

# Evaluating an ethics summer school: an innovative approach in discussing and teaching ethics

Dr Jurgen ABELA, Prof. Pierre MALLIA and Ms Marika ABELA

## ABSTRACT

### Introduction

Ethical issues commonly arise in end of life (EoL) care. An ethics summer school, part of an Erasmus+ project, was held locally. It brought together professionals to discuss problematic areas and contribute towards the development of a curriculum on ethical issues.

### Methodology

An end-of-summer school questionnaire was distributed to all participants. The questions in the questionnaire were based on a literature review carried out prior to the summer school. Mixed methodology was used, applying content analysis to describe the qualitative aspect of the study.

### Results

All 44 participants filled in their questionnaire. 86.4% felt that the summer school reached their expectations and 90% declared that their intended objectives were reached. The most common ethically challenging issue in practice was dealing with artificial nutrition and hydration (ANH) – 22% of responses - whilst the most requested topic to be included in a future curriculum on ethical issues was communication, followed by patient autonomy. 64% of respondents stated that their personal beliefs influence their decision making in EoL care.

### Conclusion

This was the first ever ethics summer school hosted locally. It is an innovative way of dealing with ethical issues in EoL care. Participants received the summer school very favourably. Areas that would be included in the eventual development of an ethics curriculum were identified. The results will also be used to inform future summer schools.

## Key words

Clinical ethics; terminal care; palliative care

## INTRODUCTION & BACKGROUND

It is a known fact that ethical issues, especially at the End of Life (EoL) prove to be challenging to professionals. Abela and Mallia (2016a) reported that physicians, for example, are concerned with the lack of legislation on EoL which covers the moral arena of futile, extraordinary and disproportionate treatment and indeed pain relief. Whilst it is accepted that death can result indirectly from pain relief, the latter may not be optimally given to patients for fear of relatives accusing professionals that they killed the patient (Berger and Vadivelu, 2013). This occurs despite increasing evidence supporting the use of morphine (Sykes, 2007). Unfortunately, studies still show that many dying patients get little pain relief (Sprinks, 2016). Central to this problem of under-treatment of pain is the scant attention given to pain control in the medical school curricula and the lack of its assessment (Thomson, 2010).

Another challenging concept in EoL care is artificial nutrition and hydration (ANH). One study showed that when ANH is removed in imminently dying patients, their symptoms actually improved (Tsiompanou, Lucas and Stroud, 2013). Studies show that recognising that death is imminent is important for planning and providing adequate care (Abashi et al., 2011; Bronnert, 2014; Gibbons et al., 2009). Further to this, palliative care input has been shown to result in better satisfaction, symptom control, reduced emergency admissions, and shorter lengths of stay in hospital (Emery, 2013). Cultural diversity at the end of life, conversely, is becoming increasingly important and care should recognise, access, and address the psychological, social, spiritual and religious issues, as well as cultural taboos realising that different cultures may require different approaches

(Searight and Gafford, 2005). Moreover it has been shown that spiritual belief may affect the outcome of bereavement (Walsh et al., 2002) and that professionals ought to recognise this need. Providing a structured training for doctors in palliative care and ethical issues is said to be the key to the new era of a value-based EoL care (Frist and Presley, 2015; Abela and Mallia, 2016b; Conn and Berry, 2010).

Given all of the above, the Bioethics Research Project – Malta, in collaboration with partners from Ireland and Italy, is running a three year Erasmus+ project on ‘Harmonisation and dissemination of best practice, educating and alleviating concerns of health care professionals (HCPs) on the proper practice of end of life’ (Mallia, Abela and Galea, 2016). This will hopefully be accomplished through a variety of initiatives within the project, amongst which one finds the summer schools. This article describes the outcomes of the first summer school on EoL issues which took place in the summer of 2016. The objectives of the summer school were to:

- Bring together health care professionals to discuss EoL issues;
- Identify the problematic areas in dealing with end of life, especially why accepted practices do not occur;
- Act as a source for the eventual collation of a curriculum on EoL.

