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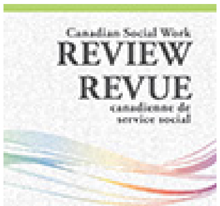

MEDICAL ASSISTANCE IN DYING (MAID)

A Policy Analysis to Provide Greater Clarity for Social Workers in Practice in Ontario

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Résumé de l'article

L’Aide médicale à mourir est un cadre juridique fédéral qui permet aux professionnels de la santé d’aider les patients admissibles qui en font la demande à mettre fin à leurs jours de façon paisible et dans la dignité. Le critère d’admissibilité entourant la compétence mentale crée actuellement de la confusion chez les travailleurs sociaux parce qu’il fournit peu de directives sur la meilleure façon de mettre en oeuvre les pratiques souhaitées pour appuyer les objectifs de l’aide médicale à mourir. Les critères actuels posent également des obstacles pour les populations vulnérables comme les patients atteints de sclérose latérale amyotrophique (SLA). Les patients atteints de SLA qui ne sont pas jugés « mentalement compétents » se voient refuser l’accès à l’aide médicale à mourir et doivent continuer de vivre dans des douleurs jusqu’à leur mort. La politique canadienne en matière entourant l’aide médicale à mourir donne ainsi un accès inégal aux services de soins de santé pour ces patients, porte atteinte à leur autonomie et à leur droit à l’autodétermination en leur enlevant le choix de mourir dans la dignité. Cette injustice exige que l’on reconsidère les façons de réformer l’aide médicale à mourir afin de servir les Canadiennes et les Canadiens près de la mort qui passent ainsi au travers des mailles du filet de l’aide humanitaire. Le présent article contient des recommandations stratégiques comme l’inclusion de directives préalables et de décideurs substituts, ainsi que des recommandations à l’intention des travailleurs sociaux, y compris l’accroissement des compétences et la sensibilisation aux dispositions entourant l’aide médicale à mourir.

MEDICAL ASSISTANCE IN DYING (MAID) A Policy Analysis to Provide Greater Clarity for Social Workers in Practice in Ontario

Alona Amurao

Abstract: Medical Assistance in Dying (MAID) is a legal federal framework for medical practitioners to assist in the cessation of life upon request from eligible patients who seek assisted death in order to die peacefully and with dignity. MAID's 'mentally competent' eligibility criteria currently create confusion for social workers because they provide little guidance on how to best implement the desired practices intended to support the aims of MAID. Secondly, current criteria pose challenges for vulnerable populations, particularly patients with amyotrophic lateral sclerosis (ALS). ALS patients who are deemed mentally incapable are denied access to MAID, suffering in pain every day until they die. Canada's MAID policy infringes on their autonomy, and removes their choice to die with dignity. This injustice calls for further reconsideration of the ways MAID can be reformed to serve dying Canadians who are falling through the cracks of MAID. Policy recommendations include inclusion of advanced directives and substitute decision makers. Due to this unequal access in health care services, this concern constitutes a social work issue. Recommendations for social work include increasing competency, and advocacy regarding the provision of MAID.

Keywords: Amyotrophic Lateral Sclerosis, End-of-life, Medical Assistance in Dying

Abrégé : L'Aide médicale à mourir est un cadre juridique fédéral qui permet aux professionnels de la santé d'aider les patients admissibles qui en font la demande à mettre fin à leurs jours de façon paisible et dans la dignité. Le critère d'admissibilité entourant la compétence mentale crée actuellement de la confusion chez les travailleurs sociaux parce qu'il fournit peu de directives sur la meilleure façon de mettre

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en œuvre les pratiques souhaitées pour appuyer les objectifs de l'aide médicale à mourir. Les critères actuels posent également des obstacles pour les populations vulnérables comme les patients atteints de sclérose latérale amyotrophique (SLA). Les patients atteints de SLA qui ne sont pas jugés « mentalement compétents » se voient refuser l'accès à l'aide médicale à mourir et doivent continuer de vivre dans des douleurs jusqu'à leur mort. La politique canadienne en matière entourant l'aide médicale à mourir donne ainsi un accès inégal aux services de soins de santé pour ces patients, porte atteinte à leur autonomie et à leur droit à l'autodétermination en leur enlevant le choix de mourir dans la dignité. Cette injustice exige que l'on reconsidère les façons de réformer l'aide médicale à mourir afin de servir les Canadiennes et les Canadiens près de la mort qui passent ainsi au travers des mailles du filet de l'aide humanitaire. Le présent article contient des recommandations stratégiques comme l'inclusion de directives préalables et de décideurs substituts, ainsi que des recommandations à l'intention des travailleurs sociaux, y compris l'accroissement des compétences et la sensibilisation aux dispositions entourant l'aide médicale à mourir.

