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Patients' perspectives on the quality of online patient education materials: A qualitative study

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Abstract:

BACKGROUND: Access to online patient education information can lead to more effective self-care and disease management. However, the large amount of online information provided through unknown or unreliable sources can challenge patients to trust and use this information. This study was designed to examine the opinions of Iranian gastrointestinal patients about the quality of online information used.

MATERIALS AND METHODS: A qualitative study was conducted using thematic analysis. Data were gathered via a semi-structured interview with 29 gastrointestinal patients, and data analysis was performed by qualitative content analysis using open coding with MAXQDA 2018 software.

RESULTS: Based on the study, 22 codes were extracted in nine subcategories named as: "Emphasis on the identity of providers," "Nature of online information," "Distrust on online information," "Poor quality of information," "Giving misinformation," "False impact," "Improve communication," "Positive effect on the patient," "Better Diagnosis."

CONCLUSIONS: In the current situation, Iranian patients are not confident enough about the quality of available online information. They believe that the use of current poor-quality information has negative consequences. However, they tend to use online patient education materials are produced in Persian by reputable scientific authorities. Using online information can increase patients' knowledge and lead to better communication with medical staff and other similar patients. They can use this information for self-care with more confidence, and such an approach can also have significant benefits for the national health system.

Keywords:

Distance, education, internet-based intervention, patient education as topic, self care

Introduction

Due to the simplicity and ease of access, internet has become an important information source that many patients trust and use it.^[1-4] They prefer it to reap the health and social benefits and the benefits of modern media.^[1,5-8] Studies have shown that the use of online patient education materials (OPEMs) as understandable educational online patient handouts that have been developed by reputable scientific authorities can have a significant impact on

patients' health information. Using OPEMs could affect their role in treatment, effective communication with medical staff, reduces the cost of educational intervention, saves time, increases patient satisfaction, provides better feedback, and promotes self-efficacy and a healthy attitude.^[3,5,9-11]

Patients use online information resources to locate and visit a doctor with more knowledge, find the right treatment or medicine, diagnose the disease, and identify similar patients or related services.^[1,6,12,13] Gastrointestinal diseases are one of the most

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common diseases in Iran among different groups that can be managed to some extent by changing behavior and improving self-care by providing information to patients. The patients' information-seeking behavior pattern is usually similar between different diseases.^[8] This pattern is sometimes affected by variables including age, gender, education, health literacy, and self-confidence.^[1,2,12,13] Iranian patients often meet their information needs by searching the internet. According to the statistics, 87.6% of the Iranian population is literate.^[14] 95.9% of households have access to mobile phones and 72.8% to the internet. Furthermore, 63.4% of Iranians use the Internet at least once a day.^[15]

However, OPEMS, as one of the most widely used online resources for patients, also has its limitations. These resources are published in a wide range of quality and nature of producers.^[16,17] It has become one of the patient's concerns and makes them hesitate in recognizing the information quality.^[2,12] OPEMS may be produced by physicians, medical teams, academic medical departments, insurance companies, biomedical industries, newsgroups, news agencies, or even individuals with unrelated specialties.^[18-20] In many cases, there is no credible evidence that who is responsible for OPEMS.^[18] Furthermore, the publication date of some OPEMS is several years ago, while the half-life of medical content is less.^[20] Most of the current OPEMS are not complete and useful in the opinion of health professionals or are presented in a complex and difficult text.^[21]

Today, a significant percentage of patients have access to mobile devices to use the internet.^[12,14,15,22] Many of them use search engines to search for any information about their diseases.^[7,23] The people trust these online results, but some even cannot say the names of the used websites.^[1,13,24] While the basis of search engine rankings is based on page views and other features that may not be properly related to the quality of content, it probably could hide quality websites from the user.^[17] Much of the retrieved OPEMS through public search engines do not meet the standard criteria,^[17,19,25-28] and the readability level of some retrieved OPEMS is higher than usual.^[29-32]

Various reasons including valid information about the producer, scientific or official support of the website, being recommended by physicians or other resources, having references for content, ability to prepare tailored information, providing reliable and evidence-based information, and having an interactive nature can increase trust in online information.^[13,20]

Considering the advantages of using OPEMS compared to other existing methods and favorable conditions of the society for accessing and using this type of

information, it is necessary to have a plan to allow patients to use quality information approved by the health system. This paper reports the views of Iranian patients with common gastrointestinal diseases as one of the most common diseases, about the current OPEMS, and the benefits and problems of using this type of information for patients.

Methods and Materials

Study design and setting

This is a qualitative study using thematic analysis to identify the patients' views and concerns regarding the quality of current online available patient education materials. This study was conducted among a group of Iranian patients with common gastrointestinal diseases.

Study participants and sampling

Twenty-nine referred patients to the hospitals of Isfahan University of Medical Sciences in 2019–2020 were selected for the study by purposeful sampling with a maximum variation of gender, education, type of diseases, and treatment experience.

Inclusion criteria were, having basic literacy, suffering from one of the most prevalent gastrointestinal diseases, including dyspepsia, irritable bowel syndrome, constipation, bloating, and fatty liver, living in Isfahan province, and following treatment for more than a year. Exclusion criteria were lack of experience using OPEMS.

Data collection tool and technique

Data collection was performed between November 2019 and December 2020. We used semi-structured interviews and the discussion included questions about patients' views on OPEMS. We asked participants to express their views clearly and freely. Data were collected using participants' voice recordings with their knowledge and consent. Open general questions were used to start the interview and where necessary, the order of the questions was changed according to the interviewer's desire and expression.

Questions included, "What disease have you been suffering from and for how long?" "How do you find information about your illness?" "What has been the quality of the information you have found so far?" "What is your opinion about the effects of using OPEMS?" "What is your opinion about the existence of a comprehensive online source for providing patient education materials to Iranian patients?" The approximate duration of each interview varied from 20 to 50 min, depending on the patient's preferences, and lasted until a new finding was added. Data collection continued until saturation was reached, and previous findings were repeated with no new points.

After each interview, we listened to the recorded interviews carefully and fully transcribed the text of the interview. Interview data were analyzed during data collection using MAXQDA 2018 software. Data analysis was performed using conventional content analysis with open coding and data saturation was met when no new concepts emerged from subsequent interviews. In subsequent revisions, the codes were merged or modified as needed. By categorizing the codes, the initial subgroups obtained, and then, by examining the subgroup relationships, the themes were identified.

To achieve credibility, participants were selected with the maximum variety of experiences. To increase dependability, we tried to avoid prolonging data collection time and tried to ask all participants questions according to a relatively specific pattern. We employed the external member-checking technique for ensuring the transferability of the study findings.

Ethical considerations

This research had approval from the Research Ethics Committee of Iran University of Medical Sciences with IR. IUMS. REC.1397.859 ethical code. Participants voluntarily cooperated with their written consent. At the beginning of each interview, we informed participants about the research objectives, methods, process, and the possibility of leaving the interview whenever they wanted. The confidentiality of information was considered through and after the interview.

Results

According to the results, the age range of the 29 patients was 18–72 years, and the maximum number of patients belonged to the 36–45 age group. Table 1 shows the demographic details of interviewees.

According to the study’s objectives, we asked patients about the quality of online information they retrieved. We derived 22 different codes with 103 repetitions from the interviews. Codes were categorized into nine sub-categories and three main categories as shown in Table 2.

Features of current online patient education materials

Based on the results, we identified six features for OPEMs in two subcategories as follows:

Emphasis on the identity of providers

According to patients, identifying the creators and providers of online information can influence their decision-making and acceptance of the educational content provided in these resources. Fifteen patients believed that they could not trust unknown providers. Everyone can generate and distribute whatever they

Table 1: Demographic characteristics of research participants

Variable	n (%)
Age	
16-25	4 (13.8)
26-35	6 (20.7)
36-45	10 (34.5)
46-55	3 (10.3)
56-65	4 (13.8)
66-75	2 (6.9)
Gender	
Male	20 (69)
Female	9 (31)
Education level	
Primary education	7 (24.1)
Diploma	11 (37.9)
Associate	2 (6.9)
BSc	7 (24.1)
MSc	1 (3.4)
Ph.D.	1 (3.4)
Types of illness	
IBS	5 (17.2)
Dyspepsia	7 (24.1)
Constipation	4 (13.8)
Flatulence	8 (27.6)
Fatty liver	5 (17.2)
Occupation	
Student	3 (10.3)
Office worker	4 (13.8)
Self-employed	6 (20.7)
Laborer	5 (17.2)
Homemaker	7 (24.1)
Retired	4 (13.8)
Place of residence	
Urban	17 (58.6)
Rural	12 (41.4)

want. “Anyone can generate information on the internet, so we could not trust every piece of information we see on the internet” (P 12).

Eleven participants expressed that they trusted more in well-known websites. Patients seemed to rely on published information by a well-known physician more than any other resources. “It is important to me who the author of the content is? If a famous specialist surgeon publishes an article through his website, I can trust it (P 19).

Seven patients believed that they had the most trust in government websites. “It depends on the website, which is managing and producing and delivering its content is very important, whether it is directed by a formal institution or not?”(P 1).

Nature of online information

Several participants believed that due to the nature of online information production and dissemination,

Table 2: Codes related to patient’s perspectives on the quality of online patient education materials

Code	Participants code	Sub-category	Category
Distrust to unknown providers	1,2,4,13,20,21,22,24,26,27,28,29	Emphasis on the identity of providers	Features of Current OPEM’s
Trust well known websites	1,14,20,22,24,27,28,29		
Trust on official organizations	1,4,22,26,28,29		
Diversity of OPEMs	4,11,14,20,28,29,30	Nature of Online Information	
Information redundancy	5,20,28,29		
More potential impact	16,17		
Unreliable drugs information	3,15,28,29	Distrust in online information	Disadvantages of using OPEM’s
Unreliable recommendations	19,24,26,27,30		
Contradiction with medical Principles	1,28		
Ambiguous quality of OPEMs	1,10,13,14,17,19,21,22,23,28	Poor quality of information	
Lack of governmental websites	8,12,24,30,		
Misleading advertising	17,20,24,27,30	Giving misinformation	
Inaccurate mentality of disease	6,27		
Increase anxiety	9,13,27	False impact	
Doubts about the prescription	12,13,27		
Usefulness of OPEMs	6,13,14,24	Improve communication	Benefits of using OPEM’s
Creating a common language	5,14,22		
Knowledge sharing	20,29		
Increase patient’s awareness	13,15	Positive effect on the Patients	
Taking disease seriously	15,17		
Preliminary diagnosis	3,24	Better Diagnosis	
Reducing medical errors	16,24		

OPEMs: Online patient education materials

there is a diversity of OPEMs that makes it somewhat challenging to identify the correct information. Eight patients reported retrieving incompatible websites with various contents. “I have retrieved several websites when I search the Internet, each of them may have provided a different recommendation or treatment” (P 4). Diversity of online information can confuse patients and prevent them from recognizing the correct information. “If the content is repeated in several websites, then people’s confidence will increase. But if each of them provided different information, people will doubt them “(P 13).

Four participants explained that when the content of search results is repetitive or visually similar, patients become confused about the quality and validity of this information. “Some online Information even is copied from other websites, so I read this content with a skeptical look. This prevents me from confidently following the solution provided on these websites” (P 27). Two patients believed that the online information may have a more significant impact on the patient’s decisions rather than other sources. “Not everything available on the Internet can be trusted. Because it is easier and more accessible, most people may accept it” (P 16).

Disadvantages of using online patient education materials

Based on the patients’ opinions regarding the provision of online information, the existing shortcomings in this area were identified as follows:

Distrust of online information

People cannot trust online information, especially when it comes to trusting medications listed on websites. Five patients admitted that they could not trust the online drug information. “I do not use online information that introduces medications unless my doctor recommendation” (P 15).

