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The photo-diary and follow-up appointment on the ICU:

Giving back the time to patients and relatives.

A descriptive and interventional study

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*To my family*

*En droppe droppad i livets älv  
Har ingen kraft att flyta själv  
Det ställs ett krav på varenda droppe*

*Hjälp till att hålla de andra oppe.*

*(Tage Danielsson)*



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# ABSTRACT

**Background:** Patients on the ICU often spend a great deal of their time either unconscious or heavily sedated. When they return from the zone between life and death they are often in a state of confusion where dreams and delusions are intertwined with reality and it is not always easy to distinguish them apart. These experiences could lead to psychological problems and post-traumatic stress disorder (PTSD). Recovery may be improved by filling in the significant memory gaps and explaining what really happened during the “chaotic” time on the ICU. The provision of a diary describing the patients’ stay in ICU on a day to day basis and a follow-up meeting (together named the ICU-diary concept), may help the whole family to understand.

**Aim:** The principal aim of this thesis was to see if the ICU-diary concept was of help to patients and relatives in the recovery after critical illness. A further aim was to look for precipitants in the ICU of PTSD.

**Material and Methods:** ICU patients in a handful of European countries and their relatives have been studied. The studies have been single and multi-centred and we have used descriptive observational, randomised controlled and cohort study designs, including matched case-control designs. Quantitative methods have been used with questionnaires and structured interviews using established instruments (i.e Post-traumatic stress syndrome screening-14, Post-traumatic diagnostic scale, ICU memory tool, Short Form-36, Pearlin-Schooler Mastery Scale, Hopelessness scale) as the principal means of data collection.

**Results:** The ICU-diary concept was seen to be a positive and useful aid in helping patients and their relatives understand the events that took place during the time on the ICU. It also decreased the risk for PTSD among patients and relatives. Patients that were supported with the ICU-diary concept perceived a better health-related quality of life even 3 years after the ICU stay. We did not find any definite improvement by the ICU-diary concept in mastery and hope. Variations in how the patients were cared for in the ICU had a significant effect on the development of PTSD. The implementation of an ICU diary, for instance, was associated with a lower frequency of PTSD.

**Conclusions:** The ICU-diary concept was found helpful by patients and their relatives. It was associated with a reduction in new onset PTSD and improved health-related quality of life. The results are encouraging and suggest that an ICU diary may represent an important first step to help patients and relatives come to terms with their experiences during critical illness.

## LIST OF PAPERS

This thesis is based on the following papers, referenced in the text by their roman numerals.

- I. Bäckman CG, Walther SM. Use of a personal diary written on the ICU during critical illness. *Intensive Care Med* 2001; 27: 426- 29
- II. Jones C, Bäckman C, Capuzzo M, Flaatten H, Rylander C, Griffiths RD. Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. *Intensive Care Med* 2007; 33: 978-985
- III. Jones C, Bäckman CG, Capuzzo M, Egerod I, Flaatten H, Granja C, Rylander C, Griffiths RD. ICU diaries reduce posttraumatic stress disorder after critical illness: a randomized, controlled study. *Crit Care* 2010; 14:R168
- IV. Bäckman CG, Orwelius L, Sjöberg F, Fredrikson M, Walther SM. Long-term effect of the ICU-diary concept on quality of life after critical illness. *Acta Anaesthesiol Scand* 2010; 6: 736-743.
- V. Jones C, Bäckman C, Griffiths R D Intensive Care diaries reduce PTSD-related symptom levels in relatives following critical illness. *Am J Crit Care*, in press (AJCC-D-11-00005R2).
- VI. Bäckman CG, Orwelius L, Sjöberg F, Fredrikson M, Walther SM. A case-control study of the influence of the ICU-diary concept on mastery and hope six months after critical illness. In manuscript

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# ABBREVIATIONS

APACHE II	Acute physiological and chronic health evaluation II
BP	Bodily pain
CAM-ICU	Confusion Assessment Method for the Intensive Care Unit
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4 th ed.
GH	General Health
HRQoL	Health Related Quality of Life
ICU	Intensive Care Unit
ICU-DQ	Intensive Care Unit - Diary Questionnaire
ICUM	Intensive Care Unit Memory Tool
LOS	Length of stay
MAAS	Motor Activity Assessment Scale
MH	Mental health
PF	Physical functioning
RE	Role-emotional
RP	Role-physical
PDS	Posttraumatic stress Diagnostic Scale
PTSD	Posttraumatic Stress Disorder
PTSS	Post Traumatic Stress Symptoms
SF-36	Measurement Outcome Scale 36-item short-form health survey
SF	Social functioning
VT	Vitality

## DEFINITIONS

Amnesia	Complete or partial loss of memory
Analgesia	The act of blunting pain, through administration of analgesic drugs
Sedation	The calming of mental excitement or abatement of physiological function, especially by the administration of a drug.
Depth of sedation	The level of consciousness or wakefulness in sedated patients.
Intubated patient	A breathing tube that is inserted through the mouth or nose, the end placed below the vocal cords in the trachea. When you are intubated you cannot talk or make sounds.
ICU-diary concept	Keeping a diary with photos while on the ICU, plus a follow-up meeting with the patient and family within 1-3 months after leaving the ICU.

## BACKGROUND

Patients on the ICU often spend a great deal of their time either unconscious or heavily sedated. When they return from the zone between life and death they are often in a state of confusion where dreams and delusions are intertwined with reality and it is not always easy to distinguish them apart [1-4].

*”The nurse said that those who were not tea-totallers would be thrown down a chute to a bath of hot water in the cellar. Next to the bath was a porter who fished out the dead bodies with a net. Since I’ve had a drink now and then, I was certain that I would end my days like this.”*

It may be difficult to tell between dreams and reality if a well-meaning nurse or doctor says ”things are looking better now” when in reality the patient still has a tracheotomy, cannot breathe himself and can hardly turn in bed because of muscle weakness. This is especially so if the last thing he remembers is going to theatre for a gallbladder operation.

*”The only thing I could do was to blink and stare at the ceiling. I couldn’t do anything. I couldn’t fix my eyes on the wall. Yet I was clear in my head so time went so slowly. It was terrible not being able to move my arms and legs and it sounded strange when they said that I was getting better.”*

Our experience is that very few patients dare to ask about their time on the ICU. Questions were often asked at the end of their hospital stay and often to the nurse on the ward who had very little knowledge about what happened on the ICU. This even applied to the doctor responsible who probably only ever saw the patient a few minutes each day on the ICU round. The usual reply would be: “Don’t worry about what has been, you’re on the mend so look to the future.”

Sometimes the patient is told that he was sedated and put on a ventilator (in Sweden we say “in a ventilator”). This leads the patient to believe that he was put into some sort of iron lung. One patient told his relatives that he had been cared for in something that resembled a little submarine.

On several occasions the doctor on the ward rang and asked if his very curious patient could possibly come up to the ICU and see what it looked like where he/she had been treated. These patients asked strange questions and often found it hard to believe that they had ever been cared for on the ICU since they had no recollection of their time there. Their picture of what the unit looked like often showed no resemblance to reality, and some were convinced that they had been cared for in another hospital in another town, or that they were on a journey the whole time. It has happened that a patient has asked about a person on the ICU, giving a name and description that did not fit anyone on the unit.

We started to ask patients who were ready to go to the ward what they remembered about their time on the unit. The majority remembered very little, so we said that it wasn't anything that they would want to anyway. Sometimes patients could recall things but found it difficult or didn't want to describe what they remembered.

*"It was an upsetting time, all those unreal dreams, or was it death showing its face?"*

*"It's not easy to understand all that is going on around you when you're drugged up to the eyeballs"*

We let it go at that and did not engage in any deeper discussion about these memories. One patient was later heard to have told his friends that we had tried to kill him but that his relatives had forced us to give him medicine and as a result he had survived. This case led us to decide to try and help patients interpret and understand their experiences. It is not reasonable just to return a patient to somatic health and then leave it up to personnel on the ward to help them understand everything they went through during weeks of intensive care. Nor should this be left to relatives who have little chance, in a situation of chaos and crisis, of understanding all that is going on, let alone give a detailed explanation at a later stage.

In the early 90's we received a telephone call which went like this:

*"During the time my husband was on the ICU everything apart from getting him well again was of little interest. I went about daily chores as though in a trance, my thoughts were with him all the time even when I wasn't by his side and I could hardly sleep. The personnel were wonderful, they explained what they were doing and what was to be done and I thought I understood. Now, when I have him home and well again, he has asked me about what happened on the ICU and I have difficulty in explaining. He doesn't realise just how sick he was and when I tell him he was seriously ill with high fever it's as though he cannot take it in. He just lies and worries, sometimes he asks strange things and has even asked me if I came and visited him. I was there every day and we laughed and joked those last days on the ICU but he cannot remember anything about that. If we come up to ICU can someone help me tell him about his time there? He cannot cope very well but he's at his best around 10 o'clock, would that be OK?"*

The examples above indicate that partial or complete amnesia and unpleasant recall are quite commonly experienced by patients and relatives. The underlying illness and the use of sedative drugs and analgesics are factors likely to predispose patients to these phenomena. We know that relatives need assistance in explaining the patient's stay on the ICU. This is a very chaotic time for them too, and their memory might be influenced by anxiety, depression and problems with sleeping. It has been suggested that these experiences may contribute to the development of long-term psychological problems and post-traumatic stress disorder (PTSD) in patients as well as in relatives.

## Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder (PTSD) is a condition triggered by experiencing some horrific event beyond the normal range of experience. The stressful experience must be extreme, not just severe and cause powerful subjective responses such as intensive fear and horror [5]. It is characterised by a range of symptoms such as re-experiencing the event (flashbacks), avoidance of situations that remind one of the event, numbed emotional reaction, and symptoms of increased arousal (see table 1 for DSM-IV Criteria for PTSD, American Psychiatric Association, 1994).

For fulfilling the diagnosis of PTSD all three symptom categories must be present (re-experiencing, avoidance/numbing and increased arousal). If the symptoms last less than one month they may be transient and self-limiting and should be diagnosed as an acute stress disorder [5]. A grief reaction to a sudden bereavement is a typical example. It can generally be said that everyone involved in a disaster will immediately experience some symptoms and behaviours related to severe stress.

It is essential to identify PTSD as soon as possible and to make early interventions to prevent development of long-standing difficulties.

