NEGLECTED TROPICAL DISEASE NGO NETWORK

A global forum for nongovernmental organizations working together on NTDs

Welcome to the NNN Conference 2020

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

Billy Weeks (2016, Chikwawa, Malawi)

Virtual Event

8th – 10th September 2020

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Enhancing the NTD Toolkit – Practical Approaches to Addressing Mental Wellbeing and Stigma

NNN Conference 2020
Workshop 4.5
10 Sept 2020

Workshop Team: Dr Maya Semrau, Dr Wim van Brakel,
Dr Ashok Agarwal, Ms Samhita Kumar, Dr Emeka Nwefoh,
Dr Joydeepa Darlong, Ms Roos Geutjes, Dr Bahadir Celiktemur

Workshop Outline	Speaker
1. Psychological First Aid for NTDs intervention in India	Dr Ashok Agarwal
2. Chronic Disease Self-Management for persons living with Lymphatic Filariasis in Haiti	Ms Samhita Kumar
3. Mental Health and NTD programmes in Nigeria	Dr Emeka Nwefoh
4. Tele-counselling for Leprosy care in India	Dr Joydeepa Darlong & Dr Rajeev Nathan
5. ILEP/NNN Revised Stigma Guides for use globally	Ms Roos Geutjes
6. Brief Questions & Answers	Group

Workshop Lead: Dr Maya Semrau; Workshop Co-Lead: Dr Wim van Brakel;
Rapporteur: Dr Bahadir Celiktemur

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Psychological First Aid for NTDs (PFA-N) intervention in India

Dr Ashok Agarwal
Country Director

until
No Leprosy Remains

Content

- Context/ background
- PFA-N development
- Content of PFA-N
- Plan for piloting
- Conclusion
- PFA-N contributors

Context/ Background

- India accounts for:
  - Around 60% of the Global Leprosy Cases
  - Around 43% of the Global Lymphatic Filariasis (LF) cases
- Both the diseases may cause lifelong disability
- They experience significant stigma & discrimination
  - A recent perception study from Uttar Pradesh depicts - 94% of the respondents displayed negative attitudes towards people affected by leprosy – Ballering et al. Community stigma and desired social distance towards people affected by leprosy in Chandauli District, India. Lepr Rev (2019) 90, 418–432
  - Between 50-70% of all participants reported some degree of depression

    -Finding from Lepra COR-NTD, Bihar project shared in PFA-N development workshop on June 9, 2020; and Bow-Bertrand et al. An exploration into the psychological impact of leprosy in Sirajganj, Bangladesh. J. Leprosy review. 2019; 90 (4) : 399–417

Context/ Background (Contd.)

- Implementation of the study “Reducing stigma and improving mental wellbeing and social participation amongst men and women affected/disabled by lymphatic filariasis and leprosy in the districts of Jaunpur and Bokaro in India” by NLR India since March 2020
- One of the research questions: ‘How suitable is an NTD-adjusted version of PFA for use as peer-counselling method to reduce stigma and improve mental wellbeing and social participation among persons with LF or leprosy-related disabilities?’
- In 2011, WHO published the PFA for field workers
- In 2014, WHO published the PFA for Ebola

Development of PFA-N

- Virtual Workshop (WS) to kick start development of Psychological First Aid (PFA) Tool for NTDs on 9-11 June 2020
  - WS attended by 30 participants from India and outside; including experts involved in development of original PFA
  - Resulted in development of PFA-N Framework and contents
  - Task Force (10 experts) and Review Committee (13 experts) set-up to develop and review drafts
- Status as of end August 2020
  - Complete draft ready for final review
  - Final print-ready version to be available by Oct 2020

Content of the PFA-N

- Purpose: to prevent and mitigate the mental health consequences of NTDs
- Disease focus – Leprosy and LF
- User: Peer supporter (PS)
    - Leprosy or LF affected
    - Above 21 years of age
    - Completed at least secondary school education (class-12)
    - Layperson from the community
    - Knows the community well
    - Well accepted by the community
    - Has good communication skill
    - Willing to volunteer time without remuneration

Content of the PFA-N (Contd.) – Chapters

1. Introduction – understanding NTDs
   - Brief on NTDs, mental health, leprosy, LF & Covid-19 – 10 pages
2. Understanding PFA
   - Consequences of NTDs; What is PFA? Who, when and where? – 5 pages
3. How to help responsibly
   - Respect safety, dignity and rights – 3 pages – the section on rights has gained from NLR experience in Indonesia
4. Providing PFA for NTDs
   - PFA action principles: Look, Listen and Link! – 12 pages
5. Caring for yourself and your colleagues
   - Getting ready to help; Managing stress; Rest and reflection – 2 pages
6. Pocket guide – 2 pages

Plan for piloting in India

- In 2 districts: Bokaro and Jaunpur
- Train 12 peer supporters (PS) per district
- 12 PSs: 3 LF affected & 3 Leprosy affected persons per district
- Each PS will counsel 4 persons selected purposively as scoring high on experienced stigma (SARI Stigma Scale) and depression (PHQ-9) and low on social participation (Participation scale) and mental wellbeing (WEMWBS)
- Total sample – 96; 48 intervention & 48 control (random allocation; with equal nos. of lymphoedema and leprosy with disabilities
- Assessment of stigma & mental wellbeing at intake and after 3 months

Conclusion

- The study experience will be widely discussed and disseminated
- Advocacy will be done with WHO for their authorisation of PFA-N
- Advocacy will be done with government, mental health institutes and experts for adoption as a strategy for addressing mental health among Leprosy and LF cases

PFA-N development team		
Julian Eaton	Neena Agrawal	Astri Ferdiana
Carmen Valle	Widya Prasetyanti	Ariana Marastuti
Charles Mackenzie	Jayashree PK	Jayaram Parasa
Wim van Brakel	Heleen Broekkamp	Chandni Srinivasan
Maya Semrau	C P Mishra	Sushil Kumar
Suma Krishnasastry	G S Kolaiya	Arun Kumar
Mary Verghese	Alok Pratap	Ashok Agarwal
Tulsi Das	Mimi Lusli	

until

No Leprosy Remains

Thank you for your attention

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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

Samhita Kumar
Associate Director, Mental Health Program, The Carter Center

The Carter Center: Integrating MH NTD programming and addressing key research needs

THE CARTER CENTER

Waging Peace. Fighting Disease. Building Hope.

