

MAID TASK FORCE REPORT & PRACTICE GUIDELINES FOR PSYCHOLOGISTS INVOLVED IN END OF LIFE DECISIONS

Canadian Psychological Association

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Executive Summary

Medical Assistance in Dying (MAiD) is now legal in Canada. Bill C-14 indicates that patients are permitted to access assistance in dying after following a clear process. This report highlights practice recommendations for psychologists involved in various aspects of end-of-life care, including the assessment and/or treatment of individuals requesting MAiD. Canadians eligible to access MAiD are at least 18 years of age, have the capacity to make their own health decisions, and have a "grievous and irremediable medical condition". They must also have without duress and of their own choosing made the request for MAiD and provided informed consent after being apprised of the alternatives, and again immediately prior to the provision of MAiD. Natural death must be reasonably foreseeable. This eligibility must be confirmed by two independent medical practitioners as defined in the legislation.

Part I of this document covers the legislation, research, and recommendations for the profession of psychology. Part II is the practice standards, based on the current research and practices that have been developing across Canada since the commencement of MAiD.

Potentially involved psychologists are encouraged to examine whether, and under what circumstances, they would be able to work with individuals who are considering MAiD. This includes personal views on quality of life, death, and dying. Our professional code of ethics underscores the need for objectivity/lack of bias in professional practice. As such, psychologists must either refer to another treating professional or offer care without judgement or debate about the care choice.

To engage in treatment, psychologists need to understand the frame of mind of the individual with whom they are working. Psychologists need to differentiate between a desire for death and a request for MAiD. However, psychologists also need to be mindful that we cannot counsel an individual to choose MAiD. Family members' treatment may target independence and meaning. Psychologists' involvement might also include staff support for the health care providers involved in MAiD.

Another key role for psychologists is capacity-to-provide-consent assessments in relation to MAiD. This necessitates specific competencies and targets the patient's understanding and appreciation, psychological state, and awareness of both MAiD and its alternatives. These assessments are only conducted to inform the medical professional's determination of eligibility.

Psychologists involved in MAiD must:

- Examine the potential impact of their own personal and professional beliefs;
- Be familiar with related legislation, regulatory requirements, and ethical principles;
- Be familiar with institutional MAiD related policies, procedures, and resources;
- Develop or seek consultation/supervision for competency;
- Restrict capacity assessments to informing medical assessment of eligibility;

- Offer psychological interventions that addresses issues related to end-of-life and unique to MAiD;
- Avoid dual roles of capacity assessment and treatment; and
- Avoid any such roles outside of a health care team.

However, any psychologist could potentially find themselves treating individuals for whom MAiD becomes a consideration, and therefore, further resources and tools are needed to support psychologists in these roles. Recommended resources include a resource bank of MAiD materials and fact sheets for individuals and families/caregivers/community on assessment for MAiD. Educational recommendations include webinars, ideally in collaboration with related professional organizations. Education surrounding MAiD should be covered in graduate programs to familiarize all students with basic issues around MAiD (legislation, ethics, culture, psychosocial, assessment, capacity and suicide assessment in the context of MAiD). Finally, there are significant knowledge gaps particularly in relation to psychological interventions and assessment in MAiD, how to best support individuals and health care providers in end of life decision making, and related end-of-life professional training programs. Further, research and advocacy is necessary to consider the needs of individuals, families, health care providers, and systemic considerations in relation to MAiD.

Introduction

With the introduction of Bill C-14 on June 17, 2016, Medical Assistance in Dying (MAiD) became legal in Canada. This followed the Supreme Court of Canada ruling in Carter v. Canada (February 2015), stating that the prohibition of MAiD violated constitutionally protected rights. Bill C-14 indicates that patients meeting clearly defined eligibility criteria are permitted to access assistance in dying after following a clear process for being assessed and providing informed consent. Although Bill C-14 also applies in Quebec, RLRQ (Recueil des lois et des règlements du Québec), c.S-32.001 (Bill 52) came into effect in Quebec on December 10, 2015, which specifies that patients can access a range of healthcare services at the end of life, including MAiD.

Subsequently, the Board of Directors of the Canadian Psychological Association struck a Task Force on "Medical Assistance in Dying and End of Life Care" (2018). One of the recommendations of this Task Force was that the CPA Board of Directors implement "*A task force charged with developing practice guidelines for psychologists involved in the various aspects of end-of-life care, including the assessment and/or counselling of individuals requesting MAiD.*"

https://www.cpa.ca/docs/File/Task_Forces/Medical%20Assistance%20in%20Dying%20and%20End%20o f%20Life%20Care_FINAL.pdf

The CPA Board of Directors sanctioned the development of a Task Force on Guidelines for End of Life care in 2018. Given the nature of the Task Force, which was to develop practice recommendations, CPA members with experience in and/or knowledge of various aspects of MAiD were approached to be part of the task group. The focus was specifically set as MAiD and targeted psychological interventions, assessment, and team and institutional collaborations." Members of the task group self-selected to serve on one of the three sub-groups. The sub-groups interacted over a period of several months via teleconferencing and email.

