



Professor Jose Pereira

Jose is the Leenaards Foundation Professor of Palliative Care at the University of Lausanne and the University of Geneva. He is also Director of the Palliative Care Service at the Centre Hospitalier Universitaire Vaudois in Lausanne and has a cross appointment at the Universities of Calgary and Alberta in Canada. He has a special interest in palliative care education.

Evaluation of palliative education: why bother?

Envisage a palliative intervention that costs a small health region with 600,000 inhabitants 250,000 euros annually. Clinicians and administrators would be justified in asking for evidence in support of it. If that evidence was lacking, a study with an appropriate design and with validated outcome measures would likely be initiated. Suppose the intervention was an education programme. Would the questions regarding evidence and cost-effectiveness still apply and what would constitute sufficient evidence?

From a broad perspective, educators such as Miller and Kirkpatrick have described a hierarchy of levels of evaluation. At the bottom of the pyramid are studies that look only at participation, in the middle participants' reactions and learning gains in terms of changes in knowledge and attitudes, and at the top the direct impact on the delivery of healthcare and patient care. The latter, the "holy grail" of education interventions, is elusive but not impossible.

With some notable exceptions, the palliative education literature has focused on descriptive reports and participant satisfaction. Wider utilisation of standardised validated instruments to evaluate changes in attitudes, knowledge and skills is encouraged. Several instruments, particularly in the domain of attitudes, are available. However, the assumption that changes in learners' personal attitudes to death translate to improvements in clinical

care warrants further study. Standardised instruments (usually MCQs) evaluating knowledge are uncommon and often lack validity, reliability and item analysis data. The use of objective structured clinical examinations and other forms of evaluation is receiving increased attention. The need for economic analyses is also stressed.

Many of the concepts and principles of biomedical research are also applicable in medical education research. The fundamental steps of hypothesis generation, uniform outcomes measures, and sound statistical analysis also apply in medical education. Education research has been classified into three broad categories; a) observational/descriptive; b) co-relational; and c) experimental. Within these are quantitative, qualitative, and mixed methods. All are important in education research. Not all medical education research is quantifiable, and qualitative research remains a key contributor to understanding education and its impact. Co-relational research attempts to establish relationships between observed differences among or between groups of participants. Experimental research is inherently difficult to conduct in medical education. Proper randomisation and double blinding are challenging. The large numbers of participants required for randomisation are often not available, particularly with small classes. It is difficult to achieve standardisation in educational interventions as there is no fixed dose and the intervention is vulnerable

to many confounding factors (eg dynamism of the instructor). Lastly, it is often difficult to separate the specific effects of different educational activities within one programme. Nevertheless, randomised studies are possible, do exist, including in palliative care, are generally promoted in medical education, and when appropriate and possible, should be considered. Collaboration with education experts is essential.

There is almost universal recognition in medical education circles of the need for improved evidence to support education interventions, hence the emergence of 'best evidence medical education' (BEME). However, what constitutes best evidence remains highly debated. Some argue for quantitative, randomised-type methods, while others argue that such designs are not appropriate for medical education. Attempts to develop an evidence-level classification for medical education (similar to that used in biomedical research) has yielded mixed results.

Comparisons between interventions are also difficult when different methods and evaluation instruments have been used. The complementary use of statistical significance and effect size (which does not rely on sample size) is advocated. Effect sizes of > 0.5 are optimal and levels of >0.8 highly desirable.

However, education research covers a much broader field than what is discussed above and palliative care is well positioned to participate in that activity. An example is interprofessional education, a current topic in healthcare. Despite its importance, it remains poorly understood from an education perspective. What are the best methods of implementing it? The introduction of spirituality in health curricula is another area.

In conclusion, education evaluation and research does matter and is an important area of work in palliative care ■



Augusto Caraceni

Augusto Caraceni trained in neurology and palliative care in Italy and the USA. His main clinical and research expertise is in cancer pain, opioids, neuropathic pain, pain measurement, delirium and palliative medicine in general. In these fields he has published about 140 different publications, both in journals and books.

The pathological states of consciousness. “*Spiritus animalis residet in substantia cerebri*” (Varolius 1543–1575)

Consciousness has been explained as a function of a number of brain structures, starting with several studies between the second half of the 19th and the first half of the 20th centuries that were able to associate lesions and diseases in humans and animals with altered states of consciousness, abnormalities of the sleep-wakefulness cycle and the neural activity of the cortex, the hypothalamus and the brainstem reticular formation and nuclei.

The “level and the content of consciousness” are relatively simplistic neurological definitions that can be used to uncover the whole complexity of human subjective experience from emotion to personal identity. The philosophical and ethical implications of the meaning of higher brain functions at the end of life are important in the discourse about general medical decision-making as well as in end-of-life decisions about limitation of treatments, but they are not within the scope of this talk. The clinical evaluation of these functions is fully in the domain of palliative care, as at least 40% of patients experience episodes of delirium and many more go through stupor or coma before they die. Therefore, the appropriate assessment and diagnosis of pathological states of consciousness require that palliative care professionals are experienced in the basic mechanisms of the underlying higher brain

functions and with the use of routine instruments to assess clinically relevant findings.

