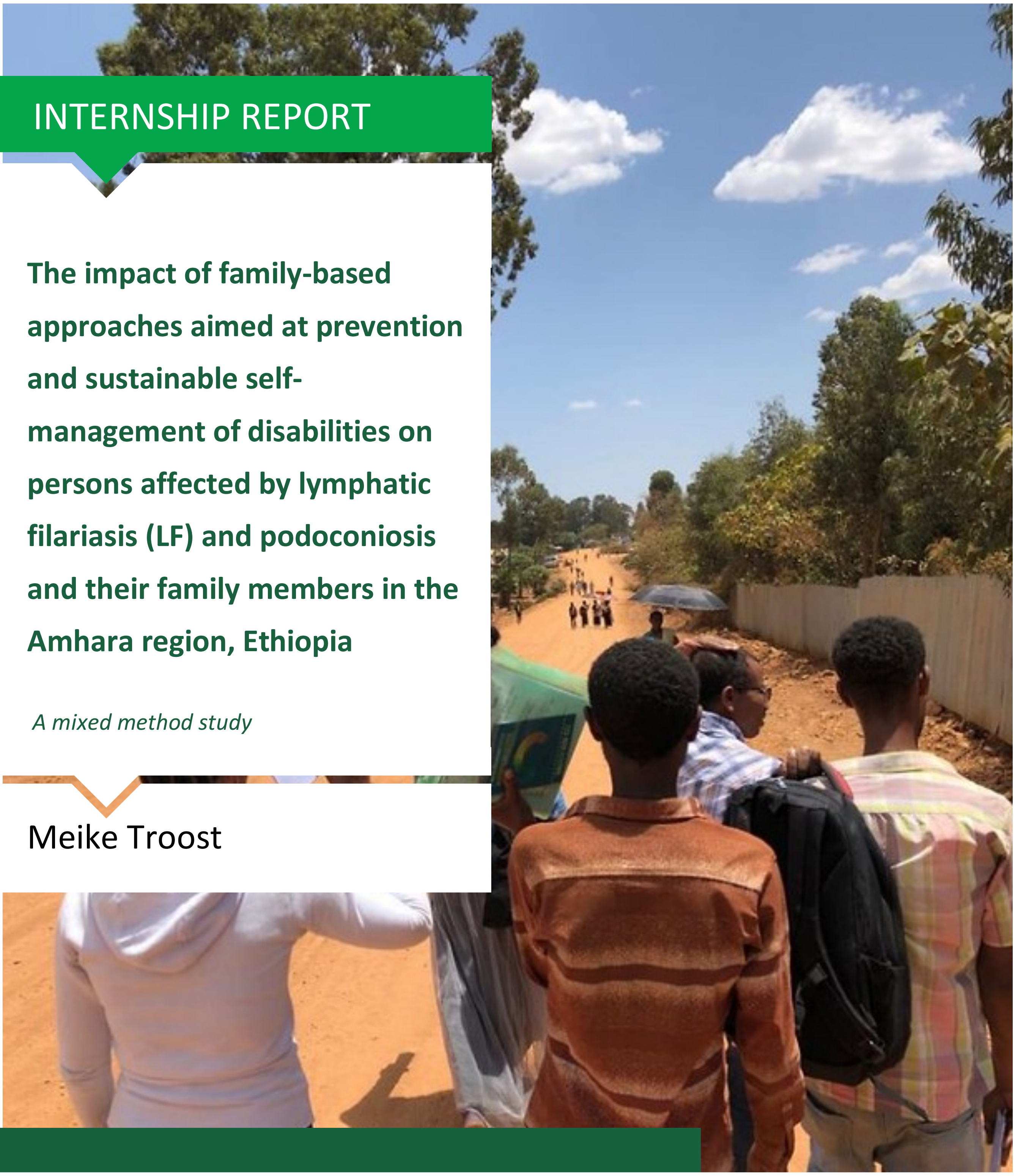

INTERNSHIP REPORT

The impact of family-based approaches aimed at prevention and sustainable self-management of disabilities on persons affected by lymphatic filariasis (LF) and podoconiosis and their family members in the Amhara region, Ethiopia

A mixed method study

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Summary

Introduction

Lymphatic filariasis (LF) and podoconiosis are disabling neglected tropical diseases (NTDs) in Ethiopia and can have multiple consequences. People can experience stigma, decreased individual and Family Quality of Life (FQoL), and there are social and economic consequences such as social exclusion and loss of income. Therefore, an intervention aiming to support persons affected by LF and podoconiosis and their families was implemented in the Zigem area in Ethiopia. Before implementing the intervention, the current situation has been assessed by measuring, among others, the FQoL of the participating persons affected and their families. The impact of the intervention was not assessed yet, indicating a knowledge gap.

The objective of this study is to evaluate the short-term impact of the family-based intervention in the Zigem area, Ethiopia on persons affected by LF and podoconiosis and their families by analyzing the baseline FQoL and FQoL data from an initial follow-up study. These results can be used to optimize the last phase of this intervention or to improve the intervention in other areas at a later stage.

Contextual background

The intervention consists of three pillars and involves persons affected, their family members and the community. The first pillar, awareness creation, is done through educational sessions, providing general information about the NTDs. These sessions are provided outdoors, thereby increasing the visibility of NTDs in the Zigem community. Disease management is the second pillar and concerns the medical part of the intervention such as learning how to treat wounds, and how to take care of others and yourself. The third pillar is socio-economic support where products such as bandages, Vaseline and jerrycans are handed out. Moreover, an income-generating association is created. This does not only create income but also creates jobs. The intervention is not completed: shoes, socks, and stoves are planned to provide in a later stage.

Theoretical framework

The FQoL framework of Beach Center on Disabilities (2006) was used to assess the impact of the intervention. The FQoL framework consists of five domains: 1) family interaction, assessing the relationships among family members, 2) parenting, focusing on the role of the caregiver in the family, 3) emotional wellbeing, looking at the emotional needs, 4) physical/material wellbeing, concerning the basic physical and material needs, and 5) disability-related support, evaluating the support families receive. These domains are assessed by 25 items with a Likert scale. Additionally, open questions are added to explore the needs and opinion of the participants more in-depth.

Methods

The study population was selected by means of an opportunity sample drawn from community members in the Zigem area. Eligibility criteria were; an age of 18 years and older, the person is affected by LF and/or podoconiosis or is a family member of a person affected, is living in the Amhara region, and participated in the intervention. This study used a mixed methods approach. Quantitative baseline data was obtained from the FQoL survey (n=119). Follow-up data was both quantitative and qualitative, with the same survey, combined with open questions (n=40). These two samples were partially overlapping. Moreover, an expert interview was conducted with the main researcher of the entire project to take into account possible cultural sensitivity of the results. Independent samples t-tests and one sample t-tests were conducted in SPSS to analyze the quantitative data. The qualitative data was open coded. Principal component analyses were used to assess the reliability of the FQoL framework.

Results

The majority of the study population was female and related to podoconiosis. Comparing persons affected and family members, 11 out of 25 items showed significant differences in scores in the baseline data. In the follow-up data, 1 out of 25 items showed significant differences. In all these differences, persons affected scored higher. Overall, persons affected had a higher FQoL during the follow-up, but family members improved their FQoL most. The domain family interaction improved, but not significantly (p=.440). The support desired by persons affected from their family all related to the household, such as help with preparing food and chopping wood. The domain parenting improved very significantly (p<.001). An open question showed that children are the main caregivers in the family. The third domain, emotional wellbeing, decreased very significantly (p<.001). Participants mainly experience stress due to the health conditions of the persons affected and a lack of freedom. The domain physical/material wellbeing improved, but not significantly (p=.250). Participants mentioned that they mainly desire shoes and clothing. The mean scores of disability-related support improved. Participants were overall very positive about the intervention. They appreciate the products provided, the home visits and the follow-up appointments. Points of improvement relate to providing medication and financial support.

Discussion

The decrease in significant differences between the two respondent groups can imply that family members are now better able to understand the needs of the persons affected. Comparing the baseline and the follow-up data showed a decrease in emotional wellbeing. It is a possibility that participants better realize the severity of their disease, due to the information provided in this intervention. It stood out that mental health is not a big part of the project. This can be incorporated more by using, for example, the association to share feelings. Other recommendations to improve the intervention are, among others, to focus the project on supporting children as well; involve community and religious leaders and provide visual health education materials to the community to decrease stigma; hand out shoes and socks earlier in the project, and initiate a sewing project. Additional literature supports the findings of this study.

The FQoL framework showed relatively low Cronbach's α, indicating low correlation within the domains. Another limitation concerned the partially overlapping sample. Strengths were among others back-forward translation and involvement of experienced people from Ethiopia in this project.

Conclusion and further research

Overall, participants perceived a higher FQoL after the intervention, than before. The FQoL perceived by family members improved more than the FQoL of persons affected. Further research should explore, among other issues, how to improve mental health for persons affected by NTDs and their family members. Additionally, further research should look at the possible negative effects of healthcare interventions on mental wellbeing. Moreover, it should be examined how to implement the recommendations, to improve the long-term impact of the intervention.

Preface

This study marks the finalization of my Master's degree. For the past five months, I have worked with a lot of enthusiasm and energy on this project, in order to obtain the best result possible. However, this would not have been possible without a valuable group of people supporting me. First, I would like to thank my VU supervisor Dr. Mitzi Waltz. I was lucky to work with her during both my thesis and my internship and got to know her as someone who is passionate about disability studies. Her supervision was so dedicated that it even included a trip to Ethiopia, which I really enjoyed. Her way of giving feedback and thinking along allowed me to bring out the best in me. Moreover, I would like to thank Anna van Luijn for her support during my entire Master's degree. Her close involvement with students and colleagues and her expertise are missed dearly.

Furthermore, I would like to thank everyone involved in this study and the related project. From Disability Studies in Nederland, Dr. Alice Schippers and Anna van 't Noordende provided a lot of valuable feedback. Also, the people I worked with in Ethiopia supported me a lot. This includes everyone working at ENAPAL, the research assistants in the field, but especially Moges Wubie. We worked closely together during my internship, and his support during the field trips was much appreciated.

Meike Troost, June 26, 2019, Utrecht.

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List of abbreviations

Abbreviation	Full name
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
DRC	Democratic Republic of the Congo
DSiN	Disability Studies in the Netherlands
FMoH	Federal Ministry of Health
FQoL	Family Quality of Life
LF	Lymphatic Filariasis
LMIC	Low- and middle-income country
MDT	Multidrug therapy
NaPAN	National Podoconiosis Action Network
NGO	Non-governmental organization
NTD	Neglected Tropical Disease
PCA	Principal component analysis
QoL	Quality of Life
SD	Standard Deviation
SDG	Sustainable Development Goal
SSA	Sub-Saharan Africa
TLMI	The Leprosy Mission International

1. Introduction

Neglected tropical diseases (NTDs) are communicable diseases that affect more than one billion people worldwide: one-seventh of the world population (Hotez & Kamath, 2009; WHO, 2019a). These tropical diseases are referred to as 'neglected' since the affected population is primarily people living in poverty, which often results in these conditions being assigned a low public health priority (WHO, 2019a). Stigma, prejudice and a lack of governmental funding for prevention and treatment also contribute to the marginalization of persons affected by NTDs (Liese et al., 2010). NTDs are closely linked to health inequalities and high morbidity and mortality (Deribe et al., 2012; WHO, 2019a). Some NTDs can cause long-lasting or permanent impairments that may result in disability.

Lymphatic filariasis (LF) and podoconiosis are examples of disabling NTDs, and occur frequently in Ethiopia (Deribe et al., 2012). These NTDs are often highly stigmatized, which is exacerbated by negative beliefs (Deribe et al., 2012). Many beliefs, especially around contagiousness and causes of diseases, exist in low- and middle-income countries (LMICs) (Yakob et al., 2008). Furthermore, negative beliefs such as causation via witchcraft and curses are shared within communities and increase stigma (Yakob et al., 2008).

LF and podoconiosis impact persons affected, their families, communities and countries in multiple ways, making this an interdisciplinary problem in the field of disability studies. The presence of stigma makes persons affected more reluctant to seek the healthcare needed, due to feelings of shame (Tsegay et al., 2014). Stigma and disability are strongly related: More visibility of impairments leads to more perceived stigma (Tsegay et al., 2014). Additionally, the aforementioned beliefs concerning witchcraft make people hesitant to seek medical help (Yakob et al., 2008). A better option is, in their opinion, to go to more traditional healers, who may use treatments such as holy water (Yakob et al., 2008). As a consequence, they lack sufficient healthcare, which typically results in late diagnosis (Alonso, 2010). Due to late diagnosis, people may already struggle with (permanent) impairments, resulting in reduced health and wellbeing of the person affected (McIntyre et al., 2006).

The wellbeing of families of affected persons is also influenced by the presence of NTDs. When a family member is diagnosed with a disease, families as a whole may experience a change in their Family Quality of Life (FQoL) (Ellenwood & Jenkins, 2007). For example, NTDs within a family can negatively change a family's flexibility and their ability to manage daily life tasks (Ellenwood & Jenkins, 2007). Moreover, NTDs can lead to impairments and physical pain, decreasing the independence of the affected person and increasing the need for support by a family member (Tekola et al., 2006). Therefore, NTDs can be challenging and stressful for families and other people close to the person affected (Ellenwood & Jenkins, 2007). NTDs can also lead to unemployment, which can lead to loss of income for households and therefore poverty (Perera et al., 2007). Poverty and disability have a mutually reinforcing relationship: due to poverty, access to healthcare decreases and consequently, disability increases (Mitra et al., 2013). This also decreases FQoL.

Moreover, LF and podoconiosis may have social consequences for both the person affected and their family, also influencing their (emotional) wellbeing. NTDs can lead to persons affected being unable to work or follow education, due to impairments and stigma (Tekola et al., 2006). As a result, the number of social relationships of a person affected in a community is negatively influenced and social exclusion can occur (Tekola et al., 2006). Moreover, NTDs can cause emotional distress among persons affected and their family members, increasing the chance of having mental disorders (Perera et al., 2007). Mental disorders can also lead to fewer social contacts and social exclusion (Kawachi & Berkman, 2001).

Finally, NTDs have consequences on a national level. NTDs can turn into chronic diseases and cause life-long impairment, resulting in high costs for a country (Deribe et al., 2012). For example, productivity in agriculture decreases due to NTDs (Deribe et al., 2012). A study conducted in Ethiopia by Tekola et al.

(2006) (n=702), showed that the productivity of persons affected by podoconiosis is 45% lower than the productivity of healthy individuals. This productivity loss has a high economic cost (Tekola et al., 2006). Furthermore, healthcare costs related to the prevention and treatment of NTDs increase health expenditure in a country and can impoverish families (McIntyre et al., 2006).

1.1 Theoretical and practical relevance

Due to the consequences outlined in the previous section, it is crucial to support not only persons affected by NTDs, but their families as well. Therefore, an intervention aiming to support persons affected by LF and podoconiosis and their families was implemented in the Zigem area in Ethiopia[1]. Before implementing the intervention, the current situation has been assessed by measuring the FQoL of the participating persons affected and their families. The intervention aims to strengthen the prevention and self-management of impairments within Ethiopian families. This is important to decrease the burden of the NTDs. The family-based intervention provides practical support, including health and medical education about the NTDs, hygiene products and the creation of an income-generating association.

The intervention has been developed and partially implemented in the Zigem area in Ethiopia. The impact of the intervention so far has not been assessed, indicating a knowledge gap that is filled by means of this study. Eventually, these insights can be used to evaluate the short-term impact of the family-based intervention, to optimize the last phase of this intervention in the Zigem area and to improve the intervention for two other areas in Ethiopia at a later stage. The final aim of the intervention, strengthening prevention and self-management of impairments of persons affected by LF and podoconiosis and their families and improving their perceived FQoL, makes the practical relevance of this study high.

1.2 Research objective and research question

The objective of this study is to evaluate the short-term impact of family-based intervention in the Zigem area, Ethiopia on persons affected by LF and podoconiosis and their families by analyzing the baseline FQoL and FQoL data from the first follow-up study. The research question guiding the work towards the research objective is: *What is the short-term impact of the family-based intervention implemented in the Zigem area, Ethiopia on persons affected by LF and podoconiosis and their family members?*

To answer the research question, a mixed methods study was conducted. First, conceptual and theoretical frameworks are provided to structure this study. Second, the methodological section elaborates on how the study was conducted. Third, the findings are presented and reviewed in the results and discussion section.

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[1] This intervention is part of a project, also including persons affected by leprosy. This project was initiated by Disability Studies in the Netherlands (DSiN) in collaboration with the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), the National Podoconiosis Action Network (NaPAN), The Leprosy Mission International (TLMI) Ethiopia and Debre Markos University. DSiN is the commissioner of this study.

2. Contextual framework

This chapter provides a contextual background by discussing the cultural background and key concepts in the context of LF and podoconiosis in Ethiopia.

2.1 Cultural background

An understanding of the cultural background helped9 to ensure the study was conducted in a culturally appropriate way. In Ethiopia, (informal) hierarchies are based on, among other criteria, age, wealth and education (Wolk, 2009). Ethiopia is a diverse country, with many different religions and languages (Schiemer, 2017). Christianity and Islam are the most common religions, although other religions are accepted as well. Amharic is the national language in Ethiopia.

Despite improvements in the last decades, Ethiopia remains one of the poorest countries in the world. This is reflected in the level of education. In 2007, the literacy rate among the population of fifteen years and older was 39% (UNESCO UIS, 2019). Over the past few years, efforts have been made to develop inclusive education, suitable for people with disabilities too. But to date, both materials and teachers are scarce and providing appropriate education to persons with disabilities remains a challenge (Schiemer, 2017).

Family is important in the Ethiopian culture (Ayers, 2015; Nidaw, 2018). Households can consist of more than just parents and their children. Due to these strong relations, family members are the first persons to rely on in times of sickness or disability. In general, Ethiopian people do not hold back in expressing their emotions (Ayers, 2015; Nidaw, 2018).

Last, it is important to realize that culture is context-dependent and can also differ within a country. The data collection is conducted in the Zigem area, which is part of the Amhara region. Aforementioned cultural aspects apply to Ethiopia in general, but do not automatically apply to the Amhara region. People in this region are described as traditional, proud and impulsive (Howard, 2011). The main religion is Christian, but there are many Muslims as well (Howard, 2011).

2.2 Relevant actor groups

Different actors are involved in the context of NTDs in Ethiopia, as shown in *Figure 1*. The relevant actor groups are: the person affected, their direct environment, healthcare professionals, non-governmental organizations (NGOs), the Ethiopian Federal Ministry of Health (FMOH) and the World Health Organization (WHO). These different actors are further discussed in *Appendix 1.*

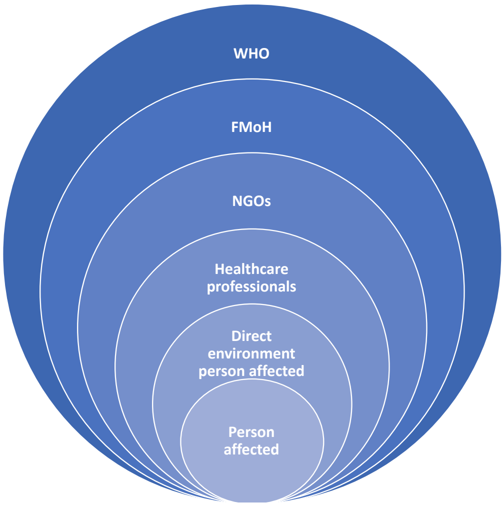

Figure 1: An overview of the relevant actors in the context of this study

2.3 Relevant key concepts

2.3.1 Tropical Neglected Diseases

This study focuses on the NTDs LF and podoconiosis in Ethiopia, a country in sub-Saharan Africa (SSA). 49% of the people living in SSA and 31% of the people in Ethiopia live on less than US$1.25 per day (Fosu, 2015). Due to poverty, sufficient sanitation and hygiene may be lacking, which can result in a higher risk of infectious diseases (WHO, 2019a). Moreover, resources to improve healthcare are scarce, looking at available workforce and budget (Kerry et al., 2011). SSA is one of the 'hotspots' for NTDs: there is a relatively high prevalence of NTDs, and therefore, a special emphasis is required (Hotez, 2014). In this section, LF and podoconiosis are discussed separately, looking at cause, prevalence and symptoms.

