

## An Investigation of Basic Needs and Related Factors in Parents of Children with Down syndrome

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### Abstract

**Background:** Down syndrome is one of the most common causes of intellectual disabilities in children. The birth of a baby requires a positive adaptation of the family to new changes, especially when the child has a disability such as Down syndrome. When a child with Down syndrome is born, parents experience many conflicting emotions and feel inadequate. Therefore, it is important to examine the needs of these parents with issues related to living with a child with Down syndrome, as well as the factors that affect the needs.

**Methods:** This is a descriptive-analytical research conducted cross-sectionally on 172 parents of families with children aged 1-19 with Down syndrome who were covered by the welfare organization of Guilan province. Simple random sampling method without placement was used in sampling for this research. The data collection tools were Glaser's Basic Needs Questionnaire to measure needs and a researcher-made questionnaire of related factors. Data were analyzed using Kolmogorov-Smirnov, Wilcoxon, Friedman, Mann-Whitney, Kruskal-Wallis and Spearman correlation coefficient tests in IBM SPSS Statistics version 26.

**Results:** The findings of this research showed that there was a weak significant negative relationship between the need for survival and the need for freedom ( $P=0.001$  and  $r=0.245$ ). There was no significant correlation between the scores of the need for recreation and the need for strength ( $P=0.534$  and  $r=0.048$ ). There was a statistically significant difference between the scores of the parents of children with Down syndrome in Glaser's basic needs scale ( $P<0.001$ ). A statistically significant difference was observed between the scores of the need for power according to the educational level of the parents ( $P=0.007$ ), and a statistically significant difference was also observed between the scores of the need for power according to the level of the parents' income ( $P=0.011$ ).

**Conclusion:** The findings of this study show that the performance of families who face fewer needs and receive higher levels of social support is better than those of the families who face multiple needs and receive limited social support.

**Key Words:** Children, Down syndrome, Needs, Parents.

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## 1- INTRODUCTION

Down syndrome is the most common chromosomal disorder with a prevalence of 1 in 1000 live births. The cause of Down syndrome is unknown (1).

Recent reports in the field of cell genetics and epidemiology studies indicate the multifactorial nature of this disease. The degree of physical and cognitive impairment depends on the percentage of cells with abnormal chromosomal structure (2). There are complications caused by these changes in the heart and blood vessels, breathing, endocrine glands, eyes, ears, digestive system, as well as sleep disorders and premature aging. However, the survival of children with Down syndrome has increased significantly. In general, this disease, as a disease with high morbidity and mortality, has a great impact on the quality of life, as well as social and educational participation. Due to specific physical characteristics, children with Down syndrome are usually diagnosed at birth. Parents usually want to know the diagnosis as soon as possible. Most of them prefer to be present during the interview to find out about the diagnosis so that they can support each other emotionally. The parents' reaction towards the child may significantly affect the decisions related to future care (3).

The parents of these children face many problems due to their children's unusual behaviors and the difficulties in taking care of the child, as well as constantly facing the changing needs of the child, which cause a disruption in the self-efficacy of the parents (4). People with special disorders inevitably take a large amount of the family's money, energy, and time, which in turn affects the relationship between family members (5).

Family adaptation refers to the result of families trying to achieve a new balance between the needs of each family member

(6). Support requests for children with severe to profound mental disabilities, who often have additional disabilities and complex needs, significantly affect family life negatively (7, 8). These parents must simultaneously play the role of caring parents and health care providers. Also, parents play a vital role in a child's education and personal development, as they are usually the first and longest caregiver (9). In addition, in case of social changes, the realization of the cooperative society creates increasing demands on the informal network of the family and social communities. As a result, families face challenges in providing the best possible life while taking care of themselves as a family (10, 11). Research shows that the time required to take care of these children has a negative effect on family life (8).

Developmental disabilities can be defined as any physical or mental disability that may impair or limit a child's ability to develop cognitively, physically and emotionally. The family of a disabled child adjusts different aspects of life according to their needs, and the mental and physical stress they suffer disrupts their quality of life (12).

Although adequate treatment is provided in tertiary care centers, there is a gap in evaluating the problems and stresses of parents in facing this situation. Compared to families without disabilities, these parents are often unstable and abandon their previous quality of life, suffer from additional economic problems and unpleasant diseases, and have less welfare (13).

