





Parental Adherence to Cranial Remolding Orthotic Treatment of Infants with Positional Cranial Deformities: A Qualitative Content Analysis

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Abstract

Background: This qualitative study was designed to investigate parental adherence to cranial remolding orthotic (CRO) treatment of infants with positional cranial deformities.

Methods: A qualitative content analysis was employed in this study. Researchers sought to find parental behavior while using a CRO for their infant with cranial deformity. Through in-depth and in-person interviews, researchers collected data from 22 participants using semi-structured questions regarding adherence to CRO treatment. Data were examined for patterns until saturation occurred, yielding categories that focused on the parents' main barriers and facilitators.

Results: Two general themes of "potential barriers to CRO treatment adherence" and "potential facilitators to CRO treatment adherence" were extracted from 12 subthemes of parental burden, transportation, availability of CRO services in hometown, financial responsibility, maternal/paternal attachment attitudes, CRO-related problems, others feedback, adjustment to the treatment, motivation and self-confidence, aesthetic satisfaction, communication with orthotist, and wife's empathy/spousal support.

Conclusion: Getting time off work, transportation to the orthotics' clinic, the lack of medical insurance coverage for CRO, reduced physical contact between parents and their child, and getting negative feedback from others were the most reported challenges. However, overcoming the initial difficulties and adjustment to the treatment with CRO, the high motivation of parents during therapy, an orthosis with good fitting and minor complications, a strong relationship between the parents and orthotist, and the father's companionship were revealed to facilitate the treatment process and increase adherence of treatment with CRO.

Keywords: Parent, Challenge, Cranial Remolding Orthosis, Facilitator, Adherence, Infant, Skull Deformity

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Introduction

Cranial deformity prevalence has grown significantly over the past 2 decades after the program suggesting laying infants in supine positions (1). When treating skull deformities, the primary goal of the treatment team and parents would be to create a more pleasant appearance (2). Appearance deformities can result in negative self-image, dissatisfaction, reduced self-esteem, negative self-view, isolation,

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^{1.} Department of Orthotics and Prosthetics, School of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, Iran

^{2.} Department of Rehabilitation Management, School of Rehabilitation Sciences, Iran University of Medical Sciences, Tehran, Iran and embarrassment and reduce one's quality of life if left untreated (3). The treatment method for this group of infants would vary depending on the deformity's severity and age (1). Positioning is recommended for infants younger than 3 months, provided that the deformation is mild to moderate; however, cranial remolding orthotic treatment (CRO) is recommended for children between the ages of 4

↑What is "already known" in this topic:

Parents' perception of the deformity and their level of satisfaction with their infant's skull appearance are the main factors involved in their choice of a treatment approach.

\rightarrow *What this article adds:*

Parental stress, transportation, availability of cranial remolding orthotic (CRO) services in hometown, financial burden, maternal/paternal attachment attitudes, CRO-related problems, others' feedback, adjustment to the treatment, motivation and self-confidence, aesthetic satisfaction, communication with orthotists, and wife's empathy/spousal support were the main challenges that parents faced while treating their infants with cranial deformities. and 12 months in cases with moderate to severe deformities that have not responded to positioning over 3 months (1). CRO redirects skull growth toward flattening area, resulting in head shape symmetry and proportion (4). CRO is built through scanning or molding and must be worn fulltime for 23 hours daily (5). After receiving a CRO, the parents must visit the CRO manufacturing center regularly so the orthotist can change the CRO if necessary (6).

The treatment team determines how severe a deformity is based on anthropometric criteria; however, the parents are the ones to choose the treatment approach (7). Parents' stress and worry can impact their decisions regarding the type of treatment (8). Parents' perception of the deformity and their level of satisfaction with the infant's appearance are the main factors in their choice of a treatment approach (9). CRO treatment success largely depends on parents' adherence to treatment instructions and the number of hours the orthosis is worn (10). Failure to complete the correction of the deformity could be due to either the lack of head growth or the parents' noncompliance with the treatment plan. Parents' low commitment rate to CRO would prolong the treatment duration and affect its results (11). Parents would probably be more compliant with faster treatments, as their exhaustion during treatment is considered a factor in abandoning treatment before success (12). The orthosis can bring about complications such as skin damage, excessive sweating, and pain. Regular visits during treatment can reduce the problems and worry and give the parents a better understanding of treatment results (1, 11). Parents generally cease therapy once they are satisfied with the infant's appearance and before reaching anthropometric proportion and symmetry criteria, which results in their refusal to return to the treatment team (13). Increased infant age and higher manual skills increase their ability to open the CRO, which can interrupt the treatment process (14). Relatives' or others' reaction to the use of CRO can also discourage the parents from showing up in the community or lead them to terminate the treatment prematurely (15).

