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Araştırma Makalesi * Research Article

The Emotional and Physical Problems of People with Friedreich's Ataxia and Their Perception about Discrimination

Friedreich Ataksisi Olan Kişilerin Duygusal ve Fiziksel Sorunları ve Ayrımcılığa İlişkin Algıları*

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Abstract: Living with disabilities might be difficult because of environmental and societal barriers. Societal barriers against people with disabilities generally include discriminative ideas of people with no disabilities. This study focuses on the experiences of people with specific kind of disability namely Friedreich's Ataxia (FA). Since it is a progressive disorder, people with FA might experience different kinds of impairments at the same time and they might confront many obstacles from society. To understand their emotional and physical problems, one qualitative and one quantitative study were conducted in the current research study. In quantitative part, 18 female and 4 male participants participated, with an average age of 29. Beside demographic questionnaire, Stress Appraisal Measure, Multidimensional Scale of Perceived Social Support, and Positive and Negative Affect Schedule were used to understand whether stress appraisal type and perceived social support affect the emotional situation. However, the results were insignificant. In qualitative part, semi-structured interview questions were used. In this part, it was revealed that people with FA face societal obstacles like discriminative behaviors towards them. In this light, in future studies researchers might focus on the ways to reduce discriminative ideas of non-disabled people.

Keywords: Friedreich's Ataxia, discrimination, emotional problems, physical problems.

Öz: Çevresel ve sosyal faktörler**,** bir veya birden fazla engelle yaşayan bireyler için hayatı zorlaştırabilmektedir. Engeli olan bireylere yönelik toplumsal engeller daha çok engeli olmayan bireylerin ayrımcı düşüncelerinden kaynaklanmaktadır. Bu çalışmada, Friedreich Ataksisi (FA) gibi belirli bir engeli olan insanların deneyimlerine odaklanılmaktadır. İlerleyici bir hastalık olduğu için, FA'lı kişiler aynı anda farklı türden bozukluklar yaşayabilir ve toplumdan gelen birçok engelle karşılaşabilirler. Mevcut araştırma çalışmasında FA ile yaşayan bireylerin duygusal ve fiziksel sorunlarını anlamak için bir nitel ve bir nicel çalışma yapılmıştır. Yaş ortalaması 29 olan 18 kadın, 4 erkek katılımcının katıldığı nicel kısımda demografik soruların yanında, Stres Değerlendirme Ölçeği, Çok Boyutlu Algılanan Sosyal Destek Ölçeği ile Olumlu ve Olumsuz Duygulanım Tablosu kullanıldı. Bu bölümde algılanan sosyal desteğin FA'lı kişilerin duygulanım durumları için önemli bir faktör olduğu bulunmuştur. Nitel kısımda yarı-yapılandırılmış görüşme soruları kullanılmıştır. Bu bölümde ise FA'lı kişilerin onlara yönelik ayrımcı davranışlar gibi toplumsal engellerle karşı karşıya kaldıkları ortaya çıkmıştır. Bu bağlamda, gelecekte yapılacak çalışmalarda araştırmacılar, engeli olmayan kişilerin ayrımcı düşüncelerini azaltmanın yollarına ya da engeli olan bireylerin sosyal destek kaynaklarını artırmak için yapılabileceklere odaklanabilir.

Anahtar Kelimeler: Friedreich ataksisi, ayrımcılık, duygusal problemler, fiziksel problemler.

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INTRODUCTION

Being disabled is one of the leading themes of interest both in the world and in Turkey (Kolat, 2009). To standardize the meaning of different concepts in disabilities, World Health Organization (WHO, 1980) defined disability as: "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". In the literature, there are different types of models to identify the meaning of disability more clearly. One of them is *medical model* of disability which says that disability is the consequence of physiological or cognitive impairments. However, medical model was challenged by sociologists with the *social model* of disability. According to this model, people are disabled because of the society which was designed for non-disabled people instead of people with physical or mental impairments. This idea has its roots in the 1976 British Union of the Physically Impaired against Segregation (UPIAS), which said that it is not people with disabilities, but the society with barriers that is actually disabled (Twardowski, 2019).

The definition of disability changes between different contexts. In addition to terms "özürlü" (defective) and "engelli" (handicapped, disabled), "sakat" (crippled) is also one of the terms used in Turkey for people with disabilities and these terms refer to people who have diminished hopes to have a job or who have social incapability because of their physical or mental disability. These people might also be unable to meet their daily needs (Kolat, 2009). Current study focused on a type of ataxia that involves many physical symptoms simultaneously. For this study, Friedreich's Ataxia (FA) which is a progressive neurodegenerative disorder with different symptoms (Cook & Giunti, 2017) was investigated. In the introduction part of the study, information about disability in general was focused on since FA includes different symptoms from different disabilities. The other reason for gathering information about different types of disabilities is also the shortage of specific information on FA in the literature.

FA was first diagnosed by Nikolaus Friedreich in 1863 (Campuzano et al., 1996). Ataxia is a Greek word which means *lack of voluntary coordination of muscle movements* which also gives the name for the disease. FA is related with degeneration of cerebellum. It is one of the chronic diseases which causes physical disabilities and cognitive impairments in the patient at the same time (Mantovan et al., 2006). Among the symptoms of it there are sensory loss, vision impairment, hearing impairment, problems in speech and coordination (Cook & Giunti, 2017). It influences 1 in 50,000 people around the world with a carrier rate of 1 in 120 which makes it the most common type of inherited ataxia (Campuzano et al., 1996; Richardson et al., 2013). It is usually seen in childhood, but onset may also occur in adulthood (Epstein et al., 2008). FA is a progressive degenerative disease (Mantovan et al., 2006) and many people living with this disease start using a wheelchair by their late 20s (Campuzano et al., 1996).

According to State Institute of Statistics (2013, 2021), there were 4.882.841 people with disabilities which include disabilities in seeing, walking, hearing, talking, mental capacities, emotional regulation and chronic illnesses in Turkey in 2011. 670.756 people among them were living in Istanbul. However these are the statistics from the people with different kinds of disabilities applying to public institutions and organizations. To the knowledge of the author, there are no statistics specifically related to FA in Turkey. In terms of education status, according to 2002 statistics in Turkey, 36% of the people with disabilities were illiterate, while 13% of the general population was illiterate. 41% of people with disabilities had only completed primary school and the percentage of people with disabilities continuing to higher education was very low (16%) (State Institute of Statistics, 2002).

