Duchesne, L., Gingras, M.-P. et Gagnon, M. (2025). Communicative participation of school-aged children with cochlear implants: parental perceptions. The Journal of Deaf Studies and Deaf Education (p. enaf021).
doi: https://doi.org/10.1093/jdsade/enaf021. CC BY-NC-ND 4.0

OXFORD

Journal of Deaf Studies and Deaf Education, 2025, 1–13
https://doi.org/10.1093/jdsade/enaf021
Empirical Manuscript

Communicative participation of school-aged children with cochlear implants: parental perceptions

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Abstract

This qualitative study aimed to explore parents' perceptions regarding the communication of their school-aged child with cochlear implants (CIs) in various social contexts. To this end, the construct of "communicative participation" (World Health Organization (2001), International Classification of Functioning, Disability, and Health, https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health) was broadly applied to the population of children with CIs. Nineteen parents participated in semi-structured interviews and described their perceptions and experiences regarding the communication of their child in social contexts. Data were analyzed using a thematic analysis approach. The results showed that overall, despite describing very positive outcomes with CIs, parents reported that their children do experience participation restrictions and activity limitations because of communication difficulties and/or environmental and social barriers. The findings from this study unveiled the communication difficulties of school-aged children with CIs, as experienced by their parents. These difficulties—which may seem subtle—can significantly impact the participation in communication. Language interventions could be improved to better support pupils who are experienced CI users.

Keywords: cochlear implants, language, communication, parents, qualitative methods

Cochlear implants (CIs) have become a widespread practice and a central element in the management of severe to profound hearing loss[1] in children. Children who receive CIs derive numerous benefits such as perception of speech sounds and acquisition of spoken language (Nicholas & Geers, 2013; Sharma et al., 2020). During the last decade, research went beyond speech perception and spoken language benefits and started to focus on the broader impacts of pediatric cochlear implantation such as quality of life (QoL) and social-emotional functioning (Kumar et al., 2015; Michael et al., 2019; Wiefferink et al., 2012). Several studies on school-aged deaf and hard-of-hearing (DHH) children (with and without CIs) showed that they are likely to experience communication barriers that impair their social relationships (Brice & Strauss, 2016; Dammeyer, 2010; Punch & Hyde, 2011) and, consequently, lead to participation restrictions and activity limitations, as defined by the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). In the context of communication, participation refers to the daily life situations and activities that one chooses that involve communication (WHO, 2001). The ICF framework has been proven useful for speech–language pathologists (SLPs) and audiologists, as it recognizes communication as a crucial part of social participation and offers a broad, integrated view of a person's functioning in natural settings (Dempsey & Skarakis-Doyle, 2010; Threats, 2008).

The term "communicative participation" (CP) has been defined as "communication in life situations where knowledge, information, ideas or feelings are exchanged" (Eadie et al., 2006, p. 309). So far, this construct has mostly been applied to adults with neurogenic communication disorders (e.g., Yorkston et al., 2007), but also to communication development in young children (Thomas-Stonell et al., 2013). Recently, in a study reporting on a multidisciplinary consensus on a definition of CP in children with language disorders, the following definition was put forward: "CP is understanding and being understood in a social context, by applying verbal and non-verbal communication skills" (Singer et al., 2020, p. 1793).

In the present study, the construct of CP was broadly applied to school-aged children who are experienced users of CIs. Several speech and language skills matching the construct of CP—as defined in Singer et al. (2020)—have been examined in studies with school-aged children with CIs and include narrative skills (e.g., Boons et al., 2013; Crosson & Geers, 2001) and a range of pragmatic abilities for which children with CIs tend to perform more poorly compared to their hearing counterparts, for example, the use of requests for clarification, the consideration of communication partners, and non-verbal communication skills (see Socher et al., 2019, for a review).

Benefits of cochlear implantation in children

Research has repeatedly demonstrated that cochlear implantation in young children—by providing access to auditory

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Received: June 19, 2024. **Revised:** March 7, 2025. **Accepted:** March 31, 2025

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input—has considerable benefits on speech recognition skills (Culbertson et al., 2022; Geal-Dor et al., 2013; Schramm et al., 2010; Sharma et al., 2020) and spoken language, especially vocabulary and grammar (Dunn et al., 2014; Nittrouer et al., 2016; Szagun & Stumper, 2012). Despite large inter-individual variability (Duchesne & Marschark, 2019), research results are consistently supportive of the speech and language benefits of cochlear implantation in children (Stacey et al., 2006).

Numerous additional benefits of cochlear implantation have also been documented, other than speech and language. A few studies have shown that the use of CIs by children and adolescents improves self-esteem (e.g., Percy-Smith et al., 2008) and QoL (e.g., Archbold et al., 2008; Loy et al., 2010). However, other studies have reported psychosocial difficulties and poorer QoL in children and adolescents with CIs. Some of these studies have shown that psychosocial difficulties might in fact be related to language skills. For example, Dammeyer (2010) found that low language abilities (oral or in sign language) were significantly associated with psychosocial difficulties in a study involving 334 DHH Danish students aged between 6 and 19 years. In addition, Haukedal et al. (2018) reported significantly poorer QoL in 106 children with CIs, compared with a group of hearing children. In the CI group, higher QoL was associated with better speech perception in everyday situations. Better expressive (spoken) language skills were also associated with higher QoL. These research results emphasize the importance of communication in social situations for the psychosocial development and QoL of children who are DHH.

Consequently, in the appreciation of the general communication benefits of cochlear implantation, it is important to "distinguish between hearing ability, the ability to pick up and utter words and sentences, and the ability to use language to successfully interact with others" (Kermit, 2010, p.1). Research so far has mainly focused on the first two elements. Whereas some studies examined conversational and pragmatic skills in CI recipients (e.g., Crowe & Dammeyer, 2021; Guerzoni et al., 2016; Mancini et al., 2015; Nicastri et al., 2014; Parola et al., 2023; Toe & Paatsch, 2013), there is a need for a better understanding of communication outcomes in school-aged CI users in the broader perspective of the use of communication in daily life. Formal language assessment measures do not necessarily reflect the whole communicative portrait of school-aged children with CIs. Furthermore, the use of contrived tasks to evaluate communication skills does not reflect real-life situations. Potential for restrictions of CP might be masked by the usual objective measures of success with CIs (e.g., speech perception scores) and the sole assessment of core language abilities such as vocabulary and grammar. Both clinicians and researchers could benefit from data that will help to understand how children with CIs communicate in actual social contexts to better capture the benefits—and limitations—of CIs (Punch & Hyde, 2011; Tuohimaa et al., 2022). A deeper understanding of communication in everyday life will inform best practices to support children with CIs by providing opportunities for improving service delivery to school-aged CI users and setting intervention goals that are better connected with various social contexts.

