Plenary abstracts

Thursday 7 June

Friday 8 June

Saturday 9 June

Faith Mwangi-Powell

Dr Faith Mwangi-Powell is currently the Executive Director of the African Palliative Care Association (APCA), a post she has held since joining in January 2005.

Dr Mwangi-Powell is a member of the board of directors for the International Association for Hospice and Palliative Care (IAHPC) and the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and a member of the advocacy committee for the Worldwide Palliative Care Alliance (WPCA). Prior to the APCA, Faith worked for two and a half years with the Diana, Princess of Wales Memorial Fund, London, UK as an International Advocacy Officer for Palliative Care.

Connecting diversities to scale up palliative care in Africa

Globally, approximately 56 million people die each year. Moreover, 42 million currently live with HIV/AIDS, and there are 15.3 million new cancer cases per annum. An estimated 60% of such people would benefit from palliative care. However, scaling up palliative care services to meet this need has numerous challenges that have worldwide applicability, including: limited workforce capacity; lack of policy integration; unavailability of effective pain relieving medication; lack of research evidence; low public awareness; uncommitted governments; the lack of funding; entrenched attitudes within the medical profession; cultural taboos surrounding death and the disclosure of diagnosis; and the absence of a consensus that regards palliative care a basic human right.

In Africa, these challenges are compounded by the high disease burden and poverty. It is against this backdrop that this presentation will provide an overview of palliative care development across Africa. Following a description of the existing levels of palliative care need, it will explore the different service models that have been developed to address that need. It will be contended that connecting the diversities in service provision, whereby achievements and successes are replicated and weaknesses identified, is essential to optimise service delivery across the continent to those in need.

One of the ways in which these connections can be forged is through differing partnership models: both at the micro (ie peer-to-peer) and the macro (ie provider-to-provider, organisation-to-organisation, both nationally and internationally) level. Drawing upon the experiences of the African Palliative Care Association, this presentation will review such collaborative partnerships, highlighting their value in collectively beginning to address the need for palliative care development, and outlining some of the challenges entailed in ensuring they function successfully ■

Barbara Monroe

Barbara has been a social worker for over 30 years. She joined St Christopher's Hospice in 1987 and became Chief Executive in 2000. She is also Chair of the national Childhood Bereavement Network. She has written extensively about the psychosocial aspect.

Resilience and palliative care

Resilience is receiving increasing research attention as we seek to explain the variety and complexities of human response to difficult circumstances and the recent understanding that many more individuals than initially thought can continue to thrive despite adverse experiences and compounding risk factors. Resilience is not just about re-forming but about the possibility of growth. It offers a unifying concept to sustain the most significant understandings of four decades of palliative care and incorporate more effective investment in community and public health approaches. This integration is vital if we are to reconcile the tension between the rhetoric of choice and equity in end-of-life care and the demands of rising healthcare expectations in aging populations with increasingly limited professional and financial resources. These Western world challenges are compounded by the huge needs of resource-poor countries.

Resilience is inextricably linked to risk in an interactive process occurring over time and influenced by individual and family variables, social context and social structure. Resilience demands a more sophisticated assessment, recognising that many of these variables are cross-cutting and can be positive or negative in impact. It is important for the future development of end-of-life care that health and social care issues remain integrated. A return to the privileging of a narrow medical definition of palliative care is presaged, 'The central aspect of palliative care is symptom control delivered humanely with adequate information… undue emphasis on attending to families is demanding of resources which might be better devoted to a wider population of patients' (Randall and Downie 2006). Fortunately some of the economic realities of modern healthcare are drivers in a more positive direction. A recent systematic review of factors influencing death at home in terminally ill patients with cancer emphasises the need to explore family support and empowerment and the role of prevention and public education (Gomes and Higginson, *BMJ* 2006). Palliative care has often been slow to respond to the challenges of disadvantage and exclusion. If it is to do so it must not lose the founding ethos of hospices which sought to empower and to promote strengths and resources.

Analysis of a series of ten study days on resilience in palliative care held at St Christopher's in 2005 revealed key themes: secure attachments, meaning and sense, hope, coherence, creativity, good memories, public education and community support, cultural awareness, internal locus of control, wellbeing, self-esteem, one supportive person and learned optimism. Insights from the field of bereavement underline the importance of balancing vulnerability and health promotion. Evidence supports the beneficial power of narrative in meaning making and the integration of difficult experiences. Studies on 'hope' emphasise the value of reminiscence therapy, humour and the nurturing of independence. Creative therapies can also increase the resources of individuals for use at time of threat. Resilience work supports the concept of brief, focused, cost-effective interventions designed to avoid pathologising and to boost confidence, coping and action. Examples include cognitive behavioural therapy and Kissane's family-focused grief therapy. A clearer understanding of the neurobiological basis of behaviour and its links to resilience is developing.

Palliative care must work in partnership with the communities in which people live to change attitudes and empower them to respond supportively. Canada and Australia have developed government and workplace initiatives to support carers and the terminally ill. Palliative care already uses professional education to extend its messages beyond its immediate sector. School-linked programmes and attempts at wider public education are emerging. Social marketing and information strategies will become more important as we try to find the right balance between expert professional interventions and general loss education. Public receptiveness to internet based resources points to some of the possibilities. Studies of user involvement and group work in palliative care demonstrate the positive therapeutic impact of engagement and increased social connectedness. The future will hold new forms of mutual help groups and volunteering.

The concept of resilience makes it clear that individual factors such as a sense of agency and seeing the world as understandable must be linked to positive family, community and cultural resources, values and connections. Efforts to improve individual welfare cannot alone meet the aspirations of society in relation to high quality, cost-effective and equitable care for all dying people. The West has much to learn from the community-funded and volunteer-supported programmes in resource-poor countries ■

Dr Peter Lawlor

Dr Lawlor worked with the Edmonton Regional Palliative Care Program prior to returning to Dublin in 2004 as a consultant at Our Lady's Hospice and St James's Hospital. He holds an adjunct Associate Professor appointment in Palliative Care Medicine at the University of Alberta.

Hydration practice: attitudes and evidence

Hydration in end-of-life care is often viewed as signifying the essence of compassionate care. Much of the literature on artificial hydration (AH) relates to rhetorical arguments and studies of limited scientific rigour. Much of the controversy has arisen from diametrically opposed viewpoints: the hydrate "all" approach of the relatively more aggressive biomedical model of care, versus the more conservative hydrate "none" approach of the more traditional hospice model of care.

The opposing views are reflected by the great variation in the practice of AH. Variation occurs in the proportion of patients who receive AH in different cultural settings and care locations. Variation has also been noted in the volumes of fluid administered and in the route used for hydration administration. It has been suggested that patients will often defer to their physicians in the decision-making process, and ultimately do what the physician suggests.

Hypovolaemia and dehydration are fluid deficit states. In hypovolaemia, the fluid deficit is in the intravascular volume, which can be iso-, hypo-, or hypertonic depending on the proportion of water and solute that is lost. In dehydration, there is a loss of total body water, which invariably comes from the intracellular department. Dehydration is associated with hypernatraemia, whereas hypovolaemia can be associated with iso-, hypo-, or hypertnatraemia. Fluid deficits can arise due to decreased intake, increased loss, or both. It should be remembered that fluid loss can occur with "third spacing" of fluid, as occurs in ascites. Physiological changes occur with aging, including a reduced proportion of total body mass due to water, a possible reduction in thirst response to dehydration, and a decrease in renal response to intravascular volume changes. Many of the classical symptoms and signs of fluid deficit are unreliable in the elderly and in cancer patients.

The identification of clinical outcome measures and biochemical indices that truly reflect hydration status has been a major research challenge. Only six studies met the inclusion criteria of a systematic review, in which no conclusion could be drawn regarding benefit. The studies that have examined dry mouth or thirst suggest that it occurs in 61–87% of patients receiving end-of-life care. However, confounding variables such as anticholinergic or psychotropic medication use, stomatitis, and mouth breathing can create difficulty in interpreting study findings. The biochemical indices of hydration have largely proved inconsistent in their reflection of hydration status. One study found that atrial natriuretic peptide levels may prove useful in determining hydration status.

