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Myanmar national study on the socioeconomic impact of HIV on households

Overview

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- Aims
- Methods
- Findings
- Implications for policy and practice

Study aims

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- To establish scientific evidence and deepen understanding of the socio-economic impact of HIV at the individual and affected household levels in Myanmar
- To develop recommendations on impact mitigation policies and programmes, to inform the national HIV/AIDS, poverty reduction and social protection strategies

BACKGROUND

- More than 220,000 PLHIV in Myanmar
- Rapid improvements in coverage of treatment (~80,000 now on ART)
- But....not much is known about the social and economic circumstances of PLHIV and their families
- Opportunity to improve health in a broader sense and to inform policies related to health, education, employment and social welfare

Study methods

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Cross-sectional comparative study

Multi-step sampling process

- Step 1 : areas excluded from the survey
- Step 2 : selection of ART clinics
- Step 3 : selection of urban and rural townships
- Step 4 : recruiting cases
- Step 5 : recruiting comparison

Questionnaire

Why this sampling process?

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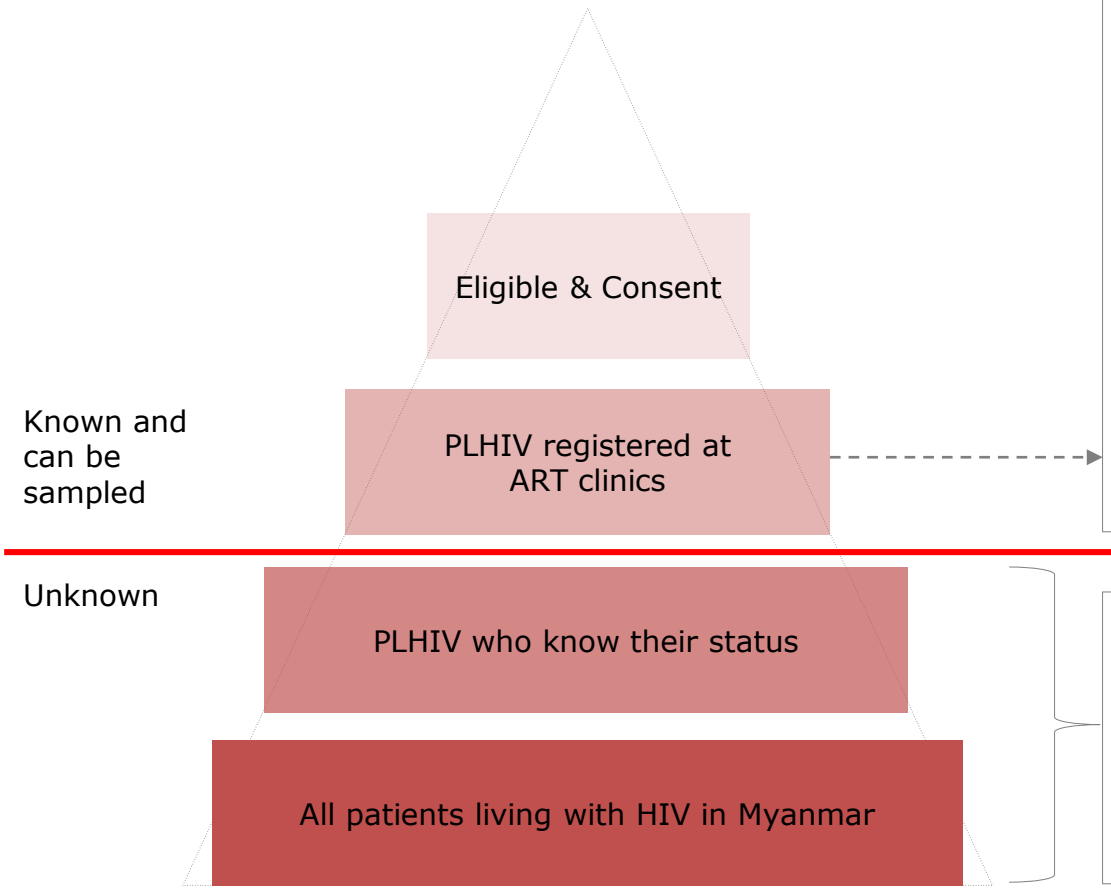

