

# Chapter 6

## ICU Diaries



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### Introduction

In this chapter, we illustrate the concept of intensive care unit (ICU) diaries by presenting theory accompanied by an authentic case. The case we have chosen describes 58-year-old Mrs. Miller (pseudonym) who was involved in a motor vehicle accident and suffered severe traumatic brain injury. She was rushed to the nearest hospital by ambulance and was immediately sedated, intubated, and mechanically ventilated. The patient was expected to stay in the ICU for a while, so the nurse started an ICU diary.

#### Mrs. Miller's Diary

Dear Mrs. Miller, you were admitted to the Intensive Care Unit at the University Hospital this morning after a serious car accident where you hurt your head badly. When you arrived by ambulance, we immediately examined you and started treatment. You will spend the next days here at the Intensive Care Unit. You are connected to monitors, infusion pumps and a ventilator that helps you breathe. This is all for your safety, but I can imagine that it might be frightening or disturbing for you. You receive medications to keep you comfortable and help you sleep. Some patients have told us that they dreamed a lot while they were here, and that the ICU might have influenced their dreams, which can lead to confusion. We are writing this diary to help you understand later what went on when you were here. We are taking good care of you. Carol Smith, RN, September 5th, 2019.

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## *Post-intensive Care Syndrome (PICS)*

Acute critical illness and intensive care put patients at risk for short- and long-term physical and psychological complications, described as post-intensive care syndrome (PICS) [1–3]. About 25–30% of ICU survivors show symptoms of anxiety, depression, or posttraumatic stress disorder (PTSD) during the first 6 months after ICU discharge. Common risk factors include younger age, benzodiazepines, frightening ICU experiences, and pre-existing psychiatric illness [4–6]. Close family, known as family caregivers, might experience similar symptoms. Depending on the circumstances, the prevalence of anxiety, depression, and PTSD in family caregivers have been recorded as 2–80%, 4–94% and 3–62%, respectively [7, 8]. Symptoms dissipate more rapidly in caregivers than survivors. Risk factors for caregivers include younger age, relationship to the patient, lower socioeconomic status, and female sex [8].

## *ICU Diaries*

ICU diaries were initiated by intensive care nurses to alleviate patients' psychological symptoms after critical illness and to help them come to terms with their illness during recovery [9]. The intervention was developed in Denmark, Norway, and Sweden in the early 1990s [10] and is now used in many countries worldwide [11]. No single purpose has been given for writing a diary [12], but diaries are assumed to:

- Help patients to come to terms with critical illness.
- Help patients and families to cope with their experiences.
- Fill memory gaps and help describe the critical illness trajectory.
- Explain physical and psychological symptoms.
- Understand hallucinations and unreal experiences.
- Support follow-up consultations.
- Improve patient-hospital communication and quality of care.
- Support bereaved after the patient has died.

ICU diaries were not based on a nursing theory but were influenced by theories of crisis, coping, and communication. They have been described as a therapeutic instrument, an act of caring, an expression of empathy, a vehicle for communication and orientation, a supplement to follow-up visits, and a humanizing factor in the technical ICU environment. The intervention emerged as a nurse-led bottom-up initiative that was later investigated, structured, and described in guidelines [13]. As a therapeutic instrument, some nurses believed that diaries could help resolve stages of crisis [10]. This was contested by other nurses who believed that a therapeutic perspective would sustain the “sick role” of the patient. An alternative perspective was using diaries as an act of care and compassion. In some cases, it was written from an existential perspective where the nurse vicariously described what the

patient might be experiencing. In later years, there has been less debate on the underpinnings and more focus on evidence of the effect of the diary. Perhaps, as the body of knowledge on ICU diaries increases, a theory of ICU diaries will emerge from increasing research describing the phenomenon.

