Journal of Pediatric Nursing xxx (xxxx) xxx

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Transition from the neonatal unit to home: Parents' educational needs to promote their psychological well-being and sleep quality

Valérie Lebel, RN. Ph.D [a,*], Marilyn Aita, RN. Ph.D [b], Isabelle Landry, R.N, PhD [a,c], Marie-Josée Martel, RN, Ph.D [c], Paméla Hamel-Hilaréguy, RN, B.Sc [a]

[a] Nursing Department, Université du Québec en Outaouais, 5 St-Joseph Street, St-Jerome, Quebec J7Z 0B7, Canada
[b] Faculty of Nursing, Université de Montréal, Pavillon Marguerite-d'Youville, 2375 de la Côte-Sainte-Catherine Street, Montreal, Quebec, H3T 1A8, Canada
[c] Nursing Department, Université du Québec à Trois-Rivières, 3351, des Forges Boulevard, Trois-Rivières, Quebec, G8Z 4M3, Canada

ARTICLE INFO

Article history:
Received 29 January 2024
Revised 22 July 2024
Accepted 22 July 2024
Available online xxxx

Keywords:
NICU
Parents
Psychological well-being
Sleep
Discharge
Educational needs

ABSTRACT

Purpose: Parents may experience altered psychological well-being and sleep following the discharge of their preterm infant. They also perceive a lack of information from healthcare professionals. This study aims to describe the educational needs of parents regarding their psychological well-being and their sleep quality following their infant's discharge from the neonatal unit.
Design and methods: This descriptive quantitative study uses an online survey to assess parental information needs. Multiple parents ($n = 87$) completed the survey. Descriptive statistics were conducted to report the results of the survey.
Results: According to parents, the most helpful information given by health professionals to reduce the stress felt during this period concerned the follow-up of the infant after hospitalization and access to a health professional in case of questions ($n = 12$; 31.6%). Few parents ($n = 17$; 19.5%) reported seeing a health professional about their sleep in the past six months. According to 54.8% of parents, none of the information received by health professionals when preparing for their infant's transition home helped improve their sleep quality.
Conclusion: After discharge, parents have several information needs that may impact their psychological well-being and the quality of their sleep.
Practice implications: Healthcare professionals must address these informational needs before and after discharge from the neonatal unit to enhance the experience of parents during the transition of their preterm infant in the family environment.

Introduction

Preterm birth and hospitalization in the neonatal intensive care unit (NICU) have multiple consequences for families (Amorim et al., 2018; Cho et al., 2012; Haddad et al., 2019; Schaaf et al., 2012), such as psychological distress defined as an uncomfortable emotional state experienced by a person as a result of a specific stressor or demand that causes harm (Ridner, 2004). They may also experience impaired parental sleep quality defined as the overall sleep experience and the fatigue experienced upon awakening (Angelhoff et al., 2020; Smith, Tallon, Smith, Angelhoff and Mörelius, 2022). These impacts emerge during hospitalization and continue up to 12 months and more after the infant is integrated into the family environment (Amorim et al., 2018; Lee & Hsu, 2012; Schaffer, 2012). Specifically, a substantial proportion (75–100%) of parents report stress (Koliouli et al., 2016; Shanmugam & Ramachandra, 2015), as well as alteration of their sleep quality (32–75%) during the hospitalization period and several months after the birth of the preterm infant (Blomqvist et al., 2017; Feeley et al., 2020). It is well-documented that parents who report stress and symptoms of depression also report poorer quality of sleep (Edell-Gustafsson et al., 2014; Lebel et al., 2022; Schmöker et al., 2020). Likewise, parents with poorer sleep quality perceive an alteration in their psychological well-being (Gogou et al., 2019; Lee & Hsu, 2012). A vicious cycle can therefore emerge in between the symptoms of psychological distress and disruption in sleep quality over several months (Amorim et al., 2018; Pinelli et al., 2008; Salomè et al., 2022). In addition to their inter-influence, the alteration of parents' psychological well-being and sleep quality leads to a lower sense of parental competence (Lebel et al., 2022), a less positive perception of their general health (Schmöker et al., 2020), an alteration in the establishment of the

* Corresponding author at: Nursing Department, Université du Québec en Outaouais, 5 St-Joseph Street, St-Jerome, Quebec J7Z 0B7, Canada.
E-mail address: valerie.lebel@uqo.ca (V. Lebel).

https://doi.org/10.1016/j.pedn.2024.07.024

parent-child bond, and less optimal child development, mainly due to the reduced interaction between parent and infant (Leahy-Warren et al., 2020; Pisoni et al., 2020; Stefana et al., 2019). Therefore, on the other hand, adequate psychological well-being and enhanced sleep quality promote parental well-being and the optimal development of the preterm infant (Haddad et al., 2019; Leahy-Warren et al., 2020; Lebel et al., 2022; Pisoni et al., 2020; Schmöker et al., 2020; Stefana et al., 2019).

It is well-documented that, during the hospitalization of their infant, parents want to receive up-to-date, easily accessible information that is specific to them (Lebel et al., 2021; Orr et al., 2017; Weems et al., 2016). They also advocate receiving personalized information that considers the particularities of their preterm infant. Following the integration of the preterm infant into the family environment, parents feel a great deal of uncertainty about their child's health condition and a lack of information, which exacerbates the deterioration of their psychological well-being and interferes with their quality of sleep (Amorim et al., 2018; Haddad et al., 2019). In addition, following hospitalization in the NICU, parents perceive a lack of support from the health professionals they see, who are better equipped to follow families with a healthy, full-term newborn. Indeed, they perceive that these professionals do not always meet their information needs (Petty et al., 2018), which, in turn, influences parental psychological well-being and quality of sleep (Griffith et al., 2022).

