

# Northumbria Research Link

Citation: Mason, D., Mackintosh, J., McConachie, H., Rodgers, J., Finch, Tracy and Parr, J. R. (2019) Quality of life for older autistic people: The impact of mental health difficulties. *Research in Autism Spectrum Disorders*, 63. pp. 13-22. ISSN 1750-9467

Published by: Elsevier

URL: <https://doi.org/10.1016/j.rasd.2019.02.007>  
<<https://doi.org/10.1016/j.rasd.2019.02.007>>

This version was downloaded from Northumbria Research Link:  
<http://nrl.northumbria.ac.uk/id/eprint/39062/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

Title: Quality of Life for older autistic people: The impact of mental health difficulties

Author names and affiliations:

Mason, D.<sup>b</sup>, Mackintosh, J.<sup>a</sup>, McConachie, H.<sup>a</sup>, Rodgers, J.<sup>b</sup>, Finch, T.<sup>c</sup>, and Parr, JR.<sup>b,d</sup>

<sup>a</sup> Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

<sup>b</sup> Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

<sup>c</sup> Department of Nursing, Midwifery and Health, Northumbria University, Newcastle upon Tyne, UK

<sup>d</sup> Northumberland, Tyne and Wear NHS Foundation Trust

Author e-mail addresses:

[David.Mason@newcastle.ac.uk](mailto:David.Mason@newcastle.ac.uk)

[joan.mackintosh@newcastle.ac.uk](mailto:joan.mackintosh@newcastle.ac.uk)

[helen.mcconachie@newcastle.ac.uk](mailto:helen.mcconachie@newcastle.ac.uk)

[jacqui.rodgers@newcastle.ac.uk](mailto:jacqui.rodgers@newcastle.ac.uk)

[tracy.finch@northumbria.ac.uk](mailto:tracy.finch@northumbria.ac.uk)

[jeremy.parr@newcastle.ac.uk](mailto:jeremy.parr@newcastle.ac.uk)

Corresponding author:

David Mason; Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK;

[David.Mason@newcastle.ac.uk](mailto:David.Mason@newcastle.ac.uk)

## Abstract

**Background:** Having a mental health condition is related to significantly lower subjective Quality of Life (QoL) for people on the autism spectrum. Many autistic people do not participate in so-called 'normative' outcomes, i.e. the achievement of lifecourse goals judged to be important by adults in the general population (e.g. being employed). This study aimed to investigate whether there is an association between the presence of mental health conditions, subjective QoL and participation in normative outcomes in older autistic people.

**Methods:** 69 autistic people (n=48 males) aged 55 years and over were identified from two studies that are part of the UK Autism Spectrum Adulthood and Ageing research programme. Participants provided demographic data to establish normative outcome participation, and completed the World Health Organisation (WHO) QoL measure (WHOQoL-BREF) and the Hospital Anxiety and Depression Scale (HADS). Illustrative quotes focusing on normative outcomes were available from in-depth interviews (n=8).

**Results:** QoL scores across all domains were lower for individuals who met indicative clinical cut-offs for depression ( $F(8,126)=6.171, p<0.001$ ); findings were similar for anxiety ( $F(8,126)=3.902, p<0.001$ ).

Subjective QoL did not differ according to participation in normative outcomes ( $F(12,124.64)=1.363, p=0.192$ ). The illustrative quotes suggested that aspects of daily life were related to QoL (i.e. friendships).

**Conclusions:** For older autistic people, the presence and severity of a likely mental health condition (i.e. anxiety and depression) were associated with poorer QoL. However, participation in general population lifecourse goals may not well represent QoL of older autistic people, suggesting that service supports should be individually responsive.

Keywords:

Quality of Life, ageing, mental health, normative outcomes, lifecourse goals

## Introduction

Mental health conditions significantly impair Quality of Life (QoL; Rapaport, Clary, Fayyad, & Endicott, 2005) and are highly prevalent in individuals on the autism spectrum (Ghaziuddin, Ghaziuddin, & Greden, 2002; Matson & Goldin, 2013). QoL is a multi-faceted construct that is usually taken to include physical, psychological, and social domains but can also include others (for example, financial and emotional wellbeing, and activity; Felce & Perry, 1995). The World Health Organisation (WHO) QoL measure, the WHOQoL-BREF, has to date been the measure used most frequently with autistic people (Ayres et al., 2017). It contains four domains assessed via 24 items - Physical, Psychological, Social, and Environment (Harper, 1998); two additional items measure global evaluations of health and QoL. This self-report measure focuses on subjective QoL including an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Harper, 1998; Skevington, Lotfy, & O'Connell, 2004; Skevington & McCrate, 2012). Using the WHOQoL-BREF, QoL is often reported to be significantly lower for autistic people compared to the general population (Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamp-Becker, Schröder, Remschmidt, & Bachmann, 2010; Lin, 2014). Likewise, several studies using different QoL measures have reported lower QoL for autistic adults. Using the SF-36, van Heijst and Geurts (2015) found QoL to be significantly lower in a sample of older aged autistic adults compared to age-matched controls (age range 51-83 years). Similarly, using the SF-12, Khanna, Jariwala-Parikh, West-Strum, and Mahabaleshwarkar (2014) found significantly lower physical component and mental component scores for autistic adults compared to general population norms (with age ranging from 18-64 years).

