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A Survey of Patients With Congenital Orthopedic Conditions in Malawi: Factors That Influence Late Presentation

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A SURVEY OF PATIENTS WITH CONGENITAL ORTHOPEDIC CONDITIONS IN MALAWI: FACTORS THAT INFLUENCE LATE PRESENTATION

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Outline

Abstract

Staff at CURE International, a non-profit organization that provides orthopedic care in Malawi, noticed a high prevalence of patients with congenital orthopedic conditions who are presenting late for treatment. Late presentation results in prolonged pain or discomfort for the patient and has the potential for increased cost to the institution, longer duration of treatment, and decreased quality of outcomes. To identify the factors that influenced presentation delays, we surveyed the caregivers of patients with congenital conditions that were seen in out-patient clinics, in-patient wards, and mobile clinics across the country. Sixty-two caregivers were surveyed; forty-two patients had a diagnosis of clubfoot and twenty patients had other diagnoses. This study found that caregivers were statistically more likely to bring their child in late for treatment if they possessed any one of the following characteristics: they were residents of the Northern or Central regions of Malawi, were illiterate, were not notified at birth of their child's condition, had a child with a congenital orthopedic condition other than clubfoot, gave birth at home rather than at a hospital, or did not live close to a main road. Other correlations were made between survey answers and late presentation, but they were either not statistically analyzed or not considered to be statistically significant. Caregivers that were older, reported unaffordable transportation, had a monthly income on the lower spectrum, or had more than three children/dependents were more likely to bring their child in late for care. The small sample size limits the statistical power of the results. Further analysis of the existing data or a larger clubfoot study across all CURE locations with a revised questionnaire would be valuable for determining these critical deterrents to timely access.

Introduction

It is well known that healthcare systems in Sub-Saharan Africa are grossly lagging behind in terms of accessibility. Malawi, a small country in Southeastern Africa, is not immune to these challenges. CURE International, a nonprofit organization, runs a hospital in Malawi that specializes in orthopedics. They provide free orthopedic services to every child that is seen at their facility. Their operations director noticed a high-volume of children that were presenting for treatment well into childhood. Late presentation results in prolonged pain or discomfort for the patient and has the potential for increased cost to the institution, longer duration of treatment, and decreased quality of outcomes. Even though not all congenital orthopedic disorders have the same urgency for early treatment, there are significant social and developmental ramifications for children with untreated physical deformities. For many congenital deformities, there is an optimum window of time to begin or finish treatment in order to achieve the maximum correction. Our study was designed and completed in order to identify factors that influence whether or not children with congenital orthopedic conditions in Malawi present on time for treatment. This is a survey-based research project. We asked caregivers to provide the patient and caregiver's sociodemographic information, the patient's clinical history, the caregiver's medical history, and appointment transportation logistics. Interviews were conducted with caregivers of children with congenital deformities during out-patient clinics at Beit CURE, in-patient ward rounds, and at mobile clinics across the country. The data collected was analyzed to determine which variables posed statistically significant differences between children who presented late and children who presented on time.

Background

Malawi

Demographics

Malawi is a landlocked country in Sub-Saharan Africa. English is the official language of the country, although Chichewa is the most widely used. According to the 2018 census report, the population was cited at 17,563,749, which is a 35% increase over the past decade.[1] According to the Central Intelligence Agency of the United States, the yearly population growth rate is approximately 3.3%, which is the sixth highest in the world.[2] 45.87% of the country is under 14 years of age, resulting in a high dependency burden that limits and slows economic growth. The average household consists of 4.4 members, which has slightly decreased since 2008, despite the drastic increase in the population.[1]

Figure 1. Map of Malawi [3]

The country is divided into three regions: Northern, Central and Southern. The Southern region constitutes 44% of the total population, the Central region constitutes 43%, and the

Northern region only 13%. Citizens that reside in rural areas represent 84% of the total population. Each region has one major city. Lilongwe is the capital and largest city by population, located in the Central region. Blantyre, located in the Southern region, is the second largest city and regarded as the the country's center for finance and commerce. Mzuzu, located in the center of the Northern region, is the third largest city. There is a total of 28 districts between all three regions.

Health

The average life expectancy is 63.2 years, which has significantly improved in the last two decades.[2] The physician density is only 0.02 per 1000 people and there are only 1.3 hospital beds per 1000 people. Malawi has the ninth highest HIV/AIDS prevalence rate in the world; 9.2% of the population were living with HIV/AIDS as of 2018, and 13,000 people died from it that year. There is a very high risk of infectious disease, including diseases such as bacterial/protozoal diarrhea, hepatitis A, typhoid, malaria, dengue fever, schistosomiasis, and rabies. 5.8% of adults are obese and 11.8% of children under 5 years old are underweight. As of 2015, 9.8% of the country still does not have access to clean drinking water and 59% of the population does not have proper sanitation facilities.

Economy

In 2017, Malawi's GDP at the official exchange rate was $6.24 billion USD. When accounting for purchasing power parity (PPP), the value was $22.42 billion USD.[2] Even though this was a 4% increase from the previous year, the GDP per capita at PPP has held at $1,200 USD from 2015 to 2017. Inflation dropped 9.5% between 2016 and 2017, but still remains incredibly high at 12.2%. These high inflation rates, coupled with a stagnant GDP per capita, pose a significant challenge to the Malawian economy.

As of 2010, 50.7% of the population lived below the poverty line. This increased slightly to 51.5% in 2016, but extreme poverty decreased from 24.5% to 20.1% during the same time period. Due to recent droughts and floods, poverty is expected to continue to rise.[4] Natural disturbances have significant implications for agriculture. Malawi's primary exports are tobacco, dried legumes, sugar, tea, cotton, peanuts, coffee, and soy. Nearly 77% of the population is employed in the agricultural sector, but due to low productivity, agriculture only accounts for 28.6% of the total GDP composition.

CURE International

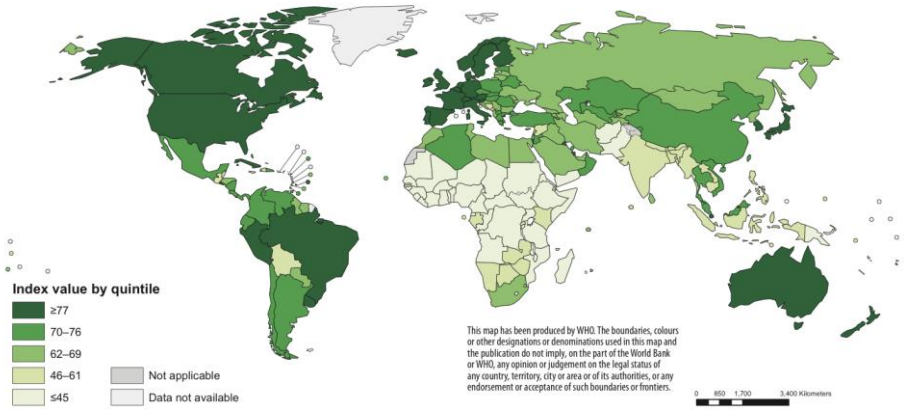
CURE International is a nonprofit organization that was established in 1996 with the joint goals of healing children with physical disabilities and spreading the gospel of Christ. They have eight established hospitals across Africa and the Philippines. As of 2018, they provided 3,000,000 out-patient visits and 200,000 surgeries. All costs for pediatric services are covered by a combination of donations from external sources and income from treating adults in the private wing.

Besides Beit CURE, there are a total of twenty-six other clinics associated with the Malawi National Clubfoot Program (MNCP) that have the capacity of treating kids with clubfoot.[5] All of these other clinics previously received support from the CURE Clubfoot program, which transitioned to become Hope Walks at the beginning of 2019. Due to budget cuts, Hope Walks is no longer providing casting supplies; it is unclear how much financial support the clinics are receiving from the government at this time. For most other congenital orthopedic conditions, Beit CURE is the only treatment facility in the entire country.

Healthcare Access

Sub-Saharan Africa is significantly behind in healthcare when compared on a global platform. The World Health Organization (WHO) ranks countries by levels of service coverage, and Sub-Saharan Africa had the lowest Universal Health Coverage (UHC) service coverage index value in the world in 2017 (**Figure 2**).[6] Four health indices contribute to the UHC service coverage index:

1. reproductive, maternal, newborn and child health
2. infectious disease control
3. noncommunicable diseases
4. service capacity and access.



SDG: Sustainable Development Goal; UHC: universal health coverage.

Area	UHC service coverage index	RMNCH	Infectious diseases	NCDs	Service capacity and access
Global	64	75	54	63	71
Africa	46	55	40	67	37
Northern Africa	64	73	50	62	77
Sub-Saharan Africa	42	51	37	69	27
Asia	64	75	51	63	71
Eastern Asia	77	86	64	64	99
Southern Asia	53	66	41	64	47
South-Eastern Asia	59	78	45	59	63
Central Asia	70	81	56	58	93
Western Asia	65	69	59	57	79
Europe and Northern America	77	88	73	58	96
Latin America and the Caribbean	75	81	65	68	88
Oceania	74	83	71	62	84

NCDs: noncommunicable diseases; RMNCH: reproductive, maternal, newborn and child health; UHC: universal health coverage.

Figure 1. Universal Health Coverage (UHC) Service Index Measurement. [6]

Beit CURE does not operate at capacity. Lack of trained hospital workers, hospital beds or treatment supplies are not limiting factors for patients seeking treatment. However, as the only

children's orthopedic facility in a country whose population is largely children, we can infer that if there were no other factors that affected access, then CURE would surpass capacity and these service issues would become legitimate concerns.[1]

In 2019, the Technical University of Berlin in Germany used survey data collected from African nations and found that nearly half of Africans went without necessary medical attention.[7] In Malawi specifically, 44-51% of individuals looking for medical attention reported having difficulties accessing healthcare (**Figure 3**). Some of the reasons cited were fear of discrimination or stigmatization, lack of education, lack of transport, and direct financial barriers. The study confirmed that individuals living in poverty across the continent experience up to 4.20 times more difficulty obtaining medical care. This study also reported that the closer in proximity that African patients live to a health clinic, the easier it becomes to obtain care.

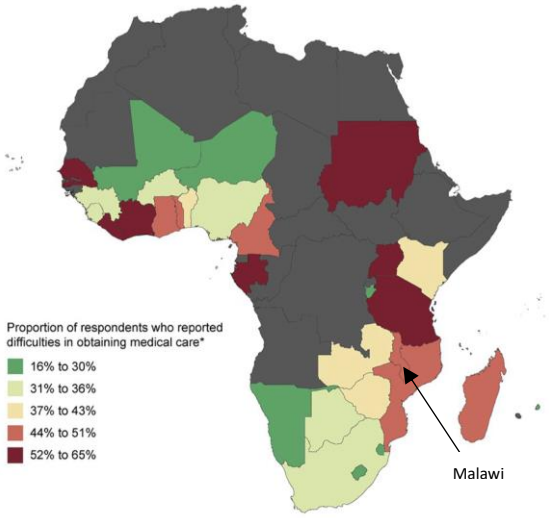


Figure 2. Proportion of individuals that reported struggling to get medical attention. [7]

A literature review of eleven studies, done at Oxford in 2016, categorized factors that affect treatment-seeking for clubfoot in low- and middle-income countries (LMIC) into a 5-tiered social-ecological model (**Figure 4**).[8] The barriers they discovered are categorized by their rank in this model. We acknowledge that clubfoot is not the only disease included in this study, but

because of its prevalence, it has the most available data. Although not ideal, we are limited by the amount of data available in a low-income setting. We are using this information about clubfoot as pertinent to all congenital orthopedic deformities.

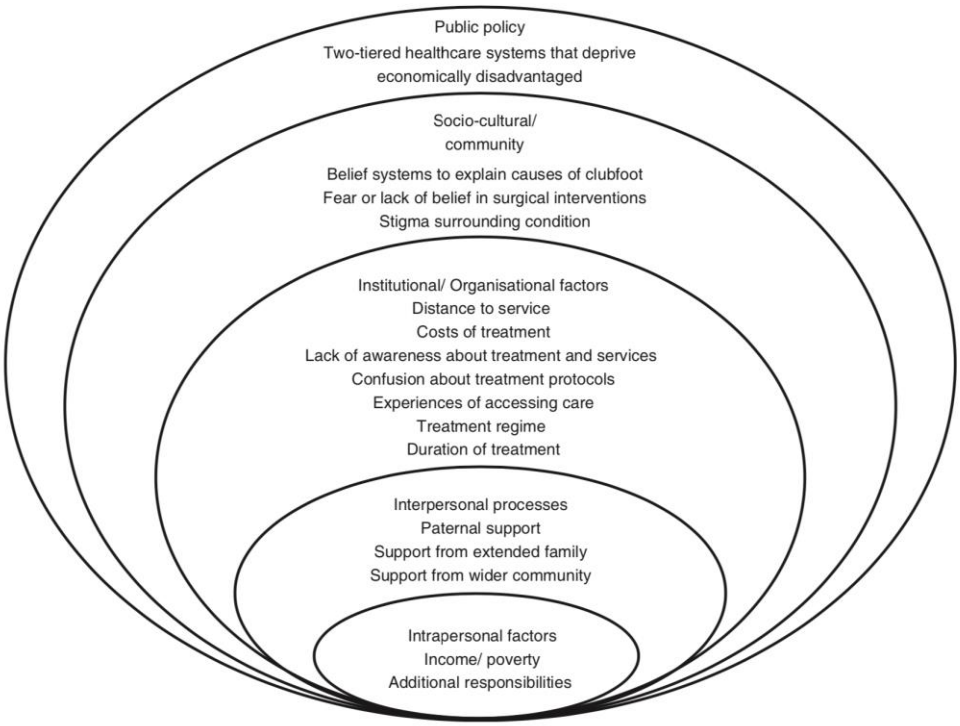


Figure 3. Factors influencing treatment-seeking behavior: codes identified and their relation to the five levels of the social-ecological model. [8]

A 2014 study done in Vietnam cited six important best practices for implementing a clubfoot program in an LMIC:

1. Diagnose early
2. Organize high volume clinics
3. Use non-physician health workers
4. Engage families in care
5. Address barriers to access
6. Provide follow-up in the patient's community.[9]

The types of barriers discovered in this study were: lack of program resources, geographical distance to the clinic, poverty, lack of paternal support, other responsibilities of the caregiver, treatment challenges, poor communication, and travel expenses. Our study aims to provide

information on how to address two of these six criteria: diagnosing early (and getting a consult) and addressing barriers to access. By eliminating barriers to care, we can hope to diagnose and consult earlier.

Beit CURE and Oxford University conducted interviews with 60 caregivers in 2011 to determine the various local theories of clubfoot etiology.[5] Local theories that were reported included: God, the devil, witchcraft or curses, biological reasons, and genetic causes. At the time of this study, it was thought that local theories were the primary barriers to care. In addition to suspicions of folklore contributing to late presentation, there was a strong belief that social stigma was preventing caregivers from seeking treatment. This hypothesis was proven incorrect. Another study done by Beit CURE and University of Oxford during the same time period determined the four main barriers to care for children diagnosed with clubfoot in Malawi were:

1. Lack of knowledge (didn't know it was treatable or thought it would correct itself)
2. Familial resistance (typically paternal opposition, or other family members)
3. Logistical obstacles (mode of transport, length of the journey, costs involved)
4. Socioeconomic pressures (no finances to cover out of pocket expense, cannot afford to miss work, priorities on other children/family).[10]

As a result of poor access to treatment, there is a high prevalence of preventable or treatable physical deformities. A study done in 2018 by Dr. James Turner, Dr. Christopher Lavy, and others determined that of the 1125 expected new Malawian clubfoot cases in the year 2003, only 30% of them presented at one of 26 clubfoot clinics for treatment.[11] This statistic only reflects one of numerous types of deformities.

Clubfoot

Talipes equinovarus, also known as clubfoot, is one of the most common congenital orthopedic conditions. Globally, it has a prevalence of 1 per 1000 live births.[12] However, there is

an incidence of 2 per 1000 live births in Malawi (one of the highest rates worldwide).[11,13] 80% of all clubfoot babies are born in an LMIC.[8,9] Clubfoot is characterized by a combination of cavus, equinus, varus and/or adductus deformity of the foot (**Figure 5**). The deformity can be either idiopathic or syndromic and unilateral or bilateral. It is classified as a developmental disorder because it is identified during the second trimester of pregnancy.[14] Although clubfoot's exact etiology is still unknown, there are numerous proposed theories including:

1. Primary soft-tissue abnormalities
2. Arrest of fetal development in the fibular stage
3. Defective cartilaginous anlage of the talus
4. Neurogenic factors
5. Retracting fibrosis
6. Anomalous tendon insertions
7. Abnormal distribution of muscle fibers[15]

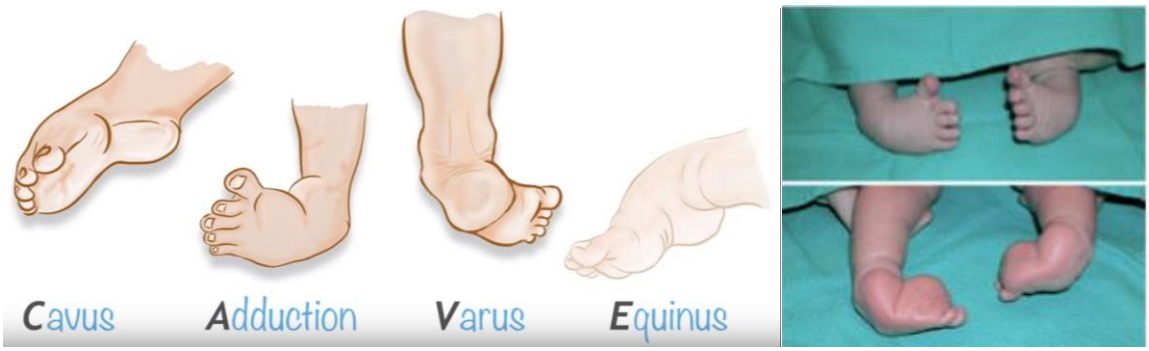
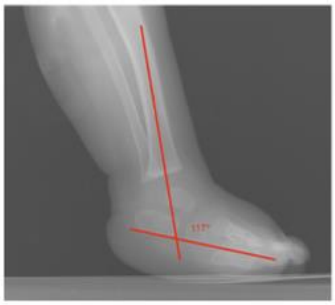


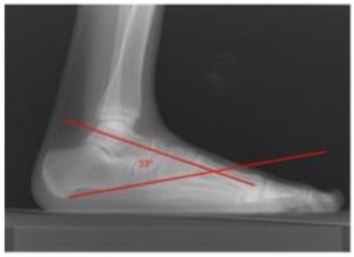
Figure 4. Deformities of clubfoot.[9, 16]

Although several genetic variants have been identified that influence the development of clubfoot, a single major gene has yet to be found.[17] The single most significant and consistent risk factor for clubfoot is smoking during pregnancy. Moreover, smoking during pregnancy, coupled with a family history of the disorder, makes a child twenty times more likely to present with clubfoot.[17]

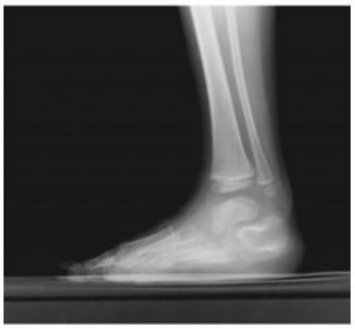


Lateral view in talipes equinovarus demonstrates an abnormally elevated tibiocalcaneal angle. A normal angle is 60-90°.

Measurement	Normal Foot	Clubfoot
Tibiocalcaneal angle	60-90° on lateral view	>90° (hindfoot equinus) on lateral view

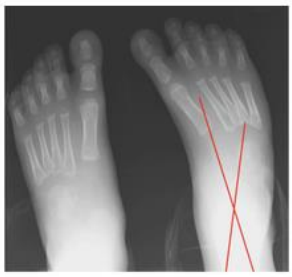


Normal lateral view shows the measurement of the talocalcaneal angle. The calcaneal long axis is drawn along the plantar surface. The normal range is 25-45°. Note the normal overlap of the metatarsals on the lateral view.

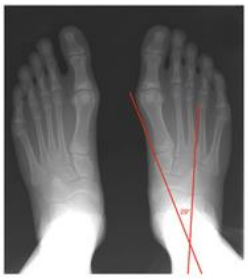


Lateral view of clubfoot shows the nearly parallel talus and calcaneus, with a talocalcaneal angle of less than 25°.

Measurement	Normal Foot	Clubfoot
Talocalcaneal angle	25-45° on lateral view, 15-40° on DP view	< 25° (hindfoot varus) on lateral view, < 15° (hindfoot varus) on DP view



Dorsoplantar views obtained in a patient with unilateral clubfoot show that the talus and calcaneus are more overlapped than in the normal condition. The talocalcaneal angle is 15° or less. Note that the line through the long axis of the talus passes lateral to the first metatarsal due to the varus position of the forefoot.



Dorsoplantar projection of a healthy foot shows that the line through the long axis of the talus passes just medial to the base of the first metatarsal. The talocalcaneal angle measurement is shown. The normal range is 15-40°.

Measurement	Normal Foot	Clubfoot
Metatarsal convergence	Slight on lateral view, slight on DP view	None (forefoot supination) on lateral view, increased (forefoot supination) on DP view

Figure 5. Comparison of radiographic imaging and angles of measurement between normal feet and clubfeet.[18]

Classification Techniques

There are two common and universally accepted classification systems that score clubbed feet based on severity: the Pirani system and the Dimeglio system. The Pirani scoring system looks at six clinical signs of contracture, each of which can receive a score of 0 (no deformity),

0.5 (moderate abnormality), and 1 (severe abnormality).[19] The six signs are grouped into two catergories: three related to the hindfoot and three related to the midfoot. Each patient is given a total score between zero and six (**Figure 7)**. The Dimeglio system scores severity based on four elements: equinus of the sagittal plane, varus of the frontal plane, de-rotation of the horizontal plane, and forefoot relative to hindfoot in the horizontal plane. Each of these is rated on a scale of zero to four. An additional point is added if there is a presence of cavus, medial crease, posterior crease, or diminished musculature in the calf. The total score is on a scale of zero to twenty, which can be grouped into four grades. The higher the classification grade, the more severe the deformity (**Figure 8**). [20]

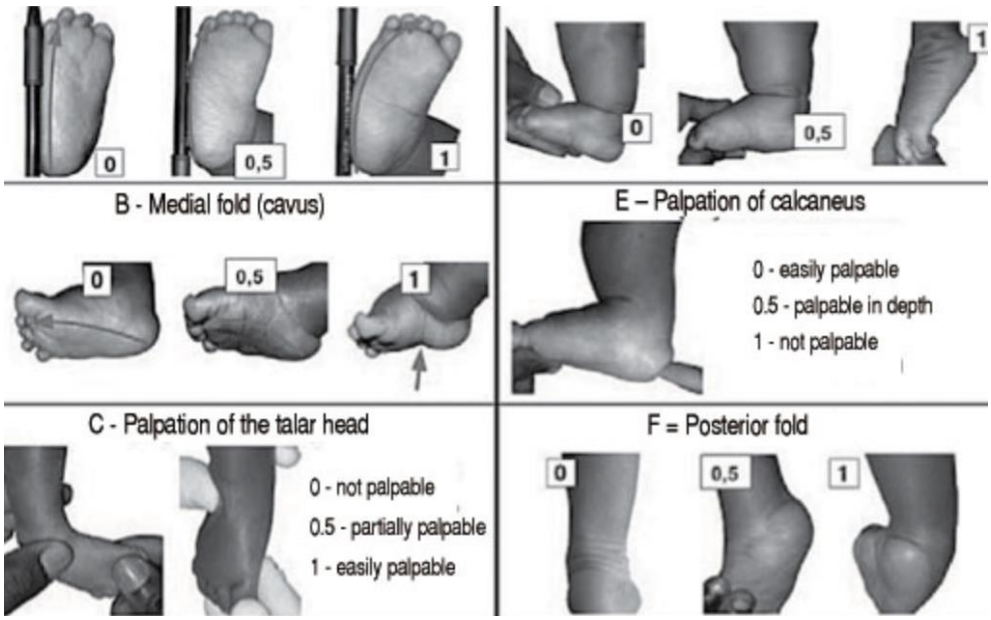
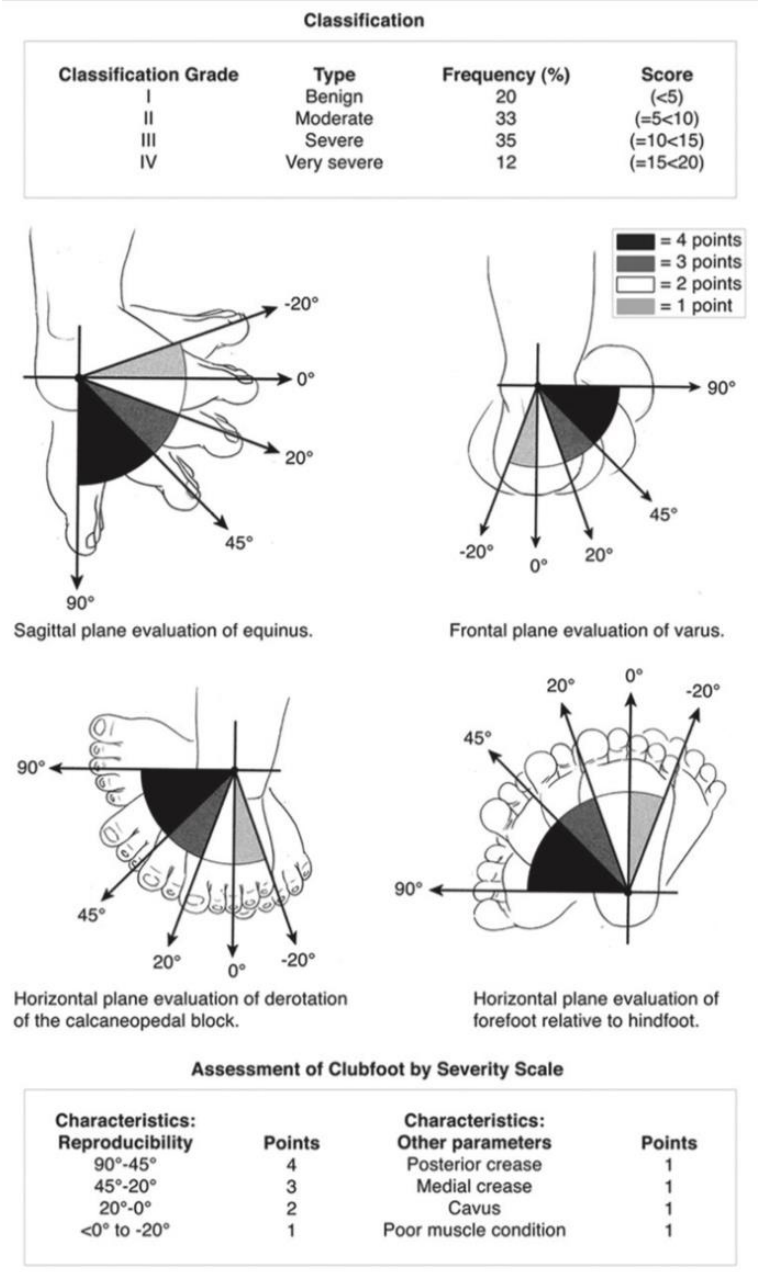


Figure 7. Pirani scoring system. [9]



Classification

Classification Grade	Type	Frequency (%)	Score
I	Benign	20	(<5)
II	Moderate	33	(=5<10)
III	Severe	35	(=10<15)
IV	Very severe	12	(=15<20)

Sagittal plane evaluation of equinus.

Frontal plane evaluation of varus.

Horizontal plane evaluation of derotation of the calcaneopedal block.

Horizontal plane evaluation of forefoot relative to hindfoot.

