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Research

Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study

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KEY WORDS

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ABSTRACT

Question: What are the perceptions of parents of children with physical disabilities about the home exercise programs that physiotherapists prescribe? How do these perceptions affect adherence to home exercise programs? **Design:** Qualitative study using focus groups and a modified grounded theory approach. **Participants:** Parents of children with physical disabilities who have been prescribed a home exercise program by physiotherapists. **Results:** Twenty-eight parents participated in the focus groups. Two key themes that related to adherence to home exercise programs in young children with physical disabilities were identified: the characteristics of the home exercise program; and the characteristics of the physiotherapist's teaching style. In the first theme, the participants described their experiences regarding their preference for exercises, which was related to the perceived effects of the exercises, their complexity, and the number of exercises undertaken. These factors determined the amount of time spent performing the exercises, the effect of the exercises on the family's relationships, and any sense of related burden. In the second theme, participants revealed that they adhered better to prescribed exercises when their physiotherapist made an effort to build their confidence in the exercises, helped the parents to incorporate the home exercise program into their daily routine, provided incentives and increased motivation. **Conclusion:** Parents perceive that their children's adherence to home-based exercises, which are supervised by the parents, is more successful when the physiotherapist's style and the content of the exercise program are positively experienced. These findings reveal which issues should be considered when prescribing home exercise programs to children with physical disabilities. [Lillo-Navarro C, Medina-Mirapeix F, Escolar-Reina P, Montilla-Herrador J, Gomez-Arnaldos F, Oliveira-Sousa SL (2015) Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study. *Journal of Physiotherapy* 61: 81–86]

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Introduction

For children with physical disabilities, the participation of their families in home activity programs is key for successful therapy interventions. Moreover, the active participation of parents during these activities has demonstrated positive effects on the children's outcomes,^{1–4} such as gains in motor skill attainment.^{2–4}

Despite the positive effects of adherence on functional outcomes, many studies have shown that children with disabilities are at risk of low levels of adherence.^{5–7} This problem is especially relevant for children with long-term conditions.^{6,8} Depending on the differences in the definition of adherence and its measurement, estimates of how many parents actually complete exercises with their children, according to prescription, vary; they average around 50%.^{7,9}

Quantitative research has identified a number of potential barriers to treatment adherence in children with disabilities; these

include: the complexity of the prescribed regimen, the parents' knowledge of the therapeutic regimen, and relations and interactions with health professionals.^{2,10} However, there is a recognised need for qualitative research in order to understand the complexities of treatment adherence.⁸

Several qualitative studies have assessed factors that affect adherence among children with disabilities,^{11–13} but these studies have not researched the influence of the interactions with physiotherapists who prescribe home exercise programs for very young children, where parents are necessarily involved. A recent systematic review and synthesis of qualitative papers on treatment adherence, which focused on children with chronic long-term conditions,⁸ found that healthcare professionals were seen as sources of support in overcoming adherence challenges. Although the existing literature provides some insight into parents' perceptions of healthcare providers who apply chronic therapeutic regimens, these perceptions could differ widely

