Title: The information needs of patients, professionals and the public with regards to medical aid in dying: a qualitative study

Authors:

Antoine Boivin, MD, PhD[1,2,3]
François-Pierre Gauvin, PhD[1, 5]
Geneviève Garnon, PhD[1]
Agustina Gancia, PhD[1]
Ghislaine Rouly[1]
Isabelle Marcoux, PhD[4]
Pascale Lehoux, PhD[3]

1. Centre of Excellence on Partnership with Patients and the Public
2. Department of family and emergency medicine, University of Montreal
3. Department of management, evaluation and health policy, University of Montreal School of Public Health.
4. Interdisciplinary school of health sciences, University of Ottawa
5. *Department of Health Research Methods, Evidence, and Impact, Centre for Health Economics and Policy Analysis,* McMaster University

Corresponding author:
Antoine Boivin, MD PhD
Antoine.boivin@umontreal.ca
(514) 775-5064
Center of Excellence for Partnership with Patients and the Public
University of Montreal Hospital Research Center (CRCHUM)
900, rue Saint-Denis, S03.304
Montréal (Québec) H2X 0A9
Canada

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Abstract:

Background: In 2016, the Canadian government legalized medical assistance in dying (MAiD) for adults with terminal illness. The objective of this study is to explore the information needs of health professionals and members of the public regarding MAiD. **Methods**: This is a qualitative study using a one-day face-to-face forum, followed by a three-week online forum across the province of Quebec. Deliberations were prompted by short informational videos about MAiD. A thematic analysis was performed to identify key information needs. **Results**: Eighty-five health professionals and members of the public (patients, caregivers and citizens) identified a majority of common information needs on the definition, eligibility criteria, medical practice and evaluation procedures for MAiD that varied along different stages of the patient's life journey. Forty-three people participated in the face-to-face meeting and 42 people participated online. Participants highlighted the need to be informed about issues that go beyond the medical and legal aspects of MAiD (eg. relational, ritual, personal and interpersonal aspects). Key principles that should drive future information strategy include the development of a shared and comprehensive information base both available to professionals and members of the public.

Interpretation: These findings call for concerted efforts to build a common information base - covering dimensions that go beyond the medical and legal aspects of MAiD - to facilitate informed conversations between patients, professionals and members of the public.

MeSH: End-of-life; Shared Decision-Making; Consultation; Seeking information; Public Policy

Introduction

In 2014, the province of Quebec adopted the Act Respecting End-of-life Care (1), allowing competent adults with terminal illness to request medical assistance in dying (MAiD). MAiD is defined as "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.” (1) At the federal level, the Supreme Court of Canada, in *Carter v Canada,* declared that criminal code prohibition of MAiD was in violation with the Canadian Charter of Rights and Freedoms. (2) In June 2016, the Canadian government passed a federal legislation (Bill C-14) amending the Criminal Code to allow MAiD across the country. (3)

Patients’ preferences towards end-of-life care have been abundantly studied. (4-6). However, an important degree of confusion on MAiD has been noted among members of the public and professionals. (7-9) One recent study showed that Quebec healthcare professionals confuse MAiD with other end-of-life practices, such as treatment withdrawal and the use of drugs for symptom management. (10) Yet, the literature addressing information needs about MAiD remains scarce and rarely focus on the respective needs of patients and professionals. (11-17) This knowledge gap is a barrier for the development of relevant and effective public information strategies on MAiD. This study aims to present key findings from a deliberative forum highlighting key information needs of healthcare professionals and the public, and areas where these needs overlap and diverge.

Methods

Deliberative forum design

We conducted a qualitative study using deliberation for data elicitation and thematic content analysis for data synthesis(18). Deliberation refers to a dialogue that involves the careful weighing of reasons for or against a proposition. (19) Deliberative forums go beyond traditional public consultation by incorporating at least three key elements: 1) provision of information to participants about the issue being discussed; 2) opportunity for interactive discussion among participants; and 3) an explicit process for collecting individual or collective input. (20) Deliberation creates an opportunity to move away from raw public opinions elicited by traditional consultation mechanisms towards more informed and responsible public judgment about complex health-system issues. (21)

In order to balance depth and geographical scope, we conducted deliberative forums in two formats: 1) a one-day face-to-face forum with participants from the greater Montreal area held in a public community building; and 2) a three-week online forum with participants from across the province of Quebec, the only Canadian province where MAiD was legal at the time of the study. Its goal was to extend the forum to participants living outside Montreal in other rural and urban areas of Quebec. The design of these forums was based on previous deliberation studies. (22, 23) The forum discussions were introduced by a short video capsule produced with legal and medical experts and was structured around the following topics,: 1) what is MAiD; 2) what are the eligibility criteria; 3) how is MAiD practiced; 4) how are practices evaluated and monitored. In the face-to-face deliberation, a professional moderator introduced questions during the plenary session, before participants were discussed each question in small groups. In the online forum, a professional moderator also introduced videos and questions, and provided summaries of discussion on a weekly basis to facilitate discussions.

