



The Support Needs of Women with Disabled Children Regarding Childbearing in Shahrekord in 2022: A Cross-Sectional Study

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Abstract

Introduction: Disabled or genetically abnormal children double the family's efforts to adapt. The purpose of this study is to determine the support needs of women with children with disabilities or genetic abnormalities regarding childbearing.

Methods: This cross-sectional analytical study was conducted on 250 women with disabled or genetically abnormal children in 2022. The data collection method was a researcher-made questionnaire consisting of two parts: demographic questions and questions measuring support needs in physical, psychological, social, and economic dimensions. Chi-square and Fisher's exact test were used for data analysis.

Results: The results of this study showed that the majority of women with disabled children felt the need for support in the physical and emotional fields (152 people, 60.8%) and in the socio-economic field (95 people, 38%), with moderate intensity. The younger mothers felt a greater need for support in both the physical-emotional ($P=0.04$) and socio-economic ($P=0.01$) dimensions, and mothers who had healthier children felt a lower need for the physical-emotional support ($P=0.04$). However, mothers with more disabled children felt a greater need for socio-economic support ($P=0.03$). Additionally, socio-economic needs showed a significant relationship with some variables such as religion ($P=0.03$), parents' education (mother $P=0.002$ and father $P=0.01$), economic status ($P=0.04$), child's mobility disability ($P=0.003$), and history of genetic problems ($P=0.01$).

Conclusion: It is necessary to focus on the mentioned issues in order to meet the basic needs of couples with disabled children, so that these people can be inclined towards having children again.

Keywords: Childbearing, Disabled child, Congenital abnormality

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Introduction

Most of the countries in the world are somehow in a state of population imbalance and are facing the resulting problems.¹ According to the data recorded in the World Bank Group, the population growth rate in Iran has decreased from 5.3% in 1982 to 1.1% in 2024.² The continuous decrease in birth rate and transition from natural fertility to controlled fertility have changed the age structure of the population gradually. For this reason, the age pyramid of Iran's population, which has always had a broad base throughout history, has changed in the last two decades due to the decrease in fertility, and a kind of indentation has been created in the base of the age pyramid.^{3,4}

Fertility and childbearing are the most important factors determining population fluctuations. Therefore, population policies in most countries primarily aim to

reduce or increase fertility.⁵

Today, delayed childbearing has become a common pattern of reproductive behavior worldwide.⁶ The continuous decrease in childbearing will gradually move the age structure of the population from youth to old age.⁷ It is possible that despite the desire to have a child, people prevent it due to the feeling of insecurity and limitations caused by having a child. In the literature, the reasons for fertility delay have been attributed to several factors, such as demographic issues, in addition to economic, political, and social conditions.⁸

When parents are waiting for the birth of their new child after months, sometimes with many worries, their most important concern is the mental and physical health of their baby.⁹ The birth of a disabled child can have adverse effects on the family, especially the mother as the main caregiver, and since congenital disabilities

have long-term effects, the caregiver will suffer mental exhaustion over time.¹⁰ The first ever World report on disability, produced jointly by WHO and the World Bank, suggests that more than a billion people in the world today experience disability.¹¹ The results of a review of qualitative studies conducted on mothers of children with cerebral palsy in 2022 showed that the lived experience of these mothers included five main themes: (1) adaptation and sacrifice; (2) guilt and cultural blame; (3) social stigma and marginalization; (4) physical, environmental, and financial challenges; and (5) healthcare experiences.¹²

Regardless of whether the child's disability is physical or mental and how severe it is, the weak emotional relationships of family members, higher rates of depression, imbalance between work and leisure time, limited social life, time constraints, and social isolation are significant factors.^{13, 14}

But this is not all, because the desire of these mothers to have healthy children to prove their feminine identity and overcome the stigma associated with having a disabled child may be even greater than that of other mothers. It should be noted that these mothers may have a desire for repeated pregnancies for various family and social reasons. It can even be said that this issue is more pronounced in cities that still retain their native texture and traditions, such as Shahrekord and its suburbs.