## METHODOLOGY

Given the intended objectives of the summer school, it was deemed best that an end-of-summer school evaluation was the most suitable method of assessment. The findings of the evaluation would eventually support the development of a curriculum on ethical EoL issues and at the same time improve upon the learning experience of participants in future summer schools.

The summer school was a week-long programme, in which different speakers facilitated discussion and workshops on a variety of topics and areas related to EoL care. The topics were wide ranging, from ethical thinking and informed consent to practical issues arising in paediatric EoL care, palliative sedation and home care.

Based on the literature review carried out prior to the start of the summer school, key themes were identified and a set of questions was compiled together in an appropriately designed questionnaire. Being an innovative approach, the literature search did not provide any similar questionnaires which could help in the collation of questions. The questions were separately

reviewed by the three authors and fell into five domains, namely: demographic details, legal and moral issues, personal values and working in a multi-disciplinary team, death and dying and the running of the summer school.

At the end of the summer school, all the participants were given a self-administered questionnaire. As no sensitive personal data was gathered during this study, no ethical approval was needed, while authorization was obtained from the EndCare project coordinators to use the anonymous data for this study.

The majority of the questions presented were of a quantitative nature using Likert-type scales. Excel 2010 and Statistical Package for the Social Sciences (SPSS) 22 were used to analyse this form of data. Participants were also asked to elaborate on their choices as well as give their opinion in support to some of their answers. Content analysis was used to code and quantify these open-ended replies.

## RESULTS

### Demographics

All 44 participants in the summer school accepted to take part in the survey. The participants came from three countries, namely Malta, Ireland and Italy, these being the three countries involved in the project. The large majority of the participants were Maltese due to the fact that this summer school was held in Malta. Seven of the participants came from overseas – three from Italy and four from Ireland. There was a mixture of HCPs ranging from consultant physicians to family doctors, nurses and paramedical professionals.

In spite of the limited number, this cohort allowed for a wide-ranging sampling of ideas due to the diversity in the professional backgrounds of the participants as well as the inclusion of a healthy number of undergraduates. This inclusive aspect of the study was also reflected in the age distribution (Table 1).

### Ethical Issues

Most of the summer school participants appreciated this mix and commented positively about it. One particular respondent said that:

*... it was a unique forum with the possibility of sharing ideas with local and foreign professionals who work in the same area.* Another respondent, whilst commenting positively on this aspect, reiterated that there should have been more opportunities to share and compare among different countries.

Table 1: Age distribution and professional background of participants

Age	Frequency	Percentage		Professional	Frequency	Percentage
<29 years	21	47.7		Academic	8	18.2
30-39 years	3	6.8		Community	7	15.9
40-49 years	9	20.5		Hospital	5	34.1
50-59 years	9	20.5		Home for elderly	15	11.4
>60 years	2	4.5		Hospice	2	4.5
Total	44	100		Other	7	15.9
				Total	44	100

On the less positive side, a few respondents (9%) commented that the audience was not targeted enough, or at least that more provision should have been made for the different professions. They felt that there was too much emphasis on the medical:

*... more focus on ethics rather than palliative care... would have been better.*

The second section of the questionnaire gathered data on previous knowledge. 70% of the participants reported that they had had some form of previous training in EoL care. 39% of these received training during their undergraduate studies and 27% during postgraduate studies. The remaining 34% attended short courses or seminars on the subject.

When asked about what concerns them more between moral and legal issues, 47.7% of the respondents chose legal and 52.3% chose moral issues. Those who chose legal issues gave fear of medico-legal litigation due to lack of adequate legal frameworks as their major concern, whereas those who chose moral issues were more afraid of conflict between their personal moral values, the law and the patient/relation values and wishes.

