What do I have to face?

End-of-Life care decision - making: the view of patients and carers – through the eyes and mouth of a doctor

EAPC Venice 2006

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the view of patients and carers

About a survey on the needs

What we know already

What this talk should add

A Swiss national survey

A project of the Swiss Society for Palliative Care

Focus group interviews

in 3 different language regions (SG, LAU, LUG)

with 3 different target groups

Coordinated by palliative care centers

Interwiewed until redundancy

- patients and family carers: **11dyads, 4 pts**.
- physicians (GP, nursing home, hospital): 64 part.
- nurses (community, nursing home, hospital): 58 p.

The domains of needs

- **Information, cooperation and decision making**
- Support for patient and family
- Institutions and finances
- Situation of severely ill patients in hospitals
- Public awareness and politics
- Education

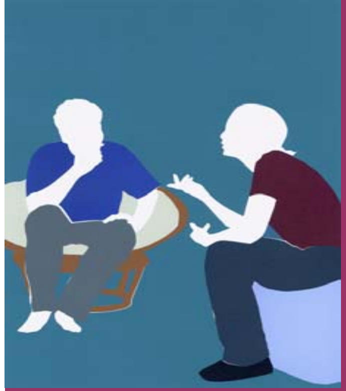
The needs in regard of decision making

I) The needs for information

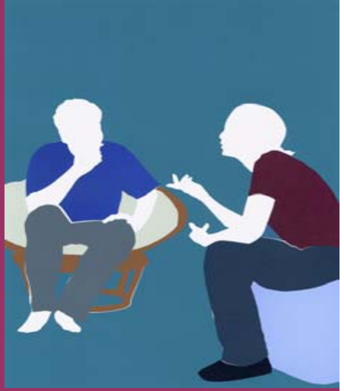
- The WHAT
- The HOW

II) The needs for Cooperation

III) The needs for education



The information needs

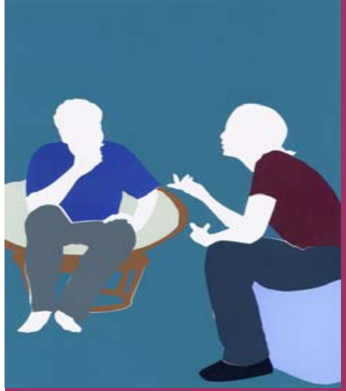


Question 1:

What will come ? Will I need to suffer ?

Prognosis:

“we want to be told, but we do not want to know”



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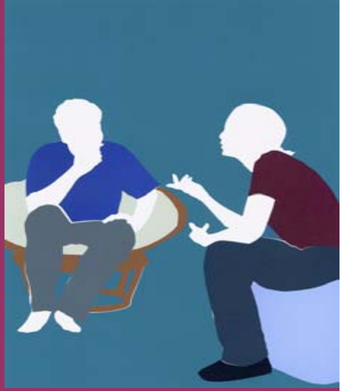


Prognosis….but….

« Et là ce médecin il m’a regardé et il m’a dit qu’avec le traitement il pouvait m’offrir encore 2 à 3 mois et sans traitement peut-être 2 semaines... .

