In their own words: The experiences of students with high-functioning autism/Asperger's disorder attending college or university

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(Nirmal, 2015)

Scope of the Lecture

- Brief Review of the Literature
- Factors related to Postsecondary Functioning for students with ASD
- Research Study- Results
- Future Directions
- Questions

*pseudonyms are used in this presentation to protect the anonymity and confidentiality of the research participants

(Nirmal, 2015)

Background Information

- Autism Spectrum Disorder (ASD) is a neurodevelopmental disability

- Increase in diagnosis (1 in 68 children)

- More children are being identified with ASD without significant cognitive impairment (High-Functioning Autism; HFA)

(APA, 2013, Brugha et al., 2011; CDC, 2014; Honda, Shimizu, Imai, & Nitto, 2005, Howlin, Goode, Hutton, & Rutter, 2004)

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Background Information

- Increase in enrollment of students with HFA in postsecondary education

- Aspirations of attending college or university

- Poor postsecondary educational outcomes

(e.g., Camarena & Sarigiani, 2009; Fombonne, 2005; Hurewitz & Berger, 2008; Nevill & White, 2011; Shattuck et al., 2012; VanBergeijk et al., 2008)

(Nirmal, 2015)

Postsecondary Aspirations

- Camarena & Sarigiani (2009)
  - Investigated postsecondary aspirations
  - 21 adolescents (ages 12-18) with HFA and their parents
  - All viewed attending college as an "important aspiration"
  - Confident that they would "actually" attend
  - 57% of the adolescents expressed pursuing a 4-year degree

(Nirmal, 2015)

Postsecondary Outcomes

- Shattuck et al. (2012)
  - US Dept. of Education National Longitudinal Transition Study- 2
  - 34.7% of youth with ASD attended college (n = 680)
  - Lowest participation rate compared to students with specific learning disorder (SLD) and speech/language impairment (SLI)
  - Youth with ASD at high risk for no enrollment

- Wei et al. (2012)
  - Less likely to enroll compared to students with SLD, SLI, hearing or vision impairment, orthopedic impairments, other health impairment, traumatic brain injury

- Drop-out soon after entry (e.g., Glennon, 2001; VanBergeijk, Klin, & Volkmar, 2008)

(Nirmal, 2015)

Factors affecting Postsecondary Functioning for Young Adults with HFA

- Social Interaction and Communication
  - Romantic relationships
- Restricted and Repetitive Behaviours
  - Sensory dysregulation
- Adaptive Behaviour Functioning
  - Independent daily living skills
  - Often not commensurate with cognitive functioning

(Nirmal, 2015)

Factors affecting Postsecondary Functioning for Young Adults with HFA

- Academic Functioning
  - Executive functioning
  - Educational accommodations
  - Disability documentation
- Self-Advocacy Skills
- Psychiatric Comorbidity
  - Anxiety and depressive disorders
  - Occurs in up to 65% of adults with HFA

(Nirmal, 2015)

Significance/Need for Research

- There is a paucity of research in the area of students with HFA in postsecondary education

- Understanding the experiences of these students may provide valuable insight into their functioning in this context

- Needed to support effective transition and postsecondary programming

(e.g., Camerana & Sarigiani, 2009; Fombonne, 2012; Gelbar et al., 2014; Howlin & Moss, 2012; Welkowitz & Baker, 2005)

(Nirmal, 2015)

Research Question

What is the meaning of the lived experiences for students with high-functioning autism or Asperger's Disorder attending college or university?

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Research Method

- Interpretive Phenomenological Analysis (IPA)

  - Examines the meaning of personal and social experiences

  - Participants are viewed as experts

  - The researcher plays an active role in interpretation

(Smith, Flowers, & Larkin, 2009)

(Nirmal, 2015)

Participants

- 12 students diagnosed with either HFA or Asperger's Disorder (9 males, 3 females)
- All participants were enrolled in either college or university
- Undergraduate students (years 1-3) and one graduate student
- Age range 18-28

(Nirmal, 2015)

Procedures

- Recruitment
  - Postsecondary disability offices
  - Community agencies
  - Autism Community Training-BC and SFU's Autism and Developmental Disorders Lab
- Telephone Screening Interview
- Informed Consent
- Background Information Form

(Nirmal, 2015)

Procedures

- Data Collection
  - In-depth semi-structured interviews
    - Mean length = 75 minutes

  - Follow-up Interview
    - Ranged from 30-45 minutes
    - Member checking process

