

# Challenges to delivering evidence-based palliative medicine

Authors: Caroline Barry,<sup>A</sup> Paul Paes,<sup>B</sup> Simon Noble<sup>C</sup> and Andrew Davies<sup>D</sup>

## ABSTRACT

Established as a medical specialty in 1987, palliative medicine approaches middle age facing existential questions of identity, purpose and vision. Time has weakened strong foundations laid by Dame Cicely Saunders in research, education and clinical excellence. Clinical knowledge gaps are wide, and widening. Palliative medicine research is underfunded and underrepresented in discourse. Despite huge advances in modern medicine, there is still clinical uncertainty about simple interventions, such as whether artificial hydration at the end of life is helpful or harmful. Where good quality data do exist, the pace of change is slow, if change is happening at all. Trial design often fails to assess the holistic impact of interventions, using primary endpoints that are inconsistent with outcomes most valued to the patient. Recent years have seen a rapid expansion in innovation and investment in digital technologies, embraced by many in palliative medicine. Experience shows that caution must be applied where the evidence base is sparse. While as a specialty we must remain forward looking and progressive in our mindset, it cannot be assumed that these new interventions alone will provide the solutions to the old problems that exist in palliative medicine.

This review summarises the key points presented in the Palliative Medicine section of the RCP Clinical Medicine Conference, 2022.

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## The modern history of palliative care

St Christopher's Hospice was founded in 1967 with the aim of 'integrating a scientific programme concerned with the discriminating use of drugs with the "tender loving care"' seen

**Authors:** <sup>A</sup>consultant in palliative medicine, Norfolk and Norwich NHS Foundation Trust, Norwich, UK, and clinical associate professor in translational and clinical medicine, University of East Anglia, Norwich, UK; <sup>B</sup>consultant/reader in palliative medicine, Northumbria Healthcare NHS Foundation Trust, Northumbria, UK; <sup>C</sup>Marie Curie professor in supportive and palliative medicine, Cardiff University, Cardiff, UK; <sup>D</sup>professor of palliative medicine, Trinity College Dublin, University College Dublin and Our Lady's Hospice, Dublin, Ireland

in traditional hospices.<sup>1</sup> Funding for research, alongside clinical services, helped to identify optimal holistic treatment methods, including comparative studies of morphine and diamorphine,<sup>2</sup> and evaluation of homecare services.<sup>3</sup>

A flurry of trials in the 1970s enhanced understanding of the safety and effectiveness of opioids in the treatment of cancer pain. Expansion in research mirrored the increase in the number of hospices, home care services and hospital palliative care teams across the country, but by the time palliative medicine was recognised as a specialty in 1987, there was increasing separation of research from clinical practice.

In the 1990s, epidemiological approaches came to the fore; there was a shift from focusing on the best care for the individual to a desire to understand the needs of the population, and a widening scope of practice, from mainly cancer care to a range of non-malignant diseases.<sup>4</sup>

Understanding the needs of the population necessitated a generalist, system-based approach. Policy,<sup>5</sup> principles<sup>6</sup> and education<sup>7</sup> were developed to facilitate, rather than deliver, 'gold standard' palliative care. The seismic fallout from the Mid Staffordshire Enquiry<sup>8</sup> and misuse of the Liverpool Care Pathway<sup>9</sup> exposed the drawbacks of this approach, dispatching the myth that providing the 'tools of the trade' was sufficient to improve end of life care.

## The present day: the evidence for innovation

The COVID-19 pandemic provided a new stimulus for innovation in palliative medicine and accelerated the use of telemedicine and other digital health interventions (DHIs). It is important in the post-pandemic era to evaluate these interventions for clinical and cost effectiveness, in comparison to standard interventions, to justify their ongoing use.

A recent meta review of DHIs (including telemedicine) in palliative care, involving 332 publications and 21 systematic reviews, found that while DHIs were '*useful, safe and acceptable*' for many, evidence of quality of life, physical and psychological benefits was deemed '*inconclusive*'.<sup>10</sup> In other words, we still don't know whether or not specific DHIs are better than the old ways or whether indeed they are worse.

