



A REVIEW OF MEDICAL ASSISTANCE IN DYING ON VANCOUVER ISLAND: THE FIRST TWO YEARS JULY 2016 – JULY 2018

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CONTENTS

Abstract.....	1
Introduction	2
Provincial and Island Health approach to MAID	2
Support for provision of MAID outside a hospital	2
Results.....	3
Calls to the Island Health Coordination phone line	3
Assessors and trained prescribers.....	3
Figure 1: Number of Prescribers and Assessors (cumulative total).....	4
MAID case analysis.....	4
Figure 2: Number of MAID Deaths per month.....	4
Figure 3: MAID Deaths By Location (percentage).....	5
Figure 4: Number of Days Between Request and MAID	5
Underlying Cause	6
Figure 5: MAID Deaths By Underlying Cause (percentage)	6
Interpretation	6
Barriers	7
Study Limitations and Future research	7
Conclusions	7
References	8
Appendix 1: Infographic.....	9

ABSTRACT

Background: Medical Assistance In Dying (MAID) became legal in Canada on June 17th 2016 (1). An Island Health MAID coordination office was established and a program developed in coordination with similar programs across British Columbia (BC). Five physicians had obtained training in MAID and been granted privileges to perform MAID prior to June 17th 2016. The rate of MAID on Vancouver Island is approximately five times that in the rest of Canada. We have completed a 24-month review of assisted deaths on Vancouver Island.

Methods: The British Columbia and Island Health approach to MAID is described. Phone logs to the coordination center were reviewed. Records of MAID deaths on Vancouver Island were reviewed.

Results: In the period from June 16th 2016 to June 15th 2018 there were 504 MAID deaths on Vancouver Island. In the first year of MAID in Canada, 10.6% of the nation’s MAID deaths took place in 2.2% of the population. The most recent federal data covering the time period from enactment to December 31, 2017 indicates the total number of medically assisted deaths in Canada to be 3,714 (2). Records for all MAID deaths on Vancouver Island for the 24 months to June 15th 2018 have been analysed for trends and details. In that time there have been 504 MAID deaths. The MAID program on Vancouver Island is described.

Interpretation: Two years after Bill C14 became law, MAID has developed into an available option, for the right patients, in the spectrum of end of life care. The rate of MAID deaths continues to rise.

INTRODUCTION

PROVINCIAL AND ISLAND HEALTH APPROACH TO MAID

In the months leading up to the legalization of MAID, a committee representing the Ministries of Justice and Health, the Coroner's Office, the Health Authorities, and the Colleges of Physicians, Nurses and Pharmacists in B.C. began to meet and continue to do so. They have been responsible for the development of standardized forms, regulations and guidelines for the provision of MAID; online learning modules; and education criteria for privileging. Over time, these have been refined and updated, but remain standardized across the province.

The approach to MAID within Island Health was to recognise that MAID is a patient-centered service and an established charter right under *Carter vs Canada* (3); that the procedure itself is not complicated and can be carried out in almost any setting; and that MAID will become part of the spectrum of options open to Canadians in end-of-life care. While the home setting is encouraged, Island Health committed to enabling access to MAID in any part of any Island Health-owned and operated facility. That is, Island Health decided not to have opt-out parts of any facility and not to have any part of any facility be a 'MAID destination.' Hospices and palliative care facilities provide MAID, but only for patients already in their care who subsequently request MAID.

The individual right of healthcare professionals to conscientiously object to involvement in MAID is respected. If all the staff in a particular unit refuse to take part in MAID, then staff from elsewhere in the facility will be found (although this situation has not yet occurred). Some publicly funded faith-based healthcare facilities in BC are given the power to opt out of the provision of aspects of healthcare that conflict with their values (4). As a result, patients have been transferred out of non-Island Health facilities that do not provide MAID. Island Health has worked with those organisations to ensure that the transfer is as smooth as possible, and is committed to admitting those patients or supporting transfer to another destination (such as home or another care setting) for the purposes of MAID or MAID-related services. Island Health supports admission to a hospital solely for the purposes of MAID.

The approach in BC has been to recognise that the process is patient-driven. MAID starts when the patient completes a publicly available witnessed Request Form (5). The patient then finds an assessor and a prescriber. Patients wishing to receive MAID on Vancouver Island can reach an assessor or prescriber by direct personal referral, by referral from their primary care provider, or through the health authority MAID coordination office. The coordinating office operates a phone and email helpline to assist with this and other questions.

