

STATISTICAL EVALUATIONS ON THE INTERNET USAGE BEHAVIOUR OF THE INDIVIDUALS WITH HAEMOPHILIA IN TURKEY

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OBJECTIVES

The behavior and attitudes of the patients and the hemophiliacs have been changed significantly by the recent developments in the world of internet. It is obviously seen that the changes in the internet world have been affecting the patients with coagulation disorders in Turkey significantly. The changes in the behavior of the patients with hemophiliacs vary individually and show different patterns at different times and different fields. The effect is also observed in the physician and the patient relations. Studies with the patients in different countries on this subject have interesting results. It is important that the hemophiliacs in Turkey can reach the information related to the health through internet. It is equally important to analyze the effect of the information they got through the internet on their behavior, their electronic communication with the medical personnel and the physicians, patient-physician/hematologist relationship. As a matter of fact, in those type of analysis that are carried out internationally, hemophiliacs have been grouped according to the socio-economic status and their age. According to the results of the study performed by Turkish Statistical Institute, while the ratio of the internet use of the male population is 59.1% countrywide, it is 61.4% in İstanbul. According to these results, the ratio of the internet use of hemophiliac males is determined to be 76%. The study population was composed of individuals between the age of 16 and 74 in the two researches "Information Technologies Usage in the Family" and "Obtaining information about health issues in the electronic environment by the hemophiliac individuals and their attitude and behavior in their communication with the Medical Doctor". The ratio of regular internet use of males among the internet users was determined to be 91.6% countrywide. This ratio was 90.3% for the hemophiliac males in Turkey. It is identified that hemophiliacs in Turkey use internet 24 days in a month and this number is 24.5 for Hemophilia A patients and 21.3 for Hemophilia B patients. These interesting results suggest that the detailed analysis of the behavior of the hemophiliacs in the electronic environment, the health knowledge they got from the internet, their attitudes and behavior towards medical doctors would provide significant contribution to the literature.

MATERIALS AND METHODS

The study population in our research includes 1720 hemophiliacs who are registered members of the Hemophilia Society of Turkey. All of the study subjects are from different parts of Turkey. The list sampling method was applied with two stage selection procedure by using Simple Random Sampling (Basit tesadüfî örnekleme) principals. To reach the samples (SUBJECTS), computer assisted telephone interview-CATI was performed. The 1720 hemophiliac subjects were divided into four different age groups and 520 were selected from these groups. Then, the interview was done by 103 subjects among 520 (n=103) individuals. The eventual subjects of the study were from 59 different district and 31 different city in Turkey. The data was obtained according to the 5 likert scale and analyzed by using PASW18 and Excelstat 2.0 software programs.

RESULTS

Our results have shown that all the hemophiliac internet users in Turkey were looking for health information in the internet. Despite that as it is seen from table 1, the ratio of the hemophiliacs who searched for health information in the internet regularly is only 25%. On the other hand, as it is clearly seen from table 1 and figure 1a, individuals who are looking up in internet rarely for health information are in the upper socio-economic status group, while the individuals looking up in the internet from now and then are in the middle or lower socio-economic groups. Besides, the regular users were more in the age group of 35 and older.

Figure 1. The ratio of the hemophiliacs looking up in the internet for health information (%).
 a. According to the Socio-Economic status b. According to the Age