It is known that the educational needs of parents whose infant is no longer hospitalized are not the same as those of parents whose child is hospitalized (Petty et al., 2018). However, while this disparity is acknowledged, needs and preferences for how this information is transmitted have not yet been documented. It is therefore imperative to explore and describe parents' needs to better adapt support services and respond in a more targeted way to parents' expectations. Specifically, a better understanding of their information needs regarding psychological well-being and parental sleep quality is of increased importance, given the significant rate of parents with impaired psychological well-being and sleep quality (Haddad et al., 2019; Lebel et al., 2022). A better understanding of these aspects could greatly improve their experience and well-being throughout their journey with their preterm infant.

The purpose of this study was to describe the educational needs of parents about their psychological well-being and sleep quality following the discharge of their preterm infant from the NICU. This study also aimed to explore parents' preferences regarding how information is accessed and transmitted.

Methods

Design

A descriptive quantitative approach was used to address the purpose of the study. This approach is suitable when a topic has been little explored previously (Polit & Beck, 2021). Data collection occurred between May 2023 and September 2023.

Settings and sample

To constitute a convenience sample of participants from different rural and urban areas, an advertisement was posted through the social network Facebook®. The advertisement was shared with a private group of French-speaking parents of premature infants on Facebook®. This recruitment method was selected to ensure the inclusion of participants with different sociodemographic characteristics (Blumenberg et al., 2019) and is efficient and inexpensive (Darko et al., 2022; Sanchez et al., 2020). To be included, parents had to: 1) be 18 years of age or older; 2) speak and read French; (3) be the mother or father of a premature infant born at less than 37 weeks gestation and discharged from the NICU for six months or less; and finally, 4) reside in Canada. French-speaking parents were targeted for recruitment to enhance the value of their opinion, which is not often represented in the scientific literature. Since the survey was developed in French, the recruitment of French-speaking parents avoids recruiting people who are unable to answer the survey adequately due to a lack of understanding of certain questions. No exclusion criteria were selected. The total sample targeted was 100 parents to represent the concerned population, considering that the rate of premature births in Quebec is 7.1% or about 6035 births per year (Institut de la statistique du Québec, 2023).

Measurements

Two questionnaires were used in this study: a socio-demographic questionnaire and a survey. The sociodemographic questionnaire consisted of 18 questions designed to collect various information to describe the sample, such as age, gender, education, number of children, and gestational age of the preterm infant.

The purpose of the survey was to collect parents' educational needs related to their psychological well-being and sleep, as well as their preferences for receiving the desired information, i.e., how and when they would like to access this information. It was developed by the research team and consisted of 13 open-ended questions and 6 multiple-choice questions. The questions were developed based on the results of an earlier study conducted by the principal investigator which indicates that parents of a preterm infant have specific information needs when preparing for their infant's discharge from the neonatal unit (Lebel et al., 2021). Examples of the questions included in the survey are presented in Table 1. The LimeSurvey® platform was used to conduct the survey. This platform is dedicated to online research questionnaires and provides secure data collection from participants with local data hosting (on the principal investigator's university server).

Data collection procedure

To reach potential participants, an advertisement was shared on a Facebook group dedicated to parents with a prematurely born infant. This private group includes only parents of a preterm infant since moderators are limiting access to the group. If parents who saw the ad were interested in participating in the study, they could click on a LimeSurvey® link to directly access the 4 questions related to the study inclusion criteria. If the parent did not correspond to the requested criteria, they were thanked for their interest and the questionnaire was terminated. If the parent met the inclusion criteria, the consent form was displayed. Once read in its entirety and after obtaining consent, the parent was automatically redirected to the sociodemographic questionnaire and the survey, which both took about 15 min to complete. At any time during the completion of the survey, the parent could terminate their participation. Parents were allowed to decline to answer one or more questions if they did not know the answer or did not wish to answer. The responses to all survey questions were not mandatory, to promote their authenticity and to avoid inaccuracy (Pozzar et al., 2020). No monetary compensation was given to participants to avoid attracting fraudulent participants and answers provided by robots to obtain financial compensation (Pozzar et al., 2020).

Ethical considerations

The study was approved by the Research Ethics Committee of the Université du Québec en Outaouais. Participation in the study was completely anonymous. Participants did not provide identifying information (i.e. name, telephone number) to the research team.

Table 1
Examples of the questions included in the survey.

