

ORIGINAL ARTICLE

Living in a bubble with profound difficulties—parents' experiences of extremely preterm survivors

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Abstract

Aim: To analyse the challenges faced by parents of extremely preterm infants born before 24 weeks of gestation and the potential buffering effect of perceived resources on the family's health continuum.

Methods: The qualitative data were obtained from 70 parents of 70 infants born before 24 weeks of gestation, through open-ended questions in a survey. An inductive content analysis was conducted to identify themes and patterns in the parents' experiences. To enhance the understanding of the findings, salutogenic theory was incorporated to contextualise the emerging patterns of resources and deficits.

Results: Parents described the neonatal care as exemplary. However, the integrated results showed that parents reported profound difficulties characterised as 'living in a bubble' with comprehensive neonatal care and varied access to support and participation. In addition, the parents had to manage a preterm born child with medical complexities and encountered significant barriers between care levels.

Conclusion: The findings highlight the need to improve support systems and address challenges for families of preterm born children. Enhancing collaboration between healthcare providers and families, identifying and overcoming barriers during care, and providing comprehensive support services are crucial. Addressing the parents' experienced deficits may mitigate potential adverse effects on family health outcomes.

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KEYWORDS

extremely preterm, parental well-being, qualitative design, salutogenesis, transition barriers

1 | INTRODUCTION

The birth of an extremely preterm infant, before 24 weeks of gestation, is a profound challenge for parents and immerses them into a multifaceted and often overwhelming healthcare journey. As advancements in medical science enable the survival of infants born at earlier gestational ages, caring for these fragile lives becomes increasingly complex.¹ Extremely preterm birth has been associated with both long- and short-term disabilities and medical complexities²⁻⁵ as well as uncertainty and emotional distress.^{6,7} It is crucial to understanding how parents navigate the healthcare system. It has been found that preterm parents receive more professional support although 28% felt that it was insufficient compared to 4% of reference parents to children born at term age.⁸

A previous quantitative study, using the same population as the present article, revealed that parents experienced significant fatigue and a decline in their satisfaction with care following hospital discharge.⁹ The current study qualitatively analysed parents' experiences within the healthcare system following the birth of an extremely preterm born child, with the theoretical framework of salutogenesis.

Antonovsky's salutogenic theory, focusing on the origin of health¹⁰ even during difficult conditions,^{11,12} is well suited to experiences like parenting an extremely preterm born child. An individual's capacity to comprehend, find meaning and effectively manage challenging life circumstances¹³ is affected by a person's generalised resistance resources, referred to as resources from here on. Resources are internal and external factors like social support, access to health care and financial stability that contribute to an individual's ability to cope with stressors and maintain their health. On the other hand, a person is also affected by generalised resistance deficits, from here on referred to as deficits. The deficits represent an insufficiency of resources like lack of access to health care, discrimination, social isolation or trauma. Deficits can lead to pathogenic impairment processes like health deterioration and disease if not balanced by the resources.^{13,14}

This article sought to unravel the intricate interplay between parental experiences and their expressed resources and deficits during their healthcare journey. Through an inductive and deductive content analysis, the aim was to analyse the challenges faced by parents of extremely preterm infants born before 24 weeks of gestation and the potential buffering effect of perceived resources on the family's health continuum.

2 | METHODS

2.1 | Study population and data collection

This prospective study used data from a questionnaire completed by parents of singleton children born before 24 weeks of gestation in Sweden between 2007 and 2018. Children were identified through

Key Notes

- It is essential to comprehend how parents of infants born before 24 weeks gestation navigate the healthcare system.
- Parents reported exemplary neonatal care, inconsistent support and participation, extensive difficulties in relation to the child's health, and in transition between care levels.
- We recommend national monitoring, family-centred care, education and support to enable healthcare professionals and policymakers to strengthen adaptability in parents of extremely preterm infants.

the Swedish Registry for Retinopathy of Prematurity and have been described elsewhere as the TINY cohort study.¹⁵ The questionnaire included questions about parents' characteristics, satisfaction with care, children's GA at birth and current age, parents' sense of coherence and other factors not analysed in this paper. The surveys were mailed in June 2022, with a reminder sent in October 2022. Of the 349 parents invited to participate, 131 (37.5%) completed the survey anonymously. This study specifically analysed responses from 70 participants who provided answers to open-ended questions in the survey.

2.2 | Design

This study employed an inductive and deductive qualitative design (Figure 1) with integration and interpretation of the qualitative results with the salutogenic theory to interpret and deepen the understanding of the themes and patterns that emerged in relation to this complex research question.¹⁶

2.3 | Data analysis

Inductive content analysis¹⁶ was used to analyse the open questions and free-text answers to make sense of the data and the whole. The qualitative analysis was conducted using NVivo 14 (Lumivero, Victoria, Australia), and the analyses started with making sense of the text as a whole. Then, open coding was conducted to create coding sheets. Next, the codes were organised and grouped into sub-categories, which were classified under higher-order headings. The main categories emerged by categorising and abstracting the data into an overarching conceptual category (Figure 2). The first author primarily performed the analysis but in constant reconciliation with the second and last author and, later in the analysis process, with the other co-authors to ensure trustworthiness and credibility.¹⁶

