

# Impact of legalization of Medical Assistance in Dying on the Use of Palliative Sedation in a Tertiary Care Hospital: A Retrospective Chart Review

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## Abstract

**Background:** Patients approaching end of life may experience intractable symptoms managed with palliative sedation. The legalization of Medical Assistance in Dying (MAiD) in Canada in 2016 offers a new option for relief of intolerable suffering, and there is limited evidence examining how the use of palliative sedation has evolved with the introduction of MAiD. **Objectives:** To compare rates of palliative sedation at a tertiary care hospital before and after the legalization of MAiD. **Methods:** This study is a retrospective chart analysis of all deaths of patients followed by the palliative care consult team in acute care, or admitted to the palliative care unit. We compared the use of palliative sedation during 1-year periods before and after the legalization of MAiD, and screened charts for MAiD requests during the second time period. **Results:** 4.7% (n = 25) of patients who died in the palliative care unit pre-legalization of MAiD received palliative sedation compared to 14.6% (n = 82) post-MAiD, with no change in acute care. Post-MAiD, 4.1% of deaths were medically-assisted deaths in the palliative care unit (n = 23) and acute care (n = 14). For patients who requested MAiD but instead received palliative sedation, the primary reason was loss of decisional capacity to consent for MAiD. **Conclusion:** We believe that the mainstream presence of MAiD has resulted in an increased recognition of MAiD and palliative sedation as distinct entities, and rates of palliative sedation increased post-MAiD due to greater awareness about patient choice and increased comfort with end-of-life options.

## Keywords

palliative sedation, medical assistance in dying, MAiD

## Introduction

Patients approaching end of life may experience a range of distressing symptoms that are sometimes refractory to standard medical therapy. In specific cases, palliative sedation (PS) may be offered to relieve intractable suffering in these patients. Palliative sedation has been defined as “(1) the use of (a) pharmacological agent(s) to reduce consciousness; (2) reserved for the treatment of intolerable and refractory symptoms and (3) only considered in a patient who has been diagnosed with an advanced progressive illness”.<sup>1</sup> Sedation is titrated to relieve the patient’s refractory and intolerable symptoms and is only used when death is expected within 1-2 weeks, virtually always continuing until death.

In June 2016, the Canadian parliament enacted federal legislation that legalized medical assistance in dying (MAiD) for Canadians living with a grievous and irremediable medical condition.<sup>2</sup> MAiD presents a relatively new end of life option for patients enduring intolerable physical or psychological suffering and in 2019, 2% of all deaths in Canada were medically assisted deaths.<sup>3</sup> Under the initial MAiD legislation (former

Bill C-14) eligibility criteria for accessing MAiD included the stipulation that natural death must be reasonably foreseeable, without necessitating a specific estimate of prognosis or a requirement that patients be at end of life. The eligibility criterion of a “reasonably foreseeable natural death” was later ruled in violation of the Canadian Charter of Rights and Freedoms in the Superior Court of Québec.<sup>4</sup> Accordingly, in March 2021 Bill C-7 amended Canada’s Criminal Code to permit MAiD for patients whose natural death is not reasonably foreseeable (amongst other amendments).

Although PS and MAiD exist on a spectrum of legal end of life care options now available to patients in Canada,

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considerable and important differences exist between the 2. While both MAiD and PS intend to relieve suffering, this is achieved through different means and with differing intents. The intent of palliative sedation is not to hasten death however this is a foreseeable (though unintended) outcome in the absence of nutrition and hydration in an unconscious person. The intent of MAiD is to end grievous and irremediable suffering directly and purposefully by causing death and is not limited to patients with a prognosis of only days.

PS and MAiD also differ in the type of intervention and medications used, and in who may provide consent for the intervention. In Canada, a patient must provide consent both at the time of request for MAiD assessment and just prior to MAiD provision (or, with the amendments in Bill C-7, have signed a waiver of consent when still capable), whereas either the patient or a substitute decision maker may provide consent to initiate PS.

There is evidence that the introduction of legal voluntary euthanasia may result in a reciprocal increase in rates of PS over time.<sup>5</sup> The reasons for such an increase have not been fully elucidated, but could represent the utilization of PS as an alternative when patients lose capacity to consent to MAiD, or when barriers to accessing MAiD exist. Gaining a more nuanced understanding of how and when palliative sedation is used, and whether this has evolved with the introduction of MAiD, can help healthcare teams to better explore the most appropriate end-of-life choices for all patients. To our knowledge, there are no studies examining the impact of the legalization of MAiD on the use of palliative sedation in Canada.

