A Profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service Hospital in the UK.

[1]Edwin J Pugh, [2]Robert Song, [3]Vicki Whittaker,[4]John Blenkinsopp

[1]*Professor in Palliative Care, University of Teesside and Consultant in Palliative Medicine*

[2]*Senior Lecturer, Department of Theology and Religion, University of Durham*

[3]*Statistician, University of Teesside*

[4]*Clinical Effectiveness Advisor, North Tees and Hartlepool NHS Foundation Trust*

Ethical approval: This study was approved by the County Durham and Tees Valley Research Ethics Committee.

Declaration of Interest: None declared

ABSTRACT

Objective

To gain a profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service Hospital in the UK.

Design

Postal questionnaire

Setting

An acute NHS Hospital in the North East of England

Participants

All consultants (N=119), key worker nurses (N=36) and specialist registrars (N=44) completing a questionnaire

Main Outcome measures

Indication of belief system or religion and religiosity. Attitudes of consultants, nurses and specialist registrars to common clinical decisions taken when a patient is at the very end of life.

Results

This study showed that consultants' religion and belief systems were markedly different from those of nurses. The belief system of the consultants contrasted with those of the population that they served. Consultants and nurses had statistically significant differences in their attitudes to common end of life decisions with consultants more likely to continue hydration and not withdraw treatment. Nurses were more sympathetic to the idea of physician assisted suicide for unbearable suffering.

Conclusion

The personal belief system of clinicians does not appear to account for the variability in attitudes to end of life decision making.

INTRODUCTION

Doctors and nurses face challenging clinical decisions as patients approach the last day or so of their lives. These decisions are becoming increasingly complex (1). They may involve legal and ethical issues as well as being a matter of conscience for the individual clinician. Decisions may include whether to withdraw or withhold treatment and whether to continue parenteral hydration. To improve end of life care, initiatives in the UK such as the Liverpool Care Pathway for the dying, advance care planning and preferred priorities for care are being rolled out nationally (2,3,4). Clinicians are being encouraged to inform patients and their relatives when patients are dying, to rationalize medicines and to determine where patients wish to die. In addition in recent years a bill to legalise physician assisted suicide has been debated in the House of Lords (5).

There is much evidence which shows that a patient's personal religious and spiritual beliefs influence their experience of and response to illness including dying. Doctors and nurses are dynamic partners in the clinician-patient relationship. There is some evidence from outside the UK to show that physicians' 'religiosity' and attitudes to life and death influence decision making at the end of life (6, 7, 8,9).

This paper is the first of its kind in the United Kingdom which presents the results of a study exploring the relation between the belief system and attitudes of clinicians and decisions which commonly must be taken when caring for individuals who are dying. The clinicians surveyed work in a national health service hospital in northern England, and comprised consultants, nurse key workers (nurses in clinical areas with a special interest in palliative care), and specialist registrars. This study provides data to further explore whether their religiosity has an influence on these clinical decisions.

METHOD

A literature review using Medline, Cinahl, Amed and Cochrane Library undertaken in November 2007 and updated in May 2008, revealed no papers published about the belief system of doctors or nurses in the UK and the effect, if any, on their decision making at the end of life.

A paper based questionnaire was devised to ascertain the spirituality and belief system of consultants, specialist registrars and nurse key workers working in an acute hospital in February 2008 and their approach to ethical issues at the 'End of Life' (Appendix 1). Names and contact details for doctors were obtained from a register held by the hospital medical education department. Names and contact details for the nurse key workers were obtained from the palliative care department.

The questionnaire had three sections. The first explored the belief system and religiosity of participants. The second asked participants to imagine that they were treating a dying patient who had a prognosis of several days and to indicate on a Likert scale their degree of agreement or disagreement to a number of specific clinical scenarios. The third allowed participants to give comments. The questionnaire had been piloted during education sessions with several groups of doctors not involved in the study.