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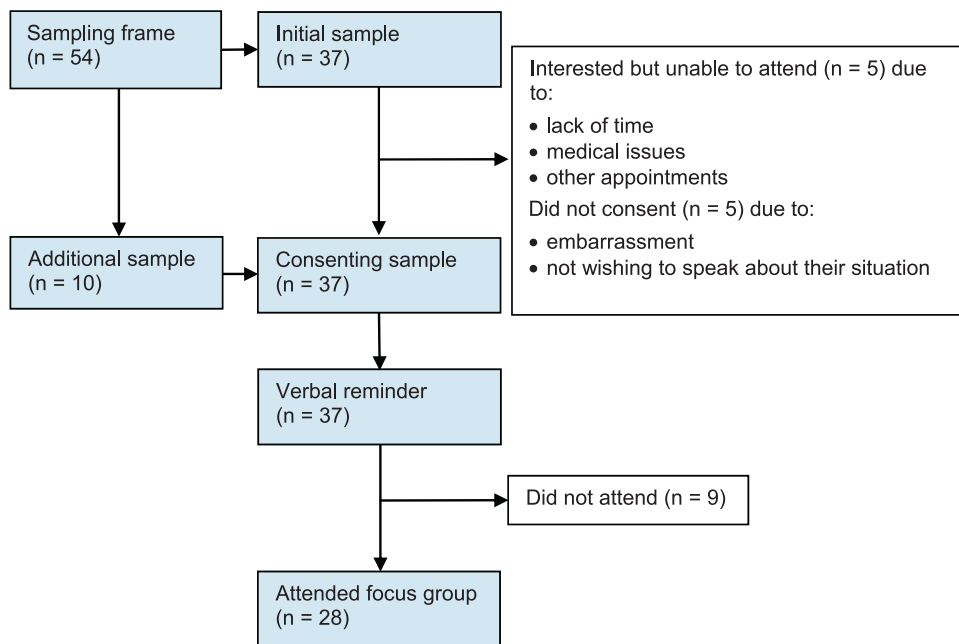


Figure 1. Flow of participant recruitment.

when physiotherapists provide exercises for children with disabilities. The present study was designed to examine the perceptions of parents who supervise exercises prescribed by physiotherapists for children with disabilities. Thus, the research questions for this study were:

1. What are the perceptions of parents of children with physical disabilities about the home exercise programs that physiotherapists prescribe?
2. How do these perceptions affect adherence to home exercise programs?

Method

Design

The qualitative design of this study involved focus groups, because group interaction can trigger responses and build insights that may not arise during interviews.¹⁴ Focus groups have been used in previous studies to identify experiences related to parents' adherence.¹⁵

Participants

This study included parents of children with physical disabilities who had been prescribed a home exercise program by physiotherapists from three early intervention centres in south-east Spain. The inclusion criteria were: parents of children aged between six months and six years, and who had been prescribed a home exercise program by a physiotherapist. Subjects were excluded if they presented with communication impairments that rendered participation in the focus groups impossible.

A purposive sampling strategy¹⁶ was used to include the parents of children in different age groups, genders, and clinical conditions. Although the final sample size was dependent on the saturation of information, 37 subjects were initially selected. An assistant researcher from each centre sent a letter to the eligible parents to invite them to participate in the focus group discussion. A week later, the research assistants called the parents to determine their willingness to participate, and to clarify any questions. When several parents declined to participate, other parents who met the appropriate criteria were sourced (Figure 1).

Data collection

Two researchers, who were unknown to the parents, conducted the focus groups with the help of a topic guide with predetermined questions (Box 1). This guide was based on a review of literature in this area. Additional questions were included, according to themes that started to emerge from the initial focus groups.¹⁷ During the focus groups, an audiotape, a videotape and field notes were used for data collection.

Parents were reassured of confidentiality before the beginning of their focus group session. Six focus groups were formed because categories were consolidated after these six groups.¹⁷ The size of the focus groups varied from four to seven participants, and sessions lasted from 40 to 80 minutes.

Data analysis

The sessions were transcribed verbatim. Each participant was assigned a number code for data entry. The following steps were used in the analysis process: a first reading of all transcripts to obtain an overall impression of content; segmentation of the sentences or paragraphs and codification of categories in the transcripts; and generation of themes.¹⁸ This data analysis was undertaken using a modified grounded theory approach,¹⁷ incorporating data collection, coding and analysis, and using a

Box 1. Thematic guide for focus group discussions.

Aim: To encourage the participants to speak freely about whatever they think is relevant to the study and their experiences from the onset of their children's disorders. Considering the home exercise program in which your child is involved:

- Do you usually perform the program? Why? Why not?
- How did you learn to perform the program?
- What benefits and problems do you find in applying the program?
- What encourages you to do it?
- How could the program be made easier to incorporate?
- What things could help you to do the program?
- Do you want to talk about something else related to the program or your experience at the centre?

process of constant comparison without the theory development component.¹⁹ Three authors (FMM, PER, CLN) independently coded segments of phrases that contained meaningful incidents and labelled these into categories using emerging codes. The categories were then combined into key themes. The authors reviewed and compared their findings to reach a consensus on all steps. Three rounds of coding and discussion took place; this was aimed at enhancing credibility of the analysis used, and developing clear themes and categories. This process was iterative with data collection and allowed new categories or themes to be inserted from the data of subsequent group transcripts. No new themes or categories emerged at the end of the sixth focus group, which implied that saturation was reached.

To check consistency of the final themes and categories, two researchers cross-checked their results via a blind review using codes for the same passages of two transcripts.²⁰ Any disagreements between the two researchers were resolved by discussion. At every step, an independent researcher reviewed whether the analysis was systematically supported by the data, with the intention of enhancing dependability.¹⁷ Confirmability was enhanced when the same categories emerged from the data of subsequent groups' transcripts.

Results

Flow of participants through the study

From the initial sample of 37 eligible participants, a final sample of 28 participants was included in this study. Six focus groups were formed, with two groups of fathers and four groups of mothers. The progress of the selection stages for the focus groups and reasons for non-participation are presented in Figure 1. The reasons for non-attendance at a scheduled focus group were unknown. Non-participants presented similar characteristics to participants. The characteristics of the participants and their children are shown in Table 1.

Characteristics of the participants

Participants reported that their children received between one and three weekly sessions of 30 to 45 minutes of treatment at the centre, and that they also routinely received prescribed home exercise programs for their children to perform. These home exercise programs varied between children. The frequencies of the main characteristics of the home exercise programs are shown in Table 2. Participants recognised problems of adherence either to the whole program or to specific types of exercises. For instance, on

Table 1
Characteristics of participating parents and their children with disabilities.

Characteristic	Participants (n = 28)
Parents	
Age over 30 yrs, n (%)	21 (75)
Female gender, n (%)	20 (71)
Number of children, n (%)	
1	12 (43)
2 or 3	16 (57)
Children	
Aged over 2 yrs, n (%)	18 (64)
Medical diagnosis, n (%)	
cerebral palsy	8 (27)
congenital disease ^a	5 (18)
developmental delay ^b	8 (29)
obstetric brachial plexus injury	2 (7)
encephalopathy of prematurity	5 (18)
Impairment, n (%)	
GMFCS level ≥ 3	19 (68)
cognitive impairment	15 (54)
visual impairment	10 (36)

GMFCS = Gross Motor Function Classification System.

^a Includes muscular torticollis, Duchenne muscular dystrophy, arthrogryposis multiplex congenita, and chromosome motor disorder,

^b without specific diagnosis.

Table 2
Characteristics of the home exercise programs.

Characteristic	Programs (n = 28)
Type of exercises, n (%)	
stretching	15 (54)
manual skills	22 (79)
locomotion	13 (46)
functional skills	28 (100)
postural stabilisation	21 (75)
sensory stimulation	16 (57)
Frequency (d/wk), n (%)	
1 to 3	4 (14)
4 to 6	9 (32)
7	15 (54)
Number of exercises, n (%)	
1 to 5	12 (43)
6 to 10	16 (57)

average, participants completed less than half of the prescribed exercise sessions and less than 50% of the stretching exercises required. According to participants, these problems were influenced by specific characteristics of both the prescribed home exercise program and the physiotherapist's performance during treatment at the early intervention centre (Box 2).

Theme 1: Characteristics of the home exercise program

Within this theme, the following subthemes were identified: preference for exercises developed through experience, and amount of exercises.

Preference for exercises developed through experience

Participants reported that their adherence differed between exercises, and admitted to developing preferred exercises over time within their home exercise program. Based on their own experiences, they were able to identify personal likes and dislikes, both on their part and on behalf of their children. Overall, participants preferred exercises that worked and were fun and enjoyable for their children.

