ICU-recovery in Scandinavia:

A comparative study of intensive care follow-up in Denmark, Norway and Sweden

Ingrid Egerod, Professor of clinical nursing
University of Copenhagen and Rigshospitalet
Context and content of ICU recovery

The Scandinavian context before 2010
• The emergence of patient diaries and follow-up 1990-2000
• ICU follow-up in Denmark, Norway and Sweden around 2008

The greater context after 2010
• International trends: ICU survivorship, burdens of critical care (human and economic cost), post-intensive care syndrome(-family)
<table>
<thead>
<tr>
<th>Country</th>
<th>Inhabitants in millions</th>
<th>Number of ICUs</th>
<th>Inhabitants per ICU</th>
<th>ICUs using diaries n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>5.4</td>
<td>48</td>
<td>112.500</td>
<td>19 (40%)</td>
</tr>
<tr>
<td>Norway</td>
<td>4.8</td>
<td>70</td>
<td>68.571</td>
<td>31 (44%)</td>
</tr>
<tr>
<td>Sweden</td>
<td>8.9</td>
<td>86</td>
<td>103.488</td>
<td>65 (76%)</td>
</tr>
</tbody>
</table>
Emergence of ICU diaries and follow-up (NOFI study)

Nursing Inquiry

Intensive care patient diaries in Scandinavia: a comparative study of emergence and evolution

Ingrid Egerod, Sissel Lisa Storli, and Eva Åkerman

The University of Copenhagen and the University Hospitals Center for Nursing and Care Research, Copenhagen University Hospital Rigshospitalet, Copenhagen O, Denmark; University of Tromsø, Tromsø, Norway; Malmö University Hospital, Malmö, Sweden
Patient diaries in Scandinavia

Emergence

• Open charting systems in Denmark 1980s
  • Project: Patient emancipation

• Patient diaries in 1990s
  • Organization: Bottom-up initiative; grassroots movement; inter-Scandinavian collaboration

• Photo-diary in 1990s
  • Project: Patient orientation
Patient diaries in Scandinavia

Emergence 1980-1990s
- Based on nurses’ experiences
  - Perceived pragmatic need (Hazzard et al. 2013)
- Vague purpose and unclear outcomes
  - Protection vs confrontation
- Nurses lacked academic preparation
  - Little research and lack of evidence-base
  - Empirical evidence vs humanistic understanding
- Nurse autonomy in Scandinavia
Patient diaries in Scandinavia

Proliferation of patient diaries

- Denmark
- Norway
- Sweden

ICU recovery

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Patient diaries in Scandinavia

Percent ICUs using diaries 2007

- Denmark
- Norway
- Sweden
Patient diaries in Scandinavia

Emergence and evolution

• Norway and Sweden: Systematic practice
  • Guidelines for inclusion and practice
  • Diary as adjunct to follow-up

• Denmark: Non-systematic practice
  • Nurses with special interest (voluntary)
  • Semi-selected patients receive diary
  • Diary without follow-up
  • Patient visits (voluntary)
Patient diaries in Scandinavia

Evolving schools of thought

Denmark: Diary as an expression of empathy - acknowledgment
  • Acknowledgment of personhood
  • Identification with emotions, feelings and reactions

Norway: Diary as an act of caring – understanding and meaning
  • Patient as interpreter of meaning and ability to wonder
  • Enabling sudden insight and meaning
  • The meaning of being somewhere else

Sweden: Diary as a therapeutic practice; orientation to reality
  • Based on theory of coping and crisis
  • Debriefing and realistic description
  • Logical and chronological information
Nordic perspectives on ICU follow-up

Diaries and follow-up were provided by nurses with a “special interest” rather than as part of the established treatment plan.

- Danish view: Humanistic
- Norwegian view: Existential
- Swedish view: Therapeutic
Nordic perspectives on ICU follow-up – reconstructing the story – filling in the gaps

- Reconstruction of personhood requires both feeling like a complete individual (i.e. reconstructed self-identity) and being accepted as one by other people (i.e. reconstructed place in the world), (Levack et al. 2010).

- Narratives not only re-enact experience in the telling, but reinforce social and cultural structures of society through their telling. Creating a sense of personhood and shared humanity.