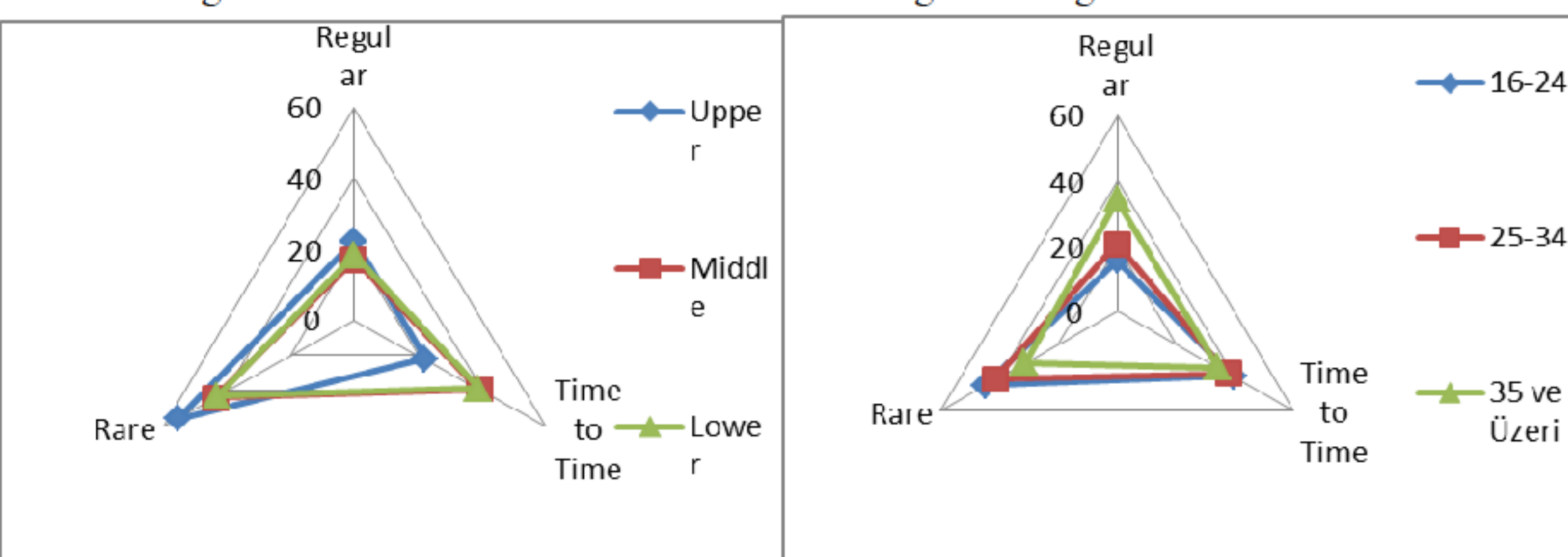
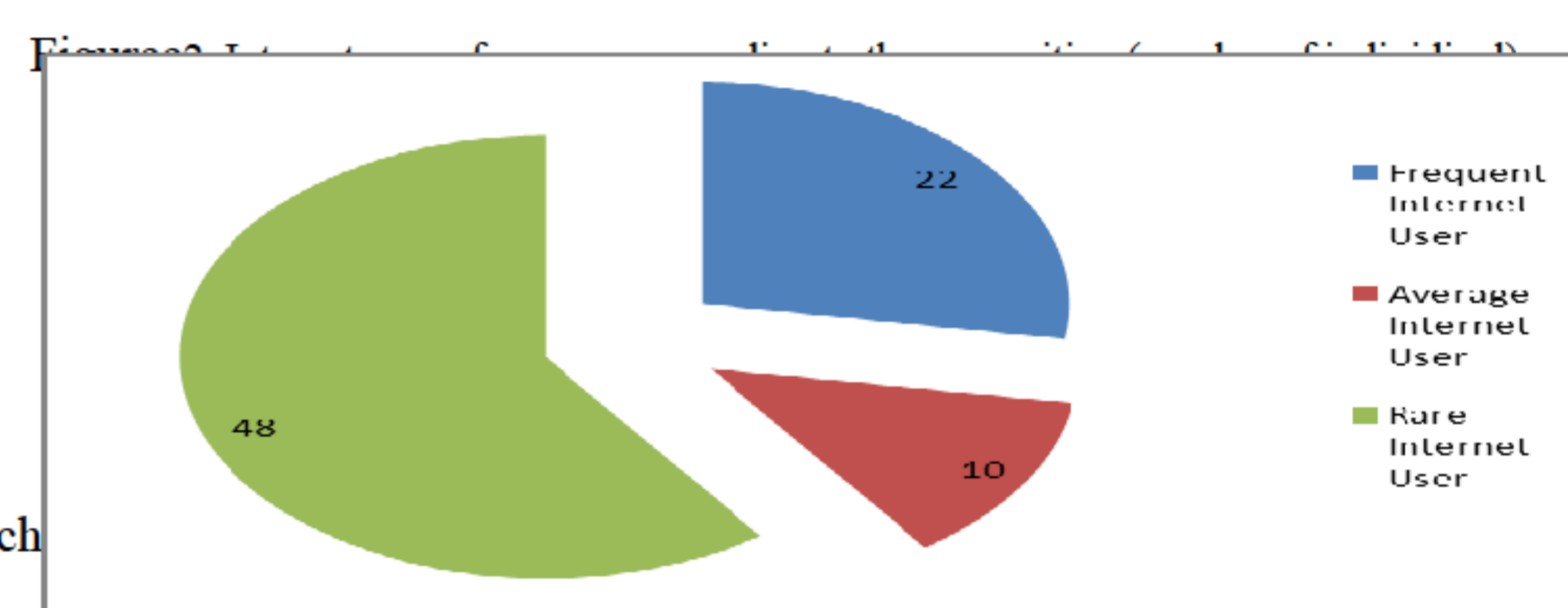


