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Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life

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Our choice for care at the end of our lives is constrained by many factors, including the options available to us, our capacity to choose and the social structures that constrain our options and therefore our choices. Working with the interaction between personal agency and social constraints is a core public health activity. An intentional public health approach to palliative and end-of-life care can elucidate the direct relationship between our social circumstances and the quality of our end of life and uncover the implications of structural inequity for end-of-life choice. The approach reorients systems and settings to achieve accessible and equitable palliative and end of-life care for all, and identifies contributions that all jurisdictions, settings, organisations, sectors and communities can make to improving end-of-life care outcomes. Frameworks that support this shift in practice and policy are however in their infancy. Implementation frameworks that can structure and guide 'how' to translate public health palliative care concepts into sustainable practice are needed. This paper reports on an evidence-based Australian public health palliative care framework designed to achieve this.

Keywords: Public health, Palliative care, Public health palliative care, Compassionate communities, Compassionate cities, End of life, Social determinants of health

Introduction

The global mission of public health is to realise and sustain the health and well-being of citizens¹. In public health literature, health is understood as a resource that facilitates human wellbeing². Wellbeing is associated with the degree of agency we possess to influence and realise our preferred choices for optimal life experiences³. However, the degree to which we are able to exercise our agency in making choices is broadly, but strongly predicted by the chances provided to us by the social and structural circumstances of our lives, over which we have little influence^{3,4}. These chances, often referred to as the 'social determinants of health'⁵⁻⁷, include factors such as gender, biogenetics, culture, race, socio-economic status and access to income and education^{8,9}. These social determinants of health can also be viewed as the social determinants of death – that is, the resources that support our living are the resources we bring to our dying.

Inherent in a public health perspective is the recognition that individuals are not solely responsible for

the status of their health¹⁰. Social inequality directly impacts our health and wellbeing¹¹, and consequently our dying, through systems and structures that either produce or reduce social disadvantage and associated 'vulnerability'. This type of vulnerability is described as 'structural vulnerability'¹²⁻¹⁴: the shortcomings of our systems and social structures creating disadvantage that is reflected in health status. Citizens at the end of their lives may be considered as 'doubly vulnerable'¹⁵ when issues arising from illness, ageing and frailty are added to pre-existing disadvantage. The implications for such disadvantaged citizens as they encounter dying, death and bereavement are two-fold; they have increased care needs as a direct result of social marginalisation, coupled with inequitable access to palliative, end-of-life care and bereavement services¹⁴. In other words, compared with the general population, their needs are higher, but access to support is lower.

Understanding the impact of social structures on the agency we have to influence health outcomes highlights the challenge of providing authentic options for care at the end of life. What agency do we have in making choices at the end of life? What are the

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constraints upon our choices? To answer these questions, we need to explore the ‘social determinants of choice’.

A public health approach to end-of-life choice provides a framework to examine the chances that shape end-of-life care options. In the palliative care literature, meeting end-of-life wishes or care preferences wherever possible is considered an important component of providing quality palliative and end-of-life care^{16,17} and a principal indicator of a good death^{18,19}. Structural constraints upon these indicators are seldom recognised. Yet if those dying wish to remain connected to people, possessions and places that are important to them at the end of life²⁰, but their care is provided by health services disconnected from the social setting in which their lives are lived, the very structure of that care limits choice. What then are the ethical implications of asking people about their preferences for end-of-life care if our formal care systems lack capacity and capability, and our social networks are inadequate, to fulfil these preferences? Providing equitable choice and improved end-of-life care outcomes for all citizens involves both a top down approach to systems, structures and policies in conjunction with a bottom up approach that leverages civic participation and engages social networks of support²¹.

