

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

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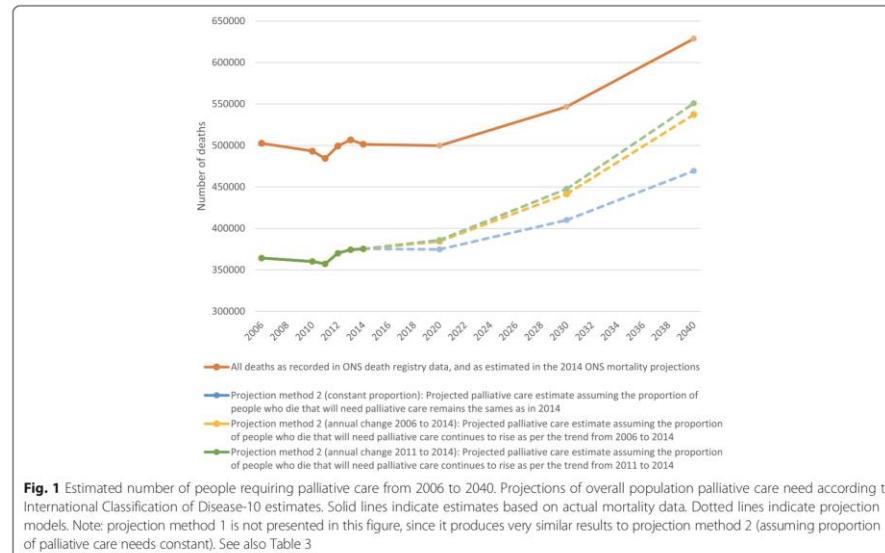
ASKING QUESTIONS

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

DYING FOR CHANGE

Charles Leadbeater
Jake Garber

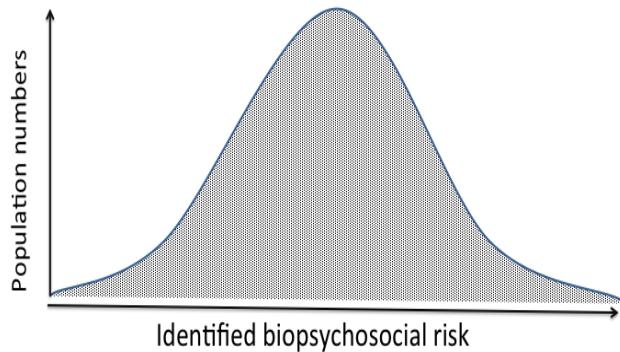
DEMOS



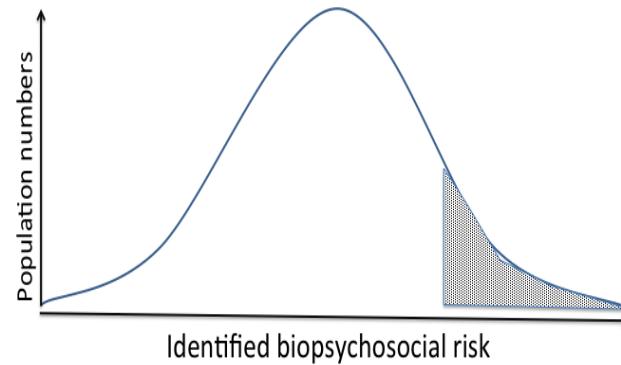
Thinking beyond clinical solutions...