This issue of personal values was further investigated in the next section. Several moral or ethical issues that could present themselves in an EoL context were presented in a Likert-type question. The data was described in terms of frequency of occurrence and of relevance to the respondents.

Eighty per cent of the respondents reported that they have never had to refuse a patient's request in an EoL context due to personal values, with the remaining 20% only having to do so rarely. Despite this, 64% reported

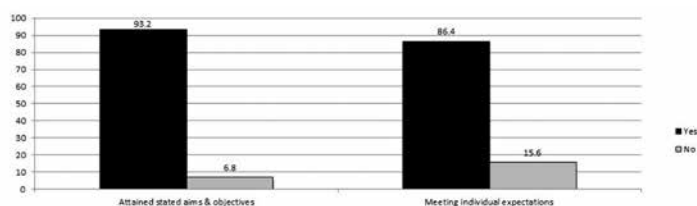
that personal values do influence their decision making in EoL care. Well over half of the respondents have experienced conflict between personal values and the views of relatives of patients with 66% of the respondents saying that it happens quite frequently or occasionally.

Moral or ethical disagreement between professionals seems to be a non-issue for 73% of the respondents, with the remaining 27% only having to face disagreement on rare occasions. On the other hand, 63% of the respondents seem to have an issue with the moral guidance provided at their place of work. Of these, 18% say that they often disagree with these guidelines whilst another 25% reported as having occasional conflicts with this moral guidance.

The respondents were also asked to indicate the frequency by which they encounter or have to deal with specific EoL care ethical issues at their place of work. The most frequently encountered issues in descending order were artificial nutrition and hydration (ANH); discussing EoL and death; diagnosing death and discontinuing life sustaining therapies. Even when one excludes respondents who answered *rarely* or *not applicable*, the same issues remain in the forefront, with discussing EoL and death at 21.2%, ANH at 17.4%, diagnosing death at 14.4% and discontinuing life sustaining therapies at 12.8%.

Respondents were then asked to identify what they feel as the single most challenging issue in EoL care. At 22%, the most quoted issue was ANH. According to the participants this issue was dealt with very well during the summer school. The other medical related issues mentioned were pain relief and palliative sedation (15%), palliative care (12%), withdrawing and withholding treatment (6%) and suctioning (3%). The remaining

Figure 1 : Participant rating of summer school(%)



responses (42%) referred to a variety of ethical and moral issues. 15% mentioned communication with patients and relatives and 6% mentioned refusal of treatment by patient and recognising and acknowledging terminal situations in non-cancer patients. Other issues mentioned included spirituality, discharging patients at EoL, lack of patient follow-up, do not resuscitate orders and extraordinary measures at EoL.

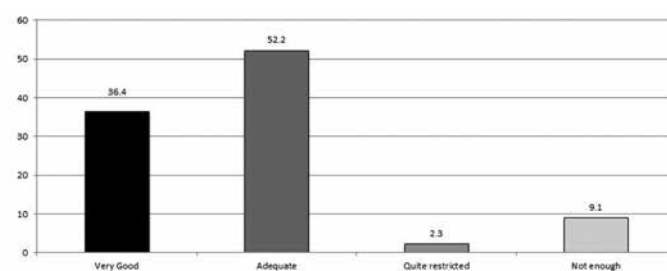
Since one of the main objectives of the project was to devise a curriculum on EoL care, respondents were asked to identify two aspects of EoL care which in their opinion should be included in the said curriculum. A list of 22 topics was identified. Interestingly enough, the most frequently mentioned topic was communication. Then, in order of frequency, there was patient autonomy and dignity, palliative sedation and pain relief, futile treatment and extraordinary care, legal issues, advance directives, palliative care and euthanasia. The rest of the topics listed included clinical guidelines on EoL, bereavement, breathing, ethical and moral issues including doctrine of double effect, patient centred approach, a multidisciplinary approach to EoL care, ANH issues, ethics in paediatric EoL care, cultural differences, spirituality and learning methods.

