



Curtin University

International Case Studies on HIV: Examples from Uganda, India, Timor Leste and West Papua

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Migration, Mobility, Vulnerability and Social Impacts



Symbolic capital, women's social position and desire for children among HIV infected women in Northern Uganda (study undertaken in 2009)

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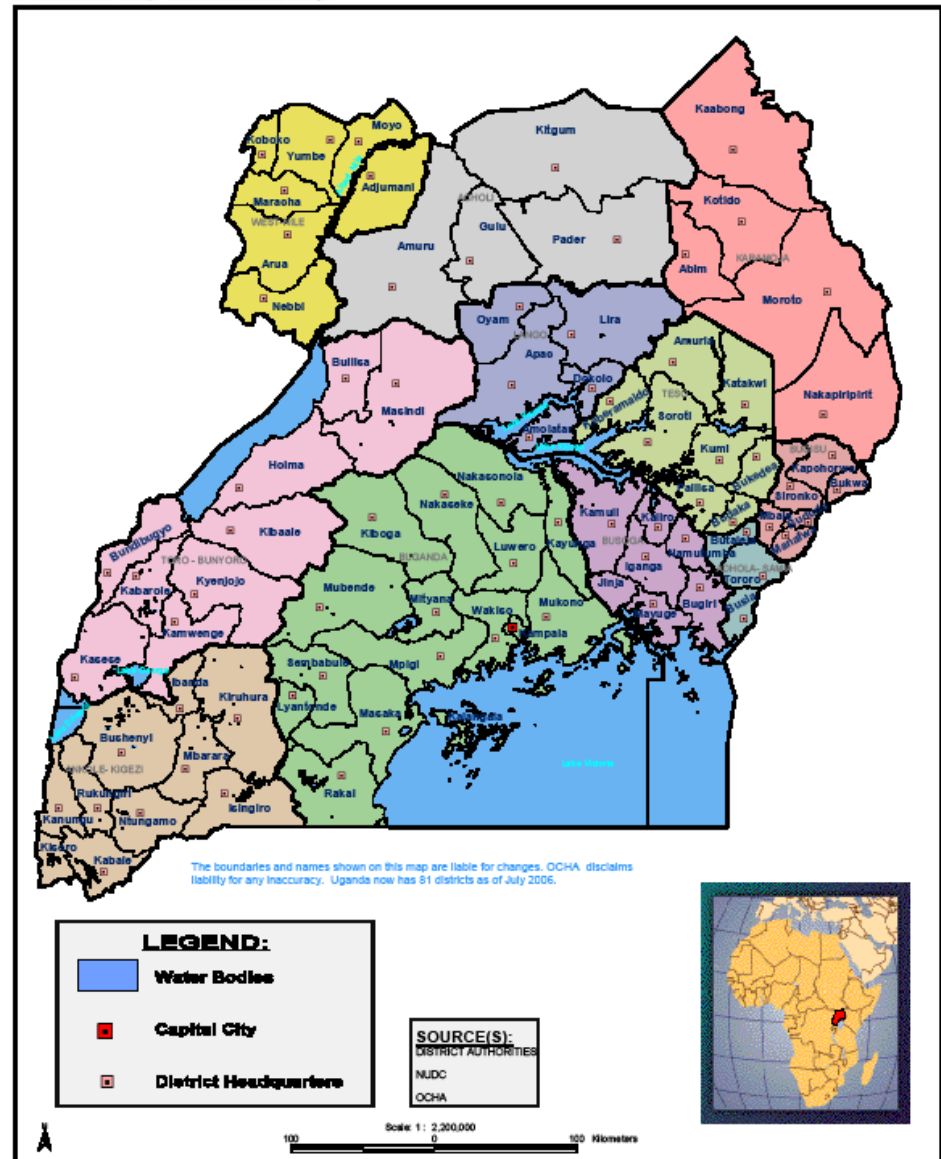
Uganda vs. Australia

	Uganda	Australia
Total population	32 million	22 million
Estimated HIV prevalence 15-49 age group (UNAIDS 2008)	7.2% (6.0-7)	0.2% (0.1-0.3)
Estimated number of people living with HIV/AIDS	1,500,000	28,600
Estimated number of children living with HIV	130,000	29*
Main transmission routes	Heterosexual (79%), MTCT (21%)	MSM (76% in 2012)
Women as percent of those infected with HIV	52%	14%
Total Fertility Rate (number of children per woman)	6.6	1.8
Rate of mother to child transmission of HIV	21.5%-33.3%**	



Uganda

- East Africa
- 32 million people
- High fertility rate: 7 children per woman
- Adult HIV prevalence 7.2% (UNAIDS 2012)
- Women are 52% of HIV population
- 2.3% males, 5.0% females 15-24 age group are HIV positive
- MTCT 21% of HIV transmission



Northern Uganda

- 2 decade civil conflict
- LRA rebels vs. Uganda Government
- Acholi region and Lango region
- 1.5 million displaced into IDP camps
- Malaria, TB, Cholera, Hepatitis E, HIV/AIDS, Ebola
- HIV prevalence 8.2%, higher than other rural areas: 2.3%



Background to research study

- ‘Successful’ ART program supported by PEPFAR
- 14,000 people on branded drugs
- Good outcomes: improved CD4 counts, reduced viral loads.
- Other issues began to come up: sexual activity, pregnancies
- Flabbergasted doctors, nurses, community workers: worried about MTCT, sexual transmission

Research Questions

1. What are fertility desires of PLHIV living in Northern Uganda?
2. What are the implications of these desires for PMTCT and Reproductive health programs in this region and elsewhere?

Symbolic Capital

Capital' occurs in three forms: economic (wealth), social (status and/or prestige) and cultural (educational attainment and/or the possession of specialized knowledge). When all of these forms of capital is recognised as legitimate it becomes transformed into symbolic capital (Bourdieu, 1986)

Symbolic capital is 'a transformed and thereby disguised form of economic capital' (Mahar et al., 1990)

Grove et al (1997) and Stoebenau (2009) have previously used Bourdieu's concept of symbolic capital to examine social construction of AIDS in America and sex work in Madagascar respectively

For this study symbolic capital is defined as the **prestige** women are granted as a result of the number of children they have.

Fertility desire

Fertility desire among PLHIV for this study was defined as:

‘the wish or intention to have more children despite the diagnosis of HIV’ (Chen et al, 2001, Nakayiwa et al, 2006)

Methods

Mixed methods: quantitative and qualitative

Data collection between February-May 2009

Quantitative arm:

- Interviewer-administered survey with 476 male and female PLHIV aged between 15-49 years from 3 health facilities in Gulu
- Structured questionnaire based on Uganda Demographic Health Survey
- 168 respondents from Lacor, 210 from TASO and 98 from Gulu National Hospital
- Analysis using SPSS 17: uni-, bi- and multivariate analysis

Methods (continued)

Qualitative arm:

- In-depth interviews with 26 purposely selected PLHIV using a semi-structured questionnaire
- Interviews with Heads of non-governmental organisations and Ministry of Health officials
- Informal interviews with AIDS ward nursing staff
- Analysis: thematic analysis underpinned by Bourdieu's notion of Symbolic capital

Reproductive and HIV history:

Respondents who have ever had children	83% (n=397)
Median number of existing children (IQ range)	3 children (1-5)
Females currently pregnant	8% (n=18)
<ul style="list-style-type: none"> ○ Have knowledge of at least one family planning method ○ Have ever discussed family planning with their health workers ○ Currently using any form of family planning method 	96% (n=457) 61% (n=281) 39% (n=181)
On HAART	50% (n=236)
Partner's HIV status <ul style="list-style-type: none"> ○ Positive ○ Negative ○ Unknown 	46% (n= 217) 11% (n=53) 15% (n=68)
Disclosure to partner <ul style="list-style-type: none"> ○ Yes 	65% (n=309)
Adequate PMTCT knowledge <ul style="list-style-type: none"> ○ Yes 	67% (n=319)

Desire for children

- 43% (184/430) desired to have more children
- Males 54.2% and females 31.7% desired to have more children

Predictors of fertility desire

Predictor	Bivariate analysis OR (95% CI):	Multivariate analysis: Adjusted OR (95% CI):
History of death of child (yes vs. no)	2.68 (1.70-4.22) p=0.000	
Discussion of family planning with health workers (yes vs. no)	0.45 (0.29-0.66) p=0.000	
Discussion of family planning with partner (never vs. at least once)	1.76 (1.17-2.64) p=0.006	
Disclosure of HIV status to partner (yes vs. no)	0.59 (0.35-0.99) p=0.044	
Family planning use (yes vs. no)	0.94 (0.64-1.39) p=0.750	
Site of interview (Catholic hospital (Lacor) vs. others)	0.89 (0.59-1.34) p=0.593	



Qualitative Findings

Themes

- Motivations for child bearing (Hoffman and Hoffman, 1973)
 - Fatalistic (fulfilment of societal and gendered expectations)
 - Narcissistic (the child will reflect glory upon the parent, prove adequacy)
 - Altruistic (affection for children)

Qualitative Findings

Themes

- Inhibiting factors for having children
 - Personal health concerns
 - Concerns for the children's health and their potential infection
- Attitudes to child bearing
 - PLWHA attitudes
 - Family and community attitudes
- Justification for child bearing

Discussion

- Low use of family planning methods despite high knowledge: reluctance to limit family sizes
- High fertility desires especially among younger PLHIV below 30 years. Those with few or no children want more children
- Women see having children as a path to respect and as obtaining social standing in this community.
- Bride wealth payment for women give her reproductive rights to her husband's lineage

Summary and recommendations

- Many men and women continue to desire and intend to have children
- Children are valuable in many traditional societies because the resultant prestige from having children is 'symbolic capital' of women, despite their HIV status
- This should be taken into account during reproductive health program development, prevention of mother to child interventions



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**MIGRATION PATTERNS AND
HIV VULNERABILITY ASSESSMENT
MAPPING
IN TIMOR LESTE
(study undertaken in 2006)**

**Dr. Jaya Earnest Centre for International Health,
Curtin University, Western Australia
& Evangelita Pereira**

MIGRATION/MOBILITY AND HIV BACKGROUND

- Well established link between migration/mobility and vulnerability to HIV/AIDS
- Lack of data on both migration/mobility patterns and HIV/AIDS vulnerability in Timor Leste
- Programming targeting highly mobile groups shown to be very effective in other countries

MOBILITY IN TIMOR LESTE

- Dramatic population migration occurred before, during and after the 1999 referendum when half the people of Timor Leste were forced to leave their homes.
- Migration to other parts of Timor Leste accounted for 300,000 people whilst approximately 200,000 fled or were forced into West Timor.
- The conflict in 2006, forced over 150,000 civilians in Dili out of their homes, currently there are between 30,000 and 50,000 displaced people.

OBJECTIVES OF THE STUDY

1. To estimate the proportion of the local population that travels elsewhere as migrant workers;
2. To measure the relative age, gender, SES, and education level of those migrating;
3. To get a reliable estimate of where the population is migrating to and from;
4. To measure basic HIV-related behavior and knowledge among migrants and mobile populations

METHODS OF DATA COLLECTION

- **The research used a developed Migration Survey**
- **A Community-based Vulnerability Assessment Mapping (VAM) participatory exercise**
- **1200 Surveys were administered and 7 VAM workshops were conducted in 6 districts: Dili, Baucau, Liquica, Cova Lima, Bobo Naro, Oecussi**

THE MIGRATION PATTERNS & MOBILITY SURVEY

The developed survey contained information on:

1. demographic,
2. socioeconomic,
3. displacement,
4. mobility,
5. general health
6. HIV-related knowledge and behaviour

It was administered in Bahasa and Tetum

THE VULNERABILITY ASSESSMENT MAPPING WORKSHOP

The Vulnerability Assessment Mapping examined the contributors to HIV vulnerability and had the following objectives:

- To identify locations where HIV-risk behavior takes place;
- To identify existing and potential service provision points for HIV prevention programmes and STI treatment;
- To map mobility patterns, including source, destination, and transit points.

CONCEPT OF VULNERABILITY WITHIN THIS PROJECT

- **Programmatic vulnerability**
(Information & services & risk locations)
- **Societal vulnerability**
(Culture, religion, poverty)
- **Personal vulnerability**
(Educational, socioeconomic status, age, gender)

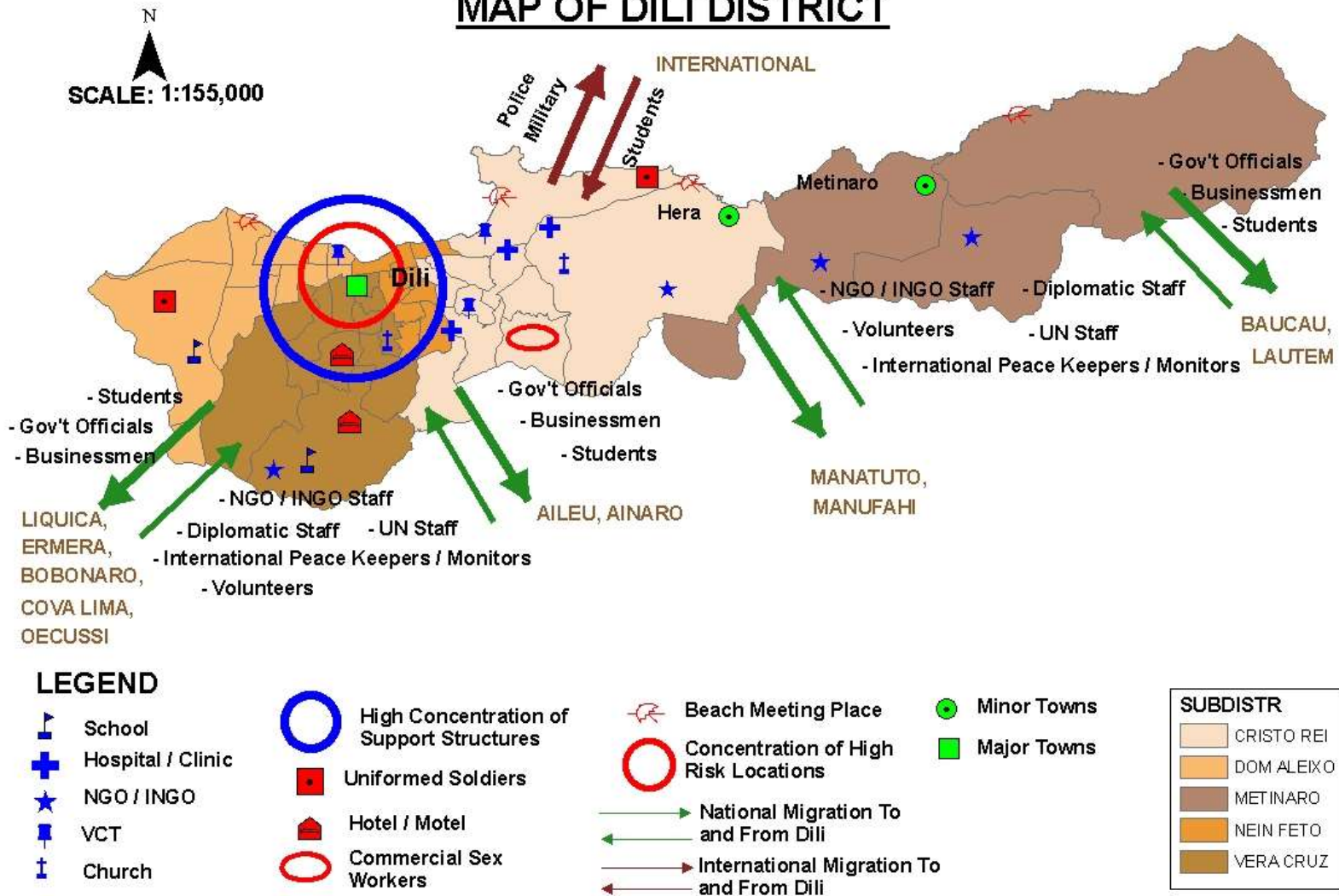
IMPRESSIONS FROM THE WORKSHOP

1. **Good participation from Ministry of Health and in some districts from Ministry of education.**
2. **HIV is not perceived to be a big issue in the country**
3. **When discussing personal and societal vulnerability participants spoke of a lack of sex education within health education in schools.**
4. **Sexual issues are a taboo and are not discussed within a family and there were a lot of misconceptions.**
5. **There are high risk groups and the participants use local terms to refer to these groups**

