



Cohort Study

Palliative care nurse: A quantitative study of caring for neonates at end-of-life stage

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ABSTRACT

Objective: This study aimed to evaluate the quality of the care provided to newborns at End-of-Life (EOL) stages and compare the care which is already being given to the infants admitted to the NICUs of the selected hospital in (XXX) with the existing standards. Knowing how End-of-Life nursing care is provided, compared with the standard in the terminal stage of neonates' life can provide accurate information for policies, research, and educational practices.

Methods: In this descriptive study, 100 nursing care services, provided to neonates at the EOL stages and their parents, were observed and compared to the standard checklist which had been developed based on the literature review and existing standards in 2015. The study setting included the NICUs of the four hospitals affiliated to (XXX) The Content and Face Validity of the checklist were determined based on specialists' comments. The Content Validity Index was 94.85%, and its reliability was evaluated too through the inter-rater correlation coefficient (ICC = 0.715).

Results: Only 11.49% of EOL nursing care services were given properly and 77.92% were not given at all. Results showed that 10.59% of EOL nursing care services were performed improperly.

Conclusion: The overall rate of accordance with the EOL nursing care standards was poor (16.78%). Nursing care given to infants and their parents at EOL stages is far from the standards. This can be due to various reasons, such as inadequate training and the lack of comprehensive guidelines.

1. Introduction

One third of neonatal death occurs in Neonatal Intensive Care Units (NICUs), where the mortality rate ranges from 0.2% to 64.4% in developed countries [1]. Despite the treatment of congenital and chromosomal diseases, perinatal deaths remain inevitable [2]. The need for palliative and End-of-Life (EOL) care in NICUs involves treatment to reduce suffering, improve quality of life and satisfaction, provide sufficient knowledge and assistance to families in making appropriate decisions, and support clinicians with ongoing treatment [3].

Neonatal EOL nursing care, one aspect of palliative care, is one of the terminal care components that is given to improve the quality of life and to make it possible for infants to have a peaceful death. This type of

nursing care has an interdisciplinary mission and addresses neonates and parents in different situations. Neonatal EOL nursing care provides complete and true information as well as sufficient and proper communication between the neonates and their parents, with respect to their religious beliefs of parents [4,5]. The World Health Organization insists that the quality of life of neonates with severe clinical conditions be improved [6], by managing the death process in the NICUs, which has received less attention than other aspects of care such as ventilation [7].

Despite the importance of EOL nursing care and guidelines provided by international authorities such as the World Health Organization, care services remain inadequate [8], plausibly due to barriers such as conflict within the care team, inadequate training, and problems in using opiates [9]. The assessment of the compatibility rate of the current nursing care

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with the recommended guideline is one of the scientific methods for determining the strengths and weakness of nursing care services. The present study was performed in order to evaluate the compliance and performance of a clinical assessment of the current EOL nursing care at the NICUs of the selected hospitals affiliated to (XXX) Sciences for neonates and their parents according to the standard checklist. Knowing how End-of-Life nursing care is, comparing with the standard protocol among terminally ill neonates can provide accurate information for policies, research and educational practices.

2. Methods

This is a descriptive study in which the population and sample consisted of all care services provided to neonates in the final stages of life. This study assessed 100 nursing care services provided for neonates at EOL and their parents. The sample size were calculated using the following formula: $(n = [P (1-P) Z^2]/d^2; P = 0.5, d = 0.1 \text{ and } \alpha = 1.96)$. The birth rate of each center was used to calculate the proportion of sample size: Hospital A, $n = 25$, Hospital B, $n = 48$ Hospital C, $n = 18$ and Hospital D, $n = 9$.

In order to prepare a checklist of EOL nursing care standards, the scientific research articles and guidelines for palliative care and reference books that had been collected from 2009 to 2014 were analyzed. The data was collected through structured observation and by using a checklist including 90 items. Both, time and event sampling, were used to collect information and nursing care for neonates at EOL stage and their parents in three shifts (morning, evening and night) and then compared with the prepared standard checklist. The answer to each item of the checklist was scored on a scale including 'performed properly' (scored 2), performed improperly (scored 1), and not performed (scored 0). The study data were entered into the SPSS V.19 and descriptive analysis was performed by frequency and percentage. A P-value lower than 0.05 was considered to be a significant result.

