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Ethical judgment in assessing requests for medical assistance in dying in Canada and Quebec: What can we learn from other jurisdictions?

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ABSTRACT

This paper concerns the ethical judgment that lies at the heart of assessing requests for Medical Assistance in Dying (MAID) in Canada and Quebec, namely is it ethically right to help the person requesting assistance to end his or her life? We address situations in which making this judgment may be challenging despite the person fulfilling legal eligibility requirements. Using three clinical cases that are challenging by virtue of the legal requirement that a person experience intolerable suffering we explore this issue. We review practice guidance provided to providers and assessors in six jurisdictions and discuss potential resources to inform the ethical judgments involved in MAID assessments.

Introduction


On 10 December 2015, an Act respecting end of life care (hereafter, the Act) came into force in the province of Quebec, Canada (Quebec, 2015). Acting on its jurisdiction in the area of health, the Quebec legislator sought to ensure that all patients at the end of life in Quebec had access to a full range of healthcare options including medical aid in dying (euthanasia). The Act defines medical aid in dying (hereafter MAID) as “care consisting in the administration by a physician of medications or substances to an end-of-life patient, at the patient’s request, in order to relieve their suffering by hastening death” (art. 3(6)). This definition makes clear that only voluntary euthanasia is permitted under the Act.

The civil society and political processes in Quebec that led to the Act occurred in parallel to legal developments elsewhere in Canada. These culminated in the Supreme Court of Canada decision in the case of *Carter v. Canada* in February 2015 (Supreme Court of Canada, 2015). In this case, the Court found that the sections of the Criminal Code prohibiting physician assisted dying violated certain rights guaranteed by the Canadian Charter of Rights and Freedoms. An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in

dying) (hereafter C-14) took effect on 17 June 2016 (Canada, 2016). In the federal law, the expression “medical assistance in dying” refers to both voluntary euthanasia and medically assisted suicide. Further, both physicians and nurse practitioners can administer MAID while under the Quebec law, only physicians can administer MAID. Unlike the Quebec legislation, noncompliance with the federal law—including in Quebec—can result in criminal sanction.

At the time of this writing (January 2020), both laws¹ give patients access to medical assistance in dying in specific circumstances, including that patients be at least 18 years old, capable of consenting to MAID, suffer from a grievous and irremediable medical condition, be in an advanced state of irreversible decline in capability, experience unbearable suffering that cannot be relieved under conditions acceptable to them, and be at the end of life (Quebec) or that the patient’s “natural death has become reasonably foreseeable” (Canada).² When the two laws came into force, Quebec and Canada became the tenth and twelfth jurisdictions in the world to allow some form of assisted death.³

Given that it is not a criminal act to end one’s own life in Canada and Quebec, it is important to note that what citizens in these jurisdictions have claimed and been accorded in the new laws is *medical*

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assistance. The eligibility criteria for medical assistance in dying in these laws do substantive ethical work by laying out the general conditions under which the Canadian and Quebec legislators, as representatives of society, consider it morally allowable for a clinician to end another person's life. At the same time, operating in the background of this decision—and indeed any clinical decision—is a specific question of the sort: is it ethically right⁴ to intervene with *this* patient at *this* time? For most clinical acts, making this specific ethical judgment is facilitated by laws guaranteeing the right to informed consent, by the regulatory framework that determines allowable medical interventions, and the general fiduciary duty of doctors to patients. That is, if a patient has a condition that requires a certain intervention which is legally available for use, the practitioner believes it to be clinically indicated and is skilled in providing it, and the person gives informed consent to receive it, in most cases the specific ethical question is answered. Indeed, this reasoning process is so implicit in usual practice that it may not even be apparent that an ethical judgment has been made. Similarly, in cases in which a person's situation unambiguously fulfills the legal criteria for accessing MAID there may not seem to be any ethical judgment involved on the part of the clinician. In such cases, we contend that an ethical judgment is made, but it is being handled by the legal criteria.

Nevertheless, there are at least three situations in which fulfilling legal eligibility criteria and the ethical judgment to be made during assessment do not overlap completely. First, it may be unclear *how* to apply a legal criterion in a given situation. For example, the criterion that a person be in an “advanced state of irreversible decline in capability” has both factual and normative components. The irreversibility of a person's decline in capability (e.g. loss of motor control) may be a matter of fact, but whether this decline is advanced requires value judgments on the part of the clinician as to what constitutes enough decline to be advanced. How should the clinician go about making this judgment? By recourse to the patient's values? Through consultation with colleagues? Regardless of the method, once the criterion is considered to be fulfilled, this is ethically determinative i.e. if the legal criteria apply, the ethical question of whether it is right to assist in this person's death is answered. Second, there may be new or unforeseen circumstances that arise following the passage of a law which raise questions as to *whether* a criterion applies. An example of unforeseen circumstances arising from the passage of both laws occurred in situations where people

voluntarily stopped eating and drinking (VSED) in order to become eligible for assisted dying such as the case of Jean Brault in Quebec reported by the press only a few months after the new law came into force (Poirier, 2016). If a person is considered to be ineligible at the time of making a request because he is not at the end of life, should she be considered eligible for MAID if as a result of a decision to engage in VSED he is at the end of life? Once again, the legal criterion is ethically determinative. If a practitioner determines that the person fulfills the criteria of “end of life” or “natural death reasonably foreseeable”—regardless of what brought him to this situation—the ethical work is done.

