

Changes to everyday-life after surgery

Experiences of caregivers of children with disabilities in rural
Kenya

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<p>Abstract:</p> <p>Disability is a complex phenomenon. Children with disabilities face several obstacles in everyday life. Due to disability, they can face discrimination and exclusion from school and health care services. The disability of the child affects the entire family and therefore these families are more vulnerable to poverty and even exclusion from community. Global pediatric surgeries are performed in low- and middle-income countries like Kenya and these surgeries are proven to be cost-efficient. To our knowledge, the impacts of pediatric surgeries on everyday life of CWDs has not been studied before using qualitative methods. Our partner organization in this thesis was ADRA Finland Foundation, which is a development and relief organization working in different parts of the world. The aim of the thesis was to describe the impact of pediatric surgery on disabled child's and family's everyday-life in rural Kenya. The research method was qualitative, and it was conducted by interviewing caregivers of children with disabilities who have undergone a pediatric surgery performed by a volunteer surgical team by AFF. Inductive content analysis was used to analyze the research data. The inductive content analysis guided the classification of the content of this thesis. The research question emerged from available data: How have the everyday lives of children with disabilities changed after the pediatric surgery? The results indicate that children and their families mainly benefited from the surgeries. Physical health improved, children's participation in daily activities increased, they were more socially accepted and their psychosocial well-being improved. Couple of postsurgical relapses occurred and few children needed new referral. For further research it would be vital to develop different ways to provide sustainable surgical care to CWDs and ensure the continuum of the care provided</p>	
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List of Abbreviations

AFF	ADRA Finland Foundation
CWDs	Children with Disabilities
LMICs	Low- and middle-income countries
NGO	Non-Governmental Organization
PWDs	People with Disabilities
UN	The United Nations
WHO	The World Health Organization

Key Words

Everyday-life, Children with Disability, People with Disabilities, Pediatric Surgery, Global Pediatric Surgery, ADRA Finland Foundation

FOREWORD

We would like to express our gratitude towards ADRA Finland Foundation especially Heimo Lempinen and Peter Segersven, for giving this valuable learning opportunity in the global health and development work field. We would also want to thank Mr. Washington Jalango and Mr. Kevin Awiti for their knowledge and time they shared with us. Without their guidance and help in Homa Bay County, it would have been impossible for us to conduct this research.

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1 INTRODUCTION

It is estimated that over 15% of the world's population lives with some kind of disability and approximately 93 million children live with a moderate or severe disability (World Health Organization [WHO], 2018a; UNICEF, 2013; WHO, 2011). Disability is recognized as a human right and global public health issue. Disabilities are more prevalent in lower-income countries, approximately 80% of the world's disabled people live in developing countries. (WHO 2015) Poverty and disability are linked to each other and poverty increases the likelihood of disabilities through poor living, working and travelling conditions and inadequate health care. Disability leads to lower educational achievements and employment, poorer health, poverty and restricted participation especially in lower-income countries. (WHO, 2015; Groce, 2018; Mitra, Posarac, & Vick, 2013) As stated in the Global Disability Action Plan (WHO, 2015), people with disabilities (PWDs), face discrimination, inequalities in accessing services and multiple violations of their rights as humans. It is time to recognize them as part of our societies and improve the opportunities in everyday day life coping.

Approximately 4,6% of the population in Kenya have some form of disability. The most prevalent types of disabilities are physical, visual, hearing and mental. (The National Coordination Agency for Population and Development and Kenya National Bureau of Statistics [NCAPD & KNBS], 2008). Different factors can cause disability for example, genetic factors which are present from birth, environmental factors which can be present from birth or later in childhood and different forms of injuries (WHO, 2011).

In this thesis the focus is on physical disabilities caused by congenital anomalies, injuries and diseases and on global pediatric surgery. Global pediatric surgery is a cost-efficient way to reduce children's morbidity and lifelong disability. (Sitkin, Ozgediz, Donkor, & Farmer, 2015; WHO, 2016)

The Global Disability Action Plan (WHO, 2015) aims to remove barriers in accessing services. ADRA Finland Foundation has volunteer surgical mission teams who have performed surgical operations for disabled children since 2006 in Homa Bay County, Kenya. This surgical mission has contributed to the "aim to remove barriers to services" for many years.

According to WHO (2015), there is not enough data regarding the needs and services people with disabilities would need. The same report also states that PWD's have unique experiences of what services are needed, but they are often excluded from decision making. Therefore, it is important to hear the opinions and experiences of those who have experienced or are still affected by disability. To our knowledge, qualitative data is lacking on this matter, especially from the point of view of the operated children and their families. The disability of a child affects the whole family.

This master thesis focuses on the everyday-life of children and families living in Homa Bay County in rural Kenya. The aim of the thesis is to gain understanding of the impact of pediatric surgery on the everyday-life of the disabled child and their family. Qualitative research was conducted in Homa Bay County, Kenya by interviewing the caregivers of disabled children who have undergone reconstructive surgery performed by a volunteer surgical team of AFF. Inductive content analysis was used to analyze the research data. The inductive content analysis guided the classification of the content of this thesis. We wanted to find out the perception of the caregivers to get a holistic point of view on how the surgery has affected their dependent child's life. The research question emerges from available data: How have the everyday lives of children with disabilities changed after the pediatric surgery?

AFF surgical team has performed pediatric surgeries in Kenya over a decade but there is no research on the outcomes of these surgeries. This thesis will provide valuable and essential information about these surgeries and hopefully will help them develop their work in the future.

2 GLOBAL HEALTH AND DISABILITIES

Koplan et al. (2009) state that global health aims for health and equity for all and it involves collaborations between different disciplines and transnational health systems. Global health aims for worldwide improvement in health.

According to Croce, (2018) there has been improvement in strategies to include people with disabilities in global health landscapes, but the question remains how to ensure their involvement. There are policies and strategies suggesting on how to continue with that aim, but the action part is still missing. Improved health services were seen as a major contributor in relieving disabilities. However, people with disabilities are more vulnerable and still suffer from poverty and they face difficulties in accessing health services. (Groce, 2018) These exclusions are interlinked, for example, a lack of money may decrease school attendance and poor education can make it hard to find a decent job, which then may deepen poverty (Kuper, Smythe & Duttine, 2018). People with disabilities tend to be excluded from communities and are also overlooked by global health and international development efforts (Groce, 2018). The number of people with disabilities is large and therefore they are becoming into the focus in international development field (Kuper et al., 2018).

People with disabilities are such a diverse group. There are a wide range of impairment types, age, gender and environments. Thus, the relationship between health and disability will not be the same for every individual. The constructs of disability are overlapping, inter-twined and reinforcing due to the complexity of the relationship between health and disability. (Kuper et al., 2018) In Fig 1. the complexity of disability and poor health is presented. Poor health does not inevitably cause disability but occurs in the context of adverse personal or environmental factors that restrain the individual's full and sufficient participation in society on an equal basis compared to others (Kuper et al., 2018). Age is a factor with PWD's that effects on the health and according to the WHO (2011), with age, PWD may experience multiple health conditions simultaneously. In terms of poverty and exclusion, PWD's are more vulnerable to poor health and injuries. (Groce, Kett, Lang, & Trani, 2011; Mitra, Posarac, & Vick, 2013)

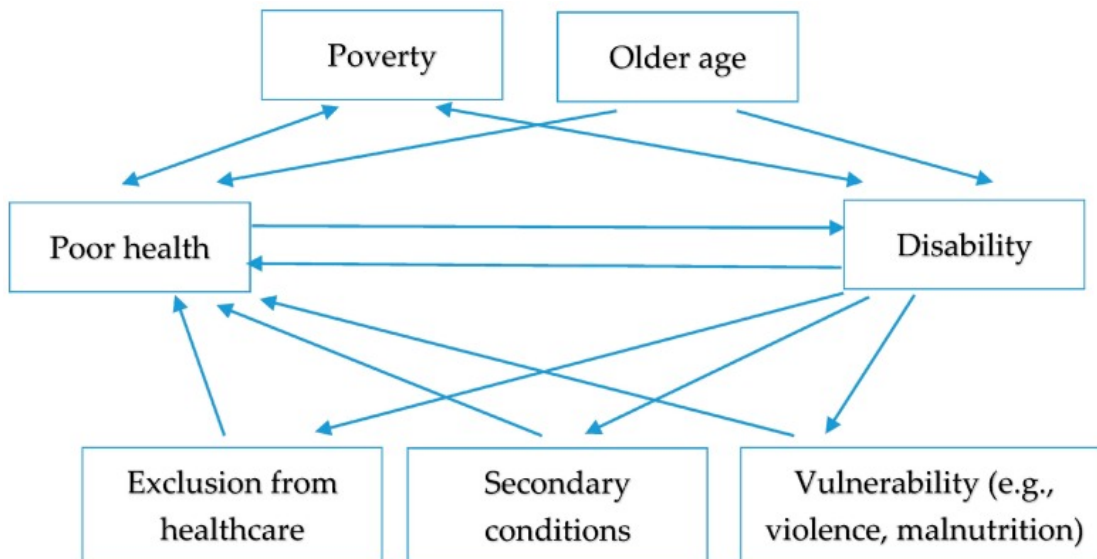


Figure 1. Complex relationship between disability and poor health. (Kuper et al., 2018)

The first United Nations Disability Inclusion Strategy was launched in 2019. The strategy aims to increase the standards of disability inclusion in the UN system. The Disability Inclusion Strategy aims to implement the Convention on the Rights of Persons with Disabilities and The 2030 agenda for Sustainable Development Goal “leave no one behind” by a policy and an accountability framework (UN, 2019).

