



NEGLECTED TROPICAL DISEASE
NGO NETWORK

A global forum for nongovernmental organizations
working together on NTDs

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Accelerating to 2030:
Building Resilient NTD
Programmes in a
Changing World

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Virtual Event

8th – 10th September 2020

Billy Weeks (2016, Chikwawa, Malawi)



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Building an Evidence Base for Addressing the Mental Health Burden of NTDs: Programmatic Examples of Integrated Care

Session Overview

Country Examples

Ethiopia with Dr. Esmael Ali, *London School of Hygiene and Tropical Medicine*

Nigeria with John Umaru, *The Carter Center*

Haiti with Dr. Luccene Desir, *The Carter Center* and Martha Desir, *Lymphatic Filariasis Clinic and Reference Center*

Audience Q&A

Panel Discussion

Moderator Dr. David Addiss, *The Task Force for Global Health*

Speakers Dr. Eve Byrd, *The Carter Center*

Kelly Callahan, *The Carter Center*

Dr. Greg Noland, *The Carter Center*

Audience Q&A



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Trachoma and Mental Health



*E.Habtamu, Z.Tadesse, F.Ambaw, M.Mekonen, T.Gebrie, A.Gebeyhu, M.Beka,
D.Macleod, J.Eaton, K. Callahan, E.Byrd, D.Addis, A.Fekadu, M.Burton*



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Collaborators

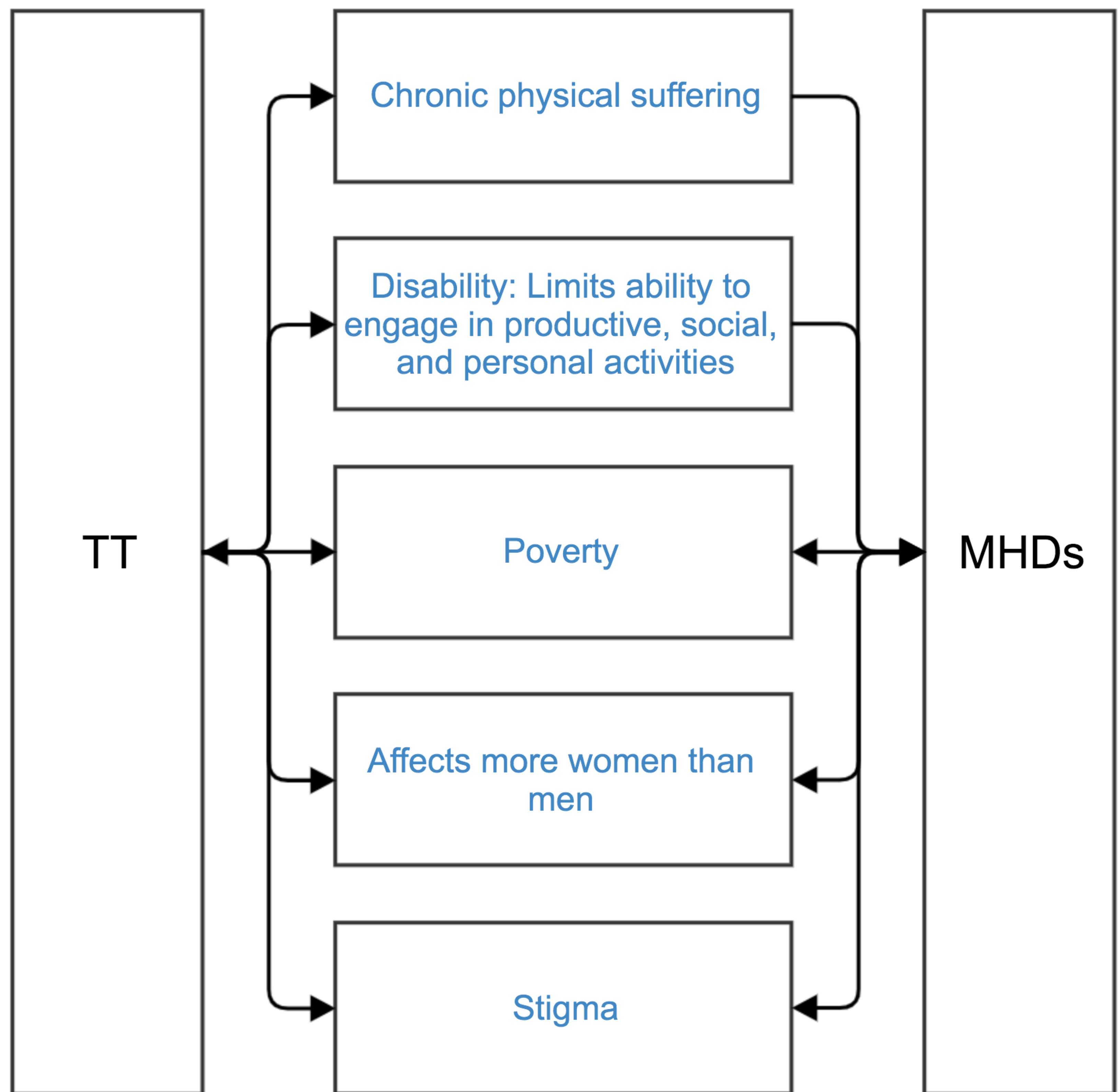
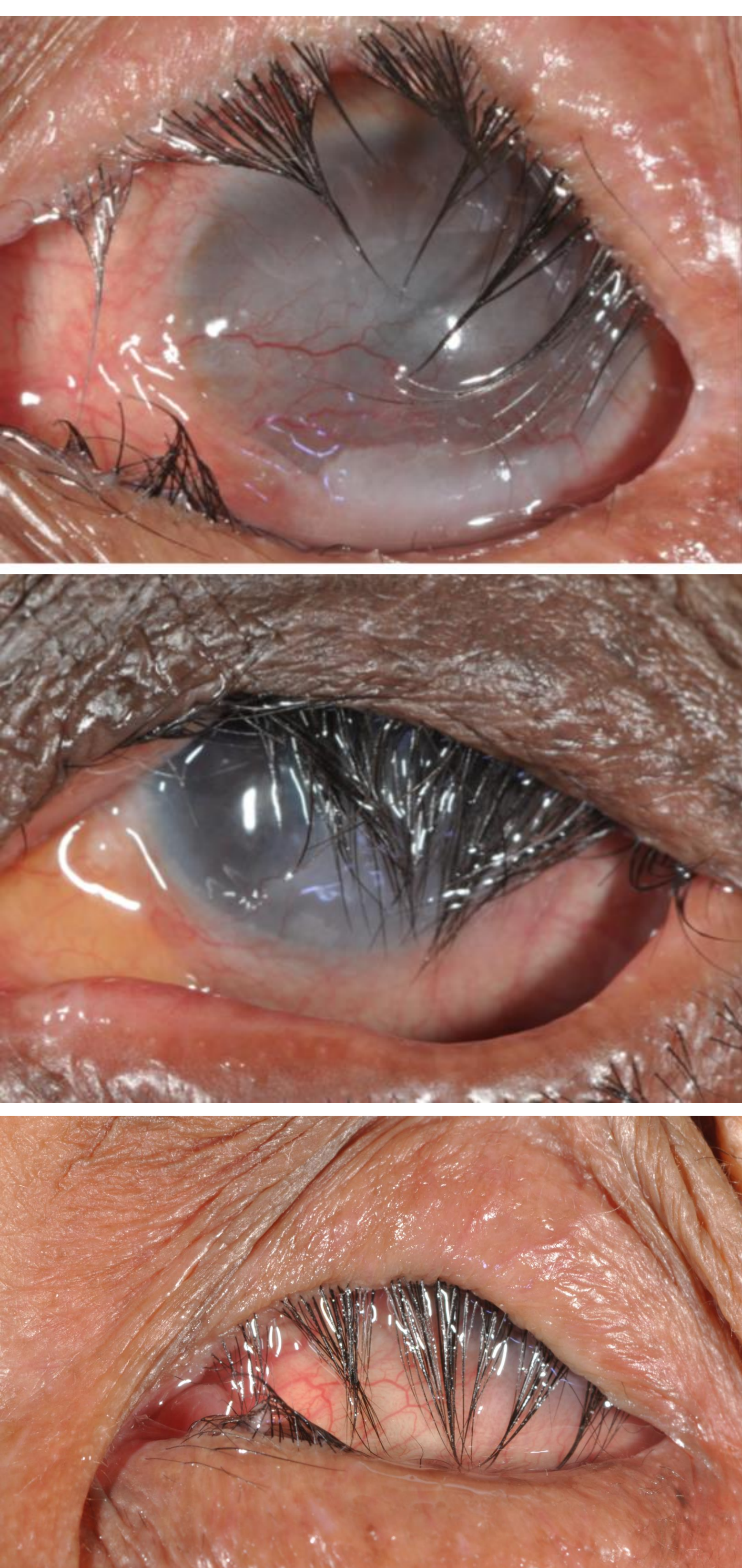
- Ethiopia
 - Amhara Regional Health Bureau,
 - The Carter Center Ethiopia
 - Eyu-Ethiopia: Eye Health Research, Training & Service Centre
 - Bahirdar University, School of Public Health
 - Department of Psychiatry, Felege Hiwot Hospital, Bahirdar
 - Addis Ababa University, Department of Psychiatry
 - Amref Health Africa, Ethiopia
- Abroad
 - London School of Hygiene & Tropical Medicine, UK
 - The Carter Center Ethiopia
 - Task Force Global Health, Atlanta
 - CBM International



Background

- Explored impact of TT and Quality of Life
 - Generic Quality of Life using WHOBREFF
 - Vision related quality of life using WHO-PBD-VF20
- Looked at the Psychological domains
- Consistent trend: cases showing poorer scores of mental health vs controls
 - “How often do you have negative feelings such as blue mood, despair, anxiety, depression?”
 - 28% of TT cases vs 3% controls (p-value <0.001) (quite/very often, always)
 - “Because of your eyesight, how often have you found that you are ashamed or embarrassed?”
 - 24% cases vs 0.5% controls (p-value <0.001) (often/very often).

