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The effect of functional independence level and age's on the quality of life of mother's with Down syndrome children.

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Abstract

Objective: This study was investigate the effect of level of functional independence and ages on the quality of life of the mothers in children with Down Syndrome.

Methods: Thirty seven Down syndrome children (7.9 ± 3.5 years) were included in this study. Functional independent level of children were evaluated by using Functional Independence Measure, mothers quality of life were evaluated by using Short Form-36. Down syndrome children were classified according their Functional Independence Measure total score into two groups; need observation (36-90 scores) (n=19) and independent (91-126 scores) (n=18) groups.

Results: Functional Independence Measure total scores of children in need obsevation group and children in independent group were 73.7 ± 15.4, 106.7 ± 11.6, respectively. Sort Form-36 Physical, Sort Form-36 Mental and Sort Form-36 Total scores of children in need obsevation group were 53.1 ± 25.1, 49.6 ± 14.9 and 102.7 ± 37.4 and children in independent group scores were 68.3 ± 21.6, 62.1 ± 13.9 and 130.5 ± 33.7, respectively. When we compared Short Form-36 Mental and Sort Form-36 Total scores of the groups were significant in favor of independent group ($p<0.05$), but the difference of Short Form-36 Physical score was insignificant ($p>0.05$). In addition, it was found no relationships between the quality of life of mothers and children age in the all groups ($p>0.05$).

Conclusion: The results of our study suggested that functional dependence level of Down syndrome children effects on mothers' quality of life and affected domain of quality of life was mental health. It was seen that the age of Down syndrome children did'nt has effect on quality of life of mothers.

Keywords: Mother, Down's syndrome, Functional level, Mental health.

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Introduction

Down Syndrome (DS) is a disorder of multiple congenital anomalies that occurs approximately 93% of cases with extra chromosome 21 [1].

The problems that are observed in Down syndrome include delay in motor development, sensory and motor problems, perceptual disorders, severe intellectual retardation and adaptive behavioral disorders [2].

Carr [3] reported that a child with Down syndrome was less successful at motor development domain as compared to mental development. Conolly and Michael [4] reported that children with Down syndrome had significantly a lower speed in walking, balance, strength, eye-hand coordination and general fine and gross motor skills. Therefore, the motor and mental deficiencies in children with Down syndrome may affect their independency in daily life.

In the historical process, it has been shown that life of parents with disabled child, particularly of mothers, is adversely affected [5-7]. Because this condition is chronic, it is indicated that self-esteem in parents is changed, confidence is reduced, and they have problems including depression, social isolation, severe emotional disorders, increased marital problems, finding a job and absenteeism [8-10].

A child with Down syndrome is likely to affect the family's system in many ways. Many studies have addressed the influences of child with Down syndrome on the family in different perspectives [11]. This influence has been suggested to be associated with cognitive and behavioral phenotypes of the child with Down syndrome. They include social interaction, language of expression, perceptual skill, motor skill and motivation which are specific forms of difficulty in information processing and weakness [12-14]. The weakness in this case affects the family and caretakers who are responsible for the basic care, on the other hand, increased burden of care, reduced satisfaction of family with care role and missing career opportunities in life adversely affect the family [15-17]. Many studies addressing the adaption of parents to their child with DS have primarily focused on the stress. The families have a higher level of stress because a child with DS has a combination of general health, education and developmental retardation [18-21].

The literature suggests that families with disabled child, especially mothers, are psychologically affected [21-28]. A study reported that behaviors and care demand of child with DS highly influenced the mental health of mothers [29]. The objective of this study was to identify whether functional level of children with DS in daily life had an influence on the families' quality of life as well as to investigate the association of child's age with mother's quality of life.

Materials and Methods

This analytic study included mothers of 37 children who were diagnosed with Down syndrome, receiving education at special education and rehabilitation center, and whose age ranged 3 to 18 years and mean age was 7.9 ± 3.5 years. Inclusion criteria were based on the voluntary of mothers and diagnose of their children with DS. The mothers who were not contacted and voluntary were excluded from the study.

This trial was approved by the Pamukkale University Faculty of Medicine, Clinical Research Ethics Committee at the meeting dated 23/06/2013 (decision number: 2013/09) and also was carried out according to the principles of the Declaration of Helsinki. The trial was explained to the parents and written information and consent of the parents were obtained.