Increased interest in psychological comorbidity among persons with Neglected Tropical Diseases (NTDs)

Evidence base for Mental Health and NTDs begins to grow

Quantification of physical disability, stigma, psychological symptoms in persons with NTDs

Exploration of effective interventions

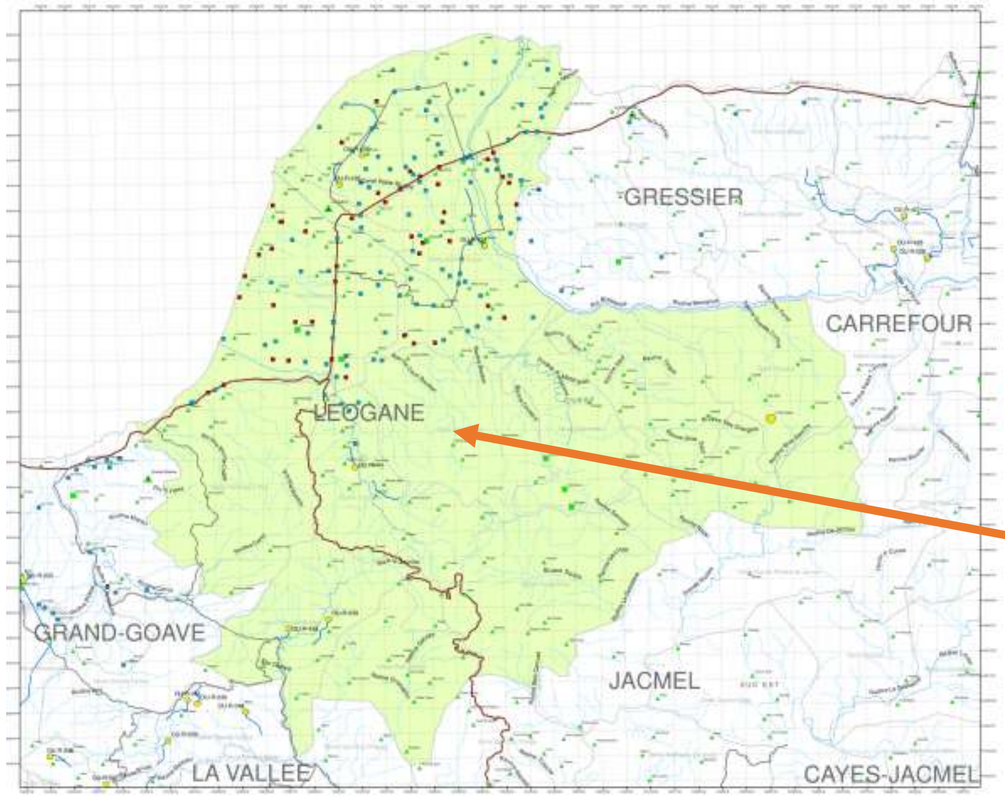
Advocacy/Policy reform

Service integration

Model psychological impact of NTDs and inform GBD estimates

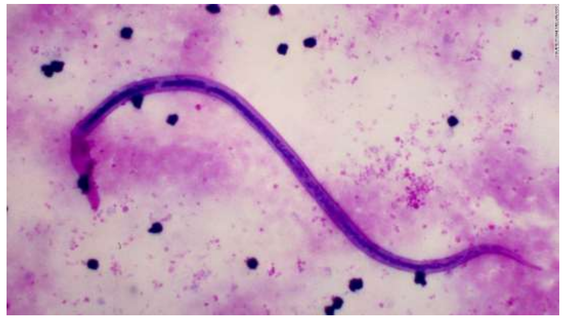
Building on TCC Lymphatic Filariasis (LF) program footprint: Léogâne, Haiti

- Hispaniola is one out of the four countries with endemic Lymphatic Filariasis transmission in America alongside Dominican Republic, Guyana and Brazil
- Hispaniola accounts for 90% of LF burden in Western Hemisphere
- 88% of Haiti LF endemic in 2000
- Hôpital Ste. Croix (HSC), Léogâne - only facility providing comprehensive LF services



About Lymphatic Filariasis (LF)

- Debilitating disease caused by thin worms transmitted to humans through the bites of mosquitoes in tropical/ subtropical regions
- Impacts aren’t limited to physical disfiguration
- Poor mental health and stigma is common
- LF is a chronic, lifetime disease just like high blood pressure, asthma, and diabetes, wherein management is needed for physical and mental health conditions



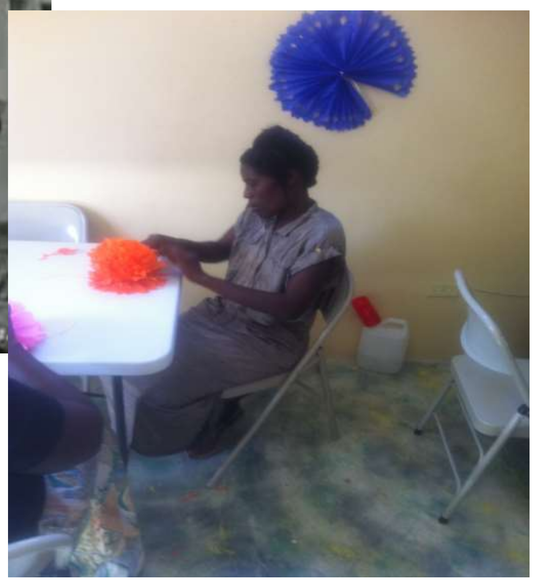
Addressing the MH impacts of LF is paramount

- The psychosocial dimension of LF is increasingly recognized and appreciated

- Needs to be a key part of morbidity management. Patients living with LF need to know how to take care of themselves physically and mentally, especially in resource constrained, insecure contexts

- Since 1996, patients at HSC in Leogane have been supporting each other through peer support groups (hope clubs).

- Since then, mental health support continued to be provided through hope clubs and home visits.



