

Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies*

Laura Brooks

School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario

RÉSUMÉ

Une grande partie des écrits sur l'aide médicale à mourir (AMM) qui traite de la perspective des prestataires de soins de santé est centrée sur le rôle des médecins, et le point de vue des infirmières n'est exprimé que dans quelques-uns d'entre eux. Toutefois, quelques provinces canadiennes ont mis en œuvre des approches multidisciplinaires pour l'AMM. Il serait donc important de mieux comprendre l'expérience des divers prestataires de soins de santé impliqués dans l'AMM, considérant que les plans provinciaux liés à l'AMM sont encore en élaboration. Cet examen de la portée a pour but de résumer les publications qualitatives existantes axées sur l'expérience des prestataires de soins dans l'AMM. Les thèmes clés retrouvés dans ces publications concernent la complexité du processus d'AMM, l'importance des relations et de la communication, les rôles et dynamiques interprofessionnels et le processus d'adaptation. Les résultats de cet examen de la portée démontrent la nécessité de poursuivre la recherche sur les expériences des divers prestataires de l'AMM, particulièrement dans le contexte canadien.

ABSTRACT

Much of the literature on health care provider perspectives on medical assistance in dying (MAiD) is focused on the role of the physician, with some literature examining the views of nurses. Some Canadian provinces however, have implemented multidisciplinary approaches to MAiD. As a result, an improved understanding of the experiences of a variety of health care providers in the MAiD process will be important to consider as provincial MAiD plans continue to develop. This scoping review aimed to summarize the existing qualitative literature focused on provider experiences in the MAiD process. Key themes emerged across the literature that were related to the complexity of the MAiD process, the importance of relationships and communication, interprofessional roles and dynamics, and the coping process. The results of this review demonstrate the need for further investigation into the experiences of diverse MAiD providers, especially within the Canadian context.

* I am grateful for the comments provided by Dr. Paul Stolee on an earlier draft of this manuscript.

Manuscript received: / manuscrit reçu : 30/05/18

Manuscript accepted: / manuscrit accepté : 24/09/18

Mots-clés : vieillissement, aide médicale à mourir, expérience des prestataires, examen de la portée

Keywords: aging, medical assistance in dying, provider experience, scoping review

La correspondance et les demandes de tirés-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Laura Brooks, M.Sc.
School of Public Health and Health Systems
University of Waterloo
200 University Avenue W
ON N2J 3G1
Canada
(labrooks@edu.uwaterloo.ca)

Background

In June 2016, medical assistance in dying (MAiD) was made legal in Canada. Since then, more than 2000 Canadians have received assistance in dying (Government of Canada, 2016). In Canada, MAiD can

be requested by persons over the age of 18; however, assistance in dying is most prevalent for older adults (Government of Canada, 2016). In fact, the average age of Canadians receiving assistance in dying is approximately 73 years (Government of Canada, 2016).

In Canada, MAiD can be administered by a physician or nurse practitioner, or through the prescription of a self-administered substance (Ontario Ministry of Health and Long Term Care, 2017). Although the responsibility for the administration of MAiD is limited to physicians and nurse practitioners, assistance in dying may have implications for a variety of other health care professionals including pharmacists, nurses, and social workers. Each Canadian province has developed a different process for coordinating referrals, care, and access for patients requesting assistance in dying. Ontario, for example, has developed a provincial care coordination service to connect those requesting MAiD to physicians and nurse practitioners willing to perform the procedure (Ontario Ministry of Health and Long Term Care, 2017). A more diverse example is Manitoba's interdisciplinary MAiD team, involving physicians, nurses, social workers, pharmacists, and speech language pathologists (Winnipeg Regional Health Authority, 2016).

To date, Canadian research has largely focused on the understanding of end-of-life legislation, cost analysis, and program implementation (Li et al., 2017; Marcoux, Boivin, Arsenault, Toupin, & Youssef, 2015; Trachtenberg & Manns, 2017). Internationally, a majority of the literature on assisted dying is focused on the physician; however, some research has also examined the roles of nurses and psychiatrists (Block & Billings, 1995; Edwards, 2016; Fujioka, Mirza, McDonald, & Klinger, 2018; Groenewoud et al., 1997; Schwarz, 1999). Much of this literature, however, is focused on opinions related to the ethics of assisted dying, and whether or not the practice is justifiable (Braverman, Marcus, Wakim, Mercurio, & Kopf, 2017; Glebock Gawor, & Ostrowski, 2013). Less explored is the experience of health care professionals working with patients, caregivers, and other providers through the process of MAiD. A scoping review by Fujioka et al. (2018) recently investigated the roles of providers involved in MAiD, and the challenges faced by providers involved in the provision of MAiD. This review ultimately concluded that, although a variety of providers are involved in assisted dying, most published literature examines the roles and experiences of physicians and nurses (Fujioka et al., 2018). Considering the variety of providers involved in Canadian contexts, it is important to understand the perspectives and experiences of all parties involved in the MAiD process. This scoping review will build on the findings of Fujioka et al. (2018) by examining and summarizing the existing qualitative literature surrounding the perspectives and experiences of health care providers involved in the care of persons receiving MAiD.

Methods

This scoping review followed the five stages proposed by Arksey and O'Malley (2005). The scoping review

methodology was selected for this study to allow for a broad exploration of the available literature, and analysis and synthesis of the results of the identified studies. After developing the research question, a search of electronic databases (PubMed, Cumulative Index to Nursing and Allied Health Literature [CINAHL], and PsycINFO) was conducted using search terms related to "assisted dying", "health care professional", and "experiences" which is outlined in Table 1.

The search results were imported into RefWorks, and sorted according to the inclusion and exclusion criteria. Duplicates were removed, followed by a title and abstract screening process. A full-text screening process was completed as a last step for inclusion. Articles that were in English, peer reviewed, and published in an academic journal between the 2000 and 2018 were included. In the abstract and full text extraction, articles that involved qualitative methods, and focused on the opinions, experiences, and/or perspectives of professionals involved in the process of MAiD were included. Articles that focused on persons who requested assistance in dying in a country where the procedure was not legal were included if they focused on health care provider perspectives on caring for these patients and complications related to their request for assistance in dying. Articles that focused on opinions about what constitutes assisted dying, the justification of assisted dying, the legalization of assisted dying, reasons for requesting assisted dying, inclusion of persons with mental illness or dementia, or the interplay between religion and assisted dying were excluded. Additionally, articles that did not use qualitative methods or that focused only on the perspectives of patients and caregivers were also excluded.