The assessment of CP

When the ICF framework is used to work with CI users and their families, it is to assess communication in social contexts, which is closely related to the construct of CP (Eadie et al., 2006; Singer et al., 2020). Moreover, there is a value in using the ICF framework with children as it "enables the SLP to focus on what should be the ultimate goal of intervention: improvement of the child's ability to communicate in natural settings" (Westby, 2007, p.271).

Eadie et al. (2006) have identified several instruments designed to assess CP and developed a series of studies resulting in the creation of the Communicative Participation Item-Bank (CPIB). The CPIB includes everyday life situations in which the individual must indicate the extent to which their condition interferes (from *not at all* to *very much*) with their participation in various situations (e.g., *Does your condition interfere with asking questions in a conversation?*). The CPIB does not include open-ended questions that would require the individual to elaborate on their experience. The purpose of this tool—designed for adults who present various communication disorders (Baylor et al., 2013)—is to "measure the extent to which communication disorders interfere with participation in a wide range of daily conversational situations" (Miller et al., 2017, p. 28). The relevance of the CPIB for adults with a hearing loss has been explored in Miller et al. (2017). In this study, cognitive interviews were conducted with adults with hearing loss to gather their feedback on the CPIB items, while a focus group with audiologists provided insights on the instrument from their professional point of view. The results showed that most of the items were viewed as relevant to adults with hearing loss and would not require revision, while those referring to speech production were perceived as placing more emphasis on articulation than on hearing or understanding (Miller et al., 2017).

For children with speech and language impairments, a specific tool, the FOCUS©, can be used by both parents and clinicians (Thomas-Stonell et al., 2013). The development of the 50 items included in the FOCUS© was based on both the ICF framework and parents' observations. The items were selected with the aim of measuring the changes caused by clinical interventions with preschool children in the following areas: speech, language, play, socialization, confidence, and behavior. Each item is rated on two scales. The first scale ranges from "Not at all like my child" to "Exactly like my child", while the second scale ranges from "Cannot do at all" to "Can always do without help". Each item is rated on a 7-point scale, producing a total score range of 50 to 350 points. Despite its numerous strengths, the FOCUS© is designed for children under the age of 6. In addition, both these tools are not designed for children who are DHH.

In sum, we currently have little, if no way to deepen our understanding of CP in school-aged children who are experienced CI users. Yet, it is an essential component of our appreciation of the broader impacts and multiple facets of cochlear implantation, and an important issue to address. One possible solution to this problem is to use a qualitative research design and to gather parental perceptions of CP of children with CIs. Qualitative research allows for a rich description and can provide an in-depth understanding of parental perspectives and perceptions (Creswell, 2007).

The richness of parental experience

Parents play a crucial role in the development of their child with a CI. Their involvement throughout the implantation process and during the habilitation/rehabilitation period is essential to the success of the child with the CI (Bruin, 2018; Cejas et al., 2021; Holt et al., 2012). The everyday challenges associated with the parenting of a child with a CI render their experience unique. For example, Zaidman-Zait (2008) interviewed 31 parents of children with a CI to explore their experiences and perceptions. The authors concluded that parents can provide valuable insights into their child's daily life, whereas clinical evaluations may not

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capture all the child's challenges. Parents identified not only the technical difficulties associated with the implant but also aspects related to their child's difficulty in making friends, communication challenges at home, and the need for advocacy. In another study, Vieira et al. (2018) conducted interviews with 32 individuals from nine families (children with CIs and their parents and siblings). The interviews provided information on several aspects including family involvement in therapy, obstacles faced in daily routines, and social challenges experienced by the children. This study also showed the evolution of parents' perspectives on their child's hearing status and their acknowledgment of the benefits of cochlear implantation. In sum, these studies demonstrate that parents' observations offer critical information that might otherwise be overlooked in clinical or educational settings. Moreover, the parental point of view has gained more importance in research (Kecman, 2022) as it offers a valuable contribution to the appreciation of the impacts of CIs on everyday communication (Tuohimaa et al., 2022). The perception of parents is thus of significant interest as their perspective can be used to gather information on participation in communication and, consequently, to support clinicians in the design of relevant intervention goals targeting communication and participation for students with CIs.

Aim of the present study

The main purpose of this qualitative study was to explore the perception of parents regarding the communication of their school-aged child with a CI in three social contexts: at home, at school, and in the community. These three contexts allowed the exploration of a range of situations in which participative communication takes place (Miller et al., 2017). In this study, parents were given time and space to talk about their perceptions and experiences. Such a goal is difficult to achieve with a questionnaire. The main research question was: According to their parents, to what extent are children with CIs able to communicate effectively and to fully participate in social contexts of everyday life?

Methods

Participants

Eligibility criteria

Ethics boards at the [name removed for blind peer-review] approved the study (#CRIR-1017-1,114). Participants were recruited from the [blinded for peer-review] CI center database. To be eligible, participants had to be the parent of a child aged from 6 to 13 years old who was an experienced CI user (i.e., had used a CI for at least 5 years) and who currently attended primary school. Children who had additional cognitive or sensory impairments that were significantly affecting their functioning were excluded from the recruitment process. Finally, families had to use French language and/or [blinded for peer-review] Sign Language [*Langue des signes [blinded for peer-review]*] for everyday family interactions. To verify eligibility, a file check was carried out by the audiologists who were collaborators in the project. All parents signed a form ensuring their informed consent.

