

## **“Sometimes I feel sad”: a qualitative study on children’s perceptions with cleft palate speech and language therapy**

### **Abstract**

**Background.** Evidence-based speech and language therapy involves the integration of (1) the scientific evidence for therapy with (2) the perspectives of clinicians concerning therapy, and (3) the perspectives of patients about therapy. In the cleft literature, attention has already been paid to the first two cornerstones of evidence-based speech and language therapy. Much less is known about how children perceive cleft speech and language therapy.

**Aims.** The purpose of the current qualitative study was to investigate the perceptions, emotions, and expectations of (blinded for review) children with a cleft (lip and) palate (CP±L), aged 5 to 12 years, with regard to the speech and language therapy they receive. In this study, a focus was made on speech and language therapy to eliminate cleft speech characteristics.

**Methods & Procedures.** Six children with a CP±L, aged between 5 and 12 years, were included in this study. Child-friendly semi-structured interviews were conducted using a participatory, art-based qualitative approach. This means that the ‘play and puppets technique’ and ‘draw-write and photo-elicitation technique’ were used to guide the children through the interviews. Data derived from these interviews were analyzed using an inductive thematic approach. Trustworthiness of the data was achieved by applying researcher triangulation, negative case analysis, and an audit trail.

**Outcomes & Results.** Analyses of the interviews revealed 3 major themes of importance to the children: (1) treatment values, (2) treatment practices, and (3) treatment outcomes. Each theme was divided into different subthemes. The theme ‘treatment values’ consisted of the subthemes expectations and emotions around therapy and interference with daily living. Information flow, therapy content, confirmation and rewards, parents’ attendance, therapy dosage, and homework were subthemes of the major theme ‘treatment practices’. The theme ‘treatment outcomes’ was divided into two subthemes, namely speech improvement and peers’ reactions.

**Conclusions & Implications.**

Most children had positive attitudes towards speech and language therapy: it was “something they liked” and “something fun”. If children had negative attitudes they were related to having fear of making mistakes during therapy. Some children had clear expectations of the purpose of speech and language therapy. Speech and language therapy should “help” improve their speech and make it more understandable to others. The children in this sample made some suggestions to decrease the experienced burden related to speech and language therapy. The results of this study will help to better tailor speech and language therapy programs to the needs and experiences of children with a CP±L.

## **Introduction**

The presence of a cleft palate with or without a cleft lip (CP±L) may have severe consequences for a child’s speech understandability and speech acceptability considering the possible development of cleft speech characteristics (Harding & Grunwell, 1998). Speech and language therapy is usually required to eliminate these errors in the child’s speech (American Cleft Palate-Craniofacial Association, 2016). About two decades ago, the World Health Organization (WHO) launched a five-year project to advance international research on craniofacial anomalies, such as a CP±L (P. A. Mossey & Catilla, 2003). One of the aims of this five-year project was to stimulate evidence-based care (P. A. Mossey & Catilla, 2003). Evidence-based care involves three different cornerstones, namely: combining the (1) best available research evidence with (2) the clinician’s perspectives and (3) the patient’s perspectives (Steglitz, Warnick, Hoffman, Johnston, & Spring, 2015). In the past years, the cleft literature has paid more and more attention to these first two cornerstones by conducting therapy studies (Alighieri, Bettens, et al., 2020; Alighieri, Van Lierde, et al., 2021; Scherer, D’Antonio, & McGahey, 2008; Sweeney et al., 2020) and studies on the therapy-related perceptions of speech-language pathologists (SLPs) (Alighieri, Bettens, Verhaeghe, & Van Lierde, 2021a, 2021b; Hardin-Jones, Jones, & Dolezal, 2020) and parents of children with a CP±L (Alighieri, Bettens, Vanoost, et al., 2021; Alighieri, Peersman, Bettens, Van Herreweghe, & Van Lierde, 2020; Alighieri, Van Lierde, Cammu, Vanoost, & Bettens, 2022; Lindeborg et al., 2020; Sommer et al., 2021).

Qualitative studies in community SLPs revealed that they are lacking professional confidence when treating children with a CP±L. They experience a fear of making mistakes during therapy possibly preventing treatment

progress. These feelings often result from a lack of experience in treating this specific population. Also, a lack of available information, both in terms of information to make appropriate diagnoses and plan treatment approaches or intensities, reinforces this insecurity. Even though there is a strong consensus among SLPs that children with a CP±L require an individualized treatment plan based on scientific evidence, they reported a need to receive practical step-by-step guidelines on speech and language therapy for this population. Concerning parental involvement, SLPs indicated that they find it important to involve parents during therapy. Unfortunately, parental involvement is not always easy in clinical practice. Therapy sessions are often provided during school time when parents cannot attend the sessions (Alighieri, Bettens, Verhaeghe, et al., 2021b).

Albeit qualitative studies in SLPs revealed insecurities when treating children with a CP±L, parents do not seem to notice this. In general, qualitative studies in parents reported high parental satisfaction with cleft speech and language therapy (Alighieri, Bettens, Vanoost, et al., 2021; Alighieri, Peersman, et al., 2020; Alighieri et al., 2022; Lindeborg et al., 2020; Sommer et al., 2021). Despite this satisfaction, some parents report specific concerns about the financial part of speech and language therapy (Alighieri, Bettens, Vanoost, et al., 2021; Lindeborg et al., 2020; Sommer et al., 2021) and the implications of speech and language therapy on the absence of their children during school hours (Lindeborg et al., 2020; Sommer et al., 2021). Cleft speech and language therapy was considered burdensome if it interfered with having a “normal life”. Alighieri, Bettens, Vanoost, et al. (2021) described that parents translated this experienced burden by listing practical issues they face. These practical issues were, in fact, not the real problem. Difficulties that are caused by these practical issues formed the real problem, for example: having too little time for their other children or themselves, the need for rescheduling their professional agenda, having to cancel enjoyable activities for speech and language therapy, etc.

