The human right to health: a right to palliative care?

Dr Felicity Hasson and Dr Claire Lougarre, Ulster University

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Ulster University

HSC Public Health Agency
Research and Development

I. The human right to health and palliative care

Dr Claire Lougarre

The recognition of a human right to health

- Historical context: from utilitarian motives… to legal obligations
- A binding right: widespread recognition in human rights instruments
- A justiciable right: increasing monitoring by human rights bodies, increasing adjudication at national level (via constitutionalisation)
- Tool increasingly used in NGOs' advocacy: e.g., COVID-19 pandemic

What does 'the right to health' mean?

- Right to '*the highest standard of health attainable*' (Article 12, International Covenant on Economic, Social and Cultural Rights) … but what is 'health'?
- *'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* (WHO Constitution 1946)
- WHO definition of health: problematic for lawyers… (e.g., palliative care)
- Palliative care: improving quality of end of life and the highest standard of health attainable

What does 'the right to health' entitle to?

- Treaty provisions on the right to health are not always comprehensive (not incl. palliative care): need for vagueness
- It is not a right to be healthy! (UN Committee on Economic Social and Cultural Rights, General Comment 14, 2000)
- "*The right to health can be understood as a right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all*" (UN Special Rapporteur on the right to health, 2006 Annual Report)

Does 'the right to health' include a right to access palliative care (1/3)?

- A right to access health services to preserve human dignity during terminal illness?
- A right to quality of life / death during terminal illness?
- A right to access sedation?
- A right to accelerate end of life? (European Court of Human Rights' case law on the right to life: no)

Does 'the right to health' include a right to access palliative care (2/3)?

- No mention in UN treaties (and no treaties on the rights of older persons) but…
- UN Committee on Economic Social and Cultural, General Comment 14 (2000): "S*tates are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons (…) to preventive, curative and palliative health services*"
- UN Special Rapporteur on the right to health, Visit to Ecuador (2020): "*Ecuador is in a good position to reach universal health coverage and other health-related goals. However, for that to happen, key elements need to be in place. In the first place, investment in (…) palliative care must be substantial and sustainable, even in times of financial constraint.*"

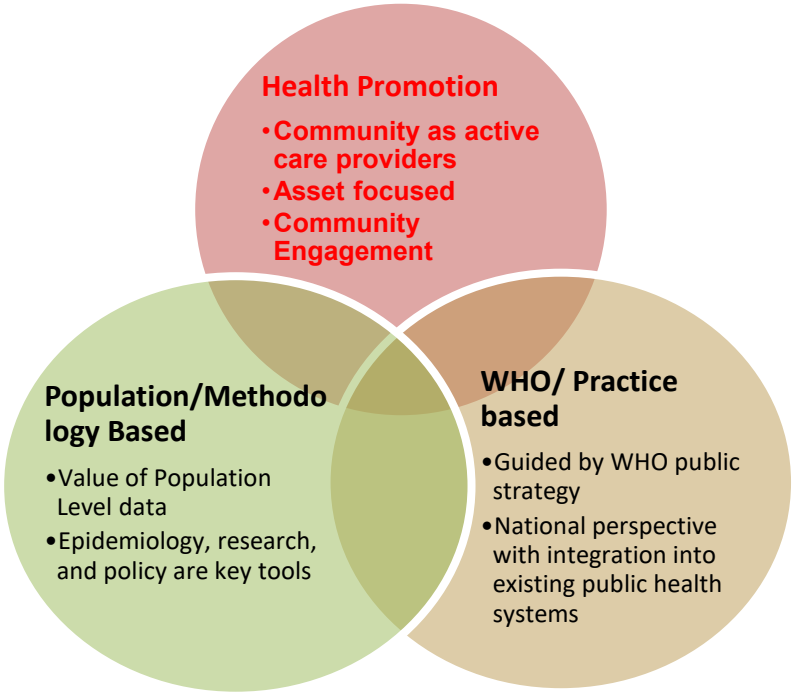
Does 'the right to health' include a right to access palliative care (3/3)?

