



Self-perceptions from people with Down syndrome in Japan

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Abstract

Self-perception of people with Down Syndrome (DS) was originally studied in the United States in 2011; this study indicated that 99% of people with DS are happy with their lives. In this study, we investigated self-perceptions of people with DS in Japan and compared the results to the previous study made in the United States. The participants ($n = 300$) were 12 years old or older and members of Japan Down Syndrome Society (JDS). The questionnaire was collected between 30 October 2015 and 26 November 2015. Of 96(32%) responses, 76 (97%) agreed they are happy with their lives. We found that most people with DS in Japan also feel positive about themselves and their lives. Along with the start of Non-Invasive Prenatal Testing in Japan, DS draws an attention from Japanese people because maternal age has been increasing. This has resulted in the growth of the number of prenatal tests marketed in Japan. Therefore, we expect our results to be relevant to genetic counseling for the couples considering prenatal tests or parents raising their children with DS so that they have a clearer image about life with DS and can better visualize their life plans.

Introduction

Self-perception of people with Down Syndrome (DS) was originally studied in the United States in 2011; this study indicated that 99% of people with DS are happy with their lives [1]. Considering cultural and social differences between Japan and the United States, the results might be different. Therefore, we took a survey from people with DS in Japan to examine their evaluation of their own life and self-perceptions and then compared these results with the results of the previous study in the United States [1].

Materials and methods

The same questionnaire from the original study administered in the United States [1] was used. All the questions were translated before being mailed to each participant's residential address obtained from the Japan Down Syndrome Society (JDS) and collected between 30 October 2015 and 26 November 2015. This study was approved as protocol 2015-9 by the Ethics Review Committee of Ochanomizu University and received permission from the JDS.

Of all participants ($n = 300$) who were 12 years old or older and members of the JDS, 96 (32%) responses were received from people with DS and 16 were excluded for the following reasons: the parents indicated the questionnaire was too difficult for their children to answer ($n = 9$), the respondents were younger than 12 years old ($n = 2$), or the questionnaires were intimidated to be completed by the parents and included the parents' point of view ($n = 5$). The data were analyzed as the same protocol as the original study as well as we used χ^2 to compare our results with the results in United States. We also analyzed the data including those five questionnaires intimidated to have been completed by the parents, yet this did not affect the significance.

Results and discussion

All results are shown in Tables 1 and 2 and Fig. 1. The functional response rate was 28% ($n = 80$), which was more

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Table 1 Characteristics of the respondents

Sex (<i>n</i> = 78)	<i>n</i> (%)
Male	33 (41%)
Female	45 (58%)
<i>Age</i> (<i>n</i> = 74)	
≥12 and <18	10 (14%)
≥18 and <25	21 (28%)
≥25 and <30	14 (19%)
≥30 and <35	9 (12%)
≥35 and <40	9 (12%)
≥40	11 (15%)
<i>Japanese/Non-Japanese</i> (<i>n</i> = 76)	
Japanese	76 (100%)
Non-Japanese	0
<i>Educational level</i> (<i>n</i> = 77)	
Elementary school	1 (1%)
Junior high school	5 (7%)
High school	7 (10%)
Finished high school and working	50 (71%)
Finished high school and not working	10 (14%)
College or university	0
Finished college and working	2 (3%)
Finished college and not working	1 (1%)
Other	1 (1%)
<i>Parents–Guardians</i> (<i>n</i> = 77)	
Have both parents	69 (89%)
Have a father or mother	8 (10%)
<i>Living Situation</i> (<i>n</i> = 78)	
Living with parent(s)	66 (82%)
Living with roommates in apt/home	0
Living in group home	10 (13%)
Other	4 (5%)

than expected and showed the participants' willingness to participate in the research. As not everyone answered every question, the total number of responses in each question are different.

From our results, 47% of the respondents were between 18 and 30 years old, and 71% had finished high school and were working. Therefore, our results tended to reflect more of the views of young people with such backgrounds.

We found that >90% of respondents agreed, "They are happy with their lives" (*n* = 76, 97%), "They like themselves" (*n* = 73, 94%), and "They love their family" (*n* = 73, 95%). In addition, respondents who have siblings tended to answer "They are happy with their lives" (*p* = 0.049, data not shown).

The life satisfaction rate was slightly lower in Japan, and the respondents who answered that they were sad about their lives numbered about four times higher in Japan (15%) than in the United States (4%). However, according to the World Happiness Report 2015 produced by the United Nations, the United States ranked higher in life satisfaction [2], which corresponds accurately with our results.

