

Living Well with Serious Illness

Joanne Lynn, MD, MA, MS

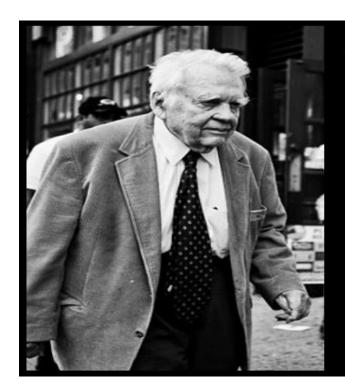
Joanne.Lynn@Altarum.org

May 15, 2016, Doha, Qatar



By permission of Johnny Hart and Creators Syndicate, Inc.



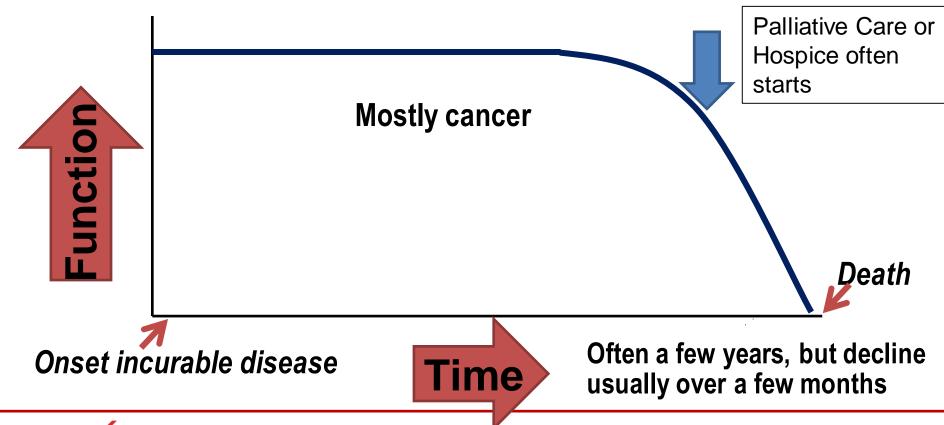


"It's paradoxical that the idea of living a LONG LIFE appeals to everyone, but the idea of GETTING OLD doesn't appeal to anyone." - Andy Rooney

WWW.HISTORYBYZIM.COM

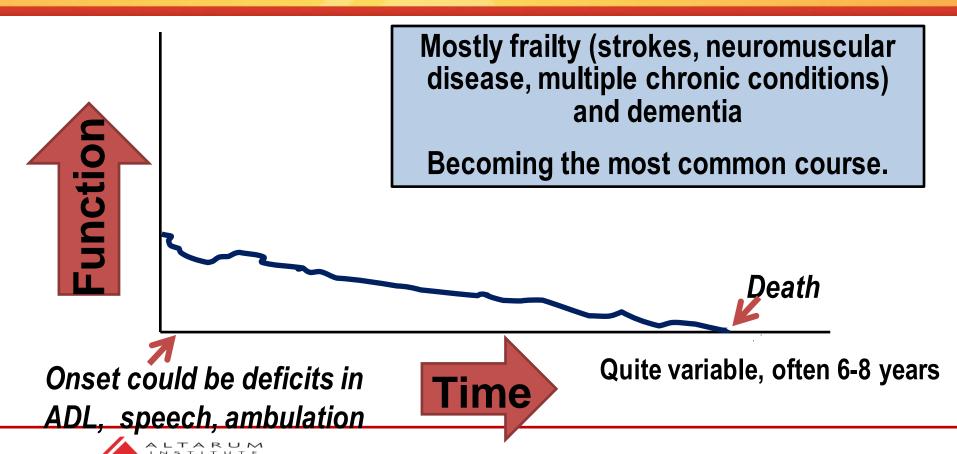


Single Classic "Terminal" Disease: "Dying"





Prolonged dwindling



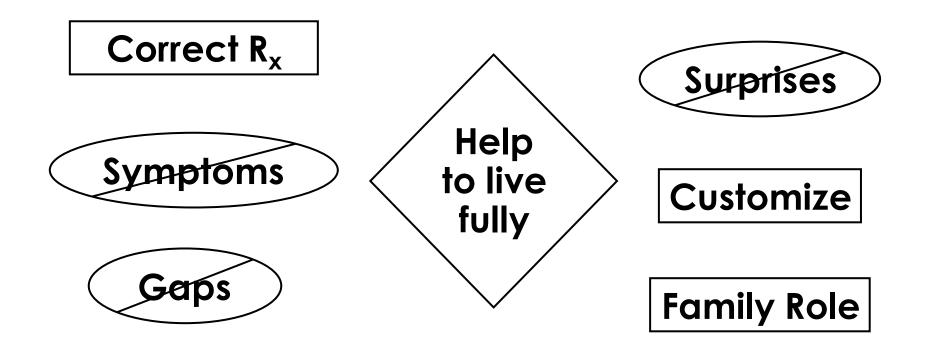
What a good care system provides for the "terminal illness" course

- Honest planning with patient and family
- Clinicians who are familiar with and able to handle all likely complications, including the process of dying
- Treatments to reduce symptoms and enhance function throughout
- Attention to burdens of treatment, including costs
- Attention to spiritual and family issues, emphasize meaningful lives and reliable services – be able to make promises for all of the remaining life
- Perhaps mobilizing services to homes?

