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Comparison of emotional bonds and reading skills in Down syndrome adults with and without Alzheimer's

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Original Article

Abstract

BACKGROUND: Alzheimer's disease (AD) is the most common cognitive disorder and people with Down syndrome face this disease from middle age onwards, leading to numerous problems for the individuals and their families. Important factors, such as psychological, health, and educational variables, have not been investigated so far. This study aimed to compare the emotional bond and reading skills in adults with Down syndrome with and without AD.

METHODS: This study has descriptive-causal-comparative prospective research aspects. The statistical population used in this research was all adults with Down syndrome in Kermanshah Province, the western part of Iran, which included 70 people from September to November 2013. The sampling was done in a census manner. Information was collected through a demographic questionnaire, a researcher-made reading skills questionnaire, and Hillburn's Emotional Scale. Data analysis was performed in the descriptive dimension using statistical indices, and in the inferential dimension using the independent t-test and SPSS software.

RESULTS: There was no significant difference between the two groups of individuals with Down syndrome with and without AD in terms of family emotional bonds and subscales ($t = 1.56$, $P = 0.05$), but there was a significant difference in reading skills and subscales between the two groups with and without AD ($t = 4.87$, $P = 0.05$).

CONCLUSION: Adults with Down syndrome without AD were at a higher level in terms of reading skills compared to adults with Down syndrome with AD. This issue shows the importance of reading skills in preventing AD in these people and makes it stand out.

KEYWORDS: Down Syndrome; Emotional Bond; Reading Skills; Alzheimer

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Introduction

In Down syndrome, which is one of the most common congenital chromosomal disorders, the affected person has three copies of chromosome 21 instead of the usual two. The most common form of intellectual disability is Down syndrome with a prevalence of 1 in 700 births and affects over 6 million people worldwide.[1,2] In Iran, the prevalence and mortality rates of Down syndrome in 2021 were 17.47 and 0.21 per 100000, respectively.[3] Down syndrome, as a genetic disorder, is associated with many defects, including cognitive impairment, epilepsy, seizures, dementia, especially Alzheimer's disease (AD).[4] Most people with Down syndrome are

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at risk of memory impairment from the age of 35 years onwards. They are also at a higher risk of developing AD than the general population.[5] AD is reported as the leading cause of death in Down syndrome in over 30% of United States of America (USA) death certificates in 2019. Studies have also shown that AD may play a role in the death of up to 80% of people with Down syndrome.[6] Family plays an important role in nurturing, forming, and shaping people's personalities and adaptability in ensuring their health and well-being.[7] Ijezie et al. in their study indicate that people with Down syndrome are inferior to normal people in terms of social, emotional, daily, and household activities.[8] Experimental evidence has also shown that expressive and cognitive emotions, family systems and types of support, and mental health in families with children with disorders are lower than normal people.[9] Additionally, coping skills are also found to be weaker among families of individuals with disabilities.[10] Margallo-Lana et al. in their study believed that social interaction skills were lost during the progression of AD,[11] while research by Skotko et al. suggests that individuals with Down syndrome have good emotional relationships with their siblings.[12] On the other hand, increased education can significantly moderate the risk of cognitive decline in AD,[13] particularly through its beneficial effect on cognitive function. Indeed, educational progress can help create a higher cognitive reserve, which refers to the brain's ability to adapt to pathology.[14] Reading skills also contribute to the development of autonomy, learning, and social growth in individuals with Down syndrome.[15,16] Due to their lower phonological awareness skills, individuals with Down syndrome face significant challenges in reading, and therefore, their language development is not the same as that of typical children.[17] Studies have also confirmed that people with Down syndrome have problems with reading skills.[18] Considering the importance of knowing the mentioned factors and the adverse consequences of AD in people with Down syndrome and pointing out that so far not much research has been done regarding family relationships and reading skills in adults with Down syndrome with and without AD, the main purpose of this study was to compare emotional communication and reading skills in adults with Down syndrome with and without AD.

Methods

The present study is a practical and causal-comparative work in terms of objective and research method, respectively. The statistical population of the study was all adults with Down syndrome in Kermanshah Province, the west part of Iran, which was a total of 70 people (60 without AD and 10 with AD) from September to November 2023. Considering the statistical population and the research entry criteria, the census sampling method was used, which according to Canning's theory, the minimum sample size ratio for each estimated parameter is 5 people, and a ratio of 10 to 1 is more appropriate and a ratio of 20 to 1 is considered desirable, which makes the study sample appropriate. Accordingly, the number of selected samples is under these criteria. Compilation of this study was done by the authors through the following steps; by receiving a letter of introduction from the university and then referring to the Kermanshah Welfare Organization and having all the files of the patients with Down syndrome, they studied the files of these patients. In the continuation of the study, patients with and without AD were identified. The next step was to identify patients who were both able and willing to participate in this study. All these steps were done legally and with the consent of the guardians of these patients.

