Journal Writing by Families of Critically III Patients: An Integrative Review

Hannah Nakashima, BSN Cara Gallegos, PhD, RN

BACKGROUND Families experience high levels of stress during a loved one's critical illness.

OBJECTIVE To provide an overview of current evidence on the use of journal writing as a coping mechanism for family members during a loved one's critical illness in a neonatal, pediatric, or adult intensive care unit. METHODS Five databases (MEDLINE, PsycINFO, CINAHL, APA PsycArticles, and Health Source: Nursing/Academic Edition) were searched to identify studies examining the benefits of journal writing for family members of critically ill patients. Eight eligible studies reported data from 426 relatives of critically ill patients.

RESULTS Regarding quality assessment, the quantitative studies met 73.1% of relevant quality criteria, whereas qualitative studies met 81.3%. Mixed-methods studies met 82.4% of quantitative and 55% of qualitative criteria. Various key themes were identified: communication and understanding, connection to the patient, emotional expression, creating something meaningful, and the importance of pictures and staff entries. Overall, writing in a diary seems to be beneficial for reducing psychological distress and posttraumatic stress disorder, but none of the studies found that it significantly decreased anxiety or depression. **CONCLUSIONS** The findings of this review suggest that having family members of critically ill patients write in a diary is a simple and cost-effective intervention that may improve their psychological outcomes. Critical care nurses are in a position to educate families about the potential benefits of writing in a diary. Future research would be valuable regarding the benefits of using a diary and an optimal approach for doing so in this population. (Critical Care Nurse. 2020;40[5]:26-37)

edical advances and technologies have vastly improved patient care and enhanced intensive care capabilities over the past 3 decades. An intensive care unit (ICU) can be a busy and frightening place for families, and family members of critically ill patients can experience substantial stress, anxiety, and depression, and posttraumatic stress disorder (PTSD)^{1,2} during the patient's hospitalization and after their discharge. These conditions may reduce quality of life and lead to social isolation, marital problems, unemployment, and long-term health problems.³

Intensive care units are a component of modern health care, and the demand for intensive care continues to grow. From 2006 to 2010, the number of critical care beds in the United States increased 15%, from 67 579 to 77 809.4 According to the Society of Critical Care Medicine, 4 5.8 million patients are admitted to an ICU each year in the United States. Recent estimates suggest that hospitals nationwide house

©2020 American Association of Critical-Care Nurses doi:https://doi.org/10.4037/ccn2020293

1500 neonatal ICUs (NICUs) with approximately 20 000 beds, 400 pediatric ICUs (PICUs) with 4044 beds, and 5686 adult ICUs with 77809 beds.⁵ Prematurity and very low birth weight (< 1500 g) account for 90% of admissions to NICUs. Approximately half of pediatric patients admitted to a PICU have a chronic condition; the most common diagnosis at admission is respiratory illness, followed by trauma, postsurgical care, infection, and fluid and electrolyte derangements. Cardiac, respiratory, and neurological conditions are common among patients in adult ICUs.4

Anxiety, stress, and depression are common emotions when a family member, regardless of their age, is in an ICU. In a systematic review, Roque et al⁶ found that parents of patients in a NICU experience feelings of guilt and shame, a high level of stress, and mood and anxiety symptoms. The prevalence of acute stress disorder in such parents is between 24% and 35%.7 In one study, 33% of fathers and 9% of mothers of patients in a NICU met the criteria for PTSD.8 Similarly, parents of children in a PICU report extreme anxiety, high stress, and PTSD. 9,10 Finally, relatives of adults in an ICU also experience substantial psychological distress, including symptoms of generalized anxiety disorder, depression, panic disorder, PTSD, and complicated grief.^{11,12}

Several interventions such as support groups, verbal and written information, and open visitation effectively decrease stress among family members. 13 Such interventions, however, usually require extensive resources that families often are not able to access.

Although people have been writing in diaries for centuries, the therapeutic potential of journaling was not recognized until the 1960s, when Dr Ira Progoff, a psychologist who studied under Carl Gustav Jung, discovered that his clients who recorded their emotions, anxieties, and fears were able to work through their

Authors

Hannah Nakashima is a clinical content specialist, Healthwise, Boise, Idaho. She was a nursing student and research assistant at Boise State University, Boise, Idaho, when this article was written.

Cara Gallegos is an associate professor, Boise State University School of Nursing, Boise, Idaho.

Corresponding author: Cara Gallegos, PhD, RN, Boise State University School of Nursing. 1910 University Dr, Boise, ID 83725 (email: caragallegos@boisestate.edu).

To purchase electronic or print reprints, contact the American Association of Critical-Care Nurses, 27071 Aliso Creek Rd, Aliso Viejo, CA 92656, Phone, (800) 899-1712 or (949) 362-2050 (ext 532); fax, (949) 362-2049; email, reprints@aacn.org.

emotions or situations much more quickly than those who did not write in a journal.¹⁴ Progoff began to offer workshops on the use of what he called the "intensive journal method."14,15 Although this method has been applied extensively in practice, only recently have researchers documented the physiological and psychological outcomes if its use. In their seminal 1986 study, Pennebaker and Beall¹⁶ were the first to document the benefits of expressive writing on physical health. Since then, more than 400 studies have demonstrated the benefits of such writing in a variety of populations.¹⁷ Research also supports the use of diaries to help patients in ICUs recover from

recover from
critical illnesses. Diaries provide a coherent narrative of
Most related the patient's ICU stay, clarifying gaps
studies indicate in memory and reducing the impact
that ICU diaries of patients' imagined occurrences
provide a coher- and hallucinations.
ent narrative of
the patient's ICU stay, clarifying gaps in memory and
reducing the impact of patients' imagined occurrences
and hallucinations.

Research suggests that writing in a
diary reduces patients' anxiety and depression,
about the effects of writing in a diary on family members
of critically ill patients. Therefore, the purpose of this
integrative review is to describe whether family members obtain any benefits from writing in a diary during
a loved one's critical illness.

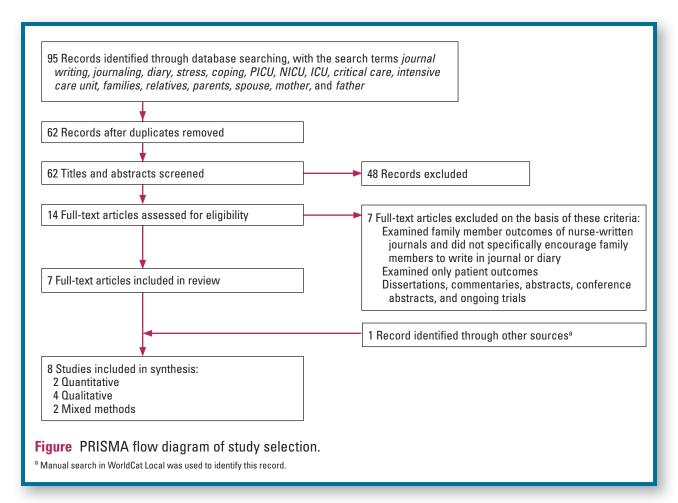
In this integrative review, we answer 2 research questions: (1) Does writing in a diary improve psychological
outcomes for family caregivers of critically ill patients in
an ICU? and (2) What are the benefits of writing in a
diary for relatives of critically ill patients in an ICU?

Methods

We show to perform an integrative review because it

Methods

We chose to perform an integrative review because it is the only method that allows the simultaneous inclusion of both experimental and nonexperimental research, which can help provide a fuller understanding of the phenomenon of concern. It also may play a larger role in evidence-based nursing practice.²¹ We searched 5 databases (MEDLINE, PsycINFO, CINAHL, APA PsycArticles, and Health Source: Nursing/Academic Edition) using the following keywords individually and in various combinations: journal writing, journaling, diary, stress, coping, PICU, NICU, ICU, critical care, intensive care



unit, families, relatives, parents, spouse, mother, and father. To identify other works of relevance, we used WorldCat Local to manually search for the references listed in the retrieved papers. The Figure illustrates the search process. We used methods from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses to guide this review.

Selection Criteria

We included peer-reviewed research articles related to the impact of diary writing on family members of

Diaries allowed family members to share information with each other, and rereading entries helped them assimilate and assess information, thereby improving the coherence of the ICU stay and filling in gaps in memories.

critically ill patients. Our searches were limited to Englishlanguage articles published after January

2000. We reviewed all articles that examined outcomes for family members who actively wrote in a diary, and

we excluded those whose primary purpose was to evaluate the impact of nurse-written journals or patientwritten diaries, and those in which family members were not instructed or encouraged to write. We also excluded dissertations, commentaries, abstracts, and conference abstracts.

Data Extraction, Appraisal, and Analysis

One author (H.N.) accessed the articles and extracted particular information from each: the study's purpose and design, the sample and setting, a description of the intervention, measurement tools, outcomes examined, and key findings. Both authors reviewed the articles. We assessed the quality of each article using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers From a Variety of Fields. 22 Qualitative studies could receive a maximal score of 20 (2 points for each of the 10 assessment criteria), whereas quantitative studies could receive a maximal score of 28 (2 points for each of the 14 assessment criteria). We assessed mixed-methods studies using both the qualitative and the quantitative criteria.

Studies received a total score that varied depending on the relevance of each criterion to the particular study. We assessed and scored each study separately, and through discussion we achieved consensus regarding study quality. After determining quality, we analyzed the content of each study, guided by methods described by Dixon-Woods et al,²³ to examine the extracted data for themes relevant to the questions of interest.

Results

By searching the various databases, we initially identified 95 articles, 33 of which were duplicate records. For the 62 remaining papers, we screened the abstracts and full text to assess their eligibility, after which we excluded 55 articles, leaving 7 eligible articles. The manual searches of the articles' bibliographies and reference lists identified 1 additional study for possible inclusion, and thus 8 studies were eligible for inclusion in this review (Figure). 24-31 Five of the studies examined relatives of patients in ICUs, 25,27-30 1 examined parents of critically ill pediatric patients in a PICU, 31 1 examined mothers of infants in a NICU,²⁶ and 1 examined relatives of patients undergoing coronary artery bypass graft surgery in a cardiothoracic ICU.²⁴ All studies were published between 2001 and 2018. Two studies were conducted in the United States, ^{24,26} 2 in France, ^{25,28} 1 in Sweden and the United Kingdom, ²⁷ 1 in Sweden, ²⁹ and 2 in Denmark. ^{30,31}

The studies included in this review represent the journal-writing experiences of 426 relatives of critically ill patients. These studies applied 3 study designs: a quantitative design, ^{26,27} a qualitative design, ²⁸⁻³¹ or a mixed-methods design. ^{24,25} Our evaluation of study quality, for which we used the *Standard Quality Assessment Criteria* for Evaluating Primary Research Papers From a Variety of Fields, ²² indicated that, on average, the quantitative studies met 73.1% of the relevant criteria, whereas the qualitative studies met 81.3%. Mixed-methods studies met, on average, 82.4% of quantitative and 55% of qualitative criteria.

