Perceptions of Caregivers Regarding Healthcare Service Accessibility of Children with Craniofacial Anomalies: A Qualitative Descriptive Study

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Abstract: Healthcare service accessibility is crucial to treatment outcomes and results in a better quality of life for children with craniofacial anomalies. This qualitative descriptive study explored caregivers' perceptions regarding healthcare service accessibility for children with craniofacial anomalies in Thailand. Participants were primary caregivers of children with non-cleft lip/palate craniofacial anomalies aged 3 months to 18 years. Data were collected through focus group interviews with 37 caregivers across six groups and semi-structured telephone interviews with five caregivers (42 caregivers) who brought their children for treatment in four super-tertiary hospitals with craniofacial centers from October 2018 to February 2021. Qualitative data were analyzed using the content analysis method.

Three main themes emerged from the findings: 1) accessing treatment required time and many steps, 2) receiving treatment from a specialist by seeking information and advice, and 3) difficulties of hospital visits, including traveling distance and expenses. Our findings reflect that healthcare access for children with craniofacial anomalies remains a complex challenge associated with socioeconomic status, geographic characteristics, and the healthcare system, including health insurance benefits. Moreover, treatment for these children usually requires specialists typically located in university hospitals in metropolitan areas, thus limiting access for children in rural or underserved areas. To improve access to optimal care for these children, healthcare personnel, including nurses, should provide comprehensive information about potential hospitals with craniofacial centers, expedite referral processes, and offer assistance tailored to individual needs to enhance healthcare effectiveness.

Keywords: Caregivers, Children, Craniofacial anomalies, Healthcare accessibility, Perceptions, Qualitative descriptive study, Thailand

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Introduction

Craniofacial anomalies (CFA) are congenital deformities affecting the structure and appearance of the skull and face. This study focused on non-cleft CFA, which refers to a group of congenital cranial and facial malformations such as craniosynostosis, facial cleft, microtia, and craniofacial microsomia. Generally, non-cleft CFA is more serious and significantly affects organ dysfunction compared to cleft lip and cleft palate. Many patients often require multidisciplinary treatments to provide medical, psychosocial, and logistical support.[1] The prevalence of non-cleft CFA varies significantly among countries, regions, and medical centers and is mainly reported in specific disease groups. For instance, a study in Norway between 2003 and 2017 reported a high prevalence of craniofacial anomalies to be 5.5 per 10,000 live births or 1:1,800,[2] whereas a study in Finland between 1988 and 2013 found a prevalence of craniofacial microsomia at 1:10,000.[3] Moreover, a study in Iraq reported a prevalence rate of craniosynostosis at 2%.[4] In Thailand, our previous study of 139 children with non-cleft CFA at a craniofacial center in Bangkok found abnormalities categorized into disease groups as follows: synostosis 48.9%, unclassified group 21.5%, clefts group 20.9%, neoplasia-hyperplasia group 5.8%, and atrophy-hypoplasia group 2.9%, respectively.[5] These abnormalities lead to severe consequences on the physical and mental aspects of children and their families in both short and long terms.

The main treatment for CFA is periodic surgical correction of the deformity according to its severity. Typically, a treatment requires a multidisciplinary approach with many specialists to cooperate, evaluate, and plan the treatment together. The multidisciplinary team also allows sub-specialists to collaborate and gain experiences essential for new treatment development for complex cases.[6,7] The appropriate treatment for young patients is based on their age, period, and urgency of the condition, regarding both physical and mental aspects, and they must periodically receive medical treatment. However, the medical care potential of each hospital varies according to the physician's expertise, medical care, equipment, and support network. In addition, child and family factors such as health insurance benefits, socioeconomic status, and residence area also affect access to medical care.[8]

In Thailand, craniofacial centers are usually located in university hospitals in different regions' metropolitan areas, while children with CFA are spread throughout the country, in both urban and rural areas. Many children living in distant domiciles tend to have delays in receiving information about craniofacial centers to provide timely surgical correction of deformities. Besides, craniofacial centers mostly require referrals based on the health insurance benefit of children, namely the Universal Health Coverage (UC) scheme, medical welfare of government and state enterprise officials[9] or disability welfare as specified in the Promotion and Development of the Quality of Life of Persons with Disabilities Act B.E. 2007 as amended by (No.2) B.E. 2013, Section 20.[10] The steps and referrals are different due to the health insurance benefit of children with CFA. Obtaining a referral letter for medical care under the UC scheme requires many steps and is a complex process. Caregivers may have to visit multiple levels of hospitals until the children receive treatment, or referrals for certain children with CFA may be denied. These factors result in delayed accessibility to treatment, losing opportunities, wasting time, and also affecting children's treatment outcomes.[8] Therefore, it can be stated that healthcare service accessibility for children with CFA still has its limitations.

