Case Study: Data Collection and Analysis

The Oregon Research & Quality Consortium Conference
April 11, 2011
0900-1000

Patricia Nardone, PhD, MS, RN, CNOR
Kaiser Permanente Northwest,
Portland, OR

Lissi Hansen, PhD, RN
Oregon Health & Science University,
Portland, OR
End-Stage Liver Disease and Treatment Decisions

- Used a multiple case study design
What was the Purpose of this Study?

- Understand life-sustaining treatment decision-making over time in the ICU from multiple perspectives:
  - Patients with end-stage liver disease
  - Family members
  - Health care providers
Aims

- **Aim 1**: Compare and contrast the experience and meanings of each life sustaining treatment and comfort care decision.

- **Aim 2**: Describe the longitudinal process of decision making:
  a) Describe how decisions evolve over time
Study Design — Ethnographic Methods

Data collected from multiple perspectives

- Patients with end-stage liver disease (n=6)
- Family members (n=19)
- Health care providers (n=118)
  - Declined during study (n=4), pre-study (n=2)

Data collection includes

- 315 Observations hours in the ICU
- 138 Interviews regarding treatment decisions
- Observation of 3 family care conferences
- Patient medical record reviews
## Participants

<table>
<thead>
<tr>
<th>Participant group</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>6</td>
</tr>
<tr>
<td>Family Members</td>
<td>19</td>
</tr>
<tr>
<td>Physicians</td>
<td>58</td>
</tr>
<tr>
<td>Nurses</td>
<td>54</td>
</tr>
<tr>
<td>Other HCP</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total participants</strong></td>
<td><strong>147</strong></td>
</tr>
<tr>
<td>Participant group</td>
<td>Interviews conducted</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Patients</td>
<td>6</td>
</tr>
<tr>
<td>Patient &amp; Family members</td>
<td>3</td>
</tr>
<tr>
<td>Family members</td>
<td>36</td>
</tr>
<tr>
<td>Physicians</td>
<td>37</td>
</tr>
<tr>
<td>Nurses</td>
<td>53</td>
</tr>
<tr>
<td>Other HCP</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total interviews conducted</strong></td>
<td><strong>138</strong></td>
</tr>
</tbody>
</table>
## Observations

<table>
<thead>
<tr>
<th>Observation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of patient stay in ICU</td>
<td>53 days</td>
</tr>
<tr>
<td>Hours at bedside</td>
<td>315 hours</td>
</tr>
<tr>
<td>Days at bedside</td>
<td>45 days</td>
</tr>
<tr>
<td>Number of family care conferences</td>
<td>3 conferences</td>
</tr>
</tbody>
</table>
Methodological Triangulation

- is the use of two or more research methods in one study and may occur at the level of design or data collection.
  - Within cases
  - Between cases

Begley, 1996
Analysis Approaches

- Qualitative description
- Phenomenology
- Grounded theory
Similar to the Process of Creative Thinking

- Be open
- Generate options
- Divergence before convergence
- Use multiple stimuli
- Side-tract, zig-zag, circumnavigate
- Change patterns
- Make linkages

Kendall, 2010
- Trust yourself
- Work at it
- Play at it
- Know when to stop

Kendall, 2010
Conditions Influencing Data Analysis

- Related to the Researcher
  - Training
  - Experience
  - Self-confidence
  - Tolerance for ambiguity

Kendall, 2010
Conditions Influencing Data Analysis (cont)

- Conditions Influencing the Research Process:
  - Framework through which research problem is viewed
  - Type and amount of data gathered
  - Inductive modes of thinking
  - Levels of abstraction

Kendall, 2010
Description of Data Analysis

- Process of bringing order, structure and meaning to raw data
- Systematic, done as a series of steps
- No absolute rules or formulas – a process of creative thinking
- No way to replicate the study – analysis is a process of specific interpreters and their interpretations

Kendall, 2010
Description of Data Analysis (cont)

- Analysis and interpretation requires judgment and creativity.
- Researchers have an obligation to monitor and report their own analytical procedures and decisions truthfully and fully.
- Data analysis is often iterative with data collection.

Kendall, 2010
Questions to Ask the Data

- What is going on here?
- What does it mean?
- What else do I need to find out?

