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Article abstract

The numbers of individuals with Alzheimer's disease and other dementias are growing rapidly in North America and the rest of the western world. In most jurisdictions there is a major societal challenge to provide appropriate care for these individuals as well as their families. At present in North America, it is not possible for a person with dementia, while anticipating the declining trajectory of their disabling illness, to indicate to their substitute decision makers (SDM or proxies in the USA) a request for medical assistance in dying (MAID). This is the case even if at the time of making the request the person is legally capable of taking such a decision using the criteria for MAID in other clinical situations. The question is why a person with Alzheimer's disease or other causes of dementia should not be able to anticipate their decline while still capable. And if so, to instruct their designated decision-maker to request and obtain MAID, their indicated preference in a legal advance directive.

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ÉTUDE DE CAS / CASE STUDY

Why Not Advance Directives for MAID in Those with Dementia?

Michael Gordon[a]

Résumé
Le nombre de personnes atteintes de la maladie d'Alzheimer et d'autres démences augmente rapidement en Amérique du Nord et dans le reste du monde occidental. Dans la plupart des pays, un défi sociétal majeur consiste à fournir des soins appropriés à ces personnes ainsi qu'à leurs familles. À l'heure actuelle, en Amérique du Nord, il n'est pas possible pour une personne atteinte de démence, tout en anticipant la trajectoire déclinante de sa maladie invalidante, d'indiquer à ses mandataires spéciaux (SDM ou proxies aux États-Unis) de demander une aide médicale à mourir (AMM). C'est le cas même si, au moment de la demande, la personne est légalement capable de prendre une telle décision en utilisant les critères de l'AMM dans d'autres situations cliniques. La question est de savoir pourquoi une personne atteinte de la maladie d'Alzheimer ou d'autres causes de démence ne devrait pas être en mesure d'anticiper son déclin alors qu'elle en est encore capable. Et si c'est le cas, de demander à leur décideur désigné de demander et d'obtenir l'AMM, la préférence indiquée dans une directive préalable légale.

Abstract
The numbers of individuals with Alzheimer's disease and other dementias are growing rapidly in North America and the rest of the western world. In most jurisdictions there is a major societal challenge to provide appropriate care for these individuals as well as their families. At present in North America, it is not possible for a person with dementia, while anticipating the declining trajectory of their disabling illness, to indicate to their substitute decision makers (SDM or proxies in the USA) a request for medical assistance in dying (MAID). This is the case even if at the time of making the request the person is legally capable of taking such a decision using the criteria for MAID in other clinical situations. The question is why a person with Alzheimer's disease or other causes of dementia should not be able to anticipate their decline while still capable. And if so, to instruct their designated decision-maker to request and obtain MAID, their indicated preference in a legal advance directive.

Mots-clés
directives anticipées, démence, fin de vie, AMM

Keywords
advance directives, dementia, end-of-life, MAID

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CASE STUDY

Mrs. ND is an 82-year-old woman who had been seeing me in my geriatric clinic in Ontario, Canada for four years. She was first referred because of episodic forgetfulness which over the years progressed to more serious cognitive decline, including losing items, getting lost and requiring more care for her basic activities of daily living. As she began to deteriorate, she asked me if she could incorporate into her advance directive a statement that should she lose her ability to care for herself because of dementia, including basic activities of daily living, she wished to receive MAID. I told her that there was no provision in the current Canadian legislation for such a document.

At the time, she would not have qualified for a Track 1 (a medical condition in which the trajectory is foreseeable, and the person is experiencing unacceptable suffering) positive assessment as her moderate dementia (likely of mixed vascular and Alzheimer's etiology was not immediately foreseeable). Track 2 (death is not foreseeable, but there are clinical grounds that might be deemed sufficient in terms of suffering) would not have been deemed permissible as the "suffering" would be hard to determine. Emotional reasons (mental health disorders) were not considered as reasonable conditions for which a person could be provided with MAID (1).

The conundrum for the family was this: although Mrs. ND could continue to participate in some of her basic activities of daily living, she already needed help in bathing and some in dressing – this was especially humiliating for a person who previously was very active and concerned about her appearance. She often expressed to her children in her somewhat mixed-up sentence structure that "I wish it were over, I want to get out of here" (meaning they thought her retirement home and her life). The family provided daily companion help, and their mother did participate in some social programs, especially the music program and continued to enjoy the music that she heard on the radio.