Survey questions	Reply options
During the preparation for your infant's discharge from the neonatal unit, did you feel any stress related to the transition home?	Yes or No
What information received from healthcare professionals helped reduce your stress about the transition home with your infant?	Open-ended question
What information about your premature infant's sleep would you have liked to receive during the transition home? *Several answers were accepted.	• Number of naps expected in 24 h • Number of possible awakenings at night • Number of hours of sleep expected in 24 h • Recommended place for baby to sleep day and night • Sleep routine (how to get baby to sleep) • Sleeping away from home (stroller, car seat, baby carrier) • Expected number of hours of sleep at night • Recommended bedtime for the night • Duration of waking periods • How to dress baby for sleep • Other information
In your opinion, what are the characteristics of an effective information tool for informing you about your premature infant and related elements? *Several answers were accepted.	• Accessible at all times • Contains information on a wide range of subjects (all topics closely or remotely related to prematurity) • Contains scientifically backed information (with references) • Contains popularized information • Contains community resources • Offers options for discussion between parents or professionals • Easily accessible (without searching) • Contains text (detailed information) • Contains photos • Contains summarized information in the form of tables, diagrams, etc. • Is visually appealing (colors, icons) • Contains stories shared by other parents (real-life experiences) • Other

Data analysis

Data from the sociodemographic questionnaire and the survey were analyzed using the IBM SPSS Statistics version 29 software. Descriptive statistics were conducted to describe the sociodemographic characteristics of parents. Descriptive analyses were also conducted to report the results of the survey. Responses to open-ended questions were grouped into categories by the research team to report the frequency of each type of response. These categories emerged inductively from participants' responses to open-ended questions. This allowed the results to be disseminated more effectively.

Results

Demographic characteristics of participants

Of the 120 parents who met the inclusion criteria, 19 did not consent to participate in the study. A total of 101 parents participated in the study. Of these, 87 responded to the sociodemographic questions and the survey questions. Participants were mostly mothers (86 mothers and 1 father). The average age of participants was 31.46 years, and the majority ($n = 76$; 87.3%) reported post-secondary education: professional ($n = 23$; 26.4%), college ($n = 20$; 23.0%), or university ($n = 33$; 37.9%). The mean gestational age at birth of infants was 30.72 weeks, hospitalization lasted an average of 76.33 days, and the mean age of the preterm infant was 6.85 months, at the time parents completed the survey. The demographic characteristics of the participants are detailed in Table 2.

Psychological well-being

A large proportion of parents reported experiencing stress ($n = 39$; 60.9%) and worries (n = 39; 61.9%) when preparing for their preterm infant's home transition. The most helpful information given by health professionals to reduce the stress felt during this period concerned the follow-up of the infant after hospitalization and access to a health professional in case of questions ($n = 12$; 31.6%). According to the parents, it was mainly the support received from loved ones (family and friends) that reduced the parents' stress level (n = 15; 40.5%) and not the information shared by their loved ones.

Parents indicated that the education they received from healthcare professionals on how to care for their infant's particular case helped reduce their concerns ($n = 12$; 33.3%). For example, instruction included how to administer medication to the infant, how to feed the infant (gavage, breastfeeding, or bottle-feeding), and how to prevent infections at home. However, 30.4% (n = 17; 54 responses in total) of parents also indicated that they would have liked to receive more information about the special care to give to their preterm infant at home to reduce their stress and worries (e.g., breastfeeding a very low birth weight infant; the cost of required specialized equipment following discharge, such as that related to the administration of oxygen; cardiopulmonary resuscitation of premature infants; and the specifics of medication). Detailed results regarding parents' information needs to support their psychological well-being are presented in Table 3.

Sleep

Some parents ($n = 17$; 19.5%) reported seeing a health professional about their sleep in the past six months. In addition, 54.8% ($n = 23$) of respondents expressed that none of the information received by health professionals when preparing for their infant's transition home helped improve their sleep. The proportion of respondents who did not receive information from loved ones (family and friends) to promote their sleep was similar ($n = 20$; 50.0%). When asked about the best advice to give to another parent of a preterm infant to promote parental sleep, many respondents would recommend resting, napping, and sleeping when their infant is asleep ($n = 18$; 42.9%). However, many parents ($n = 7$; 16.7%) indicated that they did not know what advice they would give since they did not know how to promote their sleep.

Concerning the sleep of their preterm infant, a large proportion of parents ($n = 24$; 57.2%) expressed that they had questions about the specifics of their child's sleep, such as the need to wake them up at night to feed, the amount of sleep required, the position, location, and clothing of the infant for sleeping, as well as the noises (breathing, grunting) they made while sleeping. According to the parents, the most important information about their infant's sleep is the number of hours of sleep expected in 24 h ($n = 25$; 56.8%) and the duration of periods of wakefulness ($n = 21$; 47.7%). Detailed results regarding parents' information needs to support their sleep and that of their infant are presented in Table 4.

General information needs and preferred access to information

When asked about the most important general information to give to a parent preparing for the discharge of their preterm infant, parents' responses varied widely. However, the most frequent responses concerned information on how and when to contact a health professional if needed ($n = 11$; 27.5%), as well as information on how to care for a preterm infant ($n = 10$; 25.0%), such as medication, infection prevention, and feeding. When asked about the least important information

Table 2
Description of participants.

Sociodemographic characteristics (n = 87)		Mean (±SD)/N(%)	Median (min/max)
Age (yrs)		31.46 (5.04)	32.0 (20.0/43.0)
Gender	Female	86 (98.9%)	–
	Male	1 (1.1%)	
Education	High school or less	11 (12.6%)	–
	Professional Degree	23 (26.4%)	
	College-level*	20 (23.0%)	
	University-level	33 (37.9%)	
Multiple pregnancies	No	79 (90.8%)	–
	Yes	6 (6.9%)	
Weeks of pregnancy at premature birth		30.72 (3.47)	31.4 (23.0/36.0)
Length of stay in NICU (days)		76.33 (50.20)	39.0 (1.0/152.0)
Work status	Full-time worker	52 (59.8%)	–
	Employment insurance or parental leave	21 (24.1%)	
	Other	14 (16.1%)	
Household income (CAD $)	< $60,000	20 (23.0%)	–
	$60,000 – $69,999	9 (10.3%)	
	$70,000 – $79,999	6 (6.9%)	
	$80,000 – $100.00	17 (19.5%)	
	> $100,000	28 (32.2%)	
	Prefer not to answer	7 (8.0%)	

