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Orla Breen, Shearena Doyle, BSc, Clin. Speech & Lang.
Trinity College Dublin
Ireland
ASHA
Boston
November 2018

Different diagnoses, yet similar personal impact?

Adults living with a diagnosis of ASD or ADHD:
Disclosure

Financial relationships:

1. Employed at Trinity College Dublin (TCD) Ireland
2. TCD part funded the research and my travel here (conference allowance)
3. Employed by Health Services Executive (HSE) Ireland

Nonfinancial relationships:

We received no financial gain from this research or this presentation

International Affiliates - ASHA members

1. Irene P. Walsh, PhD.
2. Orla Breen, BSc.
3. Sheafra Doyle, BSc.

Financial relationships:

1. Employed by DNC & C CAMHS Dublin Ireland
2. Employed by Health Services Executive (HSE) Ireland
3. TCD part funded the research and my travel here (conference allowance)
4. Employed at Trinity College Dublin (TCD) Ireland

Irene P. Walsh, PhD. & Orla Breen, BSc. & Sheafra Doyle, BSc.
Aim

1. To provide greater insight into the phenomenon of living with ADHD and/or ASD in adulthood, as directly reported by those who experience the conditions.

2. To explore how a late diagnosis, attitudes of others, and social communication challenges may impact sense of self, wellbeing, and identity.
1. Being diagnosed with ADHD and/or ASD in adulthood can have a marked impact on many aspects of a person’s life, especially when diagnosed in adulthood.

2. Adult lived experiences of ADHD and/or ASD under-researched when compared with childhood experiences, and particularly when diagnosed in adulthood.

3. In-depth analyses of first-person accounts may render some insights into what these diagnoses might mean for an individual in their adult years, and particularly when diagnosed in adulthood.

Rationale

Punshon, Skirrow, & Murphy, 2009; Schrevel et al., 2016; Walsh, Delmar & Jagoe, 2018.
Method
<table>
<thead>
<tr>
<th>Format</th>
<th>Criteria for Inclusion</th>
<th>Data</th>
</tr>
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<tbody>
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</table>
| Dialog | 1. ADHD diagnosed adults diagnosed in adulthood, including late diagnosis <br> 2. Proficient verbal abilities to participate in interviews <br> 3. Recency of post (Mar 2016 - Sept 2017) <br> 4. Single author <br> 5. Length (>500 words) | n=6  
ADHD adult-diagnosed |  
  - Blogs from https://themighty.com |
| Interview | 1. People with adult-diagnosed ADHD <br> 2. Age > 18 years <br> 3. In-depth interviews <br> 4. Blogs from https://themighty.com | n=4  
ADHD adult-diagnosed |  
  - Self-reported experiences of living with ADHD in adulthood, including late diagnosis |

Approved by the Research Ethics Committee of host School at TCD.
<table>
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<td>1</td>
<td>Matilda</td>
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<td>4a</td>
<td>Jessica</td>
</tr>
<tr>
<td><a href="https://theredry.com/2017/03/want-what-adhd-looks-like/">link</a></td>
<td>18/03/2017</td>
<td>570</td>
<td>5</td>
<td>Lissa</td>
</tr>
<tr>
<td><a href="https://theredry.com/2017/07/adhd/">link</a></td>
<td>17/07/2017</td>
<td>704</td>
<td>6</td>
<td>Bridgette</td>
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When a friend said, he is with ADHD and Anxiety. Exhausting for someone. When Socializing Is

When I was diagnosed with ADHD as an Adult. When I was diagnosed with ADHD as an Adult.
<table>
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<tr>
<th>Occupation</th>
<th>Current</th>
<th>Previous</th>
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<tr>
<td>Disorder of Speech</td>
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<td>Received</td>
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<td>Diagnosed Was</td>
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<td>Age When</td>
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<tr>
<td>Gender</td>
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<tr>
<td>Name</td>
<td></td>
<td></td>
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<tr>
<td>Participant Profile</td>
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<tr>
<td>Participant Profile</td>
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</tbody>
</table>

**Table 2.1: Participant Profile**
Analytic Methodology: Interpretative Phenomenological Analysis (IPA)

Phenomenon = Experience of ASD or ADHD

Stage Description

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Active Engagement with data</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Notes on descriptive, linguistic features and conceptual features</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Emergent themes identified</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Super-ordinate themes identified</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Notes must be directly linked to data</td>
</tr>
<tr>
<td>Stage 6</td>
<td>Formation of master themes</td>
</tr>
</tbody>
</table>

Describing, understanding and interpreting participant experiences in order to understand their needs to interpret that account from the experience, and that the researcher then on what participants tell us about that access to experience is always dependent.