This study aims to compare rates of PS at our institution before and after the legalization of MAiD in Canada to examine for trends that might emerge, and to investigate whether patients receiving PS had an active MAiD request prior to the initiation of PS. Of note, the study period was prior to the C-7 amendment; as such those who received MAiD needed to have retained capacity to give consent immediately prior to MAiD provision.

## Methods

### Study Setting And Participants

This study is a retrospective chart review of patients referred to an inpatient palliative care consult service or admitted to an inpatient palliative care unit at Sunnybrook Health Sciences Centre (SHSC), a 638-bed tertiary care hospital in Toronto, Canada. The SHSC Division of Palliative Care is comprised of an inpatient consult service for acute care patients, a 56-bed residential palliative care unit (PCU), and several ambulatory cancer palliative care clinics. The hospital also has an independent MAiD service, which includes a central coordinator and multiple MAiD assessors across various medical specialties. The service conducts MAiD assessments for patients in ambulatory and inpatient settings and provides MAiD to eligible patients.

The study population included all deaths during the designated study period in patients 18 years and older who were followed by either the inpatient palliative care consult team in acute care, or were admitted to the PCU. We extracted data for the period of June 1, 2015 – May 31, 2016 (period preceding the enactment of former Bill C-14, designated ‘pre-MAiD’) and compared this to June 1, 2017 – May 31, 2018 (designated ‘post-MAiD’). Medical staff in the PCU and on the inpatient consult service did not substantively change during the 2 study periods, nor did the volume of referrals change.

We included only those patients receiving PS specifically for symptom relief at end of life. The usual PS protocol in the PCU utilizes a midazolam infusion +/- a neuroleptic agent for continuous PS. In acute care (and in rare instances in the PCU) neuroleptic medications, barbiturates, and other benzodiazepines were used as a first-line for palliative sedation. We reviewed all charts of patients who died in the study period and included any for whom the Palliative Care physician had explicitly stated medications were being used to achieve sedation for control of refractory symptoms at end of life. We excluded patients in acute care who received sedation expressly for the purposes of withdrawal of life-sustaining therapies in the Intensive Care Unit if they died within 24 hours. We also excluded patients who received sedation for reasons other than symptom control (ie. procedural sedation, or seizure control where significant sedation resulted, but intent was not PS).

### Data Sources

Three distinct sources were used to extract data:

1. Inpatient acute care: The palliative care consult team administrative staff maintain a computerized database of all palliative care referrals for patients admitted to acute care. The database was expanded to capture relevant details of the hospital admission utilizing the electronic medical records (EMRs) for acute care patients.

2. Palliative Care Unit: In the PCU, all patient dispositions are tracked in a separate electronic system, and records of all deceased patients in the 2 timeframes were reviewed.

For both settings, data were extracted on basic demographics (including age and sex), primary underlying diagnosis (malignant / non-malignant), medications used for palliative sedation, and indication for palliative sedation.

3. MAiD service: For the second time period (post-MAiD), we also extracted data from our hospital’s MAiD database. The MAiD database was created after the enactment of MAiD legislation and is maintained by the hospital’s MAiD coordinator; it captures all patients who request an eligibility assessment, including their basic demographics and the outcome of their request. For both groups (PCU and acute care), we extracted data on documentation of requests for information about MAiD, formal MAiD requests / assessments, and the outcome of these requests. We also extracted data on reasons for proceeding with palliative sedation in place of MAiD if a formal request was placed but not carried out to completion.

