

Ageing with Autism:

Experiences of older individuals with Autism Spectrum Conditions - Findings from a participatory research study

Doctoral Thesis Project

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INTRODUCTIONS

- Who am I and how did I come to this topic?

BACKGROUND

- Ageing in autism is a little-researched area (NAS, 2013; Wright et al., 2013; Happé & Charlton, 2012)
- Understanding of the needs and experiences of older people on the spectrum is limited
- ASC became a recognised diagnosis about 50 years ago – people diagnosed as children then are only now reaching older adulthood
- Initially research on ageing with autism focussed on neuropsychology

BACKGROUND continued...

- Research often with carers or parents – not giving voice to individuals (Barber, 2015)
- Little known about support needs of older people with ASC raises questions regarding ‘standard care’ – care homes, social care, etc
- Autism research only recently started using participatory framework (Wright et al., 2014) – issues around validity of research, power imbalances, etc

RESEARCH thus far

- Qualitative methods not frequently used – misconception that people with autism cannot self-reflect
- Only two published studies on subjective experiences of ageing with ASC using qualitative research (Hickey et al., 2018; Elichaooff, 2015)
- Some studies have suggested that experience of ASC worsens in older people, other studies say autistic people become better at coping

RESEARCH thus far 2

- Results are mixed and often inconclusive
 - Outcomes and quality of life
 - Cognition and brain function
 - ASC symptoms
 - Coping strategies
 - Emotions

RESEARCH AIMS – the current study

- To explore the experiences of older individuals with ASC
- To develop understanding how older people with ASC make sense of relationships and what relational needs they have
- To find out what support older people with ASC may value
- To meaningfully include experts by experience in the research process (Participatory Research framework)

METHODOLOGY

- Qualitative design using semi-structured interviews
- Interviewed 7 participants
- Participants: diagnosis of ASC (or self-identified), over the age of 55, able to speak English, capacity to give informed consent
- Interpretative Phenomenological Analysis (IPA) for data analysis
- Using a Participatory Research framework

PARTICIPATORY RESEARCH

- Participatory Research (PR) = approach to research challenging traditional power imbalances in scientific studies
- Aims to empower and enable those studied to be part of the research process
- Making use of expertise from those with lived experience

PARTICIPATORY RESEARCH in this study

- Research Advisory Group
- Members: 3 males, 1 female – all self-identified as having ASC
- Tasks: refining research question, design of study materials, data analysis, dissemination of results (and lots of questions in between!)
- Benefits
- Issues: making it truly democratic, meaningful involvement, volunteer skill sets, training, ethics boards

ANALYSIS

- Qualitative analysis involved reading interview transcripts and looking for themes
- Comparing similarities and differences across interviews
- IPA is interested in the meaning people make of experiences – so some interpretation required
- Building a story

RESULTS

- 5 themes
 - 1) Growing Older
 - 2) Contemplating Difference
 - 3) Relationships
 - 4) Life so far has been a challenge
 - 5) Resources and Resilience
- Several subthemes

RESULTS – Growing Older

- Generally positive outlook on future
- Life review
- Concerns for the future
 - “I suppose it’s just possible that older autistic people could have, could be more prone to things like depression and things like that.” (Quentin)
 - “Loss of independence is a problem for everybody, must be a problem for people who are very social but it would be a problem for me in that being cared for is ... dependent on another human being which is something I’ve assiduously avoided most of my life.” (Matthew)
- Hopes for the future

RESULTS – Growing Older

- Has autism changed with age?
 - “Some of the challenges just diminish, some of them you find coping mechanisms” (Matthew)
 - “Well it’s a bit easier actually as you get older, because you’ve got choices. [] well somehow there’s more pressure when you’re young.” (Quentin)
 - “I’m worried I’m getting worse. You know I’ve got accumulative pile of stuff that’s gone wrong in my life. Feelings then get bigger and bigger and I think I’m perhaps a bit more prone to meltdowns than I was...” (Peter)

RESULTS – Growing Older

- Support needs
 - Practical Support
 - Emotional Support
 - Social Support
 - Specialist services or mainstream services?

