Adolescents with congenital limb reduction deficiency: Perceptions of treatment during childhood and its meaning for their current and future situation

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Abstract

Background: Children with congenital limb reduction deficiency live with the decisions made by their parents and healthcare professionals about treatments to be carried out during the first years of life. To understand better the meaning of treatment during childhood, it is necessary to listen to adolescents who have had this experience. The aim of this study was to investigate the perceptions of adolescents with congenital limb reduction deficiency concerning the treatment they received during childhood and what it meant to them currently and in the future.

Methods: A descriptive design with a qualitative approach was used. Semi-structured interviews were conducted with 10 adolescents (six girls and four boys) with upper and/or lower limb reduction deficiency, median age 17.5 years (range 16–19). The interview data were analysed using a phenomenographic approach.

Results: The treatment received during childhood had contributed to shaping the adolescents, as shown in the emerging description categories Creating opportunities, Choosing one’s own path and Belonging in a context. Their current situation fell into three categories: A continuous journey, indicating that they still used the skills learned during childhood; Leaving the door open, indicating that they were not currently using the skills learned during childhood, but felt that there could be opportunities ahead; and Closing a chapter, indicating that they had stopped using their prosthesis or assistive devices and no longer needed those skills. Further, the adolescents’ thoughts about the future are portrayed in the categories Uncertainty about the future and Confidence about the future.

Conclusions: An understanding of the meaning of treatment received during childhood may help improve the delivery of treatment and continued support to meet the needs of children with congenital limb reduction deficiency in the short and long term.

KEYWORDS
limb malformations, paediatric rehabilitation, phenomenography
1 | INTRODUCTION

Parents and healthcare professionals (HCPs) often decide about treatments during childhood for children with congenital limb reduction deficiency (CLRD) (Sjöberg et al., 2020). The decisions concern surgery, prosthesis fitting or prescriptions of other assistive devices, followed by training of body functions and use of devices. Usually, the outcomes of these multidisciplinary treatments are quantitatively reported in terms of body functions, activity performance and participation in society (Boonstra et al., 2000; de Jong et al., 2012; Lankhorst et al., 2017; Vasluian et al., 2013). However, in order to gather a broader picture of the outcomes of treatments during childhood, it is necessary to listen to the adolescents with CLRD who received the treatment. With this paper, we aim to give a voice to adolescents with different forms of CLRD. Specifically, we focus on their perceptions of the treatment they received during childhood and its meaning in current and future situations.

A common goal of treatment during childhood for children with CLRD is to optimize body functions, reduce activity limitations and prevent negative consequences in the child’s future (Watson, 2000). However, a number of quantitative studies have reported a large variation in outcomes of early treatments (Bellew et al., 2011; Ekblom et al., 2013; Hermansson et al., 2005; Meurs et al., 2006; Vasluian et al., 2013). For instance, prosthesis acceptance rates varied considerably among adolescents who had their first prosthesis fitting during childhood (Huizing et al., 2010; Sjöberg et al., 2018; Toda et al., 2015). Consequently, it is likely that there is a variation in both the perceptions of past treatments, as experienced by the adolescents, and the way they see their current and future situation, as a result of their experiences of the early treatments.

Individual perceptions of treatments have been studied mainly in adults with CLRD or traumatic amputation (Anwar & Alkhayer, 2016; Murray, 2004, 2009; Widehammar et al., 2018); adaptation and a mix of emotions have been the key findings. Understanding the perceptions of the treatments during childhood among adolescents with CLRD and the way that these treatments shape their views of their current and future situation may help HCPs to improve the delivery of early treatments to meet the needs of their patients with CLRD. The aim of this study is therefore to investigate the perceptions of adolescents with CLRD concerning the treatment they received during childhood and what the treatment means to them now and in the future.

2 | METHODS

The study had a qualitative design using semi-structured interviews. The interview transcripts were analysed by applying a phenomenographic approach inspired by Marton (1981) and developed by Dahlgren and Fallsberg (1991). The focus in the phenomenographic approach is on variations in the conceptions of a phenomenon, that is, to describe qualitatively the different ways that people experience, understand or conceive of a phenomenon in the world around them (Marton, 1981; Marton & Booth, 1997). The research is not directed at the phenomenon per se, but rather at the variation in people’s understanding, experience or perception of the phenomenon. These three expressions are used synonymously in this article.