Although the researchers investigated family responses to writing in a diary, the outcome variables (dependent measures) differed among most studies. Three studies specifically investigated symptoms of posttraumatic stress and used either the Post-Traumatic Stress Symptoms-14 or the Impact of Events Scale-Revised questionnaire. One study examined psychological distress using the Symptom Checklist-90-Revised. In 1 study, authors

investigated family member anxiety using the State-Trait Anxiety Inventory scale,²⁴ and in another study, investigators examined anxiety and depression using the Hospital Anxiety and Depression Scale.²⁵ In 4 studies,²⁸⁻³¹ researchers investigated family members' general experiences with writing and reading an ICU diary. The Table reports study variables, instruments, and key findings from each of the included articles.

Anxiety, Depression, Psychological Distress, and PTSD

Neither of the 2 studies that used anxiety as an outcome variable found a statistically significant decrease in anxiety among family members between the control and intervention groups. 24,25 Kloos and Daly 24 reported that anxiety decreased significantly (P<.001) over time among family members in both the control and the intervention groups; however, they found no statistically significant difference (P=.76) in the level of that reduction between the 2 groups. Similarly, Garrouste-Orgeas et al 25 investigated anxiety as well as depression (theirs was the only study to investigate depressive symptoms); they did not find any statistically significant improvement in anxiety (P=.51) or depression (P=.23) 3 months after the diary intervention.

All 3 of the quantitative studies that included PTSD as a dependent variable demonstrated a statistically significant reduction in posttraumatic stress symptoms after the diary intervention. ²⁵⁻²⁷ Barry and Singer²⁶ examined psychological distress and reported statistically significantly less psychological distress (P<.001) 4 weeks after journaling and lower traumatic stress (P<.001) among those in the intervention group. In relatives of adult patients in an ICU, Garrouste-Orgeas et al²⁵ found a statistically significant decrease in PTSD-related symptoms (P<.001) for

the interven- Including photographs of the family tion group 12 particularly helped relatives feel more months after present at the patient's bedside; such discharge photographs stood as a symbol for from the ICU. maintaining a relationship with the patient. Jones et al²⁷

reported no significant improvement in PTSD symptoms (P=.79) 1 month after the intervention; they did, however, find a statistically significant decrease in PTSD-related symptoms (P=.03) between 1 and 3 months after the intervention. By contrast, they noted a statistically

Source	Purpose of study	Study design	Sample/setting
Barry and Singer, ²⁶ 2001, USA	To assess the impact of journal writing on depressive and post-traumatic stress symptoms among mothers of patients discharged from a NICU	Experimental group comparison, quantitative design	38 Mothers of infants who were hospitalized in a NICU in the previous 2-14 months Participants were randomly assigned to treatment or control groups, with 19 participants in each group Inclusion criteria: mothers of infants who were hospitalized in a NICU for at least 1 week in the past 14 months, and had self-reported they were able to express themselves in written English; were older than 18 years; and were not attending counseling or psychotherapy
Garrouste- Orgeas et al, ²⁵ 2012, France	To assess the impact of an ICU diary on the psychological wellbeing of patients and relatives 3 and 12 months after ICU discharge	Prospective design comparing an intervention (diary) period with 2 control periods (before and after the diary period)	143 Patients admitted to an ICU between May 2008 and November 2009, and 1 relative 48 Patients and relatives were included in the prediary period, 49 in the diary period, and 46 in the postdiary period. Inclusion criteria: Patients must have spent at least 4 days in the ICU; relatives were either the person who contributed most of the family diary entries or the closest relative to the patient Exclusion criteria: Patient death on day 4; unwillingness of the family to participate; patient, family, or both not fluent in French; no visits from relatives on the discharge day; dementia in the patient
Garrouste- Orgeas et al, ²⁸ 2014, France	To investigate the families' experience with reading and writing in patients' ICU diaries kept by both the family and the staff	Qualitative method using a grounded theory approach	32 Family members of ICU patients Inclusion criteria: Relatives and friends who visited the patient; French as native language; patient stayed longer than 48 hours in the ICU and had an ICU diary
Johansson et al, ²⁹ 2015, Sweden	To explore family members' experiences with keeping a diary during a sick relative's stay in the ICU	Qualitative method with a hermeneutic approach Qualitative data were collected using 11 audiotaped interviews ranging from 35 to 70 min. The interviews were conducted 6-10 weeks after the patients had been discharged from the ICU Common interview elements were identified and grouped into subthemes, and then further clustered into themes, from which a metatheme was developed	11 Family members of patients in a general ICU, who recorded 9 diaries in total Inclusion criteria: Having a blood relative or close friend/partner who had an ICU diary; being willing to share their experiences; being 18 years of age or older; ability to speak Swedish Exclusion criteria: Family members with dementia; family members who were grieving; family members who the author of the study had directly treated in the ICU

