Undermining health care delivery

"Assisted dying' can have a significant impact on clinical practice by complicating patient care and increasing clinician workload, potentially causing stress on patient care."

Worthington A, Finlay I, Regnard C.

Assisted dying and medical practice: questions and considerations for healthcare organisations. BMJ Supportive & Palliative Care, 2022; doi:

10.1136/bmjspcare-2022-003652.

https://spcare.bmj.com/content/early/2022/04/25/b mjspcare-2022-003652.info

Expanding criteria

• *"Factors directly associated with intellectual disability and/or ASD were the sole cause of suffering described in 21% of cases and a major contributing factor in a further 42% of cases."*

Tuffrey-Wijne I, Curfs L, Hollins S, Finlay I. Euthanasia and physician-assisted suicide in people with intellectual disabilities and/or autism spectrum disorders: investigation of 39 Dutch case reports

(2012–2021).

British Journal of Psychiatry Open, 2023; 9: e87, 1–8. https://pubmed.ncbi.nlm.nih.gov/37218567/

 "While euthanasia on the grounds of unbearable suffering caused by a psychiatric disorder or dementia remains a comparatively limited practice in Belgium, its prevalence has risen since 2008."

Dierickx S, Deliens L, Cohen J. Chambaere K. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases.

BMC Psychiatry, 2017; 17: 203-12. https://bmcpsychiatry.biomedcentral.com/articles/10 .1186/s12888-017-1369-0

 "Ultimately, the debate should not be primarily focused on the question of whether to legitimise self directed death for older people but on how to build an inclusive society where they feel less useless and marginalised."

van Wijngaarden E, Klink A, Leget C, The A-M. Assisted dying for healthy older people: a step too far?

BMJ 2017; 357: j2298. https://www.bmj.com/content/357/bmj.j2298.long *"Depression and personality disorders are the most common diagnoses in psychiatric patients requesting euthanasia."*

Thienpont L, Verhofstadt M, Van Loon T, Distelmans W, Audenaert K, De Deyns PD.

Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. BMJ Open 2015; 5: e007454.

https://bmjopen.bmj.com/content/5/7/e007454.shor t

 "Organ donation after voluntary assisted dying (VAD) in Australia may potentially increase organ transplant rates."

Ray R, Martin D.

Missed opportunities: saving lives through organ donation following voluntary assisted dying. Internal Medicine Journal, 2023; 53(5): 861-5. https://onlinelibrary.wiley.com/doi/full/10.1111/imj.1 6085

 "We are greatly concerned however regarding implications of applying the label "terminal" to anorexia nervosa and the risk it will lead to unjustified deaths in individuals whose mental illness impairs their capacity to make a reasoned treatment decision."

Guarda AS, Hanson A, Mehler P, Westmoreland P. **Terminal anorexia nervosa is a dangerous term: it cannot, and should not, be defined** *Journal of Eating Disorders (2022) 10:79* https://ieatdisord.biomedcentral.com/articles/10.12

https://jeatdisord.biomedcentral.com/articles/10.118 6/s40337-022-00599-6

Impact on healthcare professionals participating in AD

"Concerns about specific aspects of the euthanasia and assisted suicide process, such as the emotional burden of preparing and performing euthanasia or assisted suicide were commonly reported by physicians who refused and who granted a request." Evenblij K, Pasman HRW, van Delden JJM, van der Heide A, van de Vathorst S, Willems DL, Onwuteaka-Philipson BD.

Physicians' experiences with euthanasia: a crosssectional survey amongst random sample of Dutch physicians to explore their concerns, feelings and pressure.

BMC Family Practice, 2019; 20: 177-87. https://bmcprimcare.biomedcentral.com/articles/10 .1186/s12875-019-1067-8 Impact of AD on nurses: "While most nurses perceived MAiD as an extension of the profession and their nursing practice, a small number also expressed moral distress as they grappled with assisted dying." Beuthin R, Bruc A, Scaia M.

Medical assistance in dying (MAiD): Canadian nurses' experiences.

Nursing Forum. 2018; 53: 511–520. https://onlinelibrary.wiley.com/doi/epdf/10.1111/nuf .12280

"Doctors who have participated in voluntary assisted dying have mixed views about the operation of the system and its safeguards. Restrictions on initiating conversations with patients and limiting interactions to face-to-face meetings cause concern, as do practical problems related to system software and documentation requirements."

Willmott L, White BP, Sellars M, Yates PM.

Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study

Medical Journal of Australia, 2021; 215(3): 125-9. https://onlinelibrary.wiley.com/doi/full/10.5694/mja2 .51123

 Each assisted death takes 60 hours work. Rutherford J, Willmott L, White BP.
 What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Australia

OMEGA—Journal of Death and Dying, 2021; 87(4): 1063-87.

https://journals.sagepub.com/doi/abs/10.1177/00302 228211033109

 "The majority of physicians who refused to participate did not oppose medical aid in dying. The reason most often cited is not based on moral and religious grounds. Rather, the emotional burden related to this act and the fear of psychological repercussions were the most expressed motivations for not participating in medical aid in dying."

Bouthillier M-E, Opatrny L.

A qualitative study of physicians' conscientious objections to medical aid in dying.

Palliative Medicine, 2019, Vol. 33(9) 1212–1220 https://journals.sagepub.com/doi/abs/10.1177/02692 16319861921

Dividing clinicians

"Despite the overall perception that palliative care and euthanasia are integrated, some palliative care professionals in Flanders questioned the character of the relationship."

Gerson SM, Koksvik GH, Richards N, Materstvedt LJ, Clark D.

Assisted dying and palliative care in three jurisdictions: Flanders, Oregon, and Quebec. Annals of Palliative Medicine, 2021; 10(3): 3528-40. https://apm.amegroups.org/article/view/57549/html

 "Despite the overwhelming desire to support patient autonomy and decision-making, some interpreted patient choice for MAiD as rejection of the natural death experience at the hospice." Freeman S, Banner D, Ward V.

Hospice care providers experiences of grappling with medical assistance in dying in a hospice setting: a qualitative descriptive study.

BMC Palliative Care, 2021; 20: 55-67. https://link.springer.com/article/10.1186/s12904-021-00740-3

Blurring of suicide prevention vs suicide promotion

 "Legalization has a substantial impact on older adult women's engagement in self-initiated death." Canetto SS, McIntosh JL.

A comparison of physician-assisted/death-withdignity-act death and suicide patterns in older adult women and men.

American Journal of Geriatric Psychiatry. 2022; 30(2): 211-20.

https://www.sciencedirect.com/science/article/abs/pi i/S1064748121003559

• "The findings of this review do not support the hypothesis that introducing EAS reduces rates of nonassisted suicide. The disproportionate impact on older women indicates unmet suicide prevention needs in this population."

Doherty AM, Axe CJ, Jones DA.

Investigating the relationship between euthanasia and/or assisted suicide and rates of non-assisted suicide: systematic review.

British Journal of Psychiatry Open, 2022; 8, e108, 1–8. https://www.cambridge.org/core/journals/bjpsychopen/article/investigating-the-relationship-betweeneuthanasia-andor-assisted-suicide-and-rates-ofnonassisted-suicide-systematic-

review/223FDD723EB5CAE84D2EF02C65A9F446#

• "The assumption that, with the increasingly accessible option of AS[assisted suicide] for patients with cancer, CS[conventional suicide] will become "superfluous" cannot be confirmed."

Güth U, Junker C, Elger BS, Elfgen C, Montagna G, Schneeberger AR.

Conventional and assisted suicide in Switzerland: Insights into a divergent development based on cancer-associated self-initiated deaths.

Cancer Medicine, 2023;

https://doi.org/10.1002/cam4.6323

https://onlinelibrary.wiley.com/doi/epdf/10.1002/ca m4.6323

Contrasting MAiD/AD practice with established healthcare practice

 Challenges of assessing capacity in elderly patients: "However, the notion of an unchangeable, unified personality is doubtful. People do change and these changes may become meaningful to us in circumstances that we cannot envisage." van den Noorgate N, van Humbeck L.
 Medical assistance in dying and older persons in Belgium: trends, emerging issues and challenges. Age and Ageing 2021; 50: 68–71. https://academic.oup.com/ageing/article/50/1/68/58 57755

Decision-making

 AD in dementia /advance directive:
 "Advance request EAS cases were complicated by ambiguous directives, patients being unaware of the EAS procedure, and physicians' difficulty assessing "unbearable suffering." Notably, some concurrent request patients were quite impaired yet deemed competent by appeals to previous statements." Mangino DR, Nicolini ME, de Vries RG, Kim SYH.
 Euthanasia and assisted suicide of persons with dementia in the Netherlands.

American Journal of Geriatric Psychiatry, 2021; 28(4): 466-77.

https://www.sciencedirect.com/science/article/abs/pi i/S1064748119304889

 "Autonomy is largely an illusion in the case of assisted dying." Hartling O.
 Euthanasia and assisted dying: the illusion of autonomy.
 BMJ 2021; 374: n2135 https://www.bmj.com/content/374/bmj.n2135 "The paper comes to the conclusion that as the grounds and application of conscience objection are no longer as widely accepted, its future application in any legislation can be called into question."
 Willis D, George R.
 Conscientious objection and physician-assisted suicide: a viable option in the UK?

