

Follow-up care of premature babies in Russia: evaluating parental experiences and associated services

The purpose of this descriptive, correlational study was to explore the experiences of parents of prematurely born infants after hospital discharge as they transition to home in Saint Petersburg, Russia. In particular, the study aimed to explore parental experiences when caring for a baby at home, to determine possible relationships between parental experiences and gestational age of their infants and to describe the parents' perceived evaluation of services provided for them and their baby once home.

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Key points

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1. Parental concerns after hospital discharge are similar to those previously reported in other countries.
2. Neither gestational age nor birthweight appear to be related to problems parents encounter.
3. Parents of preterm babies require a more individualised approach to their child's specific needs and their own concerns.
4. Low competency of health professionals in caring for post-discharge premature infant calls for special training programmes on neonatal transitional care.

The incidence of preterm and low birthweight birth is high and rising in many countries¹⁻³. The premature survival rates have increased tremendously with technological advances, but when compared with term births, prematurity and low birthweight are among the most important predictors of infant morbidity and mortality^{4,5}. Following hospital discharge, parents often have to deal with their infants' ongoing medical problems, respiratory complications, failure to thrive, feeding problems, and delayed development or other general health problems⁶⁻⁹. Mothers of preterm babies are at greater risk of psychological distress, depression, poor adjustment, and anxiety during the hospitalisation and after discharge¹⁰⁻¹². Problems with parenting a preterm infant before or after discharge can lead to depression, marital discord, potential loss of employment, and deep psychological and financial burdens¹³⁻¹⁶. Premature babies often require follow-up, closer surveillance and additional care after hospital discharge, that place added stress on the family and their resources^{17,18}.

Since 1980, numerous studies in the US, the UK, Canada and other countries have examined parental experiences in the NICU and after discharge¹⁹⁻²³. Recurring themes in these studies have underlined parental stress, the need for information and parental teaching, the requirement for adequate social and professional support, and the presence of grief related to the loss

of the expected perfect baby. Research suggests that nursing interventions such as teaching parents about health concerns, caregiving activities and behavioral characteristics of preterm infants, are important in helping parents both in the hospital and after discharge²⁴⁻²⁶. Research has also documented that home visits by health professionals as well as appointments at child health clinics promote the health of mothers and babies and improve parental ability to cope with infant care²⁷⁻²⁹. However, little is known about parenting preterm babies in Russia. There has been no research done regarding parental experiences in the NICU and after discharge. Research was needed to explore these experiences in Russian settings and to see if demographic, cultural, and healthcare system differences affect maternal responses to having a premature infant.

Standard care is to perform the first home visit to the newborn baby in the three days after discharge from a maternity or paediatric hospital. Subsequently during the first month, home visits to a prematurely born infant are made twice per week by a child health visiting nurse (called a 'patronage nurse' in Russia) and by a paediatrician from a local child health clinic (total 8-10 visits)^{30,31}. It was important to evaluate existing services and document whether or not a change is necessary in Russian guidelines and protocols.

Study aim

The overall purpose of the current study was to explore the experiences of parents of prematurely born infants during a transition period after hospital discharge to home in Saint Petersburg, Russia. The specific aims of this study were to:

1. Explore the parents' experiences at home when caring for their premature babies.
2. Identify possible relationships between the parental experiences and gestational age (GA) of their infants.
3. Describe parents' perceived evaluation of services provided for their baby and themselves once they arrive home with their preterm baby after hospital discharge.

Study theoretical framework

The current study was a replication of the research work carried out by Carole Kenner in the USA in 1988¹⁹. The Kenner's Transition Model which describes the importance of parental support to help them cope with discharge and manage stress and problems of having a fragile child at home, provided the conceptual framework for the study^{19,32}. According to this model, parental concerns and problems can be grouped into five categories:

1. Information needs
2. Parent-infant role
3. Grief
4. Stress and coping
5. Social interaction

In short, parental informational needs are related to questions regarding:

- how to provide routine newborn care
- how to recognise normal newborn characteristics
- how to keep the infant healthy
- explanation of medical diagnosis and the expected prognosis.

Parent-child relationships are related to the parent's inability to understand the behaviour of the infant and their own role when parenting. Parenting is often affected by decreased responsiveness of a preterm baby, and sleeping and feeding disturbances.

Grief is experienced by parents due to loss of the dream of having a 'perfect child' which can lead to feelings of guilt.

Stress is related to lack of preparation and feelings of shock and fear that accompany preterm birth and having a sick baby. Coping is an adaptation to the situation involving the following stages: disbelief, anger, demystification, and conditional acceptance.