**Table 1.** DSM-IV Criteria for PTSD

The following six diagnostic criteria must be met for the diagnosis of PTSD.

- A) The individual has been exposed to a traumatic event in which both the following were present:
  - experienced, witnessed, or been confronted with a situation that could lead to death or serious injury, or is a threat to the physical integrity of self or others
  - the response included intense fear, helplessness or horror.
  
- B) The traumatic event is continually re-experienced in one or more of the following ways:
  - recurrent and intrusive distressing recollections of the event including images, thoughts or perceptions
  - recurrent distressing dreams of the event.
  - acting or feeling as if the traumatic event is actually recurring: sense of reliving the experience; illusions; hallucinations; and dissociative flashbacks which can occur on awakening when intoxicated, or at other times
  - intense psychological distress on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event
  - physiologic reactivity on exposure to internal or external cues that symbolise or resemble an aspect of the traumatic event.
  
- C) Persistent avoidance of stimuli associated with the trauma and numbing of emotional responses, which were not present before the traumatic event, including three or more of the following:
  - avoidance of activities, places, or people that arouse recollections of the trauma
  - inability to recall an important aspect of the trauma
  - markedly diminished interest or participation in significant activities
  - feeling of detachment or estrangement from others
  - restricted range of affect such as being unable to feel love and anger
  - sense of foreshortened future, such as not expecting to have a career, marriage, children or a normal life span.
  
- D) Persistent symptoms of increased arousal, not present before the trauma, as indicated by two or more of the following:
  - difficulty falling or staying asleep
  - irritability or outbursts of anger
  - hyper vigilance
  - exaggerated startled responses.
  
- E) Duration of the disturbance symptoms described in A, B and C lasting more than one month.
  
- F) Clinically significant distress or impairment in social, occupational, or other important functions.

## Patient diaries in ICU

We started the diary project in 1995 with the aim of bringing back the time on the ICU to patients and their relatives. This was done by writing and taking photographs of the patient's ICU stay and after 1 to 2 months inviting the patient back together with his/her family for a follow-up meeting. The idea of writing diaries was originally from a group of nurse assistants led by Annelie Unosson at the Danderyd Hospital in Stockholm. It was only later that we discovered that the use of diaries had been written about in Norway (Ingrid Schou in a Norwegian journal for nurses, Sygepleien 1984).

Our hypothesis was that if we gave patients a realistic description of their time in ICU, they might be a little less confused about what happened. To test this, we decided to keep a diary of the individual patient's stay on the ICU. By presenting them with the diary we hoped they would more easily come to terms with what they had gone through.

### The ICU-Diary concept

The ICU-diary concept includes writing a diary, taking photographs, and a follow-up visit after discharge. The diary is written in straightforward everyday language, starting with a summary, which included the reason for admission, the initial events on the ICU, the current state of the patient's illness and the reason for keeping the diary. One of the relatives is invited to summarise the course of events preceding admission to hospital and the ICU. All entries are dated and include day to day routines, including the patient's reaction to them. Meaningless entries such as the weather are avoided [6].

The diary is brought to a close if the patient dies, this being done either by the family or a member of staff following discussion with the relatives. The diary is presented when the patient and relatives, or relatives alone in the case of a deceased, attend a follow-up visit.

Colour photographs are taken with a digital camera. The pictures should be realistic and maintain the patient's dignity. Some of them should be of day to day routines, and include staff or relatives. The photographs are kept at the ICU until the follow-up visit.

The diary is kept at the patient's bedside until discharge from the unit. When leaving for the ward, the relatives or the staff takes responsibility for it.

Patients together with their relatives are invited back for a follow-up visit about 10 weeks after discharge from the ICU. Pictures are pasted into the diary with a detailed explanation of what is happening in them. The diary is very often used as an aid when telling the patient and family about the course of the critical illness, the text and photographs being thoroughly explained. The patient is given a contact telephone number so that any questions occurring later can be answered.

### **Method for the ICU-diary project**

A regular pocket – sized notebook was used to make the diaries and standard sets of rules for writing were followed.

Rules for writing in the diary:

- Check with the patient or their relatives that they consent to a diary being kept and photographs being taken. Inform them of the concept behind the diary and its importance. When the patient is transferred, the family continues to keep the diary.
- A diary should be started if it is clear that the patient will be kept on the ICU for a while and will be sedated and ventilated.
- If a patient who is not expected to stay ends up staying longer, then a summary of the first few days is made and relatives describe what happened before coming to ICU.
- Everyone is allowed to write in the diary, but they have to sign their entry with at least their first name. Relatives are invited to contribute to the diary and read the other entries. No-one is forced to write in the diary.
- Write about things important to the patient. If he is a football fan, for example, he might find it important to know who won the cup while he was ill. Don't be afraid to describe how serious the situation is, or the meaning of the concept will be lost.
- Take photographs of the patient when significant events happen, e.g. able to sit up to eat for the first time. Leave room in the diary for photographs and explain what they show.
- The aim of the diary is to help the patient and his/her family come to terms with what happened while on the ICU.
- When the patient leaves the ICU give the diary to the relatives or the staff on the ward so they can continue the diary while the patient is still in hospital.
- Keep a record of the patient's details so that you can contact them at a later stage.
- Empty diaries should be available on the ICU, and if supplies are running low inform the diary group.

## AIMS OF THE THESIS

The general aim of this thesis was to see if the ICU-diary concept, i.e. a diary including photographs and a follow-up meeting explaining what happened to the patient on the ICU, can be of help to patients and relatives. By filling in the significant memory gaps and explaining what really happened during the “chaotic” time on the ICU, we aimed to improve psychological recovery.

### **The specific aims, as described in the following papers were:**

- I. To assess the patient’s perception of having an ICU-diary as an aid in the debriefing process after critical illness.
- II. To explore the relationships between psychological morbidity, memories of the time on ICU, and sedation routines. In this study there was no comparison between patients or relatives with or without an ICU-diary.
- III. To evaluate whether the presentation of an ICU-diary reduces the occurrence of PTSD (excluding those patients with pre-existing PTSD), particularly in patients with delusional memories.
- IV. To evaluate if the ICU-diary concept influences health-related quality of life up to 36 months after discharge from the ICU.
- V. To test whether use of the ICU-diary concept reduces the level of PTSD-related symptoms in close members of the family.
- VI. To see if the ICU-diary has a positive influence on mastery and hope during recovery from critical illness.

# MATERIAL AND METHODS

## Study design

A summary of the study designs that were used is shown in Table 2.

In the first two papers (Studies I and II) a descriptive and observational study design was used as the work was mainly exploratory. In Study I our aim was to explore and understand the usefulness of this intervention. In Study II we explored the relationships between PTSD and the patients' recollections of the intensive care unit (ICU) and sedation practices. The basic design in Study III and Study V was a randomized controlled trial where early implementation of the ICU-diary was used as experimental intervention. In Study V relatives were assessed rather than patients themselves. Study IV was a prospective observational study where we analysed the influence of the ICU-diary concept using regression analysis. Study VI was a matched case-control study where we used multiple controls per case. We also used regression analysis to control for factors that we were unable to match appropriately.

**Table 2.** Overview of the studies

	Design	Participants	Inclusion criteria	Age, mean	Centres
Study I	Observational study	41 pts 10 relatives	Supported by ICU-Diary concept	58.3 (range: 2-87)	Vrinnevi
Study II	Prospective observational study	238 pts	ICU-stay > 48 hrs incl 2h vent	61 (range: 17-86)	RACHEL group <sup>1</sup>
Study III	Randomised controlled trial	162 cases 160 controls	ICU-stay > 72 hrs Vent > 24 hrs	Cases: 60 (SD: 15.5) Controls: 59 (SD: 16)	Extended RACHEL group <sup>2</sup>
Study IV	Case-control study	38 cases 224 controls	ICU-stay > 24 hrs	Cases: 50.7 (SD: 17.2) Controls: 62.2 (SD: 17.8)	Vrinnevi
Study V	Randomised controlled trial	30 relatives	Patients: ICU-stay > 72 hrs Vent > 24 hrs	Not applicable	Vrinnevi, Whiston
Study VI	Case-control study	38 cases 76 controls	ICU stay > 24 hrs	Cases: 50.7 (SD: 17.2) Controls: 55.9 (SD: 12.0)	Vrinnevi

<sup>1</sup> The RACHEL group = Whiston Hospital, Liverpool; Haukeland University Hospital, Bergen; Ferrara University Hospital, Ferrara; Sahlgrenska University Hospital, Göteborg; Vrinnevi Hospital, Norrköping. <sup>2</sup> The extended RACHEL group = The RACHEL group (see above) and Nordsjaelland Sygehus, Odense Universitetssygehus, Århus Universitetssygehus in Denmark; Ullevål Universitetssykehus in Norway; Santo Ant'nio - Centro Hospital do Porto in Portugal; Kungälv Hospital and University Hospital, Malmö in Sweden.

## Participants and settings

An overview of participants and settings are shown in Table 2

### **Patients and bereaved relatives in study I**

This study evaluated answers to a questionnaire given to 51 patients and relatives who received an ICU-diary from 1995-1999. The patients were a selected group of severely ill intensive care patients who were treated on the ICU at Vrinnevisjukhuset, Norrköping, Sweden; a mixed medical–surgical eight-bedded ICU.

### **Patients in study II**

This study was performed at five general adult ICUs across Europe, with experience in the follow-up of ICU patients, the RACHEL group (Raising Awareness after Critical illness of adverse Health Events in the Long-term). The number of beds in the units ranged from 8 to 12. By intention the units served hospitals with differing case-mixes reflecting the diversity of adult ICU practice across Europe. Included were Sweden, United Kingdom, Norway and Italy. We included 238 patients (>17 years) who had been mechanically ventilated and had a stay on the ICU of at least 48 hrs. Exclusion criteria were admission to ICU following a suicide attempt and patients with a pre-existing or concomitant psychotic illness, e.g. schizophrenia. Data were collected from 2003-2005.

