadian Association of MAiD Assessors and Providers	United States <sup>22</sup>	Facilitating access for patients and support for caregivers	Institutional model Patient advocate ensures MAiD process
Alberta Health Services	Washington <sup>23</sup> (United States)	Peer support and information	Bottom-up initiative; community of practice ; recently funded by government <sup>2</sup> Offering conferences, webinars, tools, and practice guides for members
Shared Health (MAiD Team)	Canada <sup>24,25</sup>	Central coordination for MAiD	Medical referral not required Web site: <a href="https://www.albertahealthservices.ca/info/page/13497.aspx">https://www.albertahealthservices.ca/info/page/13497.aspx</a>
Centre for effective practice	Alberta <sup>26</sup> (Canada)	Central coordination for MAiD	Social worker's systematically involved in MAiD evaluation Web site: <a href="https://cep.health/clinical-products/medical-assistance-in-dying/">https://cep.health/clinical-products/medical-assistance-in-dying/</a>
University Health Network	Manitoba <sup>26</sup> (Canada)	Telephone and on-line information and support	Family support Web site: <a href="https://www.uhn.ca/healthcareprofessionals/MAiD">https://www.uhn.ca/healthcareprofessionals/MAiD</a>
Hamilton Health Sciences Assisted Dying Resource and Assessment Service	Ontario <sup>27</sup> (Canada)	Support and information for all caregivers; MAiD assessment	Supported by ethics services; interdisciplinary constitution MAiD case review process, debriefing to caregivers
ISG Community of Practice	Ontario <sup>28</sup> (Canada)	Support and information for all caregivers; MAiD assessment	Funded by the government; open to all those involved in MAiD Sharing and learning activities (forum, webinars)
AMM*:Quebec Community of Practice *MAiD	Ontario <sup>29</sup> (Canada)	Support and information for all caregivers ; MAiD assessment	Bottom-up initiative of Quebec provider physicians Information sharing activity and discussion forum; not funded
Interdisciplinary support groups(ISG)*	Quebec <sup>30-32</sup> (Canada)	Support and information for all caregivers MAiD coordination	Decentralized model; about 30 structures in the province; not funded Interdisciplinary constitution; no web site or information to the public
—	Quebec (Canada)	No support structure	Euthanasia Evaluation and Assurance Commission and MAiD Continuing Education Commission
—	Spain <sup>9-34</sup>	No support structure	Mandatory training on the legal and clinical framework for MAiD practice
—	Victoria <sup>35</sup> (Australia)	No support structure	

Note 1. Different databases were used to identify and collect information on support structures (PubMed, MEDLINE, PsycInfo, and Web of Science). Government reports and annual reports of control and assessment committees were also used to identify structures that were not scientifically researched. English terms were entered into the search engines (support, structure, system, consultation, interdisciplinary, practices, MAiD, euthanasia, and assisted suicide). The translation software [www.deepl.com](http://www.deepl.com) was used to translate the web sites of the Dutch, Flemish, and Colombian structures.

Participants were asked about the nature of the supporting practices organized by the ISG located on their institutions (Figure 1). Clinical support (consultation, information, training, and mentoring) and administrative support (coordination of the MAiD, organization of meetings, and construction of tools) are the most present, followed by ethical and legal support.

Less than half of the participants (42%) were in favour of centralizing the ISGs into a single support structure, as is the case in Alberta, Manitoba, Belgium, and the Netherlands. Several participants refer to the 2015 “merger fiasco”<sup>4</sup> and raise their fears about such an orientation, as expressed by this participant: “No national service can be close to the patient and their loved ones, nor close to the concerns of the stakeholders”.

Three healthcare institutions are distinguished by a marked preference for the centralization of ISGs. These are also distinguished by a lower level of activity of their ISG. Participants working in these institutions believe that centralization will lead to better accessibility, efficiency, speed, and availability of information and services related to end-of-life care. They also advocated for greater uniformity, standardization and harmonization of care, services, support, and processes. They see this as a way to limit unreported requests for MAiD.<sup>5</sup>

Other participants were opposed to the centralization of ISGs, fearing the disengagement of physicians and the delegation-of-Maid requests to the “central” ISG. Some fear that centralization will lead to a depersonalization of care, a loss of proximity, responsiveness, agility, and humanity.

