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"I NEEDED PEER SUPPORT SO I COULD SHARE MY THOUGHTS": SUPPORT FOR THE NEONATAL INTENSIVE CARE UNIT PARENTS

A Mixed-Method Research Approach

ABSTRACT

Erum Baloch Daniela Centeno-Salo "I needed peer support so I could share my thoughts": Support for the Neonatal Intensive Care Unit Parents – A Mixed-Method Research Approach 46 p., 4 appendices Published November, 2022 Diaconia University of Applied Sciences Degree Program in Social Services Bachelor of Social Services

The aim of the thesis is to find out what the needs of parents with babies in the Neonatal Intensive Care Unit (NICU) are from the social services aspect. The research-oriented thesis examines what kind of social support was given to the NICU parents and how their experience was. With the results, the work-life partner, social workers in the maternity wards and other organizations can develop and further improve their services.

A survey was drafted and through the work-life partner, Kevyt - Association of Preemie Families in Finland, was sent to members of their organization and their social media followers. The survey consisted of structured open-ended and close-ended questions.

The research data was collected via an online questionnaire using the mixedmethod research approach. The analysis methods used were descriptive statistics and interpretative phenomenological analysis. The survey was filled by 43 respondents in Finnish language over a period of 4 weeks. The most significant results were that the main support received by NICU parents was in the form of conversation discussion. The support most parents wished they would have received was peer support. Many parents ended up looking for the support on their own. The social support received was not consistent and needed improvement. Parents believe they only receive the support they ask for and know what to ask for, without it being offered routinely.

The results suggest that the social support offered to NICU parents has improved in the last years; nevertheless, parents are not fully satisfied with it. Non-birthing and non-Finnish speaking NICU parents are sometimes excluded from the support provided.

Keywords: Neonatal Intensive Care Unit (NICU), Preterm Infant, Social Support, Preventive Family Work, Peer Support

1 INTRODUCTION
2 THEORETICAL BACKGROUND
2.1 Defining the key concepts5
2.2 Existing research7
3 PURPOSE AND AIM OF THE THESIS9
4 RESEARCH ENVIRONMENT AND PARTNERS10
5 RESEARCH METHODOLOGY
5.1 Research design11
5.2 Data collection method12
5.3 Data analysis13
5.4 Ethics related to research data15
6 RESULTS
6.1 Background information17
6.2 Regarding support at the NICU20
6.3 Regarding support after discharge up to 6 months after discharge 22
6.4 Regarding social support23
7 INTERPRETATION
8 CONCLUSION
8.1 Answering the thesis questions29
8.2 Discussion
8.3 Professional development
8.4 Recommendations
REFERENCES
APPENDIX 1. Sharing of the survey on Kevyt's Facebook page
APPENDIX 2. Sharing of the survey on Kevyt's webpage
APPENDIX 3. Survey Questionnaire in English
APPENDIX 4. Survey Questionnaire in Finnish

1 INTRODUCTION

This bachelor thesis seeks to learn about the experiences and support received by parents of premature newborns admitted to the Neonatal Intensive Care Unit (NICU) in Finland over the last five years. A vulnerable group of people are the parents of infants who are admitted to the NICU because they go through trauma (due to a difficult birth along with being separated from their child) and stress (related to medical conditions and interventions). These parents frequently report having high levels of stress, guilt, shame, depression and anxiety symptoms. This is linked to a higher likelihood of later impaired child development and worsened family functioning. (Polloni, L., et al., 2021.)

Celenza and Griffin (2014) state that the experience of newborn infants being taken to the NICU can be traumatic for parents. They might experience anxiety and the situation can be overwhelming and stressful. The authors also express the importance of multi-professional cooperation between medical staff and family advisors when supporting families whose babies are admitted to the NICU. (Celenza & Griffin, 2014.)

Previously research has been conducted concerning the topic but mostly from the nursing field of study. After reviewing some literature and going through the existing research theses from Finland, it was concluded that there were gaps in research from the viewpoint of social services. Based on the gaps in the previous research, the thesis questions were formulated. The purpose of the thesis is to find out how and what kind of social support was offered to the NICU parents of preterm infants and what their needs for support are. The thesis explores how the parents' experiences were and how their wellbeing might have been affected from a social services point of view.

Kevyt - Association of Preemie Families in Finland is a member of Mannerheim League for Child Welfare (MLL). The association provides peer support for preemie families as well as promotes and supports the cooperation between professionals and the preemie families. Kevyt ry was contacted concerning work-life partner for the thesis and they agreed to provide their assistance.

The Mixed-methods research seeks to validate the use of multiple ways in addressing research topics instead of limiting or reducing the options available to researchers. Many research questions and question combinations are best and most completely answered by combining research methods. (Johnson & Onwuegbuzie, 2004, p. 17-18.) The research-oriented thesis, "I needed peer support so I could share my thoughts": Support for the Neonatal Intensive Care Unit (NICU) Parents, uses the mixed-method research approach through a structured survey questionnaire in order to answer the research questions.

2 THEORETICAL BACKGROUND

This chapter focuses on defining the key concepts used in the thesis and mentions the existing research related to the topic.

2.1 Defining the key concepts

Neonatal or Newborn Intensive Care Unit (NICU) can be described as an intensive care unit for newborn infants who need specialized treatment. An NICU combines technology, equipment and medical staff trained in the care of newborns. (Martines, 2017, pp. vii-viii.) Newborn infants, preterm or full-term infants included, who are admitted to the NICU usually have different unfavorable conditions or problems. Some of the reasons why a newborn infant might be admitted to the NICU are low birth weight, breathing issues, feeding issues, infection concerns, prematurity, and other clinically significant problems with any organ system. (Hoenig & O'Malley, 2016, pp. 83-86.)

Preterm infant is defined as a baby born alive before 37 weeks of pregnancy. Depending on the gestational age of the infant, they will be classified in different sub-categories of preterm birth: extremely preterm (less than 28 week), very preterm (28 to 32 weeks) and moderate to late preterm (32 to 37 weeks). More than 1 in 10 babies are born preterm, and about a million children die each year due to complications of preterm birth. Preterm birth might occur spontaneously, due to pregnancy complications or chronic conditions of the mother. (World Health Organization, 2018.)

Many survivors might face learning disabilities or other disabilities, visual and hearing problems during their lives. Globally, prematurity is the main cause of death in children under 5 years of age. (World Health Organization, 2018.) According to the Finnish Institute for Health and Welfare (2020), in 2019, there were 45870 births in Finland, 11.7% of the newborn infants needed intensive care, 5.5% of all births were preterm. Also, 1.2% infants of the total births in

2019 died before the age of 7 days. (Finnish Institute for Health and Welfare, 2020.)

Social support refers to assistance to others, usually to help them cope with biological, psychological, and social stressors. It can be defined as the process where an individual obtains emotional, instrumental, or financial aid from their social network. The support might be given by any interpersonal relationship from their social network, such as family members, neighbors, organization, and colleagues. (American Psychological Association, n.d.) In Finland, the Ministry of Social Affairs and Health is responsible for Finland's social policy, they prepare the legislation on social welfare.

