Compassionate Communities

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Three questions

- Why are we talking about compassionate community approaches?
- What do compassionate communities look like in practice?
- How can we understand their impact?

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Starting point

- Palliative care increasingly recognised as part of universal health care
- How are health and wellbeing created?
  - By more than clinical care alone

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Starting point

- Palliative care increasingly recognised as part of universal health care
  - Palliative care plays a role in health and wellbeing
- How are health and wellbeing created?
  - By more than clinical care alone
- Focusing on one dimension will not achieve change
- Taking this broader perspective is a public health approach

Assuming a public health perspective

- Prevention
- Early intervention
- Harm reduction

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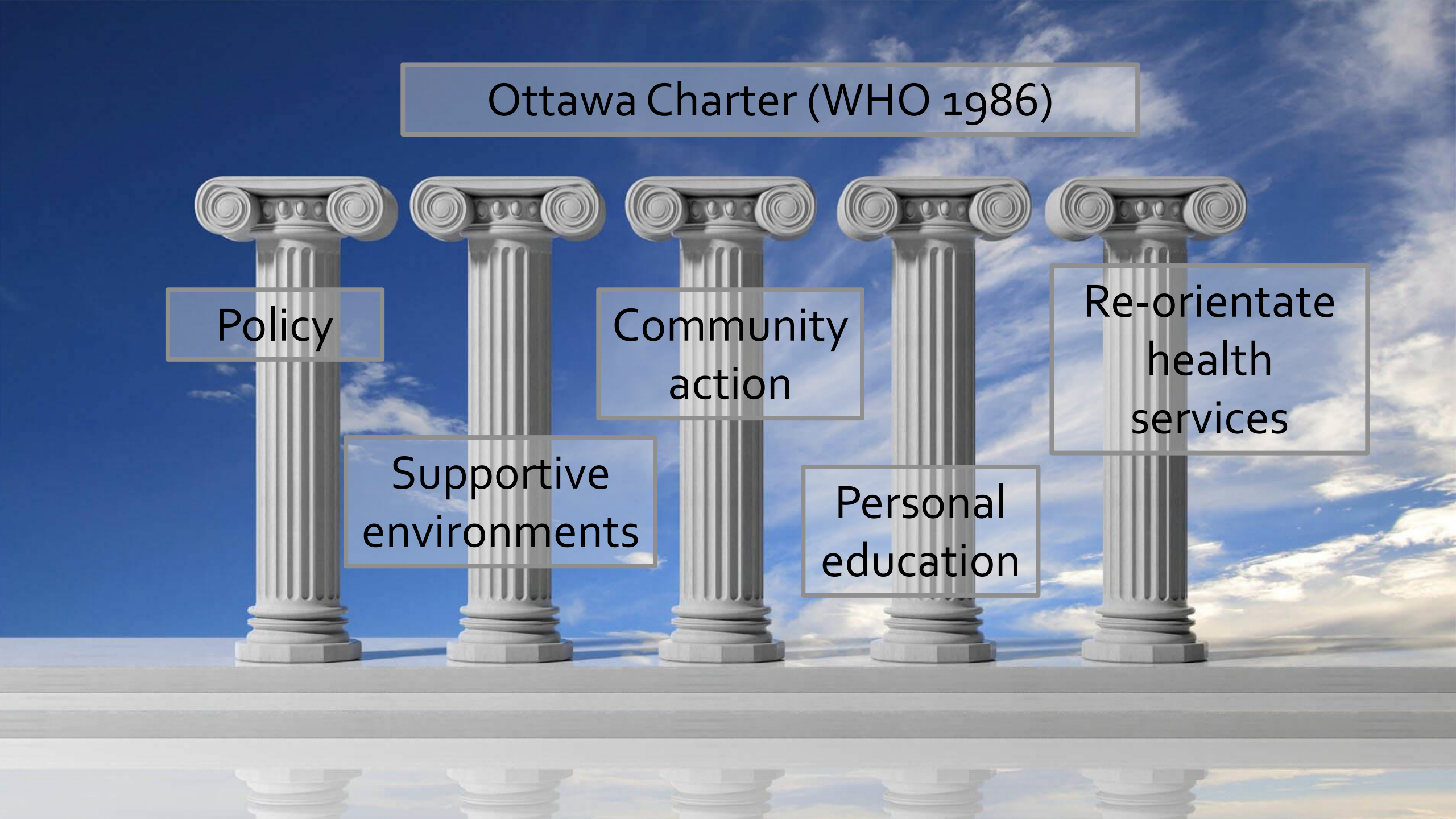
Ottawa Charter (WHO 1986)
Policy
Supportive environments
Community action
Personal education
Re-orientate health services

