Policy Advice on Medical Assistance in Dying and Mental Illness
October 2017

Medical Assistance in Dying (MAiD) is now legally available in Canada for adults with grievous and irremediable medical conditions who meet certain criteria and are capable of making that decision. The new law does not explicitly exclude people with mental illness as their only medical condition from accessing MAiD, however it is unlikely that most of these individuals will meet all of the eligibility criteria - in particular, the criteria that their 'natural death has become reasonably foreseeable'[1].

When MAiD legislation was passed, it included a requirement that the government initiate an independent review to explore the issue of requests where mental illness is the sole underlying medical condition, as well situations involving mature minors and people who have made advance requests[2]. The review on mental illness will focus specifically on situations where individuals suffering from mental illness are not nearing natural death*[3]. The Canadian Council of Academies (CCA) has been tasked with conducting this review and providing the government with their findings. The CCA has until December 2018 to submit its findings to the government.

The issue of whether people with mental illness as their sole underlying medical condition should be able to access MAiD in situations where they are not nearing a natural death is a difficult one. MAiD is not simply another healthcare treatment. Ending a life – even when it is requested by someone who is suffering – raises moral and ethical questions for all involved. This struggle is reflected in the Supreme Court and government's cautious approach to MAiD for people with mental illness to date. Canadians themselves are divided on the issue of MAiD, and most do not support making it available to those with only mental illness[4]. Public discourse has seen lawyers, ethicists, physicians, reporters and advocates passionately defend one side or the other of this complex and nuanced debate. At the Centre for Addiction and Mental Health (CAMH), this debate is exceptionally challenging. The government's ultimate decision – whatever it may be - will deeply impact the lives of our patients, their families, our physicians and staff.

Since September 2015, a group of CAMH staff with expertise in clinical, legal, ethics, public policy and lived experience have been deliberating over the issue of MAiD and mental illness. We have raised questions and concerns in deputations to Government and Senate Committees. We have consulted with our colleagues both within and external to CAMH. We have hosted an evening of catalytic

* 'Natural death' is understood to mean that death is a likely consequence of the progressive illness for which MAiD was requested. It does not simply refer to an individual's proximity to death, such as advanced age.

[1] Bill C-14, section 241.2(2)(d).
[2] Bill C-14, section 9.1(1).
[3] Downie & Chandler, 2017
[4] External Panel, 2015

conversation with clinical experts and heard from mental health service users at an event that we co-hosted with the CAMH Empowerment Council (an organization that is composed of, and represents, people with current or past mental health and addictions problems). We have received a wealth of informed and impassioned input, but there remain no easy answers.

It is difficult to develop good policy in such a morally and ethically charged environment, particularly when little medical evidence exists. It is this lack of evidence that ultimately leads CAMH to advise that there be *no amendment to MAiD legislation for people with mental illness as their sole underlying medical condition at this time.* This paper outlines our rationale for this conclusion. It also summarizes several other considerations that decision-makers should reflect on when determining if MAiD should be available to people with mental illness who are not nearing natural death.

Legal background and context

Mental illness has been a part of the MAiD debate since the Supreme Court of Canada's ruling in February 2015. In that decision, the Court struck down the law prohibiting physicians from assisting patients to die under certain circumstances. The Court gave the federal government one year to develop a law that would allow for physician assisted dying (as it was named at the time) for competent adults who are suffering from a 'grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition' (para 127). The Court did not further define 'grievous and irremediable' or name specific medical conditions that would apply.

Since the Court did not explicitly exclude mental illness in its definition of a grievous and irremediable medical condition, some individuals and groups have argued that people with mental illness as their sole underlying condition should be able to access MAiD[5]. Others note that during the trial process the Court commented that international cases related to MAiD for mental illness were not relevant to the current case (para 111)[6] implying that mental illness is not within the scope of the Court's decision[7], or at least making the Court's intentions on the matter unclear[8].