- No mention in regional treaties (incl. in the Inter-American Convention on Protecting the Human Rights of Older Persons 2015, 11 States Parties)
- CoE: some engagement from the European Committee of Social Rights (legal standard set in Conclusions 2003 on France re: Article 23: "*there should be (…) adequate palliative care services (…) in respect of older persons*")
- CoE: minor engagement from the European Court of Human Rights (*D v United Kingdom* 1997+ *N v United Kingdom* 2008; *Petukhov v. Ukraine (No.2)* 2019)

II. It's a right but is it a reality?

Dr Felicity Hasson

Typologies Public Health and Palliative Care



(Source: Dempers & Gott 2017)

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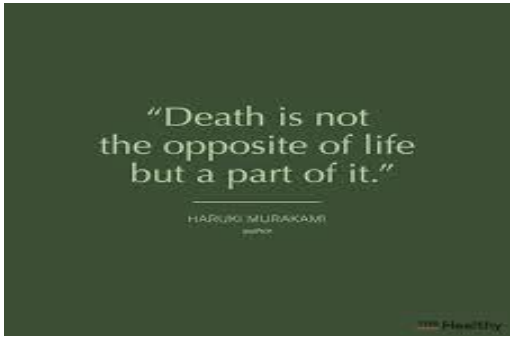
Why Engage the Public on Palliative Care?

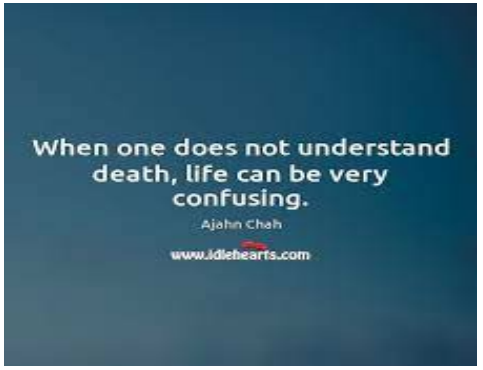


"People have to know what palliative care is in order to ask for it"

(Prof Jane Seymour)

They'll say, well you'll know what I want…. Well, you don't because we've never talked about it

(Conversations for live)



Evidence: Why don't people engage?

Cultural taboos

Dying is undervalued

Perception of care

Lack of death literacy

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Aim and Objectives

To explore the awareness, knowledge and the public views and behaviour in relation to palliative care and advance care planning and identify strategies to raise awareness within a public health framework.

Objectives

- awareness, knowledge, and views about palliative care and advance care planning among the public
- influencing factors in the provision of palliative care and advance care planning and best practice
- behaviour among the public regarding holding discussion and making advance care plans and;
- strategies to raise awareness within a public health framework

NILT
Northern Ireland LIFE & TIMES

Mixed methods design

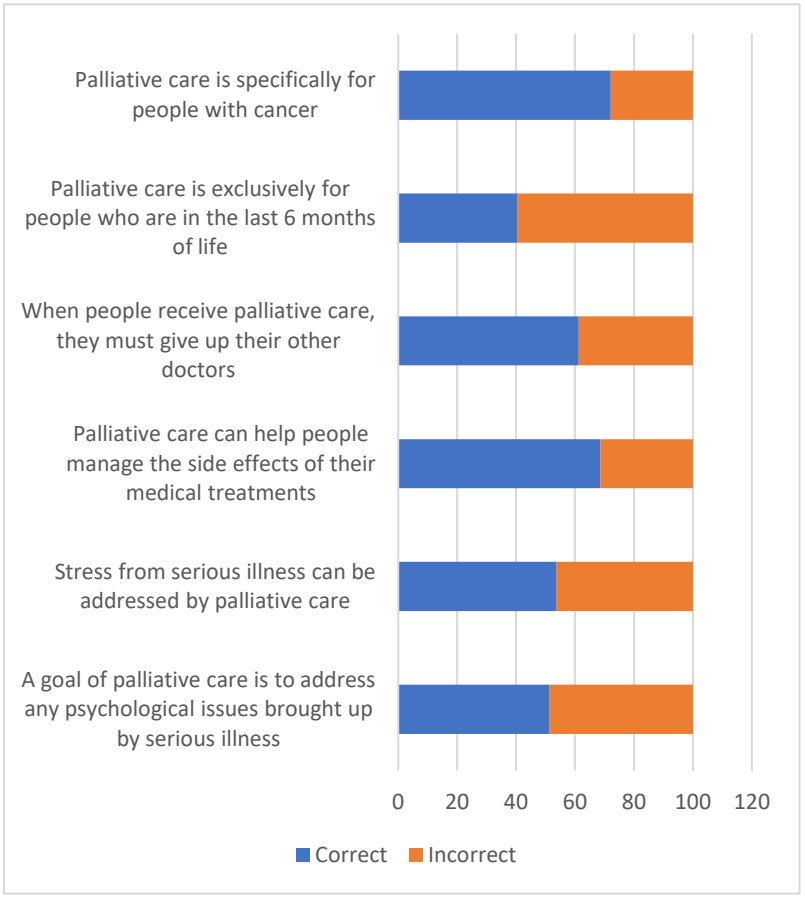
PHASE 1:
Northern Ireland Life and Times Survey
- Nationwide, modular survey run annually in NI
- Sociodemographic information collected
- Palliative Care module included PaCKS (13 items), seven yes/no questions related to palliative care
- 8 items were informed by the EAPC white paper on ACP plus 5 additional items

