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Editorial

Putting the ‘public’ into public health: community engagement in palliative and end of life care

John P. Rosenberg¹, Jason Mills², Bruce Rumbold³

¹Queensland University of Technology, Brisbane, Australia, ²University of Sydney, Sydney Australia, ³La Trobe University, Melbourne, Australia

This special issue on public health weaves together two threads introduced in previous editions of Progress in Palliative Care. In 2003, former Editor-in-Chief Emeritus Professor Ian Maddocks outlined a vision for what he called ‘the caring community’. This vision extended beyond ‘the bedside of the dying patient’ to encompass social networks, diversity, responsibility, and participation; it was, according to Maddocks, a vision ‘likely to bring health and healing to all its participants’.¹ In a 2007 editorial, Sheila Payne highlighted the recognition of palliative care as a global public health issue and, through a more specialist ‘clinical vision of end of life’, touched on the practical, ethical, clinical, and research issues that might arise when approaching palliative care from a public health perspective.² These two articles illustrate both the breadth and the ambiguity of public health frameworks. Maddocks sees health as the responsibility of the whole community, whilst Payne talks of health as an outcome of improved health services. In this collection of articles we have sought to further the dialogue between these two perspectives, focusing on community engagement expressed through partnerships that bridge the gap between palliative care services and the broader public.

Despite recent increases in the promotion and application of public health approaches to palliative and end of life care, the ‘business’ of dying remains largely in the hands of the health professions. This professionalisation of dying is well reported, and with it comes the privileging of professionals’ knowledge about how to provide care for people with life-limiting illnesses who are nearing the end of their lives. Health services – including palliative care services – are assumed to be the most suitable custodians of the business of dying.

Why is this a source of concern? One reason is pragmatic – as a society we cannot afford the costs of providing care in this way. A far more important reason is that so-called ‘informal care’, the care provided by friends and neighbours and families, differs from the ‘formal’ care of professionals, and cannot be replaced by professional care. Informal care is not a low-budget substitute for formal care, but the primary care we need to live through our dying. We need the support and regard of people who know us and love us, who can remind of us what we have been and what we have contributed, and who will support us into an unknown future. Formal care is of course vitally important to us particularly in this era of chronic and debilitating illness, but professional caregivers do not share the intimate knowledge that underpins the support of family and friends, nor do they have the time to be companions. They may be welcome visitors along the road, but they cannot share the journey in the way that our family and our friends share it.

Good care at the end of life requires active and respectful collaboration between networks of formal and informal caregivers. The greatest barrier to collaboration can be formal caregivers’ inability to appreciate the complementary contribution of informal care, or to perceive how informal care may be disrupted by the programmatic approaches of formal services. In studies of networks that have supported a friend dying at home Horsfall and colleagues³ identified the dilemma that formal care is needed, but may disrupt the care already in place because of the way that formal contribution is managed. In a subsequent study,⁴ this assumed right of formal carers was starkly illustrated by one health professional’s suggestion that it is entirely appropriate to screen community members of informal care networks, such as

Correspondence to: John P. Rosenberg Queensland University of Technology, Kelvin Grove, Queensland, Australia.
Email: jp.rosenberg@qut.edu.au

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neighbours, as ‘Mary next door could be an axe murderer’. While perhaps embellishing in order to make a point, the respondent demonstrates a profound paternalism in her assumption that services have the right to select the members of the dying person’s support network.

It is important to consider the differing understandings of public health. Behind them lie a range of ideas about the role of the public or the community. In some approaches, members of the public have an active role in creating health, collaborating with fellow citizens and a diverse range of professional practitioners in designing healthy settings and programs. In other approaches, the public is more a funder and recipient of services, deferring to the expertise of professionals who provide what they believe the public, the community, needs. Public health approaches seek to intentionally create constructive partnerships between formal and informal care at policy, research, and practice levels. In this edition, we have brought together a range of international viewpoints. In discussing palliative care in Kenya, Ali explores how the integration of public health approaches at the systems level changes policy and practices. Using an example from the UK, Hartley provides a reconceptualisation of ‘community’ that considers health professionals as members of, not simply partners with, communities. Innovative practice examples are provided by McLoughlin and colleagues (Ireland), Mills and Mills (Australia), and Lindqvist and Tishelman (Sweden). Sallnow and colleagues across Europe examine the possibilities for further research as a driver of change. Finally, from Australasia, Noonan and her colleagues explore the emerging concept of death literacy, providing a view of community engagement in palliative and end of life care where formal and informal caregivers alike are skilled and knowledgeable in complementary ways to support those requiring care. These are not imprecise or even elusive strategies; they are concrete steps towards partnerships with communities that can improve the quality of care given to people near the end of life – whilst recognising and enhancing the capacity of the community to engage in support of dying people.