This paper concerns a third type of situation of non-overlap between legal criteria and individual ethical judgments in which criteria seem to be fulfilled but certain ethical questions remain. Using three clinical cases that are challenging by virtue of the legal requirement that a person experience intolerable suffering, we explore some of the ethical questions faced by practitioners who must assess these requests for medical assistance. This should not be taken to imply that it is only the suffering criterion that poses ethical challenges⁵ but rather that having to assess suffering in the context of a MAID request is a useful entry point to discussing the ethical questions involved in MAID assessments in general. We will then provide an overview of the practice guidance that has been given concerning MAID assessments in Canada and Quebec. What, if any, instructions are given to practitioners in light of the ethical judgments that must be made? We contrast this guidance with that of three jurisdictions with similar assessment criteria (the Netherlands, Belgium, and Luxembourg). We then turn to Switzerland where limited state involvement in assisted dying, particularly in the form of an action-guiding legal framework, illustrates how one might think about the individual ethical judgments involved in assessment. Finally, we discuss potential resources to inform the ethical judgments involved in individual MAID assessments.

Cases

In this section we describe three cases in which a clinician may question whether it is ethically right to assist in the death of the persons concerned because of reasons for their requests. Under what circumstances should a practitioner take a person's reasons into consideration and to what extent? This question is unanswered by legal eligibility criteria.

One of the authors (MG) is a psychiatrist who has practiced in three large centers in Canada and has also served as an examiner for the national certifying exams in psychiatry. Based on this experience, she considers it to be standard practice in psychiatry to obtain a detailed personal history of patients in the course of consultation which often includes the reasons, feelings, and experiences surrounding life-changing decisions or events. The cases presented below are based on the stories of real people but have been fictionalized for this paper. The framing of the cases is informed by MG's experience of presenting cases in psychiatry. The authors are aware that this framing and type of personal detail is *in itself* what allows the non-overlap of legal criteria and ethical judgment to surface and in their absence the ethical issue may not be apparent. Some may argue that a personal history typical of a psychiatric consultation is not necessary for the evaluation of the MAID request. However, practice guidance from the Netherlands for example, recommends that in the course of assessing requests for assisted dying, practitioners explore patients' values and beliefs over the life course (Regional Euthanasia Review Committees [RTE], 2018; Royal Dutch Medical Association [KNMG], 2011).

Following each case, we will identify what makes it difficult to make a judgment about whether or not to provide assisted dying. We further invite the reader to consider the cases in light of the practice guidance for MAID assessments discussed in the section entitled, 'Clinical assessments of requests for assisted dying' and the resources for ethical judgment discussed in the section entitled, 'What resources exist to guide ethical judgments in MAID assessments.'

Case 1

Mr A is a 75 year old widower with no children. He was an electrician until he retired at age 65 following a diagnosis of prostate cancer. He has been pursuing treatment over the last ten years but was informed 6 months ago by his urologist that his disease has progressed. At age 73 he was diagnosed with Parkinson's disease for which he also receives treatment. Mr A's wife died three years ago from a massive heart attack. Despite his grief, Mr A continued to be socially active with his neighbors and in his church. He has an older sister who is 80 years old, who lives independently and with whom he is close.

Mr A was admitted to hospital following a fall at home during which he sustained a fracture to his

right (dominant) arm. Due to an accumulation of factors related to his medical problems (postural instability, mild cognitive impairment, and the need for several medications which could be toxic in overdose) the health care team does not believe he can return home to live alone. Due to her frailty, his sister is not able to look after him at home even with maximum allowable home care services. The team believes the only safe option is for the patient to move to a nursing home. The prospect of never returning to his home causes him intolerable suffering. Confronted with this situation, Mr A states that he would rather die than move to a nursing home and requests MAID. He has no psychiatric history and has never made a suicide attempt in the past. He does not want his sister to know about his request because he does not want her to feel guilty that she cannot have him live with her.

In this case, the relationship between the medical state and the person's suffering is indirect.⁶ It is the medical situation together with the social conditions in which the person must live that brings about his suffering. While the most financially advantaged in our society can afford the care necessary to remain in their own homes, many others will have to move into public institutional settings. These long-term care institutions may not be desirable places to live (Protecteur du Citoyen, 2018, p. 72). Knowing that Mr A's fears about the quality of life in these institutional settings are realistic, one must answer the question as to whether it is ethical to end someone's life given society's collective failure to provide desirable living conditions for disabled or ill senior citizens. Is an individual level intervention (ending the patient's life) the right approach to the societal problem of having undesirable housing for dependent seniors? On the other hand, must an individual be required to endure the consequences of a social problem when societal level solutions are not forthcoming?

Case 2

Ms B is a 48 year old single woman. She was abandoned by her parents when she was a child and raised in a series of foster homes. She was sexually abused on multiple occasions by a 17 year old foster brother when she was 11 years old. She lived on the streets for about one year following her release from the foster system at age 16 during which time she regularly used crack and at times resorted to prostitution to survive. She made two suicide attempts by drug ingestion during this period. She was arrested at age 19 but was

offered drug rehabilitation program instead of prison. As a result of this intervention and subsequent social programs, she ceased using drugs, completed her education, and obtained employment in her late 20s working at a small hotel in administration. She has had a few short-term intimate relationships. She has a few acquaintances from work and her apartment building but no close friends or known family members. She has longstanding beliefs she is worthless and unlovable.

