

PROCESS AND SYSTEMS

Access to palliative care reimaged

Authors: Julian Abel,^A Allan Kellehear,^B Jason Mills^C and Manjula Patel^D

ABSTRACT

Access to palliative care is commonly considered as solely a health services challenge rather than a community challenge. Successive healthcare reports continue to pose the question of access and its solution in terms that ask what a service can do rather than what an ally a service can become. However, the question is not what can we do for disadvantaged communities, but rather, what can we do together with them as fellow providers of palliative care. The first part of this article reviews the most common recommendations offered for increasing access to palliative care. The second part advocates an alternative way to address this challenge by employing the key practice methods of a new public health / health promotion approach to palliative care.

KEYWORDS: access, social inequality, diversity, health promotion, social justice

DOI: 10.7861/fhj.2021-0040

Introduction

Hospice and palliative care have come a long way since its medieval and Catholic origins serving the dying poor and pilgrims. Since the 1960s with the pioneering work of Cicely Saunders, palliative care has developed into a full medical and healthcare (multidisciplinary) specialism that not only focuses its expertise on symptom management of life-limiting illnesses but also in the holistic provisions of comfort and supports in psychological, social and spiritual care at the end of life. There are now extensive national networks of palliative care services providing both inpatient, outpatient and home care services variably across the UK.

However, palliative care is much more than control of physical, social, psychological or spiritual symptoms. Death, dying, loss and caregiving are events that occur in a community context, with each family and each community having their own meanings and social, understandings of these experiences. The challenge for palliative care services has always been to discover how to support these differing contexts rather than merely meeting clinical needs

that require support. To meet these broader needs, health and social care services need to specifically pay attention to the issue of palliative care access.

Yet access to palliative care remains a steady criticism and challenge dogging these services: the over-attention to cancer patients at the detriment of those living with other life-limiting disease groups; the lack of palliative care in rural and remote areas; and the lack of coordination of palliative care with aged care, intensive care or even bereavement care. On top of these service-specific criticisms exist further challenges that amount to neglect of certain social groups: ethnic, racial, religious and sexual minorities.

Commonly, the challenges of access to palliative care are viewed solely as a professional service delivery matter. This is an important, even dominant, viewpoint that is rarely assessed. Reimagined away from this perspective, access problems do not lie with communities' ability to *reach* a service, but with a failure of professional services to effectively *reach out* to communities of interest and partner with them, drawing on existing forms of community care. And by 'community' we are referring to the roles of citizens within workplaces, schools, faith groups, local government services and neighbourhoods as well as cultural and artistic groups in galleries, museums and sporting associations among others. Each of the people inside these groups experience serious illness, ageing, slow and sudden deaths, long-term caring responsibilities, and grief and loss; so, are well placed (even best placed) to provide timely support and continuity of care at the end of life. Each of these civic contexts are potentially able to develop end-of-life policies, educational experiences and practical actions with respect to their workers, students, parishioners, rate payers, neighbours or audiences.

In order to support this argument, we will commence with a brief review of some of the key reports that have attempted to address the challenge of accessing palliative care services. We will then evaluate their suggestions employing public health criteria that emphasise community development and engagement; strategies proven to have far greater success addressing these problems.¹ We then pose alternative suggestions for future practice and consideration.

A community-centred approach to health and wellbeing is recommended by Public Health England as a partnership of healthcare services, local authorities and voluntary sector community groups working together to support individual and community health.² We might then usefully ask: 'What approach has been commonly employed to increase access and participation in the field of palliative care?'

Authors: ^Adirector, Compassionate Communities UK, Helston, UK; ^Bclinical professor, College of Nursing and Health Sciences, Burlington, USA; ^Cadjunct senior research fellow, University of the Sunshine Coast, Sippy Downs, Australia; ^Ddoctoral student, University of Warwick, Warwick, UK

Past approaches to promote access to palliative care

The barriers to accessing palliative care services are very well known and the policy reports describing them just keep coming. This tradition of research rehashes the same conclusions and repeats the same recommendations for racial and ethnic minorities, indigenous populations, LGBTQ+ populations, prison populations and the homeless, to name only a few disadvantaged groups.