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But… it is not a panacea

HEALTH POLICY AND PLANNING; **16**(3): 221–230 © Oxford University Press 2001

Review article

Community participation in health: perpetual allure, persistent challenge

LYNN M MORGAN
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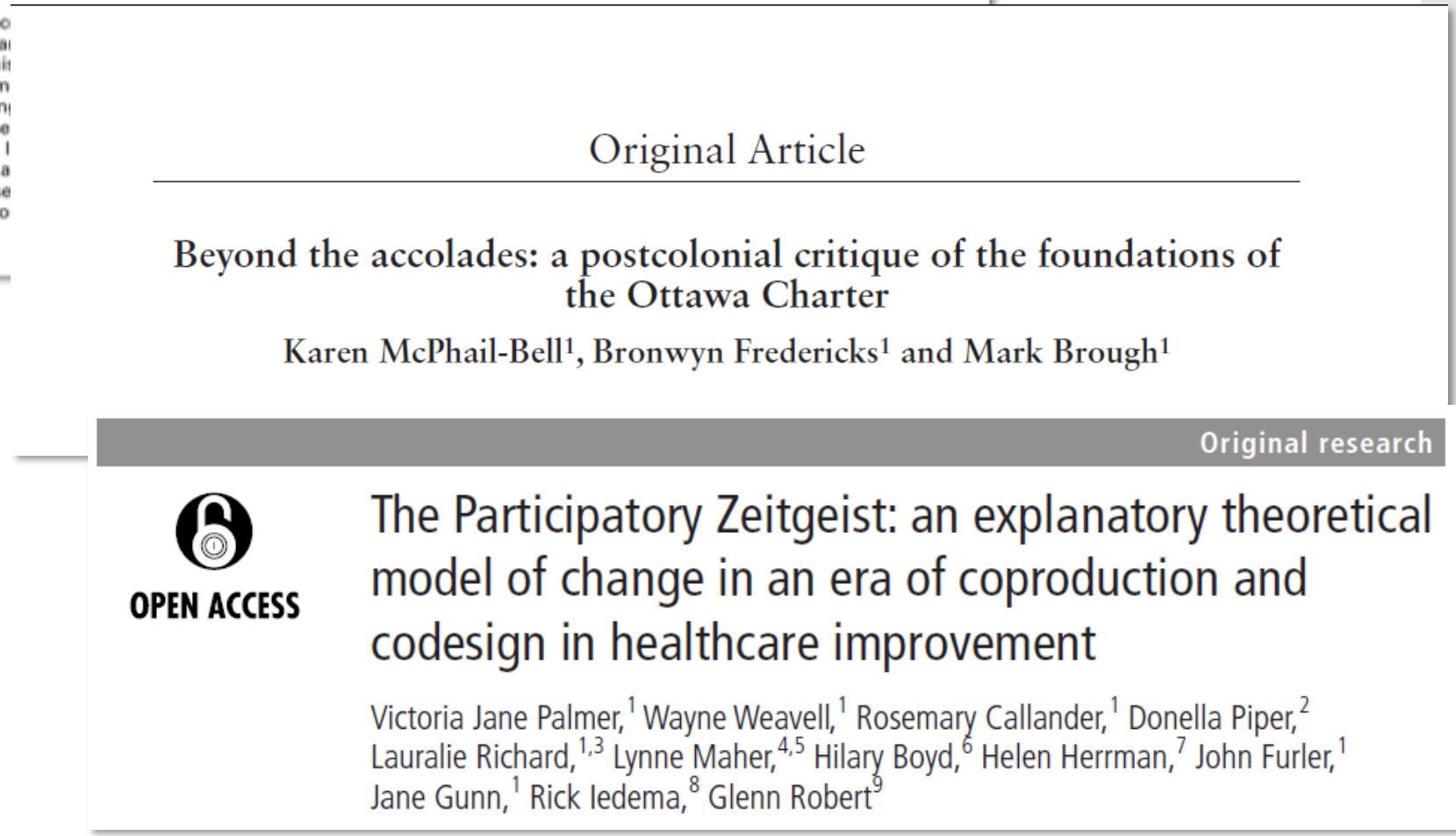

