

Phase 1 of our research: Predictors of Quality of Life

Our first study used statistical analysis of some data to look at what factors predict Quality of Life for autistic people. We wanted to know if the *demographic* information about autistic people (for example age, gender, whether you live alone, whether you have a job etc.) tells us anything about Quality of Life.

We found there are some factors that are related to Quality of Life:

- Having a mental health condition (like depression or anxiety) and having more self-reported autism characteristics predicted *lower* Quality of Life for all of the Quality of Life domains. Being female predicted *lower* Quality of Life for the Physical, Psychological, and Environment domains.
- Younger participants reported a *higher* Psychological and Environmental Quality of Life than older participants.
- Being in a relationship and receiving support (i.e. with handling money or at work or in the home) predicted better Social Quality of Life. Being in employment predicted better Physical Quality of Life

These findings are important because they provide information to services or those providing interventions; about what might make a difference in improving the Quality of Life of autistic people. If we know that people who receive support have better Quality of Life, we can highlight this, so that people trying to improve services know what to focus on. Similarly, the findings about gender show us that more work needs to be done to enhance the Quality of Life of autistic women.

Phase 2a of our research: Consultation with the autism community

Our next question was about whether the WHOQoL-BREF *accurately* measures Quality of Life when used with autistic people. It was important to ask autistic people about the questions used in the questionnaire, and we also included another WHO questionnaire – the Disabilities module. We thought these extra questions might be relevant and useful because they ask about discrimination, autonomy (making your own choices), and inclusion.

We carried out four discussion groups with autistic people in the North East of England. We asked them to order the questions from most important to least important, as a way to get people talking.

We found out three main problems with the Quality of Life questions:

- The first was that some questions are interpreted differently by autistic people. For example, one of the questions asks ‘how well are you able to get around?’ People told us they were not sure what was meant by ‘get around’ – did it mean using transport or getting around in the home?
- The second was that some of the concepts were not very clear to autistic people. For example, one of the questions asks ‘how satisfied are you with your personal relationships?’ The comments received suggest that ‘personal relationships’ was not a clear concept. Did it include family or not? Were friends included (because there is a separate question about friends)?
- The third was that the measure missed out on some indicators of Quality of Life that were important for autistic people. One such aspect, which we called ‘autism specific knowledge’, was to do with how knowledgeable others are about autism. This could be employers, friends, media representations etc. Two other missing aspects were ‘sensory issues’ and ‘autistic identity’.

These consultations were vital to the research for two main reasons. Firstly, it allowed us to hear from autistic people what issues they may have with the questions. This has allowed us to explain to others (i.e. researchers who might use the WHOQoL-BREF) how some of the items mean different things to autistic people and this should be considered when interpreting studies using the questionnaire. Secondly, it has allowed us to develop an additional set of questions (called the ASQoL) to ask autistic people about their Quality of Life.

Research Methods

Questionnaires:

- WHOQoL-BREF, the Social Responsiveness Scale-2 (SRS-2) and some demographic data.
- We used this information to understand (a) what predicts Quality of Life for autistic people and (b) how accurate the WHOQoL-BREF is for use with autistic people

Delphi survey:

- This consisted of a number of ‘rounds’ of consultation, in this case, to test out new questions.
- After each round we revised questions based on (a) how important and clearly worded each question was rated and (b) the comments people left about each question

Cognitive interview:

- This type of interview asks participants to think about *how* they answer questions.
- We asked people about our new questions: what did the words in the question mean? (i.e. what does ‘friendship’ mean?) and how they would answer the question.

Phase 2b of our research: Developing new questions

Autistic people said:

Sensory issues question:

- This is vital. I cannot leave the house without having severe issues every day.
- I am delighted to see this question – I have never seen another questionnaire that considers it important.