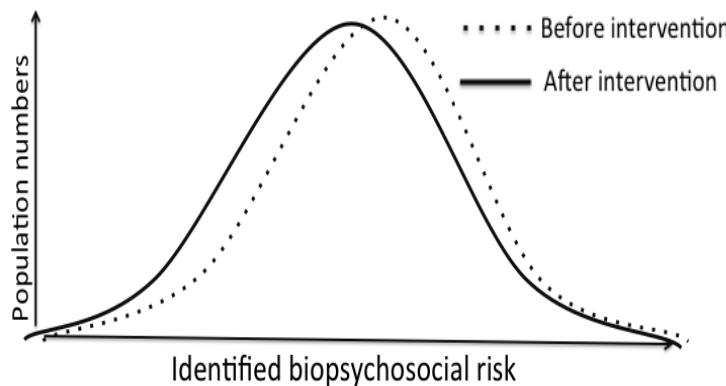
Public health research perspective



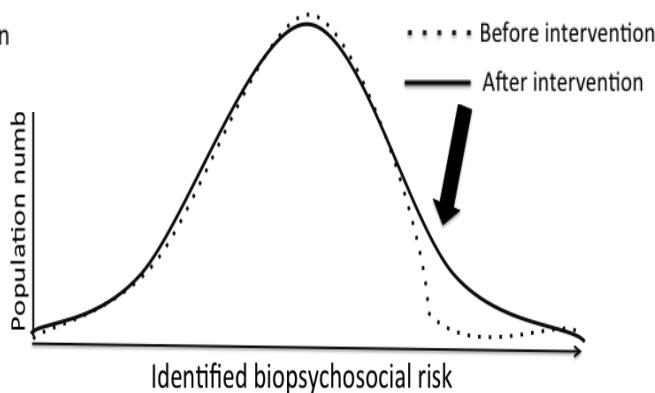
Patient care/health service research perspective



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

TRADITIONAL PUBLIC HEALTH AND PALLIATIVE CARE

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

Hughes-Hallet, T and Murray, S. (2013) Dying Healed: transforming end-of-life care through innovation

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

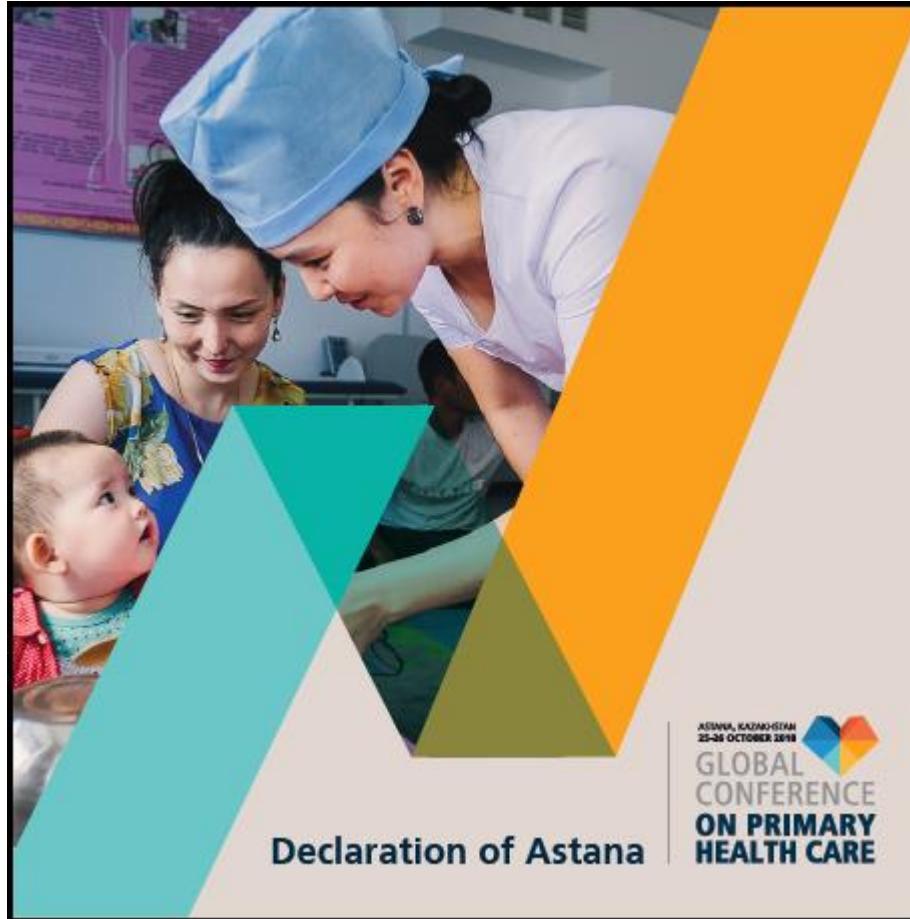


NEW PUBLIC HEALTH

Declaration of Alma Ata (WHO 1978)

“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)