The Social Welfare Act covers several social services that municipalities have to offer, some are family work, social work and guidance, social rehabilitation, mental health services, child guidance and family counselling, home services and home care. The municipalities organize the social services and support services to promote and maintain social wellbeing, safety, and inclusion. The social services received by people are based on their needs. The municipalities organize support for people who need help coping with everyday life, financial support, psychological or mental health support. The municipalities make a service needs assessment to evaluate the needs individuals or families might have. (Ministry of Social Affairs and Health, n.d.)

Preventive family work is often called family work. Family work involves multiprofessional cooperation which can include social offices, maternity clinics, kindergartens, schools, churches, and organizations. Different group activities can take part in preventive family work, such as peer support groups or hobby groups. Municipalities in Finland offer counselling, guidance, and home services as part of their preventive family services. Preventive family work aims to support the families' wellbeing. However, it does not only benefit the families but also the municipalities, by lowering the number and costs of future welfare customers. Family work is intended for children and young people under 18 years of age and their parents or guardians. (Furxhi, 2018.) Social workers support families and guide them to receive the appropriate services. Preventive child welfare refers to the special support families are entitled to within the basic public services such as maternity and child health clinics, other healthcare services, daycares, or family centers. Families using preventive child welfare services do not need to be child welfare clients. Some of the services are intended for adults, however, they are part of preventive child welfare since children's wellbeing might be affected. (Ministry of Social Affairs and Health, n.d.)

Peer support is when people use their own experiences to help each other. There are different types of peer support, but they all aim to: bring together people with shared experiences to support each other, provide a space where you feel accepted and understood, treat everyone's experiences as being equally important and involve both giving and receiving support. (Mind, 2019.)

2.2 Existing research

Celenza and Griffin (2014) express that in some cases the admissions in the NICU cannot be anticipated. Parents might be expecting a peaceful or normal birth and are not usually prepared for the experience, which can be terrifying. The unexpected emergency, the news or having to admit the newborn baby in the NICU can be overwhelming to all family members, they might feel anxious about the health of the newborn baby. Fathers or non-birthing parents can also feel upset about the decision of staying with the mother or accompanying the infant. To relieve some of the stress, communication between the medical staff and the parents is crucial. The book *Family-Centered Care for the Newborn: The Delivery Room and Beyond* describes that for planning the involvement of parents in the care of the newborn infants in the NICU, a multidisciplinary cooperation must be done. Family advisors or social workers should also support parents in hand with the medical staff. (Celenza & Griffin, 2014, pp. 79-90.)

During the literature search to find existing information about the thesis subject in Finland, several theses were found on the topic. In 2011, a research thesis had the aim to find out what the parents of infants in the NICU experienced and the psychosocial support provided to them during the time their infants were in the NICU. The results from the research showed that most parents felt the support received was not sufficient. (Hietanen & Matikainen, 2011.)

Another thesis had the objective to explore what kind of support nurses offered to parents of preterm infants in the NICU. The research is based on the experiences of 6 mothers whose infants were admitted in the NICU after being born. The aim was to know how the parents perceived the support received and how it could be improved. The results showed that the mothers were overall satisfied with the support received by the nurses. However, they wished all nurses would get the same training and the support would not vary between nurses. The thesis was based on the experiences of the mothers and suggested as a future topic to focus on the fathers' perspectives since it had not been researched. (Nikkinen & Nurminen, 2016.)

In 2021, a thesis was written focusing on the fathers' experiences of premature infants and the need for support during the child's first year. The research aimed to know how everyday life was for fathers of preterm infants and the support received as well as the one they would have wanted to get. The research showed that while a few fathers were content with the support received, most were not completely satisfied with the services offered. It was concluded that more support was needed. (Savonen, 2021.)

Support to parents who experienced preterm birth and whose children were taken to the NICU has already been researched in the past. However, the previous research has been developed by nursing students from their perspective. As Social Services students, the perspective would differ and a social support strategy could be developed or improved, depending on the results obtained.

3 PURPOSE AND AIM OF THE THESIS

Three research questions are addressed in this thesis:

- 1. What kind of social support has been given to the parents?
- 2. How did that support cover their needs?
- 3. How can the social support be provided more effectively?

The purpose of the thesis is to analyze how the social support was offered to parents of preterm infants who were admitted in the NICU. The research will also allow to examine what kind of social support was given to parents of babies in the NICU and what their needs for support are. The thesis will explore how the parents' experience was and how their wellbeing might have been affected from a social services point of view.

Based on previous research done on the topic in Finland, it seems that, from the social support perspective, the support offered to parents whose preterm children were in the NICU is not sufficient and does not cover all the needs parents might have. The aim of the thesis is to identify the needs parents with infants in the NICU might have. When needs have been identified, the worklife partner, social workers working in maternity wards and other organizations can develop their services and improve the support offered to parents based on their needs. The current preventive family work could be improved, and the social support given could cover the parents' needs, the municipalities would also benefit by avoiding future expenses. It is worth mentioning that the research would not only have a positive impact on parents of preterm babies admitted in the NICU, but it would also benefit all parents with infants admitted in the NICU.

4 RESEARCH ENVIRONMENT AND PARTNERS

Parents of preterm infants admitted in the NICU in the last five years are the participants of the research. They complete an online survey and are recommended to do so in a place that is quiet, comfortable, and allows them to concentrate solely on the survey.

Kevyt ry is the main work-life partner for the thesis research. Association of Preemie Families - Kevyt considers itself as a network for premature families. The organization promotes the wellbeing and equality of families who went through preterm births. They offer peer support and up-to-date information on different topics which might help some of the families. Kevyt is part of the Mannerheim League for Child Welfare (MLL). (Kevyt, n.d.) The contact person from Kevyt ry suggested that the research should be an online survey instead of interviews based on previous research related interviewing challenges. The work life partner provides their input and feedback at different stages of the thesis process. Kevyt ry reaches out to the members of their organization who had a preterm birth, and their babies were admitted in the NICU in the past 5 years. These members are the participants in the research that respond to the questionnaire voluntarily.

OLKA is coordinated organization and volunteering activity at hospitals. Its purpose is to offer patients and their loved ones unhurried encounters and support in coming to terms with their disease. OLKA is a joint operation of HUS (Helsinki University Hospital) and HyTe (Community of NGOs in Uusimaa region). (HUS, n.d.) The contact person at OLKA assisted the thesis authors in getting in touch with Kevyt ry and a social worker at the Neonatal Intensive care Unit Saari in Women's Hospital (Naistenklinikka).

The social worker from the Unit Saari in the Women's Hospital collaborates in the thesis process by offering their assistance in answering questions about the working system in the hospital, the different services or the kind of support that is offered to parents during the time their newborn babies are in the NICU.

5 RESEARCH METHODOLOGY

After reading through a couple of existing research done in Finland in relation to the thesis topic, such as the theses mentioned earlier above, it was noted that the research done and analyzed so far was from the aspect of nursing field in Finland and few very briefly mentioned that there is need for social support. Research questions for the thesis emerged from the perspective of social services to fill in the gap. The focus of this research-based thesis is to find out particularly about the kind of social support given to the parents whose babies were admitted in the NICU after birth in the last 5 years at two different stages, that is, at the hospital and after discharge till 6 months and whether that support was enough. The research also intends to answer how the social support can be provided more effectively which is also beneficial for the worklife partner.

Research is a process that requires researchers to make various choices. Making choices is an important part of planning and research. (Jyväskylän yliopiston Koppa, 2012.) The Method Map has been a particularly helpful tool to think, make choices, and plan holistically about the thesis research process. This chapter will now further describe the research design, data collection method and data analysis method to be used during the research process in align with the research questions of the thesis and justify them.

5.1 Research design

A mixed-method research through an online survey questionnaire is conducted in order to answer the thesis research questions. Surveys are used to collect information in a variety of fields. They are an excellent choice for learning about a group's characteristics, preferences, opinions, or beliefs. (Scribbr, 2021.) The online survey questionnaire has structured open-ended and close-ended questions, both in English and Finnish languages. For the students, the online survey is cost efficient and easy to process the data while for participants it provides anonymity. It is critical to get the right people to respond to research instruments. One is not able to progress in their research unless they have data. The individual who provides data is known as a participant or a respondent, and the group of people providing the data is referred to as the sample. Use of Purposive Sampling may be appropriate if research questions can only be answered using data from a specific population. (Stephan & Smith, 2019, pp 99.) The thesis research participants are the parents whose babies were admitted in the NICU after birth in the last 5 years i.e., from 2018 to 2022. The work-life partner is used to reach the participants. The plan was to have a sample size of at least 15-20 participants and to collect the data over a period of 6 weeks or till the minimum number of participants is reached. Kevyt ry shares the survey link on their Facebook page (APPENDIX 1) as well as on their website (APPENDIX 2) to reach the participants.

Assumptions were made based on the low number of participants in previous studies and the likelihood that our thesis research would not have enough participants. As a result, the number of responses received was not checked on a regular basis. After two and a half weeks of sharing the survey link, there were already 43 responses. Following a discussion with Kevyt ry, it was agreed to count all responses for data analysis and to keep the link open for the intended 4 weeks, adding data if more responses were received.

5.2 Data collection method

Quantitative research is a research method that produces numerical data. This method is used when the aim is to prove, measure, compare or contrast something. Qualitative research is a research method that offers descriptive data. This method is used when the objective is to explore experiences, perceptions, and conceptualizations to create a new understanding. (Benz & Newman, 1998, pp. 9-11.) Quantitative and qualitative research methodologies are combined or mixed together in a single study known as mixed-methods research. The pragmatic technique is applied in mixed research from a philosophical perspective. Its method of inquiry comprises the use of induction (or pattern recognition), deduction (testing of theories and hypotheses), and abduction

(discovering and relying on the best set of explanations for interpreting one's results). The primary premise of mixed research states that researchers should gather multiple data utilizing various tactics, approaches, and methodologies so that the resulting mixture or combination is likely to provide complementary strengths and nonoverlapping weaknesses. (Johnson & Onwuegbuzie, 2004, p. 17-18.)

At the idea paper stage of the thesis, the plan was to conduct interviews using qualitative research approach in order to gather experiences of participants. The supervising teachers as well as the work-life partner both commented realistically and recommended using the online survey option instead. It also made logic since the thesis authors aim to graduate by December 2022. The research-oriented thesis uses the mixed-method research approach via an online survey questionnaire having both open-ended and closed-ended structured questions.

Webropol platform is used as it provides anonymity as well as it is easy to reach the participants. The survey is both in English (APPENDIX 3) and Finnish (APPENDIX 4) languages. Survey link is shared with the work life partner to spread within their community members. All survey responses are saved on the Webropol site platform and a report document is created at the end. The report document is shared on Microsoft Teams only between the concerned research students in order to have access to it together for the purpose of analysis. The survey is filled out anonymously and no personal data is collected. All collected data and related documents will be deleted after the thesis publication.

5.3 Data analysis

The research data was collected via an online survey questionnaire having both quantitative and qualitative approaches hence the two analysis methods: Descriptive statistics and Interpretative phenomenological analysis were used in this thesis. Initially it was planned to use narrative analysis but the participants' responses were very brief in order to employ narrative analysis, therefore the interpretative phenomenological analysis was opted. The two analysis methods are realistic and doable given the constraints and our own research skills.

Torchim (2006) mentions in his book that Descriptive statistics is used to characterize the fundamental characteristics of data in a study. It provides concise summaries of the sample and the metrics. It is the foundation of practically every quantitative data analysis, along with simple graphical analysis. With descriptive statistics one is simply describing what is or what the data shows. Descriptive Statistics is used to present quantitative descriptions in a manageable form in this thesis.

Interpretative phenomenological analysis (IPA) is a well-known qualitative method for investigating people's lived experiences. Rather than being a theory-driven investigation, IPA is collaborative since it investigates experiential meanings through the interpretive effort between the researcher and the participant. (Smith & Fieldsend, 2021.) IPA must include the following qualities: a shift in emphasis from what is unique to an individual to what is shared by all participants, a description of the experience that leads to an interpretation of it, and a commitment to understanding the participant's point of view. (Cooper et al., 2012, p. 5.) As the research thesis seeks to understand and analyze NICU parent's own experiences therefore IPA is a better option. Analysis of the open-ended question responses is done using the IPA.

Webropol, the data gathering platform, displays the outcomes of closed-ended questions with charts, tables, and diagrams, making data analysis easy for users. In Chapters 6.1 and 6.4, the data analysis was done from the quantitative results. Analysis of qualitative data, in Chapters 6.2 and 6.3, was a lengthy time-consuming process. In order to understand, interpret and describe the responses to the open-ended questions, the authors read and re-read the responses numerous times to immerse themselves in the data along with noting their ideas or any points that were not clear, and kept track of how many respondents gave similar answers. Following that, they took individual notes and wrote down their emergent interpretations from the notes. Finally, the authors both got together to tally, discuss their interpretations of the data and write the

results collectively. Although the individual analysis of data took a long time but it was beneficial in eliminating any personal bias as well.

The Finnish language survey was completed by all 43 respondents for this thesis. The answers for qualitative questions which were in Finnish was interpreted using authors' own Finnish language skills and Google translate. Also, Kevyt ry was approached to reconfirm the authors' translations of the quotes used in the thesis. The responses were mainly one to three sentence answers and fairly simple to understand. There were some terms that were not clear to us for which the social worker at the Unit Saari was approached. It was explained what those terms meant or what the concept behind them was.