All extracted articles were read in their entirety, and their results and findings were entered into an extraction table. The results in the table were initially analyzed using line-by-line emergent coding techniques (Braun & Clarke, 2006; Lofland, Snow, Anderson, & Lofland, 2006). This initial coding led to the development of a series of nodes focused on health care provider

Table 1: Examples of search terms

	Search Terms
1	assistance in dying OR assisted death OR assisted suicide OR euthanasia
2	perspectives OR opinions OR thoughts OR feelings OR attitudes OR experiences
3	interdisciplinary OR multidisciplinary OR transdisciplinary OR physician OR doctor OR psychiatrist OR social work OR pharmacist OR professional OR nurse OR physiotherapist OR occupational therapist OR speech pathologist OR speech language pathologist
4.	qualitative

experiences during the assistance in dying process. The nodes were then sorted through a process of thematic analysis (Braun & Clarke, 2006) to develop a series of key themes existing across all extracted literature. These key themes were named, defined, and then reviewed to ensure that they accurately represented the original extracted results (Braun & Clarke, 2006).

Results

Overall, 2089 articles were retrieved. As demonstrated in Figure 1, a total of 21 articles met the inclusion criteria after full-text screening.

The studies originated from the United States (4), Belgium (7), The Netherlands (7), Australia (1), Germany (1), and Israel (1). A total of 18 of the studies reported using in-depth or semi-structured interviews; the other 3 studies opted for focus group interviews (2) or open-ended survey responses (1). Six studies reported using a grounded theory methodological approach. Interview discussions related to perceptions, experiences, and processes of euthanasia and assisted dying from the view of physicians (12), nurses (8), social workers (2), and/or psycho-spiritual workers (1). These results are summarized in Table 2.

The four overarching themes that emerged across all articles were: complex process, importance of relationships and communication, interprofessional roles and dynamics, and coping.

Complex Process

The health care professionals involved in some of the studies referred to assistance in dying and euthanasia

as a process, rather than an event (Borgsteede et al., 2007; Denier, Dierckx de Casterlé, De Bal, & Gastmans, 2010a). In one study, nurses explained that caring for a person receiving assistance in dying is a complex, dynamic process that spans from the initial request to the after-care stages (Denier et al., 2010a). In other studies, physicians explained the importance of timing, follow-up discussions, and clarity across the entire process, commenting that these factors contribute to their decision, and worked to ensure that patients are certain in their choice (Borgsteede et al., 2007; Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2014). Across multiple studies, the providers expressed the value of viewing assisted dying as a process, indicating that their confidence in the decision stemmed from the patients' consistency in expressing their desire across numerous consultations (De Bal, Dierckx de Casterlé, De Beer, & Gastmans, 2006; Dees et al., 2012; Denier, Dierckx de Casterlé, De Bal, & Gastmans, 2009; Denier et al., 2010a; Denier, Gastmans, De Bal, & Dierckx de Casterlé, 2010b; Dierckx de Casterlé, Denier, De Bal, & Gastmans, 2010; Galushko et al., 2016; Georges, The, Onwuteaka-Philipsen, & van der Wal, 2008; Snijdewind et al., 2014; van Marwijk, Haverkate, van Royen, & The, 2007; Voorhees, Rietjens, van der Heide, & Drickamer, 2013).

Importance of Relationships and Communication

A study of physicians, nurses, and psychospiritual health providers explained that a relationship with the patient was an important component of the assistance in dying process (Galushko et al., 2016). Physicians reported that their relationship with the patient influenced their decision to provide assistance in dying;

