ICU diaries reduce post traumatic stress disorder after critical illness

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How we do diaries at Whiston
ICU Diaries

• Idea originated in Scandinavia
  – Nursing intervention
  – Daily account of ICU stay in every day language
  – Photograph of patient taken at start and points of change
    » Aim to fill in memory gaps and help patients understand their illness
  – Given to the patient after their discharge from ICU
    » At a time of the patients choosing
    » With staff support to go through the diary and photos

Key requirements for starting

• Legal Team /Caldicott Guardian approval
• Diary notebooks
• Polaroid camera or digital camera with printer
  - Memory card wiped after printing
• Diary register
  - Enable tracking of which patients have a diary and where the diary currently is located
• Secure, lockable storage
  - Storage of diaries between patient discharge and follow-up
• Diary guidelines at every bed space
• Diary champions
Relatives’ entries

• Relatives encouraged to contribute to the diary

• Information sheet given to families
  – Events from home
  – Their visits to ICU
  – Family milestones
  – Information on patients interests (e.g. sport, current affairs etc)
  – Private communications can be included
Diaries across Scandinavia

• **Survey of Norwegian ICUs**
  - 31 out of 70 ICUs offered diaries
    » Most had some kind of guideline for diaries
    » Highest activity in those units with a follow-up programme
    Gjengedal et al. An act of caring – patient diaries in Norwegian intensive care units
    Nursing in Critical Care 2010;15(4):176-184

• **National survey of Swedish ICUs**
  - Of 85 ICUs 65 (75%) offered diaries
    » “To give time back to the patient”
    » “help the patient remember”
    » “individual care”

• **Survey of Danish ICUs**
  - 19 out of 48 ICUs offered diaries
    » Lead in an initiative to develop National Clinical Guidelines for diaries
    » Called for more randomised controlled trials
    Egerod I et al. Nursing in Critical Care 2007;12(3):159-167
Psychological problems
Psychological recovery

• Anxiety
  - 25 - 30% of patients attending ICU outpatient clinic
  - seemed to be related to hallucinations and paranoid delusions.

• Panic attacks, agoraphobia
  - panic on going out alone, crowded places e.g. shops.
  - don’t want to be alone in case they are taken ill again

• Post traumatic stress disorder (PTSD)
  - 15 - 30% of patients
    Koshy G et al. Intensive Care Medicine 1997; 23(S1):S160
    Schelling G et al. Critical Care Medicine 1998; 26:651-659
    Jones C et al Critical Care Medicine 2001; 29:573-580
Post Traumatic Stress Disorder

• DSM IV-R American Psychiatric Association
  – Exposure to a traumatic event/s in which the individual experienced/witnessed or was confronted with event/s involving actual or threatened death/serious injury or threat to the physical integrity of self/others AND responded with intense fear, helplessness or horror
  – 3 symptom groups
    » Intrusion (nightmares, flashbacks)
    » Avoidance (avoiding reminders)
    » Hyperarousal (not sleeping)
  – Symptoms are experienced for more than one month
  – Clinically significant distress/impairment in social, occupational or other areas of functioning
Studies - psychological recovery

<table>
<thead>
<tr>
<th>Study</th>
<th>Subgroup</th>
<th>N</th>
<th>Anxiety</th>
<th>Depression</th>
<th>PTSD</th>
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<td>28</td>
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<td>Schelling et al Crit Care Med 1998;26:651-659</td>
<td>ARDS</td>
<td>80</td>
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<td>Nelson et al Crit Care Med 2000;28(11):3626-3630</td>
<td>ARDS</td>
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<td>Schnyder et al Am J Psych 2001;158:594-599</td>
<td>Trauma</td>
<td>106</td>
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<td>Scragg et al <em>Anaesth</em> 2001;56:9-14</td>
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<td>51%</td>
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<td>Cuthbertson et al Intens Care Med 2004;30:2004-2008</td>
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<td>-</td>
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<td>Jones et al Intens Care Med 2007 DOI 10.1007/s00134-007-0600-8</td>
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<td>-</td>
<td>3-15%*</td>
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<td>Girard et al Critical Care 2007 11:R28</td>
<td>-</td>
<td>43</td>
<td></td>
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</table>
Returning to work 1-2 years

- **Mixed medical/surgical ICU**
  - 62.2% returned to work by 18 months
  Garcia et al Intensive Care Medicine 2003;29(8):1286-1293

- **Adult Respiratory Distress Syndrome patients**
  - 45% returned to work by 1 year
  - 85% had survived to 2 years
  - 65% returned to work despite no change in pulmonary function measures
    » Most to their original job
  - Reasons for not working were:-
    » depression, post traumatic stress disorder, muscle weakness, fatigue, short-term memory loss, orthopaedic disability
  Cheung et al Am J of Respiratory and Critical Care Med 2006;174:538-544
PTSD – effect on work

- Multi-centred study in 5 centres around Europe
  - Average rate of acute PTSD was 9.2%, range 3.2%-14.8%
    - 22 patients out of 238 followed up at 3 month
    - 7 patients already had undiagnosed PTSD at ICU admission
  - 96 patients had sub-clinical PTSD
    - 90 (39%) had levels of distress that affected their everyday functioning
  - 42 (18%) patients were either unable to work or had difficulty because of their symptoms