2.1. Disability Definition

WHO (2011), has defined the term disability in the following; “disabilities is an umbrella term, covering impairments, activity limitations and participation restrictions”. An impairment is an issue in body function or structure then and activity limitation is an obstacle encountered by an individual in performing a task or action. Participation restriction is experienced by an individual in taking part in life situations. (WHO, 2011)

According to the United Nations Convention on the Rights of Persons with Disabilities (2006)

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Approximately 15 percent of the world's population live with disabilities, those people represent the world's largest minority (WHO, 2018b) and according to WHO (2015), 80 percent of these people live in developing countries. Worldwide, PWDs suffer from poorer health outcomes, lower education level and poverty. This is because PWDs experience barriers in accessing services like health, education, employment and transport. (WHO, 2011; WHO, 2015)

There are many causes of disability; it can be prenatal disability caused by diseases, genetic disorders or lack of oxygen during labour. Accidents, infections or illnesses can be reason for postnatal disability. Many forms of disability can impair mobility and movement. (Nair & Sathiyaseelan, 2015; WHO, 2015; WHO, n.d.a) The major causes of disabilities are genetic like inherited diseases, congenital such as different structural anomalies, external prenatal factors like nutritional deficiencies during pregnancy, perinatal factors and postnatal factors like delivery related central nervous system complications and infections but majority of the causes are unknown. (Kaski, Manninen & Pihko, 2012; WHO, 2011) Physical disability is an individual's limitation to function a certain action in everyday-life (Nair & Sathiyaseelan, 2015).

2.2. Congenital Anomalies

Congenital anomalies are increasingly known as a major cause of pediatric disabilities. Burden of morbidity and mortality are substantially caused by congenital anomalies in children in low-and middle-income countries and congenital anomalies often cause emotional and economic harm to the children and their families. (Sitkin & Farmer, 2016) The estimations of congenital anomalies in Africa are limited by the nonexistence of population-based data. However, a research conducted by Wu, Poenaru & Poley (2017) shows the prevalence of congenital anomalies in Kenya was 6.3 per 1000 children. The most prevalent malformations were club foot (2.9 per 1000 children) following with hydrocephalus and hypospadias (0.9 per 1000 children), spina bifida (0.5 per 1000 children), cleft lip and encephalocele (0.4 per 1000 children) and imperforate anus and bladder exstrophy (0.2 per 1000 children) (Wu et al., 2013).

Congenital anomalies can be defined as functional or structural anomalies. Congenital refers to existence at or before birth, they occur during the intrauterine life. Congenital anomalies can be diagnosed prenatally or at birth but sometimes even later in infancy. Cleft lip and palate, clubfoot, hernias, heart defects and anorectal malformations are conditions known as congenital anomalies. Congenital anomalies can be caused by genetic, infectious, environmental or nutritional factors but often the exact cause of the anomaly is hard to detect. (WHO, 2016; WHO, n.d.b)

It is estimated that 303 000 newborns die due to congenital anomalies worldwide. Congenital anomalies can result in a long-term disability which can affect the individuals and families, societies and healthcare systems. Structured anomalies can be corrected with a pediatric surgery. (WHO, 2016; WHO, n.d.b) According to NCAPD & KNBS (2008), 14% of disabilities in Kenya are caused by congenital anomalies.

The identified congenital anomalies in this research were club foot, spina bifida, congenital constriction ring, tumor/lump and hernia. Fig 2. present a child who suffers from congenital anomaly called club foot.



Figure 2. Club foot. Photographer Paula Tapaninen. Kenya 2019.

2.3. Other Causes for Disabilities

A big part of disabilities is caused by different injuries. Global and national data estimate that 15% of the disabilities are caused by injuries. Disabilities can be results from road traffic accidents, violence and burns. Different forms of disabilities caused by injuries can be for example partial or complete amputation of a limb, physical and or cognitive neurological impairment, paralysis and physical limb deformation. (WHO, n.d.a) The results from NCAPD & KNBS (2008) indicate that 12% of the disabilities in Kenya were caused by accidents. Falls, road traffic accidents, domestic and general burns were among the listed accidents causing disabilities.

Ineffective burn and fracture treatments leave people suffering from disabilities in LMICs, some of these would be preventable by appropriate care delivered on time (Ozgediz, Jamison, Cherian, & McQueen, 2008). Some of the children identified in this thesis were two children suffered from burn injuries, two of them had been involved in a road traffic accident. Two of the reasons were caused by accidents but the type of the accident was unclear.

The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly. Different health conditions can lead to disability. (WHO, 2011) According to NCAPD & KNBS, (2008) the leading cause for disabilities in Kenya was diseases but the types of diseases were not indicated in the report. However, according to Institute for Health Metrics and Evaluation (n.d.), the two leading determinants for disability were low back pain and neonatal disorders in 2017.

The environment where people live can also have an effect on the prevalence of disability. Poverty, poor health (including access to health care), malnutrition and unsafe living conditions are associated with health conditions and disability. (WHO, 2011)

According to WHO (2011), infectious diseases can lead to disability or may be defined as a disability. Osteomyelitis is an infection which can cause disability and it was one of the reasons behind a disability in this thesis as well. Chronic osteomyelitis has physical, social and psychological impact on one's life. Osteomyelitis is often associated with poverty; the patients can hardly afford surgical treatment or antibiotics and such patients will

never fully recover from it. (Baldan, M., Gosselin, R. A., Osman, Z. and Barrand, K. G., 2014) If osteomyelitis is left untreated it can cause chronic disability and unnecessary harm to the affected person (Moon, Perry, & Beak, 2012).

3 DISABILITIES IN KENYA

About 10 percent of Kenya's population suffer from some form of disability and the largest form of disability is mobility limitations (Global Disability Rights Now!, n.d.) but according to NCAPD & KNBS (2008), only 4.6% of Kenyans experience some form of disability. A study on empowerment in persons with disability, conducted in the area of Homa Bay County, concluded that the most common disabilities mentioned were physical, mental disability, multiple disability and visual impairment. Not so common but mentioned were also hearing impairment, blindness, paralysis or deformities of the limbs, epilepsy, deformities of the back, Cerebral Palsy and facial disfigurement. (Angwenyi & Barongo, 2010)

The causes of disability are not always known. Approximately 15% of PWDs in Kenya do not know the origin of their disability. Known causes for disabilities are accidents, environmental factors like diseases, lack of immunization, pollutants, congenital factors, other causes like wrong medication, family planning and conditions that started gradually. (NCAPD & KNBS, 2008) The causes for disabilities in Homa Bay County area were accidents, diseases, lack of immunization and medication and proper health care services example unprofessional birth attendants, also witchcraft was mentioned (Angwenyi & Barongo, 2010).

People with disabilities are not treated equally in Kenya (Bunning, Gona, Newton & Hartley, 2017). Often communities may view PWDs as a burden and un-presentable (Angwenyi & Barongo, 2010). According to NCAPD & KNBS (2008), 65% of the people with disabilities consider the environment as a major problem in their daily lives. People with disabilities tend to be treated in a different way than people without disability and attitudes they face can occur as a bigger problem than the medical problem they are coping with (NCAPD & KNBS, 2008). A study conducted by Bunning et. al. (2017), suggested that disability is believed to be caused by inappropriate family relations, supernatural forces, by witchcraft, demons, by the will of God and also by biomedical factors.

Challenges associated with disability were found to be burden of care, caregivers stress including financial, as well as psycho-social and physical barriers to include the disabled into the families or community (Bunning et al., 2017).

Among people with disabilities, 90% felt they are part of the family and 83% felt they are involved in the family conversation. More than a half of PWDs are assisted by family members in everyday-life. Up to 75% of PWDs attended family events and the involvement increased with education attainment. (NCAPD & KNBS, 2008)

The majority of PWDs do not participate in family occasions because of prejudices and stigma. There is a belief that disability is a curse and shame to the family, in those case PWDs are isolated, neglected and even abused. Disability is often considered a burden for the family and it is connected to poverty. There are communities in Kenya where PWDs are abused and used in crime, trafficking drugs or drinks and in witchcraft. PWDs in rural areas faced more obstacles considering accessibility to education, work and healthcare and rehabilitation compared to those in urban areas. (NCAPD & KNBS, 2008)

3.1. Disability and Human Rights

The United Nations Convention on the Rights of Persons with Disabilities is a human rights instrument and it adopts a broad categorization of persons with disabilities and promises that all persons with different kind of disabilities must enjoy all human rights and fundamental freedoms (United Nations, 2006).

The general principles on the Convention on the Rights of Persons with Disabilities (United Nations, 2006) states following:

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons, non-discrimination, full and effective participation and inclusion in society, respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, equality of opportunity, accessibility, equality between men and women, respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Kenya was among the first one who signed the Convention on the Rights of Persons with Disabilities (CRPD) in 2007 and in the year 2010, the National Kenyan Constitution recognized disability rights (Global Disability Rights Now!, n.d.; Kenya National Commission on Human Rights, 2016). The Kenya National Commission on Human Rights is one

of the major institutions observing the implementation of the CRPD (Kenya National Commission on Human Rights, 2016).

Constitution of Kenya, 2010 under Article 27(4) (Kenya Law Reform Commission, n.d.), provides:

The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth.

There are many organizations in Kenya that work to improve the lives of people with disabilities. The United Disabled Persons of Kenya is an umbrella organization bringing together many different organizations for disabled people. The main target of the umbrella organization is to address disability awareness-raising, legislation, advocacy and equality. (International Labour Organization, 2009) Other organizations working to improve the life of PWDs are for example, Kenya Programmes of Disabled Persons, Kenya Union of the Blind, Kenya Association of the Intellectually Handicapped, Autism Society of Kenya and The Association for the Physically Disabled of Kenya (APDK) (International Labour Organization, 2009).

3.2. Abuse and Violence

Reports indicate that children with disabilities were more often victims of violence than non-disabled children (Stöpler, 2007; WHO, 2015). An estimated 135 000 children with disabilities were found to have experienced high levels of violence, severe forms of physical and sexual abuse, which is 15- 20% of the Kenyan children living with a disability. (Stöpler, 2007) Also, children with disabilities were reported to be particularly vulnerable to malnutrition (Kuper et al. 2014).

According to Ahern et al. (2018), children with disabilities were more vulnerable to abuse in institutions than non-disabled children. Even though they needed more support, facilities for children with disabilities often had less staff and resources available. Life threatening conditions and practices were found in a couple of institutions for children with disabilities. Also, the facilities didn't always meet the standards, poor water and sanitation and overcrowding was found. (Ahern et al., 2018)

As a result of violence, some cases of children with disabilities being killed or dying were also recorded (Stöpler, 2007). According to Ahern et al. (2018), infanticide of children with disabilities is not rare to Kenya but there is no data about it. Children under 1-year-old face four times greater risk of being murdered than any other age group (Ahern et al., 2018). Infant mortality rate, the probability of dying between birth and age 1 per 1000 live births, was 35.1, and the same number, under five mortality rate, was 48.7 in Kenya in 2015 (WHO, 2018b) When it comes to deaths of children with disabilities, cases often went unrecorded. For example, any child can die at birth or when they are discharged from the hospital, but when following the background, it has been discovered the child was disabled and that is why the family killed that child. (Ahern et al., 2018.)

