

# European Journal of Palliative Care



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# European Journal of Palliative Care



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# Love your data

*The goal is to turn data into information, and information into insight.*

Carly Fiorina, former CEO, Hewlett Packard

**“I remember Dame Barbara Monroe, retired CEO of St Christopher’s, saying that a drawer full of thank-you letters wasn’t enough to understand the impact of your service. I thought she was wrong at the time – but I now know she was right! Quality is certainly about patient and family experience, and we need to systematically collect experience data beyond letters, but it’s also about outcomes, impact and reach. The reach of a service is critical – and reach is about knowing whom you are supporting and those whose needs are not being met. Those unmet needs are the levers for change, for funds, for making a difference. So counting is one thing – but perhaps more crucially, noticing trends, benchmarking with others and understanding local demographics are vital steps on the way to comprehensive palliative care for all.**

We know that many people who might benefit from palliative care are still not being seen – this means there is physical and emotional suffering, ‘total pain’ on a significant scale in a country rated top of the world in palliative care.<sup>1</sup> Without a complete national data set, the story is so difficult to tell. My first plea then is to all organisations, NHS and charitable, who are collecting data that you are generous and brave enough to share your numbers. Only then can we tell the stories that need to be told about unmet need, about whether preferences are being met, about how people are dying.

So what do we know now? The Minimum Data Set (MDS)<sup>2</sup> has been collected from hospices and NHS teams in England, Wales and Northern Ireland for over 20 years. It is supported by Public Health England and Hospice UK and collated by the National Council for Palliative Care. About 70% of the inpatient and community data comes from charitable hospices and 90% of the hospital data comes from the NHS.

Key limitations of the MDS are that it misses out on Scottish and paediatric data and it counts numbers of people attending different aspects of a service (day care, inpatient care, home care) – it doesn’t tell us the total number of individual patients getting palliative support as a proportion of all deaths. That’s a vital unanswered question.

Despite its flaws, however, the MDS is still confirming important trends. Topline messages are that community teams (hospice and NHS) are seeing approximately 30% of expected deaths, with 81% of community palliative patients dying out of hospital, compared to the national average of 50%. This is such an important statistic. It shows that palliative support doubles the likelihood of dying at home – what we don’t know is the most effective configuration of teams to do this.

The latest MDS also highlights the fact that most hospice care now goes far beyond the hospice building. There are only 2,760 hospice beds nationally – so there will always be a cap on the number of possible inpatient hospice deaths, which stand at only about 6% of all deaths. But the MDS tells us that many hospices are influencing up to 30% of those in the last year of their lives, through their community and clinic teams – that’s a statistic we need to shout about.<sup>3</sup>

This year’s data also confirms an increase in the number of patients admitted to hospice beds from hospital. This is good for hospital patients who no longer need or want the intensity of hospital – but does this mean it is more difficult to get a hospice bed for patients in crisis at home?

Where could we do better? The answer must lie in equity and diversity. Fifty years after the birth of hospice care, services are still dominated by cancer patients. The good news is that rates of referral to palliative care for heart disease, lung disease and dementia are rising. There are initiatives all around the UK driving earlier palliative referral for all diagnoses, sharing resources and expertise and recognising that the suffering of cancer patients is universal to all those with advancing illness.<sup>4</sup>

So counting is crucial because data underpins all innovation.<sup>5</sup> We will certainly need to count different things in the future. But if we stop counting, then we will never know the extent of support being offered, the national story will never be told – and those in ‘total pain’ will continue to rise. ”

**Ros Taylor**, Clinical Director, Hospice UK

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# Managing malignant bowel obstruction with lanreotide in the community

The medical management of malignant bowel obstruction in patients with advanced carcinoma is often complicated by the presence of co-morbidities. **Kate Markham, Shan Shan Vijeratnam and Pia Amsler** recount two cases that support the use of lanreotide in suitable patients

**M**alignant bowel obstruction is a common distressing complication in patients with advanced abdominal or pelvic carcinoma.<sup>1,2</sup> In most patients with advanced disease, surgical options, such as a colostomy or venting gastrostomy, may not be feasible due to peritoneal carcinomatosis, ascites, multiple co-morbidities and poor performance status,<sup>3</sup> posing a challenge to healthcare professionals.

The medical management of bowel obstruction is complex. There is limited data to support lanreotide, a long-acting somatostatin analogue, in this situation.<sup>4</sup> In our case, lanreotide significantly improved the symptoms and quality of life of the patients described below, who were ambulatory and had an undetermined prognosis, despite advanced intra-abdominal disease. We believe that lanreotide can be an effective treatment in the community in this group of patients.

## Case report 1

This 61-year-old woman with a background history of metastatic squamous cell carcinoma of the vagina continued to have disease progression, despite treatment with chemotherapy and radiotherapy. During the initial presentation of her illness, she was taken to theatre for excision of the tumour but was found to have extensive pelvic disease and instead received an end-colostomy. Following radiotherapy she developed a right utero-cutaneous fistula, necessitating a right nephrostomy and a left-side antegrade ureteric stent.

She was admitted to hospital with a sub-acute small bowel obstruction. A CT abdomen showed 'dilated proximal small bowel'. She

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was subsequently given intravenous fluids and had a nasogastric (NG) tube inserted. Her symptoms then resolved; she was discharged home ten days later with support from the Community Palliative Care Support Team.

For the following five months, she remained well. Subsequently she re-presented with profuse bilious vomiting, particularly after meals. She had hypoactive bowel sounds on abdominal examination and a diagnosis of intermittent small bowel obstruction was made. Surgical options were not possible, and she also expressed clearly that she did not want to have further admissions to hospital. She declined a venting gastrostomy, as she already had multiple indwelling catheters *in situ*. Medications that could be used to treat her symptoms included high-dose omeprazole, hyoscine butylbromide, haloperidol, levomepromazine and oxycodone IR.

The patient continued to be mobile and live an active lifestyle, with a WHO performance status of 1; her biggest complaint was her inability to enjoy a meal with her family. Titration of hyoscine butylbromide to a

## Key points

- Consider the use of somatostatin analogue for patients in the community with malignant bowel obstruction if other medical treatments fail.
- We recommend a trial of octreotide via syringe driver for one week initially to assess responsiveness before initiating lanreotide.
- Dose titration and frequency of injections need to be based on the clinical picture.
- Wider use of such treatment may reduce the need for admission to hospice or hospitals for symptom management and should be tailored to patients' individual needs and wishes.

maximal dose of 120 mg/24 hours led to some – but not satisfying – improvement of her nausea and post-prandial vomiting. A trial of the somatostatin analogue octreotide was instigated subcutaneously; titration from 300 to 900 mcg/24 hours led to an effective control of her vomiting. During this time, she continued on oral hyoscine butylbromide four times daily. Due to convenience, district nursing time and the patient's undetermined prognosis, her treatment was converted to a single intramuscular lanreotide injection.

### **Dose and interval titration**

Given the expense of lanreotide, an initial dose of 30 mg was administered, but nausea and vomiting re-occurred after 10 days. The dose was increased to 60 mg and a second injection was given 14 days after the initial syringe driver had been discontinued; this was then repeated every four weeks. She had no further episodes of vomiting but continued to feel nauseated three weeks after the injection. Consecutively, the dose was further increased to 90 mg and the injection interval reduced to three weeks (see Table 1).

To date, the patient describes a marked improvement of her nausea and vomiting since commencement of a somatostatin analogue. Her quality of life has improved significantly – she can travel with her family in the UK instead of being homebound. She has not reported any adverse side effects related to lanreotide injection.

### **Case report 2**

This 58-year-old woman had a 14-year history of ovarian carcinoma with a slow and grumbling course, and metastases present in her liver, bowel, peritoneum and hip. She received multiple treatments, including debulking surgeries and several chemotherapies, but her disease progressed despite these. She developed a vesicovaginal fistula, which caused her considerable distress.

After ongoing abdominal pain and nausea, a CT scan confirmed intermittent small bowel obstruction. She was started on a syringe driver with hyoscine butylbromide 60 mg and midazolam 5 mg. The hyoscine butylbromide was gradually titrated up to 120 mg over 24 hours. This led to a resolve of her colicky pain on defecation and eased a lot of her loose bowel, but unfortunately she still suffered nausea.



**Table 1. Symptom control**

Case 1	First-line treatment: levomepromazine 12.5 mg/24 hrs via syringe driver; hyoscine butylbromide titrated to 120 mg/24 hrs; oxycodone 60 mg/24 hrs via syringe driver
	Second-line treatment: octreotide 300–900 mcg/24 hrs via syringe driver; oxycodone 60 mg/24 hrs and levomepromazine 12.5 mg/24 hrs via syringe driver; oral hyoscine butylbromide 20 mg qid
	Third-line treatment: lanreotide 30–90 mg 3-weekly injection; oxycodone 60 mg/24 hrs; levomepromazine 12.5 mg/24 hrs via syringe driver; oral hyoscine butylbromide 20 mg qid
Case 2	First-line treatment: hyoscine butylbromide 60–120 mg/24 hrs; midazolam 5 mg/24 hrs via syringe driver
	Second-line treatment: octreotide 600–1,200 mcg/24 hrs; midazolam 5 mg/24 hrs via syringe driver
	Third-line treatment: lanreotide 30–60 mg 4-weekly injection; oxycodone 10 mg/24 hrs; levomepromazine 12.5 mg/24 hrs; hyoscine butylbromide 60 mg/24 hrs; midazolam 5 mg/24 hrs via syringe driver

The patient was then switched to octreotide via a syringe driver, initially at 600 mcg over 24 hours, then increased to 900 mcg and finally to 1,200 mcg over 24 hours. This treatment provided effective control of both her nausea and colicky abdominal pain, and after one week she was

switched to injections of intramuscular 30 mg lanreotide every four weeks.

### **Dose and titration**

Lanreotide was initially started at 30 mg every four weeks; two weeks later it was titrated up to 60 mg every four weeks, with the patient requiring cyclizine in concordance.

Two months later the patient required an inpatient stay at the hospice, as she had nausea and vomiting. A separate syringe driver containing oxycodone 10 mg, levomepromazine 12.5 mg, hyoscine butylbromide 60 mg and midazolam 5 mg over 24 hours was commenced, which controlled her symptoms well. This was continued instead of switching back to oral drugs on discharge, as there was a significant degree of malabsorption from the small bowel. Lanreotide was continued in order to avoid a second syringe driver with octreotide, allowing the patient more freedom. To date, five months later, she continues to have this syringe driver alongside four-weekly 60 mg lanreotide injections to good effect (see Table 1). She has reported no adverse side effects from the lanreotide.

### **Discussion**

Malignant bowel obstruction remains a challenging condition to manage. Clinical practice guidelines suggest the use of anti-emetics, analgesics and antisecretory drugs, as well as proton pump inhibitors, as first-line treatment.<sup>3</sup>

Somatostatin analogues could be used when other medications are effective, or when other antisecretory agents, such as hyoscine butylbromide, only partially control the symptoms.<sup>5</sup> Somatostatin analogues work by inhibiting the secretion of insulin, glucagon, and enteropancreatic peptides such as gastrin, vasoactive intestinal peptide and substance P. This subsequently decreases blood flow at the splanchnic vein and portal system and reduces gastrointestinal motility and intestinal secretion.<sup>6</sup> Collectively, these mechanisms decrease the rate of nutrient absorption and reduce the likelihood of vomiting.

In the single clinical trial that has been published for lanreotide in patients with intestinal obstruction with peritoneal carcinomatosis, it was shown to be effective.<sup>4</sup>

In a case report comparing hyoscine butylbromide with octreotide to hyoscine butylbromide alone and octreotide alone in a man with gastric cancer and a high level of obstruction, it was found that symptoms were not controlled when either drug was administered alone.<sup>7</sup>

However, somatostatin analogues can be expensive. An injection of octreotide acetate of 200 µg/ml costs £70. A depot injection of lanreotide 30 mg costs about £320; 60 mg costs about £550 and 90 mg costs over £730.<sup>8</sup>

In order to assess whether a patient would respond to a somatostatin analogue, a trial of octreotide should be given via a syringe driver for one week; once proven to be effective, the drug can be switched to the longer-acting lanreotide, which can then be administered every 3–4 weeks. Depending on the octreotide dose required, a single monthly lanreotide injection can therefore be more cost-

effective, both in terms of nursing-time to attend to the syringe driver daily and for the medication itself.

Lanreotide was a viable alternative to octreotide for both patients described here. It was at least as effective at controlling the symptoms of intermittent small bowel obstruction and led to a marked improvement in both patients' quality of life. Although expensive, the use of lanreotide should be considered in ambulatory patients with advanced disease who are not expected to die within a few weeks.

### **Declaration of interest**

The authors declare that there is no conflict of interest.

### **Acknowledgements**

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## Hayward Medical Communications

# Treating cancer pain

**Andrew Dickman** explains some of the complexities of the generation and perception of pain, and considers established and emerging methods of dealing with complex, chronic cancer pain



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It has been suggested that the first symptom for which patients with cancer consult a physician is pain from bone metastasis.<sup>1</sup> In fact, in a recent pan-European survey of cancer patients, the most common reason for the initial consultation that led to the cancer diagnosis was pain.<sup>2</sup> Pain is believed to be experienced in 56–75% of patients with advanced disease.<sup>3–5</sup> The impact of pain on quality of life can be devastating; cancer patients with pain report significantly lower levels of performance status and higher levels of total mood disturbance than those who are pain-free, as well as significantly more anger, fatigue, depression, confusion and lethargy.<sup>6</sup>

## What is pain?

Pain, as defined by the International Association for the Study of Pain, is ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.’<sup>7</sup> Pain may be either acute or chronic, depending on its onset and duration. In addition to acute and chronic categories, pain can be further divided into three types, based on aetiology and clinical features: nociceptive, neuropathic and mixed.<sup>8,9</sup>

### Nociceptive pain

Nociceptive, or inflammatory, pain is caused by stimulation of nociceptors in the peripheral nervous system and is produced by thermal, chemical or mechanical damage. There are two types of nociceptive pain: somatic and visceral. Somatic pain is produced by the activation of peripheral nociceptors found in skin, bone, joints and muscles. Typically described as aching or throbbing, the pain is generally localised and constant and can be precipitated by movement. Visceral pain is produced by the stimulation of nociceptors within internal organs. It is often poorly localised and can be referred to non-visceral areas. Visceral pain can be described as constant and sharp.

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### Neuropathic pain

Neuropathic pain is caused by damage to or changes in the central or peripheral nervous system and can occur spontaneously in the absence of a stimulus. In essence, it is caused by a dysfunctional plasticity that alters nociceptive pain transmission, leading to enhanced responses to both noxious and innocuous stimuli. Depending on the nerve affected, the pain may be shooting, stabbing, lancinating, electric, burning, cold or itching.

### Mixed pain

Mixed pain involves both nociceptive and neuropathic pain mechanisms and is the category into which cancer pain falls. Tumour growth can induce tissue damage and the release of inflammatory mediators, as well as causing direct nerve damage through compression or infiltration. Cancer patients may also experience neuropathic pain due to chemotherapy; co-morbidities such as diabetes mellitus may also contribute to the development of neuropathic pain.<sup>10</sup>

### Neuromatrix of pain

There have been substantial developments in the understanding of pain at molecular and cellular levels since Melzack and Wall's pioneering gate theory in 1965.<sup>11</sup> It is now recognised that pain perception is not a simple

## Key points

- About a third of cancer patients continue to experience strong pain when treated using the WHO pain ladder.<sup>2,14,15</sup>
- Cancer pain is mixed, involving both nociceptive and neuropathic pain mechanisms. It is complex, with multifactorial causes, and its management must consider psychological, social and spiritual needs.
- If used as a framework rather than a strict protocol, the WHO pain ladder allows for a more individualised model of pain management.
- A multimodal, mechanism-based approach incorporates options such as adjuvant analgesics alongside opioids, methadone as a second-line opioid and tapentadol, which represents a new class of analgesics with a unique dual action.

linear experience resulting from injury, inflammation and other tissue damage. Pain is a subjective experience that can be influenced by many factors, including emotional state, past experiences, attention and distraction, which can serve to either augment or attenuate the pain experience. Indeed, Dame Cicely Saunders introduced the concept of ‘total pain’ to describe the interaction between physical, emotional, psychological and social suffering experienced by cancer patients.<sup>12</sup> Melzack’s later neuromatrix theory proposes that we experience pain as a result of a complex interplay of cognition, emotion and sensation mediated through a matrix of several diverse brain regions. The pain experience occurs when activity from all areas is integrated in the frontal cortex, rather than directly by a sensory input caused by injury or inflammation.<sup>13</sup> For example, chronic pain syndromes exist in which no obvious tissue damage is apparent. Patients experiencing pain from these syndromes can display signs of psychological or physical stress, suggesting that genetic influences and the neural–hormonal mechanisms of stress are as important as the neural mechanisms of sensory transmission to the pain experience.