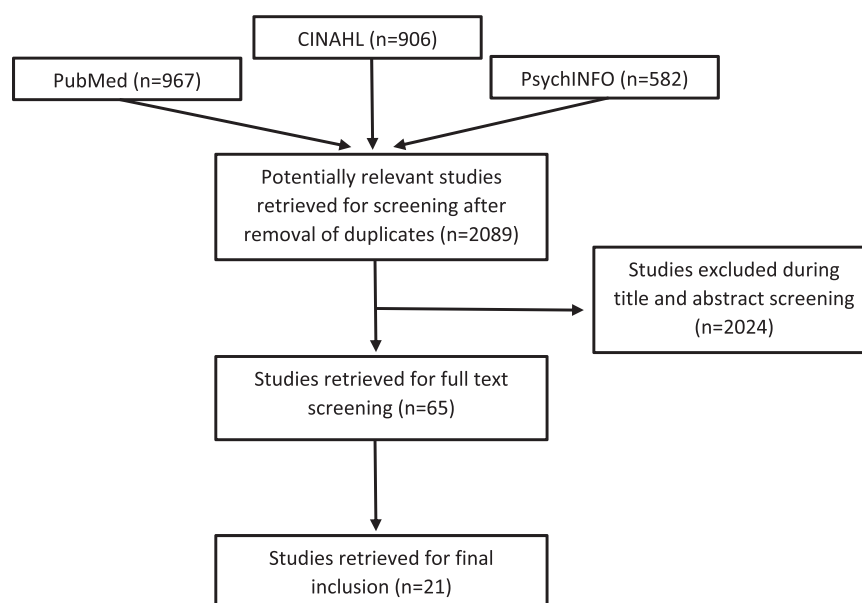


Figure 1: PRISMA flow diagram of study selection

Table 2: Study characteristics

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
"It's intense, you know." nurses' experiences in caring for patients requesting euthanasia (Denier, Dierckx de Casterlé, De Bal, Gatmans, 2010a)	Belgium	Explore nurses' experiences in caring for patients requesting euthanasia.	<ul style="list-style-type: none"> • Grounded Theory approach • Purposive sampling, followed by theoretical sampling • Individual in-depth interviews 	18 Nurses	<ul style="list-style-type: none"> • Care for persons requesting euthanasia is a complex and dynamic process. • Nurses described their experience providing care for these patients as "intense". • Nurses felt that their experiences changed, or developed, over time. • The degree to which the nurse is involved in the process impacts that person's experience. • The nurses felt that it was important to take adequate time in caring for the patients and their caregivers. • A sense of transparency and honesty in caring for the patient was important, especially in conversations involving handling the request for euthanasia.
Communication about euthanasia in general practice: Opinions and experiences of patients and their general practitioners (Borgsteede, Deliens, Graafland-Riedstra, Francke, van der Wal, Willems, 2007)	The Netherlands	Investigate whether or not patients and their general practitioners talk about euthanasia, and how they talk about euthanasia.	<ul style="list-style-type: none"> • Semi-structured in-depth interviews 	31 General practitioners Patients with cancer, chronic obstructive pulmonary disease, heart failure	<ul style="list-style-type: none"> • Physicians did not initiate conversation about euthanasia with patients they knew to be religious. • Physicians had detailed discussions about end-of-life planning and conditions under which the patient may want euthanasia. • Physicians received vague statements from patients related to euthanasia requests, and worried about miscommunications and misunderstandings. • The timing in which conversations related to euthanasia were had was important from the physician perspective. • Physicians were more confident in interpreting patient requests and agreeing to provide euthanasia when they had a longer relationship with the patient. • Euthanasia request is a process in which physician and patient grow, together, toward a final decision. • Some physicians explained that their duty was to care solely for the patient, whereas others explained the importance of involving the caregiver. • Physicians were hesitant to provide euthanasia, and more likely to decline the procedure in the absence of a growth process in the physician-patient relationship. • Miscommunications were frequent and stemmed from misunderstandings of the process or having different assumptions of the process. • Physicians had trouble sympathizing with patient requests when the suffering was invisible.
Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives (Snijdewind, van Tol, Onwuteaka-Philipsen, Willems, 2014)	The Netherlands	Identify and categorize complex euthanasia and physician-assisted suicide requests.	<ul style="list-style-type: none"> • In-depth interviews 	18 Physicians, 15 Caregivers	<ul style="list-style-type: none"> • Two perspectives taken by nurses in the process of care: (1) Procedural, action-focused; and (2) Existential-interpretative. • Procedural, action-focused nurses were determined to ensure that the process was successful by gaining certainty about the patient's decision. Separating personal and professional values and following procedure was very important to these nurses. • Existential-interpretative nurses focused on understanding the patient's request, showing respect, and creating a relationship that promoted communication and emotional sharing with the patient.
Involvement of nurses in the euthanasia care process in Flanders (Belgium): An exploration of two perspectives (Denier, Dierckx de Casterlé, De Bal, Gastmans, 2009)	Belgium	Explore nurses' involvement in caring for patients requesting euthanasia.	<ul style="list-style-type: none"> • Grounded Theory approach • Purposive sampling, followed by theoretical sampling • Individual in-depth interviews 	18 Nurses	<ul style="list-style-type: none"> • Two perspectives taken by nurses in the process of care: (1) Procedural, action-focused; and (2) Existential-interpretative. • Procedural, action-focused nurses were determined to ensure that the process was successful by gaining certainty about the patient's decision. Separating personal and professional values and following procedure was very important to these nurses. • Existential-interpretative nurses focused on understanding the patient's request, showing respect, and creating a relationship that promoted communication and emotional sharing with the patient.

Continued

Table 2: Continued

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
Dealing with requests for euthanasia: A qualitative study investigating the experience of general practitioners (Georges, The Onwuteaka-Philipsen, van der Wal, 2008)	The Netherlands	Describe the experiences of general practitioners in the Netherlands in dealing with euthanasia requests.	<ul style="list-style-type: none"> • Purposeful sampling • Interviews • Constant comparative method of analysis 	30 General practitioners	<ul style="list-style-type: none"> • Physicians felt that caring for terminally ill patients was a very meaningful part of their profession. • Physicians felt that requests for euthanasia were a very demanding and heavy responsibility that had severe emotional consequences. • Some physicians preferred other end-of-life solutions, such as sedation, which they felt were easier to cope with, whereas others felt it was their duty to enhance quality of life and reduce suffering by caring for and supporting the patient in the euthanasia process. • Physicians felt that they should approach euthanasia requests with caution, and often relied on the context of the process that drew the patient to the decision. Physicians needed to be certain that this was the only option to relieve the patient of suffering. • Physicians needed time to think about the situation, and prepare themselves for performing euthanasia.
Desire for hastened death: how do professionals in specialized palliative care react? (Galushko, Frerich, Perrar, Golla, Radbruch, Nauck, et al. 2016)	Germany	Identify specialized palliative care health providers' responses to desired for hastened death.	<ul style="list-style-type: none"> • Interviews 	19 Specialized palliative care health providers	<ul style="list-style-type: none"> • Creating and maintaining a relationship was seen as a fundamental starting point in caring for patients who requested assistance in dying. • Providers felt that it was important to include social and psychological aspects of health in their care, and explained the importance of helping the patient reconnect with family and friends. • Providers expressed the importance of maintaining realistic expectations in the patient by demonstrating the existing boundaries to the patient. • Health professionals explained the importance of working together, providing advice, delegating tasks, engaging providers outside the immediate care team, and providing specialist support when matters fell outside of their professional expertise.
Discussing physician-assisted dying: Physicians' experiences in the United States and The Netherlands (Voorhees, Rietjens, van der Heide, Drickamer, 2013)	United States of America, The Netherlands	Further the understanding of physician experience in discussing physician-assisted dying in the context of doctor-patient relationships.	<ul style="list-style-type: none"> • Purposive sampling • Semi-structured interviews 	36 Physicians	<ul style="list-style-type: none"> • Some physicians felt comfortable initiating conversation about physician-assisted death; however, most relied on the patient to bring up the topic. • Previous relationships with the patient strengthened the physician-assisted dying conversations, and were more productive in revealing patient values and goals. • Refusal of physician-assisted death was more likely when the patient and the physician did not have an existing relationship. • Physicians felt that refusals strained the relationship they had with the patient. • Physicians had mixed emotions about physician-assisted dying: it could be rewarding to bring someone relief, but also uncomfortable, exhausting, guilt-inducing, and intense to make such a serious decision. • Discussions with other health care providers, especially other physicians, were more common in the Netherlands. • Physicians described discussions as helpful, and empowering.