Bringing a public health perspective to palliative care creates both opportunities and challenges. Public health as an organising framework asserts that end-of-life care is the responsibility of everyone^{22–25}. Such care is a citizen-driven multi-sectoral activity in which everyone has a role. Palliative care policy stresses the importance of equitable access to palliative care for all citizens^{17,26,27}, emphasising equitable access to services. This poses an interesting question: ‘can the aspirational intent of one be achieved without the other?’ The emerging field of ‘public health palliative care’ has predominantly used palliative care as the entry point for practice²⁸, looking at ways of expanding the reach of palliative care and resulting in a ‘palliative care public health’ approach more than a ‘public health palliative care’ approach. A public health palliative care approach extends well beyond ‘consumer participation’ or ‘community engagement’²⁹ of health services. Public health approaches are designed to leverage ‘civic participation’ and intentionally targets populations most impacted by structural disadvantage, prioritising their inclusion in and access to care. However, frameworks that support this shift in practice and policy are in their infancy.

Implementation frameworks that can structure and guide ‘how’ to translate public health palliative care concepts into sustainable practice are needed. This paper reports on an evidence-based Australian public

health palliative care framework designed to achieve this.

Public health frameworks

Public health frameworks provide evidence-based strategies to guide practice. Among others, a key objective is to enable equitable access by exerting control over social factors that influence health and wellbeing. Examples of public health frameworks reflecting this purpose include Healthy Settings³⁰, the Ottawa Charter for Health Promotion³, Asset-Based Community Development (ABCD)³¹ and community development³². These public health frameworks have been applied in the context of caring, dying, death and bereavement as Health Promoting Palliative Care³³ where palliative care is introduced to health promotion, Compassionate Cities²³ where Healthy Settings intersect with the end of life through reorienting the settings that citizens inhabit, and a Compassionate Communities^{24,34,35} initiative, the Healthy End of Project (HELP)³⁶ a health promotion and community development framework to guide community driven initiatives. These frameworks, collectively combined, have primacy in driving practice and research in the public health palliative care interventions outlined in this paper.

As recommended by Karapliagou, Kellehear and Wegleitner³⁷ in their chapter outlining history, principles and styles of practice to public health approaches in end-of-life care, a combination of approaches is required:

Despite their empowering potential and impact upon the health and wellbeing of people with end-of-life care needs in local settings, Compassionate Communities cannot support a large-scale societal transformation ... Community development programmes cannot reach everyone in a given society. They may be suitable for homogenous towns and villages, but for diverse urban centres we need alternative public health paradigms. pg. 13–14.

Both research and practice in the public health palliative care field are beginning to focus on the links between formal and informal networks of care, but there is little empirical evidence about how to form and sustain these connections in a systemic way between government, inter-sectoral agencies, organisations and communities. The Healthy End of Life Partnerships illustrative model (Fig. 1), part of the HELP Framework³⁶, depicts how we have explored strategic multi-level links between the health and community sector in order to improve quality end-of-life care. Underpinning the HELP framework is the assumption that both types of networks, health and community, are required for settings-based (including

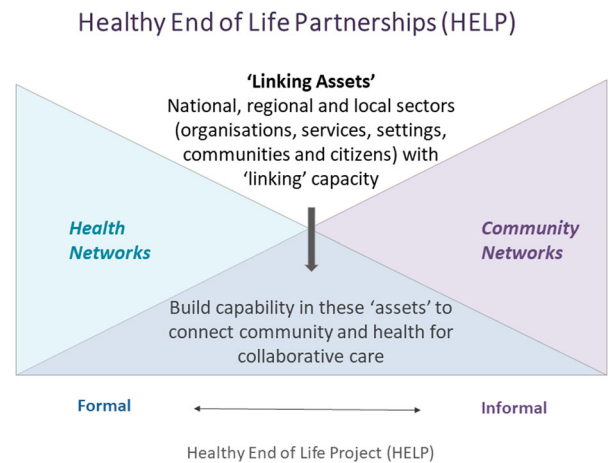


Figure 1 Healthy end of life partnerships (HELP) of the HELP framework

home) palliative care to flourish, recognising that the health sector need community care networks to support the delivery of their services in the settings in which people wish to receive care.

