

Think Tank



Citizen's Participation – The Role of Citizens in the Management of the Health Care System and Its Consequences

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Outline

1. Health Care Reform & Sisyphus Syndrome
2. Citizen Characteristics: financial, health, opportunities for participation
3. Health Reform in Canada
4. Consequences: Lessons learned from caregivers of cancer patients

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1. Health Care Reform & Sisyphus Syndrome
 - Allocate public resources to health.
 - Longevity is enhanced resulting in accelerated ageing of the population.
 - Increased population beyond retirement results in decreased government revenues.
 - Increased demand for health and public resources by seniors.
 - Allocate more public resources to health.

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1. Health Care Reform & Sisyphus Syndrome
 - In the last five years, health spending increased by 9.5%.
 - Government revenues only increased by 4.9% during the same period.
 - Health care system may not be sustainable.
 - Health care programs are jeopardized and increase the need for citizen participation.

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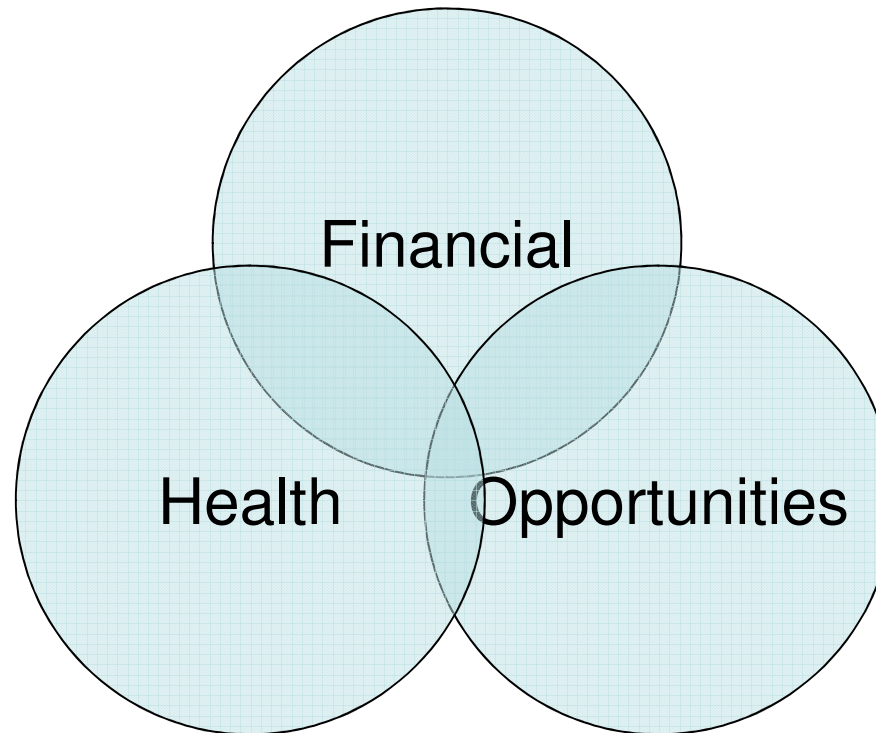
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2. Citizen Characteristics: financial, health, opportunities for participation



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2. Citizen Characteristics: financial, health, opportunities for participation
 - Ability to contribute to government revenues and consume health are largely related to age
 - Taxpayers (18-65)
 - Children (0-17); Retired (65+); End of Life
 - Personal Finances
 - Correlated With Education and Health Promotion
 - Insurance (eg consumer directed health care)

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2. Citizen Characteristics: financial, health, opportunities for participation
 - Participation is limited by health status
 - Healthy
 - Advisory Boards (others health)
 - Consensus Conferences (own and others health)
 - Unhealthy
 - Advocacy Movement
 - Education / Changing Public Expectation

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2. Citizen Characteristics: financial, health, opportunities for participation
 - Political
 - Consultation, surveys, advisory groups, boards etc.
 - Health Care System
 - Formal Caregivers (clinicians and other personnel)
 - Volunteers
 - Conscription into Health Care Provision
 - Informal Caregivers

