PERCEPTION OF EPILEPSY IN TURKEY IN THE LIGHT OF TWO DIFFERENT CITIES

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SUMMARY – The aim of this study was to investigate the perception of epilepsy in Turkey, from west to east, in Kutahya and Yuksekova, two cities of different sociocultural and ethnic status. This was a retrospective comparison study which evaluated the results of two prior studies investigating stigmatization of patients diagnosed with epilepsy and their first-degree relatives in two different cities of Turkey, Kutahya and Yuksekova. The Survey of Epileptic Patient Relatives on the Knowledge, Attitudes, and Behavior Regarding the Disorder was used and included questions on descriptive characteristics, familiarity with epilepsy, attitudes toward epilepsy, and understanding of epilepsy. Data collected by use of the SPSS 15.0 software were analyzed with $\chi^2$-test. In Yuksekova group, 88.5% of first-degree relatives of people with epilepsy felt primarily fear when they heard the diagnosis of epilepsy in their relatives; in Kutahya group, the respective rate was 19.1% (p<0.05). The number of participants who objected their child marrying someone with epilepsy was significantly higher in Yuksekova group (p<0.05); however, if married, the Yuksekova group significantly stated that they should have a baby, revealing the importance of children as an indicator of power and dignity in the eastern region of Turkey (p<0.05). Although understanding of epilepsy was favorable, educating the community about epilepsy and personal contacts are the major strategies against epileptic stigmatization.

Key words: Epilepsy perception; Understanding epilepsy; Familiarity with epilepsy; Attitudes toward epilepsy; Stigma

Introduction

Epilepsy is a neurological condition that knows no geographical, social, or racial boundaries, occurring in men and women and affecting people of all ages, though more frequently affecting young people in the first two decades of life and people over the age of 601. It has been estimated that there are at least 50 million people with epilepsy worldwide2,3. The predicted prevalence of epilepsy has been reported as 4-10/1000 in the great majority of studies1,4-3. It has to be acknowledged that more than 80% of people with epilepsy live in developing countries, where the condition remains largely untreated2. According to the results of a limited number of studies including all age groups, the prevalence in Turkey is reported to be 6.1 to 10.2 per 10007-12.

While epilepsy is a chronic condition itself, the impact of epilepsy rests not only on the individual patient, but also on the family and indirectly on the community. The burden of epilepsy may be due to the
physical hazards of epilepsy resulting from the unpredictability of seizures; social exclusion as a result of negative attitudes of the others toward people with epilepsy; and stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe\textsuperscript{13}.

Stigmatization (‘labeling’ or ‘marking’) encompasses behaviors based on assumptions about particular groups that lead to exclusion of those groups from the wider community. Religions, beliefs, culture, and tradition contribute to this stigmatization. Stigmatization and negative approaches lower the quality of life of individuals in these excluded groups, causing them to live an isolated life and delaying their receipt of assistance\textsuperscript{14}.

Epilepsy as a hidden disability makes the patients vulnerable in the society. Although the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures\textsuperscript{13}.

In our previous study, we investigated the knowledge and perceptions of epilepsy and preferred treatment options of people with epilepsy (PWE), their first-degree relatives, and healthy individuals in Yuksekova, a city in the south-east region of Turkey. Moreover, we evaluated the behaviors and approaches toward PWE of first-degree relatives of patients and healthy individuals in this region\textsuperscript{15}.

Currently, our aim was to compare our previous study results with another study on stigmatization performed in Kutahya, a city in the Aegean region of Turkey, which has a different cultural, social, economic and educational status\textsuperscript{15,16}. As a consensus among the authors of the study performed in Kutahya, we believed that this comparison would allow us to evaluate the effects of regional, sociocultural and economic differences in the knowledge and perceptions of epilepsy and preferred treatment options in PWE and their first-degree relatives.

Thus, by evaluating epileptic stigmatization in Yuksekova, a south-east city that is underdeveloped and in Kutahya, a modern, developed Aegean city with a higher socioeconomic status, we would be able to analyze regional differences in social stigmatization of epilepsy.

**Subjects and Methods**

**Study groups**

This was a retrospective comparison study which evaluated the results of two prior studies evaluating epileptic stigmatization in patients with a new and/or prior diagnosis of epilepsy, and their first-degree relatives\textsuperscript{15,16}. Our previous study on stigmatization of PWE and their relatives was conducted at the Yuksekova State Hospital outpatient neurology clinic between November 1, 2008 and January 10, 2009. Yuksekova is a small and underdeveloped city in the south-east region of Turkey. Study group consisted of 130 consecutive patients older than 7 years with a new and/or prior diagnosis of epilepsy that had no other neurologic diseases and their 130 healthy first-degree relatives. Control group included 130 healthy individuals. All participants were informed on the study protocol and gave their written consent before enrolment\textsuperscript{15}.

