# https://doi.org/10.48047/AFJBS.6.Si3.2024.2454-2469



# Analysis of Barriers and Facilitators on Congenital Talipes EquinoVarus (CTEV) Treatment During COVID-19 Pandemic

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Article Info

Volume 6, Issue Si3, 2024

Received: 12 April 2024

Accepted : 29 May 2024

Published: 17 June 2024

**ABSTRACT:** The treatment of CTEV has faced significant challenges during the COVID-19 pandemic. This study aims to explore the barriers and enablers encountered by caregivers and healthcare professionals in managing CTEV during this period. This qualitative research employs a retrospective phenomenological approach, focusing on the experiences of 8 caregivers and 6 healthcare professionals. Data were collected through indepth semi-structured interviews conducted face-to-face and online. Thematic analysis was used to identify key themes in data analysis. The study identifies several challenges and supports CTEV treatment. Major obstacles include lack of information, long distances, cultural beliefs, geographical constraints, transportation issues, insufficient family and community support, and financial difficulties. COVID-19 health protocols have further complicated access. However, educational programs by foundations and healthcare workers, financial aid from government programs like national healthcare security (BPJS Kesehatan), and transportation assistance have been crucial supports. The availability of treatment tools, COVID-19 prevention measures, referral letters, organized patient arrivals, and video consultations have also helped parents and health workers to manage CTEV treatment during the pandemic. The COVID-19 pandemic exacerbated existing barriers to CTEV treatment but also highlighted the resilience and adaptability of caregivers and healthcare professionals. Understanding these barriers and enablers is crucial for designing effective interventions and policies to improve healthcare delivery and patient outcomes during global health crises. Keywords: Congenital Talipes EquinoVarus, CTEV, clubfoot, COVID-19, qualitative research, healthcare barriers, healthcare enablers

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#### Introduction

Congenital talipes equinovarus (CTEV), commonly known as clubfoot, is a congenital anomaly that can be effectively treated shortly after birth to prevent long-term disability. However, many CTEV cases go untreated, leading to neglected CTEV, particularly in children of walking age who have not received timely intervention. Ideally, treatment should commence before the age of one year to maximize effectiveness (Alves, 2021). The Stepping Stones Bali Foundation is dedicated to treating children with CTEV, collaborating with Kerta Usada Hospital and Puspadi Bali Foundation.

A sentinel survey of congenital anomalies conducted from September 2014 to March 2018 revealed that CTEV was the most common congenital anomaly, constituting 21.9% of total congenital anomaly births. According to the Global Report on Birth Defects by the March of Dimes Birth Defects Foundation, from 1980 to 2001, Indonesia's prevalence of infants with congenital anomalies was 59.3 per 1000 live births. Among Southeast Asian countries, Indonesia ranks fourth in congenital anomaly prevalence, following Laos, Cambodia, and Thailand (Infodatin Congenital Anomalies, 2018).

The World Health Organization (WHO) states that over 8 million babies are born annually with congenital anomalies, with 94% of these cases occurring in low- and middle-income countries. Around 80% of untreated CTEV cases are found in developing nations. Congenital anomalies often lead to long-term disabilities that significantly impact families, healthcare systems, and communities. Less than 15% of children with CTEV in low- and middle-income countries receive treatment. The global incidence of CTEV ranges from 0.6 to 1.5 per 1000 live births, equating to an estimated 84,000 to 210,000 new cases each year (Ansar et al., 2018). In 2016, the incidence in low- and middle-income countries was between 0.51 and 2.03 per 1000 live births (Smythe et al., 2017).

Congenital anomalies are structural or functional abnormalities present at birth, identified either before birth, at birth, or later in infancy (WHO, 2016). These anomalies can range from mild to severe, affecting the shape or function of organs. Addressing these anomalies promptly with surgery can significantly reduce disability-adjusted life years (DALYs). For CTEV, the Ponseti method, involving serial casting, tenotomy, and bracing, is the globally accepted treatment standard (Debas et al., 2015).

CTEV is the most common serious musculoskeletal congenital anomaly affecting the foot globally, often persisting into adulthood and impairing function and quality of life. The Ponseti method has been successfully implemented worldwide, including in resource-limited settings (Cady et al., 2022). Early intervention, ideally before the child turns one, is crucial for treatment success. Delayed treatment can result in the need for more extensive surgery, lower effectiveness, increased complications, and higher costs (Morcuende, 2004).

In Indonesia, the average age at which initial treatment begins is significantly delayed compared to other countries, with Bali at 23.63 months and Sumatra at 129.6 months. This delay is attributed to various factors, including cognitive barriers, structural barriers, financial challenges, and cultural beliefs (Locke et al., 2021). Parents face difficulties in financial and social support, and travel time also influences treatment delays (Van Wijk et al., 2015). Additionally, treatment barriers include socioeconomic factors, medical issues, misinformation, and lack of support from fathers, extended family, and the community (Sananta et al., 2021; Drew et al., 2016).

The COVID-19 pandemic has exacerbated these issues, leading to a decrease in new registrations, followup visits, and surgeries for CTEV (Chand et al., 2022). Despite these challenges, the Stepping Stones Bali Foundation has seen an increase in CTEV case management during the pandemic.

