A person is shown from behind, carrying a large, heavy stone on their back. They are walking up a steep, rocky incline. The scene is dimly lit, suggesting a difficult and arduous journey. The person's posture is one of strain and effort.

Paying to Die

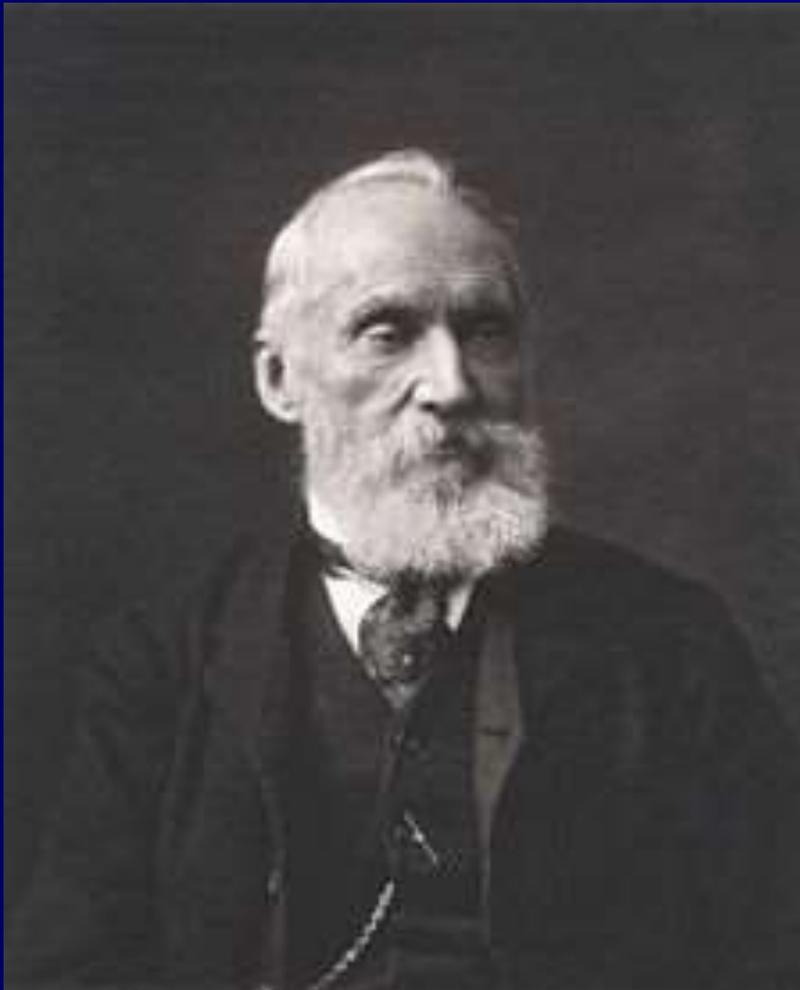
The Economic Burden of Care Faced by Patients and Their Caregivers

Konrad Fassbender, PhD.
Division of Palliative Care Medicine
University of Alberta

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Lord Kelvin, British physicist

on numbers and knowledge...



“When you can measure what you are speaking about, and express it in numbers, you know something about it...”

Robert Carlyle, Scottish Essayist

on the dismal science...

"... a dreary, desolate and, indeed, quite abject and distressing one [science]; what we might call, by way of eminence, the *dismal science*."



Outline

1. Economic and Policy Context
2. Methods
3. Results & Discussion
4. Conclusion
5. Next Steps

1. Economic and Policy Context

Canadian Health Reform – Deinstitutionalization Hypothesis

In 1983 a Task Force on Health Care Resource Allocation recommend
“development of community services for elderly with goals of reducing institutionalization, improving quality of life and lowering costs.”

Deinstitutionalization (avoidance, early discharge, reduced intensity) underpins the economic argument advocating investment into palliative care services & programs

Figure 6: Proportion of Time Spent in Various Care Settings in the Year Prior to Death, April 1993 to March 2000.