Early orthotic treatment termination could cause permanent deformity and result in parents' dissatisfaction with the medical intervention. Although CRO treatment has proven effective, parents' experience with this process has remained neglected (9). A deep description of parents' experience with adherence to CRO treatment could help develop a better perception of the essential aspects of compliance with treatment and identify the factors associated with following treatment overlooked in previous research. The present study sought to investigate parents' lived experiences with adhering to CRO treatment and discover the facilitators and barriers.

Methods

Ethical Considerations

The ethical committee of Iran University of Medical Sciences approved the study protocol (No. IR.IUMS.REC.1400.1106). First, the purpose of the research and their right to withdraw from it were explained to all participants. The informed consent form was signed by the parents participating in the study. All recorded audio files were saved with the participants' permission before conducting the interview. The confidentiality of the information they would supply was also guaranteed to the participants.

Data collection and Analyses

The present study was conducted using qualitative content analysis concerned with a systematic analysis of textual data content. Participants were selected from 3 orthotics centers and a hospital specialized in pediatric cranial reconstruction in Tehran, Iran. The study adopted an inductive data analysis approach to find the overt and latent meanings of the studied phenomenon while incorporating flexibility (16). The combination of overt and latent content analysis helps find more precise results. This technique is widely used in the field of help when the available information and text are inadequate to understand a phenomenon. The exploratory, inductive approach seeks to understand and analyze patients' deep descriptions of various processes and positions based on data generally collected through semi-structured interviews (17).

A total of 22 parents with infants suffering from non-syndromic or postural cranial deformities who had experience with orthosis or had had CRO for a minimum of 2 weeks participated in the present study. Data collection was conducted using in-depth, semi-structured interviews (Table 1). Purposive sampling was performed from April to October 2022. Participants' deep experience and rich knowledge of the study subject play a prominent part in understanding the insight into the phenomenon in purposive sampling (17). The interviews took 45 minutes on average and were held in a private room with one or both parents. Selection continued until data saturation-that is reaching a suitable information quality and maximum diversity. Repeated information was taken as a sign of data saturation and sample size adequacy. Participants were asked for their permission to record the interviews before each interview started. Table 2 demonstrates the demographic features of the participants.

The principal researcher received training on data collection in qualitative research before conducting the study. The researcher asked the parents to share their experience of their infants' CRO treatment. Parents were assured that

Table 1. Semi-structured intervi

Number	Guide questions
1	What experiences (positive or negative) have you had while using the CRO?
2	How did you manage your challenges during CRO treatment?
3	What motivates you to continue of using the CRO?
4	What situations cause discourage of you from using the CRO?

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they would be given the chance to share their important and authentic experiences relevant to the research. The parents' perspective was viewed as the vital element in interviews, and no answer was considered right or wrong. The interview was designed with 4 questions by the researchers as a basis for the discussion to leave no significant aspect of the phenomenon (i.e., the use of CRO) overlooked (Table 1). The 3 main questions were used to open the conversation, seeking to steer the interview toward parents' various experiences influencing their use of orthosis. The term "using CRO", more regularly used in daily conversation, was adopted into the conversation instead of "treatment ad-

Table 2 Demographic characteristics of the participants (n = 22)

herence." The interviewer was a professional with experience in making pediatric orthotics who could thus follow the parents' thought process well. Interviews were held with parents whose children were undergoing CRO treatment or had terminated the CRO treatment by the treatment team or by themselves, regardless of the result. After the interviews, the researcher extracted and recorded the conversations word by word. The analysis was performed over several stages using the Lincoln and Guba evaluative criteria (18). The interviews were thus noted down and reviewed by all researchers to perform an overall evaluation. Semantic units were then processed by 2 researchers separately. The researchers (N.R. and T.B.; both with good methodological