When I see that an exercise is effective and it works, I do it. (Mother of a 13-month-old boy)

I think playing with my daughter is the best way to help her. This is my experience. (Mother of a 10-month-old girl)

In contrast, participants were less likely to be engaged when exercises were perceived either as producing adverse effects or being too complex. Adverse effects were related to the children's reactions to pain or discomfort, and perceptions of complex exercises were associated with the level of technical skills the parents needed to perform the exercises. Stretching and passive range of motion exercises were mostly referred to as 'complex exercises'. During these exercises, parents experienced feelings of uncertainty regarding the final range of motion and the risks for their child. There was a consensus that physiotherapists at the centre should perform complex exercises.

At the beginning, I didn't like doing exercises that were painful for my son. I didn't understand and it bothered me to do exercises that were painful. (Mother of a 12-month-old boy)

It was more difficult in the beginning, when the baby was little and not knowing how far I could safely move his neck. (Mother of an 8-month-old boy)

I am afraid to do the exercises, because I think I might break his leg or arm while doing the exercise. I am afraid, because I'm not a professional and I do not know how far or how much to do the exercises. (Mother of a 12-month-old boy)

Box 2. Summary of factors perceived to influence adherence to home exercise programs.

Theme	Subtheme	Categories of coded statements
Characteristics of exercises and home programs	Preference for exercises	<ul style="list-style-type: none"> • Exercises that improve outcomes • Enjoyable exercises • Exercises without adverse effects (pain, discomfort) • Non-complex exercises (without the need for technical skills)
	Amount of exercises	<ul style="list-style-type: none"> • Time consumption • Disruption of the affective or recreational family relationship • Excessive burden, according to the real needs of family
Physiotherapist's teaching style	Building parents' confidence in implementing the exercise program	<ul style="list-style-type: none"> • Demonstrating exercises with the child • Providing feedback • Providing written instructions • Providing information and support to parents
	Helping incorporation into daily routines	<ul style="list-style-type: none"> • Giving reminders to incorporate into daily routines
	Incentivising adherence	<ul style="list-style-type: none"> • Perception of achievements • Incentives based on goals • Changes in the child's exercise performance • Gaining peace of mind
	Monitoring and giving support to adherence	<ul style="list-style-type: none"> • Perception of regular monitoring of home program

Amount of exercise

Often, participants reported that they initially wanted to perform the recommended amount of exercises, but they tended to reduce these over time. They reported two reasons. The first reason was that participants felt that doing a lot of exercises was problematic, as this either required excessive time taken from their daily activities or it restricted their time for recreational or affective relationships with their children.

I do not do all exercises every day, it's too much and I'm not able to find enough time in my daily routine. (Mother of a 20-month-old boy)

My son receives a lot of physiotherapy at the centre. I believe my job is to be a mum first and not a physiotherapist. (Mother of a 2-year-old boy)

The second reason was that participants felt that executing the whole program could be an excessive burden for the children.

I do not do all the exercises every day because I think it's too much effort and stimulation for my child. (Mother of a 10-month-old girl)

Theme 2: The physiotherapist's teaching style

The way that the physiotherapist taught parents to acquire skills for their child's treatment influenced adherence to the home exercise program. The following subthemes were identified: building parents' confidence in exercise performance; helping parents to incorporate the home exercise program into their daily routine; providing incentives to maintain adherence; and monitoring and giving support to adherence.

Building parents' confidence in exercise performance

Participants reported that adherence was difficult when they lacked confidence in ensuring that exercises were performed correctly at home. They also reported that when the therapist helped to build that confidence, it had a positive influence on adherence to the home exercise program. According to the participants, several actions by the physiotherapist promoted their confidence. These included: demonstrating the exercises while the parents watch their child during physiotherapy treatment; asking the parents to demonstrate the exercises at

least once per month; observing exercise practice while providing feedback and making subsequent corrections in technique; giving written instructions and explanations in a way that is accurate, understandable and convincing; and providing opportunities for the exchange of information and for resolving uncertainties regarding home exercise programs. These aspects were important for skill acquisition at the beginning of treatment and for providing reassurance in subsequent sessions.

