@DrPentaris

An uneven reconciliation of faith in end of life care

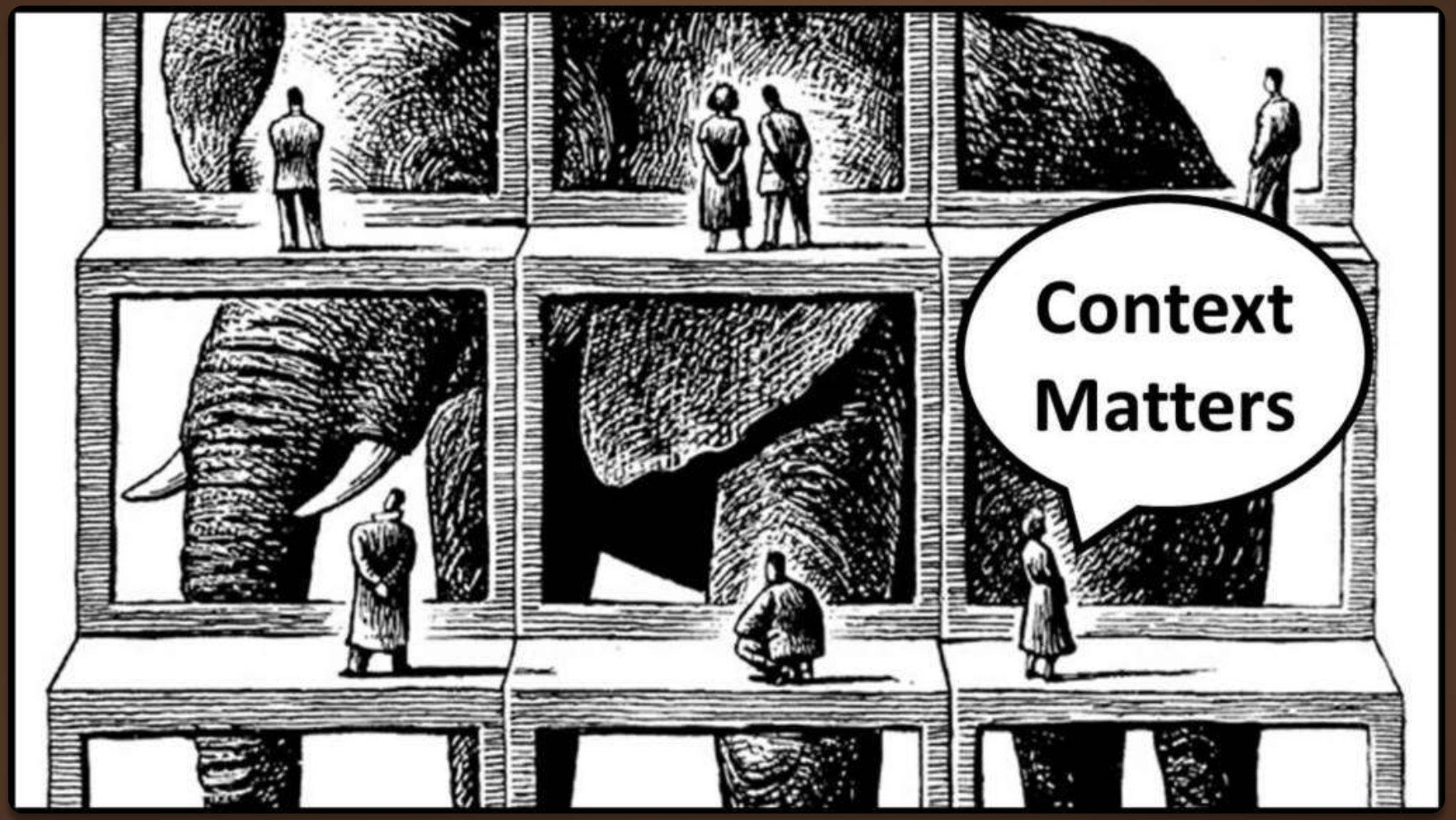
DR PANAGIOTIS PENTARIS

UNIVERSITY OF GREENWICH

6th ECRSH & 5th BASS

Content

- Context
- Methodology and methods
- Findings
  - Policy
  - Organisations
  - Professionals
- Conclusions


Context
Matters

What does end of life care involve?

End of life care should help you to live as well as possible until you die, and to die with dignity. The people providing your care should ask you about your wishes and preferences, and take these into account as they work with you to plan your care. They should also support your family, carers or other people who are important to you.

