The Role of Speech-Language Pathologists in Medical Assistance in Dying: Canadian Experience to Inform Clinical Practice

Le rôle des orthophonistes dans l'aide médicale à mourir : informer la pratique clinique par l'entremise de l'expérience canadienne

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Abstract

Communication is an integral part of the medical assistance in dying assessment process in Canada, as reflected by the legislation of Bill C-14 (2016), provincial and hospital policies, and professional association statements. For patients with communication impairments, which are common in the end-of-life patient population, the ability to communicate their wishes regarding care, including medical assistance in dying, can be very challenging. Speech-language pathologists have training in assessment and treatment of communication and cognition impairments, therefore are uniquely qualified to support these patients and ensure that their basic human right to communicate is respected. However, there is a paucity of published literature regarding the role of speech-language pathologists in medical assistance in dying. This paper reviews the role for speech-language pathologists in medical assistance in dying and recommends an approach to integrating their expertise into the medical assistance in dying assessment process.

Abrégé

Au Canada, la communication fait partie intégrante du processus d'évaluation de l'aide médicale à mourir, comme en témoignent le projet de loi C-14 (2016), les politiques provinciales et hospitalières, ainsi que les énoncés de position des associations professionnelles. Parmi les patients en fin de vie, nombreux sont ceux ayant un trouble de la communication. Pour ces patients, il peut s'avérer très difficile de communiquer les volontés qu'ils ont concernant les soins leur étant administrés, y compris ceux de l'aide médicale à mourir. La formation des orthophonistes inclut l'évaluation et le traitement des troubles de la communication et de la cognition. Ces professionnels possèdent donc des compétences uniques qui leur permettent de soutenir les patients en fin de vie et de veiller à ce que leur droit fondamental à la communication soit respecté. Peu de littérature n'a néanmoins été publiée sur le rôle des orthophonistes dans l'aide médicale à mourir. Le présent article examine le rôle des orthophonistes dans l'aide médicale à mourir et recommande une approche favorisant l'intégration de l'expertise de ces professionnels dans le processus d'évaluation de l'aide médicale à mourir.

Medical assistance in dying (MAiD) became legal in Canada in June of 2016 (Bill C-14, 2016). Worldwide, the need for clear communication, and risks of miscommunication, have been highlighted for physicians and nurses involved in MAiD (Brooks, 2019). Communication impairments can be a barrier to assessment of patients' competence and capability of making end-of-life decisions, including MAiD.

Communication is a means of connection and exchange of meaningful information between at least two individuals. The importance of communication is reflected in the Canadian legislation. Bill C-14; 241.2; 3; i (2016) states, "if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision." The legislation is paralleled by Ontario's Clinician Aid B (Ministry of Health and Long-Term Care, 2019), which is suggested for MAiD assessors and providers as well as hospital policies (The Ottawa Hospital, 2016).

Speech-language pathologists (S-LPs) are health care professionals who identify, diagnose, and treat communication and swallowing disorders across the lifespan (Speech-Language and Audiology Canada [SAC], 2016). They can be instrumental in cases where patients have communication disorders (e.g., expressive or receptive aphasia), motor speech disorders (e.g., dysarthria or apraxia), and cognitive-communication disorders (e.g., dementia). Disease processes which can lead to communication impairments include neurodegenerative diseases, certain types of cancer, cerebral vascular disease, brain injury, dementia, and hearing impairment (Buchel, 2018; Toner & Shadden, 2012). Patients may be capable of making medical decisions, including MAiD, despite having a communication impairment which limits their ability to express their wishes (Buchel, 2018). Across Canada, some MAiD teams have been incorporating S-LPs to assist with communication in challenging cases.

This paper will explore the role for S-LPs in MAiD and provide recommendations for the inclusion of S-LPs on MAiD teams. The purpose of this paper is to offer practical and implementable guidance on the role of S-LPs in MAiD, where previously there has been very little.