There is a long history behind the changes in mind about the attitudes and ideas toward people with disabilities. In 1800s people with disabilities were seen as entertainment objects to use in circuses in USA. President Roosevelt, the first president with a disability has defended the rights of treatment in rehabilitation for people with disabilities in 1930s. However he was one of the advocates of medical model. After the World War II, the veterans tried to get right for rehabilitation and vocational training so the disability issues became more visible. In these years Turkish government founded special educational schools for people with disabilities and in 1960s the rehabilitation centers were also established by the state in Turkey. United Nations celebrated the year 1981 as "International Year of Disabled People" and this improvement accelerated the action for people with disabilities in Turkey. In this year within The Ministry of Labor and Social Security, National Coordination Committee of Injured

Protection was established and this assembly works now as General Management of Disabled and Elderly Services (Kolat, 2009).

In Turkey, there are several distinct attitudes toward people with disabilities. To understand differences between the attitudes toward people with disability and with no disability, Turkish State Institute of Statistics has conducted a survey in 2002 for which Attitudes toward Persons with Disabilities Inventory was specially developed. There were 4144 participants in the study. About the beliefs toward people with disabilities, it was found that 75.8% of the participants believe that being disabled is an exam by God. In the results it was shown that when the participants were asked "with which groups of disabled people they may not prefer to marry", 50.5 % of participants would not like to marry any person with disabilities. It was also found that when participants were asked whether they agree the idea that the students with disabilities getting education together with non-disabled students are burden for teachers, 54.4 of the participants defended the idea that students with disabilities should get education together with other students. However in the same study 52.1% of the participants also stated that students with disabilities should have special schools so it seems that participants had contradicted opinions and had not much information about the school system of students with disabilities. In addition, 33% of participants did not prefer to be a close friend, colleague or neighbor of persons from especially some disability groups like people with mental disorders or psychological problems (Turkish State Institute of Statistics, 2002).

As opposed to the results of Turkish State Institute of Statistics (2002), both a review study (Mamatoğlu & Tasa, 2018) and other more recent research studies showed that people in Turkey have generally positive attitudes toward people with disabilities. For example, it was found that university students (Açak & Narinç, 2020; Çakırer Çalbayram et al., 2018; Gençtürk & Korkut, 2020) and employers (Anıl, 2019) had supportive attitudes toward people with disabilities. Thus, based on these contradictory results in the literature, in current study it was aimed to understand how individuals with FA feel about attitudes towards them. To the knowledge of the researcher, there is not any study related with discrimination or general attitudes toward people with FA in the literature. In this respect, in the current study discriminatory issues were addressed by asking people with FA what the attitudes of people were towards them.

At this point, it may be useful to define the concept of discrimination. Discrimination is treating members of a group unfairly just because they are members of that group, or treating these people negatively and performing harmful actions towards them (Aronson et al., 2012). Its origin lies in the fact that people are not equal in terms of power. Discrimination feeds on prejudice and functions as a mechanism of exclusion or domination. Due to discrimination, an exclusionary structure is formed in interpersonal relations (Göregenli, 2012). When discriminatory behavior is committed against individuals with disabilities, this situation is also called *ableism* (Terry, 1996). Although the term ableism emerged during the 1960s and 1970s as a result of civil rights movements in USA and Britain, it is known that throughout history, discriminative behaviors toward people with disabilities have been observed all around the world (Levi, 2006). Disabled individuals are included in groups called disadvantaged groups or vulnerable groups. The groups most exposed to discrimination in society are vulnerable groups (Erol-Karaca & Nam, 2021). According to the social model of disability, the people with disability are included in the disadvantaged groups because of the structure of the society. Since society can not provide necessary services to the people with disabilities, disability is seen as a pathology (Pfeiffer, 2001).

There are studies in the literature that investigate different characteristics that affect attitudes toward people with disabilities (see Wang et al., 2021). For example, Daşbaş et al. (2013) concentrated on the effect of education on attitudes toward people with disabilities. Their study which was conducted among teachers showed that teachers that have students with disabilities in their classrooms have more negative attitudes towards people with disabilities compared to other teachers. Teachers' negative in-class experiences resulting from insufficient knowledge of individuals with disabilities may have pushed them to have negative attitudes (Daşbaş et al., 2013). Therefore, providing educators with training regarding individuals with disabilities may cause attitudes towards disability to shift towards positive. In addition, for inclusive education that enables disabled individuals to benefit from their right to education, it is important that the people providing the training and other personnel have positive attitudes towards people with disabilities (Batu, 2000; Şahin & Güldenoğlu, 2013). Relatedly, research that was conducted among teachers showed that after education on people with disabilities, teachers began to have more positive attitudes toward students with disabilities (Şahin & Güldenoğlu, 2013). As Şahin and Güldenoğlu (2013) implied, attitudes toward people with disabilities are both important and may be changed for positive by education.

People with disabilities may have several stressors in their lives. In a research, which included 120 participants with loco motor disability, it was indicated that major stressors of these people were inability to fulfill traditional gender roles, problems in interpersonal relationships with family and others, physical barriers and deformed body image. This study also showed that the education level was the strongest predictor of perceived distress and that problem-focused coping was significantly associated with lower levels of distress (Pande & Tewari, 2011). However they did not research about the relationship between the stress appraisal of the people with disabilities and their general affect situation. There is not also a research on this issue which is special for people with FA. Thus, in current study it was tried to learn whether there is a relationship between these two items (stress appraisal style and affect) in people with FA.

In terms of social support, research (Yang, 2006) showed that the degree of social support which is a factor that reduces stress, is an important mediator for the effect of disability on depressive symptoms. In a research (Schulz & Decker, 1985) which included 100 participants with spinal cord injuries it was also found that people who have high levels of social support and satisfied social contacts have high levels of well-being. Another research conducted among people suffering from chronic obstructive pulmonary diseases (COPD), showed that among COPD patients the ones who declared that they receive no social support also were more likely to report depression (Arabyat & Raisch, 2019). However, to the knowledge of the author there is no research study that examines the role of social support specifically for people with FA. Thus, in the current study it was decided to examine the relationship between perceived social support of the people with FA and their degree of positive and negative affect.