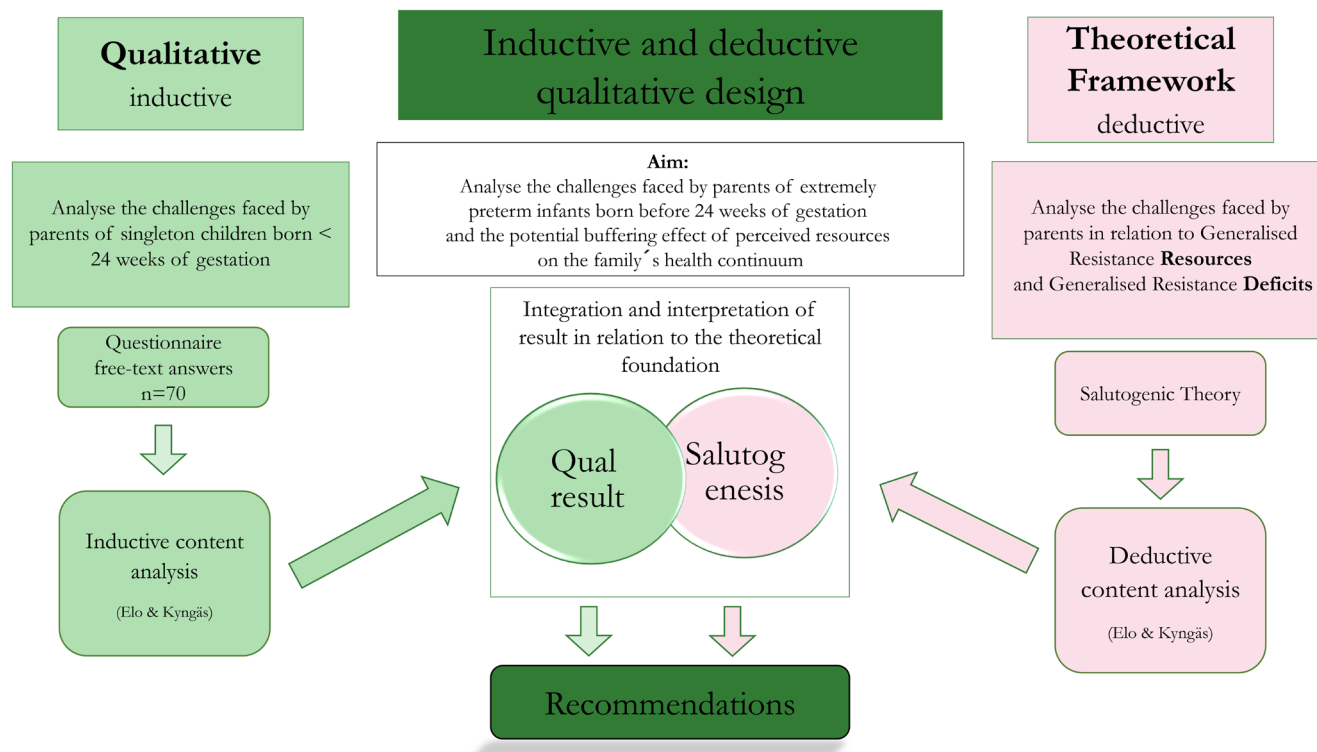
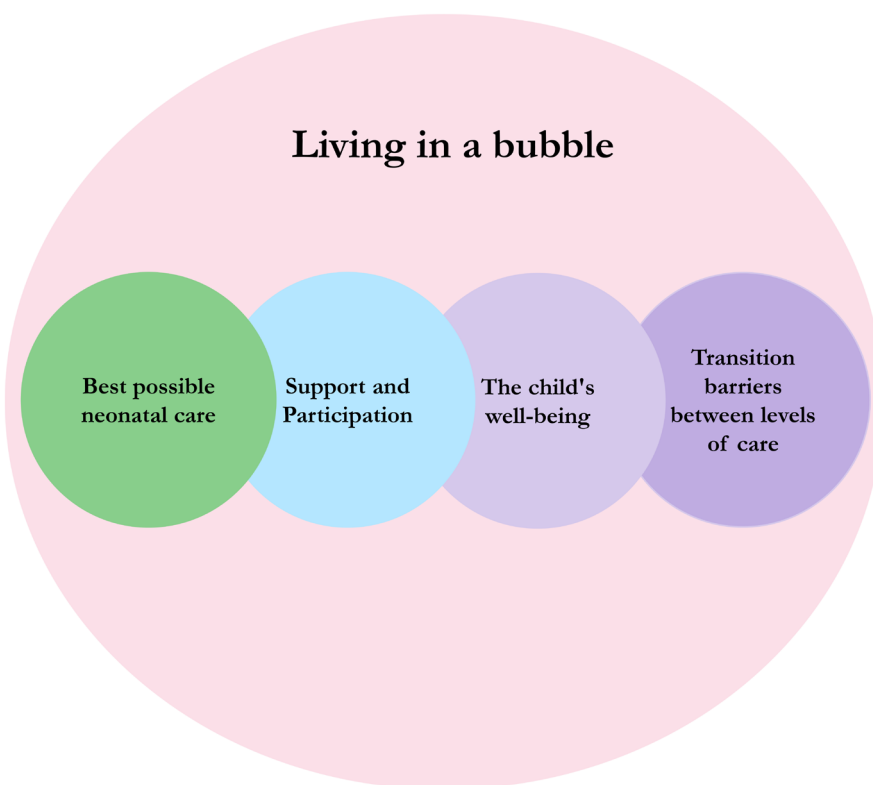


FIGURE 1 The inductive and deductive qualitative design.

FIGURE 2 The overarching category living in a bubble and its subcategories.