5.4 Ethics related to research data

TENK guidelines (2019) state that in Finland, the researcher respects the dignity and autonomy of human research participants. The rights laid down in the Finnish Constitution (1999/731, Sections 6–23) are held by everybody. These include the right to life, personal liberty and integrity, freedom of movement, freedom of religion and conscience, freedom of expression, protection of property and the right to privacy. The researcher conducts their study in such a way that it does not pose major risks, damage, or harm to study participants, communities, or other research subjects.

The need for personal data in scientific study must be determined early on. It is necessary to make an effort to process personal data as little as possible. It is important to take into account the quantity and type of personal data processed for the study. (Office of the Data Protection Ombudsman, n.d.)

Kevyt ry was reached out in regards to the research permit, and it was stated that it was not previously required, and that it was okay to proceed with our research thesis process and data collection. However, we shared with Kevyt the thesis proposal and the plan for data management. The work-life agreement was signed by Kevyt ry, thesis authors and thesis teacher supervisors electronically. Keeping in mind the ethical principles, the research-oriented thesis follows the guidelines regarding research data. The online survey questionnaire is drafted accordingly to collect only the data that is relevant. The beginning of the survey informs the participants about the research for thesis and what it aims to collect. Also, that it is voluntary to participate in the survey. The participants fill out the survey anonymously and no personal data is collected that could identify them. The students would also not know the participants, protecting the privacy of the participants. The online survey questionnaire is provided in both English and Finnish language, so the participants are comfortable in answering in their preferred language. Questions have been structured in a way that only collects data relevant to the research questions and does not harm the participants. Also, the survey questions are in an orderly format, avoiding double barreled questions and only require 10-15 minutes of the participant's time.

6 RESULTS

The survey is divided into four sections and the results of each section is described under a different heading. First, the background information about the respondents, where it was intended to find out when their experience happened, their preparedness to the situation and their overall feelings about it. The second section sought to learn which services and types of support the parents received while their baby was in the NICU. The third section of the survey had the same goal as the second section, but it focused on the time after discharge from the NICU up to the next 6 months. The final section seeks to ascertain what kind of social support the parents believe is required, who should have provided it, and what kind of support they wish they had received.

6.1 Background information

The survey was filled by 43 respondents. When asked about the relationship to the baby who was admitted in the NICU after birth, 29 of them identified as being the mother. 12 of the respondents identified as parents of the child or responded if the child was a daughter, son, or their own child. 2 respondents identified as fathers of the child. Our research was focused on families who have had their NICU experience in the last 5 years, from 2018 to 2022 (FIG-URE 1.). 12 respondents stated that their child was in the NICU in 2020, 10 chose 2018, 9 in 2021 and 8 in 2022. Only 4 of the participants had their NICU experience in 2019. It was also noted that the highest number of participants shared their experience from the pandemic time, year 2020.

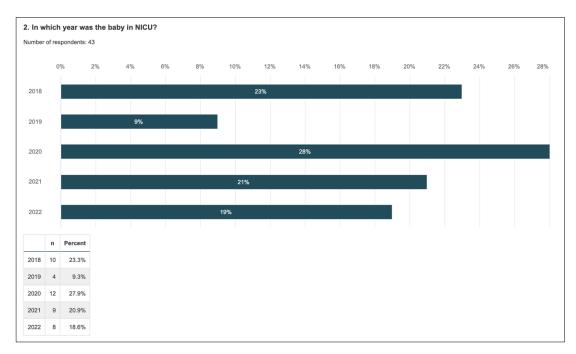


FIGURE 1. Year in which the baby was admitted in the NICU

Almost half of the respondents, 21 of them, said their baby was born very preterm, between weeks 28 and 32 of the pregnancy. 12 of the parents stated to have extremely preterm babies, born before week 28 of gestation. The other 10 parents had their babies between weeks 32 and 37 of the pregnancy, making their babies moderate to late preterm. (FIGURE 2.)

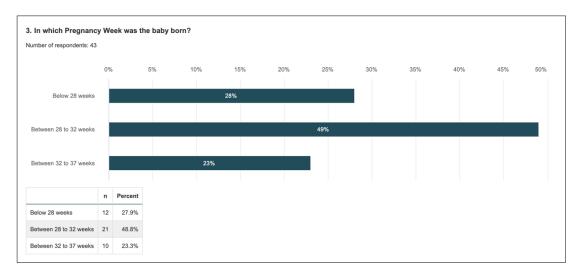


FIGURE 1. Week when the baby was born

The length of the stay in the NICU of the babies varied, 42% of the babies stayed in the NICU for over a month, the babies who stayed in the NICU from a week to a month was another 42%. Only 16% of the newborn babies admitted in the NICU had a stay of a week or less. It was also noticed that about 23% of the infants who were discharged from the NICU had to still be monitored at hospitals following their NICU stay. The majority of the respondents stated that the baby who was admitted in the NICU was their firstborn (FIGURE 3.). 40% of the total of parents knew in advance that they would have a preterm infant (FIGURE 4.). 71% of those who knew that their baby would be preterm felt prepared for the situation (FIGURE 5.). From the 60% of the parents who did not know their baby would be born prematurely (FIGURE 4.) shared feeling shocked, surprised, in disbelief, anxious, scared, and sadness. It was mentioned that doctors and midwives were busy and did not have enough time to offer support, making them feel alone. The experience was described by many respondents as 'the most traumatic event in their lives'. Several parents were worried about the wellbeing of their child, and even blamed their own bodies for not keeping their babies safe. Some of the responses are:

"...it was shocking, this kind of thing can't happen to us."

"...the whole world, life and everyday life got a shock wave. I felt a panic attack that gripped my whole body."

"...it was heavy, living in uncertainty and giving up many things and not experiencing the normal pregnancy. Felt huge sadness"

"...it was shocking! I didn't understand at all what was happening, I couldn't understand the doctors' jargon, the midwives in the ward were busy and didn't have time to support. I was alone."

"...I felt enormous guilt, worry, fear, anxiety. Worst experience of my life so far."

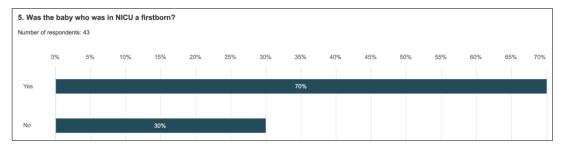


FIGURE 2. NICU experience with a firstborn

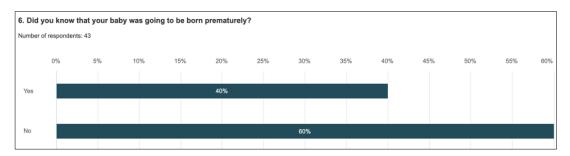


FIGURE 3. Did the parents know about their preterm baby

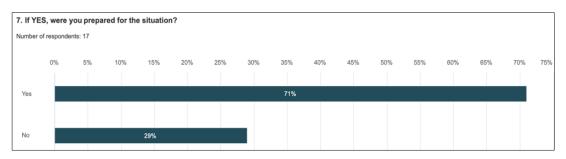


FIGURE 4. The parents who knew they would have a preterm baby, were they ready?

