Neuro-Oncology Clinicians’ Attitudes and Perspectives on Medical Assistance in Dying

Seth A. Climans, Warren P. Mason, Caroline Variath, Kim Edelstein, Jennifer A. H. Bell

ABSTRACT: Background: Medical assistance in dying (MAiD), also known as physician-assisted death, is currently legal in several locations across the globe. Brain cancer or its treatments can lead to cognitive impairment, which can impact decision-making capacity for MAiD. Objective: We sought to explore neuro-oncology clinicians’ attitudes and perspectives on MAiD, including interpretation of decision-making capacity for patient MAiD eligibility. Methods: An online survey was distributed to members of national and international neuro-oncology societies. We asked questions about decision-making capacity and MAiD, in part using hypothetical patient scenarios. Multiple choice and free-text responses were captured. Results: There were 125 survey respondents. Impaired cognition was identified as the most important factor that would signal a decline in patient capacity. At least 26% of survey respondents had moral objections to MAiD. Respondents thought that different hypothetical patients had capacity to make a decision about MAiD (range 18%–58%). In other hypothetical scenarios, fewer clinicians were willing to support a MAiD decision for a patient with an oligodendroglioma (26%) vs. glioblastoma (41%–70%, depending on the scenario). Time since diagnosis, performance status, and patient age seemed to affect support for MAiD decisions (Fisher’s exact P-values 0.007, < 0.001, and 0.049, respectively). Conclusion: While there are differing opinions on the moral permissibility of MAiD in general and for neuro-oncology patients, most clinicians agree that capacity must be assessed carefully before a decision is made. End-of-life discussions should happen early, before the capacity is lost. Our results can inform assessments of patient capacity in jurisdictions where MAiD is legal.

RÉSUMÉ : Attitudes et points de vue des cliniciens en neuro-oncologie en ce qui regarde l’aide médicale à mourir. Contexte : L’aide médicale à mourir (AMM), aussi connue comme la mort médicalement assistée (MMA), est actuellement légale dans plusieurs pays du monde. À ce sujet, on sait que les cancers du cerveau ou leurs traitements peuvent entraîner des troubles cognitifs, lesquels, en retour, peuvent avoir un impact sur la capacité de prise de décision en matière d’AMM. Objectif : Nous avons voulu nous pencher sur les attitudes et les points de vue des cliniciens en neuro-oncologie en ce qui regarde l’AMM, notamment l’interprétation qu’ils font des capacités de prise de décision des patients quand il est question de leur admissibilité à l’AMM. Méthodes : Un sondage en ligne a donc été envoyé aux membres des associations nationales et internationales en neuro-oncologie. Nous leur avons posé des questions concernant la capacité de prise de décision et l’AMM, et ce, en recourant en partie à des scénarios hypothétiques. Nous avons par la suite saisi leurs réponses à des questions à choix multiples et des questions à développement. Résultats : Au total, 125 répondants ont participé à notre sondage. Les troubles de la cognition ont été identifiés comme le facteur le plus important du déclin de la capacité de décision des patients. Au moins 26 % des répondants ont signalé avoir des objections morales à l’égard de l’AMM. Nos répondants ont par ailleurs estimé que divers patients « hypothétiques » possédaient en effet la capacité de prendre une décision en lien avec l’AMM (intervalle : 18–58 %). Dans le cas d’autres scénarios hypothétiques, moins de cliniciens étaient prés à soutenir une décision d’AMM pour un patient atteint d’un oligodendrogliome (26 %) en comparaison avec un glioblastome (41–70 % selon le scénario). Le temps écoulé depuis un diagnostic, le déclin de l’autonomie fonctionnelle (performance status) et l’âge semblent à cet égard avoir un impact sur le soutien donné à l’AMM (valeurs en p au test exact de Fisher respectivement de 0,007 ; < 0,001 et 0,049). Conclusion : Bien qu’il subsiste des opinions divergentes en ce qui concerne l’acceptabilité morale de l’AMM en général et en ce qui concerne les patients atteints de tumeurs cérébrales en particulier, la plupart des cliniciens s’accordent à dire que la capacité de prise de décision doit être évaluée avec soin avant d’aller de l’avant. En cela, les discussions sur la fin de vie doivent avoir lieu tôt avant que cette capacité ne soit altérée. Nos conclusions peuvent ainsi permettre d’éclairer l’évaluation de cette capacité dans les juridictions où l’AMM est légale.

