Original Article

Maltese doctors: views and experiences on end of life decisions and care

Jurgen Abela, Pierre Mallia

Abstract

Background: End of life (EoL) decisions are important and challenging for doctors.

Aim: To better understand, describe and quantify this aspect of care.

Methodology: A national cross-sectional validated survey was mailed to all doctors of the country.

Results: The response rate was 39.3%. The respondents had been practicing for 19.72 years (95% CI: 18.3 – 21.0). 86% of respondents declared that their religion was important in EoL care. 42.9% (25.6% disagreed, 31.5% neutral) agreed with the right of a patient to decide whether or not to hasten the end of life. 48.6% agreed (34% disagreed, 17.4% neutral) that high quality palliative care nearly removes all requests for euthanasia. 60.4% agreed (23.9% disagreed, 15.7% neutral) that physicians should aim to preserve life.

Each doctor cared for an average of 10.5 EoL (95%CI: 8.45-12.64) patients in the prior 12 months. 32.1% of doctors withdrew or withheld treatment in the care of these patients. Of the remaining 67.9%, 36.6% agreed with such practices. 50.3% had intensified analgesia at EoL with the possibility of hastening death. Only 6% had sedated patients at EoL. Lastly, 11.9% received request for euthanasia whilst 90.2% of doctors would never consider euthanasia.

Significant correlations were observed between considering euthanasia, importance of religion, withdrawing/withholding treatment, doctors' specialty, preservation of life and request for euthanasia. A thematic analysis of comments highlighted the importance of the topic, feeling uncomfortable in EoL care, the religious aspect of care, lack of legal framework and the challenge of symptom control.

Conclusions: The overall majority of doctors is against euthanasia. There is a strong sense of guidance by their religious beliefs when it comes to EoL care. Doctors believe in preserving life as a guiding principle at the end of life, but do not shun intensification of analgesia at the end of life. Different specialties have slightly different views on EoL. Doctors need guidance – legal and moral - on this subject, in the absence of which, their religion and philosophy of life is used to guide them in this rather difficult area of practice.

Jurgen Abela MD, DCH (Lond.), MSc (Warw.), FMCFD, FLCM, FRCGP(UK)*
Department of Primary Health, Malta
Medical Officer, Hospice Malta, Balzan – Malta
Visiting Senior Lecturer, Department of Family Medicine, University of Malta
jurgen.abela@um.edu.mt

Pierre Mallia MD, M.Phil, MA (Law.), PhD, MRCP, FRCGP
Department of family medicine, University of Malta
Coordinator, Bioethics Research Programme, University of Malta

**Corresponding Author*

Introduction

Palliative Care (PC) aims to improve the quality of life of the patient with a limited prognosis through a combined approach addressing the physical, psychosocial and spiritual nature aspects of the patient, including bereavement support to the relatives of the patient.[1] Historically, PC was born out of oncology. Following on a landmark study, PC has expanded to include non-cancer diseases such as heart failure and respiratory failure.[2] Such palliative approach to managing disease and symptoms is also reflected in the training curricula of various medical disciplines and in the most recent guidelines for the management of certain non-malignant conditions in their end stage.[3-5]

A particularly challenging moment in any specialty, not only in palliative care, is the end of life (EoL), due to the fact that ethical issues commonly arise with respect to symptom control, hydration, treatment withdrawal and the management of the dying process. In fact, the ethical challenges of EoL in medical practice are

reflected in a variety of documents.[6] Further to this, one should consider the effect that the (occasionally difficult to manage) suffering of the patients has on doctors. In fact, moral distress in doctors has been recently documented and frameworks to address it are being put forward.[7]

The country of Malta has experienced rapid and significant socio-cultural changes. One of the aims of this study was to inform a particular area of medical practice where controversial issues regularly arise. In addition, the authors have a particular interest in ethical issues at EoL. This study is being presented within ENDCARE Malta, an Erasmus + project aimed at supporting the harmonization and EoL practices.

Method

The aim of the study was to describe and quantify the thoughts amongst medical practitioners on EoL decision making. Hence a primarily quantitative methodology was adopted and accordingly, a questionnaire was used. The questionnaire was previously used in similar populations ie doctors, and previously validated as part of the EURELD (European end-of-life consortium) initiative.[8] The necessary permission was sought and obtained.

The questionnaire was sent by post to all medical practitioners who were listed on the Principal Register of the Medical Council of Malta as on November 2013. Only doctors who had a local address listed on the register were included (*N*=1007).

The questionnaire consisted of four sections, followed by a short comments section. The four sections related to demographic details; details on religion/philosophy of life; thoughts on palliative care and training; and lastly a section on past experiences and views in relation to end of life decisions.

Each questionnaire had a short note included where the aims of the study were explained and consent sought. The participants were asked to fill in the questionnaire and return it back by not more than one month.

Every effort was made to ensure a good response rate.[9-10] The introductory note was personalized, each participant had a prepaid envelope to return the questionnaire and the questionnaire was not long. However, contrary to existing recommendations, no reminder note was sent to the doctors. This was done since the author felt that the area being studied was 'sensitive' and consequently felt that a reminder was inappropriate.