Source: *NHS – Choises* *http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx*

Delivery

- Hospital services
- Hospice inpatient
- Hospice outpatient (day centre)
- Hospice in the community
- Night/ out of hours nurses
- Community specialist palliative care
- Elderly homes
- Social services
- Emergency services
- Clinical and Direct practice
- GP
- Out of hours GP
- District nurses
- Religious institutions

Present study

- HOSPITAL & PALLIATIVE CARE SERVICES
- HOSPICE INPATIENT
- HOSPICE OUTPATIENT (DAY CENTRE)
- HOSPICE IN THE COMMUNITY
- CARE HOMES
- COMMUNITY SERVICES

Faith

Oxford Dictionary

- ‘Complete trust or confidence in someone or something’
- ‘Strong belief in the doctrines of a religion, based on spiritual conviction rather than proof’.

- Religion: An organised form of believing
  - Extrinsic or intrinsic (Allport, 1966; Batson, 1976)
- Belief: Religious or non; a personal commitment to something or someone beyond or within scientific understanding
- Spirituality: The personal experience of someone’s belief; provides a path for meaning-making and purpose

Methodology & Epistemology

- **EPISTEMOLOGY AND ONTOLOGY**
  - Durkheimian phenomenology (Tiryakian, 1978)
  - Marxist cultural formation (Grossberg, 1984)
  - Social constructivism
- **CASE STUDY**
  - **Inductive research**
- **METHODS (TRIANGULATION)**
  - In-depth interviewing
  - Focus groups
  - Discourse analysis (policy)
- **THEMATIC ANALYSIS**

Methodology (Participants)

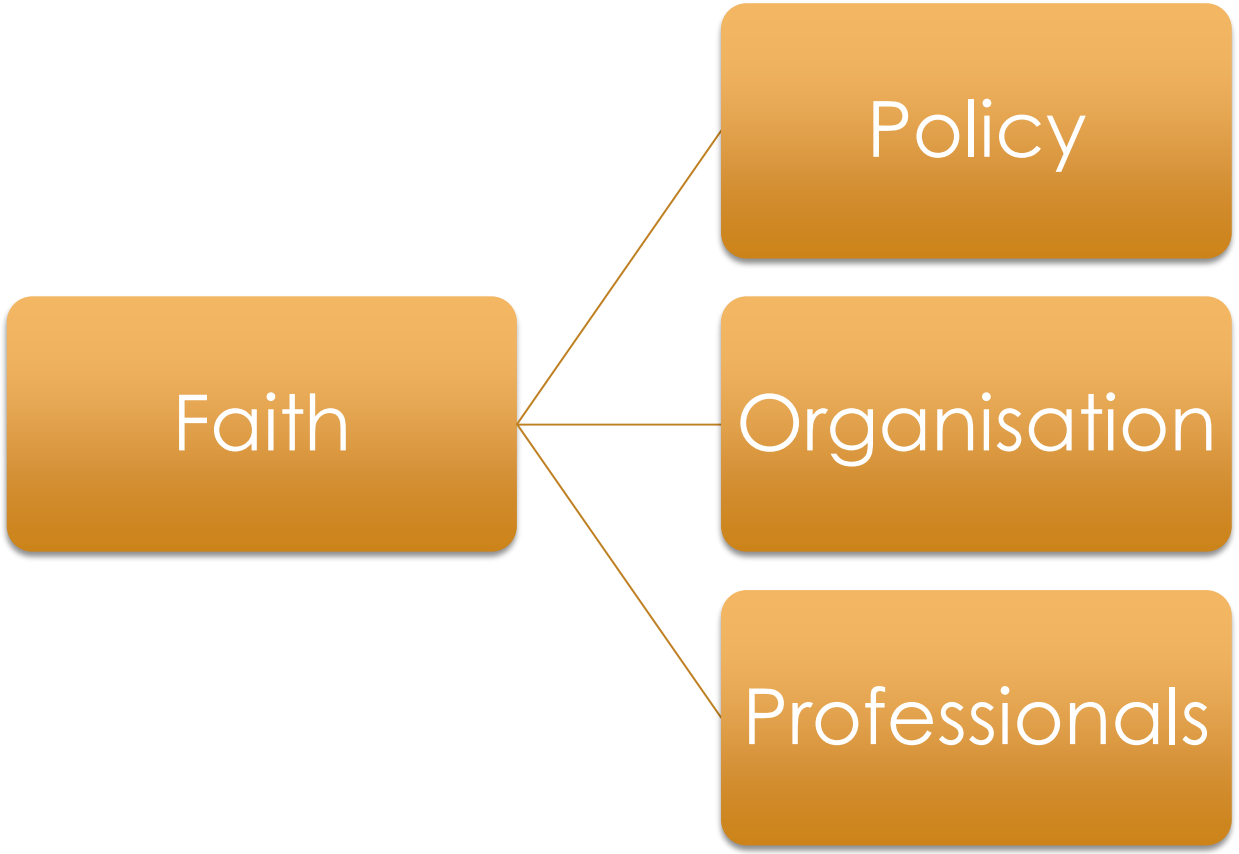
	Hospital	Hospice (inpatient)	Hospice (outpatient)	Hospice care in the community	Care homes	Total
Nurse	3	3	2	1	1	**10**
Social Worker	0	2	3	0	1	**6**
Physician/ Medical Doctor	6	4	1	0	0	**11**
Paramedic	1	0	0	1	0	**2**
Mental Health Practitioner	2	1	1	0	1	**5**
TOTAL	**12**	**10**	**7**	**2**	**3**	**34**

