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RIGHT OF ACCESS TO HEALTH INFORMATION

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Abstract

The access to health information is one of the rights of the user of the public health care system, but it is little respected in health services. This study investigates the problem from the perspective of the female clientele. A qualitative study was carried out with a sample of seventeen low-income mothers, which reside in the outskirts of the Federal District. The mothers are frequent users of the health care services, but their adherence to prescribed conducts depends on social and economic factors and how they perceive the various alternatives at their hand. Access to health information is hampered by the mother's low level of instruction, use of folklore medicine, faulty communication and lack of receptive/ nurturing environment, indifference to social rights on the part of health providers.

Descriptors*:* access to health information; communication; interrelation

Resumo

O acesso à informação em saúde é um dos direitos do usuário do sistema público de saúde, porém este direito é pouco respeitado nos serviços de saúde. Este estudo investiga a problemática a partir da ótica da clientela feminina. Realizou-se um estudo qualitativo com uma amostra de dezessete mães, de baixa renda, residentes na periferia do Distrito Federal. As mães são usuárias freqüentes dos serviços de saúde, mas sua adesão às condutas prescritas depende de fatores socioeconômicos e de como elas percebem as várias alternativas a seu alcance. O acesso à informação em saúde é dificultado pelo baixo grau de escolaridade da mãe, uso de crendices populares, comunicação deficitária e falta de acolhimento/vínculo, descaso com os direitos sociais por parte dos profissionais de saúde.

Descritores: *acesso à informação em saúde; comunicação; inter-relação*

Título: *Direito de acesso à informação em saúde*

Resumen

El acceso a la información en salud es un derecho del usuario del sistema publico de salud, todavía este derecho es muy poco respetable en los servicios de salud. Este trabajo investiga el problema bajo la perspectiva de las mujeres. Fue hecho un estudio cualitativo con una muestra de 17 mujeres, de baja escolaridad que viven en la periferia del Distrito Federal. Las madres son usuarias frecuentes de los servicios de salud, pero su adhesión a las conductas prescritas dependen del factores socioeconómicos y del como ellas perciben las varias alternativas al su alcance. El acceso a la información en salud es dificultado por el bajo grau de escolaridad de la madre, uso de creencias populares, comunicación deficitaria y falta de la acogida/vínculo, irresponsabilidad con los derechos sociales por parte de los profesionales de la salud.

Descriptores*: acceso a la información en salud; comunicación; interrelación*

Titulo: *Derecho del acceso a la información en salud*

1 Introduction

The right of access to health information is one of the basic principles of the national healthcare system[1]. The patient has the right to receive relevant information about his health status, medical treatments and health services. The suppression of such information by the health provider is liable of punishment according to ethical codes which regulate the health professions.

Traditionally, health education has been used as the main strategy to inform the public about risk factors and other health issues. Basic notions about hygiene, infectious diseases and other health information are conveyed to the patient so that he can adopt a healthier lifestyle for himself and his family seek medical attention at the right moment and follow faithfully the prescribed treatment. The idea is to constitute a cognitive base for the individual to use in making decisions about his health[2].

In an age of shared responsibility, patients need strong decision-making skills. Patients are often faced with complex information and treatment decisions. They need to articulate their health concerns and describe their symptoms accurately. They need to ask pertinent questions, and they need to understand spoken medical advice or treatment directions. Hence, a person's educational background is recognized as an important asset, for more years of education increase his chance of having acquired such skills[3].

The right of access to health information is based on the assumption that the individual with an information need should be able to obtain information that satisfies that need, including diagnostic, treatment and care information, so that he can develop health literacy which is the capacity of an individual to obtain, interpret and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing[4].

But access to health information as carried out by most health services continues to be restricted. Health professionals and managers still give little attention to the consumer's right to health information. The physician, in particular, experiences constant dilemma in that he is uncertain about the amount and depth of health information he should hand out to the patient[5-7].

The purpose of this study is to examine the access of women to health information in order to identify potential barriers that hinder this process. Although the focus of this study is on young mothers, there is no intention to emphasize the gender issue but only to understand the life experiences of a group of women representative of the target population of maternal-child health programs.