As psychologists' practice is grounded in evidence and research informed care, Part I of this document covers the legislation, research, and recommendations for the profession of psychology. Part II of the document focuses on the practice standards, based on the current research and practices that have been developing across Canada since the commencement of MAiD.

Mission of the Task Force

The mission of the Task Force was to provide:

- information on the context of MAiD, including research on the biopsychosocial factors that can influence end-of-life decision-making
- educational recommendations and resources to support psychologists in the competent practice of working with individuals through the spectrum of MAiD.
- guidelines for psychologists whose clients/patients, presenting for an unrelated issue, choose to consider or pursue MAiD.
- Guidelines for conscientious objection to working with individuals considering and pursuing MAiD.

PART 1 - Task Force Report

1. Medical Assistance in Dying (MAiD) in Canada

Eligibility Criteria for accessing MAID in Canada are as follows:

"241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria: (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;

(b) they are at least 18 years of age and capable of making decisions with respect to their health;

(c) they have a grievous and irremediable medical condition;

(d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure;

(e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

241.2 (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining. (GC, 2016)

Two independent medical or nurse practitioners must be of the opinion that the person requesting MAID meets all of the eligibility criteria. There must be 10 clear days between the formal request and the provision of MAID, unless the person's death or loss of capacity is imminent. Immediately prior to the provision of MAID, the person must be given an opportunity to withdraw their request and must give express consent to the procedure (GC, 2016)." According to the 4thInterim Report on Medical Assistance in Dying in Canada (Health Canada, 2018):

- 1,179 fulfilled MAiD requests occurred in the first 6 months of the passage of the Bill
- In the period between July 1 and December 31, 2017, there were 1523 fulfilled MAiD requests.
- In total, as of the 4th interim report, there were 6,749 individuals who accessed MAiD between ¹December 2015- October 2018.
- Due to low numbers of MAiD requests in these jurisdictions, there are privacy concerns in reporting MAiD access from the Yukon, the Northwest Territories, and Nunavut. These provinces are not included in the interim reports.
- <u>https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html</u> The vast majority of individuals who have requested MAiD thus far were 56 years of age or older; however, individuals from 18 through 90+ accessed MAiD.
- The majority of individuals had a primary diagnosis of cancer, while the second most prevalent diagnosis was respiratory/circulatory, followed by neurodegenerative (Health Canada, 2018).

¹ The 2015 information is limited to Quebec

2. Understanding Requests for MAiD

Working with individuals considering MAiD can be enhanced by an appreciation of the reasons that generally underlie patient requests. This information is not yet collected in Canada in a standardized way but is done so routinely in other jurisdictions. By way of example, in the U.S. state of Oregon, which has over 20 years' experience in the provision of MAiD via self-administration of prescribed medications, physicians who practice MAiD are required to report on patient concerns that led to the requests (Oregon Public Health Division Center for Health Statistics, 2018). Individuals tend to have more than one reason for considering MAiD. These include:

- loss of autonomy (90.9% of patients),
- inability to engage in activities that make life enjoyable (89.5%),
- loss of dignity (75.7%),
- loss of control of bodily functions (45.7%),
- concerns about being a burden to others (43.7%),
- inadequate pain control or worries about future pain control (25.8%).

Another body of research has conducted qualitative interviews with patients who have expressed a wish to hasten death (Rodríguez-Prat, Balaguer, Booth, & Monforte-Royo, 2017). Rodríguez-Prat and colleagues (2017) point out that expressions of a wish to hasten death do not always reflect a literal desire to receive MAiD; there can be different messages communicated in such expressions, some of which may be subtle and complex. In general, however, they all tend to arise from a place of suffering, due to physical, psychological, social, or existential concerns.

- *Physical factors* can include specific overwhelming symptoms and the loss of functional independence that comes with advanced disease.
- *Psychological factors* include, most prominently, fear or worry (about uncertainty, possible pain and suffering in the future, and the dying process) and hopeless resignation (due to the sense of lingering on in the face of an inevitable death).
- Social factors include self-perceived burden to others and increasing dependence for personal care. It can be difficult for people who have placed a high value on autonomy and self-reliance to accept a dependent social role. For them, MAiD offers an option that allows them to die with self-determination. In Canada, financial concerns can also be a factor for individuals and families who do not have access to extended health care benefits, which cover the cost of medications, in-home support services or respite care, etc. Financial and practical concerns also occur for individuals who do not have social support networks who can aid in their care.

• In the face of these physical, psychological and social problems, some may experience *existential concerns* around loss of identity, a diminished sense of dignity, and a lack of control that can be preserved with MAiD.

3. Psychologists' Role in End of Life Decision Making, including MAiD

A. Personal Values and Beliefs

Some psychologists have been working with individuals who have requested MAiD. Others may or may not have considered their perspective or comfort in working with individuals who have made such a request. Although psychologists who are being asked to conduct a capacity assessment for the purposes of a MAiD request would be primed to consider their beliefs and perspectives, those working in the provision of treatment, might already be providing services when the individual begins to consider MAiD.

