Review

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Compassionate communities: end-of-life care as everyone's responsibility

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Summary

In early 2013, an online survey of over 200 UK palliative care services published in the *British Medical Journal* found that most of these services were prioritizing 'community engagement' initiatives, most commonly adopting a 'compassionate community' model. Later this same year, a report released by the National Council for Palliative Care and the charity Murray Hall Community Trust, described the increasing uptake of compassionate communities by palliative care services in England. This review examines this new policy and practice development in British end-of-life care explaining its conceptual origins and describing its policy importance to current practice. Why services are increasingly turning to community partnerships and the reasons they believe that this approach might enhance the effectiveness and reach of their clinical work are described.

Introduction

An online survey of over 200 UK palliative care services published in 2013 found that most of these services were prioritizing 'community engagement' initiatives, most commonly adopting a 'compassionate communities' approach.[1] The National Council of Palliative Care in its role as partner with the Department of Health's 'Dying Matters' Coalition funded a scoping study of palliative care services in England and found that significant numbers of palliative care services were developing compassionate communities programs to enhance their service offerings.[2] Both publications make several in-common observations about these developments.

First, these developments represent an embracing of new public health ideas such as health promotion, community development and death education into a field that was previously focused primarily on

clinical bedside care matters. Past palliative care interests focused on inpatient, outpatient, day care, and home care services and not community development. Secondly, these local developments appear to be mirroring not only discussions in the academic and professional end-of-life care literature[3,4] but also policy discussions and developments in the wider UK end-of-life care leadership, particularly in England and Scotland.[5,6] Similarly broad developments include the emphasis on community development given to the Help the Hospices 2012 conference whose theme was 'Community engagement: Back to our future'.[2] Finally, these community engagement initiatives are not only increasing locally but they are also spreading internationally. For example, in 2013 The 3rd International Conference on Public Health and Palliative Care conference attracted over 250 delegates to the

Republic of Ireland.[7] The first conference on this topic attracted only 80 delegates when this was first held in India in 2009.[8] What are these community engagement approaches exactly and in what ways are they 'public health' ones'? What do these approaches offer over and above a conventional clinical approach to care, or in other words, in what ways do these approaches add value to what we already offer in end-of-life care? What epidemiological or professional factors account for their increasing popularity and are they here to stay or are they just a temporary policy fashion?

Compassionate communities: a public health approach to palliative care

Compassionate communities are derived from the WHO concept of 'Healthy Cities' or 'Healthy Communities', an earlier set of public health ideas that formally dates from the 1980s but has even earlier policy and practice roots in health education.[9,10] Based on the 'New' public health idea that health is more than mere absence of illness, the New Public Health of the 70s and 80s encouraged ordinary people everywhere to adopt an understanding that 'health' was everyone's responsibility—not just their doctors and their health services. Health services could help people when they got into trouble —unavoidable accidents, encountering disabilities, or falling ill from a developing or sudden illness. But the best cure was found in prevention and early intervention. In this way, prevention, harm reduction and early intervention became watch-words for the new public health.

Government policies, workplace policies, schools, the mass media and the law, to mention only some key social institutions were encouraged to get involved in these ideas—to discourage people from harmful substances (illicit drugs, tobacco, asbestos or high fat diets), or harmful circumstances (sedentary lifestyles, over eating, stressful or dangerous work situations, unprotected sexual behaviour), and to adopt practices that would help ward off disease or improve health outcomes (through regular exercise, better choices in nutrition or sexual practices, or creating healthier and safer workplaces and so on).

In the late 1990s and early 2000s, these ideas—ideas that had permeated all branches of public health and medicine—were gradually advocated for palliative care.[11,12] In this early experiment in knowledge transfer—bringing health promotion ideas to palliative care—palliative care services were encouraged to think about dying as a life that, though it would end soon, nevertheless had its own morbidity and mortality risks associated with the journey. People who must live with a life-limiting illness commonly encountered anxiety, depression, social isolation, social stigma, social rejection, family breakdown, premature job loss, financial strain, spiritual dilemmas or crises, even suicide, among a host of other troubles. These are key determinants of quality of life for the dying, their carers and the bereaved. Many of these social, psychological and spiritual problems are not easily addressed by health services, even less so in the last days of life.

