ICU DIARY:
Facilitating the ICU Patient’s Transition from the ICU
SYMPOSIUM PRESENTERS

• Ingrid Engenie Egerod Ph.D MSN RN  (Denmark)

• Christina Jones Ph.D RN  (England)

• Judy J Martin MSN RN  (Texas)
LEARNING OBJECTIVES 1

• The learner will be able to verbalize and understanding of the constructs of the ICU Diary:

• Written Entries

• Photographs
LEARNING OBJECT 2

• The learner will be able to verbalize an understanding of the constructs of post intensive care syndrome:
  • Gap in Memory
  • Post-Traumatic Stress Disorder
THREE KEY WORDS

• ICU Diary

• Delusional Memories

• Post Traumatic Distress Syndrome
THE EMERGENCY AND EVOLUTION OF THE INTENSIVE CARE PATIENT DIARY

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INTRODUCTION

In the 1980s nursing in the Nordic countries was influenced by Nurse-patient partnership and equality
Nurse-patient written dialogues

In the 1990s ICU diaries were inspired by written nurse-patient dialogues to promote a patient-driven approach to caring
INTRODUCTION (CON’T)

• ICU nurses in the Nordic countries of Denmark, Norway and Sweden have provided ICU patient diaries (with patient photos) and ICU follow-up since the early 1990s

• It started as a grass-roots initiative, but has become more systematic and more generally accepted

• ICU diaries were written by nurses (or family) to help patients come to terms with their illness.
DIARY AND PICTURES
PATIENT PERSPECTIVE

“When I still linger on my stay in ICU and all my treatment, it’s because these weeks had a huge impact on my life after the accident. I’ve had an incredible need to know what happened while I was there”.

(Anne Meiniche, patient, 2000)
THEORY

• Constructing a narrative of experience is a fundamental human task

• Integrative narratives of self reconstruct the past and anticipate the future, providing life with identity, meaning, and coherence

(Ref: McAdams, et al., 2004)
PURPOSE

The aim of the study was to describe and compare the emergence and evolution of ICU diaries in Denmark, Norway, and Sweden.

Research Team: Ingrid Egerod (Denmark), Sissel Lisa Storli (Norway) and Eva Åkerman (Sweden)
METHODS

Comparative international design using secondary analysis of qualitative data generated by key-informant telephone interviews with intensive care nurses in Denmark, Norway, and Sweden (n=114)
RESULTS

Scientific position in Denmark
Empathetic writing inspired by Buber’s existential philosophy of dialogue; distinction between ‘I-you’ and ‘I-it’ relationship

Diaries written in second person to the patient; the hospital chart is written about the patient

Personhood is maintained while the patient is unable to speak or act voluntarily; the nurse bears witness
RESULTS (CON’T)

Scientific position in Norway

Inspired by Merleau-Ponty’s phenomenology of perception; as positivism fails to describe human subjectivity

Interpreting bodily experience; “being somewhere else”

Nurses include information on surroundings and sensory input; e.g. description of sound and light
RESULTS (CON’T)

Scientific position in Sweden

Inspired by Cullberg’s theory of traumatic crisis; the diary promotes the process of healing

Realistic writing and photographs of the patient; observing the patient’s dignity

Debriefing; confrontation with reality and re-orientation
CONCLUSION

ICU diaries have:

• Evolved from different scientific positions and understandings of nursing care.

• The potential to fulfill the existential needs of patients (and their close relatives) as they struggle to make sense of their experiences and construct their illness narrative.
THANK YOU!
ICU DIARIES REDUCE POST TRAUMATIC STRESS DISORDER AFTER CRITICAL ILLNESS IN PATIENTS AND FAMILY MEMBERS

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Retired Nurse Consultant Critical Care Rehabilitation and Honorary Reader, Whiston Hospital, Prescot & University of Liverpool, United Kingdom
ICU DIARIES

• Idea originated in Scandinavia
  – Nursing intervention
  – Daily account of ICU stay in every day language
  – Photographs - start and points of change
    – Fill in memory gaps and
    – Help patients understand their illness

