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Dementia and MAiD

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MAiD assessors and providers will encounter patients with some form of dementia in two ways. In the first instance, they may be asked to assess a patient who has a dementia but the primary diagnosis underlying the MAiD request is based on a different underlying illness, such as cancer or heart failure. In the second instance, the MAiD request may stem directly from the dementia itself. An understanding of the context in which MAiD is provided when dementia is present may be helpful for MAiD assessors and providers. Here, we will also explore the diagnosis of dementia itself to support MAiD assessors and providers as they engage with patients and families around this complex diagnosis.

Context

It remains uncommon for a Canadian dementia patient to receive provision of MAiD. The MAiD Death Review Committee of the Office of the Chief Coroner in Ontario has specifically considered dementia with their 2025 report, “Navigating MAiD with Persons with Dementia.[1]” Between January 1, 2023 and December 31, 2024, there were 103 MAiD provisions in Ontario with cause of death indicated as dementia.[1] Of these, 102 were Track 1 MAiD provisions, occurring when patients have a naturally foreseeable death. MAiD provisions for dementia represented 1.1% of all MAiD provisions in Ontario over that time period. In addition, further analysis of the data from 2023, which included not only those who received MAiD for dementia but also those with a dementia diagnosis within two years prior to MAiD provision, identified 235 individuals who received MAiD in 2023. Of these, 39 MAiD provisions were attributable to the dementia itself. In contrast, the majority of cases (196/235, 83%) involved individuals for whom dementia was a significant aspect of their presentation but not the primary reason for requesting MAiD.[1] These findings suggest that it is more common to access MAiD with dementia, rather than for dementia. For context, in Ontario in 2023, an estimated 182,573 individuals were living with a dementia diagnosis and there were 15,662 deaths among individuals with dementia.[1] The vast majority of deaths in dementia patients are therefore not MAiD deaths.

Major Neurocognitive Disorder

Clear and consistent language is important for MAiD clinicians when assessing patients with a dementia. The category word “dementia” has been replaced in the DSM-5 by the term “major neurocognitive disorder” to describe a range of illnesses, with specific illnesses retaining the dementia label i.e., Alzheimer’s dementia, Lewy Body dementia. While this change has been adopted by many practitioners in the field, the term “dementia” has remained pervasive in the collective consciousness of the medical community and the general public. See **Table 1** for a brief overview of dementia.

A major neurocognitive disorder is defined by a significant decline in at least one of the following cognitive domains: complex attention, language, executive functioning, learning and memory, perceptual motor function, or social cognition. A major neurocognitive disorder must be accompanied by a decline in function and may be categorized as “mild”, with impairments in instrumental activities of daily living (managing finances, grocery shopping), “moderate”, with impairments in basic activities of daily living (dressing, bathing, toileting), or “severe” with total dependence.[2] Each type of neurocognitive disorder, such as Alzheimer’s disease, has specific additional criteria beyond the general criteria described above.

An understanding of cognitive domains is crucial to recognizing the profiles of the major neurocognitive disorders. Complex attention describes the ability to focus and attend to a specific task. Language refers to both expressive speech/writing and receptive language comprehension. Learning and memory refers to both the registration and retrieval of new information, as well as short-term and long-term memory function. Executive functioning includes skills such as planning, organizing, sequencing, and abstraction (an example of abstraction would be the ability to categorize two items). An example of a task that involves significant executive functioning is arranging for an appointment at a doctor's office. Perceptual motor function includes complex movements, such as dressing and bathing, as well as more basic domains of cognition such as visual and auditory processing. Social cognition refers to capacities such as empathy and the ability to follow social norms of behaviour.

Cognitive impairment, even when profound, does not always indicate the presence of a neurocognitive disorder. It is crucial to have a thorough assessment and diagnosis of a suspected major neurocognitive disorder to avoid overlooking reversible causes of cognitive impairment, such as untreated sleep apnea, B12 deficiency, delirium, untreated major depressive disorder, other mental disorder, and active or recent substance use including alcohol. An assessment to diagnose a major neurocognitive disorder should include a full history and physical, appropriate laboratory investigations, neuroimaging, and formal cognitive assessments. In addition, the diagnosis of a major neurocognitive disorder should be as specific as possible with respect to the type of disorder, such as Alzheimer's disease, vascular dementia, Lewy Body dementia, frontotemporal dementia, or mixed dementia.

An accurate diagnosis is particularly important in the context of MAiD, as it informs the prognosis and, specifically, the irremediability of the condition and the foreseeability of the person's death. Neurodegenerative etiologies such as Alzheimer's disease and Lewy body disease involve progressive deterioration in function leading to death. As patients live longer and present with increasing medical complexity, co-pathology (i.e., major neurocognitive disorder due to multiple etiologies) is common. However, there is often a predominant etiology that drives the patient's cognitive or behavioural symptoms.