- List of **individual PLHIV** not available in Myanmar
- **Township-level data** not available in Myanmar
- ART CLINIC DATA = ONLY available data at national level of numbers of HIV patients
- As data on individuals is not known, have to use multi-stage sampling to ultimately select individual households with a PLHIV

Using PLHIV registered at ART clinics

- Excludes those not registered and those who do not they are infected
- Excludes households where a PLHIV has already died

Areas excluded from the study

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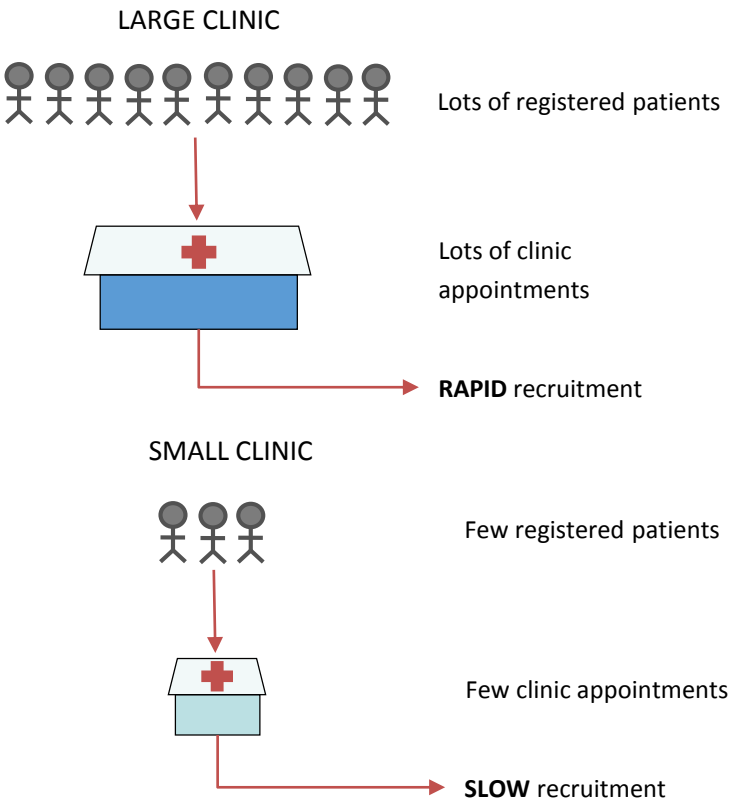
Step 1

Clinics were excluded if they were:

- In insecure areas OR
- Too small to sample within the timeframe (<57 registered patients)

Parameter	Eligible	Excluded	
States / Divisions	16	1	Chin – only 20 patients registered
ART clinics	67	68	Small or inaccessible (Chin, Rakhine)
Public clinics	43	44	Mostly small clinics
Private clinics	24	24	Mostly small clinics
Number of registered patients	65,555 (94.3%)	3,954 (5.7%)	Small fraction of total



Selection of ART Clinics

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Step 2

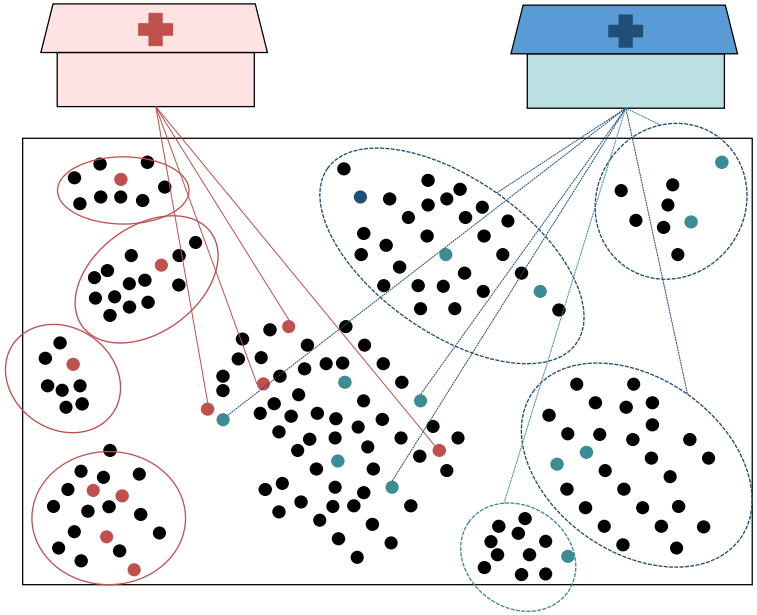
ART clinics sampled

- Total of 30 ART clinics selected
- Allocated randomly to clinics *proportional* to the number of patients registered at each clinic
- x4 randomly selected clinics replaced with x4 purposely selected clinics to improve geographic representation

