New treatments and approaches to Tuberculosis
Tuberculosis Symposium – Eastern Europe and Central Asia
RA Ministry of Health and Médecins Sans Frontières

Social media and health:
A qualitative study exploring the TB & ME blogging experience and its potential role in MDR-TB treatment

*Shona Horter¹, Beverley Stringer¹, Sarah Venis¹, Philipp du Cros¹
¹Médecins Sans Frontières (MSF), London, UK
Email: beverley.stringer@london.msf.org
Presentation Overview

- Background to TB & ME
- Qualitative study – rationale and methods
- Study findings
- Conclusions
Study Rationale

• Social media and health – potential role?
• Innovative concept
• Ethical concerns – could blogging cause patients harm?
• Exploratory qualitative study to examine patient and staff experiences of the blog
• Identifying perceived benefits or risks associated
Methods

- Qualitative study design
- Participants selected purposively
- 20 Interviews conducted in total – with patient bloggers, certain MSF project staff, MSF HQ & WHO staff
- Interviews conducted using a flexible participatory technique based on topic guides, via Skype
Participants

<table>
<thead>
<tr>
<th>Role</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blogger</td>
<td>5</td>
</tr>
<tr>
<td>Project staff</td>
<td>8</td>
</tr>
<tr>
<td>Stakeholder</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>20</td>
</tr>
</tbody>
</table>

Small potential sample size (13 patient bloggers at time of study) and several bloggers untraceable: 1 died, 7 due to project constraints e.g. MSF project closed down, no availability in study timeframe
Validity

- Triangulation
- Reflexivity
- Attention to negative cases
- Fair Dealing
- Clear Exposition of methods of data collection

New treatments and approaches to Tuberculosis
Tuberculosis Symposium – Eastern Europe and Central Asia
RA Ministry of Health and Médecins Sans Frontières
Findings 1: Blogging and the treatment-taking process

• Helping patients continue with the treatment-taking process
• Unique blog audience:
  – receiving encouraging comments
  – providing a positive example
  – not wanting to disappoint followers
• Blog providing distraction from treatment

‘The blog helped [patient]… to get motivated and use the mask’ HCW 01

‘I was happy when I heard the words of encouragement from people, then I felt like to take the drugs as soon as possible’ Blogger 04
Findings 2: Support to patients

- Peer support for other patients
- Shared experience
- Feelings of solidarity
- Reduced isolation
- Enhanced staff-patient relationships

‘Blogging makes you realise that you are not alone in the struggle, that other people are experiencing the same things that you are experiencing, and other people have already conquered the disease’ Blogger 02
Findings 3: Patient expression and voice

• Stage for story telling
  – written medium facilitating open expression

• Blog and patient voice

• Providing strength and positivity to patients – recognition of achievements

• No reported instances of harm

‘Through blogging you can share thoughts without thinking of what others will think’ Blogger 02

‘Now when I look back, whatever was written I have achieved it’ Blogger 05
Findings 4: Human face to DR-TB

• Mentioned by all stakeholder participants
• Blog said to provide a human face to DR-TB
• Helping identify priority areas requiring attention

‘The connection with the patients and their stories, understanding that side of it makes it more urgent and more real’ Stakeholder 04

‘Social media is I think the best channel to get more MDR-TB patients involved in defining the policy’ Stakeholder 06
Conclusions

- TB & Me blog associated with identified health and emotional benefits
- No reported incidences of harm subsequent to, or as a perceived result of blogging
- Blog as a useful tool to support patients with DR-TB treatment
- Role of social media in patient voice merits further exploration
Next steps

• MSF hopes to see more TB patients benefit from blogging
• Aim to increase the participation, readership and audience of the blog
Thank you to all of the patient bloggers and staff who participated in and contributed to this study.

The photographs used in this presentation are generic pictures of TB&Me bloggers, who have consented to their use on the TB&Me website and in this presentation.

All quotes used are anonymous and do not relate to particular photographs.
References

Full study report: