

PART I. DISEASES AND PROBLEMS DISTINGUISHED BY WHO AND FAO

Experiences of preterm newborns' mothers regarding neonatal care in Polish hospitals: a descriptive study**Grażyna Dykowska**^{1,2(A,B,C,D,E,F)}, **Ewelina Zimałka**^{3(A,B,C,D,E,F)}, **Jakub Świtalski**^{2(C,D,E,F)},
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Authors' contribution:

- A. Study design/planning
- B. Data collection/entry
- C. Data analysis/statistics
- D. Data interpretation
- E. Preparation of manuscript
- F. Literature analysis/search
- G. Funds collection

Abstract

Background. Premature birth is a current medical, psychological and socio-economic problem. The study attempted to determine the causes of preterm births and the experiences of mothers of preterm infants and the care they received in Polish hospital wards, as well as to invite the mothers to self-assess their preparation for further childcare.

Material and methods. The mothers of premature newborns were asked to complete a proprietary questionnaire. The study was conducted in Poland.

Results. 250 mothers of premature newborns participated in the study. The most common causes of preterm birth among the respondents were premature rupture of the amniotic membranes (n=84; 33.6%). The majority of mothers indicated that the medical staff provided them with support on the ward (n=216; 86.4%). The majority of respondents (n=191; 76.4%) also indicated that they knew what to look out for in their child's further development when they left the hospital.

Conclusions. According to the opinions of the majority of participating mothers, the postnatal care provided in the hospital wards was at a satisfactory level. At the same time, a fairly high percentage indicated shortcomings in this respect. There is a need to continuously improve standards so that even more mothers have a sense of being sufficiently cared for.

Keywords: premature infant, midwifery, mother, nurse, knowledge

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Introduction

Premature birth, as a current medical, socio-economic and psychological problem, still arouses interest among many specialists. The observed increase in the survival rate of premature newborns draws attention not only to the area of medical complications but also focuses on psychological aspects [1,2]. The World Health Organization (WHO) defines premature infants as infants born alive before the 37th week of pregnancy. There are subcategories of premature birth, depending on gestational age: extremely preterm (less than 28 weeks), very preterm (28-31 weeks) and late preterm (32-37 weeks) [3]. In 2020, the premature live birth rate in the world was approximately 10% [4]. In Poland, this rate was 7.68% of all live births in 2022 [5].

In 2019, the WHO and United Nations International Children's Emergency Fund (UNICEF) published the guidelines "Survive and thrive: transforming care for every small and sick newborn" [6]. They highlight how countries can strengthen care to support children born too small or too early. This document suggests areas of action for improvement, including better partnership with families [6]. Due to the development of medicine, premature newborns have an increasing chance of survival [7]. At the same time, the empowerment of parents of premature newborns as health promoters is increasing, which may contribute to reducing not only the costs of health care but also the costs associated with home care for premature newborns [6,8].

The experiences of both parents of newborns are described in literature as psychological trauma and related emotions such as anxiety, fear, guilt and depression [9,10]. Inadequate knowledge on premature birth results in parents feeling helpless the moment they are discharged from the hospital [11]. The nurses and midwives on the neonatology wards support the parents but also educate them. Physicians (especially neonatologists) also provide information about the newborn's health [12]. Educational programs coordinated by the medical personnel (physicians, nurses, midwives in intensive care units or neonatology wards) are part of the necessary holistic care of a newborn, which is particularly centered on the individual needs of the newborn and their parents. Most commonly they concern caring for the newborn and feeding [12,13]. Informed and cooperation-based nursing/midwifery practice improves the quality of the clinical care based on the individualized interactions with parents [14]. In hospitals in Poland, in the neonatal intensive care unit (NICU), only mothers are most commonly present. Symptoms of posttraumatic stress disorder due to the premature birth of their infant are more often observed in mothers than fathers [15].

Research shows that mothers, more often than fathers, suffer from postpartum depression, yet both mothers and fathers of premature newborns have similar needs for community support [16]. The mothers of premature newborns can have difficulties with interpretation of signals sent by the infant, and thus may be overly interfering or scared and not provide adequate care for their infant. Actions inducing a feeling of safety, such as skin-to-skin contact, are immediately helpful. This method is a unique activity of engaging parents with their infant through skin contact, which is one of the most important senses of every newborn infant. The sense of touch develops already in utero, where the fetus experiences their first feeling of touch. The feelings of safety and closeness are among the most important needs of every newborn [17,18].

Low birth-mass and related complications are leading causes of infant deaths, especially in developing and undeveloped countries, where access to technology and trained healthcare providers is restricted [19].

Aim of the work

The aim of this study was to investigate the causes of premature birth, the feelings of mothers of preterm infants with regard to the provision of contact with the child, the support received on the ward and the information about the child's condition provided by the medical staff. Additionally, the authors aimed to analyze a self-assessment of the knowledge of mothers of preterm infants concerning the care of preterm infants in the further development of the child after discharge from the hospital.

Material and methods

Study design and participants

Mothers of premature infants born in Poland participated in the study. The study was conducted after their discharge. The following eligibility criteria were adopted for inclusion in the study, which had to be met simultaneously:

1. Mothers: a) adult (≥ 18 years); b) primary caregiver of preterm infants after discharge from hospital; c) knowledge of Polish to understand the questions;
2. Preterm infants: a) gestational age < 37 weeks; b) duration of hospitalization ≥ 3 days, discharge as advised by doctor; c) home as place of residence of infants after discharge from hospital.

A proprietary questionnaire consisting of 30 questions was created to obtain information from the mothers. It consisted of 24 questions on the course of the pregnancy, support received from medical staff, feelings about being educated by medical staff and self-assessment of knowledge about caring for a child born prematurely, as well as 6 metric questions. Information regarding the child's weight at birth was also obtained.

The survey used both open and closed single- and multiple-choice questions. The survey took approximately 10-15 minutes to complete.

Data collection and statistical analysis

The survey was conducted electronically in April 2020 due to the epidemiological threat of the COVID-19 pandemic. The request to distribute the questionnaires was sent directly to the neonatology departments, which had the contact details of the patients. Representatives of the wards sent the request to complete the questionnaires directly to the patients with preterm infant (informing us how many were sent) or provided a database of email addresses to which a link to the questionnaire was then sent.

The respondents' answers were placed in a database and then statistically analyzed. All calculations were performed using SPSS and an Excel spreadsheet. A χ^2 test of independence was used to verify relationships between variables on nominal scales. Statistical inference was performed with a standardized significance level of $p < 0.05$.

Results

A request to participate in the study was sent to approximately 430 mothers of premature babies. A total of 259 completed the questionnaire. Because the inclusion criteria were not met, 9 responses were not included in the analysis. The reasons for exclusion were that the mother did not provide care for the child after discharge from the hospital ($n=3$) and that the criterion of the child staying at home after discharge from hospital was not met ($n=6$). Finally, responses from 250 women were included in the

analysis. The most numerous group was women aged 25-29 (n=85; 34%), while the smallest group was women aged 20-24 (n=35; 14%). Table 1 presents data on the marital status, education level and number of previous pregnancies of the mothers.

Table 1. Marital status, education level and number of previous pregnancies of the respondents

Variables		Data	
		n	%
Age	20-24 years	35	14.0
	25-29 years	85	34.0
	30-34 years	75	30.0
	≥35 years	55	22.0
Marital status	Not married	29	11.6
	Married	204	81.6
	Divorced	4	1.6
	Civil partnership	13	5.2
Education	Elementary	1	0.4
	Junior high	2	0.8
	Vocational	18	7.2
	Secondary	64	25.6
	Higher	165	66.0
Number of pregnancies	1	145	58.0
	2	70	28.0
	3	26	10.4
	4	8	3.2
	≥5	1	0.4

Most preterm infants in the analyzed group were born between 32-36 weeks of gestation (n=129; 51.6%). 82 babies (32.8%) were born between 28-31 weeks of gestation, and 39 babies (15.6%) were born between 23-27 weeks of gestation. Most babies were born with a low weight (1,500-2,499 g). The smallest weight was 450 g, and the largest was 3,300 g. The average weight of the baby at birth was 1,633 g (SD=653.13).

The most common causes of preterm birth among the study participants were premature rupture of the amniotic membranes (n=84; 33.6%) and intrauterine infections (n=44; 17.6%). Hypertension during pregnancy occurred in 15.6% of the respondents (n=39) and preeclampsia (a pregnancy-related phenomenon characterized by high blood pressure and proteinuria) in 11.2% of the respondents (n=28). Preterm birth occurred due to cervical insufficiency in 7.3% (n=4) of subjects aged 35 years and older and in 11% (n=8) of subjects aged 30-34 years. Among subjects aged 20-24 years, there was no such cause, and in the age group 25-29, 1% (n=1) of subjects gave birth prematurely due to cervical insufficiency. Preterm birth due to cervical insufficiency was related to the age of the respondents ($\chi^2_{(3)}=9.737$; $p<0.05$).

Complications during a previous pregnancy occurred in 41.9% (n=44) of the respondents. In contrast, the risk of preterm birth in previous pregnancies occurred in 22.86% (n=24) of the women. In 10 of these, antibiotic therapy was used as an intervention to prevent preterm birth. The use of antibiotic therapy as an intervention to prevent preterm birth was significantly dependent on whether the respondent had

previously had a pregnancy at risk of preterm birth ($\chi^2_{(1)}=6.074; p<0.05$). As many as 83.3% (n=20) of the women surveyed with a pregnancy previously at risk of preterm birth avoided excessive effort as part of the prevention of such a birth. For respondents with a previous pregnancy not at risk, avoiding excessive effort was recommended for 46.3% (n=37) of the respondents. The introduction of avoiding excessive effort as an intervention to prevent preterm birth was significantly dependent on whether the previous pregnancy was at risk of preterm birth ($\chi^2_{(1)}=10.250; p<0.01$). A pessary as an intervention used to prevent preterm birth was used in 20.8% (n=5) of the respondents and in 3.8% (n=3) of the respondents in whom there was no such risk with a previous pregnancy. The use of a pessary was significantly dependent on whether the respondent had a previous pregnancy risk of preterm delivery ($\chi^2_{(1)}=7.588; p<0.01$).

Among the respondents with secondary or higher education, 97% of the women expressed breastmilk. Among the respondents with vocational education or lower, 76% of the respondents expressed breastmilk (Table 2). Expressing breastmilk significantly depended on the education level of the respondents ($\chi^2_{(4)}=32.143; p<0.01$). There were no statistically significant differences in expressing breastmilk according to the age of the respondents ($\chi^2_{(6)}=11.148; p=0.084$).

Table 2. Expressing breastmilk for the infant regarding age and education level of the respondents

Did you express breastmilk for your child?		Answer		
		Yes	No	Sometimes
Age	20-24 years (n=35)	31 (88.6%)	0 (0.0%)	4 (11.4%)
	25-29 years (n=85)	82 (96.5%)	2 (2.4%)	1 (1.2%)
	30-34 years (n=75)	72 (96.0%)	1 (1.3%)	2 (2.7%)
	≥35 years (n=55)	54 (98.2%)	0 (0.0%)	1 (1.8%)
Education	Primary or vocational (n=21)	16 (76.2%)	0 (0.0%)	5 (23.8%)
	Secondary (n=64)	63 (98.4%)	1 (1.6%)	0 (0.0%)
	Higher (n=165)	160 (97.0%)	2 (1.2%)	3 (1.8%)

The majority of mothers of preterm infants stated that they were informed about the baby's condition and the procedures performed after birth. Most respondents also stated that the hospital provided contact with the preterm baby (Table 3).

Table 3. Informing the respondent about the condition of their infant, as well as any conducted procedures after birth and providing contact between mother and their baby

Item	Answer	n	%
After birth, were you regularly informed about your child's condition and conducted procedures?	Yes	150	60.0
	Rather yes	68	27.2
	Rather no	12	4.8
	No	19	7.6
	Don't remember	1	0.4
Did the hospital provided means for you to have contact with your child?	Yes	190	76.0
	Rather yes	37	14.8
	Rather no	5	2.0
	No	18	7.2

The majority of respondents declared that they received support on the ward from the medical staff. The highest proportion of respondents who declared a lack of support was in the group with vocational education or lower (Table 4). Declaring a lack of support on the ward significantly depended on the education level of the respondents ($\chi^2_{(2)}=9.315$; $p<0.01$). There were no statistically significant differences in declaring a lack of support from the medical staff for the child according to the age of the respondents ($\chi^2_{(3)}=6.418$; $p=0.093$).

