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**Perspectives of patients and family members regarding psychological support using intensive care diaries**

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**TITLE: Perspectives of patients and family members regarding psychological support using intensive care diaries: an exploratory mixed methods study**

**RUNNING TITLE: Perspectives on ICU diaries**

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**CONFLICT OF INTEREST:**

The authors declare that they have no conflict of interest

## **Abstract**

**Purpose:** Diaries summarising intensive care are routine practice in some countries, although evidence to support diary use is limited. The purpose of this study was to identify whether distress post-intensive care influences patients', and relatives' choice as to whether they would like to receive a diary and what information delivery method is preferred.

**Materials and Methods:** Intensive care patients admitted for  $\geq 3$  days, and their relatives participated in an exploratory mixed-methods study. Interviews were conducted 3-5 months after discharge. Psychological distress was assessed using Kessler10 and Post-traumatic Stress Disorder Symptom Checklist –5. Perceptions of benefit of diaries were assessed using a four-point Likert scale. Differences were examined using Fisher's exact test ( $p < 0.05$ ).

**Results:** Fifty-seven patients and 22 relatives consented to participation, with 22 patients and 22 relatives interviewed prior to data saturation. Psychological distress was evident in 25(47%) patients and 5(23%) relatives. Participants' psychological health was similar for those who perceived diaries as beneficial, and those who did not. Themes included memory, process, impact, although opinions were diverse.

**Conclusions:** Patient and relative preferences of receiving a diary are not related to psychological distress. Diverse opinions around common themes suggest the need for a range of interventions to aid psychological recovery.

## **Keywords**

Recovery, Post-traumatic stress, Anxiety, Depression, Intensive care, Intensive care diaries

## **INTRODUCTION**

Physical and emotional recovery from critical illness can be complex and prolonged. Survivors of critical illness and their family members frequently experience significant psychological distress, including anxiety, depression and post-traumatic stress that may continue for some time after Intensive Care Unit (ICU) discharge [1-3].

After ICU admission, many patients struggle to remember events that led to, and occurred during, their ICU stay [4]. Patients are often left with delusional memories of their ICU experience, caused by a milieu of stress, pain, illness and medications [4]. During a patient's ICU stay, family members need to comprehend and remember a new language of medical terminology, during a time when they are already under stress and experiencing new events and activities for the first time. Family members consistently report a need for improved communication with the interdisciplinary team during ICU admission [5, 6].

Intensive care diaries have been proposed to provide a written and/or pictorial account of patients' ICU experience, in order to improve communication and promote psychological recovery for patients and family members [7-10]. Although ICU diaries have been incorporated into routine care in many European countries, the diary format, content, timing and method of delivery vary considerably [9]. The effectiveness of intensive care diaries to improve psychological recovery for patients and carers has not been established [10], with only two RCTs [7, 11], one case-control [12] and one meta-analysis [10] undertaken. However, prevalent reports of patient and clinician acceptability and satisfaction have overshadowed the lack of information regarding their safety and effectiveness [9].

Published studies to date have provided preliminary evidence that intensive care diaries likely provide benefit to some patients [7, 11], although rates of patient inclusion in some studies has been low [9]. Further, patients recovering from ICU are a diverse and vulnerable population and psychological interventions can have a powerful positive, negative or mixed impact on a patient's recovery. Giving patients an ICU diary as a tool to promote recovery assumes that patients want to know about what happened whilst they were in ICU, and that this knowledge is beneficial [7]. However, the limited research suggests only 50% of patients wanted to know more about their ICU experience [13, 14]. In addition, accurate memory has not been consistently demonstrated to improve recovery [15, 16]. Providing large quantities of variable information to a patient already suffering from significant distress, without appropriate support, may inhibit recovery [17].

ICU diaries need to be developed in a manner that ensures safety, and be targeted at those who are most likely to benefit [9]. This study of ICU survivors and their families, from one Australian ICU, sought to elicit views and preferences of diaries, by identifying: a) which patients and family members would wish to receive a diary, b) whether distress post-ICU influenced patient and family members choice regarding receipt of a diary, c) what content should a diary include, and d) practical considerations regarding receipt of information, either in a diary or alternative format.

