Circles of care: should community development redefine the practice of palliative care?

Julian Abel,[1] Tony Walter,[2] Lindsay B Carey,[3] John Rosenberg,[4] Kerrie Noonan,[5] Debbie Horsfall,[5] Rosemary Leonard,[5,6] Bruce Rumbold,[7] Deborah Morris[7]

[1]Department of Palliative Care, Weston Area Health Trust and Weston Hospicecare, Weston-super-Mare, UK
[2]Centre for Death & Society, University of Bath, Bath, UK
[3]Palliative Care Unit, Faculty of Health Sciences, La Trobe University, Melbourne, Australia
[4]Calvary Centre for Palliative Care Research, Australian Catholic University and Calvary Health Care, Canberra, Australia
[5]School of Social Science and Psychology, University of Western Sydney, Sydney, New South Wales, Australia
[6]Social & Behavioural Sciences, CSIRO Perth, Wembley, Western Australia, Australia
[7]Palliative Care Unit, Faculty of Health Sciences, La Trobe University, Melbourne, Victoria, Australia

Correspondence to: Dr Julian Abel, Department of Palliative Care, Weston Area Health Trust and Weston Hospicecare, C/o Jackson-Barstow House, 28 Thornbury Road, Uphill, Weston-super-Mare, Somerset BS23 4YQ, UK; julian.abel@nhs.net, abelju@yahoo.co.uk

ABSTRACT

Specialist palliative care, within hospices in particular, has historically led and set the standard for caring for patients at end of life. The focus of this care has been mostly for patients with cancer. More recently, health and social care services have been developing equality of care for all patients approaching end of life. This has mostly been done in the context of a service delivery approach to care whereby services have become increasingly expert in identifying health and social care need and meeting this need with professional services. This model of patient centred care, with the impeccable assessment and treatment of physical, social, psychological and spiritual need, predominantly worked very well for the latter part of the 20th century. Over the last 13 years, however, there have been several international examples of community development approaches to end of life care. The patient centred model of care has limitations when there is a fundamental lack of integrated community policy, development and resourcing. Within this article, we propose a model of care which identifies a person with an illness at the centre of a network which includes inner and outer networks, communities and service delivery organisations. All of these are underpinned by policy development, supporting the overall structure. Adoption of this model would allow individuals, communities, service delivery organisations and policy makers to work together to provide end of life care that enhances value and meaning for people at end of life, both patients and communities alike.

ERA OF CHANGE

We are approaching a critical time in how we care for our dying. The arguments about the limitations and implications of a service delivery model for end of life care have been well described.[1] Over the last 50 years, palliative care has led the way in how to look after people in the last phase of life by identifying their needs and providing care to meet those needs. This approach has been of benefit to millions. As palliative care providers have become more skilled, they have developed increasing specialisation in providing services. Palliative care specialists now include doctors, nurses, chaplains, social workers, physiotherapists, occupational therapists, art and music therapists, psychotherapists, complementary therapists, and so on. Palliative care for patients with cancer is being extended to aged care and non-cancer diagnoses. In order to meet these needs we are faced with commissioning and resourcing more services at a time of global financial hardship.

At the same time, the increasing professionalisation of care has resulted in an expectation that, when someone is diagnosed with a terminal illness, institutional professional care will look after that person who becomes a patient with an illness. Over the last 3 years in the UK, there has been an extensive effort to provide high quality end of life care in the patient's chosen place. This has meant that the place of death is shifting from acute hospitals to homes, care homes and hospices.[2] This effort is laudable and right. However, who is going to care for the person in the family home?

Lay people's familiarity with caring for people at end of life has decreased, leading to a loss of knowledge and skills within the community about how to care. These losses may in part be due to the professionalisation of care and other social changes. With increasing longevity, declining retirement age and increasing

female participation in paid work, the labour market employs more women of all ages and fewer older men. The typical family carer may no longer be the middle aged daughter without paid work; more frequently, carers are the elderly spouse, employed middle aged children and children in early retirement. Age, infirmity or paid employment can reduce many of these carers' capacity to care. Further, primary carers may be reluctant to ask for help from their family, friends and neighbours. So, whether it is because of carers struggling in the wake of employment and demographic changes, or because of increased service provision following the expansion of palliative care, or both, end of life care has become professionalised and owned by health and social care institutions.[3] This has become dominated by a service delivery model of care, where services strive to meet the needs of patients through systematic care.

