



ICU DIARY:

Facilitating the ICU
Patient's Transition from the
ICU



SYMPOSIUM PRESENTERS

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- Christina Jones Ph.D RN (England)
- Judy J Martin MSN RN (Texas)

LEARNING OBJECTS 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)

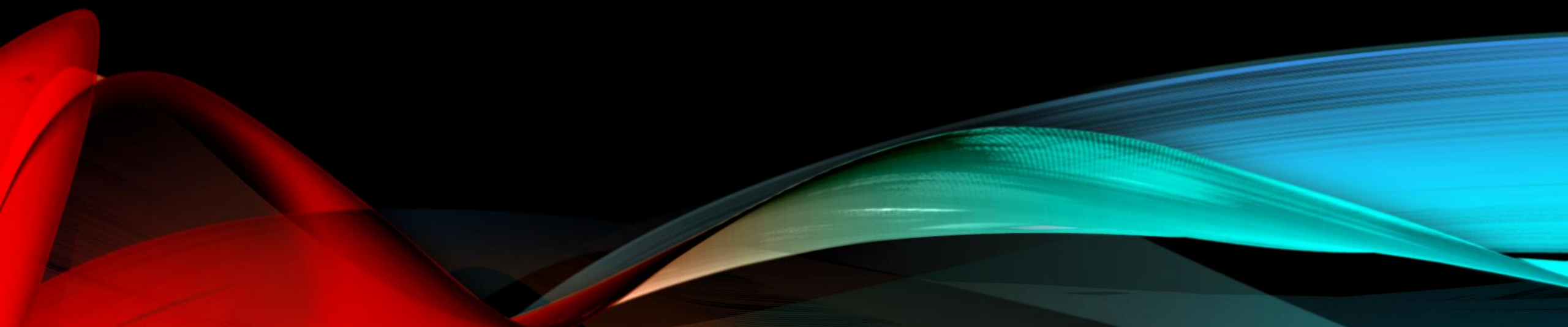
PURPOSE

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

ICU-DIARY.ORG

[START](#) [DIARY](#) [SUPPORT](#) [NEWS](#) [MAP](#) [LITERATURE](#) [LINKS](#) [ABOUT US](#)

The ICU diary is a diary that is written for ICU patients during their time of sedation and ventilation. It is written by relatives, nurses and others. The patient can read his or her diary afterwards and is more able to understand what has happened.

ICU-Diary


The website icu-diary.org is the base of an informal network for all health care workers that are interested in the ICU diary. We offer literature, descriptions and help for implementation. We try to coordinate informations, projects and new studies. And we try to connect people.

The network is founded by Eva Akerman, Carl Bäckman, Ingrid Egerod, Christina Jones, Dirk Knüick, Peter Nydahl and Sissel Storli. There are no financial or commercial conflicts or interests.

If you would like to join the network or just receive the newsletter, please mail to info@icu-diary.org

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THANK YOU!



ICU DIARIES REDUCE POST TRAUMATIC
STRESS DISORDER AFTER CRITICAL
ILLNESS IN PATIENTS AND FAMILY
MEMBERS

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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)



Patient is in recovery; wife visits him (note the paintings done by grandchild on the walls).



Patient returns for follow-up visit.

Photos Courtesy of Patient Björn Roback; ICU stay 49 days



PSYCHOLOGICAL PROBLEMS

STUDIES - PSYCHOLOGICAL RECOVERY

| Study | Subgroup | N | Anxiety | Depression | PTSD |
|--|----------|-----------------|---------|------------|--------|
| Jones et al Brit J Inten Care 1994;2:46-53 | - | 28 | 55.5% | - | - |
| Koshy et al Intens Care Med 1997;23(S1):S160 | - | 50 | - | - | 15% |
| Schelling et al Crit Care Med 1998;26:651-659 | ARDS | 80 | - | - | 27.5% |
| Nelson et al Crit Care Med 2000;28(11):3626-3630 | ARDS | 24 | 43.5% | - | 25% |
| Schnyder et al Am J Psych 2001;158:594-599 | Trauma | 106 | - | - | 14% |
| Scragg et al <i>Anaesth</i> 2001;56:9-14 | - | 80 | 47% | 47% | 15% |
| Jones et al Crit Care Med 2001;29(3):573-580 | - | 126 | 34% | 25% | 51% |
| Cuthbertson et al Intens Care Med 2004;30:2004-2008 | - | 78 | - | - | 5-15% |
| Hopkins et al 2005Am J Resp Crit Care Med 2005;171:340-347 | ARDS | 62 | 24% | 16% | |
| Jones et al Intens Care Med 2007 DOI 10.1007/s00134-007-0600-8 | - | 231 (5 ICUs) | - | - | 3-15%* |
| Girard et al Critical Care 2007 11:R28 | - | 43 | | | 14% |