LF is caused by parasitic worms (Mengistu et al., 2017). Infection occurs with a bite of an infected mosquito. In Ethiopia, 5.9 million people are estimated to be at risk of LF (Mengistu et al., 2017). Symptoms of LF can be acute, concerning local inflammation (WHO, 2019b). More chronic symptoms concern swelling of tissue or skin (so-called lymphoedema or elephantiasis) or scrotal swelling (WHO, 2019b). Preventive measures can be taken with chemotherapy, hindering parasitic infections from spreading (WHO, 2019b).

Podoconiosis is non-infectious and is caused by exposure to red clay soil (Molla et al., 2012). This material can be found in tropical areas such as Ethiopia. It is estimated that more than 1 million people in Ethiopia have podoconiosis. The symptoms resemble the symptoms of LF, and also include elephantiasis and painful swelling of legs or feet. Apart from physical pain, podoconiosis has psychosocial and economic consequences too, and health education would be helpful to increase understanding of the disease (Molla et al., 2012). Currently, podoconiosis is not well-understood and medical treatment mainly involves treating its symptoms (Allen et al., 2019). It is recommended to focus on education and providing shoes as a part of prevention (Lienhart et al., 2010).

2.3.2 The family-based intervention

This study is part of a larger project in which a family-based approach will be ultimately implemented in three areas in Ethiopia. Studies have shown that in general, family involvement is crucial for implementing successful healthcare interventions (Turnbull et al., 2007). Moreover, interventions focusing on the entire family are more effective and sustainable than interventions focused on the affected individual alone (Carman et al., 2013; Samuel et al., 2012).

The family-based intervention has three main pillars, influencing actors on three different levels, as shown in *Table 1*. Official documents of the FMoH on managing LF and podoconiosis in Ethiopia (FMoH, 2016) and focus groups with persons affected served as a basis for the intervention, and all four research assistants involved received a four-day training.

Table 1: Overview of the three main pillars and the influenced actors

Actors	Awareness creation	Disease management	Socio-economic support
Persons affected	X	X	X
Families	X	X	X
Community	X		

The aim is to create awareness creation through educational sessions for the persons affected and their family members, both together and apart. General information about NTDs, such as symptoms, different stages of the NTDs and their impact was discussed. Moreover, prevention techniques are discussed to diminish the prevalence of the NTDs. The main objective of this pillar is creating a mindset switch that decreases stigma, and to set a standard that family should take care of affected family members. The training is provided outdoors, thereby increasing the visibility of NTDs in the entire Zigem community. Therefore, this pillar aims to influence persons affected, their families and the community.

This part of the intervention has already taken place and, thus, its impact on FQoL will be reflected in this study.

Disease management is the medical part of the intervention. It trains the participants on how best to manage and prevent impairments due to LF and podoconiosis. This includes the use of medication; hygienic aspects, such as cleaning open wounds; and stressing the importance of caring for themselves and others. This part of the intervention has taken place as well, and therefore its impact on FQoL will also be reflected in this study. Moreover, three follow-up appointments are planned for every participant to check if they have any question concerning this pillar.

The socio-economic support pillar of the family-based intervention focuses on providing resources to the participants, of which an overview can be found in *Table 2*. This pillar works as an incentive to participate in the study, and also makes the medical care and prevention possible for resource-poor families. This study will show if the needs of the participants are well-served by these plans, or whether adjustments should be made.

Table 2: An overview of the resources provided in the socio-economic support pillar

Resource	Description	Status
Bandages, Vaseline, jerrycans and salt	Supplies needed to take care of the affected persons and their wounds. The salt works as a diluted antiseptic (Lienhart et al., 2010).	Already handed out
Millhouse, an income-generating association	This allows people to buy, process and sell products. This does not only create income, but also creates jobs. Participants pay a monthly fee of five Birr (€ 0,17) to invest in the millhouse, to have a shared 'saving system' and to encourage them to stay engaged to the project. In the future, there might be a possibility of economic support from the government.	Started, but not completed
Exercise books and pencils	Handed out to encourage children in the family to attend school.	Planned to be handed out later
Blankets and energy-saving stoves	These products can help to prevent burns and additional injury, and the stoves lower the labor-intensity of preparing food.	Planned to be handed out later
Shoes and socks	Can help to prevent podoconiosis.	Planned to be handed out later

3. Theoretical framework

In this study, the FQoL framework was used to assess the short-term impact of the intervention. The FQoL framework was created as a response to the Quality of Life (QoL) framework, which aims to evaluate the quality and outcome of healthcare interventions (Hu et al., 2011; Moons et al., 2006). The QoL framework covers a broad perspective, which includes social utility, satisfaction with life, and other factors (Felce & Perry, 1995). However, the QoL framework was critiqued: It was hard to measure QoL and, moreover, a clear definition was lacking (Moons et al., 2006). The QoL framework also looked solely at the experience of the impaired individual, without considering the impact of disability or ill health on family members.

As a result of this criticism of the QoL framework, the FQoL framework was developed to make measurements more family-centered (Hu et al., 2011). FQoL can be defined as *"a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family needs interact"* (Zuna et al., 2010, p.262). In LMICs, where medical resources are scarce, the family has almost always had to assume the primary care role.

FQoL can be used in multiple fields: disability studies, healthcare studies and general family studies (Hu et al., 2011). This study relates most to disability studies, since the intervention targets disabilities due to LF and podoconiosis. An FQoL scale that is especially suitable for disability studies was developed by the Beach Center (Beach Center on Disabilities, 2006). The framework was established by means of a comprehensive qualitative study (Beach Center on Disabilities, 2015). After validation and refinement, the final Beach Center FQoL survey (hereafter referred to as the FQoL survey) was developed. This survey asks both people with a disability and family members to determine their perceived level of satisfaction concerning their family life on a 5-point Likert-scale (Beach Center on Disabilities, 2006). In this context, 'family' is not limited to people related by blood or marriage, it can also include other people who care for each other on a regular basis (Beach Center on Disabilities, 2006). The FQoL survey includes five domains that are assessed by means of 25 items in total, divided unequally (Hu et al., 2011). An overview of the domains and items, including the related item numbers, is presented in *Figure 2.*

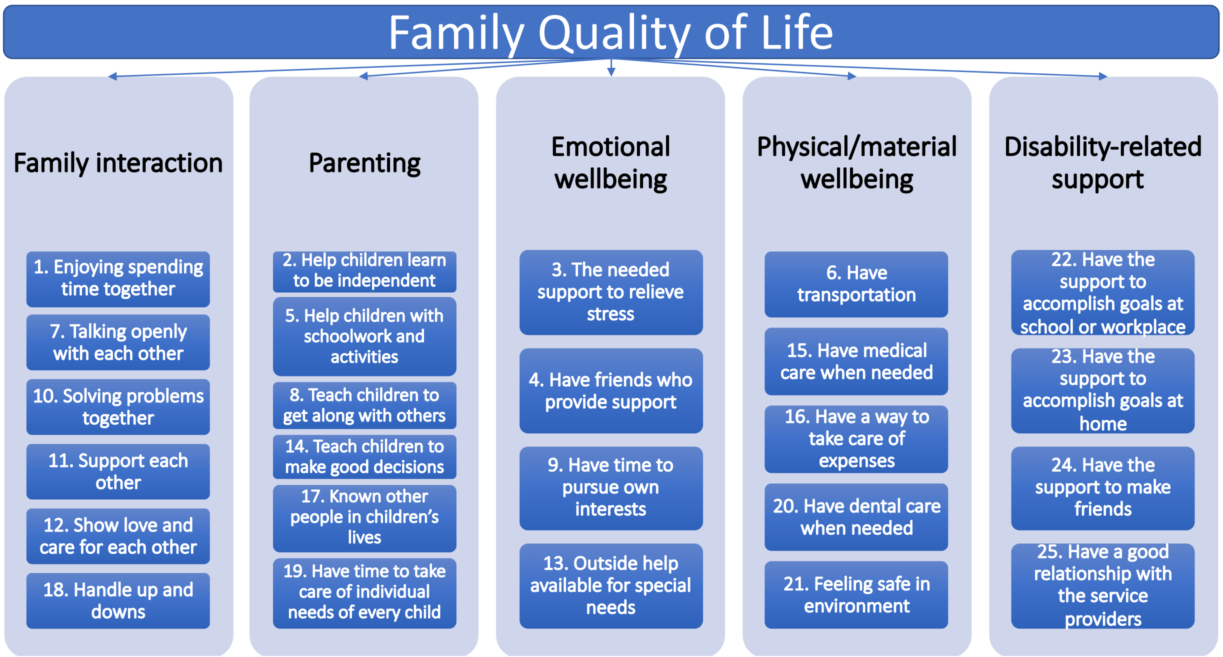

Figure 2: An overview of the domains and items of the FQoL survey

A study by Hoffman et al. (2006) found the FQoL survey to be valid, reliable and of good quality. Moreover, one of the uses of the framework is to measure the effectiveness of an intervention by measuring the FQoL pre- and post-intervention (Beach Center on Disabilities, 2006). Furthermore, the FQoL survey has been validated in other countries in SSA: in Nigeria (Ajuwon & Brown, 2012) and in the Democratic Republic of the Congo (DRC) (Aldersey et al., 2017). In the following sections, the five domains are explained and sometimes complemented with open questions. These questions aim to explore needs and opinions of the participants more in-depth.

3.1 Family interaction

This domain assesses the relationships among family members and the factors that enable participants to live a harmonious family life (Poston et al., 2003). This includes whether a family enjoys spending time together, talks openly with each other, solves problems together, supports each other, if family members show that they care for each other, and if the family is able to handle life's ups and downs (Beach Center on Disabilities, 2006). To create an image of the needed support and the required resources for support, open questions were added to item 12 for both respondent groups *(*see *Table 3*).

Table 3: Questions added to an existing item in the domain of family interaction

Target group	Item number	Question
All participants	Item 12	My family members show that they love and care for each other
Persons affected	Added	What support would you like to receive from your family?
Family members	Added	What do you need to provide more care to a family member?

The first domain leads to the first sub-question: *What is the impact of the family-based intervention on family interaction?*

3.2 Parenting

The domain 'parenting' is based on the idea that 'family' concerns parents with a disabled child (Beach Center on Disabilities, 2006). Although that is not the case in this study as persons affected are 18 years and older, this domain can still be helpful to provide insights into the role of caregivers in Ethiopian families. Therefore, 'parenting' can also be interpreted as 'caregiving' in this study. In this way, there is also captured whether the needs of the persons affected are being met, and the impact of impairments on parenting by persons affected is explored.

The parenting domain includes helping children to be independent, helping with homework or other activities, teaching how to behave, how to make good decisions, knowing other people in the children's lives and having time to take care of the individual needs of children (Beach Center on Disabilities, 2006). An additional question is added to item 19 (see *Table 4*), where persons affected are asked who their main caregiver is. This can help to focus the intervention on a specific role in the family, which has not been done yet.

Table 4: Questions added to an existing item in the domain of parenting

Target group	Item number	Question
All participants	Item 19	Adults in my family have time to take care of the individual needs of every child.
Persons affected	Added	Who is mainly responsible for taking care of you in the family?

The second sub-question examines the potential effects of the intervention on parenting: *What is the impact of the family-based intervention on parenting and caregiving?*

3.3 Emotional wellbeing

The domain 'emotional wellbeing' focuses on the emotional needs of the participants (Poston et al., 2003). This domain includes the support needed to relieve stress, the friends needed to provide support, having enough time to pursue one's own interests, and availability of external help to take care of family members with special needs (Beach Center on Disabilities, 2006). An open question was added to explore the main factors causing stress and specifying the needs for outside help (see *Table 5)*.

Table 5: Questions added to an existing item in the domain of emotional wellbeing

Target group	Item number	Question
All participants	Item 3	My family has the support we need to relieve stress
All participants	Added	Do you often experience stress?
All participants	Added	If yes: What are the main factors causing stress in your family?
All participants	Added	What outside help would you like to receive to improve the level of stress or your emotional wellbeing?

By means of the third sub-question, emotional wellbeing was evaluated: *What is the impact of the family-based intervention on emotional wellbeing?*

3.4 Physical/material wellbeing

Physical and material wellbeing concern the basic physical and material needs of family members (Aldersey et al., 2017). This includes having the medical care, dental care and transportation needed, being able to cover expenses, and feeling safe in their environment (Beach Center on Disabilities, 2006). In the DRC, this related to the costs of meeting basic needs and poverty was the factor that limited satisfaction (Aldersey et al., 2017). Since this factor is examined in the other domains as well, no open questions were added to this domain.

The fourth sub-question looks at physical/material wellbeing: *What is the impact of the family-based intervention on physical/material wellbeing?*

3.5 Disability-related support

The last domain looks at the support provided to the affected persons and their family members, both at home and in their community (Aldersey et al., 2017). This includes support at school or work, support at home, support to make friends, and having a good relationship with healthcare professionals who provide support for the affected person (Beach Center on Disabilities, 2006). To examine what additional support affected persons need at home, an open question was added (see *Table 6)*. Moreover, the intervention was evaluated by asking about positive and negative things. This includes the service providers in item 25, which are the research assistants in this study.

Table 6: Questions added to existing items in the domain of disability-related support

Target group	Item number	Question
All participants	Item 23	My family member with a disability has support to accomplish goals at home.
Persons affected	Added	What additional products or resources would help you to get things done more easily in your home?
All participants	Item 25	My family has good relationships with the service providers who provide services and support to our family member with a disability.
All participants	Added	How did you experience the help received in this project?
All participants	Added	What did you like most about the help received in this project?
All participants	Added	What do you think could be improved in this project?

Disability-related support is analyzed in the last sub-question: *What is the impact of the family-based intervention on disability-related support?*

4. Methods

The objective of this study is to evaluate the short-term impact of the family-based intervention by analyzing the baseline FQoL data and the first follow-up study. This section elaborates on how this objective was achieved and how the study was conducted.

4.1 Study design

This study used a cross-sectional design with a mixed methods approach, where both quantitative and qualitative data were collected and analyzed (Bryman, 2012). Mixed methods are useful to reflect the participants' point of view to provide a more complete image than returned via one method (Creswell, 2009). In this study, quantitative data (closed questions) offers statistical insights into the baseline and the follow-up (Bryman, 2012). Qualitative data (open questions and an expert interview), complements this information by providing in-depth information that increases understanding of participants' needs during the follow-up (Bryman, 2012).

4.2 Study site

The study is conducted in the Zigem area. The Zigem area is a district, or *woreda* in Amharic, in the Amhara region in the northwest of Ethiopia. Agriculture is the basis of the economy in this area (Tegene, 2002).

4.3 Study population and sample

The study population was selected by means of an opportunity sample drawn from community members in the Zigem area. Eligibility criteria were; an age of 18 years and older, affected by LF and/or podoconiosis or a family member of a person affected, living in the Zigem area, and participating in the project. The previously collected baseline data (n=119) consisted of a larger sample to form a general, quantitative image of the pre-intervention situation. This contained 55 persons affected and 64 family members. The follow-up data (n=40) consisted of a partially overlapping sample with the baseline of 20 persons affected and 20 related family members. While a fully overlapping sample was more desirable, the difficulties of working in a developing country where poverty and ill health can greatly impact on the ability of persons to attend appointments, made it impossible. All participants in the second group also met the inclusion criteria and had received the intervention, and therefore a comparable result could be obtained.

4.4 Data collection

Baseline data was collected in December 2018, before the intervention started. The first follow-up took place three months after starting the intervention, in March and April 2019. This study serves as a first, small pilot to explore the effects of the intervention. Later, this study can be conducted on larger scale, for example with a randomized controlled trial and a control group.

Data was collected by means of the FQoL survey, including both closed and open questions. To check the relevance and appropriateness of the open questions, short semi-structured interviews with the main researcher of the project and four research assistants took place (see *Appendix 2).* This was helpful to put the questions in perspective since the researchers have experience with the Ethiopian culture and the project.

The FQoL survey was interview-administered to avoid a bias due to misunderstanding questions, as the Zigem area is characterized by illiteracy and a low education level. The FQoL survey was translated beforehand by a professional, since the survey is used for the baseline data collection as well. The open questions were translated as recommended by the WHO, described in *Table 7* (WHO, 2019c).

Table 7: The process of translating the open questions, based on the recommended steps of the WHO (WHO, 2019c)

Step	Explanation
1. Forward translation	Forward translation (English-Amharic) was done by a health professional familiar with the terminology, who was a native speaker of Amharic.
2. Expert panel back-translation	A bilingual expert panel (n=4) was involved to identify inadequate translations. As a result, it became clear that two questions were not translated. Those questions were added. Consequently, a professional translator conducted backward translation. This translation from Amharic to English, including the original English questions, can be found in *Appendix 3.*
3. Pre-testing	The third step was pilot-testing with representative participants, with a minimum of n=10 (WHO, 2019c). The survey, including the open questions, was tested on six persons affected and six family members, selected by a convenience sample based on cases presenting at intervention events. This resulted in a total pilot-testing sample of n=12, with the main characteristics presented in *Appendix 4*. These twelve persons were not included in the final data sample.
4. Cognitive interviewing	Afterward, a short, in-depth conversation with each of the twelve participants identified points of improvement. The participants mentioned that the word 'project' was unclear to them, which was therefore replaced by 'information and products given.' Moreover, one question was sometimes interpreted incorrectly. This question was reformulated, while retaining its original meaning, to create more clarity.
5. Final version	Last, the final version of the survey was created, of which the Amharic and English version are, respectively, provided in *Appendix 5* and *Appendix 6.*

The closed questions in this survey are items of the FQoL survey. The possible answers in the items are given on a 5-point Likert-scale, where 1=very dissatisfied, 2=dissatisfied, 3=neither satisfied nor dissatisfied, 4=satisfied and 5=very satisfied (Beach Center on Disabilities, 2006). All domains related to the FQoL survey are clearly measurable, due to the related pre-existing items. The operationalization table, including the domains and items, can be found in *Appendix 7.*

4.5 Data analysis

Quantitative data entry and analysis was done in the analysis program SPSS Statistics 25. First, basic information about the study population was described using descriptive statistics. Second, the correlations within baseline data and the follow-up data were tested by means of bivariate correlation analysis. This shows the strength and direction of correlations between two continuous variables (de Vocht, 2013). Since the items of the FQoL survey are ordinal, the bivariate correlation analysis was conducted for new computed, continuous variables that represent the mean values of the five domains. Although the FQoL survey has previously been validated in SSA countries, it is always important to check the reliability, or the internal consistency, with the Cronbach's α for every domain. This is preferred to be higher than 0.7 (Tavakol & Dennick, 2011). Moreover, principal component analyses (PCAs) were conducted to see if the variables included in a construct were representative for a certain domain.

Third, the baseline data and the follow-up were analyzed separately with the help of independent samples t-tests, comparing persons affected and family members. Additionally, the distribution of the answers given by the respondent groups was presented. Since the respondent groups in the baseline data have different sizes, the distribution was expressed in percentages. The distribution of the follow-up data provides absolute numbers since that data set contains two equally sized groups. Moreover, histograms of the distribution per domain are presented, including the normal curve.