Assessment of Clubfoot by Severity Scale

Characteristics: Reproducibility	Points	Characteristics: Other parameters	Points
90°-45°	4	Posterior crease	1
45°-20°	3	Medial crease	1
20°-0°	2	Cavus	1
<0° to -20°	1	Poor muscle condition	1

Figure 6. Dimeglio scoring system.[20]

Treatment Methods

Ponseti Method

Before 1990, clubfoot was traditionally treated with a variety of extensive surgical techniques that typically resulted in rigid, painful feet.[21] These surgeries are associated with long-term pain and decreased quality of life. Today, the gold standard in clubfoot treatment is the

Ponseti method. The Ponseti method is accepted as the most cost-effective and least expensive method of clubfoot treatment worldwide. The average total cost of treating clubfoot via the Ponseti method at CURE hospitals is $167 USD.[22] The Ponseti method is a non-invasive, manipulative technique that takes advantage of the biological response of soft connective tissues, ligaments, and bone to mechanical stress.[23] These biological responses gradually reduce the degree of equinus, varus, and adductus of the foot. No published studies compare the Ponseti method to patients that underwent extensive surgical procedures, as it would be unethical to assign some children to a more invasive and outdated technique.

The success rate of the Ponseti method can surpass 95%.[14] Success is influenced by familial compliance, the experience of the surgeon, and the initial degree of stiffness in the foot. There is some variation in the definition of successful treatment across practitioners. A study in Africa done in 2016 by Dr. Christopher Lavy and Tracey Smythe used the Delphi method to decide the specific criteria for determining success of the Ponseti method.[24] The Delphi method is a tool that uses structured communication between experts, where experts answer questions anonymously and give justification for their answers. This goes on for a few rounds, with the opportunity to change or revise their answers between each round. Researchers consulted eighteen practitioners and trainers that were experienced in treating clubfoot. They were asked to rank twenty-two criteria, which were determined at a regional workshop of experts in the Ponseti technique. These initial criteria are listed in **Figure 9.**

Of these initial criteria, four were identified as being associated with the highest-rated outcomes. These included:

1. Plantigrade foot
2. No reported pain
3. Ability to wear normal footwear
4. Caregiver satisfaction

First Delphi round, January 2016		
Criterion	**Mean**	**SD**
The foot fits comfortably into a Foot Abduction Brace	8.90	0.71
The foot is plantigrade	8.78	1.26
The foot has 15 degrees of dorsiflexion or more	8.57	1.95
The heel is in a neutral position (no longer in varus)	8.23	1.53
The child can wear a normal shoe	8.16	1.76
The child reports no pain	8.13	1.83
The child demonstrates heel strike when walking	8.11	1.64
The forefoot adductus is corrected	8.09	1.15
The carer is satisfied	7.96	1.43
The foot does not supinate in swing phase when walking	7.92	1.33
The foot does not have less than 60 degrees of abduction	7.74	1.86
The Pirani score is 0.5 or less	7.67	3.04
The child keeps up with peers when walking and running	7.58	2.24
The foot has 10 degrees of dorsiflexion or more	7.52	1.81
The Pirani score is 0.5 or less	6.90	2.73
The foot is corrected within 6 casts	6.76	2.54
The Pirani score is 1 or less	6.66	2.72
The wear on the shoes are symmetrical (in unilateral clubfoot)	6.10	2.67
The child had a tenotomy	5.80	3.02
The foot has more than 30 degrees of abduction	5.44	1.74
The Pirani score is 1.5 or less	5.36	2.34
The Pirani score is 2 or less	4.94	2.74

Figure 7. Criteria established by regional experts for the defined success of the Ponseti method. [24]

The Assessing Clubfoot Treatment (ACT) score was developed in 2017 using these four criteria determined by the Delphi method.[25] Each of the criteria are graded on a scale of 0 to 3, with a possible total score of 12. The assessment has excellent interrater reliability. Moreover, it is a reliable tool for identifying patients that are more likely to require additional treatment. This is the current measurement tool used at Beit CURE. There is no global consensus on successful treatment, but there are a few other comprehensive tools that have been developed.[26] The Roye tool is used in high-income settings and is self-reported. The Bangla tool combines scores from a parental rating, gait assessment, and clinical examination to determine success, and was developed for LMIC's.[27] There is a need for a universal consensus on successful Ponseti treatment. This is a limitation of any study that involved clubfoot.

The Ponseti Method typically consists of three distinct phases (**Figure 10**):

1. serial manipulation maintained with casting
2. tenotomy (optional – dependent on the stiffness of Achilles tendon)
3. bracing

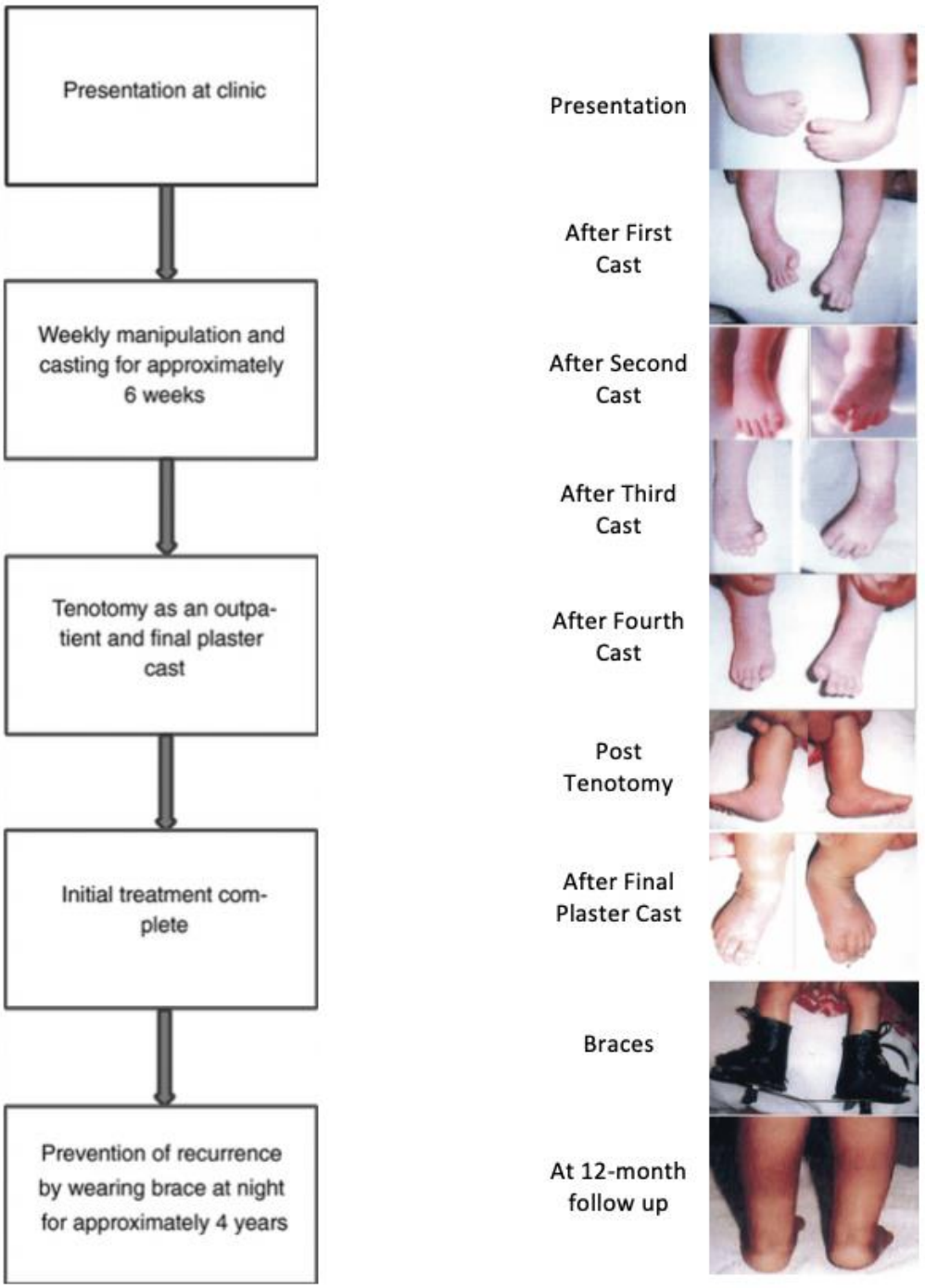


Figure 8. The Ponseti method. [28]

Typically, patients that present for treatment within the first seven to ten days of life require an average of five casts to achieve maximum correction of the cavus, equinus, adductus, and varus.[23] The long-leg casts are changed weekly. The foot is held in an abducted, supinated position, while pressure is applied to the lateral aspect of the talus. Depending on the age of the child and the degree of rigidity in the foot, additional casts may be necessary to achieve clinical and radiographic alignment of the talus. The foot should never be manipulated past its natural flexibility, which should increase with each round of casting.

A large percentage of patients require the second step, an out-patient percutaneous Achilles tenotomy, for correction of the equinus (**Figure 11**).[23] Tenotomy is used to correct equinus when adductus and varus deformities are fully corrected, but ankle dorsiflexion is less than 10 degrees.[23] After the tenotomy, the child returns to soft casting for three weeks so the tendon has adequate time to heal. This cast holds the foot in an abducted position of 60-70 degrees and dorsiflexed 15 degrees. After removal of the cast, 20 degrees of dorsiflexion should be attainable. The statistics on tenotomy rates vary from surgeon to surgeon.

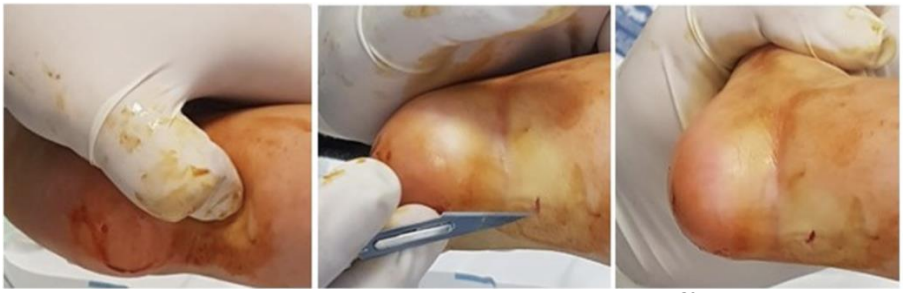


Figure 9. Percutaneous Achilles tenotomy.[29]

The final step, regardless of a tenotomy or not, is putting the child into a set of "boots and bars". These braces hold the foot in a dorsiflexed and abducted position are essential to prevent relapse. [23] The relapse rate can be as low as 6% with familial compliance, versus 80% with non-compliant caregivers. The braces are to be worn constantly for 3 months after the tenotomy, and then 14 to 16 hours a day. This protocol is followed until the child reaches 3 or 4 years of age.

Regular check-ups are still required to look for signs of relapse, in which case bracing should be reinstated immediately. The deformity has a tendency to relapse regardless of treatment protocol followed.

Surgical Intervention

For clubfeet that do not respond sufficiently to manipulation, surgical intervention is required. The surgical procedure varies based on the age of the child and the severity of the deformity.[30] Surgeries to correct relapsed, residual or neglected clubfoot are associated with long-term pain and decreased quality of life.[21] As with any surgery, there are increased risks with undergoing anesthesia and contracting an infection, especially in a developing country. There are two general categories of surgical intervention for clubfoot: soft tissue releases and bony procedures. Some of the possible surgeries include, but not are limited to:

1. Tibialis anterior tendon transfer
2. Partial epiphysiodesis
3. Posteromedial releases
4. Closing wedge osteotomies
5. Triple arthrodesis
6. Fascia plantar release
7. Use of external fixators (**Figure 12)**

Figure 10. External fixators to treat neglected clubfoot.

Neglected Clubfoot

Neglected clubfoot leads to significant disability and discomfort. The child will be forced to walk on the sides of the foot, limiting physical mobility and with it, opportunities for education and employment (**Figure 13**).[21] Once the child reaches walking age and starts to bear weight on a clubbed foot, there will be further contracture of the medial soft tissue and plastic deformation of bones, resulting in a worsening of the deformity.[31] If treatment is begun after the first three months of life, it can negatively influence the alignment of the patients' tarsal bones due to decreased viscoelastic properties of connective tissues.[32] Patients are often also impacted psychologically due to prolonged bullying or severe harassment.

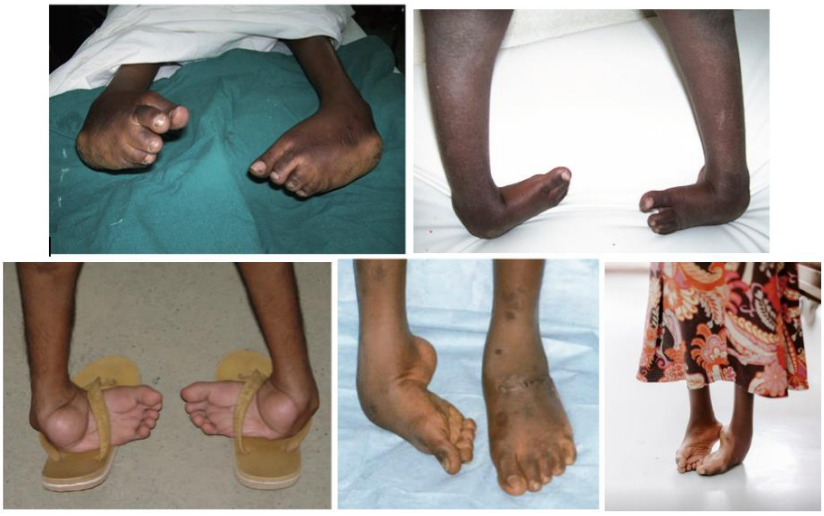


Figure 13. Neglected clubfeet. *[33,34]*

In 2016, researchers at Lady Hardinge Medical College in India found a direct relationship between age and degree of dorsiflexion obtained or the total number of casts required for adequate correction of the deformity (**Figure 14**).[31] Older children achieved less dorsiflexion and abduction than their infant counterparts. Forty-one patients between the ages of 1 and 10 years were studied; all of them were severe at initial presentation (Piriani scores ≥ 5 and Dimeglio scores ≥ 15). Despite varying degrees of success, all patients attained painless,

plantigrade feet and patients were largely satisfied with their outcomes without the need for radical surgery. The authors recognized that despite these promising findings, bracing compliance and practicality in older children is problematic. Children become completely dependent and wheelchair-bound, and there is no definitive protocol for bracing in older children.