Following the completion of the inductive analysis, relevant theoretical frameworks were considered to enhance the interpretation of the emergent themes and their effects on the family's health. The identified patterns and how they aligned with, supported or challenged the salutogenic concepts, resources and deficits were

explored. A conceptual framework was developed by combining the inductively derived categories with salutogenic theory, demonstrating their interrelation (Figure 3). Finally, the theory was used to situate the results within a broader context, allowing for a deeper analysis of the underlying mechanisms, processes, and structures

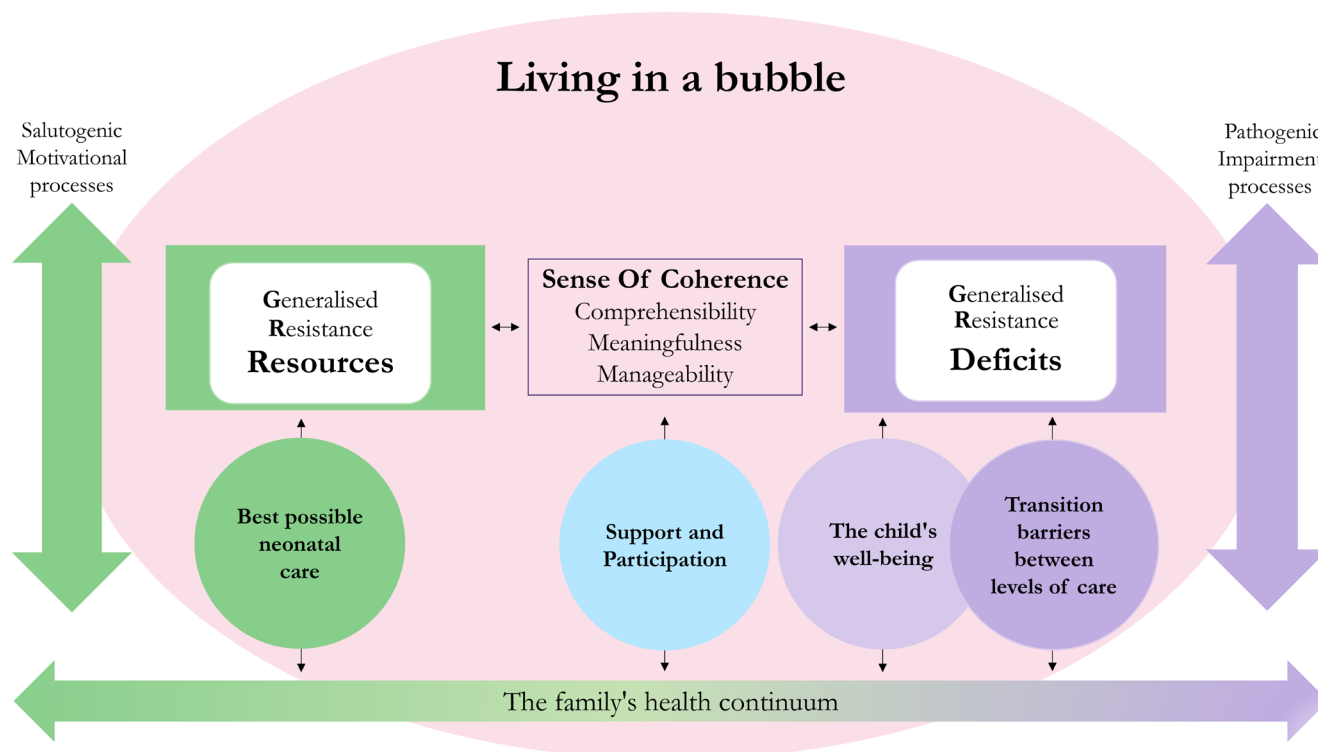


FIGURE 3 The conceptual model of the integrated results living in a bubble with the salutogenic theory.

TABLE 1 Children's characteristics.

Variable	Total N = 70
<i>Children</i>	
Born in gestational week	
21	3 (4.3%)
22	12 (17.1%)
23	55 (78.6%)
Current age (years)	
	9.2 ± 3.7
	9 (4–16)
Sex	
Girl	40 (57.1%)
Boy	30 (42.9%)

Note: Data are presented as mean ± standard deviation, median (range), or number and percentage.

that explained the observed patterns of parents' experiences. Subsequently, the findings were deductively integrated for interpretation in relation to the theoretical foundation of salutogenesis.

3 | RESULTS

3.1 | Children's and parents' characteristics

At the time of the data collection, the 70 prematurely born children had a median age of 9 years, ranging from 4 to 16, 57% were girls, and 79%

were born at 23 weeks gestation (Table 1). Of the parents choosing to answer the open questions in the survey, 74% were females, and the mean age for the parents was 43 years (range 28–58), 70% had full-time employment, and 81% were married or living with the child's other parent. Most of the parents were born in Sweden, 81% of the mothers and 84% of the fathers. The mothers (56%) reported university as the most common education level. However, fathers reported a lower level of education (40% high school) as their main education level (Table 2).

3.2 | Overarching category and subcategories

The overarching category living in a bubble emerged as an explanation of the parents' experiences of health care after having an extremely preterm born child born before 24 weeks of gestation. Living in a bubble was a symbolic image several parents expressed to describe living in a parallel world centred around the preterm born child's well-being and care. One parent expressed it this way: 'I lived in a bubble for a long time, and only much later, when I understood that everything would be fine, did I suffer burnout'. Another parent said: 'I were like in a bubble, not daring to feel anything at all because I didn't know if our child would survive or not'. The bubble was a place of limbo, filled with uncertainty and impotence where the rest of the world just lived on as if nothing had happened. The families had to watch the outside from within the bubble and could not participate in the real world. Living in a bubble was indicated by four subcategories: best possible neonatal care; support and participation; the child's well-being; and transition barriers between levels of care (Figure 2).

