Welcome to the NNN Conference 2020

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

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Virtual Event

8th – 10th September 2020

ntd-ngonetwork.org
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
Trachoma and Mental Health

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 WHO-BREFF
  - 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
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
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

<table>
<thead>
<tr>
<th>S/No</th>
<th>Activity</th>
<th>Year (Date)</th>
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<tbody>
<tr>
<td>1</td>
<td>Collection of hydrocele baseline data during LF Mapping</td>
<td>1999</td>
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<tr>
<td>2</td>
<td>Hydrocele Surgeries</td>
<td>2002 - 2005, 2020</td>
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<tr>
<td>3</td>
<td>Hope Group establishment</td>
<td>2003 - 2020</td>
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<tr>
<td>4</td>
<td>Collecting baseline data LF morbidity alleviation programs</td>
<td>2008</td>
</tr>
<tr>
<td>5</td>
<td>Mental health for LF patients and their family members</td>
<td>2018 to date</td>
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<tr>
<td>6</td>
<td>Case search</td>
<td>2018 to date</td>
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RAPID ASSESSMENT FOR LYMPHATIC FILARIASIS IN CENTRAL NIGERIA: A COMPARISON OF THE IMMUNOCHEMIGRAPHIC 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 OGAG, JOHN UMARU, M. Y. JINADU, WANIRA 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 ICT survey can supplement the ICT surveys in the mapping activities. We compared in 144 Nigerian villages using ICT and examination for clinical hydrocele, in random samples of 30 adult males obtained 15 younger males (reported age = 16–39 years old) and 15 older males (≥ 40 years old); hydrocele rates were more prevalent in older age groups. The ICT was asked and examined and tested by the ICT. We found a weakly positive correlation between ICT and hydrocele (r = 0.041, P = 0.001). Only villages with hydrocele rates of 5/100 or higher classified as having endemic filariasis by the ICT. There was no correlation between ICT results and hydrocele.

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

Elis Mathieu,* Josef Amann, Abel Eigge, Frank Richards, and Yao Sodahon
Division of Parasitic Diseases, National Center for 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 Parasitology, Faculty of Medicine and Pharmacy, Université de Lomé, Lomé, Togo.

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

1. Community Engagement
2. Identification of Suspected Cases
3. Assessment, Validation and Registration at PHC
   - Mild/Moderate: Manage at PHC
   - Severe: Referred & Managed at Secondary or Tertiary HF
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.
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
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)
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
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
The program would like to thank

And our many generous individual donors
Addressing the Mental Health of Persons Living with Lymphatic Filariasis in Leogane, Haiti: Effectiveness of a Chronic Disease Self-Management Program
Overview of the Lymphatic Filariasis Program in Haiti

Dr Luccene DESIR
Program Manager, Hispaniola Health Initiative
Special Health Projects, The Carter Center
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
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/13clBnFxv7xKT31X7C2wW2JHEwsPdmD2O/view?usp=sharing
Strategies adopted (cont’d)

MMDP:

Lymphedema
Hydrocele
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).
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 chronical diseases.
With thanks to our generous sponsors and Partners…
THANK YOU
Overview of the Chronic Disease Self-Management (CDSM) Intervention

Martha Desir, RN, BSN
Director of Clinical Services
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
• 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...
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 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 animatices 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
THANK YOU!
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.”
Elements of Compassion

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

- Dr Tedros Adhanom Ghebreyesus 
WHO Director-General
Compassion

Motivation for Quality Mental Health Care and NTD Elimination

Mental Health

NTD Control and Elimination

‘Fount’ of Compassion
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PANEL DISCUSSION w/ Q&A

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