Selection of urban & rural townships

Step 3

- Impractical to visit all or even multiple townships
- ART clinics have data on township of residence for registered PLHIV
- Townships were separated into URBAN and RURAL as per national classification
- 1 urban and 1 rural township was selected at each ART clinic with a probability proportional to the number of registered patients from each township
- 30 urban townships + 30 rural townships visited
- i.e. PLHIV were sampled from 60 individual sites throughout Myanmar



The list of patients from a township is **unique** to each ART clinic

Recruiting cases - PLHIV

Step 4

- PLHIV (cases) who attended the ART clinic were asked questions to determine eligibility
- Aimed to minimise inadvertent disclosure and potential harms of participation

Eligible township	≥18 years	Head of household	Disclosed to family	Eligible
no	.	.	.	NO
.	no	.	.	NO
yes	yes	no	no	NO
yes	yes	no	yes	YES
yes	yes	yes	no	YES
yes	yes	yes	yes	YES

Selection of Comparisons

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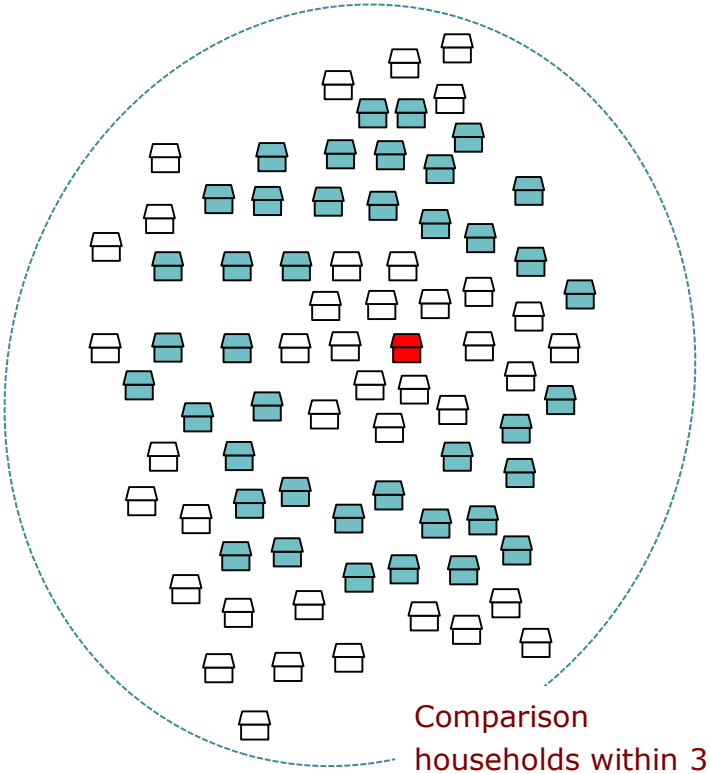
Step 5

Recruitment of COMPARISON household situated in same area as selected HIV affected household

- MATCHED cross-sectional comparative study: x1 comparison for every x1 case
- Crude **geographic** matching
- Crude **economic** matching using building materials of households)
- Excluded households that had a family member with HIV or tuberculosis (= possible HIV infection)



Comparison households within 3-5 houses of PLHIV (case) in the same township AND house built of similar materials

Content of the Questionnaire

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- Demographic data of households (age, sex, ethnicity, education, language)
- Housing (materials, water supply, lighting, fuel, ownership, rent)
- Knowledge of HIV
- Health (injuries/illness, outpatient / inpatient care seeking, health costs)
- Mortality
- Education (school attendance / absenteeism)
- Economics (type of employment, sources of income, missed work due to illness, assets, land ownership, social protection, loans, expenses, food security)
- PLHIV (transmission, date of diagnosis, symptoms, ART, formal and informal care, income pre/post diagnosis, how paying for health costs, impact on household finances, quality of life)
- Stigma and discrimination (internal, access to work/education)