Ms B has been diagnosed with ovarian cancer but is still well enough to live at home independently. She requests MAID because the thought of limited health-care resources and disability benefits being “wasted” on her causes her intolerable suffering. She says, “it would be better for everyone if I die sooner rather than later.” She agrees to a psychiatric consultation. The psychiatrist does not think she suffers from a diagnosable psychiatric condition such as major depressive disorder or post-traumatic stress disorder but acknowledges the impact of profound early life trauma on her self-perception and appraisal of her situation. Her treating physician consider her to be capable of consenting to MAID.

In this case, there are questions to be asked about whether the right thing to do for this person is to confirm her longstanding, deeply-held self-denigrating beliefs fostered by severe neglect, abuse, and exploitation, by ending her life. Others may say that after the severe trauma she had endured, to not provide MAID constitutes yet another example of disrespect of her personhood. At an individual level, this debate turns on the extent to which distorted but nevertheless longstanding beliefs should be considered to reflect the authentic (Kious & Battin, 2019) wishes of a person. At a collective level, an additional consideration is how society responds to the abuse of children and the exploitation of women. Do we do enough to prevent such occurrences and when they arise, provide sufficient assistance to survivors? In the absence of sufficient assistance, is it morally acceptable to provide MAID or is it morally acceptable to deny it?

Case 3

Mr D is a retired 78 year old widow with end stage heart failure currently in hospital recovering from a recent exacerbation of this condition. He lives independently in an apartment but is finding this increasingly difficult because even walking within the apartment leaves him short of breath. He has two adult children, a daughter who is 50 and a son who is

48. They live nearby but do not have a positive relationship with their father. When they were young their father was a heavy drinker. He was never physically abusive toward them but his angry behavior when intoxicated was a source of great distress to them. He no longer drinks and is much calmer but still, their contact is restricted to the extended family Christmas dinner and occasional phone calls.

During his life, Mr D socialized with people in his wife’s social circle. Since she was killed seven years ago in a car accident, those friends have gradually drifted away or died. Now he sees no one apart from the home care workers who help him with his hygiene and the volunteers who deliver meals on wheels. One of his neighbors occasionally does errands for him. Over the last year, he has required several hospitalizations and has been advised by his physician that he could die during any episode of cardiac decompensation. He feels hurt by the fact that his children do not visit him in hospital and says that the isolation brought about by his disease causes him intolerable suffering. However, he refuses any social intervention likely to facilitate a visit by his children because he does not want to “beg” them to come. He requests MAID in order to “make them pay” for their behavior.

In this case the physician is being asked to end the life of someone, at least in part, to cause emotional pain to his family members. The physician’s assistance is instrumentalized in the family conflict. Does this matter? Alternatively, the family members may not be hurt by their father’s death by MAID and should the possibility of this outcome be explored or even taken into consideration?

This section is not intended to provide a complete overview of cases in which legal criteria and ethical judgment do not completely overlap. Other examples including situations of intense family conflict surrounding an individual’s desire to proceed with an assisted death or situations in which a person says he wishes to use his assisted death to make a social or political statement. The option of *medical* assistance in dying requires us to reflect on the question of whether the circumstances of these people fall within the remit of medicine.

Clinical assessments of requests for assisted dying

In this section we provide an overview of the practice guidance given to clinicians who must assess patients’ requests for assisted dying in six jurisdictions where

suffering is one of the eligibility criteria for accessing assistance in dying. We will begin with Canada and Quebec which are the focus of this article and where assistance in dying is still relatively new. We then consider the more experienced Benelux countries whose laws and policies have significantly influenced those of Canada and Quebec (see Blouin et al., 2021, this issue). Finally, we turn to the ongoing debates about the assessment of requests in Switzerland, a country with a long history of tolerance of *civil* assistance in dying. While Switzerland has relatively less legal regulation of assisted dying, similar ethical questions arise compared to the other jurisdictions concerning assessments.

Canada and Quebec

When a person makes a request for MAID the law requires that two clinicians (physicians or nurse-practitioners in Canada, physicians in Quebec) come to an opinion about whether or not the eligibility criteria are fulfilled. The first physician is the one who will administer MAID if the person is eligible while the second physician's role is to confirm, independently, that the patient meets the eligibility criteria. The Quebec Act lays out certain procedural safeguards which influence the content and form of the clinical assessment. For example, section 29 of the Act requires that "the [first] physician must be of the opinion that the patient meets all the criteria of section 26, after, among other things,

- a. Discussing the patient's request with any members of the care team who are in regular contact with the patient.
- b. Discussing the patient's request with the patient's close relations, if the patient so wishes.

According to this section, these discussions are to occur before the first physician comes to the opinion that the person is eligible and are meant to inform that opinion. Therefore, part of the assessment of the patient's request requires that other health care providers participate in a discussion about the request and relatives as well, as long as this is not refused. The federal law does not lay out these same requirements. However, it does state that, "Medical assistance in dying must be provided with reasonable knowledge, care and skill and in accordance with any applicable provincial laws, rules or standards." This effectively places further guidance about the assessment in the

hands of the medical regulators of each province and territory in Canada.