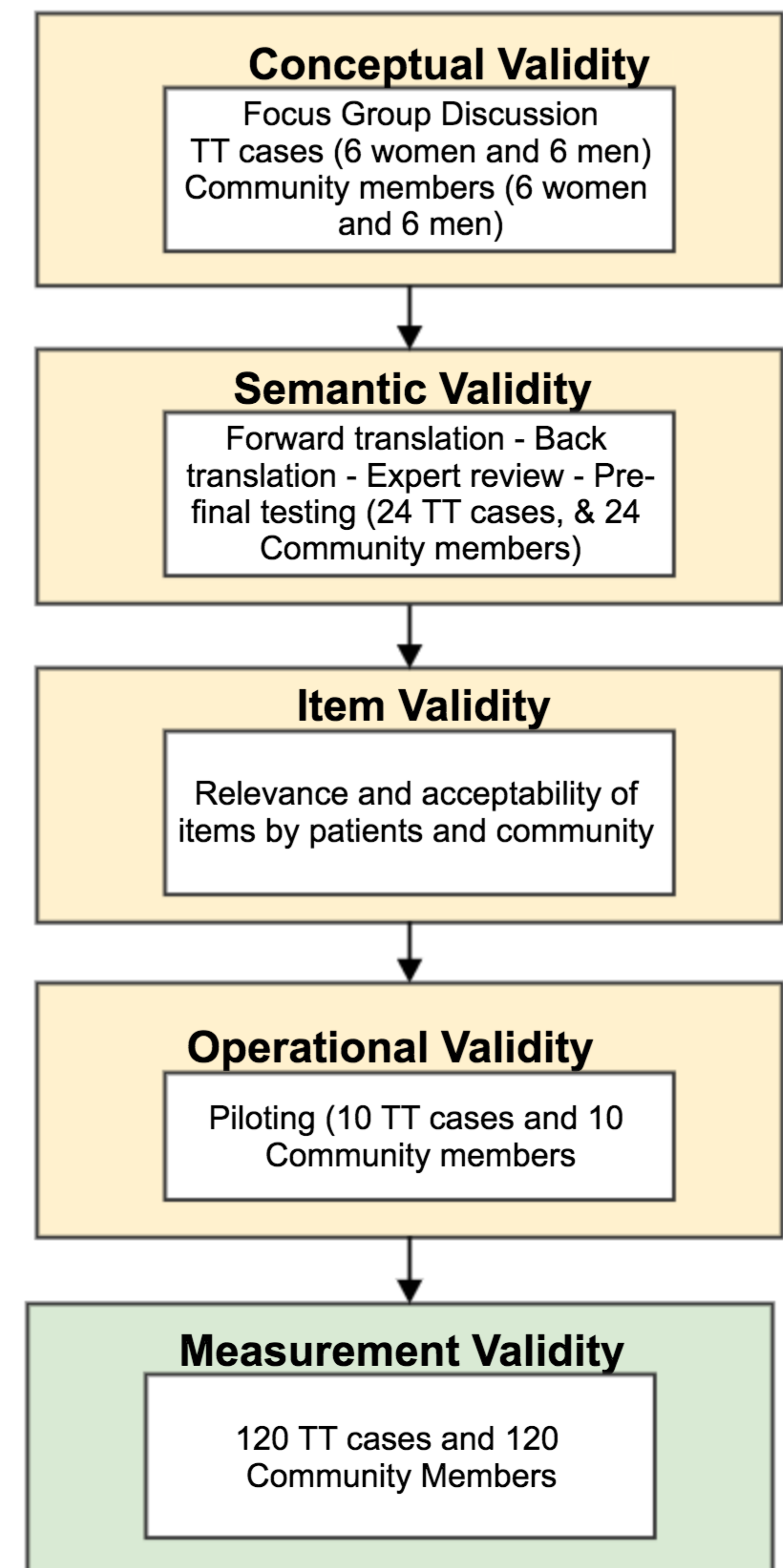




Study Components

Study 1:

- Validating Amharic versions of Stigma and Suicidal Behaviour Measurement Scales.
 - Stigma: 5-Question Stigma Indicators (5-QSI)
 - Suicidality: Suicidal Behaviours Questionnaire-Revised (SBQ-R)
- Study conducted in Amhara Region, Ethiopia
- 160 TT cases and 160 Community Members



Study Components

Study 2:

- A comparative cross-sectional study: TT and mental health disorders
 - Depression, Generalised Anxiety Disorder, Suicidal Behaviour
 - Identify main drivers for mental disorder in TT patients
 - Pain
 - Disability
 - Poverty
 - Stigma
- Study will be conducted in Ethiopia Amhara and Benishangul-Gumuz
- Target population
 - People with vision threatening TT (305 cases)
 - People without TT (305 Comparison Participants)
 - ≥ 18 years of age
 - Both Gender



Significance

- Identify the needs of trachoma affected communities
- Generate evidence to support for mental health and NTD service integration at the primary health care level
- Encourage allocation of resources for comprehensive services for NTDs and common mental health disorders
- Generate data on impact of comorbidity on global burden of disease



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NTD-SC



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**APPROACH(ES) TAKEN TO ASSESS AND ADDRESS
MENTAL HEALTH AND PSYCHO-SOCIAL WELLBEING,
USING EXISTING NTD CARE STRUCTURES –
PLATEAU/NASARAWA STATES, NIGERIA**

John Umaru

Innovative and Intensive Disease Management Consultant
THE CARTER CENTER NIGERIA



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INTRODUCTION

Map of Nigeria Showing Plateau and Nasarawa States Program Locations



Project Goals and Objectives

The basic goals and objectives of the programme for the elimination of lymphatic filariasis has been formulated focusing on:

1. Interrupting transmission and warranting halting MDA and
2. Providing basic care to all people suffering from LF-related morbidity (hydroceles and lymphoedema) which is the morbidity management and disability prevention (MMDP) component.



Timeline for Morbidity Management and Disability Prevention in Plateau and Nasarawa States, Central Nigeria

S/No	Activity	Year (Date)
1	Collection of hydrocele baseline data during LF Mapping	1999
2	Hydrocele Surgeries	2002 - 2005, 2020
3	Hope Group establishment	2003 - 2020
4	Collecting baseline data LF morbidity alleviation programs	2008
5	Mental health for LF patients and their family members	2018 to date
6	Case search	2018 to date



RAPID ASSESSMENT FOR LYMPHATIC FILARIASIS IN CENTRAL NIGERIA: A COMPARISON OF THE IMMUNOCHROMATOGRAPHIC CARD TEST AND HYDROCELE RATES IN AN AREA OF HIGH ENDEMICITY

ABEL EIGEGE, FRANK O. RICHARDS JR., DAVID D. BLANEY, EMMANUEL S. MIRI, IBRAHIM GONTOR,
GLADYS OGAH, JOHN UMARU, M. Y. JINADU, WANJIRA MATHAI, STANLEY AMADIEGWU,
AND DONALD R. HOPKINS

*The Carter Center, Jos, Nigeria and Atlanta, Georgia; State Ministry of Health, Plateau State, Jos, Nigeria; State Ministry of Health,
Nasarawa State, Lafia, Nigeria; Federal Ministry of Health, Abuja, Nigeria*

Abstract. The rapid immunochromatographic card test (ICT) for *Wuchereria bancrofti* is being used to map areas endemic for lymphatic filariasis. However, the ICT is expensive and must be relatively limited. Our study was conducted to determine if village-based methods could supplement the ICT surveys in the mapping activities. We compared in 144 villages two methods, ICT and examination for clinical hydrocele, in random samples of 30 adult males. We obtained 15 younger males (reported age = 16–39 years old) and 15 older males (≥ 40 years old) that hydrocele rates may be more prevalent in older age groups. The men were asked to undergo examination and tested by the ICT. We found a weakly positive correlation between village ICT and hydrocele ($r = 0.041$, $P < 0.001$). Only villages with hydrocele rates of 20% or greater were classified as having endemic filariasis by the ICT. There was no correlation between

Collecting Baseline Information for National Morbidity Alleviation Programs: Different Methods to Estimate Lymphatic Filariasis Morbidity Prevalence

Els Mathieu,* Josef Amann, Abel Eigege, Frank Richards, and Yao Sodahlon

Division of Parasitic Diseases, National Center of Infectious Diseases, Centers for Disease Control and Prevention, Atlanta, Georgia; Epidemic Intelligence Service, Office of Workforce and Career Development, Centers for Disease Control and Prevention, Atlanta, Georgia; The Carter Center, Jos, Nigeria; The Carter Center, Atlanta, Georgia; Department of Parasitologie, Faculté Mixte de Médecine et Pharmacie, Université de Lomé, Lomé, Togo

Abstract. The lymphatic filariasis elimination program aims not only to stop transmission, but also to alleviate the burden of disease. In the absence of limited morbidity projects exist, few have been implemented nationally. For advocates to need prevalence estimates that are currently rarely available. This article describes methods to estimate morbidity prevalence: (1) data routinely collected during mapping or sentinel surveillance; (2) data from drug coverage surveys; and (3) alternative surveys. Data were collected in Plateau State and in 6 districts in Togo. In both settings, we found that questionnaires seem to

A Pilot Program of Mass Surgery Weeks for Treatment of Hydrocele Due to Lymphatic Filariasis in Central Nigeria

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JACOB ABIMIKU, GLADYS OGAH, MUNIRAH Y. JINDAU, JONATHAN Y. JIYA, AND EMMANUEL S. MIRI

The Carter Center, Atlanta, Georgia; The Carter Center, Nigeria National Office, Jos, Plateau State, Nigeria; Jos University Teaching Hospital, Department of Surgery, Jos, Plateau State, Nigeria; Plateau State Ministry of Health, State Secretariat, Jos, Nigeria; Nasarawa State Ministry of Health, State Secretariat, Lafia, Nigeria; Public Health Department, Federal Ministry of Health, Garki, Abuja, Nigeria

Abstract. In a pilot program of mass surgery weeks (MSW) to provide hydrocelectomy services to men with filarial scrotal hydrocele, local general practitioners performed 425 surgical repairs in 301 men in five MSW in three rural Nigerian community hospitals between 2002 and 2005. The most common (94%) procedure used was the eversion technique, which was most familiar to the practitioners. Postoperative complications included hematoma (3.7%) and infection (3%), and there was one death from infection in an elderly man with previously unrecognized diabetes. In 115 patients (38%) followed for 1 to 3 years, the hydrocele recurrence rate was 7%. The eversion technique gives an acceptable outcome, and MSW are safe and effective if strict attention is paid to preoperative screening of candidates and asepsis.