Many challenges and barriers to healthcare service accessibility faced by young children with CFA and their caregivers have been reported worldwide. A recent study of craniosynostosis patients at a tertiary children's hospital in the United States of America showed that patients residing in more disadvantaged areas tended to present later at the clinic and received delayed surgical intervention.[11] Moreover, a study on immigrant Spanish-speaking parents of children with craniofacial microsomia emphasized that frequent medical appointments were the family's financial burdens. These included transportation costs and loss of income from work absence.[12] Similarly, parents of children with craniofacial anomalies in Malaysia reported that they were occasionally absent from work due to their child's regular appointments and surgeries.[13] A study of patients with CFA in Saudi Arabia exhibited that the barriers to receiving treatment were difficulty in scheduling appointments, long waiting times, and difficult travel.[14] Our previous study also revealed that caregivers of children with CFA are concerned about barriers to healthcare service accessibility in the aspects of service center facilitation and the ability to pay for services. Additionally, challenges in accessing craniofacial care were the very high cost of care and long-distance traveling.[15] However, a study was conducted at the largest craniofacial center in the capital city of Thailand, which included social workers and clinical psychologists in multidisciplinary teams. Hence, it may not provide insight into the obstacles or limitations in healthcare service accessibility for children with CFA nationwide. This study, therefore, explored caregivers' perceptions regarding healthcare service accessibility of children with CFA in four super-tertiary hospitals across Thailand using a qualitative descriptive approach to provide deeper insights into the healthcare service accessibility issues for children with CFA.

Review of Literature

Non-cleft CFA is not as common as cleft lip and cleft palate, but the results can lead to very severe disability. Treatment for non-cleft CFA is complex and needs greater health care regarding surgical repair and other health care interventions. It requires multiple surgeries and a multidisciplinary team, depending on the severity and type of anomalies. These could result in medical traumatic stress for parents in relation to their child's diagnosis and treatment.[16] Access to care for children with non-cleft CFA is indispensable since they need to visit many clinics, and it takes a long time for follow-up.

Health service accessibility is the ability of individuals to access the healthcare system. It is related to the use of health services and the right to access medical care for individuals in any community, depending on three critical factors: cost, quality of care, and ease of access to care. Balancing these three factors can enhance the quality of healthcare service accessibility.[17] It was stated by the World Health Organization (WHO) that healthcare service accessibility is a fundamental service for people in various dimensions with different aspects: 1) geographical aspect referring to the distance, time consumption, and ease of the visit without any accessibility obstacles, 2) financial aspect referring to the ability to pay for expenses from the use of healthcare services, 3) cultural aspect referring to the use of techniques and management methods in health administration, which can maintain the model and culture of the community and service users, and 4) functional aspect referring to adequate and continuous basic health service provision.[18] In addition, an Australian study on people with chronic conditions employed Levesque's model of access, which conceptualizes access to healthcare service in five dimensions: 1) ability to perceive, 2) ability to seek, 3) ability to reach, 4) ability to pay, and 5) ability to engage.[19] In the Thai context, a study defined healthcare service accessibility as the ability and attempt of an individual to access the basically appropriate healthcare and to receive medical treatment according to health insurance benefits, considering travel distance, transportation expenses, and accommodation.[20] Thai vulnerable groups also face inequality in healthcare service accessibility in terms of limited rights in hospital selection, lack of specialists, complicated referral systems, inadequate budget, and lack of coordinative government planning regarding the production and distribution of health personnel inequities.[21] Our previous study on healthcare service accessibility of children with CFA perceived by their caregivers exhibited that high cost of care and long-distance traveling were challenges in craniofacial care accessibility.[15] Similarly, several international studies addressed barriers to healthcare access for children with CFA, including low socioeconomic status, financial expenditure,[11,12] residing area distance,[10] transportation costs,[11] transportation difficulties,[13] lack of information about diseases in primary care, [22] healthcare expenses, and inadequate insurance coverage.[23]

Study Aim

In this study, we aimed to understand the situation of healthcare service accessibility better as perceived by primary caregivers of children with CFA in Thailand. The insights gained from this study will be beneficial in reducing barriers to accessing healthcare services and providing more comprehensive care for children with CFA.