COMMUNITY CARE

That may be the picture with end-stage cancer. With many other life-threatening conditions the reduced caring capacity of families and communities to care has not been matched by comparable increases in service provision. With all conditions, 'community care' typically means care not by the community per se, but care provided by family, and care by healthcare workers who drive to visit their clients rather than care for them in hospital or in another institution.

We are now seeing new alternatives to this model of care. Particular examples include Allan Kellehear's cogently argued case for public health approaches to end of life care which recommends returning end of life care to communities.[4] Various ways of doing this have been developed over the past decade such as La Trobe University's Palliative Care Unit in Melbourne which has worked with community palliative care services in implementing strategies, based on Kellehear's work, that engage local communities in end of life discussions.[5] This approach emphasises values around end of life care and familiarising participants with both traditional and contemporary approaches to death and dying. The aim of this public engagement is to break down barriers and deal with fears and concerns deriving from cultural taboos of discussing death. The UK's 'Dying Matters Coalition' has similar programmes. The overall goal of these approaches is to increase the capacity of community members to provide support and care for their dying when called upon to do so. Concepts such as social capital and social inclusion have been used to capture the theoretical bases of such initiatives.[6] [7]

Other initiatives have looked at innovative ways of directly increasing the capacity of communities to care for the dying. These include an extensive programme of public engagement across all levels of society, along with policy change to support community development, as enacted by Suresh Kumar in Kerala, India.[8]

Various initiatives are exploring how ethnic minority communities can be supported to enhance care of the dying within the community rather than in an institution.[9] [10] In Sydney, for example, a project of supporting carers to make the best use of their network of family, friends and neighbours has been in existence for nearly 30 years.[11] In this project, carers are supported on a one to one basis by a volunteer mentor who can both provide emotional support and help enable the carer to share the care among their network. It is hoped that in the longer term, there will be enough community development and resilience to do this without any kind of formal support, a kind of tipping point of development when further increases in community capacity to care for the dying grow organically from within communities.

These themes can be summarised by saying that the current dominant model of end of life care has been service delivery, with care being given from within professionalised services. The examples quoted earlier are clear evidence that there is increasing interest in community development, where the main aim is to support communities to care for the dying themselves, with service delivery as a backup or support for gaps in community provision. A core function is to assist in 'developing mature, resilient, egalitarian and heterogeneous networks which underpin and sustain the community activities'.[12]

Community development has three main principles: first, decision making by those most affected by outcomes of the decision (the subsidiarity principle); second, personal empowerment and control by individual citizens over their own life (the empowerment principle); and, third, developing ongoing structures and processes by which groups can meet their own needs (the structural principle).[13] It is not just a matter of reassigning responsibility to people who are unprepared for their role. Professional and technical expertise remains vital, regaining its rightful place as servant not master—or more precisely, as a well-resourced servant rather than a master trying to do everything and too often failing.

These new ideas are now mature enough, with supportive evidence, to consider a new model for palliative/end of life care. Such a model could provide a foundation for a focused development of end of life provision, relying on community as the basis of care. As such, services and policy development could be informed by such a model, so that an overall integrated plan could be formed, with each player knowing where they fit. At the same time, the model could provide a theoretical framework so that evaluation of services and models of care could be tested for effectiveness. In particular, the evidence that general awareness raising and skills development increases community capacity is limited: finding methods to demonstrate how capacity is increased over lengthy periods of time is a complex issue.
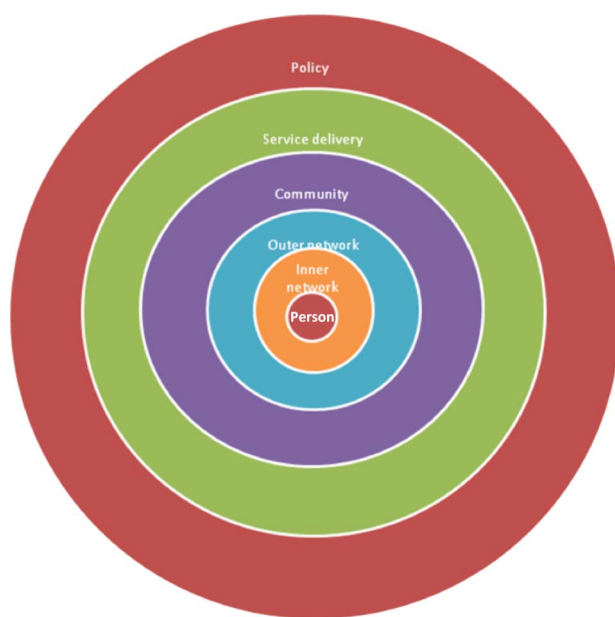
Figure 1 Circles of care.

We propose a community centred model for end of life care as illustrated by figure 1. This model is similar to one described by Cantor in 1991.[14] The proposed model, however, differs in function, with less emphasis on demographics and greater emphasis upon foundation policy change.

CIRCLES OF CARE

The model draws upon a public health approach to end of life care (noted earlier) which appreciates the persons with illness in their everyday context of living within their communities, not separate individuals with needs that have to be met. The emphasis becomes: how can communities be supported to care for people at the end of their lives in a way which enhances meaning and value for both the person with the illness and all of the community members who participate in caring? The model can be encapsulated by a figure of circles of care.

The model can be used as a practical guide to thinking about how care can be done in communities and how different services coordinate with each other and the communities they serve. The figure works in a number ways.

- The model starts by considering the persons at the centre in relation to their community. When thinking about meeting needs, the starting point is the centre and moves outward sequentially, looking to see how needs can be met by inner and outer networks, the community and then finally service delivery.
- When individuals and organisations are thinking about where they fit from a broader perspective, the figure allows them to see how what they do relates to other parts of the spectrum of care.

- There are cross cutting themes. Policy, for example, is cross cutting and can be seen to work at local, regional and national levels to support different aspects of care. Service delivery organisations will need to make assessments that include non-service delivery elements and may look to support these. Likewise, community groups may link in to outer networks and to policy.
- The barriers between the circles are 'porous'. They are both an interface and an area that needs particular attention for coordinating care.

Service delivery organisations may identify gaps in care. The order in which these gaps are addressed is determined by working from the centre of the figure outwards. Is there something that the person or carer can do themselves? If not, can the inner network or supporters help? If not, can the outer support network close the gap, and so on? Likewise, the gap in policy may be such that policy needs to be changed. Any new policy is then formed by making sure that the policy addresses issues in order, without missing vital components. We have seen historically that policy has favoured service provision over community development. There are circumstances where community development could have been a more appropriate course to take, such as funding community development posts to support community banks of care rather than looking to service provision for this care.

This model draws upon the findings of the 'Bringing our dying home: creating community at end of life' project,[6 15] which evaluated the community development potential of the HOME Hospice in Western Sydney. Groups of people who had helped care for someone at end of life discussed with researchers and with each other the many facets of their caring and drew maps of the care networks. It was the participants themselves who identified the inner and outer networks.

The model works in the following way.

1. *Person*: The entrance point is when someone is diagnosed with a life limiting illness. All of us recognise that we exist and find meaning, to a greater or lesser degree, through our relationships with the world around us, which we can call our community. This community can be extended and exists within geographical locations now extended through the telephone and internet networks.[11 16] Our relationships help us to identify our sense of identity and use in our worlds, but this can change as a result of having an illness. The challenge is how does our community respond to maintain that sense of value we have even when our role and identity change? If the essence of what we hope to achieve at end of life is to enhance well-being, of which a key component is relationships, then we have to ask how the community can participate in enhancing relations, giving a greater sense of meaning and value. For this reason, it is important to consider the central part of the model to be a person with an illness rather than a patient.

