Journal Article

GPs and End of Life Decisions: Views and Experiences

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Abstract

Background: The views and experiences of GPs with respect to end of life (EoL) care are seldom addressed.

Aim: To better understand this aspect of care.

Design and setting: A cross-sectional survey of all doctors in the country.

Method: A validated questionnaire; subgroup analysis of GPs.

Results: The overall response was 396 (39.7%), 160 of which were GPs. 28.7% of GPs received no formal training in palliative medicine. 89.8% of respondents declared that their religion was important in EoL care. 45.3% agreed with the right of a patient to decide whether or not to hasten the EoL. 70.5% agreed that physicians should aim to preserve life.

15% of GPs withdrew or withheld treatment in the care of these patients. 41.1% had intensified analgesia at EoL. 7.5% had sedated patients at EoL. Lastly, 89.1% GPs would never consider euthanasia.

Significant correlation ($p< 0.05$) was observed between considering euthanasia, using sedation, importance of religion and patients' rights in EoL. A thematic analysis of comments highlighted the importance of the topic and feeling uncomfortable in EoL care.

Conclusions: There needs to be more training in palliative care. GPs believe in preserving life, would not consider euthanasia but do not shun intensification of analgesia at the end of life. There might be some misunderstanding with respect to the role of sedation at the EoL. GPs need legal and moral guidance in EoL care, in the absence of which, their religion is used as a guide.

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Keywords

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Introduction

Family medicine is defined as the medical specialty, which, irrespective of the health care setting in which it functions, includes the six core competencies of primary care management, person-centred approach, specific problem solving skills, community orientation, comprehensive approach and holistic care.[1]

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.[2] 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.[3] From a philosophical perspective, there is a lot of overlap between the approach adopted in family medicine and palliative care. Further to this, the RCGP EoL strategy (pg.5) states that:

Caring for people nearing the end of their lives is part of the core business of general practice. The GP and the primary care team occupy a central role in the delivery of end of life care in the community.[4]

More than 90% of the last year of life of PC patients is spent at home and they are cared for by generalists.[5] The recently launched Prague Charter exhorts governments to relieve suffering and ensure the right to proper palliative care, including the community.[6] Consequently, almost every family doctor will interact with dying patients at some point and identifying the goals of care can be a challenge. A particularly challenging moment is the EoL, due to the fact that ethical issues commonly arise with respect to symptom control and the management of the dying process. In fact, the ethical challenges of EoL in family medicine are reflected in a variety of documents.[7]

Malta is a small country with an estimated population of 420,000. It has strong traditional roots, which recently have been challenged with the introduction of a variety of civil rights, including the introduction of divorce in 2011 and the introduction of civil unions and adoptions by gay couples in 2014.

Given all of these rapid socio-cultural developments and legislations locally, the need to study

a rather 'controversial' area was felt, particularly to inform any future nationwide discussion on the topic which might occur in the country. One such 'controversial' area is EoL care which includes decisions on withdrawing or withholding treatment, sedation and euthanasia.

Method

The aim of the study was to 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 i.e. doctors and previously validated as part of the EURELD (European end-of-life consortium) initiative.[8] The necessary permissions were sought.

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 present study is concerned with a sub-group analysis of all respondents who replied to the questionnaire and who identified their primary area of work as being family medicine.

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 has been 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.

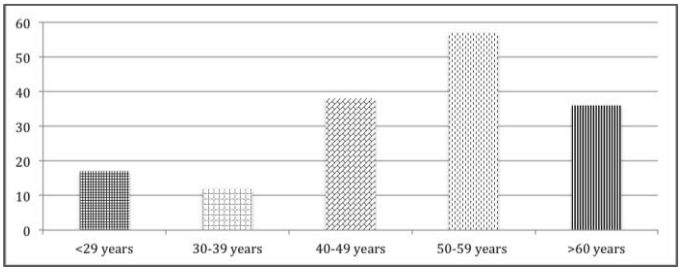
Results

396 doctors returned their questionnaire, giving a response rate of 39.7%. Of these, 356 were actively practicing doctors (40 doctors were no longer actively practicing). Out of the total practicing doctors, 160 practiced in family medicine. The results hereunder refer to the latter sub-population of the total respondents. Section A-E refer to the quantitative results whereas the final section presents the qualitative aspect of the study.