Table 4. Support received from medical personnel on the ward in relation to the age and the educational level of the participants

During your hospital stay, did you receive support from medical personnel?		Answer	
		Received support	No support
Age	20-24 years (n=35)	27 (77.1%)	8 (22.9%)
	25-29 years (n=85)	71 (83.5%)	14 (16.5%)
	30-34 years (n=75)	66 (88.0%)	9 (12.0%)
	≥35 years (n=55)	52 (94.5%)	3 (5%)
Education	Primary or vocational (n=21)	15 (71.4%)	6 (28.6%)
	Secondary (n=64)	51 (79.9%)	13 (20.3%)
	Higher (n=165)	150 (90.9%)	15 (9.1%)

Information on possible problems that may occur during the stay at home was received by 69.6% (n=174) of the respondents, while 30.4% (n=76) felt that they did not receive such information. Most of the respondents who delivered extremely premature newborns, slightly above half of the respondents who delivered very premature newborns, and 39% of the respondents who delivery so-called "late premature"

newborns declared they received information about potential complications occurring after discharge from the hospital. Participants reporting receiving information about potential complication after discharge from the hospital is significantly related to stage of the prematurity of the infant ($\chi^2_{(6)}=12.872$; $p<0.05$).

The majority of respondents ($n=191$; 76.4%) indicated that they knew what to observe in their child's further development when they left the hospital. Most (84.6%, 81.7% and 70.6%, respectively) of the respondents who delivered extremely, very and late premature infants declared that at the time of leaving the hospital, they knew that they had to pay special attention to in the child's further development (marking "yes" and "rather yes") (Table 5). Awareness of aspects requiring special attention when observing the child's further development was related to the stage of prematurity of the infant ($\chi^2_{(6)}=14.001$; $p<0.05$).

Table 5. Awareness of what to pay special attention in relation to prematurity stage

Were you aware of what aspects require special attention when observing the child's further development?		Answer			
		Yes	Rather yes	Rather no	No
Prematurity stage	Extremely preterm (n=39)	26 (66.7%)	7 (17.9%)	6 (15.4%)	0 (0.0%)
	Very preterm (n=82)	44 (53.7%)	23 (28.0%)	6 (7.3%)	9 (11.0%)
	Late preterm (n=129)	58 (45.0%)	33 (25.6%)	14 (10.9%)	24 (18.6%)

Discussion

The immediate complications of preterm birth are responsible for one million deaths per year, and preterm birth is a risk factor in more than 50% of all neonatal deaths [20]. The economic costs of preterm birth are large in terms of immediate intensive neonatal care, ongoing long-term complex health needs and lost economic productivity [20]. Premature birth can therefore be regarded as a very important problem requiring a great deal of effort on the part of both parents and the medical staff caring for the children.

Our study aimed to present both the causes of preterm births and, above all, the experiences of mothers of preterm infants with regard to postnatal care in Poland. The results obtained highlight several interesting phenomena.

Starting with methods to prevent the occurrence of preterm birth, it was observed that a common measure for those who had a previously endangered pregnancy was the use of antibiotic therapy. There is currently no scientific consensus on the use of antibiotics to counteract preterm birth. For example, the use of antibiotics as a form of preterm labor prevention was highlighted in a study by Bookstaver et al. [21] as a method requiring careful considerations for both the mother and the fetus in both the short and long term, including rising antibiotic resistance. Studies emphasize that the effectiveness of antibiotic therapy depends on a number of factors, including the type of antibiotic used, the timing of administration and the correct identification of the rationale for its use [22,23]. Recommended methods of preventing preterm birth with unequivocally proven efficacy, on the other hand, include a midwife-led continuous care model (instead of other commonly available models), screening for genitourinary infections and zinc supplementation in pregnant women without systemic diseases. Placement of a cervical circular suture was beneficial for singleton pregnancies at high risk of preterm delivery [24].

When analyzing issues of patients' behavior in expressing milk for their baby, our research showed a correlation between the propensity to express milk and the education of the participants (97% of women with secondary or higher education and 76% of women with vocational or lower education expressed milk). It is important to note that feeding a preterm newborn with the milk from its mother is not always optimal, yet the choice of the feeding source should be carefully considered regarding the influence on a newborn's health [25]. In the meta-analysis of Alves et al. [26], the authors compared quantitative and qualitative data published between 1994-2011 on breastfeeding in the NICU from the parents' perspective. The results showed that successful breastfeeding was dependent on coherent and adequate knowledge provided by medical staff of its benefits. The relationship between the parent and medical professional (nurse, midwife, lactation counsellor) was shown to be a secondary facilitatory factor [26]. Therefore, the role of medical staff in terms of patient education is crucial. In a study by Bry et al. [27] on psychosocial support provided for the parents of extremely early preterm newborns, the authors noted unclear roles of different, not only medical, professions in educating the parents (i.e. psychologists). Poor communication of the medical personnel in the NICU with parents of preterm newborns stems, according to their research, from a lack of trust from parents towards medical personnel [27]. This should be kept in mind when providing support to parents while on the ward.