In this study, socio-demographic data of children and mothers were obtained and a questionnaire was administrated to find out the number of children in family, and education level, profession and marital status of parents. The WeeFIM, the functional independence measure, was used to assess independence level of children in daily life and the Short Form-36 (SF-36) was used to assess family's quality of life.

Level of Functional Independence (WeeFIM)

The Functional Independence Measure (WeeFIM) assesses the degree of independence performance of child in daily life.

The Functional Independence Measure is a valid and reliable test for both disabled and non-disabled children in order to assess functional independence of disabled children at the age of six months to seven years and of any children under seven years of age, and to monitor their development. This test may also be carried out on children with retarded development up to 21 years. It is intended to question self-care, sphincter control, transfer activities, mobility, communication skills and cognitive skills of a child with eighteen items.

The Functional Independence Measure scores the functions of child ranging seven to one as follows: Seven: complete independence; six: modified independence; five: supervision; four: minimal assist; three: moderate assist; two: maximal assist; and one: total assist. Scoring one to four indicates the level of assist needed by the child to complete an activity. The score of five indicates supervision of child to perform a skill, or the cue provided by the adult. The score of six indicates that child is able to complete an activity independently, but needs an assisting instrument [22].

The Functional Independence Measure may be administrated by direct observation child or by interviewing a person who could provide information on the child's general and continual performance or both. Each item is scored. The lowest total score from the test is 18 (complete dependence in any skill) and the highest total score is 126 (complete independence in any skill). When we group independence level of children with DS according to score from the Functional Independence Measure, two groups were formed: Down syndrome group requiring supervision (n=18) with total score ranging 36 to 90 and independent Down syndrome group (n=19) with total score ranging 91 to 126 [23].

Health-Related Quality of Life (SF-36)

The Short Form-36 (SF-36) was used to assess the general health of mother who had a child with DS. The Short-Form-36 survey is a valid and commonly used measure to assess quality of life. It contains 36 questions under eight subscales: physical functioning, physical role functioning, emotional role functioning, bodily pain, social role functioning, mental health, vitality and general health. It has two subsections: Physical section and mental section. The physical section includes subscales of physical functioning, physical role, bodily pain and general health, and the mental section includes subscales of vitality, social functioning, emotional role and mental health. The Short Form-36 is the widely used scale for quality of life in the medical domain and Kocyigit et al. [24] performed Turkish validity study.

Statistical Analysis

The obtained data was analyzed by SPSS (Statistical

Package for the Social Sciences version 16, Chicago, IL, USA) 16 packet program. The numeric variables of study were expressed in mean ± standard deviation (mean ± SD), number and percent (n, %). The Mann-Whitney U test, a nonparametric test, was used to compare the numeric variables of two groups. The Spearman's correlation analysis was used to analyze the influence of age of child with DS on the mother's quality of life. p=0.05 was considered significant for all statistical analyses [25].

Results

Table 1 shows the information on distribution of characteristics of children with DS. The age of children with DS ranged from 3 to 18 years; the mean age was 7.9 ± 3.5 years, 54.1% of children (n=20) were girls. The demographic characteristics, education level and profession of parents and distribution of monthly aggregate revenue of family are provided in Table 1.

In total score from Wee-FIM, the Functional Independence Measure, total score of children with DS requiring supervision (n=19) from Wee-FIM was 73.7 ± 15.4, whereas total score of independent children in DS group (n=18) from Wee-FIM was 106.7 ± 11.6. All subtests of Wee-FIM and total score of groups were compared and the result was found significant in favor of independent children with DS (p<0.05) (Table 2).

Table 1. *Socio-demographic characteristics of children with Down's syndrome*

	Mean ± SD
Age (years)	7.9 ± 3.5[a]
Gender	
Girl	20 (54.1)[b]
Boy	17 (45.9)[b]
Mother's age(years)	40.1 ± 6.1[a]
Family's income rate	
0-1 499 TL (low)	14 (37.8)[b]
1 500-2 500 TL (medium)	22 (59.5)[b]
2 500 TL and up (high)	1 (2.7)[b]
Mother's education status	
Primary school	17 (45.9)[b]
Middle school	9 (24.3)[b]
High school	11 (29.7)[b]
Father's education status	
Primary school	9 (24.3)[b]
Middle school	6 (16.2)[b]
High school	19 (51.4)[b]
Primary school	3 (8.1)[b]
Mother's business status	
Working	2 (5.4)[b]
Not working	34 (91.9)[b]
Retired	1 (2.7)[b]
Father's business status	
Working	31 (83.8)[b]
Not working	5 (13.5)[b]
Retired	1 (2.7)[b]
Parental involvement	
Married living together	37 (100)[b]

[a]Mean ± SD: Mean ± Standard Deviation, [b]n(%)

The SF-36 mental, physical and total scores of mothers in two groups were 49.6 ± 14.9, 53.1 ± 25.1 and 102.7 ± 37.4 for those requiring supervision and 62.1 ± 13.9, 68.3 ± 21.6 and 130.5 ± 33.7 for independent children, respectively (Table 2).