Methods

Design: A qualitative descriptive approach was employed to achieve the aim of this study because this approach primarily focused on studying the facts of the phenomenon. Moreover, qualitative description is a very practical or pragmatic approach that helps the researcher to uncover the "who, what, or where" of certain events or experiences without the need to focus deeply on meaning and does not require a conceptual abstract rendering of the data, compared to other qualitative designs.[24] We followed the consolidated criteria for reporting qualitative research (COREQ), and a 32-item checklist for individual interviews and focus groups.[25] A previously published paper, "Healthcare Problems and Healthcare Service Accessibility for Children with Craniofacial Anomalies: Caregiver's Perceptions," conducted in the Central region, was part of this study.[15] In this study, we explored caregivers' perceptions regarding healthcare service accessibility of children with CFA in four craniofacial centers in the Northern, Northeastern, Southern, and Central regions.

Setting and Participants: This study was conducted in four super-tertiary hospitals across Thailand, each with a craniofacial center. The healthcare services provided at each center were similar in treatment protocol but differed in comprehensive care and support networks, depending on the expertise of multidisciplinary teams. Purposive sampling was applied to select 42 key informants who were primary caregivers with the following criteria: 1) aged 18 years and over; 2) being either a parent or guardian of the child with non-cleft craniofacial anomalies; 3) having childcare experience of at least 3 months; and 4) being able to speak and understand the Thai language. Primary caregivers with cognitive or memory impairments were excluded from the study. The researchers attempted to include a wide range of participants with experience caring for various CFA diseases. This study was conducted over three years, from October 2018 to September 2021, due to data collection across multiple locations and long intervals between appointments.

Ethical Considerations: This study was approved by four institutes, including (1) the Faculty of Medicine, Chulalongkorn University (COA No.901/2018), extended (COA No.1025/2019), (2) the Faculty of Medicine, Khon Kaen University (Record No.4.3.01:14/2019), (3) the Faculty of Medicine, Chiang Mai University (COA No.333/2019), and (4) the Faculty of Medicine, Prince of Songkla University (Ref no. YHNr-bPwM-7IrV-Bkhk) amended under Ref: MOE 68104.24/64-00011. Before gathering the data, we contacted and requested nurses of the craniofacial centers to act as research assistants for project announcements and recruitment of eligible participants. Then, participants were informed of the objective, process, possible risks and benefits, data collection procedures, and the participants' rights to accept or reject participation in this study. Participants signed an informed consent when they were willing to join this study. After giving consent, the research assistants contacted participants to schedule a convenient date and time for an interview. During the focus group or semi-structured telephone interviews, participants could stop the interview at any time, without affecting the benefits and healthcare services of children in the hospitals. All data were presented without identifying participants.

Data Collection: Focus group interviews and semi-structured telephone interviews were used to obtain participants'points of view and experiences after the principal investigator (PI) established trust and rapport. The research team acted as facilitators during the interview in the meeting room of the outpatient clinic. The researchers developed the semi-structured interview questions used in this study, which five experts validated. Each interview began with primary questions, for example, "How did you bring the child to receive medical care at this hospital?" and "Are there any difficulties in bringing children to treatment at this hospital?" Then, probing questions were asked to obtain sufficient descriptions, such as "How did you know about this hospital?" and "What health insurance benefits does your child have?" We recruited 13 participants from the Central center, 12 from the Northern center, and 12 from the Northeastern center. Five participants from the Southern center were also invited for semi-structured telephone interviews with the same interview questions due to a flooding situation. Focus group interviews were conducted in two groups for each center. Each group comprised 5-8 participants, and the time ranged from 60 to 90 minutes, while the time used for semi-structured telephone interviews ranged from 30 to 45 minutes. The interviews were stopped when data saturation was achieved and when the study aims were met.

Data Analysis: All interviews were audio-recorded and transcribed verbatim in Thai for a qualitative content analysis.[26] The PI and two co-researchers read the transcriptions line-by-line several times to understand the content and context. Essential data were identified from transcriptions of focus groups and semi-structured telephone interviews and were subsequently described in codes. Then, codes were systematically classified into sub-themes. Similar sub-themes were identified within the theme. Three themes and seven sub-themes were generated, then all of them were reviewed and refined.

