Research with stakeholders

Estimating and projecting the cost of dementia in Canada: harnessing evidence and values (and interests?)

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Topic
CoI of dementia

- This is **NOT** an intervention: CoI
- This is **NOT** an evaluation: narrative review
- Contacted by Larry Chambers, Alzheimer Society of Canada, early 2014
- Three Canadian studies, wide range of estimates of prevalence and costs
- Even worse on the projection side

Why on the agenda
Kingdon

- Problem: ASC needs “a number” for communication purposes, not three numbers.
- The number will be used for mobilization (fundraising and R&D)
- Since 2009: PHAC wanted to assess social impact (neurodegenerative conditions) as evidence base for policy (dementia as public health issue)
- My interpretation: mental health in general is lagging behind in HSPR (too symptomatic and subjective)

Process

1. Academia to restore order in chaos
2. Take stock of published evidence
3. GOBSAT: Ontario, economists with interest in aging, co-researchers.
4. Academics to change the question: costs (and prevalence) are stories, map stories to numbers.
5. Evidence is mapping, number to be communicated based on values (preferred story)
6. Consensus workhsop: international, stakeholders (May 7-8)
7. Between science and Gospel (building bridges with saliva?)

Reflections

- Main difficulty is with meaning of “causality”: counterfactual (simulations) versus observation. Does dementia kill, does it disable?
- Health care system is not about maximizing a SWF: balance out demands emanating from diseases.
- CIHR: seven generic institutes (including aging, youth, and genetics) and six disease-centered.