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3. Health Reform in Canada

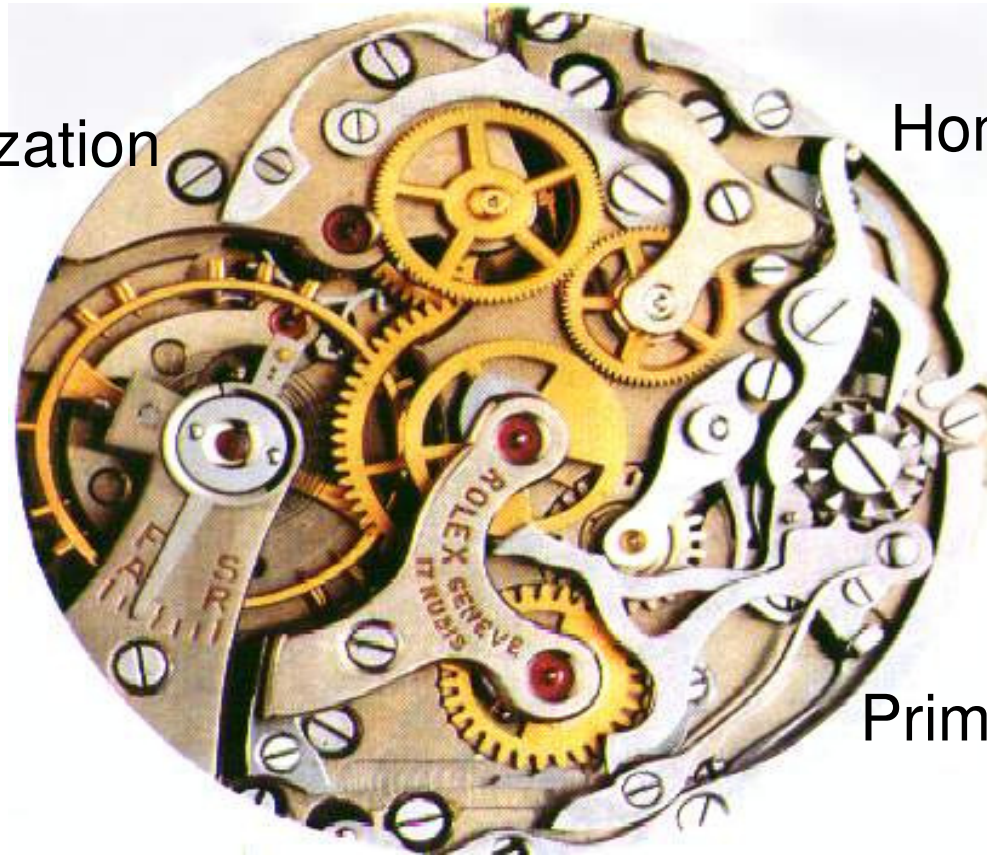
Deinstitutionalization

Home Care

Information Management

Pharmacare

Primary Care



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3. Health Reform in Canada: Deinstitutionalization
 - Deinstitutionalization defined as avoidance, early discharge or reduced intensity of hospital services
 - 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 underpins the economic argument advocating investment into community programs such as palliative and end of life care