In the HELP framework, partnerships focus on bringing together health and community networks to create an integrated public health palliative strategy. Using an assets-based approach at systems, sector, organisational and community levels, we identify 'linking assets' – defined as those assets (from systems through to individuals) who have the capacity to bring community and health service networks together. Participation in an integrated approach by both these

networks contributes different, but equally essential skills and meets different, but equally essential needs that many of us will seek when we are dying. Linking assets support a sustainable and accessible model for palliative and end-of-life care service delivery that enhances end-of-life care options (choice) through collective social capital³⁸.

Developing a public health palliative care framework from grounded practice

To apply a public health palliative care approach where public health (rather than palliative care) provides the central methodological framework, the La Trobe University Public Health Palliative Care Unit obtained funding to implement a series of projects that frame the provision of palliative and end-of-life care (matters concerning caring, dying, death and bereavement) through evidence-based public health constructs. Collectively, these projects form the basis of a funded nationwide public health palliative care approach.

An overview of the Public Health Palliative Care Framework is provided in Fig. 2. This illustrates how this practice and research-based methodology might contribute to a broader national public health palliative care strategy that articulates with, and is informed by, grounded practice. General research questions arising from the initiatives include; what contribution can various sectors, settings, jurisdictions or

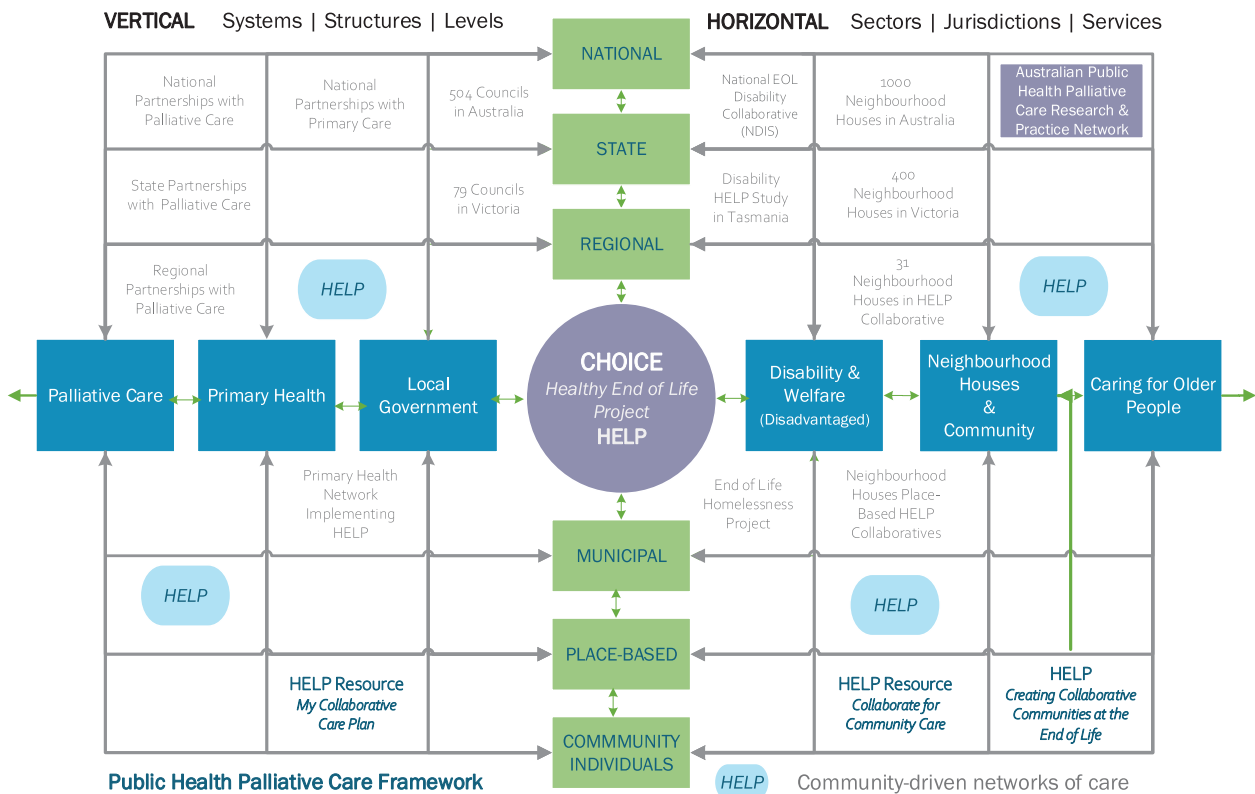


Figure 2 Public health palliative care framework

communities make towards improving the end-of-life care outcomes of those with whom they intersect?; what are the evidence-based strategies that successfully facilitate engagement and sustainable reorientation?; and what changes emerge when public health palliative care initiatives are implemented in these diverse settings?

NB: The sectors, settings or jurisdictions illustrated in this framework can be expanded or adapted depending on context.

The framework reflects an approach that concurrently operates from national through to local level. The framework is of course specific to Australia: other nations allocate these responsibilities in different ways. In general, however, the strategy reflects the advocacy principles of public health approaches. It articulates local practice wisdom gathered from settings, communities and citizens into systems and policies in ways that ensure those who are most impacted by systems have opportunities to influence them. For use by capacity builders, system influencers and advocates, the framework's strategies focus on assessing and mapping deficiencies in systems, building capacity and capability where it is absent or insufficient and advocating for disadvantaged, vulnerable and underserved citizens to redress inequity. These strategies, further enhanced by engaging diverse stakeholders, facilitate systems and public health networking^{39,40} that links systems and can reorient existing resources and networks of care in innovative and novel ways.

