Review Article

Journal of Health Services Research & Policy
2015, Vol. 20(2) 115–123

DOI: 10.1177/1355819614567743
jhsrp.rsmjournals.com
SAGE

Comparing end-of-life practices in different policy contexts: a scoping review

Antoine Boivin[1], Isabelle Marcoux[2], Geneviève Garnon[3], Pascale Lehoux[4], Nicholas Mays[5], Marie-Claude Prémont[6], Yi-Sheng Chao[7], Evert van Leeuwen[8] and Raynald Pineault[9]

Abstract

Objectives: End-of-life policy reforms are being debated in many countries. Research evidence is used to support different assumptions about the effects of public policies on end-of-life practices. It is however unclear whether reliable international practice comparisons can be conducted between different policy contexts. Our aim was to assess the feasibility of comparing similar end-of-life practices in different policy contexts.

Methods: This is a scoping review of empirical studies on medical end-of-life practices. We developed a descriptive classification of end-of-life practices that distinguishes practices according to their legal status. We focused on the intentional use of lethal drugs by physicians because of international variations in the legal status of this practice. Bibliographic database searches were supplemented by expert consultation and hand searching of reference lists. The sensitivity of the search strategy was tested using a set of 77 articles meeting our inclusion criteria. Two researchers extracted end-of-life practice definitions, study methods and available comparisons across policy contexts. Canadian decision-makers were involved to increase the policy relevance of the review.

Results: In sum, 329 empirical studies on the intentional use of lethal drugs by doctors were identified, including studies from 19 countries. The bibliographic search captured 98.7% of studies initially identified as meeting the inclusion criteria. Studies on the intentional use of lethal drugs were conducted in jurisdictions with permissive (62%) and restrictive policies (43%). The most common study objectives related to the frequency of end-of-life practices, determinants of practices, and doctors' adherence to regulatory standards. Large variations in definitions and research methods were noted across studies. The use of a descriptive classification was useful to translate end-of-life practice definitions across countries. A few studies compared end-of-life practice in countries with different policies, using consistent research methods. We identified no comprehensive review of end-of-life practices across different policy contexts.

Conclusions: It is feasible to compare end-of-life practices in different policy contexts. A systematic review of international evidence is needed to inform public deliberations on end-of-life policies and practice.

Keywords

end-of-life, euthanasia, health policy, physician practice, systematic review

[1]Assistant Professor, Department of Family Medicine, Montreal University Hospital Research Center (CRCHUM), Canada
[2]Assistant Professor, Faculty of Health Science, University of Ottawa, Canada
[3]Researcher, Université de Sherbrooke, Canada
[4]Professor, Institut de recherche en santé publique de l'Université de Montréal, Canada
[5]Professor of Health Policy, Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, UK
[6]Professor, École nationale d'administration publique, Canada
[7]Researcher, Université de Sherbrooke, Canada
[8]Professor of Medical Ethics, Scientific Institute for Quality of Healthcare, Radboud University, Netherlands
[9]Research Professor, Institut National de Santé Publique du Québec, Département de santé publique de Montréal, Canada

Corresponding author:
Antoine Boivin, Department of Family Medicine, Montréal University Hospital Research Centre (CRCHUM). 850 rue St-Denis, Montreal (Quebec) H2X 0A9, Canada.
Email: antoine.boivin@umontreal.ca

Introduction

End-of-life policy reforms are being debated in many countries. In Canada, the criminal code prohibition on the intentional use of lethal drugs by physicians is currently being challenged in the federal Supreme Court,[1] while Quebec recently adopted a law to authorise 'medical aid in dying'.[2] End-of-life policy proposals have also been recently debated in the United States,[3] France,[4] the United Kingdom[5] and Belgium.[6]

Alongside ethical and legal arguments, research evidence plays a prominent role in end-of-life policy debates. For example, Canadian court documents included an extensive discussion of international evidence,[1] as did government expert committees on end-of-life policy reforms in Quebec,[7] the United Kingdom[5] and France.[4] International evidence is used by proponents and opponents to support different assumptions about the possible effects of policy change. The 'slippery slope hypothesis' holds that permissive policies could lead to a broadening application of proposed legal norms, leading to undesirable consequences on vulnerable patients.[8] Conversely, the 'transparency hypothesis' holds that legalisation of covert practices could lead to more effective regulation and better respect of legal safeguards.[9]

While international evidence is often used to inform local policy debates, it is unclear whether reliable comparisons can be made across jurisdictions with different policy contexts. For example, the feasibility of studying prohibited practices could be problematic and limit the ability to test the impact of policy change. Also, contextualising international evidence is far from straightforward because of variations in end-of-life practice definitions and health system characteristics.