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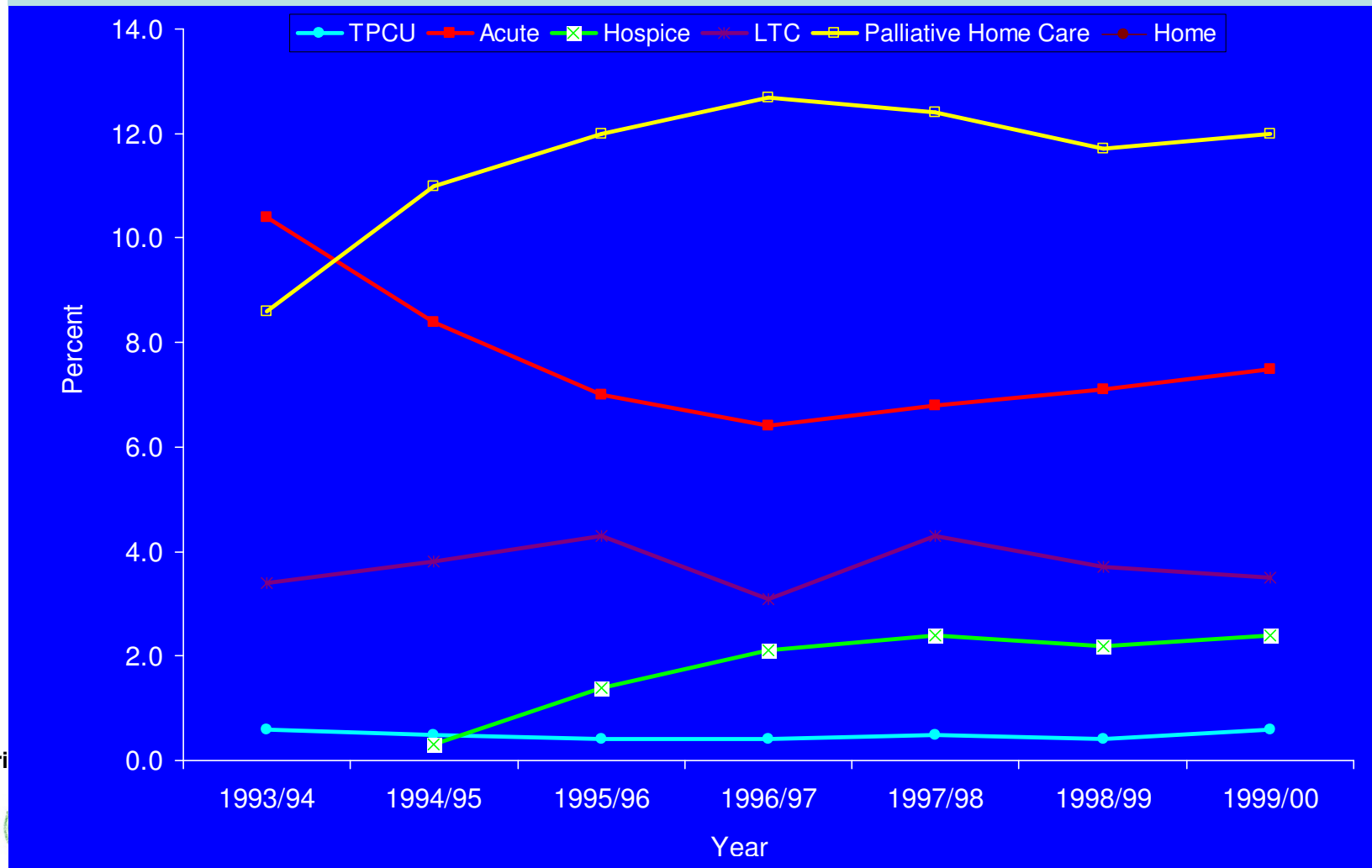
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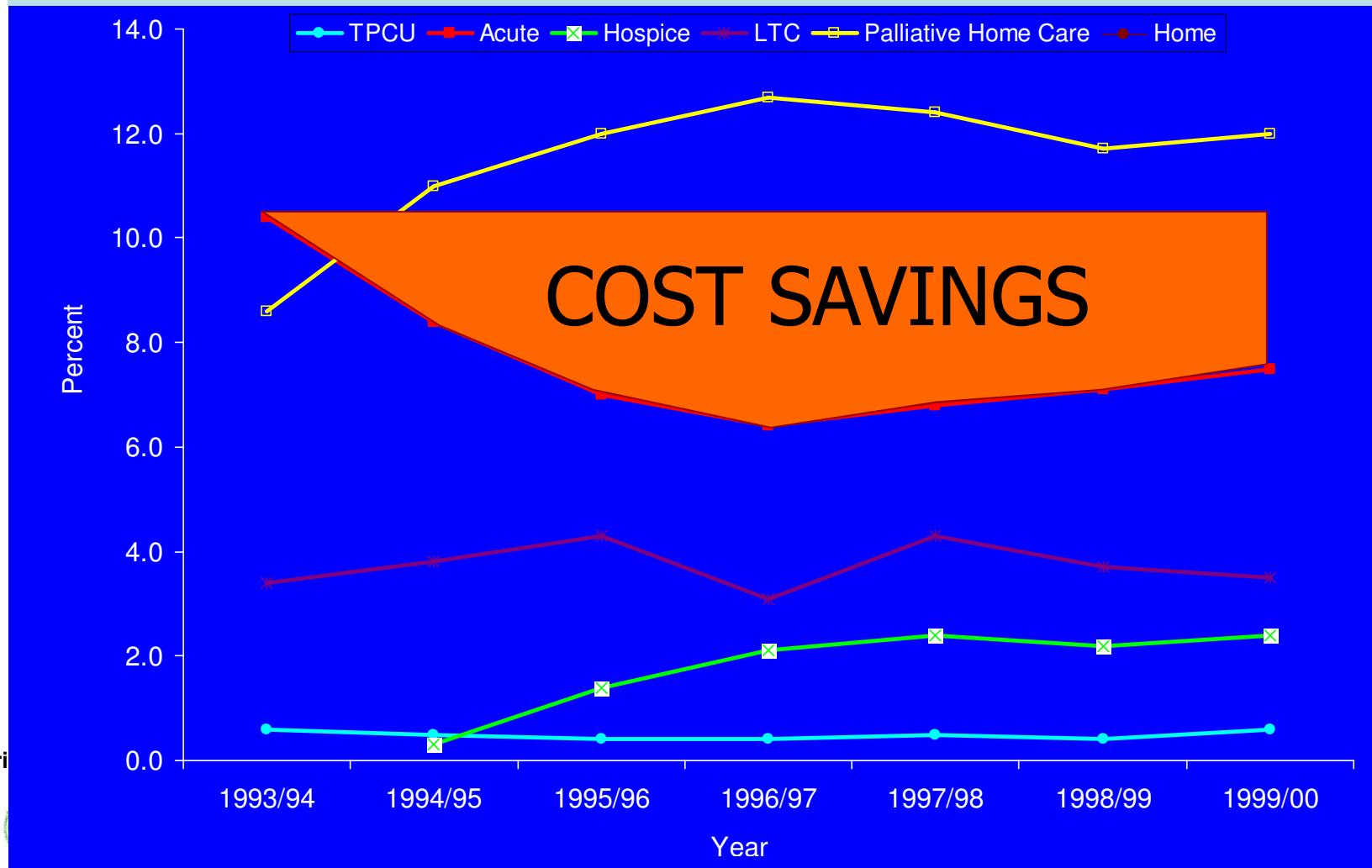
Figure 6: Proportion of Time Spent in Various Care Settings in the Year Prior to Death, April 1993 to March 2000.



