Original Article / Özgün Araştırma

Awareness of Neurological Diseases: Comparisons of Secondary and Tertiary Neurological Oupatient Centers in Ankara Sample

Nörolojik Hastalıklarda Farkındalık: Ankara İli Örneğinde 2. ve 3. Basamak Nöroloji Polikliniklerinin Karşılaştırılması

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Summary

Objective: Neurological diseases and the associated disabilities are getting increasingly more prevalent in all over the world and in our country. Awareness of neurological diseases is thought to be less than expected.

Materials and Methods: The aim of this study is to investigate the awareness of neurological diseases in secondary and tertiary neurological outpatient service visitors and to assess its correlations between the patient demographics.

Results: A total of 540 patients were included in the study. Alzheimer disease was found to be best known neurological disease while multiple sclerosis was the least known. The awareness of the diseases correlated with the level of education. Younger patients seemed be more aware of neurological diseases than the older ones. Despite the current widespread usage of internet/media, we found that patients come to neurological outpatient services mostly upon the advice from their family practitioners. We comment that this result is a positive finding in terms of the utility of health care system and patient-physician relationship.

Conclusion: There is need for increasing the awareness of the neurological diseases for both early diagnosis of neurological diseases and the reduction of associated disability. (Turkish Journal of Neurology 2014; 20:112-120)

Key Words: Awareness, disease information, neurological disorders

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Özet

Amaç: Ülkemizde ve tüm dünyada nörolojik hastalıklar ve buna bağlı özürlülük giderek artış göstermektedir. Nörolojik hastalıklar konusunda farkındalığın, beklendiğinden az olduğu düşünülmektedir.

Gereç ve Yöntem: Bu çalışmanın amacı 2. ve 3. basamak sağlık kuruluşlarındaki nöroloji poliklinikleri başvurularında nörolojik hastalıklar hakkındaki farkındalığın araştırılması ve bu farkındalığın hastaya ait demografik özelliklerle ilişkisinin değerlendirilmesidir.

Bulgular: Çalışmaya toplam 540 hasta dahil edilmiştir. Nörolojik hastalıklar arasında multipl skleroz en az tanınan hastalık iken Alzheimer hastalığı en çok tanınan olmuştur. Eğitim düzeyi artışıyla beraber hastalıkları tanıma oranı da artış göstermiştir. Gençlerde nörolojik hastalıklarla ilgili farkındalık yaşlılara göre daha fazla bulunmuştur. Günümüzde internet/medyanın yaygın kullanımına rağmen, hastaların nöroloji polikliniklerine başvuruda en fazla aile hekimlerinin görüşüne başvurduğunu bulduk. Bu durumu sağlık sisteminin kullanımı ve hasta-hekim ilişkisi yönünden olumlu bir bulgu olduğu şeklinde yorumladık.

Sonuç: Nörolojik hastalıkların erken tanısı ve özürlülüğün azaltılması için nörolojik hastalıklarla ilgili farkındalığın artırılması gereklidir. (Türk Nöroloji Dergisi 2014; 20:112-120)

Anahtar Kelimeler: Farkındalık, hastalık bilgisi, nörolojik hastalık

Çıkar çatışması: Yazarlar bu makale ile ilgili olarak herhangi bir çıkar çatışması bildirmemişlerdir.

Introduction

Neurological diseases and their associated disabilities are on the rise in Turkey and throughout the world. Neurological diseases constitute an important component of health planning due to loss of workforce they cause and the cost of treatment. It is also known that awareness of such diseases is relatively low compared to how prevalent they are. This causes late diagnosis of such diseases and poor planning of the treatment process, ultimately leading to an increased level of disability (1).

Neurological diseases may affect all age groups. Multiple sclerosis (MS), for example, is a young-middle age disease and its prevalence in America is 191/100000 (2). Prevalence of dementia is increasing globally with the increase in older population. According to World Health Organization (WHO) reports, 6.5 million people in the world had dementia in 2010 and this number is increasing every year (1). Total stroke incidence in 55 year or older individuals is 4.2-6.5/1000 (3).