**Table 1.** Rates of Palliative Sedation Before and After Legalization of MAiD and Characteristics of Recipients.

	Palliative care unit		Acute care	
	Study period before legalization of MAiD total deaths N = 530	Study period after legalization of MAiD total deaths N = 560	Study period before legalization of MAiD total deaths N = 363	Study period after legalization of MAiD total deaths N = 342
Cases of PS, n (%)	25 (4.7)	82 (14.6)	19 (5.2)	17 (5)
Sex, n (%)				
M	8 (32)	37 (45.1)	9 (47.4)	10 (58.8)
F	17 (68)	45 (54.9)	10 (52.6)	7 (41.1)
Age (years), median (range)	69 (36-86)	76.5 (38-97)	73 (39-96)	73 (46-90)
Age groups (years), n (%)				
< 60	9 (36)	10 (12.2)	5 (26.3)	2 (11.8)
60-80	14 (56)	41 (50)	8 (42.1)	10 (58.8)
>80	2 (8)	31 (37.8)	6 (31.6)	5 (29.4)
Diagnosis, n (%)				
Malignant	25 (100)	69 (84.1)	12 (63.2)	10 (58.8)
Non-Malignant	0	13 (15.9)	7 (36.8)	7 (41.2)
Primary medication used for sedation, n (%)				
Midazolam infusion	21 (84)	72 (87.8)	6 (31.5)	12 (70.6)
Methotrimeprazine	4 (16)	9 (11)	11 (57.9)	3 (17.6)
Lorazepam	0	0	1 (5.3)	2 (11.8)
Phenobarbital	0	1 (1.2)	1 (5.3)	0
Primary indication for sedation, n (%)				
Agitated delirium	12 (48)	53 (64.6)	9 (47.4)	5 (29.4)
Dyspnea	5 (20)	14 (17.1)	4 (21)	6 (35.3)
Removal of NIV <sup>a</sup>	0	0	4 (21)	3 (17.6)
Existential distress	6 (24)	10 (12.3)	0	1 (5.9)
Pain	1 (4)	1 (1.2)	1 (5.3)	1 (5.9)
Seizures	0	2 (2.4)	0	1 (5.9)
Other <sup>b</sup>	1 (4)	2 (2.4)	1 (5.3)	0

MAiD = medical assistance in dying, PS = palliative sedation, SD = standard deviation, NIV = non-invasive ventilation

<sup>a</sup>includes withdrawal of life-sustaining therapies if patient lived > 24 hrs

<sup>b</sup>includes: intractable bleeding, hiccups, bladder obstruction, and unknown

Three of the authors (A.N., R.O., D.S.) extracted the data; 2 authors (R.O., D.S.) performed an independent cross-check of a random subset of the data for accuracy.

Descriptive statistics were used to analyze the dataset.

## Results

Of the total number of deaths in the PCU pre-legalization of MAiD, 4.7% of patients received PS compared to 14.6% after legalization of MAiD (Table 1). The median age of patients receiving PS in the PCU pre-MAiD was 69 years compared to a median age of 76.5 years post-MAiD, with a higher proportion of patients aged over 80 years post-legalization (8% pre-MAiD versus 37.8% post-MAiD).

All patients who received PS in the PCU before the legalization of MAiD had a primary underlying diagnosis of malignant disease, with malignant diagnoses still comprising the majority of patients (84.1%) receiving PS post-MAiD. Midazolam was used as the primary medication for sedation in most cases of PS in the PCU both pre- and post-MAiD (84% and 87.8%, respectively). Agitated delirium was the primary indication for PS both pre- and post-legalization of MAiD (48%

and 64.6% of cases), and dyspnea in ~20% of PS cases during both time periods. Existential distress was the primary indication for 24% of PS cases pre-MAiD in the PCU compared to only 12.3% of cases post-MAiD.

In the acute care setting, the proportion of patients receiving palliative sedation pre- and post-legalization of MAiD remained unchanged (~5%), as did the median age (73 years) and the proportion of patients with non-malignant disease (36.8% versus 41.2%). Agitated delirium and dyspnea remained the most common indications for PS in acute care both pre- and post-MAiD. In acute care, removal of NIV was a primary indication in ~20% of PS cases pre- and post-legalization of MAiD.