* In Québec (Canada), College refers to a 2-year pre-university degree; M = mean, SD = Standard Deviation.

to give before discharge from the neonatal unit, 75.0% (n = 27; 36 total responses) of parents responded that no information was unimportant. The topic that raised the most questions among participants after discharge from the neonatal unit involved the particularities associated with the prematurity of their infant (n = 17; 43.6%) such as the intensity and duration of crying, feeding by gavage or breastfeeding (milk fortification, grouped feedings, etc.), as well as the expected growth and development. In addition, parents indicated that they preferred to receive information via a health professional (n = 34; 82.9%) or a website (n = 28; 68.3%), during the infant's hospitalization in the neonatal unit (n = 29; 70.7%), as well as during and shortly after the transition to home (n = 28; 68.3%). In their view, information should be available at all times (n = 38; 92.7%), be diversified (n = 30; 73.2%) and easily accessible (n = 26; 63.4%). Detailed results on general information needs, methods, and moments to access information are presented in Table 5.

Discussion

According to the results of this study, parents with a preterm infant who integrated the family environment in the last six months have several information needs to improve their psychological well-being and the quality of their sleep. In general, they would like information about the particularities of their preterm infant and their specific care, how the infant is followed up after discharge from the neonatal unit, as well as how to contact health professionals if needed. They request information and resources tailored to their unique situation related to the integration of their preterm infant into the family environment. These results contribute to the existing evidence on this topic since, to our knowledge, no previous study has explored specific information that can reduce stress and worry, as well as improve sleep in parents of a preterm infant who has been in the family environment for the past 6 months.

It is interesting to note that several parents indicated they had questions about various aspects of their preterm infant's sleep following the transition to home. This result suggests that these parents had unmet information needs and that this topic may not have been addressed given all the important aspects of preparing for discharge in which health professionals and family members are engaged. This finding contributes to current knowledge about the information needs of parents whose preterm infant has integrated into the home environment within the last 6 months. These results also contribute to our knowledge of the factors that may influence parents' readiness for discharge. Knowing that parents need very specific information about their premature infant's sleep, such as how long the infant should sleep and whether it's necessary to wake the infant to feed at night, enables healthcare professionals to provide parents with this information to make them feel more prepared for the discharge of their premature infant (Aydon et al., 2018).

Moreover, it should be noted that few parents consulted a health professional regarding their sleep in the past six months, which is significant, given that it has been documented that more than 48% of parents experience impaired sleep in the months following the integration of their preterm infant into the family environment (Blomqvist et al., 2017). This low consultation rate is worrisome since it has been documented that impaired parental sleep is linked to poorer psychological well-being (Gogou et al., 2019; Lebel et al., 2022; Lee & Hsu, 2012) and an alteration in the medium- and long-term development of the preterm infant (Leahy-Warren et al., 2020; Pisoni et al., 2020; Schmöker et al., 2020; Stefana et al., 2019). This could be explained by a high rate of parents reporting they did not receive advice on parental sleep from health professionals when their infant was discharged from the neonatal unit. This could mean that they are not equipped to help parents prevent sleep alteration and that they don't encourage them to consult about it if need be. This highlights the importance for healthcare professionals to inform parents regarding the incidence and impacts of sleep alteration following the integration of the preterm infant into the family environment, as well as the resources available to support them.

The results of this study indicate parents' preference to receive information via health professionals or a website. These preferences were also reported in previous studies, but they were conducted with parents whose preterm infants were hospitalized (Adama et al., 2022; Lebel et al., 2021; Orr et al., 2017). In addition, recent recommendations address the importance of healthcare professionals providing information to parents in preparation for discharge from the neonatal unit (Smith, Love and Goyer, 2022). However, no study, to our knowledge, has reported the preferences of parents of infants whose NICU hospitalization is terminated. These results provide a better understanding of these parents' needs, according to their point of view, and stress the importance of education provided by healthcare professionals and the importance of accessing reliable information via a website.

Also, according to the results obtained, parents want to have access to information about prematurity and the home transition both during and after hospitalization and to have easy access to it at any time. This is consistent with their preference to access information via a website

Table 3
Questions regarding parent's psychological well-being.