A score of Neonatal Acute Physiology II (SNAP-II) higher than 40 was used to determine the neonates who needed EOL nursing care [10]. SNAP-II had six variables including body temperature, lowest neonatal blood pressure, PH level, Pao₂/Fio₂, urinary output rate and the history of seizures which were assessed. Babaei et al. reported 94.9% and 83.9% as the sensitivity and specificity of the SNAP-II and 48.1% and 99% were reported as the positive and negative predictive values of SNAP-II tools respectively [11].

In this research, a demographic questionnaire included some items related to the neonates, their parents, and the nurses: the neonates' age, gender, gestational age, maternal age, birth weight, postnatal age; the nurses' ages, training and work history, as well as mothers' jobs and the Snap-11 score of each neonate. The sampling process took ten months from 2014 to 2015. All the observations were performed by one person (The first author).

Content and Face validity was used for the assessment of checklist validity. The Content Validity Index of the checklist was 94.85%. The reliability of the checklist was measured by Interclass Correlation Coefficient (ICC = 0.715). The scores were classified in the percentage format and were classified as Poor (0-33), Moderate (34-67), or Well (68-100) (Babaei et al., 2012; Richardson et al., 2001).

2.1. Ethical considerations

The study protocol was approved by the Ethical Research Committee of (XXX). The research objectives were explained to all the nursing staff and the nursing managers and the mothers of the neonates and written informed consent were obtained. The results were announced to the managers and staff of centers if they wished so. The managers of the centers were assured that the data would be used only for research purposes and would not be available to other centers and individuals.

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The methods are stated in line with STROCSS 2021 guidelines [12].

3. Results

In this study, neonatal EOL the nursing care provided for 62.5% of boys and 37.5% of girls was evaluated in the NICUs of four hospitals. The results showed that most nurses who performed EOL nursing care were under 40 years of age and had six to ten years of work experience. 2% of the nurses had a history of participation in palliative care training programs. The gestational age of 43.8% of the neonates and the birth weight of 31.3% of them were respectively 38-42 weeks and 2000-2999 g. The postnatal age of 90.6% of the neonates was 1-7 days. The maternal age of 43.8% of neonates was 21-40 years and most of the mothers (70.71%) were housewives. The main demographic characteristics are shown in Table 1.

This study assessed EOL nursing care in which total of 9000 EOL-related nursing care services were observed. The Conformity rate showed that 11.49% of care services were performed properly, 10.59% of them were performed wrongly and 77.92% were not performed in the study settings. The checklist was composed of 90 questions which were answered as performed correctly, performed incorrectly, and not performed (Table 2). The total score of Conformity rate of current End-of-Life nursing care services with the standards was 16.78%, defining a poor level of accordance.

According to the study checklist for nursing care standards, only 10% of EOL nursing care services in our study possessed well level-accordance, 8% of them were moderately compatible with the noted standards, while and 72% were poorly compatible. In comparing the compatibility rates in the studied hospitals, no significant difference was seen between the situation of nursing care in the four studied hospitals ($P = 0.095$).

4. Discussion

The present study was performed to assess the conformity rate and to perform the clinical assessment of the current End-of-Life nursing care in the NICUs of (XXX) for infants and their parents according to a prepared checklist in 2015. The findings of this study showed that the overall rate of compliance with the standards in the NICUs was 16.87% and that 77.92% of neonatal EOL-related nursing care services were not provided. This finding was in line with the results of some other studies. Keele et al. [13], in their study on 40 American pediatric hospitals, reported that only four percent of the deceased neonates received

Table 1

Frequency distribution of characters of neonates and nurses in neonatal intensive care.