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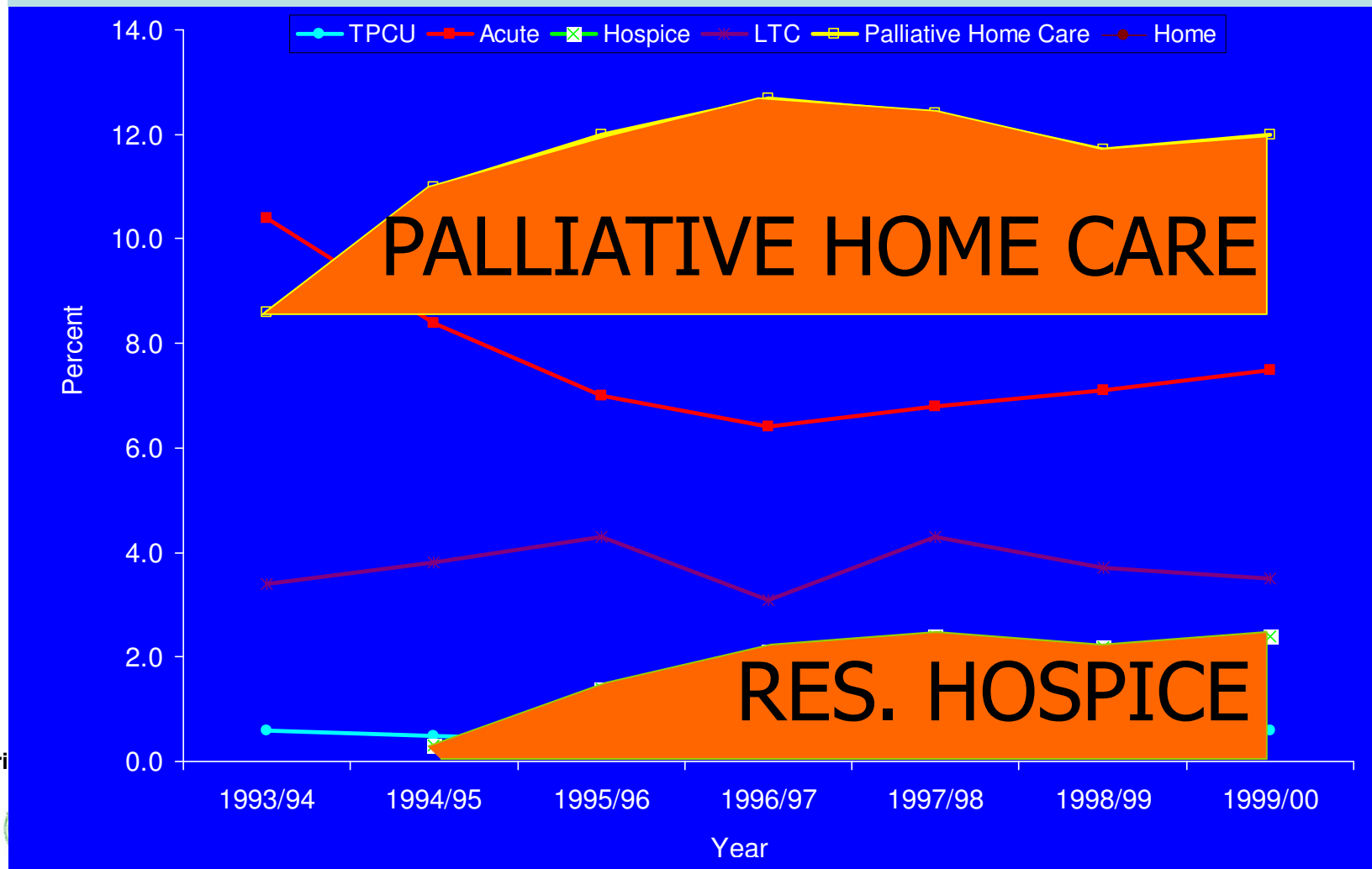
Figure 6: Proportion of Time Spent in Various Care Settings in the Year Prior to Death, April 1993 to March 2000.