2 Material and methods

A qualitative study was carried out in three cities located in the periphery of the Federal District. Using purposive sampling and "saturation" criterion, a sample of 17 mothers were randomly selected at community health centers. In depth interviews were carried out at each mother's home after obtaining informed consent and guaranteeing privacy rights. The life story, a variation of the life history technique, was used to collect information about health knowledge and use of health services. For data analysis Minayos's theme technique was used[8]. The findings, though exploratory, reveal a complex interrelation of barriers, which prevent the access of women to health information.

3 Economic barriers

The women were aged 19 to 29 years of age, most of which had a common law marriage and an average of two children. The husband was the main household provider, receiving his income from menial jobs, such as janitor, gardener, construction worker, but more than half of them were unemployed. The families lived in small houses, improperly built, and yet had basic sanitation services, such as sewage, piped water,

electricity and garbage collection.

The mothers depend on public health services; none have any type of health care plan or insurance. For the most part, the mothers attend pre-natal programs, deliver their babies at hospitals and take their children regularly to the health care center for medical examination, particularly in the first year of life.

Their day-to-day routine is spent, for the most part, carrying out domestic chores and taking care of the children. Motherhood is their primary role and they carry out a variety of health-related activities that range from hygienic and preventive measures to the treatment of certain common illnesses, as revealed in the following narrative:

You see, I always make beet syrup that a nurse at the center taught me. She said it was very good. So, I make beet syrup (Beatriz, 20 years old, 4th grade).

In general, the mothers are quite attentive to their children's health problems, carefully observing any change in feeding or behavior. Breastfeeding is a common practice and most mothers seem to have a minimum knowledge about nutrition. At the sign of any trouble, they seek medical attention at the local health care center. Compliance to medical regimen will depend on how the mother perceives the effectiveness of the treatment prescribed, but much more often it is determined by economic factors. Unable to buy the medication prescribed by the doctor, the mother will experiment with various home remedies or rely on advice given by pharmacy attendants.

> *I made a mint tea with something else that I don't know what it is, my sister in law knows, she gave it to me. I gave it to the baby; put a drop of almond oil, only a little, otherwise it can give the baby diarrhea. Then, he drank it all and his cold got better. I got the almond oil, heated it and passed some on this nose, his chest. I took good care of him, always gave him his bath, food, all at the right time, taking good care of him* (Rosa, 20 years old, 1st grade).

Much of the health information disseminated by mass communication channels and health programs has been incorporated by the population, but their capacity to fully comply with medical treatment and advice is determined primarily by economic factors. This is something that other qualitative studies carried out with families with similar socioeconomic status to those of the present study have also found[9,10].

4 Cultural and educational barriers

From a total of 17 participants, ten had more than four years of formal education; the other seven mothers had less than 4 years, all of which had grown up in rural areas where conditions for schooling were often unfavorable. The mothers are aware that lack of education affects their access to health information and try to learn the most they can from their contact with health providers and other professionals.

The mothers, in general, follow their own intuitions in caring for their children, trying to be rational and balanced in the strategies they adopt. Their knowledge base is made of both common sense knowledge as well as bits of scientific knowledge that they pick up along their contacts with health providers.

> *I didn't give him the medicine that he (doctor) gave, no, because his teeth were coming out. Also, the medicine that he gave for anemia gives dysentery, I was afraid to give it* (Beatriz, 20 years old, 4th grade).

This type of folk medicine is the result of poverty and lack of proper schooling. Evidently the numbers of years of formal study ends up influencing the way a person thinks and deals with health problems. Often mothers perceive certain abnormalities in their children, but don't always know how to explain them. Their knowledge about the causes of illnesses tends to be confused and loaded with superstitions.

about the cause of her daughter's cataract).

According to Zaborowski[10], such mothers possess a holistic type of vision about health in which signs and symptoms are not seen in an isolated way. Only after the mother observes alterations in the child's general behavior, does she identify a health problem although she may not be able to identify it.

The mother knows that the health professional expects her to be able to describe signs, symptoms and other health details in a coherent and, above all, brief manner, which is actually a very complex task for a lay person to perform for it involves a good deal of observation skill, knowledge, capacity of synthesis and oral skills.

This lack of formal knowledge can often make the mother blame herself unnecessarily for some health problem that her child presents or for feeling guilty because she is unable to carry out a specific procedure that she considers every mother should inherently possess.

> *I took care of her belly button very badly. Then, she had a hernia, it stuffed up like this, grew. Until today, it is still healing, but it is still a little stuffed up. So, I didn't know how to take care of her belly button* (Beatriz, 20 years old, 4th grade).