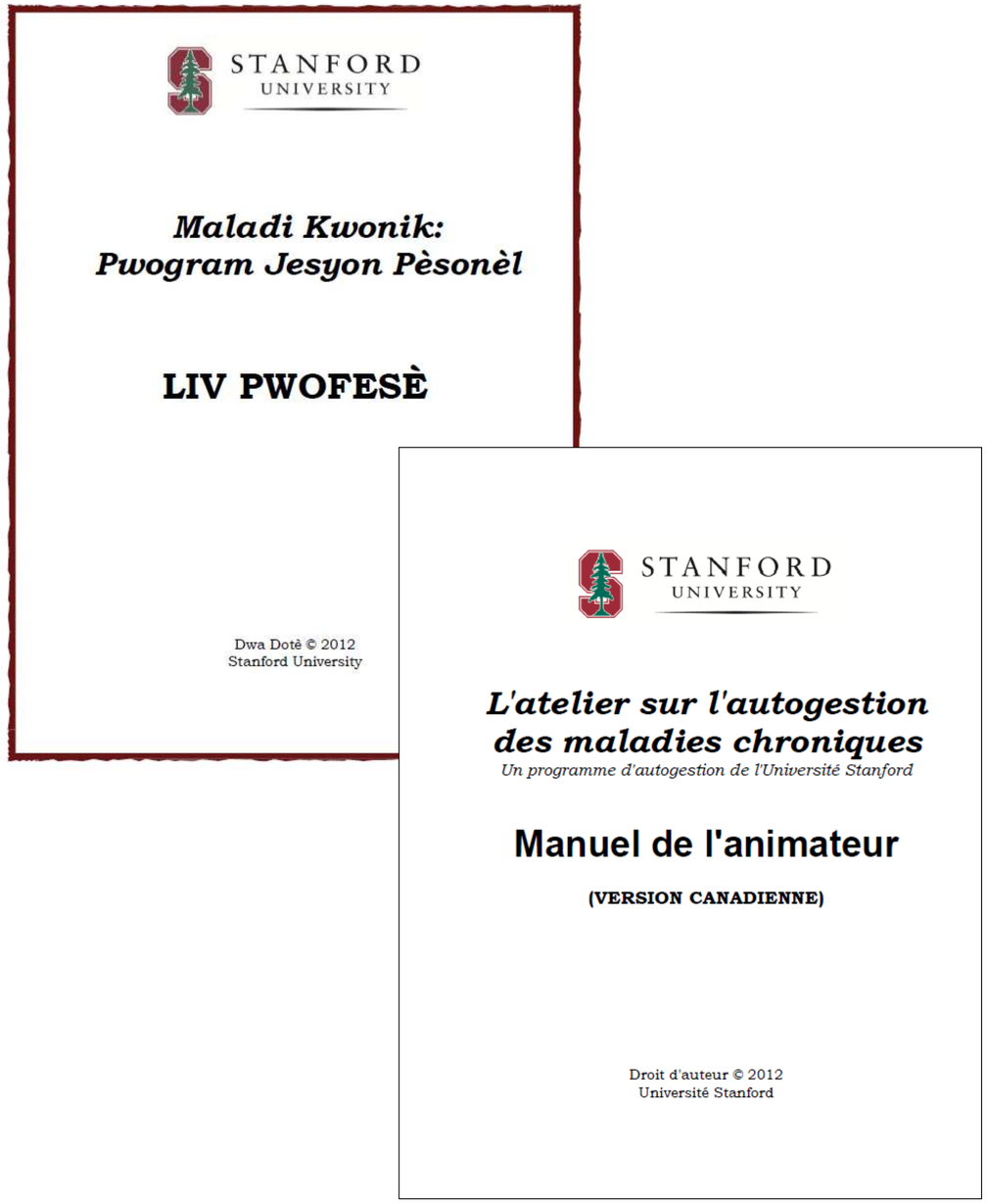
Testing Interventions:
What works to address MH for people living with LF?

Primary Research Question:

Does the introduction of a Chronic Disease Self-Management (CDSM) program into existing Hope Clubs in Léogâne, Haiti result in improvements in symptoms of depression, self-rated health, chronic disease self-efficacy, social support, and disability among patients with LF?

About the Tool:
The Chronic Disease Self-Management Program

- Developed at Stanford – a self-management education program for people with chronic health problems.
- Used and tested with a variety of chronic diseases including arthritis, diabetes, and lung and heart disease
- Teaches skills useful for managing chronic diseases through workshops held in community settings
- Workshops facilitated by 2 trained leaders, 1 or both of whom are non-health professionals with a chronic disease themselves
- Topics covered include:
  - *techniques to deal with problems associated with chronic disease;*
  - *appropriate exercise and use of medications;*
  - *communicating effectively with family, friends, and health professionals;*
  - *healthy eating;*
  - *and how to evaluate new treatments and making informed decisions*
  - *dealing with depression and difficult emotions*
  - *Working with your healthcare provider*



CDSM French and Creole Leaders Manuals

Study Design

- Methodology
  - Stepped-wedge cluster randomized trial
- Data Collection Tools
  - Quantitative (5)
    - Dermatology Life Quality Index (DLQI)
    - Multidimensional Scale of Perceived Social Support (MSPSS)
    - Self-Efficacy for Managing Chronic Disease 6-Itme Scale (SMCDS)
    - Self-Rated Health (SRH)
    - Zanmi Lasante Depression Symptom Inventory (ZLDSI)
  - Qualitative (2) – FGDs, KIIs

Training Animatrices to Deliver CDSM

- CDSM is delivered by peer leaders, or *animatrices*, to 10 groups of 20-30 patients each
  - 5 groups in Intervention Arm 1
  - 5 groups in Control Arm 2

- 5 animatrices were trained for 3 weeks prior to the implementation of the intervention

- 3 weeks of training structured as follows:
  - 2 weeks for the animatrices to learn all of the CDSM modules (6)
  - 1 week for the animatrices to show their learning skills and ability to present the CDSM modules

Delivery of the CDSM Intervention

- Over 3 months, animatrices presented the modules of CDSM to their groups

- 6 modules covered across 6 biweekly sessions

- CDSM delivered to the control group after the intervention was completed.