Mots clés : Sclérose latérale amyotrophique, fin de vie, aide médicale à mourir

IN FEBRUARY 2015, the Supreme Court of Canada decided that prohibition of physician-assisted dying by Canada's Criminal Code was unconstitutional, and it has provided patients with new options in the form of Medical Assistance in Dying (MAID) (Ontario College of Social Workers and Social Services Workers [OCSWSSW], 2016). As a federal legal framework, MAID provides guidance for medical practitioners to support dying patients who seek assisted death in order to die peacefully and with dignity (Downie, 2015). It facilitates the process of either administration or prescription of medication that causes death, at the request of a mentally competent dying patient (Government of Canada, 2017c). However, MAID challenges values and evokes ethical difficulties due to the ambiguity on how to best implement the desired practices intended to support peaceful death with dignity (Bator, Philpott, & Costa, 2017; OCSWSSW, 2016; Simpson, 2018; Suva, Penney, & McPherson, 2019; van Harreveld, van der Pligt, & de Liver, 2009). Specifically, greater clarity is needed regarding application of MAID for more vulnerable populations (Simpson, 2018), who tend to be the primary focus of care for social workers in health care settings (Craig, Bejan & Muskat, 2013).

A vulnerable population that presents complex MAID requests are individuals with health conditions that can cause cognitive deficits (Council of Canadian Academies [CCA], 2018). These requests are considered complex in that patients are at risk of becoming ineligible if they lose their mental capacity for decision-making at any point during the adjudication process. Health care providers need greater clarification on eligibility criteria relating to a patient's mental capacity (Simpson, 2018; van Harreveld et al., 2009). Current federal law forbids advance requests for MAID, which is an application for MAID prior to loss of mental capacity to make decisions. The purpose of advance requests is to facilitate patient autonomy and alleviate suffering by providing MAID after patients have lost decision-making mental capacity. Examples of suffering include physical, (i.e. loss of ability), existential (i.e. loss of meaning in life and/or self), and psychological (i.e. loss of dignity and independence). As such, without legalization of advance requests for MAID, patients must have mental capacity for decision-making when they request MAID.

As one example, ALS is a terminal neurodegenerative disease that involves a degeneration of the motor system, which controls muscle movement (Mitchell & Borasio, 2007). Site of degeneration onset varies, and may begin at muscles in the face, esophagus, upper-limbs, or lower-limbs. Degeneration causes weakness, cramps, spasms, and emotional lability. It impairs ambulation, swallowing, speech and respiration, and can progress to complete paralysis in any of the aforementioned sites (Hardiman, van den Berg, & Kiernan, 2011; Sahin, 2018). ALS is reported as the most common cause of neurological death in Canada, resulting in a mortality rate of two per 100,000 annually (Dupré & Korngut, 2013; Kehyayan, Korngut, Jetté, & Hirdes, 2014). In 2012, Statistics Canada (2012) reported approximately 4,000 Canadians diagnosed with ALS. While this may appear a relatively low statistic, it is important to bear in mind the mortality rate mentioned above. There is currently no curative treatment, and following diagnosis, individuals most commonly receive a two- to five-year prognosis (Hardiman et al., 2011; Wolfson, Kilborn, Oskoui, & Genge, 2009). About 80% of individuals die within this timeframe, while 10% proceed to live 10+ years (Pupillo, Messina, Logroscino, & Beghi, 2014). Cognitive impairments occur in 50% of Canadians with ALS. Moreover, 20-25% acquire severe cognitive impairment in the form of frontal lobe dementia (Strong et al., 2016). In relation to MAID, these Canadians are denied access, and, consequently, live in suffering while awaiting death.

In December 2016, the Council of Canadian Academies (CCA, 2018) was asked to conduct an independent review on advance MAID requests. The key findings of the review concluded that advance requests have great potential for supporting autonomy and alleviation of suffering. However, barriers stem from uncertainty on the part of medical practitioners providing MAID regarding the circumstances and timing of the advance request. Medical practitioners may face uncertainty in cases where patients have requested MAID under certain circumstances that they deemed sufferable in their advance request, yet they do not appear to be suffering as they enjoy activities, despite the outlined sufferable circumstances occurring. In these circumstances, patients' perception of quality of life may have changed over time. Additionally, uncertainty may occur in cases where patients discussed their appeal infrequently or very early in the disease, and practitioners are uncertain of the specific sufferable circumstances under which patients request MAID be enacted due to inconsistencies in their directives. However, due to the ban of advance requests for MAID, health care practitioners are legally bound to provide care within MAID eligibility criteria.

Without clarification on the 'mentally competent' criteria, health care practitioners – including social workers – will continue to struggle when encountering patients, with neurological conditions, who may exhibit cognitive deficits and request MAID (OCSWSSW, 2016; Upshur, 2016). Further, this lack of clarity may also impose undue stress, suffering, and burden for such patients and their families who are seeking MAID. MAID's 'mentally competent' eligibility criteria can pose challenges for patients suffering from neurological conditions, such as amyotrophic lateral sclerosis (ALS) (Upshur, 2016).

Why I Chose to Analyze MAID

As a newly-graduated social worker with an interest in end-of-life care, I worked in a community hospice where I began caring for a patient diagnosed with ALS. The patient expressed a desire for MAID. Although legalization of MAID was not finalized at the time, this patient's situation highlighted complications for the care team as well as the patient, who aimed for a peaceful and dignified death as their mental capacity declined. My time supporting this patient ignited a deep desire to gain clarity on how social workers can help improve the dying journey for patients with ALS, including barriers and opportunities for actualizing quality of life, and how MAID would respond to their needs.

