

# Medical end-of-life practices among Canadian physicians: a pilot study

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## Abstract

**Background:** Medical end-of-life practices are hotly debated in Canada, and data from other countries are used to support arguments. The objective of this pilot study was twofold: to adapt and validate a questionnaire designed to measure the prevalence of these practices in Canada and the underlying decision-making process, and to assess the feasibility of a nationally representative study.

**Methods:** In phase 1, questionnaires from previous studies were adapted to the Canadian context through consultations with a multi-disciplinary committee and based on a scoping review. The modified questionnaire was validated through cognitive interviews with 14 physicians from medical specialties associated with a higher probability of being involved with dying patients recruited by means of snowball sampling. In phase 2, we selected a stratified random sample of 300 Canadian physicians in active practice from a national medical directory and used the modified tailored method design for mail and Web surveys. There were 4 criteria for success: modified questions are clearly understood; response patterns for sensitive questions are similar to those for other questions; respondents are comparable to the overall sampling frame; and mean questionnaire completion time is less than 20 minutes.

**Results:** Phase 1: main modifications to the questionnaire were related to documentation of all other medical practices (including practices intended to prolong life) and a question on the proportionality of drugs used. The final questionnaire contained 45 questions in a booklet style. Phase 2: of the 280 physicians with valid addresses, 87 (31.1%) returned the questionnaire; 11 of the 87 declined to participate, for a response rate of 27.1% ( $n = 76$ ). Most respondents (64 [84%]) completed the mail questionnaire. All the criteria for success were met.

**Interpretation:** It is feasible to study medical end-of-life practices, even for practices that are currently illegal, including the intentional use of lethal drugs. Results from this pilot study support conducting a large national study, but additional strategies would be necessary to improve the response rate.

Medical end-of-life practices are hotly debated in Canada, and changes in legislation at both the provincial and the federal levels have recently been adopted. In Quebec, An Act Respecting End-of-life Care, which took effect in December 2015,<sup>1</sup> aims to clarify under which conditions the allowed medical end-of-life practices (e.g., withdrawing life-sustaining treatments, using drugs for symptom management) must be performed and also to legally authorize physicians to intentionally cause death by administering lethal drugs on the voluntary request of a terminally ill patient. In February 2015, the Supreme Court of Canada ruled that the federal Criminal Code prohibitions on physician-assisted death (prescription or administration of lethal drugs on the voluntary request of competent adults with a grievous and irremediable medical condition) were unconstitutional.<sup>2</sup> The federal government introduced legislation in April 2016 under which adults with a “grievous and irremedi-

able” condition will be able to request physician-assisted death.<sup>3</sup> During parliamentary work and Court audience, data from the Netherlands and Belgium were used to support arguments. At that time, no empirical data on medical end-of-life practices in Canada were available; such data were declared impossible to collect, as some of the medical acts discussed were illegal.

Studies on the prevalence and characteristics of medical end-of-life practices, including the intentional use of lethal

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drugs, are important to enlighten discussions regarding public policies on end of life and also to monitor these practices over time. Such studies were first conducted in the early 1990s in the Netherlands<sup>4</sup> and have been replicated 4 times since then.<sup>5–8</sup> Studies were also conducted in Belgium, both before<sup>9,10</sup> and after<sup>11,12</sup> the Belgian Act on Euthanasia<sup>13</sup> was adopted. Other countries with restrictive policies regarding the intentional use of lethal drugs have also succeeded in collecting such data (Australia,<sup>14</sup> Denmark,<sup>10</sup> France,<sup>15</sup> Italy,<sup>10</sup> the United Kingdom,<sup>16,17</sup> the United States,<sup>18</sup> New Zealand<sup>19</sup> and Sweden<sup>10</sup>), with response rates ranging from 40% to 62%. It thus seems feasible to study various medical end-of-life practices, regardless of their legal status. However, Canadian physicians appear less likely than physicians from other countries to participate in comparable surveys.<sup>20</sup> Furthermore, the Canadian Medical Association's National Physician Survey showed a decrease in the rate of response by physicians, dropping from 36% in 2004 to 16% in 2014.<sup>21</sup> Challenges can then be expected when studying controversial end-of-life medical practices and related sensitive issues in this country.

