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Aspects of quality of life in adults diagnosed with autism in childhood
A population-based study

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ABSTRACT  The present study is a long-term prospective follow-up study of a population-based cohort of 120 individuals diagnosed with autism in childhood, followed into late adolescence/early adulthood. Specific aims of the study were to attempt to measure and study social aspects/quality of life in those 108 individuals with autism alive and available for study at the time of follow-up (13–22 years after original diagnosis). A newly constructed scale for rating ‘autism-friendly environment’/quality of life was used alongside a structured parent/carer interview assessing current occupation, educational history, services provided, accommodation type, and recreational activities. The majority of the group with autism remained dependent on parents/caregivers for support in education, accommodation and occupational situations. In spite of this, the estimation of the study group’s general quality of life was encouragingly positive. Nevertheless, there was an obvious need for improvements in the areas of occupation and recreational activities. Future studies need to look in more depth at the concept of an autism-friendly environment and develop more detailed quality of life assessment tools relevant for people in the autism spectrum.

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Quality of Life (QoL) is a broad concept, which is defined by the World Health Organisation (WHO, 1995) as the individual’s perception of their position in life in the context of the culture and value system and in relation to their goals, expectations, standards and concerns. It incorporates in

KEYWORDS  autism; adult outcome; quality of life; sexuality
a complex way the individual’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment.

In autism spectrum disorder (ASD), past QoL research has looked at outcome and the focus has been on one-dimensional outcome domains such as living or working conditions, academic achievements, psychiatric functioning, and so on. The construct of QoL, though, represents a more comprehensive, multidimensional outcome measure that also takes into account subjective variables such as subjective well being and satisfaction.

‘Good outcome’ has often been used as an objective indicator for QoL, measuring the development of a normal social life and independence by adulthood (Lotter, 1978). In the group of low-to-middle functioning individuals with autism such ‘good outcome’ is extremely rare (Billstedt et al., 2005). Most individuals with autism in this group need individualised support throughout life. Few live independently, or have close friends or permanent employment (Howlin et al., 2004).

Ruble and Dalrymple (1996) have suggested that parents, educators and researchers need other frameworks to characterize and conceptualise ‘good outcome’ for this group. They proposed that ‘good outcome’ might best be conceptualised within a framework that takes account of the interaction between the environment and the person with autism. Among the components they extracted as particularly important for quality of life in people with autism were (1) accurate information and proactive training for teachers so that they may better understand the disability of autism and how it affects each individual, (2) teaching social skills, and (3) holding a job.

Experimental treatment programs based on the TEACCH philosophy, with a significant emphasis on structure and individualised programming, yielded better quality of treatment compared to control settings (Van Bourgondien et al., 2003). According to one study, adults with autism who follow the TEACCH structured teaching model in a residential setting have fewer behavioural problems, more independence, feel better adjusted to everyday life, and need less staff monitoring (Persson, 2000).

The current study is a prospective long-term follow-up study into late adolescence/early adult life of 120 individuals diagnosed with autism in childhood and recruited from three population studies (Billstedt et al., 2005). This study showed considerable stability over time of the diagnosis of autism per se. Distinctive symptoms, symptom patterns and the way in which symptoms and symptom patterns correlate with diagnostic subcategories and background factors within the broader autism spectrum have been described in a previous publication (Billstedt et al., 2007).

The study of subjective factors is challenging in individuals with a severe learning disability and ASD. This group has a limited communication or no
communication at all, and if some language exists there might be difficulties in comprehending questionnaires and expressing feelings and inner thoughts. The current study set out to try to study both subjective and objective indicators of QoL in a group with ASD where the majority have a severe learning disability. The majority in the study group lacked the ability to give their subjective point of view regarding their psychological well being. Therefore, the focus of the study is to analyse indicators/conditions of their psychological well being. The measure developed for this purpose is based upon the results from studies on interaction between the environment and the person with autism (Van Bourgondien et al., 2003; Person, 2000). Specific aims of the study are to attempt to (1) develop a measure for the study of aspects of quality of life that reflect subjective indicators of QoL, albeit by proxy, and (2) to apply this measure alongside established objective tools for studying social and adaptive functioning that can be seen to provide information relevant for (albeit not strictly a component of) QoL in a group of 108–120 individuals with autism who participate in a longitudinal follow-up study.

Method

Participants

The participants of the study comprised all individuals included in three partly overlapping population-based studies of children diagnosed with autism in childhood from the region of Gothenburg, Sweden (Gillberg, 1984; Steffenburg and Gillberg, 1986; Gillberg et al., 1991). They were targeted for follow-up in late adolescence – adult life (Billstedt et al., 2005). The original study group was followed prospectively for a period of 13–22 years (mean 17.8 years, 3.6 SD) and re-evaluated at ages 17–40 years (mean age 25.5 years, 6.4 SD).