When the federal government passed its MAiD legislation in June 2016, it restricted the 'grievous and irremediable' definition to mean a 'serious and incurable illness, disease or disability' where a person is 'in an advanced state of irreversible decline in capability', is experiencing 'enduring physical or psychological suffering intolerable to them which cannot be relieved under conditions they consider acceptable' and whose 'natural death has become reasonably foreseeable'. Similar to the Supreme Court's decision, the legislation does not specifically exclude individuals with stand-alone mental illness from accessing MAiD. However, it was acknowledged in the preamble to the legislation that it would be difficult for most people with mental illness as their only medical condition to qualify for MAiD under the law given that natural death is not typically a foreseeable outcome of mental illness (advanced eating disorders being the main exception).

Recognizing that the current law would limit most of those with only mental illness from accessing MAiD, and acknowledging the complexity of the issue, the government provided a commitment to explore 'requests where mental illness is the sole underlying medical condition'. Clarification from the

[5] Joint Centre for Bioethics, 2015; Special Joint Committee, 2016
[6] Carter v Canada, 2015
[7] Lemmens, 2017
[8] Walker Renshaw & Finley, 2015

Minister of Justice and Attorney General of Canada notes that this review will look at situations where people with mental illness are not in an advanced state of irreversible decline or nearing a natural death[9]. Essentially, the government is considering amending MAiD legislation so that people with mental illness as their only medical condition do not have to meet the criteria of irreversible decline and reasonable foreseeability of natural death.

Is mental illness a grievous and irremediable medical condition?

If the government were to decide that irreversible decline and reasonable foreseeability of natural death were no longer required criteria for MAiD, this would return us to a very broad definition of 'grievous and irremediable'. The question we are attempting to grapple with is whether mental illness even fits within a broader definition. Is mental illness a grievous and irremediable medical condition?

The grievousness of an illness is subjective and there is no doubt that mental illness can be grievous to individuals. CAMH patients and others with lived experience of mental illness talk openly about how their symptoms can cause enduring psychological and sometimes physical suffering. The irremediableness of an illness, on the other hand, is an objective determination which should be based on the best medical evidence available. And currently, there is no established standard of care that sets a threshold for when a mental illness should be considered irremediable[10].

Mental illness can be incurable

MAiD legislation equates irremediable with incurable. One interpretation of incurable is that the medical condition is terminal, irreversible or inevitable. Death by suicide can be a tragic consequence of mental illness. Fortunately, clinicians and care teams have good knowledge about the risk factors that heighten the risk of suicide and can use evidence informed interventions to reduce the likelihood that a person will die by suicide. Precautions such as acute hospitalization can also be taken if a psychiatric assessment indicates that a person is at a heightened risk of suicide. However, it is impossible for experts to predict a specific suicide event and conclude that an individual's death is proximal or inevitable due to their mental illness[11].

Incurable can also mean that it is impossible for a medical condition to fully abate. In this respect, many forms of mental illness could be considered incurable. Mental illness, like countless physical illnesses, is typically chronic and recurrent. These illnesses are not curable *per se*, but they are possible to treat and manage (e.g. with medications, rehabilitation, other lifestyle changes, etc.). Every day vast numbers of Canadians find ways to live well with chronic and recurrent illnesses. For this reason, the Canadian Psychiatric Association argues that this interpretation of irremediable is too broad to use in the current context because it would allow those with very treatable illnesses to access MAiD[12]. Others argue that MAiD should be available to the full array of individuals with chronic and recurrent illnesses[13].

Mental illness is treatable

Mental illness is usually manageable in that symptoms can improve with clinical treatment. There are currently a range of effective treatments for people with mental illness and research has provided some

[9] Downie & Chandler, 2017
[10] Gaind, 2016
[11] Large et al, 2016
[12] Gaind, 2015
[13] Downie 2017; Gokool, 2017

knowledge about personalizing these treatments[14]. The challenge is that each person responds differently to treatment and at this time it is difficult to determine which treatment will work for a particular individual[15]. Many people with mental illness and their care teams are able to find a treatment regimen that works for them after a brief period of time. For other people, this can take several years and various treatment protocols, but eventually most people are able to find ways to manage their symptoms.

