

# EXPERIENCES OF CAREGIVERS HAVING CHILDREN WITH CRANIOSYNOSTOSIS USING DISTRACTOR DEVICES

Artiteeya Dangsomboon, Veena Jirapaet\*

Faculty of Nursing, Chulalongkorn University, Bangkok, 10330, Thailand

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## ABSTRACT:

**Background:** Craniosynostosis affects the growth of the brain. Since the treatment is surgery by inserting distractor devices to reduce pressure in the skull and correct misshapen skull, the children after surgery for craniosynostosis using distractor devices have limitation in taking care of themselves and are easily exposed to injuries. Therefore, the abilities of caregivers at home are very critical and important to the treatment outcomes.

**Method:** A phenomenological study was undertaken with 14 primary caregivers of children with craniosynostosis aged 6 months to 3 years in regard to their caring experiences after post-operative reconstruction until removal of the distractor devices. Data were collected by using the in-depth interview recorded on a tape recorder. The data were transcribed verbatim and then analyzed using Colaizzi's method.

**Results:** A thematic content analysis of the interview data revealed five major themes of caregivers' experiences. Those were as follows: 1) learning and following the hospital advice, 2) facing difficulties when returning home, 3) challenging in taking care of the moving child, 4) having mixed feelings and 5) having support and help from others and build-up of inner strength.

**Conclusion:** Findings suggest that advice and support from health personnel, and help from all involved in care, are essential to caregivers' caring ability and psychological adjustment. The results have implications for the provision of guidance to improve craniosynostosis-related home care.

**Keywords:** Experience; Caregivers; Children with craniosynostosis; Distractor device

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## INTRODUCTION

Craniosynostosis is a birth defect and affects 1 in 2,000 live births worldwide [1]. This defect involves the premature fusion of one of the 6 major cranial sutures (metopic, sagittal, right or left coronal, or right or left lambdoid). It disturbs the normal growth of the brain and skull and increases intracranial pressure [2]. In Thailand, there is no national databases on the occurrence of craniosynostosis. Case statistics obtained from the Princess Sirindhorn Craniofacial (PSC) Center at King Chulalongkorn Memorial Hospital, the biggest craniofacial center in South East Asia, showed

that the number of children receiving the craniosynostosis treatment were 41 and 46 cases in 2012 and 2013, respectively. The craniosynostosis does not only cause physical disabilities but also has tremendous effect on mental well-being of the affected children and their caregivers [3]. Bannink, et al. [4] studied health outcomes and the quality of life of 111 craniosynostosis children and adolescents and the impact on parents. The problems found in these children were organ failure to function properly, slow growth and development, cognitive impairment and having trouble acknowledging their own health condition. Parents reported reduced time for self and family's activities and their emotional and behavioral issues such as violent emotion and behavior.

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\* Correspondence to: Veena Jirapaet  
E-mail: j\_veena@hotmail.com

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**Figure 1** Pre- and post-craniosynostosis surgery with distraction device (arrow pointed)  
(An original artwork of this research)

The objective of treating children with craniosynostosis is to restore their body to normal state or as much as possible. The craniosynostosis surgery is to open the prematurely fused suture, reduce pressure in the brain skull, correct misshapen head and allow for normal brain growth [5, 6]. At the PSC Center, the surgery of deformities of children with craniosynostosis are undertaken at approximately 6 months to 3 years, earlier if there is evidence of increased intracranial pressure. The insert of a distractor to expand the bones of the skull is to enhance the stability of bones building. Post-surgery children have to be hospitalized for 1-2 weeks and discharged home for further care for 12-14 weeks [7]. Therefore, the ability of caregivers at home is an important factor to the success treatment outcomes and the least possibility of complication.