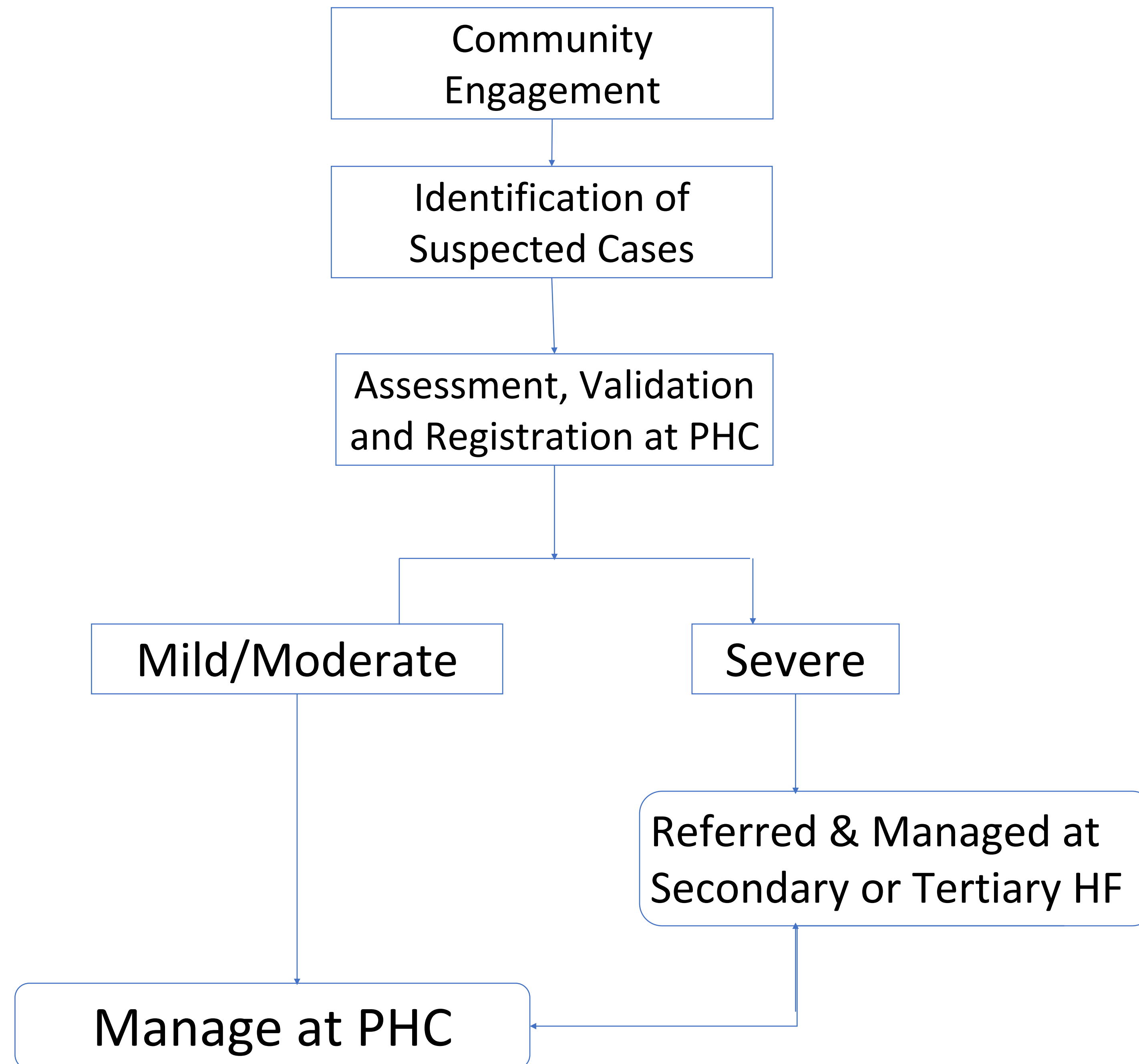


Project Activities

1. Situational analysis
2. Establishment of Hope Groups (self-help groups)
3. Training of designated health workers
4. Referral system for complicated Hydrocele surgery and lymphoedema management



Flow Chart Showing Process for Assessment of Suspected & Management of LF Manifestations



Emotional Difficulties and Experiences of Stigma among Persons with Lymphatic Filariasis in Plateau State, Nigeria

JIBRIL ABDULMALIK, EMEKA NWEFOH, JAMES OBINDO, SAMUEL DAKWAK, MOTUNRAYO AYOBOLA, JOHN UMARU, ELISHA SAMUEL, CHRISTOPHER OGOSHI, AND JULIAN EATON

Abstract

Lymphatic filariasis (LF) is a chronic and often disfiguring condition that predominantly affects the rural poor and leads to social exclusion, stigma, and discrimination. Little is currently known about the emotional difficulties and stigma experiences among persons living with LF in Nigeria. Our study evaluated the emotional difficulties and stigma experienced by persons with LF in Plateau State, Nigeria. We utilized a combination of qualitative data instruments comprising focus group discussions, McGill's Illness Narrative Interviews, and key informant interviews. We transcribed and analyzed the data using a combination of inductive and deductive coding approaches. Sixty-nine respondents were interviewed: 37 females and 32 males. The prevalent community perception of LF was the belief that it was a spiritual problem. Emotional reactions included feelings of sadness,

The prevalent community perception of LF was the belief that it was a spiritual problem. Emotional reactions included feelings of sadness, hopelessness, anger, frustration, worry, and suicidal ideation. These experiences, including those of stigma, discrimination, and social exclusion, culminated in difficulties with occupational functioning, marital life, and community participation.



RESEARCH ARTICLE

Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria

James Obindo¹, Jibril Abdulmalik^{2*}, Emeka Nwefoh³, Michael Agbir¹, Charles Nwoga¹, Aishatu Armiya'u¹, Francis Davou¹, Kurkat Maigida¹, Emmanuel Otache¹, Ajuma Ebiloma¹, Samuel Dakwak⁴, John Umaru⁵, Elisha Samuel⁶, Christopher Ogoshi⁶, Julian Eaton⁷

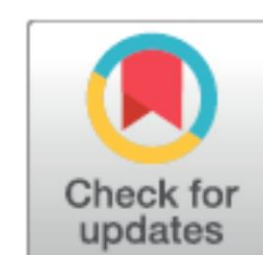
1 Department of Psychiatry, Jos University Teaching Hospital, Jos, Plateau State, Nigeria, **2** Department of Psychiatry, College of Medicine, University of Ibadan, Ibadan, Oyo State, Nigeria, **3** CBM Country Co-ordination Office, Federal Capital Territory, Abuja, Nigeria, **4** QHC, Department of Psychology, University of Jos, Jos, Plateau State, Nigeria, **5** The Carter Centre, Jos, Plateau State, Nigeria, **6** Health and Development Support Programme (HANDS), Jos, Plateau State, Nigeria, **7** CBM International and London School of Hygiene and Tropical Medicine, London, United Kingdom

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Abstract

Background

Lymphatic filariasis is a chronic, disabling and often disfiguring condition that principally impacts the world's poorest people. In addition to the well-recognised physical disability associated with lymphedema and hydrocele, affected people often experience rejection, stigma and discrimination. The resulting emotional consequences are known to impact on the quality of life and the functioning of the affected individuals. However, the management of this condition has focused on prevention and treatment through mass drug administration, with scant attention paid to the emotional impact of the condition on affected individuals. This study aimed to determine the prevalence and severity of depression among individuals with physical disfigurement from lymphatic filariasis in Plateau State, Nigeria.



OPEN ACCESS

Citation: Obindo J, Abdulmalik J, Nwefoh E, Agbir M, Nwoga C, Armiya'u A, et al. (2017) Prevalence of depression and associated clinical and socio-demographic factors in people living with lymphatic filariasis in Plateau State, Nigeria. PLoS Negl Trop Dis 11(6): e0005567. <https://doi.org/10.1371/journal.pntd.0005567>

Editor: Margaret Gyapong, Dodowa Health Research Centre, GHANA

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Copyright: © 2017 Obindo et al. This is an open access article distributed under the terms of the

Results:

“Nineteen respondents (20%) met criteria for depression, using composite international diagnostic interview (CIDI), with the severity of the depression being Mild [8 (42.1%)], Moderate [6 (31.6%)] and Severe [5 (26.3%)].”



Community Perception and Belief About LF Manifestations

- Spiritual Illness
- No treatment
- Strange and scary
- Dirty and Undesirable
- Contagious



Stigma and Discrimination of the Affected People



- Insults and disdainful stares
- Discrimination
- Self-withdrawal
- Social exclusion

EMOTIONAL CONSEQUENCES OF STIGMA AND DISCRIMINATION ON PERSONS WITH LF



- **Emotional Reaction:**

"it makes me angry". FGD 2 (female)

- **Suicidal Ideation:**

"...and I prayed to God to just take my life ..."" – KII 3 (male).

Impact of LF on Work, Family life and inter-personal relationship



1. Inability to obtain and maintain marital life
2. Vicious cycle of poverty so can hardly sustain self and family needs
3. inability to obtain gainful employment or perform optimally at work/school

Management of Mental Health in People Living with Lymphatic Filariasis



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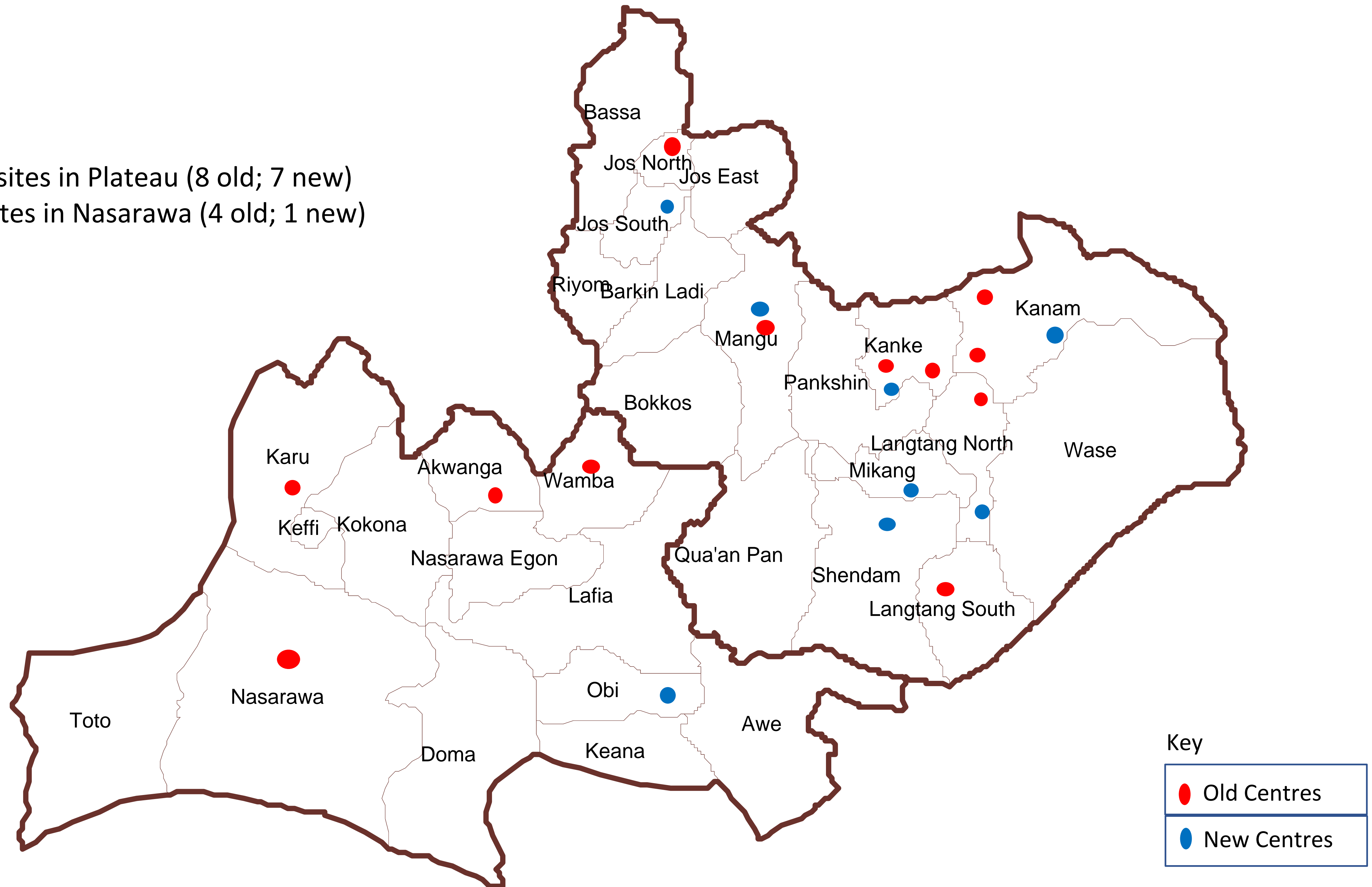
MANAGEMENT OF MENTAL HEALTH AND PSYCHO-SOCIAL WELLBEING

1. Establishment of "Hope Groups" (self/group support)
2. Health education is provided to address the common triggers of negative emotional experiences and emphasized the coping mechanisms.