Case	Child's	Deformity type	Severity	Age at	Gesta-	Inter-	Par-	Parents'	Dis-	Parents'
	sex		(%)	initiation	tional age	viewee(s)	ent's	educa-	tance to	occupation
				ment	(weeks)		age	level	(km)	
P1	Female	Deformational		5	38	Mother	27	Higher	850	Housewife
		plagiocephaly	CVAI=6.8	months				Education		
			CI=84.8	and 2						
D2	M-1-	Defermentional		weeks	20	Mathan	20	Distance	16	T-11
P2	Male	brachycenhaly	CI=98.6	4 months	39	Mother	30	Diploma	16	Tallor
		ordenyeephary	CI 90.0	and 2						
				weeks						
P3	Male	Deformational	CI=108	5	37	Both of par-	Mother:	Higher	45	Mother:
		brachycephaly		months		ents	32 Eathary	Education		Housewife
				and 5 weeks			rather:	Education		rather:
				weeks			50	Education		engineer
P4	Female	Bilateral coro-	CI= 89.6	3	36	Mother	Mother:		520	Mother:
		nal cranio-		months			22	less than		Housewife
		synostosis		and 2			Father	Diploma		Father:
				WCCKS			31	Dipiona		Marketer
P5	Female	Deformational		6	37	Mother	34	Higher	48	Teacher
		brachycephaly	CVAI =	months				Education		
			CI = 93.1	weeks						
			01 95.1	weeks						
P6	Female	Deformational		5	38	Both of par-	Mother:	Higher	335	Mother:
		plagiocephaly	CVAI=	months		ents	39	Education		Housewife
			/.6 CI= 96.6	and 3 weeks			Father: 41	Education		Father: Ar-
			01 90.0	weeks			11	Education		eniteet
P7	Male	Metopic cranio-	CI= 85	7months	37	Mother	28	Diploma	660	Housewife
		synostosis								
		(trigonoceph-								
		ary)								
P8	Female	Sagittal cranio-	CI=71.4	4	37	Mother	31	Higher	901	Designer
		synostosis		months				Education		
		(scaphoceph-		and 3						
		aly)		WEEKS						
P9	Male	Deformational		5	38	Mother	25	Diploma	13	Housewife
		brachycephaly	CVAI=	months						
			3.7	and 1						
			CI- 90.1	weeks						
P10	Male	Deformational	CI= 66.6	3	36.5	Mother	Mother:	Diploma	500	Mother:
		scaphocephaly		months			34			Housewife
				and 2			Fathor	Dinloma		Father: Cor
				WCCKS			10 rauler.	Dipionia		rauler Cal

CI-Cephalic Index; CVAI-Cranial Vault Asymmetry Index.

Table 2.	Continued									
Case	Child's sex	Deformity type	Severity (%)	Age at initia- tion of treat- ment	Gesta- tional age (weeks)	Inter- viewee(s)	Parent's age	Parents' educa- tional level	Dis- tance to clinic (km)	Parents' occupa- tion
P11	Female	Metopic crani- osynostosis (trigonoceph- aly)	CVAI= 2.9 CI= 80.7	5 months and 1 weeks	37	Both of par- ents	Mother: 29 Father:37	less than diploma less than diploma	700	Mother: Housewife Father: Lorry driver
P12	Female	Deformational plagiocephaly	CVAI= 13.3 CI= 86.2	5 months and 2 weeks	38	Both of par- ents	Mother: 31 Father: 39	Higher Education Higher Education	21	Mother: Manager Father: Civil engi- neer
P13	Female	Deformational brachycephaly	CVAI= 3.5 CI= 96.6	6 months and 1 weeks	37.5	Both of par- ents	Mother: 22 Father: 35	less than diploma Diploma	55	Mother: Housewife Father: Marketer
P14	Female	Deformational plagiocephaly	CVAI= 10.7 CI=81	4 months and 3 weeks	37	Mother	36	Higher Education	21	Assistant Professor
P15	Male	Deformational plagiocephaly	CVAI= 14.1 CI= 77.7	5 months and 3 weeks	38	Mother	Mother: 26 Father: 28	Diploma Diploma	350	Mother: Housewife Father: Shop- kaonor
P16	Female	Sagittal cranio- synostosis (scaphoceph- aly)	CVAI= 3.3 CI= 77.4	4 months	36	Both of par- ents	Mother: 29 Father: 42	Higher Education Higher Education	35	Mother: Teacher Father: electrical
P17	Male	Deformational brachycephaly	CVAI=3.2 CI= 90	7 months	37	Both of par- ents	Mother:25 Father:26	Higher Education	18	Mother: Housewife Father: Shop- keener
P18	Male	Deformational plagiocephaly	CVAI= 7.4 CI= 92.3	5 months and 2 weeks	38	Mother	34	Higher Education	70	Housewife
P19	Female	Deformational plagiocephaly	CVAI= 8.1 CI= 81.4	4 months and 1 weeks	38	Mother	30	Diploma	35	Housewife
P20	Male	Deformational brachycephaly	CI= 106.3	5 months	37	Both of par- ents	Mother:37 Father: 41	Higher Education Higher Education	12	Father: Nurse Mother: Nurse
P21	Male	Deformational plagiocephaly	CVAI= 2.9 CI= 84.3	3 months and 2 weeks	37	Mother	Mother:38 Father:46	Higher Education Higher Education	15	Mother: Manager Father: Assistant Professor
P22	Female	Metopic crani- osynostosis (trigonoceph- aly)	CVAI=2.25 CI= 96.1	4 months and 2 weeks	38	Mother	25	less than diploma	400	Housewife

Parental Adherence to CRO

CI-Cephalic Index; CVAI-Cranial Vault Asymmetry Index.

knowledge) extracted the codes and sub-codes relevant to the research objectives from the experiences described by the participants. After forming the semantic units, all research team members performed an overt and latent content analysis on the text to discover what the parents meant to convey. Similar semantic units were placed into new coded groups after in-depth discussion and ultimate consensus between the researchers. The resulting dense semantic units were carefully studied, allowing the researchers to discover new and abstract dimensions in various subcategories, codes, and themes regarding parents' adherence to treatment. This study reports on some primary findings from a sizeable mixed-method study on the decision-making Theme2.