Rigor and trustworthiness: Information from the group and semi-structured telephone interviews was checked using the four Lincoln and Guba concept criteria.[27] For credibility, all researchers had experience in healthcare services for children with CFA. The PI and two co-researchers had training in qualitative research and practiced interviewing techniques. All interviews were audio-recorded, and the researcher took notes of the participants' feelings, emotions, manners, and behaviors during the interviews. In terms of confirmability, PI and two co-researchers analyzed the transcripts independently. The research team then compared and discussed findings until consensus on the subtheme and theme. Furthermore, the findings were examined by a Thai expert with experience in qualitative research for dependability. Transferability was established by feedback from the participants. An audit trail was maintained to ensure all analysis steps could be returned to the original interview.

Findings

This study explored the perceptions of 42 participants. They were mostly mothers, most of whom had educational levels below a bachelor's degree. Family income ranged from 2,500 to 95,000 baht (72 to 2,754 USD) per month. The age of children with CFA ranged from 1 to 17 years. Over half were eligible for the Universal Health Coverage (UC) scheme. Their demographic characteristics are shown in **Table 1.** The three main themes emerged from the content analysis described below and in **Table 2.**

Table 1. Demographic characteristics of participants

Characteristics	N	%
Caregiver (N = 42)		
Sex		
Female	41	97.62
Male	1	2.38
Age (years) (Min–Max = 23–74, Mean = 40.74)		
20-40	22	52.38
41-60	19	45.24
> 60	1	2.38
Relationship with the child		
Mother	38	90.48
Grandparents	4	9.52
Marital status		
Single	3	7.14
Married	29	69.05
Widow/Divorced/ Separated	10	23.81
Education		
Non-educated	2	4.76
Primary school	11	26.20
Secondary school	5	11.91
High school/Diploma	16	38.09
Bachelor and higher	8	19.04
Occupation		
Merchant	10	23.80
Laborer	13	30.95
Agriculturist	11	26.20
Housewife/None	5	11.91
Government officer	2	4.76
Others: personal business	1	2.38
Monthly income of the family (baht) (Min–Max = 2,500–95,000 (72–2,754 USD), Mean 20,000 (580 USD)		
< 10,000 (< 290 USD)	21	50.00
10,001-30,000 (290-869 USD)	14	33.34
30,001-50,000 (870–1,449 USD)	4	9.52
> 50,000 (> 1,449 USD)	3	7.14
Ability to appointment		
Yes	37	88.09
No	5	1.91
Children with craniofacial anomalies (N = 42)		
Ages (years) (Min–Max = 1–17, Mean = 9.82)		
< 7	13	30.95
> 7-12	12	28.57
> 12-18	17	40.48
Type of craniofacial anomalies [28]		
Clefts	17	40.48
Craniosynostosis	13	30.95
Unclassified	7	16.67

Table 1. Demographic characteristics of participants (Cont.)

Characteristics	N	%
Atrophy-Hypoplasia	3	7.14
Neoplasia-Hyperplasia	2	4.76
Domicile (region)		
Northern	14	33.34
Northeastern	14	33.34
Southern	8	19.04
Central	6	14.28
First diagnosis		
Community hospital	9	21.43
Provincial/regional hospital	8	19.04
Tertiary hospital	12	28.57
Super-tertiary hospital	11	26.20
Others: private hospital, clinic	2	4.76
Outpatient visit (time) (Min-Max = 2-300, Mean = 38.81)		
< 10	16	38.09
11-30	9	21.43
31-50	11	26.20
> 50	6	14.28
Inpatient visit (time) (Min-Max = 0-120, Mean = 6.57)		
< 10	40	95.24
11-20	1	2.38
> 20	1	2.38
Surgery experienced		
Yes	33	78.56
No	9	21.43
Health insurance benefits		
Universal health care coverage scheme	25	59.53
Government and state enterprise employee	2	4.76
Disability welfare	12	28.57
Others: cash	3	7.14

Table 2. Themes and sub-themes arising from the data

Themes	Sub-themes
1. Accessing treatment required time and many steps	1.1 Different health insurance benefits, different ways to access
	1.2 Many steps before receiving treatment from UC rights
2. Receiving treatment from a specialist by seeking information and advice	2.1 Rare diseases, seeking information on craniofacial centers
	2.2 Treatment advice from healthcare providers
	2.3 Treatment advice from other persons
3. Difficulties of hospital visit, including traveling distance and expenses	3.1 Distances visiting the hospital
	3.2 Additional expenses for medicines and equipment

Theme 1: Accessing treatment requires time and many steps

Most primary caregivers visited hospitals supplied with many specialists. They shared experiences about many steps for medical treatment, especially the health insurance benefits for medical care in terms of the UC scheme, which required a referral letter from the previously treated hospital. Some children with CFA who were originally treated in district hospitals needed to be referred to either provincial or regional hospitals and subsequently to specialized hospitals. This multi-step referral required letters and was truly time-consuming. In addition, some primary caregivers mentioned that to receive surgical treatment, they had to wait for a suitable period and a surgical appointment. This theme had two sub-themes:

Sub-theme 1.1: Different health insurance benefits, different ways to access

Most primary caregivers shared that their children received medical treatment because they were referred from their primary hospital. However, they came with different health insurance benefits depending on the physician's discretion and the policies of the primary hospital. Generally, there are three types of health insurance benefits mentioned by primary caregivers: 1) the UC scheme, which rendered the most complicated referral process from the primary hospital; 2) the government and state enterprise employee welfare, which provides few difficulties in service accessibility, and 3) the disability welfare of some caregivers, which allowed their children to reach treatment more convenient, including financial support, for instance,

> *Nowadays, we pay in cash together with the 30-baht program* [UC]. *Thanks to this card, covering almost 30,000 baht* [870 USD] *after my kid's MRI scan! He luckily received the benefit.* (FG1C1)

> *Disbursements are made directly to the Comptroller General's Department [government welfare]; the hospital recommended direct disbursement, eliminating too many processes.* (FG1C3)

> *I chose disability welfare for my kids because a referral form isn't needed. The government agency has offered money if registering as a disabled person - most recently a thousand a month.* (SI5)

Sub-theme 1.2: Many steps before receiving treatment from UC rights

The caregivers mentioned that children who used the UC scheme had to use a referral form, which required many steps to get treatment from specialists at a hospital. The difficulties of this process depended on the discretion of the physicians at the primary hospital, as stated in the following statements:

> *The hospital refused to issue a referral form until I can't stand it anymore. I urged that I would get a disability card for my kid and go for treatment ourselves. It has been three times to run the process prior to the palate treatment until the head of the doctor helped move to the children's hospital.* (FG2C7)

> *It's difficult because coming here requires the 30-baht program* [UC] *and the referral form from Hospital E requires two days in advance. Further, I have to request it from Hospital C again, covering only three months, and also go to Hospital C, spending the other three months, then come here. In the past, Hospital E referred the case directly here* [Hospital D]. (FG6C4)

Theme 2: Receiving treatment from a specialist by seeking information and advice

Some caregivers mentioned that their children received treatment at the craniofacial center because they got advice and referrals from physicians at their primary hospitals. Many children were referred at birth or when craniofacial anomalies were discovered. At the same time, some young patients had come for medical treatment because someone other than health personnel had recommended a craniofacial center. Therefore, the speed of taking children for treatment varies according to the information received. There were three sub-themes in this theme:

Sub-theme 2.1: Rare diseases, seeking information on craniofacial centers

Some caregivers stated that their children's disease was not well known at first, and there were no specialists who could treat it. Then, caregivers searched for craniofacial centers on the internet by themselves.

> *Six years ago, we were in Province B, and there were no craniofacial centers in the northern region, no pediatric neurosurgeon. Fortunately, my husband was hired and moved to Bangkok. A professor who lived there was a friend of a doctor who lived here in Province B. As I am a nurse, I had been searching for information since I first found the center here; however, we had to follow the system, and Hospital B also referred my son. After the referral had been completed, I still didn't meet the doctor. Once, I called the center, and the staff told me that the doctor came on Wednesdays, and I could go to the 6th floor right away. I now still remember her speech: "Come whenever you are convenient." To me, I didn't work for a month and almost got fired, and the fastest queue was nearly a month before surgery!* (FG1C3)

> *The doctor said, "I have never seen a child in a case like this, perhaps you should go to Bangkok." We finally went there. At that time, the internet system wasn't very good. We tried searching for information about the disease though we even know what name of the disease was. Then, we found out that Hospital A provided some kind of center. I couldn't remember the name. At first, I didn't go to Hospital A but another one. We were shocked about what was going on.* (FG3C1)

Sub-theme 2.2: Treatment advice from healthcare providers

Some caregivers reported receiving treatment in a super-tertiary hospital equipped with a specialized craniofacial center. Physicians at the primary hospital agreed to make the referral, for example:

> *When I gave birth to my second child, the obstetrician recommended a center. Also, I just found a specialized one for craniofacial anomalies on the internet, so I went there to take a look.* (FG1C2)

> *When I gave birth at Hospital F a long time ago, the doctor suggested for treatment at Medical Center G which provided direct treatment with various medical fields. That was the first time I had known, then the doctor referred me here to Hospital H.* (FG4C4)