Many studies have demonstrated that the presence of a mental health condition is associated with significantly lower subjective QoL for autistic people (Kamio, Inada, & Koyama, 2013; Khanna et al., 2014; Mason et al., 2018). However, some studies have not found such an association; Hong, Bishop-Fitzpatrick, Smith, Greenberg, and Mailick (2016) found that the Adult Behaviour Checklist was not a significant predictor of QoL (though perceived stress was).

Other variables have shown a mixed association with QoL. Age, IQ, and autism spectrum severity did not significantly predict QoL in the study by van Heijst and Geurts (2015); however, the sample size (n=24) may have been insufficient to detect an effect of predictors. In contrast, in a larger sample with a broader age

range (n=52, aged 33-68 years), increasing age was found associated with decreased social QoL (Moss, Mandy, & Howlin, 2017). In a study of 370 people, older autistic people (aged 41-60) reported significantly lower environmental QoL than younger autistic people (aged 16-25; Mason et al., 2018).

Clearer understanding of the needs of older autistic people is essential to ensure that adequate and appropriate interventions can be put in place to support them (Mason et al., 2018; Michael, 2016; Wise, Smith, & Rabins, 2017; Wright, Wright, D'Astous, & Wadsworth, 2016). Bishop-Fitzpatrick et al. (2016) identified three classes from a sample of autistic adults (n = 180, aged 23-60, the majority <36 years). There was a 'greater dependence' class, a 'good physical and mental health' class, and a 'greater independence' class. These classes emerged from an analysis of 'normative outcomes' (defined as 'employment', 'independent living', and 'social engagement', i.e. the conventional markers of adulthood) and objective QoL (defined by physical health status, mental health status, quality of neighbourhood, and family contact). It was striking that those in the 'greater independence' group met more normative outcomes yet were also significantly more likely to have mental health problems than the 'good physical and mental health' group or the 'greater dependence' group (with a probability of 0.90 vs 0.26 and 0.90 vs 0.58 respectively). This suggests that, for autistic people, participating in normative outcomes (i.e. having friends, employment, and living independently) does not necessarily contribute to sound mental health, or vice versa. One interpretation of this finding could be that there is a cost to the individual in terms of stress and poor mental health associated with social performance (Howlin & Magiati, 2017). Indeed, Hull et al. (2017) report that social camouflaging is both draining, and worry-provoking (i.e. worrying about making a faux pas).

Why focus on older autistic people? The first groups of people diagnosed as autistic are now adults and as they age there is a growing need for attention to the individual support requirements of this population (Gerhardt & Lainer, 2011). In addition, many older people may not have received a diagnosis and consequently may be receiving inadequate services, or relying on families to provide care (Mukaetova-Ladinska, Perry, Baron, Povey, & Autism Ageing Writing Group, 2012). Furthermore, there are high rates of co-occurring physical and psychological comorbidities for older autistic people (Patra, 2016) which have been shown to be associated with lower QoL (Kamio et al., 2013; Mason et al., 2018). This has also been found in the general population where those deemed 'sick' (including psychiatric conditions) reported significantly lower QoL on all four WHOQoL-BREF domains compared to those in the 'well' group (Skevington & McCrate, 2012). Depression does lead to lower QoL compared to the general population; yet

those who depression goes into remission report comparable QoL to the general population (Angermeyer, Holzinger, Matschinger, & Stengler-Wenzke, 2002).

Therefore, with respect to QoL, there is a pressing need to identify what contributes to the QoL of older autistic people. Some factors (i.e. IQ and age) have been explored. However, to date, no studies have investigated how participation in normative outcomes is related to subjective QoL specifically with older autistic people. Age and IQ are not amenable to change; however interventions could support individuals in participating in normative outcomes if such outcomes are meaningfully related to QoL. Building on the above findings, the current study sought to investigate two separate research questions in a sample of older autistic people: (i) how is subjective quality of life (measured by WHOQoL-BREF domains), associated with depression and anxiety?; and (ii) are normative outcomes associated with subjective quality of life?

We hypothesised that increased probability of anxiety or depression would be associated with significantly lower subjective QoL. We predicted that people who met 'clinical caseness' for both depression and anxiety concurrently would be more likely to report significantly lower QoL on all domains of the WHOQoL-BREF than those who met clinical caseness for either anxiety or depression alone. We conducted exploratory analyses to investigate any differences in WHOQoL-BREF domain scores according to normative outcome scores. We also augmented our quantitative analysis post hoc by reviewing interview data collected from a small number of the respondents, to explore further what older autistic people thought contributed to their quality of life, and the relationship of mental health problems with participation in normative outcomes. This methodology was adopted because integrated quantitative and qualitative data can help elaborate on the relationship between variables of interest, and can lead to the generation of new hypotheses (Bryman, 2016).

## Method

### *Participants*

Participants were aged 55 years or older and were recruited via the Adult Autism Spectrum Cohort-UK (ASC-UK) longitudinal study (<http://research.ncl.ac.uk/adulthoodautismspectrum/>). The ASC-UK study explores the lived experiences of autistic adults from across the lifecourse, and using a registration questionnaire, collects

information about demographic status and autism characteristics. Subjective QoL is measured using the WHOQoL-BREF. Self-report of QoL and of mental health, using the Hospital Anxiety and Depression Scale (HADS), was available from 69 older ASC-UK participants from a larger study of QoL of autistic adults (McConachie et al., 2018). 48 males and 21 females were included (mean age 61.5 years, SD=5.27). Participants received their autism spectrum diagnosis at mean age 56.4 years (SD=7.15) (see Table 1). One participant reported a diagnosis of intellectual disability, and eight (12.0%) reported requiring help to complete the ASC-UK demographic questionnaire (reasons given included help with clarifying the question, did not like reading or writing, and help with how much information to write).