Participants targeted for the study included members of the public (citizens, patients, and caregivers), and healthcare professionals (physicians, nurses, pharmacists, managers, social workers). Two strategies were used to recruit participants: 1) a call for applications to the patient partner network of the Patient Partnership and Collaboration Unit at the Faculty of Medicine, Université de Montréal; and 2) a call for applications via social media (Twitter and Facebook) and mailing lists of partner professional and community organizations across the province of Quebec.

Interested candidates were asked to submit their application online. A purposeful sampling strategy was used to recruit a diverse group of participants based on the following criteria: age, gender, socioeconomic status, region, health status, personal experience with end-of-life care as patient or caregiver, and attitude toward MAiD. Health professionals were also selected to include a diversity of participants based on: health discipline, experience with end-of-life care, region, and attitude toward MAiD. Participants were compensated for their travel and time. No selected candidates refused or dropped out during the study.

Data collection and analysis

For each of the four themes presented in the MAiD videos, participants were asked to reflect on two questions: a) what information was new to them, and b) what questions were left unanswered. Four methods were used to collect data on the deliberation content and process during the face-to-face and online forums. For the face-to-face forums 1) audio-digital recordings of participants' discussions and 2) "placemats" were used by participants to write and compile individual and collective responses. For the online forums 3) written exchanges during the online forum; and 4) notes from two non-participant observers.

The face-to-face forum was moderated by a professional female moderator, independent from the research team and hired from a not-for-profit organization with expertise in citizen engagement (Institut du Nouveau Monde), whereas the online forum was moderated by a male independent moderator from the same organization. The forum moderators proactively ensured all participants provided their input and ensured that all topics were explored in depth. No repeat or follow-up interviews were conducted.

A qualitative thematic content analysis was used to synthesize the key information needs that emerged from the forums and to identify key principles that could guide a public information strategy on MAiD(24). Thematic content analysis was chosen because we sought categories of themes and questions raised by participants that could drive information strategies. We used a combination of deductive approach (using broad categories related to the patients' life journey) and inductive approaches (driven by data using emerging categories). (24) All data were coded by two PhD-level research team members (GG, female and FPG, male) and reviewed during analytical meetings with other team members to further refine analyses. Disagreements between the coders were resolved through discussion with the broader research team. Themes were identified within each deliberation session and compared between sessions. The analyses paid particular attention to the convergence and divergence between the perspectives of members of the public and healthcare professionals. Participants were sent a short synthesis of the data and were asked to provide feedback. Inductive thematic saturation was used to inform the completion of data analysis when no more themes emerged (25). Qualitative data analysis was conducted on NVIVO analysis software.

Ethics approval

The research ethics committee of the Centre hospitalier de l'Université de Montréal approved and monitored this project (# 2015-307). This article follows the Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist. (26)

Results

Participants

Eighty-five people participated in the forums, including 50 members of the public and 35 health professionals. Forty-three people participated in the face-to-face meeting and 42 people participated online. Among members of the public, 78%(n=39) had personal experience as patients with chronic or incurable illness, 66% (n=33) played the role of a caregiver to a patient with chronic or incurable disease and 22% (n=50) were citizens without personal experience as a patient with chronic or incurable disease. Professionals included physicians (11%, n=4), nurses (20%, n=7), pharmacists (3%, n=1), managers (3%, n=1), clinical ethicists (3%, n=1) and allied health professionals (60%, n=21) such as social workers, psychologists, respiratory therapists, spiritual workers and occupational therapists. A description of participants is provided in Table 1. No participant dropped out of the study.