Table 1. The distribution of the frequency of searching for health information in the internet by the hemophiliacs according to the socio-economic status and age (%)

Frequency for looking	General	Socio-economic status			Age		
		Upper	Middle	Low	16-24	25-34	35 and older
Regular	24.28	22.22	44.95	59.05	15.79	20.69	34.28
From now and then	36.89	22.22	81.5	64.7	39.47	37.93	34.29
Rarely	38.84	55.56	73.56	76.19	44.74	41.37	31.43

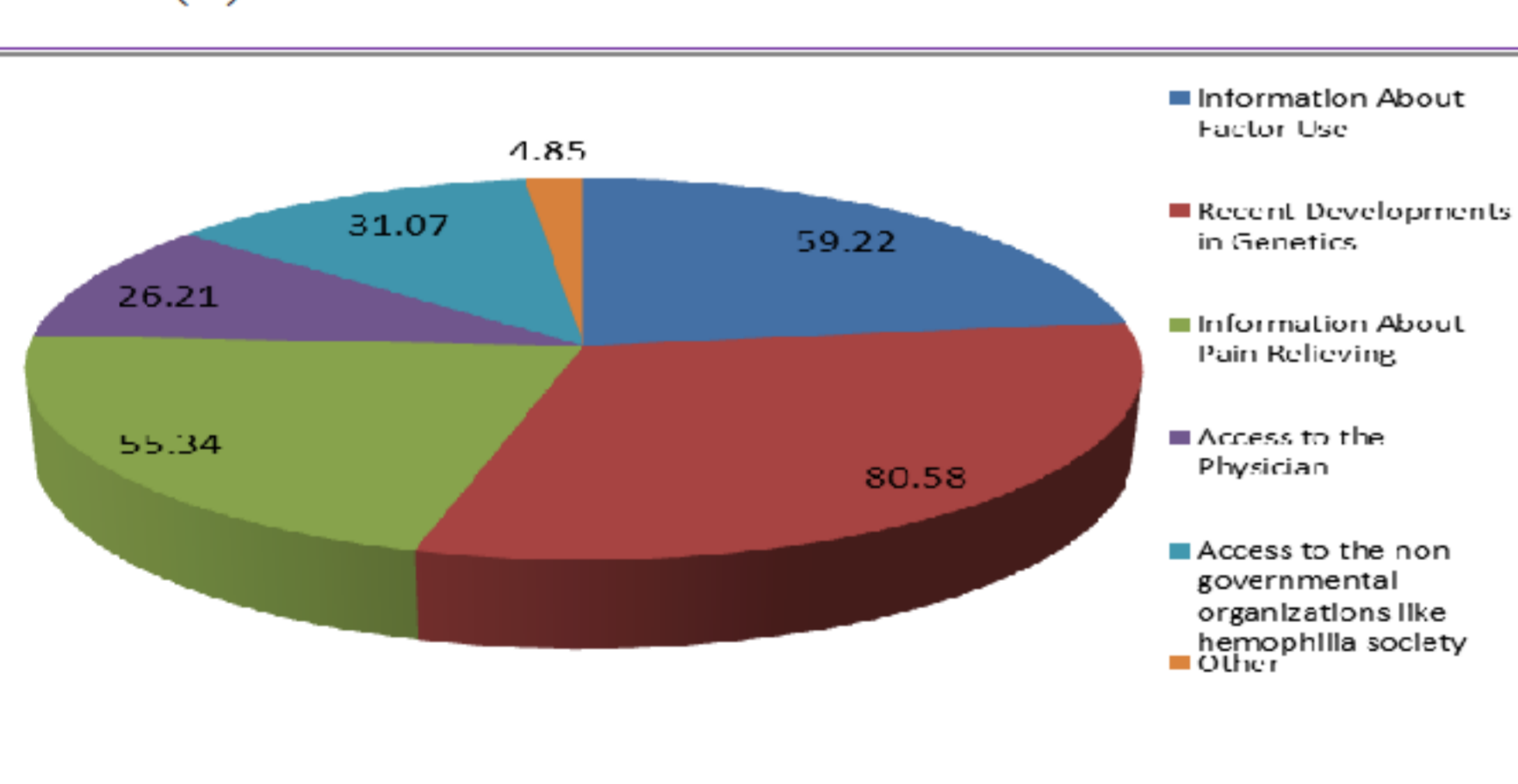
A The ordered correlation analysis (ps) was also performed to determine the effect of the recognition of the searched individual by the hemophiliac in the internet usage of the patient with hemophiliacs. This analysis demonstrated that there is a statistically significant relationship between them ($p < 0.05$) and the ratio is -37.50% (Figure 2). Moreover, analysis to determine the subject of the health information that was looked up in the internet demonstrated that alternative and new treatment options was the major search subjects with a ratio of 56.3%. On the other hand search on medical doctors was not common (45.6 %) (Figure 3).



