CONSTRUCTING THE ILLNESS NARRATIVE:
AN INTERNATIONAL PERSPECTIVE ON ICU DIARIES

Ingrid Egerod, Ph.d.
ICU diaries – the concept

- A Critical Care nursing invention
- A Critical Care nursing intervention
- A low-cost, low-tech therapy
“Things are looking better. We’re thinking of removing the tube from your throat, so you can breathe on your own. You are still sleeping too deeply, so it will have to wait till you are more awake - probably in the next day or so. I have shut off your sleeping medication and you are already wincing. You are trying to open your eyes and move your arms a little ... Sincerely Susan”.

Ingrid Egerod - ICU diaries
What are ICU diaries?
Where did ICU diaries start?
How are ICU diaries kept (author)?
How are ICU diaries used (reader)?
What is the effect of ICU diaries?
What are the benefits of ICU diaries?
What are ICU diaries?

ICU diaries are journals kept by nurses, hospital staff, or family members while the patient is in ICU.

ICU diaries are written in everyday language and supported by pictures of the patient.
“You are still very tired, but more awake than yesterday. Awake enough to become very irritated with the tube. We took this as a sign that you could do without the tube and removed it this morning – a big step in the right direction! It’s great to see you without that tube and to hear you talk. It’s still only a whisper, but it’s talking!”

Sincerely, Cathy.”
How did it start?

ICU diaries started around 1990 in Denmark, Norway, and Sweden to help patients understand what happened in ICU.


How did it start?

Several schools of thought inspired ICU diaries

- Diaries as a therapeutic instrument (crisis and coping)
- Diaries as an act of caring (existence and meaning)
- Diaries as an expression of empathy (acknowledgment)

Schools of thought

- Diaries as a therapeutic instrument
  (crisis, coping, fact, reorientation)
  - Cullberg and Lazarus

- Diaries as an act of caring
  (existence, meaning, wonder)
  - Martinsen and van Manen

- Diaries as an expression of empathy
  (acknowledgment, humanism)
  - Buber
ICU diaries have many names

- **Diaries kept by nurses** (Bergbom et al. 1999)
- **Personal diary** (Bäckman & Walther 2001)
- **Patient diaries** (Combe 2005, Storli et al. 2003)
- **Photo diaries** (Bäckman & Walther 2005)
- **Prospective patient diaries** (Knowles & Tarrier 2009)
- **Intensive care diaries** (Jones et al. 2010)
- **ICU-diary concept** (Bäckman et al. 2010)
## Extent in Nordic Countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Inhabitants in millions</th>
<th>Number of ICUs</th>
<th>ICUs using diaries n (%)</th>
<th>Years Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>5.4</td>
<td>48</td>
<td>19 (40%)</td>
<td>5 (1-18)</td>
</tr>
<tr>
<td>Norway</td>
<td>4.8</td>
<td>70</td>
<td>31 (44%)</td>
<td>7 (1-18)</td>
</tr>
<tr>
<td>Sweden</td>
<td>8.9</td>
<td>86</td>
<td>65 (76%)</td>
<td>7 (1-18)</td>
</tr>
</tbody>
</table>

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How are ICU diaries kept and how do they differ from the hospital chart?


# Anatomy of ICU diaries

<table>
<thead>
<tr>
<th>SAMPLE</th>
<th>DIARY</th>
<th>ENTRY</th>
<th>SUB-ENTRY</th>
<th>Embedded-level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Patients</td>
<td>Summary (first entry)</td>
<td>Greeting</td>
<td>Patient status</td>
<td>Neuro status</td>
</tr>
<tr>
<td>– Nurses</td>
<td>– Reason for admission</td>
<td>Establish relationship</td>
<td>– Neuro</td>
<td>– Sedated (not awake)</td>
</tr>
<tr>
<td>– Diaries</td>
<td></td>
<td></td>
<td>– Respiratory</td>
<td>– Waking (not sedated)</td>
</tr>
<tr>
<td>– Trajectories</td>
<td>Entries (daily entry)</td>
<td>Patient status</td>
<td>– Circulatory</td>
<td>– Awake (confused)</td>
</tr>
<tr>
<td></td>
<td>– Daily events</td>
<td>Family status</td>
<td>– Abdominal</td>
<td>– Awake (oriented)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contextual cues</td>
<td>– Kidneys</td>
<td></td>
</tr>
<tr>
<td></td>
<td>End-note (final entry)</td>
<td>Sign-off</td>
<td>– Mobility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>– Status at discharge</td>
<td>Encouragement</td>
<td>– Emotion</td>
<td></td>
</tr>
</tbody>
</table>

Ingrid Egerod - ICU diaries
Guidelines

PATIENT DIARY GUIDELINES

St Helens and Knowsley Hospitals NHS Trust

Whiston Hospital Intensive Care Unit & High Dependency Unit

PATIENT DIARIES IN DANISH ICUs

Constructing a National Guideline
by Ingrid Egerod, PhD, MSc, MD, associate professor, Copenhagen University Hospital, Denmark

Special Edition
ESICM
Lisbon, 28th September 2008

The Process

1. Survey
A survey was done on what patient nurses in Danish ICUs in May 2008 observed that was unique to ICUs and what providers felt was important for nurses to have easy access to

2. Workshop
A workshop was conducted in March 2008 by members of the ICUs using nurses, psychologists, legal advisors, and patients and caregivers of patients with intense care. A list of discussions regarding patient diary was then handed over to nurses who then wrote their own version of the guideline.

