

IDENTIFYING KNOWLEDGE GAPS IN MANAGING PREMATURE CHILDREN: A PARENTAL PERSPECTIVE STUDY

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Abstract

Introduction: The study, conducted as part of the PreNat HUB ERASMUS+ program, aimed to identify the main knowledge gaps of parents due to the lack of information provided by professionals involved in the management of premature children. It focused on the experiences of parents in dealing with health, educational, and social aspects of prematurity from birth to adulthood. **Methods:** A comprehensive questionnaire was developed and distributed to 187 mothers from five European countries. This survey aimed to assess the information and support provided by various professional groups, including healthcare, education, and social services, and to identify the main areas where parents felt they lacked necessary knowledge. **Results:** The study identified significant knowledge gaps among parents of premature children, covering health, developmental issues, and educational challenges. Only 39.6% were informed about developmental disorders like attention deficit disorders. Notably, 47.6% of children faced unexpected learning problems, often uncommunicated to parents. Awareness about support systems was limited; 22.5% knew of psychological support groups, and 11.2% about medical groups for parents. In education, just 9.1% believed school nurses understood their child's needs, and 13.9% felt schools were aware of these needs. Furthermore, only 19.8% were informed about state benefits, showing a critical information gap. **Conclusions:** There is a critical need for better communication and information sharing between professionals and parents of premature children. Addressing knowledge gaps is vital for managing and supporting these children's development and well-being. An integrated approach involving health, education, and social services is essential to effectively support these families.

Keywords: *Development, education, health, prematurity, support.*

1. Introduction

Premature birth, defined as birth before 37 completed weeks of gestation, is a significant global health issue affecting about 10% of births globally. Premature births are classified into three categories: extreme preterm (before 28 weeks), very preterm (between 28 and 32 weeks), and late preterm (between 32 and 37 weeks). Various factors, including maternal and fetal health issues, environmental exposures, and previous pregnancy history, contribute to the risk of premature birth.

The PreNat HUB initiative, part of the ERASMUS+ program, aims to address these issues by fostering a community of education and collaboration among families, professionals, and parents of premature infants. This study, conducted within the PreNat HUB framework, explores the informational gaps that parents face in managing the health and developmental challenges associated with prematurity.

2. Methods

The study used a mixed-methods approach, combining qualitative and quantitative data collection techniques. Participants were recruited from neonatal units and parent support groups in five European countries: Lithuania, Greece, France, Ireland, and Hungary. Data were collected through semi-structured interviews and a comprehensive questionnaire that covered health, education, and social interaction across three developmental phases: infancy, childhood, and adolescence to adulthood.

Analysis of the qualitative interviews involved thematic analysis to identify patterns in the experiences and informational needs of the parents. Quantitative data from the questionnaires were statistically analyzed to assess the prevalence of reported knowledge gaps and their correlations with demographic and clinical factors. Ethical approvals were obtained from all participating countries, and confidentiality and voluntary participation were ensured.

3. Results

The study included 187 mothers from five European countries: Lithuania, Greece, France, Ireland, and Hungary. This diverse cohort provided a broad perspective on the challenges faced by parents of premature children across different healthcare and social systems.

The findings revealed substantial gaps in parental knowledge. Only about 40% of parents were informed about common developmental disorders associated with prematurity, such as attention deficit disorders. Nearly half of the respondents reported unexpected learning difficulties in their children, indicating a significant communication gap in the education system. Awareness of available support systems was also low, with only 22.5% of parents aware of psychological support groups and even fewer aware of medical support groups for premature children.

Additionally, the interaction between educational institutions and the unique needs of premature children was inadequate, with only a small percentage of parents believing that schools and school nurses fully accommodated their children's needs. Knowledge about state benefits for families with premature children was similarly low, with less than 20% of parents informed about such support.

4. Discussion

The study's results align with international research indicating widespread challenges in communicating essential health information to parents of premature children. For instance, a study in Portugal showed that only about 10% of parents were well informed about the complications associated with prematurity. Similarly, research from Berlin and Sweden linked higher degrees of prematurity with increased incidences of developmental disorders such as autism and learning difficulties.

These findings underscore the need for improved communication strategies and information sharing among healthcare providers, educators, and social service professionals. Effective communication must ensure that parents are not only aware of the complications associated with prematurity but also informed about the available support systems and state benefits.

Future research should focus on optimizing the delivery of information to parents throughout their child's development and assessing the impact of targeted educational interventions for professionals on improving outcomes for premature children.

5. Conclusion

In conclusion, this study highlights a crucial need for systemic improvements in the dissemination of information to parents of premature children to support their immediate needs and enhance long-term developmental outcomes. Addressing these informational gaps is essential for equipping parents to effectively manage the challenges of prematurity. We recruited mothers of premature children through various neonatal units and parent support groups across the specified countries. Eligibility criteria required that participants were primary caregivers of children born prematurely (before 37 weeks of gestation), with these children ranging in age from infancy to adulthood.

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