A. Demographic details

Of the respondents, 113 (70.6%) were males, whereas 47 (29.4%) were females. Overall, the respondents had been practicing for an average 23.76 years (95% CI: 21.68 – 25.84). The age distribution of the respondent is shown below in Figure 1.

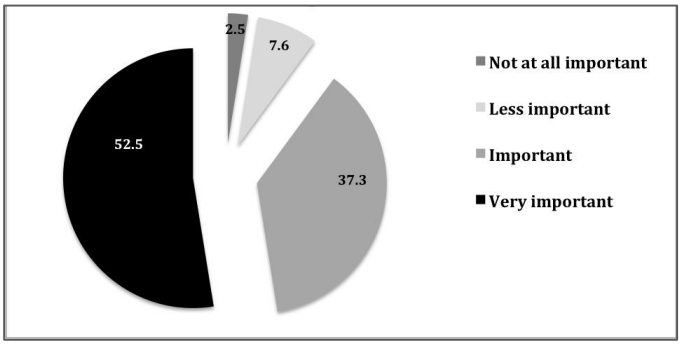
Figure 1: *Age distribution of respondents*



B. Respondents and their religion

132 GPs (82.3%) identified the Roman Catholic Church as their religion. Further to this response, the doctors were asked to rate how important was their religion/philosophy in taking EoL decisions. The results are reproduced in figure 2.

Figure 2: *How important is your religion/philosophy of life in making EoL decisions?*



C. 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. The results for these questions are summarized in Table 1.

D. Training in Palliative Care

The respondents were asked about their training in palliative care. They were also asked if they agreed that training in palliative care should be increased/extended; and if so at what level – undergraduate, postgraduate education; postgraduate course or any combination. 46 GPs (28.7%) of GPs received no form of training in palliative care and 63 GPs (39.6%) do not agree to extend training in palliative care. A detailed breakdown

of responses is shown in figures 3 & 4.

Table 1: *Questions on EoL care decisions and Palliative Care*
(p<0.001)

Questions	Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
A person should have the right to decide whether to hasten his EoL or not	1.9	43.4	31.4	12.6	10.7
Sufficient availability of high quality palliative care removes almost all requests for euthanasia in EoL	11.9	40	18.1	18.8	11.3
Physicians should always aim to preserve the life of their patients	25.8	44.7	11.9	16.4	1.3
Allowing use of drugs in lethal doses on request of patients will gradually lead to increase in the use of drugs without request by patients	20	28.1	19.4	26.9	5.6
Allowing the use of drugs in lethal doses on request by patients will harm the relationship between doctor and patient	15.6	32.5	18.8	25.6	7.5

Figure 3: *GPs and training received in palliative care*

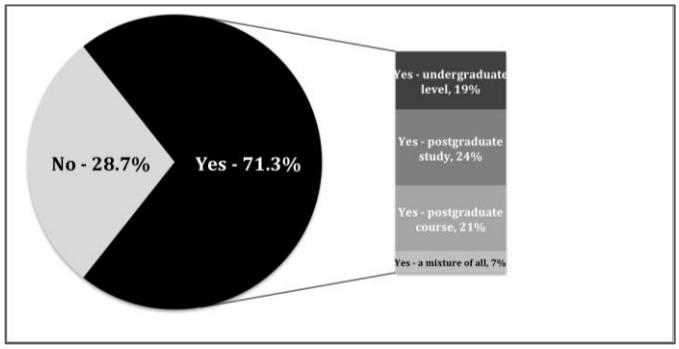
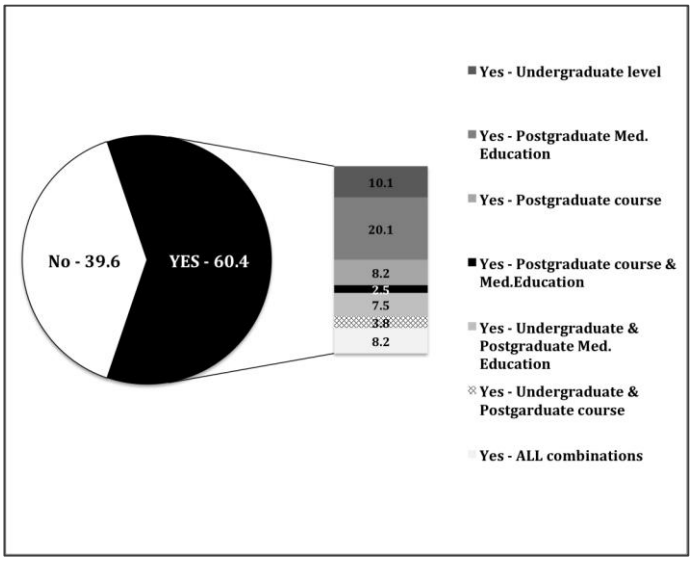


