BARRIERS TO SEEKING AND COMPLETING CLUBFOOT TREATMENT WITH THE PONSETI METHOD: A META-ETHNOGRAPHY

by

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Approved by:
Terminology

*Focus group* Multiple study participants are interviewed together, allowing study-participants to raise ideas, concepts, and concerns on the topic at hand. Focus group interviews are a dynamic process based on the interaction of the study participants.¹

*In-depth interview* These interviews are focused on a particular topic and assume that study participants have unique and important knowledge about this topic. Interviews are conducted using active asking and listening and the study participant directs the interview.¹

*Interview* Most publications did not provide details on the method of data collection and often ambiguously referenced “interviews.” While not ideal to include studies in which the methods are not fully disclosed, I recognize that due to word-limits in publication, poor reporting of methods does not necessarily indicate poorly conducted research.

*Semi-structured interview* Utilizes a set of questions while allowing some freedom to veer from the topic at hand in order to discuss what is important to them. The researcher
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will attempt to get an answer to each set question, but will not interrupt a natural conversation in which the study participant goes in a different direction.¹

*Structured interview* Each participant is asked the same series of questions. Should a study participant stray from the topic of interest, they are redirected to the interview questions.¹

*Study participant* In this meta-ethnography, “study participant” refers to the interviewees or respondents. The researchers involved in the original data collection and I myself are also “study participants” so this choice is not perfect, but appears to be the most appropriate for this work which crosses multiple forms of qualitative methods.²
Barriers to seeking and completing clubfoot treatment with the Ponseti method: a meta-ethnography

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Abstract

Background: Despite the wide-spread of a low-tech, non-surgical method of treatment for clubfoot, uptake and completion of clubfoot treatment remains suboptimal. While qualitative research has been conducted to investigate the factors influencing the uptake and completion of clubfoot treatment, systematic reviews, which can provide further understanding, are lacking.

Methods: I utilized Noblit and Hare’s methods of meta-ethnography to synthesize published qualitative research to understand the barriers to uptake and completion of clubfoot treatment. I identified 105 studies of which 19 underwent a full-text review, resulting in the synthesis of 8 papers from 8 countries. I utilized Malpass’s notion of first-, second-, and third-order constructs to organize the synthesis.

Results: The barriers to uptake of treatment are gender and power dynamics, stigma regarding clubfoot, logistics of treatment, knowledge of treatment both for caregivers and health care workers, the organization and delivery of health services, and the financial costs associated with treatment. The barriers to treatment compliance are similar: gender and power dynamics, society and stigma regarding clubfoot, logistics of treatment, organization and delivery of health services, financial costs of treatment (both direct and indirect), confusion regarding treatment and the burden on the treatment, and the duration of the treatment.

Conclusion: Despite the differences across the countries where the studies were conducted, my findings suggest comparable factors across cultures that influence the uptake and completion of clubfoot treatment. The duration of the treatment, 4-5 years, appears to exacerbate the other barriers to treatment compliance. Targeted interventions are necessary to keep families compliant in the intervention, as well as to uptake treatment.

Background and Introduction

Clubfoot is the most common musculoskeletal birth defect, affecting 1 in every 750 live births. Clubfoot causes the feet of the affected individual to point downward
and inward. Left untreated, clubfoot causes a permanent physical disability, preventing the individual from walking normally and limiting his or her mobility. Decreased ambulation can lead to the inability to perform daily tasks, such as going to school, leading to increased dependency and a negative economic impact on the family. Furthermore, deformity caused by neglected clubfoot can lead to limited social integration and stigma for both the individual and the family.  

The gold standard of clubfoot treatment is the Ponseti method, which consists of 6-8 weeks of serial castings followed by the use of a foot abduction brace (FAB) for approximately 4 years. The goal of the treatment is to correct the deformity so that the patient has a functional, painless, plantigrade foot with full mobility without the need for orthotics. The 6-8 weeks of serial casting corrects the clubfoot deformity while the use of the FAB after casting prevents the deformity from reoccurring and is required for successful treatment. Non-completion of the casting phase will result in an uncorrected foot and the noncompliance of FAB use increases the risk of relapse 17-fold. Due to the duration of the intervention, the cooperation of the family is imperative for the correction of clubfoot and prevention of disability.

