

“After Gosport: where next for
Palliative Care?”
The insider outsider problem
*Adaptations, assimilations and
assumptive worlds*

Where we are going – around a galaxy not so far away

✓ **A proposition / polemic about why we fail to progress**

- *Some philosophy to underpin it*

✓ **Some Facts**

- *The Gosport Headlines*

✓ **Some commentary**

- *a few tirades*

✓ **A suggestion**

- *Get a grip*

Some reasons why we can't play nicely together:

Identity and the insider:outsider problem

Adaptations, assimilations and assumptive worlds

✓ **Strong cultures (the worlds we inhabit)**

- **Doctors** (*I know best: that's why I am here and you are there*)
 - *Good at pattern recognition, dreadful at reasoning*
 - *Poor insight*
 - *Unreliable at process*
- **People, Groups & Organisations**
 - *The mushrooms (teams): distinctions define identity ie I know I'm me because I'm not you*
 - *The Beast (stay in budget, appear to do something, avoid complaint & have someone else to blame)*

✓ **Special knowledge**

- *objective and verifiable but usually initiationist and elitist*

✓ **Power gradients**

- *Legitimate or illegitimate*
- *Different professions have different defaults (medicine & nursing)*

✓ **Openness (groups & organisations)**

- *Learners*
 - *Near misses, audit, reflection*
- *Luddites*
 - *Go Native or get out*

Gosport Context (1998-2000, when bad practice was at its height)

The patient population

- ✓ Respite and rehab unit
- ✓ Few admitted for EoL Care
- ✓ >2000 deaths
- ✓ Over 100 families
- ✓ Over 450 patients

The clinical cover

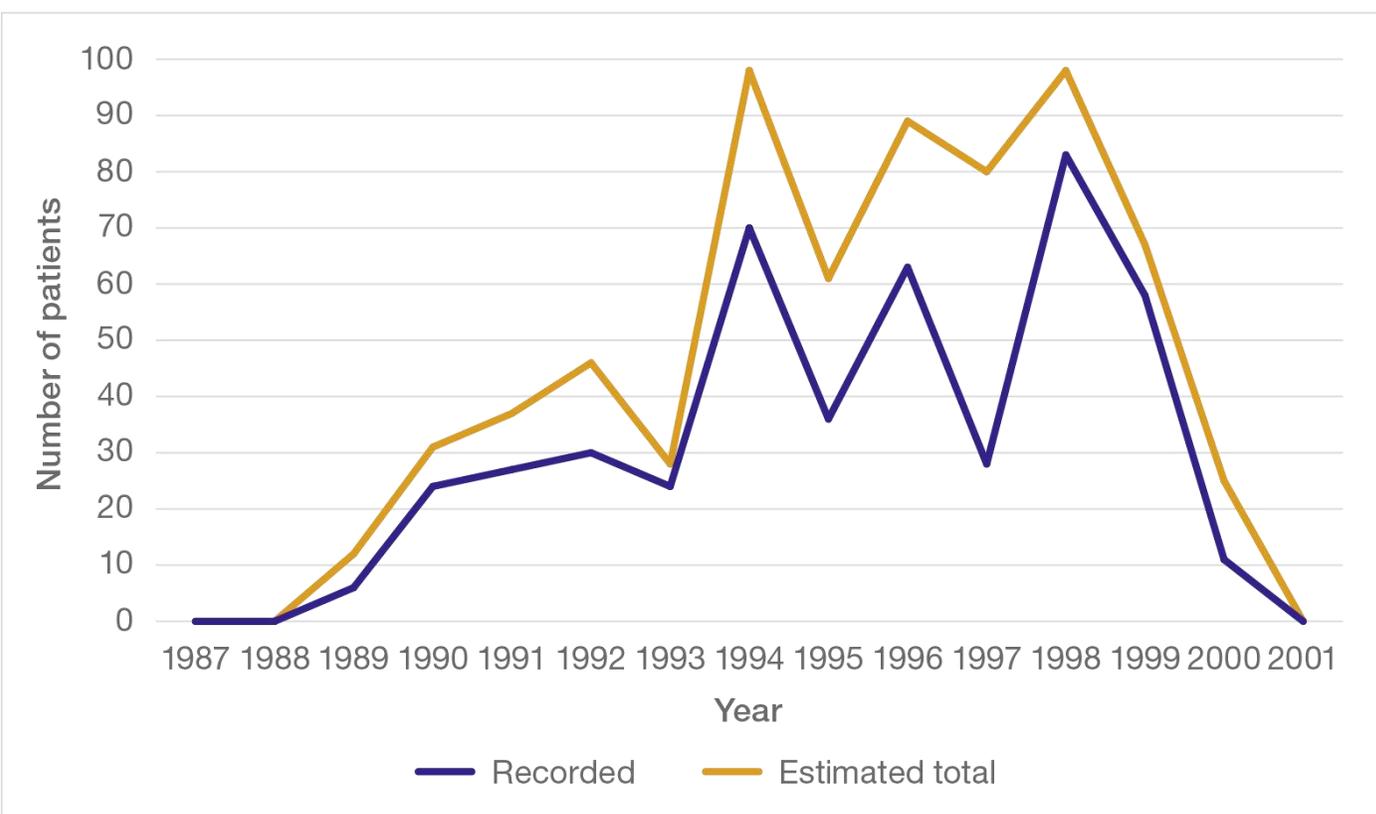
- ✓ Part time clinical assistant
- ✓ GP cover from colleagues
- ✓ Fortnightly consultant review where necessary
“knew what was going on”
- ✓ Delegated authority to nurses