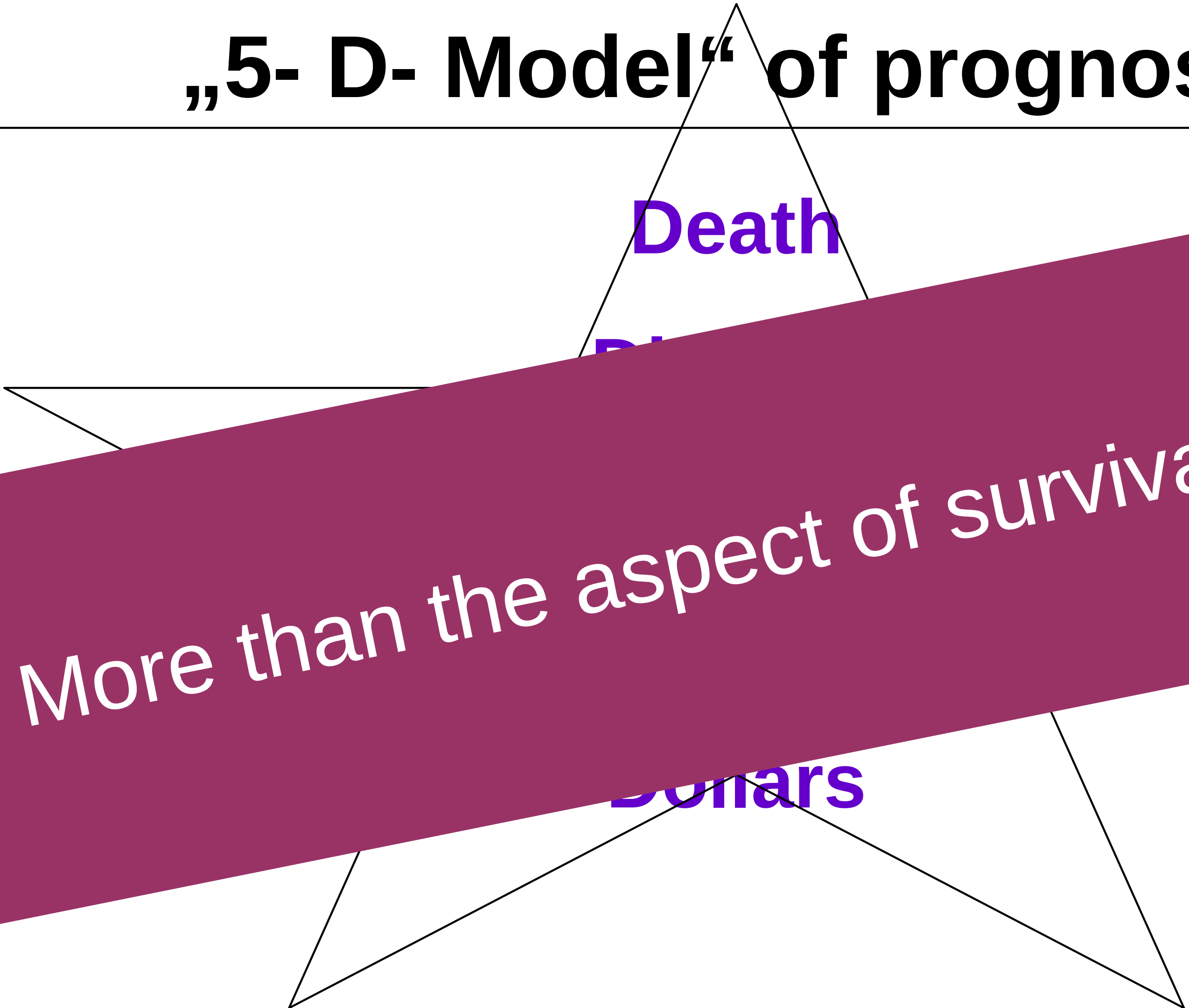
Depuis je préfère ne pas savoir où j’en suis »

« ..and this doctor looked at me and told me that I could survive 2 to 3 months with the treatment and 2 weeks without… Since I rather prefer not to know where I’m »

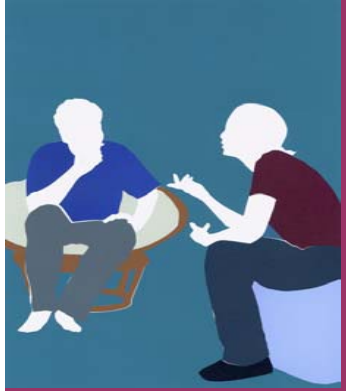
Which aspects of prognosis are relevant for the patient ?