[Table 1 about here]

As part of the ASC-UK cohort study, a series of interviews were carried out with a purposive sample of autistic participants (see Analysis, and box 1, below). These interviews were about their lives and lived experiences, including what participants thought contributed to their QoL. Interview data from participants who were aged 55 or over were examined for the current paper, i.e. 5 males (aged 59, 61, 66, 68, and 71 years) and 3 females (aged 56, 59, and 65 years).

### *Materials and design*

A cross-sectional design was employed to assess QoL in the sample of older autistic adults. Measures were completed on paper or electronically as the participant preferred. Administration of the HADS and the WHOQoL-BREF followed the procedure for the measure. No adjustments were made to the wording or format of the questions. However, participants were informed that they could ask a trusted person to help them complete the measure, or the participant could contact the research team for help with the measures.

*ASC-UK registration questionnaire.* This is a 78 item demographic questionnaire administered to autistic people when they join ASC-UK. Data are collected across 10 domains of the participant's life: diagnosis including Autism, Autism Spectrum Disorder, Asperger syndrome; everyday life including relationship status; home life including living alone and/or being supported in the home; employment status; education including type of school and qualifications achieved; support, including who supports the adult and how often support

is needed; mental health/neurological conditions including current diagnoses and type of medication/therapy; physical health conditions; and autism spectrum in other family members.

*Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983). This 14 item measure has two subscales, each comprising 7 items, designed to screen for depression and anxiety in clinical settings. Each item is scored 0-3, hence each subscale score ranges from 0-21. Indicative clinical cut-offs are based on normative data and used in these analyses (Crawford, Henry, Crombie, & Taylor, 2001): 0-7 normal, 8-10, borderline, and 11+ indicates 'clinical caseness'. Cronbach's alpha is 0.82 for the depression subscale and 0.83 for the anxiety subscale, indicating good internal consistency (Bjelland, Dahl, Haug, & Neckelmann, 2002); for the present study, the anxiety subscale showed good internal consistency ( $\alpha=0.85$ ) and acceptable consistency for the depression subscale ( $\alpha=0.67$ ). This measure has recently been validated for use with autistic people (Uljarević et al., 2017).

*WHOQoL-BREF* (Harper, 1998). This 26 item measure comprises 4 domains (Physical QoL, e.g. 'How well are you able to get around?'; Psychological QoL, e.g. 'How meaningful is your life?'; Social QoL, e.g. 'How satisfied are you with your personal relationships?', and Environment, e.g. 'Have you enough money to meet your needs?'), and two global items (one overall QoL rating and one overall rating of health). Items are scored 1-5 and three items are reverse scored. Raw scores are calculated (the mean of items for each domain) and converted into a domain score. Transformed scores, used in our analyses, can be calculated to yield domain scores ranging from 0-100; higher scores indicate better QoL. Cronbach's alpha has been reported for each domain: Physical, 0.87; Psychological, 0.74; Social, 0.55; and Environment, 0.74. This demonstrates adequate to good internal consistency (Skevington et al., 2004), comparable to the present study: 0.85, 0.82, 0.60, and 0.81 respectively. This measure has recently been validated for use with autistic people (McConachie et al., 2018).

### *Ethics*

Favourable ethical opinions were provided for the studies by Wales REC 6 (reference - 16/WA/0295) and by Wales REC 5 (reference - 14/WA/1066).

### *Analysis*

*Quantitative.* Participants' scores for each HADS subscale were computed and categorised using the criteria given above (Bell, Fairclough, Fiero, & Butow, 2016; Crawford et al., 2001). Note that as each participant is categorized for each scale (anxiety and depression) participants could score in the 'normal' range for one scale and at 'clinical caseness' for the other scale. Analyses were conducted on the full sample, and then without one participant who reported having an intellectual disability, and without those who reported needing help with completing the ASC-UK demographic questionnaires. Excluding these participants did not affect the pattern of results or main findings and so the results of the full sample are presented.

The ASC-UK registration data used in analyses were: employment status (including unemployed, supported employment, retired, student, etc.); friends they could spend time with; living arrangements (living alone or not); and whether receiving support in daily living (i.e. at home, preparing food or personal hygiene; at work, completing tasks, interacting with co-workers etc.). 'Normative outcome' scores were created for each participant based on the three criteria that are often measured in outcome studies (e.g. Henninger & Taylor, 2013): current employment (coded '1' if in employment or vocational or supported employment, otherwise coded '0'), friends to socialise with (coded '1' if the person did have friends to socialise with, otherwise coded '0'), and living status (coded '1' if the person lived independently i.e. alone, with a partner/wife, with friends etc., otherwise coded '0'). The score for each variable was totalled to give each individual a score between 0-3. A higher score indicated more normative outcomes participated in by the person. Table 1 shows the number and proportion of participants who scored 0, 1, 2, or 3.

All analyses were conducted using SPSS 23.0. Missing data were handled as follows: the WHOQoL-BREF data cleaning method was followed (data discarded if more than 20% missing data). Estimation maximisation was used to impute other missing data. This method is superior to mean substitution and, given the small sample size, avoids the biases associated with list wise deletion (Myers, 2011). All significance levels were set at 0.05 and Bonferroni correction was applied to all MANOVA post hoc analysis to protect against increased type 1 error rate associated with multiple comparisons.