In an effort to prevent disability caused by clubfoot, many countries, often with non-governmental organization (NGO) support, have established clubfoot treatment programs. These programs use specialized clubfoot clinics to treat children in an outpatient setting. Effective treatment should start as soon after birth as possible.
Often in developing countries, caregivers do not present their children for treatment until after 2 years of age and many caregivers, regardless of the child's age, miss appointments, thus causing set-backs in the treatment and wasted resources for both the family and the hospital.\textsuperscript{10}

Qualitative research is holistic, contextual, person-centered, and inductive. It generally rejects data that indicates ordinal values and favors naturalistic observation and interviewing.\textsuperscript{2} In the past 10 years, qualitative research regarding clubfoot treatment has become more frequent, highlighting the complex social dynamics influencing treatment-seeking behavior and completion of clubfoot treatment. Despite the volume of this evidence and the contribution it can make towards a better understanding of factors influencing treatment-seeking behavior and completion of clubfoot treatment, systematic reviews are lacking.

**Methods**

I utilized the meta-ethnographic approach first presented by Noblit and Hare to synthesize the published findings of qualitative research on treatment-seeking behavior and treatment compliance for clubfoot treatment.\textsuperscript{11} Noblit and Hare's method of meta-ethnography is a popular method used to synthesize and further interpret findings across multiple qualitative studies in order to produce new interpretations of the data. Induction and interpretation are conducted across the studies, producing a synthesis in
which they have been translated into one another, and where the focus is on the development of new theories and links between the studies rather than a summary of information. 11,12

Search strategy and identification of papers (Figure 1)

Medline, CINAHL, EMBASE, Web of Science, and Global Health search engines were used to search for published qualitative research findings. The first search was done on January 26, 2015, and repeated on February 9, 2015. Searches were then repeated weekly until February 28, 2015, in order to ensure no recently published studies were omitted. The key search terms were “clubfoot,” “compliance OR behavior OR behaviour,” and “treatment” in order to cast a wide net that would identify papers written about treatment seeking, uptake, and compliance. The search yielded 351 results of which 246 were duplicated. The 105 unique publications underwent title and abstract reviews and 86 were excluded due to the wrong study design or topic. When the 19 remaining publications were subjected to full-text review, 5 were excluded for the wrong study design, 5 were excluded for not using caregivers as study participants or not representing their findings as caregivers as study participants, and 1 was excluded for being of the wrong topic. I also reviewed the works cited of the selected papers to ensure that no published findings were excluded. Papers that met the inclusion criteria were subject to full-text review, resulting in 8 papers reviewed.

Quality assessment and inclusion criteria
A uniform method of determining the quality of qualitative research does not exist, leading to the contestation of quality appraisal applied to qualitative research.\textsuperscript{12-14} Quality appraisal proved to be a difficult process during this meta-ethnography. Most publications did not report on the qualitative approach used in the study, the approach to the analysis, or provide details on the method of data collection. However, I recognize that due to word-limits in publication, poor reporting of qualitative methodology does not necessarily indicate poorly conducted research. Instead, a checklist was created to assess the appropriateness for inclusion. My inclusion criteria, which were developed iteratively throughout the research process, comprised: peer-reviewed publications only; published in English; focused on barriers; used caregivers as study participants; caregivers voices were distinguishable from other study participants; utilized qualitative methods; and reported qualitative findings - including mixed-methods papers. Eight publications met the inclusion criteria (Table 1).

Determining whether or not a paper had utilized qualitative methods was a point of extensive consideration during the review process. Multiple studies were labeled as qualitative research although it was determined during the abstract review that they employed questionnaires as the sole source of data collection. My original policy was that of inclusion in order to avoid omitting publications of potential value to developing new interpretations. These pre-coded, standardized questionnaires removed the researcher's ability to act as an instrument of observation and prevented
the elaboration of any first-order constructs to be identified by the study-participant or to be pursued by the researcher. Consequently, these papers were excluded for the wrong study design.