As such, psychologists who anticipate that they will be involved with MAiD, are encouraged to examine whether, and under what circumstances, they would be able to work with individuals who are considering MAiD (Johnson et al., 2014; Katz & Johnson, 2006; Werth, Lewis, & Richmond, 2009). In the context of end of life decisions, psychologists are encouraged to examine their views on:

- quality of life
- death
- dying
- spirituality
- humanism vs. pragmatism and other relevant values

A variety of factors, including culture and religion, can influence individual beliefs around end-of-life decision making (Chakraborty *et al.*, 2017). Access to and availability of health care resources in diverse populations varies, including, but not limited to age, language, disability, religion, ethnicity, sexual identity, and socioeconomic status. These inequities can influence and limit health care choices, including end-of-life care (Batavia, 2001). In keeping with the CPA Code of Ethics (2017) on Responsible Caring and Maximizing Benefits, psychologists should reflect on access barriers as they examine their beliefs and values surrounding end of life decisions.

B. Psychological Interventions

i. Desire for Death vs. Request for MAID

Occasional, passing wishes for death are relatively common among individuals who are receiving palliative care, and they may spontaneously express them to the clinical staff. Across various studies, 11-41% of individuals sometimes experience a desire for death, but these reports of a desire for death tend to be transient, low level, and uncertain. However, a further 3-20% of individuals report a desire for

death that is apparently stable and consistent (Wilson, 2018). Not all of these individuals would request MAiD, but many would consider it. About half of the individuals who report a strong desire for death meet diagnostic criteria for depression or an anxiety disorder (Wilson, Dalgleish, Chochinov, et al., 2016). Nissim, Gagliese & Rodin (2009) identified different pathways by which individuals come to express a desire for death, and the distinctions serve as a useful starting point for working with individuals who are considering end-of-life interventions.

- Individuals may consider a hastened death in a hypothetical way, as an "escape route" in the event that their progressing disease eventually becomes intolerable. They may not initiate MAiD right away in their current circumstances, but they find comfort in knowing it is available.
- Individuals may be experiencing a desire to die that is driven by a more pervasive sense of despair. In these cases, there should be consideration given to identifying possible alternative interventions that might alleviate that despair.
- Individuals may be expressing a willingness to let go. They are ready for death, have prepared themselves for it as best they are able, and are not necessarily exhibiting concurrent symptoms that would suggest an untreated clinical problem, be it psychological or physical.

ii. Psychological Interventions - Individual

Individuals at end of life may experience a wide array of physical, psychological, social and existential challenges. These include but are not limited to the following (Kissane, 2012; Trice Loggers et al, 2013):

- Physical: pain, suffering, & symptom management (Ganzini et al., 2008; Smith et al., 2015)
- Psychological: anxiety, depression, demoralization, & hopelessness (Smith et al., 2015)
- Social: self-perceived burden to others or difficulty with acceptance, as well as the psychological, interpersonal, and financial burden that can be placed on care givers (Ganzini et al., 2008; Pestinger et al., 2015; Smith et al., 2015; Wilson et al., 2005)
- Existential: death anxiety, grief at loss and change, freedom and autonomy, dignity, fundamental aloneness, quality of relationships, meaning of life, mystery and the unknowable (Li et al, 2017; Radbruch et al., 2016)

Overall, the evidence for the efficacy and effectiveness of psychotherapeutic interventions at end-of-life remains mixed due to a number of challenging factors. In particular, most of these studies have been conducted with individuals who are not necessarily at end-of-life and/or may not have substantive levels of psychosocial, spiritual or existential distress.

iii. Psychological Interventions - Families Members

Prior to the patient's death, family members may be involved in other roles, in addition to their normal caregiving role (Gamandi et al., 2018):

• Serving as an advocate for MAiD;

• Providing practical help.

Family members themselves may experience a number of psychosocial-spiritual issues, associated with their loved one's request for MAiD including the following:

- Ambivalence regarding the request: the desire for their family member's suffering to end may be in conflict with their own personal beliefs, which could include anger, betrayal, and abandonment (Wagner et al., 2011);
- Moral dilemmas (Gamondi et al., 2013);
- Feelings of isolation (Gamondi et al., 2013).

Post-death, the mental health outcomes of family members whose "loved ones" requested and received MAiD appears to vary. In some studies, family members' mental health outcomes and grief responses were either no different (Ganzini et al., 2009) or better than (Swarte et al, 2003) comparison groups, which may be related in part to family members being more prepared and accepting of the death (Ganzini et al., 2009). In other studies, the lack of social acknowledgement and family disapproval of the death may be associated with post-traumatic stress disorder and complicated grief symptoms (Wagner et al., 2011). Other potential negative impacts include isolation, secrecy surrounding the cause of death, stigma, blame, or condemnation of family or their community, and the burden of moral dilemmas (Gamondi et al., 2015).

C. Team and Institutional Collaboration

As with psychologists, health care providers and administrators within institutions and the community can have diverse feelings about MAiD (Council of Canadian Academies, 2018a, 2018b). This is even more complex when there is a misalignment between individual views and the organizational policy regarding MAiD. Some individuals may be working in organizations in which MAiD is occurring within their units/services, and are conscientious objectors with respect to MAiD. There could also be individuals who are working in institutions that will not provide MAiD, and whose personal values are consistent with MAiD. Similarly, to the Canadian Medical Association, CPA acknowledges the importance of being united with our interprofessional teams, as colleagues, irrespective of our personal views on MAiD (CMA, 2017).

