The organisation and delivery of clubfoot treatment services in Malawi: *an ethnographic study*



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Abstract

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Background

Clubfoot is a congenital condition in which one or both feet are twisted inwards and if left untreated or 'neglected', can have a profound impact on the wellbeing of children and their families. Clubfoot can be treated through staged manipulation of the limb and treatment is delivered by Beit CURE Hospital in Malawi which coordinates 29 outreach clinics. However, implementing these services is complex; a high proportion do not present; and adherence to treatment is low. This study had three aims: 1) identify factors that impact on the implementation of services and develop a theoretical framework to inform findings; 2) understand the impact of accessing services on carers of children with clubfoot; and 3) explore the experiences of those who had not fully accessed treatment.

Methods

Ethnographic data collection comprised three elements. Element 1: Observation sessions were conducted at three clinics (totalling 90 hours) and interviews conducted with staff at an additional nine sites and members of the CURE management team. Key informants helped place findings within the wider health context (n = 58). Element 2: Fieldwork was conducted at three sites and involved single, dyad or triad interviews and focus groups with those currently accessing

treatment, those who had been discharged and clubfoot counsellors (n = 57). Element 3: In-depth case studies were conducted with those that had not fully accessed treatment (n = 4).

Results

Factors impacting on service implementation were interpreted using an implementation science theory known as extended Normalization Process Theory. Factors identified included cooperation, commitment to delivery, workability and strategies to facilitate delivery over time. An additional construct identified concerned work done to facilitate patient access. How families and the community responded on finding out the child's feet were different varied. Whilst some mothers received love and support from others, it could also be a source of conflict and division. Families were overwhelmingly satisfied with treatment although challenges were identified. Those that had been discharged described joy and were happy to be relieved of the financial burden of treatment. Factors that influenced treatment-seeking for those who had not fully accessed treatment included the anticipated outcomes of living with clubfoot, availability of social support networks, healthcare experiences and a lack of referral pathways for treatment. Challenges took place in a web of competing concerns such as poverty.

Conclusions

The study provides insights to help organisations in Malawi deliver more effective patient care. Future research should explore processes of identification and referral of children with neglected clubfoot.

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Abbreviations

WHO	World Health Organization
NGOs	Non-governmental organisations
TAs	Traditional Authorities
CHAM	Christian Health Association of Malawi
MNCP	The Malawi National Clubfoot Programme
UN	United Nations
DFID	Department for International Development
MDGs	Millennium Development Goals
SDGs	Sustainable Development Goals
PARIHS	Promoting Action on Research Implementation in Health Services
ACT	Alberta Context Tool
CFIR	Consolidated Framework for Implementation Research
COM-B	Capability, Opportunity, Motivation- Behaviour system
NPT	Normalization Process Theory
eNPT	Extended Normalization Process Theory
COACH	Context Assessment for Community Health
CASP	Critical Analysis Skills Programme
JBI-QARI	Joanna Briggs Institute Critical Appraisal tools
COREQ	Consolidated Criteria for Reporting Qualitative Research
SRQR	Standards for Reporting Qualitative Research
MMAT	Mixed Methods Appraisal Tool
CERQual	Confidence in the Evidence from Reviews of Qualitative Research

Abbreviations continued

CONQual	Confidence in the Output of Qualitative Research Synthesis
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
eMERGe	Meta-Ethnography Reporting Guidelines
NCST	National Centre for Science and Technology

Overview of the thesis

This thesis concerns the organisation and delivery of clubfoot treatment services in Malawi, including the implementation of treatment services and experiences of accessing treatment.

Chapter 1 is the first of three background chapters and provides an introduction to the clubfoot condition and the study context. It outlines the incidence and characteristics of the condition, the Ponseti method of treatment and its global use. An overview of study context includes an introduction to Malawi, delivery of healthcare services, experiences of children and their families of disability and the current state of clubfoot treatment services in the country. Finally, it outlines the principal aims of this study.

Chapter 2 outlines the literature, theories and concepts that have been used to inform this study, including relevant global health literature, theories from the field of implementation science and treatment-seeking behaviour. Doing so helps to locate the study within the wider global and research context.

Chapter 3 presents a systematic examination of existing literature on clubfoot in low and middle-income countries. It does this by providing an overview of methods to review qualitative and mixed methods research. A narrative synthesis of literature is then presented. This is followed by a meta-synthesis to synthesise findings from qualitative research to explore factors that impact on patient access and adherence to treatment, using a Social Ecological Model to structure findings. The chapter helps

to further locate the study within existing research and provide rationale for this thesis.

Chapter 4 is the methods chapter. The chapter begins by presenting an overview of ethnography and the use of abductive approaches in qualitative research studies, both of which informed this work. The three elements of fieldwork used to address the aims and objectives of this study are then discussed, along with the ethical procedures that were used to ensure all participants provided informed consent and that data was stored securely throughout the study.

Chapter 5 is the first of three results chapters. The chapter presents findings from element one of the ethnographic study to explore factors that impact on the implementation of clubfoot treatment services and develop a theoretical framework to help inform findings. It begins by detailing the characteristics of the sample and then presents findings. Findings are presented in two parts. Part 1 presents findings on the implementation of clubfoot treatment services. Part 2 then describes findings in relation to the implementation of counselling services.

Chapter 6 presents findings from element two of the study that explores experiences of guardians and carers of accessing and utilising services in infancy. It begins by detailing the characteristics of participants and then presents findings. Findings consider experiences on finding out the child's feet were different, experiences of accessing services, living with a child accessing treatment and of being formally discharged.

Chapter 7 presents findings from element three of the ethnographic study, exploring the experiences of children and their guardians that had either discontinued or not fully accessed treatment. Individual case studies are presented as 'stories' in the sequence of data collection, with the role of researcher integrated into descriptions. Accounts of overarching themes are then discussed, with an emphasis on factors that influenced subsequent treatment-seeking decisions.

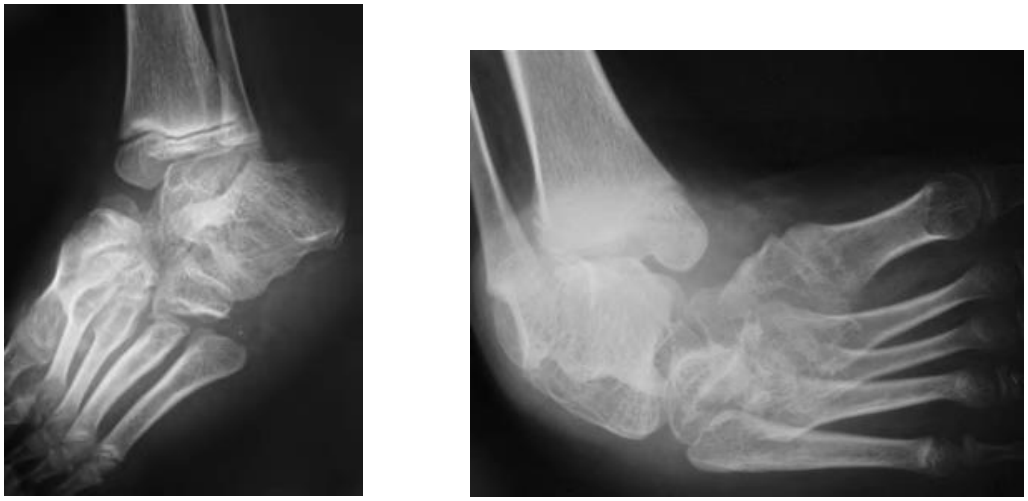
Chapter 8 is the final chapter and presents a summary of key findings, a discussion of how these relate to current literature and the strengths and weaknesses of the methods used. It then presents a reflection of my experiences of conducting fieldwork in Malawi. Finally, the chapter concludes by considering the implications of the study on service delivery, along with a series of recommendations and future research.

Chapter 1 Background

1.1 Clubfoot condition

Around 150,000 – 200,000 children are thought to be born with idiopathic clubfoot annually worldwide and of those with clubfoot, 80% live in low and middle-income counties(1). Clubfoot is a congenital condition in which one or both feet are twisted inwards. Clubfoot may be unilateral (affecting one leg), or bilateral (affecting both)(2). Around 50% of clubfoot cases are bilateral. There is a limited understanding of the causes of this condition although there is likely to be a genetic component since clubfoot can run in families and is twice as common in boys(3). Idiopathic clubfoot differs from symptomatic or non-idiopathic clubfoot which is associated with other congenital conditions such as spina bifida(4). Although it is not initially painful, if left untreated or 'neglected', clubfoot can make it very painful to walk, significantly impair function and limit participation in everyday life(5).

Figure 1: Radiograph images of idiopathic clubfoot in a child



Radiograph images courtesy of Beit CURE International Hospital, Malawi Clubfoot

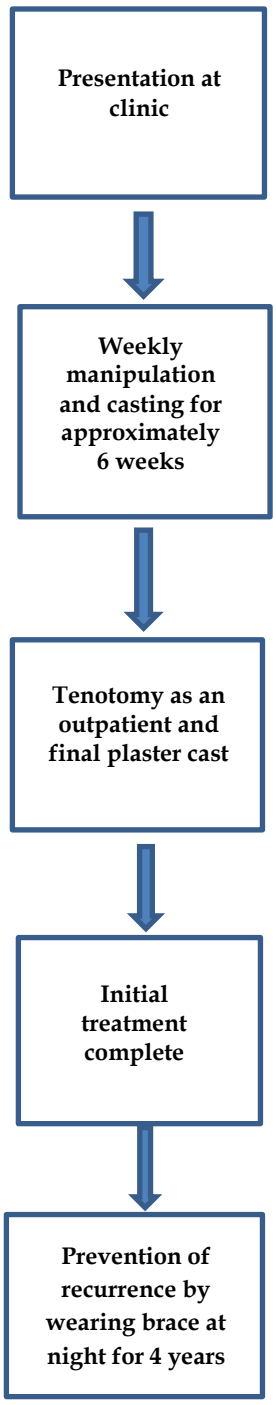
1.2 Clubfoot treatment

Clubfoot can either be treated surgically or conservatively, by stretching and manipulating the limbs. Prior to 2000 surgery was the most commonly used method of correction. However, this had high rates of relapse and often left residual stiffness. Furthermore, it was a relatively high cost intervention since it required specialist surgical skills and access to resources such as operating theatres(6). Conservative techniques for treatment include the French functional method, the Kite and Ponseti techniques(7). Of these methods the Ponseti technique has demonstrated the best functional outcomes including better alignment after treatment and a smaller incidence of recurrence(7). Success rates for initial correction using the method are over 90%(8). In addition, as a low-cost intervention that can be delivered by a range of healthcare professionals, it is well suited to resource-poor settings(9-11). The Ponseti method has been endorsed by a range of organisations including the World Health Organisation (WHO) as the most effective method of treatment for clubfoot(12).

The Ponseti method was first developed in 1948 by Ignacio V. Ponseti(2) and can broadly be divided into two phases: correction and maintenance. Treatment involves gentle manipulation of the limbs on a weekly basis that are held in place using plaster casts. Although cases differ, correction is generally achieved in 5-7 casts. A tenotomy may then be performed, involving a minor operation under local anaesthetic to release a tight Achilles tendon. Following this procedure, a final cast is applied for two weeks. Correction is then maintained using foot abduction braces which must be worn full time for 2-3 months, and then nightly for 3-4 years. These hold the feet at 70° of external rotation. In the case of unilateral clubfoot, the unaffected limb is

positioned at 40°(2). To achieve maximum correction, treatment should begin at 1-2 weeks of an infant's life(2). For a full description of the treatment see Ponseti I. V, 1996(2). An outline of the main stages of the Ponseti method is presented in Figure 2. An accelerated Ponseti method that involves shorter periods between castings has also been developed(13).

Figure 2: Outline of the main stages of clubfoot treatment using the Ponseti method



A range of scoring systems have been developed to measure the severity of clubfoot at presentation and monitor the efficacy of treatment throughout the care pathway(14). The Pirani scoring system uses six categories to describe the position of the foot: three of these are in the hindfoot and three in the midfoot. Each component of the foot is scored 0, 0.5 or 1 respectively. A score of 0 indicates no abnormality, 0.5 moderate abnormality and 1 severe abnormality. Scores may be aggregated to give an impression of the severity of the clubfoot(15).

1.3 Use of the Ponseti method

The Ponseti technique is currently the most widely used method to treat clubfoot throughout the world(16-18). A systematic review to identify clubfoot treatment services conducted in 2013 found that 113 of 193 United Nations members countries had established clinics that provide Ponseti treatment, including high volumes in low and middle-income countries(19). Global Clubfoot Initiative estimated that in 2013 28% of all expected cases of clubfoot were enrolled in treatment globally(20).

The use of the Ponseti method has grown in the past two decades. Until 1997 the method was largely confined to Iowa where it was developed(19). Since 2000 there has been an exponential rise in the number of publications referring to the Ponseti method, reflecting an increasing interest in the method(19). In addition, it is estimated that the number of children enrolled in treatment programmes increased by 94% between 2009-11 and 53% between 2011-13(20).

The wide dissemination of the Ponseti method over the past two decades has been attributed to a number of factors(19). In 1996 Ponseti published *Congenital clubfoot: fundamentals of treatment*, providing a comprehensive overview of the method(2). Descriptions of the treatment are now freely available online, including the book *Ponseti Management* that has been downloaded over 100,000 times(21), training videos(22) and website seminars and symposiums(23-25). Ponseti training programmes are delivered in low and middle-income settings by a range of organisations(26-30), usually through weekend courses with 'hands on' sessions(28, 30). Conferences are also being organised to help disseminate information(31-33) and the efficacy of the method has been repeatedly demonstrated in academic publications(19). Although most resources for healthcare professionals only refer to treatment protocols, a small number of resources also provide information on how to successfully organise and deliver clinics(34-36).

Parents and guardians of children with clubfoot and the wider public are becoming more aware of treatment options. This has been expedited by growing numbers with access to the internet(19). Resources have been developed to target these groups such as online support groups(37), lists of Ponseti practitioners(38) and accessible information about treatment(39). For those without internet access, organisations raise awareness through community outreach work(40, 41) and promoted events such as World Clubfoot Day(42-44). Patient advocacy is also valued(40).

Non-governmental organisations (NGOs) have been instrumental in raising awareness of the method and facilitating its dissemination, most notably CURE

International, Ponseti International Association and Miracle Feet. CURE International is a Christian organisation that provides surgical care in low and middle-income countries including orthopaedics and neurosurgery. 10 hospitals have been established along with a targeted clubfoot programme delivering training in the Ponseti method(45). Ponseti International Association organises international training trips that equip local healthcare professionals with the skills to train other practitioners to hasten the dissemination of the method(46). Miracle Feet partners with clinics to provide organisational and financial assistance(47). These organisations work in collaboration with a range of NGOs, universities and local governments(48-50). 'Clubfoot champions', respected clinicians working within the field, have also helped popularise the method through advocacy and training(19).

To facilitate the wide-scale spread of the Ponseti method, it has been suggested that a public health approach to Ponseti management is required(51, 52). That is, a nationwide programme that aims to enhance the capacity of local healthcare systems to treat clubfoot using local resources and healthcare personnel(53). This approach has been successfully applied in a number of settings including Uganda(53, 54), Kenya(55), Bangladesh(6) and Malawi(56). Most Ponseti treatment centres are located in public hospitals and funded by local governments(20).

Despite the efficacy of the Ponseti method and its apparent availability, a high proportion of children in low and middle-income countries fail to present and of those that do, many do not continue with it(30, 52, 57). Factors impacting on treatment-seeking include the costs of accessing services(52, 58-62), lack of paternal support(52, 58, 63), distance to treatment centres(52, 58, 60, 62-64) and illness

beliefs(58, 61-63). Previous research has also highlighted a number of barriers to service delivery in these settings including a lack of funding and resources(52, 59, 64) and insufficient training for service providers(30, 59, 65). This literature is explored in detail in chapter 3.

For the purpose of this study, we will be using the World Bank's classification of low, middle and high income countries based on gross national income per capita(66).

1.4 Surgical interventions for neglected and recurrent clubfoot

Clubfoot has a strong tendency to recur. The reason for this relapse is usually due to a failure to follow bracing protocols, although this may happen spontaneously(67). If children are not fully treated in infancy then they may develop neglected clubfoot that is much more difficult to treat. These children or adults can benefit from more invasive surgical procedures(68, 69).

1.5 Malawi

A rich, in-depth understanding of social context is necessary to strengthen an understanding of cultures, organisations and communities from the perspective of its inhabitants[15]. This has been achieved in a number of studies that explore health service delivery in low and middle-income countries(70).

Malawi is a relatively small landlocked country in east Sub-Saharan Africa bordering Zambia, Mozambique and Tanzania(71). Lilongwe is the capital city, the currency is the Malawian kwacha and the official languages are Chichewa and English(72). Its population is very young: 45% are under 15 years and only 5% are aged over 60(73).

This can be attributed to a high fertility rate of 5.4 per woman and a low life expectancy of 59 years(73). Rate of population growth is also high(74).

The country is divided into three regions: Northern, Central and Southern Regions. Within these Regions, the nation is sub-divided into 28 Districts. These Districts are divided into traditional authorities (TAs), overseen by chiefs. Villages are under these TAs. A Group Village Headman controls a number of villages(75). See Figure 3 for a geographical overview. Malawi is inhabited by people from a number of tribes including the Chewa, Yao, Tonga and Sena and these speak a range of languages. These tribes have their own individual cultural practices and as a result there is great cultural diversity(76).

Figure 3: Map of Malawi



Images ©Netmaps

Malawi is currently ranked the poorest country in the world based on GDP per capita(77) and is highly dependent on international aid(78). Around 60% of the population live below the international poverty line of $1.25 per day(79). There are high levels of illiteracy(79) and 84% of the population live in rural areas(80). The majority of the population is dependent on subsistence level farming(81).

The country emerged from British colonial rule in 1964. This was followed by an autocratic one-party state led by Hastings Banda. Since 1993 it has operated a democratic, multi-party system and in 2014 the current president, President Mutharika, was voted into office(71). Corruption is viewed by Malawians as being prevalent across all public sectors, including education, agriculture and healthcare(82). The country is currently emerging from a corruption scandal known as 'Cashgate' in which an estimated £35 million is purported to have been stolen from government funds by officials and associates(83).

There are high levels of religious participation and it is an integral part of everyday life. 83% identified themselves as Christian, 13% Muslim and 1.9% other(84). Traditional beliefs are also prevalent and vary widely between tribes and Regions(85, 86). However, Christianity and traditional religions are not necessarily mutually exclusive and many Malawians draw on elements of both(87).

Both matrilineal and patrilineal marital family arrangements exist. Southern and Central Regions are generally matrilineal whilst the Northern Region is predominantly patrilineal. In matrilineal societies, men traditionally move to their wife's home village on marriage, the maternal uncle is responsible for decision-

making and the children are seen to belong to the maternal line. In patrilineal ones, women move to their husband's home on marriage(88). However, these practices are being altered by urbanisation(89). Polygamy, with or without the consent of the first wife, is also common although attitudes to this vary(90).

The division of labour within the household tends to be gendered and women are predominantly responsible for childcare and domestic work whilst men provide financial support(63). Women are also involved in farming(89). There is a strong commitment to the extended family and households are expected to provide their kin with financial and practical support such as looking after their siblings' children. Within the household, children perform daily chores such as fetching water, collecting firewood and cooking. In addition, in 2015 38% of children between the ages of 5 – 17 years were identified as being used as child labour(91). There is also a commitment to groups outside the family such as the village(92).

Malawi has introduced a range of legislation to uphold the rights of women. This has included the ratification of the Convention on the Elimination of All Forms of Discrimination against Women(93). However, in practice it is men that predominantly exercise power in public and private life (94). Sexual, physical and psychosocial abuse against women is also prevalent(95). Patriarchal norms and values are reinforced by some practices such as initiation ceremonies that emphasise the importance of spousal obedience(90) and the country has one of the highest rates of child marriage in the world(96).

1.6 Healthcare in Malawi

Malawi has a high burden of disease: 10.3% of the adult population are estimated to be living with HIV/ AIDS(79), and around four million people are diagnosed with malaria annually(97). High rates of tuberculosis and neglected tropical diseases such as schistosomiasis present a challenge(80). Maternal and child health is poor and 1 in 34 mothers are at risk of dying in childbirth over a lifetime(79). The sub-tropical climate also makes it prone to climate-related disasters that place additional pressures on the healthcare system(98).

Malawi aims to provide Universal Health Coverage whereby all members of the population are able to access good quality, pre-paid care(99, 100). The Ministry of Health is responsible for the management of these public services(80). Services are also delivered through the private sector(101) and include a range of profit and not for profit organisations, of which the Christian Health Association of Malawi (CHAM) is the biggest provider. The Ministry of Health aims to support the integration of the public-private sectors(102).

Services are delivered on three levels: primary, secondary and tertiary levels that are all linked through a system of referral(101). An outline of the three main tiers of the healthcare system, the types of services delivered and their ownership are presented in Table 1.

Table 1: Outline of the three levels of the Malawian healthcare system, types of services delivered and ownership

Level of care	**Types of services delivered**(101)	**Ownership of services**(103)
Primary	Community initiatives such as mobile clinics, healthcare centres, community and rural hospitals.	Government, CHAM, NGOs, private for profit organisations
Secondary	District Hospitals in each of the 28 districts. Referrals received from healthcare centres and community and rural hospitals.	Primarily government and CHAM
Tertiary	Central Hospitals that offer specialized services such as gynaecology. Referrals received from respective regions.	Government

In addition to biomedical interventions, traditional medicine is widely used. Unlike biomedical models, this does not make such a clear distinction between the body and the mind or spirit(104). It can therefore be used to treat physical ailments or perform other functions such as providing protection against witches, providing good luck or helping to address personal problems. People may self-treat or consult traditional healers known as *sing'anga*(105). Biomedical interventions and traditional medicine are not necessarily mutually exclusive and patients may move between both when seeking treatment(106).

1.7 Delivery of public healthcare services in Malawi

Government spending on public healthcare is low since 8.8% of the 2014/15 national budget was allocated to healthcare(107), compared to the 15% that the country pledged to spend as a signatory of the Abuja Declaration in 2001(108). Empirical studies have shown that a major challenge that exists across all levels of service delivery is a lack of resources(99, 109-112), including insufficient facilities(99, 112), a lack of electricity and water(99, 113), a lack of ambulances to transfer patients(99,

113) and a shortage of drugs and other consumables such as laboratory equipment(114-117).

A shortage of healthcare professionals presents a persistent barrier to service delivery(99, 111, 118, 119). There is a lack of funding to meet the costs of training and employing staff(114). Many internationally recognized personnel also migrate to other countries or move into the private sector in search of better opportunities(120). There is approximately one physician per 50,000 and one member of the specialist surgical workforce per 210,000 of the population(110).

Studies that have explored experiences of delivering services identified high levels of frustration and low levels of motivation amongst many healthcare professionals(99, 112, 114, 121). Reasons for this include staff shortages leading to stress and fatigue(120, 121). A perceived failure to provide adequate supervision and support left many feeling frustrated(112, 119-122). Participants also felt they had limited opportunities for career progression(114, 120, 121, 123). They also suggested poor working conditions impacted on morale(113, 120).

In these studies, health care professionals reported that they felt they received poor pay that did not enable them to meet their needs(120, 121) and inadequate allowances or renumeration, for instance when receiving in-house training(121). To supplement their salaries, some personnel took more than one job or ran farms(123). There have also been suggestions that healthcare professionals have been involved in misappropriating drugs(123).

Regional variation in health coverage also exists. Healthcare professionals and resources are concentrated in urban areas(99), despite the fact that the majority of the population live in rural areas (124). Research has identified a lack of monitoring and evaluation systems that could be used to improve service delivery(114).

A number of policy initiatives have been introduced to try and address these challenges. Mid-level cadres such as medical assistants and orthopaedic clinical officers are increasingly being used to address the shortage of internationally recognised healthcare professionals by delivering many of the clinical services traditionally performed by doctors and nurses(125). Although healthcare assistants receive minimal training, clinical officers receive around four years training in a specialty such as orthopaedics. The Malawi Health Sector Strategic Plan 2011-16 presented a series of recommendations to address high staff turnover, improve monitoring and evaluation systems, and ensure rural communities and vulnerable groups are better able to access services(101).

1.8 Experiences of children and their families with disability and clubfoot

It has been estimated that 2.4% of children in Malawi live with a disability(126). Attitudes towards children with disabilities and their families are shaped by beliefs about its causes(127). Although beliefs are culturally diverse and differ between illness types, across East Africa they can broadly be divided into traditional beliefs, Christian fatalism and biomedical theories of causation(127). These are reflected in beliefs about causes of clubfoot in Malawi that include witchcraft or curses, God or Satan and biological causes(128).

Studies have shown that children with physical impairments in East Africa encounter multiple stigmatising behaviours including physical, emotional and sexual abuse(5, 129). A number of barriers such as a lack of transport make it more difficult for these children to access education(130, 131) and healthcare services(132). Similarly, studies have shown that children with disabilities in Malawi also face a range of social challenges such as being less favoured at home and bullied by peers. Girls with a disability are at an increased risk of sexual abuse(132). Guardians of children in these settings can also experience stress and a feeling of isolation from the community(130, 133).

A recent study found that children living with musculoskeletal conditions were bullied by peers, teachers and family members, and were excluded from everyday activities(5). Impairments also contributed to hunger as they had restricted access to food outside the home. For parents, time spent caring for the children meant less time could be spent on economically productive activities and this contributed to household poverty(5). Another study found that guardians of children with clubfoot experienced stigma and encountered negative attitudes from their neighbours and the wider community(128).

1.9 Disability rights

Disability rights are supported by governmental policies and Malawi has adopted a range of legislation to protect children with disabilities. International legislation includes the United Nations (UN) Convention for the Rights of Disabled Persons(134) and the UN Convention on the Rights of the Child(135). Nationally,

protections are included in the 1995 Constitution(136), the 2010 Child Care, Protection and Justice Act(137) and the 2012 Disability Act(138). However, these are not being effectively implemented and problems still remain(132). Disability advocacy groups are sensitising communities about disability rights and advocating for their full inclusion in society(139).

1.10 Clubfoot treatment in Malawi

CURE organisation estimates that over 800 children are born with clubfoot annually in Malawi(140, 141) and the Ponseti method has been adopted as the national standard for conservative clubfoot treatment(63).

The Malawi National Clubfoot Programme (MNCP) was launched in 2007. With financial support from CURE organisation, the programme appointed a national clubfoot coordinator and a medical director based at Beit CURE International Hospital in Blantyre. This aimed to provide clinics with centralized logistical support and guidance. The Programme works in partnership with the Ministry of Health and non-governmental organisations including Malawi Against Physical Disabilities and CHAM. As of 2015, the MNCP had established 29 clinics throughout Malawi, predominately in District Hospitals.

MNCP has two components of care: clinical and spiritual (Christian) healing that provides emotional and practical support to families accessing treatment. Clinical care is delivered by orthopaedic clinical officers, healthcare assistants and physiotherapists. Organisational support is provided by the CURE clubfoot coordinator. Spiritual healing is delivered by MNCP counsellors trained by the

Spiritual Team at Beit CURE International Hospital and support provided by a counselling coordinator(63). However, Malawi's clubfoot services face many of the difficulties associated with delivering clubfoot treatment in low and middle-income countries. Service implementation is challenging(63); a high proportion of children fail to present; adherence to treatment is low(140); and treatment is often delayed(63). However, these issues have not been systematically explored. Furthermore, no research has explored the social and emotional impacts of accessing these services and whether the needs of patients and their guardians are being met.

1.11 Aims and objectives

The study used ethnography to:

1) Explore factors that impact on the implementation of clubfoot treatment services and develop a theoretical framework to help inform findings.

2) Gain an understanding of the impact of accessing and utilising services on parents or carers of children with clubfoot presenting in infancy, and other individuals involved in their care.

3) Explore the experiences of children and their guardians who had either discontinued or not fully accessed treatment.

The study aimed to provide novel insights and it is hoped that these can help organisations in Malawi to deliver services to better meet the needs of patients. It also helped to determine whether the services are meeting their intended objectives.

Findings may also be of use to other organisations implementing clubfoot services in low income settings.

Chapter 2 Global health context and theoretical background

This chapter explores the literature, theories and concepts that have been used to inform this study, including relevant global health literature, theories from the field of implementation science and treatment-seeking behaviour. Conducting this work helped me to understand findings within the wider global health context and informed the theoretical approaches I used to shape data collection and analysis.

2.1 Global health context

Many of the issues around the provision of care for clubfoot in Malawi transcend national boundaries. To better understand the delivery of clubfoot care, it is therefore necessary to engage in wider global health issues. These include issues around models of healthcare, agencies that shape global healthcare, global healthcare initiatives, healthcare systems, the concept of 'people-centered care', health inequities and social determinants of health.

2.1.1 Models of healthcare

A distinction can be made between biomedical and social models of health. The biomedical model views health as the absence of disease or illness, although some proponents may include physical and mental health in this. As a result, care is focused on the provision of services to alleviate illness. By contrast, a social model of health as defined by WHO defines health as 'a state of complete, physical and mental wellbeing'(142, 143).

2.1.2 Agencies that shape global health care

Agencies outside national government that have been most influential in shaping the global health agenda are WHO and the World Bank. Low income countries also receive a substantial amount of health funding from high income countries such as the UK and USA through departments such as the Department for International Development (DFID). Philanthropic institutions such as the Bill and Melinda Gates Foundation are an important source of direction and finance. Civil society organisations that include large international organisations such as Oxfam and local NGOs have also been instrumental in delivering healthcare interventions(144). The relationship between organisations involved in the delivery of global health and their levels of influence are dynamic and changing. Fragmentation of global health delivery has shifted power away from individual nation states to set their own health agendas(145).

Global health initiatives have been introduced by international organisations to improve patient access and the provision of healthcare services across settings. Key initiatives that have shaped the provision of global health services include WHO's 1981 'Health for all' strategy that aimed to ensure that all members of the population were able to access high quality care. Primary healthcare services were seen as a means of realising this goal(146).

The UN's Millennium Declaration identified eight Millennium Development Goals (MDGs) to achieve by 2015 to improve the welfare of the world's population. MDGs relating to health were to reduce child mortality, improve maternal health and halt the spread of HIV/AIDS and incidence of malaria(147). Subsequent initiatives have reaffirmed the importance of providing high quality primary healthcare services as

a way of delivering universal health coverage since it provides a cost-effective way of treating simple diseases. As the first point of entry into the healthcare system, it also enables workers to refer patients to more specialist services if required(148). In 2015, 17 Sustainable Development Goals (SDGs) were introduced. Number three, to 'ensure healthy lives and promote well-being for all ages', included a commitment to providing universal health coverage, increasing funding and increasing numbers of healthcare personnel.

2.1.3 Healthcare systems

An ability of governments to achieve these aims is influenced by the performance of healthcare systems, all of which are structured in different ways(149). The WHO identified six 'building blocks' to help strengthen all health systems:

1. Delivery of high quality, effective and safe services
2. A high performing health workforce
3. Health information systems to provide information about the health status of the population and evaluate system performance
4. Access to medical products and vaccines
5. A fair and effective health financing system
6. Good leadership and governance(150)

There is a lack of consensus on how best to deliver high quality services in resource-poor settings. One important discussion centres on whether organisations should use a 'vertical' or 'horizontal' approach to service planning. A 'vertical' approach is one that focuses on the provision of programs for specific diseases such as HIV/ AIDS. By contrast, a 'horizontal' approach aims to strengthen the healthcare system more generally, including efforts to increase the numbers of healthcare

professionals(151). Whilst vertical, disease specific programs enable funders to target some of the most pressing healthcare issues and are easier to manage, there are concerns that resources that could benefit a number of programs are wasted(152). Vertical programs may also take resources away from local healthcare systems(153). More recently, a 'diagonal' approach has been suggested to address these competing challenges(151). Another discussion centres on strategies to successfully 'scale up' public health interventions. That is, expanding a local program or pilot scheme that has proved to be effective on a small scale so that it reaches a greater number of people. Methods of achieving this have been explored using theoretical models, some of which are discussed below(154).

A global shortage of trained healthcare workers presents a persistent barrier to delivering global health(155). As in Malawi, this is exacerbated by the tendency of trained workers to migrate to high income countries and the concentration of workers in urban areas(156). Strategies to address this include expanding access to education and training and financial incentives to work in rural areas. Policies have also been implemented to try and retain workers by improving their conditions of employment(156, 157). Other low and middle-income countries are also increasingly using task shifting as a way of responding to shortages(158).

Leadership and governance refers to the role the government takes in providing 'stewardship' to the healthcare system. Key functions of governance identified by WHO are: 1) 'Policy guidance', such as identifying health priorities; 2) 'Intelligence and oversight' to monitor health systems and health trends; 3) 'Collaboration or coalition building' with other groups involved in the provision of services such as

international agencies and NGOs ; 4) 'Regulation' such as the implementation of health related laws and standards; 5) 'System design', ensuring the system is structured to meet health objectives; 6) 'Accountability', ensuring that all those delivering care are held responsible for their actions. This relies on transparency(150).

2.1.4 Delivering 'people-centred care'

Having long been advocated in high income countries, there is now an increasing recognition of the need to deliver 'people-centred care' to patients in low and middle-income countries. According to WHO, this involves empowering patients by prioritizing their needs in the design of services, including those of their significant others and communities and involving them in decisions about their treatment(159). Rather than a paternalistic healthcare relationship where professionals make decisions on behalf of patients which is still prevalent in many settings, 'people-centred care' involves a more collaborative approach whereby healthcare professionals and patients make treatment decisions together(160). Meeting patient needs also includes consideration of the emotional and psychological as well as physical aspects of illness(161).

Delivering people-centred care in low and middle-income countries is challenging due to a scarcity of resources and competing priorities(162). Nevertheless, case studies have shown that people-centred care in low and middle-income countries is feasible(163) and reported benefits include increased user satisfaction, cost effectiveness, patient engagement and improved health outcomes(164).

2.1.5 Health inequities

Health inequalities or inequities are an enduring global concern. These can be

defined as 'differences in health status or in the distribution of health determinants between different population groups'. A distinction can be made between health inequalities that may be biological, such as differences in mobility between the young and old, and inequities that are avoidable. Factors that cause health inequities are social and economic(165).

WHO defined the social determinants of health as 'the conditions, in which people are born, grow, work, live, and age and the wider set of forces and systems shaping the conditions of daily life'(166). This would include income, education, employment, gender, ethnicity, rural/ urban areas and disability(167). The social gradient of health refers to the correlation between socioeconomic status and health outcomes. Whilst the poorest members of the population have the worst health outcomes, those at the top have the best(165). In general, groups that are the most disadvantaged in society, for instance by gender, ethnicity, income or disability, have the worst health outcomes(168).

2.1.6 Social determinants of health

Social and economic factors that impact on the health status of individuals and the mechanisms that drive them are complex(169). Factors can be loosely divided into materialist or structural influences and behavioural and cultural influences, both of which are linked(170).

Structural factors that impact on health status include the availability of resources, access to services and psychosocial causes(168). Those living in poverty lack access to resources such as clean sanitation and nutrition(168) and are more likely to be exposed to the impacts of climate change such as drought that impacts on food

production(171). An ability of people to access high quality services also impacts on health inequities. Services tend to be concentrated in wealthy urban areas. Costs of accessing services may present a further barrier(172). Mental health problems are also strongly correlated with social status(168). Illness or disability may push people into poverty due to a loss of earnings or costs of accessing services, a phenomena that has been termed the 'medical poverty trap'(173).

Behavioural and cultural influences associated with certain socio-economic groups affects individuals' propensity towards healthy or 'risky' behaviours that are likely to have negative health outcomes, such as smoking. However, what appears to be behavioural 'choices' may also be limited by structural constraints such as a lack of access to nutritional food(170). Finally, health is also influenced by circumstances and behaviours that have accumulated over a lifetime. For instance, a lack of nutrition in early childhood will impact on later cognitive development(174).

2.2 Implementation science theories

In order to understand the implementation of healthcare interventions, it is necessary to understand factors that facilitate or hinder implementation. An understanding of the impact of contextual factors on service delivery is particularly salient in low and middle-income countries, where interventions such as the Ponseti method may have been developed in countries with different working practices and resource allocations(175).

A complex intervention is an intervention with a number of interdependent components(176). Interventions are implemented in healthcare systems with

numerous interacting components(177). The interacting components of an intervention, combined with the contextual factors inherent to the healthcare systems, make the implementation of these interventions challenging. To help to do this effectively, there has been an increasing proliferation of theories being used in healthcare and other areas, a field known as implementation science(178, 179).

A number of reviews have been conducted that provide an overview of these theories and frameworks(180-183) (184). A narrative review of these conducted by Nilsen identified three over-arching purposes to implementation theories: 1) to describe the translation of research into practice; 2) understand factors that impact on the successful implementation of services; and 3) evaluate how successfully interventions have been implemented. Theories or frameworks used to explore factors that impact on successful implementation were sub-divided into determinant frameworks, organisational and psychological theories that can illuminate aspects of implementation and implementation theories(175). I will use this review to guide my overview of the most prominent and widely used theories and frameworks in implementation science research. This is not intended to be a systematic and exhaustive review.

2.2.1 Determinant frameworks

Determinant frameworks typically present a number of independent 'barriers' and 'facilitators' that may exist at different levels such as the individual, organisational or societal(175).

Nilsen identified a number of overlapping categories or constructs in these frameworks that influence successful implementation such as the characteristics of

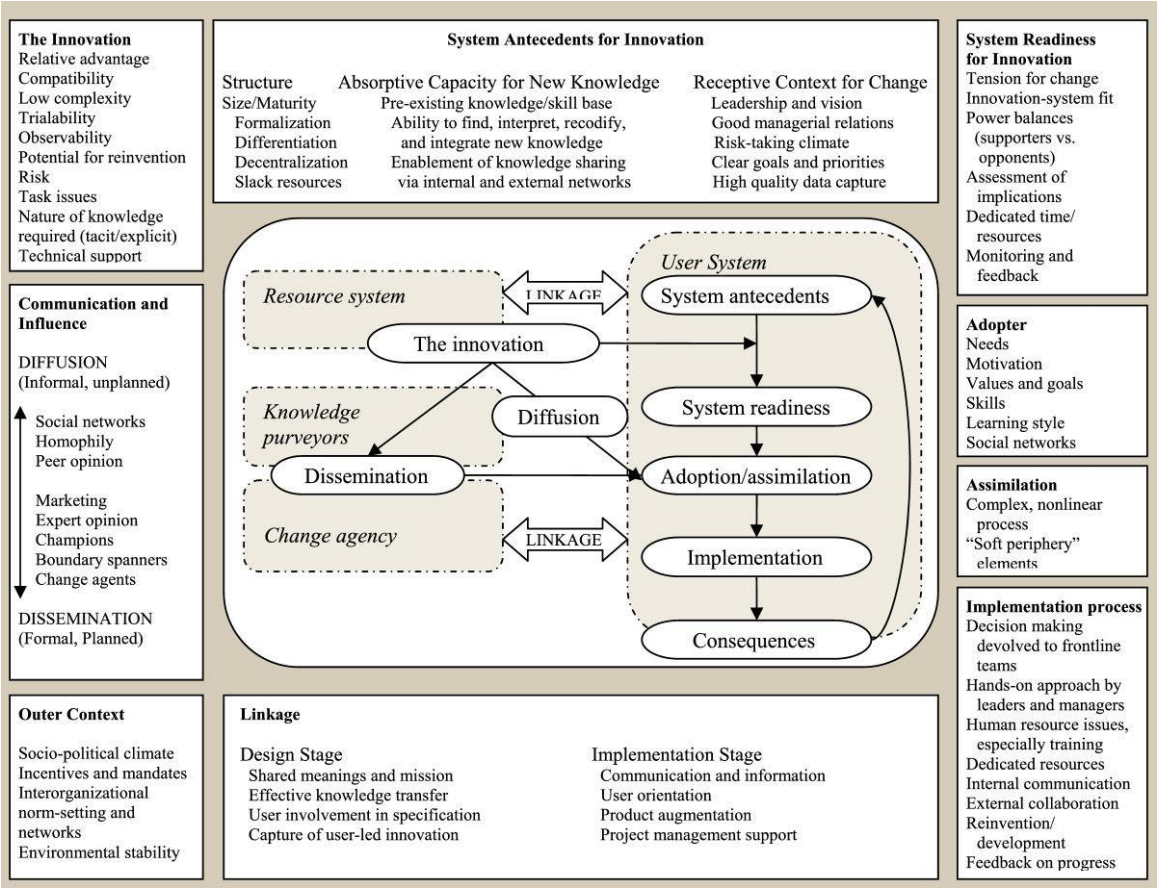
the intervention, the characteristics of those adopting it, context or environment and the way in which the intervention is implemented(175). For instance, the Promoting Action on Research Implementation in Health Services (PARIHS) framework identifies three categories that influence the implementation of research: 'evidence', 'context' and 'facilitation'. 'Evidence' the strength of the available evidence; 'context', the environment into which the innovation is going to be introduced and 'facilitation', how the implementation is facilitated. 'Facilitators', identifiable individuals that help empower people to change working practices, are key here(185). Based on the category 'context', Eastabrooks developed the Alberta Context Tool (ACT) that identified 59 items that relate to the organisational context that influence the implementation of interventions. These include leadership, informal and formal interactions and structural and electronic resources(186). Other theories include the Theoretical Domains Framework(187) and Dulak's Ecological Framework(188).

A small number of frameworks have considered the impact of patient characteristics on implementation. These include a consideration of whether patient needs have been taken into account when designing and implementing the intervention and how patient characteristics might impact on their access to treatment. The Consolidated Framework for Implementation Research (CFIR) identifies five domains that impact on implementation, which encompass a number of barriers and facilitators. These five domains are: 1) 'Intervention characteristics'; 2) 'Outer setting' that includes how well patient needs are met and how well the organisation works with other external bodies; 3) 'Inner setting' such as the structural characteristics of an organisation and its organisational culture; 4)

'Characteristics of individuals' including their attitudes towards the intervention; and 5) 'Process' such as how it has been planned, executed and evaluated(189). Another framework developed by Cochrane et al. incorporated the impact of patient characteristics and lack of adherence on implementation(190), as does Grol's framework(182).

Greenhalgh's Conceptual Model is a highly influential determinant framework. A distinction here is made between 'diffusion', the passive spread of an innovation; 'dissemination', active and planned spread of an innovation; 'implementation', attempts to integrate the innovation into an organisation; and 'sustainability', efforts to sustain the integration of an innovation so it becomes part of routine work. Factors influencing implementation are grouped into a number of domains including the perceived characteristics of the innovation, adopter attributes, communication and influence, system antecedents for the innovation, system readiness, outer context such as socio-political environment and implementation process(184). See Figure 4 below.

Figure 4: Conceptual Model for Considering the Determinants of Diffusion, Dissemination and Implementation of Innovations in Health Service Delivery, Greenhalgh 2004



Source: Greenhalgh, T., et al., *Diffusion of innovations in service organizations: systematic review and recommendations.* Milbank Q, 2004. **82**(4): p. 581-629(184).

2.2.2 Psychological and organisational theories

Psychological and organisational theories do not originate from within the field of implementation science but have been used to illuminate certain aspects of it(175). Psychological theories may be divided into those that account for individual behaviours and those that aim to explain the collective actions of agents(175). The Theory of Reasoned Action, aims to demonstrate the relationship between an individual's attitudes and the likelihood that they will perform a given behaviour. According to this, two factors influence behaviour: individual attitudes and subjective norms, or the social pressure to perform a behaviour. Subjective norms

are influenced by how the people around them think they should behave and how motivated they are to comply with social norms. The relationship between behavioural intention and behaviour is mediated by a number of factors including context. That is, how much control they have over their ability to perform the action(191). Ajzen built on this in the Theory of Planned Behaviour which added to this 'perceived behavioural control'. This is, the extent to which an individual thinks that they have control over the behaviour and how likely they think it is that they can successfully perform it(192).

Social Cognitive Theory states that observing a behaviour and viewing the outcome of it can guide the behaviour of individuals or prompt them to act in ways they have already learned(193). It also considers how emotions or affective factors and the frequency of past behaviour or habits can influence behaviour(194).

A number of organisational level theories have been considered as a means of understanding the implementation of interventions(175). Organisational theories describe how organisations interact with their socio-economic environments(195). Birken has highlighted the potential use of theories such as Institutional Theory(196) in helping to understand the impact of external environments on service implementation(197). This theory describes how actors in an organisation conform to beliefs and norms in an environment or culture(196). It also explains why NGOs located in different environments experience unique challenges since actors conform to the institutional norms in the host country(198). This need to conform, it has been argued, hinders change(196). Change occurs then when actors

that are not as well integrated into the system or exist outside of it, are able to act in ways that do not conform(199).

Other organisational theories that may help describe processes of implementation include the Punctuated Equilibrium Model of change(200), Situated-Change Theory(201) and Agency Theory(202). The Punctuated Equilibrium Model suggests that organisations are largely stable over time but punctuated by sudden and 'revolutionary' change as a result of an external stimulus(200). By contrast, the Situated-Change Theory suggests that change is a gradual process that occurs over time as a result of the evolving practices of agents within a social system(201). Agency Theory explores the relationship between 'principals' or 'agents'. 'Principals' are external actors that want to introduce change such as managers, whilst 'agents' are those responsible for carrying it out, such as those involved in service delivery. This may lead to tensions between the two groups. To initiate change, principals must therefore either incentivise agents to ensure that their priorities are aligned or monitor behaviour(202).

Rogers' influential Diffusion of Innovations theory describes the process by which innovations are diffused throughout social systems through the communication of actors. According to Rogers there are four factors that influence the implementation of an innovation: 1) the innovation itself; 2) communication channels, or how ideas are spread across a network of people; 3) time, how long it takes for the innovation to be adopted and 4) the nature of the social system or network of actors. The characteristics of an innovation make it more or less likely to be adopted. Characteristics include how useful agents perceive the innovation to be compared

to previous ways of working, how well it fits with existing methods of working, how complex or easy it is to use and how easy it is to perceive the results of the innovation. Three categories of adopters or innovators are identified: early adopters, early majority, late majority, and laggards(203).

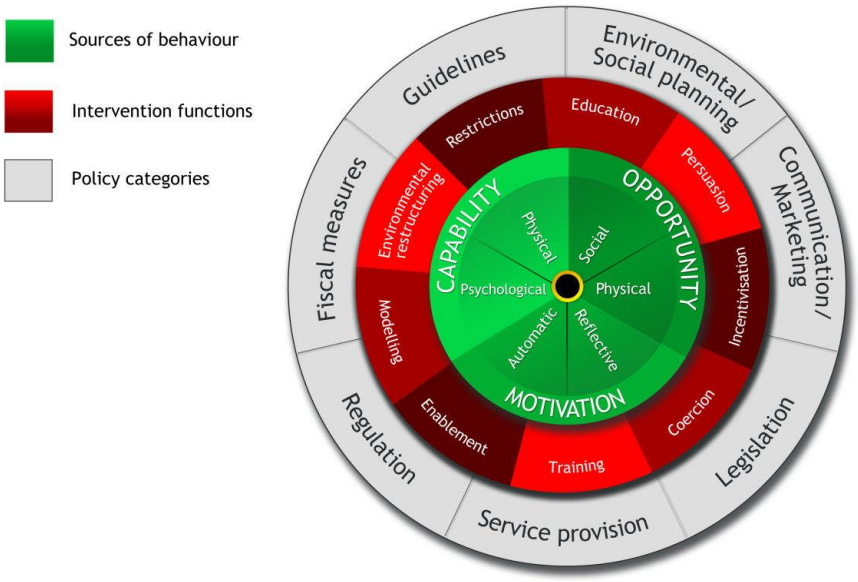
Eastabrooks also identified a number of social theories that may help us to understand processes of implementation including Social Capital Theory and Community of Practice Theory(204). Social Capital Theory refers to the ways that patients (or other actors) may use their personal relationships to help access services. A distinction can be made here between 'bonding', 'bridging' and 'linking' social capital(205). 'Bonding' social capital refers to the support that members of a network who see themselves as socially similar provide to each other, for instance in terms of 'gender', 'ethnicity' and 'social status'. 'Bridging' social capital refers to the support provided by members of the community who do not see themselves as being socially 'the same'. 'Linking' social capital by contrast, describes the bonds of trust and support between people interacting across formal institutions(206). This would include patients and healthcare professionals. Building this relationship can therefore be seen as being crucial to the implementation of services(205). Community of practice theory refers to the way that 'communities of practice' such as healthcare professionals interact on a regular basis to share ideas and improve practice. It also accounts for how ways of working improve and change over time(207).

2.2.3 Implementation theories

Implementation theories are those that have been specifically devised for the purpose of exploring the implementation of interventions(175). Many of these build

on psychological and organisational theories. Implementation Climate Theory refers to the ways that organisations may create a climate that facilitates implementation by introducing policies or practices that encourage members of staff to adopt them, such as incentives(208). These policies are specifically aimed at promoting the use of the innovation(209). Organizational Readiness for Change explores how the shared commitment of group members, or lack of it, may impact on implementation(210). The Capability, Opportunity, Motivation- Behaviour system (COM-B) system identifies three factors that influence behavioural change. 'Capability' refers to individuals' ability to perform the behaviour such as having the necessary skills and knowledge; 'motivation' that describes the conscious and unconscious decisions that individuals make to enact it; and 'opportunity' which encompasses factors external to the individual that promote or inhibit their ability to do the work. The theory identifies nine types of interventions that may promote 'capability', 'motivation' or 'opportunity', along with seven policy types to facilitate them(211). See Figure 5 below.

Figure 5: The Behaviour Change Wheel, Mitchie, Stralen, West, 2011



Source: Michie, S., M.M. van Stralen, and R. West, *The behaviour change wheel: A new method for characterising and designing behaviour change interventions.* Implementation Science, 2011. **6**(1): p. 42(211)

Normalization Process Model explores factors that determine whether an intervention becomes embedded into everyday practice. That is, whether it becomes part of the 'normal' work that healthcare professionals do(212). This was expanded into Normalization Process Theory (NPT)(213, 214). According to NPT, four factors impact on implementation: 'coherence', 'cognitive participation', 'collective action' and 'reflexive monitoring'. 'Coherence' refers to how well defined the intervention is and the extent to which is differs from other working practices. 'Cognitive participation' describes how committed the actors are to enacting it and 'collective action', how well it can be integrated into existing practices. 'Reflexive monitoring' are the formal and informal appraisals that healthcare workers undertake to evaluate the effectiveness of the intervention. NPT has been widely used in health service research(215) and an online tool called

NoMAD has been developed to assist professionals in measuring the implementation of processes based on the four constructs(216).