- Life threads represent the stories or strands of ourselves that we create and re-create though life. In order to appreciate the importance of narratives it is necessary to explore their structure. A narrative is a re-creation of events, not a mere list of episodes. (Ellis-Hill et al. 2008)
ICU-recovery in Scandinavia: A comparative study of intensive care follow-up in Denmark, Norway and Sweden (NOFI study)

Ingrid Egerod

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ORIGINAL ARTICLE

ICU-recovery in Scandinavia: A comparative study of intensive care follow-up in Denmark, Norway and Sweden

Ingrid Egerod, Signe S. Risom, Thordis Thomsen, Sissel L. Storli, Ragne S. Eskerud, Anny N. Holme, Karin A.M. Samuelson
## Four models of follow-up

<table>
<thead>
<tr>
<th>Model Type</th>
<th>With diary</th>
<th>Without diary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse-led</td>
<td>Model I. Denmark, Norway, Sweden</td>
<td>Model II. Denmark</td>
</tr>
<tr>
<td>Interdisciplinary</td>
<td>Model III. Sweden</td>
<td>Model IV. Denmark</td>
</tr>
</tbody>
</table>

ICU recovery

Ingrid Egerod
ICU follow-up goals and methods

<table>
<thead>
<tr>
<th>Focus on past</th>
<th>Goal</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Promote psychological or existential recovery</td>
<td>Patient narration Diary review ICU visit</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Focus on present</th>
<th>Goal</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient assessment Research Treatment</td>
<td>ICU-Memory Tool HADS PTS-14 SF-36</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Focus on future</th>
<th>Goal</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Promote physical and social recovery</td>
<td>Rehabilitation program</td>
</tr>
</tbody>
</table>
Basic models of follow-up

Model 1
Nurse-led follow-up with patient diary (Denmark, Norway, Sweden)
Variations
• Follow-up at ward during diary handover
• Follow-up at ICU after hospital discharge
• Follow-up at hospital 2-3 months post hospital discharge
• Follow-up at hospital > 3 months post hospital discharge
  + optional phone call after 6-12 months
• Follow-up targeted long-term patients only (> one week in ICU)

Model 2
Nurse-led follow-up without patient diary (Denmark)
• Follow-up at hospital 2-3 months post hospital discharge

Model 3
Multidisciplinary follow-up with patient diary (Sweden)
Variations
• Follow-up at hospital after discharge based on diary and hospital chart
• Follow-up at hospital after discharge based on validated instruments

Model 4
Multidisciplinary follow-up without patient diary (Denmark)
• Follow-up at hospital 2-3 months post hospital discharge
## Basic activities in Nordic follow-up programs before 2010

<table>
<thead>
<tr>
<th>Stage of trajectory</th>
<th>Time of intervention</th>
<th>Common elements in follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>During ICU stay</strong></td>
<td>In ICU</td>
<td>Patient diary written by nurses and in some cases family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehabilitative interventions: Minimal sedation, early mobilization, delirium prevention, reorientation, patient and family collaboration</td>
</tr>
<tr>
<td><strong>After ICU transfer</strong></td>
<td>At transfer</td>
<td>Transfer from ICU to ward, step-down, or other ICU</td>
</tr>
<tr>
<td></td>
<td>3-5 days post transfer</td>
<td>ICU-nurse visits patient on ward, follow-up initiated, consent for contact after discharge, assessment using ICU-Memory Tool</td>
</tr>
<tr>
<td><strong>After hospital discharge</strong></td>
<td>At discharge</td>
<td>Discharge from hospital to home or rehabilitation facility</td>
</tr>
<tr>
<td></td>
<td>1 month post discharge</td>
<td>Information material sent to patient</td>
</tr>
<tr>
<td></td>
<td>1-2 months post discharge</td>
<td>Invitation to follow-up visit</td>
</tr>
<tr>
<td></td>
<td>2-3 months post discharge</td>
<td>Follow-up visit (nurse-led or interdisciplinary), diary review, revisit ICU, patient tells story, family collaboration, patient assessment for anxiety and depression (HADS), posttraumatic stress (PTSS-14), self-assessed health (SF-36)</td>
</tr>
<tr>
<td></td>
<td>3, 6, 12 months post discharge</td>
<td>Additional follow-up, telephone contact, repeat SF-36</td>
</tr>
</tbody>
</table>
Guidelines for follow-up 2009

Quick reference guide

Issue date: March 2009

Rehabilitation after critical illness

ICU recovery
NHS Guidelines for follow-up

ICU recovery

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Trends in critical care after 2000

- Lighter sedation
- Analgo-sedation
- Sedation interruption
- More awake patients
- Delirium detection
- Role of family
Trends in critical care after 2010

- ICU survivorship
- Post-intensive care syndrome
- Post-intensive care syndrome – family
- Burdens of intensive care
Survivorship – an emerging major issue (Needham et al. 2011)

ICU survivorship
+ Aging population
+ Reduced ICU-mortality
= Growing number of ICU survivors
ICU Survivorship

High prevalence of short- and long-term sequelae impair survivors’ quality of life:
• Physical
• Cognitive
• Mental health
Post-Intensive Care Syndrome (PICS) (Davidson et al. 2013)

This model shows the physical, cognitive, and mental-health problems affecting quality of life in patients with post-intensive care syndrome (PICS). It was developed in 2010 by the Long-Term Consequences Task Force of the Society of Critical Care Medicine (SCCM).