(Bäckman & Walter, 2001)
(Bäckman & Jones, 2011)
PRESENTED TO PATIENT

– Given after their discharge from ICU

– Time of Patients choosing

– With staff support to go through the diary and photos
RELATIVES’ ENTRIES

• Relatives encouraged to contribute to the diary

• Information sheet for family members
  – Their visits to ICU
  – Family milestones
  – Patients interests
  – Private communications
PHOTOGRAPHS

• Close enough to see the patients face

• Retrospective consent

(Backman & Jones, 2011)
PSYCHOLOGICAL PROBLEMS
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<tr>
<th>Study</th>
<th>Subgroup</th>
<th>N</th>
<th>Anxiety</th>
<th>Depression</th>
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<td>-</td>
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<td>Koshy et al Intens Care Med 1997;23(S1):S160</td>
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<td>Schelling et al Crit Care Med 1998;26:651-659</td>
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<td>-</td>
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<td>3-15%*</td>
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<td>Girard et al Critical Care 2007 11:R28</td>
<td>-</td>
<td>43</td>
<td>14%</td>
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IMPORTANCE OF MEMORY FOR ICU
ADVERSE/STRESSFUL MEMORIES

• Retrospective (10yr) of patient experiences after ARDS

• 27% incidence of PTSD

• Patients recall of adverse experiences
  Nightmares (64%), Anxiety (42%), Pain (40%), Respiratory Distress (38%), None in (21%)  
  (Schelling et al., 1998)

• Depth of sedation (MAAS)
  • Lighter sedation
  • Deeper sedation - longer ICU stay recall of nightmares  
  (Samuelson., et al., 2007)
PTSD RELATED SYMPTOMS & ICU MEMORIES

30 ICU patients recall tested at 2 weeks & IES at 8 weeks post ICU

Impact of Events Scale at 8 weeks

IES > 19

Delusions but No recall of ICU

Delusions but can recall ICU

No delusions

P=0.001

IES > 19

(Ref Jones, Griffiths, Humphris, & Skirrow, 2001)
DELUSIONAL MEMORIES

• Large study (> 200) at 6 – 18 months post ICU
  – 26% delusional memories
  – younger patients and to be bothered by them
  – More common ≥ 3 days ICU stay & temperature ≥ 38°C
  – more likely not to have returned to work at 1 year

  (Ref: Ringdal, et al., 2006)

• Large study (464 patients) - 6 months post ICU
  – 93% described ICU as friendly and calm
  – Unpleasant experiences, suction, nasogastric tube, family and pain
  – 51% recalled nightmares with 14% memories disturbed daily life
  – Worse health related quality of life

  (Ref: Granja C et al., 2005)
RACHEL I PROJECT (2002-2005)

• Aims of study
  – Ratio of patients suffering from PTSD.
  – Detailed description of patients’ stay in ICU

• To investigate
  – Psychological outcome of patients after ICU, the ICU environment and patient care practice, e.g. sedation or physical restraint
  – To examine the psychological outcome where patient receives an ICU diary
RACHEL I

• PTSD associated with:-
  – Physical restraint (23% of restrained patients)
  – Deep sedation/large sedative doses
  – Recall of delusional memories for ICU associated previous psychological problems

(Ref: Jones et al., 2007)

• 3 study centres using diaries
  • 108 -- 3 month follow-up
  • 42 received an ICU diary
  • Lower levels of PTSD-related symptoms in diary group

(Ref: Jones et al., 2006)
RACHEL II DIARY STUDY

- To examine the impact of a diary on development of PTSD
- Randomised controlled trial
- Study units
  10 Hospitals:
  UK, Italy, Norway, Sweden, Portugal, Denmark
EXPERIMENTAL PLAN

• One month post ICU discharge
  – Level of symptoms of PTSD – PTSS-14
  – Randomised
  – Intervention group choose when they wanted their diary
  – Control group given their diaries at the 3 month follow-up appointment after they have completed questionnaires

• Three months post ICU discharge
  – Clinic appointment or telephoned

(Ref: Twigg et al., 2008)
(Ref: Foa EB et al., 1997)
RESULTS

• Fewer intervention patients vs. controls,
  • were diagnosed as having new onset PTSD at 3 months