The University of Malta Research Ethics Committee approved the study. The data collected was analyzed using SPSS version 22.0 and Excel version 12.3.6. For ease of analysis, the respondents were grouped in umbrella specialties. Hence medicine includes general medicine, neurology, cardiology, renal medicine, respiratory medicine and so on. The same goes for surgery which included amongst others general surgery, ENT and orthopaedics.

Results

396 doctors returned the questionnaire, giving a response rate of 39.3%. Of those that answered, 40 were no longer actively practicing as doctors. As per questionnaire, they were asked to return the questionnaire unfilled. The subsequent analysis of results is consequently limited to those doctors who were actively practicing at the time of the questionnaire (*n*= 356)

The results of the questionnaire will be presented in sections as per hereunder:

I. Demographic details

Of the respondents, 59.2% were males, whereas 40.8% were females. Overall, the respondents had been practicing for an average 19.72 years (95% CI: 18.3 – 21.0). The age of respondents is summarized in Figure 1. The distribution of specialties of respondents is summarized in Table 1. The largest specialty was general practice, the results of which have been analyzed in a separate paper.[11]

II. Respondents and their religion

The respondents were asked to identify their religion/philosophy of life. As expected, the majority of respondents (91.6%) identified the Roman Catholic Church as their religion. The importance of religion in EoL decisions is summarized in Figure 2.

III. Views of respondents on palliative care and EoL care.

The respondents were asked to rate on a 5-point scale whether they disagree/agree with a set of statements. A summary of the responses is found in Table 2.

Figure 1: *Age distribution of respondents*

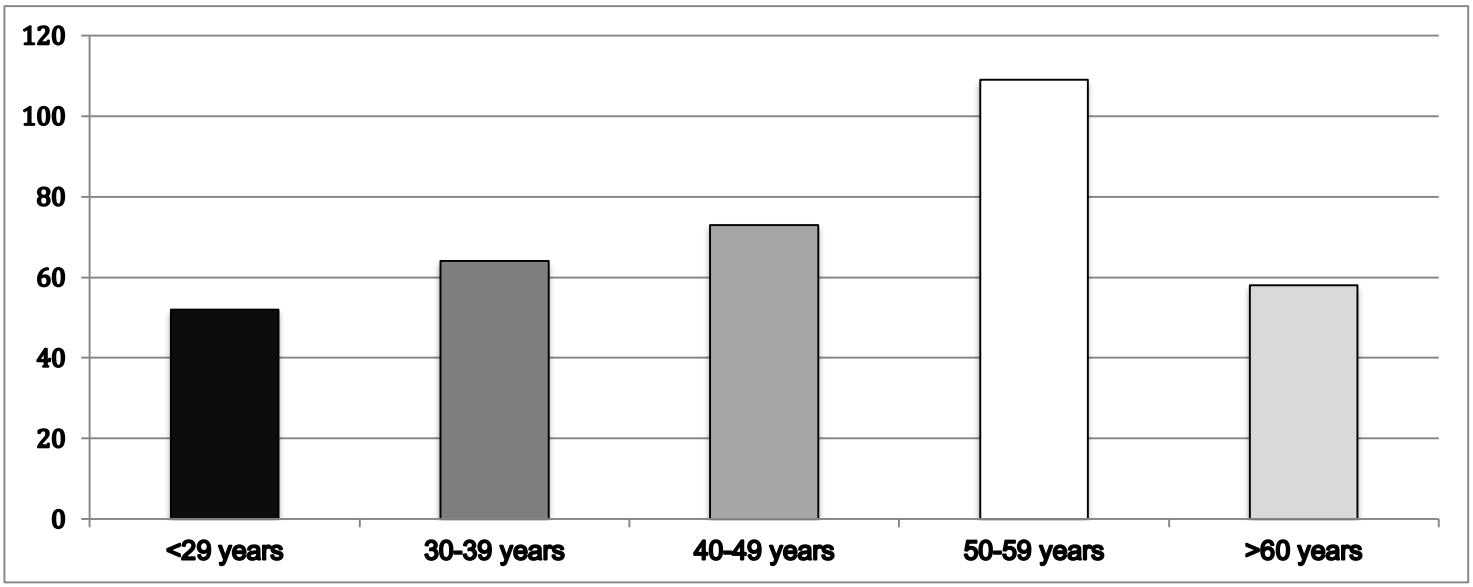


Table 1*: Respondents and their specialties*

Specialty	Number	Percentage of total (*N*=356)
General Practice	160	44.9%
Medicine *	49	12.4%
Surgery**	45	11.4%
Other***	23	5.8%
Anaesthesia	21	5.9%
Paediatrics	21	5.9%
Gynaecology	18	5.1%
Geriatrics	12	3.4%
Psychiatry	7	2.0%