## **MATERIAL AND METHODS**

### **Study design**

An exploratory, mixed methods study was undertaken in a large tertiary, metropolitan hospital in Brisbane, Australia. The study was approved by the Metro South Health (HREC/13/PAH/694), Griffith University (NRS/13/14/HREC) and University of Queensland (2014000520) Human Research Ethics Committees.

### **Participants**

Participants were recruited in two groups – ICU patients and family members. Patients with an ICU length of stay  $\geq 3$  days and who were expected to survive to hospital discharge were eligible for inclusion in the study while family members were required to be the nominated family member of patients who met the inclusion criteria. Both patients and family members were aged  $\geq 18$  years; able to speak and understand English and accessible for interview (in person or by telephone).

### **Phase 1: Psychological measures**

Psychological distress was measured using Kessler-10 Psychological Distress Scale (K10) [18] and the Post-Traumatic Stress Disorder Symptom Checklist – Civilian V5 (PCL5) [19]. K10 is a ten-item self-report cumulative scale calculated by the frequency of distress symptoms; with a total score range one to 50, with higher scores indicating greater distress. The symptoms measured include depressed mood, motor agitation, fatigue, worthless guilt and anxiety [18]. PCL5 is a 20-item self-report measure that assesses the symptoms of post-traumatic stress disorder, as described in the DSM-5 [20]. To be categorised as symptomatic, symptoms must be evident across the clusters of intrusion, avoidance, negative alterations in cognitions and mood and alterations in arousal and reactivity [20]. Participants with a K10 score greater or equal to 20 (indicating mild to severe distress [18]) and/or a PCL5 meeting the criteria of being ‘symptomatic’ were categorised as ‘distressed’.

Participants also indicated if they considered an ICU diary would have been helpful in their recovery using a four-point Likert-type scale (1=not interested, 2 = somewhat not interested, 3 = interested,

4=very interested). For categorical analysis categories 1 and 2 were grouped as 'not interested' and categories 3 and 4 as 'interested'.

## **Phase 2: Interviews**

Exploratory interviews were undertaken to gain a rich understanding of the ICU patients and family member views of the potential benefits of ICU diaries and thoughts regarding content, contribution and timing. Questions that guided the interview included:

- Would you have liked to receive a diary summarising your/your family members' ICU stay?
- If you were to receive a diary, what content would you like to have incorporated into the diary?
- If you were to receive a diary, at what time point would you like to receive this diary?
- Would you like to have photos of yourself/your family member in ICU included in the diary?
- Who would you like to write in your diary? (e.g. family members, ICU nurses, any ICU staff)
- Do you have any other thoughts about the potential value or content of ICU diaries for patients?
- Is there an alternative format that you would have liked to have received information about your/ your family members' ICU stay?

## **Data collection**

Patients and family members were approached for informed consent either upon awakening in ICU or after transfer to a ward, and was reconfirmed at the beginning of each follow-up contact. Participants were then followed up three to five months after ICU discharge. Questionnaires were sent to participants via electronic or conventional mail, and then followed-up via telephone. The order of content of follow-up was standardised with information regarding the general format and content of a potential ICU diary initially provided. Thereafter participants reported their previously completed self-report questionnaires relating to psychological distress over the past 30 days (i.e., K10 and PCL5), finally diary preferences were recorded. Interviews were conducted in person, or by phone, with both options available to increase ease of participating and reduce discrimination against potential participations who lived long distances from the hospital. Interviews were conducted as soon as possible after the completion of the psychological distress questionnaires and lasted for an average of 11 minutes (range 3 to 28 minutes). A second phone call was scheduled if the participant requested completing the interview in stages rather than in a single contact.

## **Data analysis**

Demographic and clinical characteristics of the study population were summarised using the appropriate descriptive statistics. Psychological distress symptoms were described based on categories identified by the scale developers [18, 19]. A significant relationship between level of psychological compromise and patient desire for an ICU diary was determined using Fisher's exact test ( $p < 0.05$ ). Missing data were described throughout, and a sensitivity analysis was carried out to account for the impact of attrition ( $p < 0.05$ ).

