





The implementation and impact of narrative diaries in neonatal intensive care units: A scoping review

Gabriele Sorrentino^{1,2}  | Kiara Ros Thekkan³  | Catia Genna³  | Lucia Aite⁴ | Angela Ragni⁵ | Francesca Bevilacqua⁴ | Immacolata Dall'Oglio³ | Marco Roberti⁶ | Emanuela Tiozzo³ | Orsola Gawronski³ 

¹Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Italy

²Neonatal Intensive Care Unit, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milan, Italy

³Health Professional Development, Continuing Education and Research Unit, Medical Directorate, Bambino Gesù Children's Hospital IRCCS, Rome, Italy

⁴Unit of Clinical Psychology, Department of Neuroscience, Bambino Gesù Children's Hospital IRCCS, Rome, Italy

⁵Department of Medical and Surgical Neonatology, Bambino Gesù Children's Hospital, IRCCS, Rome, Italy

⁶Clinical Area Fetal Neonatal Sciences and Cardiology, Bambino Gesù Children's Hospital, IRCCS, Rome, Italy

Correspondence

Kiara Ros Thekkan and Orsola Gawronski, Health Professional Development, Continuing Education and Research Unit, Medical Directorate, Bambino Gesù Children's Hospital IRCCS, Rome, Italy.
Email: kiararos.thekkan@opbg.net and orsola.gawronski@opbg.net

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Abstract

Background: Premature birth and the Neonatal Intensive Care Unit (NICU) experience can be challenging for parents, affecting their psychological and emotional well-being. NICU diaries could help to reduce the separation gap and strengthen the bonding process with their infant.

Aim: To review the literature on narrative diaries, definitions and use in the NICU.

Study Design: We conducted a scoping review following the Joanna Briggs Institute (JBI) methodology. We searched PubMed, Embase, Scopus, PsycINFO, Cinahl, and Grey Literature up to September 2024. Studies reporting on the use or effect of narrative diaries in the NICU were included. A descriptive and thematic analysis was conducted.

Results: Of a total of 526 records, 21 were included. Most studies had a quasi-experimental or qualitative design, including a framework conceptualization. Editorials were common. Mothers (33%), nurses (9%) and fathers (5%) were the most common diarists. Seven studies evaluated the effect of NICU diaries on family post-intensive care syndrome (PICS-F), satisfaction, and family separation. The benefits of NICU diaries for parents included improved communication, empowerment, personal emotional awareness and parental closeness with their newborn, while for staff, they reduced burnout and fostered the humanization of care. Acceptability was high.

Conclusions: Acceptability and perceived benefits of NICU diaries were widely reported. Heterogeneity in aims, use, and follow-up was high. Well-designed effective multicentre studies providing evidence of impact on PICS-F and a position statement framing the intervention in NICU are recommended.

Relevance to Clinical Practice: This study has shown that NICU diaries have the potential to improve humanization, communication between NICU staff and parents, parents' coping, and closeness to their newborn.

KEYWORDS

diary, journal, narration, neonatal intensive care units, parents

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1 | INTRODUCTION

The Neonatal Intensive Care Unit (NICU) is a highly technological and medicalized environment where premature and critically ill neonates receive the best possible care based on their conditions and for their survival.¹

NICU admission of a child interferes with the natural process of family identity and expectations that parents imagine during the pregnancy.^{2,3} At birth, a newborn who needs advanced care is separated from the parents to be admitted to the NICU. This separation, the lack of control regarding newborn care and loss of parental role can negatively affect mother-infant bonding, causing difficulties in the transition to parenthood.²⁻⁴

Therefore, premature birth and the NICU experience might be challenging for parents, as well as a traumatic and stressful event.^{1,3,5} Parents experiencing the NICU context are exposed to many stressful factors, such as sounds, alarms, invasive procedures, newborn instability and critical illness, and length of NICU stay^{4,6} affecting parental psychological and emotional well-being.^{1,7,8} Moreover, ineffective communication between parents and health care professionals regarding decision-making in the newborn's care contributes to increasing stress levels.^{9,10} Furthermore, parents of a critically ill newborn admitted to the NICU can develop the family post-intensive care syndrome (PICS-F) described as psychological impairments including anxiety, depression, and post-traumatic stress disorder (PTSD), as well as physical and socio-economic complications that could persist even after discharge from NICU.^{5,6,11-16}

Therefore, a family-centred care (FCC) approach is essential in the NICU to support and engage parents with specific interventions, thus reducing parents' psychological symptoms and PICS-F as described by the Guidelines of the Society of Critical Care Medicine.¹⁷

The use of the diary could be an efficient intervention and a support strategy for parents throughout the NICU stay to report and cope with their NICU experience and progress of their infant, thus reducing the separation gap and strengthening the bonding process with their infant, as well as improving their mental health, well-being, and communication with HCPs.^{14,15,17}

2 | BACKGROUND/JUSTIFICATION FOR THE STUDY

In adult settings, several studies have demonstrated a positive and beneficial impact on both the patient's and the family's psychophysical condition when they write about their experience in the intensive care unit (ICU) in the diaries. Indeed, the use of diaries is considered a therapeutic tool that enables mitigating the long-term outcomes, improving quality of life, and reducing post-traumatic stress disorder (PTSD) in patients and in relatives who take care of their loved ones.¹⁸⁻²⁰

In paediatric settings, potential benefits of diary writing in terms of parental satisfaction, parent coping and improvement of communication between parents and HCPs are reported, but further studies

What is known about the topic

- A family-centred care approach is recommended in the NICU to reduce family post-intensive care syndrome (PICS-F).
- In adult settings, the use of the ICU diaries is associated with reduced PICS-F, while evidence in NICU settings is limited.
- There is heterogeneity in the terminology, content, use, and authors of NICU diaries in current literature.

