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VIEWS AND REVIEWS

ACUTE PERSPECTIVE

David Oliver: "Progressive dwindling," frailty, and realistic expectations

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Relatives of sick older patients have an understandable need to know why their loved ones are deteriorating or failing to recover, or exactly why they died. This can lead to misunderstandings, formal complaints, fraught meetings, or upsetting inquests.

Over the years I've seen my share of this in my own practice. I've also worked on numerous cases as an independent investigator or expert witness. In some cases aspects of care were poor, sometimes indefensibly so. And even in someone with serious health problems, failings in care can worsen decline or cause avoidable harm and distress.

Often, however, the medical care was good or exemplary, communication was open and frequent, but still the complaints and misunderstandings came. During my career society has become ever more high tech and "can do"—and perhaps less comfortable with death and dying. I'd say that people have become less willing to accept the very real limits of medicine.

Often, no one is to blame when older, frailer people with long term conditions and acute illness deteriorate. That's just (late) life.

> People have become less willing to accept the very real limits of medicine

I'm not the only doctor who's had meetings with families asking why a 90 year old relative—who had complex multiple conditions and was admitted with, say, a hip fracture, pneumonia, acute kidney injury, and delirium—died. I'm also not the only one who's had discussions with families who rewrite history by claiming that patients were "perfectly all right" and "very independent" before admission, when in reality they were admitted acutely ill, having been deteriorating for months, increasingly struggling and dependent.

Frailty, dementia, and related presentations drive much modern hospital activity. So too do the needs of patients with multiple, life limiting, long term conditions.[1 2]

A key validation study of the electronic frailty index in over 200 000 of England's over 75s showed that those with severe frailty were four times more likely to be admitted to hospital, five times more likely to die, and six times more likely to enter a nursing home within 12 months.[3] New nursing home residents have limited average life expectancy, yet care homes get complaints when residents who are (very predictably) deteriorating or dying proceed to do so. They're also pressured to admit such patients to hospital, even when dying or when admission will distress the patient more than acceptance of dying.[4]

No one goes on forever. Yet the public seem to understand this more easily in the context of sudden death from acute illness (20% of deaths); or steep deterioration from terminal single diseases, such as cancer (20%); or progressive, long term conditions with intermittent exacerbations (20%), as set out in Lynn and Adamson's 2003 analysis of US Medicare recipients' end of life trajectories.[5] Yet 40% of the patients who died had shown "progressive dwindling," the authors found. This trajectory is typical in people with severe frailty, common dementias, or other degenerative disease.[6-8]

Once you're progressively dwindling you're likely to become more dependent, be admitted and readmitted more frequently, lose function or weight in hospital, and die, even when care is sensitive and skilled.

We have somehow to explain this better to a public who may not be ready for the message and don't readily want to discuss dying or frailty—or the complaints will grow more quickly than the population ages.

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