RESULTS – Contemplating Difference

- Feeling different
- What is normality?
 - “So, that’s the message we’re not disabled – we’re super-abled. But we don’t see it that way cause other people don’t see it that way, and other people tell us that we’re disabled.” (Chris)
 - “The thing about Asperger’s, if you’re on your own you haven’t got it any more. If you’ve got that condition you’re on your own, when no one is bothering you and it’s quiet then you can be ... normal again you know. [] I feel quite normal. Very normal actually.” (Greg)
- Negative and positive views of ASC

RESULTS – Contemplating Difference II

- Comparing to others

- Diagnosis & disclosure

“Initially a wonderful release... but... now, I realise I’m sort of trapped with this. And whilst I realise there are pros, there are also cons.” (Peter)

RESULTS – Relationships

- Relationship difficulties
 - “Well I suppose I’ve got friends, but I suppose any kind of intimacy (chuckles) I find it a bit, I always find it a bit difficult any kind of real intimacy. [] I don’t know really. It’s just lack of instinct in knowing how to sort of relate to people.” (Quentin)
- Relationships have changed with age
 - “I’m very weary that a lot of friendships have fallen apart. A lot have ended, have ended angrily” (Greg)

RESULTS – Relationships

- Positive experiences of relationships
- Need for distance
 - “I’m very weary that a lot of friendships have fallen apart. A lot have ended, have ended angrily” (Greg)

RESULTS – Life so far has been a challenge

- Negative experiences
 - “I was bullied by all the bullies and that was me” (Chris)
- Being misunderstood
 - “I feel that I am talking from a different plane. There’s certainly a problem that non-autistic people have difficulties to understand autistic people” (Walter)
- Negative emotions
 - "I'm constantly fighting stress, not always winning" (Peter)

RESULTS – Resources and Resilience

- Meeting needs another way
 - “I have organised my life around not having to deal with those difficulties. Or pursuing things I was better able to do.” (Matthew)
- Therapy and self-help
 - “Every time a negative thought comes close to me, I – banish it in my mind. I’m aware that it’s not reality, these negative thoughts.” (Chris)
- Having a veneer
 - “I’m always aware that I’m sort of bluffing my way through it.” (Matthew)
- Special interests & hobbies

WHAT DOES IT ALL MEAN?

- Results show varied experiences – everyone with ASC is different and this remains in older adulthood!
- Careful not to generalise
- Some issues (e.g. interpersonal, emotional) persist into older adulthood
- Overall, positive outlook
- Most, though not all, agreed that life with autism gets easier with age

WHAT DOES IT ALL MEAN? 2

- Many concerns and hopes similar to neurotypicals
- Support needs vary – but autism awareness is essential!
- Negative experiences, marginalisation and exclusion throughout life
- Emotional problems tricky to deal with
- Personal resources for coping important

IMPLICATIONS – what does it mean for older people with ASC?

- Awareness of some issues that might be important
- Keeping active and engaged
- Planning for the future – living will?

IMPLICATIONS – what does it mean for professionals?

- Highlights issues that may come up when working with elderly autistic people
- Emphasises person-centred care and tailored support
- Creative and alternative ways to offer therapy

IMPLICATIONS – what does it mean for service commissioners?

- Specialist autism mental health services
- Reducing waiting times for specialist services
- Need for staff training and autism awareness
- Social groups and opportunities

WHERE NEXT?

- More research on more diverse older autistic groups
- Participatory studies
- Inclusion of carers, friends, relatives

QUESTIONS?

REFERENCES

- Barber, C. (2015). Old age and people on the autism spectrum: a focus group perspective. *British Journal of Nursing*, 24, 1054-1057.
- Elichaooff, F. (2015). What's it like being you? Growing old (er) with Autism Spectrum Conditions—a scoping study. *The European Journal of Social and Behavioural Sciences*, 13(2), 1851-1864.
- Happé, F., & Charlton, R.A. (2012). Aging in autism spectrum disorders: A mini-review. *Gerontology*, 58, 70-78.
- Hickey, A., Crabtree, J. & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, 22(3), 357-367.
- Mukaetova-Ladinska, E.B., Perry, E., Baron, M., Povey, C., & Autism Ageing Writing Group. (2012). Ageing in people with autistic spectrum disorder. *International journal of geriatric psychiatry*, 27(2), 109-118.
- National Autistic Society (NAS) (2013). Getting On? Growing older with autism. www.autism.org.uk/...autism/getting%20on%20-%20campaigners%20report.ashx?...
- Piven, J., Rabins, P., & Autism-in-Older Adults Working Group. (2011). Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatrics Society*, 59(11), 2151-2155.
- Wright, S.D., Brooks, D.E., D'Astous, V., & Grandin, T. (2013). The challenge and promise of autism spectrum disorders in adulthood and aging: A systematic review of the literature (1990–2013). *Autism Insights*, 5, 21-73.
- Wright, C.A., Wright, S.D., Diener, M.L., & Eaton, J. (2014). Autism spectrum disorder and the applied collaborative approach: A review of community based participatory research and participatory action research. *Journal of Autism*, 1, 1.