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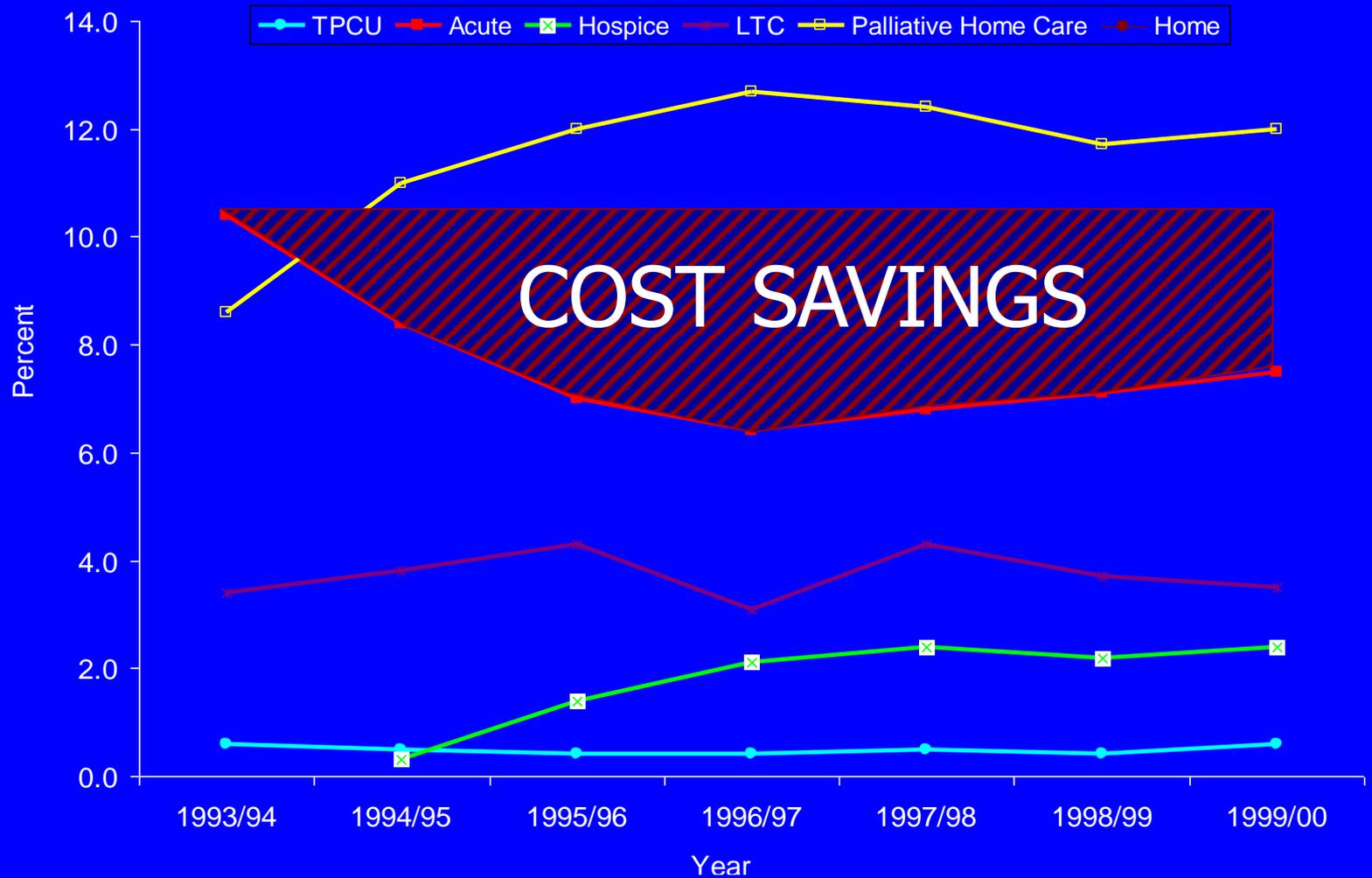
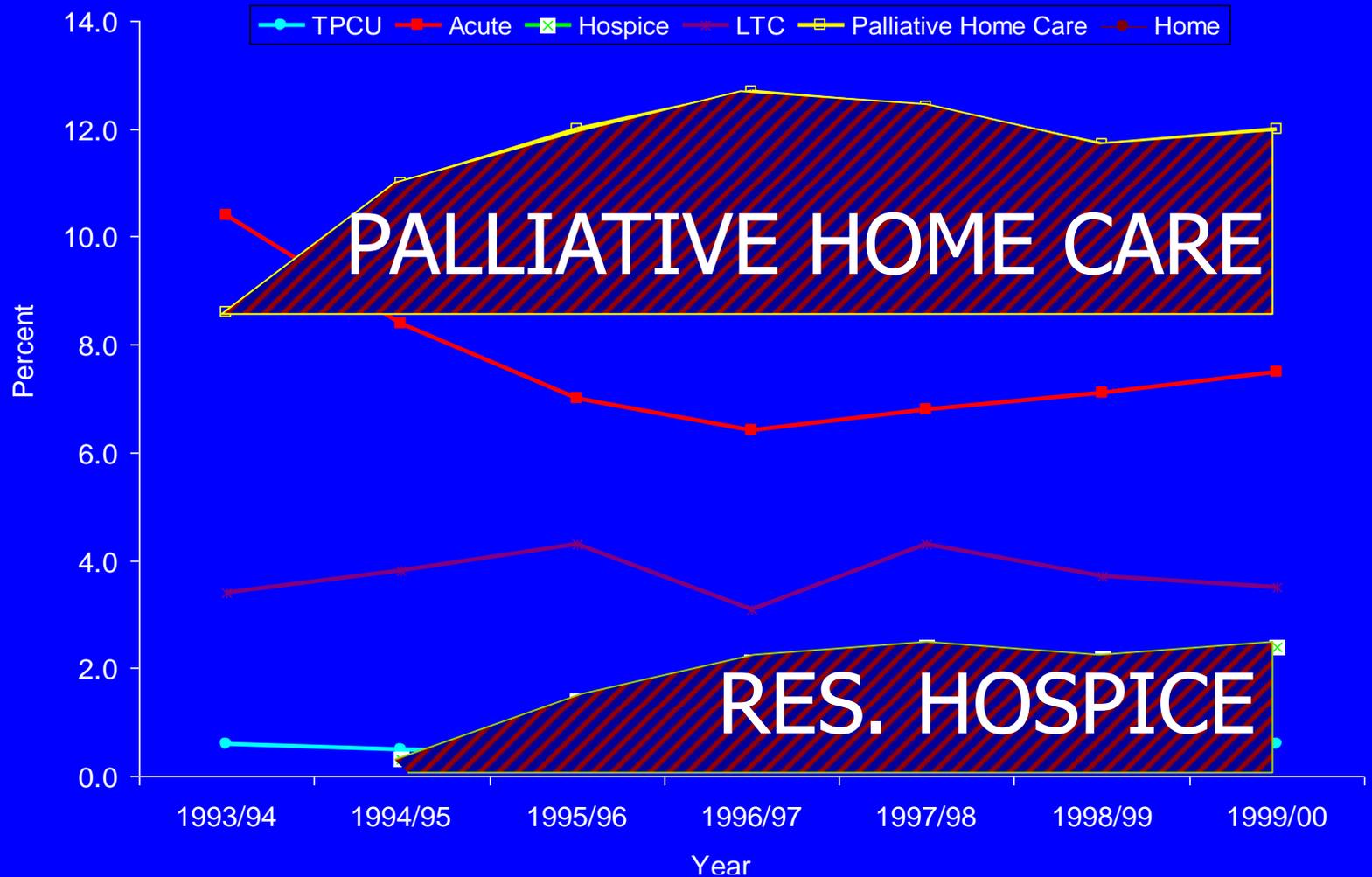