Continued

Table 2: Continued

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
Impact of euthanasia on primary care physicians in the Netherlands (van Marwijk, Haverkate, van Royen, The, 2007)	The Netherlands	Gain insight into the emotional impact on primary care physicians of performing euthanasia or assisted suicide.	<ul style="list-style-type: none"> • Snowball sampling method • Focus group interviews 	22 Primary care physicians	<ul style="list-style-type: none"> • Physicians described the emotions associated with euthanasia as traumatic, lonely, guilty, and often contradictory, explaining that the first experience held more weight than the subsequent experiences. • Physicians reported feeling tension before performing euthanasia, loss during, and relief after. • Physicians felt unable to share the emotions they had experienced. • Physicians felt that family members could provide feelings of gratitude and satisfaction, but also pressure, manipulation, tension, and conflict. • Physicians emphasized the importance of coping, and the need to take time to reflect and share their experience with colleagues. • Physicians expressed that with more experience, they became more restricted in their willingness to perform euthanasia.
Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study (De Bal, Dierckx de Casterlé, De Beer, Gastmans, 2006)	Belgium	Explore nurses' involvement in the care of patients requesting euthanasia.	<ul style="list-style-type: none"> • Grounded Theory approach • Purposive sampling, followed by theoretical sampling • Individual interviews 	15 Nurses	<ul style="list-style-type: none"> • Nurses experienced moral conflict when receiving euthanasia requests. • When euthanasia was illegal, nurses felt powerless, but also felt required to seriously consider the request. • The feeling of powerlessness was more severe when physicians ignored patient requests, and continued pursuing curative treatments. • Nurses felt that contributing to multidisciplinary team discussions was important, but with the doctor–nurse hierarchical relationship, many nurses felt frustrated by the lack of attention given to their contributions to discussions. • Nurses worried about the lack of time they had for in-depth conversations with patients about euthanasia. • Nurses explained that the process model of caring for patients with a euthanasia request involved: (a) the period before the request in which nurses often noted a change, or something “brewing”, (b) the request for euthanasia in which nurses explained the importance of understanding the patient's story and reasons for the request, (c) reporting the request to other care providers, (d) participating in decision making about how the request would be handled, (e) the result of the decision making in which nurses worked to enhance dignity and maximize comfort, and (f) the aftercare of the family. • Nurses recognized the importance of caring for themselves and coped with the experience through emotional support from colleagues.

Continued

Table 2: Continued

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
Communication in nursing care for patients requesting euthanasia: A qualitative study (Denier, Gastmans, De Bal, Dierckx de Casterlé, 2010b)	Belgium	Describe communication during the euthanasia care process in general hospitals, from the nurses' perspectives.	<ul style="list-style-type: none"> • Grounded Theory approach • In-depth semi-structured interviews 	18 Nurses	<ul style="list-style-type: none"> • Euthanasia care is a process that spans from the period before the request to the aftercare stages. • Nurses communicate with the patient alone, with the patient and the family, and with the family alone to understand the patient's needs in the final days • Nurses explain that active listening, providing information about diagnosis or prognosis, translating medical jargon, providing advice, and participating in non-euthanasia-related conversation were all important facets of communication in the euthanasia care process. • Nurses expressed the importance of an open, attentive, patient, and trustworthy attitude in communicating with patients and caregivers. • Nurses felt that it was their duty to gain certainty about the decision, to advocate for the patient, to create peace, to help the family and staff cope with the decision, and to finally follow up with family. • Nurses explained the importance of their role in interprofessional communication, explaining their unique ability to provide insight into the patient's desires and decisions. • Nurses explained that interprofessional communication required their participation in order to provide the patient with the best possible care.
Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium (Dierckx de Casterlé, Denier, De Bal, Gastmans, 2010)	Belgium	Explore nurses' involvement in the care process for terminally ill patients requesting euthanasia.	<ul style="list-style-type: none"> • Grounded Theory approach • Purposive sampling, followed by theoretical sampling • Individual in-depth interviews • Constant comparative analysis 	18 Nurses	<ul style="list-style-type: none"> • Euthanasia care occurs as a process. • Requests are never unexpected, and nurses feel it is important to be open minded and responsive to questions and concerns. • Nurses refrain from judgement and take the request seriously. • Multidisciplinary team decision making is favoured by nurses who feel that they have valuable information to provide. • Nurses focus on providing the exact care that patients and their caregivers need, regardless of usual care practices. • Nurses acknowledge the importance of saying goodbye to the patient and supporting the patient, family, or other staff while euthanasia is being carried out. • Nurses work to arrange the aftercare and provide support and grieving resources for the family, as well as to the other providers involved in the patient's care
Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives, and treating physicians in the Netherlands (Dees, Vernooij-Dassen, Dekkers, Elwyn, Vissers, van Weel, 2012)	The Netherlands	Explore the decision-making process in cases in which the patient requests euthanasia.	<ul style="list-style-type: none"> • In-depth interviews 	32 Patients and their treating physicians	<ul style="list-style-type: none"> • Most physicians did not initiate euthanasia conversations, and relied on the patient to bring up the topic. • The nature of the relationship between the patient and the physician effected the decision, where positive relationships resulted in more positive outcomes, regardless of the decision for, or refusal of, euthanasia. • Physicians required that they come to an agreement with the patient based on the patient's diagnosis, suffering, and competence to make the decision, and the supporting opinion of a second physician. • Physicians expressed that timing was crucial in setting a date for euthanasia. Physicians had to balance the patient's progression with the family's desire to prolong their goodbyes. • Physicians viewed the process as a burden, reporting feelings of surprise, pressure, reluctance, and emotional drain.