Social support is a multidimensional concept and shows the perception of being supported, loved, and valued.¹⁵ Based on the studies, social support significantly predicts the ability of people to cope with stress and have positive attitudes towards the surrounding environment.^{16, 17} According to previous studies, several factors such as the presence of stress in parents, socio-economic status, laws, customs, and norms governing the home, family and society, lack of insurance coverage, and unavailability of resources and social support can affect the quality of care for children with disabilities.^{18, 19} On the contrary, perceived social support acts as a protective factor against emotional and behavioral problems, parental depression, and life satisfaction.^{20, 21} Considering that mothers play an active role in making decisions about having children and that they are both biologically and socially responsible for raising children, it is very important to examine the support needs of women with disabled or abnormal children. Since the decline in Iran's population growth rate is also evident in Shahrekord, and given that there is no information available about the support needs of mothers with disabled children in Shahrekord, we decided to conduct a study with the aim of determining the support needs of women with disabled or genetically abnormal children regarding childbearing in Shahrekord in 2022.

Materials and Methods

Study Design and Inclusion/Exclusion Criteria

This cross-sectional study was conducted in 2022 on 250 women with disabled or genetically abnormal children who were under the supervision of the Welfare Organization or selected health centers in Shahrekord

city. Sampling was done using a convenience sampling method. Eligible people were included in the study after obtaining informed consent. The criteria for entering the study included being a married woman, willingness to participate in the study, having at least one disabled or congenitally abnormal child, not suffering from any known mental illness, not suffering from any kind of disability or abnormality, the ability to read and write. The exclusion criteria included the occurrence of any type of severe stress during the study, unwillingness to continue participating in the study, and divorce or death of the spouse during the study.

Instrument

The data collection tool was a two-part questionnaire. Demographic variables included age, level of education, ethnicity, type of residence, occupation, monthly income, age of disabled child, type of disability, and so on. The questionnaire was a researcher-made questionnaire consisting of two parts. The first part included demographic questions (24 items), and the second part included questions measuring support needs in physical, psychological, social, and economic dimensions (23 items). The questionnaire was completed by people. In the second part of the questionnaire, questions 1, 2, 5, 6, 7, 11, and 21 were negative questions, and questions 3, 4, 8, 9, 10, 12, 13, 14, 15, 16, 17, 18, 19, 20, 22, and 23 were considered as positive questions.

In the negative questions, the "completely agree" option and in the positive questions, the "completely disagree" option got the highest score. As a result, the higher the score of the questionnaire, the higher the need for support.

The field of physical and emotional needs included 11 questions with a score range of 11 to 55. Scores of 11 to 22 were classified as no need, 22 to 33 as low need, 33 to 44 as moderate need, and 44 to 55 as severe need. In addition, the area of socio-economic needs included 12 questions with a score range of 12-60. Scores of 12 to 24 were classified as no need, 24 to 36 as low need, 36 to 48 as moderate need, and 48 to 60 as severe need.

The validity of the questionnaire was examined qualitatively and quantitatively using CVR and CVI methods. For this purpose, the opinions and recommendations of 10 faculty members familiar with the subject were taken into account. Moreover, the reliability of this questionnaire was determined by the test-retest method. In this way, the questionnaire was first completed by 10 people from the research units and then completed again after 2 weeks. Given that the correlation rate of the results was more than 80% and the statistical test did not show a significant difference between the results of the two stages, the reliability of the questionnaire was confirmed.

Statistical Analysis

The way of reporting this questionnaire was descriptive and based on each item separately. The information was entered into the software after collection. The Kolmogorov-Smirnov test was used to check the

normality of the data. If the data did not follow a normal distribution, non-parametric tests such as Spearman's correlation coefficient were used to check the relationship between the variables, and if the data followed a normal distribution, parametric tests such as *t*-test, ANOVA, and Chi-square were used. A *P*-value of less than 0.05 was considered statistically significant.

Results

The mean age of the participants was 49.8 ± 13.5 years, and the mean age of their disabled or genetically abnormal child was 23.4 ± 13.8 years. The mean number of healthy children and disabled children was 2.54 ± 1.92 and 1.14 ± 0.45 , respectively.

In terms of physical and emotional needs, 2% of the participants were classified as having no need, 33.2% as having low need, 60.8% as having moderate need, and 4% as having strong need for support. Moreover, in the area of social and economic needs, 12.4% were found to have no need, 22.4% to have low need, 38% to have moderate need, and 27.2% to have strong need for support (Figure 1).

The results of the study showed that younger mothers felt a greater need for support in both the physical-emotional ($P=0.04$) and socio-economic ($P=0.01$) dimensions, and mothers who had healthier children felt a lower need for the physical-emotional support ($P=0.04$). However, mothers with more disabled children felt a greater need for the socio-economic support ($P=0.03$). The relationships between demographic variables and the intensity of the mother's needs in the physical-emotional and socio-economic domains are presented in Tables 1 and 2, respectively.