Figure 6: Proportion of Time Spent in Various Care Settings in the Year Prior to Death, April 1993 to March 2000.



Cost Neutrality

Fassbender K, Fainsinger R, Brenneis C, Brown P, Braun T, Jacobs P. Utilization and costs of the introduction of system-wide palliative care in Alberta, 1993 – 2000. *Palliative Medicine* 2005, 19: 513-520.

'High cost of dying'

Government expenditures on health routinely exceed revenues which jeopardizing sustainability and health reforms.

Governments target the dying because of their high costs.

While we know a little about revenues, not enough is known however about government expenditures and age, especially in the case of providing care for the terminally ill.

Caregiver Conscription Conspiracy?

What about the family? While home death is often desired, achieving a home death requires a great commitment from both palliative care programs and the family.

“The public supports care in the home and other forms of community-based care but does not react well to being ‘conscripted’ into [unpaid] caregiving.” (National Forum on Health 1997:19)

The big picture is incomplete and what is known hasn’t been adequately numerated.

Costs: the big picture (I)

Direct	Medical + Overhead Non-Medical
Indirect	Productivity Permanent LT/ST Disability Sick Days Time - unpaid work Time - leisure Time - personal care
Intangible	Quantity of Life Quality of Life

Costs: the big picture (II)

Third party payer	Ministry of Health Social Services Other Government Insurance Employer Private
Individual	Patient Household / Family
Voluntary Sector	Individual Organization
Employer & Other	



Progress in the forward direction...

