

Should palliative care teams be involved in medical assisted dying?

Sheri Mila Gerson¹, Claudia Gamondi^{2,3}, Ellen Wiebe⁴, Luc Deliens⁵

¹Olympia, WA, USA

²Palliative and Supportive Care Clinic, Oncology Institute of Southern Switzerland, Bellinzona, Switzerland

³Palliative and Supportive Care Service, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland

⁴ Faculty of Medicine, University of British Columbia, Vancouver, Canada

⁵ End-of Life Care Research Group, Faculty of Medicine, Vrije Universiteit Brussel and Ghent University, Brussels, Belgium

Corresponding author:

Sheri Mila Gerson, PhD, LICSW, APHSW-C

Olympia, WA 98502

E-mail: sherimila@gmail.com

ORCID ID: 0000-0002-6181-8311

Funding:

No Funding issues to disclose.

Conflict of Interest Disclosure:

The authors declare no conflicts of interest.

Key Words: assisted dying, palliative care, euthanasia, medical aid in dying, end of life, decision-making

Abstract

Palliative care teams offer holistic care for patients experiencing serious illness and related suffering, nevertheless, there are times when clinicians are asked by patients for help to obtain assisted dying. Patients in a growing number of areas may be eligible to request medically administered or self-administered lethal medications to control the timing of death and palliative care practices, established to neither hasten nor postpone death, may be challenged when caring for patients asking for assisted dying. In this “Controversies in Palliative Care” article, we invite three experts to provide a synopsis of the key studies that inform their thought processes, share practical advice on their clinical approach, and highlight the opportunities for future research.

These experts suggest palliative care teams should be and are involved in medical assisted dying, but how palliative care teams are involved may depend on type of assisted dying requested, team members’ scope of practice, legal regulations, and institutional guidelines. Research is needed on many aspects of assisted dying and palliative care including improving evidence-based clinical guidelines, addressing the needs of families, and coping strategies for all involved. An international study comparing assisted dying practices within, and outside palliative care may inform policy helping to clarify whether the integration of palliative care in assisted dying improves end-of-life care. In addition to research, it is recommended that researchers and clinicians collaborate on the development of a clinical textbook on assisted dying and palliative care to support all palliative care team members, offering guidelines and recommendations for practice.

Introduction

Palliative care teams offer holistic care for patients experiencing serious illness and related suffering. There are times when clinicians, including physicians, nurses, social workers, and chaplains, are asked by patients for help to obtain medical assisted dying because they may be experiencing or fearing the experience of unbearable suffering or to control timing of death. More and more jurisdictions around the world are decriminalizing or passing laws allowing patients who meet a specific eligibility criterion to request medically administered or self-administered lethal medications to control the timing of death. Palliative care involvement in assisted dying may enhance patients' awareness of options other than assisted dying and improve support to family members and caregivers. The International Association of Hospice and Palliative Care definition of palliative care states that palliative care "*intends neither to hasten nor postpone death ...*", therefore, some palliative care professionals and institutions may be challenged when caring for patients who ask for assisted dying.¹ Palliative care clinicians may be concerned with a 'slippery slope' where medical assisted dying can harm vulnerable patients and families who have limited access to resources needed for care.² In clinical practice, not all palliative care clinicians may be comfortable with assisted dying (even in countries in which it is legal), and may choose not to participate in the process,³ although all jurisdictions include conscientious objection for those who choose not to be involved. Palliative care clinicians may be faced with opposing tasks to support patients' autonomy to request medical assisted dying while continuing to offer physical, emotional, and spiritual comfort. Other palliative care teams or individual team members may feel medical assisted dying is against palliative care practice, and they should not be involved in any way when patients request it. In this "Controversies in Palliative Care" article, we invite palliative care clinicians and researchers living in a jurisdiction where assisted dying is a common end of life practice for some time now, to provide a synopsis of the key studies that inform their thought processes, share practical advice on their clinical approaches, and highlight opportunities for future research.

