Exploring family-based approaches aimed at prevention and sustainable self-management of disabilities due to leprosy, podoconiosis and lymphatic filariasis within the family. (705.17.30)

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Research project group members

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- Alice Schippers, PhD (Disability Studies in Nederland)
- Anna van ’t Noordende, MSc (Nederland Leprosy Relief)
- Tanny Hagens, MPH (The Leprosy Mission International (TLMI))
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Presentation outline

- Introduction
- Aim and Objectives of the research project
- Research design and tools for data collection
- Result of the research
- Intervention
- Left agendas'
Introduction

Leprosy – Oldest infectious diseases.

– 80,927 on 1982 to 2,944 on 2012 again the new case occurrence 6243 to 3776.

– It affects the skin & nerves then leads the affected people for disability.

– Disability happen mainly on the hand, foot and eye.
Lymphatic filariasis

- It is a chronic infectious disease. Around 5.7 million people at risk of infection in Ethiopia. 70 districts in six regional states are endemic for LF.
- It is stated to be the second leading cause of long term disability in the world.
Podoconiosis - It is endemic non-filarial elephantiasis, a non-communicable disease that is acquired through prolonged exposure to red clay soils of volcanic origins.

It leads to disability.
Creates disabilities this leads to stigma, discrimination, and restrictions in social participation of disease affected individuals.

Most impairments, particularly at the beginning such as wounds, swelling and contractures, are largely preventable.

Relatively simple methods exist for self-management of impairments that can be practiced at home, without the need for a lot of medical supplies.

But the challenge is not consistently practicing it.

A key issue is the life-long need to practice such self-management routines.
• A strategy shown to be successful is the formation of self-care groups (SCG).

• The two main problems with the SCG strategy are their limited long-term sustainability and problems in accessing such a group.

• Formation of groups is not practical because people may face challenges due to private matters, or financial or geographical barriers.

• In Ethiopian culture – Wife wash her husband feet, children do similar activities. people do not like to expose their problems outside the family, but prefer to keep matters to themselves.
CBR: Individual-family-community-local/provincial/national government

- People with leprosy, Podoconiosis and LF
- Village/Community leaders, teachers, health and community workers, potential employers, etc
- Local government units, NGOs, disability groups, specialists, schools, hospitals, livelihood opportunities
- Neighbours, extended family, and friends living close to the person with a disability
- The person with disability and immediate family
- Provincial and national government agencies, political leaders, media

• **Family-based support** may be a much more sustainable and feasible strategy, but has received little attention to date.
Aim of the study
To strengthen prevention and self-management of disabilities within the family by developing culturally appropriate family-based approaches.

Objectives:
1) To explore constitutes of family quality of life in the Ethiopian cultural context.
2) To explore the impact of having a family member with leprosy, podoconiosis and LF related disabilities on family quality of life.
3) To explore ideas of family members and people affected on family-based approaches for supporting prevention and self-management of disabilities.
4) To identify key elements and factors that increase the chance of success of these approaches.
Research project area

- This research project conducted in Ethiopia, Amhara region, Awi zone, Zigem, Injibara and Addis Kidam Woreda.
Research Methods and tools for data collection

- Cross sectional study conducted from August – October/2017.
- Qualitative and Quantitative data were used
- 56 IDIs, 4 FGDs and 202 - FQoL, 71 - SALSA and 88 – SARI.
Netherlands research group visited the study area

Analysis of qualitative data were performed
Analysis and Meetings performed

The Dutch and Ethiopian research team during discussion in November, 2018 in Addis Ababa Ethiopia.
Result of the research

- The qualitative data answered objectives 1 up to 3.
- We have identified three problem based on this developed and implemented three intervention measures.
Family Based approach intervention developed and implemented

- Awareness creation
- Disease Management
- Socio-economic intervention

Community

Person with disability and immediate family

People with leprosy, Podoconiosis and LF

2/4/2020
Achievements....

Training given to the research assistants and local area health workers in Injibara in January, 2019.

Practical demonstration how to manage lymphedema of Podoconiosis affected disability in Injibara, January, 2019.

Awareness creation and practical demonstration for both the disease affected people and their family members in Zigem, February 2, 2019.
Achievements 325 Diseases affected treated

Leprosy, Podoconiosis and Lymphatic filariasis affected persons during washing and bathing their feet in Zigem, in February 27, 2019.

Back view of female (A), Male (B) and research assistant (C) During visiting Injibara leprosy affected people association.
Leprosy, Podoconiosis and Lymphatic filariasis affected persons promising to practice every day to keep their foot hygiene, wear shoes

Old man family member of disease affected individual acknowledging the donors, researchers and research assistants

2/4/2020
Three billboards developed for awareness creation.
Three brochures developed for awareness creation.
Project ideas and testimony of disease affected person printed on “The Truth” yearly magazine of ENAPAL and distributed to different audiences.
Awi Zone, Zigem Woreda social affairs delegates and the Committee members of DPO discussing about the recognition of the organization.

Netherlands and Ethiopian research group during Meeting in April 2019 in Addis Ababa Ethiopia
Materials support

Exercise book, pen and pencil distributed to disease affected person family members.

Shoes purchased and distributed for affected persons.
Remaining agendas’

The research team performing the following main activities:

1. Preparing final report for submission to the LRI.
2. Analysis of Base line with Follow up data.
3. Analysis of qualitative Data.
4. Preparing manuscripts and process for publication.
5. Further RCT interventional study is needed to see the long term outcome of FBA.
Acknowledgment

☞ Disease affected individuals and their families
☞ Research assistants
THANK YOU!