*Extraction of illustrative quotes.* For a parallel study in-depth interviews were conducted with 30 autistic adults from ASC-UK across a broad age range, and covered a range of topics that included a set of general questions about the individual's life experiences, followed immediately with an open-ended question about quality of life (see box 1). Following these initial questions, the topic guide was intentionally broad to allow for

the participant to focus on the topics that were important to them. Interviews were conducted by the second author and lasted 37-91 minutes. Interviews were audio recorded and professionally transcribed with participants' consent. The second author checked, cleaned and anonymized the transcripts for analysis. For this paper, sections of the full interview transcripts that mentioned QoL were identified by the original interviewer.

[Insert Box 1 about here]

**Box 1: ASC-UK qualitative interview topics/questions**

General life experiences:

- What aspects of life go well for you nowadays? What is more difficult?
- Looking back, what has gone well for you over the years? And was there a period when things went less well? Why do you think that was? Looking back, do you think you needed more support? In what way? What might have been useful to you?
- How satisfied with your life are you, in relation to your goals, your expectations, and things that concern you?

Quality of life (first question after general questions):

- How satisfied with your life are you in relation to your goals, your expectations and things that concern you?

Other topics covered: diagnosis, post-diagnosis, physical health, mental health, personal relationship, living arrangements, social support, social communication, education, transitioning and employment

For this paper, we extracted data from the main analysis for all participants who were aged 55 and over. Sections of the full transcripts were identified where the discussion involved QoL. In order to augment the quantitative analysis (as this is a preliminary study looking at normative outcomes and subjective QoL) we looked for 'illustrative quotes'. 'Illustrative quotes' were defined as statements or examples that related to the three normative outcomes analysed in the quantitative analysis: employment, independent living, and social engagement.

## Results

### *Questionnaire results*

Table 2 includes descriptive data for each WHOQoL-BREF QoL domain and the depression and anxiety scores for the HADS. Additionally, the proportion of participants within, above, and below one standard deviation of normative WHOQoL-BREF scores (Skevington & McCrate, 2012) is included.

[Table 2 about here]

*HADS categories and subjective QoL.* A 3 x 4 MANOVA was computed for HADS depression scores. There was an overall effect of HADS depression category on QoL domains (Wilk's lambda=0.516,  $F(8,126)=6.171$ ,  $p<0.001$ ). There was a significant main effect of HADS depression category on each subscale of the WHOQoL-BREF ( $p<0.001$  for Physical and Psychological QoL,  $p=0.02$  for Social QoL, and  $p=0.028$  for Environment). A 3 x 4 MANOVA was computed for HADS anxiety scores. There was an overall effect of HADS anxiety category on QoL domains (Wilk's lambda=0.642,  $F(8,126)=3.902$ ,  $p<0.001$ ). There was a significant main effect of HADS anxiety category on three subscales of the WHOQoL-BREF: Physical, Psychological, and Environment (all  $p<0.001$ ). See Table 3 for mean (and standard deviation) QoL ratings for participants categorised as normal, borderline, or clinical caseness for both HADS depression and anxiety subscales. Post hoc comparisons, with Bonferroni correction, are highlighted in Table 3.

Post hoc analyses revealed that across all QoL domains QoL scores were significantly higher for individuals in the normal caseness domain on the HADS depression and anxiety subscales compared to those in the clinical caseness group, with the exception of the Social QoL domain where there were no differences between groups based on level of anxiety. As one would expect the pattern of results distinguishing QoL scores between those in the borderline HADS categories compared to those clearly above and below indicative clinical cut off is somewhat mixed. For Physical QoL and Environment QoL there is no significant difference between those in the normal and borderline categories for depression, whilst there are differences between normal and borderline groups for Psychological and Social QoL. With regard to anxiety there are no significant differences in any QoL domain between those classified as normal or borderline for anxiety. A similar pattern of mixed results is found if we compare QoL scores between those in the borderline and clinical caseness groups. For depression we find significant differences between those in the borderline

category and those in the caseness category for Physical and Psychological QoL (with QoL lower in the caseness group) but not for Social and Environment QoL, whilst for anxiety the only significant difference between those in the borderline and clinical caseness groups is in the Physical QoL domain.

[Table 3 about here]

*Concurrent clinical caseness and subjective QoL.* We were also interested in determining whether the presence of clinical caseness in two mental health condition, compared to none or one indicated a difference in each QoL domain score. To address this a 3 x 4 MANOVA was computed for the presence or absence of concurrent anxiety and depression above clinical caseness based on HADS cut-offs (normal or borderline, one clinical caseness, 2 clinical caseness). Clinical caseness had an overall effect on QoL domains (Wilk's  $\lambda=.478$ ,  $F(8,126)=7.023$ ,  $p<0.001$ ). There was a significant main effect of Level of clinical caseness on each QoL domain ( $p<0.001$  for Physical and Psychological QoL,  $p=0.019$  for Social QoL, and  $p=0.001$  for Environment QoL). See table 4 for means and standard deviations of QoL data for each level of caseness. Post hoc comparisons and effect sizes are also indicated in Table 3. As can be seen from Table 3 we found that individuals who met clinical caseness for both anxiety and depression had significantly lower QoL scores across all domains compared to those who did not meet clinical caseness in either. We also found that individuals who met clinical caseness for both anxiety and depression had significantly lower Physical and Psychological QoL scores compared to those who met clinical caseness for only anxiety or depression. We did not find a difference in either Social or Environment QoL for those who met either one or two clinical caseness cut offs.