** Includes general medicine; neurology; cardiology; respiratory medicine; oncology*

*** Includes general surgery, orthopaedics, ENT surgery, neurosurgery*

**** Includes dermatology, radiology, public health,*

Figure 2: *Importance of Religion in EoL Decisions (% response) (p<0.001)*

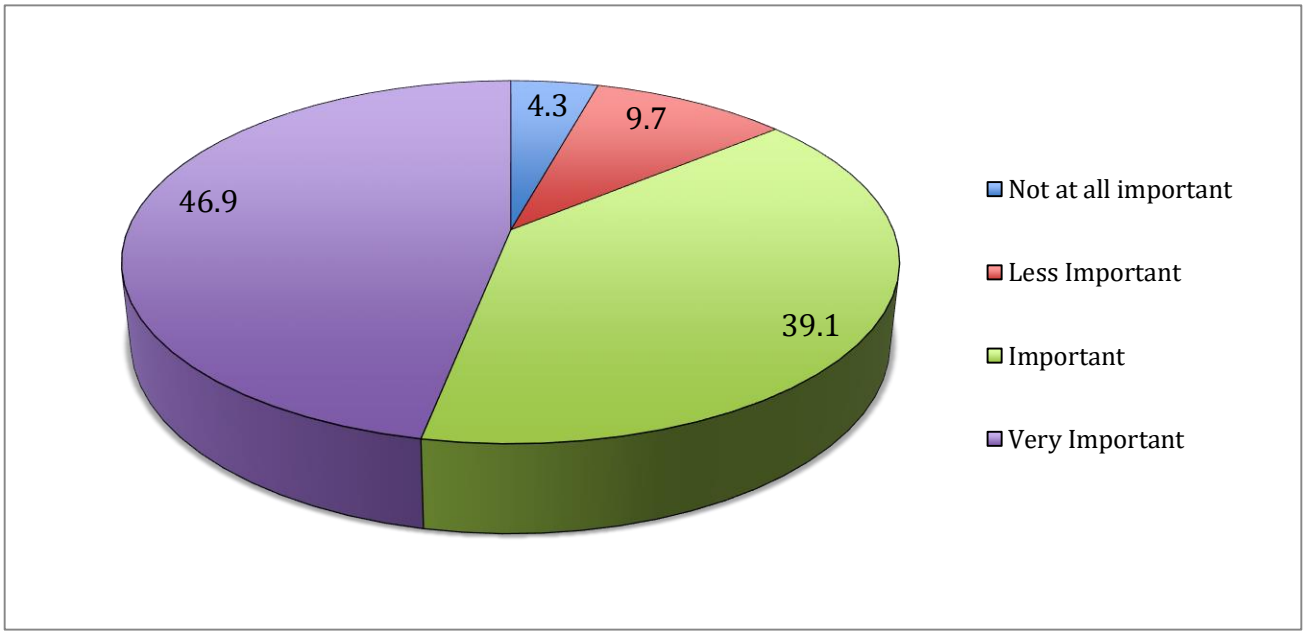


Table 2**:** *Agreement/disagreement on EoL statements*

Statements on EoL	*Disagree (%)*	*Neutral(%)*	*Agree(%)*
Patient has a right to decide whether to hasten his EoL (p<0.001)	25.6	31.5	42.9
High Quality PC removes almost all requests for euthanasia at EoL (p<0.001)	34	17.4	48.6
Physicians should always aim to preserve life (p<0.001)	23.9	15.7	60.4

IV. Respondents and situations of EoL care

The final part of the questionnaire dealt with actual experiences in EoL care. On each question, the respondents were asked whether they ever experienced a particular clinical scenario and if so, how long ago was it.

To start with, respondents were asked how many terminal patients did they care for in the last 12 months. The mean answer was 10.5 patients (95% CI: 8.45-12.64.

They were subsequently asked on whether they ever withdrew or withheld any treatment to their patients. Of all the doctors 32.1% had withdrawn/withheld treatment. Of these:

- 13.9% had withheld treatment,
- 4.0% had withdrawn treatment and
- 14.2% withheld and withdrew treatment.

Out of the remaining 67.9% who never carried out such practices:

- 13.6% of doctors would withhold treatment;
- 2.0% would withdraw treatment
- 21.0% agree to both
- 31.4% would not withdraw/withhold treatment.

Of those that answered positively to this question, the last time they had a patient in such

situation was a mean 15.8 months ago (95%CI: 7.87-23.91).

The respondents were also asked whether they ever intensified analgesia at EoL with the possibility of hastening death and whether they ever sedated patient at the EoL. The responses to these two questions are grouped together in Figure 3.

Those who responded positively to these two questions reported that they last had a patient needing intensification of analgesia 18.5 months ago (95%CI: 11.53-25.65), whilst with respect to sedation, the last patient they could recall was 36.3 months ago (95%CI: 11.13-61.3).

When asked whether they ever received a request for euthanasia from patients, 11.9% answered positively. Of these, the last time they received a request was on average 35.6 months ago (95%CI: 15.27-55.92)

Finally, the respondents were asked whether they would consider euthanasia. The response as percentage of total respondents is summarized in figure 4.

