

WHAT'S IT LIKE BEING YOU? GROWING OLD(ER) WITH AUTISM SPECTRUM CONDITIONS – A SCOPING STUDY



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Abstract

The aim of this scoping study was to understand which issues are of salience for the experiences of adults with Autism Spectrum Conditions (ASCs) as they grow older, in order to determine themes for a follow up study using in-depth interviews. Four adults (two female, two male) on the high-functioning end of the autism spectrum were interviewed with a purposely broad semi-structured interview schedule. The transcripts were analysed using Thematic Analysis to identify emerging themes. The themes identified are depression, effects of diagnosis, experiences with mental health professionals and therapists, the inverted relationship between educational level and career, the participant as autism expert, and communication/social interaction. The findings echo some existing research and present an insight into the lived experiences of older adults with autism. The themes identified in the scoping study will form the basis for further qualitative studies. Implications for further research are also discussed.

Keywords: Autism spectrum conditions, ASC, adults, aging, experiences

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1. Introduction

The prevalence of Autism Spectrum Conditions (ASCs) in the UK is currently estimated at 1/100 (Baird et al., 2006). Prevalence in the 1960s, when Autism first began to be diagnosed in children, was estimated 0.5/1,000, showing a steep increase, but Brugha et al (2011) point out that the increase in diagnoses may be attributed to a widening of the diagnostic criteria, coupled with an increased awareness of the disorder by professionals and the public alike. This can lead to the assumption that not only is there a growing population of adults with a diagnosis of ASC, but also that there are an even greater number of adults living with ASC either without a formal diagnosis, with a misdiagnosis, or with no knowledge at all that they have an Autism Spectrum Condition.

The needs of, and services for children and adolescents with ASD have been the focus of much research, but it has been recognised that the same does not apply to adults, especially as they move towards middle and old age (Pellicano, Dinsmore, & Charman, 2014; Müller, Schuler, Burton, & Yates, 2003; Wright, Brooks, D’Astous, & Grandin, 2013). Not only is research on autism in old age necessary to identify support needs, researchers are also beginning to explore the lifespan trajectory of the disorder (Happé & Charlton, 2009). In recent years, autism related research has experienced a small but decisive shift towards a focus on older adults, and a number of leading academics in the field have highlighted the paucity of available research (Happé & Charlton, 2009; Wright et al., 2013). The UK’s National Autistic Society (NAS) together with many leading autism researchers have declared an urgent need for research into the experiences and support needs of adults over the age of 50. Happé and Charlton (2012) produced a short review of research on autism in older adults, and identified three main areas for future research, one of which is Quality of Life in Old Age. Mukaetova-Ladinska, Perry, Baron, and Povey (2011) highlight the urgency to address and recognise the needs and experiences of older adults with autism.

In 2009, the Welsh government published a report of the circumstances and support needs of older people with autism, whilst in 2010, the National Adult Autism Strategy for England was published. This was the direct result of the 2009 Autism Act, legislation which was passed to secure the rights of adults with autism to access appropriate services. The authors of the Wales Report (Stuart-Hamilton et al., 2009) state specifically that there is a paucity of qualitative data available on the subjective experiences of older adults living with autism.

A systematic review of literature on Autism Spectrum Disorders and Aging conducted in 2013 (Wright, Brooks, D’Astous, & Grandin) shows that there is a growing body of research covering many aspects of aging with autism, including cognitive functioning and

decline, services for adults with autism, and the prevalence of depression and anxiety in adults with ASCs. It also highlights the need for the development of adequate services to meet the needs of older adults with ASCs. Griffith, Totsika, Nash, and Hastings (2011) focus on the absence of accessible individualised services for adults with ASCs in the UK, citing the lack of knowledge within the system of health professionals as the main reason for inadequate support for adults with autism. Unemployment and underemployment is another issue identified by Wright, Brooks, D'Astous & Grandin (2013), with emphasis on the need to develop understanding and flexibility to accommodate individuals with ASCs within the workplace.

