Compassionate Communities

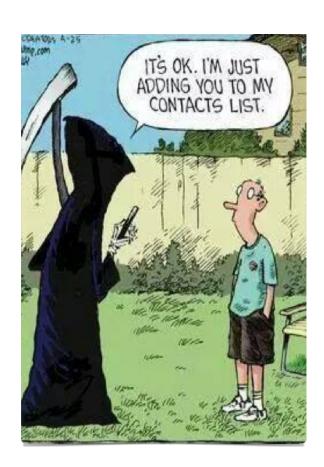
Kathy Kortes-Miller, MSW, PhD

Lakehead University

Centre for Education and Research on Aging and Health

Thinking about death

- Reactions to Death
 - Emotional impact to death is very different from birth
 - Some theories believe we live in an era of "invisible death": we cope with death through denial
 - Cultural taboos about discussing death is weakening, however



Dying in the Past....

- Normal and routine
- Death and loss are inevitable and universal
- Built on community relationships
- Considered the individuals as active citizens in community
- End of life care is more than medical care

Currently...

- 1% of our population is always in the last year of life
- 3 out of 4 visits to the GP/Family doctor in the last two months of life are for social concerns (reassurance, affirmation, accompaniment)
- An individual who is dying spends 95% of their time living in their community yet 95% of the focus of end of life is spent on the delivery of healthcare.

Public Health Approach to Palliative Care

Making death, dying and bereavement everyone's business (Kellehear, 2005)

Expanding our approach to health care to include the community as genuine partners – not simply as targets of our service provision

FROM: direct services, clinical, face-to-face, bedside, acute care, or institutional approaches

TO: community, health promotion, partnership approaches

Health-promoting palliative care encourages palliative care services to adopt a public health approach by extending end-of-life care collaborations to community partners. (Beer Mat example)

Why change how we think about dying and death?

- Need to address grief and loss which is also part of EOLC
- Need to go beyond illness bound view to include carers
- Economic argument burden on acute services can be eased
- Many prefer to remain in the community as long as possible
- Professional care is episodic; everyday care goes beyond this
- EOLC is for the well and the ill; it is everyone's responsibility

DEATHLITERACY

- Death literacy is knowledge about, and understanding of, the death system. The resulting skills strengthen individual and community capacity to take action and care for one another at times of dying, death, loss and grief.
- It is part of the new public health framework in which citizens are central to decision-making about, and access to, end of life and death care options
- Kerrie Noonan, Debbie Horsfall, Rosemary Leonard & John Rosenberg (2016)
 Developing death literacy, Progress in Palliative Care, 24:1, 31-35

Health promotion

- Health-promoting palliative care acknowledges the social character of dying and provides for the continuing healthcare needs of people with life-threatening/limiting illnesses in community settings.
- The aim is to improve health and wellbeing at the end-of-life.
- However, a public health approach to end-of-life care goes further still to encourage communities to develop their own approaches to death, dying, loss and caring.
- This is often achieved through educational activities delivered in community development programmes that enable community members to identify their unique needs.

Expanding the responsibility for end of life care

Go beyond an illness-bound view of end of life care

- Including older people
- Including both the well and the ill
- Including carers and family (biological and chosen)
- •Including schools, workplaces, businesses, unions, places of worship, media, and leisure sites and groups

.....Applies our own Ottawa Charter for Public Health, to end of life care

- Building healthy public policy
- Creating supportive environments
- Strengthening community action
- Developing personal skills
- Re-orienting health services
- Re-orients volunteers to community development

Pan-Canadian definition of a Compassionate Community (Sept 2020)

A community of people who are passionate and committed to improving the experiences and well-being of individuals who are dealing with a serious health challenge, and those who are caregiving, dying, or grieving.

Members of a Compassionate Community take an active role in supporting people affected by these experiences. This can be done through connecting people to helpful resources, raising awareness about life and end of life issues, and building supportive networks in the community

In a Compassionate Community initiative there is a clear evidence of two things:

• The initiative is led by the community: Community members, groups, and organizations work closely together to set priorities for the initiative, lay out a plan of actions, and pool existing resources from the community to implement agreed upon actions. They may even share co-leadership responsibilities.

• The initiative's support activities are <u>delivered in community settings</u> closer to people's homes, in contrast to programs and services that are delivered primarily in clinical care environments.

Talking with our Communities

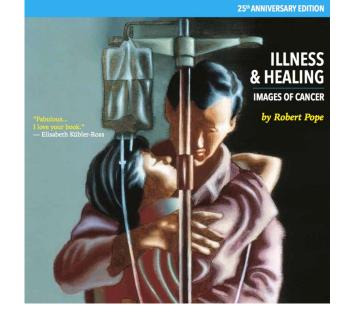
What if????

