



**Exploring the psychological suffering of a person
requesting medical assistance in dying**

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Preface

An *Act respecting end of life care* (CQLR, c. S-32.0001) (hereafter, the Act) came into force on December 10, 2015 and legalized medical assistance in dying (hereafter, MAID) for the first time in Québec. While the Act was the result of several years of political debate and public consultation, the introduction of MAID into clinical practice has given rise to numerous questions. Among these includes the requirement that to be eligible to receive MAID, a person has to experience constant and intolerable physical or psychological suffering. What is psychological suffering exactly? How can we determine if it is intolerable? The introduction of the Act offers members of the medical profession the opportunity to reflect collectively on these complex issues.

This document is the product of a spontaneous collaboration between the Collège des médecins du Québec (CMQ) and our research group at the CHUM. We wanted to participate in the dialogue about MAID by offering a psychiatric perspective to our colleagues in other areas of practice. This project is but a first attempt to face the difficult questions that surround the evaluation of psychological suffering. We recognize that this discussion will be ongoing as the understanding of these issues evolves with time and experience. We hope that this will be the first in a series of conversations on the provision of MAID that draws on the best of our knowledge and abilities as physicians, with a focus on serving the public interest.



Introduction

The Act defines MAID as a healthcare intervention “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 does not include assisted suicide, contrary to the definition adopted in the federal law, namely, the *Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (S.C. 2016, c. 3), hereafter C-14, which entered into force on June 17, 2016 and also applies in Québec. This document only discusses MAID as it is defined in the Act.¹

According to the Act, a person may receive MAID if she fulfills six criteria. One of these criteria is the requirement that the person experiences “constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable” (art. 26 (6)). A similar criterion appears in C-14: “that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable” (art. 241.2(2)c).

Determining whether a person fulfills this criterion can be difficult. Suffering, particularly psychological suffering, may seem less familiar to physicians than a symptom like pain. Nevertheless, physicians are required to determine whether psychological suffering is present and whether it is constant and unbearable. This document aims to provide physicians in Québec with the tools they need to assess these aspects in patients who request MAID.

This document includes three sections. The first offers a definition of each key term related to the suffering criterion found in the Act. The second provides a brief discussion on the way in which the suffering of another person can be assessed. The third addresses psychological suffering from a clinical perspective, as well as the psychosocial and psychiatric conditions one might find amongst patients requesting MAID.

The analysis presented in this document represents the culmination of research based on a variety of sources. We conducted a systematic search of articles related to the concept of suffering, as well as articles dealing with the psychiatric and psychosocial conditions likely to be found amongst persons at end of life and/or persons wishing a hastened death.² Our team selected, discussed, and critically reviewed these articles between January and December 2016. We developed our analysis further by reviewing the judicial decisions arising from the constitutional exemption provided for by the Supreme Court of Canada in the Carter case (2015), provincial and federal parliamentary debates concerning the proposed laws (Bills 52 and C-14), as well as several reports, discussion papers, and position statements. We

¹ The definition of MAID provided in the Act corresponds to what is also referred to as euthanasia.

² We searched the MEDLINE, PubMed, CINAHL and PsychInfo databases using the following keywords: physician-assisted dying, medical aid in dying, assisted suicide, euthanasia, suffering, burden, capacity, psychiatry and demoralization.



presented our work to various audiences at different stages of the project, which allowed us to solicit feedback and refine our analysis.³

A list of works cited and a recommended reading list can be found at the end of this document for readers who wish to consult the original sources or pursue certain topics in greater depth.

³ Memorial University Hospital of Newfoundland on March 11, 2016; the CHUM Department of Psychiatry on April 11, 2016; Centre hospitalier régional de Lanaudière April 15, 2016; the Executive Committee of the Association québécoise pour le droit de mourir dans la dignité on April 8, 2016 and its General Assembly on May 7, 2016; a joint meeting of the Collège des médecins du Québec (CMQ), the Ordre des infirmières et des infirmiers du Québec (OIIQ) and the Ordre des pharmaciens du Québec (OPQ) on October 17, 2016; and the Communauté de pratique des Groupes interdisciplinaires de soutien (GIS) on November 22, 2016.



