

Education Materials Needed for Patients with Multidrug Resistant Tuberculosis

Marya Husary, BS, Lisa True, RN, MS, Leslie Henry, BSN, RN, PHN, Pennan Barry, MD, MPH
Tuberculosis Control Branch, California Department of Public Health



Background

- Patients with multidrug resistant tuberculosis (MDR TB) face many challenges including multiple side effects, prolonged treatment, and stigma
- An internet search for patient education materials (PEMs) and inquiries with TB health educators found limited materials on MDR TB designed for patients

Objectives

- Assess the availability and need for MDR-TB PEMs in California
- Identify major concerns patients express regarding treatment
- Identify challenges to communicating with patients
- Obtain input on topics of interest and preferred format of materials

Methods

- Survey of providers and public health staff in California who had treated at least one patient with MDR TB during January 2016 through December 2018
- Fifteen-question survey administered through REDCap
- Survey questions mix of multiple choice, check-all-that-apply, open text, and 3-point Likert scale matrices that addressed the objectives

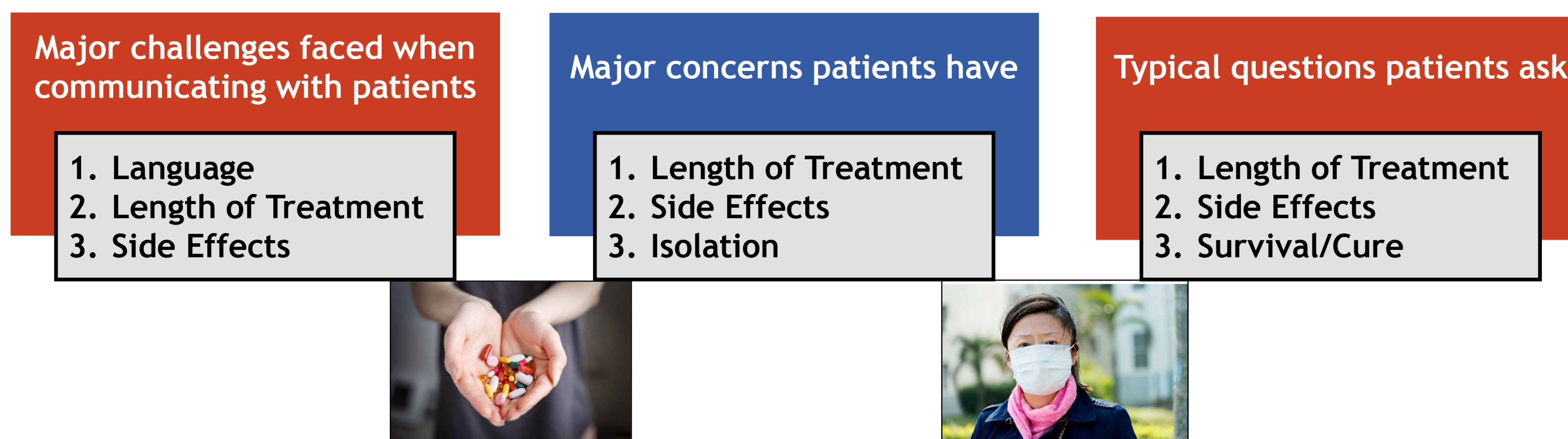
Results

- Of **166** potential participants in **25** health jurisdictions,
- **59 (36%)** responded
 - **22 (88%)** health jurisdictions
 - **37 (68%)** had treated 1-2 MDR-TB patients