Sub-theme 2.3: Treatment advice from other persons

Some caregivers received information about craniofacial centers from people other than healthcare personnel, such as neighbors or taxi drivers, for instance,

> *It took a long time to come here to Hospital A. At first, I didn't know where to go since no one recommended me. Because of a suggestion from the taxi driver, I later went to the children's hospital when my baby was eight months old. I used to have surgery at that hospital once before coming to Hospital A—it's about a year old.* (FG1C2)

> *The doctor did not recommend where to go for further treatment but suggested going to a hometown since my daughter could survive only two or three months. My neighbor suggested that I visit the children's hospital where her grandchild with abdominal paracentesis went for treatment. I had no idea, holding, seeing, and asking my daughter whether it would happen again. That*

> *time, I went to the children's hospital but didn't get checked. After being a new patient registered at the hospital, I went home with another appointment in two weeks. No sooner had I arrived home than my daughter had the same symptoms again. After she had drunk milk, she did not react as if she suffocated. We came to the children's hospital later that day, and she was sent to see a neurologist. After diagnosis, she was normal with no neuropathy, then the doctor checked x-rays, records in a CD, and advised me to come here.* (FG2C6)

Theme 3: Difficulties of hospital visits, including traveling distance and expenses

Information from caregivers reflected the difficulty of treatment in taking children to the craniofacial center because it often required many hours to travel, and they had to pay additional fees or excess expenses that health insurance benefits could not cover. However, all the caregivers stated that they would not give up because of these difficulties, so their children could access specialized medical care and undergo better surgery. There were two sub-themes in this topic:

Sub-theme 3.1: Distances visiting the hospital

Some caregivers noted that the trips from their hometowns to the hospitals with specialized centers were far and required several hours by car; however, they did not yield to these difficulties.

> *It's difficult because I came by bus. Sometimes I had to wait and see. It took a long time for the car to arrive on the main road.* (FG3C5)

> *At that time, the difficulty was that I had to disturb others to take my son and me to Bangkok by a private car because we cannot go any other way. The trip was full of obstacles. I thought that he would die during the trip because he choked on milk and his eyes bulged like the eyelids were protruding.* (SI5)

Sub-theme 3.2: Additional expenses for medicines and equipment

Some caregivers reported that sometimes they came to the hospital. Additional expenses could not be reimbursed according to health insurance benefits, mainly medicines or appliances necessary for surgery for craniofacial anomalies.

There is a cost of nearly 60,000 baht [1,739 USD] *for dental surgery to clean up the oral cavity before fixing the application. Once the surgery is done, braces are the next step. The doctor has already informed us that there should be additional expenses that I must prepare as some appliances must be ordered.* (FG5C6)

If I pay two hundred or three hundred baht for additional expenses, it will be no problem, but paying more than this amount is not ok. For surgery, more than 20,000 baht [580 USD] *must be prepared. My baby had gone for a stomach operation, and there were additional expenses i.e., suction tubes. However, I can't afford it if I have to cover all expenses.* (FG3C5)

Discussion

The primary caregivers' perceptions regarding healthcare service accessibility of children with CFA were divided into three themes described above. Children with CFA were classified as having severe abnormalities. The fundamental treatment for this group of diseases was surgery to resolve life-threatening problems, followed by periodic facial-reconstructive surgeries based on the severity of each disease group. These medical procedures require continuous treatments by an interdisciplinary healthcare team in a well-equipped hospital.[1]

In this study, most children (85.72%) with CFA resided in rural areas. More than two-thirds of the children (69.04%) were primarily diagnosed at community, regional, and tertiary hospitals, where specialists were unavailable. In addition, more than half of the children (59.53%) utilized the UC scheme, which required referral documents from primary healthcare units suggested by physicians to receive further treatment in higher-level hospitals.[29] A previous study reported that the UC scheme had promoted the accessibility to cleft lip and cleft palate treatment.[30]

It can be assumed that children with CFA need referral documents for proper treatment in super-tertiary hospitals. To request a referral document that covers the cost of treatment at a potential hospital, young patients and their caregivers had to visit many various levels of hospitals where investigation, treatment, and craniofacial anomalies surgery can be conducted.[8] These experiences led to physical, psychological, and financial burdens for caregivers. Some caregivers, therefore, allowed their children to utilize the disability welfare coverage scheme to access healthcare services since it did not require a referral form. Besides, a disability card provides various benefits for people with disabilities, such as disability allowance, cost of equipment to assist disabilities, and media to promote development and learning conditions.[31]

Likewise, the Social Welfare Department of Malaysia provides some financial assistance to parents of persons with disability, in terms of monthly allowances and tax exemption.[13] We can state that health insurance benefits affected healthcare accessibility and support for these young children. A systematic literature reported that inadequate insurance coverage and distance to hospitals with clefts teams are critical factors of medical care accessibility.[23] Hence, caregivers perceived that accessibility to healthcare services or treatment for their children required many steps and time. This reflected a challenge of healthcare accessibility for children with CFA.