Recruitment process

A purposive sampling method was used. It is a non-randomized technique that does not require a specific number of participants. It typically involves the selection of individuals who possess knowledge and experience regarding a certain phenomenon and who are willing and available to participate (Etikan et al., 2016). However, it was important to recruit enough participants to appreciate the diversity of experiences in terms of family composition (e.g., number of children, hearing and/or deaf siblings), schooling environment (mainstreaming/regular school or school for children who are DHH), communication mode (i.e., speech and/or sign language), and hearing status of the responding parent (hearing or DHH). According to the CI center database, children from approximately 95 families across the province of [removed for blind peer-review] met the age and duration of implant use criteria. We estimated that a heterogeneous sample of 20 to 24 parents should allow us to achieve maximum variation to reflect the various experiences while highlighting common patterns (Creswell, 2007), thus increasing the trustworthiness of the data and the transferability of results. (Graneheim et al., 2017).

When eligible families visited the CI center for their annual device programming appointment, their audiologist gave the parents information about the research project. A total of 23 families were offered the opportunity to participate over a period of approximately 9 months, 19 accepted, and 4 declined, due to time constraints. This sample size was considered sufficient to generate data that would provide a richness of description and variation in content, thus allowing us to achieve the goal of the study.

Data collection

Interview guide

The first author (a hearing female researcher with a PhD who had worked for 10 years with children with CIs and their families as a SLP) developed the interview guide (see Appendix 1). She was careful to include a variety of situations to capture parents' perceptions from a broader perspective of their child's use of communication in everyday life (home, at school, and in activities within the community). The questions were essentially developed following an ecological perspective. The child's immediate living environments—family, school, and peer group—are the site of many activities that influence the child's development (Jutras et al., 2005). It is precisely in these environments that social interaction and communication play a predominant role. In accordance with an ecological approach, the domains of family, school, and community have been considered to examine the point of view of parents regarding communication within these contexts.

The basic question for each context (either home, school, or community) was open-ended, allowing parents to share what they felt was most relevant: "How would you describe the communication of [name of the child] at [context]?" For each context, follow-up questions were part of the interview guide and concerned access to information, the need for adaptations, and the identification of barriers and facilitators to communication. We also asked parents to comment on their general perception of the communication and participation of their child with a CI. The interview guide was pilot tested by an SLP graduate student with three families, and some minor adjustments were made.

Interviews

After minor adjustments to the interview guide, all subsequent interviews were conducted by a trained research assistant, a hearing SLP with 1 year of experience working with children with CIs and their families. She had no professional relationship, past or present, with any of the participants. All interviews were conducted in French. Interviews were approximately 1 hour long and were audio- and videotaped for later transcription. Interviews took place in a convenient location, either at the CI center or at home. Nobody else was present besides the participants and interviewer. After each interview, the research assistant took general

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field notes. All interviews were conducted prior to the COVID-19 pandemic.

Data analysis

The analysis followed the six steps of thematic analysis described by Braun and Clarke (2022): (1) familiarization with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. All interviews were transcribed verbatim, generating approximately 450 pages of text. In the "familiarization with the data" stage, two team members independently familiarized themselves with the data. The first coder, also the interviewer, and the second coder, an experienced SLP and doctoral student, carefully read and re-read all interview transcripts. The coders took notes to identify meaningful elements and gain an in-depth understanding of the participants' perceptions.

In the next step, "generating initial codes", both coders independently developed coding trees (thematic structure) by attaching codes to extracts they identified as relevant to the research question. The terms used for codes were chosen by each coder and reflected the topics raised by participants. These codes were not predefined but were guided by the construct of CP and interpreted through the lens of the ICF framework. In subsequent coding phases, additional codes were developed to capture deeper meanings within the data while aligning with the construct of CP. Conducting multiple coding phases is recommended to refine the codes and enhance analytical rigor (Braun & Clarke, 2022).

During the "searching for themes and reviewing themes" stage, themes were added, merged, or reorganized to reflect the researchers' evolving understanding of the data. At this point, a third coder—who was also the first author—began the analysis. Having familiarized herself with the results of the other two coders, she independently followed all the steps of thematic analysis, from familiarization to theme refinement. Once she had completed her own thematic analysis, the third coder compared her identified themes with those developed by the second coder. Through collaborative discussion, the second and third coders critically examined their respective themes. This exchange allowed for a deeper analysis, ensuring that the themes were robust and accurately reflected the data's complexity.

In the "defining and naming themes" stage, the second and third coders identified and agreed on two main themes: one related to personal factors and another to environmental factors that restrained CP. A third theme—concerning strategies to enhance CP—emerged from these discussions. These steps align with Braun and Clarke's recommendation to refine and define themes in ways that capture the nuances of the data and stay aligned with the conceptual framework. The second and third coders also discussed and decided on the subthemes. The collaborative nature of the analysis process, particularly the discussions between the second and third coders, was pivotal in ensuring the richness and trustworthiness of the themes. These discussions were essential for refining the themes and ensuring that they were reflective of the data and grounded in the conceptual framework guiding the research.

The original interview extracts were in French as all parents were French speakers. We first translated them using DeepL Translator (DeepL, 2024), which is recognized for its high accuracy and for its good ability to translate from French to English (Linlin, 2024; Yulianto & Supriatnaningsih, 2021). Then, the first author [a bilingual SLP] revised the AI-generated translation and made small revisions (e.g., choice of preposition and verb tense), with the resulting text being revised by all the authors. Sometimes, original French passages are also presented to provide context.

Table 1. Social and demographic characteristics of the parents (n = 19)

Social and demographic information	Number of participants (% of sample)
Hearing status	
Hearing	16 (84%)
Deaf and hard of hearing	3 (16%)
Degree completed	
High school	3 (16%)
Pre-bachelor or technical degree	7 (37%)
Bachelor's degree	6 (31%)
Graduate studies (Master or PhD)	3 (16%)
Main activity	
At work	16 (84%)
Stay-at-home parent	3 (16%)
Type of family	
Two parents	15 (79%)
Other structure	4 (21%)
Number of children in the family (including the child with a CI (n = 20)	
1	3 (15%)
2	8 (40%)
3	4 (20%)
4	5 (25%)

Results

Description of the participants (parents)

Nineteen parents of 20 children (one parent had two children with CIs) participated in the study. Parents were aged 35 to 51 years (mean = 40.8 years, SD = 4.3). Fourteen of the 19 interviews were conducted with mothers alone, and one with a father alone. The other four interviews were conducted with both parents. All parents were hearing, except for three mothers who were DHH. Table 1 provides demographic information on the participants.