Extended Normalization Process Theory (eNPT) which is the latest iteration, builds on these by combining psychological theories(217, 218) and network perspectives(219-221), to describe factors that impact on the successful (or unsuccessful) implementation of services(222). Central to eNPT is the concept that implementation is driven by 'agentic contributions' that are contextually situated. eNPT incorporates into it Weiner's concept of 'collective commitment', the combined contribution of a group of actors to implementing an intervention(218). Implementation is seen as a process that needs to be continually (re)enacted so that the intervention may be sustained over time. According to eNPT, the implementation of interventions is dependent on the ability of agents to fulfil four criteria which are understood using four constructs(222) (Table 2):

Table 2: The four constructs of extended Normalization Process Theory

Construct	Description
'Capacity'	Implementing an intervention depends on participants' capacity to co-operate and co-ordinate their actions
'Potential'	Translating capacity into action depends on participants' commitment to operationalise the intervention
'Capability'	The capability of participants to enact the intervention depends on its workability and integration into everyday practice
'Contribution'	The implementation of an intervention over time depends on participants' contributions to enacting it by investing in meaning, commitment, effort, and appraisal

2.2.4 Implementation science in low and middle-income countries

Institutions such as the Fogarty International Centre are increasingly using implementation science theories to inform the translation of research into practice in global health settings(223, 224). However, these theories are still being underused in global health research. Furthermore, implementation theories that have been largely used and developed in high income countries may not be suited to low income settings. There is therefore a need to adapt existing theories(225). Based on the context dimension of the PARIHS framework, Eastabrooks and colleagues adapted ACT to develop the Context Assessment for Community Health (COACH) tool for low- and middle-income settings. In addition to those included in the ACT framework, COACH added additional constructs suited to low income settings that related to considerations around resources, community engagement, commitment to work and informal payments(226). Further work needs to be done to develop and build on existing theories.

2.3 Treatment-seeking behaviour

A range of studies have illustrated that some sociodemographic groups are more likely to access services than others(227). Understanding why people do or do not access healthcare services can help service providers to adapt services to facilitate treatment-seeking and promote adherence, especially amongst these unrepresented groups. Decisions to access healthcare services depend on how people respond to their perceived illness(227) and this is influenced by individual decision-making and socio-structural factors.

People may choose to enter any one of the three 'sectors': 'the popular sector', 'folk sector' and 'professional sector'. These have been identified in industrialised societies(228) but also exist in low and middle-income countries. The 'popular sector' refers to the steps that people take to diagnose and treat their conditions without consulting professionals and includes self-treatment, advice sought from family and friends, self-help groups and consulting other people with the condition. The 'folk sector' encompasses traditional medicines and healers that are prevalent across Africa and may be secular or religious. The 'professional sector' represents Western medical practices(228). 'Sectors' are not mutually exclusive and patients may move between them(106).

The relationship between illness beliefs and health-seeking behaviour has been extensively explored and this is influenced by socio-cultural factors(229). For people to want to access care, a condition must first be identified as a problem worthy of seeking treatment and this differs between socio-economic groups(230).

Beliefs about illness causation are multifarious and include concepts about changes in individual behaviour or diet, 'emotional illnesses', the weather and the supernatural such as witchcraft(228). Illness beliefs influence the types of services that people choose to access. For instance, people in Africa who believe the cause of illnesses are connected to witchcraft are more likely to seek traditional healers(231). Cultural practices also influence treatment-seeking. Women in Malawi often consult their maternal grandmothers about maternal behaviours as they are viewed as an important source of information(232). How people interpret their symptoms also influences whether they are likely to seek help. People tend to make a judgement

about which illnesses can or can't be treated and if the condition is likely to be serious or non-threatening(227).

Structural barriers to service access also have a large impact on treatment-seeking behaviour, especially in low and middle-income countries(172). Financial barriers include direct costs of accessing services and indirect costs such as travelling to services. Geography, both the physical distance and ease of reaching services is an important consideration(233). How well services are seen by patients to meet their needs is also a contributing factor(233).

2.3.1 Models to explore treatment-seeking behaviour

A number of theories deriving from a range of disciplines have been proposed to understand treatment-seeking behaviour(234). Scrimshaw has identified key theories that have been influential in global health contexts including the Health Belief Model, Theory of Reasoned Action, Diffusion of Innovations Model and the Transtheoretical Model(231). The Social Ecological Model has also been widely used(235) (236). Wyke makes a distinction between individual and collectivist theories of behaviour change. That is, those largely based on individual decision-making and those that emphasise the role of the wider socio-cultural environment. A distinction is also made between those that characterise treatment-seeking as a singular point and those that view it as a dynamic process that continues over time(234). Some of these theories have been used to explore behaviour change for healthcare providers, as above.

Individual theories of behaviour change include the Health Belief Model. According to this, a decision to change behaviour is influenced by: perceived susceptibility to

the disease, perceived severity, perceived benefits, perceived barriers to action and cues to action that encourage individuals to engage in healthy behaviours, such as national campaigns(237). Self-efficacy was later added and this described the confidence that individuals had in their ability to change their behaviour. These factors are modified by sociodemographic variables(238). The Model has been used to explore adherence to treatment and health-seeking behaviours(231, 239). The Theory of Reasoned Action that aims to demonstrate the relationship between an individual's attitudes and the likelihood that they will perform a given behaviour as above, has also been used to help understand patient behaviour. Unlike the health belief model, this also includes an understanding that individual behaviours are mediated by context(191).

Collectivist explanations such as the one proposed by Zola, consider the impact of socio-structural factors on treatment-seeking(234). According to Zola, factors that influence a decision to access care include whether care is available, affordable, how successful treatments have been within the folk or popular sectors, how the illness is viewed by the patient and how it is viewed by those around them(240). Zola also identified five 'triggers' to treatment seeking that are influenced by people's social circumstances including coercion by family or friends and negative impacts on their physical activity(227, 240).

Diffusion of innovations moves beyond individual and collective models by focussing on how communication through networks promotes wider social change, as described above(203). The theory may be used to explain how a population may choose to adopt healthcare innovations such as antibiotics(231). To promote

behaviour change, Rogers advocated the use of 'interpersonal communication' through word of mouth and mass media campaigns(203, 231).

Theories that incorporate an understanding of treatment-seeking as a dynamic process that continues over time or as part of an 'illness career', include the Illness Action Model and the Network Episode Model(234). The Transtheoretical or Stages of Change Model describes the changes that a person undergoes to change and then maintain their behaviour. According to Prochaska, DiClemente and Norcross' model, there are five stages of behaviour change: 1) 'Precontemplation', individuals at this stage have no intention to seek treatment and may not be conscious there is an issue; 2) 'Contemplation', individuals are aware there is an issue and are considering taking action; 3) 'Preparation', individuals plan to change their behaviour; 4) 'Action', individuals initiate change to their behaviour; 5) 'Maintenance', individuals maintain changes to their behaviour over a period of time. Throughout this process, patients contemplate the costs and benefits of behaviour change and maintenance(241).

The Social Ecological Model recognises the impact of multiple and inter-related factors on illness behaviour(235). This provides a counterpoint to individualistic models such as the Health Belief Model and Theory of Reasoned Action that see behaviour as the result of personal characteristics or rational decision-making processes(242). According to the Social Ecological Model, there are five inter-related determinants of illness behaviour: 1) 'Intrapersonal factors' that refer to individual characteristics such as socio-economic status and occupation; 2) 'Interpersonal processes' or personal interactions with others; 3) 'Institutional

factors' that are the processes embedded in organisations; 4) 'Community level factors' such as values and beliefs in the wider society and 5) 'Public policy'(235).

Understanding these issues enables service providers to adapt services to facilitate treatment-seeking and adherence.

2.4 Chapter summary

This chapter has explored the literature, theories and concepts that have been used to inform this study, including global health literature, theories from the field of implementation science and treatment-seeking behaviour. This helps to locate the study within the wider literature and research context. Conducting the work also informed the theories I used to help shape data collection and analysis. Theories included the Social Ecological Model to help explore treatment-seeking behaviour and extended Normalization Process Theory that was used to help understand the implementation of clubfoot treatment services. The subsequent chapter builds on this work by presenting a systematic overview of literature on clubfoot in low and middle-income countries and exploring factors that impact on treatment-seeking for clubfoot in detail.

Chapter 3 Literature review

This chapter provides an overview of methods of synthesising qualitative and mixed methods research, along with appraisal frameworks that have been used to evaluate the strength of individual studies and the strength of qualitative reviews. I then present a narrative synthesis of literature on clubfoot in low and middle-income countries, including the implementation of services delivering the Ponseti method; local theories of causation; factors impacting on treatment-seeking behaviour and experiences of accessing clubfoot treatment. This is to provide an overview of existing literature and findings, help the reader to locate the study within existing research and provide further rationale for this thesis.

Lastly, I use a meta-synthesis to synthesise findings from existing qualitative research to explore factors that impact on patient access and adherence to clubfoot treatment in low and middle-income countries and community level interventions to address them. A Social Ecological Model is used to structure analysis(235). A decision was made to present these findings as separate from the main review since it is a major theme in this thesis. It also enabled me to use a more interpretative approach to exploring the literature. The application of theory helped to place findings within the wider global health context and to illuminate the inter-related factors that impact on treatment-seeking behaviour for clubfoot.

Work from both of these literature reviews has been published in two articles for peer-reviewed journals (see Appendix).

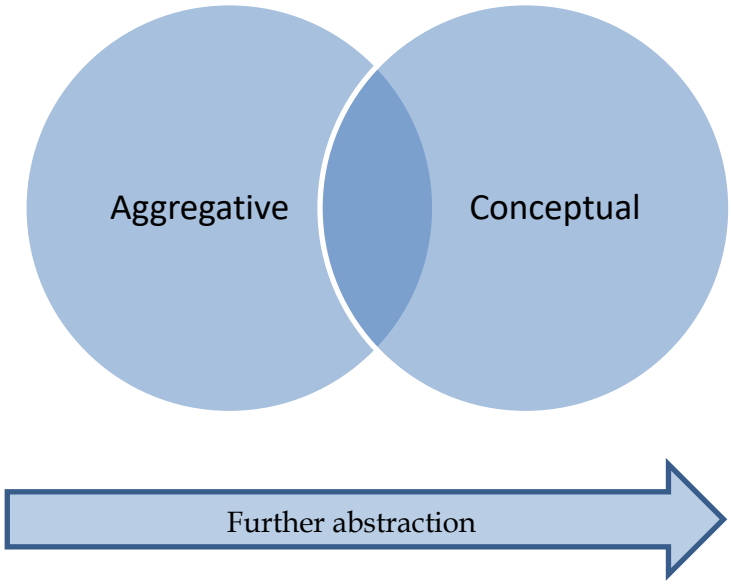
3.1 Synthesizing qualitative and mixed methods studies

3.1.1 Methods of synthesising qualitative and mixed methods studies

It is increasingly recognised that synthesising findings from qualitative and mixed methods studies can produce findings that are relevant across multiple contexts, identify gaps in the literature and develop new conceptual insights into phenomena(243). The synthesis of qualitative and mixed methods studies is a rapidly growing area of research and a number of methods have been developed to do this(244, 245).

Methods chosen for synthesis are shaped by the aims of the research and the kinds of data to be included. For instance, if the aim is to generate new theory or whether studies include mixed methods or are limited to qualitative research(244). Methods can be divided into approaches that aim to integrate findings such as narrative synthesis(246) and interpretive approaches that aim to generate new theories or concepts from existing literature(247). This is best understood as a continuum(248). See Figure 6 below.

Figure 6: Types of qualitative synthesis(248)



Main methods of synthesising qualitative, quantitative and mixed methods research include thematic synthesis, narrative synthesis, meta-synthesis, grounded theory and meta-ethnography(249). Most of these are based on analysis techniques used in primary research. The following presents an overview of some of these here. This is not intended to be an exhaustive review(250). There is a lack of consensus on the terminology used to describe each method and overlaps in approaches. Understandings of the 'labels' applied to each method may therefore vary.

Thematic analysis or synthesis involves conducting a thematic analysis to identify themes or subthemes in the literature(251). Narrative syntheses have similarities with traditional, narrative literature reviews in that they aim to present an overview of literature on a given topic, primarily through descriptive accounts and may include qualitative and quantitative studies. They also include the comparing and contrasting of respective studies(244). However, they can be distinguished from

traditional, narrative reviews by their systematic approach to study identification, quality appraisal and transparent methods of synthesis(247). Guidance has been developed by Popay as part of the ESRC Methods Programme to ensure this approach is methodologically rigorous(246).

According to Sandelowski, one of the distinguishing features of meta-synthesis is that it aims to integrate studies rather than make comparisons between them. It is also an interpretive approach since it can produce a higher level of abstraction than aggregative methods. That may include using 'imported concepts' from existing theoretical frameworks(252).

Grounded theory methods of synthesis are based on those used in primary research and aim to develop a new theory from existing qualitative research. Data collection and analysis are conducted simultaneously and theoretical categories developed and tested through theoretical sampling or the search for negative cases. In this way, a new theory may be developed(250).

Paterson's concept of a qualitative meta-study involves analysing the theory, methods used and findings of the primary studies to be included in the review, a process described as 'the research of research'. Only after this can synthesis occur. This is rooted in a social constructivist approach that views primary research as a construction and secondary research as a construction of a construction. An in-depth understanding of how the research has been produced is therefore considered necessary in order to understand the findings of the synthesis(253).

Meta-ethnography as developed by Noblit and Hare is an interpretative approach to synthesis. Methodology involves translating the studies into one another, including the translation of concepts and ideas such as the interpretations of the primary authors. Three processes are involved: 1) 'Reciprocal translational analysis' where key themes or concepts are identified; 2) 'Refutational synthesis' where possible contradictions between studies are identified and explored; 3) 'Lines-of-argument synthesis' which involves drawing together findings from the respective studies. A meta-ethnography is generally limited to a small number of studies(254).

3.1.2 Appraisal frameworks for individual studies

A range of appraisal frameworks are increasingly being used to evaluate the strength of individual qualitative studies included in the review such as the Critical Analysis Skills Programme (CASP) for qualitative research(255), Joanna Briggs Institute Critical Appraisal tools (JBI-QARI)(256) and the Consolidated Criteria for Reporting Qualitative Research (COREQ)(257). The CASP is a 10 point framework constructed to help evaluate the methodological quality and usefulness of qualitative studies. It is intended to be used to aid understanding of the research, rather than function as a scoring system(255). The JBI-QARI qualitative appraisal tool, another 10 point checklist, adds to this a consideration of the congruence between aspects of the study design. For instance, the philosophical perspective and methodology used, and research methodology and objectives(256).

The COREQ is a 32 item framework to appraise interviews and focus groups. Items are divided into three domains: Domain 1) Research team and reflexivity. Unlike CASP and JBI-QARI items, this domain considers the characteristics of the review team such as 'occupation' and 'experience and training'; Domain 2) Study design;

and Domain 3) Analysis and findings(257). More recently, the Standards for Reporting Qualitative Research (SRQR) has been developed to help consider how well researchers have reported their studies. That is, if they have been transparent and justified their approach(258).

There is a lack of consensus on the value of using qualitative frameworks for appraisal. One argument against using established frameworks is that it is impossible to make generalisations about which characteristics to prioritise since qualitative research represents such a broad field(259). Furthermore, a study by Dixon-Woods found that there was little difference in judgement between those making independent, unstructured quality judgements based on their expertise and those taking a structured approach based on appraisal frameworks, suggesting that they may be of limited value. However, they found using frameworks made reviewers more clear about reasons for their quality judgements(260).

There is also a lack of agreement on whether or not to exclude studies that have been identified as being 'low' or 'poor quality'. Whilst Campbell argues that all studies should be included since they contribute useful insights into the phenomena(247), Dixon-Woods argues that studies identified as 'fatally flawed' should be excluded(260). Appraisal frameworks should therefore be used flexibly to guide thinking about study quality, rather than used as a definitive set of rules(259).

Likewise, a range of appraisal frameworks have been developed to evaluate the quality of other study designs(261). In addition to qualitative studies, CASP frameworks have been developed to appraise systematic reviews, diagnostic tests,

economic evaluations, randomised controlled trials, case control studies, cohort studies and clinical prediction rules(262). Likewise, JBI-QARI have also been constructed to evaluate the strength of case control studies, case reports, case series, cohort studies, diagnostic test accuracy studies, economic evaluations, prevalence studies, randomised control trials, systematic reviews, text and opinion and analytical cross sectional studies(261).

The Mixed Methods Appraisal Tool (MMAT) has more recently been developed to evaluate the quality of mixed methods studies that employ qualitative and quantitative methods. The tool also enables researchers to appraise different study designs concordantly. Study designs included in the tool are qualitative, quantitative randomised control trials, quantitative non-randomised control trials, quantitative descriptive studies, along with appraisal criteria for mixed methods research. The framework includes screening questions for all studies. Appraisal is then based on four criteria for each methodological domain. Studies are assigned a score of 25% (*) – 100% (****) depending on whether they fulfil each of the criteria(263).

Although a growing number of researchers are using MMAT(264-266), it has been less widely applied than frameworks to appraise individual qualitative and quantitative studies such as CASP(262). Furthermore, the tool is limited to the appraisal of methodological quality and does not consider the quality of reporting(263). Some researchers also have misgivings about using evaluative tools that provide a numerical score since they obscure the subjective judgements involved in the appraisal process(267).

3.1.3 Evaluating the strength of qualitative reviews

Appraisal frameworks are also being used to evaluate the strength of the resultant qualitative and mixed methods reviews and include Confidence in the Evidence from Reviews of Qualitative Research (CERQual) and Confidence in the Output of Qualitative Research Synthesis (CONQual). CERQual is an interpretive tool that evaluates how much confidence should be placed in each theme identified in the review. Each theme is analysed according to four criteria: 'methodological limitations', 'relevance', 'coherence' and 'adequacy of data'. 'Methodological limitations' refers to the strength of the methodologies used in the primary studies. 'Relevance' considers how well the context of the primary studies and the context of the review question are aligned. 'Coherence' refers to the extent that the review finding is supported by the data from the primary studies. 'Adequacy of data' considers if the data included is sufficiently 'rich' and detailed to describe a phenomena or if there are a large enough quantity of primary studies to support a finding. Based on this, an assessment is made on whether there is 'very low confidence', 'low confidence', 'moderate confidence' or 'high confidence' in the review finding(268).

The CONQual appraisal tool identifies two factors that impact on confidence in review findings: 'dependability' and 'credibility'. Here, 'dependability' in qualitative research is understood as the congruence between the methodology and the research question, and 'credibility' as how well authors' interpretations reflect the primary data. Primary studies included in the review are evaluated based on these criteria. An overall assessment of synthesised findings is established based on these appraisals of primary studies(269).

Frameworks have also been developed to enhance presentation of qualitative syntheses. Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) is a 21 item framework to improve the transparency of reporting in qualitative syntheses. Items are grouped into five themes: 1) Introduction or how well the research aims are defined; 2) Methods and methodology, how well the chosen methods fit the aims of the research; 3) Literature search strategy and study selection; 4) Appraisal approach; and 5) Methods to synthesise findings(270). The Meta-Ethnography Reporting Guidelines (eMERGe) is also being developed to improve the reporting of meta-ethnographies(271).

3.2 Narrative synthesis of literature on clubfoot in low and middle-income countries

3.2.1 Introduction

A narrative synthesis was chosen to synthesise findings since it enabled the systematic identification of all literature, the inclusion of qualitative and quantitative studies(246) and to compare and contrast findings from the respective studies. A decision was made to limit the review to published studies that were more likely to be of higher quality and provide more systematic exploration of issues than grey or unpublished literature.

3.2.2 Methods

1) Identifying the review focus

To determine the review focus, I undertook a scoping review to identify key themes in clubfoot literature relevant to this study. The initial aim here was to map all existing literature on clubfoot in low and middle-income settings. Ovid MEDLINE

database was searched and the following terms applied as keyword searches and thesaurus terms or subject headings: clubfoot, "club-foot", talipes, equinovarus and "idiopathic clubfoot". Results were then combined with a current list of low and middle-income countries as defined by the World Bank(66).

488 articles were identified. Literature was dominated by clinical studies such as those exploring the aetiology of clubfoot, the incidence and distribution of the condition, description of treatment methods, evaluation of treatment outcomes and case studies. Other key areas were experiences of implementing services delivering the Ponseti method, local theories of causation and treatment-seeking behaviour. I then held a meeting to discuss these findings in relation to the study aims. Decisions were then made on whether they should be included in the formal review.

2) Specifying the review question

Based on this meeting, I aimed to conduct a narrative synthesis of literature on clubfoot in low and middle-income countries that included an overview of the implementation of services using the method, local theories of causation and treatment-seeking behaviour. Rather than formulating a precise review focus, I decided that the approach should be flexible to allow me to incorporate other key areas if they emerged. Clinical studies were excluded since it was felt that these were not relevant to the thesis.

3) Identifying studies to include in the review

Search strategies

Two search sources were used to identify studies relevant for inclusion: electronic databases and hand-searching.

Electronic databases

I conducted a comprehensive review of relevant studies using the following databases:

- Ovid MEDLINE
- PsycINFO
- Embase
- Global Health
- CINAHL

Search terms

Search terms were based on those used in two Cochrane reviews(272, 273). For consistency, low or middle income countries are defined as those identified by the World Bank(66). The search used a combination of keyword searches and thesaurus terms or subject headings.

Search terms were limited to two fields:

- The condition of clubfoot
- Setting in low and middle income countries

Searches were limited to those published in English in the last 10 years since interventions for treating clubfoot have changed, along with the social context in which the condition is experienced. See Box 1 for the search syntax used in Ovid Medline, PsyINFO, Embase and Global Health. See Box 2 for the search syntax used in CINAHL. All databases were searched in December 2017.

Box 1: Search syntax used in Ovid Medline, PsyINFO, Embase and Global Health

1. Clubfoot/
2. (clubfoot or clubfeet or "club-foot").ti,ab.
3. (equinovarus or equino-varus).ti,ab.
4. talipes.ti,ab.
5. (foot adj3 deformit*).ti,ab.
6. (foot adj3 malformation*).ti,ab.
7. 1 or 2 or 3 or 4 or 5 or 6
8. 7
9. limit 8 to (english language and yr="2007 -Current")
10. Developing Countries/
11. (Africa or Asia or Caribbean or West Indies or South America or Latin America or Central America).hw,kf,ti,ab,cp.
12. (Afghanistan or Albania or Algeria or Angola or Antigua or Barbuda or Argentina or Armenia or Armenian or Aruba or Azerbaijan or Bahrain or Bangladesh or Barbados or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brasil or Brazil or Bulgaria or Burkina Faso or Burkina Fasso or Upper Volta or Burundi or Urundi or Cambodia or Khmer Republic or Kampuchea or Cameroon or Cameroons or Cameron or Camerons or Cape Verde or Central African Republic or Chad or Chile or China or Colombia or Comoros or Comoro Islands or Comores or Mayotte or Congo or Zaire or Costa Rica or Cote d'Ivoire or Ivory Coast or Croatia or Cuba or Cyprus or Czechoslovakia or Czech Republic or Slovakia or Slovak Republic or Djibouti or French Somaliland or Dominica or Dominican Republic or East Timor or East Timur or Timor Leste or Ecuador or Egypt or United Arab Republic or El Salvador or Eritrea or Estonia or Ethiopia or Fiji or Gabon or Gabonese Republic or Gambia or Gaza or Georgia Republic or Georgian Republic or Ghana or Gold Coast or Greece or Grenada or Guatemala or Guinea or Guam or Guiana or Guyana or Haiti or Honduras or Hungary or India or Maldives or Indonesia or Iran or Iraq or Isle of Man or Jamaica or Jordan or Kazakhstan or Kazakh or Kenya or Kiribati or Korea or Kosovo or Kyrgyzstan or Kirghizia or Kyrgyz Republic or Kirghiz or Kirgizstan or Lao PDR or Laos or Latvia or Lebanon or Lesotho or Basutoland or Liberia or Libya or Lithuania or Macedonia or Madagascar or Malagasy Republic or Malaysia or Malaya or Malay or Sabah or Sarawak or Malawi or Nyasaland or Mali or Malta or Marshall Islands or Mauritania or Mauritius or Agalega Islands or Mexico or Micronesia or Middle East or Moldova or Moldovia or Moldovian or Mongolia or Montenegro or Morocco or Ifni or Mozambique or Myanmar or Myanma or Burma or Namibia or Nepal or Netherlands Antilles or New Caledonia or Nicaragua or Niger or Nigeria or Northern Mariana Islands or Oman or Muscat or Pakistan or Palau or Palestine or Panama or Paraguay or Peru or Philippines or Philipines or Phillipines or Phillippines or Poland or Portugal or Puerto Rico or Romania or Rumania or Roumania or Russia or Russian or Rwanda or Ruanda or Saint Kitts or St Kitts or Nevis or Saint Lucia or St Lucia or Saint Vincent or St Vincent or Grenadines or Samoa or Samoan Islands or Navigator Island or Navigator Islands or Sao Tome or Saudi Arabia or Senegal or Serbia or Montenegro or Seychelles or Sierra Leone or Slovenia or Sri Lanka or Ceylon or Solomon Islands or Somalia or South Africa or Sudan or Suriname or Surinam or Swaziland or Syria or Tajikistan or Tadzhikistan or Tadjikistan or Tadzhik or Tanzania or Thailand or Togo or Togolese Republic or Tonga or Trinidad or Tobago or Tunisia or Turkey or Turkmenistan or Turkmen or Uganda or Ukraine or Uruguay or USSR or Soviet Union or Union of Soviet Socialist Republics or Uzbekistan or Uzbek or Vanuatu or New Hebrides or Venezuela or Vietnam or Viet Nam or West Bank or Yemen or Yugoslavia or Zambia or Zimbabwe or Rhodesia).hw,kf,ti,ab,cp.
13. ((developing or less* developed or under developed or underdeveloped or middle income or low* income or underserved or under served or deprived or poor*) adj (countr* or nation? or population? or world)).ti,ab.
14. ((developing or less* developed or under developed or underdeveloped or middle income or low* income) adj (economy or economies)).ti,ab.
15. (low* adj (gdp or gnp or gross domestic or gross national)).ti,ab.
16. (low adj3 middle adj3 countr*).ti,ab.
17. (lmic or low and middle-income countries or third world or lami countr*).ti,ab.
18. transitional countr*.ti,ab.
19. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20. 7 and 19
21. 20
22. limit 21 to (english language and yr="2007 -Current")

Box 2: Search syntax used in CINAHL

S16 (S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14) AND (S7 AND S15)	**Limiters** - Published Date: 20070101-20171231; English Language
S15	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14
S14	TI transitional countr* OR AB transitional countr*
S13	TI (lmic or lmics or third world or lami countr*) OR AB (lmic or lmics or third world or lami countr*)
S12	TI low W3 middle W3 countr* OR AB low W3 middle W3 countr*
S11	TI (low* W1 (gdp or gnp or gross domestic or gross national) OR AB (low* W1 (gdp or gnp or gross domestic or gross national)
S10	TI ((developing or less* developed or under developed or underdeveloped or middle income or low* income) W1 (economy or economies)) OR AB ((developing or less* developed or under developed or underdeveloped or middle income or low* income) W1 (economy or economies))
S9	TI ((developing or less* developed or under developed or underdeveloped or middle income or low* income or underserved or under served or deprived or poor*) W1 (countr* or nation? or population? or world)) OR AB ((developing or less* developed or under developed or underdeveloped or middle income or low* income or underserved or under served or deprived or poor*) W1 (countr* or nation? or population? or world))
S8	Developing Countries/ OR (Africa or Asia or Caribbean or West Indies or South America or Latin America or Central America) OR (Afghanistan or Albania or Algeria or Angola or Antigua or Barbuda or Argentina or Armenia or Armenian or Aruba or Azerbaijan or Bahrain or Bangladesh or Barbados or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brasil or Brazil or Bulgaria or Burkina Faso ...
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S6	TI foot W3 malformation* OR AB foot W3 malformation*
S5	TI foot W3 deformit* OR AB foot W3 deformit*
S4	TI talipes OR AB talipes
S3	TI (equinovarus or equino-varus) OR AB (equinovarus or equino-varus)
S2	clubfoot OR TI (clubfoot or clubfeet or "club-foot") OR AB (clubfoot or clubfeet or "club-foot")
S1	clubfoot OR TI (clubfoot or clubfeet or "club-foot") OR AB (clubfoot or clubfeet or "club-foot")

Hand-searching

Bibliographies of relevant articles identified were hand-searched for additional material.

Screening

I manually screened search results to identify sources which fulfilled the following criteria:

1. Source was focused on clubfoot condition

2. Source explored one or more of the following:

    - Use of the Ponseti method
    - Implementation of services delivering the Ponseti method
    - Local theories of causation
    - Treatment-seeking behaviour
    - Any other areas that we thought may be relevant to the study aims

3. The care setting was in low or middle income countries as defined by the World Bank(66)

4. The source was written in English

5. The source was published in the last 10 years

4) Data extraction and quality appraisal

Quality appraisal for the studies identified was conducted using the Mixed Methods Appraisal Tool (MMAT)(263) to enable me to appraise the qualitative, quantitative descriptive studies and mixed methods studies concordantly. In accordance with the MMAT user protocol, studies were given a score of 1 – 4* based on the extent that they met the four MMAT criteria. 1* (25%) denotes a lower study quality, 4* (100%) a higher study quality. Quality judgements in relation to the MMAT framework are presented in Table 3. To facilitate transparency, reasons for assigning the MMAT score are presented in the table along with quality assessments. The MMAT framework is included in the Appendix section.

Since the MMAT tool did not include a tool for assessing the quality of systematic reviews, the CASP appraisal tool for assessing systematic reviews was used for these studies. Systematic reviews were judged to 'fully', 'mainly' or 'partially' address CASP criteria. Quality judgements in relation to the CASP framework for systematic reviews are presented in Table 4, along with reasons for quality judgements. The CASP appraisal tool for systematic reviews is included in the Appendix section.

Since the purpose of this review was to provide an overview of existing literature rather than to generate new findings, no studies were excluded from the review based on quality assessments.

5) The synthesis

Studies were imported into NVivo qualitative analysis software(274) and analysed using a thematic approach, that is, coding the data to identify themes and subthemes in the articles(275). Codes were then grouped into key areas. Due to the large number

of studies under review, analysis was limited to the secondary interpretations of authors.

6) Reporting the results of the review

Written accounts of the data were then generated. Since the presentation of findings was descriptive, ENTREQ framework, a 21 item list to improve the reporting of qualitative syntheses, was used to improve transparency(243).

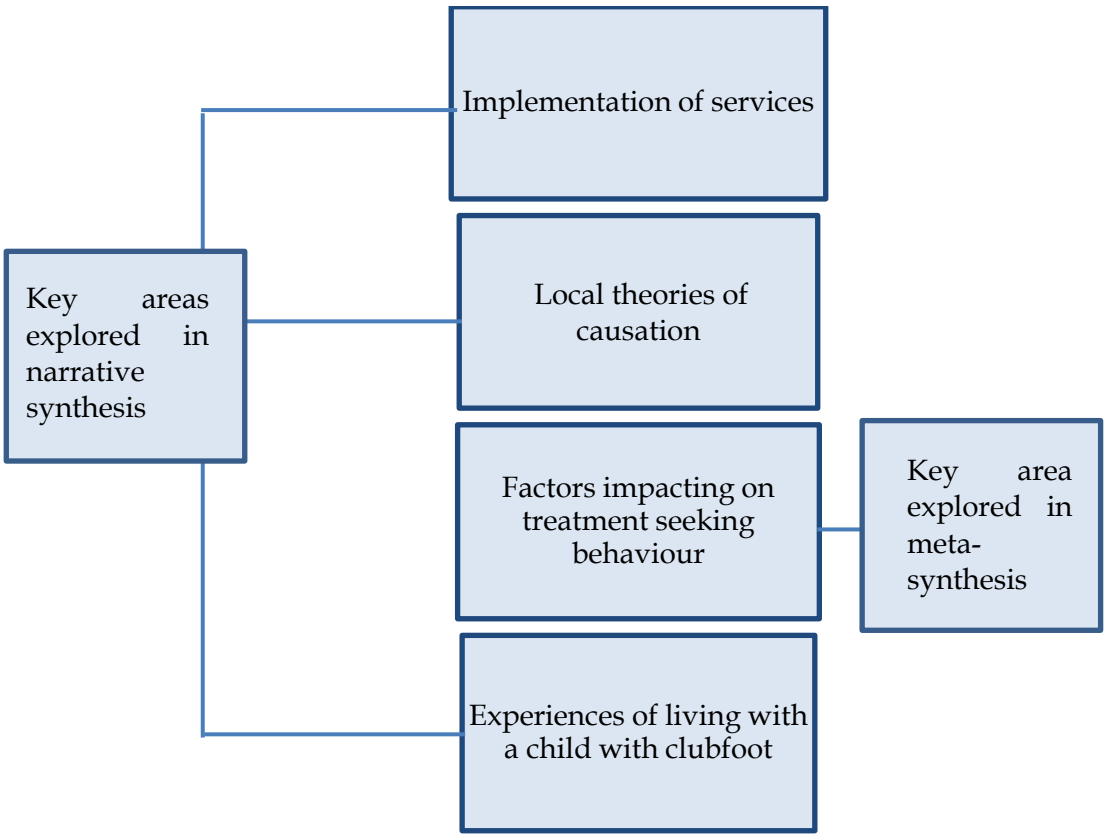
3.2.3 Results

Literature identified

The search strategies yielded a total of 1222 results. Of these, 821 were screened by title, heading, summary or abstract. The process of identifying studies or sources relevant for inclusion is detailed in a PRISMA flow chart in Figure 8. 52 results were screened for full eligibility and 25 included in the final review. A summary of the characteristics of the sources are presented in Tables 3 and 4.

Four key areas were identified in the review: the implementation of services delivering the Ponseti method; local theories of causation; factors impacting on treatment-seeking behaviour. An additional area, experiences of living with a child with clubfoot, was also identified. Findings related to the implementation of services delivering the Ponseti method; local theories of causation and experiences of living with a child with clubfoot are presented below. Factors impacting on treatment-seeking behaviour were explored using a meta-synthesis presented later in the chapter. See Figure 7 below.

Figure 7: Key themes identified in literature review



Key areas

Implementation of services

A number of studies have explored the experiences of healthcare professionals of implementing clubfoot treatment programmes using the Ponseti method in low and middle-income countries(28, 29, 51, 62, 276) (65) (30, 52) (64).

A systematic narrative review conducted in 2014 aimed to explore factors that impacted on the effective delivery of clubfoot programs in Low and middle-income countries. The review included empirical studies and non-empirical program

descriptions. The study identified six best practices to help deliver care: 1) early diagnosis; 2) establishing treatment services with high volumes of patients; 3) using non-physician health workers; 4) engaging families in care; 5) addressing patient barriers to access; 6) following patients up in their communities. Strategies to implement these practices included educating healthcare workers in the community to identify clubfoot, establishing clinics in areas with high patient catchments, training community health workers to provide treatment, educating patients about treatment protocols and establishing referral pathways to surgeons for neglected clubfoot (277). A more recent 2017 review that also included empirical studies and descriptions of services, identified similar barriers and facilitators to service delivery. Patient barriers included a lack of transportation, finances and following treatment protocols. Provider barriers identified included were a lack of training for healthcare professionals and resources(278).

All other included studies have used qualitative and mixed methods approaches. A lack of access to resources was identified(20, 28-30, 51, 65, 276). In Vietnam, some practitioners did not have access to tenotomies(29). There were also challenges with the working environment and in some settings practitioners felt they had limited space to work(28, 64, 276). Others were concerned that the environment for performing tenotomies was not sterile(28).

Participants in these studies felt that there was a shortage of healthcare personnel to treat patients(62, 276), along with a lack of time to deliver treatment during clinics(28, 276) (52) (64). Conflicting demands exacerbated this problem(28, 51, 276).

There was seen to be a lack of training and education about the treatment(29, 51, 62, 276) (65) (52) (30) (64). It was felt that the nurses and midwives attending to the child at birth and in the early years were failing to diagnose the condition or were unaware about the existence of treatment. As a result referrals were missed and treatment was delayed(62, 276) (64). Some physicians were concerned that their training had lapsed since they had seen very few cases and that they were no longer equipped to deliver the treatment effectively(51) (65) (52) (64). Senior members of staff in two settings were keen to delegate more responsibilities to lab technicians and nurses but were unable to do so due to the lack of availability of training(276) (64). In a number of settings it was found that professionals were departing from Ponseti protocols, rendering the method less or even ineffective(28, 30, 52, 62, 65) (64). Underlying many of these problems were the financial constraints of the hospitals and by implication, the healthcare systems(51, 276) (52).

Some participants identified failures in communication and cooperation within the healthcare system(51, 62, 64, 276) such as failures to identify the condition at birth(276). Referrers were often unaware of nearby Ponseti clinics, meaning carers faced unnecessarily long journeys to treatment centres(64). Inter-disciplinary disagreements between physiotherapists and orthopaedic surgeons in Nigeria meant that the production of abduction braces was delayed(276).

Although a range of challenges were identified, a small number of participants in China did not experience difficulties. Likewise, staff in Vietnam found that abduction braces were readily available(29).

Strategies were suggested to address some of these issues. Unsurprisingly it was felt that training in the method should be made more widely available(276) (65) (64). That included training midwives and nurses in the community to identify the condition(62, 64, 276), training more physicians(276) and introducing refresher courses for those that lacked confidence in delivering the treatment(276). Introducing specialised clinics or training those most likely to practice the method rather than widescale training programmes, was suggested as a means of ensuring consistently high standards of treatment(65) (52). Educating support staff such as nurses and lab technicians in specific aspects of treatment was viewed as a way of 'freeing up' more highly qualified members of staff, enabling them to treat more children(52).

There was a recognition that communication between practitioners working within the same country should be improved (64, 65). It was also suggested that communication with other countries could be facilitated as a means of sharing best practice. Suggested strategies for this were through virtual clinics and international conferences(64).

Local theories of causation

All of the studies that explored local theories of causation were qualitative. Only two studies conducted in Malawi and Pakistan focused exclusively on guardians' beliefs about the causes of clubfoot or those of the wider society only(128, 279). Four considered these as part of a wider study in China, Uganda(58), Kenya(62) and Nigeria(276). Beliefs varied between settings. However, they can broadly be divided

into four areas: biological or bodily causes, God or Satan, traditional beliefs and the natural world or environment.

Bodily causes considered were wide ranging. In Uganda and Malawi these included a small or damaged womb or having twins since this was seen to limit space in the womb(58, 128) and an illness or infection in the mother during pregnancy(58, 128, 280). Taking medication during pregnancy was suggested in Uganda, Malawi and Pakistan and this included biomedical and traditional medicines(58, 128, 279). In Malawi and Uganda the contraceptive pill was seen as being particularly risky(58, 128). In Uganda, problems while the child was in utero or during birth was also suggested, along with diseases once the child was born and a failure to vaccinate them(58). Drug abuse, smoking and drinking in either parent were viewed as risk factors in Uganda and Pakistan(58, 279). A lack of maternal nutrition was cited in Malawi, Uganda and Pakistan(58, 128, 279). Domestic violence and battery while the mothers were pregnant was thought to be a cause in Malawi and Uganda(58, 128, 280). Genetic and hereditary explanations were considered in a number of settings(58, 128, 279)

Religious explanations were prevalent, including Christianity and Islam and traditional beliefs. For those in Africa and Pakistan, the condition was considered 'God's will' and this facilitated acceptance of the condition(58, 128, 276, 279, 280). For others, it was a punishment from God for committing bad deeds(62, 128, 276, 279) (64). In Malawi, Satan or the Devil were also mentioned(128, 280). In studies conducted in Africa, traditional religious beliefs were widely discussed, especially witchcraft and curses(58, 62, 128, 276, 280). Reasons for these curses were quarrels(58, 128) and laughing at someone with a disability(58). In Pakistan a small number of

participants attributed clubfoot to spirits or 'djinns'(279).

Environmental causes were also proposed including pollution and hilly and cold terrain in one region of Uganda(58). A number of participants were unsure of the causes or cited a number of possible reasons in absence of one explanation(58, 280).

Factors impacting on treatment seeking behaviour

Only two quantitative studies have explored these issues(281-283). Qualitative studies examining factors impacting on treatment-seeking behaviour for clubfoot have been explored in a number of different contexts(52, 58, 60, 62-64).

Since treatment-seeking behaviour was a major theme in this study, qualitative studies exploring impacts on treatment-seeking behaviour are discussed later in this chapter.

Experiences of living with a child with clubfoot

A small number of studies explored the social and emotional impacts on families of living with a child with clubfoot. Many of these impacted on treatment-seeking. Studies showed that families and caregivers experienced considerable distress and anxiety after a diagnosis of clubfoot(284-286). A study conducted in Madagascar found that mothers hid their child's feet(285). In South Africa, these feelings of anxiety continued throughout treatment(287). Likewise, participants in Peru thought they were being 'judged' by some family members and the wider community for putting their child in casts(288). They were also concerned the casts and braces

would prevent the child from developing 'normally' since it meant they were unable to walk and crawl(288).

However, those in South Africa also felt they received high levels of emotional support from their family and friends and used a range of coping strategies to help them during this time, including their religious beliefs(287).

3.2.4 Discussion

This narrative synthesis has identified four key areas in the clubfoot literature of relevance to this study: the implementation of services delivering the method, local theories of causation, factors impacting on treatment-seeking behaviour and experiences of living with a child with clubfoot. Of the 25 studies identified, two were systematic reviews, seven were quantitative, 13 were qualitative and three used a mixed methods approach that incorporated qualitative and survey research.

Although a growing body of literature exists that explores the use of the Ponseti method in low and middle-income contexts, a number of gaps remain. Most notably these include patient experiences of accessing treatment, of living with and giving birth to a child with clubfoot and the social and emotional impacts of accessing treatment. The review has also highlighted the variable quality of the existing literature. Using the MMAT frameworks, no studies were considered to score 1* (25%), six studies were considered to score 2* (50%), 13 3* (75%) and three studies 4* (100%). Both systematic reviews included here were considered to fully address CASP criteria.

Strengths and weaknesses

Although I aimed to conduct an exhaustive search, it is impossible to say with certainty that all key areas were identified. However, using broad search parameters helped to ensure that the widest range of literature was captured. Relevant literature sources were also identified with input from a clinician with experience of delivering clubfoot services in low and middle-income settings. As a result, I am confident that an exhaustive search was probably achieved. As findings were descriptive, results were presented in accordance with ENTREQ guidelines to improve the transparency of the reporting of qualitative reviews(243).

The inclusion of multiple study designs in the review made it difficult to select a method of appraisal to ensure that quality judgements were comparable. Rather than using multiple frameworks such as the CASP framework for qualitative studies and the JBI-QARI for descriptive quantitative study designs, a decision was made to use the MMAT framework. This enabled me to appraise the quality of the literature concordantly. However, although the tool has been validated(289), it is less well established than the CASP(262) or JBI-QARI frameworks(261). Furthermore, there are wider concerns about using scoring systems to appraise study quality since they may obscure subjective quality judgements, as discussed(267). To facilitate transparency, reasons for quality judgements were included in Tables 3 and 4. In addition, the low quality scores of many of the qualitative studies can be attributed to the fact that authors did not discuss how their presence as researchers impacted on data collection. I feel that the importance of this in evaluating the quality of qualitative studies is debatable. Further work therefore needs to be done on the use of the MMAT tool in appraising study quality. Using the CASP appraisal tool to

evaluate the quality of systematic reviews made it difficult to compare study quality with the other included articles.

When grouping study findings into key areas, I found that some data could be coded into more than one category. Where this occurred, a decision was made to code the data into what I considered to be the most appropriate theme. Since the aim of this synthesis was not to generate new insights into the phenomena but to provide a comprehensive summary of existing literature relevant to this study, a discussion of the impact of quality appraisal on review findings is not relevant here.

3.2.5 Conclusions

Although a growing body of literature exists that explores the use of the Ponseti method in low and middle-income contexts, several gaps remain. Most notably these include patient experiences of accessing treatment, of living with and giving birth to a child with clubfoot and the social and emotional impacts of accessing treatment. The review has also highlighted the variable quality of the existing literature. Further high quality research is now needed to explore experiences of accessing treatment, of living with and giving birth to a child with clubfoot and the social and emotional impacts of accessing services.