Fascillitators for adherence to treatment

- •Adjustment to the treatment
- •Motivation and self-confidence
- •Appearance
- •Communication with orthotist
- •Wife's empathy/ spousal support

Figure 1. Themes and sub themes

process for treating infants with skull deformities.

Results

A total of 22 parents with infants suffering from non-syndromic or postural cranial deformities who had experience with orthosis participated in the present study. Each interview took 45 minutes on average. Table 2 indicates a summary of the participant's demographic data.

Two general themes of "potential barriers to CRO treatment adherence" and "potential facilitators to CRO treatment adherence" were extracted from 12 subthemes of parental burden, transportation, availability of CRO services in hometown, financial responsibility, maternal/paternal attachment attitudes, CRO-related problems, others feedback, adjustment to the treatment, motivation and self-confidence, aesthetic satisfaction, communication with orthotist, and wife's empathy/spousal support (Figure 1).

Theme 1: Potential Barriers to CRO Treatment Adherence

Parental burden, transportation, availability of CRO services in the hometown, financial burden, maternal/paternal attachment attitudes, CRO-related problems, and others' feedback were the most reported challenges regarding adherence to the CRO treatment. The following section explains more details about these challenges:

Some parents reported having to take one or several days off work to visit centers manufacturing orthotics. Taking time off work was thus considered one of the most significant challenges for the employed participants.

"We would have to schedule checkups for specified times, but neither my spouse nor my employers are particularly flexible about giving us time off. We had to use the CRO less frequently once it became too little until we could visit the clinic again." (F8)

Homemaker women also had to adapt to their husbands' jobs to revisit the clinic.

"I'd have to wait around until my husband drove me to the clinic. Because of his job, he could not take us there for frequent CRO examinations. I stopped coming regularly because of this." (F4)



Transportation problems were among the other challenges the participants faced. Most parents had to travel a long distance and spend much of their time receiving orthotic services.

"We must travel 700 km with the baby to get there, which is too difficult. Every time, I kept hoping they would tell us that we wouldn't have to go back as soon as the last time. The distance was stressful." (M7)

CRO service inaccessibility in the city of residence was another barrier preventing some parents from routine orthotic checkup visits.

"These services are unavailable in small towns and we can't visit the clinic every month. It's just too hard. I wish we could at least make the small adjustments in our town after the CRO was built." (P10)

Some participants reported the expensive commuting costs as essential barriers to regular visits or termination of their infants' treatment. RCO is not covered by insurance in Iran and can impose a heavy financial burden on families.

"CRO is not cheap. We followed up with the insurance, and they wouldn't cover it. Also, the costs are not limited to the CRO itself. The monthly commutes for adjustment cost the families a fortune as well." (P19)

Another concern with CROs was that their full-time use could have negative impacts on parents and the child, as it would reduce physical contact between them and could affect maternal/paternal attachment attitude.

"I couldn't bring myself to have him wear it for more than 16 hours. I would miss his head. I couldn't get myself to do it because I felt he was uncomfortable in the CRO." (M18)

Fear of possible complications of orthosis, such as hair loss, skin problems, and excessive sweating, also reduced the hours of use.

"I thought he may not grow any hair, so I did not use the CRO at night." (M10)

"His scalp turned scaly and red, so I stopped using the CRO." (M4)

Getting negative feedback from others during orthosis and concerns with being asked too many questions were other critical challenges most participants pointed out.

"I would not use the CRO in public and parties. I don't like to be asked too many questions about what that thing on his head is." (M22)

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"Others think you're too sensitive or don't believe that it's just an aesthetic thing. They assume the child has another problem...." (M15)

Theme 2: Potential Facilitators of CRO Treatment Adherence

Adjustment to the treatment, motivation, and self-confidence, aesthetic satisfaction, communication with the orthotist, and wife's empathy/spousal support were the potential facilitators of adherence to the CRO treatment.

All parents participating in the present study stated that CRO treatment was easy. The infant would quickly and easily get used to the CRO.