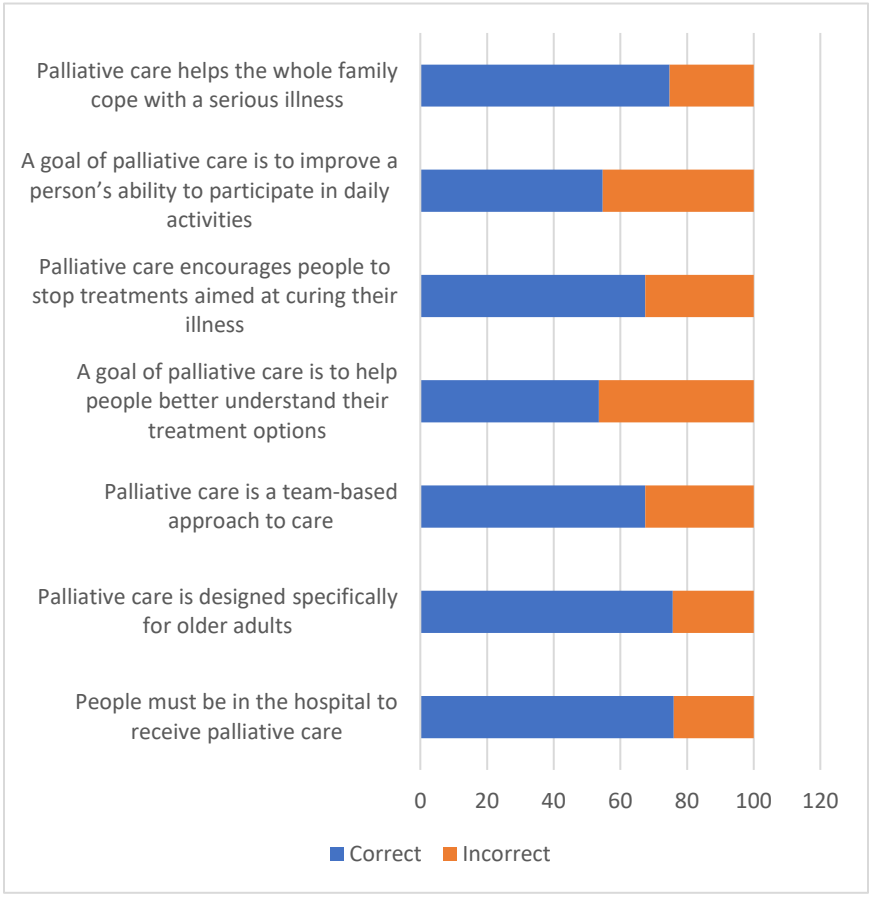
- 2022: 1,405 random representative sample of NI adults completed the survey

