

Nurses' and Parents' View on Neonatal Intensive Care Unit Diaries: A Qualitative Study and Framework Conceptualization

Tabea Willmeroth, MA¹

¹Fachbereich Gesundheit, FH Münster, University of Applied Sciences, Witten, Germany

Address for correspondence Tabea Willmeroth, MA, FH Münster, University of Applied Sciences, Cäcilienstraße 21, 58452 Witten, Germany (e-mail: tabea.willmeroth@posteo.de).

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Abstract

Objective The birth of a premature or critically ill newborn can be a traumatic event for the entire family. In these situations, the neonatal intensive care unit (NICU) diary is a relevant coping intervention to support family members. However, a profound theoretical concept is lacking, and there is little evidence about how it is applied by nurses in clinical practice. Therefore, this study aims to investigate how NICU diaries are used by nurses to support family members cope with their experiences and to develop an evidence-guided and theory-based framework for conceptualizing diary usage in the NICU.

Study Design A qualitative study design containing 12 narrative interviews with nurses from six different hospitals and two focus group interviews with nine parents from two different hospitals was chosen. The qualitative data were analyzed via content analysis inductively and separately and brought together via graphical coding in a second step.

Results Four main categories emerged from the analyzed data to describe the NICU diary in nursing practice. Regarding diary (1) “usage,” three different types of NICU diaries were identified, which seem to be established largely intuitive. The (2) “content” is constituted by the diary’s title, introduction, textual, and nontextual components. Taking into account the diary (3) “function” for the parental coping process, three subcategories emerge: (a) strengthening the parental role, (b) supporting understanding of events, and (c) bringing joy and normality to the situation. (4) “Challenges” address an appropriate writing style, the reading of parental entries by nurses and limited resources. Based on these results and taking into account relevant literature, a framework for conceptualizing NICU diaries was developed.

Conclusion NICU diaries show great potential to support the parental coping process. Nevertheless, diary conceptualization should be based on a theoretical framework to clarify its usage for nurses and parents.

Keywords

- ▶ preterm infant
- ▶ neonatal intensive care unit
- ▶ diary
- ▶ journaling
- ▶ parents
- ▶ coping

Key Points

- NICU diaries are an established intervention used by nurses to support parental coping.
- In nursing practice, different types of NICU diaries emerge.
- Writing styles, content, and reading of entries are reported heterogeneously.
- A conceptualizing framework for NICU diaries is needed.

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Premature birth and the infant's admission to a neonatal intensive care unit (NICU) can be a traumatic event for the entire family.^{1–3} Studies show that up to one-half of family members of admitted children suffer from postintensive care syndrome family, abbreviated as PICS-F. PICS-F “refers to the acute and the chronic psychological effects of critical illness on the family of the patient and includes the symptoms that are experienced by family members during the critical illness as well as those that occur following death or discharge of a loved one from the [N]ICU.”⁴ The symptoms are sleep disturbances, posttraumatic stress, personal or family conflicts during and after treatment, or depression^{5–7} and can last for years.⁸ Furthermore there is a risk that PICS-F can negatively affect parent–child interaction and attachment.^{9–11} In addition, the need of treatment can demand considerable human and financial resources from the health care system.¹²

Coping is a dynamic process during stressful encounters or situations. It is performed problem- or emotions-focused¹³ and when being effective encourages parents to react health-promoting for themselves and their infant.¹⁴ One nursing intervention to support family members coping with the intensive care unit (ICU) stay is the ICU diary.^{15,16} An ICU diary can reduce posttraumatic stress disorder, anxiety, and depression in relatives.¹⁷ This coping intervention has become increasingly established in NICUs, too.^{18,19}

However, the question arises whether the ICU diary concept, originally designed for adult patients of an ICU, can be directly expanded to the NICU for relatives of premature or critically ill newborns.

As described by Pavlacic et al,²⁰ diary writing is an intervention to help parents organize their intimate thoughts and feelings. However, we do not know whether additional entries by nurses or other caregivers—as it is common for ICU diaries²¹—could violate the privacy of family members. Moreover, a study by Perier et al²² showed that it can be challenging for caregivers to read the touching entries of patients' relatives, especially if they do not know how to deal with them. Based on reports of experiences with the NICU diary, a setting-related concept is assumed.^{18,19,23} However, to the author's knowledge, there is no overview of how NICU diaries are established in clinical practice and how different forms of diaries affect parents in coping with their experiences.

Therefore, the aim of this study was to investigate the NICU diary in Germany, as well as its meaning for parental coping. This leads to the research question: (1) How is the NICU diary established by nurses? (2) How can a diary help family members cope with their NICU experiences?

Materials and Methods

Study Design and Methods

A qualitative exploratory design considering a two-step approach was conducted based on a study protocol and scientific standards.²⁴ The two-step approach consisted of (1) narrative interviews with nurses followed by (2) focus group interviews with parents whose newborns were admitted to the NICU.

The interviews were conducted via telephone or video conferencing software (depending on the preference of the interviewee). There was no contact to the interviewees prior informed consent.

1. The qualitative narrative interviews were performed according to the procedure for qualitative interviews described by Rosenthal and Loch.²⁵ The first two interviews were used as a pretest and resulted in minor adjustments. The narrative interview procedure was chosen to achieve a comprehensive insight into NICU diaries established by nurses.
2. The qualitative guideline-based focus group interviews followed the procedure described by Misoch.²⁶ The interview guideline was developed according to the four quality criteria of focused interviews identified by Merton and colleagues (1956) in Hopf.²⁷ For each group interview, parents from different hospitals were brought together to stimulate exchange about their experiences and which concept of the diary they would prefer.

Recruitment of Participants

For the narrative interviews with nurses, homepages of all NICUs throughout Germany²⁸ were screened in July 2020 for using an NICU diary. The first contact was made via the head of nursing management of the respective clinic by e-mail, and further contacts were made with the clinic and/or ward management who were asked to distribute the information material on participation in the interviews to their nursing teams. Regarding the interviews with parents, the associated follow-up care facilities of these hospitals were asked to inform and recruit parents. To avoid undue burden on parents, only those who met the inclusion criteria (→Table 1) should be asked to take part in the interviews. To have as little inconveniences as possible with the recruitment by distribution of the information material, ward managers and follow-up care facilities were not asked to document the number of nurses and parents asked to participate in the interview. →Supplementary Material 1 (available in online version) shows the details of the recruiting process.