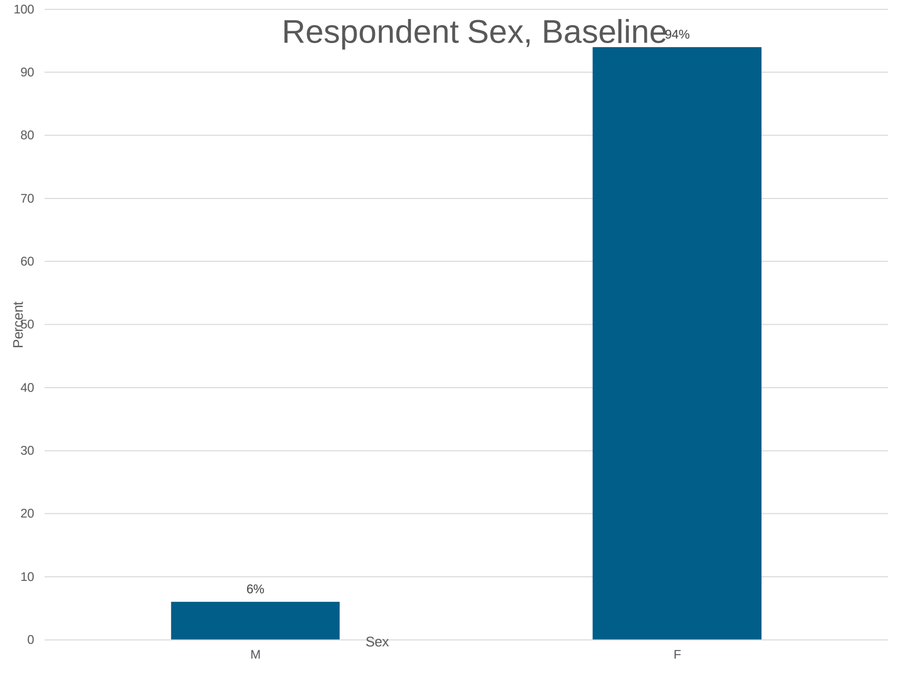
Baseline Findings

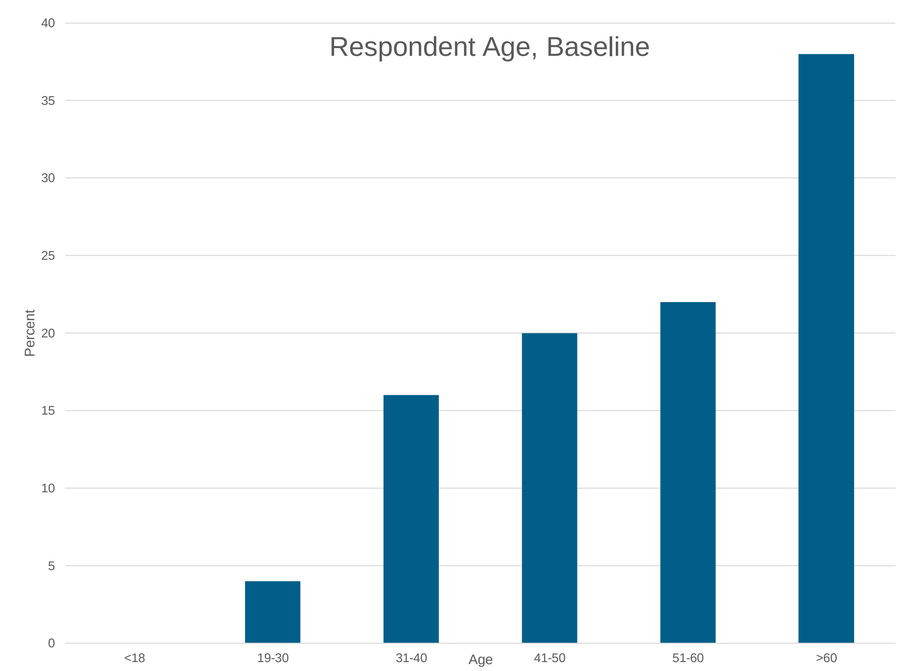
Number of Respondents

Baseline Data, Total (n=210)

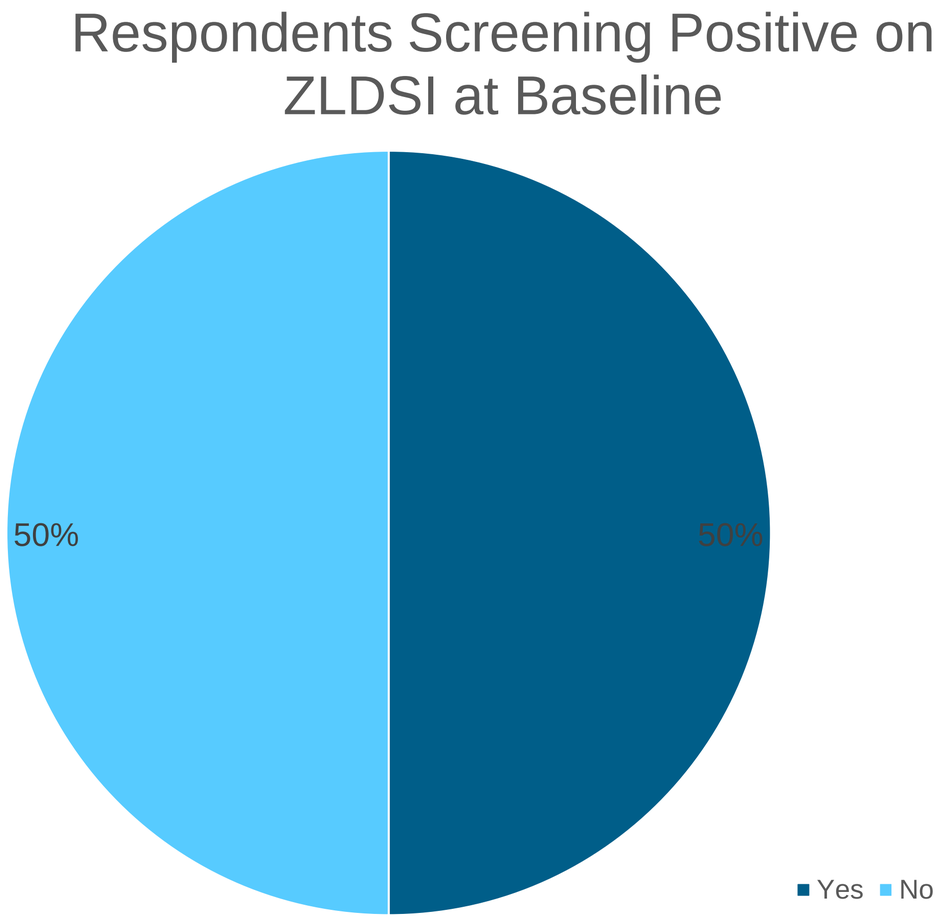
- Arm 1 (n=118)
- Arm 2 (n=92)

No statistically significant differences between Arm 1 and Arm 2 were found at baseline in the following indicators: age, gender, or scores on any of the five survey tools (DLQI, MSPSS, SMCDS, SRH, ZLDSI).





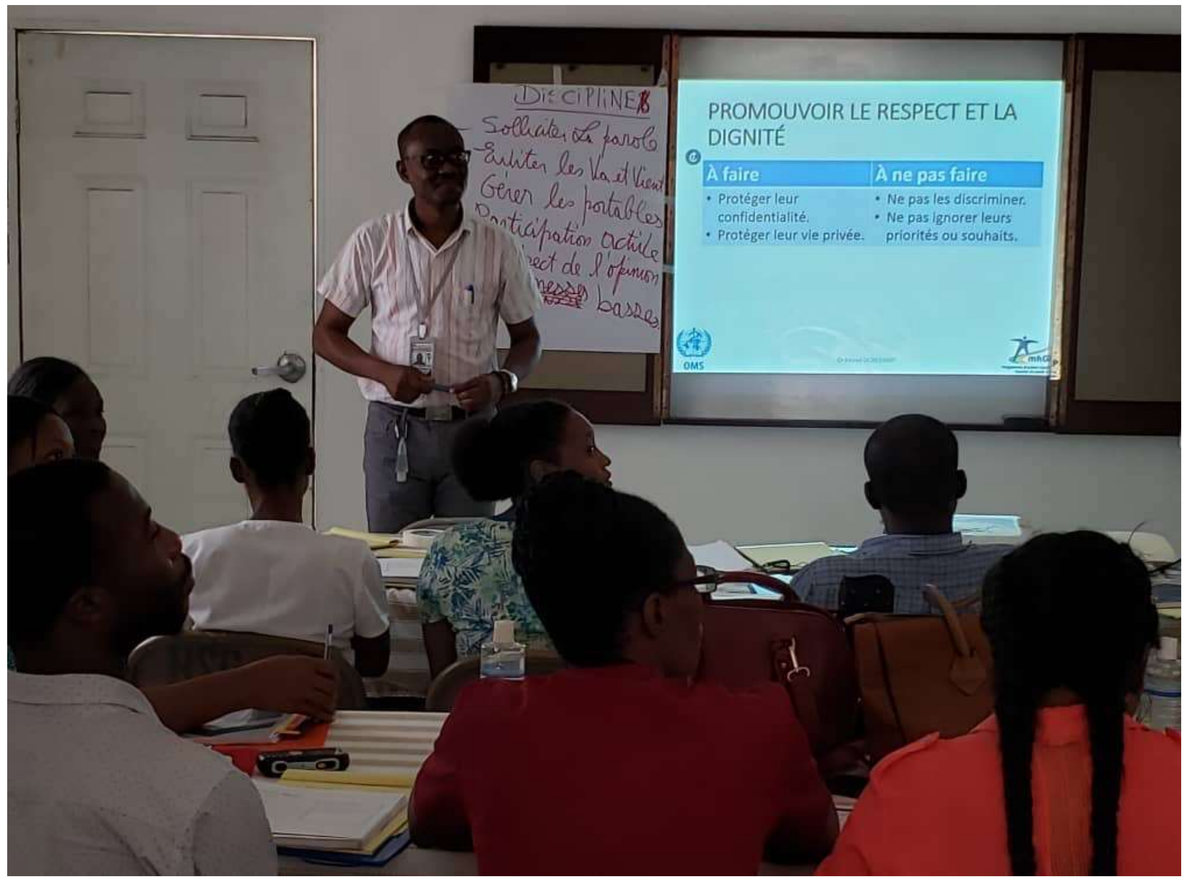
Prevalence of Symptoms of Depressive Illness at Baseline



