

# ICU Patient Notebooks: Facilitating Communication and Reconstructing Memories

Workshop on ICU Patient Diaries  
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# Background:

## From respirator to research

- Jan.-Feb., 1997: viral pneumonia
- ICU (19 days), ventilator (15 days)
- Heavy sedation, but often awake
- Non-disclosure, mis-disclosure (lying)
  - intubation
  - condition, prognosis
  - optimism, hope, survival
  - re-entry: upsetting news--exhausting, draining

# Layers of Memory (I)



# "Inadvertent Ethnography" (Rier, 2000)

- *Participant:* real time  
to communicate  
(pure lived experience)
- *Observer:* retrospectively  
to analyze/interpret  
(fieldnotes text)

# Layers of Memory (II)

- Remembered, also recorded
- Remembered, not recorded
- Recovered via prompts
- **Remembered *only* via notebook**
- Not remembered even *with* notebook
- Lost indefinitely

# Existing Clinical Literature

- Phenomenological
- Functional
- Small samples (most, 7-14)
- Memory: *unaided*, or aided by diaries (albums)
- Seldom asks sociological questions

# Methodological Problems (iceberg)

- Survival
- Memory
- Frail, ill
- Not all wish to re-live
- Ethical difficulties

# Consequences: Questions

- What is the ICU like, for *patient*?  
*Example--* private rooms:
  - Peaceful, restful?
  - Lonely? (“like not getting pain meds”)
  - Disorienting?
- What does *patient* want?
  - Communication: if, what, who, when, how
  - Disclosure: if, what, who, when, how

# Proposed Research

- Funding applications: Fall, 2008
- Recruitment: 2009
- Identify potential sample members:
  - vent or trach patients (unable to speak)
  - able (physically and mentally) to write
- Nurses offer notebooks (to appropriate patients) to communicate with staff and visitors
- Interviews
  - post-discharge
  - notebook as memory aid

# Goals

- *Demonstrate* feasibility of notebooks
  - communication: patients, nurses, visitors
  - de-briefing tool
- *Capture* ICU memories
- *Re-construct* and *describe* patients' ICU experiences
- *Generate* recommendations, questions

# Design (1) ?

- Intervention?
  - Prospective
  - Retrospective
  - RCT of notebook use: piggy-back (multi-method)
- Modalities: Isolated or holistic?
  - Notebook only
  - Notebook + photos + diary (album?)

# Design (2) ?

- Timing?
  - First interview: pre- or post-hospital discharge?
  - Follow up: 3, 6, 12 months?
- Site? Single-room vs. classic open?

# Potential Benefits:

## I. Short-range

- Patient notebooks for communication
  - Reduce frustration
  - Improve comfort
  - Improve orientation, mental acuity?
- Interviews: therapeutic?
  - Bear witness
  - “Work through”
  - Closure

# Potential Benefits:

## II. Mid-range

- Insights into ICU patient's world:
  - communication needs (what, when, how, with whom?)
  - disclosure " "
  - trust, hope, and optimism
  - gender (e.g., wife's influence, vs. husband's)
  - where are the docs?
  - visitors (life-line? burden?)
- Memory: retention, retrieval, reconstruction
- Post-ICU: re-entry, reconstruction, closure
- Questions for future research

# Potential Benefits:

## III. Long-range

- Clinical
  - Patient-centered care
  - Quality of life
  - ICU design (open vs. closed?)
  
- Sociological
  - Bringing critical illness in
  - Re-evaluating:  
autonomy, paternalism, empowerment
  - Multi-center (?): cross-cultural

# Problems: I. Have I a study?

- Sample
  - Sedation, strength (notebook)
  - Meds:
    - Versed: amnestic stronger than notebook? But...
    - Remifentanyl: patients much more awake?
  - Survival (iceberg; Primo Levi on Auschwitz)
- Nursing workloads (notebook)
  - Nurses too busy to read patient writing?
  - ?Solution: use notebooks with visitors?
- Access

# Problems: II. Practical

- IRB obstacles
  - Consent (when? who?)
  - Risks
    - depression, flash-backs → psych/social work backup
    - confidentiality
    - interfere with patient care
- Funding: Research nurse? Travel, transcription (though small n's)
- Sample size/Collaboration
  - Management
  - Foreign language (international collab., also internally)
  - Systemic Functional Linguistics to make most of limited data?