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ORIGINAL ARTICLE

Maltese doctors and their views on End of Life issues

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Background

End-of-life (EoL) decisions are challenging for doctors. They involve legal and ethical dilemmas, coupled with personal values. In 2016, a local study was carried out on the views of doctors on some EoL decisions. This study is a follow-up study, with a greater focus on advance care planning and related issues, which were not sufficiently addressed in the first study.

Methods

A mixed methods approach was used. An online questionnaire was distributed electronically to doctors and collected: demographic details of participants; the philosophy of life of the individual; training needs in palliative care; personal views and experiences on particular EoL issues. The necessary ethics approval and organizational approvals were obtained.

Results

195 doctors replied giving a response rate of 15.1%. Hence, caution needs to be applied in interpreting the data, despite a positive non-responder analysis. 142 doctors [72.8% (95%CI 66-78.9)] felt the need of further training in EoL care. For withdrawal/withholding of treatment, 129 doctors (66.1% (95%CI 59-72.8)) did not feel safeguarded. In the case of the doctrine of double effect for treatment intensification, 129 doctors [66.1% (95%CI 59-72.8)] did not feel safeguarded, whilst for advance care planning 122 doctors [62.5% (95%CI 55.4-69.4)] did not feel safeguarded. Issuing a DNR order was the least concerning since 103 doctors [52.8% (95%CI 45.1-59.5)] did not feel safeguarded in this regard.

Conclusion

Despite agreeing with various EoL practices, most doctors felt they were not medico-legally safeguarded and welcomed further training in EoL care.

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Doctors, in various specialties of work, have to care for patients at the end of life (EoL). In these situations, taking difficult decisions is often an arduous task. This has long been recognized.[1] The views of doctors on various aspects, especially EoL care, are crucial to shape and mould the future care of patients within our health system. A study carried out in Malta in 2016 had reported that 90.2% of doctors were opposed to euthanasia but did not delve into end of life care issues and the comfort or discomfort with which doctors approach these issues.[2]

The objectives of this study were to:

- To document and update the views of doctors on various issues on EoL care.
- To assess whether there is a need for training in EoL care.
- To analyze whether doctors feel safeguarded with practices they agree on.
- To put forward ways to address any issues which might arise from this study.

EoL care encompasses a multitude of issues including, for example: withdrawing and withholding of treatment (WDWH); do not resuscitate orders (DNR) and palliative sedation (PS). Each topic very well deserves an in-depth study and review on its own merits. This study was primarily concerned with highlighting the views of doctors on various issues relating to Eol, and whether doctors felt safeguarded when dealing with this subject.

MATERIALS AND METHODS

A questionnaire was constructed based on a previous study carried out locally by the author in 2016.[2] Certain important aspects of care, not covered by the previous study, were included. The questionnaire was then reviewed by colleagues for validity and reliability.

The questionnaire was primarily quantitative in nature and allowed for comments in various sections. Thus, a mixed methods approach was used. The questionnaire was divided into four sections: demographic details and working experience; philosophy of life and its importance in EoL care; experience with EoL care and lastly, EoL issues. Each time participants were asked about a particular EOL issue, they were asked whether they ever practised it themselves; whether they agreed with it and whether they felt safeguarded. Their responses were classified along a 4-point Likert scale.

The questionnaire was distributed electronically to all doctors within the following organisations, after due approval was obtained: Mater Dei Hospital (MDH); Gozo General Hospital (GGH); Mount Carmel Hospital (MCH); Primary HealthCare (PHC); St Vincent De Paule Hospital (SVPR); Karin Grech Hospital (KGH); Sir Anthony Mamo Oncology hospital (SAMOC); The Association of Private Family Doctors (APFD) and the Malta Association of Public Health Medicine (MAPHM). Before contacting the doctors, Faculty Research Ethics Committee (FREC) approval (MED-2022-00063) was sought and granted.

The questionnaire contained an introductory letter, explaining the aims of the study and an electronic link using Microsoft Forms® link to participate in the study. It was accepted that by clicking on the link, the doctor was consenting to participate in the study

The collection period was arbitrarily set for three weeks from when the email shot was sent. The period was deemed suitable so that anyone wanting to participate could participate. No reminders were sent since these were deemed to be intrusive by the author.

The data was collected on Excel® V 16.67 and elaborated using SPSS® V 28.2. Statistical analysis was carried out using a non-parametric approach. In the event of a low response rate (<20%), a non-responder analysis was planned accordingly.