Legalization of MAID coincided with my return to school to complete my graduate degree in social work. I anticipated that I would gain greater clarity on how MAID could help support patients in end-of-life care. However, during my clinical practicum in oncology I was aware of a gap in knowledge about MAID for key members of the interprofessional team, as well as a gap in the limited inclusion of content related to MAID in formal social work classes, despite the priority and inclusion of MAID in other educational programs and disciplines, such as nursing, pharmacy, and medicine (Suva et al., 2019; Verweel, Rosenberg-Yunger, Movahedi, & Malek, 2018; Wiebe, Green, & Schiff, 2018). This critical analysis of MAID was born from the need to gain a better understanding of a current policy in order to provide myself, and other social workers, with guidance for practice.

More specifically, given my experience supporting a patient with ALS and the recent introduction of MAID, this paper was inspired as a way to bring clarity for how to support patients with ALS in Ontario, within the Ontario MAID context, particularly as their cognition declines. Excluding the 50% of Canadians with ALS, who experience cognitive impairments, invalidates their suffering and results in an inequitable provision of health care. It privileges certain abilities over others, and, thus, promotes *ableism.* As such, MAID's inherent ableism violates patients with ALS rights to "life, liberty, and security of the person" and "equality," protected under the Canadian Charter of Rights and Freedoms (1982, s 6(2)(b)) (*Carter v Canada,* 2015). Hence, this analysis will focus on MAID's 'mentally competent' eligibility criteria for patients with ALS in the Ontario context, and provide recommendations for action. This paper seeks to accomplish five goals. First, the paper will begin by discussing the significance of MAID for social work practice. Second, it will discuss the implications of MAID for health care, particularly for patients with ALS. Third, it will outline MAID implications for social workers who provide care to patients with ALS and their families. Fourth, it will critique MAID options for facilitating access of MAID. Finally, it will provide recommendations for social work practice and policy.

MAID Historical Context and Policy Overview

Prior to the 2015 Supreme court judgement identified above, Ontario patients deemed palliative were afforded scant legal resources for addressing the broad spectrum of patient goals of care due to Canada's Criminal Code (1985). Palliative patients are those that have a prognosis of one year or less. The Criminal Code prohibited medical practitioners from actively providing or assisting in the provision of ending a patient's life regardless of informed consent (Criminal Code, 1985). This gap in access to health care resources impacted palliative patients whose goals of care indicated need for a dignified and peaceful death under circumstances when suffering severely infringed upon their quality of life (Attaran, 2015). Before MAID was legalized, dying individuals' autonomy was undermined.

Specific underpinnings supporting the Supreme Court's decision to amend the Criminal Code are related to the Canadian Charter of Rights and Freedoms (1982, s 6(2)(b)) right to "life, liberty and security of the person," (Attaran, 2015). The first argument detailed that MAID is a harm-reduction response to the intolerable pain and suffering palliative patients experience because of irremediable illnesses, as opposed to patients' suiciding independently via excruciating, insecure methods (Attaran, 2015). The second argument detailed that MAID restores palliative patients' liberty to make medical decisions to improve their overall health and wellbeing (Attaran, 2015). Without MAID, patients' autonomy would be limited to withdrawal and withholding of medical interventions, not active administration of interventions, despite the outcome being the same for each. For these reasons, Canada made a commitment to improve resources that address the spectrum of patients' goals of care (Attaran, 2015). Hence, the Criminal Code was amended, and MAID was legalized.

Bill C-14, known as MAID, allows physicians and, in some provinces, nurse practitioners to administer and prescribe lethal medications to adults (18 years old or older) diagnosed with a "grievous, irremediable medical condition causing intolerable suffering, and whose death is reasonably foreseeable" (Government of Canada, 2017c). Note, a "reasonably foreseeable death" does not require a specific prognosis. Rather, the individual must have a serious illness, disease, or disability, be in an advanced state of irremediable decline in capability and endure physical and psychological suffering that is intolerable to them. Lastly, adults who voluntarily request MAID must be mentally competent to give informed consent (Government of Canada, 2017a). It is important to note that each province has their own processes for how they provide MAID within Bill C-14 provisions (Government of Canada, 2017c). In order to ensure effective monitoring of the policy, in November 2018, federal regulations stipulated strict requirements for reporting MAID deaths, requests, and prescriptions (Government of Canada, 2017c).

In Ontario, the process of accessing MAID involves a series of steps (Centre for Effective Practice, 2016). First, a clinician, either physician or nurse practitioner, conducts an initial eligibility assessment based on the aforementioned requirements (The College of Physicians and Surgeons of Ontario [CPSO], 2017). If the person is deemed eligible, the clinician continues to complete a formal written request. This is followed by an independent second eligibility assessment by a secondary clinician, whereby they must provide informed consent for a second time. Once the applicant passes the second assessment, there is a required reflection period of 10 clear days until MAID can be completed (Bill C-14, 2015-2016; CPSO, 2017). This means that there must be 10 days in between the second assessment and the date of MAID administration or prescription. These days are considered "clear" because the patient is not undergoing any MAID-related assessments.

