PATIENTS AND TB: IMPROVING TREATMENT OUTCOMES THROUGH A PATIENT CENTRED APPROACH AND ACCESS TO NEW TREATMENTS

5TH TB SYMPOSIUM – EASTERN EUROPE AND CENTRAL ASIA
MINISTRY OF LABOUR, HEALTH AND SOCIAL AFFAIRS OF GEORGIA
AND MÉDECINS SANS FRONTIÈRES

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EXAMINING ADHERENCE TO MDR-TB TREATMENT IN UZBEKISTAN: A QUALITATIVE STUDY

Translating research findings into practice

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MEDECINS SANS FRONTIERES

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Background

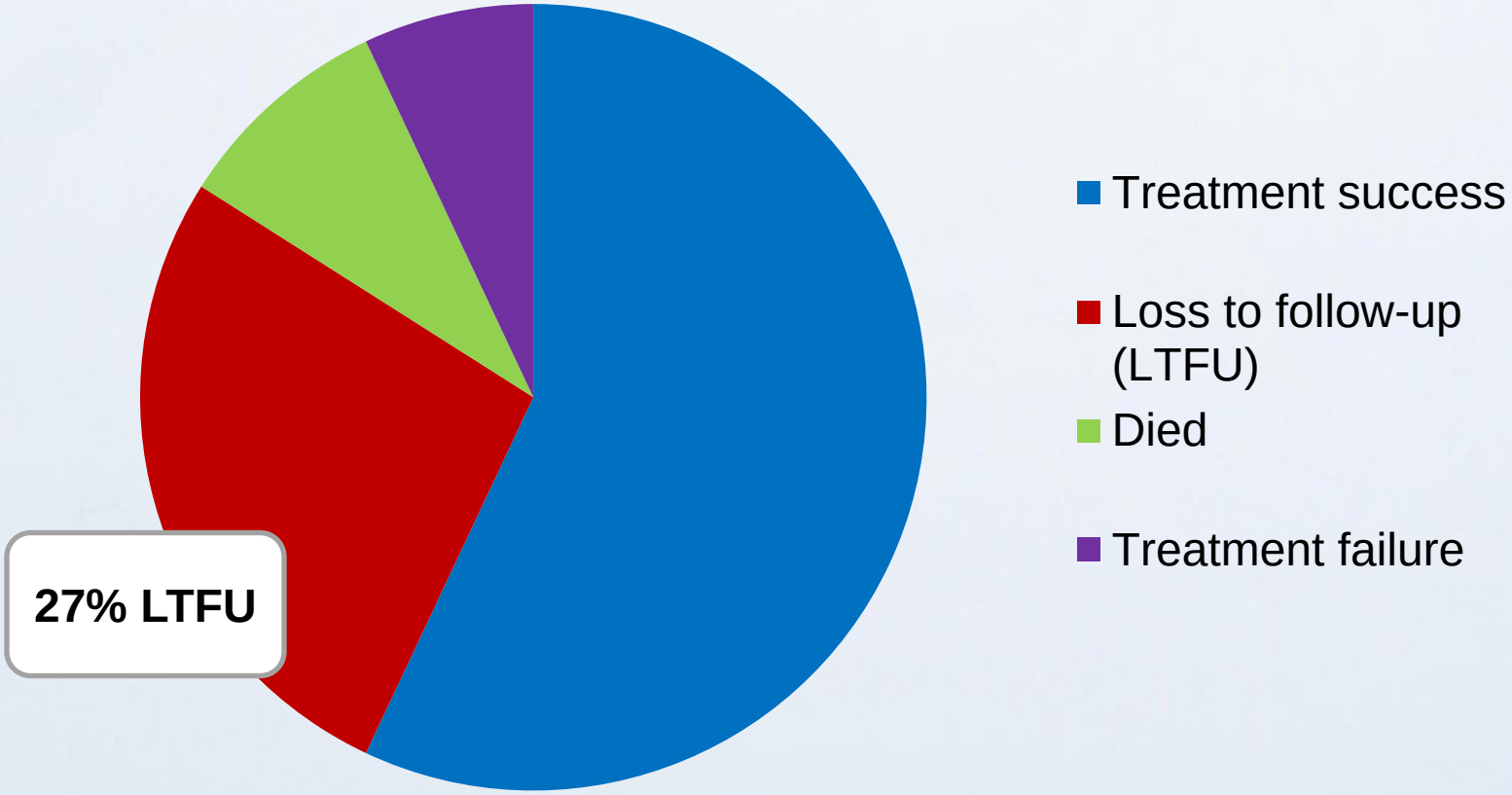
- MDR-TB “global health security risk” (WHO 2014)
- 480,000 people developed MDR-TB in 2014
- Treatment lengthy, arduous, toxic
- Low treatment success – around 50%
- Adherence to treatment is complex and challenging
- Medical and public health implications of non-adherence

MSF/MoH programme in Karakalpakstan, Uzbekistan

- 23% MDR-TB amongst new TB cases
- Karakalpakstan proportions of MDR-TB:
  - 40% new
  - 75% previously treated cases
- MSF/MoH TB programme
  - Model of treatment and care is ***ambulatory from day one***