Unfortunately, it is not known to what extent these perceptions align with the experiences of children regarding speech and language therapy to eliminate cleft speech characteristics. Accounting for the children’s experiences has become more and more important. Nevertheless, Ellingsen, Thorsen, and Størksen (2014) pointed out that it is not always easy for children to take part in research and to put their feelings, experiences, and emotions into words. Research to investigate children’s feelings and experiences should employ flexible methods to capture the children’s stories (Ellingsen et al., 2014). A balance should be found between asking open questions that often result in receiving very general answers and asking concrete questions that often result in receiving answers influenced by the questioner (Ellingsen et al., 2014).

Literature that has yet investigated the perceptions of children with a CP±L mostly focused on their experiences with the general care pathway. Hall, Gibson, James, and Rodd (2012) conducted a qualitative study to investigate the perspectives of 17 children, aged 8 to 17 years, on their participation in the cleft care pathway. Semi-structured face-to-face interviews were conducted in a child-friendly manner. Topic guides were used to guide the interview. However, they were not designed to be an exhaustive list of all the themes that needed to be discussed but they were rather used flexibly. A booklet was given to the children to complete in their free time. In this booklet, they could write 'best' or 'worst' experiences. This study demonstrated that children experienced considerable variation in participation in the cleft care pathway. Some children were very active in their participation whereas others preferred their parents to make decisions and speak on their behalf. The authors suggested that age and the capacity to make decisions were closely inter-related for children, as many children wanted to take more lead during discussions with clinicians as they got older. Even though speech and language therapy is an important part of the cleft care pathway, this study did not report any findings related to this matter. Only one study investigated children's satisfaction with speech and language therapy (Van Lierde et al., 2012). This study used a quantitative research design involving the Cleft Evaluation Profile (CEP). Forty-three children, aged 10 to 17 years, were included. Ninety-one percent of the children followed speech and language therapy to establish correct phonetic placement and to eliminate cleft speech characteristics or developmental errors. Sixty-four percent of these children indicated that they liked the therapy. Interestingly, some gender differences were observed. Significantly more boys with cleft palate (48%) reported that they disliked speech and language therapy, whilst only 8% of the girls disliked it (Van Lierde et al., 2012). Unfortunately, the use of the CEP prevented the researchers from investigating the children's underlying emotions and perceptions of the speech and language therapy they received.

To respond to this gap in the literature, the purpose of the current qualitative study was to investigate the perceptions, emotions, and expectations of (blinded for review) children with a CP±L, aged 4 to 12 years, concerning the speech and language therapy they receive. In this study, we specifically focus on speech and language therapy to eliminate cleft speech characteristics. The results of this study will help to better tailor speech and language therapy programs to the needs and experiences of children with a CP±L.

## **Methods**

This study was approved by the Ethics Committee of the Ghent University Hospital (THE-2022-0081). Parents and children provided verbal and written consent to participate in the study.

### **Participants**

(blinded for review)-speaking children with non-syndromic CP±L were recruited through the interdisciplinary cleft team at the Ghent University Hospital. Inclusion criteria included: (1) the child must be aged between 4 and 12 years old and (2) the child must at least have received 6 months of speech and language therapy to eliminate at least one cleft speech characteristics. Speech and language therapy should be provided by a private, community SLP. Children with syndromic clefts, oronasal fistula, velopharyngeal insufficiency, hearing disabilities based on pure tone audiometry (>25 dB HL) performed as part of the clinical routine, cognitive and/or related learning disabilities or neuromuscular disorders were excluded. Children who received speech and language therapy provided by a cleft team SLP were also excluded. The in- and exclusion criteria were verified through the patients' files and through questioning the parents.

### **Data collection**

A final year master's student in speech-language pathology at Ghent University conducted individual semi-structured interviews with the children. She had no relationship with any of the children nor with their parents and she did not provide speech and language therapy to the children. To train the student in qualitative research methods, a pilot interview was organized with a child with non-syndromic CP±L who received speech and language therapy. Concrete and detailed feedback was provided by the first author of this paper (C.A.) who had previous experience with qualitative study designs.

The actual interviews with the children took place in the child's home environment. The only individuals who were present during the interviews were the interviewer and the child. No parents were allowed during the interviews to avoid bias and to allow the children to speak freely. Audiovisual recordings were made of each interview using a Sony Handycam HDR-CQ280E with a high-quality built-in microphone. To not distract the children, no field notes were made during the interviews.

### **Qualitative interview approach**

A child-centered, participatory, art-based approach was used to collect the data (Carter & Ford, 2013; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010). Two different techniques were used depending on the age of the children (Gibson et al., 2010).

#### Play and puppets technique (4- and 5-year-olds)

A role-play with puppets was used to ask the children about their experiences with speech and language therapy (Gibson et al., 2010). The use of these concrete materials helped the interviewer to enter the world of the children (Gibson et al., 2010). The interviewer initiated a play about a puppet that receives speech and language therapy. Hence, the child is encouraged to talk about his/her experiences. The interviewer only used open-ended questions to follow up with the statements of the child (e.g. "Can you tell me more about that?" or "How do you feel about that?").

