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THE LIVERPOOL CARE PATHWAY: WHAT DO SPECIALISTS THINK?

Use of the Liverpool care pathway for end of life care has been heavily criticised in the media. The *BMJ* and Channel 4's *Dispatches* asked doctors for their views. **Krishna Chinthapalli** reports

Thirty years ago, a nurse observed the care given to 50 dying patients across four large hospitals. She documented poor oral hygiene, lack of assistance with eating, unquenched thirst, and increasing isolation of patients towards the time of death.¹

Then, as now, most people in England died in hospital. To improve care for some of the hundreds of thousands of people in hospital during their final hours and days of life, end of life care pathways were introduced.² The Liverpool care pathway is the most widely used integrated care pathway, but others have been developed.³ However, the Liverpool care pathway has recently received sustained media criticism in the UK,⁴ resulting in two ongoing reviews by the Department of Health and the NHS National End of Life Care Programme.^{5 6}

In February, in conjunction with Channel 4's *Dispatches*, the *BMJ* emailed 3021 UK hospital doctors for an anonymous online survey of their views on the Liverpool care pathway. Out of 647 respondents (response rate 21%), 563 doctors had used the pathway in clinical practice, and these 563 were enrolled in the full survey. They

comprised 185 palliative medicine consultants (roughly 40% of the UK total), 168 doctors in training or career grade posts in palliative medicine, and 210 doctors in other specialties but with some experience in palliative medicine. The response rate is similar to that in other online surveys of doctors, but non-response bias is possible.

Overall, 57% (321/563) of the doctors thought that recent negative press coverage had led to the Liverpool care pathway being used less (fig 1). This rose to 74% (136) for palliative medicine consultants, supporting concerns made by leaders in the specialty.⁷ Among those doctors who said there was less use of the pathway, 60% (194) said patients and relatives had asked them not to use it and 80% (258) said staff were apprehensive about relatives' complaints.

One palliative medicine doctor said, "Negative press regarding LCP [the pathway] has caused additional distress for relatives at an already distressing time when their loved one is dying. This has caused a dilemma in judging if discussing the LCP will cause more distress than

the benefit of being on the LCP for coordination of care in the dying phase."

Another specialist said: "Often where families have been against the use of the LCP because of the negative press, they have been in agreement with application of its principles."

One accusation in the press has been that the pathway has been used in patients "to save money" and that "patients are being dispatched via the LCP because—simply and crudely—the hospitals need their beds to meet overwhelming demand."⁸

In their experience, 98% (550) of respondents did not think that pressure on beds or other resources had influenced decisions to use the pathway for end of life care (fig 4). One trainee thought that staffing pressures had in fact decreased use of the pathway and said, "High levels of staffing are required to implement it properly. Doctors must have the time and training to communicate with families, and the proper implementation of the LCP requires highly trained nurses."