SUPPORT FOR PROVISION OF MAID OUTSIDE A HOSPITAL

Island Health has developed local lists of trained registered nurses (RNs) who can support MAID outside healthcare facilities. A local MAID liaison manager is identified. Local RNs are polled and those who are interested in supporting MAID in the community are given an orientation and entered into a local registry. When planning a MAID, the prescriber will contact the local MAID liaison manager, who will then arrange for an RN to be available. A MAID provider can receive and supplies needed from the nearest hospital without charge.

Education and support for staff—including web-based resources and in-person general education and ethics sessions—is ongoing. All MAID providers on Vancouver Island are required to submit records to the Island Health MAID office for assisted deaths that take place in a health authority facility. They are also requested to provide records for any community MAID. The coroner’s office is the BC record-keeper of note for MAID. Island Health reconciles our records with the coroner’s office, and we are confident that we have records for 99% of all MAID that have taken place on Vancouver Island.

Vancouver Island has a population of 799,400 (6). It is unique in North America for epidemiology studies in that it is geographically isolated and is of sufficient size to be managed by a single dedicated health authority. More than 96% of the population’s hospital health care interactions take place on the Island. It therefore provides an almost watertight sample of 800,000 people within a single health system.

RESULTS

CALLS TO THE ISLAND HEALTH COORDINATION PHONE LINE

In the first 3 months (July – September 2017), the MAID coordination phone line received an average of 6 calls per month. These were predominantly from primary care clinicians, or from dying patients seeking a prescriber. Currently, the call volume has averaged 12 per month. These calls have increased in complexity and are mostly from patients whose family or primary care providers are not supportive of MAID, or patients who do not have access to the internet.

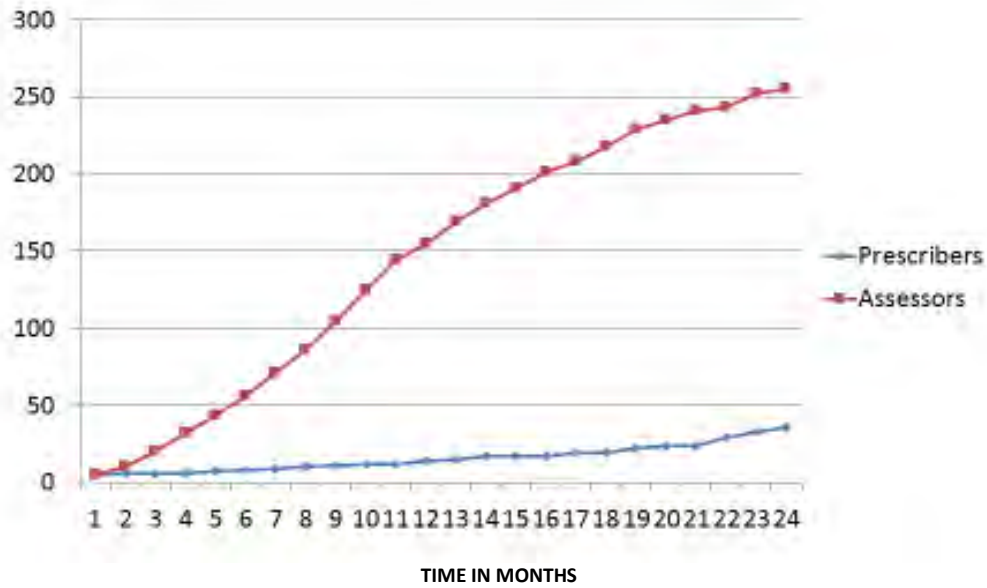
ASSESSORS AND TRAINED PRESCRIBERS

Prior to Bill C14 being enacted into law, five physicians in Vancouver Island had received comprehensive training in MAID and been granted non-core privileges to provide the service. A number of patients had also gone through the process of assessment in anticipation of MAID becoming legal. As a result, there were four MAID deaths in the first 5 days after C14 passed.

The number of MAID prescribers with Island Health privileges has slowly increased since then to 39. Of these, 19 have provided MAID to date. The active prescribers have all described the high demand for their service and most have placed limits on the distance they will travel to provide MAID, or how they will receive referrals. None of the MAID prescribers think there are enough of them. Three of the early prescribers have withdrawn because of financial compensation concerns and pressure of the demand.

