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Nurses' perspectives on whether medical aid in dying should be accessible to incompetent patients with dementia: findings from a survey conducted in Quebec, Canada

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ABSTRACT

We conducted a survey in a random sample of 514 Quebec nurses caring for the elderly to assess their attitudes towards extending medical aid in dying to incompetent patients and to explore associated factors. Attitudes were measured using clinical vignettes featuring a hypothetical patient with Alzheimer disease. Vignettes varied according to the stage of the disease (advanced or terminal) and the presence or absence of a written request. Of the 291 respondents, 83.5% agreed with the current legislation that allows physicians to administer aid in dying to competent patients who are at the end of life and suffer unbearably. A similar proportion (83%, $p = 0.871$) were in favor of extending medical aid in dying to incompetent patients who are at the terminal stage of Alzheimer disease, show signs of distress, and have made a written request before losing capacity.

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Introduction

Whether euthanasia should be accessible to patients in exceptional circumstances is an emotionally charged issue that raises heated societal and ethical debates in many countries.^{1,2} In the scientific literature, euthanasia is usually defined as the administration of drugs with the explicit intention of ending the patient's life at his or her explicit request.³ Euthanasia is legal in a few jurisdictions, including the Canadian province of Quebec since the coming into force of the *Act respecting end-of-life care* on December 10, 2015.⁴ Referred to in the *Act* as "medical aid in dying" (MAiD), this option is currently available to competent adults from Quebec, who are

at the end of life, have made persistent explicit requests for MAiD, and have a serious and incurable illness, are in an advanced state of irreversible decline in capability, and suffer unbearably (art. 26). Patients who are no longer competent to make decisions cannot access MAiD through an advance request written while they were still competent (art. 51). However, in March 2017, the Quebec Minister of Health and Social Services announced that a group of experts would be tasked with reflecting on whether MAiD should be extended to incompetent patients who made an explicit request before losing capacity.⁵ The Minister made the decision to explore this issue after a man was charged with murder in the death of his 60-year-old wife with advanced dementia whose family's request for MAiD had been denied.⁶

Many nurses are confronted daily with the complexity of end-of-life care, which may include assistance-in-dying requests regardless of their legal status.⁷⁻¹⁰ Nurses are often the first health-care professional to whom patients express – implicitly or explicitly – a desire to hasten their death.^{7,11-14} Nurses may then undertake

Abbreviation: MAiD, Medical Aid in Dying

Conflicts of interest: None.

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a variety of tasks, including: talking with patients to uncover the reasons behind their request; informing patients about legal requirements, procedures, and institutional policies regarding assistance in dying; discussing alternative means to relieve patient suffering, including continuous deep sedation; participating in the decision-making process; preparing the administration of euthanasic drugs when the decision has been made to carry out the patient's request; and providing emotional support to families and colleagues after the patient's death.^{7,8,11-16} Palliative sedation involves the use of medications to relieve refractory symptoms by a reduction of consciousness. Sedation varies from mild to deep, and may be intermittent or continuous. Continuous deep sedation is usually administered to terminal patients whose death is imminent, that is, to patients with a life expectancy of two weeks or less. Palliative sedation and MAiD are both interventions intended to relieve the patient's suffering, but with MAiD the means used to do so is to end the patient's life.¹⁷

Debates surrounding the legalization of euthanasia have commonly focused on the ethical and legal responsibility of physicians.^{1,7,8,14} Voices of nurses are heard less often, despite their daily involvement with terminally-ill patients and their specific expertise in caring for dying patients and their families.^{1,10} In Quebec, only physicians are authorized by law to administer MAiD.⁴ Nonetheless, nurses have a significant role in providing high-quality, person-centered end-of-life care that may involve MAiD. It is thus important to know whether nurses support or oppose broadening legislation to allow MAiD for incompetent patients and what conditions they believe the law should impose.¹⁸ Their unique perspective on this controversial issue should be taken in account as it can assist in creating appropriate laws and guidelines regarding end-of-life care.^{1,18}

Aims of the study

The primary aim of this study was to elicit the attitudes of Quebec nurses caring for the elderly towards extending MAiD to incompetent patients, uncover the reasons underpinning their attitudes on this issue, and determine the value they attach to proposed safeguards. A number of sociodemographic and work-related factors may influence nurses' attitudes on this issue.^{9,18} Therefore, a secondary objective was to characterize nurses who support extending MAiD to incompetent patients in certain circumstances.

