

Research Article

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**PHYSICALLY DISABLED ADULTS IN TURKEY DURING THE
COVID-19 OUTBREAK: A PHENOMENOLOGICAL RESEARCH ON
THE EXPERIENCES OF PEOPLE WITH SPINAL CORD INJURY**

TÜRKİYE'DE COVID-19 SALGINI SÜRECİNDE BEDENSEL ENGELLİ
YETİŞKİNLER: OMURİLİK FELÇLİ BİREYLERİN DENEYİMLERİ ÜZERİNE
FENOMENOLOJİK BİR ARAŞTIRMA

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ABSTRACT

This study aimed to explore the main problems that individuals with spinal cord injury (SCI) encounter in daily life based on their own experiences during the COVID-19 outbreak in Turkey. For this purpose a field study having a phenomenological research design was performed. In the study, the experiences of 19 adult individuals with SCI and 4 caregivers living in Istanbul are analysed in accordance with the themes selected for the research. The key findings are evaluated with thematic analysis within the framework of the main problematic of "The main problems that individuals with SCI face in daily life during the COVID-19 pandemic". The main research themes selected are about impact of COVID-19 on daily life, access to health, rehabilitation and social services, and participation to social life. Based on the research findings, the most significant problems that the participants encountered during the COVID-19 pandemic are as follows: 1. Stress, fear, and anxiety about infection and transmission of the virus; 2. Worsening situation for proper care and treatment for their secondary health conditions; 3. Economic difficulties caused by unemployment, loss of income and increasing costs, 4. Difficulties because of the interruption of rehabilitation and care services; 5. Difficulties in accessing digital and assistive technologies and lack of skills in using them; 6. Changes in daily routine such as eating and sleeping patterns, leisure activities, communicational and psychological problems; 7. Difficulties in following current information about public health. The COVID-19 pandemic has deepened the problems of people not only from social life perspective but about getting social support too and increased their dependence on caregiver. From our findings we can conclude that there is a great need for new multidisciplinary studies on the social services and social support models that can be applied in the pandemic for people with SCI and their families taking into consideration that the epidemic is continuing and can occur again.

Keywords: Impact of COVID-19, Spinal Cord Injury (SCI), Disabled people, Social Services, Difficulties of disabled individuals

ÖZET

Bu çalışmada, Türkiye'de SCI'li bireylerin COVID-19 salgını sürecinde günlük yaşamda karşılaştıkları temel sorunları kendi deneyimlerinden yola çıkarak keşfetmek amaçlanmıştır. Bu amaçla fenomenolojik araştırma deseninde bir alan araştırması yapılmıştır. Bu makalede, araştırma kapsamında belirlenen temalar doğrultusunda İstanbul ilinde yaşayan 19 SCI'li yetişkin birey ve bakım veren 4 kişinin deneyimleri aktarılmıştır. Temel bulgular, "SCI'li bireylerin COVID-19 salgını sürecinde günlük yaşamda karşılaştıkları temel sorunlar" ana sorunsalı çerçevesinde tema analizi ile değerlendirilmiştir. Araştırmanın ana temaları COVID-19 salgınının günlük yaşama etkisi; sağlık, rehabilitasyon ve sosyal hizmetlere erişim

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ve toplumsal yaşama katılımları olarak belirlenmiştir. Araştırmadan elde edilen bulgular değerlendirildiğinde; COVID-19 salgını döneminde katılımcıların yaşadığı en önemli sorunlar; 1. Virüsün enfeksiyonu ve bulaşması ile ilgili stres, korku ve endişe; 2. İkincil sağlık sorunlarına yönelik kaliteli bakım ve tedaviden yoksun kalma; 3. İşsizlik, gelir kaybı ve artan maliyet nedeniyle yaşadıkları ekonomik zorluklar; 4. Rehabilitasyon ve bakım hizmetlerinin kesintiye uğramasından kaynaklanan zorluklar; 5. Dijital ve yardımcı teknolojiye erişimde zorluklar ve bunları kullanmada beceri eksikliği; 6. Yeme, uyku, boş zaman etkinlikleri gibi günlük rutinde değişiklikler, iletişim ve psikolojik sorunlar; 7. Güncel halk sağlığı bilgilendirmelerini takip etmede güçlükler olarak tespit edilmiştir. Genel olarak COVID-19 salgını SCI'li bireylerin toplum yaşamında ve sosyal destek alanında yaşadıkları sorunları da derinleştirmiş ve başkasına bağımlılıklarını artırmıştır. Salgının devam edeceği ve tekrar yaşanma ihtimali göz önünde bulundurularak, SCI'li birey ve ailelerine yönelik salgında uygulanabilecek sosyal hizmetler ve sosyal destek modelleri üzerine multidisipliner çalışmalar yapılmasına ihtiyaç olduğu görülmektedir.

Anahtar kelimeler: COVID-19'un etkisi, Omurilik Felci, Engelliler, Sosyal hizmetler, Engelli bireylerin yaşadıkları zorluklar

INTRODUCTION

New type of corona virus (2019-nCoV) was detected in Wuhan city of China in December 2019, and was identified on January 13, 2020. It caused severe respiratory infections that led to deaths and spreaded to every country of the world rapidly as never seen before. The COVID-19 virus outbreak, which was declared as COVID-19 pandemic (epidemic) by the World Health Organization (WHO) in March 2020, continues to threaten humanity in physiological, psychological, social, economic and many more aspects.