Children's characteristics

At the time of the interviews, the 20 children were aged 6 to 13 years (mean = 9.9 years, SD = 2.0) and 50% were girls (n = 10). Age at implantation ranged from 7 months to 5 years (mean = 25 months, SD = 12). Academic level ranged from first to seventh grade.

At the time of the interviews with the parents, all children were communicating orally. Except for four children, who had always used exclusively oral communication, all children had been early exposed to signs at home and in therapy (i.e., auditory training with audiologists and language therapy with SLPs) until approximately 1 year after cochlear implantation. According to the children's files, parents diminished the use of signs and gradually increased their focus on spoken language. At the time of data collection, most of the children (*n* = 17) were attending regular schools and were mainstreamed with hearing peers; five of them had an oral interpreter in class. The other three children were attending an oral school for DHH children (Table 2). Each child has been assigned a pseudonym.

Presentation of the themes and subthemes

We identified three themes and six subthemes (see Fig. 1): (1) "In the end, we manage to understand each other", (2) "Being included—or not", and (3) "We need to maintain

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Table 2. Characteristics of the children with CIs (n = 20)

Pseudonym	Gender (boy/girl)	Age (years)	Age at CI (age at second CI)	Current grade	School placement
Alan	Boy	13	2 years 5 months	6–7	Oral school for children who are DHH
Anne*	Girl	8	8 months (6 years 6 months)	2	Mainstream
Arthur	Boy	9	7 months	4	Mainstream (with an oral interpreter)
Aurora	Girl	13	2 years 6 months (12 years)	6	Mainstream
Beatrice	Girl	10	5 years (8 years)	5	Mainstream
Blanche	Girl	8	9 months	3	Mainstream
Carlos	Boy	10	30 months (7 years)	3	Mainstream
Caroline	Girl	12	18 months (11 years)	5	Mainstream
Clementine	Girl	6.5	1 year (5 years 6 months)	1	Mainstream (with an oral interpreter)
Elizabeth*	Girl	9	15 months (8 years)	3	Mainstream
Jasmine	Girl	8	4 years (5 years)	2	Mainstream
Louis	Boy	13	2 years 4 months	8	Mainstream
Madeleine	Girl	12	2 years 5 months (11 years)	6-7	Mainstream (with an oral interpreter)
Norman	Boy	7	18 months (3 years 5 months)	2	Mainstream (with an oral interpreter)
Philippe	Boy	9	3 years 2 months	3	Oral school for children who are DHH
Richard	Boy	9	18 months (7 years)	3	Mainstream
Robin**	Boy	11	3 years (10 years)	5	Mainstream
Simon	Boy	11	13 months (10 years)	4-5	Oral school for children who are DHH
Tamara	Girl	9	2 years 7 months	3	Mainstream (with an oral interpreter)
Theo**	Boy	11	2 years (10 years)	5	Mainstream

*Note 1: Anne and Elizabeth are sisters. **Note 2: Robin had recently received a diagnosis of autism spectrum disorder; Theo also presented a developmental language disorder. These conditions were not severe enough to significantly affect their functioning with their CIs. DHH = deaf and hard-of-hearing.

communication: Parental strategies and children's efforts". The first and main theme, "In the end, we manage to understand each other", was salient throughout the interviews as parents, almost unanimously, said that their child is doing fine. At the same time, when asked to provide examples or to talk about specific activities, parents mostly described their child's language and communication difficulties. Under this first theme, subthemes expressed the parents' perceived difficulties related to vocabulary, sentences, figurative language, and conversational rules.

The second theme, "Being included—or not", presents how language difficulties (personal factors), but also environmental factors (e.g., noisy environments), have consequences on the child's participation in specific situations and activities at home, at school, and in the community. Finally, in the third and last main theme, "We need to maintain communication: Parental strategies and children's efforts", parents describe the strategies and adaptations deployed around the child, and the efforts deployed by the child, to maintain their CP.

At the stage of the identification of the main themes and subthemes, we realized that the parents were reporting similar experiences with CP in each of the three contexts (i.e., home, school, and community). Therefore, it was not useful to divide the presentation of the results into separate sections according to the context. In addition, although it is not current practice to report numbers or frequencies in qualitative research (see Braun & Clarke, 2022), we felt that some readers might be interested in knowing how many parents discussed specific themes and subthemes. Thus, we provided numbers when appropriate.

Theme 1: "In the end, we manage to understand each other"

Nearly all parents (17/19) frequently evoked the idea that communication with their child does not necessarily move or proceed smoothly, but in the end, the child manages to understand and to be understood. The following extracts illustrate this dichotomy in the parents' general appreciation of communication: "Well, communication is good in general, but it's not always easy [...] communication is feasible, but more tedious than with a child who hears well." (Mother of Tamara, 9 years old).

"Because, you know, it doesn't show when he's speaking, but when he comes to explain something, you can see that Alan has a problem. It doesn't flow like a normal child." (Mother of Alan, 13 years old).

Other parents were more specific about the fact that despite some difficulties or the need for various means of communication, in the end, the child can understand and be understood by others: "She can make herself understood. Either she'll go back to signs, or else she'll try to find other things, other words." (Mother of Beatrice, 10 years old).

> (Mother): "He's doing fine: when he wants us to know something, he's going to tell us. But he also writes words. (Father): But in general, for example... (Mother): We know what he wants. (Father): We know what he wants and we always end up understanding each other. It's going very well, even with the implant." (Mother and father of Simon, 11 years old).

Parents gave several reasons for this relative lack of smoothness in communication. Most of the times, it was related to language and communication skills: During the interviews, a large majority of participants made numerous comments on language skills, particularly on vocabulary, sentences, figurative language, and the rules of conversational exchange. Interestingly, only four parents reported errors in their child's speech or seemed preoccupied by speech intelligibility; on the contrary, 13 of them praised their child's articulation, presenting their child's speech as a source of pride: "Someone who doesn't know [he's profoundly deaf] could never say. That's what everyone tells me. His pronunciation is perfect." (Mother of Richard, 9 years old).

"The majority of people who don't know that she has implants, when I tell them she's deaf, she has implants, they don't believe me. They say, oh my God, she speaks well!" (Mother of Aurora, 13 years old).