Method

A literature search was performed using keyword searches on the PubMed, SCOPUS, and CINAHL databases. Keywords used included "MAiD," "medically assisted dying," and "euthanasia," or "palliative care" and "end of life care" or "ICU" and "critical care" along with "SLP," "speech language pathology," and "communication" or "alternative and augmentative communication." Titles were screened for relevance by the first author (KD), then relevant abstracts were reviewed. If the article remained of interest, the full article was read, with review of the bibliographies for further relevant articles.

The MAiD procedure remains relatively new in Canada, with a paucity of literature about including S-LPs in this process. Therefore, grey literature such as professional organization policy statements and information from the first Canadian conference for MAiD assessors and providers were reviewed. Data were also collected from the local experience of the MAiD team at The Ottawa Hospital through personal communication with members of the team. Recommendations are based on information drawn from these sources to provide initial guidelines for the inclusion of S-LPs in the MAiD process and on MAiD teams.

Review of the Literature on the Role of S-LPs in MAiD

Despite the importance of communication for the MAiD process, there is a lack of literature on the role of S-LPs in MAiD worldwide. Published research primarily focuses on the ethical considerations, perspectives, and experiences of physicians and nurses, with no published research on the experiences of other health care providers (Brooks, 2019). Therefore, literature regarding the role of S-LPs in critical care and palliative or end-of-life care was reviewed, with applicable concepts presented below.

There is a relatively extensive body of literature on the role of S-LPs in critical care settings, with the following key take away messages relevant to this discussion. Critical care literature highlights the emotional suffering of patients who are unable to communicate their wants, needs, and desires with their health care team, friends, and family. There is an association between lack of communication and feelings of anger, frustration, anxiety, fear, and powerlessness (Braun-Janzen, Sarchuk, & Murray, 2009). Often the method of communication offered by health care providers is yes/no questions, which is insufficient for involving the patient in discussing end-of-life decisions, including MAiD (Braun-Janzen et al., 2009). The impact of access to communication is powerful, with educating staff in the use of alternative and augmentative communication techniques positively impacting measures such as length of stay and morbidity (Handburg & Voss, 2018).

At the end of life, the ability to communicate is an important contributor to quality of life for both patients and their families and can be as important as pain relief

(Chahda, Mathisen, & Carey, 2017; Toner & Shadden, 2012). The American Medical Association and National Institute of Health highlight that one of the most important components in end-of-life care is supporting communication so patients can participate in discussing and planning their care (Chahda et al., 2017; Toner & Shadden, 2012). There are several factors influencing communication at the end of life which induce variability in the patient's abilities. These include the underlying disease process, level of alertness, fatigue, pain, medication, and emotional state (Chahda et al., 2017; Pollens, 2012).

There have been specific roles described for S-LPs at the end of life, three of which are particularly relevant to MAiD (Pollens, 2004, 2012). First, S-LPs can provide consultation services regarding communication and cognition. S-LPs can provide guidance on optimal communication methods for patients with communication or cognitive limitations (Pollens, 2004, 2012). This can facilitate assessment of capability to make health care decisions, as they can help patients demonstrate their ability to understand and process information, as well as communicate their desires to their health care team (Pollens, 2004, 2012). Second, S-LPs can provide intervention to develop communication strategies with patients to support their role in health care decisions, maintain social closeness, and allow them to express emotional states and concerns about dying (Pollens, 2004, 2012). Some examples of strategies include paced rate of speech in dysarthria and the use of low- and high-technology alternative and augmentative communication devices (Pollens, 2012). Third, S-LPs can have an important role on an interdisciplinary team as communication is such an important component of patient care, including sharing information about the patient's communication abilities, contributing to optimal patient care (Pollens, 2004, 2012).