Category		Frequency (N)	Percentage (%)
Nurses age	<30 years old	21	40.4
	31-40 years old	21	40.4
	41-50 years old	9	17.3
	>50 years old	1	1.5
Nurse work history	<5 years	14	26.9
	6-10 years	20	38.5
	11-15 years	5	9.6
	16-20 years	10	19.2
	21-25 years	3	5.8
Nurse working shifts	Morning	9	17.3
	Evening	1	1.9
	Night	1	1.9
	Rotational	41	78.9
SNAP-II scores	40-55	25	78.13
	56-71	7	21.87
Gestational age (week)	24-27	5	15.6
	28-32	4	12.5
	33-37	9	28.1
	38-42	14	43.8
Neonatal birth weight (gr)	<1000	8	25
	1000-1999	7	21.9
	2000-2999	10	31.3
	3000-4000	7	21.8

Table 2

Frequency distribution of nursing care at the end of life stages of infants and their parents according to the checklist of the desired status of care in neonatal intensive care units of selected hospitals of Shahid Beheshti University of Medical Sciences.

S. No	Nursing care	Yes				No	
		Correct		Incorrect		Frequency	Percentage
		Frequency	Percentage	Frequency	Percentage		
1.	Level of education of parents is assessed before educating them.	0	0	100	100%	0	0
2.	Parents are educated to enable them to make informed decisions in the later stages of their baby's life.	0	0	0	0	100%	100%
3.	Baby's condition is describe using explicit words.	0	0	54	54%	46	46%
4.	Informs parents about the baby's daily condition.	0	0	16	16%	84	84%
5.	The baby's clinical condition is honestly explained to the parents.	0	0	0	0	100	100%
6.	Parents are informed about the change from medical care to palliative care.	0	0	0	0	100	100%
7.	Informs parents when the baby is likely to be alive.	0	0	0	0	100	100%
8.	Parents are informed that they can participate in the care and hug their baby whenever they wish.	0	0	1	1%	99	99%
9.	Parents can access the baby whenever they want.	0	0	0	0	100	100%
10.	Parents are involved in providing care.	0	0	0	0	100	100%
11.	Parents are informed about things they may see, hear or experience in their later stages of life.	0	0	0	0	100	100%
12.	Parents are told that they cannot change the situation but can support the baby's short life.	0	0	0	0	100	100%
13.	Parents are informed of their options for carrying leftover baby items.	0	0	0	0	100	100%
14.	End-of-life care interventions focus on parental support.	0	0	0	0	100	100%
15.	Parents are encouraged to participate in care decisions.	0	0	0	0	100	100%
16.	Does not restrict parents from expressing their feelings when they are alone with their baby.	100	100%	0	0	0	0
17.	Assures parents that a nurse is available whenever they need help.	99	99%	1	1%	0	0
18.	Talk to friends and family members of the parents about the grieving process and how to support the parents.	0	0	0	0	100	100%
19.	Parents' concerns about palliative care are taken into account.	0	0	0	0	100	100%
20.	Assures parents about proper and timely care.	40	40%	60	60%	0	0
21.	Parents' problems such as sleep disorders, fatigue, financial and family problems are considered in the care plan.	0	0	37	37%	63	63%
22.	Encourages parents to connect with other parents who have experienced this loss.	0	0	0	0	100	100%
23.	Cares about parents' views on visiting permission for other family members.	0	0	0	0	100	100%
24.	Attention is paid to the mother whose baby is under palliative care in terms of reducing and stopping breastfeeding.	0	0	0	0	100	100%
25.	Encourages parents to express their feelings.	0	0	38	38%	62	62%
26.	There is a parental follow-up program after the baby dies by phone, weekly, monthly or on special days (mother day, date of birth or date of death of the baby) in the care program, if the parents agree.	0	0	0	0	100	100%
27.	Refuses to use words that indicate that the dying baby is recovering, such as "good", "steady", "better" in daily conversations with parents.	58	58%	02	2%	40	40%
28.	Refuses to use the sentence (we can no longer do anything).	100	100%	0	0	0	0
29.	Encourages and supports parents who can be present at the baby's crib if they wish to die.	0	0	0	0	100	100%
30.	Gives small gifts to parents who have lost their baby, so that they do not leave the hospital empty-handed.	0	0	0	0	100	100%
31.	Encourages parents to hug, caress and feel the baby.	38	38%	62	62%	0	0
32.	Encourages parents to keep baby fingerprints as souvenirs.	0	0	0	0	100	100%
33.	Encourages parents to take care of the kangaroo.	0	0	0	0	100	100%
34.	Encourages parents to participate in bathing the baby.	0	0	0	0	100	100%
35.	Encourages parents to change baby diapers.	0	0	0	0	100	100%
36.	Encourage parents to take pictures of the baby at any time during the end-of-life care process.	0	0	0	0	100	100%
37.	Encourage parents to inform the nurse whenever they feel their baby is in pain and needs help.	16	16%	79	79%	5	5%
38.	Take appropriate care based on parents' perceptions that their baby is in pain or in need of help.	0	0	30	30%	70	70%
39.	Creates as many memories for parents as possible.	0	0	0	0	100	100%
40.	Encourages parents to create final memories (as an integral part of parental relief).	0	0	0	0	100	100%
41.	Respects the wishes of parents if they do not wish to participate in end-of-life care.	45	45%	38	38%	17	17%
42.	If parents are reluctant to participate in care, it does remind them that this may be their only chance to do so.	0	0	0	0	100	100%
43.	Encourages and supports parents to take a souvenir photo with the baby's body.	0	0	0	0	100	100%
44.	Bathing the baby's body allows parents who did not have the opportunity during the baby's lifetime.	0	0	0	0	100	100%
45.	Encourages parents to name their baby before he or she dies.	0	0	0	0	100	100%
46.	Uses words that directly refer to the life and death of the baby in his conversations with the parents.	0	0	0	0	100	100%
47.	Communicates with parents in a way that helps them understand the baby's condition.	0	0	0	0	100	100%
48.	Uses active listening techniques to communicate effectively and successfully with parents.	63	63%	0	0	37	37%
49.		58	58%	0	0	42	42%