The medical regulators of each of Canada's provinces (except New Brunswick) and the governments of its territories (except Nunavut) have produced guidance concerning the assessment of patients requesting MAID. All of them review the legal eligibility criteria and provide definitions of key terms found within the criteria (e.g. capacity). However, some jurisdictions also provide practice guidance relative to the assessment process.

Ontario, Manitoba and Saskatchewan all recommend that the physicians "use their professional judgment" or "appropriate medical judgment" (College of Physicians & Surgeons of Manitoba [CPSM], 2016; College of Physicians & Surgeons of Ontario [CPSO], 2016; College of Physicians and Surgeons of Saskatchewan [CPSS], 2018) in assessing patients' fulfillment of criteria and these latter two provincial regulators also recommend that the physicians use a "reasonable method of assessment" although this is neither defined nor described.

Regarding the patient's request for assisted dying itself, the College of Physicians and Surgeons of Newfoundland and Labrador adds that it should be "genuine" (College of Physicians & Surgeons of Newfoundland & Labrador [CPSNL], 2016, p. 8) while in Saskatchewan and Manitoba, the regulators say that it should be made thoughtfully and "after due consideration" and represents "a clear and settled intention to end his/her own life by medical assistance in dying" (CPSM, 2016; CPSS, 2018). Further, the Saskatchewan and Manitoba regulators recommend that in assessing suffering "the unique circumstances and perspective of the patient, including his/her personal experiences and religious or moral beliefs and values have been seriously considered" (CPSM, 2016; CPSS, 2018).

Quebec's medical regulator, in collaboration⁷ with the regulatory bodies for nurses and pharmacists, has developed extensive practice guidance for the practice of MAID.

This hundred-page document contains a Section (3.4) entitled "Medical Decision" with a subsection (3.4.2) dedicated to medical judgment. The regulator writes,

In addition to assessing the indications, the physician must use his professional judgment as to the best treatment or intervention options available to relieve a particular patient's suffering before agreeing to or refusing the patient's request for MAID. Thus, while the physician must ensure that all the criteria prescribed by law have been met, he must also assess

the relative importance of one versus the other in order to agree with the patient as to the most appropriate treatment. (CMQ et al., 2018, p. 27)

Here the CMQ goes further than its counterparts in Ontario, Saskatchewan and Manitoba, adding that exercising judgment is not only in relation to the criteria but also about the best options or interventions available which suggests that the physician has two judgments to make: that the eligibility criteria are fulfilled and that in the physician's view, MAID is the best response to the person's situation. Further, in the following paragraph, we see explicit recognition of the physician's moral agency in making this judgment:

To agree to administer MAID, the physician should be convinced that it is the best option, not only for the patient requesting it, but also for himself, for he will have to perform the intervention and live with its professional, legal and moral repercussions. (CMQ et al., 2018, p. 28)

Canadian and Quebec legal and regulatory guidance shape assessment practices by implying that there is a method for assessing MAID requests and that judgment ought to be exercised. But beyond what is described above, they do not provide practitioners with resources to assist them in making ethical judgments about the patients' motivations to request MAID.

Assessment of requests: practice guidance from an international perspective

In jurisdictions authorizing assistance in dying, the clinical assessment for eligibility has given rise to public discussions and controversies. In this section, we provide an overview of the tensions regarding assessment.

Benelux countries

In the Netherlands, euthanasia has been legally tolerated since the 1980s provided that physicians follow the due care criteria recognized by the courts. The Netherlands and Belgium officially legalized assistance in dying in 2002, and Luxembourg followed in 2009. In these three countries, providing and assessing physicians are required to use similar legal criteria for adults, such as the patient's request being voluntary and well-considered, and having "unbearable or mental suffering without prospect of improvement." Criteria do not include any reference to the temporal proximity of death, except for minors in Belgium who must be terminally ill. A providing physician must also consult with an independent colleague that has to

assess the patient's request although these two physicians need not agree on the person's eligibility for euthanasia to take place.⁸

Of the three countries, the Netherlands has the most comprehensive set of regulatory and practice guidelines developed separately by professional societies, such as the KNMG and the Royal Dutch Pharmacists Association (KNMP). The Regional Review Committees (RTE) which are mandated by government to provide retrospective oversight to the practice⁹ also issue guidance periodically based on their review of cases. In Belgium, the Federal Commission of Control and Evaluation of Euthanasia has published a brochure detailing how to interpret certain criteria such as "intolerable suffering that cannot be relieved" (CFCEE, 2015). In Luxembourg, the Ministry of Health, the Ministry of Social Security, the National Commission for Control and Assessment (NCCA), the Association for the Right to Die with Dignity and patients association have produced jointly a brochure answering common questions regarding assistance in dying, including on how to define "intolerable suffering without prospects of improvement" (Ministry of Health & Ministry of Social Security, 2010).

In these countries, suffering in relation to assistance in dying is central to the assessment of a request. In the Netherlands, the topic of suffering occupies most of the KNMG's position paper (2011) on the role of the physician in the voluntary termination of life. According to the law, the physician must hold the conviction that the patient's suffering is lasting and unbearable (KNMG, 2011, p. 20). The position paper mentions that "lasting suffering" and "unbearable suffering" are "inextricable concepts" (KNMG, 2011, p. 20). In an article, two KNMG bioethicists provide further explanation on how to conduct the assessment of suffering:

Although it is the patient who determines whether the suffering is unbearable or not, this in itself is not determinative for the decision to perform euthanasia or not. Of course the patient's perspective is relevant, but this does not imply that his or her own assessment is authoritative. The physician who is confronted with the request to perform euthanasia also has to be convinced both that the suffering is unbearable and that there is no prospect of improvement for this particular patient. Therefore, the unbearableness of the suffering is not determined exclusively by the patient's subjective experience; the physician has to be able to 'understand' or empathise with this specific form of suffering as well. (Jong & van Dijk, 2017, p. 12)

In cases where psychosocial or existential suffering plays a key role, physicians should consult with

professionals who specialize in these issues, such as social workers, psychologists and spiritual counselors (KNMG, 2011, pp. 22–23).

