Philosophers' Consortium on Assisted Dying in Scotland

PCADS Policy Paper: Palliative Care and Assisted Dying Laws

Proposals are being developed in Scotland, the Isle of Man and Jersey to allow assisted dying for people who are terminally ill, if they request it. Some people oppose legalization because of fears about the effects that assisted dying laws might have on palliative care provision. This policy briefing evaluates the evidence for those fears. It concludes that **assisted dying laws do not have an adverse effect upon palliative care provision**. Instead, assisted dying complements existing palliative care options by upholding voluntary choice, supporting autonomy in end-of-life care.

This conclusion is supported by four key findings:

1. It is not more difficult to access expert palliative care in jurisdictions where assisted dying has been legalised;
2. Legalising assisted dying expands patient choice at the end of life;
3. Growth in palliative care has not stalled in jurisdictions where assisted dying has been legalised;
4. Legalising assisted dying does not cause palliative care provision to decline.

1. It is not more difficult to access expert palliative care in jurisdictions where assisted dying has been legalised.

Opponents of assisted dying often claim that expert palliative care is more difficult to access in jurisdictions where assisted dying has been legalised.[1] The evidence shows that this is false.

Close inspection of the sources they cite shows that none of them support this claim. In fact, one proves the opposite.

Arias-Casais et al 2020 studied palliative care trends in 51 European countries between 2005 and 2019.[2] Four countries had assisted dying laws during that period: Belgium, Luxembourg, the Netherlands, and Switzerland. Far from supporting opponents' claims, the results in Arias-Casais et al 2020 disprove them. Luxembourg and Switzerland were amongst only seven countries that exceeded the European Association for Palliative Care recommendation of 0.5 services per 100,000 inhabitants, and Belgium and the Netherlands were amongst only five that nearly met that benchmark (with a score of between 0.4 and 0.49).[3]

Finkelstein et al 2022 is a cross-country survey, carried out between May and August 2021, in which 181 experts from 81 countries assessed the quality of death and dying in their own

[1] E.g. Glenny L. et al. 2022. 'Assisted dying', *International Journal of Palliative Nursing* 28: 55-58.
[2] Arias-Casais N. et al. 2020. 'Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years', *Palliative Medicine* 34: 1044-1056.
[3] ibid: 1050.

countries. The results were then scored and ranked.[4] The study included four countries with legalised assisted dying: Belgium, Canada, Colombia, and Switzerland. All received scores in the top quartile of scores received—placing them below the UK and Ireland (which came at the top) but above the USA.

Arias-Casais et al 2020 and Finkelstein et al 2022 are both cited by as evidence of difficulty in access, but it is clear that their findings refute, rather the supporting, the claims made by opponents of assisted dying.

Other sources cited likewise fail to provide support. Jordan et al 2020 and Mitchell et al 2021 are both cited as evidence of 'difficulties in accessing expert palliative care in countries where [assisted dying] has been legalised'.[5] Jordan et al 2020 is a systematic review and meta-analysis which draws on 169 studies from 23 countries, between 2013 and 2018, determining the median duration adults in each country spent in palliative care between initiation and death.[6] Researchers found a wide range, from 6 days in Australia to 69 days in Canada. (Jordan et al 2020: 19-20). They did not discuss assisted dying, do not claim that duration of palliative care corresponds to levels of access, and their results show no correlation between median duration and legalisation of assisted dying. Mitchell et al 2021 is a study of hospital deaths in Australia between July 2015 and June 2016.[7] It preceded legalised assisted dying (which first came into effect in Victoria in 2019) by several years. The appearance of empirical support from these studies is therefore illusory.