To consider the feasibility of a full systematic review, this scoping study assessed the possibility of comparing similar end-of-life practices across different policy contexts. Mapping available evidence is important to clarify what can realistically be expected from international comparisons and to identify current gaps in research. Our review focused on two questions: what empirical evidence is available on medical end-of-life practices in contexts of prohibition and legalisation? and what are the potentials and limitations for comparing end-of-life practice frequency across policy contexts?

Methods

Design

We conducted a scoping review of empirical studies on medical end-of-life practices, with a focus on practices whose legal status differ across jurisdictions. Scoping reviews aim at mapping the main sources and types of evidence available in a field of interest.[10] Scoping studies are best suited for complex areas of research and are useful to assess the value of conducting a full systematic review and identify existing research gaps.

Descriptive classification of medical end-of-life practices

Definitions and labelling of medical end-of-life practices vary widely and no international consensus exists. For example, definitions of euthanasia have evolved over time and across countries.[11,12] In preparation for the scoping review, we developed a descriptive classification of medical end-of-life practices that distinguishes practices according to their legal status, is related to observable behaviours that can be studied empirically, and allows for the translation of different end-of-life practice definitions into comparable categories across jurisdiction and studies.

The descriptive classification distinguishes between three practices. First, withdrawing or withholding of treatments that have the potential to prolong life (e.g. cessation of an artificial ventilator). Second, the use of drugs for symptom management even if an unintended side effect may be to shorten life (e.g. chemotherapy for cancer pain, use of opiates for dyspnea, use of sedatives for convulsions). And third, intentional use (prescription, advice, supply, or administration) of a lethal drug by a doctor not justified by a specific effect on symptom management or treatment of a medical condition (e.g. injection of a neuromuscular blocker without respiratory support, injection of potassium chloride to a patient with a normal potassium level, injection of a massive dose of opiates above what is necessary for pain control, and continuous use of sedatives without artificial hydration above what is needed for symptom control).

While the last of these refers to the intentional use of lethal drugs that is not justified by a specific effect on symptom management, other legal justifications can exist for this practice in certain jurisdictions.[2,11,13] These conditions can include one or many of the following legal criteria:

- Voluntary request by a competent patient (e.g. Belgium, Luxemburg, Montana, Netherlands, Oregon, Quebec, Switzerland, Vermont, Washington);
- Presence of an advanced directive by a previously competent patient (e.g. Belgium, Luxemburg, Netherlands);
- Presence of a substituted request by the proxy decision-maker of an incompetent patient (e.g. newborn with substituted request by the parent; Netherlands);

- Presence of unbearable physical or psychological suffering (e.g. Belgium, Luxemburg, Netherlands, Quebec);
- Presence of a terminal illness (e.g. Oregon, Quebec, Vermont, Washington);
- Self-administration of the lethal drug by the patient himself (e.g. Montana, Oregon, Switzerland, Vermont, Washington);
- Absence of self-interest by the person providing the lethal drug (e.g. Switzerland).

To reflect these differences in end-of-life policies, our descriptive classification further distinguishes (a) if the intentional use of a lethal drug is carried out with a voluntary and informed request made by the patient prior to death, (b) if a voluntary advanced directive was made by a previously competent patient, (c) if a substitute request was made by the proxy decision-maker of an incompetent patient or (d) if the medical practice is carried without a patient or substitute request. We also distinguish when a lethal drug is self-administered by the patient himself or administered by someone else.

The classification does not consider the ethical or deontological justifications that may underlie different end-of-life practices. For example, some authors contest the ethical distinctions between withdrawing life-sustaining treatment, using drugs for symptom management, and the intentional use of lethal drugs.[14] Instead, the descriptive classification is useful for distinguishing practices with different legal status across jurisdictions (online Appendix 1).

Inclusion and exclusion criteria

To yield a manageable number of studies, we focused the scoping review on the intentional use of lethal drugs by physicians. This choice was justified by international variations in the legal status of this practice across jurisdictions. The identification of studies proceeded in two stages, with a progressive restriction of the inclusion criteria between each stage. In Stage 1 (mapping of the topic area), we included all studies on the intentional use of lethal drugs by doctors with data on actual practices We excluded studies on doctors' attitudes and opinions, the use of lethal drugs without medical involvement, studies conducted outside the medical context, references without abstract, animal studies and articles published in a language other than English or French. In Stage 2 (comparability of frequency studies), we further restricted our analysis to quantitative studies on the frequency of doctors' intentional use of lethal drugs. Two research assistants screened each reference against the inclusion and exclusion criteria. Disagreements were resolved through team discussions.

