COMMENT

Challenges and perspectives of palliative medicine: A webinar by the Paediatric Virology Study Group

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The art of medicine consists of amusing the patient, while nature cures the disease

Voltaire

Abstract. Palliative medicine focuses on the quality of life of patients with incurable conditions, who require the adequate relief of physical symptoms, adequate information to make decisions and spiritual wellbeing. Generalist palliative care is provided by family members, general practitioners, care home workers, community nurses and social care providers, as well as non-specialist hospital doctors and nurses. Patients with more complex, physical or psycho-social problems require the shared work of specialized doctors in palliative medicine, nurses, social workers and allied professionals. It is estimated that ~40 million patients require palliative care annually, worldwide; of these, 8 out of 10 patients reside in low- or middle-income countries, and only ~14% are able to access this type of care. Palliative medicine was recognised as a distinct medical specialty in the UK in 1987, with its own specialist curriculum and training pathway, which was recently revised in 2022. The main obstacles that palliative medicine had to overcome in order to be accepted as a separate specialization were the following: i) Defining a unique body of knowledge; ii) standardisation of training; and iii) proving that it warranted being a specialty in its own right. Over the past decade, it has been accepted as more than end-of-life care, supporting patients with an incurable illness at much earlier stages. Given the current absence of specialized palliative care in low- or middle-income countries, as well as the aging population across most European countries and the USA, it is estimated that there may be an increasing need and demand for specialists in palliative medicine in the ensuing years. This article is based on a webinar on palliative medicine, which was performed on October 20, 2022 in the context of the '8th Workshop of Paediatric Virology' organized by the Institute of Paediatric Virology based on the island of Euboea (Greece).

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Introduction

How difficult is it really for a new medical specialty or subspecialty to be created in the modern era of medical sub-specialization, recognised by the medical scientific community and introduced into the clinical practice in different countries? What are the obstacles that should be overcome in order for it obtain its own specialist curriculum and training programme? How open should modern medicine be in new educational needs, demands and perspectives?

Palliative medicine represents an excellent example of a modern educational medical field, which through recent years, has proven its undoubted increasing necessity in modern medical practice and education, and has been recognised as a separate medical specialty in the UK (1-3). Recently, a new curriculum for palliative medicine by the Joint Royal Colleges of Physicians Training Board (JRCPTB) was approved by the General Medical Council (GMC) and implemented in August, 2022 (4) (Table I). As with all curriculums for various medical specialties, it defines the process of medical training and the competencies required for the award of a certificate of completion of training (CCT), and includes the assessment system for measuring the progress of trainees, comprising

of workplace-based assessment and knowledge-based assessment. The purpose of the palliative medicine curriculum is to produce doctors with the generic professional and specialty-specific capabilities to manage patients with advanced, progressive, life-limiting diseases, for whom the focus of care is to optimise their quality of life through expert symptom management and psychological, social and spiritual support as part of a multi-professional team (4). However, in several countries worldwide, palliative care remains an unknown or unrecognised field of medicine (5-8).

Dr Fergus Maher, Consultant in Palliative Medicine at the Norfolk and Norwich University Hospitals, NHS Foundation Trust, Norwich, UK and Honorary Associate Professor in Palliative Medicine at the Norwich Medical School of the University of East Anglia, Norwich, UK, tried to provide an overview of the new medical specialty of palliative medicine to the Paediatric Virology Study Group (PVSG) and to investigate its current challenges and future perspectives. This webinar was held on October 20, 2022 in the context of the '8th Workshop on Paediatric Virology' organized by the Institute of Paediatric Virology (IPV; https://paediatricvirology.org) based on the island of Euboea in Greece (9). Since its foundation in 2019, the newly-founded IPV has introduced the subspecialty of paediatric virology, aiming to define its educational field, highlight its necessity in modern medical practice and education, evaluate its limitations and explore the perspectives of its formal recognition in modern medicine (9-12).

Questions and answers

Question: What is palliative care, what are its principal aims and how is it provided in modern medicine?
Answer: Palliative care and its aims are defined by the World Health Organization (WHO) as 'an approach that improves the quality of life of patients (adults and children) and their families, who are facing problems associated with life-threatening illnesses. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual' (13). Palliative care is not disease-specific or organ-specific, but focuses on the quality of life of people with incurable conditions. Clearly health care professionals have always cared for people with incurable conditions, but the modern concept of palliative care sprang out of the work of Cicely Saunders in 1960s England. Cicely Saunders was born in 1918 and in later life trained as a nurse, and later as a doctor. She opened St. Christopher's Hospice in South London in 1967 (https://www.stchristophers.org.uk/about/damecicely-saunders). This was regarded as the first 'modern hospice', as the focus was not only on providing nursing care for dying patients, but also on research and education. Palliative medicine was recognised as a distinct medical specialty in the UK in 1987, with its own specialist curriculum and training pathway. Palliative care can be classified as 'generalist' or 'specialist'. Generalist palliative care is provided by family, general practitioners, care home workers, community nurses and social care providers, and non-specialist hospital doctors and nurses. Specialist palliative care is provided to people with more complex physical or psychosocial problems and is provided through the shared work of doctors, nurses, social workers and allied professionals, who have received specific training. In the UK, specialist palliative care is provided in hospices (which are mostly funded through charitable donations), and via our National Health System (NHS) funding in hospitals and in the community. The majority of specialist palliative care in the UK is provided in conjunction with other branches of medicine, such as oncology, general practice, renal and respiratory medicine.