With regard to post-surgery craniosynostosis care, nurses and other health personnel in the multidisciplinary team play a significant role in preparing caregivers for their new tasks at home in terms of knowledge and skill in wound care, distractor winding, complication prevention and observation of abnormal conditions. However, information regarding caregiver ability in Thailand is limited. Only one research study, a case report, was conducted by surgeons to follow up the problems of three children aged 9 months, 3 and 8 years after inserting distractors surgery. The study reported that all of the children lost their follow-up after the initial post-surgical visit thus failed the treatment. Economic problems and lack of adequate information to patients and their parents were the main reasons for their discontinuing follow-up appointments [8].

This study aimed to examine the lived experience of caregivers having children with

craniosynostosis using distractor devices from their point of view. The findings would benefit healthcare providers to improve their care plan and deliver services that match the problem and true needs of children and caregivers in a holistic approach.

## METHODOLOGY

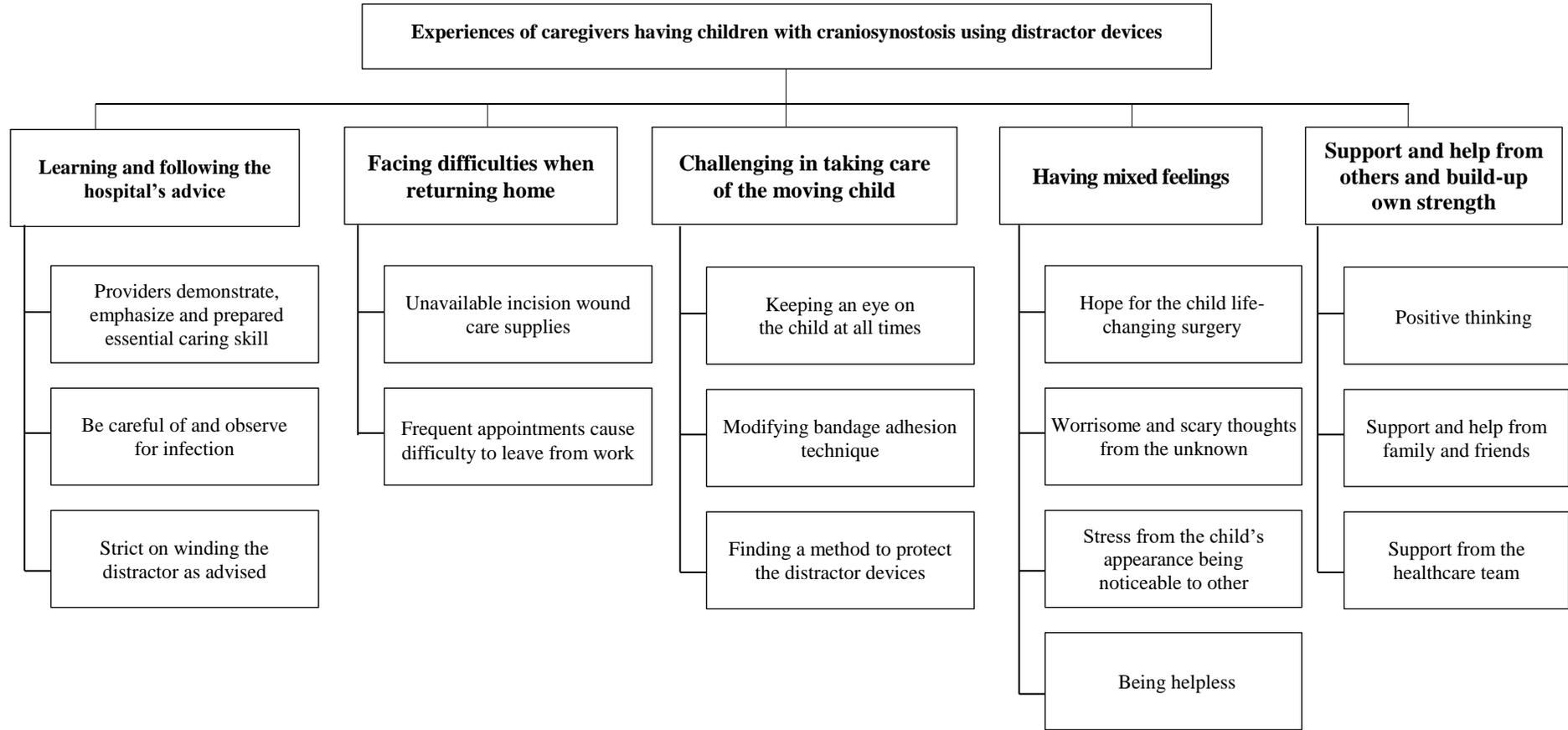
This qualitative research was designed by using phenomenology approach according to the philosophy of Husserl through in-depth interviews.

