

'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 key ways:

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

Design

- Semi-structured interviews
- 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

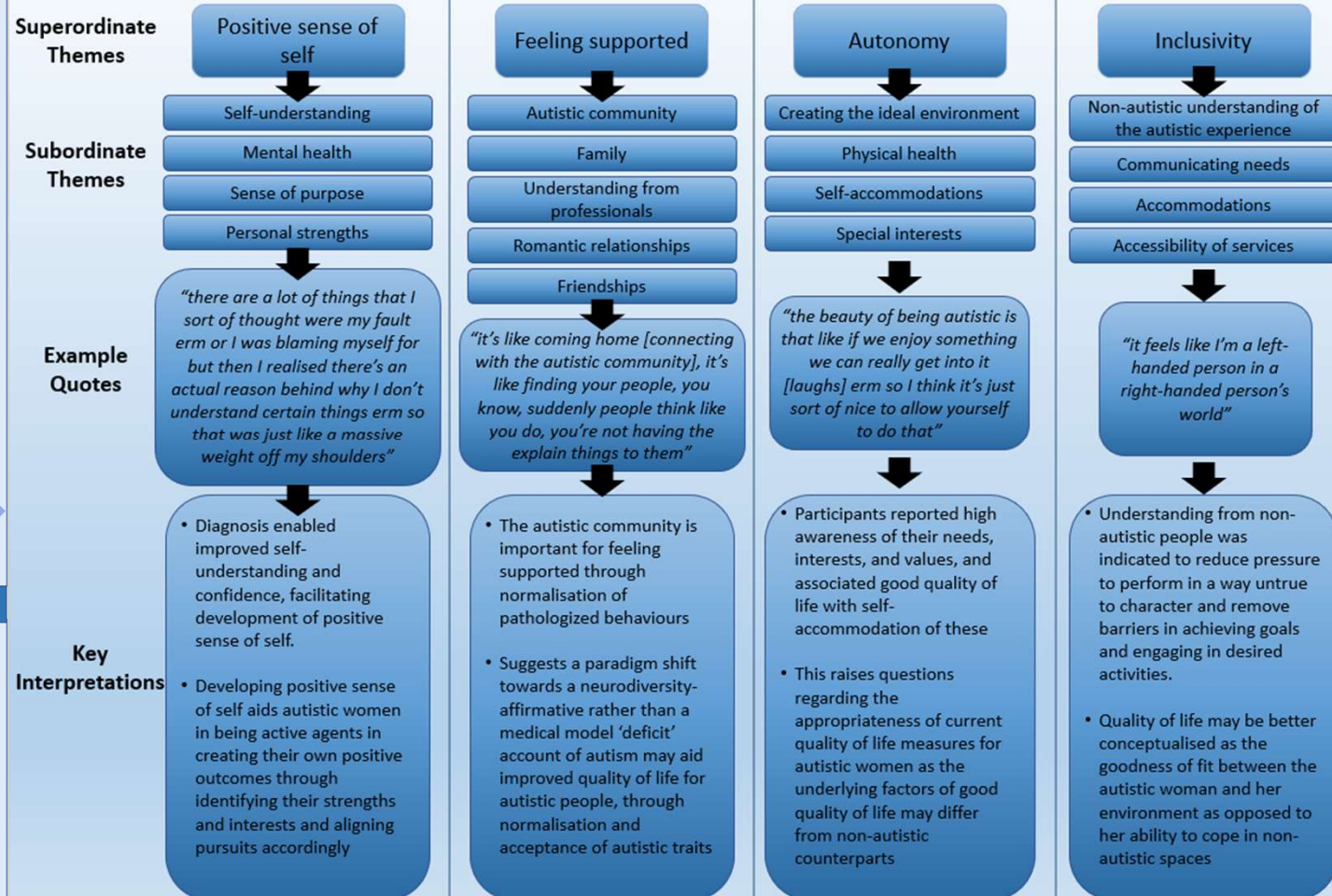
Inclusion Criteria

- ≥ 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



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 ensure and promote good quality of life for other women.

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