TABLE 2 Parents' characteristics.

Variable	Total N = 70
<i>Parents</i>	
Current age (years)	43.1 ± 7.1 43 (28–58)
Age at birth of the child (years)	33.8 ± 5.9 33 (23–47)
Female	52 (74.3%)
Male	18 (25.7%)
<i>Relation to the child</i>	
Mother	52 (74.3%)
Father	16 (22.9%)
Other	2 (2.9%)
<i>Employment</i>	
Employed full-time	49 (70.0%)
Employed part-time	15 (21.4%)
Student	2 (2.9%)
Parental leave	2 (2.9%)
Unemployed	2 (2.9%)
<i>Marital status</i>	
Married/living with the child's other parent	56 (80.0%)
Married/living with another partner	1 (1.4%)
Live apart	1 (1.4%)
Sole guardian	7 (10.0%)
Other	5 (7.1%)
Mother born in Sweden	56 (81.2%)
Father born in Sweden	59 (84.3%)
<i>Mother's highest education</i>	
Elementary school	3 (4.3%)
High school	14 (20.0%)
1–2 years after high school	14 (20.0%)
University	39 (55.7%)
<i>Father's highest education</i>	
Not finished elementary school	2 (2.9%)
Elementary school	8 (11.4%)
High school	28 (40.0%)
1–2 years after high school	10 (14.3%)
University	22 (31.4%)

Note: Data are presented as mean ± standard deviation, median (range), or number and percentage.

3.2.1 | Best possible neonatal care

Parents express gratitude for the Swedish healthcare system and acknowledge and appreciate the exemplary neonatal care. The overall satisfaction with the care and attention received is emphasised, encompassing general care and specialised treatment during the admission. The use of terms such as 'pure professionalism

throughout the neonatal period', 'top-notch' and 'fantastic' underscored the positive perception of healthcare personnel in neonatal care. Explicit mention of the patience and informativeness of the staff signified a comprehensive and compassionate approach to patient care by the professionals. The recurring theme of confidence in receiving highly specialised and best possible care permeates the experiences. The assertion that if the staff at the initial location could not aid, no one else could, underscored the high level of trust in neonatal healthcare professionals. Neonatal units were characterised by round-the-clock supervision and care, a quality parents positively acknowledged for fostering security and attention. Positive experiences were enhanced by transparent communication and assurance that parents were fully informed about medical procedures and neonatal care progress. The consistently high level of competence and professionalism experienced across different facets of neonatal care, including medical and nursing care, made the parents feel safe and reassured.

3.2.2 | Support and participation

On the one hand, the analysis highlighted a predominant theme of support and active participation, including emotional support, guidance on a preterm born child's needs, advocacy in education and compassionate care during difficult decisions. The emphasis on feeling respected and involved highlighted the importance of healthcare professionals' support in facilitating parents' participation in decision making about their children's care.

On the other hand, parents also provided a critical perspective based on their experience of a lack of support, information and participation in later care settings, like primary care centres. They emphasised the absence of comprehensive support for parents dealing with the stress and emotional challenges associated with parenting an extremely preterm born child. The lack of empathy and understanding, especially in school settings, contributed to a sense of isolation and distress among the parents. The metaphorical comparison to being 'alone in the jungle' underscored the perceived lack of support and understanding from the caregiving and school systems. The findings emphasised the critical need for parents of extremely preterm born children to have robust psychosocial support networks and enhanced professional understanding of the complexities of caring for and living with the tiniest survivors. One parent stated: 'In hindsight, I think there should perhaps have been a psychosocial team to follow-up with the parents. It is a very traumatic event, and you remain in shock for a long time'. The post-neonatal care support was criticised as inadequate, with parents having to consistently seek information, understand protocols and guide healthcare professionals in tasks expected to be handled automatically. It was expressed by one parent: 'I found out by chance that I could apply for a care allowance when, about 1.5 years after discharge, a staff member asked how things were going for us with the Social Insurance Agency and that type of support'.

3.2.3 | The child's well-being

How the families perceived care and life, in general, was also affected by the extremely premature born child's health and well-being. Many children were reported to suffer from significant health issues related to different factors; neuropsychiatric development 'My child is diagnosed with ADHD, dyslexia, language disorder and is under investigation for autism' 'My child is unable to articulate speech and communicates solely through making sounds' 'My child is also dyslectic which has made school difficult', food intake 'My child has been tube fed since birth and has never been fed orally', 'My child refrains from consuming any food orally and has minimum water intake', visual perception 'The child has a severe visual impairment', lung capacity 'Our child has reduced lung capacity', dental health 'Several teeth have cracked when my child chewed on something hard. The explanation we received is that the teeth started to form early, and that my child's body was stressed'. The consequences of having an extremely preterm born child with often multiple adverse health issues, regarding both physical and psychosocial health, were described to impact the whole family's health and well-being significantly.

