

IMPROVEMENTS IN PALLIATIVE AND END OF LIFE CARE REQUIRE A NEW APPROACH TO CHANGE

The recent article by Ireland¹ was a helpful reminder of the benefits of considering palliative care as an essential element of the health and care delivery system – one that will increasingly be required to meet the changing pattern of population healthcare needs. Palliation of symptoms, comfort and supportive care must become a more prominent feature of our approach to the planning and design of future models of care.

On a point of accuracy, the statement in Ireland's article that 50% of all hospital complaints relate to end of life care is not a statistic derived from hospital complaints data in Scotland. I could not locate a reference for this in the document cited in support. It possibly originates from the report by Leadbetter and Garber² which includes the statement: 'about 50 per cent of the **most serious complaints** [my emphasis] about acute hospitals relate to the conditions in which someone dies'. A statement which is supported by the UK Department of Health's *End of Life Care Strategy*³ which states 'Almost half of complaints about NHS services related to acute hospitals. Of these, 54 per cent related to the care given at the end of life', citing a report from the Healthcare Commission⁴ as the primary source. However, I cannot locate specific data or a supporting reference within that report. This figure on hospital complaints regarding end of life care, which has been cited widely, should therefore not be taken as representative until more definitive data are confirmed.

I highlight this repeated citation of a potentially misleading statistic to emphasise the need for urgent work to ensure that future strategic developments in palliative and end of life care are supported by accurate, timely and useful data that will drive improvements in the quality of care.

While there has been significant progress made to enhance awareness of palliative care in recent years, the problems with reliable implementation of the Liverpool Care Pathway act as a reminder that the development of action plans, resources and guidance will not lead to the pace and scale of improvements that will be required in the future. *Living and Dying Well*⁵ has not delivered all the changes needed – a new approach to support change will be required, supported by implementation and improvement science, informed by unprecedented levels of national dialogue about care preferences when cure is no longer an option and models of care that address the medicalisation of death and dying.⁶

A different approach to support change will, I believe, provide the conditions for a more sustainable system within which physicians can connect more readily with their professional values and deliver change that will see high quality palliative and end of life care be delivered for more people, more often and more consistently. The Scottish Government will be publishing a *Strategic Framework for Action for Palliative and End of Life Care* later this year to support this. The framework will set out objectives and priorities to guide our collective focus, link with national clinical strategic priorities and connect this work more explicitly with the vision beyond 2020 for health and social care in Scotland. All of this will be linked with the Scottish Government's strong track record of emphasising assets, co-production and improvement, including the links to *The 3-Step Improvement Framework for Scotland's Public Services*.⁷

I would encourage Members and Fellows to support dialogue within their teams on what should feature in the Strategic Framework and/or to share examples of improvements from other areas, countries or teams that could shape the future focus required in defining our future priorities and approaches to palliative care and care for people at the end of life.

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Author's reply

I thank Professor White for his comments on my editorial.¹

As former national clinical lead for palliative and end of life care, I welcome the Scottish Government's intention to provide the conditions for a more sustainable system within which physicians can connect more readily with their professional values and deliver change that will see high quality palliative and end of life care be delivered for more people, more often and more consistently.

Professor White is correct to point out that the reference to which he refers originates not in Scotland but from the Healthcare Commission. Its *Spotlight on Complaints* report assessed a total of just over 16,000 complaints about NHS organisations in England between July 2004 and July 2006. This is referenced in the Department of Health's *End of Life Strategy* in paragraph 1.6,² and subsequently in many national documents across the UK.

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DRESS CODE

As a doctor who retired before the imposition of the 'dress code', I first became aware of it when visiting hospitals as a visitor and/or patient. My first reaction was of surprise and I certainly found it very disconcerting when trying to identify medical staff. However I assumed that a major change like this must have had good scientific evidence. I was therefore fascinated to read the piece by Dancer and Duerden.^{1,2}

I believe that to understand how the 'white coat' problem developed we must go back to when Margaret Thatcher came to power. She said 'There is no such thing as society' and set out to change every public service, including the NHS, into self-financing independent businesses. She turned to Lord Sainsbury for advice, as he ran a large transnational business with multiple outlets of varying sizes.

According to Duerden,² the 'dress code' was introduced in response to a rising incidence of cross-infection. The code stated no white coats, even though 'of course

there is no such (scientific) evidence' that they carried infection. No ties because they might 'interfere with a clear view of the patient'. No wristwatches or jewellery. The code was drawn up by 'a group of the most senior medical and nursing officers in the Department [of Health]'. However the details suggest that the group had long since lost touch of the reality within hospitals where critical changes had taken place. The comment that 'within that management ethos, the only way to get the necessary attention and focus on the prevention and control of healthcare associated infections was to have targets for which Chief Executives were held accountable' shows that Duerden and his colleagues were more interested in 'looking good' and passing the buck for infection control to a lower level of the hierarchy than doing something effective. This looks like the behavior of a large supermarket business.

Dancer¹ provides a lot of factual evidence proving that the absence of white coats and other minor measures have had no effect on rates of infection, but the code allowed hospital authorities to ignore other, more likely, causes for the increases in cross-infection.

Dancer¹ describes the introduction of the 'dress code' as a political gesture towards hygiene and infection control with the white coat being 'a scapegoat for hospital-acquired infections' which meant 'the authorities could ignore all the other potential drivers of hospital superbugs'. I agree with her on this, and also with her suggestion that there was a purpose to reduce the status of doctors. Dancer¹ goes further and claims that the removal of white coats was a political manoeuvre designed to lower the status of doctors. I would support that possibility. Doctors now seem to be the scruffiest dressed people in the hospitals.