The questionnaire with a pre-addressed reply envelope was sent to all consultants, specialist registrars and nurse key workers in February 2008 through the hospital internal mail. A covering letter of explanation and an invitation to take part accompanied the questionnaires. This included the fact that results of the questionnaire were to be aggregated and would be anonymous. No individual clinician would be identifiable. The questionnaire had a code number to allow a second mail shot for initial non-responders. The code was known only to the researcher and his secretary. A second mailing for non responders took place 4 weeks after the initial posting. Non completion, judged by no response 4 weeks after the second mail shot was respected.

Results were recorded using SPSS 13 for Windows. Differences in responses between groups (based on clinician type) were analysed using Pearson Chi square test. Where the test was not valid due to small numbers categories were collapsed to reduce table size; new categories were (i) agree, (ii) neither agree or disagree and (iii) disagree. In addition all qualitative responses were recorded.

RESULTS

119 clinicians returned a questionnaire. This represented 77 (65%) of 119 consultants, 24 (67%) of 36 nurse key workers and 18 (41%) of 44 specialist registrars. The response rate of 65% for consultants is above the mean response rate of 54% for physician postal surveys reported in medical journals (10). Of the 74 consultants answering the question on sex 54 (73%) were male and 20 (27%) female. All nurse key workers were female. Two thirds of the specialist registrars were male. Of the clinicians indicating age group 37(49%) of consultants, 5(21%) of nurses and 0(0%) of specialist registrars were aged 50 or over.

Spirituality and Beliefs of clinicians

54(70%) of consultants, 16(67%) of nurses and 12 (67%) of SpRs stated they had a faith or belief that was important to them. Table 1 indicates the number and proportion responding by main religious groupings, including no religion. Of the three in the 'other' category one was a Sikh, one a Jew and one indicated 'Methodist'. The religion of the population served by the hospital is given for comparison (11). Consultants were 10 times more likely to not believe in an afterlife than nurses (40.5 % v 4.2%).

Table 1

23(31%) of consultants, 7(29%) of nurses and 3(16.7%) of SpRs never attended a place of worship. 90(76.9%) of 117 clinicians responding indicated they attended a place of worship a few times each year or not at all The remaining 27 (23.1%) attended once every 2 - 4 weeks or more frequently.

Table 2

Attitudes of clinicians to clinical scenario

Tables 2 shows for consultants and nurses the degree of agreement or disagreement to the clinical scenario posed in the questionnaire. The results of chi-square tests are given where valid i.e. fewer than 20% of cells have an expected count of less than 5. A statistically significance difference was shown between consultants and nurses regarding the withdrawing of life sustaining treatment, the continuation of hydration by the parenteral route and agreement to physician assisted suicide. Consultants were less likely to agree to withdraw treatment, stop hydration and be in agreement to the practice of physician assisted suicide.

Table 3

Table 3 indicates for consultants their agreement or disagreement to the clinical dilemmas faced depending on whether they have or have not a faith or belief which is important to them. The results of chi-square test are given where valid i.e. fewer than 20% of cells have an expected count of less than 5. There was no statistically significant difference shown between consultants with and without a personal belief of importance for giving life sustaining treatment and attitude to physician assisted suicide.

DISCUSSION

Within the UK there is a culture of medical decision making which is informed by a palliative care philosophy (1) This encourages multidisciplinary and multiprofessional practice both within teams and in formal multidisciplinary team meetings. In the UK it is known that clinicians report that they consult other doctors and nurses about end of life decisions more than doctors from other countries. (12).

When faced with the clinical scenario of a dying patient the attitudes of clinical staff varied both within and between professional clinical groupings. One in 5 consultants disagreed with withholding or withdrawing treatment. None of the nurses disagreed with withholding or withdrawal. Statistically significant differences were shown between consultants and nurse key workers in attitudes to withdrawing treatment and continuing parenteral hydration with consultants being more likely to continue intervention. This

was not the case for the withholding of treatment - here the consultants and nurses held similar views. It would appear that consultants are more agreeable to the concept of not initiating a life sustaining treatment than stopping one that has already been started.