FRIES/ EHRLICH 1981:

„5- D- Model“ of prognosis



More than the aspect of survival time



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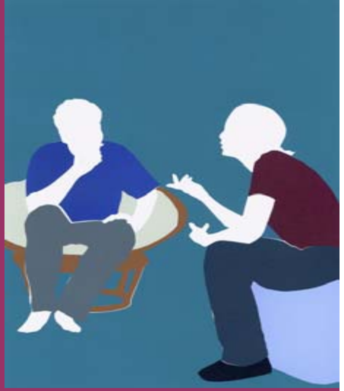
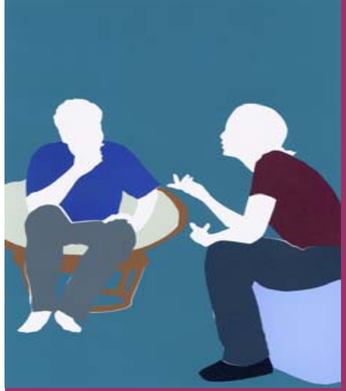


Question 2:

Will I become a burden for the family ?

McPherson Christine, Abstract 164 Venice 2006

Singer PA et al Arch Int Med 1992; 152: 478-79



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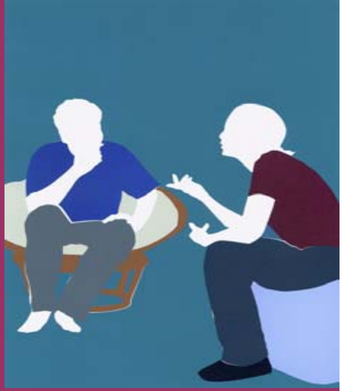
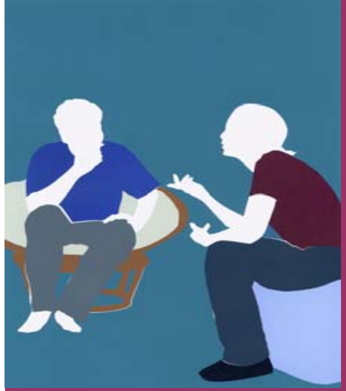


“WHAT”

- A lack of "un-biased" professional information about treatment alternatives if cared by specialists
- How to access the internet/ other sources



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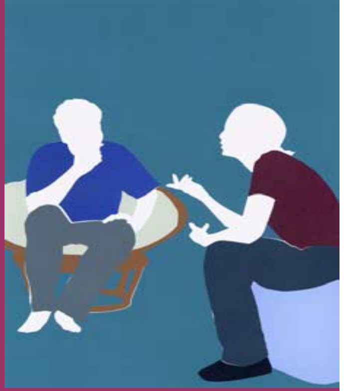
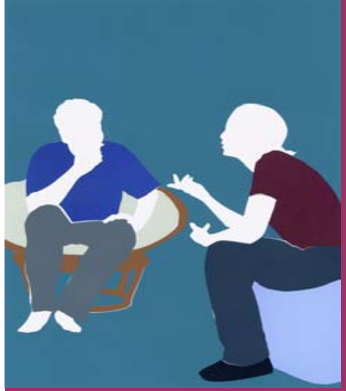


“WHAT”

- a systematic information about the options offered by Palliative Care and basic, self directed symptom management.
- Patients and their families feel insufficiently informed about the availability of concrete support systems in their region.



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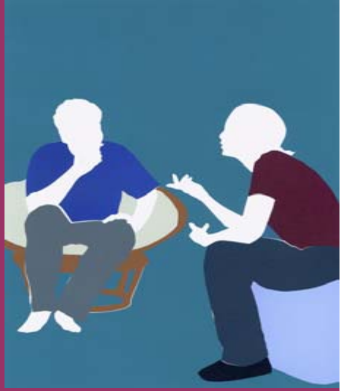


“WHAT”

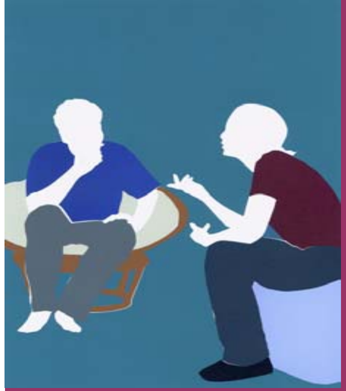
- About symptoms when death is approaching – open communication regarding all aspects of dying
- Concrete care planning instead of nebulous prophecy

