Quebec's *Act Respecting End of Life Care*

Reportable and non-reportable euthanasia

Sean Murphy, Administrator,
Protection of Conscience Project

Protection of Conscience Project
www.consciencelaws.org

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Introduction

Quebec's euthanasia law, the *Act Regarding End of Life Care* (ARELC), permits two kinds of euthanasia, distinguished here as reportable and non-reportable euthanasia.

Reportable euthanasia is identified as "medical aid in dying" in ARELC.[1] Only physicians may administer a lethal substance, and only to a legally competent person who is at least 18 years old, meets other criteria and personally gives informed consent. Physicians must conform to procedural guidelines and reporting requirements. Most people probably believe that this is the only type of euthanasia authorized by the law.

Non-reportable euthanasia is not explicitly identified in the law, but is permitted for legally incompetent patients (including those under 14 years old) who are not dying. Substitute decision makers acting under the authority of Quebec's *Civil Code*[2] can order them to be starved and dehydrated to death. There are no procedural guidelines, no reporting requirements, and it appears that the order can be carried out by anyone responsible for patient care.[3] All of this was incorporated into ARELC by a revision of the original text.

Note that section 50, the protection of conscience provision in ARELC for health care professionals, pertains ONLY to reportable euthanasia. The *Act* does not recognize the possibility of conscientious objection by health care professionals unwilling to participate in euthanasia by starvation and dehydration.

Enabling provisions in the law

Section 5 of ARELC (2014) was Section 6 in the original Bill 52 (2013). The original text stated that a competent adult could "refuse to receive, or withdraw consent to, a life-sustaining treatment or procedure." This introduced nothing new; it merely codified an existing right. Equally important, even if refusal of treatment or care by a competent patient led to his death, the law has never considered this euthanasia or assisted suicide.

However, two modifications were made to what is now Section 5 of ARELC when the bill was reintroduced in 2014:

- First: the original phrase "life-sustaining treatment or procedure" was replaced by "life-sustaining care." The latter term more readily

encompasses food and fluids in any form.

- Second: ARELC now provides that life-sustaining care (i.e., including food and fluids) can be refused on behalf of or withdrawn from an incompetent patient by a substitute medical decision-maker. The change permits a substitute decision-maker to direct that an incompetent patient who is neither terminally ill nor dying be starved and dehydrated to death.[4]

Ordering end to spoon feeding

The change from treatment to care and statutory authorization of a substitute decision maker to stop the provision of food and fluids may have been prompted by a British Columbia case that made the news in late 2013. Family members wanted caregivers to stop spoonfeeding an 82 year old nursing home resident with advanced dementia. She was not terminally ill, nor was she dying. The nursing home was unwilling to stop feeding her, so the family sought a court order to put and end to it. In February, 2014, the court ruled in favour of the nursing home.[5]

Among other things, the judge ruled that spoon-feeding was not "health care" within the meaning of the law, but a form of personal care. While he agreed that, under the common law, a competent adult could refuse food and fluids and thus commit suicide, he found no legal precedent to justify such a decision by a substitute decision maker acting for an incompetent person. On the other hand, he recognized that his conclusions could be affected by public policy or statute. However, the authority that the judge could not find in common law was supplied in Quebec when section 6 of Bill 52 was revised and became section 5 of ARELC.

Quebec legislators warned

ARELC: "terminal palliative sedation"

Professor Jocelyn Downie of Dalhousie University recognized this issue when reviewing the original Bill 52 with Quebec legislators in the fall of 2013. She questioned the novel term “terminal palliative sedation.”[6] It appears that the Quebec government used the term because it could be understood to mean terminating the life of the patient, but “terminal palliative sedation” was undefined in the bill and generated a good deal of confusion and comment during the committee hearings.

Continuous palliative sedation in palliative care

Sedation of patients “to relieve refractory symptom(s) that have not responded to other treatments during the last hours to days of life” may be used to induce “a reduced level of consciousness.”[7] This procedure — “continuous palliative sedation” or “continuous palliative sedation therapy (CPS or CPST) is normally considered only when death is imminent, clinically defined as "'dying' or 'being in the last stages of life,'" typically understood to mean a projected remaining lifespan of "hours or days, or at most less than two weeks."[8] As death approaches, oral intake of food and fluid naturally diminishes. By the time CPS is usually considered, oral intake is minimal for most patients, and artificial nutrition and hydration are not normally provided because they “are considered burdensome and offer minimal benefits.”[9] CPS provided according to these protocols does not cause or hasten

death. On the contrary, patients who receive CPS may live longer with fewer symptoms than those who do not.[10]

Professor Downie told legislators if that was what was meant by "terminal palliative sedation" the bill should say so. Thus defined, it would be considered part of regular palliative practice, not associated with euthanasia and could be managed within the usual framework of informed consent.

> . . . where death is imminent, and you define it as within ... within the amount of time that the actual ... the withholding, withdrawal of the hydration, nutrition isn't going to play any kind of a causal role in death, so, you know, within a couple of days, even up to two weeks, then it just simply is on a basis of informed consent, because that's just a kind of treatment, it's not causing death in any way, it's not contributing to death, so it should be informed consent.[11]

ARELC: "terminal palliative sedation" and euthanasia

On the other hand, she explained, if, by "terminal palliative sedation," they meant withdrawal of nutrition and hydration under deep sedation when death is not imminent — certainly more than two weeks before in advance of expected death — "it is causing the death in a very direct and obvious way."[12] In that case, the procedure should be considered euthanasia (she used the bill's term, "medical aid in dying").[13] She supported both lethal injection and death by starvation and dehydration as legitimate options,[14] at least in the case of competent patients, or when authorized by an advance directive made by a patient before becoming incompetent.[15]