Table 1. Description of participants

	Members of the public (n, %)	**Health professionals (n, %)**
Total	50	35
Gender	Male (14, 28 %) Female (36, 72 %)	Male (5, 14 %) Female (30, 86 %)
Age	18-45 (8, 16 %) 46-64 (20, 40 %) 65+ (22, 44 %)	18-39 (12, 34 %) 40-50 (6, 17 %) 51+ (17, 49 %)

Annual family income	Less than 20 000$ (8, 16 %) 20 000$ to 40 000$ (16, 32 %) 40 000 to 60 000$ (12, 24 %) 60 000$+ (7, 14 %) No answer (7, 14 %)	Not available
Attitude toward MAiD	Very favorable (18, 36 %) Favorable (22, 44 %) Uncertain (6, 12 %) Unfavorable (2, 4 %) No answer (2, 4 %)	Very favorable (9, 26 %) Favorable (15, 43 %) Uncertain (8, 23 %) Unfavorable (3, 8 %) No answer (0, 0 %)
Region	Urban (28, 56%) Semi-urban (16, 32%) Rural (6, 12%)	Urban (21, 60%) Semi-urban (14, 40%) Rural (0, 0%)

Overview of Information Needs on MAiD

Our forums on MAiD revealed 32 information needs (Table 2), where 22 were commonly expressed by members of the public and health professionals, and 10 were specific to members of the public (none were specific for health professionals). Information needs are presented along six specific stages of the patient journey with illustrative quotes presented in Table 2.

1. Reflections and discussions as the end-of-life approaches

Before receiving a diagnosis of incurable disease, information needs focused on positioning MAiD among other end-of-life practices and concepts including palliative care, palliative sedation, euthanasia and assisted suicide. Confusion was expressed among members of the public about the definition of MAiD, as expressed by the illustrative quote in section one of Table 2.

Participants expressed a general concern for access to MAiD in different end-of-life care settings (e.g. home, palliative care units, in nursing homes), since it might impact on patients' decision to receive MAiD. Because provincial and federal legislations on MAiD were adopted separately, many participants wondered how both legislations would align and which one would prevail in case of disagreement.

2. Formulating a request for MAiD

Participants wondered whether the option of MAiD could put pressure on vulnerable patients, and where MAiD would fit along the full range of options of medical end-of-life care: early, as an option within the continuum of end-of-life care, or later, when there is no other option left. Furthermore, participants' information needs focused on the support provided to patients for decision-making. MAiD cannot be requested through advanced directives, which raised questions about substituted consent for incapable patients (eg. Alzheimer's disease), as members of the public initially believed that patients suffering from degenerative disease could request MAiD before cognitive declines prevent them from doing so. Finally, given the fact that end-of-life care often involves interdisciplinary teams, participants sought to the roles of professionals other than physicians in MAiD.

3. Evaluating requests

Once a request is formulated, information needs became more procedural and focused on evaluating patients' eligibility and alignment with legal criteria. Members of the public expressed concern relating to the expected delays for evaluation and whether a request from a patient experiencing psychological distress would be evaluated, considering that some patients could rapidly become incapable of giving consent.

Many argued that interpreting certain eligibility criteria would be challenging and require interdisciplinary expertise that goes beyond that of physicians. Some questioned whether conscientious objection applied to all members of the care team or only to physicians. Questions were raised about available resources for patients who meet legal criteria but their request is denied because of conscientious objection. How disagreement and conflicts get resolved remained a question.

4. Communicating decisions

Members of the public wondered whether patients could reapply with a different physician after a rejected request, and how reluctance would be dealt with. Given concerns about its impact on the therapeutic alliance, professionals and the public wondered if a “communication protocol” would be available to help health professionals announce the evaluation results, particularly in the case of refusal. Participants expected detailed explanations justifying MAiD request decisions, as well as information on alternative care, assuming that a request may be the expression for unmet support needs (eg. psychological support).

5. Delivering MAiD

How communication between the patient and his physician will be ensured between approval and administration of MAiD was formulated more as a preoccupation than an interrogation by both professionals and the public. Concerns about the continuity of palliative care and psychosocial support to patients, relatives and the healthcare team between approval and administration of MAiD, as well as which measures would be adopted to ensure confidentiality were raised.

The lack of a clear framework as to how information would be shared with relatives and other members of the interdisciplinary team was raised by many.

The delivery of MAiD, possible medical complications, and how MAiD could be approached with humanity and respect, as opposed to being framed as a technical procedure, raised questions. Many indicated that MAiD is described in the law as a clinical, legal and administrative process, which led to the questions about the possibility to personalize the physical environment by incorporating music, religious rituals and symbols.

6. Documenting and evaluating practices

Information needs after MAiD practice focused on evaluation and accountability of the physician, healthcare care team, or institution: who evaluates practice (both from a technical and humanity standpoint), and how. The responsibilities of healthcare institutions, professional colleges and the provincial End-of-Life Care Commission raised questions around the presence of potential conflicts of interest and the type of sanctions following malpractice. Finally, participants wished to know how the evaluation results would be made public and for what use.