Data Analysis

The interviews were transcribed in full on a rule-governed basis.^{29,30} Field notes were made for each interview transcript.³¹

Table 1 Inclusion criteria for group interviews with parents

Parents, ...
• who had received a diary during their child's admission to the NICU
• who lived in a stable family situation (e.g., no obvious problems in partnership, no major problems with the siblings)
• whose newborn had been discharged home healthy after the NICU stay
• who were of legal age
• who spoke the German language fluently

Abbreviation: NICU, neonatal intensive care unit.

Data analysis using the software MAXQDA 2020 followed the rule-guided steps (determining the coding unit, paraphrasing, generalizing to the level of abstraction, first reduction, second reduction, formation of a category system) of the qualitative content analysis according to Mayring.³² Both datasets were analyzed independently, taking into account an inductive approach. The synthesis of the results was done in a separate analysis step via graphical coding based on the main categories of interviews with nurses. Combined results were presented in tabular form. Data saturation³³ was achieved after analysis of three-quarters of the interviews, as no new main categories were identified.

Ethical Considerations

For the interviews with nurses local permission was requested and granted by the nursing management and the nurse in charge of the NICU. For the interviews with parents an ethical review was requested and approved (2020-655-f-S). An informed consent was secured in accordance with the Ethical Code of Nursing Research of the German Society for Nursing Science³⁴ by participating nurses and parents: both received written information about the research project and the possibility to contact the researcher for further question before they agreed to participate. Privacy and confidentiality were ensured by pseudonymization of files, anonymization of prepared data, and the option to revoke participation at any time prior to anonymization of data.

Results

Participants

A total of 12 individual interviews ($n_{\text{nurses}} = 12$) were conducted with 2 male and 10 female nurses (N1–N12) from six different NICUs (see [–Supplementary Material 2](#), available in the online version). The interview duration varied between 28 and 74 minutes ($M = 44$). Four of the clinics state on their homepage that they work according to concepts of developmental care. Two of them also report implementing a family-centered concept. Five of the six clinics indicate that they train parents in the care of their newborn during NICU stay.

All participants were registered nurses specialized in pediatrics. The professional experience ranged from 4.5 to 30 years ($M = 16$). Experience in using the NICU diary existed for 3.5 to 15 years ($M = 7.6$), although two participants could not give any information about the time of implementation of the diary. All diaries had paper form and were handwritten.

In addition, a total of six mothers (M1–M6) and three attendant fathers (F1, F3, F4) took part in the two focus group interviews ($n_{\text{parents}} = 9$). The interview durations were 56 and 70 minutes.

Their infant's births occurred between October 2017 and July 2020, so the NICU stay was a few weeks to 3 years ago at

the time of interview. The infants were born between 26 and 30 weeks of gestation and all weighed less than 1,500 g. They were treated in two of the five eligible hospitals. No parent dropped out of the interview due to severe psychological stress.

In total the four main categories NICU diary (1) “usage,” (2) “content,” (3) “function,” and (4) “challenges” were identified. With regard to the research question, the results are presented from the nurses perspective supplemented by the parents' view.

1. NICU diary usage: three types of NICU diary

The category “usage” includes all nursing actions or specifications for issuing or keeping the diary in everyday nursing routine as well as the way parents are handling it. The analyzed data show that depending on the main responsibility for diary writing in nursing practice three different NICU diary types emerge. A detailed overview of similarities and differences of the diary types is given in [–Table 2](#).

Nurses' Perspective

All diaries are initiated by nurses at the infant's admission to the NICU, further “usage” varies between settings.

Type I remains at the patient's bedside throughout the entire NICU stay and is written mainly by the nurses with the possibility for parents to participate (N1, N2, N4, N9, N12). In type II, parents are free to decide whether they want to keep the diary on their own after the initial input of the nurses or whether the nurses should participate in it, too (N3, N11, M1, F1, M2, M4, F4). Characteristic for type III is a handing over to the parents in the first days of the infant's life after initiation by nurses through one or more entries (N5, N6, N7, N8, N10, M3, F3, M5, M6).

Introductory talks about the NICU diary are occasionally mentioned by nurses and parents. Nurses who have more detailed conversations with parents explain about the responsibility for the diary and that it is kept for the infant with the possibility for parents to process the NICU events (N2). Others hardly explain anything about the diary, even if the parents indicate difficulties in dealing with it:

Then [the parents] naturally say: “What should I write down?” Then I say: “Either the daily routine, your feelings, what you did ... like writing in a diary [...] But I won't really say more about it, that's their own [responsibility]” (N8).

Parents' Perspective

Diary usage from parents perspective involves two main activities: *writing* and *reading* the NICU diary. Regardless of the diary type, there are both mothers and fathers who take part in the diary writing. Reasons for writing can be based on the more frequent presence with the infant (M2, M5, M6), a preference for writing (F4), or the attribution of writing skills by the partner (M1). In some cases, the other partner keeps the writer company, so that both parents are involved in the writing process (F1). Shared authorship is also possible (M3, F3).

Table 2 Overview of the characteristics of the identified neonatal intensive care unit diary types depending on the main responsibility for diary writing, own presentation

NICU diary type Responsibility	I Nurses	II Parents supported by nurses	III Parents
Categories of usage			
Target group	Premature child <32 WG Newborns in need of intensive care	Premature child <32 WG ----- Newborns in need of intensive care > 1 week	Premature child <32 WG Newborns according to individual case decision ----- All preterm infants with a positive prognosis
Level of participation of nurses	Nurses write continuously during the NICU stay	Initiation through initial entry Further participation at the request of parents	Initiation through first entry ----- Isolated participation of individual nurses
Frequency of entries	No specification ----- 1x/day	No specification	No specification
Creative design of entries	Craft materials such as colored paper, cardboard, stickers, punches and stamps have become established	No	First entry is decorated ----- No
Writing perspective	Optional	Optional	First person perspective of the newborn
Writing style	Simple language, no medical jargon	Optional	Simple and cute language, no medical jargon
Reading of parental entries	Yes	Partially	No ----- Partially

Abbreviations: NICU, neonatal intensive care unit; WG, weeks of gestation.