Figure 3: *Views on Intensification of Analgesia and Sedation at EoL (% response) (p<0.001)*

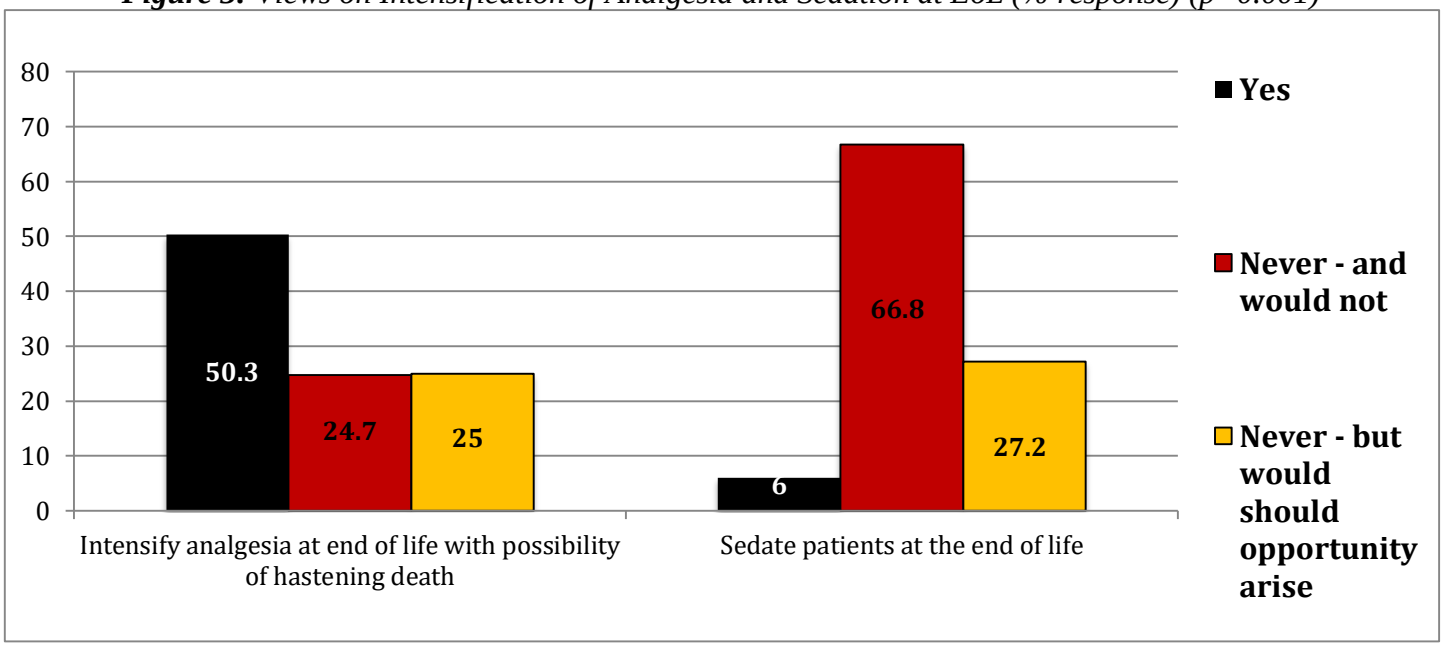
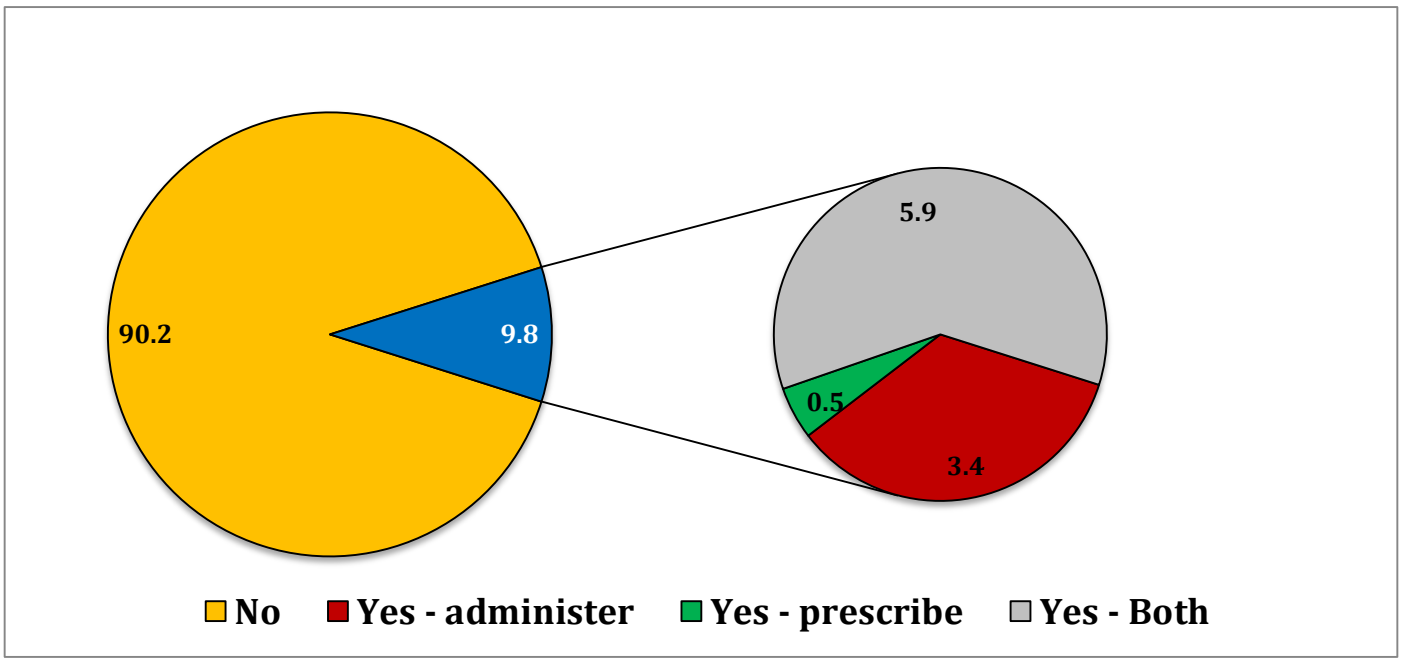