Comparison with other Asian studies

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	Myanmar	Cambodia	China	India	Indonesia	Viet Nam
Probability sampling strategy used	YES ✓	YES ✓	UNCLEAR	UNCLEAR	NO	NO
Nationally representative sample	YES ✓	YES ✓	NO	NO	NO	NO

Sampling frame for HIV affected HHs	ART clinic lists All registered patients ✓	Home-based care lists of PLHIV within 20km of an ART site
Interviews for HIV affected HHs	PLHIV + Head of Household ✓	PLHIV
Non affected HHs	Within 3-5 HHs of case HH	Within 3 HHs of case HH
Non-response PLHIV	7.8% ✗	2.9%

Myanmar study is likely the most representative sample for HIV affected households

Myanmar study likely has better quality of household level data e.g. economic data

Lower response rate of Myanmar study likely due to recruitment at clinics rather than through home-based care networks

Data Analysis

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Categories of Analysis

Individual Group		Definition	n
1	PLHIV	All people living with HIV (only members of HIV-HHs)	1,739
2	PLHIV-INT	PLHIV interviewed specifically about their personal experience living with HIV	1,256
3	PLCD	People living with a chronic disease excluding PLHIV (only members of NA-HHs)	591
4	PLCD-INT	People living with a chronic disease interviewed specifically about their personal experience living with a chronic disease (only members of NA-HHs)	261
5	PLHIVCD	PLHIV who also had a chronic disease (only members of HIV-HHs)	293
6	PLNODX	People without HIV OR a chronic disease (members of HIV-HHs and NA-HHs)	8,599
7	NODX-INT	Head of household without HIV or chronic disease interviewed about quality of life	995

Distribution of diagnosis

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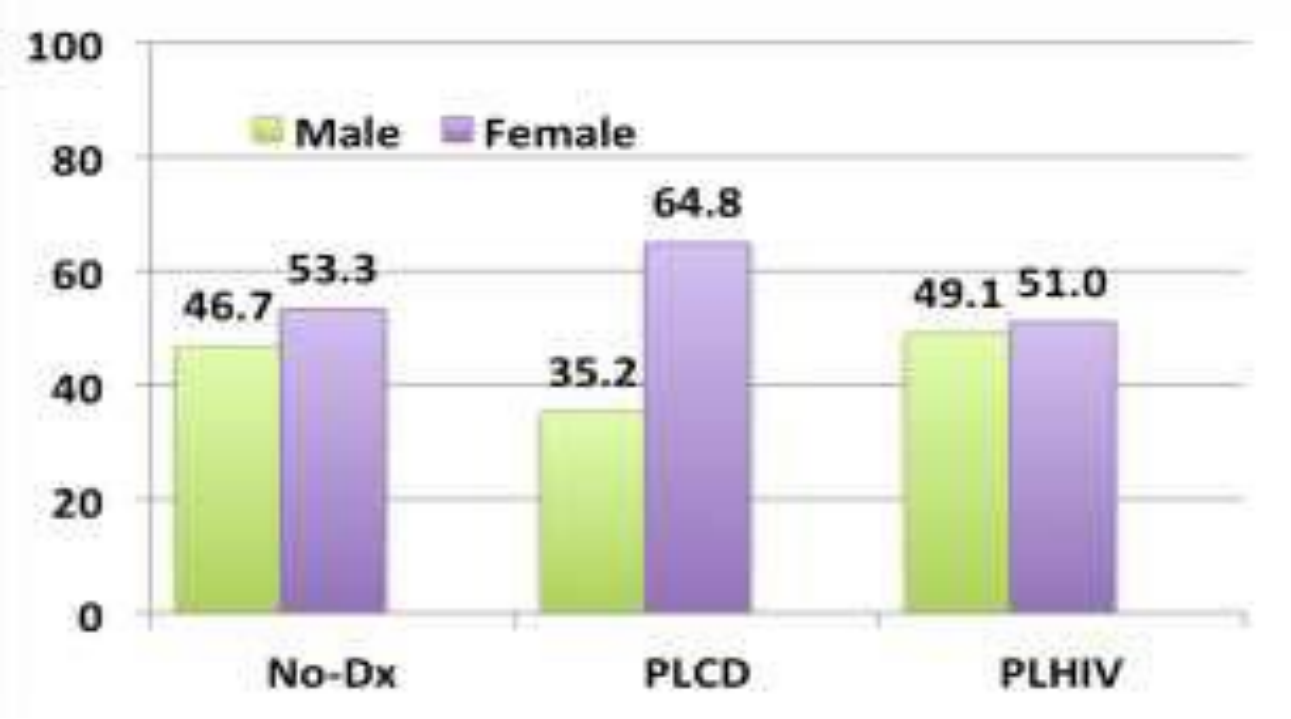