- We all knew what to do when someone was dying?
- End-of-life carers felt deeply supported by their friends, work colleagues and larger communities?
- We were all better at accepting and offering help?

The Big Picture "How"

- Community engagement and development agencies (bottom up)
- Public Education in death, dying, caregiving and loss cultural changes (across)
- Social ecology civic changes (top down) (Bill C-20 extend bereavement leave under the Canadian Labour Code)
- All these (above) to be a parallel set of social strategies

Getting Started: Some examples



- Poster campaigns
- Death café nights
- Art exhibition Robert Pope https://robertpopefoundation.com/aboutrobert-pope/the-artist/
- Book Chats
- Public forum on death & loss
- Adoption of Compassionate City Charter: https://www.compassionatecommunitiesuk.co.uk/the-compassionate-city-charter
- Movie Nights
- Compassionate Watch/Befriending programmes

It's time to shift our focus

- "Pain Management is the easy part. Communities of support is the most meaningful. Time to reframe the most important" Julian Abel
- "Network Centred care rather than patient centred care at EoL we live in the context of people around us" — Julian Abel
- "We have put too many of our eggs in the healthcare basket and left the community behind, we need to think like social activists" Barbara Gale
- "If it doesn't happen in the community it doesn't happen" Zippy Ali
- "We don't normalize, we socialize" Jessie Williams
- "How can we make the integration of palliative care and public health seen as a public health achievement." Ross Upsur

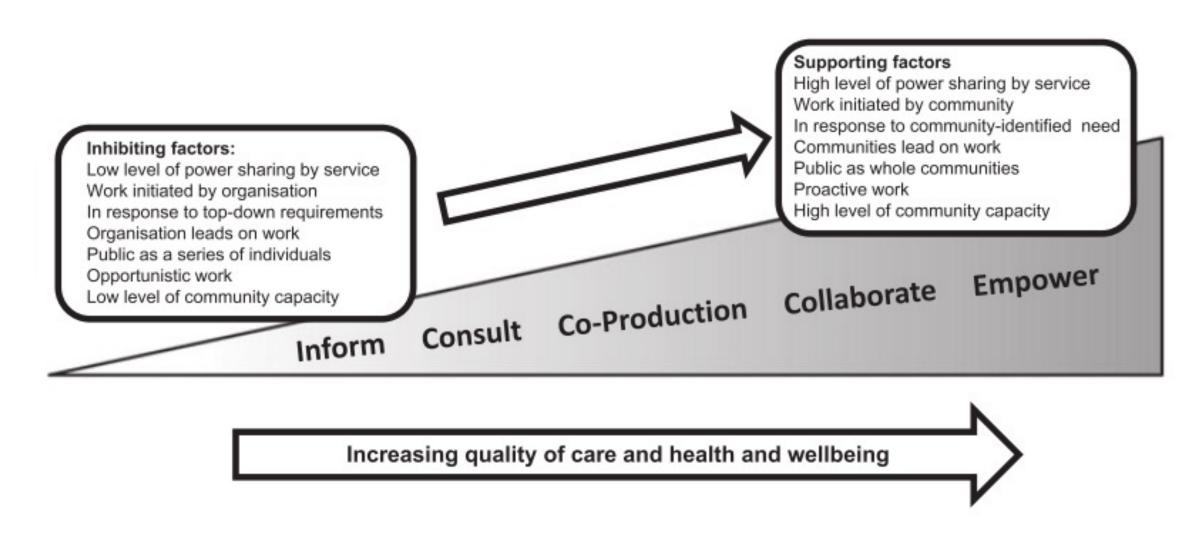


Figure 1. Spectrum of engagement in end-of-life care: developing community capacity.



Who bears the responsibility?

• "For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community." (WHO PH Strategy)

Community engagement and education required

Leadership from Palliative Care AND Public Health Communities

Imaginative collaboration needed

What does success look like...?

- We have begin to socialize death, dying, loss and bereavement
- Advance care planning conversations are part of everyday discussions at all ages and among all populations
- Compassionate communities projects everywhere
- Culture shift drives policy change

"Death, dying, loss and care is everyone's responsibility. A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life."

- Public Health Palliative Care International

To get started:

- Compassionate Ottawa: https://compassionateottawa.ca
- BC Centre for Palliative Care www.bc-cpc.ca
- Hospice Palliative Care Ontario www.hpco.ca
- Pallium Canada www.pallium.ca
- https://www.pallium.ca/toolkits/startup-toolkit/
- Public Health Palliative Care International: https://phpci.info/tools