Analysis and synthesis process

Deviating slightly from Noblit and Hare’s methods, I developed a grid and entered the themes from each paper to determine how the themes were related to one another (Table 2). I utilized Malpass’s notion of first-, second- and third-order constructs to generate the concepts. First-order constructs are representative of the views of the study participants, while second-order constructs are the author’s interpretations of the study participants’ views. I identified and compared the second order constructs in order to develop third order constructs; our own interpretations of the second order constructs.

I used a process of translation of constructs and themes across the different studies. I compared the themes of the first paper with those of the second paper. I then synthesized the themes of the two, which I compared with the third paper and repeated the process across the 11 articles. The process of translating the papers was iterative in order to ensure that the third constructs accurately reflected the second level constructs from the original publications. The process of developing third order constructs resulted in new themes, as well allowing for reinterpretation of the originals studies, leading to a deeper understanding. Finally, the third order constructs were
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used to create a conceptual model used to show the relationships between barriers to treatment seeking behavior and treatment compliance.

Results

Eight peer-reviewed qualitative papers published between 2007 and 2015 from 8 countries were included in the synthesis. Of the 8 countries represented in the selected papers, 4 are low-income countries, 2 are lower-middle-income, 1 is an upper-middle income, and 1 is a high-income country, as defined by the World Bank. Seventeen second-order constructs were generated and summarized through 9 third-order constructs (Table 2).

Discussion

Awareness

Awareness about the condition and its available treatment among both caregivers and health care providers affected caregivers' decisions about seeking treatment. Health care workers may not identify the deformity. If the deformity is detected, health care providers may provide incorrect information in the form of an incorrect diagnosis or incorrect treatment recommendations such as not seeking treatment and advise that the deformity would correct on its own or surgery. When incorrect treatment referrals were followed, various stressors and barriers were compounded due to suboptimal results and expense. Caregivers' own ignorance of the condition or its treatment, for having never seen the condition or heard of its being
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treated, delayed seeking care until a diagnosis and treatment recommendation was
made.

"I was told that with time, the feet would get well."
Caregiver of a child with clubfoot in Kenya

**Gender and power structure**

Although there are certainly fathers of children with clubfoot and other family
members that support clubfoot treatment, the studies revealed that mothers were
primarily responsible for their children’s care and treatment. Resistance to
treatment from family members, ranging from mild resistance to stalwart opposition,
was reported as primary reasons for late presentation or defaulting from treatment.

Within marital relationships, gender inequality affected women’s uptake and
completion of clubfoot treatment for their child.

"The father does not give importance to her treatment. Normally he is not concerned with the children. I took her to
the camp and would like to take her to the doctor as they
instructed, but it is the father’s attitude that prevents it."
Mother of child with clubfoot in Bangladesh

A study in Uganda found that while women are in charge of seeking health care
for their children, men are in charge of money. Studies in Uganda, Malawi, and Nigeria
show that women must ask their husbands for money and are often deterred from
doing so, for instance, in cases of polygamy where the child’s condition would be a
financial burden on the husband.
Respect for older generations also prevents seeking treatment and completing treatment. For example, respect for the older generation in Vietnam prevented a family from completing treatment because the child’s grandparents were opposed to one part of the intervention.

**Social relationships**

Fear of stigma or social exclusion was also a theme for low uptake of treatment in many different settings. In Kenya, Nigeria, and Vietnam, the mother was blamed for the child being born with clubfoot, in some instances even being accused of being cursed or a witch. In other instances, the deformity is seen as a curse or punishment from God. Shame and fear of ridicule cause some women to hide the child and their condition rather than seek treatment. Furthermore, a study in Nigeria identified community pressure to accept God’s will and not correct the condition as a deterrent to seeking treatment.