There is a significant delay in the early treatment of CTEV in Indonesia compared to other countries. This delay is influenced by factors from patients, caregivers, and healthcare providers. The COVID-19 pandemic has further impacted CTEV treatment availability and patient visits. There is a need to analyze the barriers and supports for CTEV treatment especially during the COVID-19 pandemic from the perspectives of caregivers and healthcare providers. Identifying barriers and enablers is essential for designing effective health interventions, ensuring patient adherence, optimizing healthcare delivery, and informing policies that promote equitable and efficient healthcare particularly during pandemic. This process ultimately contributes to better health outcomes, improved patient satisfaction, and more sustainable healthcare systems. **General Objective** of the research to analyze the barriers and enablers on CTEV treatment at the Stepping Stones Bali Foundation, Puspadi Bali Foundation, and Kertha Usada Hospital during the COVID-19 pandemic. **Meanwhile, Specific Objectives** (1) To analyze the barriers for treating patients with CTEV deformities during the COVID-19 pandemic from the perspective of

caregivers and healthcare providers, focusing on knowledge, attitudes, motivation, financial, and structural factors; (2) To analyze the enablers for treating patients with CTEV deformities during the COVID-19 pandemic from the perspective of caregivers and healthcare providers, focusing on knowledge, attitudes, motivation, financial, and structural factors.

#### Methods

This research is a qualitative study with a retrospective phenomenological approach to identify the barriers and enablers of CTEV treatment during the COVID-19 pandemic. To avoid recall bias, the year 2021 was chosen as it is the closest year to the research period when COVID-19 was still a pandemic. Qualitative research aims to explore and understand the meanings that individuals or groups attribute to social problems (Creswell, 2016). Phenomenology is a research design where the researcher describes human life experiences regarding a specific phenomenon as explained by the participants. This description culminates in the essence of the experiences of several individuals who have undergone the phenomenon. This approach was chosen because it aligns with the research objective to describe the experiences of caregivers and healthcare professionals in performing CTEV treatment during the COVID-19 pandemic. The advantage of this approach is that the researcher can obtain direct information about the participants' experiences through open and broad questions (Patton, 2002; Maxwell, 2013; Rudestam & Newton, 2015). However, there are also drawbacks to this method, including the potential for bias, time consumption, and the need for intensive work (Creswell, 2014). Additionally, the results cannot be generalized (Maxwell, 2013). The research was conducted with caregivers of children with CTEV deformities who underwent Ponseti method treatment in 2021 and healthcare professionals who handled CTEV in 2021. The variables the researcher aimed to explore include knowledge, attitude, motivation, financial, and structural factors. This study was conducted at the Stepping Stones Bali Foundation, the Puspadi Bali Foundation, and Kertha Usada Hospital Bali, which is a national-level hospital specializing in orthopedic cases with a high volume of CTEV cases. The research was conducted from September to November 2022.

Primary data gained from in-depth interview with informants which are caregivers and health workers. Researchers contacted health workers through the foundation and hospitals; and contacted caregivers through the foundation to arrange participation and interview schedules. The informants consist of 8 caregivers and 6 health workers who were given informed consent prior to the interview. In depth interview was performed with semi structured questions and performed in person and online. This research has been approved by the university's ethics committee.

The collected data analyzed thematically to identify common themes and patterns in the experiences of caregivers and healthcare professionals. This analysis help in understanding the core experiences and the essence of handling CTEV during the pandemic. By employing this research design, the study aims to provide valuable insights into the challenges and supports encountered in the management of CTEV during a global health crisis, contributing to better preparedness and response strategies in similar future scenarios.

#### **Results and Discussion**

The findings of the study, gathered through semi-structured face-to-face and online interviews, provide insights into caregivers' knowledge, perceptions, and experiences regarding Congenital Talipes EquinoVarus (CTEV) and its treatment, as well as the impact of the COVID-19 pandemic on healthcare-seeking behavior.

#### Theme 1: Knowledge

#### **Understanding of CTEV**

Caregivers demonstrated varied levels of understanding about CTEV, perceiving it as a congenital foot deformity in babies with an unknown cause. While some attributed it to the baby's position in the womb, others cited unrelated actions during pregnancy. This knowledge was largely consistent with medical

professionals' explanations of CTEV as a congenital condition with uncertain etiology, potentially linked to genetics.

"...Bent feet or CTEV. We don't know the cause yet..." (NN, Parent)

"...The baby's position in the womb caused the deformity..." (KP, Parent)

"...Maybe because I tied a chicken's legs when I was pregnant..." (M, Parent)

"...CTEV is a disability involving a newborn's bent foot. The main cause is unknown, but it might be genetic or other factors..." (KS, Healthcare Worker)

# **Treatment Approach**

Caregivers were familiar with the treatment modalities for CTEV, including casting, tenotomy, and bracing, having undergone these procedures as part of their child's treatment journey. Some caregivers also explored traditional treatments like massage before opting for medical interventions. Their experiences aligned with healthcare professionals' descriptions of the Ponseti method, highlighting the importance of early intervention and comprehensive treatment approaches.

"...My child underwent casting three times, then had surgery. After the surgery, a cast was put on again for three weeks. Then, special shoes were used..." (KR, Parent)

"...CTEV patients are treated with the Ponseti method, which includes casting, tenotomy, and bracing..." (ME, Healthcare Worker)

"...For standard CTEV treatment, we perform serial casting, then tenotomy to correct the equinus. After tenotomy, a cast is applied for one or two weeks, followed by a Dennis Brown splint..." (IGKY, Healthcare Worker)

# Awareness of Consequences

Caregivers expressed concerns about the consequences of untreated CTEV, emphasizing potential mobility limitations and social implications for their child's future. These apprehensions resonated with healthcare professionals' insights into the long-term impacts of untreated CTEV on both physical and mental well-being.

"...I'm afraid there will be regret when the child grows up. He might walk crookedly later..." (M, Parent)

"...The impacts are numerous, beyond physical disability. The child's mental health will also be affected..." (NWA, Healthcare Worker)

# **Information Sources**

Caregivers acquired information about CTEV from various sources, including healthcare professionals, foundations, friends, and the internet. Efforts by healthcare institutions and foundations to disseminate information through workshops, leaflets, and outreach programs played a crucial role in increasing awareness among caregivers, especially those in remote areas.