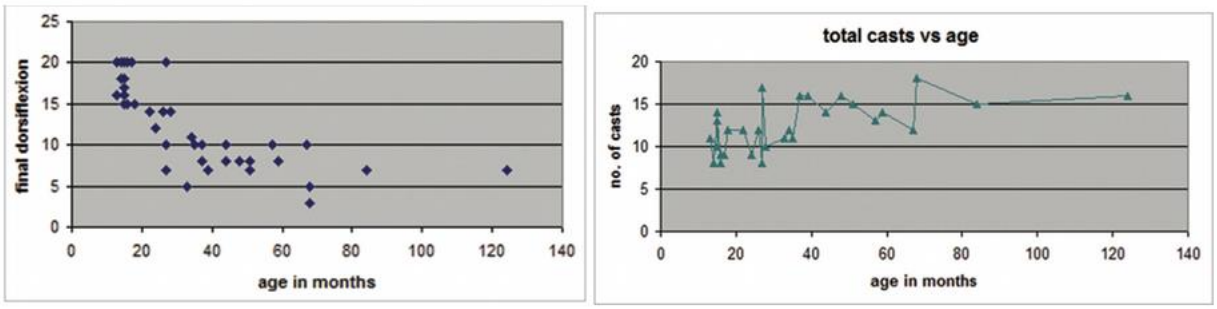


Figure 14. Relationship between the onset of treatment and final dorsiflexion and the total number of casts required. [31]

Researchers from the orthopedic department of St. Luke Catholic General Hospital in Ethiopia published evidence in 2014 that using the Ponseti method as the primary treatment, along with some minor additional surgery reduced the need for extensive surgical intervention.[33] They followed the course of treatment for twenty-two patients between the ages of 2 and 10 years old. One patient was lost to follow-up, but the remaining all achieved painless, plantigrade feet that they could walk and run on. None of them required radical surgeries.

The department of orthopedics at Zhujiang Hospital of Southern Medical University in China published a study in 2018 that compared treatment outcomes and goals between three groups of patients, separated by age. Group I patients started treatment before 28 days, group II patients started between 28 days and 3 months, and group III started between 3 months and 6 months.[32] They retrospectively studied the outcomes of ninety patients. They concluded that Group II produced the highest percentage of optimal clinical outcomes, required the fewest

number of casts and produced the lowest rates of relapse (**Figure 15**). It is widely accepted that clubfoot should be treated within the first few weeks of life, even under the guidelines that Dr. Ponseti himself created, so this result is surprising.

	Group I	Group II	Group III
No. of cases (feet)	15 (25)	15 (24)	10 (16)
Age at presentation	13 days	45 days	4.6 months
range	(3–27)	(31–87)	(3–6)
Sex			
Male	12	13	8
Female	3	2	2
Side			
Bilateral	10	9	6
Unilateral	5	6	4
Initial Pirani score [c]	4.6 (0.9)	4.5 (1.2)	4.1 (0.7)
Initial Dimeglio score [c]	14 (3.9)	13 (3.9)	14 (1.2)
No. of casts before PAT [c]	4.3 (1.8)	3.5 (0.9)	4.4 (1.0)
PAT rate [d]			
Yes	13 (22)	13 (22)	10 (16)
No	2 (3)	2 (2)	0 (0)
Brace compliance [d]			
Yes	13 (21)	13 (21)	6 (12)
No	2 (4)	2 (3)	4 (4)
Relapse rate [d]			
Yes	5 (10)	2 (3)	2 (2)
No	10 (15)	13 (21)	8 (14)
Propensity score [c]	0.5 (0.2)	0.5 (0.2)	0.6 (0.2)
ICFSG score [c]	4.9 (1.6)	3.9 (2.2)	6.8 (1.1) [a,b]

Figure 15. Demographic data by age treatment was initiated. [32]

The third published edition of the Ponseti Method suggests that children that present with clubfoot should begin with the Ponseti method, regardless of age, and then resort to additional soft tissue or bone surgeries if necessary.[23] In general, there is support that clubfoot can be treated later on in childhood, but optimum outcomes at lowest cost with smallest risks are seen most frequently in children that begin treatment before three months of age. This distinction helped us to determine a cut-off for what we would consider late presentation.

Selective Non-Clubfoot Abnormalities

All of the possible diagnoses that would make a patient eligible for inclusion are not listed here. All of the conditions described below were observed in our survey. Neurofibromatosis was reported by one patient, but it is not listed because this diagnosis itself is

not orthopedic in nature. It is classified as a nervous system disorder, although orthopedic issues are commonly associated with the disease. Orthopedic manifestations of the diagnosis can include:

1. Osteoporosis/osteopenia
2. Osteomalacia
3. Shortness of stature
4. Macrocephaly
5. Spinal deformities, such as scoliosis and kyphosis
6. Congenital bowing and pseudarthrosis of the tibia/forearm
7. Chest wall deformities
8. Extremity overgrowth
9. Soft tissue tumors[35]

The specific manifestation of the child that presented with neurofibromatosis was not recorded. Additionally, several patients were reported to have some kind of "general" or "other" congenital orthopedic deformation. These generalized descriptions are too vague for appropriate literature review.

Syndactyly

Syndactyly is a congenital condition where two or more digits are fused during gestation. This condition is less common than clubfoot, with a prevalence of 1 in every 2,000 to 3,000 births. [36] It affects twice as many males as females. Treatment protocol is surgical intervention, which may or may not require skin grafting. The ultimate goal is to give the patient good functionality and improved cosmetic appearance. The timing of treatment is widely dependent on the digits involved, the degree of completeness, and the complexity of the webbing. If the webbing is between the ring finger and pinky or thumb and index finger, there is an increased risk of flexion contracture.[36,37] These combinations are rare, but they require the most urgent intervention to avoid deformity and decreased functionality. It is widely recommended these spaces be released before 6 months of age. Webbing combinations that do not involve the thumb

or pinky finger can be postponed to avoid postoperative complications but should be performed before the child starts school so that he can develop fine motor skills and avoid peer curiosity. All releases should be completed before 24 months of age before motor habits develop.[36]

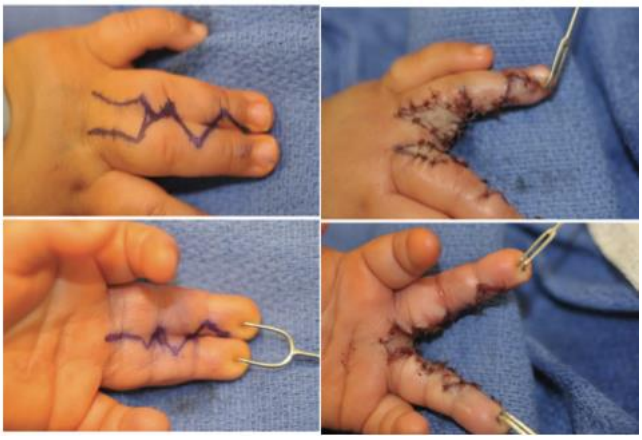


Figure 11. Syndactyly release of the middle-ring fingers using a skin graft. [36]

Pseudarthrosis of the Tibia

Pseudarthrosis of the tibia is a condition that affects the lower leg, with varying degrees of severity. An anterolateral bowing of the tibia is less severe because the bone remains intact. A frank pseudarthrosis, which means there is a nonunion of the tibia, is the most severe form of the condition.[38] The fibula is affected in roughly one-third of patients. The treatment protocol may involve bracing and/or surgical treatment, depending on the severity. A study done at Bai Jerbai Wadia Hospital for Children in India in 2019 did a study comparing different surgical protocols for treatment.[39] The age of participants ranged from 1 year to 6.5 years old. However, they cited that younger age at surgery was a risk factor for poor results. They did not advise on the best age to operate.

Arthrogryposis

Arthrogryposis is a collective definition of over 300 different diseases that are characterized by more than one joint contracture in more than one region of the body. The

incidence of multiple contractures is roughly 1 in every 3,000 to 5,000 births.[40] Interventions should begin within the first month of life for the maximal achievement of treatment goals. Ideally, we want the child to be able to live independently and function as a member of society. Physical therapy, occupational therapy, and splints or cast are the first steps of treatment. Some patients have persistent difficulties in the functionality of affected joints despite these approaches; in these cases, surgery may be recommended.

Figure 12. Infant with Arthrogryposis.

Kyphosis

Congenital kyphosis is a sharp angulation of the thoracic spine that is caused by a segmentation failure during gestation.[41] Because of the rapid growth that occurs during the first year of life, there is a significant risk of progression. Surgery can be performed in infants as young as 8 months old. The urgency of surgery is dependent on the progression of the curve. Minor curves are unlikely to cause persistent pain in adulthood, but more significant curves left untreated can cause stiffness and pain.

Tibial Deficiency

Tibial deficiency, or tibial hemimelia, is a rare condition where patients are born with a tibia that is shortened or missing completely. Its prevalence is about one in a million.[42] The

majority of patients undergo amputation, especially those with more severe deformities. It remains the tried and true gold standard of treatment. However, there are several emerging reconstructive techniques with excellent results. Brown's procedure, a surgical technique for Jones Type 1, recommends that surgery be done before one year of age. Overall, the range of timing for treatment is very wide and dependent on the classification, range of mobility, and treatment protocol desired.

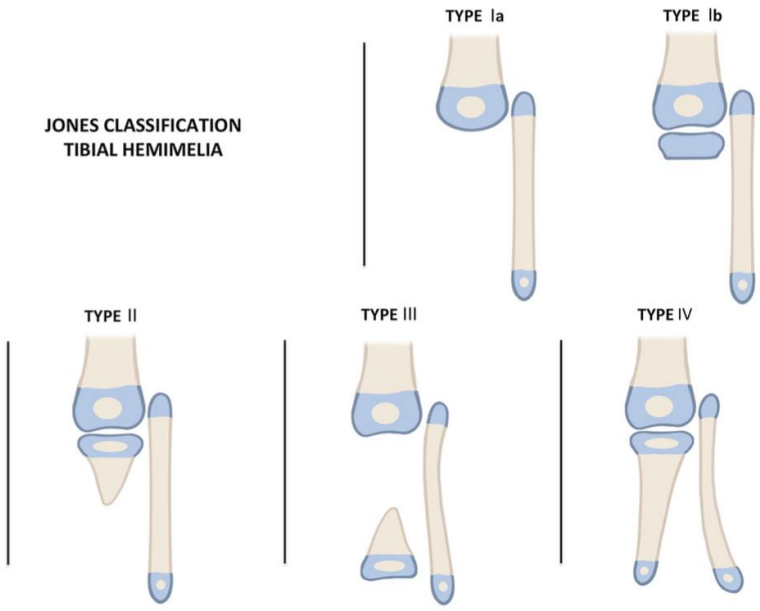


Figure 13. Jones classification of tibial hemimelia.[42]

Methods

Study Site

This study was conducted at Beit CURE International Hospital in Blantyre, Malawi. The hospital was built by CURE International in 2002 and is located directly across the street from Queen Elizabeth Central Hospital. Known as Queen's to the locals, it is the largest public hospital in the entire country. Queen Elizabeth has four orthopedic surgeons of their own, but services provided there for children are not free.

Situated in the Southern region, Blantyre is one of three centralized urban hubs in Malawi and is considered to be the center of commerce and finance. It is the second-largest city in the country, with a population of 800,264 people, or 5.1% of the total population.[1] It is the most densely populated city, with 3,328 people per square kilometer.

Selection Process

Any child that presented to the inpatient-ward, out-patient clinic, or mobile clinics that was diagnosed with a congenital orthopedic condition was eligible for inclusion in the study (**Appendix A**). Patients with congenital disorders were included regardless of gender, ethnicity, religion or any other characteristics. The only exclusion principle was having a diagnosis that was not concurrent with an orthopedic deformity present at birth.

We added an exclusion principle for non-congenital deformities for two reasons. First of all, we wanted to eliminate the potential for recall bias from the caregiver. If the condition is congenital, there is a clear and definitive mark of onset. Secondly, we wanted to reduce the total range of disorders included so that the results could be more generalizable.

Patients were admitted to the in-patient ward every Sunday evening. From the week of May 20th, 2019, to the week of June 17th, 2019, the in-patient roster was reviewed every Monday for eligible survey participants. These patients were surveyed by myself and my translator, Chipiliro Moffat, on Monday's and Tuesday's after the attending surgeons completed ward rounds. Chipiliro is a research nurse employed at Beit CURE who was assigned to help me conduct interviews.

Out-patient clinics occurred at Beit CURE one or two days a week. After they were seen by a provider in the out-patient clinics, eligible patients were asked to stop by an exam room where myself and Chipiliro were stationed. Out-patient surveys were conducted over the same time period as in-patient surveys.

Five mobile clinics were attended from November 24th through the 28th and February 2nd through the 6th. Three of these clinics were held in cities in the central region: Kasungu, Ntchisi, and Mchinji. Two of them were held in cities in the Northern region: Mzuzu and Nkhatabay. Chipiliro attended these clinics alone. Eligible patients were directed to him after they were seen by clinical personnel. The results were recorded directly into an ONA database, which could be accessed by both Chipiliro and myself.

No children were confronted during our investigation. We consulted their primary caregiver during one of three scenarios: a regular clinic visit, after admittance to the inpatient ward, or during a mobile clinic. No family was requested to make a special trip to assist in data collection. A primary caregiver had to be present at the time of the survey.