Intervention	Measurement tools	Outcome	Key findings	Quality assessment score ^a
Private journal writing: Mothers were required to write in their journal for at least 30 min/d, 4 d in a row; mothers were asked to write about the most emotional and upsetting experiences of the NICU	Symptom Checklist-90-R and IES-R, adminis- tered before interven- tion (pretest) and 4 weeks after interven- tion (posttest) for both groups	Psychological distress, post-traumatic stress (intrusion, avoidance, hyperarousal)	Significant decrease in psychological distress with journaling intervention at 4 weeks ($F_{1,37} = 26.164$; $P < .001$). Significant decrease in PTSD symptoms in intervention group at 4 weeks ($F_{1,37} = 17.817$; $P < .001$). 37% of mothers in the treatment group exhibited clinical levels of psychological distress before the intervention, and 16% of mothers exhibited clinical levels of distress after the intervention, whereas the control group remained constant at 37%.	Quantitative: 21/26
Public ICU diary: Diary started on day 4 of ICU stay and was maintained by family and staff; diary included written entries, drawings, and photos of equipment (but not patients); families and staff members were instructed to refrain from writing about confidential matters that could not be shared	Hospital Anxiety and Depression Scale (administered at dis- charge and after 3 months) Peritraumatic Dissociative Experiences Question- naire (administered 3 months after discharge) IES-R (administered 12 months after discharge) Delphi procedure	Anxiety and depression Perceived severity of traumatic event Posttraumatic stress Diary content	No significant improvement in anxiety at 3 months (P =.51) No significant improvement in depression at 3 months (P =.23); significant decrease in PTSD-related symptoms on IES-R at 12 months after diary intervention (P <.001) Diary content fell into 6 categories: defining places, spaces, and people; building a timeline of medical events; placing the timeline of the patient's experience within the timeline of family, community, and world events; establishing the continuity of the patient's life; describing feelings and emotions; and expressing the presence, commitment, and support of staff and family.	Quantitative: 19/26 Qualitative: 7/20
Public ICU diary: Single diary per patient, used by staff and family; relatives were invited directly to write freely in the diaries; only instruction given to families and staff members about diary entries was to refrain from writing about confidential matters that should not be shared	Semistructured interviews, conducted using a grounded theory approach after the patient was discharged from the ICU 22 Family members were interviewed between November 2012 and June 2013, and 10 additional family members between July 2013 and October 2013.	Families' experience with reading and writing in patient ICU diaries	Families experienced 3 dimensions: Communicative experience: Families found that the diaries helped to assess, assimilate, and share information. Emotional experience: Families found that the diaries allowed them to confide and keep hope alive. It allowed them to express active feelings and release fears and anxieties. Humanization experience: The diaries allowed families to perceive the staff and patient in a new way and served as a medium for developing a warm relationship with staff.	Qualitative: 20/20
Public ICU diary: Written by family and staff	Interviews, conducted 6-10 weeks after the patients had been dis- charged from the ICU	Family mem- bers' experi- ences with keeping a diary	Metatheme: The diary allowed family members to feel contact with the patients. Keeping a diary meets the needs of family members in several ways: to be present at the patient's bedside, to provide caregiving, to maintain hope, and to relay cogent information. Negative aspects of keeping a diary were that it created feelings of stress, guilt, and failure (when family members did not know what to write or could not be there to write).	Qualitative: 15/20
				Continued

	Table Continued					
Source	Purpose of study	Study design	Sample/setting			
Kloos et al, ²⁴ 2008, USA	To determine the effect of a family-maintained progress journal on anxiety among family member of patients undergoing CABG surgery	Quasiexperimental, mixed-methods design that used a pretest and a posttest, and included a control group	160 Family members of patients undergoing CABG surgery in a 20-bed cardiothoracic ICU; 78 were randomly assigned to the experimental group and 82 were in the control group Inclusion criteria: Older than 18 years; ability to read and write English; a relative of a patient having a first coronary artery surgery Exclusion criteria: Being related to a patient who developed major complications or underwent coronary artery surgery classified as "minimally invasive"			
Mikkelsen, 2017, ³¹ Denmark	To explore childrens' and families' experiences of using ICU diaries after discharge and the role of diaries in the process of recovering from a stay in the PICU	Qualitative, exploratory design	5 Children and their families were selected from a 6-bed multidisciplinary unit within a tertiary hospital, at which children of all age groups were treated Inclusion criteria: PICU stay > 3 days; had a diary written for them Exclusion criteria: Did not speak Danish	Downloaded from http://aacnjournals.org/ccnonline/article-pdf/40/5/26/131500/26 pdf by guest		
Nielsen and Angel, ³⁰ 2016, Denmark	To explore how relatives perceive writing in a diary for the critically ill patient	Phenomenological-hermeneutic, qualitative study building on the theory of Ricoeur	7 Relatives of 6 patients in a 6-bed ICU of a regional hospital in 2013	ne/article-pdf/40/5/26/131500/2		
Jones et al, ²⁷ 2012, UK and Sweden	To test whether providing a diary to ICU patients and their rela-	Observational, quantitative study	30 Relatives patients in ICUs at 2 general district hospitals in 2 European countries Inclusion criteria: Relative of a patient who had been	26.pdf by guest o		

Abbreviations: APACHE, Acute Physiology and Chronic Health Evaluation III; CABG, coronary artery bypass graft; ICU, intensive care unit; IES-R, Impact of Events Scale-Revised; MUIS, Mishel Uncertainty in Illness Scale; NICU, neonatal intensive care unit; PICU, pediatric intensive care unit; PTSD, posttraumatic stress disorder; PTSS-14, Post-Traumatic Stress Syndrome-14; STAI, Stat-Trait-Anxiety Inventory.

tives reduces the extent of symptoms

relatives

related to PTSD in the

in the ICU for ≥72 hours and had received mechanical

Exclusion criteria: Relative of a patient who was too confused to give informed consent; relative of a

patient who had preexisting psychotic illness

ventilation for ≥24 hours

est on 22 October 2020

^a The authors assessed the quality of each article using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.²² Qualitative studies could receive a maximal score of 20 (2 points for each of the 10 assessment criteria), whereas quantitative studies could receive a maximal score of 28 (2 points for each of the 14 assessment criteria). They assessed mixed-methods studies using both the qualitative and the quantitative criteria. Studies received a total score that varied depending on the relevance of each criterion to the particular study. They assessed and scored each study separately, and through discussion they achieved consensus regarding study quality.