We also analyzed the frequency of looking up health information about hemophilia by the patients with hemophilia. Our study demonstrated that 3% of the patients never look up, 29.1% look up rarely, 47.5% look up from now and then and 20.4% look up regularly for hemophilia. It is determined that 3 of the 4 hemophiliacs (76.70%) of the hemophiliacs look up for hemophilia in the internet rarely or from now and then. Moreover, we compared the frequency of hemophilia search of the hemophiliacs according to socio-economic status and age. This study demonstrated that the hemophiliacs who look up for hemophilia in the internet rarely are in the upper socio economic status and in the age group of 25-34, the ones who used internet for hemophilia search from now or then are in the age group of 16-24 and the ones who used the internet regularly for hemophilia search are in the middle socio economic group and 35 and older age group.

The results that demonstrate which information that the hemophiliacs look up in the internet are given in figure 4. It is clearly seen that the major area of interest of the hemophiliacs in internet include the recent developments in genetics and information about the factor use (the answers are multi-answers). The goodness of the fit between the socio-economic status and the hemophilia related search subject was analyzed by using chi-square analysis (χ^2) [18], however we could not identified a significant relationship ($df=2$, $p > 0.05$). However, there was a significant relationship between the age group and the search word, except access to the hemophilia centers [19] ($6,022 \leq \chi^2 \leq 12,308$; $p < 0,05$)

Figure 4. the searched information of the Patient with Hemophiliacs in the internet (%)



The distribution of the searched information according to the age is that, 76.3% of the searched information is about factor and its use, 68.4% is about the pain relieve and these percentages were significant ($p < 0.05$). The recent developments about genetics are searched more by the patients in the age group of 25-34 (93.1%) and 35 and older (85.71%) ($p < 0.05$). Access to the medical doctor was searched more by the patient in age group of 25-34 and 35 and older. On the other hand, there was no significant difference between the age groups in the search to find the access to the hemophilia society centers ($p > 0.05$).

internet has shown that 39.8% of the hemophiliacs have confidence in the information they obtained from the internet. In order to confirm the information they got in the internet, 93.7% ask their physician, 58.3% ask to the representatives in the hemophilia society centers, 55.2% ask to the other health institutions. Despite this, 13.6% of them did not talk about the confidence of the internet information with their physicians when they visit them. 71.6% of those talk about the information with their physicians rarely or from now and then. The seven different responses of the physicians that the hemophiliacs get when they share the internet information with them are given in Table 2. 74.1%

of the physicians make explanations about the subject. Patients in the upper socio-economic status stated that they either do not get a response or they get an explanation. However, the response of the physicians show variations when the middle or lower socio-economic status patients share the information with them. 90.3% of the hemophiliacs get suggestion from the doctors to create a web site about hemophilia, or visit a group, forum, and similar site. 8.7% of the suggested web pages were hemophilia Society web pages, 1.9% was web sites of the physicians. 90.3% of the patients don't/can't communicate with their physicians online. This ratio is higher when they would like to communicate with the other health personelles (95.1%). 11.1% of the patients who can communicate with their physicians online is in upper socio-economic group, 5.7% is in middle group and they are in the age group of 34 and younger. Those who are in 35 and older never communicate with their physician online.