**Questionnaires**

Two different questionnaires were prepared for the patient group and healthy group (relatives and controls). The relatives and controls were healthy people with no chronic diseases. Sociodemographic characteristics were obtained by a structured interview using an open questionnaire completed in person by all participants. There were a total of 16 questions in the patient questionnaire, including 3 questions on familiarity with epilepsy, 6 questions on attitudes toward epilepsy, and 7 questions on understanding of epilepsy. The questionnaire administered to the relatives and controls contained a total of 18 questions\textsuperscript{15}.

Similar to our previous study, another stigmatization study was carried out in the outpatient neurology clinic of Kutahya Dumlupınar University Medical Faculty. Differing from our study, it was performed in first-degree relatives of PWE and there was no epileptic patient group or control group. Study group consisted of 115 participants including first-degree relatives of PWE. An open questionnaire was admin-
istered to all participants in person and sociodemographic characteristics were recorded. There were a total of 18 questions in this questionnaire including 3 questions on familiarity with epilepsy, 8 questions on attitudes toward epilepsy, and 7 questions on understanding of epilepsy. Currently, we retrospectively compared the answers in the questionnaires that were filled out by first-degree relatives of PWE in two previous studies carried out in Yuksekova and Kutahya, the cities of two different ethnic origin, social, cultural, economic and educational status.

Statistical analysis

Data were organized in an SPSS Version 15.0 (Statistical Package for Social Sciences for Windows) database. Statistical analyses were performed with the $\chi^2$-test and Fisher exact test. P values <0.05 were considered to indicate statistical significance.

Results

Questionnaires were administered to the first-degree relatives of PWE in the two cities, Yuksekova and Kutahya. In the Yuksekova group, there were 130 participants including 78 (60%) men and 52 (40%) women. The Kutahya group consisted of 115 patients including 61 (53%) men and 54 (47%) women. Mean age in the Yuksekova group was 37.23±13.95 years (range 12-72 years, 95%CI=34.80-39.63). In the Kutahya group, mean age was 38.37±11.11 years (range 13-75 years, 95% CI=36.09-40.64). The sociodemographic characteristics of the patients, their first-degree relatives and controls are summarized in Table 1.

When asked what they felt when their relative was first diagnosed with epilepsy, 88.5% of the Yuksekova group said they felt fear, while this rate was 19.1% in the Kutahya group. There was a statistically significant difference in the answers to this question between the study groups ($p<0.05$). Ninety-two percent of the Yuksekova group indicated “doctor” as the source of their information about epilepsy, while this rate was 85.7% in the Kutahya group. There was a statistically significant difference between the two groups ($p<0.05$). Other information sources were found to be used infrequently in both groups. Answers to the questions on familiarity with epilepsy are given in Table 2.

When asked if they would permit their healthy child to marry a person with epilepsy, 15.4% of the participants answered “yes” in the Yuksekova group. The

| Table 1. Sociodemographic characteristics of study groups, Kutahya vs. Yuksekova, 2010 |
|-----------------|-------------------|-------------------|-----------------|---------|
| **Sex**         | **Kutahya**       | **Yuksekova**     | **Total**       | **p**   |
|                 | **n**  | **%** | **n**  | **%**   | **n**  | **%** | **p**** |
| Female          | 54    | 47.0  | 52    | 40.0    | 106    | 43.3  | 0.273   |
| Male            | 61    | 53.0  | 78    | 60.0    | 139    | 56.7  |         |
| City            |        |       |       |         |       |       |         |
| Kutahya/Yuksekova | 100   | 87.7  | 124   | 95.4    | 224    | 91.8  | 0.029   |
| Kutahya/out of Yuksekova | 14    | 12.3  | 6     | 4.6     | 20     | 8.2   |         |
| Marital status  |        |       |       |         |       |       |         |
| Married         | 100   | 87.0  | 98    | 75.4    | 198    | 80.8  |         |
| Single          | 13    | 11.3  | 30    | 23.1    | 43     | 17.6  | 0.54    |
| Widowed         | 2     | 1.7   | 2     | 1.5     | 4      | 1.6   |         |
| Social guarantee existence |        |       |       |         |       |       |         |
| Yes             | 104   | 90.4  | 127   | 97.7    | 231    | 94.3  | 0.01    |
| No              | 11    | 9.6   | 3     | 2.3     | 14     | 5.7   |         |
| Education       |        |       |       |         |       |       |         |
| Primary school and lower | 71    | 62.8  | 78    | 60.0    | 149    | 61.3  | 0.651   |
| High school and higher | 42    | 37.2  | 52    | 40.0    | 94     | 38.7  |         |