### Participants and setting

Purposive sampling was used for the caregivers' recruitment according to the study aims. They were contacted at the PSC Center, King Chulalongkorn Memorial Hospital. The caregivers were eligible if they: 1) were primary caregivers who had cared for a child age between 6 months and 3 years with craniosynostosis using distractor devices from the beginning of post-operative synostosis reconstruction until removal of the distractor, 2) could communicate in Thai, and 3) voluntarily agreed to participate in this study.

A total of 14 participants were determined at the point of data saturation as the researcher recognized a repetitive answers and no additional information was imminent from the interviews. All were mothers, ages ranged from 25 to 39 years. Ten were employed and 4 were housewives. Their educational levels, 4 were high school graduates, 5 vocational, 4 bachelor's and 1 master's. Family incomes ranged from 15,000 to 50,000 baht.

Participants had experience in caring for their children for a period of 3 to 4 months after first craniosynostosis surgery with distractor device. Their children's ages at surgery were 15 to 26 months. Causes of craniosynostosis were associated with genetic disorders, 4 with Crouzon syndrome,



**Figure 2** Summary of experience themes and subthemes of caregivers having children with craniosynostosis using distractor devices

4 with Pfeiffer syndrome and 6 with Apert syndrome. Figure 1 depicted the sketch images of pre- and post-surgery of a child with Pfeiffer syndrome for fronto orbital advancement with distraction device.

### Materials

Audio recorders, field notes and the semi-structured interview questions were used for data collection. The main questions were as follows. What are your experiences and feelings of being with your child in the hospital after surgery? What are your experiences and feelings regarding your life being with your child using distractor devices at home?

### Data collection and ethical consideration

This study received an approval from the Human Research Ethics Committee of the Faculty of Medicine, Chulalongkorn University (IRB No. 447/57), and was conducted in accordance with the ethical principles of the Helsinki Declaration. Data was collected between February 2015 and March 2016. All participants were willing to participate in a recorded interview and gave their informed written consent. The in-depth interviews were conducted by a researcher in a quiet room of the PSC Center or the pediatric surgery ward. The interviews varied from 45-60 minutes. All data obtained from the interviews were transcribed verbatim.

### Data analysis

Colaizzi's data analysis [9] was used as follows: 1) after transcription, researcher read and reread to gain sense of a whole feeling and experience of the caregivers, 2) words and sentences significant to phenomena of caregivers' experiences were labeled by highlighter pen, 3) highlight statements were cut and sorted into groups of same meaning and categorized then meanings were formulated, 4) organized formulated meanings into clusters of themes and validated the clusters of themes by referring back to the original transcript to ensure no data would be ignored or added to, 5) integrated all the gathered ideas into an exhaustive description of the caregivers' phenomenon, 6) reduced the description to the essential phenomenon structure and again referred back to transcription to find words that the caregivers had used which would best fit the themes and 7) brought back the written description to the caregivers to confirm if this analysis described their experiences in order to verify the description. No new information gained during this stage.

## RESULTS

Five major themes of caregivers' experiences having children with craniosynostosis using distractor devices emerged from the interviewed data. The themes could be described as follows (Figure 2).

### 1. Learning and following the hospital advice

All the caregivers had no previous experience in providing post-surgical care for children with craniofacial distraction. Many of them were scared to take care of their children while being admitted to the hospital and when being discharge home. However, the ongoing daily information, knowledge and skill gained from doctors and nurses were important and made them confident and ready for complex tasks of their children cared at home. Helpful contents were incision wound dressing, prevention and signs of infection and distractor windings techniques. All caregivers expressed that they had learned from doctor's and nurse's teaching instruction, demonstration with repeating practice after learning and an emphasis on the child's post-surgical care and risk situations.