Question: How is quality of life defined? Is palliative care a human right and how difficult is it for patients to realise this right?
Answer: That is a surprisingly tough question to answer! Of course, there have been lots of definitions over time from health care, health economics, philosophy, psychology, etc. Many of the definitions used within healthcare attempt to quantify quality of life in multi-domain, numerical scales. Personally, I do not think one can quantify such an inherently variable, human, subjective experience. So, it really is beyond the scope of this brief answer to give a concise definition. Within palliative care, it is recognised that quality of life tends to require adequate relief of physical symptoms, adequate information to make decisions, peace of mind, spiritual well-being and minimal mismatch between expectations and lived reality.

Palliative care provision is recognised as a human right by those who accept 'positive rights', i.e., a right to be provided with something, as opposed to negative rights or the right to not have something taken from you such as your life or freedom of movement. Palliative care is a component of the right to health, which is protected in article 12 of the United Nations (UN) International Covenant on Economic Social and Cultural Rights (14). Sadly, the question of how easy or difficult it is for patients to realise this right, depends on where in the world you live. It is estimated that ~40 million people are in need of palliative care annually. Of these, 8 out of 10 patients live in low- or middle-income countries, where improvements in infrastructure and healthcare are leading to demographic shifts meaning that chronic illness, such as cancer and heart disease, are now more of a problem than infections. Globally, only ~14% of patients who need palliative care are able to access it, and the majority of these are in Europe and North America (13).

Question: Since when has palliative care been recognized as a separate medical specialty in the UK? What were the obstacles that palliative care should overcome in order to be accepted as a separate specialization in medicine?
Answer: Palliative care was recognised as a separate medical specialty in the UK in 1987, largely through the work of a number of hard-working pioneers: Cicely Saunders, Derek Doyle, Robert Twycross and Richard Hillier, who were working in different hospices across the country in the early 1980s (http://endoflifestudies.academicblogs.co.uk/palliative-medicine-as-a-specialty/). One of the first steps was the formation of the Association for Palliative Medicine for Great Britain and Ireland, which was established in 1986. Discussions were held with the Royal College of Physicians to look into developing a training programme for clinicians interested in palliative medicine and these early pioneers were

Table I. The aims of the new curriculum for palliative medicine by the Joint Royal Colleges of Physicians Training Board (JRCPTB) implemented in the UK on August, 2022 (4).

1	Build on the knowledge, skills and attitudes acquired during stage 1 IM training and ensure that palliative medicine doctors develop and demonstrate a range of essential capabilities for managing patients with a range of life-limiting, progressive conditions.
2	Ensure trainee physicians can provide safe, high quality, holistic palliative care in all settings (including acute hospital, ambulatory, community, care home and hospice/specialist palliative care unit) during and on completion of their postgraduate training.
3	Ensure that trainee physicians can acquire and demonstrate all of the GMC-mandated GPCs, including advanced communication skills.
4	Ensure that palliative medicine doctors are capable of providing and enabling palliative care for those in harder to reach community settings such as psychiatric units, hostels and prisons.
5	Allow flexibility between specialties through GPCs and higher-level learning outcomes.
6	Further develop the attributes of professionalism, particularly recognition of the primacy of patient welfare that is required for safe and effective care of those with life-limiting, progressive conditions, and develop physicians who ensure patients' views are central to all decision making, which needs to be robust, individualised and incorporates a thorough understanding of medical ethics.
7	Ensure that palliative medicine physicians have advanced communication skills to manage complex and challenging situations with patient, carers and colleagues.
8	Provide the opportunity to further develop leadership, team working and supervisory skills in order to deliver care in the setting of a contemporary multidisciplinary team to enable them to make independent clinical decisions on completion of training.
9	Ensure the flexibility to allow trainees to train in academic medicine alongside their acquisition of clinical and generic capabilities.