Healthcare relies on efficient outreach and education. Much like the other aspects of our daily life, the use of internet and media is becoming more popular for distributing information about neurological diseases. It is also known that information propagates throughout society in its own idiosyncratic ways. There are also foundations that are trying to raise awareness on certain issues.

Neurological diseases are generally chronically progressing and the conscious participation from the patients and their relatives to the treatment process is crucial. To our knowledge, there is very limited number of studies on the awareness of neurological diseases in Turkish society.

This study aims to investigate the education level, sex, consultation reasons as well as the differences between the 2nd and 3rd step health institution policlinics in the context of neurological healthcare awareness.

Materials and Methods

The study was conducted in Ministry of Labor Ankara Research and Training Hospital (SBAEAH) Neurology Policlinic and Elmadağ State Hospital Neurology Policlinic. The study included 540 patients in total, 379 patients from SBAEAH and 161 patients from Elmadağ State Hospital. All of the participants volunteered for the study.

The patients were asked their age, sex, education level, visitation reasons, the names of diseases (MS, Parkinson's disease (PH), stroke, diabetes mellitus (DM), Alzheimer disease (AD)) and their knowledge of these diseases.

The patients were asked "what is x disease? what kind of a disease is it?". If they gave correct answers to both parts of this question, they were recoded as having knowledge of the disease.

The data was entered in SPSS 15.0 statistical package for analysis. Descriptive statistics were given as mean ($\pm$) standard deviation, median (min-max), frequency distribution and percentage. Chi-square and chi-square with Yates correction are used. The variables were inspected for their conformity to normal distribution using visual inspection (histogram and probability distributions) and analytical methods (Kolmogorov-Smirnov/ Shapiro-Wilk tests). The variables that were seen to be non-normally distributed were analyzed with Mann-Whitney U, Kruskal-Wallis test and Spearman test. Statistical significance threshold was determined as $p<0.05$.

Results

The mean age for all participants was 47.5 ± 16.6 and the mean education level was 5.9 ± 3.8 years.

The mean age for Ankara group was 46.8 ± 15.9 with mean education level being 5.4 ± 3.7 years. The mean age for Elmadağ group was 49.1 ± 18.1 with mean education level being 7.2 ± 3.7 years (Table 1). There were no differences between the groups for age, but Elmadağ group's education level was found to be higher.

Among 540 participants, 384 were women (71.1%) and 156 (28.9%) were men. For Ankara alone, 71.2% were women and 28.2% were men whereas for Elmadağ it was 70.8% women and 29.2% men. There was no difference in terms of gender between the two centers (p>0.05) (Table 1).

When the patients were asked how did they decide to come to the neurology policlinics, 52.2% of Ankara sample said referred by family practitioners, 33.5% said recommended by relatives and 2.1% said upon the advice from internet/media. For Elmadağ sample, this was 46.6%, 18.6% and 4.3% respectively. For both centers, family practitioners were the primary referrers (Table 2, Graphic 1, 2).

In Ankara sample, median age of patients who came with suggestions from relatives was 41 (18-82); 26.5 (22-68) for those who heard it on TV or internet; 49 (18-85) for those who were referred by family practitioners; 49 (18-85) for those who came without any external recommendation (Table 3).

In Elmadağ sample, median age of patients who came with suggestions from relatives was 53 (19-89); 22 (18-36) for those who heard it on TV or internet; 55 (21-84) for those who were referred by family practitioners; 38 (19-69) for those who came without any external recommendation (Table 3).

Visitation reasons in Elmadağ sample showed statistically significant relationship with age (p<0.005). Post-hoc pairwise comparisons to detect the source of this difference showed that the source is attributable to multiple groups (Table 3).

Visitation reasons in Ankara sample showed statistically significant relationship with education level (p<0.005) (Table 4). Post-hoc pairwise comparisons to detect the source of this difference showed that the education levels of patients who visited the centers because of TV or internet influence were statistically higher (Table 4).