As she became more impaired and began to have problems with maintaining her weight, despite food supplements, the family wondered what could be done. Although she expressed her "death wish" it was felt by the physicians caring for her that she was no longer capable of requesting MAID at this point, even though it was felt that her trajectory for end-stage-dementia was now in the foreseeable future. Eventually, she could no longer eat, aspirating quite often, and subsequently required hospitalization for aspiration pneumonia. She was admitted to palliative care with instructions by the family, who were her substitute decision-makers (SDM), to treat her with comfort measures only. At the next episode of chest infection, they requested that antibiotics not be given. Their mother recovered spontaneously but three months later she succumbed to an episode of pneumonia with two days of laboured breathing, disturbing coughing and acute delirium that required neuroleptic medications to calm her down and keep her from pulling on her intravenous lines and from trying to climb out of bed. She died in the presence of her three children. Her children (who included her SDM) expressed to the palliative care physician their despair that earlier in their mother's disease progression she could not indicate and legally receive MAID at the point that she required palliative care, which did not meet all her symptomatic needs.

DISCUSSION

The story of assisted suicide, or in Canada what it is called MAID (Medical Assistance in Dying), is referred to in other countries as Physician Assisted Suicide or voluntary euthanasia. It has in fact a long history before it became an issue in the 20th century, first in the Netherlands and other European Countries, then in the United States, with Oregon being the first state to legislate its existence. In Canada, the process took several years with its first approval coming in 2016 following a Supreme Court ruling. Over the following few years, it became a federal law.

In the earlier iteration of MAID, the criteria were reasonably straightforward, with the intended goal to deal with those with serious and demonstrable illnesses in the terminal phase, whose outcome was foreseeable and caused suffering on the part of the requesting person. The assessment included a determination of capacity to make the decision, an understanding of reasonable alternatives, and the opportunity to cancel the request right up until the moment of the fatal injection. There were to be two independent assessors who must agree on the clinical criteria and the reasonableness of the request. Either one of the assessors or a different third party would be responsible for administering the fatal drugs. Each case would be reported to the regional coroner to assess that all the steps were followed according to the legislation. Such cases fell into what was called the Track 1 criteria.

As a relative newcomer to MAID assessments, I have been involved with three such Track 1 cases. The first involved a patient with metastatic cholangiocarcinoma who received three courses of chemotherapy from which she suffered enormous side effects. She had constant pain which required large doses of opiates. She was offered a new round of chemotherapy with a newer medication. When questioned she told me she did not want any more chemotherapy of any kind, she could not tolerate the pain and could not tolerate the analgesia. She claimed that she had a good life, and she was prepared to die and had the support of her loving family. Because she was on the palliative care unit of a Catholic hospital, the injection would be provided in her own home – she welcomed this as she told me that she wanted to say goodbye to her much-adored cat.

The second case was that of a male nurse who, during the investigation following a motor vehicle accident, was found to have lung cancer with evidence of metastases to his bones. As he told me during my assessment, he had witnessed patients who went through the treatments for metastatic lung cancer and their suffering. He was already on substantial doses of opiates which played havoc with his body. He chose MAID. He had no family in Canada but indicated that his family overseas supported him in his decision. He went to (MAID House) an independent facility in the community to receive his fatal injections.

The third patient was a woman in her seventies with end-stage chronic lung disease. She had just been transferred to the palliative care unit. She wanted MAID because she had just survived another bout of pneumonia but was bedridden, or if helped, could sit in a chair. She needed constant low-flow oxygen and help with all her basic activities of daily living. She could not walk unassisted to the washroom and could not even shower without help, so received only sponge baths. When meeting with me in my capacity as the MAID assessor, she admitted that she had enough with her illness and could not bear to go on with living. She understood what the future had for her as she had experienced short periods on a ventilator during previous acute infections. She felt she had a good life and was ready to leave it. She said as a religious person she was prepared for the afterlife and welcomed it. She was transferred home to die by fatal injection.