Talking about options

Option A – the hope, allowing the miracle

Option B – prepared for the worst

Kirk, Kristjanson BMJ 2004 (June);328:1343 - 49



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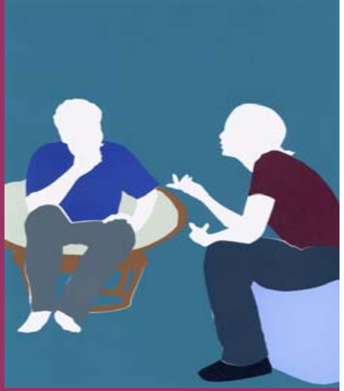
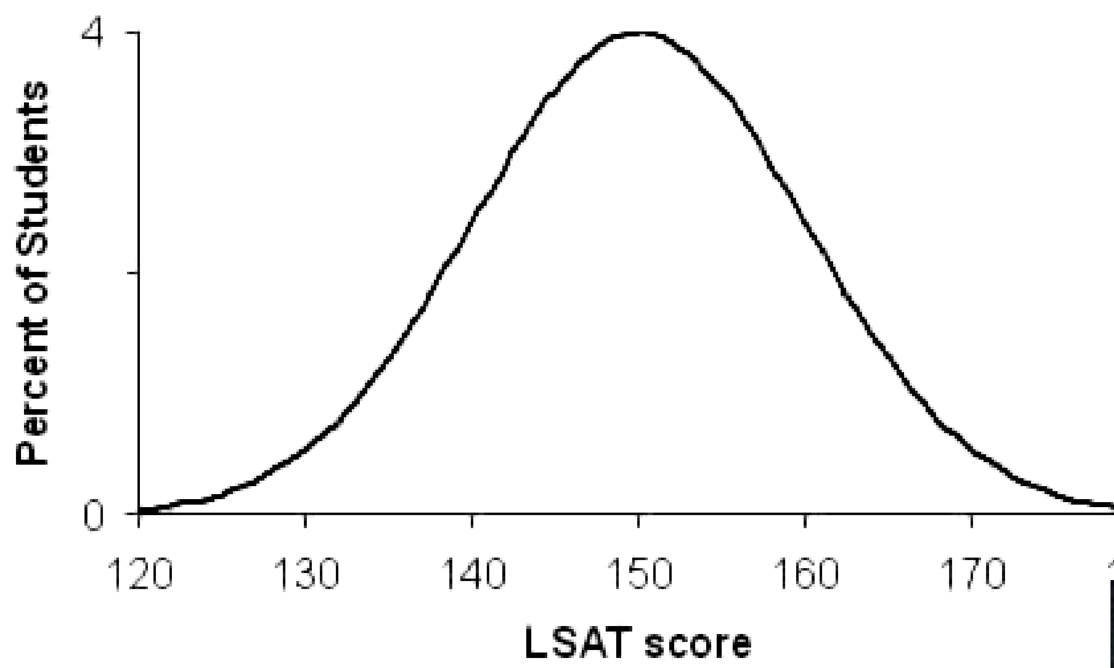
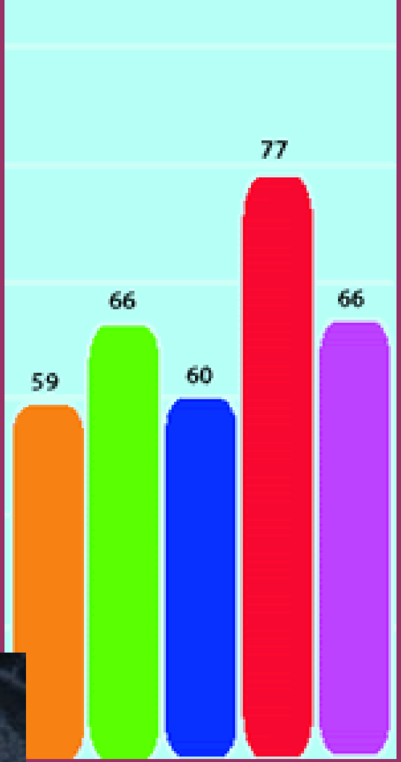


“HOW”

- Choose a simple language- easy to understand
- Patients want informations to be shared with the family