Continued

Table 2: Continued

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
Are general practitioners prepared to end life on request in a country where euthanasia is legalised? (Secru, Pype, Christiaens, Grypdonck, Derese, Deveugele, 2012)	Belgium	Explore the ways in which general practitioners “deal” with euthanasia.	• Semi-structured interviews	52 General practitioners	<ul style="list-style-type: none"> • Physicians sympathized with requests for euthanasia, but many were reluctant to provide the procedure. • Long-standing relationships with patients led to feelings of obligation among physicians. • Physicians felt more confident in decisions supported by additional physicians.
What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives and physicians (Pasman, Willems, Onwuteaka-Philipsen, 2013)	The Netherlands	Understand the patient and physician perspective about what happens when a euthanasia or physician-assisted suicide request is refused.	• In-depth interviews	11 Physicians	<ul style="list-style-type: none"> • After refusal of assistance in dying, physicians no longer discussed the desire to die or euthanasia with their patients. • Physicians and patients had different understandings about their desire to die moving forward after a refusal.
Understanding and responding to patients’ requests for assistance in dying (Schwarz, 2003)	United States of America	Explore how nurses respond to patients’ requests for assistance in dying.	<ul style="list-style-type: none"> • Interpretive phenomenology • Interviews 	10 Nurses	<ul style="list-style-type: none"> • Hearing a request for assistance in dying was described as upsetting and sometimes life-altering. • Nurses take the request seriously, knowing that it is important for them to advocate for the patient’s desires. • Nurses work to understand the underlying reasons for the request. • One nurse clarified that assistance in dying is not killing patients, but helping them die. • Nurses felt that it was important to ensure that a request for assistance in dying was not the result of poor palliative care.
Nurses’ views on their involvement in euthanasia: A qualitative study in Flanders (Belgium) (Dierckx de Casterlé, Verpoort, De Bal, Gastmans, 2006)	Belgium	Exploration of the views of palliative care nurses on their involvement in the care process for patients receiving euthanasia.	<ul style="list-style-type: none"> • Grounded Theory approach • Semi-structured interviews 	12 Palliative care nurses	<ul style="list-style-type: none"> • Nurses felt that their involvement extended far beyond assisting physicians in the administration of euthanasia medication; they believed that the care process began with the request. • Nurses had to accept the request with “active openness”, listening carefully to uncover underlying reasons for the request. Nurses wanted to ensure that the request did not stem from improperly managed pain. • Nurses felt that each request should be discussed openly, preferably in an interdisciplinary team. Nurses felt that their input was invaluable in the decision making process. • Nurses felt it was part of their duty to support the family after their loved one had died. Nurses emphasized the importance of strong communication with caregivers throughout the euthanasia process. • Nurses expressed the importance of discussing euthanasia with their colleagues in supportive environments to share their emotions and cope with the experience.

Continued

Table 2: Continued

Title and Authors	Country	Purpose	Methods	Participants	Key Findings
Doctors and their patients: A context for understanding the wish to hasten death (Kelly, Burnett, Badger, Pelusi, Varghese, Robertson, 2003)	Australia	Understanding the experiences of doctors whose patients have wished to hasten death.	<ul style="list-style-type: none"> • Semi-structured interviews • Content analysis 	12 Physicians	<ul style="list-style-type: none"> • Doctors experienced distress and frustration in caring for patients who requested assistance in dying, but also experienced rewarding feelings when they were able to alleviate some of the patient's suffering. • Doctors felt it was important to adjust their care to manage the underlying issues, allowing for the best possible care for the patient.
What their terms of living and dying might be: Hospice social workers discuss Oregon's Death with Dignity Act (Norton & Miller, 2012)	United States of America	Identify and understand hospice social worker experiences with Oregon's Death with Dignity Act.	<ul style="list-style-type: none"> • Focus group 	9 Hospice Social Workers	<ul style="list-style-type: none"> • Social workers explain that their role is more complex when conflict exists between the patient and the caregiver. • Social workers feel that they are more open to physician assisted dying than physicians and nurses. • Social workers feel that their role is often to fully inform the patient and the patient's family about the process and their options, because more often than not, the physician was not giving patient's family the full picture. • Social workers are confused by their role because of the lack of policy surrounding their involvement or a formal process. • Social workers have to consider each unique patient independently, as each is different, and there are no formal processes for their involvement. • Social workers have the unique responsibility of balancing their patient's desires against the values of the institution in which they are practicing.
Euthanasia: Israeli social workers' experiences, attitudes and meanings (Leichtentritt, 2002)	Israel	Understanding Israeli social workers' experiences of and attitudes towards euthanasia.	<ul style="list-style-type: none"> • Phenomenological approach • Purposeful selection • Interviews 	16 Social workers	<ul style="list-style-type: none"> • Social workers explained that they were often referred clients who wished to discuss passive euthanasia because of the physician's discomfort discussing the topic. • Social workers felt that their involvement was limited to the promoting discussion about the topic with the patient and the patient's family.
Developments in the practice of physician-assisted dying: Perceptions of physicians who had experience with complex cases (Snijdewind, van Tol, Onwuteaka- Philipsen, Willems, 2016)	The Netherlands	To demonstrate the developments that physicians have observed in euthanasia and assisted suicide in practice.	<ul style="list-style-type: none"> • Secondary analysis of in-depth interviews 	28 Physicians	<ul style="list-style-type: none"> • Physicians felt that the process of euthanasia was very difficult; however, they explained that the public seemed to view the practice as a simple procedure. • Physicians often felt pressured to perform euthanasia, despite their best efforts to avoid this.
Physicians' voices on physician- assisted suicide: Looking beyond the numbers (Curry, Schwartz, Gruman, Blank, 2000)	United States of America	Exploring physician attitudes towards and experiences with physician-assisted suicide and palliative care.	<ul style="list-style-type: none"> • Analysis of qualitative, open-ended survey response data 	909 Physicians	<ul style="list-style-type: none"> • Physicians felt that adequate palliative care was a better option. • Physicians expressed concern about the potential for abuse through assisted suicide. • Physicians recognized the need for proper training and regulation, and felt that consultations with multiple physicians, and perhaps a psychiatrist, were important safeguards.

specifically, they felt more comfortable agreeing to the procedure when they had a strong existing relationship with the patient (Dees et al., 2012; Sercu et al., 2012; Voorhees et al., 2013). In addition, physicians explained that relationships with their patients sometimes declined in response to a refusal to provide assistance in dying (Pasman, Willems, & Onwuteaka-Philipsen, 2013). One study discussed the significance of relationships between the physician and the patient, explaining the importance of growth in those relationships across the entire process (Snijdewind et al., 2014). Physicians in this study explained that the decision to pursue assistance in dying developed through continuous consultation and conversation until the patient and the physician grew towards a consensus (Snijdewind et al., 2014). Physicians explained that without this developing relationship, they felt much less confident in providing assistance in dying (Snijdewind et al., 2014). Similarly, nurses in a study by Denier et al. (2009) explained the importance of relationship building in caring for patients receiving assistance in dying. In this study, nurses explained that a strong relationship with the patient and family was important for providing quality care for the patient (Denier et al., 2009).