"...I looked up information on the internet, asked friends, the foundation, and pediatricians..." (KR, Parent)

"...We provide leaflets to help patients and the community get information about CTEV..." (NWA, Healthcare Worker)

"...We conduct outreach program to villages to inform the community about clubfoot or CTEV..." (KS, Healthcare Worker)

# **Understanding of COVID-19**

Caregivers demonstrated awareness of COVID-19 as a viral disease and adhered to recommended health protocols when seeking CTEV treatment, reflecting their commitment to ensuring their child's safety amidst the pandemic.

"...The patient's family is aware of COVID-19. They prepare to avoid getting infected, such as wearing masks, using hand sanitizers, frequently washing hands, and maintaining distance according to government protocols..." (IMS, Healthcare Worker)

"...Parents of patients have received information about COVID-19..." (KS, Healthcare Worker)

# **Barriers Acquiring Knowledge**

Caregivers encountered barriers such as distance, lack of immediate information after birth, and transportation issues when seeking information about their child's condition. Healthcare professionals also identified barriers such as lack of information and geographical constraints, particularly for caregivers in remote areas.

"...When my child was born, there was no examination by a doctor..." (KBA, Parent)

"...Some of them live far away in remote areas of Bali, making access to healthcare difficult..." (IAPK, Healthcare Worker)

"...There might be a lack of information, especially for people living in remote areas because social media is not yet widely used..." (KS, Healthcare Worker)

# Support Acquiring Knowledge

Caregivers highlighted the invaluable support received from healthcare professionals and foundations in navigating their child's CTEV journey. Direct guidance from doctors, assistance from foundations, and access to reliable information sources facilitated caregivers' understanding and decision-making process.

"...The foundation greatly helped with my child's CTEV treatment. Besides that, the doctors were also very helpful..." (KP, Parent)

"...Most of our patients learn about this hospital and the foundation from the internet, but some get information from health centers because our foundation collaborates with health centers to raise awareness about CTEV..." (NWA, Healthcare Worker)

# Theme 2: Attitude

Attitude plays a significant role in navigating the challenges posed by Congenital Talipes Equino Varus (CTEV) and ensuring appropriate treatment. Patient parents' reactions, responses to diagnosis, and overall demeanor towards their child's condition, as well as healthcare workers' attitudes towards patient care, were explored.

# **Initial Reactions and Responses**

Upon learning about their child's CTEV, patient parents initially experienced a range of emotions, from shock and sadness to self-blame. However, upon receiving information about potential treatments and positive outcomes, their reactions became more optimistic, characterized by relief and motivation.

"...I felt sad and regretful. I wondered what I had done to cause my child to be like this..." (M, Parent)

"...I felt relieved and happy because there was hope for recovery..." (KBA, Parent)

# **Response to Treatment**

Patient parents maintained a positive outlook and remained proactive in seeking medical help for their child, demonstrating acceptance of the condition and determination for their child's recovery. Healthcare workers expressed appreciation for parents who promptly sought treatment, recognizing their awareness and commitment to managing CTEV effectively. Moreover, healthcare workers are still being positive for parents who are late in seeking treatment.

"...I immediately seek help and continue to seek treatment for my child..." (IKS, Parent)

"...I am very enthusiastic because the parents already know the place for treating children with CTEV. This shows they understand early detection..." (KS, Healthcare Worker)

"...We also accept patients who have delayed CTEV. We provide education and motivation, assuring them that their child can be treated..." (ME, Healthcare Worker)

"...I am grateful they came, meaning we don't need to scold or be negative towards the parents because cases like this are not yet familiar to the public. We will serve them well..." (IGKY, Healthcare Worker)

# **Attitude During the COVID-19 Pandemic**

Despite the challenges posed by the COVID-19 pandemic, healthcare workers continued to provide CTEV services while adhering to safety protocols. Patient parents remained resilient, seeking treatment for their children despite concerns about the pandemic. Their willingness to comply with health guidelines reflected their commitment to their child's well-being.

"...We continue to provide services according to protocols. At the beginning of COVID-19, there was a notice from the professional organization that all non-emergency surgeries or procedures were temporarily halted. After about two weeks or up to a month, we resumed services..." (IGKY, Healthcare Worker)

# **Barriers Positive Attitude**

Various barriers hindered patient parents from maintaining a positive attitude towards their child's condition, including a lack of information from healthcare providers and dissatisfaction with previous treatment experiences. Healthcare workers identified additional challenges such as cultural beliefs, geographical constraints, and financial limitations, all of which contributed to negative attitudes among patient parents.

"...Because the previous treatment was not good and there were no results, we were reluctant to go to the hospital again..." (M, Parent)

"...In Bali, there is a belief that CTEV is the will of their ancestors. Patient parents feel that it might be their fate to have a child like that because their ancestors were like that..." (IMS, Healthcare Worker)

"...There were doubts, but we provided understanding to the family. Our foundation had prepared health protocols according to government standards..." (IMS, Healthcare Worker)

"...Challenges included difficulty accessing patients directly due to regional restrictions and WFH (work from home). Other challenges for us included the use of hazmat suits which caused heat and face shields that could fog up, impairing vision..." (IAPK, Healthcare Worker)

# Support Positive Attitude

Internal and external support systems played a crucial role in bolstering patient parents' positive attitudes towards CTEV management. Family encouragement and education provided by healthcare workers were key factors in fostering resilience and motivation among patient parents. Despite the pandemic, patient parents remained determined, supported by healthcare workers who continued to deliver essential services and reassurance.