$%*$ = column percent; $p** = \chi^2$-test
rate of the “yes” responders was 22.8% in the Kutahya group. There was a statistically significant difference in the answers to this question between the study groups (p<0.05). The “Should a person with epilepsy have a baby?” question was answered by “yes” in 70% of the Yuksekova group, while the rate of “yes” responders was 46% in the Kutahya group (p<0.05). With respect to giving jobs to PWE, 18.5% of their first-degree relatives in the Yuksekova group said “no”, whereas this rate was 7.1% in the Kutahya group (p<0.05).

When asked if they would tell other people that they have a relative with epilepsy, 63.4% of first-degree relatives of PWE in the Kutahya group said “no”, whereas 80.8% of the Yuksekova group would do so (p<0.05). Answers to the questions on attitudes toward epilepsy section of the questionnaire are listed in Table 3.

When asked what they thought had caused epilepsy, 52.2% of the Kutahya group said they believed that brain was the source of the disease, whereas the rate of this answer was 78.5% in the Yuksekova group (p<0.05). Moreover, 19.5% of the Kutahya group and 2.3% of the Yuksekova group answered this question as “hereditary”, yielding a statistically significant difference between the groups (p<0.05).

All participants in the Yuksekova group said that they went other places except doctors for epilepsy treatment (100.0%), while this answer rate was only 7.2% of the Kutahya group (p<0.05). Answers to the questions on their understanding of epilepsy are summarized in Figure 1.

When we analyzed the answers of the two groups to the questions on familiarity with epilepsy, attitudes toward epilepsy, and understanding of epilepsy with respect to sex, marital status, occupation, and educational level, there were no statistically significant differences (p>0.05).

Discussion

Epilepsy is one of the most common chronic neurologic disorders affecting people of various cultures...
Table 3. Answers to the section of the questionnaire on attitudes toward epilepsy, Kutahya vs. Yuksekova, 2010

<table>
<thead>
<tr>
<th>Would you permit your healthy child to marry a person with epilepsy?</th>
<th>Kutahya</th>
<th>Yuksekova</th>
<th>Total</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>%*</td>
<td>n</td>
<td>%*</td>
<td>n</td>
</tr>
<tr>
<td>No</td>
<td>48</td>
<td>42.1</td>
<td>92</td>
<td>70.8</td>
</tr>
<tr>
<td>Yes</td>
<td>26</td>
<td>22.8</td>
<td>20</td>
<td>15.4</td>
</tr>
<tr>
<td>I don't know</td>
<td>40</td>
<td>35.1</td>
<td>18</td>
<td>13.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Should a person with epilepsy have a baby?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>I don't know</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Would you give a job to a person with epilepsy?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>I'd give all kinds of jobs</td>
</tr>
<tr>
<td>I'd give simple jobs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Would you tell other people that you have a relative with epilepsy?†</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'd hide</td>
</tr>
<tr>
<td>I'd tell my closest friends/relatives only</td>
</tr>
<tr>
<td>I'd tell everybody</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Which activities make you feel comfortable when you are with your relatives?†a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social activity</td>
</tr>
<tr>
<td>Daily activities</td>
</tr>
<tr>
<td>Working at the same job</td>
</tr>
<tr>
<td>Sports</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What kind of difficulties did your illness cause in your social life?†a</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Left school</td>
</tr>
<tr>
<td>Had difficulties in school</td>
</tr>
<tr>
<td>Lost job</td>
</tr>
<tr>
<td>Divorce</td>
</tr>
<tr>
<td>Exclusion bad behavior</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What would you do if your relative was having a seizure†a</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'd panic, I couldn't do anything</td>
</tr>
<tr>
<td>I'd call an ambulance</td>
</tr>
<tr>
<td>I'd tell other people</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How would you intervene when your relative is having a seizure†a</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'd take him/her to a safer place</td>
</tr>
<tr>
<td>I'd turn him/her to one side</td>
</tr>
<tr>
<td>I'd pull his/her tongue</td>
</tr>
<tr>
<td>I'd make him/her smell something</td>
</tr>
<tr>
<td>I'd try to open his/her teeth</td>
</tr>
<tr>
<td>I'd give him/her medicine</td>
</tr>
<tr>
<td>I'd throw water on his/her face</td>
</tr>
</tbody>
</table>