### **Pain mechanisms**

Peripheral tissue damage generates pain signals that are usually transmitted via small, myelinated Aδ fibres (fast) and unmyelinated C-fibres (slow) to the dorsal horn of the spinal cord. Various inflammatory mediators, such as bradykinins, prostaglandins and nerve growth factor, can sensitise the nociceptor, making it more prone to activate at lower stimulation thresholds. Aδ fibres transmit rapid, sharp pain and are responsible for the initial reflex response to acute pain. C fibres respond to chemical, mechanical and thermal stimuli, often resulting in burning pain. Aδ and C fibres synapse with secondary afferent neurones in the dorsal horn. The nociceptive signal is propagated through relay synapses in the spinal cord, medulla, hindbrain and thalamus and terminates at multiple cortical sites.

### **Negative reinforcement of chronic pain**

Complex interactions occur in the dorsal horn between afferent neurones, interneurones and descending modulatory pathways. Noxious

stimuli received by dorsal horn neurones project to various regions of the brain, including the thalamus, cortex and limbic system, via the spinothalamic tract. Sensory aspects of pain are established by activity in cortical areas through relays in the thalamus, whereas emotional aspects of pain are probably established by spinal neurones projecting to limbic areas of the brain, such as the amygdala. Persistent inputs into the limbic areas are likely to be the cause of the co-morbidities that patients with cancer pain often report, such as anxiety, depression and insomnia. Neurones from higher centres of the brain, such as the amygdala, periaqueductal gray (PAG) region and the rostral ventromedial medulla (RVM), project to the spinal cord, forming descending modulatory pathways. These higher centres of

**Persistent inputs into the limbic areas are likely to be the cause of the co-morbidities that patients with cancer pain often report**

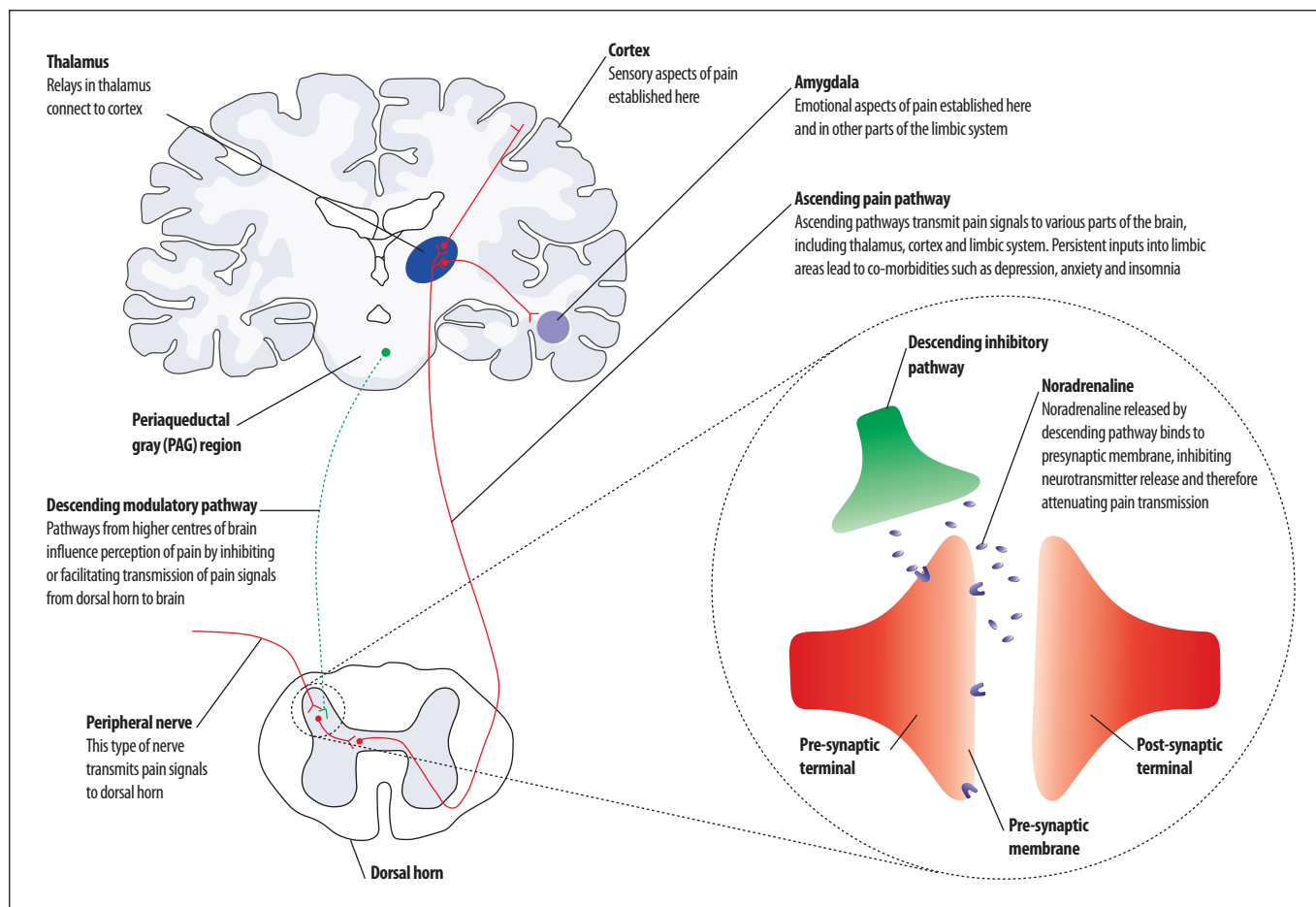
the brain exert influences on the perception of pain by either inhibiting or facilitating the transmission of nociceptive signals within the dorsal horn. In chronic pain states, such as cancer-induced bone pain, increased spinal sensitivity is

believed to be caused by abnormal descending controls; these may in turn be partly driven by changes in limbic areas of the brain precipitated by persistent inputs that cause common co-morbidities, such as anxiety and depression. Thus, these co-morbidities can impact on the pain experience, leading to a situation of negative reinforcement.<sup>9</sup>

The PAG and the RVM are key areas of the brain involved in endogenous pain control through descending inhibitory modulation. These monoaminergic pathways utilise the neurotransmitters noradrenaline and serotonin (see Figure 1). The descending noradrenergic pathway has only antinociceptive effects; the serotonergic pathway, in contrast, has been shown to exert both antinociceptive and nociceptive effects.<sup>14</sup>

### **Pain assessment**

Cancer pain is complex, chronic and often has multiple causes. Besides the pain of cancer itself, patients may also experience pain due to treatments such as chemotherapy, radiotherapy or drugs; opioids, for example, often lead to painful constipation. There may also be other issues, such as underlying anxiety, depression, insomnia, fear or anger. Such factors will have a direct effect on a patient’s pain experience, and



■ **Figure 1.**  
**Pain transmission and modulation.**  
Disruption of the pain-modulating descending pathways is thought to be involved in the development of chronic pain, such as cancer pain. Such disruption may be caused, in part, by persistent inputs to the limbic areas that lead to anxiety and depression. Thus these co-morbidities can reinforce the pain experience, leading to a vicious circle.

addressing a patient's concerns or fears, in addition to administering analgesia, can help to reduce suffering. A multidisciplinary approach to pain management must take into account psychological, social and spiritual needs. In fact, drug therapy alone is unlikely to be adequate treatment for chronic pain of any cause. The successful pharmacological treatment of cancer pain relies on an accurate pain assessment, with an appreciation of the underlying pathophysiology. Analgesia should be regularly reassessed in order to determine:

- the efficacy of the treatment
- the tolerability of the treatment
- any change in response (increasing doses of opioids do not always indicate tolerance; there could be disease progression or development of opioid-induced hyperalgesia)
- whether the treatment is ineffective or inappropriate.

### Pharmacotherapy of pain

Non-pharmacological measures undoubtedly have an important role in the comprehensive management of cancer pain, but medication-driven pain management arguably forms the critical aspect of care.

### The WHO analgesic ladder

Acceptable pain relief in up to 70% of cancer patients is thought possible using the WHO three-step analgesic ladder.<sup>2,14,15</sup> Of course, this means that at least 30% of patients do not achieve acceptable pain relief. The WHO protocol is nearly 30 years old and has its limitations, although it is clearly of benefit for the majority. It is, however, accepted today that this approach should be considered a framework rather than a rigid protocol, and the severity or type of pain should determine the analgesic to be used. We have gained a better understanding of pain mechanisms and analgesic pharmacology in recent years; it has been suggested that a more individualised model of managing cancer pain is needed, one that adopts a mechanism-based and multimodal approach.<sup>16</sup>

Step 1 of the WHO ladder involves using non-opioid drugs, such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs), with or without an adjuvant analgesic (a drug with analgesic properties but a primary indication other than alleviating pain). If pain remains uncontrolled, Step 2 is used: a 'weak' opioid, such as codeine or tramadol, for mild-

to-moderate pain, is added to Step 1 treatment. If pain persists, Step 3 is introduced: a 'strong' opioid, such as morphine, replaces the weak opioid and is titrated according to pain relief.

Paracetamol has analgesic and antipyretic activities similar to those of aspirin, but no anti-inflammatory action. NSAIDs are a heterogeneous group of analgesics and the most common class of drugs prescribed worldwide. They are analgesic, antipyretic and anti-inflammatory. Although effective in mild-to-moderate cancer pain, both paracetamol and NSAIDs have limited value in severe pain due to adverse effects as the dose escalates. NSAIDs are often used in patients with cancer pain because it is assumed there is an opioid-sparing effect. However, evidence to support the use of non-opioids as co-analgesics in cancer pain is weak.<sup>17,18</sup>

Opioids are the mainstay of cancer pain management and the only analgesics with proven benefit when the pain is severe.<sup>19</sup> It has been suggested that on Step 2, more potent opioids at lower doses should take the place of less potent opioids. For patients with mild-to-moderate pain, Step 2 of the WHO analgesic ladder still applies. Patients with severe pain, however, should be offered a stronger opioid using a clear dose titration schedule according to pain levels.<sup>20</sup> However, dose escalation of an opioid used as a sole analgesic is often limited by adverse effects, such as sedation or constipation. This issue can be addressed in several ways, including proactive management of adverse effects and using alternative routes of administration, adjuvant analgesics or a different opioid.<sup>16,21</sup> Oral morphine is commonly seen as the first-choice opioid, but the available evidence suggests no important differences between morphine, oxycodone and hydromorphone. Any one of these drugs can therefore be used as the first-choice opioid for moderate-to-severe pain.<sup>22</sup>

### Multimodal approaches

Given the complex molecular mechanisms present in the pain pathway, it is unsurprising that opioids alone often fail to control pain completely.<sup>23</sup> Opioids may be less effective in the treatment of neuropathic pain, or indeed nociceptive pain with an element of inflammation.<sup>24,25</sup> In such circumstances, it may be necessary to adopt a multimodal approach to analgesia and use drugs with multiple mechanisms.

### Adjuvant analgesics

One approach is to use an adjuvant analgesic (see Table 1) alongside the opioid treatment regimen. Whether the adjuvant should be used with the opioid initially, or whether the opioid should be titrated to its maximum tolerated dose before adding in the adjuvant, is unclear, and the available data are contradictory.<sup>26</sup> The choice of a specific adjuvant depends on a number of factors, including type of pain (nociceptive or neuropathic), co-existing morbidity and current medication; selection is as much an art as a science. In some cases, the type of pain may suggest a particular adjuvant, while in others, existing co-morbidities or concurrent medication may determine it.

### Methadone

Another approach is to use methadone, which is recommended as a second-line opioid in cases of refractory or neuropathic pain.<sup>22</sup> Methadone is a unique opioid in that it exhibits additional pharmacodynamic effects, such as inhibition of noradrenaline and serotonin reuptake, thereby enhancing the inhibitory effects of the descending pathway.<sup>27</sup> Given the wide interpatient variability in the pharmacokinetics of methadone, it should be used only under the guidance of a specialist.<sup>28</sup>

**Table 1. Adjuvant analgesics and suggested indications**

Suggested indication	Adjuvant
Neuropathic pain	Amitriptyline Carbamazepine Dexamethasone Duloxetine Gabapentin Pregabalin Ketamine*
Musculoskeletal pain	Dexamethasone Diazepam NSAIDs Bisphosphonate (e.g., pamidronate, zoledronic acid)
Smooth muscle spasm e.g., bowel colic	Glycopyrronium Hyoscine butylbromide Hyoscine hydrobromide

\*To be used only under the guidance of a specialist

### Tapentadol

A recent development in analgesia is the introduction of tapentadol. This represents a novel class of centrally acting analgesic: it is a  $\mu$ -opioid receptor agonist–noradrenaline reuptake inhibitor (MOR–NRI) and thus facilitates monoaminergic transmission in descending pain inhibitory pathways. These pharmacodynamic properties suggest that it could be a suitable agent for the sole management of moderate to severe cancer pain. Several studies have concluded that tapentadol is effective and generally well-tolerated in the management of cancer pain in patients who were previously receiving strong opioids or were opioid naive.<sup>29–36</sup> It has been shown to provide comparable efficacy to morphine and oxycodone in the management of cancer pain, with improved gastrointestinal tolerability.<sup>35,36</sup> It is clear that tapentadol represents an efficacious alternative to strong opioids, and with increasing clinical experience its place in cancer pain management will become evident.

### Concluding remarks

Cancer pain is a complex sensory and emotional experience and is always subjective. Co-morbidities, such as anxiety and depression, can have a direct effect on a patient's pain experience. The treatment of cancer pain will invariably be multimodal, incorporating analgesics with complementary modes of action, as well as non-pharmacological measures that deliver emotional, psychological and spiritual support. Patients should be advised that they may never be completely free of pain and they may have to change their lifestyles to ensure that pain does not become an overwhelming problem.

The currently accepted practices in cancer pain management are set to change dramatically with a shift towards a mechanism-based, multimodal approach to drug selection. The future promises to revolutionise pain management through the development of highly specific drugs and, potentially, genetically determined, individualised therapy. The management of cancer pain will undoubtedly become more complicated, but with the tantalising prospect of optimal analgesia with minimal adverse effects.

#### Declaration of interest

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Refer to the Summary of Product Characteristics (SmPC) before prescribing.

**Presentation:** Palexia SR: 50 mg (white), 100 mg (pale yellow), 150 mg (pale pink), 200 mg (pale orange) and 250 mg (brownish red) prolonged-release tablets contain 50 mg, 100 mg, 150 mg, 200 mg and 250 mg of tapentadol (as hydrochloride) respectively. Palexia Film-coated Tablets: 50 mg (white), 75 mg (pale yellow) and 100 mg (pale pink) film-coated tablets contain 50 mg, 75 mg and 100 mg of tapentadol (as hydrochloride) respectively. Palexia Oral Solution: 20 mg/ml oral solution containing 20 mg tapentadol (as hydrochloride) in 1 ml solution. **Indication:** Palexia SR is indicated for the management of severe chronic pain in adults, which can be adequately managed only with opioid analgesics. 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Each case study masterclass comprises a detailed case history followed by a series of questions designed to test your knowledge and give you food for thought. The suggested answers can be found on page 308 of this issue.

## Case 89. Managing symptoms of neuroendocrine tumours in a 62-year-old man with impaired cognition

■ Brian\* is a 62-year-old man who lives in a small terraced house with his wife. Following a head injury 20 years ago, his memory deteriorated and his speech became impaired, but he manages to continue with the activities of daily living with full independence. Brian does need assistance from his wife in understanding any complex discussions and to help him with decision-making.