Fourth, in order to assess the intermediate impact of the family-based intervention, the baseline data and the follow-up data were compared per domain, with the respondent groups combined and separately. A dependent t-test would be the best option if the data samples were completely overlapping, which is not the case. To remedy this limitation, the comparisons were done by means of one sample t-tests. The follow-up data were analyzed with a test value, representing the mean of the baseline data. To give insight into the differences between items, the mean and the Standard Deviation (*SD)* are presented. Last, to give a general overview, the overall mean scores of all respondents - combined and separately- were calculated by means of a new, computed variables. Explanations about the interpretations of the tests conducted are added to *Table 8.*

Table 8: Explanations of the interpretation of the tests conducted

Test	Interpretation outcomes
Bivariate correlation analysis	The outcome of this test is expressed as the Pearson's correlation coefficient, represented as the letter *r* with a value between -1 (perfect negative correlation) and +1 (perfect positive correlation). The value of *r* can be interpreted as weak ($0.1<r<0.3$), moderate ($0.3<r<0.5$), or strong ($0.5<r$) (de Vocht, 2013).
Principal component analysis	The 'component loadings' range from -1 to +1. A large value shows that the component is important to include in a construct. With a low component loading, it might be better to exclude a certain item from a domain to increase data quality. The interpretation of 'high' and 'low' is considered subjective and should be determined with the use of own knowledge and insight (Minitab, 2019).
Independent samples t-tests	With a p-value for Levene's Test for Equality of Variances of $p<0.05$, the null hypothesis can be rejected, and equal variances cannot be assumed. With $p>0.05$, equal variances can be assumed. Subsequently, the p-values were analyzed, either looking at the row where equal variances can be assumed or not. The null hypothesis assumes that the true mean differences between the FQoL in a certain domain between persons affected and family members are zero. In that case, differences can only be explained by random variation. The alternative hypothesis assumes that the true mean differences between the respondent groups in FQoL are not zero, meaning that differences between the data sets are significant ($p>0.05$) and the impact is probably due to the intervention.
Histograms of the distribution per domain	This only provides insights but does not influence any analyses since the data sample does not have to be tested on normality when $n>30$, according to the Central Limit Theorem (Kwak & Kim, 2017).
One sample t-tests	The null hypothesis assumes that there are no differences between the FQoL before the intervention and during the first follow-up. The alternative hypothesis assumes that the intervention had positive effects and the follow-up data has different scores than the baseline data. Since this hypothesis gives no direction, the one sample t-test is two-sided, with $p<0.05$ to be significant.

To complement the quantitative results, qualitative data was used. This data was helpful when interpreting statistical tests and identified further needs of participants. The answers of the open questions were translated to English and open-coded per question in the qualitative analysis program NVivo 11.4. After data collection and generation of preliminary results, a semi-structured expert interview with the main researcher of the project (a highly experienced Ethiopian health researcher) was conducted. This helped to ensure that data was correctly interpreted.

4.6 Ethical considerations

Ethical approval was obtained from the Debre Markos University Health Science Research Review Board for the entire project, including this study. All study participants were asked to sign an informed consent form beforehand. For those unable to read the form, it was read to them. Concerning this portion of the study specifically, all data remained confidential. The data was securely stored, and only the researchers and supervisors involved had access to the data retrieved.

Since this study was conducted in Ethiopia, cultural habits and factors were considered (see *2.1 Cultural background*). Furthermore, it was important to avoid causing distress to participants. Therefore, participants had unlimited time to answer questions, had the right to withdraw from the study at any time, and only experienced, local research assistants were involved in the data collection. These research assistants speak Amharic and know the participants and the culture. Field trips to the Zigem area helped the researcher to establish rapport with the research assistants and created clarity and uniformity about interviewing participants. Finally, the participants could choose the location of the interviews, wherever they felt most comfortable, whether this was at their home, under a tree or at a health center.

4.6 Research quality

The quality of research can be indicated by two measures: validity and reliability (Bryman, 2012). Validity concerns whether outcomes of the study measure the right thing, and can be divided into internal and external validity. Internal validity is obtained if logical and justifiable causal relations between two or more variables are drawn (Bryman, 2012). All quantitative test assumptions were checked before choosing and conducting a statistical test. Moreover, feedback from peers and supervisor increased internal validity. External validity concerns the extent to which a study and its outcomes are generalizable to other contexts (Bryman, 2012). Since this study evaluated a specific intervention, the results are mainly useful to improve that intervention. Moreover, it can be helpful to design or improve similar interventions, addressing a similar study population and taking into account cultural differences and other specific issues regarding the NTDs studies.

Internal reliability concerns the consistency and coherence of different indicators (Bryman, 2012). The FQoL survey is validated in the DRC, and has overall satisfactory reliability with a Cronbach's α of 0.88 (Aldersey et al., 2017). External reliability focuses on the replicability of the results of the study (Bryman, 2012). Since a survey is a structured way to collect data and a clear methods section is added, external reliability is high.

5. Results

5.1 Baseline data

Baseline data was retrieved from 55 affected persons and 64 family members of affected persons, although these participants were not necessarily related to each other. Basic characteristics are given in *Table 9,* showing that the majority of the participants is female (63%) and is related to podoconiosis (74%). Descriptive statistics about their age are presented in *Table 10*. On average, affected persons are 13.5 years older than family members.

Table 9: Basic characteristics of the persons affected included in the baseline data

	NTD	Sex of the respondent		Total
		Male	Female	
Case person affected	LF	7	10	17
	Podoconiosis	8	30	38
Subtotal		15	40	**55**
Case family member	LF	10	4	14
	Podoconiosis	19	31	50
Subtotal		29	35	**64**
Total baseline sample	LF	17	15	31
	Podoconiosis	27	61	88
	Total	44	75	**119**

Table 10: Descriptive statistics of the age of the participants included in the baseline data

Statistic	Persons affected	Family members
Mean	45.9	32.4
Median	43.0	29.0
Minimum	18	18
Maximum	80	75
SD	15.4	14.0

The results of the bivariate correlation analysis are shown in *Table 11.* All ten correlations are positive, of which six correlations are significant. The correlations can be categorized as weak (six times), moderate (one time) and strong (three times). The strongest correlation can be found between the domains ‘family interaction’ and ‘parenting’. Moreover, ‘parenting and ‘disability-related support’ show a strong correlation.

Table 11: Bivariate correlation analysis of the baseline data

Correlations						
		Family interaction	Parenting	Emotional wellbeing	Physical/ material wellbeing	Disability -related support
Family interaction	Pearson Correlation	1	$.730^{**}$	$.279^{**}$	$.232^{*}$	$.583^{**}$
Parenting	Pearson Correlation	$.730^{**}$	1	.144	.176	$.656^{**}$
Emotional wellbeing	Pearson Correlation	$.279^{**}$	.144	1	$.489^{**}$	.074
Physical/material wellbeing	Pearson Correlation	$.232^{*}$	.176	$.489^{**}$	1	.129
Disability-related support	Pearson Correlation	$.583^{**}$	$.656^{**}$	.074	.129	1

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Running independent samples t-tests (see *Appendix 8*) showed that there are significant differences in 11 out of 25 items between the answers of affected persons and family members. In all 11 differences, affected persons scored higher than family members. Most differences could be found in the domain 'family interaction,' of which five out of six items had significant differences ($p<.05$ (n=1), $p<.01$ (n=3), $p<0.001$ (n=1)). No significant differences were found in the domain 'parenting'. The other domains showed two or three significant differences. The distribution of the total answers given by the participants can be found in *Figure 3.* Both respondent groups answered 'satisfied' most, but the second most frequently mentioned answer differed: dissatisfied for affected persons (37%) and very dissatisfied for family members (29%). The distribution of the answers given per domain is presented in *Appendix 9*, including normal curves.

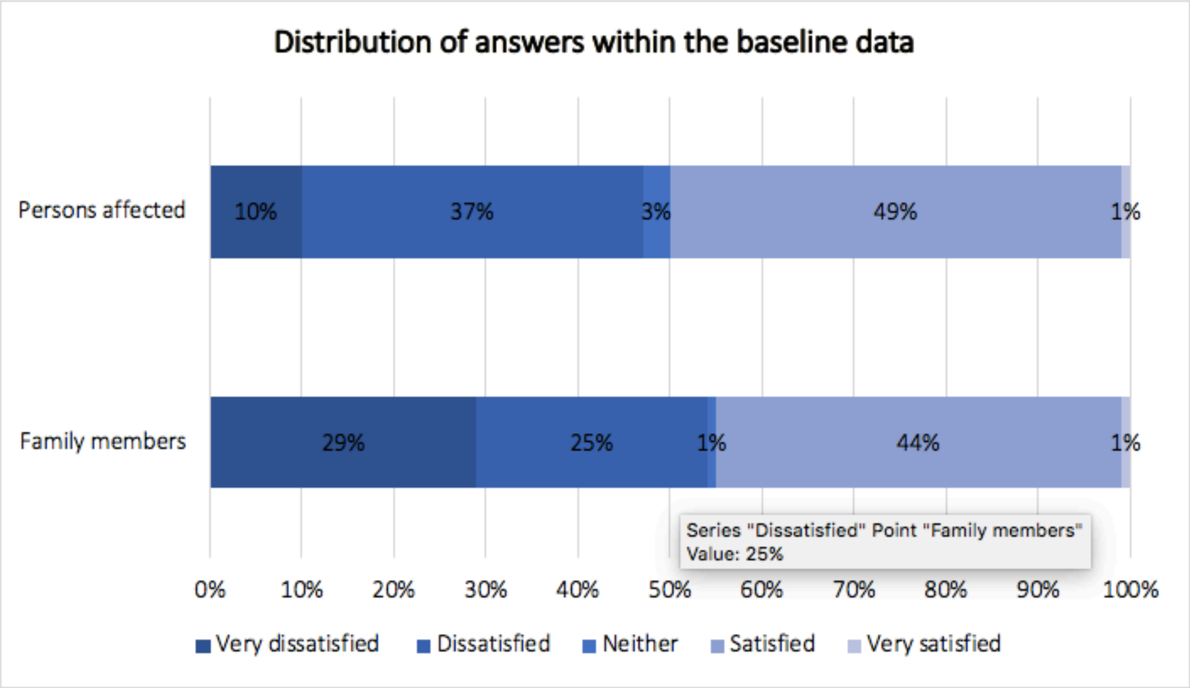

Figure 3: The distributions of answers given by the two respondent groups in the baseline data

5.2 Follow-up data

Follow-up data was retrieved from twenty affected persons and twenty related family members. An affected person with a related family member is referred to as a 'respondent pair.' Descriptive statistics are presented in *Table 12* and *Table 13.* These basic characteristics show that the majority of the follow-up sample is female (68%) and is affected (in)directly by podoconiosis (65%). On average, affected persons are 15.8 years older than family members.

Table 12: Basic characteristics of the participants included in the follow-up data

	NTD	Sex of the respondent		Total
		Male	Female	
Case person affected	LF	1	6	7
	Podoconiosis	3	10	13
Subtotal		4	16	**20**
Case family member	LF	4	3	7
	Podoconiosis	5	8	13
Subtotal		9	11	**20**
Total follow-up sample	LF	5	9	14
	Podoconiosis	8	18	26
	Total	13	27	**40**

Table 13: Descriptive statistics of the age of the persons affected included in the follow-up data

Statistic	Persons affected	Family members
Mean	46.60	30.85
Median	45.00	27.50
Minimum	23	18
Maximum	75	60
SD	16.04	10.99

Independent samples t-tests (*Appendix 10)* showed no significant differences between the scores in the follow-up data of the affected persons and the family members, except for item 9: ‘My family members have some time to pursue their own interests’ (*p*=.018). *Figure 4* shows the distribution of all answers given by all participants in the follow-up data. This distribution shows similarities between the scores of the persons affected and their family members. *Appendix 11* shows the distribution of the answers given per domain, including normal curve.

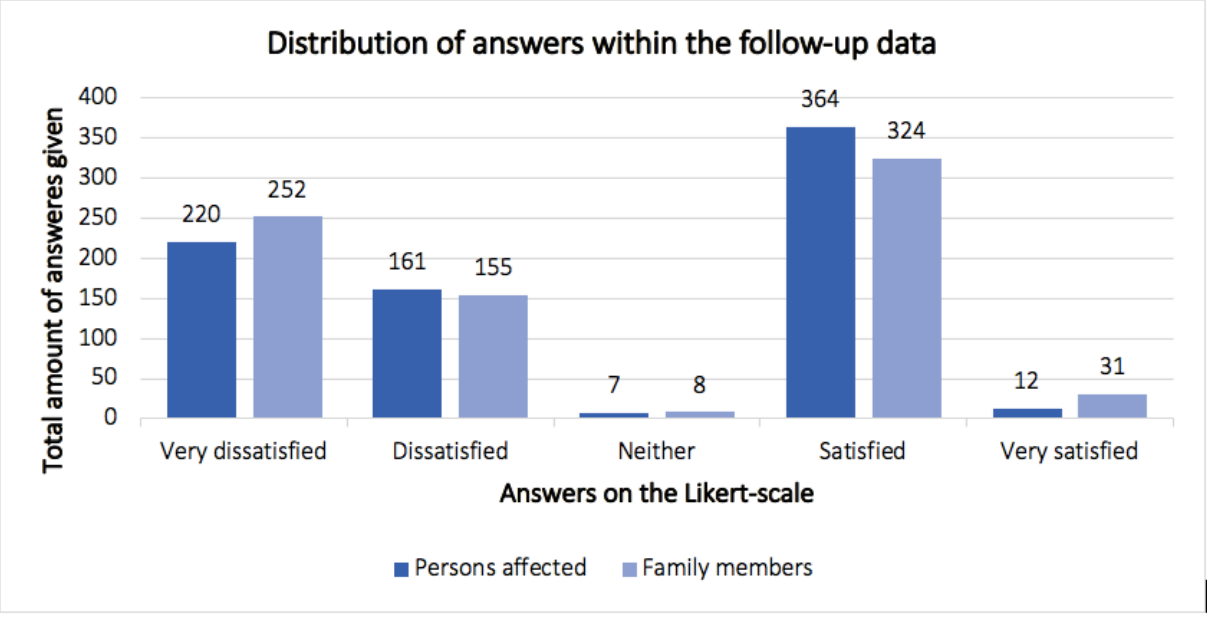

Figure 4: The total number of answers given by the two respondent groups in the follow-up data

The results of the bivariate correlation analysis conducted, are shown in *Table 14.* Of the ten correlations, six correlations are positive (of which two significant), and four are negative. The positive correlations are very weak (n=2), weak (n=2), moderate (n=1) and strong (n=1). Of the four negative correlations, one is very weak, and three are weak. The strongest correlation can be found between the domains ‘family interaction’ and ‘emotional wellbeing’.

Table 14: Bivariate correlation analysis of the follow-up data

Correlations						
		Family interaction	Parenting	Emotional wellbeing	Physical/ material wellbeing	Disability -related support
Family interaction	Pearson Correlation	1	.148	.566**	.339*	-.170
Parenting	Pearson Correlation	.148	1	.043	-.269	.031
Emotional wellbeing	Pearson Correlation	.566**	.043	1	.251	-.178
Physical/material wellbeing	Pearson Correlation	.339*	-.269	.251	1	-.064
Disability-related support	Pearson Correlation	-.170	.031	-.178	-.064	1

**Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

5.3 Comparison of the baseline data and the follow-up data

Comparing the overall mean scores shows improvement after starting the project (see *Table 15)*.

Table 15: An overview of the differences in mean values in the baseline and the follow-up data

	Mean values		
Respondent group	Mean value baseline	Mean value follow-up	Mean difference
All combined	2.76	2.99	+.23
Persons affected	2.93	3.03	+.10
Family members	2.62	2.95	+.33

Additionally, the Cronbach's α for all five domains in both data samples are compared and presented in *Table 16.* Consequently, PCAs were run for all domains. These analyses showed that item 21, ''My family feels safe at home, work, school, and in our neighborhood,'' had low correlation with the other items in the domain 'physical/material wellbeing' (*Table 17).* Therefore, item 21 is deleted from the domain 'physical/material wellbeing', resulting in increased Cronbach's α of .632 and .703. As a result, one sample t-tests are conducted with a newly computed domain 'physical/material wellbeing', consisting of four items instead of five.

Table 16: An overview of the Cronbach's α of all domains included in the baseline and the follow-up data

Domain	**Cronbach's α baseline data**	**Cronbach's α follow-up data**
Family interaction	.764	.386
Parenting	.860	.449
Emotional wellbeing	.453	.739
Physical/material wellbeing	.503 → .632	.574 → .703
Disability-related support	.697	-.440

Table 17: 'Principal component analysis' conducted for the domain 'physical/material wellbeing'

Component Matrix[a]				
	Baseline		Follow-up	
	Component		Component	
	1	2	1	2
My family members have transportation to get to the places they need to be	.678	.470	.386	.495
My family gets medical care when needed	.685	-.511	.957	-.192
My family has a way to take care of our expenses	.601	.580	.407	.506
My family feels safe at home, work, school, and in our neighborhood.	.016	.777	.038	.811
My family gets dental care when needed.	.788	-.418	.946	-.258

Extraction Method: Principal Component Analysis.
a. 2 components extracted.

The domain 'disability-related support' has a negative Cronbach's α in the follow-up data, indicating a very low correlation. *Table 18* provides an overview of potential Cronbach's α when deleting a variable. It is visible that deleting a variable would not result in a positive Cronbach's α. Therefore, this domain remains unchanged. However, this should be considered when interpreting the results.

Table 18: Cronbach's α if items in the domain 'disability-related support' were deleted

Item-Total Statistics	Cronbach's α if item Deleted
My family member with a disability has support to accomplish goals at school or at workplace.	-.070
My family member with a disability has support to accomplish goals at home.	-.086
My family member with a disability has support to make friends.	-.142
My family has good relationships with the service providers who provide services and support to our family member with a disability.	-.895

In the following paragraphs, all data is presented per domain. Numbers between brackets represent the number of missing values and the *SD*.

5.3.1 Family interaction

Table 19: Overview of the items included in the domain 'family interaction'

Item number	Item
1	My family enjoys spending time together.
7	My family members talk openly with each other.
10	Our family solves problems together.
11	My family members support each other to accomplish goals.
12	My family members show that they love and care for each other.
18	My family is able to handle life's ups and downs.

5.3.1.1 Quantitative data

Table 20 shows the mean value and the *SD* of the baseline and follow-up data, with the respondent groups separated and combined. Comparing the data samples shows three similar results: Item 11 and 18 decreased, the four other items increased. The biggest improvement overall and for persons affected can be found in item 1, which has improved .69 and .90 on average, respectively. Item 7 was with .78 the biggest improvement for family members. Item 11 deteriorated the most overall (-1.10) and for persons affected (-1.40). For family members, this was item 18 (-.82).