"...We remain enthusiastic about treatment for the child's recovery, and we are not afraid of COVID..." (Q, Parent)

"...Afraid, but this condition cannot be ignored, so we are forced to seek treatment..."(KR, Parent)

"...After we educate them and show photos and videos of successfully treated CTEV children, they become willing to undergo treatment..." (ME, Healthcare Worker)

"...Providing maximum service is our duty and obligation as healthcare workers to help children undergo the CTEV therapy program..." (NWA, Healthcare Worker)

## **Theme 3: Motivation**

Motivation emerges as a crucial factor in driving the pursuit of treatment for Congenital Talipes EquinoVarus (CTEV), especially amid the challenges posed by the COVID-19 pandemic. Understanding the reasons behind seeking or delaying treatment sheds light on the dynamics of parental motivation and its impact on treatment outcomes.

#### **Reasons for Seeking Immediate Treatment**

Parent informants demonstrated a strong motivation to seek immediate treatment for their child's CTEV, driven by a desire for a quicker recovery and the hope for their child to lead a normal life. This motivation was fueled by awareness of the importance of early intervention, as emphasized by healthcare workers who highlighted the critical window for effective treatment.

"...The sooner they receive treatment, the better, rather than waiting until they're older..." (KP, Parent)

"...The longer it is delayed, the harder it becomes. So, families must quickly start the Ponseti method to improve the prognosis of recovery..." (NWA, Healthcare Worker)

#### **Motivation During the COVID-19 Pandemic**

Despite the disruptions caused by the COVID-19 pandemic, parents informants remained resolute in seeking CTEV treatment, driven by concerns for their child's well-being and a desire to ensure continuity of care. Healthcare workers echoed this sentiment, noting that parental motivation persisted despite the challenges posed by the pandemic, highlighting the unwavering commitment of parents to their child's health.

"...To know the progress of my child's treatment, I'm afraid something might happen to their feet..." (KBA, Parent)

"...We continue treatment even during the COVID pandemic to ensure the child's care isn't hindered by COVID..." (KR, Parent)

"...Usually, parents want the best for their child. After understanding their child's CTEV condition, even during the COVID-19 pandemic, they will strive to seek treatment while following health protocols..." (IGKY, Healthcare Worker)

#### **Motivation Barriers**

While parent informants exhibited strong motivation to seek treatment, they encountered barriers, such as the increased complexity of procedures during the pandemic. Healthcare workers also faced temporary challenges in providing comprehensive care due to restrictions imposed by the pandemic, albeit manageable.

"...There are more procedures now, such as having to take a swab test..." (KR, Parent)

"...We closed services temporarily for about three months..." (ME, Healthcare Worker)

"...The barrier was the limitation on the number of patients visiting. We could only handle 50% of the patients compared to before the pandemic. Additionally, the number of participants and the duration of community outreach in villages had to be limited, so we couldn't provide comprehensive material... (IMS, Healthcare Worker)

# **Motivation Support**

External and internal support systems played a pivotal role in bolstering parental motivation to seek CTEV treatment. External support from healthcare workers and foundations provided reassurance and guidance, while internal motivation stemmed from parents' inherent desire for their child's well-being. Healthcare workers recognized the importance of support in maintaining parental motivation, emphasizing the role of financial assistance, proximity to healthcare services, and access to appropriate equipment in facilitating timely treatment.

"...The doctor and foundation supported us. Moreover, we weren't charged any fees..." (KP, Parent)

"...The foundation provided PPE (Personal Protective Equipment), so we felt confident in accepting patients during the COVID-19 pandemic... " (ME, Healthcare Worker)

"...We want to save children so they do not miss out on medical and rehabilitation treatments..." (IMS, Healthcare Worker)

#### **Theme 4: Finance**

Understanding the financial aspects of caring for a child with Congenital Talipes EquinoVarus (CTEV) is crucial for addressing affordability, identifying barriers, and providing necessary support to families. This qualitative analysis delves into the financing of treatment, perceived costs, encountered barriers, and available support systems.

#### Affordability

Parent informants highlighted the significant role of national healthcare security (BPJS Kesehatan), in financing their child's CTEV treatment. Initially unaware of this option, some parents covered treatment costs out of pocket, considering them high but proceeding for their child's well-being. However, most parents utilized BPJS from the start, with treatment costs fully covered, including surgery and swab tests. Healthcare workers corroborated this, emphasizing the foundation's role in providing additional casts when needed, and sponsorships for auxiliary equipment like AFOs (Ankle-Foot Orthosis).

"...Initially, we didn't know we could use BPJS, then at the hospital cashier, we were asked for the BPJS card..." (KP, Parent)

"...We use BPJS KIS. Casting was done 3 times, and surgery was performed. All costs were fully covered. I didn't pay anything, including the swab test..." (KR, Parent)

"...Treatment payments are made through BPJS. Casting and surgery are fully covered. However, the foundation also provides casts for cases that require more than 6 casts..." (ME, Healthcare Worker)

#### **Perceived Cost**

Parent informants without BPJS expressed concerns over the high treatment costs, especially impactful for families with lower economic means. Healthcare workers echoed this sentiment, acknowledging the financial burden on patients without BPJS coverage, underscoring the importance of financial assistance in ensuring access to care.

