How people with Asperger syndrome experience counselling

Anja Rutten

Senior Lecturer, Psychology and Counselling, Staffordshire University

Part-time PhD student, University of Strathclyde

a.h.rutten@staffs.ac.uk
What is Asperger syndrome?

- Asperger syndrome part of the high-functioning end of the autism spectrum
- Autism is a neurodevelopmental disorder, present at or shortly after birth
- About 1 in 110 people are somewhere on the autistic spectrum with a male:female ratio of approximately 4:1
- Cause unknown but likely to be at least in part genetic
- No ‘treatment’ or ‘cure’
What is Asperger syndrome?

- Common to whole spectrum – ‘Triad of Impairment’ (Wing, 1996)
- Triad of interlinked elements:
  - Communication
  - Interaction
  - Imagination
- Often accompanied by rigidity, obsessions and narrow range of interests
- Sensory differences/difficulties extremely common
In practice: Living in a non-autistic world

- Difficulties in living
  - Relating to Triad of Impairments (communication, interaction, imagination)
  - Exacerbated by lack of acceptance by other people, groups and society

- Social model of disability
  - Society’s attitude towards difference is disabling (Oliver, 1990, 1996)
  - People with Asperger syndrome often excluded from mainstream (e.g. employment, education)
Communication and interaction at work causes stress

“At the moment I am not working, but when I was working, it was constant stress and trying to cope with other people, trying to keep up with working amongst other people. Not having time to process the information throughout the day and that led to very poor mental health”.
Rigidity in having to be precise causes being ‘out of synch’ with others, leading to anxiety

“Other people aren’t accurate enough. Usually I think they’re not listening or don’t think that it’s important but I do think it’s important…. But then sometimes, if you try to tell people later that something wasn’t right before, they think you’re making a fuss, they don’t think it’s important to still be saying something about Oh I told you this last week, but actually, it was, I meant it like this. And they’re like: So?”
Participant reported casual acquaintance to the police for attempted rape – narrow/idiosyncratic interpretation

“… they [person who tried to rape participant] have broken the law, I have not broken the law. So that upsets me to this day. My reaction is that the police are ignorant and they abuse power. Their spelling is atrocious and I always get into trouble because I have given so many statements over the years and they have to make you read the statement and sign at the end of it, and there are so many spelling errors there and I always point it out, because I can’t not”
Asperger syndrome and mental health

- Many people experience high levels of distress
- Majority (65%) also meet diagnostic criteria for mental illness (Deudney & Shah, 2001; Ghaziuddin, 2005; Howlin, 1997, Tantam 2000)

Common:
- High levels of anxiety
- Depression
- Obsessive-compulsive symptoms
- ADHD/hyperactivity
The generic case for therapy

- Counselling and psychotherapy work and are highly effective (Cooper, 2008)
- Dodo bird effect (Wampold, 2001)
- Common factors (Asay & Lambert, 1999)
  - Client variables and extra-therapeutic (40%)
  - Therapeutic relationship (30%)
  - Placebo (15%)
  - Technique/model factors (15%)
Counselling for people with AS

Counselling

Imagination
Wish for change, hope, development of insight, imagining a different life

Communication
(verbali and non-verbal)

Interaction
Interaction in relationship, (taken out of day to day context)

Triad of Impairments

Wish for change, hope, development of insight, imagining a different life.
Counselling for people with AS

Client factors

‘Generic client’ evidence
- High levels of psychosocial dysfunction associated with poorer therapy outcomes (Cooper 2008)
- Good social networks are predictors for good counselling outcomes (Beutler, Castonguay, & Follette, 2006; Cooper, 2008)

People with Asperger syndrome
- Difficulties in communication, interaction, imagination
- Social isolation
- Low on extra-therapy ‘resources
Counselling for people with AS

Therapist factors

- Access to knowledge, information and training often problematic
- Factors highlighted as important to marginalised client groups (e.g. LGBT, BME, working class) (summarised in Cooper, 2008)
  - Therapist awareness of own prejudice
  - Developing knowledge/understanding of client issue
  - Not expecting client to educate
Therapy for people with AS

- Does therapy work for people with Asperger syndrome?
  - At first sight, poor outcomes and difficult experiences likely
    - Research participants’ accounts confirm much of this
    - All participants have had bad experiences, often more than one
  - Many people with AS want therapeutic help
    - Some participants have had good experiences
    - Good experiences can be life-changing
Counselling for people with AS

- Two possible explanations why therapy with this group of clients might work
  - *Because of* typical model
    - Therapy works as it does in typical populations
    - But poor client experiences show that improvements need to be made
  - *Despite* typical model
    - Excellent for clients who improve but does not serve whole client group
    - Fundamental principles of counselling for this client group flawed
Research

- Fundamental research question (because of/despite) has never been raised
- In addition, there are few outcome studies
  - Some (early) psychodynamic case studies
    - Non-replicability
    - Therapist interpretation
  - CBT outcome studies
    - Generally small samples, little follow-up
    - Often children, not adults
    - Social skills training and counselling often not differentiated
Research

Person-centred/Experiential

- No research that I know of
- Very few publications about work with this group of clients (Knibbs & Moran, 2005; Stinckens & Because, 2008)
Grounded Theory study

- In-depth interviews with people who
  - Have Asperger syndrome
  - Have received counselling
- Participants are asked to talk about
  - How Asperger syndrome affects them
  - How they experience/have experienced their counselling
- More interviews needed
Participants’ understanding of counselling

- Participants’ understanding of what counselling is seems appropriate in this group of six interviewees.
- Therefore unhelpful experiences not due to client misunderstanding of counselling.
Participants’ understanding of counselling

- Counselling I understand is when you go to a professional who can help you clarify your own issues and enable you to understand yourself and help you to clarify things, so you are able to fix your own problems. I think.

