Involvement of Older-Aged Adults in Chronic Illness Care Decisions: A Metasynthesis

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Objectives
1. Describe the significance of exploring older-aged persons' perceptions of their involvement in chronic illness care;
2. Discuss what it means to them to be involved or not to be involved in their care;
3. Identify the barriers and facilitators of involvement for this population;
4. Discuss the CNSs role in promoting person-centered care.

Background
- Normal course of involvement in health care over the lifespan
- Baby-boom generation differences
- Person-centered care
- Problems
  - Shortage of practitioners
  - Increase in number and demand of patients
  - Soaring costs
- CNS impact
Purpose & Research Questions

• Purpose: Synthesize qualitative literature exploring perceptions of older-aged persons’ involvement in chronic illness care decisions.

• Research questions:
  1. Meaning of involvement?
  2. Barriers & facilitators to involvement?

Design

• Metasynthesis: qualitative systematic review
  ▫ Interpretive integration of interpreted findings
  ▫ Analysis of each study’s findings → intensified qualitative interpretation across studies
  ▫ Moves qualitative research closer to clinical practice, making it a more useful component of evidence-based practice literature (Sandelowski & Barroso, 2007)

Methods

1. Comprehensive literature search
2. Data transformation appraisal (Sandelowski & Barroso, 2007)
3. Classification and analysis of studies (table)
   Domain analysis (Spradley, 1980)
4. Synthesis of findings (Sandelowski & Barroso, 2007)
   Comparative analysis
5. Trustworthiness techniques
Comprehensive Literature Search

- Terms:
  - Person-centered
  - Older age
  - Nursing home
  - Long-term care
  - Chronic illness
  - Involvement
  - Preferences
  - Perceptions
  - Autonomy
  - Decision-making

- Databases:
  - PubMed
  - Web of Science
  - MedLine
  - CINAHL
  - PsychINFO

- Inclusion criteria:
  - English
  - post-1996
  - sampled chronically ill, aged >/= 50 yrs.
  - mild to no cognitive impairment

Data Transformation Appraisal

- Typology of qualitative findings (Sandelowski & Barroso, 2007)
- Level 3 or above included

<table>
<thead>
<tr>
<th>Type of Finding</th>
<th>Description</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Finding*</td>
<td>Presentation of un-interpreted data (quotations, stories, incidents, etc.)</td>
<td>1</td>
</tr>
<tr>
<td>Topical survey*</td>
<td>Staying close to the surface of the data, presentation in the form of lists or categories with quotations to support the categorization</td>
<td>2</td>
</tr>
<tr>
<td>Thematic Survey</td>
<td>More in depth description of categories and themes, where themes are used to organize the data, including some interpretation by the researchers</td>
<td>3</td>
</tr>
<tr>
<td>Conceptual thematic description</td>
<td>Themes and concepts, either from theoretical frameworks, are used to explain data rather than rely on existing data; interpretation casts new light on existing data</td>
<td>4</td>
</tr>
<tr>
<td>Interpretive explanation</td>
<td>The most integrated of findings, presents a detailed description of a model or argument that explains causation or origination of events or experiences</td>
<td>5</td>
</tr>
</tbody>
</table>

Classification & Analysis (Coding)

- Domain analysis (Spradley, 1980)
  - Text from findings/discussion/conclusions searched for relevant terms; → domains
  - Domain: “x is a kind of y”
    - For example: “an oak is a kind of tree”

<table>
<thead>
<tr>
<th>Study</th>
<th>Term (or phrase)</th>
<th>Relationship</th>
<th>Coverage</th>
<th>Domain</th>
<th>Category</th>
<th>Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bastiaens, et al., 2007</td>
<td>“Easy to talk to”</td>
<td>Is a kind of</td>
<td>Provider characteristics</td>
<td>Provider quality</td>
<td>Facilitates resident involvement</td>
<td>Connections &amp; Opportunities</td>
</tr>
</tbody>
</table>

- Domains are defined & filled in from the data
- Terms → Domains → Categories → Themes
### Synthesis of Findings - Comparative analysis

(Sandelowski & Barroso, 2003)

<table>
<thead>
<tr>
<th>Findings Table</th>
<th>Themes Table</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Findings</td>
<td>• Thematic findings</td>
</tr>
<tr>
<td>• Themes</td>
<td>• Domain analysis proposed themes</td>
</tr>
<tr>
<td>• Participant quotes</td>
<td>1. Ensure congruence between themes;</td>
</tr>
<tr>
<td>• Discussion</td>
<td>2. Search for overarching themes.</td>
</tr>
<tr>
<td>• Conclusions</td>
<td>3. Ensure congruence between findings;</td>
</tr>
<tr>
<td>• Reviewers’ impressions</td>
<td>4. Determine each study’s contribution to the synthesis;</td>
</tr>
<tr>
<td></td>
<td>5. Prevent bias.</td>
</tr>
</tbody>
</table>

