



Reflections about being born extremely preterm in children and adolescents: A qualitative descriptive study

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ABSTRACT

Background: The survival of the smallest and most immature preterm infants, born at 23–24 weeks of gestation, has improved significantly. While there is a substantial amount of research on the neurocognitive and social outcomes of extremely premature birth, little is known about the survivors' subjective experience of being born preterm and its effect on later life.

Aims: The purpose was to study the subjective experiences of school-aged children born at 23–24 weeks of gestation, in order to understand their perspectives on how being born extremely early had affected their life.

Study design: Qualitative descriptive study.

Methods: 18 school-aged children (12 girls and 6 boys, 7–15 years of age), born at 23 or 24 weeks of gestation, were interviewed. The semi-structured interview guide covered six topics about quality of life: somatic health, functioning, learning and memory, emotional health, social relations, experience of prematurity and its effect.

Results: Most children reported memories, which were told to them by parents, about their premature birth and early life. Using qualitative thematic analysis, the narratives of the children were classified into three groups: 1) the *go-with-the-flow children*, who identified little or no effect of prematurity, 2) the *ponderers*, who reflected on some effects such as minor physical challenges, and 3) the *hesitants*, who either did not connect their challenges with prematurity, or did not produce much reflection overall.

Conclusions: Children had been told about their early life by the parents and repeated these memories indicating that prematurity had become a significant part of the family story. Differences were found how the children reflected on the impact of prematurity in their personal life. It is essential to include preterm survivors' own perspectives already during childhood and adolescence into the research of extreme prematurity.

1. Introduction

Neonatal intensive care of premature infants and, consequently, the survival of the smallest ones, has improved in recent decades. For example, the percentage of surviving infants born before 24 weeks of gestation has almost doubled in Sweden from 2007 to 2018 [1]. There is a substantial amount of research on how prematurity affects later health and neuro-cognitive [2] and socio-emotional development [3,4]. The risks of long-term morbidities and developmental challenges increase with earlier gestational ages and lower birth weights [5,6].

Another emphasis of prematurity research has been on studying the quality of life (QoL) in preterm-born populations [7]. The majority of studies about the QoL of preterm children have been based on parental perspectives. The parents of preterm-born children at preschool or school age have reported worse QoL in their children than the parents of the full-term control group, especially in the domains of physical health,

behavior, and functionality [7–9]. A recent multinational European study found that parent-reported health-related quality of life was particularly impaired by extremely preterm birth [10]. However, in a study that used both parental and self-reports, 8-year-old children who had been born preterm rated their QoL as better than their parents [11]. In a study by Huhtala et al., the self-reported health-related quality of life of very low birth weight children was very good, and similar to the control children [12]. When looking at adolescents, some studies report the QoL of preterm-born adolescents as satisfactory [13,14], while Wolke et al. found that adolescents born very preterm had worse QoL than full-term adolescents [15]. Uusitalo et al. found that 11-year-old preterm-born children with a developmental coordination disorder reported lower health-related quality of life than children born very preterm without motor impairment [16].

While the quantitative QoL studies on preterm-born children and adults have provided valuable insight into the impact of medical

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diagnoses and the ability to function, they still only provide a narrow window into the personal lives of the individuals [17]. To gain a richer perspective on the quality of life of an individual, it is important to take into account the person's subjective experience of the different dimensions of life and their connectedness to each other. There is very limited literature on the subjective experience of people born preterm, i. e., what the experience of being born premature means to the survivors [18–22]. D'Agata et al. [18] used a qualitative interview to gain knowledge about how adult preterm-born survivors perceived the effects of prematurity on their lives. In their analysis, the interview themes represented a continuum of experiences from positive to neutral to negative. Saroj Saigal's book "Premie Voices" [21] presented autobiographical narratives of former premature adults. These narratives were later thematically analyzed; the emerging themes ranged from living with disabilities and bullying to gratitude and experiencing support [17]. When studying children's subjective experiences, it is necessary to note their developmental stage and capacities.

