



# Internet Use Habits of Parents with Children Suffering from Food Allergy

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## ABSTRACT

**Objective:** Children with food allergy need special care. Therefore, parents of food allergic children usually seek information on the internet to improve their knowledge. However, the quality and accuracy of internet-based information may vary and misdirect parents in their daily practices.

**Materials and Methods:** We aimed to investigate the habits of internet usage in the families reporting cow's milk protein allergy or multiple food allergy in their children. This study was conducted by using a web-based questionnaire that can be completed on the Internet in Facebook groups of families who stated that their children had diagnosis of food allergy.

**Results:** A total of 458 (96% female) individuals with a mean age of  $32.03 \pm 4.49$  years participated in our survey. Three hundred forty three (74.9%) participants reported that they have preferred the internet to get information associated with the complaints of their children before seeing a physician. Two hundred ninety five (64.4%) participants reported that the information obtained on the internet and the information provided by the physicians were sometimes contradictory. As regards the contradicting information, 147 (49.8%) participants reported that they relied on the information provided by the physicians, whereas, 43 (14.9%) reported that they relied on the information on the internet. In addition, 44.3% stated that they always or most of the time gave advice to other patients and their families on the internet.

**Conclusion:** Considering that social media use is an unpreventable habit, online sources should include correct information for information-seeking parents and should possibly be supervised or be certified by health institutions and organizations.

**Keywords:** Food allergy, internet, social media, parents

## INTRODUCTION

Food allergies affect 2-10% of the population and pose an important public health problem. They can also cause morbidity, adversely affecting the quality of life of both the patients and their families (1,2). The disorder usually requires long-term treatment and follow-up, and affected families are constantly in search of information from various sources. Today, the internet is among the most influential sources of health information.

Parallel to the worldwide increase in internet usage, the use of the social media is also on the rise. While the

global rate of internet usage was 25% in 2009, nearly 50% of the world's population was online in 2015 (3). Directly proportional to these data, the usage of social media increased by 176 million individuals between 2014 and 2015, reaching 2.2 billion people or approximately 30% of the world's population (4). Consistent with this trend, internet and social media use has also increased in Turkey. 'WeAreSocial' acts as a transformation agency in the field of digital marketing and publishes reports annually on the world's digital usage. According to 'WeAreSocial', there have been 40 million (52%) active social media accounts in Turkey on June 2015. The most commonly used social media platform was Facebook, with a rate of 26% (5).

The internet and social media have various areas of use, one of which is health communication (6). These are not only vehicles for obtaining information and sharing health-related experiences, but also play a role in decision-making as individuals collect information and recommendations on health issues, health care centers, and physicians (7). There is limited information in the literature on the internet usage habits of parents of children with food allergy. The aim of this study was to investigate internet use pertaining to food allergy in families reporting cow's milk protein allergy or multiple food allergy in their children.

## MATERIAL and METHODS

After obtaining approval from the hospital ethics committee, our study was conducted in August 2016 using an online survey form created by Google Drive and presented to Facebook groups with members reporting that they were the parents of children with food allergy. Facebook was chosen as the online social media platform for this study because it is the most commonly used one in Turkey. A study investigator published the link of the online survey from his private Facebook account to the Turkish groups and with posts in the Turkish language and invited the parents to fill it. By this way, the parents could be able to answer the questions online.

There were 24 questions in a new questionnaire adapted from a previous study (8). Six of the 24 questions were related to the socio-economic status of the patients and/or parents, seven of them were related to internet usage frequency and diversity of sources, and seven of them were related to reasons for communicating with other patients' parents. The remaining four questions were about trust in the information provided on the internet. Two of the survey questions were fill-in-the-blank and 22 were multiple-choice. The survey form was uploaded to the pages of two Facebook groups founded by the parents of children with food allergy. The form was accessible for three weeks. Parents who volunteered to participate completed and submitted the form online.

The analyses were performed using SPSS 22 (IBM Corporation, Armonk, NY). Descriptive data were expressed as frequency (%); continuous data showed a normal distribution and were expressed as means ( $\pm$ standard deviation). The chi-square test was used to compare the two groups based on categorical variables. A value of  $p < 0.05$  was considered statistically significant.