6.2 Regarding support at the NICU

During the time the preterm babies were at the hospital, the parents received different types of support. Most of the support received was conversation support. Some of the parents described receiving crisis support and a few parents were able to obtain help from psychologists and psychiatric nurses. It was stated that the nurses often updated them with the latest information about their newborn. Some parents also received help from the social workers with bureaucracy and filling in papers.

Even though most parents did receive support, some explained that the professionals would sometimes come to greet them but did not receive professional support. It was also described that the support was mainly given to the mothers, leaving the partners feeling left out. Additionally, it was said by some parents that they had to reach out themselves for help as it wasn't always offered. It was also mentioned that some parents did not receive any kind of support, or that the support would vary depending on the worker on shift.

According to the parents, most of the support received came from the nurses, doctors, intensive care workers and social workers. Sometimes the support provided was referrals on where to seek further help. It was mentioned that parents had to be proactive and know where to get the support, then they could obtain the support. Some parents obtained the support needed from other parents at the hospital or from their own relatives or friends.

When the parents were asked if the support received could have been any better, some seemed satisfied with the support received while others shared many ideas for development of the services or support offered at the NICU. Parents felt that in order to get the support needed, you already need to know what you need, for many parents the situation is new, and they don't know what they need. They mentioned that they had to reach out for the social worker to help to get some paperwork, however, not everyone knew about it, and it wasn't offered unless the parents themselves reached out. It was mentioned that the support from the nurses would differ depending on who was working during the shifts, the support wasn't consistent. Parents suggested that the support should be more structured and regular. The support aimed at fathers or non-birthing parents was a point that could be improved since some felt it did not exist.

A respondent suggested a mandatory psychiatric nurse or psychologist to visit the parents, the situation can cause shock and some parents don't understand what is happening. A similar idea was given by another parent when they mentioned that crisis assistance should be automatically given to parents. Some parents mentioned there should be more peer support groups. It was stated that the support before the baby is born is low, even though they felt it was needed. A parent mentioned that it would have been nice to be able to read books about premature births, however, the books were not easy to reach so she did not notice them in the ward and that nobody mentioned there were books they could read in the NICU family room.

Some of the respondents had the NICU experience during the Covid-19 pandemic. These parents were at the hospital alone and felt peer support and discussions could have really helped them through that time. Also, because of the pandemic restrictions the parents could not mingle to talk in the NICU. They suggested that online meetings from their own rooms could have been easily arranged.

6.3 Regarding support after discharge up to 6 months after discharge

After being discharged from the NICU up to when the babies were 6 months old, some parents told they had sessions with a psychologist. Family workers, rehabilitation instructors and nurses also visited some of the families for control. The maternity clinic also supported when needed. A few respondents described getting home services every week to help with household work. However, several parents stated they did not get any additional support when they left the hospital, only routine checkups for the children. After discharge, some respondents explained that their support system were the ones offering the support.

When it was time to go home, some parents described the time as scary, and some felt they would have needed more support. Most parents would have like to have more peer support groups at the hospital even after going home, or more guidance on where to get peer support. It was also suggested to have an information booklet or package for after leaving the hospital. Many parents did not know they could get counselling services for example and would only find out on their own. Also, it was mentioned that many of the doctors and nurses did not have much experience with preterm babies and were not able to answer many of their questions when they visited their homes. Some parents would have liked to get follow-up calls from the hospital to see how they were doing; they felt these calls should be made automatically.

6.4 Regarding social support

Most of the respondents were aware that a social worker was working in the NICU or at the hospital where they were at (FIGURE 6.). The majority also stated to have a support system of family and/or friends (FIGURE 7.). However, there were services they would have liked to get. The topmost form of support that most parents chose that they would have liked was the one-on-one peer support followed by peer support groups. After which they rated counselling services and getting information. Domestic services/household support and nanny services followed next that the parents wished to get. The parents who chose 'Other Support' that they would have liked was chiefly the psychologist support. A few mentioned having the chance of both parents staying at the NICU.

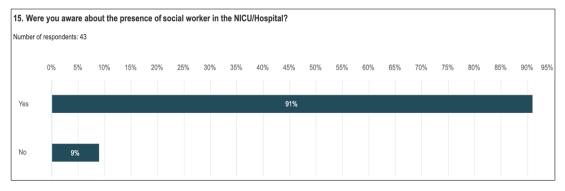
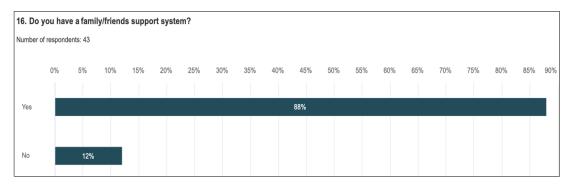
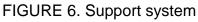


FIGURE 5. Awareness of the social worker in the NICU





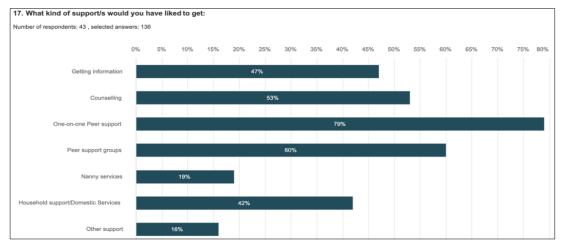


FIGURE 7. Desired support

When asked about the importance of some of the services provided, the most important ones were getting information and counselling. One-on-one peer support and other support like psychologist or online peer support also ranked high in the importance scale filled by the parents.

The respondents stated that at the NICU, they would have wished to get more support from the social workers and organizations. After discharge from the NICU, they wished to have obtained more support from the Maternity and child health clinic, nurses, organizations, and social workers. All respondents are either members of Kevyt ry or follow their social media. 60% of the NICU parents found Kevyt ry on their own and only 23% heard about it by the social worker at the NICU/hospital (FIGURE 9.). However, 16% found out about Kevyt from either the doctors, nurses, or other parents with babies in the NICU.

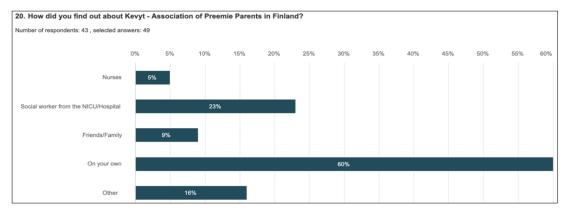


FIGURE 9. Finding Kevyt

7 INTERPRETATION

The online survey questionnaire had both English and Finnish language options. All 43 participants completed the Finnish language survey which led us to assume that the data collected does not include the experiences of many non-Finnish speaking participants. Also, the participants were reached through the community of the work-life partner hence the ones who answered to the survey had received some support from Kevyt ry. However, all participants initially showed feeling of shock and disbelief, being in a state of crisis along with feeling lost, lonely, and sad.