240 **Table 2.** Information needs of the public and healthcare professionals regarding MAiD

Stages of patient journey	**Common needs expressed by professionals and members of the public**	**Specific needs expressed by members of the public**	**Illustrative quotes**
1. Reflections and discussions as the end of life approaches	Where can MAiD be delivered? How does MAiD align with current (and future) laws? How to interpret the eligibility criteria?	How to distinguish MAiD from other end-of-life practices? What are the eligibility criteria to MAiD? How can a patient express his/her last wishes and ensure that it will be respected?	*"It seems that every time they come up with a new term, there is a whole new semantic field appearing, which escapes to ordinary mortals that are patients."* [public] *"Currently, the situation is ambiguous as to the role and obligations of some end-of-life care settings that seem to be resisting to the law"* [public] "*Who determines the time it takes (before death) for a patient to be considered in the end-of-life?"* [public].
2. Formulating request for MAiD	Who can make a request? To whom a request can be made? Is psychosocial support available when a patient is considering a request? How to create the "openness" to initiate a conversation about MAiD with their relatives and healthcare professionals? Where does MAiD fit along the full range of end-of-life care options?	When a request for MAiD can be made?	*"What are the dispositions of the law for minors, dementia and all those who are not capable to consent? Can the representative of a patient (legal representative, family council, etc.) apply for MAiD?"* [professional] *"How can we create an openness between professionals and patients to discuss properly about all these choices?"* [public] *"...will psychological support be provided? Deciding of the day and time of one's death is somehow empowering, but nevertheless distressing"* [public]
3. Evaluating requests	How are requests evaluated and by whom? If a physician refuses to evaluate a request, how will the request be transferred to another physician? What is the scope of conscientious objection to	What are the expected delays for evaluating a patient request? Can we have access to MAiD if we are experiencing psychological suffering only?	*"What is acceptable in terms of reasonable delay? ... If his condition worsens, can the patient get [MAiD] imminently?"* [public]. *"If a physician refuses to practice MAiD and relies*

	MAiD? If there is a disagreement in the evaluation of the request, is there a mediation process?		*on the chief executive officer [to forward the request to another physician], how will the request be assessed in reasonable time? This is an urgent request since, to meet criteria, one must be dying!"* [professional]
4. Communicating decisions	How are decisions communicated, both in the case of approval and refusal?	If a patient changes his/her mind after his/her request is accepted, can he/she re-apply? Is it possible for a patient to apply to another physician if a first request has been refused?	*"Will it be possible to see another doctor, if, for instance, I don't meet all the criteria? Is there some form of mediation process?"* [public]
5. Delivering MAiD	Are the necessary resources available in all institutions (and in all regions) to provide MAiD? What is the waiting time for practicing MAiD once a request is accepted? What is the role of the healthcare team and relatives during the process? What support is provided to the care team and relatives before, during and after the administration of MAiD? What are the possible harms and side-effects associated with administering MAiD? What measures are in place to preserve the confidentiality of MAiD? How to humanize the process of delivering MAiD?	How to ensure continuous communication between the patient and his/her physician, from the moment a request is made to the moment MAiD is delivered?	*"…In a hospital, the doctor often changes every week. Several doctors may see the patient and the interviews are quite short. How can we make sure that [the dialogue] will be done to the patient's satisfaction?"* [public] *Where are the interdisciplinary team and, especially, the relatives? Are they excluded?"* [public] "*Do we have support after? Are there any resources after all these steps? It is a pretty traumatic way to end a life! Nothing is mentioned in the law, as much for the health professionals, as for the patients and their relatives. I know there is an interdisciplinary support group for MAiD… but is it functional?* [professional] *"What are these drugs [used for MAiD]? Most importantly, what effect do they have on vital organs and on the brain? How can we measure the level of consciousness? Studies have shown that patients in the coma can feel pain even if they look peaceful in the outside!"* [public]

			"Is the injection method really foolproof? Could it happen, during the process, that something doesn't work? We thought the patient was dying, but a problem occurs! Are there ways to solve these kinds of problems? [professional] *"How can a hospital medical environment provide a meaningful set up for the patient receiving MAiD? For instance, would candles, usually not allowed in hospitals, be allowed for MAiD?"* [professional]
6. Documenting and evaluating practices	Who is evaluated and accountable? How will the results of the evaluation made public (and what will they be used for)?	Who evaluates the practices and how?	*"The [Quebec End-of-Life] Act creates a Commission on End-of-Life Care for the whole province, but each institution does not appear to have any evaluation or control mechanism other than the Council of Physicians, Dentists and Pharmacists of Quebec."* [public] *"What are the obligations imposed on the [healthcare] institution with regard with the quality of the patient's environment? How will a calm and respectful environment be ensured for patients and their relatives, just like in palliative care units?"* [professional] *"What are the consequences for the physician if the End-of-Life Care Commission judges that he made a mistake?"* [public] *"Ultimately, will [the Commission] only give us statistics on the places where there is more MAiD and where there is less?"* [public]