Diffusion of medical knowledge occurs in an uneven manner among different social classes. Thus, people possess a more well-informed and up-to-date repertoire about health, according to the hierarchical scale they occupy in society. Boltanski[11] points out that folk medicine are not constituted of a body of perfectly autonomous knowledge; rather much of this knowledge came from past "scientific" knowledge apprehended by the popular classes. Mothers with little schooling still conserve concepts about feeding, medication, disease etiology that were part of medicine in earlier times, but have since been overcome. When a mother stops following some given medical orientation, she does so not because of stubbornness, but because she is torn between two distinct logics: the scientific logic and a common sense logic which she inherited from her own mother. Thus, cultural values also constitute an important barrier to the access to health information.

5 Communication barriers

Educational differences between health providers and mothers ends up interfering in the communication process between the two, the latter often feeling resentful of what she perceives as indifference on the part of the health professional in relation to her knowledge or observation capacity, as stated by the following mother:

> *I didn't know what was happening. Then, I would, I cried, I would put a lot of force! Then, I saw her, like this, coming out. When I put my hand, it was Onelice's head. So, I scream for the doctor, calling help that the baby was coming out. The doctor said that I lying, that I was making a scandal for nothing. Told me to shut up, if not he would let me have the baby there in the corridor. You should see how he was fitting with me. Then, I told him that I wasn't lying, no. Aí, eu gritando o médico, chamando socorro que a menina tava saindo. So, he came, looked at it and saw that it was coming out. Then, they put me in a wheel chair, that wheel chair for crippled people, and went running with me. Put me on that stretcher. Then, I put force, a lot. Then, the baby didn't want to come out. So, they cut me like this. So, she (daughter) came out. Then, they sewed me up. I suffered! Anesthesia gave out, it began to hurt. They were sewing; it began to hurt the stitches. I suffered a lot from Onelice's birth!* (Odete, 21 years old, 3rd grade).

The health provider has a tendency to discriminate the client in view of his or her social class. Lower class consumers are seem as incapable of understanding more technical

to follow folklore remedies[12]. Thus, the health provider considers that his role is only to give orders, without needing to give any further health information. In such conditions, what should priorly be transmitted to the client remains unsaid. If the client is told the fundamental line of reasoning which underlies the medical regimen, he or she is more likely to follow it.

Communication between health providers and uneducated clients suffers a variety of cultural and linguistic barriers when compared to those with higher health literacy. Illiterate clients will often use medical terms incorrectly which, in turn, irritates the professional, or else, try to convey a variety of information about their illness, the majority of which is considered useless by the health professional.

6 Interrelational barriers

When evaluating health care, clients tend to focus their attention on the health professional, rather than the health service. In the interviews, the participants often referred to the doctor and how he treated them, as can be seen in the following deposition:

> *Then, he (son) only had one appointment here, with the pediatrician and it is not always the same doctor. They always change the pediatrician. And the pediatrician that was there yesterday, she is an excellent pediatrician. I think she is great! Because she, because there are pediatricians who only look here at the baby's belly. She no, she looks at him all over, the hear, the mouth, the eye, his whole body. He was with allergy, she saw the allergy. She would hold his foot and move it. There are pediatricians that don't do this. So, I thought she was great! She saw that he had a little thing coming out of his eye. She saw it, she passed some eye drops. His nose was stopped up, she passed nasal drops. I hadn't seen this fungus in his mouth, there was only a tiny bit of white stuff. She saw it, and then she passed some medicine to put on his mouth. I hadn't even seen it, she did. She was great! Although, there are some pediatricians who are terrible. They don't explain anything, don't say anything. Like yesterday, I went to an appointment, took him, but I didn't trust the pediatrician, no. Because he already had had an appointment with him on the 19th and his blood exam gave anemia, but he didn't see it. And Doctor A., I showed it to her and she saw it. And he didn't see it, just for you to see how it is. What if, he had to have seen it, had to have passed something and said something about it, don't you think? But no, he didn't say anything, didn't see anything. And he said like this: No, he doesn't have anything. His exam didn't show anything. So, I got scared, cause sometimes he doesn't look right* (Fatima, 19 years old, 7th grade).

