

支援やチームでの支援が促進される傾向が示唆された。

F. 健康危険情報 なし

G. 研究発表

1. 論文発表 なし
2. 学会発表 なし

H. 知的財産権の出願・登録状況

1. 特許取得 なし
2. 実用新案登録 なし
3. その他 なし

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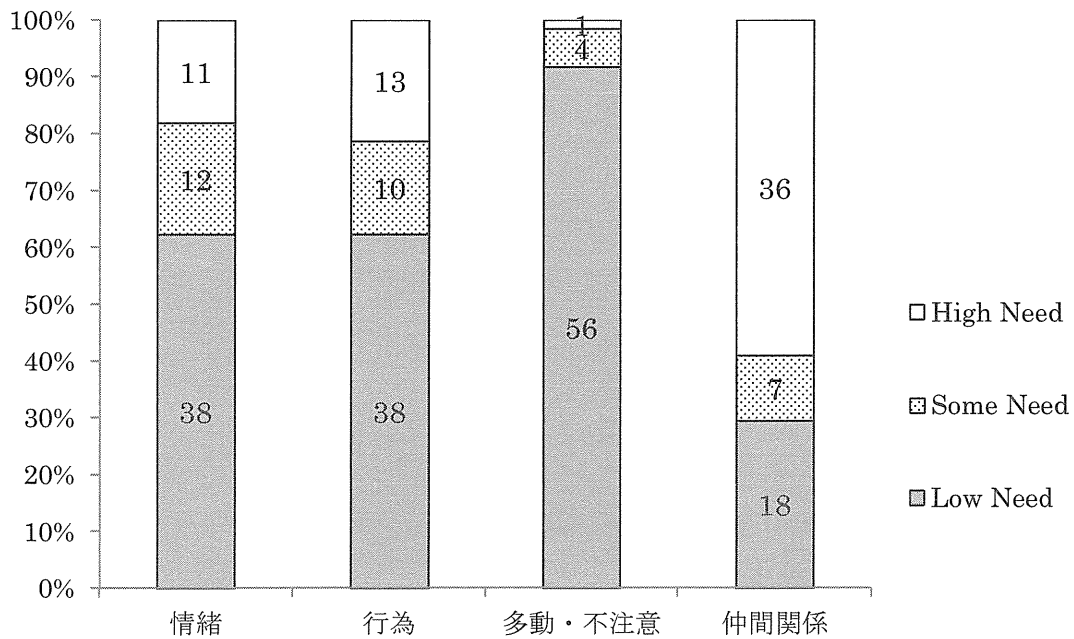