Keywords: Medical assistance in dying, End-of-life care, Brain cancer, Decision-making capacity

doi:10.1017/cjn.2021.186

Can J Neurol Sci. 2021; 48: 772–778
INTRODUCTION

Medical assistance in dying (MAiD), also known as physician-assisted death, is currently legal in several countries across the globe, including Canada, Belgium, the Netherlands, Luxembourg, Colombia, and Switzerland. It is also legal in several American states and in one Australian state. All of these jurisdictions have established patient eligibility criteria for MAiD to ensure appropriate access and safeguards. Many locations also require that two independent physicians make the determination of MAiD eligibility. MAiD can include either assisted suicide or voluntary euthanasia. Criteria often include being a competent adult suffering from a medical condition likely to cause their death although in some places, advanced directives are possible and in some places reasonably foreseeable natural death is not required.

Previous research has demonstrated that many individuals who request MAiD are patients with advanced and palliative-stage cancer. A prospective cohort of 64 cancer patients in the Netherlands who were followed by home palliative care revealed that weakness, pain, and existential suffering are common near the end of life. In a retrospective cohort study of all Ontario MAiD-related deaths 2016–2018 (compared to non-MAiD-related deaths), patients who had MAiD were more likely to have cancer. This study did not look at specific types of cancers, though. In a systematic review, it was shown that the typical patient who underwent MAiD was well-educated, male, aged 60–85 years, and had cancer.

For those who are very near death, continuation of their decision-making capacity is a concern since in most jurisdictions patients must be competent to provide informed consent at the time of MAiD intervention. Competency is a legal judgment, determined by capacity assessment, of whether someone has the legal right to make their own decisions. Capacity requires the ability to understand and appreciate the benefits and risks of a proposed treatment or intervention, the alternatives to those treatments or interventions, including receiving no disease-directed treatment or intervention.

Brain cancer poses a unique threat to patients’ decision-making capacity. Brain cancer includes primary brain tumors and metastases to the brain. Depending on the location of the cancer, individual lesions or combinations of lesions may infringe upon aspects of language, memory, and executive functions considered central to patient identity and capacity to make healthcare decisions. As a direct result of their disease, some patients may lose the capacity to choose MAiD, thus becoming ineligible to access this intervention. Since the desire to maintain control and autonomy influence MAiD requests, patient motivation for MAiD may be high in this population, while at the same time these patients may face barriers to accessing MAiD due to the nature of their specific disease.

Clinical interpretation of decision-making capacity is important for determinations of MAiD eligibility. Determinations of MAiD eligibility intersect with ethical issues such as equitable access, paternalism, respect for autonomy, fairness, and protection of the vulnerable. Healthcare providers are often the intermediary between patient requests for MAiD and access to this intervention. Therefore, it is important to understand how providers interpret the impact of brain cancer on patient capacity to make end-of-life decisions including MAiD. Although some articles have examined the impact of brain cancer on decision-making capacity, none have so far specifically looked at capacity for a MAiD decision in these patients. Capacity is decision-specific, and different decisions may require greater or lesser cognitive function. Making a decision around MAiD might constitute a different type of decision since it is an active choice to end one’s life motivated by illness. The purpose of this study was to explore neuro-oncology clinicians’ attitudes and perspectives on MAiD, including interpretation of decision-making capacity for patient MAiD eligibility.