Four participants explained that online offered prescriptions could not be used with certainty. “Regarding the accuracy of the information, I cannot always trust the online information, but if this information appears in a reliable source, we can trust it “(P 25).

Two patients believed that because providing medical advice requires specialized knowledge, online medical advice may not be reliable. “Because medicine is a complex specialty, we cannot rely too much on the online information, because every disease has different dimensions that must be examined by a specialist” (P 1).

Poor quality of information

Due to the self-publishing nature of online information, patients were skeptical about the quality of online information. Ten patients mentioned the existence of invalid information as a limitation. “I think some of my retrieved online information is not very credible because anyone can publish anything” (P 20).

Four patients stated that they did not have access to patient education websites affiliated with the Ministry

of Health and were forced to refer to unofficial websites.

"I have not found special well-known website affiliated with the Ministry of Health or medical universities except for the websites of certain Physicians or pharmaceutical and commercial companies"(P 23).

Giving misinformation

Patients believed that OPEMs might provide inaccurate information to patients. Five patients thought that if educational information is accompanied by advertisements or for-profit services or products, it may affect patients' choice. "Unfortunately, online information sometimes attracts people by a certain set of behaviors. That's why I usually ask my questions from several sources" (P 16).

Two participants believed that current OPEMs may not provide an accurate mentality of the disease. "Some websites list all the possible consequences of the disease, while expressing multiple complications may confuse the patients about their own disease"(P 26).

False impact

Three participants expressed that online information can cause patients fear, anxiety or frustration and lead to patients' discouragement. "The online information I found was mostly written in general, and had described all the possible consequences of the disease. This makes the patient worried and frightened"(P 26). In two cases, patients have doubts about the doctor's prescription because of observing various online prescriptions and inability to analyze information.

"Patients may search the internet and then protest to the physician why you prescribed this medication to me while it's related to another condition" (P 12).

Benefits of using online information

Despite the limitations of using online information, patients expressed some benefits of using these resources.

Improve communication

OPEMs are generally applicable and helps simply obtain disease information and managing it. Four patients mentioned the effect of OPEMs on getting drug information, diet, reading books and articles, gaining experiences of similar patients, gaining the physicians' specialized opinions, etc. "Most of the online contents are useful because they have finally used the experience of the involved people, and if this information produced by reputable organizations, they are more reliable" (P 13).

Three patients mentioned that having information also allows them to better bring up their uncertainties and questions during the appointment with doctor.

"However, I often try to ask my doctor indirectly about the information I have got from the Internet" (P 5).

Two participants believed that some online information derived from other people's experiences and could be helpful. "I think most of the online content is trustworthy because they have finally used the experience of the involved people" (P 13).

Positive effect on the patients

Two patients believed that due to the physician's time constraints to provide a complete description of the diseases, using OPEMs can significantly increase their awareness about the disease. It makes them have an impact on their treatment process. "Patient can use the information and understand what is happening. Most doctors do not have enough time to explain the treatment process. That's why online information is sometimes so helpful" (P 19).

Two participants stated that studying retrieved OPEMs had led them to pay more attention to the need for treatment. "The online information was good and made me take the treatment seriously and think about solving the problem" (P 3).

Better diagnosis

OPEMs help patients to identify early diagnosis of diseases. Two participants mentioned preliminary diagnosis based on symptoms as a notable advantage of using OPEMs. "Because of physician's time limitation, we had to search symptoms ourselves and then, we found that there was information according to our desired condition" (P 23).

Two patients believed that accessing OPEMs could lead to the identification of possible medical errors. "When we searched my father's prescribed medications, we discovered that he had mistakenly taken one of his drugs for more than a year" (P 23).

Discussion

We investigated patients' views regarding OPEMs. The patients' views are divided into the main theme named "Quality of current OPEMs," three categories including features of information, disadvantages and benefits of using OPEMs.