図1 対象児のSDQにおける支援ニーズ

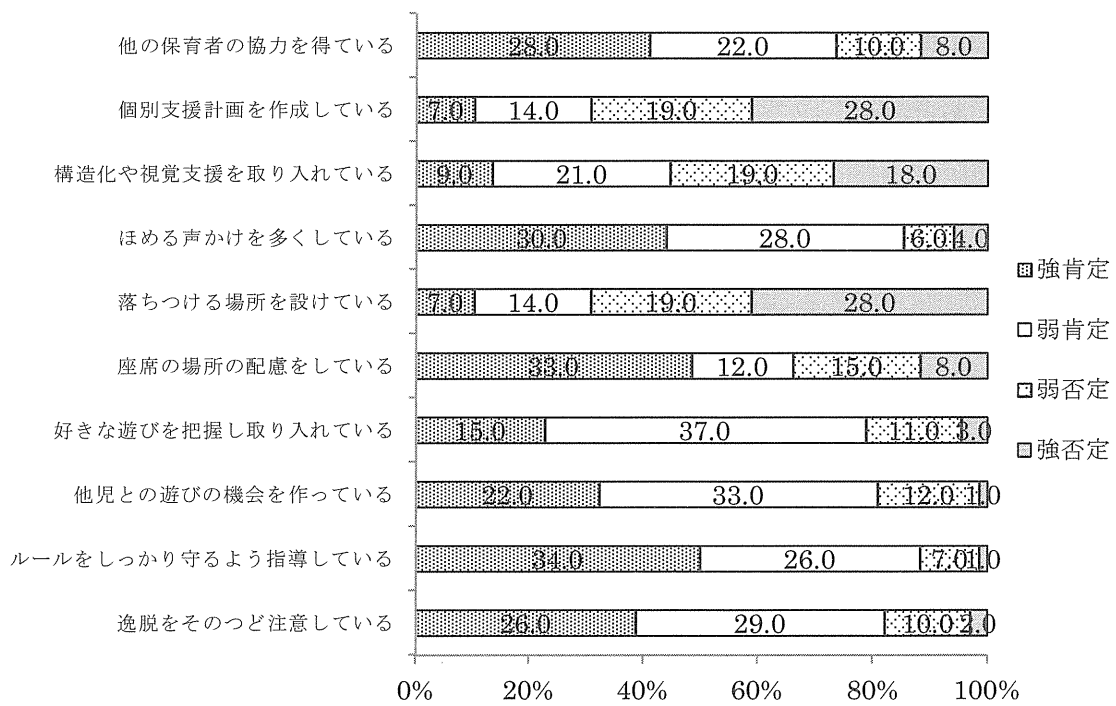


図2 保育者による対象児への支援

Ⅲ. 研究成果の刊行に関する一覧表

研究成果の刊行に関する一覧表(1 / 9)

書籍

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井口英子, 神尾陽子	振戦.	日本自閉症ス ペクトラム学 会編集.	自閉症スペクトラム 辞典.	教育出版, 中山書店	東京,	2012	pp.117.
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研究成果の刊行に関する一覧表(9 / 9)

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IV. 研究成果の刊行物・別刷

A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders

Autism
0(0) 1–12
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DOI: 10.1177/1362361312436848
aut.sagepub.com
The SAGE logo consists of a circular emblem containing a stylized 'S' followed by the word 'SAGE' in a bold, uppercase, sans-serif font.

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Abstract

The psychosocial outcomes of individuals with high-functioning autism spectrum disorder (HFASD) appear to be diverse and are often poor relative to their intellectual or language level. To identify predictive variables that are potentially ameliorable by therapeutic intervention, this study investigated self-reported psychosocial quality of life and associated factors for adults with HFASD. All participants ($n = 154$) had a diagnosis of autism spectrum disorder, were over 18 years of age, lived in the community, and had used one or more support services during the survey period. The results demonstrated that psychosocial quality of life was lower than that of the general Japanese adult population. Environmental factors, such as mother's support and early diagnosis, were associated with better quality of life, and aggressive behaviors were associated with poorer quality of life, while expressive language level at preschool years, a conventional outcome predictor, did not predict quality of life. These results emphasize that quality of life measures should be included as outcome indicators in treating individuals with HFASD.

Keywords

high-functioning autism spectrum disorder, quality of life, adult, outcome, early diagnosis

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Introduction

Because autism spectrum disorder (ASD) is a life-long developmental disorder characterized by social and communication impairments and repetitive/stereotyped behaviors, therapeutic intervention for individuals with ASD and their families should be planned for and provided throughout the life span. According to previous outcome studies of autism/ASD, long-term outcomes have repeatedly been shown to be relatively poor when measured by conventionally used indicators, such as employment or independent living, and IQ or expressive language levels during the preschool years, have been thought to be powerful predictors of long-term outcomes (Kobayashi et al., 1992; Howlin et al., 2004; Mawhood et al., 2000). A growing body of literature indicates that children with ASD can be reliably diagnosed in the second year of life (Johnson et al., 2007; Landa, 2008). Furthermore, there is accumulated evidence that early detection and intervention focusing on communication development can lead to substantially better prognosis (Landa, 2008).

Although individuals with high-functioning ASD (HFASD) usually have good intellectual or language development from a very early age, their long-term outcomes are not necessarily desirable and are rather diverse (Kamio et al., 2011). Recent studies have discovered an HFASD subgroup with comorbid psychiatric conditions, which may lead to poor long-term outcomes (Howlin et al., 2004; Tsatsanis, 2003). Counter-examples are also found; some who would have been predicted to do poorly as adults based on their modest intellectual or language development were found to be leading satisfactory lives (Persson, 2000; Ruble and Dalrymple, 1996). Given such diversity in the long-term outcomes of individuals with ASD, it is important to measure long-term outcomes more comprehensively, including subjective aspects such as quality of life (QoL) (Renty and Roeyers, 2006; Ruble and Dalrymple, 1996), and to identify predictive variables that can be changed by therapeutic intervention.

The QoL concept is increasingly being introduced into the health-related science field for children with psychiatric disorders (Bastiaansen et al., 2004). According to the World Health Organization (WHO; The WHOQOL Group, 1995), QoL is defined as 'the individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns', ranging from the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment.