METHODS

Following local research ethics board approval, an international online survey was conducted with members of Society for Neuro Oncology (SNO), European Association of Neuro-Oncology (EANO), the Oncology Special Interest Group of the International Neuropsychological Society (INS SIG), and a Canadian neuro-oncology mailing list from September to December 2020. Consent to participate was implied by completion of the survey. The survey had several subsections and was developed by the research team to understand: (1) clinician characteristics and demographics; (2) their stance on MAiD; (3) cognitive factors that they believe underlie capacity; and (4) interpretations of hypothetical scenarios. When asking about their stance on MAiD, we specifically asked about any moral objections. Morality here refers to perspectives on the rightness or wrongness of certain behaviours or actions based on ethical principles or beliefs about what is or is not acceptable. The full questionnaire can be found in the Supplementary Material. Nine scenarios of brain cancer patients requesting MAiD were presented. The scenarios were informed by our clinical practice and created to explore the challenges of assessing the nuances presented by patients’ varying degrees of cognitive impairment. The scenarios also explored opinions about patient MAiD eligibility under varying clinical situations. The first four scenarios differed with regard to clinical features that might impact their capacity. Respondents were asked whether they believe the patient would have the capacity to make this decision. The last five scenarios described patients with differing age, tumor type, performance status, and time since diagnosis. Respondents were asked whether MAiD were legally available in their jurisdiction, and they would support the patient’s decision to access MAiD. A free-text option was included to allow for elaboration. Survey data were collected and managed using REDCap electronic data capture tools hosted at University Health Network. At the end of the survey, respondents were asked to leave their contact information if they were interested in participating in a follow-up interview. Data from these interviews will be published separately.

Data Collection and Analysis

The survey was distributed to a list of Canadian neuro-oncology clinicians, to members of SNO, EANO, and the INS SIG (Figure 1). Data were analyzed using R. Exploratory logistic and ordinal regression analyses, respectively, were conducted to determine clinician predictors of (1) moral opposition to MAiD and (2) number of clinical scenarios felt to be either capable or MAiD-eligible, depending on the scenario. For the MAiD scenarios, we conducted pairwise comparisons of
proportions using Fisher’s exact test. Because multiple comparisons were conducted, $P$-values $\leq 0.01$ were considered to be statistically significant. Nonetheless, there are differences in opinion regarding the appropriate $\alpha$ level correction,\textsuperscript{16,17} and results should be interpreted with caution. Thematic analysis was applied to the free-text fields, where the researchers (SAC, JAHB) read through the replies to familiarize themselves with the data and gain an overall perspective of responses. Paying close attention to the data, similar descriptions and phrases were then identified and categorized according to codes. Codes were collapsed into broader themes and relationships between themes were explored.\textsuperscript{18}

## RESULTS

### Responses

The survey was sent to more than 10,000 people and 133 responded, 125 of whom were neuro-oncology clinicians (Figure 1).

### Clinician Demographics and Characteristics

Most respondents were neuro-oncologists (57%), including medical oncologists who treat brain tumors. Other represented professionals included neurosurgeons, radiation oncologists, advanced practice providers, psychologists and neuropsychologists, medical trainees, nurses, palliative care physicians, other physicians, research coordinators, and social workers (Table 1). Christianity was the most common religious group (45%), but the no religion or no response group was 43%. Within the Christian group, Catholic faith was the most common (52%) followed by unspecified, Protestant, and Eastern Orthodox. Survey responses came in from around the world including six continents (Figure 2). Most responses came from the United States, followed by Canada, the Netherlands, and Italy.

### Attitudes towards MAiD

A minority (39%) of respondents worked in a jurisdiction where MAiD is legal. Only 16% of respondents had participated in the MAiD process, either as an assessor or by prescribing medications. One quarter (26%) of the respondents held moral objections to MAiD while 57% did not and the remaining 17% were unsure.

Using a logistic regression analysis, factors found to make a respondent’s moral objection to MAiD significantly more likely included (1) shorter time in practice (odds ratio 0.09 (95% CI 0.01, 0.58)); (2) working in a country other than the United States, Canada, or the Netherlands (odds ratio 8.6 (95% CI 1.6, 46.5)); and (3) Christian faith, as compared to no religion (odds ratio 9.5 (95% CI 1.3, 71.2)) (Supplementary Table 1). The longer neuro-oncology clinicians have been in practice, the less likely they are to have moral objections to MAiD. Notably, factors that did not predict moral objection to MAiD were profession, gender, Catholicism, age of patients, clinical volume, and whether MAiD is allowed regionally.

### Cognitive Factors Underlying Capacity

Survey respondents were asked to rank the three most important Diagnostic and Statistical Manual of Mental Disorders cognitive domains necessary for patient capacity for consenting to MAiD.\textsuperscript{19} Executive function was ranked most important by 41% of respondents, followed by complex attention (21%), language (14%), and learning and memory (14%).

