

The Dying Game

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Spirituality

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The fork in the road

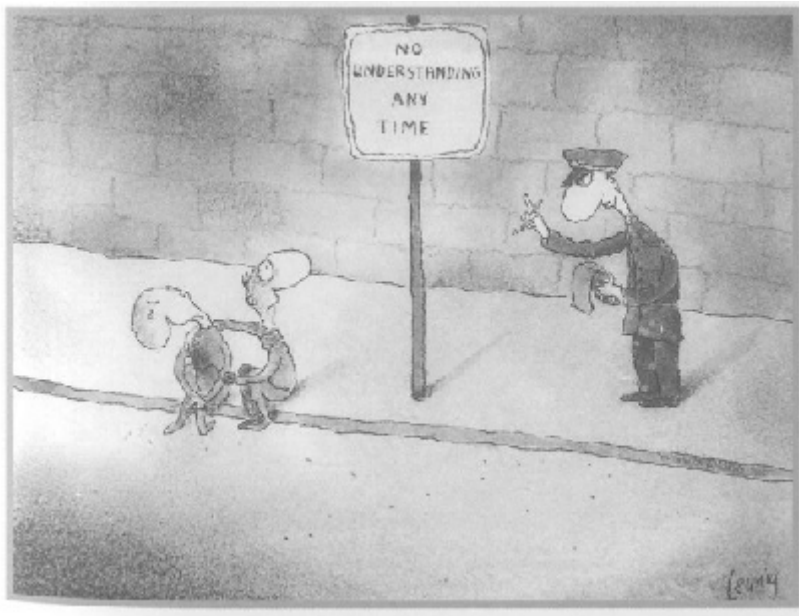
As medicine's capacity to treat disease and injury improved, it came to focus less on dying and more on its prevention

Prof. Michael Ashby



From humanistic endeavour to therapeutic imperative

The present health care system, has
become a caustic and dehumanising
environment for patient and physician
alike



Prof Z Neuwirth 2002
MJA; 176: 77-79.

Death and the therapeutic schism

The drive to prolong life and maintain homeostasis has become so deeply entrenched, it takes precedence over matters of the soul, casting a pall over those who are dying

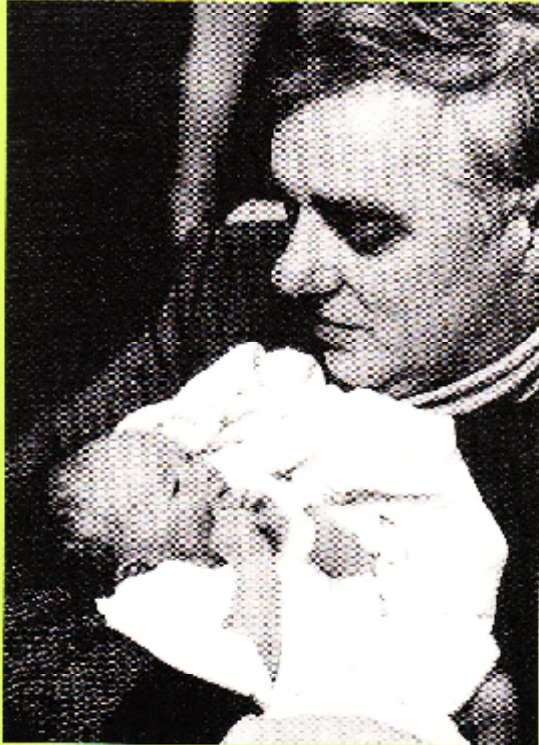
Barbato 2005
Internal Medicine Journal; 35:636-7



Patients and families view the end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences

Steinhauser 2000
JAMA; 284(19): 2476-2482

GRAHAME C. JONES



**Magnanimous
Despair**

The bitter truth

It does seem bitterly sad that my fate, the fate of me, will be decided, indirectly, through the functioning of a fleshy envelope. I see the soul thus entrapped, as being the great and ultimate casualty of Cancer's mortal war

G Jones

The Dying Game

Medicine V Death



Medicalisation of dying

- Number of subjects: 50
- Median duration of care: 28 months
- Median number of doctors seen: 32
- Least number of doctors seen: 13
- Most number of doctors seen: 97

- Continuity of care and communication??