Coordination was carried out with centers, legal guardians, and general explanations about

the research goals were provided. To observe ethical considerations in this research, general explanations about the research goals were provided to the participants and guardians, and they were also assured that the information obtained would be confidential. The consent of the participants and parents or guardians to participate in the research was obtained. Questionnaires were completed by parents, legal guardians, and several patients who were able to answer. The inclusion criteria included informed consent to participate in the research, suffering from Down syndrome, and age over 35 years, and the exclusion criterion was unwillingness to participate in the research.

Findings have been collected using the following tools:

Hillburn Family Emotional Atmosphere Questionnaire: This questionnaire was designed and compiled by Hillburn to measure the level of parent-child emotional relationships. It has 16 questions and its purpose is to evaluate the emotional atmosphere of the family. It includes eight dimensions, which are: affection, caressing, confirming, shared experiences, giving gifts, encouraging, trusting, and feeling safe. Grading is based on a Likert scale from 1 to 5. Dinkelmann and Buff confirmed the construct validity of this test and the reliability of Cronbach's alpha was 0.84.[19] Moreover, in Jafariharandi and Rajaiemoosavi study, the total reliability of this tool was calculated based on Cronbach's alpha of 0.9.[20] These results show the acceptable reliability of this scale. In this study, the Cronbach's alpha coefficient was 0.97.

Reading Skills Assessment: This researcher-made test consists of three parts. The first part includes five questions that are asked of parents of children with the disease about their children's reading skills. Higher scores indicate better reading skills. The second part involved identifying letters of the alphabet and common words, which was asked of individuals with Down syndrome with and without AD. In the final part, individuals suffering from this disease were asked to read several simple and fluent sentences. Reading words and sentences correctly and pronouncing them fluently and without hesitation was indicative of the individuals' reading skills. The scoring method was based on the Likert scale from poor (= 1) to very good (= 5). To measure the validity of the reading skill questionnaire, the questionnaire was given to three professors of the Department of Psychology and Education of Exceptional Children from Science and Research Branch of Tehran Islamic Azad University and two teachers of exceptional children with more than 10 years of work experience to evaluate its structure and content. Their comments indicated the content validity of phrases, words, and sections. Regarding the correlation of the aforementioned questionnaire with similar questionnaires such as Dastjerdi and Soleymani's phonological awareness,[21] the correlation coefficient was found to be around 0.79. The Cronbach's alpha rate of this questionnaire in the present study was 0.99.

In this study, SPSS software (version 21, IBM Corporation, Armonk, NY, USA) was used to analyze the data in both descriptive and inferential dimensions. In the descriptive dimension, descriptive statistics such as frequency, percentages, and standard deviation (SD) were used, which were presented in table form. In the inferential dimension, the independent t-test was used.

This study was conducted by the Ethics Committee of the Islamic Azad University, Science and Research Branch, Tehran, Iran, with the number IR.IAU.SRB.REC.1401.398.

Results

In this section, information from the medical records of individuals with Down syndrome at the Welfare Organization, as well as interviews with parents, guardians, and adults with Down syndrome with and without AD was extracted and recorded. The demographic information of the participants is presented in table 1.

Table 1. Demographic findings of adults with Down syndrome (n = 70)

Variables	Subgroups	n (%)
Gender of adults with Down syndrome	Men	46 (65.7)
	Women	24 (34.3)
Living place	With their families	62 (88.6)
	In boarding centers	8 (11.4)
Down syndrome	With Alzheimer	10 (14.3)
	Without Alzheimer	60 (85.7)
Current weight of adults with Down syndrome (kg)	Less than 70	3 (4.3)
	71-75	5 (7.1)
	76-80	25 (35.7)
	81-85	23 (32.9)
	86-90	14 (20.0)
Birth weight of adults with Down syndrome (kg)	Less than 2.5	8 (11.4)
	2.5-3	35 (50.0)
	More than 3	27 (38.6)
Height of adults with Down syndrome (cm)	Less than 155	1 (1.4)
	156-160	38 (54.3)
	161-165	29 (41.1)
	166-170	2 (2.9)
	More than 171	0 (0)

The descriptive statistics of the study variables are shown in table 2.