3.2.4 | Transition barriers between levels of care

The open answers outlined a substantial gap in knowledge and understanding about the difficulties faced by extremely premature infants outside of the university hospital's neonatal unit. One parent stated: 'Knowledge of extremely preterm infants is still very low outside the neonatal unit'. There was a deficiency in the knowledge of healthcare professionals in primary care centres, resulting in challenges when seeking assistance, and the families felt insecure in the transition between different levels of care. Consequently, the transition to lower care levels was overwhelming for parents, as they needed to establish a relationship with new staff, treatment routines, new health care contexts and cultures. It was described by one parent: 'It was a big step for us parents when the children were going to be relocated'. The care management paradigm shifted from being primarily overseen by neonatal staff to increasingly expecting parents to take on greater responsibility in lower levels of care. Leaving the hospital was described as distressing, with notable geographic differences across Sweden. Families' locations greatly impacted the quality and accessibility of care, highlighting disparities in healthcare services nationwide. One parent said that: 'Instead, as a family, we must accept that it just has to be the way it is when we know that others have received better care at other hospitals. It completely depends on where you live'. Although the neonatal follow-up was deemed satisfactory, parents reported facing challenges such as seizures, feeding difficulties and balance issues, for which they had to seek solutions independently. They had to persistently advocate for the health care they perceived their child needed and were entitled to. The parents' expressed frustration as they repeatedly had to explain their child's medical history at new physician appointments,

highlighting a lack of continuity in their care as another transition barrier between levels of care.

3.3 | Integrating living in a bubble with the salutogenic theory

The overarching category, living in a bubble, encapsulated the experiences of families navigating the complexities of caring for an extremely preterm born child and the associated continuum of health and well-being. Drawing on the salutogenic theory, this analysis illustrates how resources and deficits significantly influenced families' progression along the health continuum (Figure 3).

According to salutogenic theory, the sense of coherence in families is influenced by the dynamic interplay between resources and deficits. Resources, compass biological, material, and psychosocial resources and function as protective factors that facilitate the family's ability to perceive life as comprehensible, manageable and meaningful.^{17,18} These resources are integral to salutogenic motivational processes that promote adaptability and the family's health.¹³ In this study, parents consistently identified best possible neonatal care as a significant resource that reinforced comprehensibility. The high standard of neonatal care enabled families to manage the complex stressors associated with preterm birth more effectively. It provided a foundation that buffered their capacity for coherence in the face of adversity and promoted salutogenic motivational processes that enhanced health and well-being.

The subcategory support and participation occupied a complex, intermediary position on the health continuum. Effective participation and support characterised by meaningful inclusion in decision-making processes and involvement in the care of the preterm born infant could act as buffering resources fostering a greater sense of manageability and meaningfulness. Conversely, insufficient or inconsistent participation and support may introduce deficits, diminishing the family's perceived control over the situation and potentially undermining their adaptability and family health.

Other key identified deficits included the child's fluctuating health and transition barriers. These deficits obstructed the family's ability to effectively utilise available resources, maintain coherence and adapt to stressors. The deficits contributed to pathogenic impairment processes, diminishing the family's capacity to view their circumstances as comprehensible, manageable, and meaningful and adversely affecting adaptability and the overall health and well-being of the families.

4 | DISCUSSION

4.1 | Main findings

The integrated results revealed that parents described profound difficulties following the birth of their extremely preterm born infant. It affected the strategies available to an individual to cope with life's

challenges and tension effectively. A diminished sense of manageability emerged when individuals perceived a lack of control or influence over their life circumstances.¹⁹ The experience of parenting extremely preterm born infants was characterised as living in a bubble with comprehensive neonatal care and varied access to support and participation. At the same time, they had to manage a preterm born child with disabilities and medical complexities, and they encountered significant barriers between care levels. Starke et al.²⁰ presented compliant results, from a long-term perspective, where parents of extremely preterm born children expressed profound effects on the family life, where healthcare professionals could serve as an essential support to feel safe in the roller coaster bubble they perceived they were living in.²⁰ Syltern²¹ advocated for the integration of parental involvement in decisions regarding life support when the optimal course for the child's well-being was uncertain, particularly when such decisions profoundly impacted the family. This resonates with the present results where parents highlighted the need to be included in the decision-making processes regarding their child's care. Consequently, there is an urgent need for comprehensive Scandinavian guidelines addressing complex ethical medical dilemmas, such as initiating active resuscitation as early as 22 weeks of gestation, a practice most prevalent in Sweden among the Scandinavian countries. These guidelines should reflect societal moral values and be developed through inclusive collaboration with parents and stakeholders from outside the medical community.²¹

4.2 | Resources

Antonovsky's salutogenesis theory, which emphasises the role of resources and deficits in coping with stress and maintaining health, provides a valuable framework for understanding the experiences of parents of extremely preterm infants. Resources that enhanced meaningfulness included high-quality neonatal care, adequate support, active parental involvement and effective collaboration with healthcare providers. This result is consistent with prior research indicating that finding meaning in difficult circumstances can be a powerful coping mechanism for parents of preterm infants. This means helping them navigate the challenges and uncertainties associated with their child's medical conditions.²² Graungaard et al.²³ reported a positive relationship between external support resources and parental adaptability which underscores key areas for targeted interventions to bolster parental support.

However, parental expectations may play a critical role, as the high-quality care experienced in neonatal units often sets a standard that may not be consistently met in subsequent care stages, creating a disparity in expectations versus experience.

Our findings also align with previous research demonstrating the importance of family-centred care in promoting adaptability among parents of preterm infants.^{24,25} The present study's results highlighted that resources were essential for fostering salutogenic motivation and meaningfulness, positively influencing family health outcomes. Resources contribute to individuals' ability to cope with

stressors and maintain their health and well-being effectively.²⁶ Thus, interventions aimed at bolstering resources and mitigating the impact of deficits hold promise for promoting adaptability and improving overall family health and well-being.