Figure 3. The search subject of patients with hemophilia (%)

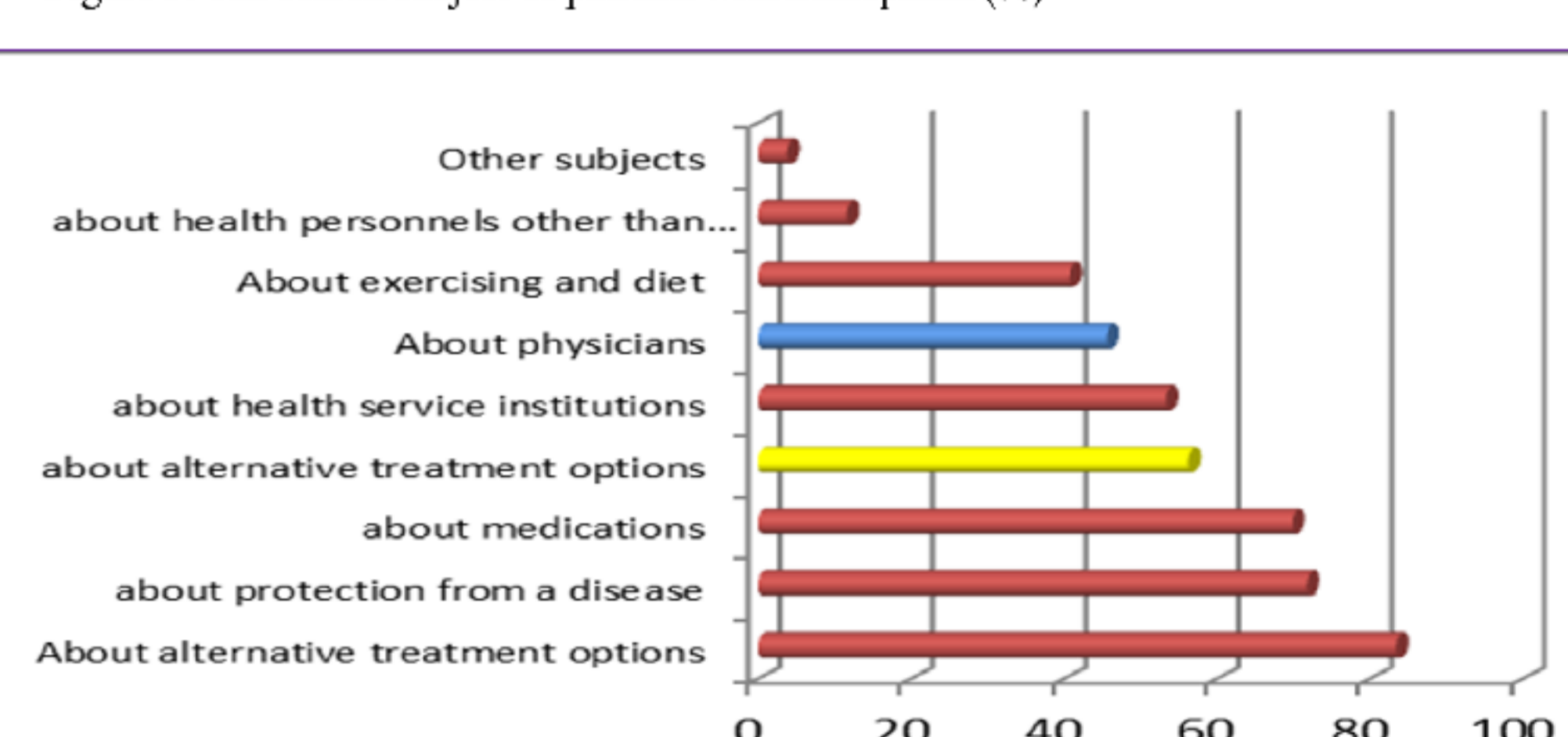


Figure 4. the searched information of the Patient with Hemophiliacs in the internet (%)

Response of the physician	General	Socio-economic group		
		Upper	middle	Lower
Make an explanation about the subject	74.16	88.89	67.47	80.555
Does not give a response	8.99	11.11	10.545	5.555
Says do not act without asking him	6.74	0	10.225	2.78
Says do not believe in everything and even reprimand	4.49	0	3.705	8.335
Says make wright and detailed search	4.49	0	4.025	5.555
Makes suggestions	4.49	0	5.555	2.78
Appreciate us being aware of it	3.37	0	5.88	0

