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Ageing and autism: loneliness and isolation

Why study autism and ageing?

Initially understood as a childhood disorder, autism is now known to be lifelong with comparable prevalence rates throughout the lifespan (Brugha et al, 2011). However, research has mostly focused on autism in childhood, while studies of autism in older age are very limited (Howlin and Moss, 2012; Mukaetova-Ladinska et al, 2012). Given an ageing population and increasing diagnosis rates (King and Bearman, 2009), it is important to investigate the outcomes and experiences of older autistic adults.

Aims of the research

It is plausible that the experiences of older people might differ from younger adults, given the likelihood that older people are without a diagnosis for most of their lives (Brugha et al, 2011), and the significant transitions that present in older age, such as retirement, loss of partner and ill-health (Zaidi, 2014). The way in which autistic people navigate these changes is largely unknown, and our research aimed to explore their experiences in older age (see Hickey et al, 2017).

To participate in the research, individuals needed to:

- be a minimum of 50 years of age
- reside in the UK
- have a diagnosis of an autism spectrum disorder without comorbid intellectual disability
- be able to communicate verbally in English

In total, 13 individuals participated, four recruited via an NHS diagnostic clinic and nine via autism support and social groups in London. All participants received their autism diagnosis in adulthood, on average six years prior to the study. Three of the study participants were married or cohabiting.

A semi-structured interview schedule was developed based on previous qualitative research with autistic people, and refined with assistance from an older autistic person. The interview transcripts were analysed using thematic analysis (Braun and Clarke, 2006).

Study results

While we focus here on experiences of isolation and loneliness, the overall themes that emerged from the thematic analysis are outlined in detail in the research paper (Hickey et al, 2017).

Loneliness

Loneliness seemed to be a defining feature of participants' experiences both growing up and getting older – in fact, this remained distressing throughout their lives. People particularly focused on the lack of romantic relationships, and described a sense of longing. Loneliness was less prominent in the accounts of those who were married or cohabiting, suggesting that one significant attachment relationship buffered the effects of social isolation, but isolation and a sense of disconnection from others were still features of their experience.

For participants who had worked, the social aspects of work were experienced as stressful, and the loss of work-based social contact following resignation or retirement was sometimes experienced as a relief.

Individuals described a sense of difference emerging in their early lives, often abetted by experiences of bullying in school. They deliberately acquired social knowledge by observing other people, and applied this knowledge to themselves to reduce the visibility of their difference and better 'fit in', although an internal sense of difference persisted.

In early adulthood, people made deliberate efforts to reach out to people and establish a social network for themselves. Structured activities with definite start and finishing points were preferred, and hobbies/interests gave some people access to a network that shared their interests. Most remained committed to engaging with others throughout their lives, although one participant said that his negative experiences of trying to socialise had prompted him to deliberately withdraw from social contact.

Alone but not lonely

Of course, it is possible to be alone without being lonely. Participants perceived this distinction and sometimes saw aloneness positively, in that it allowed them to pursue hobbies and interests which in turn provided experiences of immersion, accomplishment and mastery, and helped to regulate anxiety. Aloneness was also seen as safe, in contrast with the anxiety associated with attempting to engage socially with people.

Meeting other autistic people

Following diagnosis, a new avenue for social contact emerged: other autistic people. Most participants had involvement in autism groups after diagnosis. Some engaged with autism groups aiming to increase their social contacts, whereas most primarily engaged to access information about autism, with friendship or emotional support seen as less important.

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Meeting other autistic people offered a sense of shared experience, understanding and acceptance, and allowed people to see aspects of their experience as 'normal', thereby reducing any negative feelings they may have ascribed to themselves from others. It also enabled people to compare themselves to other autistic people and notice their own particular strengths or abilities in comparison, and to learn from other people, knowledge which could then be applied to their own circumstances.

Two participants noted that focusing on something tangible (for example a book at a book club specifically for autistic people) allowed conversation to flow more easily during groups.

Preventing loneliness

The older autistic people in this study described substantial isolation and loneliness throughout their lives, alongside lifelong efforts to reach out and connect with others. Given the known detrimental effects of isolation and loneliness on physical, mental and cognitive health (eg Beutel et al, 2017; Bhatti and Haq, 2017; Livingston et al, 2017), preventing and reducing loneliness is of paramount importance.

In terms of social loneliness, for neurotypical people group interventions that have an education or training focus and require active participation seem to work best for reducing loneliness (Cattan et al, 2005; Dickens et al, 2011). Further exploration and research needs to be carried out in this area to see if this may also apply to the autistic population. We would suggest that older autistic people be encouraged to get involved in groups with a specific focus and active participation, ideally small in size with definite start and end points. Using an interest/hobby can be a useful avenue for accessing a social network.

Following diagnosis, involvement with other autistic people seems very useful, and we feel that information on autism-specific groups should be routinely provided. Autism-specific services should consider offering social groups, which may help in improving social understanding and functioning, and in turn reduce loneliness (Spain and Blainey, 2015). Groups such as these may also equip people with the confidence to access community-based groups.

The emphasis of research on early intervention means that interventions applicable to adulthood, such as dating skills, are under-developed (Shire, 2013). Feedback from social groups suggest participants want more explicit focus on dating and romantic relationships (Blainey and Spain, 2014). Targeted support such as this may help the development of social knowledge pertaining to intimate relationships, which could help reduce emotional loneliness in the longer term.

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