The existing research on older adults with autism imparts only a fragmented picture that rarely includes subjective accounts from individuals with autism themselves.

Milton (2014) reflects on knowledge production in studies on autism, highlighting the disparity in different models used to explore autism. Although there are a small number of 'insider' researchers, they are often ignored in spite of their expertise (Milton & Bracher, 2013). However, there is a growing body of research that aims to give a voice to individuals with autism, and to narrow the gap between the academic community and researchers with autism (Nicolaidis et al., 2011; Wright, Wright, Diener, & Eaton, 2014). The question how an accurate understanding of the experience of individuals with autism can be obtained, is the subject of a number of articles, especially in relation to the positionality of the researcher as 'insider'-'outsider' and how knowledge production shows disparate findings depending on which model of autism is favoured (Jones, Huws, & Beck, 2013; Milton, 2014).

A small number of qualitative studies aim to explore the lived experiences of children and adults with autism (Hurlbutt & Chalmers, 2002; Jones, Quigney, & Huws, 2003; Huws & Jones, 2008; Preece & Jordan, 2009; Jones, Zahl, & Huws, 2010). This current study forms part of an ongoing exploratory research into the lived experiences of older adults with autism in the UK.

2. Problem Statement

Autism (ASD) is a lifelong disorder, yet there is very little research on aging with ASD, and what the experiences and needs are for older adults.

Understanding how adults with ASD subjectively experience the process of aging and living with autism is crucial to the better comprehension of the lifespan trajectory of autism as well as being informative for other areas of research that investigate aspects such as needs for services or cognitive changes in ageing adults with autism.

3. Research Questions

What are the subjective lived experiences of older adults with autism spectrum conditions (ASCs) in the UK?

The central research question is purposively very broad, as analysis of the initial study will inform themes and questions for future interviews, which form part of a complex follow-on study.

In order for the themes to emerge freely from the participants accounts, the interview schedule for the scoping study focussed on three main areas: Current life situation, including diagnosis; growing older, and coping.

4. Purpose of the Study

The central aim of this investigation is to develop insight to the experience of being an older person with autism, and how aging affects the individual's experience of their autism. This research will complement and broaden the current fragmented picture of autism in older adults, as the little available research on this topic tends to focus either on cognitive aspects, or on policy-driven surveys to inform service providers. The central aim will be accomplished through a qualitative exploration of the lived experiences of older adults with autism.

5. Research Methods

5.1. Design

A qualitative approach was chosen as the most appropriate method to address the exploratory research question, and to gain an insight into the emotional landscape of adults with autism as they are growing older. Further pluralistic qualitative analysis will be used as a form of triangulation to give a holistic understanding of a little researched area (Frost et al, 2010).

Purposive sampling of a homogenous subset of the population of older adults with ASCs was appropriate to the research question, and the chosen analyses, which consists of two parts. The initial analysis, which is presented in this paper, is a Thematic Analysis (TA) (Braun & Clarke, 2006) in order to identify the main themes that are salient to the lived experiences of the sample, and to allow for a thorough description of the data set. Further analysis in the form of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) will be conducted as the next step, to gain an in-depth understanding of how individuals with autism perceive their own experience. However, Thematic Analysis was

deemed an appropriate method to elicit the initial themes, as the aim was not to make assumptions on the nature of salient issues for older adults based on existing research findings with children and young adults.

5.2. Participants

Four participants were recruited within the UK for this scoping study. All participants are of white British ethnicity. Two are female, two male. Details of the study were advertised on online autism networks, and participants approached the researcher either through the initial advert or through snowballing.

All participants have been educated at degree level (or equivalent). All live independently, and none are currently employed full time. Three of the participants have been or are married, and have children.

The participants were aged 58-63. Due to the nature of the study, only individuals who are verbal and able to give informed consent were able to participate. Because further analysis will be conducted in the next step of the study using IPA (Interpretative Phenomenological Analysis), a homogenous sample was required and sampling was purposive. Homogeneity was provided in that all participants were middle aged, and had a diagnosis of Asperger Syndrome/Autism Spectrum Condition.