50% of respondents in Arm 1 and Arm 2 screened positive for symptoms of depressive illness at baseline

MhGAP Training

Key component of the research – as both a safeguard for patients and contribution to the health system – is building the resource base of mental health professionals



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Comprehensive Inclusive NTDs in Jigawa State Nigeria – A Pilot

Emeka NWEFOH

CBM Mental Health advisor

The rationale

- CBM is a disability organization with focus in Mental Health, Eye Health/NTD, CBID and Humanitarian action.
- CBM partners HANDS in the elimination of NTDs in Jigawa, Kano, Yobe and FCT mainly through MDA to over 23 million people at risk in supported states
- Distribution of PC-NTD medicines against Onchocerciasis, Lymphatic Filariasis, Trachoma, Schistosomiasis and Soil Transmitted Helminths across 94 LGAs/Area councils
- No attempt to provide a comprehensive approach to NTDs that combines services for the physical and mental consequences of NTDs.
- Hence the concept of a pilot comprehensive NTD project in Jigawa state.

Demographic Data of Birnin Kudu LGA:

LGA	Population		
	Male	Female	Total
Birnin Kudu	205,197	222,297	427,494

AGE DISTRIBUTION	Birnin Kudu (9.3% Growth Rate)
AGE	2017 Data
0 - 4 Years	85,499
5 - 14 Years	119,698
15 Above	222,297
TOTAL	427,494
Population Growth Rate (%)	9.3%
% Population Below Poverty Level	55.60%

Comprehensive Inclusive NTDs Approach.

- Leverage on the existing NTD structure and contribute to the strengthening of health systems to address NTD and cross cutting issues.
- Holistic care for persons with NTDs.
- Advocate for cross sectoral collaboration among government and private groups
- Obtain evidence baseline data on disability in the pilot LGA
- Promote behavioral change, environmental improvement, social inclusion, morbidity management and preventive chemotherapy

Relevance of comprehensive approach to SDGs

Poverty (SDG 1)

Zero hunger (SDG 2)

Good health and wellbeing (SDG 3)

- Ending NTDs (3.3)
- Promotion of mental health and well-being (3.4)
- Access to quality medicines (3.8)

Clean water and sanitation (SDG 6)

Specialists in tertiary health facilities

- Build capacity of health workers in PHCs
- Support service provision in MH, Eye care & NTD
- Advocacy for service improvement
- Receive referral and back refer for follow up care in the community

At the PHC & Community

Community Health Workers

- Trained to identify common mental health and eye health conditions, treat and refer
- MH, Eye and DMDI health education and awareness
- Two way referral system

CDDs, Family volunteers, care givers and Persons with Disabilities

- Trained on identification and referral of common Mental health & Eye Health conditions
- MH, EH and DMDI education
- Anti stigma interventions
- Formation and sustenance of SHGs

Livelihood & WASH

- Short term training for farmers on basic farming skills & livestock husbandry
- Provision of start up tools & items for agriculture, trade, processing etc
- Training of farmers and SHGs on Village savings and loan association (VSLA)
- Collaboration with government agencies to provide accessible water points
- Formation of water committees and training on maintaining the water pumps
- Production of inclusive IEC materials on WASH

Expected outcome of the Project

- Baseline information on NTD and MH conditions morbidity in Birnin Kudu LGA

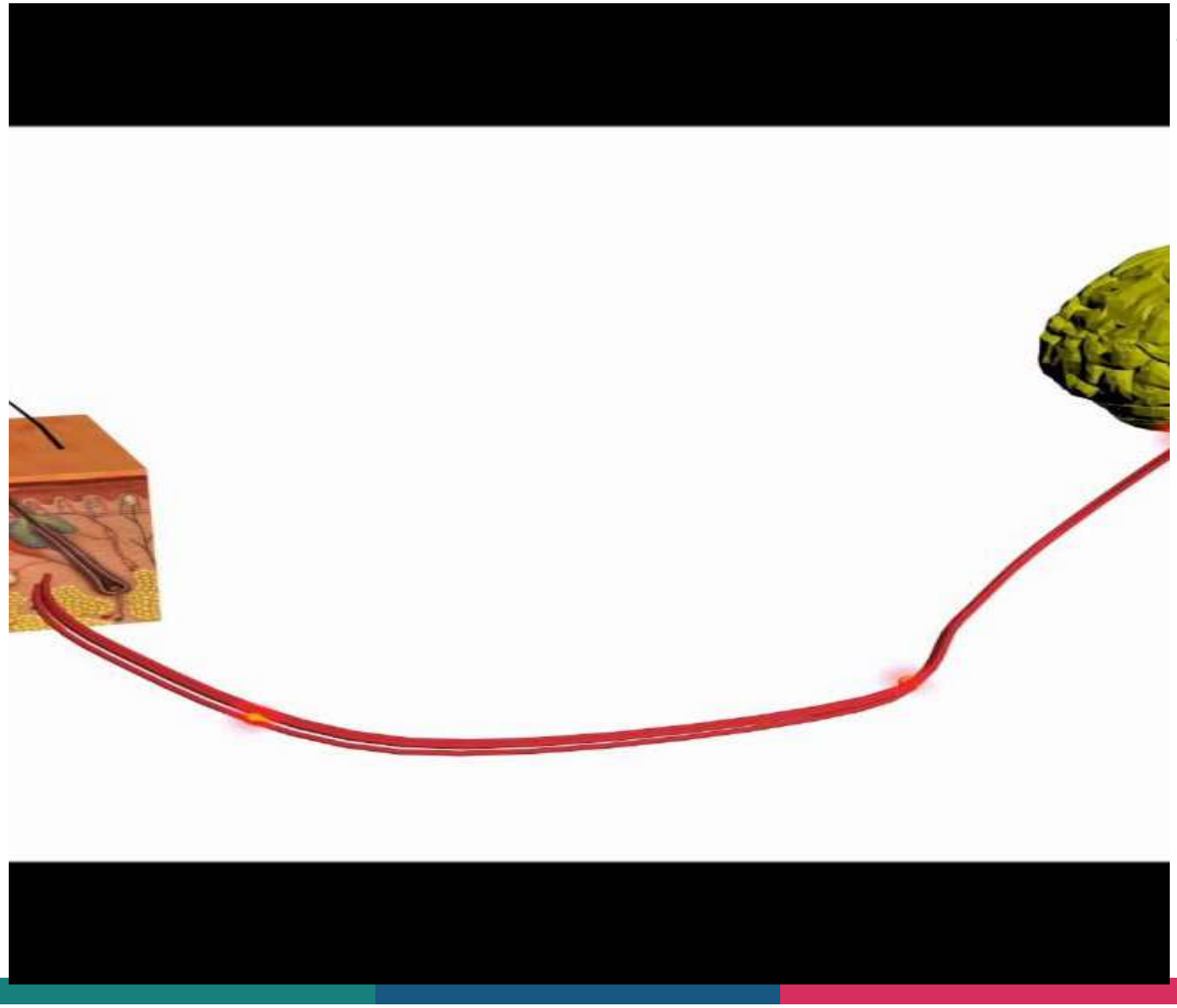
- Health system strengthened to provide holistic care for persons with NTD in the pilot area