  –8/162 (5%) versus 21/160 (13.1%) (p = 0.02)

(Ref: Jones C et al., 2010)
CHANGE IN PTSS-14 SCORES BETWEEN 1 AND 3 MONTHS

* p = 0.04
RELATIVE STUDY ARM

• Pilot study 2 out of 12 study centres

• Follow-up study patients’ closest relative
  – One month post ICU discharge level of symptoms of PTSD using the PTSS-14
  – Three months post ICU discharge relatives asked to complete follow-up PTSS-14

• 30 relatives completed 3 month follow-up
REDUCED PTSD-RELATED SYMPTOMS

Figure 1 PTSS-14 scores at 1 and 3 months by study group

* Mann Whitney U p = 0.03

(Ref: Jones et al., 2012)
IMPACT OF DIARIES

• Small RCT (n=36) showed reduction in those receiving ICU diary
  – Decrease in anxiety (p < 0.05)
  – Decrease in depression (p = 0.005)

(Ref: Knowles & Tarrier, 2009)
ICU DIARIES: THE JOURNEY TO PSYCHOLOGICAL RECOVERY FOR CRITICALLY ILL PATIENT’S FAMILY MEMBERS

Dr Carl Gosta Backman presented by Dr Christina Jones, PhD MPhil, MBACP, Bsc RN, Retired Nurse Consultant Critical Care Rehabilitation and Honorary Reader, Whiston Hospital, Prescot & University of Liverpool, United Kingdom
SHORT TERM IMPACT OF ICU ON FAMILY

• At admission to ICU
  – 97% high levels of anxiety and depression
  – 81% posttraumatic stress symptoms

• At discharge
  – 87% high levels of depression
  – 59% fulfilled posttraumatic stress reaction
  – Women had higher levels of distress & more persisting symptoms than men

(Paparrigopoulos et al., 2006)
IMPACT OF CRITICAL ILLNESS ON FAMILIES

• Post-traumatic stress symptoms moderate-major risk 33.1% family members
  – 48.4% family members felt information was incomplete
  – 47.8% sharing in decision making
  – 50% patient died in the ICU
  – 60% patient died after end-of-life decisions
  – 81.8 family shared in end-of-life decisions

(Azoulay et al., 2005)
IMPACT (CON’T)

• High PTSD-related symptoms associated

  – increased rates of anxiety and depression
  – decreased quality of life
IMPORTANCE OF COMMUNICATION

• Communication appears to influence relatives’ perceptions of whether their needs are met

• An ICU diary – sharing of information

(Ref: Rattray, 2008)
ICU DIARIES

• Family can contribute to the ICU diary
  – Patients’ illness
  – What is happening at home
  – Write about their own feelings
  – Be included in the photographs of patient

(Ref: Bäckman & Walter, 2001)
(Ref: Bäckman & Jones, 2011)
STAGES OF DIARY NARRATIVE WITHOUT FAMILY INVOLVEMENT

<table>
<thead>
<tr>
<th>Stages of narrative</th>
<th>Parallel plots</th>
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<tbody>
<tr>
<td></td>
<td>Nurse's storyline</td>
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<tr>
<td>Crisis</td>
<td>Active, focus on technology</td>
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<tr>
<td>Turning Point</td>
<td>Shifting focus to caring interventions</td>
</tr>
<tr>
<td>Normalization</td>
<td>Converging plots</td>
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</tbody>
</table>

(Igerod & Christensen, 2009)
CONTENT ANALYSIS OF JOINT DIARIES

• 8 diaries written by staff and family

• Sharing throughout the ICU time identified as major category

• diaries reflect the commitment and care of contributors to the patients' welfare

(Ref: Roulin et al., 2007)
4 themes identified – Sharing:

- Story – narrative of daily events
- Presence of health professionals and family members and Presence of the patient as a person
- Feelings through the writing
- Support offered to the patient

(Ref: Roulin et al., 2007)
DIARY FOLLOW-UP VISIT

• Patient and next of kin
  – ~ 10 weeks after discharge from the ICU

• Photos pasted into the diary
  detailed explanation of what is happening in them

  – Diary used as an aid when talking about the critical illness
  – Diary text and photographs thoroughly explained

