

Compassionate communities support those who are dying

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20 March 2017

I have been involved recently with people and organisations working in the area of hospice and palliative care. What I found intriguing was their interest in a public health approach to death and dying. As noted by Dr. Alan Kellehear, a UK-based social scientist working in this area, “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”.

On the face of it, adopting a public health approach in palliative care may seem odd, since public health is focused on preventing death and disease. But in the field of prevention we talk about several levels of prevention, beginning with ‘primordial prevention’ – looking upstream at the large environmental, social, economic and cultural factors that shape our health – and primary prevention. The latter is focused on preventing a disease or injury from occurring in the first place; think of immunisation, or creating a non-smoking society.

But there is also a less well-known form of prevention: Quaternary prevention. This is concerned with preventing harm within health care, including preventing an ‘unhealthy’ death. That puts us in the same business as palliative care and hospices. But they are also interested in public health for another reason; our community orientation, and especially our interest in creating healthy communities.

Pallium Canada, a national organization created to improve the quality of hospice and palliative care services, notes that a public health approach to palliative care “takes the responsibility . . . from a few highly trained specialists to a community that considers it ‘everybody’s business’”. This approach is known internationally as Compassionate Communities, a concept championed since the 1990s by Dr. Kellehear.

In a 2013 article, he reported that a survey of more than 200 UK palliative care programs found a significant number of them were developing ‘compassionate community’ programs. He suggested that “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”. Pallium has now brought this concept to Canada, launching its initiative in the fall of 2015.

Here in BC the BC Centre for Palliative Care has also endorsed the Compassionate Communities approach, noting that it can provide “access to the many social aspects of care that are not provided by the health care system . . . but which are central to the well-being of patients with advanced illness and their family / friend caregivers”.

But it seems to me compassion is something we need more generally in society, not just in dealing with death, but in living life. So I am heartened by the wider mandate assumed by one of the Compassionate Communities pilot sites, Windsor-Essex in Ontario. There the aim is “to increase the happiness and connectedness of everyone in the community, raise quality of life for citizens with life-long care needs, and to reduce the inequitable outcomes experienced by the most vulnerable”.

Their approach includes creating neighbourhood networks through social media to enable people to “to watch out and care for one another”; a ‘Distress Outreach’ system, operated through the Distress Centre that “aims to ensure that those who need help do not fall through the cracks”, and

creating a 'Citizens' Care Hub'.

The Hub is intended for “people in their last year of life, with dementia, or who need personal support such as help with eating, dressing and bathing - that is, people who need a high degree of social and practical help as well as medical care to live well”. The people and their caregivers are then linked to a community volunteer, who helps them set up their volunteer personal care team.

Interestingly, the Windsor-Essex project is also involving young people by using “tech savvy students . . . to help out with technical support”. This fits well with another aspect of the Compassionate Communities approach promoted by Pallium; the Compassionate School, which is “a place of learning that incorporates death education into its curriculum”. I see this as an important step in re-introducing the reality of death and dying into our lives, and making our communities more compassionate.

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