Note: --- Marks NICU-specific differences within a diary type.

Handing over snapshots of the infant to the parents can motivate them to write diary entries:

And when they took pictures and put some of them in the diary, [...] that was a bit of an incentive, [...] to write something directly about the day (M2).

Not seldom, the first diary entry of nurses is seen as a model that encourages diary writing from the infant's first-person perspective, which is experienced as very beautiful, but also demanding (M1, M3, F4, M5, M6). Writing from the parents' perspective (M2) or using bullet points (F3) was also reported. Sometimes parents use their mobile phones to record information about the infant promptly and correctly (M1, M4, M5). However, having the diary in paper form has a special meaning to the parents (M1, F3, M4, F4, M5). In one particular case a couple was inspired by the NICU diary but designed their own one (M4, F4). In retrospect, parents report that diary writing can decrease over time (M1, M2, M3, M6).

Reading the diary takes place during and after the NICU stay. During the time in the NICU, reading the first diary entry was described as particularly touching (F1, M2, M5). After discharge, there are parents who do not look at their NICU diary much (F3, M5) and others who enjoy reading the diary, whereby special days such as World Prematurity Day or the infant's birthday can encourage rereading (F4, M3).

One mother is deeply moved by diary entries even years after the birth, so that it's impossible for her to read them aloud to her infant (M1).

Regarding reading by nurses, there are parents who knew that their diary was read, but this was not equally clear to everyone. The basis for reading parental entries is a trusting relationship:

They [the nurses] were also leafing through it from time to time. But we found it totally ok because we got along with most of them really well (M1).

In contrast, some parents cannot imagine making their NICU diary accessible (F3, M6):

Little pictures [...] from the nurses – just nice, [...] but the diary belongs to the parents (laughing)! (M3).

Others consider it a valuable approach (diary type III):

I think that it would actually be important if they even read it CONSCIOUSLY, [...], because then they simply learn better from the parents what is important to whom, [...]. To ONE only data, numbers, facts are important and the OTHER is perhaps more emotionally burdened, then one can probably intervene better or simply give help (M5).

Table 3 Overview of the contents of identified NICU diary types, own presentation

NICU diary type Responsibility	I Nurses	II Parents supported by nurses	III Parents
Material shape	Flexible ring binder	Booklet	Booklet
Introduction	Poem or photos of the setting	Name and photo of the infant	Name and photo of the child
	Name and photo of the infant Initial care and people involved	Initial care and people involved	Initial care and people involved Footprints
Textual elements	Milestones and positive experiences	Milestones and positive experiences	Milestones and positive experiences
	Regressions and negative experiences	Regressions and negative experiences	Regressions and negative experiences
	Parents' feelings		
Non-textual elements	Photos of the infant and setting, postcards, letters, pictures, bag with souvenirs	Photos of the infant and setting, pictures of siblings Weight curve	Nurses hand over photos to parents for the diary

Abbreviation: NICU, neonatal intensive care unit.

Note: - - - Marks NICU-specific differences within a diary type

2. NICU diary content: textual and nontextual components

The category “content” includes the diary’s external appearance, structure, textual, and nontextual components. Overall, it can be seen that the NICU diary types are similar in terms of the content described, although the integration of nontextual elements seems to be more common for types I and II (→Table 3).

Nurses and Parents Perspective

One aspect of the external appearance of the diary is its “title.” Here, different designations emerge: “premature baby diary,” “diary,” or “intensive care diary.” One nurse stresses that the title should not refer exclusively to preterm babies, as it would exclude mature babies who receive NICU treatment (N1).

The structure of the NICU diary consists of an introduction and subsequent entries. Across all types, the diary is started by the infant’s name and a photo, as well as information on primary care. Hereby, parents receive information about the infant’s situation and get positive feedback on their parental behavior (N1, N3, N7, N8, N11). Furthermore, depending on the setting, the introduction is supplemented by an introductory poem (N2) or photos of the NICU with explanations of the equipment or footprints of the infant (N1, N2, N4, N8, N12).

Textual elements refer to milestones and positive experiences (N1, N4, and N11), regressions and negative events (N3, N12) as well as the presumed state of mind of the

parents (N1, N12), whereby some diaries are free to create (N1, N3), others have prestructured pages (N5, N11). It is noticeable that some of the parents report on progress and regression (F3, M5), whereas others need time to write about negative events (M6), mention them shortly (M2) or omit them altogether:

So what I didn't write in at all were steps backwards, [...] I don't want to write that in there because it was somehow very stressful (M1).

Nontextual elements of the diary are photos of the infant, charts that record the infant’s data (e.g., the weight), painted pictures of siblings, postcards and letters from relatives, as well as a pocket integrated into the diary for collecting mementos (N1, N3, N6, N11, N9).

3. NICU diary function: strengthening the parental role, supporting understanding of events and bringing joy and normality to the situation

The category “function” of the NICU diary includes strategies used by nurses or parents with positive effects on the family members’, especially the parents’ coping process. The consequences expected or hoped for by the nurses are taken into account as well as positive effects described by the parents.

During the analysis process, the individual diary types were considered. Three main functions could be identified, which are covered by each diary type, although in different amounts. →Table 4 describes to what extent the identified

functions of the diary are achieved through different forms of usage and by which group of people (nurses or parents) this perception is expressed. The following explanations illustrate this by way of example.

a. Strengthening the parental role

Nurses highlight joint activities between parents and infants as particularly positive in their diary entries:

Table 4 Subcategories of the main category neonatal intensive care unit diary (3) "function," own representation