What this paper adds

- There is an increasing interest in NICU narrative diaries since 2020, including the use of electronic NICU diary devices since the Covid-19 pandemic.
- A framework for the implementation of this intervention is needed to best leverage its potential for improving parent, family, and staff well-being.
- As the evidence of effect on PICS-F, parental bonding, and staff well-being is heterogeneous and limited, future research is needed.

are needed to explore the impact of narrative diaries on psychological outcomes.²¹⁻²³ Moreover, the widespread use of narrative medicine could provide several benefits for health care providers.^{24,25} Indeed, several studies have reported that diary writing improves professional satisfaction and reduces work-related stress in health care providers.¹⁹

However, the use of diaries in neonatal intensive care settings has rarely been explored. A scoping review on the use and impact of diaries in PICU and NICU was published in 2022.²⁶ For the neonatal setting, this review reported five studies, one of which reports on an intervention with diaries carried out in the home setting after hospital discharge. Our scoping review focuses exclusively on narrative diary interventions performed during NICU admission to explore a broad spectrum of literature on the use and impact of diaries in the NICU to map and synthesize existing evidence on the use, perception, impact on PICS-F, theoretical stance, and provide a summary of studies published to date on this topic.

3 | AIMS AND OBJECTIVES OF RESEARCH

The aim of this scoping review was to review the extent of the literature on narrative diaries used in the neonatal intensive care setting, to explore: (a) The use of narrative diaries in the NICU setting, including the definitions, theoretical underpinning, format, writing frequency, diarists, barriers and facilitators; (b) the extent of the literature on the impact of diaries on NICU stakeholders, including satisfaction, family post-intensive care syndrome (PICS-F) and quality of life.

The primary review questions were the following: What is the state of the science in research regarding the use of narrative diaries in the NICU setting? Secondary review questions were: What is the stakeholder's perception of NICU diaries? What is the impact of NICU diaries on PICS-F and parents' quality of life?

4 | DESIGN AND METHODS

4.1 | Study design

We conducted this scoping review following the framework described by The JBI methodology.²⁷ Initially, we developed the scoping review research protocol that was approved by the research team. Then, based on the JBI methods, the following phases were carried out: (1) Identification of the research questions based on the patient, concept, and context framework to determine the eligibility criteria, (2) identification of relevant studies, (3) selection of the studies, (4) charting the data, and (5) summarising and reporting the results. The synthesis of the literature results was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).²⁸ In this scoping review, we considered a narrative "diary" as any tool used to provide a narrative account of a newborn's admission and related experiences, reflections or emotions.^{29–32}

4.2 | Data sources and search strategy

The following databases were searched to identify the articles regarding our purpose: PubMed, Embase, Scopus, PsycINFO, and Cinahl. We also carried out a grey literature search in the following databases: GreyLit, Opengrey, EthOS, OATD (Open Access Theses and Dissertations), Ovid and Google Scholar.

The search strategy was developed and conducted with the assistance of a research librarian in August 2024 using the following search terms: Diary OR diaries, diaries as topic, journal, narration AND NICU. The search string is reported in Supplementary file 1.

The study selection process was carried out following three phases.²⁷ Initially, we conducted a preliminary search on PubMed using the keywords identified according to our purpose. Then, a full search strategy was developed with the text words reported in titles and abstracts of the selected studies and with the index terms describing the articles. This full search strategy was adapted for each database used for this scoping review. Moreover, we screened all the reference lists of the selected studies to identify additional pertinent studies that were not detected through the search strategies.

4.3 | Eligibility criteria and study selection

The search and selection of the studies was conducted using the following inclusion criteria: Written in English, no time and geographical

limits, neonatal intensive care setting, use of narrative diaries written by parents, family members, or HCPs, any diary format (paper, digital, video, audio), peer-reviewed articles (qualitative and quantitative studies, scoping reviews, systematic reviews, editorials), and grey literature.

We developed a pre-form table using a Microsoft Excel spreadsheet to collect all the selected articles, and two authors independently screened all the selected articles from searches based on the titles and the abstracts to assess if studies reported the use of diaries in the NICU. Then, based on the inclusion criteria, they evaluated the full texts and decided if they could be included in this scoping review. A third author was consulted in case the two authors disagreed on whether to include a study at any level of the screening process to reach a consensus.

4.4 | Quality appraisal

Quality appraisal is not mandatory in scoping reviews. However, it adds transparency to the review process.³³ We used the JBI Critical Appraisal Tools to evaluate systematic reviews, randomized controlled trials, quasi-experimental studies, cross-sectional studies, qualitative studies, expert opinions, and narrative.³⁴ Studies were independently evaluated by four researchers, working in pairs. A score >70% was considered indicative of high quality, a score between 50% and 70% medium quality, and <50% as low quality. However, all the studies that met the inclusion criteria, independently of their quality appraisal score, were included to ensure a comprehensive overview of the available evidence by not excluding relevant information, while acknowledging the methodological limitations of such studies.

4.5 | Data extraction process

Two authors independently extracted data from each study included in this scoping review using a data extraction tool based on the JBI methodology guidelines.³⁵ A third author supervised the extracted information. The extracted data included study characteristics (author, year, country, study design, method, objective), definition/content of the diary, term used for the diary, measures/outcomes, summary of findings, and implications for practice and/or research. Two independent reviewers validated the extracted data. Descriptive statistics of the extracted data were performed using STATA SE13 (College Station, TX; Stata Corp) and Microsoft Excel.

4.6 | Data synthesis

All the selected studies were narratively synthesized by the authors (Table 1). An inductive content analysis approach was used to analyse the included studies. This approach included three steps: reading, organizing, and developing categories.³⁶ One researcher performed an in-depth data analysis of the study characteristics, which was

TABLE 1 Studies evaluating the NICU diary intervention.