The problem of access to palliative care is commonly discussed in terms of addressing an unmet need; differential or complex access; deliberate or inadvertent differential provision; under-provision of services; narrowly defined services (viewing palliative care as only a 'clinical' service, for example); or cultural belief or distance barriers of potential users to an existing service. Although it is true that a service looking to improve its performance will examine what resources lie within the remit of that service (differential or under-provision) or recipient challenges (unmet need or cultural and linguistic barriers), the self-defeating problem for palliative care is in employing restrictive understandings about what is already being done in existing populations of interest, and in acknowledging that solely clinical definitions of access may themselves be contributing to the problem.

Inside common lists of 'barriers' identified by palliative care services there remains a lack of recognition that it is not just palliative care services that care for the dying and the bereaved.¹ Much care for the dying and the bereaved is *already* being done by and in communities, and by other health services.² Little observation and less assessment are made exploring how much a professional services approach that focuses solely on their own active clinical provision itself might contribute towards the very barriers so identified and discussed.

Past examples

Marie Curie UK have published several excellent reports attempting to address the problem of access to palliative care services especially, but not exclusively, among ethnically and sexually diverse communities.^{3,4} Their recommendations had mirrored the earlier policy reports by the Race Equality Foundation, The National Council for Palliative Care and the Cicely Saunders Institute, while supporting the more recent NHS quality report and a major report by London School of Economics and Political Science (LSE) academics.⁵⁻⁹

All of these reports strongly recommend greater staff training and awareness raising; the promotion or implementation of translating and interpreter services; greater consultation or involvement from the disadvantaged group; greater equity of actual provision; and improving communication, marketing and, more generally, the problem of under-provision. The LSE report even went so far as suggesting (rather uniquely among this genre of reports) that 'non-clinical palliative care' provision should be improved. Rather disappointingly, however, this referred to better use of social care staff and not improved partnership-working with actual communities or civic organisations.

Although these papers and reports seem determined to address the access challenges, most of them theorise from a traditional direct-service provision model of public health. Orlovic and colleagues are emblematic of this approach.¹⁰ Their list includes recommendations for expanding insurance coverage; incentivising access; improving marketing of end-of-life options; improving

communication to the disadvantaged groups; wider and improved diversity training for end-of-life care professionals; and specific targeting of 'patient' populations.

Over the last 15 years or so, the most popular policy suggestions for overcoming the access challenges in palliative care (by recurring theme) appear to be:

1. more diversity training for staff
2. improve existing knowledge of group-specific health beliefs/behaviours
3. promote the group to the palliative care field and the importance of those services to them
4. ensure our palliative care literature represents/includes these groups
5. publicise examples of excellence to the groups in question
6. work more with these groups to learn about their needs
7. explore the issues relevant to these groups
8. build 'awareness'
9. promote the service within these communities
10. create diversity-specific services
11. offer translation and interpreting services
12. promote more staff diversity
13. more research should be done (for whom?).

What is the problem here?

In the above 13 recurring recommendations, we observe a pattern of proposals with three distinct features. These features describe the solutions to increasing access to palliative care.

- > Supplying additional services (recommendations 10 and 11).
- > Improving social marketing (recommendations 5, 8 and 9).
- > Increasing professional development within the service (recommendations 1, 2, 3, 4, 7, 12 and 13).

Note the direction of travel within the pattern of recommendations. Seven of the recommendations about increasing access refer to further developing of the service itself and not the community wherein the challenge has been identified. Three of the recommendations are based on the assumption that, if particular communities are not using the service, it is incumbent upon that service to 'speak louder'. Maybe those communities have not noticed the service. Maybe they are afraid, ignorant or uninformed. Therefore, maybe the barrier is not a 'real' barrier at all, but rather a marketing problem.

Only two of the most common recommendations demand that services actually do more for the communities of concern. However, even one of these two recommendations does not demand a change to the way the service is offered, but rather ensuring that the existing services are better understood; translating and interpreting them more effectively. This last recommendation is designed for cultural and linguistic diversity and not for most of the other groups who face geographic or other social barriers. It is a specialised recommendation for one group alone, but it recurs in this list of common solutions because, so often, barriers to service are viewed in terms of culturally or linguistically diverse populations.

Ironically, we can see that the overwhelming professional response to problems identified in particular communities is to improve things for the service. Only one single recommendation does not fit within the three self-referential themes. Recommendation 6 is the suggestion, repeatedly made, that

services should 'work more with these groups to learn about their needs'. Needs are identified as community deficits that need to be filled by professional services. No mention is made of the strengths and assets of communities.