> “When he saw that the child had clubfoot, he said that the child had been bewitched.” Caregiver of child with clubfoot in Kenya

**Logistics of treatment**

The second most frequently identified barrier to seeking and sustaining treatment centered around the logistics of attending the clinic. The predominant barrier that emerged was finding and financing transportation to the treatment site, particularly in rural areas.
The mode of transport, cost of journey, and distance were dominant obstacles identified. Transportation also fits into the more general construct of coordinating treatment, including taking time away from work, finding a caregiver for other children, balancing other responsibilities, and spending many hours in the hospital.

Direct and indirect costs

The selected papers represent countries across the spectrum of development, and the barrier of direct and/or indirect costs emerged across this spectrum, particularly with respect to the fragility of livelihood in the lower-income countries. Direct costs, such as clinic fees, and indirect costs, such as transportation costs and lost wages, compete with other costs of living.

"The fees were managed under hardship. I had to sell a few goats and the money for school fees had to be used on this case." Parent of child with clubfoot in Uganda

In addition to serving as an independent barrier, it can cause problems within the family, such as emerged in the study from Uganda. The disagreement over treatment between the mother and father can be worsened by the need to reallocate funds to treatment. The costs associated with treatment, direct and indirect, must be examined as a construct that exacerbates the logistical and gendered relationship constructs that have also emerged.
“[I was] exhausting all options and ready to mortgage the house to get treatment at UIHC (University of Iowa Health Care).” Parent of a child with clubfoot in United States of America

**Burdensome treatment process and confusion regarding treatment process**

The construct of burdensome treatment was revealed through exclusive use data representing study participants interviews with caregivers and excluding those where health care providers were the study participants. What is often labeled as general non-compliance by health care providers emerges as confusion regarding treatment, the perception of the child’s discomfort, and the caregiver’s discomfort during the intervention from the perspective of the caregiver. Caregivers identify worrying about the child’s comfort due to crying, perceived discomfort caused by casts or FABs, and potential blisters and rashes, as reasons for non-adherence to treatment protocols.

Furthermore, their own discomfort caused by difficulty carrying, bathing, and adjusting to a child wearing casts or a FAB also causes non-compliance, both of which can manifest in actions such as removing the casts early or removing the FAB and using it for less time than prescribed.

“During the time when the casts are on, it is hard to carry the child. You imagine she will break. There is difficulty cleaning/bathing the child. She cries a lot, so I felt disgusted and nearly gave up treatment; but with the support of my husband, we hang on to treatment . . .” Mother of a child with clubfoot in Uganda

**Organization of health services**
As previously examined, the unclear or incorrect referral pathways cause delay in the uptake of treatment.\textsuperscript{3,4,18,19} Additional barriers include complicated payment systems. The responsiveness and governance of the system, and thus the clubfoot clinic, also emerged as a barrier. Caregivers' perceptions of low-quality care caused by crowded clinics, long wait times, and perceived poor handling by health care providers, as well as informal payments required in order to access care, serve as barriers to the completion of treatment.\textsuperscript{10,18}

"In Kenyatta here, we were told to go to the orthopedic department, occupational therapy, physiotherapy; it was like they did not know where we were supposed to go."
Caregiver of child with clubfoot in Kenya\textsuperscript{10}

**Length of treatment process**

The most recurrent theme across the studies and that permeated the majority of first- and second-order constructs was that of the length of the treatment.\textsuperscript{3,10,17-21} The barrier, a nearly 5 year treatment, compounds other barriers, specifically the burden of the treatment process, direct and indirect costs, and logistics, which are all far more challenging for needing to be maintained over the course of 4-5 years.