The MAiD assessor is not expected to make the diagnosis of a major neurocognitive disorder, but is expected to exercise due diligence in ensuring such a diagnosis is made. If concerns about cognition arise during the course of a MAiD assessment, the assessor should refer the patient to an appropriate clinical service for formal evaluation. In accordance with national guidelines on assessing capacity to consent in the context

Clinical History on Initial Presentation	**Cognitive Impairment Profile**	**Cognitive Test Affected**	**Common Disorder**
Rapidly forgetting, repetitive	Amnestic	Delayed recall	Alzheimer's disease
Slow thinking, slow movement, executive dysfunction, and vascular comorbidities	Executive dysfunction Slow processing speed	Trails Clock draw	Vascular dementia
Behavioural changes Apathy or disinhibition	Normal Or mild executive dysfunction	Normal Or clock draw	Frontotemporal dementia behavioural variant
Fluctuations Visuospatial	Executive dysfunction	Figure copy Clock draw Trails	Lewy body dementia Parkinsons disease dementia
Language impairment	Language-predominant impairment	Globally impaired Boston naming	Primary progressive aphasia (several subtypes)

Table 1. Brief Dementia Overview; *adapted from Tang-Wai, DF et al., 2018*

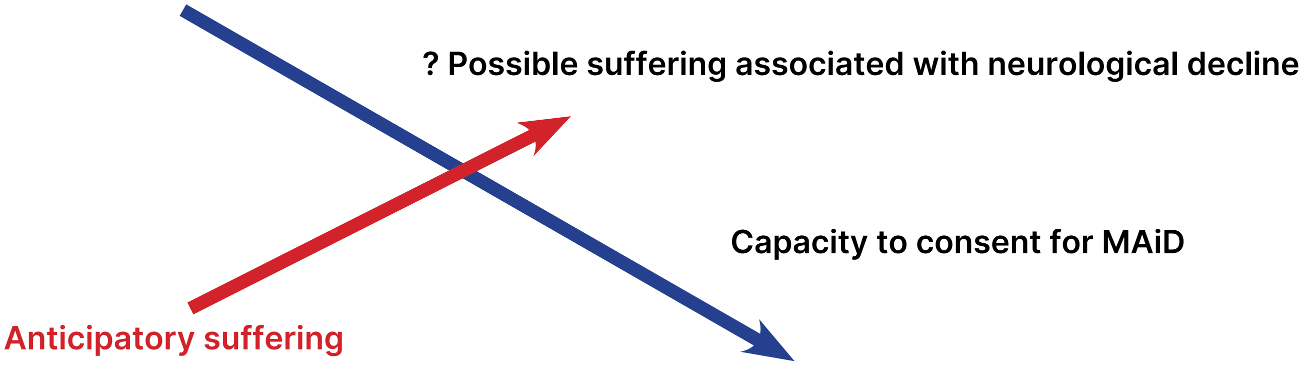

Figure 1. Anticipatory suffering in early stages of dementia; *courtesy of Mark Lachmann, MD, MHSc, MA, FCFP, FRCPC, Gina D. Eom, MD, PhD, FRCPC, Eric E. Brown, MD, MSc, FRCPC*

of cognitive impairment and MAiD, structured instruments such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) may be utilized. Cognitive screening tests are also suggested as a component of the assessment of cognition in support of a thorough capacity evaluation.

Anticipatory suffering refers to the present psychological distress experienced by individuals with dementia, arising from the awareness that they may—or will—progress to a future state of significant cognitive and functional decline. This fear of a more advanced disease state can manifest as intolerable psychological suffering in the present. According to the Alzheimer Society of Canada, many individuals living with dementia experience anticipatory suffering, and for a small subset, it may constitute a meaningful factor in seeking eligibility for MAiD. Anticipatory suffering should not be confused with "anticipating suffering" in the future, but rather a current state of significant psychological distress.

Among individuals who received MAiD for dementia (where dementia was identified as the primary condition contributing to suffering) in Ontario between January 2023 and December 2024, the top five aspects of suffering, in descending order, were inability to engage in activities, loss of independence, loss of ability to perform activities of daily living, loss of dignity, and emotional distress, including anxiety, fear and existential suffering.[1] A key eligibility criterion to access MAiD is the patient's experience of "enduring physical or psychological suffering that is intolerable to the person and cannot be relieved under acceptable conditions.[3]"

The evaluation of suffering by the MAiD clinician is an essential part of the MAiD assessment. Many common major neurocognitive disorders, including Alzheimer's disease and Lewy body disease, are neurodegenerative, progressive, and terminal illnesses, with a somewhat variable course depending on the nature of the dementia. Evaluation of suffering, however, means that the MAiD clinician must engage deeply with the patient and place the illness experience in the context of their particular life history and circumstances. When evaluating suffering in a person with a major neurocognitive disorder, the clinician must evaluate the dementia experience in the context of the patient's personhood through a detailed personal and social history.[4,5] As part of this assessment of suffering in a major neurocognitive disorder, other modes of relieving distress should also be explored, such as access to palliative care, increased home and community supports, or other supports as available.[6,7]

Available Treatments

While disease-modifying therapy is changing rapidly in the field of dementia care, there are currently still no treatments that can meaningfully reverse or halt neurodegenerative major neurocognitive disorders. Some treatments including newer biologics can help delay or slow the progression of cognitive symptoms, or alleviate some of the behavioural and psychiatric symptoms associated with dementia that can contribute to suffering, such as depression and anxiety. Ongoing physical and social engagement are key to the care of the dementia patient. Palliative care is most often engaged in subsequent dementia care stages, and plays a pivotal role to alleviate various symptoms and forms of suffering.

