

Evaluation Of The Parents' Anxiety Levels Before And After The Diagnosis Of Their Child With A Rare Genetic Disease: The Necessity Of Psychological Support

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Research

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Abstract

Background

The diagnosis of the rare genetic disease has great importance in treating multi-systemic conditions, preventing potential complications, and estimating disease risk for family members. The duration of getting genetic test results is variable. The demand of learning the diagnosis of a possible untreatable illness is a double-edged sword between obscurity and a lifetime chronic disease. The current uncertainty of their child's condition and the long duration time of diagnosis may increase the parents' anxiety level and causes difficulties to a continuation of diagnostic procedures in some families. This study aimed to investigate the pre-diagnosis and the post-diagnosis anxiety levels of parents who have a child with a rare genetic disorder.

Results

The state anxiety levels of parents decreased significantly after learning the diagnosis. However, there was no statistically significant decrease observed in trait anxiety levels.

Conclusion

Data from this study revealed that informing parents about their child's disease and properly explaining to them expected difficulties might help to reduce their anxiety levels. Psychological support from the hospital should be provided to help them cope with the stress before and after the diagnosis. Increasing the number of samples, interviews, and psychological inventory are recommended for future studies.

Background

There are about 7.000 different types of rare diseases defined so far. The definition of a rare disease may differ between countries. For instance, it is defined as a condition that affects fewer than; 1 in 1.500 people in the United States, 1 in 2.5000 individuals in Japan, and 1 in 2.000 people in Europe. Approximately 350 million individuals have been affected by a rare disease globally, and 75 percent has consisted of child [1, 2, 3]. Approximately 80% of rare diseases are based on genetic origins. Most rare genetic disorders are incurable and affect many body systems throughout life. A prolonged diagnostic process and thus obscurity may worsen the situation. According to studies, 30% of individuals with rare diseases die before age 5 [3, 4]. Even despite the modern-day advanced molecular genetic diagnostic systems, it is not possible to diagnose all rare genetic disorders. For these reasons, meeting the needs of a child with rare genetic diseases covers a much more extended period and may cause more difficulties for parents [1, 2, 5].

The onset of rare diseases can be seen at birth or infancy. Parents expect to have a healthy newborn, and the birth of a child with a genetic disorder might be a disappointment for some families. Also, it could be challenging for a family with a healthy newborn to notice the differences and problems in their child's development with time [4, 6]. Parents can have difficulties in coping with both situations. Anxiety, shock, rejection, and lack of understanding can be seen in parents when their children are first diagnosed with rare genetic diseases. Parents may feel lonely and hopeless because rare diseases are hardly seen, and there is not much information about them. They might hesitate to reintegrate their children into society. Under these stressful times, parents can struggle to find time for their relationship, which may damage their marriages. With time, stressful life and mental breakdown lead to the reduction of parents' interest and care for their child [6, 7, 8]. Lack of parental attention and inadequate healthcare utilization cause low child's adherence to therapy [9].

A broad understanding of the etiology of anxiety includes several factors, such as biological, psychological, and social determinants, mediated by various risk and protective factors [10, 11]. Prevalence rates for parents who have children with chronic diseases have been reported in various anxiety-related disorders. Accordingly, it was emphasized that psychological support is required because of parents' high stress, depression, and anxiety levels [12, 13, 14]. In this context, it is expected that the anxiety levels are increased in parents of children with a rare genetic disorder, and psychological support is also required for this group of parents.

In this study, the anxiety levels of the parents were measured by the State-Trait Anxiety Inventory (STAI) before and after the diagnosis of their children with rare genetic disorders [15]. The questionnaire consisting of 8 questions was also used at the beginning of the interview to evaluate the socio-demographic effects on anxiety.