Often, the suggestion to engage more with groups is a call for greater engagement with the communities who face the barriers. However, although concerns about access are expressed in terms of engagement, it is *not* mere engagement of community (of persons and resources) that is important in itself, rather, it is membership, composition and inclusion that are the game changers. For without visible representation, non-members can too easily assume that these services are for other people, that is, not for them. The work of Mary Lou Kelley in Canada working alongside remote indigenous populations and the work of Suresh Kumar in the development of Neighbourhood Networks in impoverished Indian populations are two clear international examples where mobilising interest in self-provision of palliative care has materialised into successful innovative examples of community provision.^{11,12} Both of these examples employ a partnership approach that recognises and promotes autonomy rather than viewing particular communities solely as recipients.

Engagement is a necessary but not a sufficient condition to address barriers to access unless community engagement is a democratic process.¹³ The community itself must become part of the palliative care offer/provision to help regulate and mediate its own internal differences and services. This is recognised in the current national palliative care policy document, the *Ambitions for palliative and end of life care* report.¹⁴ Ambition six explicitly states that each community must be prepared to help and this means not merely volunteering but rather recognising that 'everyone' (every citizen) has a role to play. Unless community engagement evolves into community development and self-provision (changing the power dynamics), the health service might seem like a foreign or distant set of helping hands.

For communities to develop, it is important to recognise that this is *not* about patients coming 'in' to a service but rather:

- > staff going 'out' (*joining* communities)
- > seeing communities as primarily *places of strength, and with valuable assets, rather than places of deficiency* that need services; recognising the positive role that communities can play is the foundation of the context in which palliative care is practised
- > communities not merely receiving but also *providing* the services
- > viewing the human resource challenges for the service not merely in terms of occupational profiles but rather *mutual participation*; in the very core of providing the service.

Aside from the self-referential character of common recommendations, the second problem with this list, therefore, is that the useful desire to work with others is frequently unaccompanied by a clear plan of social action. Social and cultural engagement, unless reciprocated by one's partners, will not produce partnerships that are sustainable. Cooperation is not community development because, unless communities literally 'own' their tasks and responsibilities, they may view their new roles as recipients of new-found attention.

Public health, community development and palliative care

A requirement of a public health approach to palliative care, with community development as its main driver, is leadership from a

service that fosters civic facilitation and not solely the proffering of professional services. Palliative care, like healthcare in general, is not *all* about what services can and should be delivered to populations viewed as passive recipients. Healthcare is everyone's responsibility, such as those who design and build cars, employers with safeguarding responsibilities, restaurant owners who must follow health and safety guidelines, and primary care services in dentistry, pharmacy and general practice.

In this public health framework, palliative care is everyone's responsibility.¹⁵ This means that the sociological question of intersectionality turns away from the more traditional one-sided view of this challenge: from 'how does one service provide a culture-sensitive service to each and every different group?' to a more mutually responsible 'how will each and every group create their own style and self-provision of palliative care, working in partnership with existing services?' Highlighting mutual responsibility of reciprocity of relations shifts the implicit power assumptions behind traditional healthcare understandings of intersectionality. Rather than solely a health services problem, intersectionality then becomes a broader civic challenge for all groups; addressed only by the power of reciprocity found only in community development and partnerships approaches.

Not everyone will supply clinical services but it is only one type of service offering in palliative care. Social, psychological and spiritual supports are also crucial parts of the 'service' that other groups can assume or partly-assume. In this way, geographic (remote and rural), institutional (prisons or homeless) or social (ethnic or sexual identities) differences can be addressed by asking not what we can offer them but what they can offer inside a partnership with us. As Dixon and colleagues rightly observe, there is indeed further scope for increasing 'non-clinical' provision of palliative care *by communities themselves*.

For communities and for clinical services, it is crucial that both recognise their mutual responsibilities for community developments. Community development in palliative care means communities hold roles not just as recipients but also providers of care; a health promotion approach that has also proven cost-effective in other areas of healthcare.^{16,17} This means that future recommendations for addressing barriers to palliative care access could contain these additional health promotion recommendations.