The original studies included a total of 120 individuals (84 males, 36 females) with DSM autistic disorder/infantile autism (61 males, 17 females) or autistic-like condition/atypical autism (23 males, 19 females), who had all been diagnosed after having gone through in-depth examination in childhood. The group with autistic disorder had met the criteria for autistic disorder of the DSM-III-R (APA, 1987) in childhood, and the group with atypical autism/autistic-like condition had met 6 or more of the 16 – but not full – DSM-III-R criteria for autistic disorder. The background and associated factors of the study group have been outlined in two previous publications (Billstedt et al., 2005; Billstedt et al., 2007).
Intellectual functioning

All participants had undergone testing before 10 years of age. In the autistic disorder group, severe mental retardation (SMR = IQ < 50) was found in 36 cases (46%), mild mental retardation (MMR = IQ 50–70) in 26 cases (33%), near average IQ (NA = 71–85) in 12 cases (15%) and average IQ (A = IQ > 85) in 4 cases (5%). Twenty-nine individuals (37%) in the autistic disorder group had no phrase speech at all at 5 years of age.

In the atypical autism group, SMR was found in 20 cases (48%), MMR in 16 cases (38%), NA in 5 cases (12%), and A in 1 case (2%). Two of the individuals in the atypical autism group had been diagnosed as suffering from ‘disintegrative psychosis’ in the first diagnostic study. Twelve individuals (29%) in the atypical autism group had no phrase speech at all at 5 years of age.

The follow-up study group

At follow-up, six families declined participation and six individuals had died (cause of death reported elsewhere; Billstedt et al., 2005), meaning that 108 individuals (77 males, 31 females) with an original childhood diagnosis of autistic disorder/infantile autism (57 males, 16 females) or autistic-like condition/atypical autism (20 males, 15 females) were included in the present study. Given that, at the symptom level, there were few differences across clinical diagnostic groups, the autistic disorder and atypical autism groups were collapsed and referred to as the ASD group.

Measures

Quality of Life measure 1 (QOL1): ‘autism-friendly environment’

A ‘level of fit’ five-item scale was developed so as to provide an overall measure of quality of life for the individuals in our follow-up study. It was completed independently both by the first and second author, who each evaluated all cases in the study. Each of the items on the scale is for global assessment (based on all available information) of a category, and is rated on a 1–5 scale (1 = very good, 2 = good, 3 = average, 4 = poor, 5 = very poor). The item quality categories are as follows:

(a) Staff and caregivers have specific ‘autism-knowledge’; that is, they are aware of the core features, including communication problems, associated with ASD;
(b) Applied structured education implemented;
(c) Individual specific treatment/training plan for the person with autism implemented;
(d) Occupation or everyday life activity corresponding to his/her level of capacity;
(e) Overall quality of life level.

Two independent clinical researchers based their ratings (a), (b) and (c) on a combination of all available information provided by the general impression and observation from the visits at group homes, schools and other occupational settings and from the interviews with staff, caregivers and with the individuals themselves. For (d), the two – clinically very experienced – independent raters estimated at face-to-face interviews/assessments whether the occupation or everyday life activities corresponded to the level of functioning of the participants. The estimation of level of capacity was based upon the level of intellectual and adaptive functioning (see below). The judgement of the (e) overall level of quality of life was a subjective clinical composite according to the evaluation of the ratings a–d.

The majority of the persons included in the study were visited at their home/group home and/or schools/jobs/day care centres. The visits lasted between 2 and 5 hours. The first and second author visited eighty-eight group homes, schools or other occupational settings. For the remaining 20 families, information about occupation and living situation were given by the families of the individuals affected by autism and by the individuals themselves. The situation for four individuals was not rated according to the quality of life scale due to lack of sufficient information.

The intraclass correlation (ICC) score for interrater reliability for (e) overall quality of life was 0.81 according to QOL1. The agreement of the ratings on remaining items (a–d) was somewhat lower (ICC = 0.67–0.76).

**Internal consistency**  The QOL1 has a good internal consistency with a Cronbach’s alpha coefficient of .96.

**Quality of Life measure 2 (QOL2): ‘parent/carer-rating of individual’s well being’**

During the social outcome interview parents/caregivers were asked to estimate how the individual with autism enjoyed/liked his/her residential conditions. They were asked to rate this on the same type of 1–5 scale as used for QOL1. A rating of 1 indicated very good and a rating of 5 very poor well being in the residential setting. No interrater reliability study was performed for QOL2.