Given the complexity of reactions when changing the legal and ethical landscape, staff support programs for health care providers involved in MAiD are worthy of consideration (Council of Canadian Academies, 2018a 2018b) and could involve:

- Health care providers and administrators working in MAiD
- Those working in organizations in which MAiD is occurring and who are conscientious objectors
- Those working in sites in which patients are transferred elsewhere for the provision of MAiD

The Council of Canadian Academies' expert panels on Advanced Directives, and Mature Minors both recommend the provision of resiliency support programs for physicians and staff involved in MAiD, particularly if MAiD becomes extended to mature minors, as well as through the use of advanced directives (Council of Canadian Academies, 2018a, 2018b). Psychologists, by virtue of their training, have the skills to develop, adapt, provide, and evaluate such offerings (e.g. HSO, 2017; Ritchie, Gerin-Lajoie, & Naik, 2017).

D. Assessment

Psychologists possess a unique skill set regarding the understanding of behaviour, cognition, and emotional health, with these skills being extremely useful when completing capacity evaluations. The role of psychologists in completing assessments related to MAiD is complex and typically revolves around the determination of capacity to provide consent according to health care consent legislation, with the information gleaned used by physicians and/or nurse practitioners to render the final opinion regarding MAiD eligibility.²

There are several models that can be used to guide the assessing psychologist during a capacity evaluation related to consent for treatment. However, there is no fixed or prescribed interview format (Dastidar & Odden, 2011); Leo, 1999; Ganzini et al., 2004; Seyfried et al., 2013) and there is little data on the assessment of capacity in the specific circumstances of MAID (i.e., in the presence of intolerable suffering) (Cartagena et al., 2016).

i. Alternatives to MAID

Assessments of competence include a determination of whether individuals understand and appreciate the alternatives to MAiD that might be applicable to their care. The goal in discussing alternatives is not to dissuade individuals from receiving MAiD, but rather to help them understand how their care would unfold if the disease process was left to take a natural course.

ii. Depression, Mental Illness and MAiD

In most jurisdictions, very few individuals who request MAiD receive referrals for formal mental health assessments (Oregon Public Health Division Center for Health Statistics, 2018). Depression is a very common concern in individuals with terminal illness. It has been estimated that 25% of those with advanced cancer have a clinically significant problem with depression (Wilson, Lander, & Chochinov, 2009). The global experience of suffering, including suffering due to physical symptoms, is much more pervasive among terminally ill individuals who are depressed than among those who are not (Wilson, Chochinov, Skirko, et al., 2007). Anywhere from 8% to 47% of individuals who request MAiD in Netherlands and Oregon were reported in the literature as experiencing symptoms of depression (Levene and Parker, 2011). Although rates of depression can also be high among those who do not seek MAID, it may be particularly common for those who are experiencing a depressive episode to consider the possibility of MAID in their end-of-life care (Wilson, Chochinov, McPherson, et al., 2007). A diagnosis

² Requirements for eligibility to conduct capacity assessments varies across jurisdictions and is not automatically considered part of a psychologist's scope of practice.

of depression, in and of itself, does not automatically mean that a person is incapable of decisionmaking (Blank, Robison, Prigerson, & Schwartz, 2001); Block, S.D., 2000; Block S.D., 2006; Chochinov, Wilson, Enns, & Lander, 1994; Cohen, S.T. & Block, S.D. (2004). When assessing depression, the issue is not whether the person is depressed but whether the extent or nature of the depression precludes the ability to make an informed decision about MAiD.

Conclusion

The practice of MAiD in Canada is relatively new and changes to eligibility are being contested through multiple legal cases across the country. The need for psychological interventions, capacity assessments, and team support are likely to grow if additional populations such as minors become eligible and if advanced directives and/or a broadening of the eligibility occurs. The research in Canada on MAiD is limited in the following priority areas:

- Psychological interventions and assessment in MAiD, particularly in terms of cultural and religious diversity and inclusivity.
- Supporting individuals (caregivers/communities) and health care providers in end-of-life decision-making.

In addition, curriculum development & training within programs in end-of-life is limited in part due to the deficiencies in the literature.

Recommendations

A. Practice

Knowledge dissemination of resources and tools to support psychologists providing MAiD-related services and other health care providers in the provision of MAiD, and in exercising conscientious objection.

MAiD is a newer area of practice. The profession does not currently have a consistent way in which to share resources and access materials/training. CPA, as the national association, in partnership with the Council of Professional Associations of Psychology (CPAP), and the Association of Canadian Psychology Regulatory Organizations could provide the following:

- Resource Bank for materials related to MAiD housed on the CPA website on a MAiD page.
- CPA fact sheet for individuals and families/caregivers/community on assessment for MAiD.

B. Training and Education

Develop a webinar on current practices in MAiD including assessment, treatment, team support, and ethical considerations.

These resources would be enhanced if other organizations such as the Canadian Medical Association, Canadian Psychiatric Association, Nurse Practitioners Association of Canada, and the Canadian Association of Social Workers could participate in areas in which there is overlap, as well as to provide the context of the interprofessional team members, and their various roles and responsibilities in providing care during MAiD. Support the development of materials that could be covered in graduate programs to familiarize all students with basic issues around MAiD (ethics, culture, psychological interventions, and assessment in the context of MAiD).

C. Science

There is limited research in MAiD, generally, and in the Canadian context specifically. As the CCA reports highlighted (Council of Canadian Academies, 2018a, 2018b), these knowledge gaps severely limit our abilities to provide research informed individual and family centered care and to create best practice standards. Such areas of research include, but are not limited to:

- Longitudinal follow up on families after MAiD.
- Research in assessment and treatment of individuals contemplating end of life decisions.
- Supporting end-of-life decision-making in the individual, family, and community.
- Systems support: examining the moral distress of care providers working in contexts in which MAiD is offered or prohibited.

We recommend advocacy to funding agencies for funding related to research in MAiD. These advocacy initiatives could be enhanced if conducted in partnership with the associations of other MAiD service provider such as the Canadian Medical Association, Canadian Psychiatric Association, Nurse Practitioners Association of Canada, and Canadian Association of Social Workers.

PART II: Practice Guidelines

A. Personal Values and Beliefs

The CPA Code of Ethics (2017) underscores the need for objectivity/lack of bias that psychologists need to bring to their professional roles. Prior to involvement in MAiD, it is essential to examine one's own personal and professional beliefs, values, attitudes and experiences about end-of-life decision-making and the extent that the above might negatively impact the ability to work with patients requesting MAiD. Self-assessment is an ongoing process, as beliefs and attitudes may change over time, based on experience within the context of MAiD. A values self assessment tool developed by Alberta Health Services may be a helpful tool to understand and verbalize one's perspective on MAiD. https://www.albertahealthservices.ca/assets/info/hp/maid/if-hp-maid-self-assessment-tool.pdf

Psychologists who do not feel comfortable working with individuals considering or pursuing MAiD may decide to refer individuals to another treating professional. To the extent possible, referrals to other practitioners cannot result in undue delays for the person seeking care, and relevant records must be made available to the alternate psychologist or care providers who assumes care.

B. MAiD Specific Knowledge

Psychologists need to have thorough knowledge of the legislation that governs MAiD as well as the psychological interventions or assessments they are providing. They also need to be aware of the provincial regulatory requirements, any directives from the regulatory body of which they are members, the practice standards or guidelines in their home jurisdiction, and the applicable ethical principles, such as respect for the dignity of persons (CPA Code of Ethics, 2017)

Psychologists should be familiar with organizational MAiD-related policies and procedures, including how to request the MAiD team's involvement, the degree of involvement of various health care team members and any policy relating to conscientious objection. Psychologists should also be familiar with resources and supports that are available to the health care team. Given that MAiD assessment and procedure requires the involvement of multiple health professionals, and psychologists are not identified in the legislation as key decision makers in the process, irrespective of whether the psychologist works in an institution or a private practice, individuals and families are best served when there is interprofessional collaboration. Different perspectives on MAiD can be approached through respectful communication with team members. This fosters a cohesive team that supports all professionals involved in MAiD, regardless of one's personal perspective.

It may be appropriate for a psychologist to engage in consultation or supervision to gain the knowledge and competency needed to engage in the delivery of MAiD-related psychological interventions or assessment services.

C. Potential Dual Roles

Wherever possible, psychologists should not serve in the dual role of providing an opinion on capacity while treating the individual (Washington State Psychological Association; the Washington Death with Dignity Act: WSPA guidelines for mental health professionals). The question of capacity for a particular treatment decision is a different relationship in kind and nature than the one that is fostered in a therapeutic relationship. The assessment itself, and the clinician's decision, could negatively impact a therapeutic relationship. In addition, if capacity for making decisions related to health care is in question, then informed consent related to the potential impact of the dual roles could also be in question. Neither capacity nor intervention are the unique scope of psychologists. It would be highly unlikely that no other health care providers are available to take on one of these roles, be it an opinion on capacity to make a decision for the MAiD procedure or psychotherapy for end of life care. In the current legislation physicians or nurse practitioners are the only health care providers who can decide on eligibility for MAiD. If psychologists are asked to be involved in both a capacity assessment related to MAiD and treatment related to end of life decisions, s/he should examine the available resources of all health care providers in the vicinity and provide the service that will be the most meaningful contribution to the individual's care. If there is no other option of care, it is recommended that psychologist commence with assessing capacity to provide informed consent for the psychologist being involved in this dual role. If the individual is deemed capable of providing informed consent, then the psychologist can discuss the potential impact of a capacity assessment for decision making regarding MAiD and a therapeutic relationship with the client after the assessment. The psychologist should also discuss alternatives for support through end of life decision making and care, and collaborate with the client on prioritizing which service they would prefer from the psychologist if the client opts to avoid entering into both services by the same psychologist

D. Psychological Interventions

i. Individual Treatment

Psychologists providing psychological interventions to patients contemplating MAiD should have the skills necessary to address psychological/psychosocial issues related to end-of-life, as well as those issues unique to MAiD.

