

Palliative Medicine: has there been mission rift?





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Why do we seek to quantify the unquantifiable?

In 1987, palliative medicine was accredited by the Royal College of Physicians (RCP), London, as a subspecialty to general internal medicine.² This milestone marked a recognition that the rigid parameters of an increasingly technological medical model were inappropriate for the provision of holistic, patient-centred care. In return, the RCP provided an important platform on which the specialty could grow.

With its new-found status, one of palliative medicine's first challenges was to confront the prospect of evidence-based medicine. This new paradigm suggested tradition, anecdote and theoretical reasoning be replaced by evidence from high-quality randomised control trials and observational studies.³ In combination with 'clinical expertise', these were to provide clinicians with the knowledge to drive healthcare into the new millennium. Thirty years later, other specialties have amassed an evidence base that stands tall over that of palliative medicine. However, somewhat contradictorily, palliative medicine is widely regarded as offering a standard of care second to none. Within this paradox lies the answer to what really matters to people.

Evidence-based medicine has its limitations. It has become distorted by vested interests, uses surrogate outcomes to establish efficacy, is a poor fit for frailty and multi-morbidity, and there are huge problems with publication bias.⁴ Despite this, we have created a volume of research and guidelines that has left us at saturation point. Compulsive reliance on evidence has created a breed of clinician trained in following a template-driven approach that stifles development of the subtleties of clinical expertise.

What lies beyond evidence-based medicine? Kearney spoke of a two-tiered approach to patient care, the surface and the deep,⁵ arguing that the totality of any experience consists of interwoven elements of both. At the surface level, knowledge is scientific and rational, requiring an evidence base. At the deep level, knowledge is intuitive and the language flush with symbolism and metaphor. Working at this level is where there is potential for healing in its purest sense. The evaluation of such a service is captured by a woman's reflections on her experience:

'I can't help thinking of Rembrandt's paintings, where the light is so glorious that it makes even the darkness look beautiful.'

Unknown⁵

■ Rembrandt van Rijn, *The Night Watch*, 1642. 'It is an icon of tolerance, diversity and the magic golden light that makes a society work. While these ordinary people stand guard, we feel a bit safer in our collective defiance of the dark.' – Jonathan Jones, *The Guardian*, 6 May 2013

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In times of economic austerity there is increasing pressure to validate and quantify the impact of services or else suffer cuts. Do we conform to the medical model and seek to prove our worth at surface level as symptomatologists? Or do we once again break with tradition and promote the judicious use of professional knowledge and status while engaging with holistic measures, harnessing the power of narrative as an evaluative measure. Whatever the answer is, we must not let the debate pass us by. As general medicine is integrated into specialist training in the UK, and hospices widely adopt quantitative outcome measures, there is concern that the specialty develops in a way that limits its potential. We must learn to once again value our intuition and use our position in the Royal College for what it was intended back in 1987: to integrate the palliative care approach into everyday practice ■

Declaration of interest

The author declares that there is no conflict of interest.

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**Editor’s response:
Reductionism or
holism? – that is
the question**

Dr Sawyer suggests that

palliative physicians have diverged from the original intentions of the specialty. We have, he suggests, sold out to the evidence-based universe, and are most at ease with our role as technical symptom managers.

But we do need to be at ease with symptom management. As the palliative pioneer Dr Derek Doyle said, ‘No man can come to terms with his god when every waking moment is taken up with pain or vomiting.’¹ Having said that, it is perhaps the most teachable aspect of our work and the easiest domain to default to when faced with patients in the midst of extreme suffering, uncertainty and multiple losses. So have we defaulted to the simple, ignoring the deeper layers of suffering that Michael Kearney alludes to?

Dr Don Berwick, US quality guru, suggests that there are three eras of medicine.² Era 1 dates back to Hippocrates, the ascendancy of doctors, science, progress and privilege, when medicine had the ‘authority to judge the quality of its own work’. This approach led to enormous variation, inequity and

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secrecy. Era 2 – the present – is dominated by marketeering, incentives and measurement of what may not matter. Health professionals feel misunderstood, hounded and demoralised. Berwick suggests that Era 3 will be the ‘moral’ era, which will reject the protectionism of Era 1 and the reductionism of Era 2. It will recognise the patient voice, establish what is truly important to measure and perhaps bring the notion of healing and ‘whole person’ care back into medicine. The word ‘heal’ forms four letters of the word ‘health’, but it is not part of the vocabulary of contemporary medicine.

A recent study suggested that patients see palliative medicine and hospices as metaphors for death.³ Doctors are also guilty of this, which has become a massive barrier to considering a palliative approach, often when it is most needed. Death may be seen as increasingly cool at death festivals and cafes,⁴ but it is still unspeakable in medicine. So the glorious technical progress of medicine has led us to do too much, too often, and we need to somehow find a way to turn this tanker round. It needs to start with medical education.

Some medical schools have less than a single day in their five-year curriculum in which to focus on what matters to patients and doctors at the end of life. Less than a day to think about the limits of medicine, how to be with distress and uncertainty. Less than a day to help doctors to think about how patients regain meaning in the midst of multiple losses – indeed how to be with helplessness. When palliative placements are given higher priority, these experiences are rated very highly by medical students, in terms of preparing them to face dying patients from day one as a new doctor.⁵

Our care must not simply be fragmented into measureable interventions – such interventions rarely make the difference patients and families are looking for. The presence, the attention, the wisdom, the stories – these all contribute to the ‘lessening of the fear’ that Kearney talks about as a key goal of care when patients feel the ‘existential slap’.⁶ These approaches need to be revered, even if they can’t be measured ■

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