In multiple studies, physicians described the complexities involved in communicating these complex issues to patients. Physicians providing assistance in dying identified miscommunication in the process as a major source for concern (Borgsteede et al., 2007; Snijdewind et al., 2014). Physicians explained that miscommunications frequently arose as a result of differing implicit expectations between the patient and the physician, misunderstandings about the rules and regulations surrounding the euthanasia process, and undetailed conversations or vague statements provided by the patient regarding important circumstances within the process (Borgsteede et al., 2007; Snijdewind et al., 2014). The prevalence of this miscommunications left many physicians hesitant in their decisions to provide assistance in dying (Borgsteede et al., 2007; Snijdewind et al., 2014). Nurses also described the significance of communication in their role in the assisted dying process: explaining the importance of their role in the patient's becoming certain about the decision, advocating for the patient, and helping the patient come to terms with the decision (Denier et al., 2009, 2010b; Dierckx de Casterlé, Verpoort, De Bal, & Gastmans, 2006; Schwarz, 2003). The nurses explained that they communicated with patients through active listening, providing information, translating jargon, consulting with the patient, providing advice, and engaging in non-euthanasia-related conversation to support patients receiving assistance in dying (Denier et al., 2009). Nurses expressed the importance of maintaining an open, attentive, patient, and trustworthy attitude in conversing with patients (Denier et al., 2009).

Interprofessional Roles and Dynamics

A number of the studies discussed interprofessional factors and roles in the assisted dying process. In these studies, providers discussed the importance of collaboration, advising, delegating, and engagement with other professionals and specialists (Denier et al., 2010b; Galushko et al., 2016; Kelly et al., 2003). Galushko et al. (2016) examined the perspectives of physicians, nurses, and psychosocial-spiritual health providers, but did not separate the perspectives by profession. Other studies that focused on physician perspectives made no mention of interdisciplinary teams, or even other providers, instead focusing on patient-physician relationships (Borgsteede et al., 2007; Dees et al., 2012; Georges et al., 2008; Kelly et al., 2003; Pasman et al., 2013; Sercu et al., 2012; Snijdewind et al., 2014; van Marwijk et al., 2007;). In one case, a physician-focused study mentioned physician-physician consultation (Voorhees et al., 2013), and in another, there was mention of the potential importance of psychiatric consultation (Curry, Shwartz, Gruman, & Blank, 2000). Physicians tended to focus their discussions on the decision to provide assistance in dying, and their process of deliberation in making such decisions (Borgsteede et al., 2007; Dees et al., 2012; Georges et al., 2008; Kelly et al., 2003; Sercu et al., 2012; Snijdewind et al., 2014; van Marwijk et al., 2007; Voorhees et al., 2013). This focus on solitary decision making from the physician perspective conflicts with the findings of Dierckx de Casterlé et al. (2010), who concluded that the practice of excluding other health care professionals from decision making was perceived as disrespectful and counterproductive by the sidelined professionals. In fact, nurses felt that interdisciplinary decision making practices actually led to better care (Dierckx de Casterlé et al., 2010). Denier et al. (2010b) specifically examined interprofessional communication from the viewpoint of nurses, and found that nurses felt that their role was particularly valuable in keeping their colleagues informed, consulting about care decisions, understanding conflicting opinions, and mitigating conflict. Complementary to the perspectives of nurses, social workers were optimistic about the potential to expand their role in the assisted dying process (Norton & Miller, 2012). However, social workers felt that they were currently only involved in the process when physicians felt uncomfortable discussing issues of death and dying themselves (Leichtentritt, 2002).

Studies focused on physician perspectives seemed to indicate that physicians viewed their role in euthanasia care as pertaining to decision making in consultation with the patient (Borgsteede et al., 2007; Dees et al., 2012; Georges et al., 2008; Kelly et al., 2003; Sercu et al., 2012; Snijdewind et al., 2014; van Marwijk et al., 2007; Voorhees et al., 2013). In contrast, nurses seemed to

view their role as providing hands-on continuous care and support for the patient throughout the entire process of assistance in dying (De Bal et al., 2006; Denier et al., 2009, 2010a; Dierckx de Casterlé et al., 2010). Nurses felt that it was their role to advocate for the patient's end-of-life desires, regardless of medical appropriateness, and to provide quality euthanasia care while creating a sense of clarity, peace, and balance for the patient (Denier et al., 2010b). Similar to the views of nurses, social workers felt that their role in caring for patients was to resolve internal conflict and promote acceptance (Norton & Miller, 2012).

Coping

Many studies investigating nurses examined the feelings that these professionals had during the assisted dying process. Nurses in these studies described their feelings as intense, conflicted, guilty, and in some cases powerless (De Bal et al., 2006; Denier et al., 2009). Many of the studies reported that nurses discussed the importance of taking time for self-care, mourning, and bereavement, recognizing that although the caregivers and family members are the immediate concern, they need to take the time to reflect on the experience for their own mental and emotional health (De Bal et al., 2006; Dierckx de Casterlé et al., 2010).

Studies that focused on physician perspectives also reported a number of complex feelings and emotions experienced throughout the assisted dying process. Physicians discussed feeling a heavy, traumatic, and difficult responsibility (Georges et al., 2008; Snijdwind et al., 2016; van Marwijk et al., 2007) that resulted in mixed feelings, loneliness, and a sense of loss (van Marwijk et al., 2007). Physicians explained that the negative effects of providing assistance in dying result in a need for emotional support (Georges et al., 2008; van Marwijk et al., 2007).

Discussion

The results of this review indicate the importance of adopting a process view of assistance in dying. Although the Government of Canada currently considers the items required prior to the administration of MAiD, there are no existing standards of care for patients moving through the MAiD process (Government of Canada, 2016). This review provides evidence of the value of various health professional perspectives, indicating that the views of all parties involved in assistance in dying should be considered in the development of future policy in Canada.