At present, the best available information from the current data suggests that when talking to individuals who have expressed a desire to die, the aim is to:

- Explore issues underpinning the statements,
- Identify the critical clinical issues,
- Discuss the interpersonal issues involved³

³Additional information on Psychosocial Interventions, including spiritual interventions is provided in the Appendix.

Some of the concerns that may be expressed by an individual requesting MAID, and possible responses, are shown in Table 1, which draws on a number of published sources (Abraham, 2008; Bascom & Tolle, 2002; Emanuel 1998; Hudson, Schofield, Kelly, et al., 2006; Tulsky et al., 2000). Many of the responses in the table are not specific to MAID but comprise principles of good palliative care more generally.

Table 1

Clinical Issue	Response Considerations
Physical	Clarify preferences (status quo, increased medications, sedation)
	Psychological therapies (meditation, relaxation, hypnosis)
Psychological	Cognitive therapy
	Behavioral activation
	Problem-solving
Social	Self-perceived burden to others - Bring couples/families together, avoid trying to "mindread" the concerns of others
	Social isolation - Provide opportunities for interaction (with staff, volunteers, other patients, hospice), group therapy
	Other social concerns – e.g. exhausted families, anger, unfinished business - Empathic listening
	Caregiver and economic burden explore availability of additional health care services such as home care, respite care, available programs to cover the cost of medications or other health care needs, etc.
Existential	Desire for Control – Facilitate provision of information (prognosis, course), develop a shared understanding of the goals of treatment, involve in decision-making, reassure regarding non-abandonment, symptom control, identify forms of available support, frequent check-in
	Dignity, meaning, hope and quality of life, as well as existential/spiritual issues regarding death and dying. Interventions that focus on meaning-making, legacy work and hope enhancement.
	Fear - Provide factual information, reassurance around catastrophic concerns, commit to being available, allow expression of concerns, empathic listening, reflection, clarification

In addition to specific therapeutic techniques, the therapeutic relationship plays a substantive role in supporting patients. Some of these factors may include, but are not limited to, therapeutic presence, therapeutic humility, and therapeutic pacing (Norcross, 2018).

ii. Family Treatment

There is a paucity of research on families in the context of end of life decision making. Burke et al (2015), focused on risk factors for anticipatory grief of individuals (terminally ill veterans) receiving palliative care services. The findings suggested that "family members who were less educated, had a dependent relationship with the patient, were uncomfortable with intimate or close relationships, had a tendency to worry excessively, were spiritually distressed, felt unsupported by others as they grieved and struggled to make sense of the veterans' forthcoming death were more likely to be psychologically debilitated by their grief." Of all of these factors, increased dependency and loss of meaning were the largest predictors for maladaptive anticipatory grief and post-death mourning. It is not possible to comment on the nature of the relationship (i.e. as being positive or negative), as this was not part of the study design. Interventions aimed at helping family members become more independent from the relationship and finding meaning in their loved one's impending death ("sense making") can help with post-death mourning and adaptation in general (Burke et al., 2015;(Neimeyer, 2018).

E. Capacity Assessment

Psychologists who are asked to provide a capacity assessment recognize that the role of the assessment is to inform the physician or nurse practitioner's assessment of the patient's eligibility for MAiD. It is essential to have the requisite competency to perform a capacity assessment in the context of MAiD. These can vary by jurisdiction.

The assessment completed by psychologists is viewed as an adjunctive and supportive evaluation to inform the decision of the physicians and nurse practitioners who can legally administer MAiD. Legislation regarding MAiD is provincial and it is important for each psychologist to be familiar with the standards for capacity in their own jurisdiction. However, the underlying constructs regarding the assessment of capacity to provide consent for health-related matters, such as MAiD, involve making an informed decision about four related questions

- 1. The ability to understand the information relevant to the decision being made and the procedure being requested.
- 2. The ability to appreciate the consequences of the decision or lack of a decision for one's own situation.
- 3. The ability to reason through the relevant information in order to weigh the relevant options.
- The ability to consistently communicate a decision in an unambiguous manner. (Appelbaum, P.S. 2007; Dunn, L. B., Nowrangi, M. A., Be, M., Palmer, B. W., Jeste, D. V., & Saks, E. R., 2006; Grisso & Appelbaum, 1998; Grisso, Appelbaum, & Hill-Fotouhi, 1997; Hall, Prochazka & Fink, 2012; Lamont, S., Jeon, Y. H., & Chiarella, M., 2013; Moye, J., Karel, M. J., Edelstein, B., Hicken, B., Armesto, J. C., & Gurrera, R. J., 2008; Quill, T. & Arnold, R.M. (2008a,b)).

Understanding and appreciation are core tenets when completing a capacity evaluation related to MAiD. *Understanding* requires sufficient capacity for comprehension, reasoning, and memory regarding details of the procedure and its consequences; it should include an awareness of all available treatment options. *Appreciation* requires the ability to provide an adequate appraisal of the outcome of the choice rendered, a rationale for the choice, and recognition of the consequences of the decision related to MAiD.

The outcome of a capacity assessment process related to the ability to consent to MAiD should not be jeopardized by a lack of knowledge or lack of information regarding potential alternative treatment options. The assessing psychologist must ensure that the individual has had the opportunity to obtain answers to all questions regarding MAiD and alternatives to MAiD prior to completing the capacity evaluation, and, if this is not the case, postpone the assessment until the necessary information has been provided.