Brian originally presents to his GP with a persistent pyrexia following a visit to the Middle East. He is investigated for a tropical disease, but when it becomes apparent that the symptoms of diarrhoea and flushing predate his trip, subsequent investigation shows an elevated urine 5-hydroxyindolacetic acid (5-HIAA), and a CT scan suggests a disseminated carcinoma. A positron emission tomography scan and somatostatin receptor scintigraphy confirm multiple liver lesions but do not reveal the existence of a primary. Brian is diagnosed with a well-differentiated metastatic gastroenteropancreatic neuroendocrine tumour (NET).

Brian is subsequently treated with lanreotide to try and manage symptoms associated with NET hormonal hypersecretion. Later the same year, he is treated with lutetium therapy and chemoembolisation, but this is of little help: although imaging suggests a reduction in the size of his liver metastases, Brian continues to deteriorate symptomatically.

### Carcinoid heart disease

Just prior to Brian's admission to the hospice, an echocardiogram shows that he has severe right heart failure and that, from a cardiology point of view, he needs a tricuspid valve replacement. The prognosis related to

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his primary cancer remains unclear, but his right heart failure is at a very late stage in the disease trajectory.

Brian is admitted to the hospice with low mood, fatigue, severe peripheral oedema, diarrhoea, breathlessness on exertion and a hard, scaly, erythematous, pruritic rash extending over both legs and hands. His abbreviated mental test score (AMTS) is 6/10. He is also struggling with the uncertainty of his prognosis. In the hospice, he becomes frustrated during discussions with healthcare professionals because he often feels that people are talking too quickly for him to be able to keep up. However, Brian has good insight into his cognition and is able to follow conversations and make decisions with the support of his wife.

Following discussions with both the cardiologists and the oncologists, Brian is advised that he could be transferred to hospital to receive acute treatment for his heart failure or he could receive similar treatment at the hospice combined with the best supportive care. Long discussions take place with Brian and his wife, both together and on their own. Emphasis is placed on the fact that there is a risk that if Brian

deteriorates secondary to treatment, the hospice would not necessarily have the backup to address the medical problems. The main challenge is to ensure that Brian makes an informed decision. Discussions over several days with the support of his wife mean that we feel confident that Brian understands the various options and can retain the information, weigh up the risks and benefits and communicate his wishes to us. He chooses to stay in the palliative care setting, where he has high-dose furosemide and daily monitoring of his renal function, weight and fluid balance. His peripheral oedema does improve, as do his exercise tolerance and mobility, although his overall condition continues to deteriorate.

### Pellagra

Brian's skin condition is his main concern. The itching prevents him sleeping and he feels that the hardening of his skin affects his mobility. He has previously been treated with potent topical steroids for dermatitis, but to little avail. Reflecting on his disease and the history of the rash starting as an erythematous, blistering rash and subsequently becoming thickened, rough and darkly pigmented, we feel that this most likely represents pellagra. He is started on a high-dose vitamin B complex three

\* All names have been changed to protect patient confidentiality

times a day, along with cetirizine 20 mg daily and ranitidine 150 mg twice daily for the itch, and regular emollients and a potent topical steroid. There was some objective improvement in the rash and a marked reduction in pruritis, although the skin remains thickened. This improvement is sustained.

### Cognition and mood

Throughout his stay in the hospice Brian's mood, cognitive ability and capacity fluctuate. His AMTS varies, as does his fatigability, which influences his ability to engage in communication. The team find discussions with Brian on his own challenging, and it is clear that Brian finds it difficult to follow conversations, which subsequently puts significant pressure on his wife. Brian's frustration is apparent, as is the effect it has on his already fragile mood. He expresses feelings of worthlessness and often thinks his situation is hopeless. An anti-depressant is considered, but after discussion regarding the risk of potentiating some carcinoid symptoms, Brian decides to continue without any pharmacological management for his depression.

Despite the communication difficulties, the team feels that Brian can make capacitous decisions through appropriately timed supported discussions. Although these cause significant stress for Brian, he is given support by the hospice psychologist, who also offers therapeutic support to Brian's wife. She is put in touch with a carer support group, offered complementary therapy and advised to see her own GP should she feel her own mood deteriorating. The facilitated discussions allow Brian to express his preferences for care and particularly that his preferred place of death is his own home. Further discussions around advanced care planning are attempted with Brian, but he is resistant to these because of the level of fatigue that follows. Nonetheless, both the team and his family feel that should Brian lose the



capacity to make decisions, they have a good understanding of his wishes and are now better placed to make decisions in Brian's best interest should the need arise.

### The outcome

Overall, Brian feels better than on admission to the hospice. His skin feels better, he is less breathless and his bowel movements have improved. However, he is generally very frail and mobile over only short distances. His liver function has deteriorated and his albumin has dropped, despite a good diet and the improvement of his symptoms. Brian reflects on the

uncertainty of his prognosis and treatments. Rather than being able to provide answers to reduce his uncertainty, the medical team acknowledge it and explain that they share it. The limitations of medical treatment are discussed and Brian comes to the conclusion that there may be a point where he is 'as well as he is going to be'.

Brian's discharge home is carefully planned with support from district nurses, hospice at home and private carers, along with close specialist palliative care follow-up. The events of his admission and the expectations for the future are shared with Brian's GP via a telephone discussion and discharge letter. The hospice psychologist continues to support both Brian and his wife after discharge.

Brian manages at home for longer than we expect. He continues to enjoy time with his family, although he does not manage to make it out to his beloved narrowboat again. He dies comfortably at his preferred place of death five months after leaving the hospice. His wife will continue to be supported by the team ■

**Declaration of interest**  
The author declares that there is no conflict of interest.

## Questions

- 1 How do NETs present?
- 2 What is the cause of pellagra, and what are the treatment options?
- 3 What is the pathophysiology of carcinoid heart disease?
- 4 What is the Mental Capacity Act, and what help can be provided to aid decision-making?

# Paediatric palliative nursing: the tension between closeness and professional distance

Caring for children who are dying puts special demands on the medical staff who care for them, and no one knows this better than palliative care nurses. **Regula Buder** and **André Fringer** look at the difficulties of the job and consider how nurses deal with them

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The closeness between nurses and children is a major characteristic of paediatric palliative care, and nurses dedicate themselves to its pursuit so that they can bring to life the very essence of their profession. Closeness encompasses the four dimensions of palliative care: physical, mental, social and spiritual. At the same time, nurses are aware, through their education and practice, of the need for professional distance in certain situations. So how do nurses in paediatric palliative care cope with the tension between these two aspects of their work, both of which are fundamental to it?

To investigate possible answers to this question, we surveyed the available literature using an integrative review design,<sup>1</sup> which incorporates different types of published material, including both qualitative and quantitative articles and grey literature such as research reports and discussion papers,

without the need for a formal quality assessment.<sup>2</sup> The literature was systematically searched with predefined inclusion and exclusion criteria in the databases PubMed and PsycINDEX. A total of 110 suitable articles were identified for an initial investigation, which produced 12 publications that were deemed suitable for a more detailed, in-depth analysis. The relevant themes that were distilled from the literature are summarised below.

## Understanding nursing's central role

Paediatric palliative care involves expertise from several professional disciplines, and particular significance is attached to nursing. Nurses become immediately and intimately involved with those whom they care for through physical touch, spatial closeness and the time spent with affected children – their role is central. In trying to understand the nurse's role, certain key questions arise. What kind of response is evoked in nurses by the dying and death of children? And how do nurses cope while carrying out this work, which is never routine? These questions are not addressed in established definitions of paediatric palliative care, making it all the more important to understand how nurses perceive their own role in this discipline.<sup>3</sup>

Paediatric palliative care has become a part of vocational training and further education, but caring for dying children requires extensive, in-depth practical experience on the part of nurses. Lack of preparation and direct experience can lead to uncertainty about the correct approach to the end of life, and these factors may have an increasingly burdensome effect on nurses' professional

## Key points

- Nurses who gain enough experience to understand their own vulnerabilities and resources, and who address the tension between them from a professional perspective, can increase the range of their abilities and set clear boundaries between themselves and the child.
- Inexperienced nurses may find it difficult to maintain a professional relationship and draw boundaries.
- It is essential for nurses to be able to acknowledge and communicate the end-of-life scenario. Relationships with dying children and their families are a key factor in nursing quality.
- Nurses need a way to express their emotional distress and thus overcome their potential isolation; they can do this by recounting their traumatic experiences to others, which reassures them that the child is not forgotten.

practice.<sup>4</sup> Experienced nurses can recognise and articulate the requirements of their professional role with clarity. With increasing proficiency, they can learn to distance themselves from burdensome emotions and situations and set a clear boundary between themselves and the child. Less experienced nurses, however, may find it difficult to maintain a professional relationship and draw boundaries.<sup>5</sup>

### Recognising vulnerability

Professional nursing requires consistent patient-centricity and ethical responsibility, as Patricia Benner explains.<sup>6</sup> She states that patients' inner experiences are always the start of a journey for the nurse. Thus nursing involves much more than simply technical and standardised activities based on medical or scientific knowledge. Benner emphasises that nurses are constantly improving their understanding of people's physical and mental vulnerabilities, which they protect by acting ethically and addressing patients' individual needs.<sup>6</sup> This requires nurses in turn to actively confront their own vulnerabilities and resilience. Paediatric palliative care nurses who successfully recognise the tension between their vulnerabilities and resources, and who address this tension from a professional perspective, can increase the range of their abilities, making themselves more open to vital encounters with dying children.

### Acknowledging the end of life

Why is it still not standard to offer paediatric palliative care at the appropriate time to children who would benefit from it? A research group led by Sharon Docherty investigated this issue, and it became clear that healthcare professionals were often unwilling to give up the hope that their patients might recover, and that advances in treating life-limiting diseases will continue in general to extend life and, sometimes, offer the possibility of curative therapy. Such advances do bring risks of increased suffering if sustaining life remains the primary focus and the understanding of palliative care is restricted to care very close to the end of life.<sup>7</sup>

Another obstacle to implementing paediatric palliative care at the most

### Experienced nurses can recognise and articulate the requirements of their professional role with clarity

to deal with the reality of the situation, and it acts like a bridge for a nurse's communication with the family.

### Establishing relationships

The term 'palliative care' implies a relationship between the person receiving care and the person giving it. Nurses must consciously shape this relationship, and their honesty and authenticity are prerequisites for



appropriate time is uncertainty in the prognosis and course of disease in children. Starting palliative care earlier while continuing curative therapy when there is uncertainty about the prognosis can increase helpful communication and improve the quality of life of affected children.<sup>8</sup>

For these reasons it is essential for nurses to be able to acknowledge and unambiguously communicate to the professional caregivers and the family that the child could or will die. If they do not, occupational stresses are not defined and emotional labour cannot be adequately explained. This is the prerequisite for implementing paediatric palliative care as a holistic encounter and providing needs-based care. However, professionals should be aware that the concept of hope remains part of palliative care until the end, particularly in children. The hope is not necessarily that the child might recover; it could be the parents' hope that the end of life will make some sense

of the situation, or the child's hope that the birthday money they are saving will one day pay for the trip around the world they have been dreaming of. Such hope can make it easier

a trusting relationship. In an atmosphere of trust, the patient feels more able to feel secure and confident in asking the questions and addressing the issues that are important to them.<sup>9</sup> Since the late 1990s, the Greek psychologist Danai Papadatou has advocated rethinking the way we build relationships. She assumes that in paediatric palliative care, a clear distinction between the professional person and the dying child and their family is impossible, and she therefore recommends a relationship-based approach.<sup>10</sup> An encounter with a dying child is a formative experience for nurses; it helps them to mature and develop an in-depth understanding of humanity and suffering.<sup>11</sup> Thus, relationships with dying children and their families are a key factor in nursing quality.

### **Balancing closeness and distance: the nurse as human being**

Conducting care in a deliberate fashion allows nurses to be more aware of their emotions, which helps to reduce the impact in their private lives of the emotional issues produced by their professional role.<sup>12</sup> However, setting professional boundaries

is not easy, particularly in the context of paediatric palliative care. Indeed, some nurses associate the term 'professional distance' with a lack of caring – although they will have learned the theoretical importance of setting

professional boundaries during their education, in their daily practice they find that the theory often cannot be applied.

Caring for dying children and supporting their families involves an extremely intimate encounter with pain, grief and loss that evokes deep empathy in the nurse. Nurses continue to be concerned about the balance between closeness and distance even after a child has died; once the patient's nursing care is complete, it is important to shape the ongoing relationship with the family. Following a child's sudden death or a long period of caring, nurses will benefit from debriefing and professional support to help them deal with the process of mourning; palliative care nurses show a high demand for such support.<sup>13</sup> Despite the fact that palliative care has been established as a specialist discipline in some

countries, nurses in paediatric palliative care may find themselves deeply isolated.<sup>14</sup>

Nurses need a way to express their emotional distress and thus overcome their isolation, but they also want to avoid confronting others with their experiences, as talking about children dying is considered a difficult subject.<sup>15</sup> By talking with people who are similarly affected and narrating their own experiences to them, nurses can impart meaning to the death of a child, which can be an important part of coping with grief.<sup>16</sup>

Judy Rashotte encourages paediatric palliative care nurses to dwell on the stories that haunt them, encouraging them to narrate and re-narrate these experiences to each other. This allows the nurses not only to feel emotional relief but also to make their personal experience accessible to others, which helps by reassuring them that the child is not forgotten.<sup>17</sup>

The Latin root of the word 'palliative' is *palliare*, which means to cloak or shield. It is important to remember that from time to time, even nurses require a protective shell. However, this shell must be permeable, so that we remain open to dying and death – and thereby open to life.

#### **Declaration of interest**

The authors declare that there is no conflict of interest

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## Book review

# A Practical Guide to End of Life Care

Sadler C (ed); London: Open University Press, 2015; 216 pages; PB (RRP: £20.99; ISBN: 9780335263561), eBook (RRP: £20.99; ISBN: 9780335263578)

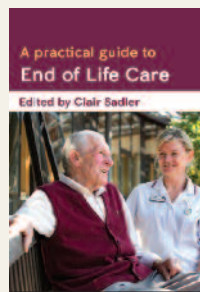
This sensible yet sensitive guide to all things end of life is thoughtfully written with a holistic approach. The reader finds instant empathy with the case studies of Maria, Albert and Jenny as the book takes us on their personal end-of-life journeys, with clear explanations of symptoms and issues along the way.

The narrative addresses the feelings and fears of all those involved, offering guidance on how to deal with the physical issues of dying and death, and providing answers to all the common questions encountered in palliative care settings. Panels in each chapter encourage the reader to reflect and research. The denial, fear and inexperience often seen at the end of life can be gently alleviated with some basic knowledge and wise counsel, and this book provides both.

How often I have wished for a simple guide like this to support communication with a grieving family who can barely hear and absorb words through their sorrow. I would love them to have access to this book, not instead of the human touch, but so that they could turn to it in quieter moments.

So much of the content resonated with me. I recognised the difficulties experienced by many families during my years on the ward, along with their questions and fears and the differing attitudes and cultural beliefs that influence how we approach the end of life. I particularly smiled at the scenario chosen to illustrate the conflict of opinion regarding the involvement of children: a deceased relative with the family spread around the room, while children play on the floor. The book describes two caregivers; the first believes this scene to be beautiful and fitting, the second feels it is wholly inappropriate to have children in the same room as a deceased relative. Of course, there is no right or wrong answer, each view is supported and the reader is inspired to explore their own thoughts and feelings.

I would have appreciated the opportunity to study such an honest and comprehensive guide when I began working in palliative care. I believe that in addition to helping families understand the situation in which they find themselves, this guide could be an effective resource in the training of future caregivers ■



**I would have appreciated the opportunity to study such an honest and comprehensive guide when I began working in palliative care**

■ *Carmel Grealish,  
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# The convenient death of King George V: a look back at history

When the role of King George V's doctor in assisting his death in 1936 came to light 50 years later, general opprobrium was heaped upon the doctor. **Sandy Macleod** and **Jane Vella-Brincat** use the case to highlight the potential role of chronological convenience in end-of-life decision-making

On the evening of 20th January 1936, King George V of Great Britain and Ireland, Emperor of India, was perhaps assisted in his dying by his physician, Lord Dawson of Penn. This remained a well-kept secret until the doctor's private diary was opened 50 years after the king's death. Dr Dawson was to describe his management of the king's final illness as 'a facet of euthanasia or so called mercy killing'.<sup>1</sup> The predominant incentive for the actions of the attending doctor appear to have included chronological convenience. This is a neglected influence in the literature about physician-hastened death.