Method

The study sample consisted of 40 randomly selected parents who applied to Bezmialem Vakıf University Medical Genetics Clinic in 2017–2018 with the suspicion of a rare genetic disorder in their children. This study aimed to compare the anxiety levels of parents before and after learning the diagnosis of their children with a rare disease. The State-Trait Anxiety Inventory (STAI), which was invented by Spielberger, was used to determine the anxiety levels of the parents. The inventory consists of two different scales, the State and Trait scale. The TX Form version of the test was used in this study. Socio-demographic data about parents was obtained by using the questionnaire. The demographic information form was presented to the parent at the time they came to the clinic, and the information about the family and their children were obtained. Two interviews were conducted with the families after they provided informed consent. The first interview was conducted one day before they learned the diagnosis of their child. The second interview was conducted with parents in the following two weeks after they learned the diagnosis. The interviews were provided face-to-face or by phone.

The findings of the research were evaluated in the SPSS 22.0 program [16].

The Spielberger's Trait-State Anxiety Inventory

The State-Trait Anxiety Inventory (STAI) is defined as a self-evaluation questionnaire for measuring the anxiety level in individuals. The STAI-TX form includes two scales designed to evaluate the transient state of state anxiety and the long-standing quality of trait anxiety. The state anxiety scale (the S-Anxiety scale) determines how an individual feels at a particular moment in certain conditions. The trait-anxiety scale (the T-Anxiety scale), on the other hand, determines how an individual feels himself/herself in general, regardless of his/her circumstances [17]. The state anxiety and trait anxiety scales have 40 different expressions totally. Each scale has 20 expressions that are evaluated as a 4-point Likert item ranging from 1 (not at all) to 4 (very much) for the status scale reflecting the intensity [18].

Personal Demographic Information Form

The questionnaire consisting of 8 questions was prepared by the researcher to obtain socio-demographic information about the family. The objectives of the questionnaire consisted of; parental status, age, occupation, educational status, level of income, marital status, number of children, psychiatric history.

Statistical analysis

The data were analyzed in IBM Statistical Package for Social Sciences (SPSS) 22.0 statistical program. Shapiro-Wilk test was used to check the distribution of the data. For each anxiety scale, the average of the scores obtained by the individuals was calculated. The differences of the continuous dependent variables within the group were analyzed by the Wilcoxon Sign test. The socio-demographic data were analyzed. For each group, the difference of continuous variables between the groups was examined with the Mann-Whitney-U test. Median (min-max), Mean \pm std. Deviation, frequency, and percentage value are given as descriptive statistics. $p < 0.05$ was considered statistically significant.

Results

The state and trait anxiety scale consist of 20 multiple-choice items in which a score of 36–41 is an average. Before learning the diagnosis, 50% ($n = 20$) of the parents had an above-average level of state anxiety, dropping to 37% ($n = 15$) after learning the diagnosis; 52% ($n = 21$) of the parents had an above-average level of trait anxiety, dropping to 40% ($n = 16$) after learning the diagnosis. An additional file shows this in more detail [see Additional file 1].

Comparing the pre and post-diagnosis S-Anxiety scale scores shows that 60% ($n = 24$) of the parents had a lower anxiety score, 32.5% ($n = 13$) of parents had higher anxiety scores, and 7.5% ($n = 3$) of them had the same anxiety score. According to the Wilcoxon Sign test, it was found that the state anxiety levels of parents decreased significantly after the diagnosis of their children ($p = 0.049$) (Table 1).

Based on the post-diagnosis T-Anxiety scale results, it was seen that 45% ($n = 18$) of the parents had a lower anxiety score, 35% ($n = 14$) of parents had a higher anxiety score, and 20% ($n = 8$) of them had the

same anxiety score. There was no statistically significant decrease seen in the scores of the T-Anxiety scale after the diagnosis ($p = 0.312$) (Table 1).

When parents' state and trait anxiety scores were compared, it was found that the state anxiety levels of mothers were significantly higher than fathers before the diagnosis, according to Mann-Whitney-U Test ($p = 0.02$). There were no statistically significant differences found between parents for the rest of the anxiety scales' scores ($p > 0.05$).