Data from other patient groups suggest that certain DHIs could be useful in palliative care. For example, remote monitoring in oncology patients has been shown to improve symptom management and quality of life and to reduce admissions and the use of hospital services such as A&E.<sup>11,12</sup> Remote monitoring may also help to mitigate some of the workforce issues affecting palliative medicine, which are likely to increase in coming years.

Feasibility studies of remote monitoring in palliative care have shown potential, and future studies involving a combination of patient-reported outcome measures (PROMs), carer-reported outcome measures, and remote monitoring of vital signs (using photoplethysmography) are about to commence. It is anticipated that this 'remote comprehensive holistic assessment' will be more effective than an isolated assessment of PROMs.

Artificial intelligence is another potentially important area for palliative care, with researchers trialling machine learning to improve prognostication in cancer patients. Models have been developed that incorporate both recognised prognostic indicators (eg C-reactive protein), and other clinical parameters (eg subjective sleep parameters). The results of an initial study (unpublished) are encouraging, although these models need further testing.<sup>13</sup>

### The future: evidence-based empathy?

Despite a promising start, over the years palliative medicine has struggled to embed its practice within a robust and systematic evidence base. The barriers to producing conventional high-quality research (namely adequately powered randomised control trials) are well documented.<sup>14</sup> Over time, these barriers have proven surmountable through improved funding, infrastructure and collaboration; however, even where there is evidence from research, the translation of evidence into practice has been slow.

The findings of several recent studies that challenge established clinical practice have faced a lukewarm reception by the specialty. Attitudes that such new data 'should not negate 20 years of generally positive experience' still prevail,<sup>15</sup> where high-quality new data emerges which runs contrary to the closely held beliefs about a preferred therapeutic approach.

Justified critique is often applied to the narrow focus of clinical research and inappropriate selection of primary outcomes, which are often not relevant to clinical practice or reflective of patient experience.<sup>16</sup> It is ironic that a specialty often perceived as particularly empathic towards the suffering of ill health produces research of limited practical application due to a lack of applied empathy in developing trial outcomes linked to patient values.

Evidence-based empathy, in this context, could be achieved by employing a systematic approach to developing a core outcome set for a particular condition. Such methodology is well established and involves using the results of a systematic review of current data and a qualitative study to inform a Delphi process.<sup>17</sup> Under the direction of a clinical/ patient expert group a core outcome set will be generated and evaluated for face validity and application. Future research should ensure that outcomes are standardised and clinically meaningful to the patient.

### Defining palliative medicine

Statutory commissioning of specialist palliative care services provided for in the Health and Social Care Act of 2022 is an opportunity to reflect on service delivery, standardise quality measures and embed evidence based practice.

In order to do so, the specialty faces an outstanding challenge, in how to define palliative care to itself and others. On one hand, there has recently been an acute-led reinvigoration of the specialty relationship with cancer, expanding beyond the last year of life to the point of diagnosis, or even to those with curative disease. This has led some teams to distance themselves from the name 'specialist palliative care' to become 'enhanced supportive care' teams.<sup>18</sup>

In contrast, the focus on specialist palliative care teams with Care Quality Commission (CQC) inspections has led in some parts to an assumption of direct responsibility for all aspects of end-of-life care by hospital palliative care teams, potentially disempowering other 'generalist' teams in providing such care while diluting the 'specialist' nature of palliative care practice.

Alongside these internal debates, the specialty must assess its readiness to challenge the wider social determinates of death, dying and grief, whilst defining its role in relation to the community that it serves.<sup>19</sup>

On the cusp of middle age, therefore, the specialty of palliative medicine is at a crossroad. Lack of clarity and consistency on the purpose of the specialty is a risk, particularly where the relationship between practice and evidence diverges.

New technologies have an important role in supporting this, but risk being clouded by some of the old challenges of palliative care delivery including service variation, ambiguous definitions, and the potential for exclusion of certain patient groups. All palliative care professionals have a responsibility for delivering evidence-based practice, and to be thoughtfully curious about the impact of new technologies in achieving equity and value across the system. ■

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**Address for correspondence: Dr Caroline Barry, Norfolk and Norwich NHS Foundation Trust, Colney Ln, Norwich NR4 7UY, UK.**  
**Email: [caroline.barry@nnuh.nhs.uk](mailto:caroline.barry@nnuh.nhs.uk)**