Interviews were digitally recorded and transcribed verbatim. Brief review of the transcripts was undertaken as interviews were occurring to determine when no new priorities or issues were emerging in the interviews. Detailed analysis was not undertaken until after all interviews were completed. Data were analysed using thematic analysis focusing on themes and patterns concerning each of the research questions [21, 22]. Standard phases of thematic analysis were followed including familiarisation, code generation, searching, reviewing and defining the identified themes. Codes were developed inductively using an iterative process. Inter-coder agreement was achieved by two members of the research team (AU and MC) independently coding the transcripts, which were then discussed to ensure consistency. The sample size for the study was determined by achievement of data saturation for the qualitative interviews.

## **RESULTS**

Between May 2014 and April 2015, 2,171 patients admitted to the ICU were assessed for eligibility (Figure 1). Of these patients, 100 patients and 42 family members consented to participate at the end of their ICU stay. Due to attrition, 57 ICU patients and 22 family members participated in phase one (psychological distress and diary preference). Twenty-two participants from both groups continued to phase two (interviews) – recruitment for this phase of the study stopped when no new themes were being identified during the interviews.

### **Participant demographics**

The majority of ICU patient participants' were male (63%) and had a mean age of 53.8 years (standard deviation (SD) 16.2). Most patients were mechanically ventilated (91%) and had a median APACHE III score of 60.0 (interquartile range (IQR) 47.5, 79.0) (Table 1). Family member participants were predominantly female (82%) with a mean age of 49.7 years (SD 12.2). There were no differences in demographic or clinical characteristics of ICU patient participants' who were lost to follow-up and those who participated in phase one of the study.



**Table 1: Demographic and clinical characteristics of participants (n=122)**

<b>Characteristic</b>	<b>Frequency (percentage)</b>	
	<b>Followed up (n=57)</b>	<b>Lost to follow up (n=43)</b>
<b>Patients (n=100)</b>		
<b>Gender</b>		
Male	37 (65)	26 (61)
Female	20 (35)	17 (39)
<b>Age (years) mean (SD)</b>	53.7 (14.8)	54.0 (18.1)
<b>APACHE III median (IQR)<sup>a</sup></b>	60.0 (47.5-79.0)	53.0 (41.0-81.0)
<b>Reason for ICU admission</b>		
Medical	22 (39)	20 (46)
Surgical elective	6 (10)	5 (12)
Surgical cardiac	8 (14)	1 (2)
Surgical emergency	5 (9)	5 (12)
Trauma	16 (28)	11 (28)
<b>Mechanical ventilation</b>		
No	7 (12)	2 (5)
Non-invasive	2 (4)	3 (7)
Invasive	48 (84)	38 (88)
<b>ICU length of stay median (IQR)</b>	7.0 (4.4-10.6)	6.2 (4.3-9.3)
<b>Hospital length of stay median (IQR)</b>	21.5 (15.7-41.6)	26.2 (17.3-35.6)
<b>History of mental health difficulties<sup>a</sup></b>	15 (26)	-
<b>Family members (n=22)</b>		
<b>Gender</b>		
Male	4 (18)	-
Female	18 (82)	-
<b>Age (years) mean (SD)</b>	49.7 (12.2)	-
<b>Relationship to patient</b>		
Spouse / partner	14 (64)	-
Parent	4 (18)	-
Child / offspring	1 (5)	-
Other	3 (14)	-
<b>History of mental health difficulties</b> (interview participants only)	5 (23)	-

ICU=intensive care unit; IQR= interquartile range; SD=standard deviation  
<sup>a</sup>42 participants lost to follow-up

**Diary preference and psychological health**

Three to five months after ICU admission the majority of ICU patient participants indicated that an ICU diary would have been helpful to them in their recovery (83%; n=47; Table 2). At this time 47% of ICU patient participants (n=27) had psychological distress (using the PCL-5 or the K10). However, we did not find a statistically significant association between patients' psychological distress and their preference for an ICU diary in this small sample (p=0.08).