During the post-MAiD study period, there were 23 MAiD recipients in the PCU and 14 in acute care (both representing 4.1% of the deaths in each area) (Table 2). There were 8 patients in the PCU who received palliative sedation but had prior documentation about a MAiD inquiry in the medical records. Of these 8 patients, 6 lost capacity during the mandatory 10-day reflection period (after a finding of eligibility), and 2 were never eligible. In acute care, 9 patients inquired about MAiD prior to receiving PS; 3 lost capacity after a finding of

**Table 2.** Number of MAiD Recipients and MAiD Inquiries During Study Period Post-Legalization of MAiD.

	Palliative care unit	Acute care
	total deaths N = 560	total deaths N = 342
Number of MAiD recipients	23 (4.1%)	14 (4.1%)
age <60 years	3	3
age 60-80 years	14	7
age >80 years	6	4
MAiD inquiry in chart <sup>a</sup> but not provided	8 (1.4%)	9 (2.6%)
Eligible, lost capacity prior to provision <sup>b</sup>	6	3
Chose PS over MAiD	0	2
Changed mind	0	1
Never eligible	2	3

<sup>a</sup>based on site of MAiD discussion NOT site of death as majority died in PCU

<sup>b</sup>all received PS after loss of capacity aside from 2 patients who died suddenly

eligibility, 2 ultimately preferred PS over MAiD, one changed his or her mind regarding MAiD, and three were never eligible.

## Discussion

This study compares patients receiving palliative sedation in acute care and the PCU before and after legalization of MAiD in Canada, and demonstrates that patients in the PCU were substantially more likely to receive PS in the period after MAiD was legalized whereas there was no change in the acute care population. This finding suggests that the decriminalization of MAiD in Canada may have indirectly resulted in an increased comfort with the provision of PS specifically in settings with staff accustomed to delivering end of life care, both as a first-line option to relieve intractable suffering and as an alternative to MAiD when decisional capacity was lost.

There is significant heterogeneity in the documented prevalence of PS in the literature across clinical care and geographical settings. A 2012 systematic review of 10 studies examining the clinical practice of PS across all settings showed considerable variability in the proportion of patients receiving PS (mean frequency 34%, range 14.6%-66.7%).<sup>6</sup> A study from a German PCU between 1995–2002 showed 14.6% of patients had palliative sedation in the last 48 hours of life,<sup>7</sup> whereas studies of the PCU setting in Japan<sup>8</sup> and the Netherlands<sup>9</sup> showed higher rates of 50.3% and 43%, respectively. A study of PS in the Brazilian acute care setting showed a prevalence of 54.2%,<sup>10</sup> while a large cohort study of an acute care population in South Korea showed 16.1% of patients received palliative sedation.<sup>11</sup> A recent study from Calgary, Canada in 2019 demonstrated the prevalence of palliative sedation as 3.3% of deaths in acute care, 4% of deaths in hospice and 22.2% of deaths in a PCU during an 8-year period.<sup>12</sup> Despite the large number of studies examining the practice of palliative sedation worldwide, there is a dearth of research exploring how the introduction of MAiD

(variably termed voluntary euthanasia or physician assisted death in different jurisdictions) has impacted the use of palliative sedation in patients at end of life. Only one study, a nationwide physician study from the Netherlands showed that the use of continuous deep sedation increased from 5.6% of deaths in 2001 to 7.1% in 2005, following the enactment of the Dutch euthanasia act in 2002.<sup>5</sup>

Similar to the Dutch experience, in the post-MAiD period at our institution we observed an increase in rates of PS, though in the PCU setting specifically. In the wake of former Bill C-14 and the decriminalization of assisted dying in Canada in 2016, it was postulated by some groups that palliative sedation would receive increasing attention and might be offered as an alternative to MAiD.<sup>13</sup> However, throughout the medical literature the primary indications for PS are almost exclusively related to physical symptoms, most commonly dyspnea and agitated delirium.<sup>14-16</sup> In contrast, there is overwhelming evidence that MAiD requests are motivated by concerns about autonomy, dignity, loss of independence and diminishing quality of life as opposed to poorly controlled physical symptoms.<sup>17-20</sup> In our study population we note that the proportion of patients receiving palliative sedation for existential distress in the PCU dropped considerably after the legalization of MAiD (Table 1) – perhaps suggesting that these patients instead elected to pursue MAiD – whereas all other primary indications for PS either increased or remained relatively stable pre- and post-MAiD. It therefore seems implausible that augmented attention to PS as a result of the legalization of MAiD in Canada would singularly account for the observed increase in the use of PS.