## The patient

George V ascended the throne in 1910. He was devoted to his country and empire and was a hard-working monarch. He was a heavy smoker, and in 1928 he suffered pleurisy complicated by a lung abscess. His physician, Dr Dawson, located and drained this abscess, undoubtedly saving the king's life and making Dawson a national celebrity.<sup>1</sup> A long, 13-week recuperation followed. A London Hospital nurse, Sister Catherine Black, was chosen to attend him full-time, and she did so until his death. She reported his recurrent daytime sleepiness and nocturnal restlessness, noting that he preferred a prone position. Sometimes she would administer oxygen to him in the early hours of the morning.

Despite his failing health, further years of adoration and personal popularity touched and amazed the king,<sup>2</sup> and his dedication to royal duties did not diminish until late 1935. In November of that year the 71-year-old king was noted by Dawson to have an 'obvious diminishment of energy and interest'. In early January 1936, Sister Black informed Dawson that the king was experiencing phases of sleepiness and breathlessness; indeed she described the king as feeling 'cheap'.<sup>3</sup>

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The king was reported in late January to be tired and often unable to concentrate, but having some 'lucid moments'.

Dr Dawson was more than the king's physician. He was a Privy Councillor, with long experience in this role.<sup>3</sup> There should be no interval in which the throne is not occupied, but there was no indication that the king himself had participated in any form of advance directive regarding his imminent demise. The formation of a Council of State was required in order to recognise his successor, but obtaining the king's written assent was practically difficult because of his poor health. At a hastily convened Council meeting the king was able to verbally approve the proceedings. He apologised for his inability to concentrate. With apparently great adroitness, Dawson put the pen in his hand and guided it, saying, 'Make a mark, Sir, and you may sign afterwards.' Two marks, XX, were made.<sup>3</sup> After the meeting the king went to bed and remained asleep during an examination by Dawson, who prognosticated that he would be unlikely to live through the night. The king was 'sinking'; Dawson took up a menu-card and, writing on his knee, composed the

## Key points

- King George V's death was in all probability hastened by his physician, Dr Dawson.
- In the lead-up to his death, the king was delirious, a situation that precipitated unique constitutional issues.
- His attending nurse, Sister Catherine Black, refused to administer the fatal injection planned by Dr Dawson.
- Palliative sedation was apparently not Dr Dawson's intent.
- Chronological convenience and/or inconvenience may impact on end-of-life decision-making in those jurisdictions in which medically assisted dying is permissible.

famous press and radio release: 'The King's life is moving peacefully towards its close.'

That evening the king was reported as being 'cyanotic, recumbent flat in bed, slowly progressive myocardial failure, no obvious lung congestion but cerebral thrombosis and almost venous stasis'.<sup>3</sup> The family, including the heir, told Dawson that they had no wish for the king's life to be prolonged if the illness was judged to be mortal. Dawson was in complete agreement and promised to direct the treatment accordingly.<sup>2</sup> Morphine was administered by injection mid-evening by his nurse as there was 'a little evidence of struggle', after which he roused and was reputed to utter to his nurse, 'God damn you,' or maybe 'Bugger Bognor!' The king then lapsed into a stupor and coma.

Dawson wrote, 'At about 11 pm it was evident that the last stage might endure for many hours. Hours of waiting just for the mechanical end when all that is really life has departed only exhausts onlookers and keeps them so strained that they cannot avail themselves of the solace of thought, communion or prayer. I therefore decided to determine the end.'<sup>2</sup> Dr Dawson injected 50 mg of morphine and 65 mg of cocaine into the comatose king's distended jugular vein. Sister Black was disturbed by these medical events, Dawson noted, and had refused to give the injection herself.<sup>1</sup> Within 15 minutes the king's breathing quietened, he became placid and the physical struggle ceased. Cheyne-Stokes breathing commenced, and at 11.55 pm he died. As revealed by Dawson's diary, one of his reasons for his medical actions that evening was 'to ensure the announcement should appear in the morning edition of *The Times* and not some lesser publication later in the day'.<sup>1</sup> Dawson was able to return promptly to his busy private practice in London the following morning.<sup>1</sup>

## The doctor

Bertrand Edward, Viscount Dawson of Penn, (1864–1945), was the physician and trusted friend to four kings.<sup>4</sup> A physician at the London Hospital, he was the most admired and respected doctor of his generation. He was an influential medical politician and an early architect of the NHS. He had the reputation of 'a very good, caring doctor', who possessed 'superb humanity' and 'kindly wisdom'.<sup>4</sup> Dawson was subsequently to support the defeat of the 1936 Voluntary Euthanasia



■ A portrait of King George V and Queen Mary, c.1914.

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(Legalisation) Bill, arguing that it was a matter best left to the conscience of the individual doctor rather than official regulators.<sup>5</sup> Dawson's actions, when revealed, did not receive praise. Sir Douglas Black, a past president of the Royal College of Physicians, said Lord Dawson appeared to have committed an 'evil' act for the sake of a 'marginal good'.<sup>6</sup>

## Discussion

The description of the sick king over his last days emphasises the acute distress that his condition was causing both to himself and those around him.<sup>3</sup> In his terminal phase the king was dysgraphic (experiencing difficulty in writing), indeed agraphic (unable to write), and experiencing a delirium. A not uncommon sign of delirium, dysgraphia would have significantly compromised the king's regal duties.<sup>7</sup> An incompetent king raised major constitutional difficulties. Reducing the cognitive and environmental load on the king's brain was clearly instituted, but pharmacological interventions for delirium were then not available. The medical irreversibility of the king's health was

undeniable. Dyspnoea is uncomfortable and distressing and is a potential indication for palliative sedation in modern practice. Intractable delirium may be a firmer indication for such sedation.

Thus a reasonable question is whether or not Dawson practised palliative sedation. We can say that the choice of 'sedating agents' would seem to have been pharmacologically unusual. Dawson's morphine dose selection was likely to have been significant in a frail patient with respiratory failure (though there is no record of the dose provided for relief of the dyspnoea earlier in the evening). This would suggest that his intent was not merely to sedate. The use in combination with cocaine was intriguing. Similar pharmaceutical agents, such as

methylphenidate, may be used to address fatigue and depression in the dying, but they tend not to be effective in the imminently terminal phase.<sup>7</sup> Perhaps Dawson was attempting to induce a fatal arrhythmia?

There is the possibility that the king died a natural, and not a hastened, death. Undoubtedly his death was imminent and misattribution of the cause of death in such situations – attributing the cause to the last medication administered – is not uncommon. Dawson obviously had discussed his proposed course of action with family. The principle of double effect – acting with the intention of bringing about a good effect (for example, relieving pain) with the unintended consequence of a bad effect (death) – is not suggested by the available evidence.

The timing of the death was a critical consideration for Dawson. The patient was unique and the circumstances extraordinary. Lord Dawson seemingly acted to protect the constitution of the kingdom and to relieve the appalling distress of his terminally ill patient. His medical intention appears to have been euthanasia. His timing was clearly convenient to himself, the press and presumably the nation. Chronological convenience may be a relevant influence in the consideration of euthanasia, but it has rarely been considered or acknowledged in the literature about medically hastening dying. It has been estimated that doctor-assisted dying in European countries shortens life by less than a month in most cases.<sup>8</sup> In addition, it has been shown that palliative sedation does not hasten death – it actually prolongs dying by perhaps a few days.<sup>9</sup> These findings would suggest that chronological convenience and/or inconvenience might impact upon end-of-life decisions in those modern jurisdictions in which medically assisted dying is allowed.

#### Declaration of interest

The authors declare that there is no conflict of interest.

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# The Sydney Institute of Palliative Medicine: evolution and contribution

**Ghauri Aggarwal, Jan Maree Davis, Frank Brennan and Kristen Turner** look at how the Sydney Institute of Palliative Medicine came into being and played a pioneering role in the transformation of palliative care provision in Australia and elsewhere in the world

The Sydney Institute of Palliative Medicine (SIPM) originated at the Royal Prince Alfred Hospital (RPAH), Sydney, in the mid-1980s, since when it has played a significant role in shaping the development of palliative medicine as a clinical science and as a speciality in New South Wales (NSW), Australia and internationally. Before the Royal Australasian College of Physicians became involved in training doctors in palliative care and the Australasian Chapter of Palliative Medicine came into being, the institute provided a focus for palliative medicine training for doctors. In time it produced leaders in this field who were instrumental in the development of many palliative care services, not only in NSW but also nationally and internationally. SIPM continues to facilitate the ongoing development of palliative medicine with continued involvement in a number of activities, including registrar training, annual symposia and the international and humanities programmes. It now is a virtual institute that is not based at any one facility but continues to be governed by an executive committee.

## Context and background

The care of patients with progressive life-limiting illness has always been a central activity in medical practice. In the 19th century, institutions were created with the care of such patients as their principal role – examples were to be found in Dublin and London.<sup>1</sup> In the 1960s, a hospice movement evolved in the UK, principally through the work of Cicely Saunders. Her work inspired clinicians around the world including Balfour Mount in Canada, Michael Kearney in Ireland

and, in Australia, Brian Dwyer, Brian Pollard, Jocelyn Kramer, Ian Maddocks, Norelle Lickiss and others.

The foundations for a hospital-based palliative care service in Sydney were laid down as a direct result of a visit from Balfour Mount to the RPAH in 1982, where he challenged senior clinicians regarding the care of dying patients. By 1985, a decision was made to expand and restructure the hospital's provision of palliative care and to appoint a full-time consultant physician to improve the care of patients within the hospital.<sup>2</sup> By the end of that year, the Palliative Care Service (PCS) at RPAH was one of three existing in teaching hospitals in Sydney, but the first that would be led by a consultant physician with full admitting rights and responsibilities, which also included the community setting.

The inspiration-led beginnings of palliative medicine elsewhere in the world were

matched by a growing recognition locally in Sydney of: the needs of

## Key points

- Palliative medicine began to evolve internationally in the late 1980s.
- The Sydney Institute of Palliative Medicine (SIPM) was established in 1989 to oversee palliative medicine training for doctors. It played a large role in shaping the development of palliative medicine as a clinical science and a speciality in NSW, Australia, and internationally.
- During the 1990s, SIPM became the largest unified group of registrar training positions – both in Australia and internationally.
- SIPM continues to facilitate the development of palliative medicine and to oversee registrar training across NSW, Australia, and attracts doctors from many countries, who, once trained, return home to establish or develop their own palliative care service.

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patients and their families; the significant dearth of understanding of the mechanisms and management of the symptomatology and psychosocial needs of patients and their families; the very small numbers of doctors involved; and the need for greater training in this evolving area of medicine.

### Origins of SIPM

SIPM's founding director, Norelle Lickiss, identified that a crucial component for the growth of palliative care services and, indeed, of palliative medicine generally, was the nurturing and training of competent and skilled doctors.<sup>3</sup> Kristen Turner shared this vision and became the first registrar of RPAH's PCS in 1986. At this time palliative medicine was not a speciality; there was no local training programme and local doctors interested in training needed to travel overseas.

Other training positions were soon established in the RPAH consultative service, the palliative care inpatient unit at Eversleigh Hospital and the community home visits service.<sup>4,5</sup> As there was still no accepted

### Cicely Saunders' ... work inspired clinicians around the world

pathway to a speciality, the Institute of Palliative Medicine was created to integrate, co-ordinate and accredit the training in these various services. It was formalised and enhanced

in 1989 and later renamed SIPM. By 1990, John Dwyer, the clinical and academic head of Prince of Wales Hospital – another teaching hospital in Sydney, affiliated with the University of New South Wales – expressed that institution's desire to enhance its existing palliative care service. A particular focus developed in the associated gynaecological cancer unit at the Royal Hospital for Women headed by Neville Hacker, as had occurred at the RPAH. Over the next decade, with expansion in all the major teaching hospitals in Sydney, SIPM became the largest unified group of registrar training positions – both in Australia and internationally – encompassing three settings: teaching hospital, palliative care inpatient unit and community services.

### Early vision

Norelle Lickiss' vision included inculcating in trainees the highest standards of internal medicine. She also emphasised the importance of understanding the depth of the

psychosocial and spiritual dimensions of serious illness, utilising perspectives drawn from the humanities, sharing her knowledge and insights in the time-honoured way of medical apprenticeship. It was clear that a comprehensive registrar training programme was required in order to ensure that certain standards implied in the College of Physicians training programmes, would be rigorously applied to palliative medicine, so that this speciality could compete with others on a level playing field and be seen as a 'proper' medical speciality in its own right. Palliative medicine was evolving worldwide – it was recognised as a medical speciality in the UK in 1987 and in Australia in 1988, with the first Chair of Palliative Care established in Flinders University, South Australia.<sup>6</sup>

For SIPM, two important philosophical underpinnings of palliative medicine clinical training were the concept of the patient as teacher and the use of the palliative medicine consultation as an educational tool in itself:<sup>7</sup> each consultation gave a rich opportunity to teach and demonstrate the learning goals in palliative care, with the patient providing the unique context of their individual problems, needs and insights.

### Comprehensive clinical training

Trainees were drawn from a variety of backgrounds and training programmes, including general practice, internal medicine and radiation oncology, for either career training in palliative medicine or skills enhancement relevant to other career paths.<sup>8</sup> Career trainees from backgrounds other than the Royal Australasian College of Physicians (RACP) training programme were required to formally complete an SIPM Certificate. This involved a core period of 18 months, and preferably two years, spent in a palliative care service associated with a teaching hospital, at least six months in a specialised inpatient palliative care unit plus experience in consultative palliative medicine in both a general hospital and a community setting. A strong apprenticeship ethos was employed.<sup>9</sup> Formal teaching sessions, weekly clinical meetings and a weekly 'journal club' supplemented the clinical work. Kristen Turner (the first SIPM registrar) was the Co-ordinator of Registrar Training from 1994 to 2003 and crucially involved in the preparation of educational

■ The Royal Prince Albert Hospital, Sydney, home of the Sydney Institute of Palliative Medicine.  
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material and mentoring of registrars. The SIPM Certificate programme was closely supervised with evaluations by an internal and external examiner. Throughout that period the latter role was filled by Geoffrey Hanks from the UK, who visited Australia every two years in the 1990s. Hanks's advice and encouragement to SIPM was pivotal and greatly appreciated. The UK recognised the quality of SIPM training and accredited one year of higher training, leading to senior registrars from the UK joining the programme in 1994–1996.

The certificate programme paralleled the pathway of training in palliative medicine established by the RACP and foreshadowed the eventual establishment of the Chapter of Palliative Medicine within the college in 1999.<sup>10</sup>

## Education

In addition to bedside teaching and clinical exposure, a strong focus of SIPM was formal teaching. From its inception there was a keen recognition by both Norelle Lickiss and Kristen Turner of the significant advances that were occurring in all aspects of palliative medicine and the importance of

incorporating that knowledge into the training of registrars.

In the institute's early days there was no formal registrar education programme. Much of the education occurred in the setting of the PCS journal club held every Tuesday afternoon. This was attended by all registrars, consultants and senior staff, including clinical

nurse consultants and the bereavement service counsellor. Following journal club, registrars convened in the local hotel to share experiences and to provide support to each other. This

informal networking was an invaluable part of the training. In addition, a core of gifted nurses, including Ralph Waldsax, Joan Hartley, Cheryl Dunn and Joan Ryan, nurtured this enterprise from its embryonic beginnings and encouraged all those involved.

As the number of trainees and training sites grew, the need to formalise and standardise aspects of the educational programme was recognised.

In the 1990s, the RACP formally established a palliative medicine curriculum. A decade later the Chapter of Palliative Medicine was established; it now oversees trainee education and supervises registrars in their requirements

**The patient provided the unique context of their individual problems, needs and insights**

of Project and Case Study. The Chapter has also established a Diploma in Palliative Medicine.