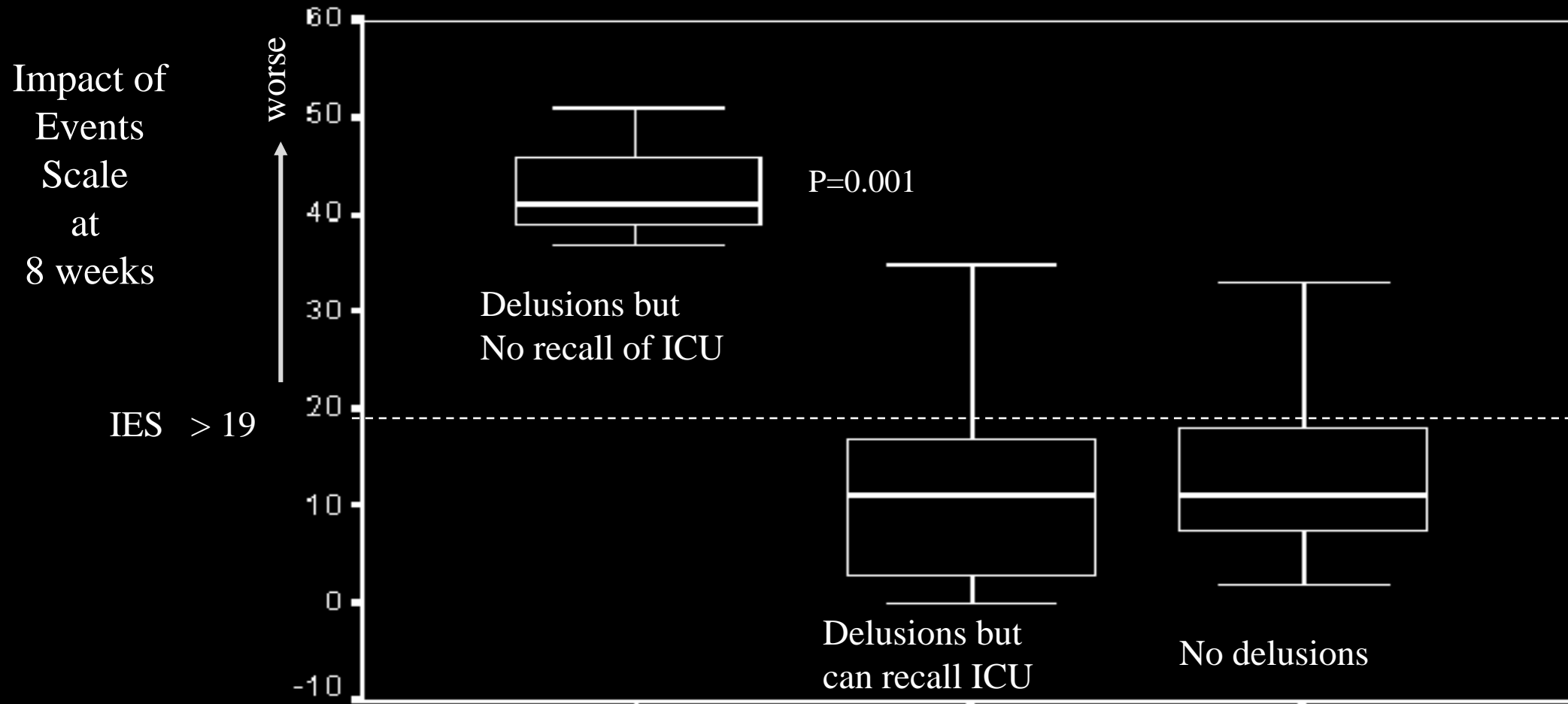
IMPORTANCE OF MEMORY FOR ICU

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



(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 $\geq 38^{\circ}\text{C}$
 - 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)