Analysis of the free-text responses revealed more detail. Impaired cognition was identified by a majority of respondents as one of the most important factors that would signal a decline in patient capacity, e.g. “when their cognitive functions are significantly impaired.” Respondents understood impaired cognition as including patients’ lack of understanding of treatments, the consequences of treatments, and lack of insight or awareness of the situation or options for care. Impaired language and impaired cognition in general was also highlighted by many respondents as influencing capacity. Impaired language was viewed as the inability to understand information and inability to recall and communicate information about intervention choices. One respondent wrote that incapacity should be suspected when “they can’t communicate their reasons for making one choice vs. another.” Additionally, impaired short-term memory, confusion, and disorientation were identified as factors that may signal a
Table 1: Respondent characteristics

| Characteristic          | Classification     | Count (%) |
|-------------------------|--------------------|-----------|
| Profession              | Neuro-oncologist   | 71 (57)   |
|                         | Neurosurgeon       | 17 (14)   |
|                         | Radiation oncologist | 11 (9)  |
|                         | Advanced practice provider | 10 (8) |
|                         | Psychologist       | 4 (3)     |
|                         | Medical trainee    | 4 (3)     |
|                         | Other              | 8 (6)     |
| Gender                  | Female             | 62 (50)   |
|                         | Male               | 63 (50)   |
| Population they treat   | Adults             | 95 (76)   |
|                         | Children           | 11 (9)    |
|                         | Both               | 19 (15)   |
| Years in practice       | 0–4 years          | 22 (18)   |
|                         | 5–9 years          | 22 (18)   |
|                         | 10–14 years        | 27 (22)   |
|                         | 15–19 years        | 18 (14)   |
|                         | 20+ years          | 36 (29)   |
| Brain tumor patient volume | 0–1 per week       | 7 (6)     |
|                         | 1–2 per week       | 12 (10)   |
|                         | 3–10 per week      | 39 (31)   |
|                         | 11–20 per week     | 39 (31)   |
|                         | 21–50 per week     | 25 (20)   |
|                         | 51+ per week       | 3 (2)     |
| Religion (if any)       | Christian          | 56 (45)   |
|                         | No religion        | 41 (33)   |
|                         | Jewish             | 8 (6)     |
|                         | Muslim             | 4 (3)     |
|                         | Other              | 3 (2)     |
|                         | No response        | 13 (10)   |

Decline in patient capacity. Taken together, these factors became very important when identified as severe or persistent, such as when there is “severe decline in memory or cognitive status.” Respondents noted how these limitations were complex, difficult to assess, and that capacity was individualized. Some reflected on patients who are able to contribute meaningfully to their care and who can articulate their understanding and wishes. Incapacity then became a sense of when conversations with the patient “no longer have depth” or the person cannot communicate their reasons for choice.

Incapacity was seen as more likely to occur in patients living with advanced disease or who were actively dying. Respondents became concerned about a patient’s potential incapacity when there was disease progression or poor scores on objective capacity tests. Comorbid conditions, such as depression, and medication use (e.g., steroids) were also flagged as potential negative influences on capacity. Some respondents identified family as a resource that could provide collateral information to help clinicians assess patient capacity.

Interpretations of Hypothetical Scenarios with Questionable Capacity

Four capacity scenarios were presented to survey respondents. Hypothetical female glioblastoma patients with deficits in language, memory, wakefulness, or personality were described. Respondents were asked whether they believe that the patient has the capacity to decide whether to opt for MAiD. Between 18% and 58% of respondents, depending on the scenario, thought that the patient had the capacity for this choice (Figure 3A). Many respondents used the accompanying textbox to elaborate on their responses, and specifically to highlight the complexity of the scenarios and the limitations of being asked to provide yes/no answers. Some wrote that there was “not enough information to judge.” Most respondents believed that in-depth-capacity assessments were necessary for these scenarios. An assessment of the extent of neurological deficit was thought to be required to ascertain how the hypotheses evolved, amnesia, somnolence, or personality changes might impact the ability to understand, appreciate, and make a decision that aligned with previously expressed patient values. Some questioned whether the requests for MAiD were consistent over time and whether they were aligned with patients’ prior expressed wishes. Respondents believed that patients could retain decision-making capacity despite short-term memory loss, somnolence, and personality changes, if patients could demonstrate consistent and stable choices. Some commented that we must determine whether patients can “make rational decisions that reflect their values.” Input from family, where available, was thought to be helpful in assessing these factors for patient capacity.