Figure 8: PRISMA flow chart detailing process of identifying studies relevant for inclusion in narrative synthesis of clubfoot literature

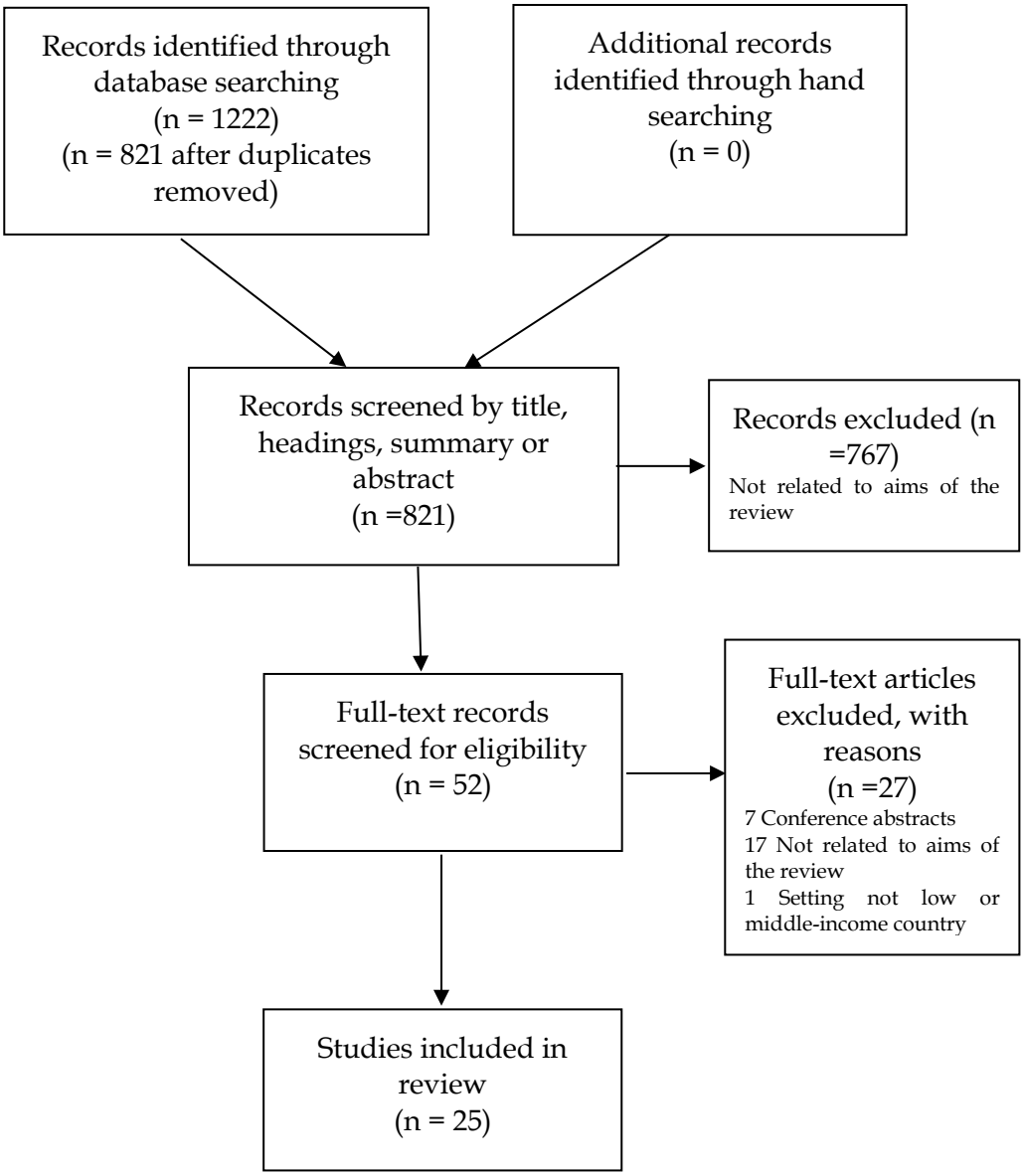


Table 3: Summary of the characteristics of qualitative, quantitative descriptive studies and mixed methods studies included in the review

First author, year	Country	Methods	Aim	Characteristics in relation MMAT	MMAT score
Aktintayo, O. A., 2012(61)	Nigeria	25 semi-structured interviews or questionnaires with physicians practising Ponseti method, 6 questionnaires with newly trained practitioners and interviews or focus groups with 42 parents of children with clubfoot	To evaluate the initial impact of the Ponseti method and identify challenges to its diffusion and implementation	Sources of data largely appropriate to the research aims but it is unclear what the questionnaires contributed to the study. Thematic analysis conducted is appropriate for analsing data but there was a lack of information on how this was carried out. Findings clearly embedded in local context. Influence of researcher on study findings not discussed.	*** **(75%)**
Bedford, J., 2009(63)	Malawi	Sixty case studies with patients and guardians of children accessing clubfoot services using semi-structure interviews	To identify local theories of the causation of clubfoot by guardians and carers of those accessing clubfoot treatment	Sources of data relevant to the research question and sampling strategy appropriate and clearly described. The process of thematic analysis undertaken is described in detail and appropriate to aims of the study.	*** **(75%)**

				Findings clearly embedded in local context including background of Ponseti method in Malawi. Influence of researcher on study findings not discussed.	
Bedford, J., 2011(290)	Malawi	60 case studies with parents of children with clubfoot using interviews, photographs, observation	To explore the treatment-seeking behaviour of guardians of patients undergoing treatment for clubfoot using the Ponseti method	Sources of data relevant to the research question and setting clearly justified. The process of thematic analysis undertaken is described in detail and appropriate to aims of the study. Findings clearly embedded in local context including background of Ponseti method in Malawi. Influence of researcher on study findings not discussed.	*** **(75%)**
Boardman, A., 2011(65)	Chile, Peru, Guatemala	30 semi-structured interviews with physicians practising the Ponseti method	To evaluate the impact and barriers to the diffusion of the Ponseti method	Sources of data relevant to the research question although the sampling strategy used is unclear. Thematic analysis conducted is appropriate for analsing data but there was a lack of information on how this was carried out. Findings clearly embedded in local context.	*** **(75%)**

				Influence of researcher on study findings not discussed.	
Burfat, A., et al(279)	Pakistan	Seven focus groups with community members and female health workers, nine in-depth interviews with parents of children with treated or untreated clubfoot, and one interview with an adult with untreated clubfoot	To explore knowledge and perceptions about clubfoot	Data collection using semi-structured interviews and focus groups relevant to the research question. However, no justification of treatment centre selected. The use of thematic analysis appropriate to aims of the study. Findings clearly embedded in local context including detailed description of hospital catchment. Influence of researcher on study findings not discussed.	*** **(75%)**
Esan, O. et al.(286)	Nigeria	Cross-sectional study with 58 parents of children with clubfoot. The Hospital Anxiety and Depression Scale (HADS) and Parenting Stress Index Short Form were used to assess emotional and parenting stress	To assess levels of emotional distress and parenting stress among parents of children with clubfoot	It is unclear how participants were sampled. The inclusion and exclusion criteria are clearly outlined. Data collection tool is appropriate and a standard instrument as been used. Response rate is not included.	** **(50%)**
Evans(29)	Vietnam	36 surveys distributed to healthcare professionals who had completed a three day	To evaluate the use of the Ponseti method by healthcare professionals who had	Sampling strategy was appropriate since it was distributed to all	**** **(100%)**

		training course in the Ponseti method	participated in a three day training course	healthcare professionals who had participated in the training course. Sample was representative of the population under study (see above). Areas included in the questionnaires clearly elucidated although the questionnaire itself was not inlcluded in the article. The response rate was over 60% so is therefore acceptable.	
Gadhok, K., 2012(52)	India	38 questionnaires completed by physicians practising the Ponseti method 15 semi-structured interviews with orthopaedic surgeons practising Ponseti method, 15 semi-structured interviews with parents of children receiving treatment with Ponseti method	To identify the challenges to the diffusion and implementation of the Ponseti method	Mixed methods study design appropriate. Integration of qualitative and quantitative data relevant to address research question. Discussion on the strengths of triangulation but no discussion of limitations of integrating qualitative and quantitative data. Limitations were identified in the design of both of the qualitative and quantitative components of the study. For instance, in the quantitative component the questionnaire used was not	** **(50%)**

				included. There was also a low response rate of less than 40%.	
Jayawardena, A., 2011(25)	Guatemala, Peru and Chile	Semi-structured interviews and observations with 33 healthcare providers participating in web conferencing sessions	To evaluate the use of web conferencing to disseminate information about the Ponseti method	Research methods appropriate for addressing research aims. Thematic analysis appropriate for analysing data and details included on how this was conducted. Context clearly described. Influence of researcher on study findings not discussed.	*** **(75%)**
Jayawardena, A., 2013(291)	Sri Lanka	162 patients and healthcare practitioners involved with clubfoot care using interviews, focus groups, observation	To evaluate the utility of a 'train the trainer' approach for disseminating the Ponseti method	Use of interviews, focus groups and observations relevant to the research question although setting of data collection not justified. Thematic analysis conducted is appropriate for analsing data although there was a lack of information on how this was carried out. Findings clearly embedded in local context. Influence of researcher on study findings not discussed.	*** **(75%)**
Kazibwe, H. and P. Struthers(283)	Uganda	A survey with 167 parents of children	To identify the barriers parents experience during the casting	Sampling strategy is clearly outlined and all parents/ carers of	*** **(75%)**

		undergoing the Ponseti method	phase of the Ponseti treatment	children with clubfoot were included. The inclusion and exclusion criteria are clearly outlined. Questionnaire design is appropriate, clearly described and a pilot study used to refine its development. The response rate has not been included in the article.	
Kingau, N. W., 2015(62)	Kenya	10 semi-structured interviews with service providers delivering clubfoot treatment, 10 semi-structured interviews with caregivers of children with clubfoot	To identify barriers experienced by service providers and carers to the effective management of clubfoot using the Ponseti method and surgical interventions	Use of semi-structured interviews relevant to the research question. Explanation of how participants were sampled and why they were most appropriate to address research aims. Thematic analysis conducted is appropriate for analsing data. Findings clearly embedded in local context. Influence of researcher on study findings not discussed.	*** **(75%)**
Lu, N., 2010(59)	China	39 physicians practising the Ponseti method, 8 sets of	To evaluate and identify barriers to the implementation of the	Use of semi-structured interviews and focus groups relevant to the research question. Explanation of	*** **(75%)**

		parents of children receiving treatment with Ponseti using semi-structured interviews and focus groups	Ponseti clubfoot program	why participations selected included. Research settings not justified. Thematic analysis conducted appropriate for analsing data and described in detail. Findings related to wider health context. Influence of researcher on study findings not discussed.	
Malagelada, F., et al.(287)	South Africa and the UK [Findings from the UK were excluded from review]	Questionnaire with 115 parents of children affected with idiopathic clubfoot. Participants completed three instruments: the Impact on Family Scale (IOFS), the Multidimensional Scale of Perceived Social Support (MSPSS), and the Brief COPE	To determine the impact of the Ponseti treatment on the lives of patients and their parents and coping strategies they adopted. To identify any potential differences between experiences in South Africa and the UK	It is unclear how participants were sampled. There is no justification for the two settings selected. The inclusion and exclusion criteria are clearly outlined. Data collection tool is appropriate and a standardised instrument as been used. Response rate is not included.	** **(50%)**
McElroy, T., 2007(57)	Uganda	42 parents of children with clubfoot, 2 adults with clubfoot , 40 community leaders, 39 traditional healers, 38 practitioners treating clubfoot using semi-	To identify barriers to adherence to the Ponseti method of clubfoot treatment	Use of semi-structured interviews, focus groups and observations relevant to the research question. Information and justification of sampling strategy and of research setting.	*** **(75%)**

		structured interviews, focus groups, observation		Thematic analysis conducted appropriate for analsing data. Findings clearly embedded in local context. Influence of researcher on study findings not discussed.	
Memon, I., et al., 2014 (281)	Pakistan	Cross-sectional survey with 120 parents of children between 6 months to 3 years who had undergone the Ponseti treatment and were at the bracing phase of treatment	To identify the frequency of early relapse after achieving good initial correction in children who were wearing clubfoot abduction braces, including discussion of reasons for lack of adherence	Sampling strategy not clearly outlined. For instance, it is not clear if a random sample was used. The inclusion and exclusion criteria are clearly outlined. Questionnaire design is appropriate and clearly described. The response rate has not been included in the article.	** **(50%)**
Nogueira, M., 2013(30)	Brazil	45 semi-structured interviews with orthopaedists trained in the Ponseti method	To identify barriers to bracing compliance	Semi-structured interviews relevant to the research question although no information provided on how participants were sampled. Description of patient attitudes and behaviour by healthcare professionals is a limitation. No information on how analysis undertaken.	** **(50%)**

				Findings clearly embedded in local context, including background of Ponseti method in Brazil. Influence of researcher on study findings not discussed.	
Owen, R., 2012(292)	Democratic Republic Congo, Rwanda, Dominican Republic, Haiti, Honduras, Ethiopia, Laos, Malawi, Nepal, Paraguay, Tanzania, Zambia	Semi-structured interviews and observations of clinics with 10 clubfoot programme coordinators, 7 programme planners, regional coordinators or trainers, 10 sets of parents attending clinics and 10 trained practitioners in Ethiopia or Laos Quantitative data on programme outcomes detailing number of practitioners who completed training, the number of children who enrolled for treatment in respective countries and the number of clubfoot clinic sites	Evaluation of implementation of 10 clubfoot treatment progammes	Sources of data relevant to the research question and justification for choosing semi-structured interviews and advantages of triangulation of data included. Thematic analysis of data appropriate and clearly outlined. Consideration of how findings relate to context. Consideration of how being seen to be a member of participating organisations could impact on participant responses.	****** (100%)**

Palma, M., 2013(60)	Peru	25 semi-structured interviews with physicians practising the Ponseti method	To evaluate how barriers to using the Ponseti method have changed in 2 years and to identify barriers to its diffusion	Semi-structured interviews appropriate for addressing study aims. However, it is unclear how participants were sampled and setting for data collection not justified. Although thematic analysis appropriate, there is limited information on how this was conducted. Findings clearly embedded in local context, including brief overview of the context of Peru. Influence of researcher on study findings not discussed.	*** **(75%)**
Pletch, A., et al., 2015(288)	Peru	A photography-based participatory research method known as Photovoice with five adult caregivers of children undergoing Ponseti treatment. Participants used a digital camera to photograph their experiences caring for a child undergoing the treatment. Four to five weekly one-on-one meetings were held	To explore caregivers' experiences of caring for a child undergoing treatment with the Ponseti method	Sources of data relevant to the research question. Processes of analysing data are clearly described and appropriate. Context clearly outlined and findings discussed in relation to it. Influence of researcher on study findings not discussed.	*** **(75%)**

		with the researcher to discuss their photos			
Ramahenina, H., R.J. O'Connor, and M.A. Chamberlain, 2016(285)	Madagascar	Questionnaires with 20 mothers of infants younger than 1 year after 3 months of treatment to identify challenges with completing treatment	To determine reasons for the failure of children to complete treatment	Sampling strategy is clearly outlined and all parents/ carers of children with clubfoot at one centre were included. The inclusion and exclusion criteria are clearly outlined. Questionnaire design is appropriate and described. Response rate is outlined and all parents meeting the inclusion criteria agreed to participate.	**** **(100%)**
Tassadaq, N., R. Rafiq, and F.A. Siddiqi, 2016(284)	Pakistan	A survey with 60 caregivers of children with clubfoot. The Hamilton Anxiety Rating Scale (HAM-A) was used to assess levels of anxiety	To assess the levels of anxiety experienced by caregivers of children with clubfoot and identify differences in levels of anxiety between men and women	Sampling strategy is clearly outlined. The inclusion criteria are clearly outlined. Data collection tool is appropriate and a standardised instrument as been used. The response rate has not been included.	*** **(75%)**
Wu, V., 2012(64)	Vietnam	47 questionnaires were completed by practitioners	To evaluate the impact, progress and challenges facing	Mixed methods study design appropriate.	** **(50%)**

		practising the Ponseti method Two focus groups were conducted with 12 practitioners practising the Ponseti method 99 parents of children with clubfoot and extended family participated in semi-structured interviews Observations were conducted in clinics	Ponseti practitioners and patients' family	Integration of qualitative and quantitative data relevant to address research question. Discussion on the strengths of triangulation but no discussion of limitations of integrating qualitative and quantitative data. Limitations with quantitative and qualitative components of study identifed. For instance, there is no information on process of analysis for qualitative component. Response rate to questionnaires was lower than 50%.	

Table 4: Summary of the characteristics of systematic review studies included in the review

First author, year	Country	Methods	Aim	Characteristics in relation to CASP	Extent it addresses CASP items
Harmer, L. and J. Rhatigan, 2014(277)	Low and middle-income countries	A systematic literature review to identify studies that have explored the implementation of the Ponseti method in low and middle-income countries	To create a framework for understanding how effective programs that treat clubfoot in low and middle-income countries choose and organise their activities	The authors addressed a clearly focused question and systematically searched relevant databases for literature. Studies identified were appropriate for addressing research aims. The level of evidence of each individual study was assessed. Analysis was thorough and based on an established analytical framework that has been extensively used in previous studies. Overall, results are clearly described and structured under key themes. Findings are of use and may be transferred to other low and middle-income countries.	Fully
Johnson, R.R., et al., 2017(278)	Low and middle-income countries	A systematic literature review to identify studies that have explored the implementation of the	To evaluate the barriers to service delivery and the solutions that have been proposed or	The authors addressed a clearly focused question and systematically searched relevant databases for literature. Studies identified were appropriate for	Fully

		Ponseti method in low and middle-income countries	implemented to address these barriers	addressing research aims and there is reasonable confidence that all relevant studies were included. The level of evidence of each individual study was assessed. Processes of identifying themes in the data was thorough. The overall results of the review are clear and data was presented under key themes. Findings are of use and may be transferred to other low and middle-income countries.	

3.3 Factors that impact on patient access and engagement in low and middle-income countries

3.3.1 Introduction

The aim of this component was to build on findings from the narrative review by using a meta-synthesis to explore factors that impact on patient access and adherence to clubfoot treatment in low and middle-income countries and community level interventions to address them. A Social Ecological Model was used to structure analysis(235).

A Social Ecological Model was selected since the model recognises the impact of multiple and inter-related factors on treatment-seeking behaviour(235), rather than being limited to rational decision-making choices(242). This includes the structural factors that are particularly salient in low and middle-income countries. The five inter-related determinants of illness behaviour are: 1) 'Intrapersonal factors' that refer to individual characteristics such as socio-economic status and occupation; 2) 'Interpersonal processes' or personal interactions with others; 3) 'Institutional factors' that are the processes embedded in organisations; 4) 'Community level factors' such as values and beliefs in the wider society and 5) 'Public policy'(235). The theory has been widely applied in low and middle-income settings(236) and could provide clinicians with a practical tool for initiating change in the management of clubfoot.

3.3.2 Methods

A meta-synthesis of existing literature exploring patient engagement and adherence to clubfoot treatment and strategies to address these challenges was conducted in four stages: identifying studies for inclusion, appraising quality, data extraction and synthesis and reporting findings.

1) **Identifying studies for inclusion**

25 articles were identified as relevant to the systematic review. I subsequently screened these articles to identify studies which fulfilled the additional criteria:

1. The population included patients, parents, guardians, their close friends and family or healthcare professionals involved in the organisation or delivery of clubfoot treatment
2. The study evaluated patient engagement with services
3. The study used qualitative research methods
4. The research output was either an article or a report

My initial objective was to limit the synthesis to studies with patients, parents, guardians or their close friends and family. However, I found that a number of studies with healthcare professionals also reported perceived patient experiences. A decision was therefore made to include them in the review because the findings included within them were likely to provide valuable information about service use.

Bibliographies of relevant articles identified were then hand-searched for additional material. Since the review was narrower in scope, a decision was made to include written reports that may have provided additional insights into the phenomena.

2) Appraising quality

Quality appraisal was based on the Critical Appraisal Skills Programme (CASP), a 10 point framework constructed to facilitate evaluation of the quality and usefulness of qualitative studies(255). A decision was made to re-appraise the studies using CASP as it enabled me to evaluate the quality of individual reporting.

To appraise the studies using CASP, I grouped the items of the CASP framework into three domains: 1) CASP items about the study's aims and appropriateness of methodology (items 1 and 2); 2) CASP items about study design and conduct, including research design, recruitment, data collection, relationship with researcher, ethics and analysis (items 3-8); and 3) CASP items about clarity of findings and value of the research (items 9-10). I then considered the characteristics of each study in relation to these items and domains. Based on these, the articles identified were classified as 'fully address CASP items', 'mainly address CASP items' or 'partially address CASP items'. Studies that fully addressed CASP items attended fully to *all* of the items; studies that mainly addressed CASP items attended fully to *most* of the items; studies that partially addressed CASP items attended fully to *some* of the items. The distinction between those considered to mainly address items and those that partially addressed items, were based on judgement rather than absolute criteria.

Articles were independently appraised by my supervisor (RGH). Both of us independently arrived at the same judgements about the 13 articles, in which three studies were deemed to fully address items, four mainly address items and four partially address items. However, as all 13 articles contributed valuable insights into

the phenomena, a decision was made to include all of them in the review. This accords with advice from Campbell and colleagues on the use of appraisal frameworks in qualitative syntheses(247). Descriptions of the characteristics of each study in relation to the three CASP domains along with quality assessments are detailed in Table 5.

The Confidence in the Evidence from Reviews of Qualitative Research (GRADE CERQual) was used to evaluate the strength of the review. CERQual evaluated how much confidence should be placed in each theme identified. Each theme was analysed according to four criteria: 'methodological limitations', 'relevance', 'coherence' and 'adequacy of data'. 'Methodological limitations' refers to the strength of the methodologies used in the primary studies. 'Relevance' considers how well the context of the primary studies and the context of the review question are aligned. 'Coherence' refers to the extent that the review finding is supported by the data from the primary studies. 'Adequacy of data' considers if the data included is sufficiently 'rich' and detailed to describe a phenomena or if there are a large enough quantity of primary studies to support a finding. Based on this, confidence in the theme or review finding was designated to be 'high confidence', 'moderate confidence', 'low confidence' or 'very low confidence'(268). The findings from the CERQual appraisal are presented in Table 6.

3) Data extraction and synthesis

The full articles or project reports were imported into NVivo qualitative analysis software(274) and analysed using a thematic approach. That is, coding the data to identify themes and subthemes in the articles(275). Analysis included primary data

such as participant quotes and field note extracts included in the articles, and the secondary interpretations of authors. An index of codes was generated. An abductive analysis(293) was then conducted such that codes were transposed onto the five levels of the Social Ecological Model(235). 50% studies were double-coded by my supervisor (RGH) and the index of codes discussed and refined to reach a single code list.

4) Reporting findings

To facilitate transparency, the review was presented in accordance with ENTREQ guidelines, a 21 item list to improve the reporting of qualitative syntheses(243).

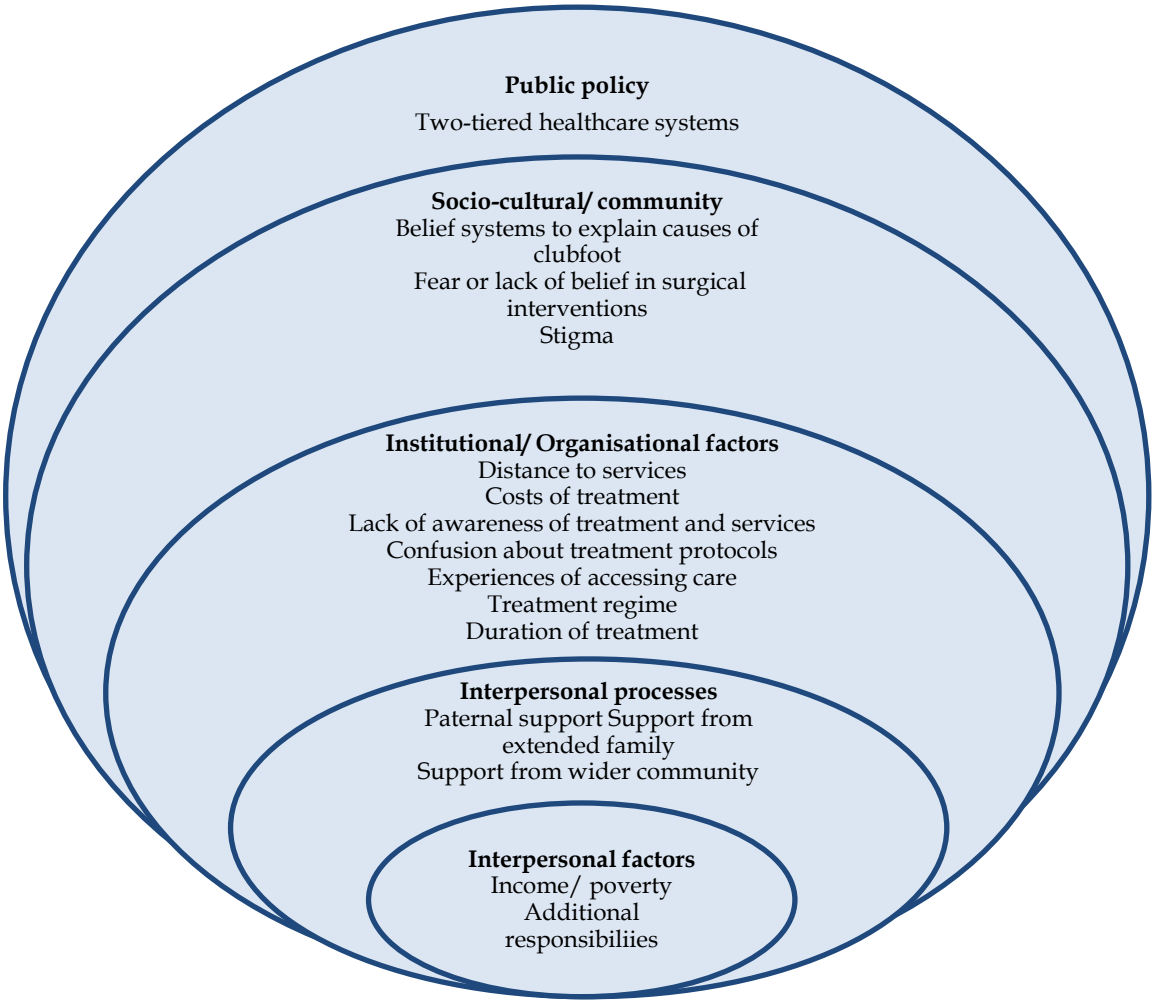
3.3.3 Results

Of the 25 articles identified in the systematic review, 13 were included in this component of the study. The process of identifying studies relevant for inclusion is detailed in a PRISMA flow chart in Figure 10. Of these, two articles were identified as being part of the same study and another three employed mixed methods. Studies explored barriers and facilitators to treatment in the following care settings: Nigeria (1), Malawi (1), Uganda (1), Kenya (1), Latin America (2), India (1), Sri Lanka (1), China (1), Brazil (1), Vietnam (1). A summary of the characteristics of the studies are presented in Table 5. This includes care settings, methodology, study aims and quality appraisal. Articles derived from the same study are grouped and indicated in blue. Articles derived from the same study are cited only once to ensure they do not appear to be over-represented in the analysis.

Factors influencing treatment-seeking behaviour were experienced throughout the care pathway from initial presentation, adherence to casting regime and bracing and

a number of community level interventions to address these challenges identified. A summary of the main factors influencing treatment-seeking and their relation to the five levels of the Social Ecological model(235) are presented in Figure 9.

Figure 9: Factors influencing treatment-seeking behaviour: codes identified and their relation to the 5 levels of the Social Ecological Model



Below I explore factors impacting on service use and treatment in more detail, using the five levels of the Social Ecological Model to inform findings. I also identify community level interventions to address these challenges.

Intrapersonal factors

The income of carers presented a potential barrier to treatment in all studies. For the poorest, a lack of access to resources presented an almost insurmountable challenge. 'Hidden costs' of accessing treatment included travel expenses(52, 58-63) and money lost taking time off from economically productive activity(52, 59, 61, 63, 64). For some, a commitment to adherence meant prioritising treatment at the expense of other essentials such as household amenities and education(58, 63). In Peru and Kenya, carers staying near the treatment centre incurred the cost of accommodation(60, 61).

Additional responsibilities were a factor since parents were often forced to manage commitments to work(52, 58-60, 63, 65) and within the home(58, 63, 65). Treatment-seeking sometimes became a secondary issue that was superseded by other, more immediate problems such as acute illness or hunger(58, 59). Practitioners in Kenya thought treatment was delayed when parents were planning to have more children(61).

Interpersonal processes

The role of social support networks in influencing access to treatment was identified in just under half of the studies(52, 58, 63-65). Paternal support was seen to have a major influence since fathers were a potential source of emotional and practical support(52, 58, 63). In some contexts, women did not seek care for their children because of fathers' decisions about access and use of family finances(58, 62, 63). Elsewhere, fathers were more likely to provide support(58) and accompany their children to clinics(59).

The potential influence of the extended family and wider community varied. For societies with a strong convention of respect for elders, treatment decisions could be made by older members of the extended family(58, 63, 64) or influenced by the advice of community leaders such as pastors(58, 62, 63). Some guardians also received practical support from the extended family(63, 291) or friends(58, 63-65).

Institutional/ organisational factors

In almost all of the studies, many guardians were seen to face long journeys to treatment centres(52, 58, 60, 62-64), resulting in high transport costs(58, 60-62) and long periods away from other responsibilities(52, 60, 62, 65). Accessing reliable transport was viewed as challenging(52, 58, 63, 65). Since the majority of treatment sites existed in urban areas, this tended to make treatment-seeking more difficult for those living rurally(52, 58-60, 63-65, 291).

Treatment costs impacted on treatment-seeking behaviour. Whilst in some care settings free treatment facilitated access(63, 290, 291), in others, carers faced substantial costs such as purchasing materials for casting and braces(30, 58, 60-62, 65, 291). In Uganda, although healthcare services state that they provide free treatment for clubfoot, carers sometimes had to purchase materials when clinics ran out or were asked by healthcare professionals to pay for treatment(58). The existence of regional variation in costs was identified(30, 58, 64, 65).

Healthcare professionals thought that some guardians were not aware that the condition could be treated and that services existed to do so(52, 58-61, 63, 64). Some

guardians did not know that the bracing portion of the treatment was an ongoing element of care and stopped using the brace after casting(30, 57, 59, 60, 63, 65). Both guardians and healthcare professionals described confusion about the bracing protocol, such as when braces should be worn and for what duration(58, 59, 61, 64, 291).

Negative experiences in accessing care meant guardians were less likely to pursue treatment. In Uganda, issues included healthcare professionals' requests for payment, the difficulty of travelling to different regions for casting and bracing(58) and healthcare professionals not arriving to provide care at clinics(58). In other areas, guardians encountered crowded clinics, long waiting times(57, 59, 64) and there were reports of intimidating or aggressive professionals(63). Some clinics ran out of materials meaning that treatment was either delayed or carers were forced to pay(30, 57, 60). Carers were also less likely to consent to casting if they felt that their children had been treated incorrectly previously(64).

The treatment regime presented a number of challenges. These included practical issues such as difficulties in holding and bathing a child wearing a brace(30, 58, 59, 61, 64) and concerns about discomfort(30, 52, 58, 59, 63-65, 291). Duration of treatment was also problematic as it meant that any barriers had to be negotiated over a number of years(58, 63, 64). For instance, although some parents were able to afford initial clinic attendance, they were unable to maintain adherence due to cumulative costs(65) or in the case of those living in a position of financial instability, unable to ensure they could regularly acquire the money needed(58).

Socio-cultural/ community factors

The impact of socio-cultural factors was explored in just over half of the studies and differed widely between care contexts. Factors included belief in biomedical models, faith in alternative belief systems that provided explanation of causes of clubfoot such as witchcraft or God(58, 61-63), fear or a disbelief in surgical interventions(58, 59, 61, 64) and stigma associated with the condition(58, 59, 62-65).

Although there was not a direct relationship between beliefs and treatment-seeking behaviour(63), these helped to shape decisions in nuanced ways. For instance, beliefs about causation and non-biomedical systems meant carers often sought traditional medicine instead, or as well as, biomedical interventions(58, 59, 61, 63). In some cases it was reported that carers were reluctant to intervene if they saw clubfoot as 'God's will'(58) or a 'gift'(64). The stigma associated with clubfoot impacted on treatment-seeking in different ways. For some, it provided a powerful impetus to seek a cure(63, 64), whilst for others it was a hindrance since they did not want to 'advertise' that their child was different to others(58, 59, 62, 63, 65).

Public policy

Participants in the included studies tended to focus on factors at the individual and organisational levels. In Latin America and Brazil, the two-tiered healthcare system presented a barrier(30, 60, 65). Guardians who were dependent on social services or cheap insurance policies experienced longer delays in acquiring braces than those accessing comprehensive private care(30), along with higher treatment costs as some insurance policies did not cover the costs of congenital conditions(60, 65). This made

it more challenging for these groups to access timely and effective care for their children.

Community level interventions to address challenges

Authors and a number of participants identified interventions at the community level to address the challenges identified. To enhance interpersonal support, it was suggested that clubfoot appointments should be arranged on the same day by clinicians, preferably in organised clinics, to enable carers to provide each other with emotional and practical support(52, 58, 63, 65). Observing the progress of other children was also thought to enable parents and guardians to continue to bring children for treatment and carry on with treatment protocols at home(52, 58, 63, 65). Building counselling into treatment was viewed as an opportunity to provide carers with emotional support and to enable practitioners to help parents and guardians with use of treatment(58, 63). It was suggested that involving fathers in this process may help strengthen paternal support(58, 63).

To mitigate the barriers identified at the institutional or organisational level, it was felt that introducing outreach clinics in rural areas(58, 63), or training professionals in these areas where this was not possible(62), could address the long journeys carers face in accessing treatment. It was thought costs of care could be diffused by creating brace recycling programmes(30, 58, 59, 65) or by procuring financial assistance from non-governmental organistions(61). Another author suggested relationships between clinicians and carers may be improved by introducing protocols to help clinicians provide care(63). Monitoring of practice would help ensure that standards and consistency were maintained(58).

Authors and participants thought that education programmes should be introduced to promote awareness of treatment and provide information to guardians accessing care. The general public could receive information through a range of media such as newspapers, radio, posters, leaflets(58, 59, 63) or the internet(59, 60). Community centres such as schools may also be used alongside influential community leaders such as pastors(58, 63). The importance of using appropriate media and taking into account levels of literacy and affluence of groups in society was emphasised in a number of studies(58, 60, 64). Educating healthcare professionals in other settings about the service to enable them to refer patients(58, 61, 63, 64, 291) and encouraging guardians to promote it to other carers was also viewed as important(60, 63, 291). The necessity of explaining the treatment protocol fully to patients was emphasised, especially during the bracing phase of treatment(30, 58)44](52, 63, 65). Employing designated professionals to do this was viewed as a means of 'freeing up' other professionals responsible for this role and ensuring that guardians received this aspect of care(30). Leaflets may be used to provide information to take home and refer to should any questions about protocol arise(30, 59, 61, 64, 65). At the level of public policy, the recognition of the Ponseti method as the gold standard of treament and the implementation of national clubfoot programmes was seen as a way of standardising treatment processes and facilitating the organisation of nationwide publicity campaigns(30, 52, 60, 61, 65).

3.3.4 Discussion

The review has identified and explored a range of factors that impact on presentation and adherence to clubfoot treatment across a range of care settings in low and middle-income countries and identified community level interventions to address

them. Results showed that people experienced impacts at the five levels outlined in the Social Ecological Model: the intrapersonal, interpersonal, institutional or organisational, socio-cultural or community levels and to a lesser extent, the level of public policy(235). Interventions to address these challenges included counselling sessions, outreach clinics, brace recycling and a range of education programmes.

Strengths and weaknesses

The studies identified were independently appraised by my supervisor (RGH) and data double-coded, helping to ensure that quality assessments were consistent and that findings reflect the data under study(294). To facilitate transparency, the review was presented in accordance with ENTREQ guidelines, a 21 item list to improve the reporting of qualitative syntheses(243).

The review findings were limited on account of studies identified. Using the CASP qualitative appraisal framework(255), three studies were deemed to fully address CASP items, four mainly address CASP items and four partially address CASP items. Studies that partially addressed CASP items tended to lack clarity about methods of data collection and analysis. Those that fully addressed CASP items included more detail on these processes. As described in the methods section, I classified the quality of each study based on how well or fully it addressed the CASP items. However, the distinction between studies that were considered to 'mainly address CASP items' or 'partially address CASP items' was based on the quality assessment of two assessors rather than an absolute quality threshold. All included papers contained information about access to clubfoot services that were of relevance to the review and all had value, even where findings could have been presented more clearly or when value

was not explicitly stated by the study authors. Some papers contributed more information to themes than others and this is reflected in the findings where these studies are cited more frequently.

The CERQual appraisal revealed varying confidence in the study findings or themes in which 10 were considered 'high confidence', five of 'moderate confidence' and one 'low confidence'. Of the five inter-related determinants of illness behaviour, themes with the lowest confidence related to socio-cultural or community factors. In three of the studies, patients' views were identified only by healthcare professionals and there may be discrepancies between clinicians' views and those of patients. This may account for the emphasis on organisational or institutional barriers rather than interpersonal or socio-cultural factors.

Due to the focused nature of the articles they did not include nuanced characteristations of practices and societal norms. Therefore, I acknowledge that the synthesis conveys findings as described in the included studies rather than more detailed information about context. The studies identified also tended to focus on barriers to treatment-seeking rather than enablers, accounting for the emphasis on barriers in this review. Also, the studies only represent a limited number of low and middle-income countries. However, given the homogeneity of experiences, we are reasonably confident that these findings are transferable to other care settings(295).

The Social Ecological Model(235) enabled me to explore the issues under study by highlighting the inter-related factors that impact on treatment-seeking behaviour for the guardians of children with clubfoot. To manage the tension between applying a

theoretical framework whilst ensuring that the data was not 'forced' into pre-defined constructs, an inductive thematic analysis(275) was conducted before data were then transposed onto the theory. This meant that any factors that did not 'fit' within the model would have been identified. A further theme—potential interventions to enhance care— was identified using the thematic approach.

3.3.5 Conclusions

This work has successfully used a meta-synthesis to synthesise findings from existing qualitative research on factors that impact on patient access to clubfoot treatment in Low and middle-income countries and identified interventions at the community level to address them. Using the Social Ecological Model(235) to inform findings highlights the inter-related factors that influence treatment seeking.

3.4 Chapter summary

This chapter has systematically explored existing literature on clubfoot including issues around the implementation of services, local theories of causation. Experiences of living with a child with clubfoot and factors impacting on treatment-seeking behaviour. In doing so, it highlights major gaps in the literature that this thesis aims to address.

Figure 10: PRISMA flow chart detailing process of identifying studies relevant for inclusion in meta-synthesis of treatment-seeking behaviour

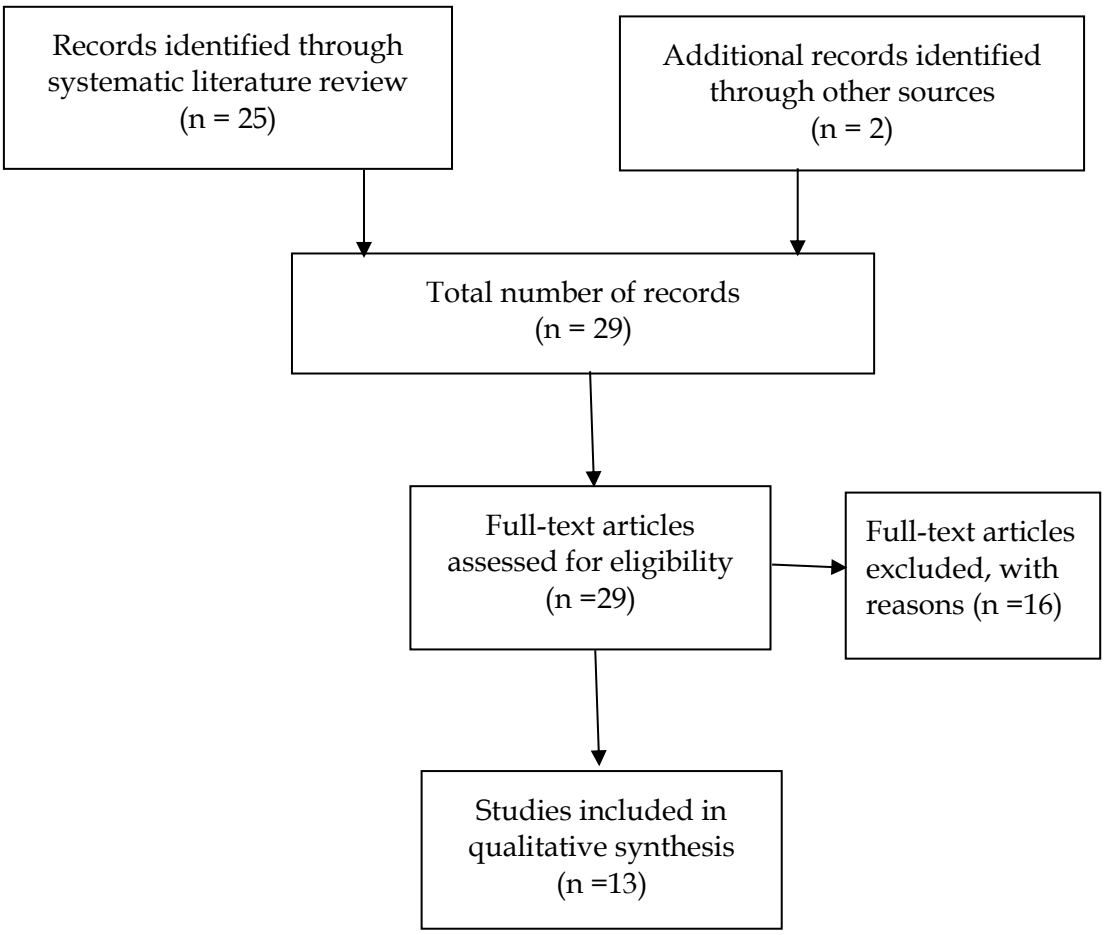


Table 5: Summary of the characteristics of papers included in the meta-analysis of treatment-seeking behaviour

First author, year	Country	Participants	Methods	Aim	Characteristics in relation to three CASP domains	Extent it meets CASP criteria
Aktintayo, O. A., 2012(61)	Nigeria	25 physicians practising Ponseti method, 6 newly trained practitioners, 42 parents of children with clubfoot	Semi-structured interviews, focus groups [As part of a mixed methods study]	To evaluate the initial impact of the Ponseti method and identify challenges to its diffusion and implementation.	**1) Aims and appropriateness** Clear statement of the aims of the research. **2) Design and conduct** Range of research methods used. However, it was unclear what each method contributed to the study. No discussion of ethical considerations. Although data was sorted into themes, there was no description on how this process was undertaken. **3) Clarity and value**	**Partially**

					Findings were grouped into dominant themes that made them reasonably clear to understand. There was no evaluation of the strengths and weaknesses of the study. Value of research was emphasised with clear discussion of how findings may be applied to help develop services.	
Bedford, J., 2011(290)	Malawi	60 case studies with parents of children with clubfoot	Interviews, photographs, observation	To explore the treatment-seeking behaviour of guardians of patients undergoing treatment for clubfoot using the Ponseti method.	**1) Aims and appropriateness** Clear statement of the aims of the research. **2) Design and conduct** Setting for data collection justified and methods clearly described. Ethical approval received from review board and informed consent sought. The process of thematic analysis undertaken is described in detail.	**Fully**

					3) Clarity and value Clear statement of research findings. Value of the research is emphasised, including discussion of how findings are being used in practice. Future areas of research identified.	
Bedford, J. 2009(63)	Malawi	60 case studies with parents of children with clubfoot	Interviews, photographs, observation	To explore perspectives on clubfoot and its treatment using the Ponseti method. To make recommendations to improve and develop services.	Quality appraisal same as for Bedford 2011.	**Fully**
Boardman, A., 2011(65)	Chile, Peru, Guatemala	30 physicians practising the Ponseti method	Semi-structured interviews	To evaluate the impact and barriers to the diffusion of the Ponseti method.	**1) Aims and appropriateness** Clear statement of the aims of the research. **2) Design and conduct** Semi-structured interviews appropriate for	**Mainly**

					addressing research aims. Ethical issues have been taken into consideration, including details about the relevant ethical review board, process of obtaining informed consent and data storage. **3) Clarity and value** Presentation of findings slightly unclear as section seems to include author interpretations alongside findings. It is unclear what represents primary data. Findings are considered in relation to existing literature. The value of the research and its potential to improve patient care are briefly discussed.	
Gadhok, K., 2012(52)	India	15 orthopaedic surgeons practising Ponseti method, 15 parents of children receiving treatment	Semi-structured interviews [As part of a mixed methods study]	To identify the challenges to the diffusion and implementation of the Ponseti method	**1) Aims and appropriateness** Clear statement on the aims of the research. **2) Design and conduct**	**Mainly**

		with Ponseti method			Study uses a range of research methods. However, it is not clear why these methods were selected or what each contibuted to the study. Researcher describes how healthcare professionals have been sampled but not the patient population. The setting for data collection has been justified. Ethical issues have been taken into consideration including information on ethical review board and data storage and consent. There is very little description on the process of analysis. **3) Clarity and value** There is a clear statement of findings. Written descriptions are grouped into dominant themes and a table is included that distills the themes identified in the study. A	

					discussion of strengths and weakness is included. However, there is limited discussion on how work contributes to the understanding of the topic and may be applied in practice.	
Jayawardena, A., 2013(291)	Sri Lanka	162 patients and healthcare practitioners involved with clubfoot care	Interviews, focus groups, observation	To evaluate the utility of a 'train the trainer' approach for disseminating the Ponseti method.	**1) Aims and appropriateness** Clear statement of study aims. **2) Design and conduct** Research methods appropriate for addressing research aims and value of using multiple methods discussed. No discussion on why participants chosen to address study aims. Setting for data collection not justified. Methodology used is clearly stated and detail included on how interviews and focus groups carried out. Ethical	**Mainly**

					considerations dicussed including anonymisation and data storage. However, no information provided on why study granted exemption from ethical review. Lack of information on process of data analysis. **3) Clarity and value** Findings clear and organised into key themes. Strengths and weaknesses of study discussed. Contribution study makes to existing knowledge discussed. Areas of future research identified.	
Kingau, N. W., 2015(62)	Kenya	10 service providers delivering clubfoot treatment, 10 caregivers of children with clubfoot.	Semi-structured interviews	To identify barriers experienced by service providers and carers to the effective management of clubfoot using the Ponseti method	**1) Aims and appropriateness** Clear statement of study aims. **2) Design and conduct** Semi-structured interviews appropriate to	**Fully**

				and surgical interventions.	address study aims. Explanation of how participants were sampled and why they were most appropriate to address research aims. Detailed description on how interviews were carried out and data saturation discussed. No discussion of ethical considerations. Data analysis rigorous and detailed description of how process was conducted. **3) Clarity and value** Primary data included to support findings. Strengths and weaknesses of study discussed. Findings considered in relation to existing research and how they may contribute to service development.	
McElroy, T., 2007(57)	Uganda	42 parents of children with	Semi-structured interviews, focus	To identify barriers to adherence to the	**1) Aims and appropriateness**	**Fully**

		clubfoot, 2 adults with clubfoot , 40 community leaders, 39 traditional healers, 38 practitioners treating clubfoot	groups, observation	Ponseti method of clubfoot treatment.	Clear statement of study aims. **2) Design and conduct** Research design appropriate to address aims and discussion of value of using multiple methods included. Information and justification of sampling strategy and of research setting. Detailed description of process of data collection. Ethical issues taken into consideration including review board, process of obtaining informed consent from participants speaking a range of languages, anonymisation of data and storage. In-depth description of analysis process. **3) Clarity and value**	

					Findings made clear and structured around dominant themes. Primary data included to support findings. No discussion of strengths and weaknesses of study. Discussion of how findings can be used in practice and areas of future research identified.	
Konde-Lule, J. 2005(58)	Uganda	42 parents of children with clubfoot, 2 adults with clubfoot , 40 community leaders, 39 traditional healers, 38 practitioners treating clubfoot	Semi-structured interviews, focus groups, observation	To explore knowledge, attitudes, beliefs, and practices about clubfoot across different regions in Uganda.	Quality appraisal same as for McElroy 2007.	**Fully**
Lu, N., 2010(59)	China	39 physicians practising the Ponseti method, 8 sets of parents of children receiving treatment with Ponseti	Semi-structured interviews, focus groups	To evaluate and identify barriers to the implementation of the Ponseti clubfoot program.	**1) Aims and appropriateness** Clear statement of study aims. **2) Design and conduct** Research design appropriate and value of multiple methods	**Mainly**

					explained. Explanation of why participations selected included. Research settings not justified. Fairly clear how data were collected. Ethical issues taken into consideration including ethical review board, informed consent, anonymisation of data and data storage. Process of data analysis described in detail. Codes discussed with wider study team to help validate findings. **3) Clarity and value** Study findings clear. No discussion of strengths and weaknesses of study. Implications of research for improving service design discussed and author makes series of recommendations for service development based on findings.	

Nogueira, M., 2013(30)	Brazil	45 orthopaedists trained in the Ponseti method	Semi-structured interviews	To identify barriers to bracing compliance.	**1) Aims and appropriateness** Clear statement of study aims. **2) Design and conduct** No information on how participants sampled or why they were appropriate for addressing study aims. Setting for data collection not justified. Unclear how semi-structured interviews conducted. No information on how analysis undertaken. **3) Clarity and value** Clear statement of findings and weaknesses of study discussed. No clear statement on value of research but strategies suggested for addressing challenges identified.	**Partially**

Palma, M., 2013(60)	Peru	25 physicians practising the Ponseti method	Semi-structured interviews	To evaluate how barriers to using the Ponseti method have changed in 2 years and to identify barriers to its diffusion.	**1) Aims and appropriateness** Clear statement of study aims in the main body of the text although these are unclear in the abstract. **2) Design and conduct** Semi-structured interviews appropriate for addressing study aims. However, it is unclear how participants were sampled and setting for data collection not justified. Ethical issues taken into consideration including details of review board, anonymisation of data and data storage. Although thematic analysis undertaken, limited information on how this was conducted. **3) Clarity and value**	**Partially**

					Findings clear and grouped into dominant themes. No discussion on strengths and weaknesses of the study. Potential of research to improve service design discussed.	
Wu, V., 2012(64)	Vietnam	12 practitioners practising Ponseti (physicians, nurses, physical therapists and case technicians), 99 parents of children with clubfoot and extended family	Semi-structured interviews, focus groups, observation [As part of a mixed methods study]	To evaluate the impact, progress and challenges facing Ponseti practitioners and patients' family.	**1) Aims and appropriateness** Clear statement of research aims. **2) Design and conduct** Research design apropriate to address study aims. Value of using multiple methods discussed. Description of sampling strategy but no discussion of why these participants were most appropriate for addressing study aims. Setting for data collection not justified. No detail on how data collected and the contribution of each method to study findings	**Partially**

					is unclear. No discussion of ethical considerations. No information on process of analysis. **3) Clarity and value** Clear statement of findings and discussion of strengths and weaknesses of the study included. Implications of research for improving service design discussed and number of recommendations made based on findings.	

Table 6: CERQual assesment of review findings

Review finding	**Studies contributing to review finding**	**Assessment of Methodology based on extent studies address CASP items**	**Assessment of Relevance**	**Assessment of Coherence**	**Assessment of Adequacy**	**Overall CERQual Assessment of Confidence**
INTRAPERSONAL FACTORS						
Income/ poverty	Lu, N., 2010 Gadhok, K., 2012	Moderate concerns (three	Minor concerns (patient	No concerns	No concerns (high number	High confidence

	Bedford, J. 2009 Konde-Lule, J. 2005 Palma, M., 2013 Aktintayo, O. A., 2012 Kingau, N. W., 2015	fully address CASP criteria, three mainly address CASP criteria, two partially address CASP criteria).	experiences are reported by healthcare professionals in one study, range of settings).		of studies, all studies providing rich data).	
Additional responsibilities	Lu, N., 2010 Gadhok, K., 2012 Boardman, A., 2011 Bedford, J. 2009 Konde-Lule, J. 2005 Palma, M., 2013 Aktintayo, O. A., 2012	Moderate concerns (two fully address CASP criteria, three mainly address CASP criteria, two partially address CASP criteria).	Minor concerns (patient experiences are reported by healthcare professionals in two studies, range of settings).	No concerns	Minor concerns (high number of studies, data not sufficiently rich).	High confidence
INTERPERSONAL FACTORS						
Paternal support	Wu, V., 2012 Lu, N., 2010 Gadhok, K., 2012 Boardman, A., 2011 Bedford, J. 2009 Konde-Lule, J. 2005 Aktintayo, O. A., 2012	Moderate concerns (three fully address CASP criteria, three mainly address CASP criteria, two partially address CASP criteria).	Minor concerns (patient experiences are reported by healthcare professionals in one study, range of settings).	No concerns	Minor concerns (high number of studies, data not sufficiently rich).	High confidence

	Kingau, N. W., 2015					
Support from extended family or friends	Wu, V., 2012 Bedford, J. 2009 Konde-Lule, J. 2005 Jayawardena, A., 2013 Boardman, A., 2011	Moderate concerns (two fully address CASP criteria, two mainly address CASP criteria, one partially address CASP criteria).	Minor concerns (patient experiences reported by healthcare professionals in one study, the utility of a 'train the trainer' approach evaluated in one study rather than the whole intervention, range of settings).	No concerns	Minor concerns (smaller number of studies, data thin).	High confidence
Support from wider community	Bedford, J. 2009 Konde-Lule, J. 2005 Kingau, N. W., 2015	No concerns (three fully address CASP criteria).	Moderate concerns (studies were limited to Africa).	No concerns	Moderate concerns (small number of studies, data thin).	Moderate confidence
INSTITUTIONAL/ ORGANISATIONAL FACTORS						
Distance to service	Wu, V., 2012 Gadhok, K., 2012 Boardman, A., 2011 Bedford, J. 2009	Moderate concerns (three fully address CASP criteria, four mainly	Minor concerns (patient experiences reported by healthcare	No concerns	No concerns (high number of studies, all studies	High confidence

	Konde-Lule, J. 2005 Palma, M., 2013 Kingau, N. W., 2015 Jayawardena, A., 2013 Aktintayo, O. A., 2012 Lu, N., 2010	address CASP criteria, three partially address CASP criteria).	professionals in two studies, the utility of a 'train the trainer' approach evaluated in one study rather than the whole intervention, range of settings).		providing rich data).	
Costs of treatment	Bedford, J. 2009 Jayawardena, A., 2013 Boardman, A., 2011 Nogueira, M., 2013 Konde-Lule, J. 2005 Palma, M., 2013 Aktintayo, O. A., 2012 Kingau, N. W., 2015 Jayawardena, A., 2013 Wu, V., 2012	Moderate concerns (three fully address CASP criteria, three mainly address CASP criteria, four partially address CASP criteria).	Minor concerns (patient experiences reported by healthcare professionals in two studies, the utility of a 'train the trainer' approach evaluated in one study rather than the whole intervention, range of settings)	No concerns	No concerns (high number of studies, all studies providing rich data)	High confidence

Lack of awareness about treatment or services	Wu, V., 2012 Lu, N., 2010 Gadhok, K., 2012 Bedford, J. 2009 Konde-Lule, J. 2005 Palma, M., 2013 Aktintayo, O. A., 2012	Moderate concerns (two fully address CASP criteria, two mainly address CASP criteria, three partially address CASP criteria)	Very minor concerns (patient experiences reported by healthcare professionals in one study, range of settings)	No concerns	No concerns (high number of studies, all studies providing rich data)	High confidence
Confusion about treatment protocols	Wu, V., 2012 Lu, N., 2010 Konde-Lule, J. 2005 Aktintayo, O. A., 2012 Jayawardena, A., 2013	Moderate concerns (one fully address CASP criteria, two mainly address CASP criteria, two partially address CASP criteria)	Very minor concerns (the utility of a 'train the trainer' approach evaluated in one study rather than the whole intervention, range of settings)	No concerns	Minor concerns – (high number of studies, data not sufficiently rich)	High confidence
Experiences of accessing care	Konde-Lule, J. 2005 Wu, V., 2012 Lu, N., 2010 McElroy, T., 2007 Bedford, J. 2009 Nogueira, M., 2013 Palma, M., 2013	Moderate concerns (three fully address CASP criteria, one mainly address CASP criteria, three partially address CASP criteria)	Very minor concerns (patient experiences reported by healthcare professionals in one study, range of settings)	No concerns	Minor concerns (high number of studies, data not sufficiently rich)	High confidence

Treatment regime	Wu, V., 2012 Lu, N., 2010 Nogueira, M., 2013 Konde-Lule, J. 2005 Aktintayo, O. A., 2012 Gadhok, K., 2012 Boardman, A., 2011 Bedford, J. 2009 Jayawardena, A., 2013	Moderate concerns (two fully address CASP criteria, four mainly address CASP criteria, three partially address CASP criteria)	Very minor concerns (patient experiences reported by healthcare professionals in two studies, the utility of a 'train the trainer' approach evaluated in one study rather than the whole intervention, range of settings)	No concerns	No concerns (high number of studies, all studies providing rich data)	High confidence
Duration of treatment	Wu, V., 2012 Bedford, J. 2009 Konde-Lule, J. 2005 Boardman, A., 2011	Moderate concerns (two fully address CASP criteria, one mainly address CASP criteria, one partially address CASP criteria)	Minor concerns (patient experiences reported by healthcare professionals in one study, range of settings)	No concerns	Moderate concerns – (smaller number of studies, data not sufficiently rich)	Moderate confidence
SOCIO-CULTURAL/ COMMUNITY FACTORS						

Belief systems to explain causes of clubfoot	Bedford, J. 2009 Konde-Lule, J. 2005 Aktintayo, O. A., 2012 Kingau, N. W., 2015 Lu, N., 2010 Wu, V., 2012	Moderate concerns (three fully address CASP criteria, one mainly address CASP criteria, two partially address CASP criteria)	Minor concerns (some patient experiences reported by healthcare professionals in one study)	No concerns	Moderate concerns (majority of studies data thin)	Moderate confidence
Fear or lack of belief in surgical interventions	Wu, V., 2012 Lu, N., 2010 Konde-Lule, J. 2005 Aktintayo, O. A., 2012	Moderate concerns (one fully address CASP criteria, one mainly address CASP criteria, two partially address CASP criteria)	Minor concerns (some patient experiences reported by healthcare professionals in one study	No concerns	Serious concerns (smaller number of studies, data thin)	Low confidence
Stigma	Wu, V., 2012 Lu, N., 2010 Boardman, A., 2011 Bedford, J. 2009 Konde-Lule, J. 2005 Kingau, N. W., 2015	Moderate concerns (three fully address CASP criteria, two mainly address CASP criteria, one partially address CASP criteria)	Minor concerns (some patient experiences reported by healthcare professionals in one study	No concerns	Moderate concerns (majority of studies data thin)	Moderate confidence
PUBLIC POLICY						

Two-tiered healthcare systems	Boardman, A., 2011 Nogueira, M., 2013 Palma, M., 2013	Serious concerns (one mainly address CASP criteria, two partially address CASP criteria)	Moderate concerns (patient experiences reported by healthcare professionals)	No concerns	Minor concerns (small number of studies but data rich)	Moderate confidence

Chapter 4 Methods

This chapter presents an overview of ethnography and the use of abductive approaches in qualitative research studies, both of which informed this work. I then present the three elements of fieldwork I used to address the aims and objectives of the study, along with the ethical procedures I used to ensure all participants provided informed consent and that data was stored securely throughout the study.