Furthermore, palliative care services often struggled to provide close follow up of the bereaved after the death of the patient. It became clear that all of these troubles were amenable to prevention, harm reduction and early intervention and that the methodologies used in other successful public health campaigns—principally enlisting the community in end-of-life caring—could be pushed into service for the purposes of increasing the effectiveness of end-of-life care as a public health goal.

In this way, promoting good social, psychological, spiritual as well as physical health while living with a life-limiting illness made equally good sense. Involving schools, workplaces, places of worship, the mass media or local businesses could help mobilize untapped sources of social and spiritual care and support as well as practical resources. End-of-life care, like contemporary health care as it currently exists, could partner with community efforts to provide support and care for death, dying, loss and practical caring. Families and palliative care, dementia care or bereavement care services for examples, would not be alone in shouldering the responsibility for these kinds of care. End-of-life care—as a form of social, psychological, spiritual and even physical support would come earlier, be more sustainable, provide after care and be less reliant on episodic direct service provision. On the other hand, direct services would be more likely freed up from the sole responsibility in dealing with earlier care, after care and sudden crises if the community was resourced and confident enough to share the care for these issues. This could leave palliative care services more time for complex case management.

Examples of compassionate communities approaches

In 2004/05, St Christopher's Hospice in South London adopted a range of health promoting

palliative care programs to engage the wider local community in which the hospice was located and also to engage with some of the local sectors of that community, for example, schools or the art and fashion community.[13] In their engagement with local schools, St Christopher's Hospice approached head teachers to begin a discussion of how children might benefit from visiting the local hospice and how such visits might help the school to meet its obligations under the UK National School curriculum for education about loss and transition. Patients and families and hospice staff were also approached at the same time as the schools so as to gauge willingness and enlist co-operation of both these groups.

Although each school chooses different age groups/classes to be involved most of the groups range from 9 to 10 year olds to teenagers of 15 and 16 years. There were generally four sessions ranging from 1 to 3 h visits and during these sessions students were encouraged to ask any questions that addressed their different fears and curiosities. For example, 'What is it like to have your breast cut off?; Why haven't you got any hair?; What happens to your body when you die?'.[13] For greater processing and learning, students and teachers commonly returned to their schools for ongoing discussion of their experiences and often produced artwork or performances based on their learning. In turn, this displayed art or public performances helped audiences that attended to reflect and discuss the student's experiences even further. St Christopher's Hospice has engaged in this process over 40 times now. The evaluations of the program describe several important health promotion outcomes—changed attitudes from uncertainty and anxiety to familiarity and confidence, normalizing the experience of death and dying, patients became educators, and the creation and sustaining of healthy relationships between the dying and the broader community.

In the case of this kind of student–teacher–parent engagement with the St Christopher's Hospice project a raft of age groups in the community experienced a greater understanding about the topics of dying, death, practical care, and grief and loss. Such knowledge has not only the initial personal value of reducing fear but also of providing practical information about serious life-limiting illness and loss, helping through this 'early intervention' to reduce harms related to ignorance, fear, social distancing and isolation, stigma and prejudice. All this is achieved before a time when many of these people would normally encounter these kinds of circumstances.

In 2009, in Shropshire, England, Severn Hospice adopted a compassionate community model of engagement by calling for volunteers in the community to undertake short training in care and support for frail and vulnerable people, including those living with life-limiting illnesses.[14] Volunteers were drawn from all walks of life—retired as well as workers—who were able to dedicate a portion of their week to visiting others at home. This program was about raising awareness of the need for every community member to become actively involved in the care of the frail and vulnerable in their own locality despite not necessarily 'knowing' these people. Through public forums and discussions Severn Hospice sent out the message that the experience of care in general and end-of-life care in particular was not solely a professional services responsibility but rather everyone's responsibility.

