The Future of Palliative Care –
(and much of Medical Care):
Optimal Support for Frail Elders

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What We Want in Old Age....
While old age may always be challenging, we have made it unnecessarily terrifying and miserable.
What We Imagine....
What We Really, Really Need…

1. The Cohort - To build a set of services and processes that are tailored to the period of frailty associated with advanced age

2. The Services – Continuity, geographic concentration, geriatric skills and insights

3. The Care Plan - To have adequate, negotiated care plans for each frail elder

4. The Scope - To include long term services & supports and livable settings, as well as medical/nursing care

5. The Manager - To have a local monitor-manager function – an integrator, an accountable entity – pursuing Triple Aim + Workforce
A Word on Language and Categories

▲ Frailty – lack of function or reserve in multiple critical areas, associated with aging

▲ “Manager” is a community system function on behalf of the population

▲ “Coordinator” is the anchoring team member for a particular person – the “navigator,” “care manager,” etc.

▲ “Medical” includes nursing; and “physician” includes a variety of responsible clinicians

▲ “Family” includes close friends – whoever cares about the elder and is touched by his/her suffering, challenges, and living

▲ “Hospital” not “acute care” – most hospital care is for chronic conditions – hospitals are often the failure mode in chronic care
Single Classic “Terminal” Disease

Onset of incurable disease

-- Often a few years, but decline usually < 2 months

Time

High

Function

Low

Death
Organ System Failure (mostly heart and lung)

<table>
<thead>
<tr>
<th>Time</th>
<th>Function</th>
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<tbody>
<tr>
<td>~ 2–5 years</td>
<td>Low</td>
</tr>
<tr>
<td>~ 2–5 years</td>
<td>Medium</td>
</tr>
<tr>
<td>~ 2–5 years</td>
<td>High</td>
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Begin to use hospital often, self-care becomes difficult.

Death usually seems “sudden”.

Time
Dementia/Frailty

Onset could be deficits in ADL, speech, ambulation

Quite variable - up to 6-8 years

Time

High

Low

Death

Function
Kaiser Permanente (Warren Wong) Estimates

Overall cost of care per segment based on membership and cost ratio: PMPM Cost x percentage /total costs

Estimated % Medicare Members:
- Healthy: 15-20%
- Chronic Conditions: 60-65%
- Advanced Illness: 10-15%
- Frailty: 5-7%
- End of life: 15-20X

PMPM Cost Ratio:
- Healthy: 1X
- Chronic Conditions: 2-3X
- Advanced Illness: 5-8X
- Frailty End of life: 15-20X
About the Frail Elder Cohort

Three common definitions:
1. Multiple chronic conditions
2. Losing muscle strength
3. Functional disability

All definitions overlap lots,
Practically, a combination of:
   a. Age (or Medicare)
   b. Functional disability
   c. Serious chronic condition
   d. Hospitalization or equivalent
What do you think?

Can we see this part of life as a cohort needing a "care system" that differs from "standard"?

Can "elder care" or "MediCaring" be a special delivery arrangement (like obstetrics or pediatrics)?

Would it be a good idea to do this?
Appropriate Services

▲ Continuity, reliability, trustworthiness
▲ Contact person – no wrong door
▲ Relationships matter – personal, professional, direct service
▲ Geriatric concepts – e.g., rehab, fragility, limitations
▲ Dying is (always) part of the plan; support is (usually) part of the service array
▲ Caregiver assessment and support
▲ Planning ahead – for services, complications, and death
Why Services *should* be Geographic

- Overlapping services are inefficient and fragmented.
- Instead, services to homes can be more efficient if allowed to be geographically concentrated – consider mail delivery, sewer systems, and schools.
- And geographic concentration allows one to build on local strengths and solve local issues.
- (Need to address risks and legal issues in anti-trust.)
What do you think?

Can you see how services might be adapted for this cohort?

