
Community Palliative Care: Service Provision or Community Engagement?



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Whose business is dying?

“Death disappeared from community life and communal awareness and [was]...relocated as an individual experience occurring within the defining power of the medical expert.”

(Clarke & Seymour, 1999: 90)



A potted history of the world (of hospice)

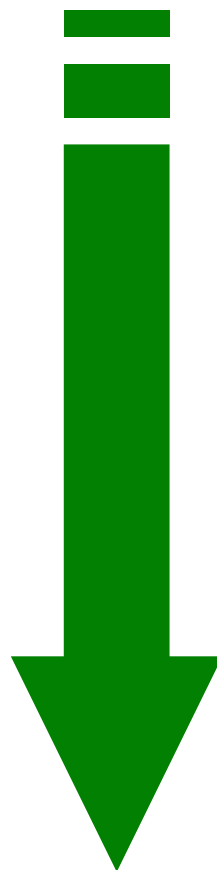
↑ health care by professions including care of dying people

A 'small rebellion' – the modern hospice movement

Specialisation and recognition

Gradual re-entry of PC into mainstream health care

Community-based PC aligned to institutional service models



↓ Involvement of family and community in care of dying people

Local development of hospices with community involvement

Professionalisation of palliative care;
↓ involvement of family and community in care of dying people



Is this still true today?



“Death disappeared from community life and communal awareness and [was]...relocated as an individual experience occurring within the defining power of the medical expert.”

(Clarke & Seymour, 1999: 90)



Whose business is dying?

- “The experiences of serious illness, dying, caregiving, grieving and death cannot be understood within a medical framework alone.
- “These events are personal, but also fundamentally communal.
- “Medical care and health services constitute essential components of community’s response, but not its entirety.”

(Byock et al., 2001: 760)



A critique of conventional palliative care

- Holistic paradigm retained and articulated in PC
- Yet emphasis on the physical, at the expense of psychological, social and spiritual domains

Kearney, 1992; Kellehear, 1999



A critique of conventional palliative care

“...so many ‘psychosocial’ programs or models in palliative care seem to have no underlying philosophy or theory.

“Who can blame students of palliative care who might mistakenly believe that these kinds of interventions ... are so arbitrary that anyone can simply invent them?”

(Kellehear, 1999: xiv)



A framework for community engagement

“The social expression of compassion should not be idiosyncratic; its analysis should not be impressionistic.

“The delivery of effective professional care always arises from planned and organised models that are both philosophically sound and sensitive to the everyday realities of people’s experience.”

(Kellehear, 1999: xiv)



Health Promoting Palliative Care

“Health promotion is not a complicated idea. Basically it is any combination of strategies that are designed to improve people’s health.” *(Kellehear, 1999: 10)*

“Since health is a desirable goal for all and death and dying are essential to a meaningful life, then palliative care may be viewed as a health promoting activity.” *(Russell & Sander 1998: 266)*



Features of health promotion

- Participatory
- Recognises social character of health and illness
- Emphasises education, information, and policy development
- Designed for the well and the ill
- Everyone's responsibility, not just the individual's

(Kellehear, 1999)



The Ottawa Charter for Health Promotion

- Promoting health and wellbeing for “**all** of life’s stages...” *(WHO, 1986)*
- Health promotion elements
 - Build public policy
 - Create supportive environments
 - Strengthen community action
 - Develop personal skills
 - Reorient health services



Putting the Ottawa Charter into practice

A Health Promoting Palliative Care Service:

- Involved in the development and/or uptake of **public policy** relating to palliative care and the support of dying people.
- Contributes to the creation of **supportive environments** to enhance well-being for consumers *and* employees of the palliative care service.
- Engaged with the wider community, beyond the recipients of palliative care services, to promote **community action** towards improved support of people at the end of life.

(Rosenberg & Yates, 2009)



Putting the Ottawa Charter into practice

A Health Promoting Palliative Care Service:

- Participates in the development of **personal skills** to assist individuals to deal with issues around death and dying, including both health care professionals and primary caregivers.
- Reorients its members to a **health promoting approach**, with a particular focus on the holistic needs of its client population, and changes in organisational attitudes.