Survey question	Answers	N (%)
Consultation of a healthcare professional for psychological state[1] ($n = 87$)	Yes	34 (39.5%)
Type of professional[2] ($n = 53$)	Psychologist	20 (58.8%)
	Family doctor	11 (32.4%)
	Social worker	11 (32.4%)
	Other	11 (32.4%)
Presence of stress during the period preceding discharge[1] ($n = 64$)	Yes	39 (60.9%)
Information received from healthcare professionals to help reduce stress[3] ($n = 38$)	Follow-up and access to a professional	12 (31.6%)
	Teaching how to care for their infant	9 (23.7%)
	A reassuring speech	8 (21.1%)
	None	7 (18.4%)
Information and other received from relatives (family, friends) to help reduce stress[3] (n = 37)	Support received	15 (40.5%)
	None	13 (35.1%)
Presence of worries during the period preceding the discharge[1] ($n = 65$)	Yes	39 (61.9%)
Information received from healthcare professionals to help reduce worries[3] ($n = 36$)	Follow-up and access to a professional	6 (16.7%)
	Teaching how to care for their infant	12 (33.3%)
	A reassuring speech	8 (22.2%)
	None	7 (19.4%)
Information and other received from relatives (family, friends) to help reduce worries[3] ($n = 32$)	Support and listening	10 (31.3%)
	None	16 (50.0%)
	A reassuring speech	2 (6.3%)
Most important information to reduce stress and worries during the first months after discharge[2] (n = 64)	Expected development according to the gestational age	50 (78.1%)
	Particularities of the preterm VS the full-term newborn	42 (65.6%)
	Medical follow-up and other follow-ups after discharge	39 (60.9%)
	Management of breastfeeding or bottle-feeding problems	36 (56.3%)
	Infection prevention (going out in public, visitors)	36 (56.3%)
	Management of fever, colic, or symptoms of discomfort	34 (53.1%)
	Adequate stimulation during periods of wakefulness	33 (51.6%)
	Strategies to promote parental psychological well-being	17 (26.6%)
	Main reasons for consulting a doctor/health professional	16 (25.0%)
	Strategies to reduce crying in the premature infant	16 (25.0%)
	Infant's hygiene (baths and other care)	7 (10.9%)

[1] Yes or no question.
[2] Multiple-choice question where several answers were accepted.
[3] Open-ended question.

Table 4
Questions regarding sleep.

Survey question	Answers	N (%)
Consultation of a healthcare professional for sleep in the last 6 months[1] ($n = 87$)	Yes	17 (19.5%)
Type of professional[2] ($n = 17$)	Family doctor	11 (64.7%)
	Psychologist	2 (2.3%)
	Nurse practitioner	2 (2.3%)
Use of aids to facilitate your sleep[1] (n = 87)	Yes	15 (17.2%)
Type of aids[2] ($n = 15$)	Relaxation, meditation, breathing techniques	11 (73.3%)
	Melatonin	2 (13.3%)
	Prescription medication	4 (26.7%)
Information received from healthcare professionals to help improve parental sleep[3] ($n = 42$)	Respect the infant's rhythm, listen to yourself, one day at a time, support each other	5 (11.9%)
	Rest when possible	7 (16.7%)
	None	23 (54.8%)
Information received from relatives (family, friends) to help improve parental sleep[3] ($n = 40$)	Rest, take a nap	7 (17.5%)
	None	20 (50.0%)
	Ask for help	5 (12.5%)
Most important information about the sleep of the preterm infant[2] ($n = 48$)	Number of hours of sleep expected in 24 h	25 (56.8%)
	Duration of wake-up periods	21 (47.7%)
	Number of naps expected in 24 h	18 (40.9%)
	Number of hours of sleep expected at night	16 (36.4%)
	The recommended location for the infant to sleep	14 (31.8%)
	The bedtime routine (how to put the infant to sleep)	13 (29.5%)
	Infant sleeping away from home (i.e. stroller, car seat)	13 (29.5%)
	Recommended bedtime for the night	13 (29.5%)
	How to dress the infant for sleep	13 (29.5%)
	Number of possible awakenings during the night	11 (25.0%)
Topics about infant's sleep that raised questions following discharge[3] (n = 42)	None	10 (23.8%)
	Waking the infant for feeding	7 (16.7%)
	Quantity of sleep	7 (16.7%)
	Position, location, and clothing for infant's sleep	6 (14.3%)
	Infant's noises and respiration	4 (9.5%)

[1] Yes or no question.
[2] Multiple-choice question where several answers were accepted.
[3] Open-ended question.

and their desire to have access to a health professional after the transition home to answer their questions and information needs. This need for follow-up by health professionals after discharge from the neonatal unit was also indicated in a scoping review to identify interventions to reduce parental stress after hospitalization (Griffith et al., 2022). Instantaneous and permanent access to desired information on prematurity and the particularities of the preterm infant has also been identified as an important element for parents whose infant is hospitalized (Lebel et al., 2021; Orr et al., 2017; Weems et al., 2016). The results of this study are therefore complementary and add to the knowledge regarding the preferences of parents whose infants are no longer hospitalized.

Limitations and strengths

Although the results of this study provide new insights into the information needs that must be met to improve parents' psychological well-being and sleep, there are some limitations to consider when interpreting these results. First, the research team decided to create a survey rather than use a validated questionnaire, as none of the available questionnaires specifically addressed all the elements related to the research problem. The results of this study must therefore be interpreted as emerging from a non-validated questionnaire. Even though the survey had a total of 87 respondents, many questions were not answered by all participants. It should be noted that open-ended questions ($n = 13$ questions) were answered by less than half of the respondents ($n =$ 37 to 42, or 42.5 to 48.3%). Also, as the questionnaire progressed, the number of respondents decreased, i.e., 87 participants for the sociodemographic questions at the beginning of the questionnaire and 41 participants for the questions on the method and timing of accessing the desired information at the end of the survey. It is possible that the survey included too many questions, which may explain why the last questions were less often answered. This underscores the importance of choosing the questions very carefully and to limit the number of survey questions. In addition, it is important to consider that the responses to all survey questions were not mandatory, and incomplete questionnaires were considered in the analysis. This decision was made to promote the authenticity of the responses obtained and to avoid inaccurate responses by parents who no longer wished to respond,

Table 5
General information, method, and moment to access information.