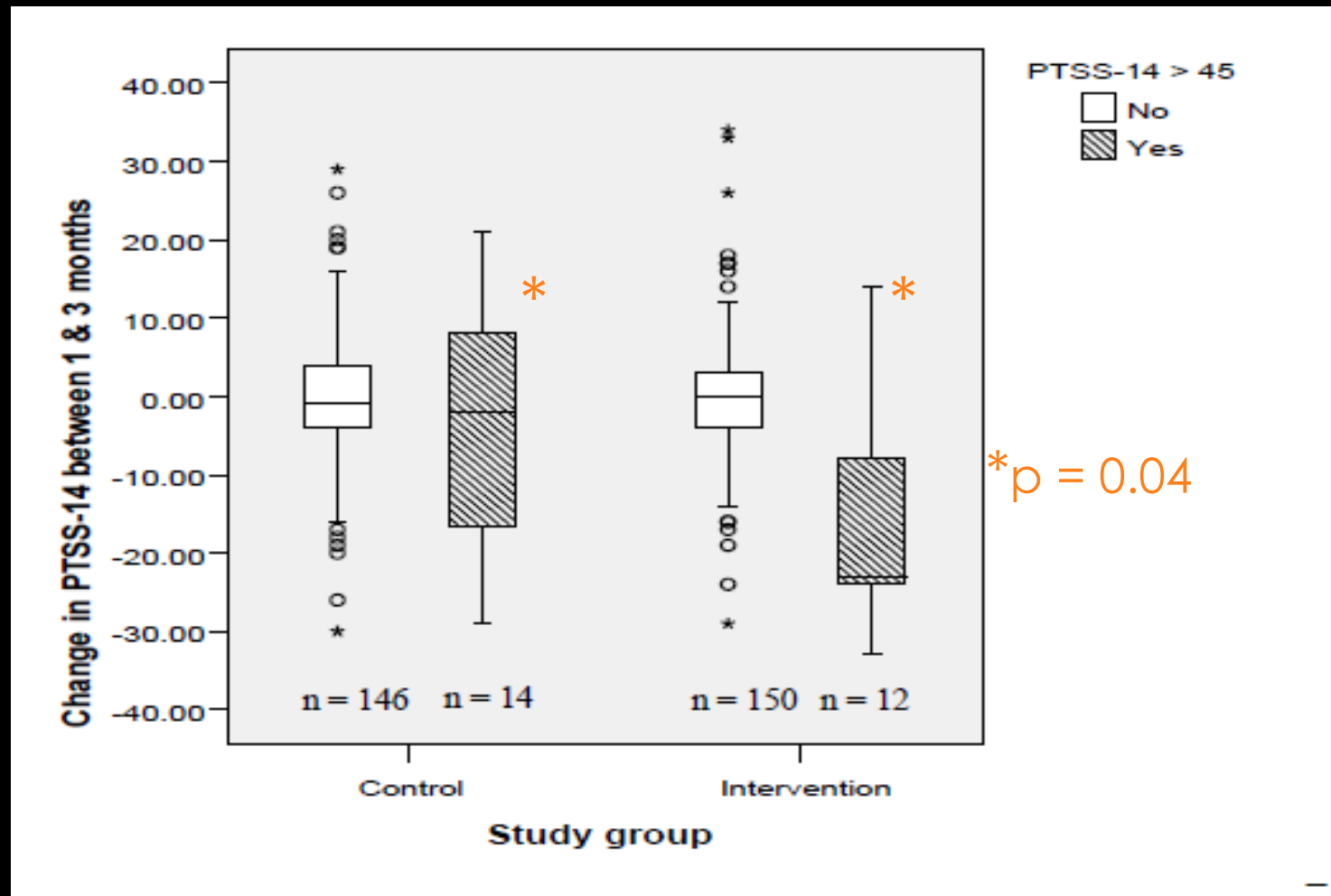
(Ref: Foa EB et al., 1997)

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)

