

The relationship between physical signs of aging and social functioning in persons with Down syndrome in Japan

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Background: In Japan, there have been no substantial studies of social function and physical aging in adults with Down syndrome. The aim of the present study was to examine social functions (movement, conversation, and daily living skills) and physical signs of aging in adults with Down syndrome in Japan, and to analyze the relationship between changes in social function and age.

Methods: A cross-sectional survey of persons with Down syndrome who were 15 years of age or older (15-65 years old) was conducted. The survey was conducted in patients associations, institutes, group homes, and workplaces from July to December 2009. Primary caregivers, such as family members and institute staff, were asked to complete a questionnaire on the subjects' living situation, movement ability, conversational skills, daily living skills, and 10 characteristics of physical aging at the time of the survey.

Results: The total number of subjects was 315. Subjects' movement ability, conversational ability, and daily living skills declined as a function of age. Canities (40.6%) were the most prevalent physical sign of aging, followed by missing teeth, hump back, and skin wrinkling. Further, physical aging was related to a decline in social functions ($p < 0.001$).

Conclusion: The present study showed that adults with Down syndrome exhibit signs of physical aging earlier than do the general population, and that physical aging is associated with social functioning. Thus, the appearance of physical aging might indicate a decline in social functioning.

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Introduction

The life expectancy for individuals with Down syndrome has been extended: while it was approximately 12 years in 1949, it was reported 60 years in 2002,^{1,2} and in a survey in Japan, approximately 50 years.³ This increase in life expectancy has led to an escalation in research focused on health problems in adults with Down syndrome^{4,5,6} and the quality

of life of their family members.^{7,8}

There have also been a number of reports addressing factors related to social adaptability such as age-related changes in movement, language ability, and daily living skills. Regarding movement, it has been noted that persons with Down syndrome have delayed motor skill development in childhood relative to healthy children;^{9,10} that they develop a characteristic manner of walking to compensate for lower

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muscle tone;¹¹ and that their movements are slower than those of healthy children.^{12, 13}

In one study on conversational ability in persons with Down syndrome, of the 374 participants (aged 14 to 62), 41.6% were able to understand the conversation without difficulty, and 15.2% were able to use words without difficulty.¹⁴ Additionally, in a survey comparing 55 persons with Down syndrome (aged 30 to 59) and 75 persons with other intellectual disabilities (aged 30 to 69), persons with Down syndrome exhibited lower conversational fluency across all ages.¹⁵

Daily living skills were not found to be appreciably impacted by age in one study,¹⁶ but Bertoli et al.¹⁴ reported that the proportion of persons with Down syndrome that exhibited functional decline increased rapidly after age 30. Esbensen et al.¹⁷ stated that although the severity of intellectual disability determined the level of assistance Down syndrome patients required for daily living activities, even some individuals with mild or moderate disability were in a self-supporting category.

Adults with Down syndrome have a greater incidence of premature cataracts than the general population.^{18,19} Regarding oral health, adults with Down syndrome have been shown to have fewer caries^{20,21} but a greater incidence of severe periodontal disease²² than do the general population. Some studies have suggested that alopecia totalis or universality²³ and skin wrinkling are more prevalent in individuals with Down syndrome²⁴.

Because there is no system of patient registration for persons with Down syndrome in Japan, placement and social function in the Down syndrome population have not been investigated. However, there has been some recent investigation into early-onset dementia^{25,26} and the consequent problems of life support system^{2,8,16} for adults with Down syndrome. Generally, persons with Down syndrome show early-onset physical aging, but there are few reports about the overall physical signs of aging. The present study therefore examines the status of social function (movement, conversation, and daily living skills) and the characteristics of physical aging in persons with Down syndrome aged 15 and older in Japan, and analyzes the change in these variables as a function of age.

Materials and methods

Research subjects

The present study is a cross-sectional study of social adaptability among persons with Down syndrome aged 15 years and older (15-65 years old). Placements considered for

persons with Down syndrome were at home, in an institute such as a welfare facility for the intellectually or physically disabled (hereafter referred to as simply, "institutes"), and in a group home (GH). Institutes and GHs were surveyed on the number of subjects accommodated, and were asked for written cooperation. For research cooperation, two groups of patient association and a total of 127 places including institutes, workplaces, and GHs accepted in their reply, and a total of 1,300 copies of the survey were distributed. The survey was carried out from July to December in 2009. The survey was conducted with the approval of the Nagasaki University Graduate School of Biomedical Sciences Ethics Committee. In implementing the survey, an emphasis was placed on protecting privacy.