Table 20: The results of the baseline and follow-up data for the domain 'family interaction'

		Mean value baseline	**Mean value follow-up**	
Item		All participants	All participants	Mean difference
1	Enjoys spending time	3.03 *(SD=1.20)*	3.73 (*SD*=0.96)	+.69
7	Talk openly with each other	3.44 *(SD=1.01)*	4.00 (1) (*SD*=0.00)	+.56
10	Solve problems together	3.41 *(SD=0.70)*	3.95 (*SD*=0.50)	+.54
11	Support to accomplish goals	2.88 *(SD=1.28)*	1.83 (*SD*=1.24)	-1.10
12	Care for each other	3.53 (*SD*=0.92)	3.98 (*SD*=0.36)	+.45
18	Able to handle ups and downs	2.55 (*SD*=1.27)	1.47 (4) (*SD*=0.81)	-1.08
Item		Persons affected	Persons affected	Mean difference
1	Enjoys spending time	3.00 *(SD=1.19)*	3.90 *(SD=0.72)*	+.90
7	Talk openly with each other	3.69 *(SD=0.80)*	4.00 (1) *(SD=0.00)*	+.31
10	Solve problems together	3.62 *(SD=0.83)*	4.05 *(SD=0.22)*	+.43
11	Support to accomplish goals	3.51 *(SD=0.90)*	2.10 *(SD=1.45)*	-1.40
12	Care for each other	3.76 *(SD=0.72)*	4.05 *(SD=0.22)*	+.29
18	Able to handle ups and downs	2.89 *(SD=1.21)*	1.50 (2) *(SD=0.51)*	-.39
Item		Family members	Family members	Mean difference
1	Enjoys spending time	3.06 *(SD=1.22)*	3.55 (*SD*=1.15)	+.49
7	Talk openly with each other	3.22 *(SD=1.19)*	4.00 (*SD*=0.00)	+.78
10	Solve problems together	*3.23 (SD=1.05)*	3.85 (*SD*=0.67)	+.62
11	Support to accomplish goals	*2.34 (SD*=1.32*)*	1.55 (*SD*=0.95)	-.79
12	Care for each other	*3.33 (SD=1.02)*	3.90 (*SD*=0.48)	+.57
18	Able to handle ups and downs	*2.27 (SD=1.25)*	1.44 (2) (*SD*=1.04)	-.82

Table 21 shows the results of the comparisons for the entire domain. The mean difference is positive for family members (+.17, *p*=.085), but negative for persons affected (-.12, *p*=.088). This results in a small overall improvement in this domain, comparing baseline and follow-up data (t(39)=.780, *p*=.440).

Table 21: Comparison of the baseline and follow-up data for the domain 'family interaction'

	Mean values			**One sample t-test**	
Respondent group	Baseline	Follow-up	Mean difference	t(df)	P-value (2-tailed)
All combined	3.14	3.19	+.05	.780 (39)	.440
Persons affected	3.41	3.29	-.12	-1.798 (19)	.088
Family members	2.91	3.08	+.17	1.820 (19)	.085

5.3.1.2 Qualitative data

An open question asked about the support affected persons desire from their family. All answers related to the household. Preparing food was mentioned most (n=9). Furthermore, washing clothes (n=6), chopping wood (n=5), fetching water from the river (n=5), making coffee (n=3) and getting tap water (n=2) were mentioned as tasks where help is required. Most of the times, persons affected mentioned multiple tasks:

> *''If they could obey me when I order them to do something; if they could chop wood and do housework. For example, if they would cook, make coffee and give it to me on time.''* – GA19

The other open question asked family members what resources they need in order to take care of a sick family member. The family members mentioned that they mainly need medication (n=5) and money (n=4). Moreover, household products that can be used to produce and prepare food were mentioned three times. Furthermore, clothing would be helpful, according to one respondent pair. Another family member mentioned the hygiene products (soap, Vaseline and salt) that were distributed earlier in this project: these were considered helpful.

5.3.2 Parenting

Table 22: Overview of the items included in the domain 'parenting'

Item number	**Item**
2	Family members help the children learn to be independent.
5	My family members help the children with schoolwork and activities.
8	Family members teach the children how to get along with others.
14	Adults in my family teach the children to make good decisions.
17	Adults in my family know other people in the children's lives (friends, teachers, etc.).
19	Adults in my family have time to take care of the individual needs of every child.

5.3.2.1 Quantitative data

Table 23 shows the quantitative results of this domain per item. All items scored higher during the first follow-up than during the baseline measurement. Looking at persons affected, the biggest improvement can be found in item 14. In case of family members and the respondent groups combined, this was item 2. In general, item 8 improved the least.

Table 23: The results of the baseline and follow-up data for the domain 'parenting'

		Mean value baseline	**Mean value follow-up**	
Item		All participants	All participants	Mean difference
2	Learn independence	2.84 *(SD=1.21)*	3.68 (*SD*=0.89)	+.84
5	Help with schoolwork	3.28 *(SD=1.09)*	4.00 (*SD*=0.23)	+.72
8	Teach how to get along	3.53 *(SD=0.98)*	4.03 (*SD*=0.28)	+.50
14	Teach to make good decisions	3.19 *(SD=1.03)*	3.98 (*SD*=0.28)	+.78
17	Know people in children's life	3.32 *(SD=0.97)*	4.00 (*SD*=0.45)	+.68
19	Time to take care of needs	2.87 *(SD=1.12)*	3.68 (*SD*=0.92)	+.80
Item		Persons affected	Persons affected	Mean difference
2	Learn independence	2.87 (*SD*=1.11)	3.60 (*SD*=1.00)	+.73
5	Help with schoolwork	3.27 (*SD*=1.06)	3.95 (*SD*=0.22)	+.68
8	Teach how to get along	3.67 (*SD*=0.84)	3.95 (*SD*=0.22)	+.28
14	Teach to make good decisions	3.11 (*SD*=1.03)	4.00 (*SD*=0.32)	+.90
17	Know people in children's life	3.42 (*SD*=0.90)	4.00 (*SD*=0.32)	+.58
19	Time to take care of needs	2.89 (*SD*=1.07)	3.60 (*SD*=1.05)	+.71
Item		Family members	Family members	Mean difference
2	Learn independence	2.81 (*SD*=1.31)	3.75 (*SD*=0.79)	+.94
5	Help with schoolwork	3.28 (*SD*=1.20)	4.05 (*SD*=0.22)	+.77
8	Teach how to get along	3.41 (*SD*=1.08)	4.10 (*SD*=0.31)	+.69
14	Teach to make good decisions	3.27 (*SD*=1.03)	3.95 (*SD*=0.22)	+.68
17	Know people in children's life	3.23 (*SD*=1.04)	4.00 (*SD*=0.56)	+.77
19	Time to take care of needs	2.86 (*SD*=1.18)	3.75 (*SD*=0.79)	+.89

Table 24 presents the results for the entire domain, both with the respondent groups separated and combined. All differences are positive and very significant ($p<.001$). Family members experienced the biggest improvement.

Table 24: Comparison of the baseline and follow-up data for the domain 'parenting'

	Mean values			**One sample t-test**	
Respondent group	Baseline	Follow-up	Mean difference	t(df)	P-value (2-tailed)
All combined	3.17	3.89	+.72	15.170 (39)	.000
Persons affected	3.21	3.85	+.64	8.487 (19)	.000
Family members	3.14	3.93	+.79	13.564 (19)	.000

5.3.2.2 Qualitative data

The open question in this domain asked affected persons who primarily takes care of them. 18 out of the 20 persons affected answered this question. Care is provided by children (n=11), spouses (n=4), and other family members (granddaughter, mother and sister; all mentioned once). Two of the four participants who answered 'spouse' were male, which is 50% of the total number of affected male persons included. The expert interviewee explained that in Ethiopia, disabled women experience difficulties with getting married. Many of them stay unmarried, since cultural values strongly influence men. They prefer healthy women who can provide food and work in the household.

5.3.3 Emotional wellbeing

Table 25: Overview of the items included in the domain 'emotional wellbeing'

Item number	Item
3	My family has the support we need to relieve stress.
4	My family members have friends or others who provide support.
9	My family members have some time to pursue their own interests.
13	My family has outside help available to us to take care of special needs of all family members.

5.3.3.1 Quantitative data

The comparisons between the data samples are presented in *Table 26.* All items scored better before the intervention than during the follow-up, meaning that 'emotional wellbeing' decreased during the first part of this project. For both respondent groups separately and combined, the biggest difference can be found in item 9. The smallest declines in scores can be found in items 4 and item 13.

Table 26: The results of the baseline and follow-up data for the domain 'emotional wellbeing'

		Mean value baseline	Mean value follow-up	
Item		All participants	All participants	Mean difference
3	Support to relieve stress	1.81 *(SD=1.01)*	1.35 (3) (*SD*=0.63)	-.46
4	Friends providing support	1.73 *(SD=0.84)*	1.45 (*SD*=0.75)	-.28
9	Time for own interests	2.45 *(SD=1.29)*	1.85 (1) (*SD*=1.11)	-.61
13	Outside help available	1.58 *(SD=0.71)*	1.33 (*SD*=0.62)	-.26
Item		Persons affected	Persons affected	Mean difference
3	Support to relieve stress	2.04 (*SD*=0.92)	1.39 (2) (*SD*=0.50)	-.65
4	Friends providing support	1.80 (*SD*=0.62)	1.60 (*SD*=0.75)	-.20
9	Time for own interests	3.18 (*SD*=1.10)	2.25 (*SD*=1.37)	-.93
13	Outside help available	1.80 (*SD*=0.70)	1.40 (*SD*=0.50)	-.40
Item		Family members	Family members	Mean difference
3	Support to relieve stress	1.61 (*SD*=1.05)	1.32 (1) (*SD*=0.75)	-.29
4	Friends providing support	1.67 (*SD*=0.99)	1.30 (*SD*=0.73)	-.37
9	Time for own interests	1.83 (*SD*=1.21)	1.42 (1) (*SD*=0.51)	-.41
13	Outside help available	1.39 (*SD*=0.66)	1.25 *(SD*=0.72)	-.14

The results of the one sample t-test and the mean values can be found in *Table 27.* All negative changes are significant, with the biggest change coming from persons affected (*p*=.004). Overall, the domain 'emotional wellbeing' scored .38 point lower during the first follow-up moment, compared to the baseline data (t(39)=-3.809, *p*<.001).

Table 27: Comparison of the baseline and follow-up data for the domain 'emotional wellbeing'

	Mean values			One sample t-test	
Respondent group	Baseline	Follow-up	Mean difference	t(df)	P-value (2-tailed)
All combined	1.89	1.51	-.38	-3.809 (39)	.000
Persons affected	2.20	1.69	-.51	-3.283 (19)	.004
Family members	1.63	1.34	-.29	-2.607 (19)	.017

5.3.3.2 Qualitative data

The open questions asked if participants often experience stress and what was the main cause of stress. All participants, except for one person affected and one family member, mentioned that they often experience stress. Looking at the causative factors, the health condition of the person affected is mentioned most. Nine persons affected stated that the feeling of being sick and having pain causes stress. Eight family members see this as a cause of stress as well; seeing their relative suffering is hard for them. For one family member, talking about the disease also causes stress. Beliefs concerning curses were seen as a source of stress related to sickness too:

> *''When the disease is triggered and I am very sick, I worry a lot because I am cursed with this disease at my age.''* – GA20

Second, three persons affected mentioned that it is hard to do things in the household when they are sick since they are bedridden most of the times. In that case, they need extra help from family members. Five family members feel stressed because the person affected is not able to help in the household, but tasks still need to be done.

Third, a lack of money is mentioned sixteen times (six persons affected, ten family members) as a cause of stress. The NTDs make it impossible to do (physical) work, causing a lack of income for the household. As a result, families run out of food and are not able to buy medication. Furthermore, both persons affected, and their family members said they worry about their children because of a lack of money:

> *''I used to be able to do physical work and support myself but now since I cannot work and since my children are not able to support themselves; I think about them a lot.''*- GA9
> *''Because I don't have the financial ability to buy exercise books and pens for sending the children off to school; also, when those children who are enrolled get dismissed from school because they have to wear uniforms.''* – GF6

The fourth mentioned cause for stress is the lack of freedom because of an impairment, which is mentioned by eight persons affected and by one family member. The impairment often causes difficulties with leaving the house, including not being able to visit family. According to the expert interviewee, this difficulty can both be connected to physical limitations that make it hard to go somewhere, and also to stigma. The interviewee mentioned that it is common to *''hide your problems inside your own house,''* creating a high threshold for people with disabilities to leave their home. The lack of freedom especially causes stress when there is a special occasion, according to two persons affected. In Ethiopia, being with family members during holidays, religious celebrations and family occasions is considered very important, according to the expert interviewee.

> *''[I experience stress] when the disease is triggered and because I cannot move from one place to another as freely as my neighbors; there is nothing more I can say.'' – GA14*

Last, three persons affected and two family members mentioned that it causes stress if they are insulted by people in their environment. Comments about their 'bulged legs' are made, resulting in the person affected feeling inferior to his or her friends. Family members said that they sometimes hear people in their neighborhood talking about their relative. Moreover, it is seen as stressful for them to see healthy friends of the persons affected being able to go to school or work, while their relative is forced to stay at home - according to two family members. The expert interview indicated that it is likely that the psychological impact of LF or podoconiosis is even bigger than the physical impact.

The second open question focused on what kind of support the participants would like to receive to reduce these feelings of stress. 22 participants (eight persons affected, 14 family members) answered that money would help. Two respondent pairs and one other family member said that the money would be used to buy sheep and raise livestock. Furthermore, money would be used to buy medication (n=11). The following quote shows that there is also a need of a place to get medication, so participants can take medication home.

> *''If medication is provided for her and there is a place where I can go and bring [the medication] for her regularly.''* – GF12

Moreover, three persons affected and four family members mentioned that receiving clothes that fit the person affected would help to reduce stress. Last, nine participants (six persons affected and three family members) mentioned more generally that they would like to receive all help available in this project.

5.3.4 Physical/material wellbeing

Table 28: Overview of the items included in the domain 'physical/material wellbeing'

Item number	Item
6	My family members have transportation to get to the places they need to be.
15	My family gets medical care when needed.
16	My family has a way to take care of our expenses.
20	My family gets dental care when needed.
21	My family feels safe at home, work, school, and in our neighborhood.

5.3.4.1 Quantitative data

The results in this domain are mixed and show both positive and negative results (see *Table 29)*. In all three analyses, the same items scored either positive or negative. Items 15, 20 and 21 scored positive. Since this project is not related to providing dental care, the expert interviewee stated that *''this question is not really relevant.''* However, he also mentioned the possibility that the visibility and the availability of this project could have given participants hope that dental care will be easier to obtain as well. Moreover, the expert interviewee mentioned that the increased feeling of safety (item 21) might relate to more awareness of NTDs and consequently, decreased stigma in their environment and fewer worries about insults or abuse.

Two items scored negatively: item 6 and item 16. The negative differences were especially visible for persons affected.

Table 29: The results of the baseline and follow-up data for the domain 'physical/material wellbeing'

		Mean value baseline	**Mean value follow-up**	
Item		All participants	All participants	Mean difference
6	Have transportation	1.76 *(SD=0.93)*	1.25 (*SD*=0.59)	-.51
15	Get medical care	2.85 *(SD=1.28)*	3.48 (*SD*=1.11)	+.63
16	Way to take care of expenses	1.66 *(SD=0.96)*	1.18 (*SD*=0.39)	-.49
20	Get dental care	2.69 *(SD=1.29)*	3.53 (*SD*=1.13)	+.84
21	Feeling safe in environment	2.86 (*SD*=1.23)	3.58 (*SD*=1.04)	+.72
Item		Persons affected	Persons affected	Mean difference
6	Have transportation	2.24 (*SD*=1.01)	1.25 (*SD*=0.44)	-.99
15	Get medical care	2.82 (*SD*=1.12)	3.45 (*SD*=1.15)	+.63
16	Way to take care of expenses	1.96 (*SD*=0.92)	1.15 (*SD*=0.37)	-.81
20	Get dental care	2.82 (*SD*=1.16)	3.45 *(SD*=1.15)	+.63
21	Feeling safe in environment	2.95 *(SD*=1.18)	3.80 (*SD*=0.83)	+.86
Item		Family members	Family members	Mean difference
6	Have transportation	1.34 (*SD*=0.60)	1.25 (*SD*=0.72)	-.09
15	Get medical care	2.88 (*SD*=1.36)	3.50 (*SD*=1.10)	+.62
16	Way to take care of expenses	1.41 (*SD*=0.92)	1.20 (*SD*=0.41)	-.21
20	Get dental care	2.58 (*SD*=1.39)	3.60 (*SD*=1.14*)*	+1.02
21	Feeling safe in environment	2.78 (*SD*=1.28)	3.35 (*SD*=1.18)	.57

Table 30 shows the results of the one sample t-tests. It is important to note that item 21 is not included in this analysis, due to low correlations with the other items in this domain (see *paragraph 5.3).* Moreover, affected persons scored lower after the first part of the intervention (-.10, *p*=.304), while family members experienced significantly improved 'physical/material wellbeing' (+.31, *p*=.004). Overall, the differences between the baseline and the follow-up data were not significant (t(39)=1.167, *p*=.250).

Table 30: Comparison of the baseline and follow-up data for the domain 'physical/material wellbeing'

	Mean values			**One sample t-test**	
Respondent group	Baseline	Follow-up	Mean difference	t(df)	P-value (2-tailed)
All combined	2.24	2.36	+.12	1.167 (39)	.250
Persons affected	2.46	2.36	-.10	-1.041 (39)	.304
Family members	2.06	2.36	+.31	3.074 (39)	.004

5.3.5 Disability-related support

Table 31: Overview of the items included in the domain 'disability-related support'

Item number	**Item**
22	My family member with a disability has support to accomplish goals at school or at workplace.
23	My family member with a disability has support to accomplish goals at home.
24	My family member with special needs has support to make friends.
25	My family has a good relationship with the service providers who work with our family member with a disability.

5.3.5.1 Quantitative data

As shown in *Table 32,* item 23, 24 and 25 scored better during the follow-up than during the baseline data collection. Item 24 and item 25 showed a large improvement, with mean differences of +.71 and +.72 respectively. Item 23 had an increased score as well, although this increase was smaller: on average +.26. Item 22 was the only item that scored lower in this domain, with the biggest negative change for family members (-1.15).

Table 32: The results of the baseline and follow-up data for the domain 'disability-related support'

		Mean value baseline	Mean value follow-up	
Item		All participants	All participants	Mean difference
22	Support at school/workplace	1.94 *(SD*=0.92)	1.64 (1) (*SD*=0.93)	-.30
23	Support at home	3.24 *(SD*=1.00*)*	3.50 (*SD*=0.96)	+.26
24	Support to make friends	3.29 *(SD*=1.04*)*	4.00 (1) (*SD*=0.56)	+.71
25	Relationship with service providers	3.34 *(SD*=1.13*)*	4.05 (1) (*SD*=0.22)	+.72
Item		Persons affected	Persons affected	Mean difference
22	Support at school/workplace	2.13 (*SD*=0.72)	1.65 (*SD*=0.74)	-.48
23	Support at home	3.15 (*SD*=0.97)	3.45 (*SD*=0.10)	+.31
24	Support to make friends	3.25 (*SD*=1.08)	4.00 (*SD*=0.00) (1)	+.74
25	Relationship with service providers	3.38 (*SD*=1.10)	4.00 (*SD*=0.00) (1)	+.62
Item		Family members	Family members	Mean difference
22	Support at school/workplace	1.78 *(SD*=1.05)	1.63 (1) (*SD*=1.12)	-1.15
23	Support at home	3.33 *(SD*=1.02)	3.55 (*SD*=0.95)	+.22
24	Support to make friends	3.31 *(SD*=1.02)	4.00 (*SD*=0.80)	+.69
25	Relationship with service providers	3.30 *(SD*=1.16)	4.10 (*SD*=0.31)	+.80

Table 33 shows the changes in the entire domain. All changes were positive and very significant. The biggest mean differences can be found for family members (+.41). However, since the Cronbach's α is negative for the follow-up data, the items should not be interpreted as a whole.

Table 33: Comparison of the baseline and follow-up data for the domain 'disability-related support'

	Mean values			One sample t-test	
Respondent group	Baseline	Follow-up	Respondent group	t(df)	P-value (2-tailed)
All combined	2.95	3.30	+.35	6.952 (39)	.000
Persons affected	2.98	3.25	+.27	6.658 (19)	.000
Family members	2.93	3.34	+.41	4.521 (19)	.000

5.3.5.2 Qualitative data

The first open question in this domain asked affected persons what type of products would support them with doing household activities. Nine persons affected mentioned that shoes would be helpful, followed by clothing (n=8), blankets that can also be used for clothing (n=4), jerrycans to fetch water from the river (n=3), and socks (n=3). Again, participants mentioned money (n=5) and medication (n=3).