*Participants gave more than one answer to the questions; * = column percentage; † = “yes” responder percentage; p* = χ²-test; p = Fisher exact test
It is a chronic condition associated with increased social discrimination. People with intractable seizures are at a constant risk of becoming unconscious and of falling and sustaining injuries and, in public, social embarrassment. Whereas epilepsy is a chronic condition, PWE can have demoralization and a negative perspective on life. Insufficient knowledge and false perceptions about the disease make epilepsy a serious and stigmatizing condition on the part of the community. In this respect, epilepsy is considered as a social label, as well as a clinical disease. Moreover, stigmatization leads to discrimination and people with epilepsy have been the target of prejudicial behavior in many spheres of life, over many centuries and in many cultures.

Previous studies have reported that perception of epilepsy in the society is commonly negative, leading to difficulties in finding a job, marrying and living a normal life. Differences in the perception of stigma may depend on cultural and regional aspects. The understanding of this aspect of epilepsy is important to promote better de-stigmatization campaigns, considering the cultural and social differences. In our study, as an indicator of stigmatization, there was a statistically significant difference in the answers to the question “What did you feel when your relative was first diagnosed with epilepsy?” between the two study groups (p<0.05). This difference was due to the Yüksekova group, where most of the participants stated that they felt fear, sorrow and thoughtfulness when their relatives were first diagnosed with epilepsy. This may be due to insufficient information and wrong beliefs and/or perceptions. The high rate of fear, sorrow and thoughtfulness in the Yüksekova group reflects the stigmatization in this rural area which is underdeveloped (Table 2). Similarly, a previous study that was carried out in four different regions of Brazil demonstrated that 28.3% of the respondents felt fear when they saw an epileptic seizure.

It is important to emphasize that the rate of correct definition of epilepsy was higher in the Kütahya group. Most of the participants in this group defined epileptic seizure as a temporary change in behavior, sliding of the eyes, screaming, crying out, clamping of the teeth and/or urinary/fecal incontinence. However, most of the participants in the Yüksekova group stated that they did not know the definition of epileptic seizure (Table 2). This statistically significant between-group difference in the definition of epilepsy can be attributed to differences in the level of education between the groups. Higher education and university graduates were more common in the Kütahya group, whereas there was a higher rate of participants unable to read and write in the Yüksekova group.

Epilepsy is considered as a social label leading to numerous problems in marriage, education, social iso...
lation, and employment, especially in developing coun-
tries. The burden of epilepsy may be due to the physical
hazards of epilepsy resulting from the unpredictability
of seizures; social exclusion as a result of negative at-
titudes of the others toward PWE; and stigma, as chil-
dren with epilepsy may be banned from school, adults
may be barred from marriage, and employment is often
denied, even when seizures would not render the work
unsuitable or unsafe.

Despite an Austrian study demonstrating that
only 15% of the respondents would object to their
child marrying a PWE, another previous study re-
vealed that healthy people with relatives with epilepsy
would not permit their children to marry individu-
als with epilepsy. Similarly, in our study, 70% of the
participants stated that they would not permit their
healthy child to marry a person with epilepsy, while
this rate was 42.1% in the Kutahya group (Table 3).
This demonstrates stigmatization and false perception
that the disease may be infectious or genetically trans-
mitted. As a dilemma, the Yuksekova group stated
that if married, PWE should have a baby. In order
to understand this conflict, it is important to evaluate
the sociological structure of the society in this region.
Cultural and sociological norms of the region suggest
fertility. Moreover, having a child is very important in
order to carry on the descent. In this aspect, people if
married, should have a baby because children reflect
the power and dignity of the family in local community.
On the contrary, a previous study revealed that about half of the respondents (43%) were either un-
sure whether PWE should have children or believed
they should not (8%).

Employment is a serious problem for PWE be-
cause of stigmatization of the disorder as a disabling
disease among healthy people in the community. A
previous study about epileptic stigmatization carried
out in the USA demonstrated that 42% of the respon-
dents believed that PWE are usually able to work. In
our study, 18.5% of the Yuksekova group stated that
they would not give a job to PWE, while this rate was
7.1% in the Kutahya group. This demonstrates that
discrimination of PWE is more common in Yuksek-
ova than in Kutahya due to stigmatization. Moreover,
by answering this question giving all kinds of jobs,
the Kutahya group showed that they did not consider
epilepsy as a reason of disability.