Respondents gave explanations for why they did or did not believe each hypothetical patient had the capacity to decide whether to opt for MAiD. Representative quotes in favor of or against capacity for each scenario are shown in Table 2. Using an ordinal regression analysis, two factors were found to predict the belief that patients have decision-making capacity for MAiD. Advanced practice practitioners (vs. neuro-oncologists, odds ratio 9.6 [95% CI 1.9, 49.3]) and Canadians (vs. Americans, odds ratio 7.1 [95% CI 1.5, 34.7]) were more likely to believe that the four hypothetical patients had decision-making capacity (Supplementary Table 2). The remaining variables in the model did not seem to predict the number of affirmative responses: religion, duration of practice, gender, age of patients, clinical volume, and whether MAiD is allowed regionally.

Interpretations of Hypothetical Scenarios with Varying Clinical Factors

Five MAiD scenarios were presented to survey respondents. The scenarios varied the hypothetical male glioma patient’s age, tumor grade, time since diagnosis, and performance status. Respondents were asked whether they would support the patient’s decision to access MAiD, assuming it was legally available. Between 26% and 78% of respondents, depending on the clinical scenario, supported the patient’s MAiD decision (Figure 3B). Many respondents used the accompanying textbox to explain that the scenarios lacked sufficient information to make this judgment. They emphasized the importance of proper
capacity assessment, neuropsychological testing, and ruling out depression. They wanted to make sure that each patient properly understands their treatment options and prognosis.

When clinicians did not support a patient’s MAiD decision, they wrote several explanations. Some felt that palliative care is a better option. Others cited moral objections. Some scenarios involved patients 1 week after diagnosis. In these situations, many felt that this was too soon after diagnosis to make a rational decision for MAiD. Others felt that it was too soon to establish rapport with the patient to know if their choice was consistent over time. In the oligodendrogioma case, many felt that death was not reasonably foreseeable and that too many treatment options were still available. Young age was sometimes brought up as a positive prognostic factor, and that in such patients, symptoms might improve with time, which cast doubt on clinicians’ belief that MAiD would be an acceptable option for these patients. When clinicians did support a patient’s MAiD decision, they generally emphasized patient autonomy. They noted that all scenarios outlined patients with incurable conditions. Some with stated moral objections to MAiD were willing to refer to a nonobjecting provider.

Using an ordinal regression analysis, we found three factors that predict support for MAiD in the scenarios. Non-American, non-Canadian, and non-Dutch (vs. American, odds ratio 0.3 (95% CI 0.1, 0.8)) clinicians were less likely to support a patient’s decision to access MAiD (Supplementary Table 3). Canadian (vs. American, odds ratio 6.7 (95% CI 1.3, 33.8)) respondents and advanced practice providers (vs. neuro-oncologists, odds ratio 8.5 (95% CI 1.2, 62.2)) were more likely to support a patient’s decision to access MAiD. The remaining variables in the model did not seem to predict the number of affirmative responses: religion, duration of practice, gender, age of patients, clinical volume, and whether MAiD is allowed regionally. Pairwise comparison of scenarios 5 vs. 6, 5 vs. 8, and 8 vs. 9 demonstrated the importance of performance status, time since diagnosis, and age, respectively. The P-values for these comparisons were 0.007, < 0.001, and 0.049. Clearly, time since diagnosis, performance status, and patient age are all important factors when choosing whether to support a patient’s request for MAiD. Tumor grade is presumably important, but limitations in the scenarios did not allow pairwise comparison over this variable.

**DISCUSSION**

Our mixed-methods analysis has revealed the opinions of some neuro-oncology clinicians on decision-making capacity around MAiD, their moral stances toward MAiD, and degree of support for different patients’ MAiD requests. While there are differing attitudes about the moral acceptability of MAiD in general, and for neuro-oncology patients in particular, most clinicians agree that patient capacity must be assessed carefully. There was a striking level of disagreement among survey participants about whether or not the hypothetical patients were eligible for MAiD. Some neuro-oncology patients are not thought to be MAiD-eligible due to lack of capacity or lack of reasonably foreseeable natural death.