#### Draw-write technique and photo-elicitation (6- to 12-year-olds)

The draw-write technique was specifically chosen for this age group because Gibson et al. (2010) indicated that school-aged children are familiar with producing drawings and writing about them which makes this a child-friendly and non-threatening method of data collection for children. Pencils and papers were given to the children and they were prompted to make drawings. The prompt was the same for all the children and included the instruction "Let's make a drawing about speech and language therapy you receive.". Children were asked to talk about their drawings while the interviewer followed up with their responses using open-ended questions (e.g. "Can you tell me more about that?" or "How do you feel about that?").

Not every child likes to draw. To increase the participation of each child during the interviews, a second technique (i.e., 'photo-elicitation') was chosen (Carter & Ford, 2013). Pictures were used as prompts during the interview (Carter & Ford, 2013). Figure 1 demonstrates an example of the stimuli that were used to initiate children to talk about their feelings and experiences.

[Please, insert Figure 1 here]

#### **Data analysis**

Each interview was transcribed verbatim by the first author (C.A.) excluding possible identifiers. The data analysis was performed using the qualitative analysis software program NVivo 12 © (NVivo, 2018). Transcribed interviews

were read repeatedly by two primary coders to be completely immersed in the data. Interviews were analyzed according to an inductive thematic approach described by Braun and Clarke (2006). Firstly, an initial open line-by-line coding was performed. This line-by-line coding resulted in 'in vivo codes' which means that codes involved phrases that were literally used by the children. In vivo codes prevented the coders to impose own frameworks on the data. These codes were combined into a first code tree. Secondly, axial coding was used to combine the different codes into larger themes. Thirdly, an interpretive analysis of the themes was performed. This interpretive analysis was based on a consensus between the two primary coders. A two-step verification procedure was performed: the themes were verified in relation to the coded extracts and in relation to the overall data. In the result section, exemplar quotes from the children are provided. The (blinded for review) quotes were translated into English based on a consensus between all the authors. Results were reported in accordance with the Consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007).

### **Trustworthiness**

To increase the trustworthiness of the data, researcher triangulation was performed (Holloway & Galvin, 2016). The authors of this paper discussed, compared, and interpreted the data from different perspectives. The different researchers had different backgrounds providing the opportunity to control for possible coding bias and allowed for an enriched interpretation of the results. C.A. had experience in qualitative research and had both scientific and clinical experience in treating cleft speech disorders. As this author's experience in qualitative research was not limited to children with a CP±L but reached diverse groups of individuals with speech-language problems and voice disorders, she could provide a unique interesting perspective on the gathered data. M.D.R. was a student speech-language pathology with general knowledge on speech disorders allowing a general perspective on the gathered data. K.V.L. had extensive scientific and clinical experience in treating cleft speech disorders and voice disorders. This senior researcher could rely on many years of clinical experience to provide a clinical viewpoint on the gathered data. Even though the seniority of the researchers differed, each member of the triangulation discussion provided the same amount of input in the discussion.

Negative case analysis of one case was included in the study (Hanson, 2017). Negative cases are included as part of the constant comparative method of qualitative data analysis (Hanson, 2017). Using a negative case, we searched outside the data for clues to shed light on why analysis of a specific interview revealed anomalous

responses that deviate from other reports or research hypotheses (Gobo & Mauceri, 2014). In this context, some deviant statements were made by participant 1, an 8-year-old boy with a unilateral cleft lip and palate who had a speech and language therapy history of 4 years with a dose of 2x30 minutes per week. An additional (negative) case was recruited with specific demographic characteristics as similar as possible to participant 1. The following characteristics were considered: age, cleft type, speech and language therapy history, and dosage. Participant 2 was recruited for this purpose.

Confirmability and credibility of the data were guaranteed by providing the audit trail above. This means that a transparent description of the research design and process, the data collection, and data analyses is provided (Lincoln, 2007).

## **Results**

### **Participants**

6 children (median age = 8,5 years, age range = 5 - 12 years) participated in this study. Five children had a unilateral cleft of the lip and palate and one child had a cleft palate only. Each child had a speech and language therapy history (median = 3 years, range = 1 – 8 years) and was currently following speech and language therapy for the treatment of cleft speech characteristics. The dose of this intervention differed among the children (Table 1). The length of the different interviews ranged from 15 minutes to 20 minutes.

[Please, insert Table 1 here]

### **Themes**

The analyses of the interviews revealed 3 major themes of importance to the children: (1) treatment values, (2) treatment practices, and (3) treatment outcomes (Table 2). Each theme was divided into different subthemes. The theme 'treatment values' consisted of the subthemes expectations and emotions around therapy and interference with daily living. Information flow, therapy content, confirmation and rewards, parents' attendance, therapy dosage, and homework were subthemes of the major theme 'treatment practices'. The theme 'treatment outcomes' was divided into two subthemes, namely speech improvement and peers' reactions.

[Please, insert Table 2 here]

### **Treatment values**



### Expectations and emotions around therapy

Most children had positive attitudes towards speech and language therapy: they “liked it” and “it (note: speech and language therapy) was fun”. Some children (participants 1 and 2), however, had negative attitudes and told that they did not enjoy speech and language therapy or were afraid to make mistakes.

*“Participant 2: Sometimes I feel sad.*

*Interviewer: Can you tell me a bit more about that?*

*Participant 2: I’m afraid that I can’t do it (note: the exercises).”*

Some children (participants 2, 3, and 5) had clear expectations around speech and language therapy: they told that they needed to go to the SLP to “help” their speech. They explained that they also expected that practicing with the SLP would make their speech more understandable to others.