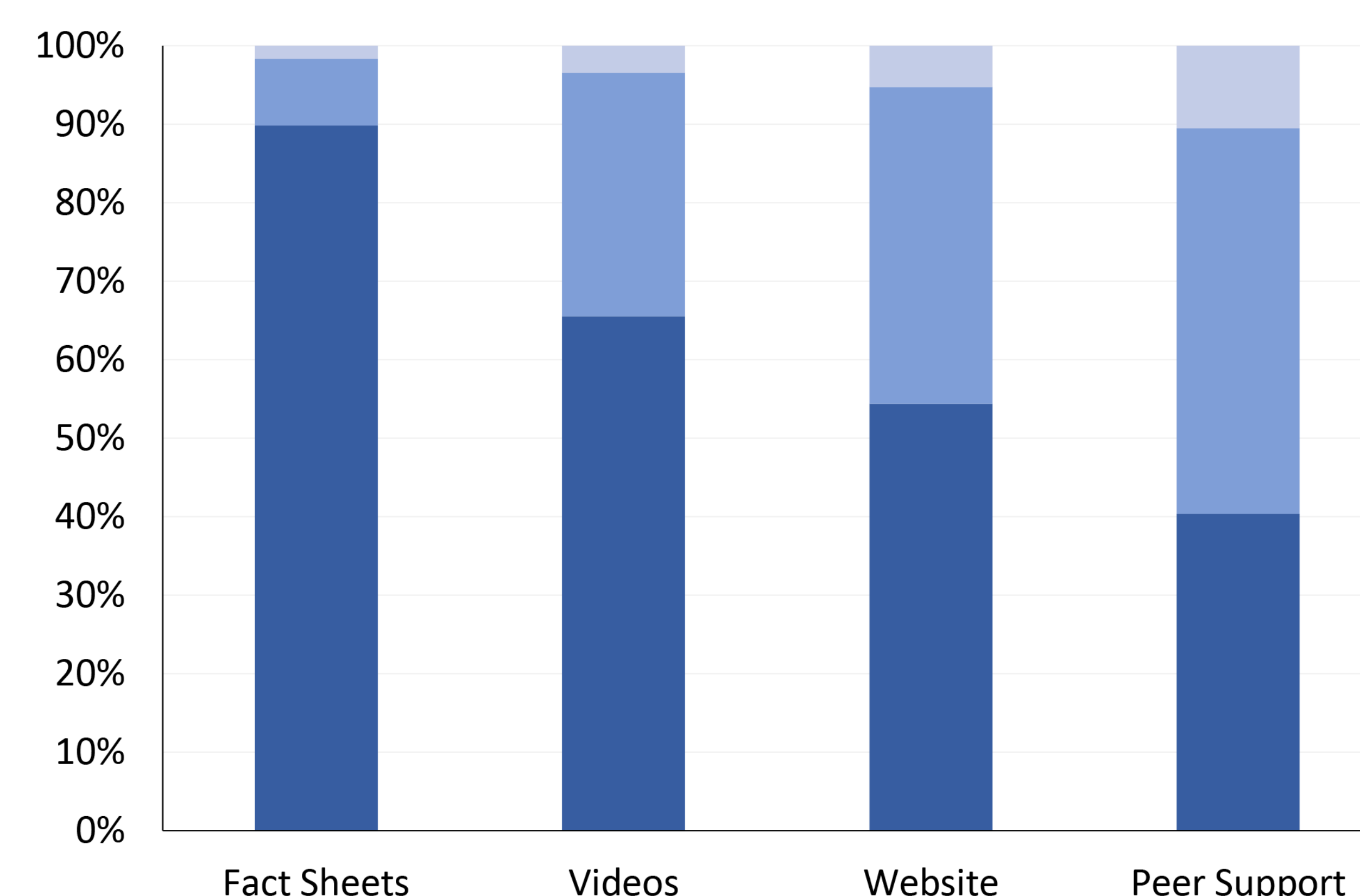
97% Say there is a need for MDR education materials

24% Report having education materials, but review shows that most were not developed for patients