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Carley, California, 2012	Editorial	N/A	N/A	Journaling	Written narrative using paper and pencil, drawings or other imagery, scrapbooking, technology-enhanced media. Journaling is made up of thoughts, feelings and negative or positive experiences.	P and families	N/A	Unknown	N/A	Reflection on stress and the NICU experience is a rationale for journaling as a support strategy for P during the hospitalization of their newborn.
Doron et al., USA, 2013	Editorial	N/A	Report on the implementation of the App 'MyPremie'	Diary: Baby journal and narrative diary	One out of 6 sections dedicated to a narrative diary for recording facts, feelings, and thoughts, photos.	P	N/A	Unknown	N/A	MyPremie app may support the empowerment and engagement of parents in decision-making and care of their newborn.
Freer et al., Edinburgh, 2005	Editorial	Report on the development and implementation of the electronic diary "BabyLink"	N/A	BabyLink supported by the clinical information system Badger	BabyLink is an electronic tool automatically generating information for P from the clinical database: diagnosis, problems, treatment and results.	P and HCPs	Satisfaction, acceptability	Unknown	Easy to use, low impact on staff, welcomed by extended family and friends.	Baby diary could be a means of improving communication with P and families.
Feinblum et al., USA, 2016	Qualitative study	To investigate the caring perspectives of mothers separated from their newborns and the impact of a diary	Qualitative using a grounded theory approach. A paper questionnaire at discharge was administered to investigate P perspectives to caring and journaling.	Journal	Unreported. Journal provided to write maternal feelings.	Mothers	Impact of journaling on caring perspectives	Unknown	Out of the 29 questionnaires administered: 11 used the journal every visit; 7 used the journal sometimes; 2 seldom used the journal; and 9 never wrote in the journal.	Journaling may facilitate the early connection between a mother and a newborn separated by illness.
Fleishman et al., USA, 2022	Editorial	N/A	N/A	Narrative neonatology	Unknown	P and HCPs	N/A	Unknown	N/A	Humanistic care can be promoted using narrative neonatology. This practice could be facilitated by performing formal training or individual mentorship.
Hofbauer et al., Austria, 2021	Qualitative study	To explore the meaning of diaries for P	Qualitative, using Reflexive Grounded Theory, based on a constructivist research	Diary	Notebook with blank sheets, which is placed at every patient's bed. Photos and stickers included.	N, P, relatives and siblings	<ul style="list-style-type: none"> P experiences P support in the coping process 	At the day of birth and/or admission to the NICU to discharge.	Trusting that everything will be fine was the core category. Five themes were reported: (a)	The use of NICU diary can represent a supportive tool for P establishing communication and humanising critical care

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Kadivar et al., Iran, 2014	Quasi-experimental study	To evaluate the effect of narrative writing on maternal stress in NICU	Intervention group: Narrative writing at least 3 times a week Control group: only Parental Stressor Scale (PSS) Pre- and post-tests with PSS administered to a sample size of 70 mothers during 6 months.	Narrative writing	Unknown	Mother	Parental stress (PSS)	From the 3rd day at the end of the 10th day of infant's hospitalization	chronological perspectives, (b) communication with the child, (c) reduction of hospital's atmosphere, (d) relationship with HCPs, and (e) parents' strategies of action Over a sample of 70 mothers, a statistically significant difference in the stress level was shown between the 2 groups on the 10th day of the study (control group: 82.5 ± 19.5 , intervention group: 48.8 ± 14.1 ; $p < .001$).	Further studies are needed to establish the effect of narrative writing.
Kadivar et al., Iran, 2016	Quasi-experimental study	To evaluate whether narrative writing is effective on the mothers' satisfaction with care in the NICU	Intervention: narrative writing at least 3 times a week Pretest and posttest with the Neonatal Index of Parental Satisfaction (NIPS) questionnaire In intervention and control group of 70 mothers	Narrative writing	Unknown	Mother	Parental satisfaction at the 3rd and 10th day of admission (NIPS)	From the 3rd to the 10th day of infant's hospitalization	Over a sample of 70 mothers: A significant difference in satisfaction between the 3rd and the 10th day of admission for both groups. In the interventional group NIPS was 107.5 ± 21.5 on the 3rd day and 137 ± 15.2 on the 10th day; $p < .001$, while in the control group NIPS was 113.1 ± 17.5 on the 3rd day and 102.3 ± 25.6 on the 10th day of the study ($p < .011$).	Further studies are needed to establish the effect of narrative writing.

(Continues)

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Kadivar et al., Iran, 2017	Quasi-experimental study	To identify the perception of stress in P using a narrative diary and P that do not.	Intervention: narrative writing at least 3 times a week. Pretest and posttest with the Parental Stressor Scale (PSS) to the intervention and control group of 70 mothers	Narrative writing	Unknown	Mother	Parental stress measured with the Parental Stressor Scale (PSS)	Unknown	Over a sample of 70 mothers, the differences in the domains of the PSS between the 3rd and 10th day of admission using multivariate analysis showed that the intervention (narrative writing) had significant effects on all three domains (Roys' largest root 2.141, $F_{4,7} 11$, p values $< .001$)	It is recommended to conduct future studies on fathers and other neonates.
Khaleghipour et al., Iran, 2022	Quasi-experimental study	To explore if the identification of the N and fathers' understanding of the stress sources facilitates nursing interventions and increases parental satisfaction.	Intervention group: Narrative writing at least 3 times a week PSS measurements for both intervention and control groups.	Narrative writing	Unknown	Father	<ul style="list-style-type: none"> Parental stress Parental satisfaction 	From the 3rd day at the end of the 10th day of infant's hospitalization	On the 3rd day, the sights and sounds domain mean (SD) showed a significant difference: in the intervention group (22.22 ± 5.43) compared with the control group (17.80 ± 7.1 , $p < .05$). By the 10th day, significant reductions were observed in the intervention group in P role and relationship (control: 31.82 ± 6.42 ; intervention: 16.74 ± 5.38 , $p < .001$), infant behaviour and appearance (control: 33.45 ± 8.16 ; intervention: 20.71 ± 5.33 , $p < .001$), and sights and sounds domains	The use of narrative writing represents an efficient supportive tool as it is not expensive and time-consuming.