2. *Inner network*: Surrounding the central person is an inner network of close family members and friends who have direct contact with the patient and carer. The separation of inner and outer networks came out of the research project entitled 'Bringing our Dying Home'[6] that considered the qualitative experiences of people involved in a mentoring programme developed by HOME Hospice in Sydney, in which local volunteers helped the main carer to mobilise their existing networks. The inner network tends to comprise people who provide intimate and direct hands-on care, companionship and support. Discovering who makes up the inner network is something that can only be determined by the person and their main carer. The inner network is a rich resource which can provide meaning, value and support that enhances the capacity of the community to care for their dying. In some cases the network consists of only a single carer and in such circumstances there is a real risk of carer burnout.[17] Key reasons for this are concerns about privacy for the carer or care recipient, feeling they should not be a burden or that they are not entitled to ask for help.[18]

3. *Outer network*: The outer network consists of people not as close as those in the inner network who are not strangers to the family. This includes less close family members, friends and neighbours who may respond to requests for help. The type of tasks that the outer network can do may relate to the sometimes mundane practicalities of living but generally relate to activities outside the home (eg, bringing meals, shopping, mowing the lawn, walking the dog). While these tasks in themselves may not be time consuming or difficult, together they add up to what can be an untenable stress when combined with being a main carer. Tasks can be taken up by different people in the outer network. These may be quite achievable in terms of time and effort in a normally busy life. The overall impact of doing this can be significant, providing support for the carer for what can be a marathon rather than a sprint, creating capacity and space for the carer to attend to what is most needed.[6] This can save carer exhaustion. It can enhance meaning by demonstrating in a real way the community's value for the person with terminal illness. Large networks require more coordination. If all the coordination falls to the primary carer this is a further workload, so ideally the carer will have help with the coordination perhaps from someone in the inner network or perhaps from a community oriented service.

4. *Community*: Some communities and individuals have extensive networks and can be considered to be network-rich. There are others who are network-poor. Even among those people who are network-rich, there may be tasks and caring that are not covered. Whereas the traditional service delivery model envisages these tasks being done by professional services, the community development model responds with community resources or social capital. This can be done in a number of different ways. Once a community development model is established, networks within a neighbourhood will have trained themselves by successfully looking after someone who has died. People within this network can be a community resource and may be willing to give similar care to someone who lives nearby. Although the people involved may be strangers to some family members, the degrees of separation may be only one or two people. A family member may know the person involved via someone else. One of the difficulties of having professional services is that the number of strangers who can pass through a house in a week can be as much as 30. This can result in a loss of privacy for the family, with increasing stress and depersonalisation. It may be possible to develop resource banks for communities. Community leaders can develop, with or without support, neighbour resources so that tasks can be completed by willing volunteers.

The community resource can be a junction for service delivery organisations and healthcare professionals to share resources. Communities have tremendous potential for supporting families of people who are dying. Some inner and outer networks will not be large or resourceful enough to meet all the needs of the dying. These needs do not have to be met by service delivery. Some communities are self-organising or have formal volunteer services to support people in their community in various ways, including transport to hospital appointments, gardening or sitting with the dying person to give the main carer a break. Health promoting palliative care initiatives engage and support local communities in becoming familiar with death and dying. This can be translated into community resource by developing community 'banks' of volunteers who are ready to help. Asking the question 'What are you prepared or would like to do for your community?' is a natural part of community engagement initiatives. A service delivery organisation, such as a hospice or community nursing service, may identify an unmet need for a family. Rather than defaulting 'automatically' to meeting that need with service delivery, the organisation could contact the community bank to see what can be provided with community support.

5. *Service delivery*: The first port of call for caring for the person with a terminal illness is community engagement. The service delivery organisation looks to the person, inner network, outer network and then community in that order to see if caring needs can be met from all these various resources. Some needs will never be met from these areas. These may require professional (such as medical, nursing or spiritual care) or personal care that may be a matter of privacy or dignity for an individual or family member. And while the capacity of the community develops, lack of community resources will need to be compensated by additional service delivery.