Several studies have investigated QoL during adulthood for people with ASD. Most studies evaluated QoL by proxy (Gerber et al., 2008; Saldaña et al., 2009) or through indirect measures (Persson, 2000) for adults with both intellectual disabilities and ASD, and Renty and Roeyers (2006) investigated self-reported QoL of 58 adults with HFASD. These results showed that the QoL of HFASD populations largely depends on the nature of support services currently being received, suggesting that QoL can be improved by changing environmental factors. Furthermore, Renty and Roeyers (2006) demonstrated that although support characteristics were significantly related to QoL in adults with HFASD, disability characteristics such as IQ or severity of autism were not. This result emphasizes the importance of an available supportive social network, individual needs assessment, and effective professional support for adults with HFASD as well as for ASD adults with intellectual disabilities. However, in the study by Renty and Roeyers (2006) neither informal nor formal support was correlated with QoL, and perceived informal support was positively correlated with it.

In Japan, a new regulation took effect in April 2005 that aims to establish multidisciplinary service systems to improve the function and social participation of individuals with high-functioning autism, Asperger syndrome, and other developmental disorders. Currently, the majority of people with HFASD were not diagnosed as children and only a few people received adequate formal or informal support throughout childhood (Kamio and Inokuchi, 2009). Moreover, mental health

professionals have become increasingly aware of undiagnosed adults with HFASD seeking psychiatric treatment for their comorbid psychiatric symptoms.

The first aim of the present study was to determine the QoL of adults with HFASD living in the community in Japan. The second aim was to identify factors associated with QoL, both in the present and the past. We predicted that ongoing support from early childhood to adulthood is associated with a better QoL in adulthood.

Methods

In January 2009, we conducted a nationwide survey by mailing questionnaires to 192 specialized facilities that provide consultation and daycare services for local residents with developmental disorders, and to prefectural centers that provide welfare and primary mental healthcare services for local residents. These facilities consisted of 61 Support Centers for Persons with Developmental Disorders, 65 Institutions for Persons with Autism, and 66 Centers for Mental Health and Welfare Services throughout Japan. Clinical staff at each facility helped identify and enroll study participants. Participants were eligible for the study if they had a diagnosis of ASD, were 18 years of age or older, and used any services provided by the facilities during the period 13 January to 13 February 2009. Among 1103 individuals who were identified as eligible, questionnaires were given to the 402 individuals who were willing to participate in the study and whose parents were also willing to participate. By the end of March 2009, 321 questionnaires had been collected from participants at 63 facilities (a response rate of 79.9%).

The protocol of this study was approved by the ethics committee of the National Center of Neurology and Psychiatry in Japan. Written informed consent to participate in our study was obtained from a parent or a guardian, and also from each participant where possible.

Participants

Out of 202 respondents who returned questionnaires with the self-report portions completed, the final study sample consisted of 154 respondents (123 males and 31 females) with complete information provided by the respondents themselves, their parents, and facility staff who knew the respondents well. For seven ASD participants, information was obtained not from parents but from facility staff who knew the respondents well. Because the self-report questionnaires were distributed only to ASD participants whom facility staff thought could understand and respond appropriately, these participants should be considered to be relatively high-functioning. Although we could not confirm their functioning levels with cognitive test data, this assignment appears to be supported by the fact that 136 of the 154 participants (88.3%) received mainstream education and completed higher education without any support, and that only four participants (2.6%) received special education throughout grades 1 to 12. The mean age of the 154 service user participants was 27.6 years (SD 6.5 years, range 18–49 years), and their characteristics based on the parent-supplied information are outlined in Table 1. In decreasing order of frequency, clinical ASD diagnoses ranged from Asperger syndrome, pervasive developmental disorders, high-functioning autism, autism, to pervasive developmental disorders not otherwise specified (PDD-NOS). Table 2 outlines the past history of the ASD service user participants as completed by the parents.

Survey questionnaires

The survey questionnaires comprised the following: parent (or staff)-rated items of the ASD service user's demographic information (listed in Table 1), past history (listed in Table 2), and performance

Table 1. Characteristics of ASD participants (N = 154)

Characteristics	N (%)
Gender	
Male	123 (79.9)
Female	31 (20.1)
Age categories (years)	
18–24	61 (39.6)
25 +	93 (60.4)
Residential status	
Independent living	11 (7.1)
Living with family	142 (92.2) ^e
Supported living (group home)	1 (0.6)
Marital status	
Married/partnered	9 (5.8)
Unmarried	145 (94.2)
Education	
≤high school ^a	92 (59.7)
Further higher education ^b	62 (40.3) ^f
Employment	
Employed ^c	37 (24.0)
Unemployed ^d	115 (74.7)
Homemaker	2 (0.1)
Comorbid with other medical conditions	
Physical conditions	16 (10.4)
Psychiatric conditions (other than ASD)	58 (37.7)
Challenging behaviors	
Self-injurious behaviors	14 (9.1)
Aggressive behaviors	45 (29.2)

^aThe category '≤high school' includes secondary high school, high school, and special schools for handicapped children.