Identified function of the NICU Diary		Acting group of persons	Achieved through	Reported by	
				Nurses	Parents
1. Strengthening the parental role	Showing parents how to respond appropriately	Nurses writing	Highlighting joint activities between parents and infants by focusing on actions where parents respond appropriately to the infant's need	X	X
	Showing parents that they are perceived in their role		Addressing the parents as "Mum" or "Dad"	X	
	Creating memories for child and parents		Giving detailed information about what happened in the NICU	X	X
	Building appreciation	Parents writing	Expressing sympathy to the parents	X	
	Being a medium of communication		Talking to the infant through the diary, expressing one's thoughts and feelings	X	
	Giving a task when feeling helpless		Being encouraged in writing the diary on a regular basis (at a self-determined interval).	X	X
2. Supporting understanding of events	Informing about the infant's situation	Nurses writing	Writing diary entries about events when parents weren't present or by explaining medical equipment or procedures in more detail and easy language	X	X
	Identifying the need for counselling	Nurses reading	Analyzing parental entries on further need of clarification, need for counselling, a doctor's consultation or psychological care	X	X
	Sensitizing the nurses		Identifying content that encourages or comforts parents, thus enabling them to tailor their posts to parents' needs		X
	Reducing misunderstanding and unnecessary worries of the parents	Nurses communicating	Talking to the parents about discrepancies between the actual situation and parental interpretation read in the diary	X	
	Gaining an overview of the situation	Parents writing	Concretizing and organizing their thoughts through writing	X	X
			Parents reading	Reading informative entries when a lot of information has to be absorbed	

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3. Bringing joy and normality to the situation	Bringing joy to the parents	Nurses writing	Designing creative and colorful diary entries by using stickers or making footprints and thus setting a counterpoint to the clinical-technical environment	X	X
	Giving courage and confidence		Presenting photos and reports from the infant's perspective about positive events on the NICU while parents were absent	X	X
			Highlighting the infant's developmental steps in general to give parents courage and confidence	X	X
	Strengthening parents by stimulating involvement of family and friends	Parents, family and friends writing	Encouraging others to write in the diary, integrating them into the situation and strengthening the parents through positive encouragement and congratulations.	X	
	Instilling confidence	Parents, family & friends reading	Reading about past developmental steps of the infant	X	X
			Seeing footprints and photos of the infant	X	X

Abbreviation: NICU, neonatal intensive care unit.

So from the infant's perspective, it's described as [...]: "I'm glad that you're here dad..." [...] and then when it goes out for bonding: "Oh, it's nice to lie on your breast again mum..." and "... your breast milk tastes so good" (laughs) (N8).

Being addressed as *Mom* or *Dad* shows parents that they are perceived in their parental role by the social environment of the NICU. One father reports that reading the first entry helped him quickly bond with his infant (F3).

Nurses of all NICU diary types strive to create memories for the parents. It is reported that there are infants who are intensively interested in their diaries at a later time (N1):

Our daughter, who has now turned three, is very interested in the photos and to hear [...] Why did she look like that? (M1).

In order for parents to grow into their parental role, it is important to be perceived by the social environment as mothers and fathers, to build a social relationship with their infant, and to respond appropriately to the newborns needs.³⁵⁻³⁷ Therefore the identified functions are summarized under the subcategory "strengthening the parental role."

b. Supporting understanding of events

The nurses mention that writing by parents seems to help them to concretize and organize their thoughts as well as gain an overview of the situation (N6, N2), which is confirmed by parents:

Writing also helped a bit, first to review the day and to think again about what really happened, what we did today (F4).

One mother even ascribes a therapeutic function to the diary writing:

Really as therapy, to write down what you experienced every day, to be able to process it a bit better, simply because it was so much (M2).

Some nurses appear impressed by how openly and honestly the parents communicate with them indirectly through the diary. This sensitizes the nurses to understand the needs of parents and in individual cases identify the need for counseling, a doctor's consultation, or psychological care (N3, N9) and is valued by parents, too (M1, M2):

We have parents who are very quiet, [...] [but] when you read [...], you think: "Oh, wow, what's going on in their minds" [...] - what they can't express is written down and you can pick up on it (N9).

c. Bringing joy and normality to the situation

Nurses design NICU diary entries creatively and colorfully. They photograph particularly cute situations of the infant and are thus setting a counterpoint to the clinical-technical environment. One nurse who initiated a diary of type I reports:

We only had these checkered sheets, then I started with stickers and I brought colorful paper and at some point, that got out of hand, so that we now have this handicrafts corner! (laughs) (N4).

A reduced feeling of having missed out on the infant's life due to the parents' absence is reported if there are photos and a report in the diary from the infant's perspective, so that the situation can be followed despite the enforced separation (N4).

Moreover, the diary allows other family members to be involved. This is considered valuable especially under the visiting restrictions due to the coronavirus 2019 crisis (N3). One couple even printed the diary for close family members and friends. They valued the ability to "catch up on the missed time" (M4) by reading the diary.

Integrating childlike elements into the NICU's daily routine through the diary, closely following the infant's developmental steps and allowing siblings and other relatives to participate in the infant's birth can be a way for parents to bring some normality into the stressful situation. These functions are therefore summarized under the subcategory "bringing joy and normality to the situation."

Overall, it appears that the majority of identified functions of the NICU diary can be observed, at least to some extent, in each of the three diary types. Two of the biggest differences seem to be how much or over what period of time parents receive information about their infant from the nurses through the diary and to what extent nurses read it and derive consequences from what they have read. The function of giving information through the diary is hardly pursued in diary type III in favor of parental privacy. Here, the parental writing process as a coping-strategy is highlighted.

4. Neonatal Intensive Care Unit Diary Challenges: Appropriate Writing Style and Reading by Nurses

Nurses' and Parents' Perspective

In addition to the positive functions, nurses and parents also mention challenges in using the NICU diary. One is writing appropriate diary entries for the parents by nurses (N1):

Maybe [I don't keep it much] because it's public (laughs) [...] because you could trace it back to my writing [...] I personally find [writing] incredibly difficult from the infant's perspective (N6).

Writing about particularly critical situations can be challenging for some nurses (N9), for others it has a healing, sometimes even therapeutic (N4) character. Parents get around the difficulty by not recording unpleasant developments in the diary (M1) or only writing about them after a few days (F3).

However, not only writing, but also reading diary entries can be stressful. If nurses do not have a professional intention for reading parents' entries, they sometimes feel like intruders (N4, N5). Even though some parents report that there is no content in the diary that is unpleasant to read (F3, M5, M6), some of them tell elsewhere that reading churns their feelings (M5, M6) and could be "insanely emotional, really bad" (M5).

Another challenge could be the strongly defined structure of the diary, e.g., through developmental milestones. These are appreciated by parents (M5), but also lead to parents whose infant deviates from the usual development or even dies not receiving a diary from the nurses because they consider it inappropriate (N6):

At the end of this book is: "Yay, I get to go home!" and of course it is also incredibly difficult to take this page out, [...] because it is a bound book (N5).