Some of these issues were dealt with during the summer school. However, respondents asked for more input especially on legal and ethical frameworks, futile treatment and extraordinary measures, spirituality, religious differences especially in Islam, pain management in difficult situations, home care and dealing with requests for collusion.

Respondents mentioned three other topics which in their opinion should have been dealt with during the summer school namely, patients' advocacy, withdrawal of artificial ventilation and dying a good death. 9% of the respondents also asked for more clinical scenarios and case studies.

88% of the respondents also stated that the ethical issues raised during the training will definitely influence

Figure 2 : Range of topics in the summer school(%)



their future decisions in EoL care. Some of the most interesting comments included:

- More awareness of patients' comfort:  
*In acute hospitals a lot of patients die with an NG tube inserted even though this is not comfortable. ...recognising that time spent with client is very valuable in care-planning.*
- More understanding towards relatives:  
*I will involve relatives in every step of the way and help them keep up-to-date with future plans of palliative care so that they know what to expect.*
- Awareness of patients' advocacy:  
*I am more aware of patients that cannot voice their opinion.*

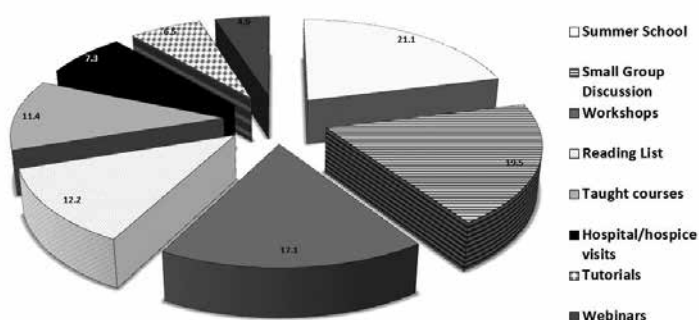
### Running of the summer school

Eighty-six point four per cent of the respondents said that the summer school had reached their expectations whilst more than 90% declared that the intended objectives of the summer school had been attained (Figure 1).

The respondents' reaction to the range of topics presented was also favourable, with 36.4% saying it was very good and 52.3% deeming it adequate (Figure 2). They were asked to identify three lectures which they found particularly relevant for them. The aim of the question was to evaluate whether the range of topics presented during the summer school appealed to all the participants considering the eclectic range of professionals participating in the training. It was interesting to note that all the lectures received a mention. For the purpose of the study, the lectures were grouped into three broad themes. Lectures on legal issues received 22% of mentions, lectures on moral and ethical issues 34% and lectures on medical issues 43%.

The final consideration in this section was for the preferred resources by which participants could improve their knowledge of ethical issues. They were allowed to choose more than one option (Figure 3). As can be seen, the concept of a summer school topped the list of most popular resources. Other useful resources included

Figure 3 : Useful resources to address ethical EoL Issues (%)



workshops and small group discussions. It is interesting to note that in the further comments section at the end of the questionnaire, some of the participants pointed out that smaller group discussions and workshops should be incorporated in future summer schools. These ideas are represented in Figure 3. To be noted also is the fact that 12.2% of the respondents asked for a reading list.

## DISCUSSION

This was the first summer school in a series of three. It was therefore expected that the feedback would be used as a learning curve and develop accordingly the subsequent summer schools. The series of talks were therefore more didactic than is to be planned in the future; it was still felt important that talks on basic legal, ethical, medical and social issues are discussed in order to help HCPs reflect on their needs. The fact that only 9% commented that the audience was not targeted enough is in fact a welcome result as sometimes, people coming from different areas might present different kinds of problems.

Curriculum development is a process. It involves defining goals, planning, implementing, reviewing and refining (McEvoy, 1998). It has been described as a peculiar animal involving a lively understanding of the underlying educational philosophy. Refining the curriculum means refining the methods and the content according to needs. In this regard, the summer school successfully acted as an important source for the content of a future curriculum.