1. What is constant and unbearable psychological suffering as defined in the Act?⁴

Suffering

There are several definitions of suffering in the medical literature and their commonalities can help physicians understand what it means to suffer (Cassel, 1991, 24; Dees, Vernooij-Dassen, Dekkers & van Weel, 2010; Svenaeus, 2014, 418-9). Suffering is not a symptom like pain or fear. It results from the meaning a person gives to her experience. Suffering occurs when a person interprets her experience as a threat to her integrity. A person has many dimensions such as her values, roles, relationships and life course. A person's existence is defined in terms of time, since it includes a past, a present and a future. Suffering consists of a person's interpretation of her situation in relation to these different elements.

Psychological

In the Act, the explicit use of the terms "physical" and "psychological" to describe suffering reminds physicians that suffering is not limited to physical symptoms. The legislator chose the term "psychological" to designate any experiences that are unrelated to the body (e.g. psychological, existential, social, etc.) (P. Sévigny personal communication, 23 March 2016). However, suffering is not something that can be easily subdivided into distinct categories (Svenaeus, 2014, 411). In fact, the different aspects of suffering influence each other. For example, a physical symptom such as pain can become unbearable if a person believes that it will not diminish and if she is afraid that it will worsen. In such cases, suffering presents both physical (pain) and psychological (beliefs, fear) aspects. When one evaluates a person's suffering, it is important to consider it as a whole.

Constant

Interpreted literally, the term "constant" suggests that intolerable suffering is present at every second. This would create a criterion that is impossible to fulfill as even at their sickest, patients can have moments of peace when surrounded by loved ones or when their medications have periods of optimal effect. Instead, for clinicians, the term "constant" designates suffering that is persistent with little or no possibility of improvement.

⁴ There are certain differences in the wording of the eligibility criterion related to suffering in the Act and C-14 in French, but not in English. First, C-14 uses the term "souffrance psychologique", while the Act refers to "souffrance psychique". The term "psychique" is broader than the term "psychologique", which refers to the study of psychological phenomena without taking into account existential, social, spiritual or other phenomena. Second, C-14 uses the term "persistent" to qualify the suffering, while the term "constant" is used in the Act. Third, C-14 refers to "intolerable" suffering and the Act to "unbearable" suffering. We consider these two terms to be synonymous.



Unbearable

Unbearability is associated with a loss of hope that a person's situation will improve, along with progressive decline (Dees et al., 2011). It implies that the existing solutions have little chance of relieving the person's suffering and that this suffering will last for as long as the person is alive.



2. The suffering of others

2.1 Can we really evaluate another person's suffering?

Suffering is not purely subjective in the sense of being entirely private (Wijsbek, 2012). It goes without saying that a person has direct access to her own experience that others cannot have. However, one can have partial access to another person's suffering. For example, we are generally aware when our loved ones suffer even if they do not tell us directly because we know them intimately as persons. Similarly, in order to gain access to a patient's suffering, the clinician must understand the person as a whole and take into account her values, roles, the nature of her relationships, and her life course. This approach represents an *intersubjective* exploration of suffering. The more a clinician and a patient share similar life experiences, the easier it will be for the clinician to understand the patient, and thus her suffering. Of course, it is possible for a physician and a patient from different backgrounds to understand each other, but the challenge is greater (Kahn & Steeves, 1986, 629).

At the same time, suffering is not objective in the sense that it is generalizable to other patients in similar disease states. Nor is suffering objective in the sense of being operator-independent, that is, that the conclusions of the evaluation will be the same regardless of the evaluator. Because all clinicians do not share the same values and experiences, their interpretations of patients' experiences may vary. Variation does not mean that the process of evaluating a patient's request for MAID is invalid. It simply reflects the fact that in matters of human understanding, we cannot achieve complete agreement. In light of these considerations, the physician's task is better understood as an exploration of the patient's suffering, rather than an evaluation.

How can a physician determine whether a person fulfills the eligibility criterion of psychological suffering? The patient's own account is essential. The observations of those around her (family, friends, healthcare providers) can also prove invaluable. After taking into account these different perspectives, the overall clinical picture, and the eligibility criteria, the physician should be able to determine whether MAID represents an appropriate intervention and one that is permitted under the Act.