Claudia Gamondi, MD, PhD, PD; Palliative and Supportive Care Clinic, Ticino, Switzerland

Palliative care teams are often confronted with requests for assisted dying, so I find the question a strange one. Palliative care teams are already involved in different ways. But to answer the question, yes, I believe palliative care teams should be involved in assisted dying.

Question 1. What are some key studies contributing to your interpretation of the literature?

Key studies from the early years of assisted dying in Oregon^{4,5}, a study from before assisted dying was lawful in Washington state⁶ and studies from the Netherlands in Europe,^{7,8} have informed my practice. Lee et al.⁴ research about physician views and Ganzini et al.,⁵ study about physician experiences in Oregon investigated critical themes in-depth. I learnt that families judged the quality of the deaths of patients who died by assisted suicide as good. I learnt that the reasons behind the choice of an assisted death lie in the existential sphere, rather than physical suffering. The authors also shed light on the benefits and limitations of palliative care interventions for these patients. Their studies have helped shape research in countries where assisted dying has been legalized, showing that there were many stakeholders involved in these procedures: patients and families, physicians, other health care professionals, right to die associations.

I was able to relate to the findings of Starks et al.,⁶ with what I was observing clinically. Patients may have thought about hastened death for many years, and in many cases the idea was embedded in their philosophy of life. Starks et al.,⁶ also demonstrated that families were deeply involved in assisted dying and their needs and experiences were under researched.

Dees et al.,^{7,8} have informed my practice about unbearable suffering: this suffering threatens the integrity of the person, and it is not simplistically correlated to physical symptoms. They also showed that patients take steps in decision making for assisted dying and it is rarely a compulsory reaction to

suffering. Their studies also helped me construct my own research questions around family involvement in assisted dying. Most of the Oregon and Dutch data were confirmed in the Swiss context.⁹

From the point of view of methodologies, the research studies I cited are complementary. The quantitative studies from Oregon,^{4,5} and the qualitative studies from the Netherlands,^{7,8} taken together, provide a multifaceted perspective away from questioning the goodness or badness of assisted dying itself and showed how important it is to study assisted dying with both these complementary methodologies.

Question 2. How do you approach this question in clinical practice?

I work as a palliative care physician and researcher in Switzerland, which has a unique model where physician input is limited to certification of the underlying disease, evaluation of mental capacity at moment of certification and prescription of the lethal drug.¹⁰ The physician is usually not present at the time of self-administration of the lethal medications. Supporting and evaluating mental capacity of the patient at the time of self-administration is left to the right to die association volunteers.

I approach the request for assisted dying as a serious request and without fears. As a palliative care service, we have implemented interdisciplinary recommendations to guide professionals including those with conscientious objection. The overarching principle was to respect values of all involved and to act considering the non-abandonment principle. We want to make sure our patients requests are taken seriously, respected by team members, and we foster open communication about wishes and concerns of all involved. We strive for a non-conflictual environment respecting patients, families, and professionals' values. We do not feel we are competent to evaluate psychiatric patients requesting assisted dying. We have chosen to stay within our field of competence.

Question 3. What are key future research directions to address this question?

We need to move on from polarized positions of being pro or against assisted dying and focus on the needs and expectations of everyone involved. Segregated practices separating usual palliative care from assisted dying may impact patients and families, and this is a critical area for further research. Another important field of research is that of families involved in assisted dying starting from the birth of the request to the process of grief and bereavement. Finally, we need evidence-based clinical recommendations, to respond to patient requests, and address the needs of families and all professionals involved on palliative care teams.

Ellen Wiebe, MD; Faculty of Medicine, University of British Columbia, Vancouver, Canada

Question 1. What are some key studies contributing to your interpretation of the literature?