Delirium is certainly one of the most common neurological syndromes seen in palliative care. Delirium, according to the DSM IV definition, can be viewed as an altered state of consciousness and attention and it is described by clinical findings ranging from a disordered sleep wakefulness cycle to hallucination or hypersomnia. The pathophysiology of delirium or of deliria is poorly understood as we know that very many causes, from metabolic changes to drug toxicities, can cause it. A common final pathway theory privileges the idea that all aetiological factors impact on the same neurological system. A more empirical theory could consider that a group of relatively similar symptoms and signs can be caused by lesions and factors that can be individually identified but not always present altogether. Hallucinations can be present as an isolated phenomenon and then evolve into frank delirium, level of consciousness can be reduced in hypoactive deliria or exaggerated in delirium tremens.

While clinically it is still practical to use the DSM IV definition and the distinction between hypoactive and hyperactive deliria, it is unlikely that we can just talk of a single clinical condition. The differential diagnosis of the

clinical syndrome requires an extra effort as again it can impact on management: non-convulsive status epilepticus, stupor-coma from structural brain lesions and drug toxicities can present with very similar clinical findings. Most recent research data show that we often do not have a better explanation to offer than the old “seed and soil” theory, understanding that advanced illness and compromised brain functions due to age or disease predispose to excessive brain reactions to most offending agents, from fevers to drugs. From a neuropharmacological point of view it is already clear that several systems are implied: acetylcholine, serotonin, dopamine, noradrenaline, histamine, hypocretine, GABA, are some of the most well known neurotransmitters who have individual and integrated roles in the modulation of consciousness and in sleep-wakefulness cycle regulation.

Therapeutic implications in palliative care include the ability to manage anxiety, insomnia, delirium, drug side-effects, and sedation at least. The wide use of sedation

as a therapeutic option in palliative care, often, but not only, at the end of life, has not been paralleled by a growth of knowledge and research among palliative care professionals about the pharmacology of sedation itself, leading to a lack of evidence-based protocols and guidelines specific to the palliative care conditions. The use of opioids, neuroleptics, benzodiazepines, antihistamines, sedatives such as propofol, noradrenergic or serotonergic agents is reported or anecdotal in palliative medicine and their indications and contribution to sedation poorly reflected in clinical practice.

To advocate more research in this area is a ritual statement, while I suggest that it represents indeed a unique opportunity to cross-fertilise the fields of anesthesiology, neurology, psychiatry and palliative medicine, to say the least, in producing an original set of data for a better understanding of the clinical, aetiopathological and therapeutic aspects of the altered states of consciousness ■



Jane Seymour

Jane Seymour is the Sue Ryder Care Professor of Palliative and End of Life Studies at the School of Nursing, University of Nottingham, UK. She is a nurse and social scientist, with research interests in palliative care beyond cancer, end-of-life decision-making and public and professional education in relation to advance care planning.

Into the unknown: advance care planning for the end of life

Advance care planning is a process of discussion between an individual and their care providers which takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity or the ability to communicate wishes to others. The goals of advance care planning have been identified as: ensuring that clinical care at the end of life is in keeping with patient preferences; improving the end-of-life care decision-making process by facilitating shared decision-making; improving wellbeing by reducing the frequency of under- or overtreatment. Outcomes of advance care planning may include the recording of: general values, wishes and preferences for care; nomination of proxies; and advance refusals of life-prolonging treatments; these are often known as 'living wills'. The legal status and frequency of use of such records varies across the developed world.

The evidence base

The apparent potential for advance care planning to provide a means of improving palliative care outcomes has led to a sharp increase in international debate and in the development of a variety of interventions. However, the evidence base for the application and use of advance care planning is conflicting. It has been associated with increasing individuals' autonomy in terms of their sense of control and a greater congruence between treatment and expressed preferences. In some contexts it appears to facilitate

understanding between patients, clinicians and families by enabling open discussion of concerns. There have been untested suggestions that advance care planning may enable care in the place of choice and that this may therefore reduce the costs of end-of-life care. Published data from North America suggest, however, that this may not be the case.

Social and cultural challenges

Challenges to advance care planning come from evidence that individuals' views and decisions may change over time as illness leads to changes in perceptions of quality of life. Concerns have been voiced that advance care planning is a means of healthcare rationing or may endorse euthanasia: this has been particularly visible in the public debate that has taken place in the UK in relation to new legislation for mental incapacity and attempts to legalise assisted dying. Additional deeply rooted cultural challenges are presented by a widespread reluctance to anticipate death, and by some evidence that patients prefer their families or clinicians to make end-of-life decisions on their behalf. How views, knowledge, and preferences in relation to advance care planning differ across different generations and cultural groups is unclear, but it is likely that 'one size' does not fit all.

Developing practice

In terms of developing clinical practice, little is known about what constitutes best practice in advance care

planning, and there is a lack of awareness among those health and social care professionals most likely to come into contact with people with palliative care needs. Moreover, providing service users and members of the public with accurate information about the risks and benefits of advance care planning is necessary but challenging.