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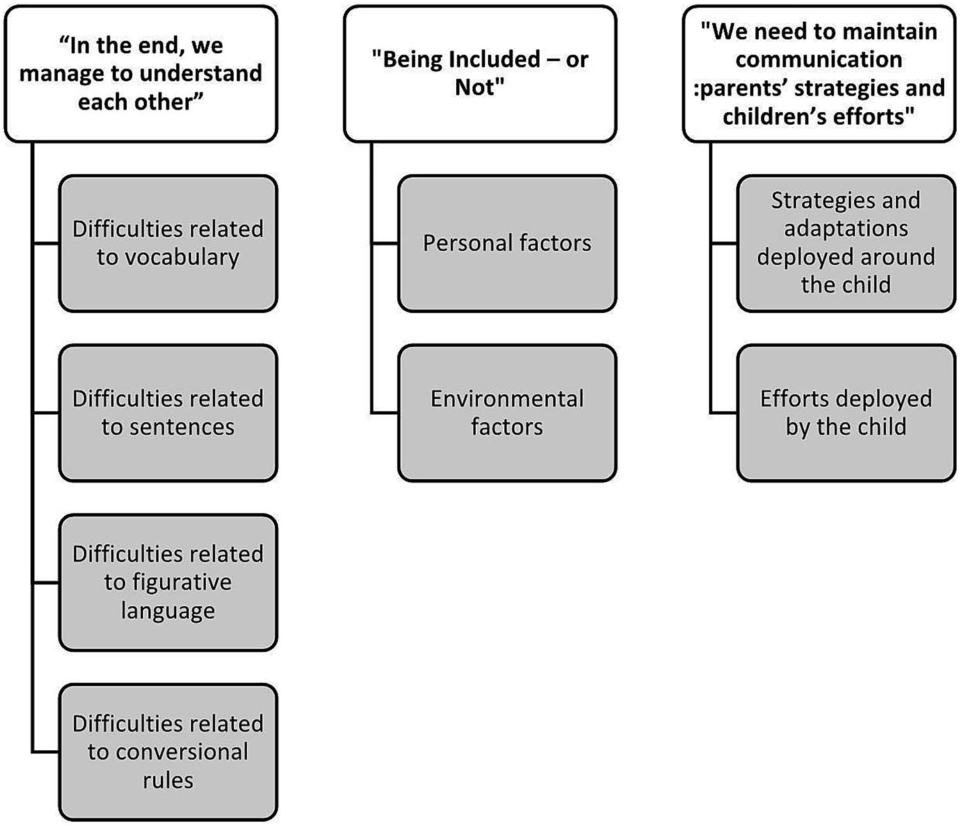

Figure 1. Thematic diagram of themes and subthemes.

Subtheme: Vocabulary. Parents used different terms to explain that their child had a smaller vocabulary than their hearing counterparts, had a "vocabulary delay", or had "vocabulary difficulties". Five of them also told that they had to "work on vocabulary", or that it needed professional intervention. The following extracts illustrates the different terms that parents used to describe their children's vocabulary difficulties: "Anne, it's really more the vocabulary, I think that's the problem. Even though we've tried to push it quite a bit. It's really her vocabulary that's lagging behind." (Mother of Anne, 8 years old).

"It's true that he doesn't have the same vocabulary, the same number of words, as a child his age." (Mother of Simon, 11 years old).

Subtheme: Sentences. Similarly to vocabulary, eight parents referred to important difficulties with sentence construction and grammar; at the same time, these parents expressed that overall, communication was not so difficult after all, again expressing a dichotomy: "Communication is going relatively well. Except for his big syntax problem, which is really the bane of his communication. [. . .] It's really his syntax. He misses a lot of little words everywhere, and sometimes, well, he loses coherence." (Mother of Alan, 13 years old).

"He made a lot of progress and started to become more and more normal for his age. [. . .] But even today, he's still...he's still using very telegraphic sentences. But we understand him well." (Mother of Louis, 13 years old).

> Because he still has a language problem. He has trouble with pronouns. You see, just like the rest of us say THE chair [*LA chaise*], he'll just say chair [*chaise*]. Let's say, "I ate at school", he'll say "school eat". You see, there are a few things missing... Determiners and pronouns. [. . .] But he manages to make himself understood quite well. (Mother of Philippe, 9 years old).

Subtheme: Figurative language. Nine parents noted that their child understands better when the language used remains at a concrete level. In the following extracts, parents provide specific examples of their child's struggle with jokes, idiomatic expressions, or metaphors:

> This week, she had read: " He put on his lynx-eye [*Il a mis son œil de lynx*]. And it was "How did he get a lynx eye?" Well [I said], "It's because you have good eyes for finding stuff...". [. . .] Metaphors and phrases like that, forget it. It needs an explanation. She doesn't understand, she really understands the first meaning: "He put on a real lynx eye". [. . .] She sticks to the first meaning. (Mother of Elizabeth, 9 years old).

> The double meanings. Stupid jokes. He doesn't understand that. But we worked on expressions like that last year. At one point, we said "to give a hand" [*donner un coup de main*], he thought it was to give [a blow with] one's own hand. (Mother of Philippe, 9 years old).

Subtheme: Conversational rules. The last subtheme regards conversational rules. Eight parents reported that their child tends to either monopolize the conversation or interrupt others.

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As illustrated by the following extracts, some of the parents explained that those attitudes are an undesired consequence of language intervention when the child was younger and the slightest attempt to communicate was reinforced. Other parents said that those attitudes likely masked comprehension difficulties. In all cases, parents evoked the idea of their child not being such a pleasant communication partner. “She really likes to have control over conversations. She always has. And by speaking herself, by starting the subject, she knows what she wants to talk about. She’ll push her own ideas.” (Mother of Beatrice, 10 years old).

> [Speaking turns] are difficult. Because for a long time, the second Norman opened his mouth, everyone was silent. "What do you want to say, Norman? [...]. We have to work on this: it’s one person at a time... He got a lot of attention when he was little. (Mother of Norman, 7 years old).

> Alan, unfortunately, they pushed him so hard to elaborate, to elaborate on everything. [...] I seem to have trouble explaining to him when it’s important to elaborate, and when it’s less necessary, or even superfluous. Or when you’re losing people in your conversation, or when you’re elaborating too much. [. . .] But we so much wanted him to talk, to elaborate, to explain . . . (Mother of Alan, 13 years old).