Autistic identity question:

- It's nice to be asked that, to have the opportunity to say "yes" to it and wave the "autism is cool" flag. It allows autistic aspects to be seen as positives, not as a "disability label".
- With hindsight being open about my disability has only brought ridicule and contempt.
- I was extremely ill at ease with myself before diagnosis. Now I am very happy being me.
- I may be OK with my identity, and yes I am, but I feel I have to cover it up sometimes because of others, which makes me not at ease under those circumstances.

Phase 3 of our research: Validation

Validation means working out if a set of questions measures what it claims to measure. So we wanted to know if the WHOQoL-BREF, the Disabilities module, and the additional questions we created (ASQoL) when added together, really measure Quality of Life for autistic people. To do this, we got the views of autistic people (via interviews and surveys) about the additional questions. We wanted to know if the questions were understandable (did autistic people interpret the question as it was intended), if they were important, and if they were clearly worded. After that, we sent out a number of questionnaires to a large number of autistic people and used some statistical analyses to tell us how good the WHOQoL-BREF, Disabilities module, and ASQoL questions are.

Delphi survey and cognitive interviews

- We asked autistic people to rate how important and how clear our additional questions (ASQoL) were. We collected over 400 responses and used these data to work out, overall, how important and clear each question was. Additionally, people could also leave comments to help us improve the questions.
- We asked 15 autistic people to take part in interviews. The type of interview was designed to find out what people think about a question – e.g. does it mean the same thing to the people using it as it does to the person who wrote it? We then used the participants' responses from these interviews to help us improve the additional questions.
- We decided to remove two questions (one was about stereotyping and the other was about helping others) as the data and comments told us that the questions were not easy to understand.

Validation with measures

- We sent out the WHOQoL-BREF, the WHOQoL-DIS, and the ASQoL questions to a large sample of autistic people. We also included questionnaires about social support, anxiety and depression, environmental barriers; and a different Quality of Life questionnaire. In total 309 people took part in the study.
- The results showed that the WHOQoL-BREF domains are good at measuring what they claim to. For example, social support was strongly related to the Social Quality of Life domain and depression was strongly related to the Psychological domain.
- The WHOQoL-DIS questions are OK to use with autistic people. However, our early analysis shows that some questions may be interpreted differently from how they are intended.

- The ASQoL questions measure additional important aspects of QoL for autistic people. The questions are about friendships, having supportive people to help with issues, and barriers to accessing health services or work.
- The ASQoL includes an 'overall' question about QoL and it is about autistic identity. This question was difficult to find the right wording for (see the quotes in the speech bubble above) but overall it was rated as being very important for QoL by autistic people.

Take home messages from this study

Quality of Life for autistic people:

- Is lower than the general population.
- is lower for people with a mental health condition, females, and those reporting higher autism characteristics.
- Is higher for those who are employed, receiving support (i.e. at home or work) and those in a relationship.

The WHOQoL-BREF:

- Is an acceptable measure of Quality of Life for autistic people.
- Each domain measures what it claims to measure. For example, the Social domain is related to questionnaires about social support.
- Lower quality of life is related to higher depression/anxiety. This means the questionnaire might be used alongside interventions to assess improvement.

The WHOQoL-Disabilities module and ASQoL questions:

- The Disabilities module is OK for use with autistic people, but some of the questions may be interpreted differently.
- The ASQoL questions measure friendship, social support, barriers and autistic identity.
- The ASQoL questions correlate with each WHOQOL-BREF domain. This means the ASQoL questions do measure QoL.

What's next?

- Researchers want to use the additional questions alongside the WHO questionnaires to evaluate service provision for autistic people.
- We are submitting our research findings to be published so more researchers find out about our new questions. We will also be sharing our new questions with service providers and practitioners to use when measuring the QoL of autistic people.
- We are continuing to highlight the importance of raising QoL for autistic people by telling people about our findings through social media.
- A summary of our research findings will be put up on the Adult Autism Spectrum Cohort-UK website (<http://research.ncl.ac.uk/adultautismspectrum/>).

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