Canadian Experience

The importance of including S-LPs in the MAiD process has received attention in Canada. In 2016, SAC released a position statement on their role in end-of-life care and have started a MAiD Community of Practice forum (SAC, n.d.) to connect S-LPs who have been involved in MAiD across the country. The statement highlights that communication impairments are common in the end-of-life patient population, can cause distressing symptoms, and put patients at risk for being misunderstood by health care providers and family (SAC, 2016). It also states "that all people should have access to comprehensive end-of-life care, which includes communication health services and resources. Communication health professionals—speech-language pathologists, audiologists, and communication health assistants—are uniquely qualified to provide essential services in end-of-life care" (SAC, 2016, p. 1). S-LPs can play an important role by optimizing communication to facilitate:

1. Determination of capacity/competency for making health-care and other decisions;
2. Comprehension of prognosis and the risks and benefits of treatment options, which allows for informed decision making;
3. Self-expression and autonomy, so patients or clients can clearly indicate pain, symptoms, needs and preferences;
4. Socialization, sharing and closeness with loved ones;
5. Advance care planning, including helping patients or clients express their wishes about goals of care and physician assisted death;
6. Fulfillment of end-of-life goals. (SAC, 2016, p. 2)

At the 2018 conference of the Canadian Association of MAiD Assessors and Providers, there was a dedicated presentation regarding the role of S-LPs as communication intermediaries (Buchel, 2018). This highlighted the role that S-LPs can play to assess communication, to provide suggestions for compensatory strategies to facilitate communication, and to act as a communication intermediary by attending MAiD eligibility assessments and procedures if necessary. As a communication intermediary, S-LPs are focused on the patient and implement communication strategies as needed, clarifying the messages from both the clinician and the patient. This decreases the burden on the assessors' time, and the burden of communication from the patient and caregiver (Buchel, 2018).

In Ottawa, the MAiD team based at The Ottawa Hospital has involved S-LPs in select cases. From January to December 2018 there were 133 requests for MAiD, with 171 physician assessments (two independent assessments are required prior to the MAiD procedure) and 46 procedures. An S-LP was consulted in five cases (3.8%) and was involved throughout the entire process in two cases (M. Kekewich, personal communication, February 5, 2019).

In the experience of the S-LPs in Ottawa who are part of the MAiD team, when S-LPs are consulted, by the nature of their role, they become closely involved in all aspects of the MAiD assessments and procedure, and with all members of the MAiD team, especially with the patient and family. Working with patients, S-LPs can

assess their speech and language skills and establish the best means of communication to allow them to express their wishes, understand the questions asked of them, ask their own questions, and demonstrate their competence. Acting as communication facilitators, they are also able to relieve family involvement in interpreting the person's communication and allow the team to assess the patient without family present when needed. The value of S-LPs' involvement also extends to the members of the MAiD team, who report benefiting from tools and strategies to communicate with their patients and being able to complete their assessments and interventions without the additional burden of having to manage communication barriers.

Physician providers reflect that while S-LPs may not be involved in most cases, S-LPs have been instrumental in the cases they have been involved with. The S-LPs' assistance with communication typically made it possible for patients to demonstrate their capacity to consent to the MAiD procedure, without which they would have been ineligible (V. Chaput, personal communication, January 25, 2019). One of the local cases had an initial assessment prior to involvement with an S-LP which found the patient ineligible, then subsequently was able to demonstrate capacity using the S-LP as a communication intermediary (M. Kekewich, personal communication, January 25, 2019).

The second author (EL) is an S-LP who has reflected on her personal experience based on years of working with patients with communication disorders who are critically ill. Patients have often expressed that one of their primary fears is not being able to communicate their wishes at end of life, and they fear being forced into undesired situations due to their inability to make themselves understood to their care providers. Through participation in end of life care, including the MAiD process, S-LPs are able to reassure patients that they will support their ability to communicate at all stages of their disease and help them demonstrate competence to the best of their ability. While it requires challenging conversations and intense involvement on the part of the S-LPs, working as part of the MAiD team is a rewarding part of the spectrum of services that S-LPs can provide. S-LPs have an active and valuable role to play to support the communication needs of critically ill patients with communication disorders throughout the MAiD process.