Visitation reasons in Elmadağ sample showed statistically significant relationship with education level (p<0.005) (Table 4). Post-hoc pairwise comparisons to detect the source of this difference showed that the source is attributable to multiple groups (Table 4).

48.5% of Ankara sample and 57.1% of Elmadağ sample knew what AD is. There was no statistically significant difference between the two centers in terms of knowledge about AD (p>0.005) (Table 5).

93.4% of Ankara sample and 88.8% of Elmadağ sample did not know what MS is. There was no statistically significant difference between the two centers in terms of knowledge about MS (p>0.005) (Table 5).

84.2% of Ankara sample and 65.4% of Elmadağ sample did not know what PD is. There was a statistically significant difference between the two centers in terms of knowledge about

Table 1. Mean and Medians of participants' age, educational level and sex, for each center				
	Ankara (n=379)		**Elmadağ (n=161)**	
	Mean±SD	**Median (Min-Max)**	**Mean±SD**	**Median (Min-Max)**
Age (n=540)	46.8±15.9	46 (18-85)	49.1±18.1	46 (18-89)
Education (n=540)	5.4±3.7	5 (0-15)	7.2±3.7	8 (0-18)
p*=0.268				
		Center		
	Ankara		**Elmadağ**	
Sex (n=540)	Sayı	%**	Sayı	%**
Female	270	70.3	114	29.7
Male	109	69.9	47	30.1
p=0.919				
*: Mann-Whitney U Test, **: Row percentage				

Table 2. Distribution of visitation reasons for each center				
	Başvuru Merkezleri			
	Ankara (n=379)		**Elmadağ (n=161)**	
	Count	**%***	**Count**	**%***
Visitation reason (n=540)				
Relative's advice	127	33.5	30	18.6
Through TV or internet	8	2.2	7	4.4
Referred by family doctor	198	52.2	75	46.6
On their own	46	12.1	49	30.4
p<0.001				

Table 3. Age distribution over visitation reasons for each center		
	Distribution of Age	
	Ankara (n=379)	**Elmadağ (n=161)**
	Median (Min-Max)	**Median (Min-Max)**
Visitation reason (n=540)		
Relative's advice	41 (18-82)	53 (19-89)
Through TV or internet	26.5 (22-68)	22 (18-36)
Referred by family doctor	49 (18-85)	55 (21-84)
On their own	43.5 (20-73)	38 (19-69)
	p*<0.001	*p<0.001
*: Kruskal-Wallis Test applied		

PD (p>0.005) (Table 5). More people in Elmadağ sample knew about PD (Graphic 3, 4).

56.5% of Ankara sample and 35.4% of Elmadağ sample did not know what stroke is. There was a statistically significant difference between the two centers in terms of knowledge about stroke (p>0.005) (Table 5). More people in Elmadağ sample knew about stroke (Table 5).

As for diabetes, selected as a control to the neurological diseases, 60.4% of Ankara sample and 23.0% of Elmadağ sample did not know what it is. There was a statistically significant difference between the two centers in terms of knowledge about diabetes (p>0.005) (Table 5). More people in Elmadağ sample knew about diabetes (Graphic 1, 2).

In Elmadağ sample, among the people who know about AD, 85.7% decided to come to neurology policlinic on their own

Table 4. Educational level of participants in each center

	Educational level	
	Ankara (n=379) Median (Min-Max)	Elmadağ (n=161) Median (Min-Max)
Visitation reason (n=540)		
Relative's advice	5 (0-14)	5 (0-11)
Through TV or internet	9.5 (0-14)	11 (8-13)
Referred by family doctor	5 (0-15)	5 (0-13)
On their own	5 (0-14)	8 (0-18)
	p*=0.002	p*<0.001