(continued on next page)

Table 2 (continued)

S. No	Nursing care	Yes				No	
		Correct		Incorrect		Frequency	Percentage
		Frequency	Percentage	Frequency	Percentage		
	Uses the full presence technique to communicate effectively and successfully with parents.						
50.	Uses the technique of relentlessly giving parents' time to communicate effectively and successfully with their parents.	0	0	0	0	100	100%
51.	Uses non-verbal methods such as touching to communicate effectively and successfully with parents.	0	0	0	0	100	100%
52.	Refers to the baby by name (if a name has been chosen for him/her) in everyday conversations with parents.	16	16%	0	0	84	84%
53.	Objectives of Nursing Care Explains the end-of-life stages to parents.	0	0	0	0	100	100%
54.	Takes appropriate steps to establish optimal communication between parents and the palliative care team.	0	0	0	0	100	100%
55.	Reduces environmental stimuli in the later stages of life.	0	0	37	37%	63	63%
56.	Adjusts the amount of ambient light (environmental stimuli) in order to maintain privacy and ensure the comfort of the baby and parents.	0	0	0	0	100	100%
57.	Provides a comfortable and private environment for parents and babies to go through the end-of-life stages.	0	0	0	0	100	100%
58.	Reduces the activity of the health care team members during the visit.	0	0	0	0	100	100%
59.	Provides a calm and private environment for educating and communicating with parents.	0	0	0	0	100	100%
60.	The appropriate palliative care environment for parents, including soft lighting, ample space, counseling room, small library, camera, religious books, musical instruments and ample bed, is included in the care plan.	0	0	0	0	100	100%
61.	Ask their parents about their religion.	0	0	0	0	100	100%
62.	The cleric, chosen on the basis of religion, informs the parents if they wish.	0	0	0	0	100	100%
63.	The type and location of nursing care Plans the end-of-life stages of the care program according to the parents' cultural priorities.	0	0	0	0	100	100%
64.	Ask parents about their religious needs.	0	0	0	0	100	100%
65.	Respects the beliefs and traditions of parents.	0	0	0	0	100	100%
66.	By considering the cultural and religious issues of the parents, it helps them to adapt to the baby's situation.	0	0	1	1%	99	99%
67.	Introduces parents to the caregiver and social worker during the estimated time for the baby to die (from minute to day).	0	0	57	57%	43	43%
68.	Prepares the baby's body for the parents to see.	0	0	98	98%	2	2%
69.	Encourages parents to observe and touch the body of the deceased baby.	0	0	2	2%	98	98%
70.	Informs parents about familiarity with burial and burial arrangements.	0	0	96	96%	4	4%
71.	Performs pain management at the end of the baby's life according to the department's approved instructions.	1	1%	1	1%	98	98%
72.	Maintains the baby's vascular access to analgesic and sedative infusions.	97	97%	1	1%	2	2%
73.	Performs pain assessment continuously using pain measurement criteria.	1	1%	0	0	99	99%
74.	Pharmacological and non-pharmacological interventions to relieve the baby's pain according to the severity of his pain.	1	1%	41	41%	58	58%
75.	Uses non-nutritious suckling with or without sucrose as a non-pharmacological intervention to relieve infant pain.	0	0	0	0	100	100%
76.	Uses kangaroo care as a non-pharmacological intervention to relieve infant pain.	0	0	0	0	100	100%
77.	Uses massage (depending on the baby's condition) as a non-pharmacological intervention to relieve the baby's pain.	0	0	1	1%	99	99%
78.	Uses narcotics to relieve the baby's pain in case of severe pain.	57	57%	41	41%	2	2%
79.	Evaluates the effectiveness of pain relief interventions.	1	1%	0	0	99	99%
80.	Routine examinations stop vital signs and laboratory examinations.	1	1	41	41%	58	58%
81.	Stops painful examinations (such as heel sampling and arterial blood gas measurements).	0	0	0	0	100	100%
82.	Stops artificial feeding and aggressive hydration.	0	0	0	0	100	100%
83.	Performs care interventions in a way that does not disturb the baby's comfort.	0	0	0	0	100	100%
84.	Stops unnecessary aggressive procedures (interventions).	0	0	0	0	100	100%
85.	Strives to maintain and provide a calm environment for the baby.	0	0	0	0	100	100%
86.	Reduces equipment alarm sound.	0	0	0	0	100	100%
87.	Talk to other members of the health care team in a calm voice.	0	0	0	0	100	100%
88.	It uses hot and humid oxygen to provide the right temperature for the baby.	99	99%	1	1%	0	0
89.	Uses oxygen to help the baby breathe easily.	99	99%	1	1%	0	0
90.	Hugs and soothes the baby if parents are not available.	0	0	0	0	100	100%
Total		11.49%		10.59%		77.92%	