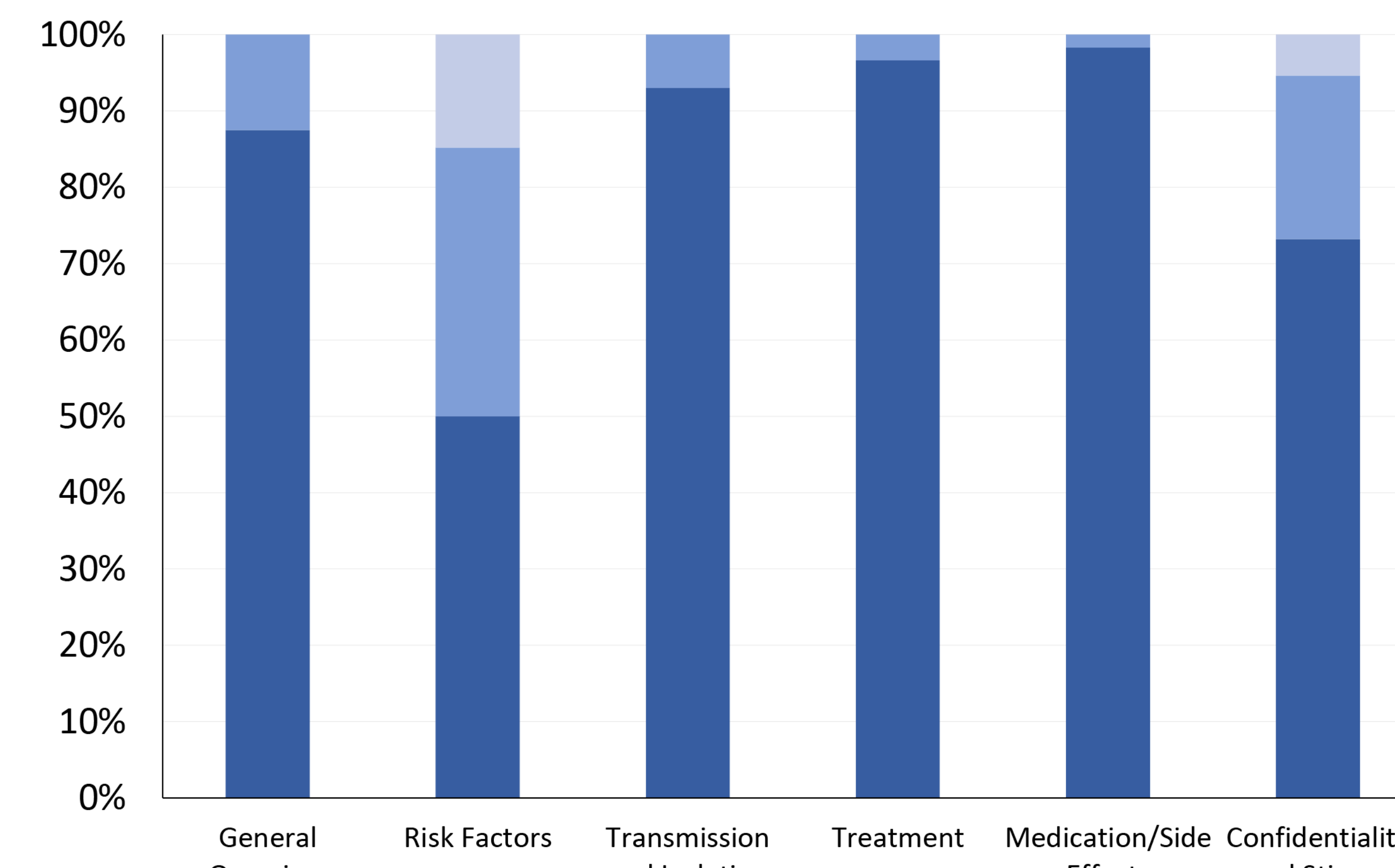
Top 3 challenges, concerns, and questions patients have about their MDR TB diagnosis and treatment



Type of education resources useful for patients



Topics of most interest to patients



■ Would be interested ■ Neutral ■ Not interested

Limitations

- No input from patients
- Most respondents treated few MDR patients

Conclusions

- There are limited MDR-TB education materials developed specifically for patients
- There is a need for patient education materials for MDR TB patients, as identified by providers and public health staff
- Materials developed should consider challenges and concerns identified and should be easily translated into other languages
- Input from patients on needed education materials should be sought

Responses

“I don’t think my patient understood the severity of MDR and was overwhelmed with the increase in medications.”

“It is difficult to fully explain potential side effects given the complexity of treatment regimens and numerous side effects.”

“Many patients experience a lot of side effects so they are more worr[ie]d about the medication and what they do to their body rather than the TB itself.”

Images from Getty Images <https://www.gettyimages.com/>