According to Table 2, socio-economic needs showed a significant relationship with some variables such as religion ($P=0.03$), parents' education (mother $P=0.002$ and father $P=0.01$), economic status ($P=0.04$), child's mobility disability ($P=0.003$), history of genetic problems ($P=0.01$), and history of disease in the father ($P=0.03$). This means that religious people, people with higher university education or better economic status, or people whose child had a mobility disability, felt more need in the socio-economic field.

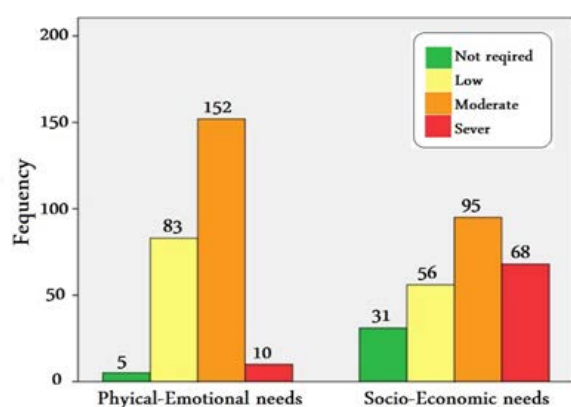


Figure 1. Frequency of Support Needs of Mothers with Disabled Children According to Severity

The relationships between variables related to disability of the child and emotional-physical needs and economic-social needs are given in Tables 3 and 4, respectively.

Discussion

The present study was conducted with the aim of determining the support needs of women with disabled or genetically abnormal children regarding childbearing in Shahrekord city in 2022. The results of this study showed that the intensity of most participants' needs was moderate, both in the area of physical and emotional needs and in the area of socio-economic needs.

The results of a qualitative study on the lived experience of Iranian mothers with disabled children in 2020 showed that the lived experience of these mothers included two main themes, namely interpersonal experiences and social experiences, and eight sub-themes, including guilt, loss of opportunities, maternal sacrifice, worry about the future, guilt about other children, social isolation, lack of socioeconomic support, and social stigma. It can be said that these themes together reflect the need for mothers' support in both physical-emotional and socio-economic dimensions.²²

In addition, the only variables that were related to the need for support in the physical and emotional dimension included the age of the mother, the age of the child, and the number of healthy children, and other variables were not related to this area of need for support.

Additionally, there was a significant relationship between socio-economic needs and the variables of religion, education of mothers and their spouses, economic status, mobility disability of disabled children, history of genetic problems, and history of physical or psychological diseases in the father.

The results of a qualitative study on the role of spirituality and religion as a coping tool among mothers of children with disabilities in Turkey revealed four main themes: "journey to acceptance", "meaning/purpose in life", "worries about the future" and "coping strategies". The results of this study showed that mothers of children with developmental disabilities in Turkey often used spirituality as a coping method. By using spirituality, they were able to manage the stress of their new life. They began to see their children as those who gave meaning/purpose to their lives and experienced greater feelings of love/commitment. Mothers were more concerned about the fate of their children after the death of their parents.²³

The results of the study conducted by Salehi et al showed that mothers with a disabled child experience painful experiences and many psychosocial concerns regarding the care of their disabled child. Moreover, not benefiting from specialized services and a lack of support and financial resources in less developed cities are the major painful experiences of mothers.¹⁵ In this regard, the qualitative study of Maulinda et al led to the extraction of 17 themes that reflected the experience of mothers in caring for children with disabilities. These themes included fate, maternal initial psychological response,

Table 1. The Association between Physical-emotional Needs and Demographic Variables

