COMPASSIONATE CITIES

A PUBLIC HEALTH APPROACH TO END OF LIFE CARE

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Introduction

- Inpatient models geographically unviable
- Cancer-focus not generalizable
- Psychosocial efforts fail the social – inadequate ideas about 'community'
- Community as patients, source of volunteers, funds, & raising awareness
- Ensuring end of life care is consistent with current approaches to health care

What is a ‘public health’ approach to palliative care?

- 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 INCLUDE**: communities and neighborhoods, civic partnership approaches, and the promotion of health and wellbeing

Why?

- To enable end of life care to conform to current developments in the rest of the health care system – palliative care as acute care & disaster mgt
- To address the burden of morbidity and mortality associated with living with life-limiting illness or loss, and the care of both ('co-morbidities')
- The epidemiology of primary care (the 40% rule – the inseparability of health & social care)
- To re-engage the community whilst recognizing the limits to professional care and service provision (Remembering the 95% rule)
- To recognize the increasing limits to national budgets for direct services of all kinds (100% and decreasing)
- To remind ourselves and our community that end of life care – like all health care – is in fact everyone's responsibility

Expanding the responsibility for end of life care

- Going beyond an illness-bound view of end of life care – esp cancer
- Including older people
- Including both the well and the ill
- Including carers and the bereaved
- Including schools, workplaces, businesses, unions, places of worship, media, and leisure sites and groups

Conceptual & practice emphasis

- Prevention
- Harm reduction
- Health and death education
- Participatory relationships (with NOT on people)
- Community development
- Service partnerships
- Ecological/settings emphasis
- Sustainability

Creating 'compassionate communities': some examples

- Poster campaigns
- Trivial Pursuit/World café nights
- Positive grieving art exhibition
- Compassionate Watch programme
- School and workplace plans for death & loss
- Nursing home pub
- Annual short story competition
- Annual Peacetime Remembrance day
- Compassionate Cities & Communities Movement

Compassionate City Charter

1. School policies or guidance documents for dying, death, loss and care
2. Workplace policies or guidance documents for dying, death, loss and care
3. Trade unions to work with employers for policies or guidance documents for dying, death, loss and care
4. Our churches and temples have a dedicated group for end of life care support
5. Our city's hospices and nursing homes have a community development program
6. Our city's major museums and art galleries hold annual exhibitions on the experiences of ageing, dying, death, loss or care

The Compassionate City Charter (continued)

7. Our city hosts an annual peacetime memorial parade ("March of Memories")
8. Our city has an incentives scheme to celebrate and highlight the most creative compassionate organization, event, and individual
9. The city will showcase its current achievements and services in ADDLC
10. The city will work with print and social media to organise annual short-story or art competitions around the themes of ADDLC
11. We will focus on diversity in everything we do
12. We will not forget the vulnerable (ie homeless, prisoners, refugees, etc)
13. We will review after 2 years and add another sector every year (eg higher ed, emergency services, sporting associations, etc)

What did success look like?

- Greater participation in end of life care from all sectors of the community
- Increase in active partnerships from the different end of life care sectors – palliative, aged, bereavement, public health, intensive care, emergency services, etc
- Greater recognition and connection between previously unconnected groups – cancer, HIV, aged care, youth, children
- New local policy developments in schools, workplaces, local govt, unions, galleries, around matters to do with DDLC

What did success look like?

- A greater sense of ‘normalization’ around DDLC
- Lowered primary care and emergency service useage
- Government policy changes in Australia, Canada, England, Scotland, Taiwan
- Major practice experiments in Austria, Germany, Ireland, India, Spain, Switzerland, South America.
- Sharp international rise in academic/clinical papers and books on this approach
- The International conference series and PHPCI (www.phpci.info) – taking the social in “social support” more seriously and critically

The overlooked palliative care 'facts' that make this approach important

- The longer part of dying occurs outside of institutional and professional care (The 95% Rule)
- Palliative care is also about grief and loss
- Dying, loss and grief are not medical matters but rather social relationship matters with medical dimensions. (Dying is not an ingrown toe nail and grief is not normally a psychiatric problem)
- 'Invisible groups' are subject to surprise, ignorance, fear, or even celebration from others. In these ways they become disenfranchised or estranged from the dominant players.

Key broad challenges

- Recognize the limits to service provision
- Restore end of life care to the wider public health sphere of policy, practice, and language
- Understand and facilitate the principle that end of life care is everyone's responsibility – it is a CIVIC responsibility
- Recognize that the successful delivery of palliative care holism means to deliver a public health holism

Practice implications

- Death education/literacy for all
- Community development initiatives
- Community and service partnerships
- Reorientation and diversification of volunteers
- From bedside to public health (learning to do both)
- Rise of public health workers (making new friends)
- Providing Leadership not Control

Further Reading

- A. Kellehear (1999) Health promoting palliative care. Oxford University Press.
- A. Kellehear (2005) Compassionate cities: Public health and end of life care. Routledge.
- L. Sallnow, S. Kumar, & A. Kellehear (eds) (2012) International Perspectives on public health and palliative care. Routledge.
- K. Wegleitner, K. Heimerl & A. Kellehear (eds) (2016) Compassionate Communities: Case studies from Britain and Europe. Routledge.
- See also: http://www.phpci.info/#!resources/c52k