After the diagnosis of their children, the state anxiety levels of mothers decreased significantly based on the Wilcoxon Sign test ($p = 0.021$). However, there was no statistically significant decrease in the trait anxiety levels ($p = 0.962$). For the state-trait anxiety levels of fathers, no statistically significant decrease was found after they learned the diagnosis of their children ($p = 0.711$ $p = 0.221$) (Table 2). Comparing the decrease in the state-trait anxiety levels between mother and father based on the Mann-Whitney-U Test, no statistically significant differences were found ($p = 0.072$ $p = 0.383$).

The result of comparing socio-demographic data shows that the decrease of state scale anxiety levels was statistically more prominent in unemployed parents than employed parents according to the Mann-Whitney-U test ($p = 0.02$) (Table 3). However, there were no statistically significant differences in the rest of the parameters according to the Mann-Whitney-U test (parental status, age, occupation, educational status, level of income, marital status, psychiatric history) ($p > 0.05$) (Table 4).

Table 1
Evaluation of changes between pre and post-diagnostic state and trait anxiety

	S-Anxiety Scale Score		T-Anxiety Scale Score	
	Pre-diagnostic	Post-diagnostic	Pre- diagnostic	Post-diagnostic
n	40	40	40	40
Median (min-max)	42 (20–78)	37 (20–59)	43.5 (21–59)	38.5 (20–64)
Mean ± Std. deviation	42.725 ± 14.137	37.675 ± 11.550	42.225 ± 10.149	40.125 ± 11.353
p-value	0.049		0.321	

Table 2
Evaluation of state and trait anxiety level decrease in parents after learning the diagnosis

Mother 1, Father 2		Pre-diagnostic State Scale	Post-diagnostic State Scale	Pre-diagnostic Trait Scale	Post-diagnostic Trait Scale
1	n	20	20	20	20
	Median (min-max)	45 (26–69)	39 (22–56)	45.5 (29–59)	45 (24–61)
	Mean ± Std. deviation	47.35 ± 12.193	38.5 ± 12.159	44.15 ± 9.016	42.95 ± 10.709
	p-value	0.021		0.0962	
2	n	20	20	20	20
	Median (min-max)	34 (20–78)	34 (20–59)	38.5 (21–57)	36 (20–64)
	Mean ± Std. deviation	38.1 ± 14.714	36.85	40.30 ± 11.060	37.30 ± 11.535
	p-value	0.711		0.221	

Table 3
 Difference between anxiety levels decreases of employed and unemployed
 parents after the diagnosis (n = 40)

Work Status	State Scale Score decrease	Trait Scale Score decrease
Employed		
n	23	23
Median (min-max)	0.00 ((-25) – 16)	0.00 ((-35) – 11)
Mean ± std. deviation	-0.39 ± 10.53	-1.70 ± 9.89
Unemployed		
n	17	17
Median (min- max)	-5((-42)-13)	-1((-30)-6)
Mean ± std. deviation	-11.00 ± 15.02	-2.65 ± 8.19
p-value	0.02	0.71

Table 4
 Profile of parents who have children with rare genetic disorder
 (n = 40)

Socio-Demographic Information	Frequency	Percentage
Age (years)	4	10
20–29	20	50
30–39	13	32.5
40–49	3	7.5
50–59		
Parental Status	20	50
Mother	20	50
Father		
Number of children	27	67.5
1–2	11	27.5
3–4	2	5
5 and > 5		
Marital Status	40	100
Married	0	0
Divorced		
Educational Level	17	42.5
Primary school	4	10
Secondary school	10	25
Highschool	8	20
Undergraduate	1	2.5
Postgraduate		
Work Status	23	57.5
Employed	17	42.5
Unemployed		

Socio-Demographic Information	Frequency	Percentage
Household income	9	22.5
Low	31	77.5
Intermediate	0	0
High		
Reported Psychiatric Disease	2	5
Anxiety related	6	15
Depression	32	80
None		
Currently psychiatric drug use	8	20
Yes	32	80
No		

Discussion

The birth of an unhealthy child adversely affects the lives, feelings, and behaviors of the family members. This could be a significant source of stress for the whole family [19, 20]. As parents have a child with a rare genetic disorder, their family life changes, and also new roles and responsibilities are assumed. Parents may have a feeling of shock, rejection, extreme sadness, guilt, and inadmissibility in the process of adapting to this responsibility [21, 22]. The long duration of the genetic diagnosis of children and the risk of rare disease for other family members could be one of the main causes of long-term anxiety disorders for parents [23]. During the diagnostic process, parents may feel hopeless and alone because of their child's illness's current uncertainty [6, 24]. Also, families may experience severe anxiety after the diagnosis that may prevent them from understanding and accepting their child's condition, interpreting events realistically, making appropriate decisions, participating in child care, and using appropriate coping strategies [20, 25, 26].