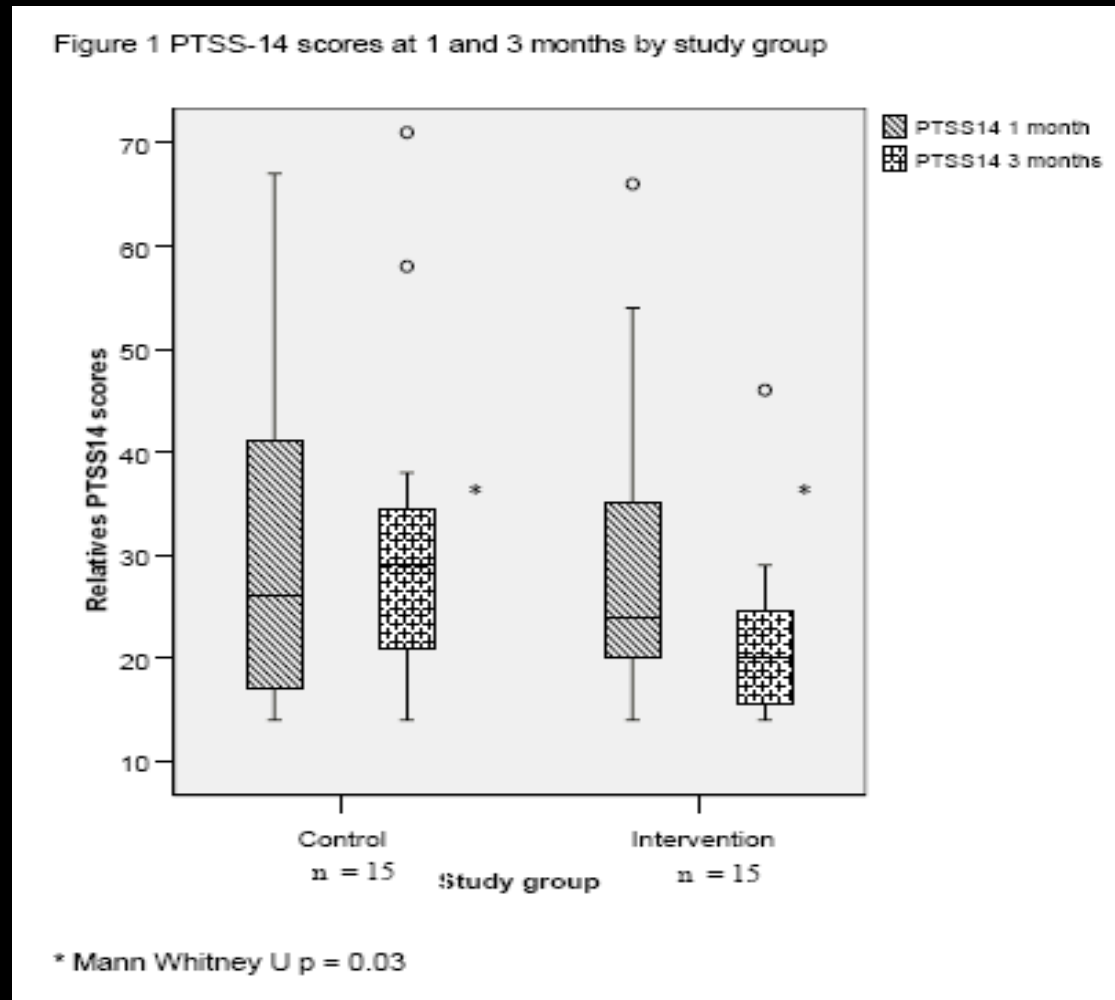
CHANGE IN PTSS-14 SCORES BETWEEN 1 AND 3 MONTHS



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



(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 ($p = 0.005$)



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

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

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

| Stages of narrative | Parallel plots | | |
|---------------------|---|--------------------------|--------------------------------|
| | Nurse's storyline | Patient's storyline | Family's storyline |
| Crisis | Active, focus on technology | Passive, depersonalized | Spectator, worried |
| Turning Point | Shifting focus to caring interventions | Emerging, repersonalized | Engaging, relief and gratitude |
| Normalization | Converging plots | | |
| | Relating, participating, connecting, letting go | | |

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)

CONTENT (CON'T)

- 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

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

WRITTEN (CON'T)

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)

EFFECT 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)

BEREAVED (CON'T)

“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

PICO QUESTION

- 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

ICU DIARY

What our diary looked Like.