Usually for days or weeks



What Good Care Systems Should PROMISE To Those with Serious Chronic Illnesses





What a good care system provides for the "long, slow decline" course

- Honest planning with patient and family
- Clinicians who are familiar with and able to handle all likely complications, including the process of dying
- ▲ Treatments to reduce symptoms and enhance function throughout
- Attention to burdens of treatment, including costs
- Attention to the capabilities and burdens of family and in-home paid caregivers
- ▲ Attention to spiritual and family issues, emphasize meaningful lives and reliable services be able to make promises for all of the remaining life
- Definitely mobilizing services to homes!

Usually for months or years (careful about "terminal")



Disaster for the Frail Elderly: A Root Cause

Social Services

- Funded as safety net
- Under-measured
- Many programs, many

Medical Services

- Open-ended funding
- Inappropriate "standard" goals







Inappropriate

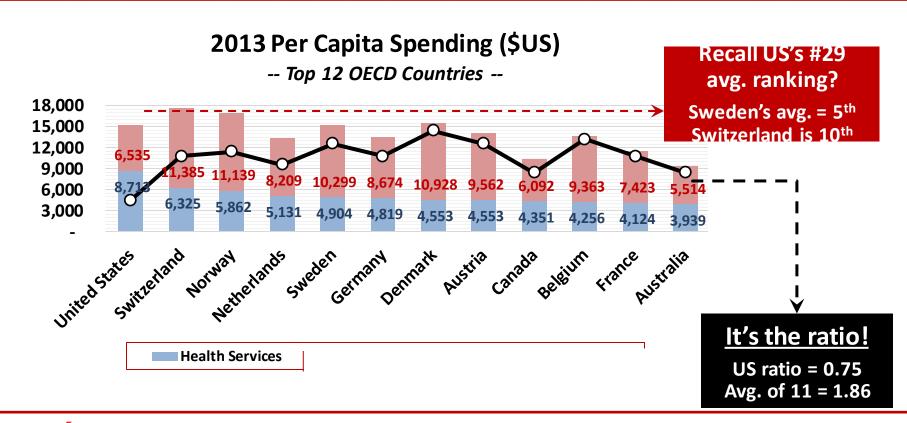
Unreliable

Unmanaged

Wasteful "care"



But, We Can't Afford Social Supports, Right?





Some difficult balancing questions

- Clarity of mind balanced with symptoms
- Altering the timing of death
 - By foregoing treatments (or withdrawing)
 - By imposing a new cause of death
 - By providing life support
- Family impoverishment
- Overwhelming burden for family caregivers
- People not eligible for the usual care system



When you are trying to find first steps...





Possible improvement initiatives

- Better care planning honest prognostic information, incorporate into the workflow, develop effective recording and presenting to users, learn from feedback, learn to aggregate
- ▲ Better options to offer well-supported care at home (through death), quick back-up, good preparation, in-home kits for urgent situations, caregiver support (training, respite, engagement in care plans, pay)
- Better symptom management; quick support of functioning widely held skills in primary care; ready availability of consultants
- Develop monitors of the aspects of quality that matter, show them in public
- ▲ Build community awareness, investment, monitors, management



The Cost of a Collapsed Vertebra in Medicare



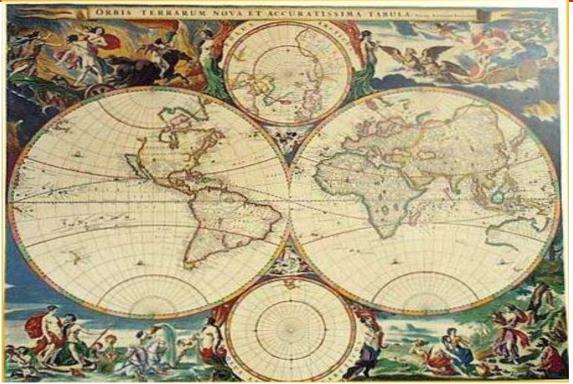


The MediCaring Community Model: Core Elements

- 1. Frail elders enrolled in a geographic community
- 2. Longitudinal, person-driven care plans
- 3. Medical care tailored to frail elders (including at home)
- 4. Incorporating health, social, and supportive services
- Monitoring and improvement guided by a Community Board
- 6. Core funding derived from shared savings from current medical overuse



Much to Learn



Orbis Terrarum, 1675 by Visscher



We can have what we want and need When we are old and frail



But only if we deliberately build that future!