KARAKALPAKSTAN PROGRAMME TREATMENT OUTCOMES

Treatment outcomes: patients starting MDR-TB treatment 2009-2012 (n=1,190)



ADHERENCE SUPPORT INTERVENTIONS

- Pre-treatment assessment
- 1:1 counselling for certain patients, psychiatric support if needed
- Family support
- Peer support group meetings
- Social support (including food parcels)

Shona Horter, PMTCT B+

STUDY RATIONALE

- Uzbekistan project persistently high rates of LTFU
- Evidence – factors associated with LTFU
  - Alcohol/substance misuse
  - History of imprisonment
  - Homelessness
  - Lower education levels
  - Side effects and fear of treatment ineffectiveness/harm
- Limited understanding of *why:*
  - These factors influence patients' completion of treatment
  - Some patients can adhere while others cannot

STUDY AIM

To provide insight into the patterns of patients' adherence, exploring the barriers and enablers to treatment-taking in order *to inform future strategies of adherence support*

METHODS

- Participants recruited purposively – maximum variation sample
- 52 In-depth interviews with MDR-TB patients (35) and health practitioners (12), including 5 follow-up interviews
- Thematic data analysis – principles of grounded theory
- Ethical approval – Uzbekistan Ethics Committee, MSF ERB

Participant	Participant information	No. participants
MDR-TB patient	**Total** Adherent Partially adherent LTFU	**35** 15 12 8
Health practitioner	**Total** Counsellor TB nurse TB doctor	**12** 5 5 2

FINDINGS

1. **Hope** and **better knowledge** offering potential to overcome non-adherence
2. **Patient autonomy** and **control** optimising engagement with treatment
3. **Side effects** and **views on TB drugs** influencing tolerance

"If you believe in it then you will be cured" P21

1. Disease and treatment knowledge

- Limited knowledge about disease and treatment
  - Misinformation – transmission, cause
  - Reported limited explanations
  - Shock at time of diagnosis
  - Vulnerability to myths/information via lay-networks
  - Doubt, disbelief, distrust
  - Desire for more information
- Perceived credibility of patient-to-patient information
- Disease knowledge and understanding described as being significant for acceptance and belief in treatment-taking

"When they told me I didn't understand… I was so much in shock that I don't even remember what I was thinking at that time" P01

1. Belief and hope for cure

- Disease denial and disbelief
  - Several LTFU patients did not believe they had disease
- Decisions around cure - stopping treatment early
- Belief in treatment efficacy and in chance of cure
- Hope for cure – motivation, perseverance, strength for treatment continuation
- Support
  - Counsellor relationship
  - Peer support (patient-patient) – shared experience, solidarity
  - Family support
  - Encouragement

"I still don't believe I have had TB… they said I got this disease. We did not believe. It didn't hurt anywhere" P27 (LTFU)

"I used to take treatment well if I had support from someone" P02

2. PATIENT AUTONOMY AND CONTROL

- Ability to choose treatment, conflicting demands
  - Men's role as breadwinner
  - Women's role as daughter-in-law
- Ownership and self-responsibility – driving perseverance
- Practitioner-patient relationship
  - Good patient / bad patient
  - Perceived blame / inspection of drug-taking

"While taking the treatment, my husband's house were against… they wouldn't let me take the treatment… so I left [treatment], being a defaulter" P03 (female)

"Due to my family reasons I had to stop the treatment. Because there was no other source of income" P32 (LTFU, male)

3. Side effects and views on TB drugs

- Side effects experienced
- Some patients perceived treatment as poisoning – seen as treating lung at expense of other organs
- Psychological 'sphere' to drug tolerance
  - Focusing on positives/distractions from treatment – fewer side effects
  - Focusing on negatives – development of (negative) drug associations, side effects felt worse
  - Visualisation techniques

"If you suffer and you think of something bad you will not be able to take the drugs, it'll be even worse. And if you are joyful and don't think of anything bad then the drugs will not affect you much" P11

"I used to vomit when I saw them" P31

OTHER FINDINGS: EMOTIONAL IMPACT MDR-TB

- Drug side effects, suffering
- Hopelessness, fear of death
- Feeling as though no future
- Severe psychological side effects
- Suicidal thoughts and attempts

"I was ready even to die but not taking those drugs" P33

"It's better to die rather than suffer everyday… I had time when I hung myself. I always wanted to die. Such thoughts. In my mind" P25

CONCLUSIONS

- Disease knowledge and belief, patient autonomy and control, and views on TB drugs influenced adherence to MDR-TB treatment
- Need for enhanced patient information, and engagement of patients as active participants in their care
- Individualised, holistic, patient-centred approach to treatment support

THANKS & QUESTIONS

Would like to thank all the patients, their families, staff and teams involved in the study.

Discussion: translating research findings into practice

- Treatment literacy versus health/scientific literacy
  - How much knowledge is enough?
  - Innovative approaches to patient education?
  - Various stages of education/knowledge?
- Adapting counselling and adherence support
  - Context specific factors
  - Individually tailored approach
- Identifying/choosing priorities
- Feasibility/resource constraints