As a further challenge, nurses report a lack of acceptance sometimes by parents or more often in the interdisciplinary team:

The doctors are also required to write in there, but nobody does it. [They] only ever see it that way, that's tinkering, we have nothing to do with it (laughs) (N4).

Finally, insufficient resources, e.g., for printing adequate photos or not handing over diaries to each patient can complicate dealing with the NICU diary (N1, N5). If parents are openly informed that nurses do not have time to write diary entries due to a high workload, they seem to accept this quite well (F1, M2, F4). However, it seems to be problematic if mothers compare their diaries with one another and differing participation by nurses is noticed:

But on the other hand it's "dangerous" [...] [when] mothers then meet and talk to each other and it's like: "Are you something better?!" and then I said to the other mum, because she was really hysterical [...] that I was sorry for her, but I guess there's a difference, [...] you stayed a week and we 103 days in the end (M5).

To summarize the results and answer the question (1) *How is the NICU diary established by nurses?* data show three different types of NICU diary depending on the responsibility for diary keeping with mostly similar contents. Challenges include formulation of appropriate diary entries, reading of parental entries by nurses, and limited resources.

Addressing the research question (2) *How can a diary help family members cope with their NICU experiences?* three functions (a) Strengthening the parental role, (b) Supporting

understanding of events, and (c) Bringing joy and normality to the situation are achieved, addressing different coping strategies. They are covered by each NICU diary type, although to a different extent, depending on the conceptual usage of writing, reading, and communicating.

Discussion

Currently, the NICU diary established by nurses is no rigidly used intervention but a flexible tool to support the parental coping process, as is reflected in a recent review.²³ Therefore, in practice, more than the identified three types may emerge over time. Even if it's used profitably, it lacks a theoretical foundation that systematically describes the addressed (3) "functions" in context of the coping process covered by different ways of writing, reading, and communicating depending on diary (1) "usage" and (2) "content." The described (4) "challenges" show that there is need of clarification on how to conceptualize diary writing.

Therefore, based on the key findings presented and taking into account current literature,^{20,37-39} a framework *Conceptualizing NICU diaries* was developed by the author to guide nursing practice directly at the bedside and maintain a flexible, setting-related use of the tool (→ Fig. 1). To have a coherent link between the presented results and the proposed conceptual framework, the following discussion will be based on NICU diary (A) writing, (B) reading and (C) communicating by nurses and parents.

A. Conceptualizing NICU diaries: writing by nurses

Davidsons (2010) theory of facilitated sensemaking, a middle-range theory "to be used in the ICU to assist patients' family members"³⁷ with the aim of preventing PICS-F,⁴⁰ provides a theoretical framework which can be used to clarify the writing process of NICU diaries by nurses: diary entries can support parents if they assist them in making sense (a) of what happened and (b) of their new role. "Sensemaking is iterative and must be readdressed as the patient's condition changes."³⁷

Davidson's theory suggests that entries can be particularly meaningful if they describe (in simple language) what is (a) happening with the infant. The given information also has to provide a proper interpretation: nurses should prioritize the information for parents and classify its significance for the infant's condition or further treatment. It would assist parents to appropriately understand the situation if some more details were mentioned (see → **Supplementary Material 3** for an example, available in the online version).

Parents' struggles with changing role expectations can be traumatic.^{2,3} This suggests that supporting the adjustment to the changed parental role could also lead to the reduction of negative consequences and prevention of PICS-F. To help parents adjust to their role (b), it is important to show parents how to perceive and respond appropriately to their infant's needs. This can be identified in reports of nurses who positively emphasize, e.g., bonding or obtaining breast milk.

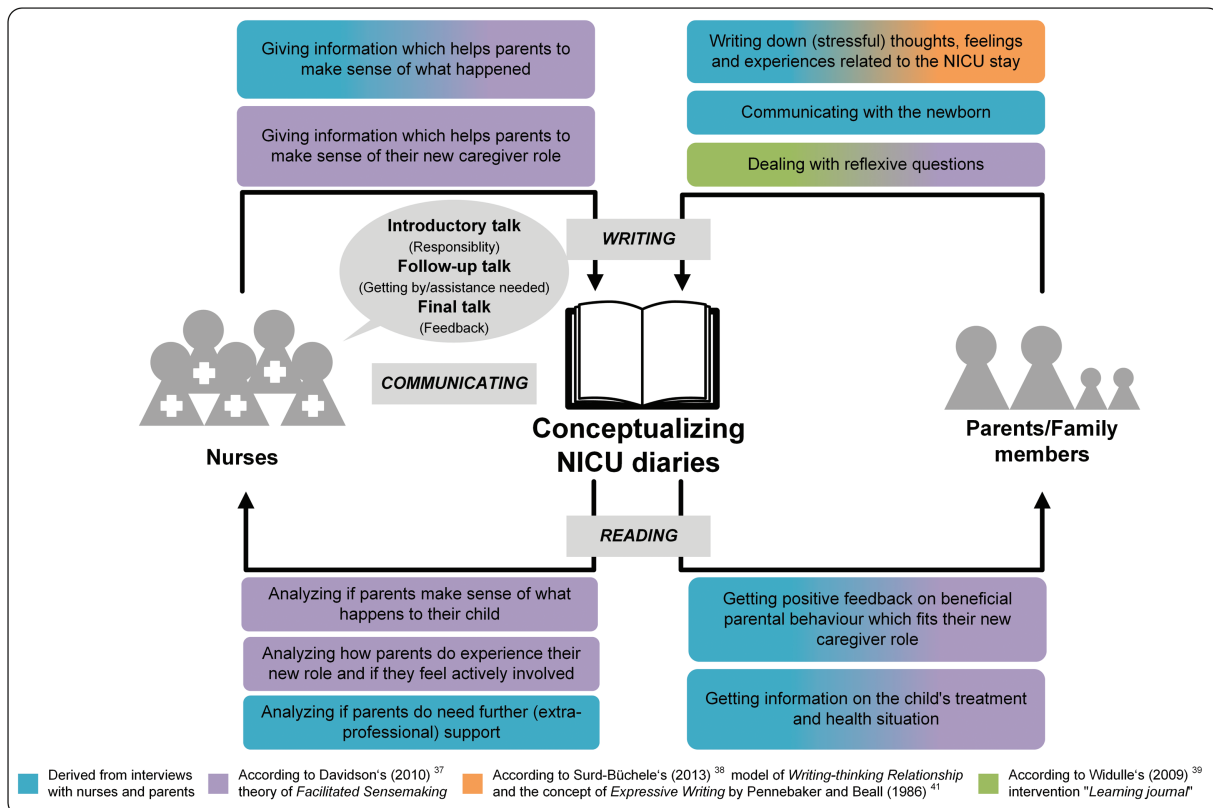


Fig. 1 Framework of Conceptualizing NICU diaries to support the parental coping process and thus contribute to the prevention of PICS-F in NICU settings, own representation. NICU, neonatal intensive care unit; PICS-F, postintensive care syndrome family.