SUPPORT AND RISK LOCATIONS IN DILI

APOIO I FATIN NEBE RISKU IHA DILI

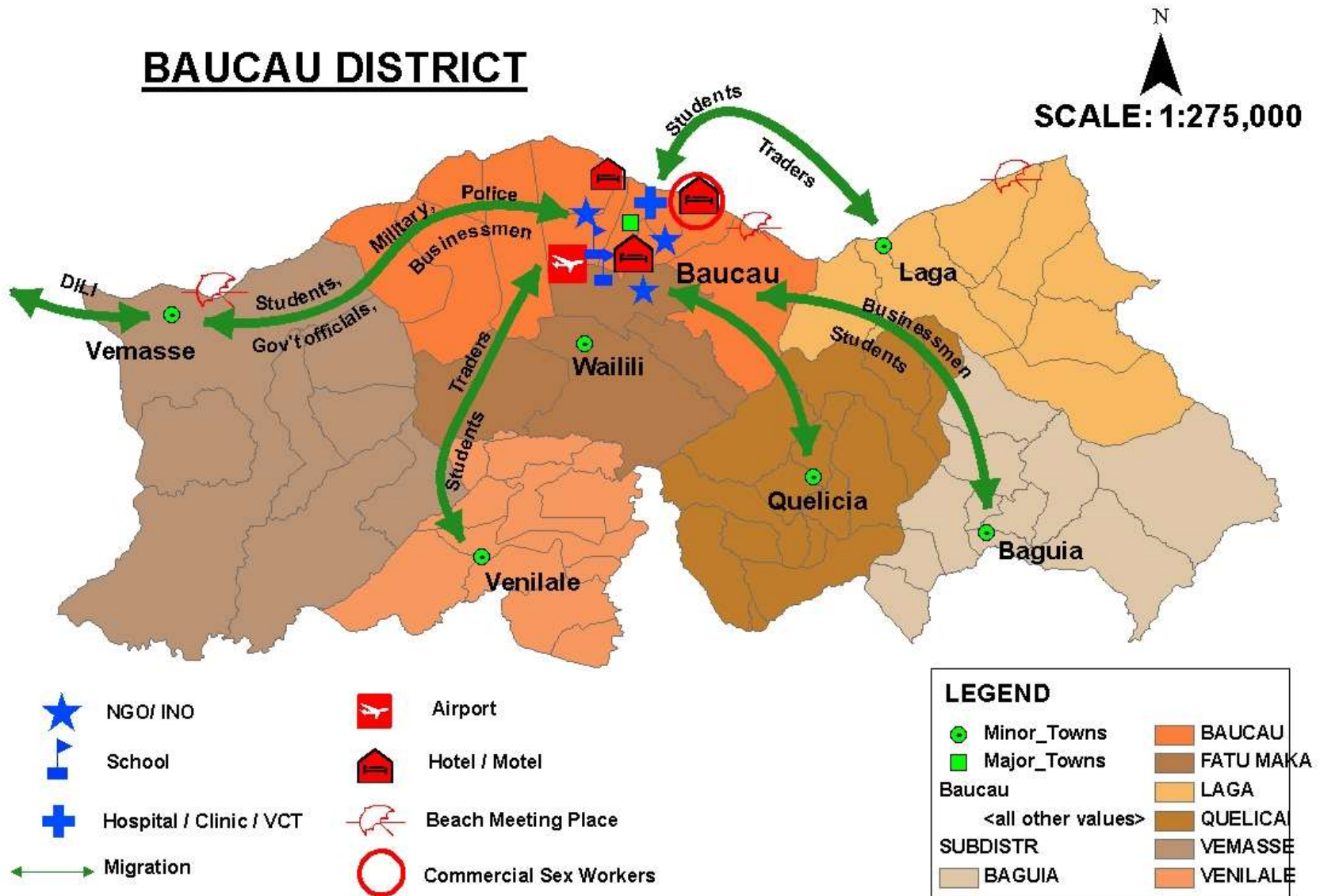
MAP OF DILI DISTRICT



SUPPORT & RISK LOCATIONS IN BAUCAU

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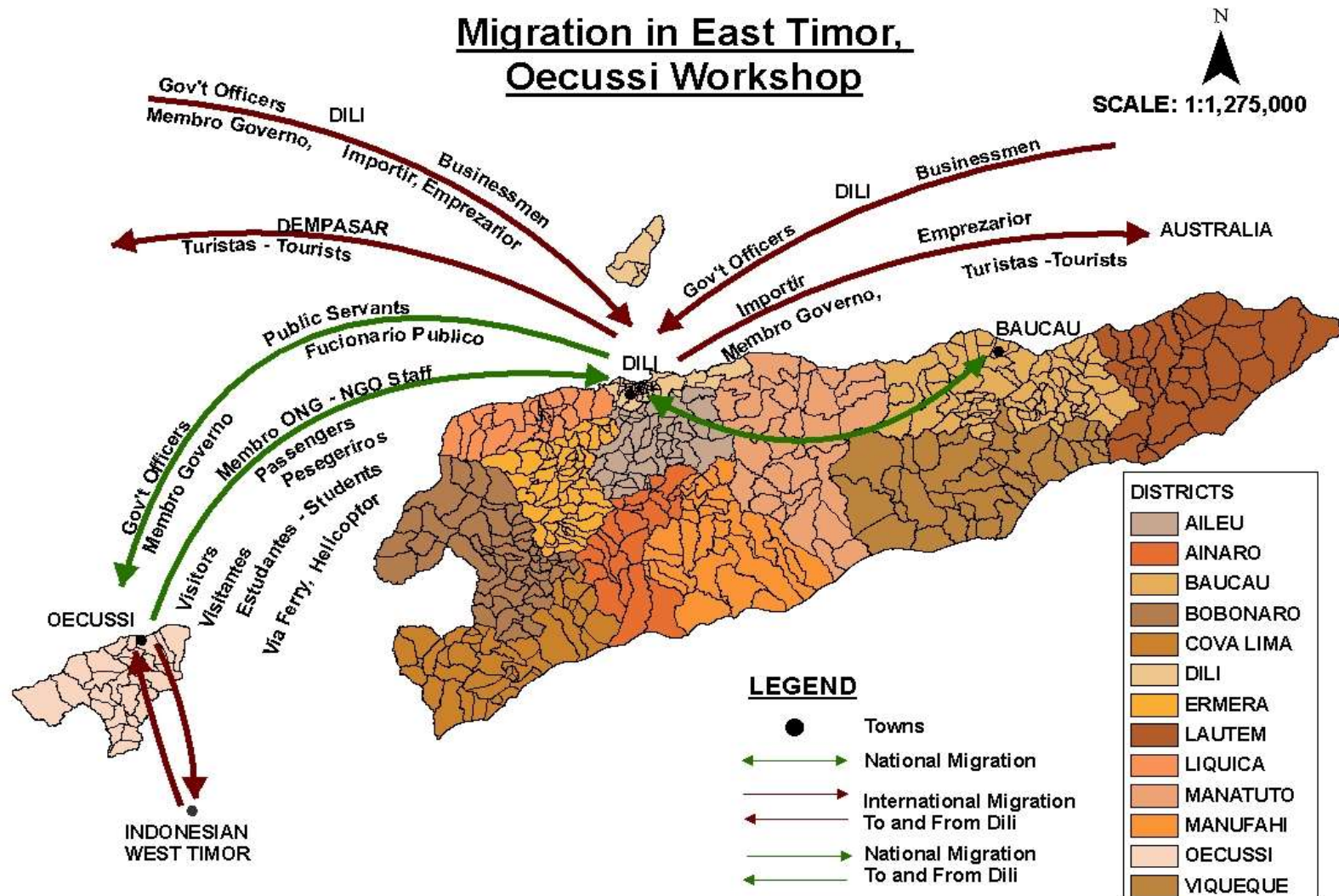
BAUCAU DISTRICT



