

Mental Illness, Stigma and Poverty in India: MISPI



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INTRODUCTION

- Project funded under DFID Cross-Cutting Disability Research Programme;
- Carried out by Leonard Cheshire Centre for Disability and Inclusive Development at University College London (UCL)
- Conducted in Partnership with RML- Psychiatric department, New Delhi;
- Mixed Methodology:
 - ✓ Quantitative Survey;
 - ✓ Qualitative Study

CONTENTS of the PRESENTATION

- **Quantitative Case-Control Survey**
 - ✓ Introduction: Mental illness, stigma and poverty;
 - ✓ Methodology;
 - ✓ Main Findings;
 - ✓ Discussion and Conclusion
- **Qualitative Study**
 - ✓ Background and objectives;
 - ✓ Methodology;
 - ✓ Main findings;
 - ✓ Discussion and next steps.
- **Policy implications and Discussion**

HOSPITAL-BASED CASE- CONTROL STUDY

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Introduction: Mental illness, stigma and poverty (i)

■ Global burden of mental illness

- ✓ Approximately 450 million people affected worldwide;
- ✓ 80% live in middle and low-income countries;
- ✓ 2,319,000 died in 2010 of mental and behavioural disorders (Lozano et al., 2010, Lancet);
- ✓ Account for 13% of the total burden of disease;
- ✓ 31% of all years lived with disability (WHO, 2010)

Introduction: Mental illness, stigma and poverty (ii)

■ Mental illness and poverty

- ✓ People with mental illness in low and middle income countries are among the poorest of the poor (Das et al., 2007)
- ✓ Stronger relationship found in low-income countries (LIC): In 11 developing-country community-based studies, significant associations between poverty indicators and common mental disorders were found in all but one study (*Patel & Kleinman, 2003*)
- ✓ **What is the role of Stigma?**
- ✓ Little has been done to examine the association between mental illness, stigma and poverty.

Introduction: Mental illness, stigma and poverty (iii)

■ Mental illness, stigma and poverty

- ✓ The biomedical approach argues that stigma is conflated with mental illness alone;
- ✓ Other factors (social, demographic, economic) have a significant bearing on the stigma of severe mental illness;
- ✓ Poverty and stigma associated with mental illness have the potential to deprive persons from access to services and opportunities (*Ngui, et al., 2010; Ssebunnya, et al., 2009*)

METHODOLOGY (i)

- **Hospital and community based case control study**
 - ✓ Between October 2011 and June 2012;
 - ✓ **647 patients** randomly selected during a visit to RML hospital;
 - ✓ Patients had been diagnosed either with **schizophrenia** or **severe affective disorders**.
 - ✓ A healthy **comparison group** matching the patients according to gender, age and place of residence randomly selected from the general population of Delhi.

METHODOLOGY (ii)

■ Procedures

- ✓ Face to face interviews were conducted with all patients or with a care-giver as a proxy respondent and controls;
- ✓ Interviews with the control group were aimed at comparing the **living conditions** and **coping strategies** of patients to those of controls;
- ✓ All respondents were asked about:
 - health conditions and accessibility to existing services,
 - education,
 - employment, income, livelihoods;
 - Living conditions and social participation.