Parents' reports suggest that positive descriptions from the infant's point of view have a particularly touching character. In order not to further strain the parents' emotional involvement by describing negative events, the observer's perspective seems more appropriate here, as it follows a more sober style of language, which can make it easier to cope with the given information.

B. Conceptualizing NICU diaries: reading by nurses

A heterogeneous picture emerges on reading of parental entries. Some nurses (diary types I and II) seem to consider the reading as self-evident and inoffensive, especially if parents were informed about it in advance. In contrast, other nurses (NICU diary type III) are concerned about violating parental privacy by reading entries and show a critical attitude toward it. Both findings are valid aspects mentioned in current literature for ICU diaries.²²

Nurses who seem to be less critical of reading parental diary entries make targeted use of what they have read: based on it, they offer individual and family-oriented support or adapt their writing style to the individual preferences of the parents. This is why the proposed framework *Conceptualizing NICU diaries* requests an analytical reading of the parental entries by nurses. It includes looking for misinterpretation of events with clarifying follow-up talks and thus supporting the parental sensemaking process.

Overall, it is hoped that this professional approach to reading parental diary entries will lead to a lower burden on nurses and increase the quality of individual parental support.

However, the present study shows that there are parents who strictly reject reading of their NICU diary by nurses. This reflects that reading is a highly sensitive act, which should be well thought through and purposefully decided upon when conceptualizing the NICU diary. Additionally, clear communication to the parents seems indispensable to enable them to engage with the diary in the way it is actively supported by nurses. Since it is conceivable that reading of parental entries by nurses can influence the parents' acceptance of the diary in general, a less rigid but more parental-preferred approach (e.g., diary type II) seems advisable. A ring binder would offer the possibility to write diary entries by nurses without getting access to the diary itself.

A. Conceptualizing NICU diaries: writing by parents

Surd-Büchle³⁸ identifies four processes that are stimulated by diary writing and, based on this, designs the model of a writing-thinking relationship, which can be seen as closely related to the sensemaking process.

(1) Writing promotes memory processes. This is also perceived by the parents and nurses interviewed. (2) Furthermore, writing helps parents to concretize and organize their thoughts and to gain an overview of the impressions and situations. This is linked to Surd-Büchle's³⁸ self-forming processes which can be strengthened as well by the parents use of the NICU diary as a medium of communication with the infant. This special significance of the diary as a medium of communication is also evident in Hofbauer et al.¹⁹ (3) In

addition, parents report that writing helps them to process the events and even has a therapeutic function for some of them. This shows a combined form of problem-focused (sorting, understanding) and emotion-focused (writing the events off your mind) coping.^{13,14} It gives them the opportunity to be active and to take on a task. This could be related to the promotion of self-directed processes and have a liberating effect.³⁸ Pavlacic et al²⁰ describe a similar effect in relation to their concept of expressive writing pioneered by Pennebaker and Beall.⁴¹ However, it is considered beneficial to explicitly describe emotionally stressful events, which some parents rarely or never do. It is possible that differentiated counseling is needed to make this function of NICU diary writing accessible to them. (4) Surd-Büchle³⁸ already emphasizes that reflexive processes can be but are not necessarily stimulated by diary writing itself. Here, reflexive questions as they were used for learning journals³⁹ or proposed by Davidson³⁷ can be adapted to the parents situation to stimulate a reflexive writing process.

Studies on the ICU diary have shown that writing can be perceived as stressful by relatives if they visit less often than desired and can therefore write fewer entries than hoped.^{42,43} Since the parents interviewed reported that they were usually present in the hospital every day, this aspect of dealing with the NICU diary is not evident in the available data material.

B. Conceptualizing NICU diaries: reading by parents

A special feature of reading is that parents can take the time needed to absorb information, especially about regressions or negative events.

It turns out that filtering information can help parents understand the situation. For example, by specifically highlighting the infant's developmental steps, the nurses are able to encourage the parents and diminish an exclusively negative perception of the situation.

Using the diary to reduce misinterpretations by informing parents not only about the successful outcome of the nurses' care (drinking a complete bottle meal by the premature baby), but also about the gradual attempts and favorable circumstances helps parents to develop reasonable expectations. One nurse observes that this information can have a calming effect on the parents and relieve them of a negative feeling if they do not achieve the same successes promptly.

Additionally, the diary acts as a medium of communication between parents and infant. This can go as far as nurses' entries being perceived as encouraging statements from the infants themselves and thus reducing grief.

If parents allow other family members or friends to read the diary, it can meet their need for information,⁴⁴ facilitate the exchange for the parents, and support more sensitive feedback, which can prove helpful for the parents' processing.

Despite the positive effects of reading NICU diary entries as highlighted here, it is also important to note that reading entries, particularly about critical events, can be emotionally challenging for parents and family members. Herrup et al⁴⁵ also point out that reading can be perceived as difficult and painful. However, the pride and joy expressed by parents in

owning the diary during the interviews indicate that the positive aspects of the diary outweigh the negative, at least in retrospective.