What is the concern of the person with dementia who is still capable of understanding and appreciating the likely trajectory of her illness? This is especially the case if, like Mrs. ND described above, she has witnessed the decline of her mother and the end-stage dementia and her suffering, bedridden, receiving nourishment via a permanent feeding tube. If rather than dementia this same person had Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) she would qualify for MAID in many cases. But an advance directive that indicates the status of the patient when a substitute can make the decision is not allowed. With ALS the person is usually cognitively capable to make such a decision at the time, whereas the person with dementia might not be so capable.

According to a recent article in the Washington Post (2), the demographic imperative is upon us. Reporting on statistics in the US (which is mirrored in much of the western world), it is noted that:

> As the over-65 demographic has ballooned, however, the number of people experiencing dementia has risen, too – to about 7 million as of 2020. The figure could approach 12 million by 2040. Inevitably, people with dementia have become much more prevalent in assisted-living centers. About a third of assisted-living residents have dementia, according to the Alzheimer's Association. (2)

The article focuses primarily on the need for care, whether in assisted living facilities or nursing homes, but does not address the issue of late-stage dementia and end-of-life care. The processes for assisted suicide in those US states that have legalized it would not be of any help to people living with later-stage dementia as they would not be deemed to be capable of making the decision. Also, in those states in which it is legalized, the process does not include euthanasia but rather the provision of medications to be taken by the person approved for assistance in dying.

In the Netherlands and other European countries, where assisted suicide has been in existence for many years, and long before it became available in Canada or the United States, it is possible to make a provision for a substitute decision-maker (SDM; or health care proxy in the United States) to act on an advance directive to obtain assistance in dying. The question should be asked, "why should not a person with diagnosed dementia of Alzheimer's or other varieties, in which the trajectory is well established not be allowed to provide an advance directive to their SDM, instructing them to request assistance in dying under defined circumstances?" (3)

From the perspective of ethics, the answer should be clear. Respect for the person's autonomy is a core value underpinning the process of advance directives and the role of the SDM. The beneficence of not requiring a person to suffer the physical and emotional indignities of end-stage dementia would seem self-evident. Many such individuals are admitted to palliative care units to meet their complex physical and emotional requirements. Depending on the jurisdiction this care may not be readily available, but increasingly such individuals qualify for and benefit from late-stage dementia care (4,5).

Providing such an option prevents unnecessary to harm to the patient which fulfills the principle of non-maleficence, defined in the four principles of Beauchamp and Childress. As I outlined clearly in my book on late-stage dementia, many treatment modalities may be required to address the physical and emotional suffering that people experience during this stage of life and illness (5). The application of the principal of justice should also be self-evident. It is unfair that persons with dementia, as compared to many other late-stage terminal illnesses, do not have access to the option and legal right to determine how they wish to die given that an SDM can fulfill that decisional wish (4).

The addition of diseases that affect the brain, especially the cognitive and psychological functions, to eligibility for MAID has caused a great deal of controversy in terms of eligibility. The exploration of what constitutes a "mental illness" and its suitability for MAID is under review in Canada (in 2024). If the legislation eventually allows for that category for inclusion, those requesting Track 2 eligibility will likely increase, and if so, the question of advance directives will become even more pressing (6,7).

QUESTIONS

1. If an advance directive were allowed for those with dementia, how would you configure one that would address the wishes of a person who is losing their cognitive abilities?
2. Would a request for MAID be a reasonable part of the current legislation or would it more likely be considered a mental health condition and be in a special category?
3. Would it be necessary to forgo the requirement of proof of capacity to confirm the MAID decision if the advance directive were formulated for late-stage dementia? Would the SDM/proxy be allowed to act on the advance directive?

CONCLUSION

Late-stage dementia is not a mental disorder, even though it may have symptoms and signs often associated with psychiatric disorders such as delusions and paranoia. It is a neurological disorder, more akin to cerebrovascular diseases (which are one of the causes or exacerbators of dementia), or late-state Parkinson's disease, or the result of frequent head injuries now recognized in many contact sports (8,9). Therefore, in Canada in particular, where MAID is available to those with neurological disorders during their later stages, individuals with dementia should be legally allowed to appoint a SDM with instructions as the circumstances under which they can access MAID to provide a humane and respectful death.

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