### **Patients in study III**

This study was conducted on ICUs in six general district hospitals and six university hospitals in six European countries (the RACHEL group, compare Table 2). All hospitals in the study had prior experience of ICU diaries. We randomized 322 intensive care patients with an ICU stay of more than 72 hours to one of two groups 1 month after discharge from ICU. The intervention group received an ICU diary immediately after randomisation while the control group received an ICU diary after the final assessment was made at 3 months. Patients were excluded if they had a severe traumatic brain injury or pre-existing psychotic illness or were too confused to give informed consent on the general ward after ICU discharge. Data were collected during a 12-month period 2007-2008.

### **Study and reference population in study IV**

This prospective 36-month follow-up was part of a three-centre study (two district general hospitals and one tertiary care hospital) on health-related quality of life (HRQoL) after critical illness [7]. We examined in detail questionnaires from 499 patients (262 responders and 237 non-responders) from one of the participating centres, the ICU at Vrinnevisjukhuset, Norrköping. Inclusion criteria were age >17 years, ICU length of stay >24 h and alive 6 months after discharge from the hospital. Among the responding patients 38 had received an ICU diary with a follow-up meeting (Diary Group) while 224 had not received any diary (No-diary Group). The patients were followed longitudinally for 36 months with a significant number dropping out during the course of the study. Data were collected between March 2002 and June 2004.

A reference group (N=6093) was used for comparison of HRQoL. This was a randomly selected group of people in the county of Östergötland, aged 20-74 years, who had responded to a questionnaire that was distributed 1999 [8]. The reference group was used to extract matched controls to the Diary and No-diary groups with one control per case using age in decades and gender for matching.

### **Relatives in study V**

This study was conducted at two ICUs within the RACHEL group (Vrinnevisjukhuset, Norrköping and Whiston Hospital, Liverpool). We recruited one close family member (N= 30) from patients that were included in Study III. Data were collected during a 12-month period between 2007-2008.

### **Patients in study VI**

This prospective study was part of the same three-centre study as Study IV. We examined questionnaires from 499 patients (262 responders and 237 non-responders) from one of the participating centres, the ICU at Vrinnevisjukhuset, Norrköping in detail. Inclusion criteria were age >17 years, ICU length of stay >24 h and alive 6 months after discharge from the hospital. Among the responding patients 38 had received an ICU diary with a follow-up meeting (Diary group). Each patient in the Diary group (case) was individually matched to two controls, that had not received an ICU-diary, by age (in 5-year intervals) and gender. Data were collected between March 2002 and June 2004.

## **Measurements and measuring instruments**

### Data collected while in ICU

Patient age and gender, severity of illness scores based on the APACHE (Acute Physiology And Chronic Health Evaluation II) model were collected in all studies [9]. Therapeutic activity was scored using the TISS system [10] in study I. We also collected time spent on ventilator, length of ICU and hospital stay in studies IV and VI.

In Study II additional data was collected on the patient's status and treatment on the ICU, these included:

- Sedative and opiate drug given, type, duration, total daily dose and peak dosage.
- Level of sedation recorded using the Motor Activity Assessment Scale (MAAS)[11]
- The presence of any withdrawal symptoms using a combination of signs and symptoms of opioid and/or benzodiazepines withdrawal according to Cammarano [12].
- The presence and duration of delirium once sedation had been stopped using the Confusion Assessment Method (CAM-ICU)[13].
- Use and duration of any physical restraint.
- Descriptors of the patient, which may contribute to the development of delirium, e.g. smoking history, pre-morbid hypertension and alcohol or drug abuse.
- Descriptors of the patients and ICU stay i.e. gender, age, length of ICU stay, length of mechanical ventilation, diagnostic category, type of ICU admission, APACHE II severity score.

### Measuring instruments

A summary of the instruments that were used are shown in Table 3. They are described in more detail in the following paragraphs.

Measuring instruments that were used in studies II, III and V were translated from English into Swedish, Norwegian, Danish, Portuguese and Italian (as applicable) and

validated by back translation. All centres were visited by one of the authors prior to their starting patient recruitment to ensure the tools were all administered in a consistent manner.

**Table 3.** Instruments and when they were used per study. All times are after ICU discharge

	Study I	Study II	Study III	Study IV	Study V	Study VI
ICU-diary questionnaire	6 months		3 months			
ICU-memory tool		1-2 weeks	1-2 weeks			
Post-traumatic stress screening-14 (PTSS-14)		2 and 3 months	1 and 3 months		1 and 3 months	
Post-traumatic diagnostic scale (PDS)		3 months	3 months			
Short form 36 (SF-36)				6, 12, 24 and 36 months		
Pearlin-Schooler mastery scale (PMS)						6 months
Hopelessness scale						6 months
CAM-ICU and MAAS		On ICU				

### The ICU-diary questionnaire (ICU-DQ)

The ICU-DQ focused on how often and by whom the diary had been read, and how the contents and photographs had been perceived. Questions were followed by ample space for open comments (Figure 1). The ICU-DQ was used in Study I and III. In Study I it was mailed 6 months after discharge from ICU to recipients of an ICU-diary or their next-of-kin. In Study III the instrument was answered after 3 months by patients in the intervention group.

In study I a person independent of the ICU and the project, graded the open comments. Grading was aimed at classifying the respondents' attitudes towards the ICU-diary concept on a nominal scale (very negative, negative, neutral, positive, and very positive).

Diary use			
Week diary received:	<input type="text"/>	Approximately how many times read	<input type="text"/>
Have other people read the diary?	Yes/No		
Who else has read the diary? (please circle)	Family	Friends	Work colleagues General practitioner
Did you find the photographs helped you understand your ICU stay?			Yes/No
Did you find the written text helped you understand your ICU stay?			Yes/No
Which helped most to make your ICU stay real?	Text		Photograph
Is there anything you would like to tell us about your ICU diary?	<input type="text"/>		

**Figure 1.** The ICU-Diary Questionnaire (ICU-DQ)

### The ICU memory tool (ICUM tool)

At 1-2 weeks post ICU discharge the patients' recall of his/hers ICU experience was assessed using the ICUM tool [14]. The instrument consists of 14 items investigating recall of hospital and ICU admission and discharge. A memory checklist is included to increase the patient's recall of ICU; the patient saying whether any memory exists or not. (Figure 2). The ICUM tool was used in Study II and III.

<i>(please circle the appropriate answer)</i>		Clearly
<b>1. Do you remember being admitted to hospital?</b>		Hazily
		Not at all
<b>2. Can you remember the time in hospital before you were admitted to intensive care?</b>		All of it
		Some of it
		Nothing
<b>3. Do you remember being in intensive care?</b>		Yes/No
<b>4a. Do you remember all the stay clearly?</b>		Yes/No
<b>4b. What do you remember?</b> <i>(circle those things you remember)</i>		
Family*	Faces*	Darkness*
Alarms*	Breathing tube*	Clock*
Voices*	Suctioning*	Tube in your nose*
Lights*	Being uncomfortable†	Ward round*
		Feeling confused‡
		Feeling down†
		Feeling anxious/frightened †
		Feeling that people were trying to hurt you‡
		Hallucinations‡
		Nightmares‡
		Dreams‡
		Panic†
		Pain†
<b>4c. If you had any feelings that someone was trying to hurt or harm you while you were in intensive care can you please describe these feelings below.</b>		
<b>4d. If you had nightmares or hallucinations while you were in intensive care could you please describe these:</b>		
<b>5. Do you remember being transferred from intensive care to the general wards?</b>		Clearly
		Hazily
		Not at all
<b>6. Have you had any unexplained feelings of panic or apprehension?</b>		Yes/No
<b>6a. If yes: What were you doing when these feelings happened?</b>		
<b>7. Have you had any intrusive memories from your time in hospital or of the event that lead up to your admission?</b>		Yes/No
<b>7a. If yes to 7: What were you doing when these intrusive memories happened?</b>		
<b>7b. If yes to 7: What did these memories consist of (e.g. frightening nightmares)?</b>		
<b>8. Have you talked about what happened to you in intensive care with:-</b>		
<input type="checkbox"/> A member of your family		
<input type="checkbox"/> A nurse on the ward		
<input type="checkbox"/> A friend		
<input type="checkbox"/> A doctor on the ward		
<input type="checkbox"/> Your family doctor		

**Figure 2.** The ICUM tool.

\* factual memories, † memories of feelings, ‡ delusional memories

### Post-traumatic stress syndrome screening - 14 (PTSS-14)

The PTSS-14 was developed from the PTSS-10 and has been previously validated to measure the level of PTSD-related symptoms in patients recovering from a critical illness [15]. The questionnaire consists of 2 parts: part A identifies the presence of traumatic memories of ICU experience; part B scores 14 items from 1 to 7 each (Fig. 3).

PTSS-14 was used to assess the level of PTSD symptoms after ICU discharge in Study II at 2 and 3 months and in Study III and V at 1 and 3 months after the patient's discharge from ICU.

#### Part A

Consists of four statements about the patient's memory of the time spent on the Intensive Care Unit.

Patients or relatives were asked to read four statements and indicate if they were false or true. The four statements concerned the presence of

- Nightmares,
- Severe Anxiety or Panic,
- Severe Pain
- Troubles to breath, feelings of suffocation

#### Part B

Patients or relatives were asked to rate 14 statements (see below). The rating scale for each item was 1 (never) to 7 (always).

I presently (i.e. the past few days) suffer from:

1. Sleep problems.
2. Nightmares.
3. Depression, I feel dejected/ downtrodden.
4. Jumpiness, I am easily frightened by sudden sounds or sudden movements.
5. The need to withdraw from others.
6. Irritability, that is, I am easily agitated/ annoyed and angry.
7. Frequent mood swings.
8. A bad conscience, blame myself, have guilt feelings.
9. A fear of places and situations, which remind me of the intensive care unit
10. Muscular tension.
11. Upsetting, unwanted thoughts or images of my time on the ICU.
12. Feeling numb (e.g. cannot cry, unable to have feelings of love).
13. Avoid places, people or situations that remind me of the ICU.
14. Feelings that my plans or dreams for the future will not come true.

### Figure 3. PTSS-14, part A and B.

The total score ranged from 14 to 98, where higher scores indicate a greater likelihood of PTSD. A cut-off point of 45 is predictable for PTSD [15]

## Part 1

Many people have lived through or witnessed a very stressful and traumatic event at some point in their lives. Below is a list of traumatic events. Put a checkmark in the box next to ALL of the events that have happened to you or that you have witnessed.