IM, internal medicine; GMC, General Medical Council; GPCs, generic professional capabilities.

often asked by medical schools to provide teaching in pain control and communication skills. The specialty was lucky in that the Deputy Chief Medical Officer for England at the time was Dr Gillian Ford, who had trained with Cicely Saunders and shared her passion for better end-of-life care. Her advocacy and the early research being carried out in hospices across the country was sufficiently impressive that the Joint Committee on Higher Medical Training helped develop a distinct curriculum and training programme for doctors, and palliative medicine was recognised as a distinct specialty by the Royal College of Physicians. A final component was the development and publication of a specialist Journal, which also came on line in 1987. I think the main obstacles were in defining a unique body of knowledge, standardisation of training and proving that palliative medicine warranted being a specialty in its own right.

Question: What are the most important advances in palliative care during the last decade? How was your clinical practice changed during the coronavirus disease 2019 (COVID-19) pandemic period?

Answer: I think the most important advances in palliative care in the last decade or so have not been exciting breakthroughs in drugs or techniques. The biggest changes we have seen in palliative care is perhaps the acceptance that palliative care is more than end-of-life care, and that we can help at much earlier stages in the patients journey with an incurable illness. This coupled with the growing recognition that palliative care can have an essential role in the care of non-malignant illnesses such as chronic kidney disease, heart failure, chronic lung conditions and neuro-degenerative conditions, such as motor neurone disease (MND) and multiple sclerosis (MS). Other developments have been in what is termed Enhanced Supportive Care, arguably a refocus on the positive aspects of quality of life rather than symptom management at end of life. Other areas of development have been in prognostication and outcome measurement.

In a sense, my clinical practice did not change much during the COVID-19 pandemic. We were very involved in the management of symptoms associated with the withdrawal of respiratory support and communication with families, but these were aspects of care we were involved with prior to the pandemic. There was perhaps an increased recognition of the need for us to support our colleagues from other specialties, who found themselves dealing with death and the uncertainty it brings far more frequently than they were used to. These were conditions that palliative care clinicians are familiar and comfortable with, and we were able to help our colleagues come to terms with them too.

Question: What are the most common ethical issues that you manage during your clinical practice in palliative care? Could you give us some examples?

Answer: I would say that the most common ethical issues relate to decisions around withholding and withdrawing medical interventions, and the use of sedating drugs at the end of life. I remember a case of a 50-year-old man, who had an out-of-hospital cardiac arrest after taking part in a bike race.

Table II. Comparison between palliative medicine and paediatric virology.

	Palliative medicine	Paediatric Virology
Educational medical field	Medical specialty	Paediatric subspecialty
Construction of training	IM Stage 1 + IM Stage 2 + specialty	Paediatrics + subspecialty (in development by the PVSG)
GPCs	Well-described	Not described yet (in development by the PVSG)
Patients	Adults	Children
Reference by Hippocrates	Yes (20)	Yes (21)
Recognition as a separate medical specialty or subspecialty in the UK	Yes (since 1987)	No
Recognition as a separate medical specialty or subspecialty in Greece	No	No
Collaboration with allied professionals	Yes	Yes
Supportive role to the patient	Yes	Yes
Patient's cure	No	Yes
Future research perspectives	Yes	Yes
Future clinical perspectives	Yes	Yes

IM, internal medicine; GPCs, generic professional capabilities; PVSG, Paediatric Virology Study Group.

He was successfully resuscitated on-site and taken to hospital, but did not regain consciousness when sedation and intubation were stopped in the intensive care unit (ICU). Magnetic resonance imaging (MRI) and electroencephalogram (EEG) had confirmed hypoxic brain injury, but he was breathing spontaneously. He was transferred to a medical ward where I met his wife and learned a little about him. She was of the opinion that her husband would not want to live in a vegetative state, and we agreed that we would not give intravenous (IV) fluids or artificial nutrition, knowing that he would potentially die from renal failure secondary to his inability to drink due to his hypoxic brain injury. Unfortunately, over the weekend he was started on both IV fluids and nasogastric (NG) feeding, despite a clearly documented decision for this not to happen. We then went through several months of distress for his wife and ethical debates between clinicians, before the gentleman was finally allowed to die of pneumonia. Months of suffering and indignity could have been avoided for this man and his wife, but as a profession, doctors seem to struggle to accept that there are fates worse than death, and that while prolonging death with IV fluids, etc., may be easier for the doctor, it is not necessarily in the patient's best interests.

Question: How vulnerable or protected are you under the law? What is the significance of the Hippocratic oath's recommendation to not 'give under threat a deadly drug to anybody who asked for it' and Hippocrates's principle to 'do good or not to harm'? How much of a Hippocratic doctor do you feel?
Answer: Palliative care doctors have the same protections and vulnerabilities under the law in the UK as any other doctor. I suspect your question about the significance of the Hippocratic oath's recommendation to not 'give under threat a deadly drug to anybody who asked for it' relates to the issue of physician assisted suicide and euthanasia. This is something that I am vehemently opposed to. I would say that probably once a week I deal with a patient who makes me think I would want to die if I were 'in their shoes'. However, empathy, sympathy, compassion and respect for autonomy have to be balanced against the legal and ethical value of life and the difficulty in providing adequate protections to vulnerable members of our society. Interestingly, a survey of doctors in the UK in 2014 found that only 4% of palliative care doctors were in favour of physician-assisted suicide (15). I think it is very telling that the people who actually deal with the complexity of death, dying and prognosticating, are so opposed.