Map of Plateau and Nasarawa States Showing MMDP PHC Centres

15 sites in Plateau (8 old; 7 new)
5 sites in Nasarawa (4 old; 1 new)



MANAGEMENT OF MENTAL HEALTH AND PSYCHO-SOCIAL WELLBEING (Cont.)

3. Family and Community sensitization, awareness are done to reduce discrimination and stigmatisation.
4. Establishment of more hope group centres closer to the patients to reduce travel time, cost and increase access to health services this was possible by the IZUMI Foundation's Grant.
5. Confirmed complicated and uncomplicated hydrocele cases are referred to hospitals for surgeries.



Hamisu and his Hope Group



Hamisu Isa also with extreme Elephantiasis (stage 7) from Jos North LGA of Plateau State



Family Support



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Working visit to Project Area



Amb. Mary Ann Peters (rtd)
interacting with members of the
Hope Group

Drs. Sienko & Richards
interacting with members of
the Hope Group



President Carter interacting with LF Patients



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The program would like to thank



And our many generous individual donors



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Addressing the Mental Health of Persons Living with Lymphatic Filariasis in Leogane, Haiti: Effectiveness of a Chronic Disease Self-Management Program



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Overview of the Lymphatic Filariasis Program in Haiti

Dr Luccene DESIR

Program Manager, Hispaniola Health Initiative

Special Health Projects, The Carter Center



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Presentation of the Country

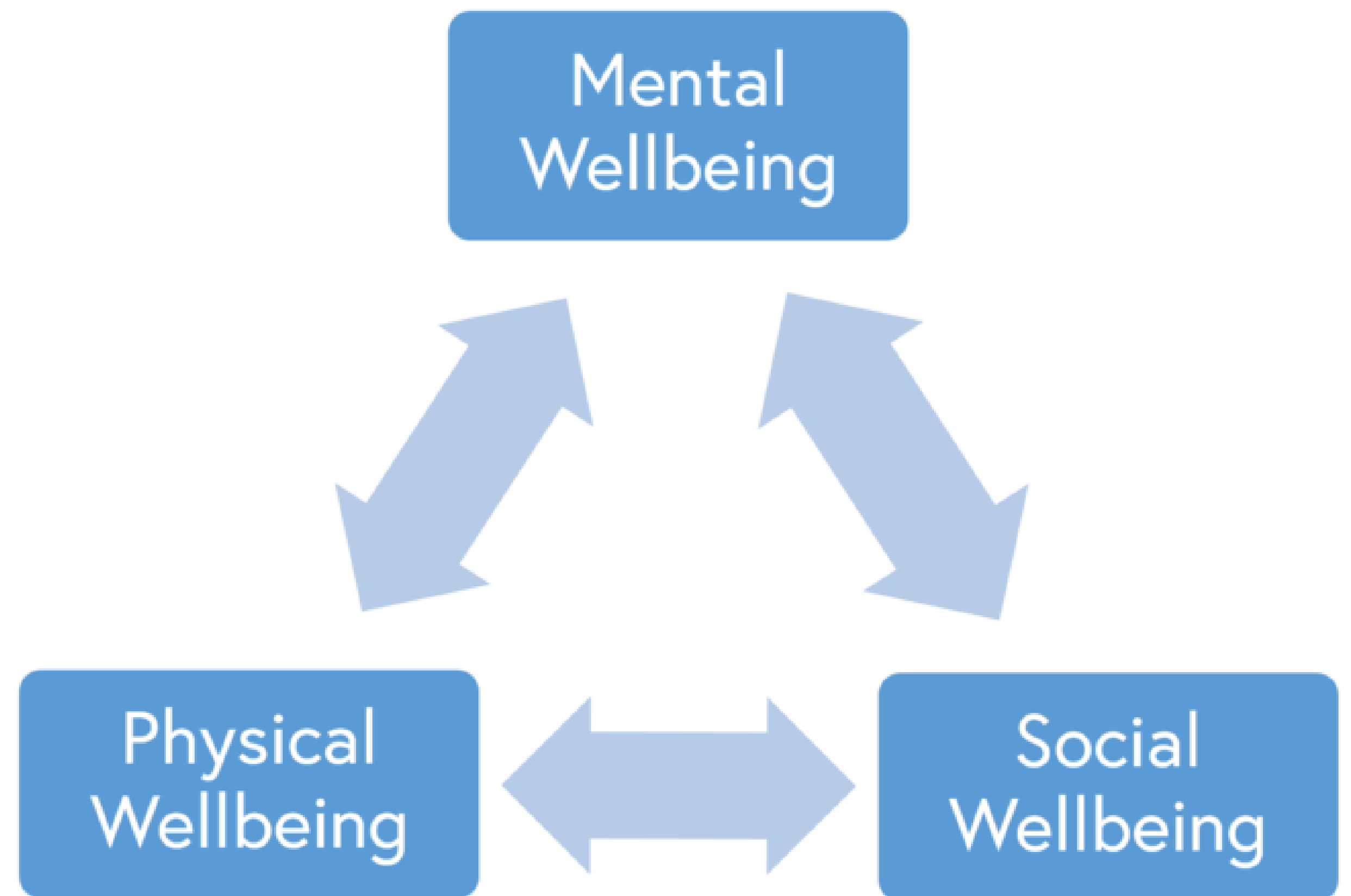
Hispaniola is one out of the four countries with endemic Lymphatic Filariasis transmission in America alongside with Dominican Republic, Guyana and Brazil.

- Geography and Population
 - Total land area: 27,750 Km²
 - Total population: 11,411,527
 - Ecological zones: Tropical
 - Climate
- Political Administrative Divisions
 - # first level (10 Departments, etc.)
 - # second level units (140 communes)
 - # community-level (570 rural sections)

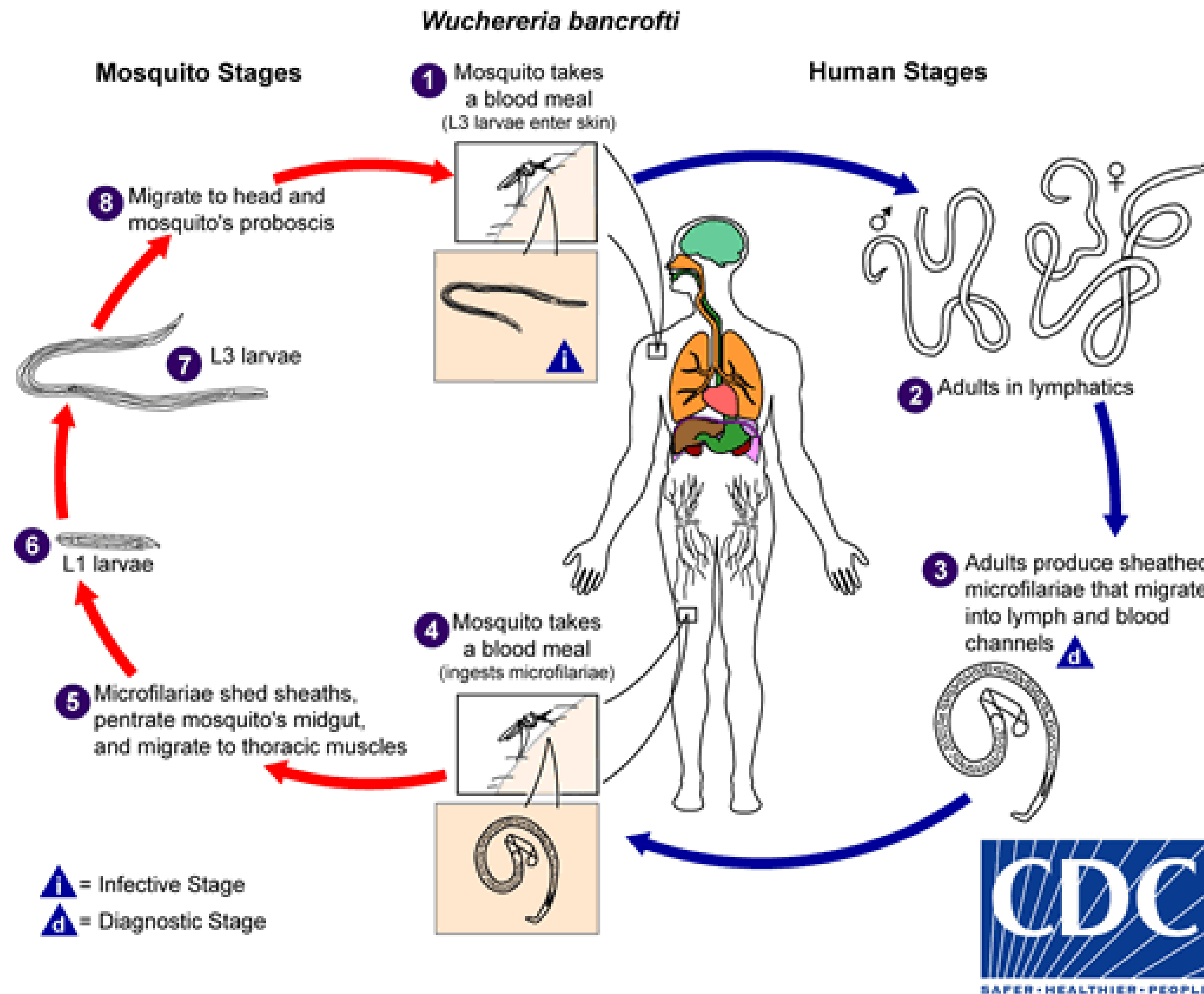


What is Health????

**Not merely the
absence of disease
or infirmity**



What is Lymphatic Filariasis????