During this period, the pandemic does not effect all groups of population equally and may have impacts that are more dramatic on disabled individuals, who are one of the most vulnerable groups in the society. Therefore, it is important to specify the needs of them based on their life experiences. Indeed, people with disabilities and their families face social inequalities, discrimination and stigmatization even under normal circumstances and they experience serious difficulties in accessing some services as well. According to the World Report on Disability produced jointly by the WHO and the World Bank in 2011, in all countries people with disabilities experience inequality in access to healthcare services, work and employment, education, public buildings, in participation in political life and even in access to information. It can be said that the areas in which discrimination is seen at its highest are accommodation, participation in social and cultural life, access to public spaces and services (WHO, 2011). Research on past pandemics show that people with disabilities have difficulties in accessing critical medical supplies as resources reduce. People with disabilities who are in need of support from the caregiver may be at high risk due to the interruption of nursing services as well as the increase of the possibility of the transmission of the virus from the caregivers (Campbell, Gilyard, Sinclair, Sternberg and Kailes, 2009). As it is already known, lack of even one or two day interruptions in essential services can have serious consequences (for example, infections occur when bandages are not changed, or chronic health conditions worsen when medical home care is interrupted) for disabled people who need daily support of service providers such as institutional or home care. Furthermore, loss of autonomy, limited financial resources, reduced mobility, and social isolation can increase their vulnerability even more. For example, some of the disabled individuals who work may experience higher levels of social isolation compared to their non-disabled colleagues (O'Sullivan and Bourgin,

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2010). In this case, it can be predicted that they are more likely to experience intense feelings of loneliness in response to physical distance measures.

In many parts of the world, after the COVID-19 virus outbreak, people with disabilities in need of information, counseling and rehabilitation found themselves isolated and deprived of social support due to reasons such as interruption, limitation or inaccessibility of services of social service institutions. In this period, the level of anxiety and stress with the financial obligations of the isolation period, insufficient income and lack of social support of the people with disabilities increased and they faced the risk of deterioration in their not only physical but also mental and social health (National Disability Institute, 2020). In a research conducted in social media (twitter), it is revealed that individuals with disabilities need access to accurate information about the impact of the pandemic on their specific disability conditions, the risk of transmission of the virus, and the risks of disease and death during the COVID-19 outbreak. In the same study, the importance of social support for meeting the basic needs of people with disabilities such as grocery shopping and care is stated (Thelwall and Jonathan, 2020).

When the studies on the impacts of the COVID-19 pandemic on people with disabilities are examined, it has been found out that they are limited as they do not focus on the complete needs of specifically disabled people. The studies analysed emphasize more physical health needs and expectations while neglecting the psychosocial problems, which are highly important. In the few studies conducted during the COVID-19 outbreak about people with spinal cord injury (SCI), it is stated that they make a unique group because of the difficulties in accessing healthcare services, diagnosing and treatment. Adult individuals with SCI are in the physical disability group and have many complex health problems together. These people become disabled as a result of the loss of function of the spinal cord due to a pressure caused by disease or trauma, and the loss of communication between the brain and organs. It is defined as a medically complex and life flow disruptive condition (WHO, 2013a). Clinicians and researchers point out the screening and triage difficulties of people with SCI during the COVID 19 outbreak (Turk and McDermott, 2020). They emphasize that in addition to the high risk of transmission of the virus for individuals in this disability group, there are numerous physiological variables that might delay the diagnosis of COVID-19 and mask acute respiratory tract illness (Korupolu et al, 2020). Furthermore, people with SCI may have to deal with situations such as fear, worries, fulfillment of care and security needs in times of crisis, access to technology, difficulties in domestic communication, isolation, lack of health literacy and need of counseling about individual precautions (O'Connell, Eriks-Hoogland and Middleton, 2020; Stillman et al., 2020).

Considering health care, rehabilitation difficulties and incomplete environmental regulations that prevent social participation, it must be taken into account that compared to other disability groups, the COVID-19 pandemic may cause individuals with SCI who are dependent on a wheelchair to experience many daily problems such as restriction of their living spaces, inaccessibility to needed social support, hygiene and care. Likewise, studies have shown that among people with SCI, the rate of those who continue their daily life without any help is only around 10% -12%; 54% of them get help for their daily chores, and the rate of those who pay fee to receive help is almost half (Çelik, 2006). Besides, it is observed that individuals have many physical health problems after SCI, as well as high rates of depression and anxiety disorders (Williams and Murray, 2015).

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People with disability with SCI have complex physical, psychological and social conditions that need to be handled with precision. Therefore, spotting the impact of the COVID-19 pandemic period on their conditions and their changing needs are important in terms of developing services to increase the quality of life. It is known that one of the important factors for all disability groups that increase the quality of life after congenital or acquired disability is to participate in activities in the society and stay connected with other people (Barclay et al., 2016). In this context, in a study in which Barclay, McDonald and Lentin (2015) critically examined existing studies on social and social participation after SCI, and they found that the effects of particularly, transportation, personal care assistance, social support, attitudes of health professionals and having special equipment on social well-being should be researched with more in-depth research methods. This finding makes even more sense during the pandemic.

In this study, it is aimed to reveal the problems experienced by people with SCI during the COVID-19 pandemic and their strategies to cope with these problems with a qualitative research based on their own experiences and narratives, and present a framework for finding solutions to the problems experienced by physically disabled people during the pandemic period. The study is important because there has not been any study in this field in Turkey yet, and it shows the problems of the individuals in the pandemic while suggesting solutions with their own expressions. In this context, it is expected that it will contribute to the researches to be conducted, social policies to be implied for the physically disabled in general, and people with SCI in particular.

METHOD

This study is designed as a qualitative research that tries to reveal how adult peoples with SCI experience the COVID-19 pandemic, and how and in which areas they encounter problems based on their own experiences and narratives. Qualitative research aims to understand how the world is seen, understood and experienced from the perspective of individuals with SCI. It is assumed that there are cases and phenomenons and complex relationships that have a social content, therefore it is accepted that the variables created as a part of the research are not separate, disconnected and independent; rather than just generalizing, It is important to study a phenomenon in detail in sufficient measure, and to understand previously undiscovered relationships within a limited framework (Yıldırım and Şimşek, 2011: 54, 57). In the study, the qualitative research method was chosen because it aims to discover the effect of the COVID-19 epidemic on adults with SCI based on their own conditions, experiences and perceptions. It gives the opportunity to examine the research problem with an interpretive approach based on an interdisciplinary holistic perspective and it is a method that has the flexibility to use different data collection tools together (Yıldırım and Şimşek, 2011:46).

The research design of the study was determined as the phenomenological qualitative research design. The phenomenology design focuses on phenomenons that we are aware of but do not have an in-depth and detailed understanding (Yıldırım and Şimşek, 2011: 72). The aim of this research is to discuss life experiences that are on the center of phenomenological research. The purpose is to explain the basic meanings or essences of the phenomenons experienced

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in the concrete lives of people. In this context, by using the phenomenological approach in data collection and analysis, a systematic process was followed in order to interpret the experiences of people reflected in a certain phenomenon and explained by them or to raise awareness. In this way, it was aimed to reveal the essence and structures of the experiences caused by the COVID-19 epidemic on different themes (Cresswell, 2012; Woodgate, Ateah and Secco, 2008).