Variable	Category	Nothing n (%)	Low n (%)	Moderate n (%)	High n (%)	P-value
Residence	City	5 (2.2)	77 (34.4)	134 (59.8)	8 (3.6)	0.36
	Village	0 (0)	6 (23.1)	18 (69.2)	2 (7.7)	
Housing	Landlord	5(2.4)	68(33.2)	124(60.5)	8(3.9)	0.90
	Tenant	0(0)	15(33.3)	28(62.2)	2(4.4)	
Religion	Shia	5(2.0)	82(33.3)	149(60.6)	10(4.1)	0.99
	Sunni	0(0)	1(25.0)	3(75.0)	0(0)	
Education	Illiterate	3(5.3)	21(36.8)	30(52.6)	3(5.3)	0.79
	Primary	1(1.6)	22(34.4)	40(62.5)	1(1.6)	
	Diploma	0(0)	25(34.7)	44(61.1)	3(4.2)	
	Associate degree	0(0)	7(31.8)	14(63.6)	1(4.5)	
	Bachelor's degree	1(3.7)	6(22.2)	18(66.7)	2(7.4)	
	Master's degree or Doctorate	0(0)	2(25.0)	6(75.0)	0(0)	
Husband education	Illiterate	2(3.4)	19(32.2)	36(61.0)	2(3.4)	0.32
	Primary	1(1.7)	22(37.9)	32(55.2)	3(5.2)	
	Diploma	0(0)	22(30.1)	49(67.1)	2(2.7)	
	Associate degree	0(0)	8(40.0)	12(60.0)	0(0)	
	Bachelor's degree	1(3.0)	12(36.4)	17(51.5)	3(9.1)	
	Master's degree or Doctorate	1(14.3)	0(0)	6(85.7)	0(0)	
Ethnicity	Fars	5(2.8)	68(37.6)	104(57.5)	4(2.2)	0.07
	Lor	0(0)	9(22.5)	28(70.0)	3(7.5)	
	Baloch or Arab	0(0)	0(0)	3(75.0)	1(25.0)	
	Turk	0(0)	6(24.0)	17(68.0)	2(8.0)	
Job	Housewife	5(2.4)	64(30.9)	128(61.8)	10(4.8)	0.49
	Employed	0(0)	17(43.6)	22(56.4)	0(0)	
	Self-employed	0(0)	2(50.0)	2(50.0)	0(0)	
Husband's job	Governmental	2(5.6)	9(25.0)	24(66.7)	1(2.8)	0.12
	Freelance	0(0)	48(36.4)	80(60.6)	4(3.0)	
	Unemployed	0(0)	9(30.0)	20(66.7)	1(3.3)	
	Retired	3(5.8)	17(32.7)	28(53.8)	4(7.7)	
Economic status	Excellent	0(0)	1(16.7)	4(66.7)	1(16.7)	0.40
	Good	2(7.4)	8(29.6)	16(59.3)	1(3.7)	
	Medium	1(0.9)	36(33.6)	68(63.6)	2(1.9)	
	Weak	1(1.3)	29(37.2)	45(57.7)	3(3.8)	
	Very weak	1(3.1)	9(28.1)	19(59.4)	3(9.4)	

maternal burden, limited budget, obstacles in daily life, social stigma, emotional changes, behavioral changes, financial support, social support, helping efforts of health workers, efforts to seek other help, maternal attitude when the child acts inappropriately, maternal attitude when the child raises a choice, expectations and limitations of disability-specific health services, wisdom of spiritual recovery, and bathing.²⁴

The review of various studies shows that social support of people with disabled children is associated with life satisfaction as a protective factor, improved quality of life, and also with some variables of parents' mental health, such as emotional and behavioral problems and depression.^{20, 21, 25} Findings of the study conducted by Park and Lee suggest that social support is an important resource that prevents the negative impact of parental

stress on depression among mothers of children with disabilities.²⁶ Among the limitations of this study are the lack of fathers in the study and the failure to measure the impact of factors such as personality traits, cultural context of societies, and interpersonal differences. Therefore, it is recommended that in addition to considering fathers with disabled children, qualitative studies be conducted to better understand the needs of these parents.

Conclusion

In general, the results of this study indicate the need for mothers with disabled children to receive support both in the field of physical and emotional care and in the field of socio-economic support in order to be inclined to have children again. This requires a more active presence of health system officials and the use of more NGOs in this