"My daughter fell asleep in the clinic 10 minutes after the first time the CRO was put on her head. That was when I figured I could easily use it." (M19)

"Wearing the CRO is not that difficult. It has only one strap. One person can easily have the CRO put on. It's evident which parts should not be in contact with the CRO to grow. My son won't even wake up if I put it on him while asleep." (M2)

Parents' motivation came up as another facilitator of persistent orthotic treatment. Seeing the before and after scans in the treatment process and noticing the changes in the head shape resulted in positive attitudes adherence to treatment.

"When we compared the before and after scans, his mother and I were relieved to know that our efforts were not in vain and got more motivated to have him wear the CRO for longer hours. We did not want to lose any time." (M3)

Orthosis covers disproportion and asymmetry. It also hides the unpleasant marks of surgery (suture marks or shaved hair). Most mothers in the present study were sensitive to orthosis appearance and color. The pleasant appearance and lightness of the CRO could increase adherence to treatment, according to the parents.

"The first CRO was prettier. Maybe I used the second CRO less often because I did not like its appearance as much as the first one." (M21)

"He looks prettier with the CRO on because his head shape was peculiar after the surgery. He did not look this way before, but now, his head looks normal with the CRO on. I don't believe wearing the CRO feels bad (laughing). His father says he looks like a biker." (M4)

In some cases, the parents decided to receive the orthosis despite their disagreement with the doctor since they held themselves responsible for the infant's future. Most parents stated that belief and trust in the therapist were the primary factors in treatment adherence.

"I would ask the orthotist my questions every time I had one, and they would respond even on holidays. This made me feel secure and pretty much kept my worries at bay." (M16)

The parents are burdened with various stresses and concerns while treating their infant. Another factor facilitating treatment adherence was the parents' agreement over the significance of orthosis, as pointed out by most participants. "My husband was the one who helped me the most emotionally in this journey. The stresses and difficulties of the treatment were easier to take with him around. He would always strap on the CRO better and more patiently than I did." (M12).

Discussion

The present qualitative study has been performed to identify potential barriers and facilitators of parents' adherence to CRO treatment. The following elaborates on the barriers and facilitators of these challenges in detail.

Getting time off work was among the essential challenges reported by the participants, which could adversely impact adherence to CRO treatment. Most parents participating in the present study were employed and had interfering working hours with clinic visiting hours, having to plan and ask for time off work for the routine checkups. According to Naidoo, getting time off work was the second factor determining the choice of CRO treatment (19). He found that parents who could get time off work were more likely to elect CRO treatment, while employed parents were more likely to choose CRO over physiotherapy. Steinberg et al. studied 4378 patients with positional cranial deformities and found that selecting each repositioning, physiotherapy, and CRO could be influenced by whether the parents were employed. Most employed parents participating in this study chose CRO because of the need for frequent visits to the physiotherapy clinic (20).

Transportation to the orthotics clinic also challenged parents with infants suffering from cranial deformities. Parents would have to visit the clinic routinely every 1 to 3 weeks after receiving the CRO, which was a cumbersome challenge for those living far from the clinic. The present found that parents traveled an average distance of 255 km to get to the clinic, which could cause delays in routine checkups or even premature termination of the treatment. Naidoo et al. found that a distance of over 50 miles to the clinic increases the probability of rejection or early termination of orthotic treatment (19).

Some participants reported that no standard center specialized in manufacturing and periodic adjustment of CRO was available in their proximity, which could intensify the challenges of the family alongside the long distance and transportation complications. Patients visiting from remote cities generally complain about the space and the lack of such services in their hometown. Lee et al. found that parents may miss their follow-up visits because of transportation costs and the time it consumes (21).

The financial burden was another crucial barrier to adherence to orthosis treatment. Such burdens include not only the cost of manufacturing orthosis and following checkups but also the costs of deformity diagnosis, transportation, accommodation, and discharge costs. The lack of medical insurance coverage for CRO is among the main reasons behind this challenge (6, 22). It must be pointed out that even those covered by private insurance do not get fully refunded for such costs (19). Results of Van Wijk et al.'s study suggested that even nonclinical factors such as parents' knowledge, social norms, service availability, and costs can be as important or even more critical in parents' decision regarding the continuation or termination of orthotic treatment in children with cranial deformities (23). Flannery et al. found that reducing the financial burdens associated with treatment could reduce parents' stress and thus increase their treatment adherence (24). The present study found the average cost of manufacturing a helmet to be approximately 100 Euros, which is relatively costly compared to the cost of living in Iran. The respective price was 150 to 5000 Euros in other countries, which is also considered a significant financial burden for patients residing in other countries. Insurance coverage for CRO services would thus reduce the financial burden imposed on the parents significantly.