When looking at individuals with physical disabilities in general, a qualitative study in the literature showed that these people often report anxiety and depressive moods (Perez-Garin et al., 2018). Relatedly, major depression is frequent in FA patients and usually associated with their structural abnormalities (Silva et al., 2012). In a study conducted with 38 participants who have FA showed that 98% of the participants experienced affective difficulty ranging from normal grief to major depression (Flood & Perlman, 1987). It was also showed that people with FA have reduced defensiveness and some mood disorders (Mantovan et al., 2006). In terms of depressive symptomatology, it was found that 23% of people with FA shows depressive symptoms in moderate level (Perez-Flores et al., 2020). Another study showed that the depression scores of people with FA is significantly higher than depression scores of general population (Nieto et al., 2018). Thus, there is information on depression levels of people with FA. However, it might be good to know their general affect situation as well and literature does not present sufficient information about this. Stepping from the relationship between structural abnormalities and depression levels in FA (Silva et al., 2012), it was thought that there may be also a relationship between the problems that were experienced by people with FA in walking and speaking, and their positive and negative affective states. Thus, this probable relationship was investigated in the quantitative part of the current study. Relatedly, although it was found that cognitive interventions in psychological therapy can lead to reduction in degree of pain for people with disabilities (Ehde & Jensen, 2004) in the literature there is not any specific psychological treatment for people with FA. Thus, in the qualitative part of this study it was also asked to participants whether they have psychological problems and whether they benefit from psychological treatments.

In light of this information, the aim of this study is to understand the physical and emotional problems of people with FA. As stated before, to the knowledge of the researcher, there is no research that addresses neither stress appraisal nor perceived social support in people with FA. Although there are some studies that focus on the level of depression in people with FA (Flood & Perlman, 1987; Nieto et al., 2018; Silva et al., 2012; Perez-Flores et al., 2020) there are not enough studies about general affective states of people with FA. Thus, to understand the impact of the problems that people with FA experience, the social support they perceive and the type of stress appraisal they use on their general affect situation and also to enrich the literature on these topics, two hypotheses were formed for quantitative part:

H1: The level of problems of people with FA experience in the areas of speaking and walking, the levels of perceived social support of people with FA and the appraisal type of stress (as controllable by self, controllable by others, uncontrollable, threatening and seeing it as a new challenge) of people with FA will predict the levels of negative affect.

H2: The level of problems of people with FA experience in the areas of speaking and walking, the levels of perceived social support of people with FA and the appraisal type of stress (as controllable by self, controllable by others, uncontrollable, threatening and seeing it as a new challenge) of people with FA will predict the levels of positive affect.

In addition to above variables, since there is no study related with attitudes toward people with FA, it may be useful to conduct research on general attitudes towards individuals with FA. Furthermore, there is no qualitative study which tries to understand general problems and opinions of people with FA in the literature. Therefore, one of the aims of the current study is to understand the general problems of people with FA and whether they encounter discrimination and if so, to understand their perceptions on discrimination. Thus, in qualitative part of the study, people with FA were asked whether they had any problems related with discrimination.

METHOD

Participants

There are two phases of this study. The first one is quantitative and the second one is qualitative. At the both of the phases participants were selected with convenience sampling. In the quantitative section, individuals with FA who applied to a rehabilitation center in Ankara for physical therapy were included. This rehabilitation center was chosen because it was the place where the author's psychologist friend worked and the time limit of the research was limited. Therefore, a convenient sampling technique was used. The inclusion criterion for the study was to be over the age of 18 among people with FA. At the quantitative phase, there were 22 participants, 18 of them were female and 4 of them were male. The mean of age was 28.59 ranging between 16 and 43. Among all participants, 12 of them were high school graduates (54.54 %), 8 of them were university graduates (36.36 %) and 2 of them were secondary school graduates. Only 1 participant was married and the other 21 were single. The mean year of diagnosing as FA were 9.77, ranging from 1 to 20.

In the qualitative phase, semi-structured interviews were conducted with the participants. Among the people who were included in the quantitative analysis, 8 people agreed to participate in the qualitative research, and 5 of these people were interviewed face to face, while 3 of them were interviewed via e-mail. There were 8 participants, 7 of them were female and 1 of them is male. The mean age was 31.37 ranging between 24 and 43. Two of the participants were working as civil servant and the others were not working. Among all participants, 3 of them were university graduates and 5 of them were high school graduates.

Materials

Interview Questionnaire

Interview questionnaire which was prepared for qualitative part of the study consists of 10 questions. Semi-structured interview questions were created based on previous findings regarding disabled individuals in general in the literature research (e.g. Açak & Narinç, 2020; Mamatoğlu & Tasa, 2018; Turkish State Institute of Statistics, 2002). Since the research on FA in the literature is limited, the focus has been on areas that have been previously studied on individuals with other disabilities.

The aim of the questionnaire is to learn participants' demographics, illness and treatment history, how his or her life changed after diagnosed with FA, difficulties his or her encountered and discrimination against them. After the questions were prepared, the psychologist at the rehabilitation center where the quantitative research was conducted also evaluated the questions in terms of whether they were suitable for individuals with FA, and it was recommended to add a new question, taking into account the multiple problems experienced by these people. In line with this recommendation, the question "Among the physical problems you experience due to FA, which one is the most challenging for you?" was added to the interview questions.

Demographic Information Form

The demographic information form was prepared for people diagnosed with FA. The form included general demographic questions about gender, education, age, income, marital status, occupation, date of diagnose, having a psychological disorder or not, number of people living with. Moreover, the effects of FA on walking and speaking ability were questioned at demographic information form with couple of questions like: “Do you have difficulty in walking?” (Yürümekte zorluk yaşıyor musunuz?) and “To what extent are you experiencing difficulty?” (Ne ölçüde zorluk yaşıyorsunuz?)

Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support was developed by Zimet et al. (1988). There are 12 items in this scale measuring perceived social support. The scale includes three subscales. The first subscale is support from family, the other one is support from friends and the last one is support from significant others. The items are rated on 7-point-likert scale and the higher points indicate higher levels of perceived social support. Multidimensional Scale of Perceived Social Support was adapted to Turkish by Eker and Arkar (1995). It was found that the total scale has good reliability in a university student sample (α = .85). The Cronbach’s alpha was found as .91 in the current study.

Positive and Negative Affect Schedule (PANAS)

PANAS was developed by Watson et al. (1988). There are 20 items and two subscales in PANAS. The first subscale, which is positive affect, consists of 10 items, and the second subscale, which is negative affect, also consists of 10 items. The PANAS was adapted to Turkish by Gençöz (2000). In terms of reliability statistics, Gençöz (2000) found that while the Cronbach’s alpha for positive affect was .83 it was .86 for negative affect. The Cronbach’s alpha was found as .83, for both positive and negative affect in the current study.

Stress Appraisal Measure

Stress Appraisal Measure developed by Peacock and Wong (1990). There are 24 items in Stress Appraisal Measure and the items based on two dimensions. The first one is primary appraisal of a stressful situation and the second one is secondary appraisal of a stressful situation. There are five factors in this scale, namely; controllable-by-self, controllable-by-others, threat, challenge and uncontrollable. The Stress Appraisal Measure was adapted to Turkish by Durak and Şenol-Durak (2013). Since the internal consistencies of the subscales ranged from .70 to .86, Durak and Şenol Durak (2013) stated that the scale is reliable. The Cronbach’s alpha levels were found as .78, .76, .82, .61, .76 for the subscales named as threat, controllable by self, controllable by others, uncontrollable and challenge respectively, in the current study.

Procedure

The permission was received from METU Human Research Ethics Committee. At the quantitative phase of this study, the data were collected through a web-based survey. The participants were reached via social media web sites. Informed consent was given to the participants before they started to fill the survey. The data of the web-based survey were analyzed with SPSS. 22 participants participated the quantitative part of the study.

At the qualitative phase of this study, the data were collected through semi-structured interviews. Five interviews were conducted face-to-face and the other three were conducted through e-mails. All of the participants were received informed consent before the interviews. The transcripts of the interviews were examined and the answers of the participants were grouped based on their themes. Since member checking and peer debriefing are among the methods that used for understanding the reliability level of qualitative analyses (Başkale, 2016) these methods were used in the analysis process of the current study. To carry out the member checking method, after the themes of the study were determined, the participants were interviewed a second time and the results were presented to them and their comments were taken. At this stage, participants stated that the themes were compatible with their experiences. To carry out the peer debriefing method, a psychologist working at the rehabilitation center evaluated the research from various aspects. Thus, it may be said that the study is a reliable one.

RESULTS

Results of Quantitative Study

In order to investigate whether appraisal type of stress (as uncontrollable, threatening, controllable by self, controllable by others, or seeing it as a challenge), perceived social support and the effects of Friedreich's Ataxia on walking and speaking abilities account for significant variance in negative affect of people with FA or not, multiple regression analysis was conducted. As a rarely seen ataxia, since there are very few participants (n = 22) in the quantitative part of the study, robust regression analysis results with bootstrapped coefficient intervals will be reported in the case of violation of the assumptions (Field, 2013). In general model, independent variables statistically significantly predicted the negative affect, $Adj\ R^2 = .52$, $F(8,13) = 3.83$, $p = .02$. Thus, the regression model is a good fit of the data. However, bootstrapped coefficients table showed that none of the independent variables significantly predict negative affect of people with FA (see Table 1).

In order to investigate whether appraisal type of stress (as uncontrollable, threatening, controllable by self, controllable by others, or seeing it as a challenge), perceived social support and the effects of Friedreich's Ataxia on walking and speaking abilities account for significant variance in positive affect of people with FA or not, multiple regression analysis was conducted. In general model, independent variables did not significantly predict positive affect, $Adj\ R^2 = .24$, $F(8,13) = 1.81$, $p = .16$.

Results of Qualitative Study

Five themes emerged from the interviews. The first one is diagnosing process of Friedreich's ataxia, the next one is occupational problems, and the other one is educational problems. Another theme emerged from interviews is treatment and the last one is discrimination against them.

Diagnosing process of Friedreich's Ataxia

Diagnosing the symptoms as Friedreich's Ataxia theme refers to participants' experiences about diagnosing process. All of the participants reported delayed diagnose of Friedreich's Ataxia. One participant mentioned that her symptoms started after the first year of high school (at 15 year old), however she was diagnosed at 43. She said: "Before that age … (Doctors) said everything. Muscle problems, spinal cord problems or meningitis... This illness (of Friedreich's Ataxia) was diagnosed by a private doctor after listening my life story" (transition from: *Daha önce her şeyi söylediler. Kas, omurilik ve menenjit kalıntısı gibi. Bu tanıyı özel bir hekim hayat hikayemi dinleyerek koydu*). Another participant mentioned that she was hospitalized for one week at the age of 11: "Lots of tests were done. I was too young and I suffered a lot, screamed a lot. And after that, the diagnose of doctors were wrong" (transition from: *11 yaşında hastahaneye yatırdılar beni. Bir çok test yaptılar ve o zamanlar çok küçüktüm, çok acı çektim, çok bağırdım. Ve doktorlar yanlış tanı koydular*). Another participant mentioned that the doctors in his hometown could not diagnose him at first, but a professor from Hacettepe University Faculty of Medicine diagnosed him (as Friedreich's Ataxia) (transition from: *Buradaki doktorlar başta tanı koyamadılar. Daha sonra Hacettepe Üniversitesi hastanesinde Profesör Doktor tanı koyabildi*). Another woman mentioned that she was diagnosed at the age of 24 but she realized the illness at the age of 20-21 (transition from: *24 yaşında kondu ama 20-21 yaşlarında fark etmeye başladım hastalığı*).