It is important to emphasize that 78.5% of the
Yuksekova group stated that the source of epilepsy
was brain, while this answer rate was 52.2% in the
Kutahya group. This statistically significant difference
on behalf of the Yuksekova study group could be at-
tributed to their direct communication with doctors.
However, the participants in the Yuksekova group had
lower education. On the contrary, there were a small
number of participants in the Yuksekova group defin-
ing the source of the disease as “hereditary”, yielding
a statistically significant difference. This could be ex-
plained by the low education level in the Yuksekova
group.

Several studies indicated that epileptic seizure is
still considered a mystic event, and traditional beliefs
along with religion play an important role in shaping
the stereotypes, attitudes, and bias of societies with
respect to epilepsy. On the basis of culture, philoso-
phy, and religion, persons in underdeveloped and de-
veloping countries often consider epilepsy as the result
of good or bad spirits. These beliefs are also frequent
in Turkey, where people perceive epilepsy as a super-
natural event. In order to deal with this mystic event,
people frequently go to the hodja, wear an amulet, and
participate in religious ceremonies. A Turkish
study revealed that 19% of Turkish PWE sought such
treatment. The various nonmedical treatment options
included visiting hodjas (17.6%), drinking curative
water (1.0%), and consuming homemade medicines
(1.0%). Similarly, in our study, all of the participants
in the Yuksekova group stated that they went to other
places in addition to doctors. This is compatible with
the strong religious beliefs of the local society and in-
dicates that they are in need of searching for alterna-
tive therapy along with medical treatments.

In summary, like other chronic diseases, epilepsy
has a great impact on everyday life of the patients as
well as on their quality of life in different ways. Since
the community has a low understanding of epilepsy,
stigma will likely continue to be. In our opinion, a
combination of personal contacts and educating the
community about the etiology of epilepsy and inform-
ing them about the nature of the disease are the major
strategies against epileptic stigmatization.
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Sažetak

PERCEPCIJA EPILEPSIJE U TURSKOJ U SVJETLU DVAJU GRADOVA

Y. Degirmenci, S. Canbaz Kabay, Z. Yılmaz, C. Bakar i H.I. Karaman Ozisik

Cilj istraživanja bio je ispitati percepciju epilepsije u Turskoj, od zapada do istoka, u gradovima Kutahya i Yuksekova različitog sociokulturalnog i etničkog statusa. Istraživanje je provedeno kao retrospektivna, usporedbena studija u kojoj su se procjenjivali rezultati dviju prethodnih studija koje su ispitivale stigmatizaciju bolesnika s dijagnosticiranim epilepsijom i njihovih srodnika prvog stupnja u dva različita turska grada, Kutahya i Yuksekova. Primijenjeno je anketiranje rodničkih epileptičnih bolesnika o znanju, stavovima i ponašanju u odnosu na bolest, a obuhvaćena su pitanja o deskriptivnim značajkama, poznawanju epilepsije, stavovima prema epilepsiji i razumijevanju epilepsije. Podaci prikupljeni uz pomoć statističkog programa SPSS 15.0 analizirani su primjenom $\chi^2$-testa. U skupini Yuksekova 88,5% srodnika prvog stupnja osoba s epilepsijom osjetilo je prvenstveno strah kad su čuli za dijagnozu epilepsije postavljenu kod njihovih rođaka, dok je u skupini Kutahya taj postotak bio 19,1% (p<0,05). Broj sudionika koji su svom djetetu zamjerili sklapanje braka s nekim tko boluje od epilepsije bio je značajno viši u skupini Yuksekova (p<0,05). No kad je takav brak već sklopljen, značajan broj sudionika skupine Yuksekova ustvrdio je kako bi oni trebali imati djecu, što ukazuje na važnost djece u istočnom dijelu Turske kao pokazatelja snage i dostojanstva (p<0,05). Iako se razumijevanje epilepsije pokazalo povoljnim, izobrazba lokalne zajednice o epilepsiji i osobni kontakti glavne su strategije protiv stigmatiziranja osoba s epilepsijom.

Ključne riječi: Percepcija epilepsije; Razumijevanje epilepsije; Poznavanje epilepsije; Stavovi prema epilepsiji; Stigma