PHASE 2:
- 2022: Follow up in-depth interviews with purposive sample (n=28)

Analysis:
- Reflexive thematic analysis
- Social Ecological model construct mapping

RESULTS: Knowledge of Palliative Care (PaCKS)





RESULTS: Advanced Care Planning

STATEMENT	Agree	Neither	Disagree
I am in good health and do not want to think about preparing an advance care plan	47.1	27.4	25.4
It would comfort me to know I have left guidance about my wishes for my family	83.8	13.7	2.5
I would worry I could not change my mind	27.5	27.5	45
I trust my family to make the right decisions for me	72.1	20.1	7.8
I cannot change what will happen in the future and so there is no point in planning	17.4	23	59.5
It is difficult to know if my wishes will be respected	25.9	26.1	48
I worry that if I make plans for my future care and treatment, doctors will stop treatment too soon	20.5	25.4	54.1
Discussing my wishes would give me a sense of control	73.2	21.4	5.5

Phase 2 Future Strategies

Increase visibility and relatability to improve death literacy: normalise death, dying and bereavement

"I think a certain proportion of society need the visibility because they're not always going to be self-sufficient enough to jump on the Internet"

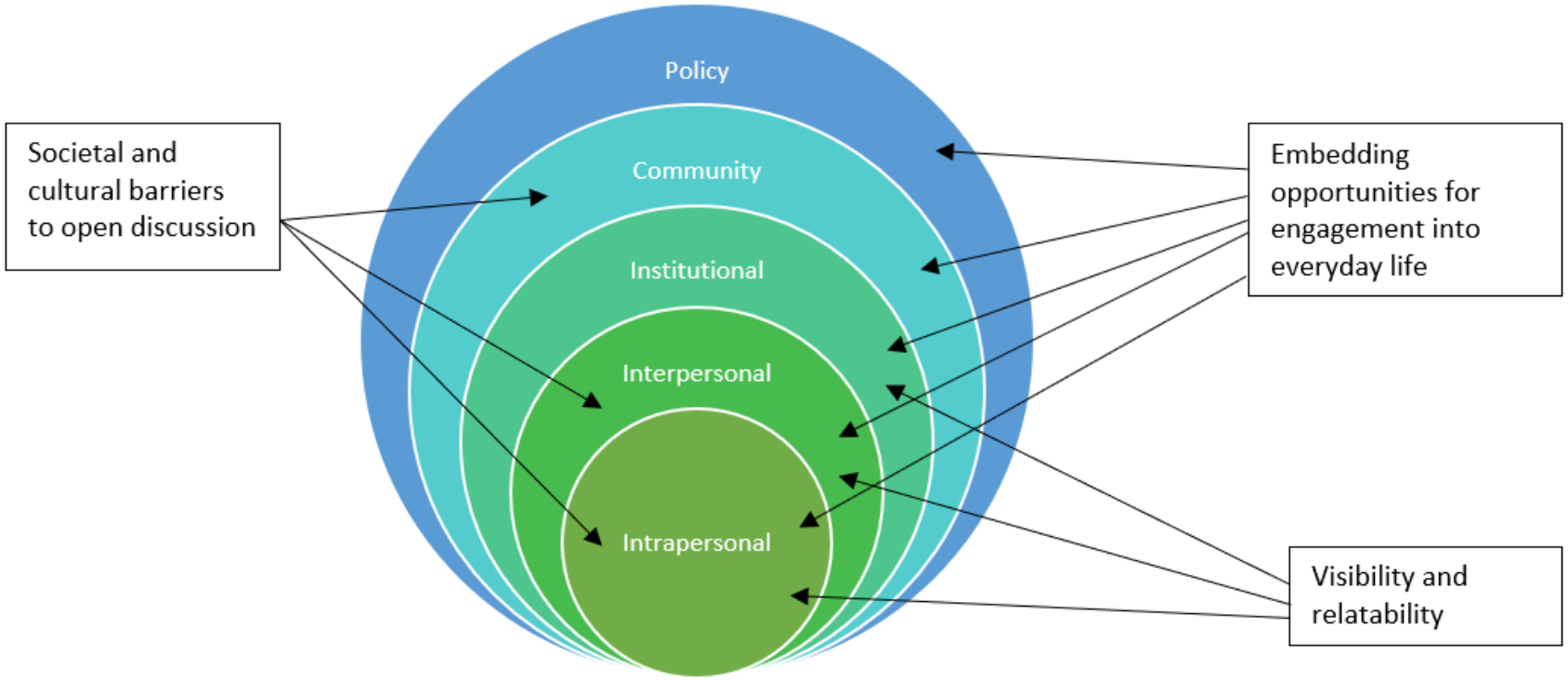
Embedding opportunities for engagement into everyday life

