Contrasting cultures of TB and HIV

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DISCLOSURE

• I received a donation of drugs from Bayer Pharmaceuticals for a TB clinical trial funded by the EDCTP.

• CAPRISA receives funding for a Extramural TB-HIV pathogenesis and treatment unit from the South African Medical Research Council.
Overview

• Disparity between investment in TB and HIV

• Scientific advances are inadequate to achieve the WHO’s goal to end TB by 2035

• Qualitative review of the contrast between TB and HIV
Clinical trials TB and HIV 2000-2015

## CURRENT CLINICAL TRIALS: MDR-TB

**IND**
- STREAM
- NIX (+ZeNix)
- NeXT
- MDR-END
- TB-PRACTECAL
- End- TB
- DELIBERATE (ACTG 5343)

**STRATEGY**
- PRAXIS
- INDEX
- PROPHYL, PK(child/adol)
- Janssen C211
- V-QUIN, TB Champ
Drugs developed/licensed for HIV & TB: past 30 years

Funding

TB remains critically underfunded

• 2005-2007: for every 1 USD spent on HIV research, 5 cents was spent on TB research

• 2015: Global Fund disbursed
  • 53.4% to HIV
  • 15.8% to TB

• NIH: >1bn USD annually on diabetes and 3X on HIV
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ART is Empowering

[ARV’s] I always take them. It’s because before you take ARVs, they tell us tablets might do this and do this, if you don’t take it on time this is what is happening…

Patients are educated and counselled on ART

Glob Pub Hlth. 2014. Daftary, Padayatchi
... versus disempowering

TB program model of care: detection, notification, cure
“If I can dodge, I can dodge TB.”
“[ARV’s] I never dodge them.”

IjtlD Daftary, Padayatchi. 2013
Barriers to TB Medication Adherence

Pill Burden

XDR-TB

HIV
ADHERENCE in XDR-TB and HIV co-infection

‘ARVs have never ever given me any problems since I started taking them but when I was taking them with TB treatment, I started to have problems.’

It would be better if they explain about tablets... no one tells us what is going on with it for that period of two years, is it treatable or not.

[For TB] I was not told that they are better ones and others are worse...

‘You have a disease which can’t be treated, you see yourself at the last stage. It’s [i.e., XDR–TB is] worse than HIV. I’m scared of it more than HIV’

Patients are poorly counseled about TB

IJTLD 2016 Daftary, Padayatchi
Potential benefits of pre-test counselling for TB

- Early opportunity to discuss TB
- Discuss risk of infection and means of protection and treatment
- Think about implications of a negative / positive test result
- Think about strategies for coping with long duration of treatment, side effects and stigma

No provision for pre-test counselling

Cramm JM. BMC Pub Health; 2007
STIGMA
Traditionally thought to be more acutely experienced with HIV
Both are devastating, stigmatizing
To... HIV is better than XDR-TB

We are used to HIV but it’s not easy to tell a person about XDR while they don’t understand what XDR is... Most people understand more about HIV and it’s easy to deal with.

It’s [i.e., XDR-TB is] worse than HIV. I’m scared of it more than HIV. To me, HIV is not a problem.

TB notification is incriminating and invokes fear
Terminology: TB SUSPECT
Fighting TB stigma: lessons learnt from HIV activism

**HIV Community**
- rallied forces to challenge the stigmatisation
- collective, grassroots human rights movements
- tangible shifts in policy

**TB community**
- inadequately contested programmatic norms that reinforce TB stigma
- raising awareness about TB stigma is insufficient to mitigate stigma
- need collective organising to change harmful practices.
Diverse Approaches of HIV and TB Care

• HIV Programs
  • Emphasis on patient confidentiality, education and empowerment
  • Driven by activism, guarding against stigma and discrimination

• TB Programs
  • Impersonal attitude discouraged patients from disclosing HIV status to TB providers
Distinct sense of community

“[TB clinic] no one is taking care of you that much, if you are in a right place, where you are. While [HIV clinic] you are taken care of. . . There is a difference. . . it’s as if we are paying money.”

“At the TB clinic, I just go and take my tablets. At the HIV clinic, I stay and talk.”
## TB & HIV control

### TB control

- *Modus operandi*: top-down focusing on TB detection, notification, adherence and cure
  
- Mandatory TB screening
  
- Mindset of empowerment is slowly emerging but still infrequent in most TB programs

### HIV control

- *Modus operandi*: case detection and adherence
  
- Equal attention to education, privacy, empowerment
  
- Voluntary testing vs routine
  
- Driven by activism
    - inherent mandate to safeguard individual rights, mitigate stigma, discrimination

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**CAPRISA**
Program collaboration amidst the contrasting cultures of HIV and tuberculosis care.
CONCLUSION

• Call to HIV and TB programs to change to a collaborative, collective approach

• Meeting the socio-medical needs of patients may improve outcomes

• Realistic, commensurate effort for a more patient-sensitive approach needed
  - Within the context of available financial and human assets
“The world has made defeating AIDS a top priority. This is a blessing. But TB remains ignored”

- Nelson Mandela

XV International AIDS Conference,
Bangkok, July 2004
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