Research Population and Sample

In qualitative data, it is difficult to include a large number of individuals in the scope of research, as the collected data must be detailed and in-depth (Yıldırım and Şimşek, 2011:45). The population of the research was created by snowball sampling from people with SCI between the ages of 18-65 living in Istanbul, and individuals who could share their experiences. In the study, individuals with SCI under the age of 18, those diagnosed with brain damage or mental disability, and those who could not express themselves verbally were excluded. The study inclusion criteria consisted people from both sexes who were paralyzed because of SCI, people from various age groups, people from different educational and employment backgrounds, and people who had experience for varying periods of time from different types of injuries. Moreover, the experiences of caregivers were included in the study as they would be guiding within the framework of the themes. Data collection continued until obtaining data suitable for the purpose of the research. For this article, a total of 23 interviews made with 19 people with SCI and 4 caregivers were analyzed. Table 1 shows the SCI type, disability duration, and socio-demographic characteristics of the participants. Participants were shown in the analysis by coding instead of using their real names. Participants consisted of volunteers who wanted to participate in the study and their consent was received.

Data Collection Tools and Analyse

In qualitative research, unlike quantitative research, measurement, verification and generalization to the population are not required in the data analysis. The key points are to understand the context, interpret the content and analytical generalization. Mixed data collection tools were used in this study. The general demographic and socio-economic data of the participants in the study were obtained with a questionnaire prepared by the researchers. In the research, in-depth interview technique was used to reveal the experiences of people during the COVID-19 outbreak with a phenomenological approach.

The interview form, main themes and sub-themes of the research were developed by the researchers in order to conduct the interviews systematically and in accordance with the aim of the research. As a part of the research, the Spinal Cord Paralytics Association of Turkey (TOFD), to which adults with SCI are associated with, was contacted with, and after the pilot interviews held on 01.08.2020-15.08.2020, the interview form and codes were put into final form. In this context, the

FINDINGS ABOUT DAILY LIFE PROBLEMS

Peoples with disabilities interviewed listed the problems they experienced before the pandemic as requiring care, frequent severe health problems and economic difficulties. As it is known, people with SCI are at high risk of experiencing

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interview form was used for the sub-themes created within the framework of three main themes. The interviews continued until sufficient data were obtained (15.01.2021) for explaining the cases discussed in the study.

Apart from the themes determined during the research process, the experiences of the caregivers in the pandemic and their relations with the participants were evaluated as a sub-theme that was found to be meaningful in order to explain the phenomenon more deeply and realistically. The interviews lasted between 45-60 minutes. Since the interviews could not be made face-to-face during the pandemic after receiving the consent of the participants, they were made via Zoom, WhatsApp and phone, audios and videos of the calls were recorded. The interviews were coded by keeping the identity of the individuals hidden, taking into account the privacy of the individuals in direct transferring of the statements and placed in the determined themes.

Descriptive data achieved from interviews form the basis of the thematic analysis. Since this study is an exploratory study, a causal relationship was not sought in the analyses. However, the existing situation was interpreted with descriptive analysis and content analysis. Ethics committee approval for this study was received by Istinye University Social and Human Sciences Ethics Committee.

FINDINGS

Sociodemographic Characteristics of Participants

Sociodemographic characteristics of participants with SCI and information about SCI types are given in Table 1. When Table 1. is scanned, in proportion to their gender, it is seen that 42.1% of the participants with SCI are women (8 people) and 57.9% (11 people) of them are men. Average age of participants is approximately 45, and the youngest of them is 29 and the oldest one is 59 years old. The monthly household income of the person with the lowest income among the participants is around 1,500 TL, while the monthly income of the participant with the highest monthly income is around 10,000 TL. Although the income levels of the participants differ, regular disability pension, home care benefit and irregular social support payments are added to the household income and still the number of those who have enough income to fulfill their needs is very low. It is observed that most of the people with SCI receive social support and cash assistance as this is very important for the participants who cannot work and do not have different extra revenue to meet their essential needs. It is crucial for people with SCI to have social security for some medical devices, drugs and in the treatment of secondary health conditions. A significant number of the participants are either unemployed or retired due to disability. The people with SCI who live alone, have support from the family get social aid payments (i.e. homecare payment) and benefit from the General Health Insurance.

Most of the people with SCI were injured in their early 20's as a result of a traffic accident (8 people) and falling down from height (7 people). The period passed after the injury is at least 10 years. They usually live with their families and receive support for care from family members (15 people). A significant number of the participants are single (13 people). Some participants were married at the time of injury and divorced a few years after it (3 people).

Information about caregivers is given in Table 2. Three of the four caregivers interviewed in the research are female and one of them is male.

¹The Social Security Institution (SGK) is a state institution established by the transfer of the Social Security Institution, Bag-Kur and Emekli Sandigi with the Social Security Institution Law No. 5502, adopted on May 16, 2006. General health insurance refers to the insurance that primarily protects the health of individuals and provides financing for the expenses incurred in case of encountering health risks. GSS.0 (formerly Yeşilkart): Covers the lowest income group of the General Health Insurance. http://www.sgk.gov.tr/wps/portal/sgk/tr/calisan/gss_tescil_sureci (Accessed 25.04.2021)

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Table 1. Socio-demographic Characteristics and Type of Injury of the Participants