Data sources and search strategy

We developed two bibliographic search strategies with an information specialist and implemented them sequentially. First, we conducted a search in Google Scholar using the terms 'end-of-life decisions', 'euthanasia', 'assisted suicide', 'assisted dying', 'assisted death', 'assisted dying', 'medical aid in dying', 'termination of life' and 'medical behaviours that shorten life'. This was supplemented with hand searching of reference lists and expert consultation. This initial search identified a set of studies meeting our inclusion criteria, which were used to develop and test a more focused search strategy in electronic databases (MEDLINE, EMBASE and CINAHL). Our final search strategy was implemented in March 2012 (online Appendix 2).

Data extraction

We extracted data on study methods, medical practice definitions and measurement, and the presence of comparisons within and across jurisdictions. Data extraction was conducted by two research assistants using a structured extraction sheet. Extracted qualitative and quantitative data were imported in a FilemakerPro database developed with an information technology expert.

Data analysis

In Stage 1, we used content analysis to describe the main study objectives. Key themes were charted and analysed using the theory of planned behaviour as an original template.[15] In Stage 2, we used descriptive statistics to report on the main characteristics of study design, seeking to identify the main sources of heterogeneity across studies. We classified the policy context as 'permissive' when the intentional use of lethal drugs was allowed by public policies at the time of data collection (e.g. Belgium after 2002, Oregon after 1997) and 'restrictive' when the intentional use of lethal drugs was prohibited by public policies (e.g. Italy).[11]

Integrated knowledge translation

We collaborated with an advisory group of decision-makers to increase the policy relevance of the review. The advisory group was composed of medical, legal, governmental and public organisations involved in end-of-life policymaking in Canada, including organisations with different positions on end-of-life policies. The first meeting, at the beginning of the study, focused on roles and responsibilities, review objectives and the descriptive classification of end-of-life practices. The second meeting, at the end of the study, aimed at reviewing preliminary findings and identifying priorities

for further research. While the advisory group's recommendations informed research decisions, researchers were responsible for the scientific integrity of the review.

Results

Identified studies

Figure 1 describes the flow chart of included studies. A total of 2037 unique references were identified, yielding 329 included studies on the intentional use of lethal drugs by physicians (Table 1). The final search strategy captured 98.7% of studies initially meeting the inclusion criteria, meaning that the database search was highly sensitive. Included studies were published between 1988 and 2012, with a majority published after 2000 ($n = 248$, 75.4%). Quantitative research designs were most frequent ($N = 235$, 71.4%). The majority of studies were conducted in the Netherlands ($n = 158$, 47.4%), Belgium ($n = 65$, 19.5%) and the United States ($n = 65$, 19.5%).

Table 2 describes the main research objective of studies. The most frequent related to determinants of practices ($N = 79$, 24.0%), frequency of lethal drug use by doctors ($N = 76$, 23.1%) and doctors' adherence to regulatory standards ($N = 52$, 15.8%). We identified only a few studies on medical complications of lethal drug use ($N = 9$, 2.7%) and its impact on relatives ($N = 7$, 2.1%).

Sixty quantitative articles aimed at assessing the frequency of lethal drug use were analysed in more detail to assess their potential for international comparisons (Table 3). There was clustering of articles from a few countries, with multiple articles reporting results of the same study. For example, six studies conducted in the Netherlands, Belgium, Denmark, Italy, Sweden and Switzerland accounted for 45% of all articles on the frequency of lethal drug use by doctors. Other end-of-life practices were also reported in some studies, including the use of drugs justified by symptom management ($N = 24$, 40.0% of articles) and the withholding or withdrawal of life-sustaining treatment ($N = 29$, 48.3%). Only 58.3% ($N = 35$) of studies included data on the use of lethal drugs without patient request.

