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Why is the end-of-life experience still not improving?

Efforts to improve symptom control near the end of life have received more attention in recent years, but the impact is often frustratingly small.

Simon Crompton asks where we are going wrong.

Seven years ago, Neil Bonser died from a sarcoma, aged 35. He was at home with his family, where he wanted to be, relatively free of pain, and supported by a Macmillan nurse. Neil's father, Tony, knows that the family got

considerably better end-of-life care than many people. But there are still regrets.

No health professional mentioned the prospect of Neil dying from the point of his diagnosis until two days before this death, five years later.

"Because of this, we lived in hope, probably long after there was, in fact, no hope," says Tony. "Most of his last six months were spent in a fruitless search for a cure, which denied him the opportunity to enjoy the time he had

left. It also meant that all of us suffered high levels of anger, as his health steadily declined.”

Tony, from Lancashire in the UK, is now a key figure in campaigns to improve end-of-life care. Would things be any better for Neil today? A lot has changed in the UK, says Tony, who has travelled around the country looking at examples of best practice: more people are able to die at home; there's greater awareness of and knowledge about symptom control and patient comfort; more professionals are trained to administer pain relief in the community.

But beyond the best practice, are people always getting access to the right medications at the right time as death approaches? Are they getting information and consultation when they need it? Are they being helped to the right balance between consciousness and pain? And is the quality of death actually improving? He's not so sure.

“There's still a lack of awareness of the dying process,” he says. “And my experience is that, at home, it's still difficult to get the drugs and people with appropriate training at the right time.”

Tony Bonser's experience reflects a contradictory situation that applies through much of Europe. On the one hand, awareness of the importance of palliative care is growing in health systems, and end-of-life care is improving in some countries. But there are still massive gaps and failings.

True, palliative care is no longer the ‘Cinderella service’ it once was in much of the world. A major step forward occurred in 2014 when the World Health Assembly adopted a resolution urging member states to integrate palliative care services into the continuum of care. And a wave of surveys and studies have indicated recent international progress.

A 2015 analysis of quality of death

by The Economist Intelligence Unit concluded: “it is clear that some countries are stepping up their efforts to ensure all citizens have access to palliative care.” The European Association for Palliative Care's *Atlas of Palliative Care in Europe* in 2005 and 2012 has shown that there has been significant development of at least one type of palliative care service in 21 of 46 European countries.

“At home, it's still difficult to get the drugs and people with appropriate training at the right time”

Yet the variations from country to country are still astounding. Carlos Centeno, who has headed work on the European Association for Palliative Care's (EAPC's) atlas says: “In western Europe we've seen some development of palliative care in in-patient units, but in central and eastern Europe, nothing. I don't know how western Europe can forget the other parts of Europe.”

What's more, it's not always clear that development of palliative care services actually results in more people having better deaths.

Research from the David Geffen School of Medicine, University of California, has indicated that, despite national efforts to improve end-of-life care in the United States, proxy reports of pain and other alarming symptoms in the last year of life increased between 1998 to 2010. Reports of pain rose from 54.3% to 60.8%, and reports of depression and confusion from 26.6% to 31.3%.

The study was in the United States, but Stein Kaasa, Professor of Oncology and Palliative Medicine at the University of Oslo and Head of the Department of Oncology, says that studies on pain intensity in Norway have similar findings. Two evaluations over five years found that, despite more resources and training being poured into pain and symptom management, there was no improvement in patient-reported pain scores.

Disappointing results

“It's very disappointing,” says Kaasa. He believes one explanation may be that improvement programmes aren't sufficiently focused and reaching into the clinical decision making process. “Pain control is still not central to decision making in oncology. The focus is still too often on the tumour and saving life, and that's why I strongly argue for integrating palliative care into the care pathway for all patients.”

Small studies of proxy and patient reported scores of pain and other symptoms may be flawed, but in the absence of population-based data on end of life, they deserve attention. Research into national trends in palliative care at end of life has been extensive over the past five years, but it uses indicators that can provide international comparisons. These demonstrate how patchy services are from nation to nation, but do not necessarily reflect patient experience.