However, one consultant had heard of "pressure exerted in some areas to get the

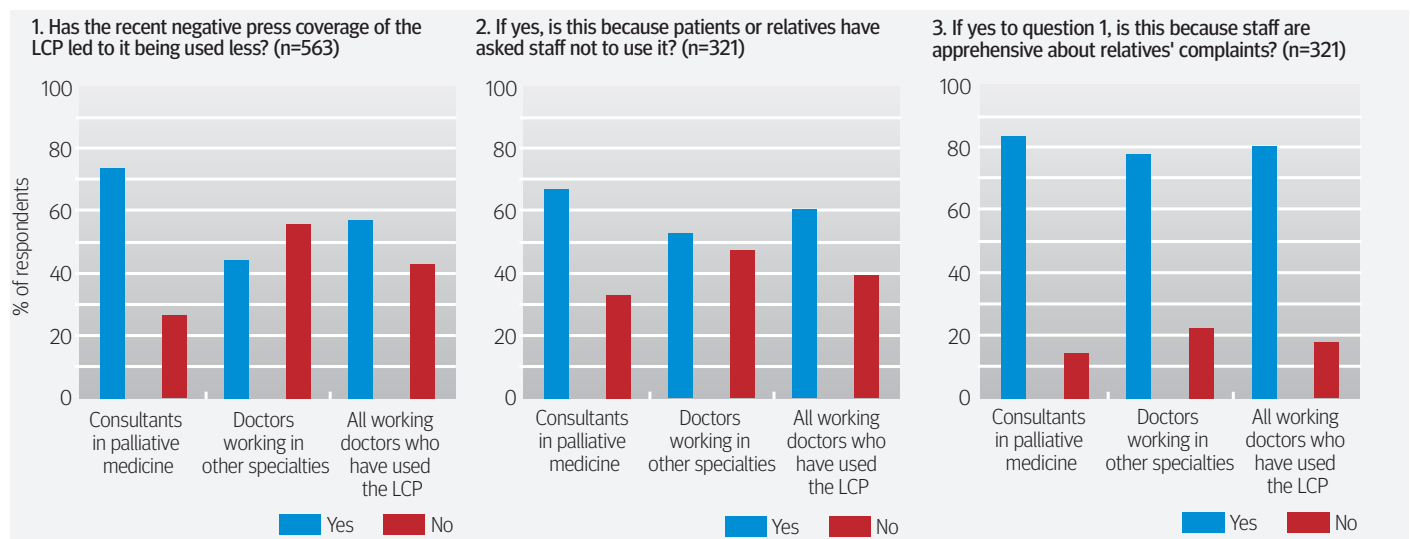


Fig 1 | Doctors' views on factors affecting use of Liverpool care pathway

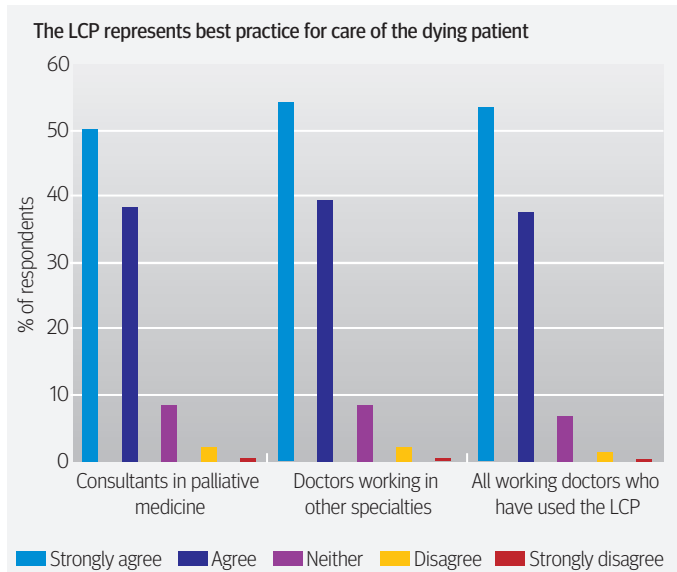


Fig 2 | Percentage of doctors who think the Liverpool care pathway represents best care (n=563)

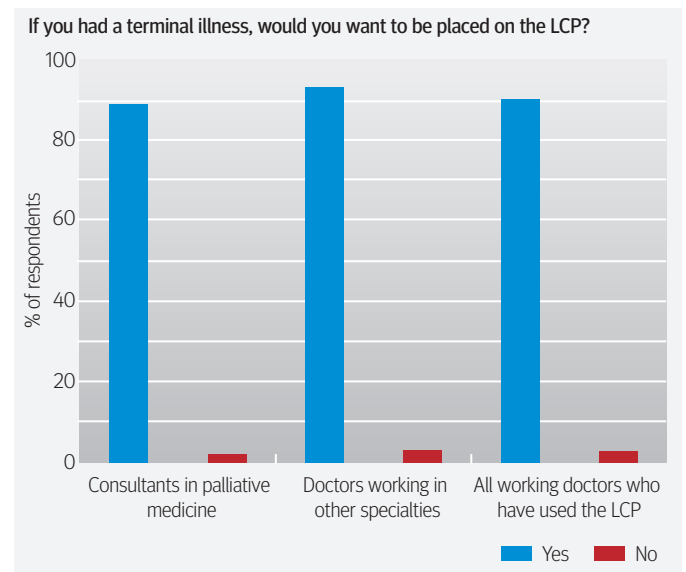


Fig 3 | Percentage of doctors who would choose the Liverpool care pathway for themselves (n=563)

numbers up so that the hospitals do not fail to reach their CQUIN [Commissioning for Quality and Innovation] targets.”