RESULTS

The results are presented in two main sections:

- Quantitative section
- Thematic analysis of responses

Quantitative Analysis

Basic Demographic details

In total, 195 doctors replied to the questionnaire. This gave an overall response rate of 15.1%. This low response rate implied that the findings needed to be interpreted with caution. Due to the low response rate, a non-responder analysis was carried out (**Table 1**). The only possible comparable participant characteristic for such analysis was the specialty of practice. However, when compared to the general medical population as listed on the specialty register of March 2023, there was no significant difference noted [X(2)((9, n=192) =16.029, p=0.0988)]. The age and gender distribution of the respondents is summarized in **Figure 1**, whilst **Figure 2** shows current stage of the respondents in their career. In

Table 1 *Non-responder Analysis*

	Observed	Expected	Expected (%)
Anaesthesia	13	21	11
Emergency Medicine	16	9	5
Family Medicine	73	73	38
Geriatrics	8	6	3
General Medicine	25	25	13
General Surgery	15	11	6
Haem&Onc&PallMed	9	6	3
Obs&Gynae	8	14	7
Paediatrics	8	10	5
Public Health	7	9	5
Psychiatry	10	8	4
	192	**192**	**100**

Total analysed was 192, since 3 responders were classified in Other specialties

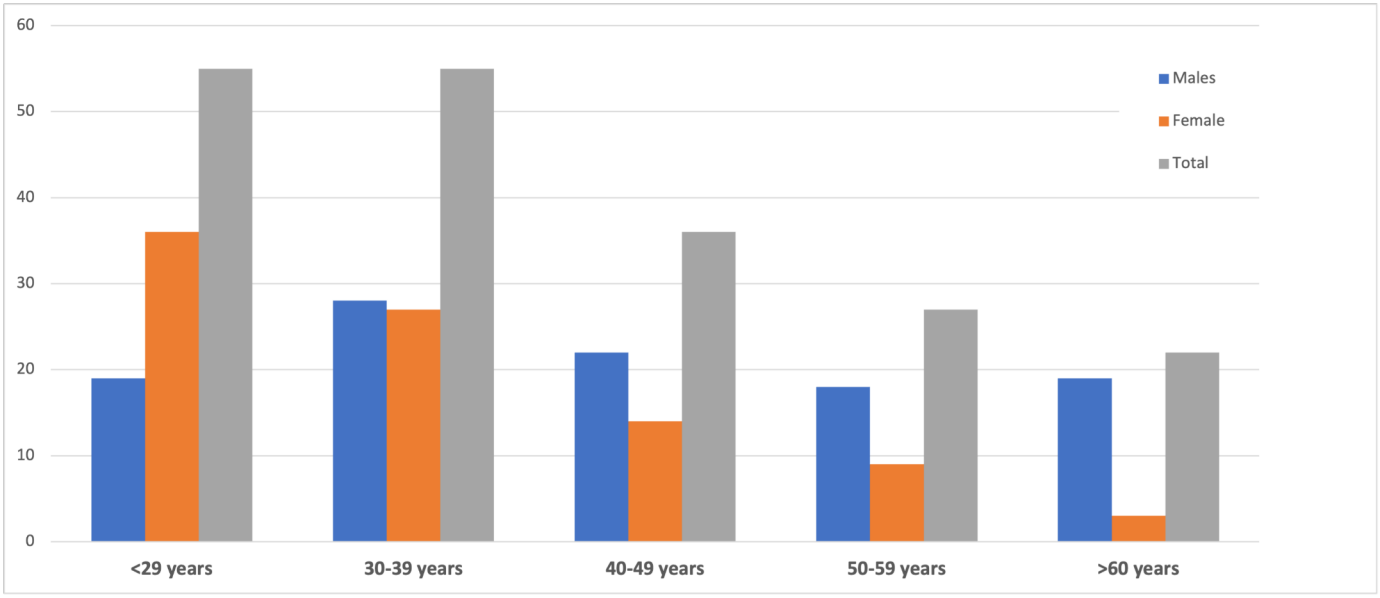

Figure 1 *Age and Gender distribution of respondents*

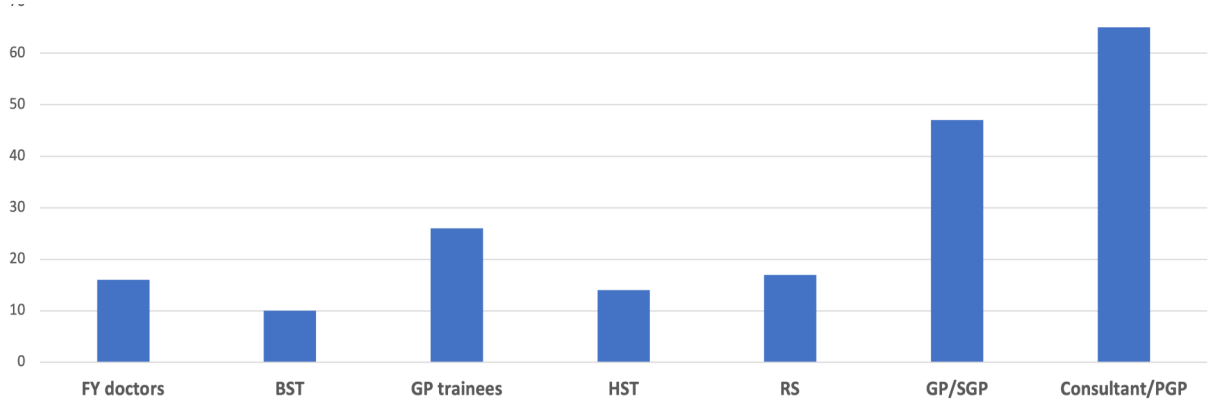

Figure 2 *Stage of Career of Participants. BST - Basic Specialist Trainee; FY - Foundation Year doctors; GP - General practitioner; HST - higher specialist Trainee; PGP - Principal General Preactitioner; SGP - Senior General Practitioner*

line with FREC recommendations, data aggregation and analysis was carried out in a manner to avoid identification of individuals.

Philosophy of Life (POL) & EoL experience

160 doctors [82% (95%CI 75.9-87.2)] identified their philosophy of life as Roman Catholic and 148 doctors [75.9% (95%CI 69.3-81.7)] doctors regarded their philosophy of life as important or very important in taking EoL decisions.

143 doctors [72.8% (95%CI 66-78.9)] admitted that they would benefit from further training in this area. The three most common areas that doctors felt they needed more training in were communication with patients and relatives; pain (and symptom) management and dealing with ethical issues.

EoL Issues and views

Doctors were asked for their views on a variety of EoL practices, including:

- Do Not Resuscitate orders (DNRs)
- Withdrawing and withholding of treatment (WDWH treatment)
- Intensifying analgesia with the aim of reducing pain - doctrine of double effect (DD)
- and Advance Care Planning (ACP)