The variations in understanding represent a relationship between the person and the phenomenon and is referred to as a second-order perspective, where different ways of understanding a phenomenon have two aspects. The ‘what’ aspect tells us what is in focus, and the ‘how’ aspect describes how various meanings are created in relation to the ‘what’ aspect (Marton & Booth, 1997). These two aspects are inseparable, as meaning is created in relation to something. A second-order perspective means that the researcher, through other peoples’ experiences of the world and how they understand it, gains insights into the phenomenon (Marton, 1981). In this study, the focus is on the various ways adolescents with CLRD perceived (gave meaning to) their treatments during childhood with respect to their current and future situation.

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden (approval number: 2018/467). Written informed consent was obtained from all study participants.

2.1 | Sample and recruitment

Participants were recruited through purposive sampling from three national clinics for persons with CLRD in Sweden. Inclusion criteria were having some form of CLRD, being aged 16–20 and having received treatments for CLRD from their first year of life. Potential participants were informed by their HCPs via mail or orally during a clinical visit and invited to participate.

The recruitment process was carried out between May 2019 and June 2020, resulting in 10 participants, from seven different regions or counties in Sweden. To confirm their participation, the adolescents gave their own written consent via email, as they were older than 15 years of age (according to the Regional Ethical Review Board).
2.2 Procedure

The participants were asked to fill in a questionnaire to provide demographic information about themselves and their form of CLRD (see Table 1). For the interviews, a study-specific interview guide was designed to cover perceptions of the treatments received during childhood as a child with CLRD. The interview guide was tested and discussed with one young person with CLRD, slightly older than 20 years of age. All questions in the interview guide were retained, but some were reworded. The more direct questions such as ‘What is your perception of …?’ were rephrased into ‘What do you think about …?’, ‘Can you describe what you feel …?’ and ‘How does it affect you …?’ to use language more familiar to the adolescents.

The final interview guide contained three main questions: (a) Which treatments were offered and performed during your childhood regarding your CLRD? (b) What have the early treatments meant to you until now? (c) What do the early treatments mean to you in the future in the short and long term? At the end of the interview, the participants were given the opportunity to add anything they considered important that had not come up in the interview.

| TABLE 1 | Participants’ demographic characteristics and received treatments (n = 10) |
|---------|-------------------------------------------------------------------|
| Sex     | Female 6, Male 4                                                  |
| Age in years | Median (range) 17.5 (16–19)                                       |
| Education | Completed elementary school, from age 7–15 (9 years) 10          |
|          | Ongoing secondary school 9                                       |
|          | Completed upper secondary school from age 16–19 (3 years) 1       |
| Daily occupationa | Studies 9, Internship 2                                          |
| CLRD type | Longitudinal 2, Transverse 6, Unknown 2                          |
| Affected limb | Hand (unilateral) 3, Upper limb (unilateral) 4, Lower limb (unilateral) 2, Hand and foot (unilateral) 1 |
| Treatment and supportb | Surgery 5, Prostheses 7, Assistive devices (other than prostheses) 8, Training (body functions/activity performance) 6, Counseling 6 |

Abbreviation: CLRD, congenital limb reduction deficiency.
aIncludes one participant who combined studies with an internship.
bMost participants had received more than one type of treatment and/or support.

Three specialized clinics and local rehabilitation centres for children with CLRD had offered and provided the early treatments. Treatment decisions and time for implementation had been made in collaboration between parents and HCPs. The treatments that were received during childhood are presented in Table 1.

The interviews were conducted during the period September 2019 to May 2020. Each participant decided how and where the interview should take place. Five participants chose to be interviewed face-to-face, and five chose online video telephony instead. The interviewer presented the questions and discussed issues in a dialogue that encouraged the participants to express their perceptions about their past treatments. The first author (LS), with experience of working with young people with CLRD, conducted the interviews, which lasted on average 29 min (range 19–46 min).

2.3 Data analysis

All interviews were audio recorded and transcribed verbatim by an independent research secretary. The transcribed interviews were checked against the audio files by the first author (LS), and some small errors in the transcripts were corrected. Then Authors 1 and 4 (LS, CF) read the interview texts separately and finally discussed it together to get a holistic view of the data. Our phenomenographic data analysis followed a seven-step procedure developed by Dahlgren and Fallsberg (1991), with a constant interplay between the steps during the process of analysis. All seven steps of analysis were performed by two of the authors (LS, CF) and are described below.