4.1 Ethnography

Ethnography is a research methodology that aims to understand cultures, organisations and communities and from the perspective of its inhabitants. Ethnographic data collection involves immersing oneself in a culture or social system for an extended period of time and this method generates insight into complex settings. Interpretations are systematically generated as the research progresses with ongoing analysis that informs further data collection(296). Studies usually begin with an exploratory, open-ended approach(297). Ethnographers are typically proponents of naturalism, the concept that participants are best studied in their own social worlds or 'naturally' occurring settings. This can be contrasted with data collection that occurs in 'artificial' settings such as interviews or surveys(298). A range of methods can be used which include observation, interviews and documentary analysis(296). 'Ethnography' is a fluid term that can have a range of different meanings(296).

Ethnography has its roots in 19th century anthropological research that involved

entering into non-western society for an extended period of time to produce a detailed description of that culture(296). Ethnology was a complementary discipline that involved comparing and contrasting these accounts of non-western cultures(296). Malinowski's *Argonauts of the Western Pacific* that was published in 1922 was the first study to fully elucidate ethnographic research methods and emphasize the importance of understanding of the social world from the perspective of participants. As such, it is considered a founding text in the discipline(299). Between the 1920s and 1950s, the University of Chicago also developed similar methods to study urban settings. Many of these used a case study approach, an in-depth study of a single or small number of 'cases'(296).

A range of overlapping theoretical perspectives have helped to shape the development of modern ethnographic research including phenomenology and symbolic interactionism(300). Symbolic interactionism forms the basis of interactionist ethnography. Epistemologically, these ethnographers believe that the behaviour of individuals is shaped by their knowledge and understanding of what is around them and their interactions within the social world. As a result, they give priority to exploring the meaning and intentions behind participants' actions. However, they also recognise that findings are mediated by the researcher and that by implication, interpretations will always be limited(300). Researchers aim to untangle these issues by reflecting on their own interpretive role in data collection and analysis, a practice known as reflexivity(301). Rather than aiming for a detailed description of a single or small number of cases, contemporary ethnography is also increasingly being used to develop theoretical ideas(301).

Ethnography has been advocated by WHO as a means of exploring the delivery of

healthcare services in low and middle-income countries(302) and widely used to help understand service organisation for a range of conditions(303-306). As a means of generating insight into complex settings, it also provides an ideal way of understanding the impact of contextual factors on the implementation of interventions(307-309). This includes factors at both the micro-level of service delivery and the wider society(307). It was therefore an ideal means of exploring the issues under study.

4.2 Abductive analysis

Theoretical frameworks are increasingly being used in qualitative research to aid understanding of data. However, there is an increasing issue in which we are often balancing the application of theory with the need to ensure that our findings are truly driven by the data(310). To ensure that my data were not 'forced' into the pre-defined categories, I drew on the work of Tavory and Timmermans who advocate the use of 'abductive reasoning' in applying and developing theory(310). To do this, I used methods developed by Charmaz in her constructivist approach to grounded theory to help structure my methods(311). This was a practical tool to aid application rather than as part of a grounded theory study.

4.2.1 Deduction, induction and abduction

To understand abduction it is necessary to recognise that there are three forms of reasoning used in the production of knowledge: deductive, inductive and abductive(312). Deductive reasoning refers to the process of inferring 'facts' from premises that are probably true. Premises are then scrutinized through empirical testing. This forms the basis of the hypothetico-deductive method that is influential in quantitative research and involves the formulation of hypotheses that are proved

or disproved through data collection(313). Applied to qualitative research, this would involve developing a hypothesis based on an existing theory and then testing it through data collection(310). In quantitative research, if the premises are proven, resultant theories are seen as reflecting an objective truth and are considered *certain*, what is called a positivist approach(314). Inductive reasoning, by contrast, begins with the evidence and uses this to develop new explanations or theories from this evidence. Strong links therefore exist between the data and the theory(315). Theories or explanations may then be generalised to other cases. Inductive reasoning is influential in qualitative research(314). Resultant theories are only *probable* since the likelihood that theories are generalizable to other cases is not certain(314).

Abduction is the third, less well known form of reasoning developed by Pierce in the late 19th century(316). This can be characterised as 'reasoning towards meaning'(317). Where no explanation exists for collected data, the researcher must develop a (new) explanation that accounts for this discovery. In this way, a new rule or theory is developed(316). Frankfurt argues that Pierce's writing suggests that rather than develop a new explanation, abductive reason involves adopting an existing hypothesis. This hypothesis forms the basis of further investigation(318). Building on Pierce's ideas, Harman describes the process of abduction as 'reasoning to the *best* explanation'. That is, although there may be several hypotheses that could explain a given phenomena, abductive reasoning involves finding the hypothesis that best fits the facts(319). This accounts for the guesswork, hunches and imagination that researchers use to develop theory(320). Rather than developing a new theory from the 'ground up', abduction in qualitative research therefore involves understanding the data using, and building on, a range of existing

theories(310). Since a number of possible explanations exist, this form of reasoning generates theories that are not certain or probable, only *plausible*(317).

4.2.2 Abduction in qualitative research

Tavory and Timmermans argue that neither an inductive or deductive approach to qualitative data analysis is sufficient in generating new theory. They argue it is improbable that a coherent and conceptually rich theory can emerge from the data using inductive analysis. Equally, beginning with a pre-defined theory and then testing it through the process of data collection stifles creativity. Abductive analysis on the other hand, creates the necessary preconditions that facilitate theory generation(310). To do this effectively, researchers must first acquire 'theoretical sensitivity'. That is, a broad knowledge of existing theories in order to make abductive inferences(310). They also emphasise the importance of collecting detailed fieldnotes, the constant comparison of data, memo-writing to help develop theoretical categories and the searching of negative cases to test the theory(311).

4.2.3 Use of abduction in this study

Charmaz developed a flexible methodology in order to facilitate theory generation. This involved the constant comparison of data through memo-writing and a three stage coding process that involved detailed line-by-line or incident-by-incident coding, focused coding to synthesise initial codes and identify emerging concepts and theoretical coding to integrate focused codes into theoretical categories. Theoretical sampling was then advocated as a means of scrutinizing emerging categories(311). I have chosen to use this to help structure methods since it provides a clear set of guidelines on how to collect and analyse data and compliments Tavory and Timmerman's abductive approach.

4.3 Methods

The ethnographic work was divided into three elements and comprised the following:

Element 1: Explore factors that impact on the implementation of clubfoot treatment services and develop a theoretical framework to help inform findings

Element 2: Gain an understanding of the impact of accessing and utilising services on parents or carers of children with clubfoot presenting in infancy, and other individuals involved in their care.

Element 3: Explore the experiences of children and their guardians that had either discontinued or not fully accessed treatment

Four periods of substantive fieldwork were conducted. These were:

1) Preparatory visit prior to ethical approval (2 weeks, November, 2014)
2) First fieldwork period (18 weeks, March – August 2015)
3) Second fieldwork period (22 weeks, April–September 2016)
4) Third fieldwork period (3 weeks, November, 2016)

4.3.1 Study approvals

Ethical approval was provided by the Oxford Tropical Research Ethics Committee (OxTREC), reference number 10-15 and the College of Medicine Research and Ethics Committee (COMREC) in Malawi, reference number P.02/15/1675. Permission to

conduct the study at Beit CURE Hospital was sought by Christopher Lavy, my supervisor at the University of Oxford who had a close relationship with the organisation. This was done informally by contacting the Executive Director at the Hospital and discussing the aims and objectives of the research, study duration and what would be required of the organisation.

4.3.2 Preparatory visit

During the two-week preparatory visit I identified a Research Assistant named Paul Chidothi to assist with data collection and visited a rural clubfoot clinic to assess the feasibility of the study. I also discussed and refined research aims with the Clinical Director at CURE and the Malawi National Clubfoot Coordinator.

4.3.3 Paul Chidothi

I met Paul during my preparatory visit while he was working at Beit CURE Hospital. At that time, he was assisting with a range of musculoskeletal projects being conducted in Malawi. He had worked on a previous qualitative study exploring attitudes to children living with musculoskeletal impairments, including neglected clubfoot. Paul's role in the project involved assistance with translation, data collection and contributing to the interpretation of data.

Figure 11: Photograph of Paul Chidothi and I outside Beit CURE Hospital



4.3.4 Element 1: Exploring factors that impact on the implementation of clubfoot treatment services

Methodology

I used an ethnographic approach(296) to explore treatment and access to healthcare for clubfoot in Malawi. As I was particularly interested in implementation of interventions(307-309) I used Tavory and Timmerman's abductive approach to data analysis and theory generation(310) to enable us to use extended Normalization Process Theory in data collection and interpretation(321). Although this was not a grounded theory study, to help structure this process, we adopted methods from Charmaz's constructivist approach to grounded theory(311).

This work took place March - August 2015, and was completed April – September 2016.

Developing 'theoretical sensitivity'

Prior to data collection I familiarised myself with theories drawn from the field of implementation science. This 'theoretical sensitivity' enabled me to draw on existing concepts to develop a theory that was conceptually rich(322).

Fieldwork

Observation sessions were conducted at three study sites and semi-structured interviews undertaken at the three sites and an additional nine sites. Further interviews were then conducted with participants to develop and explore early findings. Finally, interviews were conducted with key informants to help understand findings within the wider healthcare context.

Observation sessions at three study sites

Beit CURE Hospital and two outreach clinics were identified for data collection. Maximum variation sampling was used to include clinics with a range of characteristics(323), taking into account region, rural or urban location, whether the clinic was a designated clubfoot clinic or general orthopaedic clinic, patient catchment and year established (see Table 5). Since Beit CURE clubfoot clinic was based in a private orthopaedic hospital and had unique funding arrangements, it was not possible to anonymise the study site. This was agreed by CURE clubfoot management. All other sites were anonymised to protect the identity of healthcare professionals.

Table 5: Characteristics of study sites for observation of clinical practice and counselling services

Study site	Region	Rural/ urban location	Hospital	Funders	Designated clubfoot clinic/ general orthopaedic clinic	Healthcare professionals and counsellors delivering care	Patient catchment	Mean number of patients treated per month 2016
Beit CURE Hospital clubfoot clinic	Southern	Urban	Private orthopaedic teaching hospital	CURE International and fee paying adult patients.	Designated clubfoot clinic	1 Physiotherapist 1 Physiotherapy Assistant 1 Rehabilitation Technician 1 Orthopaedic Clinical Officer 3 Counsellors Varying numbers of students	Patients from urban and rural areas. Language spoken was mainly Chichewa although patients with a higher level of education sometimes spoke English.	46
Outreach clinic 1	Southern	Rural	Public District Hospital	CURE International and Ministry of Health	Designated clubfoot clinic	1 Rehabilitation Technician 2 Counsellors	Patients from rural areas of Malawi. Mostly Muslims from Yao tribe but included	16

						Varying numbers of students	Christians from Chewa tribe. Language spoken was mainly Yao but also Chichewa.	
Outreach clinic 2	Central	Rural	Public District Hospital	CURE International and Ministry of Health	General orthopaedic clinic	4 Orthopaedic Clinical Officers 2 Healthcare Assistants 2 Counsellors	Patients from rural areas of Malawi and neighbouring Mozambique. Language spoken was Chichewa but catchment included a small number of Portugese speakers.	6

Clinic coordinators were contacted by phone and provided with a brief overview of the research. This was conducted by Paul in the most commonly used language in Malawi, *Chichewa*, to help build rapport. A visit was then arranged to approach potential participants. Healthcare professionals and counsellors were provided with verbal information about the aims and objectives of the research, how it would be conducted and issues of consent. Information Sheets in either English or Chichewa were provided with additional details about the study and contact details. A follow-up visit was subsequently arranged two weeks later for informed consent and data collection. See Appendix for Information Sheet.

Beit CURE Hospital and Outreach clinic 1 held clubfoot clinics at a designated time each week in sessions that lasted around 4 – 5 hours, although this varied depending on the number of patients in attendance. Outreach clinic 2 treated clubfoot clinics in a weekly orthopaedic clinic for both children and adults. Using an observation checklist, observational sessions were conducted at each of the weekly clinics. Field notes described the healthcare professionals and patients attending, the setting, activities taking place, treatment protocols, methods of communication between actors and barriers and facilitators to service delivery. Informal interviews were also conducted during these sessions.

Although my primary role within the clinics was to observe clinical practice, I participated in the activity taking place by interacting with healthcare professionals and patients through discussions and performing minor tasks such as finding braces. Paul and I worked closely together during observation sessions. During clinics, Paul translated discussions so I could understand the interactions taking place. Paul also

observed counselling sessions and reported activity to me at the end of the session since these required a fluent understanding of Chichewa and other local languages. Both Paul and I took field notes during these sessions and then compared and contrasted data immediately after the clinic had ended.

Data from each observation session was then written up into full field notes and used to inform further data collection. To facilitate this process, I used memos or reflective notes to record emerging concepts in the data(324). See Appendix for observation checklistIn total, six observations sessions of approximately 4 – 5 hours were conducted at each of the three clinics (90 hours in total).

Interviews at nine further clinics

Preliminary findings from the observation and informal interviews were used to inform semi-structured interviews in nine further sites. This was because the sample of participants was relatively small given their range of occupations (n = 22), limiting the transferability findings(325). A maximum variation approach was again used to select clinics(326). Characteristics of these study sites are presented in Table 6. Numbers of healthcare professionals working in the clinics are approximations since some only worked intermittently. Similarly, the number of counsellors in each service changed during data collection.

Table 6: Characteristics of additional nine study sites for interviews with healthcare professionals and counsellors

Study site	Region	Rural/ urban location	Hospital	Funders	Designated clubfoot clinic/ general orthopaedic clinic	Healthcare professionals delivering clinical care	Patient catchment	Mean number of patients treated per month 2016 (rounded to nearest whole number)
Outreach clinic 3	Northern	Urban	Central	CURE International, Ministry of Health and CHAM	Designated	1 Orthopaedic Clinical Officer 2 Rehabilitation Technicians 2 Counsellors	People from urban and rural locations. Range of tribes including Tumbuka, Chewa, Tonga, Ngoni. Range of languages spoken because of urban location including Tumbuka, Chewa, Tonga and English.	15
Outreach clinic 4	Northern	Rural	District	CURE International,	Designated	1 Orthopaedic Clinical Officer	People from rural location and a small	10

				Ministry of Health		3 Counsellors	number from Tanzania. Northern tribes such as Tumbuka, Tongas. Other southern tribes Yao and Chewa. Languages Swahili, Chichewas, Tumbuka, English and languages from Tanzania, Nyachusya.	
Outreach clinic 5	Northern	Rural	District	CURE International, Ministry of Health	Designated	1 Orthopaedic Clinical Officer 2 Hospital Assistants 1 Rehabilitation Technician 1 Counsellor	Rural locations. Range of tribes and languages spoken due to proximity to border, including Tumbuka, Lambya, Chindali and Tonga	5
Outreach clinic 6	Central	Rural	District	CURE International, Ministry of Health	Designated	1 Rehabilitation Technician 1 Orthopaedic Clinical Officer 2 Counsellors	People from rural areas. Chewa tribe and Chichewa language and Tumbuka.	17

Outreach clinic 7	Central	Urban	District	CURE International, Ministry of Health	Designated	2 Rehabilitation Technician 1 Physiotherapy Assistant 2 Orthopaedic Clinical Officer 3 Counsellors	People from rural and urban locations. Predominantly Chewa tribe and Chichewa language but range of other tribes due to urban location.	80
Outreach clinic 8	Central	Rural	District	CURE International, Ministry of Health	Designated	1 Rehabilitation Assistant 1 Orthopaedic Clinical Officer 1 Physiotherapy Assistant 2 Counsellors	People from rural locations. Mainly chewa tribes and Chichewa language	10
Outreach clinic 9	Southern	Rural	District	CURE International, Ministry of Health	Designated	1 Orthopaedic Clinical Officer 1 Hospital Assistant 2 Counsellors	People from rural locations. Mainly Chewa but some from neighbouring Mozambique.	10
Outreach clinic 10	Southern	Rural	District	CURE International, Ministry of Health, MAP	Designated	1 Orthopaedic Clinical Officer 1 Healthcare Attendant 1 Counsellor	People from rural locations. Sena tribe and languages Sena and Chichewa. Some patients from Mozambique.	4

Outreach clinic 11	Southern	Rural	District	CURE International, Ministry of Health	General orthopaedic clinic	1 Orthopaedic Clinical Officer 1 Healthcare Assistant 1 Counsellor	People from rural locations. Tribes mainly Lomew. Languages Chichewa, Lomwe,	7

As above, clinic coordinators were contacted by phone. 56 clinic staff including healthcare professionals and counsellors were approached, and 52 provided their written consent to participation. The topic guide was devised on the basis of preliminary insights. Interviews focused on participants' views and experiences of delivering clubfoot treatment and counselling. The topic guide was flexible to enable follow-up on issues identified during the observational work or issues raised by participants. The same topic guide was used for both healthcare professionals and counsellors as I found during observations that both groups had comments on both aspects of care. If either group was unable to respond to questions because they were outside of their domain, they were not pursued. Participants were provided with the opportunity to undertake interviews in either English or Chichewa with assistance from Paul. I undertook all interviews conducted in English with Paul as observer. If these were undertaken in Chichewa or another local language, I asked questions in English whilst Paul translated between us as required. Interviews were audio-recorded, translated and transcribed by four trained transcribers fluent in Chichewa and English. Both the original Chichewa and English translation were included in the transcripts and quality checked by Paul. See Appendix for topic guide.

At the end of the interview participants were offered 1000MK (around £1) for lunch money. Although I did not originally intend to use incentives, this was consistent with the system of 'allowances' for additional work that exists within the Malawian healthcare system.

Follow-up interviews

Theoretical sampling was undertaken with clinic coordinators using telephone interviews to interrogate and build on emerging categories. Coordinators were sampled since it was felt these were able to provide the most detailed information on service delivery. Clinic coordinators were contacted by phone and a convenient date and time arranged for the interviews. Five clinic staff were approached, and five agreed to take part.

The topic guide was based on findings from Phase 1 and focused on participants' views on coordination of care and the monitoring and evaluation of services. Due to the quality of phone lines, notes were taken during the interview, including verbatim quotes where possible, and written up in full after the discussion. See Appendix for topic guide.

Interviews with CURE management

Semi-structured interviews were conducted with the CURE management team at Beit CURE Hospital that included the clubfoot coordinator and counselling coordinator. These were able to provide information about organisational processes to coordinate and monitor clinics.

Participants were approached in person at Beit CURE Hospital. Although they were aware of the research, they were provided with verbal information about the aims and objectives of the study. Both agreed to take part. Written consent was sought as above. A topic guide for the clubfoot coordinator and one for the counselling coordinator were developed to understand these organisational processes and key issues that had emerged in the previous work. Participants were interviewed in

English and interviews audio-recorded and transcribed. See Appendix for topic guides.

Interviews with key informants

Semi-structured interviews were conducted with District Health Officers, Deputy District Health Officers and Hospital Administrators working within one of the study sites with responsibility for overall management of services. These functioned as key informants that were able to provide a rich in-depth understanding of findings within the wider healthcare system(327).

Participants were approached in District Hospitals and provided with verbal information about the aims and objectives of the study. Six were approached, and four agreed to take part. Written consent to participation was sought as above. A topic guide was developed to explore key areas identified through interviews and observations. Participants were interviewed in English on account of the high levels of literacy amongst this group. Interviews were audio-recorded and transcribed. See Appendix for topic guide.

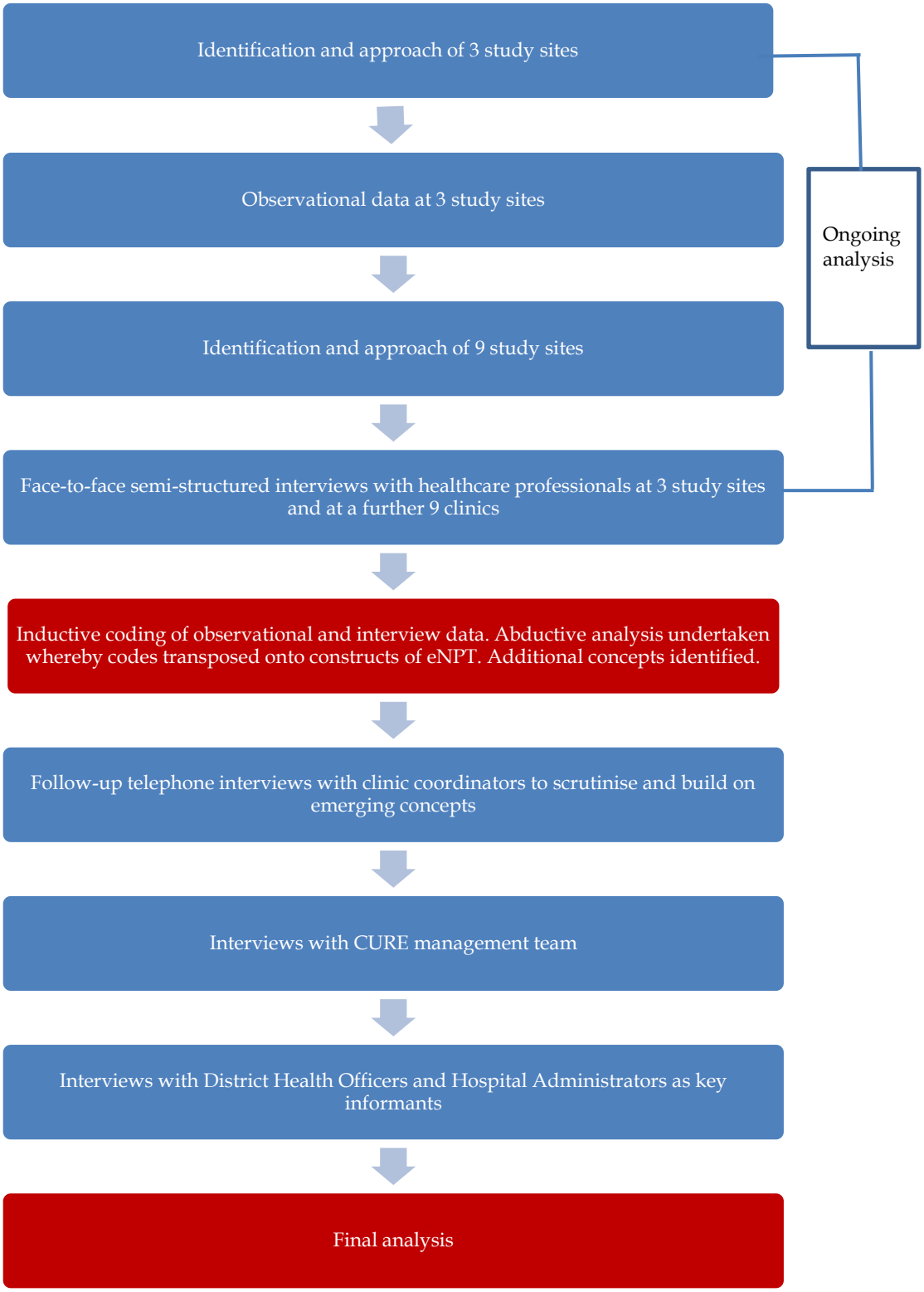
Analysis

Analysis of data from fieldwork phase 1 was iterative and ongoing and informed further data collection. Observational and interview data were then imported into NVivo qualitative analysis software(274) and analysed in detail using an inductive thematic analysis(311). Coding was undertaken in three phases: detailed line-by-line or incident-by-incident coding, focused coding to synthesise initial codes and

identify emerging concepts and theoretical coding to integrate focused codes into theoretical categories(311).

Through iterative analysis during data collection and subsequent inductive coding, I thought that data could best be understood using extended Normalization Process Theory(222). On account of this, a decision was made to transpose inductive codes onto the constructs of this theory(222). Codes that did not 'fit' within the theory were integrated into a further theoretical category. Further theoretical sampling was undertaken in fieldwork phase 2 to build on and interrogate emerging categories until it was felt that theoretical sufficiency had been achieved. That is, until categories were developed that were suggested by the data(311, 328). Data from observations and interviews with healthcare professionals working in clubfoot clinics were combined with those conducted with key informants and CURE clubfoot management to generate overall study findings. Theoretical categories were finalised. Descriptive accounts of the data were then generated. Extended Normalization Process Theory and the additional construct I identified are outlined below. See Figure 12 for full sequence of data collection and analysis.

Figure 12: Sequence of data collection and analysis


Identification and approach of 3 study sites
Observational data at 3 study sites
Identification and approach of 9 study sites
Face-to-face semi-structured interviews with healthcare professionals at 3 study sites and at a further 9 clinics
Ongoing analysis
Inductive coding of observational and interview data. Abductive analysis undertaken whereby codes transposed onto constructs of eNPT. Additional concepts identified.
Follow-up telephone interviews with clinic coordinators to scrutinise and build on emerging concepts
Interviews with CURE management team
Interviews with District Health Officers and Hospital Administrators as key informants
Final analysis

4.3.5 Element 2: Gaining an understanding of the impact of accessing and utilising services on parents or carers of children with clubfoot

Fieldwork was conducted at three study sites and explored the impact of accessing and utilising services on children and their guardians. Fieldwork comprised single, dyad or triad interviews and three focus groups with those currently accessing treatment. Interviews were also conducted with those that had completed treatment and been formally discharged. A small number of interviews were then undertaken with counsellors to obtain their views. During analysis, data was integrated with insights from observations conducted in clubfoot clinics during phase 1 of fieldwork.

This work took place April – September 2016.

Study sites

Beit CURE Hospital and two outreach clinics were identified for data collection. Due to the long distance and low volumes of patients in Outreach clinic 3 in fieldwork phase 1, I made a decision to substitute it with another clinic. However, as before maximum variation sampling was used to capture clinics with a range of characteristics(329) and I am confident that the findings were transferrable to other settings(325). Characteristics of study sites are presented in Table 7.

Table 7: Characteristics of study sites for patient interviews

Study site	Region	Rural/ urban location	Hospital	Funders	Designated clubfoot clinic/ general orthopaedic clinic	Healthcare professionals delivering clinical care	Patient catchment	Mean number of patients treated per month 2016 (rounded to nearest whole number)
Beit CURE Hospital clubfoot clinic	Southern	Urban	Private orthopaedic teaching hospital	CURE International and fee paying adult patients	Designated clubfoot clinic	2 physiotherapists 1 Rehabilitation Technician 1 Orthopaedic Clinical Officer	Patients from urban and rural areas. Language spoken was mainly Chichewa although patients with a higher level of education sometimes spoke English.	46
Outreach clinic 1	Southern	Rural	Public District Hospital	CURE International and Ministry of Health	Designated clubfoot clinic	1 Rehabilitation Technician 1 Counsellor	Patients from rural areas of Malawi. Mostly Muslims from	16

							Yao tribe but included Christians from Chewa tribe. Language spoken was mainly Yao but also Chichewa.	
Outreach clinic 2	Southern	Rural	Public District Hospital	CURE International and Ministry of Health	Designated clubfoot clinic	1 Orthopaedic Clinical Officer 4 Hospital Attendants 1 Counsellor	Patients from rural areas of Malawi. Mostly Lomwe tribe. Language spoken mainly Chichewa.	17

Interviews with those whose children were currently accessing treatment

Semi-structured one-one-one, dyad or triad interviews[25] were conducted with parents or carers of children with clubfoot and other individuals involved in their care who were accessing clubfoot treatment at one of the three sites. Through the use of probes, interviews enabled me to obtain an in-depth understanding of guardians' views and experiences(330). Dyad and triad interviews provided the opportunity to explore multiple perspectives and contexts.

To recruit participants, clinic coordinators were first contacted by phone and provided with a brief overview of the research. A visit was then arranged to provide healthcare professionals working at the clinic with further information about the study, the opportunity to ask questions and permission to access the site. A visit was then arranged for the following week to recruit participants.

In Beit CURE Hospital, potential participants were identified with assistance from the clubfoot counsellor working at the service. At the end of a counselling session, counsellors provided mothers with information on the aims and objectives of the research, what participation would involve and issues of consent. If they were willing to take part, counsellors recorded their name and phone number. Paul then contacted them to provide further information and if willing, to arrange a date and a time to conduct the interview. At the outreach clinics, potential participants were approached by us in person during or after the clinics. Mothers and guardians were provided with verbal information as above. If guardians were willing to take part

then we recorded their name, address and phone number and agreed to call them at a later date. Alternatively, if no phone number was available as was often the case, then the interview was arranged immediately.

As far as possible purposive sampling was used to capture patients with a range of characteristics(329). This included patients at different stages of the treatment trajectory, from different tribes, living in urban or rural locations and a range of distances from the study sites. However, sampling was also based on convenience(331) since it was dependent on which patients attended the clinics on a given day. Snowball sampling was also used such that participants recommended other guardians who they knew had also accessed treatment at one of the study sites(332). In total, 23 mothers or guardians were approached and 17 agreed to take part. Verbal consent was sought from participants.

The topic guide was devised on the basis of insights derived from phase 1 of fieldwork and was reviewed as refined as data collection progressed. Interviews focused on participants' views and experiences of giving birth to a child with clubfoot and accessing treatment. Participants undertook interviews in Chichewa or Yao with assistance from Paul. Interviews were audio-recorded. A transcriber trained by the study team then transcribed the interviews in the local language. These transcripts were then translated into English. Both the local language and English translation were included in the transcript for analysis and quality checked by Paul as above. See Appendix for topic guide.

Both myself and Paul were present during interviews. Interviews were conducted by me with Paul translating between English and Chichewa and Yao as required. Each interview was conducted in participants' home villages. As far as possible, interviews were conducted in a private space such as the home although this was not always feasible. A number of interviews were also attended by chaperones such as village elders or members of the extended family. At the end of the interview participants were offered a large bottle of Sobo, an orange squash popular in Malawi, to thank them for taking part.

Focus groups with those whose children were currently accessing treatment

During interviews it was felt that a small number of participants were reluctant to share details about their personal experiences. As a result a decision was made to use focus groups in order to help put participants at ease and generate discussion(333). Three focus groups were conducted with those currently accessing treatment at each of the respective study sites.

Potential participants were recruited as above. In Beit CURE Hospital, potential participants were identified with assistance from the clubfoot counsellor. At the outreach clinics, potential participants were approached by us in person. Information was provided on the aims and objectives of the research, what participation would involve and issues of consent. It was also made clear that transport costs would be reimbursed. If guardians were willing to take part then the date and time of the focus groups were provided. A combination of purposive(329) and convenience sampling(331) methods were used to identify participants as before. Three focus groups were conducted, one at each of the respective clinics with

five participants in each. In total, 15 mothers or guardians were approached and 15 agreed to take part. Verbal consent was sought as before.

The topic guide was structured as above to ensure that interview and focus group data could be easily integrated during analysis. Discussions focused on participants' views and experiences of giving birth to a child with clubfoot and accessing treatment. Focus groups were undertaken in a combination of Chichewa or Yao with assistance from Paul. Focus groups were audio-recorded, transcribed and translated.

Both Paul and I were present during focus groups. I conducted these with Paul translating between English and Chichewa and Yao as required. Focus groups were conducted in private rooms within the Hospitals. At the end, participants were provided with fizzy drinks and snacks to thank them for taking part. Transport to the study sites was also reimbursed.

Interviews with those whose children had completed treatment

Semi-structured one-on-one, dyad or triad interviews[25] were conducted with parents or carers of children with clubfoot and other individuals involved in their care who had accessed clubfoot treatment at one of the three sites and been formally discharged by clinicians.

Potential participants at each of the study sites were identified using clubfoot treatment records. Contact details provided by guardians in these records were then used to approach participants and inform them about the aims and objectives of the study. Guardians were usually contacted by Paul through phone calls. Where

telephone numbers did not exist, potential participants were visited by myself and Paul in their homes. As before, information was provided on the aims and objectives of the research, what participation would involve and issues of consent. If guardians were willing to take part then a time and a place was arranged to conduct the interview that was convenient for them. In one case, the interview was conducted immediately with the consent of the participant since the area was difficult to reach. Sampling was largely based on convenience(331) on account of the small number of potential participants that we were able to identify through these records. We were unable to trace a number of mothers or guardians due to changes in contact details or address or due to incomplete records. In total, we successfully contacted 12 mothers or guardians and 12 agreed to take part. Verbal consent was provided prior to the interview.

The topic guide was structured on the basis of insights derived from interviews with those accessing treatment and was reviewed and refined as data collection progressed. Interviews focused on participants' views and experiences of giving birth to a child with clubfoot, accessing treatment and the impacts of completing treatment. Participants undertook interviews in Chichewa or Yao with assistance from Paul. As above, interviews were audio-recorded, transcribed and translated. See Appendix for topic guide.

As before, both Paul and I were present during interviews. I conducted the interviews whilst Paul translated between English and Chichewa and Yao as required. Each interview was conducted in participants' home villages. Where possible, interviews were conducted in a private space such as the home. At the end

of the interview participants were offered a large bottle of Sobo to thank them for taking part.

Interviews with clubfoot counsellors

Semi-structured one-on-one interviews were conducted with clubfoot counsellors working at one of the three study sites. Since counsellors had built up relationships with mothers and guardians over time, they were able to provide additional, in-depth information about the views and experiences of mothers and guardians. They were also able to provide an understanding of findings within the wider cultural context of Malawi.

To recruit counsellors, we either approached them in person during or after the clinics or contacted them by phone. Calls were either made by me or Paul since these participants were largely fluent in English. Phone numbers were obtained from the counselling coordinator working at the Beit CURE Hospital. Information was provided on the aims and objectives of the research, what participation would involve and issues of consent. A time and a place were arranged that was convenient for them. In total, four counsellors were approached and four agreed to take part. If consent had not been provided during the first phase of fieldwork, written consent was sought prior to the interview.

The topic guide was constructed on the basis of insights from interviews and focus groups conducted with mothers and guardians. Interviews focused on the insights counsellors had gained into the views and experiences of mothers and guardians of giving birth to a child with clubfoot, accessing treatment and completing treatment.

In addition, they also explored some of the cultural explanations behind these responses. Interviews were mainly conducted in English with translation from Paul in places where participants chose to use Chichewa. Interviews were audio-recorded, translated and transcribed. See Appendix for topic guide.

Both Paul and I were present during interviews. I conducted the interviews whilst Paul translated when required. Interviews were conducted in a secure space within the clinical setting. Transport to the study sites was also reimbursed.

Analysis

Both the local language and English translations were included in the final transcript for analysis. To ensure that translations accurately reflected the views and experiences of participants, Paul quality checked all final transcripts. Data were then imported into NVivo data analysis software and analysed using an inductive thematic analysis to identify themes and subthemes in the responses(334). These were integrated with insights from observations conducted in clubfoot clinics during phase 1 of fieldwork. This was done by identifying codes in the observational data that expanded on or helped illuminate findings. Descriptive accounts of the data were then generated.

4.3.6 Element 3: Exploring the experiences of children and their guardians that had either discontinued or not fully accessed treatment

Four case studies were conducted with families that had either discontinued or not fully accessed treatment from one of the three study sites identified for data

collection in Element 2. In keeping with case study methodology, data was collected from a range of sources including observations in clinics and home settings and informal interviews with families, healthcare professionals and counsellors working in the clinics(335). Detailed data collection on a small number of cases enabled me to explore in-depth the experiences of help-seeking once participants had discontinued treatment(336).

As above, I aimed to identify potential participants that had ceased to attend clinics in the past five years using clubfoot treatment records. Contact details provided by guardians in these records were then used to approach participants and inform them about the aims and objectives of the study. Guardians were either contacted through phone calls or by visiting them in their homes. As before, information was provided on the aims and objectives of the research, what participation would involve and issues of consent. Two of the case studies were also identified in clinics. These participants were approached in person and provided with verbal information about the study. We recorded their names and addresses and arranged a suitable time to visit since they did not have phones. Verbal consent was requested as above.

Although I initially aimed to undertake five detailed case studies, only four cases were identified for data collection as participants were difficult to identify. Reasons for this were incomplete records in clinics, a lack of contact details or because potential participants had moved area. In Clinic 3, a number of patients had provided false names and addresses. A collective or multiple case study approach was used to compare and contrast findings from a range of cases(337). To do this effectively I aimed to select cases with a range of characteristics(335). These included

patients that had ceased to access treatment and those that were attempting to re-access services, point in the treatment trajectory when they had stopped attending services and age of child. Nevertheless, due to the logistical challenges I faced in identifying and recruiting participants, sampling was largely based on convenience(331).

To guide data collection, a list of themes were considered prior to visiting participants. These included information about context, participant experiences of accessing treatment, reasons for discontinuing treatment and impact on the family. However, themes were flexible and evolved during data collection. Likewise, methods of data collection were flexible and shaped by the demands of the individual cases(337). As before, both Paul and I were present during data collection and Paul translated between English, Chichewa and Yao as required to enable me to interact with participants and understand the interactions taking place. Data were collected through informal discussions at clinics or in the home setting. Immediately after these sessions, field notes were made in collaboration with Paul. Where possible, quotes were transcribed verbatim. These were written up into full field notes on return from the field. Analysis was iterative and ongoing and memos used to critically reflect on the data collected and record emerging ideas(324).

Individual case studies were presented as 'stories' in the sequence of data collection, with the role of researcher integrated into descriptions. Case studies were read several times so I could familiarise myself with the narratives. A thematic analysis was then conducted on each individual case to identify themes. However, care was taken not to overly fragment the 'stories' since they were situational and embedded

in their social contexts. Themes identified were then compared and contrasted across each of the four cases(338). Accounts of overarching themes were then generated. To enhance the presentation of findings I drew on Stake's criteria for assessing the rigour of case study reports(337). This criteria is included in the Appendix.

This work took place April – September 2016 and was completed November 2016.

4.4 Ethics

4.4.1 Informed consent

In accordance with guidance for research in the social sciences and humanities issued by the National Commission for Science and Technology in Malawi (NCST)(339), participants provided consent prior to data collection. This ensured that they understood the aims and objectives of the research, that their participation was voluntary, they were free to withdraw at any time and that they were willing to let the project researcher include anonymous quotations from them in the write-up of the study. All participants were informed that data would be anonymised so that no one would be able to identify them, with the exception of those who had agreed to be photographed as part of the study.

Healthcare professionals and counsellors

Healthcare professionals signed one consent form prior to data collection to provide study researchers with permission to shadow them in their clinical practice and undertake formal and more informal interviews. In addition, they had the opportunity to provide consent for the researcher to take photographs of the service.

Consent forms were stored by the study researcher. Participants had the option of providing this in either English or Chichewa. See Appendix for consent forms in both English and Chichewa.

Parents or carers of children with clubfoot, children with clubfoot, and other individuals involved in their care

In accordance with the American Anthropological Association code of ethics(340) and guidance from the British Sociological Association(341), parents or carers and their children who were being observed in public spaces such as clinics or in the community setting did not have to provide formal consent in all cases. This is because these settings were publicly available. The collection of information in this way was conducted with guidance to ensure that participants' wellbeing and best interests were protected at all times.

Children and their significant others being audio-recorded or observed in private settings or interviewed were required to provide full consent to take part.

Adults (18 or over)

Participants over the age of 18 provided verbal consent to take part on account of the low level of literacy amongst these groups. They also had the option of providing consent to take relevant photographs.

Children (under the age of 18)

Consent for children to take part, defined as being under the age of 18, was provided by their guardians or significant others unless they had the status of an emancipated minor. An emancipated minor in Malawi is considered to be a child who is released from parental control(342). Children under this age also provided assent if they were deemed to have the understanding to do so, both to be involved in interviews, observations and in photographs. Although this does not have the same legal status as consent, it recognises the right of children to make informed decisions about their participation in research(343). This is in line with the United Nations Convention on the Rights of the Child that was ratified by Malawi in 1991(344). Assent was provided verbally(as above).

Participants had the option of providing consent or assent in English, Chichewa or any other local languages as preferred. See Appendix for consent and assent scripts.

4.4.2 Data management

Access to Data

Throughout the duration of the project data was only accessible to the study team that included myself, Paul and Supervisors. Data was also made temporarily available to a transcriber.

Data recording and record keeping

Data recording and record keeping adhered to requirements outlined by the NCST in Malawi(339). To ensure that data was stored securely, confidential data was stored on the data encryption service, VeraCrypt and access controlled using a combination

of passwords. When required, data was transferred to the study team using the encrypted file exchange service, Oxfile. Participant paperwork was stored in a locked filing cabinet.

Data was transferred to transcribers using an encrypted memory stick and transcriptions saved on this device. Access to audio-recordings was controlled using a password. To ensure transcribers adhered to data protection regulations, they were required to sign a confidentiality agreement with Oxford University prior to employment.

Data will be stored for as long as is deemed necessary. Data will be anonymised and stored on encrypted files for possible future use. Permission to access data must be sought.

4.5 Chapter summary

This chapter presents a comprehensive overview of the methodology used to address the aims and objectives of this study, along with the innovative abductive approach I used to collect the data. The remaining chapters present an overview of the data collected using these approaches.

Chapter 5 Exploring the implementation of clubfoot treatment services

The chapter aims to present findings from element one of the ethnographic study and has two aims. Firstly, it aims to use ethnographic research methods to explore how clubfoot treatment services in Malawi can be successfully implemented. Secondly, it aims to identify a theoretical framework to help illuminate findings. I begin by detailing the characteristics of the sample and then present findings. My findings will be presented in two parts. Part 1 presents findings on the implementation of clubfoot treatment services. Part 2 then describes findings in relation to the implementation of counselling services.

5.1 Characteristics of sample

The total number of participants included in the sample was 58, including 52 healthcare professionals and counsellors responsible for delivering treatment, two members of the CURE Clubfoot Management Team and four Deputy Health Officers, Deputy District Health Officers or Hospital Administrators. Of the 52 participants involved in service delivery, between two to eight participants from each clinic were interviewed depending on the number assigned to the service and those that were willing to take part. These comprised eight Orthopaedic Clinical Officers, 10 Rehabilitation Technicians, three Physiotherapists, six Hospital Attendants, 10 Physiotherapy Students, one Medical Student and 14 Counsellors. Time spent working in current roles ranged from three months to 25 years and time spent in clubfoot care, excluding District Health Officers, ranged from three weeks

to 15 years. Participants' characteristics are displayed in Table 8, but summarised information is presented only in order to avoid the potential for identification of participants.

Table 8: Participant characteristics (aggregated to ensure anonymity)

Participant group	Number of participants	Age (range)	Years spent working in current roles (range)	Years spent working in clubfoot care (range)
Orthopaedic Clinical Officer	8	30 - 43	4 – 16	4 – 13
Rehabilitation Technician	10	23 - 43	<1 - 9	<1 - 12
Physiotherapist	3	29 - 48	6 - 14	2.5 - 15
Hospital Attendant	6	32 - 68	4 - 25	3 - 4
Physiotherapy Student	10	20 - 22	3 - 4	2 – 10 weeks
Medical Student	1	22	4	3 weeks
Counsellor	14	39 - 59	2 - 7	2 - 9
Beit CURE Clubfoot Management	2	31 - 47	1 – 4.5	1 – 4.5
District Health Officer, Deputy District Health Officer, Hospital Administrator	4	27 - 38	3 months – 8	3 months – 2.5 years

5.2 The theory

Using an abductive approach, we developed a theory based on extended Normalization Process Theory(222). According to eNPT, the implementation of interventions is dependent on the ability of agents to fulfil four criteria which can be understood using four constructs(222). In addition, we identified a fifth construct, which we called: 'negotiating patient access', concerning the work healthcare

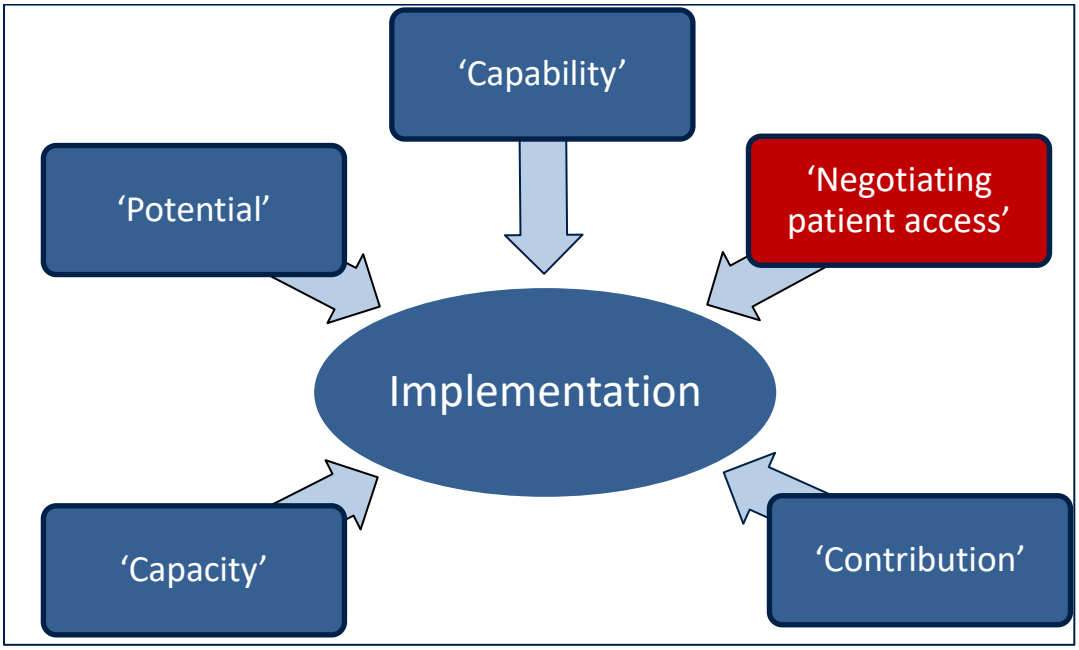
professionals did to facilitate patient access. Included in this was the formal work healthcare professionals did that was integrated into service design, and the informal work that they carried out as individuals. This builds on concepts from previous implementation theories developed within the field of health that acknowledge the importance of addressing patient needs, including barriers to access, in facilitating effective implementation(189, 345). See Table 9 for an outline of the Theory.

Table 9: The four constructs of extended Normalization Process Theory and the additional construct, 'negotiating patient access'

Construct	Description
'Capacity'	Implementing an intervention depends on participants' capacity to co-operate and co-ordinate their actions
'Potential'	Translating capacity into action depends on participants' commitment to operationalise the intervention
'Capability'	The capability of participants to enact the intervention depends on its workability and integration into everyday practice
'Negotiating patient access'	The formal work integrated into services and informal work that participants do to facilitate patient access.
'Contribution'	The implementation of an intervention over time depends on participants' contributions to enacting it by investing in meaning, commitment, effort, and appraisal

Figure 13 shows how the five constructs relate to the implementation of clubfoot services.

Figure 13: Relation of five constructs to implementation of clubfoot services



Below I explore the findings in relation to the four constructs of eNPT and our fifth construct, 'negotiating patient access'. Part 1 explores participants' experiences and views about issues that affect the implementation of clubfoot treatment services using the five constructs. Part 2 describes experiences of implementing clubfoot counselling.

5.3 Findings from Part 1: Exploring the implementation of clubfoot treatment services

Data identified and their relation to these five constructs are outlined in Table 10.

Table 10: Codes identified in data exploring the implementation of treatment services and their relation to the four main constructs of extended Normalization Process Theory and strategies to negotiate patient access

'Capacity'	'Potential'	'Capability'	'Negotiating patient access'	'Contribution'
Communication and cooperation between clinic staff Communication between medical and physiotherapy students and clinic staff Documentation to share information about patient progress Cooperation with healthcare centres in primary care Cooperation with other Departments working within District Hospitals	Variable commitment to delivering services Influence of Christian beliefs on commitment Staff arriving late or failing to attend Influence of contextual factors on commitment to service delivery	Lack of material resources Lack of braces Impact of wider factors in healthcare system Staffing levels Time to deliver treatment Working space	Familiarity with patient barriers to access Informal strategies to address lack of patient transport Follow-up for those discontinued treatment integrated into service delivery	Ability to adapt to new challenges Monthly monitoring reports Ordering materials for clinics

Relationship with clubfoot management in Beit CURE Hospital				

Below I present findings in more detail.

5.3.1 'Capacity': Implementing an intervention depends on participants' capacity to co-operate and co-ordinate their actions

I observed that relationships between healthcare professionals in clinics tended to be hierarchical. That is, senior members of staff delegated roles and made final decisions about treatment. However, staff were in constant communication and junior members consulted with more senior colleagues when required. This was facilitated by their working in close proximity. Using 'treatment stations' which patients rotated around, seemed to promote cooperation. Whilst some participants thought that allocating staff the same roles each week increased efficiency, others thought that rotating roles was useful since it meant that all staff could become familiar with each component of care.

Medical and physiotherapy students played an integral role in service delivery at two of the observed clinics. However, I found during observations that the nature of the relationship between staff and students differed. In one clinic, students were closely supervised whilst in the other, supervision was intermittent due to low staffing levels. When this happened, treatment was less effective, casts slipped off and manipulations were not performed according to protocol.

Professionals used proformas developed by Beit CURE Hospital to share information about progress of patients. However, this was more difficult for participants in outreach clinics when there was not enough stationery, when documentation was not available, and when filing systems did not meet their needs. In one clinic, I observed that staff drafted their own proformas for recording

patient progress. For these reasons a number of healthcare professionals were seen recording patient progress in health passport booklets – portable booklets owned by patients documenting all the medical care they received(346). Others explained that they used both as a way of cross-checking information.

Most participants thought that cooperation with staff working in healthcare centres was effective since they were able to identify and refer patients to clinics. However a smaller number, including members of the CURE management team, did not feel this was being done consistently. One clinical officer thought staff should be visiting healthcare centres to 'educate' them. Overall, it was agreed that children born in District Hospitals were more likely to be referred and an added advantage was that treatment could begin immediately. Participants were also concerned that those identified in the community did not present because they lacked money for transport. Key informants agreed that this problem existed across the healthcare system.