It is acknowledged that the participants present a particular subset within the population of aging adults with ASCs, especially in regard to the fact that all but one are involved in autism awareness campaigns and advocacy.

5.3. Data Collection

Prospective participants were sent information about the study and a consent form by email. In order to accommodate the needs of the participants, the interview location was determined by the participants' choice, three interviews were held at the participant's home, two on university premises. Every effort was made to make participants feel comfortable and to accommodate any sensory needs such as turning off fluorescent lighting. Permission was sought and obtained to audio record the interviews. At the beginning of the interview, participants were again given an information sheet and offered to ask any questions they may have. They signed the consent forms, and were given a copy for themselves.

A semi-structured interview schedule had been prepared covering three areas of investigation (Current life situation, including diagnosis; growing older, and coping). The aim was to let the participants shape the interview, and to not impose predetermined

assumptions on what would be considered the salient themes, therefore questions were only asked if participants did not cover the three broad areas, or if more details were required.

The interviews ranged between 47 and 95 minutes in duration, and were subsequently transcribed verbatim for analysis. Furthermore, in order to increase credibility, the researcher made field notes and kept a reflexive journal throughout the interviewing as well as the analysis process.

An inductive thematic analysis (TA) was conducted on the transcribed interviews following Braun and Clarke's guide (2006), with the aim to provide a comprehensive descriptive report of the main themes. After familiarisation with the data through repeated readings of the transcripts, the author started generating codes line by line. After this phase, the codes were then re-read to focus on emerging themes, producing thematic maps to visualise the themes and their connections. Themes that were identified were then checked against the coding in order to confirm their fit.

6. Findings

The following themes were identified as representing the salient issues the participants talked about during their interviews: the effects of the diagnosis, depression, experiences with mental health professionals, the inverted relationship between educational level and lack of career, the participant as autism expert, and communication/social interactions.

6.1. Depression

All participants stated that at some points in their lives, often prior to their autism diagnosis, they had been diagnosed with depression and three out of the four participants had attempted suicide. Some felt that the depression was reactive in that it stemmed from the difficulties of the undiagnosed autism:

“The thing is that at the time I thought I was, well, I was depressed, I spent most of the time in tears to be honest, and now I know why.”

Another participant makes a very similar statement:

“I had a lot of depressions, which I put down to the not understanding of the autism.”

One participant felt that being treated for depression and anxiety didn't help because the underlying cause (autism) wasn't diagnosed:

“They say there was a history of depression or that there was anxiety. THAT’s what I was treated for, but it never did any good. They seemed to just keep increasing things (medication) more and more, and it just, the world fell apart.”

However, the depression is also described as being difficult to separate from the autism, especially when high levels of anxiety (social and otherwise) come into play.

“It was diagnosed as depression, I mean, I put forward a theory that the depression is a result of the anxiety and the team of doctors sort of accepted that and agreed.”

6.2. Effects of the diagnosis

Most of the participants received their diagnosis within the last ten years. They spoke of the dramatic effect getting the diagnosis had on them. The path to getting a diagnosis was often a long and difficult one, in most cases preceded by diagnosis and treatment of depression and/or anxiety. The overarching response was that of “things falling into place” and of making sense of the past and present. However, for some there is also a sense of regret at not being diagnosed earlier in life:

“It wasn’t a complete surprise, to be honest, I burst into tears and just said ‘you’re a bit late’, because right from childhood things had been a bit of a disaster.”

“Because it was really too late to do any good. Now I’ve realised there is a lot of it, and yes, it makes sense, also a lot of my childhood now makes sense. It’s a pity that they couldn’t have got something right then.”

Others felt tremendous relief when they received the diagnosis:

“Yes, it felt wonderful, because it basically wiped out all the embarrassing memories, now I know why all those things have happened. [...] Now I know at least that it’s not my moral character, it’s not my basic character that’s at fault.”

“Oh look, it was just brilliant, it was just really helpful. [...] So the impact for me is that I felt that I now understood myself.”