Short Form-36 Mental (p=0.018) and SF-36 Total (p=0.036) scores were significant in favor of independent children with DS, whereas the difference in SF-36 Physical scores was non-significant (p=0.062) (Table 2).

The association between the age of children requiring supervision and independent children with DS and the mothers' scores from SF-36 was not identified (p>0.05) (Table 3).

Discussion

This study aimed to investigate the influence of functional level of children with DS on the mother's quality of life, and found that reduced independence level of children affected the mother's quality of life and this was a mental influence. In addition, increase in age of children with DS did not adversely affect the mother's quality of life.

Based on the similar results, other studies suggested that families that had disabled children or children with chronic disease psychologically experienced higher stress [26,27]. Eisenhower et al. [28] compared three year old children with DS and behavioral problem to normal children, and reported at the end of two-year follow up that children with DS had increased behavioral problems which caused family to have stress.

Analogous to results of our study, Bourke et al. [29] reported that families of children with DS were mentally affected more and they expressed that this influence was associated with child's behavior and care requirements, and that mothers that had children with DS and more maladaptive behavior had a higher level of stress. The families also expressed that functional independence level of their children in daily life such as shopping and using public transport vehicles affected them more than child's existing current health problems. In our study, children in the dependence group significantly scored low at self-care, reading comprehension skill and social communication activities, and the mothers of those children were observed to be mentally worse.

In families that have a child with cerebral palsy, it has been shown that workload of families was reduced and their physical health was better as the child's independence level was increased [30]. In contrast, there are studies that did not find an association between the child's functional level and the family's physical health [31-34]. In our study, although families were mentally affected by the child's functional level, the physical influence was not significant. Furthermore, several studies reported that families that

Table 2. *Wee-FIM of children with Down's syndrome and SF-36 results of their mothers*

Children with Down's syndrome	**Group of requiring observation (n=19)**		**Group of independent (n=18)**		**p***
	Lowest-Highest	**Mean ± SD**[a]	**Lowest-Highest**	**Mean ± SD**[a]	
Wee-FIM[b]					
Self-care	7-33	20.8 ± 7.8	23-44	35.7 ± 5.4	**0.001****
Sfinkter	2-14	7.7 ± 5.2	10-14	13.5 ± 1.0	**0.001****
Mobility	7-21	18.8 ± 3.6	18-21	20.8 ± 0.7	**0.011****
Locomotion	7-14	12.6 ± 2.0	12-14	13.8 ± 0.5	**0.008****
Cognition	2-13	6.4 ± 2.9	4-14	10.1 ± 2.6	**0.001****
Social communication	3-18	7.6 ± 4.4	5-19	13.1 ± 4.9	**0.003****
Total point	38-90	73.7 ± 15.4	91-122	106.7 ± 11.6	**0.001****
SF-36[c]					
Physical	17.50-92	53.1 ± 25.1	24-94	68.3 ± 21.6	0.062
Mental	10.50-71.75	49.6 ± 14.9	34.25-86.25	62.1 ± 13.9	**0.018****
Total	30.50-163.75	102.7 ± 37.4	58.25-167.75	130.5 ± 33.7	**0.036****

* Mann Whitney U test, [a]Mean ± SD: Mean ± Standart Deviation,b: Wee-FIM: Wee-Functional İndependent Measure, c:SF-36: Short Form-36

Table 3. *The relationship between the age of children with Down's syndrome and the quality of life of mothers*

Mother's SF-36 points[a]	**Group of requiring observation (n=19)**		**Group of independent (n=18)**	
	r	**p***	**r**	**p***
Physical	-0.121	0.621*	-0.154	0.542
Mental	-0.139	0.571*	-0.088	0.727
Total	-0.101	0.681*	-0.140	0.578

*Spearman Corelation Analysis, a: SF-36: Short Form 36

had a child with DS were more advantageous than families that had a group of disabilities including autism, mental disability and disability with unknown etiology.

