

ICU survivors experience of ICU diaries: an ancillary qualitative analysis of the ICU diary study

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Terms of use for the ICU diary

The ICU diary was opened with an account of the initial medical event. The ICU staff wrote personally to the patient at least one entry a day. Relatives were invited to write freely in the diary, without specific guidance from the ICU staff. At ICU discharge, the ICU diary was given to the patient, or to his family if the patient was confused. This could be done on the day of discharge or as close as possible to this date. Otherwise, the diary was presented in detail to the patient in his/her ICU room few days before discharge.

Interview guide

With respect to the ICU diary that you were provided with, how did you use it? What did you feel the first time you opened and read it?

what did you like most?

what did you not like? Were you scared by some points?

What was the diary used for?

how did you use it?

about the diary, what are the words or the feelings that come first in your mind?

can you tell me the content of the diary that you remind yourself?

When you read it, have you had memories that came back in your mind?

What was the role of the diary in your memory of your ICU stay?

What pieces of information was the most useful in your recovery?

Did you keep it? Where?

What do you want to do with it the upcoming times?

Do you think that your life after your ICU stay would have been different without the diary?

Few months after your hospital discharge, is this diary a good or bad memory? Why?

Would you like to tell me something else about this diary?

Procedure for the qualitative analysis

A telephone interview was conducted 6 months after ICU discharge by a research psychologist (CV), using a semi-structured interview guide. All calls were centralized at Saint Joseph Hospital Network in France. Interviews were audio-recorded with participants' consent. This technique was chosen to enable enough freedom for patients to express their experience in their own terms, while providing reliable, comparable qualitative data.

The collected transcribed interviews with the patients that were meeting the above inclusion and exclusion criteria have been subjected to Braun and Clarke's general thematic approach in qualitative research [1]. Thematic analysis is often used in mixed-method designs, mostly for its theoretical flexibility, which makes it appropriate for this part of the study, especially given the large number of interviews anticipated. This method should allow the emergence of a reliable and valid framework for capturing patients' subjective experience of the diary, which may not seem obvious from the raw data. According to the authors, a thematic analysis consists of systematically identifying, grouping and examining the themes and patterns of meaning within a body of texts (in this case: the patient interviews). It has two main functions. One is the identification of all recurring themes linked to the research question (although relevance to the research question as determined by the researchers' judgment prevails over prevalence or recurrence). The other is to understand the links and possible oppositions between themes. Coding is the primary process for developing themes. This is done by identifying items of analytic interest in the patients' verbatim and linking them to a coding label. In the inductive approach, coding is done without trying to fit the data into a pre-existing theoretical framework [2, 3]. Codes are then regrouped into overarching themes, ultimately drawing a « thematic tree », which accurately depicts the explicit (semantic) and underlying (latent) meanings identified and interpreted by the researcher.

In total, over the 101 interviews analysed, their prevalence in the transcripts lead to identifying 6 main themes. Among these, 3 themes (4, 5, 6) were selected for the critical insight they provided about results of the randomized multicentre trial [4] by a qualitative approach of the perception of their diary by the survivors.

Major themes revealed by the analysis:

1. The difficulty of the ICU experience
2. The importance of caregivers and relatives during intensive care
3. Recovery and life after intensive care
4. Reading the diary: between emotion and pain
5. How the diary helped
6. The bittersweet representation of the diary

Table 1. Characteristics of the patients

Variables	Intervention group Randomized study N=164 ^a	Intervention group Qualitative study N=101	P-value
Demographics			
Age, years, median (IQR)	62.5 (49.5-70)	64 (53-70)	0.45
Gender			0.65
Male gender	110 (67.1)	65 (64.4)	
Women gender	54 (32.9)	36 (35.6)	
Severity of illness on admission			
SAPS II, median (IQR)	51.5 (38.5-66.5)	52 (40-64)	0.88
Patient status			0.77
Medical patients	122 (74.4)	79 (78.2)	
Scheduled surgery	7 (4.3)	4 (4)	
Unscheduled surgery	35 (21.3)	18 (17.8)	
Main symptom at admission			0.95
Acute respiratory failure/COPD)	75 (45.7)	42 (41.6)	
Shock and multi-organ failure	66 (40.2)	41 (40.6)	
Acute renal failure	1 (0.6)	0 (0)	
Coma	12 (7.3)	9 (8.9)	
Monitoring/Scheduled Surgery	1 (0.6)	0 (0)	
Metabolic	2 (1.2)	2 (2)	
Trauma	7 (4.3)	3 (3)	