1. Familiarization. In the familiarization step, the two authors listened to the audio files, read the transcripts and discussed the overall content and scope of the data.

2. Condensation. The statements (meaning units) in the texts that corresponded to the purpose of the study were identified and selected. The texts were reduced to some extent to capture the significant parts, but as far as possible, the original text was retained to keep the participants’ perceptions in their original context.

3. Comparison. A preliminary comparison of the selected statements was made in order to find similarities and differences in the descriptions.

4. Grouping. Texts with similar statements were grouped together into preliminary categories, including both the ‘what’ and the ‘how’ aspects.

5. Articulating. Attempts were made to describe the content of each category. To determine the similarities within the categories and the differences between the categories, the fourth and fifth steps were repeated several times. Comparisons between statements in the categories and the transcribed texts were repeated to establish the connection to the empirical data.

6. Labelling. Each category was named with an expression that emphasized its meaning.
7. **Contrasting.** Through a description of each category’s unique character, a contrasting comparison of the categories was made. According to Uljens (1989), there are three different category systems for contrasting comparisons of the developed description categories: the vertical, the horizontal and the hierarchical. The vertical system was used in this analysis as the intention was to study perceptions of the treatments during childhood over time. Table 2 presents some examples of quotes that support the contrasting comparisons for some of the categories. The contrasting comparison resulted in a structural framework called an outcome space, showing how the categories are linked to each other. The outcome space is illustrated in Figure 1.

In order to strengthen credibility and increase trustworthiness of the analysis, three authors (LS, CF and LH) discussed the analysis, focusing on Step 4 (grouping) and Step 5 (articulating), until consensus was achieved. The data were organized and coded using NVivo 12® qualitative data analysis software.

| Quotes                                                                 | Category                              | Situation         |
|------------------------------------------------------------------------|---------------------------------------|-------------------|
| 'if they had not done something then I would either be wheelchair bound, or well, basically just think so, 'cause then I wouldn't have been able to use the foot ... it would have been, like, just a body part that I couldn't use at all' | Creating opportunities               | Childhood        |
| 'I think that's good, to have the opportunity to choose from a young age because had I not been allowed to, if I had reached the age of ten or twelve and felt that I wanted one then, I think it's much more difficult to learn all this stuff that you learn as a toddler' | Choosing one's own path               |                   |
| ‘it has helped me a lot along the way, like, that I am not alone in this so in that way, it was fun to have some others who also had limb differences and who had the same feeling so to say. I thought that was really fun. It was important too’ | Belonging in a context                |                   |
| ‘something I tend to say sometimes that some mornings I wake up, put on my prosthesis and don’t think about me having a prosthesis, I just don’t think about myself as someone with a limb difference’ | A continuous journey                  | Current situation |
| ‘I do have the choice instead of not having the opportunity to choose’ | Leaving the door open                 |                   |
| ‘Although I do not have a prosthesis today because I think I am doing well without, it has been very good and that I have had that opportunity to have a prosthesis and been able to try it out’ | Closing a chapter                     |                   |
| ‘... there are a lot of things that are, you could use, or need two hands to, to sort of, well, distribute the load correctly but since I only have the left one, as much as I use it, there will be a lot of uneven loading. So that’s a disadvantage. A lot of things that I have thought about a bit’ | Uncertainty about the future          | Future situation  |
| ‘I’m so used to meeting a lot of different people and the doctor and so on, so I think new situations aren’t that difficult for me and that does help’ | Confidence about the future           |                   |

**TABLE 2** Examples of quotes supporting the contrasting comparisons for the categories
3 | RESULTS

By compiling the participants’ descriptions, treatments performed during childhood were identified as surgery constructions and reconstructions, try-outs of assistive devices and training in activity performance and counselling, individually and/or in groups, at the clinics and camps. A combination of treatments was commonly performed. The identified treatments were delivered regardless of whether the CLRD affected upper or lower limb.

Eight categories were identified to describe adolescents’ perceptions of the treatments they received during childhood and what these treatments mean for them in their current and future situation. Each category in the outcome space (Figure 1) is illustrated by quotes from the transcripts, translated with the objective of retaining the meaning of the original statements.

