'I'm not mad, bad, and dangerous...simply wired differently' — a positive psychology exploration of quality of life in autistic women without intellectual disability

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Introduction

Quality of life is the view individuals hold of their standing in life, guided by their ambitions, hopes, ideals, apprehensions, and the socio-cultural context in which they reside (WHOQOL Group, 1998).

Typically, autistic individuals are reported to demonstrate poorer quality of life than the general population (Mason et al., 2018). However, our current understanding is limited in 3

- 1 Autism research has overwhelmingly been deficit- and behaviour-focused. However, quality of life is internally constructed and identified through personal positive narration of experiences. We aimed to address this through the use of a positive psychology and neurodiversity-affirmative stance to help establish aspects of quality of life pertinent to the community.
- 2. Quality of life research tools were developed to reflect the experiences of a broad population (including typically developing individuals). We used a qualitative approach to develop an in-depth bottom-up understanding of the factors important for good quality of life for autistic women to avoid potential constraining effects of generalised measures.
- **3.** Autistic women are one of a number of under-represented groups in autism research, with historical focus being particularly placed on the experiences of boys/men (Shefcyk, 2015). This study offers insight into the specific aspirations of autistic women, who recognisably have different profiles of ability and trajectory and different priorities (de Giambattista et al., 2021; Mandy et al., 2018).

Method

Semi-structured interviews

MANCHESTER

- Interpretative Phenomenological Analysis
- Expert-by-experience collaboration Autism@Manchester

Procedure

- Advertised via social media and mailing lists
- · Videocall, telephone call, or web-based text-exchange interviews, depending on participant preference
- Videocall and telephone call interviews ranged 36-71 minutes, text-exchanges were approximately 90 minutes

Inclusion Criteria

- ≥ 18 years old
- · Autism diagnosis from a certified professional/institution
- · Currently identify as female and were assigned female at birth
- UK Citizen
- Fluent English speaker
- Without an intellectual disability (self-defined)

Participants

- n = 10
- Age in years M(SD):41.9(14.75)
- Age when diagnosed M(SD): 37.9(16.65)

Results



Themes

Example

Quotes

Key

Positive sense of self

Self-understanding Subordinate Mental health

Sense of purpose

Personal strengths

"there are a lot of things that I sort of thought were my fault erm or I was blaming myself for but then I realised there's an actual reason behind why I don't understand certain things erm so

that was just like a massive

weight off my shoulders"

· Diagnosis enabled improved selfunderstanding and confidence, facilitating development of positive sense of self.

Interpretations • Developing positive sense of self aids autistic women in being active agents in creating their own positive outcomes through identifying their strengths and interests and aligning pursuits accordingly

Feeling supported **Autistic community** Family **Understanding from** Romantic relationships

"it's like coming home [connecting with the autistic community], it's like finding your people, you know, suddenly people think like you do, you're not having the explain things to them"

Friendships

- · The autistic community is important for feeling supported through normalisation of pathologized behaviours
- Suggests a paradigm shift towards a neurodiversityaffirmative rather than a medical model 'deficit' account of autism may aid improved quality of life for autistic people, through normalisation and acceptance of autistic traits

Autonomy Creating the ideal environment Physical health Self-accommodations

Special interests

"the beauty of being autistic is that like if we enjoy something we can really get into it [laughs] erm so I think it's just sort of nice to allow yourself to do that"



- · Participants reported high awareness of their needs, interests, and values, and associated good quality of life with selfaccommodation of these
- · This raises questions regarding the appropriateness of current quality of life measures for autistic women as the underlying factors of good quality of life may differ from non-autistic counterparts

Inclusivity Non-autistic understanding of the autistic experience Communicating needs

Accommodations

Accessibility of services



"it feels like I'm a lefthanded person in a right-handed person's world"



- Understanding from nonautistic people was indicated to reduce pressure to perform in a way untrue to character and remove barriers in achieving goals and engaging in desired activities.
- · Quality of life may be better conceptualised as the goodness of fit between the autistic woman and her environment as opposed to her ability to cope in nonautistic spaces

Future Directions

- 1. Further participatory research with wider autistic populations such as those with intellectual disability and gender-minority identification is recommended for exploration of important underlying quality of life factors for these groups.
- 2. Recommend clinically adapting quality of life measures for autistic women to address the need for greater clinician understanding of the particular aspirations of this group.
- 3. Research should be completed collaboratively with autistic individuals to ensure accurate representation of voices and priorities.
- 4. The findings of this study may serve as a basis for further exploration in how to best support this group during assessment, diagnosis, and post-diagnosis to sheftyk, A. (2015). Count us in: addressing gender disparities in autism research. Autism, 19(2), 131-132. DOI: 10.1177/1362361314566585 ensure and promote good quality of life for other women.

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de Giambattista, C., Ventura, P., Trerotoli, P., Margari, F., & Margari, L. (2021). Sex Differences in Autism Spectrum Disorder: Focus on High Functioning Children and Adolescents. Frontiers in Psychology, 12, 539835. DOI: 10.3389/fpsyt.2021.539835

Mandy, W., Pellicano, L., St Pourcain, B., Skuse, D., & Heron, J. (2018). The development of autistic social traits across childhood and adolescence

Mason, D. McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J.R. (2018). Predictors of quality of life for autistic adults. Autism Rese

WHOQOL Group (1998). The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. Social Science & Medicine, 46(12), 1569-1585. DOI: 10.1016/S0277-9536(98)00009-4