Table 2. Descriptive statistics of the study variables

Variables	Mean ± SD
Family emotional atmosphere	4.11 ± 1.01
Relationship with father	4.00 ± 1.19
Relationship with mother	4.22 ± 0.98
Reading skills	3.06 ± 1.66
Ability to read	3.02 ± 1.70
Word recognition	3.02 ± 1.66
Letter recognition	3.07 ± 1.68
Comprehension	3.17 ± 1.63
Fluent reading	3.02 ± 1.71

SD: Standard deviation

At first, skewness and kurtosis were used to check the normality of the research variables and since the family bond score (-1.6, 2) and reading skill score (-0.173, -1.6) were in the normal range (-2, +2), they had a normal distribution. An independent t-test was used to measure the difference between adults with Down syndrome with and without AD. To measure the homogeneity of the variance of family emotional atmosphere and subscales in two groups, the results of Levene's test were not significant ($F = 2.34$, $P > 0.05$). This means that the variance of this variable is homogeneous in the groups. In table 3, the results of the independent t-test with the assumption of equal variances are reported. In the family emotional atmosphere variable, the average of adults with Down syndrome without AD (4.18) was not different from the average of adults with Down syndrome with AD (3.65) [$P = 0.1$, degree of freedom (df) = 68, $t = 1.56$]. In the variable of relationship with father, the average of adults with Down syndrome without AD (4.06) was not different from the average of adults with Down syndrome with AD (3.61) ($P = 0.2$, df = 68, $t = 1.12$). In the variable of relationship with mother, the average of adults with Down syndrome without AD (4.30) was not different from the average of adults with Down syndrome with AD (3.75) ($P = 0.09$, df = 68, $t = 1.68$).

An independent samples t-test was used to assess the difference between adults with Down syndrome with and without AD. To assess the homogeneity of variance of reading skills and its subscales in the two groups, the results of Levene's test were not significant ($F = 1$, $P > 0.05$). This means that the variance of these variables is homogeneous in the groups.

Table 3. Independent samples t-test results to compare groups in family emotional atmosphere and subscales

Variables	Disease type	Number	Mean ± SD	df	t-test	P
Family Emotional Atmosphere	Without Alzheimer's	60	4.18 ± 0.94	68	1.56	0.1
	With Alzheimer's	10	3.65 ± 1.30			
Relationship with Father	Without Alzheimer's	60	4.03 ± 1.10	68	1.12	0.2
	With Alzheimer's	10	3.61 ± 1.40			
Relationship with Mother	Without Alzheimer's	60	4.30 ± 0.90	68	1.68	0.09
	With Alzheimer's	10	3.75 ± 1.30			

df: Degree of freedom; SD: Standard deviation

Table 4 shows the results of the independent-samples t-test with the assumption of equal variances. Considering equal variance in the independent t-test has led to the formation of table 4. According to table 4, in the reading skill variable, the mean of adults with Down syndrome without AD (41.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 8.74$). This means that the group of adults with Down syndrome without AD scored higher than the group with AD. In the reading ability subscale, the mean of adults with Down syndrome without AD (3.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 6.4$). This means that the group of adults with Down syndrome without AD scored higher than the group with AD. In the word recognition subscale, the mean of adults with Down syndrome without AD (3.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 7.4$). This means that the group of adults with Down syndrome without AD scored higher than the group with AD. In the letter recognition subscale, the mean of adults with Down syndrome without AD (4.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 8.4$). This means that the group of adults with Down syndrome without AD scored higher than the group with AD. In the comprehension subscale, the mean of adults with Down syndrome without AD (5.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 3.5$). This means that the group of adults with Down syndrome without AD scored higher than the group with AD. In the fluency subscale, the mean of adults with Down syndrome without AD (3.3) differed significantly from the mean of adults with Down syndrome with AD (1) ($P < 0.001$, $df = 68$, $t = 5.4$).

Table 4. Independent samples t-test results to compare two groups in reading skills and subscales

Variables	Disease type	Number	Mean ± SD	df	t-test	P
Reading Skills	Without Alzheimer's	60	3.41 ± 1.55	68	4.87	0.01
	With Alzheimer's	10	1 ± 0			
Ability to Read	Without Alzheimer's	60	3.3 ± 1.6	68	4.6	0.01
	With Alzheimer's	10	1 ± 0			
Word Recognition	Without Alzheimer's	60	3.3 ± 1.5	68	4.7	0.01
	With Alzheimer's	10	1 ± 0			
Letter Recognition	Without Alzheimer's	60	3.40 ± 1.5	68	4.8	0.01
	With Alzheimer's	10	1 ± 0			
Comprehension	Without Alzheimer's	60	3.5 ± 1.4	68	5.3	0.01
	With Alzheimer's	10	1 ± 0			
Fluent Reading	Without Alzheimer's	60	3.3 ± 1.6	68	4.5	0.01
	With Alzheimer's	10	1 ± 0			

df: Degree of freedom; SD: Standard deviation

This means that the group of adults with Down syndrome without AD scored higher than the group with AD.

