The Use of Patient Diaries in Critical Care

St Helens and Knowsley Teaching Hospitals NHS Trust

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ICU Diaries

- Idea originated in Sweden
  - Nursing intervention
  - Daily account of ICU stay in every day language
  - Photograph of patient taken at start
    - » 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

Bäckman C, Walter SM. Intensive Care Medicine 2001;27:426-429

Key requirements for starting

- Legal Team /Caldicott Guardian approval
- Diary notebooks
- Polaroid camera or digital camera with printer
- 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 champion

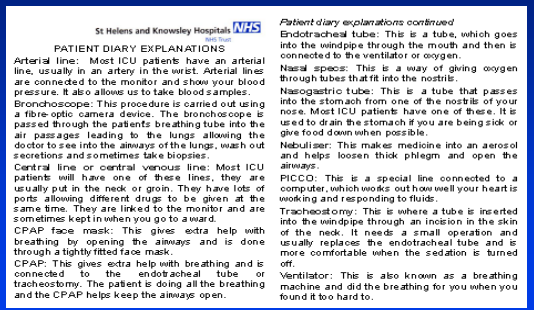
Diary tracking

- Diary register
  - Patient name
  - Date diary commenced
  - Date patient transferred out of ICU
  - Date diary passed to follow-up team
  - Date diary returned to ICU storage (if applicable)
  - Date diary destroyed (if applicable)
- Diary acceptance form
  - Documentation of acceptance or refusal of diary

Healthcare professional entries

- All healthcare staff should be encouraged to contribute to the diary
- Use black ink
- Date and sign entries
- Include significant milestones
- Avoid sensitive information
- Avoid medical jargon - use laymen's terms
- Make daily entries, where possible
- Include photographs

Diary Glossary



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PATIENT DIARY EXPLANATIONS

Arterial line: Most ICU patients have an arterial line, usually in an artery in the wrist. Arterial lines are connected to the monitor and show your blood pressure. It also allows us to take blood samples.

Bronchoscope: This procedure is carried out using a fibre-optic camera device. The bronchoscope is passed through the patients breathing tube into the air passages leading to the lungs allowing the doctor to see into the airways of the lungs, wash out secretions and sometimes take biopsies.

Central line or central venous line: Most ICU patients will have one of these lines, they are usually put in the neck or groin. They have lots of ports allowing different drugs to be given at the same time. They are linked to the monitor and are sometimes kept in when you go to a ward.

CPAP face mask: This gives extra help with breathing by opening the airways and is done through a tightly fitted face mask.

CPAP: This gives extra help with breathing and is connected to the endotracheal tube or tracheostomy. The patient is doing all the breathing and the CPAP helps keep the airways open.

Patient diary explanations continued

Endotracheal tube: This is a tube, which goes into the windpipe through the mouth and then is connected to the ventilator or oxygen.

Nasal specs: This is a way of giving oxygen through tubes that fit into the nostrils.

Nasogastric tube: This is a tube that passes into the stomach from one of the nostrils of your nose. Most ICU patients have one of these. It is used to drain the stomach if you are being sick or give food down when possible.

Nebuliser: This makes medicine into an aerosol and helps loosen thick phlegm and open the airways.

PICCO: This is a special line connected to a computer, which works out how well your heart is working and responding to fluids.

Tracheostomy: This is where a tube is inserted into the windpipe through an incision in the skin of the neck. It needs a small operation and usually replaces the endotracheal tube and is more comfortable when the sedation is turned off.

Ventilator: This is also known as a breathing machine and did the breathing for you when you found it too hard to.

Example to start diary

- This diary is being written to help you understand what has been happening to you in Intensive Care. You came to Whiston Hospital on ..... at ... am by ambulance. You had been vomiting since the day before and had tummy pain.
- This diary is being written to help you understand what has been happening to you whilst you have been a patient in Intensive Care. Originally you were admitted to Whiston with breathing problems and spent time on the general wards before coming to ICU. You had a few setbacks on the general wards. On ..... your condition deteriorated on the ward and you were found to have stopped breathing and needed resuscitation. A tube was passed through your mouth into your airway and was attached to a ventilator to do the work of breathing for you.

Examples for continuing

- You managed an hour off the ventilator with just some support from CPAP (helps keep the airways open with positive pressure) but you were really struggling to breathe. You went back on the ventilator on a mode that lets you do some of the work. This really knocked you for six and you slept most of the afternoon.
- You went for a CT scan of your chest and tummy this morning. In the afternoon you had a tracheostomy. This involves a small operation where a tube is put in to your windpipe through a cut in the skin of your neck. This is then connected to the ventilator and is much more comfortable than the tube in your mouth.
- You remain critically ill and very unstable at times. Your chest X-ray has shown that you have a condition called ARDS, which is inflamed, wet lungs, which can happen with acute illness.