The objective of this pilot study was twofold. We first aimed to translate, adapt and validate for the Canadian context a research instrument developed in Europe. Second, we assessed the feasibility of conducting a nationally representative study. The criteria for success<sup>22</sup> of this pilot study were: adapted questions are clearly understood by physicians; response patterns for sensitive questions are similar to those for other questions; survey participants are comparable to physicians in the overall sampling frame; and mean questionnaire completion time is less than 20 minutes. We also wished to document participation rates and potential biases attributable to low rates.

## Methods

### Phase 1: questionnaire development

#### Questionnaire modification

Questionnaire selection was based on previous validated studies<sup>4–19</sup> and was contingent on language (French or English) and variations of questions between them. In previous studies,<sup>4–19</sup> questionnaires were mostly based on the original Dutch study.<sup>4</sup> We selected the latest Belgian questionnaire because it has been validated in more than one study<sup>9,11</sup> and has been validated in French. Significant changes were, however, recently made in studies conducted in France<sup>15</sup> and the United Kingdom<sup>17</sup> that could be relevant for the Canadian context. We compared the questionnaires selected and then adapted them through 2 processes. First, to achieve context relevance, we identified domains of interest related to the Canadian clinical and cultural context in consultation with a Canadian multidisciplinary team (physicians, ethicists, a jurist, a psychologist and a sociologist). Second, to achieve conceptual clarity, we adapted questions for distinguishing observable medical end-of-life practices with different legal status according to a descriptive classification developed in a concurrent research study.<sup>23</sup>

After comparing the selected questionnaires,<sup>11,15,17</sup> we decided to document not only the last medical practice performed by physicians before a patient's death but also all other medical practices and the underlying decision-making processes. Our aim was to obtain a more thorough overview of patients' trajectories of care and to better assess practices in line with Canadian legislative frameworks and professional recommendations (e.g., respect of patient's consent).<sup>24</sup> We also modified and developed new questions addressing not only medical practices that could hasten a patient's death but also those intended to prolong life, with or without patient consent. The latter are not well documented in Canada, although they may be challenged in court when physicians' opinion conflicts with preferences expressed by patients and their relatives.<sup>25</sup> Furthermore, although the evidence on double effect (using drugs for symptom management that hastens death) is questioned,<sup>26</sup> the use of opioids or sedatives at the end of life may extend life expectancy according to some authors.<sup>27,28</sup> Finally, an important element in determining the legal status of medical practices in Canada is the physician's underlying intention. Results from previous studies suggest that this notion may sometimes be difficult to measure and interpret.<sup>29,30</sup> A scoping review showed that physicians' intention is not always related to the proportionality of drugs used to relieve suffering or to end a patient's life.<sup>23</sup> As this discrepancy could lead to misclassification (overestimation or underestimation) of some medical practices, we modified the questionnaire using a descriptive classification scheme developed in a concurrent study<sup>23</sup> to include questions on both physicians' intention and the adjustment of drugs according to pain and symptom control.

#### Questionnaire validation

Physicians were invited to validate the modified questionnaire using the Three-Step Test-Interview.<sup>31</sup> Initially they were referred by members of the multidisciplinary committee, followed by recruitment by means of the snowball sampling strategy until saturation, when no new information was obtained. To be included in the study, physicians had to be from medical specialties associated with a higher probability of being involved with dying patients (e.g., critical care, emergency medicine, general practice, geriatrics, nephrology, pediatrics, palliative medicine, psychiatry), be from different Canadian regions and be able to understand English.

