Videography-Based TB & HIV Patient / Family / Community Education
Four Corners TB/HIV Conference, 2016

John W. Wilson, MD
Associate Professor of Medicine
Mayo Clinic
Division of Infectious Diseases
Rochester, MN
Problems with TB Education
- Global Background

- > 95% of global TB-related deaths occur in low- and middle-income countries where education and public health information are often less accessible

- Many patients diagnosed with active TB or LTBI have minimal or no understanding what TB is, how it is acquired, transmitted or treated

Problems with TB Education - Global Background

• > 95% of global TB-related deaths occur in low- and middle-income countries where education and public health information are often less accessible\(^1\)
  • Many patients diagnosed with active TB or LTBI have minimal or no understanding what TB is, how it is acquired, transmitted or treated

• Patients’ general health beliefs are affected by their own experiences and fundamental understanding of health issues - often referred to as “health literacy”
  • When health literacy rates are low, patients become more prone towards non-adherence with medical evaluations and treatment recommendations\(^2\)

Problems with TB Education - Global Background

• For many pts & family members who have some awareness of TB:
  • There often remains an abundance of **confusion, social misperceptions** and **negative social stigma**\(^1,2\)
  • Pt / family TB misinformation is often by circulated within local community and further creating:
    • A distrust of modernized health care
    • Compromised medication tolerability and
    • Reduced treatment compliance\(^3,4\)

Problems with TB Education - Global Background

• Family / community misinformation of TB often lead to patient social isolation or ostracism
  • Pose barriers towards efficient public health contact investigations¹

Problems with TB Education – Domestic / US Background

• Face-to-face discussions with patients and family members are vital towards achieving an adequate fundamental understanding of TB

• However, many patients *commonly continue* to have unresolved questions and confusion.
Why do Patients Remain Confused after meeting with their health provider(s)?

• Patients may feel uncomfortable asking questions
  • Ashamed about asking perceived “dumb questions”
  • May feel intimidated with their doctor

• Patients may not fully understand what their provider is saying – via language, cultural differences
  • Barriers between effective patient-health provider communication commonly are encountered both within resource rich and poor countries

• Health providers may not have adequate time for more detailed discussions with their patients
  • Busy hospital or outpatient clinic
  • More problematic among many TB clinics within low- and middle-income countries, where the incidence of TB is generally much higher compared to the U.S.
External Education: Optimal approach for Patients, Families, Communities?

• Inform patients of the facts
  –not ‘freak them out’

• Tuberculosis is a very serious disease; BUT
  • It’s very treatable
  • It’s very curable

• Treatment can be challenging – many medications over a prolonged period of time
  • But very important to follow your health providers recommendation and complete treatment
Patient Education – What’s the Best Approach?
- lots of reading material available

Requires:
- Motivated patients/family members to actually read informational brochures
- Informational brochures in appropriate language
- Patients need to know how to read
Are there alternative strategies to optimize patient & family health education? - and in a culturally appropriate fashion?

• Most people like to watch movies

• Expanding upon this idea – with health educational videos
Health Education: examples – Mayo Clinic

- Videography health education project (patients/family/community)

- Tuberculosis – El Salvador, Honduras
- HIV infection – El Salvador, Honduras
- Cholera prevention – Haiti
Video Educational Principles - I
- Resource, culturally diverse groups

• Requires solid “partnership” with local medical and community leadership
  • Mutual trust and respect of project goals
  • Full transparency of project intentions

• Mayo Clinic (or other US Med. Cntr) cannot do this alone
Video Educational Principles - II
- Resource, culturally diverse groups

• **Vital roles** of *Local Medical/Community colleagues*:
  • Ensure educational *content is appropriate*:
    • C/w local practice and/or regionally published guidelines
    • Appropriate for educational levels/medical literacy of viewing patients/public
  • Ensure use of *local language* (e.g. dialect) and word choice is appropriate
  • **Co-Directorial** roles
    • What is filmed (& what is NOT filmed)
    • Video messaging
Video Educational Principles - III
- Resource, culturally diverse groups

- Filming *on-location*
  - Including local landmarks (e.g. scenery, monuments, buildings, etc)

- All people in the video are from the *local community(ies)*
  - Local health providers
  - Local / former patients (consenting)
    - Ideally with family members

- An emphasis on *Patient Testimonials*
  - Provides an opportunity for patients to:
    - “Tell their story”
    - Be heard
Selection of Video Education Topics - Tuberculosis