Hauser-Cram et al. [35] conducted a longitudinal study to investigate familial burden of parents that had a child with DS, monitored the children from three years of age and 10 years of age for seven years, and found that familial burden of parents was increased with age of children and this increase was more than the of mothers of children with retarded development with unknown etiology or mothers of children with motor disorder [35].

Another longitudinal study investigating the stress level of children with mental disability with different etiologies on the parents found that the stress level of parents of children with DS was lower than that of parents of children with other disabilities when the children was 12 months old; however the assessment carried out when the children were 45 months old showed no difference in stress levels of parents between the groups [6]. They reported that increased stress level of mothers of children with DS might be due to increased age of child and insufficient motor development. Our study found that age of children was associated with the mother's quality of life. Increase in the age of children did not have a negative influence on the mother's quality of life. Our results were different from the results of Hauser-Cram et al. [35] and Most et al. [36]; this might be due to sample size of our study and the smaller age range of other studies than the age range of our study.

The major limitation of this study was that only functional independence level of children was assessed, and other factors that might affect parents' mental health were not investigated; and we believe that such factors should be investigated by further studies.

Based on our results, mental health of mothers of child with DS and lower independence level was worse. This finding indicates that mothers of children with DS need support.

Pourmohamadreza-Tajrıshı et al. [37] reported that they developed a method for mothers to understand their children with problem-centered education strategy used to resolve psycho-social problems of mothers of children with DS so that their mental health could be improved. Douma et al. [38] suggested that 88.2% of parents of mentally disabled adolescents needed various supports which were usually not provided. King et al. [31] indicated that family-centered services would be useful to identify children with behavioral problems. Likewise, Raina et al. [30] underlined that how functionality of children as well as their behavioral problems affected the parents should be assessed on the basis on parents for the well-being of families that had a disabled child.

Disability is typically regarded as a burden by the society. A very negative opinion that almost entire society has on a child with DS and his/her parents further increases the burden of parents. A response to problems that children with DS have is considered to positively improve the child's condition and have an influence on the mothers' health. Mac Conachie et al. [39] emphasized the positive influence of early response on the mothers.

Conclusion

Based on our results, we consider that mental health of mothers of children with DS was associated with functional independence level of children but not affected by the age of child. We recommend investigating other factors that may affect the mother's mental health in further studies, and appropriate approach should be used to support mother's mental health.

References

1. Lauteslager PEM. Children with Down's Syndrome; motor development and intervention. Adv Physiother 2004; 7(3): 141.
2. Leonard S, Msall M, Bower C, et al. Functional status of school-aged children with Down syndrome. J Paediatr Child Health 2002; 38: 160-165.
3. Carr J. Mental and motor development in young mongol children. J Ment Defic Res 1970; 14: 205-220.
4. Connolly BH, Michael BT. Performance of retarded children, with and without Down's syndrome, on the Bruininks Oseretsky test of motor proficiency. Phys Ther 1986; 66: 344-48.
5. Damrosch S, Perry L. Self-reported adjustment, chronic sorrow and coping of parents of children with Down syndrome. Nurs Res 1989; 38: 25-30.
6. Olshansky S. Chronic sorrow: A response to having a mentally defective child. Soc Casework 1962; 43: 190-193.
7. Wikler L, Wasow M, Hatfied E. Chronic sorrow revisited: Parents vs. professional depiction of the adjustment of parents of mentally retarded children. Am J Orthopsychiatr 1981; 51: 63-70.
8. Olsson MB, Hwang PC. Depression in mothers and fathers of children with intellectual disability. J Intellect Disabil Res 2001; 45: 535-543.
9. Spangenberg J, Theron J. Stress and coping in parents of children with Down syndrome. Stud Psychol 2000; 43: 41-48.
10. Seltzer MM, Greenberg JS, Floyd FJ, Pettee Y, Hong J. Life course impacts of parenting a child with a disability. Am J Ment Retard 2001; 106: 265-286.
11. Hodapp RM. Families of persons with Down syndrome: New perspectives, findings and research and service needs. Ment Retard Dev Disabil Res Rev 2007; 13: 279-287.
12. Fidler DJ. The emergence of a syndrome-specific personality profile in young children with Down syndrome. Downs Syndr Res Pract 2006; 10(2): 53-60.
13. Fidler DJ, Hepburn S, Rogers S. Early learning and adaptive behaviour in toddlers with Down syndrome: Evidence of an emerging behavioural phenotype. Downs Syndr Res Pract 2006; 9(3): 37-44.
14. Silverman W. Down syndrome: Cognitive phenotype. Ment Retard Dev Disabil Res Rev 2007; 13: 228-236.
15. Scorgie K, Sobsey D. Transformational outcomes associated with parenting children who have disabilities. Ment Retard 2000; 38(3): 195-206.
16. Van Riper M. A change of plans: the birth of a child with Down syndrome doesn't have to be a negative experience. Am J Nurs 2003; 103: 71-74.
17. Van Riper M. Families of children with Down syndrome: Responding to "a change of plans" with resilience. J Pediatr Nurs 2007; 22: 116-128.
18. Baker BL, McIntyre LL, Blacher J, et al. Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. J Intellect Disabil Res 2003; 47: 217-230.
19. Hedov G, Anneren T, Wikblad K. Swedish parents of children with Down's syndrome. Scand J Caring Sci 2002; 16: 424-430.
20. Lam L, Mackenzie A. Coping with a child with Down syndrome: The experiences of mothers in Hong Kong. Qual Health Res 2002; 12: 223-237.
21. Olsson MB, Hwang PC. Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. J Intellect Disabil Res 2003; 47: 328-341.
22. Msall ME, DiGaudio K, Duffy LC, et al. WeeFIM: Normative sample of an instrument for tracking functional independence in children. Clin Pediatr 1994; 33: 431-438.
23. Wong V, Wong S, Chan K, et al. Functional Independence Measure (WeeFIM) for Chinese children: Hong Kong cohort. Pediatrics 2002; 109: E36
24. Kocyigit H, Aydemir O, Fisek G, et al. Kısa Form-36 (KF-36)' nın Turkce versiyonunun Guvenilirligi. Ilac ve Tedavi Dergisi 1998; 12: 102-106.
25. Tabachnick B, Fidell L. Computer-assisted research design and analysis. Boston: Allyn and Bacon 2001.