One can easily recognize the importance that forming an effective bond with the pediatrician had for this mother. Whenever this bonding does not occur, the client never forgets how she was treated, as revealed by this mother:

> *So then, I went to the Center and the doctor examined me, Dr. A, I hate that man until today: — ah, mother, if you are pregnant, then I am too! Have you already menstruated? No, well, this is your menstruation coming — Doctor, I am pregnant, I feeling! — No, mother, a woman when she is having her period also feels queasy and that doesn't mean she is pregnant* (Rosa, 20 years old, 1st grade).

For the most part, interrelations between health professionals and clients are impersonal and hasty, not allowing for bonding between the two. This lack of reciprocity and trust completely undermines the relationship between health provider and consumer.

> *And I didn't even tell the doctor, that day, because if I had told him that I was giving a bottle, he would have*

There are countless justifications for this impersonal interrelation. One is the frequent rotation of health professionals which occurs within health services; secondly, the preoccupation with productivity goals in detriment to the quality of the care, and thirdly, the mechanical, impersonal manner in which health care and information is provided, often leaving the client dissatisfied or wanting to seek some other service.

When the health provider establishes a link of trust and reciprocity with the client this is fully recognized and appreciated by the latter. In order to improve health care, it is fundamental that health providers establish an interrelation with their clientele[13].

Another question involves the expectations that health professionals have in relation to their clients. For instance, there is a tendency for them to idealize the mother figure, expecting women to carry out this role according to pre-set standards, without taking into account each woman´s specific situation and living conditions. Thus, it is expected that she breastfeed her children up to six months of age, complete the immunization scheme and so forth. Whenever a woman does not live up to these expectations, she feels the weight of their judgment on herself and often chooses to omit certain facts from them for she knows that such details don't interest them.

A greater recognition of women's feelings and needs could create conditions, among other things, for the reduction of some of the problems commonly seen in the day to day of health services. If health providers also considered a client's living conditions, feelings and beliefs, the more they would understand the difficulties that women encounter in their daily life and the more effectively their advice would be. Besides, it would allow them to capture those complaints of biological nature which are actually rationalizations of other problems faced by the women.

7 Ethical barriers

Another element that hinders the relationship between health provider and clientele is the disrespect that the former often demonstrate in regard to consumer's rights. Even giving simple, routine information about treatment, hospital routine and so forth is often overlooked, as revealed in the following deposition:

> *And the nurses, I think that they mistreat you a lot because when you have a C section nobody can, no one is able to get up on her own to go to the bathroom, to get out of bed. After 24 hours you can get up because you have to move early, take a bath, and make movement so that you won't have any problem to walk later. So, when I wanted to pee, they would bring me the bedpan to put underneath me and I would ask them to change my position, risking having a stitch torn, it was too soon yet. And to bathe the baby, they would tell me to walk from here until the bakery, I would walk a lot, would go over a lot of beds to get there to bathe the baby. And I couldn't…* (Rosa, 20 years old, 1st grade).

If mothers received information about their personal health and treatment, they would better understand health procedures and accept them with less anxiety. They would also have a better comprehension of health and disease

In their narratives, the mothers often made reference to information that they had received from contact with employers, teachers, health professionals and other people outside their own circle. This learning process isn't just a simple transference of knowledge; it provides uneducated mothers with the necessary instruments to create new ways to care for their children, to develop critical thinking, to investigate more deeply aspects of her daily life and living conditions and to put into practice better strategies for her family's survival[14].

8 Conclusion

women that use health services in other regions of the country. The life experience of these women is characterized by little formal education, popular superstitions, difficulty to read and limited access to health information. Personal experiences shared by the interviewees revealed painful and embarrassing situations for them. Yet, in spite of all discrimination that these women suffer, they apprehend a lot more information than is formally passed on to them.

These women ignore their right to health information. This is evident by the posture they assume before the health providers, remaining silent and passive, but internally feeling frustrated about the attention and care given. Without a doubt, mothers need to have greater access to information about childcare, women's health and other topics of their interest. From a preventive point of view, they lack an easier access to health information although they carry out daily a diversity of activities related to health and illness, prevention of disease, and promotion of health and treatment of the more common illnesses.

It is fundamental that health professionals change their attitude towards uneducated clientele. Instead of using negative clichés to explain their conducts and practices, they need to help them gain high self-esteem and empowerment and always remember that, behind the labels, they are common people that have sufferings, vanities, dreams, difficulties and the capacity to learn and to choose, as well as any other person.

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