



Palliative care, termination of ventilator treatment

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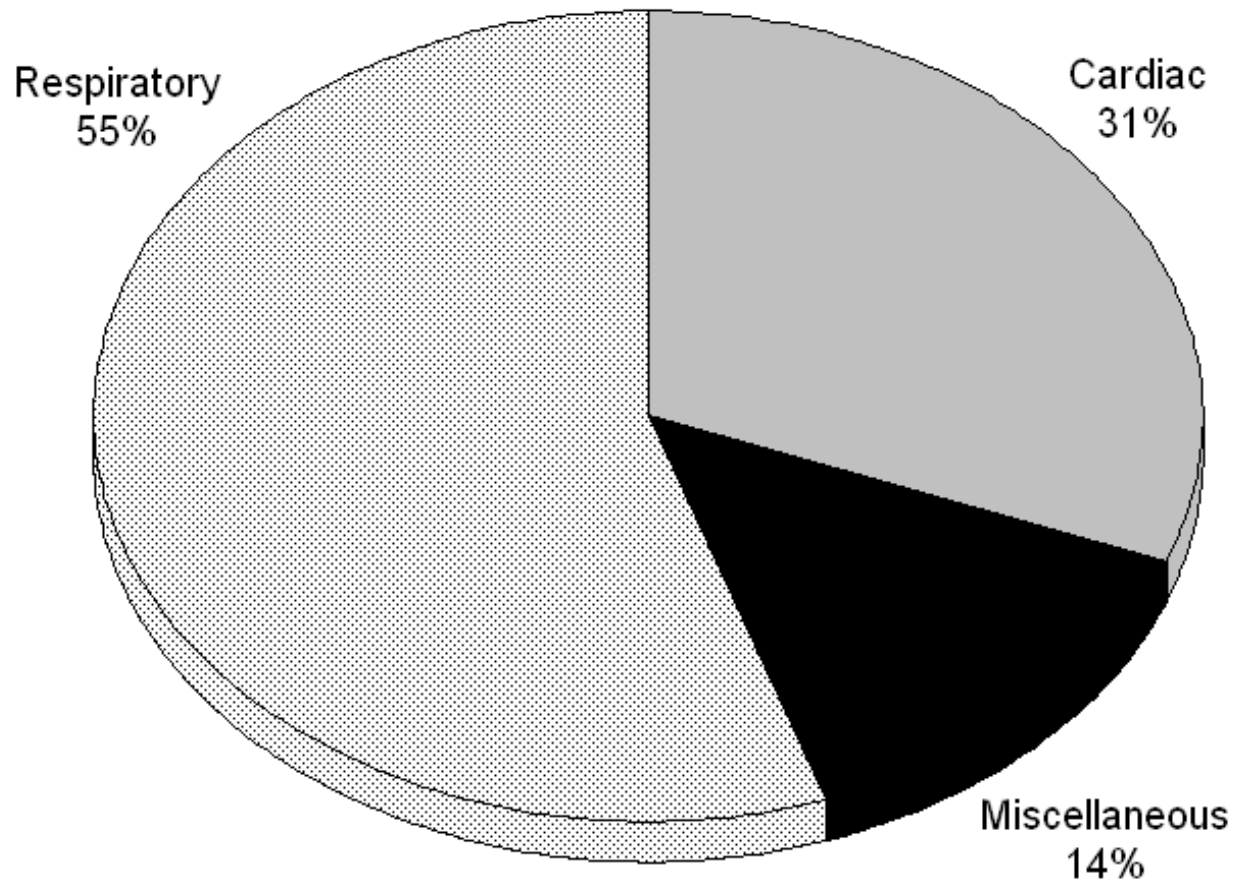
Lund University Hospital

