The Tourette OCD Alberta Network: Development of an Online Parental Peer Discussion Group

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**Background**

- Peer support is a pathway to increased knowledge and well-being through empathetic discussion.

- Peer support for parents affected by Tourette syndrome is acutely limited in a province as geographically vast as Alberta, Canada.

- Previous research foregrounded the desire and need for parents to share their lived experience with other parents.

**Method**

- In 2021, families were invited throughout Alberta to participate in virtual psychologist peer support groups for parents of children with TS.

- 26 families participated in two groups: 15 in the first group and 11 in the second.

- Parents and families proposed topics and issues for discussion.

- A discussion agenda was devised, covering a range of TS topics, comorbidities, and associated issues.

- Two peer support groups took place in blocks of 5 weeks, meeting online in the evening for 1.5 hours discussion once a week.

**Weekly Discussion Agenda**

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<thead>
<tr>
<th>Week</th>
<th>Topic</th>
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<tbody>
<tr>
<td>1</td>
<td>Relationship challenges and family dynamics</td>
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<tr>
<td>2</td>
<td>Emotion regulation, anxiety, rigidity, &amp; perfectionism</td>
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<td>3</td>
<td>Coping – for parents and for the children</td>
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<tr>
<td>4</td>
<td>Building confidence and self-efficacy to combat stigma associated with tics</td>
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<tr>
<td>5</td>
<td>ADHD, frustration, boredom tolerance, managing schoolwork and behavioral expectations</td>
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- Alberta, Canada is 660,000 sq kilometers. The discussion group took place between families in four main cities of Alberta: Calgary, Edmonton, Red Deer and Fort MacMurray.

**Results**

**1 Parental input in proposing topics**

- Parents are stakeholders in the discussion, emphasizing the value of their contribution. They are setting the agenda.

- Psychologist discussion groups models how lived experience is shared and valued: it is participatory.

**2 Post-presentation parent interviews**

**Theme 1: Psycho-social benefits of sharing lived experience**

- Parents are not alone.

- Contextualizes TS diagnosis – “what does moderate tics” mean?

- Comparing is healing and connection.

- Normalization of familial experience.

- Benefits of discussing practical application of strategies week to week

- Enables opportunity for family conversations about child’s issues.

**Theme 2: Limitations of online group**

- Timidity of some parents makes for difficulty in participating, resulting in some participants dropping out.

- Scope of discussion was too broad. Some topics required more attention and time.

- Late scheduling of discussion group was inconvenient.

**Theme 3: Role of the psychologist**

- Importance of psychologist in validating familial experiences.

- Ability of psychologist to impartially create open forum for discussion in which parents feel comfortable is vital.

- Psychologist ability to connect with parents without judgement on them.

- “I'm not alone, this isn't our own journey, there's lots of other people that are going through a similar journey and that was really comforting for me.”

- “I think mostly it was kind of normalizing that we're kind of doing it the same as everybody else and that felt good.”

- “I hate to be relativist about this but in some ways it just makes me think, okay, things aren't as off the rail as maybe I think they are.”

- “She's allowed to feel her feelings and it just opened up for great conversations between all of us.”

- “When there's so many people...and it's online, it's really hard for everybody to get an opportunity to speak because then we're also limited to time.”

- “People have the option to turn off their camera, you know, but if it was face to face sitting in a circle as a group thing, you wouldn't have that option, right and that eventually you would probably feel compelled to say something.”

- “She didn't try to 'should' us, like you should do this or you should do that, she was wonderful and just explored our answers and our questions.”

**Conclusions**

- Peer group discussion is a vital component in ensuring parents living in geographically large areas connect with other parents, increase their knowledge, and improve family well being.

- The online format is limiting in terms of the extent some parents feel uncomfortable in a relatively large virtual discussion group.

- More time discussing singular aspects/issues of TS and not comorbidities could bring greater depth to parents’ knowledge.

- The role of the psychologist moderating the discussion is vital in facilitating the conversation through their expertise and encouraging parents to share and explore their own experiences in a group setting.