End of life care must be properly recorded

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Abstract

Work carried out for a client found that end of life care was being significantly under-recorded. Further examination has shown that this is likely to be happening in all trusts. There are major implications for commissioners developing end of life care strategies and risk adjustment models for mortality. It also raises some questions about the measurement of potential improvements in length of stay.

Main Report

Introduction

End of life care is under increasing focus and our work in this area suggests that coding in end of life care needs major attention as it is being significantly under-recorded. Under-recording can have a significant impact on risk adjusted mortality rates and issues relating to length of stay, which in turn has implications for organisations that compile such data for NHS and public consumption.

Many readers will know that earlier this year the Department of Health published its End of Life Care Strategy. This strategy document followed the NHS End of Life Care Programme (2004–2007), which amongst other things contributed significantly to the roll out of Liverpool Care Pathway for the Dying Patient (LCP).

We were asked by Medway Trust to review its mortality rates after it had been questioned by Monitor as part of its application for Foundation Trust status. As result, an audit of recorded deaths and coding at the trust was undertaken.

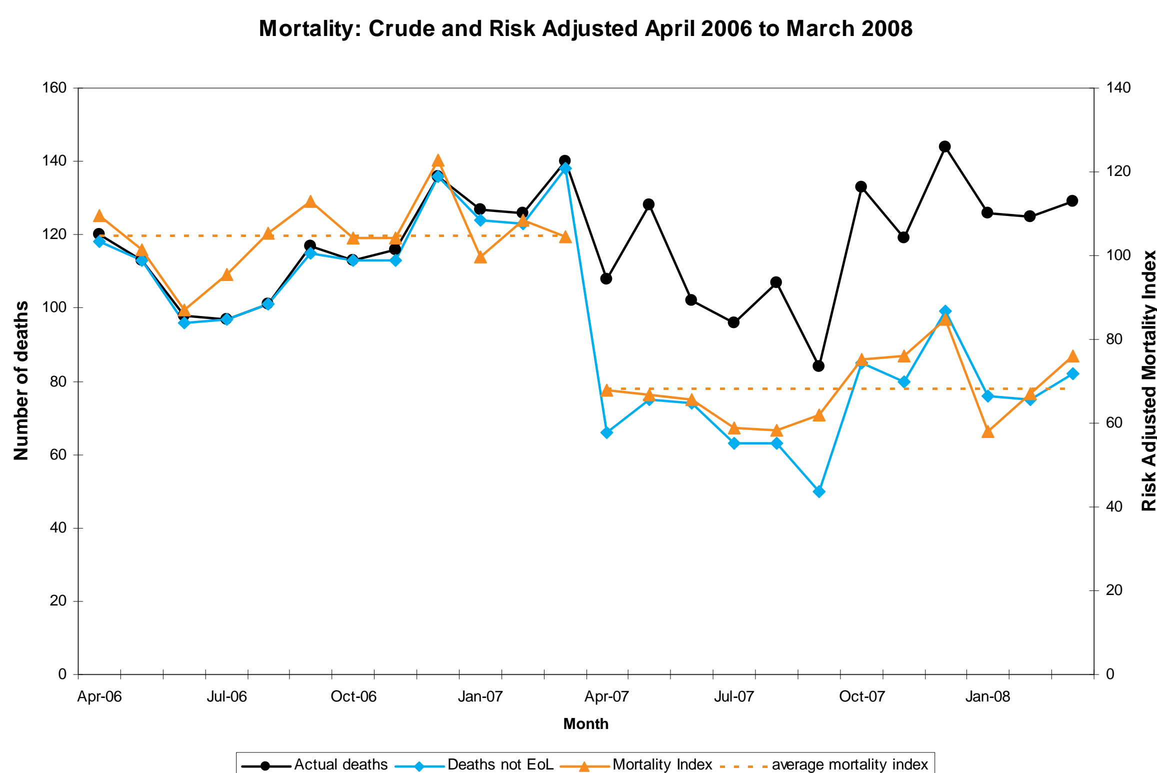
One of the themes that emerged was that a number of patients had been placed on the Liverpool Care Pathway for end of life care and had not been clinically coded as such.

The trust also had concerns that it was providing this service in an acute setting and therefore wanted to quantify the impact of these patients on its services. It also needed a good understanding of the size of the issue so that it could support the business planning of the best model of care for patients, their family and staff in

managing these cases in an acute setting.

We recommended that these patients should be clinically coded through the use of the coded Z515 (specifically designated for end of life care) supported by the documented care pathway in the patients' notes.