Tuohy, Cooney, Dowling, Murphy, & Sixsmith (2013).

Smith, Flowers, & Larkin (2009).
<table>
<thead>
<tr>
<th>Themes</th>
<th>Exploratory Comments</th>
<th>Descriptive Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emerging</td>
<td></td>
<td></td>
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<tr>
<td></td>
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</tbody>
</table>

Sample analysis: ADHD data
Findings:

Common themes from data merge
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Common Themes: ADHD & ASD

1. Diagnosis & Identity
2. Communication Challenges
3. Attitudes of others

Common Themes: ASD & ADHD
Theme 1: Diagnosis & Identity

Refers to how getting a diagnosis in adulthood impacted or affected sense of self or identity. Included references to life before and after diagnosis.
<table>
<thead>
<tr>
<th>Name</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dee</td>
<td>My fight was not with a man or external factors, but with my own mind. It’s like I was constantly digging in a sand pit to find the real me. (L1-5)</td>
</tr>
<tr>
<td>Mattie</td>
<td>The combination of treatment, medication, changes at work and working hard to find a better way of life should result in exactly that: a better life! The combination of treatment, medication, changes at work and working hard to</td>
</tr>
</tbody>
</table>
Theme 1: Diagnosis & Identity – ASD

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Theme 1: Diagnosis & Identity

- **Ben**
  - "It explains why I am the way I am, but I don’t live by it. I don’t live by my diagnosis." (line, 288)
  - "It’s an explanation of WHY I am who I am, not WHO I am." (line, 288)

- **Theresa**
  - "I DON’T consider myself ( ) like I’m a person with Autism, NOT. em. It doesn’t define me." (line 388)

- **Kevin**
  - "It’s a part of your personality and who you are, not everything about it is a negative thing. Like the social interaction stuff can be learned."
Theme 2: Communication Challenges

– Figurative language
– Spontaneity
– Engaging in social interactions
– Remaining focused in conversation
– To and fro of conversation
– Small talk / banter

Refers to a myriad of communication difficulties as reported, including:

– Small talk / banter
<table>
<thead>
<tr>
<th>Lissa</th>
<th>Jessica</th>
<th>Mattij</th>
</tr>
</thead>
</table>
| *Here’s how things typically go for me: I contingently start to engage in a conversation. I think they stopped talking. How do I respond? What did they even say? That song is still playing in my head. I need to make a grocery list when I get home.* *(L27-38)* | *I really do want to hear what you have to say. I know you are talking to me, and I know it is important to you, and I desperately want to be able to hang on to your every word...* but I really was interested the last time we spoke each other. I really tried to listen to what you were telling me. The thing is, I also participated in all the other conversations in the room, just not out loud. *Apologize. I didn’t realize I let you in the middle of our conversation and started a discussion with someone else. I was already speaking to you.* You were telling me. The thing is, I also participated in all the other conversations in the room, just not out loud. | *I really was interested the last time we spoke each other. I really tried to listen to what you were telling me.*

---

**Theme 2: Communication Challenges - ADHD**
Theresa

I’m still me with the struggle socially... the diagnosis won’t cure it, but it’ll just help it.

Ben

I never had difficulty finding friends. I was just what I was. It wasn’t having a filter. It was NOT interacting with people.

Kevin

The thing is something it’s hard for me to know how people interacting can be just so natural and easy. And then it must be the thing is something it’s hard for me to know how people

Alex

And at that point then I didn’t really know how to interact properly. Yeah 'em sort of like you’re about to fall asleep and you realise, claps hands, ‘THAT’S what they meant!’ [laugh].