Different opinions and attitudes to decisions at the end of life between consultants and nurses may lead to potential tension and conflict in agreeing an action plan for the patient unless sensitively handled. In addition it may have a practical impact on where the patient can be cared for. For example, at the time of writing, in the community served by the hospital there is no provision in supportive care to allow subcutaneous or intravenous fluids to be given outside of the hospital setting. The clinical instruction to continue parenteral hydration therefore equates to the need to keep the patient in hospital. The fact that 60% of consultants agreed that parenteral hydration should continue means that the patients under their care may not be considered for discharge home if their attitude was reflected in their practice. This compared with 25% of the nurses.

Consultant

"I would like to involve patient, family, nursing and medical staff. I am not in favour of withdrawing treatment. I would like the patient to die in a dignified way"

Nurse

"The last moments should be with the family and not in hospital……it is destiny that decides end of life."

Clinicians may not agree on what is best interest for the patient. Is best interest to hydrate or enable to be discharged home without parenteral hydration? The patient is the individual best able to judge and needs to be given the information and express a view.

In line with national good practice of using end of life tools such as the Liverpool Care Pathway, preferred choice of care and advance care planning, 74% of consultant and nurse key worker staff combined agreed that patients should be told that they are dying, 87% agreed they should be asked where they wished to die.

94% of consultants and nurses combined agreed patients should have their spiritual needs discussed if the patient brings it up. The difference between intention and actual practice is highlighted in the matter of spiritual care where results of an audit in 2008 of the documentation of the Liverpool Care Pathway in the hospital served by the clinicians surveyed revealed that very few patients had their spiritual needs assessed (13).

Spirituality remains a sensitive area for clinicians. However spiritual values and the need to address the spirituality of patients is increasingly being recognised as an integral part of care (14). The Department of Health strategy for end of life care recommends that an assessment of spiritual needs should be a part of all patient and carer assessments. (15) There is an acknowledgement that there is a training need for clinical staff which should include the adoption of spiritual and cultural care competencies (15,16).

Consultant

"Are we in danger of forcing our beliefs onto others of different faiths/ beliefs?"

Consultant

"Patient's beliefs are undoubtedly a great comfort to them."

Nationally we live in a multi-faith and multicultural society as reflected in the religious mix of the consultants. Locally however the religion of consultants differed markedly from the population served by them. This contrasted to the nurse key workers none of whom were from an ethnic minority and whose belief system mirrored the local population in being either Christian or not having a religion.

Although 7 in 10 consultants have reported having a belief which is of importance to them almost one third of that group never attended a place of worship and a further half attended only a few times a year. It would appear that stating the importance of a belief or religion may not relate to being active in that belief. Although belief may be perceived as important, its outworking and any strict doctrinal application to clinical practice may be nominal. This reflects the findings of a recent study which suggested that although religious teachings influenced end of life decisions to a degree they are not endorsed by clinicians when confronted with 'real patients and circumstances'(7).

Within the hospital under study 33% of consultants were in agreement that physician assisted suicide (euthanasia) should be allowed for patients who have unbearable pain; 47%expressed disagreement. Should physician assisted suicide become lawful the issue of personal moral conscience to opt out would need to be addressed.

Consultant "Can see some scenarios where assisted suicide may appear reasonable but could not contemplate doing it myself and would not wish it on anyone else".

In the international literature increased religiosity has been reported as affecting attitudes to euthanasia. In our study there was no statistically significant difference shown in attitudes to physician assisted suicide between consultants who had a belief which was of importance to them and those who did not. Nor was any statistically significant difference evident with regard to the withdrawing of life sustaining treatment

This study has been carried out in a single NHS hospital trust. Numerous areas of significance have been shown. However a larger multi-trust study with greater numbers for analysis may reveal further statistical significance not shown in this study. In addition this study has grouped clinicians in all specialties. As such it has given an organisational profile of the clinicians. This paper has not explored differences between consultants in different specialties.

Conclusions

The differences in attitudes to the end-of-life clinical scenario by clinicians may result in different end of life care being given. It may also influence whether the patient can be discharged from hospital – potentially depriving them of the choice to die at home. The intrinsic variability both within and between the consultants and nurses would seem more important in end of life decision making than the importance of their personal beliefs.