Regarding our findings, many caregivers clarified that their children received treatment from a specialist by seeking information and advice. This can be explained by the fact that craniofacial anomalies are complex diseases with different levels of severity. Some young patients do not have obvious symptoms at birth but are later noticeable as they age, such as having more bulging eyes and a deformed head shape. As a result, caregivers brought their children to clinics or hospitals where insight into the treatment or specialized care may not be offered, causing delayed diagnosis or surgical intervention at the beginning.[15] Some parents seek information on craniofacial centers on the internet by themselves. Our findings align with Swedish parental experiences, mentioning that most parents craved more information at the time of craniofacial detection. They had searched the internet and social media to ascertain more details about craniosynostosis.[22] In this study, more than half (54.77%) of young patients were diagnosed with CFA at tertiary and super-tertiary or university hospitals. As mentioned previously, most children with CFA resided in rural areas of Thailand; therefore, some caregivers reported ineffective care coordination to support children with CFA. However, most caregivers (88.09%) could bring their children for the check-up as scheduled.

Furthermore, a shortage of specialists in the rural areas also resulted in long waiting lists for diagnosis and treatment for children with CFA, including referrals for treatment from far-away provinces. The caregivers had to bring their children for diagnosis or treatment during many hospital visits, causing travel expense problems. These are considered as difficulties or barriers to healthcare accessibility for children with CFA perceived by caregivers. Consistent with the study of patients with craniofacial anomalies in Saudi Arabia, it showed that barriers to seeking treatment were difficulty in scheduling appointments, long waits, and a difficult journey.[14] In addition, an Australian study revealed that the availability of specialists was a frequently cited challenge for chronically ill patients.[19] Children with CFA in rural areas still face challenges in accessing treatment from specialists. When these children need to see a specialist, they must travel to a university hospital with a craniofacial center. Therefore, a training program for specialists will be served to offer specialized care for needy patients and minimize the barriers to accessing medical care.

Regarding additional expenses, the caregivers perceived that they could not be reimbursed for non-essential drugs, medical supplies, surgery equipment, and special investigations due to their health insurance benefits. Caregivers expressed that certain expenses could be covered, but not all of them. This finding accords with an international study on barriers to accessing medical services among Hispanic populations with craniofacial anomalies.[32] It was found that financial problems were barriers to treatment due to low income, unemployment or absence from work, and high healthcare expenses. Our findings on caregivers of children with craniofacial anomalies in Thailand were not different from the results of studies abroad. The caregivers still have to bear the costs of medical care, including medication, medical supplies, and equipment. Due to complex illnesses and the need for special investigations with excessive expenses beyond the coverage, caregivers were concerned about them.[15] This study revealed that care barriers for children with CFA remained a complex challenge associated with socioeconomic status, geographic characteristics, and healthcare system regarding health insurance benefits. Hence, financial support from other relevant agencies or social welfare would help diminish the barriers to healthcare accessibility for children with CFA.

Limitations

This study focused on the accessibility of healthcare services for children with craniofacial anomalies in all disease groups. The caregivers of children with craniofacial anomalies and the severity of the disease may have different experiences with healthcare service accessibility. In addition, this study was conducted in four super-tertiary university hospitals when we faced the COVID-19 pandemic and flooding in certain areas over three years. Therefore, the data collection was adjusted from focus group interviews to semi-structured telephone interviews, which may limit the completeness of data compared to face-to-face interviews.

Conclusions and Implications for Nursing Practice

This study explored caregivers' perceptions of children with CFA, including all disease groups with varying degrees of disease severity. The children's health insurance benefits were different; as a consequence, it affected accessibility to medical care for the children. Some children with CFA were treated with timely corrective surgery, while others were delayed longer than expected. The barriers to healthcare accessibility, according to caregivers' perceptions, included limitations on information of treatment sources, health insurance benefits, transportation expenses, long waiting lists, and additional expenses related to medical treatment. In conclusion, this study provides an understanding of the caregiver's perspective, especially the barriers to healthcare service accessibility for children with CFA. In this regard, we suggest that the referral system should be redesigned to directly refer young patients with CFA to hospitals with craniofacial centers to reduce barriers for this population. In addition, health personnel, including nurses, should further develop guidelines or care pathways and work with stakeholders for improving care efficiency for these children by providing thorough information, facilitating faster referrals, and offering comprehensive patient care through network support, including financial support. These findings can be applied in future research to develop a supportive program that fulfills the needs of children with CFA and their caregivers.