*“Participant 2: I hope it (note: speech and language therapy) helps me talk well.”*

*“Participant 3: Speech and language therapy is important for my speech.”*

*“Participant 5: Some children don’t understand me. I hope practicing will help me with that.”*

One child (participant 4) told that he did not know why he needed to go to the SLP. He explained that he did not know the purpose of the games he played with her. Nevertheless, he felt that he learned something during the speech and language therapy sessions. When the interviewer followed up with this statement, he could not explain what he was exactly learning. Another child (participant 1) reported that he needed to go to the speech therapist because she “helps” him. When the interviewer asked what he exactly meant by “help”, no further specifications were made. He told that he goes to speech and language therapy because his mother told him to do that.

*“Participant 4: I don’t know why we do those exercises.*

*Interviewer: But you said that you feel like you are learning something?*

*Participant 4: Yes. I notice that.”*

### Interference with daily living

Speech and language therapy had a varying influence on children's daily lives. Some children considered speech and language therapy a waste of time. Children preferred to spend their time doing other things, for example playing video games or watching movies.

*"Participant 1: I just think it is a waste of time. It is a waste of time.*

*Interviewer: Why do you experience this as a waste of time?*

*Participant 1: Because I have less time to play with my iPad."*

*"Participant 2: I would rather play with my cars than go to speech and language therapy."*

Some children mentioned that they would prefer to do their schoolwork during the speech and language therapy sessions. Otherwise, they still had to do this after the sessions. This interfered with other daily activities like playing at home or watching TV.

*"Participant 2: I would rather do my school work. Now I do things that are not related to my school. I prefer to finish school stuff so that I do not have to do that when I am back home."*

If children received speech and language therapy during school time, they did not want to skip enjoyable classes like handcrafting classes or gymnastics.

*"Participant 5: I did not like it if I was taken out of the class or the schoolyard for therapy.*

*Interviewer: Would you prefer that otherwise?*

*Participant 5: (Silence) After school or something like that."*

## **Treatment practices**

### Information flow

While some children attached importance to receiving treatment-related information from the SLPs, others did not. If children mentioned that they liked to receive information, this was related to the structure of the therapy sessions and providing a rationale for therapy exercises.

*"Participant 5: I want to know what we are going to do. And why I need to do it (note: the exercises)."*

*"Participant 1: I don't like it when she (note: the SLP) explains everything. It takes too much time."*

### Therapy content

All children agreed that exercises should be provided on varying levels. Most children considered exercises on the word level as 'too easy' and 'boring'. The older children (participants 3 and 5) in this sample mentioned the use of reading exercises. This included reading words or sentences with target consonants. These exercises were considered less challenging by the children.

*"Participant 5: I had to read a lot. While I was reading, I needed to focus on the speech sounds. I can already read, that was so boring."*

Different children attached importance to practicing on the level of spontaneous speech as this was a challenging task outside the therapy sessions.

*"Participant 3: I want to practice talking. Paying attention to it (note: speech) all the time is difficult."*

### Confirmation and rewards

Some participants (2, 4, and 6) mentioned that their SLPs used rewards (i.e., stickers) at the end of every therapy session. Other children, participants 1, 3, and 5, mentioned that they no longer received rewards. The majority of these children told that they did not feel the need to receive any rewards. Participant 1 mentioned that the stickers were not a medium for him to better like the speech and language therapy.

*"Participant 1: I do not receive any rewards anymore."*

*Interviewer: Did you like speech and language therapy more when you did receive them?*

*Participant 1: No (laughs)"*

### Parents' attendance

The majority of the children preferred that their parents were absent during therapy. When the interviewer followed up with these statements, children told that their parents were too severe or that they felt too much pressure if their parents would attend therapy. Only one child (participant 4) had no issues with his parents observing speech and language therapy. He told that he did not particularly like or dislike the presence of his parents during the sessions.

*"Participant 1: I wouldn't like it because she (note: mother) can get very mad."*

*"Participant 3: I prefer to be alone."*

*Interviewer: Can you tell me more about that?*

*Participant 3: Yes, they (note: parents) would be looking at me the whole time. No, no."*

### Therapy dosage

Some children considered 30 minutes of speech and language therapy as too long, while others did not. Children who told that 30 minutes was long also explained that this feeling faded once the therapy started.

*"Participant 1: Speech and language therapy lasts long. But when it (note: the session) is over, I think "Wow, that went by quickly."*

One child (participant 3) received 1 hour of speech intervention per week. She reported no concerns regarding this dosage.

*"Participant 3: One hour is enough. It shouldn't be more or less."*

Only one child (participant 6) received 3 speech and language therapy sessions per week. When the interviewer asked her to tell something about this, she reported no concerns regarding the therapy frequency.

### Homework

All children reported that they did not like to practice speech exercises at home. When the interviewer followed up with these statements, the children said that they preferred to do other things at home for example playing video games or watching movies.

*"Participant 3: I don't like it (laughs). I want to do other things at home."*

## **Treatment outcomes**

### Speech improvement

Different children made statements that could be coded under the subtheme "speech improvement": *"it (note: speech and language therapy) helped me"* and *"I learned different things"*. These two statements were made during different interviews. It were, however, the only quotes on this theme that we identified across all the children's answers.

### Peers' reactions

Different children made statements regarding the reactions of peers to their speech during the therapy process.