Methods

Population and sampling

This study is part of a larger research project investigating the views of various stakeholder groups towards MAiD for incompetent patients, including nurses. The larger project has been approved by the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke (file # 2016-623) and is described in greater detail elsewhere.¹⁹ Briefly, regarding nurses, we accessed a random sample of French-speaking registered nurses through their professional association. The sample was restricted to nurses working in geriatrics/gerontology or end-of-life care in the public healthcare network. Nurses known to be in full-time administrative, teaching or research positions were excluded *a priori*, because of their limited direct contact with patients. At the time of sampling, 5,376 nurses satisfied these criteria, of which 34% had authorized their professional association to provide their postal address to a third party for research purposes. Study eligibility was further restricted to nurses caring for patients with Alzheimer disease or a related disorder. As this information was not available in their association's

database, whether a sampled nurse satisfied this criterion was asked on the cover page of the questionnaire.

Overview of the survey

Each sampled nurse was mailed a survey package containing a personalized letter introducing the recipient to the survey, a 12-page questionnaire containing 35 close-ended questions, and a letter of endorsement from the Federation of Quebec Alzheimer Societies. No monetary incentive was provided. The package also included a postcard, bearing the nurse's name, with instructions to return it separately from the questionnaire so that their answers would remain anonymous. Two strategies were used to maximize the response rate: a thank-you/reminder postcard mailed two weeks after the first mailing, and a second complete survey package mailed nine weeks later. At the close of the survey, non-respondents were mailed a single-page non-response questionnaire asking (i) for their reasons for not participating (e.g., lack of time, felt questions were biased); (ii) how comfortable they are with the current Quebec legislation that gives competent patients access to MAiD if certain conditions are met; and (iii) whether they favor or oppose allowing physicians to administer MAiD to incompetent patients with proper safeguards.

Content of the questionnaire

After stating the eligibility criteria for MAiD as defined in Quebec's *Act respecting end-of-life care*, the 3-part questionnaire presents a series of multiple-choice questions and ends with space for the respondent's comments. Part 1 elicits attitudes towards MAiD and continuous deep sedation. Two sets of clinical vignettes were developed for that purpose, totaling seven questions. The first set features a cancer patient who is described as eligible for MAiD, and is thus competent to make a contemporaneous request. Using a 5-point Likert-type scale, respondents are asked to what extent they find it acceptable for a physician to sedate the patient continuously until death to relieve his suffering, or to comply with the patient's request for MAiD. This clinical case is used to measure respondents' attitudes towards currently legal practices.

The second set of vignettes depicts a woman moving along the dementia trajectory, from the early stage when the patient wrote an advance directive, to the advanced and then terminal stage of the disease. At the terminal stage, the patient is described as having only a few weeks to live according to her treating physician. In her directive, the woman explicitly asks that a physician end her life when she can no longer recognize her close relatives. Using a 5-point Likert-type scale, respondents are asked whether they favor or oppose modifying the current legislation to allow a physician to administer drugs that would end the patient's life in a few minutes. Respondents are also asked the extent to which they find it acceptable that a physician provides continuous deep sedation to the patient, assuming she had not written an advance request for MAiD, was at the terminal stage, and showed signs of distress that were refractory to treatment. Part 1 ends with a list of statements designed to uncover respondents' reasons for supporting or opposing MAiD, generally and for incompetent patients in particular. Reasons include religious objections, respect for patient autonomy, difficulties in ascertaining whether an incompetent patient is suffering unbearably, and concerns for vulnerable populations.

Part 2 explores related issues such as whether nurses had filled out an advance directive for themselves, or had ever accompanied a dying relative or friend. They were also asked the likelihood that they would make an advance request for MAiD should they be diagnosed with Alzheimer disease, or ask a physician to comply with such a request written by a loved one under similar circum-

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