The participants were instructed to *think aloud* while they were navigating the instrument and attempting to answer, with follow-up probing by the interviewer to identify problems related to the understanding, wording and order of questions as well as the range of possible answers. We also used debriefing to elicit participants' general experiences and opinions about the questionnaire. Because the questionnaire aimed to document medical practices based on the latest death that the physician had personally attended within the previous 12 months (including potentially illegal acts under legislation at the time of the study), participants were instructed to use a self-chosen fictional case.

The questionnaire tested was in English. It was translated into French by a professional translator and then translated

back into English by another professional translator blind to the original questionnaire. Bilingual research team members compared the final and original English-language versions to check the validity of the translation. Minor modifications were made to ensure equivalence between the French- and English-language versions. The final questionnaire contained 45 questions in a booklet style (Appendix 1, available at [www.cmajopen.ca/content/4/2/E222/suppl/DC1](http://www.cmajopen.ca/content/4/2/E222/suppl/DC1)).

## Phase 2: pilot study

### Sampling strategy

Two sampling methods have been used in previous studies of medical end-of-life practices: death certificate sampling<sup>4-12,15</sup> and registry sampling based on medical specialties.<sup>14,16-19</sup> Given the fragmented nature of the compilation and management of death certificates in Canada (by each province and territory) and consequent complex and lengthy access procedure, death certificate sampling was deemed unrealistic for a pan-Canadian study. Therefore, clinical experts from our multidisciplinary team classified a comprehensive list of 37 groups of Canadian medical specialties into 3 groups based on the probability of being involved in end-of-life decision-making: high ( $n = 11$ ), low ( $n = 13$ ) or nil ( $n = 13$ ). We drew a stratified sample of 300 Canadian physicians in active practice from Scott's *Canadian Medical Directory Online*,<sup>32</sup> retired physicians and those in training were excluded. We considered 3 factors in determining sample size: the fact that not all physicians may have treated or attended a patient who had died in the previous 12 months; the low and declining response rate of the National Physician Survey;<sup>21</sup> and the fact that some questions (e.g., intentional use of lethal drugs) were highly sensitive, and responses could have legal implications for participating physicians. As recommended by Viechtbauer and colleagues,<sup>33</sup> we then over-sampled to obtain at least 59 completed questionnaires, which would allow us to identify unforeseen problems. Physicians belonging to either the high- or low-probability group were included in the sample and were further stratified into 5 practice regions: Atlantic Canada, British Columbia, the Northwest region (prairie provinces and the 3 territories), Ontario and Quebec.

### Questionnaire administration

In previous studies, information was gathered through mailed questionnaire<sup>4-12,14-19</sup> or Web questionnaire or both.<sup>15</sup> We tested participants' preferences by giving them the choice between modes of completion. Initial contact was made by mail in January 2015, in the participants' language of preference as indicated in the medical directory. We compared the participation rate, completion time and answer patterns between the 2 modes of completion.

We used several strategies to maximize the response rate while also considering the sensitive nature of the subject. In accordance with the modified tailored design method,<sup>34</sup> we used a 5-contact procedure: prenotice letter, introduction letter with consent form and questionnaire, thank you card,

reminder letter with consent form and replacement questionnaire, and last reminder letter. We sent the documents at weekly intervals, and stamped return envelopes accompanied questionnaires. To ensure anonymity, the paper questionnaire, envelopes and online survey link did not include any identification marks that could provide information about respondents. This measure required that reminders be sent to all participants since it was impossible to identify nonrespondents. Only limited sociodemographic information was requested, and some characteristics (medical specialty and region of practice) were combined to avoid indirect identification by coupling answers.

Ethics approval was obtained from the Research Ethics Board of the University of Ottawa.

### Statistical analysis

To verify feasibility-related objectives, we used frequency distributions for participation and completion rates, and characterized completion time using means and SDs. To assess representativeness, we compared study participants with the overall sample using  $\chi^2$  tests because the anonymity provided to participants made it impossible to identify who had and had not responded. We analyzed the data using SPSS, version 20.