January 2004: the Canadian government enacted the Compassionate Family Care Leave Benefit program providing income and job protection for family members who care for the dying. Most provinces have also amended their labour codes to provide job protection. Is it enough?

Program of Research

To describe the societal cost of resources consumed by dying patients and their caregivers where

societal or total costs include ministry of health costs (i.e., fixed overhead and administrative costs associated with the programs as well as variable costs) and out-of-pocket and time-related costs for patients and their caregivers.

2. Methods

Methods

- Prospective, proxy questionnaire measuring total health care resource utilization
- Identified, measured and valued direct medical resource use (P), out-of-pocket expenses (F) and time related losses (F).
- Population: adult cancer patients with prognosis between 2 and 24 weeks.
- Referred to palliative care in Alberta between Feb 2004 and June 2007.

Acknowledgements

- Patients and their caregivers
- Colleagues and project staff
- Funding
 - ACB: Questionnaire and strategy to assess economic burden of palliative care patients and their families (N=50, Edmonton)
 - CIHR: Palliative Care in Canada: The Economic Perspective (N=250, Edmonton, Victoria, Winnipeg, Montreal, Halifax)
 - CIHR: Cost and Quality of Variations in Ambulatory and Home-Based Palliative Care (N=576, Edmonton, Calgary, Toronto)

3. Results and Discussion

Results I

- Baseline interviews were followed biweekly an average 2.74 times.
- In other words, respondents were followed for 64.6 days
- Responder burden averaged 34.3min at baseline and 8.8min for follow-ups.

Results II

- A total of 301 patient / 553 caregivers comprised 13.0% of the eligible palliative care population.
- Patients averaged 66.2 years of age, of which 55.1% were male.
- Caregivers averaged 52.9 years of age, of which 67.4% were female.

Results III

Relationship	Total	%
Child	238	43.0
Spouse	195	35.3
Sibling	43	7.8
Friend	28	5.1
Parent	24	4.3
Other	25	4.5
Total	553	100.0

Results IV

- Patients received care from an average 1.82 individuals (max=7)
- Providing a total of 91.6hrs of care per week (or 64.9hrs/caregiver/week).