Participants	Gender	Age	Marital Status	Living Place	Education Status	Profession	Social Security	Household Income /TL	Chronic Illnesses	Cause of Injury/ Time since Injury	Injury Type
P1	Female	30	Single	At home with her family	University	Civil Servant	SGK	8.500	Bladder problems	Traffic accident/10 years	Paraplegia
P2	Female	59	Divorced	At home with her partner	University	Disable Pensioner	SGK	3.000	Bladder problems	Traffic accident/26 years	Paraplegia
P3	Male	39	Single	At home with his mother	University	Retired Worker	SGK	2.850	Psychiatric illness Bladder problems	Shallow-water diving /21 years	Tetraplegia
P4	Male	56	Single	At home with his mother	University	Retired Worker	SGK	7.500	Kidney disease diabetes, blood pressure bladder problems	Shallow-water diving /37 years	Tetraplegia
P5	Female	54	Single	Nurcing Home Istanbul	Primary School	Unemployed	SGK	1.500	Cancer Bladder problems	Falls from a height/52 years	Tetraplegia
P6	Male	49	Divorced	Nursing Home Istanbul	High School	Disable Pensioner	SGK	2000	Kidney disease Bladder problems	Falls from a height/19 years	Tetraplegia
P7	Female	37	Single	At home with her sister's family	High School	Disable Pensioner	SGK	4.200	Depression Bladder disease	Traffic accident/14 years	Paraplegia
P8	Male	46	Single	At home-Lives alone	Primary School	Association Employee	SGK	3.500	Hypertension	Falls from a height /38 years	Paraplegia
P9	Male	57	Single	At home-Lives alone	University	Civil Engineer/Retired	SGK	6.000	Hypertension, diabetes	Traffic accident/29 years	Paraplegia
P10	Male	42	Married	At home with his family	High School	Retired worker/ Self-Employed	SGK	3.000	None	Traffic accident/20 years	Paraplegia
P11	Male	55	Married	At home with his family	Primary School	Retired Worker	SGK	4.500	Hernia and lungs surgery, bladder disease	Shallow-water diving /12 years	Tetraplegia
P12	Female	57	Divorced	At home with her children	Primary School	Unemployed	GSS	2.500	Chronic leg pain	Falls from a height /13 years	Paraplegia

Table 1. Continued

P13	Male	35	Single	At home with his mother	University	Construction Engineer/ Civil servant	SGK	10.000	Bladder disease, Chronic pain	Traffic accident/17 years	paraplegia
P14	Female	42	Single	At home with her family	Attends University	Unemployed	SGK	1.500	Pressure sore, muscle contraction, bladder disease	Traffic accident/22 years	Paraplegia
P15	Male	29	Single	At home with his family	Attends University	Civil Cervant at Ministry of Education	SGK	7.500	None	Work accident/12 years	Paraplegia
P16	Male	46	Single	At home with his family	High School	Unemployed	GSS	5.000	None	Falls from a height /24 years	Paraplegia
P17	Female	32	Single	At home with his brother	High School	Disable pensioner	SGK	3000	Pressure sore, bladder problems	Traffic accident/21years	Tetrapleji
P18	Female	53	Divorced	At home with her children	Primary School	Unemployed	GSS (General Health Insurance)	1500	Bladder, bowel and constipation problems/Chronic pain	Falls from a height /22 years	Paraplegia
P19	Male	46	Single	At home with his family	Literate (could not graduate)	Retired Worker	SGK	6500	Stomach ulcers, bladder problems, muscle contractions	Falls from a height /36 years	Paraplegia

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Table 2. Socio-demographic characteristics of the caregivers

Participants	Gender	Age	Marital Status	Relationship	Education Statu	Profession	Social Security
C1	Female	57	Widow	Her Son	Illiterate	Unemployed	GSS
C2	Male	45	Single	Her sister	High School	Unemployed	SGK
C3	Female	49	Married	Her husband	Primary School	Part time worker	SGK
C4	Female	39	Married	Her sister	Primary School	Part time worker	SGK

secondary medical complications and health problems throughout their lives including pain, spasticity, urinary tract infections, respiratory complications, pressure ulcers, cognitive disorders and depression. When Table 1 is analysed, it shows that almost all participants have secondary health conditions and have to cope with pain.

Rehabilitation in secondary health conditions and in the adaptation process is the main source of treatment for people with spinal cord injuries because there is not a medical treatment for SCI. Some participants see this as the biggest problem after dependence on a caregiver: *"The biggest problem of disabled people with SCI is being in need of a caregiver. . Another big problem is that there is no treatment for this disease."* (P16, male, 46 years old)

Most of the participants of the study stated that they could not receive regular and adequate rehabilitation services after the injury. *"I did not receive any rehabilitation service. I had a very hard period after the accident. It was not like now. They put my whole body in a plaster cast, then deep and heavy pressure wounds happened and their treatments... Time passed like this for around a year and a half."* (P4, male, 56) Another participant stated that as late as 20 years, he could actively socialize and participate in activities through a non-governmental organization *"They did not give any feedback to my family When I left the hospital and afterwards when I went back home, I was constantly lying face down. There is no treatment, no physical therapy, I lived like a plant."* (P19, male, 46) People with SCI need rehabilitation services and counseling not only at the beginning of the injury and during the medical treatment process, but throughout their lives (Keleher et al., 2003:66). Moreover, lack of mobility in daily life and not making arrangements in the house and social environment considering the disability situation cause serious accidents (P14, female, 42).

Another problem that the participants have is about psychosocial support and care of good quality. SCI can make the person dependent on caregivers and cause many complex problems both attached to the disability itself and from the social environment. A significant number of participants lost the functioning and control of their bladder and / or bowels. A participant (P6, male, 49) who told the care process after the injury summarized the difficulties of this period and the need for psychosocial support with the sentence, *"We did not know how to live, we had hard times and we could not get support."*

Economic difficulties are another important problem that people with SCI emphasize the most. In the research, it is found out that economic difficulties are one of the major problem that prevent people with SCI who have mobility and have the power to provide their own needs from establishing an independent life. On the other hand, economic difficulties cause

²Rehabilitation can be defined as the process of teaching people to live with their disability in their environment (Keleher et al., 2003:66).

