Supporting family members of people living with advanced dementia in making feeding-related decisions: an integrative review

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Background

• Advanced stage of dementia
  – Impaired cognitive function & self-care ability
  – Swallowing difficulty → dysphagia

• Challenges of making feeding-related decisions
  1. Poor understanding about the disease trajectory and prognosis among family members
  2. Lack of advance care planning
  3. Cultural consideration
     • ‘Dead with full stomach’ is perceived as ‘good death’ in Chinese culture
Service gap

• Urgent need to empower family members
  – enhancing their knowledge
  – improving self-efficacy in surrogate decision making
  – decreasing their decisional conflict
Ottawa Decision Support Framework

a. Decisional Needs
- Decisional conflict (uncertainty)
- Knowledge & Expectations
- Values
- Support & Resources
- Decision: type, timing, stage, leaning
- Personal/Clinical Characteristics

b. Decision Quality
- Informed
- Values-Based
  - Actions
    - Delay, continuance
  - Impact
    - Values-based health outcomes
    - Regret and blame
    - Appropriate use & costs of services

c. Decision Support
- Clarify decision and needs
- Provide facts, probabilities
- Clarify values
- Guide/coach/support skills
- Monitor/facilitate progress

(O’Connor & Jacobsen, 2007)
Aim and objectives of literature review

To critically appraise interventions that facilitate family members on decision-making related to feeding in the existing literature

- To identify key components that included in these interventions
- To identify outcomes for evaluating the effectiveness of these interventions
Flowchart of search strategy

Potentially relevant publications identified from the databases
N=714

Excluded N=367
∵ Duplicated

Potentially eligible papers
N=360

Exclusion criteria
- Non-experimental studies
- Health provider and patients as decision maker
- Non-English

Eligible papers
N=5

Excluded N=1
∵ Failed to obtain full-text

Included papers
N=6

Inclusion criteria
- Managements for enhancing the knowledge or decrease decisional conflict of surrogates about advanced dementia or decision-making
- Cognitive impaired people with surrogates
- Quantitative studies and systematic review
- English

From screening reference list of retrieved articles
N=1

Databases used
- Academic Search Premier (n=100)
- British Nursing Index (n=12)
- CINAHL Plus (n=120)
- Cochrane Library (n=1)
- Embase (n=280)
- MEDLINE (n=100)
- Ovid MEDLINE(R) (n=94)
- PubMed (n=7)