The indicators roughly fall into two categories: availability of symptom-relieving drugs, and availability of palliative care services. On drugs, for example, the WHO Collaborating Center for Pain Policy and Palliative Care publishes global data for total opioid consumption, which shows that people in Austria, Germany, Denmark, Switzerland and the UK are consuming

twice the amount of opioids per capita as Portugal, Slovenia, France, Iceland and Italy.

"If you look over the past 30 years, global consumption of morphine has increased considerably, although the increase has been much larger in higher-income countries," says Liliana De Lima, Executive Director of the International Association for Hospice and Palliative Care. "But it's a very raw indicator, because it may be being over used or figures may include non-palliative use."

The other basic indicator is the number of palliative care services. This forms the basis of European rankings produced by the EAPC in its atlas. The 2013 statistics show that the highest concentration of palliative care units can be found in Ireland, Iceland and Belgium, with almost 18–20 units per million inhabitants. The UK, Sweden, The Netherlands, Poland and Austria have 12–16 units per million.

But although comparisons between the data from 2005 and 2012 suggest that there has been overall growth, services in most countries are still inadequate to meet the needs of the population.

Most of the evolution is characterised by expanding in-patient palliative care services, but development of home care and hospital support teams has been slow. Carlos Centeno, who is clinical consultant at the Department of Palliative Medicine of the University of Navarra, Spain, says the lack of hospital support teams is particularly disappointing, given the impact they can have on integrating palliative considerations into all aspects of care.

"Does having more palliative care services result in more people having a better end-of-life experience? I don't have the answer to that, but many studies and all my experience over 20 years suggest this is the case."

Flexibility is important

But Kaasa believes it's more complex than that. Yes, certainly, having access to competent healthcare providers and home care nurses at end of life is vitally important. But equally important, as far as the end-of-life experience is concerned, is having sufficient flexibility within systems so that access to and transfers between hospitals, hospices and home care teams can occur at the right time for the patient and family.

"Access to hospitals, hospices and home care, and transfers between them, should be possible at the right time"

"Most patients want to stay at home as long as possible at the end of life, and it's important that this is made possible," says Kaasa. "But that shouldn't be the only benchmark for good end-of-life care. Death at home can be very hard for the family, and it should be one option, not the only one."

Kaasa is concerned that end-of-life experiences may not significantly improve as long as medical systems allow treatment to take priority over symptom management long after they should – as Tony Bonser and his family found out. "It's become more and more evident that symptom management should be in clinical pathways long before end of life is considered," says Kaasa. "And when a patient is getting to the stage where therapy isn't having any effect, then you need to start talking to the patient about end of life."

In Germany, there have been recent

advances in access to palliative care, with state funding available since 2007 for outpatient end-of-life care provided by qualified carers. Yet the culture of treatment still dominates, according to Jutta Hubner, a German palliative care doctor and currently head of the database project at the German Cancer Society.

"We are a long way from early integration and a more 'normal' contact with the palliative care. I think no active anti-tumour therapy within the last four weeks of life is an important marker of high-quality cancer care. But it's my impression that patients are still being treated nearly until their death, especially in highly specialised clinics."

"Mostly the oncologist and the palliative care physician are different people – but I think that every oncologist and every other specialist caring for cancer patients should have a foundation in palliative care and communication."

