Introduction

Prior literature has documented parental experiences with their child’s autism diagnosis. However, studies that address how parents disclose the diagnosis to their children are scarce. Previous empirical research has identified benefits of early disclosure for other conditions and anecdotal research has suggested similar benefits may be evident for autistic people but no prior study has evaluated if earlier disclosure of a child's autism to the child is associated with better outcomes. A recurring theme observed from these studies on disclosure was their emphasis on early disclosure of child’s condition to the child and its potential advantages.

The purpose of this study is to examine how parental decisions to disclose their child’s autism diagnosis influence the child’s wellbeing and quality of life as adults.

Hypothesis

- Children who were told about their autism diagnosis at an early age will have greater wellbeing and higher quality of life as adults than children who were told later in development.

Methods

- Participants: Participants in this study were autistic college students (n=85, M(age)=23.88, 50.6% male, 67.1% White, 72.9% undergraduates who represented 48 institutions and 8 countries including the United States and the United Kingdom) who all participated in an online survey. Prior to the study, participants completed an IRB approved consent form. Participants received a $20 gift card as a compensation for participating.

- Material: A participatory research method (e.g., a collaboration with autistic scholars) was used to develop the online study from which my data was extracted. Open-ended questions such as, “How old were you in years when you first learned you were autistic?”, “If your parents told you about autism, what did they tell you?”, “How do you feel about autism now?”, “If you had a child with autism, when would you tell them about autism?”, and “If you had a child with autism, what would you tell them about autism?” were presented to the participants.

- Data analysis: A qualitative analysis method was used to analyze participants’ responses to each research question, identify similar themes, and summarize each finding. Coding schemes were developed with an autistic collaborator and inter-rater reliability was 87% or higher for all codes on 20% of the data.

Results

Consistent with our hypothesis, participants who learned that they were autistic at an earlier age were discovered to have significantly greater wellbeing: r(75) = -0.419, p < 0.001 and a higher quality of life; r(75) = 0.232 = p = 0.043 than those who were told later.

When participants were asked what age they would tell their own children about autism, a majority (71.25%) of the participants did not specify a particular age, as shown in Table 1. Participants gave factors that would influence their decisions to disclose autism to their children. Some of these factors included the severity of the child’s autism, the ability to comprehend diagnosis and many also said as soon as the child is diagnosed.

Discussion

From this study, it was observed that age of disclosure is a determinant for wellbeing and quality of life for autistic people.

It was also discovered that age isn’t the only factor that should be considered when disclosing autism to a child, but also the level at which a child is in their development, including their comprehension of themselves and the world around them. Further analysis and interpretation of results from this study are still been carried out to deduce additional findings concerning autism and its different facets.

Limitations of this study were its complete reliance on retrospective self-report which is subjective.

The key recommendation from this study is that parents should explain their autistic child’s diagnosis to them in a way that the child can understand soon after diagnosis.

Table 1: If You Had a Child With Autism, When Would You Tell Them about Autism?

<table>
<thead>
<tr>
<th>Did not specify an age</th>
<th>71.25%</th>
</tr>
</thead>
<tbody>
<tr>
<td>to disclose</td>
<td></td>
</tr>
<tr>
<td>Birth to 2</td>
<td>5%</td>
</tr>
<tr>
<td>Before school starts</td>
<td>5%</td>
</tr>
<tr>
<td>3 to 8</td>
<td>15%</td>
</tr>
<tr>
<td>9 to 11</td>
<td>5%</td>
</tr>
<tr>
<td>12 to 18</td>
<td>3.75%</td>
</tr>
<tr>
<td>Adult</td>
<td>0%</td>
</tr>
</tbody>
</table>

References