According to the results of our survey, the majority of mothers felt that they had been properly educated on how to care for their child at home. However, 24.8% of the respondents held an opposing view, which is a significant portion of the study population.

Greater parental willingness to discharge a premature infant at home prepares parents to take over care and feeding tasks at home. Parents are the infant's most important caregivers during admission to the NICU, and admitting them together with the preterm infant increases the bond and prepares the parents to return home. During infant hospitalization, the relationship between parents and nurses evolves through an exchange of roles and responsibilities. However, this collaboration is difficult due to the discrepancy between parents' and nurses' expectations of their roles [28]. According to research by Kruszecka-Krówka et al. [12], there are visible differences in the form of the received support between the sources of said support. Parents received most information on the health state and care issues mainly from neonatologists (88.3%), while nurses relayed information to mothers on care issues in 11.7% [12]. Twohig et al. studied the emotional aspect of nurses' work with premature newborns. Due to the challenging character of work with preterm newborns and their parents, the medical personnel should have opportunities on the NICU to discuss and deliberate issues arising during care for premature newborns, such as unexpected difficulties due to highly complex and diverse decision processes, which was reported by neonatological nurses [29].

In the study by Bry et al. [27], the complex and individual psychosocial needs of the parents of preterm newborns were highlighted as being a great challenge for NICU staff. Clear explanations to the parents of the roles of different medical professions in supporting and teambuilding with the parents would decrease the psychological pressure perceived by the nurses. Communicating with the parents on their needs and informing the parents from the early moments of their stay in the NICU on available support is necessary for the care of preterm newborn [27]. In our research, the majority of respondents reported receiving information about potential issues occurring after hospital discharge (30.4% reported not receiving such information). The high percentage of those who felt that they were not adequately informed about these issues is worrying, as this could potentially increase mothers' experiences of anxiety and result in inadequate preparation for care. A similarly worrying phenomenon can be observed in terms

of the mothers' declared knowledge of early childhood care, where 84.6% of the mothers of extremely early premature newborn, 81.7% of early premature newborns and 70.6% of late premature newborns declared possessing knowledge about caring for their child. The differences seen indicate significant gaps in the quality of the information provided depending on the period of pregnancy in which the baby was born. Intensified activities, which could be carried out by, for example, nurses and midwives, should be undertaken in order to better educate patients, regardless of the child's clinical condition and time of birth.

A limitation of our study is undoubtedly that only women were surveyed. Many of the studies cited also include men in order to be able to compare the perspectives of both parents. This provides a more complete picture of the situation. Another limitation is the relatively small number of women in our study. Unfortunately, the research period coinciding with the COVID-19 pandemic significantly hampered the possibility of reaching more people. Furthermore, due to the way the study was conducted, the data on the causes of preterm birth are subject to a risk of error, as we were not able to see the full medical records of the patients during the study. The mentioned causes of preterm birth were cited by the patients participating in the study themselves.

In the future, it would also be worthwhile to conduct a study among the fathers of preterm infants. It would also be interesting to conduct a prospective study starting at the time of hospital stay after birth and continuing after discharge home after successive periods (e.g. one year). It would then be possible to visualize the level of knowledge imparted by the hospital's medical staff, as well as satisfaction with the services provided and how this knowledge is used by parents. It would be possible to observe changes in the perception of the challenges of caring for a premature baby in retrospect.

Conclusions

The individual psychosocial needs of parents of preterm infants are a considerable problem and an educational challenge for the medical staff of neonatal units. A continuous approach to educating parents regarding possible issues arising during preterm infant care is necessary. The key role in education should be played by members of the therapeutic team, mainly nurses and midwives, more often and for more time to be spent caring for the infants and their parents. It is important to pay closer attention on the content and educational methods of the nurses and midwives when considering the individual needs of the parents, verifying a mastering of the provided content and adjusting the educational methods to the educational level and socio-economic status of the parents. Understanding the significance of the issue by medical staff may contribute to better care for preterm infants, as well as decrease in number of deaths of preterm infants.

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