MOBILITY PATTERNS AS IDENTIFIED BY PARTICIPANTS AT OECUSSI WORKSHOP

MODELO MOBILIDADE TURIR PARTISIPANTES SIRA IDENTIFIKA IHA WORKSHOP OECUSSI

Migration in East Timor, Oecussi Workshop



CULTURAL/SOCIETAL FACTORS

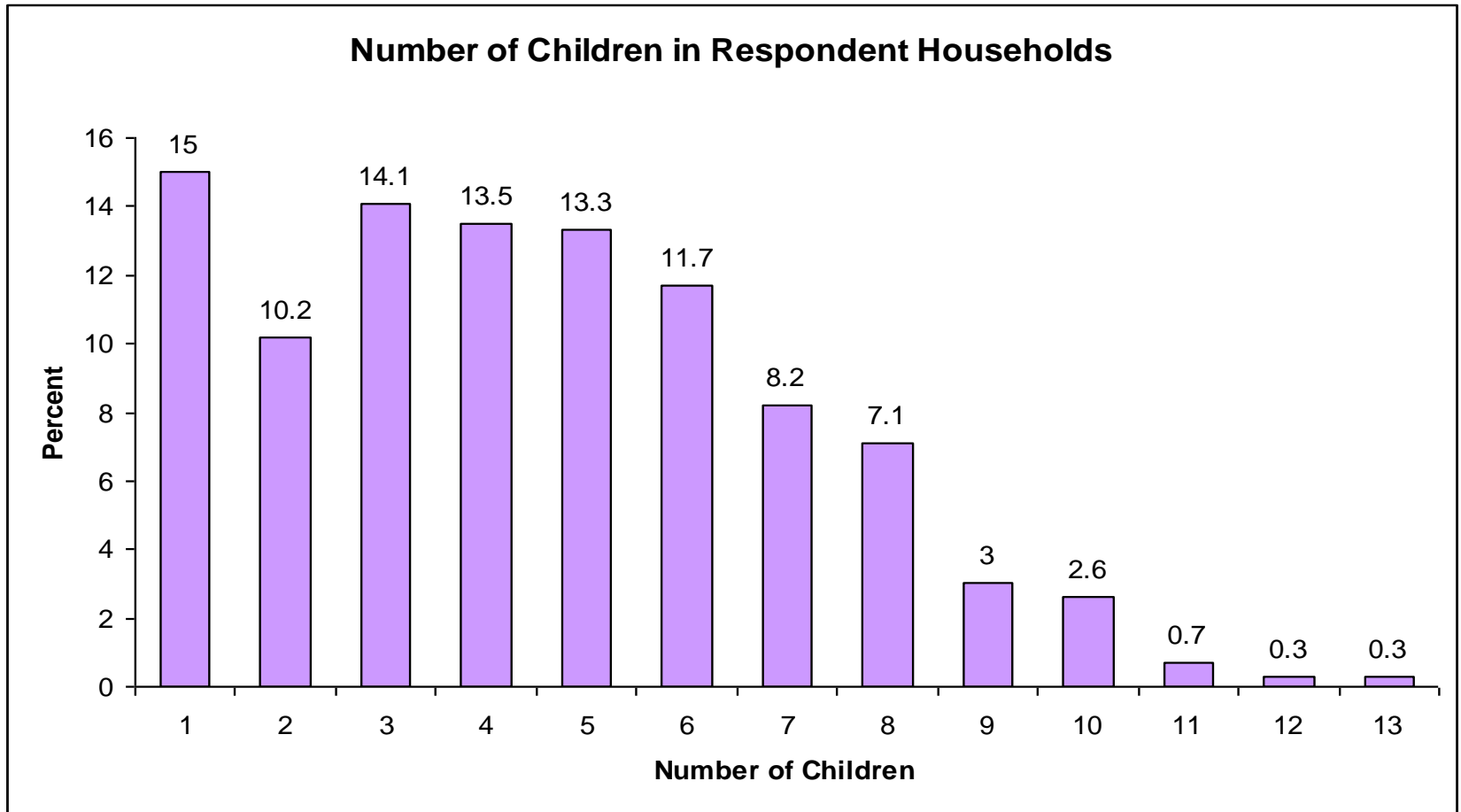
1. **Poverty**
2. **Education**
3. **Gender Roles and Norms**
4. **Marriage practices**
5. **Stigma and taboos regarding sex**
6. **The influence of the church**
7. **Westernization**
8. **Domestic violence and divorce**
9. **The environment**
10. **Homosexuality**

RESULTS OF THE MIGRATION PATTERNS SURVEY

- **Mobility was found to be related to rural-urban migration, especially towards Dili and Baucau**
- **Displacement has affected most of the population during times of conflict**