According to patients, one of the crucial points regarding the characteristics of OPEMs is the identity of their providers. People have more confidence in information released by well-known sources or from official government agencies. Charlie *et al.*^[33] similarly confirmed that the recommendations of medical professionals are more similar and relevant to the content of more reputable websites.

Goobie *et al.*^[20] showed that the quality of produced information by nonmedical experts was lower than the produced information by specialists or medical organizations. Moreover, a study by Nielsen *et al.*^[21] revealed that providing clear, accurate, and relevant information through reputable websites is necessary to realize the Internet potential in patient education. Based on the results of this study, another feature of OPEMs is the potential access to information, diversity and their greater use. However, despite the variety of available information, there are many sources whose information are precisely the same and duplicate. This indicates a tendency to use unverified information by some websites. Therefore, it is necessary to control the quality of content more carefully. Harris *et al.*^[16] also believe that content standardization needs to become a health priority for the general public.^[18] Based on the results, "Distrust on online information," "Poor quality of information," "Giving misinformation," and "false impact" are mentioned as OPEMs significant restrictions that prevent patients from trusting online information. Eliminating these restrictions requires validation of information producers, quality assessment of information and participation of scientific organizations. In this regard, Lussiez *et al.*^[8] pointed to the need to introducing reputable active websites in the field of patient education.

Based on the nature of the online information, and mentioned disadvantages, patients must be educated in obtaining reliable information. In this regard, Okagbue *et al.*^[27] pointed out the need to inform people to find reliable information. Therefore, it is necessary to produce, and present valid information under the supervision of scientific authorities. Edoh *et al.*^[2] similarly emphasized the quality of this kind of information. Based on the results, one of the advantages of providing OPEMs is helping to "create a common language" between the patient and physician. Other studies similarly pointed to the positive effects of online information on the communication between patient and physician.^[4,6,13]

Using OPEMs would increase patients' awareness and draw their attention to take treatment seriously. Similarly, Huang *et al.*^[18] showed that the awareness level of the patient and his family about the disease can prevent the occurrence of unwanted and irreparable events about their health. Furthermore, patients will be able to observe the experiences of other patients, gain helpful information about their disease, adapt their condition to the symptoms. They may understand disease characteristics and may use the obtained information to identify possible medical errors. Alternatively, Kyriacou and Sherratt^[13] showed that patients use OPEMs before seeing a doctor. The more they can evaluate the quality of information, the more they will be involved in the treatment decision process.^[12]

The study has limitations, including the effect of patients' previous experiences on their attitudes and expectations, the relatively small sample size, and limited geographical coverage of the study. With the aim of reducing restrictions, selecting patients from other geographical areas or examining the perspectives of people with other diseases, can increase the generalizability of the results of this study.

The strength of the study was its attempt to provide a comprehensive overview of the patients' perspectives, as well as key points to create a scientific model of providing OPEMs.

Conclusion

Increasing the role of patients in the disease management process, as well as advances in the field of information technology and changes in patient information-seeking behavior, and benefits of using OPEMs, potentially can increase their use. Despite current limitations, patients have positive feelings and desire to use OPEMs to increase their knowledge about the diseases. They are somewhat familiar with the different types of OPEMs and make a reasonable distinction between information produced by scientific and governmental organizations with other unapproved provided information. Online information has specific characteristics, and diversity of content producers and various platforms may confuse the audience and cause them to get negative results due to the incorrectly promoted information. It is suggested that, to reduce the current barriers in patients' use of information, an OPEM system under the supervision of official and reputable scientific authorities with a specific framework will be needed. It is also necessary to conduct a patient's needs assessment, use reliable resources to produce educational content, and define the mechanism of continuous content updating. Paying attention to these points will alleviate patients' uncertainty about the disease and lead to better communication with medical staff and other similar patients. They can use this information for self-care with more confidence and naturally, such an approach can also have significant benefits for the health system.

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Conflicts of interest

There are no conflicts of interest.

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