The checks and balances

- ✓ Recognised or available guidance not used or accessible
- ✓ Pharmacy changed in 1994 to remote service
- ✓ No audit or prescribing pattern monitoring

Strong Opioid use without appropriate clinical indication, 1987 to 2001, numbers per year

“the excessive use of diamorphine and midazolam reached a peak in 1998/99. Over that period, wards used 1,617 doses of diamorphine and 1,680 doses of midazolam. With a patient population that was in the main not admitted for palliative or end of life care, this was clearly excessive. Even superficial monitoring of pharmacy data should have sounded alarm bells.”



Finding Two: Anticipatory prescribing with a wide range of doses

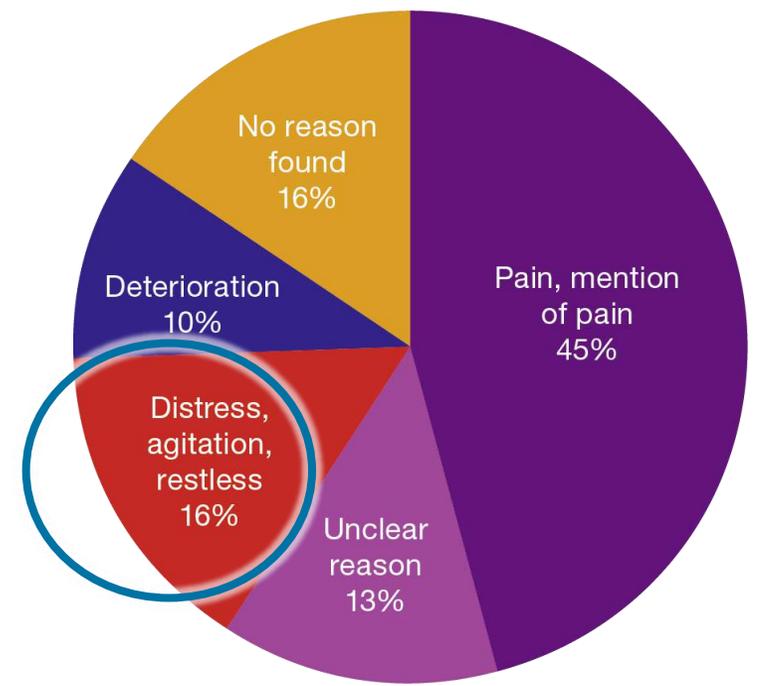


Figure 4: Starting dose of diamorphine in all patients given the drug in the Initial Group (97) and in those patients with evidence that diamorphine had been given without appropriate clinical indication