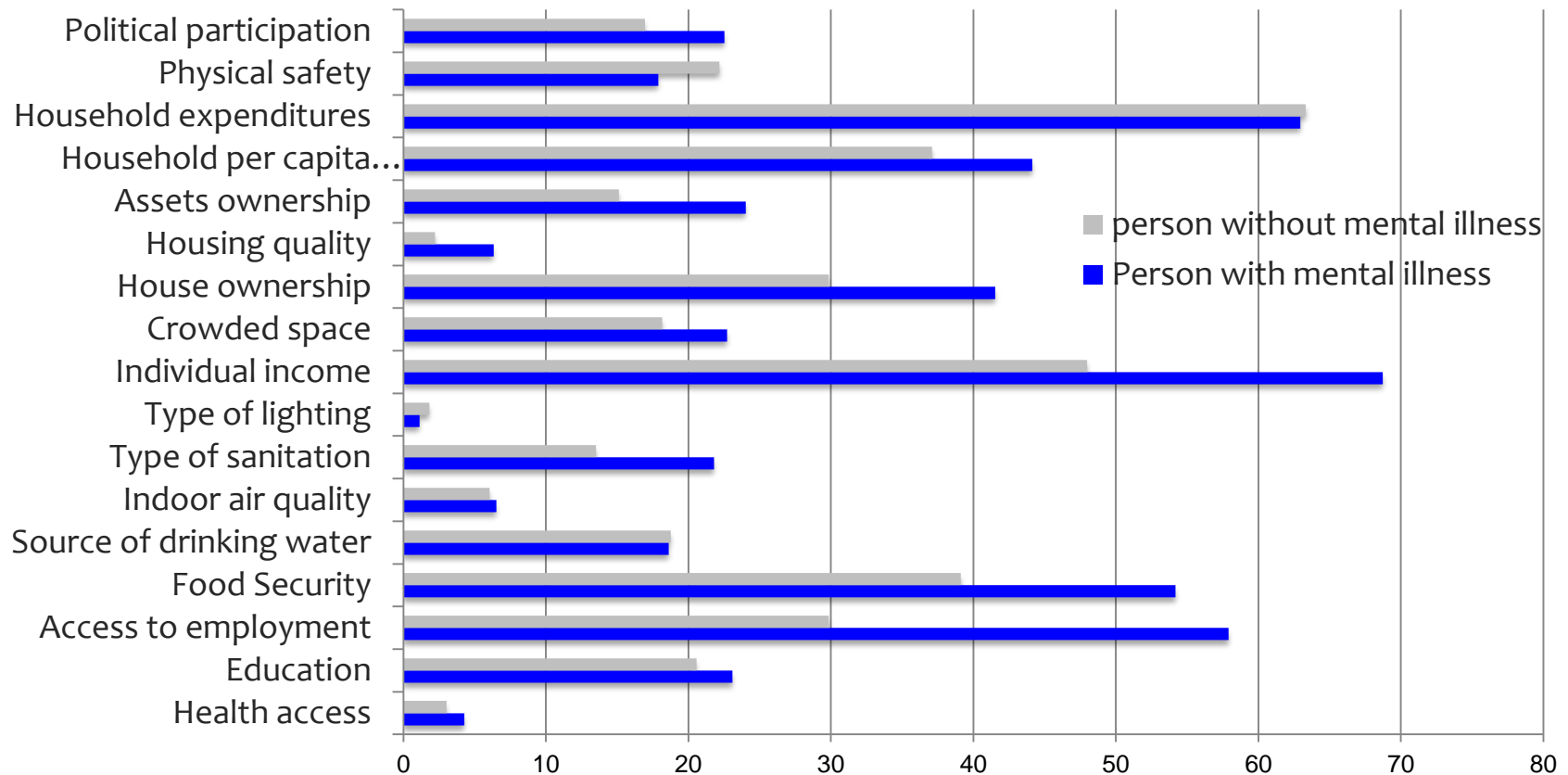
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METHODOLOGY (iii)

- **Description of dimensions and determination of cutoffs**
 - ✓ 17 indicators of deprivation reflecting aspects of wellbeing;
 - ✓ Selected indicators in three major domains of deprivation:
 - individual level capabilities;
 - household level material wellbeing;
 - and individual level psychosocial dimensions;
 - ✓ Multidimensional poverty measure to identify **differences in levels of poverty between patients and controls.**
 - ✓ Dimensions are independently assessed and the method focused on dimensional shortfalls.

RESULTS (i)

Incidence of poverty among patients and control



- High differences for: access to employment (28.1% difference), individual income (20.7%)
- Relatively high for: food security (15.1%) and house ownership (11.7%)

RESULTS (ii)

Multidimensional poverty

- The incidence is significantly higher for persons with mental illness who were less likely to:
 - ✓ be employed (42.1% versus 70.2%),
 - ✓ have an income (31.3% versus 52%),
 - ✓ benefit from food security (45.8% versus 60.9%)
 - ✓ have house ownership (58.5% versus 70.2%)
- On average, patients are deprived on 4.9 dimensions (3.8 for control);
- If a person is deprived in four, five, or six dimensions simultaneously, the proportion of poor patients (respectively poor controls) becomes 68.5% (respectively 48.6%), 51.6% (respectively 35.9%), or 38.5% (22.2%)

DISCUSSION

- **All dimensions of life are concerned by poverty:** economic (living conditions), social (social exclusion), cultural (identity), political (participation) or ethical (norms and values).
- Persons with mental illness are particularly deprived from **access to an income** (through a job); Pervasive stigma and prejudice are central to explain exclusion from the labour market:

=> *higher contribution of unemployment to the total MPI, 11.1% (versus 7.9%)*
- Next step for gathering evidence: **implementing an income generating activity support program** and measure it has an impact on social inclusion;
- By contributing to the family income, respect from family and the community is enhanced;
- As a result, self esteem increases and mental suffering may be alleviated...