DISCUSSION

All the Pwh internet user look up for health information but 25% does this regularly. The frequency for looking up for health information increases with the decrease in their SES and with the increase in their age. 83.5% of the health information searched in the internet is related to the diseases and 56.3% of the subject was about alternative treatment options. The search about physicians and hematologists is very rare. Most of the patients (76.7%) look up for hemophilia related issues rarely or from now and then. In other words only 23.3% of the Pwh look up for hemophilia in the internet regularly. The majority of the subjects looked up in the internet was the recent genetic developments. We did not identify a relationship between the SES and the search subjects but we identified a significant relationship between the age and the search subject. Pwh in the age of 16-24 group mainly search about factor, factor usage and pain relieve. However, Pwh who are 25 and older look up for a physician and genetic developments mainly. The ratio of the search about the other Hemophilia societies in the social, experience purposes had similar frequency in all age groups. 40% of the Pwh had confidence in the information they got through internet. In case of a doubt, 93.75% of them apply their physicians to confirm the information. The hemophilia societies get the second place, and the other societies get the third place to confirm the internet information. %74.16 of the physicians make an explanation when the Pwh share the internet information with them, %8.99 of the physicians do not make any comment. As the SES of the Pwh decreases, the response of the physician's response varies; even they get reprimanded by the physician. Studies have demonstrated that 3.88% of the Pwh communicate with their physicians online and they belong to the upper SES group and younger than 34 years old.

REFERENCES: Anreassen HK, Trondsen M, Kummervold PE, Ganmon D, Hjortdahl P. (2006). Patients who use e-mediated communication with their doctor: new constructions of trust in the patients-doctor relationship. *Qualitative Health Research*, 16 (2):238-248; Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. (2010). The patient-doctor relationship and online social networks: results of a national survey. *J Gen Intern Med* 26 (10):1168-74; Greene JA, Choudhry NK, Kilabuk E, Shrank WH. (2010). Online social networking by patients with diabetes: a qualitative evaluation of communication with facebook. *J Gen Intern Med* 26 (3):287-92; Khair K, Holland M, Carrington S. (2012). Social networking for adolescents with severe haemophilia. *Haemophilia*, 18 (3): 290-296; Barlow JH, Stapley J, Ellard DR, Gilchrist M. (2007). Information and self-management needs of people living with bleeding disorders: a survey. *Hemophilia*, 13: 264-270; Shachak A, Reis S. (2009). The impact of electronic medical records on patient-doctor communication during consultation: a narrative literature review. *J Evaluation Clin Practice* 15: 641-649; Leong SL, Gingrich D, Lewis PR, Mauder DT, George JH. (2005). Enhancing doctor-patient communication using email: a pilot study. *JABFP* 18 (3): 180-188; Liederman EM, Lee JC, Baquero VH. (2005). Patient-physician web messaging, the impact of message volume and satisfaction. *J Gen Intern Med* 20: 52-57; McMullan M. (2006). Patient using the internet to obtain health information: how this affects patient-health professional relationship. *Patient Education and Counseling* 63: 24-28; Bass SB, Ruzek SB, Gordon TF, Fleisher L, McKeown-Conn N, Moore D. (2006). Relationship of internet health information use with patient behavior and self-efficacy: experiences of newly diagnosed cancer patients who contact the national cancer institute's cancer information service. *J Health Communication* 11(2): 219-236; Broom A. (2005). Virtually he@lthy: the impact of internet use on disease experience and the doctor-patient relationship. *Qualitative Health Research* 15 (3): 325-345; TÜAD (Turkish Research Association-Social Economic Status Study, 2012, İstanbul; TÜİK (Turkish Statistical Institution Households Technology Usage Research 2013, 13569, www.tuik.gov.tr; Thompson SK. (1992). Sampling. John Wiley & Sons Inc., Canada, p.9-25; Chisnall P.M. (1992). Marketing Research, 4.Baskı, The Mc Graw Hill, Berkshire, p.64; yberg L, Biemer P, Collins M, Leeuw ED, Dippe C, Schwarz N, Trewin D. (2012). Data Collection Methods and Survey Quality: An Overview Leeuw E.d., Collins M., Survey Measurement and Process Quality, John Wiley & Sons, p.199-220; Uzgören N. (2012). Bilimsel Araştırmalarda Kullanılan Temel İstatistiksel Yöntemler ve SPSS Uygulamaları-2. Baskı, Ekin Basın Yayın Dağıtım, Bursa, s.36-47; Kan İ. (1994). Biyoistatistik, 2. Baskı, Uludağ Üniversitesi Basımevi, s.128-143; Alpar R. (2012). Uygulamalı İstatistik ve Geçerlilik-Güvenirlilik, 2. Ed, Detay Yayıncılık, Ankara, s.189-194