In Belgium suffering is also at the heart of concerns regarding euthanasia. Opinion no 73 of the Belgian Advisory Committee on Bioethics (2017) addresses three topics: patients who are not at the end of life, mental suffering, and persons with psychiatric conditions. The Opinion, relying in part on documents from the Netherlands, discusses the concepts of suffering, capacity, diagnosability and incurability, and of being “tired of life” and a “completed life.” However, the committee members simply could not agree about whether to specify the kinds suffering that qualify for euthanasia nor about several other aspects regarding the alleviation and evaluation of suffering. However, the Euthanasia Act itself provides some guidance regarding what is expected from physicians in their assessments of requests. Chapter 2 of the law states, among other things, that physicians “must arrive, with the patient, at the conviction that there is no other reasonable alternative in his situation and that the patient’s request is entirely voluntary” (Moniteur belge, 2002 [our trans.]) and consult with the care team and with the patient’s loved ones if s/he agrees. Physicians must comply with these requirements “[w]ithout prejudice to any additional conditions that the doctor may wish to impose on his intervention” (Moniteur belge, 2002 [our trans.]).

In Luxembourg, the brochure on euthanasia and assisted suicide provides some guidance on how suffering should be assessed, which is similar to what is recommended in the Netherlands and Belgium. It mentions that “the assessment of the unbearable suffering is to a large extent a subjective and personal question” while the question of “prospect of improvement of the suffering is one of a medical nature, but account should be taken of the fact that the patient is entitled to refuse the treatment of suffering, or even a palliative treatment” (Ministry of Health & Ministry of Social Security, 2010, p. 15). The brochure emphasizes the need of an “in-depth discussion between the doctor and the patient” with regard to suffering and encourages the doctor to have conversations with the care team and the person of trust chosen by the requester (pp. 15–16). The assessment is understood to draw upon both the patient’s and physician’s judgment.

Switzerland

In Switzerland, there are few legal restrictions for accessing assisted suicide. According to the Criminal Code, the person assisting a suicide—anyone who is

willing—must not have a selfish motive. In addition, according to case law, the person requesting assistance must have decision-making capacity. Most people requesting assistance direct their requests to one of eight not-for-profit right-to-die societies which have their own additional eligibility criteria although they are similar to each other. For example, EXIT A.D.M.D. Suisse romande (hereafter EXIT) operates in the French-speaking region of Switzerland. Its criteria are:

To be a member of the association;

The main residence must be established on Swiss territory. [...]

To be of age, therefore 18 years old.

To have decision making-capacity.

To have either an incurable disease, intolerable suffering or disabling age-related multiple disorders.” (EXIT, n.d. [our trans.])

In considering a request, EXIT requires that the person requesting assistance provides certain documents including his/her own written request as well as documentation by a physician indicating the person’s diagnosis(es) and affirming his/her capacity to consent to assisted suicide. These documents are evaluated by a volunteer physician working with EXIT in order to ascertain if the person fulfills the society’s criteria. Once approved, another volunteer meets the person requesting assistance and confirms eligibility. As the assessors are volunteers acting as individuals, EXIT does not require them to adhere to a specific assessment procedure, nor does it systematically oversee their practices.

Right-to-die societies also collaborate with those physicians¹⁰ who are willing to prescribe the lethal drug to requesters. Physicians must comply with the Federal Act on Narcotics and Psychotropic Substances and with the Federal Act on Medicinal Products and Medical Devices. These laws require that physicians are aware of the health status of a person requesting assistance in suicide and that they act with “due diligence.”¹¹ Physicians involved in assisted suicide, as prescribers and/or as providers are also expected to follow the criteria laid out in the medico-ethical guidelines issued by the Swiss Academy of Medical Sciences (SAMS, 2018).¹² The SAMS guidelines are not legally binding but have been cited in court decisions. Furthermore, the previous version is embedded in the Code of Ethics of the Swiss Federation of Physicians (FMH), a voluntary association.

In 2018 the SAMS published new medico-ethical guidelines on the “Management of dying and death.”

Assisted suicide is placed under the rubric of “controversial actions,” which means it is “a matter for physicians who are personally convinced, in a particular case, that [those actions] serve the patient’s best interests” (SAMS, 2018, p. 5). SAMS adds that, “[t]his requires an interpersonal relationship with the patient in which compassion, judgment, trustworthiness and integrity are central elements” (SAMS, 2018, p. 21). According to the guidelines, a physician can perform an assisted suicide if five criteria are met, including that, “The symptoms of disease and/or functional impairments are a source of intolerable suffering for the patient” (SAMS, 2018, p. 23). On how to assess this criterion, the SAMS states:

While this cannot be expressed in objective terms, it can—through intersubjective comprehension—be convincingly stated by the treating physician. However, in order to justify why assisted suicide should be considered a medical matter at all, medically definable symptoms of disease or functional impairments must be present. (2018, p. 22)

Nonetheless, “[i]ntolerability can only be designated as such by sufferers themselves; it is not ascribable by others. It may, however, be more or less comprehensible to others” (SAMS, 2018, p. 10).