Individuals should not be driven to MAiD because of a highly distressing clinical problem that is perhaps treatable. It is helpful to address existential issues revolving around life values, what suffering means to the patient besides physical pain, and what would make life unbearable or not worth living.

The assessing psychologist will need to incorporate and discuss the potential influence of culture, values, and beliefs on decision-making during an assessment and related to MAiD (Karel, M. J., Gurrera, R. J., Hicken, B., & Moye, J. (2010) and to consult with cultural experts whenever possible (CPA, 2018). Psychologists are well placed to complete a variety of cognitive tests. Use of standardized test instruments in assessing cognition and mental health are generally not required in circumstances related to MAiD under the current legislation. If standardized instruments are used, it is important to ensure that appropriate norms exist. Some patients may be elderly (with no reference group) or belong to cultures that were not part of a normative sample. Given the lack of normative data used with individuals at end of life, in general, should testing be used, the results should only be used for hypothesis generation and as an adjunct to other information obtained (Newberry A.M. & Pachet A.K., 2008). Standardized testing can be used to corroborate information obtained from other sources (Werth Jr, J. L., Benjamin, G. A., & Farrenkopf, T, 2000).

i. Pre-assessment Process

After receiving a request for an evaluation related to MAiD, the assessing psychologist needs to decide whether or not to take on the referral. The psychologist must:

- Have the necessary clinical background, as well as a full understanding of relevant legislation, standards of practice and ethical principles associated with MAiD assessments.
- Be aware of any policies related to MAiD that may exist within the facility, health region or province where the assessment is being completed.
- Gather background information from a variety of sources. This increases the validity and reliability of assessment findings. The assessing psychologist will want to consider sources such as the patient's medical record, interviewing/consulting with one or two members of the

patient's health care team, and interviewing family, caregivers or friends after appropriate consent is obtained.

- Gather information about potential complicating psychological or cognitive disorders that could affect judgment, such as psychotic symptoms, depression, delirium, dementia, and substance abuse.
- Gather information about potential family dynamics or support system issues that could be affecting decision-making. Identify any underlying financial concerns, spiritual issues, disability/insurance claims, cultural, ethnic, and religious factors. Be aware of potential coercion by others and the perception of being a burden.
- Have a full understanding of the medical diagnosis and prognosis in the medical record and potential for medication side effects that could impair judgement.
- Review the patient's advance directives, living will, personal directive, durable power of attorney for health care, etc.
- Review treatments provided to date and steps already taken by the patient such as refusing treatment and stopping eating and drinking.
- Review the patient's communication needs.

ii. Assessment Process

Obtain informed consent to participate in the MAiD evaluation including information such as:

- Referral source and sources of information obtained
- Any fees and the individual responsible for these
- The name of the physician or nurse practitioner who will receive the results or the report
- Nature and purpose of the evaluation
- Foreseeable discomforts, risks, and benefits of participating in the evaluation, including the potential that they may be determined to lack capacity to consent to MAiD
- The limits on confidentiality
- The general procedures to be followed
- The rights of the patient you are assessing

Patients may choose not to involve caregivers/supports in decision-making or to include family members/caregivers in the decision making process.

The interview should be comprised of questions that solicit understanding and appreciation, but the assessor should be keenly aware of response consistency and the ability to weigh pros and cons about potential treatments and potential outcomes. Consistency of the patient's position and beliefs is crucial. Vacillation or inconsistency of responses may indicate failure to remember information necessary for decision-making, the influence of others, or the fact that the patient is not certain about her/his choices.

The capacity interview may be sufficient to render an opinion of capacity to make a decision about one's own health and the health services they receive. The main goal of assessors is to evaluate the patient's abilities in the areas specified in provincial legislation relevant to capacity to consent to treatment. This will allow for the rendering of a decision by the medical practitioners regarding the patient's ability to consent to MAiD.

Clinical observations during the interview are very important and provide significant further information regarding capacity and decisional autonomy. It is important to be aware of the individual's mental status and appearance, which typically includes gathering information regarding speech, thought processes, thought content, focus and concentration, insight, and congruence of mood and affect.

It may be important to complete more than one interview with the person being assessed. Conditions which might warrant multiple interviews include: if the person being assessed becomes tired, if their condition leads to fluctuation in cognition and it appears that the first interview was not conducted when they were at their best, if subsequent information from other sources raises new issues which were not addressed in the first interview, or in particularly contentious situations, in which a very high degree of certainty is necessary.

iii. Post- Assessment Processes

The post assessment procedures include further consultation/interviews with collateral sources and formation of an opinion. The assessment report answers the question regarding capacity to consent to MAiD, but also may include recommendations for further follow-up or interventions if necessary.

Practice Guidelines Summary

Prior to involvement in MAiD, it is essential to examine one's own personal and professional beliefs, attitudes and experiences about end of life decision making and the extent that the above might negatively impact the ability to work with patients requesting MAiD. Self-assessment is an ongoing process, as beliefs and attitudes may change over time, based on experience within the context of MAiD.

Psychologists need to have thorough knowledge of the legislation that governs MAiD.