"...It's quite expensive because we're just farmers. The costs are too high. Without the foundation, my child might not continue treatment because we can't afford the expensive shoes..." (KP, Parent)

"...Expensive without BPJS..." (ME, Healthcare Worker)

"...Expensive for patients with lower economic conditions..." (NWA, Healthcare Worker)

# **Financial Barriers**

Transportation costs emerged as a notable barrier, particularly for families reliant on public transportation to reach treatment facilities, despite treatment being covered by BPJS. Healthcare informants also noted challenges for patients without BPJS, hindering access to medical care. The COVID-19 pandemic introduced additional hurdles, including delays in procurement and program implementation, and limitations on patient visits due to safety protocols.

"...The transportation cost to come here alone is 150 thousand. The most expensive cost is transportation, while the treatment is free..." (KP, Parent)

"...Transportation costs, gas money for a single trip is 250 thousand rupiahs, vehicle rental is 250 thousand rupiahs. Also, meal money, but sometimes we bring food from home. Driver fees too when the father can't drive..." (IKS, Parent)

"... There are cases where the patient's BPJS isn't paid or is overdue, which becomes an issue. Sometimes the foundation helps with half the payment. We strive for the child's recovery because many people have stopped working during the pandemic..." (KS, Healthcare Worker)

# **Financial Support**

BPJS played a pivotal role in providing financial support for treatment, alleviating the burden on families. Foundations like Puspadi and Stepping Stones offered further assistance, including transportation aid for patients with financial constraints. These collaborative efforts between healthcare institutions and foundations underscored the importance of external support systems in ensuring access to essential medical care.

"...No treatment costs because it's covered by BPJS..." (KP, Parent)

"...We use BPJS and have a private vehicle..." (M, Parent)

"...For treatment, BPJS helps and the Puspadi foundation provides transport assistance by picking up patients if there are at least 5 patients. If there are only 2 patients, we from Stepping Stones transport them to Puspadi. Generally, patients pay for their own transport, but for those with severe financial constraints, they are given financial aid..." (ME, Healthcare Worker)

"...The cost of treatment is covered by BPJS, and the Stepping Stones foundation, in collaboration with Miracle Feet, helps provide aids like braces, casts, and transport money..." (KS, Healthcare Worker)

#### Theme 5: Structural

Understanding the structural elements influencing access to Congenital Talipes EquinoVarus (CTEV) treatment is essential for addressing geographical constraints, evaluating access during the COVID-19 pandemic, assessing service procedures, identifying barriers, and recognizing support systems.

#### **Geographical Constraints**

Parent informants highlighted varying geographical challenges in accessing CTEV treatment centers. While some faced manageable journeys with good road conditions, others encountered longer travel times, congested roads, and mountainous terrain. Healthcare informants echoed these sentiments, emphasizing the accessibility of treatment centers in urban areas but acknowledging difficulties for patients from remote regions.

"...From Besakih to Buleleng is 80 km, but the roads are good, only slightly damaged. We use motorbikes for an average of 2 hours if there's no traffic..." (KP, Parent)

"...The journey from Gianyar has winding and congested roads, approximately 200 km. We use a rented car for 4 hours if there's traffic and 3 hours if there's no traffic..." (IKS, Parent)

"...The roads are all good. But if the patients are from far places like Karangasem, they have to go through mountains. They generally use motorbikes, but some use private cars. Some also rent vehicles..." (ME, Healthcare Worker)

"...The hospital is strategically located in the city center. It's easy for people to find it, but patients from remote areas face difficulties. Public transportation includes mini buses and motorcycle taxis..." (NWA, Healthcare Worker)

# **Impact on Access during the Pandemic**

The COVID-19 pandemic introduced additional hurdles to accessing CTEV treatment, with area restrictions hindering public access. Parent informants expressed difficulties leaving their homes, while healthcare informants described longer patient queues and increased checkpoints. However, healthcare institutions implemented measures such as recommendation letters to facilitate patient access, ensuring continuity of care.

"...It's hard because we're not allowed to leave the house during the pandemic..." (KR, Parent)

"...There is an impact because Puspadi's location is near a main road, so during COVID, there are checkpoints. If patients are sick or have a fever, they are not allowed through. They used to have to show rapid test results, a letter stating where they were going, or a work assignment letter. If they didn't have these, it was difficult to pass. Since COVID, we provide patient letters and scheduled appointments..." (IAPK, Healthcare Worker)

# **COVID-19 Prevention Procedures**

Parent informants adhered to recommended health protocols, including mask-wearing, hand hygiene, and social distancing, during CTEV treatment. Healthcare informants reported a decline in patient numbers due to fear of COVID-19 transmission and misinformation. Despite this, healthcare workers implemented stringent health protocols, including the use of personal protective equipment (PPE) and installation of barriers, to minimize transmission risks during treatment.

"...We take vitamins, wear masks, follow health protocols, and wash hands..." (KK, Parent)

"...We use PPE. For patients, they wash hands first, then we check their temperature, then we treat them, and use hand sanitizer. Treatment proceeds normally. If a patient has a fever, they are asked not to come..." (ME, Healthcare Worker)

"...In our hospital, we installed barriers like glass to prevent fluid splashes. We also used PPE and face shields. Now, because it's endemic, we no longer use face shields and PPE but still wear masks. Except during surgery, where it's mandatory..." (KS, Healthcare Worker)

"...Patient numbers decreased, almost all departments saw fewer patients, not just orthopedics. Because people didn't know much about COVID-19 and there was a lot of misinformation, they chose to stay home and didn't see CTEV as an emergency, so they postponed treatment..." (IGKY, Healthcare Worker)

# **Structural Barriers**

Parent informants identified location and transportation as significant barriers to accessing CTEV treatment, while healthcare informants reported delays in equipment procurement due to area restrictions during the pandemic. However, both groups noted no structural barriers in handling CTEV during the pandemic, attributing smooth treatment processes to adequate facilities and collaborative support systems.