In order to bring out supporting practices, participants were asked to identify the issues present in their institution in relation to MAiD. Figure 2 presents these issues by the number of participants. Physician recruitment, the general population’s understanding and knowledge of palliative and end-of-life care, and the understanding and interpretation of

caregivers, family members, and patients of the Act concerning end-of-life care emerged as main issues.

Qualitative analysis revealed a number of recommended improvements regarding the (1) the availability of resources (temporal, human, physical, and financial), (2) communication, (3) awareness and education about palliative and end-of-life care, (4) collaboration with palliative care, (5) physician (dis) engagement,<sup>6</sup> (6) administrative burden, (7) computerization of data, (8) remuneration of caregivers, (9) the role of the Commission on End-of-Life Care, and (10) the coexistence of two communities of practice in Quebec.

Among the strengths of the ISGs, participants noted their adaptability to the specific needs of the institutions, respect for local specificity, proactivity, interdisciplinarity, and the complementary nature of the members. Among the challenges, some deplored the lack of mutual support between ISGs, the general lack of knowledge about their service offer, the disparity and inequity of support across the province, the inactivity of certain ISGs, and the lack of investment in the ISGs on the part of the MSSS.

The ISGs that were the most active and those whose roles and practices were best known by the participants received the most positive comments, as reported by this participant: “I find that the ISG in my territory made me feel supported and accompanied. I was able to be trained. I felt a concern for my well-being, following my first-Maid experience”. This other person mentions: “The ISG has become a real regional consultation platform for MAiD, in addition to its basic functions in supporting professionals”. Conversely, the ISGs that are the least active or the least known by the participants are the subject of more unfavourable comments, as indicated by these two participants: “Phantom ISG” and “No service corridor, never heard of the ISG”.

Finally, analysis of the data reveals a great deal of confusion among participants regarding the support structures and regulatory bodies present in Quebec. In particular, the roles