- (1)  Serious accident, fire, or explosion (for example, an industrial, farm, car, plane, or boating accident)
- (2)  Natural disaster (for example, tornado, hurricane, flood, or major earthquake)
- (3)  Non-sexual assault by a family member or someone you know (for example, being mugged, physically attacked, shot, stabbed, or held at gunpoint)
- (4)  Non-sexual assault by a stranger (for example, being mugged, physically attacked, shot, stabbed, or held at gunpoint)
- (5)  Sexual assault by a family member or someone you know (for example, rape or attempted rape)
- (6)  Sexual assault by a stranger (for example, rape or attempted rape)
- (7)  Military combat or a war zone
- (8)  Sexual contact when you were younger than 18 with someone who was 5 or more years older than you (for example, contact with genitals, breasts)
- (9)  Imprisonment (for example, prison inmate, prisoner of war, hostage)
- (10)  Torture
- (11)  Life-threatening illness
- (12)  Other traumatic event
- (13) If you marked Item 12, specify the traumatic event below.

**IF YOU MARKED ANY OF THE ITEMS ABOVE, CONTINUE. IF NOT, STOP HERE.**

## Part 2

- (14) If you marked more than one traumatic event in Part 1, put a checkmark in the box below next to the event *that bothers you the most*. If you marked only one traumatic event in Part 1, mark the same one below.
- Accident
  - Disaster
  - Non-sexual assault/someone you know
  - Non-sexual assault/stranger
  - Sexual assault/someone you know
  - Sexual assault/stranger
  - Combat
  - Sexual contact under 18 with someone 5 or more years older
  - Imprisonment
  - Torture
  - Life-threatening illness
  - Other

In the box below, briefly describe the traumatic event you marked above.

**Below are several questions about the traumatic event you just described above.**

- (15) How long ago did the traumatic event happen? (circle ONE)
- 1 Less than 1 month
  - 2 1 to 3 months
  - 3 3 to 6 months
  - 4 6 months to 3 years
  - 5 3 to 5 years
  - 6 More than 5 years

**For the following questions, circle Y for Yes or N for No**

During this traumatic event:

- (16) **Y N** Were you physically injured?
- (17) **Y N** Was someone else physically injured?
- (18) **Y N** Did you think that your life was in danger?
- (19) **Y N** Did you think that someone else's life was in danger?
- (20) **Y N** Did you feel helpless?
- (21) **Y N** Did you feel terrified?

Part 3	Part 4
(34) 0 1 2 3 Having trouble falling or staying asleep	<p>Indicate below if the problems you rated in Part 3 have interfered with any of the following areas of your life DURING THE PAST MONTH. Circle Y for Yes or N for No.</p> <p>(41) Y N Work</p> <p>(42) Y N Household chores and duties</p> <p>(43) Y N Relationships with friends</p> <p>(44) Y N Fun and leisure activities</p> <p>(45) Y N Schoolwork</p> <p>(46) Y N Relationships with your family</p> <p>(47) Y N Sex life</p> <p>(48) Y N General satisfaction with life</p> <p>(49) Y N Overall level of functioning in all areas of your life</p>
(35) 0 1 2 3 Feeling irritable or having fits of anger	
(36) 0 1 2 3 Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)	
(37) 0 1 2 3 Being overly alert (for example, checking to see who is around you, being uncomfortable with your back to a door, etc.)	
(38) 0 1 2 3 Being jumpy or easily startled (for example, when someone walks up behind you)	
(39) How long have you experienced the problems that you reported above? (circle ONE)	
1 Less than 1 month	
2 1 to 3 months	
3 More than 3 months	
(40) How long after the traumatic event did these problems begin? (circle ONE)	
1 Less than 6 months	
2 6 or more months	

**Figure 4.** Posttraumatic Diagnostic Scale (PDS), part 1-4.

### Post-traumatic diagnostic scale (PDS)

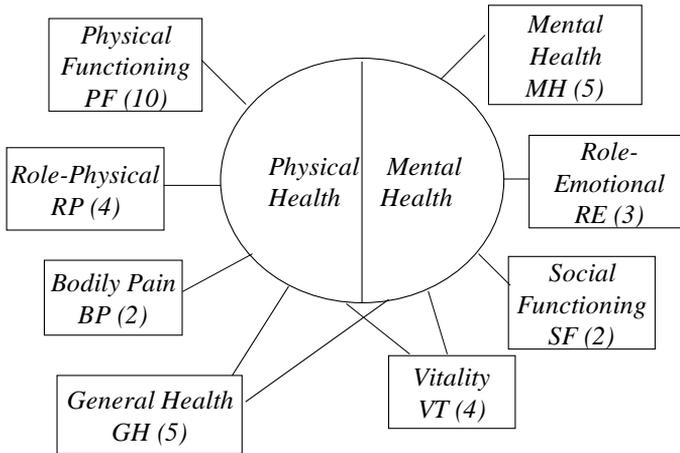
The PDS is a diagnostic interview tool that allows a diagnosis of PTSD [5]. Moreover, it allows identifying of the traumatic event responsible for symptoms as well as the time of onset of symptoms. It is one of the few measures in the PTSD literature that assesses all criteria, including functional impairment (Figure 4). PDS was used at 3 months after discharge from ICU in Study II, III and V where ICU patients attended a follow-up appointment.

### Measurement outcome scale, Short form 36 (SF-36)

The SF-36 [16, 17] (Figure 5) was developed in the early 1990's by an American research group under the direction of John Ware Jr. The SF-36 is based on WHO's broad health concept and was constructed to satisfy the minimum psychometric standards necessary for group comparisons. It contains multi-dimensional indicators of health concepts and measurement of the full range of health states, including behavioural function and dysfunction, distress and well-being, objective reports, and subjective ratings, and both favourable and unfavourable self-evaluations of general health. SF-36 uses 36 items to measure eight domains (also called subscales): physical functioning (10 items), role limitations as a result of physical problems (4 items), bodily pain (2 items), general health perceptions (5 items), vitality (4 items), social functioning (2 items), role limitations as a result of emotional problems (4 items) and mental health (5 items). All

but one of the 36 items (self-reported health transition) is used to score the eight SF-36 scales.

A total score and a summation score for each category are obtained where the scores on all subscales are transformed to a scale from 0 (worst score) to 100 (best score). At least 50 % of the items in a given scale must be present for estimating that particular item, and to complete data for all eight SF-36 scales when estimating the final scores. SF-36 was used in study IV to assess self-perceived HRQoL.



Subscale (abbreviation) with examples explaining the nature of the subscale

Physical functioning (PF):

Lifting or carrying groceries, climbing stairs

Role Function / physical causes (RP):

Accomplishes less than hoped for

Bodily pain (BP):

How intense the pain is

General health (GH):

Feeling that health will deteriorate

Vitality (VT):

Have been full of energy

Social functioning (SF):

How much health problems interfere with visiting friends

Role Function / emotional causes (RE):

Accomplished less than desired

Mental well-being (MH):

Feels very nervous

**Figure 5.** SF-36.

The schematic depicts relationships between subscales (domains). Numbers of questions per subscale are shown in parentheses. The list gives examples explaining the nature of the subscales.

### **The Pearlin-Schooler mastery scale (PMS)**

Coping is seen as the individual's own ability to cope with his life. Mastery and coping are kindred concepts. Mastery is one aspect of coping which describes the extent to which one regard one's life-chances as being under one's own control in contrast to being fatalistically ruled. Individuals with a poor ability to cope are considered to be at increased risk for disease.

The PMS consists of 7 items dealing with control in life (Table 4) [18]. Total points are converted to an index, where the performance number is a measure of an individual's sense of control over his life. The higher the number the more control he perceives him/herself to have. The PMS was used in study VI.

**Table 4.** The seven statements that comprises PMS.

1. There is really no way I can solve the problems I have.
2. I sometimes feel I'm being pushed around in life.
3. I have little control over things that happen to me.
4. I can do just about anything I really set my mind at.
5. I often feel helpless in dealing with problems in life.
6. What happens to me in the future mostly depends on myself.
7. There is little I can do to change many of the important things in my life.

Each statement is ranked on a Likert scale from 1 to 4. The PMS score ranges from 7 to 28, with a higher score reflecting greater mastery.

### **Measurement of hopelessness according to Everson**

This instrument was created by Everson and used in a study from 1996 when exploring risk for mortality and incidence of myocardial infarction and cancer [19].

Hopelessness is graded using this very simple "instrument" (Table 5) in which two statements are scored and the results added together to give a hopelessness score. Low scores on the hopelessness scale were indicative of general disagreement with each of the two statements, those in the moderate group were a mix of agreement and disagreement and those with high scores were those who agreed with the statements.

The Hopelessness scale was used in study VI

**Table 5.** The two statements that comprises the Hopelessness scale.

1. I feel that it is impossible to achieve the goals I strive for.
2. The future seems hopeless and I cannot believe that things change for the better.

Each statement is ranked on a 5-point Likert scale: 0 = Absolutely agree, 1 = Somewhat agree, 2 = Cannot say, 3 = Somewhat disagree, 4 = Absolutely disagree. Items were reverse-scored and summed to create a hopelessness score. Scores ranged from 0-8. Three groups were formed according to low (0,1 or 2), moderate (3,4 or 5) or high (6,7 or 8) points.

## Ethical aspects

The ICU-diary is considered a tool for patients and their families in aiding psychological recovery after critical illness rather than a medical record. Relatives are invited to co-authors and read it when they visit the patient. Personnel not involved in the care of the patient are not allowed to read the diary.

In case of death we let the family have the diary and photographs since they have been contributors and often also are seen on the pictures. Relatives have also expressed their thankfulness for having the diary (Study I). In Norway, Denmark and England, diaries are destroyed if the patient dies because it is seen as a private item and no-one knows if the patient wanted the family to have it. In UK the ICU-diary must be copied before the patient gets it, and the copy is stored in the medical records.

The use of ICU-diaries was not reviewed by any ethics review board or committee as this has been a standard part of care on our ICU for long-stay patients since 1995.

The studies presented in this thesis were performed in accordance with the Helsinki declaration. Study II, III, and V were approved by the Linköping University Regional Ethical Review Board (Dnr 038-03 together with The Sahlgrenska Academy Ethics committee in Study II and M 157-07 for Study III and V)

The patients and partners in study II, III and V were contacted and given verbal information about the study, the procedures, the confidential nature of the study and that withdrawal from the study would not affect their future care. The patients and partners were given both verbal and written information about the study during a visit by the research nurse to the ward after 7 days. After this they had some days to ponder before taking the decision to participate, and written consent was obtained.

