Overview

• 1) Recent changes in family care and decision making affecting clinician/family communication
• 2) Ethical guidance at key transition or decision points in family care
• 3) Resources to help families negotiate ethically charged decisions in care
• 4) Ethical challenges in family care from the perspective of two clinicians’ personal experiences

— Renea Valea, MSW & Peter Kussin, MD

Ethical Questions

• Truth-telling and its meanings.
• When do we trump autonomy?
• Risk assessment: Finances, falls, safety, and driving.
• Vulnerability, moves, and consequences.
• The roles of protective kin, surrogates, best interests, substituted judgment.
• Is equity a reasonable goal in family relationships?
• What is palliative and when is it time?

The Accidental Family Carer

• Carers become by caring about
• Carers do the best they can because they can’t imagine doing otherwise
• Family care happens: it’s just a question of when and for how many
• Culture and ethnicity matter
• Family care affects all relationships
• Family care is rarely fair, equal
• Family care disrupts lives

Changes in Family Care

• Older carers and older, more complex recipients (2009)
• More sole caregivers (2010)
• Less paid help and less secondary family support
• More adult child and male caregivers
• Serial or simultaneous elder care careers
• Employee caregiver issues: 12% of workforce in poorer health (2010)
• Economy, housing market

I’m Not A “Caregiver”

“I am NOT a caregiver. I am a daughter and my mom doesn’t have Alzheimer’s — her doc said it’s “just dementia.” I care, but it’s what I do because she’s my mother — not who I am. Can you help us or not? How much support can we get? Can you get to the point? I’m late for work.”
The 5 Cs of Family Care

- Common
- Chronic
- Complex
- Costly
- Conflict - ethical and relational

What Must Families Do?

- Define and negotiate complex situations
- Perform physically intimate tasks
- Manage emotions and communication
- Modify expectations - pace for a marathon, not a sprint
- Capitalize on preserved capacities

The Family Care Balancing Act

- Whose needs? (the myth of the well spouse caregiver)
- How long?
- How much?
- How to evaluate risk, cost and benefit?

If Only ...

Curtain Call: Ethical Issues

- What is a good child?
- The ethics of long-distance care
- Should I please my children or stand up for myself?
- Is it right to confront a vulnerable adult with mistakes?
- The family conference: How to offer help without losing yourself?

Ethical Issues in Geriatric Psychiatry

- Autonomy vs. family/group centrism
- Salience of cultural and religious values
- Beneficence & duty to prevent harm
- Capacity assessment
- Elder abuse: harm, a trust relationship, intent
- Neglect and self-neglect
- Social justice

Rabins & Black, 2010
Ethical Decision Making Considerations

- Medical facts
- Patient preference
- Quality of life
- Role of family, cost, allocation of resources, societal well-being

Rabins & Black, 2010

Dementia Family Care Means:

- Organizing daily and adapting work
- Finding, asking for and using help
- Solving problems
- Making, carrying out and living with the consequences of decisions
- Dealing with imbalances in give-and-take
- Dealing with resentment, disappointed expectations, and uncertainty

Decision-making Hazards

- Unrelenting crises
- Old promises
- Chasing ghosts
- Conflicting perceptions, expectations
- Control issues
- Too few good choices

Ten Reminders for Dementia Families

1. The desire not to think about what you are facing is normal, but you can get beyond it.
2. The process of the disease is not completely predictable. Other things happen. Your family member will need more help over time. You may be forced to make decisions that s/he will not like.
3. The person with AD can and needs to help and give too.

Ten Reminders (cont.)

4. The person with AD is doing the best he/she can. Trying harder is frustrating and doesn’t work.
5. You, not your relative, will have to change.
6. Your emotional relationship with each other will change despite your continued love and willingness to help.

Ten Reminders (cont.)