*: Kruskal-Wallis Test applied

Table 5. Participant's knowledge of certain neurological diseases in each center

	Başvuru Merkezi			
	Ankara		Elmadağ	
	Count	%*	Count	%*
Alzheimer knowledge (n=540)				
Doesn't know	195	51.5	69	42.9
Knows	184	48.5	92	57.1
p=0.068				
Multiple sclerosis knowledge (n=540)				
Doesn't know	354	93.4	143	88.8
Knows	25	6.6	18	11.2
p=0.072**				
Parkinson knowledge (n=540)				
Doesn't know	319	84.2	106	65.8
Knows	60	15.8	55	34.2
p<0.001				
Diabetes knowledge (n=540)				
Doesn't know	230	60.7	37	23.0
Knows	149	39.3	124	77.0
p<0.001				
Stroke knowledge (n=540)				
Doesn't know	214	56.5	57	35.4
Knows	165	43.5	104	64.6
p<0.001				

*: Colon percentage, **: Yates corrected chi-square test

wish, 71.4% after watching it on TV or seeing it on the internet, 52% upon referral from their family practitioners and 40% upon suggestion of their referrals (Table 6).

There were no significant differences between knowing about the diseases and the visitation reason (p>0.05). In Elmadağ sample, there was a significant difference between visitation reasons and knowing about AD (p<0.005). Those who came because of what they learned from TV and the internet seemed to know more about AD than the others (Table 6).
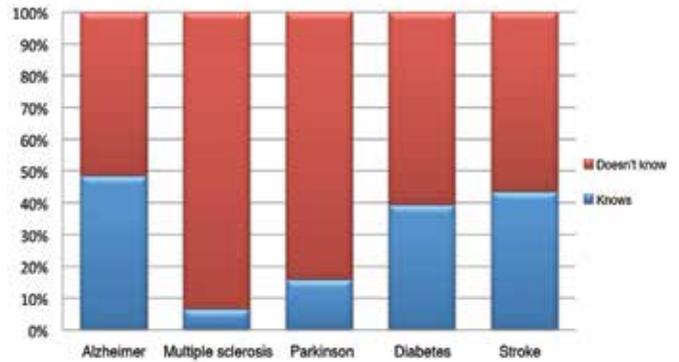
There was a statistically significant difference between the visitation reasons and the knowledge of MS, PD and DM (p<0.005). The patients who visited after watching TV or using internet had better knowledge of those three diseases compared
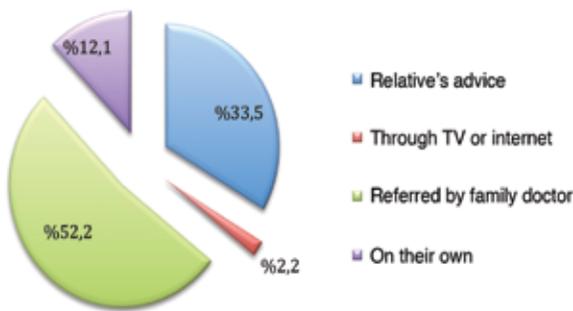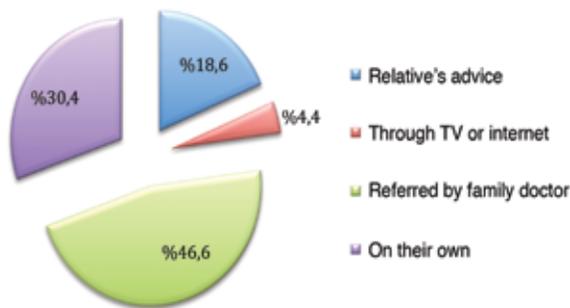
Graphic 1. Ankara group's visitation reasons to the neurology clinic