Theme 2: “Being included—or not”

Children can have a satisfying CP when they are truly and totally included in activities that involve communication. Parents provided many examples from each social context (home, school, and community) and stated whether they felt their child was included or not. Parents mostly discussed situations that revolved around family life at home, particularly the preparation of meals and family dinners. They also expressed their thoughts about access to information and communication both in the classroom and the schoolyard, and finally, they described the participation of their child in social events (such as birthday parties) and leisure activities. In many of the extracts, parents also talked about the relationship they perceive between inclusion and environmental conditions.

Subtheme: Preparing meals and having dinner. Parents said that the hardest situation for their child was when there is background noise and/or no access to lipreading; children are then likely to fail to understand what is being said. Fifteen parents described extended family gatherings, but mostly, they talked about the preparation of meals and family dinners (at home or out). Parents primarily focused on comprehension, but a few of them also described their child’s ability to express what they have to say in such contexts (i.e., ordering food at the restaurant). The following extracts describe the participation of their child during family meals, the participation in conversations, the management of turn-taking, or the comprehension difficulties when communication partners are at a distance, or in noisy environments such as restaurants.

> Sometimes [at dinner], she says “nobody talks to me”. Sometimes she feels rejected. Let’s say we’re having a conversation and she can’t keep up. Either she quits completely. Or “What? What? I don’t understand”. Then, at some point, she gets annoyed and says “Ah, that’s it. You’re not talking to me”. We try to integrate her. [We say] “ask us questions”. (Mother of Beatrice, 10 years old).

> Even at restaurants like [name of the restaurant], which are very noisy, he can’t hear a thing. You really have to get close to him to talk to him, or he’ll get close to the rest of us to understand. But what I realize is that at family dinners or whatever, he’ll go into his own bubble. (Mother of Arthur, 9 years old).

Subtheme: Classroom and schoolyard. Parents mostly shared their feeling that their child could not have complete access to information and communication at school, either in the classroom or in the schoolyard. As shown in the following extracts, parents attributed this lack of participation in communication to background noise and group talking, despite accommodation measures at school.

“Madeleine also does a lot of lip-reading. That’s one of her strengths. And with friends at school, I think that helps too. [. . .] But I’m not convinced…I’m not convinced that she understands everything that’s said during teamwork.” (Mother of Madeleine, 12 years old).

“Let’s say at the end of one class, when everyone’s putting their things away at the same time, teacher says “Take out your orange notebook, your notebook…“ then, through all the hubbub, he misses bits and pieces.” (Mother of Arthur, 9 years old).

“She was in the schoolyard then, I could see, she can’t grasp everything that’s being said. I mean, it seems impossible to me. There’s so much background noise and all that. But it never seemed to bother her.” (Mother of Blanche, 8 years old).

Subtheme: Social events and leisure activities. Eleven parents said that friends do call at home to play with their child and that they are invited to social events, such as birthday parties, even though their child does not always participate and communicate as fully as would a hearing child in such events. Nevertheless, parents do not feel that their child was being left out:

“She’s still limited both in her expression and in her comprehension, in all kinds of group and family situations, we know it’s not like the other kids. Even so, she is invited to birthday parties, she’s going, but surely, she hasn’t understood half of what’s going on. But she can pull her weight [*elle tire son épingle du jeu*] and have fun anyway.” (Mother of Tamara, 9 years old).

Of course, if they’re having a friends’ party and there’s a dozen of them, well… Yes, I had friends at my party, but what they talked to me about, I have no idea. Because they’re all girls, and they’re shouting. The decibel level is high (Mother of Anne and Elizabeth, respectively 8 and 9 years old).

All parents said that they insisted their child be enrolled in “regular” (i.e., in totally hearing settings) leisure activities, such as violin lessons, ballet, soccer, summer camp, and so on. Apart from aquatic activities, that can be problematic if the child must remove the implants, parents really feel that their child can be part of the community, despite some communication challenges, described in the following extracts:

> I had enrolled him in the scouts at one point, [...] when it comes to activities involving large groups, I’ve found that he quickly

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> loses interest because he can't understand the explanations because there's too much noise and chatter. (Mother of Arthur, 9 years old).

> Last time at summer camp, one of her friends told her, "Oh, well, I'm not playing with you anymore because you don't understand when I'm talking to you". That really hurt her, and it was like "I don't have any friends". But we resolved the situation, and after that it was fine. (Mother of Anne, 8 years old).

Theme 3: "We need to maintain communication": Parental strategies and children's efforts

The third and last main theme was less frequently raised compared to the other two main themes. Nevertheless, we found it interesting to present it as it offers solutions that parents put in place to reduce communication barriers and to maintain CP. At school, apart from the need for oral interpreters in class (see Table 2) and the use of FM systems by some children, parents mostly described measures that schools put in place to raise awareness of CIs among students. Otherwise, parents presented their own communication strategies and explained the efforts their child makes to understand and be understood in various contexts.

Subtheme: Raising awareness. Four parents talked about the different people that take responsibility for explaining their child's situation to classmates, every year or so. They said it was either the interpreter or the SLP who took the responsibility:

> "He's in 4th grade and has been at that school since kindergarten. But there are still new children in his class every year who have never been with him, and every year the interpreter just explains, "Arthur, he's deaf, that's his implant", to prevent questions." (Mother of Arthur, 9 years old).

"At the beginning of the year, she [speech-language pathologist] explains communication strategies for his classmates. 'If you want to talk to Richard, you put yourself in front of him' and so on." (Mother of Richard, 9 years old).

> A mother explained that it was her daughter herself that prepared a presentation on her hearing status and the CIs for her classmates.

> It was Madeleine who had prepared her stuff, but she was working with someone from [the rehabilitation center] to put it all together. And she did it. She presented it. She explained it in her own way, I'm sure. Yes, she did. (Mother of Madeleine, 12 years old).

Subtheme: Communication strategies. In the following extracts, the parents explained which communication strategies they were using with their child. These were basic strategies involving the efforts that the parents make regarding their articulation, speed, language level, and the importance of keeping their faces seen because their child needs to read lips. Eight parents even said they were using signs in certain situations. "It's true that, let's say, when I'm far away, even if she could hear me, if she's far away, sometimes, instead of shouting, let's say, I go look for her, she's outside at school, I'll do signs." (Mother of Clementine, 6.5 years old).