Having a disabled child can have profound effects on the family and may put additional demands, challenges and burdens on the family system. Such an experience affects the life dynamics of other family members in different ways during different stages of the life cycle. Caring parents experience challenges such

as feelings of inadequacy and stressful behaviors by the child along with their frustration with the care system. The needs of the family are probably different according to the individual circumstances of the family. Having a child with a disability creates a wide potential set of challenges for families, but knowing the strategies of adaptation will help families to manage the child with this problem (14).

## **2- MATERIALS AND METHODS**

### **2-1. Design and sampling**

This cross-sectional descriptive-analytical study was conducted on the families of children with Down syndrome. In this research, a random number table method was used. In this way, 172 individuals were selected from the community of 600 people with Down syndrome. In the table of random numbers, a field that usually includes a three-digit field was considered and was moved from top to bottom. The numbers of more than 600 were ignored and the next number was chosen. This process was repeated until the sample size reached 172 individuals.

#### **2-1.1. Inclusion and exclusion criteria**

The participants included the parents of 1-18-year-old children with Down syndrome who were introduced to the research group through the welfare center. The criteria for entering the research were to have at least one child with Down syndrome, not having physical and mental problems, and having the ability to read and write; if the samples were not willing to cooperate, they were excluded from the study.

### **2-2. Instruments**

The data collection tools in this research included the questionnaire of related factors made by the researcher and Glasser's needs questionnaire. The questionnaire of related factors includes child's age, gender, parent's age, marital status, employment status, average income, parent's education level and

number of children. Glasser's Basic Needs Questionnaire is a self-report tool designed and presented by Dr. Ali Sahebi to assess the intensity of the individuals' basic needs based on Glasser's selection theory. This instrument has seven subscales checking five basic needs, including the need for survival, love and belonging, power, freedom, and fun; and the items are scored based on a 1-5 Likert scale. The total score of each subscale fluctuates from 5 to 35, where 5 means that the needs are not satisfied and 35 means complete satisfaction. The reliability of this questionnaire has been calculated for the male population using Cronbach's alpha and two-half methods to be 0.9 and 0.83, respectively; and it was 0.78 for women using Cronbach's alpha and 0.65 using two-half method.

### **2-3. Procedure**

After obtaining a letter of introduction from the vice president of Shahid Beheshti College of Nursing and Midwifery in Rasht and permission to conduct research from the vice president of research and technology and the vice president of treatment of Guilan University of Medical Sciences, the researcher introduced himself to the management organization of the welfare organization of Guilan province and gave them the permission to conduct research. Afterwards, the researcher explained the goals of the project to the parents and obtained their informed consent to participate in the study. Then, he asked the questions of the scale in an interview manner, while the parents had the questionnaire in front of them; and the parents chose the desired options. Participation in the research was completely free and the confidentiality of the responses was emphasized at the beginning of each interview.

## **3- DATA ANALYSIS**

In this study, the values of quantitative variables were shown as mean

(standard deviation) and median (interquartile range); and the values of qualitative variables were shown as percentage and frequency. Kolmogorov-Smirnov test was used to check the normality of the data. One-sample Wilcoxon signed rank test was used to compare the scores with the average (3 points). Friedman's test was used to compare the values of scores. Also, the relationship between Glasser's basic needs scores was investigated using Spearman's correlation coefficient. The relationship between Glaser's basic needs scores and the individual characteristics of parents and their children was investigated using Mann-Whitney test, Kruskal-Wallis test and Spearman's correlation coefficient. Moreover, multiple linear regression was

used to determine factors related to Glasser's basic needs scores. The data was analyzed using IBM SPSS Statistics version 26. And the significance level was considered as 0.05.

#### 4- RESULTS

This study investigated the basic needs and their related factors among the parents of children with Down syndrome.

Individual characteristics of parents and their hospitalized children are shown in **Table 1**. Among 172 participating parents, 89 (51.7%) were women, 155 (90.1%) were married (parents lived together), 44 (25.6%) had university education, 96 (55.8%) were employed, 19 (11.0%) had favorable income, and 68 (39.5%) had 3 or more children (**Table 1**).

**Table-1:** Individual characteristics of parents of children with Down syndrome

characteristics		(Percent) Frequency
Age of the child	4-6 years	7 (4.1)
	7-14 years	88 (51.2)
	14-18 years	77 (44.8)
Gender of parents	male	83 (48.3)
	Female	89 (51.7)
Marital status of parents	married	155 (90.1)
	divorced	17 (9.9)
education	High school	60 (34.9)
	diploma	68 (39.5)
	university	44 (25.6)
Employment status	housewife	76 (55.8)
	employed	96 (44.2)
Income status	Undesirable	55 (32.0)
	Almost desirable	98 (57.0)
	Optimal	19 (11.0)
Number of children	1	30 (17.4)
	2	74 (43.0)
	≤3	68 (39.5)

The results of the Kolmogorov-Smirnov test showed that the assumption of normality was not met for all the scores ( $P < 0.001$ ), therefore, non-parametric tests were used to analyze the data.