Would you find it rewarding to participate in such a service array?
Required: Individual, Negotiated, Care Plan
A Good Care Plan?

- Honest, accurate information re: situation and likely course
- Patient/family/caregiver full participation and ownership
- Continuity across settings and time
- Oriented to achieve patient/family goals
- Starts with housing, nutrition, comfort, function: Living!
- Addresses the scope agreed by patient/representative
- Optimally uses community, family, and patient resources
- Adapted as situation changes
- Timetable and feedback are built-in
- Documented
Thinking about Medical Decisions

Choice between 2 diagnosis or Treatment options, on the Basis of preferences for outcomes, Which are far into the future
About Customized Care Plans

Negotiated Values

Goals

Plan

Integration

Implement

Outcomes

Feedback

Feedback

Evaluation of Quality

Evaluation of Quality
Care Plans for Complex Chronic Illness

Negotiated Values → Plan → Implement → Outcomes $T_1$

TIME

Negotiated Values → Plan → Implement → Outcomes $T_2$
What about an "Advance Care Plan?"

- A natural part of a good care plan
- Alongside other preventive action plans
- And plans to achieve patient goals
- POLST and other emergency care included
- Designate surrogate decision-maker(s)
- Document in care plan
- Update and feedback as for other plan elements
How to get a good care plan

- Assess situation
- Engage the caregiver, address “unbefriended”
- Examine options
- Articulate the plan
- Document the plan
- Revise the plan as needed in implementation
- Get feedback on how it worked
- Encourage patients and family members to expect (demand) good plans!
What do YOU think?

Could frail elders reliably have good care plans?

Is creating them critical?
The Scope: A New “Rebalancing”

▲ Has been from nursing home to community

▲ Needs to be from medical services to social/environmental services
Health-service and social-services expenditures for OECD countries, 2005, as % GDP

BMJ Qual Saf 2011;20:826e831.
Health-service and social-services expenditures for OECD countries, 2005, as ratio

BMJ Qual Saf 2011;20:826e831.
The Scope

▲ Care plans need to address challenges of living with disabilities and chronic conditions
▲ So – housing, transportation, nutrition are often primary needs
▲ Hands-on care can be central, including crisis care
▲ Medical/nursing care can be essential, but often only a small part
▲ Caregivers are often central – skills, willingness
What do you think?

Is this the right scope?
Disaster for the Frail Elderly: A Root Cause

**Social Services**
- Funded as safety net
- Under-measured
- Many programs, many gaps

**Medical Services**
- Open-ended funding
- Inappropriate “standard” goals
- Dysfunctional quality measures

Inappropriate
Unreliable
Unmanaged
Wasteful
“care”
I think it’s an elephant!
Local level– not just state/federal (and provider)

▲ Frail elders are tied to where they live
▲ Local leadership must respond to geography, history, leadership, and other local factors
▲ Localities can engender substantial off-budget services – time banks, volunteers, churches and other social groups
▲ Localities can address public health and environmental issues – healthy cities, aging-friendly communities, universal design, etc.
▲ Localities can encourage employer-employee issues for caregivers
▲ Having some local governance still requires having quality and productivity standards at federal/state levels
How could local management arise?

- Care Transitions
- Age-friendly cities and other urban planning
- Local coalition building for healthy communities – CDC-engendered coalitions
- Public health
- Local aging authorities – commissions, offices
- Area Agencies on Aging (and Administration for Community Living)
- And more….
What will a local manager need?

- Tools for monitoring – data, off-the-shelf metrics
- Skills in coalition-building and governance
- Visibility, value to local
- Funding – perhaps about 5-10% of the medical-social funding
- Some authority to speak out, cajole, create incentives and costs of various sorts
What do you think?

Is a system manager function essential?

Is it best to have an important layer of management be local (city/county)?
How to achieve change?

