Experience of stigma and its relationship to identification with the neurodiversity model for Indian parents of children with autism spectrum disorder

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Introduction

- ASD has been viewed extensively within the medical model, which aims to prevent and cure the condition and eliminate the deficits/impairments it gives rise to (Kapp et al., 2013).
- The social model of disability challenges the medical model (Jaarsma & Welin, 2011), pushing society to change in a way that reduces barriers for individuals with ASD.
  - The neurodiversity model adopts the social model of disability and proposes that ASD is a natural variation of human behavior that should be celebrated (Jaarsma & Welin, 2011).
- Currently, families of children with ASD face widespread stigma, including shame and social exclusion (Farrugia, 2009).
- Much of the stigma originates from misconceptions about a child’s autism-related behaviors as well as ASD’s etiology (Kinnear et al., 2015).
- Stigma leaves parents feeling blamed for their child’s behavior (Neely-Barnes et al., 2011), isolated from society (Woodgate et al., 2008), and in general, distressed (Green, 2003).
- The neurodiversity paradigm has the potential to lessen the stigma associated with ASD and allow parents to shift their focus to their child’s strengths and needs.
- Stigma associated with ASD is especially prevalent in India where there is a large emphasis on conformity to social norms (Juneja & Sainam, 2018).
- It is essential to investigate how such cultural values/beliefs evolve in different countries as well as how they change the way in which parents relate to their children with ASD.

Method

- Anonymous cross-sectional survey through online platform Qualtrics
  - Includes validated measures from previous studies, such as the Parental Stress Scale (Berry & Jones, 1995), as well as constructed scales, such as the neurodiversity alignment measure
  - Three open-ended questions regarding parental goals and child strengths also collected
  - Offered in English, Hindi, Tamil
- Participants: parents of Indian origin residing in India with children aged 17 or younger diagnosed with ASD (N=82; full data n=56)
- Recruitment: public advertisements at autism or younger diagnosed with ASD (N=82; full data n=56)
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Demographic Descriptive Statistics

<table>
<thead>
<tr>
<th>Sample Characteristics</th>
<th>n</th>
<th>Mean ± SD</th>
<th>% of Total Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>82</td>
<td>38.1 ± 6.06</td>
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</tr>
<tr>
<td>Annual household gross income (INR)</td>
<td>68</td>
<td>309014.71 ± 610153.22</td>
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<tr>
<td>% of Total Sample</td>
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<tr>
<td>Relationship to child</td>
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<td></td>
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<tr>
<td>Mother</td>
<td>66</td>
<td>81.48</td>
<td></td>
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<tr>
<td>Father</td>
<td>13</td>
<td>16.05</td>
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</tr>
<tr>
<td>Guardian</td>
<td>2</td>
<td>2.47</td>
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<td>Highest level of education</td>
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<tr>
<td>Less than secondary</td>
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<td>21.52</td>
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<tr>
<td>Completion of secondary/diploma</td>
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<td>College graduates</td>
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<td>Marital Status</td>
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<tr>
<td>No religion</td>
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<td>5.00</td>
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</tr>
</tbody>
</table>

Note: Sample size varies for each variable

Results

Fig. 1. Preliminary bivariate correlational analysis results with selected variables

- Perceived ASD Stigma
- Child’s Autism-Related Behaviors
- Parental Stress

Fig. 2. Mediation analysis with perceived ASD stigma, neurodiversity alignment, and parental stress measures

- Neurodiversity Alignment
- Isolation from Family and Friends

- Perceived ASD Stigma
- Parental Stress

Fig. 3. Raw regression coefficients for associations between variables were determined at a significance level of p< .05 with SPSS software. Significant coefficients are displayed in the figure with an asterisk. Standard errors of the coefficients are displayed in parentheses. The Sobel test was used to test whether a mediator carries the influence of the independent variable to the dependent variable, and mediation results were not significant at p< .05.

Discussion

- Perceived stigma from ASD-related behaviors can compel parents to isolate from family and friends to avoid possible rejection or exclusion.
- While perceived ASD stigma predicts parental stress, a child’s autism behaviors do not.
- Results of mediation analysis with perceived ASD stigma, neurodiversity alignment, and parental stress measures support hypothesis.
  - Demonstrate that social surroundings may have to be conducive to adopting a strength-based approach.
  - Results also support literature findings that neurodiversity paradigm is a positive and meaningful way to approach ASD (Kapp et al., 2013; Soukup, 2018), which has implications for reducing parental stress.
- Results of mediation analysis with perceived ASD stigma, neurodiversity alignment, and isolation measures do not support hypothesis.
- Child’s autism-related behaviors could act as a moderator variable on the relationship between neurodiversity alignment and isolation.
- Alternatively, although aligning with the neurodiversity model allows parents to view their children positively, they may still want to isolate from family and friends due to societal stigma associated with ASD-related behaviors.

Next Steps

- Conduct more complex mediation analyses incorporating the neurodiversity alignment variable.
- Does child's autism-related behaviors act as a moderator in the mediation models examined?
- How does culture specifically play a role: focus on mediation model incorporating adherence to Asian values and neurodiversity alignment.
- Investigate the impact of demographic characteristics on the relationships in the hypothesized model.
- Qualitatively analyze responses to the three open-ended questions by conducting a thematic analysis (e.g. what are your child’s strengths?)

Reference