In this study, it was found that the state anxiety level of parents decreased significantly after the diagnosis. This significant result showed that further and well explanation of the disease appears to be key to alleviating parental anxiety. However, the long-term anxiety level was not decreased significantly after the diagnosis. The long time spent in the diagnosis of their children with rare genetic diseases and the expected difficulties may affect the anxiety level of parents, especially if the working families do not have ample time to cope with this anxiety as it was seen in this study. Awareness of anxiety, identification of causes, and taking preventive measures are crucial for the mental health of both parents and child.

Therefore, providing psychological support to parents should be a target before and after diagnosing a child with a rare genetic disorder.

Help parents to cope with the stress may contribute to the treatment process of the sick child. It has been shown that parental anxiety may indirectly affect the anxiety level of the child. Thus, improvement of the parent's anxiety may positively affect the disease process of their children by reducing their stress [9, 27].

Research to evaluate anxiety level in the family were conducted with quantitative methods until the 1990s [28]. In this study, the anxiety level of parents with rare diseased children before and after diagnosis was evaluated by the quantitative method STAI-TX form. In recent years, the importance and interest which are given to qualitative research have increased. Accordingly, it is recommended to use qualitative and quantitative methods together for further studies to have results that reflect the truth in all conditions.

The STAI form is a reliable personal inventory to evaluate anxiety [17, 29]. However, parents should also be tested for depression because of the common coexistence of anxiety and depression. HADS would be a reliable questionnaire to assess anxiety and depression symptom severity in parents of ill children [30]. Psychosocial Assessment Tool (PAT) is another successful example that can be used to determine the family's psychosocial status [31]. For further studies, variable tests can be used together with the STAI form to assess the requirement of psychological support for parents.

It was shown in the studies with a higher sample number of parents who had chronically ill children that especially mothers are psychologically affected by the health condition of their children [8, 32, 33]. In this study, pre and post-diagnosis anxiety levels of mother and father were evaluated. It was seen that the decrease of state anxiety level in mothers was statistically significant, while the decrease of state anxiety level in fathers was not statistically significant ($p = 0.021$ $p = 0.711$). Also, there were no significant differences between their decrease in anxiety levels of both scales ($p = 0.072$ $p = 0.383$). The limitation of this study was the sample size. The effects of diagnosis on anxiety level and differences in anxiety levels between mothers and fathers during the diagnosis would be understood better with higher sample size.

The first interview was conducted with parents one day before the appointment for learning the diagnosis of their child. To have a clearer understanding of the long diagnostic duration effects, the first interview would be conducted when parents are first admitted to the clinic. Also, the number of pre and post-diagnosis interviews might be increased. Thus, the effect of the long diagnostic process on the anxiety levels of families would be understood better.

Conclusion

This study shows that the state anxiety level of parents, who have a child with a rare genetic disease, will decrease after learning the diagnosis. In this context, explaining the disease and future difficulties well has a key role in decreasing the anxiety levels of parents.

The trait anxiety level of the parents, which represents long-time anxiety level, was not significantly decreased. Psychiatric counseling and support should be provided for the parents during and after the diagnosis.

Future research should focus on increasing the study sample and the number of interviews during the diagnostic process. Qualitative methods and various tests for evaluating anxiety and diagnosing depression might be added to further studies.

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from Bezmialem Vakıf University Non-Interventional Research Ethics Committee (approval number: 10/15).

Informed consent was obtained from all individual participants included in the study.

Consent for publication

All patients provided consent to publish their data.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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