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Kirolos, UK, 2020	Quali-quantitative study	To evaluate the impact of a secure video messaging service on P and HCPs experience of neonatal care.	Pre- and post-implementation survey on video messaging service. Surveys contained quantitative (9-point Likert scale) and qualitative items	Video diary	Short video on generic update sending significant moments in a baby's life	HCPs	<ul style="list-style-type: none">• P stress and anxiety,• breastmilk expression,• involvement in care,• emotional closeness,• sleep,• relationship with HCPs,• HCPs workload,• ease of use of the service,• barriers and concerns relating to the service	Until the discharge	(control: 20.17 ± 6.55; intervention: 10.52 ± 3.39, <i>p</i> < .001). P post-implementation survey: positive impact for sleep (rating = 7), anxiety (rating = 8); extended family involvement (rating = 7) and relationship with HCPs (rating = 9)	Video diary can positively affect on P experience, emotional closeness to their baby and can build supportive relationships between families and HCPs
Kodjebacheva et al., USA, 2017	Qualitative research	To explore strategies for effective communication used by P, N, and D	Focus groups with two groups of P, two groups of N, and individual interviews with 3 full-time/permanent D	Baby diaries	They are booklets and serve to address questions to N/D and report daily progress of their newborn.	P	<ul style="list-style-type: none">• Parental satisfaction• Provider self-efficacy• Effective communication strategies	Unknown	Baby diary useful report of the infant's daily progress report and as a method for parents to write questions and/or concerns for the N or D to answer.	Baby diary can be considered a means to improve communication between HCPs and P.
Li et al., China, 2024	Single-blind, randomized, controlled, parallel-group clinical trial	To examine the effects of web NICU diaries on the mental health, quality of life, sleep quality, care ability, and hormone levels of P of preterm infants.	Intervention: a web NICU diary based on routine care updated daily. In both groups the following scores were evaluated before (T1), after (T2), and 1 month (T3) after the intervention -The Hospital Anxiety and Depression Scale	Web NICU diary shared over Tencent Documents (attached to WeChat)	Diary is composed of cover, homepage, main text (content: growth and development, treatment and care; or picture), space for parents at end of day section, and trailer page.	P	<ul style="list-style-type: none">• Anxiety and depression symptoms• PTSD symptoms• Quality of life• Care ability• Sleep quality• Urine cortisol and melatonin levels	Upon enrolment until discharge	There was a significant difference in the anxiety score between two groups at T2 (interventional group: 4.07 ± 2.73 vs control group: 5.31 ± 2.87, <i>p</i> = .005) and T3 (interventional group: 3.94 ± 2.36 vs control group: 5.61 ± 2.25, <i>p</i> < .005)	Web NICU diaries can be a convenient and economical tool to support P and improve care abilities but multicentre studies with long-term follow-up are required in the future.

(Continues)

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Low et al, Singapore, 2022	Scoping review	To explore the existing literature on the use and impact of diaries in NICU and PICU in terms of definition, conceptual boundaries, range, nature research.	Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Five studies included.	For NICU: Diary, Journal, Baby diary	Heterogeneity in definition and structure.	P, N, relatives, and siblings	<ul style="list-style-type: none">Mental well-being of the P with NICU infantsEffective health communication in the NICU.	Unknown	5 studies in NICU 4 investigated the impact of journaling on the P, 2 RCT. Four studies concluded that diaries are Beneficial support to the P and reduce psychological distress.	Optimal content and structure for NICU and PICU diaries needs to be determined. Paucity of outcome studies. Studies mainly from Western countries.
	Abstract	To develop and evaluate a system that gives P secure access to clinical information, BabyLink	Quality improvement report on website and reports development. www.babylink.info/edinburgh	BabyLink Baby diary	Clinically relevant report for P, photographs and non-clinical messages by HCPs. P can comment.	P and HCPs	Unknown	The reports and diaries have been successfully implemented. There has been no negative feedback, with P expressing very positive views.	.001). No differences were observed in the depression score between the groups at T1 (interventional group: 5.33 ± 2.60 vs control group: 5.23 ± 2.89, p = .830), T2 (interventional group: 5.23 ± 2.48 vs control group: 5.51 ± 2.80, p = .523) and T3 (interventional group: 4.89 ± 2.48 vs control group: 5.16 ± 2.48, p = .518). The prevalence of PTSD was 10 % in the interventional group and 22.9 % in the control group a T3.	This system offers the facility for P to access specific, up to date information about their baby.

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Pangborn, Holland, 2022	Auto-ethnographic account	To share a personal experience for enriching conceptualization of narrative medicine	Story	Narrative medicine	Unknown	Mother	<ul style="list-style-type: none"> Communicative action Supportive strategy Stress 	Unknown	N/A	Narrative medicine represents a means to cope with the pathway of hospitalization of their infant.
Ringham et al., Canada, 2022	Institutional ethnography	To describe maternal experiences and discover institutional processes linked to parenting involvement in the NICU	Analysed written entries in Alberta FiCare parent journals to show points of tension mothers experienced in the NICU	Journal	Standardized layout with suggestions for guiding the P entries (thoughts, questions and concerns). No photos.	Mother	Parental experiences of having a preterm infant in an Alberta NICU	Until discharge, every day.	From analysed written entries, three dominant discourses emerged: (1) feeding policies and practices; (2) roller coaster of emotions; and (3) the work of mothering in the NICU.	The journal format could lead to understanding the barriers that mothers face when caring for their infants in the NICU and main concerns about their newborn.
Russel, USA, 2021	Pilot RCT	To evaluate the uptake and impact of a P journaling program on P anxiety and depression	P were randomized to a control group (no journal) or an intervention group (journal provided). P pre- and post-intervention anxiety and depression symptoms were measured. Interviews on journal use were performed.	Journal	Blank pages for free text as well as ten pages of prompts to guide P if needed.	P	The change in means of scores the hospital anxiety and depression scale (HADS)	2 to 4 weeks	Most intervention group P used the journal (79 %) and provided positive feedback. No differences were found between treatment groups in anxiety or depression levels. Post-intervention scores were best predicted by baseline scores.	The rates of journal use and positive qualitative data support the acceptability of implementing a journaling program for P
Subhani et al., USA, 2012	Editorial	To share our experience for establishing digital scrapbooking as the standard of care.	Each newborn enrolled received a SanDisk memory card in which photos regarding typical milestones are recorded. P were encouraged to write down their thoughts.	Journaling	Software named "digital scrapbooking" composed of photos and daily notes written by P.	P and HCPs	N/A	From enrolment until discharge	Journaling and the possibility to have photos of their baby were appreciated by parents and their families considering the digital scrapbooking as a lifetime treasure.	Digital scrapbooking could become a standard of care with the implementation of specified programs.