**Social outcome interview**

Current levels of social outcome were assessed using a structured interview with a parent/caregiver that covered occupation, educational history,
accommodation type, and recreational activity (available from first author on request).

**Background factors analysed**
The variable measuring the overall quality of life level in QOL1 was related to the following background factors: IQ-level, epilepsy, speech before 5 years, no speech at follow-up, medical disorders regardless of epilepsy, anti-epileptic medication and neuroleptic medication. These factors and symptoms have been used in the previously reported global outcome study (Billstedt et al., 2007) and were believed to possibly affect quality of life in adult life.

**Statistical analysis**
Fisher’s exact test was used when comparing group frequencies. Logistic regression was used in the analysis of background factors and social variables and their contribution to QOL1 results. Correlations were calculated using Spearman’s Rank Order Correlation.

**Ethics**
The study was approved by the Medical Ethical Committee of Gothenburg University.

**Results**

**QOL 1: ‘autism-friendly environment’**
The findings from the scale are summarized in Table 1. The mean scores for all five categories were in the area ‘average’ to ‘good’.

No background factor was found to significantly contribute to the prediction of QOL1 in the logistic regression analysis.

<table>
<thead>
<tr>
<th>Category</th>
<th>1 (%)</th>
<th>2 (%)</th>
<th>3 (%)</th>
<th>4 (%)</th>
<th>5 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff/caregivers have autism knowledge</td>
<td>23</td>
<td>54</td>
<td>11</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Implementation of structured education</td>
<td>22</td>
<td>58</td>
<td>9</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Individual plan for treatment/training</td>
<td>19</td>
<td>56</td>
<td>9</td>
<td>16</td>
<td>0</td>
</tr>
<tr>
<td>Occupation at level of capacity</td>
<td>17</td>
<td>45</td>
<td>12</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Overall quality of life</td>
<td>18</td>
<td>44</td>
<td>26</td>
<td>9</td>
<td>3</td>
</tr>
</tbody>
</table>

**Table 1**  ‘Quality of life’ (QOL1) in 104 individuals with ASD

*Note. 1 = very good; 2 = good; 3 = average; 4 = poor; 5 = very poor.*
QOL 2: ‘parent/carer rating of individual’s well being’
The parent and a caregiver estimated the well being of the individuals in the study to be very good in the majority of cases (see Table 2). Ninety-one of 100 (missing information in 8) families reported their relative with autism having a very good or good quality of life. None of the background factors studied contributed significantly to the variance.

Agreement across QOL1 and QOL2
The agreement across QOL1 and QOL2 was fairly good (ICC = .65).

Educational history
The majority of the group (93%) had attended a special school or classroom for individuals with learning disabilities. Eight individuals (7%) had attended a mainstream school but only three of these had managed without any specific assistance. Two of these three (all were men with an average IQ) were estimated by the researchers to have a poor quality of life at follow-up. They had had problems finding a job after high school and were very passive during their leisure time. The third man, also with an average IQ, had had remarkably good progress and was no longer diagnosed as having a diagnosis in the autism spectrum (albeit with some autistic traits). He was still living at home (age 20.5 years) but had a regular job. Three of the eight who had attended a mainstream school had started regular high school but dropped out, two because of onset of psychosis, and the third because of lack of support. None of these continued their high school education. The remaining five individuals had completed high school education (three men and one woman) or were still attending high school (a woman) at the time of follow-up, and one of these who had completed high school, a woman who had a FSIQ score above 130, obtained an academic degree (BA) in Art History from a regular university.

<table>
<thead>
<tr>
<th>Category</th>
<th>N = 100a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very high residential well being</td>
<td>61</td>
</tr>
<tr>
<td>High residential well being</td>
<td>30</td>
</tr>
<tr>
<td>Average residential well being</td>
<td>5</td>
</tr>
<tr>
<td>Poor residential well being</td>
<td>2</td>
</tr>
<tr>
<td>Very poor residential well being</td>
<td>2</td>
</tr>
</tbody>
</table>

a. Missing information in 8 cases.
Accommodation type
The study participants were living either at their parents’ home ($n = 41$, 38% of whom (25) were 23 years of age or younger and 6 were 30 years of age or older), in community-based group homes ($n = 53$, 49%), in apartments with community-based support ($n = 9$, 8%) or in their own apartment with occasional help from relatives ($n = 4$, 4%). One man lived in an apartment with his girlfriend.