BMJ Supportive & Palliative Care, 2019; **9**: 464–467.

Monitoring

- "The Canadian MAiD regime is lacking the safeguards, data collection, and oversight necessary to protect Canadians against premature death."
 Coelho R, Maher J, Gaind KS, Lemmens T.
 The realities of Medical Assistance in Dying in Canada
 Palliative and Supportive Care, 2023; . https://doi.org/10.1017/S1478951523001025
 https://www.cambridge.org/core/journals/palliativeand-supportive-care/article/realities-of-medicalassistance-in-dying-incanada/3105E6A45E04DFA8602D54DF91A2F568
- "Elder abuse is a major public health problem, facing one in six older people globally (defined as aged 60 and older)."

Stephens C, Mays N, Issa R, Perkins L, Scott R. Elder abuse in the UK: out of the shadows and on to the agenda. *BMJ* 2021; 375: n2828

https://www.bmj.com/content/375/bmj.n2828.full

 "Approximately half of all estimated cases of euthanasia were reported to the Federal Control and Evaluation Committee." Smets T, Bilsen J, Cohen J, Rurup ML, Mortier F, Deliens L.
 Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of

reported and unreported cases. *BMJ*, 2010; 341: c5174.

https://www.bmj.com/content/341/bmj.c5174.short

"As a retrospective review of physician self-reported data, the Dutch RTEs do not focus on whether patients should have received EAS, but instead primarily gauge whether doctors conducted EAS in a thorough, professional manner. To what extent this constitutes enforcement of strict safeguards, especially when cases contain controversial features, is not clear." Miller DG, Kim SYH.

Euthanasia and physician-assisted suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgements. *BMJ Open,* 2017; 7: e017628. • "The unexplained part of the variation may include the possibility that part of the euthanasia practice may have to be understood in terms of underuse, overuse or misuse."

Groenewoud AS, Atsma F, Arvin M, Westert GP, Boer TA.

Euthanasia in the Netherlands: a claims data crosssectional study of geographical variation. BMJ Supportive & Palliative Care, 2021; doi:10.1136/bmjspcare-2020-002573 https://spcare.bmj.com/content/bmjspcare/early/202 1/01/12/bmjspcare-2020-002573.full.pdf

 "From our impression of the current state of research regarding MAiD practices, a number of shortcomings and needs in research can be identified." Dierickx S, Cohen J.

Medical assistance in dying: research directions.

BMJ Supportive & Palliative Care, 2019;**9**: 370–372. https://spcare.bmj.com/content/9/4/370.abstract

 "Inconsistency in data collection and public reporting make it difficult for researchers, policymakers and the public to assess the practice and help achieve a balance between access and compliance. Research on oversight activities is sparse, and there is a need for clarity to determine how best to handle violations of the law and how to create best practices." Riley S.

Watching the watchmen: changing tides in the oversight of medical assistance in dying. J Med Ethics 2023; **49**: 453–457.

https://jme.bmj.com/content/49/7/453.abstract

 "Many jurisdictions fail to report data measures, which could be valuable to the understanding of assisted suicide and euthanasia practices within that country."

Worthington A, Regnard C, Sleeman KE, Finlay I. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions.

BMJ Supportive & Palliative Care 2022 . doi:10.1136/spcare-2022-003944 https://spcare.bmj.com/content/bmjspcare/early/202 2/12/30/spcare-2022-003944.full.pdf

 "...little attention has been given to the problem of unmonitored prescribing and administering of lethal drug combinations, whose mode of action is unclear." Worthington A, Finlay I, Regnard C.
 Efficacy and safety of drugs used for 'assisted dying'.

British Medical Bulletin, 2022, 1–8 https://doi.org/10.1093/bmb/ldac009 https://academic.oup.com/bmb/article/142/1/15/658 0517 "The Canadian medical assistance in dying (MAID) program, based on an ambitious piece of legislation and detailed regulations, has failed to provide Canadians with sufficient publicly accessible evidence to show that it is operating as mandated by the requirements of the law, regulations, and expectations of all stakeholders."

Medical Assistance in Dying: Challenges of Monitoring the Canadian Program.

Canadian Journal of Bioethics, 2020; 3(3): 202-209. https://www.erudit.org/en/journals/bioethics/1900v1-n1-bioethics05693/1073799ar/abstract/

 "Providing medical assistance in dying in Canada should not result in any excess financial burden to the health care system, and could result in substantial savings."

Trachtenberg AJ, Manns B.

Kotalik J.