CONCLUSIONS

- **Stigma and prejudice against persons with mental illness are linked with level and intensity of poverty.**
- If persons with mental illness are refused the right to attend school and have difficulty in finding and keeping a job such factors may result in a continuing cycle of lack of opportunities and poverty, compounding low self-esteem and as a consequence, result in a worsening of mental illness status. **Future research should further explore this possible feed-back loop.**
- **Policies fostering opportunities for persons with mental illness while promoting inclusion in the community through advocacy and sensitisation programs are essential.**

NEXT STEPS

- The follow up study of MISPI was carried out in the OPD of Department of Psychiatry, Dr. Ram Manohar Lohia Hospital.
- Started after 6 months of the initial study.
- Out of 647 patients, MISPI Survey of 30 patients completed till date.
- All 30 are patients diagnosed with schizophrenia.

LOCAL CHALLENGES TO 'GLOBAL' MENTAL HEALTH

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BACKGROUND (i)

- **Current psycho-social provision in India: What are the problems?**
 - ✓ **Need for a socially oriented mental health** that also addresses development (Das & Rao, 2012)
 - ✓ **Inadequate provision of interventions and resources** to support this including appropriately trained professionals to deliver psycho-social interventions (Agarwal et al., 2004)
 - ✓ **Limited understanding of local concerns** in primary health care (Jain and Jadhav, 2008, 2009)
 - ✓ Problems already highlighted in literature, for example, **on cultural validity of western theory** and intervention in India including universal diagnostic categories (Jadhav, 2012; Summerfield, 2013)

BACKGROUND (ii)

- ✓ Applicability of International Classification of Disease, mental health section (ICD-10) training manual for low income countries and its standardised approach has been unquestioned;
- ✓ **No published results on whether it is effective for both mental health professionals and patients;**
- ✓ There is sufficient evidence that current policy and interventions are not effective (Kapur, 2004);
- ✓ International reports on mental health and development do not elaborate on the **details of training and teaching of mental health professionals** (World Health Organization, 2010);
- ✓ Review of mental health curriculum and community mental health training manuals in India (Basic Needs, 2009);

OBJECTIVES

- Is the nature of training for mental health professionals in India responsive to local concerns?
- This study aims to establish whether or not currently deployed standardized training vignettes for mental disorders used in ICD-10 training manuals are culturally valid for non-affected community population in the Union territory of Delhi.

SPECIFIC QUESTIONS

- How did **respondents interpret and conceptualize an ethnographically derived vignette and an ICD vignette** for the same diagnosis (Generalised Anxiety Disorder)?
- **How relevant is the standardised ICD 10 training manual** as compared to locally derived training / teaching material?
- **What did the community want from mental health professionals** in relation to access to care and training for delivery of psycho-social interventions?
- **What are the implications of this study** for policies relating to mental illness and development in India?

METHODOLOGY

- Focus group (n=8, total no of subjects=80) amongst semi-urban communities with adults (18-65 years) in Delhi.
- FGD-sampling (n=80) stratified by geographical locality/ gender.
- Each FGD comprised of 2 vignettes for a specific ICD-10 diagnosis:
 - 1) *an ethnographically derived narrative from field sites in Northern India, and*
 - 2) *a corresponding, ICD-10 training vignette (describing an Australian subject) and adapted for use in India. Both vignettes were matched for a specific diagnosis, Generalised Anxiety Disorder (ICD-10, F41.1).*
- Discussion focussed on 4 domains:
 - 1) *Which vignette participants identified with most and why;*
 - 2) *Their explanations of the condition described in both vignettes;*
 - 3) *Views about appropriateness of local mental health services;*
 - 4) *Their views about training of mental health professionals.*

RESULTS (i)

■ Responses to Identification with vignettes

- ✓ A majority of participants identified with the ethnographic vignette.
- ✓ Identification with the ethnographic vignette was partly based on an emotional connection with the details of the life of the affected subject.