Sweden

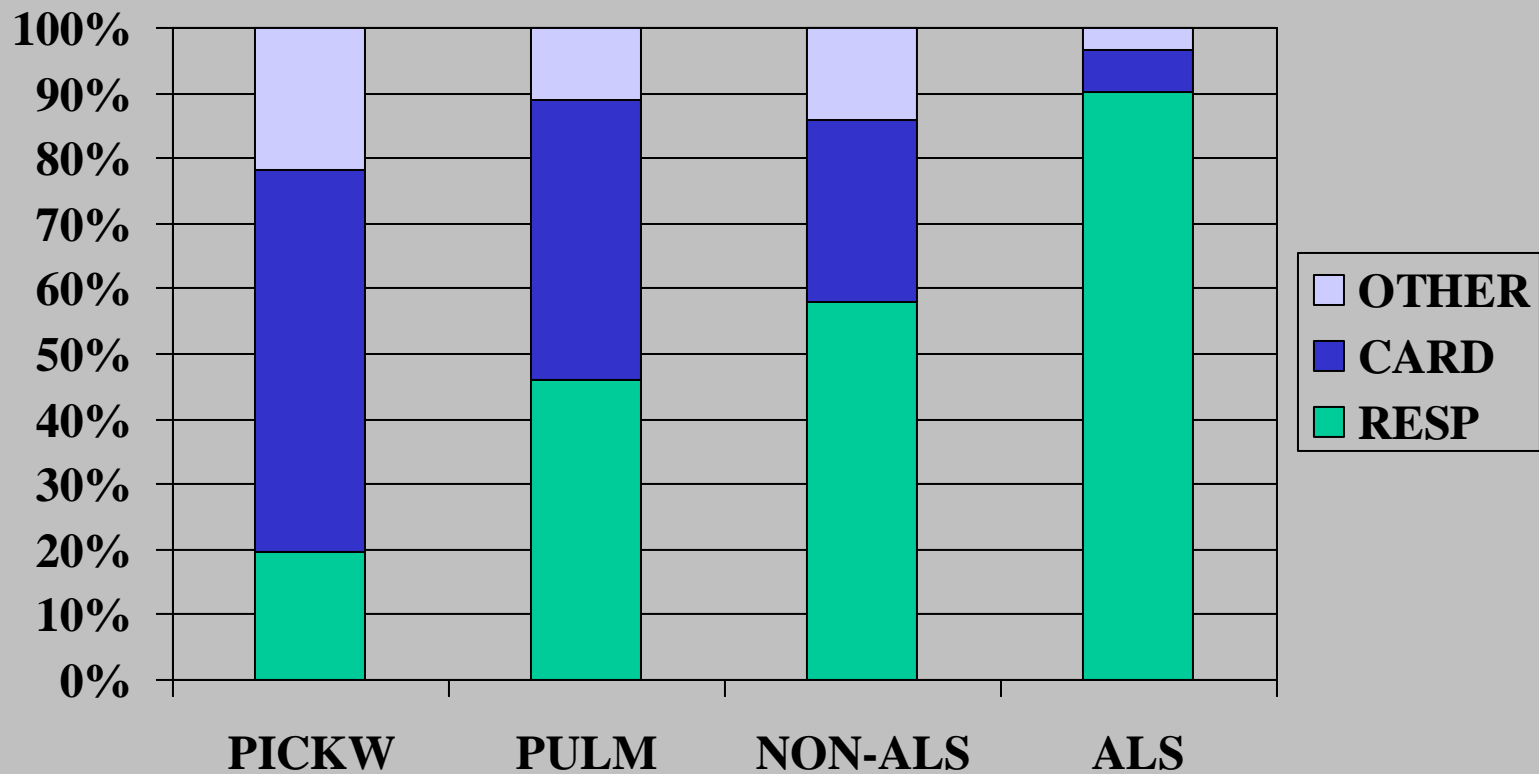
Life is a sexually contracted condition with 100% mortality

- Annual mortality in HMV users is 5 - 10%
- Is that a high mortality?
- Or is it a low mortality?