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Procedures

- Smith, Flowers, & Larkin (2009) IPA Data Analysis

  – Transcripts were analyzed case-by-case, starting with the first interview

  – Systematic, iterative, and interpretive

  – Shared experiences across participants

  – Researcher takes an active role in interpretation

  – Each analyzed transcript informed the analysis of subsequent transcripts

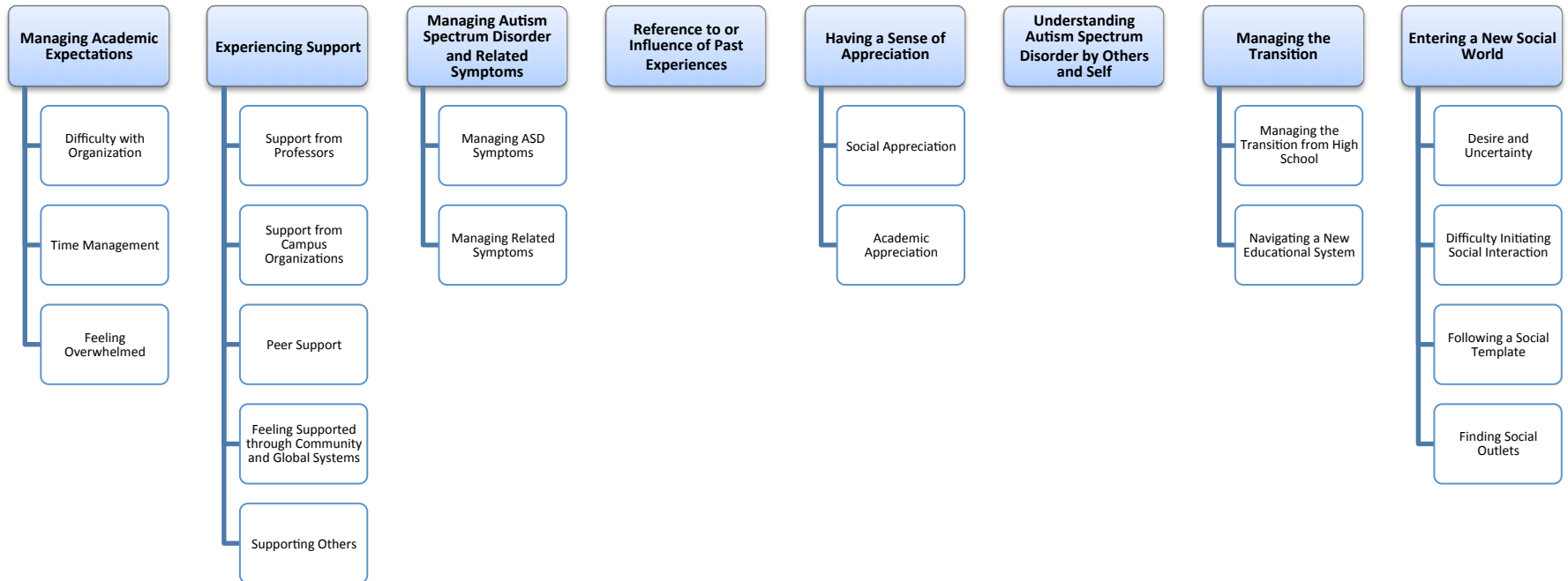(Nirmal, 2015)

Procedures

Analysis of Transcripts

- Macro-analysis (global analysis)
- Micro-analysis (coding of meaning units)
- Visual representations of the data (graphic organizers and charting)
- Emerging broad themes and subthemes

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Procedures

- Ensuring Scientific Rigour and Credibility of the Research Findings

  – Researcher Reflexivity

  – Peer Reviewer

  – Member Checking

  – Thick and Rich Description

  – External Auditor

(Creswell, 2009)

(Nirmal, 2015)

Research Findings:
Broad Themes and Subthemes

Managing Academic Expectations
- Difficulty with Organization
- Time Management
- Feeling Overwhelmed

Experiencing Support
- Support from Professors
- Support from Campus Organizations
- Peer Support
- Feeling Supported through Community and Global Systems
- Supporting Others

Managing Autism Spectrum Disorder and Related Symptoms
- Managing ASD Symptoms
- Managing Related Symptoms

Reference to or Influence of Past Experiences

Having a Sense of Appreciation
- Social Appreciation
- Academic Appreciation

Understanding Autism Spectrum Disorder by Others and Self

Managing the Transition
- Managing the Transition from High School
- Navigating a New Educational System

Entering a New Social World
- Desire and Uncertainty
- Difficulty Initiating Social Interaction
- Following a Social Template
- Finding Social Outlets

(Nirmal, 2015)

Theme 1: Managing Academic Expectations

- Difficulty with Organization
- Time Management
- Feeling Overwhelmed

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"Getting assignments in on time is very difficult for me. Being an Aspie, *losing things, being messy, professionally messy. Missing a lot deadlines.* Like my creative writing professor had to give me extensions on some of the assignments because I kept on missing them. This is when I was depressed, but at the same time I was still...double booking appointments..."