Another barrier reported by the families was that wearing the orthosis full-time could harm both the parents and the child, as it reduces physical contact between them, which may affect the maternal/paternal attachment attitude. Although the literature does not confirm this concern, future studies can further investigate it. This challenge will not likely leave long-term effects on the infant since the parents can take the orthosis off anytime. Fathers were revealed to be more sensitive and worried about orthosis problems in the case of female infants. Mothers participating in the study pointed out that their husbands' compassion for the baby may lead to shorter hours of orthosis treatment for the infant. Despite the infants' comfort and fast adaptation, it appears that parents' emotions are among the barriers leading to unsuccessful CRO treatment results. The lack of physical contact between the infant and parents could harm the infant's social development over the long term in some cases, such as infant scoliosis, which is the gold standard treatment of serial casting (25). Some mothers reported orthosis as an emotional barrier to stroking the baby's head while breastfeeding.

Orthotic treatment of cranial deformities could result in potential problems such as odor, excessive sweating, loosefitting, hair loss, and skin irritation, some of which were mentioned by the participants in the present study. Although not all these problems were mentioned in previous research, some complications reported in previous studies were consistent with the current work (4, 8, 9, 15, 21, 26). A randomized controlled trial study suggested that excessive sweating, odor, skin irritation, and pain are the prevalent problems associated with CRO treatment (4).

Previous findings suggest that others' perceptions of the infant's appearance could spark negative emotions in individuals (27). Many of the parents participating in the present study reported that negative feedback from others led them to refrain from putting the CRO on their child in social contexts or even result in early termination of the treatment. Kluba et al. conducted a study on 218 parents with infants suffering from cranial deformities and found that 38.5% of the parents had received negative feedback from others, which was a more prominent challenge compared to the other problems of CRO treatment (8). We found that many parents kept the CRO treatment a secret and did not let others know about the treatment process. An explanation for this result is that others suppose the child has a brain problem (8). Parents of infants whose CRO treatment had been finished were unwilling to keep the CRO and considered it

as a bitter reminder. In one case, the parents even put up a fake dispute with their relatives during the CRO treatment to be able to focus more on the therapy (selective relationship with acquaintances). A case report study revealed that parents reported negative feedback and sweating as their challenges during treatment in 55% and 90% of the cases, respectively (14). One of the questions the parents had frequently asked was whether taking the CRO off when others were around being okay. This suggests that parents were concerned about others' perceptions and were unwilling to let others know about their infant's treatment process. Another interview result indicated that most parents feared "hurting the child in CRO." To define this emotion, the parents tended to point out that although they knew CRO would not be painful for their infant, they wanted to make sure they were making no mistakes, which appears to stem from the parent's role and the sense of responsibility for the infant. Moreover, the high costs of CRO treatment may increase the parents' expectations of the treatment, resulting in non-adherence to the treatment plan or even premature treatment termination in cases where parents cannot discern the changes in head shape.

Compliance with treatment is among the main facilitators of cranial orthosis treatment adherence. Various concerns for the parents generally accompany the beginning of treatment. The faster these barriers are overcome, the higher the odds of orthosis treatment success. Compliance with treatment could be from various factors. In a review article, Feragen et al. categorized compliance into 4 domains based on 41 studies: emotional health, behavior, social experiences, and satisfaction with appearance. Issues associated with treatment included satisfaction, decision-making regarding treatment, and socio-psychological compliance with treatment. Satisfaction with appearance is further divided into the 2 parameters of parents' satisfaction and others' perception of appearance. Social experiences can be categorized into the following groups: social reactions; social functions; abuse; social acceptance and support; and emotional connections. Emotional health is categorized into self-perception, emotional function, and self-esteem. Different social responses cause negative internal emotions. This study pointed out increased stress levels in parents with infants suffering from craniosynostosis. The study indicated that the parents were satisfied with their infant's appearance after the surgery despite disagreements between the expectations of parents and therapists (27). The quick adaptation of the infant to CRO relieved the parents' stress and thus increased the number of hours the device was worn. Parents' proper understanding of CRO function and how it affected skull growth led to a higher treatment acceptance rate. The present study found that the parents were concerned about the helmet applying pressure or causing skin damage to the infant's head. An orthosis with good fitting and minor complications would help parents adjust to the new treatment more quickly. In this regard, the high motivation of parents during treatment is another facilitator in orthotic treatment adherence. Providing parents with before- and after treatment pictures during the orthotic treatment process enables the parents to develop a better understanding of the changes in their infant's head shape. Even