(Continues)

TABLE 1 (Continued)

Authors, country, year	Study design	Objectives	Methods	Terms	Diary structure	Authors of diaries	Outcomes	Timing of use	Results	Implication for practice research
Veronez et al., Brasil, 2017	Descriptive, exploratory, and qualitative study	To describe the process of nursing care for mothers during the hospitalization and discharge of premature babies	Mothers followed a preparation process for the discharge of their Baby and were invited to write down their experiences on hospitalization, interactions with the team, or when coping with or overcoming in a journal.	Journal	A kit was composed of notebook, pen, pencil, and eraser. Journal included the mother's experiences, no photos.	Mothers	N/A	From the admission of their infants until discharge	Three thematic categories emerged from analysis of mothers' journals: (1) experiencing the arrival of a premature baby; (2) participating in prematurity: the insertion of mother and baby in care; and 3) discharge of the baby: family expectations.	Appropriate communication plays an important role to reduce maternal anguish and encourage parents in care intervention before discharge of their infant.
Willmeroth, Germany, 2023	Qualitative exploratory design	To investigate the meaning of NICU diaries for parental coping and to develop an evidence-guide and theory-based framework for conceptualizing diary usage in the NICU.	12 narrative interviews with N from six different hospitals and 2 focus group interviews with 9 P from 2 different hospitals	Diaries	Handwritten paper booklets or ring binders including textual or non-textual components, photos.	P and N	Parental coping process	Unknown	A framework Conceptualising identified Four main categories emerged from the analysed data to describe the NICU: "usage," "content," "function," and "challenges"	A theoretical framework is needed to conceptualize the NICU diary use

Abbreviations: D, Doctors; HADS, Hospital Anxiety and Depression Scale; HCPs, Health Care Providers; IES-R, Impact of the Events Scale-Revised; N, Nurses; N/A, Not Applicable; NICU, Neonatal Intensive Care Unit; NIPS, Neonatal Index of Parental Satisfaction; P, Parents; PICU, Paediatric Intensive Care Unit; PRISMA-ScR, Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews; PSS, Parental Stressor Scale; PTSD, Post-traumatic stress disorder; RCT, Randomized Controlled trial; SD, Standard Deviation; SRSS, Self-Rating Scale of Sleep; T, Time; WHOQOL-BREF, The World Health Organization Quality of Life-BREF.

independently confirmed by the parallel analysis of two pairs of researchers. The characteristics were then summarized into categories. Patterns and themes in the study contents were discussed and summarized into categories. All the members of the research team reviewed and validated the final synthesis.

5 | RESULTS

The retrieved studies and their inclusion process are shown in Figure 1. We identified 526 records, of which 61 were selected for full-text screening, and of these, 21 studies were included in our scoping review. Table 1 reports the main results of the 21 studies and diary definitions, including terms used, structure, and users.

5.1 | Characteristics of included studies

Most of the included studies (61.9%, $N = 13$) were published in medical journals, and the remainder (38.1%, $N = 8$) in nursing journals.

The included studies were published between 2004³⁷ and 2024.³⁸ Specifically, 48% of the studies ($N = 10$) were published after 2020.^{26,38–46}

The studies were conducted mainly in the United States of America (38%, $N = 8$),^{42,44,46–51} followed by Europe (28%, $N = 6$),^{37,39–41,45,52} the Middle East (19%, $N = 4$),^{43,53–55} Asia (9.5%, $N = 2$),^{26,38}

and South America (5%, $N = 1$).⁵⁶ Of the 6 European studies, 3 (50%) were conducted in the United Kingdom (UK).^{37,45,52}

The included studies had an experimental or quasi-experimental design ($N = 6$, 28%),^{38,42,43,53–55} a qualitative design ($N = 5$, 24%),^{39,40,47,50,56} or a mixed-methods design ($N = 1$, 5%).⁴⁵ We also included a scoping review ($N = 1$, 5%),²⁶ a quality improvement study ($N = 1$, 5%)³⁷ and 7 opinion reports [editorials ($N = 5$, 24%),^{46,48,49,51,52} auto-ethnographic accounts ($N = 1$, 5%)⁴¹ and institutional ethnography ($N = 1$, 5%)⁴⁴]. The quality of the included studies was high for 11 studies (55%), medium for 4 (20%) and low for 5 (25%). The quality evaluation of the included studies is reported in Supplementary file 2.

5.2 | Use of NICU diary

In the studies included in this scoping review, the most common diarist was the newborn's mother (33%, $N = 7$),^{41,44,50,53–56} followed by parents only (19%, $N = 4$),^{38,42,47,49} fathers only (5%, $N = 1$),⁴³ nursing staff only (9.5%, $N = 2$).^{37,45} In seven studies (33%) the diary was shared with parents, nurses, and various family members.^{26,39,40,46,48,51,52}

The most frequently used terms to name the tool were “Diary or Baby Diary” (30%, $N = 6$)^{37,39,40,47,49,52} and “journal” (30%, $N = 6$).^{42,44,48,50,51,56} Other terms used were “narrative writing” (20%, $N = 4$),^{43,53–55} “narrative medicine” (10%, $N = 2$),^{41,46} “web NICU diary” (5%, $N = 1$), and “Video diary” (5%, $N = 1$).⁴⁵ Low et al. in their