She (the therapist) teaches me the exercises while she is actually doing them with my daughter. Seeing how she performs the exercises during each session gives you more confidence to do them. (Mother of a 6-month-old girl)

She (the therapist) explained to me what she was doing with the child. Then she said to me: let's see how you do it; let's see if it's done correctly. (Mother of a 12-month-old girl)

For me it was very useful to have a worksheet, because at the beginning you feel lost and you don't know what to do with the child. (Father of a 1-year-old girl)

Our physiotherapist is always available. If I have any questions or want to talk or ask about an exercise, she clearly explains and this helps me to understand. Then I can perform the treatment with confidence. (Father of an 11-month-old boy)

Helping parents to incorporate the home exercise program into their daily routine

Participants reported that adherence was also low when they had difficulties incorporating home exercises into their daily routine. They reported that fitting exercises into their daily routine was a problem due to lack of time and forgetting to do the home exercises. Participants appreciated receiving cues within their daily routines, especially adherence reminders to avoid omissions or slips. They felt that, in general, they accept reminders, especially when professionals explain that cues and reminders are aids for performing the desired behaviour.

I do not do exercises every day, because I'm not able to fit these into my daily routine. Perhaps I would have more success if she had given me instructions about when to do them. (Mother of a 4-year-old boy)

Providing incentives to maintain adherence

Participants agreed that an important incentive for reinforcing adherence was the perception of achieving progress in their child's functional health status. However, participants reported that changes in their child's functioning were often slow and difficult to perceive over time. Participants tended to lose motivation and decrease adherence when they did not see any functional changes in their child's status over a long time period.

When I see my son move a little more, I believe it's the exercises I have done with him that have helped him. This motivates me to do the exercises. (Mother of a 20-month-old boy)

When I don't see improvements in my child, I am not motivated to do the exercises. (Mother of a 2-year-old girl)

Participants agreed that incentives, beyond the child's functional changes, are also important and seldom used by physiotherapists. They appreciate receiving goal-based incentives such as changes in the exercise performance (child's tolerance, number of repetitions) or gaining peace of mind; this last item was a relevant incentive for parents. Participants were afraid of being regarded as bad parents, in the future, if they could not take advantage of all the opportunities to care for their child.

At first, my son hardly held on at all, but now I see him much better at holding after the exercises and that motivates me to continue doing them. (Mother of a 22-month-old boy)

I did the exercise to benefit my child, but I also did it for me. It was an incentive for me to say that I did all that I could to help my child. (Mother of an 8-month-old boy)

Monitoring and giving support to adherence

Adherence monitoring by the physiotherapists was important, in order to encourage participants to follow the prescribed home exercise program. Participants reported that regular adherence monitoring by health professionals allowed them to voice the problems that they had complying with the exercise program. Most parents spoke about receiving solutions to their problems from physiotherapists, which helped them to improve their adherence. When participants failed to receive any new suggestions, they felt frustrated.

He recommended that we put the child to sleep on her side. After a while we told him that we could not get her on her side, so he suggested changing the pillow to the side. Now the child sleeps on the side we want. The solution has been successful. (Father of a 6-month-old girl)

She asked if we were doing the exercise that she had recommended. We discussed that we could not and although she told us to try, she gave us no alternatives. (Father of a 1-year-old girl)

Discussion

This study supports previous research showing that children with, or at risk of, developmental disorders are susceptible to low levels of adherence to home exercises.^{7,10} The results of this study indicate that the characteristics of the home exercise program and the physiotherapist's teaching style may influence adherence. This study also provides experiential knowledge that may be used as a starting point for healthcare providers to consider the tasks and strategies that may be used to develop and implement a home exercise program with adequate levels of adherence.