Descriptive indices of Glasser's basic needs scores are shown in **Table 2**. As seen in **Table 2**, the highest average score was related to the need for freedom and the lowest average score was related to the need for power.

**Table-2:** Descriptive indices and correlations between Glasser's basic needs scores in parents of children with Down syndrome

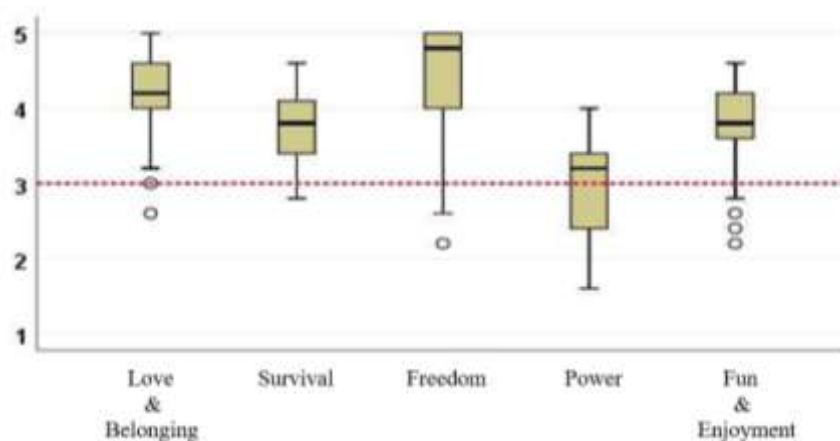
Glasser's Basic Needs	Love and Belonging	Survival	Freedom	Power	Fun & enjoyment
Love and Belonging	1	-	-	-	-
Survival	0.326***	1	-	-	-
Freedom	0.458***	-0.245**	1	-	-
Power	0.363***	0.267***	0.169*	1	-
Fun & enjoyment	0.356***	0.297***	0.302***	-0.048	1
possible domain	1-5	1-5	1-5	1-5	1-5
Viewed domain	2.6-5	2.8-4.6	2.2-5	1.6-4.0	2.2-4.6
(standard deviation) mean	4.27 (0.49)	3.79 (0.41)	4.47 (0.66)	3.03 (0.56)	3.85 (0.47)
(interquartile range) median	4.2 (4.0 – 4.6)	3.8 (3.4 – 4.2)	4.8 (4.0 – 5.0)	3.2 (2.4 – 3.4)	3.8 (3.6 – 4.2)

P<0.001\*\*\* ;P<0.01\*\* ;P<0.05\*

According to the values of Spearman's correlation coefficients, there was a weak significant negative relationship between the need for survival and the need for freedom (P=0.001, r=0.245). No significant correlation was observed between the scores of need for recreation and need for power (P=0.534 and r=0.048). In other cases, there were weak to moderate significant positive correlations between Glasser's basic needs scores. According to the results of the one-sample Wilcoxon signed rank test, the mean scores of the need for love and belonging (P<0.001), survival (P<0.001), freedom (P<0.001) and recreation (P<0.001) were significantly higher than the average, while the mean scores did not need to be significantly different from the average (P=0.664) (**Fig. 1**).

According to Friedman's test results, there was a statistically significant difference between Glasser's basic needs scores in parents of children with Down syndrome (P<0.001). The results of post hoc comparisons showed that the scores of the needs for freedom and love were significantly higher than those of the needs for fun, survival and power. Also, the scores of recreation and survival needs were significantly higher than those of power needs; but there was no significant difference between the scores of freedom and love needs, as well as between the scores of recreation and survival needs.

**Table 3** shows the relationship between the scores of Glasser's basic needs and individual characteristics of the parents of children with Down syndrome.