Methodology (Participants)

- Gender: 18 Female & 16 Male
- Age: average 46yo
- Ethnicity: **16 White British**, **9 White Other**, 5 Black/Caribbean, 4 Mixed.
- Religion: **19 Christian**, **11 Nonreligious**, 2 Muslim, 1 Hindu, 1 Other
- Years of practice in hospice and palliative care: over 30 years (n=12), **20-30 years (n=19),** 10-19 years (n=2), 5-10 (n=1), less than five years (n=0)

Findings

Three-layered approach of analysis



Policy

26 policy documents, including:

- *One year on: The Government Response to the Review of Choice in End of Life Care*
- *One Chance to Get it Right: An Overview of progress on commitments made in One Chance to Get it Right: the system -wide response to the independent review of the Liverpool care pathway.*
- *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*
- *What's important to me. A Review of Choice in End of Life Care*
- *Spiritual Care at the End of Life: a systematic review of the literature.*
- *Faith at end of Life. A resource for professionals, providers and commissioners working in communities.*
- *End of Life Strategy 2008*

Terms	N	Comments
Compassionate/ compassion	31	• Personality/ character trait • Patient-led care/ person-centred care • Sympathy or empathy
Wellbeing	3	• Spiritual • General
Spirituality/ spiritual care or support	76	• Interchangeably used with emotional support • Outside of immediate care • A category of problems to be solved • An aspect of care • Lacks definition • Generic characteristic of human beings • Caring professions rooted in spirituality • A resource • A need
Religion/ religious	33	• An issue • 80% of the times mentioned in relation to spirituality • Framework to guide care • Personal preferences
Belief	17	• Religious • Spiritual

Cont.

Terms	N	Comments
Faith	36	• Issues • Faith leaders and groups in the community • Resource • Faith rooms
Secular/ secularisation	4	• Movement • Materialism • Nonspiritual/ nonreligious

Organisational level

Religious/ spiritual care toolkit

- ‘All the tools in spiritual care help us talk about religion with patients, or not exactly talk about it, but at least we note it down’.
- ‘There are definitely forms that religion is included in them. I mean we ask people, but of course only if they are able to answer’.

Death/ Health Policies

Initial Assessment

Neutral spaces

Rituals (commemorative practices)

Study days

- ‘Spiritual care is actually seen as an important part in the culture of this hospice, and everybody who starts here does spiritual care training level 1, at the time of induction into the hospice. And there are subsequent levels of training in this as well, if you want to do them’

Contacting the chaplain (90%)

- ‘Even if the person is not well, and the relatives have informed us about the patient’s religion, we will bring in a religious leader from their own group’.
- ‘I tell patients that if they want to talk about it [religion] I can find someone to come and talk to them. Possibly from the chaplaincy team’.
- ‘There is always a list with the contact numbers of the chaplains in the office, so if needed we can look it up there’.

Professionals

Knowledge exchange (90%)

- ‘Working here also means that we get to talk to each…it is with peers that we learn. If I do not know something, then someone else does and we learn this way. I guess this is awareness anyhow…’

Increased knowledge by professional setting (75%)

- ‘Working within palliative care you are probably more aware of people’s spirituality and that it is not just around religion. Spirituality covers much more than that. I think, maybe if you don’t work within this sort of area, you might not have this sort of awareness’.
- ‘Working here helps I guess. I am definitely more aware because of being employed in palliative care’.

Lack of or distorted understanding (80%)

- Participants demonstrated their understanding of different faiths, religions, spirituality, and so on, with the use of the following terms:
  - Obscured
  - Out of the ordinary
- E.g., *'So many faiths I have seen, strange ones…and…the beliefs and practices are not so normal as we know them'. When asked to specify what the ordinary is, we end up talking about Christianity: 'Well, we are Christians here [in this country] and so the normal is to practice that, right?'*
- Other participants stated that religious requests are often weird and distort peace for other patients.
  - 'Patients and family have all these weird requests, like the bed facing Mecca when someone is dying, or lighting a flame when someone dies, but we have to meet their needs as it is part of holistic care'.