However, the “intolerable suffering” condition and the guidance for its assessment was not well received by the FMH because an intersubjective assessment is irreconcilable with the requirement that the patient be the ultimate judge of her suffering:

The physician faces a dilemma, because on the one hand it is incumbent upon him to examine whether the conditions for assisted suicide are met, and on the other hand, the suffering must be unbearable “for the patient”—in other words, this examination must be carried out from the perspective of the patient, not that of the physician. It is hardly possible to find a satisfactory solution to such a dilemma. The doctor must not replace the patient in determining whether the patient’s suffering is unbearable. However, it would also be wrong to be satisfied with the patient’s sole assertion that his suffering is unbearable, because the responsibility for assisted suicide is not borne by the patient but by the doctor. To the extent that the desire for suicide generally stems from the fact that the patient considers his situation to be unbearable, this criterion would, in practice, almost always be fulfilled and would lose all practical significance. (Barnikol, 2018, p. 1394 [our trans.])

Finally, three cantons (Vaud, Neuchâtel, Genève) have passed laws for regulating the provision of assisted suicide specifically in publicly-funded healthcare institutions (hospitals and nursing homes). Besides the procedural and substantive requirements laid out in these

cantonal laws, some institutions have their own internal protocols for dealing with assisted suicide requests. In parallel, right-to-die societies engage in their own assessment process as described above.

Ultimately, physicians whether acting in the community or in healthcare institutions have complete latitude to prescribe the lethal substance or not providing that they respect the law. Accessing assisted suicide is not a right guaranteed by the state, and providing it is not a physician’s duty (Hurst & Mauron, 2017).

This overview of six jurisdictions illustrates that despite differing legal regimes, the assessment process for accessing assisted dying—particularly as it concerns the assessment of suffering—can prove challenging for similar reasons. That is, there are situations in which regulations and/or guidelines are not sufficient to assist the assessor in making a decision as to whether or not it is ethically right to help end the life of another person. This is true even in Switzerland where a person’s suffering does not have to be judged by clinical personnel and the assistance itself does not have to be understood as a medical or therapeutic act.

What resources exist to guide ethical judgments in MAID assessments?

We have suggested that assessing a person’s request for MAID inevitably requires an ethical judgment about the moral rightness of assisting that person’s death. Earlier we presented three case vignettes in which this judgment might be difficult to make. What resources exist to guide assessors who are uncertain about what is the right thing to do? As we have seen regulatory and/or practice guidance is often insufficient to offer a path forward in specific cases (in essence, they say that the physician must make a judgment) and in Switzerland, the guidelines themselves are contested. Below we discuss two resources for guiding ethical judgments emerging from the theoretical literature: the nature of the clinical relationship and the nature of the decision-making process. We then discuss empirical work done in Switzerland and the Netherlands concerning assessment in order to assess the extent to which these resources actually do play a role and assist in decisions about whether to provide assistance in dying.

The therapeutic relationship and decision-making: theoretical approaches

Emanuel and Emanuel (1992) as well as Jones (1982) contrast doctor-patient relationship types which

describe different roles for the physician, particularly as it concerns ethical judgment (paternalistic, informative, interpretive, and deliberative). Emanuel and Emanuel favor the deliberative model in which the physician not only works to elucidate patient values but also engages in interpretation and persuasion to assist the person to come to certain moral positions. By contrast, under the informative model, the physician supplies technical information relating to diagnosis, prognosis and care options but does not engage in explicit ethical discussion or position-taking. Other authors support the idea that the physician's role is not merely to act as an information provider but to assess and evaluate the reasons for euthanasia (Savulescu, 2014). Thus, the nature of the relationship between a given assessor-requestor pair can be informative about how ethical judgments about MAID eligibility should be made. In practice however, clinical relationships may include elements of all models with their relative contribution varying by area of practice, stage of the relationship and the personalities of the individuals involved. Thus, the character of the therapeutic relationship may not be sufficiently action-guiding in ethically difficult cases.

The Quebec law traces its roots in part to the internal work of the CMQ (2009) whose analysis of assistance in dying in the context of end of life care revolved around the notion of "appropriate care." Care is appropriate when it is individualized to a given patient and proportionate to his or her clinical circumstances. As for determining what constitutes appropriate care, it is whatever is decided at the conclusion of a "well-led decision-making process" namely one that is characterized by open communication in which each party plays his or her role and assumes his or her responsibilities. The emphasis here is more on the decision-making process and less on the relationship in which that process unfolds.

This emphasis on process finds echoes in existing approaches to clinical decision-making such as values-based practice (VBP) (Loughlin, 2014). The authors of VBP argue that clinical decision-making ought to recognize the divergent values held by the different actors involved. While all actors bring values to the table, these may remain implicit or hidden unless a communicative process enables these to surface. Indeed, conflicts in clinical situations are often the result of conflicting, implicit values. Through a communicative process, values can be identified and debated with no preexisting preference for whose values should prevail as long as the resulting decision arose from respectful communication. VBP goes even

further than the CMQ in according greater ethical weight to process rather than outcome. A decision is good when it results from a fair hearing of the values of all parties regardless of the final outcome. On this view, a good MAID assessment process is inclusive of as many points of view and values as possible including those of the clinician. The appeal of such an approach is that it presents itself as value-neutral¹³ however, in so doing, it neither acknowledges substantive moral disagreement nor does it provide a means for handling it.