#### 1.1 Providers demonstrate, emphasize and prepare wound care skill

All caregivers reported that doctors and nurses had taught, emphasized and encouraged them to practice their caregiver role since post craniofacial surgery. These heightened their awareness and compliance.

*"Doctors and nurses emphasized on wound care and how to dab the wound... and what medication to use... At first, I didn't dare to do it. The doctor taught me how to do it and gave me a chance to try it on my own" (S6),*

#### 1.2 Be careful of and observe signs of infection

All caregivers reported that they were taught how to care for the incision and watch for signs of infection for seeking urgent medical help.

*"Doctor emphasizes on sanitation and using saltwater to clean. Also, I must always apply medicine on the wound at the exact time that the doctor has ordered" (S5)*

*"When dressing the wound, you must observe whether the wound is alright. Is it swollen or abnormal? ...if you are at home, you must bring the child to the hospital." (S8)*

### **1.3 Be strict about winding the distractor as advised**

Most caregivers believed and strictly followed the doctors' advice. They learned from the teach-back method. Caregivers reported that they had been taught and had practiced applying the distraction forces post-surgery under the doctor's supervision. They were also emphasized on note taking when winding the distractor. This made them feel confident in performing the tasks on their own at home.

*"When we were discharged home, we did everything as the doctor said. The millimeters and frequency that the doctors had ordered to wind. We record everything in the document given by the doctor. We are strict about what the doctor has advised"* (S11)

*"...[doctors and nurses] let me try adjusting the distractor device before returning home... I have been confident and when returned home, I dare to do it."* (S1)

## **2. Facing difficulties when returning home**

In providing care at home, many caregivers experienced difficulty from an unavailable supplies for wound care by lacking hospital preparation on this issue. Moreover, the child's follow-up appointments imposed on the employee caregiver. Their responsibilities of keeping up with the child periodically follow-up appointments made them miss their work, thus lost their incomes.

### **2.1 Unavailability of incision care supplies at home**

After returning home, most participants described the feeling of difficulties for incision dressing without the supplies that they were taught to use at the hospital. The caregivers felt uncomfortable using their hands to dress the incisions. Some caregivers adapt a disposable set of incision care and bandaging supply for reuse by either boiling the equipment kit in hot water or wiping with alcohol.

*"We don't have the same wound care supplies like those in the hospital...So I ask dad (husband) to buy a couple of these [disposable] kits...we boil them in hot water...before each wound dressing"*(S12)

### **2.2 Frequent appointments cause difficulties leaving from work**

After discharge, the caregivers had to bring their children for follow-up examination and fronto-orbital advancement. The schedule was once a week for the first month after discharge, again in every 2 or 3 weeks for the next 2 to 3 months or until uninstallation of the distractor. All caregivers reported they perceived the importance of the follow-up. Many caregivers had to travel over a long distance as they resided in the provinces other than the hospital setting. Those employed caregivers had to choose their child treatment over their work. They missed work for a day or more each appointment, thus unavoidable loss of incomes incurred.

*"To come weekly, it is tiring. We have to travel from upcountry and dad [husband] must accompany me and he has to ask for a day off from his work because sometimes I can't do it alone. So two of us come here, it means more travel cost, more expenses"* (S12)

*"We have more problems with traveling... I have to be absent from work"* (S2)

## **3. Challenging in taking care of the moving child**

Children with craniosynostosis using distractor devices were between 6 months and 3 years old. They were in a state of high level of energy. They explored an environment by crawling or walking, without abstract reasoning about compliance with the treatment plans. Thus, they refused to stay still and at risk for accidents and hazards surrounding them.

### **3.1 Keeping an eye on the child at all times**

All caregiver reported keeping their eyes on their children at all times because they could not make them stay still. They overwhelmingly expressed the concern about the possibility of trauma to the surgical site and the distractor when their children moved and played by themselves or with others.