Question: What are the implications of palliative care in paediatrics?
Answer: Paediatric palliative care is not something I have much experience of as the training programme in the UK is quite separate. I am aware that they mostly work in specialised hospices with children with inherited disorders (16). Much of their work is in providing respite and support to the family as much as it is symptom management with the child themselves.

Question: Care vs. treatment vs. cure? How care-orientated, treatment-orientated or cure-orientated is modern medicine and should these different medical approaches be further evaluated in modern medical education?
Answer: Part of the inspiration behind the founding of palliative care for Cicely Saunders was the recognition that the amazing advances in the science and technology of curative medicine in the first half of the 20th century had perhaps led to doctors losing sight of the 'human' in their patients: The 'humanity' of health care had been lost in the 'science' of medicine. So, this is a distinction that is at the heart of palliative care to this day. Unfortunately, while I suspect things are better now than they were in the 1950s in many ways, the technological advancements

made since then have also led to more and more complex situations. For example, people are living longer with cancer these days (17) - which on the one hand is a fabulous thing, but on the other hand, we find they are developing more unusual complications and unexpected metastases than in the past when people died sooner. This, coupled with the increasingly over-burdened, under-resourced and under-staffed health service means that 'care' has again been lost in much of the busy-ness of modern medicine. Without a doubt this is something that needs to be addressed in medical education, but also in government.

Question: What is your estimation about the future of palliative care in Europe?
Answer: I am optimistic that my specialty will continue to spread and grow in the coming years. Given the aging population across most European countries, as well as the USA, there can only be an increasing demand for specialists who can manage the complexity of incurable, chronic, life-limiting conditions and the symptoms and distress they bring.

Question: Finally, our last two questions. What is your most important principle in medicine? What is your favourite quote in your clinical practice?
Answer: I wouldn't say I have a single most important principle. I certainly value autonomy highly and I see a large part of my job as helping patients to make decisions for themselves. I always approach my patients with the attitude of 'how would I want my parent to be dealt with by a doctor?'. I like to think of my approach to medicine as fraternal, rather than paternalistic. I think it is important to remember that the etymology of the English word 'compassion', an English word which contains the word 'passion' coming from the Greek word 'pathos (πάθος)' and meaning 'the pain', is 'to suffer with' - we underestimate the therapeutic value of witnessing and validating a patient's suffering, particularly when there is nothing we can do to eliminate or even reduce it (18).

You assume I have a favourite Greek quote! As it happens, I like what I believe to be one of Hippocrates 'Aphorisms': 'The art of medicine consists of amusing the patient, while nature cures the disease.' Though it may actually have been Voltaire who said it!

Question: Well, Hippocrates clearly clarifies that nature cures all the diseases ('Nature cures the diseases' - 'Νούσων φύσιες ἰητροί') (19); however, in his last 'Aphorism' he gives emphasis to the curing role of different medical specialties as well as their limitations ['Those diseases which medicines (internal medicine) do not cure, iron (surgery) cures; those which iron cannot cure, fire cures; and those which fire cannot cure, are to be reckoned wholly incurable' - 'Ὁκόσα φάρμακα οὐκ ἰηται, σίδηρος ἴηται, ὅσα σίδηρος οὐκ ἰηται, πῦρ ἴηται ὅσα δέ πῦρ οὐκ ἴηται, ταῦτα χρή νομίζειν ἀνίατα'] (20).
Answer: You are right! Apparently, by accepting the presence of incurable diseases, Hippocratic medicine recognises the value of palliative care almost 2,400 ago…

Question: You persuaded us, though, Dr Fergus Maher, that your specialty, palliative medicine, offers to the patients something far more significant and respectful than just 'amusing the patients', according to Voltaire's saying, and should be, indeed, further promoted! Palliative medicine is really an excellent example of how a new medical specialty can be introduced successfully into modern medicine and could be evaluated as a realistic model by the PVSG (Table II). We wish you all the best and we would like to thank you for your participation in our webinar.
Answer: I want to thank you, too, and I would like to wish you all the best to your group as well as to the newly founded IPV based on the beautiful Greek island of Euboea in Greece. The institute's aim to introduce paediatric virology as a new paediatric subspecialty in modern paediatric health care is really innovative and I would like to congratulate you for this very interesting and - as I can estimate - very useful contribution in future medical education.

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Patient consent for publication

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Competing interests

INM and DAS are co-founders of the Institute of Paediatric Virology (IPV). FM declares no competing interests.

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