241

Interpretation

Main findings

This study assessed information needs about MAiD from the collective perspective of patients, health professionals and members of the public. Three key findings have been identified: 1) a majority of information needs are common to health professionals and members of the public; 2) information needs evolve along the patient journey; 3) information needs go beyond the medical and legal aspects of MAiD. Participants highlighted the needs to discuss the "human" dimensions of MAiD, including its relational, symbolic, psychological and spiritual aspects as opposed to a narrow focus on the technical dimensions of this practice. While some identified information needs are straightforward to address (eg. definitions and legal criteria), others would be more complex (eg. wait time and availability of MAiD in specific regions).

Findings in relation to existing literature

Findings from this study resonate with a growing literature on public understanding of MAiD, euthanasia, and end-of-life care, which have frequently highlighted confusion among different end-of-life practices. (10, 27) A unique contribution is the study's focus on information needs, as opposed to documenting opinions, attitudes and preferences toward MAiD.

An important finding is the identification of common information needs among health professionals and the public to support informed conversations and shared decision-making. This finding is important, given the fact that current information strategies are usually focused on professionals or patients separately. In addition to medical and legal criteria members of the public and healthcare professionals require information on the relational, psychological, symbolic and human aspects of MAiD. Our findings call for greater collaboration between government, public media, professional bodies, educational institutions, health institutions, researchers, patient organizations and other civil society to align their information strategies and meet specific information needs a key junctions of patients' life journey.

The study raised two issues that may warrant further investigation: (1) a need to explore how information needs evolve along different illness trajectories (eg. Long-term chronic illness vs. acute life-threatening conditions), (28) and (2) a need to identify how to optimally package information to support individual reflections, meaningful conversations with relatives and healthcare professionals, as well as decisions about MAiD. This appears particularly challenging given the full range of information needs identified in this project, but also the need to translate such complex and sensitive information for people with varying levels of literacy and the evolution of identified information needs over time. (29)

Limitations of the study

A few limitations should be noted. Although the study did not seek to compare the face-to-face vs. online deliberation, a few differences in group interactions and dynamics were noted by the research team, which may have impacted on results. Deliberation on a sensitive topic like MAiD proved easier to discuss in face-to-face meeting than in the online platform, as it appeared to have provided a "safe space" for participant discussion. We observed that face-to-face deliberations were more interactive, with participants building on each others' arguments (as per deliberation theory), while online deliberation appeared less conductive to the participation of some individuals who remained more passive. As such, online deliberations did not act as a substitute for face-to-face deliberations and may have limited in-depth input from rural participants.

Another limitation is the challenge of recruiting certain groups of participants including men, physicians, health professionals from rural areas, and people who have unfavorable views toward MAiD. Although patients and professionals were part of the research team of framed the questions, our data collection strategy was not piloted, which is a potential limitation. More specifically, it was challenging at time to shift the dynamic from debate (eg. how should MAiD criteria should be adapted?) to dialogue focused on information needs, partly because MAiD is such a highly complex and sensitive topic. These challenges must be overcome in future initiatives to pursue informed conversations about MAiD and end-of-life care more broadly. Of note, this study was conducted soon after the legalization of MAiD and we did not formally assess the proportion of participants who had actual experience with this practice. Information needs should distinguish those with and without MAiD practice experience in future studies. The study was only conducted among francophone participants from Quebec and its results should be contrasted with similar assessment in other parts of the country and cultural groups.

Conclusion

Health professionals and members of the public share common information needs on MAiD, and seek information on the relational, emotional and symbolic aspects of this practice. These findings call for concerted efforts to build a common information base and facilitate informed conversations on end-of-life care between professionals, patients and the public.