ASR = Acute stress reaction
PTSD = Posttraumatic stress disorder
PTSS = Posttraumatic stress symptoms
Burdens of survivorship – (Iwashyna & Netzer 2012)
Distinguishing Impairment, Limitations, Restrictions, and Quality of Life

- Baseline (pre ICU)
- Acute illness (ICU)
- Tissue and pathology impairment
- Activity limitations
- Participation restrictions & disability
- Quality of Life
Burdens of survivorship – (Iwashyna & Netzer 2012)
Social environment and psychological makeup

- Baseline status
- Acute illness
- Psychological effects
- Self-efficacy, depression
- Role definitions
- Adaptation
- Expectations
- Resilience
Tentative recommendations for improving long-term outcomes
(Iwashyna & Netzer 2012)

- Provide high-quality acute intensive care
- Involve rehabilitation experts as early as possible
- Consider structured assessment of limitations
- Mobilize the patient’s social resources
- Arrange close follow-up
- Learn from PRaCTIcal (Cuthbertson et al. 2009)
- Get feedback from patients on long-term outcomes
Review of ICU Follow-Up Clinics (Nebraska, USA)

Reviews

The ICU Follow-Up Clinic: A New Paradigm for Intensivists

Ariel M Modrykamien MD

Introduction
Long-Term Outcomes Post-ICU Admission
Quality of Life
Lung Function
Psychological Outcomes and Cognition
Nutrition
Polypharmacy
Complications in Family Members of ICU Survivors
Healthcare Utilization and Costs Post-ICU Discharge
ICU Follow-Up Clinic
The ICU Follow-Up Clinic Model
Physical and Psychiatric Evaluation
Cognition-Based Interventions
Airway and Pulmonary Evaluation
Medication Reconciliation Form
Palliative Care and Social Worker Assessment
Limitations in Delivery of Post-ICU Care
Summary

Respiratory Care • May 2012 Vol 57 No 5
Long-term outcomes

- Quality of life
- Lung function
- Psychological outcomes and cognition
- Nutrition
- Polypharmacy
- Complications in family members
- Healthcare utilization and costs post ICU-discharge
ICU Follow-up clinic

- The ICU follow-up clinic model
- Physical and psychiatric evaluation
- Cognition-based interventions
- Airway and pulmonary evaluation
- Medication reconciliation form
- Palliative care and social worker assessment
- Limitations in delivery of post-ICU care
ICU Follow-up clinic

The ICU follow-up clinic model

- There is no one accepted model for the delivery of ICU follow-up clinics.
- Led by a nurse or doctor, or a combination of both.
  - E.g. 4 hours/week for patients who received 48 hours of mechanical ventilation
  - QOL, Montreal Cognitive Assessment tool, pulmonary function, 6-minute walk test, medication reconciliation, weight assessment.
ICU Follow-up clinic

• The ICU follow-up clinic

• The Challenge: Lack of supporting evidence showing its effectiveness
Critical Care Recovery Center (Indianapolis, USA)

738: Critical Care Recovery Center- An Innovative Collaborative Care Model for ICU Survivors
Khan, Babar

Abstract

Introduction: 5 million Americans require admission to ICU annually due to life-threatening illnesses. Advances in critical care medicine have led to an increase in patients surviving critical illness, with resultant cognitive, physical and psychological morbidity that impact their quality of life.

Hypothesis: Implementing a critical care recovery center (CCRC) to maximize the cognitive, physical, and psychological recovery of ICU survivors, utilizing interdisciplinary team of a social worker, nurse, critical care physician, and psychometician is feasible.

Methods: CCRC was initiated using principles of implementation science and by treating

Critical Care Medicine:
December 2012
doi: 10.1097/01.ccm.0000424953.04580.3e
Poster: ABSTRACT Only
• CCRC is a new program that will assist with your recovery after being in an intensive care unit.
• You may have problems physically, emotionally and/or cognitively (thinking/memory).
• The CCRC can assist you and your family with all of your recovery needs in one place.
• Patients must be 18 years or older, and typical treatment with CCRC lasts six to twelve months.
• The program is designed to supplement, not replace, treatment from patients’ primary care physician.
• The CCRC team consists of a pulmonary/critical care specialist, nurse practitioner, social worker and medical assistant to ensure that all patients’ needs are met.
Long-Term Cognitive Impairment after Critical Illness (Vanderbilt, USA)

Survivors of critical illness often have a prolonged and disabling form of cognitive impairment that remains inadequately characterized.

Patients in medical and surgical ICUs are at high risk for long-term cognitive impairment. A longer duration of delirium in the hospital was associated with worse global cognition and executive function scores at 3 and 12 months.

(Pandharipande 2013 BRAIN-ICU Study)
What next?

- International collaborative studies and trials (Christina Jones)
- Workshops 😊 (Carl Bäckman)
- Interdisciplinary practice
- Patient and family involvement
- Drop-in programs (Peter Gibb)
- International website (Peter Nydahl)
- New ideas?
Thank you