Original Article

Beyond the accolades: a postcolonial critique of the foundations of the Ottawa Charter

Karen McPhail-Bell[1], Bronwyn Fredericks[1] and Mark Brough[1]

Original research

OPEN ACCESS

The Participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement

Victoria Jane Palmer,[1] Wayne Weavell,[1] Rosemary Callander,[1] Donella Piper,[2] Lauralie Richard,[1,3] Lynne Maher,[4,5] Hilary Boyd,[6] Helen Herrman,[7] John Furler,[1] Jane Gunn,[1] Rick Iedema,[8] Glenn Robert[9]

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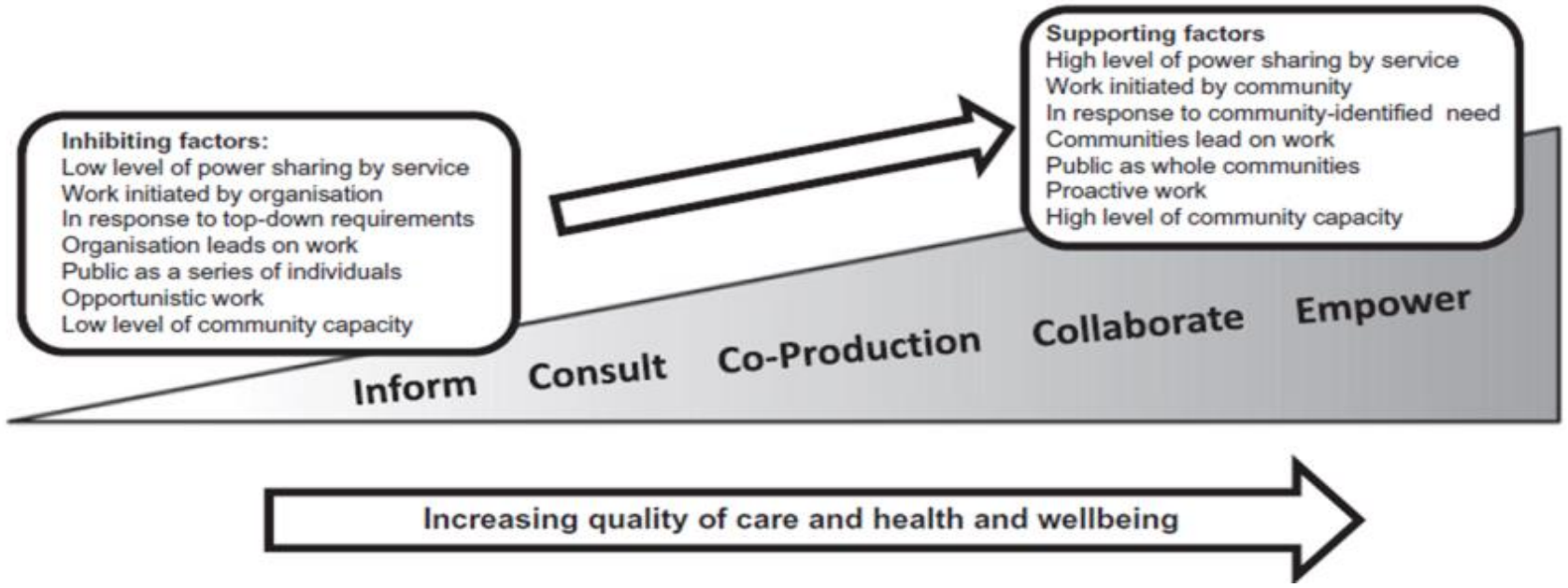
The need for conceptual clarity & to understand the principles

Understanding community engagement in end-of-life care: developing conceptual clarity