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การรับรู้ของผู้ดูแลเกี่ยวกับการเข้าถึงบริการสุขภาพของเด็กที่มีความผิดปกติของใบหน้าและศีรษะ : การศึกษาเชิงคุณภาพแบบพรรณนา

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บทคัดย่อ: การเข้าถึงบริการสุขภาพมีความสำคัญยิ่งต่อผลลัพธ์การรักษาและคุณภาพชีวิตของเด็กที่มีความผิดปกติของใบหน้าและศีรษะ การวิจัยเชิงคุณภาพแบบพรรณนาครั้งนี้มีวัตถุประสงค์เพื่อศึกษาการรับรู้ของผู้ดูแลเกี่ยวกับการเข้าถึงบริการสุขภาพของเด็กที่มีความผิดปกติของใบหน้าและศีรษะ ในประเทศไทย ผู้ให้ข้อมูล คือผู้ดูแลหลักของเด็กที่มีความผิดปกติของใบหน้าและศีรษะแต่กำเนิดที่ไม่ใช่ปากแหว่งเพดานโหว่อายุตั้งแต่ 3 เดือน ถึง 18 ปี เก็บรวบรวมข้อมูลโดยการสัมภาษณ์กลุ่มกับผู้ดูแล 37 คน จำนวน 6 กลุ่ม และการสัมภาษณ์แบบกึ่งโครงสร้างทางโทรศัพท์กับผู้ดูแล 5 คน รวมจำนวน 42 คน ที่พาเด็กมารับการรักษาในโรงพยาบาลตติยภูมิขั้นสูงที่มีศูนย์แก้ไขความผิดปกติของใบหน้าและศีรษะ จำนวน 4 แห่ง ระหว่างเดือนตุลาคม 2561 ถึงเดือนกุมภาพันธ์ 2564 วิเคราะห์ข้อมูลเชิงคุณภาพโดยใช้การวิเคราะห์แก่นสาระ ผลการศึกษาได้ข้อค้นพบ 3 ประเด็นหลัก คือ 1) การเข้าถึงการรักษาต้องใช้เวลาและผ่านหลายขั้นตอน 2) การได้รักษากับแพทย์ที่เชี่ยวชาญมาจากการแสวงหาข้อมูลและคำแนะนำ และ 3) ความลำบากของการมารักษาคือการเดินทางและค่าส่วนต่างที่ต้องจ่ายเพิ่ม ผลการศึกษานี้สะท้อนการเข้าถึงบริการสุขภาพของเด็กที่มีความผิดปกติของใบหน้าและศีรษะยังมีความท้าทายและเกี่ยวข้องกับปัจจัยทางเศรษฐกิจและสังคม ถิ่นฐานที่อยู่อาศัย และสิทธิการรักษา การดูแลรักษาเด็กโรคนี้ต้องอาศัยแพทย์ที่มีความเชี่ยวชาญเฉพาะทาง ซึ่งอยู่โรงพยาบาลระดับมหาวิทยาลัยในเมืองใหญ่ ทำให้เด็กที่อาศัยอยู่ในชนบทหรือพื้นที่ห่างไกลมีข้อจำกัดในการเข้าถึงบริการสุขภาพ การส่งเสริมให้เด็กเข้าถึงบริการสุขภาพที่เหมาะสม บุคลากรทีมสุขภาพรวมถึงพยาบาลควรให้ข้อมูลที่ครอบคลุมโรงพยาบาลที่มีศักยภาพที่มีศูนย์แก้ไขความผิดปกติของใบหน้าและศีรษะให้การส่งต่อที่รวดเร็วขึ้น รวมทั้งให้การช่วยเหลือตามความต้องการเฉพาะรายเพื่อพัฒนาประสิทธิภาพในการดูแล

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คำสำคัญ: ผู้ดูแล เด็ก ความผิดปกติของใบหน้าและศีรษะ การเข้าถึงบริการสุขภาพ การรับรู้ การศึกษาเชิงคุณภาพแบบพรรณนา ประเทศไทย

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