Participants were asked if they ever conducted such practices and whether they agreed with them in principle. Their responses are summarized in **Table 2**. They were also asked if they felt medico-legally safeguarded with respect to such practices. Their response is summarized in **Table 3**. Palliative sedation (PS) is a practice that was agreed to by 181 doctors (93.3%, 95%CI 88.9-96.4).

Thematic Analysis

For each of the four EoL issues studied, the participants were asked for their comments and personal criteria used on the specific issues. Their responses are summarized below, structured according to the issue, and applying thematic analysis to the various comments received.

DNR

For DNRs, the over-riding issues were the frailty of the patient and the low functional status at the time of such decision/discussion. The presence of comorbidities and multi-organ involvement was also mentioned. One of the more important aspects however was the irreversibility (or not) of the situation. Lastly the responsibility, felt by doctors, in undertaking a DNR order was clearly shown by a particularly striking comment – coming from the surgical field – where it was pointed out that in case of a patient with a DNR order who is undergoing a surgical procedure, such DNR needs to be lifted for 24 hours post-operatively.

Intensification of analgesia (doctrine of double effect)

The overall concept here was the quality of life and comfort of the patient, which for most doctors always came first and foremost. Although a large majority of doctors agreed with the concept of intensification of analgesia to address the quality of life of the patient, most respondents felt more comfortable with such practice at the EoL. Finally, the presence of a serious irreversible medical condition and the symptom burden of the patient were other considerations put forward by doctors.

Withdrawal and Withholding (WDWH) of treatment

In this issue, discussion with family and patient was frequently mentioned and deemed to be crucial. There was an interesting comment from a doctor working in Emergency, who actually pointed out that some EoL practices are linked together, for example, if someone is on a DNR order, he/she would 'automatically' be candidate for WDWH treatment. Finally, the issue of balancing useful treatment with useless invasion of the patient was mentioned by various doctors.

Advance care planning (ACP)

This could be initiated once there is a clear, serious, and irreversible condition. Communication skills are very important in this situation. A change of heart by patients was also put forward as an issue/challenge in this area. Many doctors mentioned the fact that although they are always aware of the need of ACP, the individual patient in front of them affects whether they feel comfortable to put forward this issue or not.

