Seminar on Living with a Dying Loved One: Tips from the East and the West

Conflict Resolution in Dementia Care

Dr David Dai
Specialist in Geriatric Medicine
Chairman, Hong Kong Alzheimer’s Disease Association
May 11, 2016
Dementia: A great Family Divider
Dementia: a great family divider

- Cracks in family solidarity
- Intra-family dynamics
- 40% of adult child caregivers have relationship conflicts with another member

(Strawbridge and Wallhagen, 1991)
Family Conflict in dementia
(Int J Geri Psy 2006; 21:485-492)

- Mild to Moderate dementia
- (End of Life care)

- Between siblings
- Service providers in 25%
- Pwd with paranoid ideation fueled by family members: neglect, exploitation, lack of communication

- Conciliation successful in 30%
Table 2. Nature of family and systems conflict in dementia

<table>
<thead>
<tr>
<th>Who is in conflict?</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling vs sibling</td>
<td>27</td>
</tr>
<tr>
<td>Other intra-familial</td>
<td>9</td>
</tr>
<tr>
<td>Family vs agency</td>
<td>6</td>
</tr>
<tr>
<td>Person with dementia versus family</td>
<td>5</td>
</tr>
<tr>
<td>Family vs friend/‘bystander’</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Themes of conflict*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate care</td>
<td>23</td>
</tr>
<tr>
<td>Money/financial exploitation</td>
<td>23</td>
</tr>
<tr>
<td>Lack of communication or sequestration</td>
<td>21</td>
</tr>
<tr>
<td>Placement/Where the person with dementia should live</td>
<td>15</td>
</tr>
<tr>
<td>Underestimation of the diagnosis</td>
<td>9</td>
</tr>
<tr>
<td>Paranoid ideation of the person with dementia</td>
<td>13</td>
</tr>
<tr>
<td>Risk</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Position of person with dementia with respect to the conflict*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Involved or allied</td>
<td>37</td>
</tr>
<tr>
<td>Inconsistent</td>
<td>13</td>
</tr>
<tr>
<td>Distressed ‘trying to keep the peace’</td>
<td>7</td>
</tr>
<tr>
<td>Neutral, uninvolved</td>
<td>9</td>
</tr>
</tbody>
</table>

*All percentages are double the frequency because n = 50.
*Not mutually exclusive categories.
<table>
<thead>
<tr>
<th>Family vs Clinician</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Son prefers life-sustaining treatment for patient</td>
<td>Physician thinks life-sustaining treatment would increase patient suffering</td>
</tr>
<tr>
<td>Husband is uncertain about patient's wishes</td>
<td>Physician finds the husband is inconsistent when discussing patient’s wishes</td>
</tr>
<tr>
<td>Husband does not trust that clinician is acting in patient’s best interests</td>
<td>Nurse thinks family is not acting in patient’s best interests</td>
</tr>
<tr>
<td>Wife does not believe prognosis given by clinicians</td>
<td>Physician believes wife is in denial</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinician vs Clinician</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist physician wishes to continue interventions targeted at disease</td>
<td>Palliative physician wishes to focus on quality of life and patient goals</td>
</tr>
<tr>
<td>Physician wants to continue life-sustaining treatment based on small chance of cure</td>
<td>Nurse wants to focus on quality of life based on large chance of treatment failure</td>
</tr>
<tr>
<td>Physician thinks that medical decisions are his/her responsibility</td>
<td>Nurse thinks his/her input is excluded from decision making</td>
</tr>
<tr>
<td>Attending physician gives resident increasing responsibility</td>
<td>Nurse thinks that resident decisions are inadequately supervised</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family vs Family</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter thinks she knows patient wishes best</td>
<td>Son thinks medical options have not been exhausted</td>
</tr>
<tr>
<td>Wife has come to accept her husband’s imminent death</td>
<td>Daughter has just arrived from out of town, insists on not giving up</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient vs Clinician</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient wants to try another chemotherapy regimen</td>
<td>Physician thinks that more chemotherapy is futile</td>
</tr>
<tr>
<td>Patient wants to live independently</td>
<td>Physician thinks patient’s debility requires assisted living</td>
</tr>
</tbody>
</table>
Effects

• Dysfunctional alliances between disgruntled family members
• Caregiver burden and depression and anger
• Post placement depression among wives
• Legal disputes about wills, power of attorney, financial management

• **Guardianship** and financial management:
  end point of family breakdown
Mediation:
At the Heart of Communication
The Modern Practitioner

Patient

Understanding of legal constraints

Ethical Considerations

Professional knowledge & skills

Communication

Public

Family Members

Colleagues
Definition of Mediation 調解
( Folberg and Taylor, 1984)

“(Mediation) can be defined as the process by which the participants, together with the assistance of a neutral third person or persons, systematically isolate disputed issues in order to develop options, consider alternatives, and reach a consensual settlement that will accommodate their needs.”
Opening Joint Caucus Joint Settlement

Position → Interest
Create Common grounds
Options Agreement

Acknowledge emotions
Active listening
Reframing
Paraphrasing
Summarsing
Reality checking
BATNA/WATNA
Empowerment
Breaking impasse

Relationship restoration
“Remember before you speak, it is necessary to listen, and only then, from the fullness of your heart you speak...”