3.1 | Creating opportunities

The treatments received during childhood created opportunities to develop an existing body function or use of an artificial body part (a prosthesis) for different activities. The treatments provided a more ‘normal’ appearance of the affected limb. Hand or foot surgeries enabled grasping, standing and walking.

if they had not done something then I would either be wheelchair bound, or well, basically just think so, ‘cause then I wouldn’t have been able to use the foot ... it would have been, like, just a body part that I couldn’t use at all. (P3)

Different assistive devices were offered during childhood to enable performance of specific activities. In one case, the early introduction of assistive devices meant that surgery, earlier offered, was perceived to give no further improvement to the child’s ability to perform activities with the two-fingered hand.

Prosthesis fitting at an early age was perceived as an advantage. It was described as a process and a preparation for more advanced hand prostheses or for learning how to use the prosthesis in different situations.

The prosthetic training during childhood was experienced as playful sessions with games, but later understood as intended for developing prosthetic skills.

... but then you trained just as much as everything else, so it sort of fooled your brain. (P1)

The availability of adapted prostheses that were designed for specific activities created opportunities for trying out different leisure activities, such as guitar playing and swimming.

3.2 | Choosing one’s own path

This category shows that, as the child matures, he or she may prefer to make independent choices about how to use a prosthesis or assistive device at an early stage to perform activities.

I think that’s good, to have the opportunity to choose from a young age because had I not been allowed to, if I had reached the age of ten or twelve and felt that I wanted one then, I think it’s much more difficult to learn all this stuff that you learn as a toddler. (P6)

The early prosthesis fitting and training made it possible to choose to perform an activity with or without using the prosthesis.

So it has probably always been a thing to sort of, like, I feel like I don’t really need it and don’t really want it. But they have told me that it’s good to have it when you ride a bike, a lot of that, it is good when you ride a bike, then you can have the prosthesis and then I learned how to ride a bike without as well. (P2)
3.3 | Belonging in a context

This category summarizes the participants' reported experiences from participating in camps or group activities, from an early age and during childhood, which created opportunities to spend time with other children with CLRD. These events helped to develop a sense of belonging to a group of children with the same diagnosis and challenges. Although the camps and groups consisted of children of different ages and with different types of CLRD, an understanding of each other's situation minimized feelings of loneliness, promoted a positive image of CLRD and provided shared experiences of early treatments and practical solutions for different situations. Participating in camps or group activities also meant opportunities that during childhood acquire role models.

...it has helped me a lot along the way, like, that I am not alone in this so in that way, it was fun to have some others who also had limb differences and who had the same feeling so to say. I thought that was really fun. It was important too. (P8)

3.4 | A continuous journey

This category encapsulates the perception that the early treatments were appropriate, with participants reporting that they were still using the prosthesis or assistive devices and maintain the skills they had learned in childhood. Early hand or foot surgeries led to a continued development and use of the hand or foot in a way they perceived as natural.

...something I tend to say sometimes that some mornings I wake up, put on my prosthesis and don't think about me having a prosthesis, I just don't think about myself as someone with a limb difference. (P3)

Some participants talked of the importance of opportunities to exchange experiences with other children in the same situation throughout their childhood, despite their geographical distance from each other. Some also expressed a wish for continued opportunities to participate in camps or group activities to meet other adolescents with CLRD.

3.5 | Leaving the door open

This category arose from participants indicating that they no longer needed the early treatments in their current situation but that they felt that a need could arise in the future. Some reported that they had replaced the skills learned when using an assistive device with other ways of performing activities and with their own solutions for managing difficulties. Others perceived the prosthetic treatment during childhood to be of great importance for their later skills; they felt secure that they would be able to resume prosthesis use in future if the need were to arise. Thanks to their earlier acquired skills in prosthesis use, they felt that they could still choose how and when to use the prosthesis.

...I do have the choice instead of not having the opportunity to choose. (P6)

3.6 | Closing a chapter

This category emerged from the participants who no longer used the prostheses or other kind of assistive devices, received during childhood. The need for assistive devices waned in early adolescence; these participants had either never wanted the devices, or they found them too uncomfortable, or both. Despite having abandoned the assistive devices, the participants emphasized that they valued the early experience of learning to use them as a child, but no longer needed what they had learned.

...Although I do not have a prosthesis today because I think I am doing well without, it has been very good and that I have had that opportunity to have a prosthesis and been able to try it out. (P2)

3.7 | Uncertainty about the future

This category reflects the participants' uncertainty about the future when it is viewed in relation to the treatments during childhood. This uncertainty is derived from worries that their limbs and functions may not meet the demands of the labour market; for example, their strength and fine motor skills may not be sufficient, and their uneven body load may not be accepted. Even though the treatments they received in childhood had improved their capability, for example two-handed execution and fine motor skills, the feelings of uncertainty that they expressed mainly referred to their individual chances of being able to follow their preferred career path.