Libby Sallnow[a,b]* and Sally Paul[b,c]



Critical Public Health, 2015
Vol. 25, No. 2, 231–238, http

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New public health and end of life care

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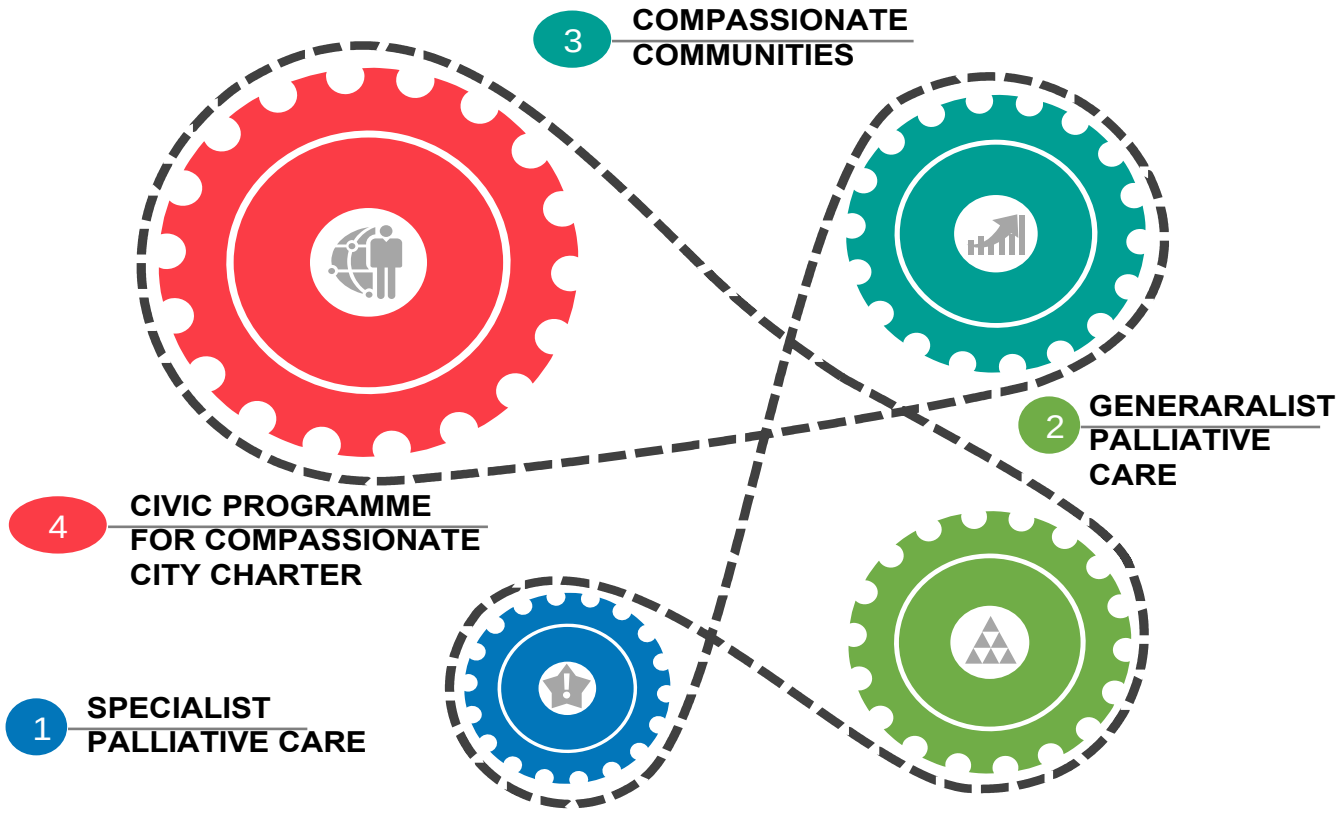
Returning to end of life care and public health

Palliative Care – The New Essentials



Abel, Kellehear and Karapliagou 2018

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Compassionate communities

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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An example

UK and Kerala

Compassionate Neighbours, UK

Neighbourhood Network in Palliative Care, Kerala

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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

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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
- Supporting people as friends rather than delivering an intervention
- Aims to make communities more compassionate places to live and die
- Community development model
- Partnership between hospice and community advocacy charity