The second open question in this domain asked participants what they think of the support of this project. 37 participants responded, of whom 36 had a positive attitude towards the intervention. One family member mentioned that it is hard to reflect on the intervention since there are no results yet from the blood samples that were taken. The following quotes show how one person affected and a respondent pair feel about this project:

> *''It is very nice. Others who live in the countryside who have not received this aid are very envious of us.''* – GA5
> *''I see [the project] just like God.''* - GA21
> *''I am very happy that [the project] is providing something which has never been done before (...). I have seen change to those people who were previously not even recognized by the government.''* – GF21

Seven participants (three persons affected and four family members) mentioned a change in health as reason for liking the project. Five participants mentioned gratefulness. They appreciated that the project came from abroad to help them and that it was set up to cure them. Moreover, a family member mentioned that without this project, family members would have never supported the persons affected.

The third open question asked about what participants liked most about the support they received during the project. The majority of the participants (12 persons affected and ten family members) mentioned that they appreciated the hygiene products received the most. The best thing about the hygiene products was that these can be used independently at home, shown in the following quotes:

> *″I love that you go around visiting house to house and that I was able to get care by receiving items at my house.″* – GA9
> *″[I liked] the fact that the organization/project has given materials and items and made it possible for those who are sick to use it inside their house.″ – GF7*

The second largest positive thing was the home visits (eleven persons affected and eight family members). It can be hard for the participants to visit a health care center, both due to impairments and poor availability of health care centers in rural areas in Ethiopia, according to the expert interviewee. Moreover, three persons affected and three family members stated the follow-up care contributed to the quality of the intervention.

> *″What is very good about the project, is that it has come to my house to teach and follow up on me so that I could be equal to the healthy people.″* – GA16

Another positive thing about the project was the training participants received. Mainly family members recognized this as the best part of the intervention (n=5). A family member mentioned the additional advantage of the training that it raised awareness about NTDs. One person affected and four family members also appreciated the existence of the association that was formed to support people. The association was seen as helpful in the long term as well, since it stimulates getting a job, according to two family members. The expert interviewee agreed with this, adding that it helps to increase awareness for NTDs as well as supporting jobs and income creation for affected people.

Asking about possible points of improvement led to multiple suggestions. In total, 24 participants (eleven persons affected and thirteen family members) mentioned the need to receive additional medication. With the help of this, they want the NTDs to be completely cured:

> *″As I have said, my leg's condition has become better, it would be nice if additional medications are brought so that the disease can be totally eliminated.″* – GA11

Two respondent pairs had specific wishes about administration of the medication. They believed that medications via injection are more efficient to cure diseases. The expert interview indicated that some Ethiopian people believe that injections are the best option, since it can be administered in the part of the body where they feel the pain. Due to lack of knowledge, some people do not understand that pills taken orally can be effective in a body part other than the mouth or the head. The following quote illustrates this belief:

> *″If another medication could be provided which could be administered by injection, so that our leg's condition can become better.″* – GA12

The second point of improvement was to receive resources, such as shoes (n=8), socks (four participants) and clothing (n=6). Due to the swelling caused by LF and podoconiosis, the participants’ own shoes, socks and clothing often do not fit anymore. Other resources that participants mentioned are more jerrycans to get water from the river more easily, additional Vaseline to take care of the wounds, and beds and blankets. These suggestions were all mentioned by persons affected.

Furthermore, 'more financial support' was mentioned by one person affected and five family members as a point of improvement. The expert interviewee stated that it is more important to create a mindset-shift that can help people to generate their own income, rather than providing money. He believes that direct grants will only help in the short term. However, he recognized that participants tend to focus on short-term results. Moreover, mainly family members mentioned the association, which they believed will help with jobs and income. One person affected mentioned this as well, stating that an office for the association would be helpful, and that it is important that the association can sustain itself. The expert interviewee believes that the government can provide support in the form of donating some land and giving a subsidy. Four family members talked about the sustainability of the association as well. According to the expert interviewee, it is helpful if the government appoints someone who will assume primary responsibility for the continuation of the association. He does not believe that that should be one of the participants, since he thinks they cannot handle such responsibility. Two family members added that it would be good if more jobs would be created for the persons affected. Finally, three participants mentioned that they had no specific points of improvement, but that it is important that the project continues, including the follow-up appointments.

6. Discussion

This study was executed with the objective of evaluating the short-term impact of a family-based intervention in the Zigem area in Ethiopia on persons affected by LF and podoconiosis and their families. In this chapter, the key findings are discussed and reflected on. Moreover, a conclusion and implications for further research are formulated.

6.1 Key findings and comparison with existing literature

This section presents and interprets the key findings and compares these, where possible and relevant, to existing literature. First, when looking at the comparison between the two respondent groups in both the baseline data and the follow-up data, big differences are in evidence. The baseline data showed eleven significant differences between persons affected and family members, the follow-up data showed only one difference. It should be considered that the respondent groups in the baseline data are not necessarily linked to each other. However, it is also possible that the perceptions of the respondent groups have become more similar during the project. This could imply that the family members are now better able to understand the needs of the persons affected, potentially facilitating their support of affected persons. Moreover, it stood out that all differences entailed a higher score from affected persons. Their mean score was higher than the mean score of the family members in both data samples as well, indicating a higher FQoL. Interestingly, the family members experienced the largest improvement in each domain. This may indicate that the intervention was especially effective for family members.

Sub-question 1 looked at the impact of the intervention on the domain 'family interaction.' Comparing the baseline and follow-up data showed similar results for the respondent groups combined and separated: four items (1, 7, 10 and 12) increased and two items (11 and 18) decreased. Overall, the mean difference was slightly positive for family members (0.17), but negative for affected persons (-0.12). Both affected persons and family members mentioned the importance of a stove and chopping wood. It is planned to hand out energy-saving stoves later in the project, which fits the participants' needs. These stoves need less fuel, making it easier for affected persons to collect and chop sufficient wood, and less time-intensive for family members to prepare food (Tigabu, 2014). The stoves are also designed to prevent burns, limiting further injury to affected persons. Some resources that could support people with safely chopping wood might be helpful as well, making persons affected more independent. Additional literature shows that maintaining independence is seen as a crucial aspect of one's quality of life (Gignac et al., 2000). Family members mainly mentioned the need of medication and money, indicating that they focus on the short-term impact. The expert interviewee agrees with this conclusion and mentioned that a focus on a mindset switch is more important than short-term results.

In *sub-question 2,* the domain 'parenting' was assessed. All items scored higher during the first follow-up than during the baseline measurement. The items combined showed significant improvements as well. The open question demonstrated that care of persons affected is mainly done by children, which matches the outcome of the study of Nidaw (2018). It could be valuable to design an intervention that is especially suitable for children. Interventions should be, for example, adapted to one's educational level, culture and language (Kumpfer et al., 2002).

The domain 'emotional wellbeing' was evaluated with *sub-question 3.* This domain stood out, since the evaluation did not show any positive results. Multiple studies show the negative effect of the caregiver burden on mental health in LMICs (Kipp et al., 2007; Schulz & Sherwood, 2008). Long term follow-up will show if the project's effect on emotional wellbeing will eventually be positive, once people are used to their increased caregiving tasks. It is a possibility that participants believed beforehand that their condition could be easily cured by getting drugs, for example, and they now realize that this is not the case. Affected persons and families may also find getting started with things like wound-cleaning unpleasant. Moreover, talking about the NTDs could have a negative impact on emotional wellbeing. One participant stated that this caused stress. Item 9, ‘my family members have some time to pursue their own interests,’ declined most. This might relate to the time required for participating in the project. This is in line with the findings of Kipp et al. (2007), who stated that caregivers in Uganda describe caregiving as a full-time job.

The open question showed that almost every participant (38 out of forty) experiences stress, which is in line with the findings of Aldersey et al. (2017). This is for both respondent groups due to the health conditions and struggling to complete household tasks. The project already addresses these problem areas, which is positive. However, ‘lack of freedom’ is also seen as a cause of stress. Aldersey et al. (2017) stated that sometimes, an appropriate infrastructure to offer disability-related support is absent in LMICs and the support is often too expensive to access. Therefore, it is recommended to invest in possibilities for improved transportation for disabled people. Moreover, mobility adaptations such as wheelchairs or devices to help affected persons on the back of a mule or horse, can be helpful.

In general, it stood out that mental health is not often mentioned by participants, and mental health is not incorporated in the project as well. However, the poor scores in the domain ‘emotional wellbeing’ show the need to invest in mental health support. The expert interviewee suggested sharing movies that show success stories of disabled people. This might create hope and show specific strategies for meeting goals, improving the respondents’ mental health. Literature showed that sharing feelings and stories with people in similar situations is important (Repper & Carter, 2011). A recommendation can be to use the association for more than income generation, by also creating a safe place to share problems and have social interactions. Self-help groups influence mental health positively by improving social resources and coping skills and stimulating problem solving related to impairment (Law et al., 2002; Moos et al., 2001).

Sub-question 4 looked at the domain of physical/material wellbeing. This domain showed mixed results, with three items positive (item 15, 20 and 21) and two items negative (item 6 and 16). Persons affected scored slightly lower during the follow-up, and family members scored significantly higher. The participants experienced more feelings of safety during the follow-up. According to the expert interviewee, this might relate to a decrease of stigma. A study conducted in the DRC stated that a person with disabilities may be socially excluded and depressed due to discrimination, and stigma is relevant to take into account (Aldersey et al., 2017). It is possible that the association can help reduce stigma as well. It might be helpful to involve community and religious leaders, since they have a big influence on stigma concerning NTDs in a community (Barney et al., 2006). Moreover, providing visual health education materials to the community might be helpful (Maulik et al., 2017).

The impact of the intervention on the disability-related support domain was examined in *sub-question 5*. Items 23, 24 and 25 scored higher after the intervention. Item 22, which was about the support to accomplish goals at school or at workplace, scored lower. Quantitative analyses for the entire domain were not reliable, due to a negative Cronbach’s α for the follow-up data. The open questions showed that participants are grateful for the support the project offers. Mainly the hygiene products that can be used independently at home, the home visits, and the training received were appreciated; the latter were mostly valued by family members. Furthermore, participants mentioned the need for shoes, blankets, jerrycans and socks, which is in line with the plans of the project. However, shoes and socks are currently only handed out at the end of the project. It might be helpful to hand out simple shoes, that do not require any individual orthopedic adjustments, or socks in the beginning as well. According to Lienhart et al. (2010), shoes are crucial for treatment. Clothing is also mentioned frequently but is not included in the project yet. It might be an idea to provide fabrics and resources to adjust those fabrics, so affected persons and their family can create fitting clothes. This could also prevent the persons affected from feeling bored at home, and can facilitate social contacts. LF and podoconiosis do not always affect hands and arms, making sewing still a possibility. Moreover, the field trips allowed the researcher to discover that sewing is not stigmatized as 'women's work.' Providing sewing lessons, basic sewing kits, and sewing machines can facilitate this idea. The low score of item 22 might be improved by this initiative as well, since it provides support to accomplish goals. In addition, if sufficient skills can be developed, sewing could present an income-generation opportunity.

Moreover, participants mentioned they appreciate the home visits and follow-up appointments. The project currently has three monthly follow-ups. To improve long-term impact, more follow-up visits are recommended. This is helpful for improving motivation by cheering successes and answering questions, and showing that the research assistants care for the participants (Greene et al., 2016). These appointments would also provide an opportunity to introduce new topics, such as mental health and income generation.

Finally, the income-generating association was mentioned as a positive aspect of the project. According to a participant, it is important that this association can sustain itself. This can be done with the help of an office and capable leaders. The expert interviewee mentioned that someone working at the government should be appointed as leader. A study of Mansuri & Rao (2004) agrees with this point of view: external actors strongly influence the success rate of a project, while projects relying on community participants have not been more effective. When using external help, it is important that they are trained and experienced (Mansuri & Rao, 2004).

6.2 Practical implications of the results

Overall, participants are very positive about this project. However, there are some adjustments that might improve the impact of this project, summarized in *Table 33.*

Table 34: A summary of the recommendations, based on the results of this study

Problem description	Possible solution
Persons affected experience stress because they have difficulties with carrying out daily activities.	Provide resources to support people with safely chopping wood.
The project focuses on adolescents, while most participants mentioned that children are the main caregivers.	A next project could focus on supporting children. Therefore, the level of the information sessions has to be adjusted for children.
'Lack of freedom' is seen as a cause of stress.	Invest in possibilities for improved transportation and mobility adaptations for affected people.
The domain 'emotional wellbeing' shows very poor scores.	Pay more attention in the project to mental health. The association might be a good place to share problems and have social interactions.
Participants might experience stigma in their environment.	Involve community and religious leaders to improve awareness of NTDs and reduce stigma.
	Provide visual health education materials to the community.
Shoes and socks are only handed out at the end of the project.	It might be helpful to hand out shoes or socks in the beginning as well to stimulate recovery.
Clothing that fits well is mentioned frequently by participants as desirable addition to the project but is currently not included in the project.	Provide fabrics and resources to adjust fabrics, so people can create and sell fitting clothes. Providing sewing lessons, basic sewing kits, and sewing machines can facilitate this idea.
It is seen as important that the association can sustain itself, but a plan to achieve that is absent.	Someone with good liaisons to the government should be appointed as leader.

6.3 Reflection on the theoretical model and the results

Although the theoretical model was a survey that was validated and previously used in comparable countries (Ajuwon & Brown, 2012; Aldersey et al., 2017), the reflection by means of quantitative tests was not always positive. The domains in the baseline data scored an average Cronbach's α of 0.68, but the follow-up data scored much lower with a Cronbach's α of 0.38. This is both lower than the desirable Cronbach's α of 0.70. The low correlation might relate to participants giving random answers, possibly due to misunderstanding or feelings of shame. Furthermore, the follow-up sample was relatively small (n=40), which could have influenced the Cronbach's α. Another option for the low correlation is that the research assistants needed more guidance with collecting the interview-based surveys. It is also possible that the FQoL survey is less applicable in the context of the Zigem area. For example, item 20 about available dental care was not really relevant: this might be important in the Western world but is not considered a basic need in Ethiopia. This cultural sensitivity should be taken into account for the entire domain of 'disability-related support'. In the Zigem area, (professional) support is barely available and might, therefore, be hard to assess. Moreover, the FQoL framework makes no distinction between professional care and informal care, which can decrease the correlation. This indicates a need for an adapted version of the FQoL framework to fit better in the context of Ethiopia. In this framework, family-based care should be the standard, with professional care as a possible extra option.

As a response to this limitation, an expert interview was added to consider possible cultural sensitivity. Moreover, the lack of correlation was handled by excluding one variable from the domain 'physical/material wellbeing' and not using the results of the domain 'disability-related support' as a whole. Looking at the correlations between the domains, shows more positive results. Of the baseline data, all correlations are positive, of which six correlations are significant. The follow-up data had six positive correlations, of which two were significant.

6.4 Strengths and limitations of the study

Several factors strengthened the validity and quality of this study. First, an elaborate process of back-forward translation took place, in line with the WHO guidelines (WHO, 2019c). This was needed due to cultural differences and the average level of education in Ethiopia. As a part of this, the survey was piloted twelve times, which is more than recommended. Second, there has been involvement of experienced people from Ethiopia in designing, carrying out and evaluating the intervention. Based on their experiences, they were able to make helpful suggestions. Third, the combination of quantitative and qualitative data provided a better understanding of the data.

Although this study was carefully designed and executed, some factors may have influenced the results. First, the baseline sample and the follow-up sample do not (necessarily) contain the same people. Therefore, it is more difficult to draw conclusions from comparisons between those two moments of time. Literature shows that 'partial overlap' in data is challenging to analyze statistically (Derrick et al., 2017). To decrease the impact of this limitation, qualitative data is used as well and statistical tests were performed where possible. It is recommended to have completely overlapping samples for the final evaluation and have a bigger follow-up sample to remedy this limitation. Second, it is a possibility that the "Hawthorne effect" has influenced the results. The Hawthorne effect causes more positive results, because the fact that people are participating in a study encourages them to report more positive results during a follow-up moment (McCarney et al., 2007). However, participants also reported lower scores in the follow-up sample in some domains, which may indicate a limited Hawthorne effect. Last, not all people in rural areas in Ethiopia know their exact age. That should be considered when looking at the descriptive statistics concerning age.

6.5 Conclusion

This study was conducted to answer the following research question: ''*What is the short-term impact of the family-based interventions implemented in the Zigem area, Ethiopia on persons affected by LF and podoconiosis and their family members?*'' Looking at the five domains of the FQoL framework showed the impact of the intervention. 'Family interaction' changed negatively for persons affected, but positively for family members, although no changes were significant. All changes in the domain 'parenting' were positive and very significant. All items of 'emotional wellbeing' scored lower after the intervention, and this decrease was significant overall. 'Physical/material wellbeing' returned mixed results. Persons affected scored lower, although not significantly. Family members scored significantly higher, therefore resulting in an overall higher score in this domain. The domain 'disability-related support' showed positive results as well. Overall, the FQoL was perceived as higher by the participants after the intervention than before and persons affected experienced the highest FQoL. The FQoL perceived by family members improved more than the FQoL of persons affected.

Looking at the qualitative data showed that participants appreciate the project because of improved health conditions, and personal attention by means of among other factors, the care provided and home visits. However, participants desire money and job creation, but also resources such as clothing, shoes, socks and products that facilitate doing household tasks, such as stoves. Health conditions, household tasks and lack of freedom are primary sources of stress to participants. Recommendations to improve the project include to focus the project on supporting children as well; to pay more attention to mental health and utilize the association for that purpose; to involve community and religious leaders and provide visual health education materials to the community to decrease stigma; to hand out simple shoes or socks earlier in the project; and to initiate a sewing project, where people can make and sell handmade clothing, thereby creating fitting clothes and potentially creating jobs, income and social interactions.

6.6 Implications for further research

The results of this study point to a need to investigate the possibilities of implementing this project on a larger scale. In order to do this, the generalizability of the results of this study should be examined. This will facilitate successful implementation in other areas.

Moreover, this study showed that emotional wellbeing has not improved during this project. Further research could explore the possibilities to improve mental health for people with NTDs and their family members in LMICs. Also, the possible negative effects of healthcare interventions on mental wellbeing is an interesting and relevant topic for future work.

Finally, to improve the long-term impact of the project, it is important to further examine the recommendations. This includes studying the possible impact of community or religious leaders and analyzing the possibilities of increasing the success rate of family associations. When conducting further research, it is crucial that the environment is similar or comparable to the Zigem area.

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Appendix 1: Explanation of relevant actor groups

1. Person affected

The first and most important actor group consists of the people directly affected by LF and podoconiosis, further elaborated on in paragraph *2.3.1.* Persons affected can experience self-stigma, resulting in low self-esteem and low self-efficacy (Ribera et al., 2009).

2. Direct environment of persons affected

The next relevant actor group is people in the direct environment of persons affected by LF and podoconiosis, such as friends, family, and people at work or at school. This group is the closest to the persons affected and they can, therefore, influence each other in the most direct way (Bronfenbrenner, 1977). This can result in both negative and positive changes (Bronfenbrenner, 1977). If stigma is present in the direct environment, perceived discrimination, low self-esteem, depression and lower Quality of Life (QoL) of the person affected may be the result (Phelan et al., 2015). In the context of this study, the family is the most important component of this actor group, as the project to be evaluated is focused on care provided within the family.