The scarcity of literature on subjective experiences of prematurity is especially true for infants, children and adolescents born preterm. According to Saigal et al. [22], the majority of the literature on the outcomes of premature infants is based on the perspectives of health care professionals, which are often discordant with those of the individuals themselves. Duffy et al. [23], reviewing the lived experience of the critically ill infant, stated that the child is often seen only as an object of research, instead of an active participant. Therefore, it is important to explore the child's experience through a qualitative lens [23]. There are no studies, to our knowledge, that have qualitatively studied the subjective experiences of prematurity among school-aged children and adolescents born extremely preterm.

To understand the subjective experiences of children and adolescents, the theoretical foundation of the development of children's thinking should be taken into account. According to Fonagy et al. [24], children's ability to construct a cohesive narrative of their autobiographical memories begins approximately at the age of six. Thus, a sense of the continuity of life is constructed, partly as a result of the child's mentalization development, and this sense of continuity, in turn, further strengthens the mentalization ability [24]. As such, children are able to reflect on their own memories, experiences and emotions from a fairly young age. Childhood experiences also have a significant impact on the child's long-term psychological well-being and quality of life [25]. During adolescence, abstract thinking skills are developed, and the child is able to understand increasingly complicated connections. The development of abstract thinking is also the basis for the formation of one's own identity, which is thought to be an important developmental task during adolescence [26]. It is worth noting that delayed intellectual development has been connected to challenges in mentalization development [27].

In conclusion, the aim of this study was to examine the subjective experiences of children and adolescents born at 23–24 weeks of gestation on how being born extremely early had affected their life. This understanding provides important information for parents and health care professionals when they face decisions about the approach to neonatal care.

2. Methods

2.1. Study approach and participants

The study approach is a qualitative description design, which aims to describe a range of responses of a phenomenon, life event, or health and illness situation [28]. The study was carried out in Finland, a high-income country with public health care available at a low cost to all citizens and high-quality neonatal intensive care.

The participants in this study were 18 children (12 girls and 6 boys) that had been born at gestational weeks 23 ($n = 4$) and 24 ($n = 14$). The children were born between the years 2002 and 2009, and they were

7–15 years of age at the time of the interview. All children were born in Turku University Hospital and received active care in the neonatal intensive care unit. There were two sets of twins in the participating group, as well as two children that had lost a twin sibling at birth. Five children had learning disabilities and attended special education. The background information on the participating children is presented in Table 1.

Purposive sampling was used: all families with surviving children born at 22–24 gestational weeks in Turku University Hospital between 2001 and 2014 had been asked to participate in the study. The families were first contacted by a NICU nurse, and if the parents expressed their interest to participate, they received a call from the first author to provide more information on the study. The parents that decided to participate signed a written consent form. All children who had turned seven years at the time of the study ($n = 27$) were asked to participate in the interview. Age seven was used as the limit, as in Finland children start their school at the age of seven, and the interview included questions about school and academic achievement. In seven families, the parents decided not to participate, either because of a busy life situation or lack of interest. One family could not be reached. Of the remaining 19 families, one family had a child attending boarding school, who therefore was not able to be interviewed. All participating children ($n = 18$) were verbally informed about the study and signed a written consent form. The study was ethically approved by the Ethical Committee of the Finnish South-West Hospital District, in December 2016. The COREQ Checklist (The Consolidated Criteria for Reporting Qualitative Studies) was used as a reporting guideline [29]. No incentive was offered for participation.

The parents of the children were also interviewed, but their interview data is not included in the analysis of this study. Analyses of the parental interviews have been reported elsewhere [30,31].

2.2. Data collection

The method used was a qualitative, semi-structured interview that covered six different areas of quality of life – somatic health, functioning, learning and memory, emotional health, social relations, experience of prematurity and its effects (see additional file 1). The development of the interview guide was based on questionnaires used in children's QoL studies [7,30], and the development process is described in more detail in Väliäho et al. [30]. Questions about the possible challenges resulting from prematurity, as well as questions about being born prematurely and its perceived effect, were added to the interview guide by the research team, which included a neonatologist, a psychotherapist focused on early parent-child interaction, and an expert in qualitative research.

The interview started with warm-up questions about the child's age

Table 1
Background information of the participants.