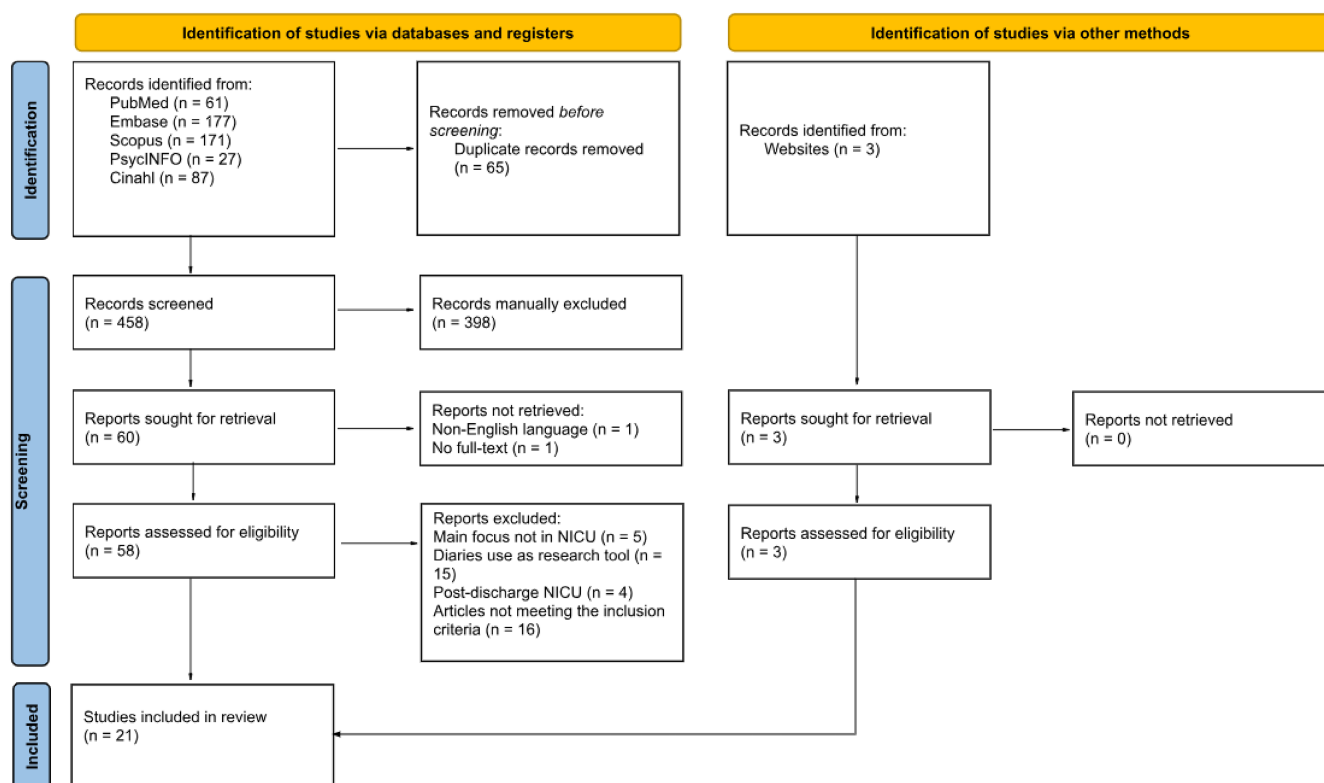


FIGURE 1 PRISMA Flow diagram of record screening and selection process.

review reported the following terms: 'Diary', 'Journal' and 'Baby Diary'.²⁶

The most common type of diary was a "paper diary" (33%, $N = 7$),^{39,40,42,44,47,50,56} followed by a structured "e-diary" (19%, $N = 4$),^{37,38,51,52} a "video-diary" (5%, $N = 1$)⁴⁵ and "app-diary" (5%, $N = 1$)⁴⁹ or mixed type (5%, $N = 1$).⁴⁸ In 7 studies (33%) the type of diary was not described.^{26,41,43,46,53-55} In 7 studies (33%), photos and pictures could be added in the diary.^{37-40,48,49,51}

In the studies included in this review, the beginning and duration of the diary writing differed. In 6 studies, the diary was kept from birth until discharge from NICU.^{38,40,44,45,51,56} In 5 studies, the diary was used for a time ranging between 3 and 28 days.^{42,43,53-55} While in 10 studies, the duration of diary keeping was not specified.^{26,37,39,41,46-50,52}

5.3 | Impact of NICU diary on parental mental health and well-being

Two experimental studies were included in this review. In a randomized controlled trial performed in the UK, parents using a journal experienced a decrease in anxiety from baseline during their newborn's NICU admission. The assessment of hospital anxiety and depression using the Hospital Anxiety and Depression Scale (HADS) was not statistically significant compared with the control group (difference in HADS means between the intervention and control group: -1.121 , $p = .056$ vs. -0.290 , $p = .623$), with a more marked decrease in fathers than in mothers in the interventional group (difference in HADS means between mothers and fathers: -0.926 , $p = .182$ vs. -2.000 , $p = .025$). No association was found with 'depression' and 'journaling' (difference in HADS means between the intervention and control group: 0.303 , $p = .650$ vs. 0.065 , $p = .888$).⁴²

Another randomized controlled trial conducted in China assessed the effect of a web NICU diary on parental mental health. The findings of this study demonstrated a significant difference between the intervention and control groups in the anxiety scores evaluated before (Mean \pm SD: 4.07 ± 2.73 vs. 5.31 ± 2.87 , $p = .005$) and after (Mean \pm SD: 3.94 ± 2.36 vs. 5.61 ± 2.25 , $p < .001$) the intervention with the use of a web NICU diary. The prevalence of PTSD was 10% in the interventional group and 22.9% in the control group measured 1 month after the intervention.³⁸

In three studies with a quasi-experimental design conducted in Iran at the same centre, the use of narrative writing was reported to reduce the parents' level of stress measured using the Parental Stressor Scale (PSS) on the 3rd and 10th days. The intervention was not randomized;^{43,53,55} in particular, two studies showed a significant reduction of stress in the intervention group on the 10th day compared with the control group.^{43,53} Kadivar et al. reported a lower overall maternal mean score of PSS at the 10th day in the intervention group (Mean \pm SD: 48.8 ± 14.1) compared with the control group (Mean \pm SD: 82.5 ± 19.5), ($p < .001$).⁵³ Khaleghipour et al.'s study, the fathers using narrative writing, 10 days after the intervention, had a significant reduction in all the three domains of the PSS compared

with the control group, respectively: Parental role and the parents' relationship (Mean \pm SD: 16.74 ± 5.38 vs. Mean \pm SD: 31.82 ± 6.42 , $p < .001$), Infant behaviour and appearance (Mean \pm SD: 20.71 ± 5.3 vs. Mean \pm SD: 33.45 ± 8.16 , $p < .001$) and Sights and Sounds (Mean \pm SD: 10.52 ± 3.39 vs. Mean \pm SD: 20.17 ± 6.55 , $p < .001$).⁴³