In Studies IV and VI the patients received a letter informing about the confidential nature of the study and that withdrawal from the study would not affect their future care. This information was repeated each time they were sent a questionnaire at 6, 12, 24 and 36 months after discharge. These two studies were part of the LIVA project - patient-perceived health-related quality-of-life after intensive care in the southeast region of Sweden which was approved by the Linköping University Regional Ethical Review Board (Dnr 00-381).

In Study II, III and V major ethical dilemmas existed. For the patients being interviewed, there was the possibility that unpleasant memories would cause emotional distress when the research questions were presented. The interviewer had a responsibility to minimise discomfort for the participants and to protect their health and rights. A back-up consulting team consisting of an ICU-physician and a psychologist was available to help the interviewer who was an expert ICU nurse. Intensive care patients are often weak, very tired, in pain and distressed, and have problem in focusing on the information they receive when asked to participate in the study. However, these patients were treated with great respect and patience by the research nurse. Every patient and his/hers relatives received information about the study, and were assured that participating was voluntary, confidential and that they could withdraw at any time. Data on patients and relatives were kept confidential and were made anonymous by coding.

## Statistical methods

Categorical variables are presented as numbers and percentages, continuous data are presented as means and standard deviations or 95% confidence intervals. Unadjusted two-sample comparisons using Pearson's chi square and Student's t test were used to assess differences in background characteristics between groups.

In Study II structural equation modelling was used to model possible precipitants of PTSD. Structural equation modelling concentrates on the pattern of co variation between variables and goes beyond the restrictions of logistic regression, and is used extensively in psychological research. Model fit is signified by a probability greater than 0.5 and a root mean square error of approximation of less than 0.05. Structural equation modelling looks for a statistically non-significant result as it looks for the closeness of the model fit.

In Study III the Student's t-test and Mann Whitney U test were employed when comparing two groups and univariable analysis of variance (ANOVA) using the F statistic to compare more than two groups. The Scheffé post hoc test was used for multiple comparisons. However, when the distribution was poor, the data were subjected to the distribution free equivalent method (Kruskal-Wallis one-way ANOVA for independent groups). Proportions were tested using Fisher's exact test.

In study IV the independent effect of the ICU-diary concept on SF-36 dimensions six months after discharge from the hospital was examined using a multiple regression model adjusted for age, sex, presence of pre existing disease, APACHE II score on admission, diagnostic category and duration of stay in hospital. The influence of the ICU-diary concept on longitudinal changes (6, 12, 24 and 36 months) on HRQoL was analysed using MANOVA for repeated measures.

In Study V proportions were tested using Fisher's exact test.

In Study VI differences between groups in mastery and hopelessness scores were examined using the Wilcoxon rank-sum test. A multiple regression model was used for adjusting for confounding factors.

Probabilities of 0.05 were considered significant. Statistical analysis were performed with computerized statistical packages STATA/SE version 11.1 (Stata Corp, College Station, TX) and SPSS version 11.0 - 17.0 (SPSS, Chicago, IL).

## RESULTS

### Use of a personal diary written on the ICU during critical illness (Study I)

Forty-one survivors and ten relatives of non-survivors received the ICU-diary concept. Four survivors died during the 6-month period before the ICU-DQ was sent. These questionnaires were filled in by the relatives answering how the patient used the diary while he or she lived. However, all ICU-DQ were answered, either by the patients (parents in cases of children) or relatives of patients that died.

Twenty-six diaries had been read more than 10 times. Comments had been made in 39 ICU-DQ: 13 of these were graded as neutral, 11 as positive and 15 as very positive. Here are some of the comments made:

From patients:

- *The diary helps me to understand what I have gone through and I think the idea of having photos and text together is **a very good idea**.*
- *By having the diary to show to friends and acquaintances I find they gain a better understanding. The photos and text provide a complete picture that is difficult to communicate in any other way.*
- *It has helped us to understand what went on during the time we spent on Intensive Care – something that is difficult when you are in the midst of it all. A valuable document which we will have use of for the rest of our lives.*

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.*
- *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.*

All patients had read the diary and most thought the diary to be positive (28%) or very positive (49%), the rest were neutral (23%).

The 12 ICU-DQ without comments in the free text were assessed in more detail, and we found that all responders in this selected group had shared the diary with relatives and friends and claimed that it had helped them to understand their time on ICU. They were also positive towards the photos and none had had difficulty in understanding what was written. Seven of the 12 responders had read the diary more than 10 times.

## Precipitants of post-traumatic stress disorder following intensive care (Study II)

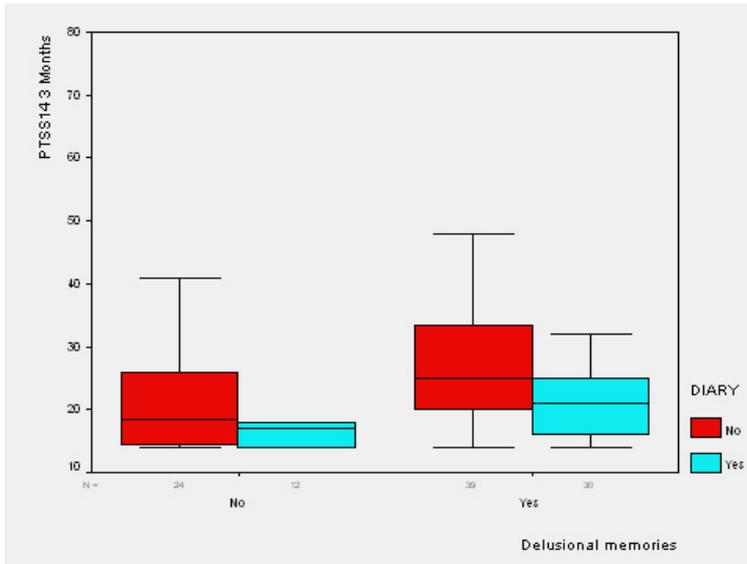
Recruitment of patients at 5 ICUs ran over a 9-month period with 3-months follow-up. The case mix of the admissions to the various centres varied in terms of the proportion of emergency admissions (55% - 100%), age (median 54 - 73 yrs) and APACHE II scores (median 12 - 15 points). The overall rate of PTSD was 9.2%. The rate was slightly lower where the ICU admission was elective (7.6%) versus emergency admissions (11.6%), however this was not statistically significant. Those patients admitted to ICU following trauma were not more likely to develop PTSD than any other patient. Furthermore the psychological characteristics of the patients differed between study centres in terms of the incidence of previous psychological problems (9 - 52 %) and patients with previous traumatic events prior to ICU admission on the PDS list of previous possible traumatic events, sexual assault for example ( $p=0.014$ ). Despite this the rate of pre-existing PTSD was low.

Sedation practices between study centres were significantly different in both the mixture of sedative and opiate drugs used but also the doses given. The occurrence of withdrawal symptoms from sedative and opiate medication varied from 1% - 48% ( $p < 0.0001$ ). The incidence of delirium also varied between 14% - 65% ( $p < 0.0001$ ), median 41%. The development of delirium was more common in patients receiving high daily doses of benzodiazepines for sedation (median dose 24 mgs vs. 13 mgs,  $p = 0.003$ ) and high daily doses of opiates (median dose 88 mgs vs. 43 mgs,  $p = 0.039$ ). Those receiving high daily doses of propofol as their main sedative drug were not more likely to become delirious ( $p = 0.634$ ).

None of the variables recorded about the patients pre-morbid lifestyle were found to be associated with the development of delirium, i.e. a previous history of smoking, hypertension, drug abuse or alcohol abuse.

The patient's recall for the ICU experience varied between different study centres. The recall of delusional memories, such as hallucinations, nightmares or paranoid delusions was common and consistent in all patients, varying between 44% - 77% (median 57%). Recall of feelings such as pain and anxiety were not consistent over the time period of the follow-up with some patients reporting remembering pain or anxiety at 2 weeks post ICU but not at 2 and 3 months, only 53% recall agreement at the 3 time points in time.

Three patients consistently reporting recall of anxiety were diagnosed as PTSD. These patients all reported recalling delusional memories. Independent risk factors for PTSD were disturbance of memory, long-term sedation and equipment that limited patient movement. An important outcome of this study was that the way in which the patients were cared for had a significant effect on the development of PTSD. The implementation of an ICU diary, for instance (Fig. 6), was associated with a lower frequency of PTSD. Since the ICU-diary concept was used in only three of the ICUs in the study, and in these for only 25-50% of patients, we chose not to comment on this in the article. Instead this was to be the subject of a larger study on the use of an ICU-diary (compare below Study III).



**Figure 6.** PTSS-14 scores at 3 months in patients with delusional memories (Study II). The scores were lower for those with recall of delusional memories who received a diary.

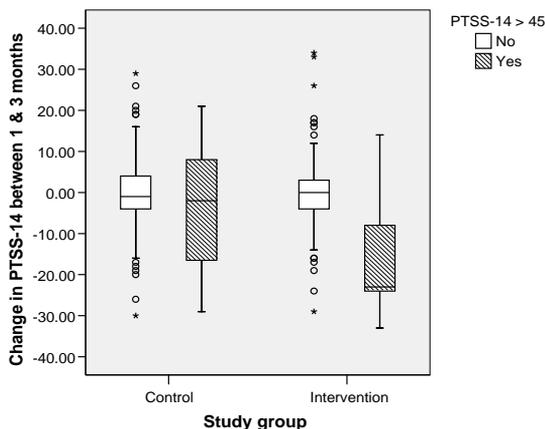
### Intensive care diaries reduce the onset of PTSD following critical illness: a randomised controlled trial (Study III)

One month after discharge from ICU, 352 patients were randomised to the study, 162 of 177 intervention patients (91.5 %) and 160 of 175 controls (91.4 %) completed the three-month follow-up questionnaires and did not have pre-existing chronic PTSD. Three control and eight intervention patients (3 %) were found to have previously undiagnosed chronic PTSD using the PDS. Only two of these patients rated their ICU stay as being one of the traumatic events in their lives on the PDS (one control and one intervention) and all named a previous event as the most traumatic event and had had PTSD symptoms for three to five years prior to their ICU admission.