**Fig. 1:** Box plot of the parents' scores in Glasser's basic needs

**Table-3:** Correlation between Glasser's basic needs and individual characteristics among the parents of children with Down syndrome

Characteristics		Love and Belonging	Survival	Freedom	Power	Fun & enjoyment
Age of the child	4-6 years	4.0 (3.8 – 4.6)	4.0 (3.6 – 4.0)	4.6 (3.4 – 5.0)	2.6 (2.4 - 3.4)	3.8 (3.4 - 4.2)
	7-14 years	4.2 (4.0 – 4.6)	3.8 (3.4 – 4.2)	4.8 (4.0 – 5.0)	3.2 (2.4 – 3.4)	3.8 (3.4 – 4.2)
	14-18 years	4.2 (4.0 – 4.6)	4.0 (3.4 – 4.2)	4.8 (4.2 – 5.0)	3.4 (2.4 – 3.4)	3.8 (3.8 – 4.2)
	P‡	0.735	0.754	0.490	0.831	0.463
Gender of parents	male	4.0 (3.8 – 4.4)	4.0 (3.6 – 4.2)	4.8 (3.8 – 5.0)	3.4 (2.6 – 3.4)	3.8 (3.4 - 4.2)
	Female	4.6 (4.0 – 5.0)	3.8 (3.4 - 4.0)	5.0 (4.2 – 5.0)	2.6 (2.4 – 3.7)	3.8 (3.8 – 4.2)
	P†	0.003	0.184	0.155	0.007	0.363
Marital status of parents	married	4.2 (4.0 – 4.6)	3.8 (3.4 – 4.2)	4.8 (3.8 – 5.0)	3.2 (2.4 – 3.4)	3.8 (3.4 - 4.2)
	divorced	4.6 (4.0 – 4.6)	4.0 (3.3 – 4.0)	4.6 (4.6 – 5.0)	2.4 (2.4 – 3.5)	4.2 (3.8 – 4.2)
	P†	0.631	0.397	0.987	0.069	0.059
education	High school	4.1 (4.0 – 4.6)	3.8 (3.4 – 4.0)	4.8 (4.0 – 5.0)	2.7 (2.4 – 3.4)	3.8 (3.8 - 4.2)
	diploma	4.2 (4.0 – 4.6)	4.0 (3.6 – 4.2)	4.8 (3.9 – 5.0)	3.2 (2.4 – 3.4)	3.8 (3.4 - 4.2)
	university	4.2 (4.0 – 4.6)	3.9 (3.6 – 4.2)	4.8 (3.8 – 5.0)	3.4 (2.6 – 3.6)	3.8 (3.5 - 4.0)
	P‡	0.895	0.303	0.736	0.049	0.719
Employment status	housewife	4.2 (4.0 – 4.6)	3.9 (3.4 – 4.0)	4.5 (3.8 – 5.0)	2.6 (2.4 – 2.8)	3.8 (3.4 - 4.2)
	employed	4.2 (4.0 – 5.0)	3.8 (3.6 – 4.2)	4.8 (4.8 – 5.0)	3.4 (3.4 – 3.8)	3.8 (3.8 - 4.2)
	P†	0.969	0.542	<0.001	<0.001	0.167
Income status	Undesirable	4.2 (4.0 – 4.6)	3.8 (3.4 – 4.0)	4.6 (3.8 – 5.0)	2.6 (2.4 – 3.4)	3.8 (3.4 - 4.2)
	Almost desirable	4.0 (4.0 – 4.6)	3.8 (3.4 – 4.2)	4.8 (4.0 – 5.0)	3.4 (2.4 – 3.4)	3.8 (3.8 - 4.2)
	Optimal	4.4 (4.0 – 5.0)	4.0 (3.8 – 4.2)	4.8 (4.2 – 5.0)	3.4 (2.6 – 3.8)	3.8 (3.4 - 4.0)
	P‡	0.261	0.592	0.196	0.011	0.911
Number of children	1	4.0 (3.8 – 4.6)	4.0 (3.4 – 4.0)	4.8 (4.3 – 5.0)	2.9 (2.4 – 3.4)	3.9 (3.8 - 4.2)
	2	4.2 (4.0 – 5.0)	3.8 (3.4 – 4.2)	4.8 (3.8 – 5.0)	3.3 (2.6 – 3.6)	3.8 (3.4 - 4.0)
	≤3	4.2 (4.0 – 4.6)	4.0 (3.4 – 4.0)	4.8 (4.2 – 5.0)	3.2 (2.4 – 3.4)	3.8 (3.6 - 4.2)
	P‡	0.261	0.989	0.911	0.308	0.052

Values are shown as median (interquartile range) Mann-Whitney test; Kruskal-Wallis test

According to the results of the Mann-Whitney test, the scores of need for love and belonging were higher in women than in men ( $P=0.003$ ), while the scores of need for power were higher in men than in women ( $P=0.007$ ). Mann-Whitney test, further, showed that the scores of need for freedom and need for power were significantly higher in working individuals than in housewives ( $P<0.001$ ). The Kruskal-Wallis test showed that a statistically significant difference was observed between the scores of the need for power according to the level of parents' education ( $P=0.007$ ), so that the scores of the need for power were higher in parents with university education than in parents with undergraduate education ( $P=0.043$ ). Also, a statistically significant difference was observed between the scores of the need for power according to the income level of the parents ( $P=0.011$ ), so that the scores of the need for power were significantly higher in parents with favorable income than in those of parents with unfavorable income ( $P=0.011$ ) (**Table 3**).