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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.



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3. Health Reform in Canada: Deinstitutionalization
 - What about the family? While home death is often desired, achieving a home death requires a great commitment from both palliative and end of life care programs in addition to 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)

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3. Health Reform in Canada: Policy Response

- 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.

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4. Consequences: Lessons learned from caregivers of cancer patients

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We need your help... **to learn more about the financial costs and caregiving effort of patients and their families.**

During advanced stages of illness most patients and families wish to receive care at home. In Alberta, the provincial government pays for some medications while programs and communities provide additional resources. The federal government provides employment insurance benefits, which allows caregivers to remain at home. We would like to hear from you whether you feel that these policies and resources are adequate.

As a result, we obtained funding from the *Canadian Institutes of Health Research* to evaluate personal finances associated with obtaining health care and the amount of time that caregivers must provide to keep their loved ones at home. Capital Health and the Alberta Cancer Board provided us with the necessary permissions to conduct the study.

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4. Consequences: Lessons learned from caregivers of cancer patients
 - Prospective, proxy interview measuring total health care resource utilization
 - Identified, measured and valued direct medical resource use, out-of-pocket expenses and time related losses.
 - Population: adult cancer patients with prognosis between 2 and 24 weeks.
 - Referred to palliative care in Alberta between Feb 2004 and June 2007.

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4. Consequences: Lessons learned from caregivers of cancer patients
 - 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.

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4. Consequences: Lessons learned from caregivers of cancer patients
 - A total of 301 patient / 553 caregivers.
 - 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.

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

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4. Consequences: Lessons learned from caregivers of cancer patients
- Patients received care from an average 1.82 individuals (max=7)
 - Providing a total of 91.6 attributable hrs of care per week per week (equivalent to 64.9hrs/caregiver/week).

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4. Consequences: Lessons learned from caregivers of cancer patients
 - 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.