The number of physicians and nurse practitioners (NPs) who have completed assessments has risen steadily to 252. 17 NPs on Vancouver Island have been trained as assessors; of this group, 8 NPs have performed assessments, and 4 NPs have completed assessments on patients who have gone on to have a MAID death. NPs were not enabled to act as providers of MAID in our health authority until very recently, for reasons related to the transitioning of their governance model. There are approximately 900 GPs actively practising on Vancouver Island.

FIGURE 1: NUMBER OF PRESCRIBERS AND ASSESSORS (CUMULATIVE TOTAL)



MAID CASE ANALYSIS

There have been 504 MAID deaths in 24 months. This represents 3.6% of all expected deaths on Vancouver Island (7). Over the most recent 6 months MAID has accounted for approximately 4.1% of all expected deaths.

FIGURE 2: NUMBER OF MAID DEATHS PER MONTH

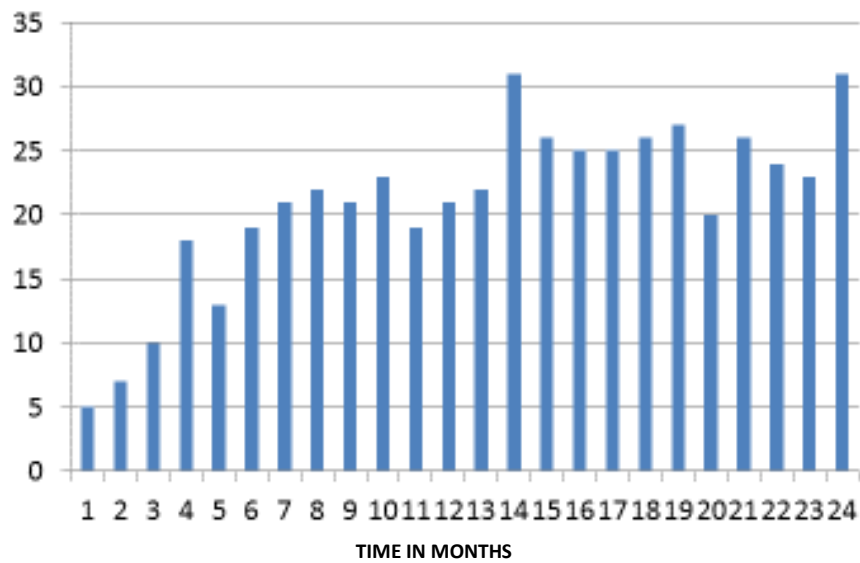
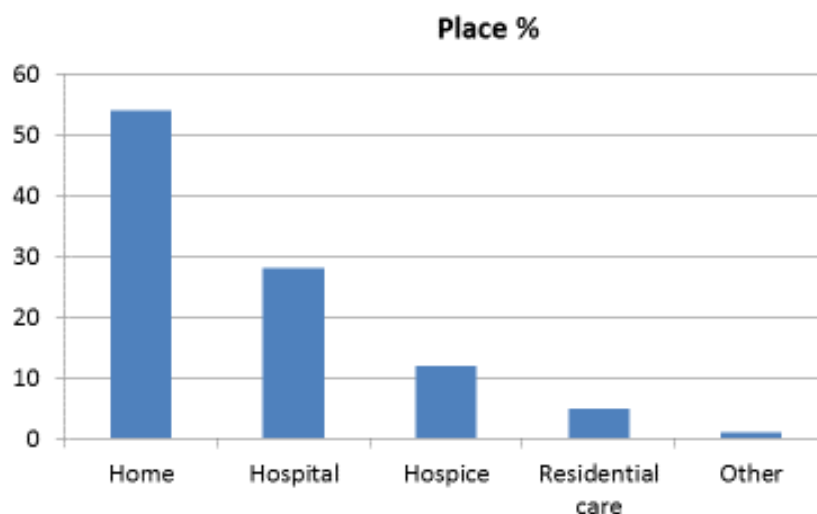
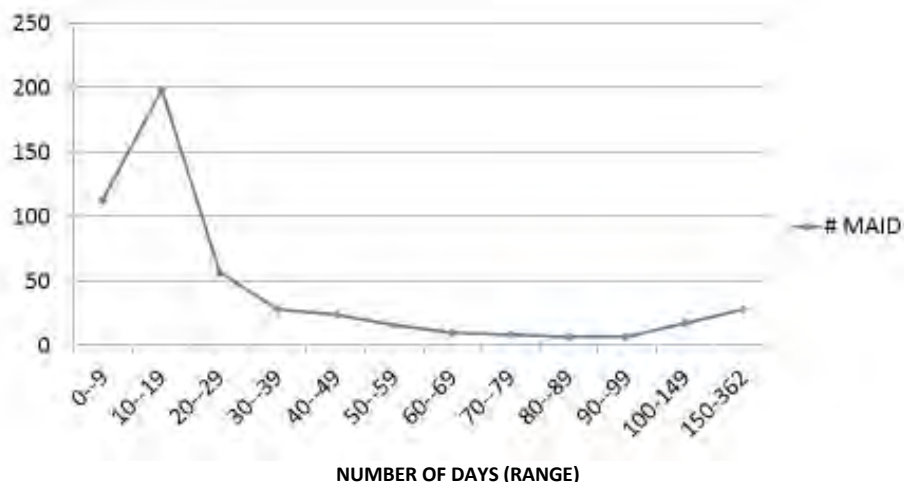