To date there is only one published randomised controlled trial that examined hydration benefits in advanced cancer patients. It demonstrated a significant improvement in the sedation and myoclonus scores in the hydration treatment group. The authors of this study reported patient accrual difficulties due to the frequent co-occurrence of dehydration signs and cognitive deficit, thereby creating difficulties with obtaining consent at study entry.

Studies of delirium, a multifaceted syndrome that is often potentially reversible, have demonstrated some conflicting results. In one study dehydration was identified as a covariate significantly associated with delirium reversibility. A Japanese study demonstrated that dehydration occurs in association with delirium but not necessary with reversibility. Most opioids and their metabolites are renally eliminated. Demonstration of opioid toxicity in association with elevated levels of opioid metabolites has been inconsistent, except in the case of renal impairment. Given that a fluid deficit state may progress inexorably to the state of prerenal renal impairment, it seems logical at least to consider AH in patients on opioids who are fluid deficient, or at risk of fluid deficit, in order to prevent prerenal renal impairment.

In the decision-making process on AH we need to consider: the true hydration status of the patient, the complications and symptom burden occurring with the fluid deficit state versus AH; the patient’s prognosis and decision-making capacity; knowledge, attitudes, beliefs and wishes, of patients, their families or proxies, and the multidisciplinary team regarding AH; concomitant use of sedatives and withholding or withdrawal of AH; the assessment of delirium reversibility. Ultimately, the best ethical and evidence based practice will involve an individualised approach to AH. A timed trial may be considered. Education and support is essential for relatives, who should receive clear and consistent communication from the multidisciplinary team ■

Lars Björklund

I was ordained as a priest in the Church of Sweden in 1979 and I have been employed as a chaplain at Sigtunastiftelsen since the autumn of 2001. Previous employment: 22 years at Akademiska Sjukhuset (the university hospital) in Uppsala, Sweden, with ten years based in the children's ward.

The courage to be

Several years ago, when I thought of writing a book about meeting people in pain and crisis and close to death, I considered naming the book *The Art of Doing Nothing*. Early on, I had the experience that in the really difficult meetings, there was nothing to be done. All attempts to make it better or maybe bring out a positive feeling were in vain. The sorrow and the pain were too great. I still felt that it was important to be there. Not for the purpose of doing something but perhaps to lessen the loneliness a bit, in the midst of all pain.

In circumstances where it is constantly important to accomplish something, and where that which is accomplished is given the greatest meaning, a person quickly becomes lonely if there is nothing to be done. Or she might also be put through unnecessary things. What is being done, is done only for the act of doing, and this involves the risk that the person who longs only for closeness is abandoned. Another risk is that what can still be done appears worthless and is seen as nothing at all. I am thinking of such things as turning the pillow for someone who is too tired to do it themselves, to stretch out the sheet and make sure there is clean and fresh water in the glass at the bedside table next to someone who is dying. If this is all that is possible to do for another human being, then this is all you can do. To do all you can for someone is a great act, and should not be called "nothing".

Sometimes we need to do absolutely nothing, and have faith that our presence is enough. But even if we can let go of the thought to accomplish something, there can still be an unspoken wish that things will get better for the one we meet, or at least that there will be a change. I dare say there are moments when our wish can be conceived as a demand and can cause us to let down the one we meet. In certain vulnerable situations the same risk arises if we give something. In the emptiness that is born if we do nothing, want nothing and give nothing, a meeting can still take place. A meeting without expectations and demands, where a fellow human being is made visible and confirmed.

My mission is that of love, and no matter how I turn the word love inside out, I always come to the conclusion that love means to demand nothing at all. If I give love, and by the act of giving accept another person, I have fulfilled my mission. Without expectations love grows. But if I expect something in return or expect something to get better, the love can die if the answer or the improvement fail to occur. A love that expects an answer can in certain situations be conceived as a threat. But love demands no success. It is there without expectations of results and without expectations of gratitude. Redone in the difficult meeting it turns into a form of method. When I meet a person who needs help I can stay without doing anything. I can be there without giving anything else than my presence and I can leave without the expectation of gratitude. Several meetings have looked exactly like this. I could do nothing, give nothing, and I could not see any measurable result. What makes me believe that it is still important to stay are stories from people who a long, long time after a crisis realise that the one who offered the most help was the one who was there with neither demands nor expectations. Patiently and lovingly ■

Finella Craig

Finella Craig has been a Consultant in Paediatric Palliative Care at Great Ormond Street Hospital for Children since 2002. Her palliative care training included two years with a community and hospital-based adult palliative care service as well as with the paediatric palliative care team at Great Ormond Street Hospital. She has particular interests in palliative care for children with non-malignant conditions.