> And I try to get him to look at me, because I know that when he looks at me, he understands. Norman is very good at lip-reading." (Mother of Norman, 7 years old).

> "[There are] situations where I may need to supplement with signs if I feel that it's going to be more difficult to hear. (Mother of Carlos, 10 years old).

Subtheme: Children's efforts to participate in communication. Finally, 10 parents evoked the idea that the responsibility for successful communication often belongs to their child. They described, in addition to their own, the efforts of their child to maintain their participation in communication. Whereas some parents encourage their child to develop their autonomy, to signal communication breakdowns, and to use repair strategies, other parents seem to prefer that their child keep a low profile and not disclose that they did not understand, apparently to "conceal" their hearing status or to resemble others. Both points of view are shown in the following extracts: "What's more, she's also been encouraged to ask questions. To validate what she hears. If she's not sure what she's heard, validate!" (Mother of Caroline, 12 years old).

> Really, to make sure he tells you when he doesn't understand. Or when there's a [communication] issue, to be more self-reliant and then proactive in making sure he understands. Because, in the end, if you don't mention it, other people can't do anything. (Mother of Richard, 9 years old).

> I think she knows she's good at lip-reading. She's very good at lip-reading, so she knows that it supports her a lot. So, if she's with someone and she's having a conversation with her friends, not to say all the time "huh? I didn't get that. Could you repeat that? To try to minimize her difference from others. (Mother of Aurora, 13 years old).

> I didn't want him to make people repeat themselves all the time, so that he wouldn't be stigmatized in some corner [...] So I'd tell him, he'd ask me when he didn't understand, but I'd say: "When you don't understand, try to see, continue the conversation, probe to figure out what people said". I didn't want him to be a victim, and I didn't want him to keep saying: I didn't understand, what did you say, well I'm deaf, I can't hear. (Mother of Arthur, 9 years old).

Discussion

The purpose of this study was to explore the perception of parents regarding the communication of their school-aged child in three social contexts by applying the construct of CP in children with

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CIs. In-depth interviews from 19 parents of school-aged children who used CIs for at least 5 years were analyzed. A thematic analysis was performed and highlighted three overarching themes, each with subthemes, related to participation in communication in social contexts.

A certain paradox: good communication that is often less than optimal

Overall, despite describing very positive communication and participation outcomes with CIs, parents reported that their children do experience participation restrictions and activity limitations because of communication difficulties (personal factors) and/or barriers (environmental factors). At home, many situations, notably family dinners, are especially challenging. At school and in activities within the community, many parents reported several situations in which the CP of their child was less than optimal. In addition, both parents and children with CIs have to make some efforts and use communication strategies to ensure adequate CP. Throughout the analysis of the interviews and the interpretation of the data, it became apparent that parents often expressed a dichotomy, even a paradox, between their global appreciation of their child's participation in communication. Their comments were different whether they were sharing their global appreciation of their child's participation in communication or they were describing how specific contexts, environmental conditions, and language skills were challenging for their child.

The positive general perception aligns with reports of parents' favorable ratings of the communication domain when assessed using hearing-related QoL questionnaires (Fortunato-Tavares et al., 2012; Kumar et al., 2015; Warner-Czyz et al., 2011; Warner-Czyz et al., 2022). Moreover, studies that examined parental satisfaction toward speech and language skills after cochlear implantation usually report high levels of satisfaction (Archbold et al., 2008; Huttunen & Välimaa, 2010; Nelson et al., 2017). We can hypothesize that the general appreciation might be related to the initial expectations of the parents. At the time of the identification of a severe to profound hearing loss in their child, hearing parents have little or no experience with deafness and are usually unaware of the potential benefits of CIs. At first, parental expectations may simply be that the child be able to say some words. It would then be likely that their global appreciation is very positive. This resonates with Huttunen and Välimaa (2010), who asked parents of children with 5 years of CI use (n = 18) whether their child's spoken language development met their original expectations. Fifteen of them responded that their expectations had been met or surpassed. Some of them, as in the present study, also emphasized "the good quality of their child's speech" (p. 394).

In contrast, parents talked a lot about communication difficulties in specific contexts. While these challenges have been extensively shown in studies that used language tests and structured tasks, they have been less frequently explored from the parents' perspective. Moreover, studies that do include parental viewpoints often rely on questionnaires, which provide limited opportunities for detailed descriptions of communication issues in social contexts (Löfqvist et al., 2020; Tuohimaa et al., 2022; Zaidman-Zait & Most, 2020). One study by Cagulada and Koller (2019) explored parents' perspectives on the well-being of children who are DHH. All ten parents stated that their child (4/10 were CI users) had some difficulties with communication. In the present study, nearly all parents provided detailed accounts of the specific language and communication challenges that their child encounters the most frequently in four domains: vocabulary, syntax, figurative language, and conversational rules. Interestingly, these results resonate with several research findings concerning these four specific language domains, thus suggesting that parents are competent to recognize and appreciate their child's strengths and difficulties. As mentioned by many parents in the present study, Davidson et al. (2014) found that receptive vocabulary knowledge of children with CIs aged 8 and 9 was significantly lower than that of hearing children. In addition, Lund (2016), in a meta-analysis, confirmed that children with CIs had both receptive and expressive vocabulary delays compared to hearing peers. Concerning syntax, Nittrouer et al. (2018) found that sixth graders with CIs had poorer abilities than their hearing peers. Similarly, in a review paper, Nittrouer and Caldwell-Tarr (2016) concluded that regarding grammar, school-aged children with CIs perform more poorly than their hearing counterparts. Although less studied, figurative language is also recognized as a challenging domain in children with CIs, and past research has demonstrated that school-aged children with CIs can indeed struggle with metaphors and figurative expressions (Bahrami et al., 2018; Nicastri et al., 2014; Parola et al., 2023), and irony comprehension (Panzeri et al., 2021). Finally, although past research suggested that conversational skills seem less of a difficult area for school-aged children with CIs (e.g., Ibertsson et al., 2009; Toe & Paatsch, 2013), both these reports state children with CIs tend to dominate or to control the conversation, thus reflecting the perceptions and experiences of the parents who took part in the present study.

The role of the environment

Our intention is not to over-emphasize difficulties; it is true that overall, these children are generally doing quite well with their CIs. They developed spoken language, some of them can have telephone conversations, and many attend regular schools. Two parents told us that they had wanted to take part in the research project to tell that their child was doing "really well" and that they were very successful with their CIs. We acknowledge that while most of the parents reported some difficulties, there are also conditions to be put in place to maximize access to information and communication. Listening conditions are not the only factor that can be detrimental to CP. To exchange knowledge, information, ideas, or feelings in life situations (Eadie et al., 2006), the child also needs sufficient language skills and adequate conversational attitudes. Nonetheless, many parents declared that their child requires specific listening conditions to have the same level of CP as their hearing peers. Our results demonstrated that physical environmental conditions have a large impact on children's CP. Almost all parents pointed out that background noise, in any given context, has a major influence on their child's ability to have access to linguistic information, to understand what is being said, and to participate in communication exchanges. This is in line with a study conducted in Brazil, where researchers used 55 codes of the ICF framework to characterize the profile of a sample of 30 children aged between 6 and 18 years who were experienced CI users. They concluded that noise was the principal barrier to communication for most children (Morettin et al., 2013).

Finally, our results showed that the communication partners who facilitate children's participation in communication are those who are making some efforts (i.e., know and use communication strategies). This suggests that children themselves have a limited influence on their own CP. However, some parents tend to encourage their child to take responsibility for successful communication exchange.

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Implications for intervention and for research

Overall findings add to the results of Eriks-Brophy et al. (2007) in highlighting the importance of effective inclusion of students with CIs and in revealing the challenges that remain for full participation. An expanded vision of the communication challenges and needs of school-aged children with CI's is important so that clinicians are able to provide services and interventions focused on improving CP. As emphasized by parents in this study, a broader perspective on their communication needs can lead to improved services and the development of interventions that go beyond standard language assessment scores to better address their everyday interactions. Our findings also suggest that to prevent later academic difficulties and long-term impacts, SLPs could target the communication that takes place in real-life contexts, as well as more subtle language skills (e.g., figurative language), with the aim of supporting academic and psychosocial development into adolescence and young adulthood. Archbold (2015)—on the topic of more complex and more subtle communication abilities—indicated that persisting delays can have significant—even though not always apparent at first glance—impacts on social inclusion and educational achievement in students with CIs. For adolescents and young adults, the communicative contexts get more and more abstract and complex over time and throughout the school years (Marschark et al., 2018). A clinical focus on CP in students with CIs could have positive impacts on the pursuit of higher education, career choices, and entry into the workforce.

More research is warranted on school-age children who received CIs during early childhood. The beneficial effects of implants in the short term (i.e., during the preschool period) are well-established. However, it would be relevant to continue monitoring the evolution of communication skills in children with CIs and look at the long-term effects of cochlear implantation on communication and participation. Too little is known about language and communication issues during school-age and adolescence. During this period, such issues might certainly be less visible but must be investigated to enable these pupils to succeed as well as hearing students. Future research could also address more specific aspects (e.g., vocabulary, socialization) at specific ages or grades. This approach would facilitate the provision of interventions that better align with the strengths and needs of the children.

Limitations of the study

All parents in this study were of similar social and demographic backgrounds. For example, all were of relatively high socioeconomic level, as is often the case in studies on children with CIs. According to Holzinger et al. (2020), "there is a tendency to disproportionally include families with high SES" (p.1080). Second, none of the parents had an immigrant background, and they were all Caucasian. However, as recommended by Kecman (2022), our sample included at least some variability, hence more richness: Three mothers who were DHH participated in the study, and a few fathers also took part in the interviews along with the mothers. Nevertheless, the relative homogeneity of the participants may hamper the transferability of the results. In addition, the content of the interviews was not validated (i.e., the authors neither offered the participants to comment on or correct the transcripts nor to provide feedback on the findings), although validating the results with participants is not a requirement for qualitative results to be considered reliable. According to Braun and Clarke (2022), thematic analysis favors reflexivity and in-depth interpretation of the data over external validation. Finally, in line with Punch and Hyde (2011) who stated: "The current study's qualitative analysis cannot accurately determine the influence of confounding factors on children's social participation and well-being; that task is more the role of quantitative research" (p. 489), we are also unable to draw any conclusions about whether the age of implantation or the child's age at the time of the parent interview was associated with experiences of communication difficulties.

Conclusion

The tremendous improvements of the last four decades regarding the evolution of hearing technologies and the improvement of educational practices have changed the landscape for families of DHH children, especially those who received CIs. It is now expected that children with CIs will be able to develop spoken language, that they will attend regular schools, and that their everyday functioning will approach that of hearing peers. However, one must keep in mind that communicative needs—sometimes subtle but essential to full participation in society—must be met through intervention. Parents in the present study confirmed that their children are experiencing participation restrictions and activity limitations because of communication difficulties (personal factors) and/or barriers (environmental factors). According to the parents who participated in the present study, many students with CIs are still not provided with the same opportunities to benefit from communication and social interaction in family, school, and community environments, compared to students with typical hearing. Raising awareness of deafness and CIs in various settings, from the extended family to schools and society, remains an important issue. Clinical interventions could also be improved to focus more on communication in real-life situations, leading to the development of better practices for supporting these children.

Endnote

1. Note that « hearing loss » is used here to refer to specific hearing levels that correspond to cochlear implants candidacy. Throughout the text, we tried as much as possible to avoid the use of the word "loss".

Supplementary material

Supplementary material is available at *Journal of Deaf Studies and Deaf Education* online.

Author contributions

Louise Duchesne (Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Writing—original draft, Writing—review & editing), Marie-Pier Gingras (Formal analysis, Validation, Writing—original draft, Writing—review & editing), and Maude Gagnon (Resources, Validation, Writing—review & editing).

Funding

This work was supported by the Fonds québécois de recherche Société et Culture (FRQSC) [grant number NP-166744] to L.D.

Conflicts of interest

None declared.

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Acknowledgments

The authors would like to thank Élise Rivard, who participated in the development of the interview guide and did the pilot testing, and Isabelle Gasse, SLP, who conducted the interviews and participated in data analysis, and also would like to thank all the parents who participated in the study.

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