The Stigma of Tourette’s Syndrome

DR MELINA MALLI
PROFESSOR RACHEL FORRESTER-JONES

UNIVERSITY OF KENT
UNIVERSITY OF BATH

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Outline of Presentation

- What is stigma?
- Why is studying stigma so important?
- Stigma and Tourette’s syndrome
- Our study on stigma of Tourette’s syndrome
What is Stigma?

- **Visible or invisible mark** that reduces the bearer from a whole and “usual” person to a tainted one (Goffman, 1963).

- The mark separates “us” from “them,” and people possessing it experience status loss and discrimination (Link & Phelan 2001).

- “Stigmatised individuals possess (or are believed to posses) some attribute, or characteristic, that conveys a social identity that is devalued in some particular social context” (Crocker et al., 1998).
### What is stigma?

<table>
<thead>
<tr>
<th>Components</th>
<th>Stigma</th>
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<tbody>
<tr>
<td>Cognitive- Stereotypes</td>
<td>Negative belief about a group. For example, all people with Tourette’s have coprolalia</td>
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<tr>
<td>Affective- Prejudice</td>
<td>Agreement with belief and/or negative emotional reaction. For example, anger and fear</td>
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<tr>
<td>Behavioural-Discrimination</td>
<td>Behavioural response to prejudice. For example avoiding hiring people with Tourette’s syndrome</td>
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Forms of stigma

- Stigma manifests at an interpersonal interaction (individualised stigma) micro-level stigma
- Stigma is applied by agencies, institutions, and laws inhibiting access to power and resources. It consequently constrains the opportunities, and wellbeing for stigmatised populations (Hatzenbeuhler & Link, 2014). Structural stigma can be intended or unintended. Macro-level stigma
- Self-stigma - Negative beliefs about the self, prejudice and discrimination towards self e.g., not pursuing employment or social activities
- Courtesy stigma - devalued through association with stigmatised person
Why is examining stigma important?

- Stigma is associated with diminished Quality of Life and negative effects on psychological well-being, self-esteem, self-perception, group-identification.

- We need to be exposed to the narratives of the marginalised.

- Interventions that aim to combat stigma should be based on what stigmatised individuals highlight as more deprecating and devaluing in the way they are viewed and treated by the society.
Tourette’s syndrome and stigma

- The study of stigma has been primarily attached to conditions such as mental illness or HIV

- Beside the hurdles, children and adolescents with TS endure because of the manifestation of tics, narrative testimonies of youth with TS provide extensive accounts of stigmatisation, harassment, bullying and teasing.

- Research on Tourette’s stigma focuses on general public attitudes and overlooks patients' subjective experiences of everyday stigma arising from significant others.

- Tourette’s syndrome may be susceptible to distinct types of negative attitudes that necessitates examining TS stigma individually.
Tourette’s syndrome and stigma

- There are no studies that delve into the first hand accounts of the experience of TS stigma.
- There is also a scarcity of knowledge pertaining to the extent, nature and impact of Tourette’s stigma and factors that influence the level of stigma.
- The coping mechanisms of people with TS
The overall **objective** of this study is to provide data regarding the stigma of Tourette’s syndrome, constructing a preliminary and in-depth picture of the impact it has on the lives of both adults and youths, which will inform current policy and practice.
Our study about the stigma of Tourette’s syndrome

1. Firstly, through an online questionnaire, to assess the prevalence estimates of stigmatisation amongst individuals with TS; and to measure the impact of Tourette’s stigma in an individual’s quality of life;

2. Secondly, through in-depth interviews to gain a comprehensive understanding of the everyday difficulties individuals experience as a result of stigma, We will also explore how individuals experience access to support.
Ethics and involvement of service users throughout the project

- The study was reviewed and given an ethically favourable opinion by the University of Kent Ethics Committee (November 2018).

- **Advisory Group was set up**

Consulted in how to best word the questions, Interview schedule, Study recruitment
 Discrimination and Stigma Scale (DISC-12) collects quantitative data to provide a rating of the degree to which discrimination has been experienced in various areas of life including work, relationships, parenting, housing, leisure, and religious activities using a 4-point Likert scale (Brohan et al., 2013).

1. Have you been treated unfairly in making or keeping friends?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td></td>
<td></td>
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</table>
Quality of life using Perceived Quality of Life Scale (Patrick et al., 2000).

How dissatisfied or satisfied are you with:

S \textbf{8}. How often you see or talk to your family and friends?

\begin{itemize}
\item Extremely dissatisfied
\item 0
\item 1
\item 2
\item 3
\item 4
\item 5
\item 6
\item 7
\item 8
\item 9
\item 10
\item Extremely satisfied
\end{itemize}
In-depth Interviews

- The interview schedule was designed by the advisory group.
- Interpretative Phenomenological Analysis will allow us to understand the subjective lived experiences of the participants.
Data so far...

- 136 individuals have taken part in the online questionnaire (110 adults, 10 children, 16 adolescents)
- 3 children have taken part in the one-to-one interview
- 13 adults with Tourette’s syndrome have taken part in the one-to-one interview