Forty-seven point seven per cent of respondents said that legal issues concern them most and 52.3 % said that moral issues concern them more. This is indeed in line with the findings from other studies. In fact in a study by Abela and Mallia (2016a), 24.7% said that they were indeed sceptical of giving enough analgesia due to fear of litigation or lack of a legal framework.

It is interesting and important to note as well that the most frequently encountered EoL issues were ANH (most frequently cited issue), discussing EoL and indeed diagnosing the imminence of death. These findings are in line with other studies (Gibbons et al., 2009). These are important issues as many may be kept on ANH, for example, out of fear of litigation or lack of moral competency, leading to undue discomfort of the dying patient (Lofmark and Niltsun, 2002). Again lack of discussion means that people may not be prepared for the eventual death. It was refreshing to note that participants stated that these issues were dealt with very well in the summer school.

Interestingly, ANH features as the most commonly met challenging issue, but communication was the most cited topic to be included in a future curriculum. This seems rather paradoxical, but might be understood in the light that despite being challenged frequently on ANH issues, professionals feel more empowered to effectively deal with this area than tackling difficult aspects of communication in EoL. (Conn and Berry, 2010). It is also a reflection of the importance that professionals give to communication and patient autonomy. Certainly, this is an area which needs further research to better understand such views.

In planning the second summer school to take place in L'Aquila, Italy during the summer of 2017 these results will be taken into consideration. One ought not to be overly encouraged by the fact that in general 86.4% felt that the summer school reached their expectations as one understands that a curriculum is a living object and one hopes to tweak and focus more in the subsequent summer schools in order to publish a final curriculum for the harmonization of EoL care. Important points have already been teased out from this first experience. For example, although initially the authors thought that a reading list in a curriculum would curtail free thought, this was actually requested by the participants. The curriculum is a contextual tool for improving professional standards. Implementing frameworks such as the UK Gold Standards Framework enabled processes of communication which was associated with high quality palliative care (Thomas, 2017). We can also learn from experiences which have been deemed to have failed due to erroneous implementation, such as the Liverpool Care Pathway (Saunders, 2013). In fact the latter pathway failed due to improper training and implementation of an otherwise good pathway.

## CONCLUSION

Ethical issues are commonly encountered at EoL. A summer school was organised as part of an ongoing Erasmus+ project in EoL care. The evaluation of the summer school was an innovative manner adopted to inform the future development of a curriculum. 70% of participants had some form of training in palliative care. The most commonly encountered challenging issues included ANH, diagnosing dying and communication at EoL. In addition, legal and moral issues at EoL concerned participants in nearly equal proportions, 47.7% and 52.3% respectively. The most commonly cited topics to be included in a future curriculum included communication and patient autonomy. Overall, most participants (86.4%) were happy with the set-up of the summer school with a substantial minority highlighting the need of more interactive sessions. These comments will be used to inform the planning of future summer schools as well as the collation of an eventual curriculum on EoL ethical issues.

### Dr Jurgen ABELA

MD, DCH(Lond.), MSc, FMCFD, FLCM, FRCGP(UK)