Conclusions

Development of policy and practice in advance care planning may be one means, among the many required, to address the consequences of the rising incidence of chronic illness as the primary route to death. Any attempts to improve end-of-life care planning must particularly take account of the challenges facing older people, who now make up the majority of those who die. Rising incidence of co-morbidity, disability and extreme general frailty in older age not only make prognostication complex but mean

that many older people receive inappropriate end-of-life care, which is out of step with their needs, wishes and preferences. It therefore seems urgent to develop a better knowledge and understanding of whether and in what ways the processes of advance care planning might assist in providing better care to dying people and equally, what are the risks that may be associated with raising the issues and with the use of any resulting record. But we need to take great care as well that we do not treat people who are facing death as just another group of 'consumers' who can easily make choices about what happens to them. Such a discourse threatens to move us too far away from the traditional model and philosophy of palliative care and risks neglecting any consideration of how best to provide care thoughtfully, compassionately and empathically to vulnerable people who cannot or do not wish to enter the world of 'choice' and 'control' so admired and sought after today ■



Professor Jacek Luczak MD PhD FRCP

Consultant in palliative medicine in Hospice Pallium, founder of palliative medicine at the University of Medical Sciences in Poznan, Chair and Department Chairman of the Eastern and Central Europe Palliative Care Task Force (ECEPT). Member of the Board of Directors of the International Association for Hospice and Palliative Care (IAHPC).

Are we prepared to unmask the face of death?

There is evidence that doctors and nurses are usually not sufficiently prepared to assess and alleviate the suffering of dying patients and their families, don't know how to communicate with dying patients and their loved ones or how to prepare the patient to die. Physicians have difficulty in addressing the clinical and emotional needs of dying patients and are uncomfortable in caring for them. Furthermore, doctors who routinely work with the dying, experience emotional anxiety as a result of been closely involved with suffering patients near death and use many coping mechanisms: medicalisation, euphemism, denial, distancing and even objectifying the patient's attitude to minimise personal distress (Schulman–Green). Many doctors avoid telling the truth and share the opinion of the patient's family that disclosure will evoke depression and anxiety, as well as destroy hope and increase the suffering of the psychologically weak patient. This situation is common in Eastern Europe, including in Poland, despite continuous progress in palliative and hospice care (PHC).

The reason that doctors in Poland, particularly those of an older generation – even prestigious clinicians – are not trained in palliative medicine is that this medical specialty was only established in 1998. PHC was instigated into all the medical and nursing university students' curricula in the time from 1991 until 2000. In a study carried out in Krakow on 870 cancer patients cared for in a home hospice setting between 1994 and

1997, it was reported that only 48% of patients referred to the hospice on admission were aware of their diagnosis and 61% of families hadn't discussed this diagnosis with the patient (Gradalski *et al*). Collusion results in avoiding discussing the psychosocial and spiritual needs of patients, including a visit from the chaplain. Patients' wishes or autonomy if not respected can lead to inappropriate futile treatment and bad symptom control (SUPPORT Study). The primary caregivers and the doctors' attitude and fear of death and dying and their unawareness of PHC can result in delayed referrals. This resulted in ineffective treatment and care of suffering patients. Opiophobia is a strong barrier for early installation of strong opioids (especially morphine, an essential analgesic recommended by the IAHPC and WHO for moderate to strong pain). The unmasked face of dying/death/EoLC has many meanings and takes into consideration the various dimensions (somatic, psychic, social, spiritual) of a person, in addition to suffering and attitude/feelings of those involved. A study of 250 Polish hospice caregivers showed that many defined masked death/dying as when patients and families are not prepared for dying (88%). This study also highlighted that many patients hadn't been given a diagnosis or prognosis and had no awareness of death.

The suffering of dying patients is frequently masked (Ventafriidda: 70% are semi or fully unconsciousness in the last 24 hours). Osler found symptoms of pain and distress only in 20% of 500 dying patients.

Unfortunately, these data only correspond to the last 24 hours of life and hence do not assess the suffering and anguish of the patient and their loved ones leading up to this. It is obvious that in the last weeks and days of life, the majority of dying patients experienced suffering which increased and is often unrelieved, including pain, anxiety and so on, especially existential–spiritual distress. Furthermore, we need to appreciate the often hidden needs or masking of the suffering patient and their loved ones and improve our EoLC. Preparing patients and their loved ones for death and dying is a very challenging task for the PHC team who may have particular problems with patients cared for previously by colluding families and professionals who are uncomfortable with dying patients. Other problems include assessment of spiritual–existential needs and

finding ways to alleviate spiritual pain. Additionally, finding the best ethical solution to appropriate management at the end of life. The opening of true dialogue can be difficult, even for patients who benefit from good PHC, which can mask the effects of an incurable disease (Rec (2003) 24: the term palliative derives from the Latin word *pallium*, meaning ‘mask’ or ‘cloak’), bringing about a false hope of recovering from a terminal disease.

It is necessary not only that we improve the programme of widespread training in palliative care and EoLC for all medical professionals, but also to provide the palliative caregivers with continuous expert skills training and support programmes to improve their coping skills alongside ongoing public education on this crucial health issue ■