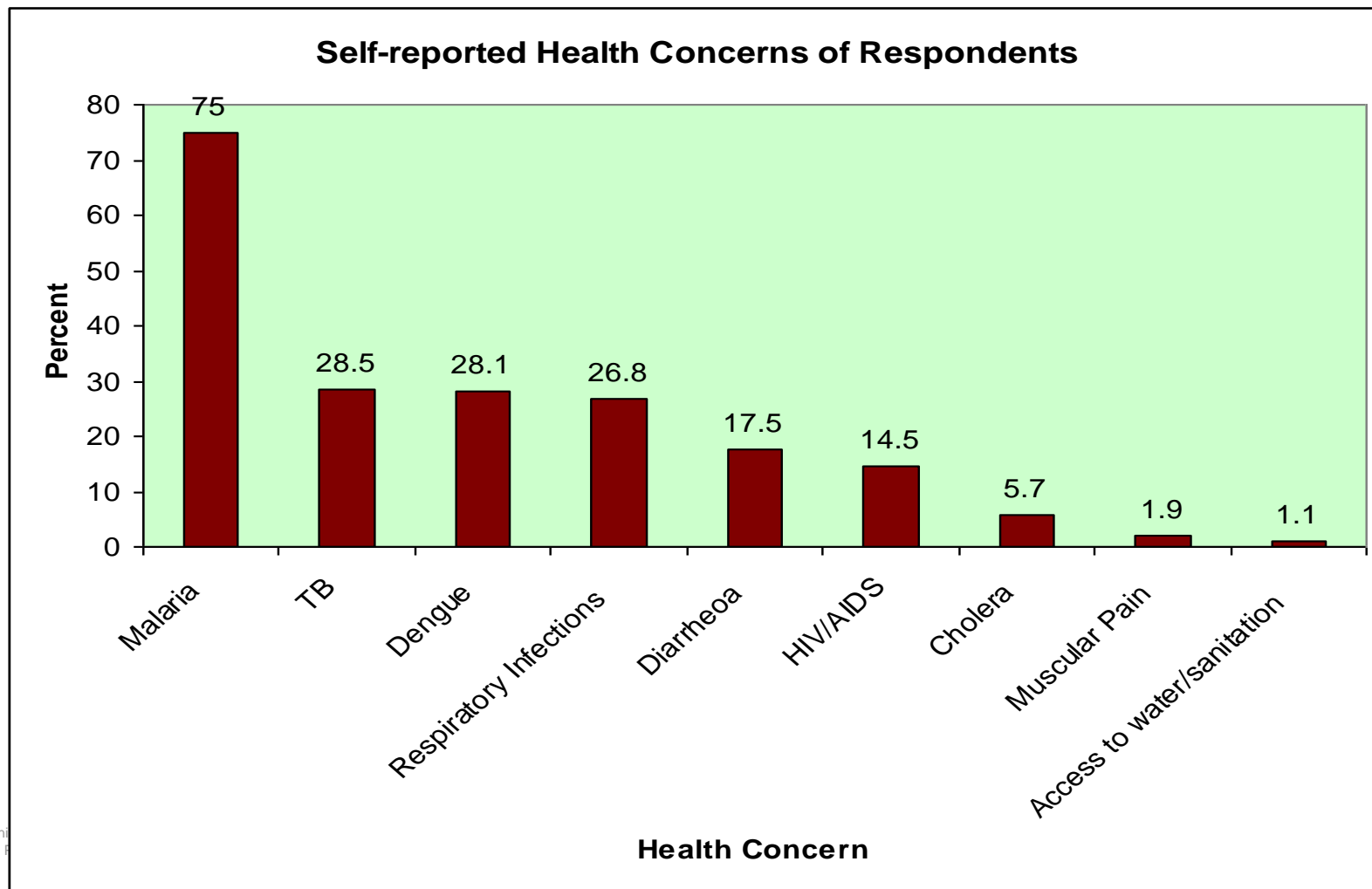
NUMBER OF CHILDREN OF RESPONDENTS IN THE SIX DISTRICTS

NUMERO LABARIK RESPONDEDORES SIRA NIAN IHA DISTRITU NEEN



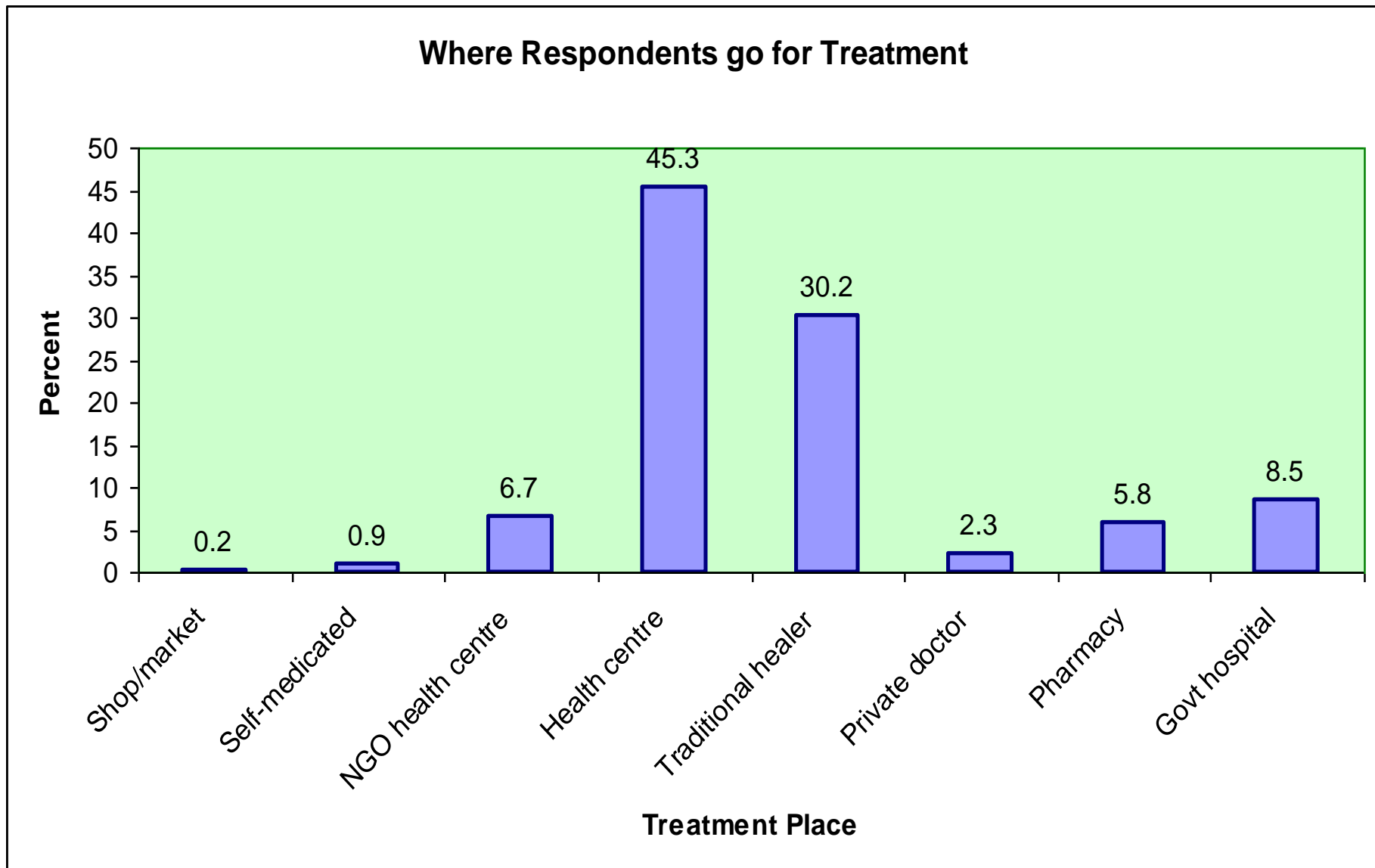
SELF-REPORTED HEALTH CONCERNS OF RESPONDENTS

REPORTAGEM SOBRE SAUDE NEBE RESPONDEDORES RASIK HATO'O:



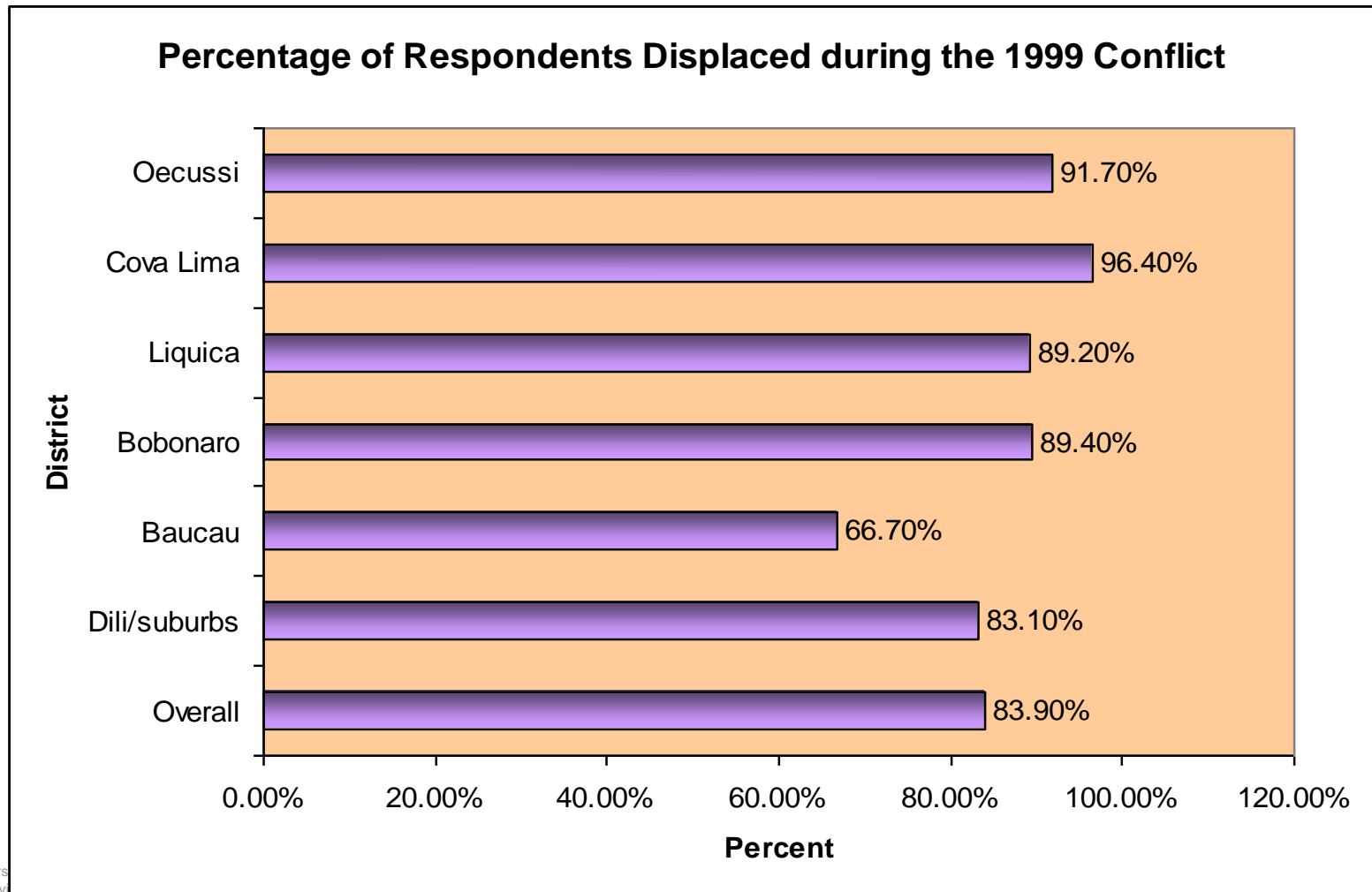
WHERE RESPONDENTS SEEK TREATMENT

FATIN NEBE RESPONDEDORES VISITA ATU HALAO TRATAMENTO



PERCENTAGE OF RESPONDENTS DISPLAYED DURING CONFLICT

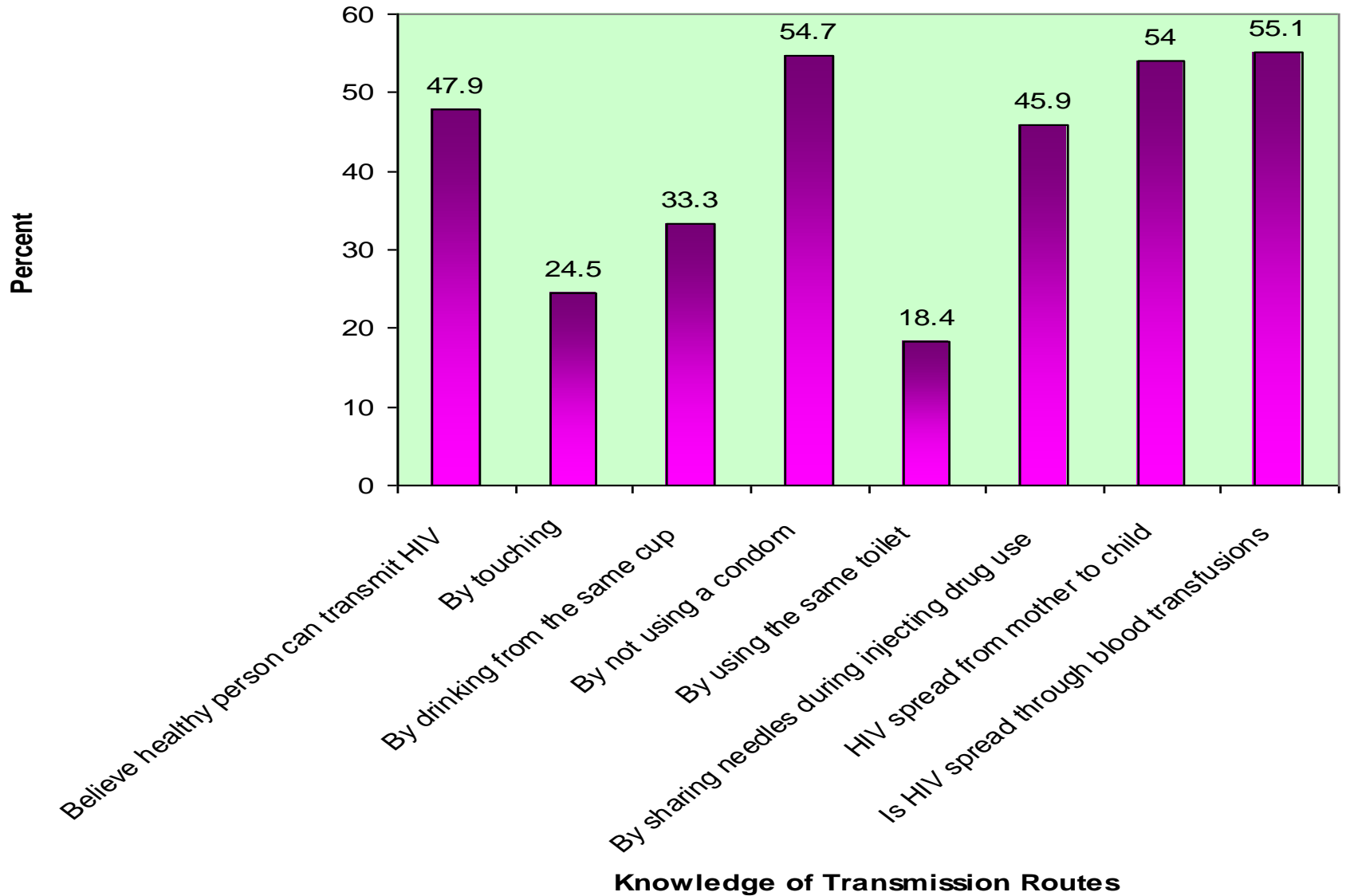
PERCENTAGEM RESPONDEDORES DURANTE KONFLITU



GENERAL HIV (KAP) KNOWLEDGE ATTITUDES AND PRACTICE

- Low knowledge about HIV
- Low condom use
- Low levels of self-reported STIs
- Low levels of self-reported extramarital sex

HIV Transmission Knowledge



RESULTS SUMMARY

1. Very small numbers of Sex workers (SWs) or Injecting Drug Users (IDUs)
2. Low levels of extramarital affairs
3. Cultural factors which are protective
4. Low measured levels of HIV prevalence (0.5% in a WHO study in Dili)
5. Limited amount of migration in and out of the country but mobility within the country

RECOMMENDATIONS

1. **Gathering of more reliable data on HIV needed**
2. **Integrated approaches are more appropriate against the background of HIV in Timor-Leste**
3. **Integration with reproductive health, family planning/antenatal services; health promotion and primary health care will prove more effective**

**VOICES OF RESILIENCE:
STIGMA, DISCRIMINATION AND
MARGINALISATION OF INDIAN WOMEN
WITH HIV/AIDS
(study completed in 2008)**

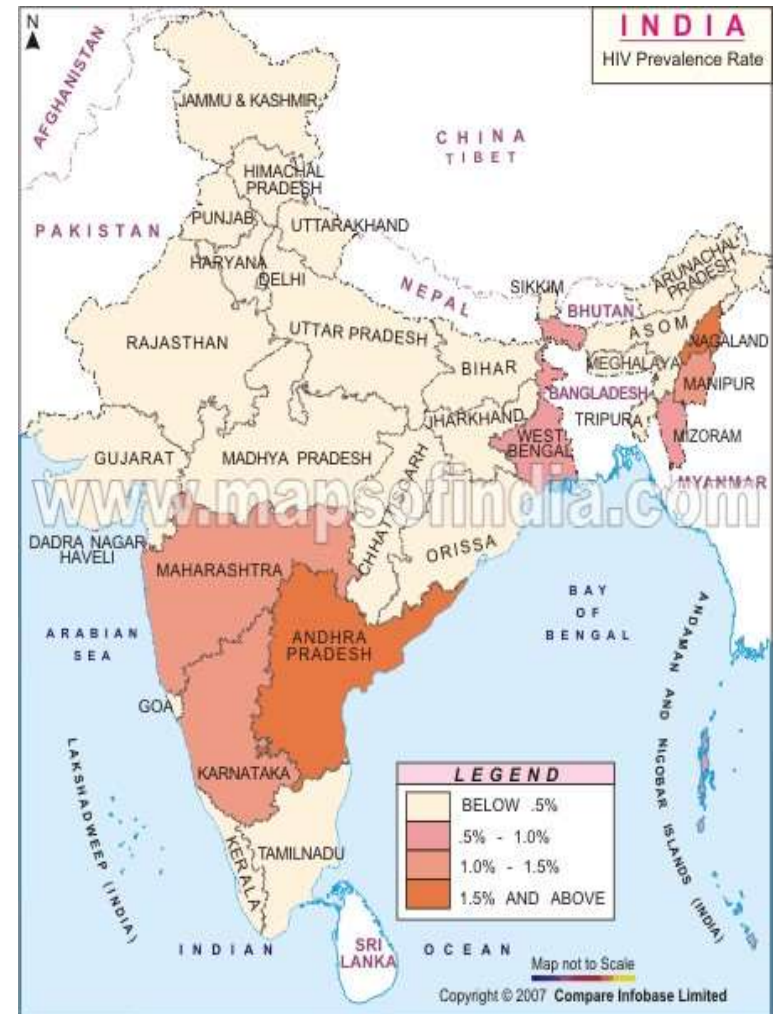
DR PAM O'CONNOR [Women's Healthworks, Joondalup]

& DR JAYA EARNEST

[Centre for International Health, Curtin University]

BACKGROUND : COUNTRY CONTEXT

- HIV/AIDS in India – 2.39 million (UNAIDS, 2012) with 39% female & 3.5% children infected;
- Married, heterosexual, monogamous females are the most vulnerable;
- Stigma and discrimination are major determinants of spread of infection and barriers to health care.