Public health palliative care implementation and research projects

The projects initiated as part of this programme are in various phases of development (Table 1). Partners with whom our relationships are well-established have produced reports, publications and resources. Those in the earlier phases of engagement of mapping are yet to produce such materials. Funding for the ongoing development of this work continues until 2023 but plans to extend beyond this timeframe are in place.

While described here as discrete projects (Table 1), the populations we intentionally target through this framework engage across multiple sectors. For example, people living with disability, older people and disadvantaged citizens are all supported by local government, neighbourhood houses, disability, welfare, aged care and primary health sectors. In contrast with the shortcomings of typically siloed efforts, this demonstrates in practice how outcomes can be potentiated through a public health system networking approach^{39,40}, as depicted in Fig. 2.

Public health palliative care methodology

Evidence-based public health principles, theories and methods informed the iterative development of the public health palliative care framework (Fig. 2). Strategic public health principles common to all projects include but are not limited to: espousing an asset-based and solution-focused framework to promote civic participation; adopting partnership and leadership building strategies to promote sustainable change; collaborating to leverage collective outcomes; and advocating for and developing policies and strategies that include disadvantaged and underserved citizens. Systems insights and strategies are used to redress circumstances where initiatives at one level risk negative consequences at another level, and to ensure that initiatives and programmes at the various levels together maintain a creative tension between top-down and bottom-up approaches²¹.

We initiated work with different sectors and settings where end of life is not considered as relevant or core practice. We looked at the sector's strengths (asset-mapping), invited partners and leaders to reflect on how their existing policies and activities might be broadened to include death, dying or bereavement support (reorientation) and identified where it might also be included in their organisational structures and in their external networks. This process formed the basis of a partnership scheme and/or a funding proposal to resource collaborative implementation and research over several years. The goal is to build capacity to enhance end-of-life care outcomes for citizens by mobilising resources that support them in their everyday lives.

In working with palliative care services, we clarified and affirmed the distinctive and valuable role that health services have in public health approaches. Two key contributions were identified. Firstly, health professionals can actively support patients and carers to identify, unlock and draw upon their personal networks of care to complement and sustain service delivery in their preferred setting. Secondly, they can map and strategically target marginalised populations in their catchment area who are not accessing palliative care services. Both these strategies are suitable, appropriate and feasible deliverables for health and palliative care services to make a valuable contribution to public health palliative care approaches.