26. Esdaile SA, Greenwood KM. A comparison of mothers' and fathers' experience of parenting stress and attributions for parent child interaction outcomes. Occup Ther Int 2003; 10: 115-126.
27. Glidden LM, Schoolcraft SA. Depression: Its trajectory and correlates in mothers rearing children with intellectual disability. J Intellect Disabil Res 2003; 47: 250-263.
28. Eisenhower AS, Baker BL, Blacher J. Preschool children with intellectual disability: Syndrome specificity, behavior problems and maternal well-being. J Intellect Disabil Res 2005; 49: 657-671.
29. Bourke J, Rıccıardo B, Bebbıngton A, et al. Physical and mental health in mothers of children with Down syndrome. J Pediatr 2008; 153: 320-6.
30. Raina P, O'Donnell M, Rosenbaum P, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatr 2005; 115: 626-36.
31. King G, King S, Rosenbaum P, et al. Family-centered care giving and well-being of parents of children with disabilities: Linking process with outcome. J Pediatr Psychol. 1999; 24: 41-53.
32. Waddington SR, Busch-Rossnagel NA. The influence of a child's disability on mother's role functioning and psychological well-being. Genet Soc Gen Psychol Monogr 1992; 118: 293-311.
33. Manuel J, Naughton MJ, Balkrishnan R, et al. Stress and adaptation in mothers of children with cerebral palsy. J Pediatr Psychol 2003; 28: 197-201.
34. Laurvick CL, Msall ME, Silburn S, et al. Physical and mental health of mothers caring for a child with Rett syndrome. Pediatr 2006; 118: e1152-64.
35. Hauser-Cram P, Warfield ME, Shonkoff JP, et al. Children with disabilities: A longitudinal study of child development and parent well-being. Monogr Soc Res Child Dev 2001; 66: 266.
36. Most DE, Fidler DJ, LaForce-Booth C, et al. Stress trajectories in mothers of young children with Down syndrome. J Intellect Disabil Res 2006; 50: 501-514.
37. Pourmohamadreza-Tajrıshı M, Azadfallah P, Hemmatı Garakanı S, et al. The effect of problem-focused coping strategy training on psychological symptoms of mothers of children with Down syndrome. Iran J Public Health 2015; 44: 254-262.
38. Douma JCH, Dekker MC, Koot HM. Supporting parents of youths with intellectual disabilities and psychopathology. J Intellect Disabil Res 2006; 50: 570-581.
39. Mac Conachie H, Diggle T. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. J Eval Clin Pract 2007; 13: 120-129.

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