In Canada, medical assistance in dying (MAiD), as it is called in Canada, has been legal since 2016 for people who meet certain criteria, including that they have a grievous and irremediable condition causing unbearable suffering.¹¹ Until 2021, their natural death had to be reasonably foreseeable and since that time people with chronic conditions could also be eligible, with additional safeguards, such as a 90-day assessment period. The 2021 government report stated that 97.8% of people receiving MAiD had a natural death that was reasonably foreseeable.¹² The majority (74.4% in 2020, 80.7% in 2022) of people requesting MAiD have been receiving palliative care.^{12,13} In a survey of Canadian palliative care providers in 2021, 75% reported having patients who requested MAiD.¹⁴ Therefore, patients who request MAiD in Canada usually have seen both palliative care and MAiD clinicians, and palliative care clinicians have usually cared for patients who requested MAiD. In a report about palliative care and assisted dying in Europe, palliative care funding and care increased with increased assisted dying.¹⁵ In an ideal world, this end-of-life care would be seamless with patients and their families' developing relationships with clinicians who would honor their requests for both comfort care and MAiD. Unfortunately, a national organization of palliative care states, "Provision of MAiD is a practice separate and distinct from hospice palliative care" and in practice, palliative care providers rarely provide MAiD.¹⁶

Question 2. How do you approach this question in clinical practice?

My background includes 30 years of full-service general practice including palliative care. Before Canada's law changed, I assumed that palliative care clinicians would be providing assisted dying. When I discovered they would not and that their national associations actively discouraged this, I chose to get training in the Netherlands and become a MAiD provider. I hoped that my palliative care colleagues would share care of their patients. At first this was not the case, and there was some active blocking of patients' access to MAiD. For example, one of my patients was given extra sedation just before a booked MAiD assessment. Several were told they were not eligible for MAiD when they were. My MAiD colleagues and I have witnessed a slow change as one patient after another was able to articulate why they wanted MAiD despite good palliative care. Some trainees in palliative care are choosing to also train in MAiD. Person by person, relationship by relationship, the attitude is slowly changing. There is still a major problem with faith-based facilities requiring forced transfer out of the facility for MAiD.¹⁷ There has been a long history of hospice and palliative care being provided in church-affiliated facilities and this has continued, despite the funding now coming mostly from government tax-revenue.¹⁸

Question 3. What are key future research directions to address this question?

We need more information about the benefits of MAiD integrated into seamless hospice/palliative care and the ways this can be accomplished. This might be done by studying two different sites where MAiD is separated from or integrated into end-of-life care. Using key informant interviews, we could explore the experiences of patients, family/support people, clinicians, administrators, and support staff. We need to explore and document this change we have witnessed in more palliative care clinicians and facilities welcoming MAiD clinicians and whether this has improved end of life care.

Professor Luc Deliens, PhD; End-of Life Care Research Group, Vrije Universiteit Brussel and Ghent University, Brussels, Belgium

Question 1. What are some key studies contributing to your interpretation of the literature?

I live in Belgium, a jurisdiction that has legalized euthanasia, as it is called in Belgium, since 2002. Belgium has more than 20 years of experience with end-of-life care that has implemented this assisted dying law across all care settings and across all disease groups, including in palliative care services in hospitals, nursing homes and in home based primary care. Understanding the relationship between assisted dying and palliative care in a jurisdiction with a legal framework for assisted dying cannot be judged by the perceptions of researchers or clinicians who live in a jurisdiction that have NOT (yet) legalized assisted dying. Only research and literature that recognize and understand this changed social, legal, and medical reality can truly understand an integrated end of life system, in which assisted dying is fully integrated into palliative care.

Three papers have been crucial to understand the relationship between assisted dying and palliative care in Belgium: Bernheim et al.,¹⁹ Cohen & Chambaere,²⁰ and Vanden Berghe et al.²¹

Although palliative care and legalized assisted dying are both based on the medical and ethical values of patient autonomy and caregiver beneficence and non-maleficence, they are often viewed as antagonistic causes. Bernheim et al.¹⁹ was the first paper in a major international medical journal presenting the model of “Integrated Palliative Care”, in which assisted dying and palliative care are not antagonistic but can be fully integrated in end-of-life care. The paper concludes stating that: “Within Belgium we found few professional stances contending that palliative care and legalization of euthanasia are antagonistic, no slippery slope effects and no evidence for the concern of the European Association for Palliative Care that the drive to legalize euthanasia would interfere with the development of palliative care. Rather, there were many indications of reciprocity and synergistic evolution.”