## Results

### Phase 1

#### Questionnaire validation

Of the 49 physicians invited to the cognitive interview, 20 did not respond, 9 refused to participate, 1 did not show up, and 5 were on a waiting list owing to scheduling conflicts when saturation was reached. The 14 participants were from 5 provinces (British Columbia, Manitoba, Nova Scotia, Ontario and Quebec). Telephone interviews were conducted over 3 rounds in French or English between April and October 2014. The average interview length was 30 minutes.

#### Understandability of questions

Based on feedback from the 14 physicians, we reformulated questions to enhance clarity and added multiple answers or nonapplicable choices when appropriate. Most of the questions were not originally applicable in the case of the death of a child and were modified accordingly. Several participants remarked on the relevance of eliciting information about medical treatments or decisions that could prolong life as well as hasten death, as our questionnaire did. Participants clearly understood changes made to the original questionnaires, including questions on underlying intention and the proportionality of drugs used for pain and symptom management. Box 1 gives a summary of the most important changes made to the questionnaire.

### Phase 2

Between January and April 2015, 13 envelopes (4.3%) were returned to sender, 1 physician asked to no longer be contacted after the prenotice mailing, 5 physicians said they did

**Box 1: Most important changes to the questionnaire****Terminology and conceptual changes**

- 1) Questions related to intention
  - removed the qualifying adjectives “partly” and “explicit”
  - changed the formulation “hasten the end of the patient’s life” to “influence the timing of death”
  - added a new question on the proportionality of drugs (to combine the intention and the means used)
- 2) Question related to the expressed desire of the patient: 2 options: delay the occurrence of death in addition to advance the occurrence of death

**Structural changes**

- 1) Documentation of the underlying decision-making process for each medical act (not only the last one performed)
- 2) Medical act of sedation was integrated in the section with other medical acts (rather than in a question at the end of the questionnaire)
- 3) Separate documentation of withholding and withdrawing treatment(s)

**Additions**

- 1) As in the French questionnaire,<sup>15</sup> we measured the medical acts regarding the continuation of life-sustaining treatment(s)
- 2) Separate section to measure the use of drugs other than opioids and sedatives
- 3) Question to identify patients of Aboriginal descent
- 4) Question regarding challenges during the process of end-of-life care related to cultural differences, language barrier, different religious beliefs or conflict between family members

not feel concerned by the subject, and 1 physician answered that he did not take part in any kind of survey (Figure 1). The valid initial sample thus consisted of 280 physicians. Of the 87 respondents, 11 declined to participate in the survey (Figure 1). Therefore, the response rate was 27.1% ( $n = 76$ ), with most respondents (64 [84%]) completing the questionnaire by mail. Almost a third (19 [31%]) of those who completed the paper questionnaire said they would not have answered if the survey had been available only online. Figure 2 shows the patterns of response (including those who declined to participate) over the data collection period.

**Response patterns**

Of the 12 participants who responded via the Web, 2 did not complete the survey (completion rate 83%); the 10 others answered all the questions. None of the respondents who answered the paper questionnaire returned an incomplete questionnaire. Few problems of completion were found. Unanswered questions were rare, ranging from 1 to 3 occurrences per question, according to the following patterns: screening questions were answered, but subsequent documentation was missing or partly missing; or screening questions were unanswered, but subsequent documentation was provided. Sensitive questions did not have more missing data than other questions. All potentially incriminating questions were answered. For example, of the 31 participants who reported administering opioids in the last 24 hours of life, 7 (23%) indicated that “opioids were used above what was

needed for pain and symptom control.” Three of the 7 thought that the decision to use opioids had hastened the person’s death, and 1 indicated that the intention was to influence the timing of death. For some questions (e.g., cause of death or who administered opioids), participants provided multiple answers when only 1 was expected, and, in fewer cases, participants provided answers other than those suggested on the questionnaire.