❖ Neglected Tropical Disease

❖ Disfiguring disease leading to:

Physical disability

Mental disability

Social loss

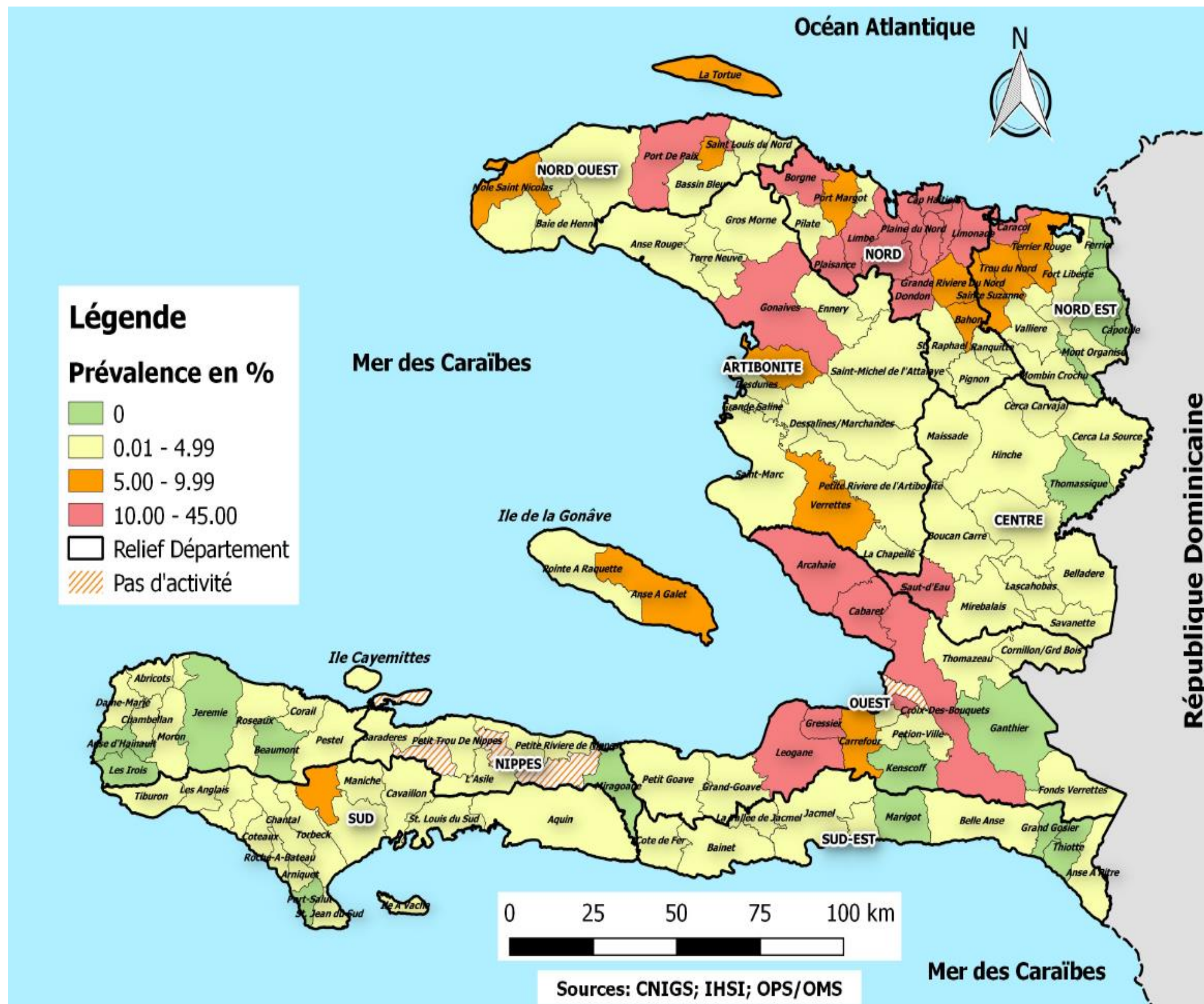
Financial loss



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Situation of Lymphatic Filariasis in Haiti



Mapping conducted in 2000-2001

❖ 84% of the communes were endemic

Strategies adopted

Mass Drug Administration to interrupt the transmission through:

Pills distribution (DEC + ALB



Co-fortified DEC-salt



<https://drive.google.com/file/d/13clBnFvx7xKT31X7C2wW2JHEwsPdmd2O/view?usp=sharing>



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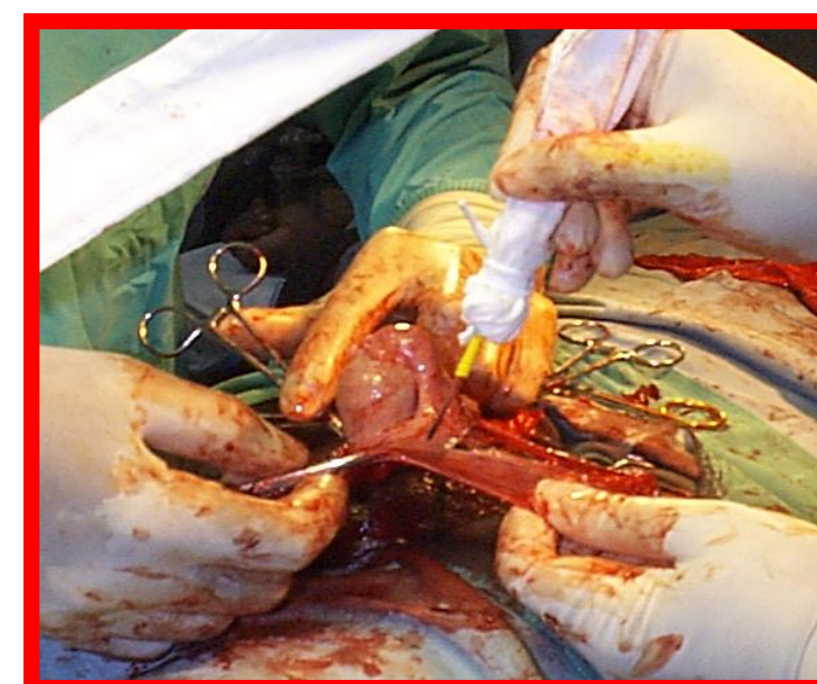


Strategies adopted (cont'd)

MMDP:



**Lymphedema
Hydrocele**



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Strategies adopted (Cont'd)

Mental
Wellbeing

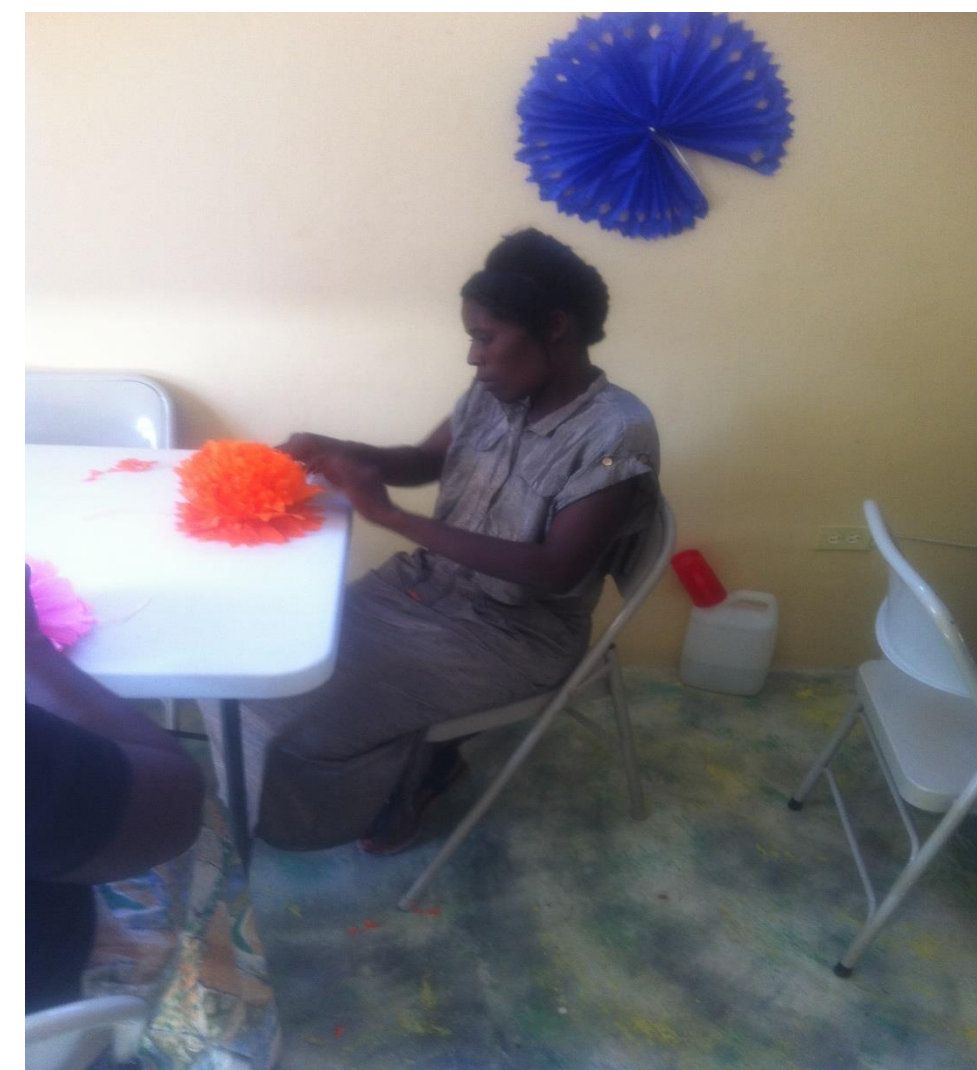
Physical
Wellbeing

Social
Wellbeing



Strategies adopted (Cont'd)

The LF Program, at the very beginning understood the psychological impact of the Disease on the wellbeing of people suffering LF. Since 1996, at Hospital Sainte, in Leogane, patients were putting together on the support group (hope club).