Figure 4: *Would you consider euthanasia on explicit request from patients? (% response)*



V. Associations

Analysis of possible relations between the various variables was carried out using appropriate non-parametric statistical tools (Chi-squared tests; Wilcoxon signed rank test). There was a significant (p=0.013) association between the practicing specialty and the number of requests for euthanasia as shown in figure 5. Another significant association (p=0.011) was observed between the practicing specialty and the response to the statement on whether physicians should always aim to preserve life (figure 6). A very significant relation (p<0.001) was observed between the importance given to religion and considering euthanasia and views on withholding/withdrawing treatment (Table 3). Finally significant associations were identified between the importance given to religion and the responses to the broad statements on EoL Care.

Figure 5: *Requests for euthanasia and Specialty (% response) (p=0.013)*

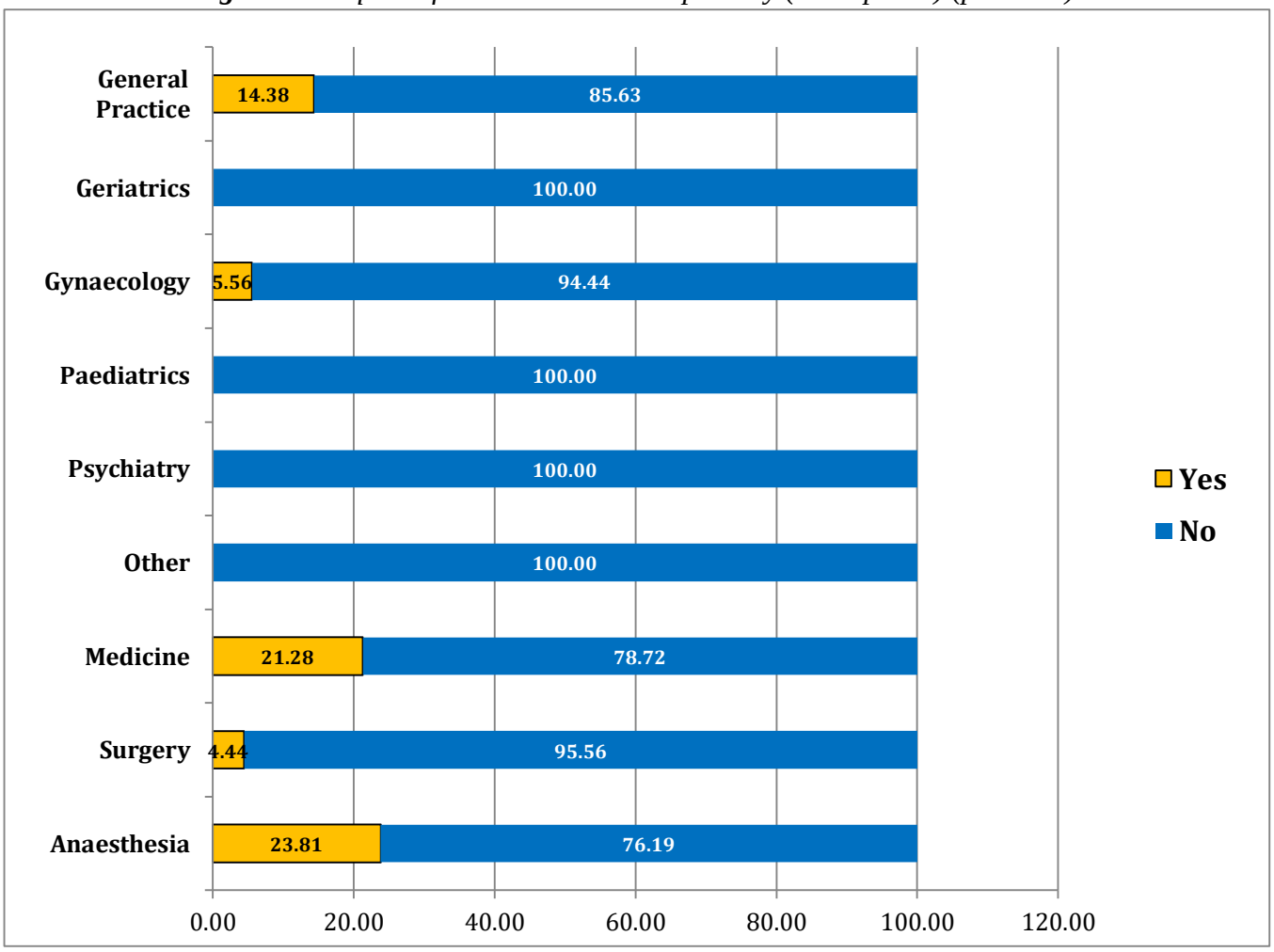


Figure 6: *Physicians should always aim to preserve life and practicing specialty (p=0.011)*