The risks of postpartum depression, posttraumatic stress disorder, and anxiety are well documented to rise for parents of newborns in NICUs. Each of these issues has the potential to impede parent-infant bonds, which can have a negative impact on a child's growth and result in poorer cognitive, behavioral, and developmental outcomes. In order to reduce the risk factors for developing these diseases, psychosocial support is essential. NICU parents may get assistance from professional mental health personnel like social workers and psychologists, but not all families may require or desire official help. (Hall, S., et al., 2015.)

Many parents mentioned that at the NICU they received support in the form of conversation support. During the personal communication with one of the social workers in the Unit Saari of Women's Hospital, it was explained that there are conversation discussion sessions with parents whose baby is in the NICU in which the parents can discuss about their situation with a psychologist and a psychiatric nurse. Further support information, for instance for contacting the social worker, is also given out to the parents during these discussions. The social worker usually makes a round in the unit to introduce themself to parents. Social support related to practical matters, hospital fees, applying for subsidies, parents' meals and stay vouchers, nanny services, paternity leave matters, meeting with the hospital Chaplain, making special arrangements upon discharge from the NICU, rehabilitation counselling etc can all be sorted with the help of the social worker. While the majority of the participants received formal support from the hospital professionals, they also felt they really needed peer support. Those parents whose babies were in the NICU particularly during the pandemic period felt the need for peer support the most. Some comments indicating this are:

"...during the Corona period, it felt like you were really alone the whole time the baby was in the hospital, when the ward had strict restrictions for a long time and you didn't get to meet other parents. After the birth of the baby, I would have needed more discussion help and peer support."

"...because of Corona, you couldn't go to the parents' break room or network with other parents. Zoom meetings could have saved the situation."

"...there were no peer support groups because of the corona. That's what I would have liked."

From the data collected it was evident that not only during the stay in the NICU but also after discharge the parents would have liked to receive peer support. As mentioned earlier, many ended up searching for support on their own.

> "...peer support was not offered anywhere, and it was not even told where to look for it. It took some time before I had the resources to look for one myself. I would also have needed discussion where the parents could go through their experiences together."

Hall, S., et al., (2015) mention in their article that peer support has been demonstrated to boost NICU parents' self-esteem, confidence, ability to solve problems and use adaptive coping strategies, as well as their perception of social support. Additionally, parents feel more empowered and connect with, nurture, and care for their babies to a greater extent during more frequent hospital visits, resulting in a shorter duration of stay for their infants. Depression, anxiety, and stress experienced by parents are all decreased.

Providing peer support to the NICU parent whether in the form of one-on-one peer support or through peer support groups is part of preventive family work. It provides psychosocial support to the parents and helps in diminishing the chances of developing poor mental wellbeing of the parents and greater chances of attachment with the baby. This in turn also would decrease the risk of adverse childhood experiences later on.

8 CONCLUSION

This chapter will review how the thesis questions were answered through the research. It will also describe how the research-based thesis has developed the authors professionally and what kind of discussions or thoughts evolved after interpreting and analyzing the results. Lastly, the chapter will be finalized by describing the recommendations for the work life partner and other social services.

8.1 Answering the thesis questions

The majority of the parents who took part in the study agreed that they obtained social support while their preterm infants were in the NICU. Conversation was the most common sort of support received. Different professionals provided assistance; some parents received conversational support from nurses or doctors, while others received it from psychologists. The style of conversational support would also differ; nurses would provide information on the babies, while others would simply listen. Social workers typically assisted parents in obtaining any available social benefits.

Most respondents believed that their needs were not sufficiently met by the social support they were receiving. Mothers were the ones getting most of the support and the significant other partners were left out. The respondents believed that in order to get the support needed, they would have to be the ones approaching the professionals to get the support. Some of the parents did not know what their needs were when their babies were first admitted in the NICU, so they were not able to ask for support.

The respondents believed that in order to receive social support more effectively, it must first be consistent. All parents should receive the same information when their infants are first admitted in the NICU, and professionals should assume that the parents have no prior information. Furthermore, services should be provided in languages other than Finnish in order to reach a larger number of parents.

8.2 Discussion

The majority of the respondents' babies were in the NICU in 2020, the year of Covid-19 pandemic. Parents described that the restrictions in the NICU during the pandemic did not allow having group meetings. Partners and guests were also not allowed in the hospital, making them feel lonelier. These parents expressed that peer support could have helped them a lot. The trustworthiness of the research can be affected since the restrictions that parents described have now been lifted.

One of the suggestions given by the respondents was to arrange online peer support to improve the feeling of loneliness during the pandemic, which was not available to them during their time at the NICU. Other parents would have liked to get chat support. It is worth mentioning that in May 2022 Kevyt ry joined OLKA's peer support application, TOIVO. The peer supporters from Kevyt are parents of premature babies who have gone through OLKA's peer support training. The TOIVO app is free to download and does not require any registration via email or phone number. NICU parents can choose to stay anonymous or not and search for peer supporter in the app. The support is individual by chat or by calling the available peer supporter, but service users can also get information if that is what they need. (Kevyt, 2022). Kevyt ry joining TOIVO is an improvement of the services offered to the NICU parents, also, non-members of Kevyt might find support more easily. However, the application is in Finnish and the non-Finnish speaking community continues being excluded.

In our opinion, there are similarities in the findings from previous research done by nursing students and our own research. The research done in 2021 about fathers' experience in the NICU concluded that they were content with the services received but more support was needed (Savonen, 2021). Some of our respondents thought that non-birthing parents might be left out and not much effort was invested in supporting them. Nikkinen and Nurminen (2016) concluded that there was no consistency in the support offered to the parents by the nurses. Several of the respondents of our questionnaire believed the same, but not only from the nurses but from the hospital staff in general. Compared to previous research, the services and support received by our respondents have ameliorated, however, there is still improvement to be made in the social support and services offered to families with babies in the NICU.

8.3 Professional development

The publication 'Ethical recommendations for thesis writing at universities of applied sciences' by Arene (2019) mentions that a researcher has ethical and moral responsibility to the study subjects, the research community, the professional field, the founder of the research, and society, among others. As research students we read the ethical recommendations and guidelines and followed them throughout the thesis process. We acquainted ourselves with the topic of the thesis, with the guidelines of research ethics, with the principles linked with the handling of personal information and data protection and the instructions from DIAK university of applied sciences. Teacher supervisors and the work-life partner were approached for assistance whenever needed. In order to avoid plagiarism, we have provided proper referencing to the best of our knowledge.

Despite the fact that both of us had previously gone through the thesis procedure for previous studies, this was the first research-based thesis we have implemented. It was challenging to follow all the steps that a research-based thesis requires. To deliver the results as accurately as possible, we did our best to delve deeper and reach out to other partners as well for additional information. Although we had heard of Webropol and we have completed many other surveys that used Webropol but it was the first time we used the platform to create our own survey. It took us a while to understand how it works and it was a good learning experience. Collaborative writing was done throughout the different thesis stages. We have been able to complement each other's work constructively. We now have a better understanding of the research process. Working on our thesis, conducting research on the topic and analyzing the results, has made us understand how important it is to work in a multidisciplinary way. During our studies and placements, we were able to see how collaboration between professionals and organizations is done. However, the thesis made us realize how service users can also be affected if this is not done correctly.