Graphic 2. Elmadağ group's visitation reasons to the neurology policlinic

Graphic 3. Ankara group's knowledge of diseases
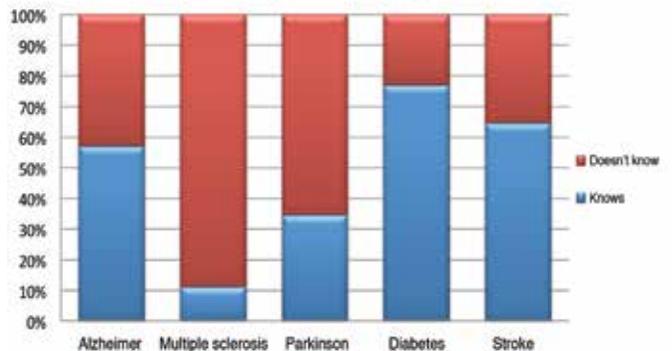
Graphic 4. Elmadağ group's knowledge of diseases

to other visitation reasons. There was no such difference for the knowledge of stroke (Table 6).

In Ankara sample, there was a moderate positive correlation between education level and knowledge of AH (38%) which was statistically significant. On the other hand, this correlation was higher in Elmadağ sample (63%) and also statistically significant.

In Ankara sample, there was a weak positive correlation between education level and knowledge of MS (14%) which was statistically significant. This correlation was higher in Elmadağ sample (33%) and also statistically significant (Table 7).

In Ankara sample, there was a weak positive correlation between education level and knowledge of PD (13%) which was statistically significant. This correlation was higher in Elmadağ sample (36%) and also statistically significant. In Ankara sample, there was a moderate positive correlation between education level and knowledge of DM (37%) which was statistically significant. This correlation was higher in Elmadağ sample (52%) and also statistically significant. In Ankara sample, there was a moderate positive correlation between education level and knowledge of stroke (25%) which was statistically significant. This correlation was higher in Elmadağ sample (28% and also statistically significant (Table 7).

There was a negative correlation between the ages of Ankara and Elmadağ groups and the knowledge of AD, MS and DM what was statistically significant.

In Ankara sample, there was not a correlation between age and knowledge of PD. However, there was a statistically significant correlation in Elmadağ sample (Table 8).

Discussion

We found in our study that the family practitioners are the primary referrers for neurology policlinics (Graphics 1, 2). The least important source of information for neurology policlinic visits is TV and internet. In a similar study by Gedizlioğlu et al., in Izmir, it was found that healthcare workers are the primary referrers for neurology policlinics (4). This finding suggests that healthcare institutions are the primary referrers for neurology policlinic in two different regions in Turkey and it is a positive finding for the functioning of the national healthcare system. The use of TV was at the second place for Izmir whereas it was at the last place in our study. This situation suggests a regional difference in terms of internet-media use for healthcare information.

Table 6. Elmadağ group's knowledge of diseases

	Visitation reason							
	Relative's advice		Through TV or internet		Referred by family doctor		On their own	
	Count	%*	Count	%*	Count	%*	Count	%*
Alzheimer Knowledge (n=540)								
Doesn't know	18	60.0	1	14.3	36	48.0	14	28.6
Knows	12	40.0	6	85.7	39	52.0	35	71.4
p=0.013								
Multiple sclerosis Knowledge (n=540)								
Doesn't know	28	93.3	4	57.1	71	94.7	40	81.6
Knows	2	6.7	3	42.9	4	5.3	9	18.4
p=0.005								
Parkinson Knowledge (n=540)								
Doesn't know	21	70.0	3	42.9	58	77.3	24	49.0
Knows	9	30.0	4	57.1	17	22.7	25	51.0
p=0.006								
Diabetes Knowledge (n=540)								
Doesn't know	14	46.7	0	0	19	25.3	4	8.2
Knows	16	53.3	7	100	56	74.7	45	91.8
p<0.001								
Stroke Knowledge (n=540)								
Doesn't know	15	50.0	3	42.9	28	37.3	11	22.4
Knows	15	50.0	4	57.1	47	62.7	38	77.6
p=0.083								