Occupational Problems

Occupational Problems theme refers to the difficulties experienced by the participants in finding a job, and the difficulties faced by the participant throughout his/her working life if s/he has a job. One participant mentioned that "at work, (colleagues) don't want to give tasks for me; they check the tasks that I completed. I controlled the task that they give me for two or three times since I know that I was perceived in that perspective (inferior)" (transition from: *Bana iş vermek istemiyorlar, yaptığım işleri kontrol ediyorlar. Ben bu şekilde algılandığımı bildiğim için (daha aşağıda olarak), yaptığım işi 2-3 kere* *kontrol ediyorum*). Among all participants only two of them were working. Another participant who was not working mentioned that: "…I don't work. Now my father and mother support me economically." (transition from: *Çalışmıyorum. Şu an anne ve babam bakıyor bana.*). Another participant stated that if she had the power, she would provide more job opportunities for people with disabilities (transition from: *Daha çok maddi imkân sağlardım. İş ve gezme imkanı sağlardım.*)

Educational Problems

The educational problems theme refers to participants' experiences during educational life, obstacles they encounter during that span of time. Only two of the eight participants went to the regular university and those two were the participants whose diseases started late. One participant mentioned that she cannot go to a university because of using wheelchair. Therefore she graduated from the open education. (transition from: …*tekerlekli sandalye kullanmaya başladığım için normal bir üniversitede okuyamadım, açık öğretimden mezun oldum*). Another one said that "I also want to study psychology but I cannot go to university because of my disability." (transition from: *ben de psikoloji okumak istiyordum ama engelimden dolayı üniversiteye gidemedim.*). The attitudes of teachers created another problem for another participant. She mentioned that her handwriting was bad because of her disability. And instead of giving exams as test, the teachers gave lower grades to her because of her handwriting (transition from: …*engelimden dolayı yazım çok çirkin. Öğretmenler de sınavları test yapacaklarına yazım çirkin diye bana düşük notlar veriyorlardı.)*

Treatment

The treatment theme refers to participants' knowledge and hopes about the treatment of FA. Only one participant mentioned that there can be a cure for this disease. Other participants (seven of them) mentioned that there is no cure for this disease. Six of them were taking physiotherapy and they said that physiotherapy is not an actual treatment but it makes the progress of the disease slower. (transition from: …*ama bu tedavi etmiyor sadece ilerlemeyi yavaşlatıyor.*) Another participant also mentioned that she has been taking physiotherapy for one year in order to make the progress of her disease slower, but it has not been working for her (transition from: …*bir yıldır yeniden fiziğe başladım. Bana pek faydası yok. Bu zaten sadece hastalık ilerlemesin diye.*) One participant mentioned that she did not take any treatment: "I do not know possible treatment options, how to benefit from them and what government covers" (transition from: …*hiçbir tedavi almıyorum. Ne gibi tedaviler var, nasıl yararlanacağım, devlet neleri ödüyor onu da bilmiyorum*).

Discrimination

Discrimination theme refers to discrimination experiences of the participants. Three of the participants mentioned that people asked them if they were drunk, because of their unbalanced walking at the beginning of their disease. Two of them were women and they said that they were chased by men because of this situation. Moreover, two women expressed how other people's looks affected them. One of that woman said: "People look at us with pity. You cannot go to places you want; you cannot do a work that you want… The things that we could not do make us unhappy. Everything is difficult for us" (Transition from*: İnsanlar acıyarak bakıyorlar. İstediğin yere gidip istediğin işi yapamıyorsun. Yalnızlaştıkça ... İçimizde kalanlar ve yapamadıklarımız bizi üzüyor. Her şey zor bizim için*.). One woman mentioned that during primary school her classmates did not want to play with her, and made fun with her. Two of the participants mentioned that people act against them as if they have a mental retardation. One of them said that: "… (at the job) people do not want to work with me, they use simple language and repeated what they say again and again as if I cannot understand them. I have a physical disability, not mental retardation. This makes me really unhappy." (Transition from: *İnsanlar benimle çalışmak istemiyor. Çalıştıkları zaman da sanki onları anlayamazmışım gibi basit bir dile konuşuyorlar, durmadan tekrar ediyorlar söylediklerini. Benim fiziksel engelim var, zihinsel engelim yok ki. Bu duruma çok üzülüyorum*).

DISCUSSION

Being disabled is one of the most popular topics in the literature both in the world and in Turkey (Kolat, 2009). According to Turkish State Institute of Statistics (2013, 2021) nearly five million people have certain kinds of disabilities in Turkey. FA is a progressive degenerative disease and causes physical disabilities in the patient (Mantovan et al., 2006). However, there are no statistics specifically for the FA in Turkey and the literature does not provide sufficient information about the problems of patients with FA or attitudes towards them. Therefore, the current study aims to contribute to the literature about FA, particularly about their problems and attitudes towards them. For this purpose, the current study includes one quantitative and one qualitative part. In the quantitative part, the role of the effects of FA on walking and speaking abilities, appraisal type of stress and perceived social support on emotional situation of people with FA were investigated. In the qualitative part, semi-structured interviews were conducted and five themes emerged.

In terms of the role of perceived social support on emotional situation (i.e. positive and negative affect) of people with FA, there was not a significant result in the current study. In previous research, it was found that when degree of social support was high, it mediates the effect of disability on the people by lessening the depressive symptoms (Yang, 2006). Schulz and Decker (1985) found that when the social support is higher with self-esteem, people have also higher levels of well-being. Another study also demonstrated the negative relationship between perceived social support and depressive states in people with chronic disease (Arabyat & Raisch, 2019). However, in current study, hypothesis related with social support could not be supported meaning that the perceived social support levels of people with FA did not predict their negative or positive affect. This result is incompatible with the results related with social support in the literature (e.g., Arabyat & Raisch, 2019; Schulz & Decker, 1985; Yang, 2006). In the literature there were not any results for social support significantly related with people with FA so the incompatibility might be resulted from this situation. Also, the non-significant results in the current study may be due to the small sample size. In the future, studies related with the levels of social support of people with FA should be conducted by paying attention to the sample size. Also, self-esteem or other indicators of well-being like life satisfaction of the participants were not investigated in current study. In future research it can be good at thinking about these variables. In this research there was not balance between the number of women and men which is another limitation for the study beside the limited numbers of participants in quantitative part. Besides, in the qualitative part, some interviews were conducted face to face, while others were conducted via e-mail. Providing standardization in the interviews conducted in future studies may help to obtain more reliable results.