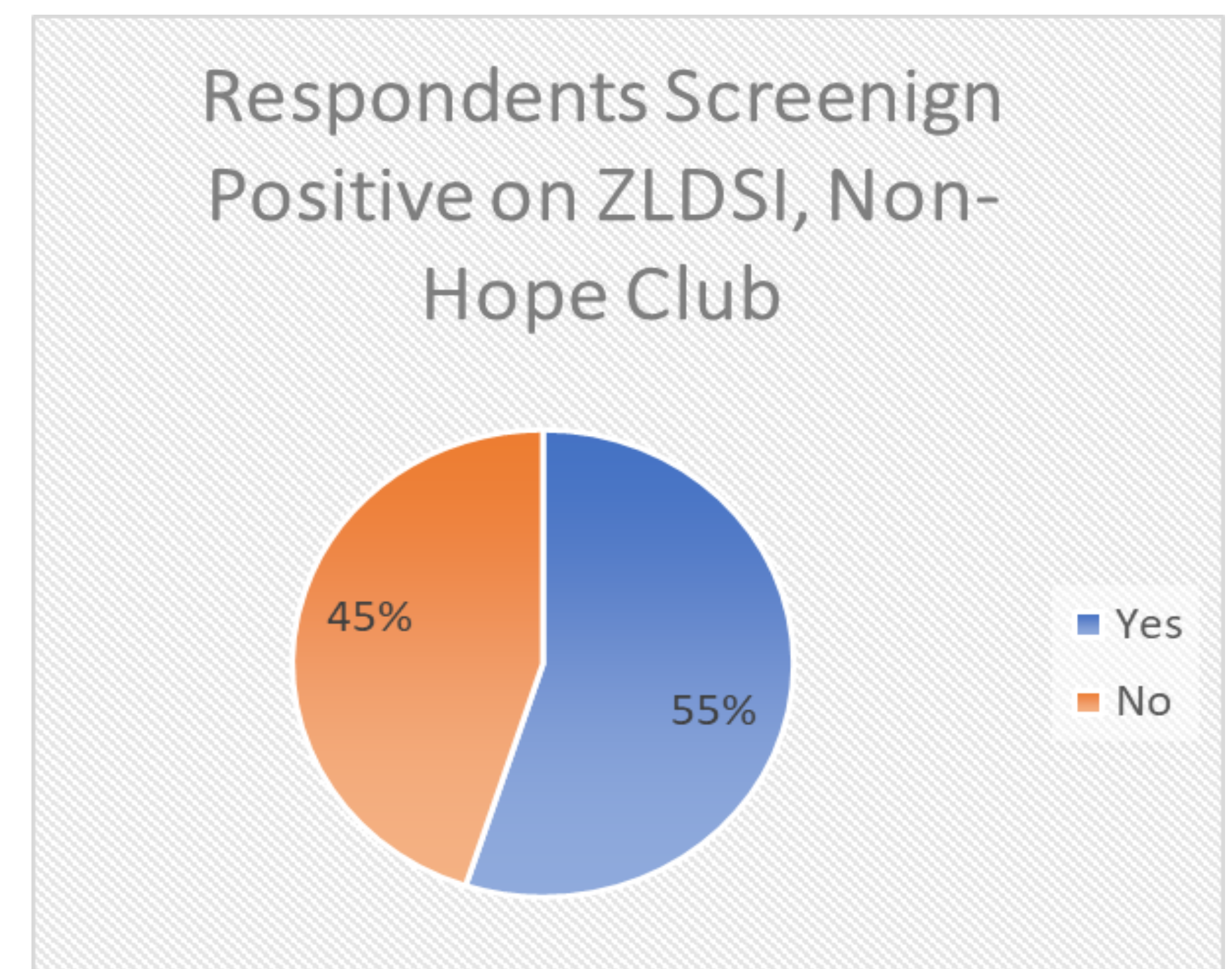
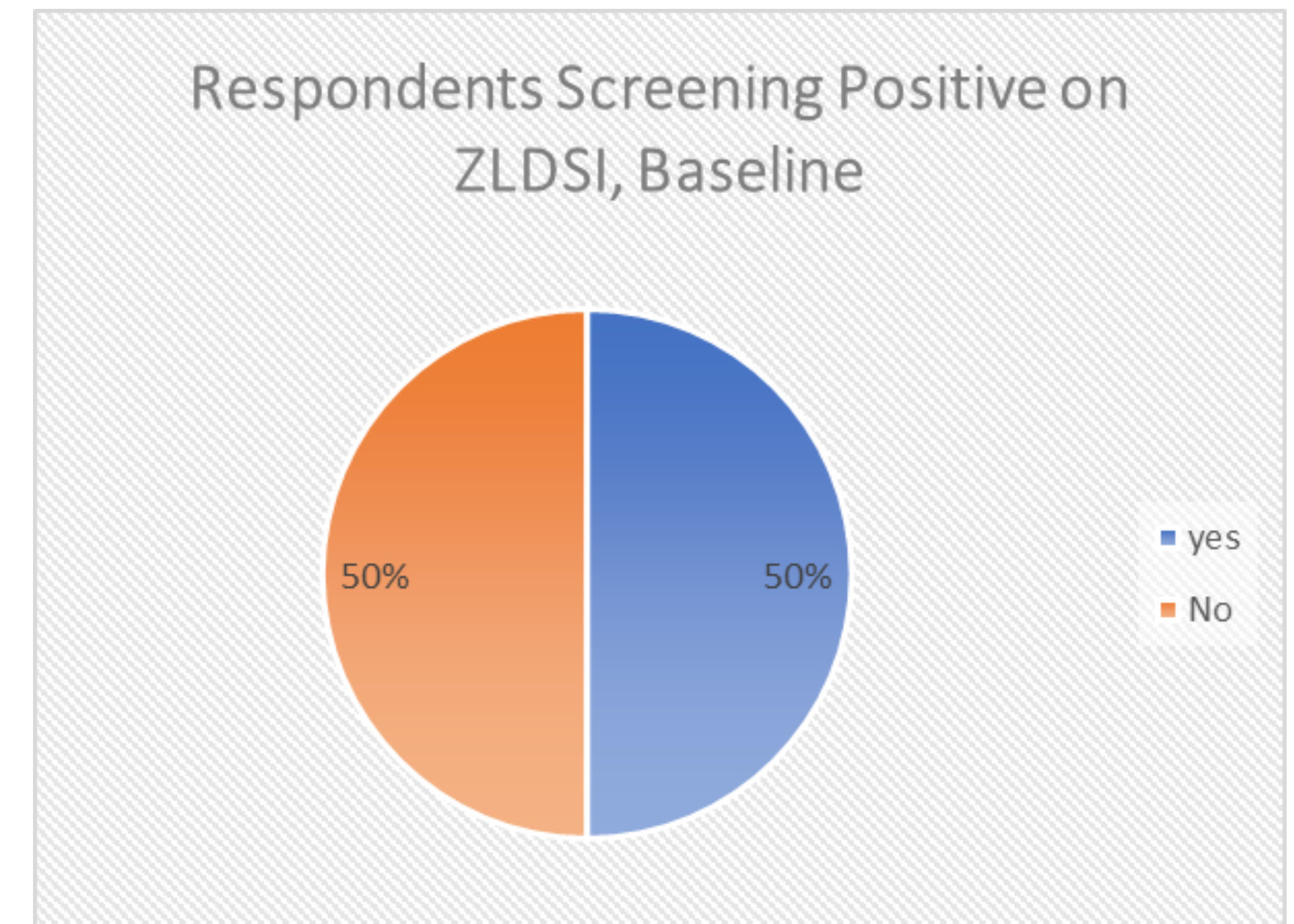


Strategies adopted (Cont'd)

In 2018, the mental health team at The Carter Center joined The LF Program to strengthen services to the patients and provide to them tools that can help to do a self-management of the disease.

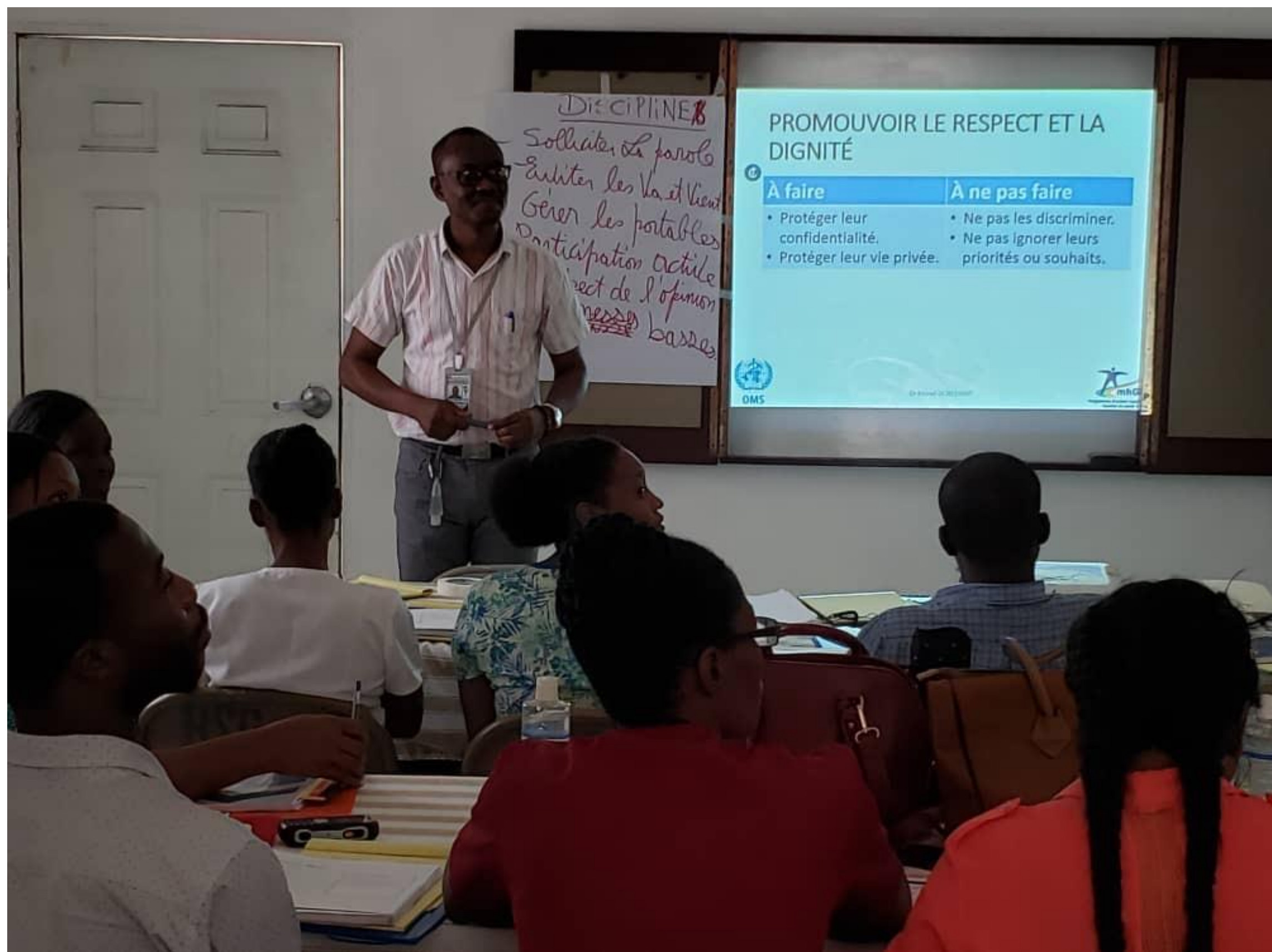
The goal of the project is to evaluate the effectiveness of the Chronic Disease Self-Management (CDSM) curriculum among Hope Club participants in Léogâne, Haiti.

We have 210 patients enrolled in the project.



MhGAP Training

After all these analysis, we think it's important to provide tools to the community to address the mental health among patients suffering chronic diseases.