Vandenbergh et al.²¹ is a position paper by the Palliative Care Association of Flanders stating that the problem is not assisted dying as such, but rather its dissociation from the context of palliative care. The antagonism is no longer between assisted dying on the one hand and palliative care on the other, but between assisted dying outside and assisted dying within the realm of palliative care. Palliative Care Association of Flanders' adoption of euthanasia and assisted suicide, the terms used in the law, embedded in palliative care was published in a mainstream palliative care journal in 2013.

Finally, in 2022, for the first time a primary palliative care journal made a plea to have a more open and nuanced debate on the relationship between assisted dying and palliative care.²⁰ As assisted dying is becoming a legal option in an increasing number of jurisdictions, palliative care organizations, services and practitioners are increasingly confronted with questions about how to position themselves morally, legally, and practically towards assisted dying. It is worth discussing experiences in contexts of legalized assisted dying that shed light on the relationship between palliative care and assisted dying.

Question 2. How do you approach this question in clinical practice?

About five to ten years after the legalization of assisted dying in Belgium, palliative care associations adopted an integrated approach. Hence, assessment of the due care criteria (as prescribed by the law in Belgium) and the involvement in the assisted dying practice is part of the daily work of palliative care professionals. These palliative care professionals support the treating doctor and team in all aspects of the patient's assisted dying request, which sometimes also includes carrying out the medically administered assisted dying, or euthanasia as it is called in Belgium. This involvement includes the clarification of the assisted dying request, the extensive communication with the patient and the family, the exploration and consideration of other treatment and care, the medical and other assistance when assisted dying is performed and supporting the team afterwards.²¹ It takes place with full respect for each professional's personal choice regarding their involvement. Conscientious objection is always possible for

all health care providers involved. The assisted dying assessments according to the Belgian law are well described in the guidelines of the Life End Information Forum (LEIF) physicians, the professional organization that is responsible for the training of physicians.²²

Question 3. What are key future research directions to address this question?

There are a growing number of scientific books on assisted dying. However, most come from ethicists, political scientists, sociologists, or legal researchers and very little published within clinical textbooks. As there is not yet a proper clinical textbook on Assisted Dying and Palliative Care, it is recommended to either prepare an edited textbook for practice, or to integrate these practices within palliative care textbooks. In order to do so, collaboration across all jurisdictions that have legalized assisted dying is needed and recommended.

The Bottom Line

Three authors with research and clinical experience from different countries that allow assisted dying arrive at similar conclusions when answering the question: ‘should palliative care teams be involved in medical assisted dying?’ These authors were selected to contribute to this article, not because they have polarized positions, but because they have experience and knowledge about the topic in their country. Dr Wiebe and Professor Deliens both comment on a shift that took place after the legalization of assisted dying in their countries, with palliative care becoming more integrated in Belgium, and a shift toward more acceptance of assisted dying by faith-based institutions in Canada. This suggests that institutions and individuals involved adapt over time, after new laws go into effect. All authors mention the need for clinician training to improve skills working with patients considering assisted dying. The authors agree that if patients are not already receiving palliative care when they request assisted dying, they should be referred to specialist palliative care. If possible, palliative care should always be involved, however, in

some cases palliative care may not be available, patients may not be accepted by the palliative care team, there may be a few patients that refuse the referral, and the referral is not mandatory in all jurisdictions.

How palliative teams are and should be involved becomes a critical question and may depend on the type of assisted dying, the training and skill of the team member, their scope of practice, legal regulations, and institutional guidelines and/or limitations. Research is needed on many aspects of assisted dying provided in the context of palliative care, including improving on evidence-based clinical guidelines, addressing the needs of families, and conscientious objection by different team members. In addition, a study comparing integrated palliative care with assisted dying with palliative care that is separate from assisted dying could inform policy and how or if the practice improves end of life care. Finally, it is recommended that researchers and clinicians collaborate on the development of a clinical textbook on Assisted Dying and Palliative Care to support all palliative care team members, offering guidelines and recommendations for practice.