As a result of this message, significant numbers of people came forward, and continue to come forward, for training and allocation to people who are frail and vulnerable in their local area. A wide and diverse network has now been established and although this network was originally established to target loneliness and isolation in their community early audits and evaluations have revealed a significant reduction in use of unscheduled health care services by people receiving this volunteer support.

In this example, the use of volunteers to provide support and practical care in the community has been a health promotion strategy that has helped reduce anxiety and panic among some patient groups by providing them with additional support, or even some support in their isolation where there was previously none, thereby preventing or reducing the need to draw all this from health service professionals. Isolation and loneliness is reduced and this has freed up crisis and 24 h services to better serve more complicated medical cases registered with the hospice.

Finally, an international example of a compassionate communities program can be seen as a result of a national Japanese prize annually offered to any community who can demonstrate being 'dementia-friendly'. In Osaka prefecture, a social welfare organization has opened a day care service on the high street (main shopping street) of their local community.[15] This centre provides day care for those living with dementia but instead of playing games or receiving passive entertainment the main program is about the design and production of the mid day meal. Seniors with dementia are asked to jointly design the meal, then to go out shopping together to buy the ingredients, and then return to help prepare the meals. Shopkeepers are briefed on the program and willingly participate in the program, learning and experiencing the complexities of communicating with seniors with dementia and also

gaining insight into the complexities of their care while sharing this in a small way. A newsletter from the Centre is regularly distributed to the shopkeepers, and seniors with dementia staff a booth during the town's Summer Fair. In this way, as the organizers argue, 'the lifestyle of our day-care centre helps us fit in naturally as members of the neighborhood.'.[15]

In this example, people living with dementia are normalized not only in terms of their day care activity—by not being treated as passive consumers of 'treatments' or 'services' but as active agents of their own preferences and activities—but also as people to be *publicly seen going about their usual business.* Furthermore, people not directly involved with care for people living with dementia are encouraged to participate in that care and to obtain basic understandings of both the challenges of living with dementia and also the challenges in its daily care. Thus the levels of public education about living with dementia and its care are significantly raised. This helps both people living with dementia and also those living with its care—gain support from community involvement because both information and support is being generated inside the community that is the daily context for family and professional care. End-of-life care becomes everyone's responsibility.

Conclusion

In the last few decades we have become accustomed to the idea—and the practice—that the achievement of optimal health and wellbeing in every nation must be a partnership with government, health services and the every major sector of the community. Health is everyone's responsibility. Schools and businesses are just as likely to be engaged in changing policies and practices in matters to do with the health of students and employees as hospitals and community clinics. Today, the call for a 'health promoting palliative care' or for the development of compassionate communities is a parallel call for just this type of engagement in matters to do with dying, death, loss and care. It is a movement towards the recognition that end-of-life care is everyone's responsibility. Everyone has a role to play, however modestly.

In the last 100 years of western European cultural life we have witnessed a growing disconnect between the basic family unit and their wider connections with extended family and broader community networks. At the same time, we have witnessed a rising dependency on professional health services.[16] Today, that set of cultural developments has led to a polarized view of care for older people, the chronically and terminally ill, as well as the bereaved. Care for these populations is now widely viewed as the responsibility of family or of health services. This polarized view is both an incorrect and unsustainable cultural and health policy position. Communities *are able* to do more to support families and health services and to bring practical resources and important supports to both. We have witnessed the success of these types of contributions in wider public health movements and we are now seeing the beginnings of them in end-of-life care.

In this way, it is unlikely that this is some temporary 'new policy fashion'. Health promotion and community engagement in end-of-life care is an extension of the growing acknowledgement of modern populations that to achieve optimal health and wellbeing in the 21st century a community engagement approach to health must extend its active concern to the end-of-life itself.

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