REFERENCES

1. Seale C National survey of end of life decisions made by UK medical practitioners Palliative Medicine 2006; 20: 3 – 10

2.Liverpool Care Pathway (LCP)
www.lcp-mariecurie.org.uk

3. Ellershaw J, Ward C Care of the dying patient: the last hours or days of life
BMJ 2003: 326; 30 -34

4.Preferred Priorities for Care (PPC)
www.cancerlancashire.org.uk

5.Assisted Dying for the Terminally Ill Bill *as introduced to House of Lords on 8 January 2004.*
http://www.publications.parliament.uk/pa/ld200304/ldbills/017/2004017.htm

6. Mortier F, Bilsen J, Vander Stichele RH, et al. *Attitudes,sociodemographic characteristics, and actual end of life decisions of physicians in Flanders, Belgium.*
Med Decis Making 2003; 23 :502-10

7. J Cohen et al. Influence of physicians' life stances on attitudes to end-of-life decisions and actual end-of-life decision-making in six countries.
Journal of medical ethics 2008; 34: 247 -253

8. Wenger NS, Carmel S. Physicians' religiosity and end-of-life care attitudes and behaviours.
Mt Sinai J Med 2004; 71: 335 -43

9. Curlin FA,Lantos JD, Roach CJ, Sellergren SA, Chin MH Characteristics of US Physicians. A National Survey
J Gen Intern Med 2005 ;7: 629 -34

10. Asch DA, Jedrziewsk MK, Christakis NA. Response rates to mail surveys published in medical journals.

Formatted: English (U.K.)

J Clin Epidemiol 1997; 50 : 1129 -36

11. Lakhani A, Olearnik H, Eayres D (Eds). Clinical and Health Outcomes Knowledge Base. London: The Information centre for health and social care/ National Centre for Health Outcomes development 2001.

12. Seale C Characteristics of end-of-life decisions: survey of UK medical practitioners Palliative Medicine 2006; 20: 653 -659

13.Pugh E J Personal Correspondence May 08: Liverpool Care pathway National Audit. Evaluations Unit, Marie Curie palliative Care Institute, Liverpool.

14. Culliford L. Editorial Spirituality and clinical care.
BMJ 2002; 325: 1434-5

15. End of Life Care Strategy. Promoting high quality care for all adults at the end of life. Department of Health July 2008
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

16. Tweddell L. Palliative care must address spirituality
Nursing Times 2007; Vol 103, No 51; 4

Table 1

Number and percentage of Consultants, Nurses and Specialist Registrars indicating a particular belief or religion compared to the population served and England and Wales.

Clinician Category	Christian	Muslim	Hindu	Buddhist	No religion	Other	Total
Consultant							
Number	34	7	16	3	15	2	77
%	44.2	9.1	20.8	3.9	19.5	2.6	100.0
Key Worker							
Number	20	0	0	0	2	1	23
%	87.0	0	0	0	8.7	4.3	100
Specialist Registrar							
Number	7	2	6	0	3	0	18
%	38.9	11.1	33.3	0	16.7	0	100
[1]**Population Served by Clinicians** [2]%	87.6	1.2	0.2	0.1	10.6	0.1	
[1]**Population of England and Wales** [2]%	77.7	3.2	1.2	0.3	16.1	0.3	

[1] Source: Office of National Statistics *(See reference 11)*

[2]The religion 'not stated' group has been excluded from the calculation therefore percentages will not add to 100

Table 2

The number and percentage of consultants and nurses agreeing, neither agreeing nor disagreeing or disagreeing with the clinical scenario posed for a patient in the last day or so of life.