Religion sets boundaries (37%)

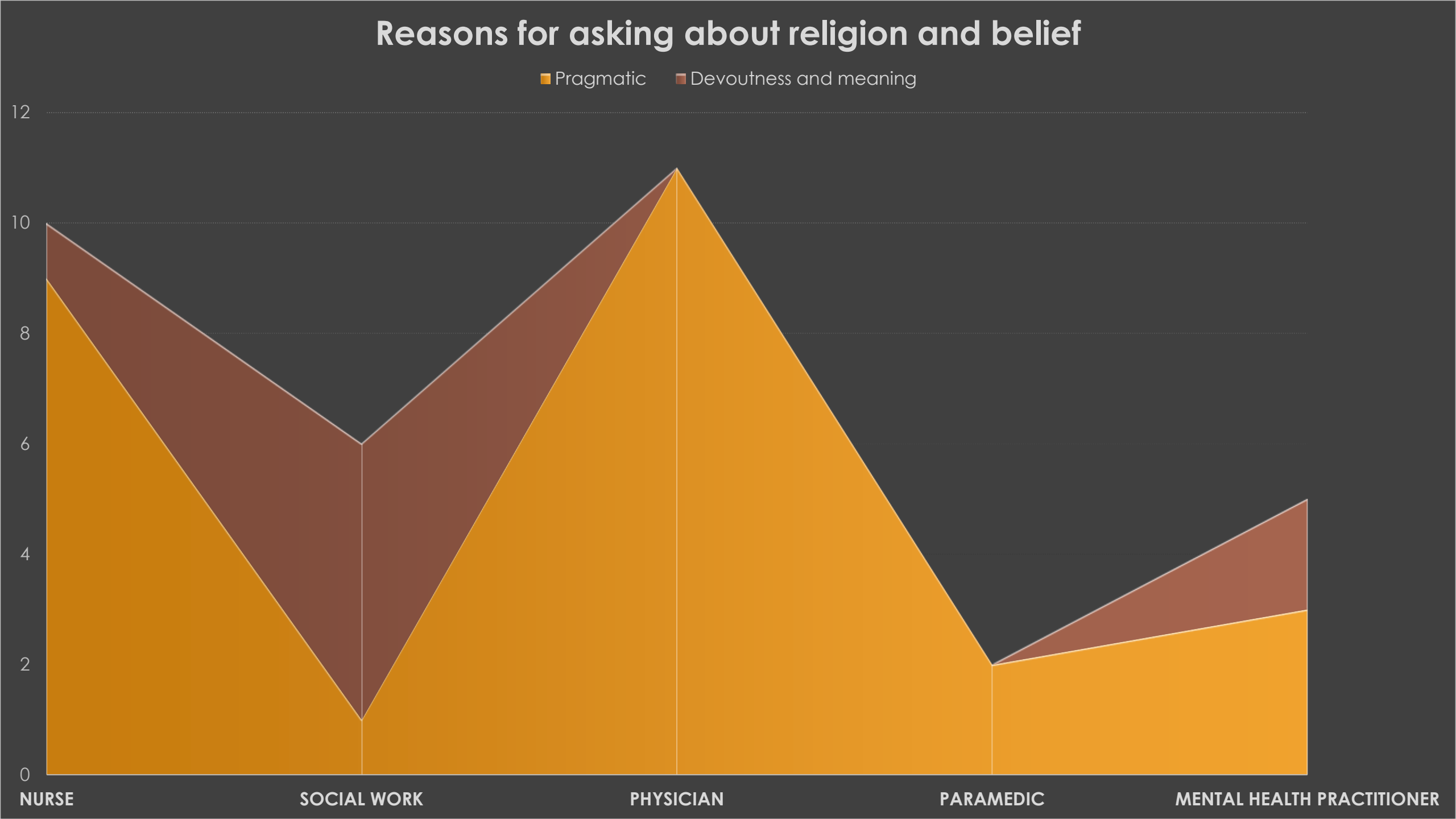
- ‘In the healthcare setting I feel that you can have expressions. For example, let us take the ones [religions] that bring up health care issues, and that would be Jehovah’s witnesses, so the religion would define the kind of care they would receive or reject. I think swinging toward the other end, certain religions have very set rights after death’.
- ‘Often times the case will be that if someone has a religion this will automatically tell us how their treatment must be delivered, which might not always be the right way’.