OBJECTIVES OF THE STUDY

- To provide urgently needed data on stigma and discrimination of Indian women living with HIV/AIDS (IWLWHA)
- To examine the role of discrimination in barriers in health care for IWLWHA
- To explore views and perceptions of IWLWHA
- To create a picture of how supportive environments can be set up

CONTEXT OF THE STUDY & HIV



Now programs have been expanded to provide :

Street plays, sensitisation for all;

Hospital staff training, income generation schemes and school for orphans.

Somaiya Action for HIV/AIDS Support (SAHAS) in India established in 2003

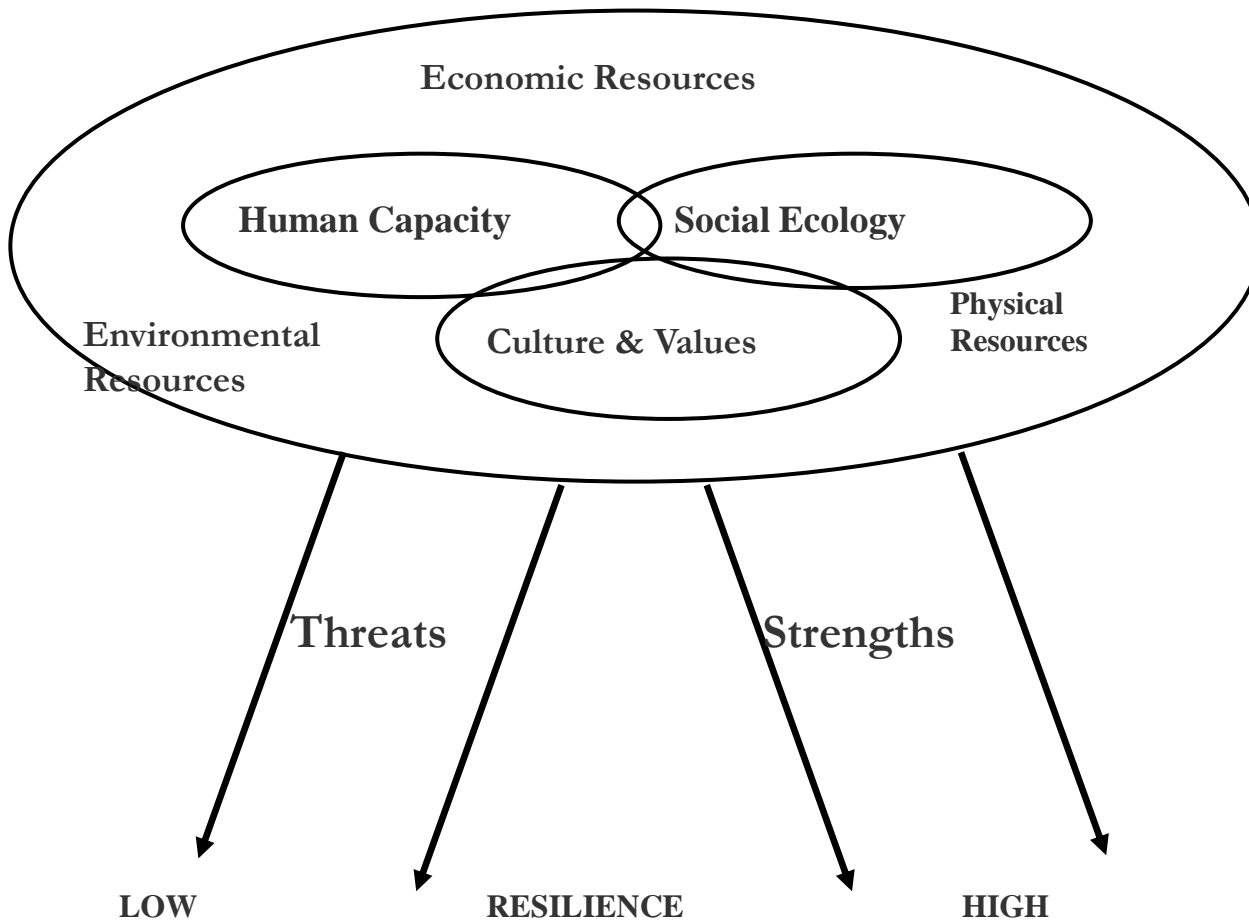
Psychologist, para-social worker, and community health care-workers;

Originally provided pre and post test counselling, nutrition and support to the most vulnerable.

METHODS OF DATA COLLECTION

- Documentary data collection
- Home visits and observations
- Interviews – target group
- Focus group discussions
- Use of a reflective journal
- Use of a cultural interpreter
- Key informant Interviews

THE MODIFIED PSYCHOSOCIAL FRAMEWORK



RESULTS: HUMAN CAPACITY

Threats and Strengths

- **Secrecy**
- **Coping strategies**
- **Care-giving**
- **Coping and adjustment**
- **Lack of information and knowledge**
- **Future focus**

RESULTS: SOCIAL ECOLOGY

- Healthcare experiences
- Actual and fear of discrimination
- Lack of power and decision making
- Disruption to families
- Caregiving
- Absence of family in the future

RESULTS: CULTURE & VALUES

- Religious faith
- Status of women
- Decision making
- Gender differences
in care
- Return to natal families

RESULTS: ECONOMIC RESOURCES

- Poverty
- Finances
- Malnutrition
- Medicines

RESULTS: PHYSICAL RESOURCES

- **Workload**
- **Illness of self**
- **Illness of other family members**

RESULTS: ENVIRONMENTAL RESOURCES



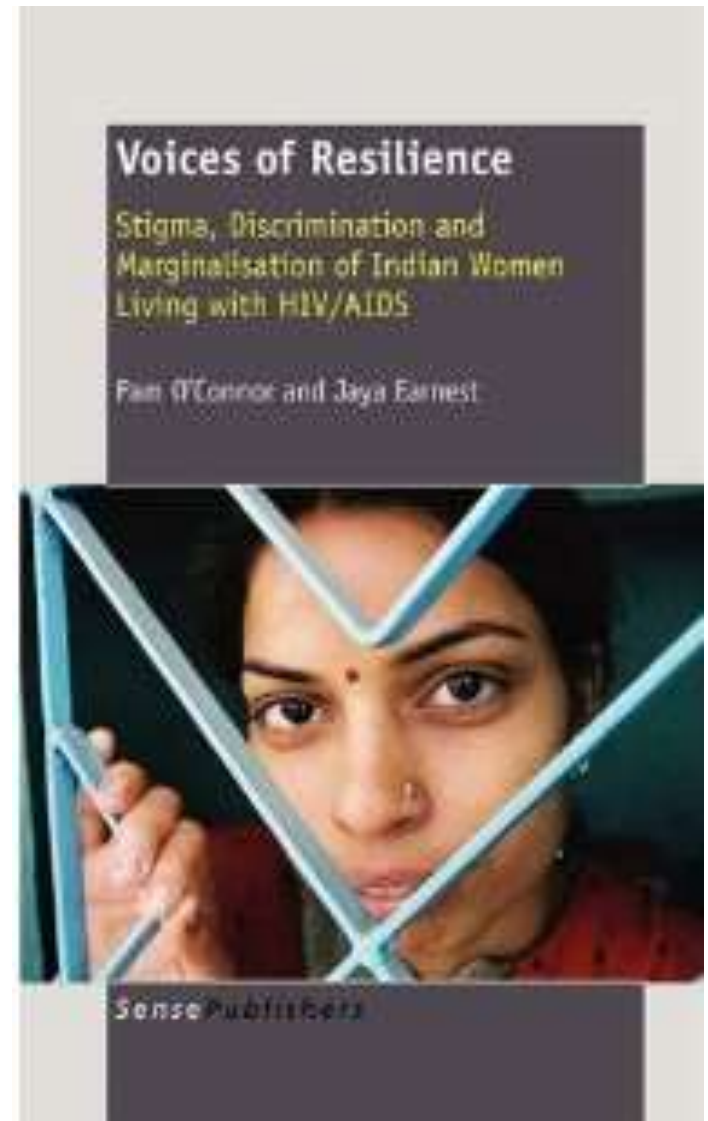
- **Overcrowding**
- **Sanitation**
- **Disease**
- **Pollution**