In another study, Kadivar et al. evaluated the difference of the mean scores in three domains of the PSS between the 3rd and 10th day of admission, observing a reduction of stress level in mothers using narrative writing compared with control mothers: Parental role and the parents' relationship (difference in means: -6.7576 vs. 4.8378), infant behaviour and appearance (difference in means: -13.3636 vs. 1.7568) and sights and sounds (difference in means: -11.4545 vs. 1.7297), $p < .001$ at univariate analysis.⁵⁵

Another study conducted in Iran using a quasi-experimental design reported that mothers experiencing the use of narrative writing during the NICU stay reported an increased level of satisfaction with care through the study between the 3rd and 10th day of admission measured with the Neonatal Index of Parental Satisfaction questionnaire (NIPS) (on the 3rd day, Mean \pm SD: 107.5 ± 21.5 vs. on the 10th day, Mean \pm SD: 137 ± 15.2 , $p < .001$) compared with the control group (on the 3rd day, Mean \pm SD: 113.1 ± 17.5 vs. on the 10th day, Mean \pm SD: 102.3 ± 25.6 , $p < .011$).⁵⁴

Another study reported the use of video messages sent by HCPs to parents during the Covid-19 pandemic. The implementation of video messages for 38 parents who responded to a post-implementation survey was commented on as having a positive impact on the parental NICU experience, potentially reducing the effect of family separation.⁴⁵

5.4 | The use of a NICU diary to talk about the NICU experience

Ringham et al. analysed how the use of the diary can help mothers face care interventions performed on their babies and reduce barriers during the NICU stay. From written entries, three main discourses emerged: Feeding policies and practices, roller coaster of emotions and the work of mothering in the NICU.⁴⁴ Another qualitative study evaluated the journal entries of seven mothers regarding their pathway and adaptation process to the care of their premature infant, and three thematic categories emerged: (a) Experiencing the arrival of a premature baby, participating in prematurity, (b) the inclusion of mother and baby in care, and (c) discharge of the baby: family expectations.⁵⁶

The perception and the implementation of the NICU diary were explored in three studies that used a grounded theory or a thematic approach. One study involving 29 mothers interviewed on the use of a NICU journal found that the use of a diary, when mothers are separated from their babies, can facilitate a caring attachment and improve the relationship of the dyad.⁵⁰ Another grounded theory study involving nine parents investigated the meaning of diaries for parents. From the semi-structured audio-recorded face-to-face interviews, a core category was identified: "trusting that everything will be fine" makes

parents strengthen the use of diaries and five themes related to the use of NICU diaries were defined: Chronological perspectives, communication with the child, mitigation of the hospital atmosphere, relationship with nursing staff, and parents' strategies for action.⁴⁰ Kodjebacheva et al. reported that the use of the baby diary could enhance parental satisfaction during the NICU stay, improving the communication between parents and HCPs. The NICU diary was used to register updates regarding the baby's progress and parents' doubts or questions, leading to better communication and support from HCPs.⁴⁷

Only one study described the development of a conceptualisation framework regarding the use and implementation of the NICU diary for parents and HCPs. Findings from 12 interviews reported on three main diary functions: writing, reading, and communicating between HCPs and parents. Four main inductively derived categories synthesized the experiences of diary usage, content, function, and challenges.³⁹

Five editorials and one abstract regarding a quality improvement were included in the present review. Carley discussed how the NICU experience can be stressful for parents, and the use of a journal can be a supportive strategy by helping them make sense of their experience.⁴⁸ Fleishman et al. reported that narrative medicine could promote humanistic care in neonatal settings and prevent burnout, and promote several benefits, such as wellness for health care providers.⁴⁶

Moreover, one editorial described the implementation of an application that includes a diary for supporting parents during the NICU stay, enhancing a sense of normality, control, and connection with the NICU experience. In addition, parents with this application could involve and inform their relatives to avoid emotional charges.⁴⁹ Freer et al. and Lyons et al. described the development and implementation of the application Baby Link. The implementation of an electronic diary was evaluated with the aim to improve communication between parents and HCPs with facilitated access to clinical information regarding their baby, trying to involve parents in the care process.^{37,52} Subhani et al. reported the initial experience regarding the use of a digital tool named "scrapbooking" that could become a standard of care for parents facing the NICU experience. This digital scrapbooking includes photos and parents' thoughts, and was considered by parents as a lifetime treasure.⁵¹ An auto-ethnographic account reported a mother's NICU experience and commented that narrative medicine helps parents make sense of and cope with what happens during the NICU stay.⁴¹

In the present scoping review, we included a recent scoping review that selected five studies concerning the neonatal setting, of which four were included in our scoping review. One was excluded because the context was the home setting after discharge from the NICU.²⁶ Other resources for parents of newborns admitted to the NICU are also available on the web.

5.5 | Grey literature

We searched the grey literature by consulting international and national websites regarding the use of diaries in hospitals. Two

examples of diaries emerged: My NICU journal⁵⁷ and the starship NICU journal app.⁵⁸ 'My NICU journal project' aims to provide support for parents and helps them in the complex NICU experience. Parents filled a paper diary documenting their infant's progress and their emotions and feelings. The 'starship NICU journal' app is a digital diary where parents and HCPs can document each step of the progress of their infant throughout the NICU stay. This application can be used on a mobile phone and is free to download.

6 | DISCUSSION

This scoping review was carried out to evaluate and map the current literature regarding the use and impact of narrative diaries in NICUs. Historically, narrative diaries have been largely used in adult ICUs since the 1980s.^{59,60} Since 2004, an increasing number of studies on the use of diaries in Paediatric ICUs and Neonatal ICUs have been published. Our scoping review describes the use of narrative diaries in the NICU setting.

