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# Using the internet to exchange information and experience on cystic fibrosis

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## Using the internet to exchange information and experience on cystic fibrosis

### Abstract

**Objective.** Describing the experience of patients with cystic fibrosis (CF) and their families using the internet as a means for information, interaction and exchange of experiences with this disease. **Methodology.** A descriptive qualitative exploratory study was carried out in 2011. The subjects of the study were patients with CF and their parents or other family members contacted via e-mail on social networking websites. The requested information included the guiding question: "Tell me about your experience on the internet as a means of information and exchange of experiences involving CF", as well as demographic information and whether the respondent was the patient or a family member. **Results.** A total of 40 invitations were sent by email asking for information and 22 were accepted (55%). According to participants (15 patients and seven family members), the most widely used internet media were websites related to seeking information about CF. The use of internet was divided in three categories: 1) scientific and technical aspects, 2) emotional aspects, and c) modes of disseminating information. **Conclusion.** The internet proved to be a medium of opinion formation which could eventually replace medical advice. It is necessary to establish criteria for constructing and monitoring information related to CF published on internet websites.

**Key words:** Internet; cystic fibrosis; /nursing.

## Uso del Internet para el intercambio de información y experiencia sobre la fibrosis quística

### Resumen

**Objetivo.** Describir la experiencia de los pacientes con fibrosis quística (FQ), y la de sus familiares a partir del uso de la Internet como medio de información, asimismo, con la interacción y el intercambio de experiencias sobre esta enfermedad. **Metodología.** En 2011, se realizó un estudio con enfoque cualitativo, descriptivo y exploratorio. Los sujetos fueron pacientes con FQ y sus padres

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u otros miembros de la familia quienes fueron contactados a través del correo electrónico en páginas de relacionamiento virtual. La información solicitada incluía la pregunta orientadora: “Hábleme de su experiencia en Internet como un medio de interacción e intercambio de experiencias sobre la FQ”, datos demográficos y si el respondiente era el paciente o un miembro de la familia. **Resultados.** Se enviaron por email 40 invitaciones para responder la información y 22 de ellas fueron aceptadas (55%). Según los participantes (15 enfermos y 7 familiares), los medios de Internet más utilizados fueron los sitios relacionados con la búsqueda de información sobre FQ. La experiencia de uso de Internet se mostró en tres categorías: 1) aspectos científicos y técnicos, 2) aspectos emocionales, y c) modo de divulgación de información. **Conclusión.** La Internet mostró ser un medio para la formación de opinión, que eventualmente podría llegar a reemplazar el consejo médico. Es necesario que se establezcan criterios para la construcción y vigilancia de la información que se publica en los sitios en Internet relacionados con la FQ.

**Palabras clave:** Internet; fibrosis quística; /enfermería.

## Uso do internet para o intercâmbio de informação e experiência sobre a fibrose cística

### ■ Resumo ■

**Objetivo.** Descrever a experiência dos pacientes com fibrose cística (FQ) e de seus familiares com o uso do Internet como meio de informação, a interação e o intercâmbio de experiências com esta doença. **Metodologia.** Realizou-se em 2011 um estudo com enfoque qualitativo, descritivo e exploratório. Os sujeitos foram pacientes com FQ e seus pais ou outros membros da família que foram contatados através do correio eletrônico em páginas de relacionamento virtual. A informação solicitada incluía a pergunta orientadora: “Fale-me de sua experiência em Internet como um meio de interação e intercâmbio de experiências sobre a FQ”, dados demográficos e se o respondente era o paciente ou um membro da família. **Resultados.** Enviaram-se por e-mail 40 convites para responder a informação e 22 delas foram aceitas (55%). Segundo os participantes (15 doentes e 7 familiares), os meios de Internet mais utilizados foram os lugares relacionados com a busca de informação sobre FQ. A experiência de uso de Internet se mostrou em três categorias: 1) aspectos científicos e técnicos, 2) aspectos emocionais, e c) modo de divulgação de informação. **Conclusão.** O Internet mostrou ser um meio para a formação de opinião, que eventualmente poderia chegar a substituir o conselho médico. É necessário que se estabeleçam critérios para a construção e vigilância da informação que se publica nos lugares em internet relacionados com a FQ.

**Palavras chave:** Internet; fibrose cística; /enfermagem.

## Introduction

Access to information has changed a lot over the last twenty years. With the advent of television and especially of the internet, the general public can search and find endless information on various subjects.<sup>1</sup> The internet has allowed patients and families to access information about their diseases, treatments, medication, side effects, among others. Due to the easy internet access, the number of people who try to update themselves with the use of this tool is noticeable.