Distribution of diagnosis

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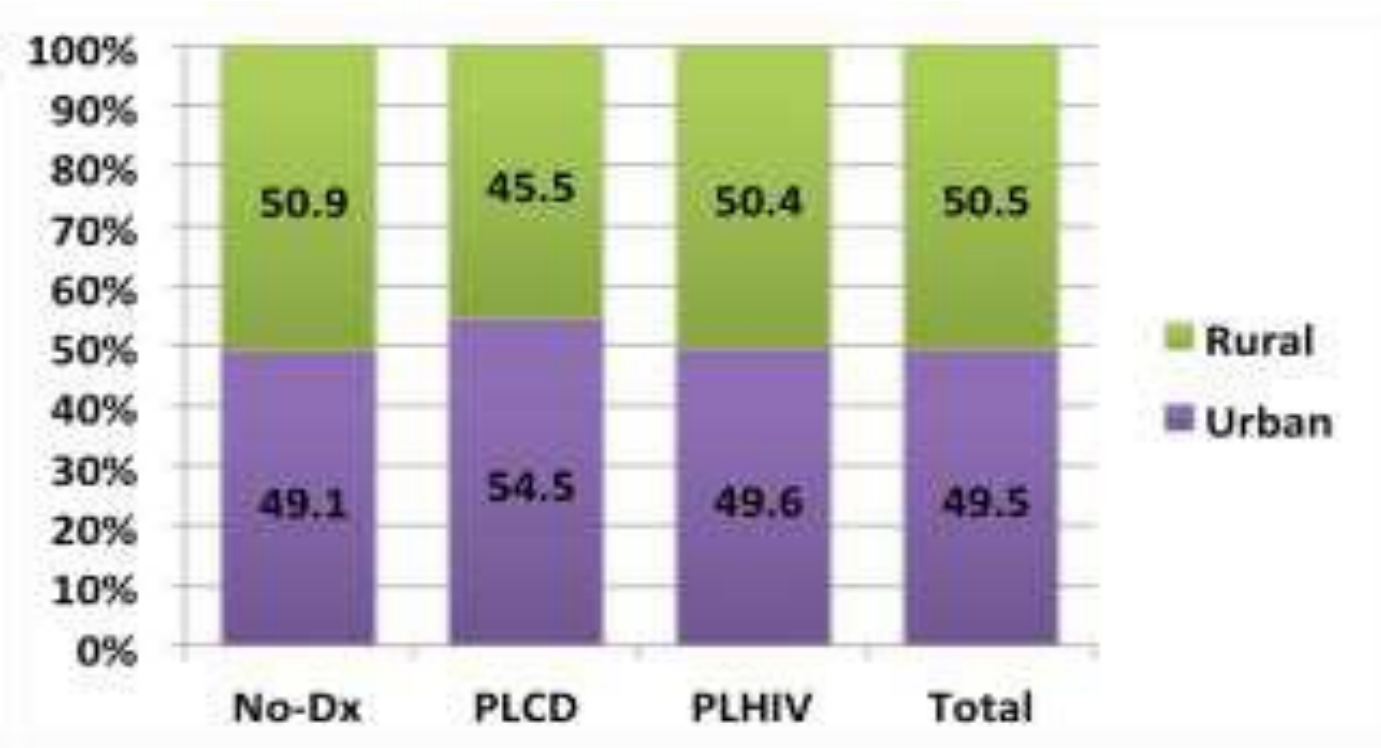