Local commissioners in England use CQUIN payments to improve service by linking up to 2.5% of NHS providers’ income, a total of roughly £700m (€800m; \$1100m), to performance targets.⁹ Of this, between £20m and £30m is for targets related to the use of the Liverpool care pathway,¹⁰ as advocated by the Department of Health’s end of life care strategy and by a National Institute for Health and Clinical Excellence (NICE) quality standard.¹¹ Targets may range from ensuring “that a meaningful conversation with a patient admitted at the end of life is recorded in a meaningful way and takes into account previous care planning”¹² to “50% of patients who die in hospital (expected deaths) should die on a Liverpool care pathway.”¹³

Only 13% (75) of respondents agreed that hospitals should be offered financial incentives for using the pathway, with 58% (325) disagreeing. One said, “Setting targets for the use of a tool that was intended simply to ensure best practice was never wise and always open to misinterpretation,” and another suggested that a better financial reward would be for achieving a set “percentage of ward based nurses and doctors who have completed training in the use of the pathway.”

Bee Wee, president of the Association for Palliative Medicine, also highlighted lack of training: “We know that there are some hospitals where the Liverpool care pathway is introduced, there is very little training of the staff, there is nobody who is going around making sure that it is used correctly.”¹⁴

In the survey, 92% (194) of doctors in non-

palliative medicine specialties thought that doctors and nurses were able to judge when a patient is dying, but only 78% (145) of palliative medicine consultants agreed. Recognition of a dying patient and communication of this to patients and relatives were highlighted as particular training needs. One consultant said “There are undoubtedly cases reported in the press where end of life care has not been managed well. These should be criticisms of training, assessment and common sense. They are not correctly directed at the pathway. It is as irresponsible as banning insulin because of the damage and deaths that have occurred over the years due to inappropriate, inaccurate or malicious use of this drug.”

Regarding the Liverpool care pathway itself, 91% (514) thought that it represented best

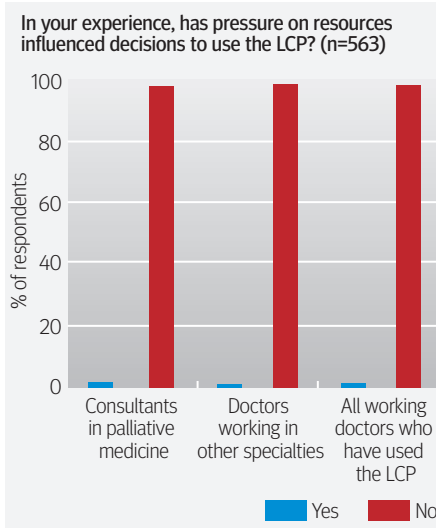


Fig 4 | Doctors’ views on factors affecting use of LCP

practice for care of the dying patient, including 89% (164) of palliative medicine consultants. If used properly, 98% (551) thought that it allowed patients to die with dignity, with two respondents disagreeing (0.4%) (fig 2).

When asked if they would want the pathway during a terminal illness, 90% (509) said yes and 3% (16) said no (fig 3). Some respondents pointed out, entirely correctly, that it was not clear whether the question meant dying from a terminal illness. We are sorry for this. Dying patients may or may not have terminal illnesses; the terminally ill may or may not be dying. Other damaging misconceptions, according to specialists, were that the pathway precludes nutrition, hydration, or antibiotics; that it is a one way process with no further patient review; and that it is an active intervention to hasten death.

One doctor said that this “scaremongering” was “putting end of life care back about twenty years, where dying patients were hidden inside rooms and not seen by a consultant.”

It was also about 20 years ago that Mina Mills and colleagues published their observations of 50 dying patients in hospitals in the *BMJ* and declared that “Our findings show the desperate need for improvements in the care of dying patients.”¹⁵

Now, as then, doctors should use the opportunity to promote further education, training, and improvements in the care of dying patients.