Very little research has been published specific to neuro-oncology and MAiD. There have been two retrospective cohort studies describing brain cancer patients who request MAiD in Washington State, one specific to high-grade glioma and another.
that included low-grade glioma patients. There is very little guidance on reasonably foreseeable natural death among different types of cancer.

Our study has some important strengths. We surveyed clinicians from around the world, addressed a timely yet understudied topic, and examined this issue with relevance for a particularly vulnerable patient population. The survey included clinicians of diverse backgrounds and opinions. Detailed interviews with our respondents are currently in progress. These should better illuminate the attitudes and perspectives of the neuro-oncology community on the topic of MAiD.

Decisions around end-of-life care are very significant, since they involve understanding complex medical information and may result in death. Brain cancer patients are often motivated to undergo MAiD by the same symptoms that also can interfere with their ability to access MAiD. Although many systemic malignancies eventually metastasize to the brain, and many cancer patients undergo MAiD, we do not know how many patients with brain metastases undergo MAiD.

When brain cancer patients lose their decision-making capacity, it is usually in their last month of life. In a retrospective cohort of 101 Dutch glioma patients, 80% retained capacity in the last months of life, 47% retained capacity in the last weeks of life, and 14% retained capacity in the last days of life. Some clinical adjuncts can be used to screen for incapacity in brain tumor patients. Clinicians involved in the care of neuro-oncology patients must be able to recognize when decision-making capacity has been lost. Consequently, it is critical to engage each patient in discussions around end-of-life care before it is too late.

Our results show that neuro-oncology clinicians are more likely to support a patient’s end-of-life request if it is expressed consistently. This is even more reason to have end-of-life discussions early, before capacity is lost. There are several end-of-life decisions that might need to occur with input from the patient: specifying the optimum location for end-of-life care, whether hospice, hospital, or home; balancing the need for symptom control and desired level of alertness, since pain and seizure medication can be sedating; and lastly, whether MAiD or palliative sedation is clinically appropriate and aligned with patient values.

The main limitation of this study is the risk for sampling bias, since we sent survey invitations to more than 10,000 subjects, but only had survey responses from 125. This is lower than other recent SNO surveys that had between 426 and 480 responses. The low participation rate in our study may in part be due to the inclusion of non-clinicians on the mailing lists of neuro-oncological societies, the controversial topic of the survey, and the fact that we did not send out reminder emails. Our questionnaire scenarios forced a yes/no response with limited presented information, which created a forced dichotomy out of otherwise nuanced decisions. This may have reduced the reliability
of our scenario responses; however, the option for free-text and our follow-up interviews to be published separately aim to capture and describe these nuances. Some questions could be interpreted ambiguously: supporting a patient’s MAiD decision could mean agreeing to actively help in the process itself. The subsequent qualitative interviews will provide clarity. Some clinicians who answered the survey treat only pediatric patients, so they might not have been able to rely on clinical experience to respond to the presented case scenarios. For the regression analyses, many of the subgroups were small, so these predictors can only be hypothesis-generating and not definitive. Our study surveyed only clinicians, but future studies ought to survey and interview patients about end-of-life options discussed with them over their disease course.

Despite the limitations, our study results may help inform best-practice guidelines for clinical assessments of MAiD decision-making capacity in neuro-oncology patients. It is now clear that there is substantial disagreement among neuro-oncologists about whether and which patients ought to be eligible for MAiD. This uncertainty needs to be built into guidelines. Our results emphasize the risk of incapacity with tumor progression, highlighting the need for early end-of-life discussions. Our findings will inform teaching tools and webinars on this topic and may help create instruments for assessing decision-making capacity. Disease experts can play an important role in both capacity assessment and predictions about prognosis. Each MAiD assessment ought to be individualized, but an understanding of the neuro-oncology community’s attitudes and perspectives on the matter can guide our care.

Funding
This research is supported by the Division of Palliative Medicine, Department of Medicine, University of Toronto; the Dalla Lana School of Public Health, University of Toronto; the Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC); the Princess Margaret Cancer Foundation, and the Ontario Ministry of Health and Long Term Care (OMOHLTC). The views expressed are not necessarily those of the OMOHLTC.

Disclosures
The authors have no conflicts of interest to disclose.