Variable	n
Age (yr)	28.8±7.01, range 18-43
Separation from baby after delivery (days)	10.7±13.2, range 1-66
Number of pregnancies	3.06±2.52, range 1-10
Abortions – 16 in total	1.34±2.07, range 0-9
Marital status	
Married	24 (75%)
Living together	7 (21.9%)
Single	1 (3.1%)
Education	
< 11 yr	2 (6.3%)
11-12 yr	11 (34.4%)
13-16 yr	12 (37.5%)
17 or more yr	7 (21.9%)
Income	
<10 000 rubles	7 (21.9%)
10-19 000 rubles	14 (43.8%)
20-29 000 rubles	6 (18.8%)
30-50 000 rubles	3 (9.4%)
>50 000 rubles	2 (6.3%)
Insurance	
State	30 (93.8%)
Private	2 (6.3%)
Coverage of hospital stay	
Covered by insurance	9 (28.1%)
Not covered by insurance	23 (71.9%)
Place of living	
City	29 (90.6%)
Countryside	3 (9.4%)
Place of delivery	
Maternity house	29 (90.6%)
Private maternity house	2 (6.3%)
Home birth	1 (3.1%)
Ability to care while in the hospital	
Could do all	26 (83.1%)
Could do some	6 (18.8%)
Previous history	
Miscarriages	5 (15.5%)
Stillbirths	2 (6.3%)
High risk infants	3 (9.4%)
Children at home	
Mothers with other children	13 (40.7%)
Age of children	mean 4.2 years old, range 2-20

TABLE 1 Demographic data of the mothers (n = 32).

Originally categorised and labelled as social support, social interaction^{32,33} refers to help and supportive attitudes from health professionals and family members. It is an important aspect of coping and managing stress and can have both positive and negative facets.

Methodology

A descriptive correlational design was chosen. An existing standardised research instrument was used – Kenner's Transition questionnaire (TQ)¹⁹⁻³² which consists of two parts:

1. A 38-item Likert scale that measures the attitudes and experiences of parents
2. Multiple choice, open-ended questions related to parental needs including demographic data.

Two questions were added to the qualitative part of TQ:

1. How would you describe services provided for you?
2. How many visits did you have from the health professionals during the first month after discharge?

In the current study, the internal consistency reliability was calculated and the Cronbach's alpha coefficient was 0.705.

Sample

The sample was a purposive convenience sample of 32 mothers of premature infants who had been hospitalised at NICUs, two intermediate care units in a paediatric teaching hospital and one maternity hospital in Saint Petersburg, Russia. For parents to be included, their preterm infant must have met the following criteria:

- weight > 800 g at birth
- gestational age ≥ 28 weeks' at birth
- Apgar scores > 3 at one minute and > 7 at five minutes of age
- no surgical anomalies
- no Grade IV intraventricular haemorrhage.

Maternal and infant demographics are presented in **TABLES 1** and **2**, respectively.

Data collection and analysis

Data collection occurred from May to October, 2006. Mothers completed the TQ one month after discharge during a personal meeting with the researcher. The Spearman rank order correlation was used to examine the association between scores on the TQ subscales (Parent-Child Role, Information Needs, Stress and Coping, Social Interaction and Grief) and the gestational age (all tests were two-tailed). Data were analysed using the Statistical Package for the Social Sciences for Windows software (SPSS, version 13.0, Chicago, IL, USA). The open-ended questions were evaluated using the constant comparison method for qualitative research data. Themes and

Background variables	Mean	SD	Range
Birthweight (grams)	1580	459.1	800-2500
Gestational age (weeks)	30.8	2.8	28-36
Length of hospital stay (days)	47.9	26.03	7-111
Weight at discharge (grams)	2364.5	331.6	2008-3590
Weight one month post discharge (grams)	3601.5	505.1	2200-4980
Ventilator support (days)	5.38	6.20	0-20
Infant complications	n (severe cases)	% affected (% severe)	
Periventricular leukomalacia	22 (cysts – 6 infants)	68.8 (18.8)	
Intraventricular haemorrhage	15 (Grade III – 5 infants)	46.9 (15.6)	
Retinopathy of prematurity	9 (Stage III – 2 infants)	28.1 (6.3)	
Patent ductus arteriosus	8 (surgery – 5 infants)	25 (15.6)	
Necrotising enterocolitis	3 (surgery – 1 infant)	9.4 (3.1)	
Chronic lung disease	9	28.1	
Sepsis	1	3.1	

TABLE 2 Infant demographic data (n = 32).

categories of responses were determined by the researcher and confirmed by an external consultant, Carole Kenner, who did the original study on transition from hospital to home.