FIGURE 3: MAID DEATHS BY LOCATION (PERCENTAGE)



57% of MAID deaths occurred at home, 26% in acute care hospitals. 12% in hospice/palliative care units, 3% in residential/assisted care, and 1% in other (6 deaths occurred in a hotel, clinic or funeral home). Of the 99 deaths that occurred in the first year of MAID among residents of Greater Victoria, 65% were registered with the Victoria Hospice palliative care program, and 17 of these deaths took place in the Victoria Hospice facility. The proportion of MAID that takes place at home remains higher than the national average (2). The average age was 76 (range 31-105). The gender balance was equal (Women 249, Men 255). No data was collected around income, education or cultural identity.

FIGURE 4: NUMBER OF DAYS BETWEEN REQUEST AND MAID



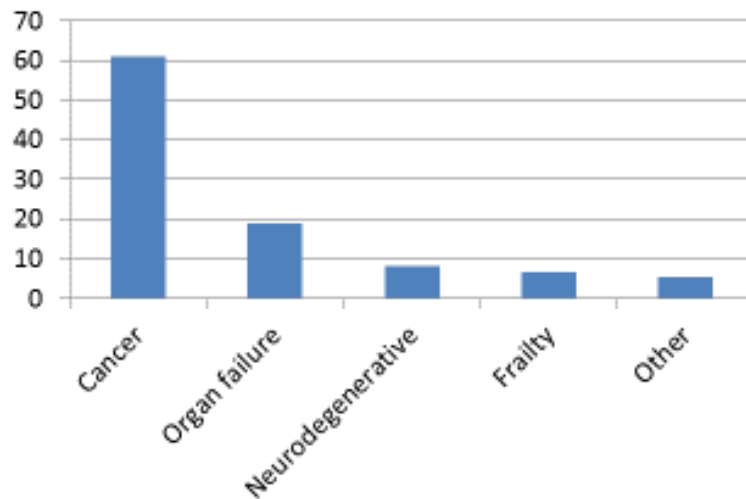
22% of MAID deaths were expedited to less than 10 days. This agrees with reported timelines from the Netherlands (8). The reasons were evenly shared between (a) concern about loss of capability to consent and (b) likelihood of death occurring before ten days in a manner the patient did not want.

24% of MAID deaths took place in the 5 days after the 'period of reflection,' suggesting that these individuals were determined to expedite their own deaths but did not meet the criteria for expediting under C14. Nearly half of all MAID deaths took place within 15 days of completing the request form.

The range of time from completion of the request to MAID was from zero to 362 days. Where the time lag was long, the underlying condition was progressive and the suitability of MAID at some time in the future was very likely (e.g. progressive debility from amyotrophic lateral sclerosis, threat of celiac axis invasion in unresectable pancreatic cancer, progressive spinal stenosis with associated loss of mobility and uncontrollable pain).

UNDERLYING CAUSE

FIGURE 5: MAID DEATHS BY UNDERLYING CAUSE (PERCENTAGE)



Underlying causes of for MAID are cancer (61%), organ failure (19%), neurodegenerative disease (8%), complex disease/frailty (6.3%), and 'Other' (5.7%: this includes AIDS, peripheral vascular disease, spinal stenosis, multi-system atrophy).