7. Grief comes with this process of loss. It is hard to see suffering.
8. There is no single right or wrong place to care or care plan.
9. This is the rainy day for which you saved.
10. Respite options protect your health and his/her future care.
Preparing Dementia Families for Tough Decisions

- New problems aren’t necessarily related to what you do or don’t do.
- It’s easy to second guess or criticize from a distance.
- Choices, options and lives are different from what they were. It’s impossible to know what s/he would have done if your positions were reversed.
- You can only do your best and be dependable.
- Doubts are inevitable, but it will be worse if you do nothing.

Ethical Challenges in Recognition and Diagnosis

- “But she refuses to see a doctor…”
- Truth telling
- What to tell whom and when
- Consequences of early or delayed diagnosis

Money Matters

- Recommend surrogate selection for Durable Financial/Health POA
- Recommend dignified supervision or assistance with bills, money management
- Recommend two names on everything: electronic deposit and payments or mail management
- Note “new” friends, causes, spending

Transitions in Dementia Care

- Event or change triggers recognition and/or diagnosis
- Changes in handling money, alcohol, driving, or travel
- Changes in behavior, mood, time perception, energy, personality, resistance, preferences
- Changes in safety – fraud, neglect, exploitation, live-alones

What Families say:

- She never would have done or wanted that before.
- I would never lie to my mother.
- I still care about our relationship – I don’t want to fight like this.
- He seems unaware of how his behavior affects us.
- Why is she so nice to strangers and so mean to us?

They’re Your Parents Too

– Francine Russo on sibling conflict

Money Matters

JAMA 305 (7) Feb 16, 2011

“He couldn’t owe back taxes – He’s a CPA”
“He didn’t want me to take over”
What Families ask:
WHAT CAN I DO WHEN:
• She accuses me of being unfaithful...
• He says we stole all his money...
• She won’t let me help but won’t bathe...
• He tries to leave the house at 2am...
• She curses in front of the grandchildren...
• He asks what I’ve done to his real wife...
• She says we never come to see her or take her anywhere...but we do...

Ethically Challenging Behaviors for Families:
• Begging, repeated accusations
• Swearing, insulting, threatening
• Shadowing, rummaging, wandering
• Hitting, biting, scratching, pinching
• Undressing, unwanted touch or intimacy
• Resistance to care

Reminders
- Being reasonable, rational and logical will just get you into trouble.
- People with dementia do not need to be grounded in reality every minute (Tomlin).
- Making agreements with the person with dementia doesn’t work.
- Pay attention to comfort, reducing anxiety, and preserving adult identity.

Complaints of a Dutiful Daughter
• Truth telling and placement
• Living in the moment vs. attachment to childhood memories
• How to be somebody—definition and identity without a past

Agitation: Helpful Talk
 unavoidably
• Apologize (even if you didn’t do it)
• I Am Sorry You Are Upset.
• I Know This Is Hard
• I Wish Things Were Easier For Us.
• I Will Stay Until You Feel Better.
**Ethical Communication**

- Do not test or ask, “Who am I?”
  - She will be angry, embarrassed or frustrated.
- Use positive statements rather than “Why won’t you?”
- Don’t offer too many choices, or choices that are unacceptable to you.

**Ethical Communication** (cont.)

- Explain directly what you will be doing or what is happening – one step at a time.
- Use appropriate respectful humor – make fun of or take yourself less seriously.
- No patronizing, talking down to, talking around, or “elder speak.”

**Who Are You To Question?**

I’ve had a clean driving record for 60 years.

[thehartford.com/alzheimers](thehartford.com/alzheimers)

**Fanny and the Driving Test**

- Balancing autonomy, individual and societal risk
- Fanny’s dignity, distress, and determination
- Daughter’s need to defer decision

AMA Physicians Guide to Assessing and Counseling Older Drivers 2010 pdf

**Safety Basics**

- Safe Return/Medic Alert Registration
- NC Silver Alert
- Medication, OTCs, toxins supervision
- Falls prevention
- Treat acute changes or delirium
- Guns, power tools, kitchen appliances
- Monitoring: Comfort Zone vs. Fisher Price vs. human

“It’s not that she can’t dress herself – it’s that she won’t let me help, even when she dresses for church in three shirts, a hat, and panties.”