Survey question	Answers	N (%)
The most important information to give a parent before discharge[2] ($n = 40$)	To contact a healthcare professional, resources if needed	11 (27.5%)
	How to take care of their preterm infant	10 (25.0%)
	Trust and believe in yourself	8 (20.0%)
General topics that raised questions following discharge[2] ($n = 37$)	Characteristics of prematurity	17 (43.6%)
	None	14 (38.9%)
	Don't know	2 (5.6%)
Convenience of methods to receive information about prematurity[1] ($n = 41$)	Healthcare professional	34 (82.9%)
	Website	28 (68.3%
	Mobile app	16 (39.0%)
	Book	14 (34.1%)
	Social networks	13 (31.7%)
	Leaflet	11 (26.8%)
The appropriate time to be informed about prematurity and the transition home[1] (n = 41)	During hospitalization in neonatology	29 (70.7%)
	A few days before discharge from the neonatology	27 (65.9%)
	In the days following the transition home	15 (36.6%)
	Before admission to neonatology/during pregnancy (if planned premature birth)	14 (34.1%)
	At the time of transition home (day of discharge)	13 (31.7%)
	After admission to neonatology (in the following days)	12 (29.3%)
Characteristics of an effective information tool about prematurity[1] (n = 41)	Accessible at all times	38 (92.7%)
	Contains information on various subjects	30 (73.2%)
	Easily accessible (without searching)	26 (63.4%)
	Contains stories shared by other parents (real-life experiences)	21 (51.2%)
	Offers options for discussions between parents or with professionals	20 (48.8%)
	Contains popularized information	17 (41.5%)
	Contains summarized information (tables, diagrams, or other)	17 (41.5%)
	Contains scientifically supported information	16 (39.0%)
	Contains pictures	16 (39.0%)
	Contains community resources	15 (36.6%)
	Is visually appealing (colors, icons)	13 (31.7%)
	Contains text (detailed information)	12 (29.3%)

[1] Multiple-choice question where several answers were accepted.
[2] Open-ended question.

but who were required by LimeSurvey® to do so to maintain their participation. In addition, a measure for preventing false responses was to share the recruitment ad only in Facebook® groups of parents with premature infants to target potential and genuine participants. Future studies should use shorter questionnaires or interviews with participants to promote comprehensive data collection or include more in-depth data on the subject.

Another limitation to consider is the quantitative analysis performed for the open-ended questions in the survey. Although it would have been interesting to conduct a qualitative content analysis, the team decided to proceed with a quantitative analysis since most responses were very short, detracting from a more in-depth qualitative analysis. Future studies could conduct interviews with parents to obtain more complete responses and conduct an in-depth qualitative analysis. In addition, it is important to consider the socio-demographic characteristics of the survey participants when interpreting the results. Most participants reported a household income of at least CAD 70,000 and a university or college education. Therefore, the results cannot be generalized to parents with more modest incomes or lower levels of education. Moreover, few fathers participated in the study. The results may be less representative of their opinion. In a future study, it would be relevant to recruit participants in another way than with the Facebook platform, to recruit more parents with various demographic characteristics and more fathers. For example, in-person recruitment during preparation for discharge from the neonatal unit could be considered.

Despite these limitations, the strengths of the study deserve to be highlighted. This is an innovative study that focuses on the needs of families who have recently experienced the transition of their preterm infant into their home environment. In addition, it addresses the psychological well-being and sleep quality of these parents, topics that have received little joint attention in previous studies. In this technological era, it is also relevant to explore parents' preferences for receiving information tailored to their needs.

Implications to practice

Since the psychological well-being and sleep quality of parents with a preterm infant differs from that of parents of a full-term newborn in the postpartum period (Blomqvist et al., 2017; Griffith et al., 2022), the results of this study are useful in educating healthcare professionals about the particularities of their informational needs to enhance their psychological well-being and their sleep quality after discharge. In addition, parents' specific needs after discharge from the NICU must be addressed by the health professionals involved in the follow-up of the infant given that parents' implication is pivotal during this period for the optimal development of the preterm infant (Leahy-Warren et al., 2020; Pisoni et al., 2020; Stefana et al., 2019).

Conclusion

Parents of a preterm infant who have transitioned into the family environment in the last six months need specific information to improve their psychological well-being and sleep. The results of this study will be useful in developing an intervention that meets the information needs of these parents. In addition, they are useful for healthcare professionals who accompany parents before, during, and after the transition of the preterm infant to the family environment. Further studies are needed to thoroughly explore all the needs of these parents who are going through a significant transition period with their preterm infant.

Funding

This project was funded by an institutional grant from the Social Sciences and Humanities Research Council (SSHRC) of Canada. This funding agency played no role in the development, implementation, data analysis, or publication of the project results.

CRediT authorship contribution statement

Valérie Lebel: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Marilyn Aita:** Writing – review & editing, Writing – original draft, Funding acquisition, Conceptualization. **Isabelle Landry:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation. **Marie-Josée Martel:** Writing – review & editing, Writing – original draft, Funding acquisition, Conceptualization. **Paméla Hamel-Hilaréguy:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation.

Declaration of competing interest

None.

Acknowledgments

The research team would like to thank all the parents who agreed to take part in the project and Geneviève Lavigne for contributing to the analysis of the data.