While most of the included studies were performed in North America and Europe, interestingly, other world regions are also represented, including Asia and the Middle East, showing a widespread use of this intervention in NICUs worldwide. Almost 50% of the literature was published after 2020, showing an increasing interest in NICU narrative diaries, including the use of electronic NICU diary devices during and since the Covid-19 pandemic. The reason for the recent uptake of narrative diaries may be the need to develop family-centred care (FCC) strategies to face the "isolating world" generated in NICUs at the beginning of the pandemic to support parental closeness and bonding, as well as psychological well-being and quality of life.⁶¹

The characteristics of the NICU population make the use of NICU narrative diaries unique compared with other settings. We found that NICU narrative diaries are used primarily for the following aims: (1) Improve communication between staff and parents or families, and parents' understanding of the clinical care provided; (2) fill knowledge gaps of events occurring to the newborn in parents' absence from the ward, and humanizing the NICU setting; (3) provide a space for self-reflection, coping and healing by expressing feelings and personal experiences; (4) establish a written dialogue with the newborn child, supporting parental bonding. These aims are similar to that reported for children admitted to the paediatric intensive care setting, with a few substantial differences.²⁶ First, narrative diaries in NICUs are focused on potential benefits for NICU parents and not directly for their newborns, because of their limited cognitive and physical stage of development required to interact with the intervention. Expected outcomes include parents' increased care abilities, reduced PICS-F and increased quality of life. Second, parents of premature babies compared with older children are known to be at risk of suffering bonding deficiencies, denial and guilt in their relationship with their newborn, because of separation at birth and critical illness limiting parent-child interactions.⁶² For these reasons, NICU diary interventions are focused on parents' well-being and supporting the activation of coping mechanisms to prevent those risks.

The concept of the narrative NICU diary and its mechanisms of action are generally poorly defined or undefined. One study reports a theoretical framework to frame the NICU diary intervention, the assumptions and propositions, based on existing theories and real-life interviews with parents and NICU staff involved in the implementation of NICU diaries in a single centre. Through a process of reading and writing, the NICU narrative diary is assumed to be an instrument supporting parental coping and information sharing. The NICU diary is assumed to have primarily a monodirectional flow of communication between staff and parents, where parents are the main recipients of information about their newborn's care, which is functional when parental presence is reduced as a result of parent unavailability or restrictive organisational policies are in place.³⁹ Conversely, the role of parents' written feedback to staff and the effect of staff self-reflection in NICU diaries is less evident. While NICU diaries are described as an instrument used primarily for parental coping, the role of reflective reading and writing for NICU staff has also been hypothesized to be beneficial for coping with moral distress and burnout,⁴⁶ and for improving empathic interactions with parents. A more inclusive approach that reduces the power imbalance between parents and NICU staff in the diary conceptual frameworks is warranted. Acknowledging in a framework the reciprocity of intents and shared values for both parents and staff may be beneficial for a full understanding of the scope of the NICU diary intervention.

Current literature portrays the use of different media and heterogeneous NICU diary structures, which, in some cases, are not reported. Diaries mainly focused on providing clinical summaries or visual memories for parents are generally structured according to clinical frameworks or framed around relevant milestones achieved by their newborn. Conversely, diaries focused on parents' and staff's narrative experiences are generally unstructured, free-flow tools with minor structural variations. The role of clinicians is generally intended to provide a narrative or visual account of clinical care, to fill parents' knowledge or information gaps while showing empathy and care. Parents are expected to write about their personal experience or questions regarding their newborn's condition or care. However, the way diaries are used in real-life NICUs, the dose of the intervention required, and content elicited is unreported, determining a clear knowledge gap on what the parameters, boundaries, and culturally produced contents of NICU diaries are, which might differ across different contexts.

Recent literature since 2014 investigates the effect of NICU diaries on parents' outcomes, particularly PICS-F. The randomized controlled trial (RCT) by Li et al. shows a significant effect on parent anxiety and the prevalence of PTSD of a NICU web diary based on information primarily given by HCPs to parents.³⁸ While the pilot RCT by Russell et al. shows no significant differences in PICS-F between parents using a narrative journal and parents randomized to usual care, other quasi-experimental studies showed a significant effect on parent anxiety, satisfaction, and stress.⁵³⁻⁵⁵ Small study sample sizes, risk of bias and heterogeneity of implementation of the NICU diaries across those studies currently limit comparability and certainty of evidence. Future well-designed multicentre studies are needed.

7 | STRENGTHS AND LIMITATIONS

The strength of this review is that we evaluated the quality of the included studies to determine the quality of the available evidence. We selected a wide range of databases, including grey literature, to make our search as thorough and complete as possible. The limitation of this scoping review is that we included only literature published in the English language, determining a potential risk of excluding relevant literature reporting the use of NICU diaries in non-English-speaking countries.

8 | IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE AND RESEARCH

A clear framework clarifying the theoretical standpoints, aims, mechanisms of action, formats, recipients, and outcomes for all NICU stakeholders, including staff and all family members, is recommended. A position statement providing recommendations on how to structure, write, and provide an effective follow-up to parents and families using the NICU diaries would support future implementation and reduce or alternatively provide a clear rationale for heterogeneity. The specific emotional and cultural needs of each family and individual family members, including young siblings, need to be taken into account when designing and approaching content development for NICU diaries. Well-designed experimental multicentre studies, clearly reporting on the characteristics and implementation of the intervention, are recommended to understand the effect of NICU diaries possibly within a bundle of other strategies designed to improve parental bonding and family centred engagement to prevent the onset of PICS-F.

9 | CONCLUSION

This scoping review revealed a growing interest in NICU diaries since 2020 onwards worldwide. The format, implementation, and use of NICU diaries are heterogeneous in current literature. A framework for the implementation of this intervention is needed to best leverage its potential for improving parent, family and staff well-being. As the evidence of effect is scant, future research on the effect of this intervention on PICS-F, parental bonding, and staff well-being is needed.

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

ETHICS STATEMENT

This article does not contain any studies with human participants performed by any of the authors.

ORCID

Gabriele Sorrentino  <https://orcid.org/0000-0003-2938-8953>

Kiara Ros Thekkan  <https://orcid.org/0000-0003-2467-6876>

Catia Genna  <https://orcid.org/0000-0002-6778-8598>

Orsola Gawronski  <https://orcid.org/0000-0001-8686-5897>

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