During the reflection period, the initial clinician formulates a plan for how MAID will be delivered and prepares for the day accordingly, i.e. gathering medications from pharmacy and IV-related equipment, informing a pharmacist of future prescriptions for MAID self-administration, etc. (Bill C-14, 2015-2016; CPSO, 2017). On the day of MAID administration or prescription, patients must provide informed consent for a third, final time. If they are mentally incapable to provide informed consent, even one second before administration or prescription, the physician is legally prohibited from enacting MAID (CPSO, 2017).

Significance of MAID for Social Work and Social Justice

The social work profession is rooted in a social justice philosophy whereby justice is maintained through equitable distribution and protection of everyone's human rights and dignity (Canadian Association of Social Workers, n.d.; Morgaine, 2014). In health care, social workers support individuals who are experiencing health-related situations that render them vulnerable to injustices and oppressions, while also striving to meet the broad array of holistic psychosocial care needs (Ashcroft, Van Katwyk, & Hogarth, 2017). Social workers help address individuals' physical, mental, and social wellbeing to support their overall health (Ashcroft et al., 2017). This requires knowledge of existing services and policies, including MAID, that guide practitioners in how they can facilitate access and inclusion.

Knowledge and understanding of MAID is significant for social workers at every level of practice. Given MAID's novelty, it is important for social work students to learn about the current political context as it may influence their career goals for facilitating social justice (Weiss-Gal, 2016). For current social work practitioners, it is important for resource counselling. Practitioners must be up to date on health care options in order to facilitate informed decision-making and access (Craig & Muskat, 2013). Lastly, it is important for social workers in academia and policy, as it is their role in interprofessional health care teams to advocate regarding the barriers vulnerable populations experience, and participate in legislative processes to improve end-of-life care (Craig & Muskat, 2013).

Awareness and understanding of MAID is important because awareness of policy helps inform social work, and facilitates commitment for social justice (Jansson, Nyamathi, Heidemann, Duan, & Kaplan, 2017). Numerous studies have demonstrated that most patients seeking MAID are doing so not because of chronic pain or unrelieved physiological issues, but for reasons such as existential suffering, poor quality of life, and loss of autonomy (Weiss, 2018). Thus, this is a social work issue most particularly for social workers in health care, whose roles are to assist with the aforementioned psychosocial issues encountered when health is declining (Ashcroft et al., 2017; Ashcroft, McMillan, Ambrose-Miller, McKee, & Brown, 2018; Craig et al., 2016). Hence, it is important to understand MAID to facilitate access and inclusion within the current political context.

It is also important to understand MAID so that practitioners can assume a policy-informed practice. A policy-informed practice refers to "efforts to change policies in legislative, agency, and community settings, whether by establishing new policies, improving existing ones, or defeating the policy initiatives of other people" (Jansson, 2008, p. 14). In health care settings, assuming a policy-informed practice can be effective in improving health care outcomes, reducing health disparities, improving access to services, and helping to address social determinants of health (Ashcroft, 2010; Jansson et al., 2017). The significance of policy awareness and understanding relates to its function in guiding medical social workers in facilitating access and inclusion within the current political context, and allowing practitioners to analyze the operationalization of a policy and further advocating to reform the policy with the aim of increasing access and inclusion (Weis-Gal, 2016; Welbourne, 2011).

In addition to the outcomes for patients and families, understanding MAID is important for social workers' occupational health. Without clear understanding of MAID, social workers in health care may experience occupational stress and an increased personal burden when they encounter resulting ethical dilemmas. A study examining the impact of vague end-of-life policies revealed that social workers felt unprepared for ethical issues in end-of-life care and had particular difficulty when questioning patients' competency (Csikai & Bass, 2001). The practitioners were unsure how to provide evidence-based, end-of-life, patient-centered care. This uncertainty in practice effectiveness and lack of legally-supported guidelines for addressing ethical dilemmas can result in occupational stress and resignation (McCormick et al., 2014; Ulrich et al., 2007). As such, patients and families may be negatively impacted as they are not being cared for with evidence-based practices. Without clear understanding of MAID, the ability to practice ethically (i.e. with integrity and competence) would be compromised and practitioners become susceptible to burnout (McCormick et al., 2014; Teixeira, Ribeiro, Fonseca, Carvhalo, 2014; Ulrich et al., 2007).

Medical social workers working with patients who are diagnosed with ALS are doubly vulnerable to these circumstances due to scarce evidence-based practices and MAID's mentally competent eligibility criteria. Considering the ambiguity in ALS progression and absence of curative treatment, the care plan for ALS is palliative (Foley, Timonen, & Hardiman, 2014; Murray & Butow, 2016). Palliative care planning for patients with ALS includes pain and symptom management, as well as advanced care planning (Hardiman et al., 2011). With intense emotions and relatively little time due to disease progression, social work practitioners have a significant role in supporting patients and families through this process of adjustment by educating and facilitating difficult end-of-life decisions. Despite the need for evidence-based best practice, systematic reviews on evidence for psychotherapy interventions for patients with ALS discovered that due to poor quality, the current evidence is insufficient for proposing a best practice (Gould et al., 2015; Walklet, Muse, Meyrick, & Moss, 2016). Additionally, given MAID's lack of clarity regarding patients' mental competence, practitioners may feel like they are practicing unethically with ALS patients, and become susceptible to burnout. As such, awareness and understanding of MAID impacts the wellbeing of practitioners, patients, and families.