ICU events			
Self-extubation	11 (6.7)	5 (5)	0.56
Weaning failure and re-intubation	18 (11)	7 (6.9)	0.27
Unexpected cardiac arrest	9 (5.5)	3 (3)	0.34
Episode of delirium ^b	56 (34.1)	30 (29.7)	0.45
Fall	4 (2.4)	1 (1)	0.40
Physical constraints	121 (73.8)	75 (74.3)	0.93
MacCabe score ^c			0.85
No fatal illness	125 (76.2)	80 (79.2)	
Fatal illness within 5 years	35 (21.3)	19 (18.8)	
Fatal illness within 1 year	4 (2.4)	2 (2)	
Knaus score ^d			0.94
No limitation	79 (48.2)	48 (47.5)	
Moderate limitation	66 (40.2)	43 (42.6)	
Severe limitation	14 (8.5)	8 (7.9)	
Total dependency	5 (3)	2 (2)	
Treatment, days, median (IQR)			
Mechanical ventilation	9 (6-15)	8 (5-15)	0.20
Non-invasive ventilation	0 (0-3)	0 (0-3)	0.40
Fentanyl	6 (3-11)	5 (3-10)	0.23
Benzodiazepines	3.5 (2-8.5)	4 (2-8)	0.77
Propofol	1 (0-3)	0 (0-2)	0.08
Duration of ICU stay, days, median (IQR)	14 (9-22)	13 (8-21)	0.38
Duration of hospital stay, days, median (IQR)	29 (16-49)	25 (16-44)	0.26

DFLST	4 (2.4)	2 (2)	0.81
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Abbreviations: IQR, Inter Quartile Range; SAPS, Simplified Acute Physiologic Score; COPD, Chronic Obstructive Pulmonary Disease; ICU, Intensive Care Unit; DFLST, Decision to forgo life-sustaining treatment

^a Among the 193 alive patients at ICU discharge, 164 patients were included in the quantitative study assessing the psychological consequences of the ICU stay at 3 months (17) 191 patients were alive at 6 months and 101 patients were included in the qualitative study

^b Episodes of delirium were diagnosed using the Confusion Assessment Method for the Intensive Care Unit

^c Based on the McCabe score, which explores subjective prognosis of comorbid conditions at ICU admission

^d Based on the Acute Physiology and Chronic Health Evaluation score

Table 2. Patients outcomes assessed on day 90.

Variables	Intervention group Randomized study N=164 ^a	Intervention group Qualitative study N=101	P-value
Primary outcomes			
Presence of PTSD symptoms ^a	49 (29.9)	30 (30.9)	0.86
IES-R score ^b , median (IQR)	12 (5-25)	12 (6-25)	0.78
PTSD symptoms, median (IQR)			
Intrusion	5 (2-9)	5 (2-9)	0.74
Avoidance	4 (1-9.5)	4 (1-9)	0.72
Hyperarousal	2 (0-6)	2 (0-5)	0.89
Secondary outcomes			
	N=163	N=99	
HADS ^c score, median (IQR)	9 (5-14)	8 (4-12)	0.46
HAS ^d score, median (IQR)	5 (2-8)	4 (2-7)	0.23
HAD ^e score, median (IQR)	4 (1-7)	4 (1-6)	0.95
Symptoms of anxiety			0.22
Yes	51 (31.3)	24 (24.2)	
No	112 (68.7)	75 (75.8)	.
Symptoms of depression			0.71
Yes	31 (19)	17 (17.2)	
No	132 (81)	82 (82.8)	