**Comparability of participants to overall sampling frame**

No statistically significant difference was found between the 76 participants and the overall sample ( $n = 300$ ) in sex ( $\chi^2 = 0.09$ ,  $p = 0.77$ ), age ( $\chi^2 = 4.51$ ,  $p = 0.34$ ), language ( $\chi^2 = 0.913$ ,  $p = 0.34$ ), medical specialty ( $\chi^2 = 2.43$ ,  $p = 0.12$ ) or region of practice ( $\chi^2 = 4.06$ ,  $p = 0.41$ ) (Table 1). Although the difference was not statistically significant, family physicians tended to be less likely than specialists to respond. Physicians younger than 35 years of age seemed most likely to respond and to complete the questionnaire on the Web ( $\chi^2 = 5.12$ ,  $p < 0.05$ ), and francophones and those practising in Quebec seemed more likely to respond than anglophones and physicians from other regions.

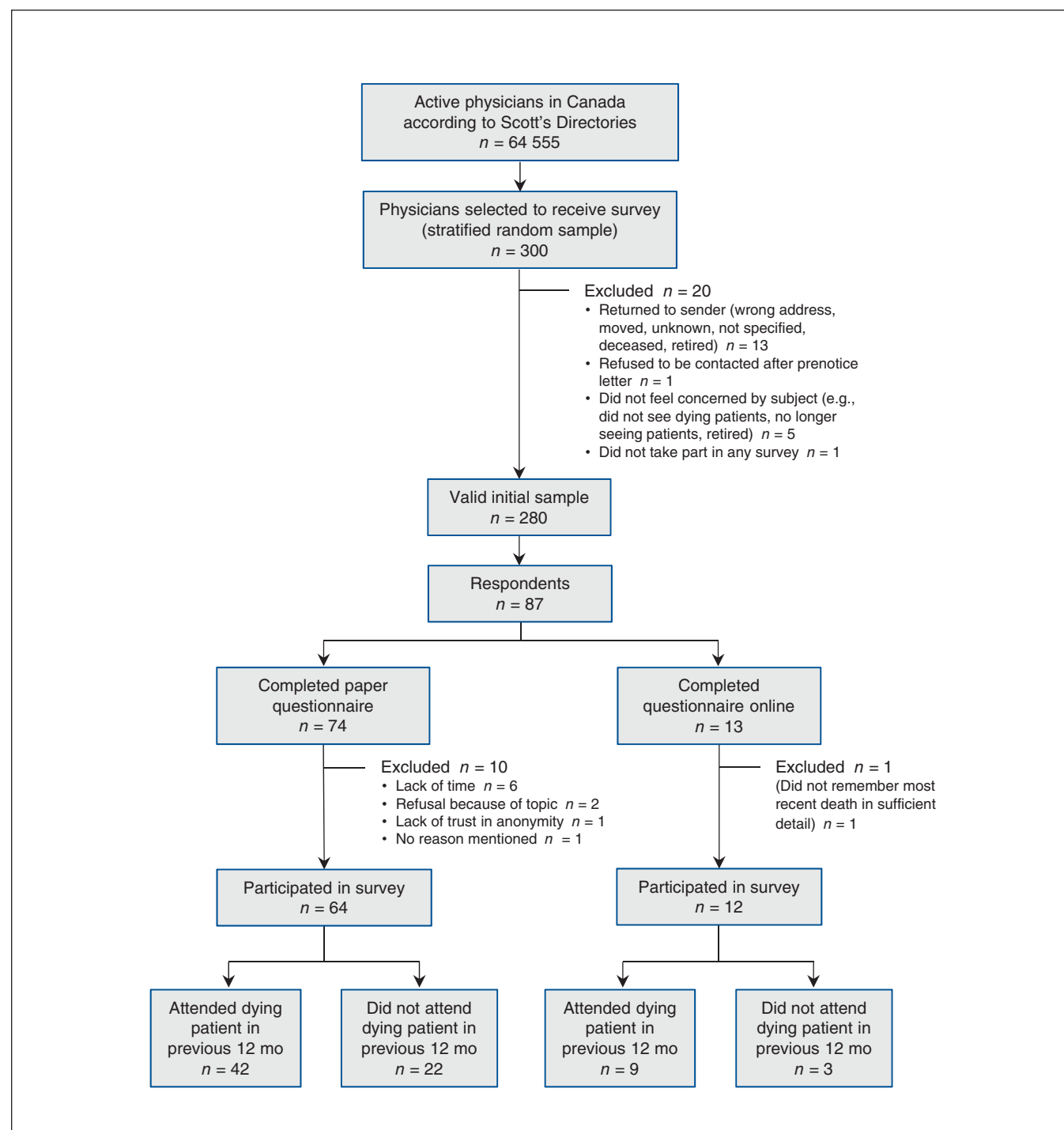
**Questionnaire completion time**

The mean completion time was 17 minutes for those who had been the attending physician in the case of a death in the previous 12 months and 4 minutes for those who had not. There was no difference in completion time between the paper and online questionnaires ( $t = 0.2$ , 65 degrees of freedom,  $p = 0.85$ ).

**Interpretation**

Using existing questionnaires from previous studies on medical end-of-life practices,<sup>11,15,17</sup> we were able to modify questions to improve relevance and clarity in a Canadian context. Despite the