The rise in cross-infection in hospitals before 2007 is likely to be due to several factors including crowded wards, A&E overflow, poor cleaning and disinterest in infection control as specified by Dancer.¹ Another cause has been the steady reduction in the number of hospital beds to reduce costs. Patients may be admitted anywhere in a hospital, and are often in several different wards during an admission. Therefore clinical staff, of all grades, have to attend patients in many different wards. This multiplying of the numbers of people crossing many wards was probably a major reason for the increase of cross-infection.

Since the dress code was introduced, with no scientific evidence to support it, and with no proven beneficial effect since its introduction, the 'dress code' should be discarded at once.

Another major factor in infection control is the loss of the traditional organisation of hospital care, based on individual wards under the authority of ward Sister(s).

They had the responsibility and authority over everything that happened within a ward, including the ward cleaners who provided a very high standard of cleanliness, not only because they had been trained by the Sister but also because they felt that they were part of the team and took a pride in the cleanliness of 'their' ward. Cleaners supplied by outside contractors had no special training and no knowledge of medical matters, e.g. the same mop and water would be used in the ward, the toilets, the treatment areas etc. They would not take orders from the Sister, and their employers, more interested in making money than in the care of patients, could reduce the time allocated to each ward, and the rate of pay. This obviously increased the risk of transmission of infections.

The time has come to reassess how healthcare is organised and provided. I strongly believe that one aim should be to remove several highly paid layers of management, who have little knowledge of the practical needs, and return the authority to where it matters; at the front line of wards and outpatient care.

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RAISING THE INDEX OF SUSPICION FOR CONSTRICTIVE PERICARDITIS

I refer to the paper by Horne et al.¹ Reading between the lines, I wonder if the index of suspicion for constrictive pericarditis (CP) would have been heightened in July 2013 (as opposed to September 2013), when the patient presented with symptoms of congestive heart failure (CHF) despite intact left ventricular systolic function, if the height of the jugular venous pressure (JVP) had been documented,² and the brain natriuretic peptide (BNP) level evaluated, the latter in compliance with Guideline Recommendations.³

Elevation of JVP is a typical finding in CP and a JVP which is elevated to the angle of the jaw (with the patient sitting up) was a feature in 75% of 62 patients in one series.² When BNP is either within normal limits in a patient with clinical stigmata of CHF or only modestly elevated (up to 186 pg/ml in one study),⁴ CP should be included in the differential diagnosis of CHF in a patient with intact left ventricular systolic function.⁴ In the latter study, among six patients with CP (and

normal left ventricular systolic function), BNP ranged from normal to 186 pg/ml vs 639–1,060 pg/ml in the subgroup of five restrictive cardiomyopathy patients.⁴ Normal levels of N-terminal pro-B type natriuretic peptide were also reported in a CP patient with intact left ventricular systolic function, despite 'markedly distended jugular veins' ascites, and peripheral oedema.⁵ Accordingly, when JVP is strikingly elevated in a patient with intact left ventricular systolic function, and the BNP level is either normal or not as high as one would expect for the observed clinical degree of severity of CHF, CP should be included in the differential diagnosis.

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OF POPPIES AND MEN – FROM TRENCH NEPHRITIS TO GULF WAR SYNDROME

John Steinbeck's novel, *Of Mice and Men*, is about what it means to be human. Sadly, to be human also means that death is inevitable and that modern medicine is not always that effective.

In 2014, 888,246 ceramic red poppies filled the Tower of London's famous moat as a stark reminder of the number of British soldiers killed during World War I.

Throughout history, war and infectious diseases have been uneasy bedfellows and it seems that this phrase still rings true today. In the spring of 1915, reports of a new disease emerged from the battlefields.^{1,2} This led to approximately 35,000 admissions to hospital among British soldiers alone; with 95% of cases occurring in frontline men, thus having a small but significant impact.¹

Trench nephritis soon provoked keen interest from both medical-military authorities and the home front.¹ Sadly no exact cause was ever found and, in September

1918, an editorial published in the *Lancet*,³ stated: 'The growth of a child is notoriously discontinuous and it often happens that knowledge of a new disease advances sometimes rapidly, sometimes with tiresome slowness, while apparently the same amount of work is being put into it by competent investigators. A striking example of this is given by war nephritis.' The editorial hereby acknowledged that no exact cause could be found for a disease that led to incomplete recovery of renal function in 40% of patients, leaving them with their general health permanently impaired.²

In 2008, another editorial was published in the *Lancet*⁴ stating that: 'a congressionally mandated group has concluded that Gulf War syndrome is a real, serious and in many cases, deadly illness.' This statement acknowledged that more than 174,000 US veterans and 6,000–12,000 UK soldiers suffered from chronic headaches, fatigue, cognitive problems, pain and chronic digestive, respiratory and skin disorders, which were initially attributed to pesticides and pyridostigmine bromide.⁴ However, Gulf War syndrome is still a topic of heated debate and no consensus on its cause has yet been reached.^{5,6}

A hundred years later, after yet another war, the 1918 *Lancet* editorial still rings true – the growth of a child is still notoriously discontinuous...

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Please note that opinions expressed in Letters to the Editor should not be taken as those of the Editorial team or the Royal College of Physicians of Edinburgh.

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