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those who are completely dependent on a caregiver to have difficulties in address their essential needs such as food, clothing, shelter, health and social care. Some people with SCI criticize the insufficient payments made by the state and social service practices for the disabled. *"The state gives money to the (private) rehabilitation centers for each disabled person in vain. On the other hand, they cut the salary of the people with disability who is wandering on the street because his brother has a house, or his father already has a salary. And now many people with disabilities I know is starving."* (P16, male, 46)

The most uttered problem by the caregivers about the care process is having difficulty in physically demanding things like giving a bath, dressing, toilet, etc., and the difficulties in providing the medical supply and medication needs of the people with SCI they care for. Some caregivers reported communication problems with the person with SCI they care for (C1, female, 57 years old; C3, female, 49 years old). During the interviews, it was observed that gender roles and some cultural norms were effective in these communication problems. For example, C3's will to work was not accepted by her husband, which caused some serious discussions. C1 stated that she was constantly insulted by her son and thinking that her son could be more active and helpful in the care process, but felt that he punished her because he is not changing his behavior. In the study, the psychosocial support needs of all caregivers and especially people with SCI who do not have family support were clearly stated.

Finally, we can say that the main issue that all participants and caregivers emphasize is accessibility. Difficulties in transportation, access to services and participation in community life stand out as a fundamental problem both before the pandemic and during the pandemic period. *"I am not comfortable in the streets; still we are in a compassionate country thank God. The sidewalks on the streets and the roads are bad, not convenient for people with disability, I am suffering much about it, but our people are good, we overcome these problems thanks to them."* (P16, male, 46)

Impact of COVID-19 on Daily Life

During the COVID-19 pandemic period, we can list the most important problems experienced by the participants as following: 1. Stress, fear and anxiety about infection and transmission of the virus, 2. Increasing health problems and related medical and social care challenges since they avoid crowded places such as hospitals and public transportation, 3. Economic difficulties, 4. Difficulties due to interruption of rehabilitation and care services, regression of physical movements, muscle losses, 5. Changes in daily routine such as food, sleep, leisure activities and psychological problems, 6. Difficulties in following up with current affairs, absence and skill deficit in the use of digital and assistive technology, 7. Communication and relationship problems with the family members.

In the interviews with the participants, we can say that the most frequently repeated problem is the secondary health conditions of people with SCI, virus transmission risk due to their chronic diseases, and the stress, fear and anxiety caused by this. P1 (female, 30), who is in active working life, expressed this concern: "Being in a wheelchair all the time is a great risk. Since we move the chair with our hands, we are always in danger of being in contact with the virus." P14 (female, 42), who has serious health problems, expressed the grueling times she had before and her fear of experiencing it all again as following: "I was previously quarantined at the hospital due to respiratory problems... If I get hospitalized and get infected there, it won't be easy for me to cope and my constitution cannot take it anyway, so I am very careful and I don't meet with anyone." It is observed that people with SCI are generally diligent in preventing the virus from being transmitted. The measures they take are remarkable. During this period, it has been seen that particularly those who live alone and has old caregivers or those who live with old parents have great difficulty. Those ones in this group stated that they go out very rarely and do not meet with

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anybody. A participant who lives alone (P9, male, 57) stated that he could not leave the house for 3 months and the doorman did his shopping. A participant who used to have an active social life before Covid 19 pandemic and who lives with his old mother, both of them having health problems had concerns about not being able to protect himself and his old mother. (P4, male, 56).

Effects of the pandemic on daily routine and mental state was generally spotted as the stress due to disturbance of regular sleep and diet routines, and not being able to leave the house. People with SCI, who had some economic difficulties at the same time, felt more dependent on their caregivers during this period. For example, P7 (female, 37) had to move in with her family because of economic reasons, expressed her despair as all her attempts to work were inconclusive, and stated that she feels depressed from time to time. P8 (male, 46), who is an active member of a non-governmental organization, states his situation as following: "Together with people, we were more active and social, and then we had to withdraw. It hurts a little when you are always dependent on someone..." A participant with tetraplegia type SCI stated that while living an active life before COVID-19, the measures taken as "social distance" completely affected his life and evoked some psychological effects: "My sleeping pattern was never good, it got even worse... You sleep during the day; you do not sleep at night." (P4, male, 56) A participant living with his family and being cared for by his wife stated some of the psychological effects of having to stay at home as following: "I became totally depressed. I have an 11-year-old son with epilepsy. When there is a curfew, I am worried that I will not be able to help my son in an emergency when my wife goes out of the house to provide the needs." (P10, male, 42)

Diet and weight control issue for people with SCI has also been reported as an important problem for both person with disability and caregivers. Among the people with SCI interviewed, especially those who actively do sports expressed that they gained weight during this period and the discomfort caused by this situation. On the other hand, caregivers stated that they had difficulties in controlling and managing the weight of the person with disability they care for.

In general, the participants reported that especially in the first period of the pandemic masks and disinfectants were not delivered to them, and that they could only supply them later on. Another problem is about the measures not taken in the workplace.

Access to Health, Rehabilitation and Social Services

Health, rehabilitation and access to social services and related problems within the scope of daily life problems of individuals with SCI can be listed as following: 1. Not being able to get the medical stuff they use regularly, 2. The lack of separate departments in hospitals where the treatment and care of the people with disability can be provided, 3. Suspension or interruption of physical therapy and rehabilitation services, 4. Postponement or cancellation of appointments, disruptions in health checks, 5. Lack of care support to get the right information in emergency situations, 6. Insufficient social and economic support.

While there were participants who see these problems directly related to the economic, social and psychological effects caused by the pandemic, there are also those who attributed these problems to the health services implemented before and the planning deficiencies during the emergency period for the people with disability in the country.

From the data obtained it is revealed that the impact of the pandemic on working and economic life directly affects the access to quality health services and required medical supplies. On the other hand economic problems are identified as one of the problems faced by the participants constantly and they are deepened by the COVID-19 period. Some business (such as peddling, self-employment) that some individuals with SCI undertook with bank loans and with the support of their relatives

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were interrupted and therefore their income has diminished. Some entrepreneurs could not get the bank loans they needed (P7, female, 37).

Moreover price increase of protective-preventive equipment and medical supplies, being directed to private clinics to receive health services etc. situations are other factors that increase the economic difficulties of individuals with SCI. P1 (female, 30), who is in active working life, stated the problems experienced by her friends with disability around her: "I have friends who left their jobs because of the pandemic. They had a financially hard time. They had many problems ranging from undernourishment to not be able to taking medication. When they could not use the medical supplies they needed to use continuously, they faced a dangerous process leading to intensive care."