Labeling and definitions of medical end-of-life practices

There were large variations in the labeling and definitions of medical end-of-life practices. In 31.6% of articles on the frequency of lethal drug use ($N = 19$), no definitions of end-of-life practices were included. When definitions were provided, similar labels had different meanings across studies. For example, some studies used euthanasia to refer to the administration of

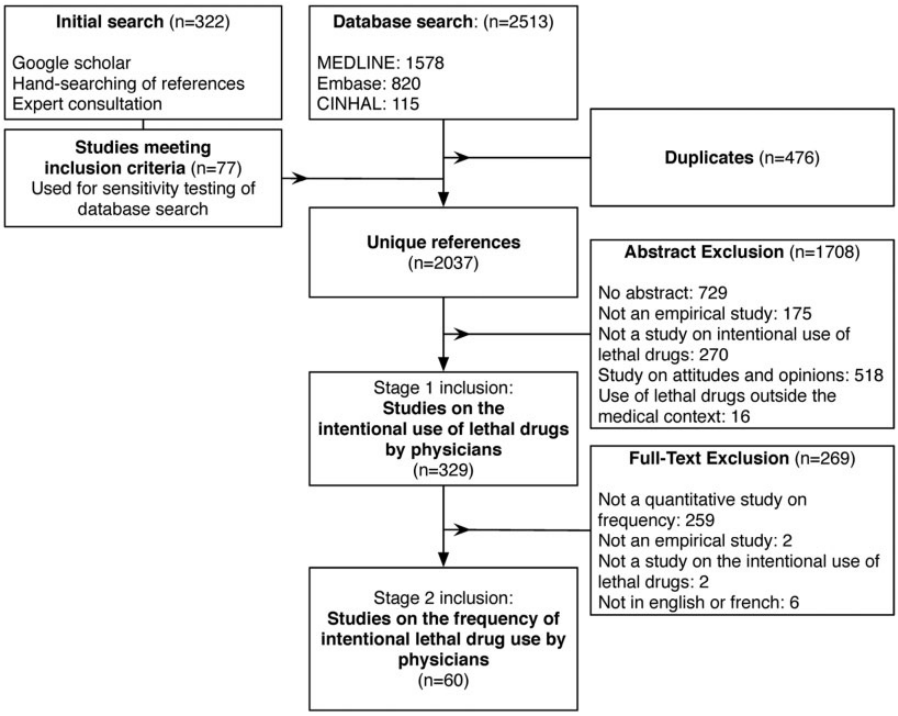

Figure 1. Flow chart of included studies.

Table 1. Characteristics of studies on the intentional use of lethal drugs by doctors ($N = 329$ articles).

	n	%
Year of publication		
<1990	1	0.3
1990–1994	19	5.8
1995–1999	61	18.5
2000–2004	79	24.0
2005–2009	105	31.9
2010–2012	64	19.5
Country		
Netherlands	158	47.4
Belgium	65	19.5
United States (other than Oregon)	40	12.0
Oregon	25	7.5
Scandinavia (Norway, Denmark, Sweden)	22	6.6
UK	17	5.1
Switzerland	16	4.8
Australia	15	4.5
France	5	1.5
Italy	5	1.5
Argentina	3	0.9
Germany	2	0.6
Japan	2	0.6
Spain	1	0.3
New Zealand	1	0.3
Austria	1	0.3
Bosnia	1	0.3
Luxembourg	1	0.3
Study design		
Quantitative	235	71.4
Qualitative	80	24.3
Systematic reviews	8	2.4
Qualitative and quantitative	6	1.8

lethal drugs by doctors, without distinguishing if this was carried out with or without voluntary patient request.[16] Other studies had more restrictive definitions and used euthanasia to refer to the intentional administration of a lethal drug *with* a voluntary patient request.[17–19] Other labels used to refer to the intentional use of lethal drugs by doctors included 'physician assisted dying',[20] 'physician assisted suicide',[21] 'help to die',[22] 'ending of life',[23] 'life-terminating act',[24] 'termination of life',[19] 'aid in dying'[25] and 'using drugs to end life'.[26]

Wording of study questionnaires varied across studies with 25% ($N = 15$) not providing information about how questions were framed and presented to participants. Some questions made it difficult to distinguish between the intentional use of lethal drugs and treatment withholding/withdrawal (e.g. Have you ever taken deliberate action that would directly cause a patient's death?[25]). Other differences in questions related to the framing of doctors' intentions, which was sometimes described as ending the patient's life,[21] bringing about the patient's death,[27] hastening the patient's death[28] or shortening the patient's life.[29]

Distinguishing between practices with different legal statuses was often difficult because of inconsistencies between classifications of end-of-life practices in empirical research and public policies. For example, the 2002 Belgian Euthanasia Act defines euthanasia as the 'intentional life-terminating action by someone other than the person concerned, at the request of the latter'.[30] However, empirical studies from Belgium and other European countries exclude from the euthanasia category all use of lethal drugs with a partial intention to hasten death.[29] Furthermore, categories labeled as 'intensification of symptom alleviation' and 'continuous deep sedation until death' also included the intentional use of lethal drugs by doctors.[31–33] This means that practices meeting the legal definition of euthanasia, as defined in public policy documents, would not be classified as such in empirical studies.