## RESULTS

A total of 458 individuals (96% female) with a mean age of  $32.03 \pm 4.49$  (min=21, max=56) years participated in our survey. The education level was undergraduate degree or higher in 358 (78.1%) of the participants. Fifteen (3.3%) participants reported allergy to food allergens other than cow's milk in their children, while 212 (46.2%) participants reported that their children were allergic to multiple foods including cow's milk. The children of the remaining 231 (50.5%) participants were allergic only to cow's milk. Of the respondents, 112 (24.4%) had children with comorbid allergic disorders. These included atopic dermatitis in 67 (14.6%), allergic rhinitis in 65 (14.2%), asthma in 55 (12%), and drug allergy in 37 (8.1%) of the children.

The physician to whom the parents first have applied was a pediatrician in 254 (55.4%), a pediatric allergist in 123 (26.8%), a pediatric gastroenterologist in 80 (17.4%), and a pediatric surgeon in 1 (0.2%). In addition, 179 (39.1%) participants reported that their children had been evaluated by a total of four or more physicians to date (Figure 1A). Three-quarters ( $n=343$ , 74.9%) of the participants reported that they used websites and social media to find information related to the complaints of their children before consulting a physician. Sixty-four per cent of the participants have referred to these sources all the time (Figure 1B).

According to the participants' responses, the most commonly used website/social media platform was Facebook and more specifically patients' and/or patients' parents groups (100%), followed by physicians' official Facebook pages (41.4%), physicians' websites (32.8%), websites presenting academic articles and research information (such as PubMed, Clinical trials.gov) (31%), personal blogs (27.2%), the websites of state institutions (19.4%), Youtube (16.3%), foreign-based web pages (such as Medscape, e-medicine) (13.9%), private hospitals' web pages (4.4%), Twitter (0.8%) and Pinterest (0.65%).

Most of the respondents (86.3%) reported that they have found the internet sources as reference by themselves using online search engines and 86% reported that they were helpful (Figure 1C). According to the participants, the most helpful sources were Facebook patients' and/or parents' groups (65.8%), followed by physicians' websites (41%) and physicians' Facebook pages (36.9%). Private hospitals' websites were reported to be the least helpful sources, with only 16.3% of the participants referring

to them (Figure 2). Table I shows the content of the information the parents obtained from these sources.

Nearly two-thirds of the participants (n=295, 64.4%) reported that the information obtained online sometimes have included contradicted information provided by their physicians (Figure 1D). Regarding this contradiction, 147 (49.8%) participants have relied on the information provided by their physicians, whereas 43 (14.9%) have relied on the information obtained online. Thirty-eight

(12.5%) participants have relied in part on both sources and 67 (22.8%) participants have preferred to consult another physician. Of the participants who relied on the online information, 37 (87%) reported that they have mostly used the Facebook pages for patients and/or parents, 17 (39.5%) physicians' Facebook pages, 17 (39.5%) websites presenting academic articles and research, 16 (37.2%) physicians' websites, eight (18.6%) state institutions' websites, five (11.6%) foreign-based websites, and three (6.9%) the websites of private hospitals.

Notably, 203 respondents (44.3%) have always or most of the time held discussions with other parents based on their experiences or knowledge. Another 171 (37.3%) participants reported that they have had discussions with other parents sometimes and 84 (18.4%) reported that they had never done so. The most common content of the topic of discussion was emotional support for 64.7%. The topics of discussion are presented in Figure 3.