In the post-MAiD period, a small number of patients explored MAiD as an option but ultimately received PS in place of MAiD (Table 2); this was almost exclusively due to loss of decisional capacity for MAiD as opposed to an expressed preference for PS. Recipients of MAiD place enormous importance on self-determination and maintaining control at the end of life.<sup>19,21</sup> These personality traits are fundamentally incongruent with PS, which requires relinquishing control while fully sedated for an indeterminate period of time through to death. MAiD recipients have also typically considered an assisted death for an extended period pre-intervention and regard MAiD as a longstanding philosophic belief<sup>19</sup>; it is rare that PS would become their choice in place of MAiD. However, we do encounter exceptional circumstances in which PS is selected in preference to MAiD at our institution. We may experience delays in accessing medications and/or staff for MAiD provision on weekends or holidays. When a patient is felt to be at imminent risk of loss of capacity before MAiD can be organized, PS is offered in place of MAiD as the most expeditious path to alleviate intolerable suffering. Outside of our hospital, other institutionally-driven barriers to MAiD may result in the selective use of PS as an alternative option, for example restrictions to MAiD provision in faith-based facilities.

We postulate that the increase in prevalence of PS in our PCU post-MAiD resulted from a much greater willingness to initiate PS for a number of reasons. In the PCU, patients' goals



of care are very clear and the intent is entirely for a comfortable death. The PCU interdisciplinary team has a specific focus on end-of-life symptom management and PS may therefore be used more readily. Further, the era of legal MAiD has amplified the importance of discussing all end-of-life choices with patients. It is possible that the team collectively felt diminished anxiety in offering PS as they gained a greater appreciation of PS as a distinct entity from MAiD. It is interesting that there was a greater number of patients over the age of 80 in the PCU who received PS in the post-MAiD period. We believe this to be in keeping with our finding that terminal delirium was the most common indication for PS in our study. In our experience, older patients develop symptoms of terminal delirium more frequently than their younger counterparts, perhaps due to increased brain vulnerability from age-related changes and pre-existing cognitive impairment. Therefore, an older cohort of patients in the PCU post-MAiD may have also contributed to the observed increase in PS.

We did not observe a similar increase in the utilization of PS in acute care after the legalization of MAiD, in fact the prevalence of PS remained stable. Patients followed by the palliative consult service in acute care will have their overall care directed by the primary admitting service; as such, the palliative care consultant has less professional autonomy to influence treatment plans. Patients may still be receiving active anti-cancer therapies and goals of care may not align with PS, even in patients who are very close to end-of-life. Additionally, continuous midazolam infusions are permitted on only a limited number of units in acute care, potentially restricting access to PS for some patients. This is reflected in our data, which showed more patients in acute care receiving sedation with a neuroleptic or other benzodiazepine as a primary agent. Nurses and other interdisciplinary staff in acute care have less exposure to managing refractory symptoms at end of life, and may have limited experience with the delivery of PS. Anecdotally we have encountered situations where initiation of PS was passively delayed by well-intentioned staff due to concerns of hastening death, re-enforcing the importance of educating staff throughout the hospital on the delivery of end of life care.

### Limitations

This study has several important limitations to consider. It is a single-centre study examining an inpatient population, thereby limiting generalizability of results to other clinical settings. It is a retrospective study, and in some rare instances it was difficult to determine if intent of PS was truly for full sedation based on documentation in chart. Further, in acute care we reviewed only those patients at end of life who were followed by the palliative care consult team and palliative sedation is occasionally initiated by other services in patients not followed by our team, particularly in the Intensive Care Unit. Therefore, we may have underestimated rates of PS overall in the acute care setting.

### Conclusion

This study demonstrates an increase in the use of PS in our hospital's PCU setting following the legalization of MAiD in Canada, whereas the proportion of patients receiving PS in acute care post-MAiD remained unchanged. Our data complements similar findings from a large retrospective study from Netherlands. While some confusion persists outside the Palliative Care profession about PS versus MAiD, we believe that the legal, mainstream presence of MAiD may have promoted an increased recognition of the 2 options as distinct entities. We believe that rates of PS increased not because of its use in place of MAiD, but rather may have been driven by greater awareness about patient choice at end-of-life and increased comfort with end-of-life options generally. Future research should expand our work to other clinical environments and geographical regions to determine if our findings are replicated in other settings. Future studies could also seek to explore how the introduction of MAiD has altered the attitudes and practices of palliative care physicians who administer PS.

### Authors' Note

This study was approved by the Research Ethics Board at Sunnybrook Health Sciences Centre.

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