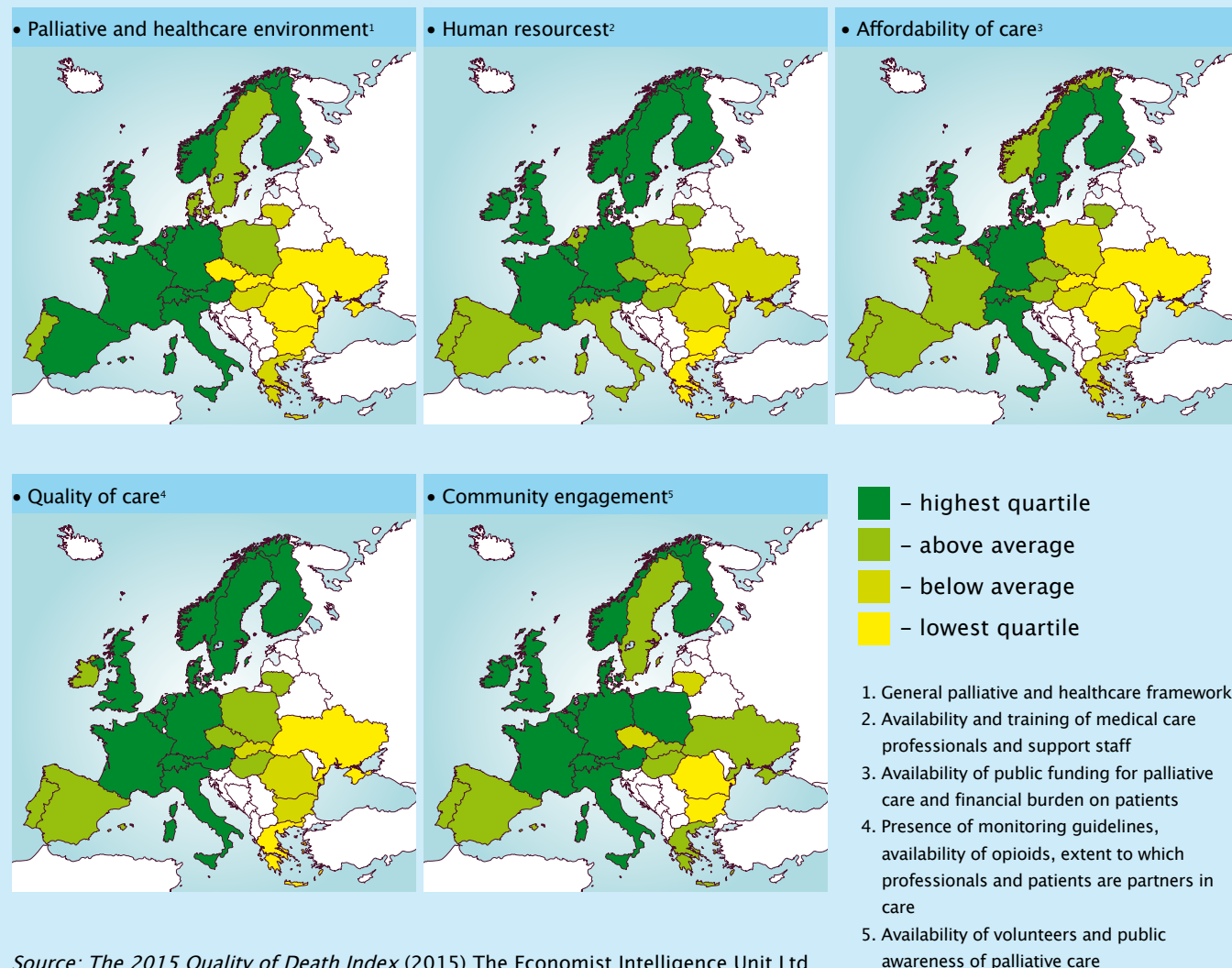
Integrating symptom control

Matti Aapro, a director of the Multidisciplinary Oncology Institute in Genolier, Switzerland, also believes the answer is integrating symptom management into a continuum of care. "Currently, when active treatment no longer works, patients are sometimes sent to another team entirely for end-of-life care," he says. "And they can feel they've been abandoned."

But though end-of-life care in western Europe is far from perfect, central and eastern Europe is in a completely lower league, whichever indicator you use. The Economist Intelligence Unit's 2015 Quality of Death Index ranked Ukraine, Romania and Bulgaria among the 20 worst performing countries in the world. The index was formed from scores of five indicators: palliative

Quality of death across Europe

The Economist Intelligence Unit ranked countries across the world according to the availability, affordability and quality of palliative care available to adults. Countries were scored according to 20 indicators, in five categories. These maps show the global quartile rankings for European countries



and healthcare environment; human resources; affordability; quality of care; and community engagement.