palliative care. Moura et al. (2011) found that until 2005, neonates in NICUs of Portugal rarely received EOL nursing care.

It seems that one of the main causes of weakness of EOL nursing care in the current study's setting could be a lack of nursing training programs regarding neonates at EOL stage care. The study findings showed that only 2% of the nurses in the hospitals under study had a history of participation in palliative neonatal care training programs. Murakami et al. (2015) showed that the EOL training programs significantly reduced weaknesses in neonatal EOL care. Nurses and health care

workers must be trained in confronting EOL situations which is an international priority in the training of nurses and similar studies confirm our comments [9,14]. On the other hand, although the education curriculum of Nursing was revised in 1996, 2006 and 2013 by Iran's ministry of health, there is no specific budget allocated to universities for EOL nursing care [15]. Zhang and Lane (2013) reported that nurses were not satisfied with their training for EOL nursing care in their university curriculum. It seems that the NICU nurses need continuous and supportive training [16]. In this regard, Matthews and O'Conner-Von

(2008) reported that health care system paid less attention to neonatal EOL nursing care in comparison with other nursing care services in NICUs. He added that only two percent of American nurses' training curriculum was related to EOL nursing care. Khanali-Mojen et al. (2015) reported in a qualitative study including 29 patients that only a 2-h training session in the curriculum of Iranian nurses was related to EOL nursing care. The training of palliative nursing care must be provided for all neonatal health care workers [17]. Iranian experts in nursing care believed that palliative nursing care must be presented as an independent field in the graduate studies of Nursing, but unfortunately no action has been taken in this regard yet [15]. We suggest that the training programs for all Nursing students be revised and that the health policy makers pay more attention to this issue.

Contrary to the findings of the current study, Soni et al. (2011) conducted a national survey to examine the quality of palliative care provided by neonatal units in the UK. Their results showed that palliative care for neonates was provided by most neonatal units (76%) among 35 responders. To explain this inconsistency, the authors believe that palliative care in all the under-study hospitals was provided in the absence of guidelines, which is a factor that may have a negative impact on the quality of care. In fact, in the present study, there was no palliative care guideline for providing care, which somehow explains the poor level of overall accordance with the EOL nursing care standards [18].