Among children with disabilities malnutrition was very common. Malnutrition may cause disability and children with disabilities were more vulnerable to malnutrition than their siblings. This might indicate that disability is associated with malnutrition rather than just poverty. Compared to children without disabilities, feeding difficulties were reported more among children with disabilities. Since children with disabilities were less likely to attend school, so therefore they were also excluded from school feeding programs. (Kuper et al., 2015) According to Ahern et al. (2018), children with disabilities living in institutions also suffered from malnutrition, especially the lack of protein in their diet.

3.3. Stigma and Social Life

Lack of support and information from health professionals and adequate medical care were felt to add the stigma and the pressure to abandon a disabled child. Mothers who refused to give up their disabled child suffered from sadness and feelings of loneliness due to the fact that they were often excluded from their families and communities. (Ahern, et al., 2018) According to Ahern et al. (2018), 72% of the women who kept their disabled children were rejected by their communities and 20% said that they were abandoned by the child's father after he knew that the child was disabled. Another study shows also that when the child with disabilities is born, caregivers of the child will feel like they've lost their dreams and aspirations and this is because in African societies, caregivers expect their children to provide them during old age. Future becomes uncertain when children with disability is born. (Gona et al., 2011)

Studies showed that parents of children with disabilities were stigmatized and accused of being cursed or bewitched. According to Ahern et al. (2018) especially mothers were often pressured to kill their babies or abandon them. In Nairobi, 37% of the women who kept their disabled child were pressured to kill her child, however in the rural areas of Kenya, it was up to 57%. Mothers who hold on to their children were pressured to leave their children in an institution. The research showed that children in institutions are at risk of suffering inhumane and degrading treatment and also torture. (Ahern et al., 2018)

Feelings of guilt were expressed by the caregivers about their child's disability that led to feelings of helplessness. Some caregivers felt that hospital staff didn't understand their emotional stress or that their need for information wasn't met. Caregivers of children with disabilities reported experiencing frustration as they were delayed in hospital without any medical attention or advice. (Gona et al., 2011)

The report from Homa Bay County area states that the challenges PWDs and their families face are discrimination and they look down on PWDs. Communities do not accept the PWDs. (Angwenyi & Barongo, 2010) According to UNESCO (2010) having physical and mental impairment is considered as a stigma that is commonly a basis for exclusion from society and school. Therefore, due to that stigma, parents are less likely to send their children to school (UNESCO, 2010; Kristensen, Omagor-Loican, Onen, & Okot, 2006).

The negative attitudes can influence the psychosocial wellbeing of children with disabilities. The psychosocial wellbeing of children in East Africa is challenged by many different features like poverty, limited access to services, abuse, neglect and HIV, not to mention additional challenges what children with disabilities may face. In general, psychosocial wellbeing can mean emotional, spiritual and cognitive resources what individuals and communities have. (East African Community, n.d.)

Studies show that disability predicts lower social participation and poorer psychological well-being (Hsieh & Waite, 2019). Children with disabilities have lower life satisfaction and poorer identity formation compared to children without disabilities. Gender differences were observed on psychological well-being. Compared to males, females had lower life satisfaction and poorer mental health. (Abubakar et al., 2013)

3.4. Access to Services

Disability is an extremely diverse concept, some health conditions associated with disability require extensive health care services and others do not. People with disabilities have the same needs for general health care services as everyone else but people with disabilities seek more health care services than people without disabilities and thus, they have greater unmet needs. (WHO, 2018a)

Disability can lead to difficulties in accessing different services like education, employment, health care, housing and transportation. The barriers in accessing services may lead disable people to poverty and lower standards of living. PWDs have more unmet healthcare needs and not the same access to health care services and that is why they can experience worse levels of health than people without disabilities. (WHO, 2015.)

According to WHO (2018a), PWDs require more health care services than people without disabilities and according to Kuper et al. (2015), only 15% of CWDs received rehabilitation. The services PWDs use are local health care centers, traditional doctors including witch doctors, orthopedics, chiropractic, rehabilitation and religious organizations. PWDs mention they are not treated as normal people by the healthcare workers because they are not taken seriously. (Angwenyi & Barongo, 2010)

More than half of the PWDs reported the access to transport as a big problem, also more than half had a problem to access information. Ability to access health services was challenging since 69% of the PWDs stated that they cannot access health services. Only 29% received rehabilitation services, but 75% were aware of the services. Up to 81% reported they had no problem in self-care and 2% of PWDs were confined to bed. (NCAPD & KNBS, 2008) PWDs and their families told they would appreciate specialized doctors, schools and rehabilitation centers to help PWDs to work and make basic income (Angwenyi & Barongo, 2010).

3.5. Access to School and Work

Disability can lead to difficulties in accessing different services like education and employment (WHO, 2015). People with disabilities don't have special schools or help from

the community (Angwenyi & Barongo, 2010). Among children with disabilities sponsored by Plan in Kenya, 26% were not attending school and the evidence showed that children with disabilities were less likely to attend formal education compared to children without disabilities. According to UNESCO (2010), access to school may be jeopardized by the inability to walk the distance to school, especially in rural and slum areas. The cost of obtaining transport is a factor that may limit the access to school. The leading cause for not attending school among CWDs was having an impairment. Also, the study showed that children with disabilities were at a lower level of schooling for their age compared to children without disabilities. (Kuper et al., 2014)

Only 67% of PWDs reached primary level of education and 19% attained secondary level, special schools were only available for 2% of those attending primary level of education. 7% of the PWDs have been denied the acceptance to school because of their disability. Lack of money was the reason to leave the school for 39% of PWD and 6% of the PWDs dropped out of school because of the disability. (NCAPD & KNBS, 2008)

A quarter of the PWDs do not work and one third of PWDs work in their family business. Reasons why PWDs stopped working were the disability itself, some sort of illness and termination and retrench. (NCAPD & KNBS, 2008)

3.6. Disability and Poverty

Poverty is commonly associated with disability and just like disability, poverty is a multi-dimensional phenomenon that is difficult to measure. The association between poverty and disability is like a two-way street; disability can lead to poverty but also the poverty can be the cause of disability. (Mitra, Posarac, & Vick, 2013) According to Mitra, Posarac, & Vick (2013) and Sen (2009), disability may cause additional expenditures to individual and household such as health care expenses, transportation, medication, assistive devices and personal care and thus to gain the same standard of living, disabled person will need more income than a person without disability.

PWD's face more social and economic disadvantages compared to people without disabilities. The major reason for economic burden resulting from disability can be loss of productivity related to reduced capability to work or educate CWDs and the loss of taxes

and productivity can affect the country's economy. The non-economic costs like stress and isolation from society are difficult to calculate. Many of these direct and indirect costs could be reduced by developing more inclusive settings for PWDs. (WHO, 2011) According to N'Dri et al. (2018), families of children with disabilities face many negative factors in society such as poverty, poor health and negative impact in social life. The most common reasons for not seeking treatment were lack of awareness and money (Angwenyi & Barongo, 2010; Kuper et al., 2015).

Caregivers of children with disabilities also expressed that poverty made it harder to take care of their children properly (Gona et al., 2011). Mothers of children with disabilities also reported that they can't get anyone to look after their child while they were working so without the support of government, charity, community or a family, the survival of the mothers of children with disabilities, it is challenging (Ahern et al., 2018). Childhood disability may lead to lower living standards and poverty through negative impact on education, employment and income. In addition, increased expenditures that are related to individual's disability may cause poverty. Among adolescents with disabilities, school attendance may be jeopardized and thus lead to restricted employment opportunities and reduced earnings in the future. (Mitra, Posarac, & Vick, 2013)

3.7. Disability and Pain

Pain has been defined in the following way; "An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." Chronic pain is often accompanied by functional impairment causing suffering and economic burden to individuals. 20 percent of people around the world suffer from chronic pain. Chronic pain is defined as pain that recurs more than three months. (The International Association for the Study of Pain, 2019)

The experiences of disability and pain are commonly closely tied or merged and are not easy to separate. People with physical disabilities described pain as a part of daily living that affected their lifestyle decisions (Dudgeon, Gerrard, Jensen, Rhodes, & Tyler, 2002).

Chronic pain among adolescents with disabilities is affecting in other important areas of life such as sleeping and therefore, it had substantial impact on the adolescent's lives. Children with functional disabilities that suffered from chronic pain also reported having depression. (Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001) Individuals living with physical disabilities and chronic pain are suffering from sleep problems (Vega et al., 2019). According to Ashworth, Davidson, & Espie (2010), people who suffered from chronic pain and their sleep was compromised by pain, were younger and reported more pain, pain-related disability, depression and pain-related anxiety.

According to Miró et al. (2017), there is a relationship between pain extent and adolescents with physical disabilities and chronic pain. In their study, almost 91 % of the participants reported having pain at more than one distinct location of their body (Miró et al., 2017). The same results were reported from another study by Dudgeon et al. (2002), where participants characterized pain as plural, meaning that it has multiple locations.

Experience, learning and culture shape the relationship between pain and ethnicity. Different cultures and languages have their own way of expressing pain. Some cultures value withdrawing their emotions in the presence of pain and others display emotions in an exaggerated way. (Peacock, & Patel, 2008)

4 EVERYDAY- LIFE IN HOMA BAY COUNTY

All human beings have everyday lives and everyday routines. Everyday-life refers to something that happens day after day and it contains routines. These routines are attached to different cultures and environments and can include routines like going to work or school, cooking food, sleeping, talking to neighbors, watching television, listening to the radio. (Felski, 1999; Inglis, 2005) According to Heller (1984), everyday-life is part of every society and in every human being, but the content and structure of everyday-life is not the same for everyone in all societies. To understand the meaning of everyday-life, one needs to understand how the society and the structures of it are organized (Inglis, 2005). Everyday-life contains a specific concept of time but it is not tied to any specific space and can happen at home, at work or outside (Felski, 1999). Individual's age plays a major role in deciding what assigned role a person can perform in a tribe or even in a family (Heller, 1984).