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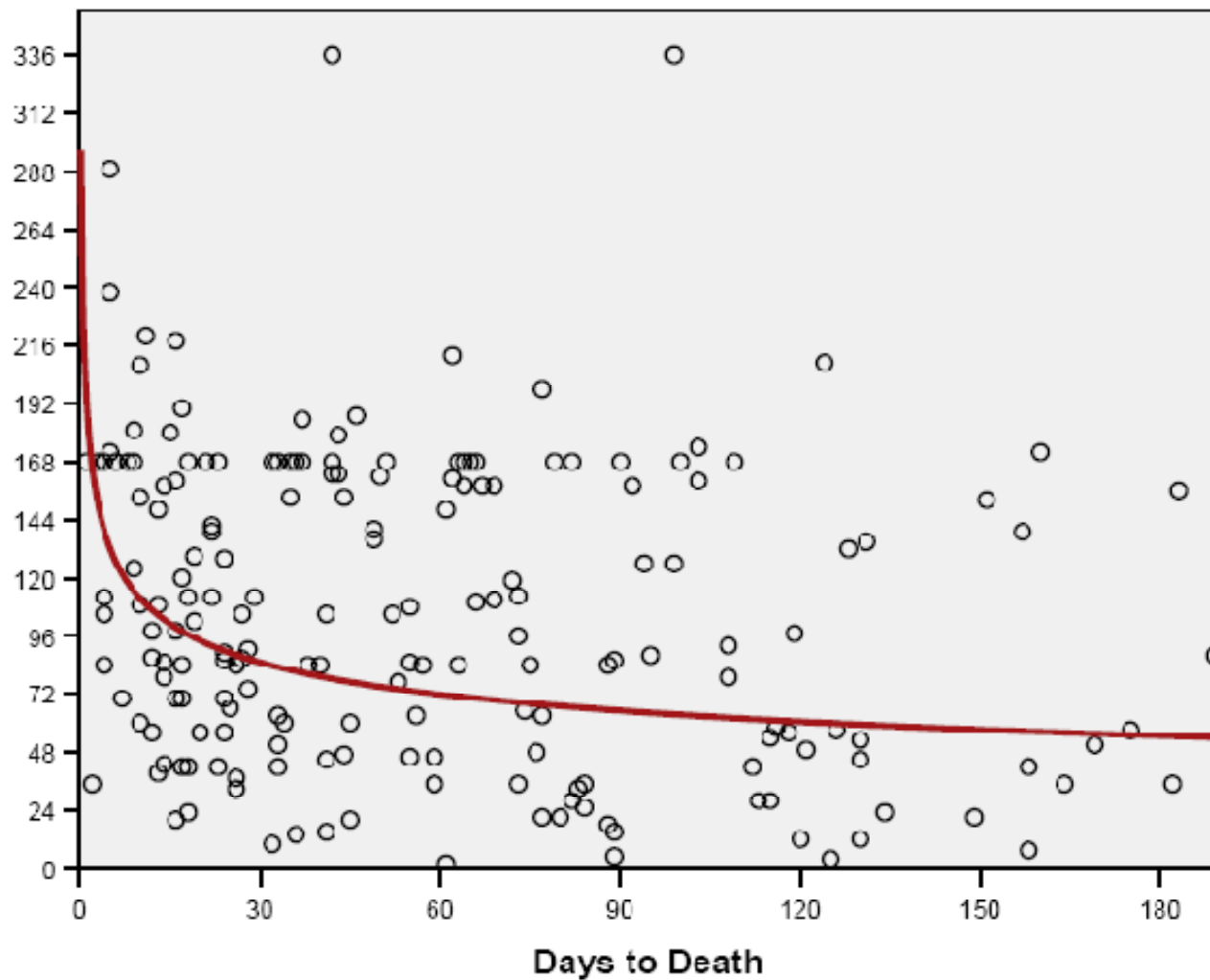
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4. Consequences: Lessons learned from caregivers of cancer patients
 - Assuming an average wage rate of \$23.90, caregiver time related losses are estimated at \$40,329 per patient.
 - The value of caregiver time rivals/exceeds direct medical and out of-pocket costs.
 - Federal caregiver assistance compensates caregivers a maximum of 6.5% of costs in the last six months of life.

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4. Consequences: Lessons learned from caregivers of cancer patients
 - 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.
 - Evidence Based Management of palliative care programs requires evidence...

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Thank-you

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