Of those with parents who rated their son’s or daughter’s well being (QOL2) to be ‘average to very poor’, two were still living at home, six were living in a group home, and one lived in an apartment with support.

Occupational situation
Twenty-nine individuals (27%) were still in junior high school/high school for people with learning disabilities at the time of follow-up. Seven (6%) had supported employment at a regular place of work, and almost half of the group ($n = 52$, 48%) were working at activity centres for people with disabilities. One man, the only one who was not diagnosed as having a clear ASD at follow-up, had a regular job at a factory. Nineteen (18%) had no daytime occupation except for some daily routines provided by their residential centres.

Contact with medical services
Medical problems were quite common (Billstedt et al., 2005). Altogether 49% of the individuals examined had a major medical problem (whether related to an underlying medical disorder possibly directly associated with autism or not) needing regular medical attention. Seventy individuals (65%) had regular contact with a psychiatrist/neurologist/other specialist doctor, and the need for medical services was expressed for four further individuals (4%) who had not received such services. Thirty individuals (28%) required no regular access to medical services (missing information in two cases).

Recreational activities
One third of the group (33%) were involved in regular recreational activities organized by others, such as horseback riding, bowling, and swimming. Specific interests involved a larger part of the group (92%) and the variation of topics was astonishing. Among the interests mentioned were aeroplanes, computers, food, flags, sticks, tyres, rhythm, church windows, walking through narrow spaces and origami. Listening to music was a very strong interest and one of the most popular activities in almost half of the group (44%), while another 22% of the group enjoyed but did not prefer music to other activities.
Friendships
Friendship was rated on the basis of caregiver’s information from the Diagnostic Interview for Social and Communication Disorders (Wing et al., 2002). Thirteen individuals (12%) had a friend or friends, regardless of the quality of the relationship, and another 12 individuals (11%) wanted friends but could not form friendships. Seven individuals (6%) understood the concept of friendship but had shown no interests in having friends. The majority (n = 73, 68%) was rated as having no concept of friendship (information on friendships was missing for 3 individuals).

‘Advice’ from families
The families were asked to formulate one piece of important advice based on their own experiences of living with a child (now an adolescent/adult) with autism to families with newly diagnosed children with autism so that their quality of life might be increased. Ninety-three families formulated such advice. Twenty-four families (26%) stressed the importance of accepting the son or daughter as he or she is and pointed to the ‘positive aspects’ of having a ‘different’ son or daughter (including change of values in life). Seventeen other families (18%) instead primarily stressed the importance of and need for support and guidance from professional or experienced others in bringing up their child with autism. Another twelve families (13%) particularly underscored the need of ‘letting go’, that respite care should be provided in order to be able to cope with the situation, to provide a welcome break, to help with transition from home and to enable the individual and his or her family to get used to separations. In contrast, three other families (3%) stressed the importance of holding on to their children as long as possible.

The importance of meeting other families in the same situation (n = 8, 9%), general adjustment of the environment to the individual with autism (n = 8, 9%), try to live as normal a life as possible (n = 7, 8%), ignore the feeling of guilt (n = 7, 8%) and the need for structured education (n = 6, 6%) were the other primary suggestions provided by some of the families.

QOL1 and social outcome measures
Table 3 illustrates the variable picture, according to social measures, seen in the study group and how these social factors are distributed within the QOL1 scale. The only significant finding was that having regular recreational activities was associated with a higher result on the QOL1 (p < .01).

Correlation between variables influencing Quality of Life
The only variable correlating to QoL was having regular recreational activities (having regular recreational activities correlated to a higher QoL, p <
Among the other variables, correlations were found between IQ and accommodation type (more individuals with a lower IQ living in group homes, individuals within the upper range of IQ living in own apartments with support, $p < .01$) and between IQ and occupational level (higher IQ correlating to having a daily occupation, $p < .05$) (see Table 4).

In the logistic regression analysis of the social factors (occupational situation, recreational activities and accommodation type) and their contribution to QOL1 results, only regular recreational activities (OR = 3.22, 95% CI 1.22–8.49, $p = .01$) contributed to the prediction of QOL1.

**Discussion**

Questionnaires with a focus on QoL have been used in studies of the high-functioning autism/Asperger syndrome group (Jennes-Coussens et al., 2006; Renty and Roeyers, 2006). Use of traditional criteria for quality of life highlights the complexity of this concept in a group of low- to middle-
functioning individuals with autism or atypical autism, and there is a need for specific consideration when studying QoL in this group (Plimely, 2007). The measures of QoL used in the present study have limitations, such as including only variables in a few domains (autism knowledge among professionals, personal development) in the construct of QOL1 scale, but is an attempt to not only include objective outcome variables traditionally used but also to include subjective variables (although by proxy).