4.1. Homa Bay County

Homa Bay County is located in Nyanza province in Western Kenya, next to Victoria lake. It is one of the poorest counties in Kenya. Kenya has extremely rich ethnic diversity. Luo people are the third biggest ethnic group in Kenya (IES, 2019; Karvinen, 2009). In Kenya, Luo people can be found along the shores of Lake Victoria in Western Kenya. Most of the tribe is scattered all around the Nyanza province. (Nyabade, 2012)

The population of Homa Bay County in the year 2015 was 1,101,901 of which 52 percent were females. Homa Bay County has the biggest household size of 4-6 members in Kenya. It has a child rich population, where 0-14 years of age constitute 48 percent of the total population. Eleven percent of the Homa Bay residents have no formal education. Only 11 percent have a primary education and 21 percent of those have secondary level or higher of education. Work for pay is less than 25 percent for those with a secondary level of education or above. This is 50 percent less than it is in Nairobi. (Kenya National Bureau of Statistics & Society for International Development – East Africa [KNBS & SID], 2013)

In the homes of Homa Bay County, the majority of the houses have earth floors; only 24 percent have cement floors. Up to 82 percent of the households have mud- wood mixed walls. Firewood is the main source of energy for cooking. Out of the households, 84 percent use firewood and 13 percent use charcoal. Less than one percent use liquefied petroleum gas. Electricity is used only in three percent of the households as their main source of lighting. (KNBS & SID, 2013)

Only 28 percent of residents of Homa Bay County use improved sources of water, the rest of the people use unimproved sources such as ponds, dams and unprotected wells. Also, the use of improved sanitation is lower than national level; only 42 percent of residents in Homa Bay County use improved sanitation. (KNBS & SID, 2013)

The HIV prevalence in Homa Bay County is 20,7 percent which is more than 4 times higher than national level. In Homa Bay County, among children aged 0-14 years, new

HIV infections were the highest at national level; in year 2017 there was 700 new HIV infections among this group. Homa Bay County is also the leading county when it comes to AIDS related deaths among children aged between 0-14 years. (National AIDS Control Council, 2018)

4.2. Luo-People

Among Kenyans, including the Luo-people, the family is seen as the most important priority for an individual and is a source of pride. Eventually, most Kenyans are expected to get married and raise a family. In most families in Kenya, the family unit usually includes the extended family. (IES, 2019) Cambridge Dictionary (Extended family, n.d) defines, extended family following, “a family unit that includes grandmothers, grandfathers, aunts, and uncles, etc. in addition to parents and children”. Among Luo-people, children are highly valued and the ideal family size 24 children according to most of the respondents. Luo men can marry more than five wives thus families tend to be large numbered. (Nyabade, 2012)

According to Karvinen (2009), the descendants of Luo- people are influenced by traditional Luo-culture and beliefs but also features of Christianity. The culture of this area goes through a transformation chapter where there are features of traditional Luo- culture and elements of Christianity. Globalization has also found its way to the lives of Luo-people; new beliefs, ideologies and products has broken the cohesive culture. (Karvinen, 2009)

In the rural areas of Kenya, gender roles and responsibilities are strong and well defined. Men are supposed to provide for the family financially and they are considered as the head of the household. The responsibilities of the women are taking care of the household and children. In the rural parts of Kenya, such as Homa Bay County, there is a lack of modern appliances, most of the houses do not have running water or electricity, therefore women are responsible for carrying water and firewood. Some women might also engage in paid labor outside their own household. (IES, 2019)

Farming, taking care of livestock and fishing are the main livelihoods for Luo- people. The closeness and access to Victoria lake has provided lots of opportunities to Luo- people even though the tribe is one of the poorest in Kenya. (Karvinen, 2009)

The majority of Kenyans identify themselves as Christian and in Kenyans life, religion plays a major role. Kenyans visit their place of worship to practice their religion but also to socialize with friends, family and other acquaintances. (IES, 2019) Religious coping methods can relate to better or poorer well-being in everyday-life and it is known that religion has an important role in one's everyday-life coping (Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl, & Prigerson, 2006).

5 SURGICAL MISSIONS

It is estimated 67%, approximately 4.8 billion people do not have access to surgical care worldwide, including 1.7 billion children (Alkire et al., 2015; Mullapudi et al., 2019; Sitkin & Farmer, 2016) and in sub-Saharan countries that number is 95%. Surgical missions deliver a substantial amount of the surgical volume in LMIC and they provide direct care delivery methods. The value of these missions is vital in terms of improving the access to surgical care to those most vulnerable. (Carlson et al., 2015; White & Close, 2016) Surgical missions can deliver short term care, but they do not address the long-term challenges presented in LMICs. That is why, developing and sustaining domestic pediatric surgical capacity would be essential. (Sitkin & Farmer, 2016; Wright et al., 2019)

5.1. Global Pediatric Surgeries

Global pediatric surgeries represent so far successful mechanism to provide adequate care to those in need in LMICs and they are an essential component of global health (Sitkin & Farmer, 2016; Wright et al., 2019). Inadequate surgical care can result in chronic disabilities which can cause unemployment which intern, can be a burden to affected families and communities (Moon et al., 2012).

Pediatric surgeries are done to reconstruct congenital anomalies and other physical deformations in children including cleft lip and cleft palate repairs, club foot, spina bifida,

inguinal hernia repairs and to treat injuries such as burns and fractured bone repairs. Adequate surgical care can reduce acute and chronic suffering of children. (Mullapudi et al., 2019; Sitkin & Farmer, 2016)

5.2. Adra Finland Foundation and Surgical Safari

Partner organization in this thesis was ADRA Finland Foundation. AFF is development and relief organization working in different parts of the world and in Finland. It is part of an international relief agency network that has been operating since 1956. ADRA International is an organization with consultative status to the UN since 1977. AFF's objective is to empower individuals and societies. In Kenya, it has had activities since the 1990s. Healthcare, education, the development of industries and status improvement of persons with disabilities are the focus areas in Kenya. AFF works in partnership with Comid Kenya (Community Initiative for Development) by supporting their Livelihood project. (ADRA Finland, n.d)

According to executive director of AFF (personal communication October 2018): In the last 11 -12 years, AFF has performed over 1200 surgeries for children with disabilities in Kendu Adventist hospital and Baraton. The operation theatre was funded by Ministry for Foreign Affairs of Finland. The surgical missions are performed by voluntary workers such as surgeons, nurses and physiotherapist, in so called "surgical safaris". The voluntary workers take part in postoperative care as well. The rehabilitation is taken care by local physiotherapist who works in nearby District Hospital of Kabondo. The physiotherapist is employed by Kenyan government. Finnish surgeons organize workshops for local physicians and nurses in the past. Global surgery courses have been arranged for Finnish surgeons.

6 THE AIM AND RESEARCH QUESTION

The aim of the thesis is to gain understanding of the impact of pediatric surgery to disabled child's and family's everyday-life in rural Kenya.

The research question is:

How the pediatric surgery has affected the everyday- life of children with disabilities and their families?

7 METHODOLOGY

For our master thesis, we chose qualitative approach as research method. Qualitative research aims to interpret different activities, experiences and cultural phenomena from the point of view of people who are the target group. Qualitative data collection methods can include participant observations, collection of documents, photography, films, interviews and recording of interaction. (Flick, 2004; Creswell & Creswell, 2018)

Data collection can be interviews, observations and group discussions. An interview can include open, general and detailed questions. Most interviews which are used to collect qualitative data are semi-structured. It is important that the informants can talk freely but still within the topics to answer the phenomena. The interview can be developed during the data collection phase when more understanding of the topic is already gained. (Moser & Korstjens, 2017.) For this master thesis, we chose theme interview for the data collection method.

There are different methods to conduct qualitative data analysis. We used thematical qualitative content analysis which can be used to analyze verbal, written or visual messages. The outcome of the content analysis can be categories or themes which are describing the phenomenon. Content analysis is divided to inductive and deductive analyzing methods and it is used to describe qualitative and quantitative data. (Elo & Kyngäs, 2008) For our research we use inductive content analysis.

Globally, quantitative research has been used to measure the financial benefit of global pediatric surgeries, but qualitative research has not been conducted to gain the experiences of these people whose everyday lives are affected by these surgeries. Theme interview highlights individual's interpretations about phenomena, the significance that is given to these phenomena and how these significations are born in interactions (Hirsjärvi & Hurme, 2008). Therefore, theme interview allows us to get the valuable experiences

from the people who hold personal knowledge of the phenomenon. Disability is a phenomenon that affects the entire family and by using theme interview as data collection method, the unique experiences of these people is gained.

7.1. Theme Interview

According to Hirsjärvi & Hurme (2008), theme interview is used to study different phenomena and seek answers to various questions. The theme interview proceeds using essential themes that are chosen in advance and also by using defining questions concerning the chosen themes. The advantage of the theme interview is that in the interview, the interviewer may ask defining additional questions according to the answers.

The purpose and the aim of the research are the defining factors when using theme interview, the questions must be composed finding meaningful answers. The chosen themes are founded on the research framework. (Hirsjärvi & Hurme, 2008)

The questions for the interviews were composed to answer our research question (Appendix 1.). The themes for the questions came from the research framework. Also, when composing the questions, we had to take into consideration our cooperation partner AFF's concerns. Before we started the interviews, the questions were asked from Kenyan students who lived in Homa Bay County and therefore understood the culture. Minor modifications were made after the feedback from the local students. The questions were open ended questions and were carefully considered to respect the privacy and culture of the informants. Follow up questions were made to specify the experiences of the caregivers.

Concerning the background data and conducting the research, there are several researches about the global pediatric surgeries, but we could not find any qualitative data how children with disabilities experienced their everyday-life after the surgery. Therefore, the questions are defined by theoretical framework and our own expertise. The questions were confirmed by our supervisors. In Fig.3, the process of creating interview questions is presented.