Background characteristics	n (total = 18)
Age	
7–9 years	4
10–12 years	7
13–15 years	7
Sex	
Girl	12
Boy	6
Developmental challenges (reported by parents)	
Learning disability/special education	5
ADHD	4
Cerebral palsy	2
Epilepsy	1
Autism	1
Hearing deficit	1
Twin status	
Singleton	12
Twin	4
Lost a twin sibling at birth	2

Table 2
Examples of meaning units, codes, subcategories and a category.

Meaning unit	Code	Subcategory	Category/ group
"When I'm running, I get out of breath faster [than my peers]."	Problems with breathing	Identifying minor consequences related to prematurity	
"I'm not really able to reach my toes because I have such stiff legs."	Problems with mobility		
"Well it's been quite nice, I don't know ... [I've had] quite a good life."	General satisfaction with life	A positive outlook on life despite challenges	Ponderers
"I don't think it [prematurity] has [affected my life] terribly much."	Experiencing the effects of prematurity as not significant		
"I still [at age 13] haven't learned to swim... I'm a little bit afraid of water."	Nervousness about learning new motor skills	"Un-athleticism"	
"I dislike a lot of things related to sports and exercise, so I haven't practiced them either"	Dislike of sports and exercise		

and school, followed by an open question asking the child to describe his or her life experiences: "What kinds of things would you like to tell me about your life, if you think about it from the very beginning until this moment?". After this question, the topics were introduced one by one. If the children mentioned challenges in some area, they were asked more specific questions about the nature of those challenges and their impact in their lives. In the sixth topic (the experience of prematurity and its effects), the children were asked to openly describe the stories their parents had told them about their birth and NICU experience, and to describe how they felt being born very preterm had affected their lives and their relationship with parents. The interview guide was piloted with two children, then aged 7 and 10, and minor changes were made to the guide after piloting by modifying questions that had been difficult for the children to understand in the pilot interviews.

The length of the interview for each child varied between 20 and 45 min. The interviews took place either at the child's home or at a research facility provided by the university. The locations were chosen by each family, and if they chose to be interviewed at their home, it was ensured that the space would be as calm and quiet as possible. The interviewer (first author) introduced herself and made initial contact with both the children and the parents present, to provide a safe and comfortable setting for the children. During the interview, only the child and the interviewer were present. Twins were interviewed separately. To ensure that no interview data would be lost due to possible technical problems, the interviews were both videotaped and audiotaped. Later, the interview data was transcribed verbatim in its entirety (including the researcher's questions, comments, and affirming sounds). The interview data was collected during spring and summer 2017 and transcribed during the following months.

2.3. Data analysis and positioning of authors

The entire interview with each child was scrutinized for relevant content on the effects of prematurity. Thematic analysis was used as a

qualitative analysis method to identify, analyse and report themes within the data [32–34]. A step-by-step guide for thematic analysis by Braun & Clarke [32] recognizes six different phases of analysis: 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report. In our analysis, the interview transcripts were first read and re-read several times to obtain a holistic understanding of the children's stories and the overall patterns in the data. Next, the entire interview data was systematically coded, first by identifying meaning units in the text — in this context, meaning units are defined as words, sentences or paragraphs containing aspects related to each other through their content and context [35]. These meaning units were then labelled with codes and initial subcategories were produced. Finally, three main categories were formed on this basis. The first author generated the initial codes, sub-categories and main categories. The analysis process was supervised by the third author, who is an expert in qualitative research. All authors discussed the initial categorization together for critical comparison and validation, and it was then refined accordingly by the first author. The coding process is exemplified in Table 2. The defining and naming of the final categories, as well as choosing the best suited quotes to credibly represent the interview data, were done collectively through mutual critical discussion.

Braun & Clarke [33,34] define three different approaches of thematic analysis and emphasize that the researchers need to be clear with the approach they are using. In this study, we chose reflexive thematic analysis, which stresses the researcher's active role in knowledge production and does not necessarily encourage the use of multiple coders, as it is not expected that two coders should reach the same conclusions [33,34].

The authors held the assumption that the extremely premature birth, followed by possible long-term consequences, had affected the children's lives. This assumption was reflected in the interview, as it included questions about areas where pre-term born children may typically encounter challenges, such as breathing and gross motor skills. However, the authors remained open to the participating children's experiences and reflections. As for the authors' positioning and its impact on the data [36], the first author, who also conducted the interviews, has a long experience as a clinical psychologist which is assumed to have been a benefit in creating a good contact with the interviewees and safeguarding their emotional and mental well-being related to the interview. In later reflection, however, she felt that she had a tendency to follow the interview guide too closely, possibly missing some probing questions that could have deepened the understanding. This tendency could have been due to her background in quantitative research methodology.