Questionnaire

A questionnaire was administered that assessed subjects' social functions (movement, conversation, and daily living skills; 3 items), physical signs of aging (ten items), disease prevalence (9 items), and mental status (36 items). Subjects were additionally asked about the attributes of age, sex, and placement (choices included living at home with family, a GH, or an institute). Social function was assessed on a three-point scale, and replies for diseases and signs were indicated by a "yes" or "no."

The criteria for movement were as follows: (1) independent group (able to run, able to walk alone), (2) assistance group (able to walk with assistance), and (3) difficulty group (able to move by crawling, unable to move independently).

The criteria we used to assign participants according to conversation were as follows: (1) independent group (conversation is clear, able to converse normally), (2) assistance group (able to converse in familiar situations), and (3) difficulty group (able to convey meaning using a single word, conversation is difficult).

The criteria for daily living skills were as follows: (1) independent group (independent), (2) assistance group (able to live independently if prompted, sometimes needs assistance), and (3) difficulty group (always needs assistance, incapable of living alone).

The ten physical signs of aging assessed were as follows: (1) long eyebrows, (2) alopecia, (3) canities, (4) missing teeth, (5) humpback, (6) cataracts, (7) flabby skin under the eyes, (8) longitudinal groove along nails, (9) senile freckles, and (10) skin wrinkling.

Persons familiar with the daily lives of the subjects who lived with subjects and caregivers who provided daily support for subjects at institutes and GHs were asked to com-

plete this survey. To facilitate compliance, care was taken to make the three-point scales of the criteria as comprehensible as possible.

Statistical analysis

The function and physical signs of aging was compared between age groups by using χ^2 test. The simultaneous effects of age and the number of physical signs of aging on social function were analyzed by multiple linear regression models. All statistical analyses were performed by using SPSS Ver.18. A p-value of less than 0.05 was considered to be statistically significant.

Results

At 551 responses to the survey, the response rate was 42.4%. Incomplete responses, with missing values of sex, age or physical signs of aging were excluded. Remaining 315 responses for analysis.

Results showed that 39% of respondents were family members (parents and siblings), 55% were facility caregivers, and 6% were unknown. The mean age of subjects in various placements living at home was 24.7 years (15–45 years, SD = 7.2); the mean age of subjects living in a GH was 38.4 years (19–59 years, SD = 10.3); and the mean age of subjects living in an institute was 42.3 years (15–65 years, SD = 11.4). Thus, results indicate that, as age increases, there is a significant reduction in the proportion of persons living at home, along with an increase in the proportion of persons living in an institute (Cochran-Armitage test, $p < 0.01$).

Table 1 shows the breakdown of sex and social functions for Down syndrome subjects of different ages. The mean age of the subjects was 33.22 years (15–65 years, SD = 12.8), with the minimum at 15 years and the maximum at 65 years. Regarding sex, 166 (52.7%) were men and 149 (47.3%) were women, and no significant difference in the sex ratio between various age groups was found. The majority of subjects could move without assistance until 40s: 298 (94.5%) of the subjects were in the independent group. In three items

Table 1. Gender, Social Function and Age of Individuals with Down syndrome

	n (%)	Age							P ^a
		Mean years (SD;Range)	15-19 n (%)	20-29 n (%)	30-39 n (%)	40-49 n (%)	50-59 n (%)	60- n (%)	
Gender									
Male	166 (52.7)	33.64 (13.2;15-63)	22 (55.0)	56 (52.3)	36 (47.4)	27 (54.0)	20 (60.6)	5 (55.6)	0.870
Female	149 (47.3)	32.75 (12.4;15-65)	18 (45.0)	51 (47.7)	40 (52.6)	23 (46.0)	13 (39.4)	4 (44.4)	
Movement									
Independence	298 (94.6)		40 (100)	107 (100)	72 (94.7)	47 (94.0)	26 (78.8)	6 (66.7)	p<0.001
Assistance	15 (4.8)		0 (0)	0 (0)	4 (5.3)	3 (6.0)	6 (18.2)	2 (22.2)	
Difficulty	2 (0.6)		0 (0)	0 (0)	0 (0)	0 (0)	1 (3.0)	1 (11.1)	
Conversation									
Independence	120 (38.1)		21 (52.5)	50 (46.7)	27 (35.5)	15 (30.0)	4 (12.1)	3 (33.3)	p<0.001
Assistance	85 (27.0)		9 (22.5)	34 (31.8)	23 (30.3)	11 (22.0)	6 (18.2)	2 (22.2)	
Difficulty	110 (34.9)		10 (25.0)	23 (21.5)	26 (34.2)	24 (48.0)	23 (69.7)	4 (44.4)	
Daily living skills									
Independence	61 (19.4)		11 (27.5)	32 (29.9)	9 (11.8)	7 (14.0)	2 (6.1)	0 (0)	p<0.001
Assistance	179 (56.8)		27 (67.5)	62 (57.9)	48 (63.2)	25 (50.0)	14 (42.4)	3 (33.3)	
Difficulty	75 (23.8)		2 (5.0)	13 (12.2)	19 (25.0)	18 (36.0)	17 (51.5)	6 (66.7)	
Total	315 (100)	33.22 (12.8;15-65)	40 (12.7)	107 (34.0)	76 (24.1)	50 (15.9)	33 (10.5)	9 (2.9)	