Providing palliative and end-of-life care whenever possible in citizens' preferred settings is a primary policy goal in Australia^{17,25,26}. Linking this new capacity built in public health settings (as described in healthy settings approach³⁰ including councils and cities, disability and welfare services, homes, ageing, schools, workplaces, communities and civic institutions) with health and palliative care services

Table 1 Public health palliative care practice and research projects

Project	Description
Victorian Councils: Supporting Communities around End of Life Project	A project in partnership with the Municipal Association of Victoria ⁴¹ that builds organisational capability of councils to incorporate end of life into local government policy, planning and municipal practice with community. Three demonstration projects were funded to inform a state-wide council approach to support their residents on matters concerning caring, dying, death and bereavement. La Trobe University Public Health Palliative Care Unit hold the funds, support implementation and are evaluating the project ⁴² .
Disability Healthy End of Life Program (HELP) ⁴³	A research and practice project in partnership with Li-Ve Tasmania ⁴⁴ , and the University of Tasmania (UTAS) to build disability sector capacity and leadership in the social dimensions of end-of-life policy, planning and practice for the people they support and their families. La Trobe University Public Health Palliative Care Unit ⁴⁵ in partnership with Li-Ve Tas and UTAS support implementation and are evaluating the broader translation of the model across the disability sector.
Healthy End of Life Project (HELP) ³⁶	A participatory research project to develop and implement an evidence-based and practice-informed health promotion and community development framework to support community-driven action on local end-of-life matters. The HELP framework guides strategy and practice for communities to lead in supporting one another to remain close to people, places and possessions during times of illness, caring, dying, death and bereavement ^{46,47} .
Community Houses Association of the Outer East (CHAOS) Be the Ripple Project HELP Framework	A capacity building project in partnership with the Neighbourhood House sector, through the Community Houses Association of the Outer Eastern Suburbs (CHAOS) Network in Melbourne's eastern suburbs. Six pilot Neighbourhood Houses are using the HELP Framework's asset-based community development approach to improve home and community-based end-of-life care coupled with a targeted strategy to support socially isolated people ⁴² . Neighbourhood Houses Community Houses Association of the Outer Eastern Suburbs (CHAOS) https://chaos000.com/
Murrumbidgee Primary Health Network (MPHN)	A partnership project with MPHN in New South Wales ⁴⁸ , to build capacity in townships through state-based Local Health Advisory Committees to adopt a public health approach to caring, dying, death, bereavement. Implementing the HELP Framework ⁴⁶ through a workshop series, anticipated outcomes include, participants are more likely to offer, accept and provide help; to develop individual support plans that mobilise personal care networks, and map and enhance access to local community assets, supports and services.
Palliative Care Sector Partners	A partnership with peak body Palliative Care Australia ^{42,49} to integrate public health principles into palliative care strategy, policy and planning. Initiatives with palliative care services build capability in public health approaches through the HELP Framework to facilitate the creation of linkages between formal palliative care services and informal community caring networks to advance an integrated public health palliative care approach.
Welfare sector	This initiative intends to engage with the welfare sector to integrate public health palliative care principles into existing practices that support structurally vulnerable people experiencing poverty, homelessness and social exclusion by building end-of-life capability of outreach support workers and case managers.
Aged Care	This initiative builds capacity and leadership in sectors, settings and community organisations that older Australians connect with and utilise in their everyday lives, including home and community support services currently available to older people. A partnership with aged-care services is underway.

provides a strategy to achieve this. New partnerships at national, state, regional and local levels provide an opportunity to support systemic approaches and to identify 'linking assets' that can connect community networks of care with health sector networks of care. Linking assets can facilitate a place-based, systematic approach to building multi-level and multi-faceted palliative and end-of-life care for citizens.