Results

Parents of preterm infants believed their knowledge preparation was adequate for caring for the infant. Of the sample, 81.3 % reported that they knew how to care for their infant, 68.8% felt they were competent in caring, 75% knew what and how to feed, 84.4% knew when to call the doctor. However, despite the fact that mothers had good knowledge and skills about basic care, the need for information remained high – mothers wanted more information about everyday infant care (81.3%), behaviour (62.5%), eating (56.3%), teeth (37.5%), safety (34.4%), and sleeping (34.4%) (TABLE 3). From the qualitative portion of the questionnaire, the recurring themes were parental concerns about feeding and behavioural problems.

Mothers received the most information about child care from relatives (50%); other sources of information included other resources (40%), physicians (37.5%), friends (15.6%), and nurses (6.3%) (TABLE 3). At home, mothers were able to share their feeling with their spouse/partner (87.5%), relatives (81.3%), friends (53.1%), physician (25%), and nurse (12.5%) (TABLE 3). Parents of preterm infants perceived the social support available as high: 93.7% said that people who lived with them supported them;

81.3% reported that there was somebody who shared the responsibility of taking care of the child with them; and 93.8% did not feel alone. About 50% reported that they had time for themselves and their partners, 75% felt comfortable when caring for their infants at home, 87.5% did not feel overwhelmed by having child at home. (Note: these percentages reflect individual items in the questionnaire).

No significant relationships were found among the five categories of the TQ and the infant's gestational age. All of the correlation coefficients were low and did not reach statistical significance at the 0.05 level. Additional tests were conducted for birth weight (BW) of the preterm infants and the categories of parental concerns. There were two significant positive correlations between two individual items of the Grief category and birth weight. The fear that their child might get sick ($\rho = 0.371$, $p = 0.05$) and their inability to control their child's health ($\rho = 0.425$, $p = 0.05$) were both significantly positively correlated with birth weight.

Home visits ranged from 0 to 13 visits (mean = 4.0 ± 2.6 , median = 2). Close to a third (31.3%) of the sample received two visits, 25% received four visits, 12.5% received six home visits, and 9.4% received seven home visits (FIGURE 1). Eighteen mothers evaluated services from unsatisfactory to bad, five mothers were more or less satisfied, and nine mothers evaluated received services as good or satisfactory (FIGURE 2). In all cases, the first home visit, performed by a nurse or a physician, was made in the first three days

Source where majority of information was received		
Source of information	n	%
Relatives	16	50.0
Other resources	13	40.6
Physician	12	37.5
Friends	5	15.6
Nurse	2	6.3
Additional health-related informational resources (n = 12, 37.5% of the sample)		
Source	n	%
Books and print materials	6	18.7
Hospital staff	3	9.4
Previous experience	2	6.2
Internet resources	1	3.1
Types of additional information requested		
Information type	n	%
Everyday infant care	26	81.3
Infant behaviour	20	62.5
Infant feeding	18	56.3
Teething	12	37.5
Infant safety	11	34.4
Infant sleeping	11	34.4
Persons with whom parent was able to share feelings		
Person	n	%
Spouse/partner	28	87.5
Relatives	26	81.3
Friends	17	53.1
Paediatrician	8	25.0
Nurse	4	12.5

TABLE 3 Mothers' experiences one month post-discharge.

after discharge. Of the sample, 40.6% were not satisfied with the information received from their home visits: visits were described as formal and short in length of time, with noted discrepancies in information given by health professionals from a local child health clinic.

Two main themes emerged from the qualitative analysis:

1. Mothers expressed the need for an individual approach to care for their child.
2. Mothers perceived a low competency level of the visiting health professionals.

Those mothers who had larger numbers of home visits expressed more positive remarks and a higher evaluation of services. Most mothers reported that the most difficult time for them was the first week after discharge. Parents were also happy to have home visits instead of bringing their infant to the clinic for the health checks.

Discussion

The results of this study support findings of research done in other countries from the 1980s through to the present time. The findings confirm the idea that parental concerns are similar between cultures and not influenced by culture or geographical settings as McKim et al stated³³. Many of the concerns expressed by the mothers in the current study – feeding, proper formula, sleep and stooling patterns, and respiratory or breathing concerns, mimicked parents' concerns in other studies^{19, 23}. The fact that Russian mothers knew how to care for their baby during the first month after discharge can be partially explained by the longer hospital stay that they experienced (in the current study 47 days) as compared to the widespread, increasingly shorter hospital stays in the US. The information received from the hospital was sufficient to care for the infant during the first month following NICU discharge, but mothers expressed concerns about future care needs and the expected development of their child. These concerns and needs existed in spite of having good knowledge about routine care one month after hospital discharge.

Similar to findings of studies completed outside Russia^{34,35}, relatives were named as the major source of support and information for Russian mothers of preterm babies. Even with the higher social support, however, the level of grief in the mothers of preterm babies was high. Mothers whose babies were heavier or weighed more at birth scored higher on these grief items. Higher grief may also be regarded as a cultural trait; however some suppositions can be made. Mothers who have more mature babies may perceive their child as 'almost term,' and they grieve more because their 'almost normal' child is sick. Mothers of more premature babies may feel less grief and be more fully engaged in thoughts about survival. The major feeling of these mothers of more premature babies may be that of hope. These findings and theories require further study.