- The project would have equipped the Health systems to identify and strengthen the referral pathway.

- Improved well beings of persons with NTD in Birnin Kudu LGA

- Partners and community members have improved skills to implement integrated programme in a holistic manner.

Formative piloting of the WHO Guide on Mental Health and NTD Integration



- **CBM and TLM Nigeria piloting it in Benue state, North central Nigeria**


Dakujem
Salamat
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ASANTE
धन्यवाद
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Благодарам
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SALAMAT
grazie
спасибо
gracias

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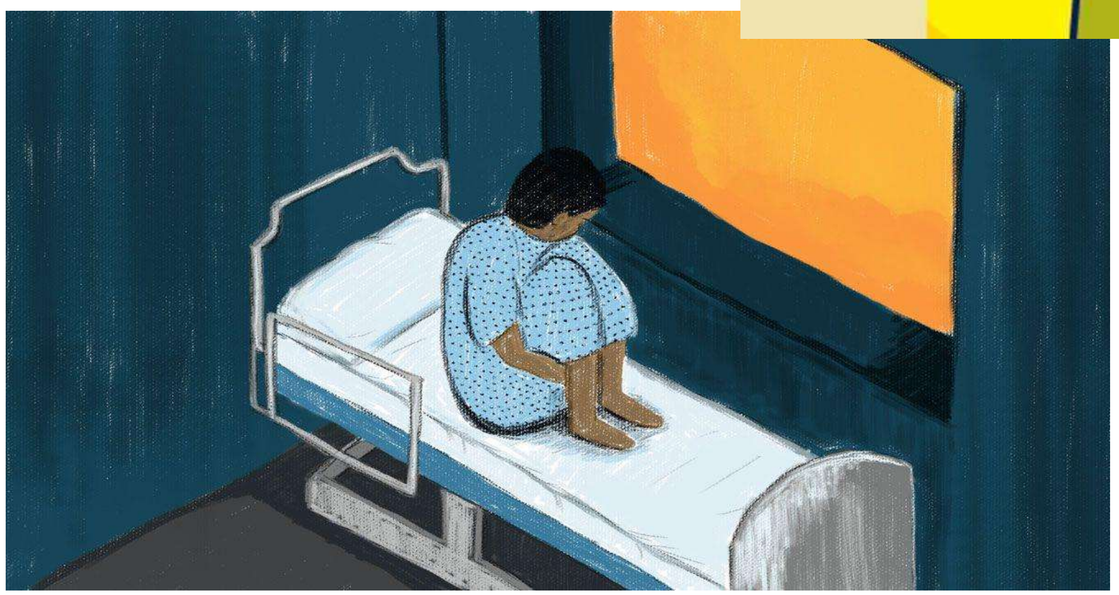
Tele counselling at The leprosy Mission Trust India

The situation !