Other examples of inconsistencies between public policies and empirical research were found in studies reporting the frequency of lethal drug use in children and in adults,[19,29] despite differences in policies for lethal drug use in these age categories. Proper analysis of end-of-life practice categories was further complicated by incomplete outcome reporting and discrepancies between the reporting of the same studies in different languages.[23,34]

A related but distinct problem is the absence of information on the actual lethal potential of drugs used by doctors with the intention to cause death. Only 33.3% of studies ($N = 20$) reported data on the type of drugs used, and 8.3% ($N = 5$) appraised their lethal potential by independent experts. This means that international variations could simply reflect doctors' subjective reporting of their intentions rather than actual differences in practice (e.g. what drugs are used, at what dose and with what lethal potential). This limitation is important given the fact that up to 81.8% of drugs used by doctors with the intention to cause death have low lethal potential (e.g. mild sedatives and low-dose opiates).[35] While the problem of end-of-life categories with mixed legal status would tend to underestimate the frequency of intentional lethal drug use by doctors, absence of data on drug lethality would overestimate the frequency of doctors' practices that actually caused patients' death.

Table 2 Main objectives of studies on the intentional use of lethal drugs by physicians ($N = 329$ articles).

Themes	*n*	%	Article's main objective
Determinants of the requests and practices of lethal drug use	79	24.0	Determinants of the requests and practices of lethal drug use.
Medical end-of-life practices frequency	76	23.1	Data on the frequency of medical end-of-life practices.
Practices regulation and control mechanisms	52	15.8	Doctors' adherence with regulatory standards and control mechanisms.
Nurse's role	30	9.1	The nurse's attitudes, practices and role in the use of lethal drugs and their involvement in the decision process and the care for patients that request and/or received lethal drugs.
Specific populations	25	7.6	The medical end-of-life practices among specific populations (elderly, newborn, diagnosed with a specific disease, etc.)
Assessment of use of lethal drug requests	14	4.3	Health professional's assessment of lethal drug requests.
Communication and consultations in the decision process of euthanasia	13	4.0	Communications between the people involved in the end-of-life decision process (patient, relatives, health professionals) including the consultation of outside expertise (consultants, experts).
Medical complications	9	2.7	Medical complications reported by health professionals with preparation and administration of a lethal drug.
Impacts on health professionals	7	2.1	The impacts (legal, emotional) of the requests and practices of lethal drug use on health professionals.
Impacts on patients and publics	7	2.1	Impact of asking or being administered a lethal drug on the experience of death (*death experience quality*).
Impacts on relatives	7	2.1	Impact of the use of lethal drugs on relatives (e.g. emotional consequences and mourning process).
Labeling by professionals	4	1.2	How the intentional use of lethal drug is named and labeled by professionals.
Psychiatric consultations	4	1.2	Role of a psychiatric consultation in the assessment of requests for lethal drug use.
Pharmacist's practices	2	0.6%	Doctors' roles and involvement in relation with the intentional use of lethal drugs by doctors.

Potential for international comparisons of end-of-life practice frequencies

Studies on the frequency of lethal drug use by doctors were conducted in jurisdictions with permissive ($N = 37$, 61.7%) and restrictive policies ($N = 26$, 43.3%), with some studies including data from both types of jurisdictions. All studies used observational cross-sectional designs, with some repeated measurement over time and across countries. Sixteen articles (26.7%) included comparison of end-of-life practice frequencies before and after a change in public policies (e.g. before and after the adoption of the 2002 Euthanasia law in Belgium),[36] and 17 articles (28.3%) included comparisons across countries with different policies.

A number of differences in sampling strategy, data collection methods and outcome measures were found, which could influence estimates of frequency. Data on end-of-life practices were mostly collected from doctors' self-administered questionnaires ($N = 44$, 73.3%), individual interviews ($N = 13$, 21.7%) or doctors' self-reporting to external regulatory authorities ($N = 5$, 8.3%). Data were most often collected retrospectively, with professionals being asked to recall a death they attended personally. We identified only one study which collected data prospectively.[37]

Response rates varied significantly across studies, ranging from 34% to 91%, according to country, the data collection method and the strategy used to ensure respondents' anonymity to protect them from legal inquiries. Some countries with restrictive policies had higher response rates than permissive countries, suggesting that factors other than the legal status of end-of-life practices influence response rates.[19]

Three main patterns of sampling strategies and outcome measures were identified. First, half of the identified articles used a sampling strategy based on

Table 3. Comparability of quantitative studies on the frequency of intentional lethal drugs use by doctors ($N = 60$ articles).