Findings from formal and brief home visits correlate with the results obtained from foreign studies – mothers wanted more friendly assistance and support from staff at the child health clinic³⁴⁻³⁶. Both the quantitative and qualitative results of the current study documented that parents want more information than was provided and information more specific to their needs³⁴⁻³⁷.

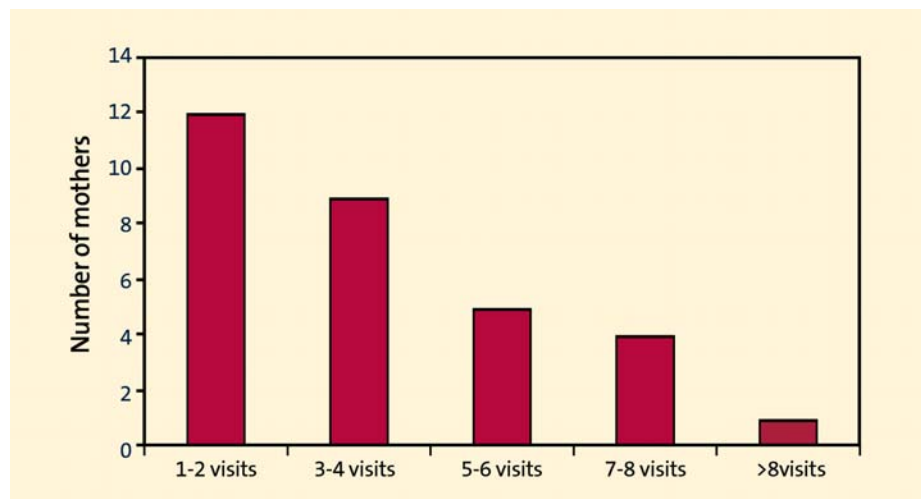


FIGURE 1 Number of home visits provided one month post-discharge.

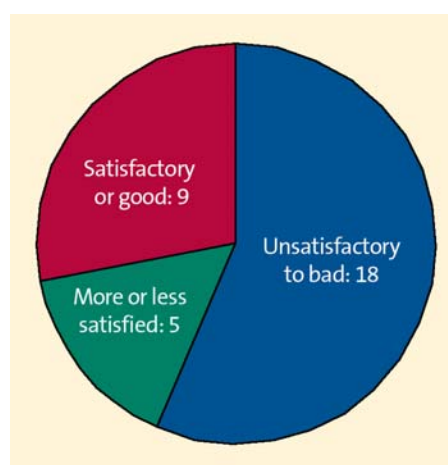


FIGURE 2 Parent's perceived evaluation of services provided.

The number of visits and the exact home visiting approach needed by parents after hospital discharge remains unclear. In the current study, there was a noticeable discrepancy between the number of visits made and those recommended by existing guidelines. This finding also supported results obtained outside Russia, which showed visits were not made as prescribed by local guidelines³⁸. Further research is needed to determine why this discrepancy occurred and also why some mothers want more visits of substance, while others want fewer visits. In general, the mothers wanted more professional support.

In this study, gestational age or birth weight did not appear to be related to parental problems during the transition period after hospital discharge. Other factors may have influenced parental experiences. The findings confirm Kenner's assumption³⁹ that once the baby requires any form of NICU stay, to the mothers it is irrelevant as to how sick or small their baby is – the fear is there that the baby

might die, especially after the transition home. The fact of being hospitalised makes mothers feel stressed and worried that they cannot keep their baby healthy.

Conclusion

It could be that different nations and cultures react differently to preterm birth, yet the current study's results confirm that some maternal problems are universal and revolve around normal parental concerns – how to keep their baby healthy and patterns of behaviour. Despite the birth weight, gestational age, or length of hospital stay, mothers worldwide have similar concerns during transitioning their infant to home. The importance of birth weight or gestational age as predictors of parental problems during the transition period from hospital to home requires more clarification and study. Parents of preterm babies require a more individualised approach to their child's specific needs and their own concerns. This study identified a need to determine the correct number of visits which need to be made and also whether these cover the right information. The low competency of health professionals from the child health clinics in caring for the post-discharge premature infant, calls for special training programmes on neonatal transitional care.

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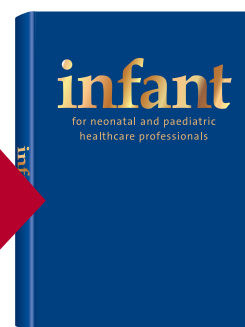
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