“I have Tourette Syndrome”

Disclosure & Tourette Syndrome

Presented By:
Michael Chichioco
(TAA Rising Leader & Youth Ambassador)
Introduction

• Diagnosed with Tourette Syndrome age 14 (onset of symptoms at age 5)
• 25 years old, Filipino-American
• First year medical student at UCSF (University of California San Francisco)
• BS in Biochemistry, minor in Psychology, Northeastern University (2020)
• TAA Youth Ambassador (2014), Rising Leader (2019)
• TAA NorCal-Hawaii Chapter Board Member
Agenda

1. Prevalence of Tourette Syndrome
2. Intersectionality, Your Story & Disclosure
3. My Story & Lessons Learned
4. Framework for Approaching Disclosure
1 out of every 160 children (0.6%) between the ages of 5 and 17 in the United States has Tourette Syndrome.

1 OF 50

Children between the ages of 5 and 14 have Tourette Syndrome or another persistent Tic Disorder.

An estimated 50% go undiagnosed.
Intersectionality & Your Story

There is no such thing as a single-issue struggle because we do not live single-issue lives.

Audre Lorde

• Interaction with other identities and life experiences
  • Racial
  • Ethnic
  • Sexual Orientation
  • Gender Identity
  • Socioeconomic Status

Tourette Syndrome is a part of you, but not the whole you.

There is so much more to your story!!
You will experience many situations where you feel pressured to disclose and talk about your diagnosis of Tourette Syndrome.

It is natural to want to think about others in this situations, and how you can help them understand…

But remember to think about yourself!

Authenticity, Needs, Timing, Safety
My Story: Learning to Self-Advocate

- Diagnosis
- Social Stigma
- Timing
- Self-Perception
- Experiences
- Family

What is important to me when disclosing?
My Story: Disclosing in Professional/Academic Environments

**School**
- Teachers
  - Beginning of Year
- Accommodations
- Extracurriculars: Sports, Theater

**Patient Care**
- Disclosing to Patients
- Disclosing to Colleagues
- Disclosing to Attendings/Supervisors

**Interviews**
- Mentioning during the interviews?
  - Positive & Negative Experiences
- Disclosing on the Resume?
My Story: Disclosing in Personal Relationships

Friendship

Romantic Relationships

Family
Disclosing in Public: You interact with so many people every day. This makes disclosing in these situations difficult & exhausting.

For me.. I think about how I’m feeling in that moment, prioritize my needs, emotions and safety in that situation.

This will change, can vary day to day & situation to situation, and that’s okay!
My Story: Lessons Learned

Whether you want to disclose or not is situation dependent
• Authenticity, Needs, Timing, Safety

I am in control of when I disclose and how much I want to share
• This isn’t easy to always do, but remember that you deserve the control over what you what, to whom you share, and when you share!

Your approach/feelings/emotions around disclosure can change over time, and that is okay!!
• What used to feel comfortable may become uncomfortable depending on where you are at in your life and the situation, that is okay and normal!!

Ultimately, the most important thing for me is staying true to myself and standing up for what I believe in
Framework for Thinking about Disclosure

- How are you feeling in the moment?
- Do you have support system available?
- How much do you want to share?
- What is your goal by sharing?
- Most importantly, remember to prioritize yourself and your needs!!
Q&A and Discussion Time!