However, she warned legislators that withdrawing nutrition and hydration from patients not imminently dying should be clearly identified as a specific category of "medical aid in dying" (euthanasia) and controlled by guidelines and reporting requirements. Otherwise, she said, "You will be setting up a situation where somebody could access terminal palliative sedation when they're not expected to die for five months and not meet your conditions of medical aid in dying."[16]

Warning ignored

Professor Downie's advice was ignored. "Terminal palliative sedation" was replaced in ARELC by "continuous palliative sedation," defined as "administering medications or substances to an end-of-life patient to relieve their suffering by rendering them unconscious without interruption until death ensues."[17]

ARELC vs. palliative care protocols

When compared to recommended palliative care practice, ARELC's definition of continuous palliative sedation is problematic. When CPS is applied in palliative care the goal is not to render the patient unconscious, but to provide sufficient sedation to alleviate the symptoms:

> The aim or intention of CPST is the relief of suffering due to refractory and intolerable symptoms and not the sedation itself. There should be no intention to shorten life and no intention to bring about complete loss of consciousness although this latter may sometimes be necessary. The level of consciousness is lowered only as far as is necessary to relieve the suffering. Thus . . . the combination and amount of

> drug used to reduce the level of consciousness should be just sufficient to alleviate distress. Viewing the actual sedation as the desired outcome is inappropriate.[18]
>
> Although CPST may be associated with a deep level of sedation, some patients may find relief of their intractable symptom(s) at a light or moderate level of sedation. The aim is to use the lowest dose of medication that achieves this goal. In some patients, symptom(s) relief may be achieved at a light level of sedation with small doses of medication. In others, comfort can only be achieved at a deeper level of sedation with higher doses of medication. Titration of the dose to achieve the goal is therefore essential.[19]

In contrast, ARELC

- defines CPS as deliberately rendering patients unconscious until death;
- requires that a patient or substitute decision maker be advised of "the irreversible nature of the sedation,"[20]
    - so "irreversibility" is characteristic of the procedure as defined in ARELC
        - though CPS is not irreversible by nature;
- imposes reporting requirements for CPS almost identical to the reporting requirements for euthanasia.[21]

Since death by starvation and dehydration would be a painful process, it is likely that, in such circumstances, what ARELC defines as continuous palliative sedation (CPS) would be used to render the patient unconscious. ARELC's provisions for CPS support the thesis that Quebec's euthanasia law authorizes two different kinds of euthanasia: reportable euthanasia by lethal injection, and unreportable euthanasia by starvation and dehydration.

Notes

1. *Act Respecting End of Life Care*, RSQ c S-32.0001, s 3(6), online: <http://legisquebec.gouv.qc.ca/en/showdoc/cs/S-32.0001> [*ARELC*].

2. *Civil Code of Quebec*, RSQ c CCQ-1991, art 11– 25, online: <http://legisquebec.gouv.qc.ca/en/pdf/cs/CCQ-1991.pdf#page=32>.

3. *ARELC*, *supra* note 1, s 5.

4. Sean Murphy, "Quebec Bill 52, An Act Respecting End-of-Life Care: Original text and text as passed by the Quebec National Assembly" (3 November, 2014), Protection Conscience Project (website), online: <http://www.consciencelaws.org/background/procedures/assist009-041.aspx#005>.

5. *Bentley v. Maplewood Seniors Care Society,* 2014 BCSC 165, online: <http://www.courts.gov.bc.ca/jdb-txt/SC/14/01/2014BCSC0165.htm>.

6. Quebec, Assemblée Nationale, la Commission permanente de la santé et des services sociaux, "Consultations particulières sur le projet de loi n° 52 - Loi concemant les soins de fin de vie (12), in *Journal des débats* , CSSS-45 (9 October 2013) at 8, para 6 (Jocelyn Downie). online: <http://www.assnat.qc.ca/Media/Process.aspx?MediaId=ANQ.Vigie.Bll.DocumentGenerique_83245&process=Original&token=ZyMoxNwUn8ikQ+TRKYwPCjWrKwg+vIv9rjij7p3xLGTZDmLVSmJLoqe/vG7/YWzz> [*CSSS*].

7. "Continuous Palliative Sedation Therapy (CPST) Guidelines" Division of Palliative Care, Dept. of Family Medicine, McMaster University (31 March, 2020) at 4, online: <https://fhs.mcmaster.ca/palliativecare/documents/McMasterPalliativeSedationGuidelines202031March2020.pdf> [*McMaster*].

8. MM Dean *et al*, "Framework for continuous palliative sedation therapy in Canada" (2012) 15(8) J Palliat Med. 870-9 at 9, online: <http://www.cspcp.ca/wp-content/uploads/2014/06/Canadian_CPST_Framework_16-June-2011.pdf> [*Dean et al*].

9. *McMaster*, *supra* note 7 at 7.

10. *McMaster*, *supra* note at 4.

11. *CSSS*, *supra* note 6 at 12, para beginning, "Yes, I think I would recommend" (Jocelyn Downie).

12. *Ibid* at 12, paragraph beginning, "The one thing I would say is" (Jocelyn Downie).

13. *Ibid* at 12, last paragraph (Jocelyn Downie).

14. *Ibid* at 13, paragraph beginning, "So I would just try and frame" (Jocelyn Downie).

15. *Ibid* at 11, last paragraph (Jocelyn Downie).

16. *Ibid* at 13, para 1 (Jocelyn Downie).

17. *ARELC*, *supra* note 1, s3(5).

18. *Dean et al*, *supra* note 7 at 6.

19. *McMaster*, *supra* note at 4.

20. *ARELC*, *supra* note 1, s24.

21. *Ibid*, s8, 34–37, 46.