As demonstrated through existing literature, relationships and communication in caring for persons receiving assistance in dying are crucial for quality care. There exists a clear potential for the use of relational

care methods to support patients in attaining peace and clarity in the assisted dying process. It is evident that the patient, the caregiver, and entire care team should be involved in consistent and clear communication across the process. Fujioka et al. (2018) identified the lack of interprofessional collaboration and role ambiguity as challenges for health care providers involved in MAiD. Additionally, recent qualitative work by McKee & Sellick (2018) concluded that, for Canadian physicians, the largest source of stress in the MAiD process stemmed from administrative or institutional barriers. The results of this review support a shift towards a more interdisciplinary approach to MAiD care in all provinces. Li et al. (2017) have implemented an interprofessional MAiD framework in Ontario hospitals, suggesting that these models can be successful in Canadian contexts. Retchin's (2008) conceptual framework for interprofessional and co-managed care also suggests that an interprofessional team-based approach would be successful in MAiD care. As explained in Retchin's (2008) framework, the longer time frame and relatively low urgency of care required in the MAiD process provide an ideal situation for interprofessional collaboration, allowing time for team meetings and care planning. A shift towards an interprofessional model would work to enhance care quality for patients, while acknowledging the contributions of all providers involved. Interprofessional approaches may also support better coping among professionals involved in the process by creating a network for support and an environment of understanding.

Limitations

This scoping review limited its search to articles published in the English language, and did not involve a grey literature search, because of the review's focus on qualitative research findings. Several of the articles included in this review were completed by the same authors, using the same data set. These articles were ultimately included, as each focused on a different topic in analyzing the data.

Conclusions

The results of this scoping review build on the work of Fujioka et al. (2018), who worked to identify key challenges faced by MAiD providers. This review uniquely identifies the major themes and findings of the qualitative research pertaining to experiences and perspectives of health care professionals involved in the assistance in dying or euthanasia care process. As identified by Fujioka et al. (2018), existing research provides some insight into the perspectives of physicians and nurses, but little has been published on the experiences of social workers or other allied health providers. In fact,

this review returned no results related to the experiences of psychiatrists, pharmacists, or speech language pathologists, despite the inclusion of these professionals in provincial plans.

Although understanding the views of health care professionals is important, it is equally as critical to recognize the perspectives of patients and caregivers who experience these processes. The experiences and perspectives of patients and their caregivers should be a crucial consideration in developing a complete understanding of the assisted dying experience, and in developing future policy and care improvement initiatives.

References

- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. doi: 10.1080/1364557032000119616
- Borgsteede, S. D., Deliens, L., Graafland-Riedstra, C., Francke, A. L., van der Wal, G., & Willems, D. L. (2007). Communication about euthanasia in general practice: Opinions and experiences of patients and their general practitioners. *Patient Education & Counseling*, 66(2), 156–161. doi: <https://doi.org/10.1016/j.pec.2006.10.006>
- Block, S. D., & Billings, J. A. (1995). Patient requests for euthanasia and assisted suicide in terminal illness: The role of the psychiatrist. *Psychosomatics*, 36(5), 445–457. doi: 10.1016/S0033-3182(95)71625-5
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi: <http://dx.doi.org/10.1191/1478088706qp0630a>
- Braverman, D. W., Marcus, B. S., Wakim, P. G., Mercurio, M. R., & Kopf, G. S. (2017). Health care professionals' attitudes about physician-assisted death: An analysis of their justifications and the roles of terminology and patient competency. *Journal of Pain and Symptom Management*, 54(4), 538–545. doi: 10.1016/j.jpainsymman.2017.07.024
- Curry, L., Schwartz, H. I., Gruman, C., & Blank, K. (2000). Physicians' voices on physician-assisted suicide: Looking beyond the numbers. *Ethics & Behavior*, 10(4), 337–361. doi: https://doi.org/10.1207/S15327019EB1004_2
- De Bal, N., Dierckx de Casterlé, B., De Beer, T., & Gastmans, C. (2006). Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. *International Journal of Nursing Studies*, 43(5), 589–599. doi: 10.1016/j.ijnurstu.2005.08.003
- Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Elwyn, G., Vissers, K. C., & van Weel, C. (2012). Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives, and treating physicians in the Netherlands. *Palliative Medicine*, 27(1), 27–37. doi: 10.1177/0269216312463259
- Denier, Y., Dierckx de Casterlé, B., De Bal, N., & Gastmans, C. (2009). Involvement of nurses in the euthanasia care process in Flanders (Belgium): An exploration of two perspectives. *Journal of Palliative Care*, 25(4), 264–274. Retrieved 30 October 2017 from: <http://www.nvkvv.be/file?file=196466&ssn=>
- Denier, Y., Dierckx de Casterlé, B., De Bal, N., & Gastmans, C. (2010a). "It's intense, you know." Nurses' experiences in caring for patients requesting euthanasia. *Medicine Health Care, and Philosophy* 13(1), 41–48. doi: 10.1007/s11019-009-9203-1
- Denier, Y., Gastmans, C., De Bal, N., & Dierckx de Casterlé, B. (2010b). Communication in nursing care for patients requesting euthanasia: A qualitative study. *Journal of Clinical Nursing*, 19(23/24), 3372–3380. doi: 10.1111/j.1365-2702.2010.03367.x
- Dierckx de Casterlé, B., Denier, Y., De Bal, N., & Gastmans, C. (2010). Nursing care for patients requesting euthanasia in general hospitals in Flanders, Belgium. *Journal of Advanced Nursing*, 66(11), 2410–2420. doi: 10.1111/j.1365-2648.2010.05401.x
- Dierckx de Casterlé, B., Verpoort, C., De Bal, N., & Gastmans, C. (2006). Nurses' views on their involvement in euthanasia: A qualitative study in Flanders (Belgium). *Journal of Medical Ethics*, 32(4), 187–192. doi: 10.1136/jme.2005.011783
- Edwards, M. (2016). Changing laws on medical assistance in dying: Implications for critical care nurses. *Canadian Journal of Critical Care Nursing*, 27(3), 18–23. Retrieved 30 October 2017 from: <https://www.caccn.ca/en/files/CACCN-27-3-2016.pdf>
- Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of medical assistance in dying (MAiD): A scoping review of health care providers' perspectives. *Journal of Pain and Symptom Management*, 55(6), 1564–1576.e9. <https://doi.org/10.1016/j.jpainsymman.2018.02.011>
- Galushko, M., Frerich, G., Ferrar, K. M., Golla, M., Radbruch, L., Nauck, F., et al. (2016). Desire for hastened death: How do professionals in specialized palliative care react? *Psycho-Oncology*, 25(5), 536–543. doi: 10.1002/pon.3959
- Georges, J. J., The, A. M., Onwuteaka-Philipsen, B. D., & van der Wal, G. (2008). Dealing with requests for euthanasia: A qualitative study investigating the experience of general practitioners. *Journal of Medical Ethics*, 34(3), 150–155. doi: 10.1136/jme.2007.020909
- Glebock, A., Gawor, A., & Ostrowski, F. (2013). Attitudes toward euthanasia among Polish physicians, nurses and people who have no professional experience with the terminally ill. *Advances in Experimental Medicine and Biology*, 788, 407–414. doi: 10.1007/978-94-007-6627-3_55
- Government of Canada. (2016). 2nd Interim Report on Medical Assistance in Dying in Canada. *Government of Canada*. Retrieved 26 October 2017 from: [<https://doi.org/10.1017/S0714980818000600> Published online by Cambridge University Press](https://www.canada.ca/en/health-canada/services/publications/health-</p>
</div>
<div data-bbox=)