Intervention	Measurement tools	Outcome	Key findings	Quality assessment score ^a
Public family-maintained progress journal: Two areas were included: 1 area included topics such as name of surgery performed, patient condition, test results, and 1 area with the topic "thoughts and feelings of the day"; family in the treatment group received the journal with directions for writing information in the topic areas and any thoughts and feelings about the day	STAI, MUIS, APACHE, diary content analysis STAI conducted during patient surgery (time 1) and postoperative day 3 (time 2) MUIS conducted at time 2 APACHE derived from patient record	Family state and trait anxiety; family uncertainty; patient health status/ severity; diary content	Significant reduction in anxiety on STAI from time 1 to time 2 for all subjects (<i>P</i> <.001). No significant difference in anxiety on STAI between intervention and control (<i>F</i> =0.138; <i>P</i> =.76) Trait anxiety on STAI significantly influenced state anxiety at time 2 (<i>P</i> =.001). Severity of illness on APACHE did not significantly influence state anxiety. Diary content included positive and negative emotions among family members; observations about the patient and health care staff; and spiritual dimensions.	Quantitative: 22/24 Qualitative: 15/20
Public PICU diary: Diary consists of daily records written by nurses, along with pictures of the child and family and prepared pictures and text explaining certain procedures and equipment; parents do not generally write entries but were encouraged to write in their own diary; the diary is kept at the bedside and given to the child and family on the day of discharge from the PICU	Semistructured interviews with child and family, conducted with child and family 4-6 months after discharge	Child and family experiences with diary	Value to the family: The diary helped to improve coherence of the PICU stay for the family and fill in the gaps in memories; it provided a common language for the family to start a dialogue with the child about the PICU experience. Creating memories: Rereading the diary helped the children to understand the reality of their PICU stay. Importance of pictures: Pictures of the child in the PICU could be more important than words when explaining situations and events.	Qualitative: 16/20
Private diary: Relatives were guided by the nurses to write a personal account of the time spent in the ICU either on their own or in collaboration with other relatives; photos were not included in the diary	Interviews, conducted 1-3 weeks after the patient was trans- ferred from the ICU	Relative's perception of writing in diary	Writing a diary was a meaningful activity while enduring a situation of uncertainty. The diary allowed for the unloading of emotions and expression of feelings. The diary let relatives unload feelings when they felt consumed by the multitude of events.	Qualitative: 14/20
Public ICU diary: All patients had an ICU diary written for them by the staff while in the ICU, which each family member could contribute to; guidelines were provided to each center to standardize the diaries. One month after the patient's ICU discharge, relatives were randomized to receive their diary as soon as they wanted, as long as it was before 2 months (intervention) or after they had completed the final follow-up questionnaires at 3 months (controls)	PTSS-14 measures were assessed 1 month after ICU dis- charge and 3 months after discharge	PTSD symptom level	No significant difference in PTSD symptoms on PTSS-14 at 1 month after the intervention compared to the control group (P =.79) Significant decrease in PTSD symptoms on PTSS-14 between 1 and 3 months after the intervention (P =.03)	Quantitative: 17/26

significant increase in PTSD symptoms (P = .03) between 1 and 3 months in the nonintervention group.

Communication and Understanding

Four studies reported that using a diary aided in communicating and understanding information.²⁸⁻³¹ The diary allowed family members to share information with each other, and rereading entries helped them assimilate and assess information, thereby improving the coherence of the ICU stay and filling in gaps in memories. Garrouste-Orgeas et al²⁸ reported that a powerful characteristic of the diary was that it allowed family members to read entries as often as and whenever they wished, helping them to assimilate information at their own pace. Johansson et al²⁹ and Nielsen and Angel³⁰ found that being exposed to and reflecting on information written in the diary gave family members deeper understanding and knowledge of the situation. In the chaos and incoherence of the ICU stay, the diary entries helped family members separate information about events and fill in gaps in their memories.³¹

Connection to the Patient

Three studies emphasized that the diary allowed family members to connect with the patient. 28,29,31 Garrouste-Orgeas et al²⁸ and Johansson et al²⁹ found that writing in the diary led family members to engage in an intimate inner dialogue with the patient; through the diary they spoke to the patient as if the patient were awake. One participant stated that "writing in the diary was life-giving for me—it's as if, since he couldn't answer me or hear me, he came to life through the writing."28 The diary was a symbol for maintaining a relationship with the patient, even when relatives could not physically be at the bedside.²⁹ In addition, Mikkelsen³¹ reported that diary entries provided information that helped relatives start important but difficult conversations about the ICU experience with patients after their discharge.