In summary, as hypothesized, QoL scores were significantly different between participants who self-reported levels of either depression or anxiety indicative of clinical caseness and those who reported no anxiety or depression. Additionally QoL scores were significantly lower for participants who self-reported the presence of both anxiety and depression at clinical levels compared to those who reported clinical caseness for one mental health condition.

*Normative outcomes and subjective QoL.* We were also interested in determining whether QoL differed significantly according to participation in normative outcomes. A 4 x 4 MANOVA with age at diagnosis entered as a co-variate (to account for the high mean age of diagnosis) was computed for the normative

outcome score (4 levels; 0, 1, 2, and 3) and QoL domains (Physical, Psychological, Social, Environment). The results indicated that QoL scores were not significantly different according to participation in normative outcomes (Wilk's lambda=0.660,  $F(12,69.08)=0.979$ ,  $p=0.478$ ).

#### *Illustrative quotes taken from interviews*

The following quotes were selected from interview transcripts. Quotes were selected if participant talked about the normative outcomes of employment, independent living, and social engagement (Bishop-Fitzpatrick et al., 2016).

*Friendships:* Three of the eight participants discussed limited social interaction with friends several times. This was reported as a source of difficulty or stress, as well as potentially a pleasure for many of the participants. This was exemplified by the following quote: *"I don't have lots and lots of friends. Even when I go to meet friends, for a drink or for the football or whatever, I've got to think about it quite a bit before I go and mentally plan myself"* (Male, aged 68).

However, one participant reported that they felt they had developed social skills as they got older. The following quote suggests that emotional responsiveness is important in social interaction and that developing this skill had led to improved friendships: *I think I have an ability now to make friends, I think I can show my emotions a bit more, that has concerned me but some of my relations and my parents said that they felt at times that I didn't always show my emotions* (Male, 61 years).

*Employment:* One participant commented on how difficult it had been to find a job despite being educated to a high level: *"Despite the fact that I had a Bachelor of Arts degree in History and English from University, it was very, very difficult to get another job. What I decided to do was fill my time with doing things I quite liked."* (Male, 61)

One participant described how their employment contributed to their poor mental health: *"They said it could be a comorbid condition, and things like changing my routine and stresses at work, environment and so on, caused a lot of problems, and I've been up and down with my mental health issues."* (Female, 56).

*Independence:* Participants described difficult aspects of responsibility related to independent living, such as daily living tasks (i.e. meal preparation, paying bills, etc.), or that they found general organization difficult and that managing too many tasks at once was stressful. For example, one participant described pressures of shopping: *"I can't stand lots of lists... then at the last minute if my wife says, "While you're there could you," that's no good to me. That just makes me panic, too much to remember, I can't go and pay that bill and do that, and keep the change in that pocket... No. It's too much for me that. I have problems with that sort of thing."* (Male, 68)

Another participant talked about how their husband was supportive and looked after their needs:

*"My husband generally does the washing, cleaning, I'll help along where I can but he reminds me to take medication. He makes sure my hair is brushed and he's taken over from my mother in terms of making sure that I'm appropriately dressed... because I struggle with buttons and stuff."* (Female, 56)

## Discussion

This study used quantitative data, supplemented with illustrative quotes, to provide some insight into QoL for a sample of older autistic people. The illustrative quotes were chosen post hoc to describe experiences relevant to the QoL of older autistic people. This approach is useful when quantitative data alone may miss important information that can be obtained from the participants (Bryman, 2016). The findings of the present study indicate that QoL is reported to be significantly lower for individuals who meet indicative clinical caseness based on self-reported symptoms of both anxiety and depression, from a robust mental health measures that has been validated for use with autistic adults. QoL scores were significantly lower across all QoL domains when clinical levels depression were reported. Interestingly significantly lower levels of QoL were found across all domains of QoL when clinical levels of anxiety were reported with the exception of the Social QoL domain, where no significant differences in QoL score were found according to levels of anxiety. This is perhaps interesting in the context of autism being a social communication disorder and warrants further exploration. We also found that QoL scores across all domains are significantly lower for those experiencing both depression and anxiety concurrently. To date, mental health conditions have been shown to negatively predict QoL for autistic people (Kamio et al., 2013; Mason et al., 2018); however, no studies have directly looked at the impact of concurrent conditions on subjective QoL.

We also explored whether there were differences according to differential rates of participation in 'normative outcomes' in this older autistic sample. A normative outcome score was created on the basis of self-reported friendships, employment and independence in living. Contrary to what might be expected, QoL scores were not significantly different according to normative outcome score. The outcome scores themselves reported here are more favourable than those reported in other studies (Howlin & Magiati, 2017; Howlin & Moss, 2012). For example, Eaves and Ho (2008) reported 21% with good or very good outcomes, and Howlin and colleagues (Howlin, Moss, Savage, & Rutter, 2013) 17% with good or very good outcomes; in the present study approximately 60% were scored as having a good outcome score (i.e. in two or three of the indicators). However, there is a large difference between the average age in the Eaves and Ho (2008) study (around 24 years) and the present study (around 61 years), and the Howlin et al (2013) study was a follow-up of people diagnosed in childhood whereas most of the current participants received their diagnosis in adulthood. One other exception to the general finding of poor outcomes is a study by Farley et al. (2009) where almost 50% of 41 autistic participants (diagnosed upon registering for a longitudinal study) had good to very good outcomes; 93% of their sample were from a religious community.