DISCUSSION

Our study findings show that 343 participants (74.9%) have referred to the internet to get information associated with their children's complaints before consulting a physician. In addition, 44.3% stated that they always or

Table I: Contents of the information that participants obtained online.

| Information acquired online                                      | Frequency n (%) |
|--|-----------------|
| Diagnostic methods   | 356 (80.5)      |
| Medical information about the disease                            | 338 (76.4)      |
| Doctor or hospital recommendations                               | 321 (72.6)      |
| Food recipes   | 336 (76.0)      |
| Diet recommendations   | 303 (68.5)      |
| Treatment, prescription, travel, school, nursery recommendations | 284 (64.2)      |
| Food ingredients   | 256 (57.0)      |
| Formula recommendations  | 210 (47.5)      |
| Results of scientific studies                                    | 191 (43.2)      |

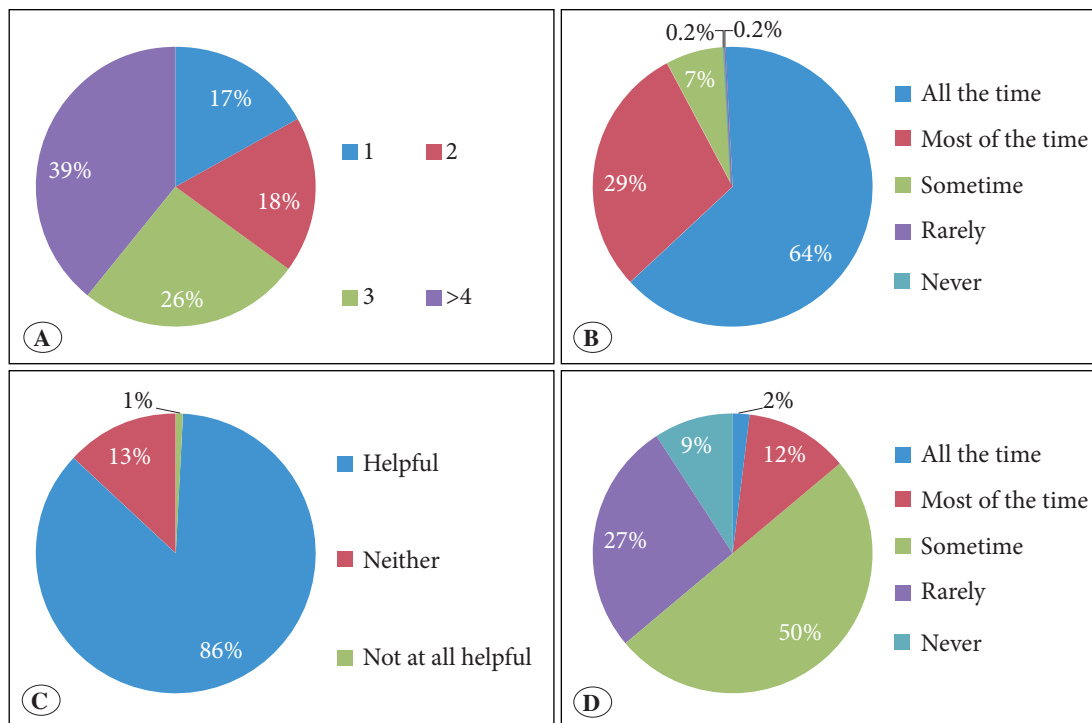
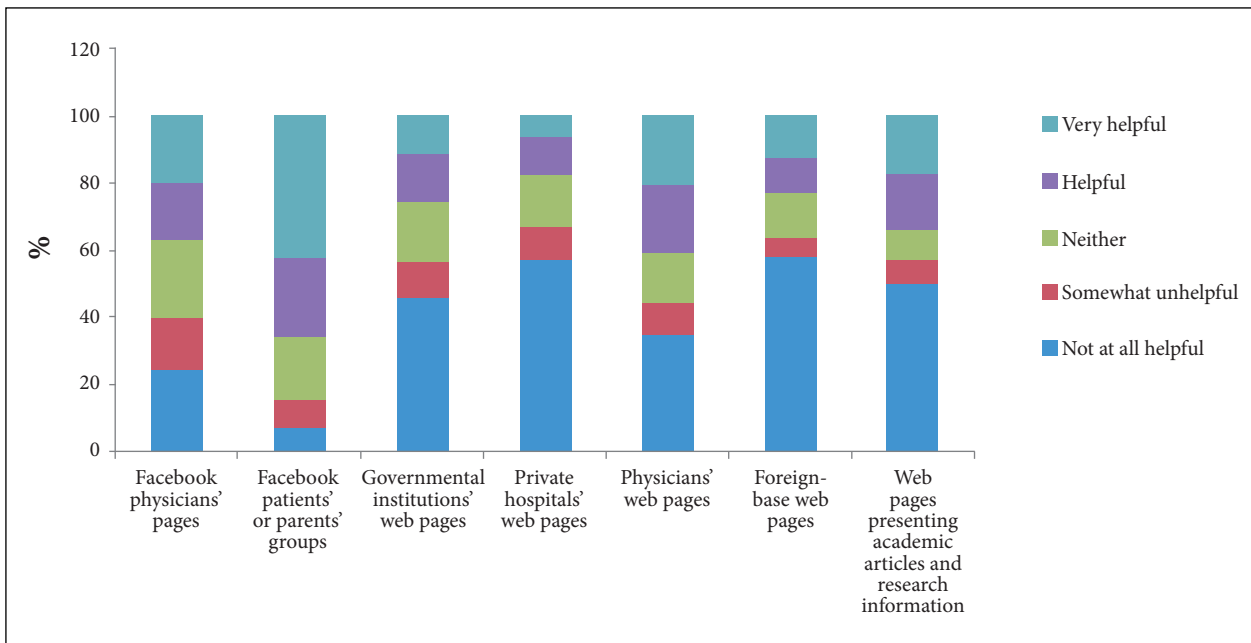
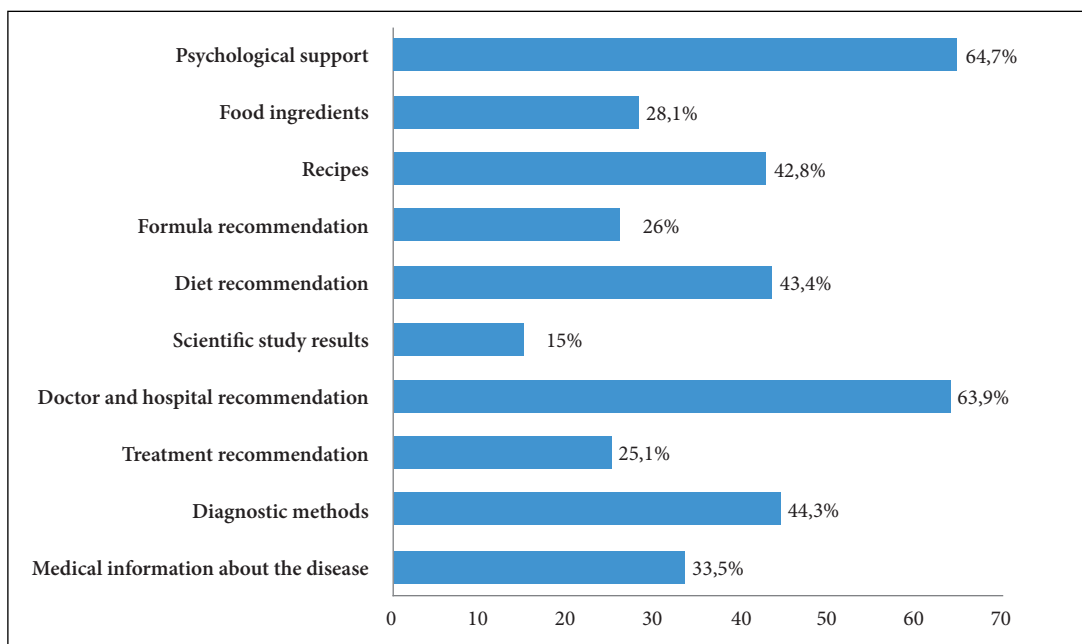


Figure 1. A) Number of physicians seen to establish a diagnosis for their children, B) Rates of internet use of the parents, C) Rating of usefulness of resources, D) Rates of contradiction between information obtained online and information provided by physicians.