**Table 2: ICU patient participants psychological health and diary preference (n=57)**

	<b>Diary- helpful (n=47)</b> Frequency (%)	<b>Diary – not helpful (n=10)</b> Frequency (%)	<b>p-value<sup>a</sup></b>
<b>PCL – 5</b>			
Symptomatic	6 (13)	1 (10)	1.0
Asymptomatic	41 (87)	9 (90)	
<b>K10</b>			
Distressed	24 (51)	2 (20)	0.09
Not distressed	23 (49)	8 (80)	
<b>Psychological distress<sup>b</sup></b>			
Yes	25 (53)	2 (20)	0.08
No	22 (47)	8 (80)	

<sup>a</sup>Fisher’s exact; <sup>b</sup>K10 $\geq$ 20 and/or symptomatic PCL-5

Similarly, three to five months after a family members’ ICU admission, the majority of family member participants expressed that an ICU diary would have been helpful in their recovery (82%; n=18; Table 3). Twenty three percent of family member participants reported symptomatic levels of psychological distress, although no statistically significant relationship between distress and diary preference was found in this small sample (p=0.54).

**Table 3: Family participants psychological health and diary preference (n=22)**

	<b>Diary- helpful (n=18)</b> Frequency (percentage)	<b>Diary – not helpful (n=4)</b> Frequency (percentage)	<b>p-value<sup>a</sup></b>
<b>PCL – 5</b>			
Symptomatic	2 (11)	0 (0)	1.0
Asymptomatic	16 (89)	4 (100)	
<b>K10</b>			
Distressed	5 (28)	0 (0)	0.54
Not distressed	13 (72)	4 (100)	
<b>Psychological distress<sup>b</sup></b>			
Yes	5 (28)	0 (0)	0.54
No	13 (72)	4 (100)	

<sup>a</sup>Fisher’s exact; <sup>b</sup>K10 $\geq$ 20 and/or symptomatic PCL-5

### Perceptions of diaries

Participants raised consistent themes regarding diaries, although with diverse opinions. Many ICU patient participants reported positive perceptions surrounding the use of diaries to promote memory

and recall of ICU and their progress. It was also considered a tool to help discriminate between reality and hallucinations, illusions and delusions. Patients viewed the diary to be a therapeutic tool that belonged to them rather than their family members (Table 4). Patient participants who did consider a diary to be potentially beneficial generally thought they should receive the diary a substantial period after ICU discharge, but their opinion regarding this period ranged from weeks to months later; they also felt it beneficial to have the content explained to them and questions answered at the time of receipt of the diary. In contrast, other ICU patient participants were reluctant to dwell on the past as they found any reminder of the critical illness was stressful. Others reported a lack of interest in what happened during their critical illness and considered that ICU diaries were not appropriate for everyone. There was mixed opinion regarding the appropriateness of including details such as photos.

**Table 4: ICU patients’ perceptions of intensive care diaries (n=22)**

<b>Theme</b>	<b>Quotes</b>
Memory and recall	P13: “Help me fill in the gaps” P41: “Pin more things together”
Reflective and inspirational tool; documentation of improvement	P20: “I would read it from time to time if I was feeling down or.. confused.” P21: “Help as I’m progressing to think wow I have come a long way. At times when you get frustrated and think this is taking forever, if you could pick up something like that and read it, you’d think wow, I have come a long way, you’re doing good.”
Discriminate between reality and fantasy	P20: “Help ground me and bring me back to reality” P31: “It’s a jigsaw and what you remember is not right. I would like to know who was there and what was going on”
Outlet and communication tool for family	P1: “Helping family deal with stress. Just as a means to kind of record and express their emotions and manage them”
Reluctant to dwell on the past	P18: “It is something I’d rather move ahead with and put behind me. I don’t want to have to dwell on the period of time I spent in there too much. It can be quite stressful and upsetting just depending on what frame of mind you’re in at the time” P31: “I don’t really want to know the honest truth. I just want to move on”
Lack of interest	P8: “It wasn’t something I ever tried to remember. I’m not really curious about what happened in ICU” P15: “It’s just something that’s never crossed my mind. I’ve never really cared enough about it. It is just move on, keep going”
Not suitable for everyone	P18: “Everyone is different and you could make the call yourself as to when you and if you wanted to read that diary”