"...The distance from home to the healthcare facility is far, but it's not difficult to reach..." (Q, Parent)

"...The distance is quite far and access is also quite challenging..." (NN, Parent)

"...No barriers. The rooms are adequate, and during the pandemic, barriers were installed, but they didn't hinder examinations. Treatment was done in the treatment room, and examinations in the exam room..." (NWA, Healthcare Worker)

"...Maybe in terms of equipment purchases, it's difficult because of area restrictions, delaying procurement by a month..." (IAPK, Healthcare Worker)

# **Structural Supports**

Parent informants acknowledged the availability of private vehicles, paved roads, and COVID-19 prevention measures as structural supports in continuing CTEV treatment during the pandemic. Healthcare informants highlighted the collaborative efforts between healthcare institutions and foundations, ensuring the availability of materials and equipment for seamless treatment delivery.

"...Handwashing stations, hand sanitizer, and paved roads are provided..." (IKS, Parent)

"...There have been no barriers; treatment has been smooth. The foundation and hospital support each other in stocking materials for CTEV..." (NWA, Healthcare Worker)

# Discussions

**Knowledge Factor** 

Knowledge is the beginning of health empowerment. An individual's behavior can be influenced by their knowledge (Notoatmodjo, 2014). Behavioral change occurs through the stages of knowledge, attitudes, and practices (Notoatmodjo, 2014). Knowledge is the result of what one learns through the sensing process of a specific object (Notoatmodjo, 2014). Knowledge is categorized into six levels: know, understand, apply, analyze, synthesize, and evaluate. Barriers in acquiring health knowledge, especially regarding the management of CTEV and COVID-19, affect the behavior of parents in seeking health treatment for their child suffering from CTEV during the COVID-19 pandemic. Support to obtain knowledge about CTEV is necessary so that parents can understand CTEV and manage it promptly and correctly. A lack of knowledge will hinder the behavior of seeking treatment (Bedford et al., 2011; Boardman et al., 2011; Muinde, 2021). Without knowledge of CTEV, parents of patients will not quickly realize the condition of CTEV in the newborn (Burfat et al., 2013). Many parents of patients do not know about CTEV at all until they have a child with CTEV (Iqbal et al., 2021). All patient parents in this study were unaware of CTEV until they had a child with CTEV, which led them to seek and obtain information about CTEV.

Lack of knowledge and misinformation are some of the barriers in the community's handling of CTEV (Bedford et al., 2011; Carillo et al., 2011; Sananta et al., 2021). Some knowledge barriers stem from a lack of family support in understanding CTEV as a medically treatable condition. In similar research, respondents believed that CTEV was incurable (Burfat et al., 2013). Knowledge-seeking barriers include understanding of the disease and its treatment, culture and beliefs, and health awareness (Locke et al., 2021). There were respondents who once believed that CTEV was a non-medical condition caused by actions during pregnancy, like tying chicken feet. A similar finding was reported in Igbal et al.'s study (2021), where the majority of respondents believed that CTEV was caused by supernatural things such as divine punishment, black magic, and eclipses; only 25% believed that CTEV is a medical disorder. Supernatural beliefs were also found in the study by Van Wijck et al (2015). Other factors hindering respondents from gaining knowledge include the long distance from health information centers, lack of transportation, and lack of information since childbirth, which led to less exposure to education about CTEV and its management. To address this, some support is provided by the foundation by visiting villages to give lectures on CTEV and to healthcare workers at health centers, as well as providing brochures about CTEV. The foundation also helps to provide transportation in some cases to transport patients to healthcare services to manage CTEV.

Muinde (2021) mentioned that there needs to be education and health promotion regarding bracing for CTEV and compliance with brace use. Communication from health workers is required to make parents of patients understand the congenital disorder, the necessary medical treatment, and how to find relevant information about the disorder (Lemacks et al., 2013). Satisfaction with the doctor's explanation of the CTEV disease and treatment plan is also important (Iqbal et al., 2021). Therefore, support is needed to overcome these barriers by promoting good health regarding CTEV. Support in obtaining information about CTEV should come not only from medical personnel but also from family, friends, community, and the internet. A variety of information sources provide a greater opportunity for parents of patients to obtain information about CTEV and its management. The search for information is motivated internally by the curiosity of the parents of patients and externally by people around them. Once exposed to information about CTEV, parents of patients understand that CTEV is a medical condition and can be managed to avoid lifelong disability. With information on preventing COVID-19 exposure through health protocols such as using masks and washing hands, parents of patients feel less fearful about managing CTEV during the pandemic. Parents of patients understand that immediate management of CTEV is crucial, so the fear of COVID-19 does not impact as significantly."

# **Attitude Factor**

Desire or will is an advanced form of understanding an object, which predisposes a person to act or not to act, also known as attitude (Notoatmodjo, 2014). However, attitude is still a latent reaction to an object. The continuity of desire into action can be influenced by several factors. According to Newcomb in Notoatmodjo (2014), attitude is the readiness or willingness to act. Allport in Notoatmodjo (2014) describes three fundamental components of attitude: belief, emotional life or evaluation, and the

tendency to act. In health, attitude is a person's evaluation of a health-related stimulus. Health attitudes consist of indicators towards illness and disease, attitudes towards care and healthy living, and attitudes towards environmental health (Notoatmodjo, 2014). Attitudes towards CTEV affect treatment-seeking behavior and are one of the obstacles in managing CTEV (Bedford et al., 2011). The attitude of parents is crucial for the development of their children (Solina, 2019).