Consent Process

The purpose and value of this study was explained to each caregiver. After giving them the necessary information, they were presented with a written consent form in their native language. If they were illiterate, the consent form was read verbatim to them by an interpreter fluent in Chichewa, English, and Tumbuka. Furthermore, we accepted a thumbprint in place of a signature on the consent form. All caregivers were reminded of their right to refuse participation and assured that their confidentiality would be maintained. Please see **Appendix B** for a copy of the consent form in English.

Context of the Survey

The survey consisted of six broad sections of questions:

1. Details of the child's general clinical history, including diagnosis, treatment history, and birthplace
2. Sociodemographic information of the patient, including name, age, sex, birth date, and inpatient status
3. Sociodemographic information of the caregiver including name, age, relationship to the patient, education, employment, literacy, support system, language, average monthly household income, belief in traditional healers and religion
4. Caregivers medical history, including overall health rating and chronic conditions such as HIV/AIDS
5. Geographic information, including proximity to traditional healers, distance of residence from a main road, address, and district
6. Transportation details including the method of transport, cost of transport per person, and affordability

Answers to the survey were directly recorded into ONA, a secure database system. Please find the entire survey in **Appendix C**.

Data Analysis

The cut-off for what we considered to be a late presentation is 3 months for children with clubfoot. In determining the cut-off, we took into account the quality of outcomes, increased risk

of complications, and additional treatments and costs associated with delayed care. As covered previously, although there is evidence that non-surgical treatment with the Ponseti Method can be successful in children of walking age, the deformity becomes worse with weight-bearing and long-term follow-up suggests an increased likelihood of rigid, painful feet after the delayed treatment.[43,44,45]

It is important to note that this definition of late presentation is not in accordance with Malawian perceptions. Surgeons at Beit CURE do not consider a child with clubfoot to be a late presenter until age two. Because it is common for Malawian doctors to treat older children, their expectations are drastically different than those of the developed world. The operations director of CURE that noted a surplus of late presenters does not share this belief; we decided on a cut-off of three months because that is the ideal window of time that we hope to achieve for the children of Malawi.

For simplicity and clarity, we kept cut-off for late presentation at 3 months for all congenital orthopedic deformities. For many but not all of the conditions observed, timely arrival is critical. Each condition has a different treatment timeline that determines the definition of late presentation, in the sense that there are negative repercussions for seeking treatment too late. However, it would be optimal if all infants with congenital orthopedic conditions consulted with a physician as early as possible.

To understand the population surveyed, we looked at a number of patient demographic details, including:

1. Gender
2. Age range
3. Diagnosis
4. Birthplace
5. Region of residence

and caregiver sociodemographic details, including:

1. Age
2. Relationship to child
3. Religion
4. Literacy
5. Education
6. Employment
7. Average monthly income
8. Number of children
9. Number of dependents
10. Belief in traditional healers

The ultimate goal of this study is to see if there are major differences in survey answers between late presenters and on time presenters and to determine if these differences were statistically significant. We performed a $\chi 2$ test of independence on factors with three possible responses or less in an Excel spreadsheet. Factors with more responses can be more appropriately analyzed with ANOVA in future research. Anything with a p-value of less than 0.05 was considered to be statistically significant, meaning that the response to that factor was statistically significant when comparing on time and late presenters.

Results

A total of sixty-two caregivers were surveyed in our study. Twenty-one caregivers were seen in an out-patient clinic (33.9%), twenty-four in the in-patient ward (33.9%), and seventeen at a mobile clinic (27.4%). Of the total number of patients, thirty-four (54.8%) were male and thirty-eight (45.2%) were female. 50% of the patients presented late and 50% presented on time (**Figure 21**). The patients ranged from 1 week old to 16 years, 2 months. The average age was 50.7 months (4yrs 3m) and the median was 28 months (2yrs 4m).

Although CURE is a Christian-affiliated institution, they do not turn away members of other faiths. In our study, 8.1% of patients practiced the Muslim faith and 91.9% practiced Christianity. At first glance, there seems to be a lack of representation of other faiths. However, 82% of the country is Christian and 13% is Muslim.[46]

Thirty-two patients (51.6%) were residents of the Southern region, nineteen (30.6%) were from the Central region, and eleven (17.7%) were from the Northern region. **Figure 19** organizes patients by their region of residence and the location of their interview. The disproportionate representation of patients from each region by survey location is expected. The twenty-one patients seen in out-patient clinics were all residents of the Southern region. Out-patient clinics were held at Beit CURE, which is in the Southern region, so this was expected. None of the patients seen in mobile clinics were residents of the Southern region. This was also expected, due to the locations where mobile clinics were held.

Figure 20 shows the distribution of diagnoses that were observed**.** Eleven discrete diagnoses were reported. Clubfoot was the most prevalent disorder at forty-two patients (67.7%). **Figure 21** is a graphical representation of each of the factors we investigated, with the exception of "trust in Malawian doctors". All of the respondents reported faith that Malawian doctors were

capable of helping their child. **Figure 22** and **Figure 23** both present each of the factors, separated by whether or not the child presented on time for treatment. Each of these factors with three or less response options were put through a $\chi 2$ test of independence to determine if there was a relationship with the timing of presentation. Factors that resulted in a p-value less than 0.05 were considered to be statistically significant. Those that were found to be statistically significant findings are recorded in **Figure 24** and those that were not are recorded in **Figure 25**.

REGION OF RESIDENCE	OUT-PATIENT	IN-PATIENT	MOBILE CLINICS	TOTALS
SOUTHERN	21	11	0	32
CENTRAL	0	9	10	19
NORTHERN	0	4	7	11
TOTALS	21	24	17	62

Figure 14. Location of interview vs. region of residence.

DIAGNOSIS	# PRESENTING
NEUROFIBROMATOSIS	1
TIBIA DEFICIENCY	1
KYPHOSIS	1
OTHER CONGENITAL FOOT	1
GENERAL CONGENITAL SYNDROMES	2
OTHER CONGENITAL HAND	2
PSEUDARTHROSIS OF THE TIBIA	2
ARTHROGYROPOSIS	2
OTHER CONGENTIAL LOWER LIMB	3
SYNDACTYLY	5
CLUBFOOT	42

Figure 15. Diagnoses.

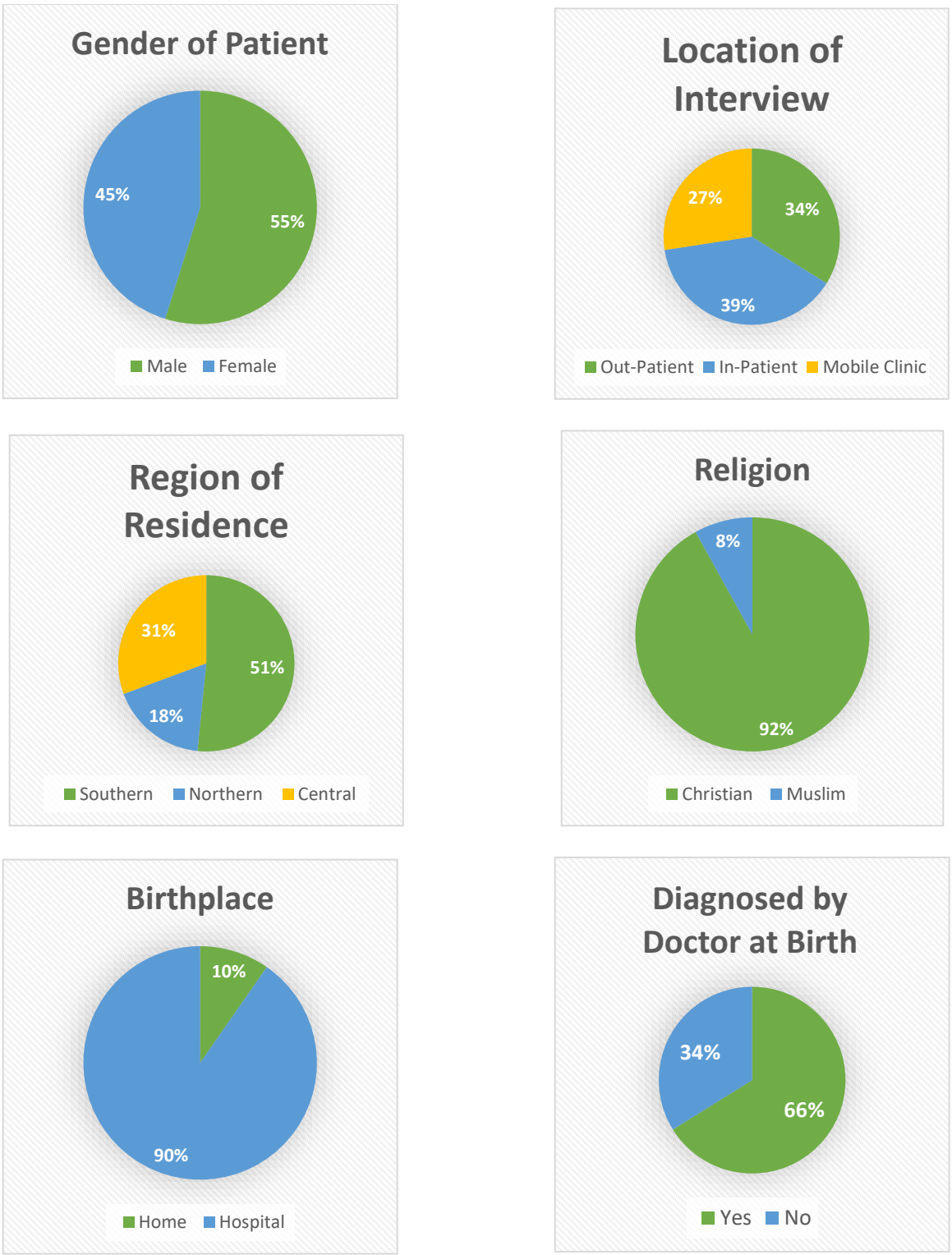


Figure 21. Breakdown of Survey Responses

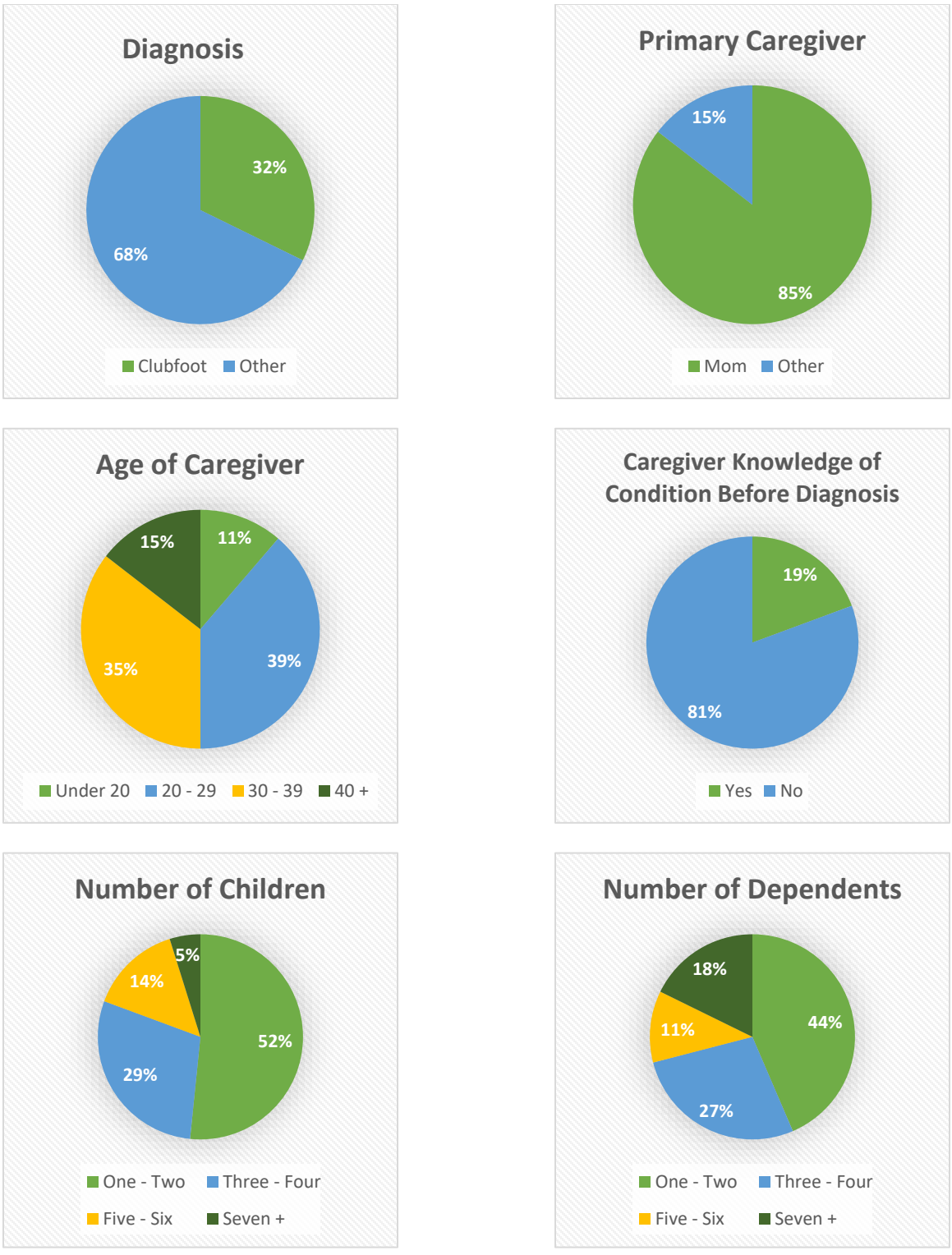


Figure 21 cont. Breakdown of Survey Responses.