4.3 | Deficits

The integrated results identified resource shortages and excessive demands, contributing to pathogenic processes that harmed family health outcomes. The absence of adequate support and participation from healthcare providers and support networks represented a significant deficit that adversely affects parents. Our results align with Franck and O'Brien's findings, which highlighted the importance of structured and informal support in fostering parental involvement, empowering strengths and building confidence in making decisions about their infant's care.²⁵ Esbjørn et al.⁸ underscore that unmet support needs not only reflected the vulnerabilities associated with preterm birth but also related to parents' experiences of psychological distress, such as loss and grief. They highlight that a lack of connection with other parents and access to knowledgeable professionals exacerbated these challenges.⁸ These and the present findings indicate the importance of reassessing follow-up procedures for parents of prematurely born children.

Another notable deficit in our findings is the child's ill health, which represented a significant stressor for parents of preterm born infants. Coping with these challenges can lead to a lack of control, strain parents' resources, and contribute to feelings of helplessness and uncertainty, ultimately compromising their ability to manage their situation effectively. This finding aligns with previous research that has highlighted the stress and uncertainty experienced by parents of preterm infants in managing their child's medical needs and hospitalisation.²⁷

Transition barriers between levels of care represent another deficit. Navigating the healthcare system and coordinating care across different providers and settings can be overwhelming, particularly in the context of preterm birth. These barriers may hinder parents' access to necessary resources and support services, weakening their sense of manageability. Spence et al.²⁸ presented similar findings where parents expressed anxiety in relation to transition and feeling a loss of control and support from the healthcare staff. It is important to prepare the parents for the transition between levels of care as they are the primary carers of the infant; this can further enhance the attachment and cohesion within the family.²⁹ The parents in the present study expressed that the quality of care varied depending on geographical location in Sweden. Thus, justice, equal access and equal outcomes are critically important. Distributive justice raises fundamental questions about how resources are allocated and how access to care can be equitable. While all families should have equal access to high-quality healthcare for their infants, achieving equal outcomes remains a significant challenge. Continuity of care and effective resource allocation are essential factors that seem to influence access to necessary services. Addressing these disparities



¹Continuous National Monitoring and Evaluation

- Allocate resources and create prerequisites to implement the continuous monitoring and evaluation systems nationwide. These systems should provide consistent oversight to improve the quality and consistency of care.
- Review the transition between levels of care, as there are fragile periods where parents feel insecure and lose confidence in the care system and their own capacity.
- Establish dedicated long-term multiprofessional follow-up centres with specialised expertise.



²Family-centred care

- Include parents in decision-making processes regarding their child's care and regarding life support.
- Structured family-centred transition planning. Provide well-organised preparation for the transition between care levels, as healthcare shifts from highly specialised and professionally controlled settings to increased parental responsibility.
- Implement gradual and well-prepared transfer of responsibility from healthcare staff to parents.



³Structured Education and Support

- Offer educational programs to parents to inform them of their rights and the key factors that impact family well-being following the birth of an extremely preterm child.
- Early support, information and education for parental empowerment, enhancing parental capacity and promote family well-being. This requires comprehensive policy development and integration across social, health, and educational sectors to ensure cohesive, accessible support for families.

FIGURE 4 Recommendations.

requires a comprehensive approach that prioritises healthcare equity. This involves implementing policies that facilitate seamless transitions between different levels of care and ensure that resources are fairly distributed across the healthcare system. By focusing on both access and outcomes, we can work towards a more just healthcare system that supports the well-being of all extremely preterm born infants and their families.

The continuum of resources and deficits highlights the dynamic interplay between factors that promote adaptability and factors that increase vulnerability to stress. Individuals and communities with robust resources are better equipped to withstand life's challenges and maintain health, and those experiencing deficits may face greater difficulties in coping and preserving the family's well-being.^{10,26} When individuals have access to sufficient resources, they are more likely to perceive critical life events as comprehensible, manageable and meaningful, which promotes better health outcomes. Antonovsky argued that addressing deficits is essential for promoting health equity and reducing disparities.¹³ Interventions to mitigate deficits may involve providing family-centred care and resources such as access to healthcare services with sufficient information and education about the preterm born child's health, structured preparation for transition between care levels, and social support networks.

Thomson et al.³⁰ emphasised that providing family-centred care requires addressing the sense of coherence from both professional and parental perspectives to promote well-being and health in the neonatal context. This research integrates parental healthcare experiences with salutogenic theory to provide insights for professionals,

policymakers and researchers in supporting parents facing the complex journey of caring for extremely preterm born infants. We propose the following recommendations (Figure 4).

By implementing these recommendations, healthcare providers and policymakers can contribute to the enhancement of resources, mitigation of deficits and ultimately promote a strong sense of coherence and positive health outcomes for families with extremely preterm infants.^{17,30,31}

4.4 | Strengths and limitations

This study's strength lies in its unique design, which combined inductive and deductive content analysis with the salutogenic theory. This integration allowed for the thorough investigation of the research question by incorporating a theoretical framework with qualitative data.^{16,32} This combined inductive-deductive approach offered several advantages: It enabled unexpected findings to emerge from the data while leveraging existing theoretical knowledge. The inductive phase ensured the analysis remained grounded in the participants' experiences. The open-ended responses provided rich qualitative insights into participants' experiences, attitudes and behaviours. The deductive phase, guided by salutogenic theory, offered a structured framework for deeper interpretation and potential theory development. This approach provided a comprehensive analysis that was both data-driven and theoretically informed.