When all the patients were examined there was no significant difference between the two study groups in the change in PTSS-14 scores between one and three months. This is not surprising as only about 10% of the patients scored more than 45 on the PTSS-14 at one month and the 90% remaining with lower scores masked the result.

However a more detailed analysis results showed that the use of an ICU diary reduced the frequency and severity of PTSD, and patients with the most severe PTSD symptoms were those who gained most from the diary (Fig 7). The lowest frequency of new-onset PTSD in the intervention group indicates this to be important first step in helping these patients reconstruct their lives after critical illness.

The results also showed that those intervention patients scoring very highly for PTSD symptoms using the PTSS-14 had the largest reduction in symptoms by three months, whereas the majority of those not scoring highly remained unchanged. However, this was a *post-hoc* analysis resulting in a low number of patients for analysis (14 pts in the control group and 12 pts. in the intervention group).



**Figure 7.** Change in PTSS-14 scores between 1 and 3 months by study group and score > 45 at 1 month (Study III). Patients in the intervention group with a PTSS-14 score above the cut-off > 45 at 1 month had a significant reduction in score at 3 months (Fishers Exact Test  $p = 0.04$ )

### Long-term effect of the ICU diary concept on HRQoL after critical illness (Study IV)

A total of 499 patients were included; 40 received the ICU-diary concept. The questionnaire response rate at 6 months in the Diary group was 38 of 40 (95%) and 224 of 459 (49%) in the No-diary group ( $P < 0.001$ ). There were no significant differences in the patient characteristics (gender, age, concurrent disease, APACHE II score, admission diagnosis, presence of mechanical ventilation, time on the ventilator, length of stay in ICU and hospital) between responders and non-responders in the No-diary group.

Patients in the Diary group had higher crude HRQoL scores at 6 months in two dimensions (general health and vitality) and in the physical component score than the No-diary group. Patients in the Diary group were younger, more severely ill on admission and the respiratory and multiple trauma diagnostic categories were more common than among patients who belonged to the No-diary group. Patients with diaries spent more time in the ICU and in the hospital. Still, the effect of the diary concept remained after adjustment for age, gender, pre-existing disease, severity of illness on admission, diagnostic category and duration of stay in hospital.

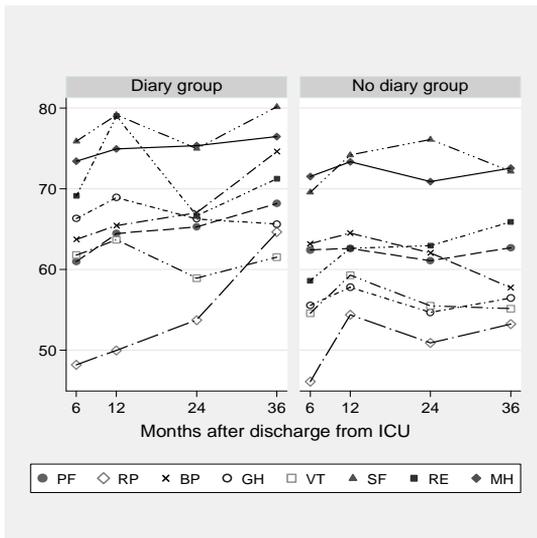
Complete follow-up from 6 to 36 months was obtained for 126 patients, 29 (73 %) in the Diary group and 97 (21 %) in the No-diary group; the characteristics differed

significantly between the groups (Table 6). The evolution of the dimensions and component scores over time (3 years) in the Diary group showed that the presence of a diary improved the dimensions general health and vitality, and the physical component score after controlling for age, APACHE II score, admission diagnosis and length of hospital stay (Figure 8).

**Table 6.** Characteristics of patients who responded to all questionnaires (6, 12, 24, and 36 months).

	Diary (n = 29)	No-diary group (n=97)	P-value <sup>1</sup>
Percentage (%) of original group	73	21	< 0.001
Male/female, numbers	13/16	62/35	NS
Mean (SD) age (years)	53 (16)	65 (14)	<0.001
Presence of pre-existing disease (%)	17 (59)	68 (70)	NS
Mean (SD) APACHE II score	18.0 (7.8)	13.9 (6.0)	<0.01
ICU admission diagnosis, numbers (%)			< 0.01
Respiratory	11 (38)	14 (14)	
Gastrointestinal	5 (17)	22 (23)	
Multiple trauma	5 (17)	3 (3)	
Sepsis	1 (3)	4 (4)	
Other	7 (24)	54 (56)	
Hours on ventilator; mean, median (interquartile)	290, 212 (47-352)	20, 0 (0-0)	<0.001
Hours on ICU; mean, median (interquartile)	355, 260 (122-414)	68, 54 (41-87)	<0.001
Days in hospital; mean, median (interquartile)	24, 14 (6-27)	16, 10 (5-22)	<0.05

<sup>1</sup> Pearsons chi<sup>2</sup>-test for categorical data and Student's t-test for continuous data.



**Figure 8.** Health related quality of life assessed by SF-36 at 6, 12, 24 and 36 months after discharge from ICU (Study IV). Mean values per dimension are shown. Changes over time in general health (GH) and vitality (VT) differed significantly between groups ( $P < 0.05$  and  $P < 0.01$ , respectively).

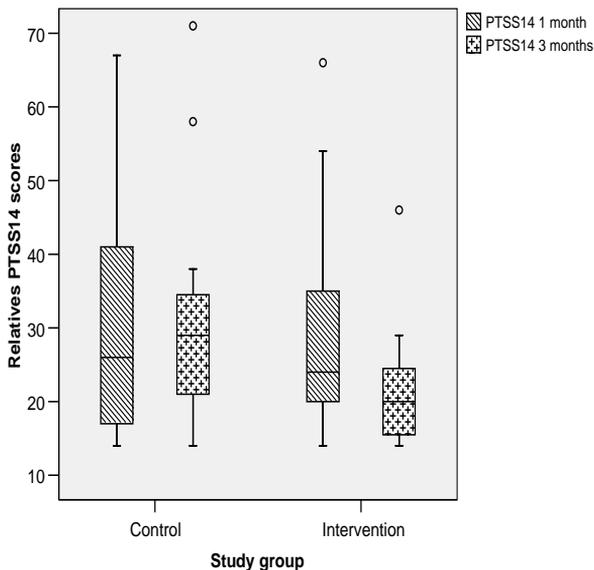
## The ICU-diary concept reduces PTSD-related symptom levels in relatives following critical illness: a pilot study (Study V)

Recruitment at the two ICUs ran over a 12 month period between 2006 and 2007 with 3 months for follow-up. Thirty six relatives were recruited to the study, 18 of the patients were randomised to the intervention group and 18 to the controls. Five relatives withdrew before the 3-month follow-up and 1 was the spouse of a patient who died. Thirty (83 %) relatives subsequently completed the 3 month follow-up questionnaires, 15 intervention and 15 controls and these data were analysed, 11 of the 30 at Whiston Hospital and 19 at Vrinnevisjukhuset. All these relatives had read the ICU diary after the patient had returned home.

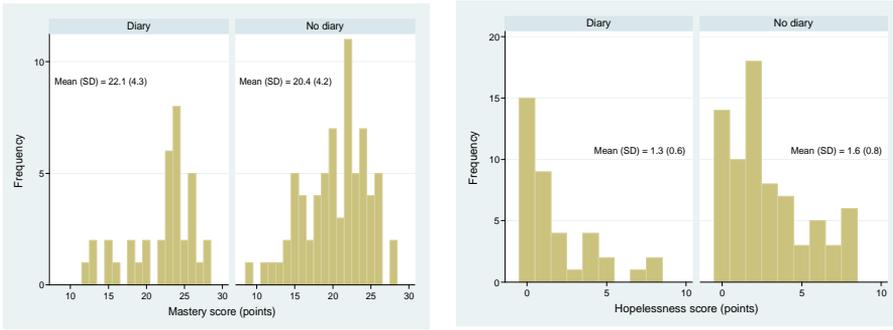
The initial PTSS-14 scores of the relatives at one month showed no significant difference between the intervention group and the controls. Recollections of the time of the critical illness reported by relatives in Part A of the PTSS-14 at the 1-month follow-up were similar in the two groups.

When changes in the PTSS-14 scores between 1 and 3 months were examined for all the relatives completing the 3-month follow-up, there was a statistically significant difference between the controls and interventions (Fig. 9). The median change in the PTSS-14 score for those relatives of patients with the intervention between 1 and 3-months was  $-5$ , showing a reduction compared to the equivalent controls where there was an increase in the score of  $+5$ .

The results showed that relatives to patients receiving an ICU diary and follow-up visit after 1 month showed less PTSD symptoms than relatives to patients who received their diary at a 3-month follow-up.



**Figure 9.** PTSS-14 scores at 1 and 3 months by study group (Study V). The changes over time in the Intervention group were significant ( $P = 0.03$ ).



**Figure 10.** Distributions of mastery and hopelessness scores in the Diary and No diary groups (Study VI).

The influence of the ICU-diary concept on mastery and hopelessness six months after critical illness (Study VI)

In this study we matched 38 patients who had received an ICU-diary with 76 controls without this intervention. The distribution of mastery and hopelessness scores are shown in Fig. 10. The ICU-diary group scored significantly higher than those in the No-diary group in mastery (22.1 vs. 20.4,  $P < 0.05$ ) and lower in hopelessness scores (1.3 vs. 1.6,  $P < 0.05$ ). There were substantial differences in baseline characteristics between the groups, which were adjusted for using a multiple regression model. The positive influence of the ICU-diary disappeared after adjustment for these possible confounding factors (Table 7). We were thus unable to verify any positive influence of the ICU-diary concept on mastery and hopelessness 6 months after critical illness.

**Table 7.** Influence of the diary in multiple regression models, adjusted for age and gender, in patients who responded to the questionnaire at 6 months.

	Diary	Co-morbidity	APACHE II score	Length of ICU stay	Duration of ventilator support	Duration of hospital stay
Mastery	NS	<0.05	NS	NS	NS	NS
Hope	NS	<0.05	NS	NS	NS	NS

# DISCUSSION

## Study I: The beginning

This work began in the mid 1990's when we started keeping a diary including photographs while the patient was on the ICU. A few months after discharge, the patient and relatives visited the ICU and the diary was presented [6].