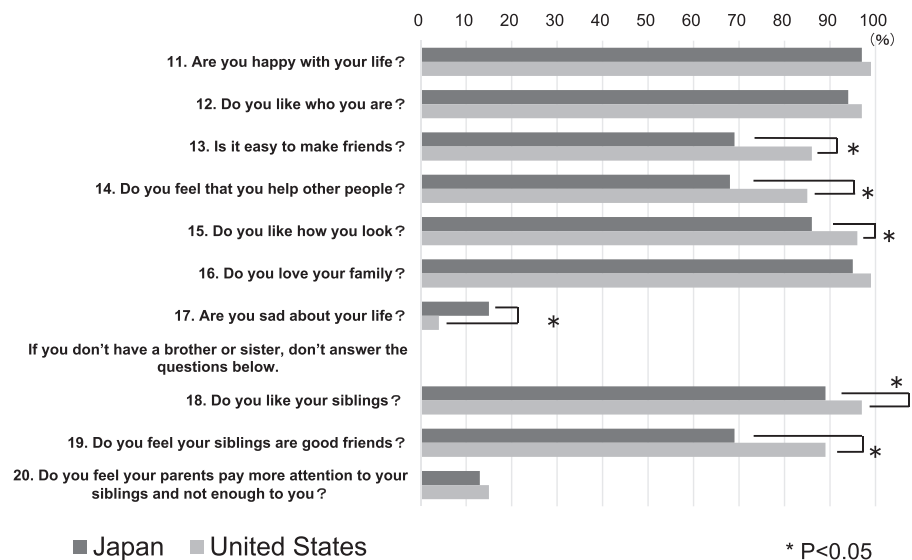
Furthermore, cultural differences may be another possible factor. From our results, satisfaction in their relationships with others, their own self-esteem, and relationships with siblings were significantly less. This could be explained by the self-values ingrained within these cultural backgrounds: Japanese people tend to think "Life is meaningful when there is a good relationship with others", whereas American people may think "Every individual has his/her own life" [3]. Therefore, it is suggested that life satisfaction in Japan is affected more by their relationships with family, siblings, and other people.

Whereas the Japanese population who thinks their life is sad may feel that they do not help others (Pearson's

Table 2 Number of the respondents who answered "yes" to each question. (**P* < 0.05)

Question	<i>n</i> (%)	US [1] (%)	<i>p</i> value	OR
11. Are you happy with your life? (<i>n</i> = 78)	76 (97%)	99	0.6651	0.42
12. Do you like who you are? (<i>n</i> = 78)	73 (94%)	97	0.262	0.43
13. Is it easy to make friends? (<i>n</i> = 75)	52 (69%)	86	0.0016*	0.37
14. Do you feel that you help other people? (<i>n</i> = 73)	50 (68%)	85	0.002*	0.38
15. Do you like how you look? (<i>n</i> = 71)	61 (86%)	96	0.0035*	0.25
16. Do you love your family? (<i>n</i> = 77)	73 (95%)	99	0.1257	0.27
17. Are you sad about your life? (<i>n</i> = 75)	11 (15%)	4	0.0018*	4.2
18. Do you like your siblings? (If you do not have a brother or sister, do not answer this question) (<i>n</i> = 61)	52 (85%)	97	0.0009*	0.18
19. Do you feel your siblings are good friends? (If you do not have a brother or sister, do not answer this question) (<i>n</i> = 61)	41 (67%)	89	0.0001*	0.25
20. Do you feel your parents pay more attention to your siblings and not enough to you? (If you do not have a brother or sister, do not answer this question) (<i>n</i> = 56)	7 (13%)	15	0.8086	0.82

Fig. 1 Results compared between the United States and Japan



correlation -0.257 , $p < 0.05$), the population in the United States did not show this correlation (Pearson's correlation 0.01). This suggests that "helping others" may be one of the key factors for Japanese to feel satisfaction with their life. In addition, participants who feel they are helping others showed correlations with "I like myself" and "I can easily make friends" in Japan. Jackson et al. [4] has indicated people with DS who have low self-esteem may have an issue in communicating with others because of stuttering. In such cases, those with low self-esteem may feel difficulty in making friends and feel helpless [5].

Since April 2013, Non-Invasive Prenatal Testing (NIPT) has been integrated into clinical research programs in Japan [6]. Along with the start of NIPT, DS has drawn more attention from Japanese people because maternal age has been increasing [7], which raises the occurrence of DS. This has resulted in the growth of the number of prenatal tests marketed in Japan [8]. As our survey was only sent out to a limited number of JDS members, these results do not represent the views of everyone with DS in Japan. Also, self-perception can be affected by the severity of the disease. There might be a significant difference in self-perception between mildly affected patients and patients with severe comorbidities such as congenital heart defects etc. However, our results can be useful in genetic counseling for the couples considering prenatal tests or parents raising their children with DS. Some of them might have no idea or misunderstand how it is like to live with DS, providing our study results could help them to have a clearer image about life with DS and can better visualize their life plans.

For future study, our results should be compared with those of the general population so that the similarities and

differences in life with and without DS may be revealed. Also, this survey could be applied to studying self-perceptions of people with other congenital diseases in order to utilize information from the results in genetic counseling for those diseases as well.

Conclusion

In this study, we investigated self-perceptions of people with DS in Japan and compared the results to the original study made in the United States.

We found most people with DS in Japan feel positive about themselves and their lives. Compared with the results in the United States, it is suggested that the relationships with families, siblings, and other people around them affect their happiness more in Japan.

We expect our results to be relevant to genetic counseling for couples considering prenatal testing, people with DS, and their families.

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Conflict of interest The authors declare that they have no conflict of interest.

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