*: Colon percentage

It is known that the source of information about the diseases change as a function of age, ethnicity, socio-economic condition and the chronicity of the disease. In a study using MS patients, there was a high correlation between media use, and female gender and education (5,6,7,8,9,10). It was reported that 35% of the patients used internet to obtain information about spinal cord injury in Canada (11). 62% of rheumatoid arthritis patients in New Jersey USA used internet to do research about their disease (12). According to the studies done in USA and Israel, internet use in MS patients is 63-82% (6,9). Even though internet was regarded as the main source of information among younger populations, physicians are still regarded as more knowledgeable on diseases. A study showed that internet was the initial source of information for MS patients but 80% of the patients trusted the opinions of their physicians more than the internet (5). Similarly, another study found that 64.4% of patients trust physicians over internet and 48.6% preferred to search online whenever they have a new health problem while 10.9% went directly to the doctor first (13). Even though internet provides the most recent information on healthcare with easy access, patients value the opinions of physicians more. Our study is also in line with this notion. Internet and media consumption is very high globally as well as in Turkey. Thus, it is promising to see that patients were primarily referred to neurology policlinics by their family practitioners in our study.

Table 7. Correlation between education and knowledge of diseases

	Educational level			
	Ankara group		Elmadağ group	
	Rho*	p	Rho*	p
Alzheimer disease knowledge	0.38	0.001	0.63	0.001
Multiple sclerosis knowledge	0.14	0.007	0.33	0.001
Parkinson disease knowledge	0.13	0.014	0.36	0.001
Diabetes knowledge	0.37	0.001	0.52	0.001
Stroke knowledge	0.25	0.001	0.28	0.001

*: Spearman correlation coefficient

Table 8. Correlation between age and knowledge of diseases

	Age			
	Ankara group		Elmadağ group	
	Rho*	p	Rho*	p
Alzheimer disease knowledge	-0.27	0.001	-0.52	0.001
Multiple sclerosis knowledge	-0.11	0.029	-0.33	0.001
Parkinson disease knowledge	0.04	0.419	-0.28	0.001
Diabetes knowledge	-0.26	0.001	-0.42	0.001
Stroke knowledge	-0.13	0.015	-0.08	0.273

*: Spearman correlation coefficient

Another study on MS patients showed that younger and more educated people are more likely to use the internet (6). In our study, neurology policlinic visitation reasons changed as a function of age. In both samples, patients tend to be referred more by their primary care physicians with the increased age. For both samples, acquiring information from TV and internet is more likely with the increased education level. Gender was not a determining factor for obtaining information before neurology policlinic visits.

We investigated the knowledge of neurological diseases in people who came to neurology clinics. We told the patients the names of certain diseases and asked them if they knew the disease and what kind of a disease it was. In both samples, AD was the most recognizable disease and MS was the least recognizable one. In a 2004 study by Mavis et al., epilepsy and dementia were the most recognizable diseases whereas MS was the least recognizable one (14). 48.5% of the Ankara and 57.1% of the Elmadağ participants knew about AD. Our study showed that those who came to neurology policlinic after hearing about it on TV and the internet were more likely to know about AD than the other visitation reasons. This finding demonstrates the importance of media in AD outreach and point out the adequacy of AD-related initiatives in raising awareness of the disease.

Due to its wide-spread incidence rate, awareness of AD is crucial in the society. The prevalence of AD in people over 65 is 10%. This increases as a function of age, reaching 45% for ages above 85. Gürvit et al. estimated the prevalence of AD as 11% in people over 70 in Turkey Alzheimer Disease Prevalence Study. According to this estimation, it is assumed that there are 250-300 thousand AD patients in Turkey (15). In most countries, dementia is seen as the natural consequence of old age and it is seen impossible to treat. Awareness of this disease may facilitate early diagnosis and effective treatment, reducing morbidity and dependencies. According to WHO reports, education is the most effective way to increase awareness. In countries with low socio-economical status, 86.3% of the population does not have awareness of dementia (1). This awareness is crucial for increasing the quality of life and care for the patients.