References

1. Quebec L. Act Respecting End-Of-Life Care 2017 [cited Bill 2]. Éditeur officiel du Québec:[17]. Available from: http://legisquebec.gouv.qc.ca/en/pdf/cs/S-32.0001.pdf.
2. Baker GR, Fancott C, Judd M, O'Connor P. Expanding patient engagement in quality improvement and health system redesign. Healthcare Management Forum. 2016;29(5):176-82.
3. Canada Po. An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) 2016 [cited Bill C-14]. 14]. Available from: http://laws-lois.justice.gc.ca/PDF/2016_3.pdf.
4. Meier EA, Gallegos JV, Thomas LP, Depp CA, Irwin SA, Jeste DV. Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. Am J Geriatr Psychiatry. 2016;24(4):261-71.
5. Freeman S, Smith TF, Neufeld E, Fisher K, Ebihara S. The wish to die among palliative home care clients in Ontario, Canada: A cross-sectional study. BMC Palliat Care. 2016;15:24.
6. Badrakalimuthu V, Barclay S. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. Age Ageing. 2014;43(1):13-9.
7. Gentile D. Aide médicale à mourir : le travail de plusieurs médecins critiqué par la Commission [Online news]. Radio-Canada.ca: Société Radio-Canada 2017; 2016 [cited 2016 30/06/2016]. Available from: http://ici.radio-canada.ca/nouvelle/790324/aide-medicale-mourir-medecins-critique-commission-soins-fin-vie.
8. Lacoursière A. Aide médicale à mourir: ce n'est pas un "bar ouvert" [Online article]. http://www.lapresse.ca2016 [updated 12/01/2016]. Available from: http://www.lapresse.ca/actualites/sante/201601/11/01-4938873-aide-medicale-a-mourir-ce-nest-pas-un-bar-ouvert.php.
9. Pelchat P. Aide médicale à mourir: Les Québécois confus: http://www.lapresse.ca; 2013. Available from: http://www.lapresse.ca/le-soleil/actualites/sante/201309/27/01-4694026-aide-medicale-a-mourir-les-quebecois-confus.php.
10. Marcoux I, Boivin A, Arsenault C, Toupin M, Youssef J. Health care professionals' comprehension of the legal status of end-of-life practices in Quebec: study of clinical scenarios. Can Fam Physician. 2015;61(4):e196-203.
11. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. JAMA. 2016;316(1):79-90.
12. Lavoie M, Godin G, Vezina-Im LA, Blondeau D, Martineau I, Roy L. Psychosocial determinants of nurses' intention to practise euthanasia in palliative care. Nurs Ethics. 2016;23(1):48-60.
13. Lavoie M, Godin G, Vezina-Im LA, Blondeau D, Martineau I, Roy L. Psychosocial determinants of physicians' intention to practice euthanasia in palliative care. BMC Med Ethics. 2015;16:6.
14. Evans L. Nurses' attitudes to assisted suicide: sociodemographic factors. Br J Nurs. 2015;24(12):629-32.
15. Claxton-Oldfield S, Miller K. A study of Canadian hospice palliative care volunteers' attitudes toward physician-assisted suicide. Am J Hosp Palliat Care. 2015;32(3):305-12.

16. Teisceira-Lessard P. Les Canadiens appuient l'aide à mourir http://www.lapresse.ca2014 [updated 09/10/2014]. Available from: http://www.lapresse.ca/actualites/sante/201410/08/01-4807662-les-canadiens-appuient-laide-a-mourir.php.

17. Vezina-Im LA, Lavoie M, Krol P, Olivier-D'Avignon M. Motivations of physicians and nurses to practice voluntary euthanasia: a systematic review. BMC Palliat Care. 2014;13(1):20.

18. Bombard Y, Abelson J, Simeonov D, Gauvin FP. Citizens' perspectives on personalized medicine: a qualitative public deliberation study. European journal of human genetics : EJHG. 2013;21(11):1197-201.

19. Fearon JD. Deliberation as discussion. . In: Elster J, editor. Deliberative Democracy Cambridge: Cambridge University Press.; 1998. p. 44-68.

20. Yankelovich D FW. Toward Wiser Public Judgment. . Nashville, United States: Vanderbilt University Press; 2011. 176 pages p.

21. J. B. Public Deliberation: Pluralism, Complexity, and Democracy. . Cambridge, MA: MIT Press; 1996. 299 pages p.

22. Lehoux P, Jimenez-Pernett J, Miller FA, Williams-Jones B. Assessment of a multimedia-based prospective method to support public deliberations on health technology design: participant survey findings and qualitative insights. BMC Health Serv Res. 2016;16(1):616.

23. Boivin A, Lehoux P, Burgers J, Grol R. What are the key ingredients for effective public involvement in health care improvement and policy decisions? A randomized trial process evaluation. Milbank Q. 2014;92(2):319-50.

24. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. International journal of qualitative methods. 2006;5(1):80-92.

25. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & Quantity. 2018;52(4):1893-907.

26. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57.

27. Marcoux I, Mishara BL, Durand C. Confusion between euthanasia and other end-of-life decisions: influences on public opinion poll results. Can J Public Health. 2007;98(3):235-9.

28. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7498):1007-11.

29. Canada PHAo. About Health Literacy 2014 [updated 29/04/201406/06/2017]. Available from: http://www.phac-aspc.gc.ca/cd-mc/hl-ls/index-eng.php - tabs-2.

Appendix 1 Public deliberations protocol

Phase 1: Preparing short informational videos

Four short informational videos (approximately 4-5 minutes each), were developed with two medical and legal experts, each focusing on a specific aspect of MAiD: 1) what is MAiD; 2) what are the eligibility criteria; 3) how MAiD is practiced; 4) how practices are evaluated and monitored. The purpose of these videos was to prompt discussion about what participants know or don't know, as well as what additional information do they need. The informational videos are available online at https://ceppp.ca/fr/que-doit-on-savoir-sur-laide-medicale-a-mourir/.

Phase 2: Recruitment of forum participants

Recruitment strategy sought to include members of the public (including citizens, patients, and caregivers), and healthcare professionals targeted by MAiD implementation (physicians, nurses, pharmacists, managers, social workers, etc). Two key strategies were implemented to recruit participants: 1) a call for applications to the patient partners network of the *Direction collaboration et partenariat patient* at the Faculty of Medicine at the Université de Montréal; and 2) a call for applications via social media (Twitter and Facebook) and mass mailing lists of several organizational partners across the province of Quebec (organizations representing patients and older adults, organizations promoting citizen engagement, and professional bodies). Participants were compensated for their travel and time.

All interested candidates were asked to submit their application online. A purposeful sampling strategy was used to recruit a diverse group of public members based on the following criteria: age, gender, socioeconomic status, region, health status, personal experience with end-of-life care as patient or caregiver, and attitude toward MAiD. Health professionals were also selected to include a diversity of participants based on the following criteria: health discipline, experience with end-of-life care, region, and level of support for MAiD. No selected candidates refused or dropped out during the study.

Phase 3: Convening the forums

A 1-day face-to-face forum, facilitated by an expert moderator unknown to the participants and external to the team of authors, was held at the Research Centre of the University of Montreal Hospital Centre (CR-CHUM) in Montreal on May 27, 2016. The moderator had extensive experience in group deliberation and was hired from a not-for-profit organization with expertise in citizen engagement (Institut du Nouveau Monde). Members of the public and health professionals discussed separately the information videos in small group, with feedback in the plenary session. After being presented each information video, participants were asked to reflect on their information needs, discuss them with members of their small group, then summarize their feedback to all participants.

The online forum was held over a 3-week period. The goal of the online forum was to extend the forum to participants living outside Montreal in other rural and urban areas of Quebec. During the first half of the online forum discussion, participants were given access to the information videos and asked to comment on their information needs. Online deliberations were hosted on the deliberative platform Agora, supported by Institut du Nouveau Monde. Two moderators facilitated online deliberations and produced weekly summaries of discussions for participants.

Table 1. Description of participants

	Members of the public (n, %)	**Health professionals (n, %)**
Total	50	35
Gender	Male (14, 28 %) Female (36, 72 %)	Male (5, 14 %) Female (30, 86 %)
Age	18-45 (8, 16 %) 46-64 (20, 40 %) 65+ (22, 44 %)	18-39 (12, 34 %) 40-50 (6, 17 %) 51+ (17, 49 %)
Annual family income	Less than 20 000$ (8, 16 %) 20 000$ to 40 000$ (16, 32 %) 40 000 to 60 000$ (12, 24 %) 60 000$+ (7, 14 %) No answer (7, 14 %)	Not available
Attitude toward MAiD	Very favorable (18, 36 %) Favorable (22, 44 %) Uncertain (6, 12 %) Unfavorable (2, 4 %) No answer (2, 4 %)	Very favorable (9, 26 %) Favorable (15, 43 %) Uncertain (8, 23 %) Unfavorable (3, 8 %) No answer (0, 0 %)
Region	Urban (28, 56%) Semi-urban (16, 32%) Rural (6, 12%)	Urban (21, 60%) Semi-urban (14, 40%) Rural (0, 0%)

Table 2. Information needs of the public and healthcare professionals regarding MAiD

Stages of patient journey	**Common needs expressed by professionals and members of the public**	**Specific needs expressed by members of the public**	**Illustrative quotes**
1. Reflections and discussions as the end of life approaches	Where can MAiD be delivered? How does MAiD align with current (and future) laws?	How to distinguish MAiD from other end-of-life practices? What are the eligibility criteria to	*"It seems that every time they come up with a new term, there is a whole new semantic field appearing, which escapes to ordinary mortals that are patients."* [public]