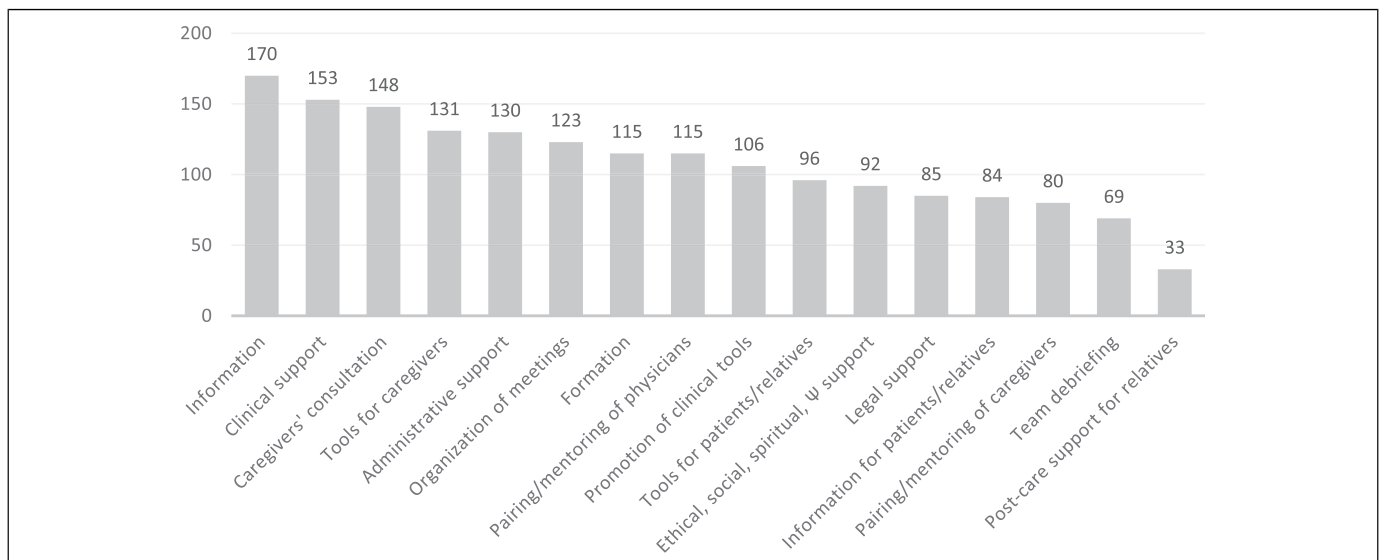
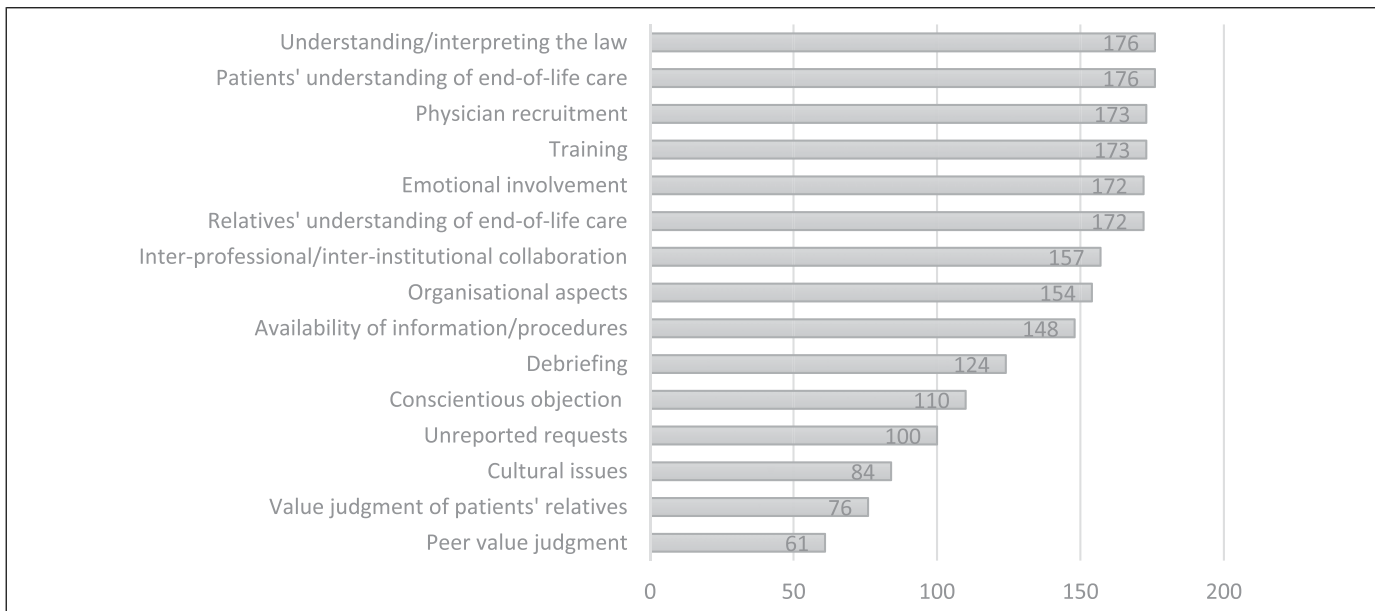


Figure 1. Supporting practices by ISGs presented by number of participants.



**Figure 2.** Issues in relation to MAiD presented by the number of participants.

and mandates of the ISGs, the ISG community of practice, the MSSS, the College of physicians, and the Commission on End-of-Life Care<sup>7</sup> remain unknown or misunderstood by a majority of participants.

## Discussion

At the time of MAiD's implementation, Quebec healthcare institutions were free to integrate their ISG into an existing service (eg, ethics or palliative care programs) or to create it entirely from regional resources and needs.<sup>33</sup> The flexibility of MSSS directives led to a great deal of variability in the development, constitution, roles, and functioning of these structures. In their analysis of Canadian MAiD programs, Silvius et al. confirm the ambiguity experienced by managers and clinicians during the implementation of MAiD in their organizations.<sup>26</sup> Our research confirms that this variability influences the availability and provision of support to caregivers, as well as the potential impact on access and quality of patient care and services.

We know that the proportions of MAiD vary significantly between regions in Quebec.<sup>6</sup> Nevertheless, the causes of these distinctions have not been studied to date. Belgian authors have pointed out similar distinctions in euthanasia practice between the regions of Flanders and Wallonia.<sup>15</sup> Several reasons explain the differences between the two regions according to the authors, including the means of communication deployed in Flanders to raise public awareness. Above all, the Belgian support structure is identified as the main factor that contributed to informing and supporting physicians in Flanders about the clinical and legal particularities of euthanasia practice, compared to Wallonia where no equivalent structure has been set up.