1. Affirmative action approaches to prospective employment, board membership and volunteers are essential.
2. Prioritise and trial community building practices in palliative care research into access (patient and public involvement is essential but insufficient if these only represent patients).
3. Co-locate and transfer staff and resources to groups that have problems of access, even if only as fractional appointments.
4. Create a two-way outreach programme of communication and action; service members go out and community members come in to exchange expertise and practice wisdom.
5. Be proactive/affirmative in the appointments process. Be creative, especially with volunteers.
6. End-of-life care design, review, policy or service development to be conducted with diverse representation.
7. Every clinical service to have a designated 'diversity champion'.
8. Provide facilitation and support for the establishment and development of new 'services' with and by groups who experience access barriers.
9. Community development workers to be an essential part of the service team.

These themes characterise the solutions to increasing access to palliative care in the following ways:

- > making the existing service permeable to outside groups (recommendations 1, 5 and 6)
- > de-centralising the functions of the service (recommendations 2, 7 and 8)
- > increasing community development outside the service (recommendations 3, 4, 8 and 9)
- > partnering community organisations to provide care and support with a community empowerment model
- > empowering the community to develop care and support.

These above features support the World Health Organization's Ottawa Charter for Health Promotion by strengthening community action and creating supportive environments. They are public health recommendations that can reframe the challenge of access to palliative care as a challenge to deliver a full and sustainable partnership model of health and wellbeing.

Conclusion

It is important to recognise that although most of the 13 earlier recommendations are self-referential, those same suggestions are important to building internal capacity and understanding within the organisation itself. The 13 suggestions made in the past complement the additional 9 described here. Past suggestions can create an organisational capital within the service that can build motivation and drive existing staff to transform the service from one that views itself as a sole provider to one that understands its cooperative function within a community of civic providers that must include all people. In this way, professional palliative care services can eventually emerge as *primus inter pares* (first among equals). ■

References

- 1 Gallan A, McColl-Kennedy T, Barakshina T *et al*. Transforming community well-being through patient's lived experiences. *Journal of Business Research* 2019;100:376–91.
- 2 Public Health England. *A guide to community centred approaches for health and wellbeing*. Public Health England, 2015.
- 3 Marie Curie. *Improving access to palliative care services for people from Black, Asian, and minority ethnic backgrounds in south east Cardiff*. Marie Curie, 2014.
- 4 Marie Curie. *Hiding who I am: The reality of end of life care for LGBT people*. Marie Curie, 2016.
- 5 Gunaratnam Y. *Improving the quality of palliative care*. Race Equality Foundation, 2007.
- 6 National Council for Palliative Care. *Ethnicity, older people and palliative care*. NCPC, 2006.
- 7 Calanzani N, Koffman J, Higginson IJ. *Palliative and end of life care for Black, Asian and minority ethnic groups in the UK*. Public Health England, 2013.
- 8 NHS Improving Quality. *End of life care case study: Increasing the number of people from a Black, Asian, and minority ethnic (BAME) background accessing palliative care services*. NHS, 2015. www.nwscsenate.nhs.uk/files/5214/4956/7087/Case_study-Increasing_the_number_of_people_from_a_BAME_background_accessing_palliative_care_services.pdf
- 9 Dixon J, King D, Matosevic T, Clark M, Knapp M. *Equity in the provision of palliative care in the UK: review of evidence*. London School of Economics and Political Science, 2015.
- 10 Orlovic M, Smith K, Mossialos E. Racial and ethnic differences in end-of-life care in the United States from the Health and Retirement Study (HRS). *SSM Popul Health* 2019;7:100331.
- 11 Kelley ML. The evolution of the Kelley community capacity development model for palliative care. *Ann Palliat Med* 2018;7(Suppl 1): AB014.
- 12 Kumar SK. Kerala, India: A regional community-based palliative care model. *J Pain Symptom Manage* 2007;33:623–7.
- 13 South J, Phillips G. Evaluating community engagement as part of the public health system. *Epidemiol Community Health* 2014;68:692–6.
- 14 National Palliative and End of Life Partnership. *Ambitions for palliative and end of life care*. National Palliative and End of Life Partnership, 2020.
- 15 Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* 2013;106:1071–5.
- 16 Abel J, Kellehear A, Karapliagou A. Palliative care – the new essentials. *Ann Palliat Med* 2018;7(Suppl 2):S3–14.
- 17 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 Research* 2013;1.

Address for correspondence: Prof Allan Kellehear, College of Nursing and Health Sciences, University of Vermont, Rowell Building, 106 Carrigan Drive, Burlington, Vermont 05405, USA. Email: allan.kellehear@uvm.edu