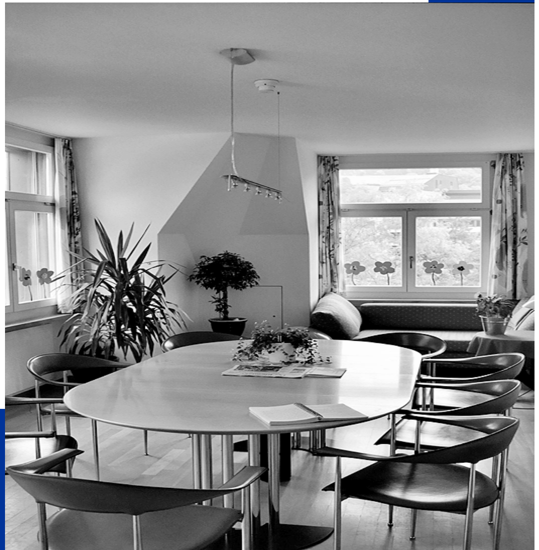
The HOW to inform
– how to come to a decision





Needs for cooperation

- A lack of concrete planning for "shared decision making" integrating the patient, his family and the physician/ other professionals (time, setting, preparation) AND
- Action plan (Who, What)



Needs for cooperation

- Insufficient communication/ transfer of information from one professional to a colleague once a decision has been made.
- A lack of integrating the patient's GP if decisions are made in the hospital/ by specialists

Needs for cooperation

There is a specialist's barrier for asking a second opinion

- Intra- / interdisciplinary
- **Interprofessional** (ex. LCP)

Needs for education

- A lack of psychological skills while counselling/ decision making by physicians, especially from a highly specialized background

Needs for education

- “Simply the most basic skills of human behaviour (answering a telefon call)….”

Needs for education

- How to train myself to get attention in the world of medical specialists
- How to change doctors’ behaviour: “Treat us as adults, human beings, as partners”
- My rights ? The “PSDA”: Patient self determination act 1991)

Silverman et al Arch Intern Med 1995 (155):502 - 510

Needs for education

- “Listen – don’t talk first”

- “I don’t think they want to learn about my individual goals and worries – even the nurses”

Butow PN et al, Cancer 1996 (77): 2630 - 37

More concerns

- Do not leave most serious decisions to the patients and families (multioptional approach)
- Do not debate about the best option in front of the patient + family

More concerns

- The money: “you get paid the most crazy chemotherapy – but almost nothing for a good care at home”
- Average cancer home care costs for 3 months: $ 4563 (1998), including family labor

Chochinov, Kristjanson: J Pall Care 1998 (14,4): 5-15

More concerns

- There should be one leader not numerous in difficult times

Conclusions for research

Lessons learned from the survey: qualitative research

- identify focus group leaders who interact in a similar way
- identify services that care for a comparable group of patients (target population)
- **it is very difficult to recruit patients and family members but well tolerated**
- grounded theory approach is difficult if you deal with different cultures/ languages
- “one party” focus groups: the “frustration bias”

Conclusion for practice

What is new? - nothing

look at the **SPIKES – model**:

- be aware of the **Setting**
- ask for the **Preferences** and goals
- give **Information**
- based on **Knowledge**
- check for the **Emotions**
- define a „shared“ **Strategy** for a defined time

Baile WE, Buckman R et al Oncologist 2000; 5: 302-11

Or in other words

- Sit down and listen
- Identify the goals of the patient and family
- improve the content of information: provide hope + option B – (needs clinical experience)
- Talk about the fears, but also concrete tasks
- Regard the patient as your partner
- Identify your collegues
- Identify and define the „leader“

Discussion for practice: some „hidden“ aspects

- DNR – discussions figure as major decision making sessions **(„the Friday afternoon syndrome“)**
- Professionalism:

what is **important** (for whom)

= where am I **competent** ?

Hypothesis

10 %	**Ethical problem (values)**
40 %	Communication-Problem (Team/ Patient/ Family)
50 %	Problem of Knowledge/ Experience Medical/ Nursing

Discussion for practice: some „hidden“ aspects

- dealing with insecurity/ probabilities: poison for scientific medicine
- the solidarity in “playing the good weather game”: ping-pong of hope
- the “team game”: life’s advocacy, death’s advocacy – ping- pong of responsibility

How effective are educational interventions to address Eol- Care issues ?