A common theme was present pervasively throughout all the study was the need of doctors, to highlight the legal implications of these issues and have a (safe) framework within which they can work. Quoting just two of the many responses:

"A clear, well defined legal framework for advanced care planning will assist patients and physicians when considering end of life care" (Consultant, Medicine)

"… There needs to be a drive to entrench palliative care into law to safeguard the practitioner and encourage compassionate care" (Consultant, Paediatrics)

Table 2 *Experience and Views on medical issues*

Question	Yes % [95%CI], (n)	No % [95%CI], (n)
DNR		
Did you ever discuss?	84.1% [78.2-88.9] (164)	15.9% [11.1-21.8] (31)
Do you agree?	98.5% [95.6-99.7] (192)	1.5% [0.3-4] (3)
WDWH treatment		
Did you ever WD/WH treatment	81% [74.8-86.3] (158)	19% [13.7-25.2] (37)
Do you agree?	94.9% [90.8-97.5] (195)	5.1% [2.5-9.2] (10)
Intensification of analgesia (doctrine of double effect)		
Did you ever intensify analgesia?	66.2% [59-72.8] (129)	33.8% [27.2-41] (66)
Do you agree?	88.7% [83.4-92.8] (173)	11.3 % [7.2-16.6] (22)
Advance Care Planning (ACP)		
Did you ever discuss ACP?	51.8% [44.5-59] (101)	48.2% [41-55.5] (94)
Do you agree with ACP?	93.8% [89.5-96.8] (183)	6.2% [3.2-10.5] (12)

Table 3 *Investigation frequency and outcome by group*

Question	Medicolegally safeguarded		Medicolegally not safeguarded		Total Safeguarded	Total Not Safeguarded
	Very much safeguarded	Appropriately safeguarded	Not safeguarded	Absolutely not safeguarded		
DNR	2.6% (5)	45.1% (88)	47.7% (93)	4.6% (9)	47.70% (95%CI 40.5-54.9)	52.30% (95%CI 45.1-59.5)
WD/WH treatment	0.5% (1)	33.3% (65)	60.5% (118)	5.6% (11)	33.80% (95%CI 27.2-41)	66.10% (95%CI 59-72.8)
Intensification of analgesia (DD)	1% (2)	32.8% (64)	52.8% (103)	13.3% (26)	33.80% (95%CI 27.2-41)	66.10% (95%CI 59-72.8)
Implementing ACP	2.1% (4)	35.4% (69)	49.7% (97)	12.8% (25)	37.5% (95%CI 30.6-44.6)	62.50% (95%CI 55.4-69.4)
Abiding to ACP	2.6%(5)	34.9%(68)	51.3&(100)	11.3%(22)	37.5% (95%CI 30.6-44.6)	62.5% (95%CI 55.4-69.4)

Another important theme which came out was the need for further training in palliative care, as highlighted by 72.8% of respondents. Quoting one Resident Specialist in Surgery response:

"… It is much needed. I feel that it should be introduced as part of training as regards how to deal with end-of-life patients and how to manage them humanely"

DISCUSSION

EoL decisions are difficult and at times leave doctors in uncomfortable positions. Unfortunately, the low response rate of this study should always be kept in mind when interpreting the findings of this study.

Palliative Sedation (PS) is defined as the "the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers".[3] The strong response agreeing with this practice (93.3%) shows that there is a willingness from doctors to use every possible tool to alleviate distress in patients

An area frequently overlooked in EoL care is the need for doctors to be trained in dealing with these situations, irrespective of their specialty of practice. Consequently, it is high time that all specialist training programmes have an obligatory component which addresses these areas. Locally, as far as is known, only the specialist training programme in family medicine has an obligatory rotation in palliative medicine.[4] The lack of training in this area has also been documented in other countries.[5]

The main objective of this study was to explore the more common ethically challenging practices and the medico-legal comfort with which doctors deal with them. All four ethical dilemmas reviewed ie DNR, ACP, WDWH and DD, are accepted medical practices and were agreed upon and supported by most doctors locally (see **Table 2**).

However, the study has shown that a large majority of doctors do not feel safeguarded abiding by these practices, despite agreeing to them (see **Table 3**). The reasons for such situations are myriad. It can be argued that one of the major factors affecting this conundrum is the confusing definitions which pervade the literature.