In terms of the role of negative effects of Friedreich's Ataxia on walking and speaking abilities on negative and positive affect, there was not a significant result in the quantitative part of the current study. However, in the literature, findings showed that depressive symptoms in people with FA is associated with structural abnormalities (Silva et al., 2012). The other factor that was investigated in the quantitative part of the study was stress appraisal. In literature, it was found that when stressors were evaluated as threat, negative emotions emerged (Nicholls et al., 2012). However, in the current study there was not any significant association between stress appraisal type and negative or positive affect. The non-significant results in the current study might be related with the small sample size. Since the study was conducted only in Ankara, in the future, researchers may try to conduct studies in several different cities simultaneously to reach a sufficient sample size.

Turkish State Institute of Statistics (2010) showed that upper levels of education is very low among people with disabilities. However, in the quantitative part of the current research it was found that 8 people among 22 participants have graduated from university so it was thought that disseminating demographic scales on the web can be the reason for this high percentage in education and this can be the limitation for the study. Thus, in future studies instead of using an online survey, conducting face-to-face surveys might be beneficial to understand the level of education of people with FA. There were also some participants who could not study at university because of their disease and some of them complained about the attitude of their teacher. This result mat imply that teachers should take education also about this ataxia or disabilities in general because they cannot be aware of the disease in recent phases and can evaluate the student negatively by thinking that they are careless or lazy.

For clinical applications, previous research showed that people with FA have higher risk for affective difficulty (Flood & Perlman, 1987). Major depression is also frequent in them (Silva et al., 2012). In current study two participants complained from depression among 22 participants, one participant indicated that he/she is angry and the other said that he/she has excessive anger. The one with excessive anger indicated that he did not benefit from psychological treatment. However other three participants and one participant who has not psychological disturbance said that they benefited from psychological treatment. This result suggests that people with FA did not know much about psychological treatment or they do not believe they can benefit from this type of treatment. In future it can be good to create a psychological treatment which is special for FA. It may also be beneficial to educate psychological therapists on issues about discrimination. Since there is not sufficient information about general emotional states of people with FA and also about their opinions on psychological treatment, it may be said that the results of current study contribute to the literature.

In qualitative part of the current study it was found that people with FA experience problems in some areas. For example, among eight participants only two of them were working. The one who had a job mentioned that she was underestimated at work by her colleagues. Another area that they experience problems is education. Some of them mentioned that even if they wanted to go to the university they could not continue their education due to their disabilities. In addition, they talked about the difficulties in the diagnosis process due to the rarity of their disease and therefore the delay in starting the treatment process. Since there is not any study that concentrate on the problems of people with FA, the current study might be seen as a first step to realize their problems. In future, researchers may study the roots of these problems. Political, social and legal steps can be taken for both individuals with FA and individuals with disabilities in general. In Turkey, The Convention on the Rights of Disabled People was approved in 2009. In this agreement, the state is obliged to ensure that individuals with disabilities can realize their rights in matters such as education, health and employment (Aile ve Sosyal Hizmetler Bakanlığı, 2021). However, we should not see these regulations alone as sufficient and we should continue to work and actively implement the laws to ensure that individuals with disabilities can participate in all layers of social life (Karaahmetoğlu, 2023).

In discrimination issue, research conducted by Turkish State Institute of Statistics (2002) in Turkey had showed that half of the participants did not want to marry with a person with disability and 33% of the participants did not prefer these people as colleagues. However, other studies (e.g., Açak & Narinç, 2020; Çakırer Çalbayram et al., 2018; Gençtürk & Korkut, 2020) showed that there is generally a positive attitude toward people with disabilities in Turkey. In the qualitative part of the current research some participants said people looked at them with pity by thinking that they cannot do anything. One of the participants declared that she had emotional problems in her adolescence because of the attitudes of the friends and she and her family changed their residence. Another also talked about the loneliness they felt because their friends started to move away after symptoms appeared. Thus, in current research, it was found that people with FA have confronted discriminatory attitudes. In future, researchers may concentrate on the ways to decrease the discriminatory attitudes of people with no disabilities.

Before this study, I was nervous about how can I behave when I am with a person with disability. However, in this study, I saw that people with FA are so supportive and positive. They also talked about their experiences freely. I actually felt sometimes sad during the study because when I asked about filling the scales they asked whether I try to find a treatment. I also confronted a man with FA who thought that this study is nonsense because there is no treatment of FA and the people already forgot about them. However, also in this example I thought that they can express their feelings freely. The majority of them follow the news about recent findings from scientists about FA to learn about the possibility to be treated and this news was generally about the changing of the responsible gene for the disease. Therefore, I thought that maybe the degree of hope is bigger in this disease as contrary to other disabilities which are resulted from accidents. This hopefulness may lead them to show supportive behavior for scientists in especially disabilities area.

I confronted with some problems during this study because some hospitals which have rehabilitation services do not rehabilitate people with FA. I also thought that since FA is seen rare, I will not find any other person to interview. However, I realized that although we ignore them sometimes, there are some people in Ankara with this disability. I also surprised when I learned that there can be more than one person with FA in the same family. All in all with this study I learned that there are many people with FA in Turkey and how they are genuine to make other people know about their disease. In future it can be good to do research on psychological treatment style that people with FA may benefit, because contrary to other people with disabilities they have more hope to be cured.

REFERENCES

Açak, M., & Narinç, Ç. (2020). Eğitim fakültesi öğrencilerinin engellilere yönelik tutumlarının incelenmesi (Malatya il örneği). *GERMENİCA Beden Eğitimi ve Spor Bilimleri Dergisi, 1*(1), 19-27.

Aile ve Sosyal Hizmetler Bakanlığı. (2021). *Engelliler için bilgilendirme rehberi*, Anıl Reklam Matbaa Limited Şirketi.

Anıl, A. (2019). İşverenlerin engellilere yönelik tutumları ile engelli çalışanların çalışma alanına yönelik görüşlerinin incelenmesi. [Yayımlanmamış yüksek lisans tezi]. Necmettin Erbakan Üniversitesi.