We felt it important that the patient should get a realistic picture of their time on ICU and thereby "win back lost time". We even invited the patient to see the bed and premises where they had been treated. For every diary that was kept, and for every family we met, we became stronger in our conviction that this was worth the extra time and workload. Our personnel found it very rewarding and interesting to meet the patients and families. We soon realised that the time in ICU was a very chaotic time for the whole family, and that it was important for them to get a realistic picture of what actually happened. Even if relatives were present a great deal of the time in the ICU, it was difficult for them to relate events in a meaningful manner.

Many ICU survivors suffer from considerable depression, anxiety, irritability and social isolation [20, 21]. They express distress at not knowing what has happened to them and what they do learn is typically gained second-hand via relatives. This lack of memory leads to unrealistic expectations regarding speed of recovery [22-26].

Since the method of giving ICU-patients and their relatives an illustrated account of their stay had not been evaluated previously, every participant was asked to fill in a questionnaire after 6 month for evaluation. These questionnaires formed the basis for Study I. This was obviously a single-centre study initiated and supported by a group interested in the psychological outcome of patients treated on the ICU. It is likely that the enthusiasm of this group influenced patients and relatives as the response rate was 100 %. An external assessor was employed to avoid observer bias in the interpretation of the responses, which were very positive.

We thought it likely that a standardised comprehensive interview procedure would have increased the validity of this study. To test this, a subgroup of seven randomly chosen patients was interviewed in depth by student nurses and the results were in agreement with the findings from the questionnaire and the impression we had gained from the follow-up visits [27].

## Study II: Exploring precipitants of PTSD

In 1998 we were approached by Christina Jones and Richard Griffiths, both prominent researchers in the field of ICU-care aftercare. Discussions lead to the development of the RACHEL group, which included 6 researchers from 4 different European countries interested in the psychological outcome after Intensive care.

Study II was designed by the group to generate hypotheses since previous work had suggested a number of associations and possible causes between ICU practices and PTSD [28-30]. The study recruited a large number of patients across five European intensive care units with a diversity of case-mix so as to reflect current intensive care and identify common factors. It is our opinion that, with the various approaches to

analgesia and sedation, choice of agents and the depth of sedation aimed for, with or without physical or pharmacological restraint, we achieved a cross-section of European practice. The factors identified were intimately connected with everyday patient care and since such diversity exists between five European ICUs it is far from clear what is the ideal approach to analgesia/sedation or use of restraint.

This study does not suggest any change in practice since it has a number of limitations, foremost of these being that this was not a randomized controlled study but observational to raise hypotheses since change and comparison of different practices had not been studied prospectively. In order to obtain reliable data, the research group found it necessary to involve intensive care units used to follow-up and this includes care after ICU. These ICUs may or may not be typical and the care provided could potentially affect the incidence of PTSD. One of the study ICU's (Whiston ICU) had already seen a change in the rate of PTSD from a previous study showing a rate of 16% [31] down to 10% in this study. This may reflect changes in care during critical illness and a greater role for psychological support after discharge from ICU. Although in this field our study is quite large, a far larger study may identify or clarify the significance of the factors identified. We are aware that in an observational study such as this one, the factors identified may not be causal and thus amenable to direct intervention, but merely markers of disease or other processes. It is inevitably in ICU studies over this nature that a number of patients are lost to follow-up and the final data become distorted. However, we were able to analyze data from 78 % of patients recruited. Only 9 % withdrew or were lost to follow-up while 13 % died after discharge from ICU.

One limitation of recruiting patients from several study centres was the problem of consistency of data collection. To eliminate this problem the various centres had staggered start dates to allow the lead investigator to visit each centre and train the staff involved. This led to the study running for over a year and also reduced the risk for seasonal bias.

### Study III and V: Effects on PTSD in patients and family members

The hypothesis in this multi-centre study was that a diary explaining what happened on the ICU might help patients fill in gaps in their memory, place delusional memories into context and aid psychological recovery. ICU patients developing PTSD may be haunted by their memories and may try to suppress them. Trying not to think about such emotionally charged memories, however, leads to more unbidden thoughts and greater physiological arousal [32-34]. Learning to modulate feelings and reduce the physiological arousal is the first step to recovery. Cognitive behavioural therapy is recommended in the treatment of PTSD [35], and similar mechanisms may be operating when applying the ICU-diary because it changes the patient's view of their illness as they read about their experience, and helps form a constructive memory.

There was one slight difference between the study groups at randomisation; there were more females in the control group and at least one study has suggested that severe PTSD symptoms are more common in women [36]. However, this is not a consistent finding across studies and in our control group gender was not related to the development of PTSD. The decision to include patients staying on the ICU for 72 hours or more was both a logistical one to ensure that a reasonable ICU diary was available for the patient, and because the risk of developing PTSD has been shown to be greater the longer the period of sedation.

### PTSS-14 and PDS assessments

The study showed that intervention patients who scored very highly for PTSD symptoms using the PTSS-14 got the largest reduction in symptoms at three months, whereas the majority of those not scoring highly remained unchanged. However, this was a post-hoc analysis resulting in a low number of patients being analysed. When all patients were examined there was no significant difference between the two study groups regarding the change in PTSS-14 scores between one and three months. This is not surprising as only 10% of the patients scored more than 45 on the PTSS-14 at one month and the remaining 90% with lower scores masked the result. The lowest occurrence of new-onset PTSD in the intervention group indicated an important first step in helping these patients to reconstruct their lives after critical illness. For the diagnosis of PTSD to be fulfilled all three PTSD symptom categories must be measured.

The PTSS-14 is a reliable screening instrument when used for former ICU-patients and applied 2 months after discharge. Access to psychology expertise is limited in most hospitals, which is why this short but accurate tool, easily applied by nurses during a follow-up visit, is important, and could help the patient receiving a quicker and more appropriate referral to specialist treatment.

PDS assessment is conducted as a diagnostic interview with the patient and allows standardisation of the diagnosis of PTSD. Moreover, it identifies the traumatic event responsible for symptoms as well as the time of the onset of symptoms. It is one of few measurements in the PTSD literature that assesses all criteria, including functional impairment. It also allows assessment of the severity of the patient's symptoms for each of the three PTSD symptom clusters i.e. re-experiencing, avoidance and physiological arousal. The higher the scores in the separate categories the more severe are the symptoms. The original validation study showed a sensitivity of 82% and a specificity of 76.7%, showing a good overall level of diagnostic agreement with PTSD diagnosed with a clinical interview [5]. This tool was chosen to provide a standardised assessment of PTSD across all the centres rather than relying on clinical assessment by 12 different psychologists. An alternative would have been to use a standardised clinical interview but we did not have the resources necessary.

Patients in the intervention group reported finding both text and photographs helpful in understanding their time on ICU, which was also the case in Study I. This study showed the ICU-diary to be a simple and very practical intervention, which was effective in reducing the incidence of PTSD after critical illness.

Study III had a number of strengths but also limitations and a possibility of bias. One of its strengths was the low drop-out rate, which can be attributed to the use of research staff with previous experience of following up patients, and the direct interview style method rather than using a postal questionnaire. Furthermore, wide recruitment including 12 ICUs increased the relevance of the results. It was not possible to fully blind the use of the diary from the investigators because patients often mentioned it. PDS scoring, however, is complicated and divided into sections, and is therefore difficult to influence subconsciously.

The interviewing investigators were kept blind to the separate symptom group scores and the overall diagnosis of PTSD. Moreover, intervention patients met an experienced investigator to go through entries in the diary that could have influenced the results.

However, routine practice at several of the study sites was to give both intervention and control patients verbal information about their illness prior to discharge from hospital, which would have entailed a similar discussion. This could be examined in further studies. Another possible limitation is the fact that not all patients could return to the ICU to receive their diary or take part in the final interview due to a long journey, and so these interviews were conducted by telephone. This was a pragmatic study trying to mimic what would be normally done clinically. The majority of study participants were interviewed face to face in a hospital setting so the likelihood of this having an influence on the incidence of PTSD is not great.

The UK NICE guidelines on the treatment of PTSD suggest that targeting at risk groups rather than blanket interventions should be practiced. This implies that ICU patients would only receive a diary if they had severe symptoms. However, diaries have been seen as simply a source of information for patients about their illness and it has been suggested that all patients staying on the ICU for more than 48 hours should have one [37-42]. Practically speaking, however, it is best to go “half way” and use the ICU-diary for long-stay patients who are likely to benefit the most and thus provides an achievable target. Patients lacking PTSD symptoms may still be happy to receive the information it contains.

### **Symptoms of PTSD among relatives of the patients in study III**

This pilot study of relatives to ICU-patients suggested that the provision of an ICU-diary, outlining the patients’ stay in ICU on a day-to-day basis, given to patients one month after discharge may help to reduce the level of PTSD-related symptoms in close family members.

There could be a number of explanations for this effect:

- The diary reduces the need for patients to ask their relative to fill in gaps in their memory.
- It forms the basis for family conversation regarding the time on ICU.
- It clarifies for the family what happened on the ICU.
- It helps to facilitate communication with the patient about his/her treatment.
- Writing in the diary allows relatives to express their feelings while the patient is on the ICU.

The focus of the study was to assess the symptoms of PTSD in relatives, not how the ICU-diary concept helped them, and further research is needed to examine these mechanisms. A strong relationship has previously been found between severe PTSD-related symptoms in relatives and those in patients at 6 months after ICU discharge [43, 44]. An intervention such as a diary which is shared between the patient and the family may be better than one that concentrates on the patient alone.

One study looking at the impact of chronic critical illness on care providers has shown that the patients’ negative emotions and pain caused the caregiver most distress [45]. This would suggest that an intervention which reduces the incidence of PTSD in patients may decrease the distress their relatives feel because the patients’ own well-being has improved. The ICU-diary may have a role in facilitating communication. It should be remembered that relatives of an ICU patient also suffer mental trauma during the period of critical illness.

A major limitation of this pilot study was the low number of family members recruited as it was only feasible to undertake this additional parallel study in 2 of the 12 centres involved in the original patient study (Study III). These two centres were chosen as they already had established follow-up programmes not only for patients but also for their families.