C. Conceptualizing NICU diaries: communication between parents and nurses

A final aspect is the communication between parents and nurses about the NICU diaries' (1) "usage," (2) "content," proposed (3) "function," and potential (4) "challenges." Here, information about the handing over by nurses remains largely unclear. Interviews with parents show a lack of information on how to write diary entries, what content could be mentioned and whether their entries were read. It seems not totally clear if the diary is a coping tool for them or (just) a memory book for their infant. In addition, some parents take the initial entries formulated by the nurses as a model. However, writing such particularly informative and affectionate entries is considered very demanding. In addition, the emotional closeness of the first-person formulations seems to make writing about negative events even more difficult and can result in an interruption or end of the writing process. That way, the relieving function of the diary would be lost. Therefore, an introductory talk should offer transparency about the aim and purpose of the NICU diary as a coping tool for parents^a. Additionally, information about the parents' previous experiences with diary writing are needed to provide them with the necessary support.

Follow-up talks on the NICU diary also seem to take place rather rarely and only by initiative of individual nurses. However, they are considered useful to inform nurses about how parents get on with the diary^b. Some nurses report that talking about parental diary entries is seen in the responsibility of psychologists. Here, the competence of the individual nurse is called upon to decide where conversations with them can help to support the sensemaking process and at which point a therapeutic conversation is needed. Current research suggests that relatives value talking about the diary.^{42,43}

Final talks on the diary are not mentioned in any of the interviews. In contrast to ICU diaries, NICU diaries are often handed over to the parents after initiation (diary type II and III) by nurses, which may lead to a lacking sense of responsibility for the intervention. A final talk at discharge could be used to get an overall assessment of the parents' opinion of the diary. Regular feedback can also reveal strengths and weaknesses in NICU diary usage. Another aspect to discuss in a final talk could be the offer to visit the NICU if this is necessary or desired to process the events at a later time. This is already implemented several times for ICU diaries.^{17,21,43}

All in all, the explanations show that conversations about the NICU diary seem to have an innovative character. This

calls for a reflection on the way the diary is currently dealt with. As nurses hardly described theoretical knowledge about the NICU diaries, there might be a lack of knowledge to explain the diary in its complexity to the parents and clarify its objective (coping or memory tool). A training concept such as the one presented by Huynh et al⁴⁶ appears to be recommendable due to its comprehensive and well-thought-out approach.

Limitations

The present study was based on established scientific methods and the chosen approach was explained and justified in detail. To the author's knowledge, this was the first study that explored the NICU diary across multiple settings. The sample size was small ($n_{\text{nurses}} = 12$, $n_{\text{parents}} = 9$), yet large enough for no new categories to emerge. Additionally, the chosen inductive approach for analysis enabled a comprehensive insight of relevant aspects regarding to NICU diaries in clinical practice. The proposed framework was derived from both an inductive (qualitative data) and deductive (relevant literature) developmental process and can form a starting point for theory-building discourses on the appropriate usage of NICU diaries.

However, some weaknesses have to be pointed out: The narrowly defined recruitment period for parents led to missing interview participants for diary type I. Unfortunately, a consensual coding³¹ was not possible, which may influence the internal validity of the results and limit their transferability. A communicative validation was not performed due to missing resources.

Conclusion

Results show that the NICU diary as used in clinical practice is a flexible tool that can achieve different functions depending on its usage and content. Nurses intuitively use the diary but only a theoretical foundation allows the NICU diary to become substantiated and enables a conscious reflection and alignment of the diary. If nurses already have experiences with the NICU diary, these results can help to reflect on the established concept in nursing practice.

Future research should address the issue of writing perspectives (child or third person) to present positive or negative information. Furthermore, data on the situation of siblings are limited, which seems problematic when considering family-centered approaches. Also, the question arises if palliative situations need a special form of diary usage: Which content is needed to cope with deep grief? How should corresponding diary entries be formulated? Overall evidence for the effectiveness of NICU diaries in preventing PICS-F would be desirable and could provide a reasonable argument for offering diaries to all parents affected by an NICU stay.

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^a In which form and about which contents do the parents/nurses write? Who has access to the diary? Who reads the entries? What is the purpose of reading and writing?

^b Is it perceived helpful? Does it cause stress? Do the parents need further suggestions on how to write the diary?

Conflict of Interest

None declared.