MAID Policy Implications for Health Care and Patients with ALS

Legalization of MAID revitalized end-of-life care and health care decision-making processes in Ontario. Eligible palliative patients have increased opportunities for actualizing their goals of care related to dying with peace and dignity. Legal guidelines require allied health professionals, including social workers, to discuss MAID in general terms, akin to what patients can research online, and advise and/or refer patients for more information from a physician or nurse practitioner (Ontario Ministry of Health and Long-Term Care [MOHLTC], 2017). Physicians and nurse practitioners can provide more in-depth information about MAID processes. Should physicians or nurse practitioners have conscientious objection due to personal or religious beliefs, they are required to make an immediate, effective referral to another medical professional who is able and willing to carry out the MAID process (MOHLTC, 2017). Similarly, pharmacists who are requested to dispense MAID drugs, may also object and make a referral (MOHLTC, 2017).

In terms of how health care professionals support patients with ALS in actualizing goals of care, physicians and nurse practitioners discuss the range of treatment options at the terminal phase of a patient's disease. Treatment options may include medication for pain and symptom management, noninvasive ventilation for breathing, gastrostomy tubes for feeding, and assistive devices to facilitate communication and ambulation (Mitchell & Borasio, 2007). For patients with ALS who are at-risk for terminal respiratory failure and fear they will choke to death, a tracheostomy is an option. However, patients with ALS often decline tracheostomy because it results in a "locked-in syndrome," which infringes on their quality of care (Mitchell & Borasio, 2007). For patients with ALS whose goals of care do not include the aforementioned options as resources optimizing their quality for life, MAID is (theoretically) another option.

Due to the short prognosis and incurable nature among ALS diagnoses, patients with ALS meet the MAID criteria for irremediable condition and reasonably foreseeable death. Despite this, for ALS patients who do not have mental capacity for decision-making, MAID is not an option. Because of MAID's novelty, there is a gap of knowledge on the frequency of mentally incompetent patients with ALS being denied MAID in Ontario. Current statistics show the most frequent reason individuals are denied MAID in Canada is loss of mental competency (Government of Canada, 2018). In Ontario, neurodegenerative disorders are the third most frequent underlying condition resulting in MAID requests in Ontario. As such, it can be hypothesized that MAID's 'mentally competent' eligibility criteria has been problematic for patients with ALS in Ontario who are requesting MAID. In support of the hypothesis that mentally incompetent patients with ALS are denied MAID in Ontario, a study analyzing the first 100 completed MAID cases in Ontario specifically reveals that ALS is the second most frequent medical condition for accessing MAID (Rosso, Huyer and Walker, 2017). Although the sample study included approved ALS cases, it can be hypothesized that due to the ALS population's increased risk for cognitive impairments, a significant percentage of mentally incompetent patients with ALS were denied access to MAID.

Considering the suffering patients with ALS endure, a nation-wide study surveying Canadian ALS physicians' and allied health providers' opinions on MAID for patients with ALS revealed that 77% of physicians and 81% of allied health professionals believed patients with ALS should have access to MAID (Abrahao et al., 2016). Furthermore, 52% of physicians and 59% of allied health professionals believed moderate stage ALS should be eligible for MAID, and 84% of physicians and 82% of allied health professionals believed severe stage ALS should be eligible. Clearly, there is a nation-wide consensus amongst ALS health care providers that patients with ALS experience intolerable suffering justifiable for MAID.

MAID Policy Implications for Front-Line Social Work Practice

According to the Ontario College of Social Workers and Social Services Workers (2016), MAID professional obligations for social workers relate to the Code of Ethics and Standards of Practice in maintaining competence and integrity, relationships with clients/patients, and responsibility to clients/patients. To maintain competence and integrity in practice social workers must maintain current knowledge of policies, legislation, programs, and issues related to MAID. To maintain relationships with patients, social workers must keep their values impartial from their work in supporting patients' needs and interests. Lastly, to maintain responsibility to patients, social workers must assist patients in actualizing their MAID goals of care by providing information and referral to an appropriate physician or nurse practitioner. If the social worker has conscientious objections, they must link the patient with a service that is willing and able to assist them.

Although MAID has implications for social workers in general, medical social workers in health care are most directly impacted. As members of interprofessional health care teams, social workers adhere to ethics and standards in practice, while liaising with physicians, nurses, and allied health professionals to provide and facilitate holistic patient-centered care (Ambrose-Miller & Ashcroft, 2016). When conducting biopsychosocial assessments, medical social workers assess patients' needs for what they deem optimal quality of life. Social work interventions to address patients' biopsychosocial needs include resource counselling and referrals to the various services and supports to facilitate their goals of care. If patients' goals of care indicate MAID or if they explicitly inquire about MAID, medical social workers must provide general information about MAID and make a referral to the patient's physician or appropriate nurse practitioner. Furthermore, this may include advocacy if there are barriers to accessing MAID, i.e. language, geography, or declining cognitive capacity. By nature of medical social workers' scope in supporting patients' preferences and values for care, social workers must collaborate and liaise with interprofessional health care teams to inform providers of patients' goals so that the respective provider can provide care that is in line with the patient's wishes.