Many of the issues highlighted by the participants in our research overlap with those identified in the literature.<sup>37,38</sup> Some

elements, however, appear to be specific to the reality of the province of Quebec. Among other things, the number of support structures, combined with the regulatory bodies involved in MAiD, makes it difficult for stakeholders to understand what course of action to take with respect to this practice. Despite the many structures available, many participants deplore not having a place to find validated information to guide them. In this regard, Quebec has not yet developed a platform or telephone line for caregivers or the public on the issue of end-of-life care. This proposal overlaps with the recommendation for a "national board" issued by the MSSS in 2015<sup>33</sup> and the "advisory service" proposed by the Commission on End-of-Life Care in 2021.<sup>6</sup> Compared to the Dutch or the Belgian structures, the ISGs do not receive any funding to carry out their mandates. Without resources, their scope can only be limited.<sup>12</sup>

European authors suggest that ownership by a government authority contributes to the success and effectiveness of support structures.<sup>12,17</sup> Similarly, investment by healthcare managers was identified by several participants as a key condition for the success of ISGs. Two Ontario studies come to the same observation.<sup>28,29</sup> These studies show that the organizational context is one of the most important factors contributing to the involvement of caregivers in MAiD.

Finally, our research leads us to the suggestion that the variability of practices between ISGs leads to real issues in terms of access and quality of support available to those involved in MAiD. At the same time, this variability favours the emergence of innovations and is an incubator of supporting practices.

## Conclusion

Our research is one of the first attempts to investigate the experience and needs of those involved in the practice of MAiD in Quebec as related to ISGs. In the first stage of a



broader study, we were able to characterize ISGs and their landscape. We also identified several issues and practices, particularly in relation to the roles, mandates, and responsibilities of ISGs, managers, partners, and regulatory bodies.

ISGs feature interesting characteristics such as interdisciplinarity, decentralization, and proximity of structures. However, the lack of knowledge of all stakeholders about the existence and service offer of the ISGs is one of the salient results of the research. Participants also expressed confusion about the role of the different regulatory bodies involved in MAiD. Another striking fact of our research is the contrast between the absence of lawyers among participants and the predominance of legal concerns shared by those who constitute our sample. Similarly, although all those involved in MAiD were invited to participate in our research, few patients and close partners were reached by our recruitment methods. In the next phases of our research, we will discover what initiatives some institutions have put in place to survey these people in order to improve the quality of care and services offered to them. The next phases will also allow us to identify practices that can meet the needs of stakeholders on the legal aspects of MAiD and ensure a better match between these needs and the support offered by the legal departments of the different institutions.

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### Ethical approval

The study was approved by the Scientific and Research Ethics Committee (REB) of the CISSS de Laval (MP-35-2021-659).

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### Notes

1. Unlike Canada, Quebec law allows MAiD in euthanasia form only. Under Quebec law, “Medical aid in dying consists of a doctor administering medication to patients, at their request, in order to relieve their suffering by bringing about their death.”<sup>1</sup>

2. As we have seen in Table 1, there is an ISG community of practice in Quebec for caregivers involved in MAiD practice.
3. These, chosen for their experiential knowledge in the healthcare system, represent the perspective of patients, relatives, and the community.
4. With the Act to amend the organization and governance of the health and social services network, Quebec experienced a major centralization of health services in 2015, going from 182 to 34 institutions, divided into 22 “megastructures” called Centre intégré de santé et de services sociaux (CISSS) and Centre intégré universitaire de santé et de services sociaux (CIUSSS). The negative impacts of this reform were confirmed by several analysts: centralization of powers, distancing of decision-making, loss of sensitivity to local realities, and reduction of services.
5. Several participants referred to unprocessed requests as being “passed over in silence” by caregivers.
6. Several participants expressed concern about the risks of disengagement that could result from the centralization of support structures. They underlined the contradiction with the spirit of the Quebec law, according to which the responsibility of physicians must be promoted.
7. In Quebec, the Commission on End-of-Life Care has a mandate to review the compliance of end-of-life care and to ensure that the requirements of MAiD are met.<sup>1</sup>

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