Something Meaningful

Two of the studies noted that families viewed using a diary as something meaningful they could do during a time of apprehension.^{29,30} Nielsen and Angel³⁰ reported that the activity of writing in a diary allowed relatives to feel useful and contribute something valuable while alleviating feelings of uncertainty. Johansson et al²⁹ also

emphasized that in the unfamiliar environment of the ICU, the diary made relatives feel that they were doing something worthwhile and were being included in the patient's care. One participant stated, "You felt that here you are sitting, and [you] cannot do anything. . . . So I thought [the diary] was good; it felt like you had a little [stress] task."29

Emotional Expression

Three of the studies reported that the diary allowed family members to express their emotions in writing. 28-30 Garrouste-Orgeas et al²⁸ and Nielsen and Angel³⁰ found that through the diary, family members could identify and unload their intimate and powerful feelings of dread, anxiety, and fear surrounding the situation, as well as feelings of love and affection for the patient. One participant stated, "I was confiding in the diary. I was able to say things, my feelings for him that he couldn't hear me describe, all my pain, all the joy I felt at seeing that he was a tiny bit better. . . . I could open my heart to it."28 Johansson et al29 also emphasized how the diary allowed some participants to put into words strong emotions that can be difficult to express; others, however, thought the diary was too public to express their thoughts, and they stopped writing for fear of exposing their feelings. Alternatively, Mikkelsen³¹ reported that reading the diary was an emotional challenge for some participants, as it evoked repressed emotions from the ICU experience.

Importance of Staff Entries

Three studies reported the importance of diary entries by nurses and staff to family members. Garrouste-Orgeas et al²⁸ and Johansson et al²⁹ described how such contributions to the diary allowed families to connect with staff and gave a sense that "we were all in this together." In addition, family members believed that entries by staff humanized them, allowing the family to see their emotions and how much they care for their patients. Garrouste-Orgeas et al²⁸ also reported that at a time when family members find it difficult to recognize their loved one and see them as "alive," supportive staff entries and well-wishes for the patient helped humanize the patient and helped the family maintain hope. Factual entries from staff were also important, providing a different perspective and an accurate recollection of the situation for family members. 29,31

Importance of Pictures

Mikkelsen³¹ and Johansson et al²⁹ reported the importance of including photos in the diary to add information that is difficult to describe with words. Mikkelsen emphasized that including pictures of the patient was most helpful in providing participants with a further understanding of the situation. Johansson et al found that including photographs of the family particularly helped relatives feel more present at the patient's bedside; such photographs stood as a symbol for maintaining a relationship with the patient.

Negative Consequences

Only two studies reported any potentially negative outcomes from a diary intervention in an ICU.^{29,31} Johansson et al²⁹ found that because the diary indicated family member visitation patterns, it created feelings of guilt when visits were infrequent and stress when family members did not know what to write. Therefore, family members sometimes felt feelings of failure and insufficiency when they were unable to write in the diary. As previously mentioned, Mikkelsen³¹ reported concern that some participants found reading the diary to be an emotional challenge because it evoked repressed emotions from the ICU experience.

Discussion

Overall, research suggests that providing a diary to families of patients in an ICU is a simple and costeffective intervention that may improve psychological outcomes for families after their loved one's intensive care. All of the studies that included PTSD as a dependent variable demonstrated a statistically significant reduction in posttraumatic stress symptoms after the diary intervention. The one study that included psychological distress as a dependent variable also found a significant decrease among family members after using a diary.²⁶ None of the studies, however, found that anxiety or depression was significantly reduced. Garrouste-Orgeas et al²⁵ suggest that psychological recovery requires time, and the benefits of a using a diary may occur via a delayed mechanism for various conditions.

The findings of this review align with previous research indicating that expressive writing in a diary can produce substantial improvement in psychological well-being and reduce stress.^{32,33} Writing in a diary may allow family members to create a story that expresses their emotions

and builds a meaningful account of the stressful event, thereby helping them cope more effectively.³⁴ Writing in a diary also allowed family members to connect with the patient and participate in something meaningful during a time of apprehension.

Families wrote in private (only the family member had access) or public (all family members and staff caring for the patient had access) diaries. Although family members from both groups experienced positive psychological outcomes, each approach resulted in different benefits and potential limitations. Families who used the private diaries were able to write about feelings and emotions that remained confidential, and thus they possibly benefitted from the emotional release that Pennebaker32 and

Lepore and Smyth³³ suggest. Symp-PTSD also decreased

Although the privacy of an ICU diary may be important to some family members, themes identified in this toms related to review indicate that public diaries may achieve additional benefits that counteract stress.

among families

who used a public diary, and this may have been related to a reduction in factors that cause stress to family members of patients in an ICU, such as poor communication and lack of support from staff, poor comprehension of medical information, and fear. 35,36 For those writing in a private diary, with little involvement of staff, the benefits of communicating information and connection between family members and staff may not have occurred in the same way. Some family members, however, may find it difficult to fully express their personal emotions in a public diary for fear of exposing their feelings.²⁹

All of the studies in this review used different approaches to the diary intervention, and only 1 study provided clear instructions for the families writing in a diary. According to Pennebaker, 37 a person should write continuously, without concern for spelling or grammar, for a minimum of 15 minutes at least 3 days per week to achieve the greatest benefit. Broad leeway on the topic should be allowed, but one should be encouraged to write about what is bothering them. Pennebaker also recommends that one's writing be kept private and not shared with a group. Although the privacy of an ICU diary may be important to some family members, themes identified in this review indicate that public diaries may achieve additional benefits that counteract stress. Both

approaches may have positive outcomes, but research suggests that the stress-reducing benefits of expressive writing may be limited to an individual's unique coping patterns. 17,38 Some evidence demonstrates that expressive writing may not be beneficial for those who are less able to express emotions, and such individuals should not use it.¹⁷ This evidence supports the idea that when used as a coping strategy in certain contexts, expressive writing in a diary is most beneficial when it is consistent with a person's natural coping tendency.¹⁷