*"Right after the surgery it wasn't difficult. But as his condition improves he becomes more active. He doesn't walk but runs"* (S7)

*"I can't let him out of my sight...I am afraid that his head will bump into something... when he plays with other kids...I am scared"*

*that the device on his head will catch something. I can't stop him from playing" (S4)*

### **3.2 Modifying bandage adhesion technique**

Most caregiver experienced frequent losses of bandages securing a gauze dressing for the scalp incision due to children's movement and sweat. Thus, it increased the risk for wound infection and further harm. Consequently, they modified bandage adhesion technique or searched other types of bandages rather than the one from the hospital to ensure longer-lasting adhesion.

*"The bandage came off easily, especially the white one from the hospital, so I use the clear one instead...I am able to change the bandage less frequently" (S5)*

*"When she plays, the bandage (on scalp) becomes loose easily...so I attach many bandages in a criss-cross fashion, they won't all fall off at the same time" (S8)*

*"My baby sweats on her head a lot...the plaster (adhesive tape) falls off...After keeping on doing it, I started realizing that I should use many plasters at once because if one falls off, another one is still firmly adhered...when I see one is starting to fall off, I put another one" (S13)*

### **3.3 Finding a method for protect the distractor devices**

Following the post-surgical advice, caregivers overwhelmingly expressed their difficulty to keep the baby sleep on his or her back all night. There was no assisting equipment from the hospital. Some invented a method for preventing potential hazards, protecting the distractor devices from breakage and awaking them from sleep whenever their children turned their body.

*"She rolls over when sleeping...I have to find something soft to place under her head... I hug her loosely, so I will feel if she moves and can wake me up to check on her" (S5)*

*"There is no assisting equipment so it is difficult to sleep. If my baby sleeps on the side, distractor will be bumped. She has to sleep on her back. But even regular person cannot sleep on the back for the entire*

*night...I have to put a pillow on the side. It is a bit difficult for me because I can't go into deep sleep" (S8)*

## **4. Having mixed feelings**

The caregivers reported various feelings experienced in child care both positive and negative as follows.

### **4.1 Hope for the child life-changing surgery**

The following are examples of statements about the first feelings happen to caregivers when their children were scheduled for treatment.

*"I felt like being reborn again. Although the doctor said that the surgery was risky, we had to do it because we wanted our kid to get better. We wanted him to be like other kids"(S5)*

*"I felt very happy that my baby would be treated because another hospital said my baby couldn't live for long not for months. It was impossible for me to just watch my baby dying. I found this place...Doctor told me that this center had treated many cases of this disease" (S12).*

### **4.2 Worrisome and scary thoughts from the unknown**

Caregiver's description showed that the unknown was one of the negative feelings occurred when taking care of their children.

*"When my kid had to undergo a surgery for craniosynostosis..., I was scared that I might not be able to take care of him. I was afraid of everything because I didn't know... I was worried about the wound and the device on the head" (S2)*

### **4.3 Being stressful from the child noticeable appearance**

Caregivers spoke of stress that came from their children's appearance of craniofacial deformities as noticeable to others.

*"When people looked at my baby with sympathy. I really disliked that look. My baby was not inferior to others" (S14).*

### **4.4 Being helpless**

Caregivers gave all they had to help their children, but still felt that what they were doing was

not enough. Caregivers reported being stressful when witnessed their children suffering from unavoidable pain which there was nothing they could help.

*“They drew my kid’s blood...my baby cried and it was very stressful to me. I couldn’t help him ...I went outside and I wanted to cry so badly” (S13)*

## **5. Support and help from others and build-up of inner strength**

Most of caregivers described source of support that empowered their abilities as follows.

### **5.1 Build-up of inner strength**

It is crucial to build up inner strength when facing uncertainty or obstacles in life. Caregivers reported using positive thinking and self-determination to get through their difficulties, especially when they felt overtired or discouraged.