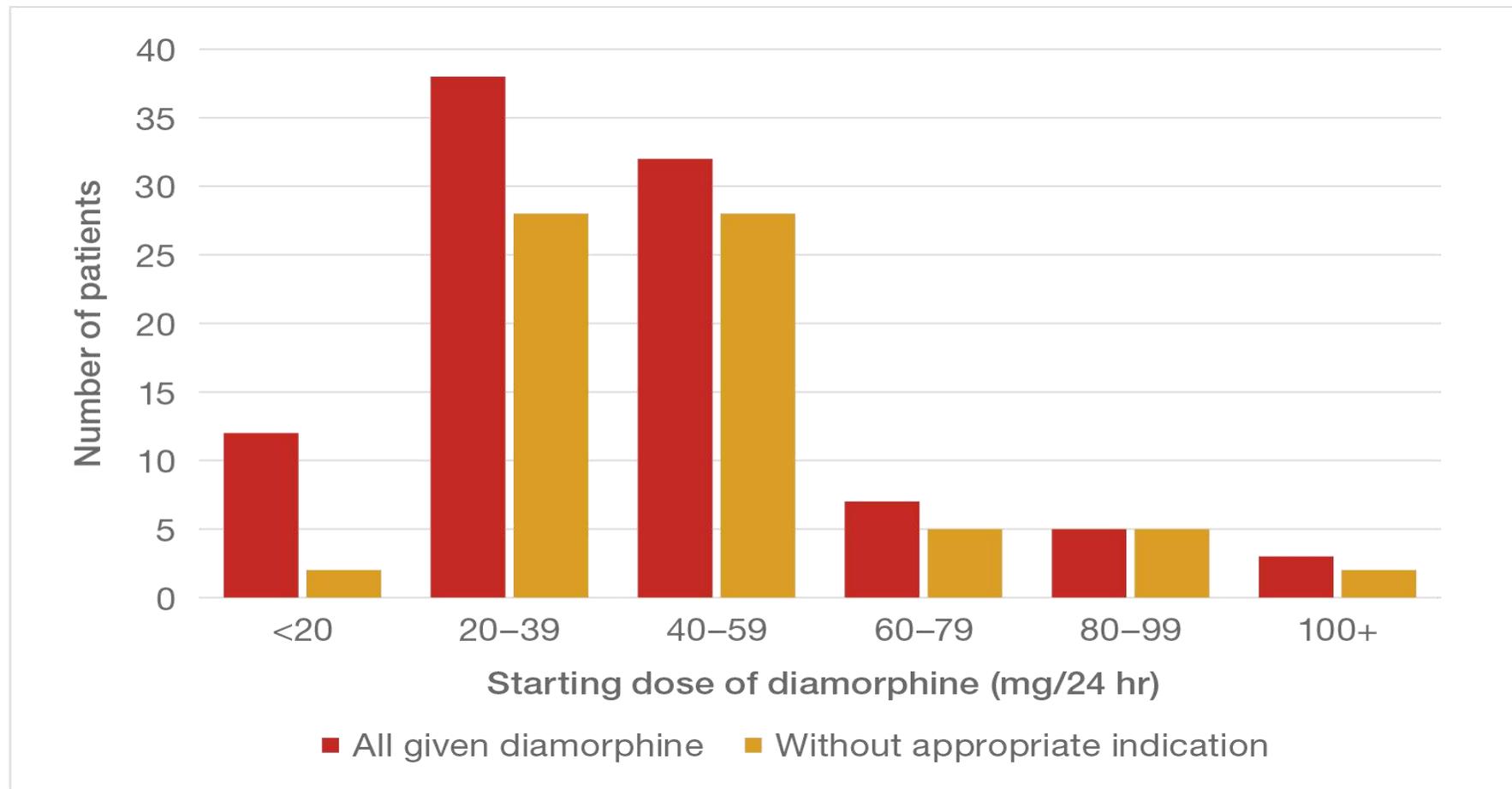


Figure 6: Relationship between first dose of diamorphine and preceding dose of oral morphine