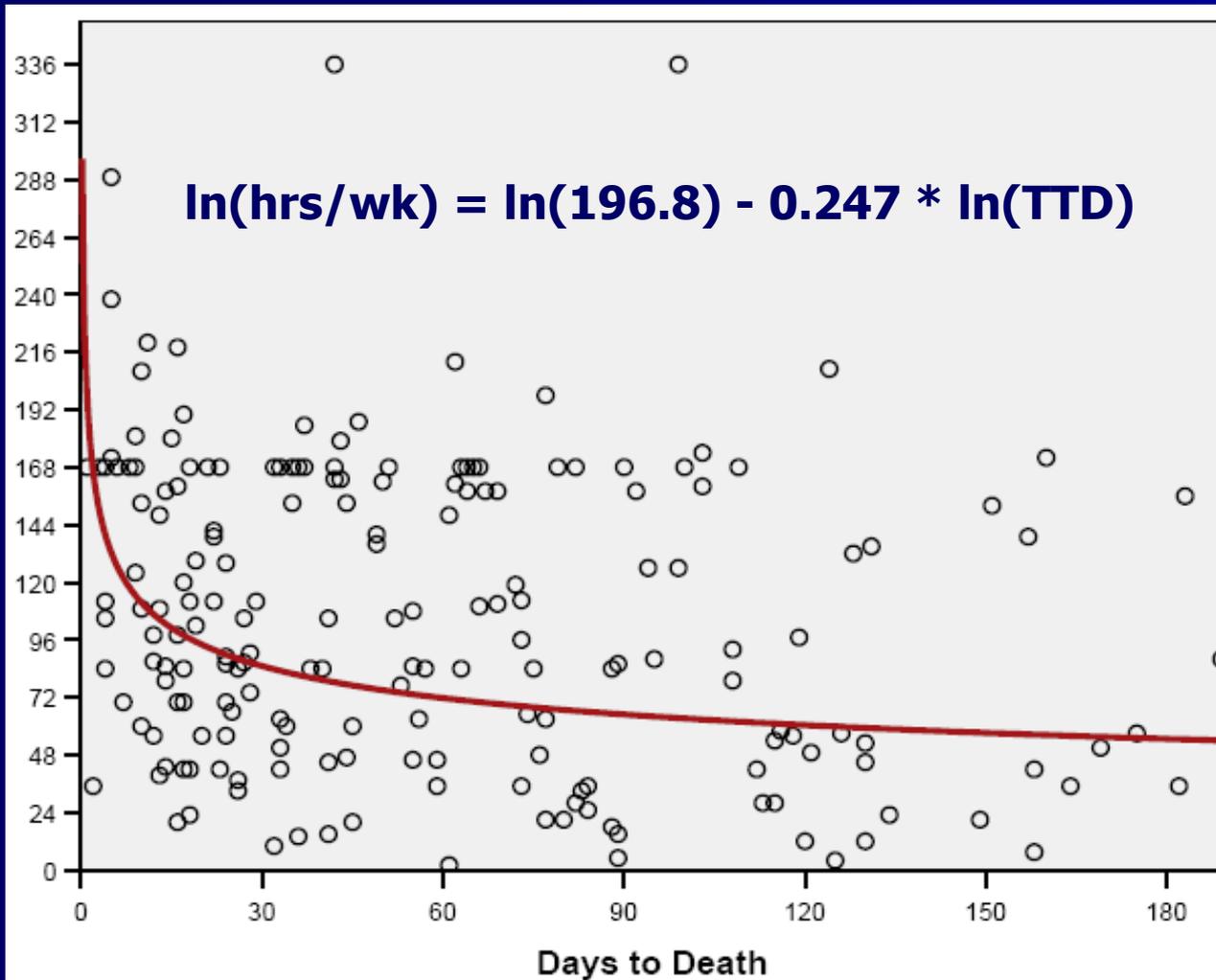
Results V

- More than half of caregivers participated in the workforce: employed (35.0%) or temporarily absent from their work (19.5%).
- Caregivers' non-work activities were severely limited: 69.3% reduction in time spent performing domestic work, 46.3% personal care and 73.2% leisure.

Results VI

- Assuming an average wage rate of \$23.90 (16.18 EUR), caregiver time related losses are estimated at \$40,329 (27 302 EUR) per patient.
- The value of caregiver time rivals/exceeds direct medical and out of-pocket costs.
- Federal caregiver assistance compensates caregivers a maximum of 6.5% of costs in the last six months of life.

Results VII

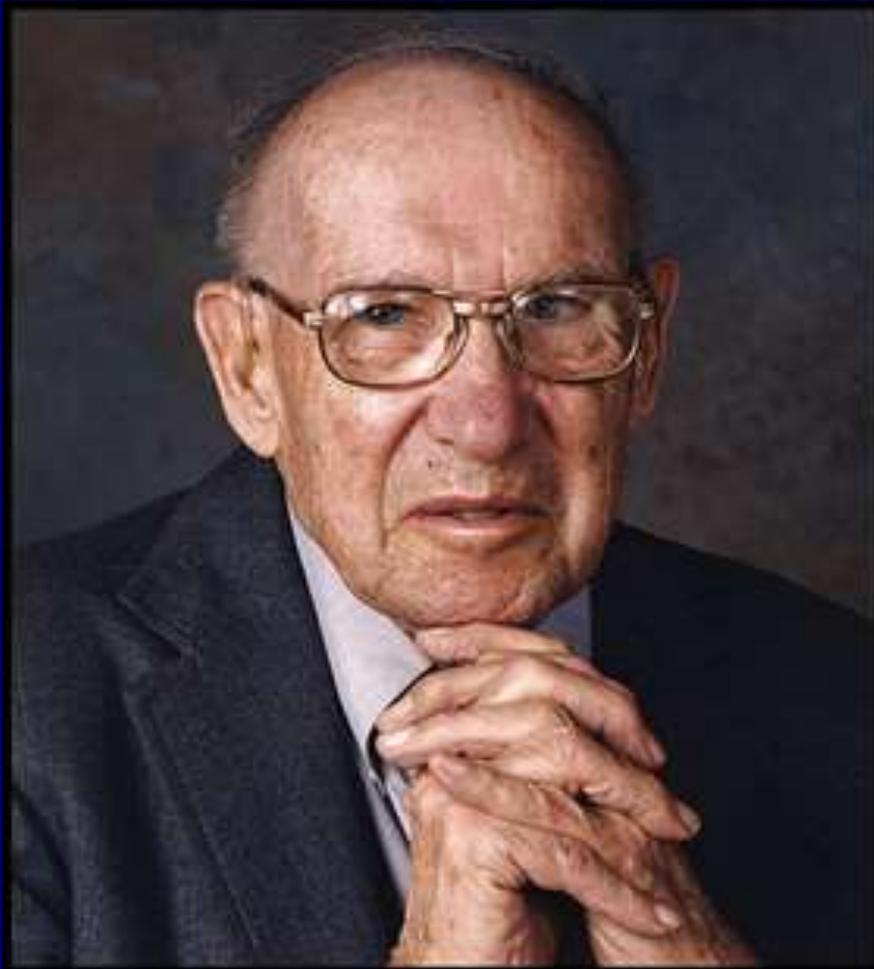


4. Conclusions

Conclusions

- Time related costs attributable to the care of dying patients impose a significant burden to families and employers.
- Inadequate financial support of dying patients and their families by governments jeopardize both the health and economic benefits associated with the continued growth of palliative care programs.

Peter F Drucker, Management Theorist



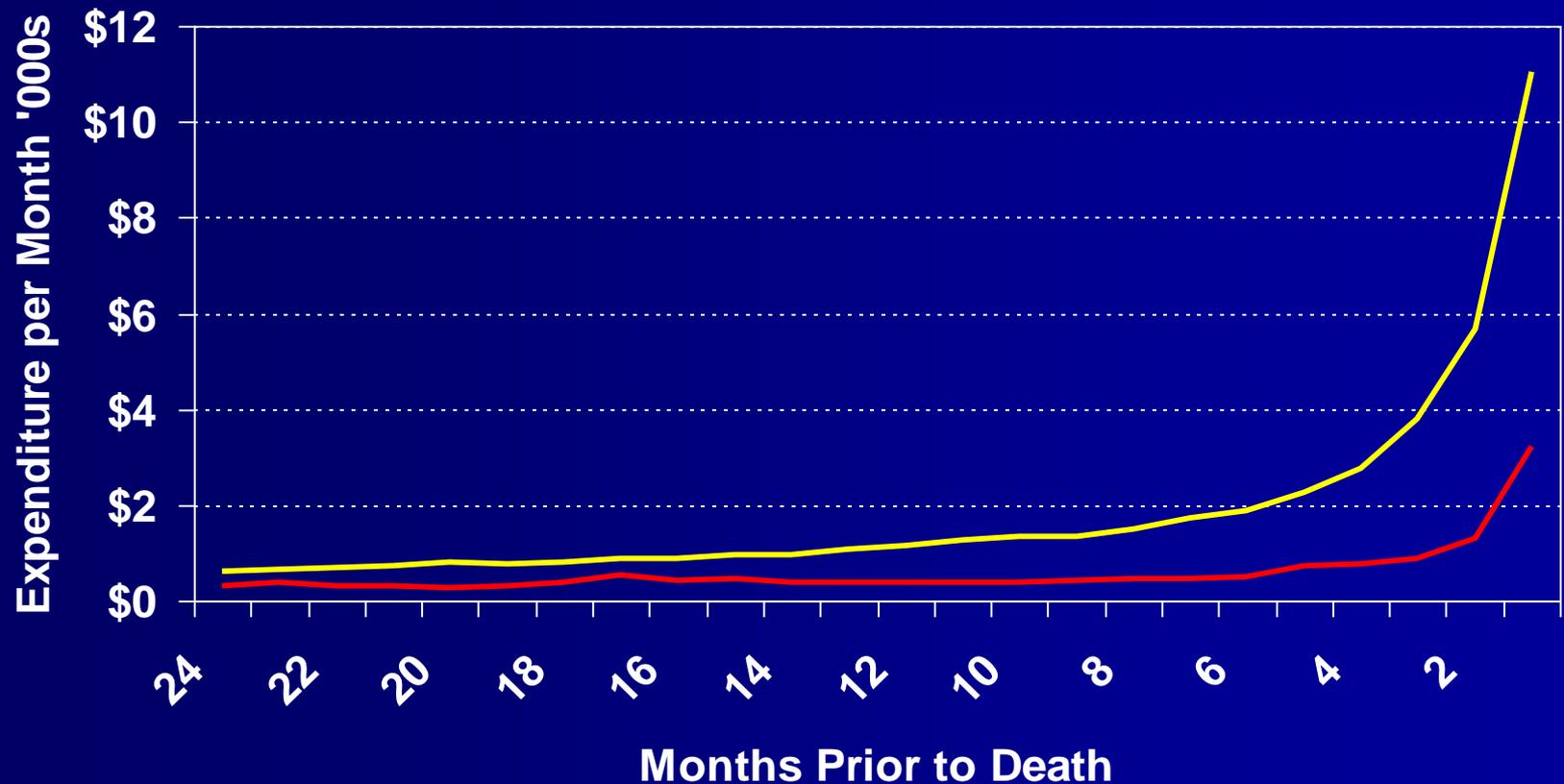
“You can’t manage what you can’t measure.”