Discussion

For the first time in Iran, this study compares family emotional bonds and reading skills in adults with Down syndrome with and without AD. The research results do not show a difference between the relationship with the father or mother present in the family emotional atmosphere between adults with Down syndrome with AD and those without AD. This means that these two groups did not differ from each other in emotional bonds. These findings are similar to the study of Ijezie et al.[8] This research shows that in people with Down syndrome with and without AD, family emotional atmosphere is maintained similarly and there is no significant difference in relationships with parents. Additionally, De Clercq et al. in their study stated that there was a positive emotional atmosphere in the families of people with disorders.[22] Their results are similar to the present study. In explaining these findings, it should be said that since all humans' basic needs are affection, friendship, social belonging, cooperation, and participation with others, people with Down syndrome are no exception to this rule and participate effectively in their family and social relationships. As a result, they receive good acceptance and support from their family members; therefore, they will not have much difference with other people regarding communication. However, due to their special situation and characteristics, they need more support and care. The level and quality of care their families provide them are different. Another reason for the lack of difference between the two groups is that both groups with and without AD are kept in protected places and conditions, and their needs are met by their families and members.

However, it should be noted that the time and process of AD onset among patients is valuable. The study population may not be in the stage of destruction in terms of the time of AD onset and may be in the early stages of AD; therefore, there is not much difference in their behavior and social relationships.

The results showed that the adults without AD differed from the adults with AD in the reading skill variable. In the subscales of reading ability, word recognition, letter recognition, comprehension, and fluency, there was a difference between the adults with and without AD.

Norling et al. also investigated the relationship between Down syndrome and AD in a study and showed that people with Down syndrome, due to the presence of certain proteins in the brain, were more at risk of AD and reduced cognitive skills such as reading.[23] The results of this research were similar to our research.

In explaining this difference, studies have shown that AD in people with Down syndrome causes impaired executive and cognitive functions and memory[24] due to a decrease in the volume of brain regions such as the hippocampus and corpus callosum. Therefore, it is natural that reading skills, which are part of cognitive abilities, also decrease in the group of adults with Down syndrome with AD. On the other hand, it may be concluded that people with Down syndrome who have better reading skills are less likely to develop AD in the future. This result suggests that cognitive abilities are protective factors against AD in people with Down syndrome.

Memory loss, learning impairment, and forgetfulness are the usual early signs of AD. Therefore, the first symptoms of AD in people with Down syndrome are in the area of memory and learning. Moreover, cognitive and memory impairments as symptoms of AD lead to a decrease in cognitive reserve and reduce the level of learning and reading skills.

Based on the nexin-27 protein sorting theory is correct, one of the functions of this protein is to protect and maintain a series of receptors on the surface of nerve cells in the brain. The proper functioning of these receptors is essential for maintaining healthy communication between nerve cells. Therefore, when the level of this protein decreases, neuron activity is disrupted and essential brain functions such as learning and memory are severely impaired.[25] In other words, impairments in memory and executive functions lead to impairments in learning and memory, which in turn, lead to a decrease in reading, speech, and communication abilities.

This study had some limitations. There is no complete standard measure for the diagnosis of dementia, its severity, and grading in people with Down syndrome. The lack of matching of the groups based on gender, intelligence, and educational status due to the small sample size makes it difficult to compare the two groups.

In light of the findings, it is suggested that further studies be conducted on psychosocial factors in people with Down syndrome with and without AD and these factors be compared with other exceptional groups. This will increase our knowledge of the needs and problems of these individuals, and will lead to the development of treatment and preventive programs that can be effective in the education, training, and well-being of people with Down syndrome and the mental health of their caregivers. In this way, educational and training materials can be made applicable to the type of disability and capabilities of these individuals, and treatment and support programs can be improved.

Conclusion

The results showed no significant difference in the family emotional climate between the two groups, but there was a significant difference in reading skills. These findings highlight the critical role of reading skills in cognitive function and educational importance of interventions for adults with Down syndrome. Additionally, family support remains crucial for the well-being of individuals with Down syndrome.

Conflict of Interests

Authors have no conflict of interests.

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