Staff reported that they valued having a service that was centrally organised by Beit CURE Hospital, led by an identifiable coordinator. Communication was through phone calls, emails and during site visits. However, staff were keen to communicate more regularly so they could "present petitions" if necessary. There were differences between what CURE management saw as the role of CURE and those working in the clinics. Healthcare professionals felt it was the responsibility of CURE to provide financial incentives and resources. By contrast, CURE management wanted the services to be self-sustaining and "owned" by the District Hospitals.

Box 3: Illustrative quotes for the construct 'Capacity' in exploring the implementation of clubfoot treatment services

Initially the orthopaedic department was very far, it was at emergency department but this time we are using a small room in here, so it's not difficult [to work together]. Orthopaedic Clinical Officer, ID: 41

Most of the times when its clinic day we meet in the morning and we plan…. We make sure that each one of us is assigned to a certain activity. For example Assistants have to make sure that water and size 15 blades are available. Orthopaedic Clinical Officer, ID: 41

I explain [the job] to my friend if they don't understand. She asks me, then we assist each other, we work together as one. There is love and things go on well. Orthopaedic Clinical Officer, ID: 37

[Working together as students] went well but at times we argued on clinical issues since we all had different sources of information. What we learnt in class was quite different to the clinical area so we had to consult the supervisor. I felt good since we had to learn from each other too. Physiotherapy Student, ID: 17

The information in the health pass book is useful if the documentation was proper so you could check the progress of the child and it's safer than the sheets we had because most of them go missing. Physiotherapy Student, ID: 21

I am not sure about all the clients but usually the [workers in the Health Centres] do identify all those with a congenital deformity. Orthopaedic Clinical Officer, ID: 13

The health centres tell the mothers to come to the clinic. However, they do not provide transport so some of the mothers do not come. Orthopaedic Clinical Officer, ID: 37

We have POP [plaster of paris] now because in February we didn't have. We can't depend on government because Government also ran out of POP so we depend on CURE. Rehabilitation Technician, ID: 07

[CURE] support the clinic by providing materials, supervision. They are run by CURE. Orthopaedic Clinical Officer, ID: 37

[CURE only supply resources] when necessary because we will not be here forever. We need to develop that spirit, that self-sustainability in them. Clubfoot Coordinator, ID: 53

5.3.2 'Potential': Translating capacity into action depends on participants' commitment to operationalise the intervention

Commitment to delivering the treatment varied although there appeared to be high support for Ponseti treatment. A number of staff expressed passionate commitment to treating clubfoot and frustration about factors that impeded service delivery. At times, commitment was described as a Christian "duty". Nevertheless, I saw that commitment to operationalizing the intervention in other clinics was less apparent since trained staff delegated to untrained professionals, arrived late and left during clinics. Some participants were concerned that their colleagues would not assist in delivering treatment when they were absent, despite the fact that they were trained to do so. Others, that tenotomies were delayed as orthopaedic clinic officers had other clinical interests.

Reasons for these behaviours were discussed by CURE management and key informants. One member of CURE thought healthcare workers felt the service fell outside their remit since it was "run" by CURE. Key informants also highlighted contextual factors that impacted on commitment such as high workloads, a lack of resources, low pay, lack of financial incentives and few opportunities for promotion.

Box 4: Illustrative quotes for the construct 'Potential' in exploring the implementation of clubfoot treatment services

When I see the happy face of the mother after the treatment it gives me courage to do more and more. Rehabilitation Technician, ID: 22

When the clinic is not busy its ok but when it's busy it's always a challenge. However due to the Christian aspect of it we do try to finish all. Orthopaedic Clinical Officer, ID: 10

Some of my friends they are not committed as such. Maybe it's because they don't have the passion and they are not interested. Even if they are trained they are not interested because they don't come sometimes even if they are free. Orthopaedic Clinical Officer, ID: 41

They are some clinicians who are very committed and some are not. For example we call them for tenotomy and they take time, maybe a week can pass. For others they take few minutes, they come to do that. So some are committed, some are not. Rehabilitation Technician, ID: 43

It's an attitude [amongst healthcare professionals] that the clubfoot clinic is CURE's. That these are CURE's patients, it is not really my job, I just do it voluntarily. They end up not attending to clubfoot patients sometimes because they think that they can either attend to them or they cannot. Clubfoot Coordinator, ID: 53

I would say commitment [amongst healthcare professionals] is low because of the environment within which they're working. They do not have adequate resources. District Health Officer, ID: 55

There is no motivation [amongst healthcare professionals] mostly because of salaries… the salary is lower as compared to the basic requirements. District Health Officer, ID: 58

5.3.3 'Capability': The capability of participants to enact the intervention depends on its workability and integration into everyday practice

Observations and interviews I conducted suggested that the ability of healthcare workers to integrate the Ponseti intervention into everyday practice was hindered by a lack of material resources and trained staff. Staff at all the outreach clinics reported that they had lacked resources in the past. Resources included plaster of Paris and gauze, equipment for cast removal, materials for carrying out tenotomies, braces and stationery. I observed staff borrowing these from other services. When there was no plaster of Paris, healthcare professionals postponed re-casting or sent patients home without treatment.

Participants wanted electric cutters to remove casts and felt these were most efficient. However, only a small number had access to these. Generally, mothers were required to soak casts in clinics which healthcare professionals saw as being time-consuming and a small number of participants were worried reusing basins could cause infection. However, when this was done at home by mothers, they were concerned that it was not done on the same day as treatment. I observed that razors or surgical blades were used to aid removal but some staff reported incidents of injuries. Likewise, staff in one clinic used a manual saw to remove casts which seemed to cause considerable distress to the mothers and children attending.

When the correct size of brace was not available, I saw healthcare professionals fitting children in the wrong size or re-casting until they became available. In one instance, I saw a child presenting at a clinic with recurrent clubfoot because braces had not been available. I observed a small number of students advising mothers to purchase ankle boots since they thought this would help maintain the position of the foot. In addition to a lack of resources, I found that clinics on two occasions were running without electricity or water.

District Health Officers attributed a lack of consumables to underfunding in the public healthcare system and reported that sending patients home without treatment was common. When hospitals could not pay debts to providers then electricity and water were stopped. One emphasized the important role of non-governmental organisations in supplementing resources. At the time of the study, key informants felt that recent budget cuts to the Ministry of Health were exacerbating these problems.

A small number of healthcare workers, including those at CURE Hospital, thought that clinics were adequately staffed with trained professionals. However, others expressed concerns. I observed that many of those working in outreach clinics had to attend to competing demands such as emergency trauma care and frustration with this was expressed in interviews. Likewise, I observed that staff sometimes did casting alone rather than in pairs as per best practice, or with assistance from mothers or counsellors. I saw treatment being delegated to untrained health workers. When this happened, materials were wasted and manipulations were sometimes ineffective. I also saw injuries such as pressure sores occurring. Key informants attributed these issues to staff shortages across the healthcare system. They advocated task shifting to lower cadres but were concerned that this could compromise quality of care. Staff wanted CURE to introduce more training, both for trained healthcare professionals and those with little or no medical background to ease the burden. This included refresher courses to ensure staff were following best practice. CURE management emphasized how important it was for staff to practice the technique regularly to maintain their skillsets.

Around half of those interviewed felt they had enough time to treat patients and this was helped by designated time in specialised clubfoot clinics. Staff who had to deal with competing demands felt under more pressure. Likewise, a number of participants, especially those working at Beit CURE Hospital, were happy with their working space. However, almost three times as many thought that clinics were overcrowded, especially when they had to share their working space with other services. They also worried that sharing hospital space compromised the

privacy of the mothers. In one clinic, I saw cast removal taking place in a general reception area. Some participants also worried that carrying out tenotomies in the same space as castings was not hygienic. In one clinic, I observed an older man with open wounds being treated on the same couch as clubfoot patients. Key informants suggested that this reflected problems in the wider healthcare system and one attributed this to the fact that hospital infrastructure had not kept pace with population growth.

Figure 14: Photograph of a healthcare assistant removing a cast with a manual saw in an outreach clinic



The healthcare professional in this photograph provided signed consent and the mother provided verbal consent for this image to be taken and used for the purposes of research.

Figure 15: Photograph of a mother removing a cast by soaking it with water in an outreach clinic



The mother in this photograph provided verbal consent for this image to be taken and used for the purposes of research.

Box 5: Illustrative quotes for the construct 'Capability' in exploring the implementation of clubfoot treatment services

[When we lack bandages and POP] we have no other option but to postpone the day for cast removal and casting. That's why we advise the mothers to remove the casts here at the hospital. Counsellor, ID: 08

Things that didn't go so well was when the materials we use were not available, so we would go to the casualty department to look for POP and sometimes we would go to the kids ward to look for gloves because they were not there. Physiotherapy Student, ID: 01

The only thing that we are missing is stationery. In terms of papers, the hospital used to provide but now can't. There are no supplies at the hospital as there is no donor. I have to go to the local market to get them photocopied. Orthopaedic Clinical Officer, ID: 41

[The manual cast cutter] is not ok because sometimes they do cut the skin of the child… Once a child was cut and they couldn't do the recast but rather they dressed the wound and sent the mother away to heal first. Counsellor, ID: 24

[Getting the mothers to soak the casts in water] works but to some extent it delays. We want to treat them first, but when we are ready they are still removing it. So it's time involving and sometimes very difficult for some mothers, they feel like they are ill treating them. Orthopaedic Clinical Officer, ID: 37

There are times when we run short of shoe sizes, some brace sizes. We end up giving something which is not very appropriate, like we end up giving a brace that is a bit smaller or bigger size… I think that can affect the treatment. When it's really tight it can be hard for caregiver to keep on getting his child to have the braces because it needs more time to squeeze in the foot. When it's very big or small the position of the feet sometimes gets affected. Rehabilitation Technician, ID: 40

[The budget cuts] have negatively impacted on the provision of services because the budget has been reduced in absolute terms…. The budget has been reduced but then the costs of providing the services has gone up, so it's negatively affected our ability to provide services. District Health Officer, ID: 55

As a program we have had challenges. Over delegation of this job to untrained health workers, that's a major challenge… It has affected our treatment. You can see length of casts going up to 21, that patient is poor, her morale is down. When you see who is doing it you see he is not supposed to be doing it. Clubfoot Coordinator, ID: 53

We have got enough time, because we have got the whole day for treatment…. We are having many patients here, we are covering a big area including other districts that's why we are having a whole day to give enough time for patients. Rehabilitation Technician, ID: 43

The time is also limited and most times a lot of people are delayed to be attended to in good time. Counsellor, ID: 12

Most of the time [the treatment is] in this office we usually share it with a clinician. He is busy attending to his patients and you are stuck here with your clients. It's way too little and when you're in there as well. It's a problem because there are a lot of disturbances so it's not that really comfortable. Rehabilitation Technician, ID: 52

Figure 16: Photograph of an orthopaedic clinical officer performing a tenotomy on a child



The mother of the child in this photograph provided verbal consent to this image being taken and used for the purposes of research.

5.3.4 'Negotiating access': Implementation is dependent on participants' ability to negotiate patient access to treatment

Participants were familiar with patient barriers to access such as a lack of transport, lack of interpersonal support, knowledge about treatment protocols and challenges of losing patients to follow-up. Strategies adopted to address these included informal work that healthcare professionals did as individuals and formal work integrated into services.

Many participants were frustrated that the healthcare system did not provide financial support for transport. I saw some giving mothers their own money,

arranging transport in ambulances or in a small number of cases, organising for them to be admitted to hospital for the duration of casting. However, these were not systematically implemented. Introducing outreach clinics in the community was suggested. District Health Officers saw this as a challenge that existed across the healthcare system but thought that ambulances should be reserved for critical cases.

Follow-up for patients that had stopped attending treatment was integrated into service delivery. CURE Management explained that counsellors should call patients if they missed an appointment, followed by a home visit if they missed 2- 3 consecutive visits. Participants thought follow-up work could reinforce the importance of treatment, help families to negotiate other barriers to access and provide emotional support. In the interviews, healthcare professionals discussed the advantages and disadvantages of contacting patients by phone or visiting them in their homes. They saw phone calls as more cost effective and enabled them to reach patients living a long way from the clinics, unlike home visits. However, they were concerned that some patients did not have telephones or network coverage in their area. Both healthcare professionals and counsellors felt counsellors were the most appropriate group to conduct this follow-up since they had fewer time constraints and counsellors were enthusiastic about doing this. Nevertheless, staff did not feel they had the resources to do so which was a source of frustration. CURE Management thought counsellors may not have been "faithful" in calling patients because they did not know that there were funds available.

Box 6: Illustrative quotes for the construct 'Negotiating patient access' in exploring the implementation of clubfoot treatment services

If we had enough resources in terms of finance, I could have provided the mother with a transportation fee so that the mother should have access to the mother hospital here in Blantyre Beit CURE. Counsellor, ID: 15

For the transport, it was really a very big problem and some of the mothers could miss their next appointment so the treatment was delayed and an ineffective one. We discussed with [the Orthopaedic Clinical Officer] of this problem. He suggested that if there was an ambulance somewhere around at least the problem would have been solved. Physiotherapy Student ID: 17

It happens when mothers miss the sessions so it is really depressing because I feel like there is nothing I am doing and there is no progress in the treatment of the child. When I ask them why they didn't come they say they did not have transport. I am thinking of admitting them in the wards since they give an issue of transport. [I have done it before], it was very good but a lot of mothers avoid being admitted at the hospital. Rehabilitation Technician, ID: 07

I feel very bad [that we don't have a system for follow-up], because we don't know what is happening to them. Sometimes we say "ah, what is happening to that child?". So it is not good at all. Sometimes we meet them with a very severe default feet so it's very bad, so it looks like we have done nothing. Follow-up is very important. Orthopaedic Clinical Officer, ID: 41

It's hard to do follow ups since we don't have transport to pay them visits in their respective homes. Counsellor, ID: 26

[The counsellors should do follow-ups] because they holistically approach individuals, physically as well as spiritually. They explain to clients the important of treatment and follow-up visits. Orthopaedic Clinical Officer, ID: 37

Our counsellors haven't been really faithful with phone calling. Or, they didn't know the money that we add there is for phone calls for following the patients. So maybe it is our fault for not informing them entirely. Clubfoot Coordinator, ID: 53

5.3.5 'Contribution': The implementation of an intervention over time depends on participants' contributions to enacting it by investing in meaning, commitment, effort, and appraisal

I observed that staff adapted to new challenges as they arose, such as finding space to work if there no electricity or identifying a means of accessing water. Clinics were each required to submit monthly monitoring reports to calculate budget allocations and assess program performance, although CURE management felt they were not always completed accurately. In addition, some healthcare professionals explained that they resisted sending reports as they felt it was outside of their remit. Information from reports was not being used to reconfigure services.

Staff were responsible for ordering materials from CURE through Whatsapp, email or an order form issued by CURE. However, some participants were frustrated that they could not access materials when they needed them and were not sure which member of CURE Management to contact. Methods of transferring materials were agreed with CURE Management and included depositing materials on buses, using

courier services or were delivered by CURE staff during service visits. Interviewees appreciated this flexibility. Members of CURE Management were worried that clinic staff were not correctly calculating the amount of resources that were required.

Box 7: Illustrative quotes for the construct 'Contribution' in exploring the implementation of clubfoot treatment services

We enter data in the files so filling in the forms that CURE gives us is quite okay. We are able to follow each and every patient. A computer to enter the data may be easier as papers can go missing. Orthopaedic Clinical Officer, ID: 34

We are supposed to give CURE monthly reports but there was some misunderstanding. All the staff in clinics were complaining the OCOs, healthcare assistants, rehab technicians. The counsellors were given a good amount of airtime, about 20,000MK per month. We only get 2000-3000MK, here this was supposed to be divided by two. So we said let us hold the data so we are able to get better airtime. Orthopaedic Clinical Officer, ID: 13

[The Africa Clubfoot Coordinator] identifies the number of tenotomies, casts being done. She does that with the data. She sends it to other people. It shows how healthy the program is in Malawi and she can base her decisions about the budgets on that data. Clubfoot Coordinator, ID: 53

I don't know what happens to it, I just send it to the coordinator. I would like to know what is happening with the data so I should compare our service with what my friends are doing. Orthopaedic Clinical Officer, ID: 41

5.4 Findings from Part 2: Exploring the implementation of clubfoot counselling services

Data identified and their relation to these five constructs are outlined in Table 11.

Table 11: Codes identified in data exploring the implementation of counselling services and their relation to the four main constructs of extended Normalization Process Theory and strategies to negotiate patient access

'Capacity'	**'Potential'**	**'Capability'**	**'Negotiating patient access'**	**'Contribution'**
Communication between staff and counsellors Rotation of counsellors on weekly basis Communication with counsellors working in other clinics Communication with CURE Spiritual Team at CURE Hospital	Variable commitment to delivering counselling Influence of Christian beliefs on commitment Counsellors arriving late, failing to attend or encouraging mothers to leave without counselling Disagreements about reimbursements	Lack of resources such as stationery Desire for refresher courses Time to deliver counselling Lack of private space for counselling	Individual or group counselling sessions Variation in topics discussed Role of Christianity Sex of counsellor Single or multiple counsellor service	Data submitted to CURE organisation

Below I present findings in more detail.

5.4.1 'Capacity': Implementing an intervention depends on participants' capacity to co-operate and co-ordinate their actions

I observed that counsellors and healthcare professionals generally communicated effectively and shared information about patients. However, I saw some staff failing to refer patients to counselling. Clinics tended to employ two or more counsellors that rotated on a weekly basis and cooperation between them was high. Written records were used to transfer information about patients and they took their own initiative to call each other to coordinate visits, discuss patients and any developments within the service. Counsellors enjoyed working on rotation as it freed them up to attend to "other business" on alternate weeks. It also meant that another counsellor could replace them if they had other commitments.

Counsellors wanted more contact with those working in other clinics and suggested that 'refresher courses' would provide them with an opportunity to share skills and experiences. They were also keen to have more regular phone calls and visits from the CURE Spiritual Team so they could "present petitions" if necessary. A number of counsellors were unhappy that they had not been consulted on changes to their working arrangements in the past.

Box 8: Illustrative quotes for the construct 'Capacity' in exploring the implementation of clubfoot counselling services

If we [the healthcare professionals] have got a problem with the client, we go to counsellor to explain "we need you to counsel on this". Rehabilitation Technician, ID: 43

When we [counsellors] see a problem with the patients we report immediately to the OCO's… It really works well because the clinicians check for the problem and the kid gets help. Counsellor, ID: 09

We do not have problems [working together as counsellors] because there is job segregation. Our relationship is quite good… We update one another through phones. We have one spirit. Counsellor, ID: 32]

One clubfoot counsellor now will not be enough. If someone happens to have an emergency there will be no one to cover. Counsellor, ID: 20

CURE should have a workshop for the counsellors reminding them of the work they do and also ask them about the challenges they are facing. Counsellor, ID: 08

5.4.2 'Potential': Translating capacity into action depends on participants' commitment to operationalise the intervention

Commitment to delivering counselling varied. Most of the counsellors were motivated by their Christian beliefs. However, I observed others arriving late, failing to attend or encouraging mothers to leave without counselling. CURE management felt that commitment could be improved by increasing contact with the clinics through telephone calls and visits to offer encouragement and listen to

their concerns, and this view was echoed by counsellors. Participants were also keen to have more contact with counsellors working in other services to engender "team spirit". They also wanted more allowances and emphasized that those provided should arrive on time.

Box 9: Illustrative quotes for the construct 'Potential' in exploring the implementation of clubfoot counselling services

CURE encourages us that this is a voluntary work, this is work you must be doing as men and women of God. If we hear that we know that we are in the right direction so we should keep doing this since we a have reward at the end of the day. Counsellor, ID: 31

The bible teaches us that Jesus came to save us and we should help others get saved when we are saved. Counsellor, ID: 12

What I have observed is that counsellors need support from us so it encourages them to do the work more since is voluntary. So if we just say that just do the work the way you can do they don't care… You encourage them through phoning, things like those. You visit them and you encourage them. Counselling Coordinator: ID: 54

When [CURE] need us, they inform us through phone calls and emails. Three years ago they used to invite us to retreats but now it's been a while… sometimes we face some challenges and it can make us forget our purpose in the first place. Counsellor, ID: 08

And for the allowance, it's just too little for the food allowance since things have gone high so we need some adjustments. The sum of 2000MK has been there for five years. Counsellor, ID: 15

[They should] raise our allowance. There is always delay in giving us the allowance, they should improve on that. Counsellor, ID: 32

5.4.3 'Capability': The capability of participants to enact the intervention depends on its workability and integration into everyday practice

Counsellors in a number of services had found themselves short of stationery or lacked the resources they needed to photocopy forms to maintain records. All participants thought they had the skills they needed to deliver counselling but wanted refresher courses to build on them. Half of the counsellors felt that they had enough time to deliver counselling. However, others reported they were unable to hold individual counselling sessions due to the high volumes of patients. I observed group counselling sessions taking place in these clinics.

Many counsellors were most concerned that they did not have private rooms to counsel patients since it compromised privacy and limited what mothers were willing to discuss. I found during observations that this appeared to be particularly problematic in the general orthopaedic clinic where patients with other conditions actively listened to discussions. In addition, counsellors felt that constant interruptions and distractions meant mothers forgot some of the information they provided and this was reflected in the interactions I saw between mothers and counsellors.

Box 10: Illustrative quotes for the construct 'Capability' in exploring the implementation of clubfoot counselling services

We buy pens using our own resources. We create forms on our own as well and we just keep one for photocopy. We receive 2000MK lunch allowance for the whole month and we use that money for photocopy. Counsellor, ID: 32

I have been in this system for five years as I have told you, so I have experience. Even when the mother comes, if I look at her I just know that this mother, she is having many worries. So I go directly to what the mother is thinking. Counsellor, ID: 31

Of course we have enough time [to counsel mothers]. We do counselling, especially on Wednesday from morning up to 12 and we still proceed to the afternoon until half 4 when we knock off. Counsellor, ID: 36

No [I don't have enough time to counsel mothers] because if we have more clients it's hard because I have to spend quite a good time with them…. When you are alone you don't give that much information to the mothers since you have pressure with the huge number of people. Counsellor, ID: 20

Not every mother was seen by the counsellors… maybe a group session would work since they spend much time on one mother and others are not seen. Physiotherapy Student, ID: 21

I was thinking if we had a separate room for counselling and receiving the patients it would really be great because we don't open up fully since we counsel them in public. Counsellor, ID: 12

> *There is no room for counselling our clients privately because the patients are mixed. [It is not a good idea to mix] because the patients get distracted by the other patients with worse conditions than clubfoot and they don't pay attention.* Counsellor, ID: 09

5.4.4 'Negotiating patient access': Implementation is dependent on participants' ability to successfully negotiate patient access to treatment

The purpose of counselling services was to provide patients with interpersonal support and information about treatment protocols to help them negotiate barriers to access. How this was delivered varied considerably between services and in many cases, was adapted to meet the demands of individual services.

I saw counsellors at different clinics using individual, group counselling sessions or a combination of both. Counsellors thought individual sessions enabled them to gain in-depth information about individual mothers and encouraged them to "open up". This approach was advocated by CURE management. Other counsellors thought group counselling sessions saved time and encouraged mothers to share their experiences with each other which was an important source of emotional support. They also thought individual sessions were unnecessary when they were imparting general information, for instance about cast care. In one service, counsellors undertook individual sessions when mothers first presented to provide them with an overview of the treatment and address specific concerns, then encouraged them to join group sessions. Counsellors explained that individual sessions were sometimes impossible when there was no private space.

I observed that the topics discussed varied between counsellors. Many provided emotional and social support such as helping mothers to "accept" the condition and discussing marital problems that had arisen. Some tried to encourage mothers to bring their husbands to treatment for additional support. Others focused on educating mothers about treatment protocols and encouraging them to attend appointments.

Counsellors had different attitudes to the role of Christianity in clubfoot counselling. I saw some counsellors encouraging the mothers to view their experiences through the prism of Christianity, for instance by suggesting that the doctors were sent from God. They also prayed with them for healing. These counsellors thought discussing Christianity, whether mothers were religious or not, was an important part of their role. However, I observed disagreements between mothers and counsellors about religion and I saw a number of counsellors objecting to the children wearing "phiris" (charms). One member of the CURE management team thought traditional beliefs should be discouraged as it meant families were less likely to continue seeking biomedical care. However, they also emphasized that mothers should not be "forced" to accept Christianity.

Members of the CURE Management team and some female counsellors thought counselling should be provided by women as mothers would feel "free" to discuss family matters. Men who were counsellors disagreed. One participant thought it was important for it to be delivered by pastors as they were respected in the community, meaning mothers were more likely to listen to their advice. Counsellors thought having single counsellor services would help provide

continuity of care. However, they were worried they would not be able to commit to counselling on a weekly basis.

Box 11: Illustrative quotes for the construct 'Negotiating patient access' in exploring the implementation of clubfoot counselling services

Maybe a group session would work since they spent much time on one mother and others are not seen but then individual counselling is fine too since the counsellors get to know better the problems of the mothers. Physiotherapy Student, ID: 21

[Group counselling] works but not that effectively like the individual counselling since on the group counselling most of the mothers are shy. [Group counselling] acts as foundation counselling whereby the information is general, not specific. Counsellor, ID: 23

We are encouraging [the mothers] to love and be responsible for the well-being of their baby. Counsellor, ID: 12

I want to make sure that their husbands too are taking part in the treatment and progress of their baby… It helps to relieve the burden from the mother. Counsellor, ID: 22

[The most important thing that we tell them is that] they should comply with the treatment and keep on coming until their child is treated. Counsellor, ID: 24

We even give [the mother] examples from the Bible, that even Jonathan had a disabled child but God still used the child. God can still use these children. Counsellor, ID: 32

[The most important information to give the mothers is] the word of God. We then follow up and ask them if they are born again Christians. Counsellor, ID: 12

[I wanted the mother to remove the charm] because those charms are just beliefs, not helpful at all. Counsellor, ID: 09

Our aim is that these mothers should be converted to Christianity because that is the only hope that we can have but we don't encourage [the counsellors] to force the mothers to be converted because when they are at the clinic they meet parents or mothers who are from different dominations. Counselling Coordinator, ID: 54

Because [the mother] felt the love I showed her, so she complied with what I told her to do. Counsellor, ID: 26

The male counsellors might be best in some areas but in most cases females are open enough to fellow women counsellors and are comfortable to present their family problems to a fellow female counsellor. Due to our cultural beliefs, women are not supposed to talk of their family issues with another man. Counsellor, ID: 15

The advantage [of a single counsellor] is the counsellor knows the client better and follows the progress of the client and the disadvantage is that maybe you are absent accidentally, then your position is vacant for that day's counselling session. Counsellor, ID: 15

5.4.5 'Contribution': The implementation of an intervention over time depends on participants' contributions to enacting it by investing in meaning, commitment, effort, and appraisal

Counsellors collected weekly data from records and submitted them to the Spiritual Team at CURE. A member of CURE Management thought these were more accurate than clinical records since they were compiled on a weekly rather than monthly basis, meaning information was less likely to be forgotten. Data supplemented medical reports to assess programme performance. They were also used to help identify major challenges being faced by families undergoing treatment to help the Spiritual Team develop strategies to address them if necessary.

5.5 Chapter summary

I have used Implementation Science theory within this ethnographic study to explore current implementation of clubfoot treatment services in Malawi. Results were based on data collected through observations and interviews. This component of the study provides information about how best to organise services and adds to the small but growing evidence base that makes use of implementation science in low and middle-income countries(225). In doing so, it highlights its potential value of this approach in these settings. Information from this component on the study complements the data presented in the following chapter, exploring the experiences of mothers and guardians of accessing these services. This helps to provide a fuller understanding of the issues under study.

Chapter 6 Exploring the impact of accessing and utilising services

This chapter presents findings from element two of the ethnographic study, exploring the impact of accessing and utilising services on children and their guardians. I begin by detailing the characteristics of participants and then present findings. Findings consider experiences on finding out the child's feet were different, experiences of accessing services, living with a child accessing treatment and of being formally discharged.

6.1 Characteristics of the sample

The total number of guardians of children with clubfoot included in this component of the study was 52. Seventeen interviews were conducted with guardians of children still accessing treatment and this included six dyad interviews, that is interviews with two participants[25]. Of these, six participants were attending outreach clinic one, seven outreach clinic two and four Beit CURE Hospital. Three focus groups were conducted with guardians of children still in treatment from each of the study sites, five in each group. 13 interviews were conducted with guardians of children that had been discharged from services, this included four dyad interviews. Of these, three children were attending outreach clinic one, four outreach clinic two and six Beit CURE Hospital. Four clubfoot counsellors were also interviewed since it was felt that these could provide valuable insights into the topic as they had built up relationships with the mothers over time.

Full participant characteristics are displayed in Tables 12 and 13. This includes characteristics of the child in treatment such as stage of treatment, unilateral/ bilateral clubfoot, age and sex. It also includes participant characteristics including age, relation to child, number of children in family, tribe, rural/ urban location, marital status, education and occupation. Characteristics of the clubfoot counsellors are also detailed in Table 14.

Table 12: Characteristics of participants that participated in interviews that were either accessing or had utilised clubfoot treatment services

Participant pseudonym n	Clinic	Stage in treatment	Unilateral / bilateral	Age of child	Sex of child	Single/ dyad/ triad interview	Age participant	Relation to child	Number of children	Tribe	Place of residence in a rural or urban setting	Marital status	Education	Occupation
Memory	Outreach clinic 1	Casting	Unilateral	5 months	Male	Single	29	Mother	5	Yao	Rural	Separated	Drop out Standard 6	Mother
Melina	Outreach clinic 1	Braces	Unilateral	6 months	Male	Single	Not sure	Mother	2	Yao	Rural	Married	Drop out Standard 4	Mother/ housewife
Henrietta	Outreach clinic 1	Braces	Bilateral	11 months	Male	Single	23	Mother	2	Yao	Urban	Married	Drop out standard 3	Housewife/ farmer
Patience	Outreach clinic 1	Braces	Unilateral	1 year	Female	Single	25	Mother	3	Yao	Rural	Married	Drop out standard 3	Housewife
Lynda	Outreach clinic 1	Braces	Unilateral	8 months	Male	Single	25	Mother	3	Yao	Rural	Married	Drop out standard 2	Housewife/ farmer
Fanny	Outreach clinic 1	Braces	Bilateral	1 month	Male	Single	28	Mother	2	Chewa	Rural	Married	Drop out Form 2	Housewife
Priscilla	Outreach clinic 2	Braces	Bilateral	5 months	Female	Single	23	Mother	3	Lomwe	Rural	Married	Standard 6	Housewife

Elipher Ernest	Outreach clinic 2	Braces	Bilateral	2 years, 8 months	Male	Dyad	30 37	Mother Father	4	Tumbuka	Rural	Married	Drop out form 2 Drop out form 2	Farmer Working
Chisomo	Outreach clinic 2	Casting	Bilateral	1 year, 2 months	Male	Single	23	Mother	2	Lomwe	Rural	Married but living separately due to work	Drop out standard 8	Farmer
Brenda	Outreach clinic 2	Braces	Unilateral	2 years, 6 months	Female	Single	39	Mother	3	Lomwe	Rural	Married	Drop out standard 2	Housewife/ farmer
Yvonne Francis	Outreach clinic 2	Braces night, ankle boots day	Bilateral	2 years, 4 months	Female	Dyad	29 32	Mother Father	5	Chewa	Rural	Married	Didn't go to school Standard 3	Farming/ housewife Farming/ Technical work
Faye	Outreach clinic 2	Casting	Bilateral	1 month old	Male	Single	19	Mother	1	Lomwe	Rural	Married	Standard 6	Housewife
Betty Hastings	Outreach clinic 2	Braces night, ankle boots day	Unilateral	1 year 6 months	Male	Dyad	33 34	Mother Father	5	Lomwe	Rural	Married	Drop out standard 1 Drop out Form 1	Housewife/ farmer Farmer
Grace Blessings	Beit CURE clubfoot clinic	Braces night, ankle boots day	Bilateral	3 years, 5 months	Male	Dyad	21 25	Mother Father	1 (taking care of sister's child too)	Yao Yao	Rural	Married	Drop out standard 6 Did not go to school	Housewife Barber

Catherine	Beit CURE clubfoot clinic	Braces night, should be wearing ankle boots day but can't afford	Bilateral	6 months	Male	Single	32	Mother	5	Nyanja	Rural	Married	Drop out Standard 7	Sells fish
Mary	Beit CURE clubfoot clinic	Ankle boots	Unilateral	2 years	Female	Single	29	Mother	1 (taking care 3 other children)	Yao	Urban	Married	Holder of MSCE, Diploma in designing for 2 years	Student redoing MSCE, housewife
Tiwonge Patrick	Beit CURE clubfoot clinic	Ankle boots in day but can't afford them so wearing sports shoes	Bilateral	4 years	Male	Dyad	31 36	Mother Father	3	Lomwe	Urban	Married	Drop out standard 6 Drop out standard 8	Sells rice Mechanic
Ellen	Outreach clinic 1	Discharge d	Unilateral	Discharge d 4 years 6 years old currently	Female	Single	28	Mother	2	Lomwe	Rural	Single parent	Drop out Form 4	Sell fizzy drinks
Kazemde	Outreach clinic 1	(2 children with clubfoot) Discharge d	Bilateral	Discharge d 7 years old	Male	Single	33	Father	3	Lomwe	Rural	Married	Drop out Form 3	Business

		Discharged		Discharged 4 years old										
Tafadzwa	Outreach clinic 1	Discharged	Bilateral	Discharged when 4 years	Male	Single	51	Grandmother	Mother has 3 children	Ngoni	Rural	Married	Drop out standard 5	Housewife
Cynthia	Outreach clinic 2	Discharged	Bilateral	Discharged when 5 years old	Male	Single	35	Mother	3	Manglanje	Rural	Widowed	Drop out standard 5	Farmer
Violet Happy	Outreach clinic 2	Discharged	Unilateral	Discharged when 3 years Child born 2009	Female	Dyad	25 38	Mother Father	3	Lomwe	Rural	Married	Drop out standard 8 Drop out Form 3, Has JCE certificate	Housewife Tour guide Mulanje mountain
Chemwenwe	Outreach clinic 2	Discharged	Bilateral	Child 7 years	Male	Dyad	38 71	Mother Grandmother	2	Lomwe	Rural	Married	No school No school	Farming Farming
Estridah	Outreach clinic 2	Discharged	Unilateral	Discharged when 5 years Child 5 years, 5 months	Male	Single	43	Mother	4	Mang'anja	Rural	Married	Drop out standard 6	Housewife

Alile	Beit CURE clubfoot clinic	Discharged	Bilateral	Discharged 4 years old	Female	Single	31	Mother	1	Yao	Urban	Married	Drop out Form 1	Housewife
Teresa	Beit CURE clubfoot clinic	Discharged	Bilateral	Discharged when 5 years old	Male	Single	35	Mother	3	Lomwe	Urban	Married	Did not attend school	Business
Dorothy	Beit CURE clubfoot clinic	Discharged	Bilateral	Discharged when 5 ½ years old	Male	Single	44	Mother	7	Tumbuka	Rural	Married	Drop out Standard 8	Sells popcorn and snacks
Chifundo	Beit CURE clubfoot clinic	Discharged	Unilateral	4 years, 11 months	Female	Dyad	25 54	Mother Grandfather	3	-	Rural	Married	Standard 8 Standard 6	Farmer and housewife Farmer
Desire Nelson	Beit CURE clubfoot clinic	Discharged	Unilateral	Discharged at 5 years	Female	Dyad	44 50	Mother Father	3	Yao Yao	Urban	Married	Form 4 Form 4	 Pastor

Table 13: Characteristics of participants that participated in focus groups that were accessing clubfoot treatment services

Participant pseudonym n	Clinic	Stage in treatment	Unilateral/ bilateral	Age of child	Sex of child	Age participant(s)	Relation to child	Number of children	Tribe	Place of residence in a rural or urban setting	Marital status	Education	Occupation
Bright	Outreach clinic 1	Casting	Bilateral	2 months	Male	17	Mother	1	Yao	Rural	Married	Drop out Standard 6	Farmer
Mavuto	Outreach clinic 1	Casting	Unilateral	4 months	Male	19	Mother	2	Yao	Rural	Married	Drop out Standard 4	Mother/ housewife
Zahra	Outreach clinic 1	Braces	Bilateral	9 months	Male	27	Mother	3	Chewa	Urban	Married	Drop out standard 6	Housewife
Etta	Outreach clinic 1	Braces during day	Bilateral	15 months	Female	-	Mother	3	Ngoni	Rural	Married	Drop out standard 3	Housewife
Aubrey	Outreach clinic 1	Casting	Unilateral	8 months	Male	26	Mother	3	Yao	Rural	Married	Drop out standard 4	Housewife/ farmer/ business woman (sells produce at market)
Pemphero	Outreach clinic 2	Casting	Bilateral	7 months	Male	29	Mother	3	Lomwe	Rural	Married	Standard 4	Housewife/ farmer
Cecilia	Outreach clinic 2	Casting	Unilateral	4 months	Female	30	Mother	4	Lomwe	Rural	Married	Drop out form 1	Farmer

Rose	Outreach clinic 2	Braces at night, boots in day	Bilateral	1 year, 2 months	Male	25	Mother	2	Lomwe	Rural	Separated	Drop out standard 8	Farmer
Vera	Outreach clinic 2	Braces	Unilateral	1 year, 6 months	Female	32	Mother	3	Lomwe	Rural	Married	Drop out standard 4	Housewife/ farmer
Hawa	Outreach clinic 2	Casting	Bilateral	7 months	Male	32	Mother	6	Sena	Rural	Married	Drop out standard 4	Business woman
Lily	Beit CURE clubfoot clinic	Casting	Bilateral	3 months old	Male	18	Mother	1	Chewa	Rural	Married	Standard 6	Housewife
Josephine	Beit CURE clubfoot clinic	Braces night	Bilateral	1 year 2 months	Male	36	Mother	5	Yao	Rural	Married	Drop out standard 2	Housewife/ farmer
Luscious	Beit CURE clubfoot clinic	Casting	Unilateral	1 month	Female	18/19	Mother	1	Lomwe	Rural	Separated	Drop out standard 4	Farmer
Fatsani	Beit CURE clubfoot clinic	Braces	Bilateral	9 months	Male	24	Mother	2	Lomwe	Urban	Married	Teaching diploma	Teacher
Nancy	Beit CURE clubfoot clinic	Casting	Bilateral	4 months	Female	29	Mother	3	Chewa	Urban	Separated	Drop out form 1	Sells clothes at market

Table 14: Characteristics of clubfoot counsellors that discussed patients' experiences of accessing treatment

Role title	Clinic	Occupation	Years spent working in occupation	Length of time working in the clinic	Age
Clubfoot counsellor	Beit CURE clubfoot clinic	Pastor	15 years	15 years	47
Clubfoot counsellor	Beit CURE clubfoot clinic	Pastor's wife	22 years	6 years	44
Clubfoot counsellor	Outreach clinic 1	Pastor	Unsure	6 years	57
Clubfoot counsellor	Outreach clinic 2	Pastor	15 years	8 years	38

6.2 Results

Below I explore participants' experiences about finding out their child's feet were different from others, including attitudes of the extended family and community, views of treatment services, living with a child accessing treatment and impacts of completing treatment. I have changed the names of participants in order to protect their anonymity.

6.2.1 Finding out the child's feet were different

Mothers

Mothers experienced a range of emotions on finding out their child's feet were different from others. Although a small minority said that they did not feel concerned, the most common feelings were of 'pain', 'worry' and 'disappointment'. Reasons for this were not knowing that there were treatment options and concerns about the child's ability to participate in everyday life, such as an inability to walk or wear shoes. Mothers were also worried that the family and child could be mocked in the community.

Finding out that the condition could be healed helped many of the mothers 'accept' the condition. Others thought that disability 'happened', that it was 'fated' and that they should not blame themselves. Attitudes towards the condition were shaped by the responses of those around them such as their husbands, extended family and community.

A number of the mothers drew on their religious beliefs to help process their experiences. Whilst some questioned the will of God, one father Nelson viewed the

experience as a test of their faith as a family. Beliefs also helped the mothers to remain resilient, as they drew strength from their beliefs. In addition, where the child was viewed as a gift from God, the mothers thought they had an obligation to love and cherish their child. Some participants also had faith that the condition would be healed through God's will.

All the mothers interviewed desperately wanted their child to be healed so that they could participate in everyday life and to secure their future. Some characterised this as wanting them to be 'normal'. Mothers also felt that they had an obligation towards the child as they loved them and didn't want to be blamed in the future if they did not seek treatment. The availability of free treatment, seeing the impacts of neglected clubfoot on other children in the community and meeting those that had been healed, also acted as encouragement. The encouragement of healthcare professionals also acted as an impetus.

Fathers and the extended family

The 28 mothers who were interviewed discussed their husband's views and those of the extended family, as did the 7 fathers who took part. Views echoed many of the mothers', including their disappointment and concerns. Acceptance of the condition was also shaped by similar considerations and they too drew on their faith as a way of understanding their experiences. Many of the mothers felt that their husbands and family were an important source of emotional support when the child was born.

In other families, the condition was a source of conflict and division. Mothers reported that their husbands and his family blamed them. Reasons for this were that

there was something 'wrong' with their womb, that their family was cursed or that they had cheated on them. Mothers felt that some fathers did not want a child with clubfoot or assume responsibility for ensuring the child received treatment, including the financial burden of accessing care. In these cases, finding out their child was different sometimes led to divorce and some mothers said this was encouraged by their husband's relatives. For instance, Esther and Teresa found that their own relatives did not want to visit their children. Esther said that she has been 'disowned' by her parents and suggested this was because they thought the child had no future and would be a burden on the family. For these reasons, a small number of participants concealed the condition from the extended family.

Many fathers encouraged the mothers to seek treatment. However, in some families there were disagreements about whether the child should be treated and if this should be in treatment clinics or by visiting traditional doctors. One counsellor explained that the matrilineal family structures in the Central and Southern Region meant that maternal uncles could make decisions about treatment seeking, even if the father disagreed. However, husbands could thwart treatment-seeking by withholding money for transport since they tended to control access to finances.

Wider community

Mothers reported that responses from the wider community also varied. Whilst a number did not comment on the child, others were curious about the condition and wanted to know more about it. Some neighbours expressed concern and compassion for the child. Other families experienced stigma and explained that their neighbours were 'gossiping', 'talking bad', 'laughing', 'mocking' and 'saying

abusive words'. Some apportioned blame to the family for having the child. For most, this was a source of intense pain. For instance, Esther said that she had withdrawn from the community and now stayed in her house and Mercy explained that it had led her to quarrel with her neighbour. Elipher explained that she thought it was because her neighbours 'don't know anything' and dismissed it.

Attitudes to treatment-seeking also varied. Some neighbours encouraged the mothers to seek treatment and even recommended the clinics. Others discouraged the mothers by telling them that it would not work and would be a waste of money. Despite these negative responses, one counsellor thought that attitudes to clubfoot were changing and that people were becoming more accepting of the condition. He suggested this was due to increasing awareness and because it could now be treated.

Box 12: Finding out child's feet were different from others

My husband was the first person who accepted the situation we had and he was the one who was always encouraging me because honestly, I was so disappointed with the condition of my child. He told me that God does not give good things only, so we should accept our baby and thank God for everything. For that I thank him so much. **Sylvia**

[I went to get treatment because] I did not want my child to worry for the rest of her life. I have seen a lot of children drop out of school because their friends are laughing at them, stigmatizing them and I don't want my child to meet such things. **Mary**

My relatives did not accept my situation and as I am talking to you now, my parents, my sister and brothers did not come to see my child. They just talk to each other saying that Esther has a disabled child. If there is something that pains me most it is that my parents have disowned me because I have given birth to a disabled child. It was not my wish to have a child who is disabled. Had it been I wanted that, how come the first two are normal? **Esther**

[When people in the village ask about the clubfoot] I have to answer them that it is true and that this is the condition of my child. So they say "iih may be the child condition will improve with Gods will". So to me those words mean that they are concerned with my situation. **Memory**

People talk a lot. Neighbours will come as if they are being friendly so they can see your child so that they can say something bad about your child's condition. They stigmatise me and I feel rejected by my friends. Since my child was born I have been indoors, I don't go out to chat with people. If they come to see you the next thing you hear is that such, such people were saying you have a disabled child. It pains me so much. **Mercy**

6.2.2 Experiences of treatment services

Diagnosis and referral

Almost half of the participants interviewed identified that their child's feet were different from others themselves, rather than the healthcare professionals involved in their care. Whilst some of the mothers identified that their child's feet were 'bent' from birth, others did not do this until they were at home. As a result, treatment was often delayed. In these cases, the mothers took their own initiative to visit either a District Hospital or a healthcare centre in the community. Identification by

healthcare professionals tended to take place at birth. Only one case was identified when the mother visited a hospital for a check-up.

Referrals to clinics were made by a range of healthcare professionals. A small number of mothers were also directed to clinics by their friends. In a small number of cases, mothers were referred to a Central Hospital in the Region before being referred to Beit CURE. This meant that they had to make two journeys in order to begin accessing treatment. Likewise, it was observed that mothers had not always been directed to the clinics closest to them.

Treatment in clinic

Nearly all the mothers reported that they were overwhelmingly satisfied with the treatment they had received. When asked why, many said they felt that they had been 'warmly welcomed'. As one counsellor explained, healthcare professionals are often seen as being 'harsh' so this was very important to them. There was also a palpable sense of relief that they were accessing treatment and that their child would be 'healed', along with a sense of thankfulness. Mothers were delighted that they were able to see the treatment progress as the feet were manipulated into the corrected position and said that this gave them encouragement. However, some expressed disappointment that the treatment duration was so long.

Despite high levels of satisfaction, mothers did encounter challenges in the clinics as they moved through the phases of casting, tenotomy and bracing. It was observed that casts were often incorrectly applied and participants noted that they sometimes came off on their own. One young mother and grandmother at Beit CURE said she

had observed that the casting stayed on when applied by the 'wakudas' (Malawians) but came off when done by the 'mzungus' (white people). This presumably referred to the Malawian healthcare professionals that worked at the clinic full time and the medical students that regularly visited the clinic from abroad. Furthermore, it was observed that mothers were turned away from clinics if there was not enough plaster of Paris. Faye said that this had caused her 'pain' and others were 'worried' about the money they had wasted on transport.

Tenotomies were a source of anxiety as mothers thought their child was in pain during the procedure. A small number also believed that their child was in pain afterwards and were worried about the healthcare professionals covering the wound with a cast before it had healed. This was emphasized by Njemile whose child had developed pressure sores after the tenotomy. One counsellor reported that some people were frightened by surgery, a view reflected by Grace who said that her neighbours had told her that her child would die during the tenotomy. Two counsellors thought informing them about the tenotomy in advance helped as it enabled them to prepare themselves. However, Betty reported that it had been unexpected and both her and Brenda said they did not understand what was happening during the procedure. This created anxiety.

Nevertheless, the majority of mothers said that they trusted the healthcare professionals and did not question how the treatment was being carried out. This reflects the type of relationships that were observed between the guardians and the healthcare professionals in the clinics. Whilst some healthcare professionals tried to engage with patients and build relationships, others exhibited a more paternalistic

approach. That is, they occupied a position of authority and took responsibility for treatment decisions without consultation with the mothers.

According to counsellors, there was a fear that healthcare professionals could withhold treatment which made mothers reluctant to challenge their decisions, even if they were clearly distressed. For instance, a mother at one of the clinics explained to us that she was worried because her baby's legs were bruised and swollen from a cast applied the previous week. Despite this, one of the healthcare professionals wanted to re-cast, causing the family considerable distress. However, instead of talking to the clinical officer, she asked one of the counsellors to advocate on her behalf. On a small number of occasions, some attendees also greeted the healthcare professionals by kneeling before in a position of subservience. Chemwenwe said that she 'didn't know' if she had received good treatment, indicating that some of the mothers may not have had enough knowledge about the healthcare system and their rights to fully reflect on the care they had received.

Box 13: Experiences of treatment services

The way they welcome us you feel that this is the way someone should be welcomed. Some hospitals when you go they don't pay attention to people. When you are at CURE you feel that you are welcome, they are talking to you with love and care. **Catherine**

[The operation] is not good because when they do the tenotomy they just cut the body and do the cast without even giving us the painkillers for the child. It is hard as the child with the pain will cry and it is the mother who will need to take care of the child. **Teresa**

We did not know that the child would have to go through an operation. We thought that after removing the cast they will just give us the shoes and that this was the tenotomy. We did not know it was an operation. **Betty**

I did not feel anything [when they did the tenotomy], I was just watching and said to myself "this is what the health workers have decided to do". **Henrietta**

Aaah honestly I had no idea of whether I was happy or not [with the treatment I received]. **Chemwenwe**

Relationships between mothers

Participants said that they valued the relationships they were able to build with other mothers attending the clinics. Fellow mothers were an important source of emotional support as they were able to sympathise with the challenges they faced and encouraged one another to attend appointments. Those that were further along the treatment trajectory offered guidance, such as on cast care. Comparing treatment progress also reassured mothers that were just entering treatment that their child would be healed.

Figure 17: A mother helping another mother to fit her child in braces in an outreach clinic



Both mothers in this photograph provided verbal consent for this image to be taken and used for the purposes of research

Ankle boots

After wearing the braces permanently for 2 – 3 months, mothers at all three treatment sites were required to purchase ankle boots to hold the foot in the corrected position during the day, despite the fact that no evidence exists for the efficacy of this component of treatment. This was highly problematic for many of the mothers and presented challenges that they were keen to discuss. The ankle boots were seen to be a huge expense for the families and many were not able to find them at their local trading centres. As a result, some were forced to travel to Limbe market near Blantyre which contributed to treatment costs. Confusion about the type of shoes required meant some mothers wasted money buying shoes that were'incorrect'. If mothers could not afford them, in some cases children had to continue wearing braces full time until they could be purchased. Henrietta and Memory had temporarily stopped attending the clinics for these reasons. To address this, mothers

suggested that shoes should be available to buy in clinics. A small number also thought that clinics could also provide them with financial assistance.

Transport

Accessing transport to the clinics was a major source of concern for most of the participants. According to some, this was the only difficulty with treatment. Methods of transport were by bike, on foot or using minibuses. One wealthier participant used the family car and another was able to access an ambulance from a healthcare centre in her village.

A small number of mothers that lived close to the clinics did not find the journey difficult. However, spending money on minibuses placed a large financial strain on most families. Mothers explained that it was particularly difficult where they had to meet other needs such as school fees and food. Some had to borrow money or do additional work to reach the clinics. One mother explained that she had sold a number of her possessions. Participants thought that the duration of the treatment made these problems more difficult as they had to obtain money on a weekly basis. On weeks where families could not afford transport, they either walked or cycled where this was feasible or were forced to miss appointments. Mothers that cycled or walked to the clinics often found the journey strenuous and had to set off early in the morning. Lynda was frightened of walking through the woods as she thought they were dangerous. Mesi expressed relief about reaching the bracing phase of treatment as it meant that she did not have to travel to the clinic on a weekly basis.