Equally, the European Association for Palliative Care (EAPC) survey of 53 countries shows that coverage of specialised palliative care services in

central and eastern Europe is very limited – with just 14% coverage for home care teams, compared with 52% in western Europe.

Yet there are hopeful signs. The experience of Romania in the past five years, for example, provides not only the

prospect of considerable improvements for cancer patients at the end of life in that country, but also a clear indication of what it takes to bring the kind of reform that Kaasa and Aapro believe is the long-term solution to improving patients' experience at end of life.

Hopeful signs

The EAPC atlas shows that Romania ranked 26th out of 28 European countries in terms of palliative care resources in 2013. Yet in terms of palliative care “vitality” – an EAPC index reflecting existence of a national association, directory of services available, existence of physician specialisation, level of attendance at conferences and level of publication – Romania ranked third, surpassed only by Germany and the UK.

Ten years ago, there were no in-patient palliative care services. Today there are 75.

Daniela Mosoiu, National Director for Education, Strategy and Development at the Hospice Casa Sperantei Foundation, Brasov, is excited at the development of palliative care in Romania. A national development strategy began in 2010 and now has backing from the World Bank.

“The state is becoming more aware of its responsibilities,” says Mosoiu. And since the strategy coincides with a long-running health service reorganisation, new initiatives are being integrated into mainstream health systems. “The body responsible for hospital accreditation has now put forward new standards for relieving suffering at end of life, and one of the criteria they are using is pain. Hospitals have to assess symptoms and have appropriate medications ready in the pharmacy. There will be an assessment system for hospitals from the beginning of next year.”

There is also progress in education, with palliative care now recognised as a subspeciality, and a long waiting list of doctors waiting to enrol in training.

Use of opioids has not increased significantly over the past 10 years, she says, even though national regulations changed in 2007 to make them available to all doctors and

pharmacies. “There’s the question of whether clinicians are confident to use them, and there are also patient fears,” she says. Interestingly, pilot studies examining the impact of symptom management by GPs in patients at home have indicated that it is counselling, emotional support and grief support that are most valued by patients and families, not pain relief.

But Mosoiu is hopeful that in five years’ time, Romania will no longer be at the bottom of the palliative care rankings. What’s been the main factor that has brought such vibrancy and willingness to change in both government and health systems? Mosoiu is clear. “The pressure has come from the grass roots – from people with knowledge in palliative care pushing authorities, putting forward proposals, persuading them of the need to change regulations. The programmes have been developed by local managers.”

Pressure from below

That message – that the individuals with knowledge and passion about palliative care are the ones who can change healthcare systems to integrate it – is echoed by many others.

Liliana De Lima says the key ingredients for improving end-of-life care are political will and palliative care champions. “Each country needs people who are energised and keep pursuing their agenda to push it forward. People like Daniela Mosoiu.”

Carlos Centeno believes you achieve that kind of energy by ensuring that as many people as possible are educated about symptom management and the potential of palliative care.

“The key to good end-of-life care is integration,” he says. “If it’s outside the health system in an independent

hospice, it doesn’t work. If it’s just for cancer patients, it doesn’t work. If it’s in the last week rather than the last months, it doesn’t work. It has to be part of a health system and part of a home care system. As I heard at a conference recently, palliative care has to be as the air that we breathe.”

“It’s people standing up locally and saying that palliative care is important that has brought real change”

“How do you get that integration? If we started teaching palliative care to all medical and nursing students today, we would have integrated palliative care in 10 years. We need all physicians to know about symptom management, and then things will change.”

And Tony Bonser is equally clear that yes, funding, infrastructure and political will are all important if end-of-life experience is to improve for patients and their families. But from what he’s seen, it’s people standing up locally and saying that palliative care is important that has brought real change.

“My impression is that improvements in experience at end of life are not driven by pathways, or schedules or inspections. They’re driven by the right people saying: ‘This is important.’ We’re still in the situation where we’re having to convince doctors that a good death is a success, not a failure. There has to be a change of perspective among medics, so that palliative care becomes a fundamental part of what they do.”