Default

Complications

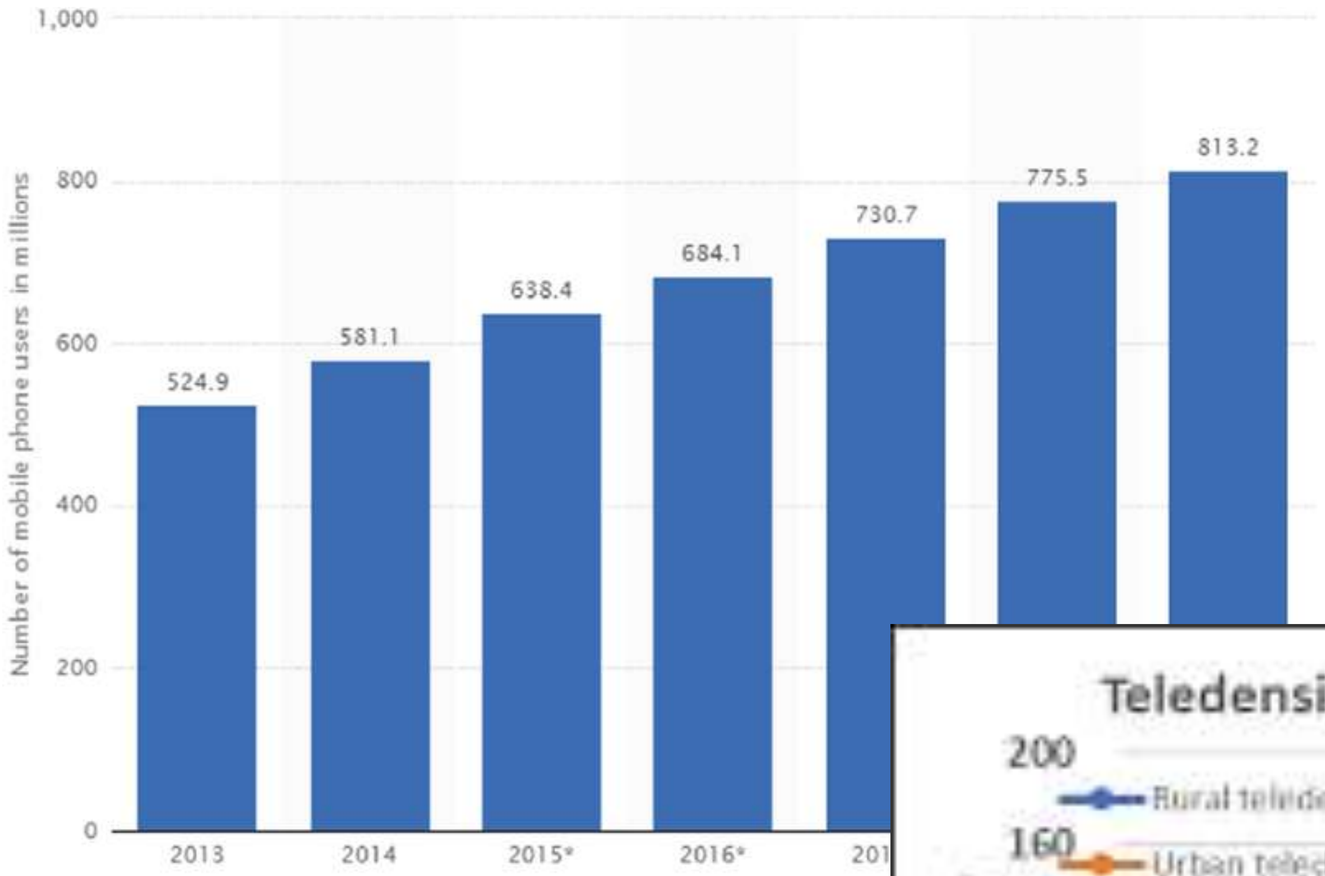
Disability

Mental stress

Helplessness

Our fears

what we had


1,000
800
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400
200
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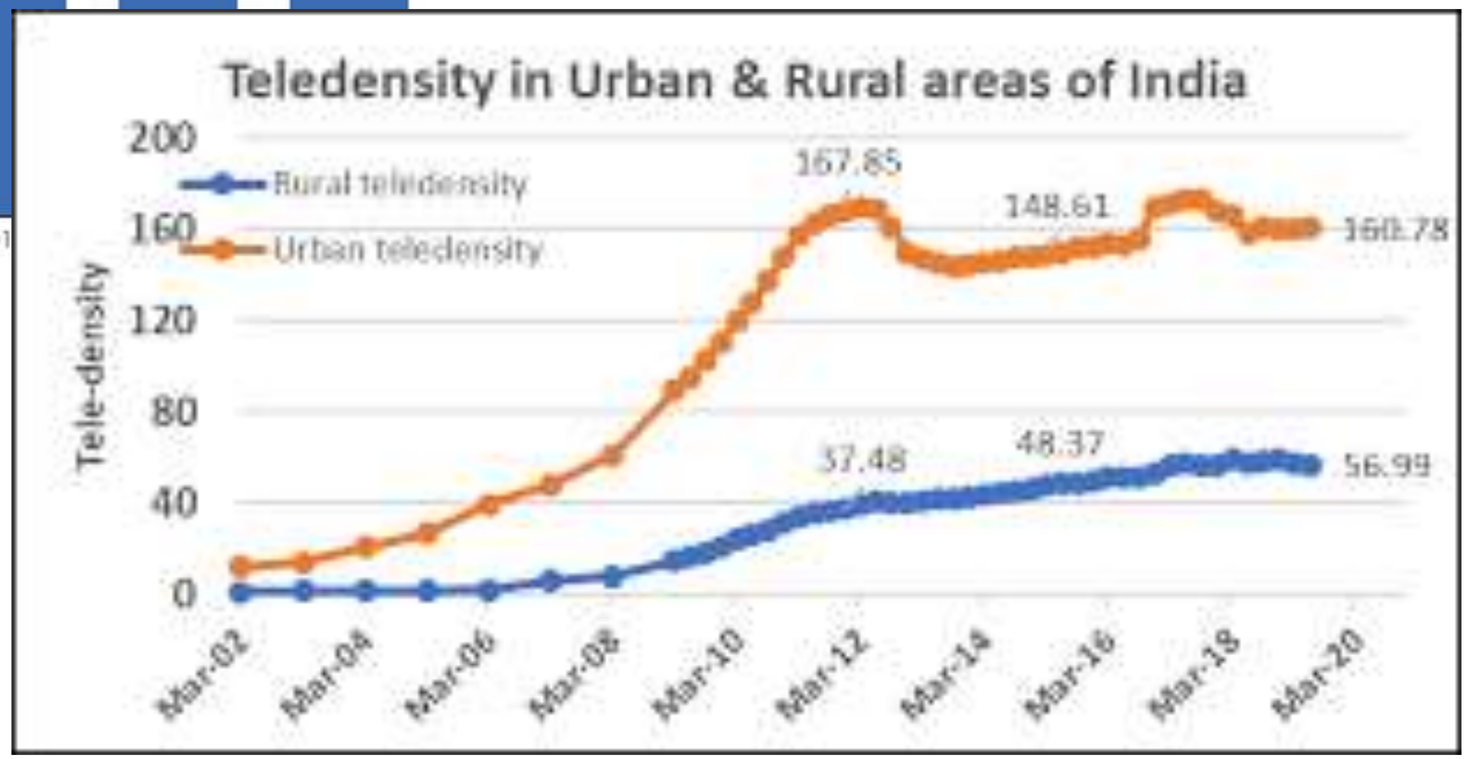
Number of mobile phone users in millions
524.9
581.1
638.4
684.1
730.7
775.5
813.2
2013
2014
2015*
2016*


Teledensity in Urban & Rural areas of India
Rural teledensity
Urban teledensity
Tele-density
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160.78
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48.37
56.99
Mar-02
Mar-04
Mar-06
Mar-08
Mar-10
Mar-12
Mar-14
Mar-16
Mar-18
Mar-20

Telemedicine Practice Guidelines

Revised

THE HCITEXPERT BLOG

In March 2020, the MoHFW, Government of India has published the Telemedicine Practice Guidelines. The article shares the document and the synopsis of the guidelines


TEAM

Who ?

- Patients on MDT
- Patients with reactions and neuritis on steroids
- Patients who scored poor on the WHO 5 index
- High risk patients to develop disability and reactions
- Those with complicated , non healing ulcers
- Those with chronic illnesses like DM and HTN
- Those on TB drugs

How ?

- Team formation
- Listing the vulnerable group
- Scanned the records
- Calling with an agenda
- Very informal
- Subtle mental health questions
- COVID preparedness and coping discussed
- Myths dispelled
- Repeat call
- Open invitation to call back

Content of conversation

- Introduction and general formalities
- Permission to speak about illness
- Current disease condition and medication
- Any complications
- Coping in COVID times
- Myths vs facts
- Addressing worry , fear, anxiety , depression
- Asking about family members
- Invitation to call back