For all people with mental illness, a recovery-based approach to mental health care can be beneficial for achieving and maintaining wellness. Recovery not only embraces personalized treatment and management of symptoms, but focuses on the development of the whole person, including autonomy and citizenship. Recovery-based care is central to the work of CAMH. Our clinicians and care teams provide ongoing support to patients as they develop skills to manage their mental illness, its symptoms and associated stigma. Recovery-based outcomes focus less on the presence or absence of symptoms, but on the ability to live as one chooses. While some individuals continue to experience symptoms of their illness, they can live meaningful lives.

The difficulty is that to date we are not able to predict the trajectory of any one individual's mental illness. Some people will recover (including from illnesses such as schizophrenia), some will have persistent symptoms and others will have worsening symptoms. At any point in time it may appear that an individual is not responding to any interventions – that their illness is currently irremediable - but it is not possible to determine with any certainty the course of this individual's illness. There is simply not enough evidence available in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness.

The law states that in order to access MAiD an individual must have an irremediable medical condition. Right now, there is not enough medical evidence to say whether someone's mental illness is irremediable or not. Given this lack of evidence and the gravity of the outcome of MAiD, it would be extremely risky at this time to amend legislation to provide access to MAiD for people whose only medical condition is mental illness and who are not in an advanced state of irreversible decline and nearing natural death. People with mental illness should have access to MAiD under the same circumstances as those with physical illnesses do - by meeting all of the criteria outlined in the current legislation.

Recommendation one: The federal government should not make an amendment to MAiD legislation for people with mental illness as their sole underlying medical condition at this time due to a lack of evidence that mental illness is an irremediable medical condition in individual cases.

Other Considerations

The core of CAMH's policy advice is informed by the lack of evidence that mental illness is an irremediable medical condition. However, there are also several other factors that decision-makers should take into consideration when determining if there should be an amendment to MAiD legislation for people with mental illness as their only medical condition.

[14] Ozomaro et al, 2013
[15] Simon & Perlis, 2010

Access to mental health care

In any given year, 1 in 5 Canadians experience a mental health or substance use problem[16]. Mental illness is the leading cause of disability in the country[17] and in Ontario the burden of mental illness is greater than the burden of cancer or infectious diseases[18]. Despite the prevalence and impact of mental illness, Canada has historically underfunded mental health care[19]. This means that many Canadians with mental illness are not able to access evidence-informed mental health care and supports.

Access to mental health care is problematic across the system. People with mental illness are less likely to have a primary care physician than those without mental illness[20] and those that do find it difficult to get proper screening, diagnosis and treatment for their mental illness in these settings[21]. Community-based mental health services have lengthy wait times, particularly for children and youth who can wait over a year and half for counselling or therapy[22]. In our own hospital, patients in CAMH's Emergency Department now wait 40% longer for an inpatient bed than they did five years ago[23]. Wait times to receive a range of vital services at CAMH and Ontario's other specialty psychiatric hospitals have also increased significantly in the past five years[24].

Individuals who live in poverty can have even more difficulty accessing mental health care. Limited resources and supports can make it difficult for them to navigate the complexities of the mental health system. Public drug plans frequently limit access to innovative medications[25]. Structured psychotherapy – a well-recognized, non-pharmaceutical treatment for mental illness - is not widely covered by provincial health insurance plans. People who live in poverty simply cannot access this highly effective treatment.

Federal and provincial investments in mental health care have increased recently, but there is still a long way to go before all Canadians have equitable access to evidence-informed mental health care and supports. This is a concern for many when it comes to MAiD. Should Canada provide access to MAiD for mental illness as a sole underlying condition when 1/3 to 1/2 of Canadians with mental illness are not getting their needs met in the current healthcare system[26]? Mental health service users talked about this at the CAMH and Empowerment Council event. They voiced concerns about lack of access to mental health care and talked about the need to improve access to a range of mental health treatments - not just medications. Some thought it was 'frightening' to think about providing MAiD for mental illness in the current health care climate. Others thought that it was unfair to restrict access to MAiD and force people who are suffering to wait for improvements in the mental health care system that could take years to materialize.