- Education of public and leadership – familiarity
- Deliberate improvement
- Planned harvesting of improvement tests
- Improved deliberate design
- Campaigns for political will
A remarkable Opportunity – Demise of the Improvement Standard in Medicare

- “Reasonable and necessary for treatment of an illness or correction of a malformed body part”

- Interpreted to mean ONLY services that IMPROVE health – not those that prevent illness or suffering, and not those that merely slow the rate of decline or make disability tolerable

- Thus, preventive services had to be individually authorized

- And hospice was set as an alternative, aimed to save money and honor choice

- But supportive care, care planning, dealing with decline, and preventing the worst that nature can offer – all are not actually covered in Medicare! – until a court settlement soon – which changes this! Major impact possible.
### How Americans Die: A Century of Change

<table>
<thead>
<tr>
<th>Year</th>
<th>Age at Death</th>
<th>Top Causes</th>
<th>Disability</th>
<th>Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900</td>
<td>46 years</td>
<td>Infection</td>
<td>Not much</td>
<td>Private, modest</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accident</td>
<td></td>
<td>in Medicare</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Childbirth</td>
<td></td>
<td>~½ of women die in</td>
</tr>
<tr>
<td>2000</td>
<td>78 years</td>
<td>Cancer</td>
<td>2–4 yrs ave. before</td>
<td>Public, substantial— in US – 83%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Organ system failure</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stroke/Dementia</td>
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To Serve One Frail Elder:

▲ Processes: systematic and standardized assessments and care planning for each elder

▲ Procedures to assure continuity of care plan, feedback loops

▲ Self-care and caregiver activation, training, and support

▲ Information and decision support – full range of options considered

▲ Personal financing
Define “Quality” (at this time) from the perspective of the individual

Well being

Length of life

Individual

Plan of care

Monitoring and adaptation during implementation

Rescue care plans for expectable crises

Service configuration, Including palliative care and home visiting

Developing plan for services and their coordination

Family support and capability

Living arrangements, including assistance with ADL/IADL

Service configuration, Including palliative care and home visiting
To Manage Services for a Community

– Production planning – correct supply of services, how will services be used, e.g. hospital
– Production scheduling- who will do what? When?
– Supplier development and management, e.g. reconfigured primary care
– Quality measurement, feedback, and control
– Information technology, real time decision support
– Financial management
Inputs to the Service Production System for Frail Elders–

Alpha version for 500,000 population in an area
Define “Quality” from the perspective of 5000 frail elders

Well being

1000 NF beds & 100 NF beds post-hospitalization

Living arrangements, including assistance with ADL/IADL

150 hospital beds &

8 Primary MD FTE

Rescue care plans

For expectable crises

Family support and capability

1000 home care workers

Developing plan for services and their coordination

X social workers/care mgrs

Service configuration, Including palliative care and home visiting

Primary MD FTEs:

5 home visiting

2 nursing home

4 office

Adapted hospitals/facilities

Monitoring and adaptation

Individuals

Plans of care

Length of life

$
Major Challenges…and Responses

1. Need monitoring tools
2. Need care plans
5. Anti-trust, Stark

7. Need manager
8. “Death Panel” issues
9. Financing

1. Develop dashboard
2. Meaningful use, quality metrics
3. Government role, change metrics for anti-com
4. Deliberately build, provide support, fund
5. Allow any medical service – change 80-20 to 20-80 utilization
6. Cut per capita costs, engender insurance at/near retirement, use volunteers
Strategies to create political openness to change

▲National leaders

– Aging, providers, elders, caregivers

▲Community examples

– US especially, but also other countries

▲Direct from caregivers

– Replace acquiescence with outrage
What do you think?

What are the key policy levers?

What are the important strategies?
If we had...

1. The Cohort - Services and processes tailored to frailty
2. The Services – Focused on support at home, pain relief
3. The Care Plan - For each frail elder
4. The Scope - Include long term supports and services
8. The Manager - A local monitor-manager function

THEN – My mother would have...
We can have what we want and need
When we are old and frail….

But only if we deliberately build our future!