While our study provides valuable insights, we acknowledge the potential biases that may arise from the specific population studied.

The unique characteristics of this cohort could influence the findings, potentially limiting the transferability.

Another limitation arises from the resource-intensive and time-consuming nature of conducting an inductive and deductive study with a salutogenic theoretical foundation, necessitating significant investments in time, analytical skills and theoretical expertise.^{16,32} The integration process was carefully managed through an abductive process to ensure coherence and consistency across the data sources and theory. The inductive and deductive theoretical design facilitated a more comprehensive and in-depth result than could not have been attained with a solely inductive design.

5 | CONCLUSION

Parents expressed appreciation for the Swedish healthcare system, particularly the high-quality neonatal care provided. Our findings offer valuable insights into ways to further support families of extremely preterm born children, including strategies to enhance collaboration between healthcare providers and families, identify and address barriers to care, and provide comprehensive support services. By implementing our recommendations, such as allocating resources and prerequisites to implement continuous national monitoring and evaluation, fostering family-centred care practices, and providing structured education and support, there is potential to improve outcomes for these families. At the same time, the impact of these initiatives on mitigating adverse health effects depends on successful implementation and effectiveness. These insights contribute meaningfully to ongoing efforts by healthcare professionals, policymakers and researchers to build an adaptable support system for families navigating the challenges of caring for extremely preterm born infants.

AUTHOR CONTRIBUTIONS

Malin Hansson: Writing – original draft; conceptualization; methodology; validation; visualization; writing – review and editing; software; formal analysis; data curation. **Aldina Pivodic:** Writing – original draft; conceptualization; methodology; validation; visualization; writing – review and editing; software; formal analysis; data curation. **Chatarina Löfqvist:** Conceptualization; methodology; writing – review and editing; investigation. **Karin Sävman:** Conceptualization; methodology; writing – review and editing; investigation. **Boubou Hallberg:** Conceptualization; investigation; methodology; writing – review and editing. **David Ley:** Conceptualization; investigation; methodology; writing – review and editing. **Eva Morsing:** Conceptualization; methodology; writing – review and editing; investigation. **Pia Lundgren:** Conceptualization; methodology; writing – review and editing; investigation. **Jenny Gyllén:** Conceptualization; investigation; methodology; writing – review and editing. **Carola Pfeiffer-Mosesson:** Conceptualization; investigation; methodology; validation; writing – review and editing; project administration; data curation. **Ann Hellström:** Conceptualization; investigation; funding

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

ETHICS STATEMENT

The Swedish Ethical Review Authority approved this study (Dnr 2021-03587). By responding to the questionnaire, the parents gave their consent to participate in the study.

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REFERENCES

- Domellöf M, Jonsson B. The Swedish approach to management of extreme prematurity at the borderline of viability: a historical and ethical perspective. *Pediatrics* (Evanston). 2018;142(Suppl 1):S533-S538. doi:[10.1542/peds.2018-0478C](https://doi.org/10.1542/peds.2018-0478C)
- Lundgren P, Jacobson L, Hård A-L, et al. High rate and large inter-centre variability in retreatment of retinopathy of prematurity in infants born < 24 gestational weeks. *BMJ Open Ophthalmology*. 2021;6(1):e000695. doi:[10.1136/bmjophth-2020-000695](https://doi.org/10.1136/bmjophth-2020-000695)
- Saigal SP, Doyle LWP. An overview of mortality and sequelae of preterm birth from infancy to adulthood. *The Lancet* (British Edition). 2008;371(9608):261-9. doi:[10.1016/S0140-6736\(08\)60136-1](https://doi.org/10.1016/S0140-6736(08)60136-1)
- Hellström A, Jacobson L, Al-Hawasi A, et al. Retrospective evaluation of ophthalmological and neurological outcomes for infants born before 24 weeks gestational age in a Swedish cohort. *BMJ Open*. 2022;12(8):e055567. doi:[10.1136/bmjopen-2021-055567](https://doi.org/10.1136/bmjopen-2021-055567)
- Pravia CI, Benny M. Long-term consequences of prematurity. *Cleve Clin J Med*. 2020;87(12):759-67. doi:[10.3949/ccjm.87a.19108](https://doi.org/10.3949/ccjm.87a.19108)
- Kantowitz-Gordon I, Altman MR, Vandermause R. Prolonged distress of parents after early preterm birth. *J Obstet Gynecol Neonatal Nurs*. 2016;45(2):196-209. doi:[10.1016/j.jogn.2015.12.004](https://doi.org/10.1016/j.jogn.2015.12.004)
- Ballantyne M, Orava T, Bernardo S, McPherson AC, Church P, Fehlings D. Parents' early healthcare transition experiences with