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[16] Smetanin et al, 2011
[17] MHCC, 2014
[18] Ratnasingham et al, 2013
[19] WHO, 2011
[20] Bradford et al, 2008
[21] CAMH, 2016
[22] CMHO, 2016
[23] OAGO, 2016
[24] Ibid
[25] CEADM, 2017
[26] Pearson et al, 2013; Patten et al, 2016

Social determinants of health

The social determinants of health have a significant impact on physical and mental health[27]. For people living with a grievous illness, poor social determinants of health can impact suffering and the ability to cope. This is particularly relevant when determining whether MAiD legislation should be amended to expressly allow access to MAiD for people with mental illness as their only medical condition, as people with mental illness disproportionately experience poor social determinants of health.

People with mental illness are vulnerable to isolation and a lack of social support[28]. They have lower incomes, are less likely to participate in the labour force and are less likely to have adequate housing than people with other types of disabilities and people without disabilities[29]. Affordable and supportive housing in particular is known to be a key component of recovery for people with mental illness[30], yet many are homeless or living in substandard accommodations[31]. This is concerning given that it is often the psychosocial dimensions of suffering that motivate individuals to request euthanasia or assisted suicide[32]. To address this, some disability advocates have recommended adding safeguards to the MAiD assessment process to ensure that poor social determinants of health are not motivating peoples' requests[33]. At the CAMH and Empowerment Council's event with mental health service users, several individuals stressed that isolation, lack of social support and quality of life must be part of the conversation on MAiD and mental illness.

Recovery

Many mental health care providers, including CAMH, are committed to the recovery philosophy. In the mental health field, recovery is seen as a life long journey that focuses on autonomy, empowerment, choice, personal growth and meaningful social inclusion[34]. Providers of recovery-based care support people by delivering self-directed, individualized and strengths-based mental health care[35]. At the core of recovery-based care is the hope and the belief that people can and will overcome obstacles[36].

When considering MAiD and mental illness through a recovery lens differing viewpoints emerge. For some, the focus on autonomy means that people with mental illness should be able to choose from a full range of health care options, and some see MAiD as one of these options. They express concern that denying people who are suffering from mental illness the same options as those suffering from physical illnesses could reinforce stigma[37], as well as discrimination and institutional paternalism towards those with mental illness. Some mental health service users at the CAMH and Empowerment Council discussion said that if they knew they might have the option of MAiD it would lessen their pain and suffering. They talked about how having the option to die on their own terms would make it easier to live. While these individuals did not think that they would actually access MAiD themselves, there are

[27] CMA, 2013; ESDC, 2016
[28] Granerud & Severnsonn, 2006; Boardman, 2011; Linz & Strum, 2013
[29] As cited by the OHRC, 2015.
[30] MHCC, 2012
[31] Ibid
[32] As cited in CACL, 2016
[33] CACL, 2016
[34] Department of Health , 2011
[35] APA, 2012
[36] Ibid
[37] Walker-Renshaw, 2015

others who, given the option, would go ahead with MAiD[38] . While some individuals would see this outcome as evidence of autonomy and empowerment, others would see it as a failure of recovery-based care.

When a person is suffering from a grievous mental illness, it is the role of recovery-based care providers to offer support, teach coping strategies and remind the individual that their life is valuable. Mental health care providers recognize that there is always a degree of risk when providing recovery-based care. Adhering to a philosophy of autonomy and empowerment means that there may be times when a mental health care provider does not agree with a person's capable decisions. But these providers do need to intervene if someone is at risk arising from decisions that are made while they do not have decision-making capacity. Mental health care providers must find a balance between supporting positive risk taking and ensuring safety[39], especially as a person's judgment becomes more impaired by illness. For many mental health care providers, empowering their patients to access MAiD would push that risk taking beyond the limits of their duty of care and compromise their other responsibilities to promote life and (to the extent possible) prevent suicide.