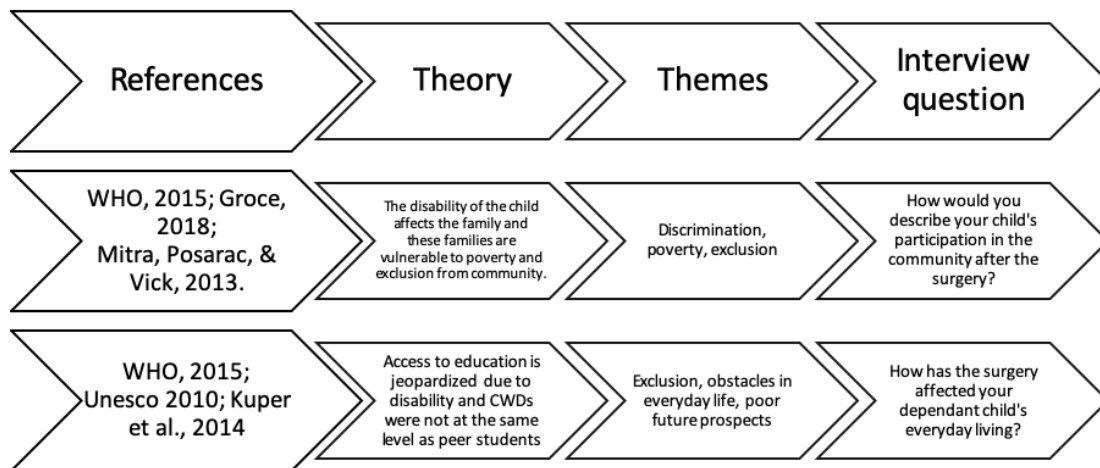


Figure 3. The process of creating interview questions (2019).

7.2. Inclusion Criteria & Sample

Our aim was to generate a sample which allows us to understand and conduct the results of the process of interest. In a qualitative sampling plan, we need to describe how many interviews we need to conduct to be able to produce rich data. The sample size in qualitative research is usually small and informants are sampled deliberately to include variety of settings to obtain diverse data. The sample will alter during the research depending of the questions raised during the process. The sampling plan is accurate if the selected setting and informants provide understanding about the phenomenon of the study. Sampling is also dependent on time, accessibility, different stakeholders and vulnerability of the informants and it is important to describe the details of the context to enable the reader to make a transferability judgement. (Moser & Korstjens, 2017)

We decided to interview not only parents of the children but also their caregivers. As stated in the section 4.2 Luo-People, the family structures are diverse, and children may live together with their grandparents or other relatives which we further refer as caregivers. For the same reason the children are referred as dependent children.

We chose to interview the caregivers of the children who had had the surgery instead of the children because interviewing children would change the focus of the study. It would

be interesting to hear the experiences of the children also, but the outcome would be different and also the focus of the thesis and data collection method would have to be reconsidered. We believed that the caregivers would be more outspoken to give us the whole experience. Furthermore, we desired to hear the experiences of the caregivers since the child's disability affects the whole family.

Our inclusion criteria were the children who have undergone the pediatric surgery performed by AFF team and exclusion the disabled children who did not undergo the surgery. The informants were chosen by Comid Kenya and the surgeries were performed between the years 2012 and 2018, because the team held the information and the locations of the patients from those years. The cases were selected randomly, there was additional wish not to choose the successful cases only. Age, gender or the operation of the dependent child did not have an affect on the inclusion process. It was voluntary for the informants to participate. The original idea was to choose 3 interviews per year within five years to have 15 interviews but locating and reaching the informants appeared challenging, so they were chosen by their willingness to participate. Altogether, 16 interviews were conducted. The informants were mainly parents but some of them were extended family members. In few cases the dependent child was present during the interview. One informant refused on the day of the interview for an unknown reason.

7.3. Data Collection

We finalized research plan in February 2019 and before that the interview questions were presented to the supervisors, peer students and AFF and advices were taken. We obtained the research permit from Research Ethics Committee of the University of Eastern Africa Baraton. AFF had documents and identification details of all the children who have undergone the surgery, that helped us and the Comid Kenya to locate the families and caregivers who could be interviewed.

We used qualitative methods to study the informant's experience how the everyday lives of disabled children have changed after the pediatric surgery. For the research, we interviewed caregivers of children with disabilities who have undergone a pediatric surgery. The interviews were individual theme interviews. The whole interview process took place in Homa Bay county and the interviews were scheduled prior to the visit. We interviewed

2- 5 caregivers per day and the interviews were conducted in five days. In total, 16 caregivers were interviewed. The number of interviews was dependable on the location and if the informants were available on the day prior scheduled. The houses were located within 50-100 km from our station and we moved with one vehicle and sometimes by foot. The area was sometimes difficult to reach as well as the families due to poor road conditions and lack of communication options.

The process started with presenting our team, the aim of the study and then we continued with the voluntary informed consent and it was asked in writing. The aim of the study was presented by the interpreter in Luo language. Out of the 16 interviews, 15 were carried out in Luo-language and one was carried out in English. The interviews were recorded using two different recorders. All the interviews were transcribed in verbatim by the Comid Kenya. The interview was interpreted by local men Washington Jalango and Kevin Awiti, both working for Comid Kenya in partnership with AFF. The use of recorder, dates and places of data collection, notes and observations were documented and kept safe to ensure confidentiality.

One interview took approximately 30 minutes to 1 hour, some informants were very eager to share the information and some families were reserved. The recorded part took from 6 minutes to 20 minutes. We met the informants mostly in their homes but sometimes the interviews were scheduled in other places such as local chiefs camp or on school premises.

Additional data such as exact year and procedure of the surgery were confirmed from the patient files that Comid Kenya possessed. Before leaving from Kenya we had a final meeting where we went through all the cases and decided for the timetable for the transcriptions. Transcription were made using the recordings and notes that were taken during the interviews. The quality of the transcription was ensured by taking notes but also by using two recorders to affirm the rightfulness of the words and sentences. Even though one interview was conducted in English language, all the transcriptions were conducted by Comid Kenya to ensure consistency. The example of the transcribed interview is presented in appendix 3.

7.4. Content Analysis

Content analysis is a data analysis method that means organizing the data, reading and looking for themes, patterns and concepts (Moser & Korstjens, 2017). By describing the data and examination of the data it can be labelled and clustered to preliminary categories. After that similar categories can be formed and named using content-characteristic words. It is also important to identify the missing information during the data analysis and in case found, continue to reanalyze the data. (Elo & Kyngäs, 2008; Flick, 2004 Moser & Korstjens, 2017). Replicable findings should be a result of content analysis and that is the most important role of reliability (Flick, 2004).

In this thesis, we used inductive content analysis which was implemented by using the methods mentioned above. In the first phase, the data was organized using inductive reasoning that was guided by qualitative content analysis by protocol of Elo & Kyngäs (2008). The transcriptions that were translated by Comid Kenya, were read several times and after that we underlined different impressions and reread the transcriptions again looking for main themes and information regarding the research question. Following this we created the preliminary themes and organized the information on a preliminary table. There were different content analysis process models and tables described by various researched and we decided to implement the model by Jokelainen, Turunen, Tossavainen, Jamookeah & Coco (2011). The model was introduced to us by our thesis supervisors. We modified the model to display the research findings from the interviews. We included verbatim, reduced impressions, sub-themes, generic themes and main themes. After creating the figure, we reread the data to identify any new information and we reorganized some data and sub-themes. We also identified the information which did not fall into any category to ensure all the information was analyzed. The complete data analysis process is shown in appendix 2. and the following Fig. 4 is an example of the abstraction process.

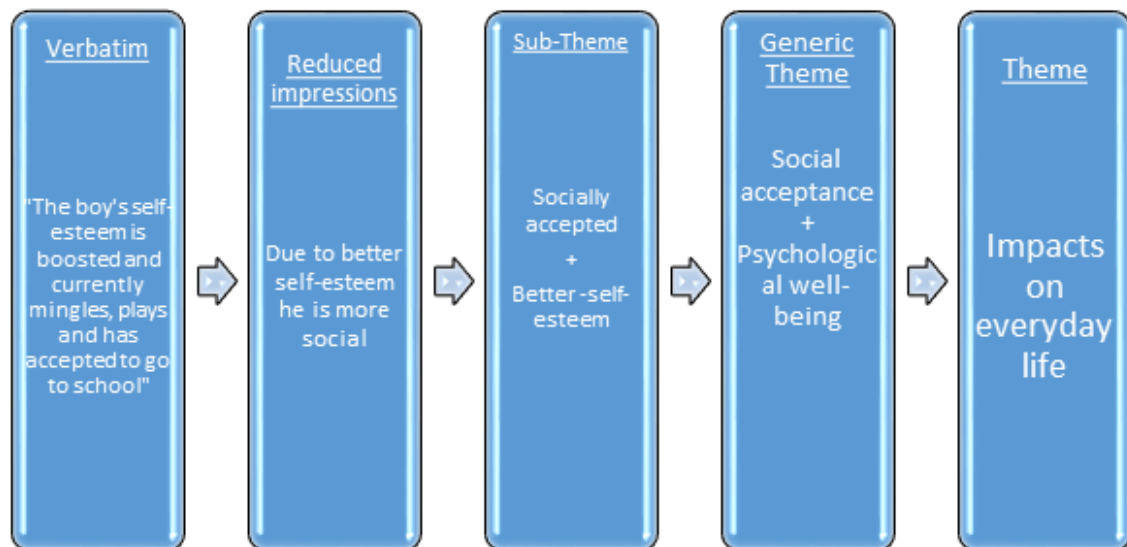


Figure 4. Example of the abstraction process (2019).

8 RESULTS

After careful analysis of the data, we grouped the information into three different main themes. The main themes are presented as follows.

- 1) The impact of the surgery to dependents life
- 2) Participation
- 3) Future perspectives

The research question is; How the pediatric surgery has affected the everyday- life of children with disabilities and their families?

8.1. The impact of the surgery to dependents life

The caregivers noticed many changes in their dependent's life after the surgery. The major ones were changes in physical well-being, daily activities, social acceptance and psychosocial well-being.

The caregivers stated that there were improvements in health and sleep, improvement in moving around, they experienced the children were more independent and were able to perform self-care, the children had more energy and they could participate in household chores. The children were able to access school and play. They did not face discrimination after the surgery, they had more friends and they were accepted socially and by the community. Self-acceptance, self-esteem increased among the children and mental health was experienced better after the surgery.