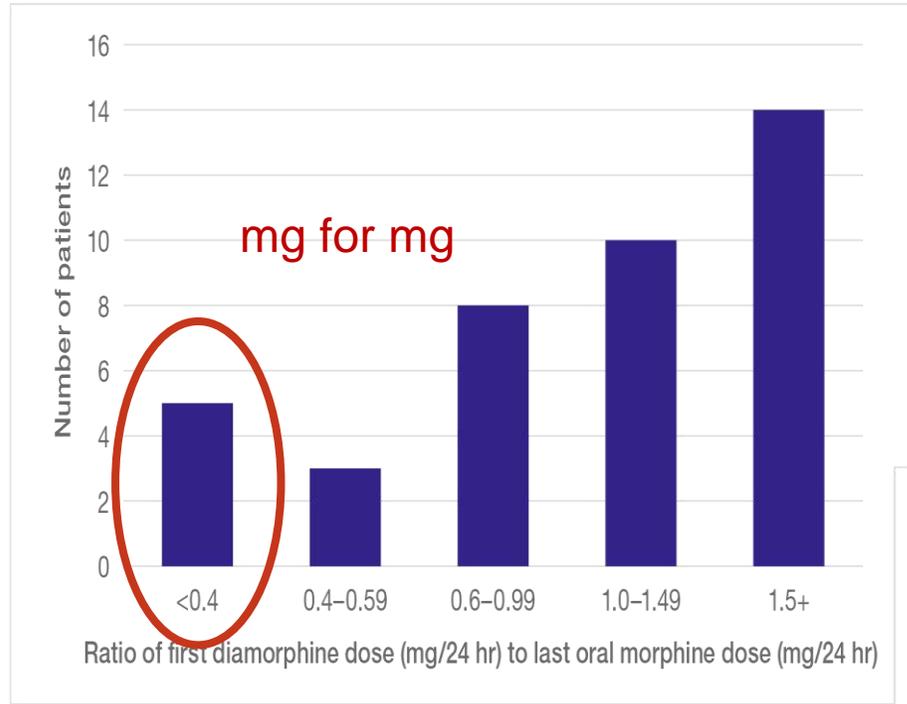


Figure 8: Survival after starting combined diamorphine, midazolam and hyoscine