Family members expressed different concerns (Table 5). Family members reported that the ICU diary was potentially an active, continuing reference tool to promote communication between healthcare workers and family, and therefore perceived it as something that remained with the patient and family throughout the ICU and hospital journey rather than being provided at a later point in time. They also envisaged its use as an instrument to promote understanding of the ICU and hospital processes. Similarly to the patient participants, several family member participants reported a reluctance to dwell on the past and an opinion that ICU diaries would not be suitable for everyone.

**Table 5: Family members’ perceptions of intensive care diaries (n=22)**

<b>Theme</b>	<b>Quotes</b>
Active, continuing reference tool	R16: “So we knew what went on each day. Things changed, then you could look back and go, when did that happen?” R14: “Keep track of what the doctors were saying to me, only because they use big words and terminology. Sometimes I don’t understand what they mean. Maybe writing it down I would have remembered more”
Understanding of the process	R40: “At the beginning... I was in the dark a lot. I wasn’t told anything for ages. I think to have everything actually written down and explained that ways things would have been made a lot easier” R12: “Just really to try and understand a bit more, because it all flashes like a movie sometimes... You really want a bit more understanding”
Communication tool for the family	R40: “Trying to explain to family members what you’ve just been told – and you can’t fully remember”.
Demonstrate their dedication to the patient	R3: “We didn’t miss a day. It would have been good for him to see how often we did come, to show him how much we cared for him and who else did visit while he was there”
Reluctant to dwell on the past	R9: “Because we want to forget about it rather than remember how it was, because it was a really depressing time”. R20: “Sometimes you don’t want to be reminded of, just move on. The thing is at the end of the day we remember what we want to remember, and if we can forget the bad times...”
Not suitable for everyone	R16: “Everyone is different”

### **Similarities and differences in patients’ and family members’ views**

Although many of the themes raised by patients and family members were similar, there were also important differences. These differences were identified in the purpose, content, ownership and timing

of delivery of a diary. Patients were more likely to view the diary as a therapeutic tool while family members considered it as an information sharing mechanism, including as a mechanism to demonstrate to the patient 'how sick he really was' and 'what he put us through'. Possibly as a result of these differences, patients considered that ownership of the diary rested with them while some relatives envisaged shared ownership. Patients were more likely to note that the diary should not be provided to them until some weeks after ICU while relatives considered an early time point soon after ICU discharge to be appropriate. Patients were more likely to raise concerns about the potential negative impact of information sharing strategies including diaries and other strategies such as return visits to the ICU.

## **DISCUSSION**

In this exploratory mixed methods study we examined whether patients and family members believed they would have liked to have received a diary after their time in ICU and whether this preference was related to psychological distress. Further, we explored the views of patients and family members regarding the benefits and practice considerations such as content, format and timing of receipt of diaries and other information sharing strategies. Fifty-seven patients and 22 family members participated in one or more phases of this study.

The frequency of psychological distress reported by patients in this study was 47%, which is similar to the numerous reports of critical illness survivors' psychological health [14, 23-29]. We know less about the psychological health of family members after they have spent time supporting a relative in an ICU. In our small cohort 23% of family members reported psychological distress which is lower than that reported in some groups [30, 31], although similar to others [3]. Importantly, the prevalence of current psychological distress in family members is the same as the previous history of psychological difficulties these participants reported, and similar to the rate of mental health disorders reported in the Australian population (20% in previous 12 months, 45% during lifetime) [32]. Variation in instruments used to measure psychological distress may have influenced these differences. While distress is less prevalent, the need for support and intervention is highlighted, and this support should probably commence as soon as possible in the critical illness continuum.