Mothers suggested strategies to address this substantial challenge. They thought that CURE could introduce outreach clinics in the Health Centres closer to them, provide money for transport or give them somewhere to stay or bicycles for those on foot so they were able to access clinics more easily.

Family roles in treatment seeking

Mothers were overwhelmingly responsible for accessing treatment and clinics tended to be populated by them. They were often accompanied by other female family members such as sisters, aunties or grandmothers. When the child's mother was not available, these women sometimes took responsibility for treatment-seeking. One counsellor attributed this to the matrilineal family structure in the south and central regions which meant children were seen as belonging to the female side of the family. For these reasons he thought that fathers attending the clinics would be 'a laughing stock'. Likewise, male members of the mother's family such as uncles often provided financial assistance, reflecting these hierarchies.

Participants reported that fathers' role in treatment seeking was generally to provide financial support, although there were exceptions. Some escorted their wives to the clinics, for instance by carrying them on bicycles. Reasons given by fathers as to why they did not attend appointments were a lack of money for transport and responsibilities at work. In another example, Ernest wanted to attend the clinics, especially counselling sessions but did not think he would be welcome. However, a small number of fathers did attend clinic appointments. Chifundo alternated visiting the clinic with her husband to share the burden of treatment-seeking. Others chose

to attend for the initial appointment. These found it useful as it meant they were both educated about the condition and could provide each other with mutual support.

Box 14: Experiences of treatment services continued

During the treatment of my child before we were discharged, I was able to talk with other mothers who were looking so down and sad because of the condition of their child. I was encouraging them, telling them that their problem is not as big as it was with me and that they will be ok. **Teresa**

The only reason I am not going to the clinic is because they told me that next time I go I am supposed to buy new shoes for the child. I told them I don't have money to buy new shoes. **Henrietta**

Travelling to the clinic is very difficult. When [the doctors] give me a date to come to the clinic, I try to keep some money for transport. If I fail to do that I go and borrow a bicycle from my friend. If that fails then I have to walk from home up to the clinic so that my child should get the treatment. **Olivia**

I talked with the counsellors that my problem is the issue of transport, that it is not easy for me to go to the clinic. I was told that it is the duty of your husband. I talked with him and he reminded me how hard it is for him to find money for my transport. The money he gets is not enough to take care of some other things in the house like buying relish and taking the child when she is sick. **Henrietta**

6.2.3 Experiences of counselling services

The majority of participants thought that counselling was useful and felt that they had received all the information and support they needed. Mothers said they thought the emotional support that they had received was useful, including the hope and encouragement that counsellors gave them and the love that they inspired them to have for their children. Counsellors also emphasized how important it was for the mothers to attend appointments and the mothers thought this was useful. Treatment information such as cast care and information about bracing protocols was also valued. Participants thought that follow-up if they missed appointments would be useful since it would demonstrate that the counsellors cared which would be an incentive to attend appointments. Mary thought it would be useful for the counsellors to follow them up in their homes as it would help them to 'understand us more' and mean they were better able to address their problems.

However, some of the participants also questioned the advice given by counsellors and the ways that they were addressed. They objected to being "told off" for being late because they had made long and difficult journeys to the clinics. Tiwonge suggested she thought it was because they did not fully understand the challenges they faced. A number of mothers were disappointed that they did not always receive counselling. Elipher said that she would prefer a private space for counselling, away from the general orthopaedic patients as she disliked seeing trauma cases and the disturbances made it difficult for her to absorb information.

Many of the participants were confident that they understood the treatment trajectory and bracing protocols. However, others experienced confusion. For instance, many did not know the treatment trajectory and were not sure when they

were going to be discharged. During a focus group the mothers discussed reasons why it would have been useful to have this knowledge from the outset. They thought it would provide an important incentive to continue with treatment and help them to plan for the future. It was observed that some of the children in their homes were not adhering to bracing protocols. Another child was wearing ankle boots all day and night. In addition to the treatment trajectory and bracing protocols, a small number of mothers wanted more information from the counsellors on the progress of their child and what to expect once the treatment had been completed. There was also a desire to discuss the challenges of obtaining ankle boots in more detail.

Participants discussed the advantages and disadvantages of taking part in one-on-one or group counselling sessions and in this, experiences and opinions varied. Mothers were divided as to whether single or group counselling was preferable. The advantages of group counselling that they reported were that they could be encouraged by the counsellor and the other mothers and that they could learn from each other. Chisomo thought it was more efficient for the Pastors who would not have the time to talk to them all individually and made sense since they all experienced the same problems. Those that preferred one-on-one counselling thought that it gave them the opportunity to discuss the progress of their own child in detail and meant they felt more comfortable sharing personal information. One focus group reported how they had received individual counselling during the first visit and then joined in group sessions on subsequent weeks. They thought this was good since it meant that they were able to obtain an overview of the condition and treatment information at the beginning.

As a Christian organisation CURE encourages the counsellors to discuss religion with the patients. This was done in different ways. A number of the participants emphasized how important it was to them to discuss their religious beliefs. Reasons given were that it gave them faith the child would be healed, ensured they kept faith in God despite the challenges they faced, and reminded them that their child was a gift from God. Catherine thought that it could also discourage them from seeking traditional medicine as Christianity was not compatible with these beliefs.

Some of those that had not discussed Christianity with the counsellors were dubious about its benefits as they felt that their beliefs were private and were irrelevant to the treatment. One Christian couple thought it could alienate patients with different beliefs and discourage them from attending. Desire was worried that counsellors would try and convert them to another denomination. For this reason she thought that discussions about religion should remain general. In one of the clinics, I watched a counsellor try to forcefully convert a mother from being a Jehovas Witness. Although he said he was concerned because Jehovas Witnesses do not believe in medical interventions, the mother responded angrily by saying "Go away, I have come here to receive treatment for my child not to talk to you. It is none of your business". In other clinics, counsellors objected to the use of charms and tried to make the mothers remove them, despite resistance.

Box 15: Experiences of counselling

At counselling they sometimes shout at us. They should understand us. It may be that you are coming from afar so you cannot be there in time. **Tiwonge**

Where we have our sessions with the counsellors it's a busy place and we see a lot of emergency accidents coming in during the counselling session. It disturbs us a lot and we get worried when we see that… It's difficult, we see others crying with pain, others being put in casts. It's hard honestly to see people from accidents. **Elipher**

[The counsellors] encourage us while we are in a group, where we are able to talk to one another and say "fellow mothers, you hear what the pastors is saying, let us come to the clinic whenever we get transport". That encourages us even more. **Betty**

One-on-one you are able to say what you think, like your secrets. You can talk about your personal stuff more openly than in a group counselling session. **Happy**

Yes [talking about God with the counsellor] is helping me very much because I was in so much in pain and disappointed but the moment I started believing in God and give all my worries to Him, at last I was able to eat nsima at home because at first, eeh it was hard for me to eat. **Mercy**

[The counsellors are] encouraging us to keep our faith in God. As you know nowadays it is good to trust in God, because here in village when you are not strong in God others will deceive you and encourage you to go to the traditional doctors for treatment. **Catherine**

The danger [of talking about religion] is that there are people from different religions. They are Christians, Muslims, Rastas and all sorts of denominations, so some believe in this way, some in another way. Even Christians they believe in different ways. **Nelson**

6.2.4 Living with a child accessing treatment

The majority of participants said that they did not find it difficult to take care of the child while they were in casts. Others said that the difficulties they experienced were the child crying because they were in pain, difficulties bathing the child without getting the casts wet and that the casts made the child heavy so they were more difficult to carry. Other problems were related to the misapplication of casts and a small number of mothers were distressed that their child had developed pressure sores. One child also had swollen feet as the cast had been applied too tightly.

Likewise, most participants did not find it difficult to care for the child when they were in braces. Some of the mothers initially found that their child cried through the night because they were uncomfortable but that most of them soon got used to it. This was particularly problematic when the child was wearing braces that were too tight for them. Others found that the braces sometimes came off on their own. Three mothers also said that they were not sure how to fit them. A small number also reported that they had difficulties in carrying the child.

6.2.5 Attitudes towards the treatment

Within the immediate family, participants that were interviewed said that they did not treat the child any differently from their siblings. Only Mercy said she did not want her other children to play with the child outside in case he got injured. Participants also thought that their siblings interacted well with them. The exception to this was Natasha who said her other children got upset because they thought the treatment was hurting their brother.

Many members of the extended family encouraged the treatment and loved the child. However, a small number continued to stigmatise them. For instance one aunt told her children not to play with the "boss with bent legs". Fear of the child being mocked, being discouraged from seeking treatment or placed under pressure to visit a traditional healer, led some parents to conceal the condition from their relatives.

Likewise, some members of the community continued to show love and encouragement to the family and child while they were accessing treatment. Nevertheless, some mothers felt ashamed of being seen with their child when they were wearing casts or braces and were mocked by their neighbours. Others simply found that people were curious. There was a common misconception that the child had been injured and that was why they were wearing casts. These experiences were reflected in the views of counsellors. One attributed this to beliefs about the causes of clubfoot as villagers thought the child was cursed. However, he also thought that there was less stigma than there had been in the past as the condition was being more openly discussed.

As the children grew older, they sometimes became more aware of the condition and being different from others. Some participants reported that their children were upset because they could not fully participate in games like football with their friends or were mocked by other children. However, others had not experienced any difficulties. Teresa said she thought it was because her child was 'too young' to be aware he was different.

Box 16: Living with a child accessing treatment and attitudes towards it

The first time the child was in cast, the other siblings were crying saying I should take her back to the hospital because babies are not supposed to be in POPs. **Natasha**

To me it was shameful [when the child was in casts] because I could see my friends carrying normal children without casts on their feet and me, I was carrying a child full of casts. It pained me so much. **Ellen**

If [the neighbours] find your child in a cast, they will laugh and say "why are you doing this to your child? Nothing will happen you are just wasting your time and you are just troubling your child with all this. Nothing will change and your child will be the same". Being as you are already in pain, they just add to your anger and make you more furious and cause so much more pain. **Mphatso**

During the treatment [my son's friends] used to say to him," why do you have bent legs?" He came and told me, so I had to call his friends to tell them to stop doing that to him. He was not crying but maybe in his heart he was pained because he was just saying "mum my friends were saying this and that to me". I just said to him that he should not bother with any of them because he did not wish to be like that. I was advising him not to do anything to his friends because it was God's will not ours. **Dorothy**

6.2.6 Completing treatment

Participants that had been formally discharged described joy, happiness and thankfulness that they had completed treatment. There were multiple reasons for

this including relief and gratitude that their children were able to walk and would not be disabled. They were also thankful that it enabled them to participate in everyday life including going to school unaided, playing with friends, helping with household jobs, going to the toilet on their own and wearing shoes. A number of participants described their child as 'normal' and took great pride in explaining that their family or friends did not 'know' or 'believe' that the child had been born with the condition.

Olivia was grateful as treatment completion meant she could still work in the farm as she would not have to take care of her child. She also thought it would make it easier for her to re-marry as men would not be 'chased away' because she had a disabled child. Likewise, Natasha thought that if the child had grown up with the condition then it might have been expensive for the family to look after her. Participants also thought if they had not accessed treatment the child may have been left out or mocked by their friends as they got older and that they may have been angry at them for failing to access treatment. Families were also happy that finishing treatment meant that the financial burden of visiting clinics had been relieved and that they could now spend the money on other necessities such as school fees.

The majority of those that had experienced stigmatisation said that it had stopped once the child's feet had been corrected. This was reflected in the experiences of counsellors who said that family members and neighbours sometimes felt ashamed for mocking them and apologized. One counsellor recalled that a family had reconciled once the treatment was completed, another that the mother's husband

had returned to live with the family. Only one family said that their neighbours still 'gossiped' even after the treatment had been completed.

Families that had completed treatment took great pride in being an example to others and many became strong advocates for treatment in the community. For instance, Chifundo described how women in her area consulted her about the condition and sought advice. Some mothers wanted to build on this by having a more formal role in advising mothers in the clinics and promoting treatment in the community, overseen by CURE. Ellen suggested she could follow up those that had discontinued treatment or identify those with neglected clubfoot.

A small number of participants that had been formally discharged were concerned that the clubfoot was recurring. However, they were unclear what they should do to address this or if they were able to return to the hospital. For instance, Chemwenwe thought that she should be buying new ankle boots to help correct the position of the foot. Participants in this situation sought advice from me during the interview.

Figure 18: Photograph of a boy who had been discharged (centre) with his mother and extended family outside their family home



The family provided verbal consent for this image to be taken and used for the purposes of research.

The boy provided verbal assent.

Figure 19: Photograph of Ellen and her daughter who is demonstrating that the clubfoot in her right foot has been cured

Ellen is holding a certificate from a CURE Clubfoot open day and wanted to help CURE follow-up those in the community that had discontinued treatment



The family provided verbal consent for this image to be taken and used for the purposes of research.

The girl provided verbal assent.

Figure 20: Photograph of Chemwenwe with her mother and son who had been discharged, in their home

Chemwenwe expressed concern the clubfoot was recurring.



The family provided verbal consent for this image to be taken and used for the purposes of research.

The boy provided verbal assent.

Box 17: Completing treatment

[I feel] joy. We know was it not for that treatment we could have been talking of a different story right now, she could have had a deformity. It's a joy that she is able to walk straight. I can say that she is perfect. **Nelson**

For me, those people who were talking bad about my child feel ashamed, those from my husband's side. When I put the shoes off they are able to see that the feet are corrected now. Oh I know they had something to say but because they are ashamed, they can't say anything.

Mphatso

When [my son] walks long distances he has problems with his feet. He feels pain but I don't have money to buy new [ankle] boots for him. His future will depend upon the boots. **Chemwenwe**

6.3 Chapter summary

This component of the study has explored the experiences and impact of accessing and utilising clubfoot treatment services on children and their guardians. Data was collected using semi-structured interviews and focus groups with carers of children with clubfoot and semi-structured interviews counsellors involved in their care. Exploring these issues provides information to Beit CURE Hospital on how best to develop services to better meet the needs of carers and children. The following chapter builds on these insights by exploring the experiences of children and their guardians that had either discontinued or not fully accessed treatment.

Chapter 7 Exploring the experiences of those that had discontinued or not fully accessed treatment

This chapter presents findings from element three of the ethnographic study, exploring the experiences of children and their guardians that had either discontinued or not fully accessed treatment. Data were collected from a range of sources including observations in clinics and home settings and informal interviews with families, healthcare professionals and counsellors working in the clinics. These provided in-depth information about treatment seeking within the context of their daily lives(335). Individual case studies are presented as 'stories' in the sequence of data collection, with the role of researcher integrated into descriptions(300). Accounts of overarching themes are then discussed, including factors that influenced subsequent treatment-seeking decisions. The amount of data presented for case study varies on account of logistical issues that we encountered. Reasons for this are described in each case.

7.1 Case study 1

Mother: Mary

Child: Mohammad, 6 or 7 years

Stage treatment discontinued: Bracing

Figure 21: Photograph of Mohammad in his family compound



The family provided verbal consent for this image to be taken and used for the purposes of research.

The boy provided verbal assent.

Figure 22: Photograph of Mohammad with members of his extended family in their compound



The family provided verbal consent for this image to be taken and used for the purposes of research. The children provided verbal assent.

Meeting with clubfoot counsellor

It was a hot day in the town and the clinic was crowded with mothers when we sat down with the clinic counsellor Ernest to discuss if he could recall any mothers and children who had stopped attending the services. To my surprise he was immediately able to recall the case of Mary and her son Mohammad. Ernest explained that Mary had been living with her husband in a nearby town where her husband had owned a business. They had started attending the clinic while their child was in infancy and he had received a tenotomy. However, her husband had fallen sick and the family had moved to his home village so that she could nurse

him. Her husband's village was further away from the clinic and since she had been busy caring for him, they had stopped attending. After her husband had died she had returned to her own village to live with "her own people". Mohammad was around six or seven years old and his clubfoot had not been fully treated. I asked Ernest in English for her contact details and to my further surprise he scrolled through his phone to retrieve them. He explained there was unlikely to be signal where she was living and advised us to visit her village, gave us directions and told us to "ask around for her". Since it was not far we made the decision to travel after the clinic had ended. We noted with interest that Ernest and Mary must have been in regular contact.

First meeting with Mary

Mary's village was a small trading centre. A handful of women were sitting by the side of the road selling tomatoes and other vegetables from baskets. There was one *Airtel* mobile phone stand selling cigarettes, biscuits and airtime. It was scorchingly hot and the earth was hard and dry. Our car attracted a cluster of children who talked excitably about the "msungu" ("white person" in Yao) sitting in the back. After making enquiries we met Mary by the side of the road. Her hair was covered by a scarf and she was carrying a basin of maize flour. She explained that her husband had been buried and she was finishing the 40 day mourning period practiced by Muslims and that as she was preparing food to take back to her husband's village she could not talk for long. Our conversation took place by the side of the road, attended by two other women and around ten delighted and curious children who giggled nervously.

Mary briefly explained that she had stopped attending treatment because she had no money to buy the ankle boots needed for treatment as her husband had not been active enough when he was ill. While she was nursing her husband, their son's clubfoot condition had become worse. Now she was back in her home village she said she was keen to return to treatment but told us she was scared in case she got in trouble with the healthcare workers. We advised her to return to the District Hospital for advice.

As Paul returned to the car he noted "it is very dry here, the climate is just so harsh. There will be hunger in the area this year".

Meeting with Rehabilitation Technician at District Hospital

Two weeks later we encountered Blessings, the Rehabilitation Technician responsible for running the clubfoot clinic at the District Hospital, after the clinic had ended. We asked him if he had heard from Mary. He informed us that she had returned to the hospital to seek treatment. However, he had not known how to move forward with treatment since neglected clubfoot fell outside the remit of the programme. To obtain advice he had called CURE but said that they didn't know what to do either. As a result, Blessings had sent the mother back home without treatment or referral. He seemed unhappy and said "there is nothing I can do, the child is too old to be casted". I had gathered from past interactions that he perceived us to some extent to be representatives of CURE and I felt uncomfortable, as if this was in some way an accusation. Undoubtedly, I felt the criticism placed us in an awkward situation, positioned somewhere between representing CURE Hospital and being independent researchers.

Second meeting with Mary

As arranged, we visited Mary in her village a week after the period of mourning for her husband had ended. She led us down to her house that was on the slope of a hill. The home was a typical Malawian mud hut with a thatched roof inside an enclosure marked by a thatched fence. We exchanged greetings although to my embarrassment I couldn't speak any Yao, which was a source of hilarity for the family and they kindly teased me.

The "agogo" (grandmother) Elipher described the family set-up and explained that Mary had undertaken a cleansing ceremony, was now free to re-marry and was living permanently in her own village again. Mary had five children and the child with clubfoot was the last one. Her first born, a daughter, was in South Africa and now had her own baby. They all lived in the same house. Mary told us Mohammad was very sociable and had lots of friends. He appeared well-loved and was sitting on his mother's knee being cuddled affectionately. He alternated this with running around, playing with his friends in a small ditch near the enclosure. According to Mary he was experiencing no pain at that time. To demonstrate the impact of the condition, Elipher told him to play football and although he could play, he often missed due to the arching of his foot caused by his clubfoot.

Elipher explained that he can't do some chores such as fetching firewood and water and believed that "children are supposed to do these things". She expressed worry for his future and was anxious that he wouldn't be able to get married and work.

"Since he is a man he won't be able to do things that a man does like cutting up firewood".

Third meeting with Mary

At our third encounter we sat with Mary and her children outside the family house. Her children listened quietly and her young daughter stared at me transfixed, while Mohammad sat on Mary's knee.

Elipher outlined how Mary had visited the clinic at Mangochi on our advice. She had gone to the clinic prepared for admission and borrowed money from her son for accommodation. When she discovered that she would not be admitted she spent the money on a hoe. According to Elipher, Blessings had told her there was nothing he could do at the clinic because they didn't have the equipment to deal with the clubfoot now Mohammad was older. He told her she must wait until staff from Beit CURE Hospital visited the orthopaedic department in February next year. While she was at the clinic, she met the counsellor who advised her to keep Mohammad in the ankle boots. According to Elipher, he also told her she was "bad for absconding" and that she should definitely not miss the clinic in February.

We asked Mary what she thought about what had happened and she said she had no choice but to accept what Blessings told her. However, she emphasised that if there was another alternative she would rather do it. Mary explained she was worried because by February it would be the rainy season and she would need to be working on her farm. There were also concerns that treatment would disrupt Mohammad's schooling. She said "I feel that now is the right time".

During the discussion, Elipher did most of the talking whilst Mary listened quietly. She then asked us for advice on what we thought they should do. Paul told the family about the clinic at Beit CURE hospital that ran on Monday and Tuesday for all paediatric orthopaedic patients. Elipher seemed enthusiastic and asked if they could go this Tuesday. We confirmed that this would be possible. Nevertheless, she expressed concern that they would not be seen or would find out Mohammad was not entitled to an operation and would be sent back.

Elipher explained how very difficult it would be for the family to get transport money to Blantyre. She said that Mary was even struggling to return the transport money that she borrowed to get to Mangochi. "If she is even struggling with this then what about Blantyre? She will be in trouble." At this point I felt that they would have liked me to have offered money for transport. I knew that I could easily afford it and felt a keen desire to ensure that the child received treatment at the hospital. However, I caught myself on the cusp of offering by remembering that my objective was to conduct observations without impacting on the treatment trajectory as far as possible. This was a dilemma that I felt on a number of occasions during fieldwork, and I return to these kinds of moral and ethical considerations in the thesis conclusion.

Once this moment had passed, Elipher, Mary and her eldest daughter discussed the possibility of waiting for an ambulance from the Hospital which they considered could be another option. They discussed communicating with Blessings to find out when the ambulance would be going to Blantyre and came to the conclusion that

this was the best option. However, they said they did not want to communicate personally with the rehabilitation technician but then deflected questions when asked why. It was clear that here too, they wanted us to intervene. As Elipher explained, "We are very happy that you have come. We think that now something will happen."

Mary had been quiet throughout most of the conversation and looked worried. Occasionally she reiterated that because she was alone, she would have to work very hard on the farm so that now was the right time to go. Her children were full of personality, trying on my necklace, giggling and staring in amazement at me. By the time the conversation ended, children from the neighbourhood were clustered around my mat. Mary and Elipher joked about me learning how to speak Yao.

Arrange surgical intervention at CURE Hospital

Fourth meeting with Mary

At our fourth encounter we met Mary while she was sitting by the side of the road selling tomatoes. Since she did not want to be far from her stall, we held the conversation on a wooden barrier in front of the small trading centre next to her village. Unlike previous discussions, this one took place with her alone. She seemed pleased to see us and smiled and hugged me enthusiastically. She called over Mohammad and sat him on her knee. Mohammad looked anxious, avoiding eye contact and playing with his hands nervously. During the time we had been away he had become noticeably thinner. His knees were nobbly, his legs thin and his belly distended.

Mary joked that he was scared of us, thinking we were going to pick him up and take him to the hospital. According to her, he'd had "bad experiences" with the wounds from the clubfoot treatment and had been in pain. Although it was not explicitly stated, Mary did not seem to be totally satisfied with the treatment. When Paul asked a series of questions about how she had found CURE, how Mohammad was and how she had found the treatment, her response was "so, so, so". She showed us Mohammad's scar and got him to demonstrate walking. It was clear from this that his foot was still twisted inwards. Mary said the way he was walking was not much different from the past. She did not seem to want to pursue any further treatment and seemed to be implicitly discouraging him from going to the hospital by saying, "You don't want to go to the hospital. You don't like the hospital, do you?"

We explained that I was going back to England and would not be visiting again. Mary asked if they could all go with me. Although this was a joke, it was a salient reminder that she knew she would probably never travel outside of Malawi and would never have access to the opportunities available to me. I laughed awkwardly and deflected the question by telling her it would be too cold for her. The discussion was brief and she returned to sit by her tomatoes. I realised the clubfoot could not be fully corrected now but my immediate concern was what would happen to the family if they could not get enough food.

7.2 Case study 2

We only met Lucia and her son Felix once because the rains had made the roads to her village impassable. When we encountered her she was pounding maize with another woman, in front of a brick house. A group of women were sheltering from the sun under some sparse trees, talking and laughing with them. Like the other women, Lucia was dressed traditionally in a chitenge, t-shirt and "boo-goo" (headscarf). We explained the purpose of our visit and she agreed to talk with us. She called over her husband who was sitting on a bench with some men and pulled up some plastic chairs that were under the porch of another brick house. Initially, they seemed reluctant to talk to us. Their body language was closed and their answers short. I thought they seemed to regard us warily, perhaps because they viewed us as representatives of CURE. To try and build rapport we engaged in conversation about John's Rastafarian beliefs. We learnt that he owned a small shop in the trading centre, fixing and charging mobile phones as well as a barbers shop.

Lucia explained that they had five children. Felix was now five years old with unilateral clubfoot in his left leg. When Felix was born in the District Hospital she was immediately informed by the healthcare professionals that he had clubfoot. Since it was a Monday, Lucia was told that she should go home and return to the Hospital on the Wednesday to begin accessing treatment. However, she said that it was too far for them to travel there and back so they had started casting. After a day or two they were discharged and went home.

According to Lucia the condition was not severe, just a small bend in one foot and she said that she had thought it would go away after two to three casts. However,

Felix had had 12 casts, a tenotomy and then another cast and this seemed to be a source of frustration for her. She emphasised this by saying that one or two times the casts just came off by themselves.

There seemed to have been a disagreement between the mother and the hospital. Lucia explained that the hospital staff told them off for not following bracing protocol, "We are giving you this advice but you are not following it". She said she responded by saying, "I am not the one providing the service, why are you asking these questions about how I am putting the braces on?". Most of the time when Lucia visited the hospital the staff would say "The child's feet are not corrected, what are you doing?". "Each and every time I went to the hospital [the OCO] shouted at me or told me it was my fault the child was not corrected." During the bracing phase she attended for three or four months and then seemed to get tired. She explained, "Each and every week we are using our monies. Each and every week we are told it is our fault". It appeared that she was not satisfied with the progress, "I've been going there but there is no good outcome for my child's feet."

Lucia said that the child did not have any problems with his foot. She motioned toward Felix who was running around playing football with his friends, although he was running with a limp. Paul gestured to Felix to come and talk to them and asked if he felt any pain and he said he didn't.

I asked both of them if they had thought about re-entering treatment she responded, "Going to the hospital once we can manage. Going there now and again, we can't manage. We don't have the monies". She also asked if it would be "you guys from

CURE" or the team from the District Hospital, as she wanted to avoid them. I then asked the father what he thought about his son re-entering treatment. He seemed disinterested in the discussion and was looking elsewhere but said "For a father, it is better if my child can walk properly". Despite expressing vague interest in attending the CURE clinic, it appeared that they did not have any real desire to return to treatment. Since they lived in a brick house and her husband owned two businesses, I guessed that they could afford transport. Unlike in previous interviews, I noted with interest that Lucia dominated the discussion rather than her husband and came to the conclusion that she was a forceful and self-assured woman.

7.3 Case study 3

Mother: Chemwemwe

Child: David, 3 months– 10 months

Stage treatment discontinued: Intermittently accessing treatment during bracing

Figure 23: Photograph of Chemwemwe and David outside their family home

David was sick and Chemwemwe thought he had malaria.



The mother provided verbal consent for this image to be taken and used for the purposes of research.

First meeting with Chemwemwe

We first met Chemwemwe as she was leaving the clubfoot clinic with her son David, who was three months old, on her back. She explained that her child had now had eight consecutive casts but that she came from very far away ("khatali"). To reach the clinic she had to board two mini buses and travel part of the way through Mozambique. Chemwemwe seemed keen to speak to us. Despite her long journey home she held back while the other mothers clustered around us. Perhaps it was curiosity but I felt quite strongly that she wanted to tell us her 'story', perhaps to gain some recognition of what she was experiencing. We were only able to visit her on two other occasions because of the length of the journey to her home.

Second meeting with Chemwemwe

For our second meeting we travelled to her village. The journey from the town was 120km and the roads were in bad condition. To get there we had to pass through Mozambique. Every person we stopped to ask for directions replied "pang'ono, pang'ono" ("little by little"). I began to appreciate the difficult journey she had to make by mini bus each week.

Chemwemwe's enclosure was situated at the far end of the village, away from the other houses. She was living in a mud hut with a thatched roof just beside the lake. Despite visiting a range of homes in Malawi, I was shocked by her poverty. Her hut was just so small and in such a bad state of disrepair. A pile of bricks were scattered on the porch. Since she was by the water there were swarms of mosquitos.

She was excited that we had come – "I did not think you would actually come!", greeted us and hugged me warmly before escorting us to a mat outside her house. She explained that she was 29 years old with five children. David was three months old and the youngest. He was wrapped in a chitenge and lying on the mat. She opened the wrap to show us his casts while she talked us through his care. He was also sick and she thought it was probably malaria.

We asked her to describe her family set up and she explained that her husband had recently left her and she believed it was because of the clubfoot – "He escorted me to my parents' house and left me here without anything". When she had returned to

her people she had found that her piece of land was occupied so decided to go down by the lakeside and build a hut for her and the children.

While they were still married, her husband had tried to refuse to give her money for transport, although he was a businessman and could afford it. Since they were now separated, she had to look for him to make him give her money for the children and transport, which he reluctantly did. She was worried that she would not be able to afford to continue paying for transport and anxious because she had heard that towards the end of treatment she would need to buy ankle boots. Throughout the discussion she reiterated that she had to go and get treatment for David "alone". Despite this, she said she was hopeful that her child would be healed.

Chemwemwe wanted us to understand the other challenges that she faced and how the treatment impacted on them:

> *What you have to know is that this year things are not ok, there is hunger especially our area and personally I have a lot of problems that need to be solved. I have a lot of children they are all looking for support from me. One will even see the place I am staying in needs to be renovated but how am I going to do that while my child is this condition?*

As we left she asked us if there was any social support she could get that would help her. We replied that we did not know of anything.

Third meeting with Chemwemwe

Our third meeting took place in her village. I had not been sure what to expect when we went to visit again. Her situation had seemed so precarious last time we visited, I did not know if she would still be there or even if all her children would all still be alive. Chemwemwe was surprised to see us and had not expected us to come. "How have you managed to come here? I thought you would have forgotten the map and area". She was still living in the same place by the lake. Although two or three small huts had been built next to hers, meaning she was less socially isolated, we found her alone sitting at the back of her house while two other mothers were working with the fish.

I was shocked again by her poverty. All her children seemed to be malnourished and their clothes dirty and torn. They were dazed and lethargic, not alert. A girl of about five stared at me constantly, almost trance-like. She lacked the energy of the other children I had met that stared shyly and giggled. David, her child with clubfoot, was now 10 months old but couldn't support his head and it lolled over Chemwnwe's arm as he laid in her lap.

She explained that two of her five children were schooling. We asked her about the progress of the treatment and she said that she had missed two months because of a lack of transport. When she went to the clinic again the Rehabilitation Technician had "shouted" at her, "Why have you come late?". She said "It hurt but they don't know what I am passing through because I am coming from afar". She said she tried not to take any notice but that it still hurt. Getting transport, she explained, was very difficult because she was a single mother. Since she was living very far away it cost 3,500MK (around £5) for transport to treatment. To get the money she was doing

seasonal piece-work, working someone else's field, and it was very hard work. She had to hoe one acre every three days. The earth, she said, "is really, really hard as the rains have not come and it is very hard for me to make a line". She gets 5,000MK for this work and of this, 3,500MK goes on transport. The rest must pay for the expenses of the children – food, soap, school uniforms, etc. Sometimes she went into the field with nothing to eat so she can save money for the children.

There was a wooden table at the front of her house in the sunshine where fish were being dried. Her main source of income was to welcome and host fishermen to use this as the fish drying sheds. She explained that she had tried to get people in her village to pay rent to use the space. According to her, "It would have been easy to pay for transport if they had done this but they said it was a communal area in the village". Her husband, who was reluctantly providing financial support when we first visited, had now disappeared and no one knew where he had gone.

David had now finished casting, had a tenotomy and was now wearing braces at night. Her last trip to the clinic was a review of braces. Chemwemwe reported that she had not seen the counsellor as he had told them to go once they had been treated because they had come from afar. I thought that this was probably an excuse from the counsellor and felt annoyed but tried not to sound judgemental. She said she had been disappointed with this as she had wanted more information about the treatment. David was now in braces for the first time but she was not sure she was putting them on correctly. She also said she didn't how long the treatment would take and wanted to know. Although she would try and carry on as much as possible, she saw herself dropping out on the way due to a lack of money for transport.

We asked her if she had any problems with the treatment such as caring for the baby. She said that it was easy to care for David but that getting treatment was difficult because of poverty. David had no problem interacting with other children and there was no stigma in the village. Her neighbours had told her she was very strong for carrying on and she was being admired by the neighbours and felt proud of it. However, she stressed again that she did not feel that she could go on much longer with the treatment. She said she heard from some of the other mothers that it took five years and that she has done two, meaning that there was three more to go and she didn't know how she would do it.

Chemwemwe's demeanour had changed since we last saw her and she seemed much more subdued. According to her, every day was the same – she got up in the morning, worked in the day and then went to bed. She said she had now accepted that this was her life and that nothing would change. This was a contrast to the first time we had met her when she had been very excited to see us, even though David had been sick. We thought that Chemwemwe seemed rather low in her mood.

It seemed that Chemwemwe had almost accepted what seemed to me to be inevitable – that David would not complete treatment, despite the tremendous sacrifices she had made. Her tenacity had been remarkable but she had become disheartened. Seeing her desperate poverty, I even wondered if treatment-seeking should be her priority and that if the money would be best spent elsewhere. I doubted in her position I would have continued with the treatment for so long.

7.4 Case study 4

Mother: Aisha

Child: Mustafa, 2 years

Stage discontinued treatment: Bracing

Figure 24: Photograph of Aisha and Mustafa outside their family home



This mother provided verbal consent for this image to be taken and used for the purposes of research.

Figure 25: Photograph of Aisha and Mustafa with the extended family in their compound



The family provided verbal consent for this image to be taken and used for the purposes of research.

Figure 26: Photograph of Mustafa crawling to move around because he was struggling to walk in casts



The mother of this child provided verbal consent for this image to be taken and used for the purposes of research.

First meeting with Aisha

We first met Aisha attending one of the clubfoot clinics. I entered the room and greeted the counsellor Ernest before sitting down on one of the benches lining the room. There was an older child of about two in the middle of the room spinning a broken office chair with gusto. He was loud and energetic and some of the other mothers in the room chatted and laughed about him. I noticed that his clubfoot did not look like it had been fully treated and as he ran to his mother on the sides of his feet, he lurched sideways, grabbing her chitenge to steady himself.

In contrast to Mustafa, Aisha was quiet and shy, almost afraid and looked very young. She was wearing a t-shirt, chitenge and head scarf so I guessed that she must be a Muslim from the Yao tribe. While Ernest asked her questions she replied quietly and stared at the floor. Ernest explained the conversation to us in English when they had finished talking, whilst Aisha continued to stare at the floor, occasionally glancing nervously at us. He narrated her background and current situation. Aisha, he told us, had given birth to Mustafa when she was 13 or 14 and had married the father on discovering that she was pregnant. However, when she bore a child with clubfoot she was chased away from her husband's village. According to her, her husband had said it would affect the family lineage because there was no one in his family with the deformity and that she would keep bearing children with the condition. She had told him she'd had no support.

She started going to the hospital when she went back to her parents' house and her elder sister was the one providing the money for transport. However, in "the middle of the treatment" she was told that she needed to go and buy boots. As she'd had no

money for this, she did not return to the hospital. Her thinking, Ernest said, was that once they got their harvest they would be able to buy boots and start treatment again. In total, she had stayed away for over a year during which time the clubfoot had become more difficult to treat. I assumed that this referred to the ankle boots but Ernest explained that due to a miscommunication of some kind, Aisha thought that she'd had to buy braces. Ernest had explained to her that they did not sell braces at the hospital and that they were given to the mothers free with treatment. Her main harvest was pigeon peas with some maize and she had taken them to the market to sell. She'd expected to harvest more but they did not have many rains and as a result, she hadn't even had enough pigeon peas to pay for the transport to the hospital. Her elder sister contributed the remaining transport money.

During this time Mustafa continued to laugh and move about the clinic. Since he found it difficult to run, he sometimes fell over, staggered sideways, crawled and grabbed onto things to steady himself. It was clear Aisha adored him as although she was shy, she laughed and played with him and smiled delightedly when we said what a clever boy he was.

Meeting with Ernest, counsellor

On a subsequent visit to the clinic, I enquired about the progress of Mustafa to the counsellor. According to him, Blessings the Rehabilitation Technician had tried to cast the child for about four weeks to no avail. As they "[do] not have the means to treat neglected clubfoot at the clinic", he decided he should be sent to CURE for further treatment. Since the mother had no money, Blessings had wanted to keep

Aisha at the hospital for two days and then arrange for an ambulance to transfer her to CURE on Monday.

Aisha was sent to CURE. However, when she arrived she was reportedly told that they would not treat Mustafa's clubfoot because "[Blessings] already knows what to do with the patient". They said that "he as a professional knows the procedure". Ernest reported that the healthcare professional who had met the mother "shouted" at her. Aisha had returned to the clubfoot clinic at the hospital and relayed this to them, he said. Ernest also said that he had overheard part of a conversation between Blessings and CURE about it. According to him, "[Blessings] was not happy at all. He did not welcome the move and the conversation was not good at all. I think [Blessings] maybe felt that he was being overlooked [that his expertise was being undermined]".

Second meeting with Aisha

Two weeks later we met Aisha on a bench outside the general orthopaedic clinic surrounded by patients with a range of different conditions. Mustafa was being characteristically lively, tottering about, steadying himself as he tried to run and giggling. It was very late, about 11am, and she had not yet been seen and did not know when she would be. She had been told to wait outside by the counsellor. I was aware that she had a long journey back to her village and felt concerned. While we were sitting with her I became aware that people sitting on the opposite benches were looking at Mustafa's feet. Aisha smiled shyly at an older man as Mustafa clambered over her but he noticeably did not smile back and remained staring at

Musafa's feet. Although I had spoken to lots of people that had told me their experiences of stigma, this was the first time I had seen it in any real interaction.

Once we said our greetings we entered the hospital and found Ernest who informed us that Blessings was not at the clinic because he was attending a course at a nearby hospital. The clubfoot treatment room was locked. Clubfoot patients were being treated in the general orthopaedic clinic alongside adult orthopaedic patients. Two other healthcare professionals whom I had not encountered before were delivering treatment and Ernest was helping to remove casts. As we were leaving Aisha was ushered into the orthopaedic clinic.

Meeting with Blessings, Rehabilitation Technician

Two weeks later we were travelling to visit Aisha in her home village but decided to stop at the District Hospital to see if we could meet Blessings to discuss what had happened to Aisha when she had been referred to CURE. We met him walking across the hospital grounds to return to the general orthopaedic clinic after lunch. He was clearly exasperated and his arms were folded when he narrated the events. According to him, Aisha was no longer attending casting.

> *The mother is no longer coming to casting, I think she is demoralised. To be sent all the way to CURE and then sent back again, ahh! The thing is, I arranged the transport. I insisted that this mother needs to see an orthopaedic surgeon. Then they sent her back on the same day. The ambulance guys reported it to the transport office so I had these guys on my neck. She did not receive a good reception either. I think the guys at the hospital were shouting but shouting at me*

indirectly so that the mother took it that they were shouting at her. The child is getting older and walking on his feet, it is getting worse. That is why I did not send the other child [Mohammed] to the hospital after what happened to her.

He suggested that we should follow up the case with CURE.

Maybe you can follow-up and try to encourage her. It is very difficult after what happened. The mother has no transport to get to CURE so even if we arranged an operation she could not get there. I could not arrange an ambulance again after what happened. She can wait for ambulance to take other patients but it would not be on the correct day.

Again, I felt a tension between wanting to help the mother and a pressure not to intervene in the treatment trajectory.

He explained that the "guys at CURE" phoned to shout at him. According to him, they said he was not professional and asked why he was sending a boy or patient to CURE when it was not a clinic day. They suggested he should have waited until CURE held a clinic at the District Hospital although this was a number of months away. Blessings reported to us that "they" had shouted at him on the phone in front of the driver and that as a result, he had been reported to the transport officer at the District Hospital. Blessings was then told by the transport officer that he was not to be trusted since the Hospital had now spent fuel and time unnecessarily. He said it would be difficult for him to send patients to CURE again because he will not be trusted by the authorities.

Third meeting with Aisha

We arrived at Aisha's compound where she lived with her grandmother and sisters in one house. Aisha's Uncle led us to the house. The village was small and in a remote area. There was no electricity, the trading centre was small and we could not see a bore hole in area. When we arrived we were welcomed by the family who were already waiting for our arrival. As we arrived, neighbours and children came to join us. In total I estimated that this included four or five of Aisha's sisters, the mother of two of Aisha's sisters and Mustafa's grandmother, two daughters of the village chief who were both heavily pregnant and between 12 – 16 children. I found it difficult to distinguish who each person was in the melee. There were no men in the group as Aisha's Uncle had left and perhaps because of this, the women were free and open with their conversation. One of the chief's pregnant daughters joked about her craving for mangoes. Only two of the sisters had husbands. Most of them had stopped education in Standard 5 (4 years of education).

We learnt that one aunty had been escorting Mustafa's mother to the hospital. When we were asking questions she answered on behalf of Aisha because "she is too young, she doesn't know the answer to the questions". Indeed, when we tried to engage Aisha, she kept repeating herself nervously. I remembered with shock that she was only a child.

Aisha's aunt described the journey to the District Hospital to attend the clinic on Fridays. According to her, Aisha had to leave on Thursday afternoon to sleep at her Uncle's home. Early on Friday morning she then set off on one of the minibuses to reach the clinic. Her elder sister escorted her some of the way and then turned back.

The transport money was 800MK. Most of the money they used for the minibuses was what they made through their harvest. However, that year there had only been a small harvest and they did not have very much money.

Aisha's mother confirmed the story that Ernest had told us about being chased away from the village by her husband and family when Mustafa had been born. "This one is young. She just got pregnant so quickly". According to her, their family had pleaded with them to let her stay. The husband had said in a mocking way, "This child is so much cuter than them [the family] so it means the child is not mine. In this lineage there is nobody with clubfoot so it can't be mine". They felt ashamed by his mocking. Aisha's mother said that they would carry on with the treatment and that her ex-husband's family would be ashamed when the child's legs were corrected.

Mustafa was very lively and keen to be independent. He was walking with difficulty on the casts and had to grab on to things to try and steady himself. When he found walking on the casts frustrating he crawled to move himself around. He was filled with personality and interacted well with other children, chatting and laughing with them in Yao. I also noticed that he was very intelligent. When Paul said "jump" in English and threw him up into the air, he understood and began repeating it when he wanted to play.

Throughout the meeting I was aware that we were being observed by the Chief's daughters who were acting as representatives of the Chief. At the end of the discussion they told us that they would tell the Chief about our program and thanked us "because no one has followed us up before". I realised once again that

our purpose had been misunderstood. During our discussion another man had joined us briefly "to check what you were doing here". When Paul explained he thanked us for visiting the mother and for having "willing hearts" and said that we were welcome in the village at any time. I was moved by the emotional and practical support that Aisha received from her family and impressed by the well-established networks of support that protected the family in the community.

Fourth meeting with Aisha

We arrived at the compound and were greeted by one of Aisha's sisters. She told us that although Mustafa was here, Aisha had gone to the forest to fetch charcoal and collect firewood. She went to call two of the other sisters and Aisha's mother. An elder man was sat outside one of the houses in the compound and we learnt that he was the grandmother's husband. He did not live with them permanently as he had another wife and was about to marry his third. Throughout the conversation he largely separated himself from us and the women and went to sit elsewhere in the compound.

Aisha, we were told, goes to collect firewood and charcoal each week and sets off at 4am to walk up mountain. When she has no money she sells some of it and uses it to pay for transport to the clinic. We were told she was getting firewood to pay for treatment the following week.

Aisha's sister explained that she had been to the clinic on Friday and was told to come back for tenotomy the following week. According to the sisters, Blessings had

told her that it would not make any difference and that there was nothing they could do for the child. After that they would be discharged without any further treatment.

The sisters and elder father looked at a leaflet that had been given to them at the clinic. They asked why they were not getting any braces and said that the treatment was not finished. He told us he was ready to support her, along with the whole family as she is his daughter so he must help. He said he would keep encouraging her to go to the hospital even though it seemed that it would not work. I understood that he wanted us to intervene with the hospital on their behalf. Her father had emerged as the spokesman for the family.

Aisha returned from collecting firewood and charcoal at about 1pm. Paul asked her sisters why it had taken so long. Her sister explained that she had to search for the wood. Furthermore, she said, the forest is a conservation forest and it is illegal to collect firewood. It is dangerous as the forest has guards to protect the trees.

The information about discharge that Aisha's sister had given us was confirmed when Paul asked to see the health passport book. Her father reiterated that he was the head of the family and that whatever happened he was responsible for them. He said, "We will do our best but what happens if the treatment fails?". He said that they wanted the child to be treated so that he could go to school and help the other children from the family in the future. Since Mustafa is the first born son it would be his responsibility.

They were clearly expecting us to intervene so we said, "We are here, we are doing research and we are not doctors. We just take what we have observed here to the doctors. When we hear from them we will get back to you". At that point, the group went quiet and there was a noticeable change in atmosphere. The group conceded this point but Aisha's father said, "While you are coming we still have hope. We've been trying, getting the money to go to the hospital and the treatment is not helpful". It was noticeable that the group were all in agreement about what had been said. Paul and I decided afterwards that they had probably had a meeting to discuss it prior to our arrival and were "prepared" for us when we returned.

Arranged transferral to CURE to continue with the Ponseti method

Fifth meeting with Aisha

Our fifth meeting with Aisha took place in her village. When we arrived at the family's home, I saw that a fence on one side of compound had collapsed. In contrast to the noise and activity that usually greeted us, the place looked like it had been deserted. Aisha's sisters emerged to greet us.

They told us that Aisha's mother had gone in search of food but they didn't know where she was, perhaps doing some piecemeal work. Two of the sisters had moved to [the North]. One was nursing another sister who was sick. Aisha and Mustafa were no longer staying with them. Aisha had found herself a husband and had been married three weeks. According to them, she had decided to get married due to a lack of food. Her sister explained that since there had been many of them living there and because the grandmother was single, it had been hard to find food for them all.

As Aisha was not far away, one of her sisters escorted us to her new home. As we drew near the house, I saw Mustafa amongst the boys and girls and Aisha sat at the house. I noticed that his feet had been corrected and that he was now running around without difficulty, interacting freely with the other children. We greeted Aisha. Her new mother-in-law came to greet us and sat on the ground watching conversation. I noticed that Aisha was less open with her mother-in-law present, probably out of respect. Her new husband was present but went round the house to do something else. I was curious about her mother-in-law's desire to separate herself from the conversation and her huband's decision not to engage with us.

Aisha had matured. She was more confident and although still shy, communicated her own views more freely. I reflected that she was becoming more grown up, less like a child. Aisha and her sister explained that they had visited the District Hospital the previous week and that Mustafa had had his cast removed. However, they reported that he had not been given any bandages to cover the wound from the tenotomy and it had been oozing. Aisha was concerned and said she didn't know why.

She explained that when Mustafa was in casts he had been going to classes (pre-school). However, he had been forced to miss school because of the wound as it meant he was failing to stand and she was worried he was falling behind his friends. Aisha was also worried the wound would get worse because he was playing around with the other mothers and children. We asked them about their experiences of

CURE and they reported that they had been very happy with the hospital and that they had been warmly welcomed. They thanked us for our support.

When Aisha's mother-in-law had left, I asked her teasingly about her new husband and she laughed and averted her eyes shyly. She briefly explained that he was a tailor and that we would meet him next time we visited. Her older sister said that he was not very old, around the same age as Aisha.

Sixth meeting with Aisha

For our sixth and final meeting with Aisha, we travelled to her new compound. When we arrived another woman informed us that Aisha was away at the mosque with her husband and mother-in-law. Mustafa was playing with a group of children, dancing, clapping and trying to play football with the older boys. He was boisterous and the centre of attention as the other children knew that we were there to visit him. I reflected again how well he was moving around now that the clubfoot had been largely corrected. When he spotted his mother in the distance, he ran down the path to meet her calling "ama, ama". She scooped him up into her arms and carried him back to meet us.

We sat down on a bench to talk. Aisha explained that she had not spent long at the clinic that day. Blessings had briefly checked the feet and wounds. There was a new counsellor at the clinic called Alfred whom she did not meet that day. She explained he had told her to leave without counselling as Mustafa was "just in braces" and therefore did not need to talk to him. He had been moving up and down hospital and had been absent from the clinic for much of the time. However, she told us that

she had been disappointed about this. Although she hadn't wanted any specific information, she had "just wanted to hear what he had to say".

Mustafa's wound from the tenotomy had almost healed and he was now wearing the braces at night. She was disappointed that he had still not been given a bandage to cover it. Knowing how exuberant and fully of energy Mustafa was, I asked how he felt about wearing the braces. Aisha laughed and said that he enjoyed it. According to her, he also wanted to wear them during the day as he enjoyed rocking himself backwards and forwards in them but she forbade it as he needed to move around. She had previously been informed by the counsellor that she should get ready to buy ankle boots but was worried as there was no money and at the moment couldn't manage to buy them.

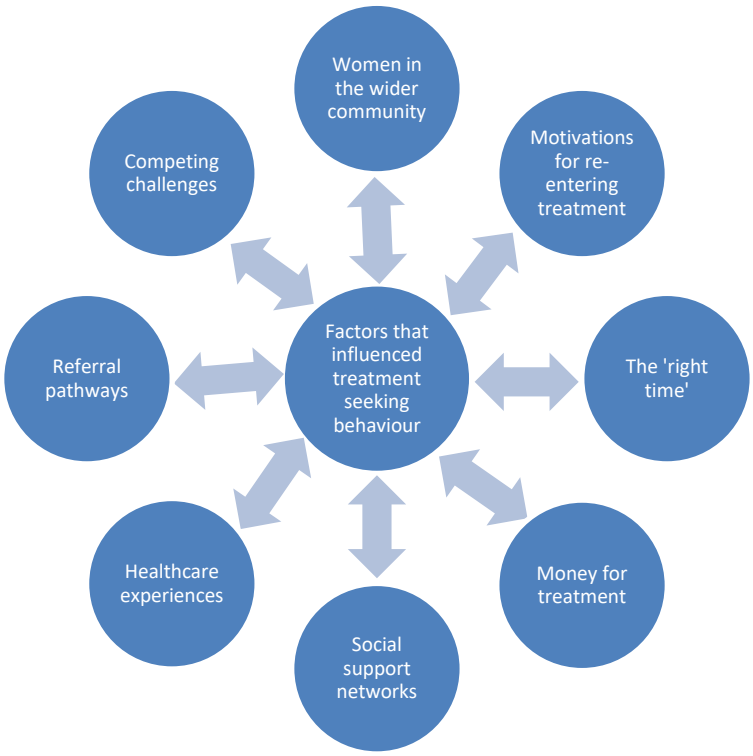
I thought the dynamic within the new family was interesting. For most of the time when we were there, her mother-in-law sat watching the conversation without intervening. Neither she nor Aisha's new husband engaged with Mustafa. When Paul talked to Aisha's husband he found out that he did not know anything about the condition or treatment and when asked, said that he did not want to. I left very happy that the clubfoot seemed to have largely been corrected but worried for Mustafa's position in his new family.