8.4 Recommendations

In this research-oriented thesis, all the respondents are members of Kevyt ry or are following their social media. This makes us assume that these NICU parents have either obtained support from the work-life partner or have received information from their social media. There is no data collection from NICU parents who have not heard of Kevyt ry. This point might affect the reliability of the results. A research thesis on the topic could be done in the future by other students.

When respondents submitted their responses to the questionnaire, it was noted that all 43 participants elected to respond in Finnish. This brought up the discussion between the research students regarding the possibility that most if not all the respondents were native Finns. Also, the website of the partner organization, Kevyt ry, is accessible only in Finnish and the service users need to know Finnish to use the services. This information excludes migrant NICU parents who do not speak Finnish. Immigrants may not have the same support network of friends and relatives as native Finns. Our work-life partner can be advised to broaden their offerings to include potential customers who might not speak Finnish. They might provide peer support groups in English and their website can be converted into English. Future researchers can look into the assistance provided to immigrant families whose infants are admitted to the NICU.

Most of the respondents received social support while their babies were in the NICU. However, the support received by the parents was usually not consistent nor enough. In the answers to the survey, it was mentioned several

times that the parents had to reach out for support on their own. Not all parents knew what kind of support to look or ask for. It was suggested by one of the respondents, that the hospitals or NICU should provide a brochure with information to the parents when the babies are discharged from the NICU. In our opinion, it would be beneficial for the families to get the brochure when the babies are admitted in the NICU. This way all families would get the same information about social benefits, peer support groups, organizations that provide support, and other support that they could receive. Some of the benefits or services can already be given while the baby is in the NICU and the social worker in the maternity wards could help with paperwork. The brochure could be translated in English and other languages as well. The brochure could be done as a thesis project in collaboration with social workers from hospitals.

It is worth noting that Kevyt ry has been providing peer support for the past 25 years. They are performing crucial work and the research shows that peer support is one of the most significant needs of the NICU parents. Although communication between Kevyt and hospital units has improved over time, still not all preemie families have access to peer support information. Kevyt is working on it to enhance and achieve better results. The recommendations proposed in this research-based thesis maybe beneficial for Kevyt ry.

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APPENDIX 1. Sharing of the survey on Kevyt's Facebook page

Kevyt-yhdistyksen ystävät

Minkälaisia tukipalveluita olisitte kaivanneet sairaala-aikana ja kotiutumisen jälkeen? 💙

Mikäli lapsenne on ollut viimeisen viiden vuoden sisällä vastasyntyneiden teho-osastolla, osallistu kyselytutkimukseen!

Diakonia-ammattikorkeakoulun sosiaalialan opiskelijat tekevät opinnäytetyötä aiheesta "Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille". Vastaukset käsitellään luottamuksellisesti ja anonyymisti. Tutkimuksen tuloksia käytetään tukipalveluiden kehittämiseen. Kyselyyn voi vastata suomeksi tai englanniksi. Kysely on auki 30.9. saakka.

Oheisen linkin kautta lisätietoa ja linkit kyselyyn.

https://tinyurl.com/2fpa5s9t

#keskosperheet #sairaalaaika #kotitutuminen #tukipalvelut #preemie #preemiefamilies #keskonen #pikkukeskonen #vastasyntyneidenteho #nicu

See Translation



KEVYT.NET

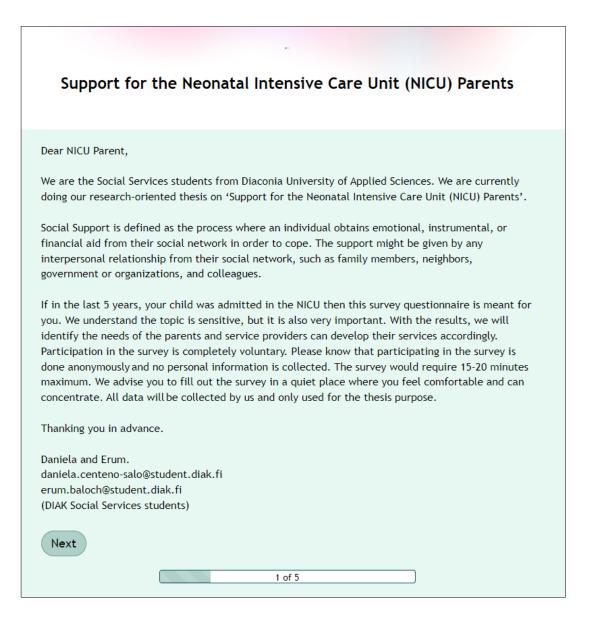
Osallistu kyselytutkimukseen: Tukipalvelut vastasyntyneiden tehoosastolla olevien lasten vanhemmille - Kevyt.net

Sosiaalialan opiskelijat Diakonia-ammattikorkeakoulusta tekevät opinnäytetyötään aiheesta "Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille". Kyselytutkimukseen voi vastata suomeksi tai englanniksi. Kysely on auki 30.9.2022 saakka. Hei! Olemme sosiaalialan opiskelijoi...

...

APPENDIX 2. Sharing of the survey on Kevyt's webpage

	Q Search			
Kevyt Tietos meistä Tietos keskosuud Ajankohtaista Verkkokauppa Keskosperheiden yhdistys	desta Tue toimintaamme Vertaistuki			
Osallistu kyselytutkimukseen: Tukipalvelut vastasyntyneiden teho-osastolla olevien last vanhemmille ®potedin: Muuta ajanlohtaista, Uutiset 1 90 Sosiaalialan opiskelijat Diakonia-ammattikorkeakoulusta tekevät opinnäytetyötään aiheesta "Tukipalvelut va				
osastolla olevien lasten vanhemmille". Kyselytutkimukseen voi vastata suomeksi tai englanniksi. Kysely on auk Heil Olemme sosiaalialan opiskelijoita Diakonia-ammattikorkeakoulusta ja teemme juuri lopputyötäm "Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille". Opinnäytetyötutkimuksemme ymmärtämään vastasyntyneiden teho-osastolla olevien lasten vanhempien tarpeita osastolla viettyn kotiutumista seuraavien ensimmäisten kuukausien sikana, jotta palveluiden tuottajat voisivat kehittää palveluita. Arvostaisimme jos tukisitte tätä kehitystyötä vastaamalla lyhyeen kyselyymme. Kyselyn näi matkapuhelimella saattaa erota alkuperäisestä näkymästä. Parhaiten kysely on katsottavissa tietokon on auki 30.9.2022 asti. Kiitos tuestanne,	me aiheesta pyrkii ajan, sekä/tai tarjoamiaan symä			
Erum ja Daniela				
https://link.webropolsurveys.com/S/6AA8F20C0909CB77				
Hi! We are Social Services students and are writing our thesis. Our thesis topic is "Support to Neonatal Intensive Care Unit Parents". Our research aims to understand the needs of parents with infants in the NICU and/or the first months after leaving the NICU, so the service providers can develop their services. We would appreciate your support by answering a short survey. The phone view of the survey might change from the original view, the best option is to use a computer/laptop. The survey will be open until the end of September (30.09.22).				
Thank you for your support,				
Erum and Daniela				
https://link.webropolsurveys.com/S/6AA8F20C0909CB77				
CLAP, kodutuminen, kyselytutkimus, opinnälytetyö, sairaala-aika, sosiaalityö, tuki, tukipäivelut, vertalatuki				