- system-services/medical-assistance-dying-interim-report-sep-2017.html
- Groenewoud, J. H., Van Der Maas, P. J., Van Der Wal, G., Hengeveld, M. W., Tholen, A. J., Schudel, W. J., et al. (1997). Physician-assisted death in psychiatric practice in the Netherlands. *New England Journal of Medicine*, 336(25), 1795–1801. doi: 10.1056/NEJM199706193362506
- Kelly, B., Burnett, P., Badger, S., Pelusi, D., Varghese, F. T., & Robertson, M. (2003). Doctors and their patients: A context for understanding the wish to hasten death. *Psycho-oncology*, 12(4), 375–384. doi: <https://doi.org/10.1002/pon.678>
- Leichtentritt, R. D. (2002). Euthanasia: Israeli social workers' experiences, attitudes and meanings. *British Journal of Social Work*, 32(4), 397–413. doi: 10.1093/bjsw/32.4.397
- Li, M., Watt, S., Escaf, M., Gardam, M., Heesters, A., O'Leary, G., et al. (2017). Medical assistance in dying – implementing a hospital-based program in Canada. *The New England Journal of Medicine*, 376(21), 2082–2088. doi: 10.1056/NEJMms1700606
- Lofland, J., Snow, D., Anderson, L., & Lofland, L. H. (2006). *Analyzing social settings: A guide to qualitative observation and analysis*. (4th ed.) Belmont, CA: Wadsworth Thomson.
- Marcoux, I., Boivin, A., Arseneault, C., Toupin, M., & Youssef, J. (2015). Health care professionals' comprehension of the legal status of end-of-life practices in Quebec. *Canadian Family Physician*, 61, e196–203. Retrieved 30 October 2017 from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4396778/>
- McKee, M., & Sellick, M. (2018). The impact on physicians of providing MAiD. Presentation to CAMAP. Retrieved 8 August 2017 from: <https://az659834.vo.msecnd.net/eventsaircaneprod/production-uottawacpd-public/bef6f6faf8bdc43fdb3552d332901b485>
- Norton, E. M., & Miller, P. J. (2012). What their terms of living and dying might be: Hospice social workers discuss Oregon's Death with Dignity Act. *Journal of Social Work in End-of-Life & Palliative Care*, 8(3), 249–264. doi: 10.1080/15524256.2012.708295
- Ontario Ministry of Health and Long Term Care. (2017). Medical assistance in dying. Ontario Ministry of Health and Long Term Care. Retrieved 26 October 2017 from: <http://health.gov.on.ca/en/pro/programs/maid/>
- Pasman, H. R. W., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2013). What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives and physicians. *Patient Education and Counseling*, 92(3), 313–318. doi: 10.1016/j.pec.2013.06.007
- Retchin, S. M. (2008). A conceptual framework for interprofessional and co-managed care. *Academic Medicine*, 83(10), 929–933. doi: 10.1097/ACM.0b013e3181850b4b
- Schwarz, J. K. (1999). Assisted dying and nursing practice. *Journal of Nursing Scholarship*, 31(4), 367–374. doi: <https://doi.org/10.1111/j.1547-5069.1999.tb00522.x>
- Schwarz, J. K. (2003). Understanding and responding to patients' requests for assistance in dying. *Journal of Nursing Scholarship*, 35(4), 377–384. doi: 10.1111/j.1547-5069.2003.00377.x
- Sercu, M., Pype, P., Christiaens, T., Grypdonck, M., Derese, A., & Deveugele, M. (2012). Are general practitioners prepared to end life on request in a country where euthanasia is legalised? *Journal of Medical Ethics*, 38(5), 274–280. doi: 10.1136/medethics-2011-100048
- Snijedewind, M. C., van Tol, D. G., Onwuteaka-Philipsen, B., & Willems, D. L. (2014). Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives. *Journal of Pain and Symptom Management*, 48(6), 1125–1134. doi: 10.1016/j.jpainsymman.2014.04.016
- Snijedewind, M. C., van Tol, D. G., Onwuteaka-Philipsen, B. D., & Willems, D. L. (2016). Developments in the practice of physician-assisted dying: Perceptions of physicians who had experience with complex cases. *Journal of Medical Ethics*. doi: 10.1136/medethics-2016-103405
- Trachtenberg, A. J., & Manns, B. (2017). Cost analysis of medical assistance in dying in Canada. *Canadian Medical Association Journal*, 23(189), e101–105. doi: 10.1503/cmaj.160650
- van Marwijk, H., Haverkate, I., van Royen, P., & The, A. M. (2007). Impact of euthanasia on primary care physicians in the Netherlands. *Palliative Medicine*, 21(7), 609–614. doi: 10.1177/0269216307082475
- Voorhees, J. R., Rietjens, J. A. C., van der Heide, A., & Drickamer, M. A. (2013). Discussing physician-assisted dying: Physicians' experiences in the United States and the Netherlands. *Gerontologist*, 54(5), 808–817. doi: 10.1093/geront/gnt087
- Winnipeg Regional Health Authority. (2016). Medical assistance in dying. The Manitoba Provincial Medical Assistance in Dying Clinical Team. Retrieved 26 October 2017 from: <http://www.wrha.mb.ca/maid/contact.html>