Voluntariness

All major neurocognitive disorders affect thinking and memory, and thus there are concerns that patients may be vulnerable to coercion across multiple domains. Careful inquiry into the motivation, degree of resolution, duration, and consistency of the patient's request for MAiD is essential and should be documented. As a MAiD assessor and provider, it is essential both to interview the patient with family and supports present, and to interview and assess the patient individually in a safe and confidential environment, with these conversations clearly documented.[8,9]

Capacity

Careful inquiry into decision-making capacity is essential in all MAiD assessments and even more so in the presence of a major neurocognitive disorder. MAiD assessments in dementia are, in practice, usually considered complex assessments de facto, due to the progressive decline in cognitive capacity to consent. Assessing capacity involves determining whether the patient understands their underlying medical condition, treatments available to them, or palliative measures available and applicable to their circumstances, and the nature of the MAiD procedure, as well as whether they appreciate how the decision to access or decline MAiD applies to their particular circumstance.[10] In exploring how a patient appreciates their own condition and the option of MAiD, the MAiD clinician also explores the patient's personhood and considers how the MAiD request aligns with the patient's pattern of decision making over their life course.[11,12] Clear documentation of the determination of the patient's capacity or incapacity, along with the facts that informed this conclusion, is essential.

Advance Requests

Advance requests for MAiD are currently permitted only in Quebec and are governed by a specific set of requirements intended to assist clinicians in determining when, along a major neurocognitive illness course, MAiD may be provided.[13] The use of advance requests for MAiD in Quebec has been described as having broad public support within the province.[14] A challenge for the use of advance requests specifically in dementia care is that the individual's current self does not actually know how their future self will, or will not, experience suffering in the face of specific loss of function, such as losing the ability to recognize family members or feed oneself.[15] While these anticipated losses may cause the present self to experience intolerable suffering, it remains unclear whether the person will subjectively experience suffering in the moment as dementia progresses. Furthermore, Quebec's legislative language around advance requests for MAiD involves the subjective opinion of the provider that the patient appears to be suffering.[16] The Canadian conversation around advance requests for MAiD is ongoing.

Waiver of Final Consent

The waiver of final consent option was established for patients seeking MAiD whose death is reasonably foreseeable and for whom, while eligible and capable, have selected a date for the MAiD procedure. The waiver permits MAiD to proceed if the patient loses capacity for final consent just prior to the MAiD procedure. However, it also instructs the MAiD provider NOT to provide MAiD if the patient "demonstrates refusal or resistance to the administration of MAiD by words, sounds, or gestures." Under Federal legislation, there is no time limit on the validity of a waiver of final consent once someone is approved for MAiD. In contrast, Quebec legislation imposes a 90-day limit, and the intent is clear that the waiver of final consent is NOT a form of advanced request[17] A good faith interpretation of the waiver of final consent is that it is intended for individuals seeking MAiD who are at risk of losing capacity due to the underlying illness state and who have scheduled a MAiD procedure while still capable, usually some weeks, or possibly several months in the future. The most common medical cause of loss of capacity to give final consent is delirium. According to Canadian Association of MAiD Assessors and Providers (CAMAP) guidelines, the waiver of final consent must be signed and documented by the intended provider of MAiD, that is, the final MAiD provider must personally obtain the prior waiver of final consent.

Conclusion

MAiD clinicians will assess patients with a major neurocognitive disorder who are requesting

MAiD either due to the major neurocognitive disorder itself or, more commonly, because of another serious illness in the context of co-existing major neurocognitive disorder. Most patients with a major neurocognitive disorder do not request MAiD. It is therefore essential to clearly identify and document that a diagnosis of a major neurocognitive disorder has been made. Establishing the type of neurocognitive disorder can inform the expected course of the illness as it relates to MAiD alternatives, as well as the MAiD process and eligibility criteria. MAiD assessors and providers should also ensure that patients with dementia, along with their care teams, have been offered local dementia and palliative care supports.[18,19] Understanding the pattern of cognitive impairment associated with a particular dementia subtype can be helpful in assessing the suffering experienced, and the decisional capacity of a particular patient. Careful exploration and documentation of the patient's lived illness experience, within the context of their life course, is essential when assessing a patient living with dementia for MAiD.

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Financial Disclosures

M.L.: None declared.
G.D.E.: None declared.
E.E.B.: None declared.

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