Period:
- 2000-2014

Searching keywords
P: dementia/ advanced dementia/ severe dementia/ feeding/ eating/ swallowing
I: intervention
O: support/decision/ decision making
## Overview of the included studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Study population</th>
<th>N</th>
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<tbody>
<tr>
<td>Catic et al. (2013)</td>
<td>Pre-and-post pilot study</td>
<td>Hospital in Boston</td>
<td>Families of admitted patients who aged ≥ 65 with advanced dementia</td>
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<tr>
<td>Ersek et al. (2014)</td>
<td>Cluster RCT</td>
<td>Nursing homes in North Carolina</td>
<td>Dyads of residents with advanced dementia and their surrogates</td>
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<tr>
<td>Kuraoka &amp; Nakayama (2014)</td>
<td>Before-and-after study</td>
<td>Acute care hospitals and mixed-care hospitals in Japan</td>
<td>Families of cognitively impaired inpatients aged ≥ 65 and were considered for placement of a percutaneous endoscopic gastrostomy tube</td>
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<td>Mitchell, Tetroe &amp; O’Connor (2001)</td>
<td>Before-and-after study</td>
<td>Acute care hospitals in Ottawa, Canada.</td>
<td>Families of cognitively impaired inpatients 65 years and older being considered for placement of a percutaneous endoscopic gastrostomy Tube</td>
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<td>Snyder et al. (2013)</td>
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<td>Skilled nursing facilities across North Carolina</td>
<td>Surrogates for nursing home residents with advanced dementia and feeding problems</td>
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</table>
| Catic et al. (2013)   | Pre-and-post pilot study    | Hospital in Boston                           | Families of admitted patients who aged ≥ 65 with advanced dementia                | 29  | - All subjects receive usual care at the first 3 months  
- In the subsequent 3 months, control group (n=24) kept received usual care; while an advanced dementia consultation service was provided to Intervention group (n=5)                                                  | there were better outcomes in the intervention group including:  
- Proxy knowledge of the disease and proxy-provider communication: After > Before  
- Feeding tube insertions rate after discharge: Before > After                                                                                       |
| Ersek et al. (2014)   | Cluster randomized controlled trial | Nursing homes in North Carolina | Dyads of residents with advanced dementia and their surrogates                    | 256 | Decision aid and usual care were provided in nursing homes with different nurse practitioners (NP) / physician assistants (PA) staffing level  
- Decision aid is effective in decisional conflicts of surrogates  
- It also discussed decisional conflicts between surrogates and health-care provider with more significant results in facilities that had lower NP/PA staffing level | - Control group: Received usual care  
- Intervention group: Received audio or print structured decision aid on feeding options in advanced dementia  
- Decisional Conflict Scale scores: Control group > Intervention group  
- Mean knowledge scores and frequency for discussed feeding options with a healthcare provider: Intervention group > Control group                                                                 |
| Hanson et al. (2011)  | Cluster randomized controlled trial | Nursing homes in North Carolina | Residents with advanced dementia and feeding problems and their surrogates        | 256 | - Control group: Received usual care  
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| Kuraoka & Nakayama (2014) | Before-and-after study | Acute care hospitals and mixed-care hospitals in Japan | Families of cognitively impaired inpatients aged ≥ 65 and were considered for placement of a percutaneous endoscopic gastrostomy tube | 13  | A modified Japanese version of tube feeding decision aid booklet designed at the Ottawa Health Research Institute inpatients aged ≥ 65 and were considered for placement of a percutaneous endoscopic gastrostomy tube | After using the decision aid:  
- Mean score for the Decisional Conflict Scale significantly ↑  
- Mean percentage of correct answers of knowledge questions significantly ↑  
- For subjects who were unsure at baseline (n = 4), 2 changed to ‘slightly in favor’ and two remained ‘unsure’ after the intervention  
- For subjects who were slightly against at baseline (n = 3), 2 changed to ‘slightly in favor’ and 1 changed to ‘clearly against!’  
- Most subjects stated that the decision aid was helpful and clear, 8 found that it was appropriate in length but 4 found it was a little too long  
- The majority found it was clear, balanced, and appropriate in length  
- Feeding tube insertions rate after discharge: Before > After  
- Proxy knowledge of the disease and proxy-provider communication: After > Before  
- Decisional Conflict Scale scores: Control group > Intervention group  
- Mean knowledge scores and frequency for discussed feeding options with a healthcare provider: Intervention group > Control group  
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- Mean knowledge scores and frequency for discussed feeding options with a healthcare provider: Intervention group > Control group | Knowledge scores: After > Before  
- Expectation of benefits from tube feeding and decisional conflict: Before > After  
- Surrogates preferred assisted oral feeding initially; they reported certainty about this choice after the decision aid |
| Mitchell, Tetroe & O’ Connor (2001) | Before-and-after study | Acute care hospitals in Ottawa, Canada. | Families of cognitively impaired patients 65 years and older being considered for placement of a percutaneous endoscopic gastrostomy tube | 15  | Tube-feeding decision aid:  
- Self-administered and self-paced audio-booklet presented in a standardized format, and a 40-minute audiotaape guides the decision maker through the booklet to the personal worksheet | After using the decision aid:  
- 87% of subjects voted decisional conflict scores: After > Before  
- Mean percentage of knowledge: After > Before  
- Among seven subjects who were unsure at baseline, four decided to opt for supportive care only, one chose tube feeding, and two remained unsure after working through the aid  
- All subjects stated that the aid was helpful and would recommend it to others  
- The majority found it was clear, balanced, and appropriate in length  
- Feeding tube insertions rate after discharge: Before > After  
- Proxy knowledge of the disease and proxy-provider communication: After > Before  
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| Snyder et al. (2013)  | Cluster randomized trial    | Skilled nursing facilities across North Carolina | Surrogates for nursing home residents with advanced dementia and feeding problems | 255 | - Intervention group: An 20-minute audiovisual-print structured decision aid was provided  
- Control group: Decision aid was not provided | Comparing performance of the Intervention group:  
- Knowledge scores: After > Before  
- Expectation of benefits from tube feeding and decisional conflict: Before > After  
- Surrogates preferred assisted oral feeding initially; they reported certainty about this choice after the decision aid |
## Location and setting

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## Study population

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<td>Surrogates</td>
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## Format of decision aid

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<td>Audiovisual version</td>
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<td>Booklet</td>
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<td>Review with researcher or physician (Time is not indicated)</td>
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<td>Took about 20 minutes for review</td>
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<td>Self-paced, with a 40-minute audiotape for guiding</td>
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## Content of discussion

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<td>Determination of primary goal of care</td>
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<td>Information about different feeding options</td>
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<td>Risks and benefits of assisted oral feeding</td>
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<td>Risks and benefits of tube feeding</td>
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<td>Affect of advanced dementia in family</td>
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<td>Option of supportive care</td>
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## Outcome measures and their results (if a/v)

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<td><strong>Communication between surrogates and healthcare providers</strong></td>
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<td><strong>Decision made by the surrogates</strong></td>
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Discussion

• Decision aids with audiovisual or print version can increase surrogates’ knowledge and decrease their decisional conflict

• **Key components** of decision aid include:
  – Information about advanced dementia
  – Information about different feeding options
  – Principles of substitute decision making / Role of family members
  – Risks and benefits of assisted oral feeding and tube feeding
Clinical Implications

Advance care planning should be initiated as early as possible!!

To engage the PWD in the decision making process
To prepare the family members for the difficult decisions

http://acpe.cuhk.edu.hk
Thank you!

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