### ***Practical Aspects of Writing a Diary***

ICU diaries can be described from a practical (clinical) aspect of how and what to write, or from a theoretical (academic) aspect of the mechanism and outcome of the intervention. The following concepts are important to ICU diaries:

- Authors: Person or persons writing the diary
- Recipient: Person receiving the diary
- Diary type: Handwritten or computerized diary
- Design and format: Cover layout, decorations, page setup, abbreviations
- Structure: Rules for first, middle, and last entry
- Content: Topics included in the diary, e.g., greetings, patient appearance, mood, etc.
- Writing style: How and what to write
- Photographs: How and when to photograph the patient or others
- Handover: Timing of diary handover and follow-up

### **Authors**

ICU diaries can be kept by hospital staff, family, or friends, depending on local practice or national guidelines. In Norway, the national guidelines state that ICU diaries should only be written by nurses or other hospital staff as the diary is regarded as part of the hospital chart [14]. ICU diaries in Norway are quality assured by peer assessment before they are handed over to the patient. Most other countries allow for a broader group of authors and consider the diary the property of the patient rather than the hospital. ICU diaries were initially considered as a “gift” from the nurses to the patient [15]. The diaries are written “to” or “for” the patient but will never convey the actual patient perspective. Each author narrates their own version of the story [15]. It is becoming more common for family caregivers to write a diary for the patient. This is a version of the caregiver perspective that can enable a shared story with the patient [16]. It is still uncommon for the patient to participate, but the diary holds the potential for the patient to continue the story during recovery.

#### **Mrs. Miller’s Diary**

Mr. Miller and their two daughters are at the bedside. One is writing in the diary.

“Dear Mum, we are so worried about you. I received a call from Dad and hurried to the hospital. Mary is also here, she cancelled her holidays. I’m crying, but the doctor told us to

be patient. They don't know how you will wake up, we must wait. You know that I can do almost everything, except waiting. I love you so much, and I can't see you like this. You are my beloved MUM! We will spend all day at your bedside, we are always at your side!

Love, Donna”

## Recipient

The ICU patient, and later the ICU survivor, is the recipient of the diary. After the handover, there might be many readers of the diary, most often close family and friends. It is up to the patient to decide who may read the diary and where to place the diary at home. In some cases, diaries have been used to document the patient's illness to obtain sickness benefits. More attention is being given to selecting the patients that will benefit most from receiving a diary. This is to control the workload of the nurses and target the effort.

## Diary Type

Diaries can be handwritten or computerized. If handwritten, different formats are used, such as small notebooks or A4/A5 size paper [17]. Some patients still prefer handwritten diaries for personal touch, whereas others prefer computerized diaries that are easier to read, store, and share. Diary examples and templates are available on [www.icu-diary.org](http://www.icu-diary.org).

## Design and Format

Diaries can include standardized information such as how to contact the ICU, daily ICU routines, glossary of common terms, photographs of the ICU (often from the view of the patient), pictures of equipment, DVDs, or questions for evaluation of the diary. To avoid legal issues, some ICUs have a general disclaimer stating the non-legal status of the diary, e.g., “The following diary entries do not constitute a form of documentation of your treatment and are not created for this purpose. The entries are therefore not part of your medical record. The diary is offered to support your recovery by helping you to understand your experiences in ICU.”

### **Mrs. Miller's Diary**

Dear Mrs. Miller, I took care of you today. Your condition has stabilized, and we are trying to wake you up. This is a process that takes time because you were sedated. You are slowly waking up: you blink when I call your name, and you have some strength when we turn you. Your breathing is slower when your daughter has visited you. I wonder if you recognize her voice or her touch? Perhaps you are dreaming – I wonder what you are experiencing.

Kelly Dawson, RN, November 7th, 2019

## Writing Style

Diaries are usually written “to” and “for” the patient and sometimes “for” and “by” the families [18]. The patient is addressed in a kind and direct manner (see diary examples). The authoring staff member signs each entry, including the date and year. In Scandinavia, the UK, and the Netherlands, it is common to use the first name of the patient and nurse. In more paternalistic societies, the patient is addressed as Mr./Mrs./Ms. using the last name. Nurses do not always use their last name in a diary, maintaining some degree of anonymity. Using last names for patient and physician and first name for nurses might indicate some degree of subordination.