The position paper issued by the European Association of Palliative Care (EAPC) in 2016 is thus welcome. It properly defined practices and shed some light on the literature.[6] In this position paper, Non-Treatment decisions are defined as "withholding or withdrawing medical treatment from a person either because of medical futility or at that person's voluntary and competent request." NTDs in fact do not hasten death but "rather accept death as a natural phenomenon through omission of ineffective, futile, very burdensome or unwanted life prolonging procedures".[6,8]

In the light of such definition, the term passive euthanasia frequently (and erroneously) associated with such concepts is indeed inappropriate since euthanasia involves a process which leads to ending the patient's life. This is being clarified since unfortunately, there are instances, even in certain texts, where the term passive euthanasia is mistakenly used to describe Non-treatment decisions.[7] This concept of NTDs falls perfectly in line with the ideas put forward by Pope Francis and the need to restrain what he calls "therapeutic obstinance" in EoL care.[9]

Another possible reason for such quandary – i.e. agreeing to a medical practice but feeling medico-legally unsafe - might lie in a slow-to-adapt local legal system. However, it can be argued that a legal response to alleviate this quandary might not be the best response. This is because the legal process is usually cumbersome and not adept to the possibility of changes in line with the dynamic process related to an illness or changing wishes of the patients. Such need of flexibility came out clearly in the thematic analysis. In addition, the legal process might remove the individual doctor-patient approach which is fundamental to dealing with such situations. This conundrum might also reflect the difficulty which doctors experience in starting conversations needed to discuss such decisions.[7]

Trying to find a way forward to address this situation is important. The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) adopted by the Resuscitation Council of UK,[10] is a plan to facilitate discussion on DNR. This can be used as an example for the process to be used as a way forward, even for other areas. Whatever process is chosen to facilitate any type of ACP, it must be based on communication with the patient and adopting an individual approach, as opposed to a purely legal approach commonly associated with a living will. Policy makers should also be cognizant of the fact that such individual approach must take into consideration the fact that patients do not exist only in secondary care, but in a variety of contexts including the community, private hospitals, old peoples' home and geriatric hospitals, and that the

data needs to be shared by all professionals involved in the care of patients. We must also not allow paperwork and form-filling to substitute effective and timely communication. Otherwise, we will run the risk of ending in a situation as happened with the Liverpool Care Pathway, where care of patients became secondary to meeting targets and filling of forms.[11] Further to this, there needs to be a greater awareness, openness and readiness to discuss these issues in public fora to raise awareness and de-mystify misconceptions. As stated by one of the participants:

"End of life care is something we do not think about while we are still young and healthy. However, accidents can happen and people can suddenly find themselves in a position where they cannot take decisions. It would be ideal if everyone can be helped to think and plan ahead. There needs to be a mentality as well as a culture change as well amongst Maltese people in order for this to happen! …" (Consultant, Geriatrics)

In the local context, there is a need of a discussion on how to formulate easy-to-use and readily available frameworks, to allow the adoption of these four pivotal medical practices (i.e. DNR, NTDs, DD, and ACP). This should be high on the national agenda. The role of the Malta Medical Council as a guarantor of such frameworks could be useful to allow serenity of practice to our doctors.

Strengths and Limitations

This study was meant to take a detailed snapshot of the ideas of doctors on various EoL issues and whether they felt safeguarded adopting accepted practices at EoL. Certainly, to carry out an in-depth analysis of each individual EoL issue covered, a different methodology would have been more appropriate. This study was not meant to present all the ramifications possible for each EoL issue.

The study tried to include as many doctors as possible. This was achieved by tapping on all government run health entities and beyond. The low response rate detracts from the robustness of the findings, but it is a well-known fact that electronic surveys tend to have the lowest response rate.[12] However, the response rate was similar to other local electronic surveys.[13] The fact that no reminder was sent might have also affected the response rate. On a positive note, the non-responder analysis showed that the population sampled was representative of the general medical population. The fact that the study was devised using a mixed methods approach allowed for a better understanding of the issues involved.

CONCLUSION

The low response impacted the robustness of findings, but the majority of respondents were in favour of practices such as DNR, NTDs, DD, and ACP. Unfortunately, most participants did not feel medico-legally safeguarded when implementing these practices. This could detract from optimal palliative care in various settings at the EoL. There is a need of further training in this area. A concerted and rational effort is needed to address this situation. Frameworks which are flexible and adaptable for a variety of contexts, including secondary care, primary care, old people's home and geriatric care, need to be drafted to address the lacunae in these four medical practices namely DNRs, NTDs, DD and ACP. Finally, there needs to be more local awareness about these four practices and the issues which prevent them from being properly implemented. They are pivotal to deliver proper dignified medical care for patients and should be given priority on the national agenda.

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