Comparing our mean QoL domain scores to normative UK data indicates that a large proportion of older autistic people self-reported QoL scores more than one standard deviation below normative scores on the WHOQoL BREF (Skevington & McCrate, 2012). Thus while some of the sample reported QoL comparable with the general population, the domain of Psychological QoL showed marked impairment (only 24.6% within one SD of the normative data). Interestingly, Moss et al. (2017) compared a sample of 22 autistic adults (aged 33-68) to the same normative QoL data. Moss et al. (2017) found that for each domain at least 91% of participants reported scores within one standard deviation of normative data. The disparity between the present sample and the Moss et al. (2017) could be due to the difference in age, or the relatively small sample sizes in both their study, and the present study. However, it could also indicate that QoL scores are highly heterogeneous and it is therefore important to try to characterize longitudinal QoL trajectories.

The pattern of results may suggest that one's subjective experience of life may not necessarily be associated with participation in 'normative outcomes' for a proportion of older autistic people. In order to suggest how services may best look to support older autistic adults, it will be important to look at a broad suite of factors that may also contribute to an individual's QoL (Billstedt, Gillberg, & Gillberg, 2010; Howlin & Moss, 2012). For example, Renty and Roeyers (2006) found perceived informal, rather than formal, support predicted

higher subjective QoL. The findings of Farley et al. (2009) provide an example whereby a religious community may offer a consistent source of informal support and acceptance. Whilst not examined in this study, providing environments suitable for autistic people (e.g. by minimizing sensory overload) could be meaningfully related to subjective QoL (Barneveld, Swaab, Fagel, van Engeland, & de Sonnevile, 2014). The results of the current study may suggest that interventions with a primary focus on increasing employment, socializing, or independent living may not be relevant or beneficial for some older autistic people. Hence, a focus on individualized provision would be required. Furthermore, Henninger and Taylor (2013) suggest that the concept of adulthood is evolving due to changing social and economic factors, and that a different perspective on adulthood (i.e. exploring identity and individualism) may be more appropriate for assessing outcomes for autistic people.

The illustrative quotes provide some preliminary insight into why normative outcomes were unrelated to QoL in this study. The interview data suggested that maintaining friendships can be stressful for autistic people. Similarly, Hull et al. (2017) describe themes such as 'masking', that is, people acting in social situations in ways to avoid appearing autistic. Participants mentioned the potential impact of employment on mental health, and also difficulty in finding employment. Whilst mental health affecting employment would not be specific to autism, autistic people are more vulnerable to mental health problems (Ghaziuddin et al., 2002). Finally, quotes related to independent living concur with research that has shown that, for some autistic people, the ability to perform daily living tasks can diminish from age 30 onwards (Smith, Maenner, & Seltzer, 2012). Given these nuances in the experiences of autistic people, it is understandable that the normative outcome score was found unrelated to subjective QoL in the current study.

### *Strengths and limitations*

The main strength of this study is the mixed methods design with a reasonably sized sample of older autistic people. Mixed methodology can use qualitative information to help elaborate on the relationships between the quantitative variables (Bryman, 2016). Our use of illustrative quotes adds valuable insights from older autistic people for future research on how to approach defining 'good outcomes' for autistic people. This is an important consideration, given recent research which identified several nuanced aspects of QoL specific to autistic people (McConachie et al., 2018). A second strength is that standard measures that have been

shown reliable and valid for use with autistic people were used to measure depression, anxiety, and QoL (McConachie et al., 2018; Uljarević et al., 2017).

This study was completed through data sharing within the Newcastle autism spectrum lifecourse and ageing research team studies; participants were able to self-report, and therefore the views of those with intellectual disability are not represented. However, our sample did contain one participant who reported an intellectual disability and eight who reported needing help with the questionnaires. It is crucial that future studies include participants who lack the capacity to consent for themselves or who have intellectual disability, so that quality of life for this group of autistic people is better understood. Whilst the sample size was comparable to other studies (e.g. van Heijst & Geurts, 2015) there is still the possibility that real effects are missed. The use of cross-sectional data means causal conclusions cannot be drawn; the comparison with normative outcome scores was exploratory. The self-selecting recruitment of participants means the degree of representativeness of the older autistic population is not known. Hence the generalisability of the findings may be limited. A specific limitation was that retired and unemployed participants were categorized together; retirement may have its own protective benefits for subjective QoL (i.e. not having to deal with workplace stress) but also may have disadvantages (e.g. social isolation, reduction in income, lack of daily structure). The analyses also lacked power to distinguish between the type of employment (i.e. full-time or part-time) and whether the participants were underemployed for their level of education. Hence future research should include broader investigation of how autistic adults experience both employment and retirement, and the relationship to QoL. Finally, the ASC-UK cohort relies on data reported from autistic adults. As such, we rely on the self-reported diagnosis and demographic data provided by the participants when they register. Despite these limitations, this study highlights the importance of further investigating the lives of older autistic people with the aim of identifying appropriate routes to increase subjective QoL. Increasing understanding is most likely to be possible in the short term through quantitative data sharing between research groups to increase sample size and generalizability of findings.

The illustrative quotes were drawn from a parallel ASC-UK study looking at facets of life related to QoL. The interviews were not explicitly about how autistic people view 'normative outcomes'. As such, the inferences here are not as robust as if the interviews were specifically focused on those outcomes. However, the illustrative quotes do point to potential future areas of research with older autistic samples.