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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)

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

Hearing from Compassionate Neighbours

- https://vimeo.com/240814701

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Results – central themes

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

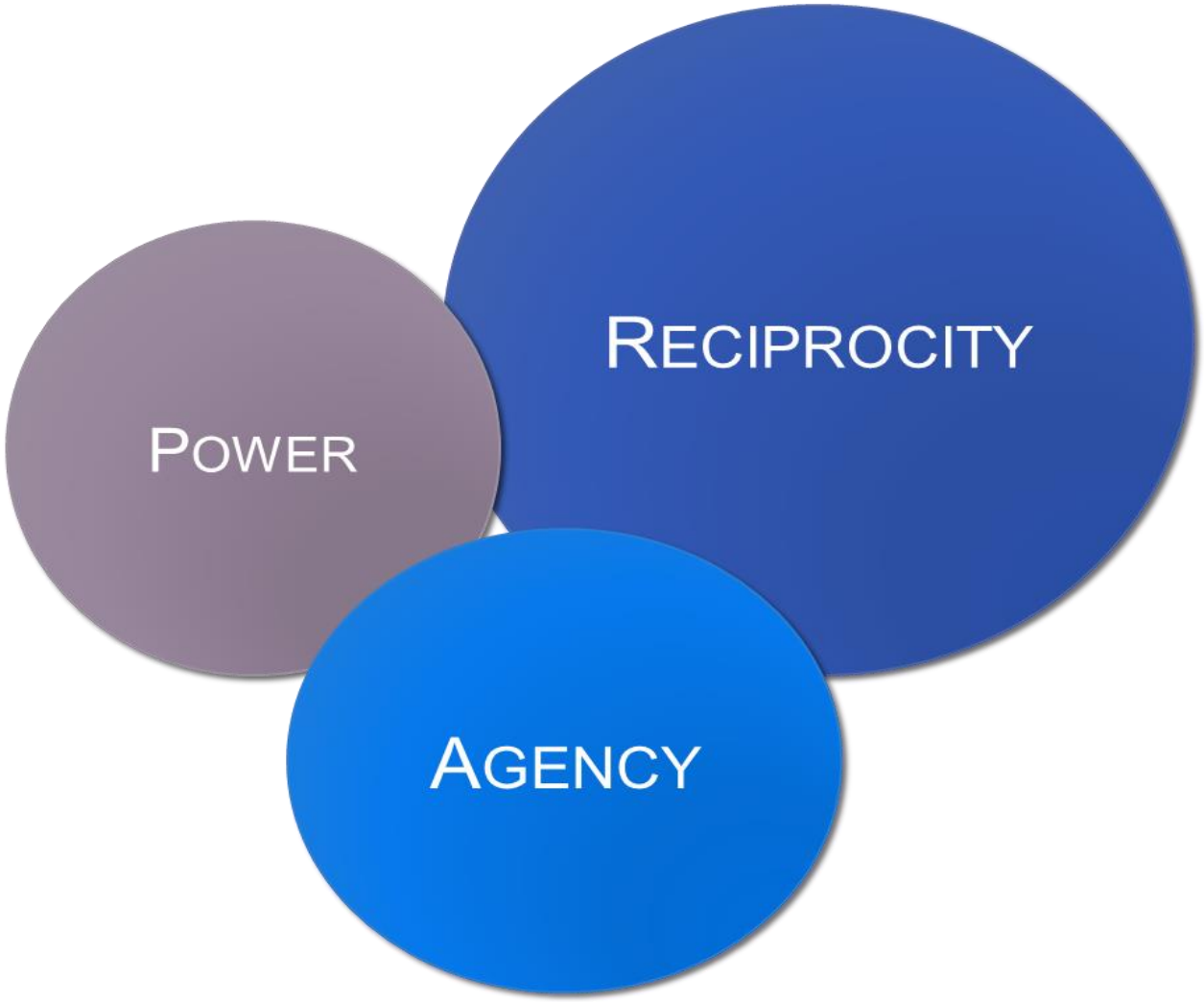
2. New relationship between community and hospice
   - Mutuality versus service delivery