This has meant evolution of SIPM's role in provision of and contribution to registrar training, with an Educational Subcommittee established in 2007. This subcommittee has established bimonthly seminars that are held and attended by all the SIPM registrars – Advanced Trainees, Diploma trainees and others – in Sydney and the entire NSW state cohort. Topics are selected in order to address knowledge 'gaps' identified by the Education Committee and/or according to topics deemed to be of general interest and relevance. Seminars cover topics such as Clinical Ethics, Pain, Pathophysiology and Pharmacology, and Grief and Bereavement, as well as topics addressing the humanities. This programme is complementary to the RACP programme, which has developed online learning modules in recent years.

### Annual symposium

From its early days, SIPM has hosted an annual symposium. The SIPM Symposium was established to educate, disseminate ideas and to maintain dialogue between clinicians. Over the years, presentations by local and international speakers – including Geoffrey Hanks and Ilora Finlay from the UK, Nicolas Christakis and Jack Coulehan from the USA, Michael Kearney from Ireland and Neil MacDonald from Canada – have inspired doctors in their practice. Today, the SIPM Symposium continues to attract prominent speakers to a two- to three-day programme, including a research afternoon at which final-year Advanced Trainees are encouraged to present projects. A unique feature of these symposia has been the creation of a doctors-only session entitled 'Cautionary Tales', at which clinicians could discuss difficult, humbling and challenging cases in a safe environment.

### NSW Palliative Care Registrar Network

In the late 1990s attempts were made to develop a board that would oversee SIPM's activities and outline the institute's vision and goals; the resultant body has now evolved into the current SIPM Executive, which is overseen by an administrative officer.

For an extended period, SIPM was the largest stakeholder in registrar training in palliative medicine in NSW. Recruitment was initially on an ad hoc basis, and interviews focused on the interest of the candidate in palliative care and their communication skills.

Over time, the number of registrar training sites increased and there needed to be a standardised recruitment and selection process. Initial discussion about how to streamline the recruitment process took place within the SIPM Executive, Medical Oncology and Radiation Oncology specialities and the Department of Health. In 2013, SIPM took leadership in forming an NSW Palliative Care Registrar Network. A rotating convenor drawn from directors of palliative care from the different local health districts formed part of the governance. This process was seen as fair and maintained an even distribution of trainees across the state. By 2016 there were 41 registrar positions.

### International activities

From the outset, Norelle Lickiss was determined to seek out the best new ideas and thinking from around the world relevant to palliative medicine and incorporate them into SIPM's activities. There was recognition of opportunities to assist colleagues in less affluent environments, notably with issues in cancer pain relief and the care of incurable and dying patients. The first few SIPM trainees spent a year or more on fellowships with some of the key international leaders in these areas.

The international dimensions of SIPM have grown organically. Norelle Lickiss did considerable international teaching in the early to mid-1990s. SIPM colleagues continue to participate in teaching in the Asia-Pacific area in collaboration with local leaders and experts. This philosophy of international teaching is valued by all involved.

From initiation, the training programme attracted international registrars and fellows, who then returned to their home nations to establish or develop services in Asia, Oceania, the Middle East and Europe.

The international programme continues to be vibrant and is expanding. Partnerships have been formed with other organisations such as Hospis Malaysia, Asia Pacific Hospice

### International registrars ... returned to their home nations to establish or develop services there

Network and the Lien Collaborative in Singapore. Future plans are underway to partner with these organisations in an attempt to develop a distance-learning programme for a diploma or masters of palliative medicine.

### Humanities programme

Humanities were always recognised within SIPM as a vital component in broadening the way in which patients are understood, and in bridging the experiential gap between a biomedical education and the need for doctors to be deeply cognisant of a shared human condition with their patients. This aspect of patient-centred care is now much better-recognised, and the humanities are seen as 'integral in the training of all those looking after human beings in the final part of their life journey.'<sup>11</sup>

The SIPM humanities programme was multifaceted, incorporating literature, art, drama and music into various educational events, including poetry reading evenings co-organised by SIPM and the University of Sydney.<sup>12</sup> Humanities sessions continue to be incorporated into the format of the annual symposium, giving the audience a diversity of learning and experiential opportunities.

### Research

The necessary focus in the early years was in training adequate numbers of skilled clinicians to provide expert hands-on care, but in-house audits and several unpublished studies were subsequently undertaken. Case reports illustrating novel approaches to symptom relief were published.<sup>13–15</sup> Further research considerations more gradually evolved, particularly after the return to RPAH of Paul Glare as Head of Palliative Care. In the mid-1990s a Sydney clinical trials group included members of SIPM who participated in pain and opioid trials. Researchers within SIPM provided important early groundwork around dignity,<sup>16</sup> opioid purchasing patterns in Australian settings,<sup>17</sup> suffering and prognostication.<sup>18</sup> SIPM-trained clinicians have also completed PhD programmes in matters relevant to palliative care and exercise academic and research leadership.

### Conclusion

SIPM continues to be as relevant today as at its inception in the 1980s. It pioneered the largest Australian training programme for palliative

medicine registrars before the creation of the Australasian Chapter of Palliative Medicine, RACP, and continues to provide leadership in the current networked recruitment process.

As influenced by its founder Norelle Lickiss, the institute continues to emphasise the patient as teacher, the practice of secular palliative care and the strength to be gained from solid internal medicine skills combined with an ability to reflect on and understand the essence of suffering. These values continue to underpin the institute's many activities.

The solid foundation provided by SIPM for many doctors has enabled us to go forth and develop services and educational programmes and to become leaders in palliative care. 'Patient as person' continues to be the focus of our care and enables the patient to become our educational resource.

#### Declaration of interest

The authors declare that there is no conflict of interest.

#### Acknowledgments

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# Does current UK research address priorities in palliative and end-of-life care?

The Palliative and end of life care Priority Setting Partnership uncovered 83 unanswered research questions.

**Florence Todd Fordham, Bridget Candy, Stevie McMillan and Sabine Best** show that, as current UK research starts to address some of these questions, UK open grant data have the potential to encourage collaboration

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The Palliative and end of life care Priority Setting Partnership (PeolcPSP) and the James Lind Alliance (JLA) sought to identify the research priorities that are most important to patients, carers, and health and social care professionals involved at the end of life.<sup>1,2</sup> The PeolcPSP identified 83 questions that were not shown to be answered by an up-to-date systematic review (through Cochrane or identified via the Database of Abstracts of Reviews of Effects<sup>3</sup>). Carers, patients and clinicians highlighted a top ten list from the 83 questions at a prioritisation workshop.

## Palliative and end-of-life care research is underfunded

This project used the UK Clinical Research Collaboration's Health Research Classification System (HRCS) dataset, composed of £2 billion of funding in 2014 from 64 governmental and charitable funders across the UK.<sup>4</sup> This dataset shows that end-of-life research represents only 0.16% of the total health-related research active in 2014. The 2014 dataset is the third to be conducted but the first to be made publicly available. Using these publicly available data, we set out to discover whether there is currently ongoing research that already addresses any of the questions put forward by the PeolcPSP.

The aims of this project were to:

- help researchers avoid duplication by highlighting current research
- foster collaboration by showing who is already active in addressing specific research questions
- encourage researchers to tackle questions that are not currently examined at all.

Interventions are treatments, care and other actions that are designed to make a difference to patients, carers and families and that can be tested and evaluated by research.

**Box 1.**  
What is an intervention?

## Methodology

Keywords for each of the 83 PeolcPSP questions were identified, and the HRCS 2014 dataset of 14,394 grant abstracts was searched for links. The resulting abstracts were screened for relevance to the individual PeolcPSP questions and divided into:

- interventional grants: projects that proposed an intervention (see Box 1) to address the question
- direct grants: projects that had a direct link to the question but did not propose an intervention.

For the purposes of this research, these are referred to together as 'strong funding'. Detailed results for all 83 questions are due to be published in a forthcoming report.<sup>5</sup> Table 1 shows the number of strong grants and the total funding allocated in 2014 for the top ten PeolcPSP priorities.

## All top ten research questions are already attracting some research interest

Our analysis shows that the top ten research priorities for palliative and end-of-life care, as highlighted by patients, carers and clinicians, are all already attracting some research interest and funding, even though at very different levels (see Table 1). The table

**Table 1. Results of the grant mapping exercise in relation to the top ten PeolcPSP priorities in 2014, ranked by funding amount<sup>5</sup>**

Top ten priority questions	Strong UK funding amount (of which proposed interventions)	Number of strong UK grants addressing the question (of which proposed interventions)	Systematic review but question remains unanswered*	Top ten rank position
What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease [COPD], heart failure, motor neurone disease [MND], AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia and stroke)?	£4,307,040 (£758,347)	31 (6)	NO	6
How can access to palliative care services be improved for everyone, regardless of where they are in the UK?	£1,915,340 (£528,256)	16 (4)	NO	2
What are the benefits, and best ways, of providing care in the patient's home, and how can home care be maintained as long as possible? Does good coordination of services affect this?	£1,565,916 (£45,820)	11 (1)	YES <sup>6</sup>	8
How can it be ensured that staff, including health care assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?	£1,414,488 (£321,796)	11 (1)	NO	5
What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?	£1,225,808 (£234,801)	13 (3)	YES <sup>7</sup>	3
What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?	£1,003,763 (£399,855)	4 (2)	NO	10
What are the core palliative care services that should be provided, no matter what the patient's diagnosis is?	£628,219 (£0)	5 (0)	NO	7
What are the best ways to make sure that there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?	£528,015 (£0)	5 (0)	NO	9
What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?	£516,924 (£0)	4 (0)	NO	1
What information and training do carers and families need in order to provide the best care for their loved one who is dying?	£343,410 (£265,383)	9 (5)	YES <sup>8</sup>	4

\* As of January 2015

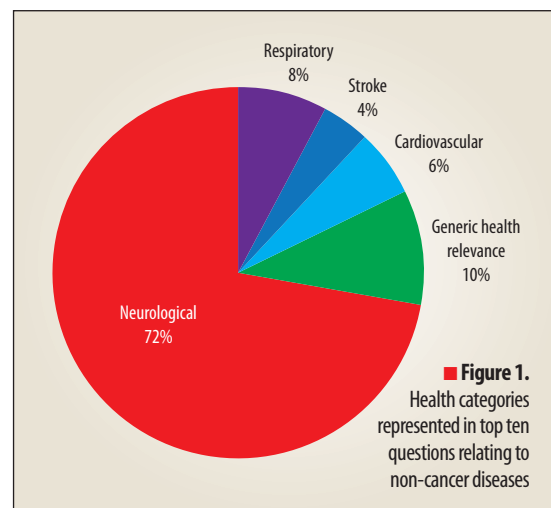
shows that three of the top ten questions received no funding to support interventions in 2014. This contrasts with the question that received the most funding, tackling palliative care in a wide number of non-cancer diseases, which received funding totalling £4.3 million in 2014, 18% of which proposed to test an intervention. This will hopefully help to bring much-needed change to practice in this area in the future.

### Research questions that currently attract little attention

The top ten priority that received the least research funding in 2014 addressed the need for further research on support and information for families and carers. The total direct funding to this question amounted to only £343,410. Of this, £265,383 came from five small interventional grants and the rest came from four direct grants. Three-quarters of this funding came from Marie Curie, with most of it funded in a one-off themed research call that focused on informal carers and was co-funded by Dimpleby Cancer Care.<sup>9</sup>

The number one priority, as decided by patients, carers and healthcare professionals, asked how best to provide out-of-hours palliative care. This priority attracted no research proposing interventions and received only £516,924 of direct funding, which is just 0.03% of the total health research funding in 2014.<sup>10</sup> It is clear that there is much need for further research to propose and test interventions to address the issue of out-of-hours palliative care, which is so important to carers, patients and health and social care professionals. The same can be said for the questions relating to continuity of care and the core palliative care services; both questions attracted no research proposing interventions and only a limited amount of direct funding in 2014.

Our wider analysis shows that of the 83 research questions identified in the PeolcPSP, 19 are not addressed by any research projects directly tackling the question.<sup>5</sup> A further 10 questions were addressed by less than £50,000 of strongly related funding in 2014. The subtheme of bereavement received no strongly related funding in 2014, with no direct or interventional grants addressing any of the four questions in the theme. The details of this analysis are included in a forthcoming full report.<sup>5</sup>



### Palliative care beyond cancer: a sizeable research community

The £4.3 million received by the PeolcPSP most funded top ten priority in 2014 – palliative care for people with non-cancer diseases – financed 31 grants, including six that proposed interventions. Research addressing this priority covers a range of conditions (see Figure 1). Neurological conditions take up almost three-quarters of the funding; of this, 80% relates to dementia, of which 82% is government-funded. This highlights the effect of a recent push by the UK government to increase dementia research in 2012.<sup>11</sup>

### Key points

- Published in 2015, the PeolcPSP report is being used to guide palliative and end-of-life care research funding.
- We have reviewed an open database of 2014 UK health research grant data to identify if and how current research is addressing the 83 PeolcPSP questions.
- The aims of this project include helping researchers avoid duplication by highlighting current research and fostering collaboration by showing who is already active in addressing specific questions.
- This project highlights that research spending in palliative and end-of-life care remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in palliative and end-of-life care.
- The number one PeolcPSP priority – how to provide palliative care out of hours – is one of the questions most in need of further research investment.
- Of the 83 questions, 19 are not addressed by any directly related research funding active in 2014.

There is a sizeable community of researchers now looking at non-cancer conditions, such as heart failure,<sup>12</sup> non-cancer lung diseases such as chronic obstructive pulmonary disease<sup>13</sup> and interstitial lung disease,<sup>14</sup> stroke,<sup>15</sup> organ failure<sup>16</sup> and dementia.<sup>17</sup> This is very encouraging, though clearly the overall amount spent on this question is split between many disease areas.

## Next steps

This project shows only a snapshot of UK research addressing the questions identified by patients, carers and clinicians. There will be research not included in this dataset that might be active now or have finished before 2014. It is clear, however, that as none of the 83 questions have been answered in a systematic review, the need for more research in palliative and end-of-life care remains. In particular, it is necessary to develop and test interventions that address patient and carer needs in this area.

The PeolcPSP project has shown that some areas of palliative and end-of-life care research are making progress, and funder initiatives such as the former UK prime minister's 'challenge on dementia', along with smaller themed calls by charities such as Dimpleby Cancer Care and Marie Curie, are clearly having an impact in an area so strongly in need of more research.

Other areas of need, such as bereavement, are not currently addressed by research at all or by only a small amount. The full report of this project, which will be released soon, allows researchers and funders to identify currently active projects and, through those, researchers and clinicians already engaged in a particular field. We hope that it might help to identify potential future collaborators since it also includes references to research that is only weakly linked to a particular question.

We hope that highlighting the questions with little current funding will encourage researchers and funders to endeavour to look into these further. Some questions, in particular in the top ten, are broad research priorities and might require further work to identify more focused research questions. A recent local initiative from the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester has demonstrated a method of achieving this. It used focus groups and workshops with local carers and health care

professionals to identify more detailed research questions relevant to local need within the PeolcPSP top ten questions.<sup>18</sup>

Research funders can help by providing clearer information about funding streams that are open for palliative and end-of-life care research and by supporting researchers in developing applications in new topic areas. Collaborations between funders in areas of common interest will help to make better use of limited research funds and avoid unnecessary duplication. In the UK, a group of funders with an interest in palliative and end-of-life care meets regularly as the UK end of life care Research Interest Group (UKeolcRIG).<sup>19</sup>

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# Mindfulness meditation and pain management in palliative care

As mindfulness meditation grows increasingly popular as a subject of study and as a practice in clinical settings, **Irene Campagnolo Maschio** looks into how the practice works and whether it has a valid application in palliative care patients

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**P**ain is one of the most common symptoms reported in palliative care and is widely recognised as impacting on all aspects of quality of life.<sup>1</sup> Much research has been, and continues to be, carried out into the processes underlying pain caused by cancer. Kumar, for example, describes a mechanism-based classification of cancer pain that contains the following categories: central and peripheral sensitisation; sympathetically maintained; nociceptive; and cognitive-affective pain.<sup>2</sup> He addresses the patho-physiology of cancer pain while providing a better understanding of patients' symptoms and response to treatments. The British Pain Society states that cancer and non-cancer pain share the same neuro-pathophysiological pathways,<sup>3</sup> but further studies are necessary to more fully understand the causes of pain in non-cancer patients.<sup>4</sup>

In cancer patients, the WHO analgesic ladder is the most commonly used medical strategy, and non-pharmacological interventions can be used in conjunction with it to maximise a patient's functionality and control 'over pain and circumstances'.<sup>2</sup> In this context of a multimodal approach to pain,

mindfulness meditation (MM) is gaining growing attention.