“He can mingle, play football and even run though I do not like him playing football”

8.1.1. Physical well-being

Physical well-being was related to pain, performance within the house and outside the house. The caregivers were relieved that the surgery helped their dependent child in multiple ways. Many parents stated the children were able to leave the house and perform different duties because the surgery enabled them to move freely and they did not suffer from pain anymore. The children had more energy to play and they could also rest and sleep better than before the surgery. Many of the caregivers described that compared to the situation before the surgery their dependent children were abler to rest and sleep. The main reasons for not being able to sleep was pain and poor health like one caregiver described in the following.

“She is comfortable and I have not seen any signs of complications or her being in pain”

Many felt that the physical well-being improved compared to the health before the surgery. One mother said that her child had constantly fever prior to the surgery.

“He used to be sick, had fever currently he doesn't. He used to fall sick frequently”

“She used to walk with the side of her foot. The foot steps down well now.”

8.1.2. Daily activities

In many cases the surgery enabled and increased children's participation in daily activities such as personal hygiene, mobilization, playing and working and also helping with the household management. They were able to help the family after the surgery. Many of the caregivers described that due to better health, the dependent children had better access to school. The children were able to play with friends and they could walk to school unlike before the surgery. Mobilization improved after the surgery, the dependent children were able to move in the household, go to school, bathe, cloth themselves and wash clothes. One caregiver described how her dependent child's improved moving positively affected his school performance.

“He no longer misses school and this reflected on his performance”

Some caregivers told the children could take care of themselves in activities such as personal hygiene and clothing and they were more independent. Many caregivers described the importance in helping the family with different household chores.

“He is self-reliant and I do not fear to leave him alone at home”

“Currently, she is a good lady and can perform duties which she could not before e.g. can fetch water; can iron clothes, clean herself and the other household chores”

8.1.3. Social acceptance

After the surgery, the caregivers felt that their dependent child was more socially accepted by the community and also by other children. Prior to the surgery, few caregivers described that their dependent child was verbally abused or neglected by others. One mother told that her disabled child was verbally abused by his brother due to the deformation on his leg and another caregiver described that before the surgery, the other children use to stare at her dependent child that made her unhappy but after the surgery, she was no longer neglected and she socializes well with other children. Improvement in social acceptance also improved dependent children's mood.

Many of the caregivers felt that their dependent children had more friends after the surgery and they were more socially accepted by other children. In some cases, the perception of the community members had changed on the child and the child was no longer seen as a disabled child.

“The changes have kept off people who used to abuse her referring to her disability.”

“There are a lot of changes. She used to be a child that you could not admire, currently she is a beautiful young lady and no one can identify her disability from a distance”

8.1.4. Psychosocial well-being

The psychosocial wellbeing of the dependent children was perceived more positive compared to the situation before the surgery. In many cases, the psychosocial well-being improved due to the surgery, but it was also linked to social acceptance like one caregiver describes in the following phrase.

“Before the surgery he did not want to attend school due to stigma, he was ashamed to mingle. Currently he resembles his peers and feels happy”

Many caregivers expressed that their dependent child’s self-esteem improved after the surgery. One caregiver described that his dependent child’s self-esteem boosted after the surgery and goes to school more willingly.

Improvement also happened in children’s self-image. In many cases, the caregivers expressed that after the surgery, the children considered themselves as normal, no longer disabled. In one case, the dependent child had accepted that she was living with a disability.

“Their mood changed after the surgery, they were seen more happy and joyful”

8.2. Participation

Many of the caregivers felt that their dependent child could participate in family life more after the surgery. The dependent could participate more in family chores, take better care of him/herself, could be left alone and could help taking care of other siblings. Sometimes the dependent could even help taking care of the cattle. The dependent child's participation in family life was seen as an asset and brought relief to the family life. In some cases, the families told that the surgery relieved their financial burden.

8.2.1. Community life

The participation in community life had also increased after the surgery of dependent child. They participated more in the community life for example singing in church or even joining a youth group where they would encourage others on different issues. Some were even given more responsibilities in school.

Better health, improvement in moving, better self-esteem were the reasons why the dependent children participated more in the community life.

Sometimes the recovery of the child that had undergone a surgery, was seen as an inspirational success story. This individual was an example to the community like one caregiver expressed in the following phrase.

“Currently she has many friends who come to our home, in school she has been given responsibilities to take care of other young ladies, attends church regularly due to good health after surgery.”

8.2.2. Family Life

The surgery also affected the family life. After the surgery, the dependent child was less burden to the family when he or she didn't need to be assisted as much as before the surgery. The dependent child could help with household chores such as washing clothes, fetching water and wood and helping with the food preparation. Sometimes the dependent

child could also help with the cattle and even take care of the other siblings. Some caregivers described that due to the better participation in family life, the dependent child was seen as a value like one caregiver described in the following sentence.

“My grandchild can now assist me and I believe he’s currently got value to me.”

In some cases, the caregivers felt that they could leave their dependent child home alone to perform house chores while going to work or running errands like one caregiver expressed in the following phrase.

“I am not worried to leave the home when she is around I believe all duties shall be attended to and assisting in household chores.”

The responsibilities also increased in some cases, one caregiver told that her child is living with his grandmother and assist her on household chores.

One of the positive effects that the surgery had on the family life was that it helped family's financial burden. Many caregivers expressed that their finances had improved after the surgery due to better health that the surgery provided. One caregiver told that before the surgery they couldn't afford taking care of the medical bills and sometimes even meals. Another caregiver told that they had to sell their livestock to provide transportation to the hospital and taking care of the medical bills. One caregiver describes their financial situation before the surgery in the following way.

“I am not working anywhere; I am just a farmer. But the moment he was sick I would sell my oxen to buy a small one to be able to have some cash left to take him to hospital.”

Many of the caregivers also expressed their feelings of gratitude towards AFF. They told that they were not capable to arrange the needed payment for the surgery of their dependent child and therefore the financial support of AFF was seen as a blessing.

“She is independent and grown bigger, can fetch water, firewood, tries to cook and even goes to school”

8.3. Future perspectives

The caregivers expressed they have higher hopes for their dependent children after the surgery. They told the children were doing better in school and in general they had better chances in life. Healing from the disability was seen as an asset to better educational possibilities but also as a possibility to get work. Better health provided the possibility to seek a better future.

Even when the surgery did not correct the disability completely, it was stated as an advance to brighter future perspectives like one caregiver described in the following.

“She is viewed as a less disadvantaged child compared to the rest. I believed my vision the child as a parent will come true if we can continue working together. She can be a teacher and even a better teacher. Currently she is an example to our community that nothing is impossible if we try because there are people who thought it was impossible for her to heal.”

“She has got change in her life and is more independent. The changes have kept off people who used to abuse her referring to her disability”

Majority of the caregivers had bright future expectations regarding their dependent child, but one caregiver told us about poor performance at school. The caregiver did not explain the situation further, so the reasons behind it are unclear.

“Her performance in school hasn’t been good, there hasn’t been a change after the surgery because she is among the last.”

“She is not consistent at school and I do not know why this happens to her”

8.4. Other findings

There were single issues rising from the interviews which did not fall into any previous category. Great majority of the caregivers experienced positive impacts after the surgery

but some stated challenges like pain or relapse after the surgery. Three caregivers expressed the need for another surgery or referral to surgical mission team. In two cases the child and the family missed the reviews due to organizational misunderstandings. Couple of postsurgical relapses occurred. One grandmother also explained her grandchild was not taken to reviews and now the clubfoot has relapsed. Sometimes the relapse was explained with lack of supportive devices or advice from the surgical team.

One caregiver expressed the need for crutches to help the child to walk.

Two children needed another referral regarding their condition, but the previous surgery had corrected the major problem. One girl was burned accidentally, and her arm was surgically released, the caregivers were happy about the surgery, but the child's face was also burned in the accident and they still wished for another surgery.

“She was ashamed of her arm before the surgery and wasn't happy because other pupils used to stare at her. “

“We would wish the lady to be reviewed by the doctors on the head and nose. “

One child had been waiting for a new referral for three years as there was a metal pin left in his leg. The caregivers were interviewed, and they explained how the child was in a better condition but there were many obstacles on their way.

“We went back to the hospital twice for review and cast removal. He had a wound and it was cleaned. After the two reviews I could not take him back because I had a motorbike accident and movement was an issue.”

“I thought that we had been abandoned and the metal will never be removed, thank you for your visit and there's now hope”

He was referred to the surgical team immediately after the interview and the surgery was performed during the surgical safari 2019.

Sometimes it was unclear if the family knew how to contact the surgical team or continue with the follow ups.

“My view the child should have been reviewed as planned. That would have assisted her, as now she should be operated on to correct the leg”.

“I have never taken him for review because I have never been called to do the same. We wish the leg to be reviewed again and be operated on”.

Faith and spirituality were present in the discussion with the caregivers. Many caregivers found relief and hope in faith which was expressed in the following ways.

“If God grants him long life all the plans he had with the boy will come true.”

9 DISCUSSION

The posed research question is: How the pediatric surgery has affected the everyday- life of children with disabilities and their families? The aim of the thesis is to gain understanding of the impact of pediatric surgery to disabled child's and family's everyday-life in rural Kenya. In the discussion part, the results of the thesis are critically examined and discussed with the literature sources presented earlier.

9.1. Discussion of the results

The families and children in Homa Bay County area have experienced difficulties in everyday-life, but findings show that the pediatric surgeries had a positive impact on the lives of children with disabilities but also on the family's life. The theoretical part could only give us an idea, what kind of experiences and challenges the disabled children and their families face in everyday-life but there is very little information, how the global pediatric surgeries impact on their everyday-life as a full.