*“I have never felt pessimistic. I believe that after the distraction, the skull will be expanded just as the doctor said. His condition will get better. I will try to stay positive” (S6)*

### **5.2 Support and help from family and close friends**

Family and friends played a significant role in protecting caregivers from burnout.

*“I have a lot of burden with my sick baby and other children. Good thing is my relatives that live next to me understand. I can ask them to look after our house when I come to the hospital...When I feel distress, I can talk to them and they comfort me” (S6)*

*“My husband and I cheer up each other” (S10)*

*“Grandmother came to look after the child. It made me feel better” (S13)*

### **5.3 Support from the healthcare team**

Support from the healthcare team was described as an important source of support for all caregivers. Most caregivers described that getting information, advice, access to care and moral support from doctors and nurses lessened their stress and built up their caregivers’ abilities.

*“I can take care of her because of the doctor’s close attention. If there is any problem, they say I can always call them. Doctors here are very kind...I can do my part of caregiving well without much to worry about” (S5)*

*“I visited him at the ICU. I saw him sleeping with eyelids and head swelling...I was in tears... The nurses sat down and talked with me, told me to think positive and be strong...It made me feel better because someone did listen and understand” (S11)*

However, one caregiver reported experiencing insensitive reaction from a healthcare provider that caused uncomfortably questioning in future.

*“I didn’t know much about this disease when she give me information ...I asked twice and she answered with acting irritable toward me...I will not ask any more questions...even if I don’t understand” (S3)*

## **DISCUSSION AND CONCLUSION**

The findings of this study give the reflective pictures of primary caregivers’ life experiences. The caregiving for children after craniofacial surgery with distraction device is a major responsibility that is time consuming, stressful and yet challenging. The caregivers in this study experienced heavy burdens, both mentally and physically. They exhibited worries and scare from the unknown of their children access to treatment and the surgical outcome. The stress is higher when being unable to take away their child suffering and confronting with social reaction to the child’s facial disfigurements. Moreover, source of caregivers’ stress at home regarding the post-surgery care with their youngster seems paramount and may be unrealized by the providers. These include unavailable hospital-like incision wound care supplies, no equipment for preventing bump of distractor device during sleep and in experience to handle the moving child toward prevention of distractor device breakage and incision dressing fall-off. It took away caregivers’ energy in finding ways to solve problems, thus caused inadequate daily rest and insufficient sleep. It was harder for employee caregivers. They had to combine time-consuming care with regular employment. Demand of periodically follow-up appointments resulted in their financial strain.

A previous study showed that caregivers having children with craniosynostosis experienced stresses from the child's demanding tasks and appearance issue more than mothers of healthy infants [10]. Systematic reviews on informal care and employment revealed the impacts of a negative care-work association on female caregiver employment. As demand for care rose, it was related to lower caregiver working hours, lower levels of labor force participation and leaving the employment [11].

Although caregivers felt overwhelmed by time pressures and how to do things right. It was remarkably reduced by support and help from an understanding family member, neighbor and health care team. The support cultivated their inner strength with positive thinking and confidence in their role. All caregivers were willing to put up with everything to make their post-surgical childcare with a distractor device ran as smooth as possible. Findings of this study suggest that healthcare providers need to deliver post- craniofacial surgery expert care that caregivers acknowledge as compassionate and competent. The preparation strategies include 1) timely, clear and compassionate communication, 2) provision of important information frequently and 3) involvement in an ongoing daily child treatment and care after surgery. Previous evidences have supported that including caregivers in the daily care of their critical ill children lowers caregiver levels of stress, increases their satisfaction and enhances their trust in the care their children is receiving [12, 13]. Before discharge, healthcare providers need to check on the individual caregiver's understanding and competencies. Any concerning barriers need to be advised and removed to meet the unique caregiver's needs in transitioning from hospital care to home care. Nurses and multidisciplinary team need to keep up with the innovation techniques of distraction osteogenesis. Studies are currently underway to determine the technical feasibility of distractor device and surgical approach with less rigid stabilization and away from the risk of dislodgement and breakage that lead children and caregivers to their usual lives [14, 15].

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