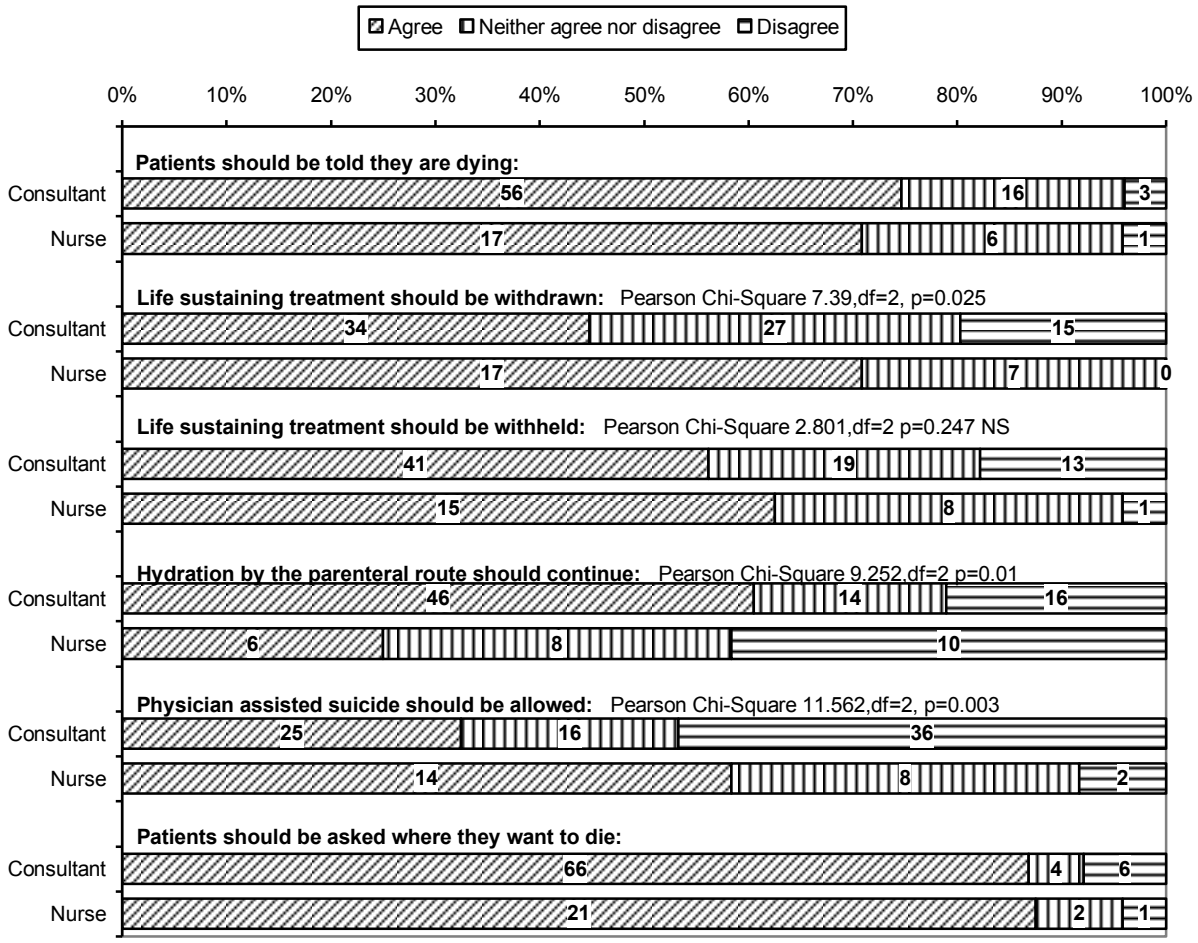
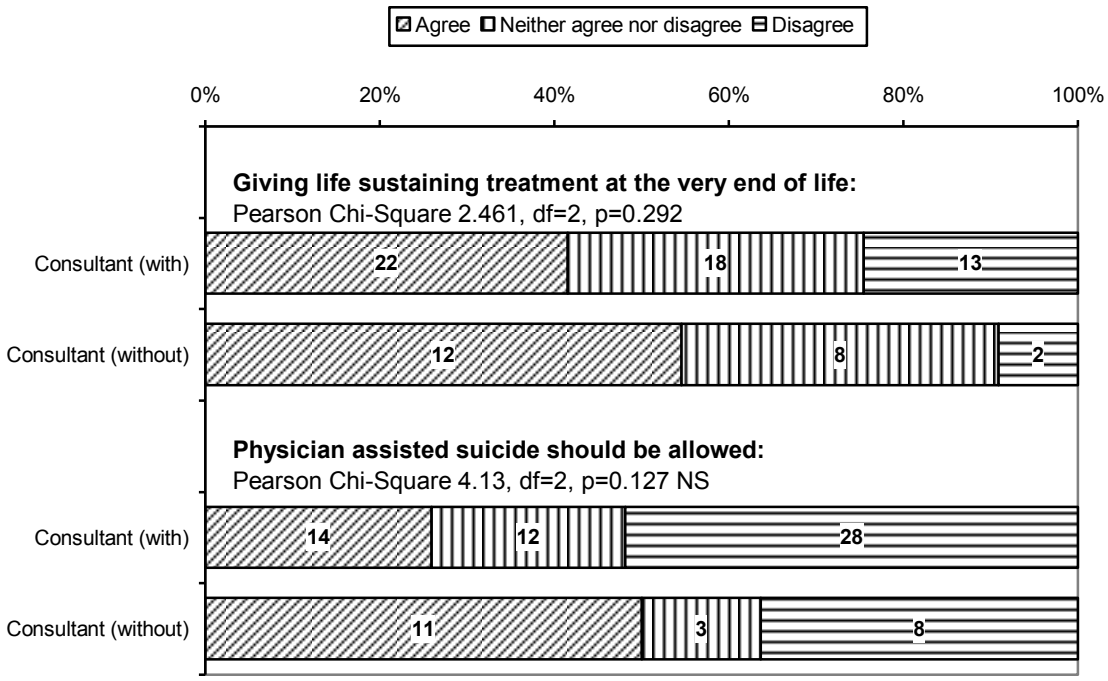