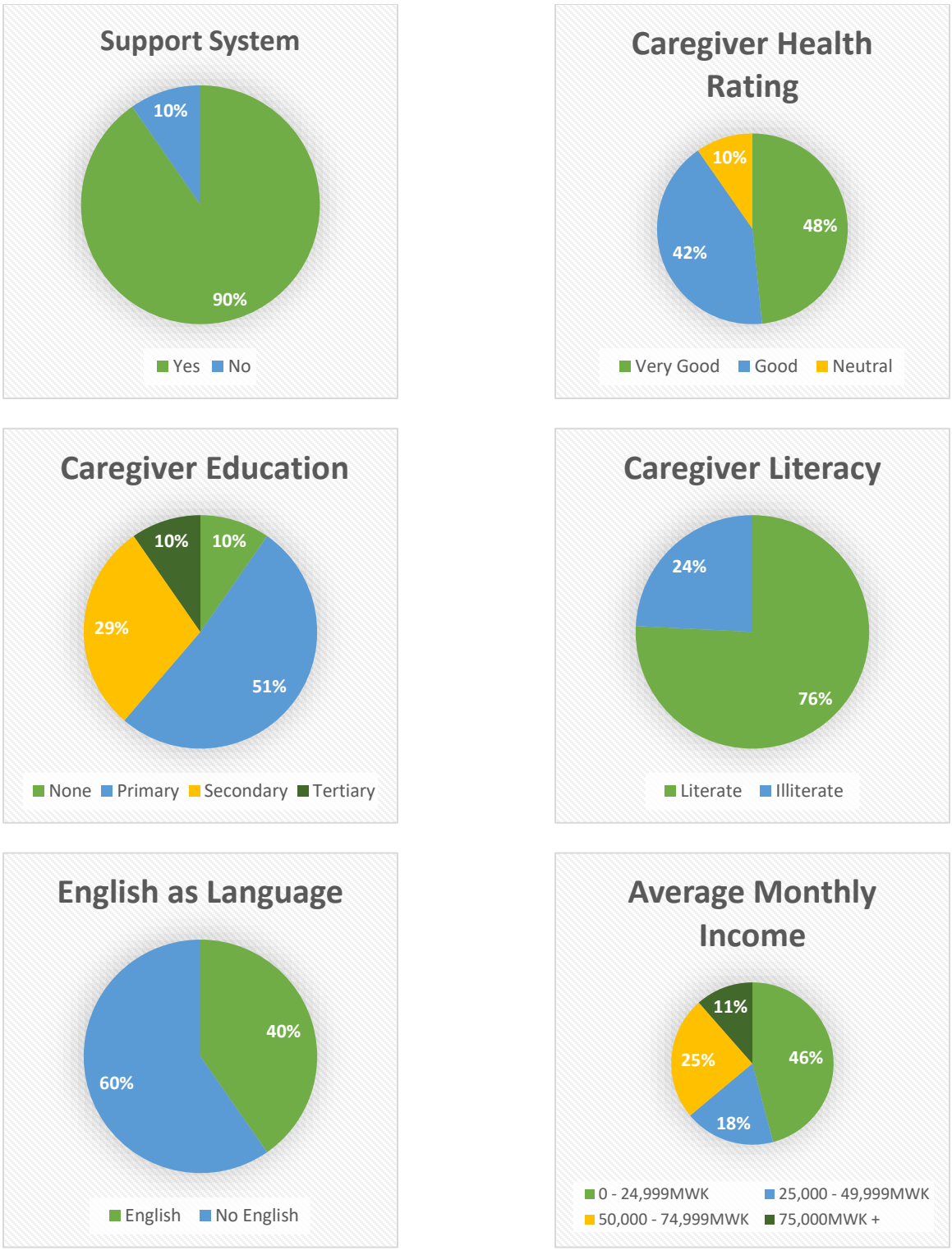
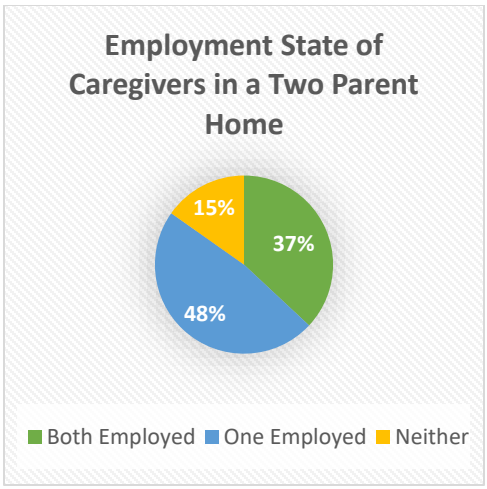
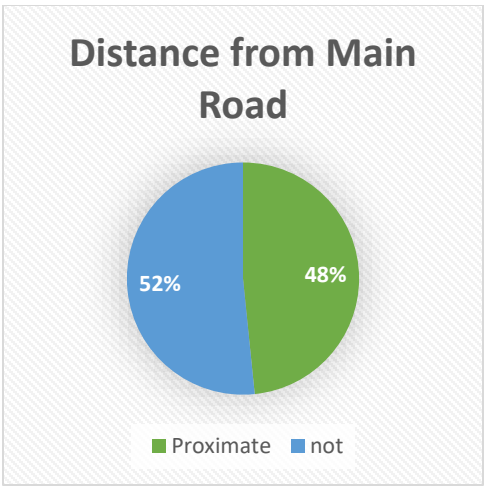


Figure 21 cont. Breakdown of Survey Responses.





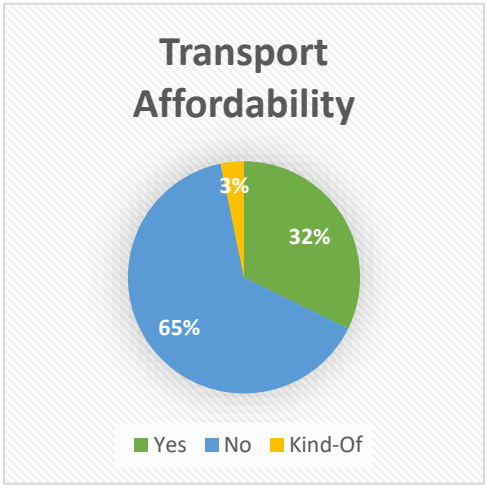


Figure 21 cont. Breakdown of Survey Responses.

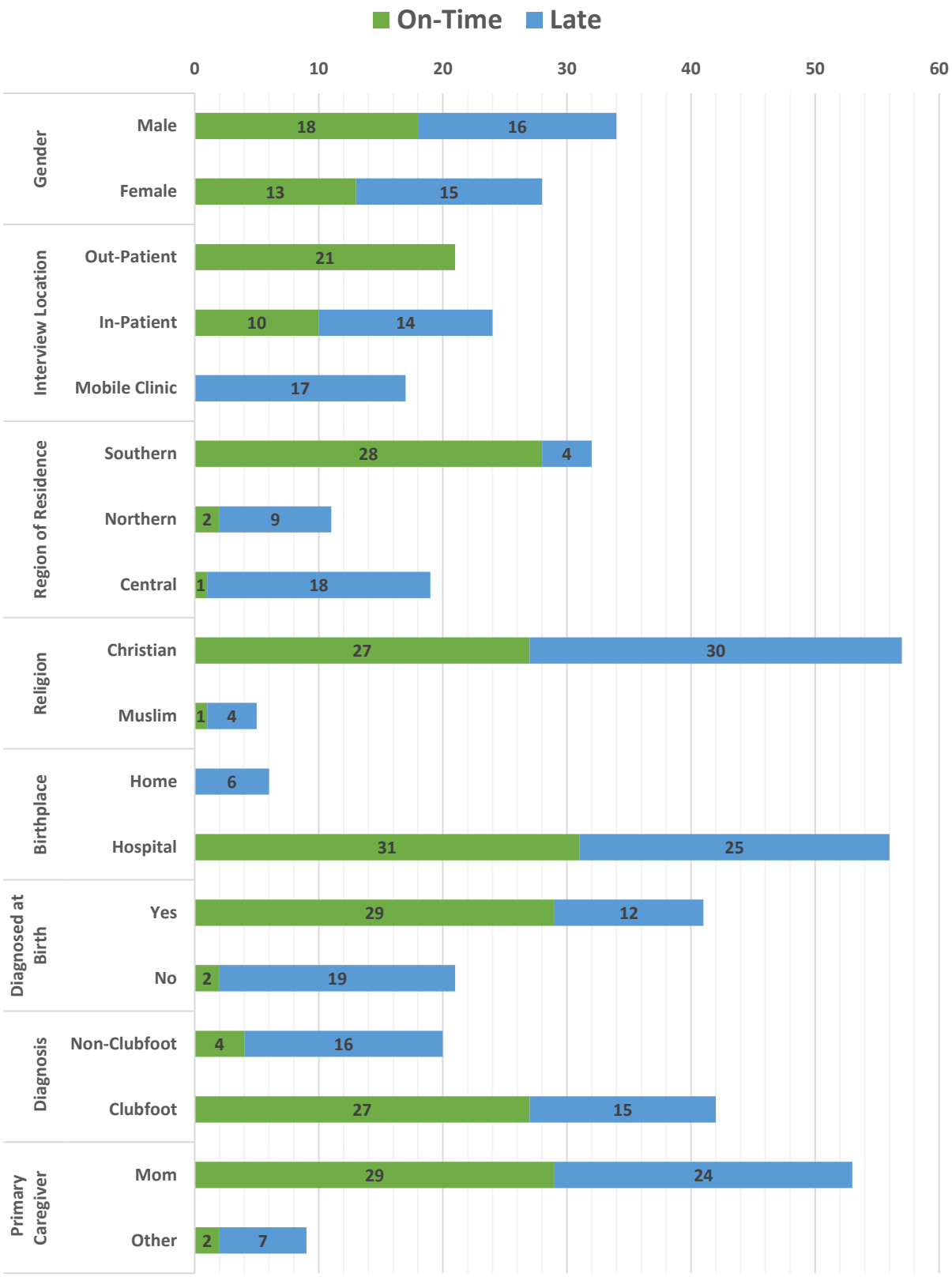


Figure 22. Factors subdivided by the timing of presentation.

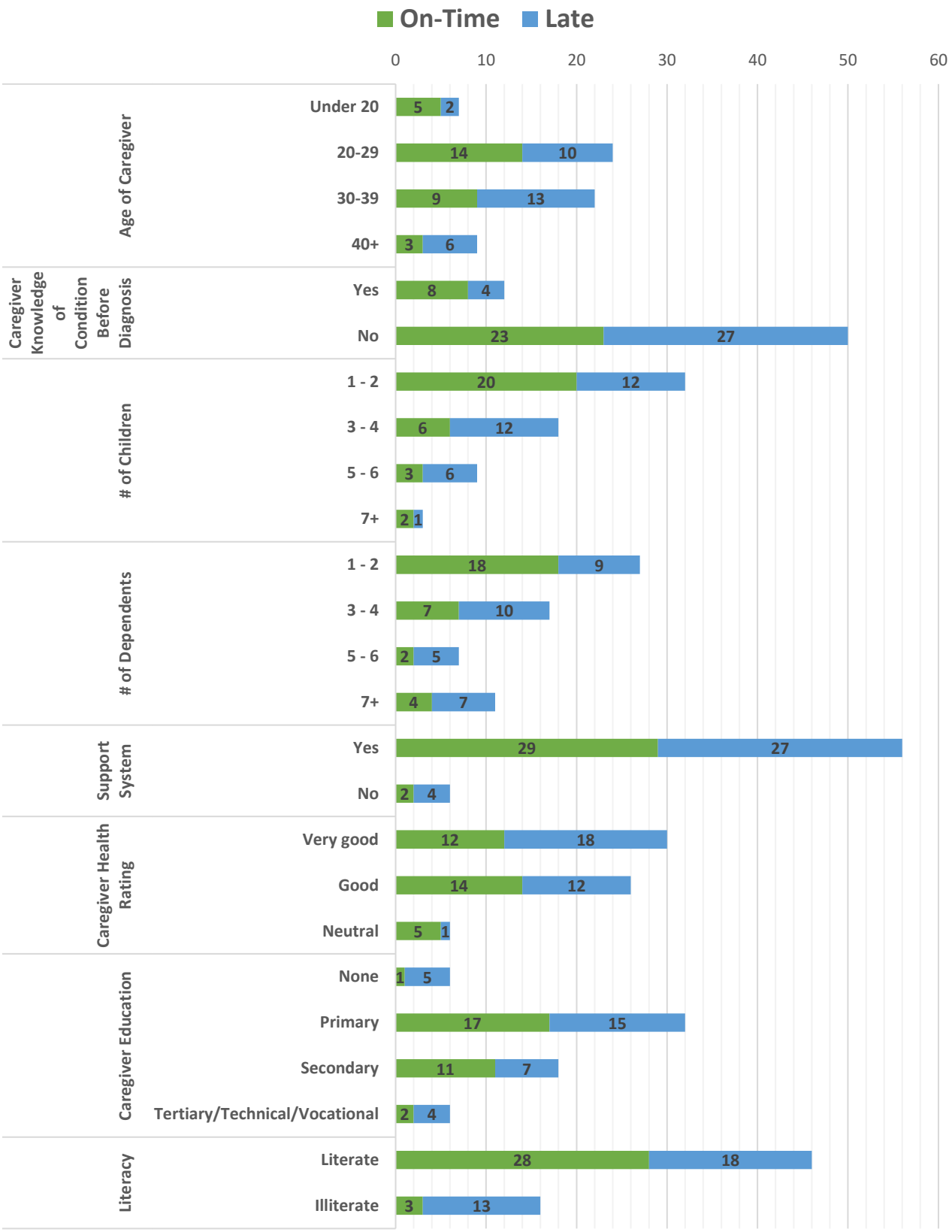


Figure 22 cont. Factors subdivided by the timing of presentation.