“It gave me a lot of explanations. I felt ‘yes, a lot of it makes sense then’.”

“You know, it hasn’t been like a straightforward easy path, but it’s just been very helpful to know.”

6.3. Experiences with mental health professionals and therapists

Because of their histories of depression/anxiety, the participants had contact with a number of mental health professionals before, during and after their diagnosis. Overall, they report a lack of knowledge about and understanding of autism they encountered, and they feel that professionals in the mental health and therapeutic fields need to be educated in order to be helpful.

“My aim, my thing is, because I trained as an art psychotherapist, and because I consulted therapists, so I know that these people don’t know about autism, it’s not part of their training, and I know a lot of autistic people who have been let down by them, so my aim is to train people like that about autism.”

“I met other autistic people, and it was just clear how people were being misdiagnosed left, right, and centre, and you know, people in the mental health field and in the therapy field need to know about it.”

Another participant received her diagnosis because of an autism aware CBT therapist, but feels that psychoanalysis is not appropriate for individuals with autism, although the participant partly attributes this to the therapist not knowing about autism.

“I’ve been to Freudian therapy which is completely inappropriate. [...] I imagine that it would be very different if you went into the therapy with the autistic diagnosis and told the therapist that you are autistic, because in the absence of that, I really felt that she despised me, and the fact that you’re not getting close, because you lie down and she’s behind you, so you’re not getting any feedback at all.”

6.4. The participant as autism expert

The sample consisted of participants who are all educated to degree or postgraduate level, and who are highly knowledgeable about the subject of autism. Not only do they feel strongly about the need to educate mental health professionals and therapists, they want to be seen and heard as experts on autism, because of their insider perspective.

“Once I found I was on the spectrum, I started developing sessions about autism.”
“To me this is stuff I learned myself, so why wouldn’t they (other adults with autism) know this, but they don’t, they get a diagnosis and if professionals don’t tell them, they

don't know. It's really appalling, the diagnosis doesn't really help people, as it could, because they don't understand what it means."

Their expertise is important to them to educate and support peers, as well as the public and professionals.

"I was actually told, and these were the exact words, to research it, [...] so I did. Hence I'm now involved with local hospitals, the council and the NAS (National Autistic Society), I'm also governor of the (...) Mental Health Trust."

"I've had a couple of articles just published, and they just make a vast amount of difference, so that people actually think you're serious."

There is also a need to be listened to and autism advocacy is important to the participants. One participant talks

about the lack of support services:

"So every time it's one of the council meetings I stick my oar in, so until they change their way of doing things, they will keep getting moaned at."

6.5. The inverted relationship between educational level and lack of career

All participants are educated to at least degree level, and some are actively involved in research and academia. However, all report a lack of career progression, have had difficulties maintaining a working life, or are unable to work due to difficulties arising from their autism.

"I've got three degrees (two undergraduate, one PhD), and I got no career, and the reason for that is, now I know, is because I've got Aspergers Syndrome. Which means I don't get on with, I don't know how to put it exactly, but I seem to get into all sorts of misunderstandings in conversations and in groups."

"I was self-employed, and as a result of various medications I was on, things just fell apart, because they were trying to treat the wrong thing."

There are reports of workplace bullying, in spite of being more than able to complete the work tasks.

"The boss was prone to giving you two hour tirades, so he would sit you down and you could set your watch by that it would be two hours by the time he'd finish. And it was all stuff about my personality, and about how difficult I was to manage and all that sort of stuff.

That was before I got my diagnosis, and there was one time he actually said to me ‘you’ve got the kind of personality people avoid’, which is like icicles in your heart, you know that is really skewering you where it hurts.”

6.6. *Communication/social interactions*

Issues with communication and social interactions seem to be pervasive throughout different areas of life for most participants. They affect their working life, as well as friendships, relationships and belonging to social groups such as church or peer groups.

“You’re always getting things wrong, you speak at the wrong time, you know, when people are in conversation, or you can’t, you’re not following the conversation properly, or you’re, you know what you want to say, but you don’t express it the way you think you’re expressing it.”