Abbreviations: IQR, Inter Quartile Range; PTSD, Post-Traumatic Stress Disorder; IES-R, Impact of Event Scale-Revised; HADS, Hospital Anxiety Depression Scale; HAS, Hospital Anxiety Scale; HAD, Hospital Depression Scale

^a Among the 193 alive patients at ICU discharge, 164 patients were included in the quantitative study assessing the psychological consequences of the ICU stay at 3 months (17) 191 patients were alive at 6 months and 101 patients were included in the qualitative study

^b IES-R, possible range score 0 (best)-88 (worst)

^c HADS, possible range score 0 (best)-42 (worst)

^d HAS, possible range score 0 (best)-21 (worst)

^e HAD, possible range score 0 (best)-21(worst)

Table 3. Verbatims theme 1: Reading the diary: between emotion and pain

Number	Verbatims
1	<p>Patient 3 male, 63 years old)</p> <p><i>“It was very comforting to see that I was supported. (...) to feel that people had been close to me and that they lived this period with me. (...) The (strongest) thing is the words from the relatives (...) people informed me of everything that was happening day by day. (...) Above all, it was the words of empathy and affection that I found (in the diary) that warmed my heart. (...) It is something very, very positive, after coming out of a coma, to know what had happened and to feel all this kindness around you”.</i></p>
2	<p>Patient 4 male, 55 years old</p> <p><i>“Whenever I would try to read it, I would have to read it several times, because it would hurt reading it, and it reminded me of things, and I would remember all these nightmares, and I then had trouble sleeping at night.”</i></p>

Table 4. Verbatims theme 2: How the diary helped

N	Verbatims
1	<p>Patient 6 male, 72 years old</p> <p><i>“It allowed me to fill in a period of time, an absence. (...) It allowed me to see by myself what did not happen, to see a period when I lost consciousness. (...) It is a testimony and an observation of what I experienced and what people experienced around me.”</i></p>
2	<p>Patient 7 male, 57 years old</p> <p><i>“It is a testimony to what happened. (...) Testimony, this is what comes up for me the most. It is important. It is not a joke. (...) It is important. In fact, it’s a whole, and I have a precise idea of what happened. If I had seen the doctors at the end of my hospitalization, well, that would have been it. (With the diary)</i></p>
3	<p>Patient 8, male, 54 years old</p> <p><i>A piece writing that stays for life, it's like a health diary, you have your pedigree on it. It will stay forever. I have it just next to me, I like it. For the moment, I like to see it. There are bad and good memories. Later on, maybe I'll move over this. Here, it is on my table, and I can see it, and it does me good. I need to see it, it does me good. I know what's behind me.”</i></p>
4	<p>Patient 9, male, 70 years old</p> <p><i>If I hadn't had the diary, I would have had to stay with what I saw, in real life (other than my hallucinations). While (with the diary), it is the true story. (...) It made me see things, reality. (...) It is a good memory in the sense that it is a reality, and that (with it) I can learn about what happened during the time I was</i></p>

	<p><i>asleep. (It was useful) information about what happened while I was in the ICU. Everyone wrote a word. (...) nurses and other caregivers. They did not have the same behaviour, the same view on things. (...) I would say that it is useful because it allows you to see what happened. (...)</i></p>
5	<p>Patient 10, female, 60 years old</p> <p><i>“(What left the strongest mark in the diary) is the description of the initiatives of the medical staff, practically hour by hour. (...) I knew what happened during the coma since everyone wrote a note, every single person who took care of me, even the doctor who intubated me when I fell into a coma. (...) The others, the nurses and all the care they provided me with, the date, the first name, what they did to me (...). Everything was reported in the diary. Every day, during these 10 days, everything was written down. (...). This is how I could know (what was done to me) during these 10 days. My family could not have told me, because they were not present from morning until evening. While there, with the diary, I could know everything from the first day up to waking up from the coma.”</i></p>
6	<p>Patient 11, female, 71 years old</p> <p><i>"It is a great help to know how things happened and not just to know it from the eyes and words of our relatives. It is interesting to have an objective point of view, to have more information, to see a bit of the room itself, to see all the equipment that is used. This gives you an afterwards understanding (of what happened), since you weren't aware (of it) during the time (of the hospitalization)."</i></p>
7	<p>Patient 7 male, 57 years old</p> <p><i>I had the flu. I almost died because of it, when generally it is not fatal. I came</i></p>