3. Results

3.1. Prematurity as a part of the family story

Most children reported that their parents had told them about their premature birth and early life. The children reported, either spontaneously or when asked by the researcher, that these memories had been shared e.g., when looking at the photographs from the NICU period or when visiting the NICU to meet the staff that had cared for the child.

While the children mostly did not report that their premature birth had affected the parent-child relationship, they did recognize examples on how the preterm birth and the NICU stay had become a part of their family's mutually shared story. The children had heard descriptions of the challenges that had arisen during the neonatal period, such as the pain they had had to endure, or about specific physical complications, such as cerebral hemorrhage. Other examples of topics included the length of the NICU stay, which had often been several months, or the fact that the NICU care had been very technical. Many children reflected on the extremely small size they had been as preemies, comparing it to things such as a carton of milk or a barbie doll, or they emphasized how much they had grown since then. When discussing the photographs that

the children had seen of themselves in the NICU, they would often describe looking at those as funny or strange.

"I was really tiny... and I was poked with many needles."

Boy, 11

"It's fun to look at those photographs, my hand used to fit in the palm of my dad's hand, but it doesn't fit there anymore."

Girl, 9

"Well, my mom said that I weighed like 600 grams and that my eyes were closed and that I was like in some kind of a box."

Girl, 14

Prematurity as a part of the family story also appeared in situations in which the child had lost a twin sibling in the premature birth. One of the children who had lost her twin during birth told her story as the surviving twin and how she felt their lives were intertwined.

"She [her twin who had died during birth] transferred her life to me... so actually it would have been me who died, but then she transferred her life to me."

Girl, 8

Another child with a similar background talked about the X-ray images that had been taken during the time her mother had been pregnant with her and her twin sister. These stories clearly signaled that the memory of the deceased twin sibling still lived on in the family story, first told by parents and later by the children themselves.

3.2. Categorization of the children's narratives about the effects of prematurity

When analyzing the stories of the children about the effects of prematurity on their personal lives, the narratives were classified into three categories. The categories have been named 1) the go-with-the-flow, 2) the ponderers, and 3) the hesitants.

3.2.1. The go-with-the-flow children (n = 7)

These children typically responded that they did not feel that being born prematurely had affected their life in any way, or that the effect had been minimal. When probed, they could not state particular examples of ways it had affected them. The go-with-the-flow children often felt that everything in their lives had gone "pretty well", and they often reported being content with their lives.

"Well, it [being born prematurely] hasn't affected me terribly much. I think it actually hasn't affected me at all. Everything's gone well."

Girl, 9

Most of the go-with-the-flow children had extra-curricular activities, often sports such as soccer, ice hockey, parkour, or cheerleading. They did not describe experiencing physical challenges, such as problems in gross motor skills, in a way that would affect athletic hobbies. Rather, they reported enjoying their hobbies. Besides sports, their activities included music, scouting, or theater. A few children mentioned that at school, they felt they needed to work harder than their peers in order to keep up with learning, often in one or two specific subjects. For this reason, some of them disliked school or at least these subjects, as they felt it required more effort. Still, when asked further, the children did not report experiencing actual learning difficulties, and one boy reported performing really well academically.

3.2.2. The ponderers (n = 5)

These children identified some consequences of having been born prematurely. The consequences they mentioned were small or moderate health challenges, such as having a strong prescription for eyeglasses and vision problems, childhood asthma and ongoing breathing problems, or gross motor challenges that had affected their choice of hobbies.

Two children mentioned health issues that were the result of neonatal care: loss of hearing and a defect in the nose (nasal septum erosion) that had required several operations.

"The only thing I can think of is that I might be able to live without glasses [if it wasn't for prematurity]. ... That I might not need my glasses so much."

Girl, 15, who had a strong prescription and had to sit at the front of the classroom to be able to see properly.

"One thing is the stiffness of my legs. I'm not really able to reach my toes because I have such tense legs. [Later, talking about hobbies:] I used to dance. But I wanted to quit dancing because everyone was so much better than me... because of the [lack of] flexibility."