• Patients and relatives found it helpful

(Ref: Backman PhD thesis Linköping University Medical Dissertations No. 1259)
WRITTEN REHABILITATION INFORMATION

• ICU recovery manual
  – 6 week rehab programme
  – 6 months follow-up – patients & family members
  – 49% high PTSD-related symptom levels in next of kin
  – No difference in levels of anxiety, depression or PTSD in intervention or controls

(Ref: Jones, et al., 2004)
Psychological distress in patients correlated with high levels in relatives
EFFECT OF DIARIES ON PTSD SYMPTOMS

• Pilot study RCT 30 relatives
  – Relatives where patient received diary lower levels of PTSD symptoms at 3 months

(Ref: Jones et al., 2012)

• Before and after study including 143 relatives
  – Lower PTSD symptoms at 12 months
  – No patient photographs
  – Handed to patient at hospital discharge without staff discussion of contents

(Ref: Garrouste-Orgeas et al., 2012)
EFECT OF DIARY FOR FAMILIES

• Explanations for effect of diaries on PTSD-related symptoms
  – Reduces need for patients to ask family to fill in gaps in their memory
  – Forms the basis for family conversations about ICU illness
  – Clarifies for the family what happened on the ICU

(Ref: Jones, C., et al., 2010)
 EFFECT ON FAMILY (CON’T)

– Allows relatives to express their feelings while the patient is in the ICU

(Ref: Jones, C., et al., 2010)
• Informal support group for patients and families
• Meet over coffee and biscuits away from hospital
  – Patients and families often bring their diaries to the support group meeting
  – Share them with other patients and relative
  – Give a feeling of togetherness
IMPACT ON BEREAVED RELATIVES

• Small study to investigate:

“Was the diary important to relatives following patients' deaths in the ICU?”

(Ref: Bergbom, et al., 1999)
IMPACT – (CON’T)

• All the relatives except one said the diary:

1. helped them to return and adjust to everyday life
2. made it easier to accept what had happened
3. help them to understand the seriousness of the patient's injury or disease

(Ref: Bergbom, et al., 1999)
BEREAVED RELATIVES

Quotes from relatives:

“During the time following my friend’s departure I used to carry the diary with me everywhere. Whenever I wondered about something I had something concrete to refer to. He was very proud of his diary and used to talk a lot about it.”

(Ref: Backman PhD thesis Linköping University Medical Dissertations No. 1259)
It is obvious to me that a diary like this should be a routine part of Intensive Care.”

“It felt good to be able to express in words the feelings of loss and sadness, thoughts that passed my mind, things I wanted to tell Dad. It was also important for us close relatives to read about Dad’s daily life on Intensive Care and to read how you, the staff helped him when we were not there.”

(Ref: Backman PhD thesis Linköping University Medical Dissertations No. 1259)
ICU DIARY: MIND THE GAP

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Intensive Care Unit
Texas Health Harris Methodist HEB Hospital
Bedford, Texas
• What intervention can be put into place to facilitate the ICU patient’s transition from the ICU?
METHODS

• Evidence-Based Practice Pilot Project

• IOWA Model of EBP

• Critically-ill Patients (n = 6)

• ICU Diary

• Photographs
What our diary looked like.
RESULTS

- 4 Patients Completed the Pilot Project
- 2 Patients withdrawn
- 4 Diaries Delivered
- Pictures Reviewed and Included
OBSERVATIONS

• Family Members Appeared Calmer

• Improved Communication

• Positive Reaction at the Point of Delivery

• Physicians Supported Project

• Difficulty Concentrating / Reading
Brain Hijack

Irritating Stimulant

Fight or Flight Solution

Physical Response: Body & Mind

Acute Stress

Reduced Circulation & Blood Flow

Brain Electric & Chemical Response

WWW.EIQ-2.COM
CONCLUSION

• The Results of the EBP suggest Patients want the ICU Diary and Photographs

• The Results of the EBP Pilot Project suggest the Diary and Pictures Addresses Psychosocial Needs of the ICU Patient

• Cost Effective Therapeutic Tool
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QUESTIONS

• Further information
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