In addition to access to qualified services for economic and health problems, some individuals with SCI, who were closed at home for a long time and could not access rehabilitation services, stated that they experienced problems such as muscle weakness, calcification and increased pain. Moreover, the inability to access the required services of individuals with SCI and their relatives who need psychological support during this period increases the risk of depression. C2 (male, 45) describes the problems they experience in this area: "My sister used to go to a psychiatrist and a psychologist since my father passed away these are interrupted I can't go to the hospitals. We can't go out. She gets in a bad mood. She has urinary infections but we can't go to the hospital. Believe or not, staying at home made people worse than the fear of death from the coronavirus."

Finally, it is seen that some of the participants with SCI and their caregivers have insecurity about COVID-19 vaccines and treatments. "... I also do not trust the treatment methods. Although our country thinks that it is good in this regard, I think that the treatments will cause extra health problems for those who have different conditions like me." (P14, female, 42)

Participation in Social Life

Saying that they had difficulty in leaving the house for various reasons before the COVID-19 pandemic, the participants stated that they were even more bound to home during this period. Emphasizing that the pandemic can also be an opportunity for other people to empathize with people with disabilities, some participants stated in similar ways that the meaning of social participation for people with disability means accessibility in the physical environment, time planning and social support opportunities. For example P1 (female, 30) described the situation she is in by saying: *"We have always had challenges. I cannot go out whenever I want. Going out means a long planning process for me like it does for you now."*

For many people with SCI and their families interviewed in the research, opportunities to participate in society and to lead an active life were possible only after membership in non-governmental organizations. A participant (P19, male, 46) who was disabled in 1984 stated this: *"After getting to know the association in 2000, I started to get involved in society."* However, these opportunities have been greatly reduced in consequence of the suspension of the activities of the association and the closure of rehabilitation centers or limited activities. One of the participants, P12 (female, 57) describes this situation as follows: *"I've been member of the association for seven years now... Being a member of the association changed our quality of life a lot..."*

The participants also repeatedly mentioned the risks of using public transportation during the COVID-19 period. P1 (female, 30) listed public transport risks: "When we get on public transportation with a wheelchair, our height stays below the heights of people and in this position we sense their breaths. Therefore, I don't want to use public transportation." Most of the participants use public transport since they do not have their own cars. They state that the most convenient public

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transportation vehicle they can use is metro, and they have difficulty in using buses and metrobuses. They listed the main obstacles prevent them from using public transportation are as elevators that are out of service, unsuitable sidewalks for wheelchairs, drivers not doing their duties properly, and social insensitivity. P12 (female, 57) tells the challenges she has in transportation as follows: *"...We cannot use overpasses. Elevators are always out of service, we can't get on the bus or metrobus. I was having a lot of trouble about transportation. We can't use public transportation. While waiting for the elevator, no one cares about you; young people are getting in the elevator. As a society, we show these behaviors."* Even so, most of the participants with SCI feel uncomfortable to spend this period at home and express their longing for their old social life. P14 (female, 42) reflects her longing as, *"I want to go out, go to the seaside, meet with my friends and eat out, and I miss all of these. I was not a person who is completely bound to home."*

Particularly for the people with disability who do not work and live alone, it is observed that the activities of the association and rehabilitation centers have a very important place in their social life. It has been stated that total shut down of associations and rehabilitation centers sometimes and their interruption in some activities negatively affected the people with disability and their families both mentally and physically. P18 (female, 53) *"We go to a state rehabilitation institution. Instructors were coming; I was participating in activities such as handicraft... We are worried about its closure since it is very good place for us we have friends with disability there, it makes us feel good to have a talk with our friends."*

DISCUSSION

As it is known, the main causes of SCI are traffic accidents, fallings and violence (including suicide attempts). A significant portion of traumatic SCI is due to work or sports-related injuries. SCI carries a high risk of developing secondary health conditions that can be debilitating and even life threatening. People with SCI also have serious health conditions such as deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure sores, chronic pain, and respiratory complications (WHO, 2013b; Williams and Murray, 2015).

Most part of the individuals with SCI included in this study have become disabled in their early 20s. This period is an important time for the emotional and psychosocial development of young people. Psychologically these years are characterized by gaining independence from family, graduation from school and early career decisions (The Asian Spinal Cord Network, 2015). One of the key findings of this study is that individuals who get adequate rehabilitation services and social support during this period can cope with problems and adjust to their new situation more easily; otherwise, their adaptation problems can continue for a long time (Matter et al, 2009: 545-546).

Living conditions of all participants have completely changed after acquiring the disability. This level of dependence on others caused many patients to have a difficult adjustment process. When individuals with SCI and their caregivers tell the challenges in this period, it is seen that adaptation problems may continue for various reasons (secondary health conditions and unbearable pain, access barriers in the physical environment, family relationships, gender roles, financial inadequacy, sexuality and spouse roles etc.). In this context, individuals with SCI need rehabilitation and social support not only at the beginning of the injury but throughout their lives (Müller et al., 2012:94). Individuals with SCI can take social support from family, peers and partners or social support professionals (psychologist, social worker, occupational therapist, religious officials). Some studies show that having a good quality of life after SCI is strongly associated with variables such as social and financial resources, transportation, access to the environment, participation in meaningful activities, chances to participate

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effectively in society, rather than biomedical variables (Russel et al., 2015). Therefore, it is important to strengthen the social support³ system of individuals with disabilities and their families.

However, it was found that the pandemic increased the dependence of the participants in the research. Increase in dependence of individuals with SCI both economic and in terms of daily health and social care, and preventing their participation in active social life, is likely to cause significant psychosocial problems that they have to cope with. These problems can last for years based on various reasons (inability to continue their education and work; not being able to get rehabilitation services adequately and at the right time, not being able to afford the treatment costs, lack of social security, break down of family relations, nonparticipation in social life etc.). Problems of individuals with SCI and their families such as loneliness, isolation, and poverty also require multidisciplinary professional response.