(Mother Teresa)
Active, Empathetic, Responsive Listening

Perception

Brain

Non Verbal Gestures

Common interests/Grounds
Create options

Paraphrasing
Summarizing
Reframing
Acknowledging

Empathy
Relationship restoration
Applied Mediation Skills in Dementia Care: From Diagnosis to EOL

Disclosure and breaking news:
preparation of clinical information
active listening
acknowledging emotions
separate sessions with patient and family members
identification of needs
Impact of disclosure
( Aging & MH, 2006; 10(5): 525-531)

- Disclosure without introducing stress
- Regular practice of careful planning and performance of diagnostic disclosure
- **Emphasize hope** in the face of a difficult diagnosis, progressive disclosure to allow preparation ( Alz Dis & Assoc Dis, 2007; 21(2): 107-114)
Changing needs
( Alz & Dis 2007; 3: 404-410)

Evolution of disease

- Individual, family, future care provider
- Progressive process:
  Diagnostic uncertainty, treatment options, future plans,
  Respite, Institutionalisation, Hospitalisation
  Financial planning, EPOA, wills and living will;
  Driving, services, research, EOL care
Cooperative Communication in Special Care
(The Geron 2007; 47(4): 504-515)

- Disagreement is common
- Shared goal of optimal QOL for resident
- Relatives tend to withhold suggestions for improving care, fearing negative repercussions
- Nursing home staff, working with resident’s families is stressful
- Racial, cultural, socioeconomic
Ms. A provided care for her father since he was diagnosed dementia in his early 90s. On an episode of acute illness in August 2001, Ms A realized that she could not take care of her father alone at home. He was subsequently admitted into a nursing home. Since then, eating difficulties became the major issue. The nursing home staff had discussed with Ms A several times on commencing long-term tube feeding. However, Ms A resisted the idea as she knew that her father loved food very much, forgoing oral feeding meant taking away the only pleasure from him (EMPATHY AND LOVE). She was able to learn over time how to feed her father (FILIAL CARING).

In October 2003, her father an episode of acute illness that rendered him warded in an acute Hospital. On admission, she told the ward staff that she would bring food to her father, and asked them not to tube feed the patient. It was the post SARS period when restricted visiting was observed. When her father was transferred to the convalescent hospital, she noted that her father was already put on tube feeding. This was done without her knowledge (RESPECT AND ACKNOWLEDGMENT).

She noted that her father’s sad and fearful face. Her father died in early January 2004, two more months after tube feeding commenced. Ms A was still in grief at the interview, which took place in September 2005. She could not forgive herself and the healthcare providers; or the pain that had inflicted on her father in the last two months of his life (GUILT, REGRET and ANGER).
Demented Patient

Ward Nurse

Daughter

Collective Decision Making
1) Separate people from the issues
2) Focus on interests
3) Invent solutions
4) Outline objective criteria
Mediated Communication

**Issues**: Feeding in a person with advanced dementia

**Parties and Positions:**
- Daughter (No suffering);
- Nursing home (facilitate task; no risk);
- Hospital (rules and accountability, professional)

**Common interests:**
- needs, fear and concern

**Reframing to change Perception:**
- Quality of life and care, Dignity
Skills: active listening, acknowledging, creating options

Options: palliative approach, consensus in care outcomes, allow hand feeding by daughter

Lesson to learn: advance care planning

Minimize Regret
Communication
Narration
Anticipatory Grief
Preparation

Advance Care planning
Advance Directive

Advance Care Planning

Advance Proxy Planning

Consensus Building, Family Covenant

Autonomy, Control

Narrative Ethics

Community Perspectives

Personal Relationship

Person- hood

Communal

Empowerment, Enrichment
A Personal Story

Regret
爸媽，我在這裡！

照顧失智雙親心路歷程

李榕燕 著

聯合推薦

Wong Chai Kee

EVEN WHEN SHE FORGOT MY NAME

Love, Life and My Mother's Alzheimer's

Filial
A residential staff fed human feces to a client with dementia
PWD

DIGNITY

Family members

Service-Providers
Palliative Care

Dignity

Advance Care Planning
Dignity

- Acceptance of identity
- Inclusion
- Safety
- Acknowledgment
- Recognition
- Fairness
- Benefit of doubt
- Understanding
- Independence
- Accountability
Collective Meaning at Ends of Life
Sanctity of Life
Dignity rises above Sanctity of Life:

Restore the Fading Personhood

The Elder
Dignity & Grace of AGEING

Two Riveting Novels Celebrating the Journey of Ageing
The Forgotten River • Listening to Letter from America

KUA EE HEOK

“A compelling, provocative and totally absorbing book.”
Henry Lim, President, Gerontological Society, Singapore

“Greatly pleased and grateful.”
Alistair Cooke, New York, (1908-2004)
Legendary Broadcaster of Radio Programme Letter from America
Dignity-conserving Care for the dying

A: attitude
B: behaviour
C: compassion
D: dialogue

Every Person has his and her inherent value and worth
Doctor’s role:

Teacher and Advocate

More than a Mediator

- Helping children help their patients make decisions
- Educate, inform and convince older patients about what is in their best interest
- Covert relatives into “therapeutic advocates” to your recommendations
We do our best to help our patients overcome the obstacles during this journey that are posed by various illnesses and accidents...The intent at that time (end of this journey) is not to cure, but to palliate; ....to be a sensitive and compassionate physician who respects the Dignity of the patient and family, and their right to refuse (and receive appropriate) treatment (in a collective decision process).