Sampling method	*n* (%)
Sampling of patients	30 (50.0%)
Sampling of professionals	30 (50.0%)
Data collection method	
Postal self-administered questionnaires	44 (73.3%)
Interviews	13 (21.7%)
Examination of medical records of reported cases	5 (8.3%)
Medical practice under study	
Intentional use of lethal drugs by doctors	60 (100%)
At the patient's request administered by the patient	47 (78.3%)
At the patient's request administered by a health professional	49 (81.7%)
Without the patient's request	35 (58.3%)
Use drugs justified by symptom control	24 (40.0%)
Withholding or withdrawal of medical treatment that has the potential to prolong life	29 (48.3%)
Information on medical end-of-life practices	
Definition within article	41 (68.3%)
Questions within article	46 (76.7%)
Data on drug used	20 (33.3%)
Data on dosage	6 (10.0%)
Lethal potential as perceived by the clinician	19 (31.7%)
Lethal potential as perceived by experts	5 (8.3%)
Legislative context	
Permissive policies	37 (61.7%)
Restrictive policies	26 (43.3%)
Comparisons of end-of-life practices frequencies	
Before and after a change in public policy	16 (26.7%)
Between jurisdictions with different public policies	17 (28.3%)

patients' death certificates, followed by anonymous questionnaire of the doctor who signed the death certificate. These studies reported the frequencies of medical practices in relation to the percentage of annual deaths.[19] A second group of studies used similar frequency measures (% of patients' annual deaths) but identified doctors through random sampling of professionals' registries.[18] And a third group used sampling methods and outcome measures based on the total number of doctors (e.g. proportion who report having intentionally used a lethal drug in their career).[16]

While international comparison of end-of-life practice frequency has been attempted across studies reporting frequency in relation with the number of annual deaths,[18] studies using the number of doctors having used lethal drugs in their career are more difficult to include in international comparisons. Additionally, a few studies sought to provide national frequency estimates but specifically excluded end-of-life practices in children, which would need to be taken into account in the interpretation of observed international variations.

We identified a number of studies that used consistent methodologies, thus offering potential for more reliable comparisons. One example is the EURELD research consortium, which used nationally representative samples of death certificates to compare the annual frequency of medical end-of-life practices across six countries with different policies (Netherlands, Belgium, Switzerland, Sweden, Italy and Denmark).[19] Subsequent national surveys used similar sampling strategies and questionnaires.[17,29]

We found no comprehensive review of international evidence about the effects of public policies on end-of-life practices. A few reviews assessed changes in medical end-of-life practices in selected countries (e.g. the Netherlands, Belgium and the United States[17,25,38]) or on specific populations.[39]

Discussion

Main findings

To the best of our knowledge, this is the first review to assess the feasibility of comparing similar end-of-life practices in different policy contexts. Our findings indicate that it is feasible to conduct studies on medical end-of-life practices in different policy contexts, as demonstrated by studies on the intentional use of lethal drugs in context of prohibition and legalisation. There has been a growth in empirical end-of-life practice studies in the past 25 years. However, heterogeneity in study methods could influence observed differences. Nonetheless, a substantial number of studies used consistent research methods, supporting the feasibility of a systematic review on this topic.

An important contribution of this study is the development of a descriptive classification of end-of-life practices. This proved useful to deal with international variations in end-of-life practice definitions and labelling. The descriptive classification was also helpful to translate definitions used in public policies and empirical practice research. A descriptive classification could facilitate more effective communication between policymakers and researchers working with different labels and definitions and could be implemented in a systematic review.

This scoping review brings clarity to the main methodological challenges for conducting reliable

international comparisons. Heterogeneity in sampling strategy, data collection methods and outcome measures limits the potential for valid comparisons. Dealing with low response rates is another challenge, particularly when non-response could differentially affect studies conducted in specific policy contexts. Another challenge is that most studies estimate the frequency of end-of-life practices based on doctors' reported intentions, without asking them which behaviours they actually performed and independently assessing the lethal potential of drugs used. Finally, studies are observational in nature, with a limited number of measures before and after policy reform, thus limiting the ability to attribute changes in end-of-life practices to public policies or to other contextual factors. These aspects will need to be considered in a systematic review.

