

Clinical Care Subcommittee

Goal 2 -- Enhance Care Quality and Efficiency

Workforce

+ focus on helping workforce become dementia capable

- HRSA as provider of training -- how many providers can be reached? How? -- Joan Weiss offered more info as to expected training numbers -- cross disciplines in 2013 -- expect around 10,000 providers trained. This is small percentage of practitioners -- currently there are about 350,000 primary care physicians in the US -- over 1 million total physicians. This does not include PA/NP's

Nursing numbers are larger

We feel there should be a focused and strategic effort to improve understanding of “dementia capable” care -- including new trainees, but also practicing providers

Why not expand partners to physician/NP/PA/med schools, nursing schools, PA?NP schools, nursing organizations, medical specialty organizations -- provide training modules and speakers to get message out more broadly. This will mean many partners -- but it will be important to develop uniform resources to each target group. What you teach a medical student is different than what you offer a seasoned NP or MD in practice -- and the site of the education is likely different too

Action 2C1 may have impact as well (education about resources for caregivers)

What incentives to providers have to attend training?

- Encourage careers in geriatric specialties -- poor reimbursement and salaries is a major disincentive to geriatrics -- not addressed. Loan forgiveness is a real option that should be considered to facilitate entry into the specialty.
- New issue -- HIPAA issues with sharing info with caregivers -- providers need guidance -- should be included in any training -- UNCLEAR area Was there a CMS taskforce on this?
- Reminder -- good dementia care takes more time -- while education is important, adequate/improved reimbursement is also crucial.

Diagnosis

+ use of tool for detection of cognitive impairment at annual Medicare visit

- Confusion about detection vs. diagnosis in how this is organized
- When will the detection tool or tools be chosen and disseminated? (for annual visit)
- Even with the tool -- we still need a broad public campaign to drive awareness (CDC)

Is Action 4A1 this effort? Should include specific efforts in diverse communities and populations

- We still feel an awareness campaign is needed targeting health professionals -- could focus on prevalence, detection at annual Medicare visit, simple resources
- Access to Diagnostic services -- Biggest challenge is poor reimbursement to provide the time and expertise needed to evaluate, disclose diagnosis and begin care planning with patient and family. Our report suggests a reimbursement “package” for this service to encourage providers to provide comprehensive service. Limited access to this type of service -- geography, limited access due to poor reimbursement is also common.
- Documentation of Dementia or AD diagnosis should be in chart when diagnosed
- Ability to bill for time spent with family when patient not present -- or include this in package of service for increased reimbursement

Support

- Shrinking state budgets -- fewer state resources -- care management and respite care
- All patients and families benefit from physician involvement in care planning (not only early stage patients)
- Omission in the plan of any effort to encourage Advance Care Planning -- this may be included in Dementia Care Guidelines -- but it is so important to start early in the disease process to elicit patient preferences for care and for surrogate decision making -- using AD's, Living Will, POLST tool, etc.

Guidelines

+ Good effort -- involve other federal partners -- so that these can be adopted rapidly

New models of care

+ independence at home model – good idea

- We still advocate for a blue ribbon panel of experts to discuss/inform various models of palliative care for advanced dementia -- including SNF/NF/Hospice/palliative care/home care/acute care hospitalizations. Suggested models could be evaluated by CMMI. One committee member suggested looking at the whole panel of studies at CMMI with an eye to finding options to study AD patients as a subgroup (rather than just propose specific projects or demonstrations).

Transitions

+ excellent addition

- Consider including more on hospitalization in this section -- we need to reduce hospitalizations not just make them safer. NH to hospital stays or stays to qualify for SNF represent huge costs to the medical system. CMMI grant program to study new models to prevent hospitalizations or re-hospitalizations.
- Still need above blue ribbon panel to look at many “drivers” of transfer behavior in patients with advanced dementia

Coordinated and integrated health and and long term care

+ time to help with models for dual-eligible persons with dementia

- Care coordination strategies/models have already been extensively studied -- they need to be funded -- or tried as Medicare demonstration projects with the hope of broader adoption

Diverse populations and those disproportionately affected

+ good to draw attention to unique challenges

- “Language suggestions -- “certain intellectual disabilities” should be “Down’s Syndrome”
- Consider including in awareness campaigns?

Goal 3 -- Expand Supports

Training and support materials

+ attention to need for culturally sensitive materials

+ good to encourage informatics

- Informatics are going to have a significant cost -- and lower income caregivers really need the help -- often have to work to survive.

Enable them to continue to provide care

+good focus on health of caregivers

- No need to study the issue -- caregivers need financial supports for caregiving -- tax credits, pay for caregiving, adult day care, respite care etc.
- Most states are cutting services, resources -- very little respite care support. We have resources only for those who can pay. Even the great programs studied at the VA are not replicable in the non-VA system -- no resources for care management/counseling services for most caregivers
- Consider asking Congress to make adult day services a state option under Medicaid
- Revise eligibility rules for all caregiver support programs to include younger onset, and those with intellectual disabilities

Future Care Planning

+ good to promote this

- Studies already done on this subject -- belief that Medicare covers LTC, denial of possible need, financial barriers to get LTC insurance. Consider tax credit to encourage
- Again a place to encourage Advance Care Planning
- We suggest Full Funding for AoA caregiver programs unless the services are replaced or expanded in a different program.

Maintain dignity, safety and rights

+ needed education of legal professionals -- many will allow living wills to be signed by patient who is not capacitated -- risk of abuse

- We suggest broadening the effort to include accountants, estate planners, who provide services to the elder and AD populations -- they need special training as well.

Housing needs

+ good ideas -- remember that aging in place requires additional supports over time, so re-evaluation of hospice eligibility for dementia (blue ribbon panel idea) is crucial to making this a real possibility

- Housing opportunities for people with AIDS may provide some ideas for a model

Goal 4 -- Enhance Awareness and Engagement

Educate public

+ Needed to drive detection, diagnosis, caregiver support -- details?

Work with states on model initiatives

+ Good to help states with national plans and learn from their ideas

- Such limited resources in most states that acting on their own plans is difficult

Convene leader

+ Good idea

Involve federal partners in ongoing effort

+ Good idea

Goal 5 -- Improve date to track progress

Policy needs

- Include needs of advanced dementia patients in reviews of models of care

Overall --

Our committee would like to see more timeframes and deadlines to see good ideas implemented into policy -- many have “study fatigue”

Family caregivers are under tremendous personal, financial stress -- we need to provide education and awareness -- but also more tangible help like respite care support, tax credits for caregiving, or income support for caregiving.