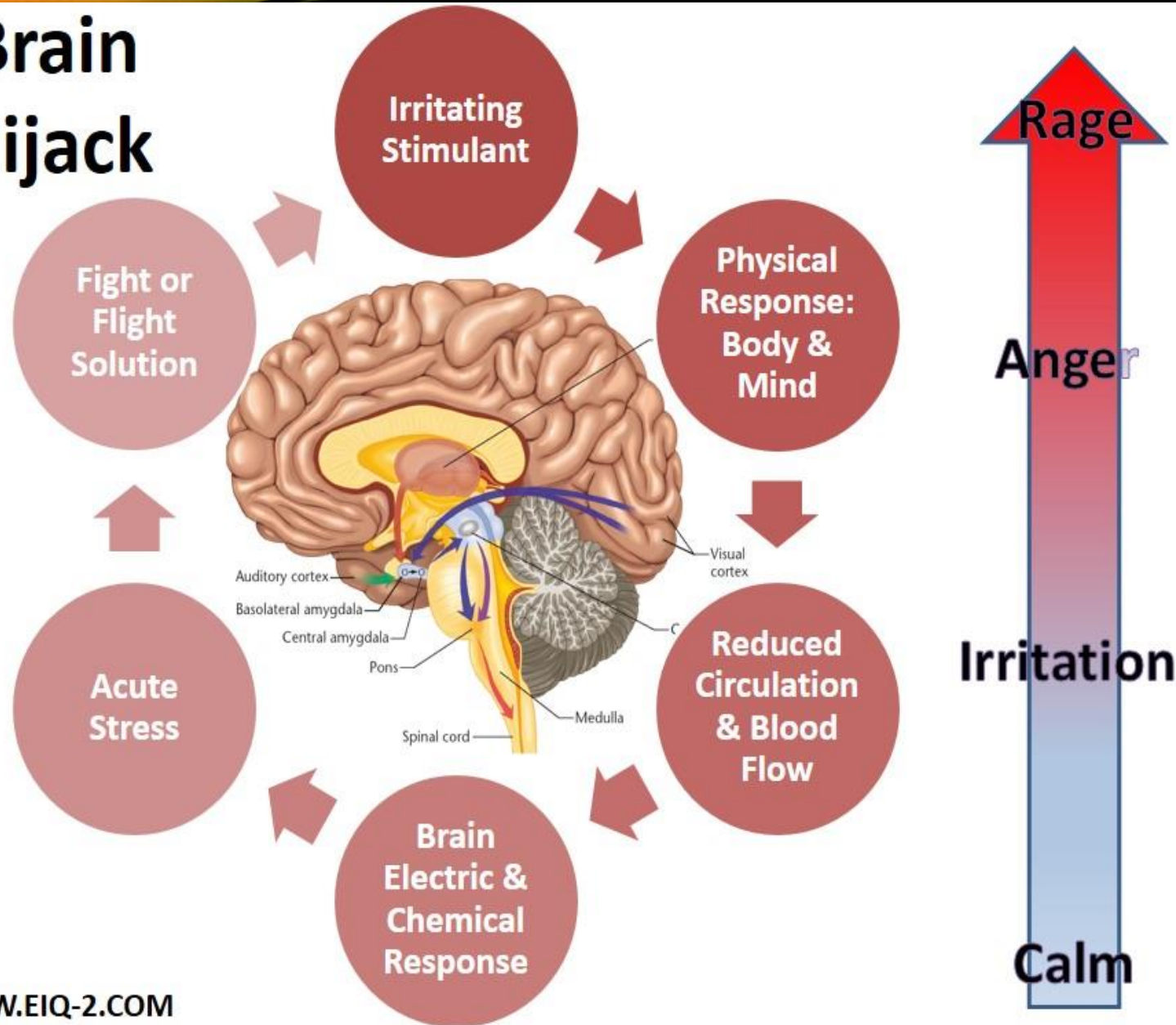
RESULTS

- 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



CEREBEL CORTEX



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

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