

# Palliative care improves society

Professor David Clark  
Wellcome Trust Investigator  
University of Glasgow

@dumfriesshire



# Cicely Saunders

*'A society which shuns the dying must have an incomplete philosophy'*



Saunders, C. (1961) And from sudden death ... *Frontier*, Winter

# The moral order of dying

- *Micro* - dynamics of family relations, personal beliefs and assumptions, concerns and priorities at end of life. Individual experience of illness, treatment, suffering and the processes of making sense and meaning. How carers of all kinds interact with a dying person
- *Meso* - health and social care organisation, work of hospices, palliative care services, professional roles and dispositions, knowledge that informs their work. Collective actions - 'compassionate communities', cultural interventions relating to dying and death
- *Macro* – societal structures – politics, government, policies, markets, laws, globalisation, migration, global health, disease and disadvantage, poverty, war, humanitarian crisis. All affect dying people. Palliative care is shaped and influenced by these factors.

# Ten categories of intervention at the end of life

## Policy

Decisions taken or rules adopted by governing authorities to deliver, facilitate, monitor or regulate end of life issues

## Advocacy

Expressions or actions on end of life issues/care that aim to influence decisions of the institutional elite and/or promote the interests of specific populations, groups or individuals in particular contexts

## Cultural

Initiatives taken to influence patterns of shared knowledge and symbolic meanings in particular communities, through which people perceive, interpret, express and respond to end of life issues

## Ethico-legal

Frameworks included within laws, guidelines or ethical codes that relate to issues at the end of life and which permit, facilitate or require specific courses of action

## Educational

Development of knowledge, skills, good judgment and character required for the delivery of appropriate end of life care

## Research

Systematic enquiry on end of life issues for the purposes of establishing new knowledge and understanding by description, prediction, improvement and/or explanation

## Service

Medical, nursing and other services for the prevention, alleviation and/or reduction of suffering at the end of life through inpatient, outpatient, home care or other forms of services

## Clinical

Medical, nursing, allied health and psycho-social procedures at the individual level to relieve symptoms and sufferings associated with advanced illnesses and when death is imminent

## Intangible

Actions to promote the recognition and significance of aspects of human existence that have intrinsic value at the end of life

## Self-determined

Actions, decisions or choices made by individuals to engage in or refrain from something that has implications for them at the end of their life or the life of another

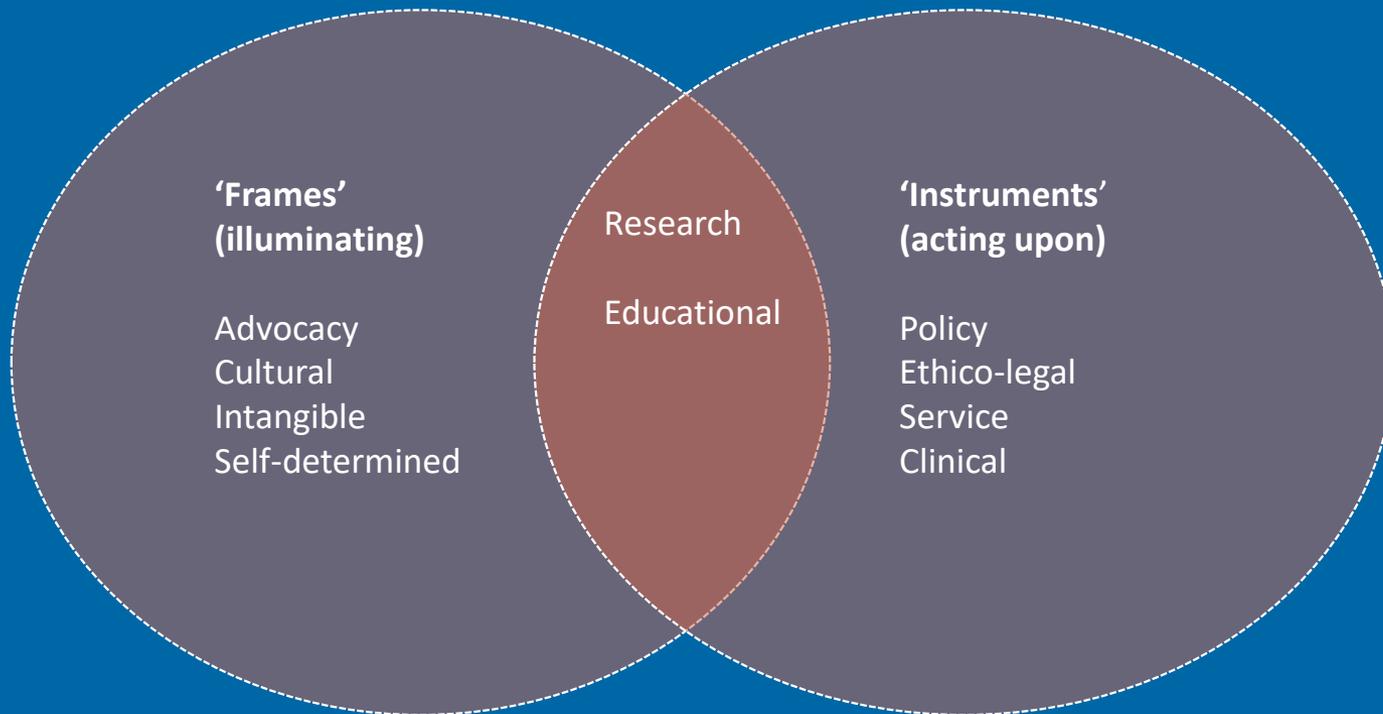
# Interventions as ‘focus’ and locus’

*Focus* - refers to the *character* of the intervention: content, orientation, its surrounding discourse and its specific properties over time. It can also include the goals and ambitions of those who construct and deploy the intervention and their perceptions of its worth

*Locus* - refers to the *geographical* scope (and spread) of the intervention – where does it originate, where is it implemented, to where does it travel?.

The *focus* of the intervention may change as it shifts from one *locus* to another, involving elements of ‘transfer’ and of ‘translation’.

# Interventions as 'frames' or 'instruments'



# Can palliative care improve society?

- Cicely Saunders thought it could – ‘I only want what is in your heart and in your mind’. A beneficial source for wider good.
- Now it is torn between a ‘social movement’ and a ‘medical specialty’
- A ‘zero sum game’
- To have wider influence it needs 1) full professional endorsement  
2) wider public understanding
- ‘Content Validity’ and ‘Face Validity’

# Recent papers

- Clark, D., Inbadas, H., Colburn, B., Forrest, C., Richards, N. , Whitelaw, S. and Zaman, S. (2017) Interventions at the end of life – a taxonomy for ‘overlapping consensus’. *Wellcome Open Research*, 2, 7.
- Seymour J and Clark D. (2018) The Liverpool Care Pathway for the Dying Patient: a critical analysis of its rise, demise and legacy in England [awaiting peer review]. *Wellcome Open Research* 3:15
- Zaman, S Inbadas, H Whitelaw, A Clark, D (2017) Common or multiple futures for end of life around the world? Ideas from the ‘waiting room of history’. *Social Science and Medicine*, Vol 17: 72-79.
- Zaman S, Whitelaw A, Richards N, Inbadas, H Clark, D (2018) A moment for compassion: emerging rhetorics in end-of-life care. *Medical Humanities* Online First.



# Glasgow End of Life Studies Group

@EndofLifeStudy

@Dumfriesshire

Email: [david.clark.2@glasgow.ac.uk](mailto:david.clark.2@glasgow.ac.uk)

**INSPIRING  
PEOPLE**