*“Interviewer: Do you talk about it with your friends?”*

*Participant 1: No, because (silence). Everyone has something to practice. I need to go to speech and language therapy and my friend practices his mathematics or something.”*

*“Participant 2: I hope it (note: speech and language therapy) helps me talking well.”*

*Interviewer: Is that difficult for you?*

*Participant 2: Yes.*

*Interviewer: Is it something you think your friends notice?*

*Participant 2: Yes, they tell me that.”*

*“Participant 5: Some children don’t understand me.”*

## **Discussion**

Qualitative research is gaining more attention in the cleft literature. Unfortunately, capturing the perceptions of children is still uncharted territory. Therefore, this qualitative study investigated the perceptions of young children, aged 5 to 12 years, about the speech and language therapy they receive. We specifically focused on speech and language therapy to eliminate cleft speech characteristics.

Interviewing the children revealed 3 major themes: (1) treatment values, (2) treatment practices, and (3) treatment outcomes.

### **Treatment values**

Most children referred to speech and language therapy as “something they liked” and “being fun”. Nevertheless, not all children had positive attitudes. Negative attitudes were related to having fear of making mistakes during therapy. The latter finding is of particular interest to SLPs. If children feel afraid of making mistakes, SLPs must anticipate this by counseling them and by providing adequate feedback. Similar to the study of Van Lierde et al., (2012), some gender differences could be observed. The latter study reported that significantly more boys with cleft palate (48%) disliked speech and language therapy compared to girls (8%). The findings of our study demonstrated that participants 1 and 2, two boys, had negative attitudes towards speech and language therapy. In the literature, however, no explanation can be found yet for these gender differences. In the future, it may be interesting to investigate whether the child’s gender plays a role in speech-language therapy outcomes.

Some children had clear expectations of the purpose of speech and language therapy. Speech and language therapy should “*help*” improve their speech and make it more understandable to others. In other words, children did perceive the purpose of the therapy as being for the benefit of themselves rather than of someone else. This finding is in contrast with a previous qualitative study that investigated the perceptions of children with communicative difficulties concerning speech and language intervention (Owen, Hayett, & Roulstone, 2004). Remarkably, children in the latter study perceived the purpose of speech and language intervention as being for the benefit of other children. Perhaps, the long and interdisciplinary treatment process that is often inherent to having a CP±L (P. Mossey, 2003) makes these children more aware of their speech problems and the need for speech intervention. Even though most of the children in this study seemed to be aware of the purpose of speech and language therapy, some children were not. Speech and language therapy seemed to be something they just accepted. One may question whether this lack of awareness may potentially have a negative impact on the child’s progression during therapy.

Similar to findings in parental qualitative research (Alighieri, Bettens, Vanoost, et al., 2021; Lindeborg et al., 2020; Sommer et al., 2021), cleft speech intervention was considered burdensome by children if it interfered with their “normal” daily life. Children spend a major amount of their time in school. If additional speech and language therapy is needed, less time can be spent on leisure activities. Integration of school work during speech and language therapy sessions was one suggested strategy of the children to decrease speech and language therapy-related burden. This may be something that SLPs could consider. Some language-related (or other) homework from school may perhaps provide some opportunities to practice certain speech sounds.

### **Treatment practices**

With regard to therapy content, children attached importance to variable practice patterns. Some specific practice levels, like exercising on the word level or reading exercises, were not considered challenging enough. These statements were made by children with a varying severity of cleft speech disorders. This finding reveals that children, regardless of the severity of the speech disorder, require a certain level of challenge during therapy sessions. Remarkably, this statement from children is in line with earlier qualitative studies in parents (Alighieri, Bettens, Vanoost, Verhaeghe, & Van Lierde, Accepted for publication; Alighieri, Peersman, et al., 2020). Parents of children who received high-frequency speech intervention (i.e., 10 hours of speech intervention divided over 2 weeks) reported a concern regarding a lack of variety in treatment exercises when their child receives speech

intervention daily. As most children in the present study received a rather low dosage of speech intervention and they do report this concern, this is an important therapy aspect for SLPs to account for. As suggested by the children in this study themselves, targeting more functional speech competencies in terms of practicing on the level of spontaneous speech would perhaps be a good solution. However, devoting enough time to more operational practice levels like sounds in isolation, words, and sentences is important before moving on to the level of spontaneous speech (Van Riper, 1972). According to the traditional motor-phonetic articulation therapy described by Van Riper (1972) and guidelines described by Golding- Kushner (2004), a next operational practice level can be introduced during speech and language therapy when the child can correctly produce the target sound in 90% of the time with minimal cues from the SLP.

Another remarkable finding that emerged from the present study is the use of rewards. Whereas previous studies have demonstrated that parents attach major importance to the use of extrinsic motivators like stickers (Alighieri, Peersman, et al., 2020), the children in the present study did not necessarily feel the need to receive these items at the end of a therapy session. One participant even mentioned that presents were not a medium for him to like the therapy. This finding suggests that intrinsic motivation for speech and language therapy is, at least for some children, as important as extrinsic motivation. As our data revealed that children had expectations around the speech and language therapy purpose (i.e., it should improve their speech), we may question whether some children have reached “integrated regulation”, which is a form of internalized extrinsic motivation (Vansteenkiste & Sheldon, 2006). Integrated regulation is a more volitional or autonomous form of motivation and means that the child integrates treatment outcomes with other values and life interests (Vansteenkiste & Sheldon, 2006). For example, a child with a CP±L attaches importance to speech and language therapy as this may increase his/her speech intelligibility to other children facilitating shared play and activities. This finding may be valuable for determining therapy activities, especially since achieving integrated regulation requires a certain amount of maturity, self-understanding, and awareness (Haerens, Bettens, Van Lierde, & Aelterman, 2021). This integrated regulation in some children may perhaps be a gateway for achieving identified regulation. This means that children engage in treatment because they understand the importance of speech and language therapy exercises (Haerens et al., 2021). As suggested before, this is interesting as it is impossible to only provide exercises that are fun (Haerens et al., 2021). SLPs must help children truly understand the meaning of specific exercises so that they will be more willing to engage in (even hard) therapy activities (Haerens et al., 2021;

Vansteenkiste & Sheldon, 2006). It must, however, also be noted that the present study included children with a varying age range. This may also be a factor why their views on receiving stickers varied.