Support for the Neonatal Intensive Care Unit (NICU) Parents

BACKGROUND INFORMATION

Relationship to the baby in NICU *

In which year was the baby in NICU? *

2018
 2019
 2020

O 2021

O 2022

In which Pregnancy Week was the baby born? *

Below 28 weeks

O Between 28 to 32 weeks

O Between 32 to 37 weeks

How long was the stay in the NICU? *

Was the baby who was in NICU a firstborn? *

Ο	Yes
Ο	No

Did you know that your baby was going to be born prematurely? *

2 of 5

O Yes O No

Previous Next

Support for the Neonatal Intensive Care Unit (NICU) Parents

REGARDING SUPPORT AT NICU

Support for the Neonatal Intensive Care Unit (NICU) Parents

REGARDING SUPPORT AFTER DISCHARGE UPTO 6 MONTHS AFTER DISCHARGE

What kind of support was provided after being discharged from the NICU? *

 Who offered the support? *

 In your opinion, could have the support received been any better? How? *

 Previous

4 of 5

Support for the Neonatal Intensive Care Unit (NICU) Parents

REGARDING SOCIAL SUPPORT

Were you aware about the presence of social worker in the NICU/Hospital? *

O Yes

Do you have a family/friends support system? *

O Yes O No

What kind of support/s would you have liked to get: *

Getting information
Counselling
One-on-one Peer support

Peer support groups

Nanny services

Household support/Domestic Services

Other support

On a scale from 1 to 4, (1 being Harmful, 2 being Useless, 3 being Important and 4 being Essential), how important were the services provided?

	1	2	3	4
Getting Information	0	0	0	0
Counselling	0	0	0	0
One-on-one Peer support	0	0	0	0
Peer support groups	0	0	0	0
Nanny services	0	0	0	0
Household support/Domestic Services	0	0	0	0
Other Support	0	0	0	0

From your own experience, at what stages (from NICU admission to 6 months after discharge) would you have liked to get support? Who would you have wished to get more support from?

	At the NICU	After Discharge from NICU for the first 6 months
Nurses		
Social worker from the NICU/Hospital		
Maternity and child health clinics (Neuvola)		
Organizations / NGOs		
Other		

How did you find out about Kevyt - Association of Preemie Parents in Finland?

Nurses	
Social worker from the NICU/Hospital	
Friends/Family	
On your own	
Other	
Previous Submit	
5 of 5	



Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille

TAUSTATIEDOT

Suhteesi lapseen joka on vastasyntyneiden teho-osastolla *

Minä vuonna lapsenne oli vastasyntyneiden teho-osastolla? *

O 2018

O 2019

O 2020

O 2021

O 2022

Monennellako raskausviikolla lapsenne syntyi? *

🔿 Alle 28 viikkoa

🔿 Välillä 28-32 viikkoa

🔿 Välillä 32-37 viikkoa

Kuinka pitkään lapsi oli vastasyntyneiden teho-osastolla? *

Oliko vastasyntyneiden teho-osastolla ollut lapsi esikoisenne? *

O KYLLÄ O EI

Tiesittekö etukäteen että lapsenne tulisi syntymään ennenaikaisesti?*

2 / 5

Edellinen Seuraava

ntymään ennenaikaisesti?

Tukipalvelut vastasyı	ntyneiden teh <mark>o-osasto</mark> lla olevien lasten vanhemmille
VASTASYNTYNEIDEN TEHO-OSASTOLTA	A SAAMAANNE TUKEA
Minkälaista tukea teille tarjo	ottiin? *
	Z
Kuka tarjosi tukea? *	
	Z
Olisiko tuki voinut olla miele	estäsi parempaa? Millä tavalla? *
	<u> </u>
Edellinen Seuraava	
	3 / 5

Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille

KOSKIEN KOTIUTUMISEN JÄLKEEN SAATUA APUA, KUUTEEN KUUKAUTEEN ASTI

Minkälaista tukea saitte	sen jälkeen kun kotiuduitte? *
	4
(uka tarjosi tukea? *	
Olisiko tuki voinut olla r	nielestäsi parempaa? Millä tavalla? *
Edellinen Seuraava	

Tukipalvelut vastasyntyneiden teho-osastolla olevien lasten vanhemmille

SOSIAALISTA TUKI

Olitko tietoinen siitä, että sairaalassa oli paikalla sosiaalityöntekijä? * O KYLLÄ O EI

Onko sinulla perheen ja ystävien muodostama tukiverkko? *

O KYLLÄ O EI

Minkälaista tukea olisit halunnut saada: *

Tiedon saamista

Neuvontaa
 reuvontaa

Vertaistukea henkilöltä joka on samassa tilanteessa

Vertaistukiryhmää

Lapsenhoitoapua

Apua kotitalouden askareisiin

Muuta tukea

Asteikolla yhdestä neljään (1. ollen vahingollinen, 2. ollen hyödytön, 3. ollen tärkeä, ja 4. ollen välttämätön), kuinka arvioisit saamiasi palveluita:

	1	2	3	4
Tiedon saamista	0	0	0	0
Neuvontaa	0	0	0	0
Vertaistukea henkilöltä joka on samassa tilanteessa	0	0	0	0
Vertaistukiryhmää	0	0	0	0
Lapsenhoitoapua	0	0	0	0
Apua kotitalouden askareisiin	0	0	0	0
Muuta tukea	0	0	0	0

Omaan kokemukseesi pohjautuen, missä vaiheessa (alkaen lapsen vastasyntyneiden teho-osastohoidosta ja loppuen kuusi kuukautta kotiutumisen jälkeiseen aikaan), olisit tarvinnut enemmän tukea? Keneltä olisit toivonut saavasi enemmän tukea?

	vastasyntyneiden teho- osastolla	6 kuukautta kotiutuksen jälkeen
Terveydenhoitajilta		
Sosiaalityöntekijältä/Sairaala		
Neuvolasta		
Järjestöiltä		
Muu taho		

Mitä kautta kuulit Keskosperheiden yhdistys Kevyestä (MLL:n Meilahden yhdistys ry)? *

Terveydenhoitajalta
Sosiaalityöntekijältä /Sairaala
Ystävältä tai perheenjäseneltä
Löysin tiedon itse
Muu taho
Edellinen Lähetä
5 / 5