...there are a lot of things that are, you could use, or need two hands to, to sort of, well, distribute the load correctly but since I only have the left one, as much as I use [it], there will be a lot of uneven loading. So that's a disadvantage. A lot of things that I have thought about a bit. (P2)

Some also expressed uncertainty surrounding circumstances requiring personal adaptations, physical or social, in work situations ahead.

...And there I feel like it's a bit hard not knowing what I want to be, but also what can I choose from based on my personal situation without having to adapt half the work. Or without the people around me having to feel that they have to adapt without me asking them to. (P6)
Regarding the need for and access to future treatments, the adolescents expressed an uncertainty about what healthcare is available and possible for an adult with CLRD.

3.8 Confidence about the future

This category reflects participants’ trust in their own capacity and future needs. This was expressed as a perception of being in control of the things they want to do in future, thanks to their treatment during childhood. And if they should need further treatments in the future, they knew who to ask. Their confidence that they would be able to maintain their ability to use an assistive device was based on previous experiences.

> Then it’s nice that yes, I know how to do things, ‘cause I have, it all comes naturally how to do it, even though I haven’t done it in like ten years. (P1)

The early treatments involved meeting with therapists, other children and their families, all contributing to self-confidence in encounters with other people in social situations, which they considered an asset for future encounters.

> I’m so used to meeting a lot of different people and the doctor and so on, so I think new situations aren’t that difficult for me and that does help. (P6)

4 DISCUSSION

In this study, adolescents with CLRD gave their perceptions of the treatments they received during childhood and what these earlier treatments meant for them in their current situation, as well as what significance they may have for their future opportunities. To our knowledge, this is the first study that investigate perceptions of treatments received during childhood through voices of adolescents’ own experiences. The perceptions showed that the early treatment decisions had contributed to shaping the adolescents by creating opportunities, allowing them to choose their own paths and enabling them to have a sense of belonging in a context. This had influenced their current situation in one of three ways: Whereas some described how they were still using the skills learned during childhood, others were not currently using those skills but felt that there could be opportunities ahead, and the remainder had discontinued the use of prosthesis or assistive devices and no longer perceived a need for those skills. Further, the adolescents expressed both uncertainty and confidence about their future lives.

Based on their treatment during childhood, the adolescents described their current situation and the choices made on their behalf. From their descriptions, three different ways that the treatment during childhood had since shaped them were identified. These variations are to some extent familiar to researchers and HCPs within the field (Boonstra et al., 2000; Lankhorst et al., 2017; Murray, 2004; Smail et al., 2020; Vasluian et al., 2015), but to our knowledge, these different perceptions have not been discerned and discussed in any previous research. The adolescents’ varied perceptions of treatment during childhood, and the life choices they later made, reinforce the importance of taking into account and fostering an awareness among HCPs that their patients’ needs may change in the long term (Kerver et al., 2020; Widehammar et al., 2018). That would justify regular follow-ups of adolescents and young adults with CLRD, as suggested by McDonald et al. (2020), whether or not early treatments are continued in some form or have been discontinued.

In accordance with previous research, the adolescents perceived that the early treatment provided valuable opportunities for the development of the necessary abilities and skills for activity performance (Buffart et al., 2007; Eklom et al., 2013; Vannah et al., 1999; Watson, 2000). In addition, our study shows that the camps and group activities provided opportunities to spend time with other children with CLRD, which contributed to a sense of belonging to a group of children in the same situation. As described by the adolescents, this sense of belonging reduced loneliness and feelings of being deviant from the norm. As shown in a study of young women with CLRD (Krantz, 2012), our findings show that encounters with others of different ages and with different forms of CLRD offered opportunities for role models and new perspectives on their own condition and situation.

Prosthesis rejection is not uncommon among persons with CLRD. Common reasons for discontinued prosthetic treatment are discomfort, heavy weight and no benefits in real-life situations for a child (Biddiss & Chau, 2008; Postema et al., 1999; Smail et al., 2020; Vasluian et al., 2013). However, instead of seeing discontinued prosthesis use as a failure and a waste of time and resources, our study shows that the early experience of prosthesis fitting, training and support had a long-term value for these adolescents and enabled them to choose their own paths through life. Their experiences provided them with an understanding and meaning of prosthesis use as well as an ability to control a prosthesis, experiences perceived as beneficial if or when motivation and needs exist for a resumption of prosthesis use later in life. The adolescents in our study greatly appreciated the opportunities that their treatment during childhood had given them for making their own choices in current and future situations. Another view presented was that meeting several therapists in the healthcare context from an early age, together with all the social gatherings with other children, youths and families, had contributed to a social experience that would be of value in encountering new people in future, for example, employers and colleagues.