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Overview of the Chronic Disease Self-Management (CDSM) Intervention

Martha Desir, RN, BSN
Director of Clinical Services



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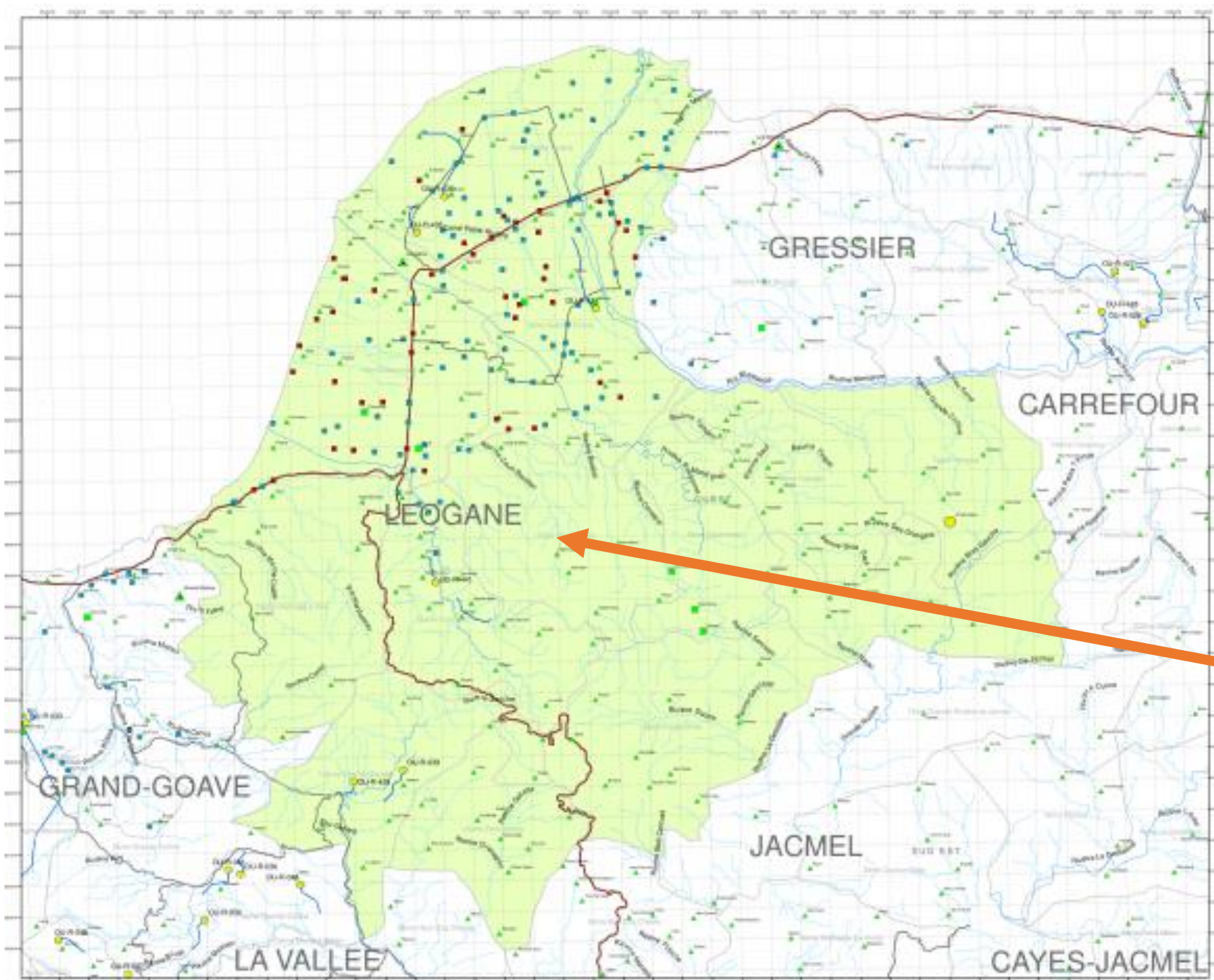
CDSM Implementation Overview

- Study Setting
- CDSM/LF Context and Tool
- Training for Animatrices in Arm 1
- Training for Patients in Arm 1
- Training for Animatrices in Arm 2
- Training for Patients in Arm 2



Study Setting

- 88% of nation LF endemic in 2000
- Hispaniola accounts for 90% of LF burden in Western Hemisphere
- Hôpital Ste. Croix (HSC) is the only facility providing comprehensive LF services



CDSM / LF CONTEXT

- Chronic Disease Self Management: High blood pressure, asthma, diabetes, lymphatic filariasis and so on
- Lymphatic Filariasis is a disease that affects patients for the rest of their life
- Patients with filariasis lymphatic need to know how to manage themselves



LF Patient Situation in Leogane, Haiti



- Hospital Sainte Croix in Leogane is the only facility in the country where LF health care is provided
- LF does not affect patients just physically. There are a lot of mental issues like stigmatization, depression, and anxiety...

LF Patient Situation in Leogane, Haiti

For this, we provide mental health care through:

- Hope clubs
- Mini hope clubs
- Home visits



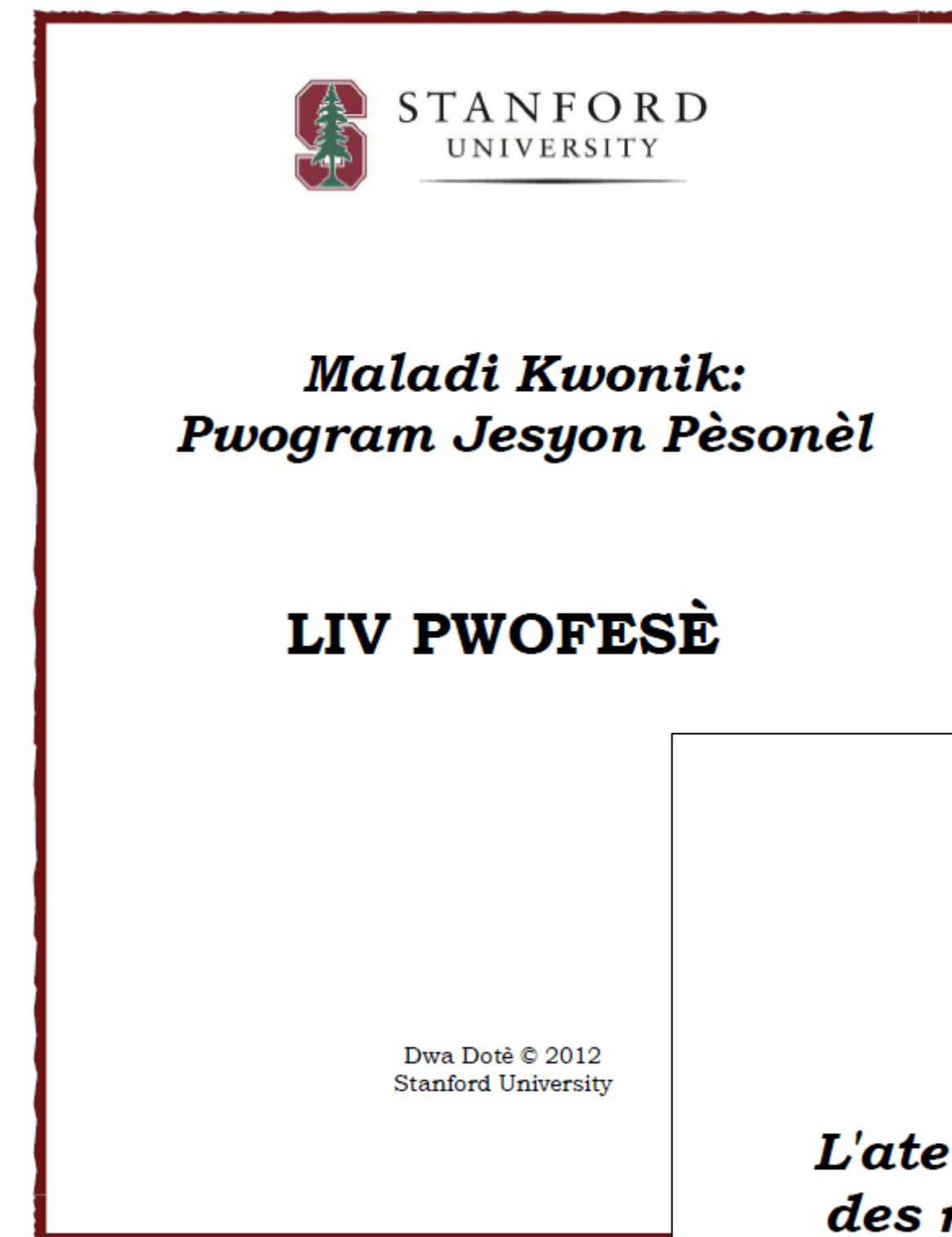
LF patient sub-groups

- 10 groups of 20-30 patients
- Meeting once a month in the field for each group (mini hope club)
- Meeting every three months for all of patients (hope club)
- For CDSM implementation, 5 groups in Arm 1 and 5 groups in Arm 2



ABOUT THE CDSM TOOL

- Mind-body connection
- Making action plans
- Problem solving
- Pain and fatigue management
- Relaxation techniques
- Exercise



CDSM French and Creole Leaders Manuals



CDSM COMPONENTS

- Healthy eating
- Communications skills
- Dealing with depression
- Dealing with difficult emotions
- Medication usage
- Making informed treatment decisions
- Working with your health care provider



Training for Animatrices in Arm 1

- The 5 animatrices of the Arm 1 patient were trained for three (3) weeks
- Took two (2) weeks for the trainers to teach all of the CDSM sessions (6 sessions)
- Took one (1) week for the animatrices to show their learning skills and ability to present the CDSM to the patient



Training for patients in Arm 1

- Over 3 months, 5 animatrices presented the CDSM to the 5 groups of Arm 1
- Groups met twice a month
- Six weeks of CDSM meetings
- One session weekly



Training for Animatrices in Arm 2

- In August 2020, the 5 animatrices in Arm 2 were trained for three (3) weeks
- Two (2) weeks for the trainers to teach all of the CDSM sessions (6 sessions).
- One (1) week for the animatrices to show their learning skills and ability to present the CDSM to the patient.
- Unfortunately because of Covid-19, this week was postponed



Training for patients in Arm 2



- We just started the CDSM intervention for the second group of hope clubs (arm 2)
- Like the first arm, we plan to have 3 months of presentation
 - Twice a month
 - Six weeks of training
 - One session weekly

VIDEO

https://drive.google.com/file/d/18bEXAoWHfSa48W_GlHiCKbm8yupCnLY9/view



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Building an Evidence Base for Addressing the Mental Health Burden of NTDs: Programmatic Examples of Integrated Care

QUESTION & ANSWER



Compassion, NTDs, and Mental Health

- “The primary motivation within GPELF for managing morbidity is to **relieve suffering**.

– WHO, *GPELF Progress Report*, 2010



Compassion, NTDs, and Mental Health

- “The primary motivation within GPELF for managing morbidity is to **relieve suffering**. Thus, this component of the programme is rooted in **compassion**.”

– WHO, *GPELF Progress Report*, 2010

- “Compassion is the feeling that arises in witnessing another’s suffering and that motivates a subsequent desire to help.”