The barriers in accessing services may lead disabled people to poverty and lower standards of living. PWDs' healthcare needs are not met in the same manner as they are for the

people without disabilities. Their access to healthcare services is often remote and limited. This has a negative impact on their health in comparison with people without disabilities. (WHO, 2015)

In the results, some of the caregivers stated that their children were discriminated due to having a disability. These caregivers explained how other people used to use abusive words or they did not believe that the child with a disability could ever attend school. According to Ahern et al. (2018) the children with disabilities are vulnerable and they face discrimination, similar information was shared by some of the caregivers in this thesis. The results of this thesis also show that dependent children were more socially accepted by the community after the pediatric surgery, which suggests the participant benefited from the surgery. These results support the findings of Angwenyi & Barongo (2010) as in their report CWDs and their families face discrimination, communities look down on PWDs and do not accept the PWDs. As CWDs face discrimination and are sometimes excluded from communities, they also might exclude themselves due to the stigma of disability as was shared by one caregiver. Same kind of conclusions was made by UNESCO (2010), as having physical and mental impairment is considered as a stigma that is commonly a basis for exclusion from society and school.

In the results, some of the caregivers stated the children could not walk to school because of the pain but after the surgery many of the impairments were eased and the children could attend the school like every other child. Studies by Kuper et al. (2014) and NCAPD & KNBS (2008) explain that CWD are less likely to attend school because of the impairment. Furthermore, in the results, many caregivers expressed that the school attendance and performance improved after the surgery and therefore the children have better changes in the future. Families were optimistic of the children's future after the surgery and the possibility to attend school was seen as an advantage. Also, the ability to work would guarantee a better future for the individual but also to the family. The results support the findings by Kuper et al. (2018), further the poor school attendance can lead to poverty as the CWD may have difficulties finding a decent job.

In the results, the surgery provided for better health and made it possible for the dependent children to perform better in the household chores and work, children were seen as an asset to their families. According to Gona et al. (2011), children were expected to provide

their caregivers during old age so therefore the surgery affected in a way that the future was seen brighter.

Many caregivers stated that after the surgery they were more carefree and could leave their dependent children by themselves. The dependent children could take care of themselves; they could take part in family chores and, they were seen as an asset to the families. Our results were quite similar to Bunning et al. (2017) as they stated, one of the challenges that caregivers faced was burden of care.

In the results, financial stress was experienced by the families and caregivers of disabled children. According to Bunning et al., (2017) and NCAPD & KNBS, (2008) the challenges that families of disabled family members had were poverty and financial stress. Many of the caregivers felt that the surgery provided for better health and eased their financial burden, but they did also state that they could not afford to pay the surgery for themselves. According to N'Dri et al. (2018), families of children with disabilities experience poverty in social life. Same kind of experience was described by one caregiver who said that she could not work because she had to take care of her disabled child.

Some caregivers stated they have more money to take care of their families and they were relieved when the child was able to live a normal life after the surgery. The similar findings were discovered by Sitkin & Farmer, (2016) as they state the pediatric surgeries reduce the burden of disease and financial struggle.

The cultural aspects like participating in the church and taking part of family chores such as fetching water or helping the family farm were repeatedly reported in the results of this thesis as well. These factors are important to the families living in the rural areas where the religion and farming are part of the everyday-life (IES, 2019; Karvinen, 2009). Religion plays a major role in Kenyans' life and practicing religion in the place of worship is a mutually important aspect but also a social event. (IES, 2019) Many caregivers stated that participating in the church increased after the surgery but also their psychosocial well-being improved after the surgery; children were more accepted that boosted their self-esteem. According to Hsieh & Waite (2019), disability effect on social participation negatively and also predicts of poorer psychological well-being. Our results support this finding.

9.2. Ethical consideration

Ethics in research narrowly defined, means normative ethics, which aims to prevent injustice and promote good practice. The ethics of using knowledge is about who and for whom the research is done. (Veijola et al., 2003) According to Diak's ethical guidelines, the basic principles are honesty, diligence and accuracy throughout the thesis process. The author has an ethical responsibility in the thesis and in all research and development activities. (Diak, 2019) Ethical decision is also the justification for the thesis and if the topic has risen from personal interest or just because it is an easy topic. (Hirsjärvi et al., 2007) The research methods and criticism in evaluating and using the results are part of the ethical considerations in the study. It is important to evaluate if the research results are useful/beneficial to the audience, especially to the informants involved in this study. (Kankkunen & Vehviläinen-Julkunen, 2013)

The guideline "Responsible conduct of research and procedures for handling allegations of misconduct in Finland" by the Finnish National Board on Research Integrity is governing the general ethics of research and it should be followed when conducting a research or thesis (The Finnish Advisory Board on Research Integrity (TENK), 2012; Diak, 2019.)

In the starting point of this thesis process, we discussed our common interests. Since we both work in health care, we have natural feelings and interest about helping people in need, especially the most vulnerable ones. We also shared the common interest in human rights. After sharing our thoughts, we discussed with our teacher who shared her knowledge about the surgical missions that AFF does in Kenya. We contacted AFF and held a meeting regarding their work and possible research needs. We agreed with the focus and the aim of the thesis with AFF and signed a cooperation agreement for thesis work. We also discussed how would the target group benefit from this research and the methods we need to concern prior planning the data collection. This thesis included very sensitive and material from the informants, so we needed to obtain Ethical Approval and consent.

We had several meetings with the AFF team in Finland to ensure we receive all the needed information regarding the destination, the team members and tasks in Kenya. We discussed about the aim of the study with the team in Finland and in Kenya and reviewed the methods how to recruit informants to participate in the study. Voluntary participation, the meaning of the research and the use of the results were highlighted to the informants prior to the interviews.

We obtained the Ethical Approval prior to the interviews and it was obtained from our partner university in Kenya (Appendix 4.). Theoretical part of this research was conducted prior to the departure to Kenya. To understand the local culture and the way of living, it was essential to have local knowledge so therefore the guidance and partnership with Comid Kenya was valuable to us. They shared their knowledge about the local customs, language and culture.

The informants were randomly selected but we could not ensure their availability, so they were also chosen by the availability and willingness to participate on the dates we were in Homa Bay County area. The caregivers of the disabled children have to be informed about the voluntary participation and that during the interview they have the right to end the interview at any time. Also, we have to be sure that we provide the information about the research that they will be involved in. (Appendix 5.)

9.3. Research reliability and validity

The reliability of qualitative research can be evaluated by assessing the relevance of the research topic, research aim, analyzing methods and ethical considerations. Critical evaluation of the research data is important. The evaluation of research data is based on whether the research confirms the existing knowledge, the purpose for which the research was conducted and the level of research. (Kankkunen & Vehviläinen-Julkunen, 2013).

The “Writing Guide” by Arcada Applied Sciences (2018) was used to increase the trustworthiness of this research. All throughout the thesis, the citations and references were applied accurately and adequately which according to Hirsjärvi et al (2007), increases the trustworthiness of the thesis. However, this is a joint degree by Arcada University of

Applied Sciences, Diaconia University of Applied Sciences and University of Eastern Africa, Baraton and there was varied information on the use of templates, guidelines and reference system.

The theoretical part was carefully constructed by using approved references like peer reviewed articles, books, material from well-known organizations like World Health Organization and the United Nations and other resources like governmental documents or doctoral disseminations. The report made by Angwenyi & Barongo: “A Baseline Survey on Persons with Disability Empowerment in Kabondo Division” was chosen due to the information that was relevant and specific regarding our thesis in Homa Bay County area.

Reliability was gained by careful analysis of the interviews and continues observation and arrangement of the subthemes, generic themes and themes. The findings were presented to the thesis supervisors several times and the “content analysis process” figure (Appendix 2.) was created together in accordance to their guidelines and previous research data by Elo & Kyngäs (2008) and Jokelainen et al. (2011).

The use of authentic quotations and the collection of rich descriptive data helped to assure reliability of the results. The sample size allowed us to conduct in depth analysis of the findings and also provided a variety of experiences. The caregivers were interviewed by familiar interviewers, in familiar surroundings, mostly in their homes that benefited to receive the authentic experience.

Even though the authors chose inductive content analysis method, they acknowledge that there are features of abductive approach in the thesis as well. In abductive reasoning the researcher or author aims to verify and enrich the already existing theoretical framework. Abductive reasoning combines both theory and data. (Kylmä & Juvakka, 2007) In the process of the thesis, both approaches were considered.

Majority, 15 of the interviews had to be translated to English which can affect the reliability if some information was lost due to the translation. Furthermore, translations can affect the quality of the results but both native speakers on Luo language and English.

Urkund plagiarism system will be used to ensure the reliability and validity of the thesis. Research integrity has been carried out throughout the thesis making process.

9.4. Conclusion and Recommendations

Living with a disability in Kenya can be very challenging. Disabilities can lead to multiple barriers in accessing different services like healthcare and school and work. Disability can cause psychosocial harm to a child and it can affect the everyday-life coping. The results of the thesis state the families are mainly satisfied with the outcomes of the pediatric surgeries. The pediatric surgery enabled disabled children in many different aspects in their everyday-life. CWDs received better opportunities to participate in family life, community and school, which made a positive impact on their future.

It is essential to find out the impact of pediatric surgery and the opinions from the care-givers. More research about involving PWDs in decision making should be conducted. We can only know these surgical missions bring financial improvement to the families and countries, but individual perspectives are important to knowledge when carrying out any aid to vulnerable groups like children with disabilities. According to Sitkin & Farmer (2016), these surgical missions are economically beneficial to individuals and communities and therefore we would like to address the importance of the work that is performed by AFF and the voluntary personnel.

Over the years, approximately 1200 children have been operated by AFF. The number of operated children could allow AFF to deliver more research qualitative and quantitative research about the impacts of the pediatric surgeries. Thus, to gain further information of the work performed by AFF and the impact of these surgeries, more research should be conducted and establish different preventive, educational programs to deliver services to disabled people.

Surgical missions are sometimes considered unethical or unsustainable way to reduce the burden of disabilities. There are ethical guidelines on how to work in LMICs and do such work without causing harm (Lasker et. al, 2018) and those guidelines also highlight the importance of follow-ups. AFF has been developing the follow up system over the years,

but as it was presented in the results, some of the cases fell under follow up and there were relapses, thus it would be beneficial to improve the follow up system in a way that no one is left behind.

In general, the surgical care is often delivered to LMICs by foreign teams. AFF could involve local people and health care professionals into decision making by interviewing them how they would want to participate or develop the surgical work in Kendu Adventist hospital. According to Corno (2016) teaching local professionals, implementing and teaching methods should be the main goal of the surgical missions in the long run.