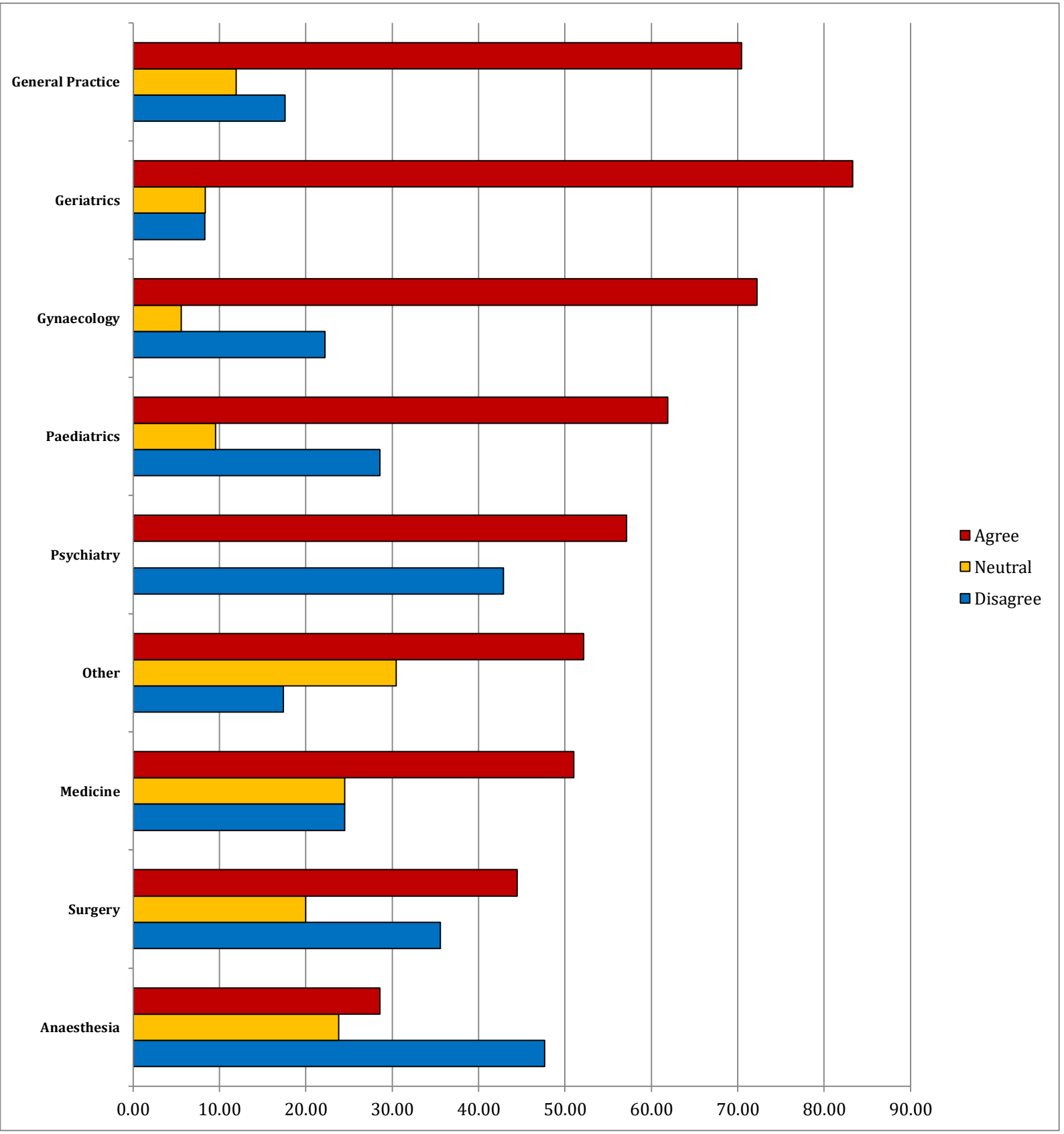


Table 3: *Importance of religion vs withholding treatment and considering euthanasia)*

Importance of religion	**Withdrawing or withholding Rx (*p*<0.001)**	
	YES	NO
Not or less important n=48	**89.6%** (43)	**10.4%** (5)
Important or Very Important (n=298)	**65.2%** (194)	**34.8%** (104)
Importance of religion	**Consider Euthanasia (*p*<0.001)**	
	YES	NO
Not or less important n=48	**66.6%** (36)	**33.3%** (12)
Important or Very Important (n=297)	**6.7** (20)	**93.3%** (277)