To provide the best care possible for patients considering assisted dying requires more than just responding to their request. The responses to what might be considered a controversial question offers a vision of care for patients and for those caring for them. The reflections highlight the need for additional views and responses from clinicians and researchers from other countries that have experiences with lawful assisted dying.

References

1. International Association of Hospice and Palliative Care. Palliative Care Definition. Available from <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/> Accessed February 6, 2023.
2. Meier DE. The Treatment of Patients With Unbearable Suffering—The Slippery Slope Is Real. *JAMA Intern Med.* 2021;181:160–161.
3. Eggertson L. Most palliative physicians want no role in assisted death. *CMAJ* 2015;187: E177
4. Lee MA, Nelson HD, Tilden VP, et al. Legalizing assisted suicide--views of physicians in Oregon. *N Engl J Med* 1996;34:310-5.
5. Ganzini L, Nelson HD, Schmidt TA, et al. Physicians' experiences with the Oregon death with dignity act. *N Engl J Med* 2000;342:557–63.
6. Starks H, Pearlman RA, Hsu C, et al. Why now? Timing and circumstances of hastened deaths. *J Pain Symptom Manage* 2005;30:215–26.
7. Dees M, Vernooij-Dassen M, Dekkers W, van Weel C. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psychooncology* 2010;19:339-52.
8. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, et al. Perspectives of decision making in requests for euthanasia: qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliat Med* 2013;27:27–37.
9. Gamondi C, Pott M, Preston N, Payne S. Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study. *J Pain Symptom Manage* 2018;55:1085-1094.
10. Hurst SA, Mauron A. Assisted Suicide in Switzerland: Clarifying Liberties and Claims. *Bioethics* 2017;31:199-208.
11. Canada's new medical assistance in dying (MAID) law. Available from <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>. Accessed February 4, 2023.
12. Third annual report on Medical Assistance in Dying in Canada 2021. Available from <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html>. Accessed February 4, 2023

13. 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-E181.
14. R. Antonacci, S. Baxter, J. D. Henderson, R. M. Mirza and C. A. Klinger. Hospice Palliative Care (HPC) and Medical Assistance in Dying (MAiD): Results From a Canada-Wide Survey. *J Palliat Care* 2021;36:151-156.
15. Bernheim JL, Chambaere K, Theuns P, Deliens L. State of palliative care development in European Countries with and without legally regulated physician-assisted dying. *Health Care* 2014;2:10-4.
16. Canadian Hospice Palliative Care Association Position Statement on Hospice Palliative Care and Medical Assistance in Dying (MAiD). Available from <https://www.chpca.ca/resource/position-statement-on-hospice-palliative-care-and-medical-assistance-in-dying-maid/> Accessed February 4, 2023
17. Wiebe E, Sum B, Kelly M, Hennawy M. Forced and chosen transfers for medical assistance in dying (MAiD) before and during the COVID 19 pandemic: A mixed methods study. *Death Stud* 2022;46:2266-2272.
18. Cataldo PJ, O'Brien D, eds. *Palliative Care and Catholic Health Care: Two Millennia of Caring for the Whole Person*. Springer; 2019.
19. Bernheim JL, Deschepper R, Distelmans W, et al. Development of palliative care and legalisation of euthanasia: antagonism or synergy? *BMJ* 2008;336:864-867.
20. Cohen J, Chambaere K. Increased legalization of medical assistance in dying: relationship to palliative care. *BMJ Support Palliat Care* 2022 Apr 15: bmjspcare-2022-003573.
21. Vanden Berghe P, Mullie A, Desmet M, Huysmans G. Assisted dying – the current situation in Flanders: euthanasia embedded in palliative care. *Eur J of Palliat Care* 2013;20:266-272.
22. Vissers S, Dierickx S, Chambaere K, et al. Assisted dying request assessments by trained consultants: changes in practice and quality - Repeated cross-sectional surveys (2008–2019) *BMJ Support Palliat Care* 2022 June 29: bmjspcare-2021-003502.