Girl, 13

In spite of describing the challenges they had noticed, the ponderers also emphasized that they saw them as minor things and that overall, they did not feel that prematurity had played a big role in their lives. They described their overall health, functioning and learning ability quite positively. It is worth noting that the pondering children were all 12 years or older.

"Perhaps the fact that my breathing is like... when I'm running, I get out of breath faster. Or when I'm climbing the stairs, like at school or somewhere. [...] Otherwise, there's really nothing special. All other things are quite similar [to everyone else]."

Boy, 12, who had needed medication for asthma until the age of eleven.

An interesting feature about these children was that they tended to describe themselves as "not very athletic", or "not liking sports", and this was also evident in the fact that all except one had no sports as hobbies and even disliked physical education at school. In terms of this feature, this group differed from the go-with-the-flow children.

3.2.3. The hesitants (n = 6)

The children in this group mostly answered "I don't know" or "I'm not sure", when asked about the effect that prematurity had had in their lives. In the hesitant group, all except one of the children had cognitive development issues and attended special education. This group also included two children with cerebral palsy, one with autism spectrum disorder, and one with epilepsy.

Some of the hesitant children had described challenges in the areas of health or functioning, such as asthma, gross motor challenges, or mobility issues caused by cerebral palsy – all of which are possible consequences of premature birth.

"Because of my cerebral palsy, my left arm hurts almost all of the time."

Girl, 8

"My little sister is a faster runner than I am... for me, it's quite slow because of my legs are so rigid. My legs are like ... if I try to stand and catch my toes, I can't reach them. Because I'm tense."

Boy, 11

However, when asked directly about the effects of prematurity, the hesitant children could not connect prematurity and the challenges they had described. Instead, they were more likely to answer either that they were not affected by prematurity at all, or that they did not know about the effects. One child mentioned being annoyed about the MRI study that had been part of the follow-up of being born preterm, and another brought up that as a newborn, she had suffered a cerebral hemorrhage. However, none of the hesitant children connected any problems affecting their current everyday life with prematurity. Also, even though all but one of the hesitant children attended special education, they did not describe any challenges relating to learning or academics. It is also worth noting that the child with epilepsy and the child with autism spectrum disorder did not mention their challenges. The hobbies that the hesitant children mentioned were athletics, music, and boy scouts, but

there was little reflection on the joys or the challenges resulting from the activities. While in the two other groups there was a clear tendency to either feel “unathletic” (the ponderers) or to enjoy an athletic free-time activity (the go-with-the-flow), there was more variation regarding athletics in the hesitant group.

Two of the hesitant children gave very short answers throughout the interview, often shrugging or responding they did not know what to say. This tendency persisted even when they were prompted and encouraged. Even when asked to elaborate and offered support through further or more detailed questions, these children still maintained elusive and short answers, signaling a possible lack of motivation or inability to concentrate.

4. Discussion

In this qualitative study, we analyzed the interviews of school-aged children ($n = 18$) born prematurely at 23–24 weeks of gestation in order to understand the children's own experiences on prematurity and its effects on their life. Our interviews showed that prematurity and the NICU period had clearly been discussed between the parents and children and had become a part of the family's mutually shared story. In the classification of the children's narratives, we divided the children into three categories: the go-with-the-flow, the ponderers, and the hesitants.

The *go-with-the-flow children* reported little or no effect of prematurity and overall good functioning in different areas of their lives such as health, school, and hobbies. Their descriptions of their situation as a whole seemed, from the perspective of the interviewer, to be consistent with minimal effects of prematurity on their lives. They did not bring up challenges that would make athletic hobbies or academic activities difficult. These children painted a picture of being content with their lives and their capacity to function. However, it is possible that the children may have wanted to highlight the positive sides of their lives because it seemed, from their perspective, to be expected in the situation.