In respect to medical social workers providing end-of-life care to patients with ALS, MAID has implications for resource counseling in advance care planning. With the knowledge that MAID is only eligible for patients with ALS who are mentally competent, practitioners must strike the delicate balance of maintaining their competence, integrity, relationship and responsibility to patients with ALS through timely MAID resource counselling. This means they must counsel before patients are mentally incompetent (Li, Watt, Escaf, & Gardam, 2017). Simultaneously, they must also meet patients where they are at through sensitive communication (Heyland et al., 2006a).

Additionally, MAID has implications for counseling family members and caregivers. When supporting a patient whose family and/or caregivers are struggling to accept the patient's choice for MAID, practitioners must provide them supportive counseling to facilitate family-centered care and support the patient's social aspect in quality of life (Foley, Timonen, & Hardiman, 2016). A patient's social aspect in quality of life refers to the social relationships that provide patients support, feelings of connectedness, and existential meaning. When patients with ALS hold different levels of acceptance of disease progression than their families, tensions related to decision-making can surface (Cornwell, 2016). Family disagreements can further exacerbate isolation and emotional withdrawal that patients with ALS experience from disease-related depression and hopelessness (Kübler, Winter, Ludolph, Hautzinger, & Birbaumer, 2005; Pagnini, 2013; Plahuta et al., 2002). Patients with ALS may disengage from family members; thus, reducing the social aspect of their quality of life. Supportive counseling for patients' and families' adjustment to disease progression and grief may occur one-on-one, or through family meetings, with the patient's health care providers.

Family meetings are particularly effective in assisting palliative patients and families to set future goals of care that are in line with their preferences and values, through informing and clarifying the patient's health condition, prognosis, and available options (Hudson, Quinn, O'Hanlon, & Aranda, 2008). While deciding future goals of care, patients and families have the opportunity to share grief-related thoughts and emotions that are then supported by the present health care team, especially the social worker. A study evaluating the effectiveness of family meetings for palliative patients in the Intensive Care Unit (ICU) revealed that family meetings have specifically been effective in reducing family conflict over care goals, anxiety, depression, and posttraumatic stress among bereaved families (Nelson, Walker, Luhrs, Cortez, & Pronovost, 2009). Given the palliative nature of the study, it is reasonable that family meetings for ALS patients and their families regarding MAID can be an effective support. Families will be able to express emotions related to MAID and interprofessional health care teams can assist in identifying a unified purpose and plan for restoring family cohesion moving forward as the MAID process is completed.

Critique of MAID Options

Currently, while MAID appears to be a useful policy for addressing gaps in end-of-life care for patients with ALS, it is not without flaws. The following are four options to access MAID:

1. The first option to access MAID is to pass all three eligibility assessments (CPSO, 2017). The rigid 'mentally competent' eligibility criteria create barriers and blatant possibilities for patients with ALS to be denied access based on their capacity, which they are at-risk of losing, as highlighted earlier. In addition to the possibility of denied access during the initial informed consent, the 'mentally competent' criterion continues to create two additional possibilities for denied access when required to provide second and third informed consents (Li et al., 2017).
2. However, if either the initial or secondary assessments deem an applicant ineligible, the second option is to consult another physician for another assessment (CPSO, 2017).
3. If, during the initial and secondary assessments, the clinicians have reason to believe an applicant's death or loss in mental capacity are imminent, the third option is to shorten the 10-day reflection period (CPSO, 2017).
4. A fourth undocumented option is for applicants to apply for a prescription, instead of physician administration, and ingest the medication on their own which they could do even while considered mentally incompetent, since it is self-administered.

Although options one to three attempt to facilitate access, the main barrier is the ALS disease progression intersecting with the processes required for those options. Referring to option one, if patients with ALS lose mental capacity any time throughout the MAID process, they are ineligible. While the second option attempts to increase access by allowing appeal requests, this option inevitably leads to a longer MAID process. Since applicants must search and arrange for another consultation, the time before which the reflection period can be enacted is prolonged. A solution to expedite this process is to arrange for a telemedicine assessment conducted online. Although this does well in facilitating access, especially for patients with ALS living in urban areas, it is a privileged option. Applicants must have technological resources, and knowledge of how to use such resources, to be able to carry out the telemedicine assessment on their end. Nonetheless, the impact of prolonged time before the reflection period is another barrier, making applicants more vulnerable to the possibility of losing mental capacity throughout the MAID process. Studies analyzing MAID cases in Ontario validate these critiques, as loss of mental capacity is the predominant reason for denying access (Government of Canada, 2017d; Li et al., 2017; Rosso et al., 2017).