Table 3

The number and percentage of consultants with and without a belief of importance agreeing, neither agreeing nor disagreeing or disagreeing with the two clinical scenarios of (i) giving life sustaining treatment at the end of life and (ii) physician assisted suicide being allowed.



Appendix 1:

END OF LIFE: SPIRITUALITY AND THE "BELIEFS" OF CLINICIANS

1 Do you have a faith or "belief" that is important to you? Yes ☐ No ☐

2 How important is your faith or belief to you? *Not at all* *of utmost importance*
(Please circle number) 0 1 2 3 4 5 6 7 8 9 10

3 Indicate the religion that best applies to you by ticking the box.

- Christian ☐ Muslim ☐
- Hindu ☐ Buddhist ☐
- No religion ☐
- Other: Please specify ……..

4 How strongly do you believe there is an "after life"? Strongly disagree 1 2 3 4 5 Strongly agree

5 How often do you attend a place of worship? *(Please tick one of the following)*

More than once a week ☐ Once a week ☐ Once every 2-4 weeks ☐

A few times a year ☐ Never ☐

6 Sex: Male Female

7 Age: 20-29 30-39 40-49 50-59 Over 60

Imagine you are treating a patient who, in your clinical view and in the view of your clinical colleagues, is dying and has several days to live.

For each of the following statements, indicate how strongly you disagree or agree:
(1 = *Strongly disagree* 2 = *Disagree* 3 = *Neither agree or disagree* 4 = *Agree* 5 = *Strongly agree)*

8	Patients should be told they are dying.	1	2	3	4	5
9	Life sustaining treatment should be withdrawn.	1	2	3	4	5
10	Life sustaining treatment should be withheld.	1	2	3	4	5
11	Hydration by the parenteral route should continue.	1	2	3	4	5
12	Physician assistant suicide (euthanasia), should be allowed for patients who have 'unbearable' suffering.	1	2	3	4	5
13	Patients should be asked where they want to die.	1	2	3	4	5

14 The religious and spiritual needs of patients should

be discussed if they bring it up.	1	2	3	4	5

Any other comments:

Ref: EJP/BC/Life Spirituality & Beliefs of Clinicians/Nov 07