Even though the current speech intervention literature emphasizes the importance of parental presence during therapy sessions (Klatte et al., 2020), the majority of the children in this study preferred that their parents were not present during the sessions. Anderson, Funk, Elliott, & Smith (2003) reported that that parental pressure can decrease children's reported enjoyment of extracurricular activities (Anderson, Funk, Elliott, & Smith, 2003). They argued that parents are probably not aware of the potency of pressuring behaviors as the relationship between these behaviors and child enjoyment has been understudied. Even though the Anderson study is an example of research in the area of extracurricular activities in the sports domain, parallels can be pulled with speech and language therapy in children with a CP±L. Parents may begin with good intentions trying to introduce their children to sports activities or in this case speech and language therapy that may ultimately bring them success in terms of speech progress. Parents may believe that pressure 'to do well' or expressing some kind of disappointment in a child's performance will provide the child motivation for improvement (Anderson et al., 2003). However, well-meant parental pressure can lower children's enjoyment and intrinsic motivation to continue (Anderson et al., 2003). The authors suggest that parents should encourage their children's activities while allowing them to make their own decisions with regard to these activities. Specifically in the context of cleft speech intervention, this could perhaps mean that we should listen more to the voices of children when determining to continue or end speech and language therapy in cases where a decrease in the child's motivation for therapy is seen. Only younger children in this sample (participants 4 and 6) had no issues with their parents being present during the sessions which is an interesting opportunity for early speech intervention in children with CP±L. Previous studies have already demonstrated the positive effects of parental training and therapy attendance in early speech intervention for children with a CP±L aged 14 to 36 months (Ha, 2015; Scherer et al., 2008; Sweeney et al., 2020). Perhaps, parents can also be more actively involved in homework exercises. Our data revealed that practicing speech exercises at home was not an enjoyable task for the children in this sample. At home, they preferred to do other things. This suggests that home speech exercises should be reconsidered to make them more enjoyable. It is, for example, possible to provide online computer exercises. In the area of speech-language pathology, there exist a wide range of online applications for speech exercises (Mashima &



Doarn, 2008; Toki & Pange, 2010). However, these are not always adapted to the specific needs of children with a CP±L which makes this domain an interesting subject for further research.

Besides speech and language therapy content, use of motivators, parents' attendance, and homework, speech and language therapy dosage is another important variable that should be considered as this can impact intervention outcomes (Baker & Williams, 2011). The majority of the children in this sample received 30-minute speech and language therapy sessions. Even though this was considered quite long for some children, they agreed that it felt like the sessions flew by. Surprisingly, children made no statements about the frequency of speech and language therapy. Only one child (participant 6) who received 3 speech and language therapy sessions per week told that she had no concerns with this frequency. This finding is interesting suggesting that children would have no problems with speech intervention that is provided with a high frequency. In the past few years, increasing attention has been paid to the effect of varying dosages of cleft speech intervention (Albery & Enderby, 1984; Alighieri et al., 2019; Alighieri, Van Lierde, et al., 2021; Hegarty, Titterington, McLeod, & Taggart, 2018). These studies demonstrated superior outcomes of cleft speech intervention delivered with a high frequency compared to cleft speech intervention delivered with a lower frequency. Previous studies have already demonstrated that, besides the superior quantitative outcomes of high-frequency speech intervention, this service delivery model is also more acceptable to parents and SLPs compared to more traditional lower-frequency service delivery models (Alighieri et al., 2022). The present study adds additional evidence for this high-frequency speech intervention as children may not seem to report any problems with the frequency of therapy sessions. In the future, it is necessary to investigate the retrospective acceptability of high-frequency cleft speech intervention from the children's point of view.

### **Treatment outcomes**

Children talked about speech and language therapy in terms of "helping" and "learning". No specific statements were made about their perceived speech improvement. This was somehow surprising as our data did reveal that children had expectations about the purpose of speech and language therapy in terms of improving their speech. This finding is in line with previous research demonstrating that children did not clearly differentiate speech and language therapy benefits from the benefits of other forms of extra support in class like academic learning support (Owen et al., 2004). SLPs may put more emphasis on the benefits of speech and language therapy for the child's daily living. Perhaps, this can additionally increase the integrated regulation in some children

(Vansteenkiste & Sheldon, 2006). Even though the children themselves did not make any specific reports about speech improvement, they were aware that peers were judging their speech. Speech disorders in children with a CP±L are associated with feeling different than peers and a greater likelihood of developing interpersonal problems (Everhart, Cochran, Lambrou, Davies, & Marik, 2022). Coping techniques differ between children. Some children from our study don't talk about it with friends whereas other children seem to attach more importance to peers' reactions. As children in this sample noticed that other individuals needed to go to the SLP too, for example, to practice school skills, they seemed to be more accepting of the process.