At present, it is not unusual for educated and/or network-rich patients to use their economic, educational and social capital to access more and better

formal service provision than those who are network-poor: this is true in education, health and social care. If you start with a service delivery model, then the best networked people will know how to access the services, while poorly networked people in fragmented communities may miss out. The care circle model, by contrast, is a tool to ensure that a more appropriate (ie, larger) share of paid services goes to those with the weakest networks in the less resourced communities. Our model enables more equitable distribution of the formal health services.

There is evidence from both Australia and Kerala that mobilising carers' networks, rather than exhausting them, actually has the potential to enrich them. Good end of life care not only *requires* community development but can actually *assist* it.

Also, consider end of life care in ethnic minority and indigenous communities. There is a significant amount of research literature demonstrating how these communities can struggle to use end of life services. Using a community development approach, it is possible to engage with these communities through what is already there that supports end of life care within their cultural context and what additional support for community resource is needed to enhance this. In the circles of care model, community resources are considered before offering services which may be culturally inappropriate. Cultural sensitivity and respect are thus enhanced.

6. *Policy*: All of the above inevitably needs to be supported by a policy framework that gives an overview of coherent interrelated services which include community development. Policy develops at local, regional and national levels. Allocation of increasingly precious resources can be made in a coordinated and cost effective way that reflects value for money, quality of care and enhanced meaning all at the same time. Longer term benefits are social inclusion and cohesiveness.

FROM SERVICE DELIVERY TO COMMUNITY DEVELOPMENT: ORGANISATIONAL CHALLENGES

Taking community development as the first course of action before service delivery may sound simple. However, it can be a significant challenge. First it assumes that the community is sufficiently developed in its capacity to provide end of life care but there will be variations in willingness and ability to develop that capacity. In complex urban environments there may be differing experiences and definitions of who constitutes the community. Considerable time and resources may be needed to identify and coordinate a particular locality's strengths. When there is a need to provide care or services, the easiest option for a professional service to achieve this is from within identified and currently endorsed established resources. Professionals, like volunteers, get meaning and value for themselves through giving care, so a tension exists when professionals have to consider which elements

of their role may not need to be done by a trained person. Services survive by being paid for the delivery of their care. Use of community resources may mean that there is less need for professional services and less need for professionally registered individuals within that service.

Consider when a ramp is needed in someone's home. Increasing frailty from severe illness may mean that someone is no longer able to walk and needs wheelchair support to be able to mobilise. This can present access problems at home. Using the service delivery approach, the professional will look to see which services could build a ramp. In this circumstance it is not uncommon for existing services, which are stretched for time and resources, to be unable to build a ramp before the person dies. Using community development approaches, the dying person's community is enabled as a resource able to build a ramp. The formal service providers may then provide information on how a ramp could be built safely, but the responsibility for the ramp rests with the community. This example highlights risk assessment and health and safety legislation that concern professional services. If the ramp is built by the community, then the community has ownership of risk, rather than the professional service. If the service builds the ramp, they are bound by health and safety legislation.

Coordination and communication may, of course, provide tougher challenges than ramps. Coordinating existing services is challenging enough. Coordinating formal service delivery with the less controllable and auditable activities of families, friends, neighbours and community initiatives may be formidable. Consider communication technology. Formal health services have sophisticated and/or clunky IT systems, firewall protected against outsiders (ie, against carers, neighbours, communities). By contrast, carers may well coordinate care more informally on line using social networks (eg, Facebook). Just as informal carers and supporters are excluded from health service IT systems, so doctors and nurses may not wish to become internet linked friends with their patients' friends and neighbours. It is not just carers who value their privacy! Software providers such as Patient Knows Best have found a way of linking the professional with the community, using in part social network protocols.

This is perhaps only the tip of a much bigger iceberg of ethics, confidentiality, power and fear. In the UK, and some parts of Australia, New Zealand and the USA, for example, hospital and hospice chaplains may access patients' notes; clergy in the community may not. While there is some evidence of continuity of care between healthcare institutions and community care via collaborating local shire/district nurses or church sponsored 'faith community nurses' (Australia), 'parish nurses' (USA) and healthcare chaplains,[19] nevertheless the firewall between the 'Service

Delivery' circle and the 'Community' circle is formidable, and will need more than IT to resolve it.