3. Regional Groups
Groups representing the five regions in Denmark then handed over a draft version of the guideline. The groups were set up at the beginning of the project in September 2008. The draft was then handed over to the Danish Society of Critical Care at their meeting in January 2009.

4. Department of Health
The draft was handed over to the Department of Health in late 2009. The guideline was adopted by nurses in 2009.

National Guideline for Patient Diaries in ICU

- How should the diary practice be organized?
  Recommendation: A designated person should be responsible for the planning and implementation of the diary. All nursing care in ICUs should be linked with care.

- Which patients should be included for diaries?
  Recommendation: Patients who are expected to have ICU stay > 3 days.

- How should the diary be written?
  Recommendation: Patients can be divided into groups. Patients can be written into the diary either for their own use and for others.

- What should be captured in the diary?
  Recommendation: Patients and families should write in the diary. The patient is aware of the process.

- How should the diary be handled in the patient?
  Recommendation: The diary should be given to the patient at the end of the hospital stay and after the patient is discharged.

- How should the diary be kept secure?
  Recommendation: The diary should be kept in a box with a lock and only be opened by the nurse in charge.

- How should the diary be kept accessible?
  Recommendation: The diary should be kept in a box with a lock and only be opened by the nurse in charge.

More Information

For more information, please visit www.icuforum.com

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The ICU diary is coherent, personal, and supportive, whereas the hospital chart is fragmented, impersonal, and technical.

The diary tells a comprehensive story that might help the patients construct or reconstruct their illness narrative.

Narrative structure in ICU diaries

Narrative research (Creswell 2007)

- Chronology and crisis
- Beginning, middle, end
- Time, place, plot, scene
Structure of illness narratives

Illness narratives – basic plots (Frank 1995)

- **Restitution**: I was healthy, I am sick, I will be healthy
- **Chaos**: Life will never get better
- **Quest**: Meaning of illness
The Illness Narrative in context

- Onset
- ICU-trajectory
- Hospitalization
- Recovery
- Illness Narrative

Life span, personal biography

Relatively good health

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Emplotment in ICU diaries

- **Crisis**: Critical illness, life and death
- **Turning point**: Waking up, breathing
- **Normalization**: Sitting, Standing, Walking
### Stages of narrative

<table>
<thead>
<tr>
<th>Stages of narrative</th>
<th>Parallel plots</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nurse's storyline</td>
<td>Patient's storyline</td>
<td>Family's storyline</td>
</tr>
<tr>
<td>Crisis</td>
<td>Active; Focus on technology</td>
<td>Passive; Depersonalized</td>
<td>Spectating; Worried</td>
</tr>
<tr>
<td>Turning Point</td>
<td>Active; Focus on caring</td>
<td>Emerging; Repersonalized</td>
<td>Engaging; Relief and gratitude</td>
</tr>
<tr>
<td>Normalization</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

#### Converging plots

- Relating, participating, connecting, letting go
How are diaries used?

ICU diaries are written during critical illness (front end) and used in ICU rehabilitation (back end).

Rehabilitative initiatives include:

- ICU diary
- Step-down unit (ICU nurse visit)
- Physiotherapy and lung function test
- Follow-up or outpatient clinic
- Drop-in support group (ICU-Steps)


What is the effect of ICU diaries?

Diaries reduce anxiety & depression

The ICU diary is designed to help patients understand what happened to them in intensive care and has a significant positive impact on anxiety and depression at about 2 months after ICU discharge.


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What is the effect of ICU diaries?

Diaries reduce posttraumatic stress disorder, PTSD

The ICU diary is effective in aiding psychological recovery and reducing the incidence of new PTSD three months after ICU discharge.

What is the effect of ICU diaries?

Diaries improve Quality of Life

The ICU-diary is associated with improved health-related QoL during a 3-year follow-up period after critical illness.

What are the down-sides?

- Lack of evidence
- Lack on consistency
- Lack of systematic follow-up
- Lack of safety studies (potential harm?)
- Not useful to all patients
What are the benefits of diaries?

Diaries facilitate sharing with the family

- Sharing the story
- Sharing the presence
- Sharing feelings
- Sharing through support

What are the benefits of diaries?

Diaries help patients in their search for meaning with their experiences and memories.

Diaries enable post-ICU reflection by providing guideposts for discussion during follow-up; patients need to tell their story.

What are the benefits of diaries?

ICU diaries are useful to patients and relatives.

Patients need to construct their illness narrative, and diaries are among the sources they use.

Patients combine various sources of information in a process of information acquisition, narration, and evolving insight progressing toward recovery.
The End