Figure 4: *Do you agree with extending training in PC for GPs?*



E. Situations of EoL care

Respondents were asked how many terminal patients they cared for in the last 12 months. The mean answer was 4.44 patients (95% CI: 3.67-5.21) with 35 (21.9%) stating that they did not care for a dying patient in the past 12 months.

They were subsequently asked on whether they ever withdrew or withheld any treatment to their patients. Of all the GPs, 24 (15%) had withdrew/withheld treatment. Of these:

- 13 (8.1%) had withheld treatment,
- 3 (1.9%) had withdrew treatment and
- 8 (5%) withheld and withdrew treatment.

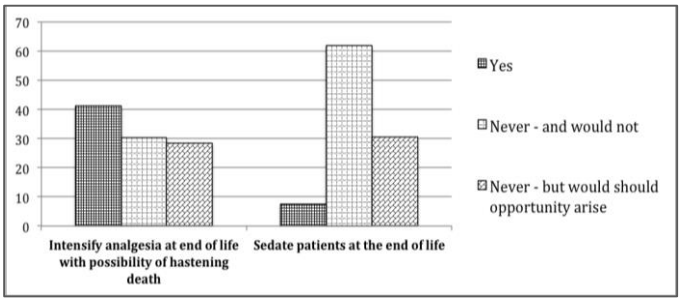
For the 136 (85%) GPs who never carried out such practices:

- 28 (17.5%) of doctors would withhold treatment;
- 2 (1.3%) would withdraw treatment
- 39 (24.4%) agree to both
- 67 (41.9%) would not withdraw/withhold treatment

For the 24 GPs (15%) who had withdrew/withheld treatment, the last time they had a patient in such situation was a mean 33.1 months ago (95%CI: 4.93 – 61.25).

The respondents were also asked about their views and experience with respect to intensification of analgesia at EoL with the possibility of hastening death and sedation of patients at the EoL. The responses to these two questions are grouped are shown in figure 5.

Figure 5*: Respondents and their views on intensification of analgesia and sedation at EoL – percentage of total*



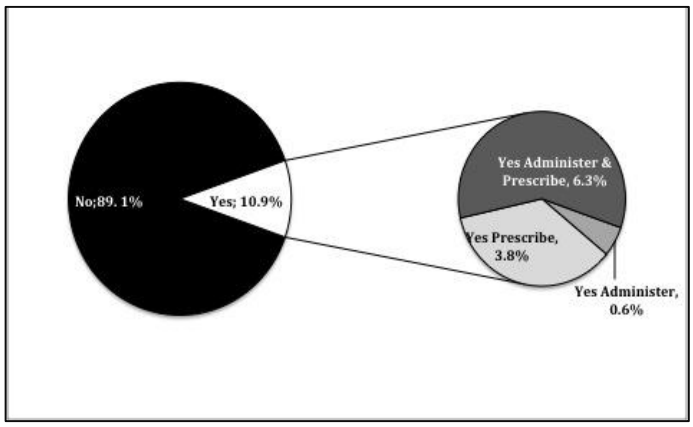
Those who responded positively to these two questions reported that they last had a patient needing intensification of analgesia 27.5 months ago (95%CI: 12.08 – 43.12), whilst with respect to sedation, the last patient they could recall was 39.27 (95%CI: 7.75 – 70.80) patients months ago.

