UNDERSTANDING THE IMPACT OF NEW PUBLIC HEALTH APPROACHES TO END OF LIFE CARE

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“To allow people the deaths they want, end of life care must be radically transformed...”

DYING FOR CHANGE

Charles Leadbeater
Jake Gurrier

Fig. 1 Estimated number of people requiring palliative care from 2006 to 2040. Projections of overall population palliative care need according to International Classification of Disease-10 estimates. Solid lines indicate estimates based on actual mortality data. Dotted lines indicate projection models. Note: projection method 1 is not presented in this figure, since it produces very similar results to projection method 2 (assuming proportion of palliative care needs constant). See also Table 3.

Thinking beyond clinical solutions...
Public health research perspective

Patient care/health service research perspective

Public health research perspective (interventions)

Patient care/health service research perspective (interventions)

Sallnow, Tishelman, Lindqvist, Richardson and Cohen, *Progress in Palliative Care* 2015; 24: 25-50
100 million people need palliative care each year, 8 million have access to it.

90% of the world’s morphine is used by 16% of the population.


0.1 of 298.5 metric tonnes morphine distributed p.a. in low income settings.

Knaul, FM et al. (2017) Lancet Commission on Palliative Care
Primary health care is essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.”
DECLARATION OF ASTANA (WHO 2018)
THE OTTAWA CHARTER
(WHO, 1986)

Build healthy public policy
Create supportive environments
Strengthen community action
Develop personal skills
Re-orientate health services
KEY EVIDENCE EMERGING
Figure 6. Comparison of odds (lnOR) of decreased mortality across several conditions associated with mortality.

http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316
SPECIAL ARTICLE

The Spread of Obesity in a Large Social Network over 32 Years
Nicholas A. Christakis, M.D., Ph.D., M.P.H., and James H. Fowler, Ph.D.


The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

The Collective Dynamics of Smoking in a Large Social Network
Nicholas A. Christakis, M.D., Ph.D., M.P.H., and James H. Fowler, Ph.D.

Identifying changes in the support networks of end-of-life carers using social network analysis

Rosemary Leonard,¹ Debbie Horsfall,² Kerrie Noonan²


**Figure 1** Jane’s network at Time 1.

**Figure 2** Jane’s network at Time 2.
The impact of a new public health approach to end-of-life care: A systematic review

Libby Sallnow\textsuperscript{1,2}, Heather Richardson\textsuperscript{3}, Scott A Murray\textsuperscript{2} and Allan Kellehear\textsuperscript{4}
NEW PUBLIC HEALTH AND END OF LIFE CARE

- Kellehear first described the ‘public health approach to end of life care’ (1999)
- Aligned the two apparently paradoxical disciplines

**Compassionate Communities** are community development initiatives that actively involve citizens in their own end-of-life care

Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care
Palliative Care – The New Essentials

Abel, Kellehear and Karapliagou 2018
Public Health Palliative Care International

Creating Compassionate Communities
TESTING THE MODEL
COMPASSIONATE NEIGHBOURS

• Recruit and train community members to become ‘Compassionate Neighbours’

• Support people emotionally, socially, practically in their homes

• Role of a neighbour, not professional

• Aims to make communities more compassionate places to live and die
People drawn from local community Linked with people in the community

Different demographic to traditional volunteers

Community development model

Led by a hospice
Understanding the impact of a new public health approach to end of life care:
A mixed methods study of a compassionate community
METHODS

• Exploratory mixed methods study (QUAL/quant)
  • Congruent with the principles of the project
  • Flexible – open to unanticipated outcomes
  • Engaging a wide range of stakeholders
  • Participatory

• Ethical approval through University of Edinburgh

• Participant researcher perspective

• Analysis: modified grounded theory (Charmaz 2014)
# DATA COLLECTION

<table>
<thead>
<tr>
<th>Method</th>
<th>Sample</th>
<th>Participants</th>
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<tbody>
<tr>
<td>21 interviews</td>
<td>7 compassionate neighbours, 4 community members, 4 hospice staff, 3 external staff</td>
<td>19</td>
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<tr>
<td>2 focus groups</td>
<td>FG1 – 15, FG2 - 16</td>
<td>31</td>
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<tr>
<td>Participant observation</td>
<td>19 events: Training, selection events, supervision, public events, home visits</td>
<td>450</td>
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<tr>
<td>Documentary analysis</td>
<td>Training, marketing materials, meeting minutes, evaluation forms</td>
<td>11 documents</td>
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<th>Method</th>
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<td>Observational longitudinal data</td>
<td>Compassionate neighbours, Community members</td>
<td>180</td>
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<td></td>
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<td>80</td>
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</table>
RESULTS — CENTRAL THEMES

1. Changes in wellbeing (loneliness, meaning, connection)
   - For Compassionate Neighbours >> Community Member
   - Control rather than company

2. New relationship between community and hospice
   - Mutuality versus service delivery

3. Compassion and tolerance expressed beyond the project
   - Social ecological change
WHAT PROCESSES ENABLE THESE?

1. Training builds networks rather than a new role

2. Relationships are both the process and the outcome

3. Community member ("recipient"), Compassionate Neighbour ("intervention"), Hospice ("funder") all seen as peers – relationships based on equity and boundaries blurred

4. Equitable relationships enabled reciprocity
WHAT DEFINES COMPASSIONATE NEIGHBOURS?
IMPLICATIONS

- Complement and transcend clinical offerings
  - These are not new services: not interventions that can be standardised and delivered
- Represents an upstream intervention for end-of-life care
- The new beneficiaries and outcomes have implications for designing, funding, commissioning and evaluating
- These outcomes facilitated by partnership, uncomfortable conversations and shifting power
FINAL THOUGHTS

This work goes beyond palliative care – touches on social justice, equity, social capital

What role do hospices, or other organisations, play in this, and what role does society?

How can we participate and collaborate with communities in authentic ways?