3. Healthcare professionals

In order to stimulate (standardization of) treatment of NTDs, the FMoH has developed several guidelines (Mengitsu et al., 2016). This includes the 'NTD pocket guide,' aiming to provide a reference for healthcare professionals working at the community level (Mengitsu et al., 2016). Healthcare professionals are an important actor group that includes physicians and others working in healthcare. Finally, health volunteers in Ethiopia are important in providing health care (Leon et al., 2015).

4. Non-governmental organizations

Non-governmental organizations (NGOs) implement health programs as well. NGOs are often able to act quicker, and sometimes individuals working in NGOs are more motivated than individuals working in governmental organizations (Yamey, 2011). NGOs can also focus on one or a small group of conditions rather than public health in general. Therefore, NGOs can play a crucial role in improving population health (Yamey, 2011). The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) is an NGO, making the entire project related to this study a non-governmental project.

5. The Ethiopian Federal Ministry of Health

The government in the context of this study is the Ethiopian government, and more specifically the Ethiopian Federal Ministry of Health (FMoH). The FMoH has implemented several prevention and treatment programs to diminish the prevalence of NTDs in Ethiopia. Mengitsu et al. (2016) stated that the Ethiopian FMoH has successfully implemented mass drug administration for LF, among other conditions. However, sufficient national programs to decrease the prevalence of podoconiosis are still absent (Mengitsu et al., 2016).

6. The World Health Organization

The World Health Organisation (WHO) acts on the highest and largest level. Their aim is to address the burden of NTDs by developing policies and making investments to improve the health and wellbeing of the affected populations (WHO, 2019a). The WHO collaborates with governmental institutions, academia, and civil society actors to fulfill the ambition to eliminate NTDs (WHO, 2019a).

Appendix 2: Interview guide

These questions were used for the short interviews to test the added open questions. The interviews were conducted with the main researcher and four research assistants.

In general:

- Do you think that these questions help to improve the intervention?
    - What knowledge do you currently miss to improve the intervention?
- What would you adjust to the questions? Why?
- What would you remove from the questions? Why?
- What would you add to the questions? Why?

About the domains with added open questions:

- What do you think about these questions?
    - Are the questions culturally appropriate to ask?
    - Do you think people will answer the questions honestly?
    - Do you think people are able to understand these questions, once translated?
    - Do you think it is helpful to make different questions for persons affected and family?
- What would you like to know concerning [add specific domain]?

About the domain ‘physical and emotional wellbeing:

- Do you think this domain needs an open question?
    - If yes, what question would you add?

Appendix 3: Backward translation of the open questions

Table 35: The original questions (left) and the backward translations from Amharic to English (right)

Item number	Question	Translated from Amharic
Added to item 3	Do you often experience stress?	Do you feel stressed most of the time?
Added to item 3	If yes: What are the main factors causing stress in your family?	If yes: what are the main things which cause stress in your family?
Added to item 3	What outside help would you like to receive to improve the level of stress or your emotional wellbeing?	What kind of support would you like to receive so as to lessen your stress or to keep up your (emotional) health?
Added to item 12	What support would you like to receive from your family?	What type of support would you like to get from your family?
Added to item 12	What do you need to provide more care to a family member?	What do you want in order to take better care of a sick family member?
Added to item 19	Who is mainly responsible for taking care of you in the family?	Who takes the primary responsibility of taking care of you inside the family?
Added to item 23	What additional products or resources would help you to get things done more easily in your home?	What other additional product/device would help you to work easily inside the house?
Added to item 25	How did you experience the help received in this project?	How do you find the support you got from this project?
Added to item 25	What did you like most about the help received in this project?	From the support that you received from this project, what did you love the most?
Added to item 25	What do you think could be improved in this project?	What things do you think could be improved from this project?

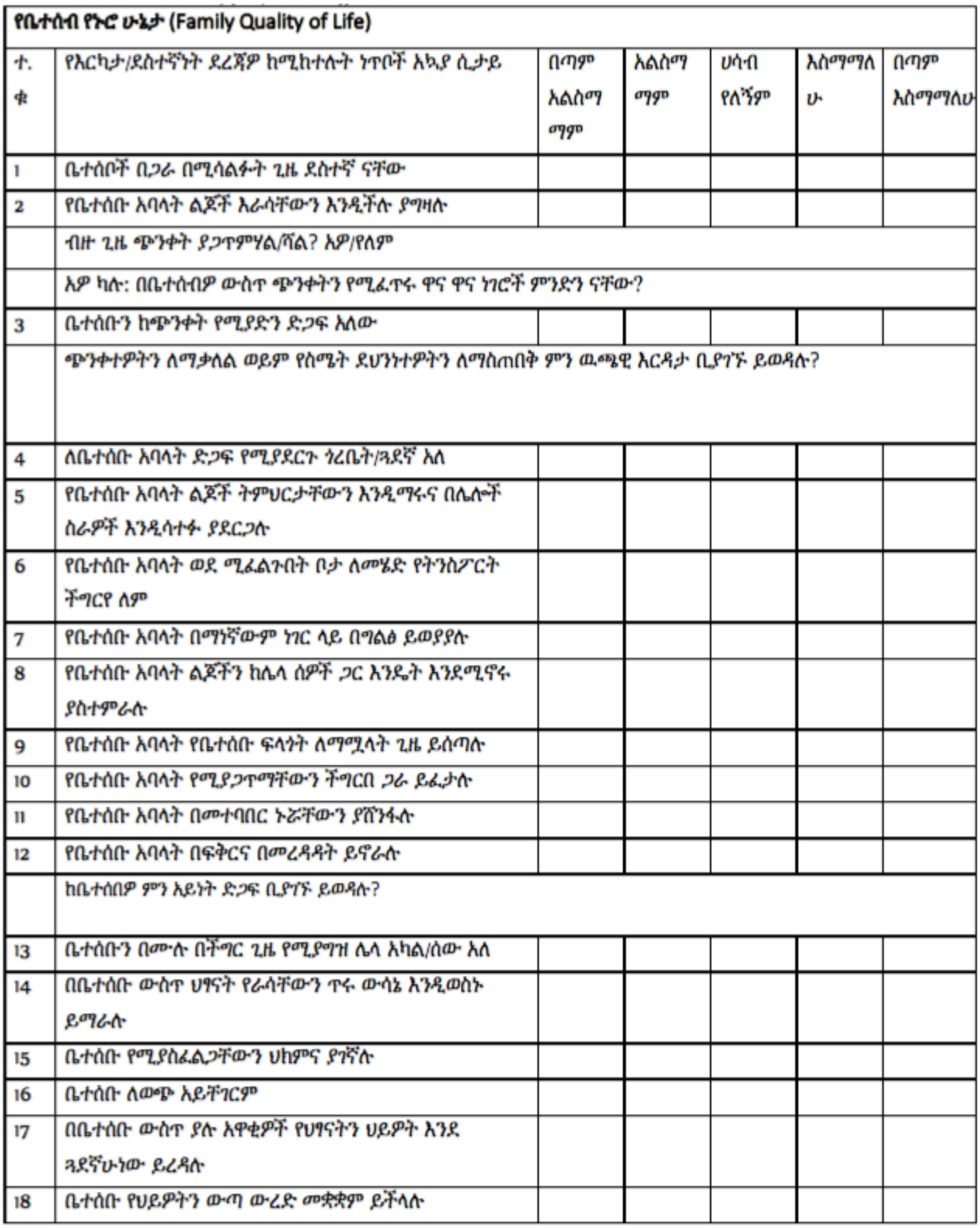
Appendix 4: Main characteristics of the pilot-testing sample

Table 36: The main characteristics of the pilot-testing sample (n=12)

Statistic	Persons affected (n=6)	Family members (n=6)
Males	1	3
Females	5	3
LF	2	2
Podoconiosis	4	4
Mean age	48.7	40.8
Median age	46.5	35.0
Minimum age	20	18
Maximum age	85	85
Standard deviation (*SD)* age	22.4	23.7

Appendix 5: Final version of the survey in Amharic

Table 37: The survey in Amharic for persons affected

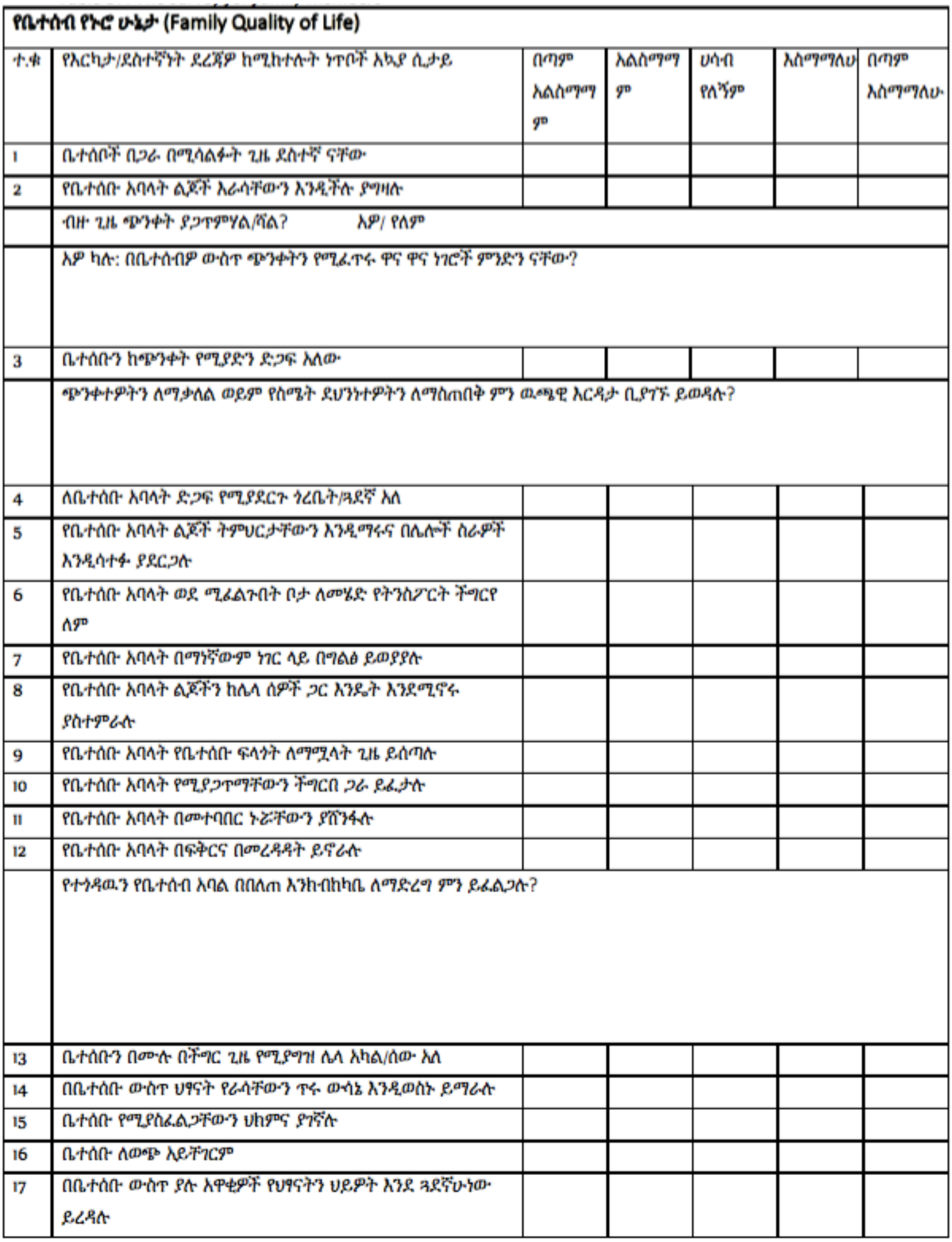


የቤተሰብ የኑሮ ሁኔታ (Family Quality of Life)						
ተ.ቁ	የእርካታ/ደስተኛነት ደረጃዎ ከሚከተሉት ነጥቦች አኳያ ሲታይ	በጣም አልስማማም	አልስማማም	ሀሳብ የለኝም	እስማማለሁ	በጣም እስማማለሁ
1	ቤተሰቦች በጋራ በሚሳልፉት ጊዜ ደስተኛ ናቸው					
2	የቤተሰቡ አባላት ልጆች እራሳቸውን እንዲችሉ ያግዛሉ					
	ብዙ ጊዜ ጭንቀት ያጋጥምሃል/ሻል? አዎ/የለም					
	አዎ ካሉ: በቤተሰብዎ ውስጥ ጭንቀትን የሚፈጥሩ ዋና ዋና ነገሮች ምንድን ናቸው?					
3	ቤተሰቡን ከጭንቀት የሚያድን ድጋፍ አለው					
	ጭንቀተዎትን ለማቃለል ወይም የስሜት ደህንነተዎትን ለማስጠበቅ ምን ዉጫዊ እርዳታ ቢያገኙ ይወዳሉ?					
4	ለቤተሰቡ አባላት ድጋፍ የሚያደርጉ ጎረቤት/ጓደኛ አለ					
5	የቤተሰቡ አባላት ልጆች ትምህርታቸውን እንዲማሩና በሌሎች ስራዎች እንዲሳተፉ ያደርጋሉ					
6	የቤተሰቡ አባላት ወደ ሚፈልጉበት ቦታ ለመሄድ የትንስፖርት ችግርየ ለም					
7	የቤተሰቡ አባላት በማነኛውም ነገር ላይ በግልፅ ይወያያሉ					
8	የቤተሰቡ አባላት ልጆችን ከሌላ ሰዎች ጋር እንዴት እንደሚኖሩ ያስተምራሉ					
9	የቤተሰቡ አባላት የቤተሰቡ ፍላጎት ለማሟላት ጊዜ ይሰጣሉ					
10	የቤተሰቡ አባላት የሚያጋጥማቸውን ችግርበ ጋራ ይፈታሉ					
11	የቤተሰቡ አባላት በመተባበር ኑሯቸውን ያሸንፋሉ					
12	የቤተሰቡ አባላት በፍቅርና በመረዳዳት ይኖራሉ					
	ከቤተሰበዎ ምን አይነት ድጋፍ ቢያገኙ ይወዳሉ?					
13	ቤተሰቡን በሙሉ በችግር ጊዜ የሚያግዝ ሌላ አካል/ሰው አለ					
14	በቤተሰቡ ውስጥ ህፃናት የራሳቸውን ጥሩ ውሳኔ እንዲወስኑ ይማራሉ					
15	ቤተሰቡ የሚያስፈልጋቸውን ህክምና ያገኛሉ					
16	ቤተሰቡ ለወጭ አይቸገርም					
17	በቤተሰቡ ውስጥ ያሉ አዋቂዎች የህፃናትን ህይወት እንደ ጓደኛሁነው ይረዳሉ					
18	ቤተሰቡ የህይዎትን ውጣ ውረድ መቋቋም ይችላሉ					

19	በቤተሰቡ ውስጥ ያሉ አዋቂዎች የእያንዳንዱን ህፃናት ፍላጎት ለማሟላት ይሰራሉ					
	እርሰዎ ወላጅ ነዎት? አዎ/አይደለሁም					
	ጉዳት ላለበት ሰዉ በቤተሰብ ዉስጥ በዋናነት እንክብካቤ ለማድረግ ሃላፊነት የሚወስደዉ ማን ነዉ?					
20	ቤተሰቡ የጥርስ ህክምና ሲያስፈልግ ማግኘት ይችላል					
21	ቤተሰቡ በስራ ቦታ፤ በት/ቤትም ሆነ በጎረቤት ምቾት/ደህንነት ይሰማቸዋል					
22	የአካል ጉዳት ያለበት የቤተሰቡ አባል በስራ ቦታም ሆነ በት/ቤት አላማውን ለማሳካት ተገቢ ድጋፍ ያገኛል					
23	የአካል ጉዳት ያለበት የቤተሰቡ አባል በቤት ውስጥ አላማውን ለማሳካት ተገቢ ድጋፍ ያገኛል					
	በቤታችሁ ነገሮችን በቀላሉ ለመስራት ሌላ ምን ተጨማሪ ምርት/ እቃ ሊረዳችሁ ይችላል?					
24	የአካል ጉዳት ያለበት የቤተሰቡ አባል ጓደኛ እንዲኖረው ድጋፍ ያገኛል					
25	የቤተሰቡ አባላት ከማንኛውም አገልግሎት ሰጭ አካላት ጋር ጥሩ ግንኙነት አላቸው					
	ከዚህ ፕሮጀክት ያገኛችሁትን ድጋፍ እንዴት አገኛችሁት?					
	ከዚህ ፕሮጀክት ካገኛችሁት ድጋፍ የትኛዉን በጣም ወደዳችሁት?					
	ከዚህ ፕሮጀክት ምን ሊሻሻል ይችላል ብለዉ ያስባሉ?					

ለሰጡኝ ቃለ መጠይቅ አመሰግናለሁ!

Table 38: The survey in Amharic for family members



የቤተሰብ የኑሮ ሁኔታ (Family Quality of Life)						
ተ.ቁ	የእርካታ/ደስተኛነት ደረጃዎ ከሚከተሉት ነጥቦች አኳያ ሲታይ	በጣም አልስማማም	አልስማማም	ሀሳብ የለኝም	እስማማለሁ	በጣም እስማማለሁ
1	ቤተሰቦች ቢጋራ በሚሳልፉት ጊዜ ደስተኛ ናቸው					
2	የቤተሰቡ አባላት ልጆች እራሳቸውን እንዲችሉ ያግዛሉ					
	ብዙ ጊዜ ጭንቀት ያጋጥምሃል/ሻል? አዎ/ የለም					
	አዎ ካሉ: በቤተሰብዎ ውስጥ ጭንቀትን የሚፈጥሩ ዋና ዋና ነገሮች ምንድን ናቸው?					
3	ቤተሰቡን ከጭንቀት የሚያድን ድጋፍ አለው					
	ጭንቀተዎትን ለማቃለል ወይም የስሜት ደህንነተዎትን ለማስጠበቅ ምን ዉጫዊ እርዳታ ቢያገኙ ይወዳሉ?					
4	ለቤተሰቡ አባላት ድጋፍ የሚያደርጉ ጎረቤት/ጓደኛ አለ					
5	የቤተሰቡ አባላት ልጆች ትምህርታቸውን እንዲማሩና በሌሎች ስራዎች እንዲሳተፉ ያደርጋሉ					
6	የቤተሰቡ አባላት ወደ ሚፈልጉበት ቦታ ለመሄድ የትንስፖርት ችግርየ ለም					
7	የቤተሰቡ አባላት በማንኛውም ነገር ላይ በግልፅ ይወያያሉ					
8	የቤተሰቡ አባላት ልጆችን ከሌላ ሰዎች ጋር እንዴት እንደሚኖሩ ያስተምራሉ					
9	የቤተሰቡ አባላት የቤተሰቡ ፍላጎት ለማሟላት ጊዜ ይሰጣሉ					
10	የቤተሰቡ አባላት የሚያጋጥማቸውን ችግርበ ጋራ ይፈታሉ					
11	የቤተሰቡ አባላት በመተባበር ኑሯቸውን ያሸንፋሉ					
12	የቤተሰቡ አባላት በፍቅርና በመረዳዳት ይኖራሉ					
	የተጎዳዉን የቤተሰብ አባል በበለጠ እንክብከካቤ ለማድረግ ምን ይፈልጋሉ?					
13	ቤተሰቡን በሙሉ በችግር ጊዜ የሚያግዝ ሌላ አካል/ሰው አለ					
14	በቤተሰቡ ውስጥ ህፃናት የራሳቸውን ጥሩ ውሳኔ እንዲወስኑ ይማራሉ					
15	ቤተሰቡ የሚያስፈልጋቸውን ህክምና ያገኛሉ					
16	ቤተሰቡ ለወጭ አይቸገርም					
17	በቤተሰቡ ውስጥ ያሉ አዋቂዎች የህፃናትን ህይወት እንደ ጓደኛሁነው ይረዳሉ					

18	ቤተሰቡ የህይዎትን ውጣ ውረድ መቋቋም ይችላሉ					
19	በቤተሰቡ ውስጥ ያሉ አዋቂዎች የእያንዳንዱን ህፃናት ፍላጎት ለማሟላት ይሰራሉ					
	እርስዎ የታማሚዉ ልጅ ወላጅ ነዎት? እዎ/ አይደለሁም					
	እዎ ካሉ፤ የአካል ጉዳተኛዉ ልጅ በመኖሩ ምን መልካም ነገር አለ?					
	ጉዳት ላለበት ሰዉ በቤተሰብ ዉስጥ በዋናነት እንክብካቤ ለማድረግ ሃላፊነት የሚወስደዉ ማን ነዉ?					
20	ቤተሰቡ የጥርስ ህክምና ሲያስፈልግ ማግኘት ይችላል					
21	ቤተሰቡ በስራ ቦታ፤ በት/ቤትም ሆነ በጎረቤት ምቾት/ደህንነት ይሰማቸዋል					
	በጣም /እጅግ/ እርካታ ካላገኙ በአካባቢዎ ለምን ደህንነት አልተሰማዎትም?					
22	የአካል ጉዳት ያለበት የቤተሰቡ አባል በስራ ቦታም ሆነ በት/ቤት አላማውን ለማሳካት ተገቢ ድጋፍ ያገኛል					
23	የአካል ጉዳት ያለበት የቤተሰቡ አባል በቤት ውስጥ አላማውን ለማሳካት ተገቢ ድጋፍ ያገኛል					
24	የአካል ጉዳት ያለበት የቤተሰቡ አባል ጓደኛ እንዲኖረው ድጋፍ ያገኛል					
25	የቤተሰቡ አባላት ከማነኛውም አገልግሎት ሰጭ አካላት ጋር ጥሩ ግንኙነት አላቸው					
	ከዚህ ፕሮጀክት ያገኛችሁትን ድጋፍ እንዴት አገኛችሁት?					
	ከዚህ ፕሮጀክት ካገኛችሁት ድጋፍ የትኛዉን በጣም ወደዳችሁት?					
	ከዚህ ፕሮጀክት ምን ሊሻሻል ይችላል ብለዉ ያስባሉ?					