VI. Qualitative analysis

At the end of the questionnaire, the respondents had the option to leave comments. 92 opted to comment and a representative summary of the various themes is listed here under, in order of decreasing frequency:

- *Importance of the subject*
  ' This is one of the greatest dilemmas I could possibly face….it is also true that reassuring the patient of a dignified death reduced the request for euthanasia. I still do not feel comfortable in any way to help anyone hasten death' (GP)
  'A much needed study!' (Medicine)
  'This is a subject of extreme importance and which touches on one of the principal aims of medical practice' (GP)
- *Ethical and religious issues*
  'I believe that a doctor's own attitudes to life and death have a great bearing on the EoL situations. Also one's own beliefs' (Orthopaedics)
  'My religion has a reply to all this' (GP)
- *Feeling uncomfortable*
  'There is a tendency to withhold proper palliative care with the fear that it hastens death' (Paediatrics)
  'PC is an important topic. I really feel sad to see a patient, on post-take round in pain and 'nothing' is done since she is palliative' (Gynae)
  'Complex and difficult in balancing out things' (Surgery)
- *Symptom Control*
  'Whether or not the death of the patient is hastened, the comfort of the patient and relief provided by medication/surgery is paramount' (Anaesthetist)
- *Legal Issues*
  'Law is totally lacking. If legal, I might consider it' (GP)
  'With euthanasia likely to come up in Malta, legislation should protect doctors' (GP)
  'Do no harm and abide by the law. The law must be sensitive…' (Other – Radiology)
  'Law is totally lacking. If legal, I might consider it' (Orthopaedics)
- *Service Provision*
  'MDH - lacuna where a lot of attention is given to treatment which is dubious. DNR orders without telling the patient' (Medicine)
- *Need of Training*
  'Radiology is not considered a specialty where doctors have to BBN. But after

working for two years I realise that patients ask and therefore I feel that I need training' (Other - Radiology)

'A&E - need of training please' (Emergency Medicine)

- *Ripple Effect*

'And as we started with abortions….you start with the hard cases and end up with the frivolous cases'….slippery slope (Orthopaedics)

Discussion

End of life decisions are challenging. This comes through in the comments put forward by the respondents. On the other hand, moral guidelines on EoL are very clear and in fact similar in most religions. There is a general acceptance that there is a difference between killing and allowing to die, that one need not give treatment which is considered futile, that one is morally correct in avoiding extraordinary measures and that it is the patient who decides for himself what he or she considers ordinary or extraordinary.[12-14] In this study, the majority of doctors are resonant with the idea of withdrawing/withholding treatment should such treatment be deemed to be futile, in line with what has been stated above.

In addition, they are in favour of intensification of analgesia (using opiods) even if this might theoretically impact on the length of survival of the patient. At the same time they strongly support the statement that physicians should always aim to preserve life. Indeed, these two responses embody the doctrine of double effect.[15] In brief the doctrine of double effect concerns the idea that the bad effect is not the intended effect and that although a harm is foreseen, it is indirect and unintended – the intention and direct action being pain relief. Only a minority agree with sedating patients (in distress) at the end of life. This arises despite the fact that it has been shown that such practice actually lengthens (not shortens) life.[16] Such issue might arise from the fact that sedation of patients at the end of life can be interpreted by fellow colleagues or family/carers as a 'modified form of euthanasia'.

Interestingly, the very strong majority of doctors *against* euthanasia (90.2%) seems to have increased from the time of the study by Inguanez and Savona Ventura where the percentage of doctors *in favour* of euthanasia was 24%.[17] Abroad, a recent survey by the Association of Palliative Medicine of Great Britain showed that 82.3% were against euthanasia. (Dr C. Gannon, Medical Director Princess Alice Hospice – personal communication).

It is interesting to note the (significant) relation identified between the doctor's own specialty and receiving requests for euthanasia. The specialties 'at risk' (general practice, medicine, geriatrics) might be so due to the possibly higher level of empowerment of the professionals involved in getting through/communicating with patients. Thus patients feel more at ease to open up, even with respect to such difficult requests. In addition, the specialty of the doctor also relates to the response given to the statement about preservation of life (figure 6). When one compares the latter with the (non-significant) association between specialties and views on euthanasia (table 4), there are some interesting differences. For example, whereas in anaesthesia, there is a large minority who do not agree with always preserving life, there is a huge majority against euthanasia. This can be interpreted as a practical approach to EoL where at times patients are 'clearly' approaching death and such aggressive drive ('*accanimento terapeutico*') to maintain life might be inappropriate.

The qualitative section of the results shows the amount of issues which EoL situations give rise to. In addition, it is quite evident that the absence of any guidance – which comes through in the plethora of comments in the qualitative section – is made up by the guidance provided by the religion of the individual doctors.