This was the first study that investigated the perceptions of young children with a CP±L concerning the speech and language therapy they receive. By doing so, we responded to the call of the WHO to pay more attention to the patients' perspectives as part of evidence-based care (P. A. Mossey & Catilla, 2003). Trustworthiness and confirmability were guaranteed by including discussions between the researchers and an audit trail. In addition, negative case analysis was included as part of the constant comparative qualitative data analysis method (Hanson, 2017). The study group was quite heterogeneous with children having different speech and language therapy histories and receiving different frequencies and intensities of speech and language therapy. In the future, it would be interesting to investigate children's opinions of and experiences with a specific speech and language therapy dosage or speech and language therapy program. This will help SLPs to better tailor treatment plans to the need of our patients with a CP±L.

## References

Albery, L., & Enderby, P. (1984). Intensive speech therapy for cleft palate children. *British Journal of Disorders of Communication*, 19(2), 115-124.

Alighieri, C., Bettens, K., Bruneel, L., D'haeseleer, E., Van Gaever, E., & Van Lierde, K. (2020). Effectiveness of speech intervention in patients with a cleft palate: comparison of motor-phonetic versus linguistic-phonological speech therapy approaches. *Journal of Speech, Language, and Hearing Research*, 63, 3909–3933. doi:[https://doi.org/10.1044/2020\\_JSLHR-20-00129](https://doi.org/10.1044/2020_JSLHR-20-00129)

Alighieri, C., Bettens, K., Bruneel, L., Vandormael, C., Musasizi, D., Ojok, I., . . . Van Lierde, K. (2019). Intensive speech therapy in Ugandan patients with cleft (lip and) palate: a pilot-study assessing long-term effectiveness. *International journal of pediatric otorhinolaryngology*, 123, 156-167. doi:<https://doi.org/10.1016/j.ijporl.2019.05.007>

Alighieri, C., Bettens, K., Vanoost, L., Demuyne, K., Verhaeghe, S., & Van Lierde, K. (2021). Parents' perceptions on speech therapy delivery models in children with a cleft palate: A mixed methods study. *International journal of pediatric otorhinolaryngology*, 151, 110958. doi:<https://doi.org/10.1016/j.ijporl.2021.110958>

Alighieri, C., Bettens, K., Vanoost, L., Verhaeghe, S., & Van Lierde, K. (Accepted for publication). Parents' perceptions on speech therapy delivery models in children with a cleft palate: a mixed methods study. *International journal of pediatric otorhinolaryngology*.

Alighieri, C., Bettens, K., Verhaeghe, S., & Van Lierde, K. (2021a). From excitement to self-doubt and insecurity: speech-language pathologists' perceptions and experiences when treating children with a cleft palate. *International journal of language and communication disorders*, 56, 739-753. doi:10.1111/1460-6984.12624

Alighieri, C., Bettens, K., Verhaeghe, S., & Van Lierde, K. (2021b). Speech diagnosis and intervention in children with a cleft palate: a qualitative study of Flemish private community speech-language pathologists' practices. *International Journal of Speech-Language Pathology*, 6, 1-14.

Alighieri, C., Peersman, W., Bettens, K., Van Herreweghe, V., & Van Lierde, K. (2020). Parental perceptions and expectations concerning speech therapy-related cleft care - a qualitative study. *Journal of communication disorders*, 87, e106028. doi:<https://doi.org/10.1016/j.jcomdis.2020.106028>

Alighieri, C., Van Lierde, K., Cammu, H., Vanoost, L., & Bettens, K. (2022). The retrospective acceptability of high intensity versus low intensity speech intervention in children with a cleft palate: A qualitative study from the parents' point of view using the Theoretical Framework of Acceptability. *International Journal of Language Communication Disorders*.

Alighieri, C., Van Lierde, K., De Caesemaeker, A., Demuyne, K., Bruneel, L., D'haeseleer, E., & Bettens, K. (2021). Is high intensity speech intervention better? – A comparison of high intensity intervention versus low intensity intervention in children with a cleft palate. *Journal of Speech, Language, and Hearing Research*, 25, 1-18.

American Cleft Palate-Craniofacial Association, A. (2016). *Standards for cleft palate and craniofacial teams*. Chapel Hill, NC: Author.

Anderson, J. C., Funk, J. B., Elliott, R., & Smith, P. H. (2003). Parental support and pressure and children's extracurricular activities: relationships with amount of involvement and affective experience of participation. *Journal of Applied Developmental Psychology*, 24(2), 241-257. doi:[https://doi.org/10.1016/S0193-3973\(03\)00046-7](https://doi.org/10.1016/S0193-3973(03)00046-7)

Baker, E., & Williams, A. (2011). *Intervention intensity for Speech Sound Disorders: How much and for how long?*