Table 2. The Association between Socio-economic Needs and Demographic Variables

Variable	Category	Nothing n (%)	Low n (%)	Moderate n (%)	High n (%)	P-value
Residence	City	29(12..9)	49(21.9)	90(40.2)	56(25.0)	0.06
	Village	2(7.7)	7(26.9)	5(19.2)	12(46.2)	
Housing	Landlord	29(14.1)	45(22.0)	76(37.1)	55(26.8)	0.36
	Tenant	2(4.4)	11(24.4)	19(42.2)	13(28.9)	
Religion	Shia	30(12.2)	53(21.5)	95(38.6)	68(27.6)	0.03
	Sunni	1(25.0)	3(75.0)	0(0)	0(0)	
Education	Unlettered	13(22.8)	15(26.3)	16(28.1)	13(22.8)	0.002
	Primary	4(6.3)	16(25.0)	34(53.1)	10(15.6)	
	Diploma	5(6.9)	18(25.0)	26(36.1)	23(31.9)	
	Associate degree	1(4.5)	3(13.6)	6(27.3)	12(54.5)	
	Bachelor's degree	5(18.5)	3(11.1)	12(44.4)	7(25.9)	
	Master's degree or Doctorate	3(37.5)	1(12.5)	1(12.5)	3(37.5)	
Husband's education	Illiterate	12(20.3)	17(28.8)	18(30.5)	12(20.3)	0.01
	Primary	5(8.6)	15(25.9)	26(44.8)	12(20.7)	
	Diploma	4(5.5)	15(20.5)	34(46.6)	20(27.4)	
	Associate degree	3(15.0)	1(5.0)	6(30.0)	10(50.0)	
	Bachelor's degree	7(21.2)	8(24.2)	10(30.3)	8(24.2)	
	Master's degree or Doctorate	0(0)	0(0)	1(14.3)	6(85.7)	
Ethnicity	Fars	24(13.3)	39(21.5)	74(40.9)	44(24.3)	0.44
	Lor	4(10.0)	8(20.0)	13(32.5)	15(37.5)	
	Baloch or Arab	1(25.0)	0(0)	1(25.0)	2(50.0)	
	Turk	2(8.0)	9(36.0)	7(28.0)	7(28.0)	
Job	Housewife	26(12.6)	48(23.2)	81(39.1)	52(25.1)	0.21
	Employed	4(10.3)	8(20.5)	11(28.2)	16(41.0)	
	Self-employed	1(25.0)	0(0)	3(75.0)	0(0)	
Husband's job	Governmental	6(16.7)	7(19.4)	10(27.8)	13(36.1)	0.10
	Freelance	10(7.6)	29(22.0)	59(44.7)	34(25.8)	
	Unemployed	3(10.0)	6(20.0)	11(36.7)	10(33.3)	
	Retired	12(23.1)	14(26.9)	15(28.8)	11(21.2)	
Economic status	Excellent	0(0)	0(0)	3(50.0)	3(50.0)	0.04
	Good	7(25.9)	3(11.1)	6(22.2)	11(40.7)	
	Medium	9(8.4)	22(20.6)	51(47.7)	25(23.4)	
	Weak	10(12.8)	20(25.6)	27(34.6)	21(26.9)	
	Very weak	5(15.6)	11(34.4)	8(25.0)	8(25.0)	

field. Therefore, it is necessary to focus on the mentioned issues in order to meet the basic needs of couples with disabled children, so that these people can be inclined towards having children again.

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Artificial Intelligence (AI) Disclosure

The authors declare that no AI was used in this article.

Authors' Contribution

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Investigation: Zeinab Tavakol, Narges Sadat Tabatabaie
Methodology: Zeinab Tavakol, Narges Sadat Tabatabaie, Hadi Raeisi Shahraki
Project Administration: Zeinab Tavakol, Narges Sadat Tabatabaie
Resources: Narges Sadat Tabatabaie
Software: Narges Sadat Tabatabaie, Hadi Raeisi Shahraki
Supervision: Zeinab Tavakol
Validation: Zeinab Tavakol, Narges Sadat Tabatabaie
Visualization: Zeinab Tavakol, Narges Sadat Tabatabaie
Writing–Original Draft: Narges Sadat Tabatabaie
Writing–Review & Editing: Zeinab Tavakol, Narges Sadat Tabatabaie, Hadi Raeisi Shahraki

Competing Interests

The authors declare that they have no conflict of interests.

Ethical Approval

All study protocols were approved by the Research Ethics Committee of the Shahrekord University of Medical Sciences (IR.