In summary, the key public health palliative care methodology used in our projects involves:

- (1) identifying and building sustainable new leadership in public health and community settings where engagement with dying, death and bereavement is absent or underdeveloped
- (2) supporting palliative care services to contribute to public health outcomes by encouraging their patients to enhance their social care networks whilst receiving clinical services and by developing strategies targeted at engaging underserved populations identified within their catchment area
- (3) linking the new capacity developed in public health, social and community settings with health and

palliative care services (1 and 2) to enhance the provision of palliative and end-of-life care in the settings and locations preferred by citizens.

Developing an integrated public health palliative care approach through implementing these three steps offers a new strategy that responds to the emerging challenge of an ageing and dying population with diverse needs and preferences²⁰.

Discussion

There are untapped national, state, regional and local assets with the potential to make valuable contributions to improving end-of-life care outcomes for Australians. The public health palliative care framework outlined in this paper locates these assets in an organised structure that acknowledges, coordinates, maps and enhances their combined contribution and impacts. Using public health frameworks and methods, assets at various levels in systems and across sectors are being reoriented through specific projects so that their potential to support citizens 'in place' during periods of caring, ageing, illness, dying and grieving is being realised.

An asset-based approach aims to build capacity and leadership by harnessing the existing strengths, resourcefulness and networks of sectors and communities to support citizens, including those who are disadvantaged, to remain connected to their preferred place, people and possessions at the end of their lives. This newly developed capacity supplements and strengthens the services delivered by health and palliative care in settings where people reside, recognising that both formal and informal support are required for optimal quality end-of-life care. However, targeted strategies to identify and mobilise existing resources that can explicitly link health and community networks of care in a systemic and sustainable way is required if palliative care is to flourish and citizens are to be provided with enhanced end-of-life care options. The linking of formal and informal care networks serves both to reduce the current challenges of delivering palliative care in settings with inadequate support and increasing choice for people at the end of their lives.

Central themes emerge through collective review of our various public health palliative care projects. Sustainable change is achieved by using evidence-based public health principles and methods, alongside an assets-based partnership and capacity building approach. Uptake is enhanced through solution-focused methods that reduce or remove barriers to sector engagement and by re-framing existing systems, structures and networks to incorporate end-of-life policy and practice. A culture of collaboration within and between sectors and settings that values diverse expertise creates an inclusive framework for

all participants. These approaches combined are essential to the successful outcomes of the framework.

Mobilising the contributions of professionals in public health settings combined with the social support offered by communities in end-of-life^{50,51} and bereavement care⁵² increases the collective capacity (social capital) available to those living through the experiences of caring, dying and grieving. Collective resources are therefore used in more intentional and efficient ways, and evidence is generated to inform the proposed national public health palliative care implementation framework outlined in this paper.

Conclusion

A strengthened public health approach to palliative and end-of-life care has the potential to elucidate the direct relationship between our social circumstances and the quality of our end of life and uncover the implications of structural inequity for end-of-life choice. The approach reorients systems and settings to achieve accessible and equitable palliative and end-of-life care for all, and identifies contributions that all jurisdictions, settings, organisations, sectors and communities can make to improving end-of-life care outcomes.

Concurrent and ongoing initiatives across settings and jurisdictions can contribute to the development of a public health palliative care multi-sector and citizen (civic)-driven framework. In the projects using this approach we've developed capacity across a range of sectors to engage with dying, death and bereavement in their respective settings. The experience of working with these diverse settings provides the opportunity to draw central conclusions and learnings with general applicability for other nations.

Our framework offers a strategy incorporating both public health aspirations that end-of-life care should be the responsibility of everyone, and palliative care policy ambitions to provide equitable access to end-of-life care for all citizens. Translating these vision statements into an evidence and practice-based framework advances the agenda of an integrated public health palliative care approach.

The next step is to develop a reporting system that measures and monitors the impact of the emerging and expanding field of public health palliative care outlined in this framework⁵³.