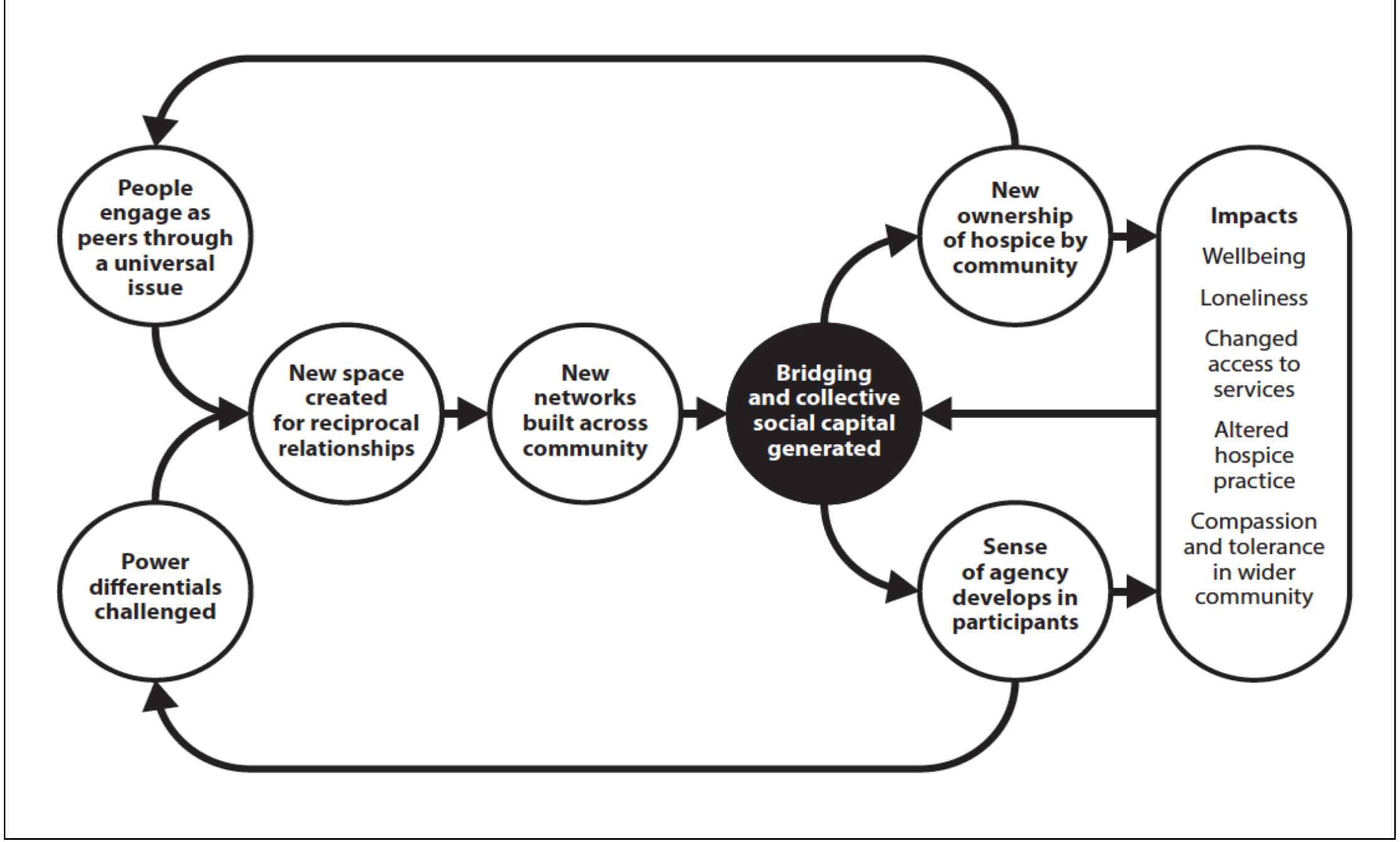
3. Compassion and tolerance expressed beyond the project
   - Social ecological change

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?





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

Summary

- Public health approaches are common-place in most areas of health & social care
- End of life care must include preventative and upstream interventions
- A developing evidence base supports this
- Considers social justice and equity alongside clinical care
- Participation and considerations of power are central

Thank you

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