Strengths and limitations

A strength of this review is that it reveals the full range of available empirical evidence. Our search strategy was highly sensitive to capture empirical studies on the intentional use of lethal drugs in different policy contexts. The comprehensiveness of our review may nonetheless have been hampered by its focus on medical databases. Also, scoping reviews focus on breath of coverage, rather than depth of analysis,[10] and so we did not synthesise study results. This review nonetheless represents an important step towards undertaking a systematic review.

Policy and research implications

Policymakers should be careful in drawing simple conclusions about the effects of end-of-life policies on medical practice. While empirical studies are frequently quoted in policy debates, variations in study methods, risks of biased frequency estimates and differences in policy contexts are rarely acknowledged. Failure to recognise these limitations could lead to inappropriate conclusions. This problem is compounded by the polarised nature of end-of-life debates, which creates pressure for the instrumental use of research evidence by different advocacy groups.[40]

This review highlights the importance of considering the full range of factors that could explain international variations in end-of-life practice, including differences in public policies, differences in health system contexts (e.g. organisations of healthcare services, cultural and religious attitudes) and differences in study methods across jurisdictions (definitions, sampling strategy, wording of study questions, response rates, data collection and analysis). Although we focused on quantitative studies, qualitative evidence is also important to understand observed end-of-life practice variations. Finally, greater collaboration between researchers, policy experts, patients, and citizens could help contextualise results and support more informed public deliberations on end-of-life policies.

Acknowledgements

We thank Sylvie Bellot, Virginie Ferrera and Jenissa Gagné who contributed to study screening and data extraction; Stéphane Ratté who developed the bibliographic search strategy; Blaise Fotso who contributed to the analysis of international end-of-life policies; Richard Boivin who developed the FileMaker Pro database; Suzanne Philips-Nootens who provided advice on end-of-life policies and legislation; Julie Caron-Malenfant (Institut du Nouveau Monde) who provided advice on our integrated knowledge translation strategy; and Amel Zertal who contributed to project coordination.

Participants in the Advisory Group included: Jeff Blackmer (Canadian Medical Association); Marie-Dominique Beaulieu and Bill Sullivan (College of Family Physicians of Canada); Pierre Deschamps, Bernard Grenier, Ann Soden and Robert Delorme (Canadian Bar Association); Jean Rodrigue, Jeanine Auger and Louis Dufresne (Ministère de la santé et des services sociaux du Québec); Justine Farley and Danielle Drouin (Réseau des soins palliatifs du Québec); Ghislaine de Langavant (Commissaire à la santé et au bien-être du Québec). Some members of the advisory committee requested that their contribution remains anonymous.

Funding

This study received financial support from the Canadian Institutes of Health Research (CIHR), the Sadock Besrour Research Chair in Family Medicine and in-kind support from the Agence de la santé et des services sociaux de l'Abitibi-Témiscamingue. AB is supported by a Canadian Institutes of Health Research clinician-scientist award. PL holds a Canada Research Chair on Health Innovations. GG was supported by Université de Sherbrooke.

References

1. *Carter v. Canada (Attorney General)*, British Columbia Supreme Court 886, 2012.
2. Loi concernant les soins de fin de vie, Assemblée Nationale du Québec (Première Session, 41e Législature). Adapted on 5 June 2014.
3. Hallenbeck T. Vermont adjusts to new way of dying. *USA Today*, http://www.usatoday.com/story/news/nation/2013/07/14/vermont-adjusts-to-new-way-of-dying/2514847/ (2013, accessed 24 December 2014).
4. Sicard D. *Penser solidairement la fin de vie – commission de réflexion sur la fin de vie en France*. France, Décembre 2012.
5. Lewis P and Black I. The effectiveness of legal safeguards in jurisdictions that allow assisted dying. *Demos* 2012; 2012: 97.