Cost analysis of medical assistance in dying in Canada. CMAJ 2017 January 23;189:E101-5. doi:

10.1503/cmaj.160650 https://www.cmaj.ca/content/189/3/E101.short

 "Death certificates substantially underestimate the frequency of euthanasia as a cause of death in Belgium."

Cohen J, Dierickx S, Penders YWH, Deliens L, Chambaere K.

How accurately is euthanasia reported on death certificates in a country with legal euthanasia: a population-based study.

European Journal of Epidemiology, 201; 33: 689–693 https://link.springer.com/article/10.1007/s10654-018-0397-5

Palliative care

- *"We project that by 2040, the number of people requiring palliative care will increase by at least 14%; and by 20% if we factor in multimorbidity."* Finucane AM, Bone AE, Etkind S, *et al.* How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. *BMJ Open* 2021; 11:e041317. https://bmjopen.bmj.com/content/11/2/e041317
- Growth in palliative care services in Belgium and the Netherlands stalled 2012-2019. Arias-Casais N, López-Fidalgo J, Garralda E, Pons JJ, Rhee JY, Lukas R, de Lima L, Centeno C. Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years

Palliative Medicine, 2020, 34(8) 1044–1056 https://journals.sagepub.com/doi/full/10.1177/02692 16320931341 • Oregon hospices:

"..Oregon hospice programs share a prohibition on assistance in PAD...."

Campbell CS, Cox JC.

Hospice-assisted death? A study of Oregon hospices on Death with Dignity.

American Journal of Hospice & Palliative Medicine, 2012; 29(3): 227-235.

https://journals.sagepub.com/doi/abs/10.1177/10499 09111418637

• "This study demonstrates an increase in the use of PS in our hospital's PCU setting following the legalization of MAiD in Canada..."

Nolen A, Olwi R, Debbie S.

Impact of legalization of medical assistance in dying on the use of palliative sedation in a tertiary care hospital: a retrospective chart review.

American Journal of Hospice & Palliative Medicine, 2021; 39(4): 442-7.

https://journals.sagepub.com/doi/10.1177/10499091 211030443

 Up to 43% of Dutch dying patients have at least on unresolved symptom.

Heijltjes MT, van Zuylen L, van Thiel GMW, van Delden JJM, van der Heide A.

Symptom evolution in the dying.

BMJ Supportive & Palliative Care, 2023; **13**: 121–124. https://spcare.bmj.com/content/13/1/121.abstract

 "Assigning unrealistic expectations and goals to palliative care teams—such as changing patients' values—will set palliative care up for failure, and undermining palliative care will affect all vulnerable, seriously ill patients.9 Palliative care is distinct from PAS and should not be part of the debate." al-Awamer A.

Physician-assisted suicide is not a failure of palliative care.

Canadian Family Physician, 2015; 61: 1039-40. https://www.cfp.ca/content/61/12/1039.short

"Before MAID request, 27.4% of patients had a community palliative care physician and 59.5% had palliative care involvement in any setting. The [hospital] palliative care team was involved in 46.4% of patients who requested MAID."
 Munro C, Romanova A, Webber C, Richard R, Tanuseputro P.
 Involvement of palliative care in patients requesting

medical assistance in dying.

Canadian Family Physician, 2020; 66: 833-42. https://www.cfp.ca/content/66/11/833.short "This study demonstrates the significant clinical effectiveness of SPCU admission across the different aspects of patient and family care." Lucey M, O'Reilly M, Currow D, Eagar K, Walsh D, Conroy M, Twomey F, O'Reilly V, Doherty M, Coffey S, Sheridan J, Moran S.

Is inpatient hospice care clinically effective? Using phase of illness to evaluate care outcomes for patients admitted to a specialist palliative care unit in Ireland.

Journal of Palliative Medicine, 2020; 23(4): 535-41. https://www.liebertpub.com/doi/abs/10.1089/jpm.20 19.0295

 "Medical Assistance in Dying has had a profound impact on palliative care providers and their practice." Mathews JJ, Hausner D, Avery J, Hannon B, Zimmermann C, al-Awamer A.

Impact of Medical Assistance in Dying on palliative care: A qualitative study.

Palliative Medicine, 2021, 35(2) 447–454 https://journals.sagepub.com/doi/abs/10.1177/02692 16320968517

Public opinion

 "Informing the public of the ethical and practical complexities in AR-EAS may have significant effects on their attitudes toward legalization."

Mangino DR, Bernhard T, Wakim P. Kim SYH. Assessing public's attitudes towards euthanasia and assisted suicide of persons with dementia based on their advance request: an experimental survey of US public.

American Journal of Geriatric Psychiatry.2021; 29(4): 384-94.

https://www.ajgponline.org/article/S1064-7481(20)30431-0/fulltext