Table 3. The Association between Physical-emotional Needs and Disability Characteristics

Variable	Category	Nothing n (%)	Low n (%)	Moderate n (%)	High n (%)	P-value
Reason for disability	Genetically	2(2.1)	28(29.5)	61(64.2)	4(4.2)	0.81
	Other	3(1.9)	55(35.5)	91(58.7)	6(3.9)	
Time of diagnosis	Pregnancy period	0(0)	3(20.0)	11(73.3)	1(6.7)	0.53
	Immediately after birth	1(1.1)	35(36.8)	54(56.8)	5(5.3)	
	The first two years of birth	1(1.4)	20(27.8)	48(66.7)	3(4.2)	
	After two years	3(4.4)	25(36.8)	39(57.4)	1(1.5)	
Ability to treat	Yes	1(4.5)	5(22.7)	15(68.2)	1(4.5)	0.38
	No	4(1.8)	78(34.2)	137(60.1)	9(3.9)	
Child rehabilitation	Yes	4(2.2)	59(32.4)	111(61.0)	8(4.4)	0.95
	No	1(1.5)	24(35.3)	41(60.3)	2(2.9)	
Physical disability	No	3(1.4)	72(34.8)	123(59.4)	9(4.3)	0.29
	Yes	2(4.7)	11(25.6)	29(67.4)	1(2.3)	
Mobility disability	No	5(2.4)	67(32.1)	131(62.7)	6(2.9)	0.12
	Yes	0(0)	16(39.0)	21(51.2)	4(9.8)	
Mental disability	No	0(0)	6(19.4)	25(80.6)	0(0)	0.12
	Yes	5(2.3)	77(35.2)	127(58.0)	10(4.6)	
Psychological disability	No	5(2.1)	82(33.9)	145(59.9)	10(4.1)	0.56
	Yes	0(0)	1(12.5)	7(87.5)	0(0)	
Genetic history	Yes	1(1.3)	23(29.9)	50(64.9)	3(3.9)	0.84
	No	4(2.3)	60(34.7)	102(59.0)	7(4.0)	
Mother's disease history	Yes	0(0)	5(26.3)	13(68.4)	1(5.3)	0.74
	No	5(2.2)	78(33.8)	139(60.2)	9(3.9)	
Father's disease history	Yes	0(0)	3(16.7)	13(72.2)	2(11.1)	0.17
	No	5(2.2)	80(34.5)	139(59.9)	8(3.4)	

Table 4. The Association between Socio-economic Needs and Disability Characteristics

Variable	Category	Nothing n (%)	Low n (%)	Moderate n (%)	High n (%)	P-value
Reason for disability	Genetically	9(9.5)	23(24.2)	35(36.8)	28(29.5)	0.65
	Other	22(14.2)	33(21.3)	60(38.7)	40(25.8)	
Time of diagnosis	Pregnancy period	1(6.7)	0(0)	6(40.0)	8(53.3)	0.15
	Immediately after birth	10(10.5)	22(23.2)	42(44.2)	21(22.1)	
	The first two years of birth	8(11.1)	16(22.2)	26(36.1)	22(30.6)	
	After two years	12(17.6)	18(26.5)	21(30.9)	17(25.0)	
Ability to treat	Yes	4(18.2)	4(18.2)	6(27.3)	8(36.4)	0.49
	No	27(11.8)	52(22.8)	89(39.0)	60(26.3)	
Child rehabilitation	Yes	22(12.1)	39(21.4)	65(35.7)	56(30.8)	0.23
	No	9(13.2)	17(25.0)	30(44.1)	12(17.6)	
Physical disability	No	24(11.6)	44(21.3)	86(41.5)	53(25.6)	0.09
	Yes	7(16.3)	12(27.9)	9(20.9)	15(34.9)	
Mobility disability	No	26(12.4)	47(22.5)	88(42.1)	48(23.0)	0.003
	Yes	5(12.2)	9(22.0)	7(17.1)	20(48.8)	
Mental disability	No	4(12.9)	8(25.8)	6(19.4)	13(41.9)	0.10
	Yes	27(12.3)	48(21.9)	89(40.6)	55(25.1)	
Psychological disability	No	31(12.8)	54(22.3)	94(38.8)	63(26.0)	0.12
	Yes	0(0)	2(25)	1(12.5)	5(62.5)	
Genetic history	Yes	6(7.8)	26(33.8)	21(27.3)	24(31.2)	0.01
	No	25(14.5)	30(17.3)	74(42.8)	44(25.4)	
Mother's disease history	Yes	3(15.8)	1(5.3)	6(31.6)	9(47.4)	0.08
	No	28(12.1)	55(23.8)	89(38.5)	59(25.5)	
Father's disease history	Yes	0(0)	4(22.2)	4(22.2)	10(55.6)	0.03
	No	31(13.4)	52(22.4)	91(39.2)	58(25.0)	

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