The review of the literature showed that clinical guidelines had a significant role in the standardization of health care and act as a guide for healthcare teams [19]. Washington Medical Association reported that clinical guidelines can improve clinical care methods and decision-making for patients in specific situations [20]. Due to the lack of unique clinical guidelines or instructions for neonate care-giving at the EOL stage, neonates and their parents may be ignored [21]. It seems that it is necessary to prepare suitable clinical guidelines for the palliative care of infants and their parents (Murakami et al., 2015). Neonates and their parents need comprehensive and sympathetic care [22].

The results of the present study showed that 100% of the nurses fail to brief the parents on the objectives of nursing care and the necessity of changing health care to palliative care, possibly due to nurses' unawareness of the principles of EOL care. This challenge can be dealt with by teaching them the principles of palliative care [23]. Similarly, in 100% of the cases, the parents were found not to be receiving the training necessary for empowering them to make informed decisions and to participate in the care-giving process. They were also found not to be allowed to see their neonates at the hospital's staff's discretion, while some studies suggest that parents (up to 81%) were supported and empowered through participating in care-giving and decision-making processes [24]. Enabling parents to adapt themselves to the absence of their child and successfully pass through the bereavement process is crucial in reducing the consequences of infant mortality for the parent's [25]. The lack of attention to the family-based approach as the cornerstone of palliative care can explain this antithesis [26].

The results of the present study also indicated that in 100% of the cases, the parents were not notified of what they would experience in the end stages of their child's life. They were deprived of visiting the other members of their family and they were not encouraged to be present by their baby's bed of death. Scientific resources assume this lack of presence beside the child while dying as the cause of parenthood disruption, the feeling of guilt, the anxiety for the child's situation; they consider the parents' fear and distress as a factor contributing to their inadaptability to the crisis, their denial of the child's death as well as their Obsessive Compulsive Disorder and depression [27].

Moreover, as for effective communication with parents, the nurses failed to listen to the parents actively in 63% of the cases, were not present to communicate with them effectively and successfully in 58% of the cases and did not mention the child's name in daily conversations with the parents in 84% of the cases even if they had a name. None of the observations suggested the use of techniques such as giving parents

uninterrupted time and nonverbal help like touching them as a means of effective and successful communication.

Interacting and communicating with the patient's family members, and even taking care of them, is a requirement in nursing [28]. The first step to solving communication-associated problems is to identify the barriers to effective communication, particularly in NICUs [29].

According to the present results, although the nurses notified the parents of their child's daily condition in 45% of the cases, they failed to effectively communicate with the parents and help them perceive the child's status. Furthermore, the nurses failed to use unambiguous words to describe the child's status in 46% of the cases. They also failed to honestly explain the child's clinical status to the parents in 84% of the cases. Helping parents accurately understand their child's status and reducing their concerns by reciting the clinical facts related to their baby using simply understandable language is crucial [30]. Qualitative research conducted by Johnson and Gray (2013) showed that parents not only need pain relief, support, and respect, but they also need communication along with empathy and understanding of their status.

Although the parents' beliefs and customs were found to be respected in 57% of the cases, they were not questioned about their religion when providing nursing care in any of the study units. The location and type of EOL nursing care were not chosen based on the parent's cultural and religious background and priorities, and the nurses did not ask the parents about their spiritual and religious requirements. One of the main principles of palliative care is to provide spiritual care at the end-of-life stage. The results of different studies show that supporting patients and their families psychologically and observing their spiritual concerns are the key factors at the end-of-life stage [31,32].

In compliance with EOL care standards, no cases of restriction were observed regarding expressing emotions when the parents were beside their child; nevertheless, the parents were encouraged to express their feelings only in 38% of the cases. Research suggests that nurses can support parents by providing them with honest information about their child's clinical and therapeutic status, encouraging them to talk about their feelings and experiences with nurses, and providing them with proper opportunities to express their emotions [33,34].