9.5. Limitations

WHO (2015) states that it would be vital to collect data about PWDs in different countries, that would help in policy planning and take actions based on evidence. We would suggest the same as one of the limitations in our study was lack of evidence and research conducted in Kenya. This thesis contains mixed information about PWDs and CWDs in Kenya and around the world in different situations, the trustworthiness of the data available can vary and therefore affect the quality.

This thesis offers insight into the life of CWDs in Homa Bay County, Kenya and comparisons of the results to different countries cannot be done without considerations.

Since the time we spent in Kenya was limited, we had to work with the time that was given to us. It affected the sample, but diverse and rich data was produced by the informants.

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APPENDIX 1. INTERVIEW TEMPLATE

Interview template

AGE OF THE CHILD _____

GENDER OF THE CHILD _____

THE YEAR OF THE SURGERY _____

THE SURGERY _____

1. How has the surgery changed the daily activities of your dependant child?

- Is she/he more independent? In what way?
- Can she/he take care of herself/himself better after the surgery? Please explain how?
- Has the participation in school/work/church increased after the surgery? Please explain how?

2. How has the surgery affected your dependant child's everyday living?

- Does she/he sleep/rest enough or better? Please explain?
- Is she/he more energetic? How?
- Does she/he have pain or discomfort? Please explain?

3. What kind of changes have you noticed in your dependant child's psychological mood after the surgery?

- Is she/he happier and more energetic than before the surgery? Please explain?
- Can you describe her/his character after the surgery? Has it changed? Please explain more?
- How does she/he feel about her/his self- image after the surgery?
- How would you describe her/his learning and thinking after the surgery?

4. How has the surgery affected the family life?

- Is she/he more present in family life? Please explain how?
- Is she/he included more in household chores? Please explain how?

5. How would you describe your child's participation in the community after the surgery?

- Is she/he more accepted in the community? Please explain how?
- Does she/he have more friends?
- What kind of opportunities she/he have in the community?
- Is she/he more independent in the community? Please explain how?

6. Could you tell how your child's recovery has been organized during the years?

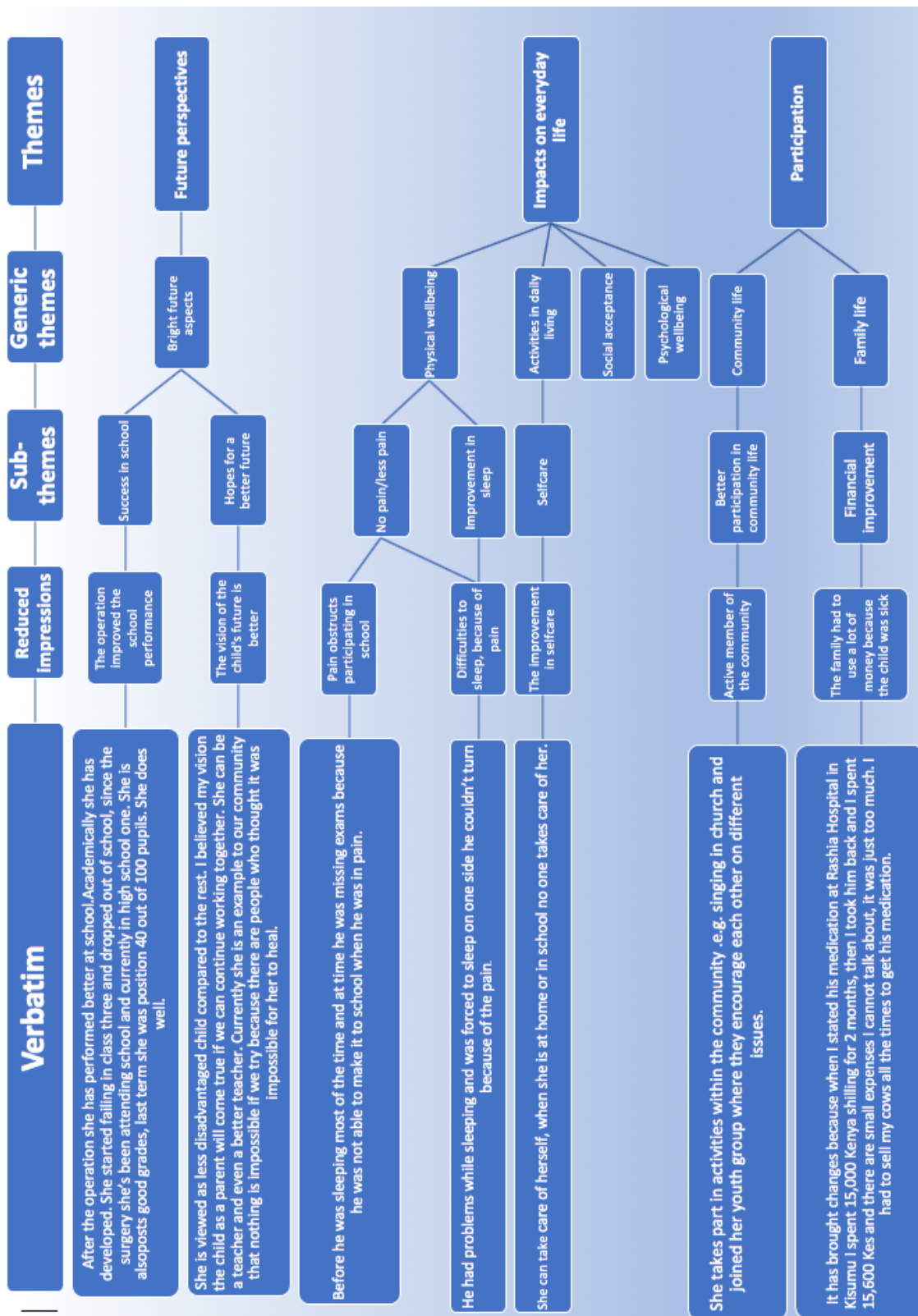
- Does she/he have regular meetings with physiotherapist? If yes, what kind?
- Have you needed some assistive devices/tools/equipment? if yes, what kind?

7. What is your opinion of the surgery?

8. How has the surgery changed your perception of your child's future?

- What kind of opportunities does she/he have after the surgery?
- Will she/he be able to live by herself/himself?

APPENDIX 2. EXAMPLE OF CONTENT ANALYSIS PROCESS



APPENDIX 3. EXAMPLE OF THE TRANSCRIBED INTERVIEW

Interview with one of the caregivers

15 March 2019, at informants home

Interviewer Washington Jalango

Enumerator: If you observe your boy what changes have you witnessed in his self-image.

Father: If I compare before and now, before he was perceived never to walk but now he is able to walk. Before when the pain started he could not do anything but now he is happy unless when the wound starts to discharge.

Enumerator: You had mentioned that you had seen some changes in his school activities. Which are these changes you have realized in relation to his learning.

Father: Currently he is doing fine, before he was not able to understand his work. When he come from the surgery his performance at school really improved. He had started having poor performance at school but currently he has really improved.

Enumerator: As the father do you have hopes with him in his education.

Father: Yes I should have hopes with him. Yes I have hopes with him because he should be able to get his right.

Enumerator: We are done with Erick. If we get back to your family, which changes has surgery brought to your house.

Father: It has brought changes because when I stated his medication at Rashia Hospital in Kisumu I spent 15,000 Kenya shilling for 2 months, then I took him back and I spent 15,600 Kes and there are small expenses I cannot talk about, it was just too much. I had to sell my cows all the times to get his medication.

Enumerator: You said the surgery has relieved you from financial burden.

Father: Yes I did have a big financial challenge, I am not working any were just a famer. But the moment he was sick I would sell my oxen to buy a small one to be able to have some cash left to take him to hospital.

APPENDIX 4. ETHICAL APPROVAL



**OFFICE OF THE DIRECTOR OF GRADUATE STUDIES
AND RESEARCH
UNIVERSITY OF EASTERN AFRICA, BARATON**

P. O. Box 2500-30100, Eldoret, Kenya, East Africa

February 22, 2019

Paula Tapaninen
Janne Markkanen
Diaconia University of Applied Sciences, Finland

Dear Paula, Janne

Re: ETHICS CLEARANCE FOR THESIS PROPOSAL (REC: UEAB/09/02/2019)

Your Master thesis proposal entitled "*Every-life of Children with disabilities who have undergone a reconstructive surgery*" was discussed by the Research Ethics Committee (REC) of the University and your request for ethics clearance was granted approval.

This approval is for one year effective February 22, 2019 until February 21, 2020. For any extension beyond this time period, you will need to apply to this committee one month prior to expiry date.

We wish you success in your research.

Sincerely yours,

A handwritten signature in blue ink, appearing to read "Jackie K. Obey".

Prof Jackie K. Obey, PhD
Chairperson, Research Ethics Committee



APPENDIX 5 CONCENT FORM FOR INFORMANTS

Project title: Everyday-life of children with disabilities who have undergone a reconstructive surgery

Researchers:

Paula Tapaninen (paula.tapaninen@student.dia.fi)

Janne Markkanen (janne.markkanen@arcada.fi)

Thank you for agreeing to be interviewed as part of the research. We are doing a research study about everyday-life of children with disabilities who have undergone a reconstructive surgery experienced by their caregivers. This research is a way to learn more about how the surgery has changed the lives of children who have undergone the reconstructive surgery. By participating to the research, you will provide information that will benefit our partner Adra Finland. If you decide that you want to be part of this study, you will be asked to description that includes your time involvement. This consent form is essential for us to ensure that you understand the purpose of your involvement. We will be using interpreter to translate the interview. The research will be recorded and transcript will be produced.

We are students from a joint degree programme by Diaconia University of Applied Sciences, Arcada University of Applied Sciences and the University of Eastern Africa, Baraton (Kenya) and the programme is Master of Global Health Care. The research will be conducted together with Adra Finland.

Consent form for informants

- I _____ voluntarily agree to participate in this research.
- I understand that even if I agree to participate now, I can interrupt at any time or refuse to answer any question without any consequences of any kind.
- I understand that I will not benefit directly from participating in this research.
- I have the right to be informed about the nature of this study and opportunity ask question about it.
- I understand that all the information that I provide, will be treated anonymously and confidentially.
- I agree to my interview being audio-recorded.
- I agree that the dependant child can participate in the interview if she/he agrees.
- I have read the information sheet.

Time and Place

Signature