**Conclusion**

Treatment seeking behavior and treatment compliance for clubfoot correction is influenced by an array of inter-related factors. This synthesis has demonstrated the similarities in barriers to uptake and completion of clubfoot treatment despite the
heterogeneous samples. The burdensome treatment discourages treatment compliance and due to confusion or misunderstanding of the treatment process, caregivers may even be unaware of their noncompliance. Caregivers’ incomplete knowledge, communities, and health care providers may prevent caregivers from ever seeking treatment or the uptake of the correct treatment. The logistics, including travel, of accessing treatments, its direct and associated costs, and the organization of health services in each location can be barriers to both treatment-seeking behavior as well as compliance. Female caregivers lack negotiating power, either with a husband or older relatives, and face stigma associated with the defect and its treatment, forcing them to weigh the societal costs and benefits of seeking and completing treatment. Finally, the length of the treatment process appears to compound the majority of these other barriers, causing emotional and financial exhaustion on the caregivers of children born with clubfoot. Although the Ponseti method’s gain in popularity and renown as the gold-standard of clubfoot treatment has increased access to treatment, sustainable and context-specific interventions aimed at increasing uptake and compliance are still needed.

**Strengths and limitations**

The strengths of this meta-ethnography lie in the extensive search into the literature. The inclusion of papers using different methodologies provides in-depth understanding of the barriers to treatment-seeking behavior and treatment compliance.
By using inclusive policy to avoid omitting publications of potential value to developing new interpretations, I was able to draw on the richness of a variety of papers and methods. This synthesis may be improved by using a team to conduct the analysis in order to compare the resulting analyses. An inherent weakness of this synthesis is the possibility of having missed publications, which I sought to attenuate by examining the references of the selected papers.