(Rosenberg & Yates, 2009)



Putting the Ottawa Charter into practice

A Health Promoting Palliative Care Service:

- Provides education and information about health, dying and death
- Provides social supports, especially personal and community supports
- Encourages inter-personal problem-solving
- Encourages reorientation of palliative care services
- Combats death-denying health policies and attitudes

(Kellehear, 1999)



A focus on community engagement

Robust engagement with the community in provision of education for living and dying, including consumer information:

- Accurate information/resources:
 - Treatment options: mainstream, complementary
 - Resources available
 - Wills, advance care directives
- Public education and awareness
 - Generic EOL information
 - PC service information
- Support groups for patients/families



A focus on community engagement

- Community involvement:
 - funding
 - distribution of material
 - sponsorship of promotional activities
- Grief support
 - local funeral directors,
 - churches/community groups
- Media profile
- Public forums



Community engagement: Australian example #1

EXAMPLE ONE: Karuna Hospice Services

- Community palliative care service
- Based on Buddhist principles, mindful of human impermanence and the exercise of compassion
- Metropolitan, regional and rural



Community engagement: Australian example #1

Strengthening community action

“We’re now looking to benefit people in a much broader spectrum of the community.

“While our core business remains home-based palliative care, and education and support for families, it’s also looking at affecting community attitudes to life and living, death and dying, funerals, the whole topic of death and preparing for death.” [senior staff] *(Rosenberg, 2007: 288)*



Community engagement: Australian example #2

EXAMPLE TWO: PallNet

- Fraser Coast, Queensland
- Vision statement: *“Promoting coordinated, accessible care and support at the end of life”*
- Key stakeholders from government providers, non-government community and RACF providers, General Medical Practitioners, consumers/carers, chaplains, local government, funeral directors, community groups, business groups



Community engagement: Australian example #2

Community stream:

- Aim to raise awareness of issues of death, dying, grief and loss
- Strategies include:
 - provision of information resources
 - public speaking
 - other public forums to cancer support groups, volunteers, National Seniors, Country Women's Association, Tiaro Business Group, 60 and Better, Mensheds, etc.



Community engagement: Australian example #2

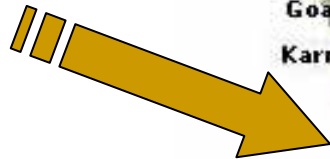
- **PallNet** Palliative Care Service Development Officer
 - Employed by GP Links Wide Bay
 - Governance by PallNet Core Group
 - Attends to aims and strategies outlined above



Community engagement: an International example



Kerala State



Community engagement: an International example

- Inaugural International Conference on Palliative Care and Public Health
- 16-17 January 2009
- Institute of Palliative Medicine, Calicut, Kerala, India



Community engagement: an International example

- Why Kerala?
 - WHO demonstration site – public health/health promotion framework in palliative care
 - State Government mandated
 - Community based organisations – Neighbourhood Network in Palliative Care [NNPC]
- Area: 38,863 km² (slightly larger than SEQ, pop: ± 2,800,000)
- Population ± 34,000,000
- Agricultural, fishing



Community engagement: an International example

- Palliative care in Kerala:
 - ± 180,000 deaths/year
 - ± 80,000 deaths/year are potential beneficiaries of PC
 - ± 100 palliative care units supported by CBOs
 - In partnership with government (State and Municipal)
 - ± 4,000 trained volunteers
 - Areas of rudimentary service provision
 - Fulltime PC personnel: 25 medical practitioners, 15 nurse specialists, 50 nurses



Community engagement: an International example

- Koyilandy
 - Small city and municipality
 - Pop: ±70,000
- One NNPC service



Community engagement: an International example

- NNPC
 - Community ownership
 - Community – government partnership: policy and practice
 - Primary care in home
 - One medical practitioner, two registered nurses
 - 2hrs/wk minimum from each volunteer
 - Sustainability



Community engagement: an International example

- Volunteering
 - Recruitment – schools, temples, mosques, churches
 - Training – formalised training
 - Duties – compared to western



Revisiting the Ottawa Charter in practice

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Putting the Ottawa Charter into practice

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The potential of community engagement

■ Consumers/patients

- Recipients of response to whole person in personal, interpersonal and social contexts
- ↑ skills, ↑ control, ↑ sense of wellbeing

■ Community

- ↑ skills, ↑ resilience, ↑ active input into EOL issues
- new understandings of “ownership” of end of life in the community



The potential of community engagement

- **Service providers / palliative care profession**
 - retain holistic models of care
 - retain advances made in symptom control, clinical care
 - ↑ volunteer recruitment
 - potential, new funding sources
 - ↑ skills, including new “social” skills
 - new understandings of “ownership”: we are an essential component of a community’s response to the end of life, but not its entirety



Community Palliative Care: Service Provision or Community Engagement?

- Both!
- Thank you for your attention today
- Contact:

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