In this study, several factors hindered both parents of CTEV patients and medical personnel from seeking and managing CTEV treatment during the COVID-19 pandemic. All parent informants felt shocked, sad, and fearful of lifelong disabilities for their children when they first learned of their child's condition. They also experienced fear of the COVID-19 pandemic. Children with CTEV often face social stigma (Iqbal et al., 2021). Parents of children with CTEV tend to suffer negative physical and mental effects, increasing parental stress, which then becomes an indicator of a negative attitude (Lemacks et al., 2013). Sociocultural pressures and ways of thinking are some of the barriers to CTEV management (Bedford et al., 2011). This stress can lead parents to have a negative attitude towards seeking treatment, but it can also trigger a positive attitude to seek help immediately. All these reactions prompt parents to seek immediate CTEV treatment. After receiving education from medical personnel about CTEV and its management, parent informants adopted a more positive attitude, accepting the situation, feeling relieved, and hopeful for their child's normalcy. Health workers also followed health protocols, which were adhered to by the parents. Additionally, support from family and healthcare workers kept the parents motivated to manage the condition even during COVID-19. Unpleasant experiences with previous treatments, such as ineffective results, also led parents to have a negative attitude. However, this attitude could change after being educated, shown examples, and meeting other parents of CTEV patients who had completed treatment, allowing them to exchange information and see evidence that CTEV can be cured with proper and immediate treatment.

The most critical factor supporting the continuation of will is the availability of facilities and infrastructure to support an action (Notoatmodjo, 2014). This was experienced by informants and became a barrier to maintaining a positive attitude, including a lack of information, long distances from health centers, and COVID-19 health protocols. Special conditions occurred during the COVID-19 pandemic when the government implemented several health protocols such as advising against crowds, restricting areas, which led foundations to limit the number of patients at one time and place supervisors at regional borders. However, these barriers were overcome by obtaining support in the form of health protocols, the use of which made parents feel safer in managing CTEV during the pandemic. Health workers and foundations also provided economic support to help parents maintain a positive attitude in managing CTEV, such as financial aid, handling national healthcare security (BPJS Kesehatan) procedures, and providing transportation facilities. Additionally, family, health workers, and foundations also provided mental support through encouragement. However, behind these obstacles, there was also support such as the availability of health protocol equipment for both medical personnel and patients, referral letters from foundations for treatment, scheduling of visits, and transportation assistance.

#### **Motivation Factor**

One of the primary elements of community participation is motivation. Motivation should arise from within the community itself but can be stimulated by external parties (Notoatmodjo, 2014). Motivation is an inner drive that causes a person to engage in specific activities to achieve a goal (Notoatmodjo, 2014). However, motives cannot be observed directly but can be observed through activities or reasons for those actions. Internal factors influencing motivation include a lack of family and community support, which becomes a barrier to managing CTEV (Drew et al., 2016). Motivation is needed not only at the beginning for initiating CTEV treatment but also for continued compliance with CTEV treatment, which can last up to 3 years. CTEV treatment consists of casting, which can last 2-3 months, tenotomy and bracing for 2 weeks, and maintaining the position with bracing until the age of 3 years. Compliance with CTEV treatment is associated with distance traveled, family support, and community support (Kazibwe & Struthers, 2009; Doris et al., 2021). Barriers to motivation can affect community participation in CTEV treatment programs, especially during the COVID-19 pandemic. Education and health promotion are essential to trigger the emergence of motivation (Notoatmodjo, 2014).

Initially, the lack of education made parents of patients motivated by the prospect of their child's condition improving. However, after being educated by medical personnel, they became motivated to seek CTEV treatment for their child's recovery. During the treatment process, parents may feel fear and hesitation about CTEV treatment because it is performed on their young children. However, early treatment for CTEV increases the chances of the feet returning to normal. Parents come to understand this after receiving explanations from healthcare providers, motivating them to seek prompt treatment with hope for their child's recovery. Institutional factors that hinder motivation include distance from treatment centers and a lack of information about treatment and bracing (Drew et al., 2016). This study found that distance from healthcare facilities, lack of education, fear of seeking CTEV treatment during the pandemic, lack of family support, and the presence of health protocols during the pandemic hindered the emergence of motivation for parents of CTEV patients to seek treatment during the COVID-19 pandemic. However, support was also found from these factors, such as providing information about available financial from goverment and foundation assistance, explaining to families so they can support the treatment process, and the availability of health protocols making parents feel safer in managing CTEV during the COVID-19 pandemic.

# **Financial Factor**

The financial factor is one of the crucial indicators that can determine whether someone's willingness to seek treatment for their medical condition progresses or regresses. Financial burdens are often found in families with children with CTEV (Doris et al., 2021). Financial resources are needed not only for treatment financing but also for covering travel expenses to healthcare services such as transportation costs, fuel expenses, vehicle rental costs, and meal expenses while traveling for treatment. Compliance with CTEV treatment is associated with transportation costs (Kazibwe & Struthers, 2009; Muinde, 2021). According to parents and medical professionals, CTEV treatment is relatively expensive. This is because treatment is not a one-time event but continuous over a certain period depending on the patient's condition, which can last for years. Therefore, if not using BPJS or insurance, it will be burdensome for the parents of the patients. Parents also add that transportation costs are also a hindrance for those located far from the foundation and for those who do not have private vehicles or those who do. External obstacles such as costs beyond treatment like fuel and meal expenses become barriers.