Works Cited


Figure 1

Aim of synthesis

Database search N=351

Title and abstract review N= 105

Excluded duplicates N=246

Excluded wrong design, topic N=86

Excluded wrong design or wrong topic N= 6

Full text review N= 19

Excluded papers that did not interview caregivers N= 5

Selected papers N= 8
<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Sample</th>
<th>Study Type</th>
<th>Methods</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedford, 2011</td>
<td>Malawi</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>In-depth interview</td>
<td>Identify drivers and barriers that influence the behaviors of caregivers seeking clubfoot treatment seeking</td>
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<tr>
<td>Akintayo, 2012</td>
<td>Nigeria</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Identify challenges to diffusion of Ponseti method of clubfoot treatment in Nigeria</td>
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<td>McElroy, 2007</td>
<td>Uganda</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Focus groups, semi-structured interviews</td>
<td>Identify barriers to adherence to clubfoot treatment in Uganda</td>
</tr>
<tr>
<td>Bedford, 2013</td>
<td>Bangladesh</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Identify reasons for non-uptake of referral for children identified with a disability (clubfoot, cerebral palsy, blindness, deafness, cleft lip/palate)</td>
</tr>
<tr>
<td>Lu, 2010</td>
<td>China</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Semi-structured interviews, focus groups, observation</td>
<td>Identify barriers to clubfoot treatment in China</td>
</tr>
<tr>
<td>Wu, 2012</td>
<td>Vietnam</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Interviews</td>
<td>Identify barriers facing family members of children in clubfoot treatment in Vietnam</td>
</tr>
<tr>
<td>Authors</td>
<td>Country</td>
<td>Study Details</td>
<td>Methodology</td>
<td>Approach</td>
<td>Research Question</td>
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<tr>
<td>Paulsen-Miller, 2011</td>
<td>USA</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>Structured interviews</td>
<td>Identify the educational needs of parents whose children are undergoing clubfoot treatment and how nurses may better address those needs</td>
</tr>
<tr>
<td>Kingau, 2015</td>
<td>Kenya</td>
<td>Caregivers to children undergoing clubfoot treatment</td>
<td>Qualitative</td>
<td>In-depth interview</td>
<td>Explore barriers to clubfoot treatment experienced in Kenya</td>
</tr>
<tr>
<td>3rd order construct</td>
<td>2nd order construct</td>
<td>Summary definition (translation) of 1st and 2nd order constructs</td>
<td>Source Papers</td>
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<tr>
<td>Lack of knowledge</td>
<td>Caregivers’ lack of knowledge</td>
<td>Caregivers’ ignorance of condition or treatment caused delay in treatment seeking</td>
<td>Bedford 2013, Lu 2010, Kingau 2015, Bedford 2013</td>
<td></td>
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<tr>
<td></td>
<td>Missed diagnosis</td>
<td>Treatment seeking is inhibited when the condition goes unnoticed or undiagnosed by healthcare providers</td>
<td>Lu 2010, Kingau 2015, Bedford 2013, Wu 2012</td>
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<td></td>
<td>Incorrect treatment recommendation</td>
<td>Different or incorrect treatments are sought when recommended by healthcare professionals, causing a delay in the uptake of appropriate treatment and causes frustration and exhaustion in caregivers</td>
<td>Lu 2010, Kingau 2015, Wu 2012</td>
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<tr>
<td>Gender and power structure</td>
<td>Relationship with older generation</td>
<td>Respect for older generations is often a barrier for seeking treatment if they do not agree or think the condition should not be treated</td>
<td>Bedford 2011, Bedford 2013, McElroy 2007, Wu 2012</td>
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<td></td>
<td>Lack of paternal support</td>
<td>Female lack of negotiating power in marital relationship, including lack of decision making power to seek or continue treatment as well as access to funds for treatment. Mothers are responsible for the treatment, but men control the finances.</td>
<td>Bedford 2011, Bedford 2013, Akintayo 2012, McElroy 2007</td>
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<tr>
<td>Logistics of treatment</td>
<td>Distance</td>
<td>Far distances to treatment sites are barriers to caregivers from both a logistical and financial perspective as transport is both more difficult to organize and more expensive the greater that distance.</td>
<td>Lu 2010, Paulsen-Miller 2011, Kingau 2015, Bedford 2013, McElroy 2007, Wu 2012</td>
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<td></td>
<td>Coordinating treatment</td>
<td>The difficulty of coordinating treatment, going to many appointments, spending many hours in the hospital, taking time away from work, finding care for other children, and balancing other responsibilities is a barrier to treatment adherence.</td>
<td>Lu 2010, Paulsen-Miller 2011, Kingau 2015, Bedford 2013, McElroy 2007, Wu 2012</td>
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<td></td>
<td>Parents' difficulty</td>
<td>Caregivers are burdened by difficulty caring for child during treatment process, such as carry, bathing, and comforting child</td>
<td>Lu 2010, McElroy 2007</td>
<td></td>
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<tr>
<td>Confusion regarding treatment</td>
<td>Confusion regarding treatment</td>
<td>Caregivers' misunderstanding of treatment phases and requirements, leading to non-adherence. This can be attributed to caregivers low educational attainment as well as low capacity of the health care provider to explain the treatment due to high patient volume.</td>
<td>Lu 2010, Paulsen-Miller 2011, Akintayo 2012</td>
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<tr>
<td>Social relationships</td>
<td>Culture/Religion</td>
<td>Religious or cultural norms indicate that the child should not be treated for the condition</td>
<td>Kingau 2015, Akintayo 2012, Wu 2012</td>
<td></td>
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<td></td>
<td>Stigma</td>
<td>Stigmatization or shame cause the family to hide the child rather than seek treatment or to cease treatment</td>
<td>Kingau 2015</td>
<td></td>
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<tr>
<td>Organization and delivery of health services</td>
<td>Responsiveness of clinic</td>
<td>Caregivers must spend many hours in the hospital waiting for treatment, may have to pay bribes, and often receive what is perceived to be substandard care from health care workers.</td>
<td>McElroy 2007, Wu 2012</td>
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<td></td>
<td>Difficulty navigating health care system</td>
<td>The difficulty of navigating the health care system is a barrier to both treatment seeking and treatment adherence. Caregivers must navigate multiple referrals to various health care centers until arriving at the correct treatment and navigate complicated payment systems for the duration of treatment.</td>
<td>Bedford 2011, Paulsen-Miller 2011, McElroy 2007, Wu 2012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of treatment process</td>
<td>Long treatment process</td>
<td>The length of the treatment process is a barrier to treatment completion. The long treatment compounds the other barriers as they must be maintained over time.</td>
<td>Lu 2010, Paulsen-Miller 2011, Kingau 2015, Bedford 2013, Akintayo 2012, McElroy 2007, Wu 2012</td>
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