References

Adama, E. A., Adua, E., Bayes, S., & Mörelius, E. (2022). Support needs of parents in neonatal intensive care unit: An integrative review. *Journal of Clinical Nursing*, *31*(5–6), 532–547. https://doi.org/10.1111/jocn.15972.

Amorim, M., Alves, E., Kelly-Irving, M., Ribeiro, A. I., & Silva, S. (2018). Quality of life of parents of very preterm infants 4 months after birth: A mixed methods study. *Health and Quality of Life Outcomes*, *16*, 178. https://doi.org/10.1186/s12955-018-1011-y.

Angelhoff, C., Sjølie, H., Mörelius, E., & Løyland, B. (2020). "like walking in a fog"-Parents' perceptions of sleep and consequences of sleep loss when staying overnight with their child in hospital. *Journal of Sleep Research*, *29*(2), Article e12945. https://doi.org/10.1111/jsr.12945.

Aydon, L., Hauck, Y., Murdoch, J., Siu, D., & Sharp, M. (2018). Transition from hospital to home: Parents' perception of their preparation and readiness for discharge with their preterm infant. *Journal of Clinical Nursing*, *27*(1–2), 269–277. https://doi.org/10.1111/jocn.13883.

Blomqvist, Y. T., Nyqvist, K. H., Rubertsson, C., & Funkquist, E. L. (2017). Parents need support to find ways to optimise their own sleep without seeing their preterm infant's sleeping patterns as a problem. *Acta Paediatrica*, *106*, 223–228. https://doi.org/10.1111/apa.13660.

Blumenberg, C., Menezes, A. M. B., Gonçalves, H., Assunção, M. C. F., Wehrmeister, F. C., & Barros, A. J. D. (2019). How different online recruitment methods impact on recruitment rates for the web-based coortesnaweb project: A randomised trial. *BMC Medical Research Methodology*, *19*(1), 127. https://doi.org/10.1186/s12874-019-0767-z.

Cho, Y., Hirose, T., Tomita, N., Shirakawa, S., Murase, K., Komoto, K., et al. (2012). Infant mental health intervention for preterm infants in Japan: Promotions of maternal mental health, mother–infant interactions, and social support by providing continuous home visits until the corrected infant age of 12 months. *Infant Mental Health Journal*, *34*, 47–59. https://doi.org/10.1002/imhj.21352.

Darko, E. M., Kleib, M., & Olson, J. (2022). Social media use for research participant recruitment: Integrative literature review. *Journal of Medical Internet Research*, *24*(8), Article e38015. https://doi.org/10.2196/38015.

Edell-Gustafsson, U., Angelhoff, C., Johnsson, E., Karlsson, J., & Morelius, E. (2014). Hindering and buffering factors for parental sleep in neonatal care. A phenomenographic study. *Journal of Clinical Nursing*, *24*(56), 717–727. https://doi.org/10.1111/jocn.12654.

Feeley, N., Robins, S., Genest, C., Stremler, R., Zelkowitz, P., & Charbonneau, L. (2020). A comparative study of mothers of infants hospitalized in an open ward neonatal intensive care unit and a combined pod and single-family room design. *BMC Pediatrics*, *20*(1), 38–46. https://doi.org/10.1186/s12887-020-1929-1.

Gogou, M., Haidopoulou, K., & Pavlou, E. (2019). Sleep and prematurity: Sleep outcomes in preterm children and influencing factors. *World Journal of Pediatrics: WJP*, *15*(3), 209–218. https://doi.org/10.1007/s12519-019-00240-8.

Griffith, T., Singh, A., Naber, M., Hummel, P., Bartholomew, C., Amin, S., White-Traut, R., & Garfield, L. (2022). Scoping review of interventions to support families with preterm infants post-NICU discharge. *Journal of Pediatric Nursing*, *67*, e135–e149. https://doi.org/10.1016/j.pedn.2022.08.014.

Haddad, S., Dennis, C. -L., Shah, P. S., & Stremler, R. (2019). Sleep in parents of preterm infants: A systematic review. *Midwifery*, *73*, 35–48.

Institut de la statistique du Québec (2023). Naissances selon la durée de la grossesse et le poids à la naissance, Québec, 1980-2021. Retreive from: https://statistique.quebec.ca/fr/produit/tableau/naissances-selon-la-duree-de-la-grossesse-et-le-poids-a-la-naissance-quebec.

Koliouli, F., Gaudron, C. Z., & Raynaud, J. -P. (2016). Stress, coping, and post-traumatic stress disorder of French fathers of premature infants. *Newborn and Infant Nursing Reviews*, *16*(3), 110–114. https://doi.org/10.1053/j.nainr.2016.08.003.

Leahy-Warren, P., Coleman, C., Bradley, R., et al. (2020). The experiences of mothers with preterm infants within the first-year post discharge from NICU: Social support, attachment and level of depressive symptoms. *BMC Pregnancy and Childbirth*, *20*, 260 (2020). https://doi.org/10.1186/s12884-020-02956-2.

Lebel, V., Feeley, N., Robins, S., & Streemler, R. (2022). Factors influencing mothers' quality of sleep during their infants' NICU hospitalization. *Behavioral Sleep Medicine*, *20*(5), 610–621. https://doi.org/10.1080/15402002.2021.1971985.

Lebel, V., Héon, M., Larone Juneau, A., Colette, K., & Feeley, N. (2021). The development of a digital educational program with parents of preterm infants and neonatal nurses to meet parents' educational needs. *Journal of Neonatal Nursing*, *27*(2021), 52–57. https://doi.org/10.1016/j.jnn.2020.06.004.