This study, which was done in a mostly Catholic country, raises concern that there might be lack of clear understanding of moral guidelines, which are accepted socially from a religious point of view. The main concerns seem a lack of a legal framework and possibly, fear of litigation by the relatives. It goes without saying that communication with relatives and patients can only occur if one knows moral guidelines well and indeed perhaps offers ethical/spiritual counselling both to patient and relatives. Further studies are needed to attenuate such concerns on behalf of professionals. In this regard, The ERASMUS+ EndCare project is currently being carried out.[18] This project will try to address the critical issues of end of life treatment and, whilst repudiating euthanasia in all its forms, will examine the short

comings of health care professionals who might be ambivalent about such situations. EndCare will propose a curriculum framework and a complementary care protocol incorporating identified best practice from diverse jurisdictions throughout the European Union be developed and implemented in the fullest respect for ethical, moral, medical and socio-political considerations.

Table 4: *Considering euthanasia and practising specialty (p>0.05)*

Specialty	Not consider euthanasia (%)	Would consider euthanasia (%)
Anaesthesia	95.24	4.76
Surgery	80.00	20.00
Medicine	100	0
Other	80.95	19.05
Psychiatry	85.71	14.29
Paediatrics	95.24	4.76
Gynaecology	88.89	11.11
Geriatrics	100	0
General Practice	89.31	10.69

Strengths and Limitations

The response rate in this study was low, possibly related to the fact that no reminder was sent to respondents.[19] Having said this, in the study by Inguanez and Savona Ventura, the response rate was the same. [17] This study concerned a difficult subject area and as such should contribute to the local literature. It was a national cross sectional survey where *all* local doctors were included. The low response rate, though similar to a previous study, might have affected the results. The study employed a mixed methods approach thereby allowing a more holistic review of the topic.

Conclusion

Doctors commonly face EOL decisions. In general, they find this topic difficult and challenging and rely on the religion as the major source of guidance. There might be some confusion as to the (accepted) moral values guiding such decisions. There is an absence of legal framework and official guidance on this topic, which further adds to the difficulty in such situations. Different specialties have slightly different views and approaches to EoL. The overall majority of doctors are against euthanasia. Finally, there needs to be broad guidance to doctors in such situations to support them better.

References

1. Charlton R, editor. Primary Palliative Care. 1st ed. Oxon: Radcliffe Medical Press; 2002.
2. Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. Palliat. Med. 1995; 9 (4):295-305.
3. Royal College of Physicians. [Internet] MRCP(UK) [updated 2015 Jun; cited 2016 Jan]. Available from: https://www.mrcpuk.org
4. European Society of Cardiology. Guidelines for the Management of acute and chronic Heart Failure. European Heart Journal (2012) 33, 1787–847.
5. Global Strategy for the management and prevention of COPD [Internet] Guidelines of the prevention and management of COPD. [updated 2015; cited 2016 Jan]. Available from: http://www.goldcopd.org
6. Treatment and care towards the end of life: good practice in decision making, General Medical Council UK, (2010).
7. Rushton CH, Aszniak AW, Halifax, JS. A Framework for Understanding Moral Distress among Palliative Care Clinicians. Journal of Palliative Medicine. 2013; 16 (9):1074-9.
8. Lofmark R, Milstum T, Cartwright C, EURELD Consortium. Physicians experiences with end-of-life decision-making: Survey in 6 European countries and Australia. BMC Palliat Care. 2008;6(4).
9. Kellerman SE, Herold J. Physician Response to Surveys - A review of the Literature. American Journal of Preventive Medicine, Am J Prev Med. 2001;20(1):61.
10. Seale C. End-of-life decisions in the UK: a response to van der Heide and colleagues. Palliat Med. 2009;23 (6):567-8.
11. Abela J. GPs and End of life decisions: views and experiences. Malta Med J. 2015; 27(2): 31-6.
12. Jecker N, Jonsen A, Pearlman R. Bioethics – An introduction to the History, Methods and Practice. Second Edition. Boston, Toronto, London Singapore. Jones and Barthlett Publishers. 2007: 484-5.
13. Magisterium of the Catholic Church. Catechism of the Catholic Church. Dublin, Vatican City. Veritas publishers, 1994.
14. Petrini M. Il Testamento biologico: status of art. Um. Nuova 2011; 6(198): 621-657
15. Jonsen AR, Siegler M, Winsdale WJ. Clinical Ethics. A practical approach to Ethical Decisions in Clinical Medicine. Second edition. New York, London Toronto: Macmillan Publishing Company. 1986, p 120.
16. Maltoni M, Scarpi E, Rosati M, Derni S, Fabbri L, Martini et al. Palliative sedation in end-of-life care and survival: a systematic review. J Clin Oncol. 2012; 30(27): 3429-33.
17. Inguanez J, Savona-Ventura C. Not a Euthanasia. DISCERN - Institute for Research on the Signs of the Times. 1st ed. Malta: Gutenberg Press Ltd.; 2008.

18. Endcare. Erasmus + 2015: On harmonization and Dissemination of Good Practice at the End of Life. Project 2015-MT01-KA203-003728. 2015: Bioethics Research Programme, University of Malta.
19. Edwards P, Roberts I, Clarke M, DiGiuseppi C, Pratap S, Wentz R, et al. Increasing response rates to postal questionnaires: systematic review. Br Med J. 2002; 324: 1183-7.