When asked whether they ever received a request for euthanasia from patients, 23 (14.4%) answered positively, whilst 137 (85.6%) of respondents never received such requests. Of those who received a request, the last time they received a request was on average 45.15 months ago (95%CI: 13.45 – 76.85).

Finally the respondents were asked whether they

would consider euthanasia. The response is summarized in figure 6.

***Figure 6**: Would you consider euthanasia?*



On further analysis, there was a significant correlation between views on considering euthanasia and views on palliative sedation (p=0.020) and between the importance of religion and consideration of euthanasia (p=0.031). There was also a very significant correlation (p<0.001) between importance of religion/philosophy of life and the response to the question on the right of patients to hasten the EoL.

F. Qualitative analysis

At the end of the questionnaire, the respondents had the option to leave comments. 77 GPs did so and a thematic analysis of their comments is presented hereunder:

F1. Ethical and religious issues

'According to my belief, God is the master of all living things. I have no authority to determine end of life. I cannot be Dr Jekyll and Mr Hyde (GP no.15)

'Morally very challenging especially if there is a good relation with the patient. Cannot force doctor to do something against his moral ground' (GP no.91)

'Religion is paramount. God gives life and only He decides when to take it' (GP no.281)

'Apart from religious teachings…..primum non nocere' (GP no. 145)

F2. Importance of the subject

'This subject is of extreme importance and which touches on one of the principal aims of medical practice..' (GP no.2)

F3. Feeling uncomfortable

'This is one of the greatest dilemmas I could possibly face…it is also true that reassuring a patient of a dignified death reduced the request for euthanasia. I still do not feel comfortable in any way to help anyone hasten his death' (GP no.24)

'Always very difficult to be ABSOLUTELY right' (GP no. 243)

'The most common scenario is that the patient does not know he is terminal' (GP no. 368)

F4. *Ripple effect*

'In general people do not agree with euthanasia because of fear it will be abused. But every invention in human history - fire knife etc - has been misused. Nothing is black or white' (GP no.76)

F5. Legal aspects

'If legal I would do it' (GP no. 122)

'Illegal in Malta' (GP no. 274)

F6. Symptom Control & Service Provision

'Difference between hastening death and prolonging status quo' (GP no. 139)

'Distinguish between withholding; Stopping Rx to accelerate death; actively end life. Legal input especially if patient is unconscious. Problems with finding a bed where patients can die, when home is not an option' (GP no.257)

Discussion

Strengths and Limitations

This was a study that explored a topic rarely studied. The response rate for the questionnaire was low. In fact, the average response rate by doctors for surveys published in medical journals is 54%.[11] It can be argued that the decision not to send a reminder could have possibly affected the response. [12] Having said this, in a past local study concerning euthanasia – and which unlike the present study included a reminder - there was a response rate of 39.3%, very similar to this study.[13] Consequently, the low response rate seems to be more reflective of the attitude towards questionnaires in Mediterranean countries – as opposed to northern countries - given that in original study carried out across different countries in Europe, Italy returned a response of 39%.[8]

The tool used – a postal based questionnaire - was informed by the conclusions of a review of physicians' responses to questionnaires.[9] Thus it was a short and easy to fill in questionnaire with simple and clear instructions. No questionnaires were lost throughout the compilation of data. The use of a semi-qualitative section allowed for some themes to emerge, which could not have been identified from a purely quantitative perspective. Finally, the fact that this study concerned all doctors in the country further strengthens its findings.

Comparison with existing literature & Implications for Practice and research

89.8% of respondents consider their respective religion/philosophy of life as being important or very important in guiding their end of life decisions. Locally and internationally, in line with a secular trend in various aspects of society, it is occasionally suggested that religious guidance should be separated from medical care in end of life strategy and care as well as in a variety of other issues. It can be argued that the results of this study would suggest that such separation might seem artificial and indeed counter-productive.