Daughter of a women with AD
What is She Thinking?

• How dare you question me?
• I bathe and dress every day.
• I make sense – you and events don’t.
• Your reasoning wears me out.
• I must defend my turf.
• I am overwhelmed & scared.

“I’m becoming someone scary. I’m not sure what I might do to him.”

(A wife)

Anger Warning Signs: Self Reports

• You are “taking it out” on your family or yourself.
• You do everything, but it is never enough.
• You are losing it more often with your relative.
• You resent everything and it’s all too much.
• You have fantasies about disappearing, running away or telling her to “just go if you want to…”

The Central Role of Caregiver Anger for Mental Health and Harmful Behavior

When Danger is Possible

• Emergency plan
• Remove weapons, other people
• Move back or out in routine manner
• Call for help or 911
• Don’t remind or blame the person after the incident

Pressure Points Alzheimer’s and Anger
Ethics of caregiving and eldercare
Lisa Gwyther, MSW, LCSW

Wait a Minute! When Anger Gets Too Much

Home Alone
“But she fired all of the help…”

“Is she OK living alone?”
- Telephone? Mail?
- Meds management?
- Day/Night Reversals?
- Travel outside home?
- Bathroom/continence?
- Falls/injuries? Kitchen risks?
- Weight loss/food management
- Available discreet surveillance?

Prepare for Resistance to Community Service Referrals
- Stigma
- Denial/poor judgment
- Too many changes at once
- Loss of control
- Cost
- Overwhelming disclosure in assessment – privacy issues

Limits of Support Groups
We are not used to talking about our business. We just go on and deal with it. We don’t realize we have to talk…

African-American Focus Group Participant
Vicki Lampley-Dallas, M.D

The Home Care Gray Market
- Indefinite expenses and no safety net drive home care underground.
- Over-the-back-fence list.
- Intimate care is less reasoned, more intuitive choice.
- Untrained, unsupervised, unscreened unseen but affordable.
- Trade-offs: loyalty vs. Churn, reduced RN monitoring.

Jane Gross, NYT, 3-1-
Transitions in Dementia Care
- Hospitalization, surgeries, medication and treatment decisions: determining capacity
- Restraints, antipsychotics
- Need for continuous supervision
- Moves to residential or skilled nursing care
- Palliative/hospice care needs

Hospitalization Happens
- Hospitalization is a choice
- Bag packed, bring a friend and stay
- Family manage & monitor meds
- Primary care and specialist follow-up
- Personal Health Record & Discharge Prep Checklist: transitionalcare.org
- nextstepincare.org

Almost Home

“Where Someone Cares”
Chandelier Assisted Living

- Independent Living for “55 And Better”
- Nursing Staff & Senior Doctor
- Home Cooked Meals Available To All
- Library- Chapels- Card Room
- Bank- Beauty Shop
- Scheduled Transportation
- Lake & Beautiful Garden
- Caring Staff & More...

821-333-2238 or 821-333-1308

“She Doesn’t Belong In A Nursing Home”

In the Moment
- Ethics of antipsychotic use
- Best care or most proximal care
- Role of spiritual beliefs
- Person-centered or family-centered care?
- Mother never wanted to be like this

Expect the Unexpected

“When I saw him coming toward me in wet socks and somebody else’s shoes, I thought, “Is this what it has come to?” I work so hard to protect him and feel betrayed by those I entrusted him to. This is symbolic of the failure of their implied contract to care for this man who was so important to us.” (wife)

“Why isn’t this more like Tuesdays with Morrie?”