It can be argued that the third option addresses impacts of the first and second options. However, it is conditional on both the initial and secondary clinicians sharing the same opinion. Despite the opinions being formulated with standard assessment protocol, there is always a possibility clinicians will report differing opinions due to personal bias (Capacity Assessment Office, Ministry of the Attorney General, 2005). The fourth option serves as a possible solution as there is no specific protocol requiring a medical practitioner's presence during self-administration. However, further ethical considerations are required regarding safety and risk evaluations.

A comparison of these analyses against the World Health Organization's (WHO & United States, 2005) principles for effective delivery of health care services reveals that MAID is not being delivered effectively. The five principles for effective delivery of health care services are public participation, accessibility of services, appropriate technology, interdisciplinary collaboration, and health promotion. The principle relevant amongst barriers related to the 'mental competence' criterion is lack of accessibility to services. MAID is not being delivered effectively due to barriers that are inherent in its eligibility criteria and required processes, which create inequitable distribution of access. Additionally, MAID's sole focus on guidelines for physicians, nurse practitioners, and pharmacists demonstrates a lack of consideration for the interdisciplinary collaboration with other allied health professions, particularly social work, that holistic end-of-life patient-centered care necessitates (Hudson et al., 2008). Another relevant theme is inappropriate technology. Related to its inaccessibility, MAID does not have appropriate technology (i.e. protocol) to support the health and wellbeing of mentally incompetent patients with ALS. Although options two and three attempt to increase access, the above analysis illuminates its inability to facilitate accessibility for all. Furthermore, option four may be a possibility but, since it is undocumented, there is a lack of appropriate technology and guidelines to safely and ethically utilize this option. A well-rounded MAID policy would have included appropriate technology facilitating equitable access for all. However, the current MAID framework lacks appropriate technology for vulnerable populations, particularly mentally incompetent patients with ALS. Thus, it provides them ineffective delivery of health care services.

Recommendations for Social Work

Based on the WHO's (WHO & United States, 2005) definition of health, which states that health is "…a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity," MAID's gaps negatively impact mentally incompetent patients with ALS. In respect to social wellbeing, MAID policy processes socially exclude mentally incompetent patients with ALS from taking an active part in their own lives. This implication leaves them no choice but to live in unbearable suffering while they are essentially waiting to die. In respect to mental wellbeing, as they wait to die, such indignity can be compounded when ALS progresses to complete paralysis and reliance on 24/7 care (Chochinov et al., 2016). With social workers' commitment to social justice and responsibility in holistically supporting patients' biopsychosocial health and wellbeing the two following recommendations boldly call social workers to take action.

The first recommendation calls for social workers to be active in increasing their competency regarding the provision of MAID, especially medical social workers. On a micro-level, social workers could consult and debrief with work colleagues or other health practitioners on MAID-related cases. On a mezzo-level, social workers could organize MAID information sessions within their organizations or attend the annual MAID Conference hosted by the Canadian Association of MAID Assessors and Providers. On a macro-level, social workers could be attentive to current research initiatives and future political directions for MAID. To further add to these points Canadian schools of social work, with undergraduate and graduate programs, can prepare future social workers to engage in MAID-related patient advocacy and policy practice by including it in the curriculum of policy and health practice courses.

The second recommendation calls for social workers to advocate regarding the provision of MAID. This can occur on micro-, mezzo-, and macro-levels through conversations. On a micro-level, social workers may advocate within their interprofessional teams, supporting MAID requests through advanced care planning. On a mezzo-level, social workers could advocate to their respective professional organizational and regulatory body regarding MAID's gaps. On a macro-level, social workers may participate in research initiatives and political discussions to increase inclusion in the provision of MAID.

Recommendations for Policy

Recommendations for policy include the use of advance directives that outline advance requests for MAID, and substitute decision makers. According to the Government of Canada (2017b), the rationale for excluding these in the current MAID framework is to safeguard vulnerable populations, i.e. mentally incompetent patients, from receiving treatment that is incongruent with their goals of care and inaccurate assumptions about their quality of life. However, other laws permit mentally incompetent patients, who are either on life-sustaining treatment or require life-sustaining treatment, to request death with the use of advance directives and substitute decision makers, despite also being vulnerable to the same possibilities indicated in the rationale. For example, nephrology patients who are on life-sustaining treatment, and wish to withdraw from treatment under certain circumstances when they are mentally incapable, can have these requests carried out through an advanced directive whereby they appoint a power of attorney for personal care (Holley, 2011). Furthermore, if they have not created an advanced directive or appointed a power of attorney for personal care, decisions for withdrawal are redirected to their substitute decision maker(s). Another example is with patients who are unresponsive and require immediate life-sustaining treatment, such as resuscitation, intubation, or surgery, and request death in these circumstances can also have these requests carried through use of advance directives and substitute decision makers (Heyland et al., 2006b). While there are bioethical differences between withdrawing and withholding versus administering treatments, the outcome of death is the same for all cases; ergo, the following recommendations.