Statement of Authorship
SAC drafted the manuscript. Article conception by SAC and JAHB. Critical revision of manuscript for intellectual content by SAC, CV, KE, WPM, and JAHB.

Supplementary Material
To view supplementary material for this article, please visit https://doi.org/10.1017/cjn.2021.186.

References
1. Emanuel EJ, Onwuteaka-Philippsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA. 2016;316:79.
2. Li M, Watt S, Escarf M, et al. Medical assistance in dying – implementing a hospital-based program in Canada. N Engl J Med. 2017;376:2082–8.
3. Duckett S. The long and winding road to assisted dying in Australia. Aust J Soc Issues. 2019;54:386–400.
4. Ruijs CD, Kerkhof AJ, van der Wal G, Onwuteaka-Philippsen BD. Symptoms, unbearable and the nature of suffering in terminal cancer patients dying at home: a prospective primary care study. BMC Fam Pract. 2013;14:201.
5. Steck N, Egger M, Maessen M, Reisch T, Zwahlen M. Euthanasia and assisted suicide in selected European countries and US states: systematic literature review. Med Care. 2013;51:938–44.
6. Downar J, Fowler RA, Halko R, et al. Early experience with medical assistance in dying in Ontario, Canada: a cohort study. CMAJ. 2020;192:E173–81.
7. Leo RJ. Competency and the capacity to make treatment decisions: a primer for primary care physicians. Prim Care Companion J Clin Psychiatry. 1999;1:131–41.
8. Eliott JA, Olver IN. Dying cancer patients talk about euthanasia. Soc Sci Med. 2008;67:647–56.
9. Hendry M, Paster K, Rogers JL, et al. The effects of brain tumours upon medical decision-making capacity. Curr Oncol Rep. 2019;21:55.
10. Pace A, Koekkoek JAF, van den Bent MJ, et al. Determining medical decision-making capacity in brain tumor patients: why and how? Neuro Oncol Pract. 2020;7:599–612.
11. Hewins W, Zienius K, Rogers JL, et al. The effects of brain tumours upon medical decision-making capacity. Curr Oncol Rep. 2019;21:55.
12. Pace A, Koekkoek JAF, van den Bent MJ, et al. Determining medical decision-making capacity in brain tumor patients: why and how? Neuro Oncol Pract. 2020;7:599–612.
13. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42:377–81.
14. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software platform partners. J Biomed Inform. 2019;95:103208.
15. R Core Team. R: a language and environment for statistical computing [Internet]. Vienna, Austria: R Foundation for Statistical Computing; 2018. Available at: https://www.R-project.org/.
16. Perneger TV. What’s wrong with Bonferroni adjustments. BMJ. 1998;316:1236–8.
17. Simes RJ. An improved Bonferroni procedure for multiple tests of significance. Biometrika. 1986;73:751–4.
18. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101.
19. American Psychiatric Association. Diagnostic and statistical manual of mental disorders [Internet]. 5th ed. American Psychiatric Association; 2013. Available at: http://psychiatryonline.org/doi/book/10.1176/appi.books.9780890425596.
20. Chamberlain M. PALL-01. Physician assisted suicide in high grade gliomas: a university-based practice perspective. Neuro-Oncology. 2016;18:v144.
21. Graber J, Sofie K, Taylor L, QOLP-26. Use of medical assistance in dying (“death with dignity”) in Washington State patients with brain tumors. Neuro-Oncology. 2020;22:i180.
22. Isenberg-Grzedea E, Sofie K, Larrievée EB, Graber JJ. Legal assistance in dying for people with brain tumors. Ann Palliat Med. 2021;10:89398–89808.
23. Sizoo EM, Pasman HR, Buttolo J, et al. Decision-making in the end-of-life phase of high-grade glioma patients. Eur J Cancer. 2012; 48:226–32.
24. Taylor JW, Armstrong T, Kim AH, et al. The lomustine crisis: awareness and impact of the 1500% price hike. Neuro-Oncology. 2019;21:1–3.
25. Rogers JL, Acquaye A, Vera E, et al. Provider-reported challenges and barriers to referring patients to neuro-oncology clinical trials: a report from the Society for Neuro-Oncology member survey. Neuro-Oncol Pract. 2020;7:38–51.