As one participant (female, 35-60 years) said, “...there is someone like this in each house”, referring to the main character in the ethnographic vignette who suffered from generalized anxiety disorder.

- ✓ For the ICD-10 vignette, identification for most participants was less clear.

RESULTS (ii)

■ Respondents Conceptualizations/understandings of vignettes

- ✓ Participants showed a **sophisticated understanding** of issues in both vignettes.

“See what happens due to this... people say that our country is progressing for the sake of saying... Now suppose that a person came after his education... but when he is not getting the job, what kind of progression is it? So the person is coming back to that condition... they don't have a source for medicine... above that.... There is no other employment source for them... the employment that is there is also so limited... one earning member and ten to eat....so the person will always be stuck in the problems only, right? From where will he be able to get his treatment done, that is the thing to think about...” (middle-aged male)

- ✓ Participant provided **multiple explanations** for the problems faced by the main characters in both vignettes;
- ✓ For the ethnographic vignette, explanations of the main subject's problems linked social, economic, and health related issues;
- ✓ A common theme across vignettes was that **participants interpreted the vignettes in social terms.**

RESULTS (iii)

- **Participants own views on how to respond to problems raised in vignettes**
- ✓ Participants were able to articulate solutions and **responses emphasising ‘psycho-social’ approaches**
- ✓ ‘Psycho-social’ was conceived mainly in terms of three main domains:
 - 1) Problems could be addressed through talking and discussing between people;
 - 2) Addressing inter-personal relationships, particularly those in the family, was central to resolving problems.
 - 3) Participants emphasized social inequalities in access to government welfare programmes and institutions including education and how this reinforced existing economic inequalities.
- **Emphasis on prevention;**
- Concerns raised about the **nature of local services** and in particular challenges in engaging with state mental health services.
- Participants expressed a **lack of confidence in government health services** as opposed to private care.

- “there is something like family atmosphere, so that openness can come. Meaning of which... Ma’am all in all we can say that what we get from family... **somewhere there is no moral support.** He didn’t get it from his father and his mother and sister weren’t in that condition... to be able to give him moral support... **So altogether, his depression increased/ deepened due to family.** All of us agree on it... I believe in it...” (middle-aged female)
- “... it is not that everyone will become rich.. here, it is there in the policy that the rich will be rich.. **development has to happen from bottom**... so it should be blocked for the rich and the development should be done from here...” (middle aged male)

Site for one of the FGDs



Municipal Corporation of Delhi building

RESULTS (v)

- **Views on training of mental health professionals in India**
 - ✓ While participants found it difficult to articulate views about training of mental health professionals they did **provided insights into the ideal qualities** of such professionals.
 - ✓ Predominantly, participants felt that doctors should **treat their patients with love and respect.**

“A doctor should be patient... sehensheel” (middle-aged female)

*‘He [doctor] should have some sympathy towards the patient, he will show full sympathy... and if he consoles him.. he [patient] will feel that he is at home... ‘
(middle-aged female)*

- ✓ Participants expressed **concerns about non-medical staff attitudes** towards poor people in government hospitals
- ✓ Participants were **understanding towards doctors who ran very busy clinics** and had so little time.

DISCUSSION and IMPLICATIONS

- People have sophisticated understandings of cross-linkages between mental health, well-being and wider structural determinants in India;
- Semi-urban Indian subjects can conceptualize a link between mental health and development ;
- This contradicts the ‘global mental health’ discourse which argues primarily for access to ‘treatment’ and ‘scaling-up of models’ derived from randomized control trials;
- Discussions reveal that there is not a uniform community view of the vignette that were discussed;
- India’s mental health policy could be significantly enhanced by taking local configurations and issues into account.

NEXT STEPS

- What needs to happen next?
 - ✓ **Ethnographies of training for mental health professionals** and health policy makers including the institutions of training;
 - ✓ Deploying an existing clinical technique **that incorporates community ideas and expectations in India** and compare this with standard existing interventions (Jadhav and Jain, 2012)
 - ✓ Inclusion of **development variables as key outcome measures** when assessing success or failures of mental health services

A person is seated at a piano in a dark room, illuminated by a single light source that creates a strong highlight on the keys and the person's hands. The background is mostly in shadow, with some faint outlines of the piano and the person's torso.

Thank you!

For further information please contact
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