## *Conclusions*

There are two main conclusions from the present study. First, the lived experiences of a significant proportion of the older autistic people in the present sample were related to concurrent mental health problems (particularly depression). These preliminary findings suggest that future investigations to develop interventions to improve mental health outcomes for older autistic people should measure broader QoL outcomes also (Helles, Gillberg, Gillberg, & Billstedt, 2017). Second, the findings indicate that the support needs of older autistic people may not necessarily be related to assumed 'normative outcomes'; friendships, employment and living situations may all carry a mixture of benefits and stresses which are particular to autistic individuals. Thorough consultation with autistic people is required to investigate how to improve QoL in older age through appropriate targeted interventions.

## *Acknowledgements*

The present study was supported by funding from Research Autism and the Shirley Foundation. The ASC-UK is funded by Autistica. The sponsor was Northumberland Tyne and Wear NHS Foundation Trust. The funders and sponsor played no role in the study design; the collection, analysis or interpretation of data; the writing of the report; and the decision to submit the article for publication.

## *Conflict of interest*

The authors have no conflicts of interest to declare.

## References

- Angermeyer, M., Holzinger, A., Matschinger, H., & Stengler-Wenzke, K. (2002). Depression and quality of life: results of a follow-up study. *International Journal of Social Psychiatry, 48*(3), 189-199.
- Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2017). A systematic review of quality of life of adults on the autism spectrum. *Autism, 1362361317714988*.
- Barneveld, P. S., Swaab, H., Fagel, S., van Engeland, H., & de Sonnevile, L. M. J. (2014). Quality of life: A case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. *Comprehensive Psychiatry, 55*(2), 302-310.
- Bell, M. L., Fairclough, D. L., Fiero, M. H., & Butow, P. N. (2016). Handling missing items in the Hospital Anxiety and Depression Scale (HADS): a simulation study. *BMC research notes, 9*(1), 479.
- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2010). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism, 7-20*.
- Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. (2016). Characterizing objective quality of life and normative outcomes in adults with autism spectrum disorder: An exploratory latent class analysis. *Journal of autism and developmental disorders, 46*(8), 2707-2719.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *Journal of psychosomatic research, 52*(2), 69-77.
- Bryman, A. (2016). *Social research methods*: Oxford university press.
- Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology, 40*(4), 429-434.
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of autism and developmental disorders, 38*(4), 739-747.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., . . . Ritvo, R. A. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research, 2*(2), 109-118.
- Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in developmental disabilities, 16*(1), 51-74.

- Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*(1), 37-45.
- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of autism and developmental disorders, 32*(4), 299-306.
- Harper, A. (1998). Development of the World Health Organisation WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558.
- Helles, A., Gillberg, I. C., Gillberg, C., & Billstedt, E. (2017). Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism, 21*(4), 458-469.
- Henninger, N. A., & Taylor, J. L. (2013). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism, 17*(1), 103-116.
- Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of autism and developmental disorders, 46*(4), 1368-1378.
- Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: outcomes in adulthood. *Current opinion in psychiatry, 30*(2), 69-76.
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry, 57*(5), 275-283.
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572-581. e571.
- Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders, 1*-16.
- Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome - A brief report. *Autism, 10*(4), 403-414.
- Kamio, Y., Inada, N., & Koyama, T. (2013). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism, 17*(1), 15-26.
- Kamp-Becker, I., Schröder, J., Remschmidt, H., & Bachmann, C. J. (2010). Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *Psychological Medicine, 31*(7), 1-10.

- Khanna, R., Jariwala-Parikh, K., West-Strum, D., & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, 8(3), 157-167.
- Lin, L., Yi. (2014). Quality of life of Taiwanese adults with autism spectrum disorder. *PLoS One*, 9(10), 1-6.
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*. doi:10.1002/aur.1965
- Matson, J. L., & Goldin, R. L. (2013). Comorbidity and autism: trends, topics and future directions. *Research in Autism Spectrum Disorders*, 7(10), 1228-1233.
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of autism and developmental disorders*, 48(5), 1596-1611.
- Michael, C. (2016). Why we need research about autism and ageing. In: SAGE Publications Sage UK: London, England.
- Moss, P., Mandy, W., & Howlin, P. (2017). Child and Adult Factors Related to Quality of Life in Adults with Autism. *Journal of autism and developmental disorders*, 47(6), 1830-1837.
- Mukaetova-Ladinska, E., 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.
- Myers, T. A. (2011). Goodbye, listwise deletion: Presenting hot deck imputation as an easy and effective tool for handling missing data. *Communication Methods and Measures*, 5(4), 297-310.
- Patra, S. (2016). Autism spectrum disorder in the elderly: a review of healthcare issues and challenges. *Journal of Geriatric Care and Research*, 3(1).
- Rapaport, M. H., Clary, C., Fayyad, R., & Endicott, J. (2005). Quality-of-life impairment in depressive and anxiety disorders. *American Journal of Psychiatry*, 162(6), 1171-1178.
- Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10(5), 511-524.
- Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of life Research*, 13(2), 299-310.
- Skevington, S. M., & McCrate, F. M. (2012). Expecting a good quality of life in health: assessing people with diverse diseases and conditions using the WHOQOL-BREF. *Health Expectations*, 15(1), 49-62.

- Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(6), 622-631.
- Uljarević, M., Richdale, A. L., McConachie, H., Hedley, D., Cai, R. Y., Merrick, H., . . . Le Couteur, A. (2017). The hospital anxiety and depression scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research*.
- van Heijst, B. F. C., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism, 19*(2), 158-167.
- Wise, E. A., Smith, M. D., & Rabins, P. V. (2017). Aging and Autism Spectrum Disorder: A Naturalistic, Longitudinal Study of the Comorbidities and Behavioral and Neuropsychiatric Symptoms in Adults with ASD. *Journal of Autism and Developmental Disorders, 1-8*.
- Wright, S. D., Wright, C. A., D'Astous, V., & Wadsworth, A. M. (2016). Autism aging. *Gerontology & geriatrics education, 1-17*.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370.

Table 1: Demographic variables: Employment, friends, living status, and support received

Demographic variable	<i>N</i>	%
Employment status		
Unemployed	15	21.7
Employed (supported or unsupported; inc. self-employed)	22	31.9
Volunteer	7	10.1
Vocational and supported employment	3	4.3
Retired	20	29.0
Other (i.e. student)	2	3.0
Friends you could spend time with		
Yes	46	66.7
No	23	33.3
Living with family		
Yes	12	17.4
No	57	82.6
Receiving support <sup>a</sup>		
Yes	25	36.2
No	35	50.7
Not reported	9	13.0
Normative outcome score		
0	1	1.4
1	11	15.9
2	31	44.9
3	11	15.9
Missing <sup>b</sup>	15	21.7

<sup>a</sup> received support includes in the home support, or support with finances etc. <sup>b</sup> missing indicates that participants had not completed some information and so a combined score could not be created.

Table 2: Mental health and QoL scores for older autistic adults (n=69)

Measure	Mean	Standard deviation		
HADS <sup>a</sup>				
Depression	9.26	4.31		
Anxiety	12.29	4.32		
WHOQoL-BREF				
Phys QoL	54.19	21.23		
Psych QoL	42.62	17.83		
Soc QoL	40.18	20.68		
Env QoL	57.36	18.00		
Proportion*, % (n)	Phys QoL	Psych QoL	Soc QoL	Env QoL
>1 SD below	56.5 (39)	75.4 (52)	62.3 (43)	37.7 (26)
Within one SD	42.0 (29)	24.6 (17)	37.7 (26)	56.5 (39)
>1 SD above	1.4 (1)	0.0 (0)	0.0 (0)	5.8 (4)

Phys - physical, Psych - psychological, Soc - social, and Env – environment

<sup>a</sup> note that the HADS scores were significantly correlated  $r=0.58$ ,  $p<0.001$

\* proportion of participants compared to normative values (Skevington and McCrate, 2012)

Table 3: Mean scores (and standard deviations) for HADS subscale categories and level of caseness. MANOVA effect sizes and post hoc comparisons are included.

	n	WHOQoL domains			
		Physical QoL (SD)	Psychological QoL (SD)	Social QoL (SD)	Environment QoL (SD)
HADS depression					
Normal	26	65.66 (19.17) <sup>a</sup>	55.45 (14.13) <sup>*</sup>	51.04 (17.00) <sup>a,b</sup>	62.89 (19.82) <sup>a</sup>
Borderline	17	56.30 (13.33) <sup>b</sup>	43.31 (10.20) <sup>*</sup>	34.80 (23.43) <sup>a</sup>	59.93 (13.63)
Clinical caseness	26	41.35 (20.83) <sup>a,b</sup>	29.33 (15.61) <sup>*</sup>	32.84 (18.03) <sup>b</sup>	50.16 (16.71) <sup>a</sup>
Partial eta squared		0.254	0.411	0.170	0.102
HADS anxiety					
Normal	9	78.97 (9.35) <sup>a</sup>	61.57 (19.52) <sup>a</sup>	50.00 (12.50)	75.35 (10.53) <sup>a</sup>
Borderline	12	65.77 (15.64) <sup>b</sup>	47.92 (12.75)	47.22 (22.29)	64.64 (14.83)
Clinical caseness	48	46.65 (19.25) <sup>a,b</sup>	37.73 (16.03) <sup>a</sup>	36.58 (20.78)	52.17 (17.19) <sup>a</sup>
Partial eta squared		0.322	0.218	0.072	0.220
Level of clinical caseness					
Normal or borderline	19	71.80 (14.18) <sup>*</sup>	53.51 (16.80) <sup>a</sup>	47.81 (17.97) <sup>a</sup>	68.95 (13.73) <sup>a</sup>
One clinical caseness	26	55.22 (16.73) <sup>*</sup>	48.99 (12.05) <sup>b</sup>	43.02 (23.41)	57.21 (18.62)
Two clinical caseness	24	39.14 (19.43) <sup>*</sup>	27.08 (12.89) <sup>a,b</sup>	31.06 (16.51) <sup>a</sup>	48.35 (15.42) <sup>a</sup>
Partial eta squared		0.371	0.421	0.114	0.204

For post hoc comparisons: for each domain score each matching superscript letter indicates significant difference for each pair of values labelled with the same letter, \* indicates all pairings significantly different. Partial eta squared = 0.01 for a small effect, 0.06 for a medium effect, and 0.14 for a large effect (Richardson, 2011).

Richardson JT. (2011) Eta squared and partial eta squared as measures of effect size in educational research. *Educational Research Review* 6: 135-147.

Skevington SM and McCrate FM. (2012) Expecting a good quality of life in health: assessing people with diverse diseases and conditions using the WHOQOL-BREF. *Health Expectations* 15: 49-62.