Lee, S. Y., & Hsu, H. C. (2012). Stress and health-related well-being among mothers with a low birth weight infant: The role of sleep. *Social Science & Medicine*, *74*(7), 958–965. https://doi.org/10.1016/j.socscimed.2011.12.030.

Orr, T., Campbell-Yeo, M., Benoit, B., Hewitt, B., Stinson, J., McGrath, P., Dowling, D., & Thibeau, S. (2017). Smartphone and internet preferences of parents. *Advances in Neonatal Care*, *17*, 131–138. https://doi.org/10.1097/ANC.0000000000000349.

Petty, J., Whiting, L., Green, J., & Fowler, C. (2018). Parents' views on preparation to care for extremely premature infants at home. *Nursing Children and Young People*, *30*, 22–27. https://doi.org/10.7748/ncyp.2018.e1084.

Pinelli, J., Saigal, S., Wu, Y. B., Cunningham, C., DiCenso, A., Steele, S., et al. (2008). Patterns of change in family functioning, resources, coping and parental depression in mothers and fathers of sick newborns over the first year of life. *Journal of Neonatal Nursing*, *14*(5), 156–165. https://doi.org/10.1016/j.jnn.2008.03.015.

Pisoni, C., Spairani, S., Fauci, F., Ariaudo, G., Tzialla, C., Tinelli, C., ... Orcesi, S. (2020). Effect of maternal psychopathology on neurodevelopmental outcome and quality of the dyadic relationship in preterm infants: An explorative study. *The Journal of Maternal-Fetal & Neonatal Medicine: The Official Journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians*, *33*(1), 103–112. https://doi.org/10.1080/14767058.2018.1487935.

Polit, D. F., & Beck, C. T. (2021). *Nursing research: Generating and assessing evidences for nursing practice* (11th ed.). Wolters Kluwer Health.

Pozzar, R., Hammer, M. J., Underhill-Blazey, M., Wright, A. A., Tulsky, J. A., Hong, F., ... Berry, D. L. (2020). Threats of bots and other bad actors to data quality following research participant recruitment through social media: Cross-sectional questionnaire. *Journal of Medical Internet Research*, *22*(10), Article e23021. https://doi.org/10.2196/23021.

Ridner, S. H. (2004). Psychological distress: Concept analysis. *Journal of Advanced Nursing*, *45*(5), 536–545. https://doi.org/10.1046/j.1365-2648.2003.02938.x.

Salomè, S., Mansi, G., Lambiase, C. V., Barone, M., Piro, V., Pesce, M., ... Capasso, L. (2022). Impact of psychological distress and psychophysical wellbeing on posttraumatic symptoms in parents of preterm infants after NICU discharge. *Italian Journal of Pediatrics*, *48*(1), 13. https://doi.org/10.1186/s13052-022-01202-z.

Sanchez, C., Grzenda, A., Varias, A., Widge, A. S., Carpenter, L. L., McDonald, W. M., ... Rodriguez, C. I. (2020). Social media recruitment for mental health research: A systematic review. *Comprehensive Psychiatry*, *103*, Article 152197. https://doi.org/10.1016/j.comppsych.2020.152197.

Schaaf, J. M., Mol, B. -W. J., Abu-Hanna, A., & Ravelli, A. C. J. (2012). Ethnic disparities in the risk of adverse outcome after spontaneous preterm birth. *Acta Obstetricia et Gynecologica Scandinavica*, *91*, 1402–1408. https://doi.org/10.1111/aogs.12013.

Schaffer, L. (2012). *The impact of guided imagery on sleep quality in mothers of preterm infants*. California: University of San Diego.

Schmöker, A., Flacking, R., Udo, C., Eriksson, M., Hellström-Westas, L., & Ericson, J. (2020). Longitudinal cohort study reveals different patterns of stress in parents of preterm infants during the first year after birth. *Acta Paediatrica*, *109*(9), 1778–1786. https://doi.org/10.1111/apa.15185.

Shanmugam, V., & Ramachandra, R. (2015). Stress and coping strategies among mothers' of neonates, admitted in neonatal intensive care unit. *Asian Journal of Nursing Education & Research*, *5*(3), 363–365. https://doi.org/10.5958/2349-2996.2015.00073.7.

Smith, S., Tallon, M., Smith, J., Angelhoff, C., & Mörelius, E. (2022). Parental sleep when their child is sick: A phased principle-based concept analysis. *Journal of Sleep Research*, *31*(5), Article e13575. https://doi.org/10.1111/jsr.13575.

Smith, V. C., Love, K., & Goyer, E. (2022). NICU discharge preparation and transition planning: Guidelines and recommendations. *Journal of Perinatology*, *42*(Suppl. 1), 7–21. https://doi.org/10.1038/s41372-022-01313-9.

Stefana, A., Lavelli, M., Rossi, G., & Beebe, B. (2019). Interactive sequences between fathers and preterm infants in the neonatal intensive care unit. *Early Human Development*, *140*, Article 104888. https://doi.org/10.1016/j.earlhumdev.2019.104888.

Weems, M. F., Graetz, I., Lan, R., DeBaer, L. R., & Beeman, G. (2016). Electronic communication preferences among mothers in the neonatal intensive care unit. *Journal of Perinatology*, *36*(11), 997–1000. https://doi.org/10.1038/jp.2016.125.