ASTANA, KAZAKHSTAN
25-26 OCTOBER 2018

GLOBAL
CONFERENCE
ON PRIMARY
HEALTH CARE

Declaration of Astana

THE OTTAWA CHARTER (WHO, 1986)

Build healthy public policy

Create supportive environments

Strengthen community action

Develop personal skills

Re-orientate health services



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KEY EVIDENCE EMERGING



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Social Relationships and Mortality Risk: A Meta-analytic Review

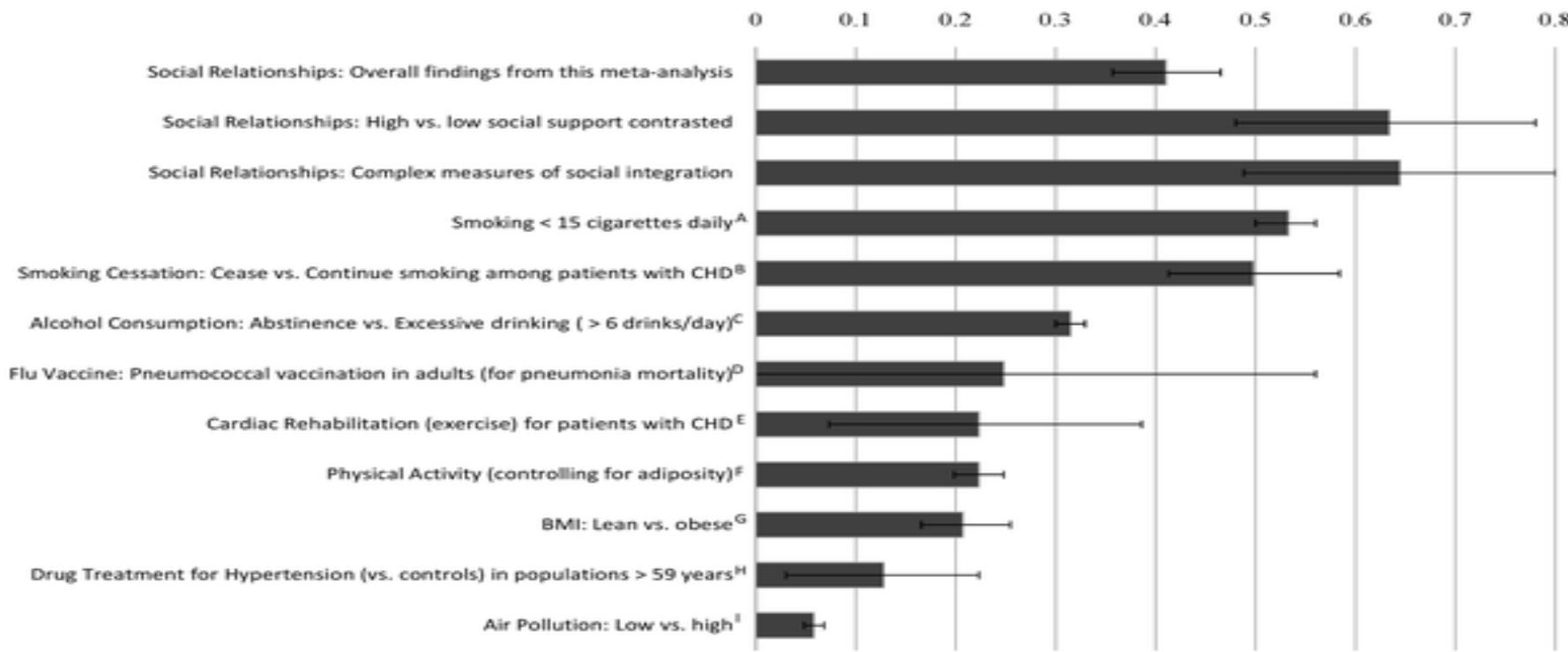
Julianne Holt-Lunstad , Timothy B. Smith , J. Bradley Layton

Published: July 27, 2010 • DOI: [10.1371/journal.pmed.1000316](https://doi.org/10.1371/journal.pmed.1000316)



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Figure 6. Comparison of odds (InOR) of decreased mortality across several conditions associated with mortality.



Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLOS Medicine 7(7): e1000316. <https://doi.org/10.1371/journal.pmed.1000316>
<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.