- Counselling for me is a way of talking through problems to arrive at a, or to relieve the stress or depression, but also to arrive at a, free the mind to arrive at new ways of thinking about things, or doing things.

- I think that generally counselling is to make progress to help you deal with, learn strategies to deal with things. I think that mostly it’s probably so people can sort out things that have bothered them in the past or, like to help their emotional development, that kind of thing.
Unhelpful experiences

- (Multiple) unhelpful experiences
- Most participants still have unresolved feelings about negative experiences
- Five participants expressed distress during interviews
Unhelpful experiences - examples

- **Counsellor not active**
  Well the counsellor didn’t really say anything and even though I sat not saying anything through the sessions, she would, she wouldn’t say anything that might help me.

- **Therapy too brief or cut short**
  It only went on for several months, it should have gone on for years, but it only went on for several months

- **Therapist has own agenda**
  My experiences were a little counterproductive because they [the therapist] were, they pretty much had their own agenda there as well, on some issues
Unhelpful experiences - examples

- Counsellor doesn’t make things explicit
  ... she had a pot of buttons and I was supposed to choose one button that was to represent myself and then buttons for each of people who were important to me such as family members and friends ..... and I didn’t know how I was supposed to choose them and if I chose a particular one was she going to think that I thought something of myself or of different people by the particular button that I chose and then I was supposed to put the buttons on a piece of paper with my button in the middle and other people in various places and..

- Counsellor is not precise/explicit
  I thought I was going to be in there for an hour and it was a 50 minute session and so she told me at twenty minutes to that we had ten minutes left and that surprised me and I took a little bit of time to deal with that
Unhelpful experiences - examples

- **Counsellor doesn’t seem to care**
  ... and the therapist was like, oh I’ve got another one here, they didn’t spend enough time orienting to my case and they had probably seen half a dozen people before so they were beginning to switch themselves off

- **Counsellor is perceived as hostile**
  He asked me if I agreed [with the decision not to offer therapy] but I didn’t want to go back because he was a horrible man and he was giving me an option not to go back ...

- **Counsellor is seen as ineffective**
  Well it was just another experience of a counsellor who was not very helpful and who didn’t seem to realise that I was struggling that I didn’t know what the answer was.
Clients with Asperger syndrome appear to have little personal power when it comes to therapy

Access to therapy (unless private) is poor

Well because that [going to GP counsellor] was only six sessions….I’m not sure if I was allowed to go to her for any more sessions

Then my social worker suggested going for private therapy, saying what was on the NHS was limited.
Power

- Ongoing therapeutic help often not available

  I wish that I could still go and see her and I don’t know, I sometimes wonder if it’s alright to write her a letter or something, I don’t know what the etiquette now is, six months later.

- Lack of choice

  It’s all to do with CBT and variations, and most of it comes across as the patient has got it wrong.....CBT is more of a thought process whereas the therapies that have helped me have been based on feelings. I might not be able to describe my feelings, but working through those feelings whatever they may be has helped me immensely.
Helpful experiences

- Participants value some counselling experiences
- Helpful experiences less common
- Often there is one good therapy experience among a number of unhelpful experiences
Helpful experiences - examples

- **Relational**
  
  the relationship was like a mother to a child, or grandmother to a child, it was, there was genuine interest there.

  I knew, well, deep down inside I knew that talking therapies or counselling was the way forward and not just medication. It was just finding the right person to have a rapport with, where you can talk freely and comfortably about things.

- **Accepting**

  I wasn’t being questioned, I wasn’t being judged and we just went through things as they came along
Helpful experiences - examples

- **Transparent and explicit**
  And she told me there was a possibility that they [NHS] would say no [to further counselling] but she thought it was likely that she would be able to get them to agree and she knew it was important and so she prepared me but also reassured me

- **Therapist flexibility**
  She agreed that she would meet me at the side door which was not the usual procedure in order that I could go there myself completely.

- **Therapist consistency**
  ..... the room was always set out in exactly the same way each time so that I didn’t have too much of a settling-in period
Helpful experiences - examples

- Listens and responds non-defensively
  If I wasn’t very happy about something that she had said or done previously, she encouraged me to tell her so that she could clear it up and she wouldn’t, it wouldn’t be a problem if I wasn’t happy about something that she’d said or done.

- Knowledge of Asperger syndrome
  ..and actually she told me later that as soon as she started reading the things about Asperger syndrome she could see, she said that it all fell into place...... and she realised that it was important to work with me rather than saying ‘you’ve got to do this or this’ and if you don’t do either of those you can’t come here’
What people with Asperger Syndrome want from therapists

- Some observations
  - Therapeutic relationship very important
    - Acceptance
    - Being understood and responded to
  - Active therapist
  - Explicit communication
  - Knowledge about AS
References

References