ለሰጡኝ ቃለ መጠይቅ አመሰግናለሁ!

Appendix 6: Final version of the survey in English

Table 39: The survey in English for both respondent groups combined

How satisfied am I that…	**Very dissatisfied**	**Dissatisfied**	**Neither**	**Satisfied**	**Very satisfied**
1. My family enjoys spending time together.	☐	☐	☐	☐	☐
2. Family members help the children learn to be independent.	☐	☐	☐	☐	☐
3. My family has the support we need to relieve stress.	☐	☐	☐	☐	☐
All participants	Do you often experience stress? Yes/no				
All participants	If yes: What are the main factors causing stress in your family?				
All participants	What outside help would you like to receive to improve the level of stress, or your emotional wellbeing?				
4. My family members have friends or others who provide support.	☐	☐	☐	☐	☐
5. Family members help the children with schoolwork and activities.	☐	☐	☐	☐	☐
6. My family members have transportation to get to the places they need to be.	☐	☐	☐	☐	☐
7. My family members talk openly with each other.	☐	☐	☐	☐	☐
8. Family members teach the children how to get along with others.	☐	☐	☐	☐	☐
9. My family members have some time to pursue their own interests.	☐	☐	☐	☐	☐
10. My family solves problems together.	☐	☐	☐	☐	☐
11. My family members support each other to accomplish goals.	☐	☐	☐	☐	☐
12. My family members show that they love and care for each other.	☐	☐	☐	☐	☐
Persons affected	What support would you like to receive from your family?				
Family	What do you need to provide more care to an affected family member?				
13. My family has outside help available to us to take care of special needs of all family members.	☐	☐	☐	☐	☐
14. Adults in my family teach the children to make good decisions.	☐	☐	☐	☐	☐
15. My family gets medical care when needed.	☐	☐	☐	☐	☐

16. My family has a way to take care of our expenses.	☐	☐	☐	☐	☐
17. Adults in my family know other people in the children's lives (i.e. friends, teachers).	☐	☐	☐	☐	☐
18. My family is able to handle life's ups and downs.	☐	☐	☐	☐	☐
19. Adults in my family have time to take care of the individual needs of every child.	☐	☐	☐	☐	☐
Person affected	Who is mainly responsible for taking care of you in the family?				
20. My family gets dental care when needed.	☐	☐	☐	☐	☐
21. My family feels safe at home, work, school, and in our neighborhood.	☐	☐	☐	☐	☐
22. My family member with a disability has support to accomplish goals at school or at workplace.	☐	☐	☐	☐	☐
23. My family member with a disability has support to accomplish goals at home.	☐	☐	☐	☐	☐
Persons affected	What additional products or resources would help you to get things done more easily in your home?				
24. My family member with special needs has support to make friends.	☐	☐	☐	☐	☐
25. My family has a good relationship with the service providers who work with our family member with a disability.	☐	☐	☐	☐	☐
All participants	How did you experience the help received in this project?				
All participants	What did you like most about the help received in this project?				
All participants	What do you think could be improved in this project?				

Thank you for the interview!

Appendix 7: Operationalization table

Table 38: Operationalization table

Concept	Indicator	Related item in FQoL survey
Family interaction	Enjoying spending time together	1
	Talking openly with each other	7
	Solving problems together	10
	Support each other	11
	Show that they love and care for each other	12
	Handle up and downs	18
Parenting	Help children learn to be independent	2
	Help children with schoolwork and activities	5
	Teach children to get along with others	8
	Teach children to make good decisions	14
	Known other people in children's lives	17
	Have time to take care of individual needs of every child	19
Emotional wellbeing	The needed support to relieve stress	3
	Have friends who provide support	4
	Have time to pursue own interests	9
	Outside help available for special needs	13
Physical/material wellbeing	Have transportation	6
	Have medical care when needed	15
	Have a way to take care of expenses	16
	Have dental care when needed	20
	Feeling safe in environment	21
Disability-related support	Have the support to accomplish goals at school or workplace	22
	Have the support to accomplish goals at home	23
	Have the support to make friends	24
	Have a good relationship with the service providers	25

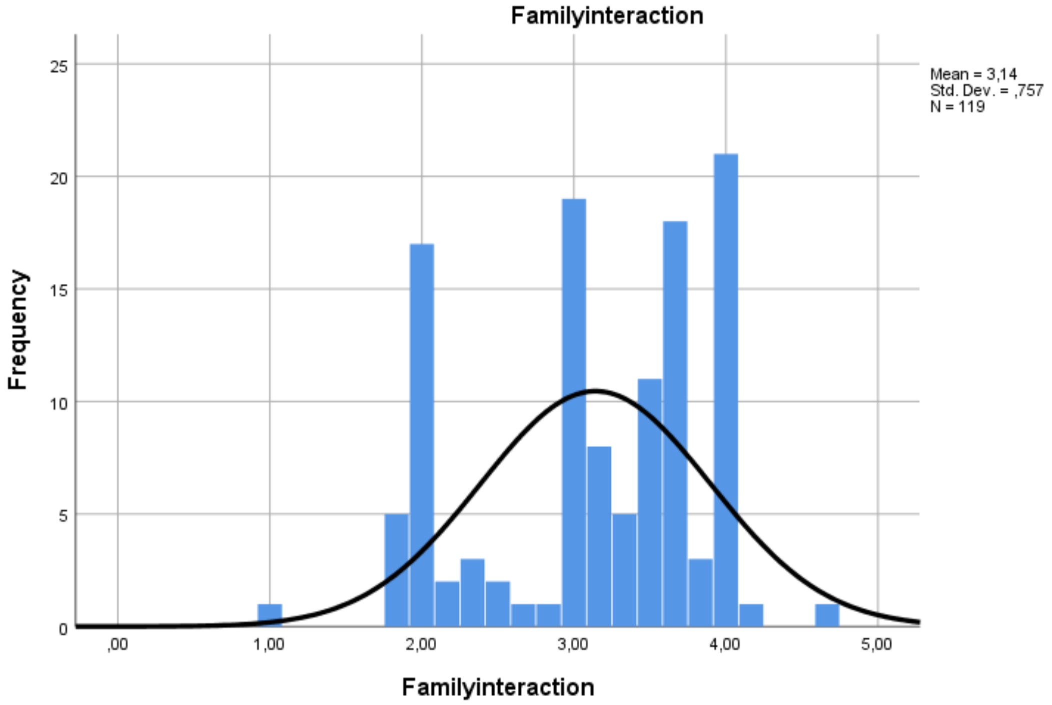
Appendix 8: Comparison within the baseline data

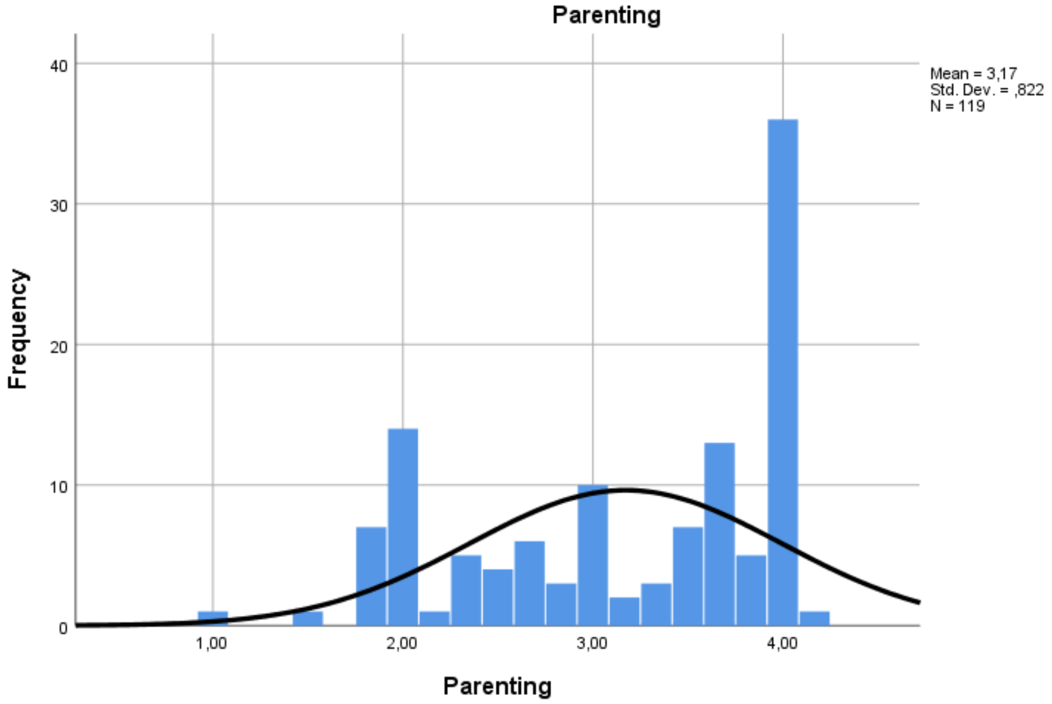
Table 39: Results of the independent samples t-test for the baseline data

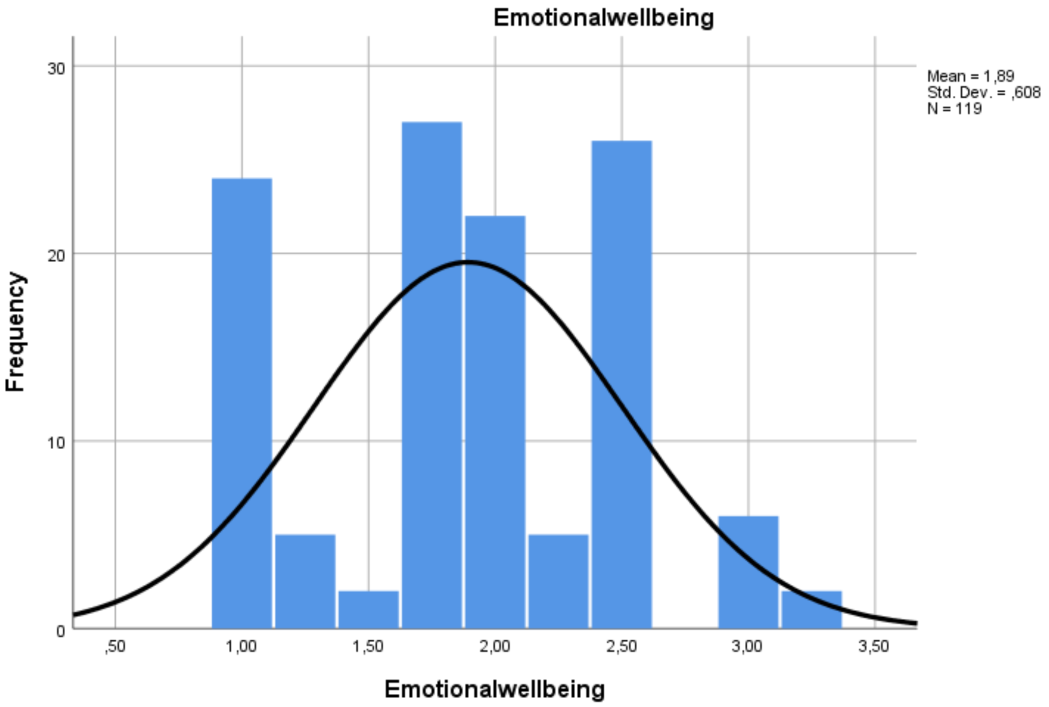
		Levene's Test for Equality of Variances		t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
1	Equal variances assumed	.064	.800	-.282	117	.778	-.063	.221
	Equal variances not assumed			-.283	115.196	.778	-.063	.221
2	Equal variances assumed	7.224	.008	.269	117	.789	.060	.224
	Equal variances not assumed			.272	116.976	.786	.060	.221
3	Equal variances assumed	3.907	.050	2.341	117	.021	.427	.182
	Equal variances not assumed			2.364	116.929	.020	.427	.181
4	Equal variances assumed	11.866	.001	.828	117	.409	.128	.155
	Equal variances not assumed			.856	107.406	.394	.128	.150
5	Equal variances assumed	.172	.679	-.042	117	.966	-.009	.201
	Equal variances not assumed			-.043	115.832	.966	-.009	.200
6	Equal variances assumed	9.193	.003	5.932	117	.000	.893	.150
	Equal variances not assumed			5.715	84.320	.000	.893	.156
7	Equal variances assumed	30.526	.000	2.617	117	.010	.472	.180
	Equal variances not assumed			2.684	112.958	.008	.472	.176
8	Equal variances assumed	8.832	.004	1.484	117	.140	.266	.180
	Equal variances not assumed			1.512	115.915	.133	.266	.176
9	Equal variances assumed	1.602	.208	6.653	117	.000	1.354	.203
	Equal variances not assumed			6.667	115.184	.000	1.354	.203
10	Equal variances assumed	18.753	.000	2.188	117	.031	.384	.175
	Equal variances not assumed			2.228	116.172	.028	.384	.172
11	Equal variances assumed	20.608	.000	5.521	117	.000	1.165	.211
	Equal variances not assumed			5.678	111.394	.000	1.165	.205
12	Equal variances assumed	28.174	.000	2.642	117	.009	.436	.165

	Equal variances not assumed			2.711	112.726	.008	.436	.161
13	Equal variances assumed	.500	.481	3.276	117	.001	.409	.125
	Equal variances not assumed			3.259	111.534	.001	.409	.126
14	Equal variances assumed	.143	.706	-.828	117	.410	-.157	.189
	Equal variances not assumed			-.827	114.216	.410	-.157	.189
15	Equal variances assumed	7.176	.008	-.240	117	.810	-.057	.236
	Equal variances not assumed			-.243	116.972	.808	-.057	.234
16	Equal variances assumed	.175	.677	3.290	117	.001	.557	.169
	Equal variances not assumed			3.289	114.277	.001	.557	.169
17	Equal variances assumed	4.856	.030	1.027	117	.307	.184	.179
	Equal variances not assumed			1.038	116.991	.301	.184	.177
18	Equal variances assumed	.138	.711	2.758	117	.007	.625	.227
	Equal variances not assumed			2.765	115.282	.007	.625	.226
19	Equal variances assumed	2.556	.113	.152	117	.879	.032	.208
	Equal variances not assumed			.153	116.696	.879	.032	.206
20	Equal variances assumed	13.885	.000	1.014	117	.312	.240	.237
	Equal variances not assumed			1.029	116.890	.306	.240	.233
21	Equal variances assumed	2.625	.108	.725	117	.470	.164	.227
	Equal variances not assumed			.729	116.420	.467	.164	.225
22	Equal variances assumed	12.663	.001	2.066	117	.041	.346	.167
	Equal variances not assumed			2.123	112.010	.036	.346	.163
23	Equal variances assumed	.101	.752	-.994	117	.322	-.183	.184
	Equal variances not assumed			-.998	115.871	.320	-.183	.183
24	Equal variances assumed	.644	.424	-.301	117	.764	-.058	.192
	Equal variances not assumed			-.300	112.332	.765	-.058	.193
25	Equal variances assumed	.904	.344	.408	117	.684	.085	.208
	Equal variances not assumed			.409	115.982	.683	.085	.207

Appendix 9: Histograms per domain in the baseline sample



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Std. Dev. = ,608
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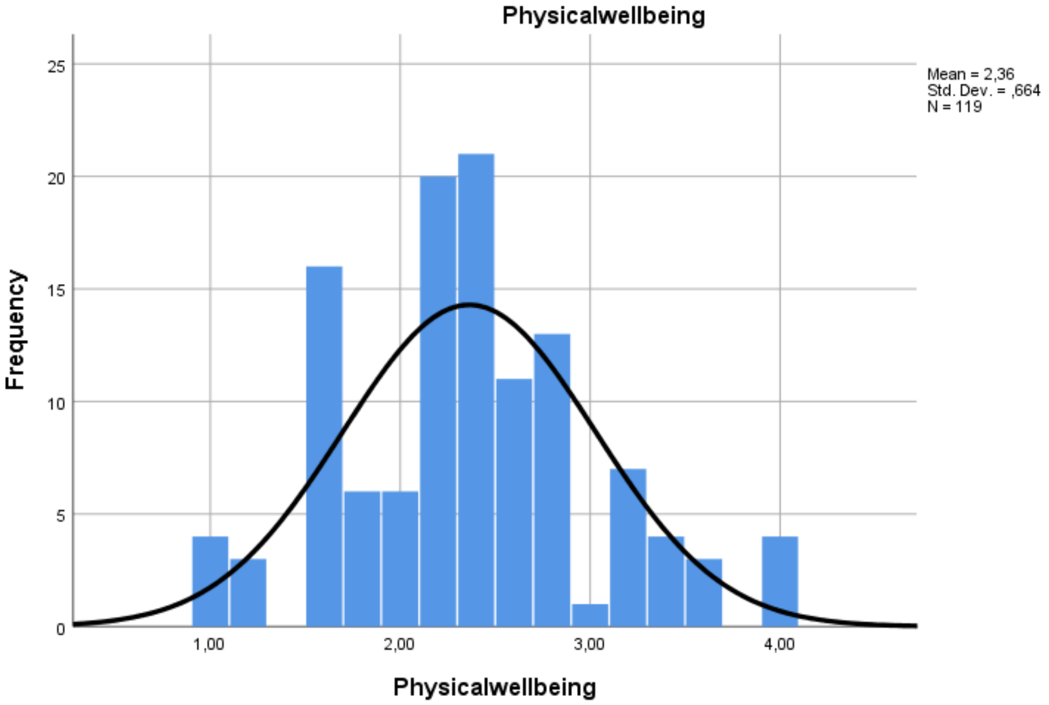
20
30
,50
1,00
1,50
2,00
2,50
3,00
3,50
Emotionalwellbeing