Another source cited by opponents of assisted dying is Munro et al 2020. This was a study of 84 patients at a hospital in Canada between February 2016 and June 2017 who requested assisted dying, and comparing rates of palliative care involvement before and after those requests. It found that there was less such involvement afterwards (46.4%) than before (59.5%).[8]

Munro et al's study does not provide evidence of 'difficulties in accessing expert palliative care in countries where [assisted dying] has been legalised'.[9] Their central finding is unrepresentative: Health Canada's most recent annual report on *all* assisted deaths in Canada found that 77.6% received palliative care before their requests, and 87.5% had it accessible throughout the process if needed. Moreover, opponents of assisted dying rely not on Munro et al's findings, but rather on their evaluative commentary, for example the suggestion that '[t]here is still inadequate provision of palliative care for those requesting [assisted dying]'.[10] This evaluation is unsupported by the research findings in the study, and Munro et al offer no reasoning to support it.

Opponents of assisted dying are wrong to claim that palliative care is difficult to access in countries where assisted dying has been legalised. The sources they themselves cite either fail to support this claim, or demonstrate that it is false. In fact, evidence shows high levels of palliative care provision in countries with legalised assisted dying.

2. Legalising assisted dying expands patient choice at the end of life.

[4] Finkelstein E.A. et al. 2022. 'Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021', *Journal of Pain and Symptom Management* 63: e419-429.
[5] Glenny et al. 2022:55.
[6] Jordan, R.I. et al. 2020. 'Duration of palliative care before death in international routine practice: a systematic review and meta-analysis', *BMC Medicine* 18: 368.
[7] Mitchell I. et al. 2021. 'Understanding end-of-life care in Australian hospitals', *Australian Health Review* 456: 540-547.
[8] Munro C. et al. 2020. 'Involvement of palliative care in patients requesting medical assistance in dying,' *Canadian Family Physician* 66: 833-842.
[9] Glenny et al. 2022:55.
[10] ibid 833.

Opponents of assisted dying sometimes argue that a key argument in favour of legalisation – that the option of assisted dying expands patient choice – is refuted because 'access to palliative care remains inequitable and inconsistent' in jurisdictions that have legalised assisted dying.[11] This claim is unsupported by the evidence and poorly reasoned on its own terms.

Two sources cited are Mitchell et al 2020 and Munro et al 2020. As discussed above, the former predates legalisation in Australia by several years,[12] and the latter's claims about Canada are problematic because its findings are unrepresentative and it is hampered by a failure to distinguish between research findings and evaluative commentary.[13] The other citations face similar problems. A Belgian study found that *home* palliative care is underused, with social inequalities in its uptake, but not that this is caused by legalised assisted dying, and made no claims about palliative care *in general*;[14] a Canadian report identified long-standing problems of equity and consistency in access to palliative care, but nowhere suggested assisted dying as a driver of those problems.[15]

So, none of these studies give reason to reject the view that legalising assisted dying expands patient choice. Even the strongest evidence appealed to shows only that legalising assisted dying doesn't by itself solve all problems of equity and consistency, but that is not a claim ever made by proponents of legalisation. This misdirection means that opponents fail to address the real point here, which is that the option of assisted dying in itself expands patient choice, supporting autonomy even for patients who do not currently want to take that option.[16] Opponents' appeals to data about access to palliative care don't even address that central point, much less refute it.

3. Growth in palliative care has not stalled in jurisdictions where assisted dying has been legalised.

Opponents of assisted dying frequently claim that growth in palliative care stalls in jurisdictions where assisted dying has been legalised.[17] This claim is refuted by the evidence.

Arias-Casais et al 2020 found 'constant increase in service provision' between 2005 and 2019 in the Netherlands and Switzerland, and an overall increase during that period in Belgium and Luxembourg (where services increased between 2005 and 2012 and held steady between 2012 and 2019, the same finding as for the UK).[18] As noted above, all four of these countries had comparatively high levels of palliative care services. Opponents of assisted dying have cited this study as evidence that palliative care provision has 'stalled.' But this is a misleading way to describe the lack of growth between 2012 and 2019. Rather, the fact that these countries (especially Belgium and Luxembourg) already had comparatively generous provision by 2012 supports Arias-Casais et al's own alternative hypothesis: those countries 'achiev[ed] a saturation of services covering their needs'.[19]

So, there is no evidence that growth in palliative care stalls in jurisdictions where assisted dying is legalised. In fact the opposite is true.

