Case Study: Data Collection and Analysis

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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

Participant group	Number of participants
Patients	6
Family Members	19
Physicians	58
Nurses	54
Other HCP	10
Total participants	**147**

Interviews

Participant group	Interviews conducted
Patients	6
Patient & Family members	3
Family members	36
Physicians	37
Nurses	53
Other HCP	3
Total interviews conducted	**138**

Observations

Observation	Total
Duration of patient stay in ICU	**53 days**
Hours at bedside	**315 hours**
Days at bedside	**45 days**
Number of family care conferences	**3 conferences**

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 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
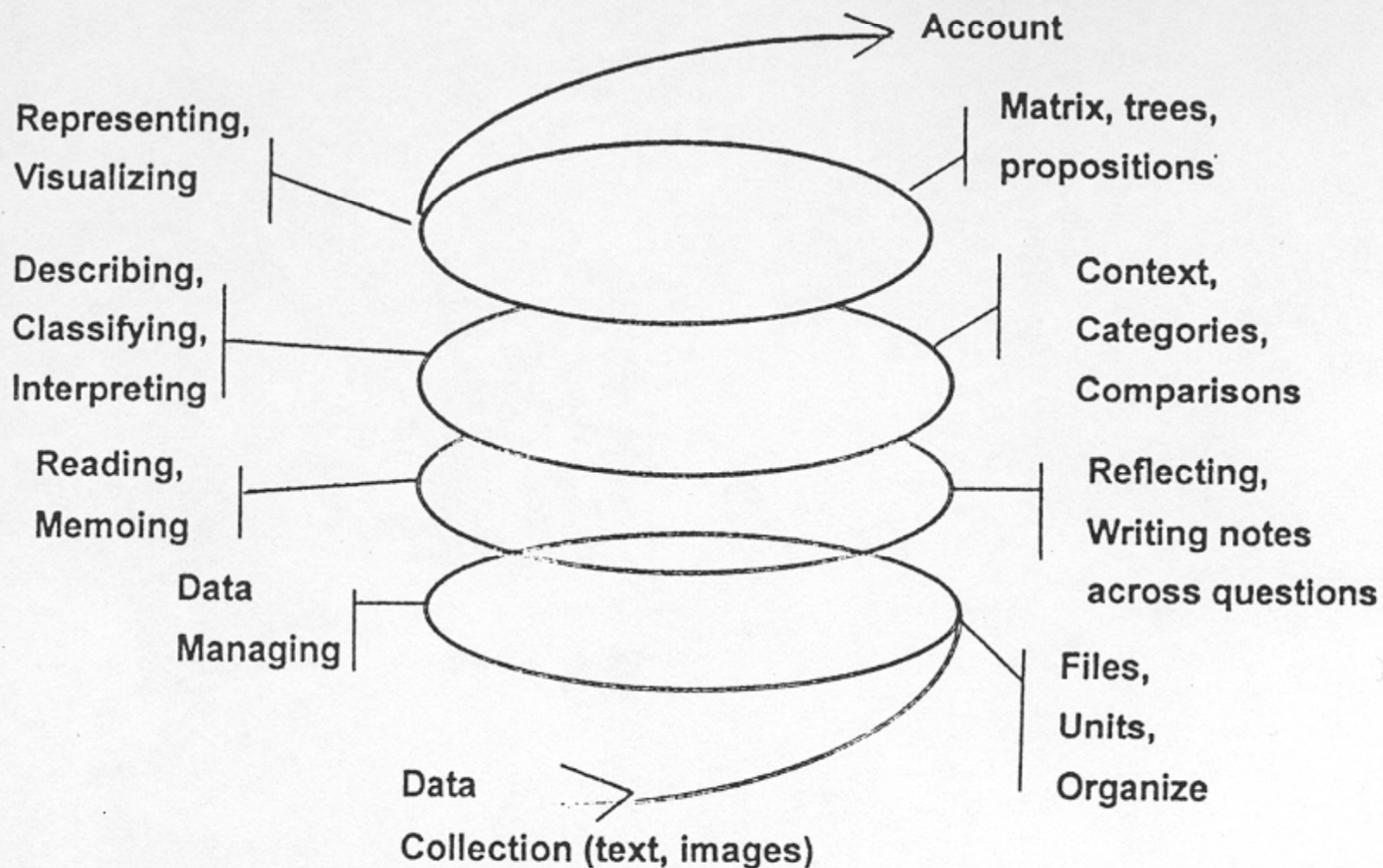 - Relate categories to each other

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

Procedures

Examples

Representing,
Visualizing

Describing,
Classifying,
Interpreting

Reading,
Memoing

Data
Managing

Data
Collection (text, images)

Account

Matrix, trees,
propositions

Context,
Categories,
Comparisons

Reflecting,
Writing notes
across questions

Files,
Units,
Organize

Findings

- Number and type of decisions
- Themes

Number and Type of Decisions

Type of decision		Number of decisions
LST	Antibiotics	5
	Blood products	30
	CPR	2
	Feeding tube	4
	Fluids	11
	Hemodialysis	8
	Procedures	5
	Vasopressors	12
	Ventilation	9
Comfort care	Pain medication	2
	Hospice	1
Total decisions		**89**

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!"

Mismatches

- Family Member:

  "I mean it was just like boohoohoohooboom 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

References

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