Arabyat, R. M., & Raisch, D. W. (2019). Relationships between social/emotional support and quality of life, depression and disability in patients with chronic obstructive pulmonary disease: An Analysis based on propensity score matching. *Annals of Behavioral Medicine*, *53*(10), 918–927. https://doi.org/10.1093/abm/kaz002

Aronson, E., Wilson, T. D., & Akert, R. M. (2012). *Sosyal Psikoloji.* Kaknüs Yayınları.

Başkale, H. (2016). Nitel araştırmalarda geçerlik, güvenirlik ve örneklem büyüklüğünün belirlenmesi. *Dokuz Eylül Üniversitesi Hemşirelik Fakültesi Elektronik Dergisi*, *9*(1), 23-28.

Batu, S.E. (2000). Kaynaştırma, destek hizmetler ve kaynaştırmaya hazırlık etkinlikleri. *Özel Eğitim Dergisi, 2*(4), 35-45.

Campuzano, V., Montermini, L., Moltò, M. D., Pianese, L., Cossée, M., Cavalcanti, F., Monros, E., Rodius, F., Duclos, F., Monticelli, A., Zara, F., Cañizares, J., Koutnikova, H., Bidichandani, S. I., Gellera, C., Brice, A., Trouillas, P., de Michele, G., Filla, A., … Ma, J.-L. (1996). Friedreich's Ataxia: Autosomal recessive disease caused by an ıntronic gaa triplet repeat expansion. *Science*, *271*, 1423-1427. https://doi/10.1126/science.271.5254.1423

Cook, A., & Giunti, P. (2017). Friedreich's ataxia: Clinical features, pathogenesis and management. *British Medical Bulletin*, *124* (1), 19–30. https://doi.org/10.1093/bmb/ldx034

Çakırer-Çalbayram, N., Aker, M. N., Akkuş, B., Kübra, F., & Tutar, S. (2018). Sağlık bilimleri fakültesi öğrencilerinin engellilere yönelik tutumları. *Ankara Sağlık Bilimleri Dergisi*, *7*(1), 30-40.

Daşbaş, S., Kesen, N. F. ve Eryılmaz, C. (2013). Eğitim kurumlarında görev yapan öğretmenlerin engellilere yönelik tutumları. *Sağlık ve Toplum. 23*(1), 39-46

Durak, M., & Senol-Durak, E. (2013). The development and psychometric properties of the Turkish version of the stress appraisal measure. *European Journal of Psychological Assessment*, *29*(1), 64–71. https://doi.org/10.1027/1015-5759/a000079

Ehde, D. M., & Jensen, M. P. (2004). Feasibility of a cognitive restructuring intervention for treatment of chronic pain in persons with disabilities. *Rehabilitation Psychology*, *49*, 254-258.

Eker, D., & Arkar H. (1995). Perceived social support: psychometric properties of the MSPSS in normal and pathological groups in a developing country. *Social Psychiatry and Psychiatric Epidemiology*, *30*, 121-126.

Epstein, E., Farmer, J. M., Tsou, A., Perlman, S., Subramany, S. H., & Gomez, C. M. (2008). Health related quality of life measures in Friedreich's Ataxia. *Journal of the Neurological Sciences*, *272*, 123-128.

Erol Karaca, Z., & Nam, D. (2021). Kronik bir sosyal sorun: Engellilere yönelik ayrımcılık. *Bilgi Sosyal Bilimler Dergisi*, *23*(1), 167-194.

Field, A. (2013). Discovering statistics using IBM SPSS statistics: and sex and drugs and rock ‘‘n” roll; 4th edition. In Sage.

Flood, M. K., & Perlman, S., L. (1987). The mental status of patients with Friedreich’s Ataxia. *Journal of Neuroscience Learning, 19*, 251-255.

Gençöz, T. (2000). Positive and negative affect schedule: A study of validity and

reliability. *Turkish Journal of Psychology, 15*(46)*,* 27-28.

Gençtürk, Z., & Korkut, G. (2020). Üniversite öğrencilerinin engelli bireylere yönelik tutumlarının incelenmesi. *Bingöl Üniversitesi Sosyal Bilimler Enstitüsü Dergisi*, *19*, 105-126. https://doi.org/ 10.29029/busbed.638308

Gökçek-Karaca, N. (2019). Uluslararası ilke ve standartlar bağlamında engelli hakları. *Anadolu Üniversitesi Hukuk Fakültesi Dergisi*, *5*(1), 1-34.

Göregenli, M. (2012). Temel kavramlar: Önyargı, kalıpyargı ve ayrımcılık. In K. Çayır & M. Ayan Ceyhan (Eds.), *Ayrımcılık: Çok Boyutlu Yaklaşımlar* (pp. 17-28). İstanbul Bilgi Üniversitesi Yayınları.

Karaahmetoğlu, A. (2023). Ayrımcılık yasağı kapsamında çalışma yaşamında engelliler açısından uluslararası normlar çerçevesinde Türkiye Cumhuriyeti mevzuatı. *Uluslararası Batı Karadeniz Sosyal ve Beşerî Bilimler Dergisi*, *7*(1), 15-42. https://doi.org/10.46452/baksoder.1223873

Kolat, S. (2009). *Avrupa Birliği Sosyal Politikası Çerçevesinde Özürlülere Yönelik Ayrımcılıkla Mücadele ve Türkiye’deki Yansımaları*. Ankara: TC Başbakanlık Özürlüler İdaresi Başkanlığı.

Levi, S. J. (2006). Ableism. In G. L. Albrecht (Ed.), *Encyclopedia of disability* (pp. 1-4). Thousand Oaks: SAGE Publications.

Mamatoğlu, N., & Tasa, H. (2018). Engelliye yönelik ayrımcılık ve iş yerinde engelli. *Türkiye Klinikleri*, *3*(1), 1-10. Retrieved June 4, 2018 from, https://www.researchgate.net/publication/330874972.