Relatives' entries

- Encourage relatives to contribute to the diary
  - Events from home
  - Their visits to ICU
  - Family milestones
  - Information on patients interests (e.g. sport, current affairs etc)
  - Private communications can be included

Patient photographs

- Photographs of patient's stay in the ICU
  - Include relatives in the photographs
  - Do not give the photographs to the family
- Label all photographs
  - Patient name
  - Date taken
- Do not include the photographs within the diary immediately
  - Leave a space in the diary
    - » mount the photographs once they have given consent
  - Store un-mounted photographs for a period of 12 months

Returning the diary

- Follow-up team
  - Discuss the diary with the patient
  - Decide if they are ready to go through the diary
- If the patient refuses the diary
  - Store for 12 months
    - » If after this time the patient still does not wish to see it, destroy by shredding
- If the patient dies
  - Store the diary for 3 months
  - Write a letter to the family to see if they would like to receive the diary

Why diaries are important

After hospital discharge

- High incidence of psychosocial dysfunction
  - one large study showed particular problems for patients aged between 30-50 years of age

  Tian & Reis Miranda. Inten Care Med 1995;21:422-428.
- Significant levels of depression, anxiety, irritability and social isolation

  Jones et al. Brit. J. Int Care 1994;Feb:46-53.
- Significant risk of developing post traumatic stress disorder (PTSD)
  - particularly where patients recall delusional memories
  - strong correlation between symptoms in relatives and in patients

  Jones et al. Critical Care Medicine 2001;29(3):573-580.

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 *Anaesth* 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%

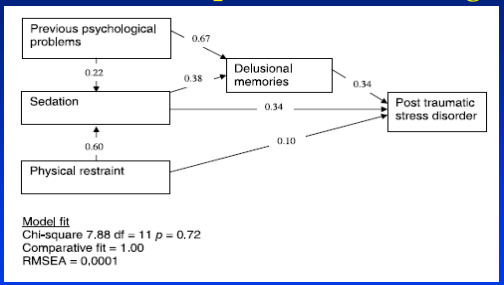
Post Traumatic Stress Disorder

- 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

RACHEL I

- 5 ICUs across Europe
  - Ratio of PTSD and relationship to:-
    - » patient previous psychological history
    - » In ICU periods of delirium or withdrawal symptoms
    - » patient care practice, e.g. sedation depth, opiate and sedation doses or physical restraint
    - » Memories for ICU
  - Secondary aim impact of diaries

Structural equation modelling



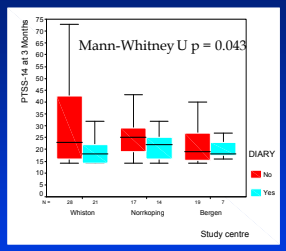
Jones et al. Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. Intens Care Med 2007;33(6):978-985

RACHEL I

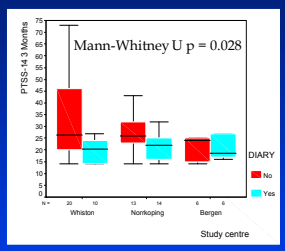
- 3 study centres using diaries
  - 108 completing 3 month follow-up
  - 42 patients received an ICU diary
  - Time of receiving diary
    - » 1 week – 1 month post ICU discharge
    - » Median 1 month

Jones et al ICU diaries my reduce symptoms of posttraumatic stress disorder. Intensive Care Medicine 2006;32(Suppl 1):S144

PTSD-related symptom levels



All patients from diary study centres



Patients recalling delusional memories

Impact of diaries

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

Knowles & Tarrier (2009) Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomised control trial Critical Care Medicine 37:184-191

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

Bergbom et al Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: pilot study. Intensive & Critical Care Nursing 1999;15(4):185-191

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
    Twigg E, Humphris G, **Jones C**, Bramwell R, Griffiths RD. Use of a screening questionnaire for post-traumatic stress disorder (PTSD) on a sample of UK ICU patients. Acta Anaesthesiol Scand 2008;52:202-208
  - Randomised to study group
  - **Intervention group**
    - » allowed to choose when they want 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
    Foa EB et al. Psych Assess 1997;9:445-45

Recruitment

- 357 recruited to the study at 1 week
  - 5 patients withdrew
  - 352 randomised to the study at 1 month
    - » 11 withdrew from the study before 3 months
    - » 8 died
  - 333 completed their 3 month follow-up
    - » 11 had undiagnosed PTSD prior to ICU admission
    - » 322 patients analysed
- Full results to be presented at ESICM Annual Congress in Vienna

Importance of information

- Diaries recommended
  - Understanding of the illness
  - To help clarify the rate of recovery

Further information

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