We did not identify a statistically significant relationship between psychological distress and preference for a diary, although this may be due to the small sample size. Approximately 20% of both patients and family members clearly indicated that they did not wish to receive a diary. Further, a number of participants who withdrew from the study, or who refused participation prior to consent, indicated that they did so as they did not wish to be reminded of their ICU experience, suggesting these patients perceived an ICU diary as creating unwanted reminders and thus did not want to receive one these. Low rates of enrolment and/or high rates of withdrawal have been a feature of studies examining the benefits and experience of using ICU diaries [11, 33-35]; further exploration of the

perceptions and psychological status of this group of participants is difficult given ethical considerations. The high rates of withdrawal may be protective, as many of the cohort of ICU patient participants reported not wanting to “dwell on the past” as it brought up difficult memories, or may indicate psychological compromise such as avoidance of reminders, a core symptom of PTSD. This highlights the challenge of developing universal interventions to assist psychological recovery after critical illness.

ICU patient and family populations are heterogeneous, with different personal backgrounds, critical illness and recovery. Using ICU diaries as a “one size fits all” solution for psychological health recovery is unlikely to be appropriate for all. This concern was frequently described by participants. Diversity was also evident within ICU patient and family member pairs, with some family members being interested in contributing and receiving intensive care diaries, while their relatives were reluctant. Within our cohort family members often expressed a desire to use the ICU diary as a continuing, reflective journal throughout the patients’ journey through hospital and recovery. The differential benefit of diaries for relatives versus patients has been identified by some in the literature [8, 30], and creates logistical challenges when needing to provide a gap between when the diary information is collected and then re-introduced to the recovering patient.

This variety of opinion regarding the use of diaries has not been identified in previous studies, with no reports of psychological screening prior to provision of an ICU diary found in our literature search. Our data suggests that identification of the appropriate patients and family members to receive diaries is necessary for safety and effectiveness. To date there are inadequate data to determine the characteristics of patients for whom ICU diaries are the appropriate intervention to promote psychological health [10] and further studies to clarify these details are essential. Universally implementing an intervention, such as ICU diaries, in psychologically distressed patients who are currently not wishing to recall traumatic memories could be harmful. Until further evidence is available, individualised interventions, with relevant follow-up and referral through forums such as outreach clinics where they exist is likely to be the most appropriate strategy to support psychologically distressed patients.

This study has several strengths. Importantly we investigated the issue of perception of diaries by both patients and relatives, with analysis identifying the two groups separately. It is possible that patients and relatives require a different intervention. The study used valid, reliable tools to comprehensively measure multiple aspects of psychological health (anxiety, depressive and posttraumatic stress symptoms) over an adequate period. The study also had some limitations. First, attrition rates between recruitment at the end of ICU admission and follow-up were high (ICU patients 43%; family members 48%). However, these rates of attrition are similar to other recent longitudinal studies of ICU survivors [36, 37]. There was no discernible difference in the demographic and clinical characteristics

of the patients who completed the study compared to those who did not. It is not known if the patients who withdrew or were lost to follow-up had similar or different views to those who completed data collection. Second, this study was completed at a single site, which limits its generalisability. However this is a large, tertiary referral centre reflective of similar ICUs. Third, the sample size of the participants was small, but adequate to answer the qualitative goals of the study. Finally, the data collected during the interviews is limited to that prompted by the questions asked, although issues and concepts raised by participants were explored by the interviewer.

## **CONCLUSION**

Psychological distress after ICU admission remains a substantial and significant problem for both patients and family members. ICU diaries have the potential to be a therapeutic tool to improve the recovery of patients and caregivers after critical care. However, the identification of the appropriate cohort to receive them is important to promote their safety and effectiveness.

The promotion of psychological health after critical illness is complex. A multi-faceted strategy for psychological health promotion after critical illness should be considered. Whilst the optimal time to commence the prevention of psychological distress during critical illness is yet to be determined, it is likely that interventions should commence during ICU, continuing into the ward stay and follow-up. The prompt identification of patients and family members with signs of psychological distress is also essential. Once the cohort is identified, various resources and interventional therapies may be necessary to effectively minimise psychological distress experienced by patients and family members.

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## **CONFLICT OF INTEREST**

The authors declare that they have no conflict of interest





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