Mantovan, M. C., Martinuzzi, A., Squarzanti, F., Bolla, A., Silvestri, I., Liessi, G., Macchi, C., Ruzza, G., Trevisan, C., P., & Angelini, C. (2006). Exploring mental status in Friedreich's ataxia: A combined neuropsychological, behavioral and neuroimaging study. *European Journal of Neurology, 13*, 827-835**.**

Nicholls, A. R., Polman, R. C. J., & Levy, A. R. (2012). A path analysis of stress appraisals, emotions, coping, and performance satisfaction among athletes. *Psychology of Sport and Exercise, 13*(3), 263–270. https://doi.org/10.1016/j.psychsport.2011.12.003

Nieto, A., Hernández-Torres, A., Pérez-Flores, J., & Montón, F. (2018). Depressive symptoms in Friedreich ataxia. *International Journal of Clinical and Health Psychology*, *18*(1), 18–26. https://doi.org/10.1016/j.ijchp.2017.11.004

Pande, N., & Tewari, S. (2011). Understanding coping with distress due to physical disability. *Psychology and Developing Societies*, *23*(2), 177–209. https://doi.org/10.1177/097133361102300203

Peacock, E.J., & Wong, P.T.P. (1990). The cognitive appraisal of stress measure (SAM): A multidimensional approach to cognitive appraisal. *Stress Medicine, 6*, 227-236.

Republic of Turkey Prime Ministry Administration for disabled people. 2002. *How Society Perceives Persons with Disabilities?* Retrieved July 19, 2023, from https://www.aile.gov.tr/eyhgm/yayin-kaynak/

Pérez-Flores, J., Hernández-Torres, A., Montón, F., & Nieto, A. (2020). Health-related quality of life and depressive symptoms in Friedreich ataxia. *Quality of Life Research*, *29*(2), 413–420. https://doi.org/10.1007/s11136-019-02311-9

Pérez-Garín, D., Recio, P., Magallares, A., Molero, F., & García-Ael, C. (2018). Perceived discrimination and emotional reactions in people with different types of disabilities: A qualitative approach. *The Spanish Journal of Psychology*, *21*. e12. https://doi.org/10.1017/sjp.2018.13

Pfeiffer, D. (2001). The conceptualization of disability. In S.N. Barnartt & B.M. Altman (Eds.), *Exploring Theories and Expanding Methodologies: Where we are and where we need to go (Research in social science and disability, Volume 2)*, (pp. 29-52). Bingley: Emerald Group Publishing.

Richardson, T. E., Kelly, H., N., Yu, A. E., & Simpkins, J. W. (2013). Therapeutic strategies in Friedreich's Ataxia. *Brain Research*, *1514*, 91-97.

Saygın, G., Rıdvanoğlu, S., Aktaş, C., Er, E., Coşkun, R. N., & Çerezci, E. T. (2010). *Toplum özürlülüğü nasıl anlıyor*. Ankara: TC Başbakanlık Özürlüler Dairesi Başkanlığı.

Schulz, R., & Decker, S. (1985). Long-term adjustment to physical disability: the role of social support, perceived control, and self-blame. *Journal of Personality and Social Psychology, 48*, 1162-1172.

Silva, C. B., Yasuda, C. L., Dabre'u A., Cendes, F., Lopes-Cendes, I., & Franca Jr., M., C. (2013). Neuroanatomical correlates of depression in Friedreich's Ataxia: A voxel-based morphometry study. *Cerebellum*, *12*, 429-436.

Şahin, F., & Güldenoğlu, B. (2013). Engelliler konusunda verilen eğitim programının engellilere yönelik tutumlar üzerindeki etkisi. *Amasya Üniversitesi Eğitim Fakültesi Dergisi, 2*(1), 214-239

Turkish State Institute of Statistics. (2002). *Turkey Disability Survey*. Retrieved July 19, 2023 from https://www.academia.edu/10452631/T%C3%BCrkiye_%C3%96z%C3%BCrl%C3%BCler_Ara%C5%9Ft%C4%B1rmas%C4%B1

Turkish State Institute of Statistics. (2010). *Özürlülerin sorun ve beklentileri araştırması 2010.* Retrieved July 19, 2023, from https://data.tuik.gov.tr/Bulten/Index?p=Ozurlulerin-Sorun-ve-Beklentileri- Arastirmasi-2010-6370

Turkish State Institute of Statistics. (2013). *Nüfus ve konut araştırması 2011*. Retrieved July 19, 2023, from https://data.tuik.gov.tr/Bulten/Index?p=Nufus-ve-Konut-Arastirmasi-2011-15843.

Twardowski, A. (2020). Controversies around the social model of disability. *Kultura-Społeczeństwo-Edukacja*, *16*(2), 7-21. https://doi.org/10.14746/kse.2019.16.1

Wang, Z., Xu, X., Han, Q., Chen, Y., Jiang, J., & Ni, G. X. (2021). Factors associated with public attitudes towards persons with disabilities: a systematic review. *BMC Public Health*, *21*(1), 1-15. https://doi.org/10.1186/s12889-021-11139-3

Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personality and Social Psychology, 54,* 1063-1070.

World Health Organization (WHO). (1980). *International classification of impairments, disabilities, and handicaps.* Retrieved July 19, 2023, from https://apps.who.int/iris/bitstream/handle/10665/41003/9241541261_eng.pdf

Yang, Y. (2006). How does functional disability affect depressive symptoms in late life? The role of perceived social support and psychological resources. *Journal of Health and Social Behavior*, *47*, 355-372.

Zimet, G.D., Dahlem, N.W., Zimet, S.G., & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *52*, 30-41.

Table 1. *The multiple regression table for all predictors and negative Affect*

	b %95 CI	SE B	β	*p*
Constant	1.78 (-3.29, 6.58)	2.41		.30
Yürüme üzerine etkisi	.43 (-.03, .98)	.25	.62	.07
Konuşma üzerine etkisi	-.23 (-.63, .28)	.21	-.39	.23
Perceived Social Support	-.35 (-.71, .00)	.18	-.72	.05
Stress Appraisal (controllable by self)	.24 (-.26, .94)	.35	.27	.32
Stress Appraisal (controllable by others)	.14 (-.38, .64)	.27	.20	.54
Stress Appraisal (uncontrollable)	-.52 (-1.38, .22)	.40	-.44	.17
Stress Appraisal (threat)	.53 (-.45, 1.63)	.50	.48	.13
Stress Appraisal (challenge)	-.09 (-.50, .33)	.20	-.16	.53