“We will never be normal”: The Lived Experience of Discovering a Partner has Autism Spectrum Disorder

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Autism Spectrum Disorder: Background

• Diagnostic and Statistical Manual of Mental Disorders (DSM-5):

  • “Persistent deficits in social communication and social interaction”
  
  • “Restricted, repetitive patterns of behavior, interests, or activities”
Autism Spectrum Disorder: Background

• Affects 1 in 100 adults\textsuperscript{1-2}

• Approximately 46% of individuals with ASD have average/above average intelligence\textsuperscript{2}

• For every 3 known cases of ASD, there are 2 unknown cases of ASD\textsuperscript{3}

• Nearly half of those with ASD and no intellectual disability enter into long-term relationships\textsuperscript{4-5}
Methodology

• What is the essence of the experience of realizing that a partner has ASD?
• Descriptive Phenomenology
• Colaizzi’s Method
• Online recruitment & data collection

“Please describe your experience of discovering that your partner had Autism Spectrum Disorder. Please share any thoughts, feelings, and specific experiences.”
Data Analysis: Colaizzi’s Method

1. Read all protocols (or interviews)
2. Extract significant statements from each protocol
3. Formulate meanings from each significant statement
4. Sort formulated meanings into theme clusters
5. Integrate theme clusters into exhaustive description of the phenomenon
6. Describe the fundamental structure of the phenomenon
7. Ask participants to review & provide feedback
Sample

Sample size: 43 participants

Sex:
- 95% female

Relationship status:
- 72% married, living together
- 16% not married, living together
- 10% married, separated
- 2% not married, not living together

Children:
- 93% have children

Diagnosis method:
- 36% formal evaluation
- 24% informal evaluation
- 22% self diagnosed
- 18% suggestion of provider based on participant’s description of partner

Countries represented:
- Australia
- Canada
- Netherlands
- Thailand
- UK
- USA
Theme 1:
“Something wasn’t right”: Issues crept in

“We always knew something wasn’t right.”

“I had been married for 21 years to a man I couldn’t figure out.”

“I had always thought that he was just quirky, and sometimes I thought he was a horrible person and I should leave him.”
Theme 2:
“Making the link”: Insisting on a diagnosis

“I was in shock and tears as I read what seemed to explain my life in words on almost every page.”

“Our marriage was at breaking point.”

“I forced him to choose between a lawyer or a therapist’s visit.”
Theme 3:
“I wasn’t crazy”: Initial relief and validation

“The validation was huge. I wasn’t crazy. I had not been imagining things. This was real!”

“We were both relieved and shocked all at the same time.”

“My first reaction to the therapist suggesting it was overwhelming relief. He wasn’t just an ass because he chose to be one!”
Theme 4:
“We will never be normal”: Disappointment and grief

“The diagnosis made me realize that I had endured quite a bit of trauma, during many years.”

“The hardest thing is knowing he cannot change.”

Fear of the future
Theme 5: “Changing my mindset”: Making compromises & accommodations

“The ‘label’ helps me more than it does him. It gives me an explanation and something I can work with. I focus on delivering information he can process, not being emotional and avoiding external stresses on him by taking care of financial and domestic matters.”
Theme 6:
“I can’t do it alone”: Desperate for help

“I want you to know how important it is that you are doing this study. Thank you for seeing this need. This is SO important, and we partners of AS people need to be heard and have our experiences understood. We often feel so isolated and misunderstood.”
Implications of Findings

Affective Deprivation Disorder (AfDD) or “Cassandra syndrome”

Education to both partners
- Mutual understanding
- Effective communication strategies
- Healthy expectations and boundaries
Thank You

To Patricia Prelock, Ph.D., CCC-SLP

To the men and women who shared their intimate stories with me
Questions?
Sources

## Putting the Pieces Together

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