low response rate, we found that physicians were as likely to respond to sensitive questions as to other questions, and we did not detect any differences in sociodemographic variables between the participants and the overall sample.

Although the difference was not statistically significant, family physicians tended to be less likely than specialists to participate in the survey. Based on observations from the cognitive interviews, this trend may have been due to differences in Canadian medical specialty designation (i.e., professional classification) and in how physicians identify themselves (e.g., palliative care physicians and gerontologists were classified as family physicians in professional directories but identified themselves as specialists). Potential problems linked to these discrepancies partly result from the anonymous nature of our research procedure. As such, the results of any future large study will have to be interpreted with caution. The finding that those younger than 35 years of age seemed most likely to respond and to complete the questionnaire on the Web justifies the use of the 2 modes of administration despite the fact that most of the respondents preferred the paper questionnaire. Finally, the finding that francophones and those practising in Quebec seemed more likely to respond may have been



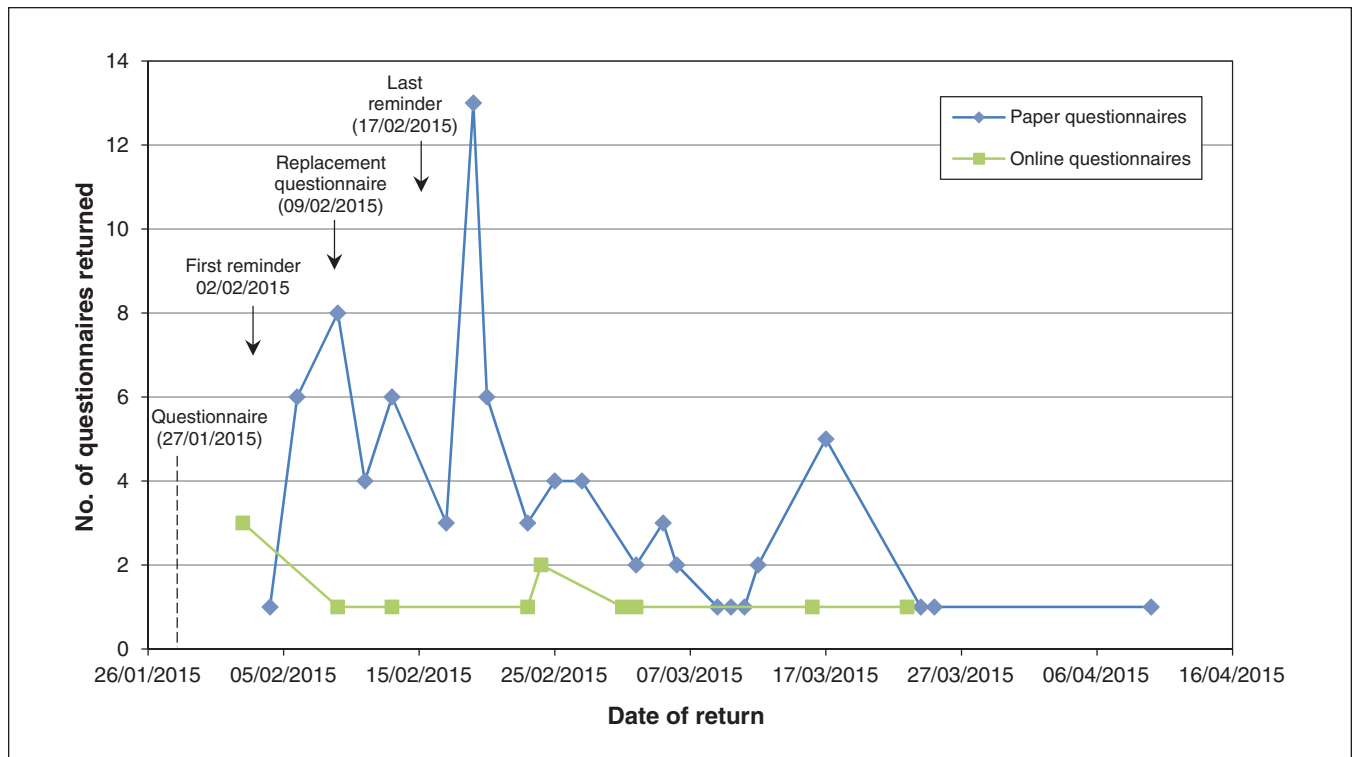
**Figure 1:** Flow diagram of the selection of study participants.

due to the fact that most French-speaking Canadians live in Quebec, where physicians may be more sensitized to the subject of physician-assisted death owing to long-standing debates around end-of-life care and recent legislation change (e.g., An Act Respecting End-of-life Care<sup>1</sup> in June 2014).

As shown by the cognitive interviews, physicians clearly understood modifications made to the original questionnaires, including questions on life-sustaining treatment,

underlying intention and the proportionality of drugs used for pain and symptom management. Although these changes decreased possible comparability with previous studies,<sup>4–12,14–19</sup> they increased the validity and relevance of our findings for the Canadian context, allowed a more thorough appreciation of end-of-life care trajectories and reduced risks of misclassification.<sup>23</sup> The fact that respondents provided answers consistently throughout the questionnaire, even for





**Figure 2:** Number of questionnaires returned during the data collection period, including refusals to participate.

the most sensitive and legally controversial questions, is another strong indication of the feasibility of conducting a larger study in Canada.

Although we devoted considerable attention to attempting to maximize the participation rate using the modified tailored design method,<sup>34</sup> certain modifications (e.g., no first-class mail, no personalized letter) were necessary to ensure anonymity. Based on a systematic review of methods that increase rates of response to postal questionnaires,<sup>35</sup> we followed recommendations such as choosing an interesting questionnaire topic, sending a prenotice letter, making follow-up contact and providing a stamped return envelope with a second copy of the questionnaire. However, we did not follow all the prescribed recommendations;<sup>35</sup> for instance, we did not use incentives owing to limited resources. Nevertheless, the link between these recommendations and higher response rates remains to be further elucidated, as several studies conducted with physicians have given inconsistent findings. Some have shown that questionnaire length<sup>36</sup> and the use of incentives<sup>37,38</sup> have a threshold effect on response rate, but others have suggested that reducing questionnaire length<sup>39–41</sup> and using incentives<sup>40,41</sup> does not make a significant difference. Moreover, a randomized trial conducted with questionnaires on a topic similar to ours, in a comparable population, showed no significant difference in response rate between a longer questionnaire (54 questions) and a shorter questionnaire (27 questions).<sup>39</sup> It is thus unlikely that the slightly greater length of our questionnaire (45 questions) compared with the 3 questionnaires<sup>11,15,17</sup> on which we based ours (2 of which contained

34 questions and 1 of which contained 40) had a significant impact on our response rate.