Kendall, 2010
Basic Operational Process of Analysis

- Prepare the data
  - Transcribe all verbal data
  - Organize and label all observation notes, field notes, demographic information, documents, journals, diaries

- Read all collected information
  - Sketch ideas
  - Jot down ideas in margins of transcripts or field notes
  - Begin to write summaries of field notes
Basic Operational Process of Analysis (cont)

- Start writing memos - keep in separate files
  - Theoretical memos - conceptualizing the data
  - Methodological memos – issues with method
  - Observational memos – reflective, observed

- Start reducing the data
  - Identify codes; develop a list of codes – make sure the raw data is tagged per each code
  - Collapse and sort codes into larger categories/themes
  - Describe the larger categories/themes
  - Relate categories to each other
Basic Operational Process of Analysis (cont)

- Continue writing memos and conceptualizing the data
  - Look at the words participants use
  - Read, reflect, describe, interpret the data
  - Note patterns, themes; identify patterned regularities

- Display data
  - Develop diagrams, matrixes, tables to display data by case, by subject, or by theme

Kendall, 2010
Data Analysis and Representation

Procedures

- Representing, Visualizing
- Describing, Classifying, Interpreting
- Reading, Memoing
- Data Managing

Examples

- Account
- Matrix, trees, propositions
- Context, Categories, Comparisons
- Reflecting, Writing notes across questions
- Files, Units, Organize

Data Collection (text, images)
Findings

- Number and type of decisions
- Themes
<table>
<thead>
<tr>
<th>Type of decision</th>
<th>Number of decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>LST</td>
<td></td>
</tr>
<tr>
<td>Antibiotics</td>
<td>5</td>
</tr>
<tr>
<td>Blood products</td>
<td>30</td>
</tr>
<tr>
<td>CPR</td>
<td>2</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>4</td>
</tr>
<tr>
<td>Fluids</td>
<td>11</td>
</tr>
<tr>
<td>Hemodialysis</td>
<td>8</td>
</tr>
<tr>
<td>Procedures</td>
<td>5</td>
</tr>
<tr>
<td>Vasopressors</td>
<td>12</td>
</tr>
<tr>
<td>Ventilation</td>
<td>9</td>
</tr>
<tr>
<td>Comfort care</td>
<td></td>
</tr>
<tr>
<td>Pain medication</td>
<td>2</td>
</tr>
<tr>
<td>Hospice</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total decisions</strong></td>
<td><strong>89</strong></td>
</tr>
</tbody>
</table>
Themes

- **On the Train**
  - Communication in regard to LST
    - Health care provider communication with family members
    - Strategies used by family members to elicit information
  - Type and weight of decisions
  - LST decision making experience
  - Mismatches
On the Train

- **MD:**
  “I guess, just imagined the whole process as moving somewhere. The surgeons and the hepatologists, we’re all on a train, so to speak, going to somewhere and the family can either fight it and not go with us, or just kind of latch onto the process and accept it.”

- **Family members:**
  - Represented a continuum of the LST decision making experience from novice to intermediate to expert
  - Saw each LST decision as separate and not as a longitudinal process
Communication in Regard to LST

- Health care provider communication with patients and family members
  - Many different individual providers
  - A variety of disciplines
    - Talk in organs
- Strategies used by family members to elicit information
  - Same questions to different providers
  - Same specific question each day
  - “Inset” oneself into the medical team
Type and Weight of Decisions

- Health care providers:
  - Immediate
  - Proactive
  - Supportive

- Family members:
  - Black and White
  - “Big” versus “Small”
    - Big = more weight
LST Decision Making Experience

- Initially patients, family members, and health care providers on the same path
  - Transplant waiting list

- Differences between “groups”:
  - Timing
  - Urgency
  - Priority
Mismatches

- The patients’ illness course
  - Nurses versus physicians
  - Family members versus physicians

- RN - RN:
  “Transplant team here. They were going on about transplant this and that: ‘We’ll get a new liver for you, etc…’ Patient’s eyes were gleaming. Got Husband and Patient all excited. We can’t even get her kidney up to goal!”
Family Member:

“I mean it was just like boohooohoohooboom and I say, well, but yet [the MD] was still talking about the possibility of a transplant, you know, and it was like this is just amazing that, you know, he is like close to death, ‘but transplant is still possible in the future,’ you know, ‘we could pull him out of it.’”
Reporting

- Helsinki Declaration
  - Authors/researchers have a duty to publish
    - Negative, inconclusive, and positive results
    - Sources of funding
    - Institutional affiliations
    - Conflicts of interest
Acknowledgements

Thank you

Study participants:
- Patients and Family Members
- Nurses
- Physicians
- Other Health Care Providers

Funding source:
- National Institutes of Health (NIH)
- National Institute of Nursing Research (NINR)
  #1 R21 NR009845-01A2
References

- Kendall, J. (2010). Material provided by Dr. Kendall, OHSU, Portland, OR (Slides 11-20).