Psychologists need to have a thorough knowledge of the Regulatory requirements for Psychologists and applicable ethical principles, such as respect for the dignity of persons (CPA Code of Ethics, 2017)

Psychologists should be familiar with organizational MAiD related policies and procedures, including how to request the MAiD team's involvement, degree of involvement of various health care team members and the policy around conscientious objection. Psychologists should also be familiar with resources and supports that are available to the health care team.

It may be appropriate for a psychologist to engage in consultation or supervision to gain the knowledge and competency needed to engage in the delivery of MAiD related assessment or treatment services. Consultation or supervision is also recommended to increase overall organizational and professional capacity and competence to provide services to patients contemplating MAiD.

Psychologists who are asked to provide a capacity assessment recognize that the role of the assessment is to inform the physician or nurse practitioner's assessment of the patient's eligibility for MAiD. It is essential to have the requisite competency to perform a capacity assessment in the context of MAiD.

Psychologists providing treatment to individuals contemplating MAiD should have the skills necessary to address psychological/psychosocial issues related to end-of-life, as well as those issues unique to MAiD.

Wherever possible, psychologists should not serve in the dual role of providing an opinion on capacity while treating the individual (Washington State Psychological Association; the Washington Death with Dignity Act: WSPA guidelines for mental health professionals).

Given that MAiD assessment and procedure requires the involvement of multiple health professionals, psychologists should not engage in MAiD related activities outside of the health care team. Different perspectives on MAiD can be approached through respectful communication with team members. This fosters a cohesive team that supports all professionals involved in MAiD, regardless of one's personal perspective.

Final Thoughts

The task group members were selected based on their expertise in end of life practice and/or Medical Assistance in Dying in the field of psychology. The scope of these practice guidelines is limited to the current Canadian eligibility requirements for MAiD. The practice guidelines were crafted using the available research to date, as well as the current clinical, ethical, regulatory, and legal context at the time of the publication. The practice of MAiD in Canada is emerging. Special populations such as individuals desiring to access MAiD within the corrections system (Office of the Coroner, 2018) or in organizations who have made the decision that MAiD will not be provided on their premises or by their staff add additional ethical considerations, as policies and perspective may or may not meet the goal of facilitating MAiD in the location of choice of the individual seeking this treatment. As the landscape of MAiD changes over time as a result of court decisions, access to care, and advances in the medical field, Canadians will likely continue to shift and/or grapple with their perspectives and comfort with end of life decisions. Research and knowledge dissemination in the field of psychology will continue to be of importance and CPA is well positioned to support this process.

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Appendix: Resource List of Psychological Interventions

There are a number of challenges in evaluating and comparing interventions, due to differing factors across studies (LeMay & Wilson, 2008; Nekolaichuk, 2011):

- theoretical frameworks
- type of intervention: focus (content), duration
- types of samples, including sample size
- therapist's competency, stance and individual uniqueness
- outcomes
- evaluation methods (methods for categorizing interventions)
- methodological issues
 - o distress levels of patients who are able to participate in research studies (low ceiling effect)
 - o inability to blind random allocation for participants and staff
 - o randomization does not always ensure group equivalency
 - o difficulty in standardizing psychosocial interventions (e.g. standard care)
 - o attrition

Despite the challenges, there are number of reviews of psychotherapeutic approaches for use with patients with advanced cancer and at end of life have been conducted, including manualized interventions (LeMay & Wilson, 2008), death anxiety interventions (Grossman et al., 2018); life review interventions (Wang et al., 2017) and treatment of holistic suffering (Best et al., 2015).

- LeMay & Wilson (2008) reviewed eight manualized psychological interventions for the treatment of
 existential distress in life-threatening illness: six group interventions and two individual
 interventions. Of the eight interventions, only supportive-expressive group therapy (SEGT) was
 assessed as being "probably efficacious."
- Grossman e al. (2018) conducted a systematic review of death anxiety interventions. They reviewed nine quantitative studies, including five randomized controlled trials, focusing on existential themes (e.g. meaning, dignity, relationships, spiritual well-being). The authors graded only two of the nine studies, involving meaning-centered group psychotherapy, with a low risk of bias. The remaining seven studies were evaluated as having a high risk of bias.

- Wang et al. (2017) conducted a systematic review and meta-analysis of life review interventions. They reviewed eight randomized controlled trials. Pooled results showed that the interventions had a desirable effect on spiritual well-being, general distress and overall quality of life. In their quality assessment of the nine studies, the authors ranked only one of the studies focusing on Dignity Therapy (Chochinov et al., 2011), as a "high-quality study," citing multiple methodological concerns of the other studies in this review.
- In their systematic review, Best et al. (2015) identified 48 studies, organized into seven categories: psycho-educational, meaning-centered (including life review and dignity therapy), supportive-expressive, stress reduction, spiritual, hope-centered and others (e.g. creative arts, animal therapy, haptotherapy). Based on this review, meaning-centered, hope-centered and stress reduction therapy were rated by the authors as being most effective. In terms of improving spiritual well-being, there were mixed results for psychoeducational and spiritual interventions. There was insufficient evidence to assess the efficacy of the remaining therapies.