At this juncture, Zohar (2003) offers an interesting solution. He argues for "cooperation despite disagreement" which he believes is necessary in certain relational circumstances, the doctor-patient relationship being one. In his view, when doctor and patient disagree about the fundamental morality of an act (e.g. whether or not it is ethical to provide euthanasia in a certain circumstance), the doctor should strive to adopt the patient's moral viewpoint which may favor acting in accordance with the patient's request despite persistent moral disagreement. It is the doctor's responsibility to adopt the patient's point of view rather than the other way around because of the asymmetry of the relationship, specifically that the moral stakes may be higher for the patient than the doctor. However, Zohar as well as other authors (see for example Jecker, 1991), point out that this takes place in the context of an established therapeutic relationship. For Zohar the physician's duty to engage in relational perspective sharing is required when patients are already part of the doctor's "moral universe." This approach may not apply in the Canadian context in which large numbers of patients do not have established relationship with physicians and several provinces have adopted centralized, mobile MAID teams in which the clinicians and patients are not necessarily known to each other prior to the MAID request.

The therapeutic relationship and decision-making: experience from Switzerland and The Netherlands

Experiences of other countries offer insights into how physicians navigate the ethics of assessment and the extent to which the therapeutic relationship and the decision-making process serve as resources in support of ethical judgment in clinical practice.

The Swiss approach to assisted suicide predates the medicalization of the end of life. At the beginning of the 20th century, committees of experts proposed to change the Criminal Code article prohibiting assisted

suicide (Beldi, 2008, pp. 7–8). According to a report of the Federal Department of Justice and Police, the intention of the legislator was to avoid punishing persons assisting in suicide, “who are acting out of friendship, to preserve a person’s honor or in the sole interest of the person committing suicide. A close relationship must exist between the person providing the assistance and the person receiving it” (Swiss Confederation, 2009, p. 28 [our trans.]). However, the existence of a relationship is not a legal requirement.

Empirical studies of assisted suicide in Switzerland illustrate that an irreducible aspect to the assessment lies within the relationship between the requester and the assessor (physician and/or volunteer). Pott et al. (2014) note that requesters’ motivations must convince right-to-die societies’ volunteers regarding the irrevocability of the decision and the intensity of suffering (p. 75). In this issue, Hamarat et al. (2021) show, based on an ethnography of assisted suicide, that volunteers have a certain margin of appreciation in the interpretation of the right-to-die society’s criteria. Volunteers who entertain doubts for example, regarding the person’s determination, or the intolerance of suffering may refuse a request or withdraw from the process. Ideally, volunteers try to reach a consensus about the legitimacy of the request and the person’s determination to have an assisted suicide. One of the authors’ own ethnography of assisted suicide in Switzerland shows that some volunteers wait to feel that it is the right moment to proceed before agreeing to a request because it is “too early” for various reasons (Blouin, 2020).

Like the SAMS, the National Advisory Commission on Biomedical Ethics (NEC) recognizes the casuistic nature of assisted dying assessment and decision-making:

The assistance in question is always assistance for a given individual. Therefore, decisions on assisted suicide always have to be based on the individual situation of the person concerned. This decision is more than merely a case of applying certain criteria and rules. (NEC, 2005, p. 65)

Empirical research in the Dutch context has shown that considerations unrelated to legal criteria and their interpretation enter into play in the assessment process. For example, ten Cate et al. (2017) suggest that such considerations “stem from GPs’ views on what ‘good dying’ entails” (p. 6). Similarly, Norwood points out that physicians’ decisions to grant euthanasia request rely, intentionally or not, on certain “ideals” of a good doctor, a good patient, a good request and a good death (Norwood, 2006, p. 331). She also

stresses (2009) the cultural importance of “overleg” in the euthanasia process. This Dutch term means the elaboration of a consensus through consultation. Thus, in real practice in both Switzerland and the Netherlands the relational context and the conversations held within it are resources to guide action for those who are called upon to provide assistance in dying.

Van Tol et al. (2008) conclude that the ideals mentioned above become implicit codes which might serve to exclude patients who are unaware of them. Their point highlights the inevitable power dynamic at play when a person wants assistance in dying with the knowledge that the other person will determine whether or not s/he has access to it but is unaware of, or unable or unwilling to fulfill the role expected of them by the assessor (Gamondi et al., 2013, p. 1642). Assessors can also feel uncomfortable in addressing moral issues and in dealing with their own personal convictions regarding assistance in dying (Gamondi et al., 2013, p. 1642). Mutual understanding can thus be hampered. Given that assessors’ values do enter into the assessment process, how to ensure that their values do not unfairly act against the person requesting assistance? Or that assessors avoid what Ogien (2013, p. 359) calls “hermeneutical futility,” attempts at finding ideal or understandable reasons for the wish to die at the expense of potentially humiliating the patient?