#### Study IV: Effects on health-related quality of life

One important result was that patients in the Diary group had higher crude HRQoL scores at 6 months in two of the SF-36 subscales (general health and vitality) and in the physical component score than the No-diary group. However, the non-randomised design yielded important baseline differences between the study groups. Patients in the Diary group were younger; were mostly admitted after trauma or with respiratory failure, were more seriously ill on admission and had a longer stay on the ICU and in hospital. These differences operate in different directions; the younger age in the Diary group should tend to increase HRQoL, while greater illness severity and longer hospital stay should be associated with reduced HRQoL [46, 47]. Multivariate techniques were used to adjust for these differences and other important confounders such as sex and pre-existing disease [7]. The effect of the ICU-diary concept at 6 months after discharge remained after adjustment, indicating a positive influence on general health and vitality, although we cannot exclude the influence of other factors such as level of education or marital status that we were unable to adjust for. It is worth noting that differences between the Diary group and its matched reference group were generally smaller than between the No diary group and its reference.

The lack of HRQoL ratings prior to ICU admission complicates interpretation of the results [48]. This is a drawback inherent to all similar studies and is difficult to avoid. Adjusting for determinants of HRQoL such as age, sex and pre-existing disease present before the critical illness may partially offset this drawback. Furthermore, the provision of HRQoL data from a large reference population served as a baseline for understanding the magnitude of the differences observed in the study cohort.

The lower response rate in the No-diary group may have led to bias when estimating the effect of the diary. There were no significant differences in patient characteristics between responders and non-responders in the No-diary group, suggesting that the patients who responded were representative. However, it is possible that the poor response rate in the No-diary group was due to avoidance behaviour indicative of PTSD [49]. This would imply that the patients with poor mental health were more likely to be those who did not return their postal questionnaires, leading to deflation of the effect regarding the diary concept [50].

Clearly, the ICU-diary concept increased the response rate to the questionnaires. The higher response rate may be secondary to a feeling of gratitude for being taken care of in more than just the usual manner (compare Study I), which could also influence the perceived HRQoL as measured by SF-36. The Diary group was quite small and was confined to a single centre. Local effects related to this specific ICU, including the deep involvement of the patients' families and extensive experience of the ICU-diary concept may have influenced the results.

## Study VI: Effects on mastery and hope

The effects of the ICU-diary concept on mastery and hope were studied using the PMS and the Hopelessness scale. These instruments are not very commonly used in the present context but they have been used earlier in different settings by the Public Health Science Centre at the University Hospital in Linköping [8]. We found, when analyzing crude scores, significant differences with greater mastery and higher hope favoring patients that had received an ICU-diary.

Critically ill patients with chaotic and fragmentary memories from their ICU stay have difficulty in understanding, comprehending and managing their traumatic experience. This leads to poor control and a feeling of hopelessness as shown by Corrigan et al. in their qualitative study on survivors after intensive care [51]. Mastery has been shown to be associated with functional disability. Presence of physical limitations, for instance, was associated with less mastery in patients with multiple sclerosis [52]. Griffiths et al. [25] have suggested that mastery could be improved in patients recovering from critical illness. They invited not only patients but also their families to meet and discuss rehabilitation and progress of recovery after ICU care. Working out a strategy together is important when adapting to changes in life after critical illness.

Hope is important for human health and quality-of-life [53-55]. This form of psychosocial resource has been the subject of growing interest in modern research, and a number of studies have shown that hopelessness is a strong and independent predictor of disease and death. Myocardial infarction is one example [56].

This study has important limitations. Patients who received a diary were younger and had less co-morbidity, but they were more serious ill on admission, stayed five times longer on the ICU and had twice as long hospital stay compared to controls. Although it may be argued that these differences operate in opposite directions, we addressed them using a matched case-control study design and adjusting in a regression model for remaining differences. Since the positive influence of the ICU-diary concept that we saw in the crude analysis disappeared following adjustments we cannot say that the concept had any influence on mastery and hope.

## Summary

The present work may be summarised as follows:

- The risk for developing PTSD after critical illness was 1:10. This risk may be affected by the nature of ICU care.
- Patients and relatives who were supported with the ICU-diary concept found it helpful when reconstructing their memory of the time on the ICU. This may reduce the level of PTSD-related symptoms in relatives of critical illness survivors.
- Relatives of non-survivors appreciated coming back for a follow-up meeting and going through the ICU-diary and photographs together with experienced staff from the ICU.
- The provision of an ICU-diary was associated with a reduction in the incidence of new-onset PTSD. The ICU-diary may represent an important first step to help patients come to terms with their experience during critical illness.
- Patients who were supported with the ICU-diary concept after their critical illness had better self-perceived HRQoL as reflected in two subscales of SF-36 related to physical and mental well-being.
- ICU patients' mastery and hope were not influenced by the ICU-diary concept.

# SVENSK SAMMANFATTNING

## **IVA-dagbok och uppföljningssamtal: att ge tillbaka tid till patienter och anhöriga**

En stor andel av patienter som vårdats på Intensivvårdsavdelning (IVA) pga. svår sjukdom har omfattande minnesluckor från sjukdomstiden. Undersökningar av patienter som vårdats i respirator visar att en stor del av patienterna inte hade något minne alls av behandlingen när de intervjuades senare.

Dessutom förekom obehagliga överklighetsupplevelser ofta. Kunskapen är begränsad om hur dessa minnesluckor kombinerat med överklighetsupplevelser påverkar patientens hälsa. Bristen på verkliga minnen kan bli plågsam och bidra till utveckling av posttraumatisk stress och depression, s.k. posttraumatiskt stress syndrom (PTSD).

I arbete 1 undersöktes om en personlig dagbok från intensivvårdsvistelsen skriven av personal och anhöriga under patientens sjukdom (IVA-dagbok) kunde användas för att fylla ut patientens minnesluckor. Erfarenheten var att IVA-dagboken uppfattades som ett positivt och användbart hjälpmedel för att hjälpa såväl patient som anhöriga att förstå skeenden under sjukdomsperioden.

Arbete 2 baserades på hypotesen att variation i vården av den kritisk sjuke påverkar förekomst av PTSD. Denna hypotes undersöktes i en observationsstudie där effekten av en rad faktorer som bedömdes vara av betydelse för utveckling av post-traumatisk stress och minnesstörningar analyserades. Studien genomfördes på fem intensivvårdsavdelningar i fyra europeiska länder. Oberoende riskfaktorer för utvecklingen av PTSD var förekomst av minnesstörningar, långvarig behandling med lugnande och sövande läkemedel samt användning av fysiska hjälpmedel som hindrar patienten från att röra sig. En viktig kunskap från denna studie var att variationer i vården hade en signifikant påverkan på utvecklingen av PTSD. En sådan faktor var förekomst av IVA-dagbok, vilken var associerad med en lägre förekomst av PTSD.

Utgångspunkten för det tredje arbetet var hypotesen att IVA-dagboken kan reducera förekomst av PTSD efter svår sjukdom och vård på intensivvårdsavdelning. Denna hypotes undersöktes i en randomiserad studie som genomfördes under 1 år på 12 intensivvårdsavdelningar i 6 länder. Resultaten visade att dagboken minskade uppkomsten av PTSD. Dessutom fann vi att patienter, som en månad efter intensivvårdsvistelsen hade uttalade symtom på PTSD, var den grupp som hade mest nytta av dagboken.

I arbete 4 utgick vi från hypotesen att dagboken påverkar hälsorelaterad livskvalitet efter intensivvård. Detta studerades genom att vi analyserade hälsorelaterad livskvalitet, självskattad med SF-36, i två grupper av patienter varav den ena gruppen hade erhållit en IVA-dagbok i samband med ett återbesök på IVA. Denna studie var en del av en större studie av livskvalitet och sömnstörningar efter intensivvård, vilket medförde att de båda grupperna skiljde sig åt avseende flera viktiga faktorer (t ex. ålder, diagnoser, tid i respirator, vårdtid på sjukhus). En statistisk metod användes för att justera för dessa snedfördelade faktorer. Resultat pekade på att förekomst av IVA-dagbok påverkade

positivt dimensionerna vitalitet och allmän hälsa i SF-36, och att denna effekt kvarstod upp till 3 år efter vistelsen på IVA.

I arbete 5 studerades anhöriga till intensivvårdspatienter, dessa löper också en större risk för att utveckla PTSD. Vi prövade hypotesen att en IVA-dagbok till patienten också minskar risken för PTSD hos anhöriga. Studien genomfördes på två intensivvårdsavdelningar. Vi fann att familjemedlemmar till patienter som hade fått en IVA-dagbok i samband med ett tidigt (1 mån) uppföljningssamtal uppvisade mindre symtom på PTSD än familjemedlemmar till patienter som lottats till att få dagbok och uppföljningssamtal sent (3 mån).

I arbete 6 utgick vi från hypotesen att IVA-dagboken positivt påverkar känslan av kontroll över det som sker samt att den bidrar till mindre hopplöshet. Detta studerades genom att vi analyserade enkätformulär där självskattad kontroll och hopplöshet undersöktes med standardiserade frågor. En fall-kontroll studie genomfördes där patienter med IVA-dagbok jämfördes med patienter utan IVA-dagbok. Även i denna studie skiljde sig dessa båda grupper åt i flera viktiga avseenden (t ex diagnoser, tid i respirator, vårdtid på sjukhus). Analysen kompletterades därför med en statistisk teknik där vi justerade för snedfördelade faktorer. De ojusterade resultaten, innan den statistiska tekniken använts, pekade på att IVA-dagboken positivt påverkade känslan av kontroll och hopp. Denna positiva påverkan försvann efter justering för viktiga faktorer som skiljde grupperna.

Sammanfattningsvis kan sägas

- att risken för att utveckla PTSD var 10 % om man vårdats på IVA under längre tid och varit nedsövd samt haft behov av respirator.
- att patienter och närstående uppskattade att återkomma för att gå igenom IVA-dagboken under ett uppföljningsmöte med erfaren IVA-personal.
- att IVA-dagboken var förknippad med en minskning av nydebuterad PTSD hos patienter
- att IVA-dagboken minskade symtom på PTSD hos närstående till IVA-patienter.
- att patienter med IVA-dagbok uppvisade en högre självuppskattad livskvalitet upp till 3 år efter IVA-vistelsen.
- att känslan av kontroll och hopplöshet hos IVA-patienter inte påverkades av dagboken.

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