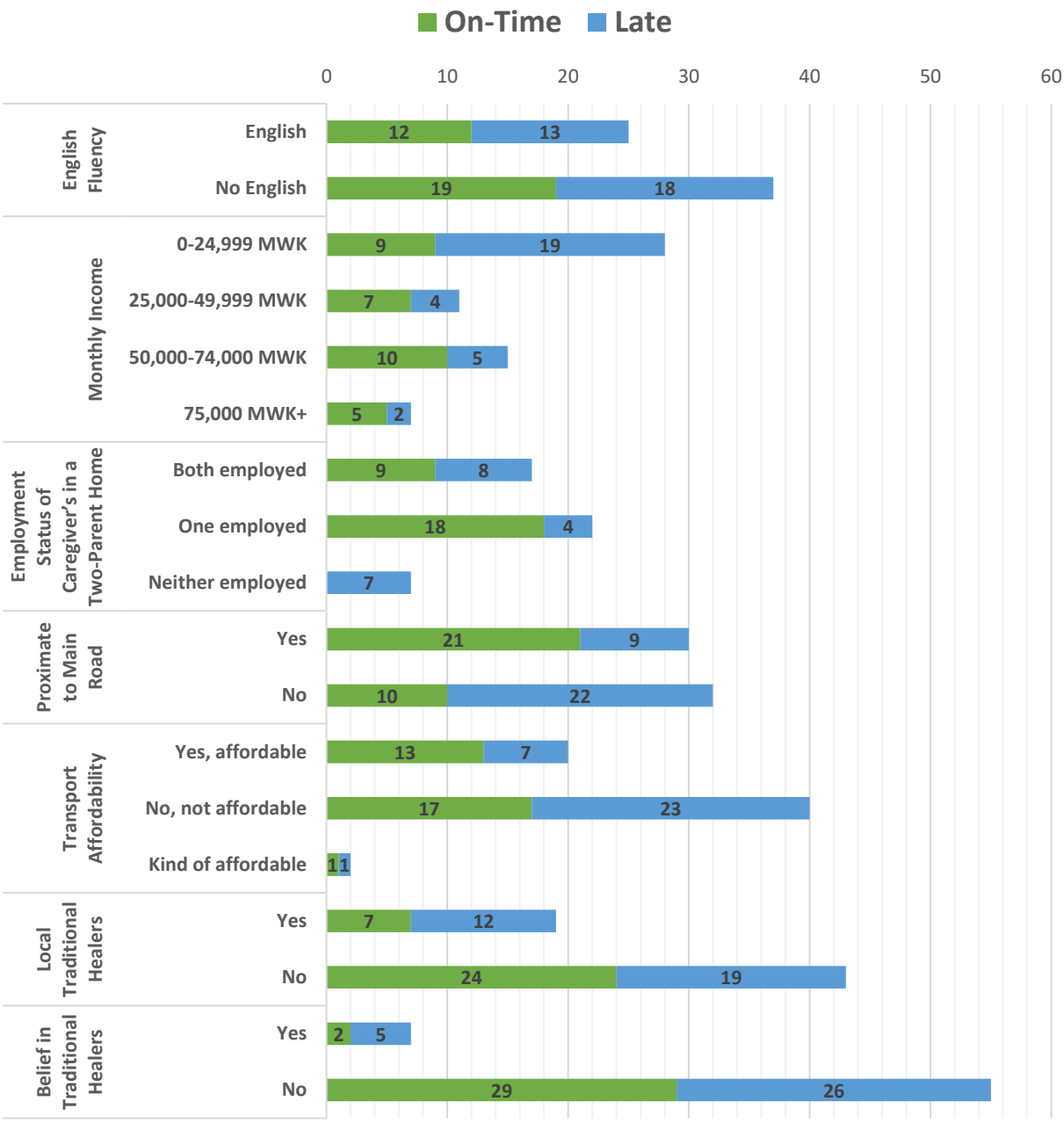


Figure 22 cont. Factors subdivided by the timing of presentation.

Variable of Interest	Category	# of Patients On Time	# of Patients Late
Gender of Patient	Male	18	16
	Female	13	15
Interview Location	Out-Patient	21	0
	In-Patient	10	14
	Mobile Clinic	0	17
Region of Residence	Southern	28	4
	Northern	2	9
	Central	1	18
Religion	Christian	27	30
	Muslim	1	4
Birthplace	Home	0	6
	Hospital	31	25
Diagnosed at Birth	Yes	29	12
	No	2	19
Clubfoot Diagnosis	Non-Clubfoot	4	16
	Clubfoot	27	15
Primary Caregiver	Mom	29	24
	Other	2	7
Age of Caregiver	Under 20	5	2
	20-29	14	10
	30-39	9	13
	40+	3	6
Caregiver Knowledge of Condition Before Diagnosis	Yes	8	4
	No	23	27
Number of Children	1 – 2	20	12
	3 – 4	6	12
	5 – 6	3	6
	7+	2	1
Number of Dependents	1 – 2	18	9
	3 – 4	7	10
	5 – 6	2	5
	7+	4	7
Support System	Yes	29	27
	No	2	4
Caregiver Health Rating	Very good	12	18
	Good	14	12
	Neutral	5	1
Caregiver Education	None	1	5
	Primary	17	15
	Secondary	11	7
	Tertiary/Technical/Vocational	2	4
Literacy	Literate	28	18
	Illiterate	3	13
English as a Language	English	12	13
	No English	19	18
Monthly Income	0-24,999 MWK	9	19
	25,000-49,999 MWK	7	4
	50,000-74,000 MWK	10	5
	75,000 MWK+	5	2
Employment Status of Caregiver's in a Two-Parent Home	Both employed	9	8
	One employed	18	4
	Neither employed	0	7
Distance from Main Road	Proximate	21	9
	Far	10	22
Transport Affordability	Yes, affordable	13	7
	No, not affordable	17	23
	Kind of affordable	1	1
Local Traditional Healers	Yes	7	12
	No	24	19
Belief in Traditional Healers	Yes	2	5
	No	29	26

Figure 23. Tabular representation of factors by timing of presentation.

TIMING OF PRESENTATION AS A FUNCTION OF VARIABLES OF INTEREST

	VARIABLE OF INTEREST	X^2 VALUE	P-VALUE
SIGNIFICANT	Location of the Interview	19.667	5.363×10^{-5}
	Region of Residence	33.642	6.624×10^{-9}
	Birthplace	6.643	0.010
	Diagnosed at Birth	20.811	5.070×10^{-6}
	Diagnosis	14.763	1.219×10^{-4}
	Literacy of Caregiver	8.424	0.004
	Proximity to the Main Road	9.300	0.002

Figure 24. Statistically significant findings using the χ2 test of independence.

	VARIABLE OF INTEREST	X^2 VALUE	P-VALUE
NOT SIGNIFICANT	Gender	0.261	0.610
	Religion	1.958	0.162
	Previous Knowledge of the Condition	1.653	0.199
	Mom Primary Caregiver	3.249	0.071
	Support System	0.738	0.390
	English Language	0.067	0.796
	Transport Affordability	2.700	0.259
	Local Traditional Healers	1.897	0.168
	Belief in Traditional Healers	1.44	0.229

Figure 25. Not statistically significant findings using the χ2 test of independence.

Discussion

Religion did not play a statistically significant role in determining whether or not a child presented late for care. However, this could be due to a low sample size. Only one of the five (20%) Muslim patients presented on time, but twenty-seven of the fifty-seven (47.4%) Christian patients presented on time. None of the caregivers reported that their religion prevented them from seeking medical attention for their child, but it is possible that members of the Muslim faith do not want to seek care at a Christian facility.

Out-patient clinics are typically reserved for children presenting on time with clubfoot who are receiving the Ponseti treatment, and there are 26 other clinics across the country that are capable of providing this service. Therefore, patients from districts outside of Blantyre would be referred to the clinic closest to them. Twenty of the twenty-one patients seen at the Beit CURE out-patient clinic had a diagnosis of clubfoot and all twenty-one patients presented on time. All of the children that were seen at mobile clinics presented late. These children were more likely to present with a condition that is not clubfoot. 56% of the patients seen in mobile clinics had a clubfoot diagnosis versus 68% of the total sample. Non-clubfoot patients are only seen at Beit CURE or at a mobile clinic. Patients with clubfoot from the Northern and Central regions that present for care on time would likely present at one of the other 26 clinics.

In our study, there is a higher prevalence of patients with clubfoot from Northern and Central regions that present late for treatment. However, we do not have the records of children that presented on time from those regions because they were likely referred to a local clinic; there is not enough data to confirm that children born with clubfoot in those regions are less likely to receive timely treatment. Moreover, only Beit CURE (or Queens, but would likely be referred to Beit CURE) can treat neglected clubfoot surgically, so the incidence of late presenters from other

regions should be expected to be high. A study from 2019 at the Technical University of Berlin reported that the closer in proximity that African patients live to a health clinic, the easier it becomes to obtain care. [7]

The location where the survey was recorded and the region of residence are interrelated variables that both significantly influenced timing of presentation. Patients that lived in the Northern or Central region, or, were seen at a mobile clinic, were much more likely to present late. This could be attributed to multiple different factors. There could be a lack of awareness about CURE by medical professionals in the area or poor advertising for mobile clinics in the region. Parents that believe their child is in need of surgery might not think to attend a mobile clinic because the only surgery center is located in the Southern region. The trip to Beit CURE Hospital may be too expensive for the caregiver. In general, there seems to be a large access problem in these regions of the country.

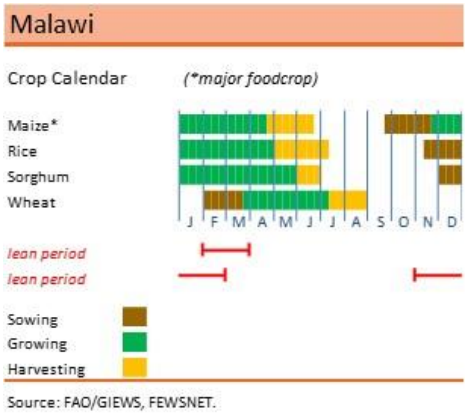


Figure 26. Farming patterns in Malawi. [47]

Surveys that were conducted in out-patient clinics or the in-patient ward were completed in May and June of 2019. However, the mobile clinics were all done in the months of November and February. According to the Food and Agriculture Organization of the United Nations, roughly 80% of Malawians are small farmers. Many families cannot leave their home and travel for care during harvesting season. Depending on the crop grown, this can impact who is

presenting for care at certain times of the year. For example, children of farmers that grow rice may not be presenting for care during the months of May, June, November or December because of sowing and harvesting seasons. Twelve caregivers reported that either themselves or their spouses were farmers. Only one of the twelve (8.3%) presented on time for treatment. Moreover, Blantyre, the city where Beit CURE is located, is considered to be the manufacturing and money capital of the country. Compared to the other regions, there are significantly higher numbers of individuals that are employed in small business or other non-agricultural, non-seasonal dependent work. Therefore, the children that reside in the Southern district may be more likely to get timely care because their caregivers have reliable, dependable jobs. We regretted not asking caregivers if they were losing any income by bringing their child in for care.

Despite improvements in maternal care over the years, 11% of Malawian moms do not deliver at a healthcare facility and the quality of care that mom and baby receive remains low.[48] Whether or not a child was born at a hospital is statistically significant indicator of whether or not he or she will seek care within the 3-month window. All six patients born at home were late presenters. Relatedly, children that are diagnosed by a physician at birth are statistically more likely to present on time. There were some children whose conditions went undiagnosed by physicians at birth, even if they were born at a hospital. Those that were not diagnosed at birth had a 90.5% chance of presenting late, whereas those that were only had a 29.3% chance.

Whether or not mom was the primary caregiver was insignificant. Numerous caregivers reported that the child's birth parents had died (AIDS, violence, malaria, etc) or could no longer support the child. We do not have exact numbers on this because our survey did not inquire about biological parents, only caregiver information. The age of the caregiver needs to be statistically analyzed using ANOVA. We suspected the much older caregivers may have health

problems or other responsibilities and younger caregivers may lack resources or knowledge on how to care for a child. However, according to our limited data, the younger the mother, the more likely the child was to present on time for treatment. Caregivers under 20-years-old were 71.4% likely to have their child present on time, 20 to 29-year-olds were 58.3% likely, 30 to 39-year-olds were 45% likely, and above 40 years were 33.3%. The average age of caregivers that had children present late was 31.7 years, compared to 28.2 years with those that presented on time.

Larger families are common in Malawi. The average household size is 4.5 people, but 30% of homes have six or more.[49] In contrast, the average household size in the United States is 2.6 people, and only 5% of homes have six or more. Often, aunts and uncles or grandparents take in children when their parents are no longer able to care for them. Moreover, older or sick individuals often end up living with other family members. For this reason, we made a distinction between the number of children and the number of dependents (sick, elderly, or other family members that are dependent on the caregiver for survival) of each caregiver. Twenty of the thirty-two (62.5%) caregivers that were only responsible for one or two children had a child who presented on time for treatment. In contrast, only eleven of the thirty (36.7%) caregivers that were responsible for three or more children presented on time for treatment. Similarly, eighteen of the twenty-seven (66.7%) caregivers that are responsible for one or two dependents presented on time, compared to thirteen of the thirty-seven (35.1%) caregivers responsible for three or more dependents. Caregivers of late presenting children had an average of 3.03 children and 4.03 dependents. Caregivers of children that presented on time had an average of 2.48 children and 3.23 dependents.

Researchers at the University of Western Cape in South Africa who were studying barriers to care for clubfoot children in Uganda in 2009 found that parents who had someone at home to care for their other children were more likely to adhere to treatment protocol.[50] Six caregivers in our study reported no additional child care assistance at home, but only four of those had more than one child. Those four caregivers had children that presented late, and the other two presented on time. Overall, having a support system was not determined to be statistically significant.

We asked caregivers if they had any pre-existing conditions such as HIV/AIDS, but there was concern of reliability so we also asked them to rate their health on a scale. Their options were very bad, bad, neutral, good, and very good. None of our participants answered bad or very bad. No correlation was seen between the health of the caregiver and timing of presentation. We suspect a degree of self-reporting bias.

The study done by the University of Western Cape that was previously mentioned reported 67% of caregivers knew nothing of clubfoot before their child's diagnosis.[50] In our study, 81% of clubfoot caregivers and 80% of non-clubfoot caregivers had no prior knowledge. Prior knowledge of the condition did not significantly correlate with the timing of presentation. Many of the reported disorders are so incredibly rare that it would be unlikely for caregivers to have heard about the particular condition before. However, some of these conditions are genetic, which may have an effect. We suspected that the prevalence and resources available to treat clubfoot may increase the likelihood that caregivers would have heard of it before, but this was not the case.