A majority of our participants did not seem to have knowledge of MS (93.4% in Ankara group and 88.8% in Elmadağ group). The prevalence for MS is 191/100,000 and incidence rate varies by 7.3/100,0000 (16). The symptoms start between 20 and 40 years of age in 2/3rd of patients, indicating that MS affects a younger population than the other diseases in question. 83% of countries conduct educational activities, seminars and conferences. According to WHO reports, outreach activities for MS are smaller in comparison to other diseases (1).

The prevalence of PD changes between 14.6 and 780 in 100.000. After 65 years, this rate becomes 1.5-2%, and after 85 3.5% (17). The incidence of PD changes between 10 and 15 in 100,000 and the risk for lifetime PD is approximately 1.6% (18). 84.2% of Ankara group and 65.4% of Elmadağ group did not know what PD is. Elmadağ group was found to be statistically significantly more knowledgeable about PD compared to Ankara group.

Incidence of stroke in developed countries is between 125 and 175 in 100.000. In Turkey, this is more likely to be around 176/100.000. The number of patients with stroke increases with the age, and reaches around 500-600/100.000 patients above 60 years old. 75% of stroke patients are above 65 years old. After standardizing for age, incidence for total stroke in 55 years and older seem to be 4.2-6.2/100.000. Compared to the other neurological disease, stroke is the one that creates the biggest disability (19,20).

43.5% of the patients in Ankara group and 64.6% of Elmadağ group did not know about stroke.

A study in India showed that 23% of 942 participants did not know even one of the symptoms of stroke (21). Since the hospitalization is delayed due to lack of knowledge on the condition (mean duration 474 minutes), the chance to administer thrombolytic treatment is very little (22). In a study by Evci et al., 64% of the population knew at least one symptom of stroke (23). With the increase knowledge of stroke symptoms, the chance to administer a timely thrombolytic treatment may be increased, reducing morbidity.

Global prevalence for adult type 2 DM was 6.4% in 2010 and is expected to rise to 7.7% by 2030 (24). In TURDEP-II study conducted in 2009 by Satman et al., the prevalence in Turkey was found to be 13.7% and that incidence and prevalence increased with age (25). A large part of our patients in Ankara group (60.4%) did not know about DM. 77% of Elmadağ group, however, knew what it is. Even though DM is seen more frequently compared to the neurological disorders in question, the awareness was surprisingly low in Ankara group, which can be explained by the low educational level.

In Ankara sample, men knew more about AD, stroke and DM compared to women. In Ankara sample, sex was not a determinant for knowledge of MS and PD. In Elmadağ sample, sex was also not the determinant for knowledge of the diseases. With the increased educational level, knowledge of the neurological diseases increased in both samples. The correlation between the educational level and disease knowledge seen in Elmadağ is even more pronounced in Ankara. This finding can be explained by the overall high educational average in Elmadağ. Also, it was found that knowledge of diseases (excluding stroke in Elmadağ and PD in Ankara) decreases with the increased age.

In Ankara sample the reasons for visiting neurology policlinic was not associated with the knowledge of the diseases. Even though highly educated people in Ankara sample came to neurology policlinic after hearing about it on TV an internet, this association was not statistically meaningful. In Elmadağ sample, people who visited after TV and internet use were more knowledgeable about neurological diseases except for stroke. This suggests that Elmadağ's highly educated population uses TV and internet more effectively. In addition, Elmadağ group was also knowledgeable about MS and PD which was not as known in Ankara sample.

Conclusion

Neurological diseases create disability and require care. The awareness for these diseases is therefor important to preserve productivity and work force. Our study found that older ages and lower educational levels bring about lower levels of knowledge of such diseases. In our study, AD was the most widely known disease. The outreach and education for multiple sclerosis has a lot of room for improvement. Family physicians were important and trusted referrers when accessing healthcare. In addition, due to the widespread use of TV and media, it is important to utilize these outlets to better educate the population about neurological diseases.

Since this study is limited to the visitations made to the neurology policlinic, it may not provide information generalizable to the rest of the population. Similar studies must be conducted using samples drawn from the general population.

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