- Significant medical problem – both domestically and internationally
- Common misperceptions & misunderstandings about TB
- Negative community / public stigma about TB
- Opportunity to educate patients/family/community:
  - TB is very treatable and curable
  - Importance of following providers recommendations
  - Need to complete all the treatment
El Salvador Tuberculosis Education Video
El Salvador 2012
Spanish (English subtitles)
Selection of Video Education Topics
- HIV

• Significant medical problem – both domestically and internationally

• Common misperceptions & misunderstandings about HIV

• Negative community / public stigma about HIV

• Opportunity to educate patients/family/community:
  • TB is very *treatable and controllable* – to maintain a healthy life
  • Importance of following providers recommendations
  • Need to take you medications *every day*
El Salvador HIV Education Video
El Salvador 2014
Spanish (English subtitles)
Selection of Video Education Topics - Cholera

- Significant medical problem – Post earthquake Haiti; post-Hurricane Matthew Haiti
- Common misperceptions & misunderstandings about cholera
- Common public fear and negative stigma about cholera
- Opportunity to educate patients/family/community:
  - Cholera is preventable through simple steps
  - Cholera is very treatable and curable
  - Clean water is very important for your health
Cholera Education Video
Haiti – 2015
Haitian Creole (English subtitles)
El Salvador: Patient / Family / Community TB Education by Videography

Pilot Project: San Salvador central region

In partnership with:
• ES Ministry of Health
• ES Division of TB Mgmt
• Local TB clinics
Patient/Family Videography-based health education (TB, HIV)

Video content - covering basic points:
- What TB is (Gen information)
- How TB is spread and not spread
- How TB is diagnosed & treated
- TB is treatable, curable and preventable
Flow Process for Patient TB Video Viewing
- El Salvador
3-tiered assessment of the TB educational video impact

**Tier 1:** Patient impact and observed changes

- “Improved patient knowledge of TB”:
  - Better understanding of what TB is, how TB affects people and how TB is treated
  - Better patient acceptance of TB diagnosis
  - More patient interest in TB

- “Improved TB treatment adherence”
  - Typically linked to a greater understanding of TB and rationale for treatment

- “Better patient understanding for producing sputum samples (why sputum collection is important in diagnosis and treatment monitoring)
3-tiered assessment of the TB educational video impact

**Tier 2:** Family members, neighbor, community

- “Reduced fear and negative stigma of TB”
  - Including the procurement of greater community TB interest

- “Improved family support of TB patients”
  - Also including an improved family knowledge of TB

- “Facilitated contact investigations and helped to identify secondary active cases/contacts”
3-tiered assessment of the TB educational video impact

**Tier 3:** MOH TB health provider observations

- “Improved contact investigations by public health nurses”
- “Improved delivery of respiratory samples for AFB testing”
- “More time-efficient health provider evaluations and discussions with patients”
  - Less time spent on repeated explanations
Using what we have learned in El Salvador, Honduras and Haiti:

**Navajo Nation Tuberculosis Educational Video**

- Short 6-minute information video
- Filmed on location – Navajo Nation (Arizona, New Mexico, 2016)
  - Window Rock
  - Ft. Defiance
  - Tuba City
- Language: Navajo
- Film involves Navajo / local health providers & Navajo former TB patients
Navajo Nation (AZ, NM, UT)
Navajo TB Educational Content - The “What”

1. TB – General information
   • What TB is, how it’s spread
   • Signs and symptoms of TB

2. Diagnosis and Treatment of TB
   • Role of Health Dept., DOT, etc

3. Addressing misconceptions/misunderstandings of TB
   • Emphasizing that TB is very treatable & curable

4. Patient Testimonials (those who have been treated for TB)
Recognizing our Navajo neighbors
- The “How”

- **Building partnerships & trust**
- **Recognition and full respect** for a people, a culture, a rich tradition
- Integrating ‘westernized medicine’ with local healers, cultural beliefs, etc.
- Production and ownership of the video and educational program – *is with Navajo Nation*
  - Navajo TB health colleagues integral with:
    - Video script information content
    - Filming, locations, persons on film
    - Implementation of educational video to Navajo patients/families/communities
Navajo Nation Tuberculosis Education Video
Arizona/New Mexico, 2016
Navajo (English subtitles) & English
Questions & Discussion