the slightest changes in the head shape allow parents to perceive a significant improvement in deformity correction (28). In this study, parents of infants with craniosynostosis who had been prescribed CRO post-surgery were pleased with its protective role for the infant's skull. A strong and close relationship between the parents and the orthotist is also among the factors influencing the outcome of CRO treatment (7). Most participants in the present study reported a close relationship with the orthodontist and his/her availability at most hours of the day (even during nonworking hours and on holidays) reduced their stress and increased their trust in sticking with the treatment process. This connection is based on a good rapport with the therapist, in which the orthotist's availability allows the parents to get the answers to their questions. Two parents reported that they were initially concerned with whether the CRO was placed right on the skull and had their worries put to rest easily with the help of the orthotist. Considering that CRO treatment success is directly associated with compliance (7, 8), parents' compliance is among the important facilitators in adherence to orthotic treatment. Results of the present study suggested that the same 2 parents do not necessarily have the same perception of their infant's cranial deformity. The father's companionship was revealed to help the mother be sufficiently motivated to adhere to the treatment and maintain the relationship between the parents less affected by the infant's problem. Mothers generally reported the deformity to be more severe compared with fathers and would thus perform extensive research into the real and virtual space to find treatment options. Meanwhile, some fathers did not consider this necessary and associated it with their spouse's over sensitiveness. The anthropometric values of infants' skulls were thus measured to investigate this disagreement. We found that perceiving deformity severity was not significantly affected by parents' stress. Fathers would ignore deformities despite understating their severity. Psychological or femininity-masculinity factors may have been involved in this regard, which requires further research to be confirmed. Since mothers consider themselves more at fault for the deformity in Iran, fear of deformity permanence, and ridicule by others in the future led mothers to be more adherent to treatment. Fear of deformity permanence, ridicule in the future, and mental problems cause parents-who consider themselves responsible for their infant's future-to try to comply strictly with treatment protocols, seeking to achieve successful results. "Feeling of guilt in the future" was among the parents' concerns that led them to adhere to the rules to treat their infant.

Limitations and Implications

Despite the importance of the role of parents—as one of the main components of the treatment team—in treating infants with skull deformities, little attention has been paid to their challenges during CRO treatment. These challenges may impact the decision-making process of CRO treatment. The findings of this study have significant implications for understanding how CRO treatment challenges can affect the parents' motivation to continue using the orthosis. This study had some limitations. First, the study participants comprised parents whose infants received CRO

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treatment at only 2 orthotics clinics. Therefore, the study is limited by the lack of information from other clinics. Those cases who receive CRO treatment at other clinics may have different challenges. The study should be repeated using a multicenter design to assess parents' experiences receiving CRO treatment from various centers. Second, only convenient parents whose infants were under CRO treatment were included in the study, and those who discontinued the treatment did not have the chance to participate. Finally, parents who initiate the CRO treatment may have different challenges compared with parents who are at the middle or end of the treatment. More research could assess parents' experiences at different phases of CRO treatment.

Conclusion

Treating an infant with cranial deformity using a CRO is not without challenges. The most reported challenges were getting time off work, transportation to the orthotics clinic, the lack of medical insurance coverage for CRO, reducing physical contact between parents and their child, and getting negative feedback from others. However, overcoming the initial challenges and adjustment to the treatment with CRO, the high motivation of parents during treatment, an orthosis with good fitting and minor complications, a strong relationship between the parents and orthotist, and the father's companionship were revealed to facilitate the treatment process and increase adherence of treatment with CRO.

Conflict of Interests

The authors declare that they have no competing interests.

References

- Fish D, Lima D, Reber D. Cranial remolding orthoses. Atlas of Orthoses and Assistive Devices: Elsevier; 2019. p. 359-75. e3.
- Rosenberg JM, Kapp-Simon KA, Starr JR, Cradock MM, Speltz ML. Mothers' and fathers' reports of stress in families of infants with and without single-suture craniosynostosis. Cleft Palate Craniofac J. 2011;48(5):509-18.
- Graham T, Millay K, Wang J, Adams-Huet B, O'Briant E, Oldham M, et al. Significant Factors in Cranial Remolding Orthotic Treatment of Asymmetrical Brachycephaly. J Clin Med. 2020;9(4):1027.
- van Wijk RM, van Vlimmeren LA, Groothuis-Oudshoorn CG, Van der Ploeg CP, IJzerman MJ, Boere-Boonekamp MM. Helmet therapy in infants with positional skull deformation: randomised controlled trial. BMJ. 2014;348:g2741.
- van Wijk RM, van Til JA, Groothuis-Oudshoorn CG, L'Hoir MP, Boere-Boonekamp MM, MJ IJ. Parents' decision for helmet therapy in infants with skull deformation. Childs Nerv Syst. 2014;30(7):1225-32. doi: 10.1007/s00381-014-2399-2. PubMed PMID: 24643710.
- Mortenson P, Steinbok P, Smith D. Deformational plagiocephaly and orthotic treatment: indications and limitations. Childs Nerv Syst. 2012;28(9):1407-12.
- 7. Picart T, Beuriat P, Szathmari A, Di Rocco F, Mottolese C. Positional cranial deformation in children: A plea for the efficacy of the cranial helmet in children. Neurochirurgie. 2020;66(2):102-9.
- Kluba S, Lypke J, Kraut W, Peters J, Calgeer B, Haas-Lude K, et al. Positional cranial deformity—the parents' point of view. Int J Oral Maxillofac Surg. 2015;44(1):57-62.
- Van Allen C, Mott S, McGrath J, DeGrazia M. Parental Perception of Cranial Orthotic Treatment for Infants with Deformational Plagiocephaly. J Prosthet Orthot. 2020;33(1):11-9.
- Kluba Š, Kraut W, Calgeer B, Reinert S, Krimmel M. Treatment of positional plagiocephaly--helmet or no helmet? J Craniomaxillofac Surg. 2014;42(5):683-8.

- 11. Wilbrand J-F, Wilbrand M, Malik CY, Howaldt H-P, Streckbein P, Schaaf H, et al. Complications in helmet therapy. J Craniomaxillofac Surg. 2012;40(4):341-6.
- Seruya M, Oh AK, Taylor JH, Sauerhammer TM, Rogers GF. Helmet treatment of deformational plagiocephaly: the relationship between age at initiation and rate of correction. Plast Recontr Surg. 2013;131(1):55e-61e.
- Keshtgar M. Evaluating the Effectiveness of Cranial Molding for Treatment of Positional Plagiocephaly Using Finite Element Analysis [dissertation]. San Luis Obispo: California Polytechnic State Univ.; 2015.
- 14. Taheri Z, Babaee T, Hajiaghaei B, Mohammadi HR. Cranial remolding orthosis for postoperative management of bilateral lambdoid and sagittal synostosis: A case report. Prosthet Orthot Int. 2021;45(3):235-9.
- 15. Choi H, Lim SH, Kim JS, Hong BY. Outcome Analysis of the Effects of Helmet Therapy in Infants with Brachycephaly. J Clin Med. 2020;9(4):1171.
- 16. Drisko JW, Maschi T. Content analysis: Pocket Guide to Social Work Re; 2016.
- 17. Burnard P. A method of analysing interview transcripts in qualitative research. Nurse education today. 1991;11(6):461-6.
- Lincoln YS, Guba EG. Judging the quality of case study reports. Int J Qual Stud Educ. 1990;3(1):53-9.
- 19. Naidoo SD, Skolnick GB, Patel KB, Woo AS, Cheng A-L. Long-term outcomes in treatment of deformational plagiocephaly and brachycephaly using helmet therapy and repositioning: a longitudinal cohort study. Childs Nerv Syst. 2015;31(9):1547-52.
- 20. Steinberg JP, Rawlani R, Humphries LS, Rawlani V, Vicari FA. Effectiveness of conservative therapy and helmet therapy for positional cranial deformation. Plast Recontr Surg. 2015;135(3):833-42.
- 21. Lee MC, Hwang J, Kim YO, Shim KW, Park EK, Lew DH, et al. Three-dimensional analysis of cranial and facial asymmetry after helmet therapy for positional plagiocephaly. Childs Nerv Syst. 2015;31(7):1113-20.
- 22. van Adrichem LN, van Vlimmeren LA, Cadanová D, Helders PJ, Engelbert RH, van Neck HJW, et al. Validation of a simple method for measuring cranial deformities (plagiocephalometry). J Craniofac Surg. 2008;19(1):15-21.
- van Wijk RM, Boere-Boonekamp MM, Groothuis-Oudshoorn CG, van Vlimmeren LA, IJzerman MJ. HElmet therapy Assessment in infants with Deformed Skulls (HEADS): protocol for a randomised controlled trial. Trials. 2012;13(1):108.
- 24. Flannery ABK, Looman WS, Kemper K. Evidence-based care of the child with deformational plagiocephaly, part II: management. J Pediatr Health Care. 2012;26(5):320-31.
- Thometz J, Liu X-C. Serial CAD/CAM bracing: an alternative to serial casting for early onset scoliosis. J Pediatr Orthop. 2019;39(3):e185-e9.
- 26. McGarry A, Dixon MT, Greig RJ, Hamilton DR, Sexton S, Smart H. Head shape measurement standards and cranial orthoses in the treatment of infants with deformational plagiocephaly. Dev Med Child Neurol. 2008;50(8):568-76.
- 27. Feragen KB, Stock NM. Psychological adjustment to craniofacial conditions (excluding oral clefts): a review of the literature. Psychol Health. 2017;32(3):253-88.
- 28. Katzel EB, Koltz PF, Sbitany H, Girotto JA. Treatment of plagiocephaly with helmet molding therapy: do actual results mimic perception? Cleft Palate Craniofac J. 2011;48(2):205-9.