Physicalwellbeing
Mean = 2,36
Std. Dev. = ,664
N = 119
Frequency
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15
20
25
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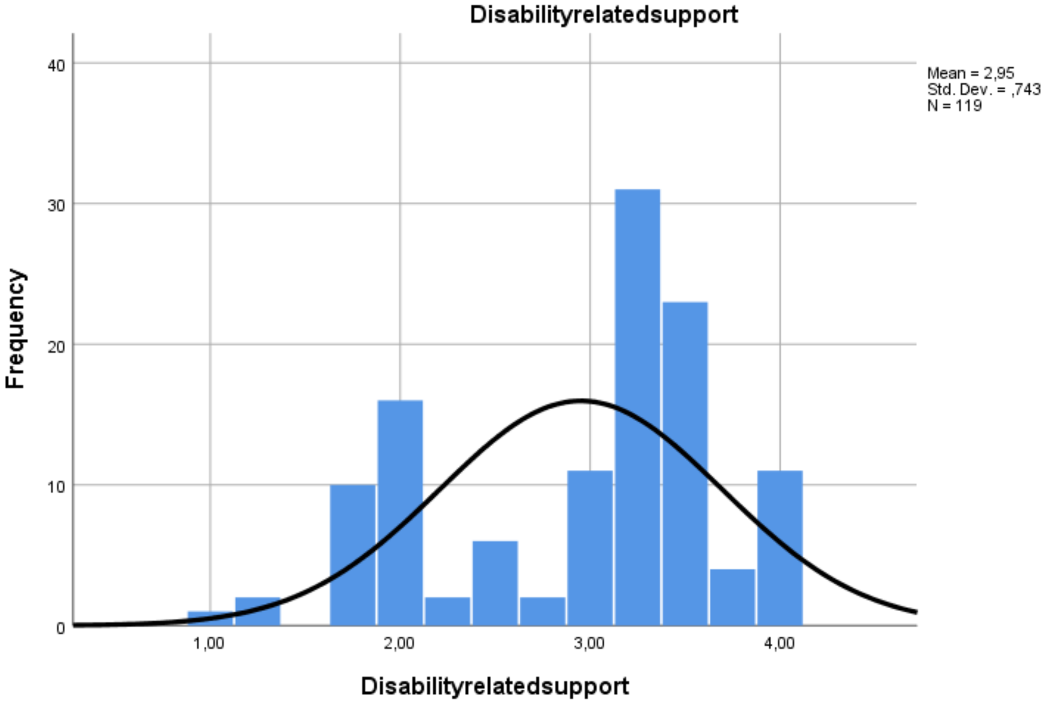
2,00
3,00
4,00
Physicalwellbeing


Disabilityrelatedsupport
Mean = 2,95
Std. Dev. = ,743
N = 119
Frequency
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20
30
40
1,00
2,00
3,00
4,00
Disabilityrelatedsupport

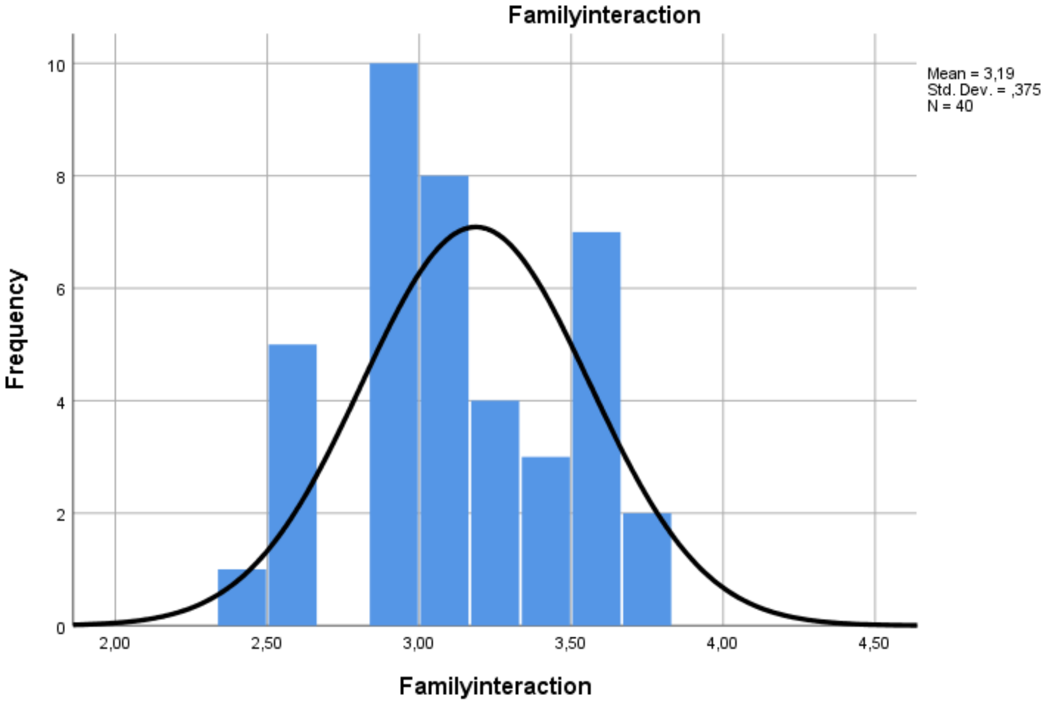
Appendix 10: Comparison within the follow-up data

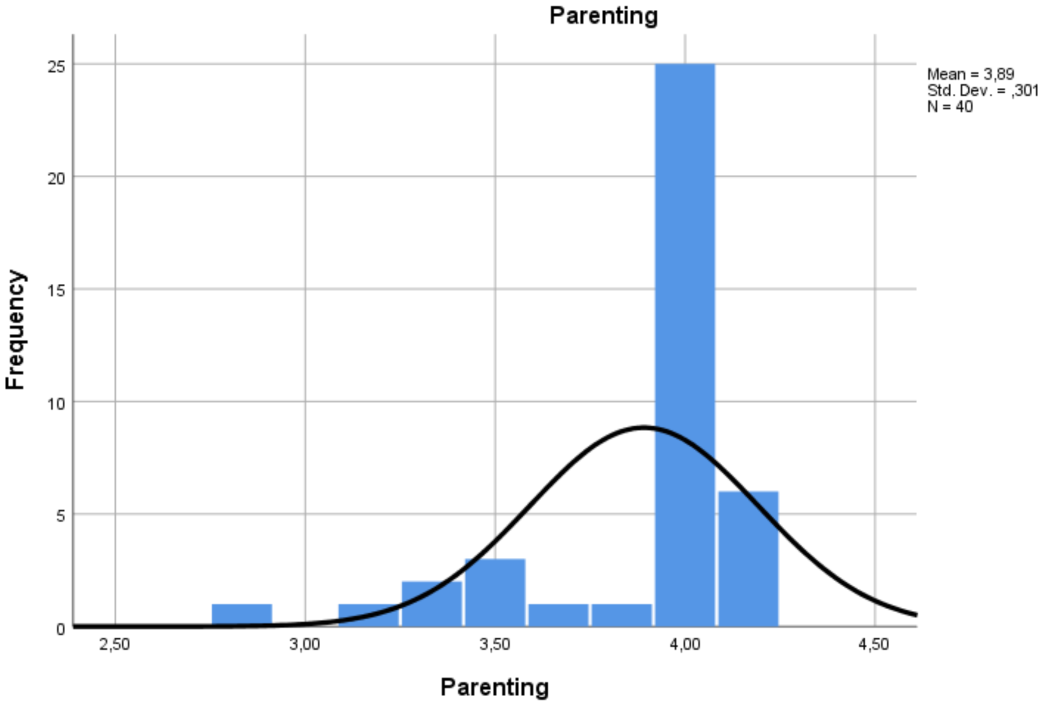
Table 40: Results of the independent samples t-test for the follow-up data

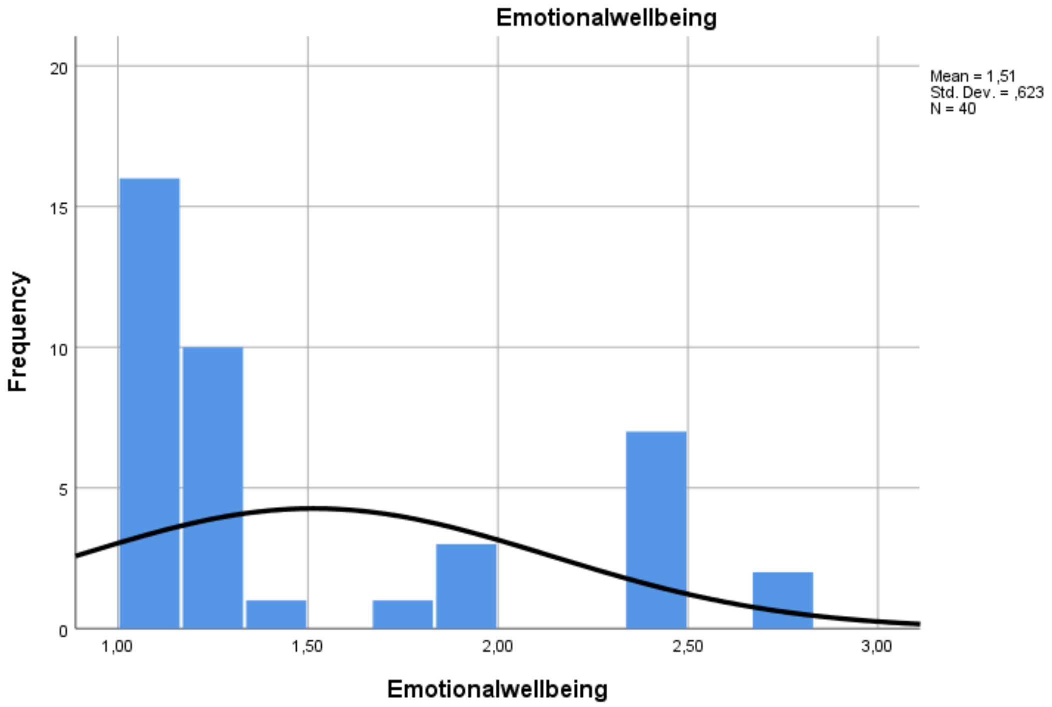
		Levene's Test for Equality of Variances		t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
1	Equal variances assumed	1.165	.287	-.529	38	.600	-.150	.284
	Equal variances not assumed			-.529	36.079	.600	-.150	.284
2	Equal variances assumed	.031	.860	.347	35	.731	.073	.211
	Equal variances not assumed			.350	31.577	.728	.073	.209
3	Equal variances assumed	.595	.445	1.276	38	.210	.300	.235
	Equal variances not assumed			1.276	37.969	.210	.300	.235
4	Equal variances assumed	.000	1.000	-1.414	38	.165	-.100	.071
	Equal variances not assumed			-1.414	38.000	.165	-.100	.071
5	Equal variances assumed	.134	.716	.000	38	1.000	.000	.188
	Equal variances not assumed			.000	31.732	1.000	.000	.188
6	Equal variances assumed	1.429	.239	-1.763	38	.086	-.150	.085
	Equal variances not assumed			-1.763	34.686	.087	-.150	.085
7	Equal variances assumed	33.499	.000	2.477	37	.018	.829	.335
	Equal variances not assumed			2.527	24.332	.018	.829	.328
8	Equal variances assumed	1.783	.190	1.265	38	.214	.200	.158
	Equal variances not assumed			1.265	23.171	.218	.200	.158
9	Equal variances assumed	12.893	.001	1.423	38	.163	.550	.386
	Equal variances not assumed			1.423	32.699	.164	.550	.386
10	Equal variances assumed	.891	.351	1.342	38	.188	.150	.112
	Equal variances not assumed			1.342	27.941	.191	.150	.112
11	Equal variances assumed	.182	.672	.767	38	.448	.150	.196
	Equal variances not assumed			.767	34.058	.449	.150	.196
12	Equal variances assumed	.004	.952	.567	38	.574	.050	.088

	Equal variances not assumed			.567	33.727	.574	.050	.088
13	Equal variances assumed	.124	.727	-.141	38	.889	-.050	.355
	Equal variances not assumed			-.141	37.937	.889	-.050	.355
14	Equal variances assumed	.669	.419	-.406	38	.687	-.050	.123
	Equal variances not assumed			-.406	37.521	.687	-.050	.123
15	Equal variances assumed	.543	.466	.000	38	1.000	.000	.145
	Equal variances not assumed			.000	30.400	1.000	.000	.145
16	Equal variances assumed	1.139	.293	.203	34	.840	.056	.274
	Equal variances not assumed			.203	24.829	.841	.056	.274
17	Equal variances assumed	1.092	.303	-.513	38	.611	-.150	.293
	Equal variances not assumed			-.513	35.273	.611	-.150	.293
18	Equal variances assumed	.172	.681	-.415	38	.681	-.150	.362
	Equal variances not assumed			-.415	38.000	.681	-.150	.362
19	Equal variances assumed	6.106	.018	1.391	38	.172	.450	.323
	Equal variances not assumed			1.391	34.148	.173	.450	.323
20	Equal variances assumed	1.163	.288	.061	37	.952	.018	.302
	Equal variances not assumed			.060	31.177	.952	.018	.305
21	Equal variances assumed	.351	.557	-.325	38	.747	-.100	.307
	Equal variances not assumed			-.325	37.882	.747	-.100	.307
22	Equal variances assumed	3.181	.083	.000	37	1.000	.000	.182
	Equal variances not assumed			.000	19.000	1.000	.000	.178
23	Equal variances assumed	10.139	.003	-1.415	37	.165	-.100	.071
	Equal variances not assumed			-1.453	19.000	.163	-.100	.069
24	Equal variances assumed	5.626	.023	1.157	38	.254	.350	.302
	Equal variances not assumed			1.157	31.931	.256	.350	.302
25	Equal variances assumed	1.165	.287	-.529	38	.600	-.150	.284
	Equal variances not assumed			-.529	36.079	.600	-.150	.284

Appendix 11: Histograms per domain in the follow-up sample



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Std. Dev. = ,623
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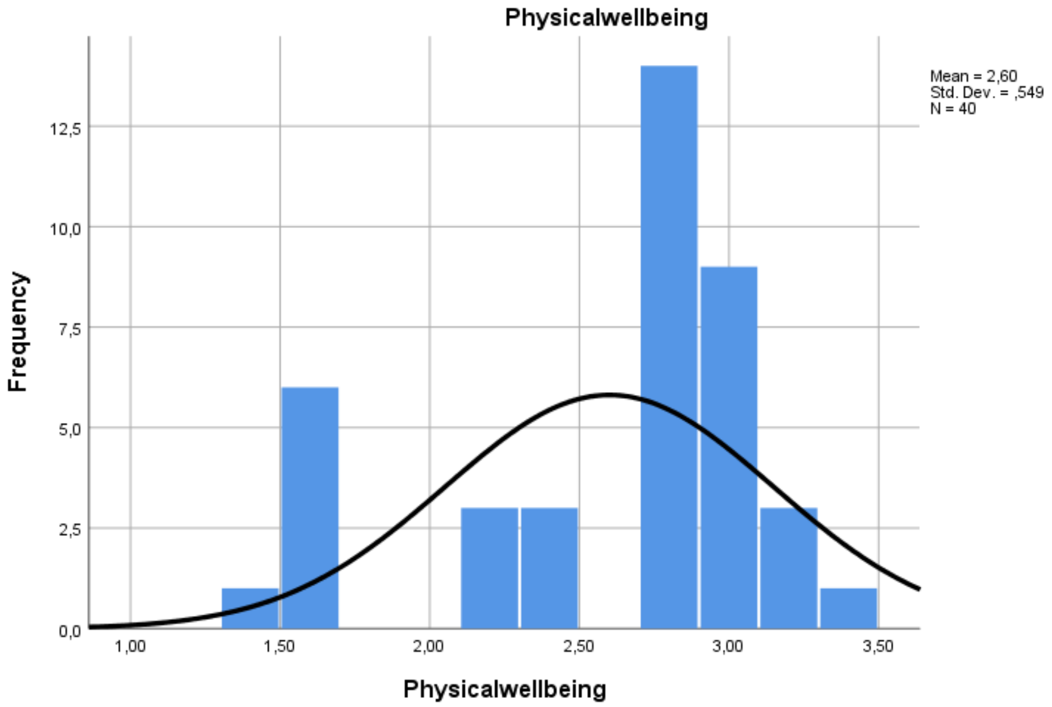
2,50
3,00
Emotionalwellbeing


Physicalwellbeing
Mean = 2,60
Std. Dev. = ,549
N = 40
Frequency
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7,5
5,0
2,5
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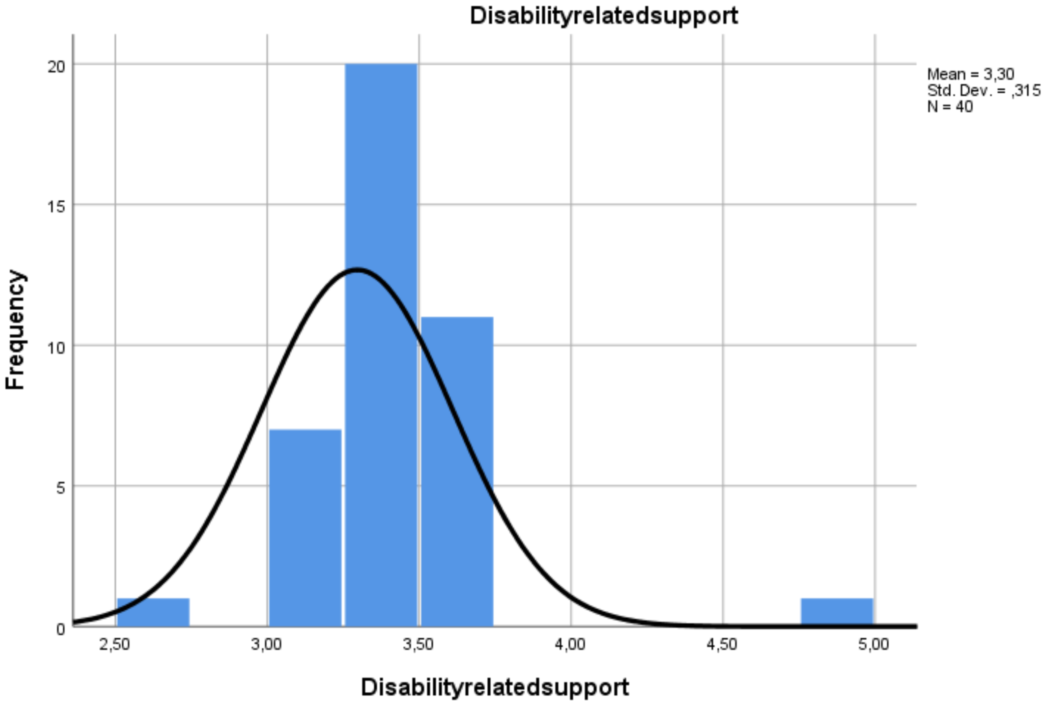
1,50
2,00
2,50
3,00
3,50
Physicalwellbeing


Disabilityrelatedsupport
Mean = 3,30
Std. Dev. = ,315
N = 40
Frequency
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5
10
15
20
2,50
3,00
3,50
4,00
4,50
5,00
Disabilityrelatedsupport