Diary entries include description of the patient status in layman’s terms [19]. The first, and usually longer, entry describes the conditions leading to ICU admission followed by daily interventions and events and finally the last entry summing up the ICU stay and patient condition. The stages identified in ICU diaries are crisis, turning point, and normalization [15]. Rehabilitation initiatives start as soon as possible, e.g., early mobilisation and continue throughout the stay. The golden rule is to write only what would be discussed in front of the patient. Due to issues of confidentiality, the diary should not contain diagnosis, prognosis, or treatment. Other things to avoid are abrasive language or information that could be misunderstood in a legal sense. In general, diaries should be written in plain language, avoiding clinical terms. The language can be individualized taking into consideration the personality and experience of the patient. Patients have expressed a need to know what they looked like, what they said, how the staff identified their needs, how they expressed their feelings, and how the staff communicated with them [20].

Some nurses like to write in a reflexive manner introducing a sense of wonder, e.g., “I wonder what you are dreaming/hearing/feeling?” This is to stimulate patients to recall and communicate their experiences and dreams that are often remarkably vivid [21]. Of course, the frequency of this type of questions should be appropriate. ICU diaries are sometimes authored by family caregivers with guidance from the nurses. Families can write more freely as they have fewer restrictions than nurses. Contributing to the diary might be a simple and effective coping strategy for the family. They can express their thoughts and feelings in the diary and share them at a later time [22], thus reducing the burden [23]. It is still debated whether the caregivers should unburden their emotions in the patient’s diary, as evidence is lacking into the potentially harmful effects of ICU diaries [24].

### **Mrs. Miller’s Diary**

Dear Mum, now you have been here for five days. Only a few days – it seems like a month. It came so suddenly, so unexpected. Do you remember: Tuesday morning we were shopping in the city, laughing and everything was as usual, and now ...? Your “vitals” are still stable, and they were able to reduce the sleep medications again. You are “flying” just above the ground, like an airplane – you know, that’s what they said from Grandpa back then. We are patient and give you time – holding your hand a bit is all we can do for you. But at the same time, I am still really scared, and can’t sleep and have bad dreams. We all worry. And all those who can’t visit you here are in your thoughts with you. I love you so much, Marie

## Photographs

Photographs have always been an integral part of ICU diaries: photos of the patient at different stages of recovery in ICU, photos of family or staff surrounding the patient, or generic photos of patients and ICU equipment. The early ICU diaries were called photo diaries, and according to the patients, the photos were appreciated [25]. The photos helped them more than words to realize how seriously ill they had been [26]. For legal reasons, the patient should not be photographed while unable to give consent. This includes patients that are unconscious or deeply sedated. This issue is often resolved by keeping photographs in a safe place until the patient is able to decide whether to keep the pictures for the diary or discard them. At first, pictures were taken with polaroid cameras, but now pictures are taken with smartphones or electronic cameras, perhaps raising concerns about patient's privacy and data protection. National and local policies for data protection should be followed. Pictures can be used to record patient progress and as the basis for follow-up consultations [27]. Some patients regard pictures as the most important part of the diary.

### **Mrs. Miller's Diary**

Dear Mrs. Miller. So, the last few days you have made great progress. I took care of you just after your admission, when you were seriously ill. That's why I'm so happy that I can experience the great success after so many days. You help when I get you up in a chair or brush your teeth. You are like a top athlete. I complement you - I know how exhausting it is, but despite the stress, you manage to smile. We took a picture of you, with the physiotherapist and me. You are looking good! Keep up the good work and you'll be out of here very quickly. Carol Smith, RN, November 20th, 2019.

## Diary Handover

There are many ways to hand over the diary. In Scandinavia and some other countries, diaries are usually handed over to the patient during a follow-up visit, where a nurse discusses the ICU stay with the patient and the patient has a chance to ask questions. The diary is read aloud by the nurse and the photographs are discussed. In other countries, there might be less time for follow-up, and the diary is instead given to the nurses at the general ward or to the family to continue writing.

The patient does not usually read the diary at handover from ICU. Most patients are not ready to confront their ICU stay before some time has passed, and patients with symptoms of PTSD and avoidance wait until they are ready after 6 months or a year, if ever [28]. Patient readiness to receive and read the diary is individual [29–31]. It is generally recommended to hand over the diary when:

- The patient is fully awake, conscious, and emotionally stable.
- The traumatic situation (critical illness) is resolved.
- The patient is interested in the process of recovery, asking questions such as “What happened to me?” “How long have I been in ICU?” or “Why am I so weak?” [11].