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Inquiry launched into newspaper story about babies on “death pathway”

Sophie Arie examines how misunderstanding led to a children’s hospital becoming embroiled in media outcry about the Liverpool care pathway



In November 2012, amid a long campaign to expose misuse of the Liverpool care pathway (LCP), the *Daily Mail* newspaper ran a front page story entitled “Now sick babies go on death pathway.”¹

The story claimed that NHS hospitals were discharging sick children and babies to hospices or their homes, where food and fluid were withdrawn until they died.

Several complaints over major inaccuracies were made at the time, including by the *BMJ*. The Press Complaints Commission has since received 10 more complaints and recently launched an inquiry into the story.

The centre piece was a doctor’s personal testimony—billed as “doctor admits starving and dehydrating ten babies to death in neonatal unit.” But that testimony—which was first published in the *BMJ*²—came from a physician practising in another country, although the location was not disclosed to protect the families involved.

The article went on to allege incorrectly that Alder Hey children’s hospital in Liverpool was discharging patients “for LCP end of life care,” based on a document the newspaper had obtained with tick boxes for doctors on medicines, nutrients, and food to be stopped.

A photo of the hospital was juxtaposed with general criticisms not related to Alder Hey saying that parents were being coerced into allowing their children to be put on a care pathway, that sometimes they recovered when taken off, and that there were big questions to be answered. The article also referred to the ongoing government review of the pathway and allegations that hospitals were receiving financial incentives for putting patients on the pathway.

Alder Hey hospital was horrified when it saw the story.

“We have an end of life care plan for children who are inevitably going to die,” Professor Ian Lewis, the hospital’s medical director, told the

BMJ. “But it is not the LCP and it is not all the other things implied.”

Unlike the LCP, Alder Hey’s pathway is not used for large numbers of patients (only 28 since 2006) and it has not involved withdrawing food and fluids, says Lewis. Alder Hey has not placed patients on its pathway without informing the patient or their family, and families whose children have died have expressed gratitude to the hospital for its expertise.

“Our children’s pathway includes a detailed review of all medical intervention, including medicines and artificial nutrition,” the medical director says. “These could be withdrawn if thought to be of harm. But if that is uncertain it is continued.”

Dissatisfaction with response

The hospital wrote to the *Daily Mail*’s editor protesting that the article was factually wrong and its attempts to explain the difference between its pathway for children and the LCP had been ignored. The editor in chief of the *BMJ*, Fiona Godlee, also complained in writing that the story was highly misleading. Her point that the main testimony in the story was not from an NHS doctor was published on the newspaper’s letters page (*BMJ* 2012;345:e8240).

But the *Daily Mail* did not remove the story from its website or correct or clarify it. A version was also published by the *Daily Telegraph*, and both stories have inspired scores of emotional responses from readers, many of whom expressed disgust that NHS doctors were using distressing methods to kill sick babies who might have survived.

The *Daily Mail* told the *BMJ* it could not comment on the story because a Press Complaints Commission inquiry is under way.

But a letter sent last year in response to Alder Hey’s complaint defended the story, and said it had not been clear at the time of publication that the doctor writing in the *BMJ* was not based in the UK.

In the paper’s view, the doctor’s testimony was still valid as an insight into what happens when food and fluids are withdrawn. “It is not apparent that this [the location of the doctor] makes any difference since the pathway clearly is being practised in this country,” the newspaper said in a letter to Alder Hey.

In the same letter, the paper insisted that Alder Hey had developed its pathway for dying children in collaboration with the same experts at Marie Curie Palliative Care Institute in Liverpool who developed the LCP. “It is not clear on what basis you are insisting that this is not a development of the LCP to cover children,” the *Daily Mail* argued.

Fundamentally, the hospital believes, media campaigning about the LCP has turned the word “pathway” into a dirty word. The message is that all pathways are a form of “euthanasia by the back door.”

“Parents are being told something sinister is being done. This isn’t representative of the care that is provided at Alder Hey,” said Louise Shepherd, chief executive of Alder Hey hospital.

Alder Hey thinks that parents of children in its care may have been panicked unnecessarily.

“The term ‘pathway’ has become so misunderstood,” says Lewis. “It’s a complex clinical medical process being reported very hysterically. There’s a need for a wider debate around care pathways in general. People need to understand what they are.”

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Editorial: Using end of life care pathways for the last hours or days of life (*BMJ* 2012;345:e7718)