CONCLUSIONS

- HIV/AIDS stigma and discrimination exist in families, communities and healthcare
- Fear of discrimination is evident
- Women have little power in decisions
- Women act as 'shock absorbers' for family
- The women interviewed have resilience, strength and dignity
- Men hold the key to change

The study resulted in a book
published in 2011.

The book portrays the resilience of
each woman's spirit and the
unique capacity
of the women to cope,
to find strength, to pursue life and
to maintain hope
when their dreams and the dreams
of their children have been
shattered through HIV/AIDS.



Knowledge, attitudes and perceptions of HIV/AIDS: An exploratory study of women of child bearing age in the highlands region of West Papua (2014)

Angela Heier & Jaya Earnest
International Health Programme,
Curtin University



BACKGROUND & AIMS

- HIV/AIDS is a serious health issue in Papua, the easternmost province of Indonesia, where the estimated prevalence rate of the virus is 15 times higher than the rest of the country ([UNAIDS, 2010](#)).
- This exploratory study investigated the knowledge and attitudes of women in the highlands region of Papua on HIV transmission, as well as locations for HIV/AIDS testing and information.
- The aim was to ascertain areas of community health education needed by women of childbearing age within the highlands in order to prevent mother-to-child transmission of HIV and to identify barriers that hinder women from accessing available

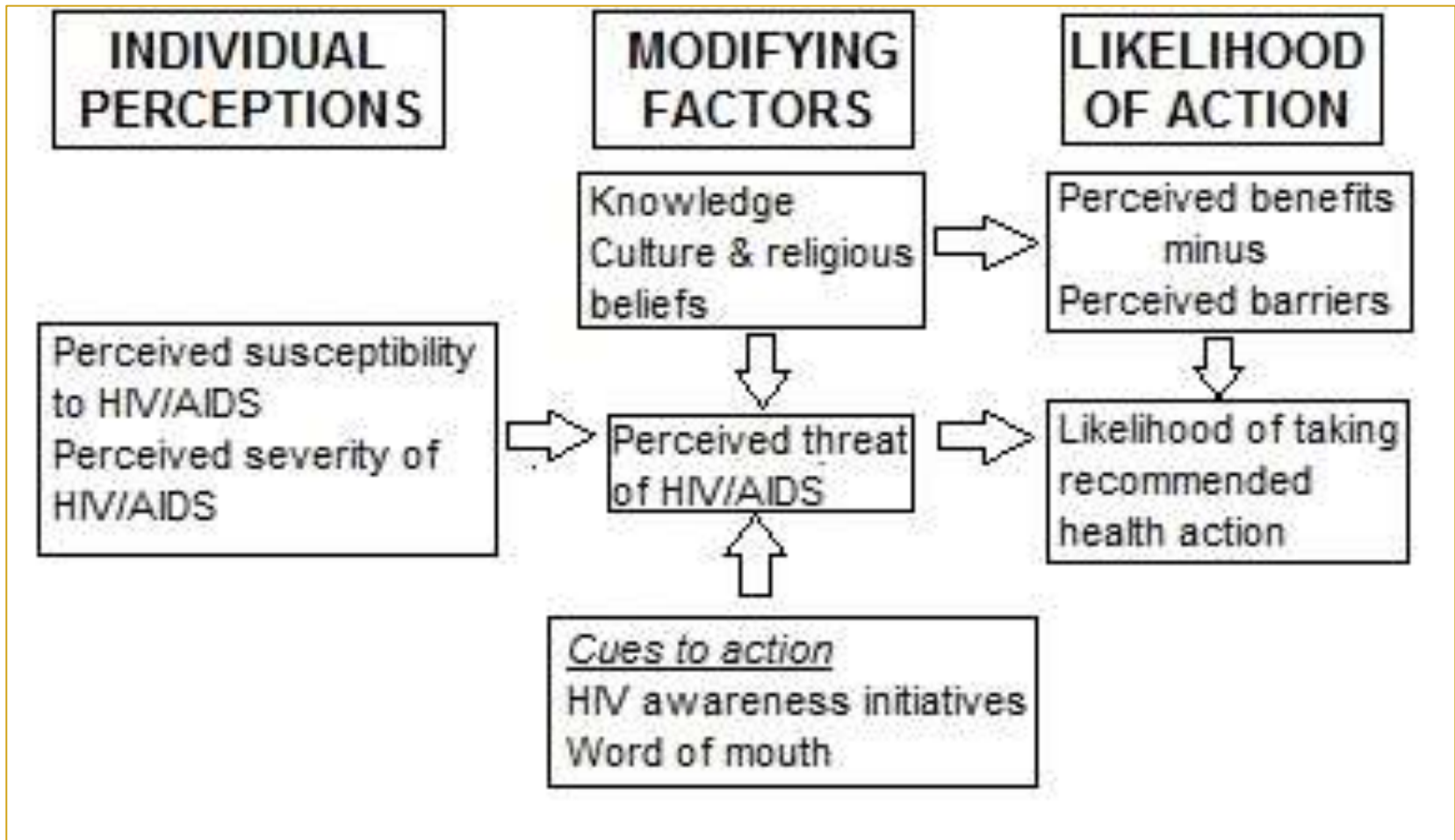
THE BOKINDINI HIGHLANDS – WEST PAPUA



METHODS

- Semi-structured interviews were conducted with women from the Papuan highlands in the local language, Lani, audio recorded and then transcribed into English.
- Data was thematically analysed and the analysis was underpinned using the health benefits model as a conceptual framework.

USE OF THE HEALTH BEHAVIOUR MODEL OF HEALTH



RESULTS

- The study documented that there was a perception of personal vulnerability for contracting HIV/AIDS amongst the participants, as well as an understanding of the severity of the virus.
- Factors that emerged which may impact the participants' perceptions regarding HIV/AIDS include both the knowledge that they already have regarding the virus, as well as misinformation regarding modes of transmission.
- Perceived benefits of accessing services included having a safe life, while stigma and fear were identified as perceived barriers.

CONCLUSIONS

- Proposed recommendations to prevent mother-to-child transmission in this region include greater number of health initiatives that promote awareness of HIV transmission and the importance of testing.
- Educational programs must take into account cultural norms and religious beliefs that impact on the perceptions and behaviour of women in this area.



DISTINCT APPROACHES FOR DISTINCT EPIDEMICS - modified from Dr D Wilson, 2008

- **Understand the epidemic. Delineate and address major drivers of transmission.**
- **Recognize that transmission is primarily among priority groups and to protect them.**
- **Ensure priority group prevention - funding needs to commensurate with proportion of priority group infections**
- **Identify best proven approaches for key determinants of success & all sites with large priority groups**
- **Selectively assess biological impact, to ensure approaches remain effective.**
- **Routinely track coverage, to ensure priority group members are reached AND track quality, to ensure key determinants of success are delivered**