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Carter, B., & Ford, K. (2013). Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in nursing & health*, 36(1), 95-107. doi:10.1002/nur.21517
- Ellingsen, I., Thorsen, A., & Størksen, I. (2014). Revealing Children's Experiences and Emotions through Q Methodology. *Child Development Research*, 2014. doi:10.1155/2014/910529
- Everhart, S. A., Cochran, K., Lambrou, N., Davies, W., & Marik, P. (2022). Psychosocial Experiences That Support Positive Self-Concept in Children with Cleft Lip and Palate Adopted From China. *The Cleft Palate Craniofacial Journal*, 59(12), 1509-1519.
- Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S., & Richardson, A. (2010). Children and young people's experiences of cancer care: a qualitative research study using participatory methods. *International journal of nursing studies*, 47(11), 1397-1407. doi:10.1016/j.ijnurstu.2010.03.019
- Gobo, G., & Mauceri, S. (2014). *Constructing Survey Data: An Interactional Approach*. In. London: SAGE Publications Ltd. Retrieved from <https://methods.sagepub.com/book/constructing-survey-data-a-critical-approach>. doi:10.4135/9781446288481
- Ha, S. (2015). Effectiveness of a parent-implemented intervention program for young children with cleft palate. *International journal of pediatric otorhinolaryngology*, 79(5), 707-715.
- Haerens, L., Bettens, K., Van Lierde, K., & Aeltermann, N. (2021). The promise of self-determination theory to study the therapist-client relationship in speech-language treatment. *Journal of communication disorders*, 89, 106059. doi:10.1016/j.jcomdis.2020.106059
- Hall, M., Gibson, B., James, A., & Rodd, H. D. (2012). Children's experiences of participation in the cleft lip and palate care pathway. *International journal of paediatric dentistry*, 22(6), 442-450. doi:10.1111/j.1365-263X.2011.01214.x
- Hanson, A. (2017). Negative case analysis. *The International Encyclopedia of Communication Research Methods*, 1-2.
- Hardin-Jones, M., Jones, D., & Dolezal, R. (2020). Opinions of Speech-Language Pathologists Regarding Speech Management for Children With Cleft Lip and Palate. *The Cleft Palate-Craniofacial Journal*, 57, 55-64. doi:10.1177/1055665619857000

Harding, A., & Grunwell, P. (1998). Active versus passive cleft-type speech characteristics. *INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS*, 33(3), 329-352.

Hegarty, N., Titterton, J., McLeod, S., & Taggart, L. (2018). Intervention for children with phonological impairment: Knowledge, practices and intervention intensity in the UK. *International journal of language and communication disorders*, 53(5), 995-1006.

Holloway, I., & Galvin, K. (2016). *Qualitative research in nursing and healthcare*: John Wiley & Sons.

Klatte, I., Lyons, R., Davies, K., Harding, S., Marshall, J., McKean, C., & Roulstone, S. (2020). Collaboration between parents and SLTs produces optimal outcomes for children attending speech and language therapy: Gathering the evidence. *INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS*. doi:10.1111/1460-6984.12538

Lincoln, Y. (2007). Naturalistic inquiry. *The Blackwell encyclopedia of sociology*.

Lindeborg, M., Shakya, P., Pradhan, B., Rai, S., Gurung, K., Niroula, S., . . . Shaye, D. (2020). A Task-Shifted Speech Therapy Program for Cleft Palate Patients in Rural Nepal: Evaluating Impact and Associated Healthcare Barriers. *International journal of pediatric otorhinolaryngology*, 134, 110026. doi:10.1016/j.ijporl.2020.110026

Mashima, P. A., & Doarn, C. R. (2008). Overview of telehealth activities in speech-language pathology. *Telemedicine e-Health*, 14(10), 1101-1117.

Mossey, P. (2003). Global strategies to reduce the healthcare burden of craniofacial anomalies. *British dental journal*, 195(10), 613-613.

Mossey, P. A., & Catilla, E. E. (2003). Global registry and database on craniofacial anomalies: Report of a WHO Registry Meeting on Craniofacial Anomalies.

NVivo. (2018). NVivo qualitative data analysis software; Version 12, 2018.: QSR International Pty Ltd.

Owen, R., Hayett, L., & Roulstone, S. (2004). Children's views of speech and language therapy in school: Consulting children with communication difficulties. *Child Language Teaching Therapy*, 20(1), 55-73.

Scherer, N. J., D'Antonio, L. L., & McGahey, H. (2008). Early intervention for speech impairment in children with cleft palate. *The Cleft Palate-Craniofacial Journal*, 45(1), 18-31.

Sommer, C. L., Wankier, A. P., Obiri-Yeboah, S., Gyamfi, S., Frimpong, B. A., & Dickerson, T. (2021). A Qualitative Analysis of Factors Impacting Comprehensive Cleft Lip and Palate Care in Ghana. *The Cleft palate-craniofacial journal : official publication of the American Cleft Palate-Craniofacial Association*, 58(6), 746-754. doi:10.1177/1055665620959995

Steglitz, J., Warnick, J. L., Hoffman, S. A., Johnston, W., & Spring, B. (2015). Evidence-based practice. *International Encyclopedia of the Social Behavioral Sciences*, 8, 332-338.

Sweeney, T., Hegarty, F., Powell, K., Deasy, L., Regan, M., & Sell, D. (2020). Randomized controlled trial comparing Parent Led Therapist Supervised Articulation Therapy (PLAT) with routine intervention for children with speech disorders associated with cleft palate. *INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS*. doi:10.1111/1460-6984.12542

Toki, E. I., & Pange, J. (2010). E-learning activities for articulation in speech language therapy and learning for preschool children. *Procedia-Social Behavioral Sciences*, 2(2), 4274-4278.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care*, 19(6), 349-357. doi:10.1093/intqhc/mzm042

Van Lierde, K. M., Dhaeseleer, E., Luyten, A., Van De Woestijne, K., Vermeersch, H., & Roche, N. (2012). Parent and child ratings of satisfaction with speech and facial appearance in Flemish pre-pubescent boys and girls with unilateral cleft lip and palate. *INTERNATIONAL JOURNAL OF ORAL AND MAXILLOFACIAL SURGERY*, 41(2), 192-199. doi:<https://doi.org/10.1016/j.ijom.2011.10.030>

Van Riper, C. (1972). *Speech correction*: Prentice-Hall.

Vansteenkiste, M., & Sheldon, K. M. (2006). There's nothing more practical than a good theory: Integrating motivational interviewing and self-determination theory. *British journal of clinical psychology*, 45(1), 63-82.