	<i>back home I had told myself it was not serious. When I read the diary, I saw that it was, in fact, very serious. (...) To know how people around me reacted (to my medical state), made me realize that I almost died, and it is a shock."</i>
8	Patient 12 female, 67 years old <i>"What I saw in the diary, well, that was finished, it was finished. I am happy to have been saved. (...) This is useful, because (without the diary) I would never have known how much the nurses do to save a person. (...) They took good care of me, they devoted themselves to bringing me back to life"</i>
9	Patient 14 female 71 years old <i>"At that moment, I said that I wanted to see the blue diary, and when I started to read it, I said: phew! Finally, things that I had not understood got back in place. The diary allowed me to make mine the story of what happened to me during my stay, and understand that no one wanted to attack me or kill me, but only to save me, only in a way that I experienced very badly."</i>
10	Patient 15 female, 65 years old <i>"When I was not well, in pain for example, I would read the diary, and read what my grand-daughter had written, and it would give me strength, it would boost me. (...) (The medical teams) had written a few encouraging words. It gave me the strength to fight. (...) It really helped, I can tell you, it gave me strength and courage."</i>
11	Patient 9, male, 70 years old <i>"My wife wrote almost every day. I said to myself: she still loves me! And then the words from the nurses, the doctor, the whole medical team. I have good memories of (the diary). (...) (My first impression when reading it for the first</i>

	<p><i>time is) that there were a lot of people taking care of me, and I was in awe of them. (What I liked the most in the diary) is a whole, it is (to see my) everyday life (during hospitalization), what was happening, how they took care of me. Yes, a lot of people around me.”</i></p>
12	<p>Patient 8 male 54 years old</p> <p><i>“You are not alone. You are accompanied. It feels good to see that.”</i></p>
13	<p>Patient 17 male, 53 years old</p> <p><i>“It is a great support and comfort (to read the messages), because after 41 days of ICU, there is life, and you discover that there are many people who love you.”</i></p>
14	<p>Patient 18 male, 42 years old</p> <p><i>“It touched me because I didn't think people cared about me. (...) What I appreciated, was (to see) that some people came to see me, and I realized that they cared about me.”</i></p>
15	<p>Patient 3 male, 63 years old</p> <p><i>“It was very comforting to see that I had been supported by others. (...) When I read (the diary) for the first time, when I got out of the coma, it supported me, and it helped me recover. (...) It was very motivating to see that people had been close to me and it helped me fight to get better. (...) I find it rather positive, and it can help people when they get out of a coma.”</i></p> <p><i>"It was very motivating to see that people were close to me, and that helped me to fight and to get back up as quickly as possible. (...) This is something that allows you to hang on a little longer.”</i></p>
16	<p>Patient 16 male, 70 years old</p>

	<p><i>“(Reading the diary) was very comforting, and it touched me. (...) (The diary) is often with me. When I am a little down, I read it. (...) especially when morale is low, I take it, it helps me to cheer myself up (...) I read little parts of it (...) I read it, and I turn my back, and I tell myself that I am going to have to get back up, put in a little effort, take my medicines without forgetting them, not like before. It is as if I had a doctor at home. Instead of going to see the doctor, I read the book and it calms me down a bit.”</i></p>
17	<p>Patient 12 female 68 years old</p> <p><i>“If I was able to do it there (in the ICU), I am able to gain strength and confidence in myself, here, at home. (...) When you come back home, you don't have (the support of the caregivers) around you anymore. You're a bit lost. And when you read the diary, you are reminded of your journey, and that gives you a little more strength. That's how I used it. It's very interesting to read, it gives you a lot of strength. You tell yourself: the progress you've made, you've made it on our own, with some help, of course, but you fought for your life (...) Everything I did there (in the ICU), I can do it at home. It gave me a lot of strength, (...) confidence and strength (...), courage.</i></p>