(Nirmal, 2015)

"I'll procrastinate and...you know, lose the course outline and then I'll find the course outline and I'll be like to the disability office...this test is this time and that doesn't work for me... and it's like: Oh, well if you had a problem you should have talked to us like a month ago..." And I was like: I didn't know a month ago because I didn't look on the sheet...*it is a failing on my part, but it's stuff that I'm not very good at.*"

(Nirmal, 2015)

"*I think that people who have executive dysfunction should be able to have a different thing...like there's just so many steps...*it's really complicated and really exhausting and sometimes I don't get my exam accommodation *because it's too much work...I'm like: I can't handle it.*"

(Nirmal, 2015)

"I only did, out of four I only did, I only completed one."

"When I first came here [to college], I took two hard courses and I dropped the first one pretty fast."

"...when you have many different courses, it's very easy to get more and more anxious...[taking five courses] was the worst decision I made this year..."

Theme 2: Experiencing Support

- Support from Professors
- Support from Campus Organizations
- Peer Support
- Feeling Supported through Community and Global Systems
- Supporting Others

(Nirmal, 2015)

"I shut down a little bit...I felt anxiety build up and anger and fear. I was reluctant to ask for help, as usually am. But the time I started saying: I don't know what to do- 'help,' they [professors] didn't know what to do either; they didn't have the support for helping someone like me."

"Some of them [professors] are actually very quite positive. Um for example…my anthropology teacher, when I was in a state of depression I came to him and I told him about my experiences and I told him about my Asperger's and he was very jovial about it."

"…last term, my web development instructor was really helpful…for my mid-term or for my final, he actually came in to check on me [at disability services]…to see how I was doing."

"Well, you've had an extension, not allowed to be stressed."

"At university it's different, they're still great... I've been really grateful to have them but it's a totally different system...more staff members with a way higher workload. So, in order to talk to somebody or get some help...you often need to be prepared like weeks in advance...like the stuff I need to do in order to get exam accommodations is really complicated and so many steps that it's just almost not worth it..."

(Nirmal, 2015)

"I'm able to connect with people online because there's no barrier...it takes out my limitations, I can talk with them forever but at the same time you're missing something...people want that physical thing and you don't get that online. But still...I can go to someone online and say: Help me please, I'm suffering. And they'll say: Ok I'll help you, I'll be here for you. And they can listen to you cry and all that."

(Nirmal, 2015)

Theme 3: Managing Autism Spectrum Disorder and Related Symptoms

- Managing ASD Symptoms

- Managing Related Symptoms

(Nirmal, 2015)

"*I was making little gains in both academic and in personal development, and having terrible mood swings all the while. And it got to the point this year where I was going:* I don't deserve to go through life hating myself and wanting to die. I don't deserve to put myself through agony in order to try and reach my goals. *I don't deserve the pain I put myself through and how hard I am on myself…which is sort of why I'm taking a break [from school]."*

(Nirmal, 2015)

"*...as an Aspie, I have a very sensitive noise, I smell things very easily and I hear things very sharply* so partying may not be the best choice but that's where you meet people..."

"*...when I smell things it's like magnified.* I can trace things back to their source with their smell sometimes...like people would always smoke below the building floor [in dorms] and I would smell it in my room and I would go like: Ugh, oh man! And when I smell cigar-students who've just finished smoking...in class I go like: ahhh quite overwhelming."

(Nirmal, 2015)

Theme 4: Reference to or Influence of Past Experiences

- Previous experiences in elementary or secondary school

- Challenges with socialization, academic functioning, and managing comorbid symptoms

- Experiences that have shaped current experiences, both positively and negatively

(Nirmal, 2015)

"I've kind of been fighting my own demons throughout middle school and early high school. It wasn't until around my grade eleven year that I really came out of my shell and started making friends, and it's a battle. I'm basically fighting my inner demons at all times, trying to work socially... it's learned...just not something I was good at as a kid even. And so to be able to make friends and get to know people is something I've had to learn myself at a different rate than everybody else."

(Nirmal, 2015)

Theme 5: Having a Sense of Appreciation

- Social Appreciation

- Academic Appreciation

"I feel more comfortable talking to people around here than I did in high school...I prefer people here because there's a sense of maturity I didn't see in high school. And the people here want to be here...where in high school you go to high school because you have to go to high school and so a lot of people there are just unbearable."