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References

- Hynan MT, Mounts KO, Vanderbilt DL. Screening parents of high-risk infants for emotional distress: rationale and recommendations. *J Perinatol* 2013;33(10):748–753
- Lasiuk GC, Comeau T, Newburn-Cook C. Unexpected: an interpretive description of parental traumas associated with preterm birth. *BMC Pregnancy Childbirth* 2013;13(01):1–10
- Spinelli M, Frigerio A, Montali L, Fasolo M, Spada MS, Mangili G. 'I still have difficulties feeling like a mother': the transition to motherhood of preterm infants mothers. *Psychol Health* 2016;31(02):184–204
- Rawal G, Yadav S, Kumar R. Post-intensive care syndrome: an overview. *J Transl Int Med* 2017;5(02):90–92
- Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med* 2017;45(01):103–128
- Singer LT, Salvator A, Guo S, Collin M, Lilien L, Baley J. Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *JAMA* 1999;281(09):799–805
- Miles MS, Holditch-Davis D, Schwartz TA, Scher M. Depressive symptoms in mothers of prematurely born infants. *J Dev Behav Pediatr* 2007;28(01):36–44
- Jezierska N. Psychological reactions in family members of patients hospitalised in intensive care units. *Anaesthesiol Intensive Ther* 2014;46(01):42–45
- Voegtline KM, Stifter CA. Late-preterm birth, maternal symptomatology, and infant negativity. *Infant Behav Dev* 2010;33(04):545–554
- Ahn Y-M, Kim N-H. Parental perception of neonates, parental stress and education for NICU parents. *Asian Nurs Res* 2007;1(03):199–210
- Wightman A, Schluchter M, Drotar D, et al. Parental protection of extremely low birth weight children at age 8 years. *J Dev Behav Pediatr* 2007;28(04):317–326
- Nelson LP, Lachman SE, Li SW, Gold JI. The effects of family functioning on the development of posttraumatic stress in children and their parents following admission to the PICU. *Pediatr Crit Care Med* 2019;20(04):e208–e215
- Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. *Eur J Pers* 1987;1(03):141–169
- Loewenstein K, Barroso J, Phillips S. The experiences of parents in the neonatal intensive care unit: an integrative review of qualitative studies within the transactional model of stress and coping. *J Perinat Neonatal Nurs* 2019;33(04):340–349
- Åkerman E. Intensive care unit diaries: a critical appraisal. *Intensive Crit Care Nurs* 2018;47:5–6
- Blair KTA, Eccleston SD, Binder HM, McCarthy MS. Improving the patient experience by implementing an ICU diary for those at risk of post-intensive care syndrome. *J Patient Exp* 2017;4(01):4–9
- Nydahl P, Fischill M, Deffner T, Neudeck V, Heindl P. Diaries for intensive care unit patients reduce the risk for psychological sequelae: systematic literature review and meta-analysis. *Med Klin Intensivmed Notf Med* 2019;114(01):68–76
- Arlt Y. Hilfe für gestresste Eltern. *Intensiv* 2011;19(05):249–253
- Hofbauer JM, Dieplinger A-M, Nydahl P. The meaning of NICU diaries to parents of premature children in the neonatal intensive care unit: trust that everything will be fine. *J Neonatal Nurs* 2021;27(06):432–438
- Pavlicic JM, Buchanan EM, Maxwell NP, Hopke TG, Schulenberg SE. A meta-analysis of expressive writing on posttraumatic stress, posttraumatic growth, and quality of life. *Rev Gen Psychol* 2019;23(02):230–250
- Beg M, Scruth E, Liu V. Developing a framework for implementing intensive care unit diaries: a focused review of the literature. *Aust Crit Care* 2016;29(04):224–234
- Perier A, Revah-Levy A, Bruel C, et al. Phenomenologic analysis of healthcare worker perceptions of intensive care unit diaries. *Crit Care* 2013;17(01):R13
- Low SZQ, Kirk A, Mok YH, Lee JH. The use and impact of diaries in PICUs and neonatal ICUs: a scoping review. *Pediatr Crit Care Med* 2023;24(02):e84–e90
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(06):349–357
- Rosenthal G, Loch U. Das narrative interview. In: Schaeffer D, Müller-Mundt G, eds. *Qualitative Gesundheits- und Pflegeforschung*. Huber; 2002:221–232
- Misoch S. *Qualitative Interviews*. de Gruyter Oldenbourg; 2015
- Hopf C. *Qualitative Interviews - ein Überblick*. In: Flick U, Kardorff E von, Steinke I, eds. *Qualitative Forschung: Ein Handbuch*. 11. Auflage, Originalausgabe. rowohlt's enzyklopädie im Rowohlt Taschenbuch Verlag; 2015:349–360
- Institut für Qualitätssicherung und Transparenz im Gesundheitswesen IQTIG. *Transparenzliste*. 2018. Accessed July 2, 2020 at: <https://www.perinatalzentren.org/transparenzliste.php>
- Kuckartz U, Dresing T, Rädiker S, Stefer C. *Qualitative Evaluation: Der Einstieg in die Praxis*. 2., aktualisierte Auflage. VS Verlag für Sozialwissenschaften / GWV Fachverlage GmbH Wiesbaden; 2008
- Dresing T, Pehl T. *Praxisbuch. Interview, Transkription & Analyse: Anleitungen und Regelsysteme für qualitativ Forschende*. 8. Auflage. Eigenverlag; 2018
- Schmidt C. *Analyse von Leitfadeninterviews*. In: Flick U, Kardorff E von, Steinke I, eds. *Qualitative Forschung: Ein Handbuch*. 11. Auflage, Originalausgabe. rowohlt's enzyklopädie im Rowohlt Taschenbuch Verlag; 2015:447–456
- Mayring P. *Qualitative Inhaltsanalyse*. In: Flick U, Kardorff E von, Steinke I, eds. *Qualitative Forschung: Ein Handbuch*. 11. Auflage, Originalausgabe. rowohlt's enzyklopädie im Rowohlt Taschenbuch Verlag; 2015:468–475
- Schreier M. *Qualitative Forschungsmethoden*. In: Hussy W, Schreier M, Echterhoff G, eds. *Forschungsmethoden in Psychologie und Sozialwissenschaften für Bachelor*. 2., überarbeitete Auflage. Springer; 2013:189–221
- Deutsche Gesellschaft für Pflegewissenschaft DGP. *Published December 2016*. Accessed July 9, 2020 at: <https://dgp-pflegewissenschaft.de/wp-content/uploads/2017/05/Ethikindex-Pflegewissenschaft-DGP-Logo-2017-05-25.pdf>
- Fegran L, Helseth S, Slettebø A. Nurses as moral practitioners encountering parents in neonatal intensive care units. *Nurs Ethics* 2006;13(01):52–64
- Cleveland LM. Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs* 2008;37(06):666–691

- 37 Davidson JE. Facilitated sensemaking: a strategy and new middle-range theory to support families of intensive care unit patients. *Crit Care Nurse* 2010;30(06):28–39
- 38 Surd-Büchele S. *Tagebuch: Schreiben und Denken: Eine empirisch basierte Verhältnisbestimmung*. Lehmanns Media; 2013
- 39 Widulle W, ed. *Handlungsorientiert Lernen im Studium: Arbeitsbuch für soziale und pädagogische Berufe*. VS Verlag für Sozialwissenschaften/GWV Fachverlage GmbH Wiesbaden; 2009
- 40 Davidson JE, Zisook S. Implementing family-centered care through facilitated sensemaking. *AACN Adv Crit Care* 2017;28(02):200–209
- 41 Pennebaker JW, Beall SK. Confronting a traumatic event: toward an understanding of inhibition and disease. *J Abnorm Psychol* 1986;95(03):274–281
- 42 Johansson M, Hanson E, Runeson I, Wählin 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(04):241–249
- 43 Storli SL, Lind R. The meaning of follow-up in intensive care: patients' perspective. *Scand J Caring Sci* 2009;23(01):45–56
- 44 Jotzo M. Trauma Früh- und Risikogeburt. In: Reichert J, Rüdiger M, eds. *Psychologie in der Neonatologie: Psychologisch-sozialmedizinische Versorgung von Familien Frühgeborener*. Hogrefe; 2013:112–139
- 45 Herrup EA, Wieczorek B, Kudchadkar SR. Feasibility and perceptions of PICU diaries. *Pediatr Crit Care Med* 2019;20(02):e83–e90
- 46 Huynh T-G, Covalsky M, Sinclair S, et al. Measuring outcomes of an intensive care unit family diary program. *AACN Adv Crit Care* 2017;28(02):179–190