Patients diagnosed with clubfoot in our study were more likely to receive treatment on time. Of the forty-two clubfoot patients, 64.2% presented on time, whereas only 20% of non-clubfoot patients did. This could be due to the availability of resources for clubfoot patients.

The study in Uganda also cited that 68% of caregivers reported that the doctor did not educate on what the diagnosis meant at the time of birth.[50] Receiving a diagnosis at birth is not of great benefit if the caregiver does not know to seek treatment. We regretted not asking caregivers who reported their child being given the diagnosis at birth whether their child's condition was explained to them and whether they were told the condition was treatable.

We divided up caregivers by the level of education at which they stopped attending school. The categories were none, primary, secondary, and tertiary, which includes trade and vocational schools. Primary school is taught in the local language, and most secondary schools teach primarily in English. Fluency in English was not a statistically significant determinant of the timing of presentation and there was no correlating trend between education completed and the timing of presentation. However, literacy of the caregiver was considered statistically significant. This surprised us. We expected education and literacy to follow a similar trend. As of 2015, 61.2% of the total population were literate.[2] Literacy may be influenced by more than just years of schooling completed. We would like to further investigate to see if information materials about clubfoot or clubfoot clinics are only supplied as handouts.

All of the caregivers reported that they had faith in Malawian doctors. Retroactively, we decided this question was poorly written. The intention behind this question was to determine whether or not previous negative experiences with Malawian doctors had led them to lack faith in their capability to treat. Instead, we should have asked whether or not they believed that

Malawian doctors were capable of healing their child and if they had any previous negative experiences with physicians during their child's treatment process.

We asked caregivers to estimate the average monthly income that their family generated. The reported values were divided into four categories: 0 -24,999 MWK, 25,000-49,999MWK, 50,000MWK-74,999MWK, and 75,000MWK +. As of April 5th, the exchange rate was 735.99 MWK to $1 USD. The international poverty line is $1.90 per day, or 1,398MWK per day. Therefore, families that make less than 41,951MWK a month live below the international poverty line. Twenty-eight of the sixty-two (45.2%) caregivers estimated their monthly income to be less than 25,000MWK a month. Nineteen of the twenty-eight (67.9%) caregivers had children that presented late. Although significantly fewer caregivers reported incomes of 75,000 MWK or higher, five of the seven (71.4%) patients from that category presented on time.

Participants were asked to rate their transportation costs as affordable, kind of affordable, or not affordable. Transportation affordability did not have a significant statistical impact on the timing of presentation. However, we suspect this is due to the small sample size. Thirteen of the twenty (65%) caregivers that reported affordable transport had children that presented on time, compared to seventeen of the forty (42.5%) caregivers who reported unaffordable transport. We acknowledge that several caregivers noted that financial costs were the primary reason for delayed care.

Living in close proximation to one of the main roads was determined to be statistically significant. 70% of patients that lived near a main road received treatment before the cut-off, compared to 30% that did not live near a main road. Living close to a main road in Malawi makes transportation much easier. The minibus system, which 87.1% of our patients utilized at some point in their journey for accessing treatment or assessment, only runs on the country's

main roads. Car ownership is not common among Malawians. Many off-roads are not drivable by minibus or car, especially during the rainy season. Therefore, caregivers that do not live close to a main road must find another mode of transportation to reach the bus, whether that be walking, biking, using an ox cart, etc. We regret not asking them the amount of time it took to travel from their home to the clinic or hospital. Although we have a general idea of geographic residence, the time spent traveling will vary because of the various modes of transportation that patients must use. We also regretted not asking the caregiver if they had received any financial assistance for transportation. Researchers at the University of the Western Cape in South Africa assessed the barriers to care for children with clubfoot in Uganda in 2009 and they discovered that parents who had financial assistance with transportation were more likely to adhere to treatment protocol.[50] Although we are not following patients through their treatment regime, it would have been interesting to see if there was a correlation between travel fee assistance and the timing of their first visit.

Several articles in the literature reported paternal, familial, or community opposition to treatment, which we failed to incorporate into our questionnaire.[8,10,51]

Limitations

Because of the limited time frame, intermittent sampling, and small numbers, it is hard to tell whether our findings are truly representative of the population. We were limited by the number of patients that presented in out-patient clinics or in-patient wards over the month that our research was conducted on site at Beit CURE, and by the number of patients that presented to the mobile clinics that were attended by Chipiliro. Moreover, we were limited by the number of mobile clinics that could be attended because of funding for travel. These surveys were conducted intermittently over time because of funding and logistical reasons. Our small sample

size limits the study's statistical power, or its ability to detect differences between the characteristics of those who presented on time and those who presented late. This reduces our ability to accurately identify the factors that influence late presentation.

There are other unavoidable limitations. We considered just on time or late presentation. There are actually varying degrees of late presentation, especially in non-clubfoot patients. For some of the listed conditions, treatment is not recommended within the three-month cut off to reduce the risks associated with anesthesia and other postoperative complications (but not so late as to cause developmental delay). For others, early intervention is still critical, but not necessarily within 3months of birth. Because presentation delay is relative in terms of the condition, longer delays in some disorders could be reasonable. Clubfoot is the only condition with a very clear and definitive cut off for late-presentation classification. There is no cut off that encompasses the spectrum of conditions that we included in our study. However, we decided to include non-clubfoot patients in order to increase our sample size.

A study conducted by the Perelman School of Medicine in Philadelphia in 2017 sought to assess a similar research question in Nepal.[51] They identified predictors of healthcare-seeking delays for all children with chronic musculoskeletal disorders, regardless if it was congenital or not. They decided on a 3-month cut-off for clinically significant delays after their own literature review and consultation with experts. They wanted to make sure they accounted for typical treatment-seeking delays whilst considering the ramifications for long-term delays. Presentation was defined as the number of months between when the condition was diagnosed and when the caregiver sought treatment for the patient. They cited self-reporting bias of the time of onset as a limitation.

Our survey has a significant difference: we only assessed children with congenital orthopedic conditions. Rather than limiting our study to only clubfoot, we included all congenital abnormalities to further increase the number of caregivers surveyed. By doing so, we may have weakened the strength of the meaning of late presentation. Many of the disorders included in our study are so rare that analyzing barriers to each individually would be futile. It is necessary to aggregate these disorders into a single study in order to have sufficient sample sizes to determine statistical significance.

It is important to remember that children that present on time are not guaranteed to benefit. We are not doing a follow-up on these patients. For many of the disorders reported, long-term follow-up care are necessary for successful outcomes. It is possible for them to drop out of treatment or fail to comply with the protocol. These ongoing visits may become problematic due to financial constraints, natural disasters, political unrest, harvest season, or any number of other barriers. In terms of clubfoot, there is no difference between a child that does not complete their initial treatment protocol and a child that has never been treated before: both fall under the umbrella of neglected clubfoot, which poses the same risks and consequences. We want to set these children up to have the greatest chance of optimum outcomes, but getting these children proper, necessary care is an ongoing and multifaceted issue.

Conclusion

Our ultimate goal is to reduce the percentage of patients that are presenting after the recommended age by removing or minimizing the factors that deter them from treatment. By identifying these factors, we can hope to address them through various intervention strategies and improve the percentage of optimum patient outcomes. Children with clubfoot that began the Ponseti treatment somewhere in the range of twenty-eight days to three months have the best clinical outcomes and the lowest rate of relapse.[31,33,51] There are striking differences in the overall cost of treatment, number of casts, and ultimately, the outcomes of neglected clubfeet treated with the Ponseti method compared to timely treatment.[11,31,45] For many of the other disorders that were included, there are potentially better outcomes with earlier presentation.

This study found that caregivers were statistically more likely to bring their child in late for treatment if they possessed any one of the following characteristics: they were residents of the Northern or Central regions of Malawi, were illiterate, were not notified at birth of their child's condition, had a child with a congenital orthopedic condition other than clubfoot, gave birth at home rather than at a hospital, or did not live close to a main road. Other correlations were made between survey answers and late presentation, but they were either not statistically analyzed or not considered to be statistically significant. Caregivers that were older, reported unaffordable transportation, had a monthly income on the lower spectrum, or had more than three children/dependents were more likely to bring their child in late for care.

Based on this information, there are several actions that CURE International and the government of Malawi can take to reduce the number of patients that present late for treatment. CURE can be more diligent in advertising mobile clinics and making sure that medical providers in the Northern and Central regions are aware of CURE's services. Furthermore, CURE could

provide transportation vouchers for patients from the Northern and Central district if transportation is an issue. To help caregivers with multiple children, CURE could consider offering day-care services.

The Malawian government is already making headway to address at-home births in order tackle Millennium Development Goal 4 (reducing under-5 mortality rates by two-thirds).[52] However, there is still work to be done.[53] A study from 2013 through the University of Oslo, Normandy, revealed that further actions needed to be taken to address local beliefs and traditions concerning labor and delivery, as well as reducing barriers to access.[53] The Malawian government could assist caregivers financially with conditional cash transfers or travel vouchers. Improving infrastructure, especially roads, could also help patients get easier access to transportation and treatment.

The size of our study is the primary limitation. Additionally, lack of a cohesive definition of late presentation across conditions weakens the ability to generalize the findings of the study. More time and funding to collect additional patients would improve the overall quality, reliability, and usefulness of the results. Ideally, a follow-up study would exclude all conditions besides clubfoot. Further analysis of the existing data should be performed using ANOVA.

This study provides updated information on barriers to access for children with deformities in Malawi. Although there are numerous existing studies that outline barriers to care for children with clubfoot in LMICs, this study is the first of its kind to address all congenital orthopedic conditions.

Future studies should be conducted to determine common reasons for patients to drop-out of care. Some patients seek treatment on time but do not graduate from care. A larger clubfoot study done through all CURE locations at their out-patient, in-patient and mobile clinics with a

revised questionnaire would be valuable to determining these critical barriers to timely access. By reducing the limitation of including other disorders and addressing the problematic questions within this study design, CURE may be able to better identify the reasons why children with clubfoot are not initiating care within the appropriate time frame.

Appendix A: Congenital orthopedic conditions that make a patient eligible for inclusion

This list was created with the help of the administrative team, the surgical support staff, and charts at Beit CURE International.

- Radial Ulnar Stenosis
- Dislocated Radial Head
- Radial Club Hand
- Ulnar Club Hand
- Cleft Hand
- Syndactyly
- Thumb Hyperplasia
- Duplication of Digit/Polydactyly
- Constriction Band
- Other Cong. Upper Limb
- Other Cong. Hand
- Developmental Dysplasia of the Hip
- Other Cong. Lower Limb
- Cleft Lip, Unilateral
- Cleft Palate
- General Congenital Syndromes
- Downs
- Neurofibromatosis
- Arthrogryposis
- Proximal Femoral Focal Deficiency
- Cong. Dislocation of the Knee
- Pseudarthrosis of the Tibia
- Tibia, Deficiency
- Fibula, Deficiency
- Clubfoot, Idiopathic, Bilateral
- Clubfoot, Idiopathic, Unilateral
- Congenital Scoliosis
- Clubfoot, Neuropathic, Bilateral
- Clubfoot, Neuropathic, Unilateral
- Vertical Talus
- Metatarsus primus
- Varus
- Macrodactyly
- Constriction Band
- Other Cong. Foot
- Cleft Lip
- Kyphosis
- Aperts
- Larsens
- Osteogenesis Imperfecta

Appendix B: Informed Consent Form

Factors that Influence Late Presentation for Care of Patients with Congenital Orthopedic Conditions in Malawi

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Local Ethics Committee: Billy Nyambalo +265111789400

Introduction:

The purpose of this study is to see what things could affect patients coming in for treatment when the child is older. This will require us to ask some questions that might relate to your life circumstances and child's care. The survey will take approximately five minutes. Our research will require this survey and looking at your child's chart. We want to speak with as many families of patients as possible so that we can be more successful in helping the hospital improve their care. You do not have to agree to answer our questions. You are allowed to say no, and your child will still be seen by the doctor and be given the exact same care. You can ask as many questions as you would like to, and we will take the time to answer them. You will be asked a series of questions by the interviewer. If there are any questions that you do not wish to answer, you may say no, and we will move on to the next question. The information that you share with us will be kept confidential. At the end of the study, we will be sharing our findings with the hospital and the community so that care can be improved. Again, no information will be directly linked back to your child. We will use a patient identification number that will be associated with your child's data if used in any publications. Their privacy is important to us. There are no risks to you or to your child to participate in this study. The general population of Malawi can benefit from our findings. This research has been approved by the IRB committees at Otterbein University and the National Health Sciences Research Committee of Malawi.

Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate in an survey concerning my child as a participant in this study.

Print Name of Parent or Guardian _____
Signature of Parent of Guardian_____
Date _____
Day/month/year

If illiterate: I have witnessed the accurate reading of the consent form to the parent of the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ AND Thumb print of participant

Signature of witness _____

Date _____
Day/month/year

Participants name: _____

Appendix C: Caregiver Survey

Patient Information

1. Name
2. Gender
3. Age
4. Birthdate
5. Location of the Interview

Parents/Guardian Information

1. How did you learn about CURE International Hospital? (if applicable)
2. Parent or Guardian Name
3. Relationship to child
4. Age
5. Phone number
6. Address
7. District
8. Occupation
9. Spouse Occupation
10. Highest education level completed
11. At what age did you quit school (if attended)
12. Literacy
13. Languages spoken
14. Monthly
15. Mode of transport
16. Transportation Cost (per person)
17. Affordability of transport
18. Distance of residence to main road
19. Religion
20. Religious influence on seeking treatment
21. Proximity of traditional healers
22. Belief in traditional healers
23. Number of children
24. Number of dependents
25. Support system
26. Medical conditions
27. Caregiver health rating

Patients Medical History

1. Diagnosis
2. First appointment at Beit CURE
3. Age at diagnosis
4. Previous knowledge of the condition
5. If yes, how
6. Trust in Malawian doctors
7. Birthplace
8. Diagnosed at birth
9. Previous treatment for this condition
10. If yes, where and when
11. Was the condition corrected
12. If no, why was treatment ceased

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