Consent and capacity

Capacity has been central to the debate on MAiD and mental illness. Criteria in both the Supreme Court's decision and government legislation require individuals to be capable of making their own healthcare decisions. Overall, there seems be consensus with this criteria.

Under the *Health Care Consent Act* (HCCA), a person is considered capable if they are able to understand information about the treatment being offered to them and appreciate the consequences of accepting or not accepting this treatment. It requires that the person be able to apply this information to their own situation[40]. It is also recognized that a person's capacity to make a particular decision about treatment can fluctuate over time and in relation to different treatment plans (that is, a person may be capable of making a decision about one kind of treatment, but not another)[41].

All people, including those with mental illness, are presumed capable unless proven otherwise[42]. A mental illness does not preclude capacity to make healthcare decisions. That being said, in cases where a person with a mental illness requests MAiD (where mental illness is the sole underlying condition or in cases of a co-occurring physical condition) determining whether or not an individual has capacity to make this request for MAiD is not an easy task. The concern is that many individuals with mental illness experience disordered insight or impairments in reasoning capacity that make it difficult for them to connect their symptoms with their illness, fully understand the risks and benefits of treatment, and/or make treatment decisions based on personal goals and values[43].

When a person experiences an acute episode of their mental illness (such as a major depressive episode or an acute psychotic episode), it is not uncommon for them to have severely distorted beliefs about themselves, the world, and their future. This can include the belief that death is a desirable option. But sometimes this sense of helplessness, worthlessness and hopelessness continues even when the

[38] Kim et al, 2016
[39] Department of Health, 2011
[40] Section 4(1) of the HCCA
[41] Neilson & Chaimowitz, 2015
[42] Ibid
[43] William & Fulford, 1998

symptoms of the mental illness are better controlled[44]. This distorted insight raises questions about the individual's capacity to make a MAID request during both the acute and less acute phases of their illness. Determining whether or not a request for MAID is driven by disordered insight is imperative given that MAID is not simply another healthcare decision.

There have been recommendations that capacity to consent to MAiD should be assessed using existing tools and practices[45]. The difficulty is that there is currently no specific tool that physicians are required to use to assess capacity in those with mental illness[46]. While the McArthur Competence Assessment Tool is seen by many authorities as the most comprehensive, neither this tool nor any others were developed specifically to assess capacity to consent to MAiD (though Trillium Health Partners have recently created their own MAiD Capacity Assessment Form)[47]. Some health care providers have recognized the complexity of assessing capacity in people with mental illness. They have argued for the development of better, more robust capacity assessment tools as well as education for health care professionals to improve their competency in assessing capacity in people with mental illness[48]. Others have called for a national standard to protect all vulnerable people who request MAiD by embedding safeguards in the criminal code that would set a benchmark for informed consent as well as requirements for a vulnerability assessment in response to all MAiD requests and prior independent review of all requests by a judge or review board[49].

International Experiences

Any decision to amend Canada's MAiD legislation to provide access to MAiD for people with mental illness as their only medical condition should be informed by the experiences in other jurisdictions where it has previously been legalized. MAiD – known internationally as euthanasia and/or assisted suicide (EAS) - is legal in Belgium, Columbia, Germany, Japan, Luxembourg, the Netherlands, Switzerland and several US states (California, Colorado, Montana, Oregon, Vermont, Washington and the District of Columbia). EAS for mental illness as a sole underlying condition is available only in Belgium, Luxembourg, the Netherlands and Sweden. The little data that exists comes primarily from Belgium and the Netherlands.

EAS for mental illness is uncommon in both Belgium and the Netherlands. In 2015, 15% of all Belgian EAS cases were individuals with non-terminal illness[50] including roughly 3% who had a mental illness[51]. That same year, 1% of all EAS cases in the Netherlands were individuals with mental illness as their main condition (this number increased from .01% of all EAS cases in 2008)[52]. Two recent case reviews provide some insights about individuals who request and follow-through with EAS for mental illness in these two countries[53].