S Smith 1999
Pall Med; 13:217-223

End of life care in USA (n = 200)

	n	%
ICU admission or transfer	110	55
Died in ICU	81	40
CPR	50	25
Withdrawal of ventilator	11/84	13
Withdrawal of artificial feeding	11/58	19

Delayed recognition of 'dying'
Appropriate care for the dying

Dying in an Australian hospital

Retrospective review of 100 deaths

- 49% had IV
- 27% receiving antibiotics
- 17% on chemotherapy
- 7% in ICU
- 5% having enteral feeds
- 2% CPR

Sue Middlewood 2001

J Pain and Sym Management; 22:1035-1041

The dying experience of older patients

Interview with surrogate decision-maker (n=3357)

- most died in hospital
- 40% had unrelieved pain
- 63% had unrelieved physical/emotional symptoms
- 11% had resuscitation attempted
- 25% ventilated
- 40% tube fed

J Lynn 1997

Ann Intern Med; 126: 97-106

Dying with advanced dementia

- USA study of 1609 patients who died within 1 year of admission to Residential Aged Care Facility
 - 55% had DNR order
 - 1.4% had DN hospitalise order
 - 25% tube feeding
 - 49% laboratory tests
 - 11% restraints
 - 10% IV therapy

S Mitchell 2004

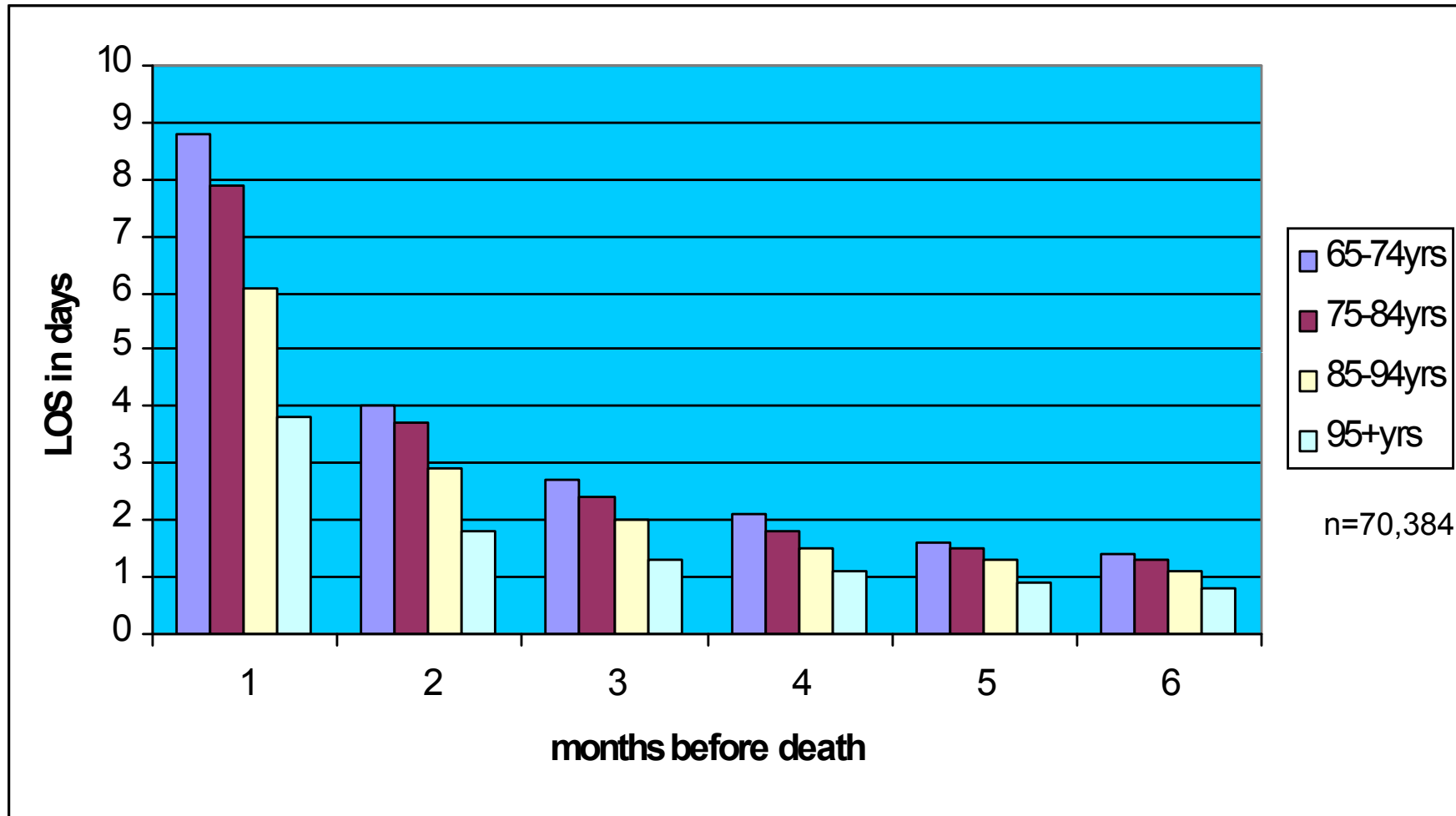
Arch Intern Med; 164: 321-326

The last year of life for those 65 yrs and over (NSW)

- Deaths 1/1/2002-31/12/2003 = 70,384
- Mean age at death: 80yrs (M), 84 Yrs (F)
- 87% hospitalised at some time
- Deaths in hospital
 - 50% overall
 - 61% for 65-74 yrs
 - 27% for > 95 yrs

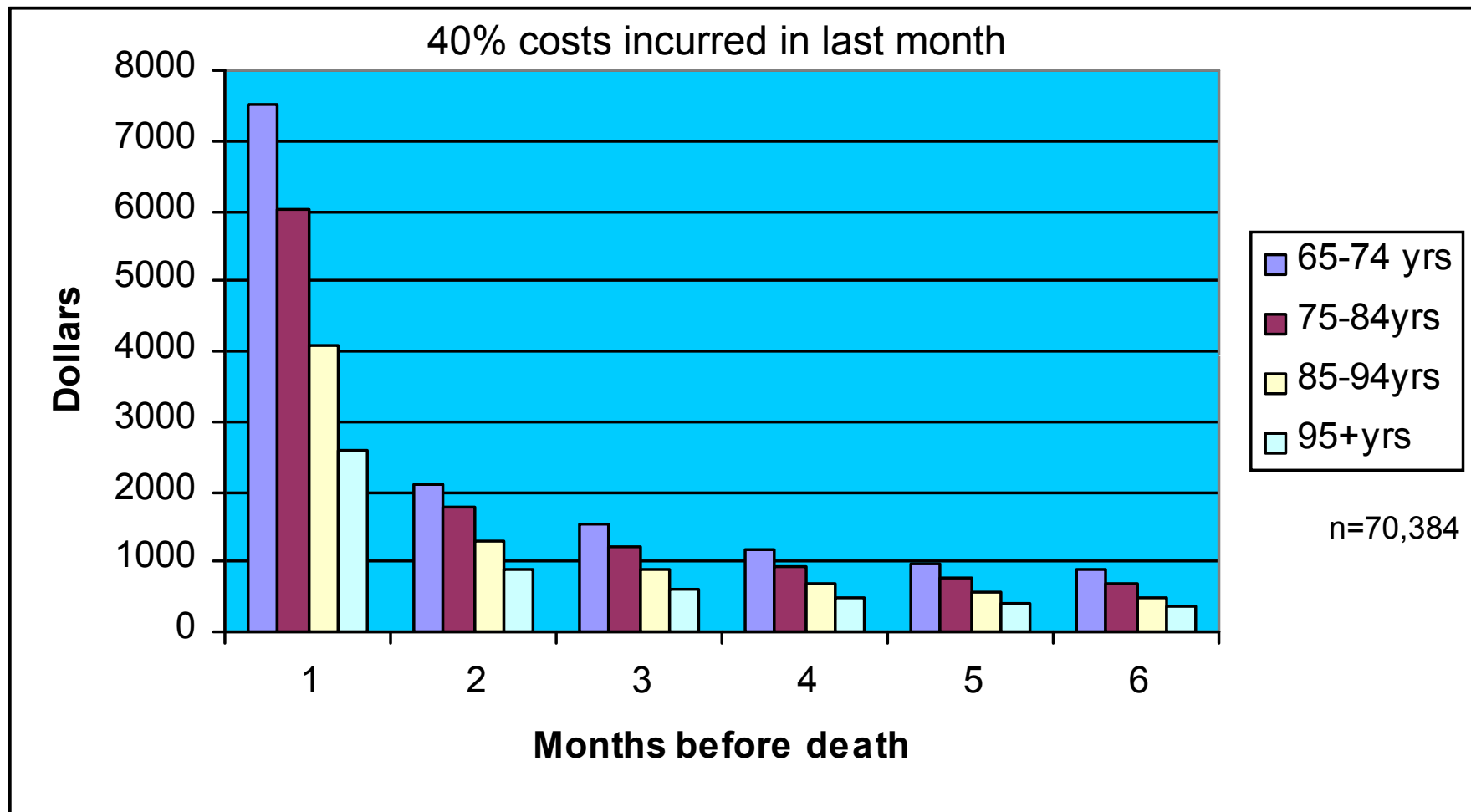
K Kardamanidis 2007
MJA; 187(7): 383-388