Secondary health conditions of research participants with SCI, which can continue for a lifetime, are another problem that should be considered carefully. The most common health problems are disorders in the functioning of the bladder and intestines and the risk of infection caused by them. This problem challenges both individuals with SCI and caregivers extremely during the pandemic period. Incontinence is assumed as the most difficult problem for the caregiver and often makes home care of the person with disability impossible. Therefore, management of bladder and bowel activities is of primary importance. Furthermore, autonomic dysreflexia, which is common in people with SCI and is caused by not completely emptying the bladder, can even cause death in some cases. Another common complication is skin or bed sores. It is necessary to prevent wounds from forming, as it may take several weeks to heal (Keleher et al., 2013: 61). Behavioral management and education programs and physical therapy applications in the rehabilitation process can minimize these problems (Perry, Nicholas and Middleton, 2011; Kruger et al., 2013).

Essentially, rehabilitation is vital for individuals with SCI and is a service they need continuously throughout their lives. The access of individuals with SCI to appropriate auxiliary devices and tools that allow them to perform daily activities that they cannot undertake otherwise, and the arrangements to be made in their environment (such as the arrangements in the toilet and bathroom) are also related to rehabilitation, and reduce functional limitations and dependency. Thus, this process requires a biopsychosocial approach rather than a medical approach (WHO, 2011: 96). Individuals with SCI can establish many meaningful connections in social life by participating in sports groups, leisure activities, visiting local stores, working or vocational training (Barclay et al., 2016: 19). These activities are also functional in increasing their ability to cope with problems and reducing feelings of loneliness and isolation. However, all these activities can be possible with transportation suitable for individuals with SCI, sidewalks and ramps suitable for wheelchairs, arranging the buildings according to the needs of the disabled; otherwise, the person with disability will have difficulty or prefer not to leave their home.

During the pandemic period, inability to access rehabilitation services, difficulties in transportation and in accessibility in the physical environment, inactivity, sleep and nutrition problems cause some participants to have physical, social and psychological problems. The fact that the participants stay in bed for a long time, the necessary arrangements are not made in the home and in the surroundings, and the conditions do not allow them to act independently, also regress their previously acquired skills. At the same time, the fear of transmitting the virus in this period, deprivation of social support and financial losses cause caregivers to have difficulties in ensuring the continuity of care. On the other hand, most of the individuals with SCI need specific information about the risk of transmission of the virus and their special conditions. They do not feel safe and they experience extreme stress and worry because of the reasons such as insufficient health policies and information

³Social support is defined as the exchange of resources between individuals, which can be instrumental, emotional or informational, aimed at enhancing the wellbeing of the person with disability. (Müller et al, 2012: 94).

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During the pandemic period, inability to access rehabilitation services, difficulties in transportation and in accessibility in the physical environment, inactivity, sleep and nutrition problems cause some participants to have physical, social and psychological problems. The fact that the participants stay in bed for a long time, the necessary arrangements are not made in the home and in the surroundings, and the conditions do not allow them to act independently, also regress their previously acquired skills. At the same time, the fear of transmitting the virus in this period, deprivation of social support and financial losses cause caregivers to have difficulties in ensuring the continuity of care. On the other hand, most of the individuals with SCI need specific information about the risk of transmission of the virus and their special conditions. They do not feel safe and they experience extreme stress and worry because of the reasons such as insufficient health policies and information supply during the pandemic period, fear of not being able to find a clean hospital that they can apply to in emergency, and not trusting the drugs and vaccines used in treatment. Some participants have tension in family relationships due to this stress and fear.

In this context, another finding of the study, which is the difference in access to desired information, stress and other psychosocial problems between individuals with SCI who receive rehabilitation and care services in a nursing and rehabilitation center and individuals living alone or with their families, become meaningful. Although nursing and rehabilitation centers have reduced the number of personnel due to the pandemic and canceled the activities that educators come from outside, the basic care needs of the people with disabilities, the hygiene and medical supplies needed are provided by the employees, and social environments are created, and so they are helped to overcome this period with minimal loss.

Another one of the findings obtained in the research that needs to be emphasized is the economic problems of individuals with SCI that deepen further during the pandemic. In this period, it is seen that some individuals with SCI are experiencing economic difficulties due to the closure of their stalls or small businesses, being unemployed or having to take unpaid leave. Particularly the ones with small dependent children experience even greater stress. Those who receive home care and disability pensions cannot afford the essential care requirements and medical supplies they need.

Although the difficulties that individuals with SCI experience in accessing services in the community and the lack of social support continue during the pandemic, perhaps one of the most striking findings of the research is the hope that the problems they face will be noticed by the society as the pandemic trap all the society in the house. Individuals with SCI emphasized that they feel the effects of the pandemic that limits social life throughout their lives.

CONCLUSION

COVID-19 pandemic that has been going on for more than one year still continues with all its devastating effects. It is clearly seen that one of the groups that most affected by this period is people with SCI. Individuals with SCI experience fear and stress of virus transmission and additionally they have difficulties in obtaining information from reliable sources. On the one hand, they have serious difficulties in accessing health services and medical supplies, on the other hand, they refrain from going to hospitals, neglect the routine checks they need to do at certain periods, and therefore they can have serious health problems. Muscle loss and calcification occur in individuals with SCI especially because of the interruption of rehabilitation services. Therefore, it is important to identify and deliver specific medical and health issues that individuals with SCI need information about during the pandemic. In this regard, working with the relevant units of local governments and non-governmental organizations will bring results that are more efficient in developing of national public health policies and implementing measures for the disabled during the pandemic.

Furthermore, with the impact of the pandemic, the dependence of people with SCI on caregivers has increased and the



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Furthermore, with the impact of the pandemic, the dependence of people with SCI on caregivers has increased and the social support they get has decreased. Because of this, people with SCI feel the need for psychosocial support services more than ever. It is very crucial to give continuing and active psychosocial support and strengthen the activities with rehabilitation services. There is an urgent need other specific researches that should be carried out for development of new methods and programs that can be used to support people with SCI for the pandemic period.