Steering committee - Members

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Ministries

1.Ministry of Health

- Director, Disease Control, DOPH (Chair)
- Director, Planning, Department of Health Planning
- Director, International Health Division
- Deputy Director, National AIDS Programme
- Representative from Department of Medical Research

2.Ministry of National Planning and Economic development

- Director from Department of Planning
- Deputy Director from FERD
- Representative from CSO

3.Ministry of Social Welfare, Relieve and Resettlement

- Deputy Director from Department of Social Welfare

4.Ministry of Labour, Employment and social security

- Representative from Department of Labour
- Deputy Director from Social Security Board

Steering committee - Members

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UN Agencies

1.UNDP

2.UNAIDS

3.WHO

4.UNICEF

Steering committee - Members

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Civil society

1.Myanmar Positive Group

- Representative from Myanmar Positive Group

2.Community based organization related to disabilities /NCD

- Representative from CBO related to disabilities/ NCD

Steering committee

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Roles and responsibilities

The Steering Committee will be responsible to;

- Facilitate the selection of principal investigator/ institution through competitive bidding;
- Facilitate ethics approval for the conduct of the study;
- Oversee the conduct of study and provide inputs to development of draft report;
- Support the dissemination of report and advocacy efforts to use the findings of the study to support evidence-informed policymaking and programming for impact mitigation and social protection; and
- Conduct meeting for sharing update, progress and suggestions for study as required.

Data Collection Team

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Team Composition

1. Coordinators
2. Team leaders
3. Supervisors
4. Interviewers

Data Collection Team

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Role and responsibility

Coordinator

- Coordinate with health departments, NAP and administrative departments at state/ region, district and township levels, ART centers for clinic based recruitment and administrative arrangement, MPG network focal person/s at ART center level – to get their assistant for clinic-based recruitment process

- Complete the township selection under each ART center in collaboration with NAP/ ART clinic focal persons

- Advocate about the sampling procedure and sample size at each ART center

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Role and responsibility

Team leader

- Assist coordinator at each and every step of coordination
- Coordinate with the township level administration and health department as necessary
- Manage filed level arrangement such as travel, accommodation, data collection plan
- Daily admin and financial management
- Monitor the supervisor and interviewers
- Conduct the interview as necessary
- Coordinate with team and care for team spirit

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Role and responsibility

Supervisor

- Assist the team leader as necessary especially for township level arrangement
- Monitor the interviewer as necessary
- Conduct the interview as necessary
- At the end of everyday, data checking, cleaning, check the coding and collecting “others” with the interviewer and team leader
- Give the feedback to Team Leader about the common errors found in checking questionnaire and remind to interviewer

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Role and responsibility

Interviewer

- Assist the team leader as necessary especially for township level arrangement
- Conduct the interview with the participants as the key role
- At the end of everyday, work on data cleaning and coding, and assist the supervisor for data cleaning process

Data Collection Team

- Four teams were recruited for data collection. Each team consist of a supervisor and 4-5 interviewers

- Coordinators were senior program and technical persons from Burnet Institute Myanmar .

- Medically trained technical advisors from the Burnet Institute Myanmar with extensive experience in study design and implementation oversaw data collection as team leader.

- Supervisors were experienced research personnel from the Department of Medical Research (DMR) with prior involvement in large surveys.

Data Collection Team

- Interviewers were a mix of male (59.5%) and female (40.5%) members of the Myanmar Positive Group (MPG) Network (Myanmar Drug Users Network, the Myanmar Positive Women Network and the MSM Network) with a minimum high school-level education

- Some of these Interviewers were HIV positive and most had been employed on previous HIV studies for the Burnet Institute

- A Melbourne-based medical epidemiologist provided additional technical support

Data Collection Team

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Team training

- Teams received 5 days training (30/09/14 – 4/10/14) including role-playing and field exercises.
- Staff were formally tested at the end of training on their knowledge of the questionnaire and their interviewer skills.
- An additional 2 days of refresher training was undertaken the following week to consolidate learning and go over common gaps in knowledge and practice.