The *ponderers* reported some effects of being born premature, many of which were small physical challenges. They also emphasized the fact that the challenges they had faced had no major impact on their lives, as they experienced good health and functional capacity. The children categorized as ponderers were among the oldest participants – 12–13 years and beyond – so their age might explain their more abstract and reflective thinking and their ability to connect prematurity with their health challenges. However, the two other categories also included older children. Compared to adult interviewees in other studies [17–22], even the ponderers provided shorter and less elaborate stories, and their reflections about prematurity and identity were not as holistic and rich as those of the adult interviewees. Another noteworthy tendency of the ponderers was that they described themselves as unathletic, which made them different from the go-with-the-flow children. It is possible that even minor physical challenges play a big role in the quality of life of a teenager, as it is known that regular physical activity is associated with higher perceived health-related quality of life in adolescents [37]. Another study also found that at 11 years of age, children born very preterm with a developmental coordination disorder reported worse health-related quality of life than children born very preterm without motor impairment [16]. As such, challenges in motor skills or other experiences of being unathletic might be an important reason for a child to feel that being born prematurely had affected his/her life.

The *hesitants* either gave very short answers throughout the interview or described their challenges without connecting them with prematurity. The hesitant children had both mild and more significant cognitive delays, as well as other issues, such as autism spectrum disorder and cerebral palsy. Therefore, they could have been expected to be the “most affected” by prematurity, for example in terms of school performance. However, the children's narratives did not reflect them being affected by prematurity, as they did not consider their challenges (for instance motor challenges like cerebral palsy) to be a consequence

of premature birth. As delayed intellectual development has been connected with challenges in mentalization development [27] and problems in more abstract thinking processes, cognitive deficits might explain why the hesitant children had difficulty connecting their challenges with being born prematurely, or even understanding the interview questions. Some hesitant children showed physical restlessness or talked about other things instead of answering the questions during the interview, which raised a question about lack of motivation and/or concentration difficulties. Of course, the children may experience their situation and possible challenges differently than an adult researcher would hypothesize. Noteworthy, in QoL studies that have compared a parent's rating of their premature child's QoL to the child's own assessment, the findings have indicated that the parents rate their children's QoL as poorer than the children themselves [11].

In all categories, it was clear that the parents' memories of the child's prematurity and NICU life had been discussed between the parents and children. The children described NICU experiences that their parents had told them: for example, the small size of the child as a preemie, the challenges they had encountered, the technicality of the NICU care, and the length of the NICU stay. In a study by D'Agata et al [18], the adult premature-born interviewees had also heard stories about themselves as tiny infants amid wires, tubes, and alarms in the NICU. The children's accounts in our study highlighted the important role that the NICU experience had taken in the family story. A similar theme was noted in the analysis of the parental interviews [30,31], as many of the parents felt their family had become emotionally close as a result of the challenging NICU period. Similarly, in the account of Janvier et al. [38], parents reported that one long-lasting result of the NICU experience with a critically ill neonate was a more profound understanding of the importance of family and connectedness. There is even some evidence that the influence of parenting and the home environment is stronger in those born preterm than those born full-term [39].

Another experience that emerged as significant in our study was the loss of a twin sibling at the premature birth, which two children spontaneously brought up during the interview. A qualitative study by Richards et al. [40] found that for many mothers who had lost one child in a multiple pregnancy, the experience of watching the surviving sibling grow up actually exacerbated their grief as milestones were reached. Pector and Smith-Levitin [41] stress that after the grief of losing one twin, parents must strive not to either reject or over-protect the surviving twin. However, no studies that we are aware of have explored the perspective of the remaining pre-term born sibling after losing a twin at birth. As the surviving twin faces the reality of growing up in a family in which memories of the lost sibling may be strong and present, the experience of the survivor is an important and relevant future study question.

In analyzing the children's reflections, it is important to consider the possibility that some children may not be comfortable discussing their premature birth with a stranger and that could be a difficult subject in general. The results also raise a concern, as some children in the hesitant group had difficulties in integrating the effects of prematurity into their self-image and identity, even though the NICU experience was included in the family story. During adolescence, the difficulties in mentalizing crucial past experiences may represent a risk to psychological well-being. Parental support may be important here: parents can be encouraged to openly discuss the topic with their children and consider how prematurity has influenced the child's everyday life and how they can cope with possible challenges together. Even healthcare professionals in neonatal follow-up care could have a facilitating role in encouraging the children to reflect on their experience of prematurity and its influences.