Under the regimes we have discussed, a person’s decision to provide assistance in dying to someone who is requesting it is specific to the individual circumstances, is relationship-dependent, and is dialogic in nature. Such a decision-making process resists standardization and risks being nontransparent to requesters and to oversight bodies. However, mentoring and assessor training that considers the resources discussed in this section and that emphasizes self-awareness and reflection on personal values can facilitate sound and defensible judgments in difficult cases.

In Quebec, experienced MAID providers have taken to offering practitioners interested in working in this area the opportunity to observe and be observed in order to share knowledge and develop confidence. In addition, the government requires every healthcare institution to create a “Groupe Interdisciplinaire de Soutien (GIS),” a multidisciplinary committee which is responsible for offering administrative and clinical support to clinicians who receive MAID requests. GIS meetings can be used to share practical experiences, and give and receive feedback in complex cases. That said, each institution’s

GIS operates independently and has more or less involvement in clinical cases depending on the needs of clinicians in a given institution. However, a province-wide community of practice of the GIS (CP-GIS) has been created offering an online discussion forum, webinars and annual meetings that allows all GIS members as well as clinicians involved in MAID and researchers (with permission) to share ideas, and best practices. Elsewhere in Canada, the Canadian Association of MAID Assessors and Providers (CAMAP) offers similar opportunities to its members. These offerings favor the development of shared understandings of the practice of MAID and the assessment of requests and open up possibilities for mentoring.

Conclusions

In this paper, we have argued that a clinician's decision to offer assistance in dying to a specific person is fundamentally an ethical one. In cases in which legal criteria are unambiguously fulfilled, this ethical judgment may be relatively easy. But there are situations in which the ethical judgment can be more difficult. Regulatory and clinical guidance does not provide much direction as to how to make such judgments.

Despite differences in culture, politics, and assisted dying regimes, various jurisdictions and authors have concluded that certain practices may assist in making such judgments. These include having a relationship with a person who is requesting assistance and ensuring a fulsome communicative process in which all parties are heard, including significant others. Such observations may be useful to informing practice in newer jurisdictions such as Canada and Quebec. At a systems level, investing in processes that allow MAID assessments and decisions to take place in the context of established relationships may be preferable to the current situation in several provinces and territories in Canada in which doctor and patient are unknown to each other prior to the assessment. There are a variety of reasons for the current set-up including the size and concentration of the population relative to the country's vast territory; the newness of the practice leading to a relatively small number of MAID practitioners, and the significant number of people who do not have a primary care physician. Notwithstanding these issues, individual clinicians who provide assistance in dying (including those who only act as assessors) ought to be offered mentoring and training opportunities that support self-awareness and reflection on personal values. Both the theoretical

literature and international experience suggest that these steps may contribute toward defensible ethical judgments in difficult MAID assessments.

Notes

1. While both laws are valid and apply in the province of Quebec, in practice, Quebec physicians practice primarily in accordance with the Quebec law while also following certain procedural requirements of the federal law.
2. For the complete version of the criteria, see the Act (art. 26), and C-14 (art. 241.2(1)(2)); In the case of *Truchon c. Procureur général du Canada* (Cour supérieure du Québec, 2019), the Quebec Superior Court determined that these two criteria were also a violation of rights guaranteed by the Canadian Charter of Rights and Freedoms. The court suspended the finding of invalidity for six months and then granted three extensions on the suspension totalling eleven months. Both federal and provincial governments have stated they will not appeal the decision. This article was written before this judgment took effect.
3. The others include Switzerland, the Netherlands, Belgium, Luxembourg, Colombia, and the states of Oregon, Washington, Montana, Vermont and California in the USA. At the time of this writing (January 2020), Colorado, the District of Columbia, Hawaii, New Jersey and Maine as well as the state of Victoria in Australia had followed suit.
4. By 'ethics' we mean the moral judgments practitioners make routinely in their clinical work which articulates with, but is not uniquely defined by, formal rules and institutional ethics. Frank refers to this as 'everyday ethics' (Frank, 2016).
5. Capacity and voluntariness may also pose challenges in assessment and invite similar questions about whether it is ethically right to provide assistance in dying for specific individuals, particularly those for whom mental disorder is the sole medical basis of the request.
6. The Canadian law explicitly states that the medical condition must be the cause of suffering. The Quebec Act merely states that these two characteristics are contemporaneous but the regulatory guidance states that there ought to be a causal relationship between the condition and the suffering (see for example Collège des Médecins du Québec [CMQ, et al.], 2018, p. 20).
7. The most recent version of the guide also includes the professional order of social work, the Quebec bar and the Notaries' society.
8. Information for this paragraph is drawn from Emanuel et al. (2016).
9. See the *Review Procedures in Practice* that explains how the Regional Euthanasia Review Committees interpret the due care criteria (RTE, 2018). There is also the SCEN network of trained consulting

physicians that are available for support, information and formal consultation.

10. In a given case, the physician who evaluates the written documents sent to EXIT is not necessarily the person who prescribes the lethal substance.
11. Courts have interpreted that 'due diligence' implies adhering to the SAMS guidelines. Before the SAMS changed its guidelines to drop the end-of-life criterion, physicians had to comply with the guidelines only in those cases in which the patient was at the end of life as the guidelines were made for those cases. In other cases, physicians had to follow the general legal framework.
12. SAMS is a funding institution that promotes research in medical sciences and relationships between science and society. For the full list of criteria, see SAMS (2018, p. 23).
13. Although the value-neutrality of VBP has been itself debated (see Hutchinson & Read, 2014).

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