### Mrs. Miller's Diary

Dear Mrs. Miller, you have almost recovered. You can care for yourself and enjoy your coffee. Only when getting up you need a little assistance. You are doing so well that you can transfer to the general ward soon and move on to rehabilitation. Everything is planned, and the other wards will be informed by us. Your daughter said that everyone at home is looking forward to seeing you again! We wish you all the best! Susan Sanchez, RN, November 26th, 2019.

Mrs. Miller's diary illustrates some of the different types of authorship and diary content, from practical to family-oriented issues. The diary is used as a tool for communication and as a receptacle for information that can be accessed by the patient at a later time. Ideally, the diary should contain an introduction explaining how and why the patient came to the ICU and a final entry summarizing events and providing a sense of closure. Mrs. Miller's diary shows the compassion of the family and the caring of the nurses. This offers the patient a sense of safety and not being abandoned while unconscious. This is a way of sustaining personhood during a time when the patient is unable to make her own choices or act at will.

## ICU Diary Research

Through the years, ICU diaries have been subject to research focusing on the qualitative and quantitative evidence of the intervention (Table 6.1). Studies on ICU diaries have described their extent and application [12]; history [32]; effect on patient PTSD [31]; effect on patient and family PTSD [33]; impact on patient and family well-being [34]; impact on teamwork and communication between patient, family, and staff [35]; impact on nurses' work satisfaction [36]; and effect on anxiety, depression, and quality of life of survivors and family [37].

Research has also covered issues on structure and content of nurse-authored diaries [15], structure and content of family-authored diaries [38], the meaning of

**Table 6.1** Potential benefits of ICU diaries

Patients	Improved well-being [34] Improved quality of life [37] Better coping [14, 20, 22, 42, 46] Better understanding [20] Less anxiety and depression [37]
Family	Improved well-being [34] Better coping [16] Better communication [35] Less PTSD [37] Less anxiety and depression [37]
Staff	Improved humanization of care [32, 50, 51] Improved quality of care [39] Improved work satisfaction [36] Improved reflection on critical care [12, 48]

diaries for nurses [39], the meaning of diaries for patient and family [16], prediction of patients benefitting from diaries [40], the workload of writing a diary [41], the experience of reading a diary [20], and the patient and family use of diaries [42].

Evidence of the usefulness of ICU diaries is still weak and lacks discussion of potential harms of the intervention, such as stimulation of frightening memories, flashbacks, or emotional disturbances [9]. More qualitative evidence is emerging on patient satisfaction of ICU diaries and nurse-led follow-up [39, 43, 44], whereas quantitative research has been unable to demonstrate a strong correlation between diaries and psychological recovery [24, 45]. In some cases, the ICU diary is a good supplement to the hospital chart. When patients have access to both, they are enabled to distinguish between real and delusional memories and to cope with their experiences [14, 20, 22, 42, 46]. Recent meta-analyses have suggested that patients receiving ICU diaries, compared to no diaries or post hoc diaries, experience significantly less anxiety and depression [37, 47].

Family caregivers can express their thoughts and experiences in a diary that might help them to cope with the patient's illness, while hospital staff perceive the diary as a vehicle for the improvement of quality of care [48, 49]. The ICU diary tells a different story than conventional documentation and highlights the human aspect of critical illness [32, 50, 51]. Finally, pediatric ICU diaries show potential to help parents and siblings to cope with the critical illness of a child [52, 53].

### ***Free Online Resources***

In 2011, an international group of diary experts founded a network with a website for ICU diaries: [www.icu-diary.org](http://www.icu-diary.org). The website offers information on diaries, contact with experts worldwide, diary templates from different countries in several languages (e.g., English, Spanish, German), implementation assistance, risk calculation, discussion of legal aspects, consent forms, and other helpful information. Participation and use of the resources are free of charge. If new papers are published, updated references are appreciated. The diary network is informal, offering newsletters on diaries and psychosocial needs of ICU patients, families, and more.

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