– Goetz J et al. Compassion: An evolutionary analysis and empirical review. *Psychol Bull* 2010; 136:3:351-374



Elements of Compassion

- Awareness of suffering (cognitive attunement)
- Empathy (emotional resonance)

***“Can It Be That God Does Not Remember Me”:
A Qualitative Study on the Psychological
Distress, Suffering, and Coping of Dominican
Women With Chronic Filarial Lymphedema
and Elephantiasis of the Leg***

BOBBIE PERSON

*Centers for Disease Control and Prevention, National Center for Preparedness, Detection,
and Control of Infectious Diseases, Atlanta, Georgia, USA*

**A qualitative study of the perceptions, practices and
socio-psychological suffering related to chronic brugian
filariasis in Kerala, southern India**

T. K. SUMA*, R. K. SHENOY[†] and V. KUMARASWAMI[‡]

**T. D. Medical College Hospital, Alappuzha – 688011, India*

OPEN ACCESS Freely available online



**Neglected Patients with a Neglected Disease?
A Qualitative Study of Lymphatic Filariasis**

Myrtle Perera¹, Margaret Whitehead^{2*}, David Molyneux³, Mirani Weerasooriya⁴, Godfrey Gunatilleke¹

¹ Marga Institute, Colombo, Sri Lanka, ² Division of Public Health, University of Liverpool, Liverpool, United Kingdom, ³ Lymphatic Filariasis Support Centre, Liverpool School of Tropical Medicine, Pembroke Place, Liverpool, United Kingdom, ⁴ Filariasis Research, Training and Service Unit, Department of Parasitology, Faculty of Medicine, University of Ruhuna, Galle, Sri Lanka

OPEN ACCESS Freely available online



Review

**The Emerging Story of Disability Associated with
Lymphatic Filariasis: A Critical Review**

Lynne Michelle Zeldenryk*, Marion Gray, Richard Speare, Susan Gordon, Wayne Melrose

School of Public Health Tropical Medicine and Rehabilitation Sciences, James Cook University, Australia



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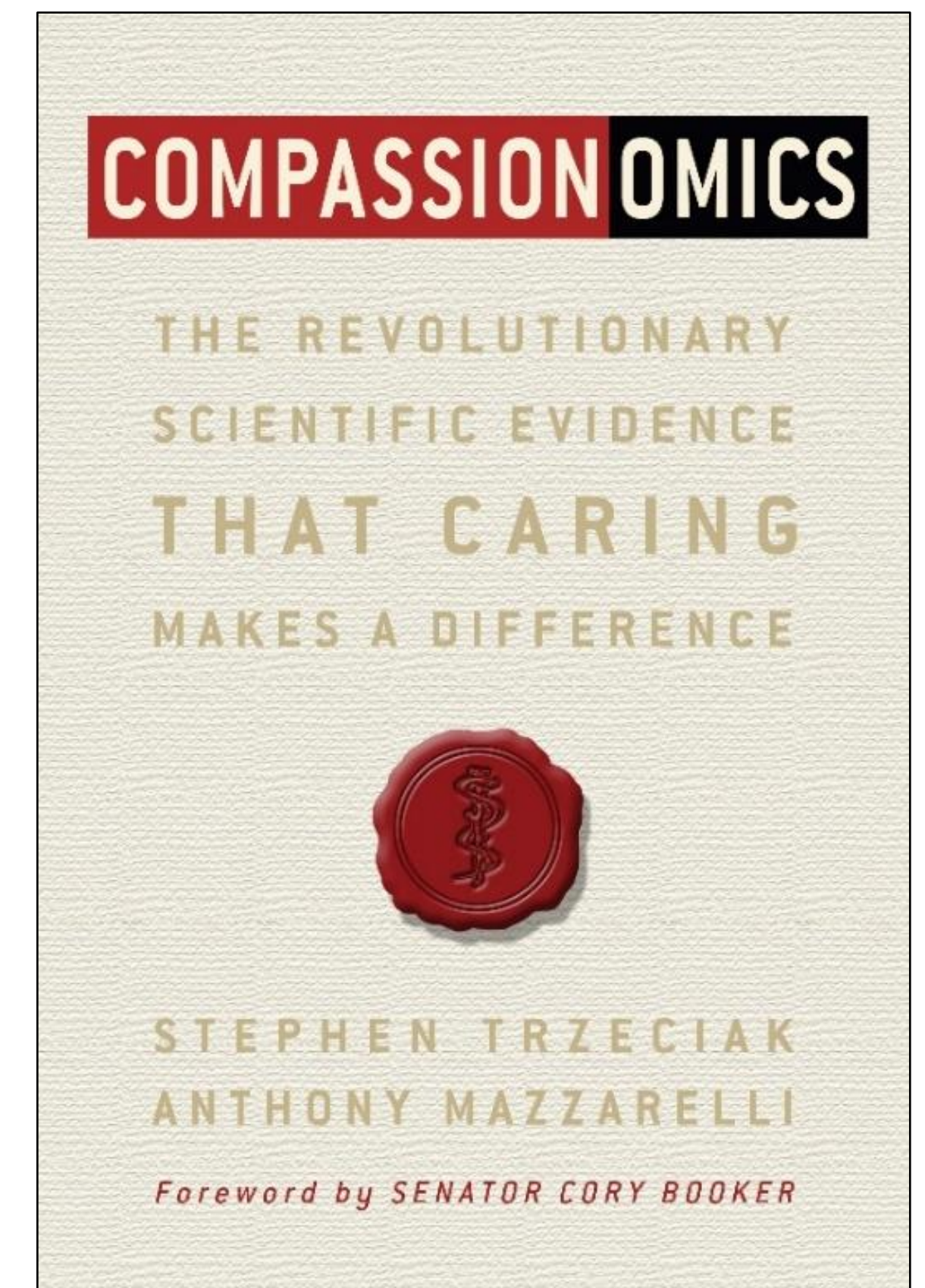
Elements of Compassion

- Awareness of suffering (cognitive attunement)
- Empathy (emotional resonance)
- Action (to relieve and prevent suffering)



Benefits of Compassion in Healthcare

- Patients
 - Improved physical and mental health
 - Enhanced self-care
- Providers
 - Professional satisfaction
 - Wellbeing
- Healthcare system
 - Improved financial performance
 - Higher quality care



Quality is not a given. It takes vision,
planning, investment,
compassion,
meticulous execution, and rigorous
monitoring, from the national level to
the smallest, remotest clinic.

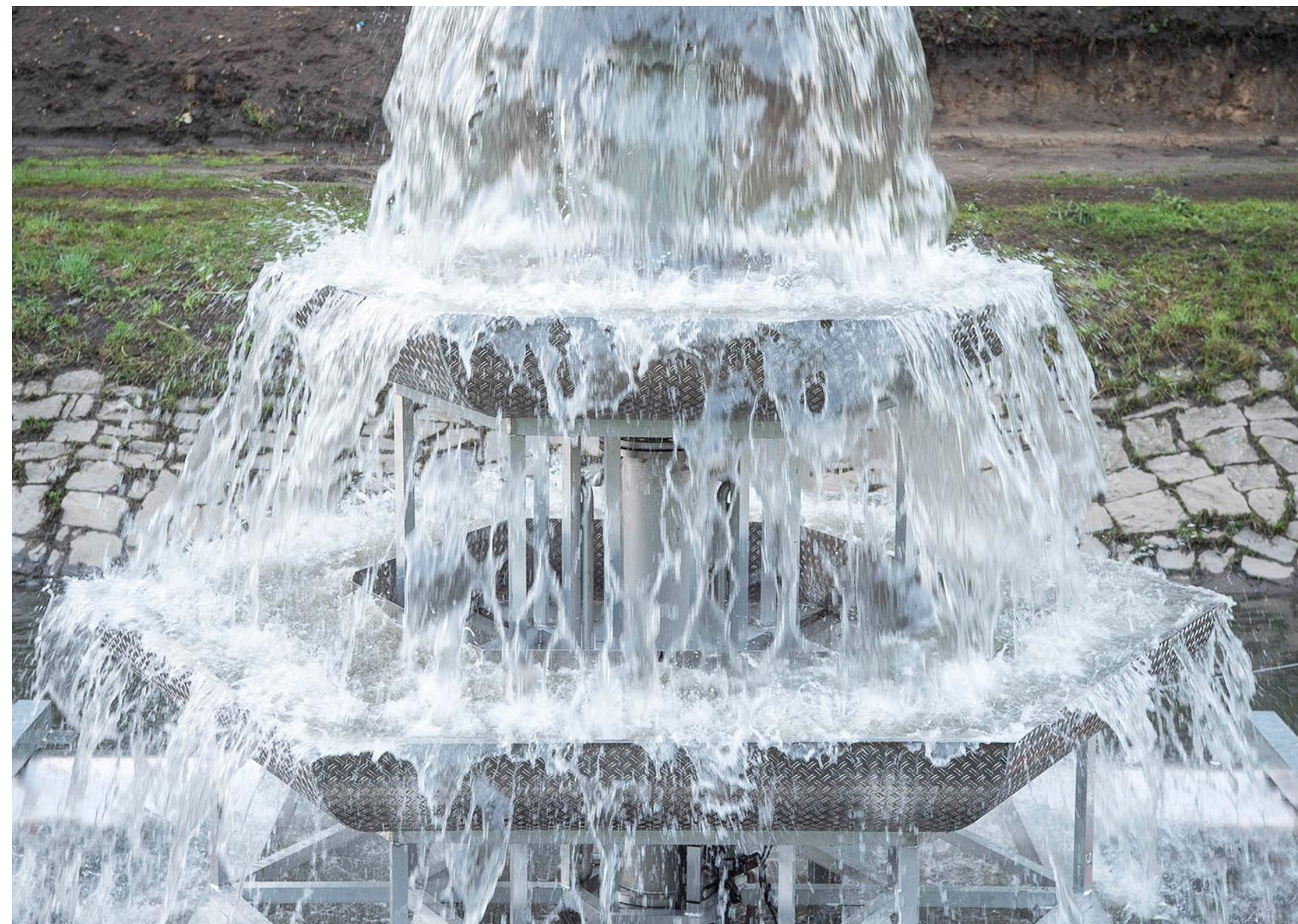
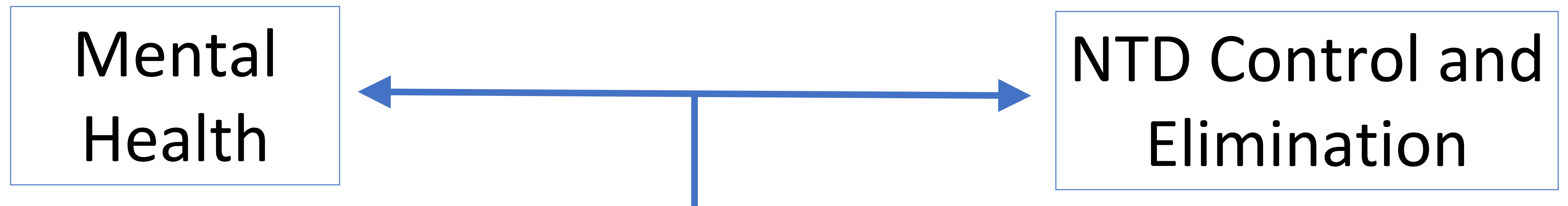
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Dr Tedros Adhanom Ghebreyesus
WHO Director-General



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