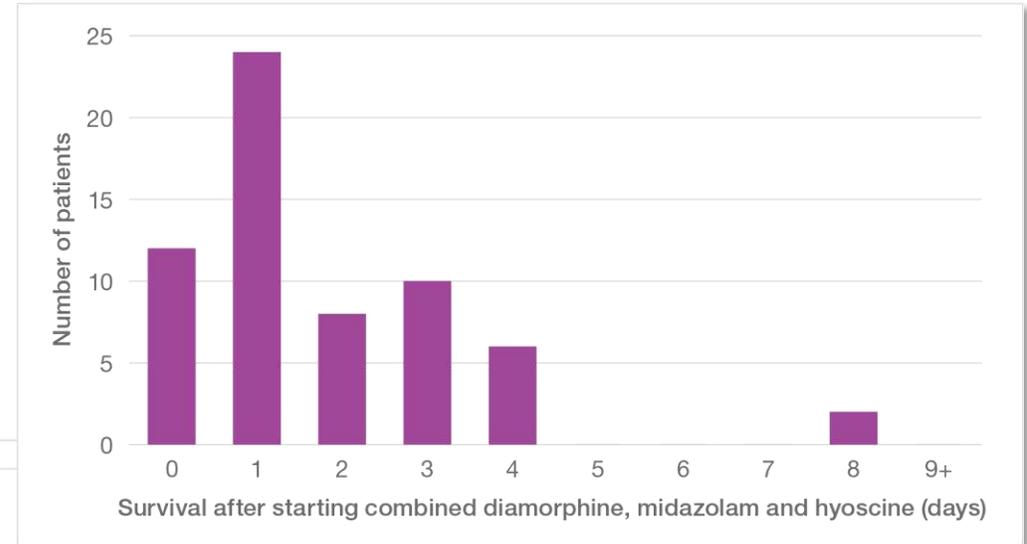
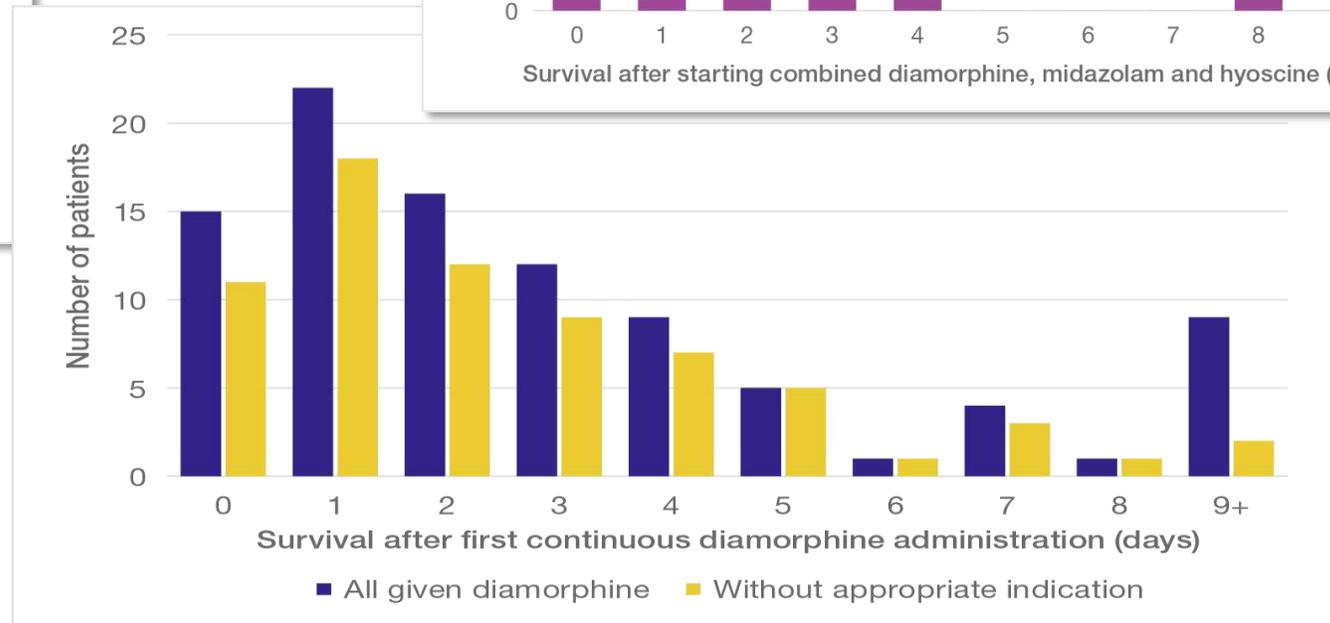
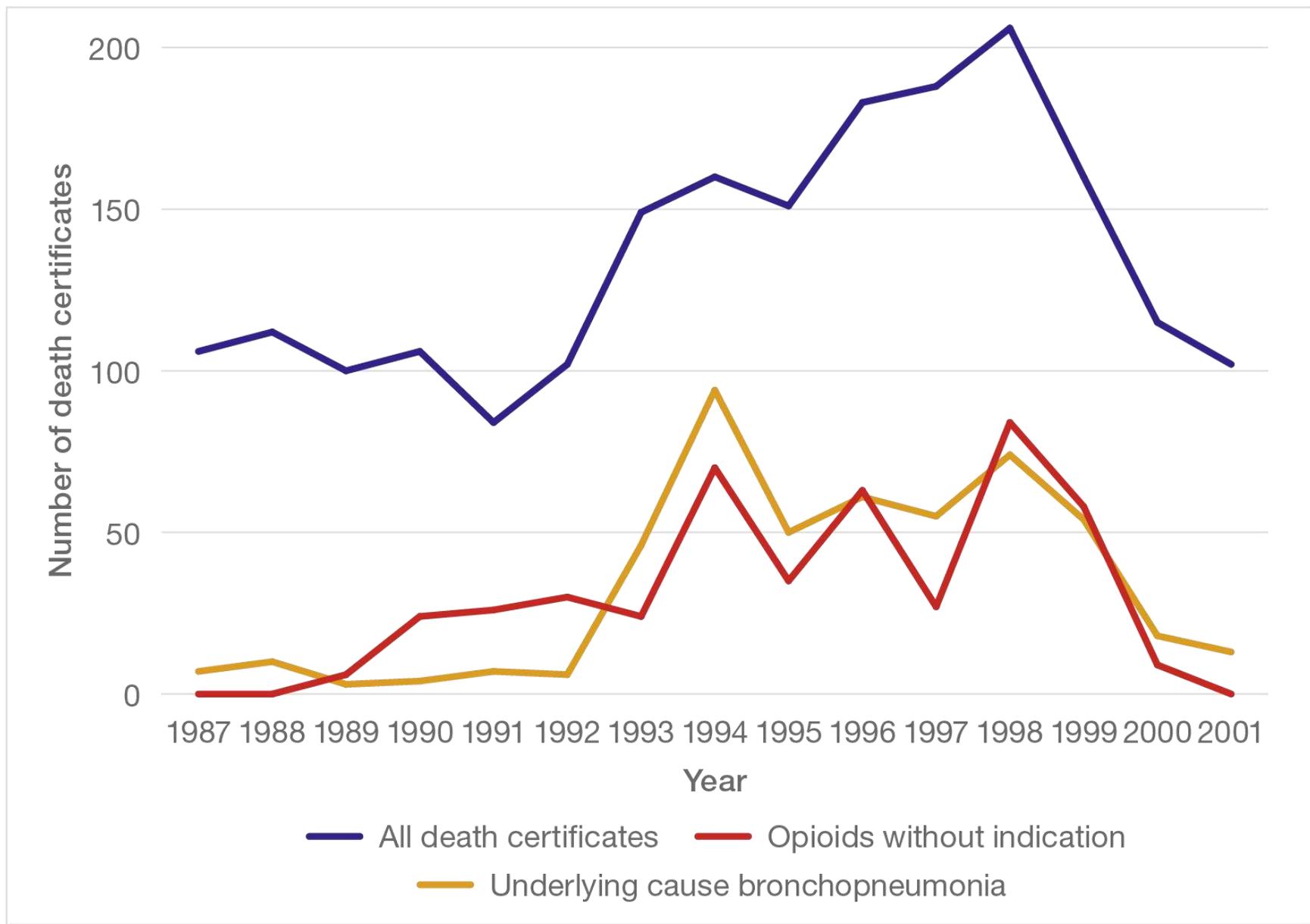