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[11] Regnard C. 2021. 'The impact of assisted dying on hospices and palliative care', *ehopsice*. https://ehospice.com/editorial_posts/the-impact-of-assisted-dying-on-hospices-and-palliative-care/.
[12] Mitchell et al 2020.
[13] Munro et al 2020.
[14] Maetens, A. et al. 2019. 'Who finds the road to palliative homecare support? A nationwide analysis on the use of supportive measures for palliative home care using linked administrative databases', *PLoS ONE* 14: e0213731.
[15] Canadian Institute for Health Information (CIHI) 2018. *Access to Palliative Care in Canada*. Ottawa: CIHI.
[16] Colburn B. 2020. 'Autonomy, voluntariness, and assisted dying', *Journal of Medical Ethics* 45: 316-319.
[17] E.g. Glenny et al 2022, Regnard C. & Proffitt A. 2022. 'Letters: Our objections to assisted dying are based on evidence, not religion', *The Guardian* 7 October 2022; Regnard C. 2023. 'Letters to the editor', *Church Times* 20 October 2023.
[18] Arias-Casais et al. 2020: 1048.
[19] Ibid: 1050.

4. Legalising assisted dying does not cause palliative care provision to decline.

The most serious fear of all is that legalising assisted dying might cause problems with palliative care services. In fact this possibility underpins the claims already considered—they provide grounds for rejecting assisted dying only if their *correlations* they assert are underpinned by *causation*. This causal connection is unsupported by the evidence.

This crucial causal claim is very often only implied or evoked obliquely by opponents of assisted dying, rather than asserted and evidenced. Reference is made to 'the potential [for] underdevelopment or devaluation of palliative care',[20] or to 'a feared decline in palliative care resourcing and standards following legalisation',[21] but frequently nothing is said to back these claims up.

Moreover, when citations are offered, they do not in fact offer support. For example, Regnard says that we should 'question claims that legalising assisted death is compatible with palliative care and does not impede its developments'.[22] He cites a study which shows that two thirds of Oregon hospices did not take part in assisted deaths',[23] and a Canadian news story about a charity hospice which had to move from a government-leased site because they didn't want to implement the regional health authority's policy that hospices should provide assisted dying.[24] Neither of these things shows that assisted dying impedes the development of palliative care. Oregon hospices that decline to administer assisted dying remain active in offering palliative care, and while the Canadian charity did in the end cease operating its hospice, it remains active in providing direct support to families facing terminal illness, and the hospice itself continues to operate as an institution owned and run by the government.[25]

Pereira claims that 'rates of palliative care involvement have been decreasing' where assisted dying is legalised,[26] but he cites only a Belgian source which shows only that the proportion of physicians consulted *about a request for assisted dying* who were palliative care specialists decreased between 2002 and 2007. The study does not show that involvement of such patients in palliative care declined, much less that 'rates of palliative care involvement have been decreasing' in Belgium more widely.[27] His further claim that 'palliative care has developed more [in countries without legal assisted dying like the UK, Australia, Ireland, France and Spain] than it has in Belgium and the Netherlands'[28] has since been refuted by Arias-Casais 2020.

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[20] Materstvedt, L.J. et al. 2003. 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force', *Palliative Medicine* 17: 97-101, at 99.
[21] Rutherford J. et al. 2021. 'What the doctor would prescribe: physician experiences of providing voluntary assisted dying in Australia', *Omega* 87: 1063-1087, at 1076.
[22] Regnard 2021.
[23] Campbell C.S. & Cox J.C. 2012. 'Hospice-assisted death? A study of Oregon Hospices on death with dignity', *American Journal of Hospice and Palliative Medicine* 29: 227-35.
[24] Harding, L. 2021. 'Delta Hospice Society in envisions new private MAID free facility', *Western Standard*, 18 July 2021. https://www.westernstandard.news/news/delta-hospice-society-envisions-new-private-maid-free-facility/article_4f547a0c-6122-5160-b673-a103677fe3ad.html.
[25] Delta Hospice Society 2024a. 'Our History', https://deltahospicesociety.org/about-us/our-history/ (accessed 31 May 2024); Harding 2021.
[26] Pereira J. 2011. 'Legalising physician-assisted dying or assisted suicide: the illusion of safeguards and controls', *Current Oncology* 18: 38–45, at 41.
[27] Smets, T. et al. 2010. 'Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases', *BMJ* 341:c5174.
[28] Pereira 2011: 41.