2.2 Should we explore the suffering of a person requesting MAID?

The Act and C-14 require that two independent physicians determine whether a patient requesting MAID fulfills the eligibility criteria. According to the Act, it seems that the patient's affirmation of unbearable suffering by itself is not necessarily sufficient to fulfill this criterion (National Assembly of Québec, December 2, 2013). This means that it must be possible to conclude that a patient does not fulfill this criterion (National Assembly of Québec, 3 December 2013). The wording of the suffering criterion in C-14 establishes a purely subjective standard when it comes to suffering.⁵ We believe that an intersubjective exploration of

⁵ The Act mentions that "[the person] experiences constant, unbearable physical or psychological suffering [...]"



suffering represents good clinical practice in that it corresponds to the usual and expected role of the physician, and also reflects the reality of the therapeutic relationship. In fact, society regularly calls upon physicians to make judgments about their patients' states, for example when they must determine whether a person should receive certain benefits, services, or healthcare interventions. However, these determinations do not invalidate people's experiences.⁶

Before they can provide MAID, physicians must inevitably call upon their clinical judgment in determining whether a person's suffering is unbearable and constant. Under what circumstances might a physician have doubts as to whether the suffering criterion has been fulfilled by a person requesting MAID? Imagine a lonely, elderly woman at the end of life who requests MAID because the death of her dog, her only companion, causes her intolerable psychological suffering (Wijsbek, 2012, 331). While a physician would be moved by this woman's suffering, she would have to conclude that her suffering is not related to a medical condition.

The eligibility criteria contained within the Act do not address directly the issue of the relationship between the patient's suffering and the medical condition, whereas this relationship is made explicit in C-14. In their jointly published practice guide for MAID, the CMQ, OPQ and OIIQ take this relationship as a given (2015, 14 and 23) otherwise, determining eligibility for MAID would not fall within the competence of physicians. But even if such a relationship must exist in order to satisfy the eligibility requirements for MAID, we think that the relationship between suffering and the medical condition does not have to be direct. This relationship can be indirect, that is, based on the overall impact of the medical condition on the person's life (e.g. complete physical dependence). As suggested in section 1, suffering is an interpretation of experience, not a sum of symptoms.

There could also be good reasons to determine that a person's suffering, and thus her reason for requesting MAID, do not correspond to the objectives of the Act. Take, for example, a patient who was abandoned by her parents when she was a child and has always believed she is worthless and undeserving of love. At the end of her life, she requests MAID because it causes her intolerable psychological suffering that limited healthcare resources will be wasted on keeping her alive. She believes that she deserves to die and consequently, she refuses other treatments offered to her. Or what about the patient who, at the end of her life, feels angry and hurt by the fact that her adult children have not visited her in hospital? Their absence, and her deteriorating condition, cause her intolerable psychological suffering. She refuses any intervention likely to facilitate a final visit because she does not want to 'beg' them to come. She requests MAID in order to 'make them pay' for their behaviour. In such cases, the physician should take the time necessary to re-assess the patient and continue to

(art. 26, (6)). This wording opens the possibility for an intersubjective exploration of suffering, in which the patient and the physician both participate, with the aim of determining whether this condition is met. C-14, on the other hand, refers to suffering that is "intolerable to the patient", thus establishing a purely subjective standard.

⁶ Nor does this amount to saying that physicians have a unilateral power of decision when it comes to healthcare (*Cuthbertson v. Rasouli, Golubchuk v. Salvation Army Grace General Hospital*).



offer therapeutic interventions likely to relieve or reduce her suffering. Despite these efforts, it remains possible that the physician will conclude that the request for MAID does not fulfill the criterion of intolerable psychological suffering.



3. Clinical considerations

To date there is no consensus about how to explore or assess psychological suffering of a patient at end of life within the context of a request for MAID.⁷ Nevertheless, certain general principles can guide physicians in their clinical practice.

GENERAL PRINCIPLES:

- In general, talking with patients at the end of life about dying or their understanding of death does not increase their distress. On the contrary, this allows patients to feel better understood and heard, and allows physicians to better understand their patients.
- A physician who is aware of her own values and attitudes with respect to suffering, the final phase of life, and death is less likely to be unduly influenced by her assumptions and to project her preferences on to the patient's experience. For example, a physician who is convinced that suffering at end of life is an opportunity for a final phase of personal growth might not be able to understand that for certain patients suffering is degrading. Being aware that her own personal convictions represent but one possibility among others offers the physician the opportunity for greater understanding of her patient.
- Empathy towards patients in end-of-life situations can lead healthcare personnel to experience and to act on a "feeling of urgency" to relieve a patient's suffering. Because of her unbearable suffering, the patient herself hopes to receive a response to her request as soon as possible. The fact remains that MAID is not usually considered an emergency procedure and that the physician must take the time to undertake a complete assessment in collaboration with the interdisciplinary team when possible.
- Even after having submitted a formal request for MAID a patient may be ambivalent or express doubts. In such a case, it is important that the physician take the time to understand the reason behind the patient's hesitation, answer her questions, and give her time to think about it.
- A request for MAID may be the expression of a disagreement with the proposed treatment plan or a refusal of certain treatments. The physician should review the plan with the patient and re-initiate discussion about her preferences.