Table 5. Verbatims theme: the bittersweet of the diary

N	Verbatims
1	Patient 19 male, 74 years old <i>“I’ll keep it forever. It will forever be a part of my life”.</i>
2	Patient 20 male, 38 years old <i>“The nurse who puts a word (in the diary) to wish me good luck, it is a more human, more personal side, which we do not necessarily have with the scientific discourse of the doctors, which is professional, but we don't need that as patients.”</i>
3	Patient 17 male, 53 years old <i>“(The diary) is by my side all the time. Even if I don't open it, it's there. (...). I won't tell you it reassures me, but it's always close to me. I can't even explain it to myself. It could be in a drawer, but it's next to my phone. I don't have to open it, but I know it's there. It is not a coincidence, it is voluntary. I will not say that (the diary) reassures me, but it is close to me. I can't explain it. It could be in a drawer, but it is next to my telephone. I do not have to open it, but it is there.”</i>
4	Patient 21 male, 70 years old <i>“When I am a bit down, I read the diary, I take the time to read it, to dissect each word, each sentence. (...) And I react to it in a way, and another day I react to it in another way, it depends on my mood. Sometimes I hide it, and then I search for it. (...) Sometimes, I put it aside (...). It's almost like there is someone by my side. It did me a lot of good.”</i>
5	Patient 23 male, 71 years old

	<p><i>"I would say that (the diary) is rather a bad memory. (...) It reminds me ... yes ... of bad times ... because after I woke up (from the coma), I suffered (...) physically, and morally. (...) Absolutely, (the diary reminds me of this suffering)</i></p>
6	<p>Patient 24 male, 42 years old</p> <p><i>"Today I have found again a taste for life, so I don't see the point of stirring up things that are painful. (...)."</i></p>
7	<p>(Patient 6 male, 72 years old)</p> <p><i>"The diary is a good memory, but I find it hard to read it again or talk about it. I try not to forget it, but to put it aside. It is a good memory. This diary is about a period of time which was not very happy for anyone. Now I am much better and I do not feel the need to plunge back into this period."</i></p>
8	<p>Patient 5 male, 67 years old.</p> <p><i>"(The diary makes me think) of difficult times. (A moment) in which you are not really conscious, but which has passed, (...) which has hurt those who were in my family (...) (because) they thought I was going to die. (...) Perhaps I should try to forget it. (...) It's at the very bottom of my soul, I am not always going to keep it on the forefront".</i></p>
9	<p>Patient 24 male, 42 years old</p> <p><i>"Today I have found again a taste for life, so I don't see the point of stirring up things that are painful. (...)."</i></p>
10	<p>Patient 25 female, 65 years old</p> <p><i>"It is nice to have it, to have a look at it, but I cannot say that it is of precious help. I cannot say it is extraordinary. Had I not had it, it would have been the same. It's good, it's nice, but hadn't it had it, it wouldn't have changed</i></p>

	<i>anything."</i>
11	<p>Patient 26 male, 44 years old</p> <p><i>"What can I say... nothing extraordinary? Nothing special. I woke up (in the ICU) and that's it. It's my wife who told me I was in the ICU for 3 days. What had happened and all...and that's it! That's it. After that I stayed for a week at the same hospital. And then I left. (...) Well that's just it, I was not shocked psychologically, that's just the way it was. I had a heart attack, that's it! An infarction, that's it! I had a stent, and I am still here! That is just it. (...) I don't even think about it...why would I? (...) (About the diary:) No, I may have read it ... but I don't know anymore ... it did not trigger my interest no more than that. (...) No, I no longer know, I would have to ask my wife. It doesn't really worry me. (...) No, no, I didn't focus on it, I didn't fixate on it."</i></p>
12	<p>Patient 27 female, 85 years old</p> <p><i>"The diary can help some people. Personally, I know I have a strong enough character to recover on my own."</i></p>
13	<p>Patient 28 female, 57 years old</p> <p><i>"I don't necessarily need it. If I have a conversation with my partner about (the ICU period), I use my own memories or what I have been told by people."</i></p>

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