## What is mindfulness?

The concept of mindfulness is rooted in ancient philosophical traditions such as Buddhism and Hinduism and is a component of vipassana (meditation practised in Theravada Buddhism) and Zen meditation. Kabat-Zinn, the pioneer of MM in Western medicine, defined it in psychological terms as 'paying total attention to the present moment with a non-judgemental awareness of the inner and/or outer experience',<sup>5</sup> extrapolating it from any religious or philosophical tradition.

During MM, the subject is asked to focus either on their breathing or on sensory, emotional and cognitive happenings without interpreting them or assigning them a positive or negative value. The aim is to learn to live deeply in the present experience without identifying with it or overlaying it with conscious or unconscious projections, thus developing acceptance.<sup>6</sup>

Pike cautions against the use of the term 'mindfulness' alone on the basis that it does not contain any reference to the body and may thus lead to misunderstanding regarding the practice. He suggests that the term 'body-mindfulness practice' focuses more on the awareness of sensations arising from the body during mindfulness practice. The suffix '-fulness' stands, in his view, for 'awareness of a full and unseparate body-mind complex', which reveals the full extent of the practice and its aim to alter physical symptoms through mind control.<sup>7</sup>

Mindfulness-based Cognitive Therapy (MBCT) and Mindfulness-based Stress Reduction (MBSR) are clinical approaches structured to organise the original concept of

## Key points

- Pain is one of the main symptoms reported in palliative care and has a huge impact on quality of life.
- Mindfulness meditation (MM) is receiving increased interest, along with other non-pharmacological interventions, for its potential to control pain and maximise patient functionality in palliative care.
- Research shows MM is able to affect pain perception by modifying the activation of specific brain areas. However, more studies in palliative settings are needed.
- MM can restore a sense of control 'over pain and circumstances', which is often lost in palliative care patients.

■ The exact mechanisms of pain remain unknown, but it is established that pain is influenced by our emotions, memories and state of mind.

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mindfulness into standardised clinical interventions. As mindfulness is their fundamental component, researchers tend to group MBCT and MBSR together with vipassana and Zen practices in studies on meditation. Specific differences exist between the above approaches, however, that impact on their ability to provide a coherent and systematic framework for mindfulness. There is also uncertainty about the role the different components of each approach have played in observed clinical outcomes.<sup>5</sup>

### How is it thought to work?

The possibility of influencing health and disease through the mind was central to the medical practices of the ancient civilisations of Egypt and Greece, traditional Chinese medicine and Indian Ayurveda. Western researchers, after focusing on the body for centuries, are now recognising and mapping the interaction between mind, nervous system, immune system and the body using scientific methods.<sup>8</sup>

Exactly how our perception of pain occurs is unknown, but scientists today generally agree that pain perception is linked not only to damage incurred by a bodily structure but is also affected by our physical, emotional and mental states, as suggested by Melzack (2001)

### It is important for the clinician to tailor the intervention to the single patient's pathology in order to increase effectiveness

in his neuromatrix theory.<sup>9</sup> The processing of information coming from our sensory system is informed by our own unique past experiences, present physical and psychological condition and future expectations; the way in which a nociceptive stimulus is transformed into the subjective experience of pain is one of the best examples of this process.<sup>10</sup> Moseley states that it is the 'implicit perception of threat that determines the outputs, not the state of the tissues, not the actual threat to the tissues'.<sup>11</sup>

Tsang *et al* describe how the diagnosis of a life-limiting illness poses a threat to the individual, resulting in a hypothalamic-pituitary-adrenal axis activation (that is linked to the fight-and-flight response) with a consequential increase in pain level.<sup>12</sup>

Edenfield and Saeed report that meditation elicits the relaxation response mediated by the parasympathetic nervous system; this reduces the state of alarm created by the hyperarousal of the sympathetic nervous system and counteracts the effects of stress hormones.<sup>13</sup> Chiesa and Serretti found that the use of MM reorganises brain activity, with sustained attention leading to a reduction in excessive emotional reactivity and thus a cognitive control of emotions.<sup>5</sup> The ability to detach

from negative emotions improves the mind-body interaction and can possibly explain the clinical results of MM.<sup>5</sup>

### **Possibilities and challenges in palliative settings**

An inverse relationship has been found between meditation experience and pain perception, but it is not clear if there are baseline differences in the people recruited that might explain this result.<sup>6</sup> Zeidan *et al* found positive changes in pain sensitivity after only one 20-minute meditation session per day for four days.<sup>10</sup> These results come from non-clinical studies and require further investigation in a clinical context. They are suggestive, however, of the possibility of effectively modifying pain perception in a short period of time, enabling its application in a palliative setting, where time is a fundamental variable.

An obvious weakness of all research in this area is the impossibility of conducting double-blind studies in meditation due to the nature of the intervention. The necessity for the patient to have an active attitude towards the technique may create a further bias linked to motivation and the ability to participate in the intervention.<sup>14</sup> Shennan *et al* point out how illiterate and poorer people are generally excluded in the studies reviewed, which can be a limit to a generalised application of MM.<sup>15</sup>

In an interesting critique of the use of MM in clinical settings, Teasdale *et al* draw attention to the fact that MM should not be regarded as a mere attentional technique that can influence clinical problems in a quick and simple way.<sup>16</sup> Because MM includes various components, such as relaxation, self-management, acceptance and cognitive changes, it is important for the clinician to tailor the intervention to the single patient's pathology in order to increase effectiveness and avoid unhelpful treatments.

This raises questions about the ethicality of applying a potentially ineffective treatment. In a vulnerable population such as those in palliative care, it is of paramount importance to weigh 'treatment burden against the potential benefits', and to discuss the patient's

preferences.<sup>17</sup> Professionals working with end-of-life patients have, however, been found to be confident in discussing and facilitating rationalised treatment refusal in order to increase quality of life.<sup>18</sup>

Davidoff describes what he calls the 'responsibility paradox', which arises from the belief embedded in most types of alternative medicine that mind and spirit hold deep within the remedy for most illnesses, inner resources that the patient needs to access in order to heal himself.<sup>19</sup> Talking in general about the use of alternative therapies, he warns practitioners of the risk of instilling in the patient a sense of guilt or fault if they are unable to modify their symptoms through mind control. On the other hand, Davidoff recognises that empowering the patient can be a 'crucial therapeutic tool'. Increasing the patient's control over body, emotions and thoughts, as offered by MM, is highly beneficial and of particular value in people suffering from life-limiting illnesses, in whom memories from past experiences, fear for the future and detachment from their own body can have a huge impact.

Gotink *et al* state that 'in chronic care both MBCT and MBSR help patients to cope with pain', with an overall improvement in quality of life thanks to the acceptance-based intervention typical of MM.<sup>14</sup>

A study by Tsang *et al* shows how the practice of body scanning (that is, becoming aware of the sensations arising from the body) can reduce overwhelming pain in terminally ill cancer patients.<sup>12</sup> Benefits were already significant after the first week of individual practice and sustained and enhanced after a month of home sessions five days per week.

Bates describes her experience of leading mindfulness groups in a hospice setting. She emphasises the value of the group in supporting individuals in the practice of MM, even if patients with serious agitation, severe deafness, psychiatric disorders and severe post-traumatic stress are better treated in individual sessions. She points out that palliative patients lack the energy to follow the strict practice of MBSR and MBCT but can benefit from a modified practice.<sup>20</sup> She gives no data regarding pain management.

**Physiotherapists are well placed among healthcare professionals to teach mindfulness in clinical settings because they are already trained in facilitating body-awareness**

## Ways of implementing MM

There is an ongoing and open discussion among researchers and practitioners about various methods of teaching mindfulness and their implications for the outcomes. Shennan *et al* found that among the 13 articles included in their systematic review, no data regarding facilitators were provided and only one author suggested that age and delivery style might influence the patient's perception of the practice.<sup>15</sup> Shennan *et al* also found no correlation between contact time and benefits, while Gotink *et al* found a positive dose–response relationship between minutes of practice and stress reduction<sup>14</sup> – meaning that the benefits are significantly greater the more MM is practised.

In Pike's opinion, physiotherapists are well placed among healthcare professionals to teach mindfulness in clinical settings because they are already trained in facilitating body-awareness through exercises, postures and breathing techniques.<sup>7</sup> Lee *et al* report a willingness among GPs to combine conventional and non-conventional treatments, along with recognition of the need to develop better knowledge and understanding of complementary and alternative therapies in order to be able to advise patients appropriately.<sup>21</sup>

Economically, MM therapy is generally considered to be cost-effective by studies and reviews. Bates, however, states that MM will not be effective in reducing costs in a hospice setting due to the amount of professional resources needed to plan and follow up the intervention.<sup>20</sup>

Mindfulness practice is considered easy to implement, with little or no risk involved on both a physical and emotional level, if led by trained and experienced practitioners.<sup>14,22</sup>

## Conclusions

To summarise, MM has been proved effective in non-clinical settings at modulating pain through the activation of specific brain areas responsible for attentional mechanisms and emotional response to pain perception. Clinical studies show its effectiveness in chronic pain management, but further studies are required to build on the evidence for the effectiveness of MM in palliative care. Guidance is also needed on the screening of patients and the most appropriate setting (group versus individual treatment), contact

time (duration of single session and programme) and facilitator characteristics. It must be remembered, however, that good-quality randomised controlled trials are difficult to apply in a palliative setting due to the nature of the patients.

The ability to pay sustained attention and develop acceptance allows the patient to work on all pain components from the physical level to the emotional and mental. MM requires an active attitude and can restore a sense of control over pain and circumstances, which is often lost in terminally ill patients. Because the palliative population is vulnerable, it is paramount that patients are screened in order to identify those most likely to benefit from the intervention and give more scientific direction to the growing popularity of MM therapy.

### Declaration of interest

The author declares that there is no conflict of interest.

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THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

# European Journal of Palliative Care



## ***EJPC* Palliative Care Policy Development Award**

In 2013, the *European Journal of Palliative Care* (EJPC), in collaboration with the European Association for Palliative Care (EAPC), launched the **EJPC Palliative Care Policy Development Award**, which is aimed at individuals who have made a substantial contribution to policy development through their research, clinical practice or as policy activists, in any country or region in the world.



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# Antibiotic use in the last two weeks of life for home hospice patients in Singapore

Studies have indicated that the use of antibiotics in palliative care settings is widespread but lacks supporting evidence. **Ong Eng Koon** and **Chong Poh Heng** used a retrospective review to assess the prevalence and standards of practice involved in the use of antibiotics for home hospice patients

The prevalence of antibiotic use in patients receiving palliative care ranges from 20% to more than 50% across different settings.<sup>1,2</sup> However, a systematic review of antibiotic use in palliative care found that the supporting evidence for this treatment is weak.<sup>3</sup> First, there have never been direct comparisons between patients who received antibiotics and those who did not. A definitive diagnosis of an infection can also be challenging in the home setting, where laboratory and radiological investigative options are limited. In addition, the perception of changes in symptoms once antibiotic therapy begins remains largely subjective; a change in clinical status may be related to other medications that are administered concurrently, or simply due to varying trajectories of the underlying disease.

Although the use of antibiotics at the end of life may alleviate symptoms associated with a urinary tract infection,<sup>3</sup> some have argued that antibiotics may inappropriately prolong life for hospice patients and unnecessarily increase the burden of treatment. The development of antimicrobial resistance is also a valid concern in hospice care, when full courses of antibiotic treatments frequently cannot be completed as recommended.<sup>4</sup>

In a study in Singapore, Lo *et al* concluded that the use of antibiotics in an inpatient hospice setting had been rational, in cases where there were clear indications for starting antibiotics and subsequent symptom improvement was fairly well documented.<sup>5</sup> However, significant patient factors – including functional status, oral intake and communication with patient and family regarding antibiotic use – were not evaluated.

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This study sought to determine the factors associated with antibiotic use in patients under the care of HCA Hospice Care (HCA), the largest home hospice service provider in Singapore. Discussion of these factors could be used to highlight deficiencies in practice and encourage improvement in the standard of care in antibiotic use for hospice patients at the end of life.

## Method

HCA provides home hospice care to patients with a life-limiting disease and prognosis of one year or less. It serves an average of 800–850 patients at any one time and has supported more than 55,500 patients since its inception in 1989.

This is a retrospective electronic case note review with subsequent descriptive study of deceased patients who had been under the

## Key points

- There is a paucity of evidence regarding the benefits of administering antibiotics to patients supported in the home setting near the end of life. Since antibiotic use is not without its burdens, we have elected to study decedent demographics and circumstances of antibiotic use within a home hospice service in Singapore to improve our understanding of prescribing patterns.
- The results of this paper show that antibiotic use in this cohort was not common, at 6%, but there were deficiencies in clinical practice in terms of indications and monitoring of antibiotic use.
- Despite initiation of antibiotics at home, 27% of patients eventually died in an acute care hospital.
- It is clear that communication with patients and caregivers regarding antibiotic use at the end of life is important. In addition, future research should compare treatment outcomes and place of death between patients who had antibiotics prescribed at home and those who did not.

care of HCA. All of the patients who died within the period of January–June 2015 and were prescribed antibiotics within two weeks of their death were included in the study; patients who were on topical antibiotics were excluded.

All patient visits were documented electronically within specific time segments of clinical care. The information on different aspects of antibiotic use was retrieved from the various segments corresponding to the visit when antibiotics were prescribed. The following factors were assessed:

- Patient demographics:
  - Age
  - Sex
  - Functional status in terms of Eastern Cooperative Oncology Group (ECOG) score, mobility and activities of daily living (ADL)
  - Presence of feeding tube
  - Volume of oral intake
  - Primary diagnoses and cognitive function.
- Characteristics of antibiotic usage:
  - Source of prescription
  - Duration of treatment
  - Type of antibiotic
  - Site of infection
  - Effect on symptoms
  - Reasons for cessation.
- Communication with patient and/or caregiver, including any documentation of communication regarding the indication, side effects, duration and outcomes of antibiotic use. Specifically, any request by the caregiver to initiate antibiotics was also noted.
- Place of death.

All data collection was performed by the first author and analysed using Microsoft Excel.

## Results

A total of 1,008 patients died during the study period of six months, of which 63 (6%) had documented antibiotic use within two weeks of their death.

### Demographics

The mean age of the patients was 75 years (see Table 1). There were slightly more men (57%) than women. Most of the patients (97%) had an ECOG score of 3–4 and 93% required some form of assistance in their daily activities;

although most were not being tube fed, only 17% of those who were still eating were taking normal amounts of food; 84% had cancer, and 75% of them were alert.

### Antibiotic use

At 43%, the most common site of infection was the chest, based on clinical signs and symptoms (see Table 2). However, 37% of patients – a significant proportion – did not have documentation on the site of infection as part of clinical assessment, even though all of them had at least one symptom or sign of sepsis noted, including fever, cough, purulent sputum or lung crepitations on auscultation.

The attending home hospice team started antibiotics in more than half – 57% – of cases, and co-amoxiclav was the most commonly prescribed antibiotic (71%). The mean time before death that

antibiotics were started was six days. The mean duration of antibiotic use was five days. Antibiotic treatment continued until the time of death in 70% of patients. Only 21% of the whole cohort had documented improvement of presenting symptoms.

### Communication

In 81% of cases there was no documentation of communication with the patient or caregiver regarding the use of antibiotics (see Table 3). Only one (2%) caregiver had requested that antibiotics be used for a patient.

### Place of demise

Of the 63 patients, 44 (70%) died at home, 17 (27%) died in the hospital following readmission, despite antibiotic use at home, and two (3%) died in the nursing home where they had lived.

## Discussion

### Demographics

The prevalence of antibiotic use in this group of patients is much lower than that previously reported in other studies.<sup>1,2</sup> This may be due to practice differences between the home hospice and hospital. In the latter, clinical management tends to be more aggressive due to the availability of a wide choice of parenteral antibiotics.