## 5- DISCUSSION

This study was conducted with the aim of determining the basic needs and their relevant factors in parents of children with Down syndrome. According to the results, the highest average score of the parents was related to the need for freedom (0.458) and the lowest average score was related to the need for power (0.363).

Skotko et al. (2016) studying the viewpoints of families of children with Down syndrome, found that the vast majority of families also express pride and empowerment for the person with Down syndrome. It can be said that the needs of a child with Down syndrome can influence choosing the type and time of activities in parts of life and hinder parents' freedom of action (15). Nevertheless, Hsiavu (2014) indicated that families with fewer needs and receiving higher levels of social

support are better able to cope with problems than people who face multiple needs and receive limited social support (16).

The results of post hoc comparisons indicated that the scores of the needs of freedom and love were significantly higher than the needs of recreation, survival and power; also, the scores of recreation and survival needs were significantly higher than those of power needs; but there was no significant difference between the scores of freedom and love needs, as well as between the scores of recreation and survival needs.

Skotko et al. (2016) reported that 83% were proud of family members with Down syndrome. Almost 87% of all respondents' family members expressed love for the member with Down syndrome. When a person with Down syndrome becomes part of a family, parents and siblings often describe significant changes. While most positive thoughts and experiences win. The vast majority of families showed their romantic feelings for the member with Down syndrome (15). In this regard, deep emotional relationships between children and parents can be stated as a reason for the superiority of the need for love and affection.

The relationship between Glasser's basic needs scores and the individual characteristics of parents of children with Down syndrome showed that the scores of the need for love and belonging were higher in women than in men ( $P=0.003$ ), while the scores of the need for power were higher in men than in women ( $P = 0.007$ ).

In another study, investigating flexibility in the families of children with Down syndrome in Korea" Yang Choi (2015) showed that family adjustment has a negative relationship with the child's developmental age, parental depression, pressure and stress, and family adjustment

has a positive relationship with parents' health, communication skills, cohesion, available social services, flexibility, and supportive relatives. Family solidarity and communication skills were effective factors on family flexibility and adaptation (17). Regarding the needs of fathers of children with Down syndrome, it is suggested to conduct more studies and generalize the results with caution. According to the researcher, since there is more emotional connection between mother and child, the need for love and belonging is higher in mothers. But considering that the majority of fathers try to provide material and welfare needs along with other needs, the need for power in them is more in order to fix these factors.

The results also indicated that the scores of need for freedom and need for power in working people were significantly higher than those of housewives ( $P < 0.001$ ). Also, a statistically significant difference was observed between the scores of need for power according to the level of education of parents ( $P = 0.007$ ), so that the scores of need for power were higher in parents with university education than in those with undergraduate education ( $P = 0.043$ ). Also, a statistically significant difference was observed between the scores of the need for power according to the income level of the parents ( $P = 0.011$ ), so that the scores of the need for power in parents with favorable income were significantly higher than those of parents with unfavorable income ( $P = 0.011$ ).

In this regard, in a research conducted by Hsiao (2014), investigating the correlation among family needs, social support, and family functioning, demonstrated that Families of a Down syndrome child in an older age, with higher parental education, more income, less family demands, and more social support, experienced a healthier family life. Family demand was a significant predictor of social support and

family functioning (16). These results support the hypothesis of the effectiveness of social support in the relationship between family needs and family functioning.

## **6- CONCLUSIONS**

The findings of this study provide support for previous research that shows families having fewer demands and receiving higher levels of social support function better than individuals facing multiple demands and receiving limited social support. Compared to previous results, raising older children with Down syndrome is positively related to family functioning. This suggests that families may adapt over time.

The results of this study can be used to improve social support and planning in order to help parents of children with Down syndrome meet their own and their children's needs and better adaptations to their conditions.

## **7- ETHICAL CONSIDERATIONS**

This study was approved by the Ethics Committee of Guilan University of Medical Science. (Ethics code: IR.GUMS.REC.1400.191). The participants were assured about the confidentiality of their identities and provided the researcher with informed consents for participation.

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