In comparison with similar studies conducted in other countries,<sup>4–12,14–19</sup> our response rate (27%) is low. However, it is comparable to and even higher than rates obtained in other national studies conducted among Canadian physicians.<sup>21,40</sup> Knowing the response rate is also helpful to determine the adequate sample size for a large national study.

### Limitations

There are a number of study limitations. A first barrier stems from the sensitive nature of the topic. In ensuring anonymity (e.g., by combining answer categories for regions and specialties with fewer physicians) for maximal survey participation, we decreased our ability to verify representativeness and generalize our findings. Also, we cannot rule out the possibility of social desirability bias, owing to fear of prosecution. However, we hypothesize that interest in participating may have been strong because the study was conducted during debates on medical end-of-life practices in Canada. Third, an important limitation of having a low response rate is that it increases the risk of nonresponse bias. However, previous studies have shown that physician surveys are more robust to nonresponse bias than surveys conducted in the general population.<sup>42–47</sup> In addition, the sociodemographic characteristics of our participants were comparable to those of the sampling frame. Consequently, we do not expect our low response rate to have translated into higher nonresponse bias. Other study limitations relate to survey design methods and to time and financial

**Table 1: Comparison of sociodemographic characteristics between the participants and the overall sample**

Characteristic	No. (%) of physicians		<i>p</i> value*
	Overall sample ( <i>n</i> = 300)	Participants ( <i>n</i> = 76)	
<b>Sex</b>			
Male	186 (62.0)	48 (63.2)	0.77
Female	114 (38.0)	27 (35.5)	
Unknown	0	1 (1.3)	
<b>Age, yr</b>			
< 35	23 (7.7)	14 (18.4)	0.34
36–45	71 (23.7)	18 (23.7)	
46–55	76 (25.3)	17 (22.4)	
56–65	72 (24.0)	15 (19.7)	
> 65	55 (18.3)	12 (15.8)	
Unknown	3 (1.0)	0	
<b>Language</b>			
English	229 (76.3)	53 (69.7)	0.34
French	71 (23.7)	23 (30.3)	
<b>Medical specialty</b>			
Family medicine/general practice	175 (58.3)	35 (46.0)	0.12
Other	125 (41.7)	40 (52.6)	
Unknown	0	1 (1.3)	
<b>Region</b>			
Atlantic Canada (New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador)	21 (7.0)	5 (6.6)	0.41
British Columbia	39 (13.0)	4 (5.3)	
Northwest region (Alberta, Saskatchewan, Manitoba, Yukon Territory, Northwest Territories, Nunavut)	54 (18.0)	14 (18.4)	
Ontario	110 (36.7)	31 (40.8)	
Quebec	76 (25.3)	22 (28.9)	

\* $\chi^2$  test.

\* $\chi^2$  test.

considerations. To maximize study participation for a future large national study, we recommend having a longer interval (2–4 weeks) between the last 2 contacts (replacement questionnaire and last reminder), as suggested by Dillman and colleagues.<sup>34</sup> Finally, although there is disagreement in the literature on the cost-effectiveness of various types of incentives with physicians, monetary incentives should be attempted.<sup>40,41,48</sup>

## Conclusion

In this pilot study we were able to successfully modify existing questionnaires designed to measure the prevalence of medical end-of-life practices and the underlying decision-making pro-

cesses, and to successfully administer them. Consequently, we were able to determine that it is indeed feasible to study these practices in Canada, even those that are currently illegal. Identification of the response rate will be useful for sample size calculations for larger studies. Additional strategies such as longer intervals between contacts and the use of incentives will be required to enhance the participation rate. Such studies are needed to further our understanding of how decisions are made before death, to identify potential areas of improvement and training needs, to study the effect of policy changes on medical end-of-life practices and to monitor their developments over time.

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