It can also be a powerful information vehicle for people with chronic diseases because these types of diseases involve difficulties in understanding the treatment when it comes to evolution in the various stages of life and in family and social relationships reorganization.

When it comes to cystic fibrosis the reality is not different. Patients constantly seek information about the disease on the internet. Cystic fibrosis

(CF) is an autosomal recessive genetic disease. In general it presents multisystemic involvement, characterized by progressive lung disease, pancreatic exocrine dysfunction, liver disease, intestinal motility disorder, male infertility and high concentrations of electrolytes in sweat.<sup>2</sup> The treatment of CF is done mainly with elective and/or emergency hospitalizations, when there is the use of antibiotics, daily respiratory physiotherapy and a hypercaloric diet aided by the use of digestive enzymes with meals.<sup>3</sup>

People who are in contact with CF for some reason - either for being carriers or family of carriers - also seek guidance on how to live and deal with the disease in daily life. In these cases not only the internet is used to find information about the disease, but it is also a great place to exchange experiences.

In the case of rare diseases such as cystic fibrosis, little literature is found in Portuguese and when it comes to researches on CF and internet, information is even scarcer. The objective of this study was to partially fill this gap and to know the experience of using the internet as a means of information and exchange of experiences involving cystic fibrosis.

## Methodology

It is a descriptive qualitative exploratory study. The subjects of the study were patients with CF and their parents or other family members of CF carriers, all contacted via e-mail. Inclusion criteria for participating were being a carrier or having a carrier of CF in the family of any age and to be registered on a social networking website.

The data collection instruments used were the guiding question "Tell me about your experience with the internet as a means of information and exchange of experiences about cystic fibrosis" and a structured questionnaire with ten questions. In 2011, between the months of January and June, 40 subjects were identified on social networking

websites. In this first contact the subjects were invited to participate of the research and asked about their email addresses. Replies were sent back after five days, on average. In the second phase, the researcher explained by email about the contents of the study and guaranteed confidentiality by reading the Informed Consent Form (ICF).

In order to respond the questionnaire, it was necessary to save it one's own computer, answer the questions, save changes and finally resubmit it to the researcher. In case the participant did not agree with the ICF, the email should be sent back with a negative reply, with no need for any kind of explanation. A total of 22 emails from many regions in Brazil were sent back with answers and these actually took part in the research. The subjects in this study were identified by Arabic numerals and the analysis instrument used was a content analysis based on Bardin. Content analysis is a set of techniques for analyzing communications. It is an empirical method that depends on the type of speech to which it engages and the type of interpretation that is intended as an objective.<sup>4</sup>

In compliance with Resolution nº 196/96 of the National health council, the study was submitted and approved by the Human research ethics committee under nº047/2011 of the Universidade Estadual de Maringá.

## Results

The subjects were 22 in total; 15 carriers (68%) and seven relatives of CF carriers (32%) and 59% of male patients. The diagnosis of CF occurred mainly at the ages under one year (36%) and between one and ten years (32%). The subjects' places of residence were in ten states of Brazil: São Paulo (6), Rio de Janeiro (3), Santa Catarina (3), Minas Gerais (1), Rio Grande do Sul (2), Bahia (1), Piauí (1), Mato Grosso do Sul (2), Paraná (1) and Espírito Santo (1). In addition, there was one subject who lived in Portugal. A great part of the subjects participated in associations that

support people with the disease. Nine national associations and one foreign were cited. There was a subject who reported attending an informal association and another one that did not reply. Among all respondents, a total of five reported not participating in associations.

The options of websites cited by the subjects were: social networking sites (MSN, ORKUT) (64%); search sites (GOOGLE, CADE) (82%); specialized sites (associations, etc - 41%); and international sites (23%). In this section of the instrument of collection, the subjects could answer more than one alternative. Three important themes emerged during the analysis of participants' speech about the experience of using the internet as a means of information and communication in FC, as follows:

### **Scientific and technical aspect of virtual information about CF**

Used as an important means of information, the internet was cited by the subjects as a tool to search for the disease. This is often their first contact with the disease and not always the accessed contents are trustworthy: *I had never heard of anything like that, so I started my search on the internet. The first result I got was the story of a little girl [...] I searched on other websites but none of them gave me complete information or what I really wanted to know* (6).