Recommendations

Communication is an important component of assessment for MAiD eligibility, and in Canada there is an expectation to take all necessary measures to facilitate reliable communication (Bill C-14; 241.2; 3; i, 2016). Therefore, the following recommendations are suggested:

1. Patients requesting MAiD who have diagnoses which may impact their communication ability should be screened for communication impairment. Examples of these diagnoses include, but are not limited to:
    - Stroke/Cerebral vascular disease, particularly if deficits include aphasia, dysarthria, or apraxia (Flowers, Silver, Fang, Rochon, & Martino, 2013)
    - Neurodegenerative conditions, including but not limited to amyotrophic lateral sclerosis, multiple sclerosis, cerebellar/ataxic disorders, Parkinson's disease, and Huntington's disease (Fried-Oken, Mooney, & Peters, 2015)
    - Certain cancers, including head and neck cancers that impair speech, or brain tumors/metastasis (Hansen, Chenoweth, Thompson, & Strouss, 2018)
    - Cognitive communication disorders, including but not limited to brain injury, dementia, psychiatric disorders, and adult autism (Papathanasiou & Coppens, 2017; Small, Gutman, Makela, & Hillhouse, 2003)
    - Pre-existing developmental language disorders (Clegg, Hollis, Mawhook, & Rutter, 2005)
    - Hearing impairments (Erber, 1994)
2. MAiD assessors and providers should consider education on basic strategies for accommodating mild communication impairments (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2017).
    - These basic strategies could include speaking louder and slower for a patient with a hearing impairment, getting a patient with mild dysarthria whose speech is sometimes difficult to understand to repeat themselves or write key words, or repeating what they believe the person said to check that they have understood correctly (Burns et al., 2017).
    - Suggested resources include supportive conversation (online training module available through the Aphasia Institute at https://www.aphasia.ca/home-page/health-care-professionals/self-directed-sca-module/) or using the FRAME framework (**Table 1**).

Table 1

The FRAME Mnemonic for Accommodating Communication Deficits

	Key principle	Example strategies
F	Familiarize with how the patient communicates before starting medical interview	Find out whether patient already has a reliable and preferred communication method.
R	Reduce Rate: Slow down!	Pause between phrases, one idea at a time, allow more time for patient to respond.
A	Assist with communication: Actively help the patient with communication	Ask questions in a different way to help patient understand (e.g., multiple choice; yes/no).
M	Mix communication methods: Show, do not tell	Keep a small white board/pad of paper handy to write key words or draw. Use pictures, alphabet boards, gestures.
E	Engage the patient first: Respect each patient's abilities and autonomy	Communicate directly with the patient. Do not ignore patient and talk only to family/caregivers.

Note. From "Heath care provider accommodations for patients with communication disorders" by M. I. Burns, C. Baylor, B. J. Dudgeon, H. Starks, and K. Yorkston, 2017, *Topics in Language Disorders, 37,* p. 317. Copyright 2017 by Wolters Kluwer Health. Adapted with permission.

3. If a significant communication impairment is suspected or identified, particularly if the assessor/provider is not confident in their ability to communicate effectively with the patient, a referral to an S-LP should be considered (Bill C-14; 241.2; 3; i, 2016; SAC, 2016).

4. If a significant communication impairment is identified, an independent communication assessment by an S-LP should be carried out prior to MAiD assessments. This allows assessment of receptive and expressive abilities, and identification of potentially beneficial compensatory strategies or alternative and augmentative communication tools (Buchel, 2018; Chahda et al., 2017; Pollens, 2004).