A relative majority of respondents (45.3%) agreed that patients had a right to decide whether to hasten their EoL or not. This is in line with similar surveys done abroad.[14] A majority of respondents (51.9%) stated that with good palliative care most requests for euthanasia can be removed. This line of thought reflects a major discussion going on at a European level about the role of palliative care.[15] There was a significant agreement that physicians should always aim to preserve life, with just 17.7% disagreeing with such statement. With regards to the use of high doses of drugs at EoL, there was a spread of responses with a skew towards agreement with the statements which actually mean that GPs are somewhat concerned about such practices. These issues could be explained by the fact that GPs usually have few palliative patients per year. Hence the lack of regular exposure to such situations might actual make them less confident to deal with such problems and drug doses.[16]
Training in palliative care is quite varied around the world.[17] It has been previously documented that training in PC for GPs can be improved.[18-19] The majority of respondents stated that they had some training in PC though worryingly, 28.7% never had training in PC. Most agreed that training should be increased, in line with the conclusions of a previous local study where 40.9% of GP trainees feared managing a dying patient in the community.[20] The need to promote training is also in line with the recently developed Primary Palliative Toolkit.[21] Local initiatives like the European Certificate in Palliative Care, which is run by Hospice Malta is a step in the right direction to address this lacuna of knowledge.[22]

The majority of GPs (58.1%) agrees with the process of withdrawing/withholding various forms of treatment at the end of life. This response might seem to contradict the strong sense of preserving life as stated previously. It should be noted that withdrawing/withholding treatment is not necessarily done with the aim or consequence of hastening death. Indeed, few are the occasions where one might argue so. Secondly, this may also suggest that GPs can clearly identify situations where a practical and flexible approach - in which death is inevitable and overtreatment becomes an issue – is necessary. There is a possibility that attitudes to withdrawal of treatment change according to whether the decline is mainly physical or cognitive.[23] However, this distinction could not be ascertained in this particular study. Comparison with a similar local study is impossible with respect to this issue, since in their study, Inguanez & Savona Ventura posed a different question which specifically associated withdrawal of treatment with shortening of life, which is not always the case.[13]

A sense of uneasiness comes in with the two questions related to intensification of analgesia and sedation at EoL in line with the literature. [10] This uneasiness comes out also in the qualitative section. Whereas a good number of GPs are not against intensification of analgesia (to achieve symptom control) there was a majority against sedating patients at the end of life. Internationally, despite there being recognized pathways for palliative sedation there is still raging controversy that palliative sedation might be abused and used as a form of euthanasia.[24] Another possible explanation of this difference in response might be difficulty in communicating such delicate issue with patients and families. This has been documented previously in the literature. [25] Indeed it estimated that in the cancer setting, only 7.8% of patients discuss difficult EoL with physicians.[26] In the non-cancer setting this is lower due to prognostic uncertainty. [27] In the community setting, communication is much more challenging than in a secondary care setting since the actual care of the (moribund) patient is usually provided by the family carers. Hence the family has more leverage and possibly need more convincing. Thirdly, in Maltese – like in the English language – a commonly used phrase in veterinary medicine is 'putting an animal to sleep'. Hence sedation in patients might be associated with 'killing' even due to a linguistic issue.

Finally, 14.4% of GPs received requests for euthanasia which is significantly lower than the previously reported 25.9%.[13] A possible explanation could be the fact that patients are increasingly dying at hospital (despite spending most of the last year of life at home) and hence such requests are usually made during the final phases.

GPs are clearly against euthanasia and would not consider it. Considering that in the study by Inguanez and Savona Ventura the percentage of GPs against euthanasia was 83.7%, it could be argued that there is an increase in GPs against euthanasia over time.[13] Overseas, the situation is not very much different – in a recent poll organized by the Royal College of Physicians, 82.3% of palliative care physicians were against measures to facilitate hastening death (Dr C. Gannon, Medical Director Princess Alice Hospice – personal communication).

In the qualitative section one can observe the religious beliefs/philosophy of life of GPs as being

important in guiding them in their actions, possibly due to the legal/moral vacuum in this field on a local level. In fact, as far as is known, there is no guidance from the Medical Council of Malta in this important topic.

Conclusion

This study was about end of life decisions by GPs. It shows that most GPs are against euthanasia. There is a practical approach to end of life, where a good number of GPs would consider withdrawing or withholding treatment. GPs believe in preserving life as a guiding principle at the end of life, but do not shun intensification of analgesia at the EoL. There might be some misunderstanding with respect to the role of sedation at the end of life. GPs 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.

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