Long term impact of PTSD

• 23 year old man RTA with fat embolus
  - 10 day stay on ICU
  - Unable to work for 12 years
    » Undiagnosed PTSD (labelled anxious)
    » Panic attacks going out
    » Unable to be alone so wife could not work
    » Co-morbid severe depression
    » Drinking heavily to self-medicate
    » Chronic pain and illness anxiety
Impact of PTSD treatment

• Referred for psychotherapy
  - due to refusal of surgery
  - 18 months intensive therapy
    » Stopped drinking
    » Panic attacks under control
    » Able to say “it’s in the past”
    » Wife able to go out to work
    » Health anxiety reduced
    » Doing voluntary job mentoring teenagers in the probation service
    » Found job working in alcohol services
    » Decided not to have surgery
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 Crit Care Med 1998; 26: 651-659

• Depth of sedation (MAAS)
  – Lighter sedation
    » More likely to remember intubation and find this bothersome
  – Deeper sedation & longer ICU stay
    » Bothered by recall of nightmares
  Samuelson KA et al Nursing in Critical Care 2007;12(2):93-104
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

Delusional memories

• Large study (> 200) at 6 – 18 months post ICU
  - 26% recalled delusional memories
    » More likely for 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

Ringdal M et al Intensive and Critical Care Nursing 2006;22(6):346-354

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

Delusional memories in children

• 102 children aged 7-17 years
  – 32% recalled delusional memories
    » Associated with longer duration of opiates & benzodiazepines
    » PTSD scores were higher

Colville G et al American Journal of Respiratory and Critical Care Medicine 2008;177:976-982
RACHEL I project (2002-2005)

• Aims of study
  – To determine the ratio of patients suffering from post traumatic stress disorder (PTSD).
  – To record a detailed description of patients’ stay in ICU
    » delirium, sedation depth, opiate and sedation doses, withdrawal symptoms
    » Memories for ICU
  – To investigate the relationship between:-
    » the 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
Factors associated with PTSD

_In ICU_

- Physical restraint (23% of restrained patients)
  - Combined with no sedation
- Deep sedation/large sedative doses
- Recall of delusional memories

_Patient factors_

- Recall of delusional memories for ICU
  - More common where history of previous psychological problems
    » Depression, anxiety, panic attacks, phobias
  - Deep sedation/large sedative doses
RACHEL I

- 3 study centres using diaries
  - 108 completing 3 month follow-up
  - 42 patients received an ICU diary

- Time of receiving diary
  » 1 week – 1 month post ICU discharge
  » Median 1 month

PTSD-related symptom levels

Mann-Whitney U p = 0.043

Mann-Whitney U p = 0.028

All patients from diary study centres

Patients recalling delusional memories
RACHEL II Diary study

• To examine the impact of a diary on development of PTSD
• Randomised controlled trial
• Study units
  - Whiston Hospital, UK
  - Ferrara University Hospital, Italy
  - Haukeland University Hospital, Bergen, Norway
  - Ullevål Hospital, Oslo, Norway
  - Vrinnevishuset, Norrköping, Sweden
  - Gotenburg, Sweden
  - Malmo, Sweden
  - Hospital Pedro Hispano, Matosinhos, Porto, Portugal
  - Hospital Geral de Santo António, Porto, Portugal
  - Hillerød, Copenhagen, Denmark coordinating three ICUs
    » Nordsjaelland, Odense, Skejby Hospitals
Experimental plan

• **One month post ICU discharge**
  - Level of symptoms of PTSD using the PTSS-14
  - Randomised to study group
  - **Intervention group**
    » allowed to 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**
  - Patients had clinic appointment or telephoned to complete follow-up PDS for diagnosis of PTSD
Recruitment

Total patients admitted ≥ 72 hrs stay
N = 1,164

Total consented 1 week
N = 357

Died
N = 309

Refused
N = 45

Excluded
N = 433

Randomised 1 month
N = 352

Withdrew prior to randomisation
N = 5

Controls
N = 175

Intervention
N = 377

Undiagnosed Pre-existing PTSD
N = 3

Undiagnosed Pre-existing PTSD
N = 8

Withdrawn following randomisation
N = 7

Withdrawn following randomisation
N = 4

Died
N = 5

Died
N = 3

Controls analysed
N = 160

Intervention analysed
N = 162
Results

• Fewer intervention patients, compared to controls, were diagnosed as having new onset PTSD at 3 months
  
  - 8/162 (5%) versus 21/160 (13.1%) (p = 0.02)

Jones C et al. Intensive Care diaries reduce new onset PTSD following critical illness: a randomised, controlled trial. Critical Care 2010 in press
Change in PTSS-14 scores between 1 and 3 months by study group and high scores

* $p = 0.04$
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)

Impact on relatives

• Small study to investigate whether a diary was important to relatives following patients' deaths in the ICU
  - All the relatives except one said the diary:-
    » helped them to return and adjust to everyday life
    » made it easier to accept what had happened
    » help them to understand the seriousness of the patient's injury or disease

Further information

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