The contact with the patients association stood out in the virtual environment, either through search sites or by recommendation of other patients: *Thanks to the internet I got in touch with the Brazilian association of CF. I was admitted to the HC of Ribeirão when I managed to get internet access and found the association [...] and through that I went there and got a better treatment, better care and support [...] if it wasn't for that contact late that night, maybe I wouldn't be here anymore* (12).

Patient associations are little known by health professionals and services and they work as an instrument of information about the daily life of illness, legal rights and bureaucratic aspects of

treatment, promoting quality of life for affected people. In addition to social support, another important factor related to patient associations was related to neonatal screening and drug delivery as a public policy. The technical-scientific information stood out as the most grasped when using the internet for searches on CF. The contact with the association and others who experience the same situation was the essence of statements highlighted in this category.

### **Emotional support through virtual relationships**

In this category, another factor of great importance when it comes to the internet and people with CF was the emotional aspect. In online interaction the subjects sought an opportunity to share questions and express intimate and personal feelings about the difficulties of living with CF. In social networking sites they found people they were not likely to meet outside the virtual reality and thus created a relationship of empathy and friendship. Patients in this study reported that these relationships brought benefits: *Through Orkut I've met many people, CF carriers, doctors, researchers that help me until today with exchange of experiences and knowledge. I think this is one of the most valuable aids of this communication channel* (5).

The necessities of families of people with cystic fibrosis can be fulfilled with the help of other families in a similar situation or by the health team, as in the following quote: *[...] I joined the community and met many people, including CF carriers. We traded a lot of information and now I know very well what cystic fibrosis is [...]* (6).

In the speeches of the subjects in this study solidarity emerged as a practice to share resources involving CF. Virtual forums of CF promoted the dissemination of news, confessions, discussions and announcements asking for help with medication. The following speech describes this scenario: *It's also good to help, I saw in the CF community a desperate woman because her son needed colymicin. I have a lot here at home and*

*I asked her to give me her address so I'd send it [...] (8).*

It is feeling more equal, more humane and being welcomed by a virtual network where people, patients, professionals and family members are always available to share ideas, doubts and confessions. The subjects emphasize that the lack of emotional understanding and information in their social relationships and in health services are the strongest points that connect them through social networking sites and email messages, as in the following lines: *I have many friends who are CF carriers, all over Brazil ... I give them advice, talk, treat everyone as if they were my brothers, because I see a bit of my brother in each one of them [...] (11).*

### **Modes of disseminating CF information: in search of healing**

In the speech of the subjects in this study it was clear that accessing information is more common at the beginning of diagnosis, and over time this habit becomes less frequent, as in the following speech: *Today my internet searches are less frequent, as during the contact with the disease and living with it we learn a lot [...] (19).*

The subjects in this study also used the internet to get updates on the activities of associations in Brazil and on CF studies around the world, as the following speech demonstrates: *[...] I discovered many things, some treatments that would be predicted for the future (10).*

Even after the evolution of Brazilian studies in the area of health, the credibility given to international websites was still significant: *In my point of view the internet is an interesting source of research. But one should be careful when receiving this information. Doing searches on reliable and institutional sites is of vital importance. I particularly like American websites because they have a greater amount of information (2).*

The ethical aspect was identified in the speeches when the subjects reported media sensationalism,

as presented in the remark: *[...] as CF is a disease that has no cure, information and data are presented with hopelessness (2).* The study subjects suggested prior knowledge about the disease before any internet consultation on CF in order to avoid reading websites with unreliable contents: *It is a means of information in which you must have a theoretical knowledge before. If you believe everything you read about CF on the internet you'll go crazy, you'll end up much worse than you already are (3).*

In relation to essential care in CF, the subjects reported the difficulty in searching on sites that address this aspect, especially in regards to nebulization and physiotherapy: *We found no information on inhalation procedures and physiotherapy treatment which is basic information for a patient with CF. Historical and statistical information about life expectancy and lung infections over the years is not found either (20).*

## **Discussion**

The internet was a powerful means of information used by the families and patients with CF in this study. In many cases, it was the first search tool for information about health services, qualified health professionals and people in similar situations. However, an accurate answer was not always found for answering the questions and anxieties generated by a disease that is still unknown.