Figure 7: Survival after starting continuous diamorphine administration



The Bottom Line



The Insiders (medicine and nursing)

75yr old male admitted for respite:
dementia, parkinson's etc.

“Transfer to Dryad Ward. Make comfortable. Give adequate analgesia. I am happy for nursing staff to confirm death.”

“I was aware ... that he would possibly very shortly be on an end-of-life pathway ... I was also aware ... that there had been problems with his tablets, difficulty swallowing them, and ... we might well need to give this subcutaneously rather than as tablets or orally ... I was minded to keep him comfortable, reduce any anxiety and distress he may have had. I was not considering him ... as being terminal. I was, however ... not very optimistic about his prognosis but I was not going to do anything to hasten his death or to his detriment ... Both the diamorphine and the midazolam would have been ideal medication to control his discomfort, distress, anxiety overnight, as well as the pain he was receiving ... So that was what the pro-active prescription was for.”

diamorphine 20–200 mg, midazolam 20–80 mg, hyoscine 200–800 micrograms, CSCI, prn, over 24 hours.

At 23:10, 20 mg of diamorphine and 20 mg of midazolam were administered by continuous subcutaneous infusion.

“... CSCI diamorphine, midazolam was commenced in the evening for pain relief and to allay his anxiety following an episode when [Mr C] tried to wipe sputum on a nurse saying he had HIV and was going to give it to her. He also tried to remove his catheter and empty the bag and removed his sacral dressing throwing it across the room. Finally he took off his covers and exposed himself.”

Over 3 days, ended up on 60 Diamorphine, 90mg Midazolam, 1.2mg Hyoscine

Family (and patients) The Outsiders

A son recollected his mother's experience:

"In fact [the doctor] said to me 'You know your mother is very unwell and we would like your permission to administer the necessary drugs to assist her through at the end.' Naturally, I was very distressed by this, and tearful, and expressed my amazement that I was being asked to sanction what appeared to be euthanasia. When we left the meeting room, [the doctor] commented to the nursing staff 'we've got another weeper here'."

"Help me, son, they're trying to kill me"

There is a pattern across the cases reviewed by the Panel.

- On admission or close to admission, there is an assumption, not shared with the family, that the patient is close to death regardless of the purpose of their admission or the clinical management plan in place.
- So when the clinical staff said to families that they were making their loved ones "comfortable", that expression was a euphemism for embarking on the pattern of prescribing which would lead to death in almost every case.