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REFERENCES

- Barclay, L. McDonald, R. and Lentin, P. (2015). Social and Community Participation Following Spinal Cord Injury: A Critical Review. *International Journal of Rehabilitation Research*, 38 (1), 1-19. doi:10.1097/MRR.0000000000000085
- Barclay, L. McDonald, R. Lentin, P. and Bourke-Taylor, H. (2015). Facilitators and Barriers to Social and Community Participation Following Spinal Cord Injury. *Australian Occupational Therapy Journal*, 63(1), 19-28. doi:10.1111/1440-1630.12241
- Campbell, V. A. Gilyard, J. A., Sinclair, L., Sternberg, T., and Kailes, J. I. (2009). Preparing for and Responding to Pandemic Influenza: Implications for People With Disabilities. *American Journal of Public Health*, 99 (S2), S294-S300. doi:10.2105/ajph.2009.162677
- Creswell, J. W. (2012). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. CA: Sage.
- Çelik, H. D. (2006). Omurilik Felçlilerinde Engellilik Durumunun ve Yaşam Kalitesinin Değerlendirilmesi. Yayınlanmamış Uzmanlık Tezi. Şişli Etfal Eğitim ve Araştırma Hastanesi, İstanbul.
- General Health Insurance (2021). http://www.sgk.gov.tr/wps/portal/sgk/tr/calisan/gss_tescil_sureci (Accessed 25.04.2021)
- Keleher, C. A. Dixon, D. R. Holliman D. and Vodde, R. (2003) Spinal Cord Injury. *Journal of Social Work in Disability & Rehabilitation*, 2 (1), 57-77. doi: 10.1300/J198v02n01_04
- Korupolu, R. Stampas, A. Gibbons, C. Hernandez J. I. Skelton, F. and Verduzco-Gutierrez M. (2020). COVID-19: Screening and Triage Challenges in People with Disability due to Spinal Cord Injury. *Spinal Cord Series Cases*, 6 (35). <https://doi.org/10.1038/s41394-020-0284-7>.
- Kruger, E. A. Pires, M. Ngann, Y. Sterling, M. and Rubayi, S. (2013). Comprehensive Management of Pressure Ulcers in Spinal Cord Injury: Current Concepts and Future Trends. *The Journal of Spinal Cord Medicine*, 36 (6), 572-585. <https://doi.org/10.1179/2045772313Y.0000000093>
- Matter, B. Feinberg, M. Schomer, K. Harniss, M. Brown, P. and Johnson, K. (2009). Information Needs of People with Spinal Cord Injuries. *The Journal of Spinal Cord Medicine*, 32 (5), 545-554. doi:10.1080/10790268.2009.11754556
- Müller, R. Peter, C. Cieza, A. and Geyh, S. (2012). The Role of Social Support and Social Skills in People with Spinal Cord Injury-a Systematic Review of the Literature. *Spinal Cord*, 50 (2), 94-106. <https://doi.org/10.1038/sc.2011.116>
- National Disability Institute (2020). COVID-19 Disability Community Survey Results: Health and Financial Crisis. <https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/04/findings-from-covid-survey.pdf> (Accessed: 23.07.2020)
- O'Connell, C.M. Eriks-Hoogland, I. and Middleton, J.W. (2020). Now, more than ever, Our Community is Needed: Spinal Cord Injury Care During a Global Pandemic. *Spinal Cord Ser Cases* 6, 18. <https://doi.org/10.1038/s41394-020-0270-0>
- O'Sullivan, T. and Bourgoin, M. (2011). Vulnerability in an Influenza Pandemic: Looking beyond medical risk, October 2010. White Paper Funded by Public Health Agency of Canada. https://homelesshub.ca/sites/default/files/Lit%20Review%20-%20Vulnerability%20in%20Pandemic_FINAL.pdf (Accessed: 11.04.2021)
- Perry, K. N. Nicholas, M. K. and Middleton, J. (2011) Multidisciplinary Cognitive Behavioural Pain Management Programmes for People with a Spinal Cord Injury: Design and Implementation. *Disability and Rehabilitation*, 33 (13-14): 1272-128. doi: 10.3109/09638288.2010.524276
- Russell, H. F. Richardson, E. J. Bombardier, C. H. Dixon, T. M. Huston, T. A. Rose, J. and Ullrich, P. M. (2015). Professional Standards of Practice for Psychologists, Social Workers, and Counselors in SCI Rehabilitation. *The Journal of Spinal Cord Medicine*, 39 (2), 127-145. doi:10.1080/10790268.2015.1119966
- Stillman, M.D. Capron, M. Alexander, M. et al. (2020). COVID-19 and Spinal Cord Injury and Disease: Results of an International Survey. *Spinal Cord Ser Cases* 6, 21. <https://doi.org/10.1038/s41394-020-0275-8>

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REFERENCES

- The Asian Spinal Cord Network (2015). Psychosocial Guidelines in Spinal Cord Injury Rehabilitation. <https://ascon.info/wp-content/uploads/2018/05/psychosocial-guidelines15.pdf> (Accessed: 20.04.2021).
- Thelwall, M. and Levitt, J. M. (2020). Retweeting Covid-19 Disability Issues: Risks, Support and Outrage. *El Profesional De La Información*, 29 (2), e290216. <https://doi.org/10.3145/epi.2020.mar.16>
- Turk, M.A. and McDermott S. (2020) The Covid-19 Pandemic and People with Disability. *Disability and Health Journal*, 13 (3), 100944. <https://doi.org/10.1016/j.dhjo.2020.100944>
- Williams, R. and Murray, A. (2015). Prevalence of Depression after Spinal Cord Injury: A Meta-Analysis. *Archives of Physical Medicine and Rehabilitation*, 96 (1), 133-140. doi:10.1016/j.apmr.2014.08.016
- WHO (2011). World Report on Disability. <https://www.who.int/publications/i/item/WHO-NMH-VIP-11.01> (Accessed: 05.02.2021)
- WHO (2013a). International Perspectives on Spinal Cord Injury. http://apps.who.int/iris/bitstream/handle/10665/94190/9789241564663_eng.pdf?sequence=1 (Accessed: 12.02.2021)
- WHO (2013b). Spinal Cord Injury. <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury> (Accessed: 05.02.2021)
- Woodgate R.L. Ateah C. and Secco L. (2008) Living in a World of Our Own: The Experience of Parents Who Have a Child With Autism. *Qualitative Health Research*, 18 (8) : 1075-1083. doi:10.1177/1049732308320112
- Yıldırım, A. and Şimsek, H. (2011). *Sosyal Bilimlerde Nitel Araştırma Yöntemleri*. Ankara: Seçkin Yayınevi.