Neonatal care is under continuous development. During this study period, advances have led to better survival of infants born at 23 and 24 weeks of gestation and, therefore, there is more need for the knowledge from this study. However, neonatal morbidities have not consistently decreased, and most studies have not shown significant changes in long-

term outcomes. In very preterm infants born in Finland, the occurrence of none of the individual neonatal morbidities decreased when comparing 2007–2011 with 2012–2015, but there was a marginal decline in composite outcome when all other morbidities were combined, excluding bronchopulmonary dysplasia [42]. An Australian study compared survival and long-term outcomes in extremely low birth-weight infants (birthweight <1000 g) over four decades. They showed a clear improvement in survival but no improvements in the neurodevelopmental outcomes of the survivors at two years of age [43]. Therefore, we believe our results are still relevant today, even if the recruitment period was long.

4.1. Strengths and limitations

The most important strength of our study was that we were able to provide valuable information on the subjective experiences of school-aged children born extremely premature. Our participants, the children born at 23 and 24 weeks of gestation, are of special interest due to the high risk of challenges in their long-term development. Additionally, the interviewer (first author), as an experienced clinical psychologist, was able to create a good contact and a confidential atmosphere with the children, taking into account their psychological safety.

Our study is not without limitations. While we gained important knowledge about the children's experiences, it is also worth noting that the children's answers were quite short and the reflections were often scarce. Short answers were especially common in the hesitant group, which included the most children with both cognitive and other, health-related challenges. In retrospect, it would have been advisable to pilot the interview guide with children who have cognitive challenges in order to ensure its applicability. In future studies, modifying the interview guide in order to make it more approachable to the children with cognitive challenges, or applying complimentary methods to gain more elaborate and rich narratives should be considered. For example, arts- or activities-based techniques have been experimented with in children's health research in order to provide a more participatory and child-centered approach [44]. Furthermore, a lack of motivation might also have influenced some children's willingness to elaborate on their stories. Even though the children had given their consent to participate in the study in advance, it is possible that some children had consented due to being prompted by their parents, and may have been lacking in motivation themselves. Coming up with ways of further motivating and encouraging the children is an important aspect to consider in future studies.

One factor worth critical evaluation is the rigor of our qualitative analysis. In our study, there was only one independent coder, even though the categorizations were discussed together by all authors for critical comparison and validation. In some approaches of thematic analysis, the use of multiple coders is favored as a way to enhance dependability and confirmability of the results. However, the approach used in our study was reflexive thematic analysis [33,34], which highlights the researcher's active role in knowledge production, stressing that it should not be an expectation that codes or themes interpreted by one researcher can be reproduced by another. Therefore, this approach does not encourage the use of multiple coders.

One final limitation is the small number of participants ($n = 18$) and the variation caused by the wide age range (7–15 years). However, as explained above, the children born at 23 and 24 weeks of gestation are a special group of premature children due to the high risk of long-term consequences. As there are few survivors born on these gestational weeks, it was necessary to include a wider age perspective.

5. Conclusion

In this study looking at the subjective experiences of school-aged children born at 23 to 24 weeks of gestation, the children exhibited different perspectives in terms of how they had experienced the effects

of their extremely premature birth: from reporting no effects at all to identifying some small or moderate, mostly physical health-related challenges. In addition, one group of children either did not connect their challenges to prematurity or reflected very little overall. Our study highlights the need to include preterm survivors' own perspectives, even the voices of children and adolescents, into the field of prematurity research.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.earlhumdev.2024.106048>.

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Institutional Review Board statement

This study was conducted in accordance with the Declaration of Helsinki, and approved by the Ethical Committee of the Finnish South-West Hospital District (protocol code ETMK/118/1802/2016), in 20 December 2016. All methods were carried out in accordance with relevant guidelines and regulations.

Informed consent statement

All participants signed an informed written consent form for participation at the point of recruitment.

CRediT authorship contribution statement

Annina Väliaho: Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Liisa Lehtonen:** Writing – review & editing, Supervision, Conceptualization. **Anna Axelin:** Writing – review & editing, Supervision, Formal analysis, Conceptualization. **Riikka Korja:** Writing – review & editing, Supervision, Conceptualization.

Declaration of competing interest

None.

Data availability

The data are not publicly available due to individual privacy and the sensitive nature of the interviews.

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