“So you constantly need a reality check that your heart is in the right place, that you don’t really mean to dismiss people, or be contemptuous, it’s just something in my body language that comes out that way.”

“I think that the whole sort of dating and you know, that thing is just much more difficult for people on the autism spectrum.”

“There was something missing in the way I connected to people and I was constantly trying to find a way of fitting in.”

7. Conclusion

These findings indicate that much further research is needed to address the issues raised by the participants’ accounts. The theme of *communication/social interactions* is one that is reflective of it being one area of impairment in Autism Spectrum Conditions, and for the participants it is one that remains pervasive throughout their lifespan. Communication issues seem to be based on a disconnect between what is perceived by the participants during interactions, and they are acutely aware that how they are perceived may differ from how they wished to communicate something. However, participants report that after having received the diagnosis, the understanding they gained about the condition helped them to become more aware of this disparity, and to share this information with others.

The fact that *Depression* was a theme identified as being a running thread throughout the lives of the participants is supported by existing research that shows that depression is highly prevalent in adults with autism, and that lack of accurate diagnosis is an issue associated with this (Ghaziuddin, Ghazziuddin, & Greden, 2002). There is some suggestion that individuals with high- functioning autism are more likely to develop depression due to greater social awareness that may affect feelings of not fitting in, however, the authors do not discuss depression as a reactive disorder in greater detail. More research into the relationship between depression and autism is needed. Treating depression can only be successful when autism is diagnosed and treated alongside. However, treatment options for autism in adults are rare, along with the existing lack of appropriate services.

The existing depression is what led to many of the participants' *Experiences with mental health professionals and therapists*, a theme that was coloured by the negative experiences expressed by the participants, in particular the described ongoing lack of understanding of autism and how symptoms are expressed in adults. The participants represent only a small subset of the population of aging adults with autism, but their drive to educate mental health professionals, therapists and the public, is also driven by the lack of diagnoses for the majority of adults with autism. As one participant stated, the treatments for his depression and anxiety didn't work because the underlying and comorbid autism had not been diagnosed. Another participant stated how her depression improved greatly after getting an autism diagnosis, because it helped her make sense of her difficulties. The inability to obtain an accurate diagnosis of autism spectrum condition, or previous experiences of misdiagnoses are serious issues for older adults, who often feel that their life course could have been quite different, had they received their autism diagnosis earlier in life (Punshon, Skirrow, & Murphy, 2009). A retrospective chart study showed that the most common diagnoses prior to the autism diagnosis were anxiety, mood disorders and psychosis-related disorders (Guerts & Jansen, 2011). These findings highlight the necessity for better identification of autism in adults, and for professionals to receive the appropriate training that will enable them to identify the disorder.

Both themes of *Depression and Experiences with mental health professionals and therapists* ties in with the theme of the *inverted relationship between the level of education and career*. Depression interferes with the ability to work; and greater awareness of autism by mental health professionals, therapists, but also employers and colleagues, could mean greater success in achieving in the workplace for individuals with autism. Previous research had shown that the majority of adults with autism are either unemployed or underemployed in menial work (Gerhardt & Lanier, 2011; Taylor & Seltzer, 2011). However, high-

functioning adults who were diagnosed late in life appear to have a higher educational level than others, and were more able to live independently (Levy & Perry, 2011). These findings are partly reflected in the sample of this current study, however, although all participants live independently, they reported many difficulties, and although education levels were high, these were not matched by successful working careers. However, they identified as communication and social interactions as a major obstacle to successful integration in the workplace, and these themes are echoed in the findings of Müller, Schuler, Burton and Yates (2003), who interviewed adults with autism about their vocational support needs.

The participant as *autism expert* partly relates to their wish to educate and inform, however it can also be seen as how the individual defines their (autistic) self. All confess a natural curiosity and love of learning, which led them to pursue the acquisition of knowledge not just about their autism, but also in terms of gaining qualifications in education. They represent knowledge about autism not just based on their 'insider' position, but by individual achievements such as acquiring expert knowledge to train others, or pursuing research within the field of adult autism. This of course is not generalizable or representative of the population of adults with autism, however, there are a growing number of research projects which include researchers on the autistic spectrum, and autism advocates who are vocal about their experiences and wish to share them with the wider public (Milton, & Bracher, 2013).