^a Cochran-Armitage test ; SD, Standard deviation

of social function, the overall distribution of subjects number who were in assistance and difficulty group increased and independence group decreased with age. Thus, results indicate movement, conversational ability, and daily living skill significantly decline with age (Cochran-Armitage test, $p < 0.01$).

Table 2 shows the frequency of the physical signs of aging for different ages of subjects with Down syndrome. The frequency of all 10 items significantly increased with age (Cochran-Armitage test, $p < 0.01$). Canities were most prevalent, reported by 40.6%. For all physical signs of aging except long eyebrows and alopecia, the proportion of participants was over 20%.

Table 3 shows the results of multiple regression analysis between the independent variables (age and the number of physical signs of aging) and the dependent variable (social function). The relationships of movement, daily living skills, and the number of physical signs of aging, with age were statistically significant. Movement was related with to the number of physical signs of aging ($p < 0.001$) and age ($p = 0.029$). Similarly, daily living skills were related to the number of physical signs of aging ($p < 0.001$) and age ($p = 0.032$). In contrast, conversational ability was related to the number of physical signs of aging ($p < 0.001$), but was not related to age ($p = 0.434$).

Table 2. Signs of Aging and Age of Individuals with Down syndrome

Physical signs of aging		Age	total	15-19	20-29	30-39	40-49	50-59	60-	P ^a
		n	315	40	107	76	50	33	9	
Long eyebrow	+	n (%)	39 (12.4)	0 (0)	5 (4.7)	10 (13.2)	5 (10.0)	16 (48.5)	3 (33.3)	p<0.001
	-	n (%)	276 (87.6)	40 (100)	102 (95.3)	66 (86.8)	45 (90.0)	17 (51.5)	6 (66.6)	
Alopecia	+	n (%)	48 (15.2)	0 (0)	6 (5.6)	17 (22.4)	7 (14.0)	11 (33.3)	7 (77.8)	p<0.001
	-	n (%)	267 (84.8)	40 (100)	101 (94.4)	59 (77.6)	43 (86.0)	22 (66.7)	2 (22.2)	
Canities	+	n (%)	128 (40.6)	6 (15.0)	23 (21.5)	32 (42.1)	31 (62.0)	27 (81.8)	9 (100)	p<0.001
	-	n (%)	187 (59.4)	34 (85.0)	84 (78.5)	44 (57.9)	19 (38.0)	6 (18.2)	0 (0)	
Missing teeth	+	n (%)	81 (25.7)	0 (0)	4 (3.7)	19 (25.0)	24 (48.0)	26 (78.8)	8 (88.9)	p<0.001
	-	n (%)	234 (74.3)	40 (100)	103 (96.3)	57 (75.0)	26 (52.0)	7 (21.2)	1 (11.1)	
Hump back	+	n (%)	89 (28.3)	6 (15.0)	19 (17.8)	26 (34.2)	17 (34.0)	14 (42.4)	7 (77.8)	p<0.001
	-	n (%)	226 (71.7)	34 (85.0)	88 (82.2)	50 (65.8)	33 (66.0)	19 (57.6)	2 (22.2)	
Cataracts	+	n (%)	71 (22.5)	4 (10.0)	15 (14.0)	14 (18.4)	14 (28.0)	18 (54.5)	6 (66.7)	p<0.001
	-	n (%)	244 (77.5)	36 (90.0)	92 (86.0)	62 (81.6)	36 (72.0)	15 (45.5)	3 (33.3)	
Flabby skin under the eyes	+	n (%)	69 (21.9)	2 (5.0)	7 (6.5)	19 (25.0)	12 (24.0)	22 (66.7)	7 (77.8)	p<0.001
	-	n (%)	246 (78.1)	38 (95.0)	100 (93.5)	57 (75.0)	38 (76.0)	11 (33.3)	2 (22.2)	
Longitudinal groove along nails	+	n (%)	65 (20.6)	0 (0)	7 (6.5)	18 (23.7)	12 (24.0)	20 (60.6)	8 (88.9)	p<0.001
	-	n (%)	250 (79.4)	40 (100)	100 (93.5)	58 (76.3)	38 (76.0)	13 (39.4)	1 (11.1)	
Senile freckles	+	n (%)	63 (20.0)	3 (7.5)	3 (2.8)	17 (22.4)	15 (30.0)	20 (60.6)	5 (55.6)	p<0.001
	-	n (%)	252 (80.0)	37 (92.5)	104 (97.2)	59 (77.6)	35 (70.0)	13 (39.4)	4 (44.4)	
Skin wrinkling	+	n (%)	90 (28.6)	0 (0)	5 (4.7)	24 (31.6)	22 (44.0)	30 (90.9)	9 (100)	p<0.001
	-	n (%)	225 (71.4)	40 (100)	102 (95.3)	52 (68.4)	28 (56.0)	3 (9.1)	0 (0)	