Limitations of the Study

A number of sampling biases need to be considered when interpreting the findings from this study:

- PLHIV who do not know their status or who have not sought care were not part of our sampling frame. There is, however, no practical way to sample these people.
- Small clinics and insecure areas were excluded from our study. While these make up only a small portion of all PLHIV registered at ART clinics, people from these areas and attending these clinics may be different from those included in our sampling frame.
- Four clinics were purposely sampled rather than randomly sampled proportional to population size. However, there was no difference in findings when including or excluding these four clinics.

Limitations of the Study

- Enrolment of PLHIV at clinics was a non-random process but the only ethically sound means of recruitment.
- 1 in 9 women with HIV refused to participate.
- The selection of control households was based on proximity to a case household. These controls may not represent the source population from which cases originate
- Recall bias is a possibility and likely to be more of a problem for questions related to longer recall periods and that asked about exact details such as expenses
- Chronic medical conditions were not confirmed by health workers or health records.
- Heads of control households with residents living with HIV or tuberculosis (exclusion criteria) may not have disclosed this to surveyors particularly given enrolment was at the household and a local midwife accompanied surveyors.

Findings

IMPACTS & VULNERABLILITIES FOR INDIVIDUALS

- 27% of PLHIV are depressed
- 27% of PLHIV describe health as poor or very poor
- 14% of PLHIV need daily care and half were not getting it
- PLHIV in rural areas have poorer access to treatment for opportunistic infections
- 42% of PLHIV smoke or chew betel nut
- 13% of PLHIV who regularly drink alcohol have missed doses of ART
- But...PLHIV face less discrimination by health workers than in the past (6% in 2014 cf. 10% in 2010) and compared to other countries (e.g. 13% in India)

Findings

ECONOMIC IMPACTS ON HOUSEHOLDS

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- Compared to households unaffected by HIV, those affected by HIV have:
  - Lower incomes (and a small group had lost jobs due to discrimination – 6%)
  - Lower home-ownership
  - Pay a higher rate of interest on debts
  - Higher overall health costs *despite* reporting better access to healthcare and lower charges for care because of exemptions

Economic impacts	HIV affected	HIV unaffected
Average annual income	$ 768	$ 807
Average out-of-pocket health expenses	$ 272	$ 146
Households with a high level of debt	33%	24%

Findings

OTHER IMPACTS ON HOUSEHOLDS

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- Compared to households unaffected by HIV, those affected by HIV are:
  - More likely to go hungry *despite* receiving food support
  - More likely to be led by a widow (30% vs. 17%)
  - More likely to have recently moved house (34% vs. 23%)
  - Twice as likely to have children skip school to help family with chores or work

Findings

KNOWLEDGE OF HIV IN THE COMMUNITY

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- Same concerning gaps in basic knowledge among people in households *unaffected by HIV*:
  - 41% did not know that HIV can be transmitted by sex
  - 58% were unaware that condoms can prevent sexual transmission of HIV
  - 93% did not know that HIV can be transmitted from a mother to her child

Findings

CHRONIC ILLNESSES

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- First national snapshot of chronic diseases in Myanmar
  - 1 in 4 households has a family member living with a non-HIV chronic illness
  - 23% need daily care (cf. 14% PLHIV)
  - More people with chronic illnesses report poor health than PLHIV
  - More are dissatisfied with their access to healthcare than PLHIV, especially in rural areas
  - 2.6 times more likely to suffer catastrophic health costs than families where no one has a chronic illness

Implications for policy and practice

PLHIV	Families affected by HIV	Wider community
• Mental health needs • Non-HIV chronic disease concerns • Differences in access to treatment in rural and urban areas	• Economic impacts – poverty reduction / income subsidy approaches → Myanmar Social Protection Strategy • Food security concerns • Mitigating negative educational impacts for children	• HIV education • HIV services • Social protection mechanisms for those with any kind of chronic illness

Implications for policy and practice

Findings relevant to a number of national policies and to international targets such as the SDGs

Roadmap Towards Universal Health Coverage in Myanmar (2016-2030)	Myanmar's second 5-year plan (2016/17 - 2020/21)
• Social determinants of health • Improving equity and inclusiveness • Achieving universal health coverage by 2030	• Sustainable Development Goals related to • Ending the HIV epidemic • Access to safe medicines • Realising universal health coverage