**Figure 2.** Resources that participants find useful.



**Figure 3.** Recommendations made by participants to other patients and their families.

most of the time gave advice to other patients and their families on the internet.

As internet access becomes easier and more widespread, more patients and parents are gaining access to health information. Social media platforms enable large populations to access health-related information with no restrictions of time or place, and also provide emotional

and motivational support during treatment processes (9). In order to get information and to connect with each other, patients and their parents refer to the internet concerning food allergy, a disorder which can have a major negative impact on individuals' daily activities. Therefore, it is important to understand the health-related internet usage habits of these patients.

The majority of the participants in our study were young women with high education level. Carpio-Escalona et al. investigated the internet usage habits of patients and parents presenting at allergy clinics and, similar to our study, most of the parents had been female and had had undergraduate degrees or higher levels of education (10). Three-quarters of the participants reported that they have always referred to printed and visual media, websites, and social media sites before consulting a physician. Carpio-Escalona et al. reported this rate to be 54% in their study (10). At the same time, according to another study, 41% of the individuals have expressed that going to health care centers for information was waste of time (11).

While all of the respondents were members of Facebook groups and used Facebook actively, only 19.4% referred to state institution websites. This suggests that the participants are interested in the opinions of peers who also have children with the same disorders and are facing similar experiences. In the present study, 86.3% of participants reported that they found their information sources by themselves using the online search engines. Similarly, Ross et al. evaluated internet use in patients with food allergy and their parents and reported that this method have also been the most commonly used one in their study (75%) (8). In our study, the parents primarily have obtained information about diagnosis and diagnostic methods from these sources; however, Carpio-Escalona et al. reported that the individuals in their study mostly had received general information.

It is noteworthy that 64.4% of the participants reported contradictions between the information obtained from online sources and the ones from their physicians. Only half of them have trusted the information they received from their physicians in our study. In contrast, in a study by Ross et al., 25% of the participants reported a contradiction between online sources and physicians, and 71% of them reported that they relied on the information they have received from their physicians (8). A previous study conducted in Turkey evaluating information regarding atopic dermatitis on the internet showed that websites related to atopic dermatitis were insufficient regarding both the authors' qualifications and the content, suggesting an important unmet need in our country (12). We suggest that this might be true for food allergy as well, leading to discrepancies between physician-provided information and online information.

Almost half of the participants in the present study reported that they have always or most of the time gave

recommendations to other parents based on their own experiences and knowledge. The most common content of the recommendations was emotional support, at a rate of 64.7%. A study evaluating health-related social media use among patients demonstrated that the patients' primary motivation for internet use was to communicate with other patients (13). Sharing support and other information to facilitate their daily activities may be beneficial for families in terms of quality of life. In addition, a substantial proportion of the parents reported giving recommendations to each other regarding treatment and diet. However, this is a very delicate situation that should be approached cautiously, as potential misinformation and incorrect dietary recommendations might pose devastating influences on the development and wellbeing of developing children.

Our survey was conducted via Facebook because it is the most commonly used social platform in Turkey. Therefore, a limitation of this study is that the results cannot be generalized to the internet usage habits of the entire population of families of children with food allergies.

Another noteworthy finding of this study is that two-thirds of the participants reported that information on the internet have contradicted information provided by physicians, and of these participants, 22.7% stated that they have consulted another physician in such cases. This suggests that there is information pollution on the internet which may foster mistrust in parents, resulting in increased use of health care services. More active participation of physicians in online media might help to resolve this problem and avoid this additional burden on the healthcare system. However, parents' preference for using Facebook over state institutions' websites demonstrates how important it is for physicians to provide relevant and reliable information in simple and understandable terms. The Ministry of Health, state agencies and national allergy associations have important responsibilities to facilitate the access of families to accurate instructions about food allergy.

In conclusion, as the use of social media is an unavoidable reality today, a stronger and more accessible online presence by physicians might be helpful in order to provide accurate information and appropriate recommendations to patients and their parents. Another possibility is to officially monitor these sites and introduce a certification process to ensure the accuracy of health information contained therein to prevent potential adverse effects on patients' wellbeing.

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