Worthington et al say that 'evidence from jurisdictions where 'assisted dying' is practised reveals a significant impact on clinical practice',[29] but the studies they cite only provide evidence of more general under-resourcing of the medical system, which is a problem regardless of whether or not assisted dying is legal.

This 'oft-invoked fear'[30] about the effect of assisted dying on palliative care is most commonly mentioned in the context of the many studies over multiple decades which have found no evidence to support it.[31] Ironically, these repeated allusions to that 'fear' contribute to what we might call a 'firehosing' phenomenon, whereby its frequent repetition influences people to think that is widely accepted.[32] In fact, that is an illusion. All the evidence in fact points to the opposite conclusion: that legalising assisted dying does not impede or damage palliative care provision.

Conclusion

People sometimes oppose assisted dying laws because of understandable and serious concerns about their effects on palliative care. However, those concerns aren't borne out in the evidence. In fact, legalising assisted dying is compatible with continuing improvements to palliative care provision. We can and should expand patients' options at the end of life while offering them better palliative care. So, this briefing has two key recommendations:

1. **Assisted dying laws should not be opposed on the basis of concerns about adverse effects on palliative care provision;**
2. **Respect for people's autonomy at end of life speaks in favour of assisted dying laws as a complement to existing palliative care options.[33]**

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[29] Worthington, A. et al. 2023. 'Assisted dying and medical practice: questions and considerations for healthcare organisations', *BMJ supportive & palliative care* 13: 438-441.
[30] Bernheim J.L. et al. 2014. 'State of Palliative Care Development in European Countries with and without Legally Regulated Physician-Assisted Dying',, *Health Care* 2: 10-14, at 11.
[31] E.g. Gordijn B. & Janssens, R. 2000. 'The prevention of euthanasia through palliative care: New developments in The Netherlands', *Patient Education and Counseling* 41: 35-46; Gordijn, B., & Janssens, R. 2004. 'Euthanasia and Palliative Care in the Netherlands: An Analysis of the Latest Developments', *Health Care Analysis* 12: 195-207; Bernheim J.L. et al. 2008. 'Development of palliative care and legalisation of euthanasia: antagonism or synergy?' *BMJ* 336(7649):864-7; Chambaere K et al. 2011. *Palliative care development in countries with a euthanasia law*. London: Commission on Assisted Dying; Smets, T. et al. 2011. 'Attitudes and experiences of Belgian physicians regarding euthanasia practice and the euthanasia law', *Journal of Pain and Symptom Management* 41: 580-93; Bernheim et al 2014; Chambaere K. & Bernheim J.L. 2015. 'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience', *Journal of Medical Ethics* 41: 657-660; Sheahan, L. 2016. 'Exploring the interface between 'physician-assisted death' and pal liative care: Cross-sectional data from Australasian palliative care specialists', *Internal Medicine Journal* 46: 443–451; Apex Consulting 2018. *Palliative Care Australia: Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector*. Melbourne, Victoria: Apex Consulting; Philip, J. et al. 2023. 'Voluntary Assisted Dying/Euthanasia: Will This Have an Impact on Cancer Care in Future Years?', *Current Treatment Options in Oncology* 24: 1351–1364.
[32] Paul, C. & Matthews, M. 2016. *The Russian "Firehose of Falsehood" Propaganda Model: Why It Might Work and Options to Counter It*. (Santa Monica CA: RAND Corporation). https://www.rand.org/pubs/perspectives/PE198.html.
[33] This briefing is based on a research paper currently under review. The draft paper is available on request, along with a full list of references to the underpinning studies. Please e-mail mailto:ben.colburn@glasgow.ac.uk to find out more.