1. Congruence between findings;
2. Determine each study’s contribution to the synthesis;
3. Prevent bias.

### Trustworthiness

- Clarification of methods
- Researchers’ discussion & agreement on data transformation appraisal and coding
- Audit trail of coding & thematic decisions

### Literature Search

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>2047</td>
<td>Include duplicates, foreign language, data of publication, off topic</td>
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<tr>
<td>1732</td>
<td>Excluded studies</td>
</tr>
<tr>
<td>1155</td>
<td>Include design, sample characteristics</td>
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<td>2047</td>
<td>Exclude data transformation score &lt; 3</td>
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<tr>
<td>9</td>
<td>Excluded studies</td>
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<tr>
<td>7</td>
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Final Sample Characteristics

<table>
<thead>
<tr>
<th>Setting</th>
<th>Design/Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 5 - community</td>
<td>• 4 - qualitative</td>
</tr>
<tr>
<td>• 2 - nursing home</td>
<td>descriptive</td>
</tr>
<tr>
<td>• 3 - U.S.</td>
<td>• 2 - grounded theory</td>
</tr>
<tr>
<td>• 4 – European including Ireland, Germany, The Netherlands</td>
<td>• 1 - ethnographic case study</td>
</tr>
</tbody>
</table>

Individual Sample Characteristics

• 541 - chronically ill older-aged persons
• 57% - female
• Age - 50-97 years old (most over 70 yrs)

Primary Aims of Included Studies

<table>
<thead>
<tr>
<th>No. of studies</th>
<th>Aspect of decisional involvement focused on by the individual research studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>involvement in medication-related decisions</td>
</tr>
<tr>
<td>2</td>
<td>involvement in primary health care &amp; relationships with providers</td>
</tr>
<tr>
<td>1</td>
<td>discussion of life &amp; health goals with providers</td>
</tr>
<tr>
<td>1</td>
<td>coping with multiple chronic illnesses</td>
</tr>
<tr>
<td>1</td>
<td>change in decision-making autonomy in nursing home over time</td>
</tr>
</tbody>
</table>

Thematic Findings

• (1) **Being recognized because I matter**

• (2) **Awareness of importance**

• (3) **Empower through connections & opportunities**

• (4) **Time is precious**
1. **Being recognized because I matter**
   - What does it mean to be involved in health care decisions?
     - Confident, informed, understood
     - Feeling of importance
       - “Well he is a good listener. He is observant. Then when I have told my bit of the tale he will ask questions for clarification and then he will give his view on things” 
     - Nurturing relationship demands time investment

2. **Awareness of importance**
   - What does it mean not to be involved in health care decisions?
     - Inferior, angry, frustrated, humiliated, insulted, lonely, powerless
       - “…I don’t think I could be much of a help. I don’t think anybody would take me seriously enough…” 
         (Belcher, Agostini, & Tinetti, 2006, p. 300).

2. **Awareness of importance**
   - Barriers to involvement?
     - Self-perceived old age, forgetfulness, frailty, lack of knowledge
     - Belief & trust in provider as “all-knowing” expert
     - Generational passivity
       - Nursing home
         - “I just take what I am given. I believe in doing what I am told” 
           (Belcher et al., 2006, p. 301).
       - Community setting
         - “I don’t know anything about them. How can I make a decision?”  
           (Belcher et al., 2006, p. 302).
3. **Empower through connections & opportunities**

   - **Barriers to patient involvement? Communication**
     
     - *Provider is disconnected, disinterested, rushed*

     "I’d like the doctor to know me, but you can’t do that now... you’re out in 10 or 15 minutes. He’s reaching for his prescription pad or something" (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2005, p. 148).

     - *Conflict over control*

   - **Facilitators to patient involvement?**

     - *Encouragement, guidance, support, opportunity*

     "Indicate how the procedures work, provide me for example with an indication, because the health care service is like a jungle, show me what the options are and what I can choose" (Schoot, Proot, ter Meulen, & de Witte, 2005, p. 175).

4. **Time is precious (overarching)**

   - Underlying message across studies and across themes

     - *Time: precious commodity for HCPs & patients*

     - *Patients feelings of being rushed & unimportant*

     - *HCP actions aimed at providing highly efficient, quality care*
Suggested Relationships

Conclusions & Implications

- Older adults who desire decisional involvement benefit from it through ↑ quality of life
- Being left out of decisions may cause emotional harm (loss of autonomy)
- CNSs can be a major contributor to assessing & meeting the decisional needs of this population both now & in the future

Study Limitations

- Small number of studies available for synthesis
- Majority sampled were in Europe
- Mixture of NH and community samples
- Cognitive capability and desire for involvement limit generalizability
Future Work

• Clarify the older-aged person’s motivation for person-centered chronic illness care decision-making
• Clarify whether the HCP will value and heed the older-aged person’s decision or choice

Relationships that should be measured:

• Effect of time spent by HCPs in chronic illness care on:
  - quality of communication
  - patient quality of life & physical health outcomes
• Effect of increased CNSs as primary HCPs in chronic illness care on:
  - economic outcomes & patient outcomes

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References