**Some have argued that antibiotics may inappropriately prolong life for hospice patients and unnecessarily increase the burden of treatment**

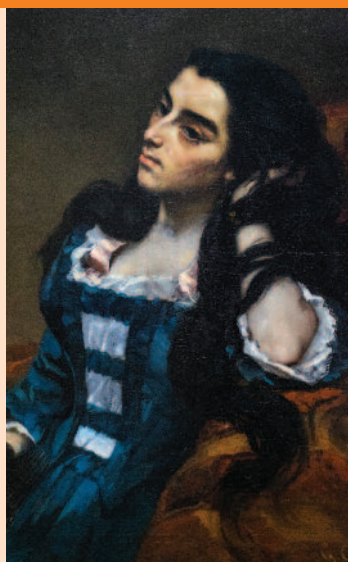
**Table 1. Patient demographics**

	Number of patients (%) N=63
<b>a. Age (years)</b>	
Range	44–99
Mean	75
Median	76
<b>b. Gender</b>	
Male	36 (57)
Female	27 (43)
<b>c. ECOG status</b>	
1	—
2	1 (2)
3	23 (37)
4	38 (60)
Not documented	1 (2)
<b>d. Mobility</b>	
Independent	—
Supervised	4 (6)
Assisted	10 (16)
Chairbound	7 (11)
Bedbound	41 (65)
Not documented	1 (2)
<b>e. Activities of daily living</b>	
Independent	2 (3)
Supervised	1 (2)
Assisted	21 (33)
Dependent	38 (60)
Not documented	1 (2)
<b>f. Oral intake</b>	
Poor	18 (29)
Moderate	24 (38)
Normal	11 (17)
Tube feeding	8 (13)
Not documented	2 (3)
<b>g. Primary Diagnoses</b>	
Cancer	53 (84)
Non-cancer	10 (16)
<b>h. Cognitive function</b>	
Unresponsive	2 (3)
Drowsy	9 (14)
Confused	3 (5)
Alert	47 (75)
Not documented	2 (3)

**Table 2. Characteristics of antibiotic use**

	Number of patients (%) N=63
<b>a. Site of infection</b>	
Chest	27 (43)
Urinary tract	7 (11)
Sacral sore	2 (3)
Soft tissue	3 (5)
Hepatobiliary tract	1 (2)
Not documented	23 (37)
<b>b. Choice of antibiotics</b>	
Co-amoxiclav	45 (71)
Ciprofloxacin	12 (19)
Clarithromycin	2 (3)
Levofloxacin	2 (3)
Metronidazole	2 (3)
<b>c. Prescribing source</b>	
Home hospice	36 (57)
Hospital	17 (27)
General practitioner	1 (2)
Not documented	9 (14)
<b>d. Time of antibiotic use before death (days)</b>	
Range	1–14
Mean	6
Median	6
<b>e. Duration of antibiotic use (days)</b>	
Range	1–14
Mean	5
Median	5
<b>f. Reason for cessation of antibiotics</b>	
Course completion	5 (8)
Deteriorating condition	12 (19)
Readmitted to hospital	1 (2)
Death	44 (70)
Not documented	1 (2)
<b>g. Change in infective symptoms</b>	
Improved	13 (21)
Worsened	3 (5)
No change	1 (2)
Not documented	46 (73)

■ In the context of the growing recognition of the emotional and psychological needs of patients and carers at the end of life, **Jenny Strachan** introduces 'Psychology in palliative practice', a new series for 2017 and beyond. The series translates some of psychology's 'big ideas' into practical advice, and Jenny begins with a look at attachment theory, in which she examines both the theory and how knowledge of it promotes psychologically informed practice for all members of the multidisciplinary team.



■ In this issue's 'European insight' section, **Wei Liu** and **Ping Guo** place palliative care in China in its global, historical, geographical and cultural contexts. They investigate the challenges faced by those seeking to implement palliative care in China and, looking to the future, ask, 'Can a good death be achieved for Chinese patients with advanced illness?'

■ Tuberculosis remains a worldwide problem that mainly affects people in Africa and Asia but also occurs in developed nations. **Fiona Runacres** and colleagues in Australia assess the clinical guidance available for providing appropriate care to patients with TB at the end of life.

■ Intriguingly, a hospice in Manchester has found that they are bucking the national trend regarding the average length of stay in a hospice, theirs being shorter. A far higher proportion of their patients die in the hospice. **Carmen Chan** and **Michael Tapley** explain how a Hospice Transfer Project between the hospice and the local hospital enables many more patients who will die imminently to benefit from the care given in the hospice.

■ **Edith Ubogagu** provides an update on symptom control in those patients receiving palliative care who experience nausea and vomiting, in which she reviews the literature on various pharmacological interventions.

■ In a paper produced by the Taskforce on Palliative Care for People with Heart Disease jointly set up by the European Association for Palliative Care and the Heart Failure Association of the European Society of Cardiology, **Manuel Martínez-Sélles et al** examine the complexities of providing palliative care to patients with advanced heart failure and the importance of timely intervention.

■ Earlier this year, the Royal Liverpool and Broadgreen University Hospitals NHS Trust opened a state-of-the-art academic palliative care unit. Its aims are to provide specialist care for patients with the most complex, high-dependency palliative and end-of-life care needs and, once these needs have been addressed, to discharge patients to the most appropriate place of care, such as home or hospice, in line with their needs and wishes. A key benefit is a reduced length of stay in hospital. **Ben O'Brien** and colleagues explain the immense benefits that a custom-designed unit can bring to patients and their families – and consequently to staff as well.

Although patients in this study who were started on antibiotics were mostly alert, their functional status was poor. Together with findings that they were also less likely to have adequate oral intake, prognosis for these patients is poor, based on several prognostic tools.<sup>6,7</sup>

However, antibiotics can improve symptoms related to infections, even at the end of life,<sup>3,8</sup> and it is worth noting that the majority of these patients (75%) were also still alert at the point of assessment. It is not so surprising that antibiotics were initiated, even though the prognosis was short.

The assessment before starting antibiotics in this special group of patients with limited prognosis would need additional predictive factors on top of those obtained by the use of general prognostic tools commonly used for hospice patients in order to validate the use of antibiotics. These factors would help to assess the reversibility of acute episodes of infection. Such factors could include assessment of: previous episodes of similar infections; previous antibiotic use; and disease-specific conditions such as anatomical disruptions, compromised immunity and poor bodily reserves.

### *Characteristics of antibiotic use*

A significant proportion of patients (37%) had no documented diagnosis regarding the site of infection. This is consistent with previous studies, in which the proportion of patients who were administered antibiotics and had actually had a documented diagnosis of infection was as low as 15%.<sup>2,9</sup>

Chest infections were the most common type of infection noted, lung malignancies being one of three most frequently diagnosed cancers locally.<sup>10</sup> Associated respiratory symptoms from cancer, such as cough or dyspnoea, are common and could overlap with those expected in chest infections, possibly explaining the high figures found in this study.

Initiation of antibiotic use was noted to be as close as one day before death (mean of six days) and was commonly continued up to the patient's death. However, there was a lack of documentation regarding improvement in symptoms or difficulty in medication administration following antibiotic initiation. It was not possible

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to ascertain if this was due to suboptimal documentation or failure to review symptoms once antibiotics had started. Without demonstrating any benefit, it would not be justified to impose this additional burden of treatment on both the patient (who is likely to have developed swallowing difficulties by this time) and their caregivers. Thus, assessment and documentation of treatment outcomes need to be improved.

### Communication

The lack of communication regarding the use of antibiotics is a cause for concern. As most of the patients were noted to be alert, the opportunity to explore goals of care and care preferences should not be missed.

Future studies should determine those factors that foster or hinder communication between the physician and patients or caregivers, as part of ethical practice.

Interestingly, only one caregiver had asked for antibiotics to be started, suggesting that the decision to start antibiotics was nearly always medically guided.

### Place of death

It has been noted that patients generally prefer to die at home.<sup>11</sup> However, a significant proportion of patients (27%) were readmitted to an acute care hospital despite prior initiation of antibiotics at home. Future research on treatment outcomes following hospital readmission and the effect of antibiotics on symptom control and mortality can provide further insight into the benefit of aggressive antibiotic treatment and escalation of care in this group of patients. Further details, including the duration of oral antibiotic use, change in the patient's condition and any caregiver stress that may contribute to subsequent hospital readmission, will also provide insight about whether initial treatment at home was warranted and advisable.

### Limitations

The number of patients assessed was relatively small and the factors assessed were based purely on the retrospective review of documented electronic case notes. Communication was also noted to be poor.

However, these results show the prevalence of antibiotic use at the end of life for home hospice patients. In addition, they illustrate

**Table 3. Communication with patient/caregiver regarding antibiotic use**

	Number of patients (%) N=63
<b>a. Documented conversation regarding antibiotic use</b>	
Yes	12 (19)
No	51 (81)
<b>b. Documentation of caregiver's request for antibiotic</b>	
Yes	1 (2)
Not documented	62 (98)

the lack of documented indications of antibiotic use and of subsequent monitoring.

Finally, a significant proportion of patients eventually sought treatment in a hospital, raising questions about whether the place of care would have been different without the use of antibiotics at home.

### Conclusion

This study demonstrates deficiencies in good clinical practice regarding antibiotic use at the end of life for home hospice patients. It provides insight into prescribing patterns and should encourage further research into the differences in outcomes between initiating and withholding antibiotic use in this group of patients.

#### Declaration of interest

The authors declare that there is no conflict of interest.

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## Reader survey results

Respondents came from across the multidisciplinary team

38%  
Palliative care physicians  
15%  
Nurses  
6%  
Oncologists  
6%  
Psychologists

82%

find the *EJPC* extremely/  
very useful

53%

use it as a  
reference  
resource

43%

use it to aid  
their own or  
others' training

78%

find the *EJPC* of great benefit; the  
remainder regard it  
as of some benefit

94%

agree/strongly  
agree that they  
find the *EJPC*  
informative

71%

agree/strongly  
agree that the *EJPC*  
influences their  
patient care

90%

agree/strongly  
agree that they trust  
the information they  
read in the *EJPC*

# EAPC Early Researcher Award 2013 – looking back

Since 2009, through its Early Researcher Award, the European Association for Palliative Care (EAPC) has recognised and supported the work of scientists and clinicians who make an outstanding contribution to palliative care research. Here, **Meera Agar**, **Barbara Gomes** and **Jeroen Hasselaar** reflect on the path their careers have taken since they won the award in 2013

## ■ Meera Agar:

'The EAPC award has given me a deeper appreciation of how to better foster in others the enthusiasm and drive needed to undertake groundbreaking research'



## First prize

### Collaboration and mentorship

**Meera Agar**, Professor of Palliative Medicine, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology Sydney, Sydney, Australia

**R** Receiving the Early Researcher Award in 2013 was a huge honour and privilege that marked 10 years as a clinician scientist trying to improve care for people with delirium at the end of life. The plenary presentation in Prague remains a defining moment in my career and highlighted that expert EAPC researchers support the fundamental importance of evidence-based delirium care. This spirit of acknowledgement comes with a recognition that the research community walks alongside us to support our success.

Three years on, I am the Professor of Palliative Medicine, University of Technology Sydney, an exciting new position in an interdisciplinary centre that aims to improve quality of life for people with chronic illness requiring palliative care, with a strong focus on equity, diversity and social justice. My research focus is on supportive care needs

relating to the impacts of advanced illness on the brain, an area in which I have now completed three clinical trials.

I particularly enjoy my roles with various national trials groups, including Improving Palliative Care through Clinical Trials (ImPaCCT) – the New South Wales (NSW) palliative care clinical trials group – the Palliative Care Clinical Studies Collaborative (PaCCSC), the Cooperative Trials Group for Neuro-Oncology (COGNO), the Psycho-oncology Co-operative Research Group (PoCoG) and the Cognitive Decline Partnership Centre (CDPC). In the areas of advocacy and policy I am also involved with National Palliative Care Standards, the Australasian Delirium Association (ADA), the European Delirium Association (EDA) and Choosing Wisely Australia. I have fostered collaborations to support our colleagues in Asia Pacific – for example the Lien Collaborative for Palliative Care in Myanmar – as they drive the agenda to improve palliative care access and services.

Moving to an academic position has also allowed me to have a more substantial role in mentoring and capacity building, and the next generation of researchers in palliative care have much to offer. Most importantly, I have been able to support higher degree research students in a truly interdisciplinary academic environment that needs to be the norm for the future. The EAPC award has given me a deeper appreciation of how to better foster in others the enthusiasm and drive needed to undertake groundbreaking research that will help ensure people who have far advanced illness receive the best care possible, so that they can focus on living their lives to the full. The best evidence is needed to guide the management of their symptoms or the configuration of their healthcare, as for most patients we have just one chance to get it right. I am also passionate about ensuring women in academic roles have the flexibility and support to achieve to their full potential. This is an area I have

been able to foster more active discussion about, in the palliative care research community in particular, as the last three years also included a period of maternity leave. I am also pleased that my son's first words weren't 'randomised controlled trial'!

As I reflect on my career since 2013, success is still defined by my mentors and collaborators from all walks of life and by being truly interdisciplinary in spirit and intent, all of which offer support and boost the drive and resilience you need to be the best you can be, regardless of the challenges. It was the questions, 'What would be the best care possible for this person?' and 'Is there a way we can do this better?' that became the driver of my clinical care and research questions and led to the work that culminated in the Early Researcher Award in 2013, and they continue to drive my approach to this day ■

■ **Barbara Gomes:**

'We trained eight promising doctors and researchers, who are now making a difference to the daily practice of family medicine, internal medicine, oncology and paediatrics'



## Joint second prize One of life's turning points

*Barbara Gomes, Invited Assistant Professor at University of Coimbra, Faculty of Medicine; Research Fellow at Cicely Saunders Institute, King's College London, UK*

**A**fter 10 years of research and training in palliative care in the UK, I was honoured to be one of the Early Research Award winners in 2013. This ended up being a major life turning point, leading to my homeland return and the award in 2016 of the first professorship in palliative care in Portugal, hosted at the Faculty of Medicine of the University of Coimbra.

New and exciting times lie ahead, building on seeds that grew at the Cicely Saunders Institute,

under Professor Irene Higginson's 'gardener's eye'. For the last few years, I have been leading a research project (the DINAMO Project) that has helped energise advanced training and optimise home palliative care in Portugal, and in that time the project has come a long way. We trained a team of eight promising medical doctors and researchers, who became masters in palliative care at King's College, London, and are now making a difference to the integration of palliative care into the daily practice of family medicine, internal medicine, oncology and paediatrics. Together, we undertook studies that showed the level of need and the impact of palliative care in the home context and at an important clinical service in the interface of hospital and community – the emergency department. Results from other studies will be forthcoming soon.

One great achievement was to inform the policy U-turn towards prioritising the development of home palliative care – this is at the heart of a new Portuguese national palliative care strategy, published in November 2016. The strategy aims to at least triple the number of home palliative care teams by 2018, which means that a lot more people will have access to an alternative to institutional care and will be able to die at home, if that is their wish, benefiting from specialist home support. We look forward to the next two years, during which changes will be implemented, and hope that these help reverse the country's upward hospital death trend.

I spent the last year conducting interviews with patients and family caregivers in Portugal for a new study to determine which attributes of home palliative care are most valued by service users. This gave me invaluable insight on how services operate in urban and rural regions and how patients and families view them. We are applying an original technique from health economics called the discrete choice experiment, which is helping us quantify the value that people give to different attributes related to home visits, family support, information and planning, and team availability. Preliminary findings were presented at the 9th World Research Congress of the EAPC in Dublin, 2016.

In September 2016, I was awarded a Professorship in Palliative Care at the Faculty of Medicine of the university of Coimbra. Coimbra is one of the oldest universities in Europe and is in the 500 top universities of the world. It is a front runner in health science and education and integrates palliative care into the curriculum for the 280 medical students who enroll each year. There is also

a successful masters course in Continuing and Palliative Care, co-ordinated by Professor Marília Dourado since 2013. I am honoured to hold the professorship and to have the means to further grow palliative care training at Coimbra and lead the development of a new European research centre of excellence in the field.