The first recommendation is to facilitate a concurrent process of MAID and advanced care planning that would begin as soon as patients with ALS are given a palliative diagnosis. If a patient wishes to enact MAID when a single or set of medical conditions develop (i.e. mental incapacity, aphasia, etc.,), they would be able to state this in their advance directive. The advance directive would include questions to prompt individuals to clearly outline and define the circumstances under which they are requesting to access MAID. This would address the barrier of physician uncertainty on circumstances, as noted in the CCA (2018) review on advance MAID request. This directive would hold true, even if they become mentally incapable. Including this feature would require social workers to support patients and families throughout advance care planning. To account for potential changes in patients' perspectives on quality of life and their goals of care, patients would be required to include any necessary changes, and sign a form, which would state they still wish to carry forward with their advance directive, along with one witness signature. This process would occur on a consistent frequency (i.e. once a month), that would be set between patients and their treating physician, who would be responsible for monitoring their underlying condition that lead to the MAID request. During these processes, the treating physician must liaise and communicate with the physician who would administer and/or prescribe MAID, to ensure continuity of care. Verbal consent along with two witness signatures would be an option for those who are physically unable to sign. The criteria for those who are valid witnesses would be the same as the criteria outlined in MAID processes. This would address the barriers of physician uncertainty on the consistency of request and on changes in patients' perspective on quality of life, which were also noted in the CCA (2018) review.

The second recommendation is to allow for substitute decision makers to request MAID when a mentally incapable ALS patient is experiencing intolerable suffering and their death is reasonably foreseeable. If the patient's health status advances to this level and there is no advance directive, a physician would defer to the substitute decision maker to discuss goals of care. If a substitute decision maker identifies that the patient's quality of life values are in line with utilizing MAID, then MAID could be administered. If physicians are uncertain about the substitute decision maker's interest and query potential for secondary gain, physicians could seek guidance from the Consent and Capacity Board of Ontario and follow the necessary steps.

For both recommendations, MAID for mentally incompetent patients with ALS would only be facilitated through physician administration. Allowing family or friends to administer MAID medications for this population could be distressing if the patient is presenting confusion immediately prior to administration. Physicians are better trained to administer lethal medications and do not have a conflict of interest.

Two barriers become evident in such conditions. A practical barrier to adopting both approaches relates to how MAID will be administered during moments of patient confusion. Ethical considerations from the College of Physicians and Surgeons is necessary for creating communication guidelines and educational training for how to respond to patients when in situations where patients are confused and ask questions when medication is being administered. Other ethical considerations and guidelines are required for instances when patients are directly objecting to MAID. A proposed guideline may be that if a patient directly objects to MAID upon three different occasions, physicians are prohibited from trying again.

A professional barrier relates to obtaining physicians who are comfortable with administering MAID to mentally incompetent patients with ALS. This is already an issue with the current MAID framework. Seeing as though these recommendations require more of an ethical shift, there may be fewer doctors willing to administer MAID for this population. Rightfully so, it can be a distressing situation for physicians. Incorporating mandatory time for debriefing and accessing psychosocial support for physicians can be useful in recruiting physicians and avoiding burnout.

Another barrier relates to the “slippery slope,” fear. Individuals may fear that physicians may become lenient in approving MAID requests, which has alarming implications for the values in the sanctity of life. However, a statement from Madam Justice Lynn Smith determined that, “… the evidence from other jurisdictions shows that the risks inherent in legally permitted assisted death have not materialized in the manner that may have been predicted. … This evidence serves to allay fears of a practical slippery slope” (as cited in Reggler, 2017). The health care system must continue to carefully monitor and evaluate MAID to safeguard against potential for lenient practice.

Conclusion

MAID affords dying Canadians the right to die with dignity. However, as this paper argued, the current framework for MAID: 1) yields inaccessibility for palliative patients who are mentally incompetent, particularly patients with ALS, and 2) offers no guidance on how social workers are to work collaboratively in interprofessional health care teams, despite their role in assisting with psychosocial issues encountered when a patient’s health is declining. The current ‘mentally competent’ eligibility criteria exclude mentally incompetent patients with ALS from accessing MAID. Their physical, mental, and social wellbeing outcomes become negatively exacerbated by such exclusion. In this light, although the rationale for excluding advance directives and substitute decision makers is to safeguard this population, it is actually reducing wellbeing outcomes.

The gaps in MAID call for social work action in terms of achieving social justice through equality of access and quality of outcome. Being informed about MAID, and actively advocating towards policy reform, improves practitioners’ competency in resource counselling and assisting advance care planning and facilitates practitioners’ commitment to social justice. With unified social work attention and engagement with MAID discussions and initiatives, policy reform is possible. Reform may include, but is not limited to, advance directives and substitute decision makers. Furthermore, it may also include guidance for how social workers are to practice in the interprofessional context.

Ball and Anderson (2017), who are physicians who facilitate MAID, discuss the appreciation they have received from families. They explain that the mere accessibility to MAID provides patients reassurance, which improves their mental and emotional wellbeing, including those who have not chosen the procedure. By including the two policy recommendations, mentally incompetent patients with ALS would be afforded this reality of choice, equity, and dignity. Future research on how to facilitate equity in MAID processes for other excluded populations, i.e. minors (CCA, 2018) and individuals whose sole underlying condition are mental disorders (Dembo, Schuklenk, & Reggler, 2018), will aid in producing a MAID policy made for all.

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