Theresa

...I know? When I talk to me, my inability sometimes to have words in the moment... it helps me understand my understanding people (.) and yeah. When they say yeah (.) just, help it. (.) (L398)

Kevin

The thing is something it’s hard for others to think how can he NOT (L272)

Ben

I’ve been? It was NOT having a filter. (L96)

Alex

...I know? (L404)
Theme 3: Attitudes of others

Refers to how attitudes of others impacted or affected the person or person’s perception of self, in the past or in the present.
<table>
<thead>
<tr>
<th>Kathleen</th>
<th>Most of the time I don’t like myself, and I’m terrified that you feel the same. (L42-43)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mattijs</td>
<td>Her shoe (L93-99). When they tell me I’m lazy or tell me to just focus they don’t see how much it hurts. They don’t see that I see myself on the inside. They are already beating myself up.</td>
</tr>
<tr>
<td>Lissa</td>
<td>Growing up, I was described as a lot of things scattered, space cadet, quiet, bitchy, aloof. None of what I felt was my flawed personality, constantly awkward, standoffish. It added up, and I was ashamed.</td>
</tr>
<tr>
<td></td>
<td>couldn’t control it. (L7-7) thinking there was something wrong with me but I</td>
</tr>
</tbody>
</table>

Theme 3: Attitude of others - ADHD
| Alex | It's kind of insulting (L286) mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going mad. It's kind of insulting (L286) didn't know anything about my situation, so I was going to look down on you. Like I remember years ago someone told me, get me a job, so it's like, I'll put my eh job hat on and get into the job cannon and get fired into the job tree, pluck the job out of the tree. Cos obviously he didn't know anything about my situation, so I was going |  |
| Kevin | And in college there are so many people that have autism, and everybody is SO much more AWARE of it, it's not even something I really say to people. (L394) It's still hard not to compare myself to others who are further on, and it's even HARDER when people kind of badger me and. be normal] as opposed to „How do we help our son” (L412) It's not about finding the help I - it's just „make my son |  |
| Ben | “normal” as opposed to „How do we help our son” (L412) It's not about finding the help I - it's just „make my son |  |
Discussion 1

1. Common themes of: Diagnosis - Identity; communication; others' attitudes

2. Commonalities across data - surprising?

3. Lived experience v 'living' experience
   
   - Tendency to focus on the 'lived experience' as if 'over' or in the past is not useful and not true to nature of accounts

   - Was welcomed; helped 'explain' or make sense of past, often painful and perplexing experiences

2. Significance of late (adult) diagnosis
   
   - Commonalities across data - surprising?

1. Common themes of: Diagnosis-Identity; communication; others' attitudes
4. People come to services with

- a story to be heard
- an identity
- a diagnosis

As SLPs / healthcare professionals we must:

- listen to and hear these stories if we are to authentically support individuals
- recognise that individuals have an ever-evolving identity,
- must not underestimate the experience of a diagnosis and the way challenging ways

impact on self worth and identity

that diagnoses may be uniquely experienced by the individual, with its

- a story to be heard
- an identity
- a diagnosis

Diagram:

- Diagnosis
- Identity
- Story

Discussion 2
Engagement with individuals

“Over time, with the right conversations and relationships, we will be able to engage better with our clinical and research partners not merely as patients but as people working synergistically together within a community of health care” (Hovey & Craig, 2011; Hovey, Rodríguez, Jordan & Morck, 2016)

Such conversations with persons living with any health conditions are fundamental to a person-centered relational process (Hovey & Craig, 2011; Hovey, Rodríguez, Jordan & Morck, 2016) or a person-anchored relational process (Walsh, Kovarsky, Mahler, Taylor-Champlin & O’Neill, 2018), where not only the person, but the perception and understanding of others can influence therapeutic outcomes.

5. Engagement with individuals

Discussion 3
Aim to:

Tailored interventions for clients attending SLP
- Realistically-designed and authentically-driven,
- Ecologically-centered and person-centered.

Day not just 'lived', but 'living' in every moment of every
better understanding reported experiences that are
facilitate enhanced communication interactions by

Pay deliberate, explicit attention to personal services

Communicate

Impact of diagnosis and its effect on

Where Next?
"The world and man [human-beings] are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical] accounts are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical] accounts are accessible through two kinds of investigations."

We have shown that reflective [philosophical] accounts can not only add to, but greatly enhance the explanatory [scientific] accounts in textbooks, where often the person at the core of the living experience is at risk of being inadvertently lost or perhaps viewed as a homogenous being, not unique in his/her own right.

"nothing about me without me" (Hovey et al., 2011).


Conclusion

"The world and man [human-beings] are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical] accounts are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical] accounts are accessible through two kinds of investigations."

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"nothing about me without me" (Hovey et al., 2011).
Thank You