Our results showed that some adolescents expressed uncertainties about work tasks and co-workers in the future, derived from concerns about their physical limitations, despite having received treatment, training and support in childhood. This is similar to a study by Lankhorst et al. (2017), which showed that young adults with CLRD experienced limitations in choosing and finding suitable study or jobs in the transition to adulthood. This is also in accordance with studies of adolescents with spina bifida (Strömffors et al., 2017) and
other physical disabilities (Lindsay et al., 2021), where uncertainties and vague concerns about careers and adulthood are presented. Johansen et al. (2016) urged HCPs and the parents to focus more closely on vocational guidance to support adolescents and young adults to manage their career.

Based on the results of our study, further research is a need to develop more effective methods for supporting young people with CLRD in their transition to adulthood. In further research, it would also be interesting to examine the experiences of young people who for various reasons did not receive any treatment during childhood.

### 4.1 Methodological considerations

In common with other studies, this study has its strengths and limitations. When recruiting participants for the study, information was sent to all three national clinics, located in different parts of Sweden. However, the majority of the participants were recruited from the same clinic, which may limit the transferability of the results. This limitation was somewhat minimized because the 10 participants lived in seven different counties in Sweden.

There were no differences in length of interviews or in the substance of the information between the two interview methods. In accordance with previous research, the online video telephony interviews were comparable with face-to-face interviews for the information they generated (Janghorban et al., 2014). Neither did age or gender have any bearing on the differences between the participants’ personal communication of experiences, perceptions and reflections.

There is no real consensus regarding optimal sample size in the phenomenographic research approach; instead, it is the richness and variety of conceptions in relation to the phenomenon in the empirical material that determine the required amount of data. Although the number of participants in our study was low, the content of the interviews was of such extent that variations in perceptions of treatments during childhood, reflected over time, have provided a satisfactory outcome space.

Through our prior knowledge in the field, we understood the complexity of the condition (CLRD), the treatments and the patients’ experiences in relation to personal and societal expectations and demands. Our intention was therefore to capture the differences in perceptions of adolescents with CLRD. On this basis, we analysed the interview texts with a phenomenographic approach (Dahlgren & Fallsberg, 1991; Marton, 1981), in an attempt to catch the essence of and describe variations in perceptions of treatments for CLRD during childhood and their implications for current and future situations. Larsson et al. (2010), with support from Marton and Booth (1997), claim that perceptions of a phenomenon should not be viewed from a psychological or physical perspective; instead, the perceptions should be seen as reflecting the relationship between an individual and a phenomenon. In our case, it has been important to listen to the adolescents’ perceptions of the treatment received during childhood with an open mind as far as possible. Therefore, and in order to strengthen the credibility, the content of the interview transcripts was analysed and discussed repeatedly by two of the authors (LS, CF) to achieve a shared understanding of the description categories. In an effort to clarify the empirical material in the process, quotes are used in this paper to illustrate the descriptive categories.

### 5 Implications for Clinical Practice

In the further development of rehabilitation for children with CLRD, it is important to consider that children forge their own paths as they mature but this is to some degree shaped by the treatment they received during childhood.

HCPs need to be aware of the different aspects of the meaning of treatment during childhood for children with CLRD, in the short-term and long-term perspectives.

Furthermore, in treating children with CLRD, HCPs should be prepared to follow each child’s own path from childhood to adulthood and take different measures to fulfil the need for support at each stage.

### 6 Conclusions

This study has given voice to adolescents with CLRD with experience of receiving treatments during childhood. Their perceptions of this treatment contribute to broadening our knowledge about the meaning of treatments in CLRD in the short and long term. In view of the findings, we conclude that the adolescents valued the treatments they received in childhood and that it helped to shape their current situation. They also perceived the treatments to be important for future situations, based on their previous experiences or on confidence in their own capacity. Nonetheless, they described some uncertainties regarding their future career choices.

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### Conflict of Interest

The authors report no conflicts of interest.
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