^bThe category 'further higher education' includes college, polytechnic junior college, and graduate school.

^cThe category 'employed' includes part-time job, full-time job, and self-employed.

^dThe category 'unemployed' includes no occupation, during vocational training, and during leave.

^eA majority of unmarried Japanese men (70.3%) and women (76.4%) (18–34 years) live with parents according to National Institute of Population and Security Research (2009).

^f68.6% of new graduates from high school proceed to higher education according to Ministry of Education, Culture, Sports, Science and Technology (2009).

in his/her current environment (described below); self-rated QoL (nine items across two domains); and for staff only, several items concerning current family support.

Performance in the current environment. Parent participants were asked to rate the extent of difficulty that the ASD service user participant experienced when doing things related to general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions, and relationships in his/her current environment. Those questions were based on WHO's International Classification of Functioning, Disability, and Health (ICF), and the definition of 'current environment' includes assistive devices or personal assistance whenever the person actually uses them to perform actions or tasks. The parent participants answered questions using a 5-point rating scale (1 = complete difficulty; 2 = severe difficulty; 3 = moderate difficulty; 4 = mild difficulty; 5 = no difficulty).

Table 2. Past history of the ASD participants (N = 154)

Early developmental concerns	N (%)
Absent	29 (19.5)
Present	120 (80.5)
Age at first concern (median age)	30 months
Age at referral	48 months
Age at first diagnosis	123 months
Speech level at 6 years	
Words or two-word phrases	34 (24.8)
Sentences with more than three words	103 (75.2)
Early diagnoses before 4 years	
Diagnosed ^a	29 (18.8)
Service utilization ^b	
No utilization at any time	124 (80.5)
Continuous utilization through the entire life stages	22 (14.3)

^aIncludes diagnoses of ASD and other developmental disorders.

^bService refers to having professional advice regularly, participating in some therapeutic programs, receiving special educational aid.

Quality of life. Subjective QoL was measured using the WHOQOL-BREF, which is derived from the 100-item WHOQOL (The WHOQOL Group, 1995). The WHOQOL was developed to measure individuals' 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, and is used widely and internationally. Its use has been validated for various populations, including psychiatric patients worldwide. Its shorter version, the WHOQOL-BREF, comprises 26 items on four domains of QoL: physical health, psychological health, social relationships, and environment. For the purpose of the present study, the six items of the 'psychological health' domain (bodily image and appearance, negative feelings, positive feelings, self-esteem, thinking, learning, and memory and concentration) and the three items of the 'social relationships' domain (personal relationships, social support, and sexual activity) of the Japanese version of the WHOQOL-BREF (WHOQOL 26) (Nakane et al., 1999; Tazaki and Nakane, 2007) were used. Each item is assessed by an individual diagnosed with ASD on a 5-point scale (1 = very poor/very dissatisfied/not at all; 2 = poor/dissatisfied/a little; 3 = neither poor nor good/a moderate amount; 4 = good/satisfied/very much; 5 = very good/very satisfied/extremely). The mean scores of these two domains were analysed.

Current family support. The family support situation was determined by responses to the question, 'Regarding the physical and psychological support provided by his/her family member, do you think it is actually helpful for him/her?' The facility staff who knew the person well answered using a 5-point rating scale (1 = very helpful; 2 = somewhat helpful; 3 = not helpful or unhelpful; 4 = not very helpful; 5 = not at all helpful) for the case of the father, mother, and sibling, respectively (Table 3).

Demographic characteristics. Demographic information was obtained through 17 items rated by parents, and included gender, age, residential status, marital status, education, employment, medical conditions, and challenging behaviors. In this study, we asked questions requiring yes or no answers regarding the presence or absence of self-injurious behaviors and aggressive behaviors. Self-injurious behaviors were defined as any kind of behaviors in which the ASD participants hurt themselves. Aggressive behaviors were defined as violent behaviors toward family members or

Table 3. Current family support to the ASD participants (N = 154)

	N (%)
Father	
Helpful	60 (39.0)
Not helpful	63 (40.9)
No father or unknown	31 (20.1)
Mother	
Helpful	119 (77.3)
Not helpful	15 (9.7)
No mother or unknown	20 (13.0)
Sibling	
Helpful	35 (22.7)
Not helpful	82 (53.3)
No sibling or unknown	37 (24.0)

other people, verbal aggression as statements such as ‘Die’ or ‘I will kill you’, and destructive behaviors as those causing serious material damage. The most important items are shown Table 1.