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References

- WHO. Constitution of WHO: principles. 1948 [cited 2017 15 Dec]. Available from: <http://www.who.int/about/mission/en/>.
- Williamson DL, Carr J. Health as a resource for everyday life: advancing the conceptualization. *Crit Publ Heal* 2009;19(1): 107–122.
- WHO. Ottawa charter for health promotion; 1986 [cited 2017 10 July]. Available from: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>.
- Marmot MG, Bell RG. Improving health: social determinants and personal choice. *Am J Prev Med* 2011;40(1):S73–S77.
- Wilkinson R, Marmot MG, H. World Health Organization. Centre for Urban. The solid facts: social determinants of health. 2nd ed. Social determinants of health: the solid facts. Copenhagen: Centre for Urban Health, World Health Organization; 2003.
- World Health Organisation. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. 2008.
- Marmot M. The health gap: improving health in an unequal world. London: Bloomsbury; 2015.
- Neergaard M, Brunoe AH, Skorstengaard MH, Nielsen MK. What socio-economic factors determine place of death for people with life-limiting illness? A systematic review and appraisal of methodological rigour. *Palliat Med* 2019;33:900–925.
- Lewis J, DiGiacomo M, Currow DC. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. *J Pain Symptom Manag* 2011;42(July): 105–118.
- Braveman P, Egerter S, Williams DR. The social determinants of health: coming of age. *Ann Rev Publ Heal* 2011;32:381–398.
- Wilkinson R, Pickett K. The spirit level: why more equal societies almost always do better. London: Allen Lane; 2009. (Penguin).
- Quesada J, Hart LK, Bourgois P. Structural vulnerability and health: Latino migrant laborers in the United States. *Med Anthropol* 2011;30(4):339–362.
- Stienstra D, Chochinov HM. Vulnerability, disability, and palliative end-of-life care. *J Palliat Care* 2006;22(3):166–174.
- Stienstra D, Chochinov HM. Palliative care for vulnerable populations. *Palliat Support Care* 2012;10(1):37–42.
- Reimer-Kirkham S, Stajduhar K, Pauly B, Giesbrecht M, Mollison A, McNeil R, et al. Death is a social justice issue: perspectives on equity-informed palliative care. *Adv Nurs Sci* 2016;39(4):293–307.
- National consensus statement: essential elements for safe and high-quality end-of-life care. Sydney: Australian Commission on Safety and Quality in Healthcare; 2015.
- National Palliative Care Strategy. D.o. Health, Editor. Canberra: Australian Government; 2018.
- Approaching death—improving care at the end of life: committee on care at the end of life, institute of medicine, division of health care services Marilyn J. Field and Christine K. Cassell, editors 1997, National Academy Press, Washington, D.C., 437 pages, hard cover, \$34.95. *Geriatric Nursing*, 1998. 19(6): p. 344–345.
- Meier EA, Gallegos JV, Thomas LP, Depp CA, Irwin SA, Jeste DV. Defining a good death (successful dying): literature review and a call for research and public dialogue. *Am J Geriatr Psych* 2016;24(4):261–271.
- Swerissen H, Duckett S. Dying well. Melbourne, Australia: Grattan Institute; 2014.
- Crisp BR, Swerissen H, Duckett SJ. Four approaches to capacity building in health: consequences for measurement and accountability. *Health Promot Int* 2000;15(2):99–107.
- Kellehear A. Health-promoting palliative care: developing a social model for practice. *Mortality* 1999;4(1):75–82.
- Kellehear A. Compassionate cities: public health and end-of-life care. London: Routledge; 2005.
- Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM Int J Med* 2013;106(12): 1071–1075.
- Victorian Government, Victoria's end of life and palliative care framework. Department of Health and Human Services, Editor. Melbourne, Victoria, Australia: Victorian Government; 2016.
- Australia P.C. Palliative care 2030 – working towards the future of quality palliative care for all. Canberra: Palliative Care Australia; 2018.