3/21/2011
Family Meeting
Mrs. P notes that her husband’s ability to swallow has been worsening over months and he is on thick liquids.
Speech therapy recommended NPO status and tube feeding four months prior. She does not think that he would want PEG feedings but worries about continued oral intake because the speech therapist told her “the only way he will be safe is with tube feeding.” A lady in her church told her that it is a sin to withhold food from the sick.

Lynn O’Neill, MD 2011

Eating Problems in Advanced Dementia

<table>
<thead>
<tr>
<th>Oral dysphagia</th>
<th>Food refusal</th>
<th>Pharyngeal dysphagia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to interpret hunger</td>
<td>Unable to perform task of eating</td>
<td></td>
</tr>
</tbody>
</table>

Pt characteristics associated with greater likelihood of feeding tube
- Younger age
- Race
- Male sex
- Recent decline in functional status
- Divorced
- No diagnosis of Alzheimer’s disease
- Lack of advance directive

So what?
- 50-fold difference in insertion rates between states
- 40-fold difference in insertion rates between hospitals

Nationally, decisions about PEG tube insertion in advanced dementia are not based on evidence or a consensus about best practice.

Death due to starvation?
Four lines of evidence suggest not:
1. Survival of very low-weight, hand-fed dementia pts can be substantial
2. PEG tube placement can cause death
3. Mortality among tube-fed pts is substantial
4. Studies demonstrate that there is no survival advantage with tube feeds

No evidence to support claims that tube feeding:
- Prevents aspiration pneumonia;
- Improves nutritional status;
- Prolongs life;
- Prevents pressure ulcers;
- Improves functional status; or
- Improves patient comfort/quality of life.
Health Policy

• Nursing home requests for PEG placement are common.
• Financial incentives from Medicaid and Medicare for pts with feeding tubes:
  – New feeding tube = 100 days of Medicare skilled nursing benefits (higher per diem)
  – In many states, Medicaid provides higher per diem for tube-fed patients
  – Less nursing time


Words that Work

• What’s your understanding of what tube feeding will accomplish?
• What do you hope tube feeding will accomplish?
• What are your worries?

What do you hope tube feeding will accomplish?

• Wife: “I hope it will help him get stronger and be able go outside for walks with our grandchildren.”
• Doctor: “I wish that we could help make your husband stronger…

Perhaps we can find other ways that he can spend time with your grandchildren.

What are your worries?

• Wife: “I’m afraid that if I don’t put in the tube, he’ll starve to death.”
• Doctor: “You’re not alone. Many families have a similar concern. It’s very hard to feel like you’re not providing something as basic as food.

Would it be helpful for me to share what I’ve observed in my clinical experience?

Careful hand-feeding

– Small frequent meals
– Reminder to swallow
– Quiet environment
– Screen for depression
– Cough after swallowing
– Ice to neck

Take Home Points

• Dementia is a terminal illness.
• PEG tubes do not improve outcomes in patients with advanced dementia.
• Speech consultations are helpful even when a PEG is not being placed.
• Communication is key!
Taking the “G” out of Golden

Down to Earth Help

• alz.org: Alzheimer’s Association
• nia.nih.gov/alzheimers: NIA
• caregiver.org: Family Caregiver Alliance
• thehartford.com/alzheimers
• benefitscheckup.org: All Benefits
• caringinfo.org/PlanningAhead: NHPCO
• Caring.com Steps and Stages

The Future: Reasons for Hope

- Principles for a dignified diagnosis
- 2010 Compassionate Allowances for young onset dementias: Alzheimer’s Assn. Checklist for SSDI and SSI applications
- Coordinated Chronic Care Demonstrations
- Alzheimer’s Assn. Quality Residential and Palliative Care Practice Recommendations

“You catch on”

“Let me tell you, we love you all, and we’re gonna keep on loving you as long as we can... What’s good about you all is you catch on, you catch on, you catch on and you know it’s not going to be perfect”

Jean Walker in her 90s.

Four Years before her death with Alzheimer’s