These achievements would not have been possible without the contributions of the patients and families who took part in our studies, the support of the Calouste Gulbenkian Foundation, which funds the DINAMO Project and the professorship, the mentorship of Professor Irene Higginson, the contributions of my clinical and academic colleagues, and the encouragement of my family and friends ■

#### ■ Jeroen Hasselaar:

'For a long time, the EAPC was quite an unknown world for me, but this changed after I received the Early Researcher Award, and also after working with so many international colleagues over the years'



## Joint second prize Building programmes ...

*Jeroen Hasselaar, Assistant Professor in Palliative Care, Radboud University Medical Center, Nijmegen, The Netherlands*

**A**t EAPC Prague 2013, I received the Early Researcher Award (second prize). I have good memories of that moment – being almost two metres tall and gently bowing to receive the prize from the hands of Professor Sheila Payne.

The Prague congress was also a turning point from another perspective. After a period of hard work seeking support for a national programme for palliative care in the Netherlands, I was worried that we would lose momentum. In Prague I organised a meeting with some influential Dutch

palliative care colleagues and we decided to make one more push. We were soon invited into the upper echelons of the Dutch Health Ministry and the Netherlands organisation for health research and development (ZonMw), and I was asked to propose a national programme for palliative care. The proposal resulted in the Dutch Parliament approving funding of 51 million euros for a national programme, which is underway and being implemented until 2020. It is so good to see palliative care growing as a field in the Netherlands, because much work remains to be done.

Late in 2012, we received a grant from the EU for an international project on best practices in integrated palliative care ([www.insup-c.eu](http://www.insup-c.eu)), of which I am co-ordinator. Imagine sitting at your computer and receiving an email from the EU stating in a few sentences that your proposal is awarded – I could hardly believe it! In January 2013 we had the startup meeting in Amsterdam, with a collaboration of 11 partners, including the WHO and EAPC. This year, the project will come to an end with a congress in Brussels and a free downloadable book on integrated palliative care. Co-ordinating such a big project is not always easy, but we have a wonderful and skilled group of people. Last year, I was invited to the ESMO congress in Vienna to talk about our project. I was also appointed as an external collaborator at the University of Navarra, Spain. And with Sheila Payne, I was invited to co-edit a special edition of *Palliative Medicine* on integrated care.

Just before InsupC started up, I travelled to Nigeria with one of my PhD students for a telemedicine and palliative care project. It was a great experience, assimilating a different culture, working with Professor Soyannwo's team and co-writing a publication. More PhDs are coming up, on subjects such as ehealth and palliative care, integrated palliative care and palliative sedation – the latter was the subject of my own PhD thesis in 2010, and I have an ongoing interest in its clinical and ethical aspects.

Looking back, I attended my first EAPC congress in 2005. For a long time, the EAPC was quite an unknown world for me, but this changed after I received the Early Researcher Award, and also after working with so many international colleagues over the years. I work in a great team led by Professor Kris Vissers at the Radboud Expertise Center of Pain and Palliative Medicine, Radboud University Medical School, and I look forward to exploring the world further. I hope that the EAPC will continue to encourage young researchers and clinicians ■

## Case 89 answers Managing symptoms of neuroendocrine tumours in a 62-year-old man with impaired cognition

### Read ...

this patient's full case history in the 'masterclass' section on pages 276–277 of this issue.

### How do NETs present?

NETs are rare in oncology practice, so exposure to symptom management in palliative care is limited. The symptoms that need to be controlled tend to be the same as at disease presentation. Non-functioning NETs usually present with local tumour effects, such as pain, nausea and vomiting or anaemia or symptoms associated with metastasis.<sup>1</sup> Ramage *et al*<sup>1</sup> summarised the symptoms of functioning NETs according to which peptide hormone is released (see Table 1). The symptoms are secondary to vasoactive compounds generally secreted by liver metastases, such as adrenocorticotrophic hormone, kallikrein, gastrin, histamine, serotonin (5-hydroxytryptamine), prostaglandins and calcitonin.<sup>1</sup>

### What is the cause of pellagra, and what are the treatment options?

Pellagra is caused by a lack of vitamin B3 (niacin) or its precursor tryptophan. Deficiency of vitamin B3 affects the cellular functions in multiple organs and tissue and can cause diarrhoea, dermatitis

and mental disturbance. While pellagra may be a primary disease due to poor dietary intake of vitamin B3, it may also be secondary to conditions that affect niacin intake, absorption or metabolism.<sup>2</sup> In carcinoid syndrome, it is the result of excess consumption of dietary tryptophan by the serotonin-producing tumour.<sup>2</sup> The mainstay of pellagra treatment is improved overall nutrition with a high-protein diet and vitamin B complex supplementation.<sup>2</sup>

### What is the pathophysiology of carcinoid heart disease?

The pathophysiology of carcinoid heart disease is unclear. Vasoactive substances with fibroblast proliferative properties are released by the tumour at a greater quantity than the liver can excrete.<sup>3</sup> These lead to the formation of endocardial plaques, mainly on the right side of the heart on the downstream side of the tricuspid and pulmonary valves, causing a mixture of valvular stenosis and regurgitation. Serotonin is thought to be the substance that plays a major role in fibrogenesis in the heart, and patients with carcinoid heart disease tend to have higher levels of urine 5-HIAA, the serotonin metabolite.<sup>3</sup>

### What is the Mental Capacity Act, and what help can be provided to aid decision-making?

The Mental Capacity Act (MCA) 2005<sup>4</sup> was designed to protect and restore power to vulnerable people aged 16 and over who lack capacity and live in England and Wales. It also supports those who do have capacity and choose to plan for their future. Five statutory principles underpin all acts carried out, and decisions taken, in relation to the act:<sup>4</sup>

- a presumption that everyone has capacity unless proved otherwise
- a person must be given all practicable help before anyone treats them as not

being able to make their own decisions

- people have the right to make decisions that others may judge as unwise
- anything done on behalf of a person who lacks capacity must be in their best interest
- any decision made must interfere the least with a person's rights and freedoms of action.

A two-stage test determines an individual's decision-making capacity:<sup>4</sup>

- Is there an impairment of or disturbance in the functioning of a person's mind or brain?
- If so, is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

The MCA says that you are unable to make your own decision if you cannot do one or more of the following four things:

- understand information given to you
- retain that information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate your decision.

In Brian's case, there were times when he lacked capacity, but with the support of his wife, the use of time and simplification of verbal communication, he did have capacity at crucial times, and as such was able to make decisions regarding his own treatment. When supporting a person in making a decision, it is prudent to think about language, form of communication, location of discussion, who may be of help, such as a carer or advocate, and the timing of any decision ■

### Declaration of interest

The author declares that there is no conflict of interest.

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**Table 1. Symptoms of functioning NETs<sup>1</sup>**

Tumour	Symptoms
Insulinoma	Confusion, sweating, dizziness, weakness, unconsciousness, relief with eating
Gastrinoma	Zollinger-Ellison syndrome of severe peptic ulceration, diarrhoea
Glucagonoma	Weight loss, diabetes mellitus, stomatitis, diarrhoea, necrolytic migratory erythema
VIPoma	Verner-Morrison syndrome or profuse watery diarrhoea with marked hypokalaemia
Somatostatinoma	Weight loss, diarrhoea, steatorrhoea, diabetes mellitus, cholelithiasis



In this section, European and international palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

## **Romanian National Association for Palliative Care:** quality assurance for palliative care in Romania

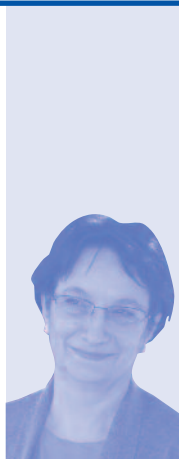
The Romanian National Association for Palliative Care has proposed a new methodology for the accreditation of palliative care services in the country

**W**ith a geographical area of almost 240 million sq km, Romania ranks as the ninth largest country in the EU and is the seventh largest by population, with just under 20 million inhabitants. With a negative birth rate, high mortality and an increasingly migratory workforce, Romania's population decreased by 7.2% between 2002 and 2011, while the proportion of people aged over 75 increased from 4.9% to 7.2% during the same period.<sup>1</sup>

In Romania, causes of death roughly follow the typical pattern prevalent in the EU, and diseases of the circulatory system and cancer are by far the leading causes of mortality. Cardiovascular diseases currently account for 1,293 deaths per 100,000 inhabitants, while cancer is the second major cause of death, averaging 270 deaths per 100,000 inhabitants.<sup>2</sup> The ageing trend of the population gradually shifts the disease pattern towards chronic progressive diseases, with people requiring long-term and palliative care interventions integrated into the general healthcare system.

### **The palliative care seed**

Palliative care started in Romania as early as 1992, when the Hospice Casa Sperantei Foundation was set up in the city of Brasov as a non-governmental charity, a UK-Romanian hospice partnership initiated by Graham Perolls from the UK. The organisation assumed the mission to introduce



**Mălina Dumitrescu and Vladimir Porocho**  
Romanian National Association for Palliative Care

and develop palliative care in Romania. The beginnings were focused on providing home-based palliative care for adult cancer patients following their discharge from the oncology hospital. In 1996, the Brasov hospice team was extended, reaching out to children with cancer and life-limiting conditions and providing palliative care in children's homes, in close co-operation with the Brasov Paediatric Hospital.

A decade later, Hospice Casa Sperantei – the first Romanian centre for palliative care services and education – was built in Brasov. The hospice hosts a 13-bed adult inpatient unit for cancer patients and a paediatric inpatient unit with six beds for children with a range of life-limiting diseases. It is now one of the largest non-governmental organisations in Romania, with over 260 employees and 350 volunteers, and provides services for 2,500 new patients each year in Bucharest and the county of Brasov. It has been actively involved in developing services and national and international education programmes in the palliative care field, and in the advancement and integration of palliative care into the Romanian healthcare system. In 2003, Hospice Casa Sperantei was nominated by the Open Society Foundations (OSF), formerly the Open Society Institute, as one of five beacons of excellence in SE Europe (along with hospices in Budapest, Poznan, St Petersburg and Warsaw) in an exhaustive study of end-of-life care, carried out among 475 services in 28 countries in Eastern Europe and Central Asia.<sup>3</sup>

**Box 1. National Association of Palliative Care pilot projects**

- Integration of palliative care in the medical treatment of advanced malignancies for the benefit of patients and for increasing quality of medical care in various healthcare institutions.<sup>6</sup>
- Overcoming disparities in access to quality basic palliative care in the community: partnerships to identify and improve clinical, educational, legal and economical barriers.<sup>7</sup>
- Creating a national evaluation system for palliative care services targeting vulnerable populations.<sup>8</sup>
- Developing a new pathway for management of palliative care patients with advanced cancer in Iași county.<sup>9</sup>
- Physicians' education for pain in NE Romania – PEPNER.<sup>10</sup>
- Open online courses with videos for the palliative clinical field and intercultural and multilingual medical communication – MedLang.<sup>11</sup>

**The National Association of Palliative Care**

In 1997, a group of enthusiastic professionals led by Dr Daniela Mosoiu founded the National Association of Palliative Care (ANIP). The association is open to any professionals working in palliative care services or interested in this field.

Several regulations specific to palliative care were advanced by ANIP and boosted the development of new services over the last decade: a new law for pain control medication (2005);<sup>4</sup> financing mechanisms<sup>5</sup> for inpatient units by fee per admission day (since 2007) and for home-based palliative care by fee per visit (since 2010), through the national health insurance system; and the establishment of minimum staffing ratios for palliative care inpatient units (2010). ANIP also publishes a palliative care services directory every second year.

ANIP members have been actively involved in several pilot projects (see Box 1) concerned with services development and national education programmes for palliative care professionals, as well as in legal initiatives in support of the new field.

**Standards for palliative care services**

Along with support for the quantitative extension of services throughout the country and the appropriate education of palliative care professionals at pre- and post-graduate level, ANIP had a significant input in elaborating national standards for palliative care services in various settings.

In 2002, ANIP initiated a consultation process with groups of various specialists in palliative care, including physicians, nurses, social workers, psychologists and services administrators, in an attempt to develop minimum standards for palliative care services in Romania. These first

standards were developed with the support of the National Hospice and Palliative Care Organization (NHPCO) in the USA. The standards were conceived as a set of criteria to be met by any potential palliative care service, and also to help health and funding authorities evaluate existing and emerging services. The standards were reviewed and upgraded for inpatient units, outpatient clinics and home-based services in a similar process in 2010.

**20 years of palliative care services development**

Since 1992, new palliative care services have been set up in both the public and private healthcare systems. The current legal framework and the funding mechanisms have been gradually encouraging the emergence of new palliative care services, particularly as inpatient units. Home-based palliative care services are still isolated private initiatives, and their funding through the health insurances system is low, despite the fact that 70% of people die at home in Romania and most of them wish to be looked after in their home environment at the end of life.

The map of specialised palliative care services, as illustrated in the last service directory published in 2014<sup>12</sup> by ANIP, shows 79 services delivered by 47 providers – 20 in the public healthcare system, 23 non-governmental charitable organisations and 4 for-profit services. It has been estimated that more than 150,000 people annually need palliative care in Romania, using an international estimation methodology<sup>13</sup> based on epidemiological criteria. Comparing the estimated needs for palliative care services for oncological and non-oncological patients to the actual services available, Romania had 7.9% needs coverage in 2015. The distribution of services was rather inconsistent, with 19 counties out of 41 still having no palliative care providers. The slow and random development of services is due to the fact that palliative care has only recently been included in the national healthcare strategy,<sup>14</sup> with an ambitious strategic objective of reaching 60% coverage of the overall needs for palliative care by 2020.

**A national strategy for palliative care**

In support of the 60% coverage objective, ANIP developed, in partnership with the Ministry of Health, a proposal for a national palliative care strategy, in a joint consultation process with palliative care services professionals and international healthcare consultants. The proposed strategy was based on the existing resources available and on a gradual and consistent development of services in all

the 41 counties of Romania, and encompassed three distinct types of service:

- patients' self-care education
- basic palliative care provided by family doctors in the community for patients with cancer and other progressive illnesses who have non-complex conditions
- specialist palliative care services for patients with complex, chronic progressive diseases and co-morbidities.

The principle of the strategy is to ensure patients' access to services at geographical levels: for relatively uncomplicated cases – basic palliative care services at local level, as close as possible to their home location; for cases with complex needs – specialised palliative care services at regional/county level. The national level is devoted to education of staff, research and raising awareness of palliative care. The principles of the national strategy were included in the recent Health Sector Reform supported by a World Bank loan<sup>15</sup> between 2014 and 2020. The project will support an equitable development of palliative care services throughout all counties, with 29 inpatient units in areas without coverage, 90 home care teams and 90 outpatient clinics.

## Quantity and quality in palliative care services delivery

Today, ANIP envisages a new stage in the development of palliative care in Romania. Following the slow and steady quantitative development of services over the past two decades, and with the current support of the World Bank health reform project, the organisation has been concerned for the quality of existing and emerging services. To this end, ANIP proposed a novel methodology for the accreditation of all services in inpatient units and home-based services, public or private. The two-year pilot project received European Economic Area (EEA) Grants funding and was a good opportunity for co-operation between public and private sector representatives; it aimed to include specific palliative care standards in the national accreditation process of hospitals and home-care. The project taskforce consisted of a wide range of stakeholders with interests in the advancement of palliative care. These included: professionals from various disciplines, such as physicians, nurses, psychologists, social workers, in public and private service providers; and representatives of public hospitals, such as the Regional Oncology Centre in Iași and the Municipal Hospital Campia Turzii, charitable hospice organisations, healthcare decision-makers and funding authorities (health insurance houses).

The group developed two specific methodologies for the accreditation of palliative care services in inpatient units and home-based services and defined the accreditation process. The methodology was detailed and published in the 'Accreditation Guidelines for Palliative Care Providers'.<sup>16</sup> The providers are awarded four levels of accreditation:

- Level A – excellence in palliative care provision
- Level B – high level of palliative care provision
- Level C – basic level of palliative care provision
- Level D – accredited with compliance plan.

The newly proposed methodology was adopted by the National Agency for the Management of Healthcare Quality and will be used in the next accreditation cycle to assess all palliative care providers in Romania in inpatient units and home-based services.

As a professional organisation, ANIP and its members are committed in the years to come to playing an increasing role in the national development of palliative care in Romania at academic, educational, professional and scientific levels, as well as working towards quality services development, advocacy and awareness ■

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