Past history. Developmental information was obtained through 19 items rated by the parents, and included age at parental concern, age at diagnosis, expressive language level at age 6, and service utilization. The most important items are shown in Table 2.

The self-rating part of the survey questionnaire was pilot tested in several clinical settings to confirm the ease of completion. It was confirmed that individuals with HFASD were able to understand and complete it satisfactorily, at levels similar to other psychiatric patients (Koyama et al., 2009).

Statistical analysis

First, to compare the QoL domain scores for our ASD participants with those for a healthy Japanese population obtained using stratified sampling methods (N = 828; 410 males; aged 20–49) (Nakane et al., 1999; Tazaki and Nakane, 2007), the raw domain scores were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age group (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007). To obtain the z scores of participants 18–19 years of age, we applied the mean and standard deviation for the age range of 20–29 years to their raw QoL domain scores. Second, Pearson correlations were calculated to assess associations between performance in the current environment and QoL in both the psychological health and social relationships domains. Third, using two sample *t*-tests, z scores of the QoL domain scores were compared between subgroups of the following demographic characteristics: gender (male vs. female), age (≤ 24 , 25+), residential status (independent living vs. other), marital status (unmarried vs. other), education (\leq high school vs. additional higher education), employment (unemployed vs. other), medical conditions and challenging behaviors (present vs. absent), sentence level at 6 years of age (present vs. absent), diagnosis before 4 years of age (present vs. absent), and service utilization (none vs. continuous). For current family support, the responses were classified into two categories of ‘helpful’ (1, 2) and ‘not helpful’ (3, 4, 5). Finally, a stepwise multiple regression analysis was used to identify the most important characteristics in predicting QoL domain scores. As independent

Table 4. Means and SD for raw scores on psychological and social domains of WHOQOL 26 rated by ASD participants themselves (N = 154), and z scores converted from the raw scores of the ASD participants (N = 154)

QOL domain ^a	Mean (SD)	<i>t</i>	<i>p</i>	95% confidential interval
Psychological health				
Raw score	2.78 (0.74)			
Z score	−.80 (1.24)	−8.0	.0001	−1.0 to −.60
Social relationships				
Raw score	2.71 (0.82)			
Z score	−.63 (1.25)	−6.2	.0001	−.83 to −.43

^aPsychological domain contains six items (1–5) and social domain contains three items (1–5). The mean raw domain scores of the ASD participants were converted to z scores using the mean and standard deviation of the Japanese standardization sample by gender and by age range (20–29, 30–39, 40–49) (Tazaki and Nakane, 2007).

variables, characteristics that were found to be significant on *t*-tests and all the demographic characteristics were used. A *p*-value < .05 was considered to indicate statistical significance. Statistical analysis was performed using SPSS version 18.0 (SPSS Inc., Chicago, USA).

Results

Psychological and social aspects of QoL in the ASD participants

The raw score means of the ‘psychological health’ and ‘social relationships’ domains of the WHOQOL 26 as rated by the ASD participants were 2.78 and 2.71, respectively (Table 4), whereas those of the Japanese standardization sample aged 20–49 ranged from 3.26 to 3.32 for the psychological health domain and from 3.19 to 3.25 for the social relationships domain, varying slightly by gender and age (Tazaki and Nakane, 2007). The differences in mean z scores of the ASD participants from those of the Japanese standardization sample were −0.80 for the psychological domain and −0.63 for the social domain, indicating that psychological and social aspects of QoL of the ASD participants were significantly lower (worse) than those of the healthy Japanese population (*p* < .000 for both).

Associations between psychological and social QoL and performance in the current environment in the ASD participants

Pearson correlations revealed that the QoL scores in both psychological and social domains for the ASD participants were not significantly correlated (*r* = 0.06 and *r* = 0.01, respectively, n.s.) with everyday performance in the current environment. This may be interpreted to suggest that the psychological and social domains of QoL capture more of the subjective aspects of QoL, and not objective function or capacity.

Factors related to psychological and social QoL in the ASD participants

As shown in Table 5, *t*-tests revealed that higher QoL was significantly associated with being male (*p* < .05 for psychological domain, *p* < .01 for social domain), having received a diagnosis before 4 years of age (*p* < .05 for psychological domain), and mother’s support being helpful (*p* < .001 for both psychological and social domains). Lower QoL was significantly associated with suffering