Herein lies the greatest challenge for public health approaches to palliative care. Any refashioning of palliative care services requires a paradigmatic shift evident in the work already done since Kellehear’s seminal introduction of Health promoting palliative care in 1999. A public health approach to palliative care demands a challenging cultural change within services not only to engage with communities as the possessors of expert knowledge, but also to recognise the need to share this knowledge – and the power it brings – in partnership with communities. In a helpful conceptual analysis of community engagement Sallnow and Paul identify a spectrum of activity that may be designated ‘community engagement’. This ranges from engagement that consists of palliative care services informing and consulting their community, through co-production to engagement characterised by collaboration and empowerment where services respond to and are shaped by community input. A great deal of the activity reported by mainstream palliative care providers as ‘community engagement’ falls at the ‘inform and consult’ end of the spectrum: that is, it is essentially social marketing of the service. Members of the public are invited to support the providers’ work and to avail themselves of it when their needs meet the criteria for admission to the providers’ programs. The projects and activities described in this edition of the journal are however directed more toward the co-design of end of life strategies.

Collaboration and co-design require renegotiating the relationships between professional services and community networks. Sharing care involves sharing power, so that professional services need to be aware both of the limits to their contributions and the need to build and support community capacity in end of life care to complement their work. A ‘circles of care’ model outlines the scope of this enterprise, although implementing it raises a raft of issues around professional power and accountability in care. A particular hurdle is the constraints imposed by risk management policies that have caused many services to turn their community partners into volunteers, and manage them such that their capacity to contribute as informal caregivers is severely compromised. They become a supervised extension of formal services. We need instead to see our community partners as assets in their own right, people whose contribution as informal caregivers should be respected, encouraged, and supported. Services must understand that, even without their efforts, many communities already possess the ‘knowledge and skills that make it possible to gain access to, understand, and act upon end of life and death care options’ – the new definition of death literacy mentioned above. Rather than presenting an alternative to the partnerships presented by a public health approach, death literacy acknowledges and endorses the existing capacities of communities and provides a complementary view of the landscape within which end of life care and dying takes place. It includes, but is not constrained to, professional health care services.

Partnerships must be carefully considered to ensure that outcomes include both ‘downstream’ and ‘upstream’ aspects. Engagement with communities should not be contingent on disease or a palliative diagnosis; the reach of health promoting palliative care must extend beyond the clinical domain. A
study by Mills, Rosenberg and McInerney\textsuperscript{9} concluded that, whilst there are communities with the capacity to respond to end of life concerns, their activities are often reserved only for ‘patients’ with a particular clinical diagnosis. Health promoting activities that precede diagnoses of disease and palliation are a priority for community engagement strategies. In the same way that collaborative partnerships must share power and responsibility, they must also give priority to engagement developed for and accessible by the whole of the community to further build its capacity.

Sallnow and colleagues\textsuperscript{10} identify, as indicators of community capacity, changes in social capital, influencing professional practice, developing community activists, and embedding sustainable change. The projects reported upon here contain evidence of these first two factors. Social capital, expressed through forming new relationships and deepening existing relationships, is a solid outcome of public health approaches. Staff members of palliative care services, and not just those directly involved in public health projects, have been drawn into participating or at least witnessing the partnership activities undertaken. The latter two factors listed by Sallnow and colleagues are indicators of the impact of public health approaches. Rather than being direct or immediate outcomes of public health initiatives they arise from the social diffusion of insights and experiences that have been developed in participants and transmitted through conversation, action and example. If there was one activity we would urge upon colleagues involved in public health initiatives in palliative and end of life care, it would be to invest in impact evaluation, to take the additional time and effort to demonstrate that changes brought about through public health action are sustainable and effective over the longer term. Unless this evidence is provided to funding bodies and policy-makers, putting the ‘public’ into public health may remain an array of short-term, project-based activities at the edges of clinical care, rather than the long-term commitment that is needed to embed public health approaches at the core of palliative care activity. It is our hope that through the examples found within this special issue, growing inspiration and activity will garner increased evidence.

We thank each of the authors for their valuable contribution to this work, with special thanks to Allan Kellehear, the founding president of the International Public Health and Palliative Care network, for concluding it with his commentary on ‘the progress so far’. Through ongoing scholarly work, initiatives in policy and practice, and with the establishment of Public Health Palliative Care International (http://www.phpci.info) those engaged in these approaches will be well-positioned to further consider achievements and challenges at the 5th International Conference on Public Health and Palliative Care in Ottawa, Canada in 2017.

ORCID
John P. Rosenberg DOI: http://orcid.org/0000-0003-2624-1083

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