

Access to palliative care: the primacy of public health partnerships and community participation



Oct 9, 2021, marks World Hospice and Palliative Care Day. The 2021 theme, *Leave No One Behind—Equity in Access to Palliative Care*, is especially pertinent given the unprecedented effects of COVID-19. In support of this theme, we propose a re-imagining of palliative-care access to promote more equitable outcomes through public-health partnerships that prioritise community development and participation in end-of-life care.

Palliative care is widely recognised as a public-health concern, with both structural and social determinants of health affecting health inequalities for disadvantaged populations across high-income and low-income countries.^{1,2} For low-income countries, palliative care development has become a key focus to promote equitable access, with the International Palliative Care Initiative producing a roadmap to guide development and expansion of palliative-care provision in resource-constrained countries.³ However, disadvantaged groups are also found in resource-rich countries—Indigenous peoples, LGBTQI+ communities, and those incarcerated or homeless, in particular. A review of hospice-patient care in the UK, Australia, New Zealand, and Canada found that older people (aged ≥ 85 years), ethnic minorities, people with non-cancer illnesses, and people living in rural locations or areas of social deprivation had unequal access to palliative care.⁴

But these findings merely confirm what many have observed for quite some time; the reality that palliative-care service provision reaches only a minority of those who need palliative care and inequities of access substantially affect those from diverse communities. Viewed through a population-health lens, present efforts to promote equity and access to palliative care are limited in that professional service provision models are increasingly unable to cope with demand to meet population needs.^{2,3} Compounding this have been ongoing recommendations to improve access that either problematise needs as community deficits to be filled by services or focus on the expansion and marketing of, or professional development within, service providers.⁵ Unfortunately, there has been little by way of new approaches to what is an old problem. Collectively, this represents both a lack of imagination

on integration of services with community and a failure to prioritise equity of access.

Palliative-care providers adopting new public health approaches, or actions framed around health-promoting palliative care, will be best-equipped to tackle the challenges of equity and access for diverse populations. This is largely because these approaches, informed by the Ottawa Charter for Health Promotion, offer empowerment and respect the ability of communities to identify strengths and needs, set priorities, and identify goals or strategies within local contexts of provision and access to palliative care.^{1,2} End-of-life care is everyone's responsibility and most of the care provided towards the end of life is given by family, friends, and community members rather than solely by health professionals.⁶ By community, we mean not merely community services or volunteers but members of neighbourhoods, faith groups, workplaces, schools, local government agencies, as well as sporting clubs, and cultural organisations such as galleries and museums. Death, dying, loss, and caregiving are experiences that occur within these kinds of community contexts, each providing love and support, practical care, policies for support, or educational experiences.⁵ Therefore, it is in partnership with these elements within communities that we can provide support towards understanding and promoting equity in access to palliative care across diverse populations.

The public-health practice of community development has proven to be effective and cost-effective in health care,⁷ while showing a clear commitment to equity as well as the inclusion of meaningful participation and empowerment. As outlined by WHO,⁸ through recognition of community assets and respect for community-defined priorities, community development empowers and enables social networks to identify shared concerns and engage in participatory action to address them.

In this way, public-health approaches to palliative care involve building community capacity and participation by working with communities rather than attempting to build it for them.⁵ Importantly, this approach does not preclude health services from initiating

Published Online
October 8, 2021
[https://doi.org/10.1016/S2468-2667\(21\)00213-9](https://doi.org/10.1016/S2468-2667(21)00213-9)

For more on **World Hospice and Palliative Care Day** see <https://www.thewhpc.org/world-hospice-and-palliative-care-day/about>

For more on the **Ottawa Charter for Health Promotion** see <https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference>

community development programmes, as reflected in compassionate communities models, which help services transcend entrenched boundaries that exclude or limit care.²

Strengthened community action that is supported by inherent community assets such as social capital and compassion, together with clinical expertise and empowerment from health services to support death literacy and personal skills for end-of-life care, can transform disadvantaged communities into compassionate communities; everyday settings in society where citizens from diverse groups can readily access and provide care through active partnerships with palliative care services.^{2,6,9,10}

Amidst longstanding inequalities in access to hospice and palliative care, if equity in access to palliative care is to be achieved it must be understood that equality of service provision for diverse populations will not necessarily equate to equity in health outcomes, as health inequities are context-bound and socially determined.

Lying at the heart of inequitable access to palliative is a failure to recognise that diverse communities might have many strengths in the ways they support their dying. Palliative-care services often do not recognise these strengths and might make common assumptions about needs that do not match the wishes or social context of diverse communities. Following a critical review of common recommendations for increasing access to palliative care,⁵ we suggest the first step towards equity in access is to explore and appreciate existing community strengths. Then the next step is, in partnership, finding out and offering the kind of support that members of diverse communities would like, to complement those strengths. Central to these steps is

the growing need to strengthen community action and create supportive environments, as supported by the Ottawa Charter for Health Promotion. In re-imagining access to palliative care to promote more equitable outcomes, palliative care services must appreciate the primacy of public health partnerships and community participation.

We declare no competing interests.

Copyright © 2021 The Author(s). Published by Elsevier Ltd. This is an Open Access article under the CC BY 4.0 license.

*Jason Mills, Julian Abel, Allan Kellehear, Manjula Patel
jmills2@usc.edu.au

School of Nursing, Midwifery and Paramedicine, University of the Sunshine Coast, Caboolture, QLD, Australia (JM); Compassionate Communities UK, Trewoon Farm, St Martin, Helston, UK (JA); College of Nursing and Health Sciences, University of Vermont, Burlington, VT, USA (AK); Warwick Medical School of Health and Social Science, University of Warwick, Coventry, UK (MP)

- 1 Kellehear A. *Compassionate cities: public health and end-of-life care*. Oxford: Routledge, 2005.
- 2 Abel J, Kellehear A, Karapliagou A. Palliative care—the new essentials. *Ann Palliat Med* 2018; 7 (suppl 2): S3–14.
- 3 Callaway MV, Connor SR, Foley KM. World Health Organization public health model: a roadmap for palliative care development. *J Pain Symptom Manage* 2018; 55: S6–13.
- 4 Tobin J, Rogers A, Winterburn I, et al. Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Support Palliat Care* 2021; published online Feb 19. <https://doi.org/10.1136/bmjspcare-2020-002719>.
- 5 Abel J, Kellehear A, Mills J, Patel M. Access to palliative care reimagined. *Future Healthc J* 2021; published online Sept 23. <https://doi.org/10.7861/fhj.2021-0040>.
- 6 Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* 2013; 106: 1071–75.
- 7 O'Mara-Eves A, Brunton G, McDaid D, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. *Public Health Res* 2013; 1.
- 8 WHO. Community participation in local health and sustainable development: approaches and techniques. 2002. World Health Organization Regional Office for Europe. <https://apps.who.int/iris/handle/10665/107341> (accessed Sept 25, 2021).
- 9 Bollig G, Brandt Kristensen F, Wolff DL. Citizens appreciate talking about death and learning end-of-life care—a mixed-methods study on views and experiences of 5469 last aid course participants. *Prog Palliat Care* 2021; 29: 140–48.
- 10 Mills J, Rosenberg JP, Bollig G, Haberecht J. Last aid and public health palliative care: towards the development of personal skills and strengthened community action. *Prog Palliat Care* 2020; 28: 343–45.