Accommodating faith

- Asking about religion and belief: resolving the pragmatic
- Religious/ spiritual care toolkit
- Dependent on the individual's skills
- Personal beliefs in the professional
- Effective communication skills
- Contacting the chaplain
- Ticking the box
- Outside of professional role

Asking about religion and belief (100%)

- *'But we do not really sit and ask people about that [religion]. I mean, rightly or wrongly, when people are really feeling ill and tired and drowsy, they are not in the right mind-set or place for those sort of debates really. But we are happy to open to their families and friends if we have the time'.*
- *'Definitely we will ask, but it is not the first thing to ask, and to be honest it might not be touched at all. I mean, it is not the most important thing when someone is admitted. If it is not brought up in the conversation, then there is no need to explore more at that point'.*


Reasons for asking about religion and belief
Pragmatic
Devoutness and meaning
12
10
8
6
4
2
0
NURSE
SOCIAL WORK
PHYSICIAN
PARAMEDIC
MENTAL HEALTH PRACTITIONER

Dependent on the individual's skills (67%)

- Predominantly nurses and physicians supported this category.
- '…if someone is on the LCP they will explicitly direct you to ask those questions, and then it is up to the nurse how skilful they are to do so, or how much to ask for, etc.'
- 'It depends on the individual [professional] whether they will decide to go deeper in understanding the importance that religious belief might have for patients'.

Personal beliefs in the professional (55%)

- 'I think having a belief system, for me personally, does help with looking after this group of patients, and to be able to face it on a day to day basis and to give the support that is needed to the relatives in particularly'.
- 'Being neutral about this myself, actually helps me being open minded to all different cultures and religions that I come across with. I don't believe in anything, so it is easier to talk about anything'.
- 'It is my obligation…because…as a Christian you have to do it. You are here to help others. That is what Christians do'.

Ticking the box (100%)

- ‘When a patient is admitted, a questionnaire is used for assessment. Part of the questions is sort of asking them their name or address, and also their religion. So, it is put down as to what religion they are, and that is how it is looked at’.
- ‘There is a question that asks the patients what their language, ethnicity and religion are. We will always tick that box so that we know that the patient has a religion’.

Outside of professional role (34%)

- ‘Obviously, saying prayers, or talking about their religious worries is not in my professional role, but I mean…every now and then you get asked these unusual requests to like talk about Allah and things, which you cannot always…you know, avoid’.
- ‘I do not think that most of us have the time to be doing this, but also if you think of it, it is not my role as a doctor to provide such services’.

Conclusions - Reconciling faith to practice

Policy

- Ambiguity
- Blurred professional boundaries
- Responsibility orientated
- Goal-orientated

Organisation

- Solution-focused approach
- Christian-centred lens
- Hospice as a Machine
- Neutrality in place of inclusivity

Professionals

- Willingness vs. ability
- Christian-centred lens
- Ambivalence

Conclusions – uneven reconciliation

Policy → focuses on providing guidance that will help professionals gain more knowledge about more religions by name, but without any advice as to how to make sense of that knowledge or how it applies, and with a great risk of making generalisations and developing misconceptions.

Organisations → seem to be moving toward a secular, or perhaps a 'no religion' attitude; the main reason appears to be the willingness to be inclusive of all religions, and the best way at the minute is to avoid talking about any.

Professionals → seem to be caught somewhere in the middle; willing to engage with religion and belief but unable to do so due to a secular-minded approach in practice which is highly informed by organisational values and culture.

Thank you

Dr Panagiotis Pentaris

University of Greenwich

Faiths & Civil Society Unit

Goldsmiths University of London

p.pentaris@gre.ac.uk

Twitter: @DrPentaris

References

Allport, G.W., 1966. The religious context of prejudice. *Journal for the scientific study of religion*, *5*(3), pp.447-457.

Batson, C.D., 1976. Religion as prosocial: Agent or double agent?. *Journal for the Scientific study of Religion*, pp.29-45.

Grossberg, L., 1984. Strategies of Marxist cultural interpretation. *Critical Studies in Media Communication*, *1*(4), pp.392-421.

Pentaris, P., 2018. *Religious literacy in hospice care: challenges and controversies*, London: Routledge.

Pentaris, P., 2018. The marginalisation of religion in end of life care: signs of microaggression?. *International Journal of Human Rights in Healthcare*, *11*(2), pp.116-128.

Tiryakian, E.A., 1978. Durkheim and Husserl: A Comparison of the Spirit of Positivism and the Spirit of Phenomenology. In *Phenomenology and The Social Science: A Dialogue* (pp. 20-43). Springer, Dordrecht.