CTEV treatment is covered by the Government through the national healthcare security (BPJS Kesehatan). In this study, the parents of the patients belong to the type of BPJS KIS. However, according to healthcare providers, some parents do not have active BPJS when they are about to undergo treatment. This is then assisted by the foundation to provide guidance on BPJS arrangements. In severe cases where BPJS no longer covers it, the foundation also helps by providing equipment and materials for CTEV treatment so that the treatment costs do not become significant. Initially, many parents did not know that CTEV treatment could be covered by BPJS, so at the beginning of treatment, they used personal funds. However, after receiving explanations from the hospital and foundation, they learned that CTEV treatment could be covered by BPJS. Caregivers relying on limited social services or insurance policies experience longer delays in obtaining braces compared to those accessing comprehensive private services (Drew et al., 2016). Financial conditions or financial factors such as family economic conditions, socio-economic status, healthcare costs, and insurance status are among the obstacles experienced by parents (Penny, 2005; Carillo et al., 2011; van Wijck et al., 2015; Drew et al., 2016; Doris et al., 2021; Sananta et al., 2021). Financial barriers to accessing healthcare and rehabilitation services include affordability, difficulty accessing financial assistance, and unclear payment pathways (Locke et al., 2021).

# **Structural Factor**

The primary factor that supports the continuation of willingness is the facilities and infrastructure to support an action (Notoatmodjo, 2014). According to Blum (1974), one of the main determinants of an individual's health status is healthcare services. However, in the implementation of CTEV treatment, there are several structural barriers and changes experienced by parents of patients and healthcare professionals during the COVID-19 pandemic. Healthcare facilities in countries with medium-low incomes do not address CTEV due to a lack of expertise, insufficient affordable facilities, and inadequate

medical equipment (Penny, 2005; Sheik-Ali et al., 2019; Sheik-Ali et al., 2021). Additionally, structural barriers to accessing healthcare services may include geographic access, time, infrastructure conditions, and training (Locke et al., 2021). Other barriers to CTEV treatment include the distance to treatment centers, travel time, transportation, and lack of information about CTEV (Carrillo et al., 2011; van Wijck et al., 2015; Drew et al., 2016). Some parents live in different regions from the foundation and hospital. The distances traveled vary. For patients living farther away, they complain about the distance they have to travel, but good road conditions and the easy location of the foundation and hospital help parents in their treatment visits.

During the COVID-19 pandemic, the government issued policies to mitigate COVID-19 by imposing regional restrictions aimed at reducing the spread of COVID-19. In some border areas, there is police surveillance to ensure compliance with regulations. This can be a barrier to CTEV treatment for patients located in different regions from the foundation. However, this barrier can be overcome by the foundation. Some informants located in different regions from the foundation and hospital receive referral letters if needed to show to regional authorities to be allowed to pass through for their child's CTEV treatment. Another government policy related to COVID-19 mitigation is the advice to avoid crowds. This has a negative impact, namely a decrease in the number of patient visits due to restrictions on the number of patients at the foundation at one time. This was then addressed by the foundation by scheduling patient visits so that patients can still receive treatment and reduce the risk of COVID-19 transmission. During face-to-face treatment, health protocols are also implemented with the provision and use of personal protective equipment such as masks and gloves, as well as temperature checks and hand washing. Additionally, online consultations are conducted through chat, telephone, and video to monitor the progress of children with CTEV. During CTEV treatment during the COVID-19 pandemic, the foundation and hospital did not experience difficulties in the provision and availability of the necessary equipment and materials to treat CTEV because planning had been done a year in advance.

# Limitations of the Study

This study has several limitations. The limited research time resulted in a restricted number of informants involved. Additionally, due to time and distance constraints, interviews could not always be conducted in person. This may have affected the depth and quality of the information obtained from informants, as some interactions and non-verbal expressions may not have been observed.

# Conclusions

Based on the research and analysis of the obstacles and support faced by parents of CTEV patients and medical personnel during the COVID-19 pandemic at the Stepping Stones Bali Foundation, several conclusions were made. Lack of education and information about CTEV and its treatment can hinder parents from seeking CTEV treatment and impact on their knowledge, attitude, motivation, and financial factors in CTEV treatment. Long distances and transportation issues can also be barriers affecting to these same factors, along with structural challenges. Additionally, the lack of support from family, community, and healthcare workers can further hinder parents on knowledge, attitude, and motivation factors. The implementation of COVID-19 policies and health protocols has posed additional challenges, affecting knowledge, attitude, motivation, financial, and structural factors. Poor economic conditions have also been a significant barrier impacted on attitude and financial factors. However, the education provided by the foundation and healthcare workers has been instrumental in helping parents understand CTEV, access financial assistance, maintain a positive attitude, and stay motivated during the pandemic. Support from family, community, and healthcare workers through education and motivation has been crucial in managing CTEV during these times. The availability of tools and materials for CTEV treatment and COVID-19 prevention protocols has further supported parents and healthcare workers. Economic assistance from the government through national healthcare security (BPJS Kesehatan) and transportation support from the foundation has positively impacted parents' attitude, motivation, financial, and structural aspects in managing CTEV during the pandemic. Additionally, referral letters, patient arrival arrangements, and video chat examinations have provided essential structural support for parents. To address these obstacles and support needs, the following recommendations are made.

First, there is a need to enhance education and information about CTEV and its treatment through broader outreach campaigns, brochures, websites, and social media. Improving accessibility to CTEV treatment services, especially for those facing distance and transportation challenges, by providing transportation services or partnering with local providers is also crucial. Strengthening social support from family, community, and healthcare workers through programs like support groups or family meetings can further aid in CTEV management. Adapting COVID-19 policies and health protocols to not hinder access to CTEV treatment and providing online services or telemedicine as alternatives are also recommended. Lastly, increasing the availability and use of online or telemedicine services can help reach more patients during the pandemic. Implementing these recommendations is expected to reduce the obstacles faced by parents of CTEV patients in seeking and obtaining necessary treatment, especially during the pandemic.

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