5. Next Steps

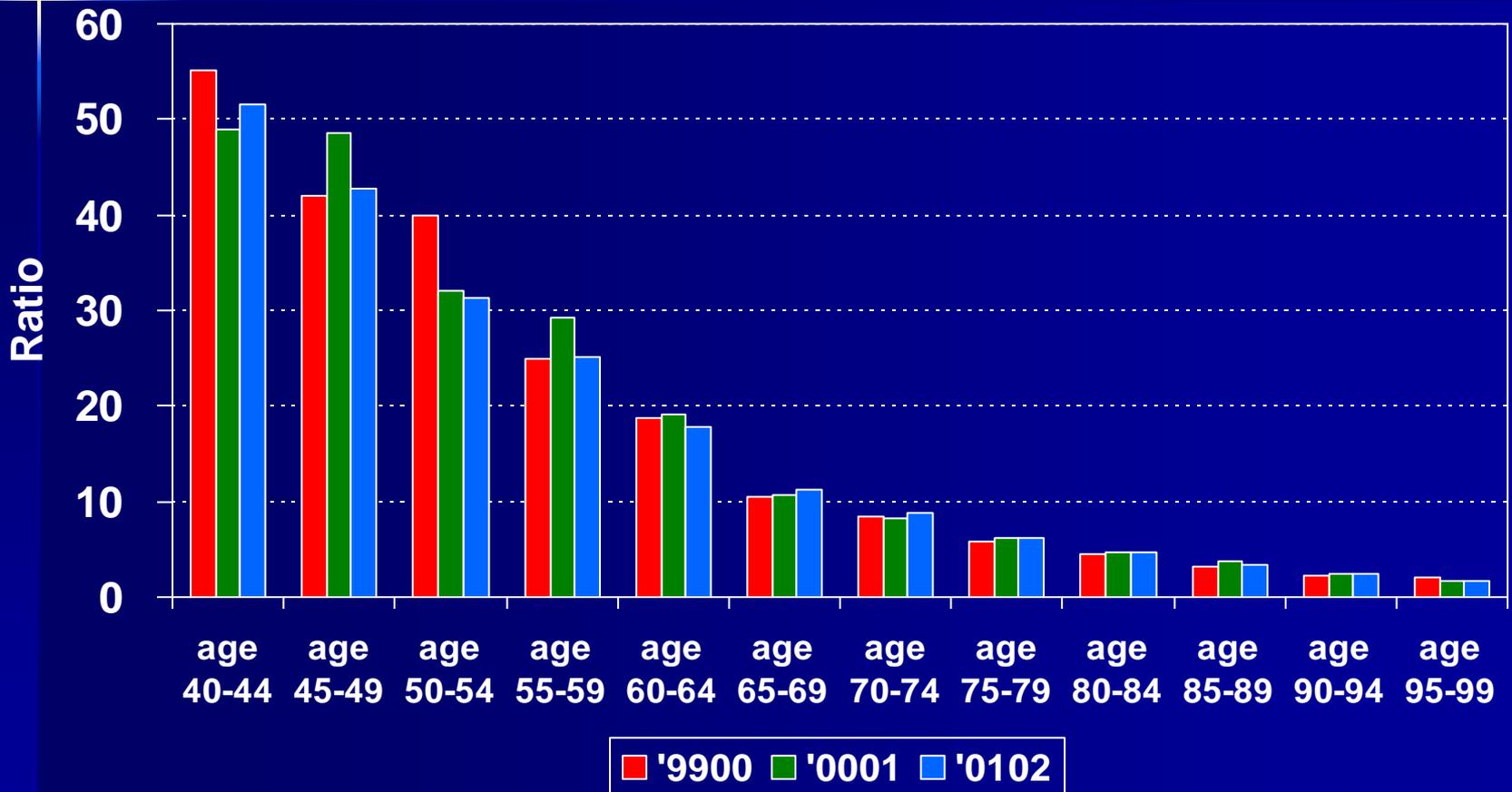
I: Continue work toward describing the big picture



II: Does age or time to death better explain HCE?