    - Basic recommendations may include face to face assessments in a quiet room with the patient wearing all their assistive devices such as glasses and hearing aids (Buchel, 2018).
    - Compensatory strategies may include using close-ended or multiple choice questions, changing rate and/or volume of speech, over articulation, use of short simple sentences, summarization, and sign-posting (Buchel, 2018).
    - Augmentative and alternative communication device recommendations may include low-technology (e.g., white boards, paper and pen for writing/drawing, alphabet boards, picture boards, eye gaze board and portable speech amplifiers) and high technology devices (e.g., iPad apps, speech generating devices; Buchel, 2018).
    - An example of a picture-based communication board designed specifically for use in discussions and assessments for MAiD was developed in Ottawa. This will be made available through the Canadian Association of MAiD Assessors and Providers website (https://camapcanada.ca/). Other resources are being developed and distributed through the MAiD Community of Practice Forum of SAC (n.d.).

5. Following assessment, S-LPs should provide the MAiD team with information regarding the patient's communication abilities, compensatory strategies that are needed, and whether an S-LP should be present at MAiD eligibility assessments to act as a communication intermediary (Buchel, 2018; Pollens, 2004; SAC, 2016).

6. If necessary, S-LPs should attend MAiD eligibility assessments and procedures to act as a communication intermediary (Bill C-14; 241.2; 3; i, 2016; Buchel, 2018).

Anticipated Challenges

There are anticipated challenges to implement these recommendations in Canada. First, MAiD assessors and providers may not recognize cases where S-LPs' involvement may be useful. For example, a survey of family and internal medicine physicians revealed that only 46% of participants were likely to refer patients with a diagnosis of dementia to an S-LP (Korstjens, Haak, Phillips, & Molt, 2011). Addressing this knowledge gap is one of the goals of these recommendations. Second, as this is a relatively new procedure in Canada, S-LPs may not feel they have the appropriate experience to assess terminally ill patients. This may be mitigated in part by opportunities such as the MAiD Community of Practice forum through SAC (n.d.), which connects S-LPs from across the country who are involved in the MAiD process as well as provides a mechanism for sharing resources. A third anticipated challenge is access to S-LPs to be involved on MAiD teams. Certain S-LPs may not wish to be involved in the MAiD process due to conscientious objection, like other health professions including physicians and nurses (Petropanagos, n.d.). Within hospital settings the addition of involvement on a MAiD team may be challenging to balance with other clinical expectations of the institution. The MAiD team at each institution could advocate for institutional level support of S-LPs' involvement in applicable cases. Availability could be addressed by compiling a pool of experienced S-LPs who consent to be involved, both on a local and a national level.

S-LPs, like all clinicians involved in MAiD, are at risk for burnout or compassion fatigue, which would be expected to be similar to the high reported rates in palliative care of 62% (Kamal et al., 2016). S-LPs may be at higher risk than other clinicians given the extent of their involvement throughout the MAiD process, at an independent S-LP assessment, both physician assessments, and the procedure (M. Kekewich, personal communication, January 25, 2019). While clinician well-being has been acknowledged as a concern for those involved in MAiD, there is a lack of published information on management strategies (Canadian Institute for Health Information, 2017). Strategies that have been identified as helpful to prevent and improve burnout in other health care settings include mind-body skills, education, developing personal coping mechanisms, physical well-being, professional relationships, seeking emotional support from colleagues and friends, taking time away, taking a transcendental approach, clinical variety, establishing personal boundaries, and involvement in hobbies (Boyle, 2011; Kamal et al., 2016; Perez et al., 2015; Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009). In this context, initial resources could include peer support through the MAiD Community of Practice forum as well as debriefing with other members of the S-LP's local MAiD team (SAC, n.d.).

Conclusion

Communication is of key importance in MAiD assessments of eligibility in all patients. In patients with communication impairments, the involvement of speech-language pathology should be considered to assess their cognitive and communication abilities, facilitate assessment of capability to make health care decisions, and recommend strategies to augment their communication abilities.

The paucity of literature regarding the role of S-LPs in MAiD, as well as the potential impact on clinicians involved in MAiD is another challenge for implementing these recommendations. There is ample opportunity for research as clinicians gain experience with this relatively new process in Canada.

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