Social softwares or social applications are widely used by people of different economic levels. They offer different types of tools (forum, chat, messages or instant messages) that enable interactions (mediated by the internet) between people or groups of people, and also the creation of social networks and communities with affinities and common interests, enabling to share and discuss different themes. In the majority of searches the deficiency of information was a reality that made it difficult for patients and their families to understand the disease. A study with the purpose of knowing the perception of patients



about the effect of the internet in the relationship with doctors found that internet information was normally complementary to information received in the consultation and therefore a support to therapeutic.<sup>5</sup>

As an instrument of confirmation, expansion of information and assistance in decision making, the internet seems to be a secondary alternative.<sup>6</sup> On the other hand, some authors have reported that the increase in knowledge of patients can promote deprofessionalization of doctors and also transform the doctor-patient relationship. They argue that “the empowerment of patients may counteract the paternalistic model, where the decision-making power is in the hands of the doctor and the patient adopts a more passive attitude”.<sup>1:583</sup> No studies on the relationship nurse/patient/internet were found, but all information that comes from patients can also be a moment of exchange, sharing and mutual understanding in order to assist them, taking into consideration their beliefs, culture and social level. Therefore, it can be said that the existence of this gap in nursing is positive as the professional is nearer to the patient and can better receive the knowledge exposed through a symmetrical relationship.

As a device for multiplication of information, the internet has been an important technology to understand the disease, the legal rights of patients, specialized services and seek emotional comfort. The opportunity to share their experiences with others who often go through the same problems was very rich and comforting. Furthermore, there was always the possibility to understand more about the disease. It can be seen in the speeches that social softwares used by patients and their families allowed communication for constructing knowledge about CF. Virtual interaction encouraged people with similar interests to share different ideas.

The virtual communication gave people with CF and their families and friends the opportunity to get in touch with the reality of CF in various states of Brazil. Approximating of strangers who at the same time are so intimate in understanding the routine of the disease seems to bring a sense of fraternity among these individuals. Seeing

themselves in others cemented the feelings of friendship and partnership among the subjects, a partnership to exchange information and medicines. When the contact is personal, the study reveals that patients' associations can promote these same feelings, especially towards solidarity, equity and empowerment.<sup>7</sup>

The findings about CF are expressed as feelings of relief and tranquility in the speeches, in face of information which decreased ignorance of the disease. Perceiving oneself as a normal person when meeting so many people with the same problem in the virtual space makes the rarity condition of the disease less significant. As a space for dissemination, the internet becomes a place for consuming more updated information on health.<sup>8</sup> Updates to virtual sites and publications are involuntarily faster than printed literature, which stimulates increased access of people around the world. This is a practice that has aroused even a change in the attitude of health professionals when dealing with patients with an expert profile.<sup>9</sup>

For the family the time of diagnosis is usually a difficult phase of denial, and this reaction may explain the speeches in this study that showed a more frequent use of the internet in the beginning of diagnosis.<sup>10</sup> This reality may be visible in other genetic diseases such as sickle cell anemia.<sup>11</sup> A study aimed to evaluate the quality of information about heart disease provided on the internet demonstrated that the most common problem during internet searches is the form information is transmitted and not the content itself. The most reliable websites were doctor's personal sites and health institutional sites, considering that the majority of websites analyzed in the study were not recommended in the aspect of ethics.<sup>12</sup>

Few Brazilian websites address information about CF in a clear and correct way. In 2009, with the need for information to the lay public, one patient envisioned the creation of a website ([www.unidospelavidafc.com](http://www.unidospelavidafc.com)) aiming to form a mutual support group.<sup>13</sup> Thus, many families even when connected to social software are informed about the reliability of this website that currently has

partnerships with health professionals from various fields, as well as contacts in associations in Brazilian states, events, treatment centers, videos, reports of patients and families, among other curiosities about the disease.

**Final considerations** The study subjects considered information found on the internet as updated, but at the same time there is concern regarding the reliability. Disseminating correct information about CF is to promote the construction of knowledge among patients, families and health professionals. The relationships of affection and friendship created between the virtual groups of patients and families brought emotional comfort, knowledge about the disease itself and legal rights of patients as well as mutual help regarding medications.

The early stage of diagnosis of CF and ignorance of the disease appear to be the main conditions that favored the decision of the subjects in this study to experience the internet as a means of search for information. Thus, it is necessary to rethink a program of health education for families and people newly diagnosed with CF, in the same way it already exists in some countries. Although few national studies reflect upon the role of nursing in CF, this study provides clues about the aspects involving the question of the rarity of some diseases and the devices used by people with CF and their families to meet the need for information in health services. The Internet was a safety valve to lessen fears, doubts and lack of information about CF. Even if positive consequences have been perceived in the speech of subjects, this study suggests that others should be carried out with patients and families deprived of this means of virtual communication as they may describe different strategies for capturing information about CF.

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