According to the results of the present study, a majority remained very dependent on parents or other caregivers for support in education, residential and occupational situations in late adolescence and early adult life. The association found between having regular recreational activities and good/very good QoL (independent of intellectual functioning) suggests the importance of further development in this area. There is also an obvious need for improvements in the area of occupation, where a large minority of the group lacked regular daytime occupation. In the interviews, staffs/parents/caretakers expressed their concern about not being able to offer a meaningful occupation and daily activity to the individuals with ASD. Finding activities that are meaningful for the individual with autism and realising that ‘meaningfulness’ might not mean the same thing if you have autism as if you do not, are major challenges for staff, parents, and other caretakers. Several parents missed the structure their children had had during their time in school and argued for a ‘lifelong’ school for adults with autism. This would give adults with autism the possibility of maintaining the standards of functioning and the opportunity to achieve new knowledge. In spite of this, the estimation of the study group’s general QoL was encouragingly positive (independent of intellectual functioning), which was shown on QoL scales, both as rated by carers/parents and researchers.

### Table 4  Correlations between variables influencing quality of life in adults with ASD including total IQ, accommodation type, occupational activities, and recreational activities

<table>
<thead>
<tr>
<th></th>
<th>Total QoL</th>
<th>IQ</th>
<th>Accommodation type</th>
<th>Occupational activities</th>
<th>Recreation activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total QoL</td>
<td>1.000</td>
<td>-0.029</td>
<td>-0.101</td>
<td>0.148</td>
<td>0.289**</td>
</tr>
<tr>
<td>IQ</td>
<td>-0.029</td>
<td>1.000</td>
<td>0.249**</td>
<td>0.246*</td>
<td>0.175</td>
</tr>
<tr>
<td>Accommodation type</td>
<td>-0.101</td>
<td>0.249**</td>
<td>1.000</td>
<td>0.109</td>
<td>0.149</td>
</tr>
<tr>
<td>Occupational activities</td>
<td>0.148</td>
<td>0.246*</td>
<td>0.109</td>
<td>1.000</td>
<td>0.145</td>
</tr>
<tr>
<td>Recreational activities</td>
<td>0.289**</td>
<td>0.175</td>
<td>0.149</td>
<td>0.145</td>
<td>1.000</td>
</tr>
</tbody>
</table>

*Correlation is significant at the .05 level (2-tailed).
**Correlation is significant at the .01 level (2-tailed).

Note. Positive correlation = higher QoL corresponds to more positive outcome (having more independent accommodation, having daily occupation and regular recreation activities).
There is a subgroup that at 30 years of age still lives in the home of their parents. It is most likely that this would influence the quality of life of the parents, at least in the parents’ rating of their quality of life, which was not gathered in this study.

The families’ advice regarding how to increase QoL given to other families with a newly diagnosed child with autism is an important source of information, not only to other families but also to professionals in the field and to the community. About one in four families expressed spontaneously the importance of ‘accepting’ the individual with autism.

The variation of interests reported in this paper is an example of the individuality seen in individuals with autism. In order to comprehend the differences in individuals with autism, the environment and the community in which the individual with autism lives have to be flexible and to adjust to the person with autism and not always demand the opposite. Since a majority of the group remained very dependent on their parents or other caregivers for support in education, residential and occupational situations, the need for respite care provided by the community and need for support and guidance from professional or experienced others is strongly underscored.

**Limitations of present study and future research**

A limitation of the present study is that it relates to individuals considered typical or (slightly) atypical of autism 15 to 30 years ago. The outcome seen in the present group is probably not typical of high-functioning individuals with autism and ASD, and our findings cannot be generalized to apply to individuals within the upper ranges of the autism spectrum. Another more obvious limitation is that the study group often were unable to give their subjective point of view, so that we had to rely on other informants in order to estimate QoL. The QOL1 scale enables an approach where the researcher or clinician gathers information from caregivers and others and uses that information in order to independently estimate the QoL in individuals with ASD.

In the future, there is a need to look in more depth at the concept of an autism-friendly environment and to develop a more detailed QoL assessment tool for people in the autism spectrum. The newly developed QOL1 scale includes only 5 items/categories and it would probably benefit from adding additional sub-items for each category in order to capture QoL in this group in more detail.
Conclusions

In summary, quality of life, as measured by our tools, was better than expected in many individuals despite a very low level of independence. A need for improvement was identified in the area of occupation, where a large minority of the group lacked any kind of regular daytime occupation. Quality of life was found to correlate to having regular recreational activities.

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