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- Hypotheses regarding age and time to death
 - life-cycle (also referred to as 'fair innings')
 - compression
 - expensive elderly
 - substitution

II: Does age or time to death better explain HCE?

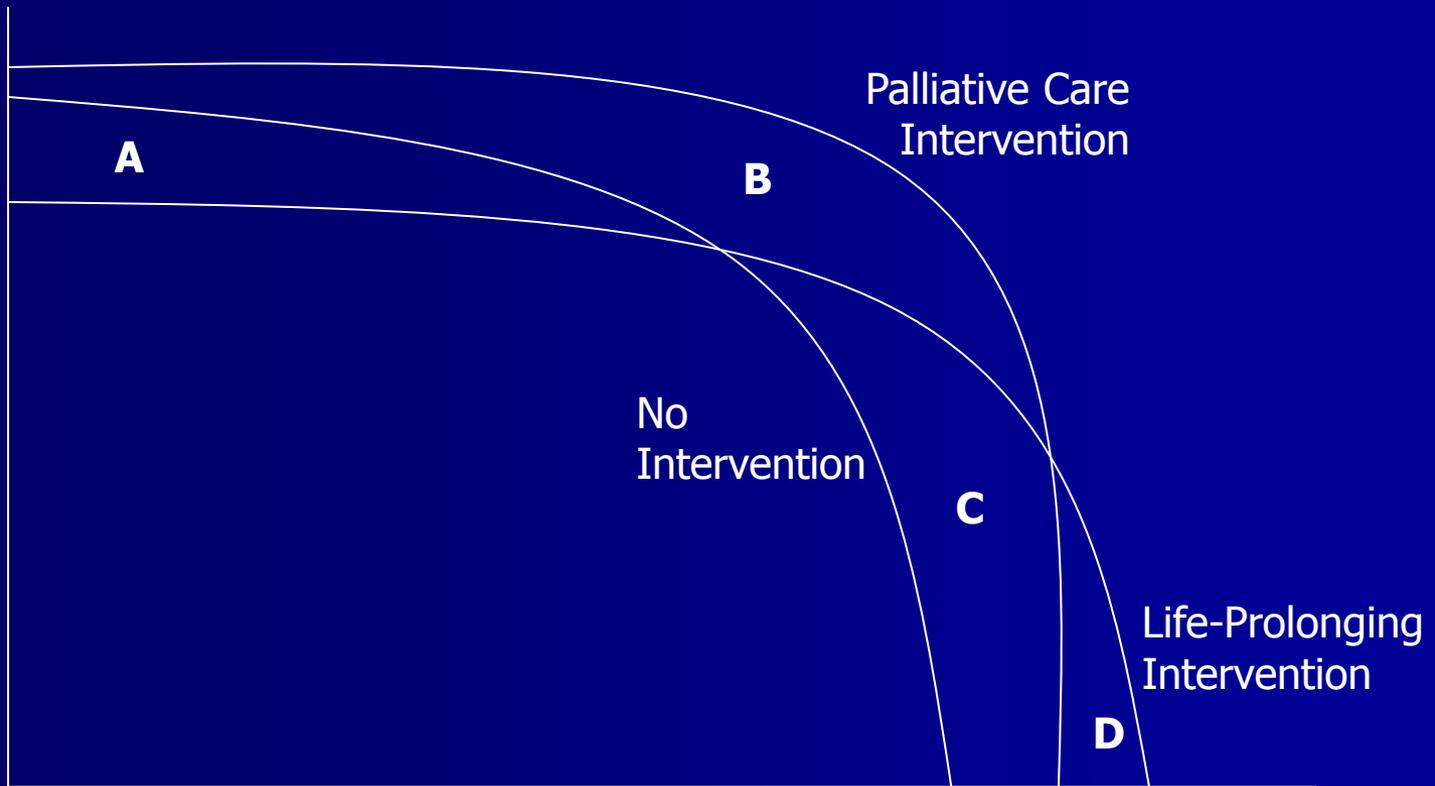
Adopting a clinico-econometrics approach and hypothesize the following system of equations:

$$\text{HCE} = f(\text{Age}, \text{Gender}, \text{Dx}, \text{TTD}, \text{Z1})$$

$$\text{TTD} = g(\text{Age}, \text{Gender}, \text{Dx}, \text{FS}, \text{HCE}, \text{Z2})$$

III: Intangible costs and tradeoffs between the Q's

Quality of Life



Length of Life





Thank-you