In this study, some parents rarely performed the whole home exercise program, instead only performing the exercises that they preferred. The finding that parents preferred enjoyable and simple exercises for themselves and their children is supported by previous research.^{21,22} Boas identified cases of parents and

children who did not enjoy taking part in some home exercises, and argued that the imposition of a prescribed exercise may increase the treatment-related burden and, thus, decrease adherence. The present study also suggests that the presence of pain during exercise plays a crucial role in the application and maintenance of a child's home exercise program. Child pain has also been cited as a relevant issue for parental stress.²³

In the present study, the amount of exercises was also noted to be a problem that developed over time. Some studies performed with parents of children with long-term conditions have also suggested that it is difficult to maintain adherence to home programs over time. However, the literature regarding home exercise programs specifically varies concerning the relevance of the amount of exercises: some authors have suggested that extensive programs often result in poor adherence,¹² while others have found this aspect to be irrelevant.⁹

Building confidence in exercise performance had an impact on the parents' ability to cope with their adherence. Three factors that were particularly important for confidence-building were: regular contact with parents; allowing parents to watch the physiotherapist interact with their child; and physiotherapists' involvement in reviewing the home exercises and providing information regarding their child's illness and treatment. Regular contact with healthcare providers has also been identified as a support strategy for learning home-based care.⁸ The opportunity to receive information about a child's illness and treatment has been identified as a relevant resource to help parents cope with the situation of having a child with health problems.²⁴ In the present study, feelings of uncertainty and fear were common and constantly shaped the parents' need for information.

These findings suggest that parents appreciate professional suggestions for incorporating home exercises into their daily routine and for overcoming challenges to adherence. This is consistent with a recent systematic review of qualitative papers on adherence, which focused on children with chronic long-term conditions.⁸ Parents also value the role of the therapist in encouraging adherence, by providing information about achieving objectives and seeing their child's development in response to the treatment. According to some authors, parents' knowledge of improvements seems to have a paradoxical effect: on the one hand, the perception of results in children can encourage parents to continue treatment, and on the other, it could cause parents to relax and decrease their adherence.²⁵

The experiences presented by parents in this study may be different from those presented by parents of children with other disorders. However, within the physical disabilities presented in the present study, several pathologies were represented, such as cerebral palsy and different types of congenital syndromes and diseases.

The present study was cross-sectional and the participants' recollection of events was retrospective, relying on their memory of past events. Therefore, longitudinal and prospective studies that include parents of children with different health conditions and that follow the children throughout the entire rehabilitation process may offer additional information. Also, the perceptions of the children performing the exercises were not taken into account, although this would have been difficult with the very young children involved in the study. Another limitation is that a systematic analysis of differences in the type of responses received from subgroups of parents was not performed (eg, by gender or the children's ages).

Given the sample size and the fact that the focus groups were conducted in only three early-intervention centres, caution should be taken when generalising the results. More research is required for this purpose, as well as for researching parent-related factors, because the findings were limited to factors related to exercises and therapists that contribute to poor adherence.

This study identified factors that might help physiotherapists to recognise early signs of poor adherence. Examples of these are concerns over correct techniques, fear of causing harm, difficulties incorporating the exercises into daily routines, boredom, and feelings of uncertainty. Therapists should remain alert for the

appearance of these signs over time, especially in the case of parents of younger children, or at the beginning of treatment.

This study also identified factors that physiotherapists might use to try to improve adherence. These include developing individualised paediatric home programs for each family, respecting their preferences, resources, and daily routines. Physiotherapists should be very sensitive to detecting the needs of families at each stage of their development within the home programs, in order to facilitate adherence, despite the changes in family situations.^{11,13,26} During the first treatment sessions, physiotherapists should also maintain frequent contact with parents in order to review their performance and grant feedback to build parents' confidence.¹⁰ Physiotherapists should be easily contacted throughout the process.⁸ The findings of the study also suggest that physiotherapists should strive to develop effective teaching techniques in order to promote parental involvement in the program.

What is already known on this topic: Home exercise programs have positive effects on the functional outcomes of children with disabilities. However, adherence to home exercise programs is difficult to achieve.

What this study adds: Parents of children with physical disabilities who have been prescribed home exercise programs by physiotherapists perceive that some characteristics of the programs and the physiotherapist's teaching style can influence their adherence. In order to promote adherence, physiotherapists should consider these factors when developing and teaching home exercise programs.

Ethics approval: The University of Murcia's Ethics and Research Committee approved this study. All participants gave written, informed consent before data collection began.

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