

VIEWS & REVIEWS

PERSONAL VIEW

Late presentation, late diagnosis, late stage diagnosis, delayed diagnosis, delayed presentation: terminology confuses the message in UK cancer policy

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Cancer survival rates make big headlines. Recently the government has used survival rates as part of the case for the major NHS structural reforms, and it is estimated that up to 10 000 lives a year could be saved in England if we had the best survival rates in Europe.¹

So, to catch up with our European neighbours, patients need to be diagnosed earlier. Or do they need to present earlier? Which ever it is, the overall message is clear: the earlier your diagnosis, the better your chances. But less clear is the collection of phrases used when talking about cancer survival, from the media to government policy documents.

To untangle these phrases we need to delve a little deeper. What constitutes an early or late diagnosis of cancer? In the UK, the term “late diagnosis” usually means a late stage tumour, one that is locally advanced or has metastasised. Studies reporting cancer survival will use the TNM (tumour size; spread to lymph nodes; metastasis) staging system to identify these “late stage” tumours.

These results highlight the importance of “early diagnosis,” while “late presentation” is blamed for late stage tumours and poor survival rates. In the US, the identification is similar, where the Collaborative Stage (CS) staging system is used to classify “regional” or “distant” stages as “late stage.” However, the language and terminology is consistent. The US Centers for Disease Control and Prevention use the term “late stage” to describe both the tumour and the diagnosis as a whole.

This is an important distinction—not least because for both the tumour and the pathway to diagnosis many factors play a huge role in determining what is actually late. For example, a recent study in the UK by the National Patient Safety Agency identified several reasons why patients may be diagnosed at a later stage.² These factors are unsurprising, including difficulties in getting an appointment, fear of wasting their doctor’s time for what seem like minor symptoms, and embarrassment around certain symptoms, particularly in bowel cancers.

The figures also tell us that one in three patients was not initially referred for a hospital appointment, with one in five seeing their general practitioner three or more times before a referral was made. In a conference speech,³ the national cancer director described the problems of “late diagnostics” [sic] and “late presentation,” using these phrases interchangeably in explaining poorer survival rates, while the National Patient Safety Agency study favoured the term “delayed diagnosis,” which encompasses all of the reasons why patients might have had a late stage diagnosis.

We are all clear on the solution. Cancers need to be diagnosed earlier; this is when treatment, particularly surgery, is more effective and the data show us that, for cancers such as non-small cell lung cancer, one year survival rates improve dramatically when diagnosed earlier. However, if we are encouraging “early diagnosis” we need to be clear on what this phrase really means. Again, in the US, the term “early stage” diagnosis is used, describing what the Centers for Disease Control and Prevention notes as cancers that are diagnosed where “treatment is most effective.”⁴ In the UK, the continued use of the phrase “late presentation” in explaining why fewer people are diagnosed earlier can be both confusing to patients and, at an extreme, stigmatising. For example, if the first time a patient presents with symptoms and is subsequently diagnosed with a late stage cancer is this “earlier diagnosis”? The person was aware of symptoms, sought actions, and did not delay. In their eyes they were diagnosed earlier; in the eyes of health services they presented late. Are we saying it’s the patient’s fault for not presenting earlier? In other diseases, we have learnt to avoid terminology that implies blame. For example, in HIV literature and policy, “late diagnosis” is used rather than the word “presentation.”

The UK government’s continued focus on cancer outcomes and desire for world class cancer outcomes are laudable.⁵ Equally laudable are the benefits reaped in the past decade from a coordinated national strategy coupled with investment. The

focus on ensuring patients are diagnosed earlier is also clearly the right one. However, the fusion of phrases used nationally in the media and locally can paint a confusing picture. A better phrase to explain the reasons for being 10 000 lives short of the best European cancer outcomes is required. The US use of the phrases “early stage diagnosis” and “late stage diagnosis” achieves clarity by incorporating the word “stage.”

“Late stage diagnosis” is preferable to the phrase “late presentation.” It would be great if all those involved in cancer care in the UK could use it.

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- 5 Department of Health. Improving outcomes: a strategy for cancer. 12 January 2011. www.dh.gov.uk/en/Aboutus/Features/DH_123441.

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