Teaching and Learning Tourette’s: Development of a Standardized Patient Training Program

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Introduction

• Treatment of patients with Tourette’s Disorder (TD) can be improved by precise administration of rating scales.
• The Yale Global Tic Severity Scale (YGTSS) is a commonly used tool to assess symptoms of TD (Storch et al, 2005) focusing both on motor and phonic (verbal) tics.

In order to enhance the training for raters using the YGTSS in clinical trials, and hence increase inter-rater reliability and psychometric properties of the outcome, an applied training program that engages raters in participatory learning was developed. During an applied training session raters are asked to administer a YGTSS interview on a standardized patient (SP) under the supervision of an expert rater.

• To train actors to serve as SPs we devised an educational program that inverts the paradigm of traditional behavioral therapies through which patients are taught how to best manage symptoms of Tourette’s. Instead, we trained five professional actors to accurately portray symptoms of TD.

• By studying the development of this program, important knowledge can be gained for future development of behavioral therapies that typically convey teaching patients how to best manage symptoms of TD.

Methods

A training program for SPs was developed using a narrative analysis scheme (Labov, 1972) as follows:
1) Seven transcripts of YGTSS interviews were developed into thematic chapters including symptom frequency, intensity, complexity, interference and impairment;
2) Script/story analysis of transcribed interviews were conducted;
3) Linguistic markers (words or phrases indicative of symptoms and their severity) that effectively represent symptoms of TD were identified;
4) Symptoms were divided into two severity levels (mild and moderate), and two YGTSS interview scripts were built;
5) A workshop for five professional actors was conducted under the supervision of an expert YGTSS Interviewer.

Implementation

For each of the two scripts actors were provided with a general description of the case which is meant to give them general information about the patient they are portraying, as well as, an overview of patient’s symptomatology. Below is an example of one general description:

General description of the case:
Patient displays both simple and more complicated phonic tics, which occur in a flurry which is manifested in oralized sounds of both motor and phonic tics. Patient displays at least five movement tics, with at least one more complex motor tic involving lifting the arms half way up his chest and producing a sound in conjunction with the movement. In addition, patient displays occasional para-noises of tics, where a number of tics come together. Most of paragraphs are on the simple side but at times there are burst of tics in ten second to flurries. With sound tics, patient also displays several simple tics as well as several different complex tics. No displays include the, the repeating of sounds and words as well as physicality that strengthens a number of words and multiple repeating “Oh, oh, oh” or “Yes, yes, yes” enough times to make sure that he is saying the word right, where volume comes out abnormally.

The actor was provided with two scripts that describe dialogues between an interviewer and a patient. These scripts were divided into thematic chapters which match YGTSS interview guide. At the beginning of each thematic chapter, actors were given general information about severity of symptoms in a particular domain, as shown in examples below:

Intensity:
Motor – Mild – Patient’s motor tics are not as forceful as comparable voluntary actions and are not typically noticed by others. Tics are at least as forceful as comparable voluntary actions.
Phonic – Moderate – Patient’s vocal tics are far more complex than comparable voluntary actions (at home more than at school) and could call attention at home given the forcedness.

Interface:
Motor – Marked – Tic frequently disrupt a behavior ("water often"), as well as occasionally or sometimes disrupt action. He noted that he does things, and his tic interfere with videogames and school.
Phonic – Marked – Vocal tic “slow” lives down by interfering with speech. Child noted that it prevents him from saying what he wants when he wants it. Tic frequently interrupt speech but only occasionally disrupt action.

As a supplement to the YGTSS data provided by the patient, scripts included an appendix which describes parental response to the YGTSS interview:

YGTSS – Informant Data – Don’t’s Father
Don’t’s father reports that over the past week, his tic’s have varied according to context. When the patient is at school, his tic’s are usually quiet, most of the time. He’s not going to be overly stimulated or agitated to the point where his tic’s would be forceful. When he’s home and in his own little world and is engaged in the computer or Wii video games, his tic’s are extremely noticeable.

On occasions when he is overly stimulated, such as when he’s playing video games he can be seen moving a lot of hand tics, for example, with the controller he’ll flap it back and forth for no reason other than just flipping it back and forth. On such occasions he’ll have a lot of vocalizations: this is usually the same word “yes”. Frequently, he’ll change the way that he speaks by changing his voice. It’s almost like he is doing a funny voice or a cartoon voice but it’s not. Alternatively, he will repeat a dialogue throughout a movie or a show.

Ocasionally, the father noticed that the patient will raise his arms up and shrug and at the same time display a vocal tic.

In terms of self-esteem, his father notes that when he’s having a normally day, that’s when he really starts feeling sorry for himself, but on average he’s very confident kid. He doesn’t have any social issues with school and whenever he does come across an uncomfortable situation he shrugs it off rather confidently.

To implement the training program a training teleconference was organized which included one expert YGTSS rater, a clinical research team from ProPhase LLC Training Group, and five professional actors.

The training teleconference lasted two hours during which we discussed general etiology and presentation of symptomatology of TD, discursive practices of TD patients with different severity levels, as well as how to adjust the actors’ presentation of symptomatology for purposes of a telephone interview.

Actors were asked to perform specific parts of the interview, and were given feedback on their performance by the expert YGTSS rater.

Conclusion

Findings of this project indicate that:
1) narrative analysis can be successfully utilized to develop teaching tools for symptomatology of TD
2) rater training programs can be enhanced through participatory learning methods.

Review of literature suggests that this is the first attempt to develop a SP program for TD. By studying the development of this program – in addition to enhancing rater training – important knowledge can be gained for future development of behavioral therapies in TD.