N Engl J Med 2007;357:370-9.

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.

N Engl J Med 2008;358:2249-58.



OPEN ACCESS

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

Rosemary Leonard,¹ Debbie Horsfall,² Kerrie Noonan²

Leonard R, et al. *BMJ Supportive & Palliative Care* 2013;0:1–7. doi:10.1136/bmjspcare-2012-000257

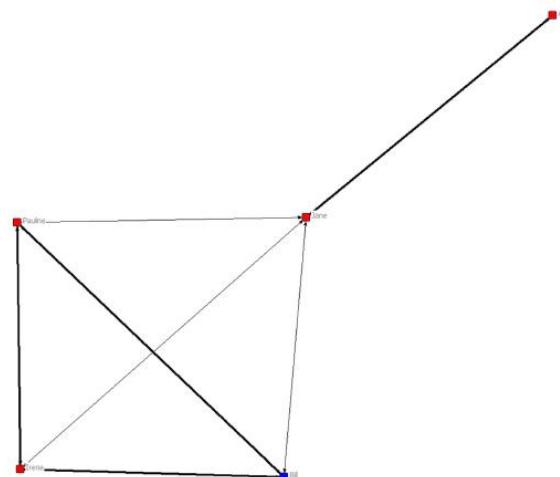


Figure 1 Jane's network at Time 1.

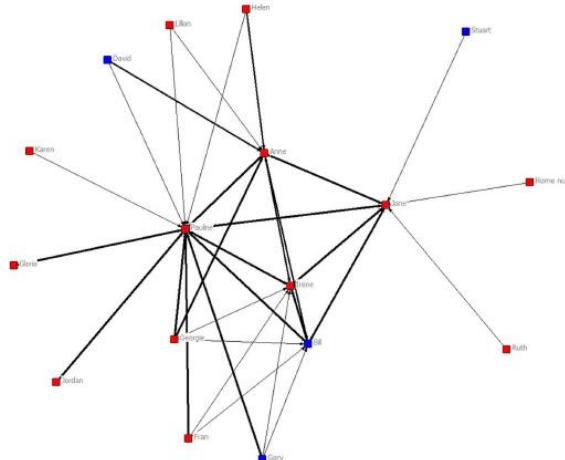


Figure 2 Jane's network at Time 2.

The impact of a new public health approach to end-of-life care: A systematic review

Libby Sallnow^{1,2}, Heather Richardson³, Scott A Murray² and Allan Kellehear⁴

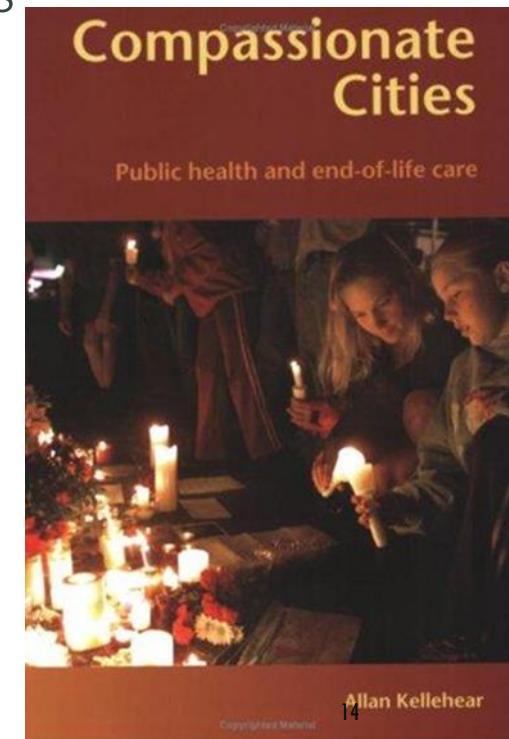
Palliative Medicine
2016, Vol. 30(3) 200–211
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DOI: 10.1177/0269216315599869
pmj.sagepub.com


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

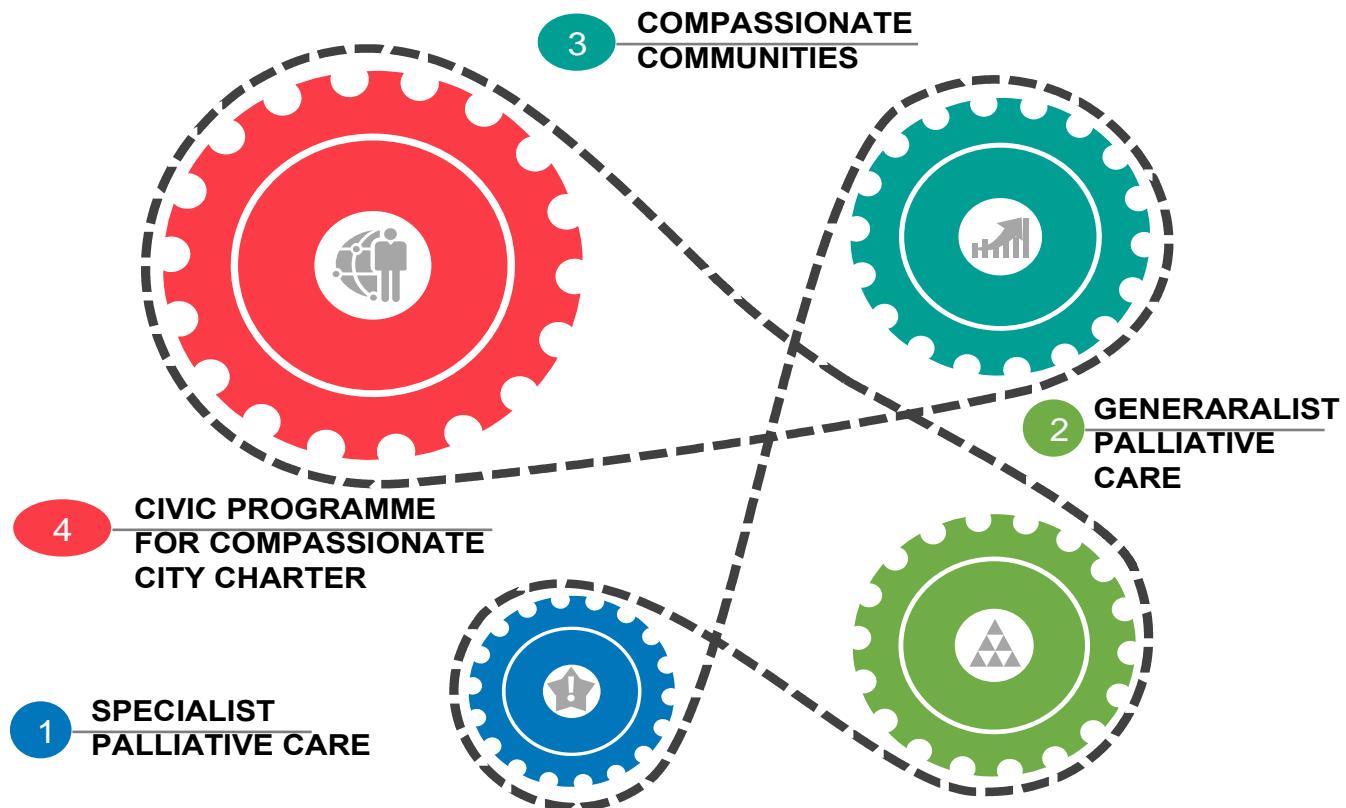
Compassionate Communities are community development initiatives that actively involve citizens in their own end-of-life care

Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care



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Palliative Care – The New Essentials



Abel, Kellehear and Karapliagou 2018



Public Health Palliative Care International

Creating Compassionate Communities



TESTING THE MODEL



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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

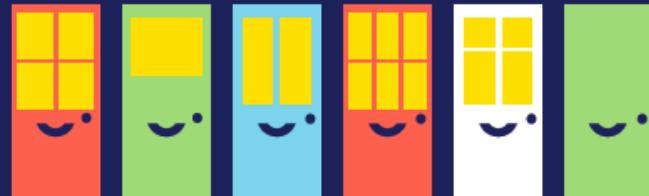
Community development model

Led by a hospice



Compassionate
Neighbours

Compassionate
Neighbours
in East London



St Joseph's
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

Method	Sample	Participants
21 interviews	7 compassionate neighbours 4 community members 4 hospice staff 3 external staff	19
2 focus groups	FG1 – 15 FG2 - 16	31
Participant observation	19 events: Training, selection events, supervision, public events, home visits	450
Documentary analysis	Training, marketing materials, meeting minutes, evaluation forms	11 documents