Paediatric palliative care

Living with a life-threatening or life-limiting condition can be challenging, particularly for adolescents and young adults as they face the physical, cognitive and emotional changes of the transition to independent adulthood. Some may have been progressing through normal adolescent development prior acute illness. For those with progressive disorders, adolescence may be accompanied by deteriorating physical health and/or mental ability. Others may be coping with lifelong chronic conditions, which may not fit easily alongside adolescent development and activities.

This presentation will explore the impact of life-limiting illness on adolescent development and how, as professionals, we can support children with life-limiting illness through adolescence to adulthood. The presentation will address issues of physical independence, independence in decision-making, financial independence, peer group identification, changing relationships with parents, sexuality and spirituality. We will discuss how, with the right support, a young person's sense of individuality, autonomy, value and continuity can develop and be reinforced ■

Frank D Ferris MD

Frank D Ferris, MD is the Medical Director of Palliative Care Standards and Outcome Measures and responsible for the international programmes at San Diego Hospice & Palliative Care. He is a Clinical Professor, Voluntary, in both the Department of Family & Preventative Medicine, and the Department of Medicine, at the University of California, San Diego School of Medicine, San Diego, California.

Implementing quality palliative care – how to prove it

Quality palliative care is of interest to everyone who is receiving or providing care. The quality of the care that is provided depends on everyone's understanding of the underlying model that is guiding patient/family care; the organisation's mission and vision; and the consistency of the language, practice and treatment guidelines, outcome assessment and performance improvement strategies that everyone is using from day to day.

Implementation of quality palliative care within an organisation starts with careful strategic planning followed by the systematic development of guidelines, outcome measures, standards and a performance improvement process through an inclusive consensus-building process. By modifying existing widely-accepted models, organisations can expedite their implementation of quality palliative care. Through careful attention to evolving this process over time, everyone will be the benefactors of a high-quality palliative care experience.

This plenary presentation will focus on the process and the potential outcomes/benefits for key stakeholders ■

Katalin Muszbek MD

Katalin Muszbek MD, psychiatrist, psychoanalyst, Director and founder of the Hungarian Hospice Foundation, Vice-president of the board of the Eastern and Central European Palliative Task Force and member of the International Psycho-oncology Society.

Cultural issues in facing death

Individual and social attitudes relating to reaction for loss have been undergoing significant changes during the last decade. The aftermath of loss depends on various conditions. The presentation separates the role of traditions and psychological aspects of the individual while it also touches the role of palliative care.

1. Social attitudes: attending to a dying person in traditional cultures relies on both the family and the society while in the developed world individual autonomy is dominant. Formerly it was the community, the rituals and the traditions that helped facing death. In traditional communities mourning was not only accepted, but it was an expected form of behaviour associated with numerous rituals.

   By today the majority of these traditions have ceased and the attitude system of the society regarding death and bereavement have also undergone changes. Effective bereavement today means rapid mourning process, few personal reactions and an early back-to-normal lifestyle.

2. The individual psychological reactions depend on personality structure. Coping and defensive mechanisms in facing death and loss processing both vary with the individual. It is important to analyse aggression and remorse handling linked to loss as well as the role and the consequences of suppression.

3. Healers – enchanters, shamans and doctors are omnipotent people helping us to cope with illnesses and symptoms. Cultural differences in this area are substantial but the omnipotent saver is a determinative personality in all different cultures. In today's modern societies this mission is completed through palliative care. The need for it is universal, regardless of frontiers and nations ■

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 pathophysioloy 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: acethycholyne, serotonine, 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 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 (Ventafridda: 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 ■