LOS by age and time to death



Kardamanidis *MJA* 2007; 187(7): 383-388

Inpatient costs by age and time of death



Kardamanidis *MJA* 2007; 187(7): 383-388

Patient and family satisfaction

Survey of 2 million hospitalised patients

- Spiritual care most in need of quality improvement

H. Koenig 2008

Medicine, Religion and Health

Survey of 200 cancer patients

- 75% dissatisfied with spiritual care

T Balboni 2007

J Clin. Oncology;25:550-560

Reasons for the dying game

- The therapeutic imperative
- The research imperative
- A doctor's underlying fear of death
- Medical training- a denial of the place and meaning of death in human life
- Fear of failure
- A moral, legal and ethical obligation to preserve life
- Difficulty with prognosis (determining when death is inevitable) and letting go
- Community expectations
- Patient and family expectations

The therapeutic and research imperative

- Discontinuing aggressive care means giving up and, in effect, represents failure

Morgan E (2000). *NEJM*; 342: 347-348

- Death is a series of preventable diseases

William Haseltine
Chairman and CEO of the Human Genome Sciences

Coping with death and dying

‘in order to deal with these aspects of my work I have developed something like a Ned Kelly suit of armour – an outer shell that protects me from the anguish and stress of people dying; a mask that prevents too much eye contact...while at the same time preventing the emotion within me from escaping’



Keith Edwards 2003
MJA; 179: 647-648

The crucial issue

For meaningful change to occur in the quality of end-of-life care, the lived experience of patients and caregivers in their cultural context of illness must become as alive and vibrant to the physician as is the disease that is being treated – [this requires change at the practice, personal and systemic level]

S Faber 2003

J of Palliative Medicine; 6:19-31

Death and dying

- Is part of life
- Is not simply the end of life; it is a profound, complex human experience
- Is something we can prepare for
- Require respect and holistic care

Demedicalising death

- Respect the 'Rights of the Dying'
- Greater awareness of when death is inevitable
- Institute appropriate end-of-life strategies
- Communicate and negotiate
- Deal with psych-spiritual needs of the patient and family
- Deal with own fear of death
- Systemic change

Rights of the dying

- To know when death is coming and what to expect
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptoms
- To have choice and control over place of death
- To have access to information & expertise
- To have access to spiritual & emotional support
- To have access to palliative care
- To have control over who is present and who shares in your death
- To ensure wishes are respected
- To have time to say goodbye
- To be able to leave when it is time to go

Richard Smith 2000
BMJ; 320: 129-130