- preterm and acutely ill infants: a scoping review. *Child Care Health Dev.* 2017;43(6):783-96. doi:[10.1111/cch.12458](https://doi.org/10.1111/cch.12458)
8. Esbjörn BH, Madsen BM, Munck H, Greisen G. Extremely prematurely born children's and their parents' need for support. *Ugeskr Laeger.* 2008;170(42):3331-4. Ekstremt tidligt fødte børn og forældrenes behov for støtte.
 9. Pivodic A, Hansson M, Löfqvist C, et al. Challenges of parenting children born before 24 weeks of gestation. *Acta Paediatr.* 2024;113:2414-22. doi:[10.1111/apa.17350](https://doi.org/10.1111/apa.17350)
 10. Antonovsky A. *Health, Stress, and Coping.* 1st ed. Jossey-Bass; 1979.
 11. Eriksson M, Lindström B. Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. *J Epidemiol Community Health.* 2007;61(11):938-44. doi:[10.1136/jech.2006.056028](https://doi.org/10.1136/jech.2006.056028)
 12. Eriksson M, Lindstrom B. Antonovsky's sense of coherence scale and the relation with health: a systematic review. *J Epidemiol Community Health.* 2006;60(5):376-81.
 13. Mittelmark MB, Bauer GF, Vaandrager L, et al. *The Handbook of Salutogenesis*; 2022.
 14. Vinje HF, Langeland E, Bull T. Aaron Antonovsky's development of Salutogenesis, 1979-1994. In: M. B. Mittelmark et al. *The Handbook of Salutogenesis.* Springer, Cham; 2022. https://doi.org/10.1007/978-3-030-79515-3_5
 15. Lundgren P, Morsing E, Hard AL, et al. National cohort of infants born before 24 gestational weeks showed increased survival rates but no improvement in neonatal morbidity. *Acta Paediatr.* 2022;111(8):1515-25. doi:[10.1111/apa.16354](https://doi.org/10.1111/apa.16354)
 16. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* 2008;62(1):107-15. doi:[10.1111/j.1365-2648.2007.04569.x](https://doi.org/10.1111/j.1365-2648.2007.04569.x)
 17. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Int.* 1996;11(1):11-8. doi:[10.1093/heapro/11.1.11](https://doi.org/10.1093/heapro/11.1.11)
 18. Mittelmark MB, Sagy S, Eriksson M, et al. *The Handbook of Salutogenesis.* Cham: Springer International Publishing; Imprint: Springer. 2017.
 19. Pelikan JM. The Application of Salutogenesis in Healthcare Settings. In: M. Mittelmark et al. *The Handbook of Salutogenesis.* Springer, Cham; 2016. https://doi.org/10.1007/978-3-319-04600-6_25
 20. Starke V, Diderholm B, Heyman M, Blomqvist YT. Being parents of extremely preterm children, from a long-term perspective: a qualitative study of parents' experiences. *Early Hum Dev.* 2023;183:105819. doi:[10.1016/j.earlhumdev.2023.105819](https://doi.org/10.1016/j.earlhumdev.2023.105819)
 21. Syltern J. Scandinavian perspectives on life support at the border of viability. Mini review. *Frontiers in Pediatrics.* 2024;12:1394077. doi:[10.3389/fped.2024.1394077](https://doi.org/10.3389/fped.2024.1394077)
 22. Lau R, Morse CA. Parents' coping in the neonatal intensive care unit: a theoretical framework. *J Psychosom Obstet Gynaecol.* 2001;22(1):41-7. doi:[10.3109/01674820109049949](https://doi.org/10.3109/01674820109049949)
 23. Graungaard AH, Andersen JS, Skov L. When resources get sparse: a longitudinal, qualitative study of emotions, coping and resource-creation when parenting a young child with severe disabilities. *Health (London).* 2011;15(2):115-36. doi:[10.1177/1363459309360794](https://doi.org/10.1177/1363459309360794)
 24. Altimier L, Phillips R. The neonatal integrative developmental care model: advanced clinical applications of the seven Core measures for neuroprotective family-centered developmental care. *Newborn Infant Nurs Rev.* 2016;16(4):230-44. doi:[10.1053/j.nainr.2016.09.030](https://doi.org/10.1053/j.nainr.2016.09.030)
 25. Franck LS, O'Brien K. The evolution of family-centered care: from supporting parent-delivered interventions to a model of family integrated care: from supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Research.* 2019;111(15):1044-59. doi:[10.1002/bdr2.1521](https://doi.org/10.1002/bdr2.1521)
 26. Antonovsky A. *Unraveling the Mystery of Health: how People Manage Stress and Stay Well.* 1st ed. Calif. Jossey-Bass; 1987.
 27. Hendy A, El-Sayed S, Bakry S, et al. The stress levels of premature Infants' parents and related factors in NICU. *SAGE Open Nurs.* 2024;10:23779608241231172. doi:[10.1177/23779608241231172](https://doi.org/10.1177/23779608241231172)
 28. Spence CM, Stuyvenberg CL, Kane AE, Burnsed J, Dusing SC. Parent experiences in the NICU and transition to home. *Int J Environ Res Public Health.* 2023;20(11):6050. doi:[10.3390/ijerph20116050](https://doi.org/10.3390/ijerph20116050)
 29. Lester BM, Hawes K, Abar B, et al. Single-family room care and neurobehavioral and medical outcomes in preterm infants. *Pediatrics.* 2014;134(4):754-60. doi:[10.1542/peds.2013-4252](https://doi.org/10.1542/peds.2013-4252)
 30. Thomson G, Moran VH, Axelin A, Dykes F, Flacking R. Integrating a sense of coherence into the neonatal environment. *BMC Pediatr.* 2013;13(1):84. doi:[10.1186/1471-2431-13-84](https://doi.org/10.1186/1471-2431-13-84)
 31. Downe S, Magistretti CM, Shorey S, Lindström B. *The Application of Salutogenesis in Birth, Neonatal, and Infant Care Settings.* Springer International Publishing; 2022:465-77.
 32. Creswell JW. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* Sixth ed. SAGE; 2023.

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