Although palliative care guidelines emphasize the reduction and suspension of unnecessary invasive interventions for children at their end-of-life stages to provide them with comfort and help them experience a peaceful death [13], the results of the present study indicate that these interventions still existed in the care services observed.

Non-pharmacological methods, including Non-Nutritive Sucking and Kangaroo Care, were not applied to relieve and control the child's and their parents' pain in any of the care services observed. Only in 1% of the cases, massage was used as a non-pharmacological method to relieve the child's pain depending on their status, but the effectiveness of pain relief interventions was not investigated. Hugging and calming the baby in the absence of their parents were not performed in any of the observed care services. The results indicated that vascular access was available in 97% of the cases for the infusion of analgesics and sedatives and that opioids were used in 57% of the cases for the relief of infant severe pain. Scientific resources emphasize that using non-pharmacological methods and non-narcotic drugs is the first step in relieving pain at the end-of-life stage, and recommend opioids in case the pain is not relieved [35].

In none of the cases, the parents were contacted after losing their child; however, research suggests that parents experiencing their child's death leave the hospital in a state of shock and psychological trauma. These parents can be helped to adapt to the situation and get through this period by providing them with special care (Shahnazary, 2011). A study demonstrated that the parents of the infants dying in the NICUs who received palliative care obtained lower bereavement scores compared to that of the other group [36].

Observing privacy and offering comfort to infants who are at the end of life stage and their parents is crucial [37]. Nevertheless, the present study shows that environmental stimuli were not suppressed in 63% of the cases and that no efforts were made in any of the care services to

provide the infants and the parents with a peaceful environment and maintain it.

In all the nursing care services observed, the nurses failed to provide the parents even with remembrances of their child and did not encourage them to keep the baby's fingerprint or something like that which could help them remember their child. The parents were encouraged to hug, caress and touch their child in only 38% of the cases. The remembrance of infants is crucial for their parents, especially during bereavement and heartbreak periods [38].

As a limitation of the study, nurses in some hospitals changed their nursing cares in the presence of study investigators and we decided to solve the noted study limitations with a repeated observation of nursing care of EOL neonates. The study does not include data regarding nursing training programs at the selected centers, and that is related to cultural and traditional factors. Furthermore, the work experience of the nurses included in the study had variations.

5. Conclusion

The results of the present study show that end-of-life nursing care services for Iranian neonates were way far from the standards. This weakness was reported to be the result of inadequate training and a lack of comprehensive guidelines on palliative care and EOL care of newborns and their parents. The findings of the present study suggest that nurses must be trained in EOL nursing care, and although palliative care has developed among Iranian nurses, neonatal palliative care turns out to be in the first stages and there is a need for more nursing training curriculum.

Sources of funding for your research

No funding was secured for this study.

Ethical approval

All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Consent

Not applicable.

Author contribution

Sepideh Shahintab and Dr. Manijeh Nourian: conceptualized and designed the study, drafted the initial manuscript, and reviewed and revised the manuscript. Dr. Mohamad Amin Pourhoseingholi: Designed the data collection instruments, collected data, carried out the initial analyses, and reviewed and revised the manuscript. Dr. Maryam Ras-souli: Coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content.

Registration of research studies

1. Name of the registry: N/a
2. Unique Identifying number or registration ID: IR.SBMU.RAM.REC.1394.353
3. Hyperlink to the registration (must be publicly accessible):

Guarantor

Sepideh Shahintab.

Ethical considerations

The study protocol was approved in the Ethical Research Committee of Shahid Beheshti University of Medical Sciences (approval number IR.SBMU.RAM.REC.1394.353).

Availability of data and material

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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Contributors' statement page

Sepideh Shahintab and Dr. Manijeh Nourian: conceptualized and designed the study, drafted the initial manuscript, and reviewed and revised the manuscript. Dr. Mohamad Amin Pourhoseingholi: Designed the data collection instruments, collected data, carried out the initial analyses, and reviewed and revised the manuscript. Dr. Maryam Ras-souli: Coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content.

Provenance and peer review

Not commissioned, externally peer-reviewed.

Declaration of competing interest

The authors deny any conflict of interest in any terms or by any means during the study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.amsu.2022.104729>.

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