6. Dan B, Fonteyne C and de Clety SC. Self-requested euthanasia for children in Belgium. *Lancet* 2014; 383: 671–672.
7. Ménard J, Giroux M and Hébert J. Mettre en oeuvre les recommandations de la commission spéciale de l'Assemblée nationale du Québec sur la question de mourir dans la dignité (Rapport du comité de juristes experts). 2013: 417.
8. Shariff MJ. Assisted death and the slippery slope-finding clarity amid advocacy, convergence, and complexity. *Curr Oncol* 2012; 19: 143–154.
9. Shuklenk U, van Delden J, Downie J, et al. *End-of-life decision making*. Ottawa: The Royal Society of Canada, 2011.
10. Arksey H and O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005; 8: 19–32.
11. Griffiths J, Weyers H and Adams M. *Euthanasia and law in Europe*. Oxford: Hart Publishing, 2008.
12. Marcoux I. Euthanasia: a confounding and intricate issue. In: *Euthanasia – the "good death" controversy in humans and animals*, http://www.intechopen.com/books/euthanasia-the-good-death-controversy-in-humans-and-animals (2011, accessed 8 January 2015).
13. Reporting requirements of the Oregon Death with Dignity Act, 2003.
14. Quill TE, Dresser R and Brock DW. The rule of double effect – a critique of its role in end-of-life decision making. *N Engl J Med* 1997; 337: 1768–1771.
15. Ajzen I. The theory of planned behavior. *Org Behav Human Decision Process* 1991; 50: 179–211.
16. Meier DE, Emmons CA, Wallenstein S, et al. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med* 1998; 338: 1193–1201.
17. Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, et al. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 2012; 380: 908–915.
18. Seale C. National survey of end-of-life decisions made by UK medical practitioners. *Palliat Med* 2006; 20: 3–10.
19. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003; 362: 345–350.
20. Battin M, van der Heide A, Ganzini L, et al. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *Law Ethics Med* 2007; 33: 591–597.
21. Chin AE, Hedberg K, Higginson GK, et al. Legalized physician-assisted suicide in Oregon – the first year's experience. *N Engl J Med* 1999; 340: 577–583.
22. Gysels M, Evans N, Menaca A, et al. Culture and end of life care: a scoping exercise in seven European countries. *PloS ONE* 2012; 7: e34188.
23. van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med* 2007; 356: 1957–1965.
24. Pijnenborg L and van der Maas PJ. Life-terminating acts without explicit request of patient. *Lancet* 1993; 341: 4.
25. Emanuel EJ. Euthanasia and physician-assisted suicide: a review of the empirical data from the United States. *Arch Intern Med* 2002; 162: 142–152.
26. Rietjens JA, Bilsen J, Fischer S, et al. Using drugs to end life without an explicit request of the patient. *Death Stud* 2007; 31: 205–221.
27. Atsushi Asai MO, Shizuko K, Nagata, Noritoshi Tanida, et al. Doctors' and nurses' attitudes towards and experiences of voluntary euthanasia: survey of members of the Japanese Association of Palliative Medicine. *J Med Ethics* 2001; 27: 324–330.
28. Buiting HM, Karelse MA, Brouwers HA, et al. Dutch experience of monitoring active ending of life for newborns. *J Medl Ethics* 2010; 36: 234–237.
29. Chambaere K, Bilsen J, Cohen J, et al. Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *CMAJ* 2010; 182: 895–901.
30. Adams M and Nys H. Comparative reflections on the Belgian euthanasia act 2002. *Med Law Rev* 2003; 11: 353–376.
31. Bilsen J, Norup M, Deliens L, et al. Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. *J Pain Symptom Manage* 2006; 31: 111–121.
32. Miccinesi G, Rietjens JA, Deliens L, et al. Continuous deep sedation: physicians' experiences in six European countries. *J Pain Symptom Manage* 2006; 31: 122–129.
33. Rietjens JA, van Delden JJ, van der Heide A, et al. Terminal sedation and euthanasia: a comparison of clinical practices. *Arch Intern Med* 2006; 166: 749–753.
34. Onwuteaka-Philipsen B, Gevers J, van der Heide A, et al. *Evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*. Den Haag: ZONMW, 2007.
35. Vander Stichele RH, Bilsen JJ, Bernheim JL, et al. Drugs used for euthanasia in Flanders, Belgium. *Pharmacoepidemiol Drug Saf* 2004; 13: 89–95.
36. Bilsen J, Cohen J, Chambaere K, et al. Medical end-of-life practices under the euthanasia law in Belgium. *N Engl J Med* 2009; 361: 1119–1121.
37. Van Der Maas PJ, Van Delden JJ, Pijnenborg L, et al. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991; 338: 669–674.
38. Lewis P. The empirical slippery slope from voluntary to non-voluntary euthanasia. *J Law Med Ethics* 2007; 35: 197–210.
39. Rietjens J, Deschepper R, Pasman R, et al. Medical end-of-life decisions: does its use differ in vulnerable patient groups? A systematic review and meta-analysis. *Soc Sci Med* 2012; 74: 1282–1287.
40. Pielke RA. *The honest broker: making sense of science in policy and politics*. Cambridge, NY: Cambridge University Press, 2007.