^a Cochran-Armitage test

Table 3. Multiple regression analysis for Social Function with Age and Number of Physical Signs of Aging as Independent variable

Dependent variable	Independent variable	B	SE	P
Movement	Number of Physical signs of aging	0.023	0.007	0.001
	Age	0.032	0.015	0.029
Conversation	Number of Physical signs of aging	0.106	0.022	p<0.001
	Age	0.037	0.047	0.434
Daily living skills	Number of Physical signs of aging	0.079	0.016	p<0.001
	Age	0.075	0.035	0.032

B, Regression coefficient ; SE, Standard Error

Discussion

This study showed that social function declined with age and physical signs of aging increased with age. Conversational ability and daily living skills began declining in Down syndrome patients at a relatively young age, however, movement ability remained stable until approximately age 50 in the present study. The results of a previous study that assessed walking ability in persons with Down syndrome¹³ showed a significant decline in both walking speed and distance in an older group (aged 55–61) compared with a younger group (aged 41–46). The present study supports the results this study, with walking ability being comparatively maintained.

Carr^{25,27,28} reported that persons with Down syndrome aged 9–45 have relatively stable language ability in his longitudinal study. It has, however, also been reported that language ability also declined significantly as age increases²⁸. The present study showed that conversation declined significantly as aging. The difference to the research results by Carr presumably included the difference in assessment scale, subjects, and the social background.

Longitudinal studies^{27,28} that analyzed the daily living skills of Down syndrome patients over time found that daily living skills peak at age 30 and thereafter decline slowly.²⁵ Furthermore, a cross-sectional study¹⁴ showed that the proportion of individuals who exhibited a functional decline in daily living skills increased at age 30 and beyond. Despite slight differences in the peaking ages, the present results appear to be relatively consistent with previous results in that there was a gradual decline following age 30.

It is known that persons with Down syndrome may age prematurely and display signs of aging as early as 30–40 years of age.¹³ In the present study, the frequency of 10 physical signs of aging were assessed. Canities, missing teeth, humpback, and skin wrinkling were the most prevalent (>25%) physical signs of aging found in the present study. It has been previously observed that Down syndrome patients

have fewer teeth²⁰ and a greater frequency of missing teeth than the general population.²² Additionally, the present study demonstrated an increase in missing teeth with advancing age (30–39 years, 25.0%; 40–49 years, 48.0%; 50–59 years, 78.8%). It has been stated that adults with Down syndrome have a lower incidence of caries^{20,21} but a greater incidence of severe periodontal disease²² than do the general population. Therefore, it is possible that periodontal disease is the cause of the increased prevalence of missing teeth in people with Down syndrome. However, these reports did not include data on the frequency of missing teeth, because the number of subjects was low.

In one report,²⁴ skin wrinkling of the forearm and periorbital region increased with age in persons with Down syndrome, and the frequency of this was greater than in the general population. Our results are in general consistent with prior research: the frequency of skin wrinkling and that frequency of flabby skin under the eye increased dramatically aged 40–49 to 50–59.

Social functions, movement ability, and daily living skills were related to the number of physical signs of aging and age. This suggests that physical aging and the decline in movement ability appear simultaneously. However, conversational ability was associated with physical aging, but not age. Therefore, when physical changes appear in young adults with Down syndrome, these individuals should be screened for deficits in conversational ability.

A limitation of the present study is that the subject pool was limited to individuals with social connections, meaning that our results cannot generalize to persons without social support. If caregivers are aware that the appearance of physical changes and a decline in social function may co-occur, adults with Down syndrome might receive greater daily living support and a better quality of life. A longitudinal study on the relationship between changes in social function and physical aging in adults with Down syndrome should be conducted in the future.

Conclusion

The present study provides important suggestion regarding the natural course of a decline in adults with Down syndrome in Japan. The present study showed that adults with Down syndrome exhibit age-related declines in social functions, and show signs of physical aging earlier than does the general population. Furthermore, the number of physical signs of aging was associated with the decline in social function. This result suggests that the appearance of physical aging and the decline in social functions may co-occur. If caregivers are aware of this, they can lend more support upon observance of physical aging, thus improving the quality of life of people with Down syndrome.

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