Hospice Malta

Department of Primary Health Care, Malta

Email: jurgen.abela@um.edu.mt

### Prof Pierre MALLIA

MD PhD CBiol MPhil MA(Law) DipICGP MMCFD MRCP FRCGP

Bioethics Research Programme, Malta

Professor of Family Medicine, Bioethics & Patients' Rights

Chairperson, National Health Ethics Committee, Dept. of Health

Chairperson, Bioethics Consultative Committee, Ministry of Health

Coordinator, Bioethics Research Programme, Univ. of Malta

Malta Representative, Council of Europe DH-BiO

President, Malta College of Family Doctors

### Ms Marika ABELA

B.Ed (Hons.), M.Ed, LLCM

Secretariat for Catholic Education, Malta

## ACKNOWLEDGMENT

The study is part of an ERASMUS+ project 2015-1-MT01-KA203-003728

## REFERENCES

- Abashi, E., Ehteld, M., Van den Block, L., Donker, G., Deliens, L. and Onwuteaka-Philipsen, B.D., 2011. Recognising patients who will die in the near future: a nationwide study via the Dutch sentinel network of GPs. *British Journal of General Practice*, 61(587) pp. 401-402.
- Abela, J. and Mallia, P., 2016a. Maltese doctors: views and experiences on end of life decisions and care. *Malta Medical Journal*, 28(2) pp. 16-26.
- Abela, J. and Mallia, P., 2016b. Training in Palliative Medicine and Maltese doctors: a cross-sectional survey. *Journal of the Malta College of Family Doctors*, 15(2) pp. 13-17.
- Berger, J. and Vadivelu, N., 2013. The common misconceptions about opioid use for pain management at the end of life. *American Medical Association Journal of Ethics*, 15(5) pp. 403-409.
- Bronnert, R., 2014. Discussing and planning care for people approaching the end of their life. *Clinical Medicine*, 14(3) pp. 296-299.
- Conn, R. and Berry, P., 2010. The decision to engage in end-of-life discussions: a structured approach for doctors in training. *Clinical Medicine*, 10(5) pp. 468-471.
- Emery, J., 2013. End-of-life care: identification, communication, training, and commissioning. *British Journal of General Practice*, 63(606) pp. 6-7.
- Frist, W. and Presley, M., 2015. Training the next generation of doctors in palliative care is the key to the new era of vale-based care. *Academic Medicine*, 90(3) pp. 268-71.
- Gibbons, J., McCoubrie, R., Kinzel, C. and Forbes, K., 2009. Diagnosing dying in the acute hospital setting - are we too late? *Clinical Medicine*, 9(2) pp. 116-119.
- Lofmark, R. and Nilstun, T., 2002. Conditions and consequences of medical futility - from a literature review to a clinical model. *Journal of medical ethics*, 28(2) pp. 115-119.
- Mallia, P., Abela, J. and Galea, D., 2016. Harmonisation and dissemination of best practice - educating and alleviating the concerns of health care professionals on the proper practice of end of life care. [online] University of Malta. Available from: [www.um.edu.mt/ms/endcare](http://www.um.edu.mt/ms/endcare) [Accessed 23 March 2016]
- McEvoy, P., 1998. *Educating the future GP. The course organiser's handbook*. 2nd edn. Oxford: Radcliff Medical Press.
- Saunders, J., 2013. The Liverpool Care Pathway. *Journal of the Malta College of Family Doctors*, 2(2) pp. 5-10.
- Searight, H. and Gafford, J., 2005. Cultural diversity at the end of life: issues and guidelines for family physicians. *American Family Physician*, 71(3) pp. 515-522.
- Sprinks, J., 2016. Insufficient pain relief at end of life. *Cancer nursing practice*, 15(2) pp. 32-35.
- Sykes, N., 2007. Morphine kills the pain, not the patient. *The Lancet*, 369(9570) pp. 1325-1326.
- Thomas, K., 2017. *The Gold Standards Framework*. [online] Available at: <http://www.goldstandardsframework.org.uk/> [Accessed 13 July 2017].
- Thomson, H., 2001. A new law to improve pain management and end-of-life care. *Western Journal of Medicine*, 174(3) pp. 161-162
- Tsiompanou, E., Lucas, C. and Stroud, M., 2013. Overfeeding and overhydration in elderly medical patients: lessons from the Liverpool Care Pathway. *Clinical Medicine*, 13(3) pp. 248-251.
- Walsh, K., King, M., Jones, L., Tookman, A. and Blizard, R., 2002. Spiritual beliefs may affect outcome of bereavement: prospective study. *British Medical Journal*, 324(7353) pp. 1551-1554.