In another part of the Galaxy: Reports and Investigations (avoid complaint and have someone else to blame)

The Trust 1988 ff

- ✓ nurses' concerns
 - *"that patients suffered distress from other symptoms besides pain but also had the right to a peaceful and dignified death. ... the majority of patients had complex problems."*
 - *"only a small group of night staff who are 'making waves'"*
- ✓ Family complaints 1989ff
 - Poorly dealt with
 - Case boxes destroyed 2013

External Bodies 2001 ff

- ✓ South East Regional Office (SERO), Commission for Health Improvement (CHI) and DH.
- Liam Donaldson:
- ✓ *"Past experience has taught that a great deal of pressure has to be exerted centrally before these issues are gripped [locally]"*

Criminal (Police & CPS) & Regulatory (GMC, NMC)

- ✓ 2001 Hampshire Constabulary 5 deaths
- ✓ 2003 CHI & DH inquiries suspended on Police advice
- ✓ 2007 ditto
- ✓ Issues unresolved around gross negligence manslaughter and corporate liability
- ✓ Censure and action ended up being minimal

**INDEPENDENT
INQUIRY REPORTED 2018**

A view from the Sun (LD & The Inquiry)

Sir Liam concluded:

“I am concerned that neither the CHI, nor the public, nor the health authority investigation[s] has properly examined the deaths associated with Dr Barton’s practice or in relation to care of the team. I do not think that this can be left as it is, even though others appear to regard the NHS part of the investigation as concluded and are simply awaiting the GMC’s verdict.”

Following receipt of Professor Baker’s proposals for the review, it was launched on 13 September 2002 (DOH000032, DOH000013). On 16 September, a meeting was held in the hospital to brief staff about the review. ... While waiting for the meeting to start, a senior nurse was approached by ... and handed a folder of documents dating from 1991/92, covering the nurses’ concerns (Chapter 1). She realised the implications immediately: *“When I read the minutes I felt sick. I considered the minutes to be very damning.”* The nurses, ... with the material *“had seen an article in a Sunday newspaper about GWMH which stated that no one had ever brought their concerns about syringe drivers to the attention of management before”*

having met Professor Livesley, who *“believes that the police did not investigate adequately and were wrong to drop their investigation”*. Sir Liam also stated:

“The CHI investigation did not look at individual cases ... The GMC investigation may take a couple of years (on past experience) and they have not suspended the doctor concerned ...

Professor Livesley’s report, ... makes worrying reading ... one case. ... there had been mention of other cases in which death had been hastened ... not been asked to look any more widely ... Locally there is a high degree of concern amongst a number of relatives.”

December 1991, “management was one side of the room and ward staff on the other ... they were put on the spot ... they had not got any further, they were fed up, not supported, angry and frustrated”

Asked whether things had changed after the meeting, they said that they had, briefly, but they “... started again gradually ... you can only be told so many times that you don’t know what you are talking about”. They were concerned “they would be sacked or moved ... wouldn’t be supported ... would be named a trouble maker”

Snapshot from the Police

a nursing auxiliary ... had been in touch following the newspaper article.

“She describes the ward as the ‘Dead Loss’ ward as opposed to Daedlus. She describes the regime of [the nurse] as being geared towards euthanasia. ... she recalls coming into conflict ... over the death of an elderly cancer patient who was put onto a syringe driver and subsequently died. The patient was always making demands and was considered a nuisance. In her estimation he was some way from death when the driver was introduced. He quickly lapsed into unconsciousness and died after 4-5 days. She also recalls an elderly lady brought onto the ward very ill and immediately put onto a driver. Her family insisted that she be allowed to die naturally without a syringe driver being used. Following the withdrawal she recovered sufficiently to be discharged home to her daughter ... The can has been opened!!!!”

In her statement Pauline Spilka said that the:

“Indiscriminate use of Syringe Drivers on Patients in the Daedalus Ward at Gosport War Memorial Hospital is my main concern. It appeared to me then and more so now that euthanasia was practised by the nursing staff. I cannot offer an explanation as to why I did not challenge what I saw at that time.”

What does this mean for us?

✓ **Assumptive Worlds**

- What are we looking at?
- Pattern recognition
- Suspend belief regularly
- Be neighbours who look over fences
- Critical friendships, not power games or lip-curling

✓ **Familiarity breeding *Content***

- Insight and scepticism
- Self-awareness
- Accountability

✓ **Specialism risks breeding contempt**

- Delete the term inappropriate
- We need our prescribing house in order. Consistency & coherence

✓ **Turn dots into lines**

- *Specialism and generalism*
 - Mutuality
 - Support
 - Learning entails equality
 - IT & ECHO
 - Join up the trainees in Primary & Secondary Care
- *Macrosystems, meso & microsystems*
 - Same by default
 - Different where needed