	How to interpret the eligibility criteria?	MAiD? How can a patient express his/her last wishes and ensure that it will be respected?	*“Currently, the situation is ambiguous as to the role and obligations of some end-of-life care settings that seem to be resisting to the law”* [public] “*Who determines the time it takes (before death) for a patient to be considered in the end-of-life?”* [public].
2. Formulating request for MAiD	Who can make a request? To whom a request can be made? Is psychosocial support available when a patient is considering a request? How to create the "openness" to initiate a conversation about MAiD with their relatives and healthcare professionals? Where does MAiD fit along the full range of end-of-life care options?	When a request for MAiD can be made?	*“What are the dispositions of the law for minors, dementia and all those who are not capable to consent? Can the representative of a patient (legal representative, family council, etc.) apply for MAiD?”* [professional] *“How can we create an openness between professionals and patients to discuss properly about all these choices?”* [public] *“...will psychological support be provided? Deciding of the day and time of one’s death is somehow empowering, but nevertheless distressing”* [public]
3. Evaluating requests	How are requests evaluated and by whom? If a physician refuses to evaluate a request, how will the request be transferred to another physician? What is the scope of conscientious objection to MAiD? If there is a disagreement in the evaluation of the request, is there a mediation process?	What are the expected delays for evaluating a patient request? Can we have access to MAiD if we are experiencing psychological suffering only?	*“What is acceptable in terms of reasonable delay? … If his condition worsens, can the patient get [MAiD] imminently?”* [public]. *“If a physician refuses to practice MAiD and relies on the chief executive officer [to forward the request to another physician], how will the request be assessed in reasonable time? This is an urgent request since, to meet criteria, one must be dying!”* [professional]
4. Communicating decisions	How are decisions communicated, both in the case of approval and refusal?	If a patient changes his/her mind after his/her request is accepted, can he/she re-apply? Is it possible for a patient to apply to another physician if a first request has been refused?	*“Will it be possible to see another doctor, if, for instance, I don’t meet all the criteria? Is there some form of mediation process?”* [public]

5. Delivering MAiD	Are the necessary resources available in all institutions (and in all regions) to provide MAiD? What is the waiting time for practicing MAiD once a request is accepted? What is the role of the healthcare team and relatives during the process? What support is provided to the care team and relatives before, during and after the administration of MAiD? What are the possible harms and side-effects associated with administering MAiD? What measures are in place to preserve the confidentiality of MAiD? How to humanize the process of delivering MAiD?	How to ensure continuous communication between the patient and his/her physician, from the moment a request is made to the moment MAiD is delivered?	*“…In a hospital, the doctor often changes every week. Several doctors may see the patient and the interviews are quite short. How can we make sure that [the dialogue] will be done to the patient’s satisfaction?”* [public] *Where are the interdisciplinary team and, especially, the relatives? Are they excluded?”* [public] “*Do we have support after? Are there any resources after all these steps? It is a pretty traumatic way to end a life! Nothing is mentioned in the law, as much for the health professionals, as for the patients and their relatives. I know there is an interdisciplinary support group for MAiD… but is it functional?* [professional] *“What are these drugs [used for MAiD]? Most importantly, what effect do they have on vital organs and on the brain? How can we measure the level of consciousness? Studies have shown that patients in the coma can feel pain even if they look peaceful in the outside!”* [public] *“Is the injection method really foolproof? Could it happen, during the process, that something doesn’t work? We thought the patient was dying, but a problem occurs! Are there ways to solve these kinds of problems?* [professional] *“How can a hospital medical environment provide a meaningful set up for the patient receiving MAiD? For instance, would candles, usually not allowed in hospitals, be allowed for MAiD?”* [professional]
6. Documenting and evaluating practices	Who is evaluated and accountable? How will the results of the evaluation made public (and what will they be used for)?	Who evaluates the practices and how?	*“The [Quebec End-of-Life] Act creates a Commission on End-of-Life Care for the whole province, but each institution does not appear to have any evaluation or control mechanism other*

			than the Council of Physicians, Dentists and Pharmacists of Quebec." [public] *"What are the obligations imposed on the [healthcare] institution with regard with the quality of the patient's environment? How will a calm and respectful environment be ensured for patients and their relatives, just like in palliative care units?"* [professional] *"What are the consequences for the physician if the End-of-Life Care Commission judges that he made a mistake?"* [public] *"Ultimately, will [the Commission] only give us statistics on the places where there is more MAiD and where there is less?"* [public]