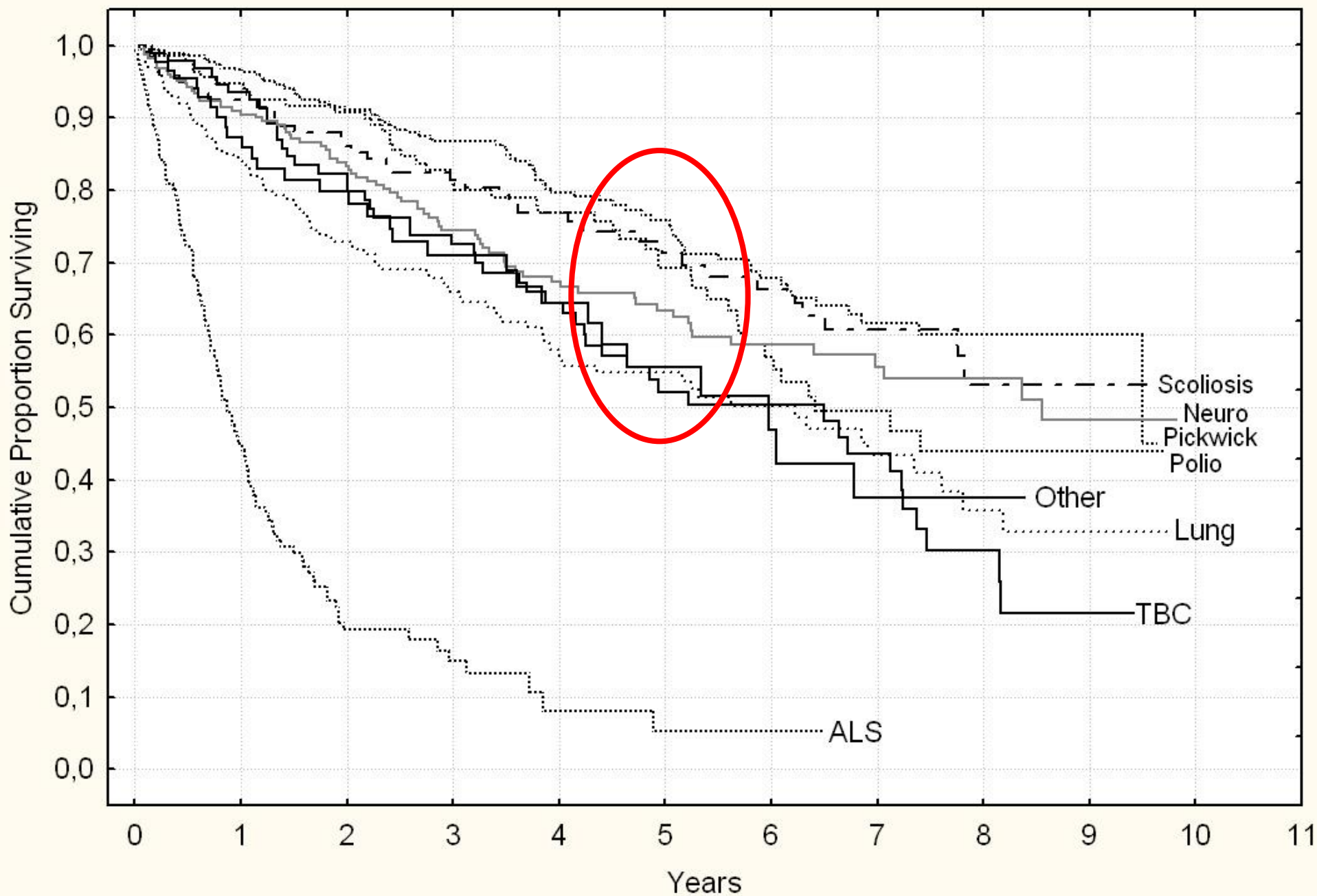
Causes of death in HMV users



Diagnosis-specific causes of death



Survival after starting HMV in Sweden
N = 1474



How do we manage the inevitable terminal phase in ALS?

- The Swedish model:
Don't cross that bridge till you come to it

Personal experience

- Nature has usually solved the problem
- The last months may be a nuisance, no matter whether the patient has a tracheostomy or is noninvasively ventilated
- Only one patient has asked for "assistance"
- Many patients are reluctant to discuss advance directives

Legislation

- Euthanasia is not allowed in Sweden
- If treatment is considered futile, you are allowed to withdraw it and you are allowed to give as much sedation as the patient needs to overcome anxiety and pain

No problems

- Everybody accepts that you stop TPN or tube feeding to *e.g.* cancer patients with a bad prognosis
- Everybody accepts that you stop hemodialysis in patients with *e.g.* advanced dementia
- Everybody accepts that you stop ventilator treatment in the ICU in patients with *e.g.* terminal COPD

Problems

- How do we manage the occasional patient with NMD (incl ALS) who wants to stop ventilator treatment in a non-emergency setting?
- In theory it is not a legal problem
- In practical experience: how do we do the procedure without taking the risk of being accused of euthanasia?

No simple solution

- The decentralized organisation in Sweden is a disadvantage
- and so is the speciality: pulmonary medicine
- And how do we deal with the team?
- Is it possible to do it outside hospital?
 - If not – do we say to the patients ”just call us and we will arrange for a bed at the hospital for a scheduled death?

When is the right time to cross that bridge,
and which bridge is the right one?

