Engaging adolescents in care: Experience from MSF, India

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MSF DRTB Clinic

- Since 1999: Médecins Sans Frontières (MSF) collaborates with National TB & HIV Programme, Mumbai, India.
- MSF clinic in Mumbai treats patients free of cost with complex clinical profile and limited treatment options available under programmatic conditions.
- A multi-disciplinary team provide medical care and psycho-social support including palliative care from the start of the treatment.
- MSF clinic has contributed to evidence generation for certain key WHO recommendations on usage of newer drugs like Bedaquiline and Delamanid as a combination regimen for FQ resistant eligible patients.
- Till date MSF clinic has catered to 833 DRTB patients (since 2006): Adults (>19 yrs) = 632, Adolescent (11–19yrs) = 168, Paediatric <10 = 33)
“I used to spent hours watching my friends from the window. Every evening they gathered in ground to play. I was not able to go out, as I was on the treatment and also experienced some side effects, like change of skin color, rashes. I thought better to minimize my socialization and stay inside house”

- Nishchaya, An Adolescent on XDR TB Treatment in M
Engaging adolescents in care...

• Common issues shared by adolescents during counselling sessions are as follows:

• **Stigmatization and body image issues**: skin discoloration, PICC line in-situ leading to lack of confidence

• **SRH issues**

• **Acceptability of PICC line is not easy in this group**

• **Lack of family support.**

• **Discrimination**: blaming them for the financial burden and discrimination of the whole family by neighbours and relatives.

• **Difficulty to maintain romantic relationships**

• **Gaps in studies and future insecurity in career**

• **Fear of death, hospitalization and guilt looking at the family suffering.**

• **Lack of entertainment**
Engaging adolescents in care...

• Adolescent cohort is unique and vulnerable considering the physiological, social, psychological changes taking place in this period

• Engagement of adolescents was done through:
  - Individual counselling sessions
  - Support group meetings
  - Group Health Education sessions

• Since 2016: 172 Support group Meetings, 14 Focus group Meetings, 160 Group Health Educations were conducted.

• Frequency- twice a month, 60-70% patients attended these
Patient centered approach:

- Create safe space to speak about issues
- Emotional support, 'care giver meetings to share emotions
- Prioritizing & feel important
- Connecting them with peers, creating a place to express their emotions and find support
- Non-judgmental staff during clinical appointments
Solutions:

Some other services provided in MSF Clinic...

- Separate clinic spaces with more inviting décor
- Vocational rehabilitation activities:
  
  Eg: Basic nursing course, driving course, basic administration course.
- Training to empower caregivers to more effectively support and communicate with adolescents
- Linkages to family planning services as needed

Future initiatives planned...

- Community- and school-based campaigns to increase TB awareness
- Linkages to post-TB care and palliative services
Recommendations for way forward:

1. Adolescents require a holistic care package customised to their unique needs including individual and group counselling, life skills capacity building, vocational guidance etc

2. Platforms for peer based emotional support and recreation - adolescent TB champions can act as peer support and be included in strategic decision making

3. Caregiver counselling and engagement is important for them to understand the challenges faced by patients and to address caregiver fatigue

4. Sensitisation of key stakeholders including teachers in schools/colleges is very essential to support to avoid stigma/discrimination
Acknowledgement and Thanks

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