Communication skills courses: no

Palliative Care Teams: no

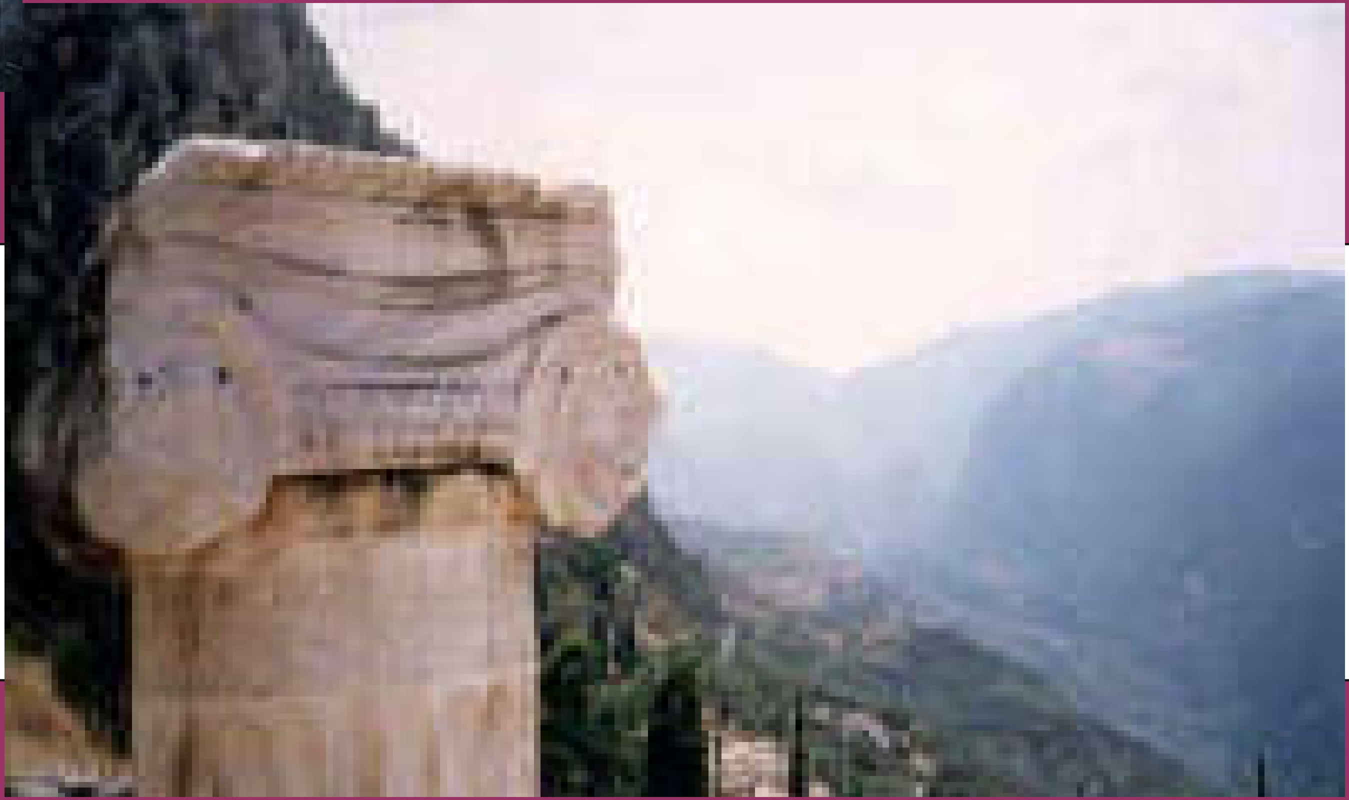
Courses on DNR- discussions: fair

Examinations: no

Use of screening criteria (SUPPORT): no

Rapid cycle quality improvement (J.Lynn): advance care planning from 20 to 80%

Shorr et al JPSM 2000;19(3): 168; editorial: Joanne Lynn



And many things we want to be told,
but we don‘t want to know

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