CONCLUSIONS

So, 'should community development redefine the practice of palliative care?' Palliative care has led the way in developing models of care which have done a tremendous amount to relieve suffering for patients and their families at end of life. Recent thinking has emphasised the need for community development to restore the abilities of families and communities to be able to look after their dying. To achieve this, end of life services will need to change their emphasis from a service delivery model towards initiatives that enhance family, neighbourhood and community capacity. This will mean an increase in resourcing for community development and a new mindset for service providers. Our proposed model of circles of care could provide a theoretical basis on which this could be achieved. The model is practical and applicable, and could provide a basis for a systematic evaluation of services to see if community development is being achieved and if people are indeed being cared for in a manner that works best for everyone and in a way that is sustainable.

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REFERENCES

1 Conway S. *Governing death and loss empowerment, involvement and participation*. Oxford: Oxford University Press, 2011.
2 Gomes B, Calanzani N, Higginson IJ. Reversal of the British trends in place of death: Time series analysis 2004–2010. *Palliat Med* 2012;26:102–7.
3 Rosenberg JP. Whose business is dying? Death, the home and palliative care'. *Cultur Stud Rev* 2011;17:15–30.
4 Kellehear A. *Compassionate cities: public health and end-of-life care*. London: Routledge, 2005.
5 Salau S, Rumbold B, Young B. From concept to care: enabling community care through a health promoting palliative care approach. *Contemp Nurs* 2007;27:132–40.
6 Horsfall D, Noonan K, Leonard R. Bringing our dying home: creating community at end of life. *Health Sociol Rev* 2013;21:370–2.
7 Rumbold B, Dickson-Swift V. Social determinants of health: Historical developments and global implications. In: Liamuttong P, Fanany R, Verrinder G, eds. *Health, illness and well-being*. Oxford: Oxford University Press, 2012:177–96.
8 Kumar S. Public health approaches to palliative care: the neighbourhood network in Kerala. In: Salnow E, Kumar S, Kellehear A, eds. *International perspectives on public health and palliative care*. London: Routledge, 2012:98–109.
9 Richardson H. A public health approach to palliative care in East London. In: Salnow E, Kumar S, Kellehear A, eds. *International perspectives on public health and palliative care*. London: Routledge, 2012:110–12.
10 Greene A, Aranda S, Tieman J, *et al*. Can assessing caregiver needs and activating community networks improve caregiver-defined outcomes? A single-blind, quasi-experimental pilot study: community facilitator pilot. *Palliat Med* 2011;26:917–23.
11 Horsfall D, Noonan K, Leonard R. *Bringing our dying home: creating community at end of life*. 2nd edn. Sydney: Cancer Council of New South Wales, 2012.
12 Gilchrist A. The well-connected community: networking to the "edge of chaos". *Community Dev J* 2000;35:264–75.
13 Kenny S. *Developing communities for the future: community development in Australia*. South Melbourne: Thomas Nelson Australia, 1994.
14 Cantor MH. Family and community: changing roles in an aging society. *Gerontologist* 1991;31:337–46.
15 Leonard R, Horsfall D, Noonan K. Identifying changes in the support networks of end of life carers using social network analysis. *BMJ Support Palliat Care* under review.
16 Walter T, Hourizi R, Moncur W, *et al*. Does the internet change how we die and mourn? *Omega* 2011;64:275–302.
17 PCA. *The hardest thing we've ever done: full report of the (Australian) national Inquiry into the social impact of caring for terminally ill people*. Canberra: Palliative Care Australia, 2004.
18 Noonan K, Leonard R, Horsfall D. You can't do that! Researching alternative stories of community participation at end of life. *Third Sector Rev* 2011;17:75–89.
19 Carey LB. Chaplains and health care communication. In: Millar AN, Rubin DL, eds. *Health communication and faith communities*. New York: Hampton Press, 2011:263–76.

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