Method	Sample	Participants
Observational longitudinal data	Compassionate neighbours Community members	180 80

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



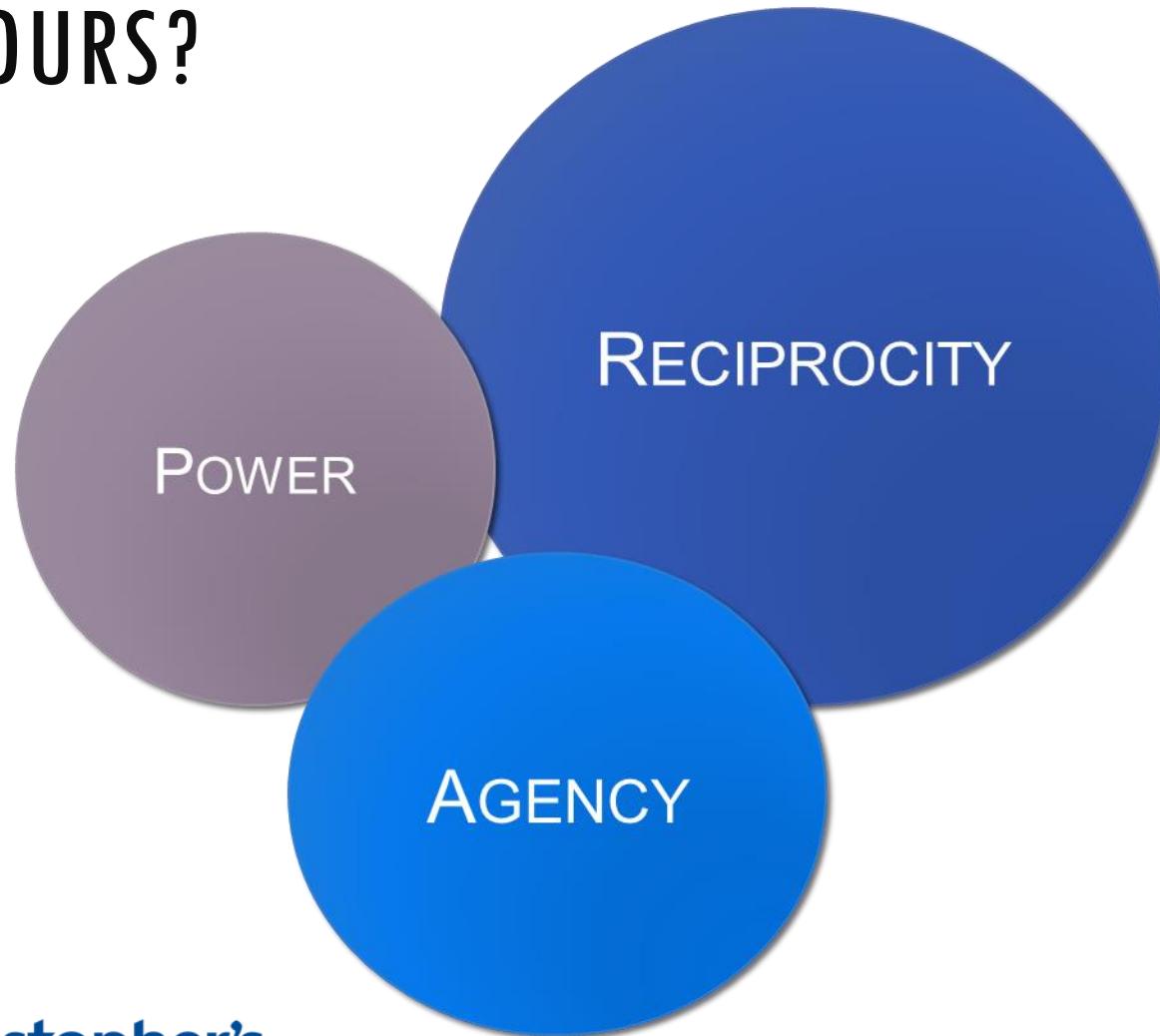
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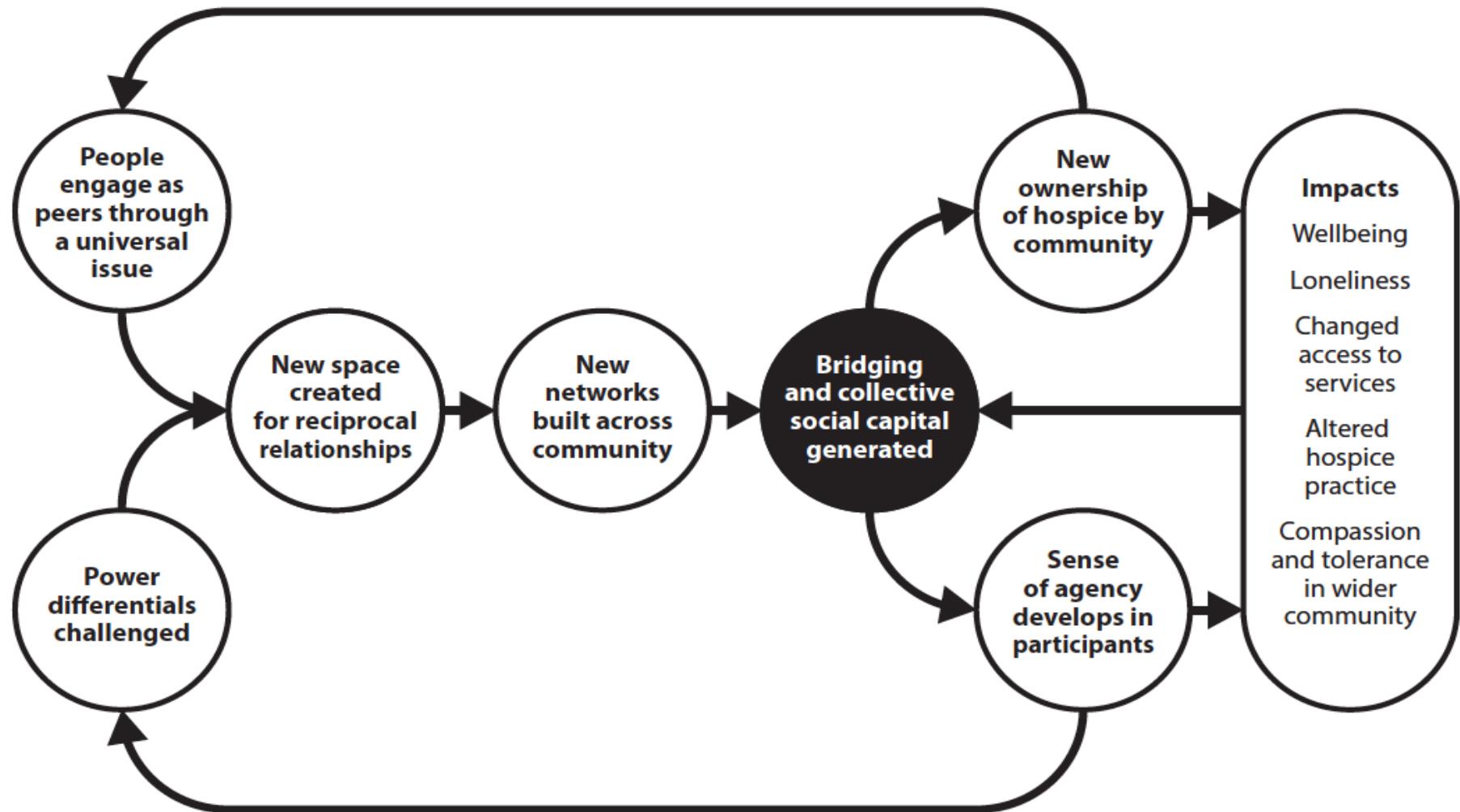
WHAT PROCESSES ENABLE THESE?

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?





Sallnow, L (2017) Collective Social Capital: a new model of social capital in end-of-life care

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?