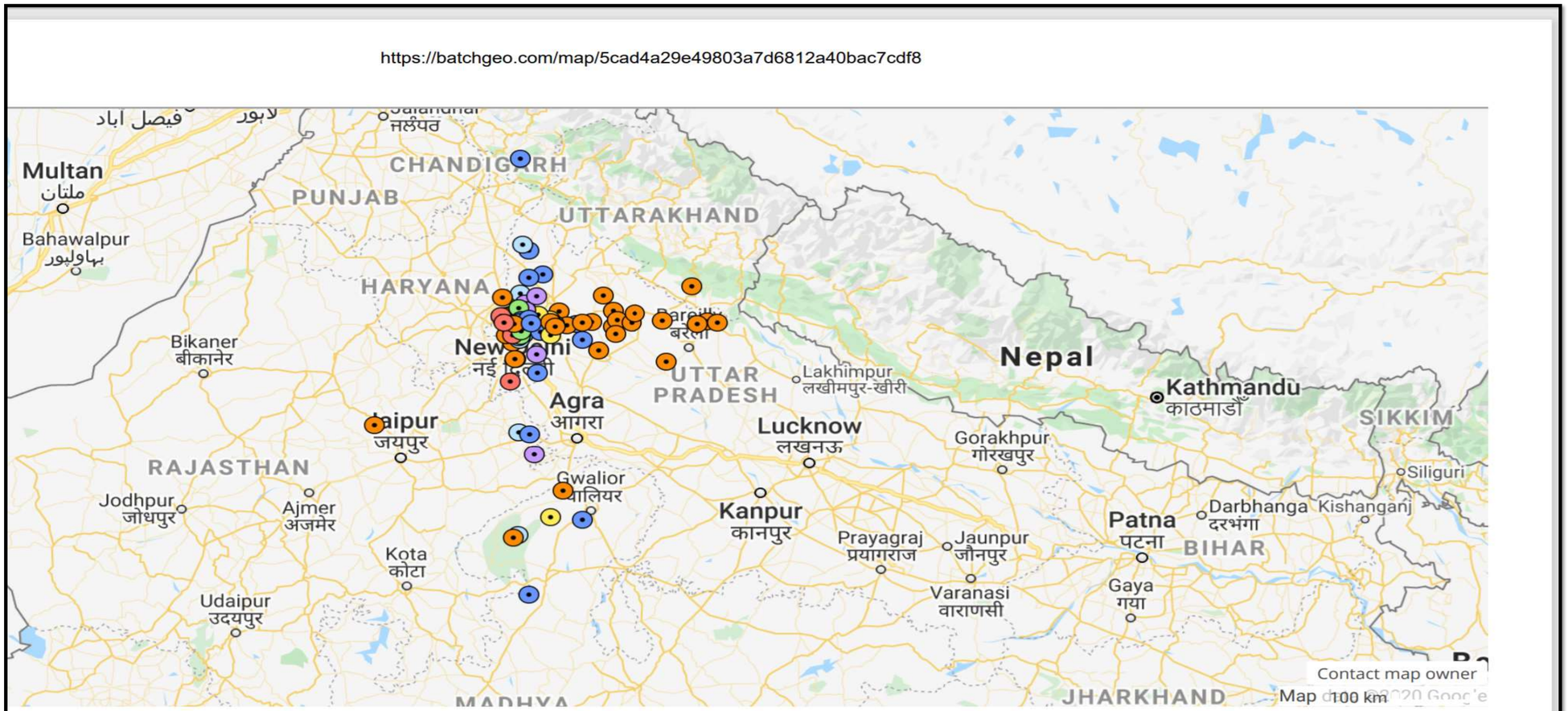
Demographic data

- 138 patients were called
- Maximum distance was 700 km
- 39% were from a different state.
- 30% were females
- Average age range – between 37-42 years (min 15 , Max 70)
- 115 called in multiple times with queries on medications and health
- 37 had mental health issues like panic , anxiety and depression

Disease data

- 129 (92%) were MB patients
- 31% were BI +ve
- (82%) on MDT
- 46% on steroids for reaction (1 and 2)
- 12% on steroids for neuritis
- 13% had ulcers
- 11.4% had concomitant comorbidities
- 92% expressed worry over the situation
- 31% said they were depressed.
- 65% called back .

GIS coordinates for area covered



lhi Ghaziabad North East Delhi Meerut Gautam Buddh Nagar North East Delhi Others

Learnings

Mental illness communication :

- person to person and not expert to victim
- relation and trust building
- non judgemental
- tangible questions to understand the unseen

Face to face vs phone call

- body language unknown
- Trained to understand nuances in voice change.
- Less confronting

Challenges

- It was a pilot activity – not fully prepared
- Females do not have privacy – Usually households share 1 phone between them.
- Unfamiliar counsellor -Trust building takes time – reaps benefit
- Gender privacy to be maintained
- Network can be a challenge

Future

This is the way forward for many of us

Modules needed

Capacity building

Research – face to face vs phone counselling

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The leprosy mission trust India
The leprosy mission community hospital,Shahdara
Patients affected by leprosy

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ILEP / NNN Guides on Stigma and Mental Wellbeing

- Mental well-being and stigma are increasingly core considerations of NTD prevention and morbidity management
- Temporary Expert Group – 2018-2020
- Developed and supported by partners from the NTD sector

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brighton and sussex medical school

american leprosy missions

cbm
together we can do more

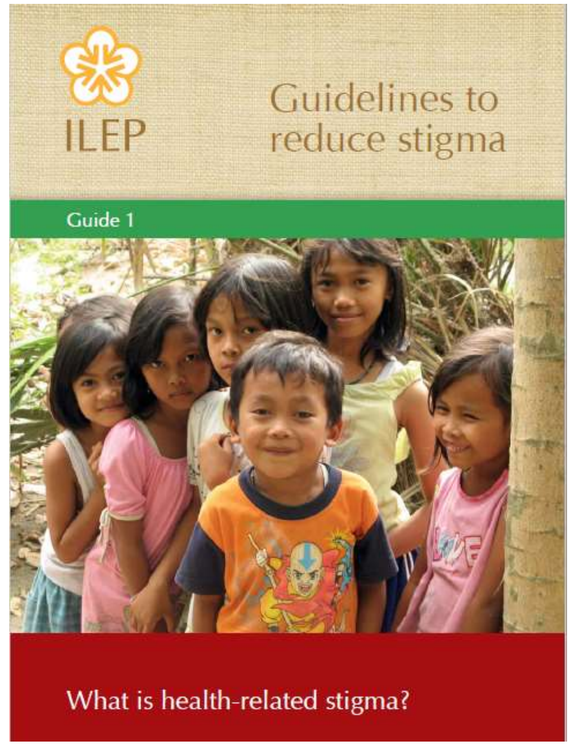
THE CARTER CENTER

lepra
We will beat leprosy together

2011 vs 2020

ILEP Stigma Guides **2011**

- 4 modules in book form
- PDFs available via Infolep and InfoNTD
- Focused on stigma reduction – persons affected by leprosy



ILEP/NNN Guides on Stigma and Mental Wellbeing **2020**

- 4 modules
- Available online and as a PDF via Infolep and InfoNTD
- Focused on stigma reduction and mental wellbeing – persons affected by NTDs
- Including practical exercises

Requirements

- Easy navigation
- Easy translation
- Easy to search through content
- Easy to edit
- Easy to access via a mobile phone
- Ability to monitor use

InfoNTD renewed website 2019

infoNTD
your NTD information portal

An online portal on cross-cutting issues in NTDs for researchers and health professionals

StigmaGuides.org

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IMPROVING HEALTH UNLOCKING POTENTIAL

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HELEN KELLER INTL

UNITING TO COMBAT
NEGLECTED TROPICAL DISEASES

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