In cases where frailty or another undefined diagnosis was given as the underlying condition, the records were reviewed to confirm that multiple complex conditions lead to an overall state of health meeting the criteria for MAID. Clinicians now use standardized assessment tools to quantify the finding and degree of frailty and complex diseases. In 14 cases, an additional assessment of capability to consent was completed by a psychiatrist or geriatrician.

INTERPRETATION

On Vancouver Island, the rate of MAID rose rapidly to more than 2% of expected monthly deaths in the first 6 months (9) and is currently at 4% of expected monthly deaths. In Canada, this rate has risen more slowly to 0.8% in the first year (10). In the Netherlands, the rate of MAID in 2015 was 3.9% of all deaths, and had risen to this level steadily over more than 15 years. On Vancouver Island, this increase occurred in under a year. Reasons for this are a combination of high demand, availability of a few dedicated prescribers, and also probably demographic and social factors. BC has a long history of legal and social activism in favour of assisted dying, and the level of awareness of MAID is very high across the province.

Approximately 28% of all GPs on Vancouver Island have completed at least one assessment of a patient who has gone on to MAID, and this number continues to rise. This confirms a strong level of support for access to MAID among family physicians. Approximately half of all MAID took place in 15 days after completion of the request. For these patients, the required period of reflection may represent an additional period of suffering. If the rate of MAID across Canada rises to the levels seen in Vancouver Island, it will surpass the levels expected in the Canada Gazette of 2.7% of all deaths (13).

BARRIERS

The time commitment to provide an ‘at home’ MAID is a minimum of 2 hours plus travel time, taking into account leaving the office, picking up and returning medication, providing the procedure, completing a debrief with the family and the team, and completing the records after returning to the office. This, combined with the uncertain frequency of demand, make the provision of MAID an unattractive business proposition for any office-based family physician or for a fee for service model of compensation. In BC, travel for MAID has recently been compensated for rural communities but not for urban or suburban areas (11). While this is a significant improvement for those in rural and remote communities, it will leave a substantial number of people unable to access MAID at home. The refusal of certain facilities to permit MAID results in patient transfers at a time of life that is, by definition, one of grievous and irremediable suffering. A rising number of physicians are completing assessments for their own patients and thereby supporting access to MAID, but the number performing MAID remains low. While this number is slowly growing, it is inadequate to meet demand. The small numbers of prescribers confirm the results in a recently published study from Laval; however, we have no research on whether this is due to conscientious objection or moral reluctance (12).

STUDY LIMITATIONS AND FUTURE RESEARCH

This is only a review of records of completed MAID deaths. We have no reliable data for any of the steps up to completion of a MAID death, and therefore do not know how many persons actually started the process. All aspects of patient care trajectories—from completion of the request form to death—should be studied. This will be aided by the proposed scope of data to be gathered by the federal government (13). The reasons why the growth in numbers of prescribers is so slow need to be explored.

CONCLUSIONS

The rate of MAID in Vancouver Island in the first 24 months was approximately five times that in the rest of the country. The demand for MAID from the population is not being met. There is broad support for access to MAID among family physicians. There are too few prescribers on Vancouver Island.

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MEDICAL ASSISTANCE IN DYING ON VANCOUVER ISLAND

2016 - 2018

THE BIG PICTURE

Medical Assistance in Dying (MAiD) became legal in Canada on June 17, 2016, and has since become an available option for patients and families as part of the spectrum of end-of-life care. Island Health views MAiD as a patient-centred service and a patient-driven process.

BY THE NUMBERS

MAiD accounts for

4%

of expected deaths
on Vancouver Island

...compared to

<1%

across
Canada

5x

higher than the
national average

504

MAiD deaths occurred
in the past two years
on Vancouver Island

50%

Occurred within 15
days of the request

39

Physicians trained
to provide MAiD

Where did MAiD take place?



57 % at home
26 % in hospital
12 % in hospice
3 % in long-term care
1 % elsewhere

What were the underlying causes?

61 % cancer
19 % organ failure
8 % neurodegeneration
6 % frailty/complex conditions
6 % other

THE FUTURE

More MAiD practitioners are needed in order to meet demand. Further research is also required so that we can better understand the barriers for interested clinicians, and the reasons behind the high demand for MAiD on Vancouver Island.