(Nirmal, 2015)

"...everyone treats you differently [in college], they treat you more like an adult now...less condescending I would say....they don't really try to baby you...like in high school where they kind of treat you as if you're below them..."

Theme 6: Understanding Autism Spectrum Disorder by Others and Self

"I get anxious...I am bad socially...a lot of people don't understand...because I'm articulate, people think that I should be fine socially and there's nothing outwardly wrong with me. I get treated as if I should know what I've done wrong instead of: No, I actually have no idea what I did wrong."

(Nirmal, 2015)

"I seem very high functioning and for a lot of people I don't seem like an Aspie. So one of the problems with being well adapted is: upside you don't have a lot of problems; downside, nobody recognizes it as easily and it may be a bit hard to convince some people that you made need the help."

(Nirmal, 2015)

"...I guess it's the imposter syndrome. You're so good at mimicking other people...that you feel like: well maybe I don't have Asperger's, maybe all the tests are wrong and maybe I don't have this condition where I need special accommodations because...*some part of me feels like all these other people, I can relate to them*."

(Nirmal, 2015)

Theme 7: Managing the Transition

- Managing the Transition from High School
- Navigating a New Educational System

"I felt like going to college would be a better step up for me than just going straight to university…I felt more comfortable going through more one-on-one stuff where you better know your instructors… so smaller class sizes makes it feel a bit more…is a better step up from high school…"

(Nirmal, 2015)

"Realizing that this one dude [disability advisor] has like two hundred students or so in his case file. And realizing that it wasn't going to be like high school, I wasn't going to be assigned a teaching assistant. I wasn't going to have someone I could confide in and who could give the lesson back to me one-on-one."

(Nirmal, 2015)

"One thing I regretted when I first came here that I didn't get to know disability services a little sooner, like, after I registered, I got to know them. And...it turns out I had an outdated psychoeducational assessment that was from 2007. But they were still willing to give me basic accommodations."

(Nirmal, 2015)

Theme 8: Entering a New Social World

- Desire and Uncertainty
- Difficulty Initiating Social Interaction
- Following a Social Template
- Finding Social Outlets

"It's one of those sorts of things where you almost just poke, poke, poke: did you get a good reaction? Did you get no reaction? And if you're shy, no reaction means: Oh, they don't like me, I'll just go over here."

(Nirmal, 2015)

"Aspies learn about people, learn how to socialize instead of just having it...often when I'm talking to people...I ask myself, what are they expecting? What am I expecting? What's the best thing for this...what's the best thing to say to get this reaction? So, it's very, almost a mathematical way to socialize."

(Nirmal, 2015)

"I didn't relate, I didn't get to choose who I roomed with. Two guys were brothers, golfers from Nova Scotia, majoring in Business and Economics, respectively...*we might as well have been from different planets.* The only thing we had in common was that one guy really liked Gladiator [the movie]."

(Nirmal, 2015)

"If there was like some kind of a club or something, you know...an easier way to meet people. At least where people would have some kind of shared common ground. That makes it easier because then...[I] can have a conversation about such and such and I can branch into other things"*

(Nirmal, 2015)

Contributions of the Study

- Findings have filled a significant gap in the literature

- Confirms our understanding based on theoretical challenges documented in the literature

- Adds and expands our understanding of the phenomenon

(Nirmal, 2015)

Strengths and Limitations

- Males were disproportionally represented in this study
- Six of the participants had just completed year 1 of college or university
- Study may represent a sub-group of students with HFA

Strengths

- Provided the opportunity for students with HFA to lend their voice and share their stories

(Nirmal, 2015)

Strengths

- Participants represented 5 postsecondary institutions
- Participants had confirmed diagnoses of either HFA or Asperger's Disorder
- The study was subjected to considerable scientific rigour
- The focus on breadth and depth of experiences

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Implications: Where do we go from here?

- Intervention and planning in high school
- Postsecondary programming and support (e.g., mentorship programs, disability awareness)
- Psychologists working in secondary and post-secondary settings
- Policy development

(Nirmal, 2015)

Recommendations for Future Research

- Executive functioning deficits in college or university students with HFA
- Mental health functioning of postsecondary students with HFA
- Experiences of 4th year students and graduate students
- Experiences of postsecondary educators (e.g., disability advisors, counselors, professors)

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"Thank you for doing this research because they forget about us after high school"

- Zach (participant)

(Nirmal, 2015)

Thank You

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