⁷ Only persons at "end of life" can have access to MAID under the Act, whereas persons whose deaths are "reasonably foreseeable" can avail themselves of MAID under C-14.



3.1 Psychological suffering amongst patients at the end of life

The majority of patients grappling with an incurable and terminal disease will face the end of life without asking for assistance and without experiencing overwhelming distress (Gagnon & Rivest, 2016). Nevertheless, some will experience temporary moments of distress, persistent psychological suffering, or even psychiatric symptoms or disorders (see next section). Clinically, persistent suffering of a psychological nature at end of life can include:

- psychological (e.g. fear of experiencing unbearable suffering at end of life, feeling alone, grief reactions);
- social (e.g. social isolation, witnessing the exhaustion of loved ones dealing with the illness);
- existential (e.g. loss of dignity, search for meaning in the experience of the disease, freedom of choice versus the loss of control, anticipation of death);
- spiritual or religious (e.g. spiritual distress; questioning one’s belief in the afterlife, religious faith, or the existence of God)

(Werth et al., 2002; Baarsen, 2009; Kübler-Ross, 1981 [1977]; Robinson et al., 2016; Breitbart et al., 2000; Chochinov et al., 2005; Chochinov et al., 2007; Wilson et al., 2005; Vachon, 2009; Kissane, 2012; LeMay & Wilson, 2008).

NOTE:

- Not all patients at the end of life suffer during the terminal phase of their disease and not all will ask for help. The transition from curative treatment to palliative care nevertheless represents a period of vulnerability in which distress can be intense, even if it is usually temporary.
- By definition, suffering is comprehensive, multidimensional (Monforte-Royo et al., 2012) and indivisible. As a result, it is usually unnecessary in practice to distinguish psychological from physical suffering, nor is it necessary to categorize or subdivide suffering.

3.2 Psychosocial characteristics and psychiatric disorders present in patients requesting MAID

Certain psychosocial characteristics occur frequently amongst patients suffering from a serious illness who wish to see their deaths hastened. These include a low level of religiosity, a feeling of hopelessness, reduction in functioning, higher levels of distress, as well as a fear of seeing the suffering worsen or one’s condition deteriorate (Villavicencio-Chávez et al., 2014; Monforte-Royo et al., 2012; Monforte-Royo et al., 2011).



NOTE:

- Preoccupations with the meaning of life are frequent at end of life, but existential distress is not. The latter can be associated with poor quality of life, depression or anxiety, as well as a wish for a hastened death (LeMay & Wilson, 2008; Kissane, 2012).

In other jurisdictions, depression is one of the most frequent psychiatric problems (8 to 47%) amongst patients who request euthanasia or assisted suicide (Wilson et al., 2007; Breitbart, 2000; Kelly et al., 2004).⁸ It is important to remember that a patient at the end of life who requests MAID could have a psychiatric disorder (see table 1 for an inventory of the most common presentations in this population). These problems remain under-identified and under-treated by healthcare teams (Irwin, 2008a, 2008b). Insomnia has also been associated with requests to see one's death hastened (Ruijs, 2012).

Table 1: Prevalence of the most frequently occurring psychiatric problems at the end of life⁹

Psychiatric disorder	Prevalence amongst patients at the end of life
Delirium	Up to 80%
Anxiety	10 to 30%
Depression	5 to 26%

The physician, in collaboration with the interdisciplinary team, should offer all therapeutic interventions likely to reduce or ease a patient's suffering at the end of life, whether she persists in her request for MAID or not. There are various therapeutic interventions (pharmacological, psychosocial or spiritual) that can be effective in treating psychiatric disorders or improving quality of life.

⁸ At present, there is little data on the prevalence of psychiatric disorders specific to patients at the end of life who request MAID. We describe data on the prevalence of psychiatric disorders present in those who request euthanasia or assisted suicide, but these do not necessarily correspond to the clinical population requesting MAID.

⁹ These figures represent data for patients at the end of life but not necessarily having requested euthanasia or assisted suicide whereas those cited in the preceding paragraph are specific to patients who requested euthanasia or assisted suicide and are not necessarily at the end of life.



Some key concepts concerning psychiatric disorders at end of life:

- We estimate that in at least 50% of cases of delirium at the end of life, the condition is reversible or likely to improve (Gagnon & Rivest, 2016).
- Depression is treatable (pharmacologically or psychotherapeutically), even at the end of life.
- The presence of a psychiatric disorder at end of life will only rarely alter the patient's capacity to consent to MAID (Soliman & Hall, 2015).
- Patients suffering from cognitive impairments, whether they are temporary (e.g. delirium) or permanent (e.g. cognitive impairment arising from a vascular cause), can also request that their deaths be hastened (Draper, 2015; Tomlinson et al., 2015). In these cases, the physician will need to pay particular attention to the patient's capacity to consent.

3.3 Suicidal ideation and requests for MAID

Clinicians may wonder whether a patient who requests MAID is suicidal. A request for MAID and suicidal ideation have certain differences that usually allow clinicians to distinguish between them.

Table 2: Comparison between a request for MAID and suicidal ideation

	Request for MAID	Suicidal ideation
Principal characteristic	A considered desire to see one's death hastened in order to relieve suffering caused by an illness	A desire to end one's life that is generally caused by a mental health problem or that occurs in the context of a difficult life situation
Association with a mental health problem?	Sometimes	Almost always
Recommended response	The MAID assessment and decision-making process (as laid out in the Act)	Risk assessment and the adoption of protective measures if appropriate

However, in certain circumstances, a patient requesting MAID may also present suicidal ideation. Here are a few examples:

- The request for MAID masks a wish to commit suicide;
- Suicidal gestures or ideation are a means by which to negotiate with the healthcare team to obtain MAID or other interventions;



- Suicide constitutes the only solution for a person who is ineligible for MAID but wishes for a hastened death.

In the presence of clear suicidal ideation, the level of risk must be completely evaluated by a qualified professional and protective measures put in place if needed. A mental health problem should be suspected in any patient expressing suicidal ideation.

3.4 The relationship between suffering and decision-making capacity

When assessing a request for MAID, physicians must ensure that the patient has decision-making capacity. They must ensure that patients receiving MAID have clearly expressed informed choices free from any form of coercion or exploitation.

A capable patient must be able to understand and remember the information provided by the physician, including the risks and benefits of the intervention proposed. In order to make an informed decision, the patient must be able to apply the information received to her own situation (*Starson v. Swayze*).

A patient's suffering can impair her ability to consent to MAID. For example, a patient grappling with treatment-resistant depression could experience a level of distress such that her ability to pay close attention or remember the information provided could be limited. These difficulties reflect a compromise of her cognitive functions. A deeply anxious patient at end of life could develop an unrealistic fear of symptoms that are unlikely to appear and request MAID to prevent them. This person would have difficulty applying the information related to her condition to her own situation.

3.5 When is a psychiatric consultation indicated?

In certain complex situations, or ones that require more in-depth assessment, the physician may seek the opinion of a psychiatrist in order to:

- Ensure that the patient is capable of consenting to MAID (e.g. in situations of ambivalence or repeated doubts, signs of mental health problems, etc.);
- Evaluate the patient's mental state and/or advise the healthcare team on certain types of interventions to offer (psychosocial, spiritual or pharmacotherapy);
- Estimate suicide risk;
- Assist, while working collaboratively with the team, in resolving an impasse in the relationship between the patient, her family and her healthcare providers (Roy-Desruisseaux et al., 2015; Lyness, 2004; Gagnon & Rivest, 2016).



3.6 Summary

In the presence of psychological suffering, the physician and patient must:

- Take the time to proceed with a complete assessment of the patient's mental state;
- Explore the reasons behind the patient's request, her values, preferences, end of life care options, and her psychosocial or spiritual needs;
- Review what interventions have been tried to alleviate suffering and offer untried interventions, including interventions provided by other physicians or health care providers;
- Evaluate whether suffering impairs decision-making capacity.



Conclusion

The exploration of psychological suffering presents healthcare professionals with clinical, ethical and personal challenges. In each case of a request for MAID, the physician must be able to explore the patient's suffering and attempt to relieve it, whether or not the patient persists in her wish to receive MAID and whether or not she is deemed to be eligible.

First and foremost, exploring the suffering of a patient requesting MAID requires active listening. The physician must also develop a relationship with the patient that allows her to understand the reasons behind the request. Although the physician plays a central role, this intersubjective assessment will be enhanced by the input of the interdisciplinary team, whose members may appreciate other aspects of a person's suffering and propose additional therapeutic interventions.



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