The trust took this on board and in fact went through all the deaths in the year 2007-2008 and updated the clinical codes accordingly. We then completely refreshed the data. Because the trust actually went back, recoded and refreshed the data we have a complete year of data to compare with the previous trend. The results are shown in the first graph.

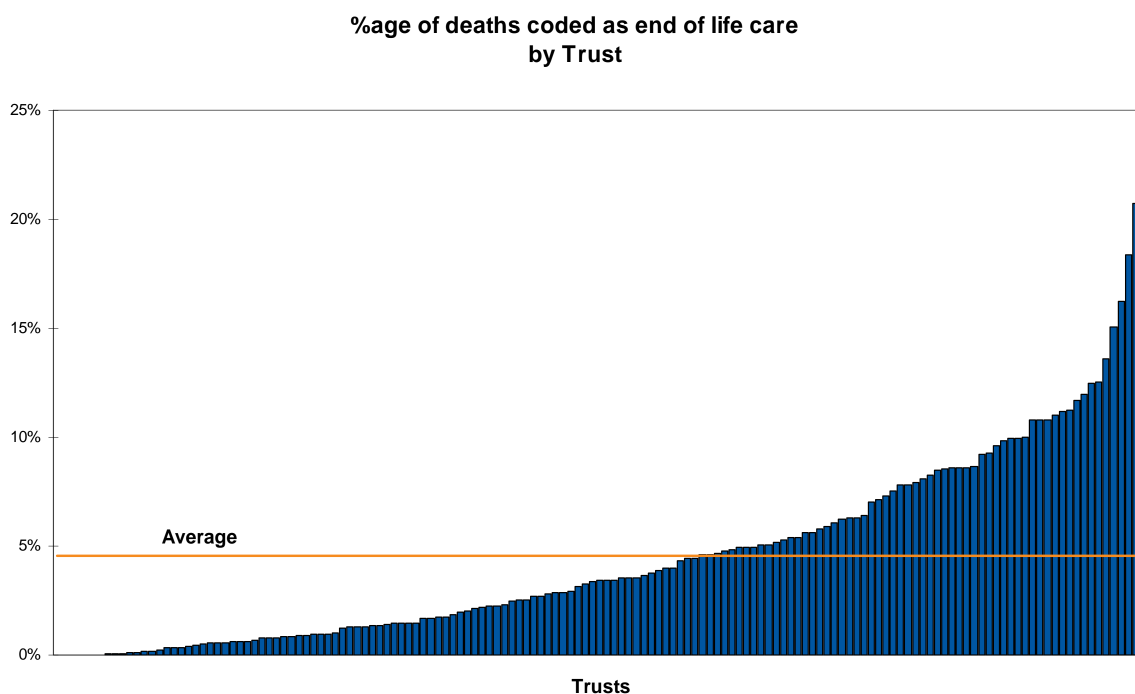


The effect of the review was that 37 per cent (513/1401) of the deaths were excluded from the risk adjusted profile (previously only some 8 per cent had been classified as end of life care), thereby the risk adjusted scores now reflect the acute deaths rather than including end of life care.

To see if the problem is widespread we carried out a simple analysis of HES data looking at the proportion of deaths that were coded as end of life care across all general acute hospitals (the specialist hospitals were excluded).

The results are shown in the second graph. As usual with this style of analysis, there is a wide degree of variation. Most strikingly though, the mean is only 4.5 per cent - and even the high end outlier has only 22 per cent of its deaths coded this way.

Medway, a fairly typical general acute trust, is now showing 37 per cent of its deaths as end of life care. It would therefore appear that this element of care is being massively under-recorded across the country.



This has a number of implications. First, if plans are to be drawn up for better end of life care then both commissioners and providers need to get a proper fix on the scale of the issue. Assuming Medway to be typical would imply an under-recording of almost 750 per cent.

Second, most of the methodologies for risk adjustment of mortality (producing a hospital standard mortality rate, or HSMR) will be including a lot of deaths that should be excluded, thus distorting the relative positions of providers. The first graph shows the risk adjusted mortality index (or HSMR) moving from 105 to 68 – a drop of over one third. This means that until all trusts are recording this accurately it will cause HSMRs to be highly erratic.

Third, providers are under a great deal of pressure to reduce length of stay and yet this is clearly a group of patients for whom length of stay is not about improving discharge processes and not amenable to “improvement”. These patients need to be separated from length of stay measurements.

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