"If you look at the way, government have been promoting organ donation and that. You know, that sort of thing. And people have really bought into it. So, I think that's sort of similar approach would be good"

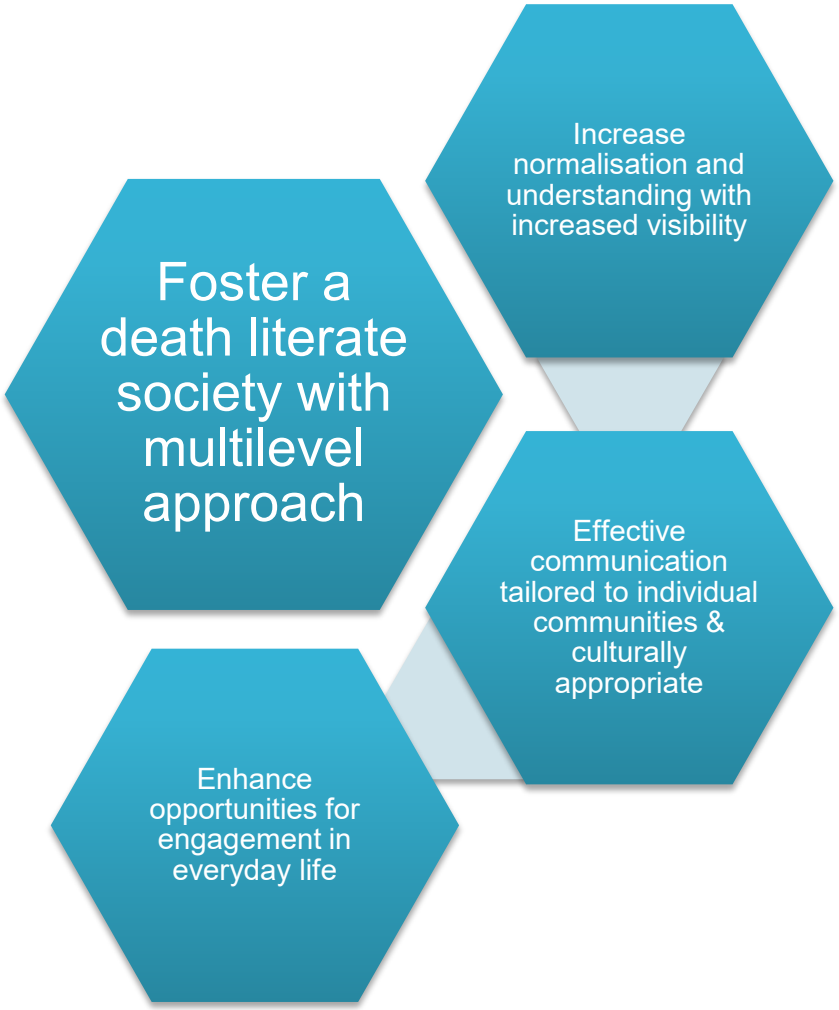
Societal and Cultural barriers to open discussion

"…people just want to leave stuff in God's hands"

Social Ecological Model Mapping



Recommendations



Thank you for your attention.

Study team:

- Prof Sonja McIlfatrick, Dr Paul Slater, Dr Esther Beck, Dr Rachel Black & Dr Felicity Hasson

Contact details:

- www.ulstrer.ac.uk/staff/c-lougarre
- @ClaireLougarre
- www.ulster.ac.uk/staff-hasson
- @Felicity_Hasson