In Belgium, a review of 100 consecutive cases of requests for EAS by individuals with mental illness as their main condition found that most were women with depression and/or a personality disorder. Their

[44] Grant & Beck, 2009
[45] Special Joint Committee, 2015
[46] Dembo, 2017
[47] Ibid
[48] Expert Advisory Group, 2015
[49] CACL, 2016
[50] As cited by Kim, 2017
[51] As cited by Aviv, 2015
[52] As cited by Kim, 2017
[53] Thienpont et al, 2015; Kim, 2016

average age was 47. Of the 100 requests, 35 went ahead with EAS. Of the 65 who did not proceed with EAS, 38 withdrew their request before a decision was made and 11 withdrew their request after approval. Eight (8) individuals continued to pursue their requests, 6 died by suicide and 2 died of natural causes. At follow-up a year later, 48 of the 57 people who were still living had put their requests on hold because they were 'managing with regular, occasional or no therapy'[54].

In the Netherlands, a review of 66 cases of completed EAS for mental illness also found that most were women with depression. The majority were older than 50. Most patients had extensive treatment histories, but 56% had refused at least some treatment due to low motivation. Only 39% of patients had received ECT at some point in their treatment trajectories. In 24% of cases there were disagreements amongst physicians on whether the individual met all of the EAS criteria. Most physician disagreement was around the futility of the person's illness (81%) and/or the patient's competence (50%). Researchers also noted that social isolation and loneliness were key themes in patients' histories[55].

While the number of EAS cases is low and interpretation of case histories is potentially subjective, these two studies raise some concerns about the practice of EAS in situations where mental illness is the main condition. Specifically, doctors are not always consistent in applying EAS criteria, which are vague and rely on clinical judgments in situations where there is little evidence. This can be exacerbated in the absence of practice guidelines[56]. The findings of both of these studies raise concerns about the possibility that some patients receiving EAS for mental illness will not be capable, will have a treatable condition that would have improved, and will have changed their minds about EAS even if they had continued to experience suffering[57].

Inclusive consultation

Public discourse on MAiD has mainly been dominated by professionals, many of whom are white and belong to mainstream culture. CAMH has engaged with people with lived experience in the development of our policy advice, but we recognize that we have still only heard from a limited number of individuals. It was clear at the event that we hosted with the Empowerment Council that many people were only beginning to hear about the possibility of a change to MAiD legislation for people with mental illness as a sole underlying condition. There was a sense that they had not had enough time to process the complexity of the issue, the implications of such a legislative change, and the arising dilemmas. Questions of community responsibility, discrimination, accountability and care have yet to be explored and appraised. CAMH recognizes that the CCA must gather, summarize and submit its findings to the government by December 2018. It is imperative, however, that decision-makers ensure that people with lived experience of mental illness are fully engaged in this process throughout. The voices of family members, racialized groups, ethnic communities and Indigenous peoples should also be sought to help inform this decision.

The decision of whether to amend MAiD legislation should be grounded primarily in the lack of medical evidence that mental illness is an irremediable medical condition. Other considerations, however, should also help inform the decision.

[54] Thienpont et al, 2015
[55] Kim, 2016
[56] Dierickx et al, 2017
[57] Kim, 2017

Recommendation two: Decision-makers should consider the following when determining whether or not to amend MAiD legislation for people with mental illness as a sole underlying medical condition: access to mental health care; the social determinants of health; recovery and recovery-based care; consent and capacity; international experiences; and inclusive consultation.

In summary, MAiD is a complex moral and ethical issue. Determining whether to amend MAiD legislation so that people with mental illness as their only medical condition do not have to meet the criteria of irreversible decline and reasonable foreseeability of natural death adds further emotion and opinion to the debate. While there are various factors that decision-makers should consider – including the ones we have outlined in this paper – good public policy should be evidence-informed. And in this case, the lack of evidence that mental illness is an irremediable medical condition in individual cases should ultimately guide decision-makers to conclude that an amendment to MAiD legislation for people with mental illness as their sole underlying medical condition should not be made at this time.

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