7.5 Interpretation of the case studies

Below I discuss some of the themes that emerged in the case studies. Although each case represents a unique 'story', there are a number of discernible similarities and differences between the mothers' experiences of accessing, leaving treatment and

attempting to re-enter it. This component of the study suggests eight factors that influenced the treatment seeking behaviour of those responsible. These factors are illustrated in the model below (Figure 27).

Figure 27: Model illustrating factors that influenced the treatment-seeking behaviour of the carers of children with neglected clubfoot



7.5.1 Responsibility for treatment-seeking decisions

In all of the case studies, women were overwhelmingly responsible for making decisions about when or if to seek treatment. Men who were members of the family, when they were present, seemed to have a peripheral role. Aisha's father presented himself as the traditional Malawian patriarch or 'head' of the family when he emerged as the 'group spokesman'(94) but for the majority of our visit he physically removed himself from the discussion and did not participate. He was not present at any of our other meetings. Likewise, Lucia had made the decision on behalf of her

family not to continue with treatment. This may be because children in matrilineal kinship systems are primarily seen as members of the female line(88).

Below I discuss some of the factors that influenced the treatment-seeking behaviour of carers of children with neglected clubfoot.

7.5.2 Women in the wider community

In the case of Mary and Aisha, decisions to seek treatment were also influenced by women in the wider community. For instance, one of Mary's neighbours actively encouraged her to attend Beit CURE Hospital. During discussions with Aisha and her family, it was often difficult to determine which women were members of the family and which were neighbours. These raucous meetings created the impression that treatment-seeking was a collective decision-making process amongst women in the community, even if the immediate family ultimately made the final decision. Such an approach may be indicative of Malawi's collectivist culture(92).

7.5.3 Motivations for re-entering treatment

Motivations for re-entering treatment were shaped by their concerns for their children's future. Aisha's father was worried that Mustafa would not be able to go to school or care for his other siblings, as he would be expected to do as the eldest boy in the family. As older children, Mustafa, Felix and Mohammad were beginning to experience the challenges of living with neglected clubfoot. This enabled their carers to better assess the potential impact of clubfoot on their lives, unlike those accessing treatment for their children in infancy. As the oldest child in the case studies, Mohammad's clubfoot was preventing him from fully participating in everyday life as he could not perform daily chores. This was an incentive for his family to seek treatment. By contrast, Lucia felt that it did not have an impact on his

life, telling us he did not have any problems with his foot. As a result, she did not seem to be highly motivated to re-enter treatment.

7.5.4 The 'right time' to re-enter treatment

Mary and her family spoke of it being the 'right time' to seek treatment as her husband had passed away, leaving her with time to attend clinics. What she considered to be the 'right time' was also influenced by cyclical changes throughout the year such as the planting season and the school term. Similarly, Aisha had to consider schooling when accessing treatment as Mustafa had not been able to attend pre-school whilst he was recovering from his tenotomy.

7.5.5 Money for treatment

Using longitudinal case studies highlighted the ongoing work that families did to obtain money for treatment, along with their resourcefulness. This included borrowing money, doing piecemeal work and collecting firewood, despite the dangers this presented. Subsistence level poverty meant families did not have the means to save money and had to work to find it on a weekly basis. Access to money was threatened by unexpected changes in their situation. For instance, a poor harvest made it difficult for Aisha to access the money needed for treatment. Likewise, Mary stopped attending treatment when her husband fell ill and was no longer able to provide money for ankle boots.

7.5.6 Social support networks

Mothers were also resourceful in the ways they leveraged their social networks to help gain access to services, drawing on their extended families for emotional and practical support. As before, male members of the family when they were present

were primarily expected to provide financial support. This included Lucia and Chemwemwe's husbands and Mary's son.

The community of women around them also provided emotional support, advice and practical assistance. When we intervened to arrange a surgical intervention on behalf of Mary, one of her neighbours was instrumental in persuading her to visit CURE, took her referral forms "to keep them safe from the children" and helped her to navigate her way to CURE Hospital. For Mary and Aisha's children there was a strong sense that this was a collective endeavour and that the community was invested in their welfare. Again, this reflects the reciprocal relationships that exist within communities and families in Malawi(92). By contrast, Chemwemwe's social isolation was apparent as she emphasised that she was responsible for seeking treatment "alone". The case studies also reveal how the families of Mary and Aisha attempted to utilise the relationships they had built with us to regain access to services.

7.5.7 Healthcare experiences

All the families presented positive and negative experiences of accessing treatment. Both David and Felix had had in excess of the five recommended casts for the Ponseti method. Although Chemwemwe seemed to accept this, Lucia found it frustrating. Furthermore, that she chose to raise this, along with the fact that the casts had come off by themselves, suggests that it had contributed to her decision to cease treatment.

In all the case studies, the mothers' communication with healthcare professionals and counsellors emerged as a key theme. Chemwemwe and Aisha reported that

healthcare professionals had "shouted" at them and it was Mary's fear of this that had made her reluctant to re-enter treatment. This behaviour seems to reflect the power imbalance between patients and healthcare professionals in Malawi's healthcare system. However, Lucia's resistance when she thought she was being "blamed" by the Rehabilitation Technician, suggests a willingness to challenge this hierarchy. This may be in part because she was more socially and economically empowered than the other women. Aisha's case also highlights the dangers of miscommunication between patients and staff since the reason she had left treatment was because she thought she had to pay for braces. Chemwemwe and Aisha were also keen to receive more information about treatment.

7.5.8 Referral pathway for neglected clubfoot

Case studies highlighted the lack of referral pathway for children with neglected clubfoot for further interventions. As a result, despite the fact Ernest knew Mary was keen to re-enter treatment, she had not been assisted back into care. The case studies demonstrate the potential emotional impact of this uncertainty on families. Concern amongst the families was evident and Blessings described Aisha as "demoralised" and doubted whether she would return to treatment.

There were challenges in communication and coordination between CURE Hospital and the outreach clinic that made it more difficult to refer patients. This was a source of frustration for Blessings and he tried different ways to navigate the organisation. Hierarchies at CURE meant he was not able to contact the orthopaedic surgeon directly and this made it more challenging. These issues created tensions.

7.5.9 Competing challenges

Worries about the clubfoot and difficulties with accessing treatment took place in a web of competing challenges that changed over time. Mothers had to make decisions about which issues to prioritise and when. For Lucy, caring for her husband had meant that she was unable to continue accessing treatment for a number of years. Chemwemwe, on the other hand, decided to prioritise treatment above other necessities such as food for herself until this became untenable.

Underlying the causes of most of these competing challenges was extreme poverty. For Mary and Aisha it was apparent that access to sufficient food was a concern that dominated their lives and impacted heavily on their decision-making. Understanding access to clubfoot treatment must therefore be understood alongside an awareness of the ongoing complexities of the families' daily lives.

7.6 Chapter summary

This component of the study has explored the experiences of children and their guardians that had either discontinued or not fully accessed treatment. This included identifying those responsible for treatment-seeking decisions and factors that subsequently impacted on their treatment-seeking behaviour. Exploring these issues draws attention to the importance of establishing effective communication with patients so as not to deter treatment-seeking and the need to establish effective referral pathways for those who have not sought or received full treatment for clubfoot, for whatever reason. It also highlights the need for healthcare professionals to understand treatment seeking within the context of the families' daily lives. The case study approach enabled me to explore these issues

within the context of the families' daily lives. Doing so helped to provide a more nuanced, in-depth understanding of the experiences of those who had discontinued or not fully accessed treatment.

Chapter 8 Conclusions

Themes of treatment-seeking behaviour, implementation of treatment services and experiences of accessing services for clubfoot in Malawi, have been explored throughout this thesis. This study used ethnography to:

1. Explore the implementation of clubfoot treatment services using theories from the field of implementation science

2. Gain an understanding of the impact of accessing and utilising services on parents or carers of children with clubfoot presenting in infancy, and other individuals involved in their care.

3. Explore the experiences of children and their guardians that had either discontinued or not fully accessed treatment

Here I present an overview of key findings, a discussion of how these relate to current literature and the strengths and weaknesses of the methods used. I will then present a reflection of my experiences of conducting fieldwork in Malawi. Finally, the chapter concludes by considering the implications on service delivery and a series of recommendations and future research.

8.1 Overview of findings

8.1.1 Exploring the implementation of clubfoot treatment services

This component of the study identified and explored implementation of clubfoot treatment services in Malawi, using theory from implementation science to inform findings(222). Theory was based on the four constructs of extended Normalization Process Theory and a fifth construct, 'negotiating patient access' that concerned the work healthcare professionals did to facilitate patient access to services. Part 1 presented findings on the implementation of clubfoot treatment services. Part 2 described findings in relation to the implementation of counselling services. Results showed that the capacity of healthcare professionals working within the clinics to work together was made easier by their working in close proximity and junior members of staff were assisted by senior colleagues. However, there was a lack of agreement about how successfully cases were being identified and referred to services from the community. Staff valued having a service that was centrally organised by Beit CURE Hospital although there were disagreements between clinic staff and Management about the organisations' role in service delivery. Potential or commitment to delivering the service was influenced by contextual factors in the healthcare system such as high workloads and low pay. The capability of staff to integrate the service into everyday practice was hindered by a lack of material resources and trained staff and some felt they did not have enough time to treat patients as they would like, or a suitable space to work. In negotiating patient access, participants were familiar with barriers such as a lack of transport and tried to adopt strategies to address these. Follow-up of patients who had stopped attending treatment was integrated into service design but hindered by a lack of resources. Healthcare professionals' contribution to the continuation of treatment over time

was helped by their ability to adapted to new challenges. Although there were monitoring and evaluation processes in place, these were not being used to reconfigure services.

Since data collection, a number of strategies are being planned by Beit CURE Hospital to address the challenges identified. These include strategies to aid identification in the community, increase contact with clinics through phone calls and visits and 'clinic contracts', detailing the respective roles of CURE and the District Hospitals. Commitment is being enhanced by increased monitoring, along with guidance from healthcare professionals working in established clinics. To facilitate capability, additional training courses are being introduced. The delivery of services over time is being promoted by changes to methods of data collection and the use of this data to reconfigure services if necessary. New monitoring and evaluation processes have been developed to improve standards of service delivery. Counsellors are also being encouraged to undertake follow-up of those failing to attend appointments.

Findings from Part 2, exploring factors that impact on the implementation of counselling services, found that the capacity between counsellors and healthcare professionals to cooperate was generally successful. However, some healthcare professionals were failing to refer mothers meaning that they left without this component of care. Communication between counsellors within the service was facilitated by the use of records that detailed the content of discussions and informal methods of communication such as phone calls. There was a desire for increased contact with the Spiritual Team and concerns that they were not being consulted on

changes to their working arrangements. Potential or commitment from counsellors was generally high since Pastors saw its delivery as a religious commitment. However, in some clinics this was lower. It was felt that closer working relationships with CURE and an increase in personal allowances would help. Counsellors thought that they had the skills to deliver counselling although some did not think they had enough time. A suggested strategy to address this was by using group instead of individual counselling sessions. Participants thought that a lack of private space in the hospitals compromised privacy and meant mothers were less likely to be open in their discussions. How counselling was delivered varied considerably between services. Both individual and group counselling sessions were used and participants discussed the advantages and disadvantages of each. Topics discussed also varied. Christianity and faith had a more prominent role in some discussions than others. The strengths and weaknesses of employing women rather than men or having single or multiple counsellor services was discussed. Since data collection, changes have been introduced to the services to increase motivation amongst counsellors such as increased allowances and refresher courses to enhance communication with the Spiritual Team at Beit CURE Hospital. Female counsellors and single counsellor services are being used to try and improve communication with mothers.

8.1.2 Exploring the impact of accessing and utilising services

This component explored the impact of accessing and utilising services on children and their guardians. Findings showed that many mothers experienced 'pain' and disappointment' on finding out their child's feet were different from others. However, finding out the condition could be healed helped them to 'accept' the condition and they drew on their religious beliefs to help process their experiences. Attitudes of the wider family varied and some mothers experienced stigmatisation.

Almost half of the participants identified that their child's feet were different from others, rather than professionals, meaning that treatment was delayed. Nearly all the mothers reported that they were overwhelmingly satisfied with treatment. However, they did experience some challenges and tenotomies could also be a source of anxiety. The majority of those interviewed said that they 'trusted' the healthcare professionals which may reflect the paternalistic relationship between patients and healthcare professionals in Malawi. Counsellors suggested patients were sometimes scared to question healthcare professionals. Participants valued the relationships that they were able to build with the other mothers. Paying for transport and ankle boots was problematic. Treatment-seeking was generally the responsibility of female members of the family, although there were exceptions to this.

The majority thought counselling was very useful and explained that it helped to give them hope. They also valued the practical information they received. However, there were sometimes disagreements between counsellors and families and some were disappointed when they did not receive this component of care. Although many were confident that they understood the treatment protocols, others wanted further clarification. Advantages and disadvantages of taking part in one-on-one or group counselling were explored. Participant attitudes to counsellors discussing and promoting Christianity in the clinics also differed.

The majority of participants said they did not find it difficult to care for the child when they were in casts or braces. Treatment was encouraged by members of the extended family although some parents chose to conceal the condition from them.

Attitudes of the wider community towards the child once they were in treatment varied. Some of the children were also teased by their peers as they got older.

Those that had been discharged felt joy and were thankful for the treatment. Reasons for this were that the child would be able to walk, participate fully in everyday life and would not be mocked by their peers. Many of the mothers had become advocates for treatment in the community and some wanted to build on this by taking on a more formal role overseen by CURE. A small number of participants were concerned that the condition was recurring but were unclear about the steps they should take to address this.

8.1.3 Exploring the experiences of those who had discontinued or not fully accessed treatment

This component of the study has explored the experiences of children and their guardians that had either discontinued or not fully accessed treatment. Although each case represented a unique 'story', there were a number of similarities between them. The narratives reinforce the impression in the previous chapter that women were overwhelmingly responsible for making treatment decisions. Eight factors were identified that influenced treatment-seeking behaviour, including the influence of women in the wider community. Motivations for entering treatment were influential and reflect those outlined previously. Nevertheless, since these children were older, their mothers could more realistically assess how the condition would impact on their participation in everyday life. Another factor concerned the "right time" to seek treatment and this was influenced by wider considerations in their lives.

Using longitudinal case studies illustrated in detail the ongoing work that mothers did to access treatment. The importance of social networks to facilitate treatment-seeking was again identified, alongside the importance of healthcare professionals building empathic relationships with mothers. A key finding here was the lack of an effective referral pathway to interventions for children with neglected clubfoot. Challenges in communication between staff in Beit CURE Hospital and outreach clinics were identified. The case studies also emphasise how challenges in accessing treatment took place in a web of competing concerns and that underlying most of these was extreme poverty. Understanding access to treatment must therefore be understood in the context of these complexities.

8.2 Relationship to current literature

8.2.1 Service implementation

Previous studies that have explored the implementation of clubfoot clinics in other low and middle-income settings that were identified in the literature reviews reavealed a number of similar barriers and facilitators to service delivery. Healthcare professionals in these studies reported that they had also experienced difficulties with levels of communication and cooperation between services. However, these issues were largely focused on cooperation with external health organisations operating in the community that were seen to be failing to identify and refer to treatment centres(51, 62, 276) (64).

A lack of resources such as a lack of casting materials, cotton padding and braces were identified as salient issues in previous work(28-30, 51, 65, 276). Low staffing levels were also viewed as an area of considerable concern and this was made more

problematic where staff had competing demands(62, 276). Some participants felt they lacked space in which to work(28, 64, 276). Similarly, concerns about a lack of available training for staff operating within the hospitals have been identified in previous literature(64, 65, 276). As in this study, a number of participants wanted to train less qualified staff members such as lab technicians to 'free up' more qualified healthcare professionals(64, 276).

Means of facilitating patient access to treatment and adherence were also a central theme in existing literature. Strategies suggested were building counselling into services to provide emotional and practical support(58, 63), introducing outreach clinics in rural areas(58, 63), diffusing costs of care in some settings by esablishing brace recycling programmes(30, 58, 59, 65) and providing education to patients about treatment protocols to encourage adherence(30, 58)44](52, 63, 65). This study contributes to existing literature by identifying additional issues that have hitherto been unexplored in the context of clubfoot, including a detailed exploration of communication and cooperation within services and potential or commitment to delivering treatment. It also incorporates an understanding that the implementation of clubfoot treatment is a continuous process and that services are changeable over time. To sustain these services then, this study suggests monitoring and evaluation processes must be integrated into service design.

Although studies have suggested that counselling services may be used as a means of promoting adherence to clubfoot treatment(58, 63), no previous work has explored factors that impact on the implementation of these services. Issues identified here confirm those that have been identified in the delivery of lay counselling in low

income settings for other conditions, especially HIV and AIDS(347) and mental health issues(348, 349). These confirm the potential of lay counsellors to influence patient behaviour(347) (348-350) and to relieve pressure on specialist healthcare professionals(347). One of the key components of success identified was that lay counsellors are able to understand the cultural context of patients' experiences(351). However, findings from a meta-synthesis of experiences of lay counselling for chronic conditions in South Africa identified wide variation in the provision of training and a desire amongst counsellors for more training and support. Problems with remuneration were identified leading to low motivation and a poor work ethic. Other issues were a lack of time to deliver counselling and poor follow-up of those who stopped attending services, and a lack of clear referral pathways for these patients. How these workers delivered counselling also varied between services and some did not adhere to the guidelines outlined by the host organisation(347). All these issues were identified in this study.

Challenges identified in the study also support findings from previous work that has explored the delivery of healthcare services in Malawi. These have included a lack of resources(99, 109-112), insufficient facilities(99, 112) and a lack of electricity and water(99, 113). Low levels of motivation amongst healthcare staff working within public services have been highlighted and extensively explored in previous work(99, 112, 114, 121). Reasons identified for this reflect the understandings of key informants that were interviewed as part of the study. These include the impact of staff shortages leading to stress and fatigue(120, 121), pressures of taking on multiple roles within the hospital(112, 352) and poor working conditions due to a lack of

resources(113, 120). Low pay was identified as a significant factor that demotivated staff and impacted on standards of service delivery(113, 114, 120, 121, 123).

Pressures on healthcare services identified in this study must also be understood within the context of changes that took place in Malawi during data collection, including reductions in healthcare spending(107). In addition, public services were placed under additional pressure due to a series of climate-related disasters during this time. In January 2015, the Southern Region was subject to severe flooding that displaced around 230,000, killed 267 people and destroyed around 160,000 acres of land(353). This was followed by drought in 2016 that placed nearly 20% of the population in food insecurity(354). Food insecurity can broadly be defined as a situation where people lack economic and physical access to a reliable source of nutritious food that enables them to live a full and active life(355). Impacts of food insecurity on the healthcare system identified by the Malawian government include increased malnutrition leading to higher admission rates in child feeding centres and increased susceptibility to diseases such as malaria and measles(356).

Communication and cooperation between CURE management and the outreach clinics located in District Hospitals was an important influence on the successful implementation of services. Issues discussed may reflect some of the challenges of using a collaborative public health approach between NGOs and public health services in low and middle income countries(357). These include the lack of clarity in the roles and expectations of CURE and the Malawian public health services identified here(358). Furthermore, strategies being used by CURE to build successful relationships also support those that have been previously advocated. These include

using contracts to formalise and define the roles of each party and efforts to promote local ownership of services(359).

Some of the difficulties identified in the study of using healthcare workers without standard professional qualifications to deliver aspects of care reflect some of the challenges of using a task-shifting approach to delegate work to non- or lower trained professionals in low income settings. These include concerns about reduced quality and safety of services(360). It also highlights how the informal delegation of care in services may pose a risk to care quality(361). To address these issues, WHO has advocated clearly defining the roles and levels of training required of these new cadres, support and mentorship and monitoring of practice(361). A consideration of factors impacting on the implementation of treatment services must therefore be understood within the wider global health context.

The use of implementation science helped to place considerations around the issues of service delivery within the wider research context where these theories have been widely used in high income countries(361). Here, the addition of a fifth construct to extended Normalization Process Theory that relates to the work healthcare professionals did to help facilitate patient access, is indicative of the substantial, almost insurmountable barriers to treatment-seeking that have been identified in a range of low income settings(346, 362), including in the context of clubfoot(363). Its inclusion here demonstrates how implementation theories developed in high income contexts may be adapted to the context of lower income settings. In doing so, it contributes to the small body of work that is beginning to adapt these theories to low and middle-income settings(226).

8.2.2 Patient access and engagement

Previous studies that have explored factors that impact on patient access and engagement with clubfoot services in low and middle-income countries identified a number of similar experiences. These included challenges carers experienced in accessing transport(52, 58-63), the impact of the family on attitudes towards treatment seeking, particularly paternal support(52, 58, 63-65) and a lack of understanding about bracing protocols(58, 59, 61, 64, 291). Practical issues such as difficulties in bathing the child while they were in casts and carrying the child in braces(30, 58, 59, 61, 64) and the duration of treatment have been identified(58, 63, 64). The emotional and practical support mothers provided to each other in clubfoot clinics(52, 58, 63, 65), along with the suggestion of establishing outreach clinics in rural areas to address the long journeys carers faced in accessing treatment have been discussed(58, 63).

Experiences of mothers and families were also embedded in the context of Malawi and East Africa. Failure to access treatment is an enduring concern in the Malawian healthcare system that was reflected in the experiences of families and the views of key participants. A recent study in Malawi estimated that 4% of children in two Districts were living with a hearing, physical, vision or intellectual impairment or epilepsy. Of the 3,520 children per million of this population with physical impairments, it was estimated that 2,100 could benefit from physiotherapy or occupational therapy and 300 could have benefited from a wheelchair. One of the recommendations to emerge from the study was planning to increase service capacity(364). Other reasons for low numbers of service access in Malawi reflect those identified in the clubfoot literature above such as distance, associated costs of accessing services, absence of healthcare professionals and lack of mediation or other

healthcare consumables(365, 366). These findings are consistent with the wider treatment-seeking literature(227).

Common illness beliefs about disability in Malawi are echoed in the experiences of participants. Although beliefs about causation are culturally diverse and differ between illness types, across East Africa they can broadly be divided into traditional beliefs, Christian fatalism and biomedical theories of causation(127). Some traditional beliefs and biomedical theories attributed an element of 'blame' to family members, particularly mothers. For instance, some mothers reported that their husbands left them because there was "something wrong with their womb" or that the clubfoot was a result of a quarrel. An element of personal 'blame' is reflected in previous studies that have explored theories of illness causation in Malawi(367, 368).

The attitudes about clubfoot that participants encountered or feared also reflect those in previous studies. Older children with physical impairments in East Africa have been found to encounter multiple stigmatising behaviours including physical, emotional and sexual abuse(5, 129). A recent study found that children living with musculoskeletal conditions were bullied by peers, teachers and family members(5). Families' concerns about their child's ability to participate in everyday life as adults are also borne out in studies that have explored the lived experiences of disabled adults and older children in Malawi. Adults with disabilities in Africa experience physical barriers to participation such as accessing services and transport, especially amongst those living in rural areas(369, 370). Older children are less likely to attend school as learning materials were inappropriate, making it more difficult for them to access education(130, 131, 371). Similarly, older children with musculoskeletal

conditions are excluded from everyday activities such as home chores and schooling(5).

The experiences of families of caring for a child with clubfoot support those from existing literature that have explored experiences of caring for a child with a disability in sub-Saharan Africa, although research in this area is limited. As in this study, carers were found to experience a range of emotions on finding out their child was different such as 'pain', 'devastation' and concerns for their future(133, 372, 373). Caring and living with the child also had a negative impact on their own emotional well-being(133, 372). This was exacerbated by stigmatisation, often caused by speculation from members of the community as to the cause of the condition(133, 372) and when this led to divorce(374, 375). Some parents also felt ashamed about their child's condition and tried to conceal it from other people(376). Coping strategies used by families in this study also echo those identified in previous literature and included seeking a cure for the condition(133) and drawing on their religious beliefs to search for an explanation(133, 372, 376). Sharing their experiences with other families who had a disabled child(133, 372), along with talking to healthcare professionals, family and friends, helped with this(376).

The influence of religion, predominantly Christianity but also Islam, ran through the narratives as participants used their beliefs to help come to terms with the condition and understand the treatment. Previous studies have demonstrated how spirituality and religion in sub-Saharan Africa can help people to develop resilience and coping strategies for living with chronic diseases such as HIV/AIDS(377, 378). One study explored how religious participation and beliefs had changed since participants had

been diagnosed with HIV/ AIDS. The study found that diagnosis did not lead to feelings of religious alienation, although some participants reported asking God, "Why me?". Religious participation amongst this group increased on diagnosis and participants believed in the strength and power of God to help make the treatment effective(379). Use of religion as a coping strategy and a belief in the role of God to facilitate the treatment, are present in the views and experiences of families in this study. The power of prayer and belief to assist in healing is promoted by CURE organisation and the Pastors working in the clubfoot clinics. This study also demonstrated how pastors in the clubfoot clinics used religious teaching to promote treatment adherence. For instance, by telling families that doctors had been sent by God to cure their children.

Dynamics and structure of the family, particularly in the extended family, influenced patterns of treatment-seeking and decision-making. The role of the maternal uncle in helping mothers to access treatment reflects the hierarchies within the matrilineal family structure where the maternal uncle is responsible for decision-making and the children are seen to belong to the maternal line(90). Other members of the extended family also provided financial and practical support to mothers and these exchanges took place vertically between generations and horizontally between siblings(380). Participants' commitment to the extended family in the study is reinforced by the living arrangements I encountered where families often lived with members of the extended maternal line of the family or in 'compounds', a group of huts sometimes demarcated by a boundary(381). Strong kinship bonds exist in part as a result of the absence of a social welfare system meaning that families have to share resources in order to ensure their survival(380). Commitment to the extended

family meant that conflicts about the condition could also include members of the wider family, where relatives were keen to protect the interests of their own kinship line. However, this was not universally true as some confined decisions about treatment to the immediate family. For instance, some couples made a joint decision to conceal the condition from their relatives. This may reflect what some view as the gradual erosion of kinship bonds in Malawi and the increasing nuclearisation of the family(382).

Gendered divisions of labour within the family in Malawi also influenced treatment-seeking roles(63). For instance, mothers were primarily responsible for taking their child to the clinics, sometimes accompanied by female members of the extended family, whilst fathers and other male members of the family provided the necessary financial assistance. Previous research on financial exchanges in Malawi have shown that women are more likely to receive financial support and men to provide it(383).

However, family structures in Malawi should not be oversimplified and other research has shown that contrary to gender stereotypes, some Malawian men are highly involved in household activities and childcare(384). A recent study exploring the involvement of fathers in reproductive health has explored the diverse and changing role of male engagement with these issues, including attending antenatal classes and being involved in infertility care. On account of these changes, infertility interventions are increasingly being targeted at couples(385). This diversity of experiences is reflected in our study where some fathers were engaged in the treatment of their children, especially in urbanised Blantyre. CURE is capitalising on these changes by encouraging men to be more involved in clubfoot care.

The role of the community in encouraging or discouraging treatment-seeking is indicative of Malawi's collectivist culture where there is a strong sense of belonging to the wider community and a sense that the individual is part of a wider whole(92). On account of this, taking care of vulnerable members of the community such as those who are unwell, is seen as a collective responsibility(386). As with the extended family, networks of support amongst neighbours provides protection in a country where very little is provided by the state. Contrary to previous research which has emphasized the role of community elders in influencing treatment seeking decisions, the major impact that I identified was from immediate peers and neighbours. This was through practical support and advice. Likewise, once some mothers had been discharged they adopted an advocacy role in the community to try and influence the behaviour of others.

Some participants' attitudes to the treatment received were shaped by Malawi's largely paternalistic healthcare system that is also present in many other low-income settings. As described above, paternalism refers to a situation where professionals make decisions on behalf of patients without adequate consultation or the provision of information. This is in contrast to more collaborative models of care whereby healthcare professionals and patients make treatment decisions together(160). WHO advocates the development of 'people-centred' care that involves the introduction of more collaborative care models(161). Families' experiences and attitudes towards receiving care that can be attributed to a paternalistic healthcare model include not being fully informed about all aspects of treatment such as tenotomies and a reluctance to criticize the care received in case healthcare professionals withheld

treatment. An associated fear of being "told off" by healthcare professionals by those that had not fully accessed treatment when re-entering services, is confirmed by the views of families in previous studies set in Malawi(365) and other African counties(387). Reasons for the negative attitudes towards patients described by healthcare professionals in South Africa were associated with the difficulties of working within challenging healthcare contexts(387). However, findings showed that participant experiences varied and a number reported feeling "warmly welcomed" when they visited services.

Despite the challenges identified in delivering counselling, by building these services into treatment design, CURE organisation aims to attend to the emotional and psychological as well as physical aspects of illness. The understanding of health implicitly built into these services is therefore a 'social model', as defined by the World Health Organization, which understands health as 'a state of complete, physical and mental wellbeing'(142, 143). WHO suggests that a desire to attend to these needs should be built into service design as part of a commitment to 'people-centred' care(161).

The study highlights the relationship between poverty and clubfoot in Malawi. For those already in a precarious financial situation, giving birth to a child with clubfoot could exacerbate poverty. Many of the families appeared to suffer from 'catastrophic health expenditure', whereby the high expenditure to access treatment pushed the household into further poverty(388). This issue emerged most clearly in the case studies which highlighted the ongoing and strenuous work that families did to seek money for treatment. As in this study, the existence of wider support networks has

been shown to act as a form of protection against poverty caused by health costs(365). Women who were abandoned by their husbands as a result of giving birth to a child with clubfoot were thrust into further poverty. One mother was concerned that accessing clubfoot treatment during the planting season would impact on the financial security of the family. Her concerns confirm findings from previous studies that have highlighted how treatment-seeking in low income settings, means family members and patients can spend less time engaging in economically productive activities that puts the economic stability of the family at risk(388, 389).

The case studies illustrate how poverty tended to shape every aspect of the women's lives, including an ability to seek treatment. Case studies also demonstrate how fluctuations in household poverty over time shaped patterns of treatment-seeking behaviour as participants engaged and disengaged with treatment. Causes of fluctuations in household poverty identified elsewhere include illness, natural disaster, harvest failure and challenges in accessing income-earning work(390). These factors were present in the narratives of families. Participants cited the impact of illness and challenges in accessing paid employment, as reasons for discontinuing treatment. One participant also emphasised the impact of recent environmental changes on treatment-seeking that had damaged harvests and led to food insecurity throughout Malawi(353, 354).

8.3 Strengths and weaknesses

8.3.1 Service implementation

The use of ethnographic research methods that involved immersion in the Malawian healthcare system for an extended period of time helped to generate an in-depth

understanding of the issues under study. This was enhanced by the use of multiple research methods. Since the sample size of healthcare professionals from observations was relatively small given their range of occupations (n = 22), a decision was made to conduct semi-structured interviews with healthcare professionals working in a further nine clinics (n = 30). This large sample size, use of purposive sampling to capture participants with a range of characteristics, and high rates of participation (58 of 65 approached agreed to take part), provides confidence that findings may be transferable to other clinics(325). Since there was very little difference between the views of different groups of healthcare professionals, I have only distinguished between their perspectives where relevant, for instance when discussing the views of counsellors or the CURE management team.

I recognise that there is the potential for tension between using extended Normalization Process Theory(222) to explore findings and ensuring that data are not forced into predefined constructs. To help address this, I used an abductive approach. This involved developing theoretical sensitivity, the constant comparison of data, use of memos, coding in three phases: detailed line-by-line or incident-by-incident coding, focused coding to synthesise initial codes and theoretical coding to integrate focused codes into theoretical categories, and theoretical sampling(311). Using this approach I was able to construct a theory that built on existing theoretical concepts. A challenge I experienced in applying and developing this theory was the overlapping nature of the constructs. As a result, data was coded into more than one construct where necessary. This issue is reflected in existing literature(215, 391).

There are a number of potential ways of interpreting and applying theory to data using an abductive approach and some are more successful than others. According to Tavory and Timmermans there are three criteria against which an abductive analysis should be judged: Firstly, 'fit' refers to how well the theory is able to account for the data presented; secondly, 'plausability', if there are any other theories that would have accounted for the data more effectively; and thirdly, 'relevance', if the theory is useful to the wider research community and may be generalised to other settings. These can be considered in relation to my resultant theory.

Adopting Charmaz's structured methodology that included the constant comparison of data, memo-writing, a three-stage coding process and the searching of negative cases to test the theory(311), gave me some confidence that the resultant theory 'fit' the data. This confidence was enhanced by my identification of a fifth construct, 'negotiating patient access', through using this process. It is possible that other theories may have been used to explore these processes. However, conducting a comprehensive review of existing theories from implementation science prior to analysis, provides me with confidence that eNPT and the additional construct identified were able to account for the data most effectively. There is also the potential for this theory to be generalised to other settings.

8.3.2 Patient access and engagement

Using focus groups to explore the experiences of those accessing treatment, helped those that were shy about discussing these issues to open up as they were able to sympathise with the views of other mothers. Likewise, one-on-one interviews in a home setting helped others feel at ease and encouraged them to share personal information. Interviews with clubfoot counsellors provided valuable data since they

had built up relationships with the patients over time. Given the large sample size (n = 57) and high rates of participation (of 58 approached, 57 agreed to take part), it is also likely that findings may be transferable to other settings(325). This was enhanced by using a maximum variation approach to sample clinics with a wide range of characteristics(323).

There is the potential for recall bias since participants were being asked to describe past events and experiences such as their feelings when they first found out that their child's feet were different from others. In addition, although we interviewed a small number of fathers and other family members, most of the data concerning the experiences of these groups were reported by mothers and may not therefore accurately present their views. Dyad interviews that included male members of the family tended to change the interview dynamic so that mothers often deferred to them, even if they had not been directly involved in treatment-seeking. This is probably a result of the patriarchal relationships that tend to exist within the home(94) and impacted on the data I collected.

Due to logistical challenges, data collection was limited to the Southern Region of Malawi. Since Malawi is very culturally diverse it is therefore possible that the views presented here do not reflect those of patients located in other areas, particularly those of other tribes such as the Chewa tribe that is located in the Central Region or the Tumbuka in the North. Those in the Northern Region tend to have patrilineal family arrangements, unlike those in the South and Central Regions which are matrilineal(90). Among other factors this may impact on family roles in treatment-seeking. Logistical challenges also meant that I had to use some convenience

sampling to recruit those in treatment. There is therefore no guarantee that I captured participants with the widest range of experiences.

To explore the experiences of those who had either discontinued or not fully accessed treatment, the use of in-depth case studies that involved multiple visits to participants helped to place their experiences in the context of their daily lives. Including multiple participants in these case studies enabled me to examine the role of the wider family and community in treatment-seeking. Furthermore, data collection on the same events from different participants, such as healthcare professionals and families, provided a range of perspectives and therefore a fuller understanding of the issues. Using longitudinal case studies also allowed me to collect in-depth human stories, capture changes that occurred in the families and explore how they attempted to negotiate challenges to treatment-seeking over time. Repeated visits helped me to develop more substantive relationships with participants and improved my rapport with the families. Doing so enhanced the quality of the data that I was able to collect. A decision was made to integrate my experiences into participants' accounts as I wanted to emphasise my role in shaping data collection and analysis(300). I also acknowledge that how the families related to me and understood my role impacted on how they presented their experiences(392). To facilitate the quality of reporting, data were presented in accordance with Stake's criteria for assessing quality of case reports. That included providing the reader with adequate context, vicarious experience and highlighting the role of the researcher in data collection. Doing so provided confidence that the presentation of the case studies was rigorous and transparent.

Although I intended to undertake purposive sampling to capture participants with a range of characteristics in the case studies(393), due to a number of logical challenges that we encountered, this was not feasible. As a result, sampling was based largely on convenience(331). Although I aimed to identify participants from each of the three study sites, three were drawn from the same site. This limited the variation in the sample characteristics. For instance, three of the four mothers were members of the Yao tribe. This convenience sampling was due to the varying quality of documentation at the clinics that meant it was difficult to follow-up those that had discontinued treatment. At one of the clinics, a number of mothers had also provided false names and addresses making them impossible to identify. The number of follow-up visits we undertook was also shaped by logistical challenges. For instance, we were forced to abandon our second follow-up visit to Lucia and Felix as heavy rainfall had made the roads impassable. Likewise, since Chemwemwe and David lived so far away from the treatment centre we were only able to visit on two occasions. Using a small number of in-depth case studies also limits the transferability of these findings(325).

Conducting case studies with those that were finding it difficult to re-enter treatment created ethical dilemmas about how or if to intervene in care. This was compounded by the pressure I faced from families and healthcare professionals to do so. In making these choices, I had to balance what I felt was my duty of care to participants, whilst trying not to compromise the integrity of my research. To do this I held extensive discussions with the wider study team. As there was no referral pathway for patients with neglected clubfoot, I worked with healthcare professionals and patients to decide how best to navigate the healthcare system. I am aware that this has parallels

with an action research approach. That is, introducing and evaluating an intervention alongside participants to improve practice(393). However, this was unintentional and outside the scope of the study. As a result, a decision was made to exclude these processes from the case studies.

8.3.3 Using a translator

Challenges in using a translator such as Paul in ethnographic studies have been well documented. Translation is not a straightforward process that simply involves finding "equivalent" words in another language. Language is embedded in its social context and reflects unique ways of viewing the world. Conveying these meanings in another language so that they can be understood by someone outside of this context is challenging and through this process, meaning may be lost(395).

Paul became instrumental in helping me to understand the meanings and actions of participants and make decisions within the field. For instance, after data collection we compared our interpretation of situations and these discussions were recorded in field notes. Nevertheless, this raised issues about the impact of 'double interpretation' or 'double subjectivity' on data collection and analysis. That is, where an understanding of the data is filtered through two interpretations, further complicating the relationship between researcher and the phenomena under study(395).

8.4 Experiences of conducting fieldwork in Malawi

Achieving an understanding of experiences from the perspective of participants takes time and is not necessarily straightforward. Part of the process of fieldwork depends on ethnographers reflecting on their own position and the relationships they build with participants(392). This section focuses on some of the challenges I encountered of working within a new context, including personal interaction and mutual understanding of roles, based on excerpts from the diary I kept during fieldwork(394). This work has been published in a non-peer reviewed article online (see Appendix).

8.4.1 Interpreting a new context

My difficulties in navigating an unfamiliar context had implications on ethical conduct, processes of data collection and analysis. For instance, throughout data collection I had become aware that it was not normal for people in Malawi to say an outright "no" to doing something when asked, something that raised difficult questions about the notion of informed consent. I was also aware it was very difficult for me to 'read' the body language of participants during interviews. Were they uncomfortable with the line of questioning? Should I interpret their silences as distress and move on to another topic, or shyness, in which case should I probe deeper? In one case, I came away from an interview mortified that I had upset a couple who had been very reticent to speak throughout the interview only for my Research Assistant Paul to inform me that he thought they were going through a crisis at home: "they need marital counselling, not an interview on clubfoot".

Most notably, a lack of understanding of the social context impacted on my ability to analyse data and understand the lives of participants, at least initially. During

discussions with Paul, I was often dismayed by these failures. Halfway through data collection one of the young mothers we had followed longitudinally had married because, as her elder sister explained, "there was no food in this family". I was pleasantly surprised when we met the newly married couple – the man was around her own age, the compound was respectable and he was teaching her how to sew, an activity that I assumed could provide her with a livelihood in the future. Paul was less optimistic: "in our culture it is an abomination to marry someone who already has a child. Which raises the question, why is he doing it? Maybe he is just enjoying the game. She is covering one problem [hunger] with another problem". Sure enough, on a subsequent visit we found out that he was planning to move to South Africa without her the following year.

Figure 28: Photograph of me waiting to conduct an interview during fieldwork



Figure 29: Photograph of me conducting observations in an outreach clinic



This healthcare professional provided written consent for this image to be taken and used for the purposes of research. The mother provided verbal consent.

8.4.2 Relationships with participants

Participants attributed different identifies to me throughout the study based on their previous interactions with 'outsiders' of Western origin. Healthcare professionals naturally saw me as a representative of CURE organisation rather than an independent researcher. In the villages, I was often mistaken for a doctor or a representative from a donor organisation, no doubt encouraged by our association with Beit CURE Hospital. There was also concern about our motives when we visited the villages, probably as a result of recent sensitisation campaigns around child trafficking. In one village, we were greeted by children singing a song in Yao about 'the blood suckers'. This singing was based on worries amongst villages about people who broke into compounds and forced villagers to donate blood before the practice had been regulated.

Participants' perceptions impacted on their responses to us. For instance, one tearful counsellor "begged" us to talk to CURE Spiritual Team to enable them to continue working as a group of counsellors, rather than changing to a single counsellor service. Participants in the villages and their friends asked us to assess other children and arrange transport for patients to the hospital. I was also asked to pay for the school fees of a young participant. On a memorable occasion I was led around the compound of a school by a head teacher and representatives from the community. It was only late into the discussion that I realised they thought I was there to build a school. To protect villagers from the malign influence of the 'outsiders', interviews were sometimes attended by the chief's representatives who were able to monitor and report back on discussions.

My white skin engendered "respect" from people, making it easier for us to recruit participants. Paul explained that in Malawi a hierarchy existed: "at the top there are the mzungus [white people], then the Chinese, the Indians and right at the very bottom are the Malawians". I felt confident that I would have not have gained access to District Health Officers had I been a Malawian. Although I was grateful for this, I often found myself feeling embarrassed by my white skin with its association with wealth and privilege. I worried that it presented an insurmountable barrier to fully engaging with participants or that people secretly felt scornful or envious towards me. In one instance, an older woman knelt in front of me when I visited her. However, I viewed my gender and age, which was around that of my female participants, as a factor that helped bond us together.

To try and address some of these issues in the villages, I developed creative ways of building rapport with participants to try and challenge their perceptions of me. I was excessively apologetic about not being able to speak local languages and tried to engage in activities such as pounding maize to try and have a little bit of fun and help put them at ease. My efforts to engage in and appropriate Malawian manners and dress also met with some success. An older lady told our Research Assistant he should be very proud of me, "she is a Yao, she is one of us. She has good manners, she can speak some of our language and sits on the mat without any trouble. No mini-skirts or trousers here!". I was also secretly delighted when participants teasingly gave me the Chewa clan name "Anaphiri" meaning "from the mountains".

As a perceived representative of CURE, parents asked me on a number of cases to intervene in their child's care at the hospital. A family who had a child with clubfoot that had not received full treatment and were struggling to re-enter treatment, told

us “While you are still visiting us, we have hope [for the treatment of the child]”. This created challenging ethical dilemmas about how or if to intervene in care. Although I felt very deeply that I wanted to assist, I also felt under pressure to protect the integrity of my research by observing processes rather than disrupting them. This was compounded by the pressure I faced from healthcare professionals to do so. To make these decisions I held extensive discussions with the wider study team. The impact of this on the research process has been discussed above.

Figure 30: Photograph of an older woman kneeling in front of me during fieldwork



This woman provided verbal consent for this image to be taken and used for the purposes of research.

Figure 31: Photograph of me decorating spoons for market during fieldwork



The family of these children provided verbal consent for this image to be taken and used for the purposes of research. The children provided verbal assent.

8.4.3 Conclusions

This explores some of the challenges I encountered conducting ethnographic fieldwork on clubfoot treatment services in Malawi. I found a fieldwork diary provided me with the chance to record and reflect on these challenges.

8.5 Recommendations for service delivery

This study has used implementation science theory to explore the implementation of clubfoot treatment services in Malawi. Identifying factors that impact on the implementation of these services provides information to Beit CURE Hospital on

how best to develop services to better meet the needs of patients. Exploring the experiences of children and their guardians, that had either discontinued or not fully accessed treatment, provides information to Beit CURE Hospital on ways to develop services to meet the needs of these patients who may be living with neglected clubfoot. These include the importance of establishing effective communication with patients so as not to deter treatment-seeking and the need to establish effective referral pathways for those presenting with neglected clubfoot. It also highlights the need for healthcare professionals to understand treatment seeking within the context of the families' daily lives.

Based on insights from the data and recommendations from participants, I have formulated a list of recommendations detailed below:

8.5.1 Treatment delivery

1) Make sure that students are fully supervised and monitored in clinics to ensure treatment is performed according to protocol.

2) Work with healthcare workers in the community to educate them about clubfoot condition, the Ponseti method and the location of treatment clinics. Means of doing this may include educational visits or by distributing posters in healthcare centres.

3) Increase contact with clinic staff through phone calls, emails and site visits. Establish processes for clinicians and counsellors to provide feedback to staff at Beit CURE Hospital.

4) Ensure that clinics have adequate resources such as plaster of paris, gauze and proformas for recording treatment progress. To do this, ensure that reports that provide information about service capacity are completed accurately and in a timely manner. Identify a dedicated person at each clinic to submit these reports and consider incentives if this is considered to fall outside of their remit.

5) Make sure that braces are distributed in a range of sizes to all clinics.

6) Educate healthcare professionals about appropriate methods of removing casts such as electric cutters or soaking casts in clinics. Caution about the use of surgical blades to remove casts and other methods which may cause injury. This may be undertaken through refresher courses or through education sessions held by CURE clubfoot manager when visiting clinics for monitoring.

7) Increase the availability of training in the Ponseti method to staff working in clinics. Consider extending training to lower cadres to ease the burden on more experienced workers.

8) Work with management staff in District and Central Hospitals to identify ring-fenced time to run dedicated clubfoot clinics.

9) Work with hospitals to identify designated space for clubfoot clinics to protect the privacy of mothers attending.

10) Consider ways of helping mothers and guardians to access treatment by providing money for transport, helping mothers locate ambulances in the community to travel to hospitals or organising inpatient stays during the casting phase of treatment.

11) Ensure counsellors are aware of the existence of funds to follow-up patients. Communicate with counsellors to encourage them to implement CURE's follow-up policy. Monitor activity to make sure this is taking place.

12) Negotiate with clinics to provide timely and accurate reports. Consider introducing incentives for staff to encourage this.

13) Ensure clinics have a single point of contact at Beit CURE Hospital to make it easier to discuss service delivery and order materials.

14) Inform clinic staff that there is no evidence using ankle boots after the bracing phase of treatment helps to maintain correction. Unless evidence of efficacy can be provided consider phasing out this component of care. Use established channels to disseminate this information such as written information when distributing resources, in initial training sessions in the Ponseti method, refresher courses or through phone calls with clinic coordinators. Counsellors should also be informed of this through the Spiritual Team. This practice should be monitored by CURE clubfoot management during clinic visits.

15) Develop strategies to monitor the delivery of treatment, including monitoring the attendance of healthcare professionals and adherence to treatment protocols. This should consider if treatment is being delivered by trained professionals and if casting is being undertaken by individuals or in pairs, as per best practice. Appropriate action should be taken if clinics are seen as under-performing.

8.5.2 Counselling services

1) Provide opportunities for counsellors working in different services to communicate with each other to share skills and offer advice and encouragement. This may be through internet forums, by distributing contact information or in refresher courses.

2) Increase contact with counsellors through more regular phone calls and clinic visits to offer encouragement and guidance. Encourage them to provide feedback to CURE Spiritual Team and consult them on changes in working practice.

3) Ensure counsellors are provided with adequate stationery to maintain records or provide sufficient allowances for photocopying.

4) Introduce regular refresher courses to help counsellors build on their skillsets.

5) Negotiate with public hospitals to find a private room to hold counselling sessions with patients to provide them with privacy and encourage them to share their experiences and concerns.

6) Consider using group counselling sessions in busy clinics to ensure that all mothers and guardians receive this component of care and encourage them to share their experiences with each other. This recommendation may be built into training or included in the "counsellor's handbook" which details how best to deliver this component of care. Strategies should be tailored to individual clinics and discussed in collaboration with the Spiritual Team.

7) Standardise the delivery of counselling to ensure that all guardians receive relevant information and support.

8) Ensure mothers are fully informed about treatment protocols, including the duration of treatment, so they are aware of the financial demands of accessing care and bracing protocols. Provide information about tenotomies in advance of the procedure.

9) Provide guidance to counsellors on how to broach the issues of Christianity and guardians' beliefs, to ensure that their approach is standardised and consistent with CURE's "message". The religious beliefs of participants should be respected and traditional practices such as the wearing of charms should not be discouraged.

10) Encourage mothers to involve their families, especially fathers, in the treatment. If fathers are unable to attend on a weekly basis, consider encouraging them to attend one counselling session so they can be educated about the different components of care.

11) Encourage counsellors to recognise the barriers guardians face in accessing treatment and refrain from apportioning blame. Instead, encourage them to focus on helping mothers to develop strategies to mitigate these challenges.

12) Guardians should be encouraged to share their experiences with other mothers in clinics and promote the treatment within their communities. CURE should consider formalising these roles.

8.5.3 Neglected clubfoot

1) Develop strategies to identify children living with neglected clubfoot in the community. This should involve close collaborations with healthcare professionals working in the community, including Health Surveillance Assistants or community health workers, who may be educated to identify the condition.

2) Develop a referral pathway for children living with neglected clubfoot from the community to secondary care services to enable them to access surgical or other treatments. This should be developed in collaboration with a range of healthcare professionals, including those working in orthopaedic services in District Hospitals, taking into account service capacity and resourcing.

Information about the pathway should be disseminated to all the healthcare professionals working within paediatric orthopaedics at these services.

8.6 Dissemination of research

Research findings were disseminated at a meeting in November 2016 with around 25 stakeholders involved in the organisation and delivery of clubfoot treatment services in Malawi. This included the Clubfoot Coordinator, members of the Spiritual Team, the Clinical Director and Chief Executive Officer at Beit CURE Hospital. All those involved in the delivery of care at Beit CURE Hospital were invited. The global CURE Clubfoot Operations Director was also present. Stakeholders discussed how findings could be integrated into the Malawi National Clubfoot Programme 5 year plan. Following the completion of this project, findings will be presented as written reports to Beit CURE Hospital and the global CURE organisation. It is hoped that this may help to inform service delivery.

8.7 Future research

Research should aim to explore in-depth the experiences and impact of clubfoot on fathers and the wider family. This would provide a more comprehensive understanding of the impacts of clubfoot and enable healthcare professionals or other organisations to develop interventions to support the whole family. Likewise, conducting an in-depth study to explore communication between patients and healthcare professionals in further detail may help identify effective methods of communication that could be built into clubfoot training. These studies could aim to incorporate the experiences of those living in different areas, particularly those in the Northern Region. Doing so would enable researchers to compare and contrast the

experiences of those in different Regions and provide a fuller understanding of these issues. This is particularly salient within such a culturally diverse setting.