- World Health Organisation. WHO statement on palliative care. WHO statement on palliative care. [cited 2019 28 Oct]. Available from: <https://www.who.int/palliativecare/en/>.
- Whitelaw S, Clark D. Palliative care and public health: an asymmetrical relationship? *Palliat Care Res Treat* 2019;12: 117822421881974.
- Sallnow L, Paul S. Understanding community engagement in end-of-life care: developing conceptual clarity. *Crit Publ Heal* 2015;25:231–238.
- WHO. Introduction to healthy settings; 1980 [cited 2017 14 Mar]. Available from: http://www.who.int/healthy_settings/about/en/.
- Mathie A, Cunningham G. From clients to citizens: asset-based community development as a strategy for community-driven development. *Dev Pract* 2003;13(5):474–486.
- DeFilippis J. Community development. S. Saegert and L. Ebook, editors. 2nd ed. Hoboken: Taylor and Francis; 2013.
- Kellehear A. Health promoting palliative care. Melbourne: Oxford University Press; 1999.
- Wegleitner, K., K. Heimerl, and A. Kellehear. Compassionate communities. Case studies from Britain and Europe; 2015.
- Abel J, Bowra J, Walter T, Howarth G. Compassionate community networks: supporting home dying. *BMJ Support Palliat Care* 2011;1(2):129–133.
- Grindrod A, Rumbold B. Healthy end of life project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. *Ann Palliat Med* 2018;7(Suppl 2):S73–S83.
- Lloyd-Williams M. Psychosocial issues in palliative care: a community based approach for life limiting illness. 3rd ed. Oxford, England: Oxford University Press; 2018.
- Sallnow L. Collective social capital: a study of new public health and end-of-life care. Edinburgh, United Kingdom: The University of Edinburgh; 2018.
- Wholey DR, Gregg W, Moscovice I. Public health systems: a social networks perspective. *Heal Serv Res* 2009;44(5p2): 1842–1862.
- Varda MD, Chandra A, Stern SA, Lurie N. Core dimensions of connectivity in public health collaboratives. *J Public Heal Manag Pract* 2008;14(5):E1–E7.
- Municipal Association of Victoria End-of-life Project [cited 2019 28 October]. Available from: <https://www.mav.asn.au/what-we-do/policy-advocacy/social-community/positive-ageing/end-of-life-project>.
- La Trobe University Public Health Palliative Care Unit: Research [cited 2019 28 October]. Available from: <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research>.
- Grindrod A, Rumbold B. Providing end-of-life care in disability community living services: an organizational capacity-building model using a public health approach. *J Appl Res Intell Disabil* 2017;30(6):1125–1137.
- Li-Ve Tasmania End-of-life Project [cited 2019 28 Oct]. Available from: <https://livetasmantia.org/end-of-life>.
- La Trobe University Public Health Palliative Care Unit: Disability HELP [cited 2019 28 Oct]. Available from: <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research/disability-healthy-end-of-life-program>.
- La Trobe University Public Health Palliative Care Unit: Healthy End of Life Project [cited 2019 28 Oct]. Available from: <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research/help>.
- HELP Ottawa. Available from: <https://compassionateottawa.ca/help-ottawa/>.
- Murrumbidgee Primary Health Network Palliative Care [cited 2019 28 Oct]. Available from: <https://mphn.org.au/palliative-care>.
- Available from: <https://palliativecare.org.au/>.
- Horsfall D, Noonan K, Leonard R. Bringing our dying home: how caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociol Rev* 2012;21(4):373–382.
- Rosenberg JP, Horsfall D, Leonard R, Noonan K. Informal caring networks for people at end of life: building social capital in Australian communities. *Health Sociol Rev* 2015;24(1):29–37.
- Rumbold B, Aoun S. An assets-based approach to bereavement care. *Bereavement Care* 2015;34(3):99–102.
- Public Health Palliative Care Quality End of Life Indicators. Available from: <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research/publications>.