Effects of the diagnosis

In spite of all participants receiving their diagnosis relatively late in life, the effects overall have had a beneficial impact on their lives. Although most participants reported that the diagnosis did little to nothing in terms of access to services or benefits, the benefits were felt in making sense of the past, which in turn enabled them to find coping mechanisms for present. One participant's comment that they were relieved that their difficulties were not due to a faulty character is an echo of existing research, which found similar expressions of relief and being able to redefine their 'self' (Punshon, Skirrow, Murphy, 2009). Their experiences were also reflective of a study on the experience of diagnosis for young people with autism, which suggested that themes such as 'disclosure delay' and 'providing explanations' were equally salient to receiving the diagnosis at a young age (Huws & Jones, 2008).

Participants reported that in the majority of instances, support and benefits were based on diagnoses other than the autism, either mental health or physical disability. However, although they stated that an improvement in the availability of services was crucial, the overarching response to what they wished to see improvement in the most, was

understanding of autism by those around them. One participant compared the situation to the slow and ongoing change in the public's perception and acceptance of homosexuality, with the hope that eventually a diagnosis of autism will lose the associated stigma.

The need to listen to how adults with autism experience living with the condition is important, as it impacts directly on identifying suitable services that accurately meet their needs. A qualitative study examining the experiences of parents of aging adults with autism identified themes that differed quite strongly from those that emerged during this current study (Griffith, Totsika, Nash, Roberts, Jones, & Hastings, 2012). For example, parents' experiences centred on the support they were providing, and their role of advocate. The adults in the current study did not mention parents much, or in the context of now having to care for them. However, a qualitative study exploring the support experiences of middle-aged adults with Asperger Syndrome identified themes that were similar to those identified in this current study, however, the authors warn that although research in this area is increasing, it is still limited, not reflecting the increasing demand for information (Griffith, Totsika, Nash, & Hastings, 2011).

The lack of available research on these identified themes, as well as other associated areas, is a serious issue for the growing population of older adults with autism spectrum conditions. This research adds to the understanding of the lived experiences of these adults, however, there are a number of limitations to this study. The sample for this scoping study is small, and presents a highly defined subset of the population of aging adults with autism in the UK. However, due to the nature of the study, it was not possible to interview adults that are non-verbal or have learning difficulties. The needs of adults on the lower end of the autism spectrum would be different and much more defined than those on the high-functioning end, and it is important to bear in mind that high-functioning cannot be equated with 'mild', a term most of the participants rejected. The aim of the study was to gain an understanding of the salient issues of growing older with autism from the perspective of the participants, rather than making assumption based on existing research into younger age groups. A number of findings have been reflected in related research, and it would be useful to further this research with a larger sample in order to see if findings can be generalised to the population of aging adults with autism (Müller, Schuler, & Yates, 2008). Because this phase was conceptualised as a scoping study, the findings of this study will form the basis for the second phase of interviews, which will aim to gain in depth understanding of some of the themes identified here. Although a qualitative study based on a small sample cannot be generalised, insights into the lived experiences of those with autism are valuable to translate research findings into gaining an understanding of the nature of how it is experienced.

However, it is recognised that autism research needs to listen to the needs of those with the condition in terms of foci for research. Pellicano, Dinsmore and Charman (2014) state that research in biology, brain and cognition (related to autism) overshadows research into other area. They highlight the approach of involving stakeholders in research in order to identify priority areas for research, yet this approach has not often been adopted for autism research. In conclusion, this study adds to the growing number of qualitative studies that aim to explore the lived experiences of older adults with autism, and identifies areas of interest for further research. The themes that emerged during analysis reflect many of the findings of existing studies, and support the call for deeper involvement of autistic adults in the research process in order to accurately identify needs and develop appropriate support services.

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