This work also highlights the need to examine processes of identification and referral of children with neglected clubfoot that have discontinued treatment. Doing so could provide researchers and healthcare professionals with the groundwork to develop an intervention to assist these children. Finally, future research should explore the application of extended Normalization Process Theory and our additional construct, 'negotiating patient access', in other low-income country settings. This would contribute to the evidence base that makes use of this theory.

8.8 Conclusions

Clubfoot can have a profound impact on the well-being of children and their families. Clubfoot can be treated through staged manipulation of the limb and treatment is delivered by Beit CURE Hospital in Malawi which coordinates 29 outreach clinics. However, previous research has highlighted that implementing clubfoot treatment services is complex; a high proportion do not present; and adherence is low. This study had three aims: 1) identify factors that impact on the implementation of services and develop a theoretical framework to inform findings; 2) understand the impact of accessing services on carers of children with clubfoot and; 3) explore the experiences of those who had not fully accessed treatment.

Ethnographic data collection comprised three elements. Element 1: Observation sessions were conducted at three clinics and interviews conducted with staff at an additional nine sites. Key informants placed findings within the wider health context

(n = 52). Element 2: Fieldwork was conducted at three sites and involved single, dyad or triad interviews and focus groups with those currently accessing treatment, those that had been discharged and clubfoot counsellors (n = 57). Element 3: In-depth case studies were conducted with those that had not fully accessed treatment (n = 4).

Factors impacting on service implementation were interpreted using an implementation science theory known as extended Normalization Process Theory. Factors identified included cooperation, commitment to delivery, workability and strategies to facilitate delivery over time. An additional construct identified concerned work done to facilitate patient access. Attitudes of families and the community on finding out the child was different varied and ranged from love and support to a source of conflict and division. Families were overwhelmingly satisfied with treatment although challenges were identified. Those that had been discharged described joy and were happy to be relieved of the financial burden of treatment. Factors that influenced treatment-seeking for those that had not fully accessed treatment included the anticipated outcomes of living with clubfoot, social support networks, healthcare experiences and a lack of referral pathways. Challenges took place in a web of competing concerns such as poverty.

This study provides valuable insights into the delivery of clubfoot treatment services in Malawi that can be used to inform service delivery. In capturing the views and experiences of patients and stakeholders and prioritising them in service design, CURE Organisation is aiming to deliver 'people-centred' care in a low-income country context.

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Appendices

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Appendix 1: Publications and outputs associated with this thesis

Peer reviewed publications

Drew S, Gooberman-Hill R, Lavy C. What factors impact on the implementation of clubfoot treatment services in low and middle-income countries?: a narrative synthesis of existing qualitative studies. BMC Musculoskelet Disord, 2018. **19**(1): p. 72

Drew S, Lavy C, Gooberman-Hill R. What factors affect patient access and engagement with clubfoot treatment in low- and middle-income countries? Meta-synthesis of existing qualitative studies using a social ecological model. Trop Med Int Health, 2016. **21**(5): p. 570-89

Non referred outputs

Drew S. Field video diary: Changing clubfoot care in sub-Saharan Africa' [Online video]. NDORMS University of Oxford; 2017. Available from: https://www.youtube.com/watch?v=OYtQbFN6lx0

Drew S. Experiences conducting ethnographic fieldwork in Malawi: challenges in navigating a new culture and participant perceptions [Online article]. The Global Health Network; 2016. Available from: https://globalhealthtrials.tghn.org/articles/experiences-conducting-ethnographic-fieldwork-malawi-challenges-navigating-new-culture-and-participant-perceptions/

Conference presentations

Drew S, Lavy C, Gooberman-Hill R. What factors impact on patient access and engagement with clubfoot treatment in low and middle-income countries?: a meta-synthesis of existing qualitative studies using a Social Ecological Model. Presented at: International Health Policy Conference, London School of Economics, London UK**;** February 2017

Conference posters

Drew S, Chidothie P, Lavy C, Gooberman-Hill R. Exploring the implementation of clubfoot treatment services in Malawi using Extended Normalization Process Theory: an ethnographic study. Poster session presented at: Healthy People, Healthy Ecosystems: Implementation, Leadership & Sustainability in Global Health, Consortium of Universities for Global Health, Washington DC; April 2017

Appendix 2: Appraisal frameworks and data collection tools

1. MMAT mixed methods appraisal framework

2. CASP systematic review checklist

3. CASP qualitative checklist

4. Stake's criteria for assessing the quality of a case study report

5. Information sheet for healthcare professionals working in clinics (English and Chichewa)

6. Observation checklist used in clinics

7. Topic guide for exploring service implementation with healthcare professionals and counsellors

8. Topic guide for follow-up telephone interviews with clinic organisers

9. Topic guide for interview with Clubfoot Coordinator

10. Topic guide for interview with Cure Counselling Coordinator

1. MMAT mixed methods appraisal framework

PART I. MMAT criteria & one-page template (to be included in appraisal forms)

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	• Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

PART II. MMAT tutorial

Types of mixed methods study components or primary studies	Methodological quality criteria
1. Qualitative Common types of qualitative research methodology include: A. Ethnography The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals. B. Phenomenology The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. C. Narrative The study analyzes life experiences of an individual or a group. D. Grounded theory Generation of theory from data in the process of conducting research (data collection occurs first). E. Case study In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country. F. Qualitative description There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive). Key references: Creswell, 1998; Schwandt, 2001; Sandelowski, 2010.	**1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?** E.g., consider whether (a) the selection of the participants is clear, and appropriate to collect relevant and rich data; and (b) reasons why certain potential participants chose not to participate are explained.
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? E.g., consider whether (a) the method of data collection is clear (in depth interviews and/or group interviews, and/or observations and/or documentary sources); (b) the form of the data is clear (tape recording, video material, and/or field notes for instance); (c) changes are explained when methods are altered during the study; and (d) the qualitative data analysis addresses the question.
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? * E.g., consider whether the study context and how findings relate to the context or characteristics of the context are explained (how findings are influenced by or influence the context). "For example, a researcher wishing to observe care in an acute hospital around the clock may not be able to study more than one hospital. (…) Here, it is essential to take care to describe the context and particulars of the case [the hospital] and to flag up for the reader the similarities and differences between the case and other settings of the same type" (Mays & Pope, 1995). The notion of context may be conceived in different ways depending on the approach (methodology) tradition.
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants? * E.g., consider whether (a) researchers critically explain how findings relate to their perspective, role, and interactions with participants (how the research process is influenced by or influences the researcher); (b) researcher's role is influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings); and (c) researchers explain their reaction to critical events that occurred during the study. The notion of reflexivity may be conceived in different ways depending on the approach (methodology) tradition. E.g., "at a minimum, researchers employing a generic approach [qualitative description] must explicitly identify their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest" (Caelli, Ray & Mill, 2003, p. 5).

*See suggestion on the MMAT wiki homepage (under '2011 version'): Independent reviewers can establish a common understanding of these two items prior to beginning the critical appraisal.

Types of mixed methods study components or primary studies	Methodological quality criteria
2. Quantitative randomized controlled (trials) Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins & Green, 2008; Porta, 2008; Oxford Center for Evidence based medicine, 2009.	**2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?** In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance, and researchers describe how the randomization schedule is generated. "A simple statement such as 'we randomly allocated' or 'using a randomized design' is insufficient". *Simple randomization:* Allocation of participants to groups by chance by following a predetermined plan/sequence. "Usually it is achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer". *Sequence generation:* "The rule for allocating interventions to participants must be specified, based on some chance (random) process". Researchers provide sufficient detail to allow a readers' appraisal of whether it produces comparable groups. E.g., blocked randomization (to ensure particular allocation ratios to the intervention groups), or stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics).
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? *The allocation concealment protects assignment sequence until allocation.* E.g., researchers and participants are unaware of the assignment sequence up to the point of allocation. E.g., group assignment is concealed in opaque envelops until allocation. *The blinding protects assignment sequence after allocation.* E.g., researchers and/or participants are unaware of the group a participant is allocated to during the course of the study.
	2.3. Are there complete outcome data (80% or above)? E.g., almost all the participants contributed to almost all measures.
	2.4. Is there low withdrawal/drop-out (below 20%)? E.g., almost all the participants completed the study.

Types of mixed methods study components or primary studies	Methodological quality criteria
3. Quantitative non-randomized Common types of design include (A) non-randomized controlled trials, and (B-C-D) observational analytic study or component where the intervention/exposure is defined/assessed, but not assigned by researchers. A. Non-randomized controlled trials The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups. B. Cohort study Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). C. Case-control study Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). D. Cross-sectional analytic study At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population sub-groups according to the presence/absence (or level) of the intervention/exposure. Key references for observational analytic studies: Higgins & Green, 2008; Wells, Shea, O'Connell, Peterson, et al., 2009.	**3.1. Are participants (organizations) recruited in a way that minimizes selection bias?** At recruitment stage: For cohort studies, e.g., consider whether the exposed (or with intervention) and non-exposed (or without intervention) groups are recruited from the same population. For case-control studies, e.g., consider whether same inclusion and exclusion criteria were applied to cases and controls, and whether recruitment was done independently of the intervention or exposure status. For cross-sectional analytic studies, e.g., consider whether the sample is representative of the population. **3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?** At data collection stage: E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) the measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure. For non-randomized controlled trials, the intervention is assigned by researchers, and so consider whether there was absence/presence of a contamination. E.g., the control group may be indirectly exposed to the intervention through family or community relationships. **3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?** At data analysis stage: For cohort, case-control and cross-sectional, e.g., consider whether (a) the most important factors are taken into account in the analysis; (b) a table lists key demographic information comparing both groups, and there are no obvious dissimilarities between groups that may account for any differences in outcomes, or dissimilarities are taken into account in the analysis. **3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?**

Types of mixed methods study components or primary studies	Methodological quality criteria
4. Quantitative descriptive studies Common types of design include single-group studies: A. Incidence or prevalence study without comparison group In a defined population at one particular time, what is happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). B. Case series A collection of individuals with similar characteristics are used to describe an outcome. C. Case report An individual or a group with a unique/unusual outcome is described in details. Key references: Critical Appraisal Skills Programme, 2009; Draugalis, Coons & Plaza, 2008.	**4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?** E.g., consider whether (a) the source of sample is relevant to the population under study; (b) when appropriate, there is a standard procedure for sampling, and the sample size is justified (using power calculation for instance).
	4.2. Is the sample representative of the population understudy? E.g., consider whether (a) inclusion and exclusion criteria are explained; and (b) reasons why certain eligible individuals chose not to participate are explained.
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? E.g., consider whether (a) the variables are clearly defined and accurately measured; (b) measurements are justified and appropriate for answering the research question; and (c) the measurements reflect what they are supposed to measure.
	4.4. Is there an acceptable response rate (60% or above)? The response rate is not pertinent for case series and case report. E.g., there is no expectation that a case series would include all patients in a similar situation.

Types of mixed methods study components or primary studies	Methodological quality criteria
5. Mixed methods Common types of design include: A. Sequential explanatory design The quantitative component is followed by the qualitative. The purpose is to explain quantitative results using qualitative findings. E.g., the quantitative results guide the selection of qualitative data sources and data collection, and the qualitative findings contribute to the interpretation of quantitative results. B. Sequential exploratory design The qualitative component is followed by the quantitative. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the qualitative findings inform the quantitative data collection, and the quantitative results allow a generalization of the qualitative findings. C. Triangulation design The qualitative and quantitative components are concomitant. The purpose is to examine the same phenomenon by interpreting qualitative and quantitative results (bringing data analysis together at the interpretation stage), or by integrating qualitative and quantitative datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). D. Embedded design The qualitative and quantitative components are concomitant. The purpose is to support a qualitative study with a quantitative sub-study (measures), or to better understand a specific issue of a quantitative study using a qualitative sub-study, e.g., the efficacy or the implementation of an intervention based on the views of participants. Key references: Creswell & Plano Clark, 2007; O'Cathain, 2010.	**5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?** E.g., the rationale for integrating qualitative and quantitative methods to answer the research question is explained. **5.2. Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?** E.g., there is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration. **5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?**

2. Systematic review checklist



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CASP Checklist: 10 questions to help you make sense of a Systematic Review

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Systematic Review) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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CASP
Critical Appraisal Skills Programme

Section A: Are the results of the review valid?		
1. Did the review address a clearly focused question?	Yes ☐ Can't Tell ☐ No ☐	HINT: An issue can be 'focused' In terms of • the population studied • the intervention given • the outcome considered
Comments:		
2. Did the authors look for the right type of papers?	Yes ☐ Can't Tell ☐ No ☐	HINT: 'The best sort of studies' would • address the review's question • have an appropriate study design (usually RCTs for papers evaluating interventions)
Comments:		
Is it worth continuing?		
3. Do you think all the important, relevant studies were included?	Yes ☐ Can't Tell ☐ No ☐	HINT: Look for • which bibliographic databases were used • follow up from reference lists • personal contact with experts • unpublished as well as published studies • non-English language studies
Comments:		

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4. Did the review's authors do enough to assess quality of the included studies?

Yes ☐
Can't Tell ☐
No ☐

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider
- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:

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7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments:

9. Were all important outcomes considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- even if this is not addressed by the review, what do **you** think?

Comments:

3. CASP qualitative checklist



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Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Section A: Are the results valid?			
1. Was there a clear statement of the aims of the research?	Yes Can't Tell No	☐ ☐ ☐	HINT: Consider • what was the goal of the research • why it was thought important • its relevance
Comments:			
2. Is a qualitative methodology appropriate?	Yes Can't Tell No	☐ ☐ ☐	HINT: Consider • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the tight methodology for addressing the research goal
Comments:			
Is it worth continuing?			
3. Was the research design appropriate to address the aims of the research?	Yes Can't Tell No	☐ ☐ ☐	HINT: Consider • if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
Comments:			

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4. Was the recruitment strategy appropriate to the aims of the research?

Yes	
Can't Tell	
No	

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	
Can't Tell	
No	

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

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8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

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Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

4. Stake's criteria for assessing the quality of a case study report

1. Is this report easy to read?
2. Does it fit together, each sentence contributing to the whole?
3. Does this report have a conceptual structure (i.e. themes or issues)?
4. Are its issues developed in a series and scholarly way?
5. Is the case adequately defined?
6. Is there a sense of story to the presentation?
7. Is the reader provided some vicarious experience?
8. Have quotations been used effectively?
9. Are headings, figures, artefacts, appendices, indexes effectively used?
10. Was it edited well, then again with a last minute polish?
11. Has the writer made sound assertions, neither over- or under-interpreting?
12. Has adequate attention been paid to various contexts?
13. Were sufficient raw data presented?
14. Were data sources well chosen and in sufficient number?
15. Do observations and interpretations appear to have been triangulated?
16. Is the role and point of view of the researcher nicely apparent?
17. Is the nature of the intended audience apparent?
18. Is empathy shown for all sides?
19. Are personal intentions examined?
20. Does it appear individuals were put at risk?

5. **Information Sheet for healthcare professionals working in clinics (English and Chichewa)**

Exploring the delivery of clubfoot services in Malawi
Information sheet for healthcare professionals

Reasons for the project: This is a research project to understand and improve health care for clubfoot in Malawi. The project involves shadowing of practice, interviews with patients, parents/carers and health professionals.

What will you be asked to do?: We will ask to spend time with you in your clinical practice to see how services are delivered and to talk to clients about services, informally and in more formal interviews. We will ask permission to tape-record (audio only) the interviews to ensure that there is an accurate record of what was said. The tape-recordings will be transcribed and we will also write some notes.

What will happen to the information collected? The information collected will be kept safe for as long as we need to after the project. What has been said will be written up into reports and publications, and everyone's names will be taken out so that no one else will be able to identify you. An overview of findings will be provided to you if you wish.

What are the benefits and risks? Taking part will take some of your time. We will try our best not to inconvenience you. We hope that the project may help to improve treatment for clubfoot in the future.

Do I have to take part? Your participation is voluntary. You can stop at any time, without affecting your rights or employment.

Who has approved the study? This study has been reviewed and approved by the College of Medicine Research and Ethics Committee (COMREC) in Malawi (COMREC ref: P.02/15/1675) and the Oxford Tropical Research Ethics Committee (OxTREC) at Oxford University in England (OXTREC ref: 10-15).

If you are have any questions about the research please contact: Sarah Drew, Beit CURE International Hospital, Blantyre, email sarah.drew@ndorms.ox.ac.uk, telephone 0997771932

COMREC Secretariat: College of Medicine, 3rd Floor, John Chiphangwi Learning Resource Centre, Private Bag 360, Chichiri, Blantyre 3, Malawi, **email** : comrec@medcol.mw, telephone 011871911

KUFUFUZA M'MENE THANDIZO LA CLUBFOOT LIMAPELEKEDWERA M'MALAWI
KALATA YA OGWIRA NTCHITO ZA CHIPATALA

CHOLINGA CHA KAFUKUFUKU?: Ndikufuna kumva komanso kupititsa patsogolo thandizo la chipatala kwa amene ali ndi clubfoot mdziko muno.tikhala tikuonanso kagwiridwe ka ntchito,kuchendi odwala, makolo awo komanso ogwira ntchito za chipatala.

ZOYENERA KUCHITA?: Tikhala tikukufunsani mafunso okhuza dela lanu la ntchito,mmene mumapelekera chithandizo, komanso kukambirana mwa padela dela. Tikupemphani kuti tijambule zokambirana zathuzi kuti pakhale chilungamo pa zonse zomwe tikhale tikuyankhulanazi. Zojambulazi tikazitsindikiza komanso tikhala tikulemba.tijambulanso zithunzi malo anu ogwirira ntchito, ngati mungatilore kutero.zilibe kanthu kuti mukhala mukafukufukumu kwa nthawi yaitali bwanji.

ZOTSATIRA ZA KAFUKUFUKUYU?: Zonse zimene tipeze pofufuzaku tizazisunga mwa chinsisi komanso malo otetezeka bwino mpaka pamene tizathere kafukufukuyu. Tizalemba zotsatira za zofufuzazi komanso kuzitsindikiza m'mabuku ndipo maina anu sitizawalemba,ndipo palibe amene azakuzindikireni.zotsatila zimene tizapeze mukufufuzaku tidzakupatsani ngati mukufuna.

KODI PALI PHINDU KAPENA CHIOPSEZO CHINA CHILLI CHONSE NDIKALOWA KAFUKUFUKUYU?: Mudzakhala muli mukafukufukuyu kwa ka nthawi ndithu,tizayetsetsa kuti tisaukulemetseni pamene muli kutenga gawo mukafukufukuyu, tili ndi chiyembekezo kuti kafukufukuyu azathandiza ndi kupititsa pa tsogolo pothandiza amene ali ndi zilema za clubfoot mt'sogolo muno.

KODI NDINGALOWE NAWO MUKAFUKUFUKUYU?: Kulowa mukafukufukuyu, ndikufuna kwanu osati kukakamizidwa. Mutha kutuluka nthawi ina iliyonse popanada kukhuza ntchito yanu kapena ufulu wanu.

NDI NDANI AMENE AVOMELEZA KAFUKUFUKUYU KUTI ACHITIKE?: Kafukufukuyu waonedwa komanso kuvomelezedwa ndi a College of Medicine Research and Ethics Committee (COMREC) in Malawi (COMREC ref: P.02/15/1675) and the Oxford Tropical Research Ethics Committee (OxTREC) at Oxford University in England (OXTREC ref: 10-15)

Ngati mukufuna kulowa nawo mukafukufukuyu kapena muli ndi mafunso.
Lembelani kwa: Sarah Drew, Beit CURE International Hospital, Blantyre, email sarah.drew@ndorms.ox.ac.uk, telephone 0997771932

COMREC Secretariat: College of Medicine, 3rd Floor, John Chiphangwi Learning Resource Centre, Private Bag 360, Chichiri, Blantyre 3, Malawi, email : comrec@medcol.mw, telephone 01871911

6. Observation checklist used in clinics

Exploring the delivery of clubfoot services in Malawi

Observation checklist

Details of observation session:

Location of clinic:

Time and date:

Observation number:

Length of time spent observing:

Topics to explore:

- Types of healthcare professionals, numbers of healthcare professionals
- Description of children (including their impairments) and carers, numbers of each
- Description of setting including layout of clinic
- Activities taking place including treatment and counselling services
- Treatment protocols being followed
- Methods of communication between professionals and patients
- Interactions between professionals
- Identification of barriers and facilitators to service delivery

7. Topic guide for exploring service implementation with healthcare professionals and counsellors about experiences of delivering treatment

Clubfoot treatment services in Malawi: an ethnographic study

Topic guide for interviews: staff

Aims and objectives

Identify the best models of care for the delivery of treatment for children with clubfoot

Main objectives are to explore:

Background information

Experiences and views of working in the clinic

Barriers/ facilitators to the delivery of the services

Introduction

- Introduce self and Paul, work for Oxford University – stress that do not work as part of the Hospital
- Introduce the study: who is it for, what is it about
- Key points:
  - Length of the interview
  - Voluntary nature of participation and right to withdraw
  - Recording of the interview
- Confidentiality and how findings will be reported
- Participant Information Sheet – copy to keep
- Any questions that they have
- Consent form

Section 1: Background information

- Job title, years spent in role, age
- Length of time spent work working in the clinic
- Describe what role you do in clinic
- Describe what happens when a mother arrives at the clinic
    - Mother arrives at clinic – health passport book.
    - Cast removal – who does that? How is cast removed?
    - Scoring – who does that?
    - Casting – who does that
    - Providing information about treatment

Section 2: Service delivery and organisation

Delivery of treatment

What works well about service/ not so well/ improvements

Opinions on specific stages of treatment

- Cast removal – How done/ How well works/ what works well/ not so well/ improvements
- Scoring – How done/ How well works/ what works well/ not so well/ improvements
- Casting – How done/ How well works/ what works well/ not so well/ improvements
- Tenotomies - How done/ How well works/ what works well/ not so well/ improvements
- Review – What time points/ why/ what works well/ not so well/ improvements
- Fitting children out in ankle boots - How done/ How well works/ what works well/ not so well/ improvements
- Follow-up if do not return to clinic – Any done/ why/ what works well/ not so well/ improvements
- Providing mothers/ guardians with information about treatment – How done/ How well works/ what works well/ not so well/ improvements
- Questions related to specific events/ things they said, e.g. students at clinic, healthcare professionals doing specific roles,

Counselling

What works well about service/ not so well/ improvements

- What do you think your role is in the clinics – questions related to specific events/ things they said
- Describe a counselling session that you had with a mother/ guardian that went well/ why
- Describe a counselling session that you had with a mother/ guardian that did not go so well/ why/ improvements
- Had an experience with someone who was not a Christian. What happened.
- Had an experience with counselling a father/ male guardian. What happened.
- What information most important to tell mothers/ why

  [Probes: care of casts, spiritual guidance, bracing protocol]
- How useful counselling is for mothers/ guardians/ why

  [Probes: whether informative/ changes behaviour]
- What do you think about Cure using female counsellors for counselling
- What do you think about Cure using one counsellor per counselling service
- Questions related to specific events/ things that they said

---

Part 3: Barriers/ facilitators to the delivery of services

Potential

- How committed team is to delivering treatment

Capability

- Whether they have everything they need to carry out treatment effectively or not/ improvements
  - Skills

    [Probes: received training for role]
  - Time

[Probes: too many patients, conflicting demands such as other roles in hospital or elsewhere]

- Resources

  [Probes: stationery, plaster, implements for cast removal, braces]

- Space in clinic

  [Probes: space for scoring, plastering, undertaking tenotomy, counselling, e.g. no private room for counselling]

Capacity

- How well everyone works together to deliver the service – How they communicate/ what works well/ not so well/ improvements.

  - Professional groups delivering treatment, e.g. clinical officers and assistants

  - Professional groups and counsellors

  - Counsellors (if more than one)

  - Those working in outreach clinic and Cure

  - Referrals from healthcare centres when children identified with clubfoot

    [Probe: Monthly visits from clubfoot coordinator/ communications from spiritual centre/ other forms of communication]

Contribution

- Identifying patients when they arrive at the clinic and provide information
  - Health passport book – how useful?/ improvements

- Recording patient progress
  - Scoring sheets to record patient progress and then filed – how well system works?/ improvements

- How details from counselling sessions recorded – how done/ how well works/ what works well/ what not so well/ improvements

  [Probes: Forms for counselling sessions, monitoring forms submitted to Cure]

Part 4: Close

- Any other things they would like to discuss

- Any questions about the project.

- End, thank the participant, reaffirm consent

8. Topic guide for follow-up telephone interviews with clinic organisers

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for follow-up interviews: staff

Aims and objectives

Identify the best models of care for the delivery of treatment for children with clubfoot

Main objectives are to explore:

Background information

Role of Cure

Resources

Data collection

Referrals

Introduction

- Introduce self – work for Cure
- Remind them what the study is: who is it for, what is it about
- Key points
  - Length of the interview
- Remind them of voluntary nature of participation and right to withdraw
- Recording of the interview
- Remind them of confidentiality and how findings will be reported
- Any questions that they have
- Remind them that signed consent form and not necessary to do again.

Section 1: Background information

- Not needed as have this information

Section 2: Role of Cure

- What do you think Cure's role is in running services? (NB: supplying resources, collecting data).
- What do you think Cure could do to improve how they run services?
- What do you think the role of District Hospitals is in running the services? (NB: Providing plaster of Paris).

Section 3: Resources

- What resources is it Cure's responsibility to provide?
- How do you order materials from Cure?

  How well does system work?/ Any improvements?

  Sometimes lack braces. Why is this?
- What resources is it the District Hospital's responsibility to provide?

  If you run out of resources then who do you contact?

  What is the system for ordering new materials? How well does it work?
- Do you prepare for clinic before it begins?

  How? Who does this?
- How motivated do you think everyone who works at the service is to delivering treatment?

Section 4: Data collection

- You collect data for Cure.

  What does this involve?

How well does this system work?

- What happens to data collected?

Section 5: Referrals

- You get referrals from Health Centres and District Hospitals when babies are born with clubfoot.

  Do you feel all children are identified?

  How do they refer? (NB: tell the mothers to attend clinics). How well does this work?

  What could be done to improve this?

Part 6: Close

- Any other things they would like to discuss
- Any questions about the project.
- End, thank the participant, reaffirm consent

9. Topic guide for interview with Clubfoot Coordinator

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for interview Clubfoot Coordinator

Aims and objectives

Identify the best models of care for the delivery of treatment for children with clubfoot

Main objectives are to explore:

Background information

Changes made to service since arrived

Monitoring and evaluation of services

Changes to number of clinics

Supply of resources

Role of Cure and District Hospitals

Introduction

- Introduce self and Paul, work for Oxford University – stress that do not work as part of the Hospital
- Introduce the study: who is it for, what is it about
- Key points:
  - Length of the interview
  - Voluntary nature of participation and right to withdraw
  - Recording of the interview
- Confidentiality and how findings will be reported
- Any questions that they have
- Consent form

Section 1: Background information

- Job title, age
- Length of time spent work working in the role
- Describe what you do

Section 2: Changes made to service since arrived

- Describe changes made to services since arrived
- How useful

Section 3: Monitoring and evaluation of services

- Tell us about service evaluation and what it involves.

  What do with information?
- Working with District Hospitals to improve services. What does that involve?
- Clinics collect data then send to Cure. How do you collect data?

  What data do you collect?/ What happens to data?/ How useful is it?

  How well does that system of collecting data?

  Is the data sent back to central office?/ Is it sent back to clinics?

Section 4: Changes to number of clinics

- You said that you were shutting some of the clinics down. Why?

Section 5: Supply of resources

- What resources do you send clinics? (NB: stationery for recording progress, data collection materials, braces).

  Has that changed since you started in your role? If so, why have you changed that?

- How do clinics order materials?

  How do you transport materials to clinics?

  How well does system work?

- Many clinics do not have enough braces or sizes that they need. Why?

- Know it is responsibility of District Hospitals to provide plaster of paris, cast cutters, gauze etc. Many do not have. Why do you think this is?

Section 6: Role of Cure/ District Hospitals

- What is role of Cure?

  Some healthcare professionals think it is job to provide plaster of paris and cutters. What think of that? Can think of ways to address this?

- What is role of District Hospitals?

- Said that you were trying to work with District Hospitals to improve clinics. How are you doing that?/ How well is that working?

- Any improvements to how Cure and District Hospitals can work together?

Section 7: Healthcare professionals in clinics

- Training

  How often?

  How select who attends?

  Often enough/ want more often?

- Motivation

  Number of healthcare professionals turn up late, delegate to untrained professionals etc. Why do you think this is?

Section 8: Follow-up those did not complete treatment

- Many healthcare professionals, counsellors want to follow-up patients that do not complete treatment.

Would need airtime for contacting patients, form of transport/ petrol.

Is this something considered doing? Why/ why not?

Part 9: Close

- Any other things they would like to discuss
- Any questions about the project.
- End, thank the participant, reaffirm consent

10. Topic guide for interview with Counselling Coordinator

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for interview with Cure Counselling Coordinator

Aims and objectives

Identify the best models of care for the delivery of treatment for children with clubfoot

Main objectives are to explore:

Background information

Role of counsellors

Recruitment

Monitoring and evaluation of counselling services

Follow-up those did not complete treatment

Introduction

- Introduce self and Paul, work for Oxford University – stress that do not work as part of the Hospital
- Introduce the study: who is it for, what is it about
- Key points:
    - Length of the interview
    - Voluntary nature of participation and right to withdraw
    - Recording of the interview
- Confidentiality and how findings will be reported
- Participant Information Sheet – copy to keep
- Any questions that they have
- Consent form

Section 1: Background information

- Job title, age
- Length of time spent working as Pastor
- Length of time spent work working in the role
- Describe what you do

Section 2: Role of counsellors

- What is role of counsellors?
- What are most important things to tell patients?
- Are they called clubfoot counsellors or spiritual counsellors?
- Number of counsellors thought it was very important to spread the word of God. Is the role of counsellors to convert people to Christianity?
- Number of counsellors tried to discourage the mothers from practising traditional religion. What is Cure's policy on this?
- Understand this is a voluntary role. What do they get paid for? [allowances for travel, money for photocopying].

  How do you transfer these payments to them? How well does that system work?

Section 3: Recruitment

- How counsellors recruited?
- What do you look for in a counsellor?
- Changed from number of counsellors at each service to 1. Why? How well this worked?
- Wanted to keep female counsellors rather than male. Why?
- Number of counsellors wanted re-fresher courses to re-fresh skills and share ideas with other counsellors.

  How often do you run them or is it not possible?

Section 4: Monitoring and evaluation of counselling services

- Collect data on the services. Tell me about how you do that.

What data do you collect?

How well does system work?

What do you do with it? How useful is this?

- What resources do you provide to counsellors to help them do their work? [stationery].

  How do you get these resources to them? Do you have any problems doing that or is it okay?

- Do you monitor the work they do in any other ways? How?

  [Visit them in clinics, telephone calls]

- Do you have any other contact with counsellors working in outreach clinics or not? What?

- How well does the spiritual team and the counsellors work together? What do you do to stay in contact? Any improvements?

Section 5: Follow-up those did not complete treatment

- Counsellors handbook says that Cure supports following up clients that are no longer attending appointments. How important do you think this is?

- What is the Hospital's policy on following up clients?

  When is it appropriate to do?

- If a counsellor wanted to follow up a client then what is the process for doing this? Know in handbook say that they have to contact spiritual lead first. Is that correct?

  Tell me how that works.

  Would you like to make any improvements to that system?

- Many counsellors wanted to follow-up clients that do not complete treatment but only very few did.

  Why do you think this is?

- Many counsellors wanted to follow up clients but said they did not have airtime for contacting patients, form of transport/ petrol.

  Does Cure have resources to follow-up clients?

Part 6: Close

- Any other things they would like to discuss
- Any questions about the project.
- End, thank the participant, reaffirm consent

11. Topic guide for interviews with key informants

Topic guide District Health Officers/ Key informants

Aims and objectives

Conducted study on delivery of services for clubfoot that are organised by Cure. Want to understand findings within context of wider healthcare system

Main objectives are to explore:

Background information

System of referral

Resources

Changes to healthcare system

Introduction

- Introduce self, work for Oxford University in England and Cure
- Introduce the study: who is it for, what is it about
- Key points:
  - Length of the interview – 20 – 30 mins
  - Voluntary nature of participation and right to withdraw
  - Recording of the interview
- Confidentiality and how findings will be reported
- Any questions that they have
- Sign consent form

Emphasising that discussing healthcare services in Malawi generally, have not observed those in Blantyre. Work undertaken in District Hospitals.

Part 1: Background

- Job title, years spent working as DHO, age

- Length of time spent work working as DHO in Blantyre

Part 2: System of referral

- System of referral from Health Centres to District Hospitals

  How system works?

  How well does this work?

Part 3: Behaviour of healthcare professionals

- How high is motivation amongst HCPs working in District Hospitals to delivering care?

  Why?

- Some wanted incentives for delivering care.

  How common incentives in healthcare system?/ When used?

- What do you think healthcare professionals in Malawi do well?

- What do you think healthcare professionals in Malawi don't do so well?

- Do you think HCPs experience any challenges in delivering care? What are they?

Part 4: Resources

- Do healthcare professionals working in District Hospitals have all the resources they need to deliver care?

- How are resources in District Hospitals allocated to services?

  How well system work?

- In some of the clubfoot clinics, healthcare professionals were sharing space with other services.

  How common?/ Why?

- Healthcare assistants are involved in delivering treatment in clubfoot clinics alongside healthcare professionals with more training such as orthopaedic clinical officers.

How common is this?/ Why?

Part 5: Changes to healthcare system

- There have been recent changes to the healthcare budget in Malawi.

  Has this impacted on services or not? How?

- What do you think works well about how the Malawian healthcare system is organised?/ What not so well?

- If could change one thing about healthcare services in Malawi what would it be?

Part 6: Close

- Are there other things that you would like to talk about today?

12. Topic guide for interviews with those current accessing treatment

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for those currently accessing services

Aims and objectives

To find out what patients think of treatment, whether it can be improved and if treatment is making any difference to lives of patients. Will help improve services.

Main objectives are to explore:

Background information

Accessing services

Experiences of living with child with clubfoot

Experiences of treatment and services

Hopes for the future

Introduction

- Introduce self and Paul, work for Cure
- Introduce the study: who is it for, what is it about
- Key points:
    - Length of the interview – follow-up interview at a later date to see if situation has changed/ get more information from you
    - Voluntary nature of participation and right to withdraw
    - Recording of the interview
- Confidentiality and how findings will be reported
- Any questions that they have
- Verbal consent/ consent form

Part 1: Background

1. What name is/ what name of child is

   Bilateral/ unilateral

   What stage child is in treatment

   Home set up

2. Age/ Sex/ Family: who do they will with, where family is/ Tribe/ Where live/ Educational background/ What they do on a daily basis

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Part 2: Accessing services

1. How did you find out it was clubfoot?

2. Where did you hear about treatment?

3. What made you decide to get treatment?

4. How easy/ difficult was it for you to get treatment? Why?

   (Transport, obtaining shoes).

5. Anything hospital could do to make it easier for you to access treatment?

Part 3: Experiences of living with child with clubfoot

5. How did you feel when you found out your child's feet were different from others?/ How did your husband/ rest of family feel?

   How did you respond?/ Your husband respond?/ Rest of the family respond?

6. What did people around you think?

   How did they respond?

7. What did you think caused it?

8. Could you tell me what it is like for you/ your family to live with a child with clubfoot?

   Is there anything that is difficult about it or is it quite okay?

Part 4: Experience of treatment and services

1. How do you/ your husband/ family feel about you getting treatment?

2. What do people around you say about you getting treatment?

3. Do you have any worries about treatment?

4. When did you last get treatment?

   What time did you set off/ how did you travel/ what happened when you got to the clinic

5. Things that were good/ bad/ improvements with treatment?

   - Relationship with healthcare professionals
   - Lack of resources
   - Clinic space

6. Experiences casting

   - How casts removed? How found this?
   - Who did casting? How found this?
   - Anything healthcare professionals could have done to improve experience?

7. Experiences tenotomy

   - Can describe what happened?
   - How did you find this?
   - Anything healthcare professionals could have done to make this easier?

8. Braces

   - Who fitted out in braces?
   - Did you experience any difficulties with this?

9. Boots

   - What advice did you get on getting braces?
   - Did you get hold of these okay or did you have problems?

10. Have you ever missed an appointment? Why?

11. Could you tell me what you talked about when you were last counselled?

    Things that were good/ anything bad

    Improvements, e.g. anything you would have liked to discuss but didn't?

    How did it make you feel?

    Did Pastor discuss faith? What did they say? How useful was this?

12. Could you tell me what you talked about when you were first counselled?

Things that were good/ anything bad

Improvements, e.g. anything you would have liked to discuss but didn't?

How did it make you feel?

13. Has husband ever attended treatment with you? How useful was this? Anything clinics could do to make it easier for husbands to attend?

14. Can you tell me what it is like for you/ your family living with the child while they are going through treatment?

    Casts – cast care

    Braces

    Ankle boots

15. What is it like for the child being in braces around other children?

16. Have there been any changes to the way that you/ your husband/ family/ wider community treat you/ the child since starting treatment?

Part 5: Hopes for the future

1. What do you hope to get out of the treatment?

2. What are you hoping for in the future?

Part 7: Close

1. Are there other things that you would like to talk about today?

2. Do you have any questions for me about the project?

13. Topic guide for interviews with those that had been discharged

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for interviews with patients once treatment completed

Aims and objectives

To find out what patients think of treatment, whether it can be improved and if treatment is making any difference to lives of patients. Will help improve services.

Main objectives are to explore:

Background information about you and your family

What it was like having a child with clubfoot

Experiences of getting treatment

How you feel now the treatment has been completed

Introduction and consent

- Introduce self and Paul, work for Oxford University – stress that do not work as part of the Hospital
- Introduce the study: who is it for, what is it about
- Key points:
    - Length of the interview
    - Follow-up interviews at a later date for more information – get more information from you
    - Voluntary nature of participation and right to withdraw
    - Recording of the interview
- Confidentiality and how findings will be reported
- Any questions that they have
- Consent form/ verbal consent

Part 1: Demographics

1. A bit about you, your child/children and family; a bit of life history.
2. Age/ family – who live with, how many children/ where live/ educational background/ what they do on a daily basis/ age of child with clubfoot/ one foot affected or two?
3. What age was child when started treatment?
4. What age when child finish treatment?

Part 2: Having a child with clubfoot

1. How did you feel when you found out your child's feet were different from other children's?

   How did your husband feel? What did he do?

   Extended family? What did they do?

   Siblings? What did they do?
2. How did the wider community respond?
3. How did you find out about treatment?
4. What made you decide to get treatment?

Part 3: Accessing treatment

5. Can you tell me what happened when you got treatment?

   Journey to the clinic – what time set off/ how did you get there? Anything clinic could do to help?

   What happened at clinic when you received treatment. Anything did well/ anything not so well/ improvements?

   Casting – anything could have done to improve your experience?

   Tenotomy – how did you find this? Anything could have done to improve experience?

   Fitting out in braces – how did you find this? Anything could have been done to improve experience?
6. First counselling session.

What talk about during counselling?

Useful?

Anything did well/ anything not so well/ improvements?

Anything else you would have liked to discuss with counsellor but didn't?

Did you discuss issues of faith? How useful?

7. Counselling sessions had after that.

   What talk about?

   Useful?

   Anything did well/ anything not so well/ improvements?

   Anything else you would have liked to discuss with counsellor but didn't?

   Did you discuss issues of faith? How useful?

8. Could you tell me what it was like for you/ your family to live with the child when they were going through treatment?

   Casting?

   Bracing?

   Ankle boots?

9. What was it like for the child when they were in braces around other children?

Part 4: Completing treatment

10. What it is like for you/ family now treatment has been completed?

    Your husband?

    Extended family?

    Wider community?

    Other children?

11. Has getting treatment changed you/ your family's life in any way? How?

12. What is it like for the child now treatment has been completed?

13. Has getting treatment changed your child's life in any way?

14. What do you think would have happened to the child if have not received treatment?

15. What do you hope for the child in the future?

Part 3: Close

3. Are there other things that you would like to talk about today?

4. Do you have any questions for me about the project?

End, thank the participant, reaffirm consent

14. Topic guide for interviews with counsellors about experiences of accessing treatment

Clubfoot treatment services in Malawi: an ethnographic study
Topic guide for interviews with counsellors about experiences accessing treatment

Aims and objectives

Experiences of mothers of having child with clubfoot and accessing treatment

Main objectives are to explore:

Background information

Mothers' experiences of giving birth to child with clubfoot

Experience of treatment and services

Experiences after treatment completed

Introduction

- Introduce self and Cure
- Introduce the study: who is it for, what is it about
- Key points:
  - Length of the interview – 20 – 30 mins
  - Voluntary nature of participation and right to withdraw
  - Recording of the interview
- Confidentiality and how findings will be reported
- Any questions that they have
- Signed consent form

Part 1: Background

- Job title, years spent working as Pastor, age

- Length of time spent work working in the clinic

Part 2: Mothers' experiences of giving birth to child with clubfoot

Have spoken to mothers about their experiences but you have had longer to build up relationships with them so may have been more open with you.

9. What have some of the mother's said to you about how they felt when they found out their child had clubfoot?

   [Worried, disappointed, accepted]

10. How their husbands reacted?

    Why?

11. Rest of family reacted?

    Why?

12. Wider community?

    Why?

13. Stigma. What sort of stigma do mother's face?

    Why?

14. Witchcraft. Can you tell us more about these beliefs.

Part 3: Experience of treatment and services

17. How do mothers feel about getting treatment?

18. Mothers and other female members of the family tend to be the ones that take children to clinic. Why think this is?

19. Religion was very important to some mothers when going through treatment. Why think this is?

20. Some mothers use charms to help heal the child. Can you tell us about these beliefs?

21. Some problems identified in other clinics. For instance, no plaster to cast children so sent home. Mothers seemed to accept this and didn't challenge it. Why?

22. What worries do mothers have about treatment?

Casts – what problem with casts?

Braces - any problems with braces?

Ankle boots – problems?

Transport – what things have been said about this?

23. What is it like for mothers to be out with child in casts/ braces in public?
24. What is it like for the child being in braces around other children?

Part 4: Experiences after treatment completed

1. How do mothers react when they are told they have been discharged?
2. Do attitudes to children with clubfoot change once child is cured?

Part 5: Close

5. Are there other things that you would like to talk about today?

15. Consent form for healthcare professionals, counsellors, Cure Management and key informants (English and Chichewa)

Exploring the delivery of clubfoot services in Malawi

Agreement to take part in the project (Consent Form for Staff)

Reasons for the project: This is a research project to understand and improve health care for clubfoot in Malawi. The project involves shadowing of practice, interviews with patients, parents/carers and health professionals.

What you will be asked to do: We will ask to spend time with you in your clinical practice to see how services are delivered and to talk about services, informally and in a more formal interview. We will ask your permission to tape-record (audio only) the interviews to ensure that there is an accurate record of what was said. The tape-recordings will be transcribed and we will also write some notes. We would also like to take photographs of the service, if you agree to this. How much time you contribute to this research is up to you.

What will happen to the information collected? The information collected will be kept safe for as long as we need to after the project. What you say will be written up into reports and publications, and everyone's names will be taken out so that no one else will be able to identify you. An overview of findings will be provided to you if you wish.

What the benefits and risks? Taking part will take some of your time. We will try our best not to inconvenience you. We hope that the project may help to improve treatment for clubfoot in the future.

Do I have to take part? Whether you take part or not is up to you. You can stop at any time, without affecting your rights or employment.

I voluntarily agree to take part in the study:

Person taking part:

Sign: _____

Name: _____

Date:

I voluntarily agree to you taking photographs of the service:

Person taking part:
Sign: _____
Name: _____
Date:

Researcher taking consent
Sign: _____
Name: _____
Date:

If you have any questions about the project please contact: Sarah Drew, Beit CURE International Hospital, Blantyre, telephone 0997303429

If you have any complaints about the project please contact: COMREC secretariat, College of Medicine, 3rd Floor, John Chiphangwi Learning Resource Centre, Private Bag 360, Chichiri, Blantyre 3, Malawi, email **:** comrec@medcol.mw, telephone 01871911

KUFUFUZA MMENE THANDIZO LA CLUBFOOT LIMAPELEKEDWERA M'MALAWI

KALATA YOVOMELEZA KULOWA MUKAFUKUFUKU- YA OGWIRA NTCHITO

CHOLINGA CHA KAFUKUFUKU?: uyu ndi kafukufuku wofuna kudziwa komanso kupititsa patsogolo thandizo la chipatala kwa amene ali ndi clubfoot m'dziko muno. tikhala tikuonanso kagwiridwe ka ntchito,kucheza komanso kufunsa mafunso kwa odwala, makolo a Ana. komanso ogwira ntchito za chipatala.

ZOYENERA KUCHITA?: Tikhala tikukufunsani mafunso okhuza dela lanu la ntchito,m'mene mumapelekera chithandizo, komanso kukambirana mwa padela-dela. Tikupemphaninso kuti tijambule zokambirana zathuzi kuti pakhale chilungamo pa zonse zomwe tikhale tikuyankhulanazi. Zojambulazi tikazitsindikiza komanso tikhala tikulemba.tijambulanso zithunzi malo anu ogwirira ntchito, ngati mungatilore kutero.

ZOTSATIRA ZA KAFUKUFUKUYU?: Zonse zimene tipeze pofufuzaku tizazisunga mwa chinsisi komanso malo otetezeka bwino mpaka pamene tizathere kafukufukuyu. Tizalemba zotsatira za zofufuzazi komanso kuzitsindikiza m'mabuku ndipo maina anu sitizawalemba,ndipo palibe amene azakuzindikireni.

KODI PALI PHINDU KAPENA CHIOPSEZO CHINA CHILLI CHONSE NDIKALOWA KAFUKUFUKUYU?: Mudzakhala muli mukafukufukuyu kwa ka nthawi ndithu,tizayetsetsa kuti tisaukulemetseni pamene muli kutenga gawo mukafukufukuyu, tili ndi chiyembekezo kuti kafukufukuyu azathandiza ndi kupititsa pa tsogolo pothandiza amene ali ndi zilema za clubfoot mtsogolo muno.

KODI NDI NGALOWE NAWO MUKAFUKUFUKUYU?: Kulowa kapena kusalowa nawo mukafukufukuyu ndi chisankho chanu, sizokakamiza ayi.mutha kutuluka nthawi ina iliyonse, popanda kukhuza ntchito kapena ufulu wanu.

Mwakufuna kwanga ndikuvomeleza kulow`a nawo mukafukufuku.

Munthu amene akutenga mbali mukafukufuku posainira _____

Dzina: _____

Date: _____

Mwakufuna kwanga,ndikukulolezani kuti mujambule zithunzi.

Munthu amene akutenga mbali mukafukufuku

posainila: _____

Dzina: _____

Date: _____

Wakafukufuku amene akutenga chilolezo

posainira_____

Dzina _____

Date:_____

Ngati muli ndi mafunso okhuza kafukufukuyu. Chonde lembelani kwa: Sarah Drew, Beit CURE International Hospital, Blantyre, telephone 0997771932

Ngati muli ndi chidandaulo chokhuza kafukufukuyu chonde lemberani ku: COMREC secretariat, College of Medicine, 3rd Floor, John Chiphangwi Learning Resource Centre, Private Bag 360, Chichiri, Blantyre 3, Malawi, **email** : comrec@medcol.mw, telephone 01871911

16. Oral consent and assent scripts for adults and children accessing treatment and those that had been discharged (English and Chichewa)

Exploring the delivery of clubfoot services in Malawi
Agreement to take part in the project (Oral consent script)

We are doing a research project to understand and improve health care for children with clubfoot.

We would like to talk to you and your child about clubfoot treatment and possibly spend time with you to see what it is like for you to look after someone with clubfoot or live with it. We would also like to take photographs of where you live, if you agree to this. Things you say will be tape-recorded so that we can remember what you said. We will also make notes on some of the things that you do which we find interesting. How much of your time you give to this research is up to you.

What we have tape-recorded and made notes on will be written down. We will keep these safe for as long as we need to after the project. What you say and do will be written up into reports, and everyone's names will be taken out so that no one else will know who said what.

Taking part will take some of your time, and you may be speaking about things that might be upsetting. The project may not help you but it may help to improve how health services are run.

Whether you take part or not is up to you. You can stop at any time. Tell the person who you are speaking to if you want to stop.

Do you have any questions about the project?

[**To parent or carer**] Do you voluntarily agree to take part in the project?

[**If yes**] Do you voluntarily agree to us taking photographs of you as part of the project?

[**To parent or carer**] Do you voluntarily agree to let your child to take part in the project?

[**If yes**] Do you voluntarily agree to us taking photographs of your child as part of the project?

[**To child if relevant**] Do you voluntarily agree to take part in the project? Do you voluntarily agree to us taking photographs?

KUCHIZA MATENDA A CLUBFOOT M'MALAWI

Kafukufuku Ofuna Kudziwa Khalidwe Komanso Chikhalidwe Cha Anthu Pa Matenda A Clubfoot.

KALATA YOVOMELEZA KULOWA MUKAFUKUFUKU (ZOKAMBIRANA)

Tikupanga kafukufukuyu cholinga,chathu ndikufuna kuti timvetsetse komanso kupititsa patsogolo ntchito za chipatala kwa Ana amene ali ndi clubfoot.

Tikupemphani kuti tithe kuyankhula ndi Mwana wanu komanso inuyo, zokhuza matenda a kukhota kwa mapazi (clubfoot) chithandizo chachipatala. Tifunanso tidziwe kuti mumamva bwanji,mukamakhala komanso kuyang'anira. Mwana amene ali ndi mapazi okhota (clubfoot)**.** Tifunanso tijambule zithunzi za kwanu kumene mumakhala, ngati mungatilore kuti titero. Tijambulanso mau anu kuti tizikakumbukira zimene takambirana komanso tikhala tikulemba zina zimene mumachita ngati zili zopatsa chidwi.

Zimene tajambula komanso kulemba, tizazisunga malo otetezeka kwambiri mpaka mapeto a kafukufukuyu, zokambirana komanso zimene mumachita, tizazilemba ma buku,ndipo maina anu sazakhalamo tizachotsa,ndipo palibe adzazindikire kuti munayankhula ndi inu.

Zikutengerani nthawi muli mukafukufukuyu, ngati mukutenga nawo gawo. Ndipo ife ofufuza udindo wathu ndi kupititsa pa tsogolo ntchito komanso thandizo lachipatala m'mene likuyendera Osati madela ena.

Ichi ndi chisankho chanu kulowa kapena ayi.mutha kutuluka nthawi ina iliyonse imene mukufuna.ndipo tidziwitseni ngati mukufuna kutuluka.

Kodi muli ndifunso lina lililonse lokhuza kafukufukuyu?

[**Kwa kholo kapena osamalira mwana**] kodi mukuzipeleka mwakufuna kwanu, kuti mutenga mbali mukafukufuku?

[**Ngati Mwavomeleza**] mukuzipeleka nokha mwakufuna kwanu,kuti tikajambule zithunzi za kwanu kumene mumakhala?

[**Kwa mwana ngati kuli kofunika**] kodi ukuzipeleka mwakufuna kwako,kuti ulowe nawo mukafukufuku?