Limitations and Strengths

The lack of research evidence limits this integrative review, as do methodological issues. We found several inconsistencies in how outcome variables were operationalized and in how the diary intervention was implemented. The studies included in this review had different approaches for the diary, most of which were not completely clear, as only 1 study gave specific instructions for writing. For example, some studies encouraged family members to write, whereas others offered them a journal but the health care team wrote most of the entries. In addition, some family members could write freely, with little guidance about what to write, whereas others were required to write for a certain amount of time and were asked to write specifically about their feelings and emotions. This review is, to our knowledge, the first to examine the evidence to determine the effects of writing in a diary on relatives of a critically ill patient. Although this review was based on a heterogeneous sample, the studies we evaluated consistently reported a decrease in PTSD symptoms, supporting the notion that writing in a diary may improve psychological outcomes across populations.

Conclusions

Providing access to a journal for family members of patients in an ICU is considered a standard of care in many European hospitals.³⁹⁻⁴² Findings of this review support this standard, but despite the increasing amount of empirical evidence confirming the benefits of such an intervention, it has yet to become common practice in American hospitals. A diary is a simple and cost-effective intervention that critical care nurses can offer to families. 26 Nurses can educate families about the potential benefits of writing and give them directions on how to start. More formal programs in which the hospital provides the diary and directions for families as a standard

of care can also be implemented. After a patient's ICU stay, their family members can experience extensive stress, anxiety, depression, and PTSD, leading to potential long-term health problems.^{1,2} The Nursing Code of Ethics calls all nurses to commit to preventing illness and to promoting and restoring health, and to work toward creating innovative approaches that reduce health disparities. 43 Critical care nurses are in a key position to provide an individualized diary intervention that may reduce adverse physiological outcomes and promote health among family members of patients in ICUs. CCN

Financial Disclosures None reported.



To learn more about ICU diaries, read "Measuring Outcomes of an Intensive Care Unit Family Diary Program" by Huynh et al in AACN Advanced Critical Care, 2017;28(2):179-190. Available at www.aacnacconline.org.

References

- 1. Azoulay E, Pochard F, Kentish-Barnes N, et al; FAMIREA Study Group. Risk of post-traumatic stress symptoms in family members of intensive care patients. Am J Respir Crit Care Med. 2005;171(9):987-994.
- 2. Jones C, Skirrow P, Griffiths RD, et al. Post-traumatic stress disorder-related symptoms in relatives of patients following intensive care. Intensive Care Med. 2004;30:456-460.
- 3. Friedman H, Tucker JS, Schwartz JE, et al. Psychosocial and behavioral predictors of longevity: the aging and death of the "termites." Am Psychol. 1995:50:69-78
- 4. Society for Critical Care Medicine. Critical care statistics. Accessed October 3, 2018. http://www.sccm.org/Communications/Critical-Care-Statistics
- American Hospital Association. AHA Hospital Statistics. Health Forum; 2015.
- Roque AT, Lasiuk GC, Radunz VR, Hegadoren K. Scoping review of the mental health of parents of infants in the NICU. J Obstet Gynecol Neonatal Nurs. 2017;46(4):576-587.
- 7. Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *J Clin Psychol Med Settings*. 2010;17(3):230-237. doi:10.1007/s10880-010-9202-7
- Shaw RJ, Bernard RS, Deblois T, Ikuta LM, Ginzburg K, Koopman C. The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. Psychosomatics. 2009;50(2):131-137. doi: 10.1176/appi.psy.50.2.131 Muscara F, Mccarthy M, Woolf C, Hearps S, Burke K, Anderson V. Early
- psychological reactions in parents of children with a life threatening illness within a pediatric hospital setting. Eur Psychiatry. 2015;30(5):555-561. doi:10.1016/ĵ.eurpsy.2014.12.008
- Rodríguez-Rey R, Alonso-Tapia J, Colville G. Prediction of parental post-traumatic stress, anxiety and depression after a child's critical hospitalization. J Crit Care. 2018;45:149-155. doi:10.1016/j.jcrc.2018.02.006
- 11. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J Gen Intern Med. 2008;23:1871-1876.
- 12. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest. 2011;139:795-801.
- 13. Kynoch K, Chang A, Coyer F, McArdle A. The Effectiveness of interventions to meet family needs of critically ill patients in an adult intensive care unit: a systematic review update. IBI Database System Rev Implement Rep. 2016; 14(3):134-135. doi: 10.11124/JBISRIR-2016-2477
- 14. Adams K. Journal therapy. In Allison N, ed. The Illustrated Encyclopedia of Mind-Body Medicine. Rosen Publishing Group; 1999:361-363.
- 15. Kaiser RB. The way of the journal. *Psychology Today*. March 1981:64-76.16. Pennebaker JW, Beall SK. Confronting a traumatic event: toward an
- understanding of inhibition and disease. J Abnorm Psychol. 1986;95(3): 274-281. doi:10.1037//0021-843x.95.3.274

- Niles AN, Byrne Haltom KE, Mulvenna CM, Lieberman MD, Stanton AL. Randomized controlled trial of expressive writing for psychological and physical health: the moderating role of emotional expressivity. *Anxiety Stress Coping*. 2014;27(1):1-17. doi:10.1080/10615806.2013.802308
- Úllman AJ, Aitken LM, Rattray J, Kenardy J, Le Brocque R, MacGillivray S, Hull AM. Diaries for recovery from critical illness. *Cochrane Database Syst Rev.* 2014;2014(12):CD010468. doi:10.1002/14651858.CD010468.pub2
- Knowles RE, Tarrier N. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomized controlled trial. *Crit Care Med.* 2010;37(1):184-191. doi:10.1097/CCM.0b013e31819287f7
- Jones C, Backman C, Capuzzo M, et al; RACHEL group. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Crit Care*. 2010;14(5):1-10. doi:org/10.1186/cc9260
- 21. Whittemore R, Knafl K. The integrative review: Updated methodology. *J Adv Nurs*. 2005;52(5):546-553. doi:10.1111/j.1365-2648.2005.03621.x
- 22. Kmet LM, Lee RC, Cook LS. Standard Quality Assessment Criteria for Evaluating Primary Research Papers From a Variety of Fields. Alberta Heritage Foundation for Medical Research; 2004.
- Dixon-Woods M, Agarwal S, Young B, Jones DR, Sutton AJ. Integrative Approaches to Qualitative and Quantitative Evidence. Health Development Agency; 2004.
- Kloos JA, Daly BJ. Effect of a family-maintained progress journal on anxiety of families of critically ill patients. *Crit Care Nurs Q*. 2008;31(2):108-109. doi:10.1097/01.cnq.0000314470.49130.49
- Garrouste-Orgeas M, Coquet I, Périer A, et al. Impact of an intensive care unit diary on psychological distress in patients and relatives. *Crit Care Med.* 2012;40(7): 2033-2040. doi:10.1097/ccm.0b013e31824e1b43
- 26. Barry LM, Singer GHS. Reducing maternal psychological distress after the NICU experience through journal writing. *J Early Intervent*. 2001;24(4):287-297.
- 27. Jones C, Backman C, Griffiths RD. Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness: a pilot study. *Am J Crit Care*. 2012;21(3):172-176. doi:10.4037/ajcc2012569
- Garrouste-Orgeas M, Périer A, Mouricou P, et al. Writing in and reading ICU diaries: qualitative study of families' experience in the ICU. PLoS One. 2014;9(10):e110146. doi:10.1371/journal.pone.0110146
- Johansson M, Hanson E, Runeson I, Wåhlin I. Family members' experiences of keeping a diary during a sick relative's stay in the intensive care unit: a hermeneutic interview study. *Intensive Crit Care Nurs*. 2015;31(4):241-249. doi:10.1016/j.iccn.2014.11.002
- Nielsen AH, Angel S. Relatives perception of writing diaries for critically ill. A phenomenological hermeneutical study. *Nurs Crit Care*. 2016;21(6):351-357. doi:10.1111/nicc.12147
- 31. Mikkelsen G. The meaning of personal diaries to children and families in the paediatric intensive care unit: a qualitative study. *Intensive Crit Care Nurs*. 2018;45:25-30. doi:10.1016/j.iccn.2017.10.001
- Pennebaker JW. Emotion, Disclosure and Health. 5th ed. American Psychological Services; 2007.
- 33. Lepore SJ, Smyth JM. *The Writing Cure: How Expressive Writing Promotes Health and Emotional Well-being.* American Psychological Association; 2002.
- 34. Fivush R, Sales JM. Coping, attachment, and mother-child narratives of stressful events. *Merrell Palmer Q.* 2006;52(1):125-150.
- 35. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. *Crit Care Med.* 2000;28(8):3044-3049.
- Davidson JE, Powers K, Hedayat KM, et al; American College of Critical Care Medicine Task Force 2004-2005; Society of Critical Care Medicine. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med. 2007;35(2):605-622. doi:10.1097/01. ccm.0000254067.14607.eb
- Pennebaker JW. Expressive writing in a clinical setting. Independent Practitioner. 2010:23-25.
- Stanton AL, Low CA. Expressing emotions in stressful contexts. Curr Dir Psychol Sci. 2012;21(2):124-128. doi:10.1177/0963721411434978
- Egerod I, Christensen D, Schwartz-Nielsen KH, Agård AS. Constructing the illness narrative: a grounded theory exploring patients' and relatives' use of intensive care diaries. Crit Care Med. 2011;39(8):1922-1928. doi:10.1097/ccm.0b013e31821e89c8
- Heindl P, Bachlechner A, Nydahl P, Egerod I. Extent and application of patient diaries in Austria: process of continuing adaptation. *Nurs Crit Care*. 2019;24(6):343-348. doi:10.1111/nicc.12257
- Nair R, Mitchell M, Keogh S. The extent and application of patient diaries in Australian intensive care units: a national survey. *Aust Crit Care*. 2015;28(2):93-102. doi:10.1016/j.aucc.2014.09.001

- 42. Nydahl P, Knueck D, Egerod I. Extent and application of ICU diaries in Germany in 2014. *Nurs Crit Care*. 2014;20(3):155-162. doi:10.1111/nicc 12143
- 43. American Nurses Association. *Code of Ethics for Nurses, With Interpretive Statements*. American Nurses Association; 2015.